



Australian Government
Cancer Australia



Tools for consumers

Are you new to
consumer involvement?



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Tools for consumers: I am new to this

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I am new to this:

How can I make a difference?

The involvement of consumers in cancer services in Australia over the past few decades has already had a significant impact on all aspects of cancer control. But there is far more work to be done and involved consumers are usually in short supply!

Because consumers bring a unique view to health services and organisations, there is potential for you to contribute immediately. Whether you are involved in a committee, attend consultations, help design a research study or fill in a survey, you will be making a contribution to the planning and evaluation of services.

You will join a vibrant consumer movement in Australia and will receive support from other consumers and the organisations that need your expertise and experience. [Read about how consumers make a difference to one health professional](#)

Are there any benefits for me?

Many consumers get involved in health services or health organisations as a way of 'giving back' to those who have helped them. Others do it to improve services. Still others may get involved because of a negative experience that they don't want to see repeated with anybody else. There can be enormous satisfaction in making a difference to something very important like quality health care.

While you should be reimbursed for any out-of-pocket expenses, most of your work as an involved consumer in health care will be voluntary. Getting involved is also unlikely to mean immediate changes in your own or your family's health care, though hopefully there will be noticeable improvements for everyone in the medium to long term.

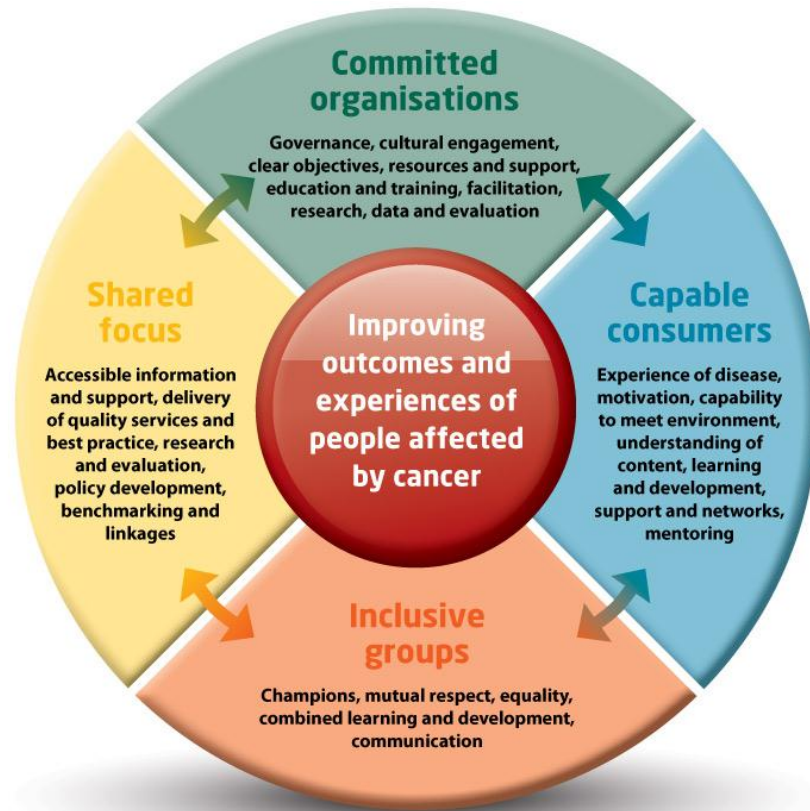
Read about the benefits from another consumer

'It's been very valuable to me as an individual, even just through my own cancer experience because I've been much better informed... And I think for me it offered a sense of individual power over my disease. It's also provided me with a really challenging, stimulating environment. And it's brought up a whole lot of stuff in me that I didn't know I had: the ability to carry an argument, the ability to speak strongly and to be a respected voice, and to be able to influence an agenda. Just from that personal perspective it's been extremely challenging, stimulating and rewarding for me.'

—Lyn Swinburne, consumer, Founding CEO Breast Cancer Network Australia

What are the elements of the Framework?

The *National Framework for Consumer Involvement in Cancer Control* (the Framework) identifies the four key elements essential for effective consumer involvement in all levels of cancer control.



