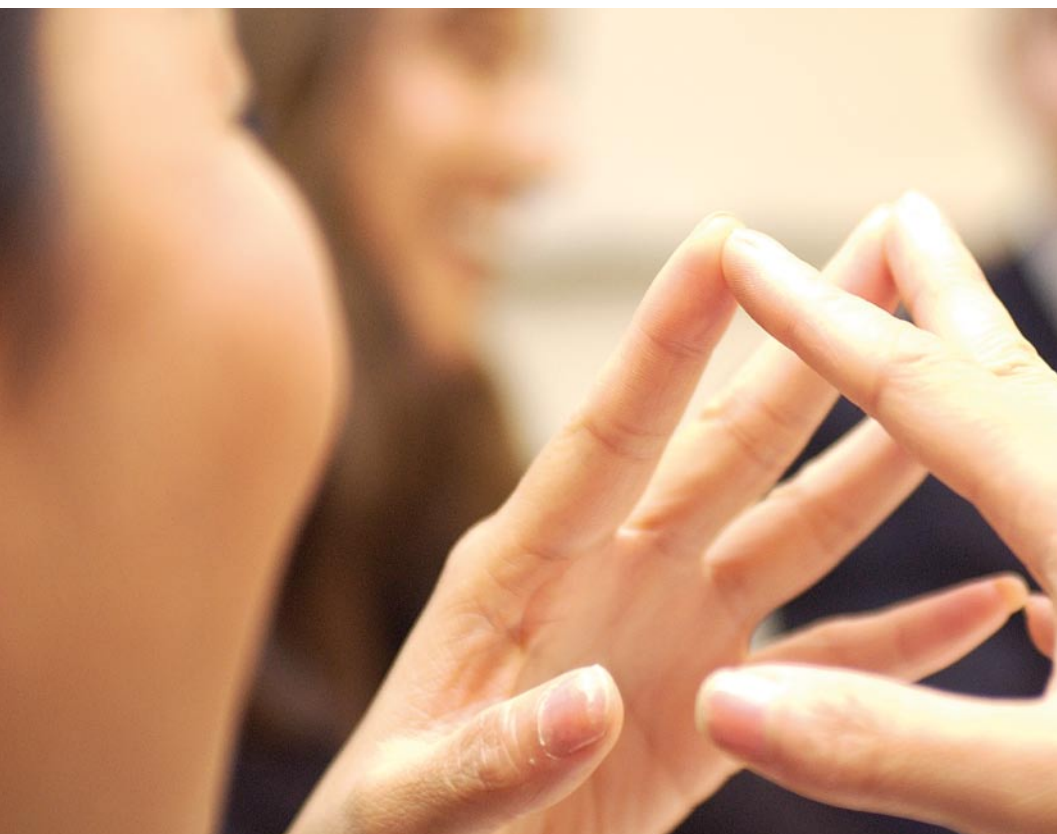


# A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services



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Published by Metropolitan Health and Aged Care Services Division, Victorian Government  
Department of Human Services, Melbourne, Victoria

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Authorised by the State Government of Victoria, 50 Lonsdale Street, Melbourne.

This document published on [www.health.vic.gov.au/cancer](http://www.health.vic.gov.au/cancer)

Printed by (insert name and address of printer).

February 2007 (061206)

ISBN 0 7311 6255 2

## Foreword

The Victorian Government is committed to involving people in decision making about health care services and has developed the *Doing it with us not for us participation policy* (Department of Human Services 2006) to guide the process for consumer and carer participation in service delivery and planning. Consumer and carer participation is grounded in a number of key principles including trust, respect, equal opportunity, openness, responsiveness and shared ownership and accountability (ibid).

In 2005, the Clinical Services Working Group of the Ministerial Taskforce for Cancer commissioned the Health Issues Centre to develop options for an integrated strategy for consumer and carer participation in cancer service reforms, including involvement across tumour streams and Integrated Cancer Services.

This guide, developed by the Health Issues Centre in collaboration with key stakeholders, emerged from the project findings and is available (along with the final project report) at [www.health.vic.gov.au/cancer](http://www.health.vic.gov.au/cancer).

## Acknowledgements

Health Issues Centre wishes to thank the many people involved in the development of this guide. Jackie Kearney and Claire Higgins from the Cancer and Palliative Care Unit, Department of Human Services, offered valuable support to the project team, facilitated the establishment and operation of the Project Advisory Group, and actively engaged with Health Issues Centre in the implementation of the project.

Thanks also to the members of the Project Advisory Group who provided valuable comments and participated actively in the development of the guide:

Pauline Church (Consumer representative)

Phillippa Hartney (Loddon Mallee Regional Integrated Cancer Service)

Julie Hassard (The Cancer Council Victoria)

Sue Lockwood (Consumer representative)

Jane Miller (Southern Melbourne Integrated Cancer Service)

Colleen O'Hara (Grampians Regional Integrated Cancer Service)

Margot Rosenbloom (Carer representative)

Terri Smith (Breast Cancer Network Australia)

Michael Summers (Carers Victoria)

Mary-Jane White (St Vincent's Health)

Peter Williams (The Cancer Council Victoria)

We thank members of the Ministerial Taskforce for Cancer who provided valuable information by giving personal interviews for the project.

We also thank the Integrated Cancer Services strategic managers who collaborated actively by providing interviews, facilitated the recruitment for the focus groups and attended the focus groups in their region.

Thanks to The Cancer Council Victoria and Carers Victoria who sent invitations to consumers and carers to participate in focus groups across Victoria.

Thanks to the facilitators of cancer support groups who participated in telephone interviews, and to the Community Advisory Committee (CAC) Resource Officers who provided valuable information about consumer and carer participation in cancer services at their health services.

Thank you finally to the consumers, carers and service providers who responded to the invitation to participate in focus groups, and especially to those who attended.

This guide was written by Tere Dawson, Lauren Cordwell and Tony McBride.

## Contents

<b>Introduction</b>	<b>1</b>
<b>Part I</b>	<b>3</b>
1 Background	3
2 Victorian policy context	4
3 Consumer and carer participation in Victoria	5
4 Principles of consumer and carer participation	6
5 Evidence and examples of consumer and carer participation	8
6 Summary of findings from literature review	10
7 Summary of findings from consultations	12
8 Underlying support for consumer and carer participation	14
9 Levels of participation	15
10 Types of participation	17
<b>Part II</b>	<b>19</b>
11 Strategic planning for consumer and carer participation in cancer services	19
12 An example of a consumer and carer participation plan for Integrated Cancer Services	25
13 References	30
<b>Appendix 1: Types of health and medical research and potential areas of consumer, carer and community participation</b>	<b>33</b>
<b>Appendix 2: Methods of consumer and carer participation for Integrated Cancer Services</b>	<b>34</b>



## Introduction

Health Issues Centre was commissioned by the Department of Human Services (DHS) to undertake a project to develop this guide. This project was an initiative of the Ministerial Taskforce for Cancer, and was supported by the DHS Cancer and Palliative Care Unit.

### How the guide was developed

The guide was developed through a process of consultation with more than 150 people and a review of the literature pertaining to consumer and carer participation in cancer services in Australia. The consultation included members of the Ministerial Taskforce for Cancer, members of the Project Advisory Group, Integrated Cancer Services (ICS) directors, managers and staff, health service providers and consumer and carers. The development of the guide also drew on Health Issues Centre's own consumer participation experience and materials. A full report of the project undertaken by Health Issues Centre is available at the Victorian Government Cancer Initiatives website [www.health.vic.gov.au/cancer](http://www.health.vic.gov.au/cancer).

### Aim of the guide

The guide aims to assist ICS to strategically plan for consumer and carer participation as part of their overall quality improvement approach. It aims to respond to the needs and capacities of service providers, consumers and carers to meaningfully participate in cancer services reform, and includes practical consumer and carer participation methods, case studies and references to support planning in a strategic way for consumer and carer participation.

### Context for the guide

Cancer services are delivered through a continuum of services at all levels:

- primary and community-based health services—such as general practitioners (GPs), community health services and community-based palliative care services

- secondary level health services—such as specialist oncology, radiotherapy and screening services
- tertiary levels of health care services—such as surgery, oncology and palliative care units located in hospitals.

The methods outlined in the guide assume that consumer and carer participation could potentially take place in any of these settings. The methods could also be used at all levels of an organisation. These levels, as defined in the Department's consumer participation policy (Department of Human Services 2006), include the individual, unit or program, and health service or organisational levels. Further, the methods cover a variety of types of participation including consumers and carers receiving and providing information, participating in consultations, and acting as partners in service planning, delivery, research and evaluation of health services.

The guide is divided into two parts. Part I outlines the policy context for consumer participation in cancer services. It describes the principles, evidence and definitions for consumer and carer participation; systems and processes that need to be in place for effective consumer and carer participation; and levels and types of participation.

Part II presents practical principles for planning strategically; a draft set of goals and objectives to guide the strategic planning process; a summary table of types of participation; and an example of a proposed model for strategic planning. A description of a range of methods for cancer services to use in developing their own consumer and carer participation plan, including relevant case studies and references, is included in Appendix 2.





## 1 Background

Victoria has established a strategic and planned approach to cancer reform, including setting up a Ministerial Taskforce for Cancer and implementing the *Fighting Cancer* policy (Australian Labor Party 2002) and *A cancer services framework for Victoria* (Collaboration for cancer outcomes research and evaluation 2003). Two significant directions of the Cancer Services Framework are the establishment of ICS in metropolitan and regional Victoria, and the development of service delivery and improvement through a tumour stream model.

The Cancer Services Framework encourages ICS to develop collaborative partnerships with a wide range of stakeholders to implement the reforms. This includes the active involvement of consumers and carers as 'partners in health care service planning and delivery' (Department of Human Services 2004a).

## 2 Victorian policy context

In the last decade, the Victorian Government has developed a series of key policy documents that provide an overarching context for this guide. Policies that identify principles for 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 Government 2005).

