



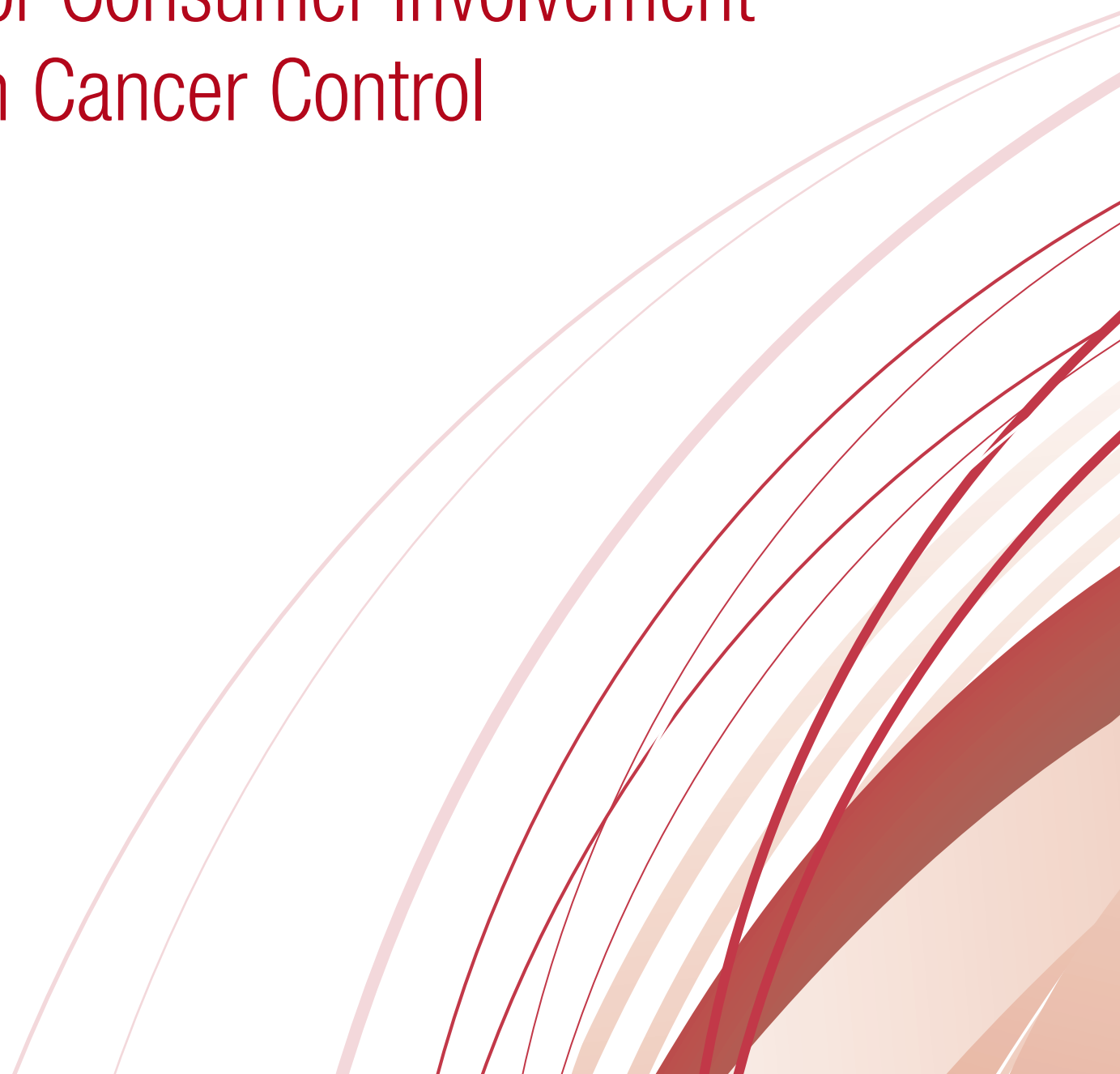
Australian Government
Cancer Australia

National Framework for Consumer Involvement in Cancer Control



Australian Government
Cancer Australia

National Framework for Consumer Involvement in Cancer Control



Cancer Australia

National Framework for Consumer Involvement in Cancer Control

This report is available in print from 39 libraries around Australia and online at www.canceraustralia.gov.au

ISBN: 978-1-74241-465-2

Online ISBN: 978-1-74241-466-9

Publications Approval Number –D0400

Suggested citation

Cancer Australia and Cancer Voices Australia, 2011. *National Framework for Consumer Involvement in Cancer Control*. Cancer Australia, Canberra, ACT.

Paper-based publications

© Commonwealth of Australia 2011

This work is copyright. You may reproduce the whole or part of this work in unaltered form for your own personal use or, if you are part of an organisation, for internal use within your organisation, but only if you or your organisation do not use the reproduction for any commercial purpose and retain this copyright notice and all disclaimer notices as part of that reproduction. Apart from rights to use as permitted by the Copyright Act 1968 or allowed by this copyright notice, all other rights are reserved and you are not allowed to reproduce the whole or any part of this work in any way (electronic or otherwise) without first being given the specific written permission from the Commonwealth to do so. Requests and inquiries concerning reproduction and rights are to be sent to the Publications and Copyright contact officer, Cancer Australia, Locked Bag 3, Strawberry Hills, NSW 2012.

Internet sites

© Commonwealth of Australia 2011

This work is copyright. You may download, display, print and reproduce the whole or part of this work in unaltered form for your own personal use or, if you are part of an organisation, for internal use within your organisation, but only if you or your organisation do not use the reproduction for any commercial purpose and retain this copyright notice and all disclaimer notices as part of that reproduction. Apart from rights to use as permitted by the Copyright Act 1968 or allowed by this copyright notice, all other rights are reserved and you are not allowed to reproduce the whole or any part of this work in any way (electronic or otherwise) without first being given the specific written permission from the Commonwealth to do so. Requests and inquiries concerning reproduction and rights are to be sent to the Publications and Copyright contact officer, Cancer Australia, Locked Bag 3, Strawberry Hills, NSW 2012.



Table of Contents

Acknowledgements.....	ii
Preface.....	iii
1 Introduction.....	1
2 National Framework for Consumer Involvement in Cancer Control.....	4
3 Core Principles of Consumer Engagement in Cancer Control.....	4
4 Key Elements of the Framework.....	5
5 Criteria for each Framework Element.....	7
6 Consumer Involvement.....	9
7 Types of Consumer Involvement.....	10
8 Consumer involvement spanning the cancer pathway.....	12
9 Appendices.....	14
A Framework elements and criteria.....	15
B Depth of consumer participation.....	19
C Levels of consumer participation.....	21
D Consumer involvement roles.....	22
E Project methodology.....	23
F Literature summary.....	25
G Consumer needs for involvement in cancer control.....	27
H Expectations of cancer organisations and professional bodies.....	32
I Consultation findings.....	36
J Drivers for change.....	38
K Members of the project governance.....	39
10 Glossary.....	43
11 References.....	47

List of Figures

1 Elements for effective consumer involvement in cancer control.....	6
2 Consumer involvement capability.....	9
3 Types of consumer involvement.....	11
4 Depth of consumer participation.....	19

List of Tables

1 Consumer involvement framework spanning the cancer pathway.....	12
2 Framework elements and criteria.....	15
3 Degrees of consumer control.....	20
4 Levels of consumer participation.....	21
5 Consumer involvement roles.....	22
6 Consumer needs for involvement in cancer control.....	27
7 Expectations of cancer organisations and professional bodies.....	32
8 Summary of consultation findings.....	36

Acknowledgements

Cancer Australia and Cancer Voices Australia would like to thank the following people and organisations who have been instrumental in developing the *National Framework for Consumer Involvement in Cancer Control*:

Membership of the Project Steering Group

Dr Ian Roos OAM (Chair)
Ms Lyn Swinburne AM
Dr Helen Zorbas (CEO)
Dr Anna Williamson
Ms Cathy Mitchell
Professor Annette Street
Dr Nicola Dunbar
Assoc Professor Christine Giles
Dr Joanne Ramadge
Ms Susan Hanson (project lead)

Membership of Consumer Informant Group

Mr John Newsom (Chair)
Mr Tony Addiscott
Ms Agnes Vitry
Ms Anne Kay
Mr David Gregory
Ms Danielle Tindle
Dr Anne Atkinson
Ms Sharna Chenery
Ms Linda Christenson
Ms Kay Duffy OAM
Ms Joyce Graham
Ms Karen Forster
Mr Tony Cocchiario
Mr Michael Powell
Ms Roslyn Weetra
Ms Leonie Young
Ms Kathy Smith
Mr Ashleigh Moore

Membership of the National Reference Group

Dr Julie Thompson (Chair)
Ms Mary Reid
Ms Joan Hughes
Ms Amanda Winiata
Ms Sally Crossing AM
Ms Catherine Bullivant
Dr Ian Roos OAM
Dr Claire Treadgold
Assoc Professor Bogda Koczwara
Ms Margaret McJannett
Professor John Zalcborg
Ms Karen Livingstone
Ms Cheryl Grant
Professor Michael Milward
Professor Nik Zeps
Mr John Newsom
Assoc Professor Rosemary Knight
Assoc Professor Sundram Sivamalai
Dr Anna Williamson
Mr William Darbishire
Ms Kerry Callaghan
Ms Kay Francis
Ms Kate Kelleher
Ms Tricia Elarde
Assoc Professor Christine Giles
Ms Cathy Mitchell
Dr Jessica Harris
Mr Gordon Gregory
Ms Annabel Davies
Dr Yvonne Luxford
Mr Graham Higgs
Dr Meron Pitcher
Dr Beres Wenck
Ms Gabrielle Prest
Dr Liz Kenny

Professor Jeanette Ward
Ms Elise Davies
Dr Euan Walpole
Professor Patsy Yates
Professor Phyllis Butow
Professor Sanchia Aranda
Assoc Professor Tim Shaw
Ms Marie Malica
Dr Anne Atkinson
Dr Dell Horey
Ms Catherine Holliday

Members of the International Linkages Group

Ms Lyn Swinburne AM (Chair)
Dr Helen Zorbas (CEO)
Ms Kathy Redmond
Professor Jessica Corner
Ms Christine Brunswick
Dr Ian Roos OAM
Ms Susan Hanson

Cancer Australia staff

Dr Norman Swan **Medical Communications** who facilitated the workshop and assisted with writing the final report.

Cate Riley **FADStudios** who undertook the design of the report.

The authors also acknowledge the many other consumers, researchers, health professionals, policy makers and service providers from across Australia and internationally who participated in the consultation process.

Preface

The *National Framework for Consumer Involvement in Cancer Control* has been developed by Cancer Australia in partnership with Cancer Voices Australia to enhance meaningful consumer involvement at all levels of cancer control in order to improve outcomes and experiences for people affected by cancer.

The development of the Framework was undertaken using a systematic approach with engagement from a broad range of people and organisations committed to improved outcomes in cancer control. Following extensive consultation, a review of the evidence and supported by a national development workshop, the project found high-level agreement for this National Framework to set the direction for effective consumer participation.

The Framework identifies the needs of consumers participating in cancer control and the expectations of health professionals, service managers, researchers and policy makers who seek to engage consumers successfully. The Framework identifies the key elements to help guide organisations to engage consumers in cancer control more effectively to achieve better care, beneficial policy and more targeted research.

Cancer Australia and Cancer Voices Australia would like to thank all those people and organisations, both in Australia and overseas, who have been actively involved in the development of the Framework.

We hope that organisations aiming for best practice in consumer involvement will find this Framework valuable in developing strategies that build sustained consumer involvement, which in turn will improve the lives of people affected by cancer.




Dr Helen Zorbas
CEO
Cancer Australia



Dr Ian Roos OAM
Chair
Cancer Voices Australia

National Framework for Consumer Involvement in Cancer Control



Introduction

The Purpose

The *National Framework for Consumer Involvement in Cancer Control* (The Framework) aims to support organisations committed to involving consumers in cancer control and has been designed to facilitate consistent approaches to consumer engagement. It is a national resource which complements jurisdictional frameworks, policies and tools already in place. The evidence is that where consumers are viewed as equal and integral members of health services, cancer research groups and policy development, there will be improved outcomes and experiences for those affected by cancer. In addition, meaningful consumer engagement can build a trusted and confident health service.

This Framework offers principles to govern consumer engagement and elements and guidance which can be adapted to local circumstances.

While the Framework has been developed for cancer control it may be transferable to other areas of health care, research and policy development.

The Context

Cancer is a leading cause of death globally [1]. Consumers are people affected by cancer, whether as a patient, a person caring for a loved one with cancer, or a family member or friend [2].

Engaging consumers in all aspects of cancer control adds a depth of knowledge that complements cancer control strategies with the reality and practicality of the consumer experience. The increasing complexity of health care requires a system which engages with the beneficiaries of care and moves away from a focus of acting upon rather than with [2,3, 4, 5].

Organisations committed to improving consumer participation have developed and agreed on this Framework. It is applicable to policy, health service delivery and research activities spanning the cancer pathway. The Framework will also be useful for government and non-government organisations, consumer and cancer organisations and professional bodies.

Cancer control refers to all actions taken to reduce the impact of cancer and as such the Framework encompasses the whole pathway from prevention, to early diagnosis and treatment, psychosocial care and survival, to palliative care, and to research, including clinical trials and policy development. Every aspect of the cancer journey stands to benefit from consumer involvement, at an individual level, service level, local and organisational levels, and at regional, state, national and international levels [6]. There is sound evidence that involving consumers will lead to improved outcomes and therefore implementation of the Framework has the potential to build sustainable and effective consumer engagement for the benefit of all people affected by cancer [6–8].

The Project

Cancer Australia, in partnership with Cancer Voices Australia, is committed to involving consumers in all aspects of cancer control to improve the outcomes and experiences of people affected by cancer. The Framework is the result of a joint research, development and consultation project advised by consumers, health professionals, researchers, policy makers and service planners as well as government, non-government organisations and professional bodies.

The project received ethics approval and aimed to:

- Identify the needs and expectations of consumers participating in cancer control

- ▶ Describe the purpose and role of consumers and their support needs for effective participation
- ▶ Ascertain the expectations of health professionals, researchers, policy makers and service planners and seek agreement on the key elements required for effective consumer involvement in cancer control
- ▶ Achieve consensus about the components that best support consumer involvement in cancer control.

