

Doing it with us not for us

Participation in your health service system 2006–09: Victorian consumers, carers, and the community working together with their health services and the Department of Human Services



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Foreword

Consumer, carer and community participation is a key enabling strategy in working with and meeting the health needs of our community. It is valued as an aid to improve health outcomes and the quality of health care, a mechanism to ensure accountability, and an important democratic right. The *Doing it with us not for us participation policy* is underpinned by the *Growing Victoria Together* policies (Victorian Government, November 2001; Victorian Government, 2005). It reflects existing participation policies in the mental health, primary and community health areas and the current work being undertaken by disability services on active participation.

It gives me great pleasure to present to you this new strategic direction in consumer, carer and community participation across our health service system. The seven guiding objectives of the policy state how participation can be a key to improving health policy, care and treatment, and the wellbeing of all Victorians. The priority actions give clear direction on what needs to be achieved to meet the objectives, and examples are provided of current action and different types of participation.

The strategic direction is targeted at all the stakeholders – consumers, carers, community members, community organisations, health services and the Department of Human Services – working together. The achievement of the priority actions will only occur through a willingness to collaborate and support the process. Many of you are already well on the way to achieving a number of the priority actions outlined in the strategic direction. However, as noted in the policy, we have room to build on this start and for some it will be a new approach. *Doing it with us not for us* provides guidance on how we can all work together.



Hon Bronwyn Pike MP
Minister for Health

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Alzheimer's Australia Victoria – staff

Alzheimer's Australia Victoria – consumers and carers group and rural member

Austin Health

Australian Vietnamese Women's Welfare Association

Bayside Health

Benalla and District Memorial Hospital

Carers Victoria

Culturally and linguistically diverse community – young person

Communication Aid User Society

Dental Health Services Victoria

Department of Human Services – Disability Services

Department of Human Services – Metropolitan and Rural and Regional Health and Aged Care Services divisions

Department of Human Services – Primary Care Partnership Consumer and Carer Advisory Group

Diversitat Geelong

Genetic Support Network of Victoria – staff

Genetic Support Network – rural member

Goulburn Valley Health – Consumer Consultative Committee

Goulburn Valley Health – staff

Heart Support Australia – Castlemaine

Heart Support Australia – Knox

Heart Support Australia – Monash

Heart Support Australia – South Gippsland

Heartbeat Victoria Inc.

Maryborough District Health Service

Mt Alexander Hospital

Peter MacCallum Cancer Centre

Platform Team Orygen Youth Health, Youth Mental Health Service

SIDS and KIDS – staff and consumers

Southern Health

St Vincent's Health

Upper Murray Health & Community Services – consumers, carers and community nominees group

Upper Murray Health & Community Services – staff

Werribee Mercy Hospital

West Gippsland Healthcare Group

Wimmera Health Care Group

1 Introduction

The Doing it with us not for us – Participation in your health service system 2006–09: Victorian consumers, carers and the community working together with their health services and the Department of Human Services policy (the ‘Doing it with us not for us participation policy’) grew from:

- the Victorian Government’s commitment to involving people in decision making about health care services
- the value placed on consumer, carer and community participation
- the identified need for a strategic policy to guide the process (Department of Human Services 2005).

As identified in the *Consultation paper – Participation in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services* (the ‘consultation paper’), participation in health is an essential principle of:

- health development
- community capacity building
- the development of social capital (Kahssay & Oakley 1999: Department of Human Services 2005).

In particular, it is an enabling strategy for working with and meeting the health needs of those community members who are most socially and economically disadvantaged (Victorian Government November 2001; Consumer Focus Collaboration 2001). This commitment to participation was supported by the evidence reviewed on the effectiveness of participation in the consultation paper (Department of Human Services 2005).

The evidence set out in the consultation paper was complemented by the review of information in the *Performance indicators – Participation in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services* paper (the ‘participation indicator paper’). The participation indicator paper developed a minimum set of participation performance indicators. The indicators sit within a quality improvement model and have been incorporated into the evaluation

and monitoring section of this policy. The indicators target the acute and sub-acute areas of the health service system, as these areas were found to need greatest policy direction. They link into existing policy drivers in primary, community, mental health and aged care.

To complete the policy development process, consultations were conducted and further resources were reviewed to develop the third paper: *How to develop a community participation plan: minimum guidelines*. The material contained in this third paper also contributed to and supports the *Doing it with us not for us* participation policy.

The policy targets the collective stakeholders of consumers, carers, community members, community organisations, health services and the Department of Human Services. Different groups within the stakeholders are targeted throughout the policy. To facilitate these shifts, the policy sets out priority actions across four levels of the health service system. The levels are:

- individual level
- program and department level
- health service organisational level
- Department of Human Services level.

At the start of each level, the target groups within the collective of stakeholders are identified.

The *Doing it with us not for us* participation policy provides strategic direction for all policy stakeholders on participation and a model to continuously improve our participation actions.

2 Participation

It is important to have a policy on participation for our health service system because of the value that we place on participation and the benefits that it provides to the health and wellbeing of our communities. To understand how we value participation we first need to know what participation means to us.

In talking with and collecting written feedback from people during the development of the policy, comments included:

‘Participation includes communication, listening to ideas taking on board new ideas and feedback on ideas.’

‘Health services need to be willing enough to go out and ask the community - able to take criticism, and work with them, show the community they have a voice and power to make decisions and then move on them, willing to get involved.’

‘User participation is very important because health professionals have different views from consumers and you need to come to a shared understanding.’

‘The term [participation] refers to a more proactive relationship between health services and consumers, carers and members of the community. Participation aims to ensure meaningful input into decision making.’

‘Need an open mind and be prepared to listen to each other.’

‘If you are going to ask for participation you had better be prepared to hear it.’

‘Don’t want things imposed; not participation.’

These comments, together with reading about how other groups understand participation, as outlined in the consultation paper, has led to the following definition of participation (Department of Human Services 2005):

Participation occurs when consumers, carers and community members are meaningfully involved in decision making about health policy and planning, care and treatment, and the wellbeing of themselves and the community. It is about having your say, thinking about why you believe in your views, and listening to the views and ideas of others. In working together, decisions may include a range of perspectives.

The definition of participation includes the terms ‘consumer’, ‘carer’ and ‘community’. Through the consultation process and reviewing the definitions used in the Consumer Focus Collaboration and Primary Care Partnership, the following understanding of these terms was developed (Consumer Focus Collaboration 2000; Department of Human Services 2005).

Consumers are people who are current or potential users of health services. This includes children, women and men, people living with a disability, people from diverse cultural and religious experiences, socioeconomic status and social circumstances, sexual orientations, health and illness conditions.

Carers are families and friends providing unpaid care to consumers.

Communities are groups of people who have interests in the development of an accessible, effective and efficient health and aged care service that best meets their needs.

When participating in the health service system, a consumer, carer or community member may be supported by an **advocate**. This is a person who assists them to have their views and ideas heard and understood. Advocates often work for **community organisations** that have been formed by groups of consumers and/or carers around a particular health issue, illness, cultural, social or ability need.

Consumers, carers and other community members may participate as individuals or they may take on a specific role in participation. These roles include that of a **representative**, as outlined by the Consumer’s Health Forum of Australia (1990) or a **nominee**.

Representative is a consumer, carer or community member who is nominated by and **accountable to** an organisation of consumers, carers or community members. The term ‘representative’ is linked to living in a democracy. Hence, they are there to represent the formal views of a particular group and report back to that group.

Nominee is the term used to describe somebody who is representative or has links with a particular group(s). They are not accountable in the way that a representative is but are participating because of their links with a group(s).

3 Reasons for participation

We can also understand why participation in the health service system is valued from the reasons people gave about why they believe participation is important.

‘If we can’t communicate, then not able to make decisions, can’t participate. It is a human right to be part of that process.’

‘To make sure we are delivering services that meet people’s needs.’

‘People become involved because they want to help others and saying thank you to the hospital.’

‘Keep participating just to help others. You end up educating so many other people.’

‘Are we spending our budgets on the priorities identified by the community?’

These comments about the importance of participation are supported by a review of the research into participation. As outlined in the consultation paper, research identifies that participation is valued because it is:

- an aid to **improve health outcomes and the quality of health care** (Victorian Quality Council 2003; Australian Council on Healthcare Standards 2002; Henry 2004; Consumer Focus Collaboration 2001)
- an important **democratic right** (Pickars et al. 2002; Draper 1997, Kilmany Uniting Care 2004; Hindess 1997; Victorian Government 2005)
- a mechanism to ensure **accountability** (Department of Human Services 2000; Parliament of Victoria, Department of Health 2003; Strategic Health Authority Patient and Public Involvement Leads Network 2003).

Improve health outcomes and the quality of health care

Participation as an aid to **improve health outcomes and the quality of health care** was supported by a review of the evidence as outlined in the consultation paper. Examples from the evidence that **participation improves health outcomes** include:

- increased control of their chronic illness (Weingarten et al. 2002)
- improved control of hypertension on an acute ward of a hospital (Zernike & Henderson 1998)
- reduced need to access health services for follow-up care (Henderson & Zernike 2001)
- improved lung function, self efficacy, reduced emergency visits, absenteeism from school and days of restricted activity in children and young people living with asthma (Grevara et al. 2003)
- increased patient satisfaction, engagement and task orientation, reduced anxiety and improved quality of life among people with asthma and diabetes (Bauman et al. 2003)
- 'The Australian response to HIV and AIDS is internationally recognised for its success in controlling the spread of HIV and minimising the impacts of disease. Partnership approaches to policy development, along with bipartisan political support, have been identified as the critical elements of this success' (Consumer Focus Collaboration 2001).

Similarly, the **quality of health care** has been shown to improve through participation of consumers, carers and community members by:

- changed standards for working with bereaved carers and disfigured consumers (Birchall et al. 2002)
- prioritised research agenda to focus on supporting a provider-consumer partnership (Kaplan & Brennan 2001)
- ethically accepted trial of thrombolysis for acute ischaemic stroke and improved information to consumers and carers (Koops & Lindley 2002)

- consumer identified priority areas for clinicians within the Australian national guidelines on psychosocial care for women with breast cancer (Rankin et al. 2000).

Democratic right

Participation as an important democratic right is primarily supported in Victoria through the voting system for government representatives at regular intervals. Consumers, carers and other community members can nominate to be elected as a representative of the people of the state and/or can vote on policies and programs. Secondly, in relation to health, people can nominate to be community representatives on boards of community health centres and public health services. These boards govern within government guidelines.

Accountability

Participation as a mechanism to ensure accountability is strongly identified throughout the health system. For example, in Victoria health services are required to involve consumers, carers and community members in the development of their quality care reports (Department of Human Services 2004). This is to ensure that the reports meet the needs of their community. Consumers and carers also have a right to complain about health services, and participation in complaint mediation through the Office of the Health Services Commissioner is an important process of accountability <http://www.health.vic.gov.au/hsc>.

Participation is a valuable way to work together to improve health policy and planning, care and treatment, and the wellbeing of all Victorians.

4 Types of participation

During the development of the policy, people talked about what participation meant to them and often discussed different types of participation that they used. In addition, through the consultation paper process a list of different types of participation was developed (Bishop & Davis 2002, Wensing et al. 2002; Bauman et al. 2003).

The types are:

- information
- consultation
- partnership
- delegation
- control

When choosing a type of participation to use, it is important to remember that each type is valuable and suits a particular situation. It is recommended that, before you start any other decision making, you talk with all the stakeholders and decide which type of participation is going to achieve the best results for your particular situation. The following examples of the different types of participation are drawn from those provided by people as part of the development of the policy. A brief overview of the different types of participation is in Table 6 of Appendix 2.

Information – supporting participation

Giving out information is not participation, as the information flow is one-way. Giving information does not change how services, policy, research, treatment or care are made or provided. However, information is often used to support or invite participation, for example, information about how to access a service and what is involved in the care or treatment of an illness. Without the information the consumer would be less able to make a decision about their health care. For this reason, information is usually identified as supporting participation (Consumer Focus Collaboration 2000).

