Consumer representative handbook

Information, ideas and suggestions to support your participation as a consumer representative

First edition

July 2015
The Paediatric Integrated Cancer Service would like to thank the staff at the partnering health services, specifically the Children’s Cancer Centres at The Royal Children’s Hospital and Monash Children’s Hospital, for their involvement in the development of this consumer representative handbook.

The PICS would also like to thank the chair and members of the PICS Consumer and Community Advisory Committee (C&CAC) and the Children’s Cancer Centres Parents Advisory Group (CCC PAG) at The Royal Children’s Hospital and Monash Children’s Hospital for their invaluable contribution from a consumer perspective.
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The Paediatric Integrated Cancer Service would like to acknowledge the following resources that were consulted in the development of this consumer representative handbook:

- Consumer Involvement Toolkit. Canberra: Cancer Australia, 2013 <consumerinvolvement.canceraustralia.gov.au>
- Consumer Health Forum of Australia, 2011 <www.chf.org.au>
- The Health Issues Centre, 2015 <www.healthissuescentre.org.au>
- The Royal Children’s Hospital, 2015 <www.rch.org.au>
- Volunteering Victoria, 2015 <www.volunteeringvictoria.org.au>
Welcome

As a family member of a child or adolescent who has experienced cancer, we value your participation and gratefully acknowledge the contribution you will make to improve services for children and adolescents with cancer in Victoria.

This handbook has been developed by the Paediatric Integrated Cancer Service (PICS) to support you in your role as a consumer representative in health. This handbook will provide you with some essential information about being a consumer representative, advice for getting started, guidelines for when you are in the role and general information about the PICS and partnering health services.

We ask that you read this handbook carefully, and refer to it whenever questions arise. However, we also encourage you to talk with the consumer coordinator at your health service if you have any further questions about the content of this handbook.

Thank you for giving your time and sharing your experiences to help other children, adolescents and families affected by childhood cancer.

We hope you find your participation to be a positive and rewarding experience.

Best wishes,

Jane Williamson
Program Manager
Paediatric Integrated Cancer Service
Being a consumer representative in health

While there are many ways you can become involved as a consumer representative in health, the following provides a general explanation of the role of a consumer representative and why consumer participation is important.

What is a consumer representative?

A consumer representative is a person who voices consumer or community perspectives to governments, professional bodies or organisations, such as hospitals and often contributes to decisions made on behalf of patients, carers and their families to ensure that the consumer perspective is considered. It is important to note that a consumer representative may also be known as a ‘consumer advisor’ or ‘consumer volunteer’ depending on the level of service and health organisation in which they are involved. For the purpose of this handbook, the term ‘consumer representative’ refers to any role consumers may have within the health system.

What is the role of a consumer representative?

Consumer representatives provide unique perspectives that complement the different perspectives of health services. The role of a consumer representative in health is to:

- promote the interests of consumers, including current and future patients and their families
- communicate how consumers may think and feel about certain issues
- share their experience as a consumer of healthcare services
- ensure health services recognise consumer concerns
- share the activities of health services with other consumers
- ensure the accountability of health services to consumers
- provide information about issues that affect consumers
- reflect a community or population specific perspective.

Why do we need consumer participation?

Consumer participation in health service decision making results in positive health outcomes for patients and their families\(^1\). In particular, the involvement of consumers in cancer services across Australia has had a significant impact on several aspects of cancer care such as:

- improving the quality and safety of cancer services
- promoting the accountability and transparency of cancer services
- ensuring that cancer services are more responsive to consumer needs and issues
- providing new sources of feedback and solutions to improve cancer services\(^1\).

Consumers share an essential and unique perspective on health services and can contribute to improved decision making by providing a balanced view to those held by healthcare professionals and health service managers.

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What are the benefits for me?

There are many benefits to becoming a consumer representative. As a consumer representative you will:

- help to deliver a better experience for children with cancer and their families
- have the opportunity to positively influence health outcomes for your child and children in the future
- gain skills, knowledge and personal satisfaction from positively contributing to change
- engage with other consumer networks and the broader community.

You may be motivated to become a consumer representative for many reasons including the opportunity to ‘give back’ to the health services that helped you and your child, the potential to improve cancer services for children or to ensure that a negative experience you may have had in your child’s journey is not repeated for other children and their families.

What experience, knowledge and skills do I have to be a consumer representative?

As the family member of a child with cancer, you have significant experience, knowledge and skills that will allow you to contribute as a consumer representative. Your experience has connected you with healthcare professionals, children’s cancer services and cancer support groups. You have also accumulated significant knowledge around how paediatric cancer services are delivered and how children and their families access these services. This knowledge has provided you with the skills to navigate the health system and to identify the supports that other children and families may need.

You may have experienced some of the following and are able to offer comments or advice about how health services could improve:

- the experience of when a diagnosis of childhood cancer is made
- the in-patient experience (for example, receiving treatment, chemotherapy, radiotherapy or surgery)
- the way you and your child were treated
- communication, teamwork and coordination of care in the hospital or between hospitals
- the range of services available and your ability to access them
- symptom management, palliative care and end-of-life decision making
- supportive care, follow-up care and survivorship
- hospital facilities (for example, equipment or food choices)
- involvement in a clinical trial or other research project.
How do I further develop my knowledge, skills and experience?

There are several ways you can further develop the knowledge and skills that will help you to contribute as a consumer representative, such as undertaking consumer training. The PICS is committed to supporting you in your role as a consumer representative with training and in-hospital opportunities where necessary. You may also wish to:

- develop a better understanding of the Australian healthcare system
- have regular briefings and de-briefings before or after consumer activities
- receive mentoring from other consumer representatives
- learn more about self-care strategies (see page 37).

If you would like further assistance with developing your knowledge and skills as a consumer representative, please feel free to discuss this with your consumer coordinator at the health service where you are volunteering.

What can I expect as a consumer representative?

As a consumer representative, you can expect to be considered as part of the team and to have your views heard and considered. You can expect to be respected for the knowledge and skills you contribute and the experiences you share.

You can expect the following from the health service at which you are volunteering:

- orientation to and information about the health service or organisation
- information (including a member list) about the group or committee you will be attending
- preparation and any background information you may need to understand the context of issues to be discussed
- an introduction to staff and other consumer representatives
- an explanation of unclear terms and health-related jargon
- information to help you prepare for your role, such as pre-reading for meetings and receiving a meeting agenda within a reasonable timeframe
- preparation before and/or de-briefing after activities or meetings, when requested
- printing and postal delivery of hard copies of long documents, when requested
- reimbursement for reasonable out-of-pocket expenses incurred when undertaking consumer activities or as negotiated.

