

Cancer Consumer Involvement in Research (CIR) in Australia

Celebrating ten years of Cancer Voices' CIR Program: 2005 - 2015

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About Cancer Voices

Cancer Voices is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy. To achieve this we work with decision-makers, ensuring the patient perspective is heard.

Cancer Voices has led the cancer consumer movement in Australia since 2000. It facilitates the 30-strong Australian Cancer Consumer Network, established in 2014 to enable a bigger voice on national generic issues.

Something to celebrate

Cancer Voices NSW, the independent volunteer voice of people affected by cancer, is proud of its first decade and ground-breaking achievements in the field of consumer involvement in research. This overview records the pathway from our first advocacy steps to what is now a well-developed program, and the first of its kind in Australia. Over 2005 - 2015 it has become a practical and proven model to share with other states, nationally and indeed, with other diseases.



Why is Consumer Involvement in Research (CIR) important?

The first years of this century saw substantial evidence and acceptance of the need to make research efforts more effective and relevant by engaging stakeholders – consumers, clinicians and funders (government and charity) – in selecting research questions, designing studies and making funding decisions. Among the stakeholders, the biggest challenge was to engage meaningfully with consumers and the community.

Also studied and accepted has been the acknowledgement that consumer involvement can and does add value to research. By 2014, the British Medical Journal (BMJ) had instituted its Partnering with Patients project, whose Editor tweeted (3 Sep 2015) "Why I am passionate about patient involvement in research: Without it, researchers risk designing irrelevant pathways". The BMJ sees it as an ethical imperative, to ask authors to state the nature of consumer involvement and embed patient review of papers into their standard processes. They have received and prominently display the 'Patients Included' certificate.



"Why I am passionate about patient involvement in research. Without it, researchers risk designing irrelevant pathways"

BMJ PtEditor 3 Sep 2015

Most funders realise that their donors are more engaged when they can be assured that research funded by their charity or institution is not only of high scientific merit, but also includes the needs and views of those who will ultimately benefit by it, ie. consumers. A number of major funders now require evidence in grant applications that effective consumer engagement has taken place.

Cancer Voices quickly recognised these issues and that it was well-placed to provide the informed consumer view – either group view, or through its database of informed, broad-view consumer nominees. We left the wider 'community' view on public health and prevention research to the more generic health consumer organisations, in order to concentrate on research which could improve cancer diagnosis, treatment, care and survivorship – core aims for Cancer Voices NSW (CVN), and later Cancer Voices Australia (CVA).

Developing then implementing the concept of CIR

Utilising Cancer Voices' access to the informed consumer view, we developed the highly workable Consumer Involvement in Research Program, with the assistance of an interested and willing partner, the Cancer Council NSW. We explore the facets of this program over the decade 2005-2015: they include training for interested consumers, identifying their priorities for research, implementing a successful electronic service to link researchers with trained consumers and various forms of consumer review.

Beginnings of the partnership: Cancer Voices and Cancer Council NSW

Cancer Voices NSW was founded in October 2000 by a group of cancer consumer advocates who recognised the need for a combined voice about issues of interest or concern to people affected by cancer, including the need for consumer involvement in research. To realise this particular need, we collaborated with the Cancer Council NSW (CCNSW), the state's preeminent cancer charity and funder of cancer research.

Being aware of early positive developments overseas, especially in the USA, Cancer Voices put a three pronged proposal for consumer involvement in research to the Cancer Council's Cancer Research Committee in November 2001 and to its Board in December 2002.

- Increasing the rate and level of consumer involvement in the development of cancer research
- Collecting and promoting consumers' priorities for cancer research
- Ensuring consumer participation in cancer research funding decisions and review

These goals were approved by CCNSW and Cancer Voices began to work closely with CCNSW staff towards effecting them, supported by four peer reviewed studies:

Implementation: Training for consumers

The CCNSW and CVN agreed that for involvement to be meaningful and useful to researchers and funders, potential 'engagees' needed to have an interest in research, and the opportunity to understand the five main research streams and how the research cycle operates. We worked together to develop a short, two-day, training course to be offered annually at least. A one-day version offered by CCNSW in 2014 and 2015 forms the basis of a number of in-house courses for other funders and research institutes.

In 2005, the first formal training for consumers was held so that consumers could:

- Assist the CCNSW in review of grant proposals each year through a Consumer Review Panel

- Be introduced to the world of cancer research so as to be able to provide the informed consumer view to specific cancer research projects. This became important as cancer research funders required evidence that this had occurred, and as a funding criteria.

Online training: In 2012, we participated in a COSA Steering Group which developed the 'Consumer Involvement in Cancer Clinical Trials Groups'. These were learning modules for consumers working with the 14 Clinical Trials Groups and are found on the Cancer Australia website.

