



A Toolkit for Consumer Participation and Engagement

PAEDIATRIC ONCOLOGY





This Toolkit was developed by the Paediatric Integrated Cancer Service (PICS), in collaboration with the Australian and New Zealand Children's Haematology Oncology Group (ANZCHOG).



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Australian Government
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A Toolkit for Consumer Participation and Engagement

This Consumer Participation and Engagement Toolkit has been developed specifically as a resource for Australian health services and organisations providing care to paediatric oncology patients, although the general nature of the information may be useful to other service areas and general consumer advisory groups. The ideas and thoughts presented in the Toolkit have been collated by the Paediatric Integrated Cancer Service (PICS) in conjunction with the Australian and New Zealand Childrens Haematology/Oncology Group (ANZCHOG) and the Supporting People with Cancer (SPwC) Steering Group.

This Toolkit has been produced as part of the Cancer Australia *Supporting People with Cancer* grant initiative, funded by the Australian government.

It is envisaged that this Toolkit will assist health services to meet their individual needs and enhance effective consumer participation. Health services using this Toolkit should ensure that resources used meet the governance, mission, vision, procedures and protocols of the organisation, including privacy and confidentiality requirements.

Glossary of acronyms

ANZCHOG	Australian and New Zealand Childrens Haematology/Oncology Group
AYA	Adolescent and Young Adult
CALD	Culturally and Linguistically Diverse
CCCPAG	Children's Cancer Centres' Parent Advisory Group
CEO	Chief Executive Officer
NSQHS Standards	National Safety and Quality Health Service Standards
PICS	Paediatric Integrated Cancer Service
SPwC Steering Group	Supporting People with Cancer Steering Group
ToR	Terms of Reference

Section 1

Introduction to consumer participation and engagement



1.1 Introduction

This Toolkit has been developed specifically as a resource for Australian health services providing care to paediatric oncology patients and consumer representatives, although the general nature of the information may be useful to other service areas. The Toolkit provides guidance in developing consumer advisory groups and engaging consumers, with the aim of supporting a consistent national approach to consumer participation and engagement. The Toolkit includes background information, practical tools and a resource list of appropriate additional information available, to inform health service staff and consumer representatives. The Toolkit is designed to be used by staff, to incrementally build a consumer engagement structure appropriate for the individual health service.

1.2 Background

There is growing consensus within the Australian health care system to support partnerships between consumers and health professionals and organisations.¹ According to the Victorian Government, “*participation is a key enabling strategy in working with and meeting the health needs of our community*”.² Consumer participation is known to improve both the quality and safety of health services as well as individual health outcomes, whilst also making health services more responsive to the needs of consumers.³

“Actively creating a space for the public to be heard not only allows a rich source of information on the patient journey and experience to be gathered, but is also a way for the system to recognise the value of the contributions that patients, carers and the community can make. The consumer voice is essential to full understanding about how to build a safe and quality health system”.

Australian Commission on Safety and Quality in Health Care (2008). *Submission 428 to the National Health and Hospitals Reform Commission: First Round Submissions*. ACSQHC. Retrieved 11 January, 2013 from www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/nhrc-report-toc~nhrc-report-ch5~nhrc-report-ch5.1#163

¹ Australian Commission on Safety and Quality in Health Care (ACSQHC) (2012). *Standard 2: Partnering with Consumers Safety and Quality Improvement Guide*. ACSQHC. Retrieved 31 January, 2013 from http://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard2_Oct_2012_WEB.pdf

² Department of Human Services (2005). *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 Health*. Victorian Government Department of Human Services. Retrieved 25 March, 2013 from http://health.vic.gov.au/consumer/downloads/do_it_with_us.pdf

³ Flinders University (2000). *Improving health services through consumer participation: A resource guide for organisations*. Department of Public Health, Flinders University and the South Australian Community Health Research Unit. Retrieved 11 January, 2013 from <http://www.healthissuescentre.org.au/documents/items/2008/08/226533-upload-00001.pdf>

On an individual level, consumer participation allows individuals and their families to play an active role in their treatment and care planning, supporting shared decision making and self-management where appropriate. At a systemic level, engaging with consumers allows service improvements, through partnerships to enhance systems, processes, policies and models of care.⁴

“Consumers should not only be the focus of the health system, they should be at the centre of decision-making in health. Both at a policy level and an individual level, consumer experiences and preferences should help lead health system reforms, alongside the evidence base.”

National Prescribing Service (2008), Submission 431 to the National Health and Hospitals Reform Commission: First Round Submissions. National Prescribing Service. Retrieved 11 January, 2013 from www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/nhhrc-report-toc~nhhrc-report-ch5~nhhrc-report-ch5.1#163

1.2.1 National health and consumer priorities

The importance of the consumer voice is reflected in the recently released National Safety and Quality Health Service Standards (NSQHS Standards).⁵ The NSQHS Standards were developed by the Australian Commission on Safety and Quality in Health Care in consultation and collaboration with a wide range of experts, organisations and individuals including health professionals and patients. *“The primary aims of the NSQHS Standards are to protect the public from harm and to improve the quality of health service provision”.*⁵ Health services in Australia are required to meet the NSQHS Standards as they provide a governance structure for quality assurance and quality improvement. There are ten standards, the second of which is ‘partnering with consumers’. This standard aims to *“create a health service that is responsive to patient, carer and consumer input and needs”* through partnerships with consumers.⁵



⁴ Department of Human Services (2005). *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 Health.* Victorian Government Department of Human Services. Retrieved 25 March, 2013 from http://health.vic.gov.au/consumer/downloads/do_it_with_us.pdf

⁵ Australian Commission of Safety and Quality in Health Care (ACSQHC) (2011). *National Safety and Quality Health Service Standards.* ACSQHC, Sydney. Retrieved 11 January, 2013 from <http://www.safetyandquality.gov.au/wp-content/uploads/2011/09/NSQHS-Standards-Sept-2012.pdf>

From a national perspective, the role of consumer participation in health service quality and planning is well recognised in ongoing improvements in care for cancer control. Cancer Voices Australia, together with the Australian Government recently released the 'National Framework for Consumer Involvement in Cancer Control'.⁶ This Framework clearly outlines the importance of patient feedback and consultation as mechanisms to engage consumers. In order to support the principles of this Framework, Cancer Australia has developed an online resource for consumer involvement.⁷ The Cancer Australia resource provides information on consumer engagement as it specifically relates to CEOs and Executives, Service Managers, Health Professionals, Researchers, Policy Makers and Consumers.

This Toolkit has been designed to align with the NSQHS Standards and the 'National Framework for Consumer Involvement in Cancer Control'. This document is not intended to duplicate information developed by Cancer Australia. Rather the information included in this Toolkit provides health services with additional practical, user-friendly tools for building a comprehensive consumer engagement structure.

⁶ Cancer Australia and Cancer Voices Australia (2011). *National Framework for Consumer Involvement in Cancer Control*. Cancer Australia, Canberra ACT. Retrieved 11 January, 2013 from http://canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf

⁷ Cancer Australia (2013). *Consumer Involvement Toolkit*. Cancer Australia. Retrieved 2 May, 2013 from www.consumerinvolvement.canceraustralia.gov.au/document-library/service-managers/types-consumer-involvement-diagram



1.3 Defining consumers

“Consumers and carers can be people who currently use your health service or people who have used your service in the past; they can be representatives of community groups, consumer groups or disease-based advocacy groups. Consumers and carers can be interested in contributing to your organisation as a patient, as a general consumer of health services or as a citizen interested in improving health care generally.”

Source: Australian Commission on Safety and Quality in Health Care (ACSQHC) (2012). *Standard 2: Partnering with Consumers Safety and Quality Improvement Guide*. ACSQHC. Retrieved 31 January, 2013 from http://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard2_Oct_2012_WEB.pdf

1.3.1 What is a consumer?

Consumer participation should consider both users of health services, carers and the wider community. The following definitions are provided for health consumers, consumer representatives and the community:

- A **‘health consumer’** includes *“patients, potential patients, carers, organisations representing consumers’ interests, members of the public who are targets of health promotion programs and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services”*.⁸
- A **‘consumer representative’** includes *“a member of a committee, steering group or similar, who voices the consumer perspective and takes part in the decision making process on behalf of consumers. The person is usually nominated by an organisation of consumers and is accountable to them”*.⁸
- A **‘community’** is *“a group of people sharing a common interest (e.g. cultural, social, political, health, economic interest) but not necessarily a particular geographic association. Within this definition, it is important to recognise that different types of communities are likely to have different approaches to participation”*.⁸

⁸ Consumers’ Health Forum of Australia (2004). *A Model Framework for Consumer and Community Participation in Health and Medical Research*. Consumers’ Health Forum of Australia. Retrieved 4 April, 2013 from <http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/r33.pdf>

1.3.2 Example definition:

The Paediatric Integrated Cancer Service (PICS) defines consumers as:

- Children and adolescents with cancer
- Children, adolescent and young adult survivors of cancer.

Whilst parents and families are often referred to as carers, given the nature of paediatric care and the whole of family approach to treatment planning, the PICS also define consumers as:

- Parents/guardians and siblings
- Wider family members (i.e. grandparents).

In addition to consumers, the PICS recognise the wider paediatric oncology community, including:

- Consumers extended family and friends
- Consumers local community (i.e. school, recreational groups, religious groups)
- Support services (i.e. palliative care, hospital in the home etc.)
- Regional service providers
- Specialist providers
- Philanthropic organisations
- Cancer community charities for children and adolescents.



1.4 What is consumer participation and why is it important?

“Rather than partnering with only one person it is often useful to include a range of consumers and/or carers in your partnership activities to ensure that different voices and views contribute to the design, delivery and evaluation of health services.”

Source: Australian Commission on Safety and Quality in Health Care (ACSQHC) (2012). *Standard 2: Partnering with Consumers Safety and Quality Improvement Guide*. ACSQHC. Retrieved 31 January, 2013 from http://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard2_Oct_2012_WEB.pdf

1.4.1 What is consumer/patient centred care?

Consumer or patient centred care is *“healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers”*.⁹ Effectively partnering with consumers requires acknowledgement of the skills, experiences and knowledge of the consumer and mechanisms to utilise consumer views systematically.

According to the NSQHS Standards, a consumer-centred approach to care involves:¹⁰

- *“Treating consumers and/or carers with dignity and respect”*
- *“Communicating and sharing information between consumers and/or carers and healthcare providers”*
- *“Encouraging and supporting participation in decision-making”*
- *“Fostering collaboration with consumers and/or carers and healthcare organisations in the planning, design, delivery and evaluation of healthcare”*.

1.4.2 What is consumer participation?

According to the Victorian Government, consumer participation involves the meaningful participation of consumers, carers and community members. Meaningful involvement requires contribution to and decision making in regards to care and treatment of individuals and the community, health policy and planning.¹¹

⁹ Australia Commission on Safety and Quality in Health Care (2010). *Patient-centred care: improving quality and safety by focusing care on patients and consumers*. ACSQHC. Retrieved 4 April 2013 from <http://www.healthissuescentre.org.au/documents/items/2010/10/353730-upload-00001.pdf>

¹⁰ Australian Commission on Safety and Quality in Health Care (ACSQHC) (2012). *Standard 2: Partnering with Consumers Safety and Quality Improvement Guide*. ACSQHC. Retrieved 31 January, 2013 from http://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard2_Oct_2012_WEB.pdf

¹¹ Department of Human Services (2005). *Doing it with us not for us. Participation in your health service system 2006-09*. Victorian Government Department of Human Services. Retrieved 25 March, 2013 from http://health.vic.gov.au/consumer/downloads/do_it_with_us.pdf

The NSQHS Standards have identified meaningful consumer participation as the partnership of health services, patients and carers, who in collaboration are involved in:¹²

- *“Making decisions for service planning”*
- *“Developing models of care”*
- *“Measuring service and evaluating systems of care”.*

1.4.3 Why engage consumers?

According to Flinders University and the South Australian Community Health Research Unit, there are four key reasons why health services should engage consumers in meaningful participation:¹³

- *“Participation is an ethical and democratic right”*
- *“Participation improves service quality and safety and helps gain health service accreditation”*
- *“Participation improves health outcomes, including:*
 - o *Decreased mortality*
 - o *Decreased readmission rates*
 - o *Decreased rates of healthcare acquired infections*
 - o *Reduced length of stay*
 - o *Improved adherence to healthcare regimes*
 - o *Improved functional status”*
- *“Participation makes services more responsive to the needs of consumers.”*

1.4.4 Methods of consumer participation

Consumer participation can take place in a range of formal and informal forums, including:

- Surveys and feedback forms
- Focus groups
- Volunteering
- Peer support groups
- Consumer reference groups
- Consumer networks
- Committee membership.

According to the Cancer Australia ‘Consumer Involvement Toolkit’, consumers can be involved in health services for the following reasons:¹⁴

- Service planning and redesign
- Improving patient care throughout the cancer pathway
- Education and information
- Service measurement and evaluation

¹² Australian Commission on safety and Quality in Health Care (ACSQHC) (2012). *Standard 2: Partnering with Consumers Safety and Quality Improvement Guide*. ACSQHC. Retrieved 31 January, 2013 from http://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard2_Oct_2012_WEB.pdf

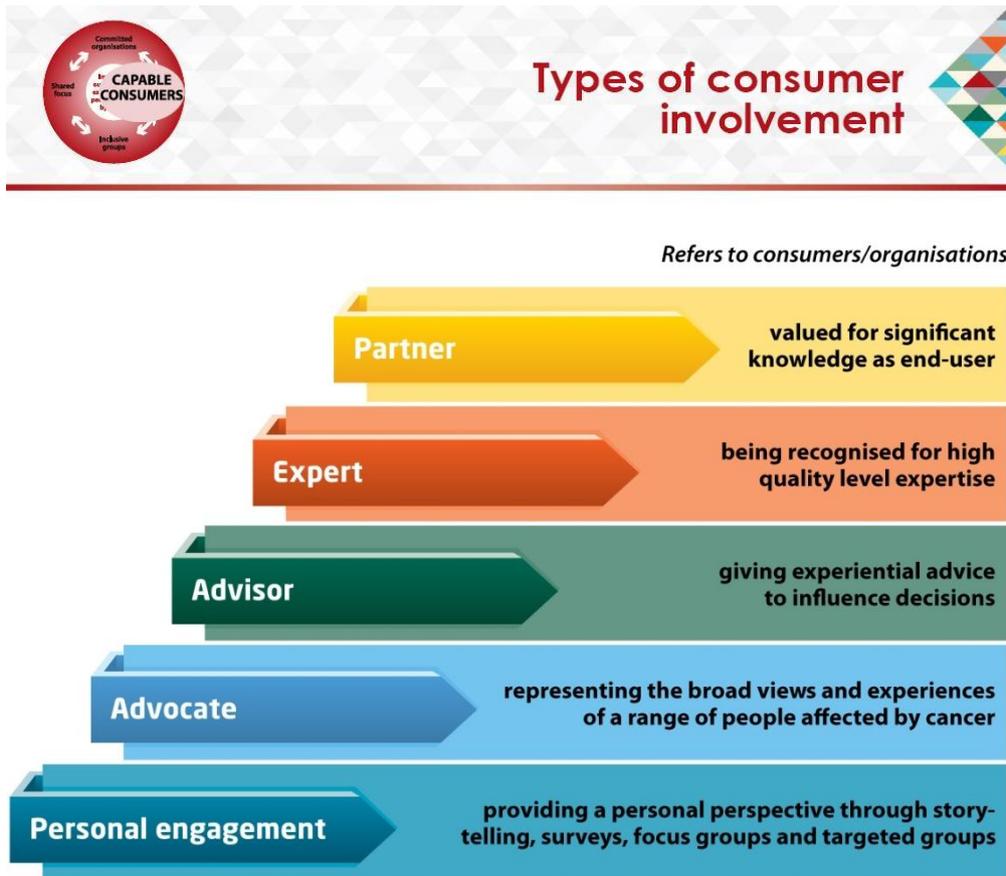
¹³ Department of Public Health, Flinders University and the South Australian Community Health Research Unit (2000). *Improving Health Services Through Consumer Participation: A Resource Guide for Organisations*. Commonwealth of Australia. Retrieved 4 April, 2013 from <http://www.healthissuescentre.org.au/documents/items/2008/08/226533-upload-00001.pdf>

¹⁴ Cancer Australia (2013). *Ways to involve consumers*. Cancer Australia. Retrieved 6 February, 2013 from <http://consumerinvolvement.canceraustralia.gov.au/service-managers/ways-to-involve>

- Participation in the research cycle
- Policy planning and development
- Priority setting.

