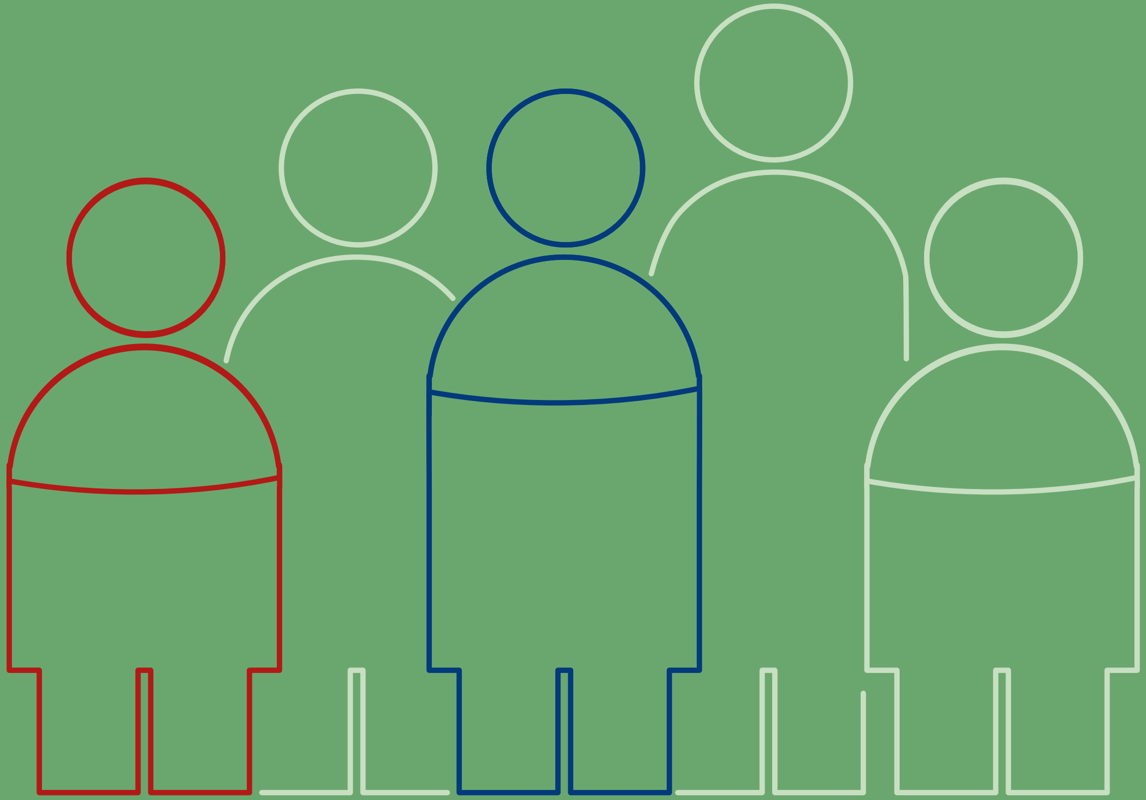
Victorian Integrated
Cancer Services

Consumer Participation Toolkit

Victorian Integrated Cancer Services
Consumer Participation Network

2012



CONTENTS

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- Barwon South West Regional Integrated Cancer Service
- Gippsland Regional Integrated Cancer Services
- Grampians Integrated Cancer Service
- Hume Region Integrated Cancer Services
- Loddon Mallee Integrated Cancer Services
- North East Melbourne Integrated Cancer Service
- Paediatric Integrated Cancer Service
- Southern Melbourne Integrated Cancer Service
- Western Central Melbourne Integrated Cancer Service

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CanNET

Cancer Service Networks
National Demonstration Program

Linking regional and metropolitan
cancer services for better
cancer outcomes

INTRODUCTION

This toolkit will assist Integrated Cancer Services (ICS) staff who have consumer participation as part of their work portfolio. It introduces consumer participation and provides resources to assist staff build a consumer role in cancer service development and improvement.

Background

In 2009 the Victorian Department of Health released its policy document on consumer participation, *Doing it with us not for us. Strategic direction 2010–13.*[1] This document built on the Department of Health's 2006 policy, Doing it with us not for us, and reinforced its position that 'participation in health is an essential principle of health development, clinical governance, community capacity building and the development of social capital'.[2] The 2010–2013 strategic direction targets the Victorian public health service system including acute, subacute, mental health, community health, and residential aged care facilities.

In May 2010, the Department of Health released a report following a review of consumer and carer participation in the ICS.[3] This report highlighted a number of recommendations to improve consumer participation and included sustained consumer and carer participation through the sharing of publications, resources, templates and learnings among ICS; linking with consumer advocacy organisations; undertaking regular needs analysis of consumer and carer training requirements; education for clinical staff to enhance awareness and acceptance of consumer and carer participation; and developing practical resources and tools to guide the engagement of consumers and carers in research.

To address these recommendations, and in collaboration with the CanNET Victoria project, the ICS established the ICS Consumer Participation Network.

The network has produced this guide based on our shared experience and desire to see consumers be meaningfully engaged in ICS work.

