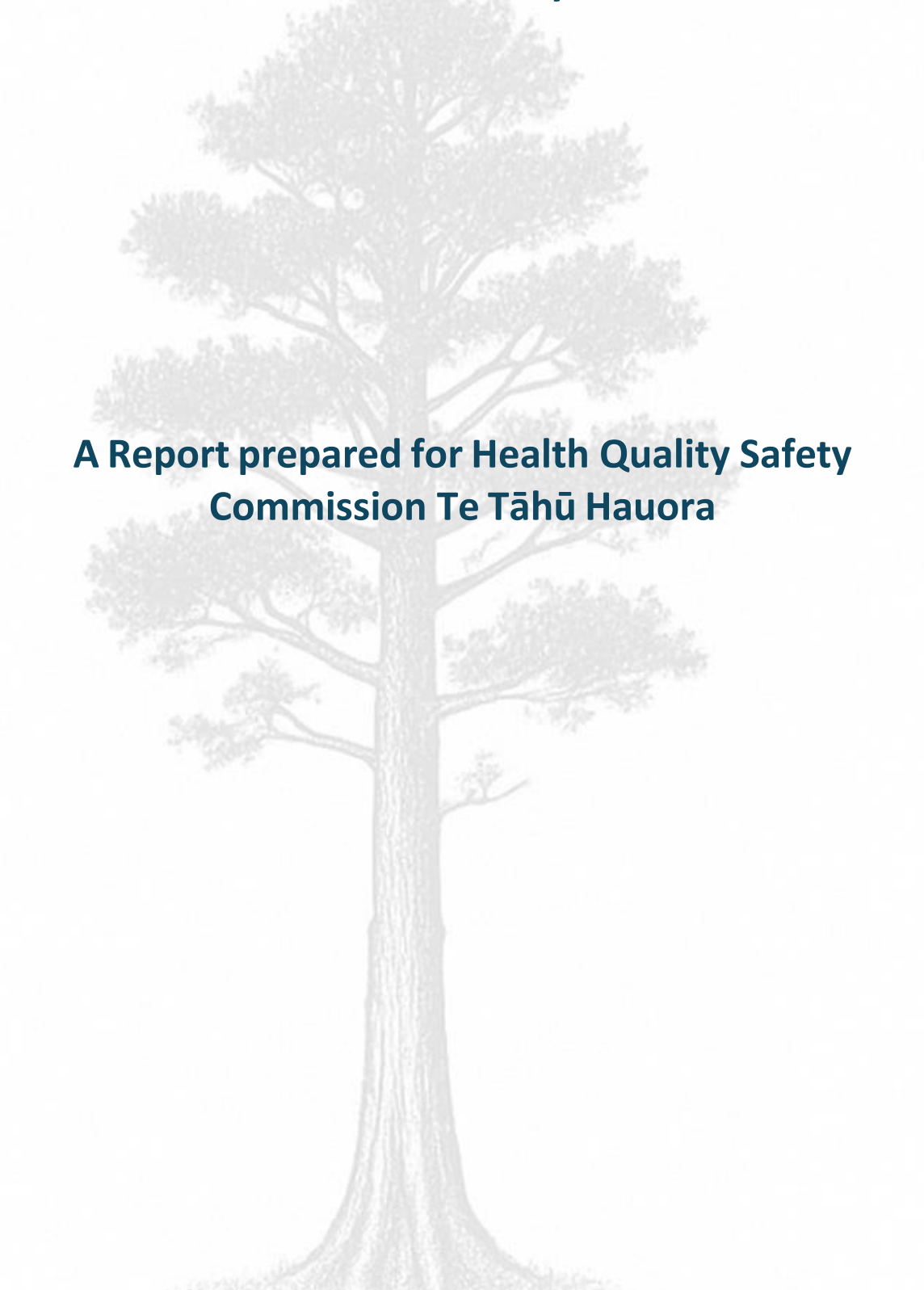


Survey Analysis Report: Experiences of Māori Living with Chronic Kidney Disease

**A Report prepared for Health Quality Safety
Commission Te Tāhū Hauora**



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Survey Analysis Report: Experiences of Māori Living with Chronic Kidney Disease (CKD)

1. Executive Summary

This report presents findings from a survey undertaken by a researcher with lived experience of Chronic Kidney Disease (CKD) and renal replacement therapy. Nine participants, all of Māori descent, were interviewed to explore their journey to diagnosis, access to information, healthcare interactions, and the broader personal and social impact of living with CKD. This research is unique and groundbreaking as it is believed to be the first study led by a person with CKD, bringing cultural alignment and lived insight to every stage of the research process.

