ACT HEALTH CONSUMER AND CARER PARTICIPATION FRAMEWORK

DRAFT FOR CONSULTATION

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1. **FOREWORD FROM THE MINISTER FOR HEALTH**

2. **FOREWORD FROM THE HCCA PRESIDENT**

3. **EXECUTIVE SUMMARY**

Consumers and carers in the health care system mirror the diversity of contemporary society. Their experiences and outcomes define the essential nature of the services that they have received, and that they will receive in the future. Consumers, carers and community members are partners with clinicians and policy makers in the provision of high quality, safe, respectful and inclusive health care practices and services.

ACT Health has required consumer and carer participation for some time, however consumers, carers and ACT Health staff often seek clarification of the best ways for consumers, carers and community members to be included in health care planning and policy development. The Framework will address many of these questions. The Framework will also play a role in heightening community and staff awareness of the importance of consumer and carer participation in achieving health quality and safety.

The Framework sets out the principles for participation and the structures required for continuous improvements to the quality of relationships between consumers, carers and staff of ACT Health, and the quality of services. Integral to participation is growth of individuals, groups and organisations. The Framework recognises the varying degrees of readiness for participation and values constant reflection and evaluation to support the growth of all individuals, groups and organisations.

The Framework acknowledges the need for systemic change that will support genuine consumer and carer participation. Its focus is on organisational development, workforce development and resourcing that will build capacity within ACT Health and the community. The Framework details strategies for consumer and carer participation in policy development, planning, implementation and evaluation of services, individual advocacy and systems advocacy, staff development and research.

There are barriers and enablers for successful participation by consumers, carers and community members. These provide a salient reminder that this Framework provides strategies for high level and high quality consumer and carer partnerships with the health system, however it also requires commitment to the integrity of the process. Commitment to the integrity of the process produces the strength, flexibility and resilience required for the Framework to be effective and far-reaching.

Implementation of the Framework and the Evaluation, Monitoring and Public Reporting are the last major components of the document, and these are all iterative processes.

The Priority actions contained within the Implementation of the Framework are designed to be a checklist of evidence-based practice and also a plan to take forward into the future for the operational elements of the Framework. The Evaluation, Monitoring and Public Reporting is an important element of the process of continuous improvement. It will be a mechanism to ensure that commitment to this Framework is amplified into the future by ACT Health, clinicians, consumers, carers and community members.
4. **INTRODUCTION**

"Community participation is integral to recognising human rights and strengthening civil society. It promotes trust and respect between the community and government by enabling stakeholders to have a say in decisions that affect their lives. It enhances openness and accountability on the part of the government."¹

4.1 Including consumers, carers and community members in health

Historically health services were designed by health professionals and administrators and delivered to the community. Consumers and their family, other carers and community members have had little or no opportunity to provide ideas or input to improving health services.

Over the past two decades there has been a shift to include consumers, carers and community members in decision-making about service development and delivery and to view this inclusion as essential for maintaining quality and safety in healthcare. Increasingly, consumers, carers and community members are sitting at the table where policies and strategic decisions are made about the health services they use². In 2008 ACT Health involves consumers, carers and community members in a range of ways across the organisation, for example on committees, and in provision of staff education.

A consumer or carer perspective brings different and important dimensions to what constitutes safe and quality health care. It is only by working in partnership with consumers, carers and community members and listening to and learning from their participation, that it is possible for health services to truly appreciate what constitutes quality, safe health care.

4.2 Democratic Right

The rights and responsibilities of individuals to participate in the planning and delivery of health services was recognised in the 1978 World Health Organisation Declaration of Alma Ata.³ This sentiment was repeated in the Ottawa Charter for Health Promotion which recognised that effective health promotion requires the involvement of communities in setting priorities, planning, implementing and evaluating health initiatives.⁴

Consumers, carers and other community representatives can nominate to be elected as representatives of the people of the ACT and/or can vote on policies and programs. Secondly, in relation to health, people can nominate to be community or consumer representatives on boards and committees of public health services. These boards and committees operate within government guidelines.

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² ACT Health *Come to the Table: A Discussion Paper, A proposed model for effective and genuine participation of consumers and carers across Mental Health ACT*, June 2006 p 3
³ International Conference on Primary Health Care, Alma-Ata, USSR, September 1978
⁴ *Ottawa Charter for Health Promotion*, First International Conference on Health Promotion, Ottawa, 21 November 1986 – WHO/HPR/HEP/95.1
4.3 Accountability
Participation as a mechanism to ensure accountability is strongly identified throughout the health system. Consumers, carers and community members have a right to provide feedback about health services. Consumers can provide feedback on public health services through any ACT Health staff member or via feedback forms available at all ACT Health sites, by email to HealthFeedback@act.gov.au or by telephone 6244 2447 or 6244 2947. Consumers, carers and community members can also choose to have their feedback addressed by writing to the Health Services Commissioner. This is an important process of accountability. More information in relation to the ACT Health feedback management process can be found at www.health.act.gov.au and following the links from 'Contact Us' or the ACT Health Services Commissioner can be found at http://www.hrc.act.gov.au.