Definitions

The following definitions are derived from the Victorian Department of Health's policy statement "Doing it with us, not for us, Strategic direction 2010-2013"

Health consumers are users or potential users of health services. Included are family members/carers, and members of the broader community. The Health Issues Centre recommends that when planning consumer participation, the consumers engaged reflect the demographic constituency and come from a range of diverse backgrounds and experiences. This may involve women and men; people living with a disability or from culturally and linguistically diverse backgrounds; people from different socioeconomic status and social circumstances; and people with different sexual orientations, health and illness conditions.[4]

Participation occurs when consumers, carers and community members are meaningfully involved in decision making about health policy and planning, care and treatment, and the wellbeing of themselves and the community. It is about having your say, thinking about why you believe in your views, and listening to the views and ideas of others. In thus working together, decisions may include a range of perspectives.[5]

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[1] Department of Health Rural and Regional Health and Aged Care Services Division. *Doing it with us not for us. Strategic direction 2010–13*. Melbourne: Victorian Government Department of Health, 2009.

[2] Department of Human Services. *Doing it with us not for us: Participation in your health service system 2006–09.* Melbourne: Victorian Government Department of Human Services, 2006.

[3] Department of Health. *Consumer and carer participation in the Integrated Cancer Services*, Project report May 2010. Melbourne: Victorian Government Department of Health, 2010.

[4] Health Issues Centre. *Getting started: Involving consumers on committees.* Melbourne: Health Issues Centre, 2008. Available at: www.healthissuescentre.org.au/documents/items/2008/07/222372-upload-00001.pdf

[5] Victorian Government Department of Health, 2009, op. cit.

Key documents

A number of documents and policies guide ICS consumer participation activities. These should be available for staff and consumers involved in ICS committee activities.

Doing it with us not for us: Strategic direction 2010–13. Melbourne: Victorian Government Department of Health, 2009.

A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services. Melbourne: Victorian Government Department of Human Services, 2007.

Consumer participation guide. Canberra: Cancer Australia, 2009.

Consumer and carer participation in the Integrated Cancer Services: Project report. Melbourne: Victorian Government Department of Health, 2010.

Victoria's Cancer Action Plan 2008–2011. Melbourne: Victorian Government Department of Human Services, 2008.

National Framework for Consumer Involvement in Cancer Control. Cancer Australia and Cancer Voices Australia. Canberra: Cancer Australia, 2011.

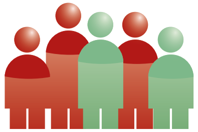
Local ICS consumer participation plans.

More resources

Consumer training and mentoring guide. Canberra: Cancer Australia, 2009.

Communicating with consumers. Series volume 1. Well-written health information – a guide. Melbourne: Department of Human Services, 2000.

RECRUITMENT



A number of strategies can be used to recruit consumers to the work of ICS. We recommend using a combination of approaches. This section also discusses access and equity and selection criteria.

Strategies

Recruitment strategies may include any or a combination of the following:

- Direct invitation to individuals
- Advertising in local papers for individuals to be involved on committees
- Participation in focus groups
- Invitations and presentations to community organisations such as cancer support groups (which may be contacted through the Cancer Council Victoria support group network), Probus clubs, Lions clubs, the Country Women's Association and local communities and/or organisations representing people from culturally and linguistically diverse backgrounds
- Contact with Health Service Community Advisory Committees
- Contact with consumer organisations such as Cancer Voices, the Health Issues Centre and the Breast Cancer Network of Australia (see box)
- Development and broad distribution of brochures to promote and invite consumer participation
- Promotion through ICS newsletters and websites

Consumers registered with the **Health Issues Centre Consumer Register** receive information regarding available positions on committees, consultations and focus groups. An e-newsletter provides information on consumer events and training opportunities, information about the Consumer Support and Development Network, consumer participation resources, and opportunities to comment on health, policy and service issues.

Cancer Voices Victoria is a state-based advocacy organisation. It aims to provide a unified, independent voice for all Victorians affected by cancer. It is an umbrella organisation for advocacy and support groups. Cancer patients, survivors, carers, medical providers, and any interested persons are welcome to be involved.

Breast Cancer Network Australia works to ensure that women diagnosed with breast cancer and their families receive the best information, treatment, care and support, no matter who they are or where they live. This is the peak national organisation for Australians affected by breast cancer.

Access and equity

Identify strategies to include traditionally hard to reach groups (people from Aboriginal and Torres Strait Islander backgrounds, from culturally and linguistically diverse backgrounds, from low socio-economic backgrounds and remote communities, and people with disabilities and mental health issues).

Consider how to include people at different stages in the cancer journey, including diagnosis, treatment, survivorship and palliative care.

To obtain representative and inclusive views, you may need to contact groups such as multicultural resource centres, Aboriginal controlled health organisations and community health centres.

Selection criteria

Each ICS will need to develop their consumer selection criteria and the process for engagement. It is important for new consumers to understand this process and the terms of their involvement.

Your selection criteria may change depending on the particular activity you are seeking consumers for. Consideration may need to be given to the time frame, location and demands of a particular role.

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For a sample of a pamphlet for recruiting consumers see Appendix 1.

WAYS CONSUMERS MAY PARTICIPATE IN ICS ACTIVITIES

Consumer participation can occur formally and informally and on various levels.

Key documents mentioned earlier provide excellent references to the ways that consumers may be involved in cancer control.