The project covered consumer involvement ranging from the individual level of health care as a patient to advocating for health improvements for others. It also included influencing research priorities and contributing to decision making on government and non-government committees and boards at a service, regional, state, national and international level.

The project included three phases:

- ▶ Establishing project governance and conducting a literature review
- ▶ A broad consultation phase involving interviews and a Delphi survey
- ▶ A final framework development phase including a national workshop.

The project governance and advisory structure included expert assistance by members of the Project Steering Group, Consumer Informant Group, National Reference Group, and an International Linkages Group.

The consultation process and findings in detail, along with the literature summary are attached as appendices. Implementation and evaluation of the Framework are outside the scope of this project.

Terminology

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

'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 [9].

'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 [10].

'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 [9–11].

'Cancer control' refers to all actions taken to reduce the impact of cancer, on people affected by cancer and on the community. Cancer control aims to reduce the incidence, morbidity and mortality of cancer and to improve the quality of life of cancer patients in a defined population, through the systematic implementation of evidence-based interventions for prevention, early detection, diagnosis, treatment, recovery, supportive care, survival and palliative care. Comprehensive cancer control addresses the whole population, while seeking to respond to the needs of the different subgroups at risk. The components of cancer control include planning, prevention, early detection, diagnosis and treatment, recovery, supportive care, survival, palliative care, policy, service delivery and advocacy and research. Cancer control involves hospital and community health care providers and also a strong voluntary sector led by the Cancer Councils. More broadly, cancer control involves the behaviour and lifestyle of every person in the community [1, 6].

'Professional' for the purpose of the Framework includes health administrators, health professionals, researchers, policy makers, and service providers and refers to: 'A disciplined group of individuals who adhere to high ethical standards and uphold themselves to, and are accepted by, the public as possessing special knowledge and skills in a widely recognised, organised body of learning derived from education and training at a high level, and who are prepared to exercise this knowledge and these skills in the interest of others'^[12].

A more complete list of terms are defined in the glossary.

National Framework for Consumer Involvement in Cancer Control

The Framework aims to provide generic guidance which can be adapted to local circumstances. To that end, core principles fundamental to meaningful consumer engagement are the Framework's foundation. From the principles, four elements, focused on results, describe the responsibility and accountability of organisations, consumers and groups. Each element has criteria necessary for effective consumer involvement in cancer control [8, 12–14, 17, 24, 26–37].

Core Principles of Consumer Engagement in Cancer Control

These principles 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 all policy planning, service delivery, research, information and support [13–18 19–25].

Accomplished organisations:

Organisations integrate consumers into organisational governance and involve consumers transparently in strategic planning and decisions about resource allocation.

Active consumers:

Consumers prepared and informed to optimise their involvement and advocate for all people affected by cancer.

Respect and acknowledgement for cultural, social and geographical diversity:

Consumers from Aboriginal and Torres Strait Islander, culturally and linguistically diverse and regional, rural and remote communities are engaged in an appropriate and culturally safe manner.

Dedicated professionals:

Clinicians, managers, health professionals, planners, researchers and policy makers engage with consumers respectfully and as equals.

Confirmed outcomes:

Measurable outcomes agreed with consumers are used to build the evidence of meaningful and sustained consumer engagement.

Act ethically, responsibly, honestly and transparently:

Ethical, accountable behaviour is practised by all people and organisations involved in cancer control.

Key Elements of the Framework

Four elements, described below and in Figure 1, have been identified as essential for effective consumer involvement in cancer control [8, 12–14, 17, 24, 26–37]. Each element comprises criteria which are described following the elements and introduced in Figure 1. The elements are interrelated and inter-reliant for quality improvement and sustainable consumer engagement.

Committed organisations:

The organisation is committed to meaningful consumer engagement by integrating consumer involvement in all aspects of organisational practice, processes and systems from governance structures through to service delivery, policy development, research and evaluation.

Capable consumers:

Consumers are supported, trained and selected for their capability to engage meaningfully and advocate effectively for people affected by cancer. Bringing the knowledge and experience of cancer as a person diagnosed with cancer, a carer, a family member or survivor leads to increased experiential learning for all engaged. Consumers who are trained and well prepared are able to look beyond their personal experience and able to provide a broad consumer perspective representing the views of those unable to represent themselves or those with poor outcomes.

Inclusive groups:

Effective consumer engagement occurs in groups or teams and therefore education of those teams in the benefits of consumer engagement and how to engage, is important.

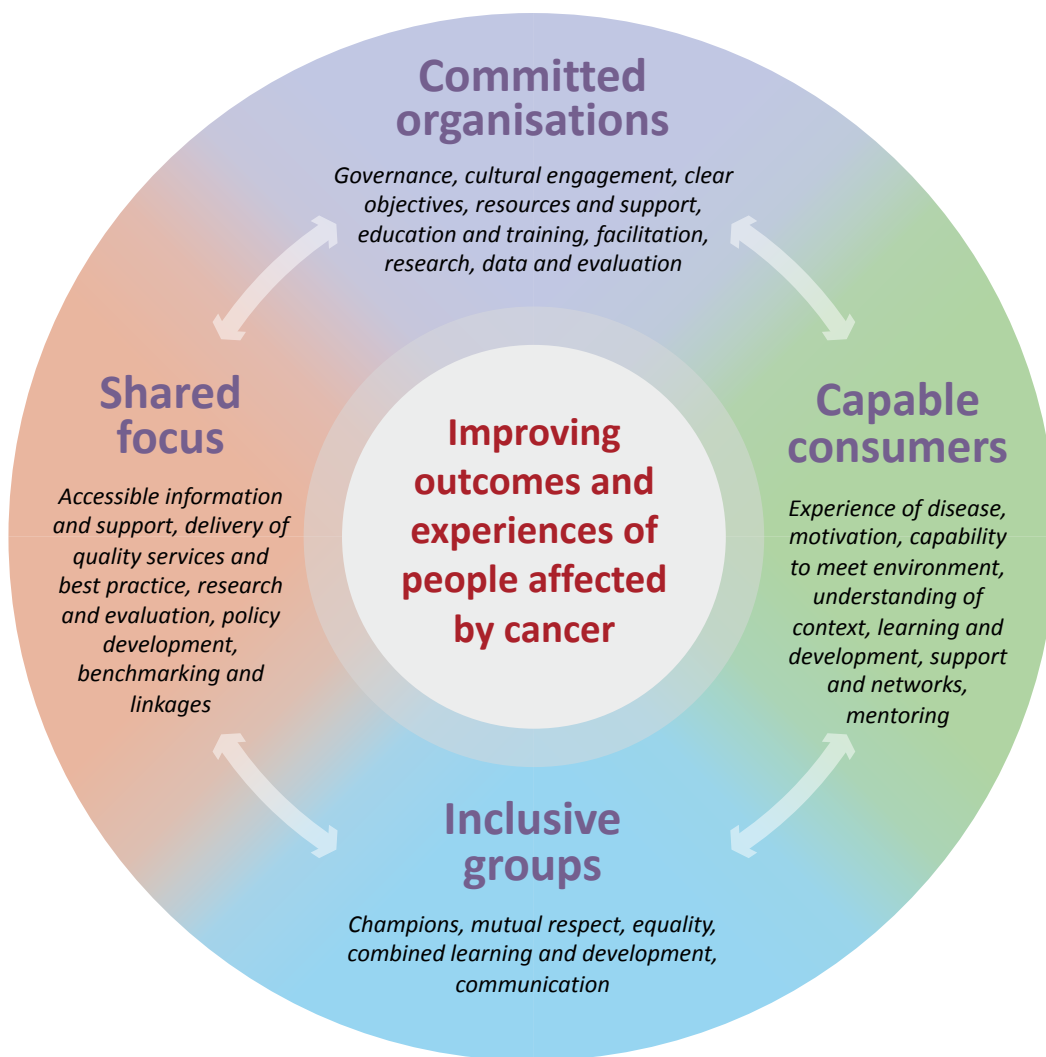
Professionals who involve consumers benefit from education to prepare them to incorporate the consumer experience into team activities. Leaders can assist by championing the benefits of consumer engagement and involve consumers as respected, equal members of the team. This will encourage well-developed, mature and effective groups.

Shared focus:

The desired objectives are mutually agreed in these groups and used to monitor and sustain the effectiveness of consumer engagement.

Consumers and professionals supported by systems, work together to act for mutual benefit. The purpose, goals and outcomes of the group are well described and understood by all participants. This element includes the development of performance measures to facilitate learning and build knowledge in areas where consumer involvement can make the greatest difference.

Figure 1: Elements for effective consumer involvement in cancer control



Criteria for each Framework Element

Each element of the Framework comprises criteria that will support effective consumer engagement. They are summarised below and covered in more detail in Appendix 1.

Committed organisations

'Committed organisations' integrate consumer involvement throughout every level of their institution, service or group. The following criteria demonstrate committed organisations:

- ▶ **Governance:** governance structures, including boards and committees, policies and procedures, incorporate the principles, values and elements for effective consumer participation.
- ▶ **Cultural engagement:** organisations actively involve people with respect to their cultural needs and work with those whose outcomes are poorer e.g. Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities and rural, remote and regional communities.
- ▶ **Clear objectives:** consumer involvement is informed by clear objectives in Terms of Reference documents, policies and procedures to assist consumers and health professionals, researchers, policy makers and service planners to understand the role requirements and the context within which they participate.
- ▶ **Resources and support:** organisations explicitly resource and provide appropriate support to enable consumers to be effectively engaged, including sitting fees and out-of-pocket expenses, and travel and accommodation, where appropriate.
- ▶ **Education and training:** training and development opportunities are made available to assist consumers in their consumer participation role. Organisations provide shared development opportunities for professionals that strengthen their understanding of the benefits of consumer participation.
- ▶ **Facilitation:** organisations actively facilitate and coordinate consumer involvement activities and enable consumer feedback and participation in organisational business strategies, aiming for improved outcomes.
- ▶ **Research, data and evaluation:** organisations monitor consumer involvement activities and research and evaluate consumer involvement strategies to help build continuous quality improvement and benchmarking.

Capable consumers

'Capable consumers' refers to consumers who have developed knowledge from their experience and are able to represent the views of others.

- ▶ **Consumer experience:** consumers have an experience of cancer either as a patient, carer, family member or survivor.
- ▶ **Consumer motivation:** consumers are motivated, with an interest in participating in a largely voluntary role to improve outcomes for others.
- ▶ **Consumer capability to match the environment:** consumers develop their skills and capabilities to meet the requirements of the role.
- ▶ **Consumer understanding of context:** consumers develop an understanding of the context within which they participate and understand the types of consumer engagement.

- ▶ **Learning and development:** consumers undertake learning and development opportunities to build their expertise in consumer participation.
- ▶ **Consumer support and networks:** consumers seek support to perform in the consumer role through involvement in consumer organisations, consumer networks, support groups and the like.
- ▶ **Consumer mentoring:** consumers support other consumers to develop in the role of consumer representation and contribute to conferences and journals to share their knowledge and expertise.

Inclusive groups

‘Inclusive groups’ refer to groups that clearly understand the value of each member and how they contribute to achieving their goal.

- ▶ **Champions:** professionals elect to champion the benefits of consumer engagement. Key leaders with experience in consumer involvement advocate to improve the level of understanding among peers.
- ▶ **Mutual respect:** consumers are respected and valued for their contribution. This involves consumer views being actively sought, listened to and considered.
- ▶ **Equality:** consumers are considered equal members of the group or team.
- ▶ **Combined professional development:** professionals and consumers are encouraged to undertake professional development together to learn from each other’s knowledge and experience.
- ▶ **Communication:** professionals communicate with consumers in a way that builds knowledge, understanding and mutual respect.

Shared focus

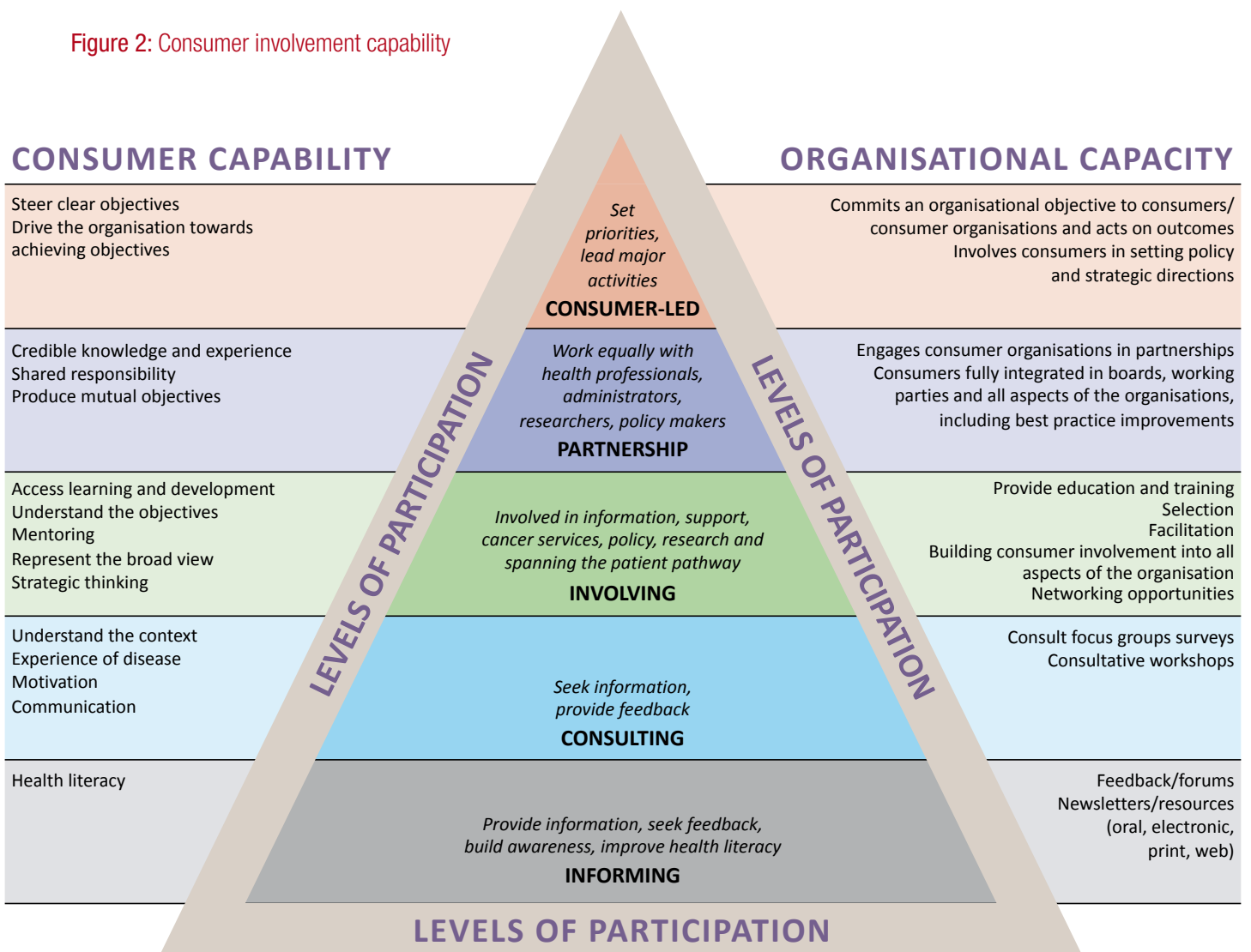
‘Shared focus’ refers to the need to bring all the elements together to act effectively. Well-informed consumers, supported by organisational systems and processes, participate as members of the team to achieve objectives. Consumers are active participants in all areas of cancer control.