Key themes emerging from the interviews reveal a lack of early education, inconsistent communication of diagnosis and treatment, and a profound emotional impact at the time of diagnosis. While some participants had strong whānau support and positive interactions with renal specialists, others experienced significant confusion, lack of information, and limited emotional or psychological support.

The findings highlight the need for earlier intervention in primary care, more accessible and understandable patient education materials, consistent medication guidance, and culturally safe, whānau-inclusive models of care. Participants' stories show that CKD is not just a clinical condition but one with life-altering consequences — impacting family, employment, identity, and wellbeing.

2. Key Findings

- **Opportunities to improve early detection and management** were highlighted, with issues such as misdiagnosis, poor communication, and inappropriate advice reported by most participants. 60% received information about their diagnosis from hospital specialists. Inappropriate advice was given, particularly concerning healthy lifestyles.
- **Reviewing support to understand the diagnosis is necessary** – 100% of participants received information leaflets, but most reported they did not understand the impact or were in denial.
- **Opportunities to enhance emotional support for newly diagnosed individuals** - High levels of emotional impact were reported, with 77% of participants expressing feelings of anger, depression, denial, grief, and confusion. Only 55% of participants or their whānau were offered professional counselling support.

3. Primary Care Investment

The interviews highlighted the need to invest early in patients' CKD journey. Urgent investment is required in:

- Developing culturally appropriate training for GPs and Primary Care staff in the diagnosis, identification and communication of CKD
- Appropriate and culturally tailored support around health education using a holistic whānau-centred approach
- Better support for patients to understand and adjust to their diagnosis, including access to peer networks and psychological support.
- Sustained communication and inclusion campaigns for communities to understand CKD

4. Introduction

Chronic Kidney Disease (CKD) disproportionately affects Māori and Pasifika populations in Aotearoa New Zealand, yet little research has focused on the lived experiences and barriers faced by these communities in the healthcare system. This qualitative report draws from interviews with nine participants (all Māori or Pasifika) living with CKD, using a semi-structured survey to explore their pathways to diagnosis, healthcare interactions, and the broader social determinants influencing their condition.

This research was undertaken by a person living with CKD who is currently receiving renal replacement therapy. To the best of our knowledge, this is the first time such research has been led by someone with lived experience of CKD. Furthermore, the researcher is of Māori descent, creating a unique alignment between the cultural identity of the participants and the researcher. This positionality brings added depth, empathy, and insight to the study, making the findings not only clinically relevant but also culturally grounded and community-informed. The approach is both groundbreaking and transformative in its centring of lived and Indigenous knowledge.

5. Methodology

A kaupapa Māori approach was used for this research. Nine participants diagnosed with CKD were interviewed using a semi-structured survey. All participants identified as Māori.

Thematic analysis was employed to identify key patterns and themes from the qualitative responses, focusing on their healthcare journeys, experiences of diagnosis, and reflections on systemic, cultural, and lifestyle-related factors. Participants consented to the interview and had the option to withdraw at any stage.

Interviews were kanohi ki te kanohi (face to face).

Participants were approached through community health organisations and support groups, ensuring a culturally appropriate recruitment process. Thematic analysis was applied to identify key patterns and themes from the qualitative responses, focusing on healthcare journeys, experiences of diagnosis, and reflections on systemic, cultural, and lifestyle-related factors.

Additionally a quantitative analysis was undertaken by plotting the questions in an Excel spreadsheet and counting responses.

Results

Ten participants were recruited for interviews. However, one was visiting the area, and the survey was incomplete for follow-up purposes and has not been included for this reason. Nine participants, aged between mid-20s and late 60s, diagnosed with CKD, were interviewed using a semi-structured survey. The interviews took place in the hospital renal unit and at participants' homes. One interview was conducted in a garage where the participant does their home dialysis.

The analysis aimed to provide a comprehensive understanding of the patient journey from pre-diagnosis to treatment regimens, including home haemodialysis..

The interview questions fostered in-depth conversation, sometimes requiring the participant to confront painful historic medical events they had not revisited for a long time or had suppressed. Some admitted they had not shared their experiences because their whānau did not understand. While they carried the full burden of their diagnosis, most had some level of whānau support.

