

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



Rare Disorders Research Network

Leadership Group

Terms of Reference

Purpose

People living with a rare disorder are estimated to make up 6% of the population in Aotearoa. To further support Rare Disorders New Zealand (RDNZ)'s advocacy for those living with a rare disorder, expressions of interest are invited from tangata whenua and tangata tiriti who wish to participate on its Rare Disorders Research Network Leadership Group.

The purpose of the Leadership Group is to support the establishment, growth and evidence based and whakaaro Māori impact of a network of Aotearoa New Zealand rare disorders researchers, consistent with the context set out in Appendix 1.

Scope

The Rare Disorders Research Network Leadership Group will:

1. Develop and maintain a contact database of New Zealand based rare disorders researchers.
2. Connect rare disorders researchers with each other and raise mutual awareness of their areas of research.
3. Facilitate bi-annual rare disorders research forums and meetings.
4. Identify opportunities for interdisciplinary research, funding collaborations and research strategies.
5. Promote external sharing of research, including with media and people living with rare disorders.
6. Promote translation of research results into policy and practice.
7. Identify and promote career opportunities for aspiring and new rare disorders researchers.
8. Develop and oversee implementation of a community led rare disorders research prioritisation strategy.
9. Advise the RDNZ Clinical Advisory Panel as appropriate
10. Respond to ad hoc requests for rare disorders research advice from designated RDNZ personnel.

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11. Meet annually to review and report to the RDNZ Board on the group's contribution to RDNZ, including the extent to which it has delivered on its scope.

Chairs

As a reflection of RDNZ's commitment to Te Tiriti o Waitangi, the Network Leadership Group will be co-chaired by a Māori rare disorder research specialist and RDNZ's Chief Executive.

Membership of the Leadership Group

1. Members of the group, including the Māori rare disorder specialist co-chair, shall be appointed by the RDNZ Board in consultation with Professor Karen McBride-Henry, who will be a founding member of the group.
2. The RDNZ Board will aim to ensure that the group's composition comprises a cross representation of ten to twelve internationally respected and networked Aotearoa New Zealand rare disorders researchers, fifty percent of whom will have Māori rare disorder specialist mātauranga Māori expertise.
3. Members shall be appointed for three-year terms and may be reappointed for subsequent three-year terms.

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.

Appendix 1: Context

In June 2023 Professor Karen McBride-Henry and her team at Victoria University School of Nursing, Midwifery and Health Practice received confirmation of Health Research Council (HRC) funding to develop a rare disorders research network.

The proposal said that "we will bring together a network of RDNZ, RD experts, healthcare researchers, and those from the RD community to develop a RD research strategy for Aotearoa. Given the limited evidence of RDs within Aotearoa, this research network will allow the development

of a strategy that can inform future research grant bids that meet the RD communities' needs."

"Furthermore, the network will identify those with RDs who want to pursue a research career, building health services research capability and capacity by creating an opportunity to be nested within a committed, supportive and value-driven research team. Finally, this network will facilitate the timely transfer of research knowledge between those working in academia, clinical practice, and policy"

"The RD Research Network will be comprised of up to 15 individuals comprising Māori and tauīwi with RD lived experience, healthcare researchers, and clinicians interested in developing an Aotearoa RD research strategy. Identifying network members will start in the

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first half of 2024. Research Network members will attend a minimum of two hui, with the initial one in September 2024 and another in December 2024”.

“A Māori rare disorder specialist and Chris Higgins the CEO of RDNZ will co-chair the network to facilitate network engagements and guide the underlying philosophy to ensure tikanga throughout. The hui will be hosted at RDNZ, with people outside Wellington able to Zoom in. The purpose of each hui is whakawhanaungatanga (establish relationships) and developing a research prioritisation strategy. The final strategy will be released in January 2025”.

Recent developments have identified a larger number of New Zealand rare disorders researchers than contemplated by the original proposal. Accordingly, the rare disorders researchers network refers to all New Zealand based rare disorders researchers (and networks of researchers) who wish to be connected to each other under an RDNZ umbrella, and the terms of reference are for a Leadership group which will be established to give effect to the above and to support the network itself.