1.4.5 Degrees of consumer participation

Consumer involvement can occur along a continuum from no participation at all to advising or partnering with health services. The ‘Consumer Involvement Toolkit’ by Cancer Australia describes the different types of consumer involvement.¹⁵



Source: Cancer Australia (2013). Consumer Involvement Toolkit. Cancer Australia. Retrieved 2 May, 2013 from www.consumerinvolvement.canceraustralia.gov.au/document-library/service-managers/types-consumer-involvement-diagram

¹⁵ Cancer Australia (2013). Consumer Involvement Toolkit. Cancer Australia. Retrieved 2 May, 2013 from www.consumerinvolvement.canceraustralia.gov.au/document-library/service-managers/types-consumer-involvement-diagram

1.5 Suggested strategies for improving consumer involvement

The NSQHS Standards include a range of suggestions for health services related to partnering with consumers in governance, including:¹⁶

- *“Involving consumers as representatives on the board or on existing committees”*
- *“Creating a new, or using an existing, consumer advisory group to gain advice from consumers about specific issues or a specific project”*
- *“Creating a new, or using an existing, ‘critical friends’ group. This strategy may be more suited to smaller organisations. It involves identifying and approaching a small group of patients and/or carers that use the service to help identify and consider quality improvement strategies together”*
- *“Systematically seeking feedback and information from consumers on governance issues. There are many strategies for seeking feedback from consumers”,* some of which are described in the NSQHS Standard 2 Continuum of Participation table (see over page).

When identifying strategies for engaging consumers in the governance of health services, Executive teams must consider any potential barriers for engagement, and should identify strategies to mitigate these barriers.

1.5.1 Diverse representation

According to the NSQHS Standards, *“Governance partnerships should be reflective of the diverse range of backgrounds in the population served by the health service organisation, including those people that do not usually provide feedback”*.¹⁶ It is important to include representation from a diverse range of backgrounds including culturally and linguistically diverse (CALD) communities, Aboriginal Australians and asylum and migrant populations. The Standards suggest that health services *“identify the types of consumers who access your organisation’s services by undertaking a community profiling project, administering a survey, using demographic data and/or networking with other organisations or individuals in the community”*.¹⁶

¹⁶ Australian Commission on safety and Quality in Health Care (ACSQHC) (2012). *Standard 2: Partnering with Consumers Safety and Quality Improvement Guide*. ACSQHC. Retrieved 31 January, 2013 from http://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard2_Oct_2012_WEB.pdf

NSQHS National Standard 2 Continuum of Participation Table

Table 1: Continuum of participation

	Information	Consultation	Partnership	Delegation	Control
Description	The organisation develops or adopts a policy, plan or program and provides information about this to the consumers and/or carers and the community.	The organisation identifies an issue and proposes a policy, plan or program which responds to the issue. It then provides information to consumers and/or carers and the community on that proposal and seeks views and comments with a view to maximising acceptance.	The organisation identifies an issue and presents a tentative policy, plan or program which responds to the issue. The organisation seeks active involvement and feedback from consumers and/or carers and the community which is incorporated into the plan.	The organisation identifies an issue, presents this to consumers and/or carers and the community for them to make decisions or propose actions to address the issue.	The organisation asks consumers and/or carers and the community to identify an issue and make all the key decisions on the development of solutions to address the issue. The organisation supports them to accomplish this.
Examples	<p>Giving: Flyers, mailouts, factsheets, press releases, brochures, newsletters, public displays, websites, public meetings</p> <p>Gathering: Surveys, phone-ins, focus groups, in-depth interviews, suggestion boxes</p>	<p>Workshops</p> <p>Consumer representatives on management committees, advisory groups</p> <p>Public meetings/patient forums</p> <p>Online discussion groups</p> <p>Circulation of proposal for comment</p> <p>Conferences or seminars</p> <p>Evaluation surveys</p>	<p>Strategic alliances built utilising a combination of other methods (including those mentioned in Information and Consultation) for example:</p> <ul style="list-style-type: none"> workshops consumer representatives on committees or advisory groups round tables patient forums surveys focus groups 	<p>Shifting some or all of decision making on particular issues to consumers. For example: spending on specific budget items, management of particular programs by consumers eg. mental health consumer advisory groups</p>	<p>Community appointed management committees eg. Aboriginal Community Controlled Health Organisations</p>



Source: Australian Commission on safety and Quality in Health Care (ACSQHC) (2012). *Standard 2: Partnering with Consumers Safety and Quality Improvement Guide*. ACSQHC. Retrieved 31 January, 2013 from http://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard2_Oct_2012_WEB.pdf

1.6 Evaluating consumer engagement

Evaluation is an ongoing process which begins during the planning phase. It involves *“making judgements about the worth and appropriateness of your strategies for participation and reaching conclusions that will inform future practice”*.¹⁷

Evaluation is essential to determining whether consumer engagement activities within health services are meaningful. Formal evaluation allows health services to reflect upon the strengths and weaknesses of their consumer participation model, which in turn can influence future participation. Evaluation of consumer participation activities allows health services to identify strategies for better engagement, whilst providing evidence to support the organisations model for consumer participation.¹⁷

1.6.1 Evaluation methods and tools

If your organisation already has a consumer participation model in practice, the Partnership Self-Assessment Tool (USA), Patient Based Care Challenge (Aus), or A Guide to Supporting Consumer Participation in Evaluation (Monash Health)¹⁸ can be implemented to evaluate the effectiveness of consumer participation activities.

Evaluations can be undertaken via a myriad of tools and processes. The type of tool used will depend on what the health service aims to evaluate. Evaluation methods may include, but are not limited to:¹⁸

- *“Documents—keeping and analysing records such as journals, minutes of meetings, annual reports, newsletters, newspaper reports*
- *Story telling—sharing the narratives of what happened, why, what this meant to different consumers involved and what can be improved*
- *Focus group interviews and discussions*
- *Informal feedback—this can include snippets of information heard or received (e.g. comments about how consumers experienced a meeting, feedback about how things are run or how consumers/providers feel, ideas about what works or does not work, suggestions for improvement)*
- *Observation—what is observed and reflected upon along the way (e.g. whether people are satisfied, happy, angry, quiet, frustrated, whether they attend, speak when they come to an advisory meeting, appear more confident, do not come back, cultural groups involved and not involved)*
- *Face-to-face and telephone interviews*
- *Self-completed questionnaires*
- *Photos*
- *Statistics*
- *Complaints”*

¹⁷ Department of Public Health, Flinders University and the South Australian Community Health Research Unit (2000). *Improving Health Services Through Consumer Participation: A Resource Guide for Organisations*. Commonwealth of Australia. Retrieved 4 April, 2013 from www.healthissuescentre.org.au/documents/items/2008/08/226533-upload-00001.pdf

¹⁸ Monash Health Centre for Clinical Excellence (2011). *A Guide to Supporting Consumer Participation in Evaluation*. Monash Health. Retrieved 2 May, 2013 from www.monashhealth.org/icms_docs/6175_Consumer_participation_in_evaluation_PIE_guide_and_matrix.pdf

Section 2

Resources, templates and practical tools



2.1 How to Engage Consumers

- 2.1(a) Ideas on how to engage consumers**
- 2.1(b) Developing a name for your consumer group**
- 2.1(c) How to set up a consumer group**

2.2 Recruiting Consumer Representatives

- 2.2(a) Consumer Group Brochure**
- 2.2(b) Consumer Group Website Content**
- 2.2(c) Consumer Registry Application Form**
- 2.2(d) Application for Consumer Group Membership**
- 2.2(e) Consumer Group Membership Interview Questions**
- 2.2(f) Letter of Consumer Group Membership Offer**
- 2.2(g) Letter of Consumer Group Membership - Unsuccessful Applicant**
- 2.2(h) Consumer Group Member Agreement and Guidelines**
- 2.2 (i) Orientation Checklist for Volunteer Group Members**
- 2.2(j) Consumer Group Membership Register**
- 2.2(k) Privacy and Confidentiality Statement**
- 2.2(l) Infection Control for Volunteers**

2.3 Governance of Consumer Advisory Groups

- 2.3(a) Consumer Group Terms of Reference**
- 2.3(b) Position Description: Chairperson**
- 2.3(c) Position Description: Member (Consumer)**
- 2.3(d) Position Description: Member (Health Service)**
- 2.3(e) Position Description: Group Coordinator**
- 2.3(f) Meeting Agenda Template**
- 2.3(g) Meeting Minutes Template**
- 2.3(h) Feedback Documentation**
- 2.3(i) Example - Consumer Satisfaction Survey**
- 2.3(j) Reimbursement Schedule**
- 2.3(k) Volunteer Thankyou Letter**

2.4 Support and Information for Consumer Representatives

- 2.4(a) Ideas for volunteer parents on how to start conversations with other parents**
- 2.4(b) Support versus Advice: Guidelines for Volunteers**
- 2.4(c) Looking after yourself – Tips for Consumer Representatives**
- 2.4(d) The difference between a complaint and a criticism**
- 2.4(e) Tips for parents from parents**
- 2.4(f) Tips for family and friends**
- 2.4(g) Social Media: Volunteer Policy**



2.1 How to Engage Consumers

2.1(a): Ideas on how to engage consumers

Engaging consumers in health service planning and delivery is essential to ensuring high quality health care. Listed below are some ideas on how to facilitate ongoing involvement of consumer representatives within your organisation.

Establish a formalised consumer/parent advisory group	
Benefits	Challenges
<ul style="list-style-type: none"> - Formal structure recognised within the health service - Provides a formal pattern for 2-way communication 	<ul style="list-style-type: none"> - Finding enough consumers/parents who are willing to participate - A health service member is required to coordinate and run the group - Having one group of consumers providing feedback on a range of topics may mean that the feedback is limited (i.e., the members of the group may not be knowledgeable about all of the topics discussed) - Members are usually not in the treatment phase so feedback about being on treatment may not be current
Recommendations	Guidance offered in this toolkit
<p>Please refer to guidance documents in this toolkit</p>	<ul style="list-style-type: none"> - How to set up a consumer group -2.1(c) - Application for Consumer Group Membership – 2.2(d) - Infection Control for Volunteers – 2.2(l) - Consumer Group Terms of Reference - 2.3(a) - Position Description <ul style="list-style-type: none"> o Chairperson – 2.3(b) o Member (Consumer) - 2.3(c) o Member (Health Service) – 2.3(d) o Group Coordinator – 2.3(e) - Meeting Agenda Template – 2.3(f) - Meeting Minutes Template – 2.3(g) - Reimbursement Schedule – 2.3(j)

Hold a Focus Group	
Benefits	Challenges
<ul style="list-style-type: none"> - Allows for information/feedback to be obtained on specific areas of interest as required - Minimal resources required 	<ul style="list-style-type: none"> - Finding enough willing participants on specific topics - Consumers may not provide feedback as openly when discussing within a group - May require the health service to invest a large amount of time
Recommendations	Guidance offered in this toolkit
<ul style="list-style-type: none"> - Include details on a consumer registry about each consumer's areas of interest 	<ul style="list-style-type: none"> - Privacy and Confidentiality Statement – 2.2(k) - Meeting Agenda Template – 2.3(f) - Feedback Documentation – 2.3(h)

Host a Morning Tea (for advisory group members to meet with new parents/families)	
Benefits	Challenges
<ul style="list-style-type: none"> - Feedback from consumers currently on treatment - Engaging a wide range of consumers - Provides support to new parents (“I have walked the path before you”) 	<ul style="list-style-type: none"> - Consumers may not be ready or willing to provide feedback/discuss service improvement whilst on treatment - May be confronting for the consumer representatives to meet other families and talk about their experience
Recommendations	Guidance offered in this toolkit
<ul style="list-style-type: none"> - Hold a variety of events (morning teas, evening supper, inpatient and outpatient) to enable a variety of opportunities for interaction 	<ul style="list-style-type: none"> - Meeting Minutes Template – 2.3g) - Feedback Documentation – 2.3(h)

Implement Feedback Forms/Boxes in Hospital Wards	
Benefits	Challenges
<ul style="list-style-type: none"> - The ability to submit a form anonymously may increase the scope of feedback received - Consumers are able to complete forms in their own time with minimal time commitment - If promoted well, feedback forms may encourage positive feedback which includes staff satisfaction 	<ul style="list-style-type: none"> - Inability to 'tease out' the feedback when forms are submitted anonymously
Recommendations	Guidance offered in this toolkit
<ul style="list-style-type: none"> - Send consumer a letter of receipt to acknowledge feedback form received (if not anonymous) - Contact consumer about the outcome of their feedback - Group the feedback into themes - Ensure that the positive feedback is relayed to staff 	<ul style="list-style-type: none"> - Feedback forms/boxes in hospital wards - Feedback Documentation – 2.3(h)

