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Submission: Review of Canberra Health Services Procedure: Sharing Information with Carers – Mental Health Adult In-Patient Units.

Submitted by email to:
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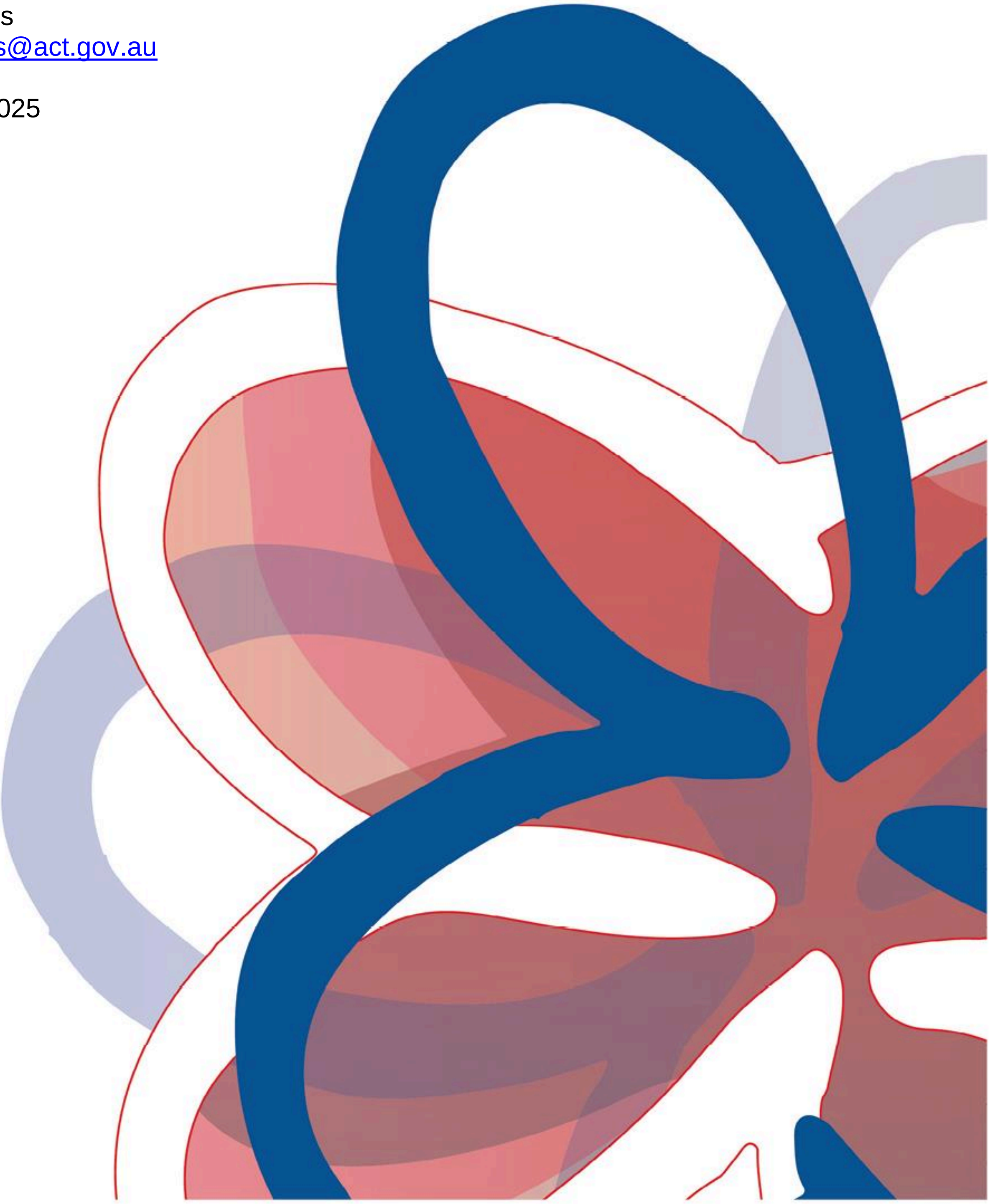

Submission: Review of Canberra Health Services Procedure: Sharing Information with Carers – Mental Health Adult In-Patient Units.

This submission has been prepared by the ACT Mental Health Consumer Network (the Network) in response to the invitation from Canberra Health Services (CHS) and the Mental Health Justice Health Alcohol and Drug Services (MHJHADS).

