

Getting Started

INVOLVING CONSUMERS ON COMMITTEES



Acknowledgements

This Kit is designed to provide information and advice to health professionals who are new to consumer participation and want to understand how to work effectively and meaningfully with consumers. It provides information and guidance about the first crucial steps involved in working with consumers.

It has been developed as a result of Health Issues Centre's work in consumer participation with health services towards their organisational development and changing practice with consumers in particular through the HIC's Consumer Nominee Program.

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1. Purpose

This resource is specifically designed to assist health professionals and organisations to include consumers on their advisory and other committees.

Additional information about consumer participation is available at:

www.healthissuescentre.org.au or www.participateinhealth.org.au

At the end of this guide is a list of other resources and some information that will be of help to you.

2. About Health Issues Centre

Health Issues Centre (HIC) is an independent, non-government, not-for-profit organisation that has been promoting consumer perspectives in the Australian health system for over 22 years. HIC works towards a more consumer-centred and equitable health system.

HIC collaborates with a wide range of consumers, health providers, researchers, governments and other health organisations through:

- ▶ Policy analysis and advocacy from consumer perspectives
- ▶ Consumer-focused research
- ▶ Supporting consumer participation through practice change, organisational development and training
- ▶ Providing ongoing information through its unique library collection, websites, bi-monthly journal *Health Issues* and monthly electronic bulletin eNews.

You can find out more about us at www.healthissuescentre.org.au

3. What is consumer participation?

Who are consumers?

Health consumers are defined as users or potential users of health services. This also includes family members/carers, and broader members of the community.¹

When planning participation, we recommend that the consumers you engage reflect your demographic constituency and come from relevant diverse backgrounds and experiences. This might include women and men, people living with a disability, people from culturally and linguistically diverse backgrounds, people from different socioeconomic status and social circumstances, and people with different sexual orientations, health and illness conditions.

Consumer participation

Consumer participation occurs when consumers are meaningfully involved in decision-making about their care and treatment, or providing input on decision-making about service delivery, health policy and planning, or about the broader wellbeing of themselves and the community (Department of Human Services, 2006).

Consumer participation happens in many ways, formally and informally. It can also happen on a number of levels:

- ▶ Individual level – on decisions about own care, self-management
- ▶ Unit or Program level – feedback for service improvement or new developments
- ▶ Organisational level – policy, new services, access
- ▶ Broader community level – advocacy in consumer and community groups, participation in state-wide organisations, government department processes.

¹ In the rest of this document the term ‘consumers’ is used to include family, carers and community.

Why engage consumers?

Engaging consumers:

- ▶ Gives you critical information about how your services are perceived and received as well as the impact of your services
- ▶ Improves the quality of your services, programs and projects
- ▶ Improves relationships with your community and the people who use your services
- ▶ Improves health outcomes for your clients.

A number of government policies, reporting and legislative requirements as well as accreditation standards mandate or guide the health sector to involve consumers. In Victoria, legislation requires public health services to establish a Community Advisory Committee. Information about CACs can be found at www.health.vic.gov.au/consumer

4. Planning to involve consumers on your committees

Why and when?

Most health service committees are dominated by health professionals. Involving consumers on committees in your health service will bring new views—from critical stakeholders—to the table, and assist in developing ongoing dialogue between consumers and health professionals.

A committee structure provides an opportunity to move beyond one-off consumer feedback to a more interactive approach, and allows consumers to have direct input into decision-making processes.

Inviting consumers onto a committee makes sense when:

- ▶ The committee will meet at least several times and its deliberations are unfolding (i.e. consumer input cannot be alternatively provided by a pre-survey)
- ▶ It is developmental and the consumers' perspectives will add to the creative effort and bring non-professional perspectives and challenges to the table
- ▶ Only consumers are likely to have some of the information the committee requires to complete its tasks.

In some circumstances, it may not be the most effective strategy; for example, when:

- ▶ You need a wide diversity of consumer input
- ▶ It is unlikely you can find a consumer who can bring the relevant information
- ▶ Timelines are very short
- ▶ The committee is highly technical or it is likely to be difficult for an outsider to part of the committee
- ▶ The chair is not sympathetic to consumers (and you can't change him/her) or does not have the appropriate facilitation skills to ensure the consumer can participate fully.