[Understanding the Framework](#)

How will the Framework help me?

The Framework is a consistent and well-researched pathway, a means to developing lasting partnerships with consumers. As a new consumer, it may help you to understand the 'big picture'—the overall aim of consumer involvement—and the approach that your organisation is taking.

Key Framework questions:

- Is your organisation **committed** and ready to work with consumers?
- [What is a committed organisation?](#)
- [Committed organisations checklist](#)
- Does your organisation have **capable consumers**? Are **you** a capable consumer?
- [What knowledge, skills and experience do consumers need to be capable?](#)
- [Are you a capable consumer?](#)
- [Capable consumer checklist](#)
- Does your organisation work in **inclusive groups**?
- [Developing inclusive groups](#)
- [Inclusive group checklist](#)
- What is the **shared focus** of your organisation's consumer engagement program?
- [What is our shared focus?](#)
- [Shared focus checklist](#)

Read the [full Framework document here](#)

Make a start

For some consumers it can be challenging to attend meetings, read long documents, provide regular feedback or commit time on an ongoing basis to work on serious issues if they (or their family member) are not well. Your health service or organisation understands this, but believes that your contribution is still of value, even when you cannot contribute consistently. Make sure you let people know if you cannot fulfil an expectation, and they can brief you about what you missed when you are feeling better.

If you have to travel long distances, pay for petrol, public transport, or parking, speak to your health service or organisation for support. You should not be out-of-pocket because of your involvement.

For some committees or groups there may be significant pre-reading prior to meetings. Health care and research are full of long documents! If you're finding this overwhelming, speak to the staff who invited you to get involved to find a solution.

According to [one experienced consumer](#) one of the challenges of involvement is knowing when to speak up, and when to remain quiet on issues of great importance. Developing a clear sense of who you represent can make this easier.

Health care is an area with great complexity and, as a result, change doesn't generally happen overnight. Consumers can find the pace of change to be a challenge and often have to reorder their thinking to take a 'long view' of influencing the system.

What are the different ways that I might be involved?

The options for being involved as a consumer include an enormous range of activities. Consumers can participate in surveys and focus groups or consultations. Other participation activities include consumer representation on committees (from ethics committees to patient safety committees), involvement in organisational strategic planning and many aspects of quality improvement.

Some of the main ways that consumers are involved with health organisations and services are:

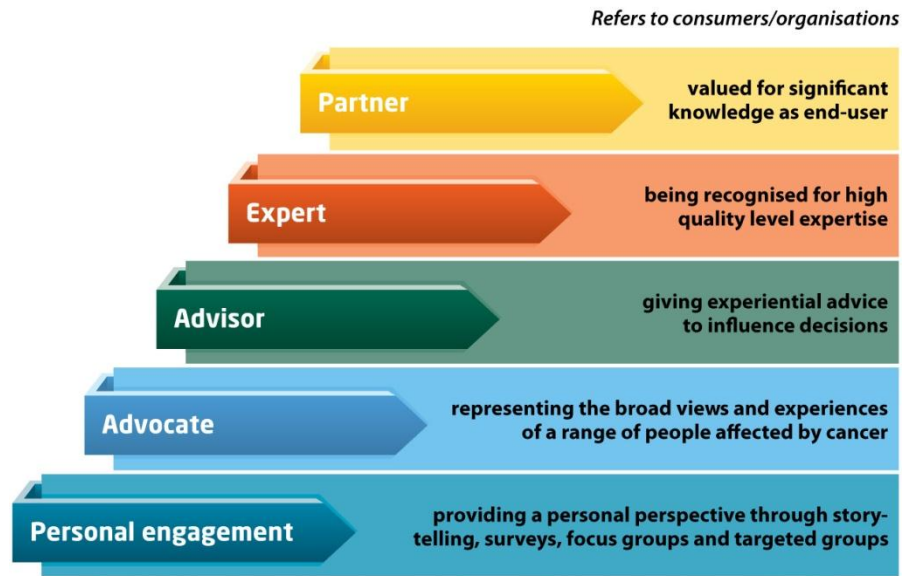
- service planning
- improving patient care throughout the cancer pathway
- education and information
- service measurement and evaluation
- participation in the research cycle
- policy development
- priority setting.

