IMPACT FOR WHĀNAU MĀORI OF LIVING WITH A RARE DISORDER IN AOTEAROA NEW ZEALAND

Delivering improved outcomes for Māori living with rare disorders and their whānau

2024

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This white paper was written by HealthiNZ

Acknowledgements

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About HealthiNZ

Andrew Cameron is the Principal Consultant at HealthiNZ, providing a range of strategic advisory healthcare services in NZ and overseas. Andrew has over 20 years' commercial healthcare experience, with a passion for healthcare innovation and new technologies that deliver patient outcome-led advances in healthcare and wellbeing. Believing that in order to ensure health innovations are truly people centred it is critical that we first listen to the voice of the patient.

Beyond his role at HealthiNZ Andrew has a personal interest in rare disorders as a parent of a child who has cystic fibrosis and currently sits on the Board of their patient organisation Cystic Fibrosis NZ.

Ko koe ki tēnā, ko au ki tēnei kīwai o te kete

You carry your handle and I'll carry my handle of our kete

Contents

Executive summary

For Māori living with a rare disorder the impact continues to be significant, affecting not only themselves but extending to families/whānau, the health system and society.

Key findings from the 2023 survey:

The 2023 New Zealand Voice of Rare Disorders Survey had a specific community engagement objective to better understand and reflect the impact for Māori living with rare disorders. At 144 responses and 13.3% of the total, the 400% increase in participation from Māori provides the largest collective voice for people living with a rare disorder in Aotearoa. In terms of representativeness, 12% more Māori respondents were a parent of a child with a rare disorder, compared with non-Māori, and this should be considered in making direct comparisons.

For Māori living with a rare disorder today, the impact for them was similar to, or sometimes greater, compared with non-Māori. The majority reported that the rare disorder impacts a lot on their health and everyday life, is disabling and makes a number of everyday activities difficult. Approximately half of people are self-funding costs of their healthcare (e.g. healthcare professionals, treatments and medications and special diets) to some extent with the majority finding this hard to manage, or unable to afford it. Full employment is a challenge for people and their carers, often requiring modified work arrangements or the need to leave their jobs. Their rare disorder has serious effects, not only on their own mental health and wellbeing, but also on their family/whānau, with one in three often unhappy and depressed and feeling they cannot overcome their problems.

Need to close healthcare service and support gaps in health and other systems

Results paint a picture for Māori of isolation, lack of timely and accurate diagnosis, high utilisation of healthcare services, poor treatment access, lack of coordinated care, significant carer impact, lack of access to care services including suitable mental health and wellbeing support, and for many, being lost in the system.

These results point to the need for improvements in how healthcare services are delivered to people with rare disorders regardless of their ethnicity. Māori were generally able to access healthcare services at least at a similar rate to non-Māori, with overall similar perceptions of how effective these were. Given this, there is a need to close healthcare service and support gaps in health and other systems for Māori, similar to non-Māori.

Need for better access for rare disorders medicines

The survey results confirmed that there were few accessible effective modern medicines available for the majority of Māori, with only a few successfully gaining access to medicines through the Named Patient Pharmaceutical Assessment (NPPA) process. Importantly, most were worried that promising treatments and medicines (e.g. gene therapy/ CRISPR) will not be funded by New Zealand's public health system in the future.

These results were consistent for all people with rare disorders, generally being similar for Māori and non-Māori. These point to the need for improvements in how people with rare disorders get access to the publicly funded medicines they need.

Need for Rare Disorders NZ to continue to improve community engagement with Māori

Rare Disorders NZ (RDNZ) is the only national organisation supporting all New Zealanders, including Māori, living with a rare disorder and their carers. They have been valued as a key partner with Manatū Hauora (Ministry of Health), Te Aka Whai Ora (Māori Health Authority) and Te Whatu Ora (Health New Zealand) in the development of the Rare Disorders Strategy and it is intended by RDNZ that this will continue with its implementation. In addition, it continues to provide the most representative and collective voice for people with rare disorders including for Māori. There is a key need for RDNZ to continue on its journey to being a culturally safe Tiriti partner and improve its engagement with whānau Māori.

Full implementation of the above key essential actions will be important changes to improve outcomes for Māori living with a rare disorder in Aotearoa.

The remainder of this White Paper presents results of responses from the 144 whānau Māori who responded to the survey. Notable differences between Māori and non-Māori respondents are highlighted wherever they occur, otherwise it can be understood that patterns of responses are similar across both samples.

Significant challenges remain for Māori living with rare disorders

Rare disorders have widespread impacts on people living with them, their whānau, the health system and society[1]. This can include significant impacts on hauora (spiritual, mental, physical and social health), and the ability for whānau to thrive due to financial stress, employment opportunities and career pathways. These factors impact heavily on Māori living with a rare disorder.

Māori often report being lost in a health system not designed for them, starting with a long pathway to diagnosis, and difficulty in accessing culturally safe treatments, care services or healthcare services, including challenges surrounding coordination of care. People can experience inequitable health outcomes and these outcomes are often influenced by unfair barriers, such as the lack of timely access to services and trying to navigate a health system ill-equipped to support them[2].

Need for wider community engagement, in particular with Māori

There is the need for a representative and unified voice for rare disorders that acknowledges Te Tiriti obligations to inform sensible future health policy. This includes engaging with tāngata whenua

However previous surveys had a low percentage of people responding that identified as being Māori, Pasifika or Asian. Given this, one of the 2021 survey recommendations was the need to create new ways to achieve greater inclusion for Māori through increased engagement. As a result, the role of Kaiāwhina Māori (Māori Engagement Officer) at Rare Disorders NZ was established. In addition, the 2023 survey had a specific emphasis on improving community engagement with Māori, which was supported by both the Kaiāwhina Māori and the more recently appointed Kaitakawaenga (Māori Advisor) roles. Additionally, the board and employees of RDNZ have a collective responsibility in meeting the obligations set by Te Tiriti.

2023 Voice of Rare Disorders Survey

The Voice of Rare Disorders Survey was first developed in 2019 to better understand the impact for people living with a rare disorder in New Zealand and has since been repeated, both in 2021 and 2023[2]. These surveys have been conducted by Rare Disorders NZ on behalf of rare disorders support organisations and individuals, with anonymised data provided to HealthiNZ to analyse for reporting.

The survey was designed to be self-completed online and covered the following areas: Health Profile, Healthcare services, Treatments (Medicine), Coordination of Care, Cost of the Disorder, Employment, Care Services, Whānau/Family and social life, stress and wellbeing. Eligible participants were people with a rare disorder in New Zealand or were a family member and carer and over 18 years of age.

Rare Disorders NZ currently engages with 159 support groups representing at least 33,000 people living with different rare disorders. All groups were encouraged to send personalised emails to their members, stating the project objectives and providing a link to a web-based questionnaire. The data collection period ran from 18th September to 2nd December 2023.

