

Interests:

Member, Pharmac Interim Consumer Transition Committee
Chair, RDNZ Round Table of Companies
Chair, Liggins Institute Rare Disorders Advisory Panel
Co-chair RDNZ Rare Disorders Research Network Leadership Group
Chair, NZ ERDERA National Mirror Group
Brand Ambassador, New Zealanders for Health Research



Experiences of New Zealanders Living With Rare Disorders and RDNZ's response

Chris Higgins
Chief Executive
Rare Disorders New Zealand

NZ ERDERA NMG Research Forum
Christchurch NZ

6 August 2026

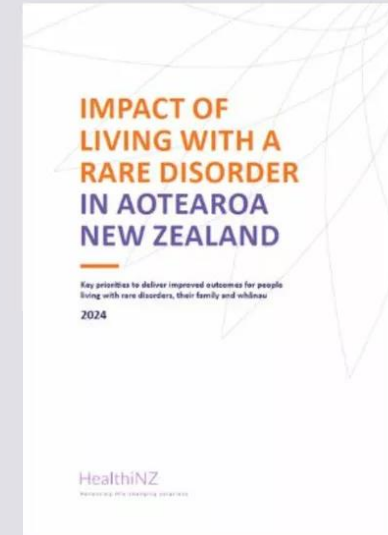
WHO ARE WE?

- ▶ 300,000 people or 5.8% of the population
- ▶ 7000 different disorders
- ▶ 75% experience rare disorder-related difficulty with seeing, hearing, moving
- ▶ 72% genetic
- ▶ 50% children
- ▶ 150+ support groups
- ▶ Prevalence of 1: 2000 or less

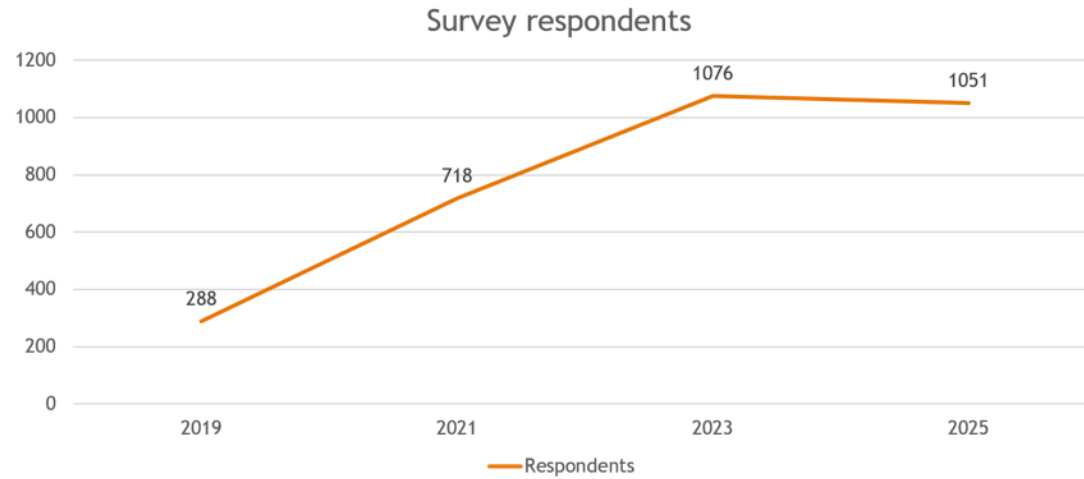
WHO ARE WE?