The way you are involved will depend on several things:

- your knowledge, skills and experience
- your interest and availability
- your organisation's consumer involvement plan and level of engagement
- current consumer openings at your organisation.

What roles are there for consumers?

Types of consumer involvement



See examples of types of consumer involvement from health professionals experienced in involving consumers:

- [Partner](#)
- [Expert](#)
- [Advisor](#)
- [Advocate](#)
- [Personal engagement](#)

What knowledge, skills and experience are most useful as a consumer?

'As a consumer representative, it's important to move from the 'I' to the 'we'. You have to be speaking on behalf of other people.'

—Nicola Bruce, consumer researcher

- [Consumer knowledge, skills and experience \(for consumers\)](#)
- [Are you a capable consumer?](#)
- [Storytelling tips for consumers](#)
- [Tips for consumers working on committees](#)

What knowledge, skills and experience do I currently have?

You have lots of knowledge and experience based on your own lived situation as a person affected by cancer, either because you are affected directly or because you look after someone affected by cancer.

This experience has put you in touch with cancer services and clinicians and you have accumulated knowledge about how the health services are delivered, and how people like you access these services.

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You may have had some of the following experiences (as a consumer or carer) and be able to offer comment and advise on quality improvement related to them:

- diagnosis with cancer
- in-patient experience (receiving treatment, chemotherapy or radiotherapy; having surgery)
- involvement in a clinical trial or other research project
- supportive care, follow up care and survivorship
- palliative care and the process of end-of-life decisions.

It is this personal journey from diagnosis through to survivorship or to end-of-life that consumers contribute when they are asked to provide views as an advocate or an advisor to a health service or committee.

If you are considering working with your health service, you may find it helpful to take a few minutes to consider your skills and motivation using this [consumer self-assessment tool](#) and [personal stocktake](#).

How do I further develop the knowledge, skills and experience for these roles?

There are several things that you can do to improve your knowledge and skills. For example, you can attend:

- consumer representative training
- leadership training
- effective storytelling workshops
- science and specific health background training for advocacy
- conferences, and possibly co-author journal articles with staff members.

You may also wish to:

- gain better knowledge of the Australian health system
- set-up regular briefings and debriefings before and after meetings
- seek mentoring programs (where consumers mentor other consumers)
- learn about and commit to self-care strategies.

Information and training for consumers is available. Cancer Australia, the Cancer Council in your state, other cancer organisations and the consumer peak bodies will be able to direct you to many training and education opportunities. Click [here](#) for a list of cancer and consumer organisations.

As an involved consumer, what can I expect?

You can expect to be considered part of the team, to have your views listened to and taken into account. You will be respected for the knowledge, skills and experience you contribute, but you will not be expected to be knowledgeable across all areas of discussion in a meeting or project. As any other member of the team would be fully informed, you will also be kept up-to-date about any relevant practical information regarding meetings or changes (time, date and location) and can expect to receive reasonable lead-time on any pre-reading. You can also expect to have a support person or mentor from within the organisation available for briefings before and after meetings, if necessary. Here is a list of some of these [practical expectations for consumer involvement](#).

The health service or organisation that you are working with will have a series of policies developed for working with consumers. These are particularly important for those consumers working at the levels of partner, expert and advisor. Take a look at some of the [policies](#)



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you can expect from your organisation.

What about inclusive groups?

The delivery of health services occurs in groups or teams and thus consumers will be engaged in steering groups, working groups or multidisciplinary teams involving a diverse range of health professionals. Inclusive groups and teams understand the value of each member and the contribution each member makes to achieve the goal. Inclusive groups are led by champions who value the voice and expertise of the consumer experience.

Read the following case studies where health professionals discuss inclusive groups.

[Inclusive groups](#)

[Developing inclusive groups](#)

[Inclusive groups checklist](#)

What is a shared focus?