The objectives of giving information are usually:

- to support participation
- to convey facts
- to educate.

The development of information with consumers, carers and community members is important to ensure that the information meets their needs, is comprehensive, based on evidence and presented in an unbiased way (Currie et al. 2000).

Example

Title/service: *Communicating with consumers* series (Currie et al. 2000; Department of Human Services 2000)

Aim: To develop a guide for hospitals in the provision of information to consumers, based on existing knowledge about good practice in information provision to consumers by hospitals in Victoria.

How: The project was based on the King's Fund study *Informing patients: an assessment of the quality of patient information materials* (Coulter et al 1998). The project assessed the quality of written consumer information in six health conditions using input from consumers, clinicians and publishers. The evidence base of the information and its relevance to consumers were taken into account during the assessments (Currie et al. 2000).

Outcome: Multiple examples and a simple checklist to assess the quality of written consumer health information (Volume 1) can be found in the series.

We learnt: It reinforces the critical role that consumers play in the planning, development, dissemination and evaluation of consumer health information. The work acknowledges the importance of the process of developing consumer health information and reinforces the important role of information based on evidence (Currie et al. 2000).

Contact: Available from the website:
<http://www.health.vic.gov.au/consumer/pubs.htm>

Consultation

Consultation is only considered to be participation when the information gathered from consumers, carers or community members is used to make or change policy, planning, research, care or treatment. Consultation is used to find out what consumers, carers and community members think of something that is proposed by the health service or the Department of Human Services. However, the health service or the Department of Human Services remains in control of the process. Consultation can improve services and increase acceptance.

A range of different consultation strategies can be used, including focus groups, public meetings, family meetings and individual health consultations. These are outlined in Appendix 2.

The objectives of consultation are:

- to find out people's views and ideas
- to use people's views and ideas to improve
- to increase acceptance.

Example

- Title/service:** Development of a video and DVD about the side effects of chemotherapy. Funded by the Peter MacCallum Cancer Foundation, a collaborative project between the Peter MacCallum Cancer Centre, volunteers from the Cancer Council of Victoria's Cancer Connect Program, and consumers.
- Aim:** To provide information in a format that consumers can use at home with their carers and as often as they need. Evidence suggests that consumers forget some verbal information and cannot, or do not, always use written information. [Increase acceptance]
- How:** The process involved a survey of current consumers, about the content of the video. Consumers were consulted during the script development and they viewed the rough edit. The final version was evaluated through pilot testing with current patients, other consumers and health professionals.
- Outcome:** A video and DVD were produced to meets the needs identified by consumers. These are now available for all patients.
- We learnt:** Consumer participation was necessary to get the balance right between making the video/DVD positive enough to reduce anxiety and improve confidence to chemotherapy, yet still be realistic enough to portray the experience.
- Contact:** Patient Advocate
Peter MacCallum Cancer Centre
Phone (03) **9656 1870**

Partnership

In a partnership there is a move towards joint decision making. Consumers, carers, community members and the health service and/or Department of Human Services jointly own the process and outcomes. Partnerships are often achieved through advisory boards or committees that provide input over a long period of time, usually years. The partners make an agreement to work together to decide on a policy direction, research, plan, treatment or care.

The objectives of partnership are:

- to make joint decisions
- to agree on process
- to collectively own the outcomes.

Example

Title/service: Community participation plan developed by the Community Advisory Committee of Dental Health Services Victoria

Aim: To involve consumers and the wider community in the planning and delivery of public oral health services underpinning all that the service provides.

How: The Dental Health Services Victoria Community Participation Plan is created out of the divisional business plans. The five organisational key result areas include engagement with stakeholders and, within this, divisions take responsibility for ensuring consumer and community participation are appropriately considered and actioned in all work undertaken. The content for the plan is derived from the actions agreed at divisional level, as well as being informed and influenced by discussion with the community advisory committee. Most of the key actions included in the plan are intended to facilitate effective consumer and community involvement in service planning and development or refinement.

Outcome:	The plan ensures that all areas of the organisation include participation in their planning. For example, the plan is linked to the organisation's business plan. The chief executive officer and divisional general managers present annually to the community advisory committee to discuss progress in relation to the plan and future action. They are accountable to meeting the outcomes of the plan.
We learnt:	It is important to have strong endorsement from the chief executive officer and the executive sponsor, who attend the bi-monthly community advisory committee meetings. This has raised the profile of the community advisory committee and participation. There is now a base on which to strengthen community outreach and a bottom-up approach to participation.
Contact:	General Manager, Health Promotion Dental Health Services Victoria (03) 9341 1135

Delegation

Delegation means to give control to consumers, carers and community members for making decisions, within specific guidelines. The government may set out guidelines for the decision making roles of particular groups in legislation or through a government department. This is how boards of community health services and public health services operate. Similarly, ethics committees for research are delegated with responsibility for making decisions as to whether research is ethically appropriate.

The objectives of delegation are:

- to hand control to a board or community representatives within a specified framework
- to ensure policy options are made at arms length from partisan politics.

Example

Title/service: Health Services (Community Health Centre Elections) Regulations 2001

Aim: To ensure that board members of community health centres are elected by the community and their election is accountable to the public through the regulations of the Victorian Electoral Commission.

How: Part 3 of the regulations sets out the process for electing board members, including how to vote, counting of votes and letting people know the outcome of the vote. The Governor in Council also appoints some board members on the recommendation of the Minister for Health.

Outcome: Control of the community health centre is given to the board within the guidelines set out under the regulations and the *Health Services Act 1988*.

We learnt: The regulations provide a way of ensuring accountability to the public for the management of their health service.

Contact: Department of Human Services
(03) 9616 8470
[www.dms.dpc.vic.gov.au/Domino/Web_Notes/LDMS/PubLawToday.nsf/b12e276826f7c27fca256de50022686b/ce4d9abef05d003eca256f0f000892ee/\\$FILE/01-51sr002.pdf](http://www.dms.dpc.vic.gov.au/Domino/Web_Notes/LDMS/PubLawToday.nsf/b12e276826f7c27fca256de50022686b/ce4d9abef05d003eca256f0f000892ee/$FILE/01-51sr002.pdf)

Control

In handing control to the community, consumer or carer, the decision making power is given directly to these people. The health professional, service, government department or government hands over power in the decision making process. It is up to the consumer, carer or the community to make the decision.

The objectives of control are:

- to hand control of an issue to the electorate
- to hand control to the consumer of health care or, where appropriate, their carer.

Example

Title/service: The Respecting Patient Choices Program supports advance care planning. Advance care planning is a process enabling a person to make decisions about their future health care. This can be done in consultation with health care providers, family members and other important people in their lives.

- Aims:**
- respect every person's right to autonomy, dignity and fully informed consent
 - assist individuals to reflect upon, express and communicate their wishes regarding their current and future health care
 - respect individuals' wishes
 - educate and support health professionals to facilitate this.

How: By initiating conversations with adults about their future medical care, assisting them to document their preferences, and making sure any documented wishes are available when needed and are followed in a thoughtful and respectful way.

- Outcomes:**
- patient's wishes are being discussed and documented, and are available when required
 - patients are assisted to speak to their family and friends about their wishes
 - wishes are being respected now and at the end of life

- less conflict between staff, patients and families regarding patient management
 - improved communication between staff and patients as Advance Care Plans are available and accessible.
- We learnt:**
- patients want to be asked their views about their current and future health care by a health care professional
 - advance care planning challenges the current culture in health care in Victoria – ‘patient preferences matter’
 - takes time to ‘catch on’ and be normalised
 - the message needs to be clear
 - community promotion of advance care planning is important.
- Contact:** Respecting Patient Choices Program
Austin Health
Phone (03) **9496 5660**
<http://www.respectingpatientchoices.org.au>

Other examples include governments calling for a referendum on specific, usually contentious, public policy issues. This lets the community make the decision directly on the issue.

5 Principles of participation

For participation to work, the Department of Human Services and each health service needs to build a way of working with consumers, carers and community members. Likewise, consumers, carers and community members need to work cooperatively with their health service and the Department of Human Services. To support this, a set of guiding principles of participation was developed through the consultation process with the stakeholders. These are outlined below in Table 1.

The principles underlie how the policy should be put into action. The priority actions in Section 2 reflect these principles and the mission and values of the Department of Human Services (Appendix 3) support the principles of participation. This is important, as the Department of Human Services is responsible for administering health care funding and ensuring public accountability of services provided with that funding in Victoria.

Table 1 Principles of participation

Principle	Operation
1. Trust	<ul style="list-style-type: none"> • Participation works best where there is mutual agreement of the processes and assessment of the issues under consideration as developed through productive working relationships.
2. Respect	<ul style="list-style-type: none"> • All participants need to show consideration and value each other as equal contributors to the participation process.
3. Openness	<ul style="list-style-type: none"> • 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.
4. Equal opportunity	<ul style="list-style-type: none"> • 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.
5. Advocacy and support	<ul style="list-style-type: none"> • Participation must be supported from the top and resourced so that participation is meaningful for the consumer, carer and community member.
6. Responsiveness	<ul style="list-style-type: none"> • The capacity to undertake participation requires skilled organisations and benefits from multiple strategies and resources.
7. Shared ownership and accountability	<ul style="list-style-type: none"> • All involved share ownership of the process and decisions and are responsible for monitoring and evaluating the impact and outcomes. How the responsibility is distributed should be defined as part of the participation arrangement.
8. Dissemination	<ul style="list-style-type: none"> • The decisions made, and how consumers, carers or community members' participation influenced those decisions, should be communicated to all those involved and affected by the decisions.
9. Evaluation	<ul style="list-style-type: none"> • Lessons learnt from the participation process should be identified and communicated as widely as possible.

6 Policy drivers

A series of broader policies and guidelines drive the participation policy and support the three key reasons why we value participation: improvement, democratic right and accountability. These policies and guidelines are:

- *Growing Victoria Together: a vision for Victoria to 2010 and beyond* (Victorian Government 2005)
- *Directions for your health system: metropolitan health strategy* (Department of Human Services 2004)
- *Departmental plan 2004–05: Department of Human Services* (Department of Human Services 2004)
- *Cultural diversity guide: multicultural strategy* (Policy and Strategic Projects Division 2004)
- *Victorian women’s health and wellbeing strategy: policy statement and implementation framework 2002–2006* (Policy and Strategic Projects Division 2002)
- *Department of Human Services Aboriginal services plan, January 2004* (Department of Human Services 2004)
- *Partnership agreement: Department of Human Services/ health, housing and community sector* (Department of Human Services 2002)
- *Guidelines for Department of Human Services advisory committees* (Department of Human Services Victoria 2004)
- *Department for Victorian Communities corporate plan 2003–2006* (Department for Victorian Communities 2003).

The *Doing it with us not for us* participation policy links to and has been informed by policies and guidelines specific to the acute and sub-acute, mental health, primary and community health areas. These include:

- *Primary care partnerships strategic directions 2004–2006* (Primary and Community Health Branch 2004)
- *Community health services – creating a healthier Victoria* (Primary and Community Health Branch 2004)

- *Caring together: an action plan for carer involvement in Victorian public mental health services* (Department of Human Services Victoria 2004)
- *Victoria's mental health service working with consumers: guidelines for consumer participation in mental health services* (Department of Human Services 1996)
- *Community advisory committee guidelines: non-statutory guidelines for metropolitan health services* (Department of Human Services 2000)
- *Inquiry on the roles of community advisory committees of metropolitan health services* (Family and Community Development Committee 2004).

Further to these state policies supporting participation, other key Australian and international policies related to the importance of participation are referred to in the consultation paper.

7 Strategic direction

Aim

For consumers, carers and community members to participate with their health services and the Department of Human Services in improving health policy and planning, care and treatment, and the wellbeing of all Victorians.

