



Feedback from Palliative Care Victoria Members

Report on the survey conducted in 2018

Summary

Eighty-two members of Palliative Care Victoria provided feedback on its performance in 2017 and strategic priorities. The survey was conducted between 23 February and 23 March 2018 and the number of respondents increased by 46% compared to the 2016 survey.

PCV's overall performance in 2017 was well received with 89% of the respondents indicating that they were either very satisfied or satisfied.

Eighty-one respondents provided qualitative comments about what they valued most about PCV. Most comments cited several things they valued most. These related to: the information PCV provides to the palliative care sector (32%); other support by PCV to the palliative care sector, such as advice, networking, events, volunteering support (23%); advocacy activities for consumers and the sector (25%); and PCV's resources for the community (19%).

PCV's contribution to the palliative care sector was well regarded (91% very satisfied or satisfied). More than 80% of respondents reported they were very satisfied or satisfied with PCV's work to raise community awareness of palliative care, improve access and responsiveness to cultural diversity and advocacy activities.

Feedback confirmed the need for continuing efforts to strengthen our focus on regional and rural palliative care issues, as well collaboration with other sectors and organisations.

Respondents indicated very high levels of satisfaction with our weekly newsflash (92%) and our palliative care resources for the community (89%).

Future activities by PCV

Respondents were invited to indicate levels of support for potential activities by PCV in relation to: community awareness; community capacity building; representation, advocacy, and solution-facilitation; and events.

Respondents indicated very strong support for activities by PCV to strengthen the capacity of community members and volunteers to: have conversations about advance care preferences and related matters (97%); to support carers (93%) and to support people dealing with loss and grief (93%).

There was also strong support (88% to 96%) by respondents for six possible activities by PCV to raise community awareness and understanding of palliative care. The activities attracting most support were: collaboration with chronic disease groups to raise community awareness and engagement; facilitating community forums on relevant issues for the public; producing resources for engagement activities; and a communications campaign to reach target audiences.

There was also strong support for PCV to strengthening its representation of consumer voices and experiences and to facilitate solution-focused forums including consumers.

Respondents had the opportunity to cite activities that they thought PCV should pay more attention to. These included: community awareness and engagement; increased access to palliative care especially in rural and regional areas; focus more on the quality of life aspects of palliative care

(rather than death and dying) and provision of more education and training to the sector. Several respondents noted that there will be a need to consider workforce support, communication and service responses in relation to the introduction of voluntary assisted dying in June 2019.

Perhaps unsurprisingly, only two respondents suggested activities that PCV could reduce. As PCV has a team of four people, this highlights our need to focus on our unique role, areas where we can add the greatest value and have the greatest strategic impact. Communicating the rationale for our areas of focus will be important in managing the expectations of PCV members and other stakeholders in a sustainable way.

Profile of respondents

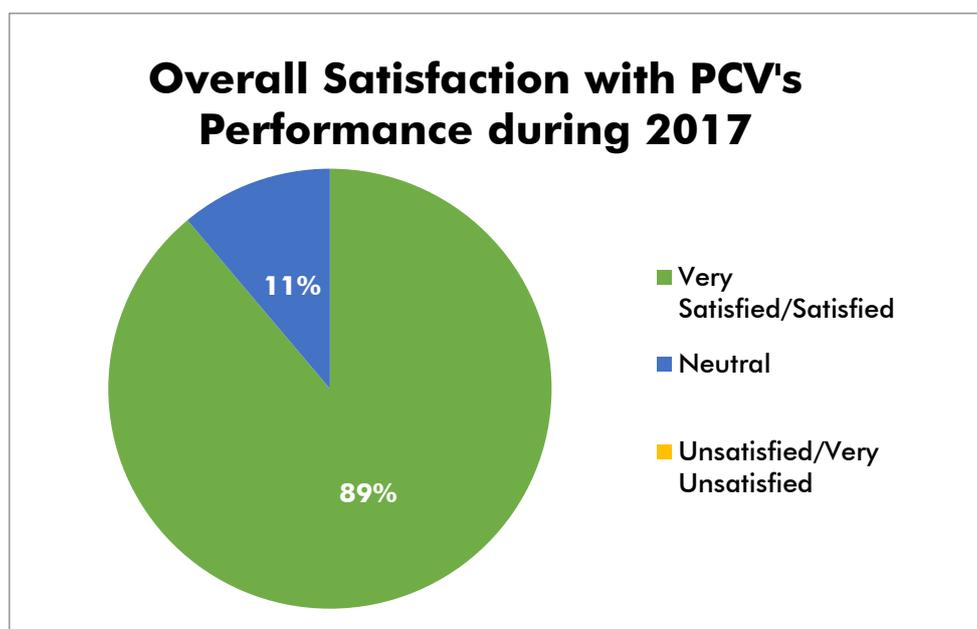
Eighty-two PCV members completed the survey; the majority (N=58, 71%) identified as organisational members or working for organisations that are PCV members. Individual members comprised 15% of respondents (N=12) and 12 respondents were unsure of their membership type or did not answer this question.

