



Clinical practice guidelines for management of chronic kidney disease for Māori in Aotearoa New Zealand

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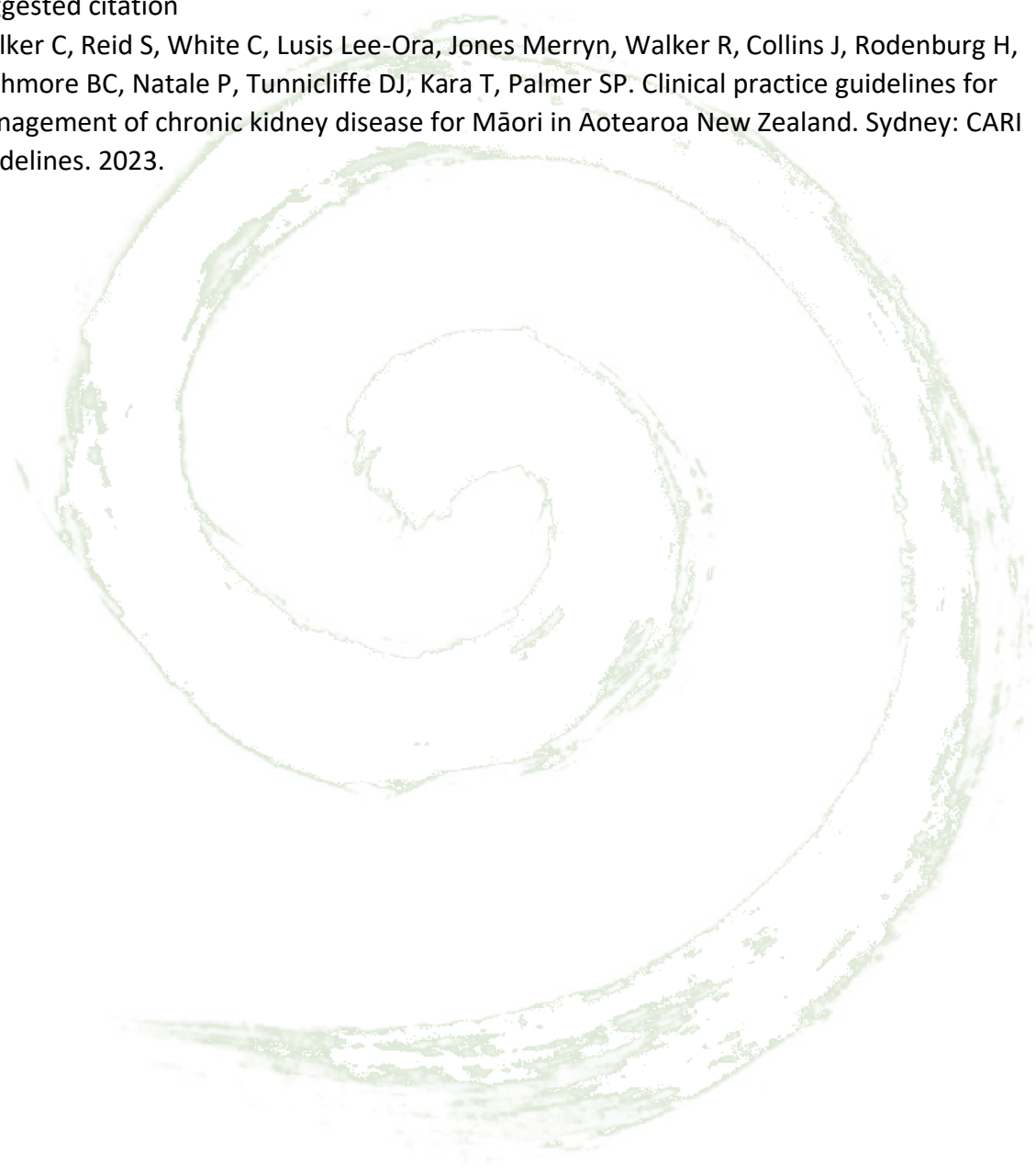
Clinical practice guidelines for management of chronic kidney disease for Māori in Aotearoa New Zealand

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Executive Summary

Clinical practice guidelines for management of chronic kidney disease for Māori in Aotearoa New Zealand

Recommendations for health systems and health services

Equity

We recommend that health systems and providers prioritise actions to achieve equitable outcomes in kidney health for whānau Māori.

Strong recommendation. Evidence: Pai (Good).

We recommend that health systems and providers advance equity in kidney health through the collection, reporting, monitoring, and use of high-quality Māori-centred data over time, to inform quality improvement.

Strong recommendation. Evidence: Āhua pai (Moderate).

Governance and accountability

We recommend that health systems and providers include Māori leadership and governance and hold providers accountable for healthcare quality.

Strong recommendation. Evidence: Pai (Good).

Cultural safety

We recommend that health systems and providers ensure that cultural safety is a key aspect of workforce training and professional development to ensure that culturally safe care is delivered to whānau Māori.

Strong recommendation. Evidence: Pai (Good).

Case management

We recommend that health systems and providers of services for Māori with or at risk of chronic kidney disease are led in primary care or Kaupapa Māori services providing case management and support throughout the patient journey.

Strong recommendation. Evidence: Pai (Good).

Information systems

We suggest that health systems and providers of care for Māori with or at risk of chronic kidney disease are supported by a unified, integrated information and referral system.

Strong recommendation. Evidence: Āhua pai (Moderate).

Social determinants of equity and wellbeing

We recommend that health systems and services for Māori with or at risk of chronic kidney disease partner with organisations to address social determinants of risk factors for kidney health, such as justice, housing, education, and poverty.

Strong recommendation. Evidence: Āhua pai (Moderate).

Screening

We recommend that health systems and providers calculate five-year cardiovascular disease risk using the New Zealand Primary Prevention Equation including urine albumin to creatinine ratio and estimated glomerular filtration rate for all tāne Māori (men) aged 30 years or older, wāhine Māori (women) aged 40 years or older, and all Māori with diabetes from diagnosis.

Strong recommendation. Evidence: Āhua pai (Moderate).

Recommendations for clinicians and health service providers

Clinical assessment framework

We recommend that individual providers of care to Māori with or at risk of chronic kidney disease provide whānau-based care within an Indigenous Health Framework. This includes the importance of respect and reciprocity within the clinical relationship-building process that draws on Māori rituals of encounter, the importance of ethnicity data collection, and a process to clarify key messages and identify outstanding issues or concerns.

Strong recommendation. Evidence: Pai (Good).

Whānau knowledge and learning

We recommend that individual providers of care to Māori with or at risk for chronic kidney disease build whānau knowledge about chronic kidney disease and health issues that contribute to it using learning strategies that are whānau-focussed and culturally safe to support whānau goals.

Strong recommendation. Evidence: Pai (Good).

Contents

Acknowledgements	1
Abbreviations and terms	3
Patient and whānau priorities	4
Questions and critically important outcomes	4
Guideline principles	5
Guideline pou.....	6
Guideline recommendations	7
Explanation	7
Recommendations for health systems and health services	8
Recommendations for clinicians and health services providers	9
Kaupapa (purpose and scope)	10
Methods for guideline development.....	11
Principles.....	11
Development of guideline	11
Contributors to the guideline	11
Health providers	11
Identification of priority questions	12
Identification and retrieval of evidence	13
Appraising evidence methodological quality	14
Grading of the evidence	15
Development of recommendations.....	15
Background	17
Evidence for guideline recommendations.....	18
Equity	18
Governance and accountability	20
Cultural safety	21
Case management	22
Information systems	24
Social determinants of health and equity	25
Screening	27
Clinical assessment framework	28
Whānau knowledge and learning.....	29
Evidence alignment.....	30
Implementation	32

Actions targeted at healthcare governance	32
Actions targeted at healthcare organisations	32
Actions targeted at healthcare workers	33
References	34
Appendix 1	48



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The development of this guideline was coordinated by CARI (Caring for Australians and New Zealanders with Kidney Impairment).