In terms of consumer and community participation in health services, mental health services have been some of the leaders in Victoria in the past decade. The document *Victoria's mental health services working with consumers: guidelines for consumer participation in mental health services* (Department of Human Services 1996) has been pivotal in these developments. Many health services in both acute and primary health now have a consumer participation policy.

Other more recent government policy documents that outline participatory models and argue for meaningful consumer, carer and community participation in health services are:

- *Directions for your health system: Metropolitan Health Strategy* (Department of Human Services 2003)
- *Primary Care Partnerships strategic directions 2004–2006* (Department of Human Services 2004b)
- *Community health services—creating a healthier Victoria* (Department of Human Services 2004c)
- *Doing it with us not for us. Participation in your health service system 2006–2009: Victorian consumers, carers and the community working together with their health services and the Department of Human Services* (Department of Human Services 2006)
- *Participation 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* (Department of Human Services 2005c).

An important step forward for consumer participation in Victoria has been the legislated establishment of community advisory committees in metropolitan and regional health services, and the development of internal processes to establish advisory committees in the Department of Human Services. The *Community advisory committee guidelines: Victorian public health services* (Department of Human Services 2006) and the *Guidelines for Department of Human Services advisory committees* (Department of Human Services 2004d) document these initiatives.

### 3 Consumer and carer participation in Victoria

In Victoria, a series of initiatives for consumer, carer and community participation have been developed. The initiatives most relevant to this guide include the establishment of community advisory committees (CACs) in each metropolitan and regional health service. CACs have been established as mechanisms for enabling the boards of public health services to ensure the services they provide meet the needs of their communities and the views of consumers are taken into account in the decisions made by the board. CACs also have an important role in enabling community views to influence quality and safety in public health services (Department of Human Services 2006).

The Victorian Quality Council (2003) and The Australian Council on Healthcare Standards (2005) have developed frameworks and principles that emphasise strong consumer participation as a key component of their recommended quality improvement approach. The two most common accreditation regimes (Evaluation and Quality Improvement Program (EQulP) and Quality Improvement Council) include standards for the participation of consumers and carers at different levels of the organisation, including quality improvement (Quality Improvement Council 2004). Most recently, the Department of Human Services has published a document outlining a minimum data set of key performance indicators (KPIs) applicable to participation in Victorian health services (Department of Human Services 2005c). It is expected that implementation of this guide in cancer services will be influenced and supported by the KPIs in the broader context of metropolitan health services.



Most health services have also established complaint and feedback mechanisms and some have a community liaison position that serves as a link between the health service and consumers, carers and the community. Some health services have consumer and carer reference groups for specific programs or projects and/or consumer and carer representatives on quality committees or boards of management. A needs assessment of consumer and carer participation initiatives in quality and safety in the acute health sector was undertaken by Health Issues Centre in 2004. The findings suggested there is a surprising range of consumer and community participation activities occurring, and being appreciated, in Victoria (McBride et al. 2004).

## 4 Principles of consumer and carer participation

The conceptual background for consumer participation is found within the principles of primary health care as defined by the World Health Organization (WHO) in the 1970s. The International Conference on Primary Health Care, held in Alma-Ata in 1978, stated that primary health care was the key to attaining health for all. Primary health care requires and promotes maximum community and individual self-reliance and participation in the planning, organisation, operation and control of primary health care, using local, national and other available resources (World Health Organization 2003).

The WHO claims that health is not merely the absence of disease and infirmity but a complete state of well-being. A health service that embraces this concept recognises that, rather than focusing on illness, resources must be appropriately and equitably used in generating good health by addressing socioeconomic and cultural factors that affect health and well-being. According to this concept, users of health services should be able to meaningfully participate in the design and delivery of health services that respond to their complex needs. This is in line with the social model of health which aims to recognise the social, economic, cultural and spiritual as well as biophysical factors contributing to health status (World Health Organization 2000).

In Australia in 1993, the National Health Strategy established that consumer participation in health implies that:

- all citizens have a democratic right to participate in their own health care and the organisations that provide care
- participation produces better health outcomes and improves the quality of health
- most people would like to have information about their own health and the processes involved in the delivery of health services.



Although the principles of consumer participation are commonly agreed upon, there is still considerable diversity of opinion about the term 'consumer' instead of 'patient' or 'client'. It has been proposed that the concept of 'consumer' represents an attempt to reconceptualise the relationship between health providers and those treated by the health system (Draper 1997). The change in word usage from 'patient' (with its connotations of passivity) to 'consumer' (with its implications of choice) was an attempt to establish that users of the health system are individuals with rights, preferences and responsibilities.



The Department of Human Services uses the following definitions:

**Consumers** are people who are current or potential users of health services.

**Carers** are family and friends providing unpaid care to consumers. Carers may receive a government benefit or allowance.

**Communities** are defined as groups of citizens who have interests in the development of an accessible, effective and efficient health service that best meets their needs.

**Consumer, carer and community participation** encourages consideration and debate through processes that allow people to be involved in decision making about their health care and that of the community. Through involvement, decisions are made that may accommodate a range of perspectives (Department of Human Services 2005a).

Consumer participation has become a generic term used to indicate the active participation of consumers, carers and the community. It should happen at all levels of health care, including strategic and service planning, service delivery, and evaluation of health services, as well as in decision making about individual health care planning, treatment and rehabilitation (Draper 1997; Department of Human Services 2005a).

A more detailed rationale for consumer and carer participation and key concepts are given in the policy document, *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* (Department of Human Services 2006).

## 5 Evidence and examples of consumer and carer participation

A body of literature is slowly accumulating which suggests that consumer, carer and community participation in health is beneficial for all those involved in the provision and use of health services (Consumer Focus Collaboration 2000). A recent review of evidence for consumer participation shows that there are only a small number of formal evaluations of consumer participation and that, at this early stage in the development of understanding about participation in health services, the evidence is based on a relatively limited number of randomised control trials and qualitative and descriptive statistical analyses (Department of Human Services 2005a).

Most of the harder evidence for consumer participation has been related to individual participation, where the patient is encouraged to engage in making decisions about his or her own care plan and treatment options. Thus, there is evidence that:

- Active participation in care and self-management, education and written action plans leads to reduced hospital admissions, visits to emergency departments, unscheduled visits to the doctor, and days off work/school (Lahdensuo 1999).
- Chronic disease self-management can improve health status and reduce hospitalisations (Lorig et al. 1999).
- Active involvement of patients in the management of their diabetes can lead to more effective control of blood sugar levels (Kaplan et al. 1998).
- Decision aids are effective tools for improving people's knowledge of treatment, screening options and outcomes (O'Connor et al. 2003).



A range of examples of consumer and carer participation at the individual level can be found across Victoria, implemented by the many cancer support groups that provide personal support and advice. Some support groups are attached to a health service; for example, the Koala Support Group based at Monash Medical Centre, the Chum House Day Hospice Support Group based at Bendigo Health Palliative Care Services, the Heidelberg Cancer Support Group based at Austin Health, and the Waratah Breast Cancer Support Group that works with Gippsland Women's Health Service. Some support groups are independent of any specific health service but serve people in a specific geographic location, such as the Bendigo Cancer Support Group and Building Rural Equality and Strengthening Ties (BREAST). Most of these 150 groups in Victoria are affiliated with The Cancer Council Victoria, which supports them with information and training. The Cancer Council also supports about 120 individuals who have become members of Cancer Connect, a program to train and support individuals who in turn assist other cancer patients via telephone conversations.

In Australia, and Victoria especially, there are many examples of consumer and carer participation at an organisational level in the mental health, aged care, disability, and acute and primary health sectors (Royal College of Nursing and Australian Nursing Federation 2001; Department of Human Services 1999; Department of Human Services 1996; Flinders Medical Centre 2002; Flinders Medical Centre 2000; Goodes et al. 1996). Examples of consumer and carer participation in cancer services are mainly from the breast cancer field. New models are emerging; for example, the 'Seat at the Table' program, run by the Breast Cancer Network Australia. This program:

*incorporates formal processes for recruiting, training and supporting women who have had breast cancer to become consumer representatives for a variety of decision making forums with regard to breast cancer. The program aims to ensure that women who have experienced the disease are appointed to, and can inform the work of, relevant and targeted committees, working parties, boards and project teams, including those of government and medical institutions (Breast Cancer Network Australia 2005).*

Another example of participation in cancer is CancerVoices NSW (CVN). This is:

*an independent, peak advocacy organisation providing a unified voice for all people affected by cancer in New South Wales. CVN is an umbrella coalition for the combined activities of its support and advocacy members... As a network, CVN provides a forum for people affected by cancer to share ideas and experiences that are common to us all. We aim to be heard where decisions are made about our disease (CancerVoices NSW 2006).*

Following NSW's lead, in 2005 The Cancer Council Victoria convened a group of interested people to establish a similar peak advocacy group for people in Victoria affected by cancer. The objectives of CancerVoices Victoria are:

*to provide a forum for Victorians touched by cancer, to minimise the impact of cancer on the community, and to promote a balanced public awareness of the effects of cancer (CancerVoices Victoria 2006).*

An initial activity of this group was to undertake training in advocacy and consumer participation.

At a national level, Brain Tumour Australia has been granted funding from the Federal Government to improve access to information, assist in the development of awareness of brain and central nervous system tumours among support groups, and to assist in the development of self-sustaining support groups (M. Rosenbloom, personal communication, 9 August 2005).

Examples also exist of consumer and carer participation in research and evaluation. Carers Western Australia (an independent not-for-profit organisation of carers) obtained funding to develop an exploratory survey of GPs' awareness of carers' needs. Carers Western Australia sought advice on research methodologies and formulated the survey questions, driven by consumers' priorities and issues. The study was then commissioned to the Survey Research Centre (SRC) at the University of Western Australia. The analysis of the results was completed by the SRC and the report written in collaboration with Carers Western Australia and the SRC (Beacham and Dawson 2005).





