



Partnering with Consumers: A Toolkit

For Victorian Integrated Cancer Services

2018



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This toolkit was initially developed in 2012 as part of the Cancer Service Networks National Program, (CanNET). It has been updated in August 2018 by consumer representatives and staff of the Victorian Integrated Cancer Services, to assist with planning and implementing consumer engagement initiatives.

INTRODUCTION



This toolkit has been developed to assist Integrated Cancer Services (ICS) in their consumer engagement initiatives.

POLICY CONTEXT

Across the Victorian public health service system, there is now a strong emphasis on partnering with consumers across most health policy documents.

Health 2040: Advancing health, access and care identifies partnering with patients as a key outcome with the government and healthcare services harnessing the perspective and experience of patients, to provide input into how the health system is designed and managed. A range of policies provides the framework for consumer engagement across integrated cancer services: The Department of Health and Human Services: Public Participation Framework²: (2018) and *Doing it with us not for us. Strategic direction 2010–13*.¹ Safer Care Victoria is developing a partnering in healthcare framework to strengthen person and family centred healthcare and improve the healthcare experience and outcomes for Victorians. A core component of this is supporting and improving consumer participation in Victorian hospitals and health services.

Within the cancer sphere, engaging consumers has been a key principle for a number of years. The *National Framework for Consumer Involvement in Cancer Control* was developed by Cancer Australia in partnership with Cancer Voices Australia in 2011 to enhance meaningful consumer involvement at all levels of cancer control to improve outcomes and experiences for people affected by cancer. More recently, the *Victorian Cancer Plan 2016–2020* outlines activities for improving patients' experience of treatment and care, aligned with a service system shift to person centred care.

From a quality assurance perspective, The National Safety and Quality Health Service Standards now include a specific standard on partnering with consumers. This standard describes the systems and strategies to create a person-centred health system by including consumers in shared decision making, to ensure that they are partners in their own care and are involved in the development and design of quality health care.

DEFINITIONS

The following definitions are derived from the Victorian Department of Health and Human Services 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. When planning consumer participation, the consumers engaged should 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 working together, decisions may include a range of perspectives.⁵

Co design: is about engaging consumers and users of products and services in the design process, with the idea that this will ultimately lead to improvements and innovation.

¹ *Health 2040: Advancing health, access and care. State of Victoria, Department of Health and Human Services (2016)*

² *Public Participation Framework: Department of Health and Human Services (2018)*

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.

Discussion Paper: Evaluation of Doing it with us not for us KPMG (2014)
<https://www2.health.vic.gov.au/about/participation-and-communication/consumer-participation/summative-evaluation-of-participation-policy>

Victorian Cancer Action Plan: Improving cancer outcomes for all Victorians 2016-2020. Melbourne: Victorian Government Department of Health and Human Services, 2016.

Public Participation Framework: Department of Health and Human Services (2018)

Stakeholder Engagement Toolkit: Department of Health and Human Services (2018)

Australian Charter of Healthcare Rights:
<https://www2.health.vic.gov.au/about/participation-and-communication/australian-charter-healthcare-rights/about-the-charter>

National Safety and Quality Health Service Standards <http://nationalstandards.safetyandquality.gov.au/>. Standard 2: Partnering with Consumers recognizes the importance of involving consumers as partners in planning, design, delivery, measurement and evaluation of systems and services as well as involving patients in their own care to the extent they choose.