The Australian Council of Healthcare Standards (ACHS) accreditation programs provide a framework for continuous improvement involving consumer participation. The ACHS Evaluation and Quality Improvement Program (EQuIP) provides health care organisations with a framework to deliver a consumer-centred service focusing on the continuum of care by incorporating systematic external peer review. Accreditation of standards under the ACHS requires consumer participation. For more information, the ACHS website can be found at www.achs.org.au.

4.4 Evidence for Participation
The published evidence regarding the benefits of consumer and carer participation is beginning to grow across the levels (government department, hospital/service organisation, ward/department, and individual care) of health service provision. This is important because historically there has been a lack of evaluation of studies (projects) on participation.

A recent study undertaken by the Cochrane Collaboration found evidence:
- that consumer involvement in developing patient information material can improve the clarity of the information and the knowledge of people who read the material;
- that using consumer interviewers instead of staff interviewers can result in small differences in satisfaction surveys; and
- of differences in the views of participants towards priorities for community health goals when telephone discussions were used, compared with face-to-face meetings, to involve the public. ³

Overall, there is evidence that participation frequently added different information from that provided by government, researchers and health service providers. Participation was seen to improve or contribute to:
- guidelines that had previously been developed by expert bodies;
- psychosocial indicators of health;
- how and when information is provided;
- the evidence base for choice of education strategies or programs for consumers, carers and community members;
- the reduction in the use of follow-up and emergency services;
- design of clinical trials in relation to ethically challenging studies; and
- the quality of health care.

³ Nilsen ES, Myrhaug HT, Johansen M, Oliver S (2006), Oxman AD, Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material, John Wiley & Sons Ltd
4.5 Development of the Framework
In May 2007 ACT Health developed a steering committee to work together to develop this Framework for consumer, carer and community participation across the organisation. This initiative came in response to recommendations from the Health Care Consumers Association of the ACT (HCCA) and feedback received from other consumers and from carers.

Question:
2. Why do you think consumer, carer and community member participation is important in health care?

5. PRINCIPLES OF PARTICIPATION

5.1 Overview
For participation to work ACT consumers, carers and community members need to work cooperatively with each other and with ACT Health to an agreed set of principles. These principles are consistent with legislation, the ACT access health, the National Health Charter of Rights and other available evidence.

A guiding set of principles has been adopted and is outlined below. These principles underlie how the Framework should be put into action.

<table>
<thead>
<tr>
<th>Principle</th>
<th>Operation</th>
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<tbody>
<tr>
<td>Trust</td>
<td>Participation works best where there is mutual agreement of the processes and assessment of the issues under consideration as developed through productive working relationships</td>
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<tr>
<td>Respect</td>
<td>All participants need to show consideration and value each other as equal contributors to the participation processes</td>
</tr>
<tr>
<td>Openness</td>
<td>Participation must be built from the ground up and this can only be ensured if all participants are open to considering the ideas of consumers, carers and the community and are willing to accept change</td>
</tr>
<tr>
<td>Equal Opportunity</td>
<td>At the earliest possible time, involve all those who will be affected by the decisions, inform them of the decision making process and ensure they have access to the information and the means to participate</td>
</tr>
<tr>
<td>Equity</td>
<td>Whilst the terms equity and equal are often used interchangeably, their different meanings are critical in the application of principles and in policy development – equal relates to sameness, whereas, equity relates to fairness. In relation to consumer and carer participation a good example of the difference in these two terms is – consumers and carers being offered equal or the same opportunities as staff to participate. Versus, consumers and carers being provided different or equitable opportunities, so as to enable them to participate on the same basis as staff.</td>
</tr>
<tr>
<td>Advocacy and Support</td>
<td>Participation must be supported from the top and resourced so that participation is meaningful for the consumer, carer and community member</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>The capacity to undertake participation requires skilled organisations and benefits from multiple strategies and resources</td>
</tr>
<tr>
<td>Shared ownership and</td>
<td>All involved share ownership of the process and decisions and are responsible for monitoring and evaluating the impact and outcomes. How</td>
</tr>
<tr>
<td>accountability</td>
<td></td>
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</tbody>
</table>

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<tbody>
<tr>
<td>the responsibility is distributed should be defined as part of the participation arrangement</td>
<td></td>
</tr>
<tr>
<td><strong>Dissemination</strong></td>
<td>The decisions made, and how consumers, carers or community members' participation influenced these decisions, should be communicated to all those involved and affected by the decisions</td>
</tr>
<tr>
<td><strong>Evaluation</strong></td>
<td>Lessons learnt from the participation process should be identified and communicated as widely as possible</td>
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</table>

**Questions:**

3. Are the principles selected for inclusion in this Framework relevant?
4. Are there any principles inherent in this Framework that would be more appropriate for this section?

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**6. FEATURES OF GOOD PRACTICE**

A number of features of good practice were identified in the 2003 report *Consumer and Provider Partnerships: What Makes Them Work*[^8]. The Framework has recognised some of these features as central to the development of consumer and carer partnerships and important for participation.

