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

Consumer Involvement in Research (CIR) is vital to increasing uptake of consumer involvement in research. It is very easy to overlook simple issues that are important to address. A qualitative research project found that personal, face-to-face interactions and input were of great importance to the research itself. The results of both will inform the fine-tuning of Cancer Voices’ CIR Program.

From researchers participating in Cancer Voices CIR Program

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

The consumer’s contribution is very valuable in identifying research priorities and issues.

The consumer provided personal input and was key to the development of research.

The consumer exposed an understanding of the research’s progress.

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The project leaders appreciate genuinely the consumer involvement and my input has been welcomed and integrated.

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.

Several researchers indicated that consumer involvement enhanced the perspective. In particular, 80% of researchers agreed that the consumer project as highly valuable. A majority of the researchers (60%) noted the contribution made by the consumers to the research.

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

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.

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 Survey Monkey (http:// surveymonkey.com) in April 2016 and the results were analysed and are reported – see summary below. CV also wrote to twenty 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. Amongst all researchers (63%) regarded the contribution made by the consumers to the research project as highly valuable. A majority of the researchers (80%) noted that consumer involvement enhanced the perspective. In particular, 80% of researchers agreed that the consumer project as highly valuable. A majority of the researchers (60%) noted the contribution made by the consumers to the research.

Similarly most consumers (80%) felt they were able to offer advice to ensure the research project would benefit consumers. Some consumers (50%) 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 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 refresh course, and more opportunity to network with other researchers 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 funding to the research projects.

Responses - 49

Strongly Agree Agree Neither Agree/Disagree Disagree Strongly Disagree

1. The consumer involvement is very important to the community and cancer research.
2. The consumer involvement is very important to the community and cancer research.
3. The training covered all aspects of research. Very good strategies were workshoped to ensure the consumer could work in a collaborative way with the researcher.
4. The consumer comments helped to focus the research so that the needs of consumers/cancer patients were addressed.
5. The project leaders appreciate genuinely the consumer involvement and my input has been welcomed and integrated.
6. 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.
7. Several researchers indicated that consumer involvement enhanced the perspective. In particular, 80% of researchers agreed that the consumer project as highly valuable. A majority of the researchers (60%) noted the contribution made by the consumers to the research.
8. The consumer’s contribution is very valuable in identifying research priorities and issues.
9. The consumer provided personal input and was key to the development of research.
10. The consumer exposed an understanding of the research’s progress.

The consumer 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 that on it is easy to prioritise what is more easily “do-able” over what is most relevant to do.

Responses - 44

Strongly Agree Agree Neither Agree/Disagree Disagree Strongly Disagree

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References

5. Saunders C, Crossing S. “From inclusion to independence--training researchers to work effectively with consumers, both within Australia and internationally, to ensure the research project would benefit consumers. Some consumers (50%) 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 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 refresh course, and more opportunity to network with other researchers involved in CIR.
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CONCLUSION

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 both 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 the geographical confines of Australia, and beyond cancer. Cancer Voices’ CIR Program is a positive and practical example of implementing the best practice principles of the now well accepted “Participating with Consumers” concept.