Put up a Notice board with feedback outcomes in hospital wards	
Benefits	Challenges
<ul style="list-style-type: none"> - Consumers are able to see that their feedback is being addressed by the health service 	<ul style="list-style-type: none"> - Needs to be a balance between positive and negative feedback and outcomes - Ensuring that confidentiality is maintained and that feedback is de-identified
Recommendations	Guidance offered in this toolkit
<ul style="list-style-type: none"> - Notice board with feedback outcomes in hospital wards 	Not required

Hold In-depth Consumer Interviews	
Benefits	Challenges
<ul style="list-style-type: none"> - Provides an opportunity to obtain detailed feedback about specific issues 	<ul style="list-style-type: none"> - Time-consuming, staff required to conduct interviews - Will need ethics approval
Recommendations	Guidance offered in this toolkit
<ul style="list-style-type: none"> - A letter should be sent/phone call made to determine a mutually agreed date/time - Meetings should be face to face - A letter of acknowledgement should be sent following the interview 	Not required

Implement Patient Experience Surveys/Audits	
Benefits	Challenges
<ul style="list-style-type: none"> - Provides an opportunity to obtain detailed feedback about specific issues - Can focus on specific areas of interest or broader topics of patient experience 	<ul style="list-style-type: none"> - Finding willing participants - Will need ethics approval (depending on the health service policy) - Ensuring that confidentiality is maintained and that any commentary is de-identified
Recommendations	Guidance offered in this toolkit
<ul style="list-style-type: none"> - Patient experience surveys/audits - Look for short surveys about specific topics that can be completed quickly 	<ul style="list-style-type: none"> - Example: Consumer Satisfaction Survey – 2.3(i)



Suggestions on how to make consumer engagement work effectively
1. Making it easy for consumers
<ul style="list-style-type: none"> - Consider having a reimbursement policy to cover expenses incurred by consumers who are volunteering - Provide consumers with the opportunity to use teleconference to provide feedback/attend meetings - Provide consumers with volunteer opportunities
2. Making it easy for hospitals
<ul style="list-style-type: none"> - Set up a database <ul style="list-style-type: none"> o The database should include consumer contact details, areas of interest, reimbursement details, details of signed consent, training completed etc. - Link in with other health service consumer advisory committees - Involve consumers in strategic planning - Consider having a consumer representative on department committees/working groups as required
3. Keeping in touch with your consumers
<ul style="list-style-type: none"> - Offer consumers the opportunity to attend relevant training and education sessions, including orientation - Ask consumers to review information for families, including new or existing patient/service information - Provide the opportunity for consumers to join a project working group or organisational strategic or operational advisory group - Run an annual consumer forum specific to a topic or audience (i.e., young people, CALD or Aboriginal Australians) - Provide a regular newsletter to your consumers - Maintain a website page especially for engaging consumers with up to date information



2.1(b): Developing a name for your consumer group

1. Is it a group, committee, panel or council?	
Group*	‘A number of people that work together or share certain beliefs’ ‘A commercial organisation’
Committee*	‘A group of people appointed for a specific function by a larger group and typically consisting of members of that group’
Panel*	‘A small group of people brought together to investigate or decide on a particular matter’
Council*	‘An advisory, deliberative, or administrative body of people formally constituted and meeting regularly’ ‘A body of people elected to manage the affairs of a city, county, or other municipal district’
2. Is the nature of the (group/committee/panel/council) support, advisory or advocacy?	
Support*	‘Give approval, comfort or encouragement to’
Advisory*	‘Having or consisting in the power to make recommendations but not to take action enforcing them’
Advocacy*	‘Public support for or recommendation of a particular cause or policy’
3. Is it a consumer or community (group/committee/panel/council)?	
It is important to define who the consumers are. It is also important to define the community that the group is representing.	
Consumer	The group/committee/panel/council is composed of mostly consumers. Paediatric oncology consumers can be defined as: <ul style="list-style-type: none"> - Children or adolescents with cancer - Children, adolescent and young adult survivors of cancer - Parent/guardian and siblings of children with cancer or children who have survived cancer - Wider family members (e.g., grandparents) of children with cancer or who have survived cancer Consumers can be from a range of specific groups, e.g., youth, CALD, bereaved
Community	The group/committee/panel/council represents the voice of the community. The paediatric oncology community includes: <ul style="list-style-type: none"> - Support services (e.g., palliative care, hospital in the home) - Regional service providers - Specialist providers - Philanthropic organisations - Children’s or adolescents’ cancer community charities

4. Is the purpose of the (group/committee/panel/council) to offer feedback or provide support?

Please refer to the 'How to set up a consumer group' document.

Examples of consumer group names – any combination from the 3 columns below is possible

Consumer Community Parent Family Youth Paediatric Health Service Children's	Advisory Advocacy Support Feedback Assistance	Group Committee Panel Council
--	---	--

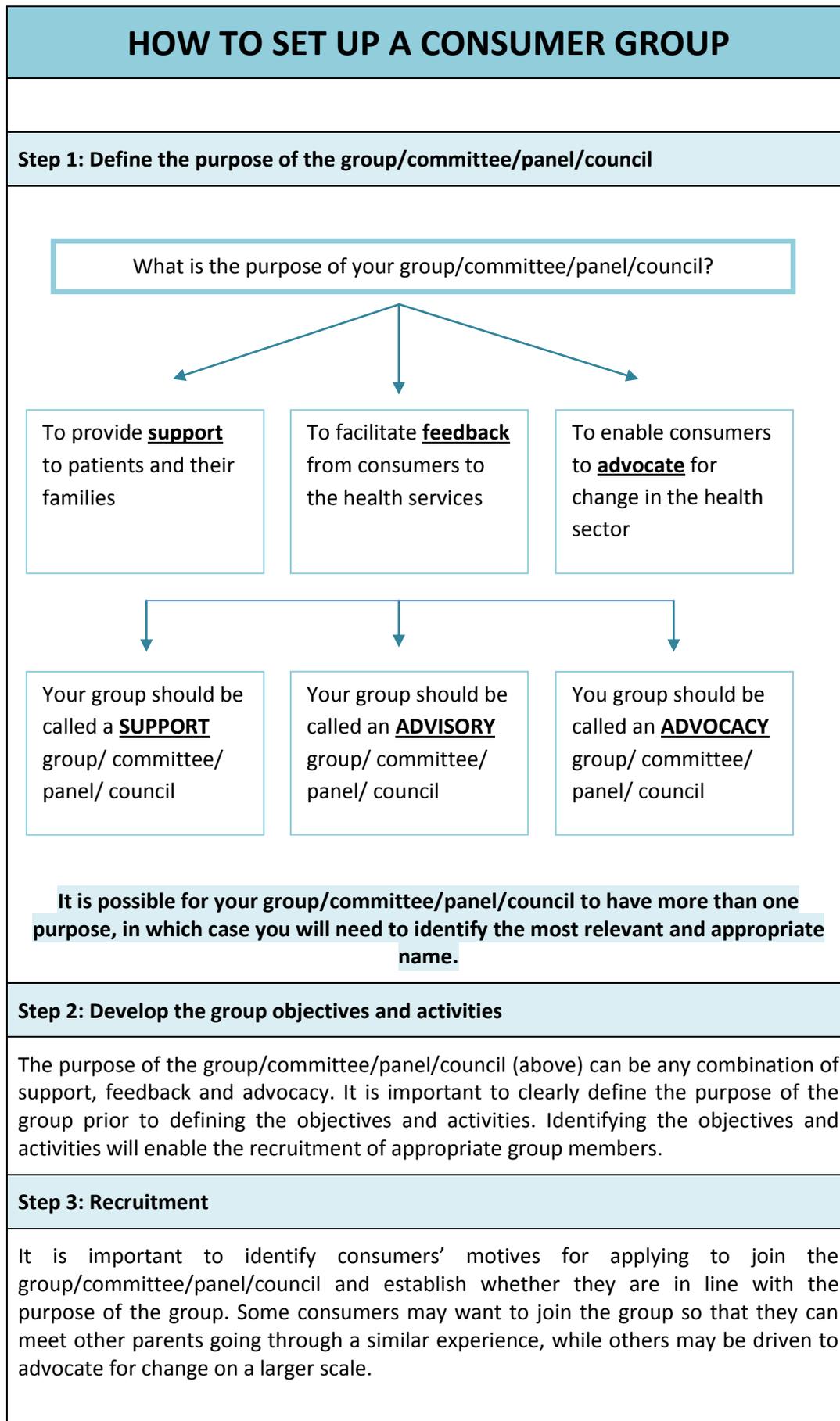
Examples of consumer groups/committees/councils/panels

- The Royal Children's Hospital Children's Cancer Centre Parent Advisory Group
- Monash Health Parent and Family Advisory Group
- Peter MacCallum Cancer Centre Community Advisory Committee
- Westmead Children's Hospital Family Advisory Council
- Johns Hopkins Pediatric Family Advisory Council
- Royal Children's Hospital Brisbane Family Advisory Council
- Adelaide Women's and Children's Hospital Consumer and Community Advisory Committee

*Definitions from Oxford English Language Dictionary (www.oxforddictionaries.com)



2.1(c): How to set up a consumer group



Listed below are some ideas on how you could recruit for the group/committee/panel/council:

1. Brochures/flyers about the group in the cancer centre/service targeting families at long-term follow up appointments
2. Get your nursing and psychosocial staff involved in thinking about suitable parents and family members
3. Contact individuals who have previously submitted feedback to the health service (privacy and confidentiality permitting)
4. Approaching consumers listed on a pre-existing consumer registry
5. Interview applicants who have submitted Application for Group Membership form (see template- Consumer Group Membership Interview Questions - 2.2e)

Step 4: Selection and Appointment

- Have an application/expression of interest form
- Arrange a formal meeting/interview
- Send letter of offer to selected applicants
- Signed position description (see template)
- Signed confidentiality and privacy agreement (see template)
- Signed Consumer Agreement (see template)
- Arrange application for Working With Children Check and Police Check
- Provide the consumer with a copy of the cancer centre/hospital visitor policy
- Add name of consumer to the group membership register (see template)
- Provide terms of reference (see template)
- Ensure that the Director of the unit/department and other relevant staff at the health service meet the consumer

Step 5: Set up regular meetings

- Appoint a Coordinator from the hospital if appropriate
- Find out availability of each group member
- Select a day that suits the members. Some groups find www.doodle.com useful for scheduling.
- Book a room and send out meeting invitations
- In the initial meeting:
 - o Clearly define the purpose and goals of the group and individual roles of members
 - o Discuss and reach agreement on the dates, times, frequency and duration of the meetings
 - o Inform the group members about the reimbursement policy of the health service
- Determine which health service staff will attend the meetings (e.g., Nurse Unit Manager, Social Worker, Medical Officer, Community Liaison Officer)

Resources included in this toolkit to assist you

Recruitment Documents:

- Developing a name for your consumer group – 2.1(b)
- Consumer Group Brochure – 2.2(a)
- Consumer Group Membership Interview Questions – 2.2(e)
- Letter of Consumer Group Membership Offer – 2.2(f)
- Consumer Group Membership Agreement and Guidelines – 2.2(h)
- Consumer Group Membership Register – 2.2(j)

Governance Documents:

- Application for Consumer Group Membership – 2.2(d)
- Consumer Group Terms of Reference – 2.3(a)
- Position Description – Chairperson – 2.3(b)
- Position Description – Consumer – 2.3(c)
- Position Description – Health Service – 2.3(d)
- Position Description – Group Coordinator- 2.3(e)
- Meeting Agenda Template – 2.3(f)
- Meeting Minutes Template – 2.3(g)
- Reimbursement Schedules – 2.3(i)

2.2 Recruiting Consumer Representatives

2.2(a): Consumer Group Brochure

INTERESTED IN THE (insert group name here)?	WANT MORE INFORMATION?	(Insert logo here)
		(Insert slogan here)
I am interested in finding out more about the (insert group name) <input type="checkbox"/>	For more information about the (insert group name here) visit our webpage at www.xxxxxxx.org.au	
I am interested in joining the (insert group name) <input type="checkbox"/>	Other useful websites include: Insert relevant logos/information here	(Insert photo or picture relating to group here)
Name: _____		
Address (option): _____ _____ _____		
Email address: _____		
Contact Phone No: H _____ W _____		HAVE YOUR SAY & HELP OTHERS HAVE THEIRS!
Send to: xxxxxxxx XXXXXXXXXXXXXXXXXXXX XXXXXXXXXXXXXXXXXXXX XXXXXXXXXXXXXXXXXXXX	Supported by: _____ Insert relevant logos here	Share your experience about what's happening for you and your family and help other families

WHAT CAN WE DO FOR YOU?

We invite you to share your experience about what's happening for you and your family – what's working well and what could be improved in your interaction with your health service. We respect your confidence and may be able to take up issues or give feedback on your behalf. The (insert group name) is also important in helping health services to plan for the future.
We really want you to be part of this process.

MAKING CONTACT WITH THE (insert group name)

Talk to us. We will endeavour to introduce ourselves. If you are having a bad day, then we shall respect this! If you want to say hello, then don't be afraid to do so!

WHAT IS THIS GROUP?

The (insert group name here) is a group of parents and health service staff working towards improved care within (insert region/state here) paediatric oncology services.

We are a group primarily of parents of children that are having, or who have had, treatment at (insert hospital name/s here).

The group acts in an advisory capacity to the health services and also takes on an advocacy role where necessary. The group also interacts with the broader cancer community and other related groups involved in similar issues.

The group holds monthly meetings, where we work with health service staff to resolve consumer issues and work on initiatives to improve the experiences of families.

The group holds regular events such as morning/afternoon teas where parents are encouraged to share their experiences.

PROVIDE FEEDBACK TO THE PARENT ADVISORY GROUP?

Name (optional): _____

Contact details (optional): _____

Your Health Service (optional): _____

Do you have an issue, something that concerns you or a great idea for the future?

How would you like to be kept informed regarding the progress of the group in resolving this issue?

Do you have any positive feedback about the care your child has received?

Send to: xxxxxxxxxxxxxxxx
XXXXXXXXXXXXXXXXXXXX
XXXXXXXXXXXXXXXXXXXX
XXXXXXXXXXXXXXXXXXXX

2.2(b): Consumer Group Website Content

The [Insert group name here]

- Who are we?
- Why?
- What?
- How?
- When?
- Our team
- Contact us

Who are we?

The [Insert group name here] is a team of people who are passionate about continual improvement to the services provided to children and adolescents with cancer in [Insert region here]. The [Insert group name here] has two types of members: parents and carers of children or adolescents who are, or have been, treated for cancer, as well as staff representatives from [Insert relevant health service here]. We work together to ensure consumer expertise and experience is available to the health service. The Chairperson of the group is a position that is always held by a parent member.

Why?