Acknowledgment of Country

We wish to acknowledge the Ngunnawal people as traditional custodians of the land upon which we sit and recognise any other people or families with connection to the lands of the ACT and region. We wish to acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region. We would also like to acknowledge and welcome other Aboriginal and Torres Strait Islander people that may be reading this submission. The Network acknowledges the ongoing contributions of all Indigenous peoples to ACT society and Australia more broadly.

The ACT Mental Health Consumer Network

The Network is a consumer-led peak organisation representing the interests of mental health consumers in the ACT in policy and decision-making forums. The Network is committed to social justice and the inclusion of people with experience of mental illness. Run by consumers for consumers, our aim is to advocate for services and supports for mental health consumers which better enable them to live fuller, healthier and more valued lives in the community.

A meeting of the Policy Reference Group was held and additional feedback was sought via email in relation to the CHS Procedure: Sharing Information with Carers – Mental Health Adult In-patient Units (the SIC Procedure). Written and verbal feedback was received from consumers. This submission incorporates both the written feedback and verbal feedback received.

General comments.

The Network welcomes this opportunity to contribute to the SIC Procedure. The SIC procedure should ideally be written in plain language and should include illustrations such as flow-charts, floor plans etc.

Information sharing between consumers, carers and services during and post-discharge from mental health inpatient units is a delicate but important component of ensuring that consumers are supported once they return to the community. Consumers appreciated the inclusion of references, evidence and the extended glossary of terms.

Consumers nonetheless raised several points of concern across the SIC Procedure regarding misrepresentations of the legislated rights and responsibilities of Advance Agreements (AA) and Advance Consent Directions (ACD) and aspects of the process for obtaining consumer consent. Alongside these two primary topics, there were several additional but discrete points of consumer feedback. These are presented after the two primary topics and, where appropriate, in the Editorial Recommendations section.

Advance Agreements & Advance Consent Directions

Consumers highlighted several points throughout the SIC Procedure where the rights and responsibilities of health workers and consumers concerning AA and ACD processes are lacking in appropriate detail or are mispresented. Each instance of this will be treated in turn.

In Section 2 the SIC Procedure states that:

> *If the person is too unwell or distressed to provide this information, it is important to check whether there is an Advance Agreement or an Advance Consent Direction in place that states the person's preferences for future mental health treatment, care or support. (p. 7)*

Consumers noted that s28(1) of the *Mental Health Act* (2015) (MHA) specifies that mental health professionals "must, before giving treatment, care or support … take all reasonable steps" (*MHA*, p. 27) to determine if there is an AA or ACD in place for a consumer. In view of this, the SIC Procedure should not present the obligation to confirm whether an AA or ACD is in place as a requirement that is conditional upon the consumer's presentation or state of mind.

In the same section the SIC Procedure states that:

> *An Advance Agreement includes the contact details of important people such as carers, guardians, legal representatives, or a nominated person" (p. 7)*

Consumers observed that an AA or ACD *may* contain such information, but this will not always be the case. More importantly, from a consumer's perspective, an AA or ACD is likely to include details about people who are ***not*** to be provided information regarding the consumer. This statement should therefore be clarified to stress that an AA or ACD may include this information as well as instructions for persons who should not have the consumer’s information shared with them.

Also in Section 2, the SIC states that:

> *While such Agreements may include ‘carers’ staff should note that families do not have the same status as a ‘nominated person’ and they will not automatically receive information in the same way that they would if they are a ‘nominated person’. (p. 7)*

Consumers highlighted the phrasing of this statement due to the need for clarity around who is permitted access to information about a consumer and how they are to receive it. As phrased, this statement can be read as stating that families or family members are entitled to information about a consumer, but they won’t receive said information in the same way (i.e., manner) as a carer or Nominated Person. Because family members are not automatically entitled to a consumer’s information, consumers proposed that this statement should be rephrased.

