

CONSUMER ENGAGEMENT FRAMEWORK



'To speak of me, speak with me'

Consumer Engagement Framework

Published by:
PCOC

This Framework document was developed using a collaborative and co-design approach by the PCOC Consumer Engagement Framework Working Group. PCOC would like to acknowledge the consumer members of the Group: Heather Wullemin, Kathryn Jenkins, Howard Lance and Brigitte Phillips.

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Introduction

This Framework aims to strengthen and sustain meaningful and effective consumer partnerships across the PCOC program, to improve palliative care outcomes for patients and their family and carers across Australia.

The Palliative Care Outcomes Collaboration (PCOC) is committed to partnering with all palliative care consumer representatives across Australia to improve palliative care outcomes for patients and their family and carers. By listening to consumers with knowledge and personal experiences of palliative care—patients, family members, and carers, we can better ensure the PCOC program meets the needs of palliative care services, clinicians and the patients, family and carers they provide care for.

PCOC acknowledges the unique challenges of capturing contemporary consumer voices in the end-of-life space and values the spectrum of perspectives consumers can offer.

This Framework has been developed by the PCOC Consumer Engagement Framework Working Group using a mixed collaborative and co-design approach. The Group consisted of four PCOC staff members and four consumer members who met monthly over an 8-month period.

Acknowledgement of Traditional Owners

We acknowledge First Nations people as the Traditional Custodians of the lands on which we live and work. As a national quality improvement program, we are grateful to collaborate with palliative care services across many lands and communities.

We recognise the diverse knowledge, perspectives, strengths and continuing connection of First Nations peoples to land, waters, and culture. We pay our respects to Elders past and present and extend that respect to all First Nations peoples. We acknowledge that for First Nations peoples, Country is a place of deep connection, knowledge, and relationship, and we are committed to listening, learning, and working together to improve care for all.

(Flame Tree Artwork by Samantha Hill, Dharawal/Wandandian Woman for University of Wollongong Acknowledgement of Country)



Acknowledgement of lived experience

The Palliative Care Outcomes Collaboration (PCOC) values the contributions of individuals with lived experience, including consumers, carers, families, and support persons. The valuable input of people with lived experience helps PCOC to understand how we can best support health professionals and services who provide quality palliative care.

The insights and perspectives shared by those with lived experience are essential in shaping meaningful change. Their involvement strengthens the relevance, quality, and responsiveness of health care practices and supports informed decision-making.

Definitions

The following definitions are used in this Framework:

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Consumer

A person who has used or may potentially use, any type of health care service. It includes their family and caregivers.

Palliative care consumer

A person with lived experience of a life-limiting illness, either directly or as a family member or carer of someone who has received palliative care.

Palliative care consumer representative

A person who has taken up a formal role to provide a palliative care consumer perspective and advocates for the collective interests of current and potential users of palliative care services. This includes the perspectives and experiences of patients, carers, families, and support people.

Palliative care consumer participation

Palliative care consumer participation involves a consumer representative actively engaging—individually or on behalf of groups—to contribute lived experience and expertise to the planning, design, delivery, evaluation, governance, research, and policy development of palliative care services and programs.

Palliative care healthcare professional or clinician #

A person employed by a health service organisation to deliver palliative care services to patients and their family and carers. In the context of consumer engagement activities, PCOC does not consider healthcare professionals as consumers when they are participating as part of their paid healthcare role.

Patient

A person who is receiving care provided by a health service organisation.

We are all users of health services. Palliative care consumer representatives generally come from outside the health system or are not current employees of the health system, and their primary or most significant experience is that of receiving care. They bring fresh perspectives and ask questions that others within the system may not think to ask.

A staff member serving as a consumer representative may have a conflict of interest between their organisational role and their consumer role. This may cause confusion for other consumer representatives and members participating in the committee or activity who are not clear whether their feedback or ideas come from the perspective of a consumer or a staff member. It may also prevent them from seeing barriers and solutions to issues and make it difficult to speak up where other staff are present.

What is palliative care?

Palliative Care is care and support provided to people who have a progressive, life-limiting illness. A life-limiting illness is one likely to cause death in the foreseeable future.

Palliative Care aims to improve the quality of life for patients, their families, and carers by addressing their many needs; physical (including treatment assessment and management of pain and other symptoms), emotional, social, cultural and spiritual needs. Care offered may include medical treatment, relief from distressing symptoms (such as pain, nausea, breathlessness), psychological and spiritual support (anxiety, depression, distress), access to resources such as equipment and support to help the family cope during the person's illness and in their own bereavement.

