

Background

Cancer Australia was established by the Australian Government to benefit all Australians who are diagnosed with cancer, their families and carers.

Cancer remains a national health priority in Australia with significant implications for individuals, families, communities and the health system.¹

As a specialist Government agency providing national leadership in cancer control, Cancer Australia aims to reduce the impact of cancer, address disparities and improve outcomes for people affected by cancer by leading and coordinating national, evidence-based interventions across the continuum of care.

Cancer Australia is uniquely positioned to achieve impacts in cancer control at the health system, health professional, community and consumer levels. Cancer Australia achieves this through shared leadership; working together to identify and address defined priorities to maximise outcomes from cancer control efforts.¹

Cancer Australia's *Consumer engagement strategy* utilises a strategic approach to harnessing consumer engagement for better outcomes in health policy, health services, and research.

The Cancer Australia Strategic Plan 2014-2019 is working towards the following goals in cancer control:



Consumer engagement and Cancer Australia

People affected by cancer and the broader community are seeking to be active participants in decision making about their health. Cancer Australia values the integral role of consumers in patient centred care and cancer control.²

The *Cancer Australia Strategic Plan 2014-2019* identifies the opportunity to work with various stakeholders, consumers being key among these, on our direction and contribution to cancer control.¹

The *National Framework for Consumer Involvement in Cancer Control* (the Framework) developed in collaboration with Cancer Voices Australia, provides international leadership in promoting effective engagement of consumers at all levels in cancer control. Cancer Australia's strategic and operational approach to consumer involvement is underpinned by the Framework.³

Cancer Australia recognises that higher levels of consumer involvement within the health system result in greater impact on health outcomes.⁴



Strategic goals for consumer engagement

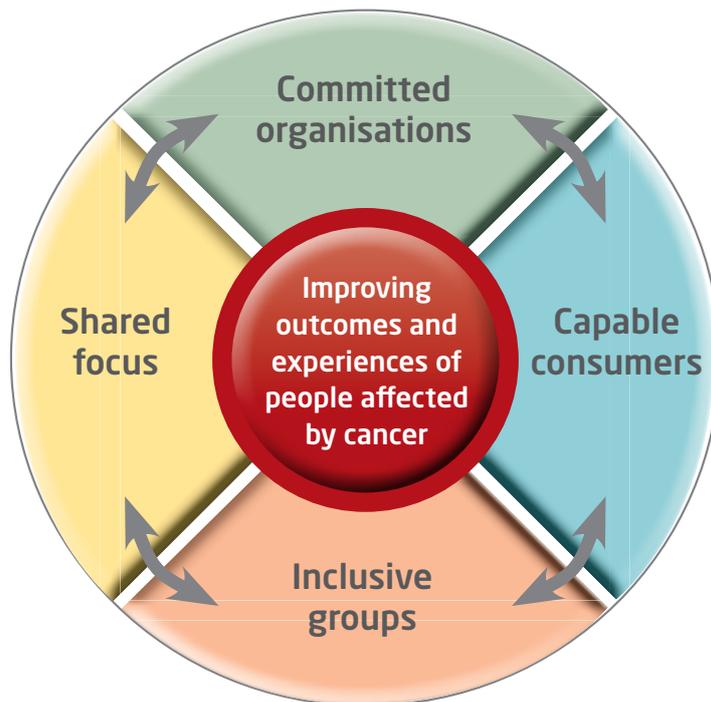
- ▶ Cancer Australia is building consumer awareness and understanding so that consumers can actively participate in decisions affecting their health and in health care more broadly.
- ▶ Consumer capability is developed through education, training and online resources to support meaningful consumer engagement in the national cancer care and control agenda.
- ▶ Cancer Australia engages a broad range of consumers including Aboriginal and Torres Strait Islanders, culturally and linguistically diverse communities and rural and remote communities whose outcomes are poorer.
- ▶ Consumer involvement is integrated throughout Cancer Australia's leadership and operational programs through the creation of opportunities for involvement with key stakeholders in each of our advisory and working groups and forums.