Last, there is the issue of representativeness of consumer members—a relatively simple issue but one that causes concern among many professionals. A consumer on a committee will sometimes be appointed as a 'representative'. This term is used when the person has a constituency or organisation to which they are accountable. More commonly, a consumer is appointed as a 'consumer member' because she/he can bring a different perspective to the decision-making process; they bring views based on their experience of a condition or care or their knowledge of a particular population group. In this case, rather than being a representative of a particular group, they are simply members who act as individuals or advocates.

5. Recruiting consumers

The process for engaging consumers for your committee is somewhat similar to recruiting staff, and is articulated here in a stepped sequence:

Step One

If it is an existing committee you probably already have a description of the role of the committee, its terms of reference, and how the committee will contribute to a broader decision-making process.

As health professionals we can sometimes use terms and phrases that consumers may be unfamiliar with, so take the time to read your information; if necessary, rewrite it so that it can be understood by everyone. Some consumers, for example, may not know what is meant by the phrase "terms of reference", some may have low English proficiency or a have a disability.

You can use some tips from the Easy English guide:

http://www.scopevic.org.au/therapy_crc_easyenglishstyleguide.html

Step Two

Develop a position description that includes information about the committee as well as information about:

- ▶ The role of consumers
- ▶ Time and place of meeting
- ▶ Length of commitment
- ▶ What kind of characteristics, skills, attributes you require
- ▶ Reimbursement details and/or sitting fee
- ▶ Application process
- ▶ Contact person if the consumer has any questions.

It is recommended that you recruit two consumers for a committee rather than one. This may help prevent feelings of isolation and powerlessness, allow them to offer each other support, ensure at least one is present if the other is sick, and allow for some succession planning.

Remember to encourage people from diverse backgrounds and abilities to apply.

Step Three

Distribute the position description and information by using your existing networks to recruit consumers.

Internally you can:

- ▶ Use your client database
- ▶ Directly approach consumers who use your services or develop posters for waiting room areas
- ▶ Use your organisation's Consumer Bank (if it has one)
- ▶ Ask staff in other programs or units for suggestions
- ▶ Ask your Community Advisory Committee or community members of the Board.

Depending on whether you are working at a local regional or state level you could also:

- ▶ Ask community or consumer organisations (with which your service has an ongoing relationship) to nominate or to advertise in their e-bulletin/newsletter
- ▶ Place notices in the local paper or on radio
- ▶ Talk with community groups in your local area that are likely to have an interest in the area in which you are seeking participation
- ▶ Talk with other community health services, primary care partnerships and divisions of general practice
- ▶ Contact Health Issues Centre.

Don't forget to include people who are not using your services or are potential users of your services.

Step Four

Generally, recruiting for a committee will require a process which is similar to a job application:

- ▶ Ask consumers to fill in a short application form, an expression of interest or send in a resumé. Be careful not to make this a complex process as it may discourage some people from applying.
- ▶ Arrange to meet and talk with potential consumer representatives at a place that is convenient to them.
- ▶ Once you have made your decision, notify the consumer in writing or by phone.

Have at least two people from the committee when you meet with the consumer. If you already have consumer participants on your committee, ask them to attend as well.

6. Keeping consumers engaged and supported

Effective consumer participation requires ongoing commitment, organisational leadership and resources. Make sure that you have supports in place that will produce a good outcome for yourself and the consumers. You could nominate a mentor, resource officer or key contact in the organisation to be available to consumers who want to ask questions or who need support.

Financial resources to reimburse consumers for their participation

Most professionals attend committees as part of their salaried positions. Consumers, however, often have to take time off from other commitments to participate. This can place financial as well as physical strain on them, especially if they are not in full-time employment. HIC recommends that, at a minimum, organisations cover all out-of-pocket expenses. They should also consider paying consumers a sitting fee.

Any discussion about financial arrangements should be conducted in private and individually with each consumer.

HIC has a position statement on consumer payments that includes a list of recommended amounts.

If you would like more information please contact Health Issues Centre on (03) 9479 5827.