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

Safer Care Victoria (2018) Partnering in healthcare framework:describes a co-design approach to developing a healthcare framework for consumer participation <https://bettersafercare.vic.gov.au/our-work/patient-participation-and-engagement/partnering-in-healthcare-framework>

USEFUL RESOURCES

A toolkit for Consumer Participation and Engagement Paediatric Integrated Cancer Services (2013): www.pics.org.au

Updated tools to support consumer engagement developed by the Health Issues Centre with the Victorian health system in mind
<http://www.healthissuescentre.org.au/health-services/consumer-engagement-guide>

Consumer Involvement toolkit developed by Cancer Australia (2009)
<https://consumerinvolvement.canceraustralia.gov.au/>

VMIA (2017). have produced a number of resources to support health services in building a culture of listening, particularly in improving governance of health services. <https://www.vmia.vic.gov.au/risk/risk-tools/patient-voice>

Scottish Health Council (2014) developed a Public Participation Toolkit aimed at supporting NHS staff to involve patients, carers and members of the public in their own care and in the design and delivery of local services. It offers a number of tried and tested tools along with some more recently developed approaches http://www.scottishhealthcouncil.org/patient_public_participation/participation_toolkit/the_participation_toolkit.aspx

Facilitation guide for participant experience focus groups (2016)
https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0006/333861/Participant-experience-focus-group-guide.pdf

RECRUITMENT



Before recruitment begins, it is important to be clear about the purpose of the consumer engagement and the type of consumer/s required?

This can be achieved by describing:

- The activity and tasks the consumer/s will be involved in.
- The skills, experience and interests required of consumers.
- The time commitment that consumers will be required to give. This can include the meeting time, reading time and research time. It will also include whether the engagement is short-term, project based or ongoing.

It is also important to clarify what level of involvement the consumer is seeking to ensure their needs are compatible with the needs of the project/activity

STRATEGIES

Once the purpose is clear, a recruitment plan can be developed that may include a position description and any or a combination of the following strategies:

- The need to target certain hard to reach groups (if any), including people from Aboriginal and Torres Strait Islander backgrounds, culturally and linguistically diverse backgrounds, low socio-economic backgrounds, remote communities etc.
- Ask ICS staff members, clinicians, nurses, health care staff and/or the health service consumer liaison departments to recommend consumers.
- Ask consumers already engaged to recommend someone they know.
- Ask consumers from advisory groups within member hospitals.
- Ask members of cancer support groups.
- Advertise in local papers, Health Issues Centre (HIC) consumer advertising and health service newsletters.
- Promotion via presentations to community organisations such as multicultural resource centres, Aboriginal controlled health organisations, Probus clubs, neighborhood houses, libraries and community health centres.
- Ask consumer organisations such as Cancer Action Victoria, the Health Issues Centre and peak cancer advocacy groups such as the Breast Cancer Network of Australia, Prostate Cancer Foundation of Australia.
- Advertise via volunteering websites such as www.govolunteer.com.au, www.volunteer.com.au, www.ethicaljobs.com.au, www.volunteer.vic.gov.au
- Liaise with Cancer Council Victoria and consider their links with consumers via cancer support groups and their Cancer Connect program.
- Promote through ICS newsletters, websites, projects, presentations, forums and the ambassador program.
- Pamphlets/brochures/flyers promoting and inviting consumer partnership (Appendix 1).

To obtain representative and inclusive views, you may need to contact groups such as multicultural resource centres, Aboriginal controlled health organisations. For more information about inclusive stakeholder engagement, refer to the Public Participation Framework developed by the Department of Health and Human Services (2018)

SELECTION CRITERIA

The selection criteria will vary dependent on the particular activity/engagement level for which the consumer is being recruited.

For example, the selection criteria for a one-off focus group may require that the consumer has a relevant lived experience. Conversely, the selection criteria to become a member of a consumer advisory group may require the consumer to fill in an application form, have an interview, a police check and become a registered volunteer.

If an interview is required, it is important to consider the processes that would be required – who will conduct the interview, what questions will be asked and how consumers will be formally notified if an appointment is to be made.

The selection criteria and process should be outlined in the recruitment plan.

BECOMING A REGISTERED VOLUNTEER

Many of the ICS are part of a host health service that has an existing volunteer program. The volunteer programs may suggest consumers engaged with the ICS to also be formally registered with their program.

The advantages of formally registering consumers with the host site volunteer program is to ensure the appropriate insurance indemnity will be maintained to compensate consumers if they sustain an injury while engaged in duties or while travelling between their place of residence and the place where the consumer engagement activity takes place.