In Section 3 part 4, the SIC Procedure states:

> *There is an important point of difference between an Advance Agreement and an Advance Consent Direction, i.e. an Advance Agreement is not binding, and the person’s preferences will only be followed if it is in that person’s best interests at the time, whereas an Advance Consent Direction is binding. A copy of the Agreement can be shown to the person to confirm their position provided the person has decision making capacity. (p.12)*

This statement caused the most consternation as it misrepresents the responsibilities of mental health professionals. Specifically, the statement that an AA is “*not binding*” (Ibid.) misrepresents s28 (2) of the *MHA* which states that:

> *(2) If an advance agreement is in force and the person does not have decision-making capacity, a mental health professional –*
>
> > *(a) must, if reasonably practicable, give treatment, care or support to the person in accordance with the preferences expressed in the agreement.; and,*
> >
> > *(b) must not apprehend, detain, restrain or use force to give effect to the agreement.*

Per the terms of s28 (2) then, an AA must be followed unless it cannot be. There *may* be circumstances under which a person’s best interest conflicts with the condition that the treatment, care or support be “reasonably practicable”. However, the statement in the SIC Procedure does not specify circumstances, rather, it falsely instructs that an AA “will only be followed if it is in that person’s best interests” (p. 7).

This statement therefore undermines the purpose of an AA and provides health workers with instruction that, should it be followed, would result in the violation of a consumer's rights. This misrepresentation of the nature of an AA is also repeated later in the Definition of Terms section where under the definition of an AA it states that an "Advance Agreement is not binding and the person's preferences will only be followed if it is in that person's best interests at the time" (p. 20). Due to this, consumers proposed that this statement should be removed from the SIC Procedure and redrafted to reflect the actual stipulations of the MHA.

Consent

Consumers identified the topic of implied consent in Section 3 part 2.3 as an area of significant concern. Specifically, consumers proposed that the discussion of implied consent will encourage staff make assumptions about what information they believe a consumer wants to share. The SIC procedure explains implied consent as follows:

> *Implied consent is more difficult to prove than explicit consent. Implied consent occurs through the actions or conduct of the person rather than direct communication. It implies a passive process, rather than an active deliberation. Implied consent results from implications drawn from a person's behaviour. For example, a person phoning their carer may be taken as implying that they wish their carer to be involved in their treatment and care. However, implied consent is only valid if the person knows and understands what they are consenting to. If you are not sure you have implied consent, you should endeavour to get explicit consent. Nonverbal or oral consent should always be recorded and witnessed in the person's clinical record. (p. 11)*

Consumers argued that this explanation of implied consent is far too ambiguous for the purposes of inferring what information a consumer consents to sharing with others. For instance, the discussion treats behavioural implications as transparent for the purposes of establishing implied consent. This is highly problematic insofar as behaviour is not a consistent indicator of a consumer's understanding, let alone for inferring their consent. Additionally, both 'passive process' and 'direct communication' are undefined such that what behaviours or interactions may or may not be included or excluded as valid for deriving inferences about a consumer's consent is entirely unknown.

The problems here can be illustrated using an example from the same section:

> *A person might be happy for information about their diagnosis and care to be shared, but they do not agree to information about their drug use being divulged. (p. 11)*

For the purposes of establishing implied consent, what behaviours, action or conduct that do not involve direct communication could a staff member rely upon to determine whether a consumer gives their consent to having some, but not all, of their information provided to this other person? The problem is that the right of a consumer to control their information is not an all-or-nothing proposition; Consumers have the right to partition the information that they disclose to different people. Yet without direct communication of some kind there are few *reliable* ways by which to infer what parts of their information that a consumer does or does not consent to being shared with which persons.

A major risk then is that this explanation of implied consent suggests to staff that they can make assumptions about what information a consumer consents to sharing with others. Here, consumers also highlighted the risk that this could be used by staff for post-hoc justifications of sharing a consumer's information with a carer even though a consumer did not provide explicit consent and would not have provided consent if asked. Due to these issues, consumers proposed that the use of implied consent in the context of sharing information with carers should not be encouraged or relied upon by staff.

The other matter regarding consent highlighted by consumers concerns the statement that "[i]t is important to explore the reasons why consent is being withheld" (p. 13). Consumers noted that while such conversations are important, how they are conducted can be the difference between a staff member asking questions to establish facts versus a staff member asking questions to pressure a consumer into changing their mind about giving consent. This concern was flagged because the "Conversation starting" (Ibid.) examples provided included "discussing the importance of carers received useful and relevant information" (Ibid.). This example is not 'exploring' the reasons for consent being withheld. Rather, this example suggests that staff should pressure a consumer to change their mind by re-explaining to the consumer that it is important for carers to have said information.

