

# The Victorian Paediatric Integrated Cancer Service Consumer Participation Framework

Version 1 October 2021

# Introduction

## ***What is the purpose of this framework?***

The Victorian Cancer Plan 2020-2024 recognises the value of collaboration with consumers in improving cancer care (1). Consumers of the Paediatric Integrated Cancer Services (PICS) are unique because they include children and young people. This framework aims to embed consumer participation in the PICS's service improvement work. It will ensure that diverse and meaningful participation becomes a core part of all PICS projects and programs.

## ***Who is this framework for?***

This framework is for PICS staff. It will guide WHAT, WHERE, WHEN and HOW consumers can participate in PICS service improvement projects.

This framework is also for PICS consumers so that they understand how they can make an impact to improve services.

## ***Who are PICS consumers?***

Consumers are those who have used cancer services in Victoria. This includes children, young people and their siblings, parents, family, or carers.

## ***Levels of participation***

The type of participation can range from incidental and one-off, to ongoing partnerships. PICS has adapted the Spectrum of Public Participation (2) and uses the following levels of participation with its consumers:

- **Inform** – to assist consumers to understand the situation by providing balanced information.
- **Consult** – to get feedback from consumers on a service, alternatives and/or decisions.
- **Involve** – to work with consumers throughout the development process. This includes understanding and considering their thoughts.
- **Collaborate** – to partner with consumers in each aspect of the decision. This includes brainstorming and the development of preferred and alternative solutions.
- **Co-Create** – make decisions and progress work together to develop a solution.

## ***How did we develop this framework?***

Early in 2021, PICS held three workshops with parents/carers and young people. The purpose of the workshops was to hear about their cancer care experiences, identify areas for improvement and learn about the best ways to work with families.

The great feedback and ideas from families encouraged PICS to think about encouraging engagement at the right time and for the right reason. These conversations inspired PICS to explore what makes effective consumer engagement. They also highlighted the importance of co-creating an engagement framework with consumers themselves. As a result, PICS recruited a Consumer Working Group (CWG). The working group consisted of consumers who received services from the Royal Children's Hospital (RCH), Monash Children's Hospital and Peter MacCallum Cancer Centre.

Sharing a desire to improve services, PICS and CWG identified principles and practices, ultimately giving rise to this framework.

# The Consumer Participation Framework

The framework consists of four main principles: value of the lived experience; collaboration; embracing diversity & expertise; and enabling & supporting participation.

The principles and how they practically apply to our work are listed below.

## **Consumer Participation Principles:**

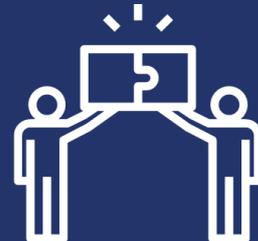
### **Value of the Lived Experience**



Going through cancer treatment gives rise to many views and experiences. PICS will seek, listen to, and incorporate different voices and views of consumers. This includes the voices of parents, carers, children and young people.

### **Collaboration**

PICS handles the delivery of service improvement projects and recognises that meaningful service improvement is the result of working with all stakeholders. Consumers are valuable stakeholders who participate in each service improvement project



### **Embracing Diversity & Expertise**



PICS recognises every consumer has their own valuable skill set. This could be skills from their own profession, jobs, interests and cultural background. As such, participation needs to be accessible, inclusive and in simple language.

### **Enabling Support & Participation**

Participation level will consider the needs of the project and the consumer's capacity. Participation needs to be ethical, meaningful and supported. Consumers also need to be shown the positive actions resulting from participation.



## *The Principles in Practice:*



### *Value of the lived experience*

- Lived experience is included in each service improvement project through consumer participation.
- PICS aims to provide all groups of consumers, a gateway for participation. Such groups include those in Surveillance and those who had surgery only. PICS can access medical records, consumer groups or clinics to engage with these groups.

### **The lived experience of children and young people**

- PICS will work with groups of patients of different ages to learn how to improve experiences during specific moments that matter.
- Recruitment methods, language, and messages may need to be tailored to engage young people.
- Questions for children and young people need to be made age-appropriate. This includes the use of verbal instead of written questions or providing alternative response options such as face/emoji (Likert) scales.



### *Collaboration*

PICS seeks collaboration with consumer groups, clinicians and other relevant stakeholders so that:

- consumer participation opportunities are planned throughout a service improvement project.
- levels and ways of participation are appropriately aligned to the consumer's cancer journey stage.
- consumer participation is as seamless as possible, for example, by timing participation to occur during a hospital visit.



### *Embracing Diversity & Expertise*

- PICS encourages young people and their families/carers to share their expertise/interests. They can use their skills when participating to optimise project design or outcomes.
- PICS strives to encourage participation of patients and families who live in all parts of Victoria. This could involve working with regional networks and partners to promote engagement activities.
- PICS aims to include consumers from a wide range of cultures and backgrounds.
- PICS will minimise barriers to participation, such as expenses, time, and language where possible. This will help to gather a wider representation of consumers.
- PICS will continue to upskill in the use of online tools and platforms to effectively facilitate online workshops. This will especially support regional participation.



### *Enabling & Supporting Participation*

#### **Consent and orientation:**

- Participation is inclusive, yet optional. Young people, families/carers can opt out as they need.
- The PICS Consumer Register is a way for PICS to identify consumers who are interested in participating. The register captures information that allows PICS to invite participation according to consumer preference, knowledge and experience.
- Consent to engage is always obtained. Engaging children and young people sometimes needs extra consent from their parents/carers. This will depend on the project scope and the type of engagement the child/young person provides, as well as the child/young person's ability to understand what the project involves.