In addition, other benefits may include access to hospital staff programs such as the employee assistance program, car park access, professional development opportunities, the vaccination program, access to the hospital IT system and staff recognition programs.

Being registered with a volunteer program can include any or all of the following:

- Completion of a health and capacity form.
- Statement of consent to process a police check.
- Referee checks.
- Completion of a statement of understanding and confidentiality.
- Details registered on a database.
- Completion of volunteer training, covering policies and procedures, values and diversity, fire and emergency management, Occupational Health and Safety (OHS).
- Completion of a working with children check.
- Undertaking an induction session.
- Identification badge issued.

WAYS OF ENGAGING WITH CONSUMERS



People affected by cancer and the broader community are increasingly seeking to be active participants in decision-making about their health.

Evidence suggests that involving consumers leads to improved health outcomes, a more trusted health system and a more satisfied workforce.

Consumer engagement refers to the wide range of strategies in which consumers can be involved, from being involved in their own health care, to planning and developing health policies, service planning, contributing to research and clinical trials, project implementation and evaluation. It is a broad term to cover the range of activities used by governments, organisations and individuals to involve consumers in activities of service improvement.

Consumer engagement can occur formally and informally and it should be made available at various levels and employing diverse approaches, to accommodate the experiences, availability and preferences of different consumers. The skills and support needs of individual consumers will also vary according to the type of consumer engagement required.

The National Framework for Consumer Involvement in Cancer Control supports effective engagement of consumers at all levels of cancer control, similar to the International Association for Public Participation (IAP2)'s spectrum of engagement:

- **Inform**
- **Consult**
- **Involve**
- **Collaborate**
- **Consumer led**

Examples of ICS activities that consumers have been successfully engaged in, include involvement in the following:

- consumer reference groups.
- strategic direction and policy development.
- consumer networks.
- committee and steering group membership.
- providing the consumer perspective on issues raised and advocating for the concerns of those affected by cancer.
- focus groups.
- attendance at conferences and education forums.
- as educators – providing presentations/stories for educational tools for other consumers or healthcare staff.
- survey development and survey completion.
- peer support.
- identifying issues and priorities that would improve cancer services
- reviewing and assessing grant applications.
- leading the development of/ reviewing and contributing to development of documents and other resources.
- promotion of resources and projects.
- presenting at forums.
- contributing written articles for newsletters and annual reports .
- planning developing and assisting in the implementation of consumer projects.

LEVELS OF INVOLVEMENT	EXAMPLES
<p>Informing</p> <p>Consumers involved at this level will provide information, seek feedback, build awareness and improve health literacy about cancer care. This will be achieved by asking questions, seeking information and also receiving and providing information.</p>	<p>Provision of information to such engaged consumers can be facilitated via ICS newsletters, annual reports, Health Issues Centre news, updates from Cancer Australia as well as provision of information regarding education-related opportunities such as Living with Cancer forums, invitations to attend forums or cancer conferences.</p>
<p>Consulting</p> <p>Consumers engaging at this level will seek information and provide feedback and this may occur via periodic involvement in surveys, focus groups and consultative workshops</p>	<p>This could include reviewing written materials, assessing the readability and plain language used in surveys or pamphlets. Other examples could include engagement of consumers in information gathering or exchange opportunities such as focus groups and workshops.</p>
<p>Involving</p> <p>Consumers engaging at this level will work directly with stakeholders to ensure that concerns are consistently understood and considered.</p>	<p>Engagement with health care professionals in determining directions for improvement such as being included in co-design events or as a panel member with health professionals reviewing service improvement grant applications.</p>
<p>Partnership</p> <p>Consumers engaging at this level work alongside health professionals, administrators, researchers and policy makers and on working parties, reference groups and steering committees.</p>	<p>Committees, projects, working parties and other collaborations engage consumers from the planning stage through to evaluation and monitoring. Such groups typically have Terms of Reference that outline the purpose of the group or committee, the specific role of members and when, where and for how long the group will meet. Such examples include an ICS consumer reference group.</p>
<p>Consumer led</p> <p>Consumers engaging at this level work equally with health professionals, administrators, researchers and policy makers and are fully integrated on boards, working parties and steering committees.</p>	<p>Appoint consumer to a leadership role on a working group to help shape strategies.</p>
<p>Consumer-led</p> <p>At this level the consumers set priorities such as policy and strategic directions and lead major activities.</p>	<p>Consumers identify the initiative, lead and steer the project and hold overall control and responsibility of the project direction and outcomes.</p>
<p>Further resources:</p> <p>Tips on involving culturally and linguistically diverse consumers (CALD) can be found via contact with the Centre for Culture, Ethnicity and Health. This organisation aims to improve the health and well being of people from refugee and migrant backgrounds and do this by working with health and community services, to help improve the way they engage with people from CALD backgrounds. https://www.ceh.org.au/consumer-participation-strategies</p>	<p>Engagement with Indigenous communities:</p> <p>Refer to Korin Korin Balit-Djak and the Aboriginal governance and accountability framework on the Department of Health website.</p> <p>Contact Aboriginal Health and Wellbeing branch of the Department of Health and Humans Services for further advice on Aboriginal self determination and engaging with Aboriginal people and communities.</p>