Palliative care is for people of any age with a life-limiting illness. It can be provided at any time depending on a person's needs. It is now accepted that combining palliative care with active treatment improves symptom control, quality of life, and family/carer experiences. Palliative care may be provided in hospitals or community settings (private homes, residential aged care, general practices, community palliative care clinics and day centres). (Palliative Care Australia)

There is still misunderstanding for consumers about what palliative care can and cannot offer.....PCOC offers a great opportunity for service providers to better educate consumers and to achieve optimal outcomes for patients and families. Palliative services will most likely be needed more as the population ages. Education is key.

(Heather, PCOC Consumer Advisory Panel member)

About PCOC

The Palliative Care Outcomes Collaboration (PCOC) is a national program funded by the Australian Government Department of Health and Ageing. PCOC is based at the University of Wollongong. Participation in PCOC is voluntary.

PCOC is responsible for supporting Palliative Care Services and clinicians in the acute (hospital and hospice) and primary care (community and general practice) settings, to improve palliative care patient, carer and family outcomes.

Measuring patient outcomes is critical for quality and safe care, and for the accountability of a service to its patients, families and carers. PCOC aims to improve palliative care patient, carer and family outcomes. PCOC uses a cycle of routine assessment, measurement of patient outcomes, reporting and benchmarking through Communities of Practice, to support care planning and drive improvements in palliative care in Australia.

There are over 230 palliative care services across Australia that participate in the PCOC program.

These services are based in hospitals, hospices and in the community. They use the set of PCOC screening and assessment tools to provide quality care that meets the needs of the patient and their family and carers.

PCOC collects data about the care patients receive and shares it back to services in clear, actionable reports. These reports help services to see what is working well and where they can improve. The information is de-identified, meaning it does not include any personal details about patients and their family and carers.

Why have we developed this Framework?

The purpose of this Framework is to strengthen and sustain meaningful and effective consumer partnerships across the PCOC program, to improve palliative care outcomes for patients and their family and carers across Australia.

This Framework will guide and support PCOC community and consumer engagement processes and activities across all areas of the PCOC program—including in governance, research, development of consumer resources, and program planning and improvement.

We recognise that the primary users of PCOC are the palliative care services and clinicians who use the program’s tools, data and resources to provide quality person-centered palliative care and drive continuous quality improvement.

A key part of PCOC’s collaborative approach, is working closely with services and clinicians to hear their knowledge and understand their experiences to identify opportunities for improvement in the PCOC program.

It is equally important to listen to people in the community with knowledge and personal experiences of palliative care—patients, family members, and carers. Their insights, alongside those of service providers, clinicians, palliative care leaders and researchers, and PCOC staff, are essential for shaping decisions and ensuring the PCOC program continues to contribute to the provision of quality palliative care across Australia.



What does community and consumer engagement look like?

PCOC consumer representatives contribute meaningfully across a range of engagement levels — from participating in governance committees, to reviewing consumer-facing resources, and co-designing key documents such as this Framework.

Their involvement is essential to ensuring that PCOC’s tools and resources are clear, practical, and grounded in lived experience. This Framework outlines the principles, objectives, and processes that support and strengthen this engagement, enabling consumers to be meaningfully involved in all relevant aspects of the program.

PCOC supports a range of consumer involvement activities - examples include:

- ✚ Providing feedback on consumer resources
- ✚ Co-designing consumer governance documents
- ✚ Participating in advisory groups or committees
- ✚ Contributing to governance or research initiatives
- ✚ Sharing lived experience to inform training and education

My experience with palliative care has mainly been limited to that experienced by my late wife. The biggest change that I am aware of over the last twenty or, so years is that palliative care is mentioned a lot more within society. I suspect that most people (myself included at the time) still do not fully understand what palliative is. I became involved with PCOC in the hope that I could in some small way help to correct that fact.

Howard, PCOC Consumer Advisory Panel member

As a consumer with PCOC I have been fortunate to have the opportunity to contribute to the work in orientation, documents and the thoughts on what a consumer is and how they operate in the consumer role. It's made me feel worthwhile where I am less able in general due to my terminal disease. The opportunity to contribute has been greatly appreciated by me.

