Voices for Palliative Care

CONSUMER ENGAGEMENT TOOLKIT

For more information, please contact
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Voices for Palliative Care
ST VINCENT'S HOSPITAL MELBOURNE
Centre for Palliative Care
Informing Choice. Enabling Care.
THE WICKING TRUST
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Who are Voices for Palliative Care?

Voices is a group of people with lived experience of serious illness, who are committed to creating meaningful research outcomes, contributing to health service planning and advocating for improvements in palliative care. This is a unique group of consumers from all different personal and career backgrounds, with lived experiences of accompanying their loved ones through the palliative care journey. Voices aims to contribute to the work of researchers who are passionate about providing the best possible palliative care journey for all. This group offers a platform for researchers to engage with consumers, either collectively or individually, in order to enrich their studies and projects.

What are the goals of Voices?

- To increase the opportunity for community involvement in and interface with palliative care.
- To build the capacity of patients and the public to partner with palliative care researchers, health professionals and leaders.
- To build capacity of palliative care researchers, health professionals and leaders to partner with patients and the public.
- To develop the role of people with lived experience in publicly advocating for, and raising awareness of, quality palliative care in serious illness.
- To build a national and international collaborative network of palliative care researchers, health professionals, leaders and community members with expertise in patient and public involvement specific to this field.
- To map the impact of patient and public involvement in palliative care to promote the benefit and advance the science underpinning methods of engagement specific to this field.

Principles of Engagement

- Engaging with Voices represents a collaborative partnership built on mutual respect between consumers and researchers, while fostering a bilateral exchange of perspectives.
- Engaging with Voices signifies a mutual commitment to mutual collaboration. This group will provide you with their detailed and well-considered feedback, as well as their intellectual property, to assist you with your project design, on the understanding that their contribution will be acknowledged.
- This initial engagement with Voices marks the commencement of an ongoing relationship, allowing for their continued involvement from the start of your project until its completion.
- Consulting Voices can help connect you with the most appropriate consumer(s) for your project, while fostering an ongoing partnership between the consumer and researcher.

Why choose Voices?

Involving consumers in your research through collaboration with Voices for Palliative Care can significantly enhance the relevance and impact of your findings. This group is uniquely positioned as an advocacy body dedicated to improving palliative care based on the lived experiences of its members. By incorporating their perspectives, you can develop more relevant, patient-centered solutions that address the nuanced challenges of palliative care, ultimately leading to improved quality of life for patients and their families.

This collaboration will not only enhance your research with invaluable insights, but will also empower consumers and foster a more inclusive approach to health care advancements. Voices can help you clarify and source the type of consumer who would best suit your research team in an ongoing capacity.
This partnership may also provide a valuable opportunity to influence policy, ensuring that the insights gathered resonate beyond the research setting and drive meaningful changes in healthcare practices.

What does it involve?

- Submitting an **Expression of Interest Form** requesting the involvement of individual Voices members in your research projects; AND/OR
- Submitting a **Project Pitch** for a **15–20-minute consultation** at least two weeks prior to a Voices meeting. This may include topics like checking language on a recruitment flyer, bouncing research ideas before funding application is submitted etc.
- Filling out a **Researcher Feedback Form** within 10 days of the consultation. This form is used to measure the impact Voices had on your research.

How to maximise consumer involvement

What should the researcher do?

- Be aware of the benefits of consumer involvement and how it can help you.
- Ensure your presentations can be understood by a diverse range of people. Minimise jargon where possible.
- Clearly explain your research and what you require from the consumer.
- Consumers are eager to share their experiences and insights with researchers. They expect to be fully briefed on the research project and intended outcomes.
- Acknowledge the consumers’ contributions and respectfully consider their feedback.
- Approach Voices at the stage where you are prepared to involve consumers in co-design.

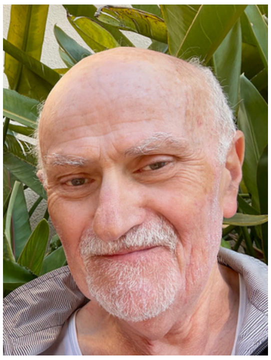
Case Study Examples

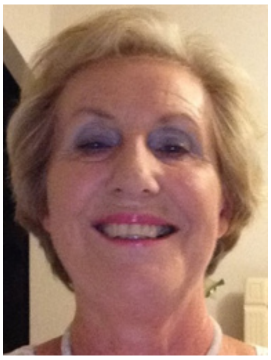
1. Belinda was leading a research project that involved testing an online intervention for patients with cancer and their families. “Voices” provided feedback on the content and utility of the intervention. This helped Belinda refine the intervention prior to recruitment
2. Steven was developing content for a public lecture about palliative care with the intent of discussing some of the common misconceptions. “Voices” helped by reviewing the draft presentation and helping prioritise the main aspects of palliative care that the public typically finds confusing.
3. Aaron had developed a draft strategy for improving end of life care in the intensive care unit as part of his PhD. Several members of Voices attended a focus group with ICU staff so that Aaron could get some insights about how the proposed model of care could be improved.

“Each of us in VOICES possesses a unique lived experience and we believe it is these personal encounters with illness, caregiving, and end of life that enable us to offer invaluable insights to help shape and enrich approaches to care. How? Lived experience not only fosters empathy and deep understanding, it helps drive innovation. Working with consumers through VOICES and utilising our knowledge and lived experience brings a patient-centred perspective to new initiatives. It reminds us that behind every medical diagnosis is a person with a unique story, preferences and needs, and by embracing and integrating consumers’ lived experience into approaches to care, we can all foster a culture of empathy, empowerment, and excellence in palliative care.”

- Voices Member

Meet our Members


Abe (Avi) Paluch


Adrienne Copley


Catherine Dooley


Christine Hofmeyer
(Co-Chair)


Imelda Gilmore

John Chu


John Clements


Les Leckie


Michelle Denman


Simon Waring


Tristan Jallais