COMMUNICATION CONSIDERATIONS



When partnering with consumers for any ICS-related activities, it is good practice to consider the communication preferences of the consumer from the outset.

It is important to consider the communication preferences both in relation to information flow to and from the consumer.

As most consumers are volunteering in their own time and have other commitments, it is important to allow consumers sufficient time to manage the communication requests for any ICS related activities/ meetings that they may be engaged in.

It is also important to provide prompt and timely responses to consumers and their requests for information.

Below is a list of considerations for all forms of consumer-related communication:

- Determine how and/or in what format consumers prefer to receive information – *phone, email, post or a combination.*
- Determine what sort of communication the consumers are interested in receiving from your ICS – for example *only related to particular cancer types, from certain health services.*
- Consider if the consumer has any limitations on when and/or how often they would like to receive information.
- Ensure that introductions are always made when consumers are participating in project/ committee meetings so that everyone is aware that consumers are present and also so that consumers are aware of the background/discipline of other participating members.

In relation to face to face meetings, this may be facilitated by the use of place cards on the table so that all members know the names/roles and relevant health service links.

- Facilitate meetings to take place so consumers have options to participate in person or remotely.
- If engaging with consumers remotely via web or phone based options, ensure that consumers are provided with clear instructions on how to manage the technology, including how to ensure their contributions are made and heard. It is also important that the staff facilitating the meeting remembers to connect and engage with consumers linked remotely.
- Ensure that sufficient notice is provided to consumers in relation to invitation to meetings.
- Ensure that the provision of written materials for consumers to either read and/or provide feedback on prior to meetings are given in a timely manner and with sufficient preparation time for consumers to read, digest and feedback. This is especially relevant for higher level committees, where there may be a larger quantity of more complex papers to review.
- Such considerations and timelines should be further specified in the Terms of Reference of the relevant committee or working party.
- When seeking feedback from consumers on written materials, provide consumers with a point of contact for them to clarify any queries and a timeline by when the feedback is required.
- Ensure the use of clear, concise plain language for any written and verbal communication.
- Avoid jargon, abbreviations/acronyms or explain on first use.
- Consider the use of a workspace platform to share and house consumer-related documents and which allows for the provision of a chat /discussion platform.