This companion report provides insight into the impact for whānau Māori with a rare disorder, including comparisons of Māori and non-Māori responses.

1 ANSEA report, 2019.

2 2023 NZ Voice of Rare Disorders Survey.

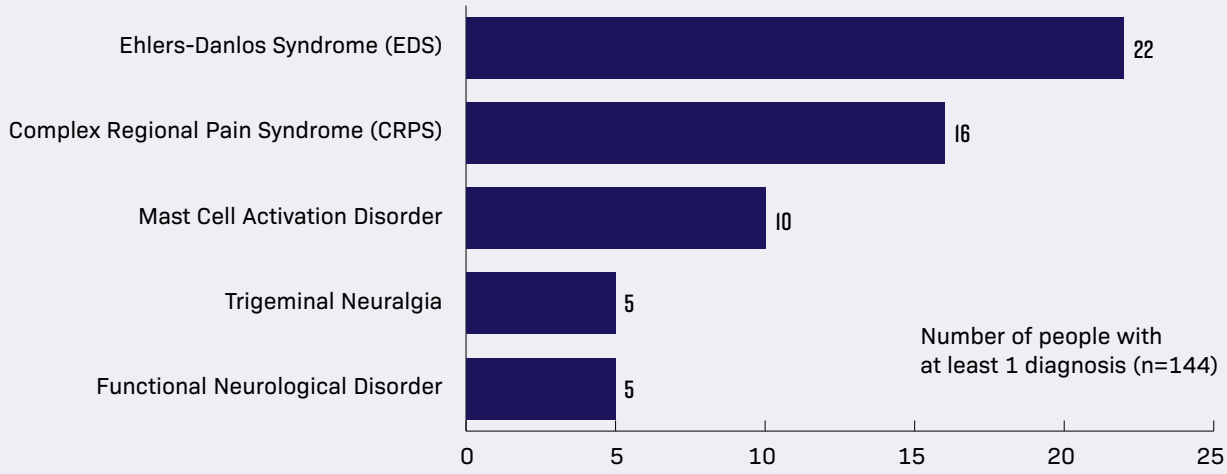
Results

Rare Disorder Diagnosis

Overall there were 144 Māori responses with a confirmed diagnosis included in the primary analysis. This was almost a 400% increase in response from the 2021 survey.

The primary analysis reported on the overall population of people with a confirmed rare disorder diagnosis. For Māori there were 118 different diagnoses; with the most common listed being Ehlers-Danlos Syndrome (EDS), Complex Regional Pain Syndrome (CRPS), Mast Cell Activation Disorder, Functional Neurological Disorder and Trigeminal Neuralgia. Taking into account that Māori represented 13.3% of all survey respondents, the range of diagnoses among Māori was at least similar to that of non-Māori.

Figure 1: Most common rare disease diagnoses for Māori in 2023 Voice of Rare Disorders Survey



Overall, 32% of people reported more than one diagnosis, with 9% reporting 3 or more diagnoses. The inclusion of a number of new, as well as a wider range of, diagnoses in this survey reflects expanding engagement with Rare Disorders NZ reaching new communities.

The proportion of people that included Māori as an ethnic group was 13.3% (144 people), much closer to National Census estimates[3] than previous 2019 and 2021 surveys. This improvement in Māori representation will need to continue into the future with much work still to be done.

3 https://www.stats.govt.nz/information-releases/maori-population-estimates-at-30-june-2023/#:~:text=At%2030%20June%202023%3A,453%2C900%20females%20identifying%20as%20Māori

The survey had responses from Māori affiliated with 41 iwi (Table 1).

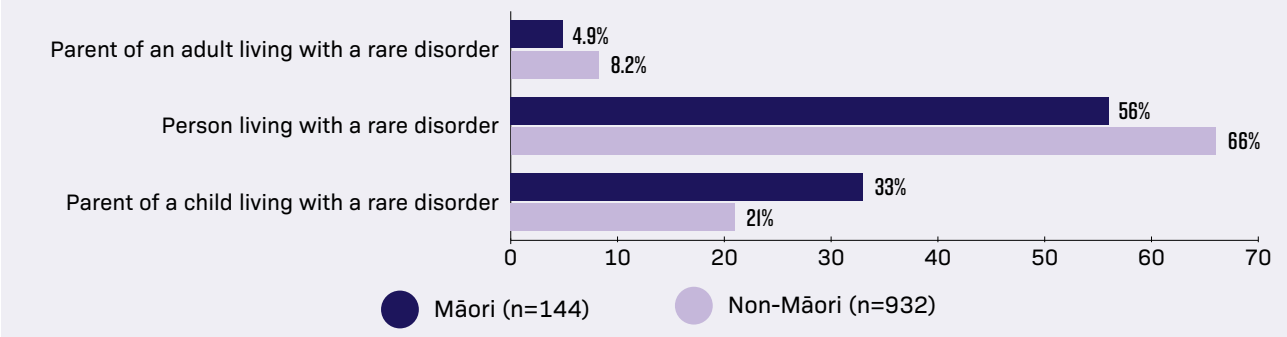
Table 1 Iwi affiliation for Māori with rare disorders

Iwi	Māori #	Māori %
Ngāpuhi	32	17%
Ngāi Tahu/Kāi Tahu	26	14%
Ngāti Porou	18	10%
Tainui	13	7%
Ngāti Raukawa (Horowhenua/Manawatū)	12	6%
Te Āti Awa (Taranaki)	11	6%
Ngāti Maniapoto	10	5%
Ngāti Kahangungu ki Te Wairoa	8	4%
Te Arawa	7	4%
Waikato	7	4%
Tūhoe	5	3%
Ngāti Kahungunu ki Heretaunga	4	2%
Ngāti Tūwharetoa	4	2%
Te Rarawa	3	2%
Ngāti Toa	3	2%
Ngā Mahanga	1	1%
Nga Ruahine	1	1%
Ngaa Rauru	1	1%
Ngaati Whanaunga	1	1%
Ngāi Tai	1	1%
Ngāti Apa	1	1%
Ngāti Awa	1	1%
Ngāti Hine kii Ngapuhi nui tonu	1	1%
Ngāti Kahungungu ki wairarapa	1	1%
Ngāti Kuia	1	1%
Ngāti Porou ki Hauraki	1	1%
Ngāti Pourua	1	1%
Ngāti rahiri tumutumu	1	1%
Ngāti Rangi	1	1%
Ngāti Ranginui	1	1%
Ngāti Rarua	1	1%
Ngāti Ruapani	1	1%
Ngāti Whatua	1	1%
Ngāti Whitikaupeka	1	1%
Rangitane	1	1%
Rongomaiwahine	1	1%
Rongowhakaata	1	1%
Tamahaki	1	1%
Taranaki	1	1%
Te atiawa Wellington	1	1%
Whakatohea	1	1%
Grand Total	**189**	**100%**

In line with population, the majority of Māori respondents were from Auckland, Canterbury, Wellington and Waikato regions. Overall, **over 80% of responses were from people living in urban areas** or areas with moderate to high urban influence.

