

Consumers influencing research

“Nothing about us without us, please”

Sally Crossing AM

Chair, Cancer Voices NSW www.cancervoices.org.au



Aims

To consider the value and translatability of developed processes for consumer involvement in research

Background

The value of consumer involvement in research is becoming recognised internationally and more recently, better understood in Australia. Most funders of cancer research require evidence of consumer input, preferably from protocol development to funding proposal. This overview documents enabling processes proposed and developed by Cancer Voices NSW

Value added to the research itself, to decisions of funding charities, their donors and eventually, to the end beneficiaries. Recognising this, the Consumer Involvement in Research Program (CIR) initiated by the cancer consumer advocacy group, Cancer Voices NSW, and developed in partnership with the Cancer Council NSW since 2002, is a lead example for Australia.

Cancer Voices NSW provides the independent voice of people affected by cancer. It is the peak coalition for cancer support and advocacy groups in NSW, working to improve the cancer experience of the 40,000 people who are diagnosed each year. Established in 2000, it is active in the areas of diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with providers of these services, ensuring the patient perspective is heard.

Methods

Several prongs of Cancer Voices NSW's Consumer Involvement in Research Program are examined:

- development of an **annual training course** to familiarise consumers with the cancer research world, presented by Cancer Council NSW; & evaluation after 5 years (2010)
- “Matchmaking” - an **electronic nomination process** to request informed “graduates” for research projects - as advisers, reviewers or Investigators - on www.cancervoices.org.au
- development of, and participation in, a **Consumer Review Panel**, whose rating of research project grants has a value of 50%, based on robust research ⁽¹⁾
- seeking **funding of consumer identified research priorities** - eg the Australian Cancer Trials Online and PRIME projects
- scoping consumers' priorities** for cancer research - via regular Cancer Voices NSW surveys, and though a Consumer Research Priorities Forum.
- advice to research organisations** about connecting with informed trained researchers

Annual research training

A training program for consumers interested in becoming involved in the direction of cancer research of 1 to 2 days is offered each year by the Cancer Council NSW. This has been developed in consultation with Cancer Voices NSW, and refined since it began in 2005. The training now offers a basic understanding of the five main fields of research, of the research process and cycle, of governance and ethics and opportunities for and value of consumer involvement, CHECK Other research funders (eg National Breast Cancer Foundation, Cancer Australia) use this course, adding their own modules before or afterwards to suit their specific needs. The template is adaptable and specialised modules are planned.

Cancer Voices NSW recommended that the training and its use be fully evaluated and this was affected by the Cancer Council in 2010. One result of the evaluation is to expand the reach of this essential training, possibly as a national basic component for training those consumers who wish to be more deeply involved in providing the consumer perspective for:

- Influencing the direction of research by developing and promoting priorities for research
- Participation in formal review for funding organisations
- Participating in development of research projects per se

Consumer Review Panel

Cancer Voices NSW worked with the Cancer Council NSW to devise a process for contributing the informed consumer perspective to the review of program grants each year. The consumer rating outcome, based on five identified consumer criteria, has equal value to the medical and scientific rating provided by the NHMRC process. Consumer criteria to be applied in review were developed in a robust manner as described in the articles referenced below. *They are extent of benefit, pathway for realising benefit, equity, consumer involvement, potential for application of findings and dissemination of results.*

This process has been in operation since 2005, supported by the Cancer Council NSW. Aspects of it have been adapted by other cancer research funders, eg Cancer Australia. It was formally evaluated in 2010, and fine-tuned as a result. This kind of consumer-only panel review is regarded as the best way of gaining consumer input which is uninfluenced by the impact of non-consumer panellists. Only trained informed consumers are invited to join the panel, after providing expressions of interest.

“Matchmaking” process – consumers and researchers

Cancer Voices NSW offers a free service to researchers and research organisations to connect them with appropriate graduates of the Consumer Research Training. To do this, Cancer Voices NSW maintains a Register against which it matches requests which come via the electronic Request Form, hosted on its website www.cancervoices.org.au - see below. This process ensures that the correct information can be assessed and passed on for the best consumer match, as well as for good record keeping purposes. Cancer Voices NSW has placed trained consumers on 65 research projects for 20 research institutions, and sees potential for this service to be used as the basis for a national register.

