

Doing it with us not for us

Strategic direction

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

This policy grew from the Victorian Government's commitment to involving people in decision making about health care services and the need for a strategic policy to guide the process. Participation in health is an essential principle of health development, community capacity building and the development of social capital. Participation is valued because it is:

- an aid to improve health outcomes and the quality of health care
- an important democratic right
- a mechanism to ensure accountability.

The policy targets the acute and sub-acute areas of the health service system as these were identified as having a gap in participation policy.¹

Participation

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.

There are many different types of participation and these have been commonly grouped as:

- Information
- Consultation
- Partnership
- Delegation
- Control

No one type of participation is better than another. It is important to use the type of participation that suits the particular need².

Guiding the way in which consumers, carers, the community, community organisations, health services and the Department of Human Services work together to make participation successful are the nine principles of participation:

- Trust
- Equal opportunity
- Dissemination
- Openness
- Shared ownership and accountability
- Respect
- Advocacy and support
- Evaluation
- Responsiveness

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.

To achieve the aim, seven objectives outlining what needs to be done in order to make participation happen give further direction to all stakeholders:

Objectives

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.

1. Department of Human Services (2005) *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*, Metropolitan Health and Aged Care Service Division, Victorian Government Department of Human Services, Melbourne.

2. Please see the last pages for a table providing examples of the different types of participation.

Priority actions

Priority actions, for all of the stakeholders to implement to ensure the aim and objectives are met, are set out below. The priority actions integrate the strategic direction across the four key levels of the health service system.

1. Individual care level
2. Program or department level
3. Health service organisation level
4. 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. It should also respect the diversity of people within our community including:

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

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.
2. Communicate clearly and respectfully with consumers and carers.
3. Provide accessible information to consumers, carers and community members about health care and treatment.
4. Communicate and provide information about treatments and care to consumers and carers that is developed with consumers and, where appropriate, carers.
5. Listen and act on the decisions the consumer and, where appropriate, their carer(s) make about their care and treatment.

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.
7. Create welcoming and accessible services for the diverse members of your community.
8. Provide training to staff in communication skills and how to involve consumers and carers in decision making.
9. Promote the importance of consumers and carers providing feedback to improve services.
10. Establish links with community organisations to provide emotional support and ongoing information to consumers and carers.
11. Involve consumers, carers and community members in the development of clinical guidelines and research.

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.
13. Community representatives or nominees to be involved in the review of system level issues regarding consumer and carer feedback and complaints.
14. Include the involvement of consumers, carers, community members, representatives or nominees in all aspects of the organisation's planning and development.
15. Provide staff training and education on how to use the different types of participation.
16. Ensure position descriptions include participation components.
17. Evaluate, monitor and report on participation to the community and the Department of Human Services.

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 Services³ (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.
19. Provide support, guidance and resources to health services and consumers, carers and community members on participation.