The concept of these guidelines was first suggested by Kidney Health Australia in 2016 and agreed to by the CARI Steering Committee chaired by Martin Gallagher. The proposed guideline was supported by Aotearoa New Zealand members of the Steering Committee and Kidney Health New Zealand, who facilitated a funding application to the New Zealand Ministry of Health. Funding of \$17,000 was provided by the Ministry to conduct a community review of the need for this guideline and formal discussions with whānau Māori affected by chronic kidney disease. Consultations were held at four hui with whānau in 2019.

The most significant feature of these guidelines' development has been the widespread engagement and consultation with whānau Māori who experience kidney disease and utilise kidney services. Their insights and kōrero were invaluable in informing the priorities we needed to address. Ngā mihi tino mahana ki ngā hapori kua whakahoahoa i ō koutou kōrero ki a mātou.

Consultation with whānau Māori indicated practice gaps and care quality

issues that could be supported by a clinical practice guideline.

The initial guideline process was championed by Dr Tonya Kara, a paediatric kidney specialist, who motivated the formation of the guideline working group. Tonya has passed away and will always be remembered as a fierce and effective advocate for equity in her own practice and throughout Aotearoa New Zealand. Moe mai rā e te wahine koi, e te wahine rangatira.

The CARI Working Group acknowledge and thank whānau who shared their values, perspectives, and experiences of healthcare for kidney disease during the development of these guidelines.

The members of the CARI working group for this guideline are Dr Curtis Walker (Whakatōhea, Ngāti Porou, Nephrologist, Te Whatu Ora Te Pae Hauora o Ruahine o Tararua), Professor Suetonia Palmer (Nephrologist, Te Whatu Ora Waitaha, Ōtakou Whakaihu Waka), Susan Reid (Te Rarawa, Health Literacy specialist), Carla White (Ngāti Tama, Ngāti Toarangatira, Health Literacy specialist), Lee-ora Lusia (Ngāti Kahungunu ki Heretaunga, Ngāti Rakaipaaka, Te Atihaunui-a-Paparangi, Te Atiawa, Nurse Practitioner), Merryn Jones (Ngāti Rakaipaaka, Clinical Nurse Specialist, Te Whatu Ora Te Matau a Māui), Professor Rachael Walker (Te

Pūkenga, Nurse Practitioner, Te Whatu Ora Te Matau a Māui Hawke's Bay), Clinical Associate Professor John Collins (Nephrologist, Mercy Specialist Centre), Dr Helen Rodenburg (General Practitioner, Island Bay Medical Centre), Dr Tonya Kara (Paediatric Nephrologist, Starship Hospital, Te Whatu Ora Te Toka Tumai Auckland). We acknowledge the work that Associate Professor John Collins did as inaugural co-convener of our rōpu. We acknowledge the contribution of Carmel Gregan-Ford in her role as Nurse Educator with Kidney Health New Zealand during the guideline development process. We acknowledge the assistance of Kidney Health New Zealand in obtaining initial funding support from Manatū Hauora.

We thank Associate Professor Elana Curtis (Ngāti Rongomai, Ngāti Pūkiao, Te Arawa, Māori Public Health Physician) for her detailed peer review of these guidelines. We also thank Janine Hale, Nurse Specialist, for helpful feedback.

The working group provided their time and expertise in kind without specific funding. The University of Otago funded participation of Susan Reid and Carla White in all-day hui on guideline development held in 2019 and 2020.

The CARI Office team provided technical assistance and supervision: Dr David Tunncliffe, Dr Pamela Lopez-Vargas, Talia Gutman, Karine Manera, Patrizia Natale.

CARI acknowledges the work of the CARI Steering Committee, currently chaired by Associate Professor Rathika Krishnasamy.

CARI acknowledges funding from the Ministry of Health Manatū Hauora.

CARI recognises the source of the whakatauki on the cover. We were given permission to use this whakatauki (proverb) from the authors of a report commissioned by the Ministry of Health National Renal Service Improvement Project.


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In the context of these guidelines, the whakatauki describes the building and strengthening of an existing health system through the implementation of best practice.

Our most important acknowledgements are to whānau Māori and health professionals for working with us.

Abbreviations and terms

He aha te mea nunui o te Ao? He tāngata, he tāngata, he tāngata. Engari, he aha te mea nunui o te tāngata? He kōrero me Te Reo.



Ae	Yes
Āhua	Partial
Āhua pai	Moderate
Hapori	Community
Hauora	Health and wellbeing
Kaupapa Māori	Māori-led
Kōrero	Talk/discussion
Mātauranga	Knowledge
Oranga	Wellbeing
Pou	Pillar
Rangatiratanga	Autonomy/self-determination
Rōpu	Group/committee
Tāne	Men
Te Ao	World (view)
Te Reo	Language
Wāhine	Women
Whakatauki	Proverb
Whakawhanaungatanga	Building and sustaining relationships
Whānau	Extended family
Whekowheko	Poor/weak

Patient and whānau priorities

Questions and critically important outcomes

The topics in these guidelines were identified as important by Māori patients and whānau who attended one of four hui (focus groups), facilitated by Susan Reid (Te Rarawa, Health Literacy specialist) and Carla White (Ngāti Tama, Ngāti Toarangatira, Health Literacy specialist). Both are experienced focus group facilitators with extensive knowledge of te ao Māori.

The critical topics described by hui participants were:

Prevention

- Opportunities to build an understanding of kidney health
- Support to enable self-management
- Continuity of care
- Accessing timely treatment
- Education in formats and at times that whānau can access, including in video format with a healthcare worker/clinician
- Being able to talk with trustworthy clinicians to ask questions

Diagnosis

- Support to manage emotional implications
- Information and education as part of the diagnosis discussion
- Regular opportunities to discuss kidney health
- Messages from healthcare professionals and clinicians need to be consistent and coordinated
- Health professionals as collaborative with whānau

Informed decision-making

- Checking patient and whānau understanding of treatment options, including benefits and potential harms
- Delivery of services to enable decision-making
- Practical aspects of treatment planning including location of services, transport availability

