



## When experience becomes expertise: Influencing national palliative care

Reflections from consumer members of New Zealand's National Palliative Care Steering Group<sup>1</sup> (steering group) show how consumer and whānau engagement can help shape national palliative care, and the experiences of consumer involvement with the steering group.

This case study has been informed by the perspectives of VH and GJ<sup>2</sup>, who generously shared their experiences as consumer members of the steering group. We are grateful for their openness and willingness to reflect on their involvement.

This case study does not evaluate the steering group or the technical quality of its work. Instead, it focuses on how consumer members experience being engaged in the process.

### Purpose of this case study

This case study is designed as a practical learning tool for:

- health services or programme teams wanting to partner meaningfully with consumers and whānau
- consumers thinking about engaging in health system improvement activities.

It describes what worked well, what was challenging, and what consumer engagement looked like in practice in the steering group.

### What worked well in practice

#### **Setting clear parameters: purpose, scope and accountabilities**

A critical foundation for the success of this work was being clear about what the group is there to do – and what it is not.

*“We have to remind ourselves – what’s our purpose? Why are we here?”*

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<sup>1</sup> Note: The National Palliative Care Steering Group is part of a much larger Palliative Care Work Programme which includes five working groups, an equity steering group and multiple ways that people can contribute including surveys, webinars and consultation on recommendations for change.

<sup>2</sup> The consumer members that contributed to this case study are referred to throughout the document as VH and GJ.

The steering group provides advice and oversight for the National Palliative Care Work Programme and recommendations to Health New Zealand - Te Whatu Ora - for national service improvements. It operates at a system level, focusing on:

- models of care
- equity in the provision and outcomes from palliative care services in Aotearoa
- workforce issues
- outcomes for patients and whānau.

It does not:

- make funding decisions
- design individual clinical pathways
- resolve local service delivery issues.

Being clear about this scope from the outset was critical. Consumer steering group members understood where their influence sat, which helped avoid frustration or unrealistic expectations.

*“We always bring it back to our purpose and our terms of reference. Actually, the whole team redirects us back to why we are here.”*

### **Strong facilitation and chairing**

Good chairing ensured that all voices were heard, not just from the most confident or senior people.

*“There can be dominating voices. A good chair, or co-chairs, want to hear every voice around the table.”*

### **Values-based ways of working**

The steering group intentionally used values such as whanaungatanga<sup>3</sup>, manaakitanga<sup>4</sup>, compassion and shared accountability. This created trust, psychological safety and supported honest conversations.

*“Seeing genuine openness to consumer voice has been the most rewarding part. I felt that consumer perspectives were treated as essential rather than optional.”*

*“Being able to ground the kōrero in values – compassion, dignity, manaakitanga – made the work feel safer and more human.”*

### **Designing the conditions for meaningful consumer engagement**

- Be explicit about why consumers are being engaged, what influence they can reasonably expect to have, and what decisions sit outside the group’s role.
- Revisit the purpose and what the limits are regularly, especially when tensions arise.
- Invest in strong, values-based leadership. Skilled facilitation helps balance power, foster respect and ensure all voices are heard.

<sup>3</sup> Relationships and connection that are respectful and reciprocal

<sup>4</sup> Hospitality, kindness, and generosity

## Supporting consumer members

Effective consumer engagement requires more than simply inviting consumers to the table.

### **Emotional and relational support**

In response to the emotional weight described above, the group deliberately created space for relational support, shared responsibility and informal check-ins.

### **Resourcing and recognition**

Consumer members were remunerated and reimbursed for expenses, in line with the Health Quality & Safety Commission Te Tāhū Hauora policy for consumer and whānau engagement, fees and reimbursement<sup>5</sup>. This recognises lived experience as skilled work, not voluntary goodwill.

### **Feedback loops**

The steering group actively fed back on how consumer input shaped decisions, which helped reduce fatigue and cynicism.

### **Induction and ongoing learning**

Orientation was treated as an ongoing process, not a one-off event.

