

Cancer Consumer Involvement in Research

Celebrating ten years (2005 – 2015) of Cancer Voices' CIR Program

Cancer Voices NSW, the independent volunteer voice of people affected by cancer in our state, is proud of its ground-breaking achievements in this field. The following is a brief overview and record from first advocacy steps towards what is now a well-developed program of consumer involvement and engagement in cancer research – a first of its kind in Australia. We believe it is a useful model to share with other states, and indeed nationally.

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 has been 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. Most funders now 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 - consumers. A number of funders now require evidence in grant proposals that effective consumer engagement has indeed 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 informed, broad view, consumer nominees. We left the wider “community” view on public health 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).

History

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. As a volunteer, unfunded organisation we realised that to implement our recommendations and policy we would need a strong, committed, well-resourced partner. For our CIR purpose the perfect partner was the Cancer Council NSW (CCNSW), the state's preminent 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, through its representative on each, to the Cancer Council's Cancer Research Committee in November 2001 and to its Board in December 2002.

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

The Board approved the goals of the proposal and Cancer Voices began to work closely with CCNSW staff towards affecting them, supported by peer reviewed studies, over 2002-2004.

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 streams and how the research cycle operates. We worked together to develop a short – two days, training course to be offered annually at least.

In 2005, the first **formal training for consumers interested in involvement** 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.

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, on 14 May 2009, with a reach beyond Cancer Voices members, including some interstate participants. We suggested and used the “global café” technique so that all 40 participants could discuss and log their priorities on five major cancer research topic areas. The outcome of this exercise has 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 (see below). It would be good to repeat this exercise soon.

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” them with an informed 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 (all this on www.cancervoices.org.au)

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

Priorities directly initiated and funded – two examples

Cancer Voices consumer representatives proposed the concepts and participated in the design, development and implementation of two 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 CVN 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 his 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 criteria to rate grant applications, consumers consider 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 CVN and CCNSW. Early adopters include Cancer Australia, the National Breast Cancer Foundation, the Kolling Medical Research Institute, Macquarie University Medical Research Institute, the Lowy Cancer Institute and the Kinghorn / Garvan Research Institutes.

Significance and future

Cancer Voices see value in sharing this successful model. Four peer reviewed journal papers have been published about this program (see below). Cancer Voices NSW and the CCNSW have made presentations to, and had posters accepted at a number of Australian cancer conferences over the ten years since implementation fully began. This is an excellent example of consumers, those people affected by cancer, partnering with an organisation which could make its proposals really happen. More 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.

References:

Saunders C, **Crossing S**. *Towards meeting the research needs of Australian cancer consumers*. BMC Res Notes. 2012 Dec 3;5:667. doi: 10.1186/1756-0500-5-667.

Saunders C, Girgis A, Butow P, **Crossing S**, Penman A. *From inclusion to independence--training consumers to review research*. Health research policy and systems / BioMed Central 6: 3, 2008.

Saunders C, Girgis A, Butow P, **Crossing S**, Penman A. *Beyond scientific rigour: Funding cancer research of public value*. Health Policy 84: 234-242, 2007.

Saunders C, **Crossing S**, Girgis A, Butow P, Penman A. *Operationalising a model framework for consumer and community participation in health and medical research*. Australia and New Zealand health policy 4: 13, 2007.

Crossing S. *Consumer-friendly clinical trials information is here!* Medical Journal of Australia 195: 56, 2011.

Crossing S. *Individual to collective – Cancer consumer advocacy and the Australian experience*. Psycho-Oncology 16: S59-S59, 2007.

Dear R, Barratt A, Askie L, McGeechan K, Arora S, **Crossing S**, Currow D, Tattersall M. *Adding value to clinical trial registries: insights from Australian Cancer Trials Online, a website for consumers*. Clinical Trials 8: 70-76, 2011.

Dear RF, Barratt AL, **Crossing S**, Butow PN, Hanson S, Tattersall M. *Consumer input into research: the Australian Cancer Trials website*. Health research policy and systems / BioMed Central 9: 30, 2011.

Sally Crossing AM - 15 June 2015
Chair, Cancer Voices NSW
Convenor, Cancer Voices Australia