Ways that consumers have been successfully involved in ICS include:

- Consumer reference groups
- Strategic direction and policy development
- Consumer networks
  - Information dissemination
  - Capacity building
- Committee membership
  - ICS Governance Committees
  - Project steering committees
  - Tumour group committees
- Focus groups
- Attendance at conferences and education forums
- As educators: presentations, stories for advocacy and professional development for healthcare workers
- Surveys
- Peer support
- Volunteer opportunities
  - Cancer resource centres
  - Wellness centres

Examples within the ICS	
NEMICS/ SMICS/ GRICS	Consumer network newsletters distributed (CanNET VIC 1, SMICS, NEMICS and GRICS)
NEMICS	Consumer members of the NEMICS clinical reference group since 2006
GICS	Consumer needs analysis 2010, through consumer participation forums, case studies and questionnaires – 300 participants from across the region
Hume RICS	Consumer presented at Department of Health Participate in Health Conference 2009: My story matters
BSWRICS	Consumer presented a poster at the 2011 International Consumer's Reforming Health Conference: The next wave in community engagement in healthcare
LMICS	Development of Cancer Voices Victoria: Loddon Mallee Chapter 2011

See Appendix 2 for how to set up a consumer reference group and an example of terms of reference.

CONSUMER PARTICIPATION ORIENTATION

When an expression of interest is received, we recommend the person is contacted by a member of the organisation to clarify how they want to participate. Clarifying what their expectations are will guide how much and what type of information they need for orientation.

In some organisations consumers may need to be registered with the auspice agency as volunteers. This may require them to have police checks and attend volunteer orientation sessions. Some organisations may require consumers to sign confidentiality agreements.

Individuals who just wish to receive information about the activities of the ICS may only require basic information about the ICS and ongoing newsletters.

Consumers wishing to participate in ICS activities that require attendance at meetings and committees should receive appropriate information and background so that they are clear on expectations of their involvement. The following is a list of what they may require.

Background and ICS information

- Introduction (including establishment of the ICS and need for consumer participation)
- Victorian ICS distribution map
- Local ICS region and map
- Contact details for ICS secretariat staff
- Types of participation available
- List of useful consumer participation websites (Appendix 3)
- Vision and mission statements of the organisation
- Definitions
- Victoria’s Cancer Action Plan 2008–2011
- ICS Strategic Plan
- ICS Consumer Participation Plan
- ICS Supportive Care Strategic Plan
- Communication strategy
- Information about the specific role they are undertaking
- Information on self care (i.e. Cancer Australia Consumer Participation Guide)
- Local demographic and health service data
- Local cancer statistics
- Reimbursement information

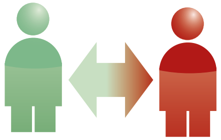
Meeting procedures

- Meeting schedule
- Terms of reference
- Teleconference etiquette (Appendix 4)
- Videoconferencing etiquette
- Permission to distribute contact details form
- Minutes/Agendas

Training available

- Advocacy training
- Leadership training
- Local ICS training/professional development opportunities
- Media

COMMUNICATION STRATEGIES

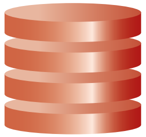


The purpose of a communication plan is to ensure that all stakeholders are provided with appropriate, up-to-date information. This will vary with the level of involvement with the ICS. There also needs to be a clear mechanism for feedback to the ICS.

A communication plan needs to:

- identify stakeholders
- define what it is you want to communicate to your consumers, i.e. what's on, participation opportunities
- define how information can be fed back from consumers to your organisation
- determine a range of strategies for effectively communicating with them
- encourage engagement of stakeholders and foster commitment
- develop user-friendly information sharing through access to information about the aims and specific projects being undertaken by your organisation
- promote the concept of cancer services improvement.

CONSUMER MANAGEMENT DATABASE



One method of managing your consumer network is through a database. This can be used to record each member's contact and diagnostic details, their skills and areas of interest, how they wish to participate and as a method of recording and keeping track to the types of participation opportunities each member contributes to.

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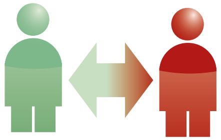
See Appendix 5 for a sample database to support management and communication for a consumer network.

SUPPORT



Once consumers have been recruited and their role clarified, consideration needs to be given to supporting them in their role. This support should include mentoring, training (see next section), having a designated contact person within the ICS for consumers, and practical aspects such as reimbursement.

Mentoring

Consider introducing new consumers to those who have already been involved in committees or other service improvement activities. Mentors are an invaluable way of helping new consumers learn about their role and what may be expected of them

Cancer Australia's 2009 *Consumer training and mentoring guide* describes mentoring as 'a process of mutual benefit where a more experienced person assists a less experienced person in their personal or professional development. The most common application of the mentoring process is when an experienced person helps a person new to their role adapt to the situation or helps a person prepare to take on a new role. It is built on a relationship of trust, sharing of knowledge and experience, communication and collaborative effort.'

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For further information on mentoring, refer to the Cancer Australia document *Consumer training and mentoring guide* **(see Key documents for details).**

Reimbursement

Each ICS will need to formalise its local policy on reimbursing consumers who are involved in the work of their ICS.

The Department of Health policy documents on consumer participation Doing it with us not for us: *Strategic direction 2010–2013 and A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services* (2007) provide some guidance for ICS in relation to reimbursing consumers for their expenses.

Accepted principles

A statement of local principles could include recognition of:

- the benefit of consumer input
- consumers not being out of pocket for attending agreed events such as meetings, functions or training
- reimbursement coming from an arrangement that is predetermined and pre-approved
- consumers having the option of opting out of local reimbursement arrangements
- consumers not being impeded in receiving reimbursement by onerous administrative procedures.

Areas to be considered for reimbursement

Each ICS will need to recognise the practices of their host organisation.

