MENTAL HEALTH

Consumer & Carer Participation
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Purpose of Consumer and Carer Participation

There is growing evidence to demonstrate that commitment to consumer and carer participation (CCP) results in improved health care for consumers and promotes a transparent and also accountable health service that includes consumers, carers and communities in the planning and evaluation of its services. Through participation and sharing their perspectives, consumers and carers make a valuable contribution to the Mental Health Service and strengthen links between the Service and communities.

Participation is a practice that embraces a philosophy of ‘working with’ rather than ‘doing to’ people. Participation is the involvement of consumers and carers in decisions about individual health care, as well as the involvement of consumers and carers in decisions about the provision of health care services.

The Charter of Healthcare Rights for Consumers, National Mental Health Standards and the national standards developed by the Australian Commission on Safety and Quality in Healthcare CCP to improve outcomes in the consumer journey through health services and will underpin all activities within the health service.

Aims of Consumer and Carer Participation

The aims of CCP are to ensure that:

- the health service involves consumers, carers and the community in planning, delivery and evaluation of services;
- there is transparency and accountability in health service decision-making and evaluation; and
- relevant local community groups are informed about mental health service issues and priorities.

The Mental Health Service is committed to involving consumers and carers at all levels of the organisation through a range of processes to enable an empowered and coordinated voice to be included in decision-making.

We will achieve this by:

- working in partnership with consumers, carers and community organisations;
- building the capacity of staff and the organisation to undertake consumer, carer, and community participation - from the level of individual care to the level of system changes;
- providing structures and processes for participation in all aspects of policy development, health service planning and quality improvement processes;
- providing resources to ensure that CCP occurs equitably throughout the District;
- promoting, supporting and developing the capacity of community members to participate in health service planning, delivery and evaluation;
- training and supporting staff to undertake CCP; and
- creating an open, transparent and accountable organisation.
### Principles of Consumer and Carer Participation in the Mental Health Service

<table>
<thead>
<tr>
<th>Respect</th>
<th>Accountability</th>
<th>Communication</th>
<th>Teamwork</th>
<th>Commitment</th>
<th>Support</th>
</tr>
</thead>
</table>
| • Promote a culture of collaboration by listening, involving and responding to concerns  
• Committed to including consumer and carer views and concerns in decision making  
• Ensure there is mutual agreement of the processes and assessment of issues under consideration as developed through productive working relationships  
• Consideration for and value of each other as equal contributors to the consumer and carer participation process | • Ensure that outcomes of consumer and carer participation are fed back to communities  
• Committed to developing services based on our communities identified needs and ensuring they are understood and acted upon  
• Provide information to consumers, carers and community members | • Ensure that consumers, carers and community members have information about their own health and health care services in order to make their own decisions, and that the information is provided in ways that they understand  
• Create an open, transparent and accountable organisation | • Work in partnership with consumers, carers and communities  
• Ensure that consultation and participation processes are inclusive and provide equity of access for consumers, carers and community members  
• Build trust and credibility throughout the participation process  
• Value, welcome and recognise consumers, carers and community experience(s) and expertise within the health system | • Willing to negotiate on key decisions  
• Committed to building the capacity of the organisation to enable effective consumer and community participation at all levels  
• Committed to providing a range of methods of participation to enable effective consumer and carer involvement  
• Committed to involving consumers and carers in making decisions about how they will participate | • Provide resources and support to consumer and carer participation activities and staff  
• Train and support staff to undertake consumer and carer participation |
Model of Consumer & Carer Participation

**Individual Level**
How will I be able to make decisions about my care and treatment based on information I can understand?

Consumer & Carer participants are included and involved in the decision making about their own care and treatment plans, informed about rights and responsibilities and through informed consent processes.

**Facility / Service Level**
How will I be able to provide feedback about services and help improve them for all consumers?

Consumers & Carers are able to directly contribute to planning, delivery and evaluation by being involved in committees, reference groups and working groups. Feedback is also provided via MH-CoPES questionnaires, inpatient Consumer Evaluation of Services surveys, NSW Health Patient Survey, and directly to the Service.