This aim is based on the understanding that:

Participation occurs when consumers, carers and community members are meaningfully involved in decision making about health policy and planning, care and treatment, and the wellbeing of themselves and the community. It is about having your say, thinking about why you believe in your view, and listening to the views and ideas of others. In working together, decisions may include a range of perspectives.

Objectives

To achieve the policy aim, seven objectives have been identified. These objectives come from reviewing the evidence on participation, feedback on the recommendations made in the consultation paper, and listening to stakeholders at a series of focus groups held across the state and with the policy reference committee.

The stakeholders at the focus groups were invited to talk about:

- what participation meant to them
- what enabled participation and acted as a barrier
- what the priorities for participation should be.

The objectives of the policy are:

1. To take participation seriously – ‘doing it with us not for us’.
2. To share information to create consumer and carer friendly access to services.
3. To improve communication between all stakeholders.
4. To build the capacity of all stakeholders to undertake participation.
5. To integrate participation into the quality and safety program.
6. To learn from our experiences and the evidence on participation.
7. To ensure participation resources are available to all stakeholders.

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

Priority actions

To give direction to all stakeholders on what they need to do to achieve the objectives, a set of priority actions is outlined below. As with the objectives, the priority actions come from the policy development process. They are set out across four key levels of the health service system:

- individual care level
- program or department level
- health service organisational level
- Department of Human Services level.

At each level there is a need for all stakeholders to work together to create an environment that encourages participation. The environment should be based on the principles of participation as set out in Section 5. It should respect the diversity of people within our community including:

- children and young people
- women and men
- people living with a disability
- diverse health and illness conditions
- culturally and linguistically diverse communities.
- different socio-economic status
- different social circumstances
- different sexual orientations
- Aboriginal and Torres Strait Islanders

For each priority action, examples of participation are given as well as quotes, as identified from the policy development process. These examples show what is already happening and what can be achieved. To help achieve the priority actions at each health service and within the Department of Human Services, a list of enablers and resources are provided in Section 8.

Priority actions - individual care level

This level is about the consumer and, if appropriate, their carer(s), being actively involved in their own care and treatment. Health services and the Department of Human Services need to support this participation through the following priority actions.

1. Promote the rights and responsibilities of 'patients' to the community, consumers and carers.

- 'Prior to people being admitted to the hospital a lot of information is given including the patient's charter information. You need to aim this information so that the general community can understand it.' *Benalla Memorial Hospital*
- The rights and responsibilities for Victoria's public patients can be found at <http://www.health.vic.gov.au/patientcharter/>.
- People may not feel confident to raise their rights or to ask questions of health professionals. You need to create a supportive environment and educate health professionals to assist consumers and carers (Global Learning Services Pty Ltd 2000).
- The *Ten tips for safer health care: what everyone needs to know* (Australian Council for Safety and Quality in Health Care 2003), can be accessed through the website <http://www.health.vic.gov.au/consumer/pubs.htm>

2. Communicate clearly and respectfully with consumers and carers.

- 'Rehabilitation course was excellent for person and good family sessions, plus some for carers just to ask questions and express concerns.' *Knox Heart Support Group*
- 'When people are not well they are afraid they will not talk correctly, so do not talk. Need more time to become comfortable and to be able to ask their questions.' *Australian Vietnamese Women's Welfare Association*
- 'Need to educate staff on how they speak to people, the healing words that can be used. How people react to words when they are in pain or shock. Those first few words can make all the difference. For example, when you are in shock you don't hear modifying language.' *Consumer Consultative Committee, Goulburn Valley Health*

- ‘The individual owns the communication and the communication aid; it is theirs and does not stay with the health service. It is about how they want to use it. Some people choose to use an aid while at other times they may not – it is their right to choose the method and means of communication.’ *Communication Aid User Society*

3. Provide accessible information to consumers, carers and community members about health care and treatment.

- ‘Feel very vulnerable and ask questions and got answers, but if you don’t ask then maybe would not have got information.’ *Knox Heart Support Group*
- ‘We have to share our knowledge. Don’t use information as power over one another.’ *Upper Murray Health and Community Services-staff*
- ‘Diabetes project where you attended to learn new information got a broad range of information so people got a good understanding and would be able to manage it sensibly. Staff were very approachable and people knew where to go to get more help. Got good printed material to go back over. Diabetes was not quite as disastrous as I first thought.’ *Consumer Consultative Committee Goulburn Valley Health*
- ‘Availability of not just written information but photos, quotes from other young people, easy to read – simple material, presentation makes an impact.’ Young person from culturally and linguistically diverse background
- ‘People think if written in another language that all these people can read it. Think this has fulfilled their responsibility. Would be good to sample this with local groups to see if they understand and if the information is useful.’ *Diversitat, Migrant Resource Centre, Geelong*
- A number of people during the policy consultation identified the following websites and guides on writing as particularly useful:

<http://www.health.vic.gov.au/consumer/pubs.htm>

<http://www.chronicillness.org.au/technicl.htm>

<http://www.wats.ca/resources/determiningreadability/1>

4. Communicate and provide evidence based information about treatments and care to consumers and carers that is developed with consumers and, where appropriate, carers.

- Tables 8 and 9 in the consultation paper outline the evidence for participation (Department of Human services 2005)
- *The evidence supporting consumer participation in health* (Consumer Focus Collaboration 2001)
- Evidence on effective treatments can be found at <http://www.thecochranelibrary.com>
- Evidence related to effective ways to communicate with and involve people in their care can be accessed via <http://www.latrobe.edu.au/cochrane/>

5. Listen and act on the decisions the consumer and, where appropriate, their carer(s) make about their care and treatment.

- ‘A formal process was developed in our residential care areas, years ago, for the resident and their family to work together with us in the development of a care plan in an environment that meets their needs. This is formally reviewed annually and also when the resident’s needs or wishes change. The doctors are encouraged to have input into the care plan.’ *Mt Alexander Hospital Aged Care Residential Services*
- ‘The Patient Decision Aids research program was developed to help patients and their health practitioners make “tough” health care decisions. “Tough” health care decisions may have many options, uncertain outcomes or benefits and harms that people value differently’. This website includes a critical review of decision aids and a tutorial for health service staff to develop skills in giving decision making support to consumers <http://decisionaid.ohri.ca/index.html>.’
- ‘Our information to patients now includes a form of questions that you should ask your doctor.’ *Monash Heart Support Group*

Priority actions - program or department level

This level is about staff 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.

6. Involve consumers, carers and community members from the planning stage through to evaluation and monitoring.

- ‘It was the people who said we are not healthy, need somewhere to go, would like to access a gym. The health service made it credible and acceptable. It came out of the 1998 needs assessment done by our group for the health service, and the health service has really delivered. The community voted for the health service to buy the gym and run their programs from there.’
Community Liaison Group for Upper Murray Health and Community Service
- ‘West Gippsland Health Care Group recently participated in the Baw Baw Aged Services Plan. Four major providers of ageing and disability services in the shire came together with the support of the Department of Human Services Gippsland Regional Office to identify the changing needs of the ageing and disabled in the community and put into place an action plan to improve service delivery. Using the local newspapers to promote the consultation process, community members, service providers and representatives of ageing/disability residents were consulted during the plans preparation providing a strong commitment to achieving mutual goals.’ *West Gippsland Health Care Group*

7. Create welcoming and accessible services for the diverse members of your community.

- Gay and Lesbian Health Victoria has recently produced posters, postcards and pamphlets that health services can use to make the service more welcoming to a diverse range of community members <http://www.glhv.org.au>
- The Royal Women's Hospital outlined a number of ways to make their service welcoming and accessible to a range of culturally and linguistically diverse communities in their annual quality of care report (The Royal Women's Hospital 2004).
- West Gippsland Healthcare Group highlighted working with their local Aboriginal community to increase access and service provision in their annual quality of care report (West Gippsland Healthcare Group 2004).

8. Provide training to staff in communication skills and how to involve consumers and carers in decision making.

- 'We have a kit for staff on how to involve consumers, so we are aware of it but just need to get it going – coach people to do it.' *West Gippsland Health Care Group*
- 'Consumer participation takes time - it is more effort. It can be threatening for a health professional and so need to work and mentor staff through this and that it is acceptable for consumers to question what we're doing. Often it is not questioning ability but wanting to know.' *Goulburn Valley Health*
- One of the principles of patient centred care is the formation of a partnership between the clinician and patient (Bauman et al. 2003)
- An observational study of acute care at the bedside in Victoria identified that staff needed training in relationship development and involvement skills (Wellard et al. 2003)
- There is a wide range of workshops for managers and direct care staff on how to work more effectively with carers, including carer needs, Indigenous carers, and carer-inclusive practices, available from Carers Victoria <http://www.carersvic.org.au>

9. Promote the importance of consumers and carers providing feedback to improve services.

- ‘We developed a Speak out form, a way for people to make complaints and it goes straight to head management. You can post it back as well and can use for complaints and comments.’ *Platform Team Orygen Youth Health, Youth Mental Health Service*
- In Victoria, a consultation and partnership approach identified that services need to be made more accessible, and improve transition from teenager to young adult, pre pregnancy and obstetric care for people living with type 1 diabetes (Rasmussen et al. 2001).
- There is a variety of workshops and training programs to help carers participate more actively and effectively in service improvement. These courses include: ‘Having your say’, ‘Assertiveness for carers’ and ‘Carer presentation skills’. Carers Victoria <http://www.carersvic.org.au>.
- ‘Person doing complaints job has worked really hard at encouraging people to put in complaints and it has worked. Now when staff are told that there has been a complaint they say “what can we do”.’ *Wimmera Health Care Group*

10. Establish links with community organisations to provide emotional support and ongoing information to consumers and carers.

- ‘We do lay counselling and work with the staff. We go in regularly to the ward and leave our newsletter, and staff give talks to our group. It works really well.’ *South Gippsland Heart Support Group*
- A consultation process supported the selection and implementation of a parent role and support program in research into neonatal intensive care services with consumers in the Australian Capital Territory (Gardner et al. 2002).
- A wide variety of health care providers regularly refer carers to regional Carelink and carer respite centres for support and information. *Carers Victoria*

11. Involve consumers, carers and community members in the development of clinical guidelines and research.

- Australian consumer audit of breast cancer guidelines implemented by consumers using a telephone survey (Williams et al. 2002).
- Outcome of national standards for head and neck cancer changed with consumer and carer participation in United Kingdom using a partnership participation approach (Birchall et al. 2002).
- A study on the development of maternal and infant care guidelines in Australia reviewed consumer views on participation in process (Carr, 2001).
- A new model and resource pack for consumer and community participation in health and medical research has been published (National Health and Medical Research Council 2005).

Priority actions - health service organisational level

This level targets the organisational decision makers in health services, hospitals, community health 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.

12. Integrate participation of consumers, carers and community members, representatives or nominees into the quality and safety program.

- ‘Our consumer consultative council [community advisory committee] will be set up through the quality structure so the chair of the committee sits on the quality committee. It will be challenging with consumers [and carers], board, executive and staff all looking at the same information.’ *Goulburn Valley Health*
- ‘With our quality of care report, one community advisory committee member works with the quality coordinator in developing the report. This person takes the report up to the community advisory committee for comment.’ *West Gippsland Healthcare Group*

13. Community representatives or nominees to be involved in the review of system level issues regarding consumer and carer feedback and complaints.

- There were a number of services that identified consumers and carers being involved in their individual complaint resolution process and that were interested in moving to a systems level approach.
- ‘Our complaints liaison officer attends the community advisory committee meeting and provides quarterly updates on complaint issues and our annual complainant satisfaction survey findings. The committee discusses strategies to prevent issues recurring and recommends actions. A progress report is provided back to the community advisory committee on the outcomes.’

St Vincent’s Health Service

14. Include the involvement of consumers, carers, community members, representatives or nominees in all aspects of the organisation’s planning and development.

