Professional Practice Guideline 20 Information sharing with families/whānau/carers

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Purpose

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) has developed this professional practice guideline for information sharing with carers¹. Carers, who are often family members/whānau²/aiga³ (referred to as 'carers' in this document), play a central role in the care and recovery of individuals who are experiencing a mental health condition.[1] The purpose of this document is to assist psychiatrists to work effectively with carers and assist them to establish and maintain working relationships with mental health services and staff.

Scope of the Guideline

The scope of this guideline is broad and concerns all areas of psychiatry and/or where psychiatric treatment of adults is involved. It is important to note that the principles and considerations of good clinical practice should continue to be applied by psychiatrists when sharing information, and psychiatrists are responsible for assessing the appropriateness of implementing information sharing arrangements in each case. Best practice in collaborative mental health care aims to ensure that, wherever possible, consumer privacy is maintained and respected, and equally that carers are informed, involved, and have their own confidentiality respected.[2, 3] Information sharing is a mutual process, which sits in the broader context of relationships with carers. Where a consumer consents to a psychiatrist sharing information, this does not equate to the carer/s having substitute decision-making authority. Consequently, this professional practice guideline does not address issues relating to substitute decision-making.

1 The role of the carer

It is important for psychiatrists to remember that:

- 1.1 A person who provides care may not identify with the term 'carer'.[4] As they are often family members/whānau/aiga, it is important to recognise the relationship they have with the consumer first, e.g. daughter, son, partner, friend, aunty. Psychiatrists should aim to use the preferred term/s relevant to each individual situation. These relationships may change and fluctuate over time, and the wellness and needs of the consumer may fluctuate over time, impacting the types of support they may require.
- 1.2 A carer's own wellness and needs may also fluctuate over time, and these changes can affect their role and their own support needs.[5] They may have significant health problems

¹ The terms 'carer' and 'consumer' are used where differentiation is required for the purposes of document clarity. The RANZCP acknowledges that both carers and consumers have a lived experience and that the roles are not mutually exclusive. The RANZCP also acknowledges that 'carer' and 'consumer' may not be the preferred terms of individuals.

² Whānau' (pronunciation: *fa:no*) - A Māori word that can be used to describe an extended family group spanning three to four generations. The whānau continues to form the basic unit of Māori society (Rāwiri Taonui)

³ Aiga - The term, as used in the Samoan sense, includes not only the immediate family, father, mother and children, but also the whole union of families of a clan and even those who, although not related, are yet subject to the family control. (Victoria University).

- of their own and 'co-caring' is not uncommon.[5, 6] It is important to remember that caring roles are complex and diverse.
- 1.3 Regardless of ability or expertise, caring for someone with an acute mental health condition or fluctuating illness is a multifaceted and potentially challenging support role.[7] Some people may experience feeling ill-prepared and equipped for this role, requiring support and referrals of their own.[8]
- 1.4 The role of the carer may be to support the consumer's dignity, optimal functioning, or independence. They have unique expertise and knowledge of the consumer's situation and their needs, which should be recognised and valued, including knowledge from sharing a household with the consumer.[9-11]
- 1.5 Caring for someone can be a demanding and stressful commitment, especially for family/whānau with limited resources.[7, 12] The required duties can impact financial security, physical or mental health, social, educational and workplace participation and outcomes.[6, 13-16] It is therefore vital that carers are supported to undertake their role in a way that maintains their own wellbeing as well as the wellbeing of the person they are supporting.[6, 17] This is particularly true where the carer themselves may experience health/mental health concerns.[7]

2 The role of the psychiatrist

It is the role of the psychiatrist to:

- 2.1 Be aware of what information can be shared with whom, how to obtain consumer consent to share information, and where to obtain guidance on information sharing.[9] Trust has an important role in a positive psychiatrist-consumer relationship.[18]
- 2.2 Provide a person-centred approach to optimise mental health support for the consumer.[2] An important part of this involves supporting and empowering the people who care for the consumer at home, in their relationships, and in the community. Psychiatrists can play a positive role in providing valuable information and options for support to carers, within the boundaries of legislation.[18]
- 2.3 Help the person experiencing a mental health condition identify their support network. This includes what types of information they are comfortable sharing with whom, and any person within that network, if any, that they want included in shared decision making.[12] This process can be complex, and it may take some time to gain a full picture of the support network. Relationships can also change over time and psychiatrists should view the maintenance of partnership with those in the support network as an ongoing process.[2]
- 2.4 Practice cultural safety in communication with both the consumer and their carer/s.[19] It is important to gain an understanding of cultural relationships and care arrangements in each individual situation.[12]

For more information, see the RANZCP Position Statement 62: <u>Partnering with people with a lived</u> experience, and Position Statement 76: <u>Partnering with carers in mental healthcare</u>.