- It is important for consumers to have opportunities to communicate with ICS managers and senior ICS staff and to be kept regularly updated on projects and activities occurring in and beyond their ICS.
- Ensure that staff engaging with consumers are suitably skilled in their communication skills and how to involve consumers in the activities of the ICS.
- Consumers should be provided with terms of reference for any formal committees/projects they are being asked to be involved with, that outline their required commitment/role/meeting details and how and when they will receive any meeting related papers.
- Ensure consumers are provided the opportunity to be briefed pre and post meetings as required and that any grievances are handled at the time and/or escalated as required.
- It is important that consumers are kept engaged, consulted and communicated with throughout the term of their involvement on a project or committee and as such during the initiation or development of a project, the implementation period and at the time of evaluation or conclusion of the committee/project.
- Have a nominated ICS program staff member available to provide support to the consumer/s for any written or verbal communication that the consumer/s may be asked to prepare or deliver related to ICS work – this may include presenting at a forum, workshop or preparing an article or summary of thoughts ahead of a meeting.
- Formal and informal opportunities should be facilitated for consumers to raise their suggestions for service improvement and share their views and concerns.
- There should also be opportunities for consumers engaged with ICS across the state to come together to share ideas and views and learn from each other.
- It is always important to remind consumers that they have a choice and that they do not have to participate if they are not interested, available or feeling well enough.

CONSUMER RECORD MANAGEMENT



ICS that maintain a consumer network should adopt a secure method to safely record, maintain and update the details of the consumers engaged in their work.

A database can be used to record each members contact details, their cancer experience, skills and areas of interest, how they wish to participate and this also provides a means by which they can maintain a record of the types of projects/activities members are engaged in.

Consumers should be informed how their personal details will be maintained and used. Their consent for maintaining such details should also be obtained. All consumer information should be locked securely as agreed.

Below is a list of the useful details that a consumer management database could include:

Contact details

- Name, home address, phone numbers, preferred method of contact.
- Gender, age group, ATSI/CALD, languages spoken.
- NOK – name, contact number and relationship to the consumer.
- Emergency contact - name, contact number and relationship to the consumer.
- Employment status.

Availability

- Preferred days/times of engagement.

Participation log

- Record of the consumer's involvement on specific groups/projects/committees.
- Dates and types of engagement.
- Last contact date.

Recruitment details

- How, when and by whom the consumer was recruited.
- When they commenced engagement.
- Reasons for participating.
- Areas of cancer and cancer service improvement are they interested?
- Preferred level of engagement.
- Agreement to being contacted by health services in the ICS region/beyond.

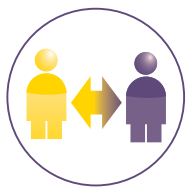
Cancer experience

- Self-experienced/ carer/ family member.
- Cancer type.
- Year of diagnosis.
- Treatment status – undergoing treatment, completed treatment, no treatment, palliative, unknown.
- Treatment type/s.
- Location of care and cancer treatment.
- Other health issues – including sensory/mobility impacts that may need consideration during involvement in meetings.

Consumer engagement experience

- Any previous consumer engagement/advocacy experience.
- Involvement on other consumer groups, research groups and/or support groups.
- Previous experience on committees, working with people/projects.
- Other relevant skills.

SUPPORT



Once consumers have been recruited, consideration needs to be given to supporting them in their role. This support should include orientation, mentoring, training (see next section), and reward/reimbursement.

ORIENTATION

It is recommended that consumers with an established ongoing role within the ICS receive a formal orientation.

This can include any or a combination of the following:

- Orientation of the ICS office, member health partners, the directorate staff and other consumer members.
- Familiarization with the cancer program and services within the local area.
- The terms of reference of the relevant group/project committee.
- The reimbursement policy and relevant forms.
- The local ICS strategic plan.
- Victorian ICS vision, mission and strategic goals.
- Victorian cancer plan and key priority areas.
- Current ICS projects/activities.
- The opportunity to attend committees and working groups - initially as an observer.
- If involved in a specific project, introductions to key project members may be appropriate. If the location of a meeting is hard to find, provide assistance with maps or providing an escort on the first attendance.
- Information pack including all or a combination of optimal care pathway materials, terminology sheet and contact names & numbers, annual report, newsletters.

If consumers are registered with the host agency volunteer program, they may also receive an induction/orientation with the host health service.

