



Australian Government
Cancer Australia



Leading your organisation

Tools for
Service Managers



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Leading your organisation: Tools for managers

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Remind me why we're doing this!

Involving consumers throughout health service delivery and cancer care and control will have multi-layered effects, including building a responsive and trusted health system.

Benefits of consumer involvement:

- improve outcomes and experiences of people affected by cancer
- advance quality and safety through patient centred care
- informed consumers and communities better able to meet their own health needs
- engage consumers in building the evidence and best practice
- bring accountability and transparency.

Take a look at the evidence and support for working with consumers-

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

'Involving consumers should be something, just like good project management principles, that is considered right at the outset of how we plan our projects.'

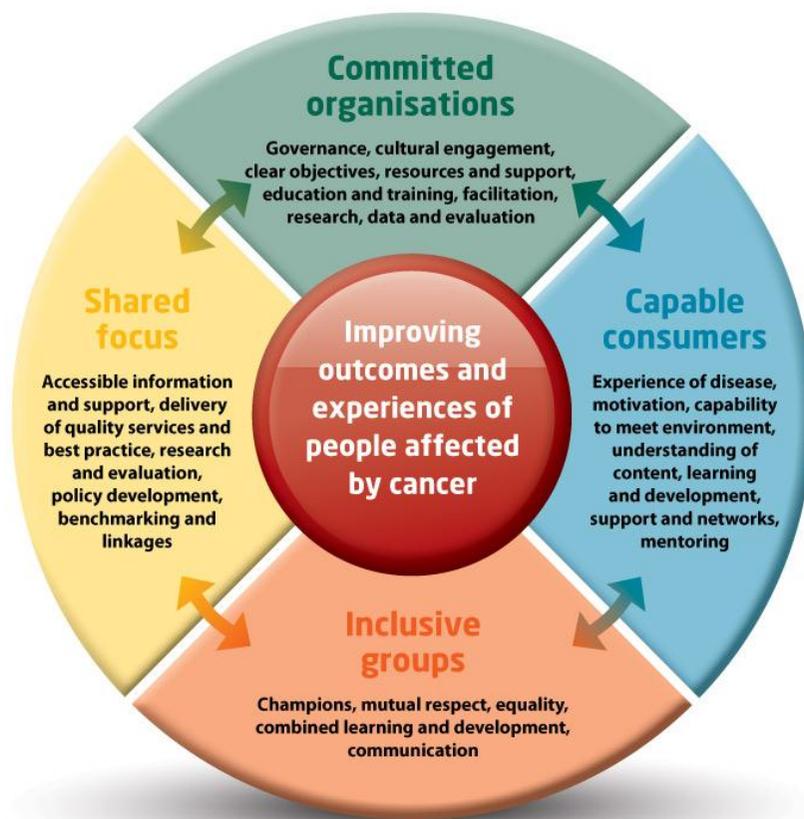
—Patsy Yates, Chair, Queensland University of Technology School of Nursing

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 has been designed to facilitate consistent approaches to consumer engagement. Four elements describe the responsibility and accountability of organisations, consumers and groups. Each element is connected and interdependent, and all are necessary for quality and sustainable consumer engagement.

- 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

Before you begin, you need to know where you are. Many managers are surprised to discover that there is often significant consumer engagement occurring in different areas of their organisation, but it has never been properly assessed or centralised. If your organisation has not recently assessed its consumer involvement, this is the time to do it.

The [organisational self-assessment survey](#) can be used in a variety of settings. For example, you may wish to work through it at an organisation-wide strategy session or at a locally-based planning meeting.

Make a plan

Getting started involves planning. This may include surveys to ascertain consumer and staff needs, assessment of organisational responses and identification and scoping of priorities. If you are just getting started the following steps toward a consumer engagement plan may assist.

If you're not sure how to assess the activity, look at these questions.

[Activity audit](#)

[Steps toward a consumer engagement plan](#)

In order to develop a sustainable and efficient consumer involvement program, you will need a series of policies for working with consumers. Take a look at some of the policies you might think about developing for your organisation, if they don't already exist.

[policies](#)

[communication plan](#)

Ways to involve consumers

'Organisations need to be clear [about] 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](#)

Evidence suggests that the higher the level of consumer involvement (from informing through to community-led) the greater the impact on health outcomes; this is a clear incentive for organisations committed to making a difference.

Examples of consumer involvement:

1. service planning
2. improving patient care throughout the cancer pathway
3. education and information
4. service measurement and evaluation
5. participation in the research cycle
6. policy planning and development
7. priority setting.

All levels of consumer engagement are essential for effective consumer involvement – from building health literacy and community awareness through to incorporating consumer input into organisational strategic planning and priority setting. Engaging at

every level will depend not only on the consumer's knowledge, skills and experience, but the organisation's capacity to resource, train, support and engage them.

What can consumers expect from organisations?