Our vision is for the children, adolescents and young adults accessing our service to have the best paediatric cancer services in the world - both in terms of patient outcomes and delivering a holistic and compassionate approach to patient management and care. The [Insert group name here], in collaboration with the health service(s), want to ensure that paediatric cancer services meet the needs of children and families. We aim to promote and support the practices that are working well and also identify areas that might require improvement.

What do we do?

As consumer members we....

- Share our cancer service experiences and comments gathered from parents with health service staff to help shape (improve) children's cancer services and cancer care
- Identify areas where care could be improved and recommend ways this might occur
- Review any materials, brochures and booklets that are to be given to families to ensure they are both readable and sensitive

As health professional members we...

- Listen to the voice of our parents and families and action feedback to improve the quality of care in children's cancer services
- Actively ensure our parents are kept abreast of health service activities
- Facilitate the involvement of consumers in relevant projects and other health service activities

How do we connect with our families?

The [Insert group name here] consumer/parent members interact with families in a variety of ways including:

- [Insert relevant group activities and their purpose here e.g., regular morning teas/suppers, regularly organised in the wards/day oncology unit at Morning teas give the group the opportunity to come to families and converse in person]. We are good listeners and we have our own experiences to help us better relate to families
- Casual conversations with parents and children in waiting rooms, wards and family retreats
- We are always eager to meet, whether families have any specific feedback for us or not.

How do we interact with the health services?

The [Insert group name here] consumer/parent members regularly interact with the health services through:

- Regular advisory meetings
- Informal follow-up to action items agreed
- Liaising with the health service Community Advisory Committee via the Chair
- Liaising with hospital administration either through correspondence or meetings
- Representation on steering committees as appropriate
- Reporting achievements, improvements as well as issues and challenges via various mediums.

Our team

Our team consists of consumers and health service staff members who are passionate about continuous improvement of care for our children and adolescents. The consumers have had experience with children undergoing treatment for cancer. These consumers bring their own experiences as well as the ability to closely relate to the children, adolescents and carers who are receiving paediatric oncology services. The team together presents a strong group with a profound empathy towards the children, adolescents and carers and an appreciation of organisational challenges and opportunities in providing the best possible care to our children.

[Insert picture and brief description of each group member here]

Regular [Insert group name here] Staff Representatives

[Insert staff representatives and their titles here]

Would you like to join the team?

We would like to hear from you if:

- You have experience with a child or adolescent who has undergone treatment or is currently being treated for cancer and
 - o You have ideas, opinions and points of view that may be translated to actionable changes to the way the health services operate



- You are interested in working with a team to positively influence how the health services provide care.

We would very much like you to consider joining our team. Together we can truly make a difference.

Contact us

You can contact the [Insert group name here] via the

[Insert contact details here]



2.2(c): Consumer Registry Application Form

Consumer Registry Application Form	
<p>An important way to ensure that our services meet the needs of children and families is to receive your feedback about current services and seek your advice on future service development. If you would like to be on our contact list and/or be available to participate in future projects as a consumer, please complete this form and return it to [Insert details here]</p>	
<p>There are many ways in which children, adolescents and families can provide feedback and advice on current and new services. These include:</p>	
<ul style="list-style-type: none"> - Participating in a one-off telephone interview - Completing a survey - Joining in a group discussion with other parents/patients - Joining a short-term working group with a specific focus - Participating as a member of the [Insert group name here] 	
<p>In addition, we would like to provide you with information that may be of interest to you from time to time</p>	
<p>To do this, we are collecting email and/or postal contact details of patients and parents/carers of children and adolescents who have attended [Insert health service here]</p>	
<p>If you would like to be on our contact list, please complete and return this form.</p>	
<p>You will be able to unsubscribe from this contact list at any time by indicating your wish to do so by return email to [Insert email address here]</p>	
<p>I am interested in receiving: (please indicate all preferences)</p>	
<p><input type="checkbox"/> Details regarding any updates/changes to clinical services at [Insert health service here], including details of groups or education sessions that are run by the centre</p> <p><input type="checkbox"/> Newsletters and other relevant material deemed useful for families</p> <p><input type="checkbox"/> Information about opportunities to participate in feedback forums regarding services related to [Insert health service here] (e.g., a focus group or parent survey)</p> <p><input type="checkbox"/> Information about joining the [Insert group name here]</p>	
<p>Contact details</p>	
Full name	
Email address	
Postal address <i>If you would prefer to be contacted by post</i>	
Telephone number	
I am a	<input type="checkbox"/> Parent/carer of a child <input type="checkbox"/> Patient (age _____) <input type="checkbox"/> Member of the extended family
My child is	<input type="checkbox"/> 0-5 years <input type="checkbox"/> Primary School age <input type="checkbox"/> Secondary School age <input type="checkbox"/> Other _____

<p>The information you provide on this form and any feedback will be stored in the [Insert name of registry here]. This information will be treated confidentially and only accessed by authorised hospital staff. Please note that the hospital policy restricts or excludes the inclusion of children less than 14 years of age in this database. If you are aged 14 years or over, you can join this database by completing this form. Any feedback provided will be used to improve the quality of services provided and to inform you of new services and resources.</p> <p><i>Consumer agreement</i></p> <p>I understand that by providing consent my details will be added to the database. I understand that depending on my preference the database may be used to send information and/or contact me regarding feedback on issues relevant to the care of children with cancer and to improve the quality of services provided. I understand that I may revoke this consent at any time in writing by return email to [Insert email address here].</p>	
Signature	
Name	
Date	



2.2(d): Application for Consumer Group Membership

[Insert group name and logo here]		Application for Group Membership			
Date					
.. / .. /					
Title					
Surname			Given Name		
Street Address					
Suburb			State	Postcode	
Contact numbers		B	H	M	
Email					
PLEASE COMPLETE THE FOLLOWING		1. Please indicate why you are interested in joining the [Insert group name here]			
		2. What specific skills or experience do you believe you can bring to the [Insert group name here]?			
		3. Are there any particular areas of interest you would like the [Insert group name here] to pursue?			
OPTIONAL SUPPORTING INFORMATION		If you would like to provide your CV/Resume or a summary page indicating your work, education or life experience relevant to this group we would be happy to receive it as part of your application.			
SEND APPLICATION		Please send this application form, together with any additional supporting information to: [Contact Name] [Position] [Organisation] [Postal Address][Suburb] [State] [Postcode] [Phone Number] [Fax] [Email]			
A representative from the group will contact you within [x] weeks.					
ENQUIRIES		[Contact Name] [Email] [Phone Number]			
Developed by		Endorsed by			
Version number		Date of next review			

2.2(e) : Consumer Group Membership Interview Questions

Membership Interview Questions	
[Insert group name and logo here]	
Applicant Name	
Date	
Interviewed by	
1. What prompted you to express interest in joining this group?	
2. Can you tell us about your experience and understanding of consumer representation on committees?	
3. Do you have any specific skills, qualities or experience that would lend itself to being part of the group?	
4. Why do you think it is important for paediatric cancer services to have a consumer reference group?	
5. How would you describe the difference between a 'complaint' a 'comment' and 'criticism' and when do you feel the feedback should be escalated?	
6. Would you be available for working group activities (e.g., portfolio responsibilities at home) in addition to a monthly meeting?	

7. As a formal member of this group, if there was a need to liaise with parents and families, would you be prepared to do this?			
8. From your personal experience as a parent of a child with cancer, what do you perceive to be the major issues facing families that you think the group can help with?			
9. How would you deal with a confronting patient story? Please feel free to use an example if you have one.			
10. Which of the following are you most interested in being a part of: consumer support, consumer advice or consumer advocacy? (Provide applicant with examples if necessary)			
11. Is there anything further you would like to ask us about this group?			
Further questions, comments and assessment			
Developed by		Endorsed by	
Version number		Date of next review	



2.2(f): Letter of Consumer Group Membership Offer

[Insert logo here]

[Insert group name here]

[Name]

[Date]

[Address]

[Suburb]

[Postcode]

Dear [Name],

Re: Membership of [Insert group name here].

I am writing to invite you to join the [Insert group name here].

The [Insert group name here] provides a mechanism for consumer feedback to be addressed in a spirit of partnership with the health services, with the overall goal of providing better outcomes for children and adolescents with cancer and their families. I have included the Terms of Reference and an information pack to assist you to understand the group's role, membership and functioning.

Administrative support is provided by the [Insert group name here] Coordinator who can be contacted on [Insert email address here] and/or [Insert phone number here].

Prior to your first meeting, we would like to arrange a time to discuss the group and arrange orientation for you including completion of the application for a Working with Children Check, Police Check and privacy and confidentiality form. It is also an opportunity to address any queries you may have. [Specify meeting requirements here].

On behalf of the [Insert group name here], I would like to take this opportunity to welcome you. We look forward to utilising your experience, skills and advice as a consumer in this important forum.

Yours sincerely,

[Insert Chair's name here]

Chair of [Insert group name here]

[Insert contact details here]

2.2(g): Letter of Consumer Group Membership - Unsuccessful Applicant

Not all applicants will have the skills and experience to match the position description for 'Group Member'. However, it is important to provide all willing and enthusiastic consumers with the opportunity to contribute to feedback and service improvement. Aside from joining the formalised groups/committees, there are many ways consumers can be involved in health services. It is important to work to the strengths of the individual consumer.

The following letter template provides a structure for informing applicants that they were unsuccessful in their application to join a formalised group, whilst identifying alternative ways in which they can become involved in the health service.

This letter should be sent after an initial phone call is made to inform the consumer that their application was unsuccessful and discuss other ways they could be involved.



[Insert logo here]

[Insert group name here]

[Name]
[Address]
[Suburb]
[Postcode]

[Date]

Dear [Name],

Re: Membership of [Insert group name here].

Thank you for expressing an interest in undertaking a consumer position on [Insert group name here]. We appreciate the time you have taken to apply for this position; however as discussed with you earlier today we regret to advise that your application has not been successful on this occasion.

We will continue to work with you to find opportunities as a consumer representative, including exploring other committees that may interest you.

If you have any queries please do not hesitate to contact me.

Yours sincerely,

[Insert Chair's name here]
Chair of [Insert group name here]

[Insert contact details here]

2.2(h): Consumer Group Member Agreement and Guidelines

[Insert group name and logo here]	Consumer Group Member Agreement and Guidelines
<p>Congratulations on being nominated as a consumer member of the [Insert group name here]. Please find below the contact details of the group Coordinator for your records.</p>	
Name:	[Insert relevant details here]
Position:	[Insert relevant details here]
Phone Number:	[Insert relevant details here]
Email:	[Insert relevant details here]
<p>We ask that you read this agreement, sign it and return it to us as soon as possible.</p>	
Your role	
<p>As a consumer member you bring your knowledge and experience in paediatric oncology to the [Insert group name here].</p> <p>The role of a consumer member on the group is to:</p> <ul style="list-style-type: none"> - Inform the group how consumers (child, adolescent or family) may feel and think about a certain issue - Ensure the group recognises consumer concerns - Ensure the group or organisation has a range of consumer engagement strategies in place - Obtain feedback from your broader consumer network to inform the group - Report the activities of the group to other consumers (where appropriate and in line with the Terms of Reference and Confidentiality agreement of the group) - Act as the link between the families and the health service for constructive and positive feedback 	
Membership agreement	
<p>The [Insert group name here] will deal with matters that are confidential. As a member of the group you are bound by the membership agreement as set out in the Terms of Reference (ToR) of the [Insert group name here]. It is the responsibility of the individual to ensure that they are familiar with this ToR.</p>	
Support from the [Insert group name here] staff	
<p>[Insert health service name here] supports consumer members by:</p> <ul style="list-style-type: none"> - Facilitating opportunities for networking with other consumers - Responding to issues raised in reports - Providing information, support and guidance upon request. <p>If you have a complaint or difficulty with the group we suggest that you talk to the Chair of the</p>	

[Insert group name here]. If you wish to discuss the matter further we advise that you contact the [Insert group name here] Coordinator.

Chair	Signature		Date	.. / .. /
	Print Name		Department	

I, as a consumer nominee have read and understood this agreement

New Member	Signature		Date	.. / .. /
	Print Name		Department	

COPY 1 – to be signed and held by consumer representative

COPY 2 – to be signed and held by the Chair



Supported by:

[Insert logos here].



2.2(i): Orientation Checklist for Volunteer Group Members

Orientation Checklist for Volunteer Group Members				
[Insert group name and logo here]				
<p>All consumer members of the [Insert group name here] are required to undergo the following orientation:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Consumer Group Member Agreement and Guidelines signed <input type="checkbox"/> Privacy and Confidentiality Agreement signed <input type="checkbox"/> Name/contact details added to Consumer Group Member Register <input type="checkbox"/> Hospital tour completed <input type="checkbox"/> Terms of Reference provided <input type="checkbox"/> Position Description provided <input type="checkbox"/> Reimbursement Schedule provided <input type="checkbox"/> Infection Control Policy provided <input type="checkbox"/> Social Media Policy provided 				
<p>By signing this, I agree that I have undertaken orientation as indicated above.</p>				
Volunteer	Signature		Date	.. / .. /
	Print Name		Department	
Hospital Employee	Signature		Date	.. / .. /
	Print Name		Department	
<p>COPY 1 – to be signed and held by consumer representative</p> <p>COPY 2 – to be signed and held in employee record within Human Resources</p>				

2.2(k): Privacy and Confidentiality Statement

Please note: your health service may already have a privacy and confidentiality agreement which may be used in preference to this document

[Insert group name and logo here]

Privacy and Confidentiality Statement: Consumer Representatives

All persons who come into contact with, or have access to confidential information have a responsibility to maintain the privacy, confidentiality and security of that information. As a volunteer, you may or may not come into contact with patient medical records and other confidential information.

Examples of confidential information include, but are not limited to¹⁹:

- Patient and/or family members
E.g., conversations, medical records, financial information
- Employees, Contractors, Volunteers, Students
Such as salaries, employment records, disciplinary actions, health status
- Business information
Such as financial records, reports, memos, contracts, computer programs, technology
- Operations Improvement, Quality Assurance, Peer Review
Such as reports, presentations, survey results

Examples of breaches²¹:

The following are examples of privacy, confidentiality or security breaches covered by this agreement. It is recommended that consumer representatives also read the confidentiality policies and procedures of the health services at which they are volunteering.

Accessing information that you do not need to know to carry out your volunteer role is a breach and is not permitted. For example:

- Unauthorised reading of a patient's medical record or an employee file
- Random searching of Patient Master Index for familiar names
- Accessing information on family, friends, or co-workers.

Disclosing personal information about a patient or family without consent. For example:

- Discussing or gossiping about a patient or family or information about a staff member, including their personal details
- Having a conversation relating to patient or staff information in a public place
- Telling a relative or friend about a patient or family you had seen or heard about
- Discussing confidential information in a public area such as a waiting room or elevator
- Disclosing any patient information at all via any form of web media e.g., Facebook, Twitter.

