



**Australian Government**  
**Cancer Australia**



# Tools for researchers



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# Take the lead - researchers

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## Why should I involve consumers in research?

Evidence shows that where consumers are involved in the design of research and data collection tools—such as surveys or questionnaires—the tools are better received by the participants. There is also [evidence](#) that involving consumers is helpful in improving the dissemination of research findings to the community.

For example, involving consumers in setting research agendas or identifying research priorities places consumer needs at the centre of cancer research.

Involving consumers in research:

- ensures that issues important to consumers are identified and prioritised
- supports the dissemination of research results
- helps to translate research findings into clinical practice and implemented within health service delivery
- protects against money and resources being wasted on research that has little or no benefit or impact for consumers.

[Why involve consumers?](#) [LINK TBA: LINK TO INTERNAL WEBPAGE]

If those aren't enough reasons, listen to the thoughts of [these experts](#).

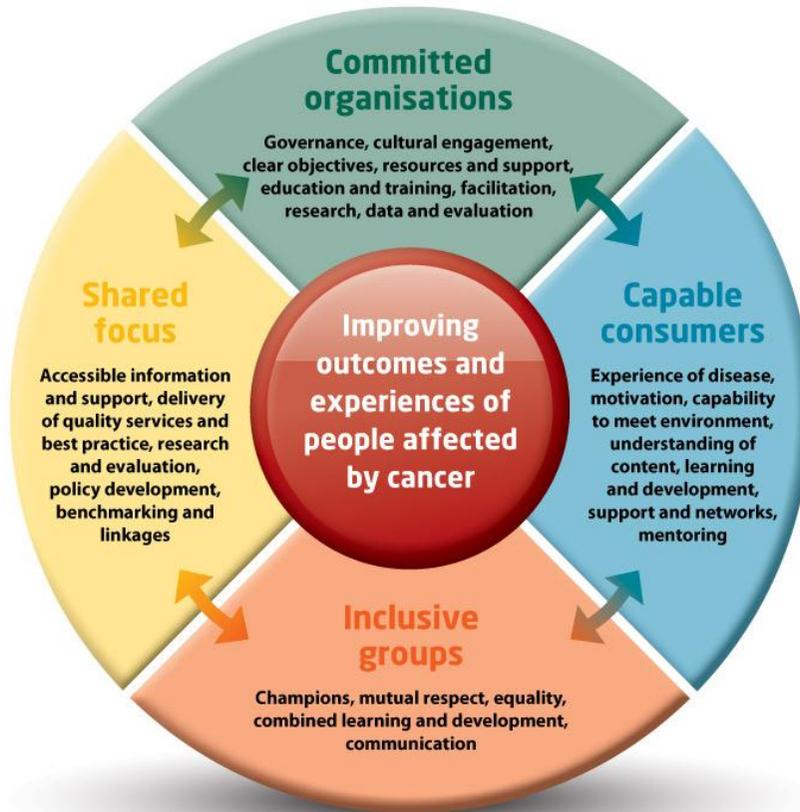
## I involve consumers as participants in my research—isn't that enough?

Most of the literature about consumer involvement in research establishes that consumer engagement is NOT about recruiting patients or members of the public as participants in research or randomised control trials.

Involving consumers is about engaging them in the:

- design of the research agendas
- identification of research priorities
- design of research tools
- undertaking of interviews
- dissemination of results.

## What are the elements of the Framework?



[Understanding the Framework](#)

## How does the Framework help me with consumer involvement in research?

Before moving forward, think about how the Framework will apply to your situation. The Framework is a consistent and well-researched pathway, a means to developing lasting partnerships with consumers. As a researcher, it should help you answer the question: 'HOW do I engage consumers in our research?' The Framework can help to get you started on the right track and keep you there.

### Key Framework questions:

- Do we have a **committed organisation** which is ready to work with consumers?
- [What is a committed organisation?](#)
- [Committed organisations checklist](#)
- Do we have **capable consumers**?
- [What knowledge, skills and experience do consumers need to be capable?](#)
- [Capable consumer checklist](#)
- Do we have **inclusive groups**?
- [Developing inclusive groups](#)
- [Inclusive group checklist](#)
- What will be the **shared focus** of our consumer engagement program?
- [What is our shared focus?](#)
- [Shared focus checklist](#)

## Make a start

- Ask yourself: why do I want to engage consumers in my research?
- Identify the type of consumers who will make a contribution to your research team.
- Make sure you have the systems and structures in place to engage consumers in your team.
- See more about recruiting, selecting and supporting consumers in Recruitment and selection guide: [consumer recruitment process guide](#)
- A couple of documents may help as you begin or progress your work with consumers: [Principles and indicators of successful consumer involvement in research: A guide](#) and [the checklist for researchers](#).

## Ways to involve consumers

### Do consumers want to participate in research?

*'Consumers felt that they were best able to comment on the relevance of the research to their experience and their perceptions of the importance of that research....They [consumers] felt that they had an important role to play in commenting on the relevance and the involvement of consumers in the whole research process, and the plans to disseminate results to consumers and influence practice.'*

—Phyllis Butow, Chair, Psycho-Oncology Co-operative Research Group

## What ways can we involve consumers in our organisation?

*'Organisations need to be clear what they want from a consumer and spell out exactly what the consumer's role is. There has to be a complete alignment between what is expected and what can be delivered.'*

—David Sandoe, consumer, Chair Prostate Cancer Foundation of Australia

[See consumer involvement model](#)

## How have other researchers involved consumers in their work?

- designing research methodologies
- interviewing other consumers
- reviewing draft questionnaires
- participating in pilot stages
- dissemination of research findings
- consumer organisations consulted about research priorities

[Areas for consumer involvement in research](#)

[Read about how other researchers are involving consumers](#)

and about [Cancer Australia's innovative approach to training consumers for involvement in research](#)

## What knowledge, skills and experience do consumers need to be involved in research?

The answer to this question will depend on the purpose of the organisation or activity and the roles expected of consumers. The following tools will assist in matching consumer skills to organisational goals.