Assistance with administration

Discussions and correspondence between meetings may be a significant part of the work of the committee. Consumers may be unable to print or receive large e-documents. Always check with consumers and offer to post or fax hard copies if required.

Orientation process or package for consumers

For ongoing committees provide consumers with information that will give them a sense of the organisation and their role on the committee. Orientation packages can include fact sheets, annual reports, terms of reference, background reports, information on services, list of contacts and any forms needed to claim reimbursement or provide feedback.

Offer training and support

Consumers may require specific training to enhance their skills, so it is worthwhile investing in consumer members by offering training and support. This could include one-off training sessions, regular workshops, arranging mentoring and debriefing support. Remember, their involvement with your organisation may be longer term and they could go on to play valuable roles on other committees.

Involving diverse consumers

Most committees benefit from having diverse perspectives. People from culturally and linguistically diverse (CALD) backgrounds or people with a disability, for example, often have a different experience of services and bring a different perspective to the committee's deliberations. However, for a variety of well-known barriers, they may not feel like they are able to participate. You may need to offer specific encouragement and undertake a number of support strategies to engage these groups, including the following:

- ▶ Consider modifying your recruitment or interview process to be more inclusive
- ▶ Offer access to language interpreters or an Auslan interpreter
- ▶ People with a disability or people who are newly arrived often don't have access to a vehicle or are unable to drive, so ensure that you allocate financial resources for transport
- ▶ Choose a venue that has disability access and is easily reached by transport
- ▶ Some people with a disability may need to be accompanied by a carer
- ▶ If catering, be aware of cultural, religious and health considerations
- ▶ Ask the person what support they need to participate effectively
- ▶ If using an interpreter always allow more time for a meeting
- ▶ Avoid making assumptions based on cultural stereotypes, and always ask if you are not sure.

If you need more information about working with interpreters, go to "Making the Connection" online training resource

<http://www.dhs.vic.gov.au/multicultural/connection/index.htm>

7. Using diverse methods

Involving diverse consumers in your committees can bring rich new perspectives to your organisation. However, while consumer participation on committees can be extremely rewarding for the consumer and the organisation, it is not the only way that consumers can or should participate. Ensure that you have a variety of participation methodologies so that everyone can contribute. If you require further assistance visit www.healthissuescentre.org.au or www.participateinhealth.org.au

8. Frequently Asked Questions

How can one consumer represent all consumers?

The role of consumers is not to provide answers on behalf of all consumers, but to raise issues and prompt the committee to debate matters from a different experience-base and range of perspectives.

What if a consumer breaches confidentiality requirements?

Consumers must be subject to the same confidentiality requirements as other members of a committee, and should be held accountable to members for maintaining confidentiality and protecting privacy.

To whom are consumers accountable?

Consumers are accountable to the agency that recruited them and to the nominating organisation if they are a formal representative of that organisation. They must operate within the invitation covering their appointment (including the Terms of Reference), which they agreed to when accepting the position.

Does ‘conflict of interest’ apply to consumers?

As with any other committee members, conflicts of interest also apply to consumers. Therefore, conflict of interest requirements and protocols need to be included in orientation information, and also listed as a standing item on the agenda.

What if the project/committee cannot afford to pay consumers?

If a project has an approved budget that has not allowed for remuneration costs for consumers, the agency should consider ways of paying the consumer “in kind”, which recognises the consumer’s contributions as important.

As consumer participation becomes more integrated into the work of health providers, the costs of consumer participation need to be identified and built into forward budgets. Consumers should not be out-of-pocket through their involvement and the organisation should always cover out-of-pocket expenses. If you would like information on suggested sitting fees and reimbursement costs please contact us at the Health Issues Centre on (03) 9479 5827.

Appendices

1. Sample text for an advertisement for Consumers to Join a Committee
2. Sample application form for Consumers to a Join a Committee
3. Sample selection criteria for membership of a committee
4. Sample interview questions

Websites

Health Issues Centre

www.healthissuescentre.org.au

www.participateinhealth.org.au

Consumers Health Forum of Australia

www.chf.org.au

Victorian Government

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

Appendix I:

Sample text for an advertisement for Consumers to Join a Committee

Consumer Position
Position Number

Name of committee/ etc.