## 6 Summary of findings from literature review

A literature review was undertaken of consumer and carer participation in cancer services in Australia. The key findings from the literature review relevant to the development of consumer and carer participation plans for ICS are summarised as follows:

- **Four levels:** consumer participation and the activities to support it can take place at four distinct levels: individual; program/department; organisational/health service; and statewide. This suggests that the model used by any ICS should include activities at the first three levels, and that the Department of Human Services should address activity at the fourth level to support the ICS participatory activities.
- **Key factors and areas of activity:** the literature does suggest a range of areas within each level where activity is possible and sometimes necessary in order to support effective participation across a health service.
- **Involvement in policy development:** builds acceptance by consumers and support for subsequent change.
- **Shared decision making:** there is increasing evidence about the value of involving consumers in decision making about their own care. Question prompt lists have been used; there is especially strong evidence about the use of decision aids to assist this.
- **Information plays an important role:** this is crucial for increasing the capacity of consumers and their families to participate in their care. Audio-taping of interviews increases consumer understanding.

- **Building on other involvement:** using methods that expand on previously successful approaches and/or involving people who have already had some community or consumer involvement is more effective than starting from scratch.
- **Due to health concerns some consumers might find participation difficult:** participatory methods need to be sensitive to this.
- **Need to make special efforts to attract particular groups:** in meeting the needs of a diverse community, some specific groups may have greater difficulty in participating. For example, three different types of groups with specific needs were identified in the literature review—consumers and carers from rural areas, groups with different cultural understandings of cancer, and people from non-English speaking backgrounds. The review identified some solutions, including the development of a long-term commitment to involving consumers; the employment of community members; and consulting with consumers about appropriate strategies for their involvement. A collaborative approach with Indigenous communities is also required to make action effective.
- **Invitations by clinicians are influential:** personal invitations, especially from clinicians, may be necessary to persuade some people to be involved—this may be especially effective with culturally and linguistically diverse groups or those not used to participating.
- **Clear roles and expectations of consumers, carers and staff/clinicians:** assists people to make choices about whether to participate and how.
- **Staff practices:** including staff/clinician education and the way roles are organised; practices may sometimes exclude active participation by consumers at the individual level.
- **Need to ensure costs are not a barrier:** individual consumers should not be out of pocket through their involvement.
- **Training and skill development:** training of consumers and carers increases their willingness and ability to participate in quality improvement processes.

A full report of the literature review is available in the final project report *Developing a strategy for consumer and carer participation in cancer services reform* (available at [www.health.vic.gov.au/cancer](http://www.health.vic.gov.au/cancer)).

## 7 Summary of findings from consultations

Consultations were conducted with more than 150 people to inform the development of this guide. The key findings from the consultation are shown below.

- Cancer services are perceived as being of good quality by staff and consumers but with some key gaps.
- Consumers and staff agree there is a lack of coordination of some services, including the transition from children's to adult care, and for those consumers who use a mix of private and public services.
- Most consumers and carers and The Cancer Council Victoria felt that access to services was a concern, especially for rural consumers; for example, access to specialists in general and radiotherapy services specifically.
- Consumer participation activities in cancer services are fragmented. With the exception of breast cancer, relatively little consumer and carer participation at the service level is occurring. When it happens it tends to depend on specific committed staff, not organisational decisions. There is a diversity of understanding and commitment to consumer and carer participation among service providers.
- The consultations revealed four types of consumer and carer participation at the organisational level: cancer support groups, feedback and advice, committees, and advocacy; although there is often more emphasis on working with consumers and carers at the individual care level. Successful examples within services at the non-individual level included information development committees; Living with Cancer education program; palliative care consumer working groups; consumer advocates or consultants; project working groups; and, at a broader level, the CACs.
- Most participants agreed that consumers and carers offer a unique perspective to cancer services, which stems from their journey through the cancer service system. Consumers and carers expressed a willingness to have a greater say in cancer services, although many did not know of such opportunities.
- Most participants agreed that participation is essential at the individual, program and organisational levels. At an individual level, consumers spoke about wanting more information, more control over their care and treatment and greater involvement of their carers.
- At a service development level, staff saw the provision of regular information to consumers, and mechanisms such as patient follow-up or review meetings, as good avenues to gain feedback and to seek further involvement. Health promotion and community development techniques were identified as possible mechanisms to facilitate broader involvement.
- Diverse participation strategies need to be employed to cater for consumers' and carers' busy lives and wide interests, and to encompass all stages of the cancer journey. However, some consumers and carers were sceptical about the service system and its perceived commitment to participation, having been involved in tokenistic processes in the past.
- There was a strong consensus that strategies for consumer participation should be supported by systems, structures and policy (see constraints below).

- Many health professionals saw the current policy context for consumer participation as reasonably supportive. There is some baseline knowledge and understanding of consumer and carer participation and some infrastructure including policies, CACs, accreditation processes, quality and safety frameworks, active volunteer programs and, in some services, key staff such as social workers and breast care nurses who facilitate participation with consumers and carers.
- Constraints to participation identified included lack of commitment and understanding by senior management; negative attitudes of clinicians and administrators; lack of internal systems and structures to recruit, support and sustain consumer and carer participation; lack of resources; lack of training for staff and consumers and carers (for example, advocacy and committee skills); fear among some staff about working with consumers; sickness and time commitments for consumers and carers; transport costs in regional areas; and difficulties in ensuring a diversity of consumer and carer perspectives.
- Other barriers included lack of flexibility in models of participation; facilitating participation in broad geographical areas; and competing constraints of the medical versus the social model of health.
- Participants thought the target audience for the guide should include the full range of health service staff involved in cancer services.

A full report of the findings from the consultations is available in the final project report.



## 8 Underlying support for consumer and carer participation



Consumer and carer participation should lead to positive change, and managers and staff should see the potential for using consumer participation to improve their service and produce positive health outcomes. Participants in the consultations emphasised what the literature told us—that consumer and carer participation requires investment, leadership, processes and structures to make it effective.

A full analysis of the preconditions and infrastructure for consumer participation

suggested by Australian and international experience is given in the *Participation indicators* document (Department of Human Services 2005c). This document includes a framework for monitoring participation and a list of key factors identified in the literature that contribute to effective participation. These key factors are identified according to individual care, ward/program/department and organisational levels. Examples at the organisational level include development of policies and structures on how participation can be achieved as well as promoted throughout the organisation; development of policies for appropriate resource allocation; consumers being made aware of the processes for participating in their care and treatment; support from the top of the organisation being clearly communicated and the organisation being willing to change where necessary. Further actions are shown in Table 1.

## 9 Levels of participation

The Department of Human Services consumer and carer policy outlines four levels of participation in health services: individual, program/department, health service/organisational, and Department of Human Services (or statewide). There has also been a suggestion that a fifth level of participation be included—research. The following table shows the priority actions required to implement the first four levels of consumer and carer participation in health services.

**Table 1: Priority actions in consumer participation**

<b>1. Individual care level</b>
<ul style="list-style-type: none"> <li>1.1 Promote the rights and responsibilities of patients to the community, consumers and carers.</li> <li>1.2 Communicate clearly and respectfully with consumers and carers.</li> <li>1.3 Provide accessible information to consumers, carers and community members about health care and treatment.</li> <li>1.4 Communicate and provide information about treatments and care to consumers and carers that is developed with consumers and, where appropriate, carers.</li> <li>1.5 Listen and act on the decisions the consumer and, where appropriate, their carer(s) make about their care and treatment.</li> </ul>
<b>2. Program/department level</b>
<ul style="list-style-type: none"> <li>2.1 Involve consumers, carers and community members from the planning stage through to evaluation and monitoring.</li> <li>2.2 Create welcoming and accessible services for the diverse members of your community.</li> <li>2.3 Provide training to staff in communication skills and how to involve consumers and carers in decision making.</li> <li>2.4 Promote the importance of consumers and carers providing feedback to improve services.</li> <li>2.5 Establish links with community organisations to provide emotional support and ongoing information to consumers and carers.</li> <li>2.6 Involve consumers, carers and community members in the development of clinical guidelines and research.</li> </ul>
<i>Continued over &gt;</i>

### 3. Health service organisational level

- 3.1 Integrate participation of consumers, carers and community members, representatives or nominees into the quality and safety program.
- 3.2 Involve community representatives or nominees in the review of system level issues regarding consumer and carer feedback and complaints.
- 3.3 Involve consumers, carers and community members, representatives or nominees in all aspects of the organisation's planning and development.
- 3.4 Provide staff training and education on how to use the different types of participation.
- 3.5 Ensure position descriptions include participation components.
- 3.6 Evaluate, monitor and report on participation to the community and the Department of Human Services.

### 4. Department of Human Services level

- 4.1 Use the same processes of working with and accessing consumers, carers and community members, representatives or nominees across the Department.
- 4.2 Provide support, guidance and resources to health services and consumers, carers and community members on participation.
- 4.3 Provide training and education to Department staff on how to use the different types of participation, and evidence-based participation and communication.
- 4.4 Encourage health services to evaluate and monitor participation within a quality improvement framework.
- 4.5 Encourage the inclusion of participation skills and knowledge in the tertiary education of health professionals.
- 4.6 Advocate for a whole of Department policy on participation.

*Source: Department of Human Services, 2006, 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, pp. 25-36, Department of Human Services, Melbourne.*

Consumer and carer participation in research has been seen as an activity that could be implemented at different levels of health and medical research: biomedical, clinical, public health/ population health and health services, health economics and social research. A table summarising types of health research and potential areas for consumer and carer participation is included as Appendix 1.

For the purposes of this guide, which is aimed at consumer and carer participation in cancer service planning and delivery, participation at the individual, program and organisational levels are most relevant.