IMPACT OF LIVING WITH A RARE DISORDER

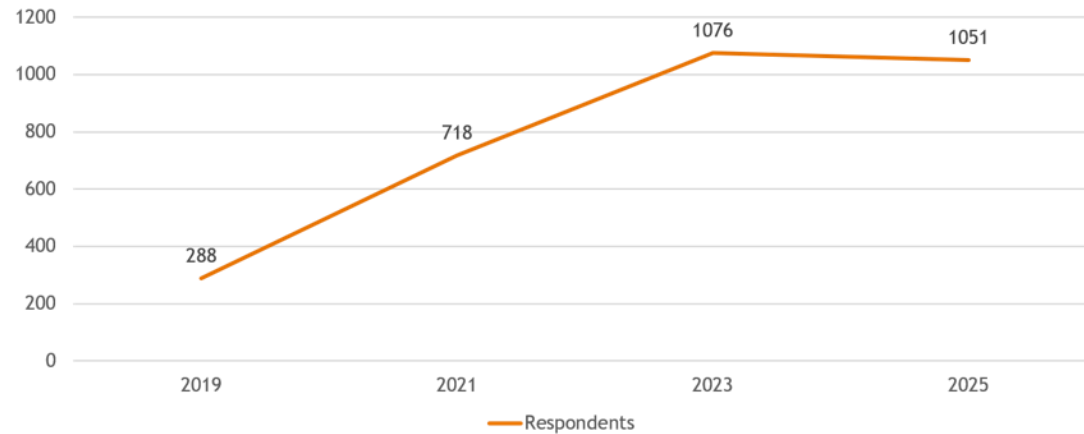


IMPACT OF LIVING WITH A RARE DISORDER

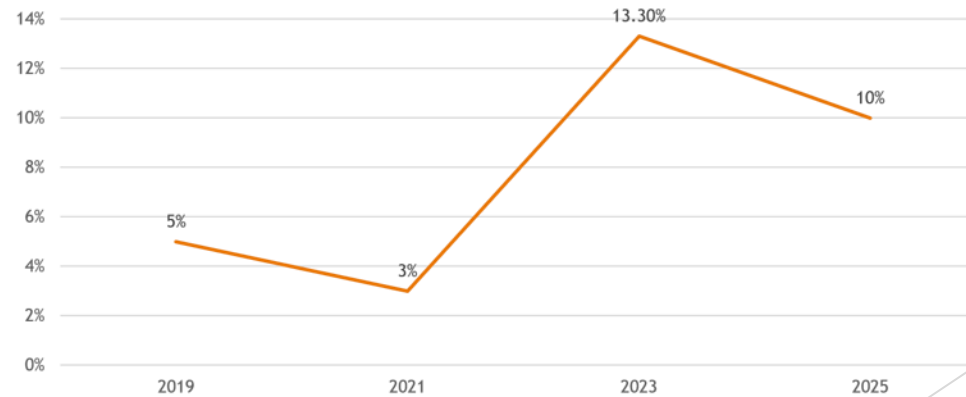


IMPACT OF LIVING WITH A RARE DISORDER

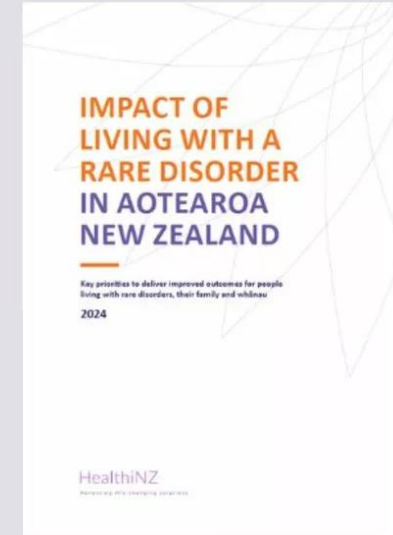
Survey respondents



Māori respondents

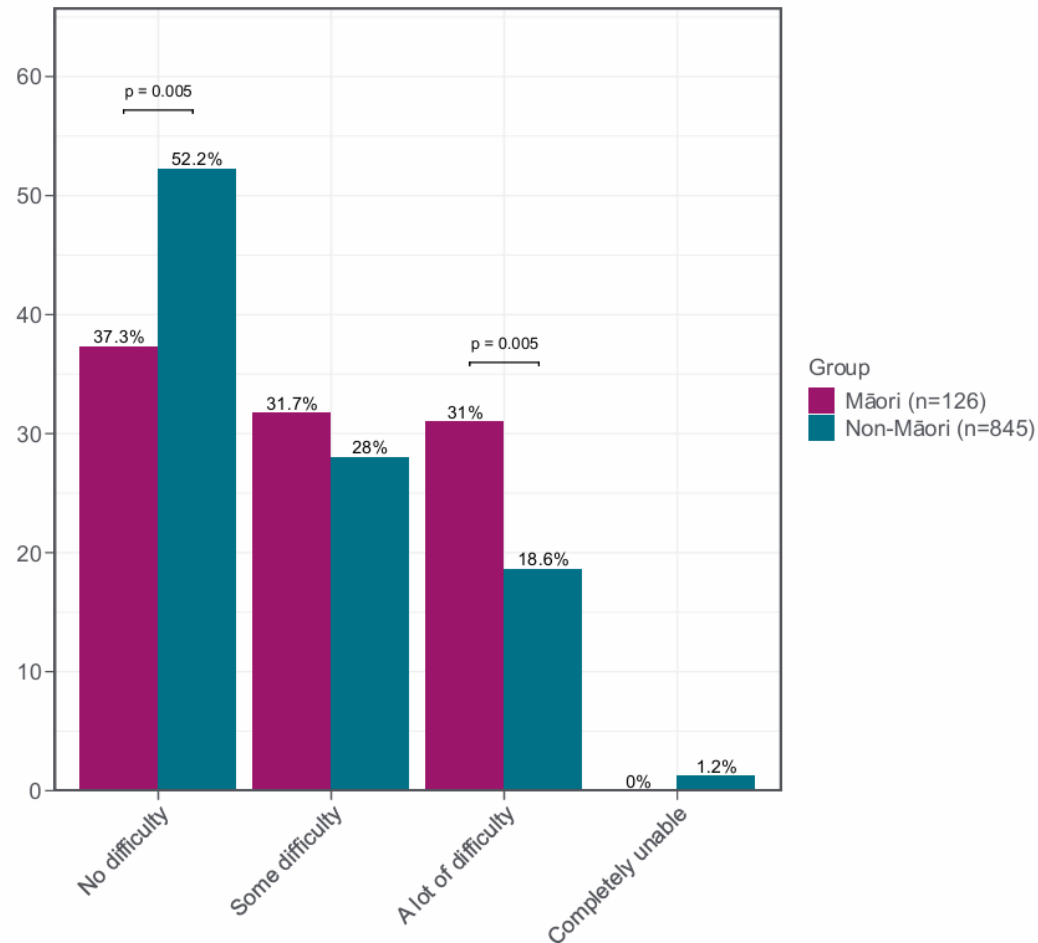


IMPACT OF LIVING WITH A RARE DISORDER



DIFFERENCES BETWEEN MĀORI AND NON-MĀORI

Impact on Understanding and Learning



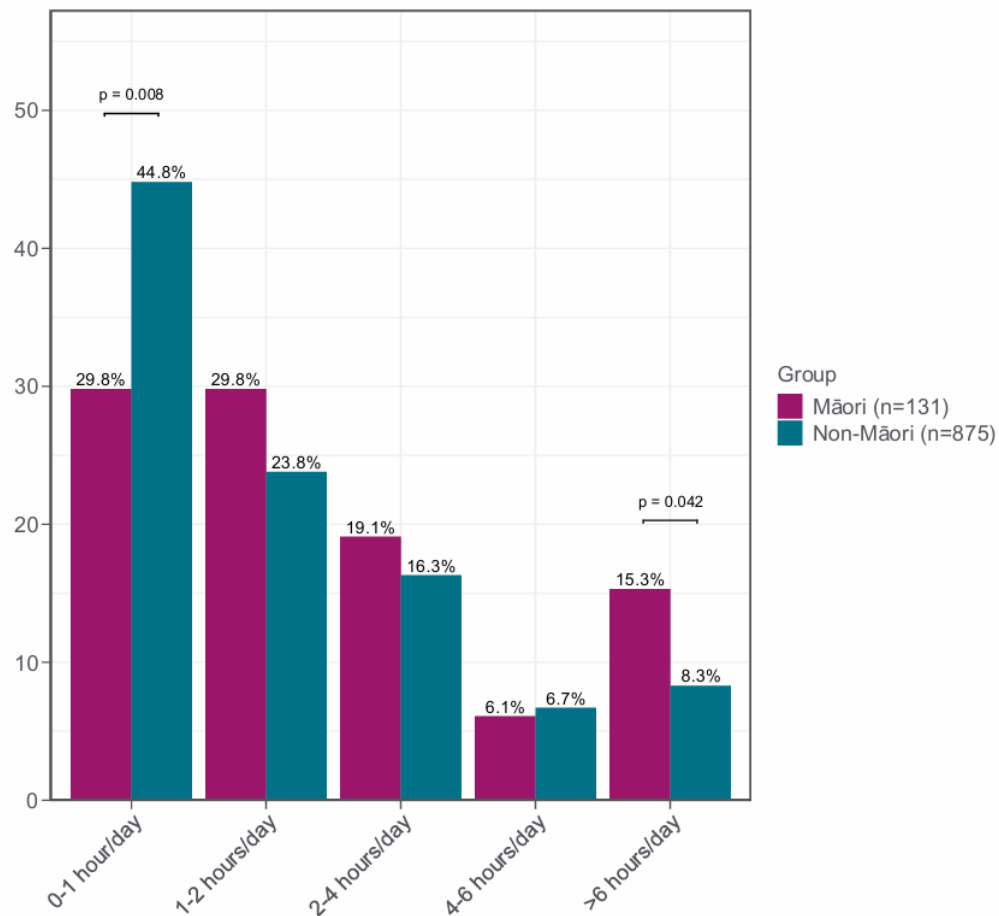
Key Findings:

- There was a **statistically significant** difference in the reported levels of **difficulty with understanding and learning** due to the rare disorder between Māori and non-Māori ($p=0.015$)
 - Māori **less frequently** chose **[No difficulty]** compared to non-Māori
 - Māori **more frequently** chose **[A lot of difficulty]** compared to non-Māori



DIFFERENCES BETWEEN MĀORI AND NON-MĀORI

Additional Daily Time Spent on Tasks



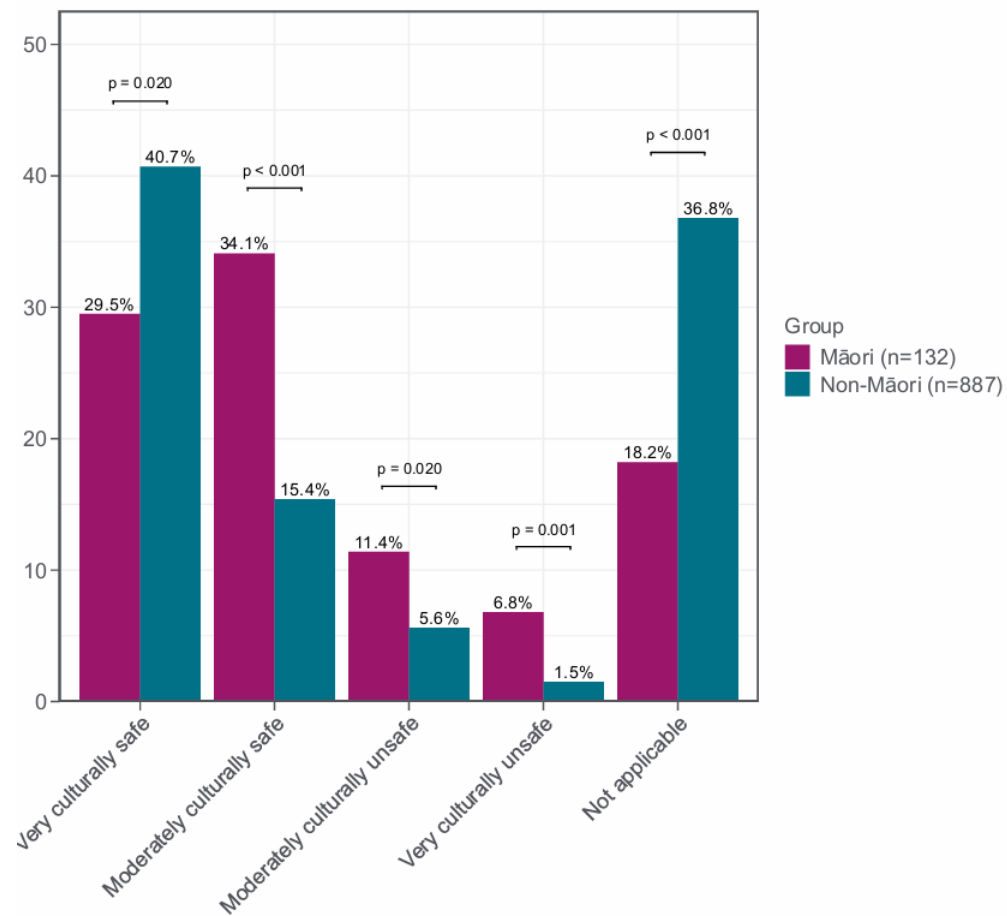
Key Findings:

- There was a **statistically significant** difference in the reported **amount of additional time spent on daily tasks due to the rare disorder** between Māori and non-Māori (p=0.029)
 - Māori **less frequently** chose **[0-1 hour/day]** compared to non-Māori
 - Māori **more frequently** chose **[>6 hours/day]** compared to non-Māori
- A higher proportion of Māori reported spending **>1 hour/day** on additional daily tasks due to the rare disorder (70.3% vs 55.1%) compared with non-Māori



DIFFERENCES BETWEEN MĀORI AND NON-MĀORI

Perceived Cultural Safety in Healthcare Visits



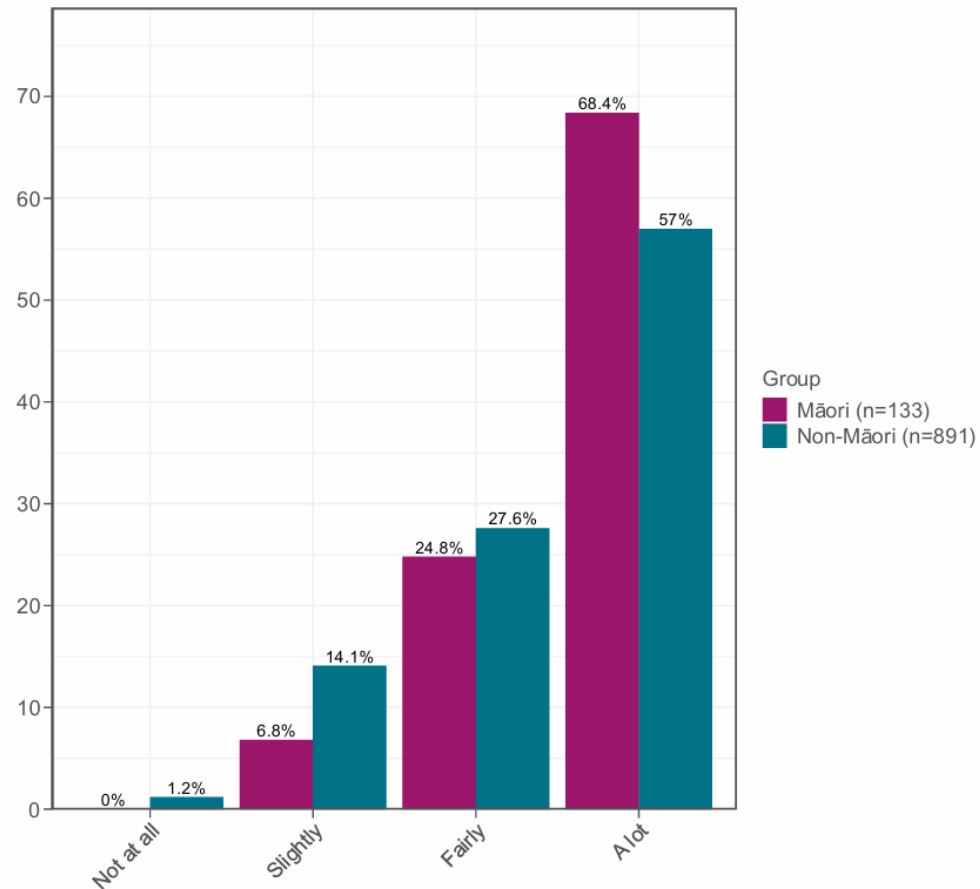
Key Findings:

- There was a **statistically significant** difference in the reported level of **cultural safety when accessing health services for a rare disorder** between Māori and non-Māori (p=0.001)
 - Māori **less frequently** chose **[Very culturally safe]** and **[Not applicable]** compared to non-Māori
 - Māori **more frequently** chose **[Moderately culturally safe]**, **[Moderately culturally unsafe]**, and **[Very culturally unsafe]** compared to non-Māori



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Overall Impact on Health and Daily Life



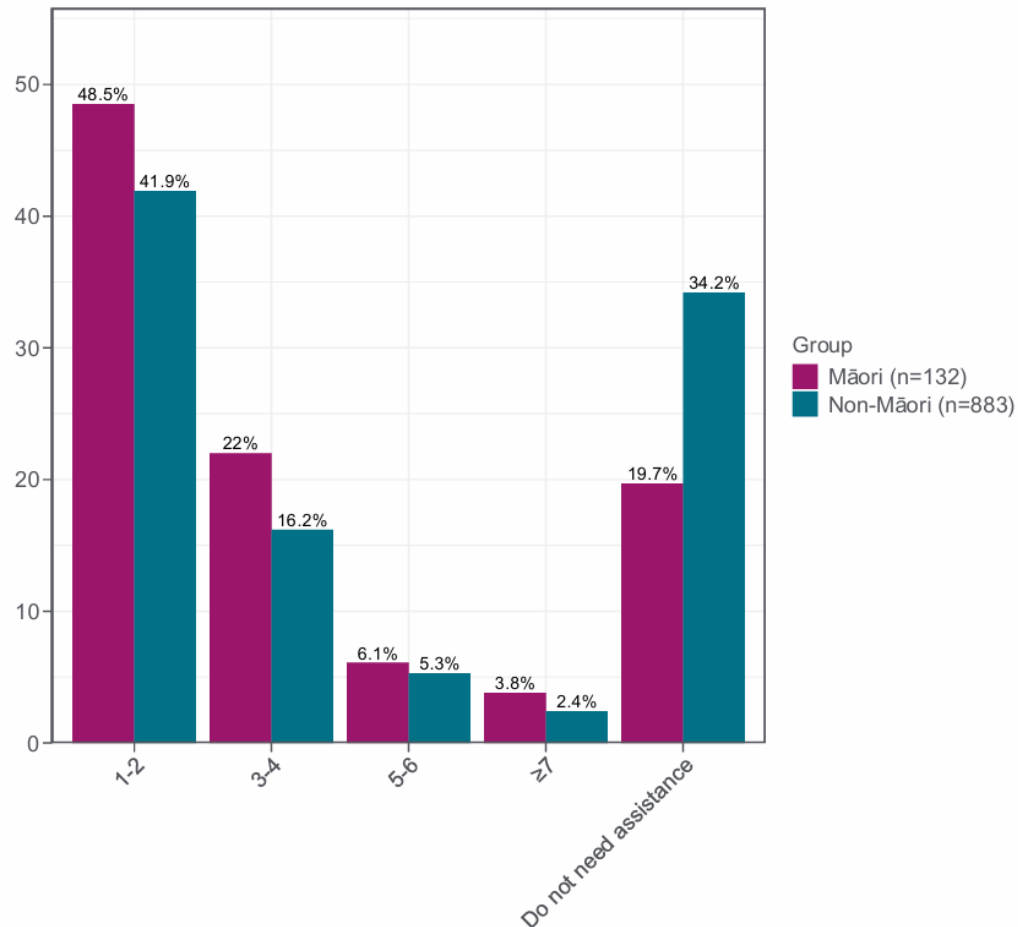
Key Findings:

- There was **no statistically significant difference** in the reported **overall level of impact of the rare disorder on health and daily life** between Māori and non-Māori ($p=0.074$)
- The overall ranking of responses was similar between groups. Across both groups, a substantial proportion reported that their rare disorder had **“a lot”** of impact on their health and daily life, with 68.4% of Māori and 57% of non-Māori



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Amount of Informal Care and Support

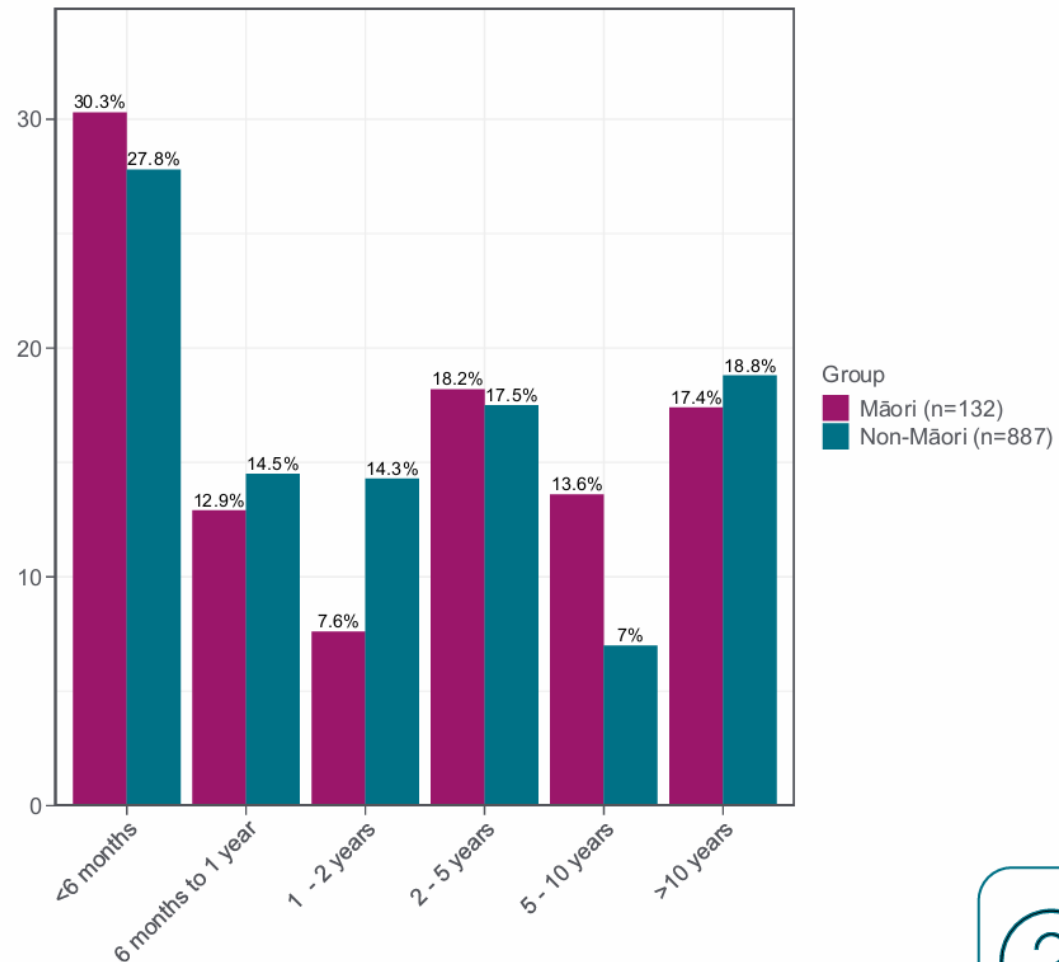


Key Findings:

- There was **no statistically significant difference** in the reported **number of whānau/family and friends involved in weekly care and/or support** for the person with the rare disorder between Māori and non-Māori ($p=0.062$)
- Most respondents reported having a small number (1–2) of whānau/family and friends involved in their weekly care and/or support, with similar patterns observed for Māori (48.5%) and non-Māori (41.9%)

SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Time to Accurate Diagnosis

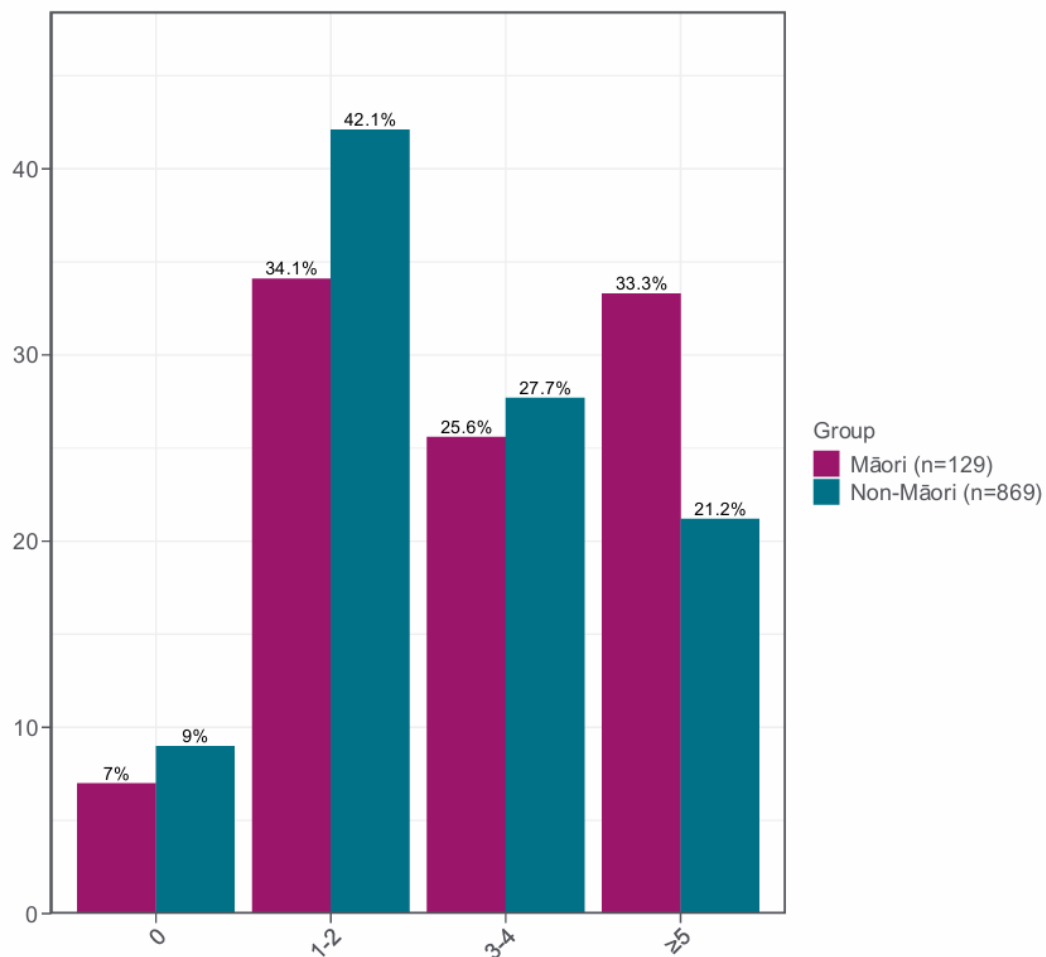


Key Findings:

- There was **no statistically significant difference** in the **time taken to receive an accurate diagnosis** for the rare disorder between Māori and non-Māori ($p=0.109$)
- Across both groups, a substantial proportion of respondents had long delays in receiving an accurate diagnosis, with over 15% taking **over 10 years**



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI GP Visits in the Past 6 Months



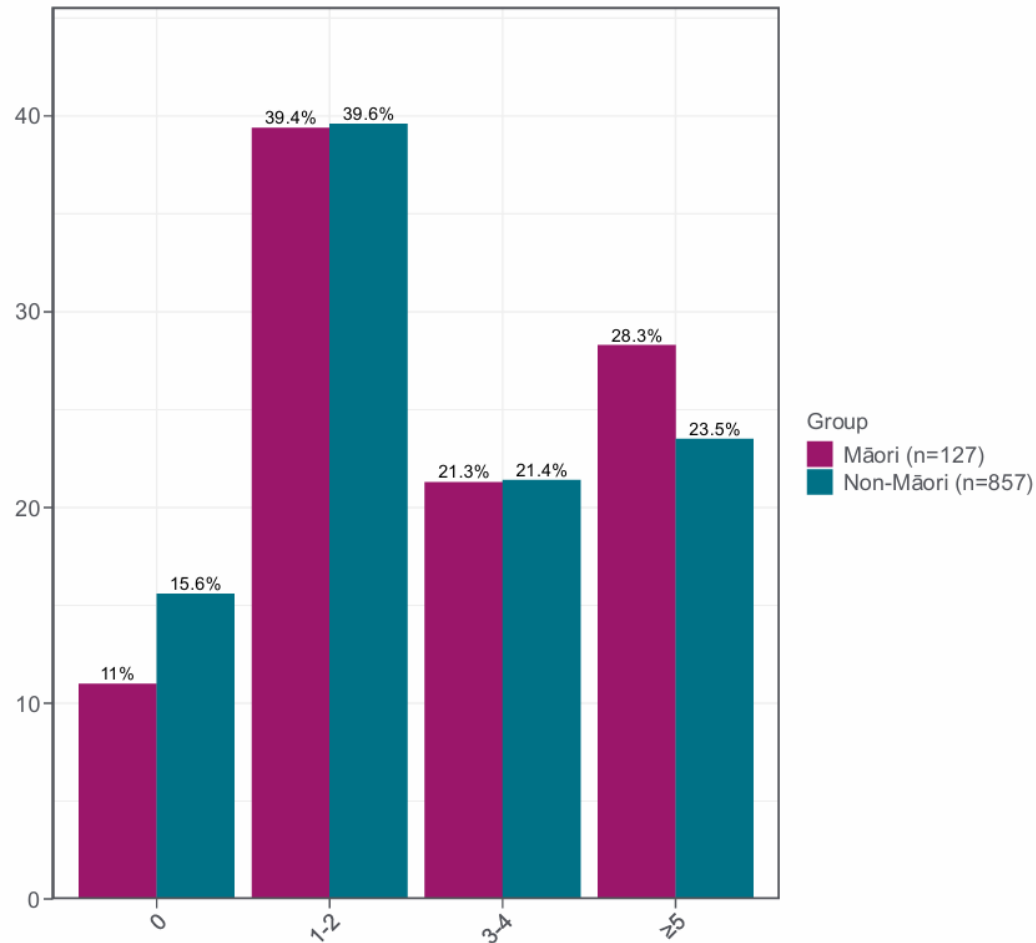
Key Findings:

- There was **no statistically significant difference** in the number of GP visits in the past 6 months for the rare disorder between Māori and non-Māori ($p=0.062$)
- Across both groups, a substantial proportion reported **3 or more GP visits** in the past 6 months for their rare disorder, with 58.9% of Māori and 48.9% of non-Māori



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Specialist Visits in the Past 6 Months



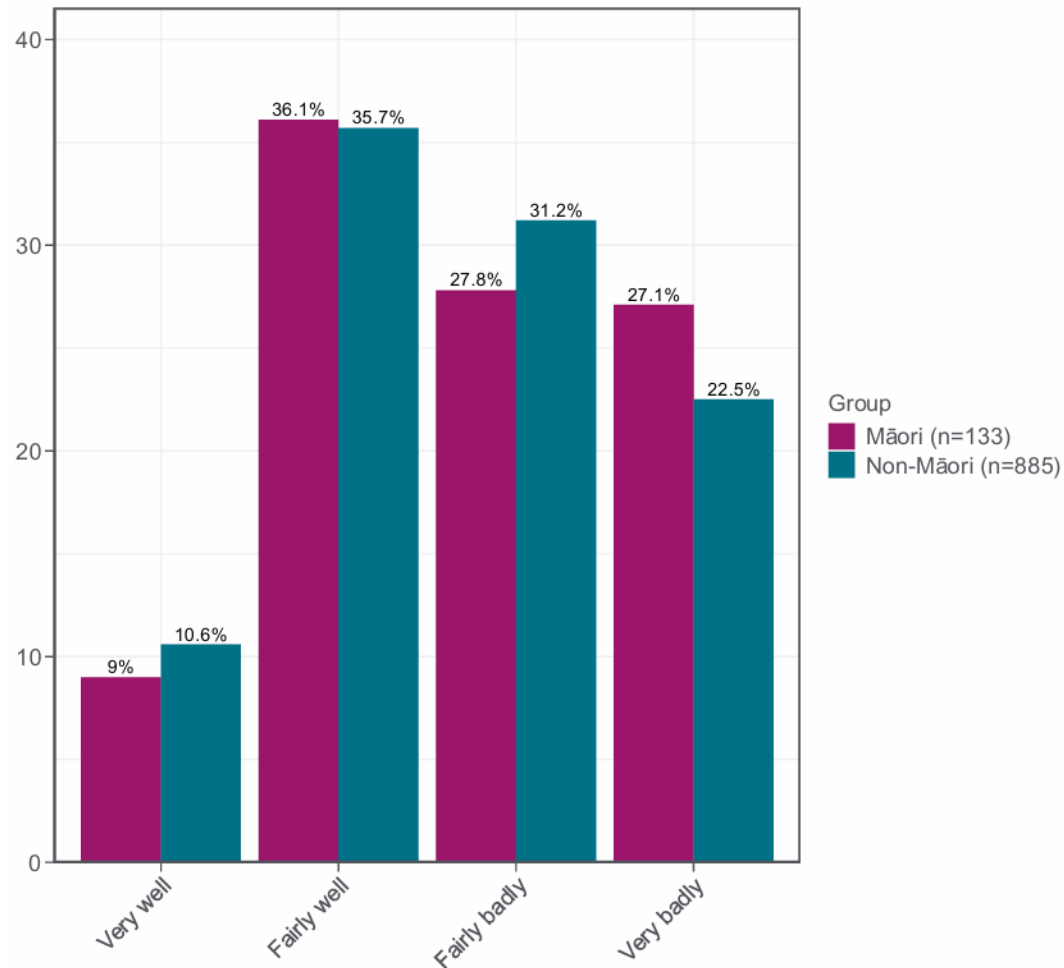
Key Findings:

- There was **no statistically significant difference** in the number of specialist doctor visits in the past 6 months for the rare disorder between Māori and non-Māori ($p=0.535$)
- Across both groups, a substantial proportion of respondents reported **multiple specialist visits** in the past six months, with over 20% reporting more than 5 visits



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Communication Between Service Providers