Reimbursement areas to consider could relate to a combination or all of the following:

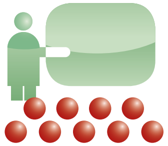
Sitting fee	A set dollar value for specific types of meetings, particularly where a consumer is involved in some form of governance role or specific task group.
Travel costs	Method of calculation or reimbursement may be made on a choice of methods, such as: • rate per kilometre travelled • provision of fuel vouchers • a set payment provided for people needing to travel • reimbursement on train or tram tickets • reimbursement of travel costs via ICS directly making travel bookings (significant travel only).
Other expenses	Consumers may have considerable other out of pocket expenses, which could include: • parking • meals • carer respite • child care • printing and materials costs (reimbursed costs or materials provided).
Other types of reimbursement	Gift vouchers may be provided in recognition of consumer contribution (this form of reimbursement may be useful as it does not affect any pension or income issues for the consumer).

Administration

The policies of the host organisation need to be considered. However, consumers should not be required to raise an invoice in order to receive reimbursement and simple claim forms should be available.

Where significant expenditure is required (e.g. interstate travel) it may be preferable, in consultation with the consumer, for these costs to be organised directly by the ICS.

TRAINING



A key enabler for meaningful consumer participation is the provision and uptake of training opportunities for consumers, health professionals and administrators.

Cancer Australia cites capable consumers as the second element in The National Framework for Consumer Involvement in Cancer Control.[6] It describes capable consumers as ‘those consumers who have developed knowledge from their experience and are able to represent the views of others’. These consumers need to have experience of cancer, motivation to improve outcomes for others, capability for the role they are in and an understanding of the context of their participation.

There is a ‘need for both formal and informal strategies to meet the diverse needs for training, education and learning for consumer participation’.[7] This requires a range of education and training opportunities that acknowledge the needs of adults as learners.

In the Health Issues Centre’s *Model of consumer recruitment and management December 2007*[8] a number of principles of training for formal activities are listed. These may be useful for other ICS. The model asserts that training should:

- be built on and value the personal and life experiences of the participant
- be delivered in a manner that is clear and accessible
- employ a range of training styles (information provision, small group activities, and large group activities)
- actively involve relevant consumers, carers, service providers and clinicians in delivering training
- provide relevant reading materials and resources
- be undertaken by facilitators who have expertise in consumer participation and facilitation skills
- be undertaken at accessible locations and at suitable times
- provide appropriate mechanisms to ensure feedback is obtained from participants.

Consideration needs to be given to the amount of time that consumer and health professionals have available for training. As consumers are participating in a voluntary capacity they often have other commitments and may be constrained at times by changes in their health status.

The tables on the following pages outline some of the training programs available. The training programs have been loosely categorised into where they may fit in terms of the participation levels described in the National Framework for Consumer Participation in Cancer Control.

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[6] Cancer Australia and Cancer Voices Australia. *National Framework for Consumer Involvement in Cancer Control*. Canberra: Cancer Australia, 2011.

[7] Consumer Focus Collaboration. *Education and training for consumer participation in health care: Resource guide and final report*. Canberra: Commonwealth Department of Health and Aged Care, 2000.

[8] Health Issues Centre. *Model of consumer recruitment and management*. Southern Melbourne Integrated Cancer Service, 2007.

Consumer participation education for consumers

NOTE: The training programs listed within each level are examples of what is available. Where the course has been placed does not imply that it is a requirement or that the training is only relevant to that level of consumer participation.

Informing	• CCV Living with Cancer Education Program • CCV Cancer Carer Forums • CCV When Cancer Won't Go Away • CCV Sexuality and Intimacy • Cancer Voices Victoria Advocacy Training
Consulting	• Cancer Voices Victoria • BCNA Community Liaison Training • CCV Group Facilitator Training • HIC Consumer Participation in Cancer Research Training Program
Involving	• BCNA Advocate Training Program • HIC Certificate in Consumer Leadership
Partnership	• Certificate IV in Business (Governance) • HIC Certificate in Consumer Leadership
Consumer-led	• Certificate IV in Business (Governance) • HIC Certificate in Consumer Leadership

Consumer participation education for health professionals

NOTE: The training programs listed within each level are examples of what is available. Where the course has been placed does not imply that it is a requirement or that the training is only relevant to that level of consumer participation.

Informing	• CCV Living with Cancer Education Program Facilitator Training • CCV VCCCP Training • CCV Sexuality and Intimacy Forums • Cultural Awareness Training • Cultural Communications Skills Training
Consulting	• CCV Living with Cancer Education Program Facilitator Training • CCV VCCCP Training • CCV Sexuality and Intimacy Forums • CCV Group Facilitator Training • Cultural Awareness Training • Cultural Communications Skills Training
Involving	• HIC Certificate in Consumer Engagement
Partnership	• HIC Certificate in Consumer Engagement
Consumer-led	• HIC Certificate in Consumer Engagement

