Cancer Voices Australia

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POSITION STATEMENT

BEST PRACTICE CONSUMER REPRESENTATION

Issue

Cancer Voices Australia (CVA) recommends that the principles of best practice consumer representation should be reflected in the policies and practice of all cancer organisations and other stakeholders with which it works. The objective is to enable an informed and broad consumer perspective to be considered wherever decisions are made which impact people affected by cancer.

Background & Present Position

Since 2000, the Cancer Voices movement uses established best practice principles developed by the Consumers Health Forum (CHF) of Australia, the National Breast Cancer Centre, the Charter of Paris against Cancer (2000), the Commonwealth Consumer Affairs Advisory Council (CCAAC) and most recently, Cancer Australia (2011), to engage with a range of organisations which make decisions about cancer, in a way that is constructive for all parties.

For its part, CVA's responsibility is to:

- ♦ offer access to training in consumer advocacy and representation
- provide a network of support, mentoring and information for cancer consumer representatives
- provide decision-makers with trained and informed consumer representatives who are able to offer a broad view

Definitions: CVA endorses the following definition:

Consumer representative: "A committee member who voices the consumer perspective and takes part in the decision making process on behalf of consumers. This person is usually nominated by, and is accountable to, an organisation of consumers". (CHF)

The CCAAC recommends the following principles be adopted:

"Representatives of consumer interests in the overseeing entity are

- (a) capable of reflecting the viewpoints and concerns of consumers; and
- (b) persons in whom consumers and consumer organisations have confidence"

Consumer organisation: "a group

- ♦ whose main objective is to genuinely advance the interest of consumers:
- \Diamond that is independent of industry and government in its decision-making
- due to its activities, membership and other relevant factors, is publicly recognised as playing a legitimate role in advancing the interests of consumers" (CCAAC)

Recommendations

Cancer Voices Australia believes that these principles should be reflected in the policies and practice of cancer organisations and other stakeholders with which it works.

This is especially pertinent when CVA nominates cancer consumer representatives to participate in national level decision-making which could affect the people we represent. The occasional practice of appointments of non-networked individuals is not recommended, due to the limitations of personal experience only, rather than ability to contribute the value of the broader informed view.

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