**District Level**
How will I be able to contribute to the direction of the health service?

Consumers and carers are able to participate in District committees / networks that report to the District Board or to the MH Executive. The needs of the diverse community are considered in all health planning.

**State & National Level**
How will I be able to contribute to policy making and improved standards of care?

Consumers and carers are engaged in planning and development of health services through peak state and national health agencies to improve patient outcomes.

Consumer Centred Care
Strategic District and Facility / Service Level Participation

The Mental Health Service has several avenues for consumer and carer participation that enable consumers / carers to have input into Service development and setting of strategic direction.

- South Western Sydney LHD has a Consumer and Community Council with membership open to Mental Health consumers and carers. The Council reports to the District Chief Executive and has representatives on the District’s Clinical & Quality Council.

- The Mental Health Service has a Consumer Advisory Committee (CAC) whose membership includes consumer representatives, consumer workers and Mental Health management. The aims of the Committee are to promote consumer participation in Mental Health Services and facilitate integration of consumer perspectives in the planning, development and implementation of local mental health services. CAC reports to the District MH Senior Managers’ meeting.

- Consumer workers have been employed in the Mental Health Service for many years. The range of roles undertaken by Consumer workers is diverse, covering systemic advocacy, peer support, education, and developing of partnerships with other organisations such as the NSW Consumer Advisory Group.

- A Carer Worker is employed part-time at Liverpool MHS, providing support to carers in the inpatient units and input into service development and evaluation.

- The two Districts have an extremely culturally diverse range of communities. The Mental Health Service attempts to address this diversity through employment of bilingual MH counsellors and clinical staff and bilingual consumer workers when possible. The MHS was recently one of two trial sites for the development of the Chinese language version of the MH-CoPES questionnaire. A bilingual consumer worker from SWS LHD MHS is on the steering committee of this project.

- Consumer workers are members of MHS peak committees and have access to the MHS executive. They are able to express a consumer perspective in discussions and provide feedback to consumer groups.

- The adolescent inpatient unit, Gna Ka Lun endeavours to have a carer / consumer representative member of its services planning meeting, which is the unit’s peak clinical decision making body.

- The MHS Patient Liaison Officer (PLO) meets with consumer and carer representatives on a regular basis: Family & Carer Mental Health Interagency (Carer Assist), carer worker, SWS LHD MHS carer group, consumer rights & issues meeting, and CAC. As a member of the MHS Clinical Governance Unit, the PLO is able to represent views and issues of carers and consumers to MHS executive members and senior managers.

- A biannual survey (Consumer Evaluation of Services Questionnaire) of all inpatient consumers is conducted each March and September to obtain feedback on consumers’ perceptions of their hospital experience. The results are used to determine areas of possible service improvement.
Individual Level Participation

Consumers and carers are able to have individual participation through direct contact with care providers or indirectly through intermediaries such as a consumer worker, Official Visitor, Member of Parliament, Health Care Complaints Commission, legal representative at a Mental Health Review Tribunal hearing, and various administrative review tribunals.

- Consumers and carers are offered the opportunity to participate in decisions about their treatment and care planning. In community settings, this involves discussions with their care coordinator and treating psychiatrist / registrar. In inpatient settings, the opportunity is available to attend the weekly multidisciplinary clinical team meetings where decisions are made about treatment options, discharge and community follow-up. Consumers are encouraged to sign the individual care plans that are developed as a result of these collaborative discussions.

- Inpatient units hold group meetings at least weekly where consumers are encouraged to raise any issues they have about their care or the ward environment.

- Consumer workers (and a carer worker at Liverpool) attend many inpatient units and community centres to talk with consumers about their care experience. Any issues raised by the consumers / carers can be relayed to the Nurse Unit Manager / Team Leader, entered in the Consumer Issues Log monitored by the Patient Liaison Officer or passed on to senior management.

