



28<sup>th</sup> June 2024

Tēnā koutou katoa

## **Being a better Tiriti partner | hei hoa Tiriti pai ake**

This document is a position statement co-signed by RDNZ's Chair, Deputy Chair and Chief Executive. It is intended as a stake in the ground which marks both where RDNZ has arrived to date on its Tiriti journey and the direction that we will follow for the future. We think that it is fitting that the issuing of this document coincides with the period of Matariki, signalling a time of remembrance, reflection, and renewal in a uniquely Māori way.

### **Looking back | titiro whakamuri**

Rare Disorders New Zealand is on a journey to be a better Tiriti partner.

In recent times this has been reflected in

- the appointment of Awhina Hollis-English to the role of Deputy RDNZ Board Chairperson
- the appointment of Julian Laking to the role of Kaiāwhina Māori (Māori engagement officer)
- the establishment of the te whanāu kōtuku Facebook support group page
- RDNZ's values being conveyed in both te reo and English
- bestowal of the interim name Te Toropaepae o te Kōtuku to mark the opening of RDNZ's new offices in September 2023
- success in having whānau Māori heard when we conducted our Voice of Rare Disorders survey in late 2023 as reported in the ensuing [White Paper](#) "2024 Impact for Whānau Māori of Living With a Rare Disorder in Aotearoa New Zealand"
- our collaboration with Te Aka Whai Ora, ensuring that whānau Māori voices were heard by Manatū Hauora | Ministry of Health in developing the Rare Disorders Strategy
- our steps to ensure that mātauranga Māori is well valued as we establish RDNZ's clinical advisory panel and rare disorders research network
- the temporary appointment of Misty Kimura to the role of Kaitakawaenga Māori Advisor which culminated in a report and set of recommendations to the RDNZ Board in April as to how we should continue on our Tiriti partner journey

With Julian's role as Kaiāwhina Māori concluding on 17<sup>th</sup> May, and with the Board having made some initial decisions as to how to respond to Misty's recommendations we thank Julian and Misty for their contribution to RDNZ's Tiriti journey so far. Their mahi and recommendations have built the foundation for the tiriti journey and next steps for RDNZ.

***Ka mihi au ki a Julian raua ko Misty mo ta raua koha ki te haerenga Tiriti a RDNZ. Tēnā kōrua***

We will invite Julian and Misty to a poroporoaki function to properly acknowledge their contributions.

## Looking forward | titiro whakamua

In looking forward it is important to understand how the articles of Te Tiriti can be used as a framework for establishing meaningful relationships with Māori stakeholders and our rare communities for RDNZ. By embracing and embodying these, RDNZ can cultivate a culture of respect, understanding and unity, leading to sustainable growth, positive outcomes and a more inclusive and harmonious workplace for all. This is elaborated upon in Appendix 1, and in addition to the specific responses detailed below RDNZ will develop a Te Tiriti policy to provide context for their implementation.




1. The RDNZ Board of Trustees is currently considering what its composition and membership should look like to ensure that its governance is fit for purpose as RDNZ grows and develops in line with its vision, mission, values and strategic plan. The Board is committed to supporting RDNZ to continue on its Tiriti partnership journey and recognises that it is unrealistic for Awhina to be the Board's sole kaitiaki of this mahi. Accordingly the Board will increase the number of Māori trustees as part of determining its overall composition and membership
2. The Board will then consider whether it should also be supported by a Māori advisory group, with the decision to be informed both by the number of Māori trustees who are eventually appointed and the views of those Trustees themselves. Long term the Board hopes that RDNZ can embed Te Tiriti values deeply within our work so that a separate advisory group is not needed - so the Board would see this group as a transitional body. In this context the Board will also consider identifying an RDNZ kaumatua
3. Subject to RDNZ Board approval a new staff member with kaupapa Māori expertise and whakapapa will be recruited to the existing RDNZ team as the Rare Disorders Strategy (RDS) implementation lead, and an appropriate ingoa Māori for the role will be developed as part of the process. The *"2024 Impact for Whānau Māori of Living With a Rare Disorder in Aotearoa New Zealand"* White Paper report found that Māori and non-Māori reported similar experiences and levels of unsatisfactory outcomes from accessing and using health and disability and other support services. However there is also a strong body of literature evidencing that Māori typically experience poorer health and disability services experiences and outcomes than non-Māori. We infer therefore that Māori and those living with rare disorders are both vulnerable populations who are equally poorly served by New Zealand's health and disability systems. An NZHR Māori led response to implementing the RDS will promote improvements which will simultaneously benefit Māori and non-Māori alike.
4. The rationale for the above approach will be supported by an RDNZ CE developed paper which will bring together the findings of the Te Aka Whai Ora Whānau Voice 2023 [report](#), the findings of the Whānau Māori White paper report, and subsequent additional statistical analysis.
5. We intend that RDNZ's RDS implementation lead role will have a leavening effect on how the RDNZ staff team learns to embrace te ao Māori and communicate externally through a te ao Māori lens. This will occur as the person in the role communicates what support is required

from RDNZ and the team in order for that person to have credibility with whānau Māori living with a rare disorder, and be effective in the role for both Māori and non-Māori.