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

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

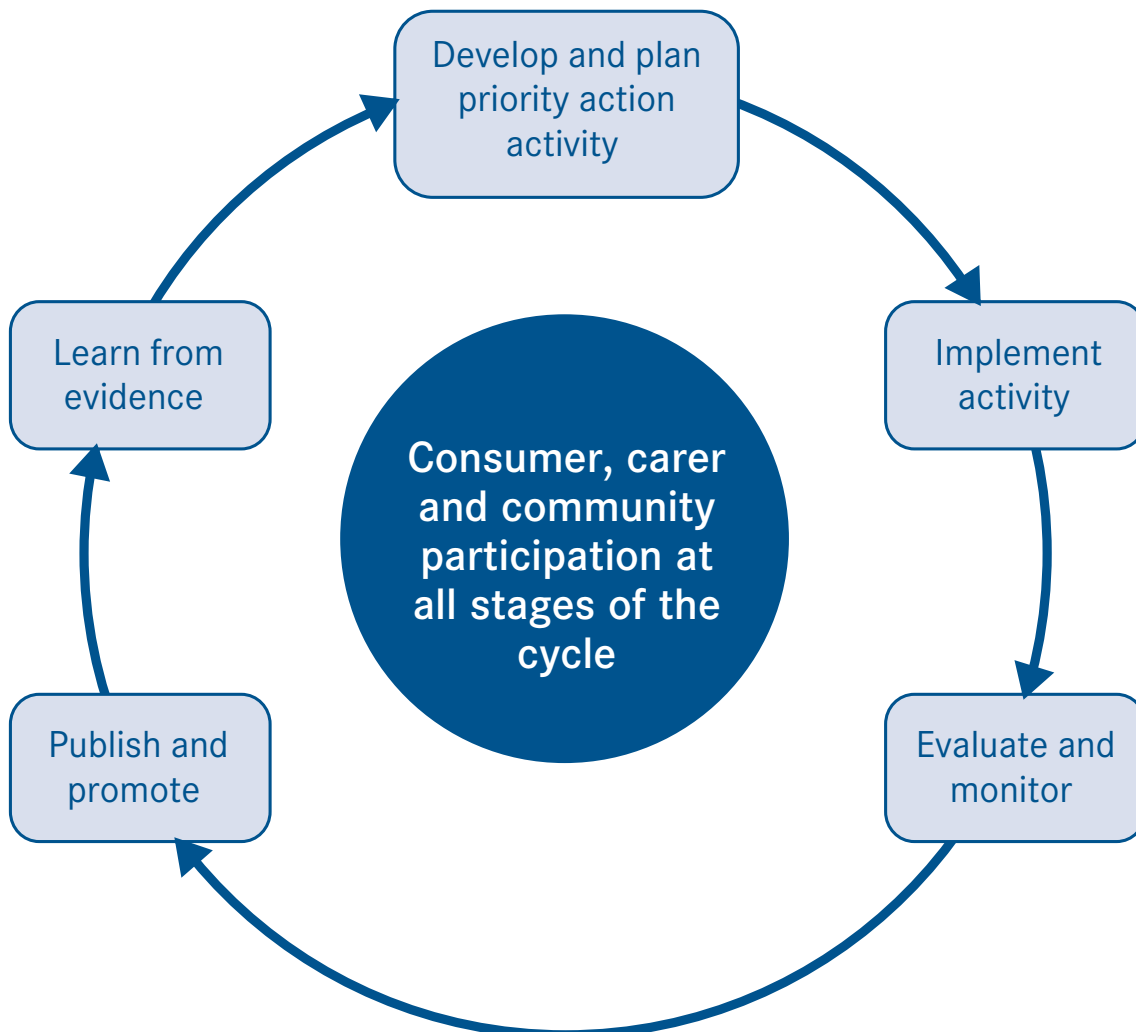
22. Encourage the inclusion of participation skills and knowledge in the tertiary education of health professionals.

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

Evaluation and monitoring

To identify if the priority actions are being implemented, an evaluation and monitoring process is required. This includes implementing the continuous quality improvement cycle outlined in Figure 1. The cycle shows how stakeholders can improve their participation activities, based on the evidence obtained from evaluating and monitoring participation activities.

Figure 1 Participation evaluation and monitoring cycle



Monitoring

It is recommended that health services commence reporting on a minimum set of participation indicators using the following staged introduction process⁴:

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.

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.

Details of reporting requirements will be outlined in the annual policy and funding guidelines for Victorian public hospitals.

Evaluation

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

4. Refer to the full policy document *Doing it with us not for us* for the targets and achievements for each indicator.

Types of participation

Participation type*	Objective
Information (needed for participation)	<ul style="list-style-type: none"> • To support participation • To convey facts • To educate
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.
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
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
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

* 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)⁵.

5 Bishop, P & Davis, G 2002 'Mapping public participation in policy choices', *Australian Journal of Public Administration*, 61, 14-29.

Bauman, A, Fardy, H & Harris, P 2003, 'Getting it right: why bother with patient-centred care?', *Medical Journal of Australia*, 179, 253-256.

Wensing, M, Elwyn, G, Edwards, A, Vingerhoets, E & Grol, R 2002, 'Deconstructing patient centred communication and uncovering shared decision making: an observational study', *BMC Medical Informatics and Decision Making*, 2, 2.

Key tools

- Public information campaigns
- Health consultation (pre-admission, hospital admission, discharge, outpatient clinic or at community health centre and rehabilitation setting)

- Key contacts
- Surveys
- Interest group meetings, focus groups
- Public meetings
- Discussion papers
- Public hearings
- Consumer (patient) and carer (family) meetings
- Health consultation

- Advisory boards
- Community advisory committees
- Policy community forum
- Shared decision making
- Community development
- Patient-centred care

- Public enquiries
- Impact assessment studies
- Health service boards
- Ethics committee

- Referenda
- Community-elected board of management
- Advance care planning

Make sure

- 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.
- 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.

- 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.

- 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.

- 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.