3 Principles

The RANZCP has developed the following principles to guide the practice of information sharing by psychiatrists. It may also be useful to utilise the <u>RANZCP Comparative Tables for Mental Health Acts</u> which may provide jurisdiction-specific legislation on information sharing.

3.1 Partnership

Best practice psychiatric care involves a collaborative approach between consumers, their carers, other family/whānau members, and clinicians.[2] Evidence shows that involving carers in the assessment, diagnosis and treatment of consumers can enhance the recovery process.[20, 21]

Carers may be well placed to assist psychiatrists to understand the individual context and how well the treatment plan is progressing.[22] They will often be able to recognise early warning signs and observe changes in behaviour.[18] It is also beneficial to the wellbeing of the carer/s to be included in the treatment process, and can positively impact the relationship between the consumer and carer/s.[23] Through meeting with family members, psychiatrists can become aware of and assist with responding to family needs, and become better informed about the context and history of the consumer they are treating and more effectively tailor a treatment plan to meet their needs.

A psychiatrist's role is to:

- Aim to collaboratively identify all members of a consumer's support network, considering oftenoverlooked family/whānau who may play a key role, such as children, same-sex partners, or members of a wider cultural community.[24-26]
- Develop and maintain an equal partnership with carers, listening carefully and communicating as openly as possible throughout the process.[17, 27]
- Help both consumers and carers contribute to and gain a shared understanding of care plans with the aim of better, more sensitive implementation.[17]
- Invite communication and negotiate how ongoing contact between carers and any treating
 professionals should occur.[17] Communication is important in any type of information sharing
 agreement.
- Consider setting up support groups for carers in order to establish social support networks, create a sense of hope and enable problem solving.[12]
- As needed, provide or enable access to family/whānau services and support to resolve conflict, develop relevant skills and strengthen positive family/whānau relationships; this may include family psychoeducation.[12, 20, 21] For Māori and Pacific peoples, it may be appropriate to make referrals to Whānau Ora services.[11] For more information, see the RANZCP Position Statement 104: Whānau Ora.

3.2 Information

'Information' in this context refers to the consumer's health information, including mental health and wellbeing, care plans, health services and treatments accessed by the consumer. This is differentiated in this document from 'particularly sensitive information', which may include details about information disclosed in therapy and the consumer's thoughts, feelings and personal history.[18] Psychiatrists should be aware of the legal definition of health information and personal information in their jurisdiction and the associated applicable laws and regulations.

A psychiatrist's role is to:

- Discuss the therapeutic benefits of involving family/whānau/carers in the treatment process.[18] The purpose for sharing information and discussing issues, risks and challenges with carers should be made clear to all parties early in the process.[12]
- Gain an understanding of what kinds of information each consumer is comfortable sharing with others.
- Respect the privacy and confidentiality of the carer/s themselves.
- Assist carers in understanding how to access information, contact services and staff, and access available support (help lines, counselling, financial support).[9, 20, 21] This may include how to support consumers with medication management, accommodation and psychosocial support.[17]
- Support the carer/s towards realistic expectations of the treatment program and what the mental health team is able to provide.[17]
- Consider including a carer nomination form as part of the regular documentation process, to be updated regularly.[8]

3.3 Agreement

There should be a transparent understanding between the psychiatrist and the consumer on the nature on the agreement and consent regarding information and guidance that will be shared with any nominated carer.[2] A consumer may be unable or unwilling to consent to the involvement of carers. Please see the RANZCP desktop resource on how to have the conversation (link when published).

A psychiatrist's role is to:

- Reach an agreement regarding what information will be exchanged, with who, and how.[2] A
 psychiatrist should also explain the benefits of carer involvement.[17, 18] The agreement
 should be made early in the therapeutic relationship. If a family member or carer contacts you
 to request information prior to an agreement being made, communicate respectfully and
 transparently about the limitations of what information can and cannot currently be shared.
- Provide clear information to the consumer to assist in understanding their right to change agreements regarding information sharing; consent can be amended at any time. Adapted practice may be required to suit the consumer where they have a disability or disorder which may make it difficult to process new information.[28, 29] Simplification of language or visual aids may support provision of clear information.[29]
- Record any agreement made between the consumer, carer/s and the clinician in the medical record and treatment plan, and make a copy available to all parties.[18] Collaborative writing of reports or letters may assist in a mutual understanding. Where the agreed information sharing instructions change, this should be updated on all relevant documents and provided to all parties.[18]
- Consider, if the consumer consents, holding a meeting for their support network. This may be helpful in opening a dialogue around care and treatment.[17] Through meeting with the support network, psychiatrists can be better informed about the context and history of the consumer and more effectively tailor a treatment plan to meet their needs, as well as the needs of carer/s. Meeting both sets of needs is likely to positively impact the consumer's recovery.[18]