The geographical coverage of respondents was 29% (N=24) from regional areas, 40% (N=33) from metropolitan Melbourne and 10% (N=8) state-wide. 13% (N=11) of the 82 respondents did not provide an answer.

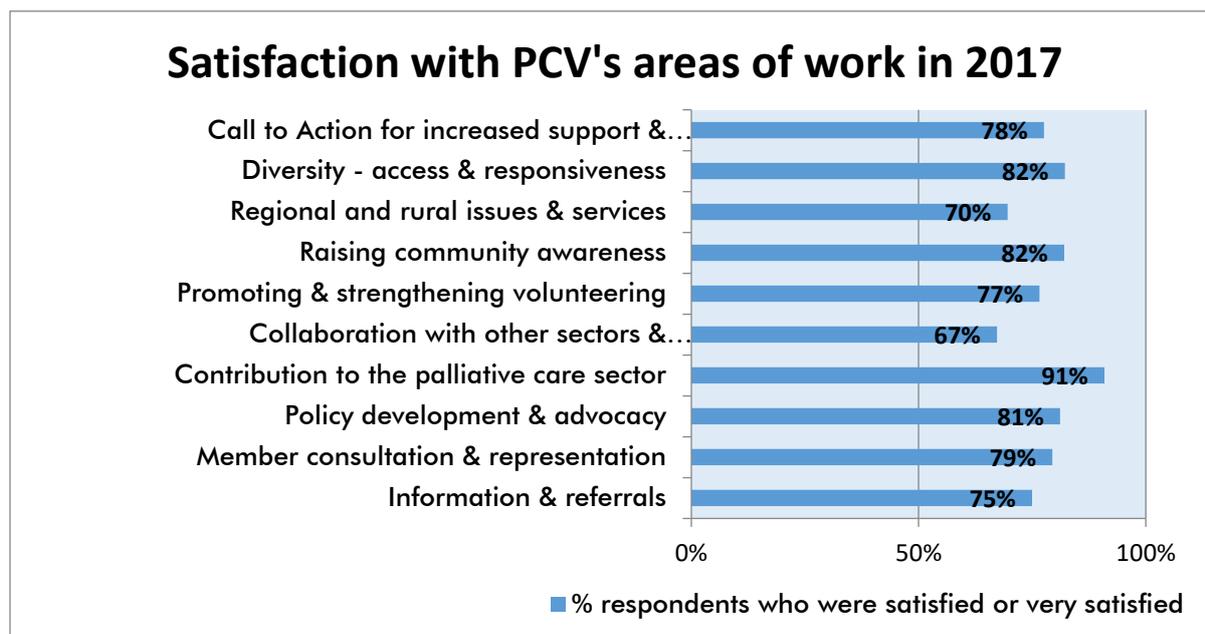
The range of palliative care disciplines and roles covered by respondents was extensive. Of the 74 respondents who answered the question, the majority (N=41, 55%) held clinical roles in a range of disciplines. Respondents with managerial roles (clinical and service management) comprised 14% (N=10), respondents with administrative roles comprised 9% (N=7) and palliative care volunteers or manager of volunteers 7% (N=5). 5% (N=4) of respondents were working in research or education, 3% (N=2) in community engagement, and 7% (N=5) in other roles including palliative care consultancy and diagnostic services.

PCV's Overall Performance

The majority of respondents (89%) indicated that they were *satisfied* or *very satisfied* with PCV's overall performance during 2017. This compares with 88% in 2015, 90% in 2014 and 84% in 2013.