Over 2014-2015, Cancer Voices provided consumer input to a broader online CIR training course of four modules, guided by the National Breast Cancer Foundation, the Cancer Council NSW. This will be hosted by Cancer Council Australia.

Linking researchers with informed consumer advisors

Cancer Voices' CIR matching program is probably its most innovative product and service.

The process is supported by an online application form in which researchers provide all the information needed for Cancer Voices to 'match' their request with an informed and trained consumer advisor for their project, preferably as early in the cycle as possible. Both researchers and CIR nominated consumers receive a Cancer Voices Guide which clarifies their respective roles and expectations. The online Request a Consumer Representative form and the supportive Guides are found at www.cancervoices.org.au and www.cancervoicesaustralia.org.au.

Due to the high usage of this free service, linking currently around 100 cancer research projects with consumers each year, Cancer Voices would eventually like to find a well-resourced, unconflicted partner to share the load.

Consumer priorities for cancer research

Cancer Voices, after surveying its members about directions of research over some years, proposed that a wider Consumer Research Forum be held. This took place, again in partnership with CCNSW, in May 2009. It had a reach beyond Cancer Voices members, including interstate participants. We suggested and used the 'global café' process so that all 40 participants could discuss and log their priorities on five major cancer research topic areas. The outcomes of this exercise have been used by Cancer Voices to alert researchers and funders to consumer priorities. We subsequently published a peer reviewed paper to inform other interested cancer research funders about what people affected by cancer would like to see researched. This exercise should be repeated regularly.

Priorities directly initiated and funded – two examples

Cancer Voices consumer representatives proposed the concepts and participated in the design, development and implementation of two research projects which reflected identified consumer priorities:

- Australian Cancer Trials Online Project** with USyd, ANZCTR and Cancer Australia, receiving a major NHMRC grant. The ongoing outcome of this research is a consumer friendly website www.australiancancertrials.gov.au which facilitates searches for suitable clinical trials – a gap identified by consumers, with high potential to increase participation in clinical trials. This concept was later taken on by the NHMRC and applied to all clinical trials with Cancer Voices advice.

- PRIME (Pharmacogenomic Research for Personalised Medicine):** another Cancer Voices initiative, taken up by

a consortium of seven institutions and funded for five years by CCNSW. Our aim was to speed up progress in this most promising for patients area of research by encouraging collaboration between the best researchers in the state. A very successful model, which continues post funding.

Consumer Review

Again the Cancer Council NSW led the way in establishing Australia's first fully fledged Consumer Review Panel. Using defined and researched criteria to rate grant applications, the consumer panel considers up to thirty each year. Originally their rating was weighted at 20%, with standard scientific merit review at 80%. This was soon (2007) upgraded to 50-50%, a clear commitment to the value of the process.

Other government agencies, cancer charities and research institutions have adopted the main elements of Consumer Review, to greater and lesser degrees. Most also incorporate training based on that developed between Cancer Voices and CCNSW. Early adopters include Cancer Australia, the National Breast Cancer Foundation, the Kolling Medical Research Institute, Macquarie University Research Institute, the Lowy Cancer Institute and the Kinghorn/Garvan Research Institute.

Recognition

Cancer Voices CIR Program is now recognised and used by most of the major cancer research institutes, in NSW and beyond, who wish to include the informed consumer view in their development of their own studies. Each year, Cancer Voices recognises its own 'stars' at the CCNSW's Research Awards event. CIR Program Manager, Bridget Whelan received the 2015 Award for Excellence in Cancer Consumer Advocacy for her role in this and other Cancer Voices activities. The CIR program was a feature in Sally Crossing AM's citation for the Honorary Doctorate she received from the University of Sydney in 2014.

Significance

Cancer Voices CIR Program is an excellent example of how consumers, those people actually affected by cancer, advance their cause by partnering with an organisation which can make their proposals really happen. Most importantly, it has shown that the involvement of consumers in research does make a valuable difference, and has become well accepted by funders and researchers alike.

Cancer Voices see value in sharing this successful model with other states, nationally and beyond cancer. Four peer reviewed journal papers have been published and underpin this program (see below). Promotion is important. Cancer Voices NSW and the CCNSW have made presentations to, and had posters displayed, at a number of Australian cancer conferences over the ten years since implementation fully began.

The impact of Cancer Voices CIR program has been far-reaching. A number of government agencies, cancer charities and research institutions have adopted the main elements of consumer involvement and review in research. Most incorporate training based on that developed between Cancer Voices and Cancer Council NSW. Collaboration and partnership are the essential ingredients.

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