## 10 Types of participation

The following definition of participation provides a context for the types of participation proposed in this guide:

*Participation encourages consideration and debate through processes that allow people to be involved in decision making about their health care and that of the community. It necessitates the communication of your views, scrutiny of motives and an ability to listen and appreciate others' views and ideas. Through involvement decisions are made that may accommodate a range of perspectives.*

*Within a health care system, different types of participation can occur across service delivery, planning and policy-making. The following types and precursors of participation outline this discontinuous interaction model of participation: control, delegation, partnership, consultation and information (Department of Human Services 2006).*

There are several ways of conceiving the variety of participatory approaches available. The Department of Human Services consumer participation policy paper uses an adapted interaction model of participation (Department of Human Services 2005a) described in Table 2 below.

**Table 2: Types of consumer and carer participation**

Participation type	Objective
Information	To support participation, convey facts and educate.
Consultation	To gauge reaction to a proposal, a care plan or a treatment plan and invite feedback. Consultation is only participation when information gathered can influence subsequent policy, care and treatment choices.
Partnership	To involve consumers, carers and representatives in aspects of government or health service organisational decision making, and in health care or treatment decision making.
Delegation	To hand control to a board of community representatives within a specified framework, and to ensure policy options are formulated at arms length from partisan politics.
Control	To hand control of an issue to the electorate, and/or to the consumer of health care.

*Source: Department of Human Services, 2005a, Consultation paper, Participate in your health service system, Victorian consumers, carers and the community working together with their health service and the Department of Human Services, pp. 14-15.*

In terms of this guide, it is suggested that participation via partnership, consultation and information are the most feasible and valuable.





## Summary

**Part I** of this guide has outlined the policy context for consumer and carer participation in Victoria, the principles and evidence for participation and the processes and structures that are needed for participation to be effective. References to the minimum data set of consumer and carer participation indicators and the levels and types of consumer participation as developed by the Department of Human Services are also presented.

**Part II** of the guide outlines a process for planning strategically for consumer and carer participation in ICS. A plan with suggested goals and objectives is provided, in addition to a description of a series of methods for consumer and carer participation, including case studies and relevant references.

## 11 Strategic planning for consumer and carer participation in cancer services

### 11.1 Introduction

This section outlines a process for an ICS to plan strategically for consumer and carer participation in cancer reforms in its region. This section builds on the definitions, principles and evidence provided in Part I.

The section includes:

- practical principles for strategic planning
- a framework for a plan
- a draft set of goals and objectives (as a starting point)
- a summary table of potential methods for consumer and carer participation
- a proposed model for planning strategically
- a description of potential methods, supporting case studies and relevant references (in Appendix 2).

The section does not prescribe one particular method for consumer and carer participation but outlines a range of approaches that can be adapted by ICS according to their needs, context and capacity.

### 11.2 Practical principles for planning strategically for consumer and carer participation

The following practical principles and assumptions may be used as a basis for the design, implementation and sustainability of a consumer and carer participation plan for an ICS. These principles are based on relevant literature, documented best practice examples, and consultations with ICS strategic managers, clinicians, consumers and carers.

#### Internal resources and process

- Consumer participation will need support to be effective; this includes senior management support, leadership, shared visions, policies, partnerships, training and education for clinicians, staff and consumers, linking with existing accreditation processes and adequate human and financial resources.
- ICS should ensure that consumers and carers are involved as partners in the planning and implementation of consumer and carer participation.
- ICS should, where possible, build on existing information and consumer and carer participation avenues available within their health services.
- ICS should have a communication strategy to communicate the consumer and carer participation strategic plan to the whole organisation.

- ICS should consider linking with or accessing:
  - CACs, support groups, volunteers and other quality improvement or research and health promotion projects involving consumers and carers
  - routinely collected information (such as patient satisfaction surveys, feedback and complaints data) and previous participation audits
  - broader health promotion and community development strategies being used elsewhere within their health services.
- Consumer and carer participation should be implemented within the context of the patient management frameworks and other quality initiatives, as well as being integral to broader service planning, delivery, evaluation and research.

### Consumer and carer perspectives

- ICS should develop processes that will enable diverse perspectives to be included in consultations and partnership activities. For example, these might include a range of ages, gender perspectives, culturally and linguistically diverse communities, Indigenous communities and consumers and carers with a variety of cancer journey experiences.
- ICS should be sensitive to the current situation (health, stage of illness, time commitments) of consumers and carers as it may impact on the effectiveness of their involvement and their capacity to participate. Appropriate recruitment and selection processes should be developed.
- Where possible, more than one consumer should be invited to take part on a committee.
- Staff need to be open and honest with the consumers involved (remembering that some are sceptical because of their involvement in tokenistic processes in the past) and feed back outcomes to them.
- To be effective, consumer participation methods need to respond to the abilities, capacities and interests of consumers and carers.

### Implementation

- ICS should develop their consumer and carer participation plan in a realistic manner, which considers existing practices and aims for small early successes.
- Using a variety of consumer and carer participation methods in combination is the most effective approach.
- Participation with a focus on quality improvement can be a strategic use of effort and resources, as the lived experience of cancer patients offers a new and unique perspective.

### 11.3 A framework for a consumer and carer participation strategic plan

Table 3 outlines a sample framework for the development of a consumer and carer participation plan for an ICS. The development and implementation of this framework should be based on the principles for planning strategically, identified in 11.2.

The framework provided in Table 3 allows for the identification of the broader context for consumer and carer participation in cancer services; the specific goals and objectives within a region; the appropriate methods to achieve those goals (see Appendix 2); the resources and timelines required for implementation; and the structures and processes required for monitoring and evaluation. A detailed example of a consumer and carer participation plan for an ICS, which has been developed using this framework, is presented in section 12.

**Table 3: A framework for a consumer and carer participation strategic plan for Integrated Cancer Services**

<b>1. Introduction</b>
<b>2. Context</b> <ul style="list-style-type: none"> <li>• Broader cancer reform</li> <li>• Local cancer reform priorities</li> <li>• Local consumer participation context (current participation activities in the general health services, current participation activities in cancer services, and strength of networks to draw upon)</li> </ul>
<b>3. Goals and objectives of consumer participation in cancer reform in region</b>
<b>4. Methods to achieve each goal</b>
<b>5. Resources, timelines required to implement</b>
<b>6. Monitoring and evaluation processes</b>

### 11.4 Goals and objectives

Following the identification of the broader context for the consumer and carer participation plan for an ICS, goals and objectives need to be identified. These goals and objectives should address the needs of the individual cancer services and build on existing resources, abilities and capacities.

Some specific areas for cancer service improvement were identified through the consultations and the literature review. Listed below are a few examples of potential goals and objectives which were developed from the key findings outlined in section 7. These goals and objectives could be used to guide the development of an ICS consumer and carer participation plan.

## Goals

These goals represent a statement about desired long-term outcomes and relate to improving the health and well-being of cancer patients and their carers through changes to cancer service delivery.

### Examples:

- Improve coordination of cancer service delivery, especially for consumers using a mix of private and public services.
- Improve the transition from children's to adult care.
- Increase the level of involvement of consumers and carers in decision making about their treatment and care.
- Improve access to services, especially radiotherapy services in rural areas.
- Improve consumers' knowledge about their conditions and treatment options to enable them to participate in decision making about their own care.

## Objectives

These objectives describe what changes must occur for the above goals to be achieved.

### Examples:

- Establish a patient-centred focus of care for all consumers and carers.
- Develop consumer-friendly information about care and treatment options.
- Involve consumers and carers in local collaborating tumour groups.
- Establish processes and mechanisms to enable consumers and carers to increase participation in their care and treatment.
- Establish appropriate mechanisms to increase the involvement of consumers and carers in service planning.
- Allocate adequate infrastructure (including management support, policy framework, training, human and financial resources) to make participation effective.

## 11.5 Infrastructure

For a consumer and carer participation plan to be effectively implemented, policies, process and structures may need to be developed or existing ones enhanced. Examples of policies include terms of appointment for consumers on committees, terms of reference, consumer reimbursement or payment policies, and confidentiality and ethical behaviour protocols. New reporting and accountability systems may need to be established and clarity gained on the relationship between the ICS consumer and carer participation plan and other consumer and carer participation activities taking place in member health services.

## 11.6 Monitoring and evaluation

Evaluation and monitoring should be an integral part of the planning process. ICS should:

- identify evaluation indicators that are linked to goals and objectives
- conduct process, impact and outcome evaluations
- allocate appropriate resources for evaluation
- establish mechanisms for the dissemination of evaluation results
- establish mechanisms for the integration of evaluation results into future strategic planning.

The planning for evaluation should ensure that consumers and carers are actively involved in the evaluation design, implementation and dissemination of results. A model and a set of indicators to support evaluation of consumer and carer participation strategic plans are available in Departmental consumer participation policy documents (Department of Human Services 2005c).

## 11.7 Summary table of potential methods for consumer and carer participation

Table 4 provides a summary of the potential methods ICS may use for consumer and carer participation. It can be used as a quick guide to identify relevant methods to address goals and objectives. A full description of each method, including case studies and relevant references, is given in Appendix 2.

The table is organised according to the types of participation (information, consultation, partnership) and the settings where implementation could occur, with each method being able to be used in a variety of settings and in several combinations. The methods were identified through the consultation, literature review and knowledge of existing consumer participation practices. The table was prepared in consultation with ICS managers and attempts to include methods that are practical and applicable to ICS. The table does not intend to be an exhaustive list of all the methods ICS could use for consumer participation.