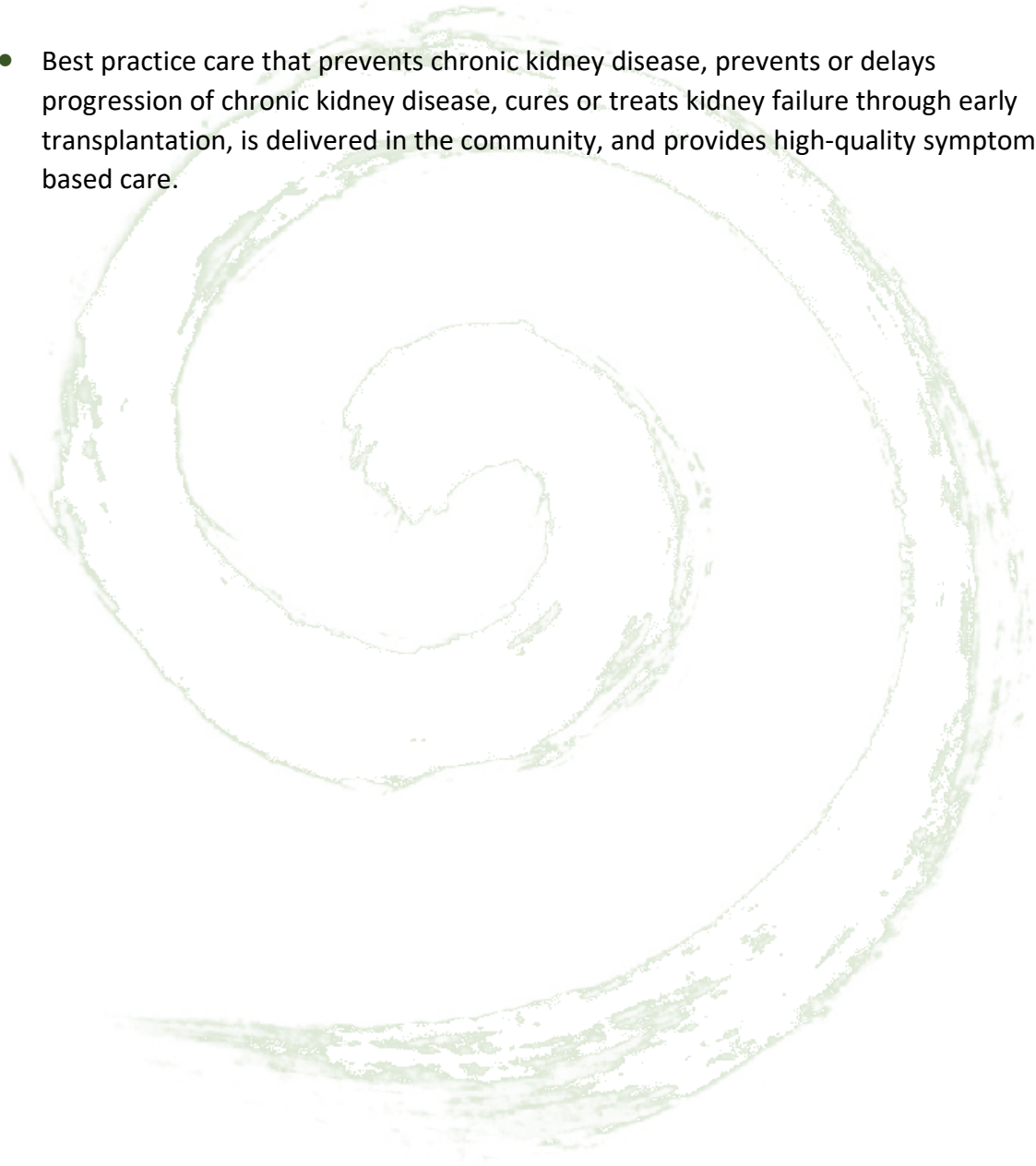
Working with Māori

- Patient and whānau centred, health literate and culturally safe care
- In-person consultation with health professionals with sufficient time to have discussions
- Clinicians and health professionals who understand whānau experiences and circumstances

Guideline principles

Healthcare services for Māori with chronic kidney disease are based on:

- Giving effect to the Treaty of Waitangi guarantee of tino rangatiratanga—autonomy, self-determination, sovereignty, self-government—to enact the principle of partnership, the principle of active protection, the principle of equity, and the principle of options.¹
- Best practice care that prevents chronic kidney disease, prevents or delays progression of chronic kidney disease, cures or treats kidney failure through early transplantation, is delivered in the community, and provides high-quality symptom-based care.



Guideline pou

The guidelines are grounded by four pou (pillars), as considered collectively by the guideline writing panel. These pou are drawn from mātauranga shared by whānau Māori during guideline development and form the underlying aspirations of safe and effective healthcare expressed within the guideline recommendations.

Whakawhanaungatanga

High-quality care for chronic kidney disease is provided by health systems, organisations and practitioners through meaningful partnerships and enduring relationships with Māori organisations, patients and whānau.

Mātauranga

Health systems, organisations and providers enable quality care of chronic kidney disease for Māori in environments that build on existing knowledge and support learning through effective sharing of high-quality information.

Rangatiratanga

Māori have the right to participate in decision-making about their kidney health and have meaningful ways to decide how health services for chronic kidney disease are provided.

Oranga

Health systems, organisations and providers are committed to providing high-quality care of chronic kidney disease that meet the rights, expectations and aspirations of Māori

Guideline recommendations

Explanation

Each guideline recommendation includes the strength of the recommendation and the certainty of the evidence on which the recommendation is made.

Evaluation of the evidence certainty underpinning these guideline recommendations is based on an appraisal of the quality of the underlying research, using an Indigenous Quality Appraisal Tool, combined with whether contributing studies were consistent in their findings, and provided evidence directly relevant to Māori patients and whānau.

The evidence certainty was adjudicated as

- **pai (good)** when the underlying research was conducted aligned to best practices when involving Māori, was consistent across studies, and involved evidence from research conducted with Māori.
- **āhua pai (moderate)** when the research was less well aligned to best practices when involving Māori, or findings were not consistent, or studies were not conducted involving Māori.
- **whekowheko (poor/weak)** when the research was less well aligned to best practices when involving Māori, *and* findings were not consistent, *and* studies were not conducted involving Māori.

The strength of the recommendation (strong or conditional) considers the balance between benefits and harms, evidence certainty and applicability to Māori health and wellbeing.

A strong recommendation is based on the quality of the evidence, a lack of evidence of important harms, and a judgement about whether translation of the evidence into practice will improve Māori health and wellbeing.

A strong recommendation indicates that most stakeholders would make the same choice as the suggested guideline action.

A conditional recommendation indicates that most stakeholders would make the same choice as the guideline action, but a substantial minority would not.

Clinical practice guidelines for management of chronic kidney disease for Māori in Aotearoa New Zealand

Recommendations for health systems and health services

Equity

We recommend that health systems and providers prioritise actions to achieve equitable outcomes in kidney health for whānau Māori.

Strong recommendation. Evidence certainty: Pai (Good)

We recommend that health systems and providers advance equity in kidney health through the collection, reporting, monitoring, and use of high-quality Māori-centred data over time, to inform quality improvement.

Strong recommendation. Evidence: Āhua pai (Moderate).

Governance and accountability

We recommend that health systems and providers include Māori leadership and governance and hold providers accountable for healthcare quality.

Strong recommendation. Evidence: Pai (Good).

Cultural safety

We recommend that health systems and providers ensure that cultural safety is a key aspect of workforce training and professional development to ensure culturally safe care is delivered to whānau Māori.

Strong recommendation. Evidence: Pai (Good).

Case management

We recommend that health systems and providers of services for Māori with or at risk of chronic kidney disease are led in primary care or Kaupapa Māori services providing case management and support throughout the patient journey.

Strong recommendation. Evidence: Pai (Good).

Information systems

We suggest that health systems and providers of care for Māori with or at risk of chronic kidney disease are supported by single, integrated information and referral system.

Strong recommendation. Evidence: Āhua pai (Moderate).

Social determinants of equity and wellbeing

We recommend that health systems and services for Māori with or at risk of chronic kidney disease partner with organisations to address social determinants of risk factors for kidney health, such as justice, housing, education, and poverty.

Strong recommendation. Evidence: Āhua pai (Moderate).

Screening

We recommend that health systems and providers calculate five-year cardiovascular disease risk using the NZ Primary Prevention Equation including urine albumin to creatinine ratio and estimated glomerular filtration rate for all tāne Māori (men) aged 30 years or older, wāhine Māori (women) aged 40 years or older, and all Māori with diabetes from diagnosis.

Strong recommendation. Evidence: Āhua pai (Moderate).

Recommendations for clinicians and health services providers

Clinical assessment framework

We recommend that individual providers of care to Māori with or at risk of chronic kidney disease provide care within an Indigenous Health Framework.

Strong recommendation. Evidence: Pai (Good).

Whānau knowledge and learning

We recommend that individual providers of care to Māori with or at risk for chronic kidney disease build whānau knowledge about chronic kidney disease and health issues that contribute to it using learning strategies that are whānau-focussed and culturally safe to support whānau goals.

Strong recommendation. Evidence: Pai (Good).

Kaupapa (purpose and scope)

New Zealand European patients are three times less likely to commence dialysis for kidney failure and have one-third the risk of kidney failure due to diabetes compared with Māori.² In addition, New Zealand European patients have benefited from recent quality improvement resources for transplantation in New Zealand, and are much more likely to receive a kidney transplant as their first treatment for kidney failure.

Evidence is available to support health providers to deliver safe and effective management of chronic kidney disease to whānau Māori.

The purpose of this guideline is to assist health providers in making decisions about the management of chronic kidney disease affecting Māori. This guideline can also be used to develop policies and inform service development and treatment protocols.

This guideline is informed by whānau Māori partnership, a systematic evidence

review, and evidence-informed recommendations on:

- equity
- governance and accountability
- cultural safety
- case management
- information systems
- social determinants of health and equity
- screening and awareness of chronic kidney disease
- models of care
- knowledge and learning

The guideline has a focus on the early stages of chronic kidney disease and does not include discussions of methods for dialysis and transplantation, which will be the subject of a separate guideline.

Methods for guideline development

Principles

Healthcare services for Māori with chronic kidney disease are based on:

- Giving effect to the Treaty of Waitangi guarantee of tino rangatiratanga—autonomy, self-determination, sovereignty, self-government—to enact the principle of partnership, the principle of active protection, the principle of equity and the principle of options.¹
- Best practice care that prevents chronic kidney disease, prevents or delays progression of chronic kidney disease, cures or treats kidney failure through timely transplantation, is delivered in the community, and provides high-quality symptom-based care.

