

## POSITION STATEMENT

### Best practice consumer representation

#### Issue

Cancer Voices NSW (CVN) recommends that 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. These principles enable an informed and broad consumer perspective to be included in decisions that impact on people affected by cancer, and to have their voices heard.

#### Background

To engage with a range of organisations concerning their decisions about cancer which is constructive to all parties, CVN uses established best practice principles developed by the Consumers Health Forum (CHF) of Australia, the Charter of Paris against Cancer, the Commonwealth Consumer Affairs Advisory Council (CCAAC) and Cancer Australia together with Cancer Voices Australia (2011). These principles are reflected in MOUs with major partners, eg Cancer Council NSW.

For its part CVN's responsibility is to:

- ◇ offer access to training in consumer advocacy and representation
- ◇ provide a network of support, mentoring and information for its consumer nominees
- ◇ provide decision-makers with trained and informed consumer representatives who are able to offer a broad, informed consumer view – not an organisational one.

#### Present Position

**Definitions:** CVN endorses the following definitions:

**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** (again CCAAC): *“is a group*

- ◇ whose main objective is to genuinely advance the interest of consumers;*
- ◇ 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”*

#### Recommendations

**Cancer Voices NSW 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 CVN nominates cancer consumer representatives to participate in decision-making which could affect people with cancer. The occasional practice of appointments of non-networked individuals is not recommended, due to the limitations of personal-only experience.

**Reviewed April 2014**

#### References:

Principles for the Appointment of Consumer Representatives: A Process for Governments and Industry, CCAAC June 2005  
Guidelines for Consumer Representatives, CHF 2001 (4<sup>th</sup> edition)

CHFA Position Statement – Consumer Representatives Shape Health in Australia 2007

National Framework for Consumer Involvement in Cancer Control (Cancer Australia & Cancer Voices Australia 2011)