6.1.1 *Investing time*

Investing time is an important facet of any participation. Consumer, carer and provider relationships are no exception. All parties need time to understand each other's perspectives and to set up management structures and processes that enhance rather than impede the process of working together.

6.1.2 *Flexibility and listening*

Flexibility and recognition of the sovereignty of consumer and carer needs is required, particularly when designing services or tools for consumers, carers and community members. There needs to be organisational willingness and support for the consumer and carer voice to be heard.

6.1.3 *Power and empowerment*

Relationships between consumers, carers and providers have traditionally been characterised by an imbalance of power. However, as ACT Health develops partnerships with consumers, carers and community members the nature of these relationships inevitably changes. Good partnerships should be empowering for all parties. ACT Health working together with consumers, carers and community members can be more effective than when all parties work on their own, so that the whole is significantly greater than the sum of its parts.

6.1.4 *Responding to Feedback*

ACT Health must ensure that feedback is not a one-way process, by sharing and responding to feedback received.

6.1.5 *Supporting Consumers, carers and community members*

Participation is often not easy for consumers, carers and community members. They can face a variety of barriers and sometimes need support for them to be actively involved. Because their

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[^7]: State of Victoria, Department of Human Services, *Doing it with us not for us*, Participation in your health system 2006-2009, Melbourne 2005, p 20
[^8]: Moore, Kate, *Consumer and Provider Partnerships: What makes them work*, The Consumer and Provider Partnerships in Health Project, an initiative of the Consumer Focus Collaboration and funded by the Australian Government Department of Health and Ageing, February 2003, p 12
participation can bring about change, it is often misunderstood or resisted by providers. It can even bring about a hostile response. Support systems should be put in place and a review undertaken of existing practices that might be a barrier to consumer and carer participation.

6.1.6 Engendering Realistic Expectations
Participants must be aware that any process to improve services will inevitably be the subject of high expectations by many providers, consumers, carers and community members. While it is unrealistic to expect that dramatic changes will happen overnight, ACT Health is making a fundamental commitment to build a responsive and inclusive health care system as a long term goal.

6.1.7 Valuing the work and expertise of consumers, carers and community members
Many consumers, carers and community members participate in different aspects of service planning and delivery but are often expected to do what can be a large amount of work purely as a voluntary activity. ACT Health should ensure that all contributions are given appropriate recognition and appreciation. In some circumstances payment for participation may be appropriate, in line with ACT Health's Consumer and Carer Reimbursement Policy.

6.1.8 Health care relationships
With the formation of consumer, carer and provider partnerships, people who had previously encountered each other only in a patient/health care provider relationship may suddenly find themselves in an awkward situation with the potential to affect the relationship. ACT Health, consumers, carers and community members should maintain an awareness of the difficulties that may be encountered as a result of the change in relationship.

For consumers, carers and community members participating in planning, delivery or even evaluation of the same service they attend for health care raises issues about their future use of the service. If they provide feedback or perspectives that are in any way critical they may fear that it will have an adverse impact on their relationship with the provider. Providers who have been working hard to deliver what they believe is a good service may be offended by critical feedback. Some providers may also react negatively to the way in which the feedback is provided. Care needs to be taken to manage potential issues arising as a result.

Question:
5. If you or your organisation have been involved in consumer, carer or community participation, what methods have you found to be effective?

7. PARTICIPATION STRATEGIES

7.1 Overview
The Framework sets out the features of good practice and the structures required for continuous improvements to the quality of relationships between consumers, carers, community members and staff of ACT Health in order to improve the safety and quality of services.

Central to the Framework is recognition of the need for a range of strategies for consumer, carer and community member participation. This range of strategies acknowledges that some consumers, carers and community members will prefer involvement that relies on giving feedback about services they have received or were unable to access, whilst others will prefer involvement that is

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Moore, Kate, Consumer and Provider Partnerships: What makes them work, The Consumer and Provider Partnerships in Health Project, an initiative of the Consumer Focus Collaboration and funded by the Australian Government Department of Health and Ageing, February 2003, p 48
more active. Informed participation provides opportunities for meaningful dialogue on all issues of importance to consumers, carers, community members and ACT Health.

7.2 Participation Models

7.2.1 Participation through dialogue
Central to effective participation is reciprocal learning between consumers, carers, community members and service providers. This type of learning occurs best when meaningful dialogue takes place in a safe environment. A dialogue allows consumers, carers, community members and service providers to discuss an issue in depth so that all participants may gain a deeper understanding of the perspectives of others.

7.2.2 Building capacity for participation
Some of the fundamental principles of a community development approach include: community ownership of approaches, issues, processes and solutions, participation, capacity building and change that is sustainable and beneficial. Capacity building refers to the development of sustainable skills, organisational structures, resources and commitment to health improvement in health and other sectors, to prolong and multiply gains many times over. To ensure participation of consumers, carers and community members is genuine, effective and sustainable over time, attention is needed in the areas of leadership and policy, workforce development, and consumer and carer development.