6. This will be supported through a neutral externally facilitated workshop or workshops to build cultural capability, develop openness to te ao Māori and tikanga, and foster mutual team understanding of what it means to honour Te Tiriti o Waitangi and why this is important. We also expect to run the Riki Consultancy facilitated values session which was postponed from the April Board meeting.
7. In our external and outward facing communications we will intentionally and increasingly kōrero with Māori in ways that they will relate to and appreciate. This will involve running our communications through a te ao Māori lens. At times and for specific documents (such as what has already happened with the terms of reference for the [clinical advisory panel](#) and the [rare disorders research network](#)) this will require external support to make sure we get things right. In these circumstances we will work initially with our current communications agency, and other organisations, which have te ao Māori capability. Other times we can experiment ourselves, seek support from the RDS implementation lead, have some fun, learn conversational Māori to develop confidence, and also learn both as we go along and from mistakes.
8. RDNZ staff will communicate through te whanāu kōtuku Facebook page as appropriate. This page was originally established as an RDNZ initiative and will stay in place unless and until whanāu Māori who engage through it decide it is no longer required, or otherwise opt out.
9. We don't know who on our Nation Builder database would choose to be identified as Māori if they were to be asked. We will adopt a tikanga informed approach to both extend this opportunity to them, and to include contact details of Māori who are not yet recorded as contacts.
10. A segment of the population (eg Māori) may feel disaffected because we don't communicate like this already. It may well be that another segment of the population will feel disaffected when we start doing it. This is a risk that we must take, albeit that many New Zealanders seem happy enough to embrace ways of communicating involving liberal use of te reo. It's likely that by shifting the dial in a te ao Māori direction our net reach and relevance will increase.
11. Given that we are committing to both a Māori led approach to the implementation of the RDS, and to communicating with Māori through a te ao Māori lens using te reo where appropriate for this purpose, it will be important for RDNZ to march to the beat of its own drum when referring to government agencies, including those that are under government pressure to revert to the primary use of the English versions of their names when the te reo versions had already become part of the vernacular. RDNZ will continue to refer to RDS co-implementing agencies as Manatū Hauora, Te Whatu Ora and Whaikaha by default, with the English versions appearing second only as necessary. Pharmac can continue to be Pharmac unless we're double barrelling in which case it will be Pharmac | Te Pātaka Whaioranga.

12. One of the issues raised in the Te Aka Whai Ora Whānau Voice report was the wish for a te reo Māori alternative to the term ‘rare disorder’. The RDNZ Board will progress this and its possible implications for rebranding after governance decisions have been made regarding Māori representation on the Board and the formation of a Māori Advisory Group.
13. The above steps are embedded for implementation in RDNZ’s 2024/25 annual operating plan.

Ngā mihi nui.

<p>James McGoram RDNZ Chairperson</p> 	<p>Awhina Hollis-English RDNZ Deputy Chairperson</p>  <p><a href="#">Awhina Hollis-English</a></p>	<p>Chris Higgins RDNZ Chief Executive</p> 
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## Appendix 1: Te Tiriti

It is important to understand how the articles of Te Tiriti can be used as a framework for establishing meaningful relationships with Māori stakeholders and our rare communities for RDNZ. By embracing and embodying these, RDNZ can cultivate a culture of respect, understanding and unity, leading to sustainable growth, positive outcomes and a more inclusive and harmonious workplace for all.

The first article of Te Tiriti ensures Māori the rights to kāwanatanga (governance), this requires adequate consultation at every stage of decision making of matters which affect Māori. It is important to recognise that when taking a population level approach, this involves Māori and care must be taken to not unintentionally increase inequities in health outcomes experienced by Māori. Moreover, proper consultation does not involve a 5 minute conversation in passing. Instead, consultation is better managed by a team of indigenous voices, rather than single reporting lines. This is important in order to reflect the heterogeneous perspectives of Māori.

The second article of Te Tiriti ensure Māori the rights to tino rangatiratanga (self-determination), protection of our rangatira , ngā hapū and koutou ngā tangata Māori over our lands, villages and all of our treasures. By honouring this article we can create opportunities for meaningful collaboration, dialogue and fostering a more inclusive and diverse decision making process. This approach will enrich RDNZ with different viewpoints and insights but also a sense of empowerment, respect, and belonging among Māori employees and our communities.

The third article of Te Tiriti ensures Māori the right to ōritetanga (equity), and therefore the right to equitable health outcomes. Equity is a concept familiar to the rare disorders

community. However, when addressing inequities at a population level it is imperative that RDNZ takes an approach which will work for whānau Māori. Otherwise the inequities between Māori and non-Māori *will* be increased. This requires the recognition and implementation of the first two articles of Te Tiriti o Waitangi.

By upholding the articles of Te Tiriti RDNZ can demonstrate their commitment to creating a supportive and culturally safe environment for kaimahi Māori (Māori employees) to use their mātauranga Māori (cultural knowledge). This also calls for recognition, respect of the unique cultural identity and heritage of Whānau Māori, Māori employees and integrating cultural practices and values into the policies and practices.