- ‘We do have consumers on staff selection committees. The young person gets training on recruitment, interview skills and then gets called up to participate.’ *Platform Team Orygen Youth Health, Youth Mental Health Service*
- ‘The Royal Women’s Hospital involved its community in the strategic planning of the redevelopment of their service. This was done through public meetings, panel hearings, written submissions and calls to a 24-hour 1800 number. Following on from this, the community advisory committee developed a set of guiding principles based on the consultation findings to guide the redevelopment process.’ *The Royal Women’s Hospital*
http://www.rwh.org.au/cacwh/projects.cfm?doc_id=4225

15. Provide staff training and education on how to use the different types of participation.

- ‘The Health Issues Centre was funded by the Department of Human Services during 2002–2005 to provide training on participation to Primary Care Partnership staff and community members.’ *Primary Care Partnership Consumer and Carer Advisory Group - Department of Human Services*

16. Ensure position descriptions include participation components.

- Many groups raised this as a suggestion during the consultation process and saw it as a key action to undertake.
- Austin Health’s *Consumer participation plan 2004–05* has a key strategy to ‘(2.1.6) Develop a process to review and update staff position descriptions to include consumer participation and community language skills in key selection criteria and role statements where appropriate’. This is supported by a second key strategy ‘(2.1.7) Develop a process to include consumer participation in staff performance appraisals where appropriate’.
Austin Health

17. Evaluate, monitor and report on participation to the community and the Department of Human Services.

- The findings from the Victorian Patient Satisfaction Monitor are reported to the Department of Human Services and, as part of the policy development process, a sub-index of consumer participation has been developed.
- In the Victoria – public hospitals and mental health services: policy and funding guidelines 2004–05, those services required by legislation to have a consumer advisory committee were asked to report annually on the achievements towards meeting the targets or outcomes identified in their community participation plan (Department of Human Services 2004).
- Section 9 of this policy outlines a framework for evaluation and monitoring.

Priority actions - Department of Human Services level

This level relates to the Rural and Regional Health and Aged Care Services and Metropolitan Health and Aged Care Services divisions within the Department of Human Services¹ (for the purposes of this policy, these two divisions are known as ‘the Department of Human Services’). It describes how the staff within these health divisions should work with consumers, carers and community members and encourage participation in the Department of Human Services.

18. Use the same processes of working with and accessing consumers, carers and community members, representatives or nominees across the Department of Human Services.

- There are Cabinet Handbook guidelines on appointments to ministerial and Department of Human Services advisory committees (Department of Premier and Cabinet 2004).
- The Department of Human Services has guidelines on the establishment of advisory committees (Department of Human Services Victoria 2004).
- A guide on processes for advertising, interviewing and supporting consumers, carers and community members on reference and advisory committees based on the Cabinet Handbook and Department of Human Services guidelines for advisory committees has been established within the Quality and Safety Branch and is available at:
<http://www.health.vic.gov.au/consumer/conspartguide.pdf>.
This guide needs to be reviewed for its applicability across the Department of Human Services.

¹ It does not include the divisions of Disability Services, Financial and Corporate Services, Housing and Community Building, Office for Children, Operations and Policy and Strategic Projects

19. Provide support, guidance and resources to health services, consumers, carers and community members on participation.

- The Health Issues Centre is funded by the Department of Human Services to provide a level of support through the Consumer Nominee Program and resources to the community advisory committees.

20. Provide training and education to Department of Human Services on how to use the different types of participation, and evidence-based participation and communication.

- The Health Issues Centre, under their funding and service agreement with the Department of Human Services, undertakes to resource Department of Human Services staff on participation.
- The Cochrane Consumers and Communication Review Group, under their funding and service agreement with the Department of Human Services, undertakes to provide information and education, based on the evidence contained within their review group's protocols and reviews, to the Department of Human Services.

21. Encourage health services to evaluate and monitor participation within a quality improvement framework.

- This has been partially achieved through the quality of care report guidelines (Department of Human Services 2004) and Section 9 of this policy outlines a systematic approach.
- Health services required under legislation to have a community advisory committee are asked to report annually on their achievements towards meeting their community participation plans from 2005-06 (Department of Human Services 2004).
- The Victorian Quality Council has supported a pilot project to examine how hospitals can take a systematic and evidence-based approach to quality improvement on issues of communication and participation.

22. Encourage the inclusion of participation skills and knowledge in the tertiary education of health professionals.

- This was regarded as important by a number of focus group participants and examples were provided of where patient and family centred care education was being provided to a range of health professionals.
- A number of postgraduate courses, targeted to health professionals and policy makers, where public policy processes are studied, also highlight the role of community participation in the development of public health policy.

23. Advocate for a whole of Department of Human Services policy on participation.

- Towards this end the Disability Services active citizen participation policy and this policy process have been working closely together.
- This policy has taken into consideration what is already written in the mental health, primary and community health areas on participation.

8 Enabling implementation

To help consumers, carers and community members participate with their health services and the Department of Human Services to achieve the priority actions; the following enablers and resources of participation have been identified. These came from the policy development process.

Enablers

Through the consultation paper process, multiple enabling factors for participation were identified. A summary of the enablers is presented here for **organisational staff members** (health service or the Department of Human Services) and **consumers, carers and community members**.

These enablers assist in overcoming corresponding barriers. For more information on participation enablers, see the Information Series on the Participate in Health website <http://http://www.participateinhealth.org.au/> and the report *Improving health services through consumer participation: a resource guide for organisations* (Consumer Focus Collaboration 2000).

Table 2 Enablers of participation

Organisational staff members	Consumers, carers and community members
<ul style="list-style-type: none"> • Communicate to all staff that there is support for participation from the top of the organisation and that the organisation has a willingness to accept change. 	<ul style="list-style-type: none"> • Consumers, carers and community members should be involved from the earliest possible time and be given adequate notice.
<ul style="list-style-type: none"> • Promote to staff the organisational policies and structures that facilitate participation. 	<ul style="list-style-type: none"> • Accessible training on how to participate across the health service system.
<ul style="list-style-type: none"> • Provide staff with training and information on how to facilitate participation. 	<ul style="list-style-type: none"> • They should be involved in developing the processes and issues under consideration.
<ul style="list-style-type: none"> • Work with each other to create trust and mutual understanding. 	<ul style="list-style-type: none"> • Ensure they understand the language and systems the organisation uses.
<ul style="list-style-type: none"> • Decide on lines of accountability and terms of reference. 	<ul style="list-style-type: none"> • Check information is accessible to diverse community needs.
<ul style="list-style-type: none"> • At the earliest possible time, inform all staff who will be affected by the decisions and provide access to information. 	<ul style="list-style-type: none"> • Ensure they are not isolated. Use open and inclusive processes and identify key staff that can provide individual support.
<ul style="list-style-type: none"> • Consider and provide resources for a range of strategies to facilitate the particular participation aim. 	<ul style="list-style-type: none"> • Reimburse costs of participation and provide resources to allow participation.
<ul style="list-style-type: none"> • From the beginning, identify organisational mechanisms to incorporate the lessons learnt into daily practice or future planning and policy development. 	<ul style="list-style-type: none"> • Do not overburden people. Remember there are other important components of their lives.
<ul style="list-style-type: none"> • Ensure staff are skilled in evaluating participation activities and can publish results. 	<ul style="list-style-type: none"> • Inform people of the outcomes of their participation.

Resources

The resources are divided into key participation organisations and publications. The organisations listed are primarily located in Victoria and include some peak national groups. Many of the groups listed have links to national and international organisations available on their websites.

The key publications on participation are listed within the references to this policy and to the consultation paper. The listed references are not an exhaustive list; however, they provide a good starting point.

Organisations

The organisations below can be contacted by telephone for further assistance, such as training and hard copies of publications. Many of their resources can be accessed from their websites. Most of the organisations listed have been accessed from the *Finding consumers and carers: a guide to sourcing consumers, carers and community members for collaborative health service improvement* directory (Victorian Quality Council 2004), which contains an extensive list for stakeholders wishing to contact community organisations.

Table 3 Key participation resource contacts

- **Active Participation Strategy - Department of Human Services**
<http://www.dhs.vic.gov.au/ds/disabilitysite/>

The Active Participation Strategy is an initiative of the Disability Services Division and seeks to promote and create opportunities for people with a disability to be actively engaged in all aspects of decision making that impact on their lives. The Active Participation Strategy works with government, support providers and the community to explore a range of practical and creative ways to actively involve people with a disability in all levels of individual, organisational and community management decision making processes.

The Department of Human Services Disability Services Division has developed guidelines to help government and non-government organisations make their communication practices more accessible to, and inclusive of, people with a disability. Inclusive consultation and communication with people with a disability, *A guide for Victorian Government departments and agencies* can be accessed at: <http://www.dhs.vic.gov.au/ds/communicate>

Contact details

Disability Services Division
Department of Human Services
Level 18, 555 Collins Street
Melbourne Vic 3000
Telephone: (03) 9616 8617

- **Carers Victoria**

<http://www.carersvic.org.au>

Carers Victoria is a statewide organisation that has carers as its primary focus. It offers direct services to support carers in their caring role, and education and training for professionals to increase awareness of carers and carers' issues. The Commonwealth Carer Resource Centre (located at Carers Victoria) can provide information, referrals, support and resources on a range of topics. Carers Victoria is also the central organisation and voice for carers and carer issues in Victoria, and works extensively with other organisations and government agencies on carer issues. The website contains a wide range of information for carers, research and policy reports, and links to other organisations and resources.

Contact details

Level 1, 37 Albert Street
Footscray Vic 3011
Telephone: (03) 9396 9500
Free Call: 1800 242 636

- **Chronic Illness Alliance**

<http://www.chronicillness.org.au>

The Chronic Illness Alliance Incorporated is an organisation representing more than 40 consumer and advocacy groups on policy matters of common concern. The alliance is based in Melbourne and represents groups throughout Victoria. It aims to build a better focus in health policy and health services for people with chronic illness through education, research and maintenance of an email list.

Contact details

818 Burke Road
Camberwell VIC 3124
Telephone: (03) 9805 9126

- **Cochrane Consumers and Communication Review Group:**

<http://www.latrobe.edu.au/cochrance>

This group coordinates the preparation and production of systematic reviews of interventions that affect consumers' interactions with health care professionals, services and researchers. This website has information and resources on the evidence for people's participation in health care at different levels of the system. In addition, their website has an easy link to *The Cochrane Library*, the Internet-based library of summaries of evidence-based treatments.

Contact details

cochrane@latrobe.edu.au
Postal address:
School of Public Health
La Trobe University VIC 3086
Telephone: (03) 9479 5779

- **Collective of Self-Help Groups**

<http://home.vicnet.net.au/~coshg/>

The Collective of Self-Help Groups aims to develop the self-help movement through promoting and supporting self-help groups and assisting in their establishment by providing telephone information, a resource library, website, workshops for groups, help with starting a group, a directory of self-help and social action groups, a resource kit, *In the same boat*, a news sheet, *Collective notes*, and other publications.

Contact details

PO Box 251
Brunswick East Vic 3057
Telephone: (03) 9349 2301

- **Consumers Health Forum of Australia**

<http://www.chf.org.au>

This is the leading national organisation providing a voice for all health consumers. Consumers Health Forum works to promote consumers' views in all areas of health care. It contains links, publications and resources and has a consumer representative program.

Contact details

Unit 10, 11 National Circuit, Barton
Level 2, Engineering House
Telephone: (02) 6273 5444

- **Consumer participation and information program - Department of Human Services**

<http://www.health.vic.gov.au/consumer>

The Department of Human Services supports a range of initiatives that promote consumer involvement in decision making about their own treatment and care, in-service development and quality improvement, and health policy developments. It contains information on Victorian quality of care report guidelines, community advisory committees, and links to international websites and to other Department of Human Services websites. It also has links to Victorian hospital websites and has a range of participation publications, including *Communicating with consumers: good practice guide to providing information*.