- ▶ **Accessible information and support:** consumers and professionals develop accessible information and support for people affected by cancer.
- ▶ **Delivery of quality services and best practice:** consumers and professionals work together for the delivery of safe and quality cancer services based on best practice.
- ▶ **Research and evaluation:** researchers involve consumers in the design, conduct, translation and evaluation of research to improve the evidence of cancer care and control and identify and respond to the latest cancer treatments through clinical trials.
- ▶ **Policy development:** consumers and professionals participate in policy development for improved cancer outcomes.
- ▶ **Benchmarking and linkages:** consumers and professionals develop performance measures that assist in measuring the effectiveness of consumer engagement and facilitate benchmarking opportunities for quality improvement. Group leaders develop linkages to help build sustainability and facilitate involvement of communities whose outcomes are poorer.

Consumer Involvement

The experience of consumers will vary depending on their level of involvement. At the population level, consumers will be receivers of information and build awareness and health literacy about cancer care and control as a result of asking questions, seeking information and receiving organisational key messages. These consumers may be consulted periodically through surveys and feedback opportunities. Many consumers may be selected to participate in cancer care and control and may be actively involved in the cancer control pathway and related activities. Some consumers may be working in partnership with professionals or organisations for mutually agreed outcomes. A small number of consumers may be leading activities or setting priorities. The model in Figure 2 sets out the levels of consumer involvement opportunities, recognising that a smaller number of consumers/organisations will be leading cancer control activities, with the greatest number of consumers exchanging information. The model also depicts the different skill set (capability) consumers need in addition at each level and the organisational supports necessary to sustain effective consumer engagement.

Figure 2: Consumer involvement capability



Types of Consumer Involvement

A critical part of the process of engagement for organisations, groups and consumers is understanding the role consumers are being expected to play and being explicit about it. This minimises confusion, saves time and energy and facilitates effective goal setting. These types of consumer involvement roles are shown in Figure 3. These consumer roles are provided in more detail in Appendix 4 and have been summarised into five key roles.

As consumers develop their engagement capability they are called upon to advocate for others and further to provide advice. Subsequently, consumers who have been providing advice become experts and are actively sought for their proficient knowledge and capability. The highest level of consumer involvement is partnering (also known as co-design) where consumer knowledge is valued equally [13]. Improving healthcare, policy and research requires bringing consumers and professionals together to design, implement and evaluate each and every aspect of cancer control. A major aspect in achieving long term change is the need to build capability [13–14].

Five types of consumer involvement:

Personal Engagement refers to consumers who actively participate to raise awareness from a personal perspective and provide feedback to assist services to recognise what is working well and what needs to be improved from an end users direct experience. Engagement occurs through consumers sharing stories and participating in focus groups, surveys and targeted working groups [10, 13].

The Advocate is the most common and well-understood term. Advocates represent the broad views and experiences of a range of people affected by cancer. This may include persons or groups that are unable to represent themselves. Consumers advocate for improved information and support, for better cancer services and coordinated care, for enhanced research and policy and to be involved in decision making. Advocacy is at its strongest when the consumer voice cannot be heard [15]. Consumer advocates need mechanisms whereby they maintain contact with, or are provided with information from, those who have difficulty having their voices heard. Organisations need to actively seek the voices of those with the poorest outcomes. So advocacy is an important role when the voices of consumers are absent. The needs, for example, of people whose outcomes are poorer, rural, remote and regional consumers, Aboriginal and Torres Strait Islander people and culturally and linguistically diverse communities are not always heard. This necessitates other consumers to advocate in a culturally appropriate way on their behalf. Such consumers need to have established mechanisms, with the ability to build alliances and networks with cultural organisations where they are able to consult with such groups or be informed of the outcomes of such consultation.

The Advisor describes a role where consumers participate in government policy or cancer services when the views of a diverse range of stakeholders are sought to provide advice and to influence the final decision. Advice refers to providing opinion and guidance from a consumer perspective based on identifying all the issues, analysing the strengths and weaknesses and making a recommendation based on the best evidence available [43].

Policy makers, researchers, health professionals, government and non-government organisations and professional bodies usually seek advice from a broad range of people, including consumers, to present a balanced and consultative view. This style where consumers aim to influence the outcome from a consumer needs perspective requires a different set of capabilities to advocacy; however, advocacy training can help consumers participate in this role.

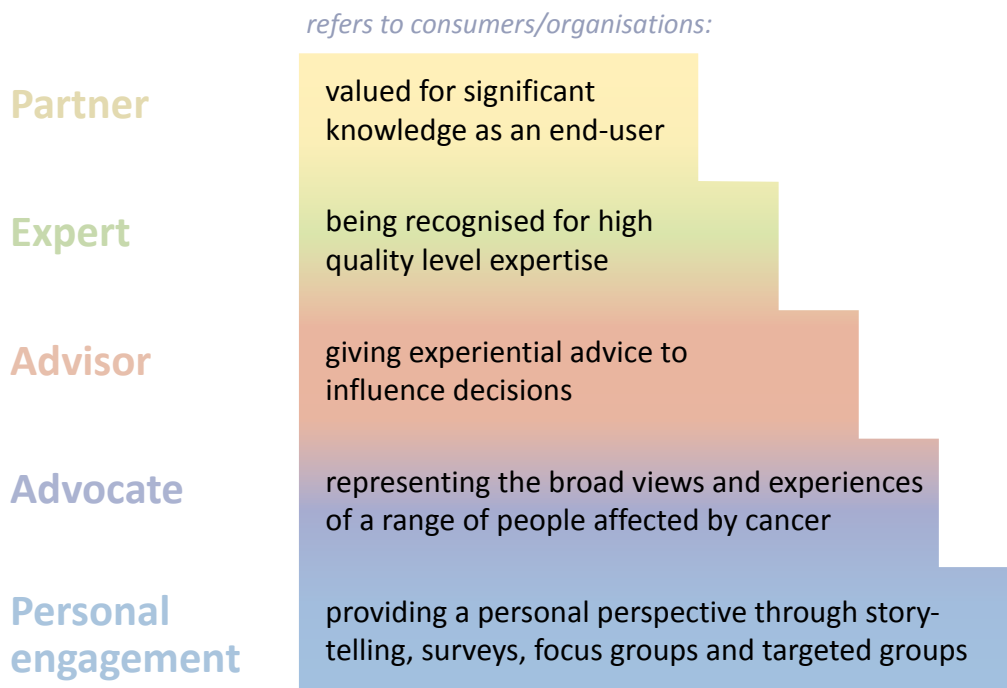
The Expert is where consumers participate on organisational boards or are involved in high-level advisory committees or major projects and are invited for their high-level expertise. These consumers are sought because of the expertise they bring. An expert is a person who is proficient in their area of expertise as a consumer. They may

also be referred to as a specialist or a professional. Consumer experts are knowledgeable across a broad range of cancer care and control and supported by a network of consumers who advise their work [16]. Consumer experts are people who are called upon regularly by organisations due to their longstanding experience in consumer involvement and their ability to engage a diverse range of consumers to assist them in presenting the consumer perspective.

The Partner is where consumers are considered as equal partners with essential knowledge necessary for health reform, research and policy development and system change. Evidence is emerging that when consumers are involved as partners (also referred to as co-design) this has the potential to leave consumers feeling safer and more valued, and make professionals involving consumers feel more positive and rewarded [13–14].

For consumer involvement to succeed in guiding people, organisations and outcomes each of the roles are required. Consumers and those involving them need to recognise which approach is best suited for each circumstance and also articulate the role required for the purpose. Furthermore the types of consumer involvement need to be considered within the levels of consumer engagement and participation. The depth and levels of consumer participation are described in more detail in Appendix 2 and Appendix 3.

Figure 3: Types of consumer involvement



Consumer involvement spanning the cancer pathway

Applying the elements across the cancer pathway will help build effective consumer engagement [26, 38–55].

Implementation of these four elements aims to achieve:

- ▶ consumers utilised to make a difference at all points of the cancer pathway
- ▶ working together with consumers to improve outcomes and experiences of people affected by cancer
- ▶ the delivery of safe, quality health services through patient centred care and based on the best available evidence.

Involving consumers in projects, health services, and research and policy activities at critical points along the pathway necessitates each Framework element to be addressed. This is best achieved by asking the following four questions:

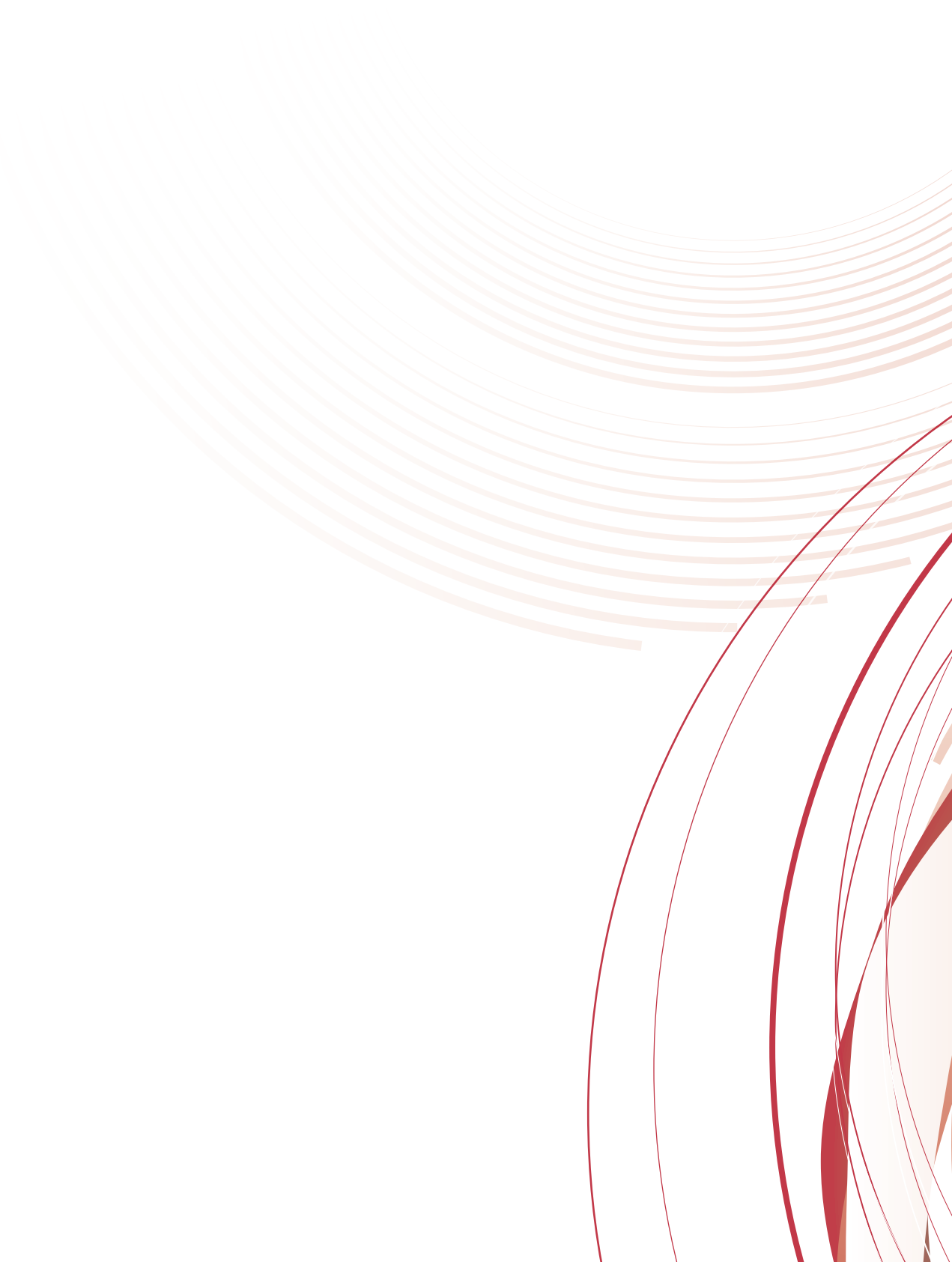
1. What is the organisational responsibility?
2. How will consumers be selected, supported and engaged?
3. How will the group work together?
4. Why is the group involved, what is the mutual goal and outcome and how will it make a difference?

Involving consumers in all aspects of cancer control requires all four elements [1]. Organisations, whether they provide information and support services, health services, policy, or research will include all Framework elements as they work towards improving organisational performance and outcomes for people affected by cancer. Table 1 is a matrix designed to assist organisations to signal achievements at a service or system level spanning the care continuum and areas of cancer control.

Table 1: Consumer involvement framework spanning the cancer pathway

Framework Elements	Prevention	Screening	Early Diagnosis	Treatment	Supportive Care	Survival	Palliative Care	Organisational Performance
Committed organisations								Accessible information & support
Capable consumers								Quality service delivery
Inclusive groups								Stronger research
Focus on outcomes								Enhanced policy development
	Consumer and Patient Pathway							

Appendices



Appendices

The image features a dark red background with a series of curved, overlapping lines in lighter shades of red and white. These lines originate from the bottom left corner and sweep upwards and to the right, creating a sense of motion and depth. The lines vary in thickness and color, with some being thin and light, and others being thicker and more vibrant. The overall effect is a modern, abstract graphic design.