Details of training courses for consumers

Organisation	Content	Target audience	Contact	Costs	Types and level of consumer participation applicable to:
Australian Institute of Community Practice & Governance	Certificate IV in Business (Governance) Practical, accredited, staff governance training	For members and supporters of Boards, Management Committees and Councils of Australian community groups and schools	03 9320 6805	Yes	• Consulting • Involving • Partnership • Consumer-led
Breast Cancer Network of Australia (BCNA)	Advocate Training Program: Seat at the Table Provides thorough understanding of BCNA, programs, priority areas and events; also helps you present your story to various audiences.	Consumers and carers	03 9805 2500 1800 500 258, Community Programs Team	No	• Informing • Consulting • Involving • Partnership • Consumer-led
	Community Liaison Training Program Community Liaisons are happy to share their experience of breast cancer. They can speak at fundraising events and other community activities. They provide an overview of the programs, information and support BCNA offers people affected by breast cancer	Women who have experienced breast cancer	03 9805 2500 1800 500 258, Community Programs Team	No	• Informing • Consulting • Involving
Cancer Voices Victoria (in collaboration with CCV)	Advocacy Training Program Provides the skills and knowledge required to become active and effective advocates for improvement to cancer policies and systems: consumer participation sharing experience patients and carer issues cancer awareness principles of advocacy understanding the cancer industry using your story as an advocacy tool.	Consumers and carers	enquiries@cancervoicesvic.org.au 03 9635 5069	Yes	• Informing • Consulting • Involving • Partnership • Consumer-led

Organisation	Content	Target audience	Contact	Costs	Types and level of consumer participation applicable to:
Cancer Council Victoria	Group Facilitator Training Seminar These include 1-day seminars about facilitation as well as information seminars. A guide to setting up a cancer support group is also available.	People who facilitate cancer support groups	9635 5000 13 11 20	No	• Informing • Consulting • Involving
	Living with Cancer Education Program Run by trained health professionals, provides the chance to learn more about cancer, its treatment and their emotional reactions to it.	People with cancer, their friends and family	13 11 20 cis@cancervic.org.au	No	• Informing
	Cancer Carer Forums Provide an opportunity to share experiences with others and receive the latest information and support. Cover: • caring for yourself • effects on relationships • when the carer has cancer • information and support.	Family and friends caring for someone with cancer	13 11 20 cis@cancervic.org.au	No	• Informing • Consulting
	When Cancer Won't Go Away Provide the chance to speak with others in similar situations	People with advanced cancer, and their friends and families	13 11 20	No	• Informing • Consulting
	Life after Cancer Forums Provide an opportunity to share experiences with others and receive the latest information and support	People who have finished cancer treatment and their family and friends	13 11 20	No	• Informing • Consulting

Organisation	Content	Target audience	Contact	Costs	Types and level of consumer participation applicable to:
Health Issues Centre (HIC) Note: Some of HIC's programs have prerequisites for people participating	Certificate level course in Consumer Leadership Programs can be run at a central location or as a customised learning program • Engage as a consumer in health care services • Promote consumer engagement • Provide consumer leadership May be offered at a central location but can also be customised and run at a location convenient for the group arranging the program.	Consumers and carers	03 9479 5827 www.healthissuescentre.org.au	Yes	• Informing • Consulting • Involving • Partnership • Consumer-led
	Consumer Participation in Cancer Research Training program to support consumers to be involved in cancer research as members of the research team	Consumers and carers	www.healthissuescentre.org.au	Yes	• Informing • Consulting • Involving • Partnership • Consumer-led

Details of training courses for health professionals

Organisation	Content	Target audience	Contact details	Costs	Types and level of consumer participation applicable to:
Health Issues Centre Note: Some of these programs have prerequisites for people participating	Training includes: A vocational graduate level course in ‘Consumer Engagement’ Work within a consumer engagement framework Support consumer engagement planning Support the implementation of consumer engagement Develop and implement consumer engagement strategies Research skills courses are offered during the year May be offered at a central location but can also be customised and run at a location convenient for the group arranging the program.	Health professionals	03 9479 5827 www.healthissuescentre.org.au	Yes	• Informing • Consulting • Involving • Partnership • Consumer-led
Centre for Cultural Diversity & Aging	Cultural Awareness Training	Health professionals	(03) 88237900 0418 353 752 www.culturaldiversity.com.au	Yes, sometimes	• Informing • Consulting • Involving
	Cultural Communication Skills Training	Health professionals	(03) 88237900 0418353752 www.culturaldiversity.com.au	Yes, sometimes	• Informing • Consulting • Involving
Widders Consultancy	Aboriginal Cultural Awareness Training	Health professionals	(02) 6772 0204 0448 655 113 dwidders@dodo.com.au	Yes	• Informing • Consulting • Involving

Organisation	Content	Target audience	Contact details	Costs	Types and level of consumer participation applicable to:
Cancer Council Victoria	Victorian Cancer Clinicians Communication Program Provides cancer clinicians with evidence-based communication skills through training Delivered in the workplace by VCCCP facilitators to a maximum of 10 participants	Health professionals	13 11 20	Yes	• Informing
	GP Education A range of workshops for GPs and practice nurses	GPs/ Practice nurses	13 11 20	Yes	• Informing
	BreastHealth	Health and community workers new to breast health	13 11 20 BreastHealth@cancervic.org.au	Yes	• Informing
	Cancer Prevention for Health Professionals Working in Mental Health	Mental health professionals and community workers who want to update their skills and knowledge about cancer prevention and early detection strategies	13 11 20 cis@cancervic.org.au	Yes	• Informing
	Men's cancers Aimed at prevention and early detection strategies Gives participants the skills and knowledge required to present men's cancer education to individuals and groups of men	Health and community workers who want to update their skills and knowledge about men's cancer	13 11 20 cis@cancervic.org.au	Yes	• Informing
	Living with Cancer Facilitator Training Program Covers group facilitation skills, adult learning techniques, marketing skills, and orients participants to the facilitators' manual and DVD. The course provides a chance to network with other professionals who are program providers as well as Cancer Council staff.	Health professionals, including oncology nurses, social workers, occupational therapists, pastoral care workers, radiotherapists and other allied health professionals who wish to be facilitators	13 11 20 cis@cancervic.org.au	Yes	• Informing • Consulting
	Sexuality and Cancer Workshops Learn how to support patients through this difficult territory		13 11 20 cis@cancervic.org.au	Yes	• Informing • Consulting