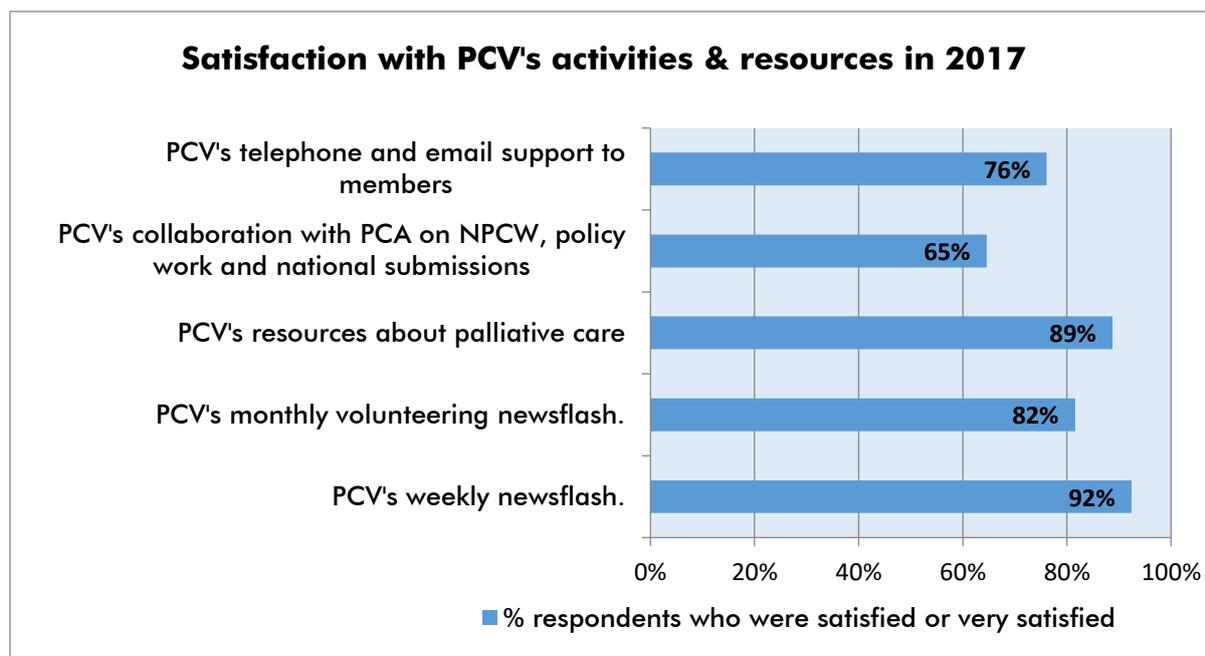


Satisfaction with PCV's main areas of work in 2017



Respondents reported strong to moderate levels of satisfaction with PCV's performance in most areas of its work in 2017. PCV's contribution to the palliative care sector was most highly rated. PCV's work to promote access and responsiveness for diverse communities, raising community awareness, and policy development and advocacy was also well regarded. Respondents were satisfied with our work in member consultation and representation, information and referrals, promoting and strengthening volunteering, and our Call to Action for increased support for palliative care. There was an indication for increased collaboration with other sectors and a greater focus on regional and rural issues and services.

Satisfaction with PCV activities in 2017



The chart above indicates strong levels of satisfaction with most PCV activities and resources during 2017. Consistent with previous years, the newflash is our most highly rated resource, with this also featuring in many of the qualitative comments. Our printed materials and online

information were also considered valuable resources by our members. Members also indicated a strong level of satisfaction with our monthly volunteering newsflash, commenced in 2017.

Members indicated moderate satisfaction with the telephone and email support provided. This may be due to the fact that a high number of respondents answered the question with not applicable or did not know, possibly due to their limited contact with our office via telephone and email.

What respondents value most about PCV

Eighty-one respondents provided qualitative comments about what they valued most about PCV. Many comments cited several activities that they valued most. These have been clustered into four key areas, with examples of comments below:

- Information PCV provides to the palliative care sector (32%)

“Availability of quality resources mean I don't have to 'reinvent the wheel' or start from scratch in my community education work.”
- Advocacy activities (25%)

“The advocacy role for palliative care, both from a patient/family perspective as well as from a service delivery one.”