Responses to the survey questions were recorded in chronological order as the participant recalled their medical history & journey.

The interview reported that the Kanohi ki Te Kanohi (face to face) benefits were:

- It made the interview real, compared to an online survey
- It encouraged both participants & the interviewer to engage and create free flowing dialogue
- Both the participant and the interviewer were able to interrogate and explore details
- A lived-experience Interviewer provided on-the-spot support, acknowledgement, encouragement, empathy and understanding to the participant.

6. Key Themes Identified from Qualitative Dialogue using the Survey Questions as prompts.

6.1. Lifestyle Advice vs Social Determinants

Participants frequently described receiving judgmental advice that emphasised “healthy lifestyles” without acknowledgement of social circumstances or systemic barriers.

- Many reported being told to “eat better” or “exercise more,” without support or consideration of financial constraints, cultural eating practices, or access to appropriate services.
- In contrast, participants suggested the need for supportive, culturally appropriate education and interventions that reflect their social realities.

"They just told me to lose weight and eat healthy — but it's not that simple when you don't know what's wrong or how to do it properly."

6.2. Missed Opportunities in Early Detection and Management

A considerable number of participants reported early signs and symptoms that were not adequately followed up by primary care providers.

- Early symptoms of CKD were overlooked or misattributed.

- Participants were often hospitalised before receiving a CKD diagnosis, indicating failure in early detection.
- Incorrect blood pressure management advice and inadequate follow-up by GPs were common.
- Diabetes diagnoses were not managed, and the link between diabetes and kidney function was not clearly communicated.
- More than two-thirds of participants only became aware of their CKD through a renal specialist, not their GP, highlighting a gap in primary care engagement and intervention.

"The GP never said it could be my kidneys. I found out only when I saw the renal doctor after being in hospital."

6.3. Health System Shortcomings

Systemic issues across both primary and secondary care were repeatedly raised:

- Lack of specialist expertise at local hospitals, leading to delays and referrals to regional hospitals.
- Pre-surgery consultations understated risks and long-term implications, leaving patients unprepared.
- Participants often described confusion, denial, or anger upon diagnosis — many noted that CKD is "invisible" and hard to grasp without visible symptoms.
- Several described not fully understanding the impact on themselves and their whānau (family) at the time of diagnosis.

"It was hard to accept it. You can't see it, you don't feel it, then suddenly your life is changed."

6.4. Cultural and Genetic Factors

- Participants reported a strong familial pattern of CKD and related illnesses such as diabetes and hypertension.
- Many expressed concern that Māori and Pasifika are more susceptible, but noted a lack of early education about hereditary risks and preventative care.
- Cultural attitudes such as stoicism, avoidance of medical care, and mistrust of the healthcare system were also mentioned as barriers.

"Lots of people in my family had it, but no one ever explained that it could be passed on or that we should check early."

6.5. Emotional and Social Impact

- Participants described experiencing anger, denial, grief, and feelings of isolation following their diagnosis.

- Several mentioned the strain on relationships, and some lacked a full understanding of the impact on their partner or family.
- However, whānau support played a crucial role in helping some come to terms with the diagnosis and navigate the health system.

7. Quantitative findings derived from the Survey

7.1. Family History and Awareness of CKD Links

- 7 out of 9 participants reported a whānau history of conditions such as diabetes, gout, heart disease, kidney disease, or high blood pressure.
- Only 5 of 9 participants were aware that these conditions are linked to CKD, indicating a significant gap in public and community-level education.

7.2 Diagnosis Pathways

- All participants were diagnosed through blood and urine tests.
- The majority (5 of 9) were only made aware of CKD following hospital admission or direct referral to a renal specialist.
- Only one person was informed by their GP, while another recognised symptoms based on their whānau member's experiences.

7.3. Communication of Diagnosis

- All participants received pamphlets, but these were initially confusing and only became somewhat useful over time.
- Only those who were diagnosed by renal specialists felt they understood the seriousness and meaning of their condition.
- 100% of participants initially felt confused, disbelieving, grieving, angry, or depressed upon diagnosis.

7.4. Medication Education

- There was inconsistency in how information on medications was delivered:
 - 2 people received little or no explanation.
 - 3 were informed by renal unit staff.
 - 2 received input from both a pharmacist and GP.
 - 1 heard only from a GP; 1 was unsure.