Development of guideline

A key aspect of these guidelines was to ensure Māori community engagement over whānau Māori experiences of chronic kidney disease and the health system's response. This was undertaken in accordance with partnership, participation and to inform options.

This guideline was developed using the CARI guidelines development manual.

CARI guideline development includes:

- Defining scope and priority topics
- Retrieving evidence
- Assessment of evidence with synthesis
- Formulating recommendations
- Planning implementation of the guideline

The CARI process Conflicts of interest were managed using CARI procedures.

Contributors to the guideline

The guideline was developed with whānau Māori, health providers, a working group, the CARI guideline development team and external reviewers.

Whānau Māori

Whānau Māori affected by chronic kidney disease met with two members of the working group (SR, CW) to share values, experiences, and expectations about safe and effective management of chronic kidney disease. These data were synthesised and informed the scope and outline of the guideline.

Health providers

Nephrologists and nephrologists in training and primary care clinicians met separately at two meetings with the guideline working group (SP, CGF, CW, RW) to determine provider-led

expectations for the scope of the guidelines.

Working group

Guideline development was supported by a working group. The group was co-convened by Dr Curtis Walker and Professor Suetonia Palmer. The working group reviewed the evidence provided by whānau Māori and healthcare providers to refine the scope of the guidelines and the key review topics. The group considered and discussed the systematic literature review and evidence synthesis to formulate and grade the guideline recommendations as strong or weak.

CARI guideline development team

Guideline development was supervised by the CARI guidelines development group based at The University of Sydney and the CARI Steering Committee, which approved the guideline development and final version.

External peer review

The guidelines underwent external peer review by Associate Professor Elana Curtis (Ngāti Rongomai, Ngāti Pikiao, Te Arawa, Public Health Physician, Waipapa Taumata Rau and Janine Hale (Nephrology Clinical Nurse Specialist)

Identification of priority questions

The CARI working group drafted the guideline topics based on sharing of knowledge by whānau Māori affected by chronic kidney disease and primary and secondary care health providers.

All data were gathered in community consultations with patients and their whānau. Four patients' and whānau hui were convened by Susan Reid and Carla White. The hui involving nephrologists and nephrologists in training was convened by Suetonia Palmer and Carmel Gregan-Ford. The hui with primary care providers was convened by Curtis Walker and Rachael Walker. The hui were part-funded by the Ministry of Health. The number of hui were limited by a lack of funding.

The findings of the hui were presented and discussed among the guideline working group on 15 March 2019.

The feedback from each hui was evaluated inductively.

Whānau described not knowing how they developed kidney disease or knowing that blood pressure and diabetes were risk factors. They described missed opportunities to build knowledge about chronic kidney disease and learn ways to prevent or delay progression. Whānau described problems with continuity of care and accessing timely treatment. Learning methods such as building understanding through relationships with clinicians were missing. Whānau described not knowing where to find trustworthy information. They described complex secondary care with a focus on the functional aspects of care including dialysis. Whānau experienced feeling blamed for their condition and being told what to do—and wanted shared decision-making within a trusted therapeutic relationship. Most whānau did not recall any discussion about transplantation. Māori patients and whānau described

many examples where a reasonable standard of care was not provided due to poor access to primary care, poorly coordinated care services and providers, and insufficient time to have discussions face-to-face with health professionals.

Secondary care providers indicated that these guidelines need to be focussed on primary care, enable care that supports equity, and address issues of relevance to policy and practice change. Primary care providers preferred that these guidelines were directed at primary care.

Evidence reviews were carried out following community consultation hui to address:

- equity
- governance and accountability
- cultural safety
- case management
- information systems
- social determinants of health and equity
- screening and awareness of chronic kidney disease
- models of care
- knowledge and learning

Identification and retrieval of evidence

We first conducted an electronic literature search in MEDLINE, nzresearch.org and Google Scholar without a language or date restriction. We used keyword search terms including Māori, Indigenous, First Nations, Aboriginal and Torres Strait Islander, Native, and Oceanian. We combined these terms with keyword search terms related to health and

knowledge including mātauranga, ōranga, health outcomes, equity, and critical.

We did not use search terms for a particular study design or publication type. We searched the reference lists of retrieved publications to identify additional eligible studies.

We reviewed the retrieved citations by title and abstract to identify potentially eligible data. The full text of potentially included studies was then examined to adjudicate study eligibility. The flow of information during the literature search is shown in Appendix 1.

We included reports, articles, and publications that were peer-reviewed and reported data for the management of chronic kidney disease and risk factors for chronic kidney disease including cardiovascular risk factors, smoking, physical movement, nutrition, lipid abnormalities, cardiovascular disease and diabetes and pre-diabetes (any type). We included systematic reviews, scoping reviews, narrative reviews based on empirical evidence, government and non-governmental reports and policies, randomised controlled trials, cohort and cross-sectional studies, and qualitative and survey data.

We considered studies to be eligible if they reported data for the management of long-term conditions including chronic kidney disease, diabetes, hypertension, cardiovascular disease, and risk factors for chronic kidney disease. We included studies involving Indigenous Peoples in any region or location. We considered any health-related role as eligible including health systems, health providers, health services, health professionals, clinicians,

patients and whānau. We also considered non-health settings including education and justice. Studies proved eligible if they reported models of care or health services improvement or reform, equity approaches, or care quality and determinants of inequity including racism, marginalisation and colonisation.

Appraising evidence methodological quality

We used the Consolidated Criteria for Strengthening Reporting of Health Research involving Indigenous Peoples (CONSIDER) statement to adjudicate the methodological practices of studies underpinning these guidelines.³ The CONSIDER statement provides a checklist for the reporting of health research involving Indigenous peoples to strengthen research praxis and advance Indigenous health outcomes.

The CONSIDER statement assesses whether each research study or report had:

Domain 1: Research governance

1. Indigenous governance
2. An accountability mechanism to minimise harm to Indigenous stakeholders
3. Protected Indigenous intellectual property and knowledge

Domain 2: Research prioritisation

4. Prioritisation with Indigenous stakeholders

Domain 3: Research relationships

5. Adherence to Indigenous ethical guidelines and processes
6. Involved Indigenous stakeholders in the research processes

7. Expertise in the research team in Indigenous health research

Domain 4: Research methodologies and methods

8. Described the theoretical framework that underpinned the study.
9. Considered the physical, social, economic, and cultural environment of Indigenous stakeholders including implications of colonisation, racism and social injustice.

Domain 5: Research participation

10. Individual and collective consent for future use of collected samples and data
11. Considered the resource demands placed on Indigenous communities and participants
12. Described the storage and removal of tissues and samples from Indigenous lands and disposal

Domain 6: Research capacities

13. Supported the development and sustainability of Indigenous research capacities
14. Professional development by the research team to develop capacity to partner with Indigenous Peoples

Domain 7: Research analysis and interpretation

15. Analysed and reported results using a critical inquiry and strengths-based approach

Domain 8: Research dissemination

16. Dissemination in partnership with Indigenous stakeholders
17. Described process for knowledge translation to support Indigenous health advancement

Each study was assessed on each domain as “Yes”, “No”, “Partial” or “Unclear”.

The overall study was considered to have higher methodological quality if most domains were adjudicated as “Yes”. The overall study was considered to have lower methodological quality if most domains were adjudicated as “No”.

to an Indigenous, *and* findings were not consistent, *and* studies were not conducted involving Māori

Grading of the evidence

The quality of the evidence for each guideline recommendation was then assessed, in which the certainty of the evidence for each guideline statement was rated as pai (good), āhua pai (moderate), or whekowheko (poor/weak).⁴

The guideline panel considered 1) whether the methodologies of the contributing research evidence aligned with the CONSIDER statement, 2) whether the research was conducted involving Māori stakeholders and 3) whether the research evidence was consistent across available studies and reports.