Contact details

Consumer participation and information program
Level 16, 555 Collins Street
Melbourne Vic 3000
Telephone: (03) 9616 9055

- **Council on the Ageing**

<http://www.cotavic.org.au/>

Council on the Ageing's vision embraces the shaping of a just, equitable and humane community in which older people, in all their diversity, are a vibrant part and able to contribute and grow to their fullest capacity. They advocate for the rights and interests of older people through the provision of information and advice, input on government policy issues, written submissions and development of specific projects.

Contact details

Block Arcade, 98 Elizabeth Street
Melbourne Vic 3000
Telephone: (03) 9654 4443

- **Ethnic Communities' Council of Victoria**

<http://www.eccv.org.au>

The Ethnic Communities' Council of Victoria is the peak non-government body representing ethnic communities throughout Victoria working to promote equity of opportunity. It involves itself in policy development, advocacy and information provision. The Centre for Culture, Ethnicity and Health also provides training in cultural sensitivity and has a comprehensive library (<http://www.ceh.org.au> or tel (03) 9427 8766).

Contact details

150 Palmerston Street
Carlton Vic 3053
Telephone: (03) 9349 4967

- **Gay and Lesbian Health Victoria**

<http://www.glhv.org.au/>

The role of Gay and Lesbian Health Victoria is 'to enhance and promote the health and wellbeing of gay, lesbian, bisexual, transgender and intersex (GLBTI) Victorians'. The plan to do this includes:

- training health care providers and health organisations about GLBTI health needs and appropriate service delivery
- developing health resources for GLBTI communities, in conjunction with mainstream services

- establishing a research and information clearinghouse as a resource for health care providers, researchers and individuals to use in researching their own health issues
- providing advice to government on the planning and development of future LGBTI programs.

Contact details

La Trobe University
1st Floor, 215 Franklin St
Melbourne Vic 3000
Telephone (03) 9285 5382

• Health Consumers of Rural and Remote Australia

<http://www.ruralhealth.org.au>

This not-for-profit organisation works to improve rural health outcomes by involving consumers in the planning, implementation, management and evaluation of health services throughout non-metropolitan Australia.

Contact details

PO Box 280
Deakin West, ACT 2600
Telephone: (02) 6285 4660

• Health Issues Centre

<http://www.healthissuescentre.org.au>

The Health Issues Centre has gained a strong reputation around Australia for its public interest research and analysis of the health system, particularly promoting awareness of consumer perspectives and needs. Its website provides access to the consumer nominee program in Victoria, national and international links, a journal, library, policy analysis and publications. The Health Issues Centre maintains the National Resource Centre for Participation in Health website <http://www.participateinhealth.org.au>. The website has many training resources and tools on participation, Consumer Focus Collaboration resources, and links.

Contact details

Level 5, Health Sciences Building 2
La Trobe University Vic 3800
Telephone: (03) 9479 5827

- **Our Community**

<http://www.ourcommunity.com.au>

This is a one-stop gateway for practical resources, support and links between community networks and the general public, business and government. It builds capacity to strengthen the community in every Australian state and territory. Our Community holds an annual conference and has a calendar of events and a directory of non-profit community organisations.

Contact details

51 Stanley St
West Melbourne Vic 3003
Telephone: (03) 9320 6800

- **Victorian Aboriginal Council of Health Organisations**

<http://www.vaccho.com.au>

This organisation represents the collective of all Aboriginal community controlled organisations around Victoria. It serves as a channel for communities to direct Aboriginal health policies, support locally planned initiatives and works on behalf of members as requested. It also coordinates statewide opinion on Aboriginal health issues that affect all member communities. Their website provides resources and links and a list of every local Aboriginal community controlled organisation with a health function.

Contact details

5-7 Smith Street
Fitzroy Vic 3065
Telephone: (03) 9419 3350

- **Victorian Mental Illness Alliance**

<http://www.vmiac.com.au>

This alliance enables people with a mental illness or emotional problems to have a say in decision making using individual, group and systemic methods. The organisation provides advocacy, mutual support and self-help for consumers, and education to consumers and providers in the mental health area. They have a newsletter for members and provide training and support for rural and metropolitan consumer consultants.

Contact details

23 Weston Street
Brunswick Vic 3056
Telephone: (03) 9387 8317

- **Victorian Quality Council**

<http://www.health.vic.gov.au/qualitycouncil>

The Victorian Quality Council is responsible for fostering better quality health services in Victoria by working with stakeholders to develop useful tools and strategies to improve health service safety and quality. One of the council's five key strategic areas is increasing the involvement of consumers in improving safety and quality of health care in Victoria. To assist health services to source consumers to collaborate on safety and quality improvement, the council developed a guide, *Finding consumers and carers*, which is available on the website. Further information on participation in relation to the quality and safety of health care can be found on the website of the Australian Council for Safety and Quality in Health Care <http://www.safetyandquality.org>.

Contact details

Level 7, 589 Collins Street
Melbourne Vic 3000
Telephone: 1300 135 427

- **Women's Health Victoria**

<http://www.whv.org.au>

Women's Health Victoria aims to ensure that all women have access to quality responsive services that meet their health needs, and that an understanding of women's health is maintained and promoted from a feminist perspective. The organisation provides an information clearinghouse, advocacy, works with service providers for better health outcomes, health promotion work and works with public policy makers.

Contact details

1st Floor, 123 Lonsdale Street
Melbourne Vic 3000
Telephone: (03) 9662 3755

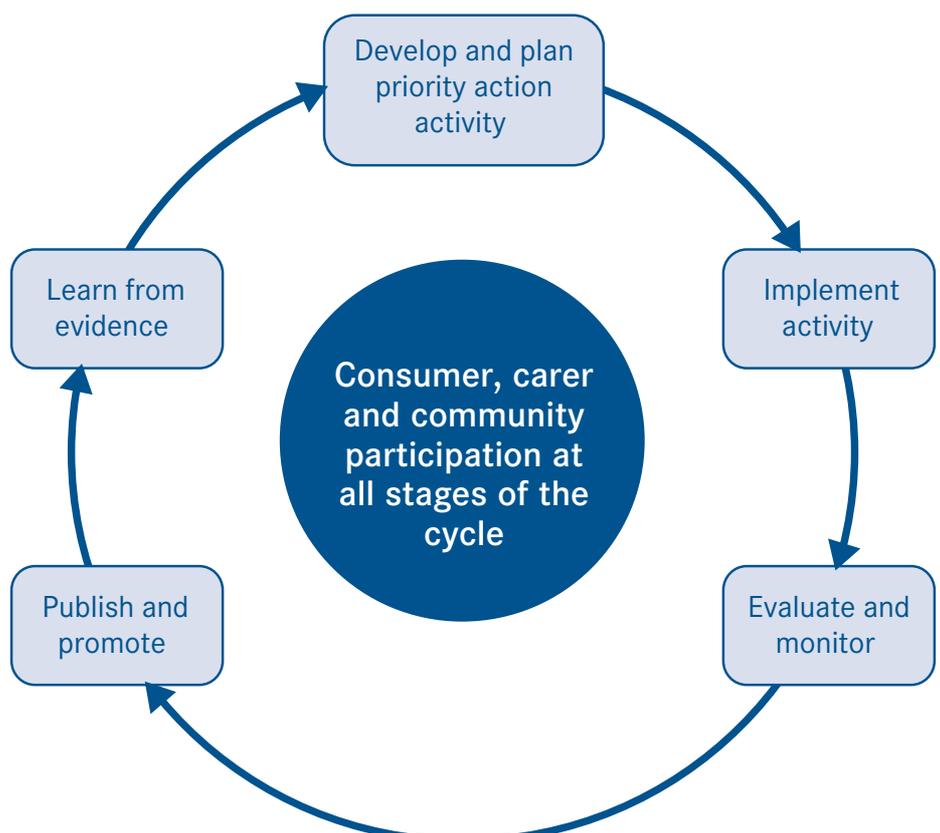
9 Evaluation and monitoring

An evaluation and monitoring process is required to know if the policy priority actions are being implemented. As part of the consultation paper, an evaluation and monitoring framework was proposed. This framework has been enhanced by the feedback received and the research undertaken to develop the participation indicator paper.

Framework

The framework is based on a quality improvement approach to participation and includes evaluation of individual activities and monitoring of performance indicators. All stakeholders can improve their participation activities by using the evidence obtained from evaluating and monitoring the participation priority actions. The continuous quality improvement cycle in Figure 1 outlines the key steps in the framework.

Figure 1 Participation evaluation and monitoring cycle



Evaluation

When evaluating a participation activity, consider if the evaluation is of the processes, impacts or outcomes of the activity. A description of these stages is in Appendix 4. Table 4 sets out key evaluations required at each of these stages. The suggested evaluations link to the priority action statements made under each level of the policy. The evaluations are not an exhaustive list and should be used to stimulate further evaluation activity.

Table 4 Evaluation of participation activities*

Policy level	Process	Impact	Outcome
Individual level	<ul style="list-style-type: none"> Evaluate feedback strategies and information development and distribution processes. 	<ul style="list-style-type: none"> Evaluate if feedback strategies and information distribution objectives have been achieved. Evaluate the impact of consumer and carer participation in decision making about care and treatment at pre-admission, during admission and post-admission. 	<ul style="list-style-type: none"> Evaluate the effect of participation in decision making on readmission rates and primary care use. Evaluate the effect of participation on indicators of chronic disease management.
Program or department level	<ul style="list-style-type: none"> Evaluate efficacy, accessibility or efficiency of participation processes in projects. Evaluate processes of participation in clinical guideline development. Evaluate processes of participation in research development and implementation. 	<ul style="list-style-type: none"> Evaluate immediate effectiveness or efficiency of participation within a project or research. Evaluate staff participation skills, as part of staff development, in decision making about care and treatment. Evaluate accessibility of your program or department. 	<ul style="list-style-type: none"> Evaluate long-term participation goal or aim of projects and research to identify effectiveness or efficiency of participation.
Health service organisational level	<ul style="list-style-type: none"> Evaluate if Victorian Quality Council checklists for participation have been achieved (Victorian Quality Council 2003 and 2004). Evaluate if processes of participation in programs, policies and governance requirements have been met. 	<ul style="list-style-type: none"> Evaluate if immediate outcomes of participation have been achieved for programs, policies and governance requirements. 	<ul style="list-style-type: none"> Evaluate if the long-term goal of participation for a specific program or policy has been achieved.
Department of Human Services level (health divisions)	<ul style="list-style-type: none"> Evaluate if Cabinet Handbook guidelines on appointments to committees have been met (Department of Premier and Cabinet 2004). Evaluate if advisory committee guidelines and individual terms of reference on participation have been met (Department of Human Services Victoria 2004). Evaluate if the <i>Partnership in practice: partnership agreement</i> guidelines have been met (Department of Human Services 2002). 	<ul style="list-style-type: none"> Evaluate if immediate outcomes of participation have been achieved for a policy, program or planning strategy. 	<ul style="list-style-type: none"> Evaluate how effective participation has been in achieving its role as an enabler of Department of Human Services planning, policy and programs.

* As set out in Figure 1 Participation evaluation and monitoring cycle, consumers, carers and community members should be involved in the evaluation itself.

Monitoring

The participation indicator paper recommended health services report on a minimum set of participation indicators, as outlined in Table 5, to the Department of Human Services. The indicators were based on information health services currently report on, legislative requirements and accreditation reporting in acute and sub-acute care. This is because the participation indicator paper identified that the aged care, community health and mental health areas of the health service system have their own monitoring and reporting systems. The paper also recommended a second set of possible indicators for later implementation across the acute and sub-acute areas and these are set out in Appendix 5.

