



Australian Government
Cancer Australia



Tools for consumers
Are you an experienced
consumer in cancer control?



Contents

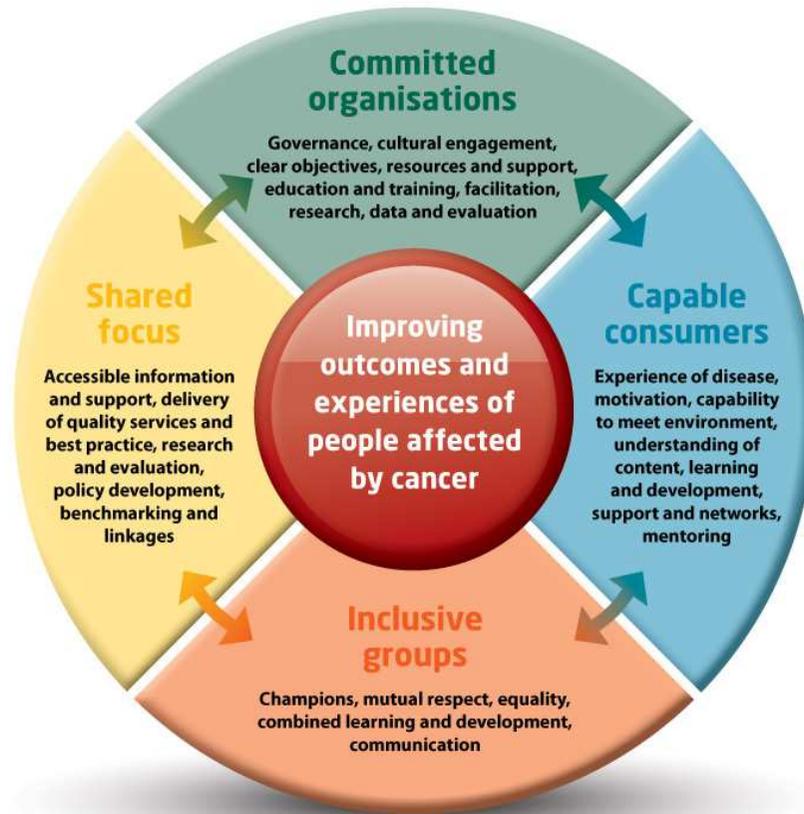
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Tools for consumers: I have some experience

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I have some experience:

What are the elements of the Framework?



[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 an experienced 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

How will the Framework change my involvement as a consumer?

By offering support and a clear pathway to consumer involvement for organisations and consumers, the Framework will improve your experience. As the Framework provides ideas and examples of how others have worked with consumers, this may be inspiration for new ideas and avenues of involvement both for you and your organisation.

What one consumer organisation thinks of the Framework

'I think the Framework and the whole project that Cancer Australia has led is really important because it provides guidelines for people on how to do it. Because the guidelines are being developed and people are thinking about it, then the next step is that people start learning how to engage with consumers and so it's not the big unknown that it always seems to have been.

It's actually a well-defined process. The role of the consumer representative is well defined. When consumers are recruited into an organisation for a particular role and go through an induction process, they understand what is expected of them and what is not expected of them. So it really helps to define the process and manage the expectations.

Because part of the fear, I think – and there has been some fear associated with consumer representation – is because it hasn't been well understood what the role of the consumer representative is.

I think the whole Framework process and the development of the toolkit is really helping to clarify that for everybody.'

—Anna Williamson, General Manager Research and Advocacy, The Leukaemia Foundation

Although I have experience, remind me of the 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 levels of participation 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 services are:

- service planning
- improving patient care throughout the cancer pathway
- education and information
- service measurement and evaluation
- research
- policy development.

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The way you have been involved, and will be in the future, depends 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 the types of consumer involvement from experienced professionals:

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

Remind me what I can reasonably expect from my health service or organisation?

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 hopefully 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](#) you can expect from your organisation.

What knowledge, skills and experience are 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?

As you know, your experience of cancer has put you in touch with cancer services and clinicians through which you have accumulated some knowledge about how the health services are delivered, and how people like you access these services. You may have had some of the following experiences (as a consumer or carer), and be able to offer comment and advice 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
- palliative care and the process of end-of-life decisions.

It is this personal journey from diagnosis 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.

Although you may already be working (or have worked) with your health service, you may still find it useful to take a few minutes to consider your skills and motivation using this [consumer self-assessment tool](#) and [personal stocktake](#)

How do I develop the knowledge, skills and experience that I need?

Although you may have done some of these things in the past, you might want to brush up on some skills or consider getting more advanced training in some of these areas. For example, you can attend:

- advocacy 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.

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Information and training for consumers is available from a number of organisations. 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. Also, below there is a list of good resources you can read to help you with your engagement work.

'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

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

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

Evaluate

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>

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>



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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>