You are not expected to be knowledgeable about everything being discussed at activities or meetings.
What are my rights and responsibilities?

As a consumer representative you will have the right to:

- be informed about the activity you have agreed to participate in
- be supported in the activity you have agreed to participate in
- have a healthy and safe working environment
- an orientation or induction session
- be provided with sufficient training and mentoring
- information about the organisation you are working for, including policies and procedures
- decline to participate in any activity if you feel uncomfortable
- be informed and consulted on matters that affect you and your participation
- know to whom you are accountable
- have your personal information kept confidential
- be reimbursed reasonable out-of-pocket expenses.

As a consumer representative you will be required to:

- respect confidentiality and privacy
- be punctual, accountable and reliable for any activity you are involved in
- undertake the activity responsibly and ethically
- be committed to the activity
- undertake training as necessary
- ask for support when needed or required
- value, respect and support other consumer representatives, patients, families and staff members.
What can I be involved in as a consumer representative?

As a consumer representative, you will have many opportunities to become involved depending on your knowledge, skills, experience, area of interest and the time you are able to commit. Furthermore, your involvement will also depend on the current improvement activities or projects being undertaken by the health services that require or may benefit from consumer participation. Your involvement as a consumer representation may be formal such as becoming a member of a committee or informal by completing online surveys. Some of the ways you may be involved as a consumer representative include:

- participating in focus groups or in-depth interviews
- contributing to working groups or patient forums
- reviewing educational resources, publications or documents
- organising and participating in patient information events
- participating in research activities
- becoming a member of a committee
- sharing your experiences for education and training programs
- assisting with service planning, development and evaluation.

Should I become a consumer representative?

It is important for your satisfaction in the role that you clearly understand your motivation for becoming a consumer representative, as well as your needs and expectations of the organisation in which you will be involved. Carefully considering the way you want to become involved will also ensure you have a positive experience.

If you are unsure if you would like to become a consumer representative, you may find completing the Checklist for getting involved on page 33 helpful in making your decision, or alternatively you can discuss any concerns you may have with your consumer coordinator.
Getting started

How we work...

In the paediatric cancer community, you may be involved as a consumer representative with one or more of the following groups.

**The Paediatric Integrated Cancer Service**

Consumer representatives with the Paediatric Integrated Cancer Service (PICS) are involved in a variety of activities from participating in focus groups to reviewing patient resources or publications. The PICS also has consumer representatives on the PICS Consumer and Community Advisory Committee (C&CAC). This committee aims to address state-wide issues and priorities identified by the partnering health services and wider paediatric cancer community. There is a strong link (shown below) between the PICS C&CAC, the Parents Advisory Group (PAG) and the Children’s Cancer Centres at both The Royal Children’s Hospital and Monash Children’s Hospital. The PAG chairperson regularly reports local issues to the PICS C&CAC that could be addressed at the state-wide level.
The Victorian Paediatric Oncology Consumer Registry

The Victorian Paediatric Oncology Consumer Registry is coordinated by the PICS. By joining the registry, consumers will receive information about upcoming events, resources that are available and opportunities to provide consumer feedback. A copy of the registry form will be provided in addition to this handbook or can be found online at <www.pics.org.au/registry>.

Parents Advisory Group at the Children’s Cancer Centre, The Royal Children’s Hospital

Consumers volunteering with the Children’s Cancer Centre at The Royal Children’s Hospital are primarily involved in the Children’s Cancer Centre Parents Advisory Group (CCCPAG). The CCCPAG aims to continually improve the care provided to all children and adolescents receiving treatment for cancer or haematological diseases at the Children’s Cancer Centre. For more information, please visit <www.rch.org.au/ccc/pag>.

Consumer participation at the Children’s Cancer Centre, Monash Children’s Hospital

Consumers may also volunteer with the Children’s Cancer Centre at the Monash Children’s Hospital. Similarly, consumer participation at the Children’s Cancer Centre at Monash Children’s Hospital aims to continually improve the care provided to all children and adolescents receiving treatment for cancer or haematological diseases at the Children’s Cancer Centre at the Monash Children’s Hospital. For more information, please contact the Family and Community Resource Liaison at the Children’s Cancer Centre on (03) 9594 7660.

Consumer participation at The Royal Children’s Hospital

Consumers may also be involved more broadly at The Royal Children’s Hospital. There are many different ways that patients, their families and interested members of the community can contribute to high-quality healthcare at The Royal Children’s Hospital. To register your interest in becoming involved, complete the online form at <www.rch.org.au/quality/getinvolved.cfm>. For more information, please contact the Quality Unit at The Royal Children’s Hospital on (03) 9345 4892 or visit <www.rch.org.au/quality>.

Consumer participation at Monash Health

Consumers may also be involved more broadly at Monash Health. Monash Health recognises that involving consumer, carers and community members at all levels of the organisation is important for providing optimal, effective and quality treatment and care to the community. To register your interest in becoming involved, complete the online form at <www.monashhealth.org/page/consumer_participation>. For more information, please contact the Consumer Participation Coordinator at Monash Health on (03) 9594 6230 or email <consumerparticipation@monashhealth.org>.

Consumer participation at Peter MacCallum Cancer Centre

Peter MacCallum Cancer Centre’s consumer register consists of individuals who are interested in providing a consumer perspective by participating in a range of improvement activities across the organisation. Consumers may be past or present patients, carers, family members or representatives of other community groups. Once joining Peter Mac’s consumer register, consumers are able to participate in a number of ways, such as becoming a member of the Community Advisory Committee or other strategic and operational committees, participating in working groups or cancer-specific projects, or sharing their views and experiences by participating in interviews and surveys. For more information, please contact the Consumer Engagement and Liaison Officer at Peter Mac on (03) 9656 1561 or email <commparticipation@petermac.org>.
Required checks

Consumer representatives who participate in activities that involve contact with children and their families, or that are undertaken at the hospitals, are required to undertake a National Police Record Check and Working with Children Check prior to commencing.