MENTORING

Mentors are an invaluable way of helping new consumers learn about their role and what is expected of them. Consider introducing new consumers to those who have already been involved in committees or other service improvement activities to provide a peer to peer explanation of the project, the expected requirements and the consumer engagement approach.

REIMBURSEMENT

Each ICS will formalise its own local reward and reimbursement policy, which can include:

- A position statement on payments to consumers.
- A clear process for administering payments to consumers.
- A schedule of payments for consumers undertaking various roles within the organization.
- An approved budget for making payments to consumers.

AREAS TO BE CONSIDERED FOR REIMBURSEMENT

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

As an acknowledgment of the consumer's engagement, time and the value of their contribution, it is recommended offering some or all of the following:

Sitting fee	A set dollar value for specific types of meetings
Travel costs	The method of calculating travel costs must be defined in the reimbursement policy. Options include: <ul style="list-style-type: none"> • rate per kilometer travelled • provision of fuel or Cab Charge vouchers • a set payment • reimbursement based on the cost of public transport use on train or tram tickets • provision of car parking facilities • 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: <ul style="list-style-type: none"> • parking • meals • carer respite • child care • printing and materials costs (reimbursed costs or materials provided).
Other types of reimbursement	<ul style="list-style-type: none"> • Provision of gift vouchers • Paid registration fees for attendance at professional development opportunities • Thank you lunches

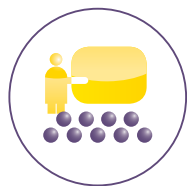
In addition, the following is regarded as good practice:

- The reimbursement process is explained to the consumer prior to their engagement
- The consumer is provided the option to receive their reimbursement for travel expenses prior to attending the meeting or activity
- The consumer is provided the option to donate their payment to their favourite charity
- The consumer should not be required to raise an invoice in order to receive reimbursement and simple claim forms should be available
- Prompt payment

For more information regarding reimbursement, please refer to the Health Issues Centre website:

<http://healthissuescentre.org.au/images/uploads/hic-publications/Paying-and-reimbursing-consumers-position-statement.pdf>

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.

The provision of 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, online learning including webinars).
- 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 consumers 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. It is therefore important to regularly review the capacity of consumers to participate in training.

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 Involvement in Cancer Control: ie informing, consulting, involving, partnership and consumer-led participation.

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.

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	Diploma of Business (Governance) Australia's only currently approved diploma-level governance qualification. Gain the knowledge and skills required to sit on or work with boards at the highest level.	For members and supporters of Boards, Management Committees and Councils of Australian community groups and schools.	03 9320 6800 service@ourcommunity.com.au website: https://www.communitydirectors.com.au/icda/courses/	Yes	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Informing • Consulting • Involving • Partnership • Consumer-led
	Community Liaison Training Program Community Liaisons are happy to share their personal 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	<ul style="list-style-type: none"> • Informing • Consulting • Involving
Cancer Action Victoria (in collaboration with CCV)	Consumer Advocacy Training Program Provides the skills and knowledge required to become active and effective advocates for improvement to cancer policies and systems: <ul style="list-style-type: none"> • Understanding diversity and your community • Health literacy • Governance • Consumer participation • Sharing experience • Patients and carer issues • Cancer awareness • Principles of advocacy • Understanding the cancer 	Consumers and carers.	admin@canceractionvic.org.au 03 95146100	Yes	<ul style="list-style-type: none"> • 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	13 11 20 csg@cancervic.org.au	No	<ul style="list-style-type: none"> • 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 askanurse@cancervic.org.au	No	<ul style="list-style-type: none"> • Informing
	Cancer Carer Forums Provide an opportunity to share experiences with others and receive the latest information and support. Cover: <ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Informing • Consulting
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 <ul style="list-style-type: none"> • Engage as a consumer in health care services • Promote consumer engagement • Provide consumer leadership 	Consumers and carers	03 8676 9050 http://www.healthissuescentre.org.au/training-events/consumer-training/	Yes	<ul style="list-style-type: none"> • 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	03 8676 9050 info@healthissuescentre.org.au or: Dr Tere Dawson t.dawson@healthissuescentre.org.au	Yes	<ul style="list-style-type: none"> • Informing • Consulting • Involving • Partnership • Consumer-led

