



Australian Commission on Safety and Quality in Healthcare
Consultation on Consumer Engagement Strategies

SUBMISSION

The *Private Mental Health Consumer Carer Network (Australia)* (hereafter Network) represents Australians who have private health insurance and/or who receive their treatment and care, and those that care for them, from private sector settings for their *mental illnesses or disorders*. As our title implies, the Network is the authoritative voice for consumers and carers of private mental health settings.

The Network is committed to working with Governments and other key entities and would be pleased to work with the Commission in addressing the development of a consumer engagement strategy. Mental health brings with it many challenges. As a consumer and carer organisation we are in a unique position to provide direct lived experiences and would welcome the opportunity to engage in further consultations, either independently or with other relevant organisations.

The nature of mental illness is quite unique. The Network draws attention to the distinct hierarchy of health even within the area of illness. Mental illness is the most stigmatised and least understood health condition/disability and there are particular challenges to people with mental illness. Legal issues impact on us. **At times**, we can lose the right to decide to, or not to, take medications or other forms of treatment and under a *Community Treatment Order/ Involuntary Treatment Order*, treatment is forced upon us often via depot injections. If people do not voluntarily attend a mental health service for medications, health professionals seek them out in their place of residence and require them to comply. This is in contrast to the application of the principle of 'informed consent' which applies to most all other forms of health treatment.

Identified Issues for consultation

Issue one:

In terms of the first issue, the Network confirms and supports the Commission's approach to the development of the strategy.

Issue two:

Which specific groups or individuals should be involved in the Commission's work and why?

The Network has made the following formal Submission to the Commission:

- Australian Commission on Safety and Quality in Health Care - *National Patient Charter of Rights* – March 2008 (Input was via direct invitation to the Network)
- Australian Commission on Safety and Quality in Healthcare, *National Safety and Quality Accreditation Standards* - March 2007

The Network also participated in the following Commission Workshop via direct invitation:

- the Australian Commission on Safety and Quality in Health Care National Forum 2007 –*National Safety and Quality Accreditation Standards* November 2007

We have welcomed the direct involvement with the Commission in the past. In this regard we believe that as a peak national *mental health* consumer and carer peak body, we should have a more prominent role with the Commission into the future. We are in the unique position of being able to provide a *mental health* consumer and carer perspective into all the Commission's activities.

We also note the Consumers Health Forum (CHF) has a greater role with direct advices to the Commission. The Network believes that as mental health is our core business, we can bring unique perspectives that the CHF may struggle to represent and provide.

In terms of the Commission's approach outlined with the first part of the Background Paper, we note the following statements to develop the Strategy, and feel that we can strengthen the Network's call for a greater more direct involvement with the Commission by the following points:

- **The Commission is committed to involving consumers and patients in its work.**

As we have noted above, we believe we are in a unique position to offer the perspectives of both consumers *and* carers, the mental health area and we seek greater involvement in the work of the Commission.

- **The Commission sees the experiences, knowledge, wisdom and perceptions of patients and consumers as essential to its work to improve safety and quality.**

As a national and peak organisation specialising in the mental health area, the Network knows it can provide informed views, perspectives and experiences to the Commission.

- **The Commission acknowledges that a number of different methods of engagement will be required.**

Again, the Network continues to have input via Submissions and workshop attendance but believes we can have a greater and more direct part to play.

- **The Commission acknowledges the long history of consumer engagement in health that has been driven by consumers and consumer organisations.**

The Network draws attention to mental health which must be acknowledged as the most prominent area regarding consumer and carer participation. The foundation of this participation was firmly embedded within the 1992 National Mental Health Strategy and First Plan. We continue today within that Strategy with health ministers agreeing on 22 July, 2008 to the continuation of a Fourth Plan. An integral process within the Strategy saw the development of a number of key consumer organisations with the task of shaping the quality and safety of mental health services including policy, service delivery and evaluation within Australia. The Network is one of those organisations and in an excellent position to value add to the work of the Commission.

To summarise this issue, as a grass roots organisation with representation in all states in Australia, the Network firmly believes that it should be engaged more directly into the directions, work and activities of the Commission.

Issues 3, 4, and 5.

What aspects of the Commission's work are most important for consumer involvement?