National Police Record Check

To obtain the National Police Record Check, complete and return the Consent to Check and Release National Police Record form provided in addition to this handbook. The cost associated with obtaining a National Police Record Check will be covered by the PICS or the health service depending on where your activities will take place. When you receive your National Police Record Check, please present a copy to your consumer coordinator. Existing National Police Record Checks may be used; however, they must have been issued within the past three months. The Consent to Check and Release National Police Record form can also be accessed online at <www.police.vic.gov.au/content.asp?Document_ID=274>.

Please be aware that information is released by the Information Management Department at Victoria Police to your consumer coordinator only. This information is regarded as strictly confidential and no electronic or manual record of the results are retained. For further information, please contact Victoria Police on (03) 9247 6666 or visit <www.police.vic.gov.au>.

Working with Children Check

Consumer representatives who participate in child-related work are required by law to obtain a Working with Children Check. There is no fee for consumer representatives to obtain a Working with Children Check (because you are volunteering). You can complete the Working with Children Check application form online at <www.workingwithchildren.vic.gov.au/home/applications>.

Once you have completed the online application form, finalise your application by presenting the Application Summary, proof of identity documents and a passport-quality photo at a participating Australia Post retail outlet. Once you receive your Working with Children card, present you card to your consumer coordinator. If you already have a Working with Children card, please ensure you register the PICS, The Royal Children’s Hospital, Monash Health or Peter MacCallum Cancer Centre as an additional organisation, and provide your consumer coordinator with evidence that you have completed this process. You can register additional organisations online at <www.workingwithchildren.vic.gov.au/home/cardholders/update+your+details>.

Please be aware that applicants and holders of a Working with Children card have continuing obligations regarding the disclosure of certain information, including change of personal details. For further information, please contact the Working with Children Check Unit at the Department of Justice Victoria on 1300 652 879 or visit <www.workingwithchildren.vic.gov.au>.
Training

Consumer representatives will be offered training opportunities. Training sessions may be either tailored sessions or general sessions. Tailored training sessions will cover content specifically developed to meet the needs of consumer representatives, or provide consumer representatives with the special skills to undertake a particular activity. The PICS will facilitate tailored training sessions each year. Topics covered during tailored training sessions may include:

- communication skills
- effective storytelling
- presentation and public speaking
- participating effectively on committees
- consumer leadership.

If you would like training on any topics other than those listed above, please complete the *Training needs assessment* on page 35 and discuss with your consumer coordinator.

General training sessions can be undertaken with the Health Issues Centre. The Health Issues Centre helps consumer representatives and health services to partner for improvements in healthcare and provides general training sessions to consumer representatives. To participate in this training free of charge, consumer representatives are required to become a Consumer Step Up (CSU) member. There is no fee associated with becoming a CSU member. A calendar of Health Issues Centre training sessions for the year will be provided in addition to this handbook. For further information, please contact the Health Issues Centre on (03) 9664 9343 or visit <www.healthissuescentre.org.au>.

Volunteering and orientation

Consumer representatives who are required to attend the hospital to undertake their activities may be required to register with the hospital volunteer database. You may also be able to attend training and orientation specific to the hospital which will provide you with an understanding of the health service at a local organisational level and what consumer participation in this environment looks like in practice. Your consumer coordinator will provide you with more information about how to register for the volunteer database and training and orientation opportunities.
Once you have started...

Personal details

Please advise your consumer coordinator of any change of name, address, phone number, availability or areas of interest as soon as possible.

Preparing to participate in an activity

Your consumer coordinator will endeavour to provide you with any necessary documentation within an appropriate timeframe; however, if you feel you are not given sufficient time, please share this feedback.

If you are unable to attend an activity

If you are unable to attend an arranged activity for any reason, please advise the activity representative or your consumer coordinator as soon as possible. If you are unable to attend a long-term activity that you participate in on a regular basis, any relevant information can be forwarded to you so that you may continue to contribute to the activity.

If you would like to take a break

If you would like to take a break from your role as a consumer representative or your participation in a regular activity for any reason, please advise your consumer coordinator as soon as possible.

Withdrawing from an activity

If you wish to withdraw from a scheduled activity for any reason, please advise the activity representative or your consumer coordinator as soon as possible.

Resignation

If you wish to resign from your role as a consumer representative, you may do so at any time by telephone, email or letter to your consumer coordinator.
Grievances and concerns

Any grievances you have that relate to your experience as a consumer representative should be raised with your activity representative or consumer coordinator as soon as possible after the issue has arisen. If your grievance is with another person, your activity or consumer coordinator may organise a discussion between your and the other person. This discussion will usually be informal; however, you may request written statements or agreements. If the grievance cannot be resolved satisfactorily, there are other avenues to pursue, such as speaking with the manager of the area or the director of the Children’s Cancer Centre. If your grievance or concern is about the care provided by the health service you can also discuss this with the Consumer Liaison Officer at the health service.

| For the Consumer Liaison Officer at The Royal Children’s Hospital, phone 9345 5676 |
| For the Consumer Liaison Officer at Monash Children’s Hospital, phone 9594 2702 |
| For the Consumer Liaison Officer at Peter MacCallum Cancer Centre, phone 9656 1561 |

Out-of-pocket expenses

Consumer representatives will be reimbursed reasonable out-of-pocket expenses incurred as a result of participating in an activity. Please remember to retain any relevant receipts. Agreement to be reimbursed for out-of-pocket expenses should be sought before the expense is incurred. A copy of the Consumer Reimbursement Schedule and Consumer Reimbursement Form can be obtained from your consumer coordinator. If you have any questions about out-of-pocket expenses, please discuss these with your consumer coordinator directly.
General guidelines for consumer representatives

Confidentiality and privacy

As a consumer representative you may have access to confidential information, data and materials about the PICS and partnering health services, patients, families, staff members and other consumers. Consumer representatives are asked not to discuss any confidential information with any person internal or external to the PICS and partnering health services, except in the course of your activities. Any confidential information provided to unauthorised individuals or organisations will lead to dismissal. You may be required to sign a privacy and confidentiality agreement with the health service at which you are volunteering. If this is required, your consumer coordinator will provide you with more information.

Conflict of interest

Consumer representatives are expected to declare any conflict of interest. A conflict of interest is where your actions, opinions or decisions while participating in activities with the PICS or partnering health services may be influenced or perceived to be influenced by your own personal interests, financial or otherwise. Consumer representatives should be aware that declaring a conflict of interest will not necessarily restrict your involvement in activities but will allow the PICS and partnering health services to manage these conflicts appropriately.