Due to this, consumers proposed that an additional statement should be included to stress that exploring reasons for why consent is being withheld should be 'fact-finding' in nature and not used to pressure a consumer to change their mind about giving consent. Consumers also proposed that the second example should be retracted:

> *discussing the importance of carers receiving useful and relevant information that will improve their understanding of the person's needs and how best they can provide ongoing support for recovery. (p. 13)*

Additional Notes.

Concerning the Background section (pp. 3-4) consumers were confused about the relevance of the information to the procedure. The SIC procedure is about information sharing between consumers and carers and yet the Background section presents a statement of intent about collaboration and a list of benefits that can accrue from consumer and carer participation. This Background statement seems to be irrelevant to both the SIC Procedure itself and for staff who need to use it. Consumers proposed that the Background section should be redrafted to be relevant to the procedure.

In Section 1: Introduction, the SIC Procedure states that it is “important to note that there may be more than one carer involved in a person’s life” (p. 5). Consumers noted that this statement should be accompanied by another that makes it clear to staff that under the MHA a consumer does not need to recognise a person as a carer for a person to meet the definition of a carer.

Throughout the SIC Procedure whenever reference is made to Nominated Person, it is made with single quotation marks ‘’ and without proper capitalisation. Firstly, the use of single quotation marks suggests that Nominated Person is a paraphrased term at best or a sarcastic term at worst. Secondly, Nominated Person is a legislated role under the MHA and it is not an informal relationship. It should therefore be capitalised without single quotation marks throughout the SIC Procedure.

Substantive Recommendations: CHS Procedure: Sharing Information with Carers – Mental Health Adult In-patient Units.

Recommendation 1:

In section 2, the SIC Procedure should not present the obligation to confirm whether an AA or ACD is in place as a requirement that is conditional upon the consumer’s presentation or state of mind. The following paragraph should be redrafted to remove this conditional clause:

> *If the person is too unwell or distressed to provide this information, it is important to check whether there is an Advance Agreement or an Advance Consent Direction in place that states the person’s preferences for future mental health treatment, care or support.* *(p. 7)*

For example,

> *Staff must check whether there is an Advance Agreement or an Advance*

> *Consent Direction in place that states the person’s preferences for future mental health treatment, care or support.*

Recommendation 2:

In section 2, the following statement should be clarified to stress that an AA or ACD may include information about important contacts as well as instructions about which persons should not have a consumer’s information shared with them:

> *An Advance Agreement includes the contact details of important people such as carers, guardians, legal representatives, or a nominated person. (p. 7)*

For example,

> *An Advance Agreement may include contact details of important people such as carers, guardians, legal representatives, or a nominated person. An Advance Agreement may also include instructions about which persons should not have a consumer’s information shared with them.*

Recommendation 3:

In Section 2, the following statement needs to be clarified to avoid suggesting that families or family members will have access to a consumer’s information, albeit via means different to that of a carer or Nominated Person.

> *While such Agreements may include ‘carers’ staff should note that families do not have the same status as a ‘nominated person’ and they will not automatically receive information in the same way that they would if they are a ‘nominated person’. (p. 7)*

For example,

> *While agreements such as an AA or ACD may include carers, staff should not that families or family members do not have the same status as a carer or Nominated Person. Unless they are recognised as a carer or identified in an AA or ACD as a Nominated Person families or family members are not entitled to the same information that a carer or Nominated Person is.*

Recommendation 4:

The following statement on pages 12 and 20 should be removed from the SIC Procedure:

> *An Advance Agreement is not binding and the person’s preferences will only be followed if it is in that person’s best interests at the time.*

A new statement that reflects the actual stipulations of s28 of the *MHA* should be drafted and used instead.

Recommendation 5:

In Section 3 part 2.3, the use of implied consent in the context of determining a consumer’s consent to sharing information with carers should not be encouraged or relied upon by staff. The section on implied consent on pages 10-11 and the explanation of implied consent on pages 21-22 should be removed from the SIC Procedure.

Recommendation 6:

In Section 3 part 4, the statement that “[i]t is important to explore the reasons why consent is being withheld” (p. 13) should be accompanied by an additional statement that specifies that exploring reasons why a consumer is withholding consent should be fact-finding in nature and should not be used to pressure a consumer to change their mind.

