


Date:	17 th June 2024	
Review date:	17 th June 2026	

Rare Disorders NZ (RDNZ) Clinical Advisory Panel

Terms of Reference

Purpose

People living with a rare disorder are estimated to make up 6% of the population in Aotearoa. To provide further support and advocacy for those living with a rare disorder, RDNZ is in search of clinical expertise for our advisory panel amongst tangata whenua and tangata tiriti.

The purpose of the RDNZ clinical advisory panel is to provide solicited and unsolicited expert clinical advice to RDNZ's Board and staff to ensure that all aspects of RDNZ's work is informed by contemporary evidence based best clinical practice and whakaaro Māori that considers and protects the best interest of those we engage with.


Scope

The advisory panel will:

1. Inform RDNZ's contribution to the implementation of the New Zealand Rare Disorders Strategy
2. Inform the development and implementation of a rare and undiagnosed disorders centre of expertise including:
 - a. Best practice in early and contemporary diagnosis
 - b. Development, adoption and implementation of evidence based best practice guidelines and standards of care
 - c. Service co-ordination
 - d. Workforce development
 - e. Contributing to and implementing rare disorders research strategies
3. Contribute to the development of a rare disorders research network
4. Advise RDNZ staff as required from time to time on how to best support people living with rare disorders challenged with navigating the health system. This will not involve providing clinical advice for individual patients.
5. Advise on rare disorders data requirements in the roll-out of the nationwide Electronic Medical Record (EMR) and other data sets
6. Advise on any other matters requiring expert clinical advice such as medicines access, responding to media queries etc

Chairs

1. The panel shall be co-chaired by one tangata whenua representative and one tangata tiriti representative.

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2. The co-chairs shall be appointed by the RDNZ Board.

Membership

Members of the panel shall be appointed by the RDNZ Board with the intention that it comprises:

1. Between eight and twelve members (including the co-chairs)
2. A cross representation of internationally respected and networked New Zealand rare disorders clinicians (including nurses, allied health professionals, and general and specialist medical practitioners)
3. Two or more mātanga Māori clinicians with expertise in te ao Māori
4. At least one RDNZ Board member
5. Other members as identified by the RDNZ Board

All members will be willing to develop their understanding of Te Tiriti and to demonstrate culturally appropriate behaviour, reflecting RDNZ's commitment to operating in a way that honours tangata whenua and Te Tiriti o Waitangi.

Members shall be appointed for three year terms and may be reappointed for subsequent three year terms.

Modus operandi

Panel members:

1. Agree to make themselves collectively and individually available to respond to ad hoc requests for expert clinical and mātauranga Māori advice from designated RDNZ personnel
2. May collectively or individually offer unsolicited expert clinical and mātauranga Māori advice to designated RDNZ personnel
3. Shall meet annually to review and report to the RDNZ Board on the panel's contribution to RDNZ including the extent to which it has delivered on its scope.