Emergency and fire procedures

Consumer representatives will attend the health services with different levels of understanding of emergency and fire procedures. Any consumer representative who discovers an emergency should notify a staff member or if no staff members are available, should follow the ‘RACE’ approach outlined in the box below.

<table>
<thead>
<tr>
<th>Remove</th>
<th>Look after your own safety first and move anyone in immediate danger to a safe area if it is safe to do so.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alert</td>
<td>Alert your activity coordinator or other staff member, who will call the health service emergency number.</td>
</tr>
<tr>
<td></td>
<td>In an emergency at The Royal Children’s Hospital, phone 777.</td>
</tr>
<tr>
<td></td>
<td>In an emergency at Monash Children’s Hospital, phone 999.</td>
</tr>
<tr>
<td></td>
<td>In an emergency at Peter MacCallum Cancer Centre, phone 3333.</td>
</tr>
<tr>
<td>Contain</td>
<td>Attempt to contain the fire, spill or leak if it is safe to do so.</td>
</tr>
<tr>
<td>Evacuate</td>
<td>Move to a safe area if you are in immediate danger or await instructions from a staff member.</td>
</tr>
</tbody>
</table>
As consumer representative, you should follow the procedures and instructions given by staff members in an emergency situation at all times. Some examples of an emergency include accidents or medical emergencies, personal threats or aggression, fire or suspicion of fire (for example, smoke), flooding, a hazardous material spill or leak and a utility failure (for example, power, medical gases, water or sewage).

Most health services classify different types of emergencies according to colour codes so that they may be easily identified. The following is an example of these classifications; however, please be aware of the codes specific to the health service where you are volunteering.

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Red</td>
<td>Fire or smoke</td>
</tr>
<tr>
<td>Orange</td>
<td>Evacuation</td>
</tr>
<tr>
<td>Black</td>
<td>Armed confrontation</td>
</tr>
<tr>
<td>Grey</td>
<td>Unarmed confrontation</td>
</tr>
<tr>
<td>Purple</td>
<td>Bomb threat</td>
</tr>
<tr>
<td>Brown</td>
<td>External emergency</td>
</tr>
<tr>
<td>Yellow</td>
<td>Internal emergency</td>
</tr>
<tr>
<td>Blue</td>
<td>Medical emergency</td>
</tr>
<tr>
<td>MET Call</td>
<td>Medical emergency</td>
</tr>
</tbody>
</table>

### Food handling

Consumer representatives who prepare food in their activities have a responsibility to make sure they do not make food unsafe or unsuitable for people to eat. Food poisoning is a serious health problem and can be prevented by:

- maintaining good personal hygiene, such as thoroughly washing and drying your hands when handling food
- avoiding cross-contamination, such as keeping raw foods and ready-to-eat foods separate and using separate, clean utensils, containers and equipment
- cooking foods thoroughly – making sure foods such as meats and poultry are cooked until their core temperature reaches 75°C
- keeping chilled foods cold at 5°C or colder and hot foods at 60°C or hotter
- avoiding spoiled foods, foods past their use-by dates or food in damaged containers or packaging
- throwing out any food that could be unsafe – ‘when in doubt, throw it out’.

A copy of *Your Guide to Food Safety* will be provided in addition to this handbook.

Infection control

Handwashing is the most important measure to prevent the transmission of infection.

Healthcare-associated infections are infections that occur as a result of healthcare interventions. Everyone, including patients, families, consumers and staff members, have a role in preventing and controlling healthcare-associated infections. A routine handwash involves cleaning your hands carefully with soap and water and drying your hands thoroughly with a clean, dry towel. Alternatively, you can clean your hands by using an alcohol-based hand rub for 20 seconds. You should wash your hands:

- before touching or eating food
- after touching your eyes, nose or mouth
- before visiting a patient
- after you have gone to the bathroom/toilet
- after sneezing, coughing or disposing of tissues
- after handling dirty clothes, linen or garbage
- after visiting a patient.

Consumers are also encouraged to complete the Hand Hygiene Australia online learning package for non-clinical staff available at <www.hha.org.au/LearningPackage/nonclinicalpackage.aspx>.

For consumer representatives who are required to attend the hospital, there are a number of other ways you can help to reduce the risk of infection:

- Cover your mouth and nose with a tissue when you cough or sneeze (or into your hand if you don’t have a tissue), and clean your hands afterwards.
- Do not visit patients if you feel unwell or have a cold, have been vomiting or had diarrhoea.
- Avoid too many visitors in a patient’s room at one time.
- Avoid touching dressings, drips or other equipment in the hospital.
- Wash your hands each time you enter or leave a patient space.

Insurance and liability

Consumer representatives who are required to attend the hospital will be covered for personal accident and public liability insurance under the relevant hospital policy. If you would like more information about insurance and liability, please speak with your consumer coordinator directly.

Media

Any requests from the media must be referred to your consumer coordinator at all times. Consumer representatives with the PICS and partnering health services are not permitted to make any statement to the media concerning the PICS and partnering health services, or the patients and families who receive their services. Under no circumstances may any statement be made to the print, online, radio or television media.
Social media

All consumer representatives are expected to communicate on social media appropriately, professionally and respectfully when referring to the PICS or partnering health services. Consumer representatives must not post material that threatens, insults or ridicules any person or groups based on their race, religion, gender, disability or other characteristics. Consumer representatives are encouraged to ensure that online content and conduct reflects their professionalism, especially when identifying themselves as a consumer representative. Remember that you are responsible for what you publish in any form of social media. If you are unsure if posting any material that refers to the PICS or partnering health services is appropriate, please contact your consumer coordinator.

Photos and videos

Photos or video images of patients, families, staff members or the hospital environment taken for any purpose are not permitted without prior approval obtained through the consumer coordinator and the communications and media departments of The Royal Children’s Hospital, Monash Health or Peter MacCallum Cancer Centre.

Occupational health and safety

As a consumer representative you have the right to feel safe while undertaking activities. The PICS and partnering health services are committed to ensuring the health, safety and wellbeing of consumers, patients, families and staff members, so far as is reasonably practicable, by minimising the risk of accidents, injury or illness. All consumer representatives have the following responsibilities, authority and accountability for health and safety:

- Be careful when undertaking activities so that you don’t accidentally injure yourself, patients, visitors or staff members.
- Take reasonable care to ensure that you don’t affect the health and safety of others through your actions or inaction.
- Follow the instructions, policies and training provided by those in supervisory positions.
- Report all accidents, injuries, near misses and unsafe conditions you encounter while undertaking activities to your consumer coordinator.
- Do not undertake activities while under the influence of alcohol or illicit drugs.

