



NMHCCF Advocacy Brief

Issue: Privacy and Confidentiality

Background

Current practices around privacy, confidentiality and information-sharing are a significant concern for mental health consumers, their families and their carers.

There is a lack of knowledge about the laws governing privacy and confidentiality, which vary between states and territories. This inconsistency has the potential to compromise both the privacy of consumers' information and their ability to access and provide information to family/carers which is required for their caring role.

The NMHCCF is calling for clarification of all privacy and confidentiality legislation – or the lack of it – across Australia.

Key Points for Consumers and Carers

In 2007-08, the NMHCCF conducted a consumer and carer survey on privacy and confidentiality issues and concerns. The data was collated and analysed in a preliminary way to form the basis of an Issues Paper, which was written by research consultants and completed in September 2009.

The key points from the preliminary survey include:

- **Consumers and carers** reported privacy and confidentiality is sometimes used as a way to exclude them from gaining information;
- **Consumers and carers** were not satisfied when mental health services did not acknowledge the importance of talking with them about how they would like their health information to be shared;
- **Consumers and carers** said that there were some issues regarding privacy and confidentiality and information sharing on which they could agree and others where they could not;

*Prepared by National Mental Health Consumer & Carer Forum
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- **Consumers and carers** liked the concept of an agreed approach to exchange of information;
- **Consumers and carers** believed that additional assistance and support from clinicians would allow better management of information-sharing between them;
- **Consumers** denied access to their health information saw this refusal as potentially harmful to the relationship between clinician and consumer;
- **Consumers** would like the opportunity to decide what information is shared with their carers;
- **Consumers** would like to be advised and consulted about who has the right to access their personal health information; and
- **Carers** are not always provided with the information they need to assist them in their caring role.

Key Issues for the Future

The Issues Paper

An Issues Paper has been written by consultants using a collaborative approach with consumer, carer and clinician project teams, to ensure that the views and perspectives of the three major stakeholders are fully explored. The paper examines the impact of privacy and confidentiality on the experience of consumers and carers in our national mental health system and will help generate a comprehensive range of solutions and recommendations for the final report following input from key stakeholders across Australia.

The NMHCCF will use the Issues Paper to develop a position statement on Privacy and Confidentiality, which will be finalised and published in 2010.

The findings and recommendations listed in this Advocacy Brief will be reviewed and possibly modified after this work is complete.

Recommendations for change from the preliminary survey analysis

- Consumers, carers and clinicians should engage in open discussion about what information can be shared with whom, and when, and how.

The NMHCCF endorses the promotion of three-way dialogue between treating clinicians/mental health services, consumers and carers about what information can be shared, and how and when it should be shared. Open communication has the potential to reduce misunderstandings and antagonism around information sharing

Name of Nominated NMHCCF contact on this issue

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