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## Why should we involve consumers?

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| 'If you don’t involve consumers, you don’t understand your business. Whatever type of business it is, it’s got to have relevance to the people who will be the end users. And this is particularly true in cancer, where a lot of the issues are not self-evident to health professionals or to CEOs of health organisations. They’re often things which, nevertheless, have a large impact on people who are undergoing a lot of stress and difficult times in their lives and what’s important to them is often not that front-of-mind for such people….I think there’s a real opportunity to engage consumers into building a system that is much more responsive to everyone’s needs.’  —Jim Bishop, Executive Director, Victorian Comprehensive Cancer Centre |

Benefits to your organisation:

* a better understanding of your consumers
* a stronger, more respected and trusted presence among consumers
* increased consumer understanding of your organisation’s constraints
* access to untapped source of feedback and solutions
* enhanced quality improvement and patient experience

improved patient experience, leading to greater job satisfaction among your staff.

Benefits to consumers:

* a health service that is more responsive to consumer needs and issues
* improved quality and safety in a service that hears the voice of the consumer
* empowerment leads to improved health outcomes for involved individuals
* involvement and participation lead to peer support and connection among consumers

skills, knowledge and satisfaction for consumers from contributing to change.

## What are the elements of the Framework?



[Understanding the Framework](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M3.0-2_GUIDE_UnderstandingTheFramework.docx)

## How does the Framework help me involve consumers?

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.

**Key Framework questions**

* Do we have a ***committed organisation*** which is ready to work with consumers?

[What is a committed organisation?](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M3.1-3_DESCRIPTION_WhatIsCommittedOrganisation.docx)

[Committed organisations checklist](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M3.1-4_CHECKLIST_CommittedOrganisationsChecklist.docx)

* Do we have ***capable consumers***?

[Knowledge, skills and experiences](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M3.1-5_DESCRIPTION_WhatKnowledgeSkillsExperienceConsumersNeedCapable.docx)

[Capable consumer checklist](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M3.1-6_CHECKLIST_CapableConsumerChecklist.docx)

* Do we have ***inclusive groups***?

[Developing inclusive groups](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M3.1-7_GUIDE_DevelopingInclusiveGroups.docx)

[Inclusive group checklist](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M3.1-8&%20M7-42_CHECKLIST_InclusiveGroupsChecklist.docx)

* What will be the ***shared focus*** of our consumer engagement program?

[What is our shared focus?](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M3.1-9&M8-43_DESCRIPTION_WhatisaSharedFocus.docx)

[Shared focus checklist](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M3.1-10&M8-44_CHECKLIST_SharedFocusChecklist.docx)

## Is executive leadership important?

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| ‘If you get the structure right, it should be a win-win for everybody. No one loses in that situation. The consumer comes out having made a real contribution. The people around them feel encouraged and stimulated knowing that there’s a better outcome at the end of the day for that project and for the people who will benefit from it.’  —Lyn Swinburne, consumer, Founding CEO Breast Cancer Network Australia |

Consumer involvement across all aspects of a health service provides the opportunity for enormous improvements and benefits to all parties. But if it is to be successful—like any large and sustained project leading to lasting change that makes a difference—it requires active and ongoing executive leadership.

Executive commitment is important in allocation of financial and human resources. But that leadership is equally important in setting relevant policies and priorities, including embedding consumer involvement in your organisation’s vision and strategy. For many health professionals, involving consumers will be a relatively new and possibly challenging prospect.

The best way to achieve widespread acceptance among staff is through consistent and clear executive leadership, inspiration and support.

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| ‘Whether you’re doing research, providing clinical care, or developing policy, the end user and the end result is going to be consumers. Unless we have a clear idea of their needs, we can never optimise those programs. It’s an essential core element of feedback and understanding.’  —Jim Bishop, Executive Director, Victorian Comprehensive Cancer Centre |

Read more about consumer involvement from [Jim Bishop](CEO4.0-10_InvolvingConsumersFromCEO&ExecutivePerspective.docx), an Executive Director.

**How can I support consumer involvement?**

Active and ongoing executive leadership is essential. Some of the initial fundamentals are:

1. Commit a staff resource to lead consumer engagement.
2. Make certain you find the right person to lead the work.

[Finding and forming staff consumer champions](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M4.3-16_1_GUIDE_FindingFormingStaffConsumerChampions.docx)

1. Agree to a budget for consumer training and other essential expenditures.

Find out how committed your organisation is, in involving consumers by working through this brief checklist. [Committed organisations checklist](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M3.1-4_CHECKLIST_CommittedOrganisationsChecklist.docx)

**Is my organisation committed to working with consumers?**

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](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M4.1-15_FRAMEWORK_ConsumerInvolvementModel.docx)

## Ways to involve consumers?

The options for involving consumers are almost unlimited and include an enormous range of activities.

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. The broader levels of participation include surveys and focus groups. The higher levels of participation include consumer representation on committees (from ethics committees to patient safety), involvement in organisational strategic planning and many aspects of quality improvement.

There is now clear evidence that the higher the level of consumer involvement the greater the impact on health outcomes.

Some of the main ways that consumers are involved with health services are:

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

policy planning and development

priority setting.

## 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](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M3.1-10&M8-44_CHECKLIST_SharedFocusChecklist.docx)

[Activity Audit](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M4.1-12&M9-46.0_CHECKLIST_ActivityAudit.docx)

## Evaluation

Quality care and safe practice and service delivery is a precondition to improving health outcomes. Good safe practice is dependent on effective systems and processes, implemented by organisations and health professionals delivering best practice standards of care.

Best practice care 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.

[evaluation of consumer involvement guide](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M9-46_GUIDE_EvaluationConsumerInvolvement.docx)

[organisational self-assessment survey](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M9-47_CHECKLIST_OrganisationalSelfAssessmentSurvey.docx)

[Accreditation and consumer involvement standards -responsibilities](file:///S:\_CA_Legacy_T_Drive\Consumers\Consumer%20Framework-%20Tool%20Kit\Website\Final%20web%20booklets\Managers%20Booklet%20and%20Tools\M9-48_AccreditationConsumerInvolvementStandards%20(2).docx)