

Consumer Involvement in Research (CIR): Does it work?

An Evaluation of Cancer Voices' CIR Program

July 2016 • Sally Crossing AM, Lee Hunt, Lillian Leigh (Cancer Voices NSW)

From Consumers participating in Cancer Voices CIR Program

"The project leaders appear genuinely interested in consumer involvement and my input has been welcomed and integrated."

"My advice reflects what I understand to be the broad views and priorities of people affected by cancer. It's important to ask what may seem to be the obvious questions from this perspective - ones which the researchers may not have considered."

"The training covered all aspects of research. Very good strategies were workshopped to ensure the consumer could work in a collaborative way with the researcher."

"I am proud to be a consumer rep. and a part of Cancer Voices. I have been involved with Cancer Voices CIR Program throughout its first ten years. Watching it grow from a good concept to a now very well regarded and accepted service to connect researchers with informed consumers. WELL DONE, Cancer Voices! This is the sort of thing that needed to be put in place, but only doable by an independent cancer consumer advocacy group."

"The training covered all aspects of research. Very good strategies were workshopped to ensure the consumer could work in a collaborative way with the researcher."

From researchers participating in Cancer Voices CIR program

"The consumer's comments helped to focus the research so that the needs of consumers/cancer patients were addressed."

"Personally, I have found interacting with the consumer assigned to me to be inspiring and motivating."

"Before having a consumer representative involved, you think you have a consumer perspective fully in mind. After having a consumer representative involved, you see it is very easy to overlook simple issues that are important to address. With a researcher hat on it is easy to prioritise what is more easily 'do-able' over what is most relevant to do."

"I had been led to believe by other researchers that consumer involvement was something to be resented or at best tolerated, however my experience has been overwhelmingly positive."

ABOUT CANCER VOICES and its CIR Program

Cancer Voices provides the independent, 100% volunteer, voice of people affected by cancer. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with decision makers and providers of these services, ensuring the patient perspective is heard from planning to delivery.

Cancer Voices (CV) recognises the value of consumer involvement in both research and research funding decisions. In recognition of this value, CV developed a *Consumer Involvement in Research (CIR) Program* which matches trained consumers to interested researchers, and is believed to be the first service of its kind in Australia. Originally developed in collaboration with Cancer Council NSW (CCNSW), the service electronically facilitates access by researchers to informed, trained consumers. The process has been documented by four peer reviewed publications^{1,2,3,4}.

Our study aimed to evaluate the effectiveness of the Program after ten years of implementation, and to briefly examine the current landscape of consumer involvement in cancer research funding in Australia. The results of both will inform the fine-tuning of CV's future direction in its continual efforts to increase consumer involvement in research and its funding.

Method

Consumers and researchers who have participated in the CIR Program were surveyed separately about their experiences, views and recommendations. We created online surveys through by Survey Monkey (<http://surveymonkey.com>) in April 2016 and the results were analysed and are reported – see summary below. CV also wrote to seven major cancer research funders seeking information about their degree of consumer involvement in research

Key Results

Of the 80 consumers and 70 researchers surveyed, 49 (61%) consumers and 44 (63%) researchers responded. Almost all researchers (95%) regarded the contribution made by the consumers to the research project as highly valuable. A majority of the researchers (60%) noted that consumers played a significant role in shaping research direction and helped researchers gain a deeper understanding of the consumer perspective. In particular, 80% of researchers agreed that the consumer provided insight into issues that were important to the community. Several researchers indicated that consumer involvement enhanced the comprehensiveness and credibility of their research. Some commented that they would like access to a broader range of consumers.

Similarly, most consumers (80%) felt they were able to offer advice to ensure the research project would benefit consumers. Some consumers (19%) did not feel valued because they had received little feedback from the researchers as to the value of their contribution and of the research's progress. In regards to the training course, 88% of the consumers felt that the CIR training course prepared them for their role in research. Their comments included a need for more time to share experiences with other consumers, an annual refresher course, and more opportunity to network with other consumers involved in CIR.

Responses were received from five of the seven cancer research funders contacted. Only three of the five have the requirement that grant applicants show evidence that they had engaged with consumers and would continue to do so if funded. Four funders include at least two consumers on their Grant Review Panels, one of which, the CCNSW, has a Consumer Review Panel which provides 50% of the final rating.