The Network considers that the work of the commission in the areas below:

- Safety and quality
- Consumer AND carer rights
- Health standards
- Alignment with existing health/area specific standards
- Accreditation
- Education and training of accreditation surveyors
- Consumer and carer engagement, involvement and participation within ALL health organisations including the Commission
- Promotion of best practice in the safety and quality areas
- Monitoring role of safety and quality within Australian health

In what ways should consumers be involved in the Commission's work?

The Network feels strongly that organisations such as ours should be very involved in the work of the Commission.

Preferred model(s)?

- The Network should be a member of any Reference Group;
- The Network should be included as a partner in the activities of the Commission as is the CHF;
- The Network must be a member of any Expert Panel bringing the crucial mental health aspects to the Commission from a consumer AND carer perspective; and
- As happens now, the Network should continue to be the contact point for mental health perspectives.

Least preferred model(s)?

We do not believe the appointment of one consumer to the Commission's staff could possibly fulfil the broad perspectives of all health consumers. This option must not be entertained by the Commission as it is likely to bring a significant backlash especially from health specific areas such as mental health. This would present a compromise to the Commission which could be avoided with the options outlined above.

We do support the continued consultation processes that currently obtain feedback. However this option only presents an opportunity to comment on **already defined** areas, discussion papers. This does not allow for the **direction** of key activities that could be undertaken by the Commission.

Issue 6, 7, and 8.

How could the Commission best support effective consumer involvement in its work?.

The principles of effective consumer participation include:

- Involvement must first involve identification of a range of expert consumer organisations;
- Involvement must be acknowledged;
- Involvement must be actively sought;
- Involvement must be accurately costed;
- Involvement must be fully funded; and
- Involvement must be inclusive.

Are there any barriers to effective consumer engagement by the Commission that would need to be overcome: and how?

- Insufficient support and funding. (overcome by: Involvement must be accurately costed and budgeted for);
- Lack of identification of key organisations that could value add to the work of the Commission. (overcome by: Ensuring all health specific sectors which have formal established consumer and carer organisations be identified);

- Lack of understanding of the role, advantages and expert information that can be provided to the Commission from consumer organisations. (overcome by: Seeking greater understanding and engagement of consumer and carer organisations which have had formal input thus far to the Commission's consultation processes); and
- Expectation that one consumer advocacy organisation like the Health Consumers Forum can speak in an expert manner on behalf of all consumers. (overcome by: Engaging established *national* consumer and carer organisations in the consultation processes).

Whilst the Commission has identified the following 5 levels of involvement, the Network would like to turn this concept around to make it applicable to the levels of involvement of the Network with the Commission.

The Network knows that we can provide expert advice into the Commission's work and believe we should be involved in the following levels.

Level 1 – information or education: The Network be included in all print material forthcoming from the Commission.

Level 2 – listening and gathering information: The Network believes that we can provide expert information to the Commission. This level identifies the Commission as listening and gathering information and views.

Level 3 – discussing and consulting: The Network is in a position to be involved in a two way information exchange with the Commission. The Network believes that not only do we have an interest in the areas of safety and quality, because of the uniqueness of mental illness, we have a duty to the people that we represent to advocate for them. People within mental health facilities can be detained against their will, be subjected to seclusion and restraint. It is particularly in these areas, not encountered in general health, that the Network has expertise.

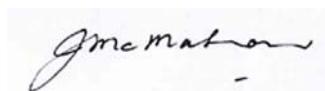
Level 4 - engaging: The Network is currently part of key policy and decision making processes across the mental health sector. As such, we are an identified organisation which shapes policy. We have been invited now to appear before **five** parliamentary inquiries/roundtables on behalf of mental health consumers and carers.

Level 5 - partnering: Because of the Network's standing, reputation and activities we believe we are partners in current policy processes.

Closing Remarks

The Network thanks the Commission for the opportunity to provide commentary to this important aspect of the development of a consumer engagement strategy. We would welcome further discussions as to how the Network could be used more fully in the work that the Commission undertakes.

Should you require further information or seek clarification of any aspect of this Submission, please contact the Network's Independent Chair, details below.



Janne McMahon OAM
Independent Chair
19 August 2008