- The Consumer Issues Log was developed jointly by consumer workers and the Patient Liaison Officer as a way to record and analyse issues raised by individual consumers that are not considered to be a health care related incident as defined by the Ministry of Health’s Incident Management policy.

- Consumer workers assist consumers to complete the MH-CoPES questionnaire if requested. This questionnaire gives an individual’s feedback on his/her care experience but results are aggregated and utilised at a facility and service level.

- Many inpatient units and community teams solicit feedback from consumers and carers separately from the service-wide feedback surveys, e.g. Banks House surveys the experience of admission via the Emergency Department, Rivendell conducts a post-discharge satisfaction survey, Campbelltown community centre conducts satisfaction surveys about its depot clinic, and rehabilitation services conduct evaluation surveys of programs and groups.
Evaluating Consumer and Carer Participation

**Internal Audits**

From 2009 to 2011, the Mental Health Service conducted clinical file audits on a range of themes identified through Root Cause Analyses of serious incidents. In the latter half of 2011, these audits were reviewed and a new suite of audits developed. These were implemented in early 2012. Reports on the projects that developed the audit suites are available elsewhere, e.g. evaluation reports on clinical documentation compliance, physical examination, risk assessment, clinical audit tool evaluation, etc.

The MHS has an audit calendar that schedules a range of audits across the year, including items relevant to consumer and carer participation.

- Discharge audit reviews whether the consumer and carer were consulted about discharge planning.
- Physical Health Care audit asks whether physical health care issues were discussed with the consumer and with the carer.
- Clinical Risk Assessment audit asks whether family / carers have been involved in assessment of risk and discussion about identified risks.
- Care Planning audit reviews whether the consumer / carer / family were involved in the care planning process.
- Assessment audit reviews whether a corroborative history was obtained from family / carers as part of the assessment process. It also asks whether the consumer has been advised of rights and responsibilities and whether a Primary Carer nomination has been sought from admitted inpatient consumers.

A baseline audit series was conducted in early 2012 and a follow-up in April / May 2012. Subsequent audits will follow the audit calendar schedule.

Audit results are reviewed by senior management, clinicians, teams and wards in community and inpatient services. Remedial plans are developed to address any deficits at an individual clinical level and unit / team / facility level.

The various projects are addressing issues such as low compliance in some areas, inadequate understanding of requirements to reach compliance, cultural factors, resource, and practice matters. In some instances, approaches to raise compliance have had to be broken down into stages because of the range of identified concerns.

Responses to some audit questions are able to be cross checked against other sources such as the inpatient survey and MH-CoPES, e.g. input into own care, family/carer involvement and discharge planning consumer involvement are questions in the MH-CoPES questionnaire.
MH CoPES

The Mental Health Consumer Perceptions and Experiences of Service project has been providing consumer feedback to Mental Health services across the state since 2007. It is a valuable form of communication providing a direct link between the consumer and service.

The MHS has a MH-CoPES working party consisting of clinical staff, consumer workers, a liaison project worker from NSW Consumer Advisory Group (NSW CAG) and a representative from InforMH (Information Mental Health). The working met monthly until recently. It now meets bi-monthly. It reviews the returns and assists in developing plans to address any issues identified through the questionnaires.

A senior MHS consumer worker and MHS manager are members of the state-wide MH-CoPES steering committee chaired by NSW CAG, which has overall responsibility for the project.

Ideally, MH-CoPES questionnaires are to be given to consumers on discharge from an inpatient or community service or at regular intervals for long-term consumers. This has been problematic with historically low return rates when distributed to consumers on discharge. The MHS attempts to address this problem through distributing and collecting questionnaires on set days in inpatient and community settings; monthly in inpatient and 6 monthly in community. Consumer workers and clinical staff are involved in these ‘blitzes’.

Locked boxes for completed questionnaires are being installed in all inpatient wards and community centres along with printed information about MH-CoPES located in stands next to the boxes. A combination of increased opportunity to provide ad hoc feedback via the boxes, blitzes, and increased consumer / staff education about MH-CoPES is expected to increase the return rate.