3.4 Privacy

The disclosure of information to carers is governed by applicable laws across jurisdictions. Inclusion of carers in the therapeutic process is often beneficial, and possible in any information sharing agreement while maintaining privacy and confidentiality.[2] When a consumer does not consent to information being shared with their support network, this should be managed, but does not prevent the development of a working relationship with carers in accordance with applicable legislation and regulations.[22] Psychiatrists can communicate with carers by listening to concerns and providing broad information about mental health, treatment plans, medications and services.[8]

A psychiatrist's role is to:

- Be familiar with jurisdictional requirements, and review these as needed. The Australian privacy principles or New Zealand privacy principles should be adhered to. State and Territory privacy laws may also be applicable.
- Be aware of the relevant legislation in both their own jurisdiction and that of the consumer when the psychiatrist is in a different jurisdiction from the consumer.
- Remember that consumers can refuse to consent for their information to be shared with their carer/s, subject to any exceptions provided for in the relevant legislation, regulation, or duty of care requirements.[18] Legislation for consumers detained under Mental Health Acts can affect the way information is shared.[2]

- Obtain and record specific consent before sharing any particularly sensitive information.[2]
 Particular consideration must be taken if a consumer discloses information regarding family
 violence or trauma.[9] For more information, see the RANZCP Position statement 100:_
 Trauma-informed practice.
- Note that psychiatrists should assess the capacity of consumer to consent to information sharing agreements in accordance with the relevant laws and regulations. Special circumstances may apply to consumers who have an intellectual disability. This guideline is appropriate for adult consumers; special circumstances and considerations apply to consumers who are children, depending on your jurisdiction.[23, 30]

3.5 Cultural safety

Cultural safety is an outcome of the way that psychiatrist's practice and is crucial in achieving equity for all cultures. Please see the RANZCP Position Statement 105: Cultural safety.

A psychiatrist's role is to:

- Engage with consumers and their carers in a way that is responsive to cultural, emotional, physical, social and spiritual needs.[19] This may include making changes to the clinic or meeting space to create an environment which is culturally safe and comfortable to the consumer and carer/s.[19] Take a flexible approach; where necessary and possible, meet in a location chosen by them.[31]
- Consult or work directly with Elders for Aboriginal and Torres Strait Islander consumers, if this is appropriate.[19] Aboriginal and Torres Strait Islander community mental health services and community liaison officers may be able to assist in this process.[19]
- Remember when working with Māori, whānau play an important part in supporting a consumer's health outcomes. Kaumātua⁴ have a role working with the consumer, whānau and the health system. There is a wider whānau beyond the consumer therefore focusing just on the consumer may not result in the best outcomes.[32] Information is likely to be considered not only by the consumer but their whānau too. For example, a consumer may not make a decision unless they had discussions with their whanau. Psychiatrists must also be cognisant of mātauranga⁵ and how these may influence decision making.[33]
- Consider that families are diverse and changeable; psychiatrists should take a style of
 engagement that is tailored to each situation. Even if consumers and carers come from the
 same cultural group they may differ in their preferences.[31] For more information, see the
 RANZCP Position statement 104: Whānau Ora. The RANZCP also supports the Medical
 Council of New Zealand Statement on Cultural Safety.
- Connect with carers; use language they can understand.[17] This may involve providing a translator or interpreter where required.[17] In some cases, the caring role will be taken on by children and adolescents; in New Zealand, a recent report has found that 8% of carers are between 15-24 years old.[24, 34] Referrals to support services for children and adolescents should be made as necessary.[24] All information and support given to young carers should be appropriate for their age.[9] For more information, see the RANZCP Position statement 56:_
 Children of parents with mental illness.
- Note that in some cases, Aboriginal and Torres Strait Islander mental health workers may be required to negotiate the dual roles of both family member and service provider.[35] The Māori workforce may experience similar challenges.[36] Other culturally and linguistically diverse members of the workforce may have this experience. If a worker is also a part of a consumer's family, or wider cultural group, employers should take steps to ensure the worker receives adequate support.[35, 36]

⁴ Kaumātua - a respected elder in a Māori community with long-term involvement in their whānau.

⁵ Mātauranga - Māori knowledge systems.

3.6 Review

A psychiatrist's role is to:

- Review any agreement on information sharing regularly to ensure it reflects the current consent and wishes of the consumer, particularly where a change in circumstances or their support network occurs.[2]
- Develop ways in which the carers can participate in review processes.[2]
- Engage consistently to ensure carers are kept informed where possible to assist in providing the best possible support to the consumer.[8] It is important to maintain transparency and accountability in interactions with carers in accordance with agreements.[8]

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DISCLAIMER

This information is intended to provide general guidance to practitioners, and should not be relied on as a substitute for proper assessment with respect to the merits of each case and the needs of the consumer. The RANZCP endeavours to ensure that information is accurate and current at the time of preparation, but takes no responsibility for matters arising from changed circumstances, information or material that may have become subsequently available.

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