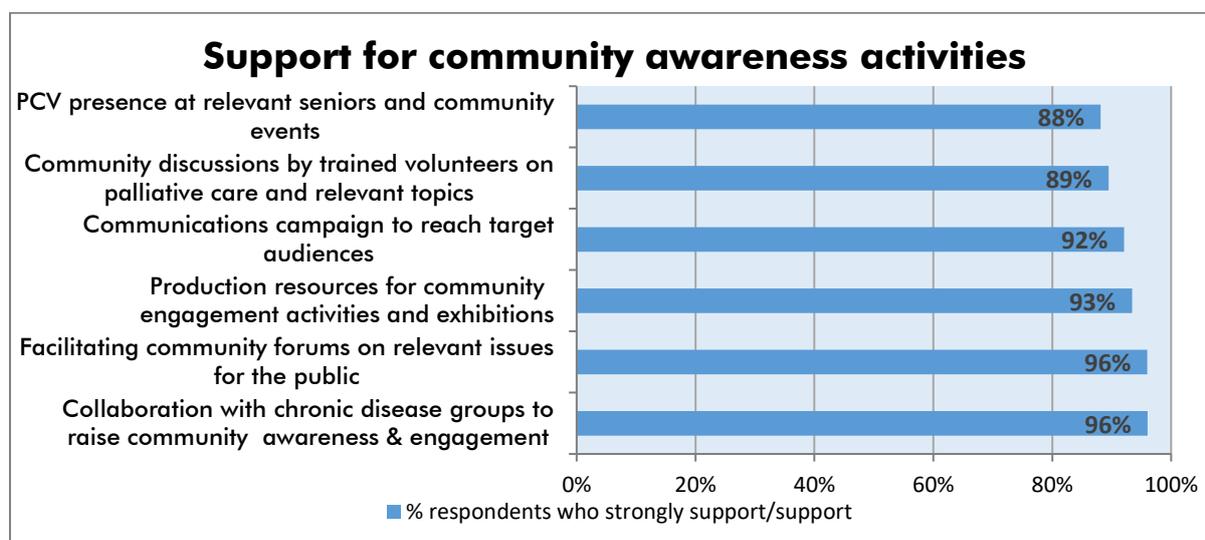
“Advocacy with Governments ensures collective representation and not individual flavours are presented.”
- Other support to the palliative care sector, such as advice, networking, events, volunteering support (23%)

“The commitment of PCV staff to serve the sector to the highest standard, an example of this is seen in the friendly and welcoming way that phone communication is received and responded to.”

“Helpfulness, resources, opening debate, extent of activity.”
- PCV's resources for the community (19%)

Promotion to general public - printed brochures comprehensive, accessible.

Support for community awareness activities



The chart above indicates very strong levels of support from respondents for possible community

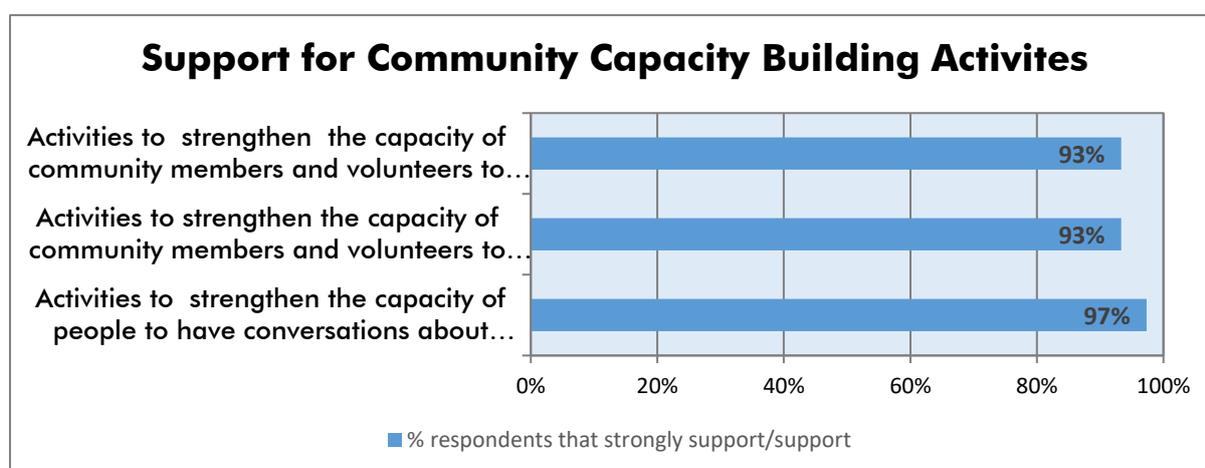
awareness and engagement activities to be undertaken by PCV in the next three years. This emphasises the strategic importance of developing community awareness.