Reporting incidents, accidents and safety issues

All accidents involving consumer representatives, patients, visitors and staff members that occur while you are participating in consumer activities, irrespective of how minor, must be reported immediately to your consumer coordinator. The time, date, location and all relevant details of the incident, accident or safety issue are needed so that an incident report can be completed. A submitted incident report will allow for further investigation and action if necessary.

Should the incident or accident result in the need for medical attention, please ensure you obtain a medical certificate that clearly states the injury was sustained while undertaking your role as a consumer representative. If you have any concerns regarding the personal or environmental safety of yourself or others, please report these issues to the consumer coordinator immediately.
Patient contact

Consumer representatives are expected to abide by the following guidelines if their activities involve contact with patients and their families. Consumer representatives should:

- maintain a high level of professionalism at all times
- refrain from offering advice or purchasing medications for patients and families
- refrain from discussing treatment options or providing explanations about treatment, diagnosis or cancer
- where patients and/or families disclose to you any concerns or complaints, encourage patients and families to discuss these concerns with the health service
- avoid becoming ‘friends’ with patients and their families on social media.

Personal challenges

Remember – you are a volunteer and your family comes first!

Becoming a consumer representative is an exciting and positive experience, and consumer representatives usually gain a great deal from their working relationship with health services. Nevertheless, at the beginning, consumer representatives should acknowledge that active participation may be demanding and tiring. It is important that consumer representatives review their individual capability to be able to perform their new role and to not feel frustrated by the demands of the role or if they need to take a break for a while.

It can be challenging to attend activities, read long documents, provide comprehensive feedback and commit time on a regular basis if you or your child are unwell, or life is just busy. However, please remember the PICS and partnering health services value your contribution, even when you cannot contribute consistently.

For some consumer activities there may be pre-reading or other tasks that will help you to contribute fully. If you find these tasks overwhelming, let your activity or consumer coordinator know so they may help you to find a solution.

Healthcare is a complex environment and, as a result, change does not generally happen immediately. Consumer representatives may find the rate of change to be challenging and may have to alter their thinking to focus on the ‘long-term’ plan of improving health services.

Policies and procedures

Health services have many policies and procedures that govern how they operate. If any of these policies or procedures apply to you in your role as a consumer representative, your consumer coordinator will let you know and will provide you with copies of any relevant documents.

Professional boundaries

The PICS and partnering health services aim to ensure that all consumer representatives, patients, families and staff members have positive, safe and empowering relationships free from confusion, uncertainty and exploitation. In order to achieve this, consumer representatives are expected to maintain emotional and professional boundaries when participating in activities. In your role as a consumer representative, maintaining boundaries is important to prevent over involvement, emotional distress and burnout, and to encourage independence rather than dependence for patients and their families.
Respectful behaviour

Consumer representatives have a responsibility to show respect and consideration for those with whom they meet, and can expect the same in return. The PICS and partnering health services are committed to providing an environment that is free from behaviour that amounts to discrimination, harassment, bullying, victimisation, vilification or occupational violence for all consumer representatives, patients, families and staff members. If you are subjected to any of these behaviours, please contact your consumer coordinator, who will address your concerns promptly and confidentially.

Self-care

Self-care is a highly relevant issue for consumer representatives. From time to time you may find the role overwhelming, and this may affect your ability to undertake activities. Some consumer representatives take on many activities as the requests for their voice increases, which may become tiring or a burden. Alternatively, some consumers may find their involvement triggers memories and emotions that are distressing. As a consumer representative, knowing how to take care of yourself, both physically and emotionally, and knowing how to limit your contribution to a safe level, will aid in managing the stress that may be associated with the role.

Smoke-free environment

The building and grounds of The Royal Children’s Hospital, Monash Children’s Hospital and Peter MacCallum Cancer Centre are strictly non-smoking. Cigarette smoke can enter the hospital building through doorways and air-intake vents. To protect the health of sick children, the buildings and grounds must remain a strictly smoke-free environment. If you wish to smoke at The Royal Children’s Hospital, you must leave the hospital grounds and move to an adjacent area in the parklands. If you wish to smoke at the Monash Children’s Hospital, you must leave the Monash Health site as there are no designated smoking areas on site. Smoking is not permitted within or adjacent to any Peter MacCallum Cancer Centre facility.
Paediatric Integrated Cancer Service

About us

The Paediatric Integrated Cancer Service (PICS) was established as a part of the Victorian Government’s cancer reform strategy. Partnering with The Royal Children’s Hospital, Monash Health, Peter MacCallum Cancer Centre and regional health services, the PICS aims to improve Victorian paediatric cancer care, working with the paediatric cancer community to establish coordinated services that are consistent, evidence-based and family-centred.

Our vision

The PICS vision is to ensure children and adolescents with cancer receive the best care in the best facility as close to home as possible.

Our governance

The PICS is governed by the PICS Governance Executive Committee (GEC), which is supported by the PICS Clinical Advisory Committee (CAC). The PICS acknowledges the need for consumer engagement and participation, and the GEC and CAC include consumer representation. Furthermore, the PICS has established a state-wide Consumer and Community Advisory Committee (C&CAC).

Contact us

Jane Williamson
Program Manager
Paediatric Integrated Cancer Service
The Royal Children’s Hospital
1st floor, South Building
50 Flemington Road
Parkville Victoria 3052
Phone: (03) 9345 4433
Email: pics.consumer@rch.org.au
Children’s Cancer Centre at The Royal Children’s Hospital

About us

The Royal Children’s Hospital is a specialist paediatric hospital providing a full range of clinical services, tertiary care and health promotion and prevention programs for children and adolescents. The Children’s Cancer Centre at The Royal Children’s Hospital provides complex children’s cancer care and is the only provider of paediatric stem cell transplantation in Victoria. The Children’s Cancer Centre treats 70 per cent of Victoria’s cancer patients under the age of 16.