7.3 General Participation Strategies

7.3.1 Consumer Initiated Feedback
Community consultations and consumer feedback forms are general participation strategies. Consumer consultations generally take place on specific issues, whilst consumer feedback forms can be used by consumers, carers and community members to provide compliments or comments about any aspect of ACT public health. These strategies may also be described as consumer initiated feedback, although ACT Health provides the tools and encouragement to participate.

The ACT Health Listening and Learning Standards set the framework for managing consumer initiated feedback. In the standards, consumer feedback is defined as "information provided by consumers, in their own words and in their own time, about their experiences of any aspect of health care, treatment or services."  

7.3.2 Satisfaction Surveys
ACT Health contracts independent, benchmarked, formal satisfaction surveys to gather feedback from people who have used the service. Information gained by consumer satisfaction surveys assists with prioritising and actioning quality improvement initiatives.

7.4 Consumer strategies

7.4.1 Consumer Representatives
Consumer Representatives provide a consumer perspective on decision-making bodies, during consultations, working groups, steering committees, on tender selection panels, and staff selection panels. Additionally, Consumer Representatives can play a valuable role in evaluation and research conducted by ACT Health.

7.4.2 Health Care Consumers Association Representatives Program

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10 Raising the standard, Section 1 Good practice standards for community service organisations, ACT Government, January 2002, p 46
11 ACT Health Consumer Feedback Standards, Listening and Learning, ACT 2003, p 1
The Consumer Representatives Program is a focal point for both consumer groups and government for the nomination, training and support of consumer representatives. It provides skilled representatives to more than 50 committees across the ACT health system. The Program provides training, policy support and resource materials for consumer representatives, establishes channels for representatives to feedback to the community and identifies potential nominees for committees and advisory boards.

Representatives are people who use healthcare services and have particular knowledge not otherwise available to policy makers. They ensure health service users have input into policies and direction and remind committee members that the public interest is of primary concern.

7.4.3 Consumer Engagement Team
The Consumer Engagement Team is employed within ACT Health to provide consultation to ACT Health staff on consumer engagement and to promote consumer participation throughout the organisation. The promotion of consumer participation may require the Consumer Engagement Team to provide orientation for new consumer representatives as well as participate in the delivery of staff education. The Consumer Engagement Team may participate to provide a consumer voice however is never involved as a consumer representative or in the provision of individual advocacy services.

The Consumer Engagement Team is responsible for overseeing and reporting on consumer feedback received by ACT Health.

7.4.4 Individual and Self Advocacy
Individual Consumer Advocacy provides advocacy services for consumers of ACT Health. The preferred model for advocacy, known as self-advocacy requires advocates to support consumers to advocate for themselves. Self advocacy is undertaken by a person or group who share the same characteristics or interests on behalf of the same person or group. Self-advocacy involves imparting of skills and knowledge so that consumers may advocate for themselves many times over. The difficulty with this form of advocacy is that sometimes those undertaking advocacy and speaking up for themselves are likely to be further exposed and be more vulnerable as a result. Only when it has been determined that a person is unable to advocate for themselves would an advocate provide individual advocacy, that is, advocate on behalf of the consumer. ACT Health provides and produces a number of consumer resources aimed to assist consumers to advocate for themselves. For example "10 tips for safer health care" which is available via the ACT Health website.

7.4.5 Systems Advocacy
This form of advocacy is primarily concerned with influencing and changing the system (legislation, policy and practices) in ways that will benefit people as a group within society. Systems advocates will encourage changes to the law, government and service policies, and community attitudes.

7.4.6 Consumer Educators
Consumer educators can deliver education to ACT Health staff on the consumer experience by telling their personal story. This model of education has been shown to be effective for increasing knowledge and reducing stigma.

7.5 Carer participation roles
7.5.1 Carer Representatives
Carer Representatives provide a carer perspective to decision-making bodies, during consultations, working groups, steering committees, on tender select panels and staff selection panels.
Carers are already a ‘time poor’ group, but they appreciate the value of input pathways on carer needs. Therefore there may be opportunity for Carers ACT and ACT Health to negotiate on carer input via professional consultancy and advocacy pathways. While carers frequently express concern about the small number of carers available to fulfil carer participation roles, it appears there may also be an issue of insufficient resourcing in fulfilling these roles.

Carers ACT is the single provider of comprehensive carers' support services in the ACT. Carers ACT provides quality information and direct support services to unpaid family carers including young carers. They also provide community education, advocacy and are the 'voice' of carers in the ACT. More information regarding Carers ACT can be found at www.carersact.asn.au.

7.5.2 Carer Educators
Carer educators deliver education to ACT Health staff on the carer experience by telling their personal story. This model of education has been shown to be effective in creating a balanced and informed understanding of the challenges facing carers and the benefits of support they provide to the consumer when involved in a caring role.

7.5.3 Carer Advisory Group
The Carer Advisory Group is an opportunity for Carer Representatives, Carer Educators and Carer Peer Support Workers to meet for the purpose of identifying and discussing carer issues in addition to providing support to each other. Meetings provide a venue to discuss any new and recurrent issues of concern for carers.

7.6 Participation of young people
As with participation of the general community, young people have a right to be involved in decision making about services that affect their lives.