Responses indicate highest levels of support for collaborating with chronic disease groups and community forums on relevant issues for members of the public in collaboration with stakeholders.

Qualitative suggestions made by respondents include: an increased online and mainstream media presence; a stronger focus on our approach in dementia care to improve quality of life; providing further education regarding palliative care and end-of-life choices; and an increased focus on communication and engagement with younger people with life limiting illnesses.

Support for community capacity building activities

The chart below demonstrates outstanding levels of support for possible community capacity building activities to be undertaken by PCV over the next three years. This indicates the area of community capacity building is of great significance to our members.

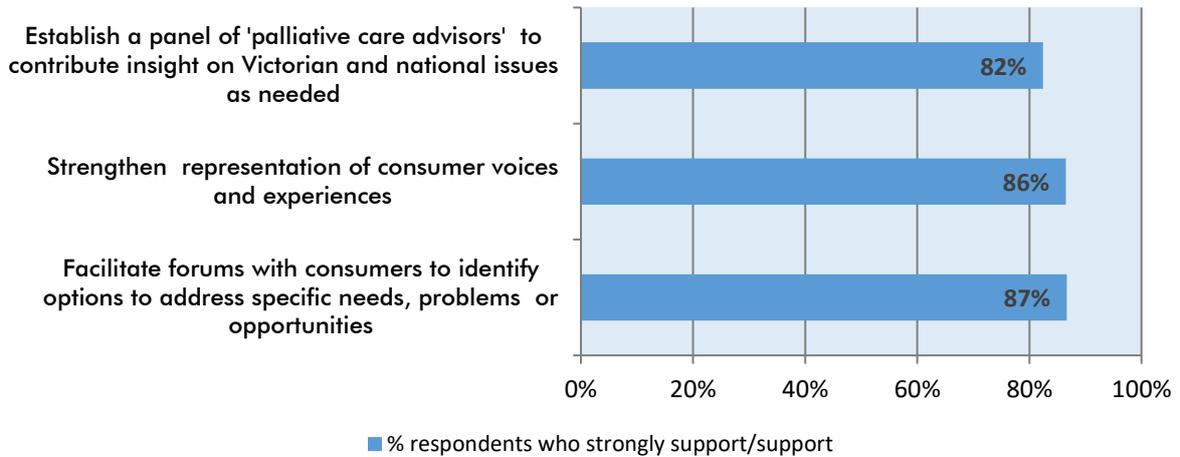


There was a shared sentiment that other organisations and sectors have a role in relation to some of these community capacity building activities, such as those for loss and grief. Collaboration with these agencies has been suggested as a way to reach our aligned goals more effectively. Other comments made include encouraging greater community involvement and further development of public awareness and education.

Support for representation, advocacy and solution-facilitation activities

Respondents demonstrated strong levels of support for the representation, advocacy and solution-facilitation activities suggested by PCV. The most supported potential activity was facilitating forums with consumers and relevant services to identify options, solutions and action plans to address specific needs, problems and opportunities. A significant level of support was also shown for strengthening PCV's representation of consumer voices and experiences, including consumer focus groups on specific issues, supporting a panel of consumers willing to provide input and feedback, and including more consumer voices and experiences in relevant activities.