[Consumer knowledge, skills and experience \(for organisations\)](#)

## How do I find consumers to be involved?

Consumer involvement in research requires some skills and you will find it easier if you are able to [recruit consumers](#) who are already experienced consumer advocates or representatives in your health service or organisation. You can also approach consumer groups and organisations that are already established and who can nominate consumers to be involved in your research team.

## How one consumer involved others...

*'About 13 years ago, we took over the support group at the Sydney Adventist Hospital, where I had my operation. But prior to that we were engaging with people who had suffered the same fate as me, talking to them on the telephone, following up a request from my urologist. So that's how we started to engage with people. And we realised the most important thing for us to do was to listen to their plight and where they're at in their journey and then apply our experience to that and build on it. The first thing for us to do in engaging with people and building up people who can work well at all the different levels is to engage with them personally, see what their skill sets are and*

*then take it from there. That's our grassroots support group network type approach. The support group network of the Prostate Cancer Foundation of Australia has over 135 groups. It's a rich source for recruiting people and a stepping stone for people to get involved with advocacy.'*

*—David Sandoe, consumer, Chair Prostate Cancer Foundation of Australia*

Link to [cancer and consumer health organisations](#)

## Cultural engagement

Evidence reminds us that Aboriginal and Torres Strait Islanders and rural and remote communities have greater disparities when compared to non-Aboriginals and large urban communities. In engaging diverse communities develop strategies that facilitate positive social participation. Encourage your organisation to be proactive in addressing issues that will lead to improved outcomes.

Approaches of cultural engagement include, working closely with organisations that are able to represent the views of community groups, working with Aboriginal and Torres Strait Islander Elders advisory groups and community liaison staff members, Always remember to engage with people 'where they are' both geographically and in their own lives and circumstances. Go to them; do not expect them to come to you. Below are some examples of successful cultural engagement.

- [Involving consumers from Aboriginal and Torres Strait Islander communities](#)
- [Involving consumers from culturally and linguistically diverse communities](#)



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- [Meet the experts](#) [TO BE PROVIDED [39]

## Developing an inclusive group

### How do we incorporate consumers into a research team?

Effective consumer engagement occurs in groups or teams and thus your working group will need to understand the **BENEFITS** of consumer engagement and **HOW** to do it. 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.

[Inclusive groups](#)

[Inclusive groups checklist](#)

Read what some experienced professionals and consumers think about [developing inclusive groups](#)

### 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](#)

Activity [audit](#)

*'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*

## Evaluate

Evaluation requires an honest look not only at what you are actually doing with consumers but also reviewing which consumer activities are working and which aren't. Can an ineffective activity be improved? If so, work closely with staff and consumers through education or system change. If not, stop it. Consumer involvement that is ineffective, poorly managed or where there's a skill mismatch can be damaging for the consumer and for future efforts.

Developing a consumer engagement program requires ongoing evaluation. Monitor your progress by conducting regular review.

[evaluation of consumer involvement guide](#)

[organisational self-assessment survey](#)

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Evaluations can be internal or external and you will need to decide if you want to do this in-house, or engage an external consultant. You may decide to allocate funding for an external evaluation which has the advantage of being totally independent.

Ideally, the evaluation process will involve both consumers and staff. Remember to invite consumers early in the process and remember to let them know the results of the evaluation.

In addition to all of this, consumer engagement is now an essential element of accreditation and reporting at both state and national levels.

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

### Resources for researchers

Involve is a national advisory body supporting public involvement in NHS, public health and social care research and development.

<http://www.invo.org.uk/>

Consumers in NHS Research Support Unit. 2005. Involving consumers in research and development in the NHS: Briefing notes for researchers. pp. 5 – 6

<http://www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf>

Consumers Health Forum of Australia. 2001. A guide for consumers doing health research. Canberra

<http://www.chf.org.au/pdfs/rep/rep-269-research-guide.pdf>

Saunders C, Crossing S, Girgis A and Butow P. 2007. Operationalising a model framework for consumer and community participation in health and medical research. Australia and New Zealand Health Policy. 4 (13).

<http://www.anzhealthpolicy.com/content/pdf/1743-8462-4-13.pdf>

Saunders C, Girgis A, Butow P, Crossing S and Penman A. 2007. Beyond scientific rigour: Funding cancer research of public value. Health Policy. 84(2-3):234-42.

National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2002. Statement on consumer and community participation in health and medical research. Canberra.

<http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/r22.pdf?q=publications/synopses/files/r22.pdf>

National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2004. A model framework for consumer and community participation in health and medical research. Canberra.

<http://www.nhmrc.gov.au/publications/synopses/files/r33.pdf>

National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2004. Resource Pack for Consumer and Community Participation in Health and Medical Research. Canberra

<http://www.nhmrc.gov.au/files/nhmrc/file/publications/synopses/r34.pdf>