Table 5 Minimum participation indicator set: Victorian acute and sub-acute services

Recommended standard	Indicator	Target or achievement
1. Governance		
1.1 The governing body is committed to consumer, carer and community participation.	1.1.1 Health service meets the accreditation standards in the Evaluation and Quality Program (Australian Council on Healthcare Standards 2002): 'The governing body is committed to consumer participation' (currently Standard 2.4) or its equivalent, to the level of 'MA' (Moderate Achievement).	The service reports its accreditation outcome and associated comments and recommendations to the Department of Human Services against this standard. If standard not met, summary of proposed action and progress is reported annually to the Department of Human Services.
1.2 There is participation in higher level decision making	1.2.1 There are consumers, carers or community members on key governance and clinical governance structures.	There are consumers, carers or community members on the service's human research and ethics committee and the quality committee. There is ongoing support and networking of consumers involved in these committees
	1.2.2 A community advisory committee has been established in accordance with the <i>Health Services Act 1988</i> section 239.*	Yes/No
	1.2.3 A community advisory committee has been established in accordance with the non-statutory guidelines.*	Yes/No
2. Accountability		
2.1 The service reports openly to its communities on quality and safety, and the participation in its processes.	2.1.1 The quality of care report outlines quality and safety performance and systems in the key care areas that address the health care needs of the service's communities, consumers and carer populations. 2.1.2 A community participation plan has been developed and is being reported against annually to the Department of Human Services.*	The report documents how it has met the 'minimum reporting requirements' ** The report indicates at least process and impact evaluation findings in meeting 'minimum reporting requirements' on participation activities. **
3. Health care and treatment		
3.1 There is consumer and, where appropriate, carer participation in clinical care.	3.1.1 Consumer participation in decision making about their care and treatment is assessed on the Victorian Patient Satisfaction Monitor's Consumer Participation sub-index. *** 3.1.2 Appropriate information is available to enable all consumers and carers, where appropriate, to choose to share in decision making about their care.	The Victorian Patient Satisfaction Monitor Consumer Participation Sub-Index, and the Information Sub-Index improve over time. Health services can demonstrate that their processes for developing consumer and carer information for treatment and care options meet the <i>Well-written health information: a guide</i> , checklist (Currie et al. 2000).

* Only those services required under the *Health Services Act 1988* to have community advisory committees need to meet these indicators.

** 'Minimum reporting requirements' refers to those requirements outlined in the *Quality of care reports – guidelines and reporting requirements*, located at <http://www.health.vic.gov.au/consumer/>.

*** As part of the Department of Human Service's development of the participation policy, an investigation into a reliable, valid and logical sub-index of consumer participation from existing experience-based questions on the Victorian Patient Satisfaction Monitor was investigated. The outcome being the identification of such an index that can be made available to health services.

Implementing evaluation and monitoring

Implementing the evaluation and monitoring framework and reporting on participation is the responsibility of all policy stakeholders. However, as stated in priority actions 17 and 21, the health services and the Department of Human Services have key responsibilities to ensure monitoring and evaluation occur. Consumers, carers and community members should be involved in developing and implementing monitoring and evaluation processes with health services and the Department of Human Services.

Monitoring plan

Health services should commence reporting on the minimum set of participation indicators, as listed in Table 5, using the following staged introduction process²:

2005-06 reporting period

- A community advisory committee has been established in accordance with the *Health Services Act 1988* section 239.
- A community advisory committee has been established in accordance with the non-statutory guidelines.
- The quality of care report outlines quality and safety performance and systems in the key care areas that address the health care needs of the service's communities, consumers and carer populations.
- A community participation plan has been developed and is being reported against annually to the Department of Human Services by **metropolitan** health services.
- Consumer participation in decision making about their care and treatment is assessed on the Victorian Patient Satisfaction Monitor's Consumer Participation sub-index.

² Some health services may be able to successfully report on all the indicators earlier than the proposed scheduled.

2006–07 reporting period

- A community participation plan has been developed and is being reported against annually to the Department of Human Services by metropolitan and **regional** health services.
- Appropriate information is available to enable all consumers and carers, where appropriate, to choose to share in decision making about their care.

2007–08 reporting period

- Health service meets the accreditation standards in the Evaluation and Quality Program (Australian Council on Healthcare Standards 2002): ‘The governing body is committed to consumer participation’ (currently Standard 2.4) or its equivalent, to the level of ‘MA’ (Moderate Achievement).
- There are consumers, carers or community members on key governance and clinical governance structures.

2008–09 reporting period

- Continue implementation of the minimum set of indicators.
- Review the introduction and use of the minimum set of indicators.
- Develop with stakeholders an agreed set of second stage indicators and an introduction process.

Health services will report on if they have achieved the *target or achievement* for each indicator, as outlined in Table 5. Further details of reporting requirements will be outlined in the annual policy and funding guidelines for Victorian public hospitals.

As described in the participation indicators paper, indicators should be reported on not only to the Department of Human Services but also to the health service’s **board**. Health service boards can then identify strengths and areas for improvement. To facilitate the reporting on indicators, each health service should develop an **internal implementation plan** addressing the most common **risks and limitations** of indicators. The common risks and limitations are outlined in Appendix 3 of the participation indicators paper.

Evaluation plan

Through **project funding guidelines** and **service agreements**, health services and organisations will be encouraged to conduct evaluation of participation. Evaluations should reflect the priority actions as outlined in Table 4 and the **participation evaluation and monitoring cycle** described in Figure 1.

Participation advisory group

To ensure that the framework is implemented and to assist in reviewing the reporting on participation, a new advisory group to the Department of Human Services will be formed. This group will be made up of consumers, carers, community members, community organisations, health services and the Department of Human Services.

Appendix 1 Reference Committee



Chair: Dr Jenny Bartlett (to November 2005)

Dr Jenny Bartlett is the Director Quality and Safety (formerly Chief Clinical Advisor) for the Department of Human Services and heads up the Quality and Safety branch (formerly Office of Chief Clinical Advisor). This office is responsible for developing and implementing clinical quality and innovation programs for health services in Victoria. The program covers clinical improvement, clinical risk management, infection control, consumer policy and other aspects of consumer safety.

In addition she provides specialist clinical advice on all aspects of the division's activities, including advice to health services. She established the Victorian Quality Council and the Surgical Consultative Council as well as managing the Consultative Council on Anaesthetic Morbidity and Mortality. Management of the critical care and trauma programs for the state also sit within her portfolio.



Deputy Chair: Ms Helen Kurincic

Helen Kurincic became the Executive Director of Benetas (formerly Anglican Aged Care Services Group) in October 2000. Benetas offers an integrated network of residential and community aged care services to more than 1500 clients across 17 sites in Melbourne and employs 700 staff supported by several hundred volunteers. Helen first qualified as a registered nurse specialising in critical care. She went on to complete a Graduate Diploma in Women's Studies, a Master of Business Administration (specialising in accounting and finance) and a Company Director's Course. Prior to working in a variety of leadership roles in aged care, Helen held consultancy, academic, counselling/advocacy and nursing positions.

She is actively involved in aged care policy and sector planning, representing the interests of the aged at many national and state forums. Helen is also on the Board of Melbourne Health Metropolitan Health Service (currently Chairperson Workforce Governance Committee and Acting Chair Community Advisory Committee) and the Board of the Victorian Association of Health & Extended Care. Helen was awarded the 2002 Telstra Victorian Business Woman of the Year. Helen was also a finalist in the national top five of the leading CEO for the advancement of women in the 2003 EOWA annual business achievement awards.



Mrs Judy Rynhart

I am married with five children and live on a farm at Elmore, which is half way between Bendigo and Echuca. My husband, Robert, and I farm hay and sheep.

I am a consumer representative on BreastScreen Victoria's Board of Management as well as being on the Victorian Consumer Advisory Committee for BreastScreen. I started on the BreastScreen Board about nine years ago and four years later became the Chair of this meeting and two years ago we started a consumer group at Bendigo which I also chair. The Elmore branch of the Country Women's Association plays a big part in my life and at present I am their president as well as regional chair for Red Cross.

I feel it is important to have consumers on committees as consumers bring a different point of view to the discussion around the table and it keeps the basic tone of the meeting honest.



Ms Dell Horey

I have been an active consumer representative in Australia for more than a decade, prompted by my experiences in maternity care. It seems obvious to me that people using health care services are in a good position to offer input into how health care can be improved and could better meet the needs of individuals.

My interest in perinatal research encouraged me to undertake a masters degree in clinical epidemiology. This was followed by studies towards a PhD looking at issues related to information given to women in pregnancy.

I am a member of the board of the Health Issues Centre and the Australasian coordinator of the consumer panel of the Cochrane Pregnancy and Childbirth Review Group. In this role I encourage women to comment on reviews of research in this area. I am also an editor with the Cochrane Consumers and Communication Review Group. I am also interested in health workforce issues and have participated in a range of working parties that have looked at specific aspects of the workforce.



Ms Carol Makhoul

My involvement on this reference committee stems from my interest in the development of a policy that is inclusive of, and reflects, the health needs and experiences of Victoria's culturally and linguistically diverse communities, and young people. Both culturally and linguistically diverse community members and youth have specific health needs and experiences in accessing and using health services, including barriers to full consumer participation, which need to be addressed.

My recent exposure to community health related needs and issues has come from telephone counselling, and a research project completed with Deakin University, Centre for Citizenship and Human Rights. The research sought to identify the needs of the Arabic-speaking community and gaps in service provision. A range of health needs and issues were raised by these members of the community, which are also relevant to other culturally and linguistically diverse communities.

My honours degree at the University of Melbourne sought to examine the accessibility and cultural sensitivity of domestic violence services to non-English speaking background women. Both these research projects have furthered my understanding of the need for culturally responsive services. Further, I am passionate about working with and empowering young people. I have pursued this through project development and research at the Victorian Arabic Social Services, mentoring with the Centre for Multicultural Youth Issues and, direct support through the Youth Referral and Independent Person Program.



Mr Robin Ould

Robin Ould is the Chief Executive Officer of the Asthma Foundation of Victoria, a position he has held since 1997. Robin has had considerable experience in both the corporate and not for profit sector in the fields of human resource management, training and strategic planning. With family experience of asthma, Robin is personally driven to ensure that people with asthma have access to relevant, up to date education and information to better understand and manage their asthma.

Ms Jill Thompson

Jill is Policy Officer for the Victorian office of Council on the Ageing where she has been working for the past nine years. Prior to taking this position, Jill worked in Aged Care Services in Local Government (Moorabbin) for eight years.

Council on the Ageing is an organisation, which has represented the rights and interests of older people at both the State and Federal level for over 50 years. We advocate to government and to service providers, on all the social and political factors, which affect their lives.



Mr Tony McBride

Tony is the Chief Executive Officer of the Health Issues Centre, a health consumer- focused policy and research organisation based in Melbourne. He is currently involved in policy advocacy around increased oral health services and Medicare, and in managing the wide range of Health Issues Centre's other research and practice change projects. He was a director of the National Resource Centre for Consumer Participation in Health until its recent closure. Tony has wide experience in a range of sectors: community health and community development in Melbourne and Docklands London; teaching and research in health promotion at Deakin University; managing health and community services for Brunswick and Moreland Councils; coordinating the statewide Healthy Localities Project at the Municipal Association of Victoria; and managing a range of population health funding programs for the Commonwealth Government. Tony was also Chairperson of the Centre for Development and Innovation in Health for many years.

Tony is very supportive of this initiative to develop a Department of Human Services consumer participation policy for health. The research (including recent Health Issues Centre research in Victoria) clearly shows strong policies are an essential component for creating change. Although there are other important factors that will drive increased levels and effectiveness of consumer participation in Victoria, clear departmental policies give a clear message about expectations, offer guidance about directions, and provide a valuable lever for champions at more local levels to utilise.

Mr Ian Pollerd

I began my working life as a Secondary School teacher. I taught economics, legal studies and accounting at a number of schools in metropolitan Melbourne. Whilst teaching I added to my additional qualifications with a Bachelor of Education and Diploma in Criminology.

I had the opportunity to work as an analyst with the Police Complaints Authority before being appointed to a managerial position at the Baltara Reception Centre. I was then appointed to a number of managerial positions in the Western Metropolitan Region of Melbourne – Specialist Children, Family Services, Community Programs, Disability Services, and Aged Care. I am currently Manager of Rural Health Policy Projects in the Rural and Regional Health Services Branch.

I have a great deal of experience in both policy and operations and believe that I can make a worthwhile contribution to the reference group. I am an advocate of community participation at all levels of decision-making.