For example,

> *It is important to explore the reasons why consent is being withheld. Exploring the reasons for why consent is being withheld is to learn more about the consumer and their needs. Staff should not use the premise of exploring the consumer’s reasons for withholding consent as a means to pressure a consumer to change their mind.*

Recommendation 7:

In Section 3 part 4, the following example of a conversation starter for exploring the reasons why a consumer is withholding consent should be removed from the SIC Procedure:

> *discussing the importance of carers receiving useful and relevant information that will improve their understanding of the person’s needs and how best they can provide ongoing support for recovery. (p. 13)*

Recommendation 8:

Consumers proposed that the Background section should be redrafted to be relevant to the procedure.

Recommendation 9:

In Section 1, the following statement that “[i]t is important to note that there may be more than one carer involved in a person’s life” (p. 5) should be accompanied by another statement that under the MHA a consumer does not need to recognise a person as a carer for a person to meet the definition of a carer.

For example,

> *It is important to note that there may be more than one carer involved in a person’s life. A consumer does not need to recognise a person as a carer for a person to meet the definition of a carer for the purposes of the Mental Health Act (2015).*

Recommendation 10:

Throughout the SIC Procedure, Nominated Person should be capitalised without single quotation marks.

Editorial Recommendations:

The References section of the SIC Procedure (pp. 19-20) should use a consistent, standard referencing style such as Harvard or APA.

There were several grammatical and typographical errors throughout the Procedure. The Procedure should be thoroughly proofed before finalisation. The editorial recommendations noted below are the most urgent corrections that need to be addressed.

The following edits are recommended:

- Section: Purpose, p. 3, ¶2:

  The procedure is intended to balance the carer’s need for information that will help them support the person after discharge against the person’s right to confidentiality and privacy.

  Balancing a carer’s need against a consumer’s rights creates characterises the carer-consumer relationship as adversarial. By changing ‘against’ to ‘with’, the statement characterises the relationship as collaborative.

- Section: Purpose, p. 3, ¶4;
  The following statement is a run on sentence that creates significant confusion about the instruction that is supposed to be being provided:
  As this procedure is not a CHS Mental Health Facility inpatient discharge planning document, staff are to refer to the Operational Guideline for the inpatient unit in which they work and to read other relevant CHS documents, located on the CHS Policy Register and as are indicated in the related Policies, Procedures, Guidelines and Legislation section of this document.
  This sentence should be broken into two separate statements and the instruction clarified.

- Section 1: Introduction, p. 5, ¶3; and, Section 2, p. 7, ¶6:

  The terms ‘carer’ & ‘carers’ do not need single quotation marks, the single quotation marks should be removed.

- Section 1: Introduction, p. 5, ¶1:
  This sentence is missing the ‘of’ preposition; “*the important role that a range people play*”. It should read, “*the important role that a range of people play*”.

- Section 2: Admission to an Adult Inpatient Unit – Identifying the Person’s Carers, p. 6, ¶2:
  The following statement has been duplicated on the succeeding page.
  Staff to identify and contact the carer(s) if this is a person’s first admission to an inpatient unit or the person has an inpatient stay of less than 48 hours.
  The syntax of this sentence is also awkward and should be rephrased.
  For example,
  If this is a person’s first admission to an inpatient unit or the person has an inpatient stay of less than 48 hours, staff should identify and contact the carer(s).

- Section 3: Seeking consent from the Person to Share Information with the Carer, p. 9, ¶4:
  The syntax of the following sentence is awkward and should be rephrased:

  For example, a person might be agreeable for information about their diagnosis and care to be shared, but they do not agree to information about their drug use being divulged.
  For example,

  For example, a person may agree to have information about their diagnosis and care to be shared, but they may also not agree to having information about their substance use being disclosed.

- Section 3: Seeking consent from the Person to Share Information with the Carer, p. 15, ¶3:
  The following sentence is missing a conjunction: “*Additional supports for the carer the person they care for should be explored.*” It should read, “*Additional supports for the carer and the person they care for should be explored.*”

- Section 4: Sharing information on discharge from MHJHADS Inpatient Units, p. 15, ¶10:
  The following statement “[t]he Discharge Procedure states…” refers to a procedure that is not indicated in the body of the SIC Procedure or in the Related Policies, Procedures, Guidelines and Legislation section (pp. 18-19). If this is referring to the ‘Discharge Checklist’ Attachment, it should be rewritten as such.

Conclusion

These recommendations are based on consumer feedback provided to enhance the policy and procedure documents.