The majority of responses for Māori (56%) were provided by people with a rare disorder, which was lower than for non-Māori (Figure 2). Of the remainder, **one in three people were parents of a child living with a rare disorder**.

Figure 2: Relationship to person with rare disorder

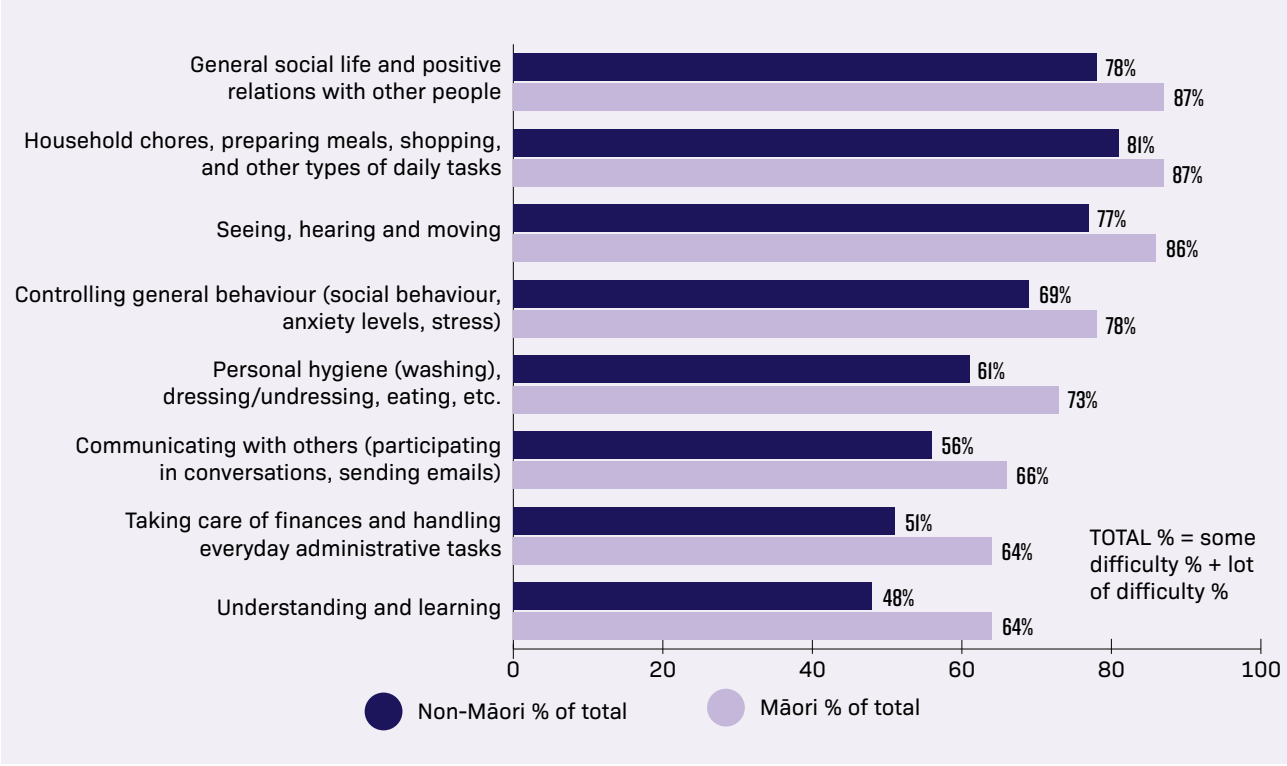


Given this difference between groups in the relationship of the respondents to the person with a rare disorder any small differences between Māori and non-Māori should be interpreted with some caution.

Daily impact of living with rare disorder

The extent to which the person with the rare disorder could perform certain activities varied with the activity although the trend was higher for Māori vs non- Māori. For **64-87% of people and their families surveyed, the rare disorder makes a number of everyday activities difficult** (social life, household chores, seeing, hearing and moving).

Figure 3: Activities of daily living that provide greatest difficulty

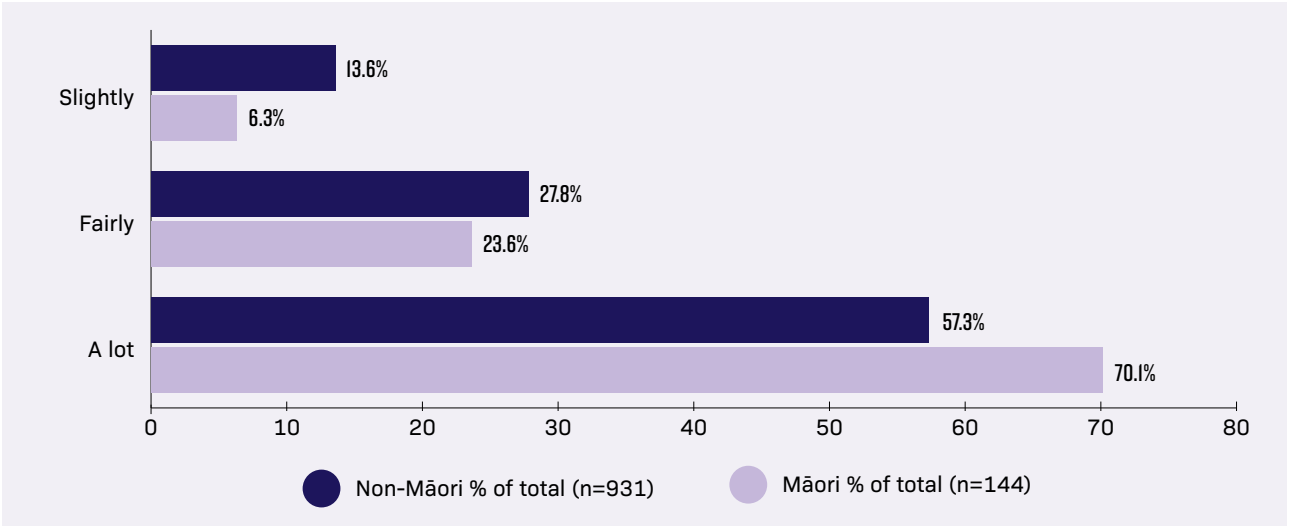


While the most frequently reported main household carer was the person living with the rare disorder, this was considerably lower for Māori than for non-Māori.

