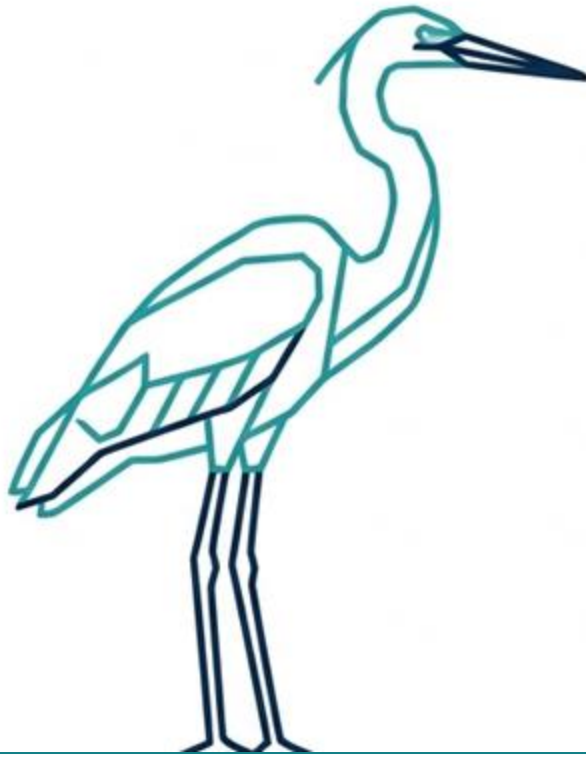




He Kōhanga Kōtuku

A Te Tiriti-Consistent Framework for Rare Disorders in General Practice

Samantha La Hood, Awhina Hollis-English, & Chris Higgins (Rare Disorders NZ)
Xinyi Zhang, Christopher J. Michaels, & Yan Ran Wee (Costello Medical)

He Kōhanga Kōtuku: Version 1 consultation draft

**Live feedback: slido.com
#1238133**



**Full consultation draft
+ feedback form**



The challenge



A rare disorder affects fewer than 1 in 2,000 people.

The whole picture

Condition · mental health · housing · finances · whānau

Continuity

Care across clinicians, services and years

Cultural safety

Safety influences whether people return for care

General practice may be the most consistent point of contact in a fragmented system.

What the data shows

2023 Voice of Rare Disorders Survey Comparative Analysis – Rare Disorders NZ with Costello Medical

1,076

respondents living
with a rare disorder
or caring for
someone who is

144

identified as Māori
(13.4% of the
cohort)

30

categorical
variables analysed

Methods: χ^2 tests · post-hoc comparisons · false discovery rate control

Analytical lens: Te Tiriti o Waitangi, grounded in the Māori text

The findings tell two stories: Māori-specific disparities · system-wide failures



Story one: disparities specific to Māori

18.2% vs 7.1%

Culturally unsafe
healthcare
experiences

$\approx 2.5\times \cdot p = 0.001$

15.3% vs 8.3%

More than six
hours of daily care
burden

$\approx 2\times \cdot p = 0.042$

58.9%

Māori respondents
whose
wairuatanga was
entirely ignored

$p < 0.001$

Only 17.8% of Māori selected “not applicable,” compared with 45.4% of non-Māori.

Wairua was relevant to care and was not provided for.

Source: Voice of Rare Disorders Survey 2023 (n = 1,076; Māori n = 144), RDNZ & Costello Medical.



Story two: failures affecting everyone

>15%

waited more than 10 years
for an accurate diagnosis

~50%

had 3+ GP visits and 3+
specialist visits in six months

>50%

rated provider information
exchange poorly

>65%

were not informed about
relevant social services

No significant Māori/non-Māori difference on most measures.

This is the structural reality of living with a rare disorder in Aotearoa.



The Nest:
He Kōhanga Kōtuku.



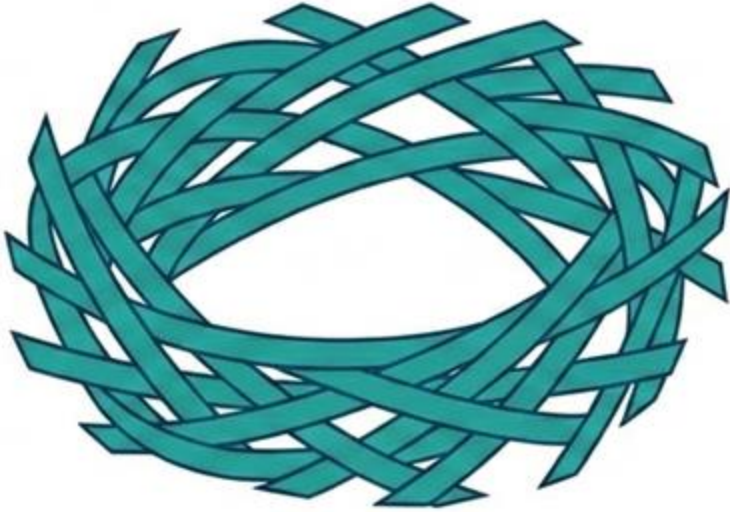
The Patient: Te Kōtuku
(holding Mana Motuhake).

The Goal: Stabilize Mauri Ora.