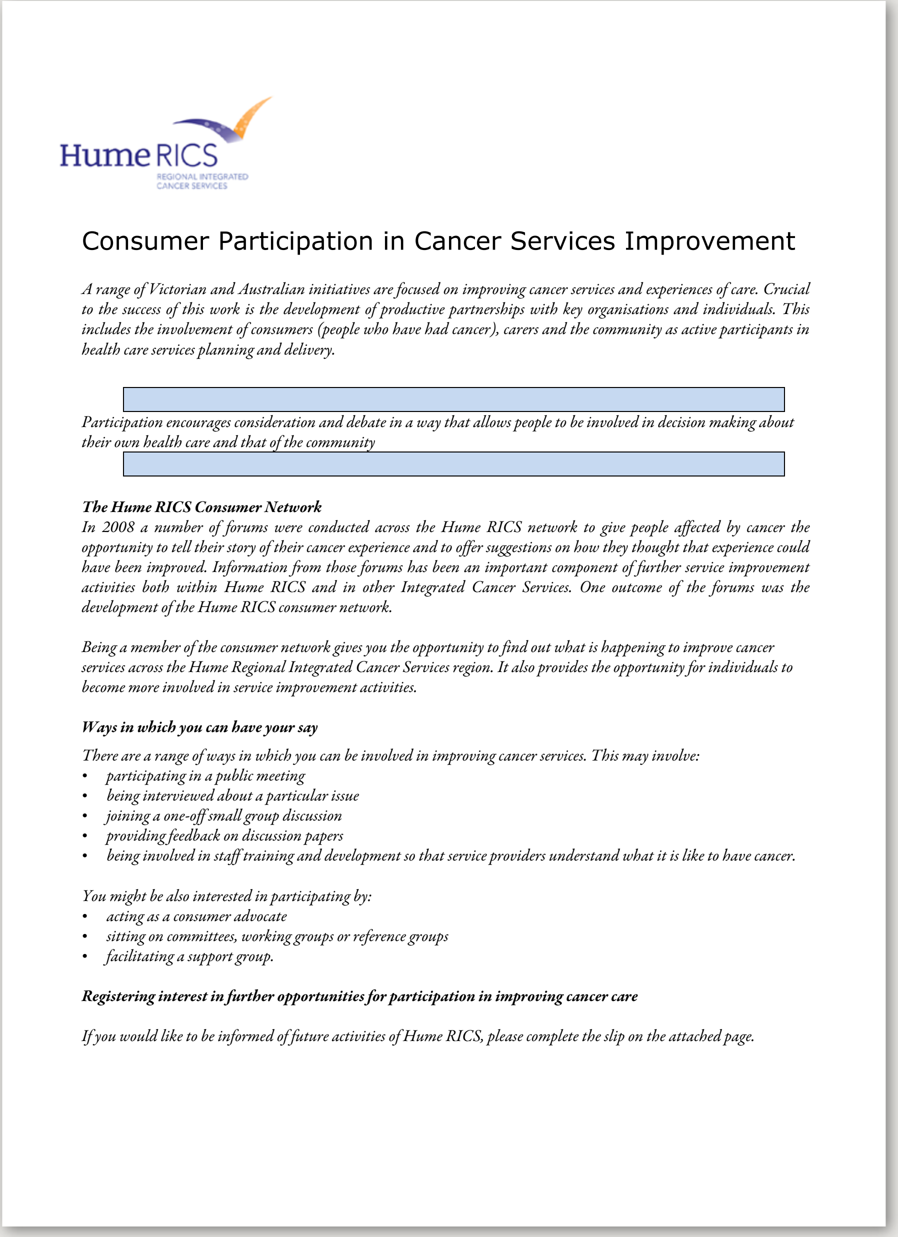
EVALUATION

At the time of printing this toolkit does not include a section about the evaluation of consumer participation.

It is acknowledged that evaluation of any program is an important component. The VICS Consumer Participation Network Group will be considering what elements an evaluation plan for consumer participation activities should include in work during 2012.

APPENDICES

Appendix 1: Sample of pamphlet for recruiting consumers



Hume RICS
REGIONAL INTEGRATED CANCER SERVICES

Consumer Participation in Cancer Services Improvement

A range of Victorian and Australian initiatives are focused on improving cancer services and experiences of care. Crucial to the success of this work is the development of productive partnerships with key organisations and individuals. This includes the involvement of consumers (people who have had cancer), carers and the community as active participants in health care services planning and delivery.

Participation encourages consideration and debate in a way that allows people to be involved in decision making about their own health care and that of the community

The Hume RICS Consumer Network

In 2008 a number of forums were conducted across the Hume RICS network to give people affected by cancer the opportunity to tell their story of their cancer experience and to offer suggestions on how they thought that experience could have been improved. Information from those forums has been an important component of further service improvement activities both within Hume RICS and in other Integrated Cancer Services. One outcome of the forums was the development of the Hume RICS consumer network.

Being a member of the consumer network gives you the opportunity to find out what is happening to improve cancer services across the Hume Regional Integrated Cancer Services region. It also provides the opportunity for individuals to become more involved in service improvement activities.