The evidence was adjudicated as:

- **Pai (good)** when the underlying research was conducted aligned to an Indigenous framework, was consistent across studies, and involved evidence from research conducted with Māori.
- **Āhua pai (moderate)** when the research was less well aligned to an Indigenous framework or findings were not consistent, or studies were not conducted involving Māori
- **Whekowheko (poor/weak)** when the research was less well aligned

Development of recommendations

The strength of the recommendations was initially aligned with the evidence. Evidence adjudicated as pai or āhua pai led to a strong recommendation. Evidence adjudicated as whekowheko led to a conditional recommendation.

At meetings of the guideline development group, the evidence found in each review was presented. The guideline development group took note of the evidence, formulated recommendations, and confirmed the strength of each recommendation.

The strength of the recommendation was based on the certainty of the evidence, a lack of evidence of important harms, and a judgement about whether translation of the evidence into practice will improve Māori health and wellbeing.

The working group adjudicated a guideline statement as a strong recommendation when they were confident that following the recommendation would provide benefits that outweighed undesirable consequences to hauora Māori (health and wellbeing).

Conditional recommendations were made when the group considered that the benefits of following the recommendation were likely to outweigh any harmful

effects on hauora Māori (health and wellbeing), although they were less confident of this conclusion.



Background

Māori in Aotearoa me Te Waipounamu/ New Zealand have endured poor health experiences and outcomes related to chronic kidney disease and increased exposure to risk factors for chronic kidney disease.^{5,6} Health services delay diagnosis of chronic kidney disease and referral to secondary care to treat progressive kidney disease for Māori, and deliver a substantially lower rate of kidney transplantation.^{7,8} Pre-emptive kidney transplantation is rarely provided to Māori even in the context of a national quality improvement program.

Healthcare providers and whānau Māori describe health services for chronic kidney disease that fail to uphold the principles of the Treaty of Waitangi (partnership, active protection, equity, and options). Health services are fragmented, lack continuity between primary and secondary health services, have inadequate infrastructure to support decision-making and are not culturally safe.^{2,8,9}

Health inequities for Māori are determined by ongoing colonisation, marginalisation, and institutional, personally mediated, and internalised racism. These determinants of inequity cause multigenerational loss of resources and land, and increased exposure to risk factors for long-term health conditions, including incarceration, inadequate education delivery, inadequate housing and failure to provide safe healthcare.^{10,11}

Health systems often fail to deliver best practices to Māori that should include identifying the risk factors for chronic kidney disease, appropriate management to prevent disease progression and access to treatments such as kidney transplantation to support maximal wellbeing for Māori who experience kidney failure.

These guidelines take a strengths-based approach and focus on interventions at a health services and health provider level to provide hauora (health and wellbeing) among whānau Māori affected by chronic kidney disease.

Evidence for guideline recommendations

Equity

We recommend that health systems and providers prioritise actions to achieve equitable outcomes in kidney health for Māori patients and whānau.

Strong recommendation. Evidence: Pai (good).

Studies and reports consistently demonstrate that health services need to be designed specifically to address and attain equity^{12 13} including through national policies and frameworks.¹⁴⁻¹⁷

Effective interventions for equity include quality of care and reimbursement policies, accountability through transparent monitoring and reporting, and sufficient resourcing. In addition, equity is effectively addressed through coordinated approaches in health, social, education and justice systems, and led and governed by and with Māori.¹⁸⁻²¹ Indigenous health care services and Kaupapa Maori services are effective at addressing social and cultural determinants of equity.²⁰

Evidence shows that equity requires critical analysis by those with the power to sustain or address inequities²²—to share power and governance authentically and to support self-determination in health and social services by Māori.^{12 17 23}

²⁴

Existing epidemiological practices fail to examine the basic and social causes of inequities in chronic kidney disease such as racism, economic, political and legal

power, and socioeconomic factors within affected Māori communities.²⁵ Indigenous measures and values related to health and wellbeing will be required to monitor the impact of quality improvement actions to attain equity.²⁶

Evidence was summarised from 20 studies and reports.¹²⁻³¹

We recommend that health systems and providers advance equity in kidney health through the collection, reporting, monitoring, and use of high-quality Māori-centred data over time, to inform quality improvement.

Strong recommendation. Evidence: Āhua pai (moderate).

Collection, evaluation and reporting of high-quality data are critical to effective strategies that attain equity.¹²

Longitudinal data establish knowledge of healthcare quality and support monitoring and evaluating the impact of service delivery and service improvements on health outcomes.³²

Data collected specifically on equity of access, quality, outcomes of service improvement, and basic causes of inequity are necessary to design effective responses through the life course including for chronic kidney disease.²⁹ For example, data collection shows that the proportion of non-Māori who received at least one albumin:creatinine ratio (ACR) test in Aotearoa New Zealand between 2014-2017 was consistently higher than for Māori (page 30 of the A window on the quality of Aotearoa New Zealand's health care 2019—a view on Māori health equity). A higher ACR is associated with a higher proportion of people requiring a lower limb amputation. Data need to be governed by and with Māori to ensure Māori are involved in setting priorities. Measuring, reporting and regular monitoring against benchmark standards

will enable health services to improve Māori health and wellbeing.^{29 33}

Frameworks, tools, systems and processes to monitor, and report on results for Māori whānau and communities are being established through commissioning, partnerships between researchers and health providers and iwi, including standardisation of data capture.^{29 33-35}

Notably, Indigenous measures of health and valuing of health states will be required to monitor equity and healthcare quality in ways that align to Māori priorities and values and inform cost-effectiveness analyses.²⁶ These have not yet been established specifically for chronic kidney disease. A framework has been developed for quality measurement of health services for Indigenous populations by the International Group for Indigenous Health Measurement (IGIHM) that can be considered when developing and evaluating health services improvement.³⁶

Evidence was summarised from 11 papers and reports.^{12 26 29 32-39}

Governance and accountability

We recommend that health systems and providers include Māori leadership and governance and hold providers accountable for healthcare quality.

Strong recommendation. Evidence: Pai (good).

The Health and Disability System Review 2020 report indicated that “Māori leadership and control over using and applying mātauranga Māori are critical to ensure the appropriate protections are in place to protect the integrity of mātauranga in health.”⁵ Deliberate leadership between Iwi and research and health services provides strength-based, community-driven, sustainable care practices.¹⁷

Health provision led by Māori supports health services delivery that has high use and level of satisfaction, meeting the expectations of Māori who are underserved by existing services.⁴⁰ While co-design and partnership in health services implementation has been viewed positively, Māori leaders and communities have reported doubt about the

sustainability of interventions and their ability to effect wider change without sustained funding and evaluation.³⁹

Holding health providers to account for health equity is challenging due to there being fewer data sources for te ao Māori health outcomes. Measures of Māori health, wellbeing and outcomes have been developed and evaluated⁴¹⁻⁴⁴ although they are collected and evaluated less frequently.⁴²

Māori-specific wellbeing measures and data for Māori affected by chronic kidney disease are not yet available to monitor and hold healthcare providers accountable for healthcare quality and equity.

Evidence was summarised from 28 papers and reports.^{5 9 12 15-17 19 22 27-29 33 39-54}

Cultural safety

We recommend that health systems and providers ensure that cultural safety is a key aspect of workforce training and professional development to ensure culturally safe care is delivered to Māori.

Strong recommendation. Evidence: Pai (good).

Cultural safety is recommended for health service delivery, health organisations, and health providers to address low-quality services and outcomes for Māori with chronic kidney disease.

Cultural safety is defined as requiring “healthcare professionals and their associated healthcare organisations to examine themselves and the potential impact of their own culture on clinical interactions and healthcare service. This requires individual healthcare professionals and healthcare organisations to acknowledge and address their own biases, attitudes, assumptions, stereotypes, prejudices, structures, and characteristics that may affect the quality of care provided. In doing so, cultural safety encompasses a critical consciousness where healthcare professionals and healthcare organisations engage in ongoing self-reflection and self-awareness and hold themselves accountable for providing culturally safe care, as defined by the patient and their communities, and as measured through progress towards achieving health equity. Cultural safety requires healthcare professionals and their associated healthcare organisations to influence healthcare to reduce bias and achieve equity within the workforce and working environment.”