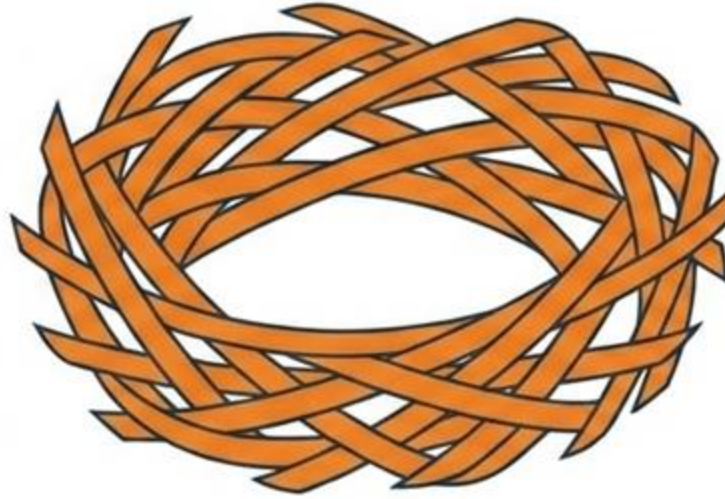
He Kōhanga Kōtuku: The nest

The GP, patient and whānau are kaiwhatu: co-weavers with equal mana



The GP weaves the structure

- Clinical coordination
- Referrals and system navigation
- Longitudinal oversight



Patient & whānau weave the inner lining

- Lived expertise
- Cultural knowledge and wairuatanga
- Daily realities and priorities

Equal mana · shared construction · mauri ora



What this framework is (and is not)

The framework IS

- Practical actions for existing general practice
- Grounded in rare-disorder evidence
- Te Tiriti-consistent
- Relevant to all rare-disorder whānau
- Version 1, open to consultation

The framework is NOT

- A requirement to become a cultural expert
- A generic values statement
- A textbook on 7,000+ rare conditions
- A finished product



Te Tiriti grounding

Three articles of the Māori text · three strands

Whakamana

Article II

Tino Rangatiratanga

Uphold patient and
whānau authority

Tūhono

Article I

Kāwanatanga

Connect people with
systems and
supports

Tiaki

Article III

Ōritetanga

Actively pursue
equitable outcomes

Cultural safety underpins every strand

The patient defines whether care was safe.



Strand one: Whakamana

Article II • Tino Rangatiratanga — uphold the authority of patient and whānau

1.1 The Expert Handover

Begin by explicitly recognising patient expertise

1.2 Whānau as co-weavers in the room

Invite – never assume or pressure

1.3 The Wairua Check-in

Ask permission first; know the next step

1.4 Genomic data sovereignty

Explain, consent and document preferences

The Wairua Check-in suggested framing

“Some whānau find it helpful to talk about how their condition is affecting them spiritually (/their wairua), or in terms of what gives their life meaning. Is that something you’d like to talk about today?”

Only if invited:

“How is this journey affecting your sense of wairua, your spirit and connection to what matters to you?”



Strand two: Tūhono

Article 1 • Kāwanatanga — connect the patient with the system

2.1 Whānau Ora navigator partnership

Refer near diagnosis;
partner as a co-weaver

2.2 The Weaver's Review

Translate, reconnect and
identify what has been
missed

2.3 The Emergency Passport

Co-created • portable •
accessible at 2 a.m.

2.4 Connection to hauora Māori providers

Build networks, not cultural
handoffs



Strand three: Tiaki

Article III · Ōritetanga — actively pursue equity

3.1 Code for visibility

ORPHA / SNOMED-CT

Accurate ethnicity and iwi data

3.2 Advocacy for access to medicines

Know the NPPA process well enough to explain it; raise it early

Contribute to the clinical narrative

3.3 Protect the kaiāwhina

Mental health is critical for both patient and carer

K10 at diagnosis, six months, and annually with a real follow-up pathway.

A kaiwhatu who is exhausted cannot weave.



How we will know it is working

Patient experience

- Cultural safety
- Wairuatanga acknowledged

System visibility

- Rare-disorder coding
- Whānau Ora referral

Equity and access

- Carer wellbeing
- NPPA access and outcomes

Existing 2023 baselines: cultural safety and wairuatanga

Not yet routinely measured: coding, referrals, carer wellbeing and medicine access

Open question: Who owns audit and accountability?



A vision: leadership and coordination

Waitangirotu

One protected breeding ground in Te Tai Poutini, Ngāi Tahu.

No such dedicated infrastructure yet exists for people living with rare disorders.

In progress

Multidisciplinary clinical reference group in development

Longer term aspiration

A national centre of expertise for referral, coordination and knowledge



This is v1 – help shape Version 2

What must Version 2 get right?

1. Where is the analysis right or incomplete?
2. Which actions would work in real practice?
3. Whose voice or experience is missing?

This week in your practice

- Try the Expert Handover once
- Check whether your PMS records rare disorders
- Access, share, and discuss the framework

Tell us now:

slido.com #1238133



**Full consultation draft +
feedback form**

Ngā mihi

This framework rests on the experiences of 1,076 people living with rare disorders in Aotearoa, or caring for someone who does.

Comparative analysis: Awhina Hollis-English · Chris Higgins · Samantha La Hood · Xinyi Zhang · Christopher J. Michaels · Yan Ran Wee

Review and feedback: Ariane Tuapola · Angela Nielsen

Shaping Version 2: RDNZ Māori Advisory Group · whānau kōtuku and the wider rare disorders community · Māori health practitioners · general practice community



He kōtuku rerenga tahi

The flight of the white heron is seen but once.

General practice can become a secure nest where clinical uncertainty is met with relational security and the kōtuku is empowered to soar.



**Full consultation draft +
feedback form**