Paediatric Palliative Care
Centre of Research Excellence

Lived Experience Satisfaction Survey

Version 1.0, Updated May 2026

Please use these survey questions to understand the experience of people with lived experience within your project. This survey has been co-designed with families, researchers, and community advocates in paediatric palliative care, but may be useful in other contexts.

If you are part of the Paediatric Palliative Care Centre of Research Excellence projects, please email a team member to gain access to a usable version of this resource in Qualtrics, and information on how to embed this survey into quality improvement and reporting.

Suggested Reference (Publication Pending)

Rolfe ML, Hilton G, Kaden B, Paxton S, Treadgold C, Waring S, & Bradford N (2026) *Lived Experience Satisfaction Survey*, Paediatric Palliative Care Centre of Research Excellence

Question	Response Type
Demographics	
What project or committee are you responding about?	Projects and committees listed, can select multiple.
[Demographics as required]	
Onboarding (only for first survey completion) *Thinking about the time between expressing interest in the group and starting the project, how much do you agree with each of these statements?*	Likert scale- Strongly disagree- strongly agree
The goal of the project was clear	
My role in the project was clear	
Everything I needed to participate was clear (eg, the meeting times were communicated to me appropriately, I knew how to access the meetings, I knew the process for payment)	
I could decide how I wanted to take part in meetings (Eg, you could write or speak in meetings, send emails between meetings, step away from the project or meetings as you needed)	
I could communicate with the research team before the first meeting	

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Equity *Thinking about your overall experience in the group, how much do you agree with each of these statements?*	Likert scale- Strongly disagree- strongly agree
The group has/d a diverse range of lived experience of children's palliative care	
Information was presented in a way that made sense to people who aren't clinicians or researchers	
I felt comfortable asking for help	
I felt comfortable voicing my opinion	
My opinion was heard and valued by the others with lived experience in the group	
My opinion was heard and valued by the research team members	
I felt respected in (meetings/ workshops/ communication)	
My role remained clear and valued throughout the project	
When there were chances to take leadership roles, I could tell people I was interested in this	
Communication Process	Open Questions
What helped you feel your voice and opinion were heard?	
What barriers did you experience to expressing yourself?	
Impact *Considering the impact of the group, how much do you agree with each of these statements?*	Likert scale- Strongly disagree- strongly agree
I was told of ways the project would create impact	
I was able to contribute to the impact of the project	
Satisfaction	
I'm glad I gave my time to this project	Yes/No
I would recommend being part of this group to others	Yes/No
What could be improved to make the experience better for the next family coming through?	Open question