Overall, 70% of Māori reported that the disorder impacted a lot on their health and everyday life, which was higher than for non-Māori (Figure 4).

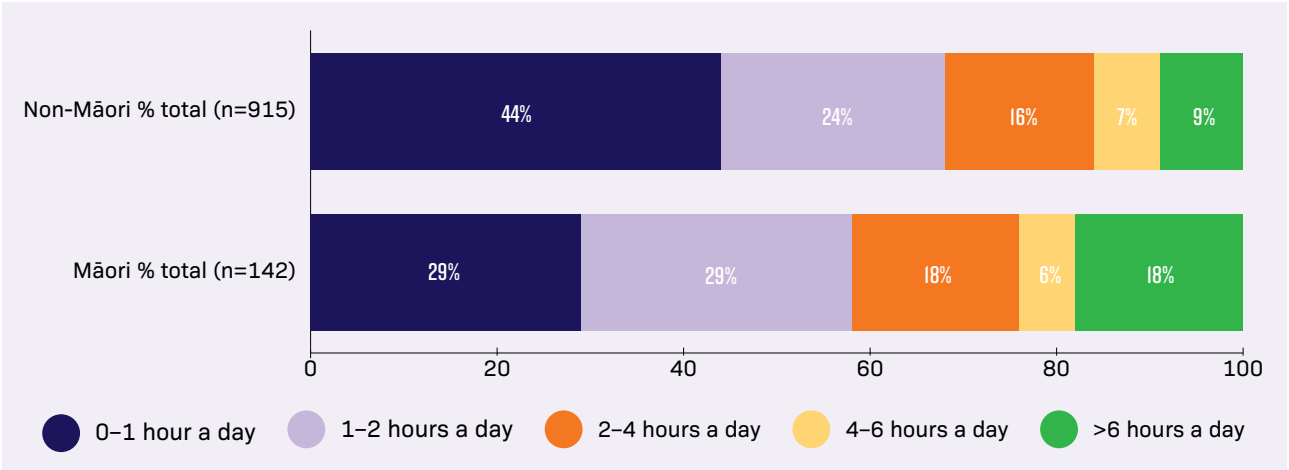
> **It was the 10 months prior to my diagnosis. The multiple GP visits, leaving without a proper answer to my discomfort. The agony I felt like I was slowly dying and no one knew how to help me.**
>
> **I couldn't help myself I was utterly dependent on others to help me like cook for me do my shopping, I couldn't bend down, I couldn't lay down, even sleeping was difficult my body was in immense agony sleep times were the worse for me every bone felt like they were gonna snap.**
>
> **I didn't know anything about my condition until my neurosurgeon informed me and I started researching.**
>
> **Person with a rare disorder**

Figure 4: Impact on health and everyday life



42% required more than 2 hours per day for illness-related daily tasks including hygiene, helping with house chores, moving the person and administration of treatments. This was higher than for non-Māori (Figure 5). 82% had at least one person involved in their care and support throughout an average week and, for one in three, at least 3 people were involved.

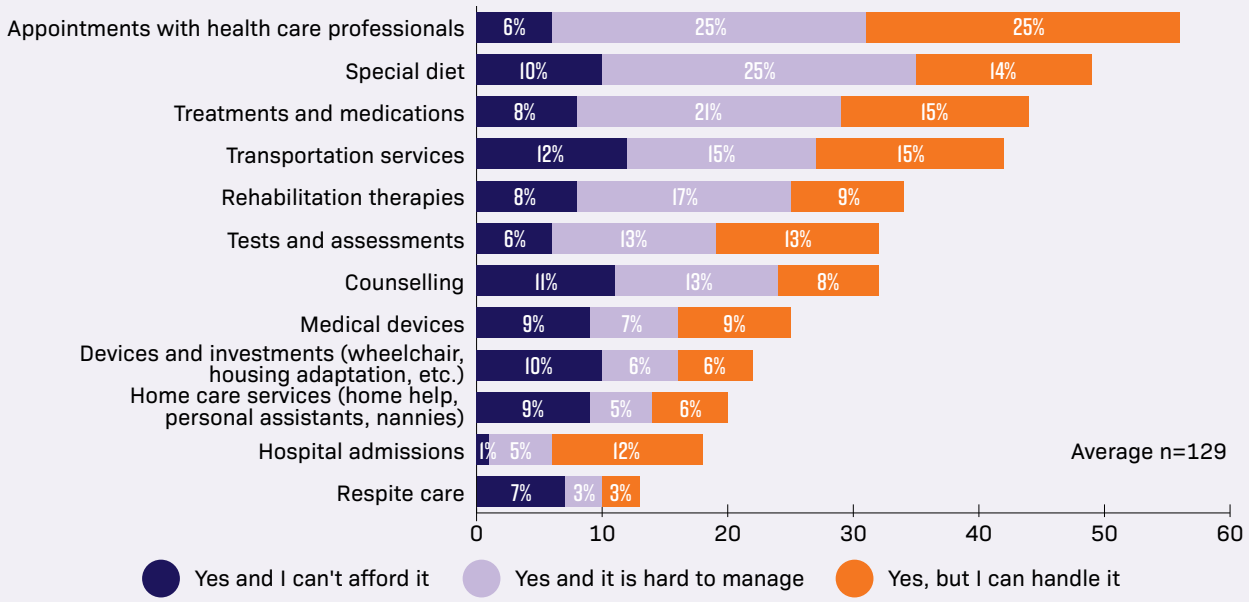
Figure 5: Daily time investment for illness-related tasks



Cost of living with a rare disorder

There were many costs covered by people living with the rare disorder or their whānau with approximately half self-funding to some extent.

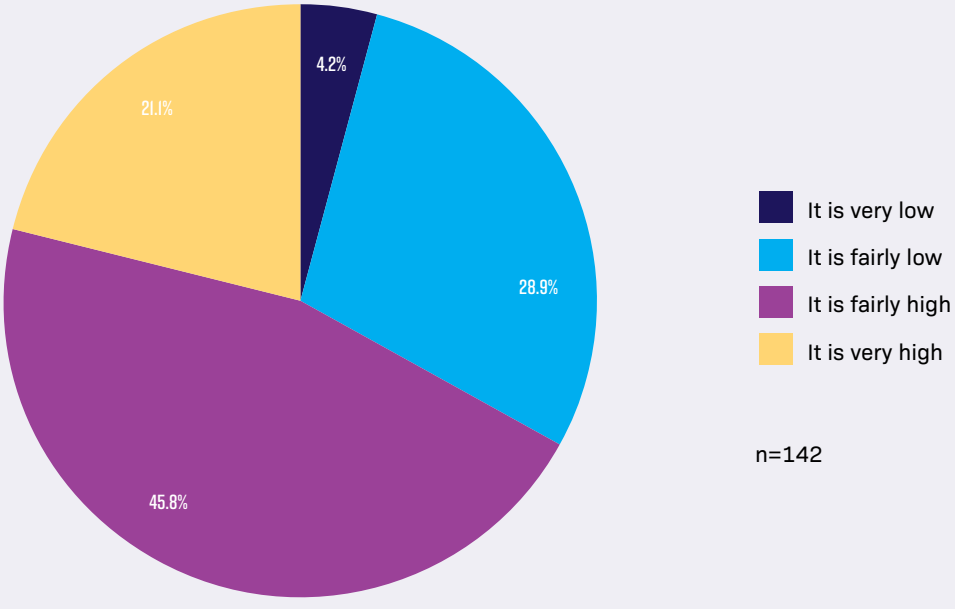
Figure 6: Level of self-funding for healthcare costs



Of those that self-funded at least some of their healthcare costs, the majority found these were hard to manage, or couldn't afford it.

