Lived experience is real world knowledge about what works in practice, not just on paper

This case study shows how consumers' contributions to reviews of the Australasian Health Facility Guidelines help shape better health environments.

It examines how consumer members experienced being engaged in the review process, and what helped or limited their ability to contribute based on their lived experience of using health services. It does not evaluate the Australasian Health Facility Guidelines or the technical quality of the guideline review process.

Sharing lived experience while navigating acute life events – such as childbirth, critical care, or serious illness – can be challenging. It can also be deeply meaningful. By sharing what worked and what didn't, these people helped shape better health environments for others.

We thank everyone who shared their experience. This case study is intended as a practical learning tool for health services and programme teams, and as encouragement for other consumers who may be considering participating in design work.

Background

In 2004, Health New Zealand | Te Whatu Ora (Health NZ) joined the Australasian Health Infrastructure Alliance (AHIA), a partnership between Australian and New Zealand public health organisations. Together, they develop the Australasian Health Facility Guidelines[1] – detailed guidance that shapes how health spaces are designed, everything from layout and room size to lighting, power outlets, and bathroom fittings.

Guidelines are reviewed every three to five years through research, consultation, and collaboration between clinicians, technical experts and consumers. Opportunities to participate are advertised through Health NZ and the Consumer Health Forum Aotearoa. What we found through these interviews was that consumer networks are tight and word of mouth plays a powerful role in recruiting to roles such as these.

Each interviewee contributed to a different guideline review. While their experiences varied, what they valued was consistent.

[1] https://healthfacilityguidelines.com.au/australasian-health-facility-guidelines

Why people got involved

Across multiple interviews, contributors were motivated by their own experiences of gaps or shortcomings and by a belief that those experiences gave them insights that could help improve things for others.

"There are things built into health spaces that just don't work for people like me – and unless we're in the room, no one notices."

"I wanted to use my experience to create positive change for other whānau. Knowing that something good came from a very difficult experience – beyond my children – and that others may have less traumatic journeys because of it, matters to me."

Their motivation was practical: make health spaces safer, more dignified, and more usable for real people.

What consumer representatives valued

Participants consistently valued:

- a clear purpose and structure
- getting information early – and updates along the way
- enough time to read, think and respond
- meaningful engagement
- skilled facilitation that balanced quieter and louder voices
- respectful, emotionally and culturally safe environments
- empathy of the experience that led people to this work
- responsiveness and closing loops.

Designing the conditions for meaningful consumer input

- Be clear about the purpose, scope and expectations from the outset.
- Provide information early and allow time for people to prepare, reflect and contribute.
- Use skilled facilitation to balance different voices and create a respectful, culturally safe environment.

Challenges and what made a difference

Not all experiences were the same. For some, this work felt familiar and accessible. For others, it felt clinical, fast-paced, and unclear.

"The project didn't quite seem clear. An information session would've helped us prepare and build relationships."

Early engagement sessions included both consumers and clinicians in large groups. These settings worked well for some, and not so well for others.

To address this, the project shifted to add a separate consumer only group session with focused facilitation in addition to the larger group meetings, and people had multiple forums to contribute.

Adapting the process improves participation

- One approach will not work for everyone.
- Offering different ways to engage, such as smaller or consumer-only sessions alongside larger group discussions can improve confidence, clarity and contribution
- Iterating the process in response to feedback is a key part of meaningful engagement.

Impact on design decisions

Consumer input shifted assumptions and directly influenced design choices – particularly around dignity, independence and everyday usability.
Examples included:

- adding grab rails
- installing overbed tables, power and wifi so patients could work or stay connected.

“The ward I was in, I couldn't toilet independently. There weren’t grab rails.”

“I suggested an overbed table and somewhere where they could plug both power and wifi in. Patients who are stuck on dialysis 5 or 6 hours, three days a week sitting in that chair, it's going to be hugely useful if those people especially if they're employed, they can actually work.”

Some examples drew on experiences of much older facilities, highlighting why design guidance has continued to evolve over time and helped reinforce the importance of infection prevention principles that are now routinely embedded in contemporary Intensive Care Unit (ICU) design.

“They had carpet all through most of the ICU and it was a terrible idea.”

These were not abstract ideas – they were practical, experience-based insights that reshaped outcomes.

What health services can learn from this

- Be clear about the purpose and expectations from the start.
- Recruit when the work is tangible and meaningful.
- Remember: Embed lived experience and whānau voice at the earliest stages of service planning, design, and evaluation.
- Skilled facilitation and pre-briefing are key.
- Close feedback loops and respond in real time where possible.
- Make conflict of interest and safety checks explicit.

- Remember the context in which people are contributing from.

“I had just arrived home with my baby after leaving Neonatal Intensive Care Unit (NICU). That was the context I was contributing from.”

Applying these insights in practice
Embed lived experience early — not as an add-on, but as part of core design and planning.
Recruit consumers when the work is meaningful and clearly defined.
Invest in facilitation, preparation and ongoing communication.
Make expectations, roles and safety processes explicit.
Close the loop by showing how input has influenced decisions

What consumers can learn from this

- You don’t need to speak for everyone.
- Your value lies in what you notice that others don’t.
- It’s okay to ask for context, clarity and time.
- You may not see every suggestion land – but your input can still shift thinking.
- Small observations often lead to systemwide improvements.

Consumers are not expected to represent everyone nor should they. What matters is the insight they bring from where they sit and how that fits into the wider system.

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