Table 4: Potential methods for consumer and carer participation

Types of participation	Settings			
	Individual patient/ carer	Unit/ Department	Health service	Integrated Cancer Service
<b>Information</b>				
Improve quality and timeliness of dissemination of information to consumers about services and treatment options	X	X		
Use decision aids and question prompt lists where possible	X	X		
Publications, media releases and displays		X	X	X
Internet	X		X	X
<b>Consultation</b>				
Public meetings/forums/open days			X	X
In-depth consumer and carer interviews	X	X		
Focus groups		X	X	X
<b>Partnership</b>				
Working with volunteers	X	X	X	
Workshops		X	X	X
Patient forums	X	X	X	
Discussion papers			X	X
Involve consumers/carers in staff training, development and selection		X	X	
Employ consumer/carer advocates/consultants		X	X	X
Involve consumers/carers on committees		X	X	X
Involve consumers/carers on project/working groups		X	X	X
Involve consumers/carers on reference groups			X	X
Partnerships of consumers/carers and providers for service planning and/or delivery			X	X
Involve consumers and carers in research		X	X	X
Involve consumers and carers in evaluation of services			X	X
Facilitating support groups and involving members	X	X		

X – indicates preferred settings

## 12 An example of a consumer and carer participation plan for Integrated Cancer Services

This is an example of a consumer and carer participation plan based on the framework outlined in Table 1. For content, some of the issues that emerged from the literature review and the consultation are used as a basis for the development of goals and objectives. These examples were then worked through in more detail using the methods suggested in Appendix 2. Clearly, each ICS will develop its own goals and objectives in line with knowledge of local context, existing work and development partnerships.

There are other ways to develop a consumer and carer participation plan. The more obvious one is to focus on consumer participation activities across the organisation and not on specific change objectives. However, Health Issues Centre recommends that a focused strategic approach might be more useful. Further, the development of this plan has used the principles for planning strategically detailed in 11.2.

A brief commentary on elements of the plan is also provided under each section.



## A consumer and carer participation plan for [insert name] Integrated Cancer Service for the period [insert timeframe]

### 1. Introduction

This plan describes a set of participation activities (and associated supports) aimed at making an optimal contribution to quality improvement for cancer services in this region over the next two years. This will be reviewed annually.

#### Comments

We suggest a two-year plan. The developmental activities likely to be specified in the plan typically need some time to be undertaken and come to fruition. Further, the context is also very likely to change as the service tries new activities; as consumers start to be recruited and have some input; and as the local collaborating tumour groups develop their work plans. So a review after 12 months will probably be necessary.

### 2. Context

#### 2.1 Broader cancer reform

Victoria has established a strategic and planned approach to cancer reform, including setting up a Ministerial Taskforce for Cancer, and implementing the *Fighting cancer* policy (2002) and *A cancer services framework for Victoria* (2003). Two significant directions of the *cancer services framework* are the establishment of Integrated Cancer Services (ICS) in metropolitan and regional Victoria, and the development of service delivery and improvement through a tumour streams model. Funding is also being provided for service improvement activities in four priority areas: multidisciplinary care; care coordination; psychosocial and supportive care; and reducing unwanted variation in practice (quality monitoring and support).

The Cancer Services Framework encourages ICS to develop collaborative partnerships with a wide range of stakeholders, including consumers. Consequently, developing ways to increase the participation of people who have experienced cancer in the cancer reforms is one of the key deliverables for the Ministerial Taskforce for Cancer in its 2005–06 action plan. The active involvement of consumers as ‘partners in health care service planning and delivery’ is integral to the development of cancer services that improve treatment outcomes and patients’ experience of the cancer service system.

Other more recent government policy documents that outline participatory models and argue for meaningful consumer, carer and community participation in health services are:

- *Directions for your health system: Metropolitan Health Strategy.*
- *Primary Care Partnerships strategic directions 2004–2006.*
- *Community health services – creating a healthier Victoria.*
- *Doing it with us not for us. Participate in your health service system 2006–2009: Victorian consumers, carers and the community working together with their health service and the Department of Human Services.*
- *Participation indicators. Participate in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services.*

An important step forward for consumer participation in Victoria has been the legislated establishment of Community Advisory Committees (CACs) in metropolitan and regional health services. The *Community Advisory Committee guidelines: Victorian public health services* documents these initiatives.

#### Comments

This was written by Department of Human Services and might need finetuning for your audience. Note that these context sections are intended to create a common understanding of the reforms and the ICS’ view of the place of consumer participation in the reforms among all local stakeholders.

## 2.2 Local cancer reform priorities

The ICS has prioritised the following areas for improvement in the short to medium term:

*[insert local priorities here].*

Other priorities will emerge as the local collaborating tumour groups develop their work plans and the patient management frameworks are implemented.

The ICS is also committed to quality improvement by ensuring consumers and carers are actively involved in service planning *[or amend to suit local policies].*

## 2.3 Local consumer and carer participation context

This plan recognises that there are already a range of participation activities being undertaken in local health services and the community, and considers that it will be effective and efficient if cancer reform participation activities can be linked to and strengthened by some of these activities. Current activities of particular importance include:

- the CACs
- the range of participation activities at organisational, program and individual care levels within each of the ICS member health services, and especially those linked to cancer services *[insert specifics]*
- participation activities *[insert specifics]* undertaken by the local divisions of general practice
- participation activities *[insert specifics]* of local community health services
- local consumer groups especially cancer support groups *[insert specifics]*
- others *[insert specifics].*

The ICS notes that the relationships and mutual understanding and trust between these organisations and the ICS cancer services are *[insert specifics of strengths or weaknesses of such relationships and implications of that].*

This has affected the strategies selected for this plan in the following way *[insert specifics]*

### Comments

This recognises that intended participation activities are not occurring in a vacuum but that much local work may already be underway. This existing expertise and consumer engagement needs to be linked into, so that wherever possible, the cancer reform effort does not start from scratch.

Further, work in partnerships has often been shown to be both more effective and sustainable. Clearly, the stronger these existing relationships are, the easier it is to develop initiatives. If not well developed, some of the plan will need to address this and build stronger networks and relationships.

## 3. Goals, objectives and methods of consumer participation

**Goal #1: To build consumer and carer engagement into the structures of the ICS to ensure that initial directions for the ICS quality improvement work are responsive to consumer and carer needs.**

### Objectives

- 1.1 Identify the appropriate level of involvement and the key roles for consumers and carers in ICS infrastructure (for example, ICS executive, advisory groups, tumour groups) and develop policies and mechanisms to recruit.

### Strategies and methods

- Establish consumer and carer roles and the types of individuals sought to fill the roles.
- Establish complementary policies on consumer engagement, reimbursement/payment arrangements.
- Develop a recruitment strategy.

**Objectives**

1.2 Recruit a diverse range of consumers, able and ready to make a contribution to ICS infrastructure and other future activities.

**Strategies and methods**

- Implement recruitment strategies (for example, newspaper ads, letters and emails to local consumer organisations, using staff networks).
- Provide orientation and training to facilitate their involvement.
- Build a network of contacts and relationships, as part of the recruitment process, to facilitate future recruitment of consumers and carers.
- Plan ongoing support to those consumers and carers engaged (for example, mentoring, training, regular briefings).
- Develop strategies to communicate progress and outcomes to your consumers and consumer network (for example, via own or other organisations' newsletters or email bulletins, forums).
- Provide training or other supports to enable staff to work effectively with consumers and carers in the reform process.

**Comments**

This section proposes that there needs to be consumer involvement in the establishment of the ICS and the development of its initial priorities. This will ensure that consumer perspectives and priorities are included in consideration of future work, and will therefore make consumer recruitment easier (as the issues will seem more relevant to them).

Ensuring feedback to consumers involved and their broader networks is essential in maintaining involvement and satisfaction from participants.

**Goal #2: To increase the level of involvement of consumers and carers in decision making about their treatment and care through increased use of decision aids.****Objectives**

2.1 Develop decision aids where they are considered to be of most value (with clinician and consumer input).

**Strategies and methods**

- Identify where decision aids are most valuable.
- Adapt an existing aid or develop a new one (with clinician and consumer input via project committee, focus groups, surveys, patient diaries).
- Explore implementation issues with staff and consumers (for example, workshop or focus group).
- Pilot and evaluate.

**Objectives**

2.2 Establish processes to incorporate use of decision aid as part of normal care.

**Strategies and methods**

- Develop local protocols.
- Train staff in rationale and methods, how to incorporate into current practice, how to respect consumer decisions (using consumers to provide input to such sessions).
- Facilitate collection of feedback from consumers and carers and establish review and monitoring processes.
- Develop communication strategy for consumers to promote use of aids (for example, brochures, signs or posters, videos).

**Comments**

This section assumes a strategic approach to participation. That is, it assumes that effort to involve consumers will be focused on areas that are crucial to the quality improvement approach and, within that, to areas where consumers can make the most difference. This will benefit the organisations and consumers' satisfaction in their involvement. For instance, the issue of decision aids was highlighted in the literature review as having significant benefits for consumers' care and health outcomes.

**Goal #3 [insert]**

Objectives and strategies

**Comments**

Identify other goals and develop objectives in line with ICS priorities, and then develop appropriate strategies/ methods as above and using this guide.

Health Issues Centre recommends a focused and achievable approach (for example, perhaps 3–4 goals only in the first 12 months). ICS may wish to prioritise goals using an impact-effort decision grid.

**4. Resources and timelines**

The following funding and resources have been allocated to the implementation of the strategies outlined above:

- budget and resources for recruitment, training and ongoing support of consumers
- budget and resources for running workshops, focus groups etc
- some specified project worker time to develop relevant processes and policies (for example, reimbursement, reporting)
- budget and/or resources to provide staff training on participation or new processes
- budget and/or resources for communication.

This plan covers a 24-month period.

Goal #1 is expected to be completed in *[insert timeframe]* months.

Goals #2 is expected to be completed in *[insert timeframe]* months.

**5. Monitoring and evaluation**

The following activities will be undertaken to evaluate the progress and success of the consumer and carer participation strategies outlined above:

- undertake planning for evaluation, including:
  - develop the study design
  - identify evaluation indicators linked to each goal and objective (refer to Department of Human Services Participation indicators document (2005c))
  - develop strategy for dissemination of results
  - allocate resources for evaluation
- conduct process, impact and outcome evaluation
- disseminate evaluation results to all key stakeholders
- ensure integration of evaluation results into future strategic planning

Consumers and carers will be actively involved in all stages of the evaluation process, including its design, dissemination of the results, and incorporation of the results into future planning processes.