Shared focus is the element most commonly at risk of being overlooked. Yet when shared focus is included this leads to mutually agreed goals with consumers and health professionals supported by systems working together to act for mutual benefit.

Building knowledge and best practice together and implementing evaluation strategies for continuous improvement draws all four elements together in a process that integrates and completes the consumer engagement cycle.

[What is a shared focus](#)

[Shared focus checklist](#)

'We have consumers at pretty much every table when we're doing anything involved in strategy for cancer in South Australia. The Cancer Clinical Network is a strategic committee providing advice to the health department. It's composed of external advisors. There are consumer members of the Cancer Clinical Network Steering Committee and they have the same rights and responsibilities as any other member on the committee, but they are there because of their consumer expertise.'

Historically over the last 5 or so years, it's become imperative to always include consumers on everything we do in health care. We have been learning over that period how to work with consumers and how to engage consumers effectively and how to make the most of their contribution...'

—Dorothy Keefe, Clinical Director, Royal Adelaide Hospital Cancer Centre

How can I talk to other consumers with more experience?

'Peer support is one the most important aspects of any part of consumer perspective. Peer support comes through interacting with other people...You don't become an expert overnight. People need to be prepared to work at learning and finding a mentor and being with others who might be a little more experienced and be willing to listen and learn.'

—Leonie Young, consumer, Chair CanSpeak Queensland

It is important that you are able to connect with more experienced consumers. You may wish to speak with consumers specifically within the cancer sector. There are experienced consumers throughout the sector and consumer organisations, cancer councils and charitable organisations around Australia have a list of groups and organisations where you can make these connections.

Sage advice from an experienced consumer...

'You get much farther by building relationships than you ever do by militancy. You can always achieve more from the inside than from the outside, provided you don't forget your purpose....But you really can't act solo, without links to the community. You won't have the ability to represent what matters to consumers.'

—Ian Roos, consumer, Interim Chair CanSpeak Australia

Evaluation

Quality care and safe practice and service delivery is a precondition to improving health outcomes. Good safe practice is dependent on effective systems and process, implemented by organisations and health professionals delivering best practice standards of care. Quality care and safe practice relies on people affected by cancer being properly informed so they can make decisions, as well as being encouraged to ask questions and to share their experience for common learning.

Developing a consumer engagement program requires ongoing evaluation. Monitor your progress by conducting regular review. These tools below can assist.

Activity [audit](#)

[evaluation of consumer involvement guide](#)

[organisational self-assessment survey](#)

[accreditation and consumer involvement standard -responsibilities](#)

Consumer resources

Mental Health Council of Australia 1998, **The Kit: A guide to the advocacy we choose to do.** A Resource Kit for Consumers of Mental Health Services and Family Carers, 1st edn, Commonwealth Department of Health and Family Services. pp. 13 – 16
<http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-k-kit>



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Consumers' Health Forum of Australia 1999, **Guidelines for consumer representatives**, 4th edn, Consumer's Health Forum of Australia, Canberra, viewed 14 Jan 2008,
<http://www.healthissuescentre.org.au/documents/items/2008/08/22/6516-upload-00001.pdf>

Adelaide Central Community Health Service 2003, **The little purple book of community rep-ing. Not just a token rep Project**, 3rd edn, Adelaide Central Community Health, Adelaide, viewed 15 Jan 2008,
<http://www.healthissuescentre.org.au/documents/items/2008/08/22/6726-upload-00001.pdf>

Health Issues Centre. 2005. Getting involved. A kit for consumers interested in joining the consumer nominee program.
<http://www.healthissuescentre.org.au/documents/items/2008/07/22/0176-upload-00001.pdf>

Health Issues Centre. 2006. Making space for the consumer voice in quality and safety. A resource guide for community advisory committees in public health services.
<http://www.healthissuescentre.org.au/documents/items/2008/04/20/4794-upload-00001.pdf>

Health Issues Centre. 2008. Getting started. Involving consumers on committees.
<http://www.healthissuescentre.org.au/documents/items/2008/07/22/2372-upload-00001.pdf>