Consumer engagement approach

Cancer Australia's approach to consumer involvement is driven by the Framework principles and underpinned by the Framework elements:³

- ▶ Committed organisations that integrate consumer involvement in all aspects of organisational practice, processes and systems from governance structures through to service delivery, policy development and research;
- ▶ Capable consumers who are supported, trained and selected for their cancer experience and capability to engage meaningfully and represent the views of people affected by cancer;
- ▶ Inclusive groups including advisory groups, working groups and multidisciplinary teams who involve consumers as respected, equal members of the team, and;
- ▶ Shared focus where the desired goals are mutually agreed and all the elements are integrated and interrelated for effective consumer engagement towards improved outcomes.

Figure 1: Elements for effective consumer engagement



Guiding principles for consumer engagement

Cancer Australia's guiding principles for consumer engagement are based on the Framework's core principles which aim to guide and strengthen consumer engagement in all aspects of cancer care and control and place the needs of people most affected at the centre of policy, health systems, service delivery, health care and research:³

- ▶ Consumers are involved at all levels of the agency including Cancer Australia's Advisory Council and consumer representatives on each of our advisory groups, working groups and steering committees.
- ▶ Consumers are provided with training and support to improve their knowledge and understanding and optimise their involvement in providing the consumer perspective in reducing the impact of cancer.
- ▶ Consumers are respected and acknowledged for their cultural, social and geographical diversity. Consumers from Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities and rural and remote communities are engaged in an appropriate and culturally safe environment.
- ▶ Cancer Australia staff and key stakeholders involved in our program of work engage with consumers respectfully and as equals.
- ▶ Consumers are actively involved in building the evidence for improved cancer care and improved outcomes.

Cancer Australia Consumer Engagement Strategy

Committed Organisation	Cancer Australia is committed to meaningful consumer engagement and integrates consumer involvement across all programs.	<ul style="list-style-type: none"> ▶ Advisory Council ▶ Advisory groups ▶ Partnerships
Capable Consumers	Cancer Australia harnesses the valuable expertise of consumers to inform activities. Consumer participation is based on experience, motivation and capability.	<ul style="list-style-type: none"> ▶ Recruitment ▶ Selection ▶ Invitation ▶ Support ▶ Training
Inclusive Groups	Meaningful consumer engagement occurs in groups and teams. Cancer Australia works with key stakeholders to improve understanding of the value and contribution of consumers.	<ul style="list-style-type: none"> ▶ Breast ▶ Gynaecological ▶ Lung cancers ▶ Project groups ▶ Assessment panels
Shared Focus	Consumers and group members contribute best with a clear understanding of the group's purpose and the organisational context. This results in a shared focus, agreed outcomes, key targets, milestones and evaluation.	<ul style="list-style-type: none"> ▶ Information resources ▶ Clinical guidance ▶ Education ▶ Models of care ▶ Consumer support grants ▶ Priority research grants

Improving outcomes, better care, evidence-based practice, world class research, beneficial policy through stronger consumer involvement to improve the lives of people affected by cancer.