- Terms of reference clarified roles, expectations and values.
- A tuakana–teina approach<sup>6</sup> supported learning within the steering group, allowing people to both teach and learn from one another over time.
- Programme staff provided the opportunity to support consumer members to engage with technical information between meetings if needed.

#### **What is required to sustain engagement**

- Consumer engagement requires time, energy, and preparation – support must extend beyond attending meetings.
- Induction is not a one-off activity. Ongoing orientation and context-setting help consumer members participate effectively.
- Remuneration, practical support and flexibility are essential for participation.
- Close the feedback loop – show how input has shaped decisions, even when not all recommendations are adopted.

## Advice for consumers

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<sup>5</sup> <https://www.hqsc.govt.nz/resources/resource-library/policy-for-paying-consumers-who-are-involved-health-quality-and-safety-commission-work/>

<sup>6</sup> The concept of tuakana–teina, is an integral part of Māori society and offers a strong framework for buddy or peer-support systems. In this approach, a tuakana – someone with greater experience or knowledge – supports and guides a teina who is still learning. Importantly, these roles may reverse at any time/any given situation. For example, a long-standing member of a palliative care steering group may act as tuakana, guiding a new member through key processes and relationships. At the same time, the newer member may take on the tuakana role by contributing lived experience that enriches the group’s collective understanding.

*“Bring your whole self – your lived experience, your cultural grounding, your compassion. Be present. Don’t underestimate the value of your voice, and remember that this work, while heavy, is also a privilege: we are shaping the care people receive at one of the most important moments of their lives.”*

## Where the challenges were

Even with strong intent, challenges were unavoidable.

### **System thinking versus lived experience**

Tension sometimes arose between system-level models and what consumers knew from lived experience.

*“There was system thinking – how the model should work – but the lived experience was actually quite different.”*

*“Sometimes I’d be sitting there thinking, have you actually ever looked after somebody?”*

The steering group used a consensus-based decision-making model, where differing views could be discussed openly and formally recorded rather than smoothed over.

*“People weren’t happy at times. But we worked through it with open dialogue and a shared commitment to doing better for our whānau.”*

*“What helped most was having space to speak honestly without judgement.”*

### **Emotional weight of the work**

Palliative care, especially paediatric palliative care, can be emotionally heavy. VH and GJ spoke about the challenge of repeatedly engaging with deeply personal material.

*“It was the emotional heaviness of the kaupapa, particularly around paediatric palliative care.”*

This underscored the importance of deliberate emotional and relational support, described below.

#### **Normalising tension and emotional load**

- Many tensions occur because of limited resources and system complexity, not because of disagreement on values. Transparency about constraints builds trust, even when outcomes are imperfect.
- Build expectation that differing views – especially between lived experience and technical perspectives – are normal and valuable. Disagreement is not a failure of consumer engagement, it is a sign that real perspectives are being brought to the table.

## Why consumers wanted to be involved

It is often a connection with the purpose that catches people’s attention. Both VH and GJ had been closely involved with and looked after whānau when they were at the end of their life.

*“My interest was about families and having been in that position... We nursed our dad for a whole month, and it was an amazing experience. But we were lucky. We were a family who could do that.”*

The opportunity to participate in this work was advertised through Health New Zealand | Te Whatu Ora (Health NZ) and the Consumer Health Forum Aotearoa. While these networks reach well over 1,000 people, interviews highlighted that consumer networks are close knit, and word of mouth plays a strong role in recruiting people into roles such as this.

### Why consumer involvement matters

Palliative care is not just a clinical service – it is deeply personal, cultural and relational.

*“Without consumer involvement, the system risks being designed around organisational convenience rather than human need. We bring the lived truth of what actually matters to whānau.”*

Sharing perspectives grounded in lived experience, particularly while navigating acute life events, can be both challenging and deeply meaningful.

For more information on the National Palliative Care Steering Group and the wider National Palliative Care Work Programme: [www.healthnz.govt.nz/about-us/who-we-are/expert-groups-and-networks/expert-groups/national-palliative-care-steering-group](http://www.healthnz.govt.nz/about-us/who-we-are/expert-groups-and-networks/expert-groups/national-palliative-care-steering-group)

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