Appendix A Framework elements and criteria

Table 2: Framework elements and criteria

FRAMEWORK ELEMENTS	DESCRIPTION
Element 1	
Committed organisations	
Governance	<p>Governance is defined as:</p> <p>‘...the set of responsibilities and practices, policies and procedures, exercised by an agency’s executive, to provide strategic direction, ensure objectives are achieved, manage risks and use resources responsibly and with accountability.’</p> <p>Good governance is about both:</p> <p>performance—how an agency uses governance arrangements to contribute to its overall performance and the delivery of goods, services or programs, and</p> <p>conformance—how an agency uses governance arrangements to ensure it meets the requirements of the law, regulations, published standards and community expectations of probity, accountability and openness.</p> <p>The governance framework is based on the following principles:</p> <p>accountability—being answerable for decisions and having meaningful mechanisms in place to ensure the agency adheres to all applicable standards</p> <p>transparency/openness—having clear roles and responsibilities and clear procedures for making decisions and exercising power</p> <p>integrity—acting impartially, ethically and in the interests of the agency, and not misusing information acquired through a position of trust</p> <p>stewardship—using every opportunity to enhance the value of the public assets and institutions that have been entrusted to care</p> <p>efficiency—ensuring the best use of resources to further the aims of the organisation, with a commitment to evidence-based strategies for improvement</p> <p>leadership—achieving an agency-wide commitment to good governance through leadership from the top.</p> <p>The following practices are reflective of sound governance:</p> <ul style="list-style-type: none"> ▶ organisations include consumers at all levels of organisational management, commencing at board level ▶ organisations include consumer involvement as part of their core values ▶ organisations develop and prepare consumers, clinicians and health professionals, researchers, policy makers and service planners for effective consumer involvement [17].

Cultural engagement	<p>Working in partnership with Aboriginal and Torres Strait Islander organisations, and culturally and linguistically diverse organisations, to meet the needs of the communities they represent will lead to improved outcomes.</p> <p>Actively engaging organisations to develop implement and evaluate targeted approaches to consumer involvement for Aboriginal and Torres Strait Islander people, and culturally and linguistically diverse communities strengthen cultural engagement.</p> <p>Cultural engagement as a core value of organisations assists organisations to engage with diverse communities for improved outcomes.</p> <p>Cultural diversity training programs to be provided for consumers and staff.</p> <p>Target groups who are disadvantaged, such as rural, regional and remote communities, the elderly, and people whose outcomes are poorer (e.g. rare cancers) with culturally appropriate methods of consumer engagement.</p>
Clear objectives	Organisations have clear objectives for their consumer involvement activities.
Resources and support	<p>Organisations provide direct resourcing towards consumer involvement activities.</p> <p>Organisations provide appropriate support for consumers and for health professionals, researchers, policy makers and service planners engaging consumers in their work.</p>
Education and training	Organisations fund education and training opportunities to consumers involved in organisational strategies and provide education in consumer involvement for health professionals, researchers, policy makers and service planners.
Facilitation	Organisations facilitate consumer involvement activities at each level of the organisation.
Research, data and evaluation	Organisations collect data on consumer involvement activities and outcomes and research and evaluate consumer involvement activities.
Element 2	
Capable consumers	
Experience of the disease	<p>Consumers have a personal experience of cancer as a patient, carer, survivor, family member.</p> <p>Consumers are able to see beyond their personal experience and provide a broad perspective to better the experience of all people affected by cancer, particularly for those whose voices cannot be heard.</p> <p>Consumers bring a strategic approach to their consumer involvement.</p> <p>Consumers disseminate information and provide feedback through their organisation and community linkages.</p> <p>Consumers are participants in their own right and will only speak on behalf of their organisation when invited to do so.</p>
Consumer motivation	<p>Consumers are motivated to participate to give something back, to contribute.</p> <p>Consumers are selected through a process that matches the consumer capability to the organisational purpose.</p>

Consumer capability to meet environment	<p>Consumers are experienced in cancer services as end users.</p> <p>Consumers are trained in consumer participation including the purpose, terms of reference and consumer role requirements.</p> <p>Consumers develop capability to ensure consumer participation makes a difference to outcomes.</p>
Consumer understanding of the context	<p>Consumers have an understanding of the context and the organisation in which they participate.</p>
Learning and development for consumers	<p>Consumers receive regular professional development.</p> <p>Consumers are invited to participate in conferences and co-author journal articles.</p>
Consumer support and networks	<p>Consumers are supported to participate, including assistance with sitting fees, travel and accommodation expenses. Consumers link with networks and alliances to strengthen the broad range of consumer needs.</p>
Consumer mentoring	<p>Consumers support consumers to actively participate.</p> <p>Consumers encourage participation of Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities and communities whose outcomes are poor, such as rural, regional and remote communities and people affected by cancers with poor survival, e.g. rare cancers, the elderly and the young.</p>
Element 3	
Inclusive groups	
Champions	<p>Clinicians and health professionals, researchers, policy makers and service planners demonstrate leadership and assist groups to understand the value and contribution of the consumer experience.</p>
Mutual respect	<p>Professionals encourage and demonstrate mutual respect for the expertise of each member of the group.</p>
Equality	<p>The consumer is considered an equal member of the team.</p>
Combined learning and development	<p>Professionals and consumers attend professional development and conferences together and share the experience from their perspective.</p>
Communication	<p>Professionals communicate effectively with consumers and involve them in meaningful ways.</p>
Element 4	
Shared focus	
Accessible information and support	<p>Consumers participate in the development of information resources and support options for improved outcomes.</p>

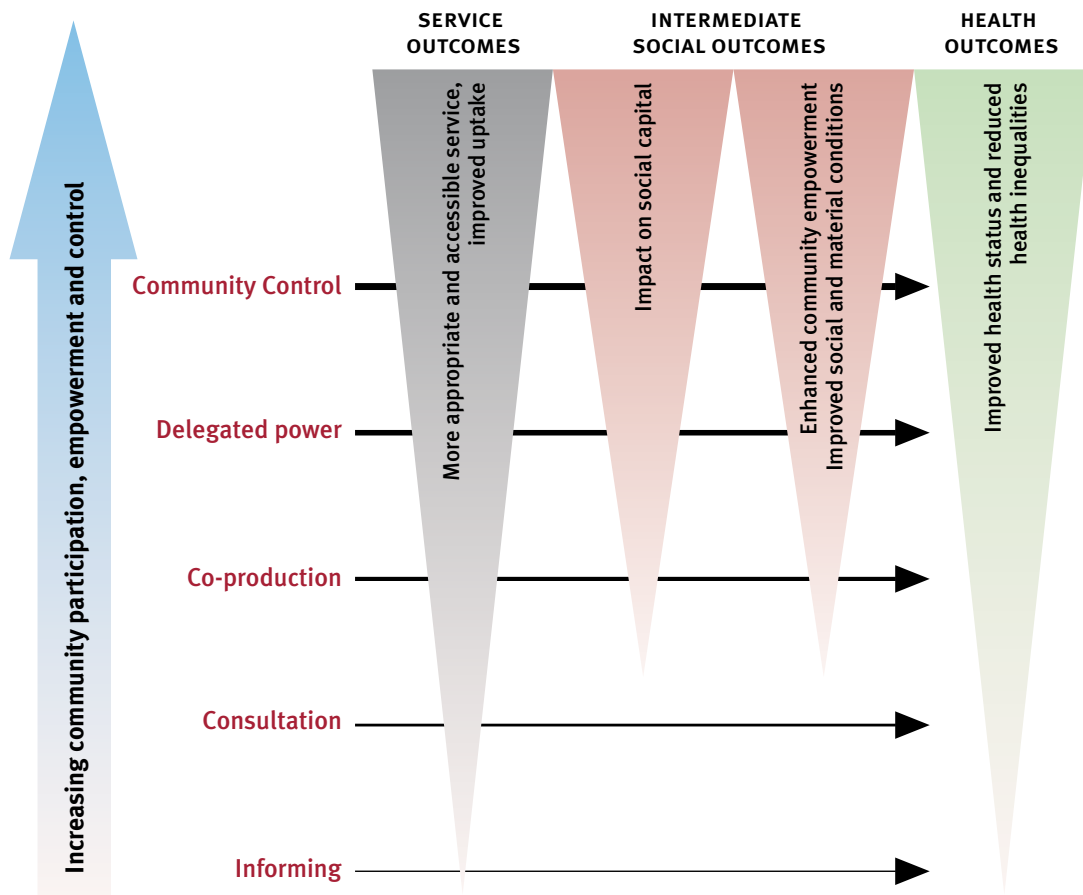
<p>Delivery of quality services and best practice</p>	<p>Consumers are diagnosed and treated responsively. Care is well coordinated. Consumers and their carers and family members are equal partners in the care delivery. Consumers participate in setting service delivery priorities. Consumers participate in service delivery design, development, implementation and evaluation.</p>
<p>Research, clinical trials and evaluation</p>	<p>Consumers participate in setting research priorities. Consumers participate in the design, development, implementation and evaluation of research. Consumers participate in clinical trial design, proposals and protocols and build consumer awareness [18].</p>
<p>Policy development</p>	<p>Consumers are involved in setting policy priorities, developing policy proposals, and implementing, reviewing and evaluating policy programs and initiatives.</p>
<p>Benchmarking and linkages</p>	<p>Organisations develop linkages for effective consumer engagement, reduce duplication and develop measures for benchmarking opportunities and quality improvement.</p>

Appendix B Depth of consumer participation

The consumer participation approach below indicates the level of consumer involvement and demonstrates the higher the level of consumer involvement the larger the impact on health outcomes. Five levels of participation for strengthening consumer involvement have been identified by Popay and used with the National Institute of Clinical Studies (NICE) to describe best practice consumer involvement [19]. These levels have been adapted for use in describing the depth of consumer involvement within the Framework. A common language can be communicated when describing consumer involvement and participation using this consumer participation pathway:

1. informing
2. consultation
3. co-production
4. delegated power
5. community control [6, 23]

Figure 4: Depth of consumer participation



Source: J. Popay, 2006, Community Engagement, community development and health improvement. A Background Paper prepared for NICE.

The consumer participation approach indicates that the *informing* and *consultation* levels (levels 1 and 2) have marginal impact on health outcomes, but they may impact on the appropriateness, accessibility and uptake of services and may also impact on health literacy. Approaches that help communities to work as equal partners (*co-production*), that delegate power to communities (*delegated power*) or provide them with total control (*community control*) may lead to more positive outcomes, improve aspects of consumers' lives and their sense of belonging to a community, and also empower consumers and improve their sense of wellbeing. It is further argued that the higher level approaches to community engagement utilise people's *experiential knowledge* to design or involve more effective, cost-effective and sustainable services; *empower* people by giving them the chance to co-produce services, while at the same time building confidence and self-efficacy; build more trust in government bodies and improve *democratic renewal*; contribute to building *social capital*; and encourage health-enhancing attitudes and behaviour [20].

Table 3: Degrees of consumer control

Table 3 provides an example of the measure of consumer control by depicting the degree of control into decisions that consumers hold for each of the five levels of participation [21].

DEGREE OF CONTROL	PARTICIPANTS ACTION	DESCRIPTION
<p style="text-align: center;">High</p>  <p style="text-align: center;">Low</p>	Consumer-led	Consumers may be asked to lead a project for organisations and to make all key decisions, and work with the community to achieve a particular goal.
	Partnerships	All involved (consumers and the organisations) share ownership and accountability for the process and decisions made. All are equal contributors to the engagement process.
	Involving	Consumers and communities are involved in issues/ projects together with an organisation.
	Consultation	Consumers and communities are consulted on key issues that affect them. This may include providing a plan or completed document for feedback.
	Informing	Consumers and communities are kept informed by organisations.

Appendix C Levels of consumer participation

Table 4: Levels of consumer participation

CONSUMER PATHWAY	DESCRIPTION
Individual level	Refers to a person's experience of cancer services as a patient, carer, family member or survivor.
Local/organisational	Refers to consumers participating in their local service area or community.
Regional level	Regional cancer services level refers to consumer participation across a number of cancer services.
State level	Includes consumer participation in one or all aspects of cancer control at a state level.
National level	Includes consumer participation in one or all areas of cancer control at a national level.
International level	Includes consumer participation in one or more cancer control areas at an international level.

- ▶ Service delivery, policy development, research, and information and support are based on the needs of consumers.
- ▶ Consumer involvement is based on evidence and best practice.
- ▶ Consumers are empowered in decision making.
- ▶ Cancer services are improved through consumer involvement when consumers are prepared and orientated for a specific purpose.

Appendix D Consumer involvement roles

Table 5: Consumer involvement roles

ROLES OF INVOLVEMENT	DESCRIPTION
Ambassador/liaison role	In this role consumers are trained to promote the goals of the organisation, and link community members with organisations to demonstrate the impact of policy, practice and research.
Shared personal stories	In this role consumers present and deliver their story based on their cancer experience.
Advocacy role	Advocacy refers to consumers who represent the views of a broad range of people affected by cancer.
Advisory committees	Advisory committees are usually high-level organisational or strategic committees that require knowledge and skills of the organisational objectives and the ability to communicate the needs of consumers and influence and act for mutually agreed outcomes.
Research development (including design, implementation and evaluation)	In this role consumers are involved in design of research proposals, evaluating research proposals, developing protocols and implementing research.
Policy and planning committees	These are usually government committees and include advisory committees, project committees on high-level strategic projects and policy development.
Service development committees	These committees are formed at national, state, regional and local organisational levels. Consumers participate in developing consumer information, consumer support and service planning, service review, implementation and evaluation.
Review and evaluation	In this role consumers may review research proposals, request for tender documents and service development proposals.

Appendix E Project methodology

Ethics

Ethics approval for the development of the *National Framework for Consumer Involvement in Cancer Control* was provided by La Trobe University, Faculty of Health Science under Professor Annette Street and Dr Dell Horey, who provided expert guidance and advice to the project [22].

Governance phase

A Project Steering Group was formed to advise the project leader and ensure project deliverables were met. A Consumer Informant Group was established to ensure the Framework was centred on consumer needs. A National Reference Group comprising consumers and cancer organisations, government and non-government agencies, and professional bodies involving health professionals, researchers, policy makers and service planners, was established to provide expert advice on the development of the Framework. An International Linkages Group involving three international members with international expertise in consumer involvement was established to review the development of the Framework from an international perspective.