> **Conversely we initially were referred to two private specialists to investigate an unusual finding. The wait to see both wasted 6 months of time and plenty of money.**
>
> **Person with a rare disorder**

Figure 7: Perception of costs associated with the rare disorder

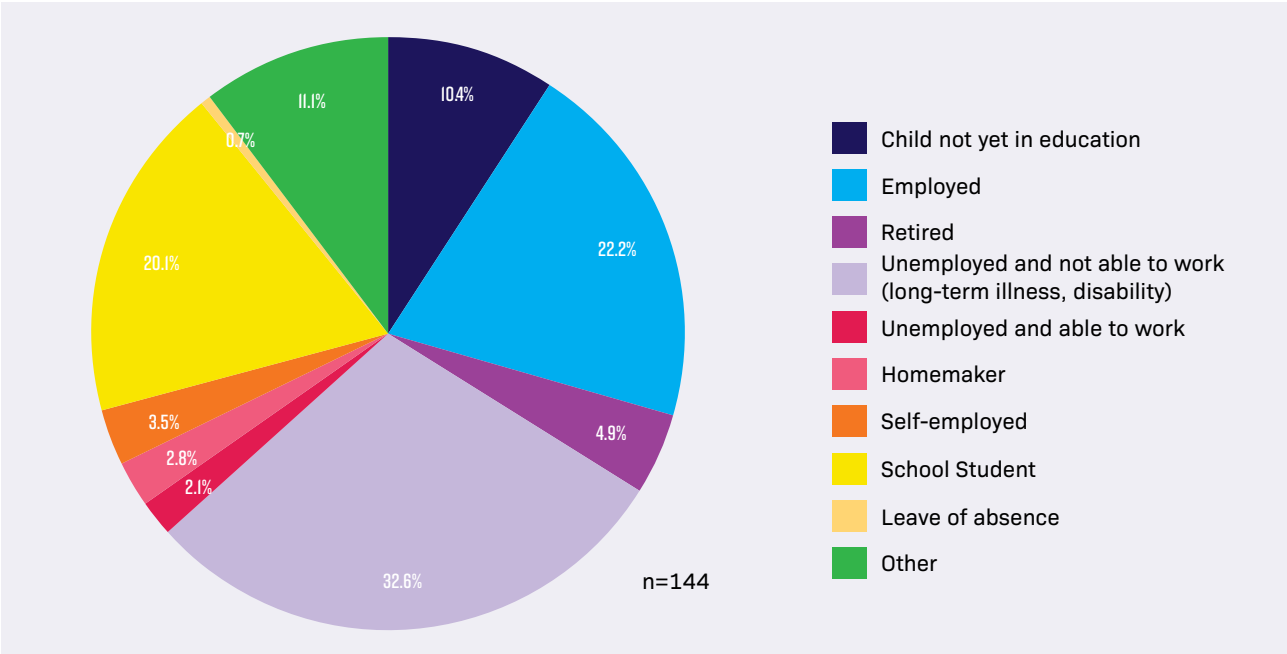


The majority (67%) of people felt that the costs associated with the rare disorder were high (Figure 7).

In addition, 65% felt the costs associated with managing their rare disorder were hard to manage, which was higher than for non-Māori (+12.4%).

Employment

Figure 8: Employment status of person with rare disorder



> **I can only manage so much, so can't move any further along in my chosen career as it risk my health and there are no supports that would help available.**
>
> **Person with a rare disorder**

31% of Māori respondents listed the person with the rare disorder as being a child or school student, which was higher than for non-Māori (11%).

26% of people with a rare disorder were in some form of employment, either being full-time, part-time or self-employed. However, 35% were unemployed, with the majority citing long-term illness or disability.

Of those who were employed, 66% of Māori were in full-time employment which was higher than for non-Māori (+12%).

A number had to leave previous jobs due to their rare disorder. For those, 16% were declared unable to work and 13% had to retire early due to their illness or disability. A further 6% resigned because their previous job was not adapted for their condition. In addition to this, a majority would like adapted accessible work environments that took account of their rare disorder to allow for their working hours and responsibilities to remain similar or increase.

There was a slightly changed picture of employment for the main carers of the person with a rare disorder. Of these, 52% were either employed part time, full time, or self-employed. However, in many cases the carer needed to leave their previous job with 8% working in paid work part-time or on reduced hours given their responsibilities and a further 16% of carers needing to look after the person with a rare disorder full-time.

Overall, there were many ways the person's employment was affected by the rare disorder that included limiting professional choices, reducing or stopping professional activity and limiting job opportunities, although on average these were lower for Māori than for non-Māori (-10%).

> **Lots of time off work. Over the amount of sick leave, so having to take unpaid leave. Stress of needing to be with sick child but needing money.**
>
> **Carer of a person with a rare disorder**

Family/whānau and social life, stress and wellbeing

> **Finding a qualified carer. Flexibility as my girl can get quite sick sometimes and we need help but only get respite, we need an extra pair of hands. The time it takes to process Carer Support Days, some of us aren't able to be reimbursed and to pay the carer first. Relying on whānau to offer time for respite as everyone works full time and them not living in the same city. Being a single Mother and having to be extra organised to take a break, its a job within itself and if it's too hard I simply just don't do it. It's important to me to keep my cup full so I can do the best I can for my girl. But the current system and what we are allocated isn't a lot. So I have to slot in time in my school hour day to make sure I get respite because outside of that is a struggle.**
>
> **Carer of a person with a rare disorder**

Since the symptoms started, the majority of people have experienced increased tension between family members (70%) and isolation from family/whānau and friends (82%), amplified, or caused by, their rare disorder. This was 11% and 12% higher, respectively, for Māori than for non-Māori.

