

# Cancer Australia Case study on partnership



## How you have involved consumers in your work?

As a manager who is fortunate to work for an organisation, Cancer Australia, that is responsible for leading and coordinating cancer control efforts in Australia, I was involved in the development of the *National Framework for Consumer Involvement in Cancer Control*<sup>1</sup> with Cancer Voices Australia. The development and publication of the Framework is a leading example of an effective partnership with consumers, in this case Cancer Voices Australia, a peak cancer consumer organisation.

In order to successfully engage consumers in my work I need firstly to have the support and guidance of my organisation. Over the last five years, working professionally with consumers, I have investigated the evidence and best practice to ensure that Cancer Australia remains at the forefront. It became clear to me not just from the evidence, but also from consumers I had the privilege to work with, and health professionals, policy makers and researchers, that whilst there was a commitment to involving consumers there was not an understanding of how best this could occur.

So together with the voice of consumers a project plan was endorsed by Cancer Australia as the project sponsor. The project was further guided by a broad governance group including a *Consumer informant group* to guide the project, a *Project reference group* comprising of 50 organisations committed to consumer engagement in cancer control, a *Project steering group* responsible for ensuring the project met its deliverables and an *International linkages group* to assist with peer review. The project also received ethics approval through Latrobe University, which provided evidence based review of the project methodology and outcomes.

<sup>1</sup> Cancer Australia and Cancer Voices Australia, 2011. *National Framework for Consumer Involvement in Cancer Control*. Cancer Australia, Canberra, ACT.

Thus as you can see from the start this was an extensive collaborative and evidenced based process, with consumers central to the initial planning, guidance and delivery of the project. Further it is a partnership, recognised by Cancer Australia and Cancer Voices Australia's partnership acknowledgement on the cover of the document.

## Why did your organisation decide to include them?

You have heard the term '*nothing about us without us*'. In my view this sums up well that consumers have a desire to be involved and consider they have a valuable perspective to contribute that cannot be provided by other means. As manager of the Consumers program for Cancer Australia I hold that same view: consumers give us a rich perspective that will only strengthen our capability as an organisation that is responsive to the needs of those whose lives we aim to improve.

Consumers from across Australia were invited through peak consumer organisations and as a result of their previous involvement with Cancer Australia, to participate in the working and reference groups of all projects. Consumers, including indigenous Australians, from a diverse range of states, regions, age groups and ethnic backgrounds brought a wide breadth of experience in a range of cancers to the project.

## Has it been difficult finding consumers with the skills to do this high-level work?

Not at all. You would be surprised just how many skilled and committed individuals want to give something back, and want to contribute to making a difference to the lives of people affected by cancer. I like to call it "*motivated by a common good*". Their personal experience helps them empathise - helps them understand some of the issues that face people who are vulnerable as a result of their illness, and



who require the right information at the right time, delivered in a sensitive manner, to enable them to take back some personal control and be active managers of their illness. People who have been there have an understanding of this need, and bring this need front and centre to everything we do.

We also advertise for consumers, and undertake a merit based selection process by a panel which includes consumer members. Furthermore we write to consumer organisations seeking nominees, and we also carry out surveys. In developing the *National Framework for Consumer Involvement in Cancer Control* we undertook a national survey and received over 500 responses.

### **How have you found them?**

It is a privilege working with consumers. This is the reason I am here. I do believe that consumers have an enormous contribution to make. Their experience is insightful, practical, knowledgeable and able to resonate not just with other consumers, but with all the dedicated professionals working hard to make a positive impact in cancer control.

### **What has been the best thing about working with consumers?**

The best thing about working with consumers is seeing how issues and projects evolve and develop as a result of their knowledge, experience, and cogent advice. It ensures that when we develop a resource, a guide or an evidence based tool it will support and meet the needs of people who are affected by this disease.

### **What advice would you give to others who are considering involving consumers in their work?**

To embrace the opportunity and to engage consumers and view them as a valuable resource to your organisation; to provide achievable structures and systems that will effectively support your involvement of consumers; to gain the support of your organisation, and; to promote the successes to your peers.

--Susan Hanson, Manager, Consumers, Cancer Australia