Ways in which you can have your say

There are a range of ways in which you can be involved in improving cancer services. This may involve:

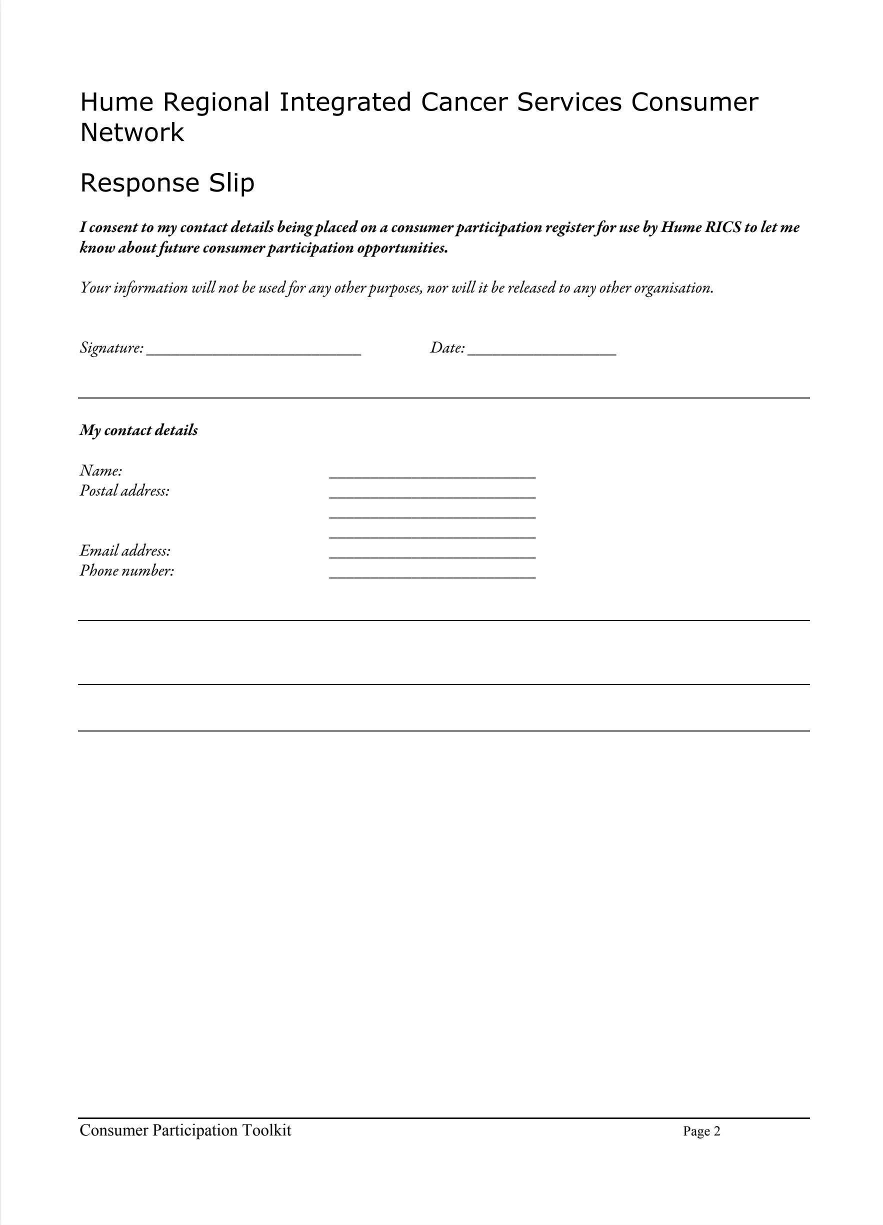
- *participating in a public meeting*
- *being interviewed about a particular issue*
- *joining a one-off small group discussion*
- *providing feedback on discussion papers*
- *being involved in staff training and development so that service providers understand what it is like to have cancer.*

You might be also interested in participating by:

- *acting as a consumer advocate*
- *sitting on committees, working groups or reference groups*
- *facilitating a support group.*

Registering interest in further opportunities for participation in improving cancer care

If you would like to be informed of future activities of Hume RICS, please complete the slip on the attached page.



Hume Regional Integrated Cancer Services Consumer Network

Response Slip

I consent to my contact details being placed on a consumer participation register for use by Hume RICS to let me know about future consumer participation opportunities.

Your information will not be used for any other purposes, nor will it be released to any other organisation.

Signature: ________________________ *Date:* ________________

My contact details

Name: ________________________
Postal address: ________________________
____
____
Email address: ________________________
Phone number: ________________________

Consumer Participation Toolkit Page 2

Appendix 2: Setting up a consumer reference group

Not all Integrated Cancer Services will establish a Consumer Reference Group (CRG). This will depend on the needs of each individual ICS and the readiness and skills of their consumers to form such a group.

If you are establishing a group, you will need to consider:

- The Department of Health policy documents on consumer participation: *Doing it with us not for us: Strategic direction 2010–13 and A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services* (2007). These documents identify the types of participation and the principles and methods for achieving them. These should inform the development of your CRG to guide the way in which consumers contribute to cancer service improvement within the region.
- What is the function this group will undertake and how does this fit into the structure of your ICS?
- What are the reporting and communication lines between the CRG, the Directorate/Secretariat and its governance groups?
- What is the meeting schedule for the group and how does this support the communication lines?
- What resources do the ICS have to support the group (e.g. staff time to undertake the administrative tasks associated with running such a group)?
- What skills do group members already possess and what do they need to develop in order to effectively participate in the group and advocate for service improvement?