Concerningly, one in three people often felt unhappy and depressed and felt they could not overcome their problems (Figure 9, Figure 10). An additional 31-49% of Māori reported sometimes having these feelings, which was higher than for non-Māori. Moreover, Māori were around 50% as likely to report that they never experienced these feelings when compared to non-Māori (Figure 10).

Figure 9: Extent person felt unhappy and/or depressed in last month

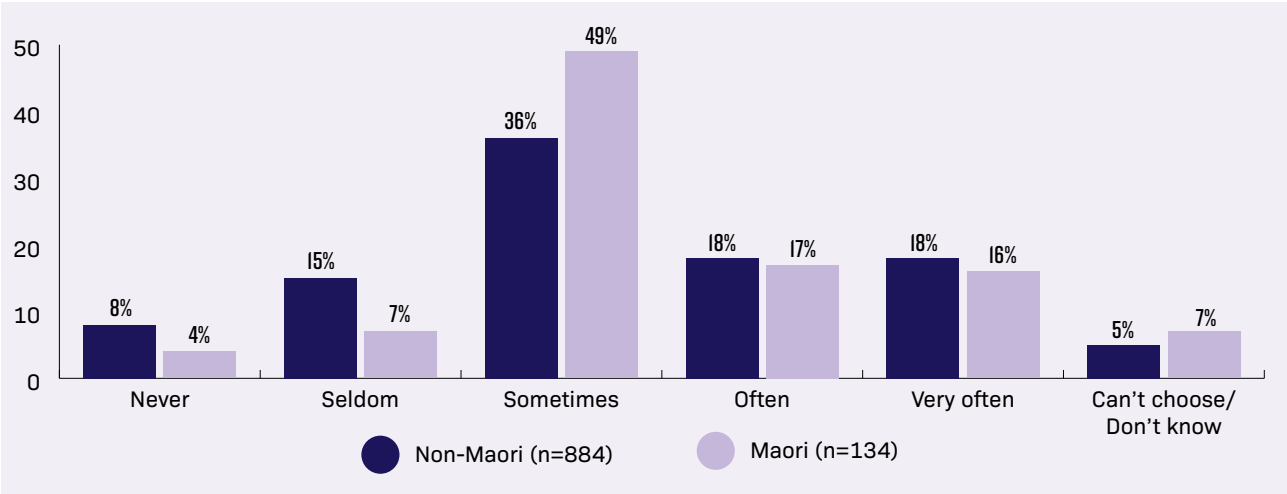
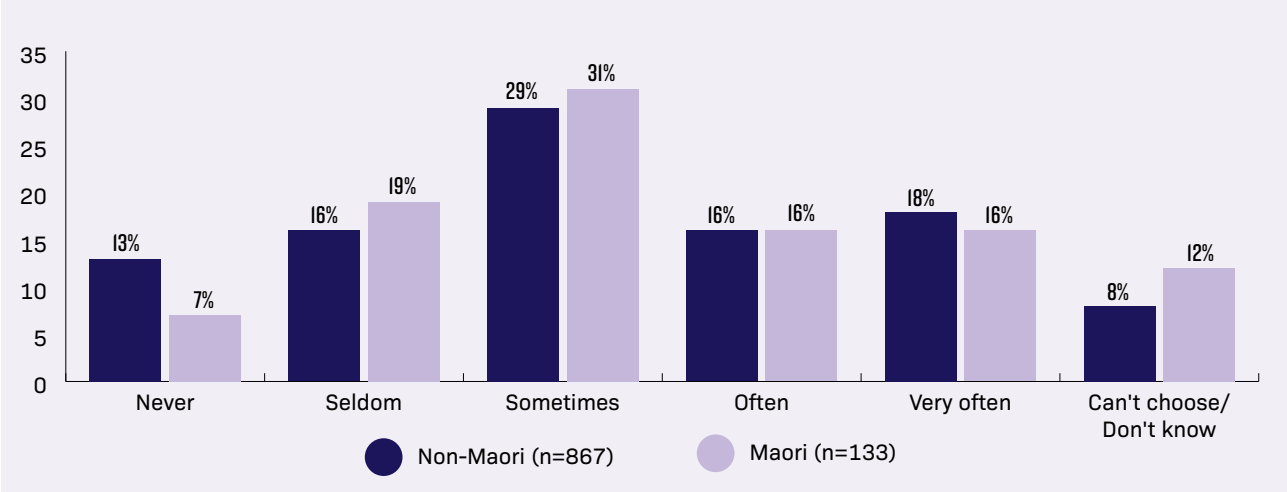


Figure 10: Extent person felt they could not overcome their problems in last month



The impact on mental health and wellbeing extended to carers with one in three carers often feeling unhappy and depressed and that they could not overcome their problems.

The importance of connection with others with the same condition should not be underestimated.

However, while 65% of people or their carers thought that this was important, only 37% felt well-connected to others with the condition.

Hinengaro ora (mental health) and wairua ora (spiritual health) need to be recognised and prioritised in the care of whānau living with a rare disorder.

> **Whānau and Te Ao Māori. Other than the medical care it was my culture and family that really got me through. It's about the spiritual side of things as well.**
>
> **Person with a rare disorder**

Concluding Comment

Overall, the daily impact of living with a rare disorder proves to be a challenge for whānau to thrive in the domains of their hauora (spiritual, mental, physical and social health) and social life. This can be attributed to the associated financial stress, employment opportunities and career pathways which were similar, or sometimes greater for Māori, when compared with non-Māori.

It is acknowledged that there were differences in the type of respondents across Māori and non-Māori, with the former being more likely to be a parent of a child with a rare disorder (+12%). Given this, it is recommended that any small differences between groups should be interpreted with some caution.