The vision of the Children’s Cancer Centre at The Royal Children’s Hospital is to:

- improve the outcome for all children with cancer throughout Victoria
- seek to cure children with cancer and enhance their quality of life
- be leaders in improving the treatment and prevention of cancer in children and diminish potential adverse consequences of treatment
- provide excellence in patient care
- have programs encompassing basic biological science, translational and clinical research with the aim of understanding cancer development and prevention
- continue its strong educational program for healthcare and scientific research professionals and share knowledge.

Visiting us

Drop off

There are restricted drop-off and pick-up zones outside the emergency department and in the circular driveway outside the main entrance. These areas are monitored by security staff and you risk a fine if you stay longer than the designated time.

Parking

Car parking is available beneath the hospital in the underground car park. Access is via Entry 1 or Entry 2 on Flemington Road. The car park is open 24 hours a day, seven days a week.

Accessible parking

Parking bays for people with disabilities are located on each level of the car park, and you are required to display your disability parking permit at all times.

Street parking

There is limited short-term, free and metered parking close to the hospital on selected streets in Parkville and North Melbourne, but do be mindful that City of Melbourne parking officers are very vigilant in these areas. Pay particular attention to signage as some areas may be clearways, tow-away zones or permit zones at particular times. For more information, please contact the City of Melbourne on (03) 9658 9658 or visit <www.melbourne.vic.gov.au>.
Public transport

Trams

There is a tram stop right outside the hospital, and trams on routes 55 and 59 run through this stop. Although this tram stop is a ‘super stop’, at this time low-floor trams do not run on these routes. Trams running towards the city stop on the side closest to the hospital, while trams running away from the city stop on the opposite side. Trams on route 57 stop in Abbotsford Street, which intersects with Flemington Road just west of the hospital.

Contact us

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Children’s Cancer Centre at Monash Children’s Hospital

About us

Monash Children’s Hospital at Monash Health is part of Victoria’s largest health service uniquely providing primary, secondary and tertiary health services in one organisation. The Monash Children’s Cancer Centre is an integral part of the new Monash Children’s Hospital and cares for 30 per cent of Victoria’s childhood cancer patients. The centre incorporates purpose-built treatment rooms, medical consulting rooms, a day treatment facility and an innovative facility capable of providing general anaesthesia for minor oncology procedures.

At the Monash Children’s Cancer Centre, an integrated multidisciplinary team of specialist medical, nursing and allied health professionals provide care and services to meet the clinical, physical, social and psychological needs of patients and parents. This multidisciplinary approach aims to maximise the quality of life of patients undergoing cancer treatments and improve their long-term survivorship. The clinical service is supported by a range of sub-specialty paediatric and administrative services.

Visiting us

Drop off

There are restricted drop-off and pick-up zones outside the main entrance. These areas are monitored by security staff, and you risk a fine if you stay longer than the designated time.

Parking

Car parking is available within the hospital grounds and can be accessed from Clayton Road. The car park is attended Monday to Friday from 7am to 9pm.

Accessible parking

Parking bays for people with disabilities are located within the car park, and you are required to display your disability parking permit at all times.

Street parking

There is limited short-term, free and metered parking close to the hospital on selected streets. Parking is also available at the nearby Clayton Railway Station. Pay particular attention to signage as some areas may have parking restrictions at particular times. For more information, please contact the City of Monash on (03) 9518 3555 or visit <www.monash.vic.gov.au>.
Public transport

Trains

The closest station to Monash Children’s Hospital is Clayton Railway Station, running on the Dandenong/Pakenham Line. The hospital is a five-minute walk from the station along Clayton Road.

Buses

Buses 703 (Brighton to Blackburn via Clayton and Monash University), 631 (Southland to Waverley Gardens via Clayton and Monash University), 733 (Oakleigh to Box Hill via Clayton and Monash University) and the 630 ‘SmartBus’ (Elwood to Monash University via Gardenvale, Ormond and Huntingdale) stop on Clayton Road, immediately out the front of Monash Hospital.

Contact us

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Peter MacCallum Cancer Centre

About us

Peter MacCallum Cancer Centre (‘Peter Mac’) is the only site in Victoria offering radiotherapy to children under the age of 16 years and is the largest paediatric radiation centre in Australia. It is a public hospital solely dedicated to cancer treatment, research and care.

The Paediatric, Adolescent and Young Adult Service at Peter Mac includes medical staff, nursing staff, radiation therapists, a social worker, a pastoral care worker, a music therapist and the ONTrac at Peter Mac program. The Peter Mac team work closely with the team at the PICS, The Royal Children’s Hospital and the Monash Children’s Hospital.

Visiting us

Drop off

A patient drop-off area is available at the hospital’s main entrance on St Andrews Place (adjacent to the specialist clinics). This area is monitored by security staff, and you risk a fine if you stay longer than the designated time.

Parking

Limited underground car parking is available at East Melbourne. Patients are asked to limit their stay in the car park to 48 hours by making alternative arrangements for longer stays. The car park entrance is located on Lansdowne Street, near the corner of St Andrews Place. Lifts operate at levels P1 and P3 of the car park. Patients or visitors with accessibility issues should use the car parking bays next to the lifts on CP1 and CP3. Access to the car park from the hospital is available from the lift opposite the main enquiry desk.

Accessible parking

Parking bays for people with disabilities are located within the car park, and you are required to display your disability parking permit at all times.

Street parking

Metered street parking surrounding the hospital is limited to one and two hours, and parking officers regularly patrol the area. At the end of the allocated time period you must move your car to another bay. Simply putting more money in the meter may result in you incurring a fine. Be sure to carefully read the parking signs and not overstay the limit shown on the sign. For more information, please contact the City of Melbourne on (03) 9658 9658 or visit www.melbourne.vic.gov.au.

Public transport

Trains

Parliament Railway Station is a 500-metre walk from Peter Mac. Use the Macarthur Street exit, cross Macarthur Street at the pedestrian lights and walk along St Andrews Place. The entrance to Peter Mac is on the left.
Buses

Bus 402 (Footscray to East Melbourne) terminates at St Vincent’s Hospital. Cross Victoria Parade, walk down Gisborne Street and turn left into St Andrews Place.

Trams

Trams that run along Flinders Street are numbered 70, 71, 75 and 76. Alight at stop 14A, on the corner of Wellington Parade and Lansdowne Street, and walk north along Lansdowne Street. Peter Mac is located on the second corner.

Trams that run along Macarthur and Gisborne streets are numbered 11, 31, 42, 109 and 112. Alight at stop 10 and walk along St Andrews Place.

