



Australian Government
Cancer Australia

Tools for health professionals



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Take the lead - health professionals

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Why should I involve consumers?

'It keeps you honest. Having patients involved from the beginning—not paying lip-service—but getting consumers involved right at the development of ideas...We've done surveys with the Cancer Network of cancer patients to see what issues there are in their cancer care when we've been developing new cancer centres. And that's been extremely helpful. Sometimes some unexpected things are more important to them, like parking.'

—Christobel Saunders, Deputy Head, University of Western Australia School of Surgery

There is considerable evidence that consumer involvement in health care improves the quality of health information and the health outcomes for people using the health service. Consumer engagement has also been shown to improve quality and safety and increase both consumer and community support. [Why involve consumers?](#)

If these aren't enough reasons, partnering with consumers is now an essential requirement of [accreditation and reporting](#) at both state and national levels.

What can consumers offer me?

People affected by cancer view the health service through a different lens. Their feedback and suggestions are often surprising and can lead to major improvements in quality and safety.

I don't have time to do this!

Some health professionals worry that working with consumers will be time consuming. In fact, most find the following to be true:

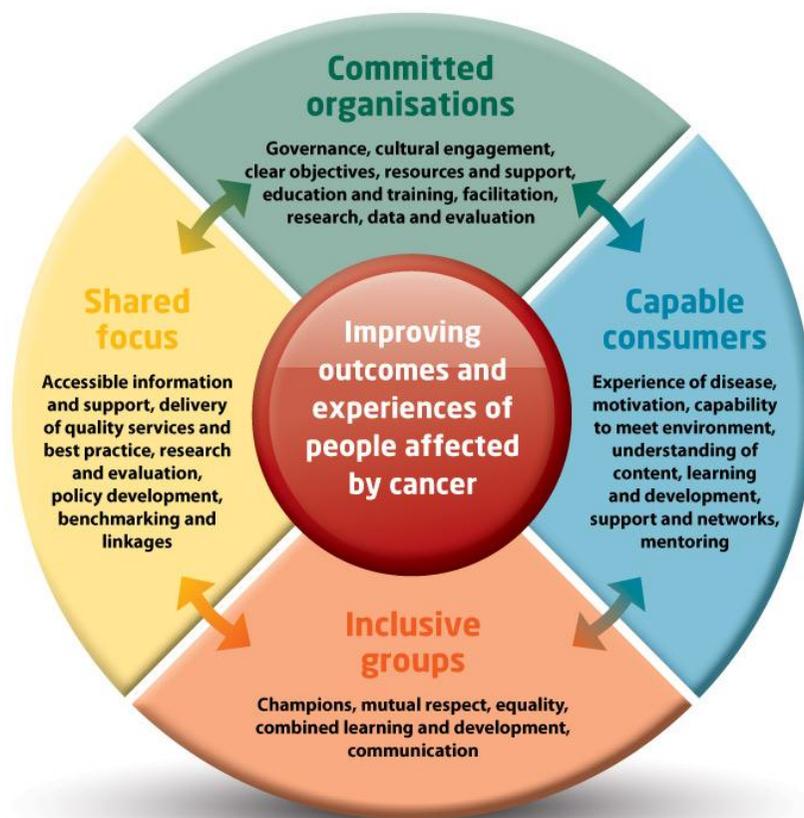
- Talking with patients and families about what is important to them can be built into many of your routine episodes of care.
- Improvements that come from consumer involvement make your health service more efficient and effective.
- Many aspects of consumer involvement are fairly self-sustaining once initiated.
- There are significant resources (such as this Toolkit) which can help you to begin or continue the process of involving consumers.
- Your organisation may be able to provide administrative and logistical support which should relieve you of much of the burden of time.

Case study-is it worth the time...

'The rewards are great, not only in the way I do my business because I actually find it a value-add for me....So if we actually invest up-front with empowerment of patients, they're much better able to look after themselves. And I think that's the way forward. And it doesn't just have to fall on the shoulders of any one health professional; this is very much a joint approach and a joint commitment of the whole of the health team involved with the patient.'

—Tony Hobbs, General Practitioner, Cootamundra Medical Centre

What are the elements of the Framework?



[Understanding the Framework](#)

How will the Framework guide me?

As you progress, think about how the Framework will apply to your situation. It provides a consistent and well-researched pathway for working with consumers and can help to get you started on the right track and keep you there.

As a health professional, the Framework can help you answer the question: 'HOW do I engage consumers in my work?'

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: What do I want to change in my health service?
- What do I want to know from my patients?
- Identify the type of consumers who will have this information and can provide it to you.
- Consider appropriate strategies for involving these consumers in your service.
- Read more about [consumer involvement strategies for health professionals](#).

Before starting, check your readiness with this quick [checklist for health professionals](#).

How have other health professionals involved consumers?

- redesign of waiting areas
- reviewing architectural plans for new wards
- peer support for other consumers after cancer diagnosis
- providing input into day surgery process
- clinical reviews for the prevention of adverse events
- quality improvement projects
- discharge from ward process

[Read about what other health professionals think about involving consumers](#)

Ways to involve consumers

What types of involvement are there for consumers?

The range of opportunities for consumer engagement is enormous. It may begin with consumers giving feedback on surveys about your health service and participating in focus groups, but can move on to serving on the Quality & Safety Committee at your hospital or on the selection panels for staff hiring. How you, as a health professional, decide to involve consumers will depend largely on two issues:

1. What aspects of your service you want to change or improve.
2. The skill base of the consumers in your service.

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](#)

What knowledge, skills and experience do consumers need?

- an experience of cancer with the ability to look beyond their own experience in the health system
- willingness to discuss their treatment and care with health professionals
- knowledge of the processes for providing feedback to health services (e.g. annual satisfaction survey, compliments and complaints systems)
- knowledge about patients' rights and responsibilities

- 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 \(for organisations\)](#)

Do consumers want to participate?

Many consumers 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

Link to [cancer and consumer organisations](#)

Finding consumers who can be involved in service improvement

Consider the patients and families from your clinical practice, both current and past. Start a running list of those who have the experience and skills (or who you think could develop the skills). Ask the nursing and allied health staff to contribute names. Consider advertising for volunteers. The person in charge of consumers at your organisation will also be able to help you with suggestions. However, generally you, as health professionals, are the best source of possible consumers from within your organisation, as you know them best.

Read about the [recruitment and selection process for consumers](#)

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 peoples and Torres Strait Islanders and rural and remote communities have greater disparities when compared to non-Indigenous Australians 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 that - [involve consumers](#)

[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.

'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.

Resource Tools

Below are some practical tools for recruitment, selection and support for engaging consumers:

[training needs assessment](#)

[conducting focus groups](#)

[position description for a community advisory member](#)

[position description for a community representative](#)

[consumer orientation workshop](#)

[principles of training](#)

[consumer recruitment process guide](#)

[consumer interview template](#)

[reimbursement protocol](#)