



**NATIONAL MENTAL HEALTH
CONSUMER & CARER FORUM**

Privacy, Confidentiality & Information Sharing – Consumers, Carers & Clinicians



A POSITION STATEMENT BY THE NATIONAL MENTAL HEALTH CONSUMER & CARER FORUM (NMHCCF) SEPTEMBER 2011

The National Mental Health Consumer & Carer Forum (NMHCCF) has identified privacy and confidentiality as matters of great concern for mental health consumers and carers.

In 2007-08 the NMHCCF conducted a survey entitled "Confidentiality and Information Sharing with Families and Carers in Mental Health".¹ The survey results formed the basis of the NMHCCF *Privacy and Confidentiality Issues Paper*,² prepared by research consultants and published in 2009.

The Issues Paper examined the impact of privacy and confidentiality on the experience of consumers and carers in the Australian mental health system. It also identified examples of best practice and potential solutions and ways forward.

This Position Statement is guided by the key issues identified in the Issues Paper and outlines strategies for the mental health sector to improve its approach to privacy, confidentiality and information sharing. The Position Statement and Issues Paper should be read together for a comprehensive overview of privacy, confidentiality and information sharing in Australian mental health services.

Definitions of privacy, confidentiality and information sharing are provided in this Position Statement, together with explanations of the role of legislation and the influence of professional codes of conduct. While the NMHCCF acknowledges these constraints, we challenge the way the concepts are frequently applied and support a tripartite approach, where information is shared between individual consumers, carers and clinicians.

¹ National Mental Health Consumer and Carer Forum (unpublished). *Confidentiality and Information Sharing with Families and Carers in Mental Health* [survey results].

² National Mental Health Consumer and Carer Forum (2009). *Privacy and Confidentiality Issues Paper*. Canberra: NMHCCF.



Privacy, Confidentiality & Information Sharing³

Privacy relates to an individual's ability to control the extent to which their personal information, enabling identification, is available to others.

Confidentiality is an obligation that restricts an agency from using or disclosing any information in a way that is contrary to the interests of the person or organisation that provided it.

Privacy and **confidentiality** are enforced by legislation and underpinned by professional codes of conduct to protect mental health information from unauthorised disclosure.

For the purposes of this Position Statement, **information sharing** refers to the sharing of appropriate clinical and non clinical information between clinician, consumer and carer(s).

Consumer & Carer Views on Privacy, Confidentiality & Information Sharing

The 2007-2008 NMHCCF consumer and carer survey on confidentiality and information sharing found that:

- privacy and confidentiality is sometimes used as a way to exclude consumers and carers from gaining information
- consumers and carers are not satisfied when mental health services do not acknowledge the importance of talking with them about how they would like health information to be shared
- consumers and carers like the concept of an agreed approach to exchange of information
- consumers and carers think additional assistance and support from clinicians will allow better management of information sharing between them
- consumers who are denied access to their health information see 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

³ Definitions adapted from: New South Wales Department of Health (2005). *Privacy management plan – NSW Health* [Policy directive circular]. Sydney: NSW Department of Health.



- carers are not always provided with the information they need to assist them in their caring role.

The National Mental Health Consumer & Carer Forum Position on Privacy, Confidentiality & Information Sharing

It is the position of the NMHCCF that:

- the privacy of consumers is a basic human right
- each consumer's right to privacy should be balanced with their nominated carers' need to give and receive information relevant to their caring role
- nominated carers should be identified, supported and incorporated into service provision
- nominated carers play a vital support role in a consumer's recovery and should be included in information exchanges, where appropriate and with the consumer's consent
- nominated carers' involvement should be regularly reviewed
- consumer and carer participation is essential in developing best practice guidelines for information sharing.

The NMHCCF encourages the mental health sector to endorse these principles and implement the key strategies and actions that arise from them.

Key Strategies to Improve Privacy, Confidentiality & Information Sharing Processes

Open communication between consumers, carers and clinicians

There should be a cultural shift towards a tripartite approach to information sharing. Open communication between consumers, carers and clinicians has the potential to reduce misunderstandings and antagonism around information sharing.

The NMHCCF calls for service level changes, including:

- increased communication between consumers, carers and clinicians about what information needs to be shared with whom, and how, when and why it should be done
- the development of workplace policies about information sharing with nominated carers
- written agreements developed about information management
- on-going staff education and support on this issue for all disciplines, together with supervision and peer review
- the involvement of consumers and carers in the development of practical guidelines and the provision of training about information sharing.

Clarify and disseminate privacy and confidentiality legislation and information sharing policies

There is a lack of knowledge and understanding amongst consumers, carers and clinicians about privacy and confidentiality laws and information sharing policies. This has the potential to compromise both the privacy of a consumer's information and the accessibility and provision of information to carers.

The NMHCCF calls for:

- privacy and confidentiality legislation to be easier to understand
- consumer and carer involvement in the development and improvement of mental health privacy and confidentiality legislation and policies
- the dissemination of mental health privacy and confidentiality legislation and policies widely within the mental health sector, with systems in place to ensure they are easy to access and implement.

Review ethical codes of mental health professional bodies

For clinicians, ethical frameworks generally influence decision making about privacy and confidentiality more than legal requirements. Unfortunately, professional ethics guidelines currently provide little advice to clinicians about information sharing with carers.

The NMHCCF calls for:

- the review of ethical codes, to broaden their focus from maintaining consumer confidentiality to including appropriate information sharing with carers to enhance recovery
- ongoing ethics training and support for clinicians.

Develop practical guidelines on privacy, confidentiality and information sharing

Supplementing legislation and ethical codes with practical guidance will help consumers, clinicians and carers make informed decisions about information sharing.

The NMHCCF calls for:

- the development and dissemination of clear practical guidance about legislation, policies and ethical codes.



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