Cultural safety is operationalised through fostering of critical consciousness of the self, others and the system to enact social and health justice and meet human rights.^{23 55 56} Drawn from the work of Dr Irihapeti Ramsden, cultural safety is a practice requirement for medical practitioners from the Medical Council of New Zealand, and nurses from the Nursing Council of New Zealand.^{57 58} In health professional education, cultural safety is fostered through context in education and practice, identifying and changing power structure, moving beyond usual procedures, enacting self-reflection, and promoting equity and social justice.⁵⁹
60

Racism, due to power imbalances, inadequate reflection and outdated models of care is actively present in healthcare leading to poor healthcare services and outcomes, unmet need and dissatisfaction.^{34 61 62} Leadership is required to advance health equity and healthcare services responsiveness to Māori.⁶³

Training guided by cultural safety and anti-racism principles is recommended for all members of the healthcare team.⁶⁴

Evidence was summarised from 22 reports and studies.^{22 23 29 34 55-72}

Case management

We recommend that health systems and providers of services for Māori with or at risk of chronic kidney disease are led in primary care or Kaupapa Māori services providing case management and support throughout the patient journey.

Strong recommendation: Evidence: Pai (good).

Community-based nurse-led models of primary care of type 2 diabetes and chronic kidney disease among Māori and First Nations lower blood pressure,⁷³ increase antihypertensive treatment and reduce protein excretion and cardiac injury.⁷⁴

A nurse-led strategy can identify disease, provide access to appropriate secondary services, commence medical treatments, and educate primary care providers.⁷⁵ Intensive primary care screening for proteinuria, and intensive treatment of diabetes and hypertension is more effective than standard care and is value for money.⁷⁶

Common features of effective and acceptable programs include “integration within existing services, nurse-led care, intensive follow-up, provision of culturally-appropriate education, governance structures supporting community ownership, robust clinical systems supporting communication and a central role for Indigenous Health Workers.”⁷⁷

Whānau centred programs led by primary care are most effective when they include competent and compassionate healthcare

providers, provide flexible access, provide continuous care and integrated care, and are culturally supportive.⁷⁸

Failure to build collaboration between health and social services leads to persistent and unattended psychosocial issues and intergenerational poverty.⁷⁹

Successful case management includes prolonged, no-cost nurse consultations, written wellness plans, formal health provider training to support patient and whānau self-management and information technology that supports structured care.²⁴ Community health workers trained as case managers provide high-quality care comparable to registered nurses in long-term condition programs.⁸⁰

⁸¹ Whānau carer-provider partnerships enable continuity of care that enables shared values and family-centred wellbeing.⁸²

Local autonomy and Indigenous governance of primary care services lowers rates of hospitalisation for ambulatory sensitive conditions.^{21 52 77 83}

Regional health workforce planning in partnership with existing health services provides a sustainable and stable workforce.⁸⁴ Interagency integration is required to link health outcomes with

determinants of health, and is implemented by effective interactions across sector and organisation boundaries.⁴⁶ This will require contracting and commissioning of health services that are responsive to whānau priorities including prevention-based care—existing innovative practices undertaken in

primary care and Kaupapa Māori health services is underfunded due to the constrained focus of contracting, especially in smaller providers.^{9 48}

Evidence was summarised from 49 reports and studies.^{9 13 16 20 21 24 33 37-40 46 49 52 53 65 69 73-105}



Information systems

We recommend that health systems and providers of care for Māori with or at risk of chronic kidney disease are supported by unified, integrated information and referral system.

Strong recommendation: Evidence: Āhua pai (moderate).

Effective linkage between the information systems of community providers, primary care and secondary care provides high-quality care for chronic conditions including diabetes and chronic kidney disease.⁴⁶ Collecting and utilising data meets the needs of each community through identifying patients who require a specific service and providing proactive follow-up visits.^{49 74 106}

Indigenous health data more commonly include misclassification errors and non-response biases to cause inequities in knowledge of health determinants and access, and requiring a focus on effective data collection and sharing systems.¹⁰⁷

Services should be integrated at a regional level to increase linkages between

services and provide a “one-stop-shop” for care that is highly effective within a preventative health framework. A network with a shared health record and consistent cultural safety improves service provision. Holistic treatment of Indigenous patients from their *first* point of contact increases Indigenous health checks and improves outcomes.¹⁰⁸

Clinical systems that aggregate medical record data facilitate coordination and tracking of care across different settings. Standard data formats support accurate data at the time of clinical decision-making and referral processes.¹⁰⁵

Evidence was summarised from 28 reports and studies.^{20 38 39 46 48-50 53 74 77 79 91 98-100 102 103 105-115}

Social determinants of health and equity

We recommend that health systems and services for Māori with or at risk of chronic kidney disease and their whānau are integrated with organisations to address social determinants of kidney health including maternal and child health, justice, housing, education and poverty.

Strong recommendation: Evidence: Āhua pai (moderate).

An intersectoral approach to health and social services is necessary to address the wider determinants of health and equity that cause the impacts of chronic kidney disease for Māori and their whānau. An across-systems approach involves strategic planning and funding across government and non-government agencies.^{9 46}

Cross-sector action is a priority area in Whakamaua: Māori Health Action Plan 2020–2025, contributing to a health and disability system that is fair, sustainable, and delivers equitable outcomes for Māori.¹¹⁶ Cross-sector action is locally centred partnerships between providers and governments to align health and social services that plan, integrate and support health services for Māori and their whānau. Rates of diabetes complications for Māori compared with non-Māori, non-Pacific is a planned initial measure to monitoring the impact of health service and system quality in Whakamaua.

The World Health Organization recommends that all ministries (and not just health ministries) work toward improving health by acting on social determinants of health, including cross-

government mechanisms and strategic plans to improve health equity. In Aotearoa me Te Waipounamu/New Zealand, this is enacted by Whakamaua.¹¹⁷ The Commission for the Social Determinants of Health conceptual framework recommends that the socioeconomic and political context of health is supported through governance, macroeconomic policies, social policies (including the labour market, housing and land), public policies (education, health and social protection), mediated through social cohesion and social capital on to the health system and individual determinants of health. The Commission identifies that the most significant impact of the framework is that interventions and policies need to be intersectoral and address structural determinants of health including economic, social and public policies.¹¹⁸

Data show which interventions are effective at the levels of the patient and their whānau, the practice organisation and the community.¹¹⁹ These include asking patients about social challenges in a sensitive and caring way, referring patients and helping them access benefits and support services, improving access and quality of care to specific patient

