



Case study:

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

A Māori-led research project from the National Clinical Renal Network aims to improve services for people living with the diagnosis and management of chronic kidney disease.

Chronic kidney disease affects many people – especially Māori, Pacific whānau, disabled communities, and those living in rural areas. Too often, people are diagnosed late, feel confused about what's happening, and don't feel culturally safe in the health system.

As part of this mahi, the National Clinical Renal Network established Te Roopū Kahika, a consumer and whānau voice advisory group into all service design discussions. Guided by the kaupapa symbolised in the kahikatea tree, this roopū stands tall for the communities.

A unique and important piece of mahi

To understand what people were experiencing, Te Roopū Kahika conducted a research project in Te Tai Tokerau. This meant meeting kanohi ki te kanohi, (face to face), listening and valuing shared lived experience.

This work supports the Code of expectations, which promotes that the health system must partner with consumers, whānau and communities in planning and improving services.

The project was led by John Timoti-Hohaia (a member of Te Roopū Kahika) with lived experience of chronic kidney disease and dialysis. His leadership and expertise helped people feel safe to open up and share their experiences of living with the diagnosis and management of chronic kidney disease.

This unique position ensured:

- shared cultural respect
- shared clinical experience
- empathy
- authenticity
- mana-enhancing engagement.

The study has laid a strong foundation for how Te Roopū Kahika continue to advance and elevate whānau voice.

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

What whānau told Te Roopū Kahika

Nine Māori participants shared their stories and journeys. Their kōrero revealed strong themes.

There is not enough early support

Many participants did not know they had kidney problems until they were very sick or in hospital. General practice visits didn't always detect early signs of kidney disease. For people with type 2 diabetes, the link between diabetes and chronic kidney disease was not clear or explained.

Lifestyle advice doesn't match real life

Participants were told to lose weight or change their diet, but they weren't asked about the cost of food, transport, their cultural preferences, or whether the advice even made sense for their whānau.

There is a heavy emotional burden

Many felt shocked, scared, overwhelmed and didn't always know how to talk about it with whānau.

“I didn't know how to tell my partner. I didn't understand it myself.”

Cultural safety was missing

Some participants felt judged or unheard. Others felt they couldn't ask questions or bring whānau into appointments.

“They gave me a leaflet, but I still didn't understand what was happening.”

There is a strong desire for whānau-inclusive, culturally grounded care

People wanted:

- clear information written in plain language
- early education about whakapapa (hereditary) risk
- whānau to be involved.

Lessons learned

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.

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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.

Where to next

Te Roopū Kahika is committed to:

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

Its goal is simple: care that reflects the realities, values, and hopes of the people and whānau it serves.

If you want to be involved

Te Roopū Kahika welcomes whānau, community leaders, people with lived experience, and local providers to be part of this kaupapa.

For more information, please contact:

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o Aotearoa**
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