



Case studies of expert involvement: Leonie Young and Chris Milross



The Australia & New Zealand Breast Cancer Trials Group (ANZBCTG) was the first clinical trials group among the two countries to institute a consumer panel and certainly one of the first, if not the very first, internationally to have this type of consumer input. In 1994, the first consumer was invited to take part in the ANZBCTG Scientific Advisory Committee. In 1998, a Consumer Advisory Panel was established and is currently chaired by consumer Leonie Young.

Ms Young credits Professor John Forbes, ANZBCTG Director of Research, as a ground-breaking champion of the idea that consumers should be at the table in the development of clinical trials. Prof Forbes remains a strong supporter to this day. According to Ms Young, 'If an organisation or a group has a champion who really believes in the value of consumers and nurtures it, it will be successful.'

This doesn't mean the high level of consumer engagement ANZBCTG enjoys came about instantaneously. 'In the early days, people were very accepting but still a little bit wary,' Ms Young explains. Researchers had heard stories of instances where work had been delayed by consumers who were not informed enough to contribute in a helpful way. 'We've really worked hard at becoming well-informed. We go to all the scientific meetings and try to upgrade our knowledge base all the time.'

Over time, the ANZBCTG Consumer Advisory Panel participants have seen an evolution in the priority placed on the input they provide. 'At first, we had to keep reminding them [the rest of the panel] that we were there.' But today Ms Young says the consumer representatives constantly need to be at the ready as they are regularly called upon to give the consumer perspective on the topic at hand, including during major forums such as the organisation's annual scientific meeting.

Ms Young recalls that when consumers first joined the ANZBCTG Scientific Advisory Committee, the Consumer Advisory Panel report was placed at the end of the agenda where it was often forgotten as people rushed off at the end of the meeting. But today, it is featured when everyone is present to hear it. She says the adjustment was deliberate when the group realised consumer input was being short-changed. The consumer report is now item three on the committee's agenda, a top priority. According to Ms Young, 'They do that because they realise the input we do give makes a difference to their research programs. It's been a huge success.'

—Leonie Young, consumer, Chair CanSpeak Queensland



When the Faculty of Radiation Oncology (FRO)—a sub-section of The Royal Australian and New Zealand College of Radiologists—first discussed inviting a consumer representative to join its board of directors, not everyone was ready for the change. To introduce the idea, the FRO board agreed to trial the appointment and evaluate the outcome after 12 months. It focused on developing a well-defined process of selection and approached the Consumer Health Forum for help with requesting expressions of interest. After conducting a series of interviews, the Faculty invited its chosen candidate to join the board. Recently the FRO board reached the end of its 12-month trial and set about evaluating the experience. The board was unanimous in its decision to offer re-appointment to its consumer representative.

'People have been incredibly impressed by what the consumer representative has brought to the meetings,' said Chris Milross, dean of the Faculty of Radiation Oncology.

Chris outlined what the FRO saw as the principle strengths of including a consumer voice at the highest level of its decision-making: 'There's an immediate reality check in having a cancer survivor as a member of the team that is making decisions about things that are important for all the cancer patients we treat. It creates an incontestable sense of what we are really here for,' he explained.

'As well as being a cancer survivor, the person we have on our board is actually an incredibly experienced director and quite honestly would function well on any board because he understands clearly the principles of directorship. He comes with a breadth of experience that is very valuable to us and he would bring that skill-set with him whether he was a cancer survivor or not.'

The board has also found great success in asking its consumer board member to play a key role in representing the FRO when meeting with government decision-makers. 'It's been a pretty powerful way of getting a balance that was missing before because we go together and it's about the patient.'

Following the Faculty of Radiation Oncology's success with inviting a consumer to join its board, the organisation approached its Tripartite Committee to do the same thing. The Tripartite Committee is a peak group in radiation oncology, representing the three key professions involved in radiotherapy, which, besides the FRO, also includes the Australian Institute of Radiography and The Australasian College of Physical Scientists and Engineers in Medicine. The group meets four times annually to discuss broad issues across the radiation oncology sector. A consumer joined the committee membership about a year ago, which coincided with the Tripartite Committee receiving a Commonwealth grant to develop a strategic plan for radiation oncology in Australia for the next 10 years. The strategic plan was developed not only with the direct input of the Tripartite Committee's consumer member, but also with the engagement of a number of different consumer organisations.

'I can't tell you how important it was to have consumer representation on that strategic plan,' he concluded. 'Without consumer involvement, we wouldn't have had as good of a product as we do today and it also wouldn't have been as credible.'

—Chris Milross, Dean, Faculty of Radiation Oncology Board, RANZCR

