

# CONSUMER AND CARER PARTICIPATION POLICY TEMPLATE



*Promoting the mental health of all Australians*

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# CONSUMER AND CARER PARTICIPATION POLICY TEMPLATE

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- **BACKGROUND**

## **Purpose**

The Mental Health Council of Australia<sup>1</sup> endorses this document as a guide for all mental health services within the public, private and non-government sectors, to utilise in the development of consumer and carer participation policies.

While the current processes and initiatives of Commonwealth, State/Territory, non-government, and private mental health organisations in promoting consumer and carer participation in mental health service delivery are recognised and acknowledged, this template is presented for consideration in the development of a consumer and carer participation policy which will attempt to address identified gaps and ensure consumer and carer participation exists in its fullest capacity.

## **National Mental Health Strategy<sup>2</sup>**

The progress of Australia's mental health service delivery is well documented<sup>3</sup>. The establishment and focus of the *National Mental Health Strategies* is clearly to improve the quality of mental health service delivery in Australia. A central platform to these improvements was the realisation that

***consumer and carer input is essential if improvements in service delivery are to be achieved.***

The *National Mental Health Strategies* and the documents which underpin them<sup>4</sup> have put in place principles, objectives and strategies to guide the continual reform and required changes within the Australian mental health sector, including those activities required to improve consumer and carer participation.

The evaluation report of the initial *National Mental Health Strategy* highlighted the achievements in progressing consumer and carer participation. The evaluation identified the central role that consumers and carers are required to play in the planning, development, implementation, delivery, and evaluation of services.

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<sup>1</sup> The Mental Health Council of Australia (MHCA) is the peak, national, non-government organisation established to represent and promote the interests of the Australian mental health sector ([www.mhca.com.au](http://www.mhca.com.au))

<sup>2</sup> Reference throughout this document made to a *National Mental Health Strategy* recognises the development of an initial *National Mental Health Strategy* that ran from 1993 – 1998. At the end of this period, the Strategy was revised. In this document, the revised Strategy is referred to as the renewed *National Mental Health Strategy* which covers the period 1998 – 2003. Reference to a third *National Mental Health Strategy* is intended for implementation at the end of the period of the renewed *National Mental Health Strategy*.

<sup>3</sup> For example, the *National Mental Health Report 2000*, the *Evaluation of the National Mental Health Strategy*.

<sup>4</sup> *National Mental Health Policy*, *National Mental Health Plans*, *National Mental Health Statement of Rights and Responsibilities*, the *Medicare Agreements (the Australian Healthcare Agreements)*.

The findings of the evaluation of the initial *National Mental Health Strategy* highlighted that much work remains in the reform of mental health systems. This resulted in the extension of the *National Mental Health Strategy* for implementation over a further period from 1998 to 2003. The renewed *National Mental Health Strategy* attempts to build on the successes, outcomes, and evaluation of the initial *National Mental Health Strategy*.

The policy framework of the renewed Strategy is maintained through the *National Mental Health Policy*, the *Mental Health Statement of Rights and Responsibilities*, the *Second National Mental Health Plan*, and the *Australian Health Care Agreements*. The renewed Strategy is further enhanced through documents such as the *National Standards for Mental Health Services*, the *National Action Plan for Promotion, Prevention and Early Intervention for Mental Health 2000*, the *National Action Plan for Depression*, as well as other documents under the national framework of the Strategy.

The aims of the renewed Strategy complement the aims of the initial Strategy, and are achieved under the themes of the *Second National Mental Health Plan* (promotion/prevention, quality and effectiveness of service delivery, and development of partnerships in service reform). Commonwealth funding to State/Territory governments is considered through broader renegotiations of the *Australian Health Care Agreements*.

## **Consumer and Carer Participation**

Currently, a universally agreed-upon working definition of consumer and carer participation does not exist. For the purposes of this document, consumer and carer participation may be defined as:

Either voluntary or paid participation by consumers and carers in formal or informal planning, delivery, implementation, and evaluation of all activities associated with mental health services, as well as in all processes which effect the lives of consumers and carers, through sharing of information, opinions, and decision making power.

The aim of consumer and carer participation is to provide a process to improve the quality of service delivery through participation in development, implementation, and evaluation, and increase the level of consumer and carer satisfaction with mental health services.

***All participants involved in the mental health sector must display a high level of commitment and belief in the value of consumer and carer participation, for it to be truly effective rather than just tokenistic.***

Consumer and carer participation in determining mental health priorities ensures a sound basis for successful processes, programs and services to maintain and improve the mental health for all Australians.

Roles, responsibilities, and reporting mechanisms are important considerations when consumer and carer participation involves representation on committees established to progress mental health issues.