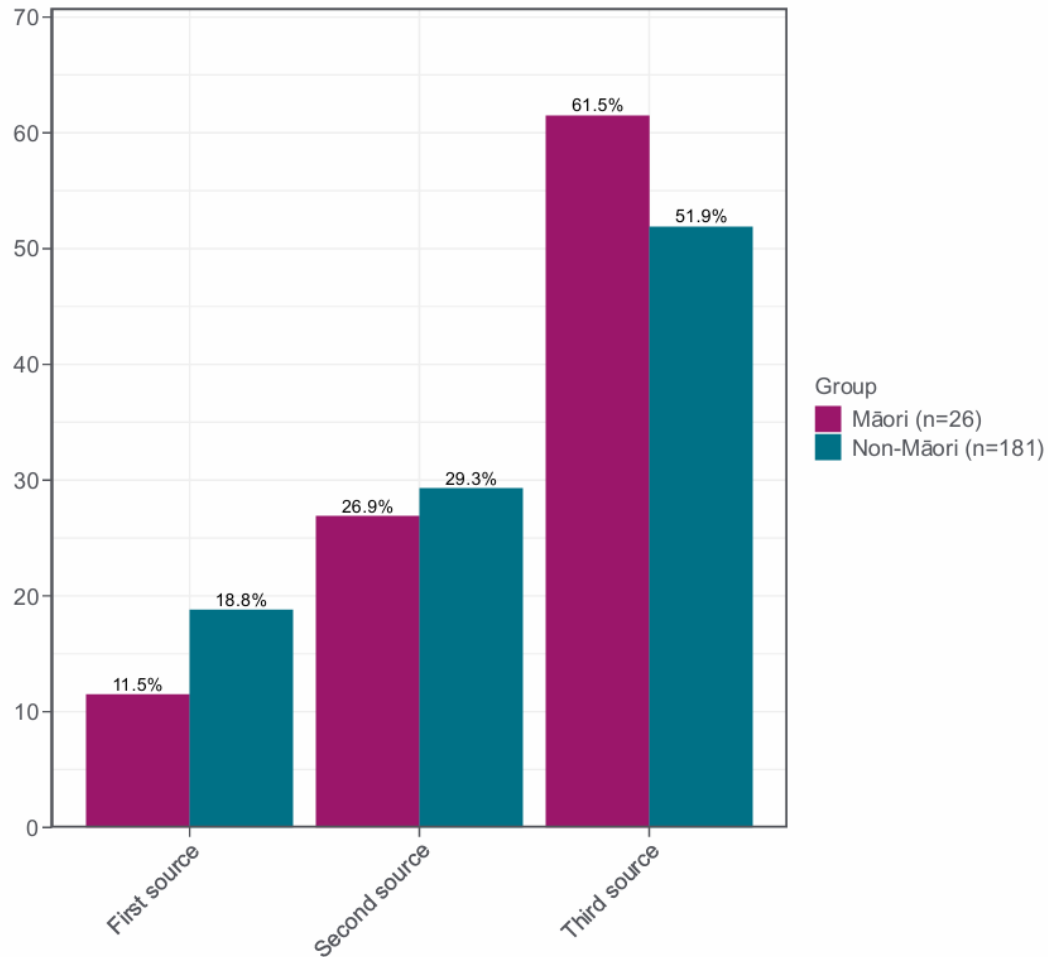
Key Findings:

- There was **no statistically significant difference** in how well service providers are perceived to communicate and share information about the person with a rare disorder between Māori and non-Māori ($p=0.644$)
- Across both groups, **more than half** of respondents rated communication and information-sharing by service providers about the person with a rare disorder as “fairly badly” or “very badly”



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Ranking of RDNZ as an Information Source



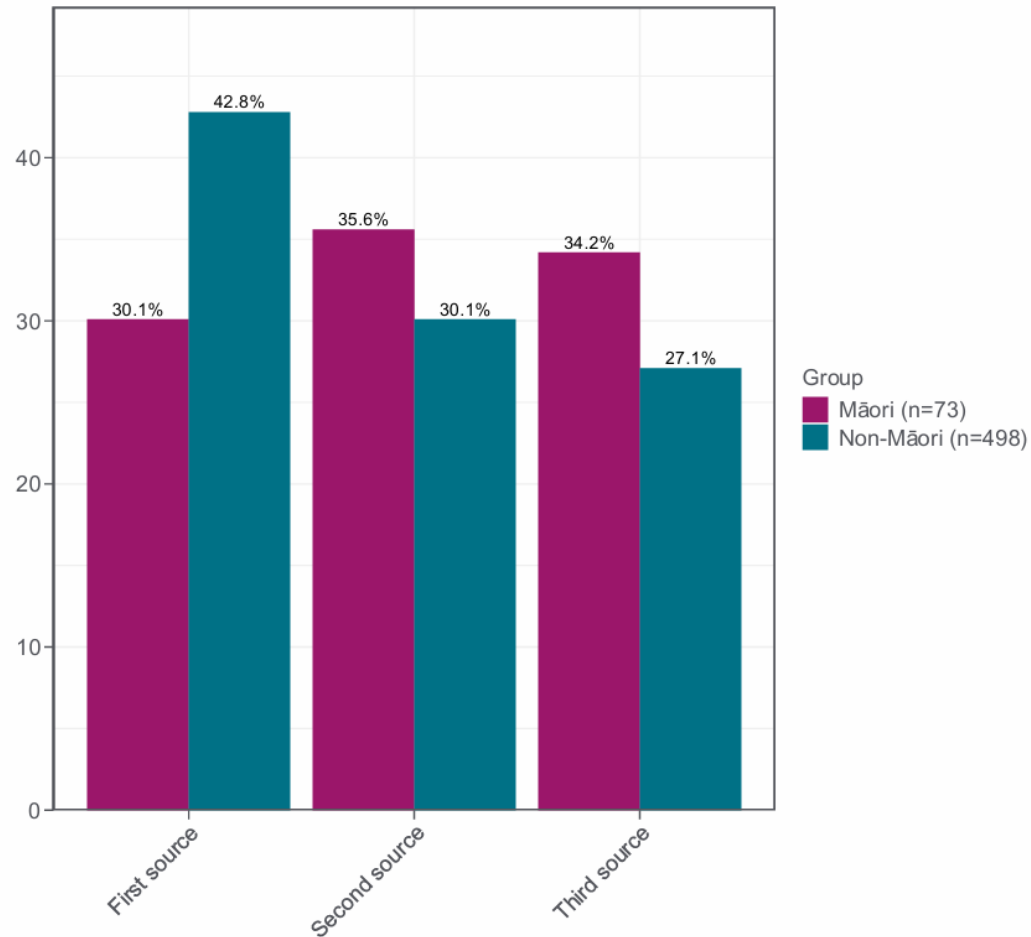
Key Findings:

- There was **no statistically significant difference** in the ranking of Rare Disorders NZ as a primary source of information for rare disorder treatment and care between Māori and non-Māori ($p=0.612$)
- Across both groups, **Rare Disorders NZ** was most commonly ranked as the **third source of information** for rare disorder treatment and care



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Support Groups as an Information Source



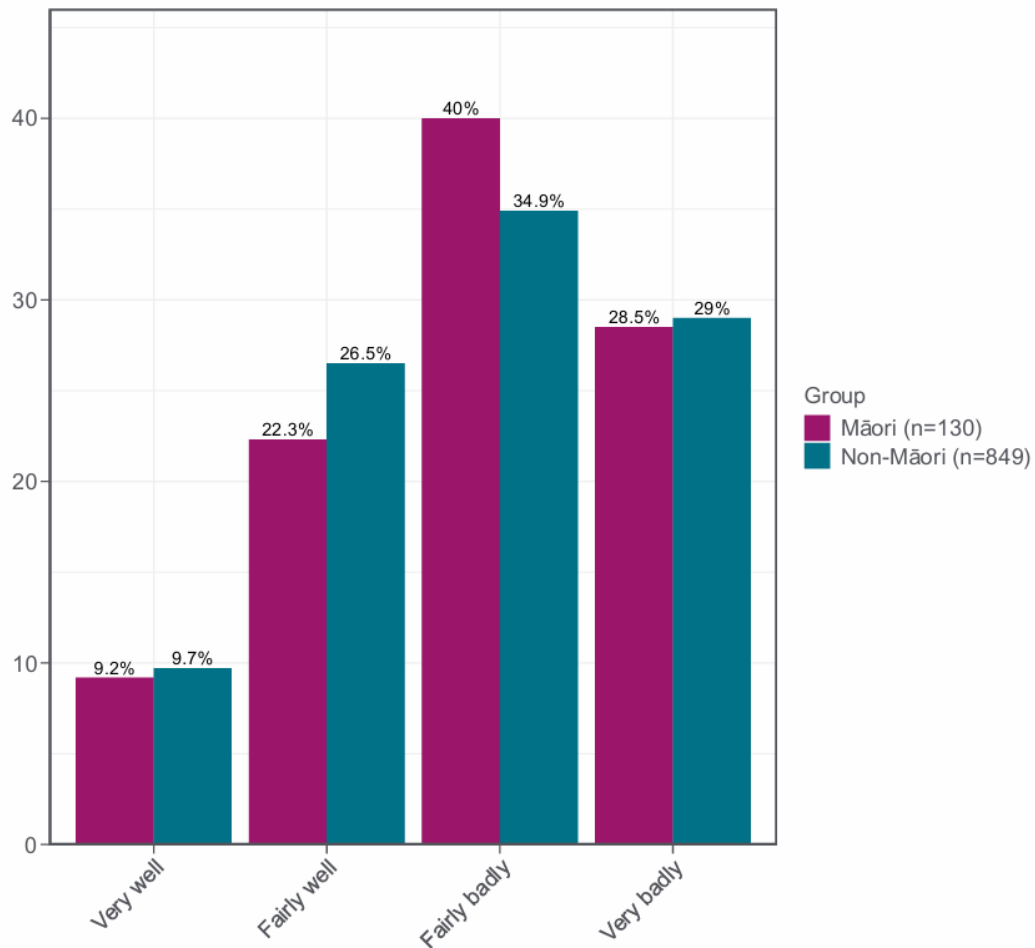
Key Findings:

- There was **no statistically significant difference** in the **ranking of support group as a primary source of information for rare disorder treatment and care** between Māori and non-Māori ($p=0.194$)
- Across both groups, **support groups** were ranked **fairly evenly** as the first, second, or third source of information for rare disorder treatment and care



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Understanding of the Disorder by Support Services



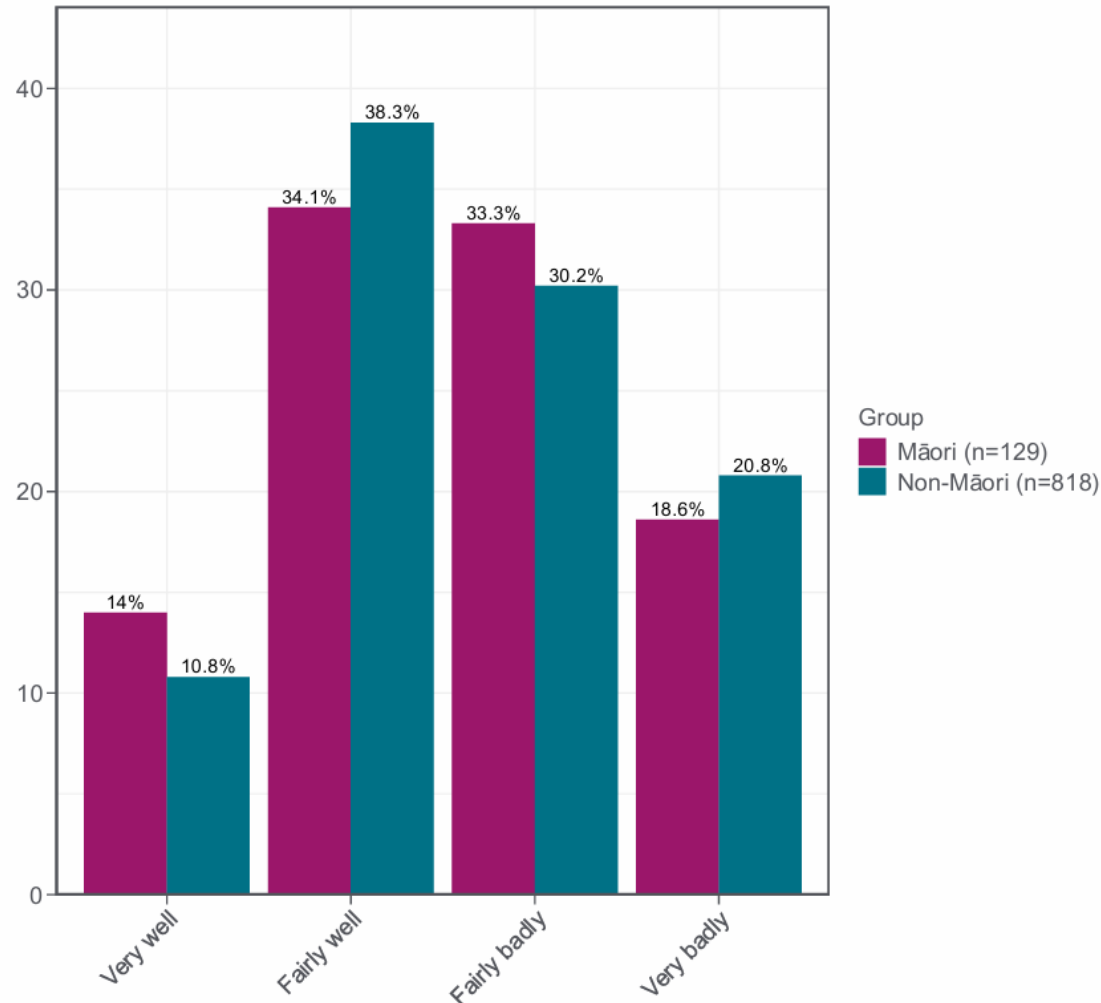
Key Findings:

- There was **no statistically significant difference** in how well professionals from social, local, and support services are perceived to know the rare disorder and its consequences between Māori and non-Māori ($p=0.652$)
- Across both groups, a substantial proportion of respondents rated professionals from social, local, and support services as knowing the rare disorder and its consequences “**fairly badly**” or “**very badly**”, with 68.5% of Māori and 63.9% of non-Māori



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Preparedness to Support Whānau/Family



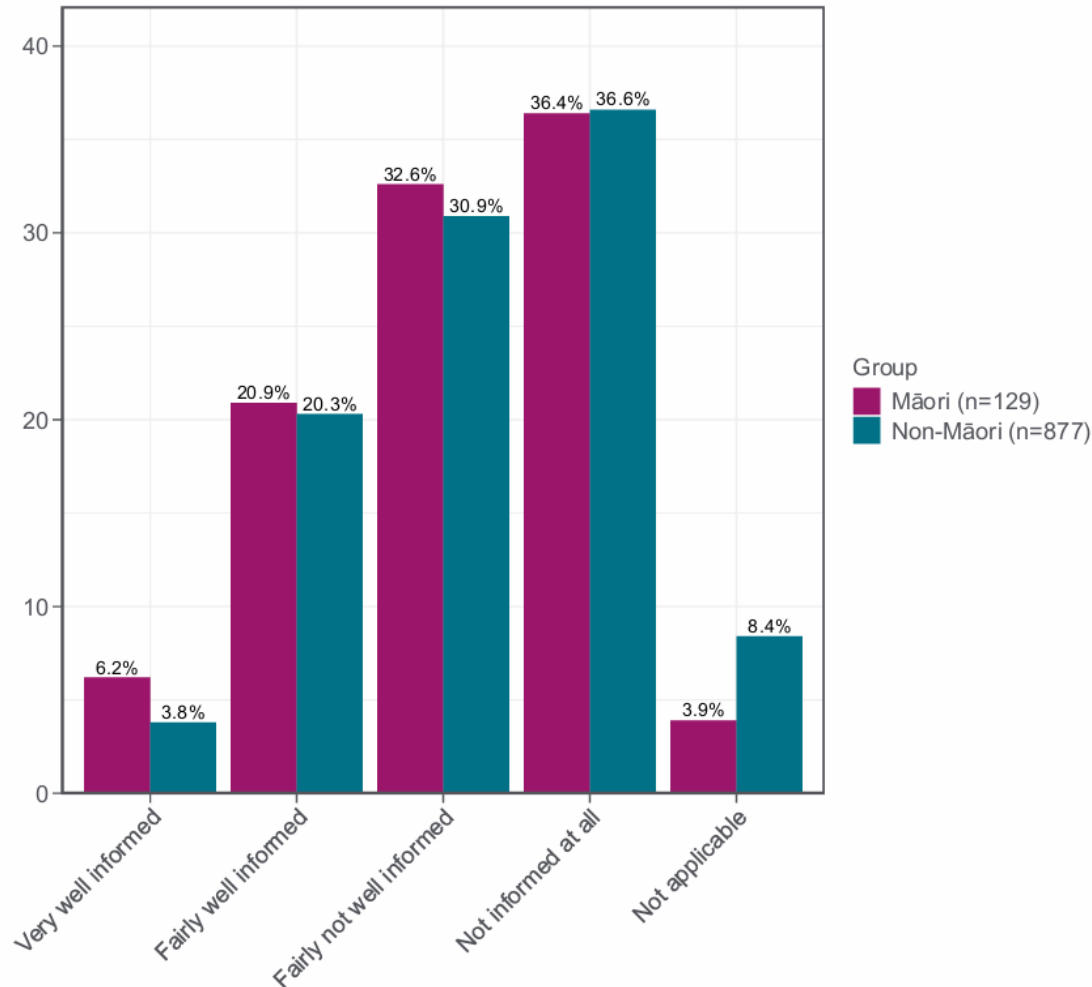
Key Findings:

- There was **no statistically significant difference** in how well professionals are perceived to be prepared to support whānau/family in dealing with the consequences of the rare disorder between Māori and non-Māori ($p=0.604$)
- Across both groups, **over half** of respondents perceived professionals as being prepared “**fairly badly**” or “**very badly**” to support whānau/family in dealing with the consequences of the rare disorder, reported by 51.9% of Māori and 51.0% of non-Māori



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Feeling Informed About Social Services