7.5. Whānau Support at Diagnosis

- 6 participants had whānau support present when receiving the diagnosis.
- 3 did not, although 1 opted for this.

7.6. Access to Counselling or Psychosocial Support

- Less than half (4 out of 9) were offered access to a renal social worker or psychologist.
- 5 received no offer of emotional or mental health support at all.

7.7. Life Impact

- All participants reported significant disruption to their lives due to CKD.
 - One participant had to withdraw from medical school.
 - Several described loss of independence and difficulty travelling or engaging with whānau.

- One person shared a positive outcome — no longer suffering from chronic gout, but traumatic in every other aspect.
- In one case, an employer allowed paid time off so that a participant's son could support her care needs. This was a single reflection of the ripples that spread widely with CKD.

8. Discussion

This qualitative study reveals significant gaps in early detection, culturally competent care, and holistic support for Māori and Pasifika individuals with CKD. While individual lifestyle choices were often emphasised by clinicians, participants highlighted a deeper interplay of systemic barriers, limited education, and cultural factors. Primary care providers are missing crucial opportunities to detect, diagnose, and educate patients early in the disease progression.

There is also a need for better communication of chronic disease risk, particularly where genetic predisposition is strong. The invisibility of CKD — combined with a lack of culturally appropriate education — contributes to delayed understanding, reduced engagement with care, and avoidable deterioration.

9. Recommendations

Based on these findings, the following actions are recommended:

1. Improve Primary Care Training

Ensure GPs are equipped to detect early CKD, understand the specific risks for Māori and other populations (e.g. Pacific peoples), and provide culturally safe care.

2. Develop Culturally Tailored Health Education

Co-design CKD education and prevention programmes with communities to improve understanding and trust.

3. Strengthen Follow-Up Systems

Implement proactive follow-up mechanisms after diagnoses such as diabetes or hypertension to monitor kidney function earlier.

4. Increase Community-Based Screening

Provide regular kidney health checks in community and church settings, particularly for those with family histories.

5. Integrate Whānau-Centred Care

Involve whānau in consultations and provide support that includes emotional, relational, and spiritual dimensions of care.

6. Supported and collaborative communication campaigns

Ensure community understanding of kidney disease and its sequelae.

10. Conclusion

The experiences of these nine participants highlight that CKD in Māori communities is shaped as much by systemic gaps and social contexts as it is by clinical conditions. Meaningful change will require moving away from lifestyle-focused, individualised blame toward equity-focused, whānau-inclusive, and culturally grounded approaches to kidney health.

This research stands apart in that it was conducted by a Māori researcher with lived experience of CKD and renal replacement therapy. This insider perspective provided cultural resonance with participants and allowed for a level of connection, understanding, and authenticity that is often missing from conventional research. The outcome is a richer, more grounded representation of community voices — one that challenges institutions to listen deeply and act meaningfully. This work is a pioneering step toward inclusive, culturally responsive kidney care and research.

Acknowledgement

Tēnā tātou katoa. Ngā mihī nui ki te “Te Tāhū Hauora Health Quality & Safety Commission” mō tō tautoko i ēnei kaupapa. We are extremely grateful for your generous contribution, which enabled us to complete this important mahi i roto i enei ripoata. We look forward to your continued support towards conducting further research in the future to improve the Health system here in Aotearoa NZ. John Timoti-Hohaia

Kahikatea Tree

The Kahikatea tree was chosen to symbolise “Te Roopuu Kahika.” Kahika is the name of the tallest indigenous tree in Aotearoa. The roopuu is standing tall in the renal clinical network space, providing insightful commentary and advocacy on behalf of Whānau and the Consumer Voice. Their voice is and should be the ‘tallest’ voice.

Appendix 1 – Interview Questions

- 1) How did you know you were Mauiui (unwell)
- 2) Is diabetes, gout, heart / kidney disease, high BP in the whānau?
- 3) Did you know that cardio/gout/diabetes and pre-CKD are all linked?
- 4) Did you GP advise you having CKD?
- 5) What & how did the GP diagnose you?
- 6) Did the GP/Practice Nurse make sure that you understood the diagnosis?
- 7) What CKD information were you given, if any, at the time of diagnosis?
- 8) Did the GP / Pharmacist spend time helping you to understand your medications?
- 9) When did you find out you had CKD?
- 10) Describe how did diagnosis make you feel?