

POSITION STATEMENT

Consumer involvement in research (CIR)

Issues

- Increasing the rate and level of consumer participation in the direction and development of cancer research, and in cancer research funding decisions
- Making the cancer research and research funding communities aware of research priorities for people affected by cancer

Background

Cancer Voices NSW believes, and there is strong evidence to support its view, that consumers can and do add value to research both through their participation in the process and by research question prioritisation.

Participation can take place at a range of levels – from posing issues and questions for research, to providing input during the development of a project and its protocols, acting as Associate Investigator, providing review services of research proposals, checking patient information for clinical trials, to participating in decision-making about which projects are funded by research funding organisations.

Present Position

Cancer Voices was successful (2001) in proposing that the Cancer Council NSW (CCNSW) adopt the principle of consumer involvement in research, initially in research funding decisions. This concept appealed to CCNSW as a way of validating that its research funding reflected the needs of the community which supports it. Since 2006 Consumer Research Training has been offered annually and a Consumer Review Panel uses specific consumer values criteria to assess research grant applications. This process was publicised in three peer reviewed journals in 2007/08, and at national and international conferences, to encourage its adoption by other research funding organisations. Principal elements have now been adopted by the major cancer funding bodies.

In 2009, CVN and CCNSW held a Consumer Research Priorities Forum, which identified a large number of issues cancer consumers wish to see studied. The outcome of this was co-authored by CVN's Sally Crossing in a 2012 peer reviewed journal. In 2010 CCNSW funded a major consumer research priority, a collaboration of pharmacogenomics researchers, with continuing CVN input.

Cancer Voices itself operates a free, electronic “match-making” service for cancer researchers at state and national levels - to be connected to informed, trained consumer advisors. This is widely used in NSW. See www.cancervoices.org.au for request forms and more information.

Recommendations

- That the value of consumer involvement in research is formally recognised and its contribution required by researchers and research funders
- That mechanisms are developed and adopted to enable consumer participation and representation at all appropriate and value-adding levels, including funding decisions.
- That consumer organisations, such as CVN, regularly collect, collate and present the research questions regarded by consumers as having priority for them.
- That research institutes, organisations and foundations take note of the research priorities of consumers and factor them into their work.

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