Tram number 48 runs along Collins Street. Alight at stop 0 and walk along Macarthur Street to St Andrews Place.

The free City Circle Tram runs along Spring Street. Get off at Collins Street and walk along Macarthur Street to St Andrews Place.

Contact us

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Consumer Engagement and Liaison Officer
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Information and resources for consumers
This consumer representative checklist for getting involved may help you determine your motivation and readiness for becoming a consumer representative. If you are considering becoming a consumer representative, you may like to consider the following questions.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tbody>
<tr>
<td>1. Why am I interested in getting involved as a consumer representative?</td>
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<td>2. What do I expect to get out of it?</td>
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<td>3. Have I had sufficient time since my or my child’s cancer experience to be able to work on these issues in an objective way?</td>
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<td>4. What do I want to achieve from my engagement as a consumer representative?</td>
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<tr>
<td>5. What can I bring to this activity? (for example, ideas, information, knowledge, skills and experience)</td>
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<tr>
<td>6. What type of support do I need in my role as a consumer representative?</td>
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<tr>
<td>7. What are the PICS or health service’s expectations of me as a consumer representative?</td>
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<tr>
<td>8. How do I think the PICS or health services will benefit from my involvement as a consumer representative?</td>
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Disclaimer: For education and information only.
Adapted from the Consumer Involvement Toolkit. Cancer Australia. March 2015
Training needs assessment

Completing this assessment will help us ensure you receive the most appropriate training opportunities. Please tick the topics for training that you would find most useful to support you in your role as a consumer representative, and return the checklist to your consumer coordinator.

- Consumer expectations about their role
- Definitions, terminology, policy context, history of consumer participation
- The evidence for consumer participation
- Explaining terminology: ‘consumer representative’, ‘consumer advisor’, ‘consumer perspective’
- Peer support: how to establish and manage a peer support group
- Consumer leadership
- Presentation skills
- Meetings 101 – participation, roles etc.
- Effective storytelling
- Advocacy and types of advocacy
- Consumer representatives on committees
- How the paediatric health system works
- Health information and health literacy
- Human rights in health
- Other (please specify) ........................................................................................................................................................................

Disclaimer: For education and information only.
As a consumer representative you will be working with families of children 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 while 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.

**Learn to recognise possible signs of stress**

**Possible emotional symptoms of stress include:**

- 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 (for example, misuse of alcohol).

**Possible physical symptoms of stress include:**

- changes in sleeping and/or eating patterns
- headaches and muscle tension
- racing heart or sweating with no obvious cause.

**Ideas on ways to respond to stress**

- 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 or role.
- Eat well, exercise regularly and get plenty of sleep.
- Have ‘time out’ doing something that you find relaxing.
- Talk to a health professional if you feel that stress is affecting your health.
- You may be over committing to your role. Scale back your workload if necessary.
Information and resources for consumers

Looking after yourself

- 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.
- At your own pace, talk to friends, family or someone in a similar position to you (for example, 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.

More information

- For relaxation techniques visit <www.beyondblue.org.au/index>.
Confidentiality and privacy

As a volunteer consumer representative you will be working with families of children currently receiving treatment for cancer. In this role, families may share with you private and confidential information about themselves or their child. You may also come into contact with patient medical records and other medical information. All people who come into contact with, or have access to, confidential information have a responsibility to maintain the privacy, confidentiality and security of that information. Listed below are some examples of confidential information and situations where privacy and confidentiality have been breached.

Examples of confidential information

You may come into contact with confidential information such as:

- medical records or financial information about patients and/or their family members
- employment records regarding employees, contractors, volunteers or students in the form of salaries, disciplinary actions or health status
- business information about the health services such as financial records, memos, contracts, computer programs or technology
- operational information about the health services such as quality improvement, quality assurance or peer review activities that are disclosed in reports, presentations or survey results.

Breaches of confidentiality

The following are examples of occasions where privacy and confidentiality has been breached. It is recommended that you also read the confidentiality policies and procedures of the health services at which you are volunteering.

1. Accessing information that you do not need to know to carry out your consumer representative role is not permitted and is a breach of confidentiality. For example:
   - unauthorised reading of a patient’s medical record or an employee file
   - random searching of patient databases for familiar names
   - accessing information on family, friends or co-workers.
2. 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, for example, Facebook or Twitter.

3. Sharing, copying or changing information within proper authorisation. For example:
   - 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.

4. Using another person’s password to access the hospital’s computer systems: For example:
   - using another person’s password to log into the hospital’s computer system
   - unauthorised use of a password to access employee files or patient accounts
   - using another person’s computer after he or she has logged in.
Parents have reported that 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 help consumer representatives start conversations with other parents.

The benefits of parents talking to parents

Parents talking to other parents who may be further ‘down the track’ can be beneficial for the following reasons:

- the opportunity to share experiences, ideas and knowledge
- social interaction when you are spending a lot of time in hospital with your child
- one-to-one 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. It is important to keep in mind, however, that each parent’s journey is unique and each parent is the expert about their own family.

Ideas on how to approach another parent

- Choose an appropriate location – sitting in a comfortable environment is better than having a conversation in passing (for example, in a public corridor).
- Minimise distraction and interruptions during your conversation (for example, turn your mobile phone off).
- Introduce yourself at an appropriate time (for example, 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 hospital.
- Ask if it is a suitable time to have a chat. If the parent doesn’t seem up to talking, offer to return at a more suitable time.
- Be an active listener during conversations (see over).
Starting conversations

How to be an active listener

- 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 (for example, encourage them to continue by nodding ‘yes’ and letting them know that you are listening).
- Acknowledge what you don’t know where appropriate (for example, if asked your opinion on a medical question, acknowledge that this is not within your expertise and suggest the parent speaks with a doctor or 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.
Support versus advice

Consumer representatives are encouraged to offer support to patients and families rather than offering advice on medical issues or telling parents ‘what to do’. This is the role of trained health professionals at the health service, and consumer representatives can encourage parents to discuss their concerns with the health professionals directly.

Offering support to a patient or family may include:

- listening patiently when patients and families want to talk
- helping family members find out which health professional to direct their questions to
- offering to make tea or coffee and sitting with them for a while
- with their permission, relaying feedback from patients and families to the nurse unit manager or consumer liaison officer of the health service.

