



National Register of Palliative Care Consumers and Carers

FACT SHEET

Palliative Care Australia (PCA) is the national peak body for palliative care. We represent all those who work towards high quality palliative care for all Australians. PCA truly believes in the important contributions palliative care consumers and carers can make to improve palliative care. The National Register of Palliative Care Consumers and Carers gives a voice to those living with a life-limiting illness, people who are receiving palliative care, their family, carers and the palliative care volunteers who support them. The ultimate goal is to improve the quality of, and access to, palliative care throughout the country.

What is the National Register of Palliative Care Consumers and Carers?

The National Register is designed to foster opportunities for palliative care consumers and carers to engage in the development of palliative care health policy, service delivery and reform activities at a national or jurisdictional level.

How many consumer representatives are on the National Register?

The National Register currently consists of six palliative care consumers and carers from across Australia. We aim to develop a diverse and representative group, and will continue to expand membership on an annual basis. To find out more about our current members visit the [website](#).

How can consumer representatives contribute to my project?

Our palliative care consumer and carer representatives use their lived experience and communication skills to share their stories and provide input into public policy and service delivery related to palliative care in Australia. PCA has an ongoing schedule of support and training opportunities for members of the National Register. This will provide members with sector insights, developing their knowledge of palliative care issues and networks, and empowering them to participate in strategic decision making and input into policy, health service design and relevant projects.

You might seek to have representatives positioned on national committees, boards, working groups and evaluations, or to advise on the development of a new project, program or service.

How do I go about engaging a representative?

To engage one of our consumer representatives you will need to submit an [application form](#) (available from the PCA website) and either identify a specific individual(s) based on information in their online biography, or request a recommendation based on the requirements of your project.

The information you include in your application form will then be provided to the consumer representative(s) you nominate. Participation in a project is at the discretion of each individual consumer representative. If a consumer representative is unwell or believes they cannot contribute in a meaningful way they may choose to withdraw themselves from consideration. In these cases PCA will work with the organisation to identify another suitable consumer representative.

Once a representative opportunity has been confirmed, the consumer representatives contact information will be shared with you. Unless otherwise agreed, you will then need to make and manage project arrangements with the consumer representative you have engaged.

How much should consumer representatives be paid?

PCA strongly believes in the important contributions and insights that Consumers and Carers can provide. When you engage a consumer representative we encourage you to recognise these contributions by covering travel, accommodation and associated project costs. Additionally, you are encouraged to pay consumer representatives in line with PCA's Remuneration Policy.

PCA recommended participation payments are:

- \$100 for half a day (up to four (4) hours)
- \$200 for a full day (more than four (4) hours)

PCA will work with you prior to approaching consumer representatives to ensure the conditions are reasonable. If you are unable to fund payment, a consumer representative may choose to take part in the project in an unfunded way, but this will be at their discretion.

How will consumer representatives be paid?

Payment to consumer representatives can be facilitated through your organisation's existing processes for reimbursement and remuneration. Once you engage a palliative care consumer representative, you are encouraged to negotiate directly with them to communicate and agree on this process.

What is Palliative Care Australia's role?

PCA will provide education and training opportunities, and self-care resources to assist consumer representatives carry out their roles efficiently and effectively. PCA will also work with, and provide administrative and project support to consumer representatives in order to identify and allocate engagement opportunities. However, once you have engaged with a consumer representative, you are encouraged to negotiate and communicate directly with your representative.

If required, where issues arise PCA will work with you and the consumer representative to help resolve any issues, provide support and determine the best way forward.

What information do I need to share with Palliative Care Australia regarding outcomes of my project?

Once your project is completed, you will be asked to complete an evaluation of your engagement with the consumer representative, and the outcomes you were able to achieve with their participation. The consumer representative will also be asked to complete an evaluation, outlining the extent of their engagement with your project, with a view to help us improve the program in the future.

Who do I contact if I have questions about the National Register?

If you have any questions about the panel please contact Tim van Ierschoot, Community Engagement Coordinator, on 02 6232 0700 or pca@palliativecare.org.au.