Strategies for engaging with young people must be developed with consideration of the different needs and resources of young people compared with the general population. A range of strategies is required to ensure engagement with a range of young people. Consideration should be made of the preferences of young people for participation, as well as the number and capacity of young people able to take on these roles. The most effective strategies will be those designed in partnership with young people and organisations that work directly with young people. It cannot be assumed that young people will participate through recognised community or government organisations.

Organisations who work with young consumers, family members or young carers require the capacity to support young people for a variety of participation roles. For young people to participate as representatives, advocates, peer supporters and educators, specific training and ongoing support is required.

7.7 Diverse Populations
For effective representation, it is essential that representatives have access to a range of consumer, carer and community member views. This would include the views of people of all age groups, people of culturally and linguistically diverse background and people with differing experiences of mental illness and health, as examples.

The ACT population represents a large range of people from culturally diverse backgrounds. It is well recognised that the health needs of this diverse population differs according to different understandings of health and community, and different historical and current relationships with service providers.
One of the great challenges for consumer and carer participation is to ensure that those consumers, carers and community members who are from culturally and linguistically diverse backgrounds have a voice in decision making regarding services that are designed to meet their needs. This can be extended to those groups who are often marginalised in decision-making around public policy.

Carers ACT runs the Culturally and Linguistically Diverse (CALD) Carers Program to provide support and facilitate access to services for Carers from non English speaking backgrounds. The CALD Carers program aims to assist CALD Carers to break down the barriers and ensure they have access to the services they are entitled to. As part of this, the program maintains 18 cultural support groups for CALD Carers. The support groups allow CALD carers to meet and talk to other carers who share the same language and culture.

7.7.1 Barriers and enablers specific to culturally and linguistically diverse populations

Barriers particular to diverse communities have been identified by the Health Issues Centre and include:

1. Lack of understanding by service providers of socio-cultural factors;
2. Lack of effective communication; and
3. Systemic and organisational barriers, such as lack of language services, lack of data, lack of awareness and access to health information.\textsuperscript{12}

The Health Issues Centre found that most effective participation depends on:

1. Cultural competency;
2. Comparative analysis between demographic and service utilisation data: knowing who is out there and who is and isn't using the services;
3. Accessible and appropriate language services;
4. Developing equal partnerships with multicultural and ethno specific agencies, organisations and multiple community groups;
5. Availability of health information;
6. Workplace diversity;
7. Whole of community approach; and
8. Adequate resourcing.\textsuperscript{13}

7.8 Aboriginal and Torres Strait Islander People

The ACT Government is committed to including people from Aboriginal and Torres Strait Islander backgrounds in ceremonies and official events, including acknowledgement of the Ngunnawal people, the traditional custodians of the land on which the Australian Capital Territory stands. It is important that the unique position of Aboriginal and Torres Strait Islanders in our culture and history is recognised.

The need for, and potential benefits of participation of people of Aboriginal and Torres Strait Islander background is clear. These populations currently access services at reduced rates compared with the general population, and are rarely involved in formal participation with ACT Health. It is recognised that the strategies for participation of these groups will likely be different to those for the general population and the strategies outlined in the Framework may not meet the needs of these populations.

Question:

6. What would enable you and/or your organisation to be more effective in your participation? e.g. supporting consumers and building capacity in the community

\textsuperscript{12} Romios, McBride and Mansourian, Consumer Participation and Culturally and Linguistically Diverse Communities, A Discussion Paper, Health Issues Centre, March 2007, p 15

\textsuperscript{13} Romios, McBride and Mansourian, 2007, p 17-18
8. **Enablers and Barriers**

8.1 **Enablers**
A summary of multiple enabling factors for participation are presented here for the broad participant categories of ACT Health employees and consumers, carers, and community members. This section draws extensively on the Victorian Government document *Doing it With Us Not For us*, Participation Policy.

<table>
<thead>
<tr>
<th>ACT Health employees</th>
<th>Consumers, carers and community members</th>
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<tbody>
<tr>
<td>Employees understand that support for participation throughout ACT Health is</td>
<td>Consumers, carers and community members are involved from the earliest possible time and are</td>
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<tr>
<td>forthcoming and that ACT Health has a willingness to accept change.</td>
<td>given adequate notice.</td>
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<tr>
<td>The ACT Health policies and structures that facilitate participation are promoted to</td>
<td>Consumers, carers and community members are involved in developing the processes and issues</td>
</tr>
<tr>
<td>employees.</td>
<td>under consideration.</td>
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<tr>
<td>Employees are provided with training and information on how to facilitate</td>
<td>Consumers, carers and community members understand the language and systems the organisation uses.</td>
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<tr>
<td>participation.</td>
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<tr>
<td>Information presented by the Health Service is culturally and age appropriate.</td>
<td>Consumers, carers and community members provide feedback on information sheets, pamphlets and other</td>
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<td>documents for relevance and ease of understanding.</td>
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<tr>
<td>Lines of accountability and terms of reference are clearly communicated.</td>
<td>Consumers, carers and community members are not isolated.</td>
</tr>
<tr>
<td>Employees may be affected by decisions, therefore all decisions and information on</td>
<td>Costs of participation are reimbursed and ACT Health provides resources to allow participation.</td>
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<td>the process are clearly communicated.</td>
<td></td>
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<tr>
<td>ACT Health provides resources for a range of strategies to facilitate the particular</td>
<td>Consumers, carers and community members are not overburdened. They may have competing</td>
</tr>
<tr>
<td>participation aim.</td>
<td>priorities and limited time and resources.</td>
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<tr>
<td>ACT Health identifies organisational mechanisms to incorporate the lessons learnt</td>
<td>Consumers, carers or community members are informed of the outcomes of their participation.</td>
</tr>
<tr>
<td>into daily practice or future planning and policy development.</td>
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<tr>
<td>Employees are skilled in evaluating participation activities.</td>
<td>There are opportunities for feedback on consumers', carers' and community members' participation</td>
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<td></td>
<td>experience.</td>
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8.2 **Barriers to consumer participation**
Barriers can be inherent to an organisational structure and systems, attitudinal, or arise from a lack of cultural and socio-economic considerations. These could include the following:

<table>
<thead>
<tr>
<th>ACT Health Employees</th>
<th>Consumers Carers and Community Members</th>
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<tbody>
<tr>
<td>A lack of overt and equitable support for participation from the ACT Health Executive.</td>
<td>A lack of power concerning health and organisational knowledge.</td>
</tr>
<tr>
<td>Not providing policies and structures on how participation can be achieved.</td>
<td>An unquestioning approach to receiving medical information or receiving inadequate</td>
</tr>
</tbody>
</table>
Not providing training to employees on facilitating participation and not recognising that resources are necessary to achieve participation.

Inequitable provision of support and resources for the individual consumer, carer or community member to participate.

Strategies are chosen by employees in isolation from consumers, carers and the community.

No or poor feedback to processes from consumer representatives to constituents.

Not providing resources for skilled evaluation; lessons learnt are lost and not incorporated into the whole of ACT Health.

Escalation of poor health or caring role, preventing participation as previously established.

**Question:**

7. What enablers or barriers do you and/or your organisation experience in providing feedback on the development, delivery and review of health services in the ACT?

### 9. **IMPLEMENTATION OF THE FRAMEWORK**

**9.1 Objectives**

The Framework is based on a quality improvement approach to participation and includes evaluation of individual activities and monitoring of performance indicators. Consumers, carers and community members can improve their participation activities by using the evidence obtained from evaluating and monitoring the participation priority actions.

To achieve successful implementation seven objectives have been adopted from the Victorian Government's *"Doing it with us, not for us" Participating in your Health System 2006-2009.*

The objectives of the Framework are:

1. To take participation seriously;
2. To share information to create consumer and carer friendly access to services;
3. To improve communication between ACT Health, consumers, carers and community members;
4. To build the capacity of consumers, carers and community members to undertake participation;
5. To integrate participation into the safety and quality program;
6. To learn from experience and the evidence on participation; and
7. To ensure participation resources are available to ACT Health, consumers, carers and community members.

Together these objectives identify what needs to be done to make participation happen throughout the ACT health service system.

**9.2 Priority actions**

To give direction to consumers, carers, community members and ACT Health on what they need to do to achieve the objectives, a set of priority actions is outlined below. They are set out across four key areas of the ACT health service system:

- Individual care;
- Program areas;
- Health service organisational areas; and
- ACT Health department level.
In each area there is a need to work together to create an environment that encourages participation. Each area should take consideration of:

- Children and young people
- Different socio-economic status
- Women and men
- Different social and marital circumstances
- People living with a disability
- People living with a mental illness
- Different sexual orientations
- Levels of literacy and education
- Diverse health and illness conditions
- Aboriginal and Torres Strait Islanders
- Culturally and linguistically diverse communities

9.3 Priority actions - individual care
Consumers, and, if appropriate, carers, need to be actively involved in the care and treatment provided to them or to the person they care for. Health services and ACT Health need to support this participation through the following priority actions:

1. Promote the rights and responsibilities of health consumers to the community, consumers and carers;
2. Communicate clearly and respectfully with consumers, carers and community members;
3. Communicate and provide accessible evidence-based information about health care and treatment, including benefits, risks and options, to consumers, carers and community members;
4. Assist consumers, carers and community members in the development of sustainable skills, resources and commitment to health improvement; and
5. Listen and act on the decisions the consumer and, where appropriate, their carer(s) make about their care and treatment.

9.4 Priority actions – program areas
Program areas consist of employees working in the wards, programs and departments in hospitals, rehabilitation settings, community health centres, primary care services, mental health and aged care services. It is about these staff developing and providing information, care treatment and research with consumers, carers and the community:

1. Involve consumers, carers and community members from the planning stage through to evaluation and monitoring;
2. Create welcoming and accessible services for members of the community from diverse backgrounds;
3. Provide training to staff in communication skills and how to involve consumers, carers and community members in decision making;
4. Promote the importance of consumers, carers and community members providing feedback to improve services;
5. Establish links with community organisations to provide emotional support and ongoing information to consumers, carers and community members;
6. Involve consumers, carers and community members in the development of clinical guidelines and research; and
7. Provide clear information to communicate about the service.