Developing terms of reference document for the consumer reference group

The following headings are recommendations only for consideration when developing terms of reference. They can be modified or added to depending on your individual ICS requirements.

Background

Provide background to the ICS, benefits and policy background to consumer participation in health service improvement.

Objectives/role/purpose

Establish the purpose of the group and how it will contribute to service improvement initiatives. You can also include how the CRG will receive and provide information.

Key performance indicators

Membership

Consider:

- who will be a member of the CRG (e.g. selected members of the available consumers and how they will be selected)
- number of members
- term of membership
- whether it will be an open or closed group.

What is the role of the ICS staff attending the meetings?

Chair

Consider:

- who will chair the group
- whether they will be an elected consumer, how they will be elected and for how long
- whether the chair will be an employee of the ICS. What would be the implications of this?

Meeting schedule

Consider:

- whether you need a quorum for the meeting to occur and what constitutes a quorum
- when / how often will meetings be held (consider lines of communication when scheduling this)
- where will they be held and what time.

Consider how often the terms of reference needs to be reviewed and add this to the document.

Appendix 3: Useful websites

Australian Cancer Survivorship Centre www.petermac.org/cancersurvivorship/Home

Australian Commission on Safety and Quality in Healthcare www.safetyandquality.gov.au

Australian Government australia.gov.au

Cancer Australia www.canceraustralia.gov.au

Cancer Council Victoria www.cancervic.org.au

Cancer Voices Australia www.cancervoicesaustralia.org.au

Cancer Voices Victoria www.cancervoicesvic.org.au

Centre for Health Communication and Participation www.latrobe.edu.au/chcp

Consumers Health Forum of Australia www.chf.org.au

Health Issues Centre www.healthissuescentre.org.au

MacMillan Cancer Support Learn Zone learnzone.macmillan.org.uk/course/view.php?id=265

TargetMyCancer Jargon Buster www.targetmycancer.com.au/jargon.html#a

Victorian Government www.vic.gov.au

Appendix 4: Teleconference etiquette

If you are chairing a teleconference meeting:

- **Be prepared** – set the teleconference call up in advance, and start the meeting on time.
- **Introductions** – state the names of everyone present at the table, and then ask each attendee teleconferencing to state their name.
- **Audibility** – make sure everyone can hear.
- **Etiquette** – remind everyone of teleconference etiquette.
- **Latecomers** – introduce anyone who arrives late.
- **Conversations** – during the meeting, encourage anyone who starts to speak to say their name before they begin, and ensure there is only one conversation at a time.

If you are teleconferencing in to a meeting:

- **Be prepared** – have your meeting documentation and phone numbers ready, and be on time.
- **Phone** – use a landline wherever possible. If the landline has a second line or call waiting, please disable it or silence it first. If you must use a mobile phone, please ensure it is charged.
- **Noise** – reduce the amount of noise around you by finding a quiet place to call from, closing doors, turning off other devices.
- **Interruptions and distractions** – avoid sitting at your computer while involved in a teleconference, put a sign up on your closed door, and switch off other phones.
- **Conversations** – when you wish to speak, state your name first, and use the Chair as the ‘traffic police’ if necessary. Ensure there is only one conversation at a time.
- **Agenda** – adhere to the agenda.

If you are present at a meeting where others are teleconferencing in:

- **Be prepared** – have your meeting documentation and phone numbers ready, and be on time.
- **Noise** – get yourself organised in your seat before the meeting starts, so that you are not shuffling paper during the meeting. If you do need to move about, do it very quietly as everything is amplified to those teleconferencing in. Remove watches, bangles or other items that will be noisy against the table.
- **Mobile phones** – turn your mobile phone off. If it must be left on, turn it to silent and leave it in your pocket or bag, as far away from the teleconference equipment as possible. The electrical noise created from even a silent mobile phone ringing can be extremely loud to those teleconferencing in.
- **Microphones** – feel free to check whether those teleconferencing in can hear you. At the same time it’s important to make sure you don’t yell into the microphones. Be very conscious of extendable microphones on the table, as these will pick up any extraneous noise. Use the mute button on the extendable microphones if necessary.
- **Conversations** – when you wish to speak, state your name first, and use the Chair as the ‘traffic police’ if necessary. Ensure there is only one conversation at a time. Also remember that you are talking to those in the room and those teleconferencing.
- **Agenda** – adhere to the agenda.

Appendix 5: Consumer networks – sample database details

Demographic information

- Date of enquiry
- Name
- Address
- Phone
  - (H)
  - (W)
  - (M)
- Email
- How would you prefer we contact you?
  - home phone
  - mobile
  - email
  - letter/post
- Where did you hear about us?
  - newspaper
  - poster
  - website
  - brochure
  - word of mouth

Cancer experience / area of interest

- Which types of cancer are you most interested in?
  - breast
  - head and neck
  - colorectal
  - lung
  - genito-urinary (including prostate and testicular)
  - neurological
  - gynaecological
  - skin
  - haematological (including lymphoma, myeloma, leukaemia)
  - upper gastro-intestinal (including pancreas, stomach and oesophagus)
  - all types
  - other cancer related issues (e.g. palliative care, supportive care, research)
- Interest
  - join registry to comment on documents, etc.
  - steering/working group (or specific project/s)
  - other