Brief description

The Role of the Committee

The Role of the Consumer

Commitment Required

Selection Criteria

Support Offered

If you are interested in applying for this position please **briefly** respond to the key selection criteria and forward to

If you would like more information please contact:

EOI closing date:

Appendix 2

Sample application form for Consumers to a Join a Committee

Consumer Position Application Form

Name:
Address:
Phone:
Email:
Name of Committee you are applying for:
Position number:
Please tell us why you are interested in joining this committee and what experience you will bring:
If you have participated on other health committees, please provide details of two committees:
Please tell us what other supports you will need to help you participate:

Please forward to xxxxxxxxx

Appendix 3

Sample selection criteria for membership of a committee

Choose ones that are appropriate to your health service and committee

Key Selection Criteria

Applicants to this vacancy should:

- Be 16 years of age and over.
- Have used XXXX services or capable of representing XXXX users.
- Be from or have an understanding of the experiences of people from culturally and linguistically diverse (CALD) backgrounds or people with disabilities or Aboriginal and Torres Strait Islander people in using health services.
- Be able to reflect the needs and interests of a broad range of consumers and communities.
- Be able to articulate the potential issues that confront patients, families and carers who receive services from XXXX.
- Preferably have established links with health consumer or community groups. These links could be demonstrated by an affiliation with an interest group or health peak body.
- Have a capacity to work constructively with fellow committee members and XXXX staff and management to improve the quality and accessibility of XXXX services.

Appendix 4

Sample interview questions

DRAFT Interview Questions

Welcome and introductions

1. Would you like me to give you an overview of why we want consumers to participate?
.....
2. Grading of applicant's response is in relation to how well we thought the applicant answered that question and how well their answer meets the skill/role on the Reference Committee.

Grades are: **H**=High **M**=Medium **L**=Low

Question	Skill/Role on Reference Committee	Applicants Response	Grade
Tell us about yourself and why you are interested in this committee.	Interest and experience		
Why is consumer and/ community participation important to you?	Being a consumer representative		
What experiences have you or your family had in/with.....?	Policy relates to the health system		
Have you had any experience in providing feedback on	This will be part of the role of committee		
All committee members are bound by confidentiality. What things do you anticipate would be confidential?	Confidentiality clause in the terms of reference		
On committees there may be conflict of opinion. Can you describe a situation where you have disagreed with a person but had to keep working with them – and how you did this?	Need to work as part of a large committee		
The meetings are going to beas outlined in the meeting times. Can you commit to these meetings?	Commitment to the committee and the policy development process		
What, if any, supports do you think you would need to help you participate in the committee?			
Do you have any questions that you would like to ask of us?			

Thank you for coming in today. We will be advising people of the outcome of the interview process early next week. Are your referees contactable later today or on Monday?

Overall Grade: _____

Comments:

Appendix 5

Policies about participation

In the last decade, the Victorian Government has developed a series of key policy documents that provide an overarching policy context to consumer participation. Policies that identify a vision and principles for consumer, carer and community participation as a pillar for democratic processes of government are set out in *Growing Victoria Together* (Victorian Government, 2001) and *A Fairer Victoria* (Victorian Department of Premier and Cabinet, 2005, 2006).

The key policy of reference in this Kit was *Doing it with us not for us*, the Victorian Department of Human Services' (DHS) participation policy.

Other recent government policy documents published by DHS, which outline participatory models and promote meaningful consumer participation in health services are:

- Directions for Your Health System: Metropolitan Health Strategy (DHS, 2003)
- Primary Care Partnerships Strategic Directions 2004–2006 (DHS, 2004)
- Community Health Services – Creating a Healthier Victoria (DHS, 2004)
- Participation Indicators (DHS, 2005)
- Doing it with us not for us: Participation in your health service system 2006 – 2009 (DHS, 2006)
- Community and Women's Health Integrated Health Promotion Planning and Reporting Guidelines for 2006-2009 (DHS, 2006)
- How to Develop a Community Participation Plan (DHS, 2006)
- Community Advisory Committee Guidelines: Victorian Public Health Services (DHS, 2006)

References

Department of Human Services. (2006). *Doing it with us and 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*. Australia: Rural and Regional Health and Aged Care Services Division, Victorian Government Department of Human Services.