Kathryn, PCOC Consumer Panel member

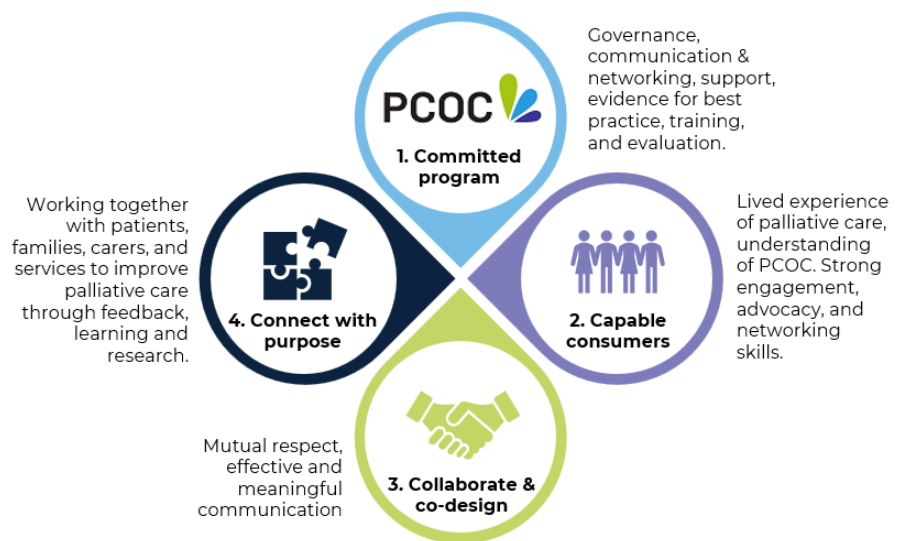
Objectives and principles for engagement

Objectives		
<p>1 Empower staff and consumers for collaborative, meaningful and impactful engagement.</p>	<p>2 Ensure diverse consumer voices, feedback loops and acknowledge consumer contributions in PCOC reporting.</p>	<p>3 Evaluate the effectiveness and impact of consumer engagement and build trust.</p>

Principles of engagement				
PURPOSEFUL	RESPECTFUL, INCLUSIVE	TRANSPARENT	VALUE, SUPPORT AND EMPOWER	COLLABORATE, CO-DESIGN
Clear purpose, goals and indicators for success	Hear and value diverse perspectives and experiences. Support consumer engagement.	Open communication and feedback.	Provide resources and remuneration to support genuine engagement.	Commitment to co-design and collaborative decision-making.

Figure 1: Key components for effective collaboration

This figure was created by the Framework Working Group. It sets out the core components for effective and meaningful collaboration between PCOC and community and consumers.



Implementing the Framework

Levels and types of engagement

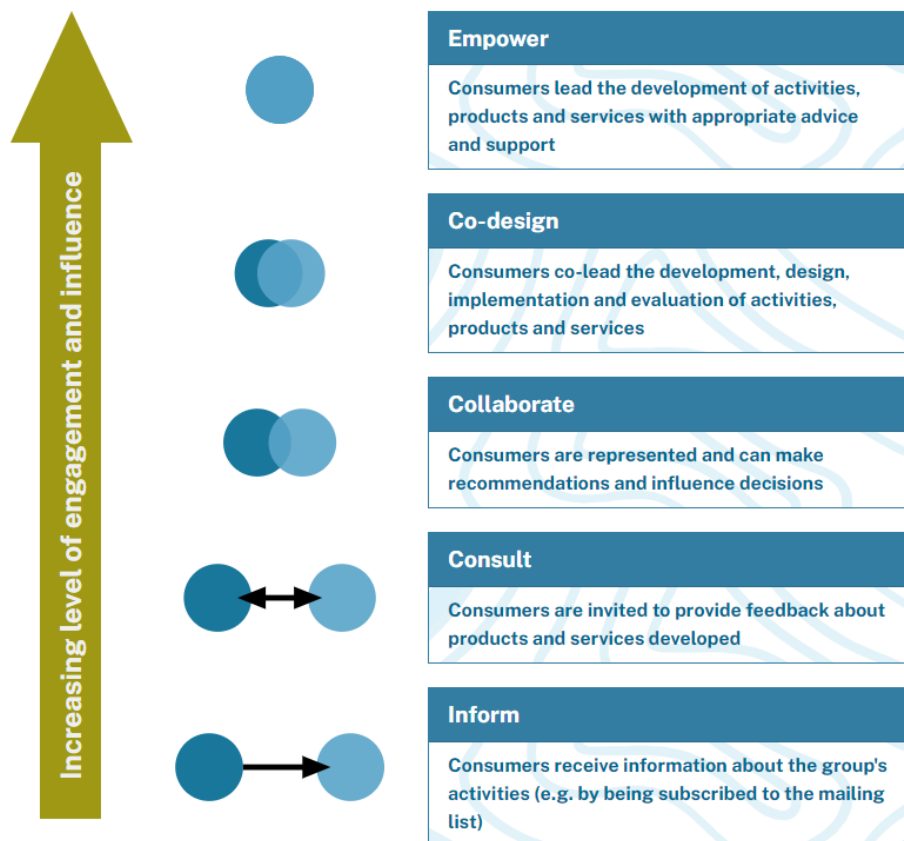
PCOC is committed to implementing this Framework into its routine work by ensuring we:

- ✚ Move beyond committee representation to five levels of participation
- ✚ Use varied engagement methods (e.g., consumers on governance committees, consistent processes to obtain feedback on consumer information)
- ✚ Establish a formal Consumer Panel with orientation and support.

Figure 2 shows the five levels of partnership and types of consumer engagement – the experience of consumers will vary depending on the type of engagement activity and their level of involvement.

Table 1 examples of current PCOC consumer engagement activities.

Figure 2: Levels and types of consumer engagement



(The spectrum of public participation adapted with permission by the Agency for Clinical Innovation, NSW Health.)

Table 1: Examples of current PCOC consumer engagement activities

ACTIVITY	EXAMPLES
Disseminate information to community and consumers	<ul style="list-style-type: none"> Patients and their family and carers receive information about the PCOC program, and how assessment information is collected and used to plan and improve care
Review and provide feedback	<ul style="list-style-type: none"> Consumers provide feedback on all PCOC consumer-facing resources to ensure quality and relevance
Participate in governance activities	<ul style="list-style-type: none"> Consumers participate as members of PCOC governance, project and/or research committees, with equal input in discussion and decision-making
Co-design information and resources	<ul style="list-style-type: none"> Consumers collaborate with PCOC to create consumer-facing PCOC resources. An example is this Framework
Lead the development of activities	<ul style="list-style-type: none"> Consumers in leadership roles, e.g. Consumer Co-Chair of the PCOC Consumer Advisory Panel <p>Examples of aspirational engagement activities:</p> <ul style="list-style-type: none"> Consumers provide training to health professionals of palliative care services participating in PCOC Members of the PCOC Consumer Panel represent PCOC at an approved event, e.g. Palliative Care conference.

PCOC commitment

To ensure effective and meaningful consumer engagement across all relevant program functions and activities, PCOC will:

- ✚ Embed consumer engagement in governance and establish a formal Consumer Panel
- ✚ Ensure and sustain appropriate funding to support consumer engagement
- ✚ Provide orientation, ongoing support, and remuneration for all PCOC consumer representatives
- ✚ Use varied communication methods (e.g. virtual meetings, printed materials)
- ✚ Seek and incorporate consumer feedback on all PCOC consumer-facing resources
- ✚ Develop and maintain a dedicated consumer engagement page on the PCOC website
- ✚ Train staff in formal consumer engagement principles and practices
- ✚ Monitor and report on engagement activities and outcomes
- ✚ Assign a designated PCOC team member as the Consumer Engagement Lead.

Remuneration

PCOC recognises the value of lived experience and the time and effort contributed by consumers who participate as members of the Consumer Panel and / or in other PCOC consumer-related activities.

In line with our principles of engagement, PCOC provides payment to consumers who participate in approved consumer engagement activities, such as participating as members of PCOC governance committees or on the PCOC Consumer Panel.

Evaluation

Monitoring and evaluating the effectiveness of consumer engagement is vital to implementing this Framework successfully. It helps identify what's working well and where improvements are needed, ensuring the program remains responsive and relevant.

Transparency and trust are foundational to meaningful engagement. All stakeholders—including PCOC Chief Investigators, staff, consumer representatives, and services—must see clear evidence that consumer perspectives are actively sought, valued, and acted upon.


To support this, the PCOC Consumer Engagement Lead and Consumer Panel will co-develop an annual PCOC Consumer Engagement Report. This report will include the following information in line with the objectives and principles of this Framework:

- ✚ Key activities involving consumer participation
- ✚ Achievements and highlights





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