A DVD about MH-CoPES has been developed by NSW CAG and will be used as a training tool for staff when released. It will be placed on the MH intranet as a training resource. Access will be able to be tracked.

One of the ACHS recommendations in 2010 was to look at ways to increase the return rate, which has been low (a problem across the State, not just in our Districts). Data for 2011 shows that we increased our return rate by 93% from Jan-Jun 2011 to Jul-Dec 2011.

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<tr>
<th></th>
<th>2011 Jan-Jun</th>
<th>2011 Jul-Dec</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Returns</td>
<td>168</td>
<td>325</td>
<td>93%</td>
</tr>
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Return rates are still lower than desired but improving.

NSW CAG and InforMH analyse the returns on a six monthly basis giving aggregate feedback on particular issues and domains of care. The last collated report was Jan-Jun 2011.

There are 23 questions in the community version and 24 in the inpatient version. The questions are able to be grouped into four community domains and five inpatient domains:

- Choice of treatment
- Information
- Privacy
- Treatment and care
- Discharge (inpatient only)
A dashboard style of red / yellow / green bar graphs is used to indicate how satisfied consumers were with a particular component of care. Red indicates major improvement is needed, yellow indicates some improvement is needed and green indicates no improvement is needed.

Included in the questions are three relevant to consumer / carer involvement.

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<th></th>
<th>Red</th>
<th>Yellow</th>
<th>Green</th>
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<tbody>
<tr>
<td>Input into my own care</td>
<td>27</td>
<td>25</td>
<td>47</td>
</tr>
<tr>
<td>Family / carer involvement</td>
<td>32</td>
<td>27</td>
<td>41</td>
</tr>
<tr>
<td>Involvement in discharge planning</td>
<td>27</td>
<td>12</td>
<td>66</td>
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Aggregated returns are provided for the District, facility and individual community centres / wards. Centres and wards hold meetings with consumers to determine which three issues are most pressing and capable of some resolution. An Action & Change plan is jointly developed by consumers and staff, published as a poster and actions implemented. Subsequent six-monthly reports are expected to show improvements in the ratings for those three issues.

As an example, attached is a community MH-CoPES review presentation, the Action & Change consultation plan and the resultant poster.

**Patient Satisfaction Surveys**

The Mental Health Service has conducted six inpatient surveys since the closure of Rozelle Hospital. The first was solely for consumers at Concord Centre for Mental Health to obtain their perceptions of CCMH compared to Rozelle Hospital.

Five subsequent surveys were held service wide (inpatient) in March and September of 2009 and 2010 and March 2012.

The principle question relevant to consumer / carer involvement in the survey is:
- Opportunity to be involved in decisions about treatment

Consumers are asked to rate this topic on a five point scale: Excellent, Very Good, Good, Fair, Poor

Depending on how the data is interpreted, the result can be seen as stable and an example of a reasonable level of engagement across the five surveys or as needing more work to ensure consumers feel engaged in their own treatment decisions.

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<tbody>
<tr>
<td>Excellent / Very Good / Good</td>
<td>64</td>
<td>46</td>
<td>54</td>
<td>60</td>
<td>48</td>
</tr>
<tr>
<td>Poor / Fair</td>
<td>36</td>
<td>54</td>
<td>46</td>
<td>40</td>
<td>52</td>
</tr>
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</table>
Reviewing the item across the MH-CoPES and Satisfaction surveys indicates that there is little change in three years and that a substantial number of consumers consider there could be improvements made in their opportunity to take part in their own inpatient treatment / care planning.

Data from the latest clinical audits indicates that there has been an improvement by April 2012 in the number of consumers who have signed their individual care plan. The discrepancy between clinical audit data and consumer satisfaction and MH-CoPES surveys may be that many inpatient admissions are involuntary. Information from consumer surveys may reflect the individual’s perspective of the coercive nature of those admissions and associated treatment.