How we engage with consumers

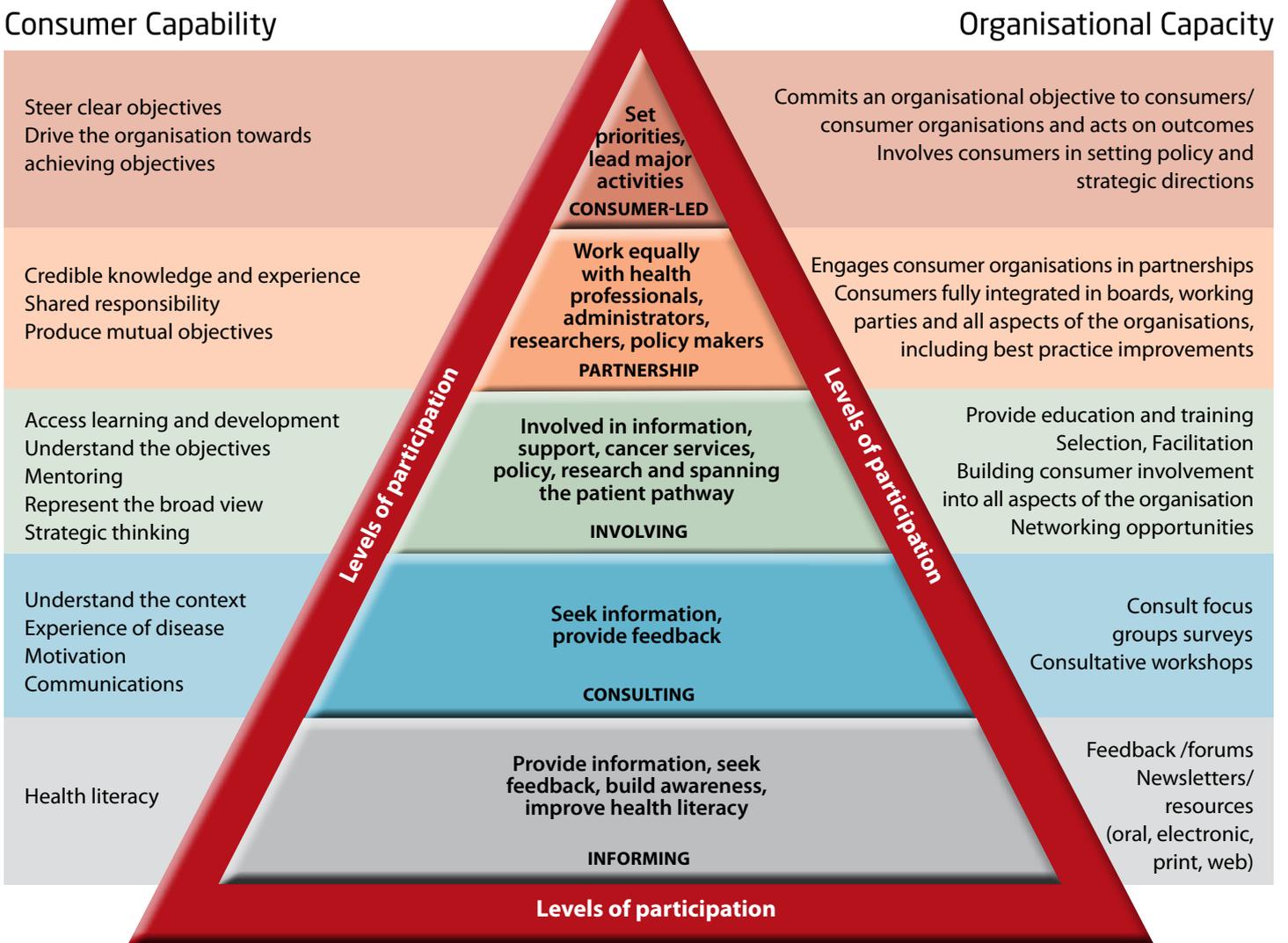
- ▶ Cancer Australia selects consumers best suited to support different aspects of its work. This may include advertising and selection through a merit based process, and/or by invitation due to the particular experience and skills required and relevance for the consumer role.
- ▶ To enable consumers to be effectively engaged and supported, consumers are provided with training and orientation. This training may be provided by the consumer organisation in which they are involved, for example Cancer Councils, Breast Cancer Network Australia, or may be provided by Cancer Australia.
- ▶ To support consumer participation as members of Grant Review Committees in the Priority-driven Collaborative Cancer Research Scheme (PdCCRS), Cancer Australia's consumers are provided with training in the assessment of applications. These consumers are identified through a national call for Expressions of Interest, and the training workshop held in partnership with Cancer Council NSW.
- ▶ Cancer Australia has established and maintains a network of consumers and invites consumers to participate on each of its advisory groups and working groups. Cancer Australia also holds forums and workshops with consumers and key stakeholders, including Aboriginal and Torres Strait Islanders, culturally and linguistically diverse communities and rural and regional communities, to identify consumer needs, develop evidence based resources and identify/implement strategies to reduce the impact of cancer and improve outcomes for people affected by cancer.
- ▶ Cancer Australia respects and values the contribution made by consumers in progressing our program of work. We build relationships with consumers for best effect. We provide administrative support including hard copy materials for meetings and provide travel and out of pocket expenses. Cancer Australia provides sitting fees consistent with other Commonwealth agencies for consumers who do not receive funding from any other source.
- ▶ Consumers participating in Cancer Australia advisory groups and project working groups include consumers from rural and remote communities, Aboriginal and Torres Strait Islanders, and culturally and linguistically diverse communities and, bring skills in a broad range of cancer experiences. Cancer Australia benefits from consumers sharing their experiences to inform knowledge, evidence based practice and patient centred approaches to cancer care and research.
- ▶ Cancer Australia aims to acknowledge and on occasion recognise consumers for their significant contribution to the work of Cancer Australia in reducing the impact of cancer on the Australian community.