Guidelines for talking with patients and families

Consumer representatives who are visiting families in the hospital must:

- maintain a high level of professionalism throughout your visit
- refrain from offering advice or purchasing medications for parents
- refuse to accept gifts from families or give gifts to families
- refrain from discussing treatment options or giving any explanations about treatment, diagnosis or cancer
- avoid bringing any unauthorised visitors with them
- inform the hospital or health professional caring for the child if the child or family tell you something is worrying them or has a genuine complaint
- meet the hospital requirements for visitors.
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 or parent is making a complaint or just ‘letting off steam’. This guide has been prepared to assist you with making this distinction.

A complaint versus a criticism

A complaint is a statement that something is unsatisfactory or unacceptable, while a criticism is an expression of disapproval of someone or something on the basis of perceived faults or mistakes. In other words, a complaint is a criticism without personal judgement.

Feedback from patients or parents that is escalated within the health service should be focused on processes and outcomes, rather than on personal opinions. Constructive feedback can be used productively by the health service to change a negative outcome into a positive solution. Consumer complaints are an indicator of the quality of healthcare services and can contribute to strategies that improve clinical care and provide consumer input into the improvement of healthcare delivery.

How health services use complaints

Health services can use complaints from patients and families to improve their services by:

- educating consumer representatives and volunteers about how to respond to complaints from patients and families during the volunteer orientation process
- provide clear guidance on the health service’s complaint escalation policy
- provide a form for consumer representatives and volunteers to complete when they receive feedback from patients and families to ensure that all complaints are documented
- link to the health service consumer advisory consumer advisory committee at the hospital
- link to the health service adverse event processes (for example, Riskman).
Information and resources for consumers

The difference between a complaint and a criticism

Suggestions for escalating a complaint

When working with patients and families to obtain feedback, consumer representatives are likely to encounter a variety of complaints. Some suggestions on how to manage complaints include the following:

- Listen to the patient or family member patiently and allow them enough time to express their concerns. Acknowledge their concerns but avoid offering solutions to the problem.
- Determine if the complaint is:
  - a local health service issue (for example, a complaint about the food on the ward)
  - a personnel issue (for example, a complaint about a specific staff member)
  - a safety issue.
- Before you tell anyone about the complaint, you will need to ask permission from the patient or family member. For example:
  - if the patient or family member 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 given)
  - if the patient or family member does not give you permission to forward their complaint, it is important to explain that their feedback with not be escalated or actioned.
Infection control

Children undergoing treatment for cancer have a lowered immunity and are more susceptible to infection. Any interactions between consumer representatives, staff, patients and their families must comply with hospital infection control guidelines.

Hand hygiene

When you are visiting patients or families in the hospital consumer representatives can maintain good hand hygiene by ensuring that:

- your hands are washed thoroughly with soap and water, or decontaminated with an alcohol rub before entering and upon leaving a patient’s room
- if you have direct physical contact with the patient, your hands are washed before and after contact
- your hands are washed with soap and water before preparing food, after meals and following toilet breaks.

If you would like more information, please visit Hand Hygiene Australia’s website at <www.hha.org.au>.

General health

As a consumer representative, you should not visit the hospital if you are unwell or recovering from any of the following symptoms:

- gastro (you should not visit the hospital until at least 48 hours after symptoms have resolved)
- respiratory illness
- moist cold sores
- unexpected rashes.

Minor illnesses such as cold sores or a runny nose can become a serious infection for a child with cancer. You can call to ask your consumer coordinator or the nurse in charge of the ward if you are unsure of whether you should come to the hospital.
Information and resources for consumers

Infection control

Immunisations

For consumer representatives who are visiting the hospital, it is important that your vaccination status for the following conditions is up to date to protect patients and their families, as well as to protect yourself:

- chickenpox
- measles
- whooping cough (pertussis)
- seasonal flu vaccine.

Entering rooms

Some patients are isolated while they are admitted to hospital due to their illness or infectious state. Sometimes family members, visitors and health professionals need to take extra precautions, such as wearing gowns, gloves or masks, when visiting children on the ward. Please be aware of all signage located outside patients’ rooms on the ward, and enquire with the child’s nurse if you are unsure about entering a room. Remember that 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 any food for patients from home because food must be prepared in accordance with the hospital’s stringent food handling guidelines.
Social media is a well-established platform for communication. Balanced with the many benefits of social media are problems and risks when used in the context of healthcare. The following suggestions outline what may be considered acceptable versus not acceptable for consumer representatives using social media within the health service.

What is social media?

Social media includes:

- social networking sites (for example, Facebook and Instagram)
- photo- and video-sharing sites
- blogs
- micro-blogging (for example, Twitter)
- wikis and online collaborations (for example, Wikipedia)
- forums, discussion boards and group conversations
- podcasting
- instant messaging
- online multiplayer gaming platforms (for example, World of Warcraft).

Guidelines for using social media

- Social media should not be used by consumer representatives for consumer or volunteer duties without prior approval from the health service.
- Consumer representatives who use social media for personal purposes must not publicly disclose information about patients, families, health professionals or health services that may intentionally or unintentionally:
  - reveal confidential or personal information, or
  - adversely affect the public image or reputation.
- The expression of personal opinions must not be in any way associated with the health service.
- Photographs, videos and images of patients, families, visitors or staff in their professional capacity are not to be used on social media or personal interest sites.
- Consumer representatives should never imply on social media that they are speaking on behalf of others or the health service unless authorised to do so.
These guidelines do not intend to limit or discourage the use of social media in your personal life; however, consumer representatives should be aware that they are personally responsible for the content that they publish on social media. When in doubt, seek guidance from your consumer coordinator.

When you can be identified as a consumer representative, you must:

- only disclose and discuss publicly available information
- expressly state on all postings that the views are your own and not those of the health service
- adhere to the terms of use of the relevant social media website
- be polite and respectful to people with whom you interact.

When you can be identified as a consumer representative, you must not:

- post material that is, or might be construed as, offensive, obscene, threatening or discriminatory towards any patient, family, other consumer representative or staff member of the health service
- imply that you are authorised to speak as a representative of the health service
- give the impression that the views you express are those of the health service
- use or disclose any information obtained in your role as a consumer representative, especially when the information is confidential.

Patients and families may wish to connect with a consumer representative via social media. Consumer representatives are advised not to form social relationships with patients and family members inside or outside of the hospital. Consumer representatives are also advised to avoid becoming ‘friends’ with patients and family members on social media sites such as Facebook.