DETAILS OF TRAINING COURSES FOR HEALTH PROFESSIONALS

Organisation	Content	Target audience	Contact	Costs	Types and level of consumer participation applicable to:
Health Issues Centre Note: Some of these programs have prerequisites for people participating	Graduate Certificate in Consumer and Community Engagement Course in Consumer Leadership		www.healthissuescentre.org.au info@healthissuescentre.org.au or: Dr Tere Dawson 03 8676 9057 t.dawson@healthissuescentre.org.au	Yes	<ul style="list-style-type: none"> • Informing • Consulting • Involving • Partnership • Consumer-led
Centre for Culture, Ethnicity and Health	Consumer Participation and Culturally Diverse Communities	Health professionals	039418 9929 https://www.ceh.org.au	Yes	<ul style="list-style-type: none"> • Informing • Consulting • Involving
Widders Consultancy	Aboriginal Cultural Awareness Training	Health professionals	(02) 6772 0204 0448 655 113 (preferred) dwidders@gmail.com	Yes	<ul style="list-style-type: none"> • Informing • Consulting • Involving
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 vccp@cancervic.org.au	Yes	<ul style="list-style-type: none"> • Informing
	GP Education Cancer Council National GP Portal: provides access to the most up-to-date, evidence based cancer information and resources	GPs/ Practice nurses	http://gp.cancer.org.au	Yes	<ul style="list-style-type: none"> • Informing
	Facilitator Training Program (to deliver Living with Cancer Education Program and Wellness and Life After Cancer Program) Covers group facilitation and presentation skills, adult learning techniques, program planning, promotion and recruitment strategies, access to facilitators manual and program resources	Health professionals, including oncology nurses, social workers, occupational therapists, pastoral care workers, radiotherapists and other allied health professionals who wish to be facilitators	cep@cancervic.org.au	Yes	<ul style="list-style-type: none"> • Informing • Consulting • Involving

EVALUATION

Evaluation is essential to determining whether consumer engagement activities are meaningful and effective. Formal evaluation allows ICS to reflect upon the strengths and weaknesses of their engagement approaches, identify areas for improvement, and enhance the evidence base for partnering with consumers.

As outlined in the toolkit for Consumer Participation and Engagement Paediatric Integrated Cancer Services (2013), evaluation can be undertaken using a variety of approaches and tools. The type of tool used will depend on your evaluation aims. Evaluation methods may include:

- Story telling – sharing the narratives of an experience.
- Focus group discussions.
- Face to face and telephone interviews.
- Self completed questionnaires.
- Observation (for example whether people are satisfied, happy, quiet, frustrated, whether they attend, speak during meetings, do not come back, cultural groups involved/not involved).
- Document analysis (eg meeting minutes).
- Informal feedback (eg comments about how consumers experienced a meeting, feedback on how things are run, suggestions for improvement).

Reference: K.Hider and D.Farjou, Guide to supporting consumer participation in evaluation, Centre for Clinical Excellence, Monash Health (2011)

http://www.monashhealth.org/images/CCE_Website/CCE_Resources/Evaluation/Consumer_participation_in_evaluation_PIE_guide_and_matrix.pdf



APPENDICES

APPENDIX 1: SETTING UP A CONSUMER ADVISORY GROUP

Not all Integrated Cancer Services will establish a Consumer Advisory Group (CAG). 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 and Human Services 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 CAG, 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 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 CAG will receive and provide information.

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 2: USEFUL WEBSITES

Australian Cancer Survivorship Centre	www.petermac.org/services/support-services/australian-cancer-survivorship-centre
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
Cancer Action Victoria	www.canceractionvic.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
Victorian Government	www.vic.gov.au

APPENDIX 3: 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 ask the Chair to talk 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 ask the Chair to talk 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.