Cancer Voices NSW Online Electronic Request for a Consumer Representative				
<small>For Cancer World stakeholders, research decision making organisations Cancer Voices NSW provides a voice for all people affected by cancer and we thank you for asking us to help assist your organisation in recruiting consumer representatives for your specific needs. To help us select the best nominee for you please complete this electronic request form in as much detail as possible.</small>				
A. Number of Representatives Requested <input type="text"/>				
B. Requesting Organisation Details				
Name of organisation <input type="text"/>				
Contact person <input type="text"/>	Position <input type="text"/>			
Postal Address <input type="text"/>				
Suburb <input type="text"/>	City <input type="text"/>	State <input type="text"/>	Postcode <input type="text"/>	
Phone (day) <input type="text"/>	(evening) <input type="text"/>	(mobile) <input type="text"/>		
Fax <input type="text"/>	Email <input type="text"/>	Website <input type="text"/>		
C. Requested Consumer Representation Details				
1. Representation Type Please tick the appropriate box or complete the OTHER section				
Working group <input type="checkbox"/>	Review panel <input type="checkbox"/>			
Research project <input type="checkbox"/>	Guideline development panel <input type="checkbox"/>			
Committee <input type="checkbox"/>	Other (please specify) <input type="text"/>			
Other <input type="text"/>				
2. Name of Working group/Research Project /Committee/ Panel or Other <input type="text"/>				
3. Membership composition <input type="text"/>				
4. Project description/Terms of reference (in layperson's terms please) <input type="text"/>				
5. Experience or interests required of consumer representative Please outline full requirements (ie - cancer type /gender/ geographical location) <input type="text"/>				
6. Proposed commitment required from consumer representative				
Duration of each meeting <input type="text"/>	Meeting frequency <input type="text"/>			
Times of meetings <input type="text"/>	AM <input type="checkbox"/>	PM <input type="checkbox"/>	Evening <input type="checkbox"/>	Weekends <input type="checkbox"/>
First/next meeting date <input type="text"/>	Meeting location <input type="text"/>			
7. Available subsidies for consumer representative We expect travel expenses and other related costs to be met by your organisation. Please specify if subsidies are not available, and the expected costs likely to be incurred. <input type="text"/>				
Note: It may take up to three weeks for the nomination and selection process to be completed, although we will aim for a speedier turn around.				
Submit <input type="button"/>	Press this button once after completing the form. This will send the information you have typed in the boxes above to us by email.			

Scoping consumers' priorities

Facilitating the development and promotion of consumers' priorities for cancer research, and its broad direction, has been on the agenda of Cancer Voices NSW since its inception in 2000.

As a consumer organisation with a wide network, we have surveyed our members' priorities for the direction of research several times. The results have been used in several ways

- to inform a Consumer Research Priorities Workshop, held by Cancer Council NSW and Cancer Voices NSW in May 2009, with subsequent survey and a paper in preparation for publication
- to inform research funders of specific research topics identified as being of particular interest to people affected by cancer (see below).
- to inform government of consumer needs and priorities for research

Seeking funding of consumer identified research priorities

Reflecting its role to promote the research priorities of cancer consumers, Cancer Voices NSW has had a number of successes, including two major projects:

- Pharmacogenomics Research for Personalised Medicine (PRIME):** this study reflects the great interest of people affected by cancer in advancing the benefits of personalised treatment for faster access. The Cancer Council NSW has funded a collaboration of 7 major NSW research organisations towards this goal.
- Australian Cancer Trials Online;** a patient need for access to a consumer-friendly website, based on authoritative clinical trials registers was identified and promoted by Cancer Voices NSW. This was funded by the NHMRC, included a consumer Investigator, Sally Crossing, and extensive broad consumer input through the Cancer Voices and Cancer Australia networks. The study focussed on the value of such a website via a clinical trial. It was launched and presented upon at COSA 2010. A suite of papers are to be published.

Advice to partner research organisations

Some cancer research organisation seek the advice of Cancer Voices NSW in setting up “in house” Consumer Advisory Panels (Garvan Institute, UNSW, USyd Sydney Cancer Network). We are able to advise on structure and processes, and can offer to provide nominations of trained informed consumers from our Register, especially in the first instance. Cancer Voices NSW also offers to address research staff about the value on feasibility of involving consumers in research projects, whether as advisers, Investigators or reviewers.

Results

Impact has been far-reaching. Three peer reviewed articles have been published and a fourth is in preparation.⁽¹⁾ Other cancer research organisations and funders have taken up various aspects of this program. Cancer Voices has made 64 nominations to 20 research/funding organisations, to provide the informed consumer view. Cancer charities can tell their donors that the research they fund is not only of high scientific worth, but is also meets the needs of people affected by cancer. This best practice conforms with NHMRC Guidelines.

Conclusion:

This overview of the Consumer Involvement in Research program after six years in operation, discusses processes through which researchers can most benefit from consumer engagement. It is part of Cancer Voices NSW's celebration of ten years of providing the voice of people affected by cancer.

References:

- ⁽¹⁾ From inclusion to independence - training consumers to review research. Carla Saunders, Afaf Girgis, Phyllis Butow, Sally Crossing, Andrew Penman [My paper] Health Res Policy Syst. 2008 Mar 9; 6(1):3-18328108
- Operationalising a model framework for consumer and community participation in health and medical research. Carla Saunders, Sally Crossing, Afaf Girgis, Phyllis Butow, Andrew Penman [My paper] Aust New Zealand Health Policy 2007 Jun 26; 4(1):13-17592651
- Beyond scientific rigour: Funding cancer research of public value. <http://lib.bioinfo.pl/pmid:17573444> Carla Saunders, Afaf Girgis, Phyllis Butow, Sally Crossing, Andrew Penman [My paper] Health Policy. 2007 Jun 14; 17573444