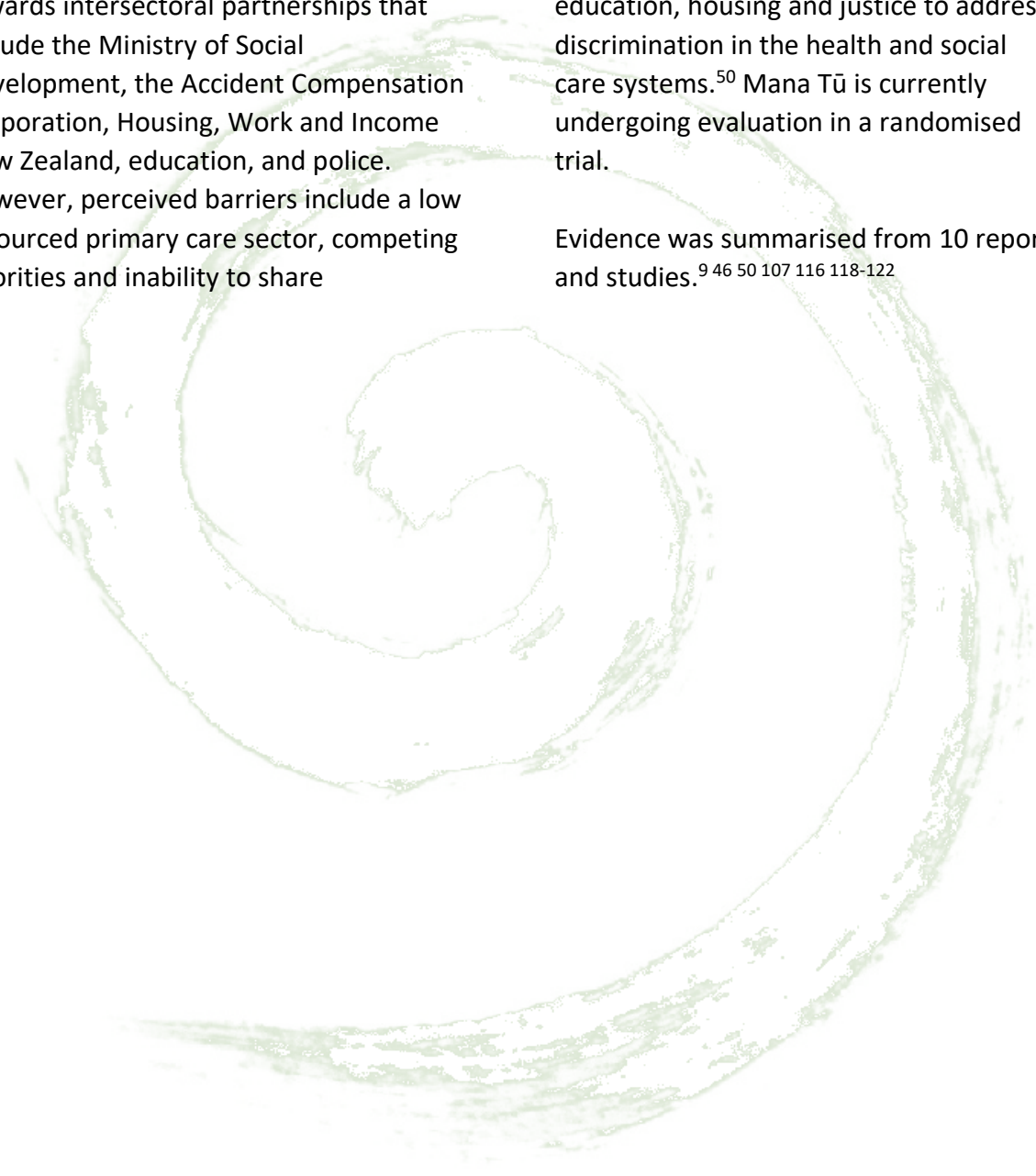
groups, partnerships with community groups and public health, and advocating for social change. Small-scale changes at the local level may provide insufficient progress toward equity if not supported by national policies and resourcing.¹²⁰

The Health Quality and Safety Commission found in 2019 that consumers and health organisation strongly desire to move towards intersectoral partnerships that include the Ministry of Social Development, the Accident Compensation Corporation, Housing, Work and Income New Zealand, education, and police. However, perceived barriers include a low resourced primary care sector, competing priorities and inability to share

information across the system.¹²¹ Mana Tū is an example of a system of care addressing the wider determinants of health in management for type 2 diabetes for people and their whānau.

Based on evidence for quality improvement, Mana Tū is a Kaupapa Māori model of care that includes a cross-sector network of services including education, housing and justice to address discrimination in the health and social care systems.⁵⁰ Mana Tū is currently undergoing evaluation in a randomised trial.

Evidence was summarised from 10 reports and studies.^{9 46 50 107 116 118-122}



Screening

We recommend that health systems and providers calculate five-year cardiovascular disease risk using the NZ Primary Prevention Equation including urine albumin to creatinine ratio and estimated glomerular filtration rate for all tāne Māori (men) aged 30 years or older, wāhine Māori (women) aged 40 years or older, and all Māori with type 1 or 2 diabetes from diagnosis.

Strong recommendation: Evidence: Āhua pai (moderate).

The Ministry of Health recommends cardiovascular risk assessment for Māori commencing at 30 years for men and 40 years for women and all patients with type 1 or 2 diabetes from diagnosis.¹²³ These guidelines are applicable to patients with chronic kidney disease, an important marker of cardiovascular risk.

Targeted cardiovascular risk assessment includes measurement of the urine albumin:creatinine ratio and serum creatinine/estimated glomerular filtration rate, which will identify the presence of kidney disease. Screening for cardiovascular risk among Māori

commences 15 years earlier than for New Zealand European adults. The data supporting this screening recommendation was derived from the PREDICT study.¹²⁴

Early screening for chronic kidney disease is cost-effective and delays death and dialysis.^{76 125 126} Māori are screened at rates below those indicated by guideline recommendations. Screening rates are increased by computer-guided assessments.^{38 127}

Evidence was summarised from 18 reports and studies.^{38 74 76 93 99 113 122-133}

Clinical assessment framework

We recommend that individual providers of care to Māori with or at risk of chronic kidney disease provide care within an Indigenous Health Framework. This includes the importance of respect and reciprocity within the clinical relationship-building process that draws on Māori rituals of encounter, the importance of ethnicity data collection, and a process to clarify key messages and identify outstanding issues or concerns.

Strong recommendation: Evidence: Pai (good).

Clinical assessment of chronic kidney disease and its risk factors in Māori patients is most effective when guided by a clinical assessment framework that enables the provider to evaluate all dimensions of hauora (health and wellbeing): taha tinana (physical health), taha hinengaro (mental health); taha whānau (family health) and taha wairua (spiritual health).¹³⁴ Incomplete or inaccurate evaluation of Māori health and wellbeing can lead to miscommunication, impaired diagnosis, and inadequate intervention.^{23 135 136}

Evidence was summarised from 9 reports and studies^{23 134-141}

Models of clinical interaction with whānau Māori provide clinicians with approaches that centre respect and reciprocity in the clinical encounter, to build and sustain relationships.¹³⁷⁻¹³⁹ These models draw on Māori rituals of encounter, to facilitate information sharing and ensure whānau Māori issues and concerns are explored and addressed within clinical care. An Indigenous Clinical Framework will assist clinicians to consider the broader socio-political context of health and wellbeing that is relevant to providing best practice – including impacts of colonisation, marginalisation and racism.^{138 139}

Whānau knowledge and learning

We recommend that individual providers of care to Māori with or risk factors for chronic kidney disease build patient and whānau knowledge about chronic kidney disease and health issues that contribute to it using learning strategies that are whānau-focussed and culturally safe to support patient and whānau goals.

Strong recommendation: Evidence: Pai (good).

Health information provided to whānau during clinical care and case management enables increased clinician health literacy and directly improves kidney health outcomes, such as risks of hospitalisation.⁷⁴

Effective facilitation to build whānau knowledge includes clear information, manageable strategies, and supportive relationships.^{142 143} A longer time for education and consultations increases whānau satisfaction and self-efficacy.²⁸

Community-integrated education and learning is effective and improves clinical outcomes.^{63 81 144 145}

Learning is likely to be more effective when information is shared by a community-based culturally safe health worker taking into context whānau goals and life circumstances.^{81 142}

Positive, sustained, longstanding relationships assist patients and whānau with information gathering and practical supports.^{55 146}

Evidence was summarised from 13 reports and studies.^{8 26 28 63 81 82 110 142-147}

Evidence alignment

We provide a table below reporting the adjudication of evidence for each guideline recommendation. The evidence for each guideline statement was rated as pai (good), āhua pai (moderate), or whekowheko (low/weak).⁴ The panel’s assessment of each study or report is provided in a separate document.