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## Appendix 1: Types of health and medical research and potential areas of consumer, carer and community participation

Type of research	Key characteristics	Potential areas of consumer, carer and community participation
<b>Biomedical research</b>	<ul style="list-style-type: none"> <li>• Laboratory-based</li> <li>• Complex</li> <li>• Controlled experimental designs</li> <li>• Molecular, cellular</li> </ul>	<ul style="list-style-type: none"> <li>• Ethics</li> <li>• Member of a steering committee</li> <li>• Member of the project team</li> <li>• Communicating results broadly, in ways that are meaningful to consumers and community members</li> </ul>
<b>Clinical research</b>	<ul style="list-style-type: none"> <li>• Laboratory-based and/or human subjects</li> <li>• Controlled experimental designs</li> <li>• Quantitative methods</li> </ul>	<ul style="list-style-type: none"> <li>• Ethics</li> <li>• Ownership or access to human tissue samples</li> <li>• Identifying areas for further research</li> <li>• Advocacy</li> <li>• Communicating results to participants and wider community in consumer-friendly ways</li> <li>• Member of a steering committee</li> <li>• Member of the project team</li> </ul>
<b>Public health/ population health research</b>	<ul style="list-style-type: none"> <li>• Study of communities or populations</li> <li>• Social setting</li> <li>• Focus on epidemiology, health promotion and prevention, social and behavioural sciences, population-based health interventions</li> <li>• Quantitative and qualitative methods</li> </ul>	<ul style="list-style-type: none"> <li>• Identifying gaps in current knowledge</li> <li>• Identifying need</li> <li>• Contributing consumer-focused research</li> <li>• Advocacy</li> <li>• Informing policy development</li> <li>• Assisting/collaborating in research processes</li> <li>• Networking support and liaison</li> <li>• Communicating results</li> <li>• Translating results into practice</li> <li>• Member of a steering committee</li> <li>• Member of the project team</li> </ul>
<b>Health services, health economics and social research</b>	<ul style="list-style-type: none"> <li>• Study of health-related institutions, including their operation within the broader system</li> <li>• Systems/policy focus</li> <li>• Complex social settings</li> <li>• Quantitative and qualitative methods</li> </ul>	<ul style="list-style-type: none"> <li>• Identifying breakdown in systems</li> <li>• Feedback about quality, relevance and appropriateness of services</li> <li>• Collaboration in research processes</li> <li>• Contributing consumer-focused research</li> <li>• Research subjects</li> <li>• Member of a steering committee</li> <li>• Member of the project team</li> <li>• Providing consumer perspective on system issues</li> <li>• Networking support and liaison</li> <li>• Advocacy</li> <li>• Communicating results</li> <li>• Implementing results</li> </ul>

Adapted from: National Health and Medical Research Council and Consumers' Health Forum of Australia, 2004, *Resource pack for consumer and community participation in health and medical research, Investing in Australia's health*, pp. 15-16, Commonwealth of Australia, Canberra.



## Appendix 2: Methods of consumer and carer participation for Integrated Cancer Services

Table 5 provides a detailed description of the methods that can be used in the implementation of the consumer and carer participation plan. The table includes a brief description of each method, where the method was sourced from and why it was included. In most cases a relevant case study and references for further reading are given. The methods were identified through the consultation, literature review and knowledge of existing consumer participation practices. The table was prepared in consultation with ICS managers and attempts to include methods that are practical and applicable to ICS. The table is not intended to be an exhaustive list of all of the methods ICS could use for consumer participation.

**Table 5: Methods of consumer and carer participation for Integrated Cancer Services**

## Written information to consumers about services and treatment options

*(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Provision of written information on how consumers can be involved in decision making about treatment and services.

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

### Case study

#### The Patient Education Material Project (PEP)

The PEP was a project to improve written information for patients receiving colorectal cancer surgery at Austin Health. Pre-operative and discharge written information is important for patients. The project evaluated existing consumer education material and produced new information material in collaboration with consumers and carers (Naksook et al. 2003).

### Relevant references

Carrol, M., 2003, 'Prescribed drugs: the information chain deficit', *Health Issues*, Issue 75, pp. 12-15.

Department of Human Services, 2005a, *Consultation paper, Participate in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services*, Department of Human Services, Melbourne

Hill, S., 1999, 'Communicating with consumers having elective surgery: a framework for information provision', *Health Issues*, Issue 58, pp. 17-19.

Johnson, A., Sandford, J. and Tyndall, J., 2004, *Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home* (Cochrane Review), The Cochrane Library, 2. [www.cochrane.org/cochrane/revabstr/ab003716.htm](http://www.cochrane.org/cochrane/revabstr/ab003716.htm)

In addition, a checklist for developing written information and many examples can be found in the Communicating with Consumers series available from the website: [www.health.vic.gov.au/consumer/pubs.htm](http://www.health.vic.gov.au/consumer/pubs.htm)

## Use decision aids and question prompts where possible

(Source: Project literature review)

### Decision aids

#### Description

Decision aids are self-administered or clinician-administered tools which help patients to participate with their practitioners in making deliberative, personalised choices among health care options (O'Connor 2001).

Decision aids for people facing health treatment or screening decisions are effective in improving people's knowledge of treatment and screening options and outcomes. They also increase realistic expectations, reduce uncertainty about decisions (also known as decisional conflict), decrease the proportion of people remaining undecided, and encourage a more active role in decision making among those seeking care.

#### Relevant references

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- Wolf, A.M.D. and Schorling, J.B., 2000, 'Does informed consent alter elderly patients' preferences for colorectal cancer screening', *Journal of General Internal Medicine*, Volume 15, pp. 24-30.
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## Question prompt lists

### Description

A question prompt list is a structured list of questions designed to encourage patients to acquire information during a medical consultation (McJannett et al. 2003).

The value of cancer patients using question prompt lists to facilitate consumer participation in consultations with their doctors is supported by a high level of evidence.

### Relevant references

Brown, R., Butow, P., Dunn, S. and Tattersall, M., 2001, 'Promoting patient participation and shortening cancer consultations: a randomised trial', *British Journal of Cancer*, Volume 85, no 9, pp. 1273-1279.

Brown, R., Butow, P., Henman, M., Dunn, S., Boyle, F. and Tattersall, M., 2002, 'Responding to the active and passive patient: flexibility is the key', *Health Expectations*, Volume 5, no 3, pp. 236-245.

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Butow, P., Devine, R., Boyer, M., Pendlebury, S., Jackson, M. and Tattersall, M., 2004, 'Cancer consultation preparation package: changing patients but not physicians is not enough', *Journal of Clinical Oncology*, Volume 22, no 21, pp. 4401-4409.

McJannett, M., Butow, P., Tattersall, M.H. and Thompson, J.F., 2003, 'Asking questions can help: development of a question prompt list for cancer patients seeing a surgeon', *European Journal of Cancer Prevention*, Volume 12, no 5, pp. 397-405.

## Publications, media releases and displays

*(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Written or verbal information promoting consumer participation or consumer input to information on cancer-related issues. Advertisements, posters or invitations to inform consumers of service developments, research findings or opportunities to participate in focus groups, committees, planning days and workshops.

### Case study

#### Cancer Council Victoria

Consumers are regularly invited to review patient information booklets.

## Internet

*(Source: Project consultations)*

### Description

Services can use the internet to communicate with consumer, carer and community stakeholders, disseminate invitations to formal consumer participation activities, distribute surveys, organise and conduct focus groups, launch chat rooms to facilitate conversation among consumers and carers etc.

### Case study

#### Royal Women's Hospital

Hospitals are increasingly using their websites to inform consumers and encourage consumer participation. For example, The Royal Women's Hospital home page provides links to a consumer information site that has fact sheets in 16 different community languages; a new resource for prospective lesbian parents in Victoria that consumers can evaluate by reading it online and sending in an email; and an email facility for rural consumers who don't have easy phone access and who want to ask questions of health nurses ([www.rwh.org.au](http://www.rwh.org.au)).

## Promotions and campaigns

*(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

An avenue to inform the public about a new program, initiative or service. Processes can be innovative and creative, and can involve consumers and carers through, for example, consultation in planning and partnerships for implementation.

### Case study

#### Austin Health and Mercy

The Austin Health Redevelopment and Mercy Hospital for Women Relocation Project has been keeping consumers informed of progress via a designated website ([www.armproject.org](http://www.armproject.org)). This has included advertising an open day where the public could tour the premises and meet the staff, as well as enjoy music and displays.

## Public meetings, forums and open days

*(Source: Project consultations; Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Larger meetings (usually more than 20 people). Meetings structured to canvas views, debate an issue, deliver information.

### Case study

#### West Gippsland Primary Care Partnership (PCP)

The West Gippsland PCP organised a one-off open day to disseminate information about their consumer participation strategy and invite interested members of the community to participate in the activities of the PCP agencies.

## In-depth consumer and carer interviews

*(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Extended, semi-structured and (usually) face-to-face interviews. Provide rich information from selected consumers and carers. Useful as a follow-up to surveys to explore particular issues and/or for specific population groups. Can be time-consuming.

### Case study

#### Women's Health Goulburn North East and Breast Services Enhancement Program

*Woman to woman: A research report on the experience of rural women with breast cancer and implications for the provision of health services* was an example of participatory research. It was designed to explore the effects of breast cancer and breast cancer treatment on rural women. Twenty women in the Hume Region who had been diagnosed and treated for breast cancer were asked to reflect on the effect of breast cancer on their lives, and on the nature and quality of the services they received. They spoke about what was helpful to them and gave their views on how services could be improved (Department of Human Services 2004).

### Relevant references

Patton, M.Q., 1990, *Qualitative evaluation and research methods*, Sage, Newbury Park.