Consultation phase

Consultation to inform the Framework occurred from November 2010 through to June 2011. The information gathered through interviews with members identified the barriers and enablers to effective consumer involvement and assisted in the development of a Delphi survey to gain broader participation from the cancer control community [23–24]. Two rounds of the Delphi survey were undertaken during March and April with the first survey seeking the barriers and enablers for effective engagement and the second survey gaining consensus on the elements and components of the Framework. Survey results included over 200 respondents for Round 1 and 190 respondents for Round 2. Respondents included consumers and consumer organisations, health professionals, policy makers, researchers and service planners from government, non-government and professional organisations. The needs of consumers were identified along with the expectations of professionals. There was broad agreement on the Framework elements and components.

Development phase

A national workshop was held in April 2011 and brought all the groups of 50 participants together to agree on the elements and components necessary for effective consumer engagement to be included in the Framework [25]. Dr Norman Swan facilitated the workshop and an international colleague (Ms Kathy Redmond) presented along with national colleagues (Dr Helen Zorbas, Ms Lyn Swinburne, Dr Ian Roos and Dr Julie Thompson). The goal was to take a broad aspirational view in developing the Framework in order that it would provide real guidance for quality and meaningful consumer engagement that is sustainable into the future.

Project outcomes

While consumer involvement in cancer control is acknowledged as an essential component of cancer control, the sector has yet to share and agree on successful approaches to consumer engagement.

A national framework will:

- improve cancer outcomes through the development of an agreed national framework for consumer involvement in cancer control

- ▶ improve the experience of people affected by cancer as a result of consumer involvement in cancer control
- ▶ guide professionals and health service providers towards effective consumer engagement for improved outcomes
- ▶ strengthen the responsiveness of all levels of the health system, including policy development, service development and research, as a result of consumer involvement in cancer control
- ▶ partner with cancer control organisations and professional bodies for a coordinated approach to consumer involvement in cancer control that is consistent with both federal and state government guidelines and policy.

Project rationale

While consumer involvement is recognised as an integral component of cancer control in Australia, there is little understanding of the best method for consumer engagement that will deliver improved outcomes for people affected by cancer [22]. Internationally there are a number of successful models that guide consumer engagement; Cancer Australia has utilised the approach of Professor Nora Kearney from the Cancer Care Research Centre in Scotland and integrated this method throughout the Cancer Service Networks National Program (CanNET) projects. Professor Kearney's techniques include consumer engagement at a local level and utilising the consumer experience to bring about service change [26–28].

Closer to home the National Health and Medical Research Council has developed a model for consumer involvement in research in 2004 [9]. Similarly the National Breast and Ovarian Cancer Centre is known for its strong consumer focus and collaborative strategies in engaging consumers. More recently the Australian Commission on Safety and Quality in Health Care developed a consumer engagement statement [29–30]. This statement underpinned the development of the *Australian Safety and Quality Framework for Health Care* [31] with three themes:

- i. consumer centred
- ii. driven by information
- iii. organised for safety.

In addition, successful models of consumer engagement can be seen in advocacy groups like the Breast Cancer Networks Australia, whose consumer engagement program Seat at the Table (SATT) involves consumer participation in decision-making forums and advisory groups at both the service and policy level [32].

What is not well known is how consumer involvement approaches work in all settings of cancer control at a policy, service development or research level [33–35]. Cancer Australia in partnership with Cancer Voices Australia plans to work with key cancer control organisations committed to involving consumers for improved outcomes in cancer control to address this knowledge gap.

Deliverables

- ▶ Establish project governance including: a Project Steering Group to support the project leader and ensure deliverables are met; a Consumer Informant Group to inform the development of the Framework from a consumer needs perspective; a National Reference Group comprising consumers, health professionals, researchers, policy makers and health service providers to provide expert advice; and an International Linkages Group to review and comment on the Framework from an international perspective.
- ▶ Develop a consultation plan.
- ▶ Development of a *National Framework for Consumer Involvement in Cancer Control*.

Appendix F Literature summary

The literature review outlined below assisted in informing the Framework.

Pathways for consumer participation

Popay et. al. describe the theoretical framework for community participation that leads to better health outcomes [19]. Popay's pathways were further reviewed by the National Institute of Clinical Studies and adopted as a public health guideline [20]. This pathway has been further adapted by health services in Australia and Canada [12, 14–18, 38, 44, 45].

The pathway describes the different levels of community engagement, including how community participation directly and indirectly affects health outcomes in the intermediate and long term. Popay's theory suggests a variety of approaches can contribute to successful community engagement at different levels identified in the framework.

Five levels of participation have been identified:

1. informing
2. consultation
3. co-production
4. delegated power
5. community control.

Canadian and Australian health services continue to utilise the five levels of consultation; however, the terms have been adapted using language that has more meaning in the Canadian and Australian contexts. These terms include informing, consulting, involving, collaborating and empowering [21, 24, 36]. The Canadian spectrum of community participation is defined below:

- ▶ Informing—the community receives information and announcements.
- ▶ Consulting—the community is consulted on draft plans or issues and provides feedback on the impact of decisions.
- ▶ Involving—systems involve stakeholders in planning and policy processes.
- ▶ Collaborating—the community shares decision making and the system defines the limitations.
- ▶ Empowering—the system supports community-identified issues, solutions and actions [36–37].

Consumer involvement in cancer care is gaining more acceptance with consumers encouraged to participate in policy and planning, research and service delivery [28, 37–38]. In Australia a network of consumer organisations has evolved to coordinate, advocate and participate in cancer policy and programs to improve outcomes for people affected by cancer [39]. The Australian Government has released a policy toolkit to help guide policy design and development in a way that enables people who are socially disadvantaged to be included in policy and to ensure policy development is focused on the needs of those who need it most [40].

Similarly, the Government's national preventative health strategy has identified seven strategic directions for government policy: i) shared responsibilities—developing strategic partnerships; ii) act early throughout life; iii) engage communities; iv) influence markets and develop coherent policies; reduce inequity through targeting; Indigenous Australians—close the gap; refocus primary healthcare towards prevention [41].

Australian states and territories have made significant progress in developing policy documents to guide consumer participation at all levels of health service delivery [4, 5, 7]. In addition, the Department of Health and Ageing engaged the National Health Priority Action Council to develop the National Service Improvement Framework for Cancer

(2006) which was subsequently endorsed by the Australian Health Ministers' Conference. The framework outlines opportunities for improving cancer prevention and care. It supports the National Chronic Disease Strategy. It is intended to outline what all Australians, with or at risk of developing cancer, should expect to receive through the Australian health system, irrespective of where they live [42].

The Australian Government Treasury released an Issues paper in 2009 releasing a new consumer policy framework [7]. The Issues paper highlighted that under the Council of Australian Government (COAG), reforms will take place to strengthen consumer involvement. This will result in new legislation which will be consistent across all Australian jurisdictions.

A systematic review of methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material undertaken by Nilsen et al. (2006)[43] and reviewed by Cochrane (2010)[34] identified six randomised controlled trials with moderate or high risk bias involving 2123 participants. The review found moderate quality evidence involving consumers in the development of patient information resulting in more relevant information. The information improved patient understanding and increased patient knowledge. The evidence for consumer interviewers versus staff interviewers in satisfaction surveys was of low quality, only yielding a small influence on survey results. There was one trial comparing informed consent documents developed by consumers and another developed by health professionals with very little impact on the level of understanding of the trial. Little evidence was found at a population level, however it was found that randomised controlled trials to inform decision making was feasible [34].

In September 2010, the Australian Commission on Safety and Quality in Health Care established a model national accreditation scheme for safety and quality in health care. The model includes 10 National Safety and Quality Health Service Standards and revised processes for accreditation of health services organisations and reporting of performance against the standards. One of the standards is *Partnering for Consumer Engagement* which creates a consumer-centred health system by including consumers in the design and delivery of quality health care. The Commission highlighted a number of areas for reform:

- i. reducing harm to patients and reducing the costs of care
- ii. improving system and consumer productivity
- iii. improving consumer trust in the healthcare system [30, 44].

In 2004, the National Medical Health and Research Council in partnership with the Consumer Health Forum developed a model framework for consumer and community participation in health and medical research [9]. The components of this framework include: the need for senior leadership and operational capacity to underpin its success; building consumer and community participation into the structures of the organisation; and groups to strengthen and support implementation. Resources to help consumer and community participation work well. Developing and sustaining consumer and community participation would require changes to structures, and attitudes which the report highlighted take time and commitment. This framework was operationalised by a charitable organisation involved in extensive cancer research and found to be a useful framework for consumer engagement in research [45].

There is a body of literature on consumer involvement; however, there is little evidence of the impact of this consumer involvement at a population level or in identifying the best ways to involve consumers for positive effects [34, 46]. The literature suggests that the majority of consumer involvement occurs at the consultation and involvement level. Consumer participation strategies focus on the development of information resources, e.g. information brochures and satisfaction surveys. However, there is little evidence of the preparation consumers might need to participate effectively, nor the attributes that a consumer might bring to the role. Similarly there is little evidence on the responsibilities of organisations engaging consumers for improved outcomes in cancer control.

Appendix G Consumer needs for involvement in cancer control

The Framework components have been developed in response to identified consumer needs and underpinned by the core principles. The needs described in Table 6 have been identified by consumers to assist them in effective participation.

Table 6: Consumer needs for involvement in cancer control

CONSUMER NEEDS	DESCRIPTION
<p>Consumers will bring experiential knowledge and be well informed</p>	<p>Consumers are well informed in the subject matter with skills in communication, critique and strategic analysis. This knowledge and experience will vary in terms of the role required, with some roles requiring higher skills or a more unique set of skills than others. The skills required will depend on whether a consumer is communicating their story and personal experience to inform the sector or contributing to high-level committee work in regard to service development, policy and research.</p> <p>Consumers are well informed and prepared for their roles in order for them to contribute meaningfully.</p> <p>At an individual level consumers are supported to be informed and involved in decisions making.</p> <p>At all other levels consumers have a broad view of consumer participation that looks beyond personal experience to the needs of all consumers, particularly those with poorer outcomes or whose voice is silent due to disadvantage [16].</p>
<p>Consumers will be involved throughout the cancer care and control pathway, including but not limited to:</p> <ul style="list-style-type: none"> ▶ information and support ▶ cancer services ▶ cancer policy ▶ cancer research and clinical trials 	<p>All aspects of the cancer pathway—from prevention to screening, treatment, supportive care, survival, palliative care, research and clinical trials, policy and service delivery—benefit from consumer involvement [20, 47]. As the patient journey has the greatest impact on consumers, there is a need to ensure consumers are involved in all aspects of planning, implementation and evaluation with a focus on improving the quality of services and outcomes of people affected by cancer [23, 34,].</p> <p>Preventative care</p> <p>Consumers are involved in planning, promoting and preventative care measures to reduce the risk of cancer.</p> <p>Information and supportive care</p> <p>Consumer involvement in the development of information resources leads to benefits for people affected by cancer [38, 40].</p> <p>Consumer participation in supportive care areas as peer supporters or as co-facilitators of support networks further improves the experiences of people affected by cancer [48]. These needs are also supported in the literature, with the greatest level of consumer involvement occurring in the area of development of information resources and decision aids [40–43].</p> <p>Consumers are involved in the prioritisation and development of information and support services and resources to support people with cancer.</p>

Cancer services

Involving consumers in the development, implementation and evaluation of cancer services is seen as crucial for safe, quality services [8, 13, 23, 44]. Consumer involvement in all aspects of care including primary care, aged care, rural and regional care and comprehensive cancer centres would lead to a better informed community and improved quality and safety [49–50]. Examples where consumers have participated include areas of peer support, risk minimisation, quality and safety improvement, patient feedback, service priorities and service planning and infrastructure [19]. Further, the involvement of consumers has been identified as a core component of the *Australian Safety and Quality Framework for Health Care* [19, 51].

Consumers are involved in the development, implementation and evaluation of cancer services including: the design of services; the quality improvement of services; risk minimisation and service evaluation; and consumer/patient consultation and feedback.

Cancer policy

Involving consumers in all policy work, including priority setting, the development of policy proposals and the implementation and evaluation of programs that affect them, is highly valued by governments and health and cancer services [16, 24, 32, 38, 45]. Policy documents and programs repeatedly outline the benefits and essential inclusion of consumers for the development of high-quality effective programs that support people affected by cancer [8, 18, 23, 38, 46].

Consumers are involved in the development of new policy proposals, the setting of priorities and the monitoring and evaluation of policy program implementation.

Cancer research and clinical trials

Consumer contributions can enhance cancer research from bench to bedside. This includes cancer research priority setting, design, evaluation, implementation and translation of research [28]. Consumer input in the design phase can lead to benefits and improve research outcomes [28].

Consumers are involved in the setting of research priorities and involvement in clinical trials including in the design, conduct, implementation and evaluation of cancer research.

