



Case Study:

Embedding the Code of expectations in the diagnosis and management of chronic kidney disease

The National Clinical Renal Network (the Network) was established by Health New Zealand | Te Whatu Ora (Health NZ) in 2023 to guide and strengthen the approach to chronic kidney disease across New Zealand. The Network brings together clinicians, community partners, people with lived experience and whānau voices to drive better and equitable outcomes for those living with chronic kidney disease.

The work of the Network spans the full continuum of kidney health – from community awareness and early detection to hospital-based care, renal replacement therapies, dialysis services and transplant pathways, and whānau support. Central to this work is creating consistent, needs-based models of care that ensure quality for all communities.

Why this matters

Chronic kidney disease is a global "silent epidemic" often progressing unnoticed to advanced stages without symptoms. Early detection via blood/urine tests is critical to prevent irreversible, severe, and costly late-stage or fatal outcomes.

Chronic kidney disease disproportionately affects Māori, Pacific peoples, disabled communities and those living rurally. Addressing chronic kidney disease in these communities will mean addressing some of the inequities in health outcomes that exist.

Driven by the Code of Expectations¹, the Network aims to place people, stories and lived realities at the centre of system change.

Connecting the Code of expectations to support consumer and whānau engagement

The Network established Te Roopū Kahika in 2024. It is a consumer and whānau voice advisory group bringing together diverse lived experiences across ethnicity, geography, gender, age and disability.

Te Roopū Kahika takes its name from the towering kahikatea tree – symbolising resilience, collective strength and standing tall together. It also acknowledges that chronic kidney

¹ [Code of expectations for health entities' engagement with consumers and whānau \(hqsc.govt.nz\)](https://www.hqsc.govt.nz)

disease is largely due to suboptimal management of many other illnesses, for example, high blood pressure and other heart problems, diabetes, gout and inappropriate use of medicines.

The Code sets expectations for health entities' engagement with consumers and whānau.

The Network is embedding the SURE Framework², which emphasises supporting, understanding, responding and evaluating consumer and whānau voice across services. In 2025, the Network, in partnership with the Commission, conducted a project to further the development of a chronic kidney disease pathway.

Purpose of this project

The purpose of this initiative was to embed consumer, whānau and lived-experience leadership across service design for chronic kidney disease in Te Tai Tokerau.

The full report – Survey Analysis Report: Experiences of Māori Living with Chronic Kidney Disease – that describes this project is available at www.hqsc.govt.nz

The project sought to explore the perspectives of consumers and whānau on:

- journey to diagnosis
- access to information
- healthcare interactions
- the broader personal and social impacts of living with chronic kidney disease.

Alignment with the Code of Expectations

Guided by the kaupapa symbolised in the kahikatea tree, Te Roopū Kahika brings forward a strong, collective voice to highlight where care is working well, where it is falling short, and how partnership with whānau can be strengthened.

The work of Te Roopū Kahika is an enactment of the Code of Expectations by:

- strengthening participation through authentic partnership
- shared planning and decision-making
- ensuring cultural safety and safe consumer and whānau engagement
- grounding service improvement in lived experience
- genuine partnerships, between clinicians, health professionals and consumer representatives
- ensuring transparency of decision making.

Consumer and whānau engagement

The project engagement centred on kanohi ki te kanohi (face to face) kōrero in places chosen by participants – homes, renal units, and community spaces, including a garage where home dialysis was taking place. This ensured safety, dignity and choice.

Participants gave informed consent to participate in kōrero and could withdraw at any time.

² [Consumer and Whānau Engagement SURE framework \(hqsc.govt.nz\)](http://www.hqsc.govt.nz)

The project was funded by the Commission and led by John Timoti-Hohaia (a valued member of Te Roopū Kahika), who has lived experience of chronic kidney disease and renal replacement therapy. This approach fostered relational trust and cultural safety.

Kanohi ki te kanohi interviews were conducted to encourage storytelling and reflection, drawing insights from participants aged from mid-20s to late 60s. John spoke with nine Māori participants. Many shared experiences they had never discussed with their own whānau.

Insights from consumers and whānau

Key data

- 100 percent of kōrero participants received leaflets but did not understand the information.
- 77 percent of participants experienced significant emotional distress as a result of the diagnosis received.
- 60 percent of participants received their diagnosis from hospital specialists rather than primary care.
- 55 percent of participants were offered counselling.

Emerging themes

There were missed opportunities for early detection

Symptoms were often missed in primary care. Many were diagnosed only after hospitalisation or specialist referral.

Lifestyle advice was not grounded in lived realities

Advice on diet or exercise ignored financial pressures, cultural practices and access barriers, this resulted in whakamā and mistrust.

Cultural and genetic factors were not recognised

Participants wanted clear information from Primary care about hereditary risks and whānau-inclusive education.

Emotional and social impacts

Chronic kidney disease affected relationships, confidence and mental health.

System challenges

Challenges included:

- inconsistent specialist expertise within the hospital environment
- inadequate explanations of diagnosis and management options
- poor preparation for surgery or dialysis
- consumers and whānau described chronic kidney disease as “invisible”, hard to understand
- emotional distress was common and rarely acknowledged by health professionals.

Voices from participants

“They just told me to lose weight. It’s not that simple when you don’t even understand what’s wrong.”

“I only found out it was my kidneys when I got to the renal specialist after being in hospital.”

“I didn’t know how to tell my partner. I barely understood what it meant for me.”

These voices underscore the need for early education, equity-based practice and culturally grounded support.

Impact and outcomes

For practice and governance

The findings highlight the need to shift focus from individual blame to the requirement for system changes addressing long-standing gaps by:

- increasing the early identification of people with kidney decline to prevent irreversible kidney damage
- developing culturally grounded training for clinicians and primary care teams
- providing holistic, accessible health education for whānau
- building psychosocial and peer support options
- strengthening community-led engagement and awareness of kidney health
- stronger consumer partnerships
- culturally grounded quality improvements
- clearer, more accessible information pathways
- proactive integrated collaboration between primary and secondary care teams to address chronic kidney disease.

These findings have been communicated to the Network and are being embedded in service design and delivery.

Lessons learned for consumer and whānau engagement

What worked well included:

- Te Whare Tapa Whā framework informed this kaupapa, shaping the approach and analysis throughout
- kanohi ki te kanohi engagement
- storytelling and relational approaches
- leadership grounded in lived experience.

Challenges and how Te Roopū Kahika addressed them included:

- geographical barriers → flexible meeting formats
- emotional sensitivity → on-the-spot support

- cultural diversity → tikanga-responsive engagement.

Sustainability and next steps

Embedding consumer and whānau voice

The National Clinical Renal Network will continue to work with Te Roopū Kahika through ongoing:

- hui
- co-design wānanga
- kōrero-surveys
- feedback mechanisms.

Related resources

- [Code of expectations for health entities' engagement with consumers and whānau \(hqsc.govt.nz\)](https://www.hqsc.govt.nz)
- [Code of expectations implementation guide \(hqsc.govt.nz\)](https://www.hqsc.govt.nz)
- [Consumer and Whānau Engagement SURE framework \(hqsc.govt.nz\)](https://www.hqsc.govt.nz)
- [Survey Analysis Report: Experiences of Māori Living with Chronic Kidney Disease \(hqsc.govt.nz\)](https://www.hqsc.govt.nz)

Published April 2026 by Health Quality & Safety Commission Te Tāhū Hauora, PO Box 25496, Wellington, 6146. Available online at www.hqsc.govt.nz.

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