

Review of Health & Medical Research in Australia (McKeon Review) 2012: Cancer Voices NSW Submission

Thankyou for the opportunity to contribute to this independent review of strategic health and medical research and which will recommend a ten year plan for Australia: the McKeon Review.

Cancer Voices welcomes the Terms of Reference (ToR)'s recognition of major context changes for research since the previous Review, particularly:

- the increase of chronic disease, in which cancer plays an increasing part as more people are living with cancer than die of it
- the impact of genomic profiling and targeted therapies on treatment options, and
- the value of translating research into clinical practice more quickly.

ToR 7: Enhancing consumer and community participation

Cancer Voices NSW wishes to comment principally on the need to include substantive reference to the value of health consumer participation and involvement in health and medical research. This concept, noted by ToR No 7, has been adopted by a number of researchers and research funders, including the NHMRC (to varying degrees) since the Wills Review. We suggest that its recognition by the present review would show that the Australian health and medical research sector understands the value of this relatively new development.

However we recommend that comparison of the NHMRC's practices in this area should first be made with those of other research funders within Australia, then internationally. Several Australian funders are very well advanced and use best practice in this area – in the cancer world with which we are familiar, the Cancer Council NSW and some other states Cancer Councils, the Victorian Cancer Agency, Cancer Australia, the National Breast Cancer Research Foundation, and Cure Cancer Australia to mention a few. Cancer consumer organisations like Cancer Voices NSW, Cancer Voices SA and the Breast Cancer Network Australia have well developed processes to assist the researcher to engage with informed, preferably trained consumer representatives to meet their own and their funders' requirements and to add value.

Case Study: Cancer Voices NSW's Consumer Involvement in Research (CIR) Program

Cancer Voices NSW is Australia's oldest (est. 2000) generic cancer consumer advocacy group and has had a great deal of experience in the area of consumer engagement in research. Our CIR program addresses the following activities, all of which we believe enable the value of consumer input to enhance the value of research:

- Prioritising the direction of cancer research
- Providing informed consumer input to grant making decisions for funders
- Training for consumers interested in research and for researchers wanting to understand how to engage with consumers
- Fulfilling requests from researchers looking to engage with informed consumers in the development of their projects ("match-making")

Expertise of Cancer Voices NSW

Cancer Voices NSW has a well developed program to deliver the above, in use over the last seven years and supported by several peer reviewed journal papers. These are referenced in a description of our CIR Program in the booklet, *A Decade of Success: Cancer Voices NSW 2000-2010* (pages 22 & 23) ISBN 978-0-645-55881-3, which also includes the text of a poster prepared for a COSA Annual Scientific meeting which outlines our comprehensive program.

Several of our members have served as consumer representatives (ie representing consumers, not their organisations) on grant review panels for the NBCF, Cancer Australia and for the Cancer Council NSW, as well as on a number of other research related committees, including the NBCF's National Consumer Advisory Group. Cancer Voices NSW has nominated informed consumers to 91 research studies and projects for 21 research organisations in and beyond our state.

We are working closely with the Clinical Oncology Society of Australia on its project to develop of a Consumer Engagement in Research module for the clinical trials groups. Our experience is also being contributed to the current review of the NHMRC and Consumers Health Forum of Australia's Statement on Consumer and Community Participation in Health and Medical Research.

Sometimes we initiate studies ourselves, seeking partners and funders to make them a reality. We may become Investigators and co-authors in reporting those studies which are of particular interest to us. For example:

- Cancer Voices NSW successfully advocated for substantial funding (\$5m) by Cancer Council NSW for a consortium of NSW research institutions working in the area of personalised medicine – reflecting a strongly endorsed consumer priority.
- Cancer Voices NSW initiated the development and implementation of the Australian Cancer Trials website through a large NHMRC grant. It is a consumer friendly portal which enables patients, clinicians and researchers to access open clinical trials in Australia. This was launched in 2011 and is now maintained by Cancer Australia.

More generally we welcome the scope and direction of the Review, as outlined in the thirteen Matters for Review. We suggest that developments and programs like ours may exist in other major disease groupings – consumers, researchers and funders - and that it may be well worth the Review investigating the extent of this if possible. Cancer Voices will attend the Sydney public meeting and would be pleased to participate further if requested to do so.

Sally Crossing AM

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Cancer Voices NSW

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Cancer Voices NSW provides the independent voice of people affected by cancer, working to improve the cancer experience of the 40,000 people who are diagnosed each year. 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 providers of these services, ensuring the patient perspective is heard.

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