<p>Learning and mentoring will be provided to consumers involved in cancer care and control</p>	<p>Consumers receive training specific to the area of participation and involvement. For example, consumers who are involved in developing research proposals have an understanding of research, ethics and the rationale for undertaking the research. Consumers are well informed with a broad understanding to enable them to contribute meaningfully to the development of a policy proposal.</p> <p>Similarly consumers selected to develop information resources, or support people affected by cancer and/or contributing to cancer services, receive training appropriate to these areas of cancer care and control.</p> <p>Training and mentoring of consumers is essential if consumers are to acquire the levels of expertise required for their roles [6, 28, 35, 52] Consumers recognise that varying levels of preparation are required for different roles. Opportunities that enable consumers to develop expertise in areas of interest, while matching their skills to a role's requirements, are considered a necessary component of effective consumer engagement.</p>
<p>Role and scope of area of cancer care and control will be well described with a clear purpose</p>	<p>The value of consumer involvement is improved with clear goals and purpose set with terms of reference that guide all members towards clear outcomes. The role of consumers may vary as may the specific activity: advocacy; promoting a particular cancer type, sharing a personal story to help set the context and cancer journey for a particular event; providing advice to governments on policy approaches and program management; involving consumers in targeted projects; clinical guidelines; research projects; quality service development and policy development; and assisting in the design, implementation and outcomes of projects and programs.</p> <p>Consumer involvement encompasses a diverse range of roles including, but not limited to, participating in organisational boards, committees, project working groups, service delivery and the development of information resources. The role and scope of an activity and the expectations of consumers and other member participants need to be well articulated in order that everyone has a clear understanding of the overall objectives [27].</p>
<p>Remuneration and resourcing to support consumer involvement</p>	<p>Remuneration and resourcing for consumers involved in cancer care and control enables a broader level of consumer participation. Costs including sitting fees (where applicable), air travel, accommodation and out-of-pocket expenses will be met.</p> <p>In order for consumers to be able to fulfil their role effectively they require time and remuneration, such as sitting fees (where applicable), and out-of-pocket expenses, including travel and accommodation. Failure to meet these needs results in involvement only of those who can afford to participate [17, 28].</p>

<p>Training for clinical staff, managers, policy makers and researchers to effectively involve consumers in their activity</p>	<p>The role of health professionals, researchers, policy makers and service planners to engage consumers meaningfully and value their contribution was considered pivotal to success.</p> <p>Health professionals, researchers, policy makers and service planners are trained and supported to understand the benefits and approaches for effective consumer involvement in cancer care and control.</p> <p>Consumers have long recognised that on many occasions, while health professionals, researchers, policy makers and service planners are committed to involving consumers in their activity, they simply do not know how to do so effectively.</p> <p>Health professionals, researchers, policy makers and service planners require the same level of training as consumers in order to understand how consumers can benefit their work and how best to engage them [53].</p> <p>Training consumers and health professionals, researchers, policy makers and service planners together has the added value of building knowledge and skills that will strengthen consumer engagement. Consumers and health professionals, researchers, policy makers and service planners experienced in consumer engagement can teach and act as role models for others who are learning to participate in consumer engagement groups [19].</p>
<p>Organisational support and facilitation to support consumers in their role</p>	<p>Organisations responsible for cancer care and control provide appropriate support to consumers involved in organisational activities. Appropriate support includes champions who support the consumer role, and facilitators who promote and prepare consumers for their role and provide a link that consumers and health professionals, researchers, policy makers and service planners can go to for improving consumer involvement.</p> <p>Facilitators undertake the recruitment of consumers to specific projects and program areas; undertake needs assessment and plan training and development opportunities for consumer participants and health professionals, researchers, policy makers and service planners involved; implement a quality improvement program for consumers; and seek feedback on consumer participation. Consumer facilitators also support health professionals, researchers, policy makers and service planners and program/service areas to adequately prepare and support consumer participation for meaningful effect.</p> <p>Without embedded organisational support, consumer involvement is unable to progress to the level required for sustained long-term benefits and improved outcomes [19]. Organisations' governance structures are strengthened when consumers are included on boards, high-level committees, working groups, cancer, information and support services, policy and research [27–28]. Promoting consumer involvement through organisational policies and processes and providing facilitation and infrastructure can support consumers in their role [14, 18, 23, 48, 58].</p>

<p>Culturally appropriate and targeted methods of consumer involvement for population groups with poor outcomes</p>	<p>Organisations engage consumers who can represent their communities as presenters and mentors, sharing their personal cancer experience in committee work and project work to address hard-to-reach areas, and working with communities to address poor outcomes. Targeted focus groups and strategies that target population groups, demographic areas and tumour types with poorer outcomes lead to better outcomes.</p> <p>Difficulties in involving consumers whose voices are not well heard, including Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, rural and remote communities, or people with poor cancer outcomes (rare cancers, population groups such as older people and young people), has led to criticism and failure of consumer involvement as a whole due to lack of representation [36, 50]. It is now well recognised that community-owned targeted culturally appropriate approaches work better for communities whose cultures or disadvantage require different strategies of engagement [54]. Targeted strategies are much more resource-intensive and work best through community development models where community leaders are engaged to bring about consumer involvement in cancer care and control [55–56].</p>
<p>Integrate consumer involvement into organisational structure and systems for sustainability</p>	<p>Sustainability of consumer involvement embedded into all levels of an organisation, including systems and processes, leads to improved knowledge, skill and capability of consumers and meaningful contributions. Building a network of consumers facilitates broad representation and minimises the need to call on small numbers of consumers to contribute. Advisory groups and networks that consumers could join and cancer consumer organisations that sought wide representation are viewed as an enabler for sustainability.</p> <p>Sustainability of the networks are further strengthened through building alliances that spread the breadth, skill and availability of consumers.</p> <p>The effectiveness of consumer involvement relies on that involvement being well integrated into organisational structures and systems for sustainability [5]. For the consumer perspective to be a valued resource that informs quality cancer services and supportive care, policy development, research and clinical trials, it needs to be promoted as an essential component of organisational practice that is no different than the inclusion of a highly skilled workforce. Including the voluntary role of consumers in the provision of cancer care and control leads to improvements in quality care [57].</p>

Appendix H Expectations of cancer organisations and professional bodies

Professionals and organisations acknowledge the importance of identifying, selecting and matching consumers to specific areas of cancer care and control for the best effect. While there are some commonalities between the areas of cancer control, there are also differences that need to be recognised. These differences require a different level of preparation and skill. The following expectations have been identified by those involving consumers in areas of cancer control and are supported by the literature.

Table 7: Expectations of cancer organisations and professional bodies

ORGANISATIONAL EXPECTATIONS	DESCRIPTION
Consumer involvement in cancer control	<p>Consumer involvement in the development of information resources is viewed as essential to ensuring the information is relevant and useful to those it is meant to inform. Health professionals, researchers, policy makers and service planners listen and respond to the consumer contribution and develop resources to support people on their cancer journey.</p> <p>Examples identified where organisations facilitate consumer involvement:</p> <ul style="list-style-type: none"> • the development of information about cancer • priority setting of consumer information requirements • mentoring • priority setting of cancer support options • cancer services development • cancer service design and infrastructure development • cancer services implementation and evaluation • research including design, development, implementation and evaluation • evaluation and feedback for quality improvement • priority setting of policy • policy proposals • policy development implementation and evaluation <p>Health professionals, researchers, policy makers and service planners believe that consumers are involved in all areas of cancer control [18, 33, 91]. However, they recognise that while there are some generic skills that consumers could benefit from being trained in (e.g. advocacy, communication and strategic planning skills), the particulars of research, cancer services or supportive care services, for example, necessitate consumers to undertake more specialised training in order to optimise their contribution.</p>

<p>Consumer selection</p>	<p>There is great value to be found in the involvement of consumer organisations and subsequently consumers who have received training. It is recognised that access to consumer organisations has benefited cancer control organisations and strengthened consumer participation in a way that could not have occurred previously. Health professionals, researchers, policy makers and service planners and organisations invite consumer organisations to nominate consumers.</p> <p>Some organisations (health professionals, researchers, policy makers and service planners) also supported the opportunity of selecting consumers who had an interest in contributing to their cancer control activity. This usually involved advertising and selecting through an open process, including a consumer panel to recruit consumers based on merit.</p> <p>The consultation revealed that there were many approaches to selecting consumers to participate in consumer involvement activities, with the majority of approaches including:</p> <ul style="list-style-type: none"> ▶ a request to consumer organisations for a nomination ▶ advertising and recruiting consumers based on selection criteria for a specific purpose or project, or ▶ selecting consumers through clinical, policy or research networks. <p>The Commonwealth Consumer Affairs Advisory Council has outlined a number of principles to guide consumer selection processes, including the need for appointments to be made on merit, with successful consumers demonstrating expertise in relevant consumer affairs and links to relevant consumer organisations for consultation [16].</p>
<p>Consumer networks</p>	<p>Health professionals, researchers, policy makers and service planners and cancer organisations require a network of consumers on which to draw. This enables training to be cost-effective and prepares consumers for potential work. This creates difficulties, however, with consumers being utilised in an ad hoc way. This is particularly an issue for government and non-government organisations that do not provide advocacy services. Some consumers elect to participate in non-advocacy groups because they do not view themselves as advocates. Creating consumer networks where consumers feel supported and part of a larger team of colleagues is viewed as important. Supporting networks requires resourcing to keep consumers engaged and informed of organisational activities.</p> <p>Effective cancer services provide real opportunities to form well-supported consumer networks [28, 58]. Building networks of consumers to support cancer control activity provides opportunities for consumers to receive training and development, helps link them to other consumers for peer support and helps build knowledge and awareness that facilitates meaningful engagement. Building alliances between organisations (and in particular between consumer organisations and Aboriginal and Torres Strait Islander people, community organisations and multicultural organisations) further strengthens consumer engagement.</p>

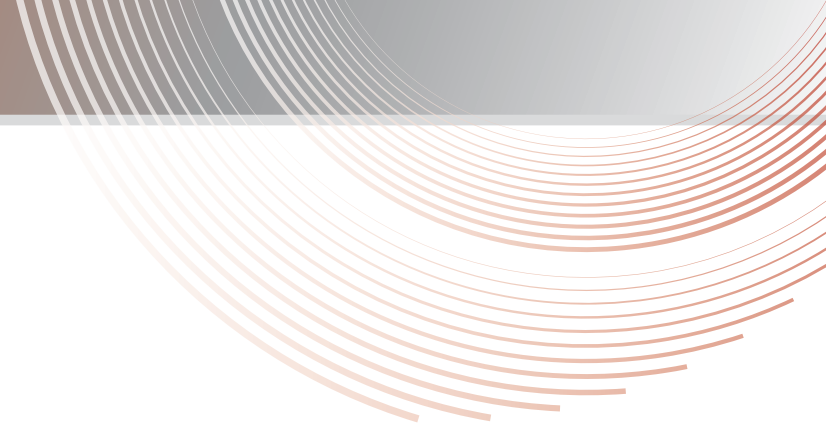
<p>Consumer self-care</p>	<p>Due to the very nature of consumer involvement being a largely voluntary activity, there are risks in consumers taking on too much and burning out. Burnout symptoms result in consumers not being able to see the big picture or the mutual benefits of activities. This becomes a burden for health professionals, researchers, policy makers and service planners and impacts on future consumer engagement activities. Consumers require training in self-care management to prevent burnout and consumer organisations need to recognise the warning signs and act when a consumer exhibits burnout.</p> <p>While there have been studies in professional burnout [37, 49, 52], the risk of consumer burnout is also identified as a potential consequence of ineffective consumer involvement [59–60]. Health professionals, researchers, policy makers and service planners have experienced consumers who have lost sight of the big picture. If consumer involvement becomes more about personal needs and ego rather than the needs of others, this compromises the quality of consumer engagement and impacts on the trust required for effective consumer participation [18, 49, 64]. Promoting self-care as a component of training and preparation is therefore viewed as essential to effective consumer engagement [59].</p>
<p>Training and support</p>	<p>Health professionals, researchers, policy makers and service planners require consumers to be trained first in advocacy and then in modules specific to the tasks. This might require a research module, an information and supportive care module and a cancer services module. Offering modules of training and development enables consumers to develop their expertise over time and to contribute to areas of interest.</p> <p>Providing training and support for consumers to enable them to participate in a meaningful way is viewed by health professionals, researchers, policy makers and service planners as essential to effective consumer participation [28]. Furthermore, they see benefit in involving consumers and health professionals, researchers, policy makers and service planners in combined professional development opportunities in order to learn from one another and to improve the understandings created through the combination of clinical knowledge and practical experience.</p>
<p>Resourcing</p>	<p>It is widely recognised that supporting consumers to be involved requires effective resourcing. Resourcing is required to train, develop and support consumers. Regular meetings and workshops in addition to electronic media enable consumers to be effectively engaged.</p> <p>Health professionals, researchers, policy makers and service planners recognise that supporting consumers to be actively involved in cancer control activities requires dedicated resources [21, 28]. Resources include facilitators to train and support consumers to actively participate, as well as leaders and champions to promote the benefits and rewards of consumer engagement. Providing resources to support consumer engagement groups and undertaking research, evaluation and quality improvement activities to measure the effectiveness of consumer participation were also identified as enablers to effective consumer participation.</p>

<p>Representation</p>	<p>Consumers who participate in cancer control represent the broad views of consumers. They do not represent an organisational viewpoint. Consumers require an understanding of the needs of people they represent. They are usually engaged by organisations to identify the needs of people affected by an issue, but they may also have links through other networks, e.g. consumer organisations, Aboriginal and Torres Strait Islander organisations, multicultural organisations, Country Women’s Association, Rotary, sport organisations. Consumers assist organisations in addressing the needs of people affected by cancer in ways that are mutually beneficial [16].</p>
<p>Advocacy</p>	<p>Advocacy promotes the broad views of a range of people affected by cancer.</p> <p>The role advocacy plays in consumer involvement has at times led to confusion or hesitancy on the part of health professionals, researchers, policy makers and service planners when considering involving consumers. Consumers have at times been criticised for being inflexible and pushing a particular position and this has been labelled as ‘advocacy’ however it is more in keeping with ‘lobbying’ which concerns promoting a particular point of view.</p> <p>Consumers and organisations have an understanding of the particular role required and discern the advocacy approach as defined in this paper to represent the broad views of people affected by cancer [15].</p>

Appendix I Consultation findings

Table 8: Summary of consultation findings

ENABLERS OF EFFECTIVE CONSUMER INVOLVEMENT IN CANCER CONTROL	BARRIERS TO EFFECTIVE CONSUMER INVOLVEMENT IN CANCER CONTROL
<ul style="list-style-type: none"> ▶ Good relationships between multidisciplinary members of committees—it was found that when relationships were built between consumers, consumer organisations, cancer organisations, professional organisations and government agencies, consumers were able to influence at higher levels of engagement. ▶ External relationships—forming relationships with media to facilitate good news stories and help influence behaviour. ▶ Consumer organisations that could represent the views of consumers were viewed as a strength in terms of capacity building and encouraging a system of consumer participation. ▶ Building a mutually shared understanding of the context, objectives and outcomes of a committee was viewed as essential to effective consumer involvement. ▶ The motivation of consumers who generously volunteer their time. ▶ Health professionals, researchers, policy makers, health service providers who genuinely want to make things better. 	<ul style="list-style-type: none"> ▶ Lack of diverse representation of population groups with poorest outcomes, e.g. Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, rural and regional communities and people affected by cancers with high mortality, i.e. rare cancers and population groups such as the elderly and the young. ▶ Knowledge, skills and preparedness of consumers to strategically articulate the needs and views of consumers. ▶ Lack of compensation and remuneration for consumers for their time and contribution. Perceived inequity due to health professionals, researchers, policy makers and health service providers being paid and consumers volunteering their time, which may be seen not to be valued as highly. ▶ Consumers pushing their own vested interests; advocacy and lobbying from a personal perspective. ▶ Consumers, policy makers, health professionals and researchers not having an understanding of their roles. ▶ The dominance of organisational cultures (of health professionals, researchers, policy makers and health service providers) imposing judgements and solutions and the lack of skills and competence of organisations to effectively engage consumers. ▶ Organisations not being systematic in their approach to consumer involvement. ▶ Consumers being 'time poor', particularly populations with poorer outcomes such as rural and regional communities, which affected their voices being heard. ▶ The lack of consumer participation policies to guide engagement at a national level.