¹⁹ The Royal Children's Hospital. *Privacy, Confidentiality and Security Agreement*. Retrieved 14 March 2013, from www.rch.org.au/uploadedFiles/Main/Content/hr/Privacy_confidentiality_agreement.pdf#xml=http://www2.rch.org.au/cgi-bin/texis/webinator/search/pdfhi.txt?query=confidentiality+&pr=ektron-int-e64d2e4d&prox=page&rorder=500&rprox=500&rdfreq=500&rfreq=500&rlead=500&rdepth=0&sufs=0&order=&q=&id=505413a73e7

Sharing, copying or changing information without proper authorisation:

- Copying and forwarding patient or staff information to a third party without having written or verbal consent from health service staff
- Making unauthorised entries or changes to a patient’s medical record or file.

Using another person’s password to access the hospital’s computer system:

- Using another person’s password to log into the hospital’s computer system
- Unauthorised use of password to access employee files or patient accounts
- Using another person’s computer after he/she has logged in.

Privacy, Confidentiality and Security Agreement

As part of my role I am required to understand and agree to the following:

1. I WILL ONLY access information I need to perform my role.
2. I WILL NOT disclose, copy, release, sell, alter or destroy any confidential information, either electronic or paper based unless it is part of my role. If it is part of my role to do any of these tasks, I will follow the correct procedure (such as putting confidential papers in appropriate security bins).
3. I WILL NOT misuse or be careless with confidential information.
4. I WILL ONLY use shared computer passwords in authorised situations.
5. I KNOW that my access to confidential information may be audited.
6. I WILL NOT remove confidential information (e.g., medical records, photocopied patient forms or electronic data) from the hospital unless it is an authorised work practice.
7. I WILL report any activities to my manager that I suspect may compromise the confidentiality and integrity of information. I understand these reports, made in good faith, will be held in confidence to the extent permitted by the law.
8. I WILL wear my hospital identification badge/visitor pass at all times whilst on the hospital premises.
9. I WILL protect the privacy of the patients and employees of the hospital.
10. I AM RESPONSIBLE for my use or misuse of confidential information.
11. I UNDERSTAND my obligations under this Agreement will continue after termination of my employment.

I am aware that failure to comply with this agreement may result in the termination of my role at the [Insert hospital name here] and/or civil or criminal legal penalties.

By signing this, I agree that I have read, understand and will comply with this agreement.

Volunteer	Signature		Date	.. / .. /
	Print Name		Department	
Hospital Employee	Signature		Date	.. / .. /
	Print Name		Department	

COPY 1 – to be signed and held by consumer representative

COPY 2 – to be signed and held in employee record within Human Resources

2.2(I): Infection Control for Volunteers

<p>[Insert group name and logo here]</p>	<h3>Infection Control for Volunteers – Keeping the Children Safe</h3>
<p>Children undergoing treatment for cancer have a lowered immunity and are more susceptible to infection. Any interactions between volunteers, staff and patients must comply with hospital infection control guidelines.</p>	
<h4>Hand Hygiene</h4>	
<ul style="list-style-type: none">- Hands should be washed thoroughly with soap and water or decontaminated with an alcohol rub before entering and upon leaving a patient room- If you have direct physical contact with the patient, hands should be washed before and after patient contact- Hands should be washed with soap and water before preparing food, after meals and following toilet breaks	
<p>Please refer to Hand Hygiene Australia for additional information: http://www.hha.org.au/ForConsumers.aspx http://www.hha.org.au/ForConsumers/faqs.aspx</p>	
<h4>Immunisations</h4>	
<p>It is important to know your vaccine status for the following:</p> <ul style="list-style-type: none">- Chicken pox- Measles- Whooping Cough (Pertussis)- Seasonal flu Vaccine <p>It is important that these vaccines are up to date to protect the patient and their family, as well as to protect yourself.</p>	
<h4>Health</h4>	
<p>You should not visit the hospital if you are unwell or are recovering from any of the following symptoms:</p> <ul style="list-style-type: none">- Gastro (you should not visit the hospital until at least 48 hours after symptoms have resolved)- Respiratory illness- Moist cold sores- Unexpected rashes <p>Small things such as cold sores or a runny nose can become a serious infection for a child with cancer. Call your cancer centre supervisor if you are unsure of whether you should come to the hospital.</p>	

Entering Rooms

Many patients are isolated due to illness or infectious state. Sometimes individuals need to take extra precautions, such as wearing gowns, masks or gloves. Please be aware of all signs outside patient rooms and enquire with the child's nurse if you are at all unsure about entering a room. Remember, infections can also spread from the patient to you.

Toys, Food and Personal Items

Please do not bring any items from home for patients, especially toys, books and magazines. These items can hold harmful organisms and are difficult to clean.

Please do not bring food from home as food must be prepared in accordance with the hospital's stringent food handling guidelines.



2.3 Governance of Consumer Advisory Groups

2.3(a): Consumer Group Terms of Reference

<p>[Insert group name and logo here]</p>	<h2 style="margin: 0;">TERMS OF REFERENCE</h2> <p style="margin: 0;">[Insert date here]</p>
Objective	
<p>The [Insert group name here] functions as a consumer representative voice for children and adolescents who are diagnosed with cancer and treated within the [Insert relevant health service here]. This group, consisting of consumers and service providers, supports a collaborative process to improve the patient experience and quality and safety of [Insert State/region here] paediatric cancer services.</p> <p>Representation consists of family members who have been affected by paediatric cancer and staff from [Insert relevant health service here].</p> <p>The aim of the advisory group is to improve and enhance child focused, family-centred paediatric cancer care for all families affected by paediatric cancer by directly involving consumers in the health services and cancer related activities. By working together, the [Insert group name here] provides a mechanism for the consumer voice to be addressed in a spirit of partnership, with the overall goal of providing better services for children and adolescents with cancer and their families.</p>	
Role	
<p>The group, in its advisory capacity, will:</p> <ul style="list-style-type: none"> - Maintain a strong and positive partnership between staff and families to represent the wider population of families who use the [Insert relevant health service here] - Promote sensitivity and attention to meeting the needs of different consumers and communities affected by paediatric cancer - Actively seek feedback from consumers affected by paediatric cancer - Address issues and priorities identified by consumers as appropriate - Suggest service delivery solutions that are well matched to consumer needs - Provide input into resources developed for families - Facilitate communication of outcomes to the [Insert relevant health service here] and other stakeholders as appropriate - Document [Insert group name here] activities and outcomes annually. 	
Responsibilities	
<ul style="list-style-type: none"> - Support opportunities for joint consumer and staff initiatives - Work with people of diverse backgrounds and experiences - Maintain confidentiality regarding sensitive information and organisational matters discussed with the group - Act as the primary source for consumer consultation for the [Insert relevant health service here] - Provide a representative view of the wider community 	

Membership
<p>Consumer membership representatives: approximately ten in total, of which it is recommended that there be a mix of consumers familiar with paediatric oncology services at the [Insert relevant health service here] and at least one consumer who has experienced regional shared care. There should be a minimum of six consumer members at all times.</p>
<p>Health service representatives: including medical, nursing, allied health/psychosocial representation from the health services. Up to five health service staff, plus the program manager of [Insert relevant oncology service here e.g., integrated cancer service] should be included in this group.</p>
<p>All members of the [Insert group name here] will maintain confidentiality regarding sensitive information and organisational matters discussed within the group.</p> <p>The [Insert group name here] may invite any person or body of persons to attend and assist the group as an invited participant. The [Insert group name here] may consider membership of other health services with paediatric oncology specific treatment centres in the future.</p>
Chair & Deputy Chair
<p>The Chair and Deputy Chair of the [Insert group name here] will be voted by secret ballot on an annual basis. The Chair will be a member of the [Insert relevant health service here] Clinical Advisory Committee (the Deputy Chair may attend the Clinical Advisory Committee meetings as proxy).</p>
Coordinator
<p>The Coordinator of the [Insert group name here] will be an employee of the health service. The Coordinator is responsible for the coordination of meetings (including meeting invitations, agendas and minutes), recruitment, obtaining volunteer status, orientation of new consumer members, facilitating the group activities e.g., morning/afternoon teas and ongoing support and facilitation of training for consumer members as required.</p>
Tenure
<p>Consumer members of the [Insert group name here] will be appointed for two years with the opportunity for reappointment of two (2) further terms. Vacancies to the [Insert group name here] must follow the procedure outlined under 'recruitment'. Health service staff membership will be reviewed bi-annually by the Director of the paediatric oncology service at which the staff member is employed.</p>
Reporting
<p>The [Insert group name here] will provide an annual report at 30 June each year, which should be made available to the relevant health services and the State Department of Health. Other brief activity reports may be provided as appropriate.</p> <p>State-wide priorities: As appropriate, the [Insert group name here] will liaise at a state-wide level through the Chair to the [Insert relevant health service department here].</p> <p>Health service specific priorities: The [Insert group name here] will liaise directly with the health services Director of paediatric oncology services. The Director will be responsible for reporting</p>

[Insert group name here] activities to [Insert relevant people here e.g., Chief of Medicine at..., Medical Director of..., General Manager, Division of... at ... etc.]. The [Insert group name here] should also link in with the appropriate consumer representative body at each of the health services.

Meetings

The [Insert group name here] will meet [monthly/bimonthly/quarterly] with a minimum of [x] meetings held per annum. A quorum shall consist of at least one health service representative and 30% of the number of consumer representatives. It is expected that all members will attend at a minimum 75% of meetings per annum. Attendance by teleconferencing is welcomed.

Meetings will be held at [Insert meeting venue here] from [Insert meeting time here], unless specific needs of the group decree the need to modify these times.

Agenda papers and reports for noting will be disseminated to [Insert group name here] members no less than one week prior to the scheduled meeting. Members should be familiar with the content. Minutes from the meetings will be disseminated no more than two weeks post meeting.

Recruitment

Consumer representative members of the [Insert group name here] will be appointed through a formal recruitment process. Positions will be advertised at the appropriate site via mechanisms decided as appropriate at the time. The position description, application form and selection criteria will be reviewed at a minimum every two years by the Chair and Coordinator. Two consumer members from the [Insert group name here] and one staff member will form the selection panel and will undertake interviews supported by the [Insert group name here] Coordinator. If required, the selection panel may discuss the appointment with the relevant health service Director of the paediatric oncology service.

Health service staff membership will be appointed via the Director of the paediatric oncology service at the relevant health service.

Volunteer Registration

All consumer members will need to meet the volunteer requirements of the [Insert relevant health service here]. As a Registered Volunteer, members will act in accordance with individual hospital policies and procedures and sign confidentiality agreements. The registration process will require both a valid Police Check and Working with Children Check, both of which will be coordinated via the [Insert group name here] Coordinator.

Orientation

The Chair or Deputy Chair of the [Insert group name here] and the [Insert group name here] Coordinator will provide initial orientation to the new consumer member, as well as providing an ongoing point of contact for any questions the consumer members may have. Appropriate materials and resources will guide a structured approach to orientation and ongoing support and training at the [Insert relevant health service here].

Reimbursement

The [Insert group name here] does not hold any budget. Membership of the [Insert group name here] is a voluntary position but funding may be available for reimbursement of costs to attend

meetings in extraordinary circumstances and after discussion and resolution by the [Insert group name here]. Parking costs will be reimbursed.

Terms of Reference Review

The [Insert group name here] TOR will be reviewed every two years as a minimum.

Developed by		Endorsed by	
Version number		Date of next review	

Supported by:

[Insert relevant logo here]



2.3(b): Position Description: Chairperson

<p>[Insert group name and logo here]</p>	<h1>POSITION DESCRIPTION</h1> <h2>Chairperson</h2> <p>[Insert date here]</p>
<h3>Objective</h3>	
<p>The [Insert group name here] is a [Insert details about group composition here], endorsed to represent the consumer voice for families with a child or adolescent with cancer in [Insert health service name here]. This group supports a shared vision, working together to share responsibilities, work and outcomes.</p> <p>The [Insert group name here] will provide a mechanism for the consumer voice to be addressed in a spirit of partnership, with the overall goal of providing better outcomes for children and adolescents with cancer and their families.</p> <p>This position description is for the Chairperson of the [Insert group name here]. The [Insert group name here] consumer and health service members have a separate specific position description.</p>	
<h3>Role</h3>	
<p>The chairperson will:</p> <ul style="list-style-type: none"> - Attend a minimum of 75% of meetings per annum - Speak on behalf of the [Insert group name here] - Represent the views of the [Insert group name here] at all formal and informal occasions - Chair the [Insert group name here] meetings - Formalise annual objectives - Coordinate the reporting requirements - Review agenda minutes and the annual report - Meet/liaise with key stakeholders as required - Be the link between the health service and consumers. 	
<h3>Selection Process</h3>	
<ul style="list-style-type: none"> - The Chairperson of the [Insert group name here] will be elected on an annual basis in [Insert month here] each year - Only consumers are eligible to nominate for the Chair - Nominations will be requested and received up to [Insert date here] each year for the following period - Nominations received will be forwarded to the [Insert group name here] membership via email prior to the [Insert month here] meeting - Nominations should include an expression of interest from the nominees along with a <i>brief</i> synopsis of specific skills/experience they bring and/or particular issues or processes they would like to address as Chairperson of the committee - All members of the [Insert group name here] are eligible to vote - Voting shall occur via secret ballot at the [Insert month here] meeting. Postal/email votes will be accepted if received 24hrs prior to the [Insert month here] meeting - The Coordinator will take leave during the meeting to compile the votes. In the event that 	

a tied result occurs, members present will undertake a second secret ballot to decide between the tied members

The second highest vote will have the opportunity to be the vice chair for the 12 month period.

Selection Criteria

- Experience with [Insert State/region here] paediatric oncology services
- Strong communication skills (written and verbal)
- Demonstrated commitment to the group
- Ability to identify issues of importance to service users and their families
- Ability to attend meetings
- Breadth of view/strategic ability
- Demonstrated understanding of privacy, anonymity and confidentiality
- Willingness to participate in discussions with the committee in an open and constructive manner
- Ability to present a consumer perspective to discussions
- Well developed interpersonal and communication skills
- Demonstrated ability to work as part of a group
- Clear vision of 12 month goals and objectives for the group

Tenure

12 months, but may be re-elected for multiple terms (no more than 5 years).

Reporting

The [Insert group name here] will report through the Chairperson to the Director(s) of paediatric oncology service(s).

Volunteer Registration

The Chairperson will need to be registered as a volunteer with [Insert relevant health service here]. As a Registered Volunteer the Chairperson must act in accordance with hospital policies and procedures and sign the confidentiality agreement.

A valid Police Check and Working with Children Check, both of which will be coordinated via the health service is required.