Consumers participating in your organisation can expect to be considered part of the team, to have their views listened to and taken into account. They will be respected for the knowledge, skills and experience they bring to the table. Consumers will be involved in your organisational board and working groups, and your policies and systems will support both consumers and your staff in effective consumer engagement.

As any other member of the team would be fully informed, consumers also will 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.

Consumers can also expect to have a support person or mentor from within the organisation available for briefings before and after meetings, as necessary. Here is a list of some examples to guide your consumer implementation plan.

[Practical expectations for consumer involvement](#)

What about leadership?

Engaging consumers within the organisation requires leadership and some administrative work and management of a system which will make it easier for you and consumers to participate effectively. Think about the best person in your organisation to facilitate, and allocate resources accordingly.

[Finding and forming staff consumer champions](#)

At what stage of the pathway should I be involving consumers?

Consumers may be involved at every stage of the cancer pathway, including: prevention, screening, early diagnosis, treatment, supportive care, survival and palliative care, research, policy, planning and service development. Determining consumer readiness for involvement is an important issue regardless of where the consumer is along the cancer pathway. Several consumer self-assessment resources may prove particularly helpful:

[Consumer self-assessment tool](#)

[Capable consumer checklist](#)

What are the types of consumer roles?

'I'd like to see more of a critical mass for consumer participation, so organisations don't keep relying on all the same people. When I first became involved, it was a new concept to involve consumers. Nowadays it's more common. But I think people think they just have to snap their fingers and they'll have consumers. Instead it's important to take the time to find the right consumers for the right roles.'

—Nicola Bruce, consumer researcher

The Framework summarises consumer roles into five key types. As consumers develop their engagement capability they are called upon to advocate for others and provide advice. The highest levels of consumer involvement include consumer-led, partnering or co-design. Building consumer capability that will lead to achieving long term change is dependent on organisational capacity and support.

There are five main types of consumer involvement: [diagram](#):

1. [Partner](#)
2. [Expert](#)
3. [Advisor](#)
4. [Advocate](#)
5. [Personal engagement](#)

For consumer involvement to succeed each of the roles are required. The important issue is to recognise which approach is best suited to your purpose. Whether this is involving consumers in improving their own health literacy, giving feedback on printed material or working in small project groups, then you will probably be looking primarily at personal engagement, advocates and advisors.

If you are keen to place consumers on high-level committees or involve them in strategic planning, then you are going to need to begin recruiting consumers who have skills that allow them to participate as experts and partners.

Case studies of consumer involvement

Hear from experienced health professionals on approaches they have taken to engage consumers effectively.

- [Partner](#)
- [Expert](#)

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

What knowledge, skills and experience do consumers need?

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 \(for organisations\)](#)
- [Consumer knowledge, skills and experience \(for consumers\)](#)
- [Capable consumer checklist](#)
- [Consumer storytelling for health services](#)
- [Tips for consumers working on committees](#)

Consumer recruitment and support

There are many approaches to **selecting** consumers to participate in activities. These include:

- A request to consumer organisations for a nomination
- Advertising and recruiting consumers based on selection criteria for a specific project or purpose
- Selecting consumers through clinical, policy or research networks.

Tools for engaging consumers

Once you know what type of consumer involvement roles you need, then orientating and **training** consumers in the goals of your organisation and the contribution consumers will make will sustain your approach. Below are some tools and resources to support your training needs.

[training needs assessment](#)

[cancer and consumer health organisations](#)

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

[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](#)

Once you have your consumers, think about these three key pillars of success:

1. Orientation
2. Support
3. Training

Supporting consumers to be involved in your activity will enable a broader range of consumer participation. Enabling consumers to fulfil their role effectively will be met by providing out of pocket

expenses, accommodation and travel and sitting fees as appropriate.

For networking and mentoring, organise an annual networking meeting for all consumers involved in your organisation or enable your consumers to meet with consumers from other organisations.

Alternatively, consumers and networks can learn from each other, and benefit from a mentoring program where they are supported by experienced consumers.

A further benefit for your consumers will come from attending workshops and conferences, including presenting their work.

Tools for engaging consumers at the broader levels of participation:

You may choose to engage consumers in your organisation's activities through inviting consumer feedback about service provision or organisational planning, or by running a one-off consultation about a specific issue or project. Informing and consulting based involvement is considered to be on the broader levels of engagement. It is expected, though, that through these consultation methods you will begin establishing relationships with your consumers who will, over time, move to greater levels of engagement.

There are many methods of consultation. Some of the most commonly used are:

- focus groups: [Conducting focus groups](#)
- surveys

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 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

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. [Activity audit](#)

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.

Resources for managers

'Your care, Your Say: consumer, carer and community engagement. A guide to engagement techniques.'

www.dhhs.tas.gov.au/_data/assets/pdf_file/0008/76283/Toolkit_December_2010_finalised.pdf

Clarke, M and Brindle, R. 2010. Straight from the source: a practical guide to consumer participation in the Victorian alcohol and other drug sector. Association of Participating Service Users 2010.