	<ul style="list-style-type: none"> ▶ The difficulty of national organisations accessing consumers directly rather than through the states. Some national organisations functioned in a federated system that resulted in their working through the states and territories for consumer involvement. This became problematic simply because the role of the national organisations in many circumstances was different from the roles of state-based organisations. This resulted in consumers requiring a different preparation, skills and training and national organisations grappling with the best approach to engage consumers directly in the activities of their own organisations. In addition, when national organisations engaged consumers directly this resulted in consumers not being connected to a network or system, and therefore sitting outside of government agencies, charitable organisations and professional bodies.
<p>FUTURE OPPORTUNITIES FOR IMPROVED CONSUMER INVOLVEMENT</p>	<p>CHANGES NECESSARY TO FURTHER IMPROVE CONSUMER INVOLVEMENT</p>
<ul style="list-style-type: none"> ▶ Encouraging leadership roles and champions, consumers, policy makers, health professionals and researchers to help build capacity in consumer participation. ▶ Developing strategic partnerships that improve the involvement of a broad range of consumers. ▶ Compensating and acknowledging consumer participation through offering associate membership, inclusion in publications and conference registrations, abstracts and presentations. ▶ Utilising the social media (online forums, news, surveys) to engage a broader range of consumers and providing resources to better inform communities. ▶ Increasing research, evaluation and feedback relating to the impact of consumer participation in cancer control. 	<ul style="list-style-type: none"> ▶ Placing a greater value on the lived experience to improve policy, service development and research for improved outcomes. ▶ Working collaboratively at local, regional, state and national levels to strengthen consumer participation. ▶ Acknowledging the value and legitimacy of voluntary consumer input with no conflict of interest. ▶ Improving structures, philosophy and resources that will integrate consumer participation at all levels and across the cancer continuum. ▶ Capacity building and mutual support for consumer participation. ▶ System change that supports consumer involvement as an essential component of policy, service development and research. ▶ Building confidence in the sector to effectively involve consumers, and in consumers to participate. ▶ Recognising that consumer involvement requires consumers to be well prepared for the roles through training and development programs for consumers and professionals. ▶ Building sustainable consumer involvement models that focus on overall health rather than disease-specific streams.

Appendix J Drivers for change

- ▶ Political drivers that view consumer involvement as essential, not an optional extra.
- ▶ Promoting the principles of consumer engagement for greater understanding of the benefits.
- ▶ Legislative changes that embed consumer involvement within health service outcomes, policy, planning, service delivery and research.
- ▶ Evidence that involving consumers/communities leads to improved outcomes, improved health literacy and improved health management and research.
- ▶ Quality consumer-centred approaches that lead to improvements and better health outcomes.
- ▶ Health reforms and changing demographics.

Appendix K Members of the project governance

Membership of the Project Steering Group

REPRESENTATIVE	ORGANISATION
Dr Ian Roos OAM (Chair)	Chair, Cancer Voices Australia and Victoria
Ms Lyn Swinburne AM	Breast Cancer Network Australia
Dr Helen Zorbas (CEO)	National Breast and Ovarian Cancer Centre and Cancer Australia
Dr Anna Williamson	Leukaemia Foundation
Ms Cathy Mitchell	National Health and Medical Research Council
Professor Annette Street	La Trobe University
Dr Nicola Dunbar	Australian Commission on Safety and Quality in Health Care
Assoc Professor Christine Giles	National Breast and Ovarian Cancer Centre
Dr Joanne Ramadge	Cancer Australia
Ms Susan Hanson (project lead)	Cancer Australia

Membership of the Consumer Informant Group

Mr John Newsom (Chair)	Chair, National Consumer Advisory Group
Mr Tony Addiscott	Cancer Voices Western Australia
Ms Agnes Vitry	Cancer Voices South Australia
Ms Anne Kay	Cancer Voices Victoria
Mr David Gregory	Cancer Voices Tasmania
Ms Danielle Tindle	Cancer Voices Queensland
Ms Kathy Smith	Cancer Voices New South Wales
Dr Anne Atkinson	National Consumer Advisory Group
Ms Sharna Chenery	National Consumer Advisory Group
Ms Linda Christenson	National Consumer Advisory Group
Ms Kay Duffy OAM	National Consumer Advisory Group

Ms Joyce Graham	National Consumer Advisory Group
Ms Karen Forster	National Consumer Advisory Group
Mr Tony Cocchiaro	National Consumer Advisory Group
Mr Michael Powell	National Consumer Advisory Group
Ms Roslyn Weetra	National Consumer Advisory Group
Ms Leonie Young	National Consumer Advisory Group
Mr Ashleigh Moore	National Consumer Advisory Group

Membership of the National Reference Group

Dr Julie Thompson (Chair)	Cancer Australia Advisory Council
Ms Mary Reid	Carers Australia
Ms Joan Hughes	Carers Australia
Ms Amanda Winiata	Breast Cancer Network Australia
Ms Sally Crossing AM	Consumer Health Forum
Ms Catherine Bullivant	Cancer Institute NSW
Dr Ian Roos OAM	Cancer Voices Australia
Dr Claire Treadgold	CanTeen
Assoc Professor Bogda Koczwara	President—Clinical Oncological Society Australia
Ms Margaret McJannett	Executive Officer—ANZUP Cancer Trials Group Limited
Professor John Zalcborg	Chair—Australasian Gastro-Intestinal Trials Group
Ms Karen Livingstone	Executive Member—Australian New Zealand Gynaecological Oncology Group
Ms Cheryl Grant	Secretary—Breast Cancer Action Group NSW
Professor Michael Milward	President—Australasian Lung Cancer Trials Group
Professor Nik Zeps	Chair—National Research Advisory Group
Mr John Newsom	Chair—National Consumer Advisory Group

Assoc Professor Rosemary Knight	Department of Health and Ageing
Assoc Professor Sundram Sivamalai	Federation of Ethnic Communities Council of Australia
Dr Anna Williamson	Leukaemia Foundation
Mr William Darbishire	The Australian Lung Foundation
Ms Kerry Callaghan	The Australian Lung Foundation
Ms Kay Francis	Medical Oncology Group of Australia
Ms Kate Kelleher	National Aboriginal Community Controlled Health Organisation
Ms Tricia Elarde	National Aboriginal Community Controlled Health Organisation
Assoc Professor Christine Giles	National Breast and Ovarian Cancer Centre
Dr Jessica Harris	National Breast Cancer Foundation
Ms Cathy Mitchell	National Health and Medical Research Council
Mr Gordon Gregory	National Rural Health Alliance
Ms Lynne Strathie	National Rural Health Alliance
Ms Annabel Davies	Ovarian Cancer Australia
Dr Yvonne Luxford	Palliative Care Australia
Mr Graham Higgs	Prostate Cancer Foundation of Australia
Dr Meron Pitcher	Royal Australasian College of Surgeons
Dr Beres Wenck	Royal Australian College of General Practitioners
Ms Gabrielle Prest	Royal College of Nursing, Australia
Dr Liz Kenny	Chair—Strategic Forum
Professor Jeanette Ward	Royal Australian College of Physicians
Ms Elise Davies	State and Territory Health Authorities (Strategic Forum)
Dr Euan Walpole	State and Territory Health Authorities (Strategic Forum)
Professor Patsy Yates	Queensland University of Technology
Professor Phyllis Butow	University of Sydney
Professor Sanchia Aranda	Director of Cancer Services and Information CINSW

Assoc Professor Tim Shaw	University of Sydney
Dr Dell Horey	LaTrobe University
Ms Marie Malica	Clinical Oncological Society of Australia
Dr Anne Atkinson	Deputy Chair—National Consumer Advisory Group
Ms Catherine Holliday	Cancer Council New South Wales

Members of the International Linkages Group

Ms Lyn Swinburne AM (Chair)	Breast Cancer Network Australia
Dr Helen Zorbas	Cancer Australia
Ms Kathy Redmond	Editor, Cancer World magazine, European School of Oncology, Lugano Switzerland CEO, Redmond Consulting (provides consulting services to professional and patient organisations as well as the pharmaceutical industry)
Professor Jessica Corner	Head of School of Health Sciences University of Southampton, United Kingdom
Ms Christine Brunswick	Vice-President—National Breast Cancer Coalition, Washington, United States of America
Dr Ian Roos OAM	Cancer Voices Australia
Professor Sanchia Aranda	Director of Cancer Services and Information, Cancer Institute New South Wales
Ms Susan Hanson	Cancer Australia (project lead)

Glossary

The definitions in this glossary have been applied to the *National Framework for Consumer Involvement in Cancer Control*.

Advocate

An advocate represents the broad views and experiences of a range of people affected by cancer. This includes persons or groups of people who are unable to represent themselves. Advocacy is speaking, acting or writing, with minimum conflict of interest, on behalf of the interests of a disadvantaged person or group, to promote, protect and defend their welfare [7, 9, 14, 62–67].

Consumer

A consumer of cancer services is a person with cancer, their carer or family member. Their journey through the cancer continuum can provide an insight into how a cancer diagnosis impacts on the lives of people with cancer. Collectively, the experiences and views of consumers help identify key areas that will assist in reducing the impact of cancer on all people affected and lessening disparities for those groups that have poorer cancer outcomes.

Cancer control

Cancer control refers to all actions taken to reduce the impact of cancer, on people affected by cancer and on the community. Cancer control aims to reduce the incidence, morbidity and mortality of cancer and to improve the quality of life of cancer patients in a defined population, through the systematic implementation of evidence-based interventions for prevention, early detection, diagnosis, treatment, recovery, supportive care, survival and palliative care. Comprehensive cancer control addresses the whole population, while seeking to respond to the needs of the different subgroups at risk. The components of cancer control include planning, prevention, early detection, diagnosis and treatment, recovery, supportive care, survival, palliative care, policy, service delivery and advocacy and research. Cancer control involves hospital and community health care providers and also a strong voluntary sector led by the Cancer Councils. More broadly, cancer control involves the behaviour and lifestyle of every person in the community [1, 6].

The **principles** of cancer control include:

Leadership to create clarity and unity of purpose, encourage team building and broad participation, ownership of the process, continuous improvement and mutual recognition of efforts made.

Involvement of stakeholders of all related sectors and at all levels of the decision making process to enable active participation

Creation of partnerships to enhance effectiveness through mutually beneficial relationships and build trust and complementary capacities of partners from different disciplines and sectors

Responding to the needs of people at risk of developing cancer or already presenting with the disease in order to meet their physical psychosocial and spiritual needs across through full spectrum of care

Decision making based on the evidence, social values and effective and efficient use of resources that benefit the target population in a sustainable and equitable way.

Application of a systematic approach by implementing a comprehensive program with interrelated key components sharing the same goals and interrelated with other related health programs and to the health

Seeking continuous improvement innovation and creativity to maximise performance and to address social and cultural diversity as well as the needs and challenges presented by a changing environment

Adoption of a stepwise approach to planning and implementing interventions based on local considerations and needs for chronic disease prevention and control as applied to cancer control. Cancer control activities include public education, research, early diagnosis and screening, specific cancer therapy, and support and care (including palliative care) of people affected by cancer [1, 6].

Capability

Capability refers to the ability of a person or organisation to act confidently in both familiar and unfamiliar situations. More than just skills and knowledge, it also involves utilising values, judgement, the self-confidence to take risks and an ability to reflect on and learn from practice [61].

Co-design

Co-design recognises that all human works are designed and with a purpose. The aim of co-design is to include those perspectives that are related to the design in the process. It is generally recognised that the quality of design increases if end user interests are considered in the design process. Co-design is a development of systems thinking, which begins when first you view the world through the eyes of another. [13–14]

Consumer participation

Consumer participation includes the following types:

Consultation

Consultation is when consumers are asked for their views. Consultation is a level of participation at which people are offered some choices on what is to happen, but are not involved in developing additional options or actions [9].

Participation

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 [9].

Involvement

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 [9].

Consumer engagement

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. Engagement may include sharing a personal experience, participating in focus groups, or surveys [10, 13].

Consumer organisation

A consumer organisation is a group:

- ▶ whose main objective is to genuinely advance the interests of consumers
- ▶ that is independent of industry and government in its decision making
- ▶ that due to its activities, membership or other relevant factors is publicly recognised as playing a legitimate role in advancing the interests of consumers [16, 62].

Community

A community is a group of people sharing a common interest (e.g. cultural, social, political, health or economic interests) but not necessarily a particular geographic association [16].

Consumer representative

A consumer representative requires specific skills, beyond an individual's own personal experiences as a consumer. The most useful definition of these skills is set out in the Benchmarks for Industry-Based Customer Dispute Resolution Schemes [63] and specifies that consumer representatives must be:

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

The broad skills a consumer representative should bring to decision making and advisory bodies are defined in a number of places, including government guidelines and industry self-regulation terms of reference. The underlying principle in all definitions is that a consumer representative should bring positive benefits to the position, including understanding of consumer issues and viewpoints, and have the confidence of the consumer movement [64].

Framework

A framework is a high-level document which can be used to help guide policy development, quality service delivery and research. Framework documents are designed to inform senior health policy makers, health services, peak consumer organisations, health professionals, researchers and service planners, and for this reason they do not specifically target a general audience. The National Service Improvement Framework for Cancers is an example of a framework document that helps guide quality cancer care and delivery [65].

Level of participation in cancer care

Six levels of participation in cancer care have been identified [65]:

1. individual level refers to a person affected by cancer
2. local level refers to consumers participating in their local service area or community
3. regional level refers to consumer participation across a number of cancer services
4. state level includes consumer participation in one or all aspects of cancer control at a state level
5. national level includes consumer participation in one or all areas of cancer control at a national level
6. international level includes consumer participation in one or more cancer control areas at an international level.

Group

A group refers to an association of people in the broadest sense and is not necessarily confined to a clinical or medical multidisciplinary team. These broad groups are boards and committees, clinical teams, service teams, policy groups or research groups. Members of such groups bring an essential skill to the outcome of the project/organisation. These groups will involve the consumer experience.

