Paediatric Palliative Care
Centre of Research Excellence

FACTSHEET

# Engaging with Lived Experience in Paediatric Palliative Care Research

## From Foundations to Best Practice

*This document summarises key frameworks, principles and practical guidance. It is intended as a reference you can return to as you plan or review consumer and community involvement (CCI) in your own research.*

**Remember:** The question is not whether to involve consumers — it is how to do it well.

## A Framework for Involvement

Consumer involvement exists on a spectrum. Understanding where your research currently sits — and where you intend to move — is the starting point for all CCI planning.

### Research done on, with, or led by consumers

- **ON —** Research on people: Consumers are subjects or participants. Researchers define the questions, design the study, and interpret the findings. Risk: questions may not reflect lived priorities, and real-world translation is often limited.
- **WITH —** Research with people: Consumers are genuine partners throughout — contributing to design, methods, interpretation, and dissemination. This produces stronger relevance, improved recruitment, greater community trust, and better translation.
- **LED BY —** Research by people: Consumers define the questions and drive the agenda. Researchers provide technical support at the community's invitation. This produces maximum relevance and community ownership.

### Key principle

Most research currently sits in the 'on' category. The aspiration is not to leap immediately to 'led by' — it is to honestly assess where you are and move deliberately toward greater partnership.

# Why Consumer Involvement Matters

### Funder expectation

NHMRC, MRFF and Cancer Australia now require meaningful CCI as a condition of grant assessment. This is current policy, not a future direction. Researchers who do not engage will find themselves at a disadvantage in competitive grant rounds.

> **Funder expectation:** NHMRC and MRFF expect meaningful involvement across phases from priority setting through to implementation — not just dissemination. Build this into your ethics applications and grant budgets from the start.

### Better research

Participatory approaches consistently produce research that asks better questions, recruits more effectively, and translates more reliably into practice. This is not altruism — it is good methodology.

### An ethical baseline

Research that affects communities should be shaped by those communities. For those working in paediatric palliative care, families and carers carry enormous burden. Their expertise about what matters, what is feasible, and what is harmful is irreplaceable.

# The Engagement Spectrum

The IAP2 Spectrum of Public Participation provides a credible, internationally recognised framework for understanding levels of consumer engagement.

- **INFORM:** We provide consumers with information. One-directional — no feedback loop.
- **CONSULT:** We ask for input on our plans. The decision remains ours.
- **INVOLVE:** We work with consumers throughout. Their views shape outcomes.
- **COLLABORATE:** Decision-making is shared. Consumers are genuine co-investigators.
- **EMPOWER:** Consumers lead. We provide technical support to their agenda.

Most researchers currently operate at Inform or Consult — and that is a legitimate starting point. The goal is to make a conscious, resourced decision to progress one level at a time.

# Consumer Involvement Across the Research Lifecycle

Consumer involvement is possible at every stage of the research lifecycle. Earlier entry produces deeper impact. Involving consumers only at dissemination is community notification — not CCI.

### Priority setting and design (Stages 1–2)

This is where consumer involvement has the greatest impact. Consumers identify what questions matter most, not just what is scientifically interesting.

*Example: James Lind Alliance Priority Setting Partnerships; consumer members on grant review panels.*

### Ethics and data collection (Stages 3–4)

Consumers reviewing participant materials often identify problems that ethics committees miss — inaccessible language, unreasonable burden, or dehumanising framing.

*Example: Consumers on ethics review committees; co-designing interview guides; improving recruitment messaging.*

### Analysis and translation (Stages 5–6)

Member checking — sharing themes with consumers to validate or challenge researcher interpretation — strengthens rigour. Co-authorship of plain language summaries is increasingly expected by funders.

# Getting the Basics Right

Six elements must be in place before involvement begins. If any are absent, involvement is likely to be tokenistic or harmful.

1. **Role clarity:** Write it down. What is the consumer's role? What decisions can they influence? What is outside scope? Ambiguity is where disengagement and harm begin.

2. **Early involvement:** If consumers are invited only after research questions are fixed, the most important decisions have already been made without them. Build involvement into grant applications at the design stage.

3. **Plain language:** All materials — information sheets, ethics documents, steering committee papers, findings reports — must be accessible. Jargon is exclusion.

4. **Fair reimbursement:** Budget for payment, transport, parking, childcare, and interpreter costs. Acknowledging that time and expertise have value is part of an honest partnership.

5. **A named support person:** A dedicated research liaison or consumer mentor is the single highest-yield structural change most teams can make. It dramatically improves retention and quality of involvement.