## Focus groups

(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)

### Description

A semi-structured group interview with six to eight people for 30 minutes to two hours. Participants can be invited on the basis of who they are and what they can contribute to discussion. Interactions among participants can help explore issues rapidly and in depth. Focus is on a specific issue to collect information (not used for decision making). Provides rich information, but may not be representative of all consumers and carers.

### Case study

#### St Vincent's Health

To improve health services for Aboriginal patients, St Vincent's Health reviewed its existing practices, including its Koori Hospital Liaison Officer program. The most important part of the review were interviews and focus groups involving Aboriginal patients, local organisations and St Vincent's Health staff. The review highlighted the importance of relationships with the local Aboriginal community and has led to a committee partnership and a new position of Aboriginal Policy and Strategic Planning Officer (Department of Human Services 2005).

### Case study

#### Ballarat Health Services

In 2003, Ballarat Health Services ran a series of focus groups for people with dementia and their carers to identify key issues related to acute hospital care. This resulted in a hospital-wide education program and a bedside Cognitive Impairment Identifier being introduced to the ward setting. The model has been extended to the sub-acute area and a partnership to further expand this model of care is planned for the future (Department of Human Services 2005).

### Case study

#### National Breast Cancer Centre

The National Breast Cancer Centre recently embarked on a project to review evidence around the use and efficacy of complementary therapies. To ensure the project would be useful to consumers, they contacted Breast Cancer Network Australia (BCNA). Through BCNA's Seat at the Table program they could easily access a group of 12 breast cancer survivors from across the country to participate in a telephone focus group. This feedback at the commencement of the project ensured that the needs of consumers were addressed from the beginning.

### Relevant references

Patton, M.Q., 1990, *Qualitative evaluation and research methods*, Sage, Newbury Park.

Powel, R. and Single, H., 1996, 'Methodological matters V: Focus groups', *International Journal of Quality in Health Care*, Volume 8, no 5, pp. 499-504.

## Working with volunteers

*(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Regular and ongoing consultation with volunteers in the organisation. May promote formal consumer and carer participation by current volunteers in the service.

### Case study

#### Cancer Connect

This is a telephone support service linking people through their experience of cancer. Cancer Connect puts people in touch with other volunteers who have had a similar cancer experience, are coping well since treatment ceased (a minimum of two years) and are specially trained. All volunteers are trained in effective and supportive communication. The issues most often discussed include treatment and management, side effects, diagnosis, partner/family issues, psychosocial and emotional support, cancer support group and sexuality. Anecdotal feedback from people who received support from the service has been that their ability to cope with their situation has increased substantially ([www.cancervic.org.au](http://www.cancervic.org.au)).

### Relevant references

Volunteering Australia [www.volunteeringaustralia.org](http://www.volunteeringaustralia.org)

Volunteering Victoria [www.volunteeringvictoria.org.au](http://www.volunteeringvictoria.org.au)

## Workshops

*(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Working meeting, usually of 12–25 consumers and carers (could also include providers), to share information and develop a shared approach to a specified issue. Participants usually selected on the basis of particular skills, knowledge or experience. Requires informed participants.

### Case study

#### Western District Health Service

This service's Sustainable Farm Families project works with farmers and industry groups to achieve change at individual, couple, family, community and industry levels. The three-year project engages farming families in decision making about their health, well-being and safety, including collecting physical assessment data and tracking it over the three years. As well as the project achieving measurable improvements in health, workshop evaluations by the participants demonstrated a 100 per cent rate of recommendation to other farmers and a greater feeling of empowerment about personal health.

### Relevant references

Department of Human Services, 2005, *2005 Victorian Public Healthcare Awards Showcase*, Department of Human Services, Melbourne.



## Patient forums

*(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Patients invited to focus on an area/issue. Usually structured. For education, health promotion, new technology, new service, 'have a say', etc. Patient feedback is a vital tool to inform organisations of appropriate quality improvement activities.

### Case study

#### St. Vincent's Health

St Vincent's Aged Care and Allied Health Directorate started patient forums as a way of obtaining information about key issues important to patients, their family and carers. The objective is to use the feedback to promote a patient-centred practice and culture, thereby improving quality. Two independent facilitators conducted a 45-minute session, with questions covering pre-information, ward rounds, family meetings, goal setting, dignity and communication. The patient forum was a very useful tool for identifying important issues from the patient/carer perspective. Having face-to-face contact enabled detailed questioning and allowed patient/carer suggestions for improvements to be heard. All of this helps to ensure that any quality improvement activities undertaken are patient-focused.

## Advance care planning

*(Source: Health Issues Centre)*

### Description

Service providers discuss with patients and their families their wishes regarding their end-of-life care. Patients and families are actively part of the process and agree on a plan for the patient's end-of-life care.

### Case Study

#### Austin Health

The Respecting Patient Choices (RPC) model of advance care planning (ACP) being implemented by Austin Health is based on a modified version of the US Respecting Choices program. A key aim of the program is to identify patients' wishes regarding their health care, particularly around end-of-life issues, and document these in some form of advance directive (AD). Other benefits arising from this process include ensuring appropriate timing for discussions around end-of-life care, reducing the burden of family decision making by knowing what the patient would want, and ensuring that documented wishes are available to staff when required. The RPC program has significant potential to reduce the incidence of adverse events by avoiding unwanted and inappropriate medical intervention. The Commonwealth Department of Health and Ageing has provided funding for the extension of the RPC program from the hospital setting to the residential aged care and palliative care service community in Austin Health's catchment. Early evaluation results are positive, especially for consumers and carers.

### Relevant references

Respecting Patient Choices Program [www.respectingpatientchoices.org.au](http://www.respectingpatientchoices.org.au)

## Consumer and carer participation in staff selection, training and development

*(Source: Our Community 2006; Pinches 2006)*

### Description

Acquaints all staff with consumer and carer perspectives and knowledge of how consumers and carers experience services. Consumers and carers may be trained to carry out these educational tasks. Consumer and carers participate in defining selection criteria, in staff selection (interview) and in periodic performance assessment reviews for staff.

### Case study

#### Northern Area Mental Health Service (NAMHS)

NAMHS has a Consumer Participation in Staff Selection (CPSS) strategy, which was initiated by consumers and developed through cooperation between consumers and service management. The process began with workshopping segments of meetings, facilitated by the NAMHS consumer consultant, leading to a set of consumer-based selection criteria and a discussion paper outlining the potential usefulness of the strategy. A subsequent formal evaluation of the CPSS strategy after it was introduced in 2000 found that it 'appeared to have profoundly influenced the culture of the service, including factors like the quality of staff appointments, staff attitudes and practices'. The initiative was also found to have increased mutual respect and enhanced relationships between consumers and staff (Grimshaw 2003).

## Consumer and carer advocates and consultants

*(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Health care organisation employs a person to consult with consumers and carers and advocate on their behalf for service improvement. Can be a service provider staff member (for example, breast care nurse, community liaison officer, Royal District nurse).

### Case study

#### Breast Cancer Nurse Consultant – Bendigo

A Breast Care Nurse Consultant (BCNC) position was established in 2001 in the Bendigo area. The position is a joint appointment covering private and public health care facilities at St John of God Healthcare and Bendigo Health Care Group. The role of the BCNC is to provide a high

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level of best practice care and support to all breast care patients in the greater Bendigo area. The BCNC becomes involved from the point of diagnosis and throughout the journey of breast cancer and follow-up. The BCNC coordinates quality care, information, education and support for people with breast cancer across both organisations in the acute and community areas, using a multidisciplinary approach.

In the development phase of the role, local consumers, support groups and clinicians were consulted to identify how the BCNC could best meet their needs and at critical points of care. The role was piloted in 2001 and evaluated by the Collaborative Health Education and Research Centre (Bendigo Health Care Group). The pilot was found to be highly successful and supported by consumers and clinicians, leading to a sustainable ongoing position in the Bendigo area. The success of the BCNC position is largely attributed to the engagement of local stakeholders in the planning, development and implementation stages, and the partnership between the health care organisations.

### Relevant information

Consumer's Health Forum of Australia [www.chf.org.au](http://www.chf.org.au)

## Consumers and carers on committees

*(Source: Project consultations; Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Informing, training and supporting consumer and carer representatives on committees. Ensuring that representatives have a relationship with their constituency. Clarifying representatives' roles and the terms of reference of their committees. A medium to long-term strategy.

### Case Study

#### St Vincent's Health

Consumer involvement on committees and in project work groups has been trialled at St Vincent's since 2002. The redesign of outpatient/emergency department processes to reduce waiting times and improve communication and satisfaction among patients has been an effective and satisfying use of consumers' time.

### Relevant references

Consumer's Health forum of Australia, 1999, *Guidelines for consumer representatives*, viewed 11 December 2006, [www.chf.org.au/consumer\\_reps\\_program/chf\\_guidelines.asp](http://www.chf.org.au/consumer_reps_program/chf_guidelines.asp).

Department of Human Services, 2006, *Community advisory committee guidelines: Victorian public health services*, viewed 11 December 2006, [www.health.vic.gov.au/consumer/pubs/cacg.htm](http://www.health.vic.gov.au/consumer/pubs/cacg.htm).

## Consumers and carers on project or working groups

*(Source: Project consultations; Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Structure and role prescribed by the organisation. Made up of consumers and carers who advise the organisation on a specific project. Need to ensure consumers and carers have links

with appropriate constituency and support them in this. Members need to have tenure long enough to contribute to the project, but not so long that they become part of the organisation. Short-term strategy.

### Case study

#### **Bendigo Palliative Care Hospice**

A consumer reference group worked towards changing the name for the hospice house. The group considered that the name 'hospice' had negative connotations for residents and potential residents. They decided to give the house the name of the street in which it is located. The service acknowledged that although the consumers were sick and fatigued, if they facilitated the process in an appropriate way the consumers were able to contribute in a meaningful way.

## **Consumers and carers on reference groups**

*(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Made up of consumers and carers who advise the organisation and/or a specific program. Need to support consumers and carers to have links with appropriate constituency. Need to develop clear description of role and committee terms of reference. Short-term involvement.