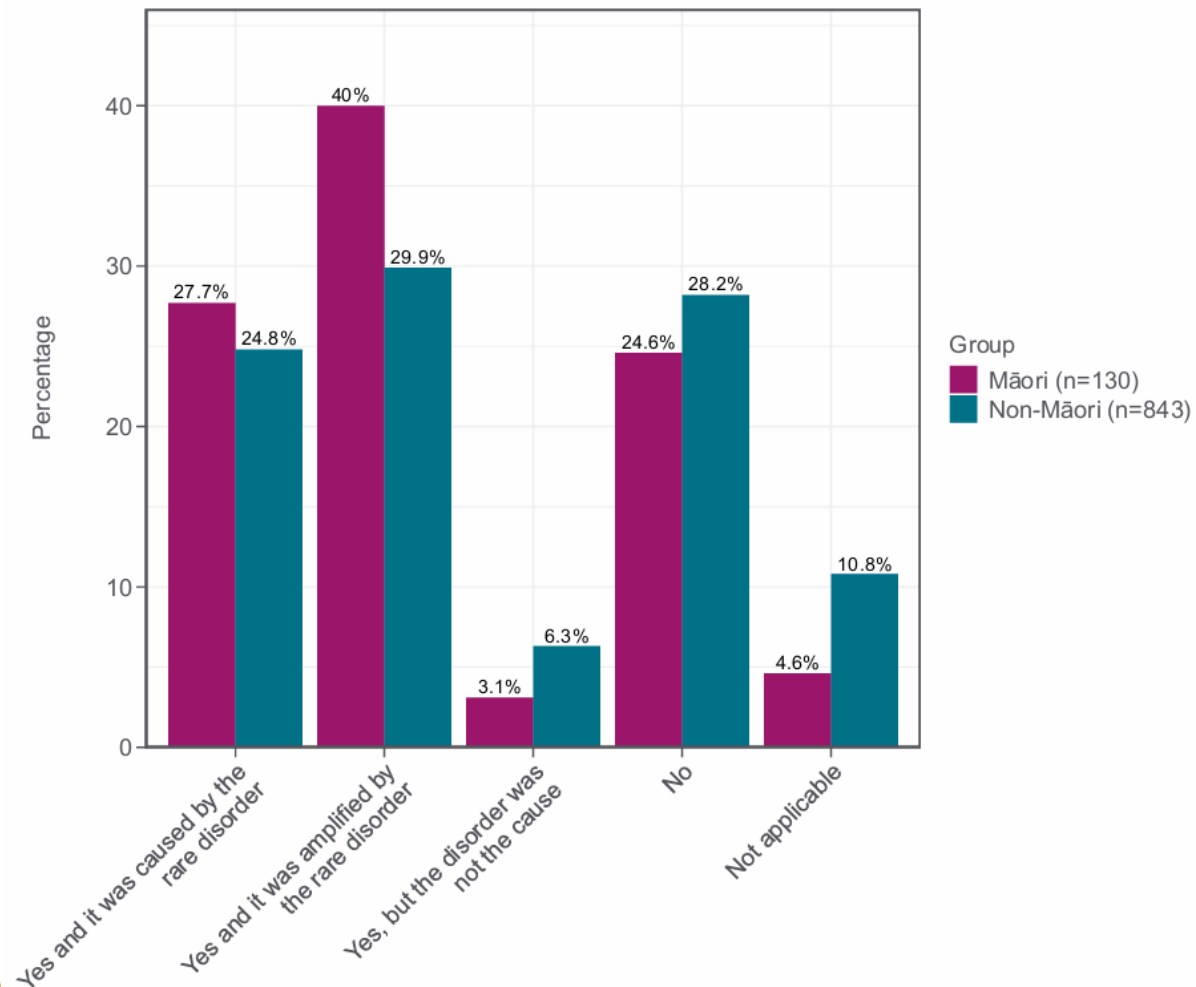
Key Findings:

- There was **no statistically significant difference** in **how well informed respondents feel about relevant social services for rare disorder support** between Māori and non-Māori ($p=0.399$)
- Across both groups, the majority of respondents felt **“fairly not well informed”** or **“not informed at all”** about relevant social services for rare disorder support, reported by 69.0% of Māori and 67.5% of non-Māori



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Whānau/Family Tensions Related to Rare Disorder



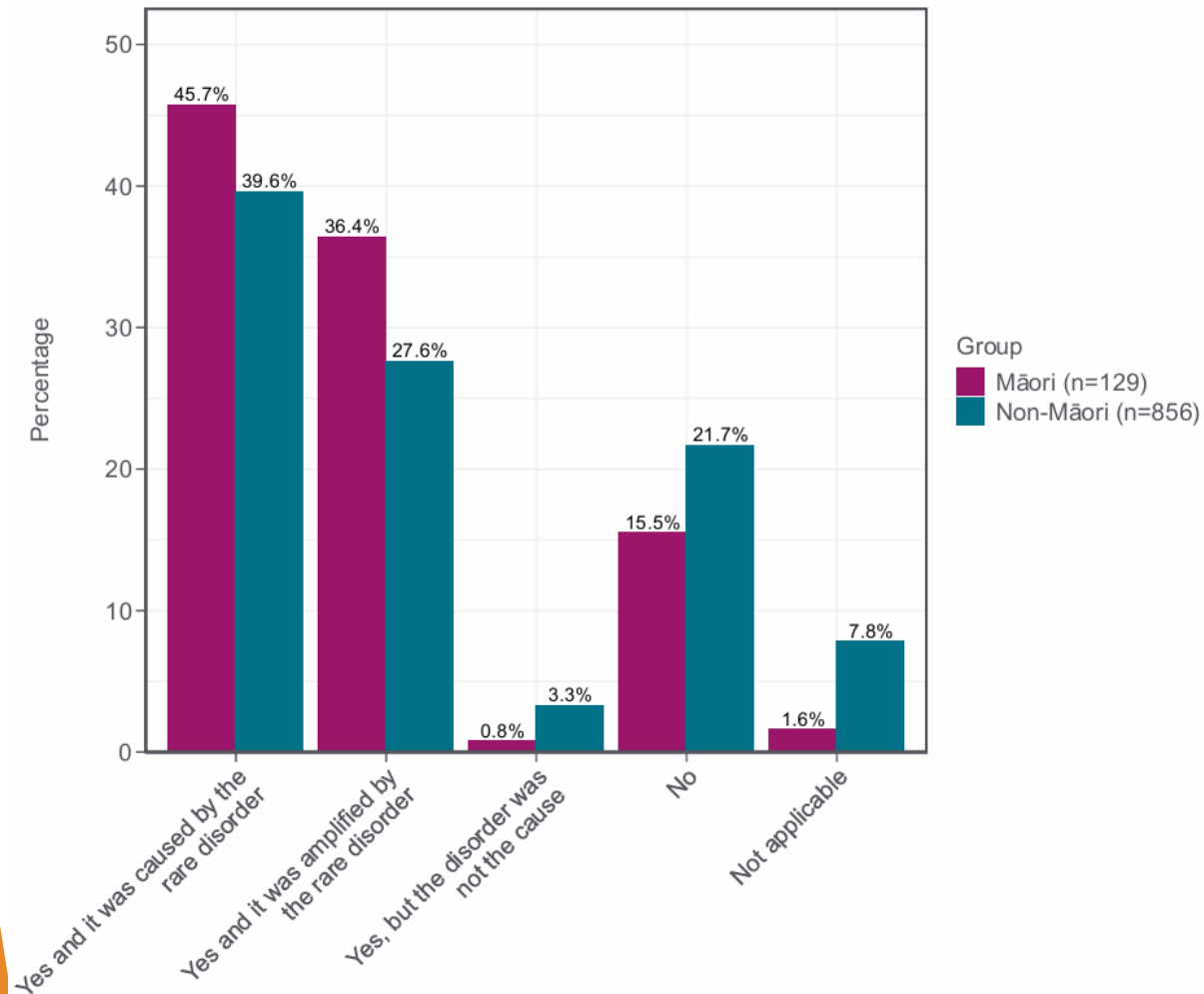
Key Findings:

- There was **no statistically significant difference** in the reported **experience of whānau/family tensions due to a rare disorder** between Māori and non-Māori ($p=0.074$)
- Across both groups, a substantial proportion of respondents reported that **whānau/family tensions were caused or amplified by the rare disorder**, with 67.7% of Māori and 54.7% of non-Māori



SIMILARITIES BETWEEN MĀORI AND NON-MĀORI

Isolation from Friends or Whānau/Family



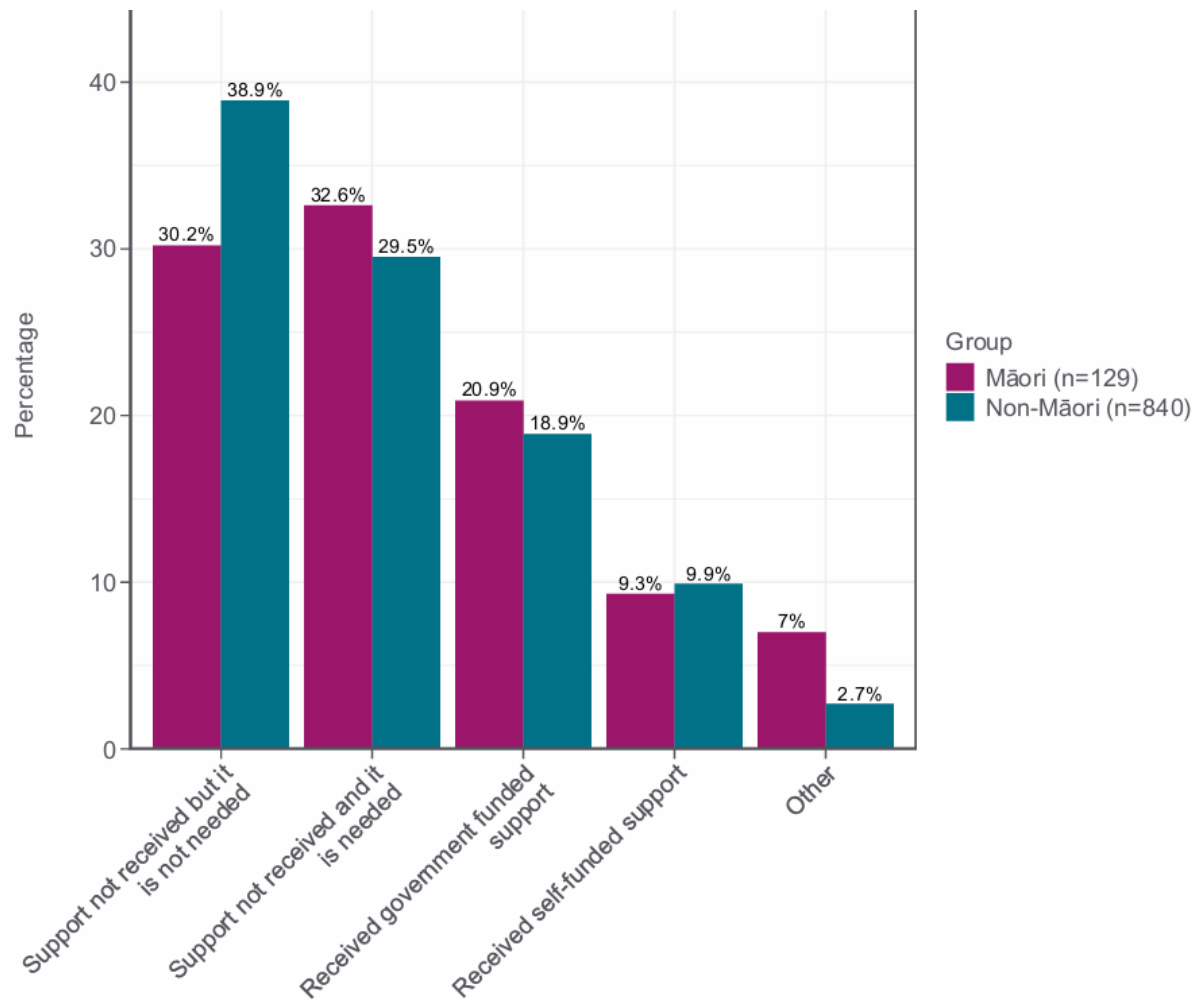
Key Findings:

Across both groups, a substantial proportion of respondents reported experiencing isolation from friends and/or whānau/family that was caused or amplified by the rare disorder



DIFFERENCES BETWEEN MĀORI AND NON-MĀORI

Received Mental Health or Wellbeing Support



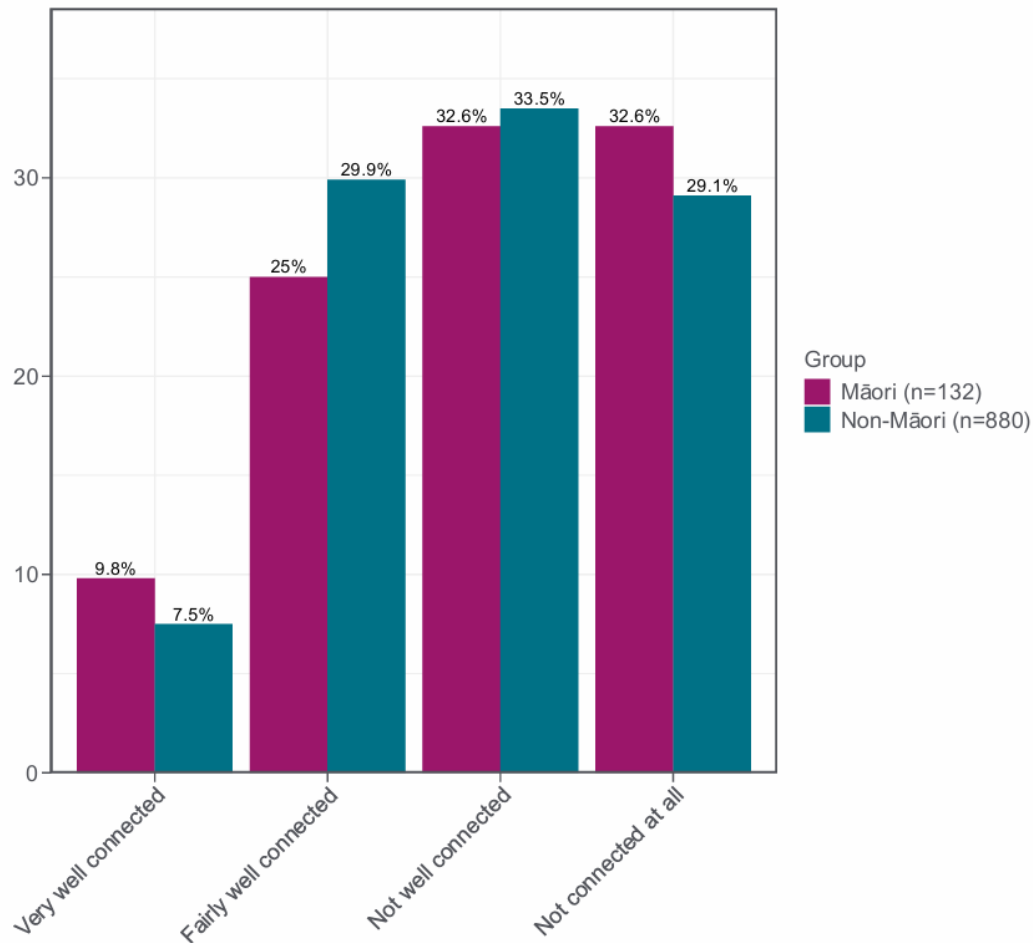
Key Findings:

- There was **no statistically significant difference** in whether the person with a rare disorder has received mental health or wellbeing support between Māori and non-Māori ($p=0.112$)
- Across both groups, a substantial proportion of respondents reported **not** receiving mental health or wellbeing support **despite needing it**, with 32.6% of Māori and 29.5% of non-Māori



DIFFERENCES BETWEEN MĀORI AND NON-MĀORI

Connected with Others Living with the Same Condition



Key Findings:

- There was **no statistically significant difference** in **how well the person with a rare disorder and/or their whānau/family feel connected with others who share the same condition** between Māori and non-Māori ($p=0.602$)
- Across both groups, most respondents and/or their whānau/family felt **not well connected** or **not connected at all** with others who share the same condition, with 65.2% of Māori and 62.6% of non-Māori



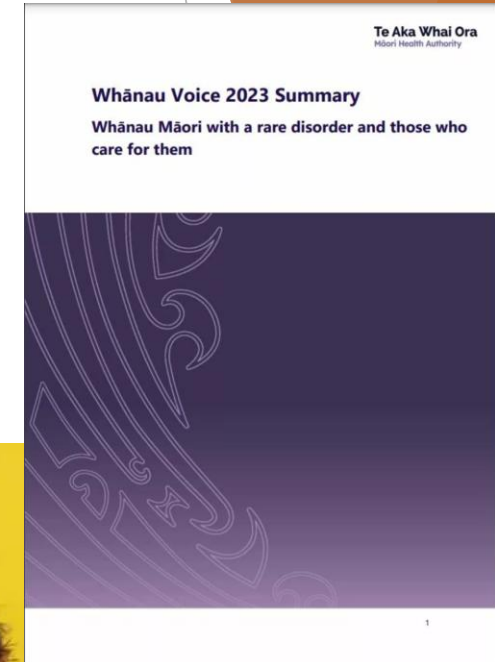
DIFFERENCES BETWEEN MĀORI AND NON-MĀORI



DIFFERENCES BETWEEN MĀORI AND NON-MĀORI



DIFFERENCES BETWEEN MĀORI AND NON-MĀORI



BEING A BETTER TIRITI PARTNER

- ▶ Complete and respond to implications of the Costello Medical funded report comparing whānau Māori and non-Māori experiences of living with a rare disorder (two vulnerable population groups/low base)
- ▶ Pursue a mātauranga Māori informed approach to implementing the Rare Disorders Strategy
- ▶ Operate RDNZ's CAP and RDRN in ways that demonstrate RDNZ's commitment to being a better Tiriti partner
- ▶ Recruit and retain tangata whenua RDNZ Board members
- ▶ Establish and be responsive to an RDNZ Māori advisory group

BEING A BETTER TIRITI PARTNER

Māori advisory group

- ▶ identification of a kaumatua;
- ▶ identification of te ao Māori kupu for rare;
- ▶ confirming the name *te toropaepae o te kōtuku* for our office space;
- ▶ identifying a name and confirming (or otherwise) the branding for the rare disorders research network/NZ ERDERA National Mirror Group;
- ▶ recommending next steps for te whānau kōtuku support group;
- ▶ assisting in identifying a kaupapa Māori co-chair for RDNZ's clinical advisory panel;
- ▶ monitoring progress on, and unlocking sources of funding to implement, annual plan actions relating to the strategy to become an effective and relevant Tiriti partner.
- ▶ any and all other aspects of RDNZ's mahi

WHAT DO WE WANT?

Based on successive VRD surveys and numerous consultations with the rare disorders communities we want:

- Early and accurate diagnosis
- Coordinated and integrated healthcare pathways
- Access to disability and social supports
- Fair access to modern rare disorders medicines
- Coordinated funded programme of rare disorders research
- Coding for rare disorders in the health and other records
- Health professional and support staff training

WHAT HAVE WE GOT?



WHAT HAVE WE GOT?



WHAT HAVE WE GOT?



WHAT HAVE WE GOT?



WHAT HAVE WE GOT?



WHAT HAVE WE GOT?



WHAT HAVE WE GOT?



WHAT HAVE WE GOT?



WHAT HAVE WE GOT?

- ▶ Rare Disorders Clinical Reference Group by October 2026
- ▶ A two-year clinical pilot of Whole Genome Sequencing of patients with rare diseases.
- ▶ National Clinical Network for Radiology workplan that considers inclusion of rare disorders.
- ▶ Complete the Exceptional Circumstances Framework review, including funding of and considering a specific pathway for funding medicines to treat rare disorders.
- ▶ The Ministry will hold a cross-agency forum with Pharmac, Health New Zealand, HQSC and Rare Disorders New Zealand every six months.
- ▶ The Ministry will review how planning and reporting processes can further develop to more clearly track progress over the ten year life of the Strategy

WHAT HAVE WE GOT?

- ▶ Publish a SNOMED CT code set of all 7,000 approx. rare disorders covered in the Orphacodes. 20 July 2026
- ▶ Guidance to software suppliers on how to use the code set (including how to map between SNOMED CT and Read Codes). September 2026 and ongoing
- ▶ Develop resources and information so the public and clinicians can navigate the system and find the rare disorders information they require
- ▶ A revised Pharmac consumer advisory committee function to better incorporate consumer voices including those of people living with rare disorders.
- ▶ RDNZ leadership of the rare disorders research network and the European Rare Diseases Research Alliance (ERDERA) New Zealand National Mirror Group, contributing to an expanded health research infrastructure that will support rare disorders research and evaluation.

NGĀ MIHI NUI