Cancer Australia model of engagement

Cancer Australia has an integrated and effective model of engagement and uses strategic, coordinated, cross disciplinary collaboration as a key enabler of achieving outcomes. This involves collaboration across sectors and amongst cancer control stakeholders including consumers with a shared focus in cancer control.^{1,5}

Figure 2: Consumer involvement model



Summary

▶ Cancer Australia aims to strengthen consumer involvement to achieve better care, beneficial policy and targeted research to improve the lives of people affected by cancer.

Glossary of Terms

Consumer refers to a person affected by cancer as a patient, survivor, carer or family member; or a consumer organisation representing the views of consumers.³

Consumer involvement refers to an active partnership between consumers and an organisation in the policy, service delivery and research process. This refers to doing projects 'with' or 'by' consumers, rather than 'to', 'about' or 'for' the consumer.³

Consumer engagement informs broader community engagement. It refers to consumers being involved in their own health care, planning and developing health policies, service planning, contributing to research and clinical trials, implementation and evaluation. It is a broad term to cover the range of activities used by governments, organisations and individuals to involve consumers in activities of cancer control.⁵

Consumer engagement strategies and **patient centred** care are synonymous and aim to have active and informed consumers as equal partners in decision making processes at all levels of the healthcare system.⁶

Consumer participation refers to being part of the process. It is more than observing and commenting; it refers to actual involvement in decisions, the authoring of solutions and development of sustainable frameworks.³

Patient-centred care is care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.⁷

Consumer-centred care is sometimes preferred to 'patient-centred care' to acknowledge that care should focus on people who are actual or potential users of healthcare services. For some, the term 'patient' has passive overtones. In contrast, the term 'consumer' is seen as a more active term, encompassing the need to engage people as partners in health service delivery. The term 'consumer' also aligns with 'client' and 'user' in business and management models of service delivery.⁸

Person-centred care is often used interchangeably in primary care settings with terms such as 'patient-centred care', 'person-centredness', 'relationship-centred care' and 'personalised care'. This term appears more frequently in literature on the care of older people, and focuses on developing relationships and plans of care collaboratively between staff and patients. This term values the needs of patients, carers and staff, with emphasis on the reciprocal nature of all relationships.⁸

Personalised care is the integrated practice of medicine and patient care based on one's unique biology, behaviour and environment. Personalised care uses genomics and other molecular-level techniques in clinical care; as well as health information technology, to integrate clinical care with the individualised treatment of patients.⁸

Citizens Council brings the views of the public to decision making about promotion of good health and the prevention and treatment of ill health. A group of 30 people drawn from all walks of life, the Citizens Council tackles challenging questions about values- such as fairness and need.⁹

References

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