Support for representation, advocacy and solution-facilitation activities

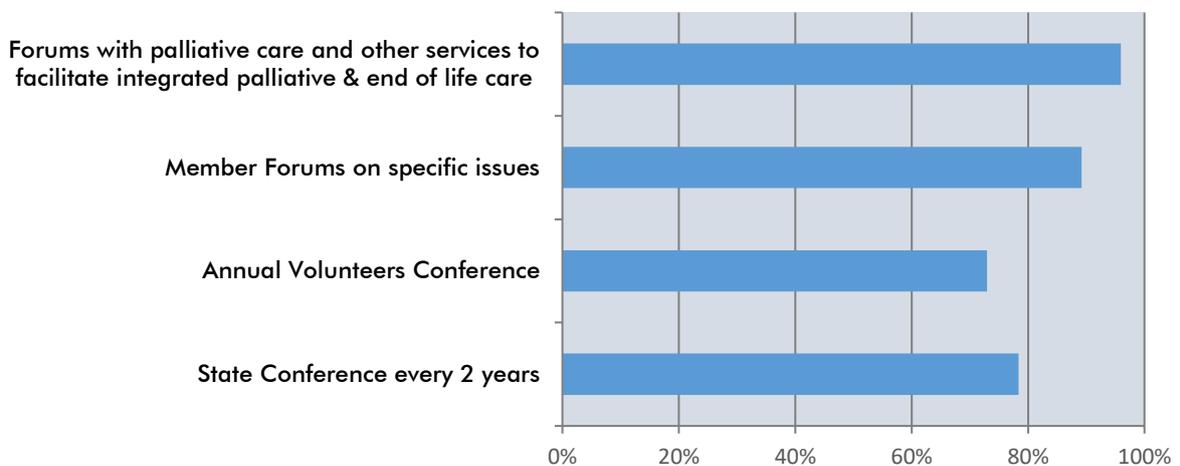


A number of suggestions were also made in the comments by respondents. These included ensuring that consumer representation would be balanced and representative across the whole of the community, including CALD, Aboriginal Australians and Torres Strait Islanders. It was also commented that all community forums should come up with solutions or action plans that are achievable, and that these groups should offer advice to the Government to influence decisions and policies. Another suggestion made was that palliative care volunteers working one on one with patients within the community could also be a good source of feedback for potential representation, advocacy and solution-facilitation activities in the future.

Support for events by PCV

There were moderate to strong levels of support for events by PCV over the next three years. Forums with palliative care and other services and sectors to facilitate integrated palliative care and end-of-life care received the highest levels of support. The lower level of support (73%) for the Volunteers Conference may be due to the smaller proportion of respondents involved in volunteer roles, given that most other respondents indicated they were neutral on the matter.

Support for events by PCV



A common theme in the qualitative comments was to hold events that would be more accessible to those outside of metropolitan Melbourne, providing equal opportunities for attendance across the state for those in rural and regional areas. Suggestions included the use of video conferences and webinars to broadcast events that would be accessible across the state.

Issues or activities requiring more or less attention by PCV

Thirty-two respondents (39%) took up the opportunity to provide feedback regarding areas they would like PCV to give more attention to. These can be clustered into 4 themes, with the first two receiving greatest attention:

- a. **Improving the understanding, awareness and engagement of palliative care.**
Many respondents indicated this was an ongoing area of significant importance. The comments made suggested targeting various audiences around the community, including health professionals, CALD, Aboriginal Australians & Torres Strait Islanders, LGBTQI, politicians and legal services. They suggested: focusing on the benefits of palliative care; providing more information in community languages; and focus more on the quality of life aspects, instead of end-of-life issues and dying.
- b. **Increasing access and support to palliative care in rural and regional areas.**
This was also a concern that arose from the comments in multiple instances. Areas of focus that were suggested included the provision of care earlier in illness, in non-malignant diseases, and further support in relation to aged care and dementia.
- c. **Providing education.**
Suggestions included educating: politicians, policy makers, volunteers, carers, administrative and clinical staff, and the public. Suggested topics included: the economic and quality of life benefits of palliative; compassionate communities; palliative care for people with dementia; pain management for people with non-malignant disease.
- d. **The voluntary assisted dying legislation.**
Respondents noted that palliative care services will need to prepare their workforce and agree on how to respond to consumer questions regarding the VAD.

Only two suggestions were made regarding areas for less attention by PCV: the VAD Bill (now law) and that PCV focus less on specialist palliative care.

Appreciation

We would like to thank the eighty-two PCV members who responded to the survey and shared with us their feedback and insights.

In addition, we wish to thank Angela Liu (a PCV part-time volunteer) who reviewed the survey responses and prepared most of this report.

Next Steps

The valuable feedback and suggestions provided by PCV members is being considered by the Board, including in the current development of PCV's strategic plan and priorities for the next 3 years.

Odette Waanders
CEO