Professional

Professional refers to: 'A disciplined group of individuals who adhere to high ethical standards and uphold themselves to, and are accepted by, the public as possessing special knowledge and skills in a widely recognised, organised body of learning derived from education and training at a high level, and who are prepared to exercise this knowledge and these skills in the interest of others.'

Inherent in this definition is the concept that the responsibility for the welfare, health and safety of the community shall take precedence over other considerations [12].'

References

1. World Health Organization, *Cancer Control. Knowledge into Action. WHO Guide for Effective Programmes. Policy and Advocacy*. 2008, WHO: Ch-1211 Geneva 27 Switzerland. p. 1–49.
2. Sinding Chris, Wiernikowski Jennifer, *Treatment Decision Making and Its Discontents*. *Social Work in Health Care* 2009. 48(2009): p. 614–634.
3. Australian Institute of Health and Welfare & National Breast Cancer Centre 2006, *Breast cancer in Australia: an overview, 2006*. 2006, AIHW Canberra ACT 2601.
4. Australian Institute of Health and Welfare, Cancer Australia, and the Australasian Association of Cancer Registries, *Cancer survival and prevalence in Australia Cancers diagnosed from 1982 to 2004*. CANCER SERIES Number 42, ed. A.I.o.H.a.W. AIHW. 2008, Canberra: AIHW.
5. Australian Government, *Closing the Gap Indigenous Chronic Disease Package*, Department of Health and Ageing, Editor. 2010, Commonwealth Copyright Administration Attorney Generals Department Robert Garran Offices National Circuit, Barton ACT. p. 1–17.
6. Cancer Australia, *Annual Report 2008–09*, Cancer Australia, Editor. 2009, Commonwealth of Australia: Canberra ACT.
7. The Treasury. *Consumer Voices Sustaining advocacy and research in Australia's new consumer policy framework Issues Paper*. 2009 [cited 2009 9 May 2009].
8. Coney Sandra, *Effective consumer participation for New Zealand: a systematic review of the evidence*, in *Promoting Effective Health and Disability Services*, N.Z.G. Group, Editor. 2004, Summary for the 2nd Guidelines International Conference Evidence in Action Wellington 1–3 November 2004: Wellington.
9. National Health and Medical Research Council. *A Model Framework for Consumer and Community Participation in Health and Medical Research*. 2004 [cited 2009 16 June 2009].
10. Health Consumers Queensland Queensland Health (2010) *Consumer engagement framework*. August, 1–36.
11. Gregory Judy Dr, *A framework of consumer engagement in Australian Health Policy: developing a framework for the AIHPS study*, in *working paper 2*, Australian Institute of Health Policy Studies, Editor. 2006, Australian Institute of Health Policy Studies: Melbourne.
12. Australian Competition and Consumer Commission. *Definition of professional*. 2011 [cited 2011 20 November].
13. NHS Institute (National Health Service Institute for Innovation and Improvement). *Using design to innovate*. 2011 29 May 2011; Available from: http://www.institute.nhs.uk/innovation/innovation/using_design_to_innovate.html
14. Wikipedia the free encyclopedia. *Co-Design*. 2011 [cited 2011 29 May]; Available from: http://en.wikipedia.org/wiki/Co-Design#cite_note-0
15. The Institute for Family Advocacy and Leadership Development in Australia. *What is Advocacy*. 2010 [cited 2010 14 March]; Available from: <http://www.agedrights.asn.au/rights/whatis.html>
16. Australian Commission on Safety and Quality in Health Care, *Patient-Centred Care: Improving the quality and safety by focusing care on patient and consumers 2010*, Australian Commission on Safety and Quality in Health Care ACSQHC: Sydney NSW 2001. p. 1–81.
17. ANAO & Department of Prime Minister and Cabinet, *Implementation of Programs and Policy Initiatives: Making Implementation Matter Better Practice Guide* Department of Prime Minister and Cabinet, Editor. 2006, Commonwealth of Australia: Canberra ACT.

18. Hanley Bec Truesdale Ann King Andy Elbourne Diana Chalmers Iain, *Involving consumers in designing, conducting, and interpreting randomised controlled trials: questionnaire survey*. *BMJ*, 2001. 322(3 March 2001): p. 519–523.
19. Popay, J., et al., *Community engagement in initiatives addressing the wider social determinants of health. A rapid review of evidence on impact, experience and process.*, in *Social Determinants Effectiveness Review*. 2007, Universities of Lancaster, Liverpool and Central Lancashire: Lancaster, UK. p. 1–226.
20. National Institute of Clinical Excellence, *Community engagement to improve health*, in *NICE public health guidance 9 Community engagement to improve health*, NICE, Editor. 2008, National Institute of Clinical Excellence Holborn, London WC1V 6NA. p. 1–91.
21. Government of Western Australia, *WA Health Consumer Carer and Community Engagement Framework: for health services, hospitals and WA Health following consultation across WA Health*, Department of Health, Editor. 2007, Department of Health,: Perth. p. 1–31.
22. Cancer Australia, *National Framework for Consumer Involvement in Cancer Control Project Plan*. 2010: Canberra ACT.
23. Brouwers Dr Melissa (May 2009) *Appraisal of Guidelines for Research & Evaluation II AGREE II Instrument The AGREE Next Steps Consortium*, 1–41.
24. Department of Human Services Victoria, *Doing it with us not for us: Participation in your health service system 2006–09: Victorian consumers, carers, and the community working together with their health services and the Department of Human Services*, Rural and Regional Health and Aged Care Services Division Victorian Government Department of Human Services Melbourne Victoria Australia, Editor. 2006, State Government of Victoria 555 Collins Street Melbourne. Also published on <http://www.health.vic.gov.au/consumer> . Victoria 3168,.
25. Cancer Australia and Cancer Voices Australia, *National Framework for Consumer Involvement in Cancer Care and Control Draft Framework for development Prepared by Susan Hanson Director Consumer Networks*. 2011: Canberra ACT. p. 1–39.
26. Knighting Dr Katherine Forbat Dr Liz Cayless Dr Sandi Kearney Professor Nora (Principal Investigator), *Enabling Change: Patient experiences as a driver for service improvement.*, 2007, Scotland: Cancer Research Centre University of Stirling, .
27. Amos A Hirst S Picco L, *CanNET Cancer Service Networks National Demonstration Project.*, 2008, Department of Health Services: Victoria.
28. Wright David Corner Jessica Hopkinson Jan Foster Claire, *Listening to the views of people affected by cancer about cancer research: an example of participatory research in setting the cancer research agenda*. *Health Expectations*, 2006. 9(2006): p. 3–12.
29. Turner Jane. McAvoxy Brian. Luxford Karen. Fletcher Jane (2004) *Clinical practice guidelines for the psychosocial care of adults with cancer Welcome support for GPs*. Reprinted from *Australian Family Physician* 33, 63–65.
30. Australian Commission on Safety and Quality in Health. *Consumer Engagement Statement*. 2009 [cited 2010 4 October]; Available from: <http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/CES-consult>.
31. Australian Commission on Safety and Quality in Health, *Australian Safety and Quality Framework for Health Care*. 2010: Sydney NSW.
32. Breast Cancer Network Australia. *Advocates*. 2011 [cited 2011 23 March]; Available from: <http://www.bcna.org.au/about-bcna/advocacy/consumer-representatives>.

33. Niazi AD, A.-D.A., *Impact of community participation on treatment outcomes and compliance of DOTS patients in Iraq*. Eastern Mediterranean Health Journal 2003 July. Vol 9(Issue 4).
34. Nilsen ES Myrhaug HT Johansen M Oliver S Oxman AD (2010) *Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (Review)*. The Cochrane Collaboration, DOI: 10.1002/14651858.
35. Craig T, D.I., Jamieson-Craig R, Boocock A, Attafua G, *The consumer-employee as a member of a Mental Health Assertive Outreach Team. I. Clinical and social outcomes*. Journal of Mental Health, 2004. Vol 13 (Issue 1).
36. Canadian Health Services Research Foundation, *Public Engagement (Part 1): Engaging the Public in Healthcare Policy: Why do it? and What are the challenges?* Insight and Action, 2009(48).
37. Canadian Health Services Research Foundation, *Public Engagement (Part II): How do deliberative processes achieve meaningful public engagement*. Insight and Action, 2009(49).
38. Hubbard G Knighting K Rowa-Dewer N Forbat L Illingworth N Wilson M Kearney N, *People's experience of Cancer within the First Year Following Diagnosis Final Report*. 2007, Cancer Care Research Centre University of Stirling: Scotland United Kingdom. p. 1–240.
39. Cancer Voices Australia. *Cancer Voices Australia Rules of Association of Cancer Voices Australia (ABN 93 322 703 427)*. Constitution 2007 [cited 2009 23 March]; Available from: <http://www.cancervoicesaustralia.org.au/pdfs/constitution.pdf>.
40. Commonwealth of Australia, *The Australian Public Service Social Inclusion policy design and delivery toolkit*, Department of Prime Minister and Cabinet, Editor. 2009, Social Inclusion Unit: National Circuit Barton ACT 2600. p. 1–26.
41. Australian Government, *Australia: The Healthiest Country by 2020 — National Preventative Health Strategy — Overview*, in *National Preventative Health Strategy Overview*, N.P.H. Taskforce, Editor. 2009, Commonwealth of Australia: Barton ACT. p. pp 1–51.
42. Australian Government, *National Service Improvement Framework for Cancer*, National Health Priority Action Council (NHPAC), Editor. 2006, Department of Health and Ageing: Canberra.
43. Nilsen ES Myrhaug HT Johansen M Oliver S Oxman AD, *Methods of consumer involvement in developing health cancer policy and research, clinical practice guidelines and patient information material (Review)*. The Cochrane Collaboration, 2009(Issue 3): p. 1–31.
44. Australian Commission on Safety and Quality in Health. *National Safety and Quality Health Service Standards and their use in a Model National Accreditation Scheme Consultation Regulatory Impact Statement*,. September 2010 [cited 2010 4 October]; Available from: http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/com-pubs_ConsultRegImpactStatement.
45. Saunders C. Crossing S. Girgis A. Butow P. Penman A, *Operationalising a model framework for consumer and community participation in health and medical research*. Australian and New Zealand Health Policy, 2007. 4(14).
46. Wetzels R, H.M., Van Weel C, Grol R, Wensing M., *Interventions for improving older patients' involvement in primary care episodes*. Cochrane Database of Systematic Reviews, 2007(Issue 1.).
47. Cancer Australia, *National Consumer Advisory Group*, in *National Consumer Advisory Group Minutes*. 2007: unpublished.
48. Australian Government, *Towards a National Carer Strategy A discussion paper from the Australian Government*, A.G.s. Department, Editor. 2010, Commonwealth of Australia: Canberra. p. 1–20.
49. Consumer Health Forum of Australia, *Position Statement in Consumer representatives shape health in Australia*. 2007, Consumer Health Forum of Australia: www.chf.org.au. p. 1–2.

50. Commonwealth of Australia, *A National Health and Hospitals Network for Australia's Future— delivering better health and better hospitals*, Attorney-General's Department, Editor. 2010, Commonwealth of Australia, : National Circuit Barton ACT,.
51. ACT Health, *Draft Cancer Services Plan 2008 – 2012* ACT Health, Editor. October 2007, Draft in progress: ACT. p. 1–80.
52. Department of Human Services. *Developing a strategy for consumer and carer participation in cancer service reform*. 2007 [cited 2008 February 2008]; Available from: www.health.vic.gov.au/cancer.
53. Hibbard Judith Collins Peter Mahoney Eldon Baker Laurence, *The development and testing of a measure assessing clinician beliefs about patient self-management*. Health Expectations, 2009. 13: p. 65–72.
54. Caicedo L Zabora J Brinzenhofeszoc K Drake M, *Impact of Nueva Vida's model of self efficacy in Latina with breast cancer*. Psycho-Oncology Conference: 6th Annual Conference of the American Psychosocial Oncology Society, 2009. 18: p. 84.
55. Miller J Knott V Wilson C Cunningham J Condon J Roder D, *Aboriginal and Torres Strait Islander Cancer Control Research Report*, C. Australia, Editor. 2010, Commonwealth of Australia: Canberra. p. 1–135.
56. Hennessey Lavery S Smith M L Avila Esparza A Hrushow A, *The Community Action Model: A Community-Driven Model designed to Address Disparities in Health*. American Journal of Public Health, 2005. 95(4): p. pg. 611–.
57. Health Issues Centre, *A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services*, State of Victoria Department of Human Services, Editor. 2007, Metropolitan Health and Aged Care Services Division Victorian Government Department of Human Services Melbourne Victoria: Melbourne Victoria,.
58. Government of Western Australia, *WA Health Cancer Services Framework October 2005*, Health Reform Implementation Taskforce Department of Health WA Health Cancer Services Framework, Editor. 2005, WA Health: Perth. p. 1–50.
59. Cancer Australia. *Cancer Australia Consumer participation guide*. 2009 14 June 2010 [cited 2010 14 June 2010]; Available from: www.canceraustralia.gov.au.
60. Halbesleben Jonathon R. B. Rathert Cheryl, *Linking physician burnout and patient outcomes: Exploring the dyadic relationship between physicians and patients*. Health Care Management Review, 2008. 33(1 January/ March): p. 29–39.
61. The National Cancer Nursing Education Project (EdCaN) (2008), *National Education Framework — Cancer Nursing: A national professional development framework for cancer nursing*. 2008, Cancer Australia, : Canberra ACT 2602.
62. Australian Commission on Safety and Quality in Health Care, *Development of a Consumer Engagement Strategy for the Commission Background Paper*, Australian Commission on Safety and Quality in Health Care, Editor. 2008, Australian Commission on Safety and Quality in Health Care, : Sydney. p. 1–16.
63. Australian Government, *Benchmarks For Industry-based Customer dispute resolution schemes*, C.A. Division, Editor. 1997, Department of Industry, Science and Tourism: GPO Box 9839 Canberra City ACT 2601. p. 1–23.
64. Commonwealth Consumer Affairs Advisory Council, *Principles for the Appointment of Consumer Representatives: A Process for Governments and Industry*, The Commonwealth Copyright Administration Intellectual Property Branch Department of Communications Information Technology and the Arts, Editor. 2005, Printed by Ego Print, 31–37 Howleys Road, Notting Hill Victoria 3168: CANBERRA ACT 2601. p. 1–15.
65. Adams R., Boscarino J., and Figley C. *Compassion Fatigue and Psychological Distress among Social Workers: A Validation Study*. 2004 [cited 2005 3/4]; Compassion Fatigue Scale].