Position Description Review

The Chairperson Position Description will be reviewed every two years as a minimum.

Developed by		Endorsed by	
Version number		Date of next review	

Supported by:

[Insert relevant logo here]

2.3(c): Position Description: Member (Consumer)

<p>[Insert group name and logo here]</p>	<h1>POSITION DESCRIPTION</h1> <h2>Member (Consumer)</h2> <p>[Insert date here]</p>
<h3>Objective</h3>	
<p>The [Insert group name here] is a [Insert details about group composition here], endorsed to represent the consumer voice for families with a child or adolescent with cancer in [Insert health service name here]. This group supports a shared vision, working together to share responsibilities, work and outcomes.</p> <p>The [Insert group name here] will provide a mechanism for the consumer voice to be addressed in a spirit of partnership, with the overall goal of providing better outcomes for children and adolescents with cancer and their families.</p> <p>This position description is for consumer members of the [Insert group name here]. The [Insert group name here] Chairperson and health service members have a separate specific position description.</p>	
<h3>Role</h3>	
<p>Members (consumers) will:</p> <ul style="list-style-type: none"> - Attend a minimum of 50% of meetings per annum - Participate in, and where appropriate, coordinate activities e.g., [Insert relevant group activities here] - Speak on behalf of consumers at the [Insert group name here] meetings and communicate consumer feedback to the health services as appropriate - On behalf of the [Insert group name here], represent consumers at a state-wide level as appropriate - Work towards achieving the [Insert group name here] annual objectives - Contribute to the six monthly and annual reporting requirements. 	
<h3>Selection Process</h3>	
<p>Consumer representative members of the committees will be appointed through a formal recruitment process. Positions will be advertised at the appropriate site via appropriate mechanisms decided as appropriate at the time. The position description, application form and selection criteria will be reviewed at a minimum every two years. Two members (consumers) from the [Insert group name here] and one staff member will undertake interviews supported by the [Insert relevant health service here] Group Coordinator.</p>	
<h3>Selection Criteria</h3>	
<ul style="list-style-type: none"> - Experience with paediatric oncology services (e.g., a parent, family member, sibling, survivor) - Demonstrated commitment to the group - Ability to identify issues of importance to service users and their families - Ability to attend meetings 	

- Breadth of view/strategic ability
- Demonstrated understanding of privacy, anonymity and confidentiality
- Willingness to participate in discussions with the committee in an open and constructive manner
- Ability to present a consumer perspective to discussions
- Well developed interpersonal and communication skills
- Demonstrated ability to work as part of a group

Tenure

Members (consumers) of the [Insert group name here] will be appointed for two years with the opportunity for reappointment of two (2) further terms.

Volunteer Registration

Members (consumers) will need to be registered as a volunteer with [Insert relevant health service here] Volunteers Program. As a Registered Volunteer the Member (consumer) must act in accordance with hospital policies and procedures and sign the confidentiality agreement.

The registration process will require both a valid Police Check and Working with Children Check, both of which will be coordinated via the health service.

Position Description Review

The Members (consumers) Position Description will be reviewed every two years as a minimum.

Developed by		Endorsed by	
Version number		Date of next review	

Supported by:

[Insert relevant logo here]

2.3(d): Position Description: Member (Health Service)

<p>[Insert group name and logo here]</p>	<h1>POSITION DESCRIPTION</h1> <h2>Member (Health Service)</h2> <p>[Insert date here]</p>
<h3>Objective</h3>	
<p>The [Insert group name here] is a [Insert details about group composition here], endorsed to represent the consumer voice for families with a child or adolescent with cancer in [Insert health service name here]. This group supports a shared vision, working together to share responsibilities, work and outcomes.</p> <p>The [Insert group name here] will provide a mechanism for the consumer voice to be addressed in a spirit of partnership, with the overall goal of providing better outcomes for children and adolescents with cancer and their families.</p> <p>This position description is for health service members of the [Insert group name here]. The [Insert group name here] Chairperson and consumer members have a separate specific position description.</p>	
<h3>Role</h3>	
<p>Health Service members will:</p> <ul style="list-style-type: none"> - Attend a minimum of 75% of meetings per annum - Represent the [Insert group name here] and report to their own health service on behalf of the group as appropriate - Participate in group activities as required - Represent the views of the [Insert group name here] at all formal and informal occasions - Assist with coordinating the reporting requirements as required - Meet/liaise with key stakeholders as required - Be an active member of the [Insert group name here] - Take consumer feedback to the health service, act upon it and report on actions taken. 	
<h3>Selection Process</h3>	
<p>Health service members will be representative of a relevant paediatric oncology health service. Positions will be nominated as appropriate by the health service using appropriate mechanisms as appropriate at the time. The position description and responsibilities will be reviewed at a minimum every two years.</p>	
<h3>Selection Criteria</h3>	
<ul style="list-style-type: none"> - Experience with [Insert Health Service/State/region here] paediatric oncology services - Demonstrated commitment to consumer engagement - Ability to identify issues of importance to service users and their families - Ability to attend meetings - Breadth of view/strategic ability - Demonstrated understanding of privacy, anonymity and confidentiality - Willingness to participate in discussions with the committee in an open and constructive 	

manner

- Ability to present a health service perspective to discussions
- Well developed interpersonal and communication skills
- Demonstrated ability to work as part of a group

Reporting

The [Insert group name here] will report through the Chairperson to the Director(s) of the paediatric oncology service(s).

Tenure

[Insert relevant tenure here]

Position Description Review

The Members (Health Service) Position Description will be reviewed every two years as a minimum.

Developed by		Endorsed by	
Version number		Date of next review	

Supported by:

[Insert relevant logo here]

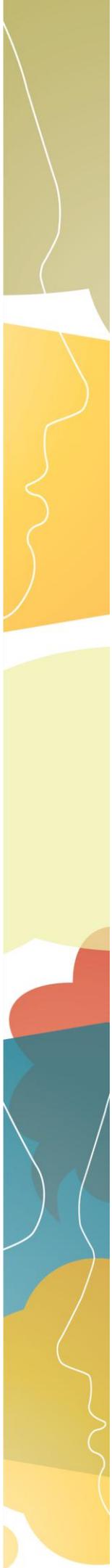
2.3(e): Position Description: Group Coordinator

<p>[Insert group name and logo here]</p>	<p style="text-align: center;">POSITION DESCRIPTION</p> <p style="text-align: center;">Group Coordinator</p> <p style="text-align: right;">[Insert date here]</p>
<p>Objective</p>	
<p>The [Insert group name here] is a [Insert details about group composition here], endorsed to represent the consumer voice for families with a child or adolescent with cancer in [Insert health service name here]. This group supports a shared vision, working together to share responsibilities, work and outcomes.</p> <p>The [Insert group name here] will provide a mechanism for the consumer voice to be addressed in a spirit of partnership, with the overall goal of providing better outcomes for children and adolescents with cancer and their families.</p> <p>This position description is for the Coordinator of the [Insert group name here].</p>	
<p>Role</p>	
<p>The Group Coordinator will:</p> <ul style="list-style-type: none"> - Be a staff member of the health service - Attend a minimum of 75% of meetings per annum - Speak on behalf of the [Insert group name here] - Represent the views of the [Insert group name here] at all formal and informal occasions - Assist with formalising annual objectives - Prepare meeting minutes, agendas and other documents of correspondence and circulate to appropriate and agreed health service and government agencies - Prepare the Annual Report of the group - Meet/liaise with key stakeholders as required - Be an active member of the [Insert group name here]. 	
<p>Appointment Process</p>	
<p>The [Insert relevant health service here] will appoint an employee to act as the Group Coordinator of the [Insert group name here].</p>	
<p>Selection Criteria</p>	
<ul style="list-style-type: none"> - Demonstrated commitment to consumer engagement - Ability to identify issues of importance to service users and their families - Ability to attend meetings (75%) - Breadth of view/strategic ability - Demonstrated understanding of privacy, anonymity and confidentiality - Willingness to participate in discussions with the committee in an open and constructive manner - Ability to present a health service perspective to discussions - Well developed interpersonal and communication skills - Demonstrated ability to work as part of a group 	

Reporting			
The Group Coordinator will report through the Health Service as per normal employment.			
Volunteer Registration			
The Group Coordinator must act in accordance with hospital policies and procedures of the health service. This includes having a valid Police Check and Working with Children Check.			
Position Description Review			
The Group Coordinator Position Description will be reviewed every two years as a minimum.			
Developed by		Endorsed by	
Version number		Date of next review	

Supported by:

[Insert relevant logo here]



2.3(f): Meeting Agenda Template

[Insert group logo here]		[Insert group name here]		AGENDA [Insert DATE, year here] [Insert venue here]	
MEMBERS:					
Name	(Intials)	Name	(Initials)	Name	(Initials)
INVITED PARTICIPANTS:					
Name	(Intials)	Name	(Initials)	Name	(Initials)
Agenda Items	Topic	Details/Discussion		Action/Outcomes <small>(To Note/To Approve/For Verbal Update)</small>	(Initials)
1.0	Welcome and Apologies 1.1 Apologies:				
2.0	Minutes of the Previous Meeting 2.1 Meeting held (DATE)				
	Business Arising from the previous Minutes 2.2				

3.0	New Business 3.1			
4.0	Other Business 4.1			
Next Meeting (DATE & TIME) Venue				
Meeting Dates for [Insert Year here]				
Date		Time		Venue



2.3(g): Meeting Minutes Template

[Insert group logo here]		[Insert group name here]		MINUTES [Insert DATE, year here] [Insert venue here]	
MEMBERS:	Name	(Initials)	Position/Job Title	Present (v)	Apology (x)
INVITED PARTICIPANTS:					
Agenda Items	Topic	Action/Responsibilities (To Note/To Approve/For Verbal Update)			(Initials)
1.0	Welcome and Apologies 1.1 Apologies:				
2.0	Minutes of the Previous Meeting 2.1 Meeting held (DATE)				
	Business Arising from the Previous Minutes 2.1				

3.0	New Business 3.1		
4.0	Other Business 4.1		
Meeting Dates for [Insert Year here]:			
1.	[insert date and venue here]	<p style="text-align: center;">Next Meeting</p> <p style="text-align: center;">(DATE & TIME)</p> <p style="text-align: center;">Venue</p>	
2.	[insert date and venue here]		
3.	[insert date and venue here]		
4.	[insert date and venue here]		
5.	[insert date and venue here]		
6.	[insert date and venue here]		

2.3(h): Feedback Documentation

[Insert Group Name and Logo Here]		Feedback Documentation	
<p>Parent/family feedback is one of the key sources of input in determining the group's discussion and plan for feedback to the health services. It is imperative that a structured approach be used for gathering and presenting the feedback received.</p> <p>The following is a suggested template for this purpose. At each event (e.g. morning tea) a [Insert group name here] representative is required to record feedback and where appropriate, actions. This will be achieved as follows:</p> <ul style="list-style-type: none"> - Event hosts will provide feedback as appropriate, grouping into themes were possible - The feedback is collated, de-identified, documented and presented as appropriate to the monthly group meeting by the hosts - Consider discussing feedback across a couple of meetings so the health services staff are provided with themes rather than individual situations - Feedback can be positive as well as constructive. 			
Event	Date:		
Prepared by			
Issue / Theme #1	[e.g., Communication]	Action	By Whom
Parent/consumer feedback			
Issue / Theme #2	[e.g., Coordination]	Action	By Whom
Parent/consumer feedback			
Issue / Theme #3	[e.g., In-patient Care]	Action	By Whom
Parent/consumer feedback			
Issue / Theme #4	[e.g., Feedback relating to staff]	Action	By Whom
Parent/consumer feedback			
Issue / Theme #5		Action	By Whom
Parent/consumer feedback			
Issue / Theme #6		Action	By Whom
Parent/consumer feedback			

Issue / Theme #7		Action	By Whom
Parent/consumer feedback			
Issue / Theme #8		Action	By Whom
Parent/consumer feedback			
Issue / Theme #9		Action	By Whom
Parent/consumer feedback			
Issue / Theme #10		Action	By Whom
Parent/consumer feedback			



2.3(i): Example - Consumer Satisfaction Survey

This consumer satisfaction survey was designed by the Paediatric Integrated Cancer Service Long Term Follow-up Team. It has been included in this toolkit as an example of one way a consumer satisfaction survey could be structured.

Long Term Follow-Up Program Evaluation

As part of our quality improvement cycle, the Long Term Follow-Up Program is seeking feedback, opinions and suggestions from parents and young people who have attended the LTF clinic. Your valued feedback will enable us to improve the service we provide.



Patient's name: <small>(optional)</small>		At the clinic How useful did you find the service provided by the ...		very good	good	fair	poor	very poor	n/a
Location of clinic: <input type="radio"/> Monash Children's <input type="radio"/> Royal Children's Hospital		1. Clinical nurse coordinator	<input type="radio"/>						
Was this your first LTF clinic? <input type="radio"/> Yes <input type="radio"/> No		2. Dietitian	<input type="radio"/>						
How did you first hear about the LTF clinic? <input type="radio"/> Primary Oncology Consultant <input type="radio"/> Nurse Coordinator <input type="radio"/> Other Oncology Patient <input type="radio"/> Other, please specify...		3. Education adviser (Teacher)	<input type="radio"/>						
Before the clinic What did you think of the ...		4. Endocrinologist	<input type="radio"/>						
1. pre clinic telephone call?	<input type="radio"/>	5. Fertility specialist	<input type="radio"/>						
2. instructions provided during pre clinic telephone call?	<input type="radio"/>	6. Neuropsychologist	<input type="radio"/>						
3. content of the pre-clinic letter?	<input type="radio"/>	7. Occupational therapist	<input type="radio"/>						
4. content of the clinic brochure?	<input type="radio"/>	8. Oncologist (Doctor)	<input type="radio"/>						
5. pre-clinic questionnaire in preparing you for the clinic?	<input type="radio"/>	9. Physiotherapist	<input type="radio"/>						
6. amount of notice period given to you to attend the clinic?	<input type="radio"/>	10. Radiation oncologist (Doctor)	<input type="radio"/>						
7. SMS phone appointment reminder service?	<input type="radio"/>	11. Social Worker	<input type="radio"/>						
		12. Did you have enough time to see the health professionals you wanted to see?						Yes	No
		13. Were there other health professionals that you would have liked to have seen? <i>If yes please detail in additional comments.</i>						Yes	No
		14. Did the pre-clinic questionnaire assist you to identify specific concerns you wanted to discuss at the clinic?						Yes	No
		15. Were you satisfied with the discussions at the clinic? <i>If no please detail in additional comments.</i>						Yes	No
		16. Did you understand the information given to you at the clinic? <i>If no please detail in additional comments.</i>						Yes	No
		17. Were you satisfied with the instructions of what to do after your appointment? <i>If no please detail in additional comments.</i>						Yes	No
		18. How long did you spend at the clinic? <input type="radio"/> 1 hour <input type="radio"/> 2 hours <input type="radio"/> 3 hours <input type="radio"/> 4 hours <input type="radio"/> 5 hours							

After the clinic What did you think of the ...		very good	good	fair	poor	very poor	n/a
1. Health record book given to you at the LTF clinic?	<input type="radio"/>						
2. Transition document (patient medical history)?	<input type="radio"/>						
3. Chemotherapy summary?	<input type="radio"/>						
4. Road map (plan of investigations)?	<input type="radio"/>						
5. Information letter to understand?	<input type="radio"/>						
6. Clinic summary?	<input type="radio"/>						
7. Have your concerns been followed up? <i>If no please detail in additional comments.</i>						Yes	No
8. Did you find the clinic helpful and relevant to your needs?						Yes	No
9. Do you have a clear understanding of when you are due for review?						Yes	No
Overall did your experience at the LTF clinic							
Exceed your expectations		<input type="radio"/>					
Meet your expectations		<input type="radio"/>					
Not meet your expectations		<input type="radio"/>					
Additional comments Please describe good or bad experiences ...							