9.5 Priority actions - health service organisational areas
This area consists of the organisational decision makers in health services, hospitals, community health, cancer services, population health and business and infrastructure centres, aged care, mental
health and primary health services. It focuses on how participation can be promoted and increased at the organisational level at each health care service.

1. Encourage feedback through ACT Health consumer feedback mechanisms;
2. Support and encourage consumer, carer and community organisations to be involved with health service organisations;
3. Acknowledge the importance of the partnership between the organisation and consumers, carers and community members;
4. Community representatives or nominees should be encouraged to be involved in the review of system level issues using consumer and carer feedback and complaints;
5. Involve consumers, carers and community members in all aspects of the organisation’s planning and development;
6. Provide staff training and education on how to use the different types of participation;
7. Ensure position descriptions include participation components; and
8. Evaluate, monitor and report on participation to the community and ACT Health.

9.6 Priority actions – ACT Health
How ACT Health Executive should encourage consumer, carer and community member participation in ACT Health.

1. Use consistent processes of working with and accessing consumers, carers and community members across ACT Health;
2. Provide support, guidance and resources to health services, consumers, carers and community members on participation;
3. Provide training and education to ACT Health on how to use the different types of participation, and evidence-based participation and communication;
4. Encourage health services to evaluate and monitor participation within a quality improvement framework;
5. Prioritise participation and ensure it is an integral part of policy development; and
6. Encourage the inclusion of participation skills and knowledge in the tertiary education of health professionals.

Question:
8. Are there other priority actions that can be taken to fully implement this Framework?

10. Evaluation, Monitoring and Public Reporting

10.1 Evaluation
Evaluation is concerned with participation outcomes as well as practice, processes and management. The methods used are non-threatening and appropriate and the results are shared with those involved and used in reports.

10.1.1 Evaluation of Participation Activities
When evaluating a participation activity, consider if the evaluation is of the processes, impacts or outcomes of the activity.

<table>
<thead>
<tr>
<th>Individual care</th>
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<tbody>
<tr>
<td><strong>Process</strong></td>
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<tr>
<td><strong>Impact</strong></td>
</tr>
<tr>
<td><strong>Outcomes</strong></td>
</tr>
<tr>
<td>--------------</td>
</tr>
<tr>
<td>• Evaluate the impact on consumer, carer and community member participation in decision making about care and treatment at pre-admission, during admission and post-admission.</td>
</tr>
<tr>
<td>• Evaluate the effect of participation in decision making on readmission rates.(^{14})</td>
</tr>
<tr>
<td>• Evaluate if ACT Health Consumer Feedback Standards have been met.</td>
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</table>

**Program areas**

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<thead>
<tr>
<th><strong>Process</strong></th>
<th><strong>Evaluation</strong></th>
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<tbody>
<tr>
<td>• Evaluate efficacy, accessibility or efficiency of participation processes in projects.</td>
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<tr>
<td>• Evaluate processes of participation in clinical guideline development.</td>
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<tr>
<td>• Evaluate processes of participation in research development and implementation.</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Impact</strong></th>
<th><strong>Evaluation</strong></th>
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<tbody>
<tr>
<td>• Evaluate immediate effectiveness or efficiency of participation within a project or research activity.</td>
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<tr>
<td>• Evaluate employee participation skills, as part of staff development, in decision making about care and treatment.</td>
<td></td>
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<tr>
<td>• Evaluate accessibility of the program or department.</td>
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<table>
<thead>
<tr>
<th><strong>Outcomes</strong></th>
<th><strong>Evaluation</strong></th>
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<tbody>
<tr>
<td>• Evaluate long-term participation goal or aim of projects and research to identify effectiveness or efficiency of participation.(^ {15})</td>
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<tr>
<td>• Evaluate if ACT Health Consumer Feedback Standards have been met.</td>
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**Health service organisational areas**

<table>
<thead>
<tr>
<th><strong>Process</strong></th>
<th><strong>Evaluation</strong></th>
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<tbody>
<tr>
<td>• Evaluate if processes of participation in programs, policies and governance requirements have been met.</td>
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<table>
<thead>
<tr>
<th><strong>Impact</strong></th>
<th><strong>Evaluation</strong></th>
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<tbody>
<tr>
<td>• Evaluate if immediate outcomes of participation have been achieved for programs, policies and governance requirements.</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Outcomes</strong></th>
<th><strong>Evaluation</strong></th>
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</thead>
<tbody>
<tr>
<td>• Evaluate if the long-term goal of participation for a specific program or policy has been achieved.</td>
<td></td>
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<tr>
<td>• Evaluate if ACT Health Consumer Feedback Standards have been met.</td>
<td></td>
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</table>