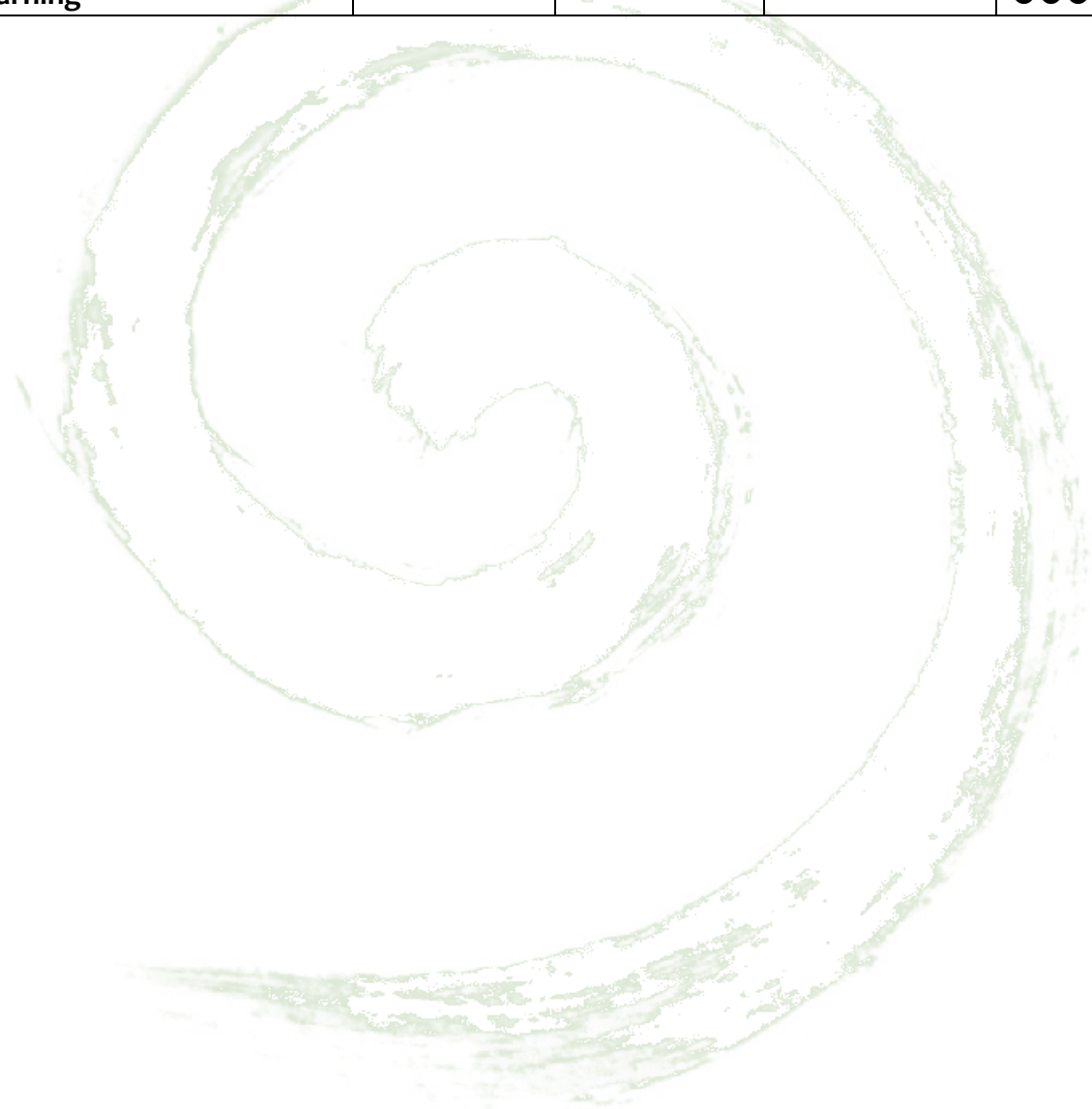
The guideline panel considered for each guideline recommendation whether the: 1) methodologies of the contributing research evidence aligned with the CONSIDER statement, 2) research was conducted involving Māori stakeholders and 3) research evidence was consistent across available studies and reports.

The evidence was adjudicated as:

- **Pai (good)** when the underlying research was conducted aligned to an Indigenous framework, was consistent across studies, and involved evidence from research conducted with Māori.
- **Āhua pai (moderate)** when the research was less well aligned to an Indigenous framework or findings were not consistent, or studies were mainly not conducted involving Māori.
- **Whekowheko (poor/weak)** when the research was less well aligned to an Indigenous, *and* findings were not consistent, *and* studies were not conducted involving Māori

Guideline statement	Evidence alignment to CONSIDER statement	Evidence involving Māori stakeholders	Evidence has consistent findings across studies/reports	Overall assessment of evidence
Equity – health system	Pai (good)	Ae (yes)	Ae (yes)	Pai (good) ●●●
Equity – quality improvement	Pai (good)	Āhua pai (moderate)	Ae (yes)	Āhua pai (moderate) ●●○
Governance and accountability	Pai (good)	Ae (yes)	Ae (yes)	Pai (good) ●●●
Cultural safety	Pai (good)	Ae (yes)	Ae (yes)	Pai (good) ●●●
Case management	Pai (good)	Ae (yes)	Ae (yes)	Pai (good) ●●●
Information systems	Āhua pai (moderate)	Ae (yes)	Ae (yes)	Āhua pai (moderate) ●●○

Guideline statement	Evidence alignment to CONSIDER statement	Evidence involving Māori stakeholders	Evidence has consistent findings across studies/reports	Overall assessment of evidence
Social determinants	Āhua pai (moderate)	Ae (yes)	Ae (yes)	Āhua pai (moderate) ●●○
Screening	Whekowheko (poor/weak)	Ae (yes)	Ae (yes)	Āhua pai (moderate) ●●○
Clinical assessment framework	Pai (good)	Ae (yes)	Ae (yes)	Pai (good) ●●●
Whānau knowledge and learning	Pai (good)	Ae (yes)	Ae (yes)	Pai (good) ●●●



Implementation

Actions for healthcare governance and leadership

- We recommend that these guidelines are considered by Te Whatu Ora during development and delivery of 2022 Interim Te Pae Tata New Zealand Health Plan in partnership with Te Aka Whai Ora.¹ Specifically:
 - Resource implementation of coordinated multidisciplinary teams at a primary care/community level to support screening, management, and appropriate referrals for chronic kidney disease (*priority action 4 – Keep people well in their communities*)
 - Increase capacity for community and Kaupapa Māori case management of chronic kidney disease with whānau Māori (*priority action 3 – develop an inclusive workforce*)
 - Increase secondary care capacity to provide specialist support of primary care organisations (*priority action 1 – place whānau at the heart of the system to improve equity and outcomes*)
 - Enable resources for sufficient time and space for clinicians to deliver culturally safe care in a sustainable framework (*priority action 1 – place whānau at the heart of the system to improve equity and outcomes*)
 - Collect and report high quality, longitudinal Māori-centred data about care quality of chronic kidney disease (*priority action 5 - develop greater use of digital services to provide more care in homes and communities*)
 - Develop key performance indicators to audit the delivery and outcomes of health system design and resourcing related to Māori health advancement (*priority action 1 – place whānau at the heart of the system to improve equity and outcomes*)

Actions for healthcare organisations

- Professional organisations to support curricula that include competency programs in Māori health advancement and culturally safe care (*priority action 3 – develop an inclusive workforce*)

¹ <https://www.tewhatauora.govt.nz/about-us/publications/te-pae-tata-interim-new-zealand-health-plan-2022/>

- Develop, resource and mandate training programs for cultural safety for clinicians and healthcare workers (*priority action 3 – develop an inclusive workforce*)
- Resource space and time in clinical operations to enable clinicians to provide culturally safe care (*priority action 1 – place whānau at the heart of the system to improve equity and outcomes*)
- Implement a unified information and referral system to assist case management of chronic kidney disease at all stages of care (early kidney disease, progressive and advanced kidney disease, preparing for transplantation and/or dialysis, end-of-life care, supportive care (*priority action 5 - develop greater use of digital services to provide more care in homes and communities*))
- Embed guidelines for management of chronic kidney disease for Māori in clinical health pathways and online decision tools at point of care (*priority action 5 - develop greater use of digital services to provide more care in homes and communities*)
- Resource, train, and support clinicians to provide whanau-focused education to build knowledge and best practice care of kidney disease (*priority action 1 – place whānau at the heart of the system to improve equity and outcomes*)
- Resource healthcare providers and systems to work collaboratively with community and primary care- and Kaupapa Māori- based case management of chronic kidney disease (*priority action 4 – Keep people well in their communities*)

Actions for healthcare workers

- Complete cultural safety training and deliver culturally safe care (*priority action 3 – develop an inclusive workforce*)
- Advocate for adequate space and time in clinical settings to deliver culturally safe care (*priority action 1 – place whānau at the heart of the system to improve equity and outcomes*)
- Conduct cardiovascular risk assessment for Māori commencing at 30 years for men and 40 years for women and all patients with type 1 or 2 diabetes from diagnosis including measures of albuminuria and glomerular filtration rate and whānau Māori with a whānau history of cardiovascular or kidney disease (*priority action 4 – Keep people well in their communities*)

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Appendix 1

Flow chart of study selection during the literature searching.