Thank you for helping us review our service
Please return this evaluation, within the next week, in the pre paid envelope provided
or email: ltf_program@rch.org.au or fax: (03) 9345 9165
If you have any questions please do not hesitate to contact The Long Term Follow-up Team on (03) 9345 9152

2.3(i): Reimbursement Schedule

[DELETE ITEMS THAT ARE NOT APPLICABLE]

<p>[Insert Group Name and Logo Here]</p>	<h3>Consumer Representative Reimbursement Schedule</h3>
<p>To support consumer participation in the [Insert health service name here] a reimbursement policy for consumers has been developed.</p>	
<p>Travel Expenses (delete items that are not applicable)</p>	
<ul style="list-style-type: none"> - Personal vehicle: travel reimbursement is available on a 'per km' basis (mileage is required) when consumers are required to travel to/from meetings and other approved activities. - Taxi costs: the health service will provide a cab charge voucher for the consumer to use for travel to/from meetings and other approved activities. - Public transport: reimbursement is available on the provision of a tax invoice/receipt. 	
<p>Parking Expenses (delete items that are not applicable)</p>	
<ul style="list-style-type: none"> - Parking expenses incurred when consumers are required to attend meetings may be reimbursed upon provision of a tax invoice/receipt. 	
<p>Meal Expenses (delete items that are not applicable)</p>	
<ul style="list-style-type: none"> - Meal reimbursement is available to consumers who are expected to remain on site over meal times. Consumers may receive funding support to cover meals. This may be in the form of a prepaid voucher to use at a hospital venue or provision of a tax invoice/receipt for a meal. 	
<p>Babysitting/Childcare Expenses (delete items that are not applicable)</p>	
<ul style="list-style-type: none"> - Babysitting/childcare reimbursement to enable the consumer to attend meetings is available up to [Insert \$ value]. 	
<p>Chairperson/Member Stationary Expenses (delete items that are not applicable)</p>	
<ul style="list-style-type: none"> - The Chairperson may request reimbursement of reasonable stationary expenses, although the health service may wish to provide supplies. For example, the health service could print meeting papers or consider providing the chair with an iPad to reduce the cost of stationary and printing 	
<p>Telecommunication Expenses (delete items that are not applicable)</p>	
<ul style="list-style-type: none"> - Identified phone calls (mobile or landline) can be reimbursed upon submission of appropriate information and form. 	
<p>Guidelines for Reimbursement</p>	
<ol style="list-style-type: none"> 1. Reimbursement will follow the policy of the health service. 2. It is the responsibility of the individual to complete and submit the claim form for payment. 	

3. Attendance at the [Insert group name here] meetings will be confirmed by meeting minutes.
4. Teleconference into an approved meeting is also considered attending and will be reimbursed accordingly
5. If you have any concerns around payment, please contact [Insert relevant contact here] on [Insert phone number here]

Developed by		Endorsed by	
Version number		Date of next review	



2.3(k): Volunteer Thankyou Letter

[Insert logo here]

[Insert group name here]

[Name]

[Date]

[Address]

[Suburb]

[Postcode]

Dear [Name],

I am writing to thank you for volunteering to be a member of the [Insert group name here] in [Insert current year here]. The [Insert group name here] sincerely appreciates the time you have put into fulfilling this commitment. We would also like to thank you for the energy and enthusiasm you have brought to the role and your generosity in sharing feedback with the health service. The input gained from consumers is invaluable in improving the quality and safety of [Insert health service here] and your input enables us to be more responsive to the needs of our patients and families. We look forward to continuing to work in partnership with you in [Insert upcoming year here].

Yours sincerely,

[Insert Chair's name here]

Chair of [Insert group name here]

[Insert contact details here]

2.4 Support and Information for Consumer Representatives

2.4(a): Ideas for volunteer parents on how to start conversations with other parents

[Insert Group Name and Logo Here]	<h2 style="text-align: center;">Ideas for volunteer parents on how to start conversations with other parents</h2>
<p>Parents have reported they value the opportunity of meeting other parents who are further down the track in receiving treatment for their child’s cancer. The tips below have been prepared to assist with facilitating conversations with other parents.</p>	
<p>Talking to another parent who may be further ‘down the track’ can be beneficial for the following reasons:</p>	
<ul style="list-style-type: none"> - The opportunity to share experiences, ideas and knowledge - Social interaction when you are spending a lot of time in hospital with your child - 1:1 support - Sharing ideas on advocating for your child - Finding out about sources of information you previously didn’t know existed - With information, resources and support, parents are able to make decisions that best meet their needs. 	
<p>It is important to keep in mind:</p>	
<ul style="list-style-type: none"> - Each parent’s journey is unique - Parents are the experts about their own family. <p style="text-align: right;">www.parenttoparent.org</p>	
<p>How to approach another parent:</p>	
<ul style="list-style-type: none"> - Choose an appropriate location – sitting in a comfortable environment is better than having a conversation in passing (e.g., in a public corridor) - Minimise distractions and interruptions during your conversation (e.g., turn mobile phone off) - Introduce yourself at an appropriate time (i.e., not during a medical procedure or when the parent has other visitors) - Explain that you are also a parent of a child who has experienced cancer and your purpose for being at the cancer centre. Ask if it is a suitable time to have a chat and if the parent doesn’t seem up to talking, offer to return at a more suitable time - Be an active listener (see ideas below). 	
<p>How to be an active listener:</p>	
<ul style="list-style-type: none"> - Pay close attention to the parent and try to avoid interrupting - Encourage the parent to elaborate without prompting for specifics - Acknowledge the parent’s feedback without agreeing or disagreeing with what they are saying (encourage them to continue by nodding “yes” and letting them know that you are listening) 	

- Acknowledge what you don't know where appropriate (e.g., if asked your opinion on a clinical question, acknowledge this is not within your expertise and suggest the parent consults the doctor/nurse)
- Provide reassurance – rather than interpreting, reiterate what the parent has said
- At the end of the conversation, summarise the key points that the parent has raised.

http://www.cancer.org.au/content/pdf/AboutCancer/support/workingwithcancer_sect3.pdf

Patient contact guidelines

Visitor parents:

- Must maintain a high level of professionalism throughout their visit
- Must not offer advice or purchase medications for parents
- Must not accept gifts from families or give gifts to families
- Must not discuss treatment options or give any explanation about treatment, diagnosis or cancer
- Must not bring any unauthorised visitors with them
- If a child/family tells the visitor that something is worrying them or has a genuine complaint, the visitor should inform the hospital or professional staff looking after the child
- Must meet the hospital requirements for visitors to the hospital.

2.4(b): Support versus Advice: Guidelines for Volunteers

<p>[Insert Group Name and Logo Here]</p>	<h3>Support versus Advice: Guidelines for Volunteers</h3>
Support versus Advice	
<p>Volunteers are reminded that they should not offer advice to patients and their families regarding clinical topics or “what to do”. This is the role of the trained health practitioners at the health service. Volunteers are encouraged to offer support.</p> <p>For example, offering support may include:</p> <ul style="list-style-type: none">- Listening patiently when patients/families want to talk- Helping family members find out which health professional to direct their questions towards- Offering to make tea/coffee and sitting with them for a while- With permission, relaying feedback from patients/families to the health service Nurse Unit Manager or Consumer Liaison Officer.	
Patient Contact Guidelines	
<ul style="list-style-type: none">- Volunteers should maintain a high level of professionalism throughout their visit- Volunteers must not offer advice or purchase medications for patients- Volunteers must not discuss treatment options or give any explanation about treatment, diagnosis or cancer- If a child/family tells the visitor that something is worrying them or has a genuine complaint, the volunteer should encourage the family/parent to speak to the health service. If the family/parent is nervous about speaking to the health service, the volunteer could coordinate and facilitate a meeting with the Nurse Unit Manager- Volunteers should adhere to the social media guidelines of the health service (refer to Social Media Volunteer Policy for details).	



2.4(c): Looking After Yourself – Tips for Consumer Representatives

<p>[Insert Group Name and Logo Here]</p>	<h3>Looking After Yourself – Tips for Consumer Representatives</h3>
<p>As a volunteer consumer representative you will be working with families whose child is currently receiving treatment for cancer. In this role, you will meet with families who may have difficult stories to tell and it is possible and even expected, that this may have an emotional impact on you. Therefore, it is important to counterbalance this with strategies to look after your own wellbeing, whilst also being aware of when you may need to seek support. Listed below are some tips on how to recognise and address possible signs of stress.</p>	
<h4>Learn to recognise possible signs of stress</h4>	
<p>Possible Emotional Symptoms:</p> <ul style="list-style-type: none">- Feeling overwhelmed or uncertain about your role- Lack of confidence in your abilities- Feeling upset or distressed after talking with other families- Forgetfulness or indecision- Feeling irritable or negative about things- Not feeling a sense of reward from your role- Using unhealthy coping strategies e.g., misuse of alcohol. <p>Possible Physical Symptoms:</p> <ul style="list-style-type: none">- Changes in sleeping and/or eating patterns- Headaches and muscle tension- Racing heart or sweating with no obvious cause. <p>http://www.carersnsw.asn.au/advice/look-after-yourself/managing-stress/</p>	
<h4>Ideas on ways to respond to stress</h4>	
<ul style="list-style-type: none">- Seek support/advice from your colleagues- Identify a mentor who can support you in your role- Seek clarification if you are unclear about a task/role- You may be over committing to your role. Scale back your workload if necessary- At your own pace, talk to friends, family or someone in a similar position to you (e.g., another consumer representative). It is important to note that the confidentiality of the families you work with must be respected when discussing your work with others- Eat well, exercise regularly and get plenty of sleep- Have 'time out' doing something that you find relaxing- Build resilience: focus on the positive outcomes and experiences of your role, accept unpleasantness, learn from it and move on, try to see the funny side of things and work on building your self-esteem- Talk to a health professional if you feel that stress is impacting on your health <p>http://www.carersvictoria.org.au/advice/look-after-yourself/managing-stress</p>	
<h4>For more information</h4>	
<p>Relaxation techniques: http://www.beyondblue.org.au/index.aspx?link_id=90.621&tmp=FileDownload&fid=326</p> <p>The importance of exercise: http://www.carersvictoria.org.au/advice/look-after-yourself/exercise</p> <p>Healthy eating: http://www.carersvictoria.org.au/advice/look-after-yourself/eating-well</p>	

2.4(d): The difference between a complaint and a criticism

<p>[Insert Group Name and Logo Here]</p>	<h3>The difference between a complaint and a criticism</h3>
<p>When consumer representatives meet and interact with current patients, parents and families statements can be made about the hospital staff or an episode of care. Consumer representatives can sometimes find it difficult to differentiate whether a patient/parent is making a complaint or just 'letting off steam'. This guidance has been prepared to assist you with making this distinction. Escalated feedback should be focused on processes and outcomes rather than on personal opinions. Constructive feedback can be productively used by health services to change a negative outcome into a positive solution.</p> <p>A complaint is 'a statement that something is unsatisfactory or unacceptable' (Oxford Dictionary Online).</p> <p>Criticism is 'the expression of disapproval of someone or something on the basis of perceived faults or mistakes' (Oxford Dictionary Online). Criticism is often used by individuals as a means to have their needs met.</p>	
<p style="text-align: center;">Complaint = Criticism – Personal Judgement</p>	
<h4>Why Consumer Complaints are Important in Health Care</h4>	
<p><i>"Assessment, monitoring and exploration of patient complaints and patient satisfaction data provide one indicator of quality of care, can contribute to clinical care improvement strategies and provide healthcare consumers input into improvement of health care services and delivery."</i></p> <p style="text-align: center;">(University of New South Wales, 'Complaints and Patient Satisfaction: a comprehensive review of the literature').</p>	
<h4>Suggestions for the health service on how to turn consumer complaints into service improvements</h4>	
<p>The health service should:</p> <ul style="list-style-type: none"> - Educate volunteers about how to respond to consumer complaints during the volunteer orientation process - Provide clear guidance on the health service's complaint escalation policy - Provide a form for volunteers to complete upon receiving feedback from consumers to ensure that all complaints are documented - Link into the health service consumer advisory committee at the hospital - Link into the health service adverse events process i.e., RiskMan. 	
<h4>How to escalate a complaint made in the cancer centre – suggestions for volunteers</h4>	
<p>When working with consumers to obtain feedback, volunteers are likely to find that they encounter a variety of complaints. Listed below are suggestions on how to manage complaints.</p> <ol style="list-style-type: none"> 1. Listen to the parent/consumer patiently. Allow them enough time to express their concerns. Acknowledge their concerns but avoid offering solutions to the problem. 	

2. Determine if the complaint is:
 - A local health service issue (e.g., a complaint about the food in the cancer centre) and whether it is once-off or ongoing
 - A personnel issue (e.g., a complaint about a specific staff member)
 - A safety issue.

3. Before you tell anyone about the complaint, you will need to ask for permission from the consumer:
 - If the consumer gives you permission, ask for their name and contact details and approach the Nurse Unit Manager. If the consumer does not wish for their personal details to be forwarded to the health service but gives permission for their complaint to be communicated, anonymous feedback can be provided
 - If the consumer does not give you permission to forward their complaint, it is important to explain that their feedback will not be escalated or actioned.