Consistent with the *Mental Health Statement of Rights and Responsibilities*:

***'individuals seeking promotion or enhancement of mental health care or protection when suffering mental health problems or disorders have the right to contribute and participate as far as possible in the development of mental health policy, provision of mental health care and representation of mental health consumer interests.'***

Along with this right, comes the responsibility of consumers and carers to **actively** contribute and participate in committees / forums where they are representing the perspective of consumers, carers, or an organisation. In addition, reporting mechanisms, either verbal or written, are required to ensure transparency and clarity in such representation and to ensure the body being represented is kept well informed of activities, processes and outcomes.

For participation to lead to strong partnerships, the input and contributions of all stakeholders, including those of consumers, carers, special needs groups, clinical service providers, private mental health service providers, non-Government and Government organisations, Aboriginal and Torres Strait Islander groups, and State/Territory peak mental health bodies, needs to be valued, respected, and appreciated. With such recognition, there is an expectation that all groups will willingly and actively contribute their special expertise and knowledge, and provide valid representation. With such collaborative practice and sharing of special expertise from all key stakeholders, the mental health sector is in a greater position to promote the mental health of all Australians and assist in enhancing mental health outcomes.

## • **DEVELOPING A CONSUMER AND CARER PARTICIPATION POLICY**

The following issues are presented for consideration in the development of a consumer and carer participation policy. Once implemented, such a policy will ensure organisations are held accountable for consumer and carer participation in its fullest capacity.

### **Components for Inclusion in a Consumer and Carer Participation Policy**

1. The purpose of the policy should be clear, achieved through a concise statement of purpose/aim.
2. The policy should be grounded by a set of principles that reflect the value the organisation places on consumer and carer participation. For example:
  - Consumers and carers have a right to participate and have a direct and active role in all processes that affect their lives.
  - Consumers and carers with appropriate skills and expertise should be appointed to represent the interests of consumers and carers.
  - Priority should be given to the appointment of consumers and carers who are members of groups able to provide support and a network for consultation.
  - A single person should not be appointed to represent the views of both consumers and carers. Both a consumer **and** a carer representative are required to represent the views of each respective group.
  - Participation of consumers and carers is an essential component of continuous quality improvement.
  - Communication links between the organisation and consumers and carers are effective two-way processes. Information is shared and exchanged with consumers and carers to enable effective participation.
  - The organisation recognizes the need for resources and support for the consumer and carer participation process to enable effective participation.
  - Opportunities are provided for the ongoing support and relevant training and education for consumers and carers to assist in their effectiveness as consumer and carer representatives.
  - Consumers and carers must be aware that responsibilities are associated with participation, primarily the active contribution to quality improvement processes.

3. The policy should articulate the organisation's position in relation to consumer and carer participation in:

- strategic planning for the organisation;
- service planning;
- service delivery;
- service implementation;
- service evaluation;
- health decision-making; and
- resource allocation and development.

4. The policy should state:

- the responsibilities of all parties in implementing the policy;
- what measures will be taken to monitor the policy's implementation;
- whether/when the policy should be reviewed; and
- how the policy will be evaluated (including consideration of what measures or indicators may be used in the evaluation).

## Best Practice Principles for Inclusion in Participation Policy

The following best practice principles have been identified as necessary considerations in the development of a consumer and carer participation policy, and are presented as a standard benchmark for mental health organisations to aim for when promoting and practicing consumer and carer participation.

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|-------------------|---|
| <b>Practice 1</b> | All public, private, and non-government mental health systems will promote, through practice, consumer and carer participation in all processes that affect the lives of consumers and carers, for instance, recruitment, resource allocation, planning, service delivery, research, evaluation, and continuous quality improvement processes including accreditation against the <i>National Standards for Mental Health Services</i> .                              |
| <b>Practice 2</b> | All public, private, and non-government mental health organisations will engage consumers and carers with special expertise to participate in all processes and activities that affect the lives of consumers and carers. Reimbursement for such engagement will be negotiated between consumers and carers and the organisation on a paid or volunteer, part-time or full-time basis.  |
| <b>Practice 3</b> | Consumers and carers will be employed by external agencies, such as, but not limited to, accrediting agencies, as people who have special expertise, to participate in all processes and activities that affect their lives (consumer consultant model).  |
| <b>Practice 4</b> | All public, private, and non-government mental health organisations will have a consumer and carer participation policy that adopts the principles and practices outlined in this policy template to suit individual needs and is 'locally owned'.  |
| <b>Practice 5</b> | Each State/Territory will have a recognised peak mental health body representing that State/Territory, with consumers and carers involved in the management and operation of the organisation, and which operates for the benefit of people with mental illness and carers.   |
| <b>Practice 6</b> | When considering consumer and carer participation, the selection process will ensure potential applicants are sought from key consumer and carer groups who are able to provide support and a network for consultation, for example, local, State/Territory, national, public, private, and non-government peak bodies.   |
| <b>Practice 7</b> | Consumer and carer representatives at committees / forums, have the responsibility to <b>actively</b> participate in the discussions, decision-making and activities of that committee, and ensure the views of the body they are representing are adequately portrayed. In addition, consumer and carer representatives have a responsibility to report back, either verbally or written, to the body they are representing on the outcomes of their representation. |
| <b>Practice 8</b> | Terms of Reference and Duty Statements will be developed for consumer and carer representation and participation at all committees. This will ensure clarity and transparency in the roles and responsibilities of all positions.   |