#### **WHEN to Engage:**

Consumers can participate in different ways, at different time points. During Diagnosis and Intensive Treatment, consumers are usually only open to receiving information to support health literacy or their understanding of the situation. As consumers head towards Maintenance, Surveillance and Survivorship, they may have the desire to take part in higher levels of participation.

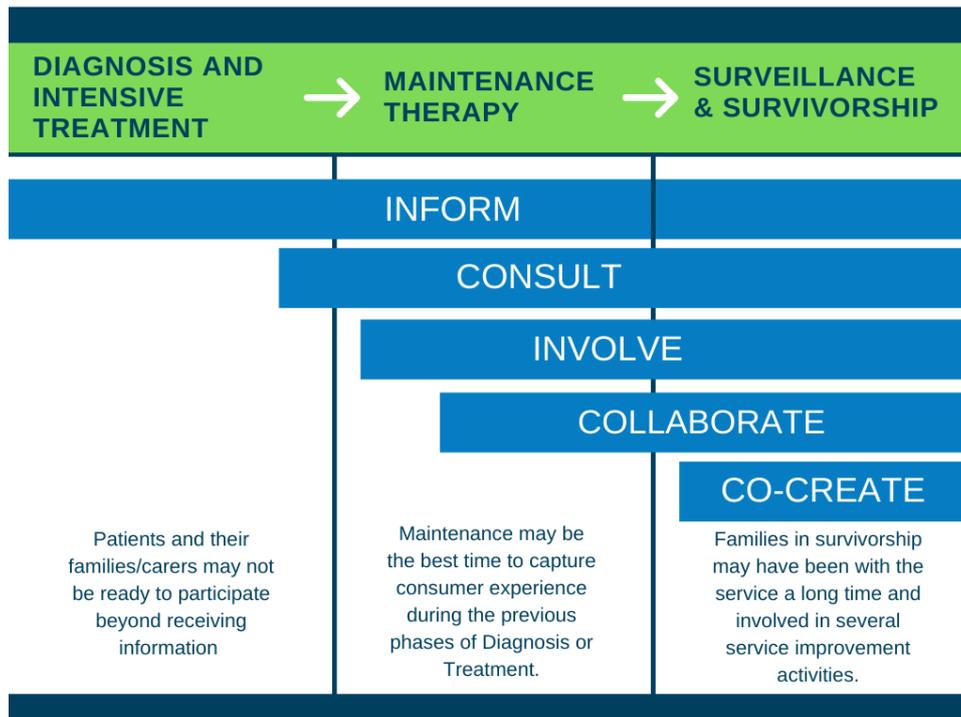


Figure 1: Participation activity according to stage of a family's cancer journey

#### WHERE & HOW PICS will engage:

- PICS will aim to engage families when they are in hospital to reduce intrusions into home life.
- Information for parents and carers is valuable, especially during Diagnosis or Intensive Treatment. Formats need not be restricted to hard copies or downloadable documents.
- For children and young people, information can help them anticipate or normalise situations. Formats could be video stories from their peers, age-appropriate websites, or social media. Play and music therapy can also help the process of providing information.
- During the Treatment phase, consumers prefer a personal, conversational approach. A mid-treatment check-in is a way for consumers to provide some feedback, and for PICS to monitor service improvement opportunities.
- During Surveillance and Survivorship, visits to hospital are infrequent, so regular communications will help consumers participate. PICS consumers have identified that emails or text messages are appropriate ways to reach out to them during this period. The messages can have embedded QR codes for easy access to participation opportunities.
- PICS will continue to investigate preferred contact methods, as this may vary between projects.
- PICS will continue to learn about participation preferences of children and young people.
- At times, PICS will use online tools and platforms for facilitating participation. These formats can make participation, such as meetings and workshops more accessible, as they remove barriers of travel, time and money.

## Ensuring participation is supported and meaningful for consumers:

- All service improvement work undertaken by PICS aligns with the Victorian Cancer Plan 2020-2024. PICS will ensure that consumers understand that the work they do contributes to improving outcomes and experiences for children and families affected by cancer.
- PICS supports consumers by allowing them to prepare and optimise their contribution. This support may be in the form of information, education or reimbursement for travel.
- Sharing experiences of the cancer journey can take an emotional toll. PICS will encourage consumers to contribute in a way that is safe and appropriate for them.
- PICS and consumers will agree on rules for participation. These rules provide a shared understanding on how to work together, flag triggers and provide an avenue for feedback, be it a compliment or a complaint. Additional support would also be provided outside the group setting if this is required. Careful planning of communications to consumers will help to guide and support meaningful participation.
- Group participation, such as workshops, have an added benefit for consumers. They are a safe place where they can connect, share experiences, and support each other.
- Participation of young people should be a positive and skill-building experience for all involved. Including fostering peer support for each other within the consumer group.
- PICS communicates the results and actions from participation back to consumers. Consumers may be involved in the dissemination of results.
- PICS acknowledges consumers in resources that they help to produce.

## What does success look like?

- PICS includes consumer participation for all cancer service improvement projects.
- PICS consumers feel supported when participating in PICS projects.
- The lived experience of consumers reflects diverse geography and culture. It also includes the voice of young people.
- Participation of consumers is of mutual benefit for PICS and consumers.
- PICS staff feel more confident in engaging with consumers for their projects.
- PICS consumers understand what to expect when they engage with PICS.

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## References:

1. State of Victoria Department of Health and Human Services. Victorian Cancer Plan 2020-2024: Improving cancer outcomes for all Victorians. Melbourne: Horner Press; 2020.
2. International Association for Public Participation. IAP2 Spectrum of Public Participation 2018 [Available from: [https://iap2.org.au/wp-content/uploads/2020/01/2018\\_IAP2\\_Spectrum.pdf](https://iap2.org.au/wp-content/uploads/2020/01/2018_IAP2_Spectrum.pdf)].