



POSITION STATEMENT

Supporting consumers to attend cancer conferences

Issue

Supporting consumers and independent consumer organisations to attend cancer conferences enhances their capacity, understanding, knowledge and ability to contribute. There is an identified need for resourced organisations to support this kind of engagement.

Background

Independent cancer consumer organisations and their members benefit from being kept well informed about new developments in cancer research and clinical practice. They also benefit by the opportunity to meet key players in the cancer world, national and overseas. This underpins the value of their advocacy towards improving the experience of people affected by cancer. Well informed and networked consumers are able to make more valuable contributions to discussion and can advise their own networks. This principle is recognised by ASCO, and demonstrates a supporting organisation's commitment to consumer engagement. The most direct way to achieve this is through consumers being able to attend cancer conferences on topics across the spectrum – from basic through to psychosocial research and service developments.

Present situation

Cancer organisations such as the Cancer Councils and the Clinical Oncology Society of Australia (COSA) used to underwrite the cost for a small number of cancer consumer representatives to attend conferences. This support was largely available to cancer consumers who belonged to unfunded, independent and volunteer cancer consumer organisations. Unfortunately this practice has fallen away. Sometimes the "student" rate registration fees are offered, but such assistance is minimal and does not nearly cover the cost of registration, travel and accommodation - necessary to enable unsalaried consumers to attend. Pharmaceutical companies may offer support to attend conferences organised by themselves or by others, but this kind of assistance is usually not acceptable due to the possibilities of conflict of interest and influence factors, whether transparent or not.

Recommendation

Cancer Voices recommends:

- That options for addressing this kind of investment be considered by organisations at senior level, including the Cancer Councils, COSA and any other generic cancer agencies and organisations.
- That the benefits of helping members of cancer consumer organisations keep up to date with developments in the cancer world, providing networking opportunities and showing respect for their contributions, be noted by these organisations.
- That the benefits of enhanced engagement with independent, informed consumers be recognised by the organisations.
- That industry support may be acceptable if pooled through an industry association, or other appropriate third parties.
- That suitable nominees for attendance are sourced through independent networks like the Australian Cancer Consumer Network (30 cancer consumer groups), Cancer Voices and their members.

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Cancer Voices Australia is the independent, the volunteer voice of people affected by cancer - since 2000.