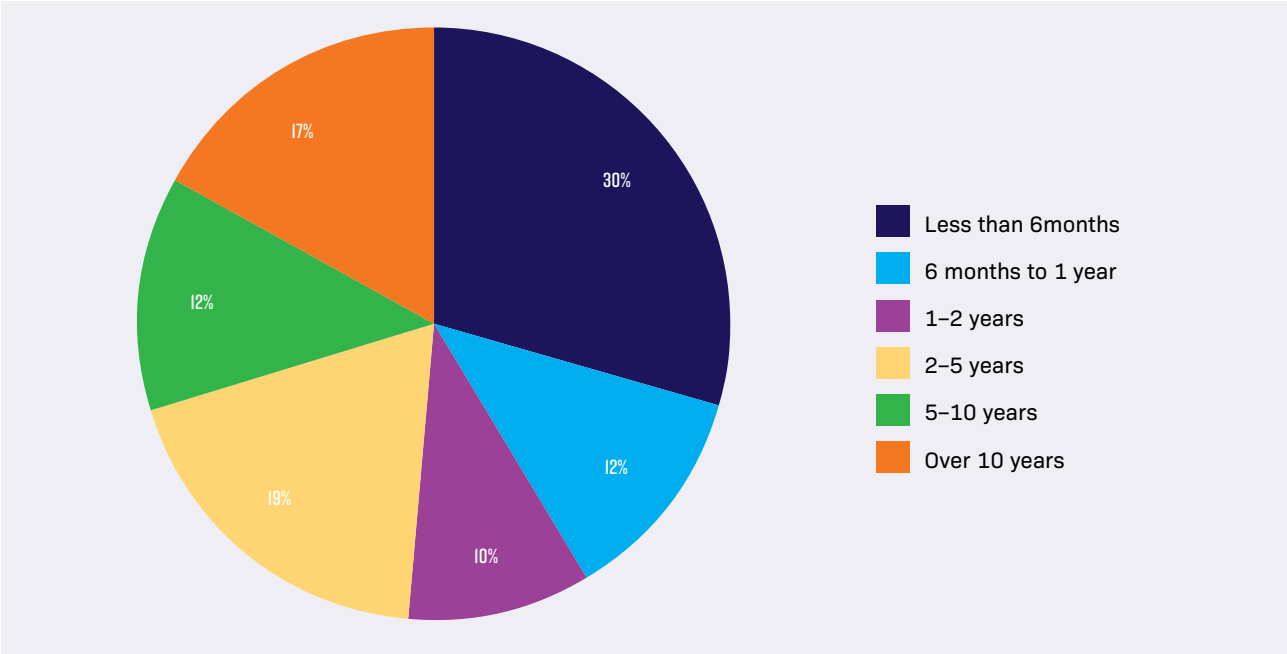
Healthcare services

Diagnosis

Early and accurate diagnosis of a rare disorder remains important to accessing a range of treatments and healthcare services.

The majority of Māori had challenges in getting an accurate diagnosis for their rare disorder, similar to non-Māori. Over half (58%) took longer than 1 year to get a diagnosis and for one in six the time taken to get a diagnosis was over 10 years (Figure 11).

Figure 11: Time taken to get diagnosis



The majority of Māori (75%), had to visit 3 or more doctors to get a diagnosis and for one in ten, over 10 doctors were visited.

66% of people with a rare disorder were misdiagnosed at least once before the final diagnosis was confirmed. Four in ten were misdiagnosed at least twice.

Almost half had had access to genetic testing to confirm or investigate their diagnosis, with the overwhelming majority being through the public health system. For the remainder that needed it, a small number (6%) either had their referral declined or were still on a waiting list for genetic services.

> **The only successes I've had are in finally getting a diagnosis after over 20 years of dismissal or misdiagnosis as a psychiatric problem, and I only achieved that through my own persistence and stubbornness, having to figure out for myself what might potentially be the problem and what specialist I needed to see.**
>
> **Person with a rare disorder**

Healthcare utilisation

There was a need to frequently access a wide range of healthcare services for people living with rare disorders including their GP and medical teams, specialists, diagnostic testing and inpatient services (Table 2). Overall there were generally more healthcare services used by Māori compared to non-Māori.

Table 2: Healthcare service utilisation for Māori with rare disorders

Service	Utilisation rate (%) Māori	Utilisation rate (%) non-Māori	Total average annual frequency	Cost per test/ visit/day[4]	Average cost/year
GP visits	93%	91%	6.7 visits	$80	$534
Specialist visits	88%	85%	5.9 visits	$250	$1,379
Diagnostic tests	87%	82%	5.4 tests		
ED visits	45%	42%	2.3 visits	$370	$868
Admissions	42%	40%	1.1 admissions		
Inpatient days	42%	38%	13.1 days	$1,200	$15,681
ICU Inpatient days	11%	7%	4.3 days	$5,500	$23,466

Most Māori had seen a specialist or GP over the last 180 days (88-93% utilisation rate) with almost 6 visits to each. This is similar to non-Māori. There were also more than four in ten people with a rare disorder that presented at the emergency department in the last year.

On average, for those admitted to hospital they spent 13 days as an inpatient in the last year. And, for one in nine people, they spent over 4 days in ICU. This is a significant finding and highlights the continuing impact and pressure on ICUs and other inpatient services, especially as admission rates are higher than the general population.[5,6]

While most people were successful in getting a specialist referral from their GP or medical team, for over one in four people, they had their referral to a medical specialist declined (e.g. general medicine, endocrinology, rheumatology, cardiology).

In addition, while the majority of people felt culturally safe when visiting health services, 19% of Māori considered visits to a nurse, doctor, health service, hospital service or genetic testing service to be culturally unsafe. This was higher than for non-Māori.

> **When the professionals actually listen to the whānau. We know our child best. When we can work together so our daughter is looked after medically and culturally. Our experience is how we learn about what is best for her and also our connection to Te Ao Māori.**
>
> **Carer of a person with rare disorder**

4 Using the Cost Resource Manual (PHARMAC): cost per specialist visits has been applied at $250 (based on physician outpatient costs, subsequent visit); cost per GP Practice visit applied at $80; cost per nurse visit applied at $40; cost per emergency department visit applied at $370; cost per day for a hospital medical ward at $1,200 (not including procedures); cost per day for intensive care unit (ICU) at $5,500.

5 https://www.health.govt.nz/publication/publicly-funded-hospital-discharges-1-july-2018-30-june-2019

6 https://www.health.govt.nz/new-zealand-health-system/accountability-and-funding/planning-and-performance-data/reducing-acute-readmissions-hospital

Coordination of Care

Coordinating care is challenging for people with rare disorders, and this can be further complicated by healthcare teams.

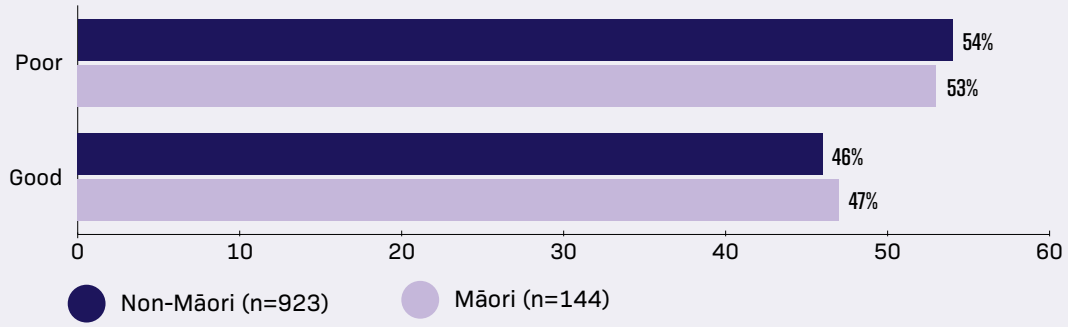
Around one in two people felt that organising care was difficult to manage. This included travel to and from appointments (57%) finding needed information on your disorder, your rights and the administrative procedures (58%), finding the right professionals (56%) or arranging and attending appointments with different people who support you in health, social or local services (54%).