6. **Shared expectations:** Have the reciprocity conversation early. Researchers benefit from CCI — say so explicitly. Consumers are not there to serve researchers at their own expense.

# What Gets in the Way

These are not individual researcher failures. They are systemic challenges that require collective, structural solutions.

- **Attitudes on both sides:** Scepticism about CCI exists among researchers and consumers alike. Neither group is immune to assumptions about the other's expertise or motives.
- **Power imbalance and tokenism:** Placing a consumer in a formal committee without adequate briefing, support, or genuine authority is not involvement — it is performance. It is a structural problem requiring structural solutions.
- **Reflecting true diversity:** The same pool of experienced consumer advocates tends to be engaged repeatedly. Active design is required to include First Nations, CALD, rural, paediatric family, and otherwise marginalised communities.
- **Consumer fatigue and sustainability:** Many consumers involved in research are simultaneously managing their own or their child's serious illness. Poorly supported involvement compounds harm. Wellbeing is a research governance responsibility.
- **Time and resource constraints:** Meaningful CCI costs money and time. Under-resourced involvement produces poor outcomes and erodes trust from both parties. Budget for it properly.
- **Biomedical vs lived experience frameworks:** A clinician's view of what matters in paediatric palliative care and a family's view may be genuinely different. Good CCI makes space for both without privileging the clinical perspective as more legitimate.

# Trauma-Informed Practice and Harm Minimisation

This is a foundational competency, not an advanced add-on. People with lived experience of serious illness, disability, grief, or marginalisation frequently carry trauma. Research processes — even well-intentioned ones — can cause harm through retraumatisation, tokenism, or loss of control. This is especially significant in paediatric palliative care, where families may be bereaved, actively caregiving, or both.

! **Retraumatisation:** Well-intentioned research can cause harm when consumers are repeatedly asked to relive difficult experiences without adequate preparation, support, and debrief. Never require personal disclosure as a condition of involvement. Always return findings to participants in accessible form. Personal story sharing is never a condition of involvement. Preparation before and debrief after any session involving difficult content is standard practice, not optional.

## The five principles

**Safety**
Physical, emotional, and psychological. Not just 'will they be comfortable in the room' but 'does this process ask more of them than they can give, without adequate support'?

**Trustworthiness**
Transparency at every stage: what will involvement require, what will happen with information shared, and what influence will the consumer actually have? Do not overstate the impact of their contribution.

**Choice**
Genuine opt-out points throughout the process — not just at recruitment. People's circumstances change. The ability to step back without consequence or explanation must be real, not nominal.

**Collaboration**
Involve consumers in decisions about how their involvement is structured, not just in the research itself. This includes meeting formats, communication preferences, and how their contribution is acknowledged.

**Empowerment**
People should leave their involvement with more agency, more knowledge, and more connection than they arrived with. If they leave feeling used, that is a failure of design.

# Your Next Three Steps

**1 Self-assess your current engagement level**

Use the IAP2 spectrum honestly. Not 'where would I like to be' but 'where am I now, based on my last project?' Then ask: what would it take to move one level?

**2 Complete free CCI training**

Telethon Kids Institute's Introduction to Consumer and Community Involvement in Health Research is freely available online. No cost. A well-regarded starting point for researchers at any career stage.

**3 Complete trauma-informed practice training before commencing any consumer involvement**

Phoenix Australia's Trauma-Informed Care training and the NSW Health Integrated Trauma-Informed Care Framework are both accessible and clinically rigorous. For researchers working with vulnerable populations in paediatric palliative care contexts, this is not optional.

! **Reflection question:** At what point in your current project could you meaningfully involve a consumer — and what would you need to make that safe for both of you?

# Key Resources

## CCI training

> Telethon Kids Institute — Introduction to Consumer and Community Involvement in Health Research (free, online)

## Trauma-informed practice

> Phoenix Australia — Trauma-Informed Care Training (free, online)
> NSW Health — Integrated Trauma-Informed Care Framework

## CCI guidelines and frameworks

> Involve Australia — Guidelines for Community Involvement in Genomic Research
> WAHTN — Consumer Involvement in Health and Medical Research Handbook
> IAP2 — Spectrum of Public Participation (2018)

## Measuring and reporting impact

> AHRA — CCI Measuring Impact Resource
> Staniszewska et al. (2017) — GRIPP2 reporting checklists for patient and public involvement in research. BMJ 358:j3453

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