Ms Beth Wilson

Beth Wilson has a Bachelor of Arts and a Bachelor of Laws from Monash University and a Graduate Diploma in Information Technology from Royal Melbourne Institute of Technology and an Honorary Doctorate in Education from Royal Melbourne Institute of Technology University. She is currently the Health Services Commissioner (health ombudsman) in Victoria, Australia. The Commissioner receives and resolves complaints from consumers of health services about health service providers with a view to improving the quality of health services for all. Prior to becoming the Commissioner Beth was the president of the Mental Health Review Board. Her areas of special interest are in medico/legal issues especially ethical aspects, alternative disputes resolution in health care complaints and medical ethics.



Ms Lesley Thornton

Lesley is currently a Senior Project Officer with the Victorian Quality Council. A ministerial commitment was made to establish a new quality council in an announcement to the media in 2000. This followed a recommendation from the Health Services Policy Review Final Report that identified the need for such a body. Launched by the then Minister for Health, the Hon John Thwaites MP in October 2001, the Victorian Quality Council is responsible for fostering better quality health services in Victoria by working with stakeholders to develop useful tools and strategies to improve health service safety and quality.



Mr Graeme Roberts

Graeme was born in Carlton in 1938 the eldest of seven children. He grew up in Footscray and attended Geelong Rd Primary School followed by Williamstown High School. Graeme joined the Government Aircraft Factories then Sir George Godfrey and Partners, makers of aircraft equipment in Airport West. He moved to Gippsland and joined the State Electricity Commission as a linesman assistant and went on to qualify firstly as a Linesman C Grade and then as a Linesman A Grade. Graeme enjoyed life in Gippsland playing cricket, squash and football in Moe. He later transferred to Essendon and married in 1964. They moved to Broadmeadows and later Epping where they raised their two children.

Graeme currently serves the Northern Hospital as a volunteer driver and is a serving member of the Austin Hospital's HARP Program reference group. He applied to join the Participation in your health service system policy reference committee as he feels that the health system and the hospital system in particular need a rethink on operational matters.



Ms Trish Karadimos

Hi, I'm Trish Karadimos a former carer of seven years of a mother with Lewy Bodies Disease (Dementia with Parkinsons). I'm also married, have two great kids, Jean-Louis and Andre. Previous to being a mum and carer, I had a varied work background from being a Chairman's secretary in a maternity hospital, to marketing and sales in fashion and furniture then going back to school at 32, in a mature aged capacity, of course, to do hospitality management. My path was planned for me and my journey really became meaningful when I had to care for mum. One becomes very resilient, strong-willed, tolerant and compassionate with this role. I lie, sometimes my tolerance failed me, but my journey has lead me to now do volunteer advocacy work on behalf of carers for Carers Victoria and volunteer work in public speaking for dementia awareness with Alzheimer's Victoria.

My passion and belief in a health system that needs major change, restructuring, more respect for the disabled and elderly's needs, more understanding for the cultural and linguistically diverse and the many that cannot advocate for themselves has lead me to be a committee member as a carer representative in a reference group to create a policy for the importance of consumer participation in our health system. I have also been involved in other projects but my biggest highlight and my claim to fame was when I spoke at Government House for Carer's Week in 2002.

That was a day in October that I was very humbled to be part of a very special group of people that dedicate their lives to helping their sick family members. It was also the day for my very first public speaking assignment. What a way to be launched into volunteer work!



Dr Tracey Batten

Dr Batten was appointed as the Chief Executive Officer for Eastern Health in January 2004. Eastern Health is the main provider of health services to patients who reside in the central east, outer east and Yarra Ranges regions of greater metropolitan Melbourne. With an annual turnover of \$400 million and approximately 6,900 staff, Eastern Health provides acute, mental health, aged care, rehabilitation and community health services across five main campuses: Angliss Hospital; Box Hill Hospital; Healesville & District Hospital; Maroondah Hospital and the Peter James Centre. Prior to 2004, Tracey was the Chief Executive Officer of Dental Health Services Victoria. Tracey has worked in

health management roles for the past ten years including the Chief of Health Programs at the Inner & Eastern Health Care Network and Director of Clinical Services at St Vincent's Hospital. Tracey's qualifications include a Bachelor of Medicine and Surgery from the University of Melbourne, a Master of Health Administration from the University of New South Wales, Fellowship of the Royal Australasian College of Medical Administrators, and a Master of Business Administration from Harvard Business School.



Ms Debra Cerasa

Debra Cerasa is the Chief Nursing Officer at Latrobe Regional Hospital and is currently studying for her Doctorate of Business Administration. Debra is a senior health manager with more than 30 years experience in the health industry. Following general nurse training in Deniliquin, NSW, Debra returned to Melbourne where she gained clinical experience in general surgical, medical and operating theatre nursing, along with certificates in intensive care and midwifery.

Debra has a keen interest in quality management systems and has been involved in public education and nursing education in a number of Melbourne hospitals. She has also worked with the undergraduate and postgraduate paramedic programs of the Victorian Ambulance Service. Debra held an executive management position as Country Manager - Clinics and Training with International SOS, a privately owned international medical service company based in Indonesia, before being appointed to her current position in 2001.

Her interests in nursing are stimulated by innovation and new concepts in care delivery. Debra's commitment to the professionalism of nursing is evidenced by the many initiatives that she has introduced for the Latrobe Regional Hospital nurses, including the annual nurses forum, the quarterly nurses newsletter, the annual nurses International Conference Scholarship and the Hospital Professional Awards for nurses.



Ms Marija Joyce

Marija is the Coordinator, Consumer Participation for the Royal Women's Hospital and acts as Resource Officer for the legislatively-based Community Advisory Committee on Women's Health (CACWH). The ten community-based members of this committee are committed to enhancing links between women in the community and the Board, management and staff of the hospital.

The CACWH has, over the last four years, played a significant role in planning for the redevelopment and building of a new hospital for women, due to open in 2008. This planning has included a series of community consultations detailing issues relevant to both the physical design and service provision of the new hospital, ensuring that the needs of the community are well reflected.

In her role Marija also acts as a resource for staff in the hospital, advising them on the best ways to involve consumers in the planning and review of services. Prior to this role, Marija has been involved in management and coordinating roles in the health and community sector for over twenty years. This has included a focus on working with marginalised communities in a range of international development projects and counselling and group work for people, including adolescents, with long term illnesses such as cancer. Marija looks forward to contributing to the development of a new policy that will hopefully improve the experience of consumers involved in the hospital and health system in Victoria.

Due to leaving her position at the Royal Women's Hospital Marija resigned from the Committee in December 2004. Her position on the committee was filled by Mr Phill Goulding of the Royal Children's Hospital.



Mr Phill Goulding

Phill has been associated with the Royal Children's Hospital since he commenced his nurse training in 1984. Over that time he has worked in a variety of roles: clinical, management, pharmacy sales, human resources (industrial relations) and has most recently been working as a senior manager in the Division of Surgery. Phill has three children of his own who have utilised the services of Royal Children's Hospital. A key driver for Phill is improving the quality of care for children and families that are associated with the hospital. He is also an accreditor with the Australian Council on Healthcare Standards. He comes to the role of Consumer Engagement Consultant with the expressed aim of facilitating improved involvement of community members, carers and consumers in all that is done at the Royal Children's Hospital.



Dr Sophie Hill

Dr. Sophie Hill is the Coordinating Editor of the Cochrane Consumers and Communication Review Group. The review group coordinates the production of systematic reviews of the effectiveness of interventions to improve people's interactions with the health system. She is the lead reviewer for a Cochrane review on interventions for informed decision making by consumers on end-of-life decision making, and a co-reviewer with a team examining interventions to prepare children and adolescents for hospital and treatment therein.

In her capacity as Senior Research Fellow in the School of Public Health at La Trobe University, she is the Manager of the PHERP Innovations Program, 'Promoting and facilitating evidence-based policy and practice in public health and health promotion: tertiary education', that has led to the establishment of a tertiary subject on evidence-based public health for public health professionals at La Trobe University. She is also the lead investigator for several projects, including the following in 2004:

- GPs' and consumers' views of the issues of format and communication of absolute risk for cardiovascular disease
- consumers' views of the risks, benefits and regulatory requirements of the professions of naturopathy and western herbal medicine
- an evidence-based approach to quality improvement on communication issues in three Victorian hospitals.

Sophie has extensive experience in working for health consumer organisations and government, researching people's experiences of health care and investigating ways to improve service delivery, including five years with Health Issues Centre. Sophie is a member of the NHMRC Health Advisory Committee and co-edited *Technologies and Health: Critical Compromises* (OUP, 2001).



Mr Paul Butler

Paul Butler is currently the Manager of Policy for the Primary and Community Health Branch of the Department of Human Services. In this role, Paul is responsible for future planning and directions for Victoria's Community and Women's Health Services, Public Dental Services and Primary Care Partnerships. Paul and his team have responsibility for promoting consumer, carer and community participation in Victoria's primary health care services. The branch has a Consumer, Carer and Community Advisory Group that provides advice to the Branch from a consumer perspective

Prior to working for the department, Paul has worked in a range of jobs in Victoria's primary health care sector, most recently in a research and consultancy role at La Trobe University. Paul has written extensively about primary health care in Victoria and Australia and on the importance of consumer and community involvement.



Ms Robyn Humphries

Robyn Humphries has 25 years experience working in the public mental health sector in Melbourne. Her background is in social work, and in 2000 she achieved a Master of Business Leadership qualification. In 2002 she was appointed Manager of the Northern Area Mental Health Service, NorthWestern Mental Health. Robyn has a strong commitment to consumer and carer participation in the mental health service system, and is pleased to contribute to the development of consumer and carer participation strategies in the broader health services system.

Mr Graham Ludecke

Graham Ludecke, a retired senior banker, has a long association with the Sandringham and District Memorial Hospital (SDMH) on whose Board he served. He was made a life Governor of SDMH in 1981. He has a particular interest in service quality, community health and welfare and the continual improvement of family, local and global values.

He is currently a member of the Bayside Health, Community Advisory Committee (CAC) and was a member of the Southern Health Care Network CAC. Mr Ludecke has recently retired as a Director of Southern Family Life and is currently President of the Black Rock Sports Auxiliary, the main fund raising auxiliary for SDMH, Board Secretary of the Banking and Finance Service Ombudsman and Committee Member of



ABIE (Australian Business in Europe). He was a Director of the public company, Data Advantage Ltd and continues to be involved in local community activities.

Mr Ludecke welcomed the opportunity to be a member of the Participation in your health service system, Project Reference Committee and to contribute to the development of a policy that will encourage community participation in the health service and subsequently lead to improvements in the delivery of services.

He is particularly interested in exchanging best practice between the various Health Services and to give disadvantaged and under resourced groups a voice in the delivery of health services.

Mr Timothy Moore

Timothy is the Senior Policy Officer at the Victorian Aboriginal Community Controlled Health Organisation Inc (VACCHO). VACCHO is the peak body that represents the Aboriginal Community Controlled Health Services in Victoria. It is the channel for communities to direct Aboriginal health policies, and co-ordinate national and statewide opinion and direction on Aboriginal health issues that affect member organisations. VACCHO supports locally planned, statewide and national initiatives and works on behalf of members as requested.

Senior Project Officer: Ms Cath Harmer

Cath joined the Victorian Department of Human Services in 2004 to manage the Consumer Participation and Information Program in acute health. She has been greatly impressed by the activity between consumers and health service providers working together to improve the systems, particularly, the quality of health care. Prior to this Cath has spent over 10 years working in the community sector for consumer managed organisations. She has been a support worker, consumer advocate, trainer, community development worker and gone on to manage direct care services in the community. Cath worked in the areas of youth homelessness, mental health, acquired brain injury and diabetes. She has also conducted research projects with a strong public health focus and has completed several courses including a Master of Public Health and the Victorian Public Health Officers Trainee Program.