2.4(e): Tips from parents for parents

<h1>Tips for parents from parents</h1>		7	<p><i>‘Let me know if there’s anything I can do...’</i> is a phrase you will hear a lot.</p> <p>Graciously accept the offer and be specific. Ask them to walk the dog, mow the lawns, drop off a meal every Monday, pick up notices from school, get video blogs from your child’s friends.</p> <p>If every person who asks, does just one thing, it’s not too much of a burden to them, but a wonderful way of shortening your to-do list.</p>
<p>This list does not cover everything, but provides the best advice we have gathered so far. Please share any of your ideas or strategies with the [Insert group name here] so that we can add them, to continue to help families in the future.</p>		8	<p>Tell someone in your medical team if you are feeling very worried about your child’s treatment or an upcoming test result. Generally speaking they will respond with sensitivity and haste to your anxiety.</p>
1	Do what you need to get through each day. Sometimes that's enough.	9	<p>Do something kind for yourself <u>whenever</u> you are able. We all know it is hard to find the time in amongst the demands of caring for a child with cancer, but even something small can help you recharge a little.</p> <div style="background-color: #FFA500; border-radius: 50%; padding: 10px; text-align: center; margin: 10px 0;"> <p><i>“A friend gave me a lovely hand cream so I made it a point to put that on every day. The aroma reminded me to stop for just a second and breathe a little each time.”</i></p> </div>
2	<p>Don't be afraid to ask questions.</p> <p>It's okay to say <i>'I'm not sure I understand, can you tell me more...'</i> or <i>'what does that mean?'</i>. Medical language takes a little while to learn and occasionally medical staff need to be reminded of this!</p>		
3	<p>Don't feel pressured to tell everyone everything. Re- telling information is exhausting and often time consuming. Friends and family should understand this.</p>		
4	<p>Ask your consultant how things are going. Sometimes we are too polite to ask and are left wondering and worrying in our silence.</p>	10	<p>Find a support system and lean on them as often as you need to. If you don’t have family or friends nearby then make contact with some of the organisations that offer support to families. The first phone call can be difficult but most parents report it being well worth it.</p>
5	<p>At the introduction of a new treatment drug ask your consultant:</p> <ul style="list-style-type: none"> - <i>What do we need to be worried about?</i> - <i>What do we need to look out for?</i> <p>Forewarned is definitely forearmed.</p>	11	<p>Remind yourself that you are doing a remarkable job in the most challenging of situations. You have probably discovered that you are stronger and more capable than you even knew and it is important to acknowledge this.</p>
6	<p><i>'I've walked a mile in your shoes.'</i> Families affected by paediatric cancer seem to have a natural empathy with each other, which is wonderful. Remember, however, that every experience is unique and each family is allowed to travel the road in <u>their own way</u> and own time.</p>	12	<div style="text-align: center;">  </div> <p>Print off and/or email this Tip Sheet to the people who are supporting you to offer them some additional ideas.</p>

[Insert Group Name and Logo Here]

If you have an experience within the [Insert hospital/health service name here] that either exceeds or fails to meet your expectations please share it with the [Insert group name here]. Complaints should be directed to the hospital via the Nurse Unit Manager or Director of the Cancer Service.

Often themes emerge in the feedback that allows us to celebrate and promote the successes of the centre but also work on identifying and developing areas for improvement. Please make contact if there are any additional tips you would like to see included in this sheet.

You can contact the [Insert group name here] via:
(insert relevant contact details here)

This document was produced by the Children's Cancer Centres' Parent Advisory Group (CCCPAG). The CCCPAG has generously agreed to share their work to assist other families affected by paediatric cancer.

2.4(f): Tips for family and friends

Tips for family and friends		5	<p>Try not to make light of the experience. However, you want to avoid overplaying the experience too, especially in front of the child.</p> <p>It is confronting and distressing to have a family member or friend with cancer but it is important to make sure that the child doesn't feel like they are responsible for causing that distress.</p>
It is hard to know what to do when a child you know is diagnosed with cancer. We all want to help but we worry about saying the wrong thing or intruding on the family. The following tips come from families who have faced these challenges and are designed to make it a little easier to offer support that is helpful and useful.		6	Be careful when sharing internet facts and figures. Childhood cancers are not standard and treatments are highly specific and personal. Information available may not be applicable to your child.
1	Offering words of comfort is very much appreciated, although words should be chosen carefully. Having a child with cancer cannot be explained and does not make sense. It is often better to simply say "I don't know what to say".	7	<p>Show up at the hospital if you can. Text first to check its okay, bring a coffee, stay for a little while.</p> <p>While it can be confronting to visit a cancer ward, it is far more confronting to be a cancer patient. No one loves hospitals! A little effort and thoughtfulness can make a world of difference to a child who would love company of his/her own age.</p>
2	<p>Everyone says 'let me know if I can do anything to help'. Instead, just do what you know is helpful. Mow the lawn, walk the dog, make sure they get fundraising lamingtons from the Kinder. Cancer treatment is really time intensive, especially in the early stages so it's hard to keep up with the rest of your commitments.</p> <p>Offering to help with household chores, such as vacuuming, washing a window, returning library books etc is always very much appreciated and at the same time can reduce family stress.</p>	8	<p>Keep including and inviting the family to events even if they rarely attend. Families often report feeling isolated and disconnected from their social networks, so it helps to keep the door open.</p> <p>Try not to be disappointed if texts, voicemail, emails etc are not responded to. They are usually appreciated but sometimes in the midst of treatment the energy is not always there to respond to everyone.</p>
3	Make food, in small serves that can be frozen and reheated at the hospital. Parents need meals and the cafe is expensive. Write the name of the meal on the top so the family knows what it is.	9	<p>KEEP UP YOUR SUPPORT.</p> <p>Cancer treatments are often long and continue over months and years. Support often drops away dramatically after the first stage but the family continues to manage the many needs for a long time. All support is appreciated.</p>
4	Be interested but not too curious. Let the family share information at their own pace. It can be really difficult telling and re- telling the information.		

10	Notice and celebrate treatment milestones. Finishing stages, coming off treatment, getting through, getting back to school, out of hospital. It doesn't need to be a big gesture, just a card in the mail will mean a lot.		<p>Listen, laugh, text, email, post. Be present and sensitive and know that your support and care is truly appreciated by a family going through the most challenging of circumstances.</p> <p>If you have an experience within the [Insert hospital/health service name here] that either exceeds or fails to meet your expectations please share it with the [Insert group name here]. Complaints should be directed to the hospital via the Nurse Unit Manager or Director of the Cancer Service.</p> <p>Often themes emerge in the feedback that allows us to celebrate and promote the successes of the centre but also work on identifying and developing areas for improvement. Please make contact if there are any additional tips you would like to see included in this sheet.</p> <p>You can contact the [Insert group name here] via: (insert relevant contact details here)</p>
11	Look after yourself too. Being a supporter is a wonderfully rewarding role but also exhausting and distressing at times. It can be helpful to find someone a bit removed from the situation to debrief with from time to time.		
12		Print off and/or email this Tip Sheets to others. It has some really great ideas.	

This document was produced by the Children's Cancer Centres' Parent Advisory Group (CCCPAG). The CCCPAG has generously agreed to share their work to assist other families affected by paediatric cancer.

2.4(g): Social Media: Volunteer Policy

[Insert Group Name and Logo Here]	Social Media: Volunteer Policy
<p>Social media is a rapidly growing platform for communication in society. Balanced with the many benefits of social media are problems and risks associated with its use in the context of healthcare. The following suggestions outline what may be considered acceptable versus not acceptable for volunteers using social media within your health service.</p>	
<p>Social media may include (but is not limited to):</p>	
<ul style="list-style-type: none"> - Social networking sites (e.g., Facebook, LinkedIn) - Photo and video sharing sites - Blogs - Micro-blogging (e.g., twitter) - Wikis and online collaborations (e.g., Wikipedia) - Forums, discussion boards and groups - Podcasting - Instant messaging - Online multiplayer gaming platforms (e.g., World of Warcraft). 	
<p>Social Media Policy</p>	
<ul style="list-style-type: none"> - Social media should not be used by volunteers for work/volunteer duties without prior approval from [Insert health service name here] - Volunteers who use social media for personal purposes must not publicly disclose information about the [Insert health service name here] that may intentionally or unintentionally disclose confidential information or adversely affect the public image or reputation of [Insert health service name here] - The expression of personal opinions must not be in any way associated with the [Insert health service name here] name - Photographs, videos or images of patients, families, visitors or staff in their professional capacity are not to be used on social media or personal internet sites - Volunteers should never imply that they are speaking on the hospitals' behalf unless authorised to do so 	
<p>Personal Use of Social Media</p>	
<p>This policy does not intend to limit or discourage the use of social media in your personal life, however you must be aware that you are personally responsible for the content that you publish on social media. When in doubt, you should seek guidance from [Insert relevant contact details here].</p>	
<p>Where you can be identified as a volunteer at [Insert health service name here], you must:</p> <ul style="list-style-type: none"> - Only disclose and discuss publicly available information - Expressly state on all postings that the stated views are your own and not those of [Insert health service name here] 	

- Adhere to the Terms of Use of the relevant social media website
- Be polite and respectful to all people you interact with.

You must not:

- Post material that is offensive, obscene, defamatory, threatening, harassing, bullying, discriminatory, hateful, racist, sexist, infringes copyright, constitutes contempt of court, breaches a Court suppression order, or is otherwise unlawful
- Imply that you are authorised to speak as a representative of [Insert health service name here]
- Give the impression that the views you express are those of [Insert health service name here]
- Use or disclose any information obtained in your role as a volunteer, especially when the information is confidential
- Post material that is, or might be construed as, threatening, harassing, bullying or discriminatory towards another volunteer or employee of [Insert health service name here].

Interaction with patients and/or family members

Patients and/or their families may wish to connect with a volunteer via social media. Volunteers should not form social relationships with patients or their family members in the workplace or outside of the hospital.

Source: The Royal Children's Hospital. *Social Media Policy*. Retrieved 13 March 2013, from http://ww2.rch.org.au/policy_rch/?doc_id=15400

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- The Chair and members of the **Children’s Cancer Centres’ Parent Advisory Group** (The Royal Children’s Hospital and Monash Health) for generously providing feedback from the consumer perspective. The Parent Advisory Group has allowed the PICS and ANZCHOG to include the Tip Sheets in the Toolkit and worked to ensure that all other material is relevant and helpful to health services engaging with consumers. The Parent Advisory Group continues to illuminate the experiences of families and provides both the PICS and the health services with rich feedback demonstrating the merit of consumer engagement and contribution.
- **Rebecca Edwards** (Consumer Participation Coordinator, Monash Health) who reviewed the toolkit and provided valuable insight into consumer participation and additional resources.
- **Scott Swanwick** (Manager of Consumer Participation and Quality Improvement Manager, The Royal Children’s Hospital Melbourne) who generously provided valuable information about consumer engagement in health services.



Supporting People with Cancer Project Steering Group Members			
	Name, Title	Organisation	Project/Steering Group Role
Project Team	Jane Williamson, Program Manager	Paediatric Integrated Cancer Service	Chair (Project Sponsor)
	Amy Shelly, Strategic Planning Coordinator	Paediatric Integrated Cancer Service	Project Manager
	Alice Hill, Project Officer	Paediatric Integrated Cancer Service	Project Officer
Health Service / ANZCHOG Representatives	Janelle Jones, Project Officer	Australian and New Zealand Childrens Haematology/Oncology Group	National health service facilitation and representation
	Mary McGowan, Community Liaison Manager	The Royal Children's Hospital, Children's Cancer Centre	The Royal Children's Hospital representative
	Helen Stewart, Social Work Team Leader	The Royal Children's Hospital, Children's Cancer Centre	Psychosocial representative
	Sharon De Graves, Nurse Unit Manager	Monash Health, Children's Cancer Centre	Monash Health representative
Consumer Representatives	Carolyn Blakemore, Consumer Member	ANZCHOG Consumer Group	ANZCHOG Consumer Group representative
	Anne Kay, Chair	Children's Cancer Centres' Parent Advisory Group	Parent Advisory Group representative
	Tanya Sanders, Consumer	Consumer (regional)	Regional consumer representative
	Brigitte Walker, Consumer Member	Children's Cancer Centres' Parent Advisory Group	Parent Advisory Group representative

Section 3

Additional information: resource list



3.1 Additional information: resource list

Australian Charter of Healthcare Rights

- [The Australian Charter of Healthcare Rights in Victoria](#). Victoria: Victorian Government and the Australian Commission on Safety and Quality in Healthcare, 2011.

Consumer Participation

- [Consumer Involvement Toolkit](#). Canberra: Cancer Australia, 2013
The Consumer Involvement Toolkit by Cancer Australia presents a framework designed to facilitate consistent approaches to consumer engagement. The framework consists of 4 elements which describe the responsibility and accountability of organisations, consumers and groups. The 4 elements are: 'Committed Organisations', 'Capable Consumers', 'Shared Focus' and 'Inclusive Groups'. The elements are connected and interdependent. All are necessary for quality and sustainable consumer engagement. Documents offering guidance to CEOs and Executives, Service Managers, Health Professionals, Researchers, Policy Makers and Consumers are available on the website.
- [Consumer Participation Toolkit](#). Victoria: Integrated Cancer Services Consumer Participation Network, 2012.
- [Consumer participation in health: Understanding consumers as social participants: ISP Seminar Series](#). Victoria: La Trobe University and Health Issues Centre, 2011.
- [National Framework for Consumer Involvement in Cancer Control](#). Cancer Australia and Cancer Voices Australia. Canberra: Cancer Australia, 2011.
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- [The evidence supporting consumer participation in health](#). Consumer Focus Collaboration, 2001.
- [Improving Health Services through Consumer Participation: A Resource Guide for Organisations](#). South Australia: Department of Public Health, Flinders University and the South Australian Community Health Research Unit, 2000.
- http://www.monashhealth.org/icms_docs/6175_consumer_participation_in_evaluation_PIE_guide_and_matrix.pdf A Guide to Supporting Consumer Participation in Evaluation. Monash Health Centre for Clinical Excellence.

National Safety and Quality Health Service Standards

- [National Safety and Quality Health Service Standards](#). Sydney: Australian Commission on Safety and Quality in Healthcare, 2012.
- [Partnering with Consumers: Standard 2](#) (National Safety and Quality Health Service Standards Fact Sheet). Sydney: Australian Commission on Safety and Quality in Healthcare, 2012.
- [Standard 2- Partnering with Consumers: Safety and Quality Improvement Guide](#). Sydney: Australia Commission on Safety and Quality in Healthcare, 2012





**Paediatric Integrated
Cancer Service**

A statewide cancer service for children

**The Victorian Paediatric
Integrated Cancer Service**

Administrative Host:

The Royal Children's Hospital Melbourne
50 Flemington Road Parkville
Victoria 3052 Australia

Telephone 03 9345 4433

Email paediatric.ics@rch.org.au
www.pics.org.au



This Toolkit will support health services to work towards 'Standard 2: Partnering with Consumers' of the National Safety and Quality Health Service Standards.



**Australian Government
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