



STATEMENT OF CONSUMER VALUES ON CANCER RESEARCH

Background

In a survey of consumers (including patients, survivors and carers) by Cancer Voices SA in 2006, 33% of respondents identified that “influencing the research agenda” was a priority issue¹. The SA Statewide Cancer Control Plan identifies collaboration between researchers and community representatives as desirable².

This is reflected in the *Cancer Australia National Consumer Advisory Group Consensus Values Statement* which urges that “all people affected by cancer ... 10. are viewed as important strategic partners by medical, research, industry, government and policy making groups, in all aspects of decision making across the cancer continuum of prevention, early detection, diagnosis, treatment, rehabilitation, survival and palliative care; and the direction of research”³.

In turn, the *Charter of Paris* from the World Summit Against Cancer 2000, Article VII says of “Open and collaborative communication between people with cancer and health care professionals and scientists is essential”, and that “The medical research, industry and policy communities will regard informed patient advocates as key strategic partners in all aspects of the fight against cancer”⁴.

The national government body *Cancer Australia* has an expectation that all research funded through its programs will have consumer involvement, and has involved consumers in determining priorities and assessment of grant applications⁵.

The Communique of the *Involving People in Research* Symposium, Perth, 2008 urged the NHMRC and other research funding bodies that “consumer resources should be more formally involved in research design, priorities, funding and dissemination”⁶. There is a useful NHMRC/Consumers Health Forum of Australia *Model Framework for Consumer and Community Participation in Health and Medical Research* adopted in 2004⁷.

Apart from the democratic angle, consumers have a different perspective to bring to determinations about cancer research including practical experiences, particular views on cancer issues and priorities, and ideas about what might work and how.

¹ M Beresford, *Cancer Voices SA Questionnaire Report 18/1/07*

² *Statewide Cancer Control Plan SA Govt/Cancer Council SA 2006* p62 item 6

³ Australian Government, *Cancer Australia National Consumer Advisory Group Consensus Values Statement 2008*

⁴ World Summit Against Cancer 2000 *Charter of Paris* Article VII principles 2 and 6

⁵ *Cancer Australia* Minutes of National Consumer Advisory Group 19/3/08 page 3 item 3

⁶ Communique of the *Involving People in Research* Symposium, Perth, March 5-6 2008

⁷ See *Consumers Health Forum of Australia* website or Saunders, Crossing, Girgis, Butow & Penman “Operationalising a model framework for consumer and community participation in health and medical research” 2007 *Australia and New Zealand Health Policy* 4:13; see also *Consumer and Community Participation in Health and Medical Research*, March 2010, University of WA School of Population Health & UK Consumer Advocate (www.sph.uwa.edu.au).

Statement of consumer values on cancer research

In accord with the statements above, the more detailed aims of SA consumers in relation to cancer research through both public and private organisations are as follows:

1. Cancer consumers include cancer patients, survivors, carers and supporters, but not paid medical health professionals providing services to a patient or paid cancer researchers.
2. Cancer consumers should be involved in all stages of cancer research including:
 - Determination of desirable research aims and outcomes;
 - Consideration of research opportunities;
 - Determination of research priorities;
 - Planning and determination of the means or mechanisms for achieving those priorities, such as research programs, establishment of research facilities or centres, necessary funding, infrastructure and other elements;
 - Determination of guidelines for researchers including appropriate levels of consumer collaboration and participation
 - Consideration of applications and awards of funding for cancer research;
 - Participation in planning, design and implementation of actual research projects;
 - Review of information (including form of advice on potential data use, how data may be provided to other agencies), questionnaires and consent letters to be provided to participants;
 - Participation in evaluation of research;
 - Participation in translation of research into practical outcomes.
3. Because consumers may feel intimidated by health professionals and others with scientific knowledge, and to facilitate continuity in the event of recurrent illness, cancer consumer representation on committees, boards or any decision, policy making, or consultative groups in relation to cancer research should include a deputy. Such deputies should be free to attend and participate in the proceedings of such a group, desirably (if not necessarily) having a right to vote even when the other representative is present.
4. Consumer representatives should be offered a sitting fee equivalent to other professional members of any committee or group, and where others are involved in the course of their paid employment, fees should be determined by reference to an equivalent body. If fees are not offered at least travel and incidental costs (such as parking, copying etc) and gift such as a voucher should be offered.
5. To help achieve consumer aims there should be practical assistance and funding to develop skills in SA consumer involvement in cancer research, through either voluntary or government bodies, and this should include training and peer support programs⁸.
6. Consumer representatives from existing cancer/advocacy groups are likely to be able to participate more effectively due to access to networks of cancer consumers and current information, than individuals selected by public advertisement (but the latter may have some role as a back-up source of nominees or in terms of special expertise and could be encouraged to join existing consumer networks).

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(2nd Draft)

⁸ e.g. *Consumer Involvement in Research* program, a joint initiative of Cancer Voices NSW and Cancer Council of NSW, see www.cancervoices.org.au .