

Principles of quality consumer and carer participation

Consumer and carer involvement delivers significant benefits for healthcare policy organisations as well as for healthcare consumers. In palliative care policy contexts, consumer and carer involvement has been shown to demystify palliative care, build public awareness of and support for palliative care services, and to assist palliative care services to better understand and respond to the needs of consumers, especially vulnerable people. As well as delivering benefits to organisations, participating palliative care consumers and carers are offered opportunities to share experiences with others, participate in educational trainings and make a significant impact on the palliative care sector.

Palliative Care Australia seeks to engage consumer and carers through listening, collaborating, informing and empowering to enable organisations access to advocacy and policy insight on end-of-life matters. This panel is designed to facilitate opportunities for consumers and carers to actively engage in national palliative care health policy, service delivery and reform activities on a national level. Panel members use their lived experience, knowledge of the palliative care sector and communication skills to advocate for and promote the issues and concerns of palliative care consumers and carers.

In 2016, Palliative Care Australia (PCA) sought guidance in identifying approaches, structures and processes to support sustainable and meaningful consumer involvement in the organisations policy and advocacy work. Being mindful of the realities of the circumstances for people receiving palliative care and their unpaid caregivers and loved one, PCA has committed to establishing a consumer and carer panel to deliver advocacy and policy outcomes on a national level.

Based on best practices and recommendations included in the report, 'Options for a consumer involvement framework for palliative care Australia' the following guiding principles have been identified and will be followed to support effective consumer and carer involvement:

Core Principles

- Consumers and carers are valued for their unique expertise due to their lived experience of palliative care
- Consumer and carer participation will be promoted across the project or policy development cycle and at all levels of palliative care
- PCA will follow a transparent process for selection of panel members and of all panel workings, stated in operating guidelines.
- PCA will recruit appropriately skilled consumer and carer panel members
- PCA will review and evaluate consumer and carer participation and operating guidelines on an annual basis for continued improvement
- Ensure senior organisational leaders support the program
- Work collaboratively with member organisations and their consumer strategy programs
- Provide regular recognition regarding the value of panel members contributions to the development of policy and to the public
 - Evaluate and communicate the difference that consumer input made to outcomes

Principles for defining the role of consumer and carer representatives

- PCA shall clearly articulate the aims of consumer involvement on national level
- Roles and expectations of consumer and carer panel members shall be clearly defined
- Provide consistent and responsive administrative support for involved consumers and carers
 - A Secretariat shall be nominated to ensure a responsive contact person with whom to raise questions, concerns and liaise with organisations to secure optimal work standards for panel members
 - Provide training or information for staff who may not be familiar with principles and practices of consumer engagement
- PCA will employ specific strategies to support people receiving palliative care or those caring for someone receiving palliative care

Principles for engagement of consumer and carer representatives

- Utilise mixed methods of engagement – this assists to support the participation of people in diverse situations, and with varying capacity to contribute as well as different preferences for how they would like to contribute.
 - In person and online participation opportunities will be offered to panel members
 - Engagement opportunities will be time limited
- Provide training and education opportunities for consumers to support their effective participation, including an orientation to the organisations work; training in relevant health system issues; training in communication, advocacy and representation skills.
- Provide remuneration for expenses incurred where appropriate