Conclusions

CV's CIR Program is highly valued by both researchers and consumers. The high response rate to both surveys of over sixty percent supports the importance of the program to both parties, and to the benefit of the research itself. The results of the two surveys will help CV further refine the matching process and its associated training course.

CV recommends that a more in depth study be made of cancer research funders' practices regarding meaningful involvement with consumers, both within Australia and internationally, to encourage more cancer research funders to appreciate the benefits of consumer involvement in research.

We see substantial transitional potential for the CIR Program and process to be implemented beyond NSW, and indeed beyond cancer. Cancer Voices' CIR Program is a positive and practical example of implementing the best practice principles of the now well accepted "Partnering with Consumers" concept.

References

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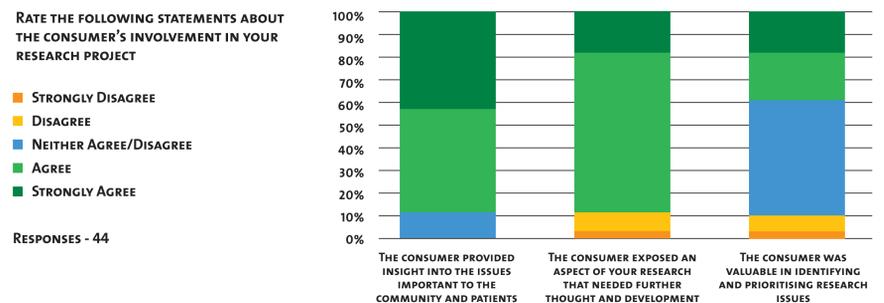
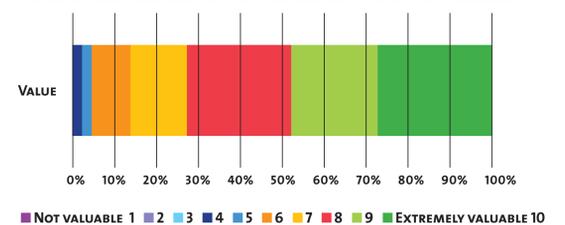
Consumers in Research - Researchers' Survey

RATE THE FOLLOWING STATEMENTS ABOUT THE CONSUMER'S INVOLVEMENT IN YOUR RESEARCH PROJECT

- STRONGLY DISAGREE
- DISAGREE
- NEITHER AGREE/DISAGREE
- AGREE
- STRONGLY AGREE

RESPONSES - 44

THE CONSUMER'S CONTRIBUTION TO YOUR RESEARCH PROJECT WAS VALUABLE



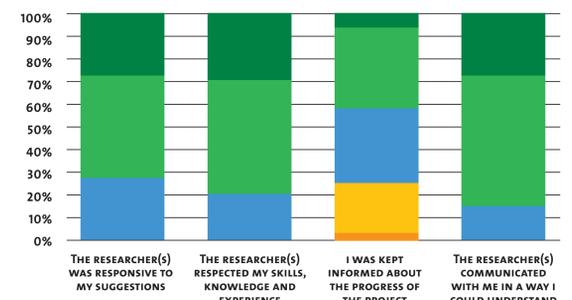
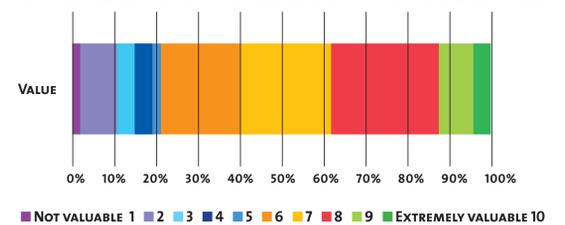
Consumers in Research - Consumers' Survey

RATE THE FOLLOWING STATEMENTS ABOUT YOUR EXPERIENCE WHEN WORKING WITH RESEARCHER(S)

- STRONGLY DISAGREE
- DISAGREE
- NEITHER AGREE/DISAGREE
- AGREE
- STRONGLY AGREE

RESPONSES - 49

HOW VALUABLE DO YOU THINK YOUR CONTRIBUTION WAS TO THE RESEARCH PROJECT?



cancer voices australia



cancer voices nsw