Paediatric Palliative Care
Centre of Research Excellence

Lived Experience Engagement Checklist for Projects

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Use this checklist throughout the project lifecycle to support high-quality lived experience engagement.

Across stages, focus on developing relationships with your lived experience team. It's ok to be human. Try to develop a rapport, treating them as you would colleagues who are new to the project. You bring knowledge of the project and research, and they bring expertise from having lived through experiences in the health system. Get to know what other skills they might contribute to the project.

Always remember that their experience is not part of their work life but stems from their personal experiences with a child they love. Something that's a positive work development for you might be something they wish their child had experienced, and bring complex emotions. They might think of this work as part of their child's legacy. Be open to however they experience this work.

1 STAGE 1 Project Design (Before Recruitment)

- ☐ Define project purpose, impact, and roles for lived experience members
- ☐ Develop a plain language project summary
- ☐ Plan for diversity and identify any barriers to participation for particular groups
- ☐ Allocate budget for remuneration and supports for lived experience team members
- ☐ Establish payment processes and timelines
- ☐ Assign a contact person and communication plan
- ☐ Define how lived experience input influences the project

2 STAGE 2 Recruitment & Pre-Onboarding

- ☐ Define a role description for lived experience roles
- ☐ Provide potential lived experience collaborators with clear information on goals, expectations, and time commitment
- ☐ Explain payment arrangements and withdrawal options
- ☐ Offer opportunities for questions before they commit to the project
- ☐ Explain how lived experience members contribute to project impact

3 STAGE 3 Onboarding (Before First Meeting)

- ☐ **Meet with each member individually to:**
  - Confirm understanding of roles and expectations, answer any questions
  - Understand what support might be needed to contribute
  - Offer support of appropriate emotional support service if needed
  - Ask how they would like to be supported if they become upset during a meeting
  - Ask how they would like to be paid (if there are options)
- ☐ **Send a follow-up individual email to:**
  - Provide meeting schedule, invites, and access instructions
  - Clearly explain payment process and timing
  - Provide support service information in writing (eg Griefline, 13YARN, Lifeline)
  - Re-affirm their ability to opt in and out, and participate in ways that feel optimal for them and their current availability

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4 STAGE 4 Early Project Meetings

- ☐ Use plain language and explain jargon
- ☐ Invite all lived experience members to contribute
- ☐ Provide multiple ways to provide input and feedback
- ☐ Establish group ground rules, emphasise safe space and try to minimise power imbalances

5 STAGE 5 Ongoing Project Work

- ☐ At the 12-month mark of Lived Experience Engagement, ask lived experience members to complete the Lived Experience Satisfaction Survey
- ☐ Read all feedback from the Lived Experience Satisfaction Survey and address any issues
- ☐ Provide regular updates and summaries to lived experience members in plain language
- ☐ Demonstrate how lived experience input is used
- ☐ Check in regularly and address barriers
- ☐ Maintain role clarity, address if this has evolved over the project
- ☐ Utilise the expertise of the group for demonstrable effect on the project, and share with the group how this has occurred
- ☐ Process payments promptly and acknowledge contributions

6 STAGE 6 Outputs Phase

- ☐ Share findings and outputs with the group
- ☐ Highlight lived experience impact on outcomes
- ☐ Provide recognition and dissemination opportunities (eg, co-authorship, co-presenting where suitable)

7 STAGE 7 Project Close-Out

- ☐ Provide clear summary of outcomes and impact
- ☐ Thank lived experience members and recognise contributions
- ☐ Ensure all payments are completed
- ☐ Ask lived experience members to do the lived experience Satisfaction Survey

8 STAGE 8 Post-Project Reflection

- ☐ Review survey feedback and address any issues
- ☐ Identify strengths and improvement areas
- ☐ Integrate learnings into future projects
- ☐ Share final results of the lived experience Satisfaction Survey as part of your reporting

Suggested Reference (Publication Pending)

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