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| <b>Practice 9</b>  | Unless otherwise agreed by consumers and carers, consumers and carers will receive payment for their representative participation <sup>5</sup> and reimbursement of expenses (e.g. travel and meals) incurred during their recognised active participation in externally organised mental health activities and processes that affect their lives.  |
| <b>Practice 10</b> | All public, private, and non-government mental health organisations will ensure adequate feedback mechanisms exist to facilitate information flow between the organisation and consumers and carers. For instance, satisfaction and evaluation surveys; focus groups; support groups; regular meetings with local, State/Territory, public, private, and non-government community advisory groups; newsletters; mental health consumer and carer networks; meetings with senior management; websites; consumer and carer representation on steering committees, reference groups, and State/Territory ministerial committees. |
| <b>Practice 11</b> | An evaluation and ongoing review process of consumer and carer participation will occur annually within all public, private, and non-government mental health organisations, to ensure sound principles and practices are maintained and mental health organisations remain accountable for their actions. This may occur in conjunction with continuous quality improvement processes and accreditation against the <i>National Standards for Mental Health Services</i> . Following the review process, where required, policies and practices will be changed to reflect the outcomes of the evaluation.                   |
| <b>Practice 12</b> | Consumers and carers with special expertise will participate in staff education/orientation activities in all public, private, and non-government mental health organisations.  |
| <b>Practice 13</b> | All public, private, and non-government mental health organisations will provide ongoing support, education, and training for consumers and carers on their rights and responsibilities as consumer and carer participants/contributors in all processes that affect their lives, including the planning, development, implementation, and evaluation of mental health services.  |
| <b>Practice 14</b> | All public, private, and non-government mental health organisations promoting and practicing consumer and carer participation will maintain a database of consumers and carers available for participation once consumers and carers have agreed to have their details recorded on a database. Such a database will ensure a broad network of consumers and carers who are easily contactable and readily available to participate.   |

<sup>5</sup> That is, participation where the individual is providing a consumer perspective or a carer perspective; rather than participation in the management of treatment for their mental health problem or mental illness.

- **CHECKLIST**

**Does the consumer and carer participation policy:**

- ✓ State a clear purpose?
- ✓ Have a set of principles that reflect the value the organisation places on consumer and carer participation?

Articulate the organisation's position in relation to consumer and carer participation in:

- ✓ Strategic planning for the organisation
- ✓ Service planning
- ✓ Service delivery
- ✓ Service implementation
- ✓ Service evaluation
- ✓ Health decision-making
- ✓ Resource allocation and development
- ✓ Other
- ✓ State responsibilities of all parties in implementing the policy?
- ✓ State what measures will be taken to monitor the policy's implementation?
- ✓ State whether / when the policy should be revised and evaluated?
- ✓ State how the policy will be evaluated (including consideration of what measures or indicators may be used in the evaluation)?
- ✓ Ensures the service promotes consumer and carer participation in all processes that affect the lives of consumers and carers?

Includes consumers and carers in every process that affects their lives, for instance:

- ✓ Recruitment
- ✓ Workforce
- ✓ Resource allocation
- ✓ Evaluation

- ✓Planning
- ✓Service delivery
- ✓Research
- ✓Evaluation
- ✓Other
- ✓ Allow for the employment of consumers and carers with special expertise to participate in all processes and activities that affect their lives?
- ✓ Promote the employment of consumers and carers by external agencies (e.g. accrediting agencies) to participate in all processes and activities that affect their lives?
- ✓ Ensure Terms of Reference and Duty Statements are developed for consumer and carer representation and participation on all committees?
- ✓ Ensure consumer and carer representatives on committees abide to reporting mechanisms, either written or verbal, upon completion of their representation?
- ✓ Adopt the principles and practices outlined in the National Consumer and Carer Participation Policy Template and adopt them to suit local need?
- ✓ If a State/Territory peak body, ensure consumers and carers are involved in the management and operation of the organisation?
- ✓ Ensure processes are established for the payment for consumer and carer participation and reimbursement of their expenses resulting from their active participation?
- ✓ Ensure adequate feedback mechanisms exist to facilitate information flow between the organisation and consumers and carers?
- ✓ Ensure consumers and carers with special expertise participate in staff education/orientation activities within the organisation?
- ✓ Ensure the organisation provides ongoing support, education and training for consumers and carers on their rights and responsibilities and in their participation?
- ✓ Ensure requests for employment or representation of consumers and carers is sought from key consumer and carer groups who are able to provide support and a network of consultation?
- ✓ Ensure a database is maintained of consumers and carers available for participation?