### Case study

#### **North Yarra Community Health Service (NYCHS)**

NYCHS in partnership with local communities and services used a pilot project to develop new ways of building community partnerships and strengthening community participation in planning services and responding to health needs. This included working with a broad reference group of local organisations, as well as other partners, to ensure that strategies were appropriate and effective. This produced outcomes such as a Vietnamese community consultant working with the Neighbourhood House to start English classes for elderly Vietnamese people; and a consultant for the drug-using community advising a NYCHS staff member about a new dental service planned for that community (North Yarra Community Health 2001).

### Case study

#### **Austin Health**

The Austin Bowel Cancer Consortium used action research and recruited doctors and patients from three Victorian hospitals. As part of the project's aim of improving the management of bowel cancer, consumer reference groups produced a 'patient pathway' for surgery, a set of questions to ask doctors, and public education material about warning signs for bowel cancer (Mitchell and White 2004).

### Relevant references

Consumer's Health Forum of Australia, 1999, *Guidelines for consumer representatives*, viewed 11 December 2006, [www.chf.org.au/consumer\\_reps\\_program/chf\\_guidelines.asp](http://www.chf.org.au/consumer_reps_program/chf_guidelines.asp).

## Consumers and carers as partners with providers for service planning and delivery

*(Source: Project consultations; Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

This includes several levels of activity:

Decision making process at the **individual** level of care where the patient and the doctor establish a meaningful communication, allowing the patient to understand their medical condition and make informed decisions about their medical care and treatment.

Decision making process at the **organisational** level, implying a structured cyclical planning process with specified roles for consumers and carers in shared decision making. Process and outcomes are a shared responsibility. Usually the result of years of development of consumer and carer participation and a strong consumer and carer focus/culture within the organisation.

### Case study

#### Handover at the Bedside

St Vincent's Hospital introduced a new style of patient handover to increase patients' participation in their own care and improve aspects of patient safety. The nurse-to-nurse handover is done at the bedside at the end of each shift and involves the patient. There was a 100 per cent positive response from patients involved in the new process, in terms of how they valued the opportunity to participate. Nurses had been concerned that patient confidentiality/privacy would be placed at significant risk, but this was not an issue for any of the patients interviewed. A Handover Education Manual is now kept on the relevant wards as a ready reference for new staff and for ongoing education. The challenge for the future is to instigate a similar procedure for the medical ward round.

### Case study

#### Southern Melbourne Integrated Cancer Service (SMICS)

SMICS, in collaboration with Health Issues Centre, is conducting a project, Optimising Consumer Participation in Cancer Services, to develop a model for active consumer/carers participation as a key strategy for improving cancer service delivery in southern Melbourne. This two-year (May 2005–June 2007) project involves:

- developing a framework for consumer/carers participation in quality improvement activities for use by SMICS' three member health services and across the ten tumour streams
- developing strategies and tools to support SMICS to recruit, select, support and train consumers/carers to participate in cancer service planning and delivery
- establishing processes for gathering feedback from consumers/carers regarding their cancer journey to assist with the identification of opportunities for improvement and the evaluation of activities implemented to improve the quality of cancer services
- developing strategies and tools to support clinicians to work with consumers/carers to improve cancer service delivery.

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Project implementation is being guided by a steering committee that comprises health care professional representatives and consumer/carer/community representatives. The first phase of this project focused on developing and implementing a sustainable Model for Consumer/Carer Recruitment and Management, which is congruent with relevant policies (for example, consumer participation) of the SMICS member health services. This model is guiding the recruitment and training of consumers and carers who will be involved in tumour group activities.

### Relevant references

Bauman, A.E., Fardy, H.J. and Harris, P.G., 2003, 'Getting it right: why bother with patient-centred care?', *Medical Journal of Australia*, Volume 179, no 5, pp. 253–256.

Thistlethwaite, J., 2005, 'Patient partnership and shared decision making: involving patients in management decisions', *Health Issues*, Issue 83, pp. 22–25.

## Consumer and carer participation in research

(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)

### Description

Different models depending on values and approach. Outcomes research, qualitative research, action research and clinical epidemiology can overlap with consumer and carer participation.

### Case study

#### Women's Health Goulburn North East (WHGNE)

*The Empowerment: Women's Sexual Health Through Education – A Peer Leadership Model* project was a partnership between women with intellectual disabilities and health practitioners. The project used an action research approach to explore what women had found to be barriers to sexual health and what they had found helpful. The women worked with a community artist, leading to a pilot group work program designed to deliver sexual health education. The pilot program was later extended so that the women participants were trained as peer leaders for the next group of young women choosing to access the group (Women's Health Goulburn North East 2004).

### Case study

#### Breast Cancer network Australia (BCNA)

BCNA wanted to obtain feedback from readers about its quarterly magazine *The Beacon*. BCNA developed a short survey to be sent to one in ten readers. It then forwarded the survey to eight consumer representatives to get feedback about the usability of the survey. The feedback was practical and helpful and ensured that the survey was easy to complete and provided good unambiguous feedback. If you are developing a tool that seeks feedback from consumers it is always a good idea to trial it with the target group before you finalise the tool.

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## Relevant references

Beacham, B., Dawson, T. and members of the Primary Health Care Research Evaluation and Development Research and Capacity Building Initiative Consumer Participation Working Party, 2005, *Strengthening the participation of consumers and community members in research and evaluation: Future directions for the Australian PHCRED Strategy*, Flinders University Primary Health Care Research Evaluation and Development Research Program and Health Issues Centre. Unpublished.

National Health and Medical Research Council & Consumers' Health Forum of Australia, 2001, *Statement on consumer and community participation in health and medical research*, Commonwealth of Australia, Canberra.

National Health and Medical Research Council & Consumers' Health Forum of Australia, 2004a, *A model framework for consumer and community participation in health and medical research*, Commonwealth of Australia, Canberra.

National Health and Medical Research Council & Consumers' Health Forum of Australia, 2004b, *Resource pack for consumer and community participation in health and medical research*, Commonwealth of Australia, Canberra.

Oliver, S., Clarke-Jones, L., Rees, R., Milne, R., Buchanan, P., Gabbay, J. et al., 2004, 'Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach', *Health Technology Assessment*, Volume 8, no 5, pp. iii-iv.

## Consumers and carers in evaluation of services

(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)

### Description

Consumer and carer participation in the design, conduct and analysis of evaluation processes. Essential component of consumer participation. Many methods.

### Case study

#### Northern Area Mental Health Service (NAMHS)

The NAMHS Consumer Participation in Staff Selection (CPSS) strategy was formally evaluated via interviews with staff on selection panels, staff employed by selection panels and consumers on the selection panels. The evaluation found that the CPSS 'appeared to have profoundly influenced the culture of the service, including factors like the quality of staff appointments, staff attitudes and practices'. The initiative was also found to have increased mutual respect and enhanced relationships between consumers and staff (Grimshaw 2003).

### Relevant references

National Health and Medical Research Council & Consumers' Health Forum of Australia, 2001, *Statement on consumer and community participation in health and medical research*, Commonwealth of Australia, Canberra.

National Health and Medical Research Council & Consumers' Health Forum of Australia, 2004a, *A model framework for consumer and community participation in health and medical research*, Commonwealth of Australia, Canberra.

National Health and Medical Research Council & Consumers' Health Forum of Australia, 2004b, *Resource pack for consumer and community participation in health and medical research*, Commonwealth of Australia, Canberra.

## Facilitating support groups and involving members

*(Source: Project consultations; Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Enhancing the work of existing cancer support groups. Service can promote other formal consumer and carer participation possibilities. Support group members can actively promote other formal consumer and carer participation strategies. Groups can be consulted about service improvement. Clinicians can enter into partnership with groups as expert advisers. Support groups can promote networking activities among themselves. Service providers can promote and support this networking activity.

### Relevant references

Cancer Voices Victoria [www.cancervoicesvic.org.au](http://www.cancervoicesvic.org.au)

Cancer Voices NSW [www.cancervoices.org.au](http://www.cancervoices.org.au)

The Cancer Council Victoria [www.cancervic.org.au](http://www.cancervic.org.au)

## Working with clinicians

*(Source: Project consultations)*

### Description

Actively engaging cancer clinicians in activities related to consumer and carer participation.

### Case study

#### **Breast Cancer Network Australia (BCNA)**

BCNA has developed the *My journey kit*—a comprehensive resource for Australians newly diagnosed with breast cancer. As a consumer-based organisation, BCNA developed the kit with input from hundreds of Australians affected by breast cancer. To ensure that health professionals would let women know about this important resource, BCNA consulted with relevant colleges about the kit and gained endorsement from seven colleges including the Royal Australasian College of Surgeons and the Medical Oncology Group of Australia.



## Networking

*(Source: Department of Public Health, Flinders University and the South Australian Community Health Research Unit 2000)*

### Description

Informal relationship building with people who have a common interest or goal. Will include links to consumer organisations, advocacy groups, etc.

### Case study

#### Western Health

The breast care nurse at Western Health approached the Breast Cancer Action Group (BCAG) following their peer review which had included the participation of a consumer representative, asking for ideas about how to set up their own reference group. BCAG requested that a member of the Breast Cancer Southern Health Reference Group attend the Western Health's strategic planning meeting. The member who attended was able to convey to the group, which included clinicians, how consumers can make a contribution and gave feedback about how her group had advocated to the hospital management for the retention of breast cancer nurses and for the lymphoedema clinic.

## References for Appendix 2

- Currie, K., Spink, J. and Rajedran, M., 2000, *Well-written information: a guide*, Communicating with Consumers Series, Department of Human Services, Melbourne.
- Department of Human Services, 2004, *Woman to Woman: A research report on the experience of rural women with breast cancer and implications for the provision of health services*, Women's Health Goulburn North East and Breast Services Enhancement Program, Department of Human Services, Melbourne.
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