



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



# Tools for policy makers



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# Take a lead- policy makers

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## Why involve consumers in policy?

There is considerable evidence that consumer involvement in health care improves the quality of health information and the health outcomes for those using the health service. Consumer engagement has also been shown to improve quality and safety and increase both consumer and community support.

There are specific benefits of involving consumers in policy development. For example, getting views and consumer opinions about new approaches that may affect the way health care will be planned and delivered in the community. Interacting with consumers as policies are developed can provide unique perspectives to those on the policy development team.

Other benefits:

- opportunity for consumers to influence the final outcome
- means for including people who may have an interest in the issue and will likely be affected by the outcome
- way to encourage discussion among and with stakeholders
- means for consumers to provide input to the shape of policy directions
- two-way information exchange

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

*'In breast cancer, people would not even think about developing a policy, working a program, or undertaking service development without involving a consumer.'*

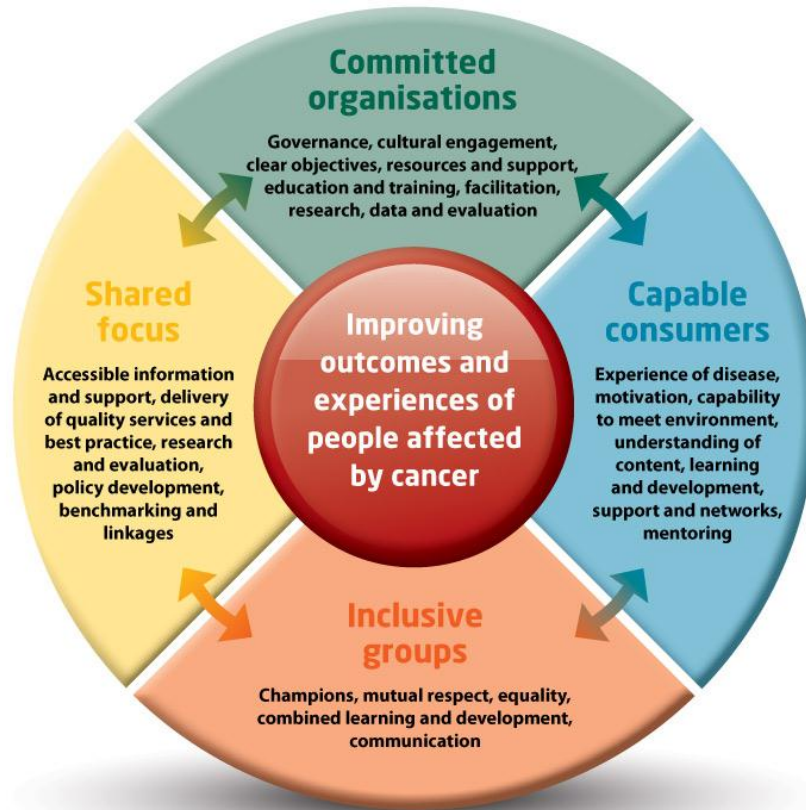
—Lyn Swinburne, consumer, Founding CEO Breast Cancer Network Australia

## How does the Framework help me involve consumers?

The *National Framework for Consumer Involvement in Cancer Control* (the Framework) is a pathway, a means to developing lasting partnerships with consumers. It answers the question: 'HOW do I engage with consumers?'

This Toolkit enables people across Australia to easily follow that pathway as they begin or continue their work with consumers.

## What are the elements of the Framework?



### [Understanding the Framework](#)

## Key Framework questions

The Framework is a consistent and well-researched pathway, a means to developing lasting partnerships with consumers. As a policy maker, it should help you answer the question: 'HOW do I engage consumers in policy development?' The Framework can help to get you started on the right track and keep you there.

- Do we have a **committed organisation** 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 policy?
- Identify the type of consumers who will make a contribution to your policy team.
- Determine the approach or approaches you wish to take.
- 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 the [consumer recruitment process guide](#).

Before starting, check your readiness with this quick [checklist for policy makers](#)

## Ways to involve consumers

*'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*

The Framework provides examples of activities for involving consumers. A significant part of consumer engagement is understanding and being explicit about the role consumers are expected to fulfil.

[See consumer involvement model](#)

## How have other government organisations involved consumers in cancer policy?

Consumers have been involved in:

- development of policies associated with the national cancer reform
- state-level cancer reforms as consumer representatives in policy development teams
- development of specific policies such the national policy on advance care planning.

[Hear what one policy maker](#) thinks about involving consumers in policy.

Example of involvement of a [consumer on a high-level board](#)

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

- an experience of cancer with an ability to look beyond their own experience in the health system
- knowledge of the processes for policy development
- knowledge of the context of the policy being developed
- skills as a consumer representative and working in teams and committees.
- [Consumer knowledge, skills and experience \(for organisations\)](#)

## Do consumers want to participate?

Many consumers of health services want to have a say in their own health and in the way services are provided. The opportunity to give feedback and improve care is highly motivating for consumers **if they believe their input will be heard**. Some view it as an opportunity to 'give something back' or to 'improve the experience for others'.

*'You get great satisfaction out of being able to help people who are on their cancer journey. And they're not in it alone: cancer not only affects the person, but also partners and families. It's really important that, as Australians, we try to make that journey as good as possible.... The quick satisfaction comes from supporting people at a personal level. But of course there's a whole other level of satisfaction when you can do it on a grand scale.'*

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

## What's the role of consumer organisations in policy?

Consumer groups have an active interest in the issues and are likely to be much more knowledgeable than the general public about health policy. They can provide a useful perspective on the issues from an important and distinctly different perspective. They are also a great resource for finding active and experienced consumers. Because consumers who are members of these groups will usually be accountable to the wider group for the contributions that they make at a policy level, they can provide a useful consultative link.

Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian health care consumers. CHF runs the Consumer Representatives Program in which organisations nominate consumer representatives to sit on select high level, national committees.

In addition, there are many cancer consumer organisations, charitable organisations and non-government organisations that are led by active consumers or support active consumer involvement.

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

## How do I find consumers to be involved in policy?

Consumer involvement in policy development requires some particular skills; thus, it will be easier if you are able to recruit [consumers](#) with previous experience as consumer advocates or representatives. You can also approach consumer groups and organisations that are already established and who can nominate consumers to be involved in your policy development work. But remember, start early:

*'Consumers have certainly educated me over the last twenty years that they don't want to be consulted at the last minute; they want to be in from the beginning. And that's good because it means that you formulate better policies and programs.'*

—Rosemary Knight, Principal Advisor, Department of Health and Ageing

### 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*

## 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](#)

## Developing an inclusive group

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.

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](#)

[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](#)

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

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.





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## Resources for policy makers

Canadian Health Services Research Foundation. 2009. Public engagement (Part I): engaging the public in healthcare policy: why do it? And what are the challenges?

[http://www.chsrf.ca/Migrated/PDF/insightAction/Insight\\_and\\_Action\\_48\\_e.pdf](http://www.chsrf.ca/Migrated/PDF/insightAction/Insight_and_Action_48_e.pdf)

Gregory, J. 2006. Consumer engagement in Australian health policy: Investigating current approaches and developing new models for more effective consumer participation. Australian Institute of Health Policy Studies. Working Paper 2.

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Health Canada. 2000. Health Canada policy toolkit for public involvement in decision making. Health Canada. Ottawa.

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