**ACT Health Department**

<table>
<thead>
<tr>
<th><strong>Process</strong></th>
<th><strong>Evaluation</strong></th>
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</thead>
<tbody>
<tr>
<td>• Evaluate if ACT Health Consumer Feedback Standards have been met.</td>
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<tr>
<th><strong>Impact</strong></th>
<th><strong>Evaluation</strong></th>
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<tbody>
<tr>
<td>• Evaluate if immediate outcomes of participation have been achieved for a policy, program or planning strategy.</td>
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<tr>
<th><strong>Outcomes</strong></th>
<th><strong>Evaluation</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Evaluate how effective participation has been in achieving Aboriginal and Torres Strait Islanders roles as participants of and contributors to ACT Health planning, policy and programs.(^ {16})</td>
<td></td>
</tr>
</tbody>
</table>

\(^{14}\) State of Victoria, Department of Human Services, 2005, p 49
\(^{15}\) State of Victoria, Department of Human Services, 2005, p 49
\(^{16}\) Ibid, p 49
10.2 Implementation of evaluation and monitoring
Implementing the evaluation and monitoring framework and reporting on participation is the responsibility of all stakeholders. To facilitate the reporting on participation, each health service should develop an internal implementation plan addressing the most common risks and limitations.

10.3 Public Reporting of Results
Through project funding guidelines and Service Funding Agreements, health services and other organisations will be encouraged to conduct evaluation of participation and annually publish the results.

Question:
9. Are there other methods of evaluation, monitoring and/or public reporting that would be beneficial to include in this section?
11. REFERENCES

ACT Health *Come to the Table: A Discussion Paper, A proposed model for effective and genuine participation of consumers and carers across Mental Health ACT*, June 2006


ACT Government *Caring for Carers Policy*, 2003


*ACT Carers Recognition Legislation Amendment Act 2006*

*Declaration of Alma-Ata* International Conference on Primary Health Care, Alma-Ata, USSR, September 1978


http://mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD004563/frame.html

National Health & Medical Research Council, Commonwealth of Australia, *Summary Statement on Consumer and Community Participation in Health and Medical Research*, 2001


Moore, Kate, *Consumer and Provider Partnerships: What makes them work*, The Consumer and Provider Partnerships in Health Project, an initiative of the Consumer Focus Collaboration and funded by the Australian Government Department of Health and Ageing, February 2003

National Resource Centre for Consumer Participation in Health, “Methods of Consumer Participation”, “Fact Sheet No 2”


*Ottawa Charter for Health Promotion*, First International Conference on Health Promotion, Ottawa, 21 November 1986 – WHO/HPR/HEP/95.1

Queensland Health Position Statement “Consumer and Community Participation”, January 2003


State of Victoria, Department of Human Services, *Doing it with us not for us*, Participation in your health system 2006-2009, Melbourne 2005

Raising the standard, Section 1 Good practice standards for community service organisations, ACT Government, January 2002
A1.1 Who is a Consumer?
The ACT Health Consumer Feedback Standards define consumer to mean:

- People who directly access a health service;
  - Their nominated representative or representative with legal authority
  - Their carer, family member or advocate
- Groups of consumers or consumer organisations; or
- Members of the community\textsuperscript{17}.

A1.2 Who is a Carer?
The ACT Government’s Caring for Carers Policy defines a carer as "a person who provides, or has provided, unpaid care and support to a person who has needs associated with disability, ageing, ongoing physical or mental illness, or substance abuse."\textsuperscript{18}

A1.3 What is a community?
A community is defined as a group of people sharing a common interest. Within this definition, it is important to recognise that different types of communities are likely to have different approaches to participation in health\textsuperscript{19}.

A1.4 What is participation?
"…the involvement of people in decisions that affect their lives. It acknowledges the importance of consulting with communities about their needs, and satisfaction with services, policies, structures and programmes. Community participation is about change."\textsuperscript{20}

A1.5 What is Consumer, Carer and Community Participation?
Either in a voluntary or paid capacity, consumers, carers or members of the community participate in formal or informal planning, delivery, implementation, and evaluation of all activities associated with health services. They are integral to the processes which affect their lives, through the sharing of information, opinions and decision making power.

Consumer participation is “the process of involving health consumers in decision making about health service planning, policy development, setting priorities and quality issues in the delivery of health services”\textsuperscript{21}. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives, or communities\textsuperscript{22}.

Carer participation is the process of enabling carer input into decision-making about the health care of the consumer, where appropriate, and in allowing for input into health service planning, policy development, priority setting and addressing quality issues in the delivery of health services. Carers may participate as individuals, groups, organisations of carers, carer representatives, or as communities.

\textsuperscript{17} ACT Health Consumer Feedback Standards, Listening and Learning, ACT 2003, p 1
\textsuperscript{18} ACT Government Caring for Carers Policy, 2003, p 3
\textsuperscript{19} National Health & Medical Research Council, Commonwealth of Australia, Summary Statement on Consumer and Community Participation in Health and Medical Research, 2001, p 6
\textsuperscript{20} Not Just A Token Rep Project, 2003 (3rd ed), The Little Purple Book of Community Rep-ing, p 1
\textsuperscript{22} Queensland Health Position Statement “Consumer and Community Participation”, January 2003