Appendix 2 Types of participation

Table 6 Participation types in a health care system*

Participation type	Objective	Key tools	Make sure
Information (needed for participation)	<ul style="list-style-type: none"> To support participation To convey facts To educate 	<ul style="list-style-type: none"> Public information campaigns Health consultation (pre-admission, hospital admission, discharge, outpatient clinic or at community health centre and rehabilitation setting) 	<ul style="list-style-type: none"> You have a distribution strategy researched with your target consumers, carers or community. Try hard to use common words and pictures for medical and technical words. Train and educate staff in patient-centred communication.
Consultation	<ul style="list-style-type: none"> To gauge reaction to a proposal/care plan/treatment plan and invite feedback Consultation is only participation when information gathered can influence subsequent policy, care and treatment choices. 	<ul style="list-style-type: none"> Key contacts Surveys Interest group meetings, focus groups Public meetings Discussion papers Public hearings Consumer (patient) and carer (family) meetings Health consultation 	<ul style="list-style-type: none"> Let all stakeholders know how their input will be used and the outcomes of their participation. If input has not been used, let stakeholders know why. When clinical decisions have to be made quickly, explain why and how as soon as possible. Educate staff in patient-centred communication skills.
Partnership	<ul style="list-style-type: none"> To involve consumers, carers and representatives in aspects of government or health service organisational decision making To involve consumers, carers and representatives in health care or treatment decision making 	<ul style="list-style-type: none"> Advisory boards Community advisory committees Policy community forum Shared decision making Community development Patient-centred care 	<ul style="list-style-type: none"> Talk with the stakeholders and decide if you should have members, representatives or nominees. Consider having a balance between community organisations and individuals. Can you use a variety of partnership opportunities to achieve your aim? Alternate meetings to suit the range of stakeholder needs. Educate and train staff in shared decision making and patient-centred care.

Table 6 Participation types in a health care system* (continued)

Participation type	Objective	Key tools	Make sure
Delegation	<ul style="list-style-type: none"> To hand control to a board of community representatives within a specified framework To ensure policy options are formulated at arms length from partisan politics 	<ul style="list-style-type: none"> Public enquiries Impact assessment studies Health service boards Ethics committee 	<ul style="list-style-type: none"> Hold briefing sessions for new members to meet and learn the systems. For people from a diverse range of backgrounds to feel confident to participate, have a long-term training and mentor program in place.
Control	<ul style="list-style-type: none"> To hand control of an issue to the electorate To hand control to the consumer of health care 	<ul style="list-style-type: none"> Referenda Community-elected board of management Advance care planning 	<ul style="list-style-type: none"> Develop your budget and leave time for planning with your stakeholders. Provide a wide range of information on the issue to the public. Regularly advertise the processes to check for advance care plans and for staff to respect consumer choices.

* Based on the work of Bishop and Davis (2002) and Shand and Arnberg (1996), as outlined in Bishop and Davis (2002). Inclusion of patient-centred care and shared decision making informed by the work of Wensing et al. (2002) and Bauman et al. (2003).

Appendix 3 Department of Human Services mission statement

The Department of Human Services has as its mission to:

enhance and protect the health and wellbeing of all Victorians, emphasising vulnerable groups and those most in need.

Its values are:

Client [consumer] focus	We work towards improving the health and wellbeing of our clients [consumers] and community [including carers].
Professional integrity	We treat all people with dignity and respect.
Quality	We always strive to do our best and improve the way we do things.
Collaborative relationships	We work together to achieve better results.
Responsibility	We commit to the actions we take to achieve the best possible outcomes for our clients [consumers] and community [including cares].

Appendix 4 Program evaluation

Process evaluation

Process evaluation verifies whether or not a program was delivered as intended, including to the degree intended, and is usually concerned with questions of efficacy and availability . For example, have public health services developed community advisory committees in accordance with the legislation and the non-statutory guidelines?

Impact evaluation

Impact evaluation determines if the immediate outcomes of a program were achieved and often relies on data that are indicators of long-term outcome aims. For example, staff were identified as communicating more effectively with culturally and linguistically diverse consumers following a training program on using translating and interpreting services.

Outcome evaluation

Outcome evaluation determines if a program's longer-term aims (often over two to three years) were achieved and relies on the availability of end result data. Judgements are made as to 'the extent to which and the ways in which outcomes are caused by the program' . For example, consumers were found to use medications and education strategies effectively two years after group education at a community health centre following introduction of a new education program based on shared decision making.

Appendix 5 Possible participation performance indicators

Table 7 Potential indicators: Victorian acute and sub-acute services

Recommended standard	Indicator	Target or achievement
1. Governance		
1.1 The governing body is committed to consumer participation.	Health service meets ACHS EQulP standard 'The governing body is committed to consumer participation' to the level of 'EA' (Extensive Achievement).	The service reports its accreditation outcome and associated comments and recommendations to the Department of Human Services against this standard. If the standard is not met, a summary of proposed actions and their progress is reported annually.
1.2 There is participation in higher level decision making	Non-legislated services have developed mechanisms for consumer participation. Partnerships are established between consumer, carer or community groups and the service.	Services have developed a context-relevant consumer, carer and community advisory mechanism and a plan for their participation activities. Number and description of type of partnerships.
2. Accountability		
2.1 The service reports openly to its communities on quality and safety, and consumer participation in its processes.	The service is actively monitoring and evaluating its participation activities. Legislated services are committed to achieving the goals in their community participation plan. Legislated services are committed to improving service delivery to identifiably hard to engage communities and consumers.	Data is collected on participation at organisational level regularly. A program of audits of participation is in operation. Project or program evaluations (processes and impacts) of specific initiatives or services measuring participation benefit. The majority of objectives (including both process and impact) in the community participation plan have been met. There are an increasing number of impact goals being met over time. Data are being collected routinely. Relevant goals are set for identified hard to engage communities and consumer groups There is a measurable improvement against those goals.

Table 7 Potential indicators: Victorian acute and sub-acute services (continued)

Recommended standard	Indicator	Target or achievement
	There is participation in consumer health information development.	At least 80% of reviewed information meets the Well-written health information: a guide check list items (Currie et al. 2000).
	There is participation in policy development.	Consumers are involved and consulted about policy developments at program and organisational level.
	There is participation in service delivery and planning.	Consumers are involved and consulted service delivery and planning in a range of areas of organisation.
	There is participation in quality improvement.	Consumers are involved and consulted about range of quality improvement initiatives.
	There is ongoing program of evaluation within the service.	There are a number of evaluations of programs each year, including an evaluation of the consumer participation component.
3. Health care and treatment		
3.1 There is consumer and, where appropriate, carer participation in clinical care.	The service is actively facilitating involvement by consumers and carers in decision making about their care and treatment.	Appropriate valid and reliable decision aids are being provided in a supportive environment to consumers and, where appropriate, carers.

Table 8 Potential measures of participation

Individual care level - key domains of activity	
Provision of condition-specific information, evidence-based where possible	<ul style="list-style-type: none"> • Consumers and carers receive regular, updated, appropriate and culturally sensitive information about services. • Consumers are provided with evidence-based information about conditions and treatment options. • Consumers and carers receive information about rights and responsibilities, and Australian Council on Safety and Quality in Health Care's '10 tips' or the equivalent. • Consumers and carers participate actively in decision making about individual care and rehabilitation and care planning. • Consumers with chronic conditions are provided with referrals to self-management programs, self-help groups and so on. • Services have informed consent processes. • Consumers and carers benefit from open communication with services. • Consumers and carers provide feedback and lodge complaints. • Participation in delivery of services.
Shared decision making in care	
Consumer-focused care with appropriate carer involvement	
Other	
Ward/program/department level – key domains of activity	
Consumer and carer participation in planning and evaluation of service delivery	<ul style="list-style-type: none"> • There is participation in development of new health programs (policy decisions, design). • There is participation in the development and provision of health information.
Monitoring, evaluation and reporting of consumer participation, including its scope and effectiveness	<ul style="list-style-type: none"> • Programs have mechanisms for feedback. • Programs have complaint management systems. • Participation in monitoring and evaluation of programs.
Organisational level – key domains of activity	
Organisational commitment (leadership, supportive policies, active promotion of concept, budgets allocated, specified staff roles, and other resources)	<ul style="list-style-type: none"> • Service has philosophical framework or value system supporting consumer and community participation. • Services have written consumer and community participation policies. • Participation principles are embedded in services' documentation, culture and actions. • Services identify and address barriers to participation. • Services have financial and physical resources for consumer and community participation.
Staff capacity (ensuring sufficient skills, expertise, training provision)	<ul style="list-style-type: none"> • There is participation in training of staff.

Table 8 Potential measures of participation (continued)

Participation in decision making structures at organisational level, through formal, informal, ongoing and ad hoc or strategic involvement

- Services work in collaboration with consumer representative bodies, advocacy groups and communities of interest.
- There is participation in the management of services (boards, committees), including ethics and research.
- There is participation in major service planning (policy decisions, design).
- There is participation in quality processes.
- Mechanisms exist for engaging marginalised groups.
- Consumers are involved in analysis and reporting of adverse events.
- Services address needs of culturally and linguistically diverse communities, Indigenous and other diverse communities.

Capacity of consumer carer and community members involved

Monitoring and evaluation and public reporting

- Services monitor and evaluate consumer participation strategies.
- Services have variety of accessible mechanisms for feedback.
- Services have complaint management systems.
- There is participation in monitoring and evaluation of services.

Definitions

Advocate – a person or group who assists the consumer, carer or community member to have their views and ideas heard and understood.

Carers – families and friends providing unpaid care to consumers. Carers may often be receiving a government benefit or allowance.

Communities – defined as groups of people who have interests in the development of an accessible, effective and efficient health and aged care service that best meets their needs.

Community advisory committee – a legislated committee under section 239 of the *Victorian Health Services Act 1988* and established under the *Community advisory committee guidelines: non-statutory guidelines for metropolitan health services* (Department of Human Services 2000).

Community member – a member of a health and aged care service community.

Community organisations – can take the form of self-help groups, or come together to advocate for a particular group of consumers, or from a general consumer perspective. Some organisations have resources to research particular issues and develop policies and ideas on changes that would improve the health system from a consumer perspective (Draper 1997).

Consumers – people who are current or potential users of health services. This includes children, women and men, people living with a disability, people from diverse cultural and religious experiences, socioeconomic status and social circumstances, sexual orientations, health and illness conditions.

Consumer/carer/community nominee – the term used to describe somebody who is representative or has links with a particular group(s). They are not accountable in the way that a representative is but are participating because of their links with a group(s).

Consumer/carer/community representative is a consumer, carer or community member who is nominated by and **accountable** to an organisation of consumers, carers or community members. The term 'representative' is linked to living in a democracy. Hence, representatives are there to represent the formal views of a particular group and report back to that group.

Department of Human Services – for the purpose of this policy refers to the divisions of Rural and Regional Health and Aged Care Services and Metropolitan Health and Aged Care Services being the two health divisions within the Department of Human Services of Victoria.

Health service – a publicly funded organisation providing health care. This includes hospitals, rehabilitation centres, aged care services, community health centres and primary care services.

Performance measurement – a strategy that enables an organisation to systematically assess progress against defined goals and objectives. It measures how well current strategies, plans and processes are working and provides information to aid decision making and shape future action.

Performance indicator is variously defined. One common definition is:

‘a statistic or other unit of information which reflects, directly or indirectly, the extent to which an anticipated outcome is achieved or the quality of the process leading to that outcome’ (National Health Performance Committee 2002).

Participation – occurs when consumers, carers and community members are meaningfully involved in decision making about health policy and planning, care and treatment, and the wellbeing of themselves and the community. It is about having your say, thinking about why you believe in your view, and listening to the views and ideas of others. In working together decisions may include a range of perspectives.

Note that the term 'participation' is used here to encompass consumer, carer and community participation, unless otherwise specified.

Stakeholders – includes consumers, carers, the community, community organisations, health services and the Department of Human Services.

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