Overwhelmingly for Māori the internet was the main first source of information about the disorder, treatment and care. This was then followed by various healthcare professionals. By comparison, patient organisation, Rare Disorders NZ and Support Groups were all rated lower by Māori as the main first source of information, also compared with non-Māori.

> **My doctors rarely communicated with each other. I couldn't convince any GPs to talk to my surgeon, they usually would not communicate with other health professionals I was involved with and would just skim over my notes at best. I had to keep track of who I saw and what was ruled in/out myself and brief anyone I saw.**
>
> **Person with rare disorder**

Over 50% felt that communication and information exchange between different service providers was poor (Figure 12). This was sometimes linked to co-ordination or ability of healthcare professionals to access data, leading to frustration.

Figure 12: Quality of communication between service providers



A majority of people said that professionals from social, local and support services are not well prepared to support their whānau, nor informed about the disorder and its consequences (Figure 13, Figure 14).

Figure 13: Degree of professional knowledge of rare disease and its consequences

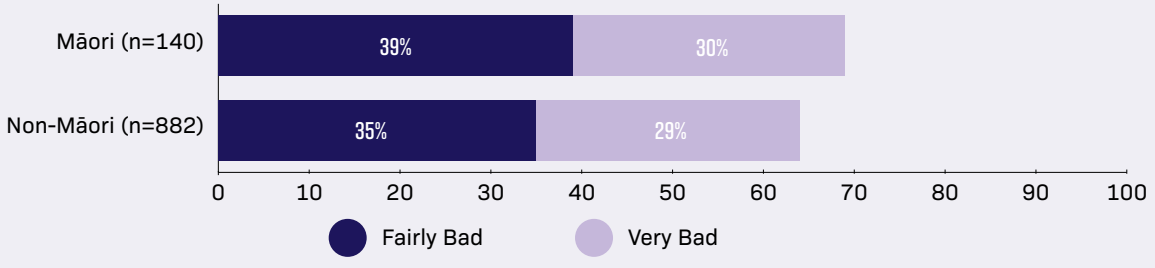
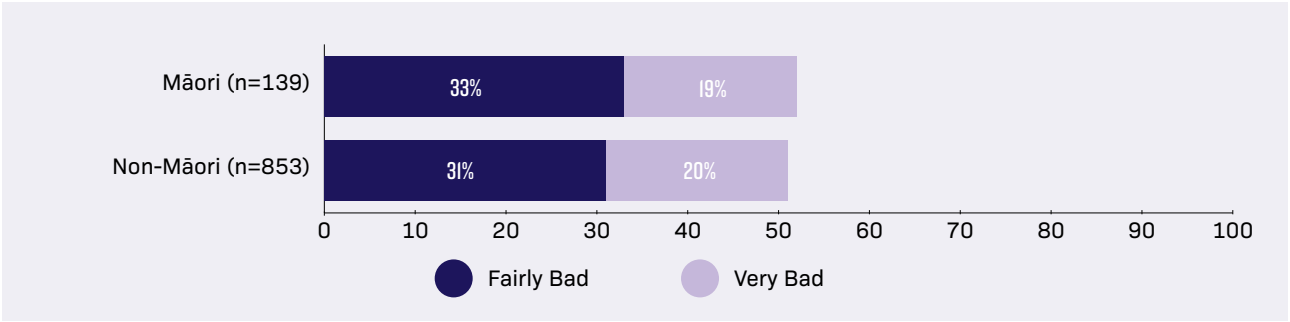


Figure 14: Degree professionals are prepared to support your family in dealing with the consequences of the rare disease



> **There is a real bias by medical professionals against people like my daughter. We took her to hospital on a Sunday and although she deteriorated significantly throughout the day ICU refused to admit her. We (the parents) had to fight to have her placed in ICU and eventually she was taken up the following morning. It was too little too late and she passed away that day.**
>
> **Carer of a person with rare disorder**

Overall, people did not feel informed at all around the rights related to the consequences of their rare disorder (79%), relevant social services that can help them (71%), financial help they could be entitled to (63%), cultural services e.g. interpreters, whānau care services (61%), nor relevant health specialists and services for the disease (58%).

A Needs Assessment will help people with a rare disorder gain an understanding of the support they need, and to learn more about goals and what help truly looks like. Every person who wishes to receive funded disability support services must be assessed by the Needs Assessment Service Coordination (NASC). In this case almost four in ten people had either had not heard of a Needs Assessment or did not want one. And even for those people that had undergone a Needs Assessment and qualified for funded services and support, over half (64%) believed they needed more than they were eligible for.

> **The success was how we battled with NASC in order to get the right package. The NASC are not mana enhancing and we had to really fight for it. So we succeeded despite their best/ worst efforts.**
>
> **Person with rare disorder**

Care Services

Access to appropriate care services was often variable for people living with a rare disorder.

The number of hours per week received for various government-funded supports varied greatly among the 10-20% of people that qualified for it. There remains a significant unmet need for support for house chores and tasks (32%) and rehabilitation services and therapies (43%)

Where applicable and known, some type of government-funded assistance was received by 62-96% of people with a rare disorder. The most common decline was for psychological support (38%) and rehabilitation services (33%).

One in four people had some respite care in the last 12 months, with a range from 1 day to more than 30 days. This respite care access was higher than for non-Māori. Also, while another 8% of people qualified for respite care, they were unable to use it as it was either unavailable or did not meet their requirements.

For almost three in ten people with a rare disorder (31%), or for their family/whānau (42%), they reported a gap in receiving needed mental health and wellbeing support.

Finally, more than one in two Māori did not feel that their wairua ora/spiritual health had been considered in their healthcare, higher than for non-Māori.

> **I reached out not long after diagnosis 1yrs old and was told we weren't entitled to anything, it wasn't until my daughter was 6 that someone mentioned them again and they said we should be entitled to funding, I reached out and turns out all along we could have had this! Getting the respite care funding finally was great, not so great experience reaching out for more respite hours sometimes feeling like you are stealing out of there own wallet or having to jump through hoop after hoop, still being on waiting lists for things like horse riding for kids with disabilities a year later. Feeling like when you ask about certain things for your child, getting shut down with a no you don't qualify but never really getting an understanding of why and of at some point you will…do I have to remember and reach out again or do they etc.**
>
> **Carer of person with rare disorder**

Concluding Comment

These results point to the need for improvements in how healthcare services are delivered to people with rare disorders regardless of their ethnicity. While noting that the evidence from the wider literature shows that Māori experience barriers to accessing healthcare in Aotearoa to a greater extent than non-Māori[7], the results presented in this White Paper show that Māori were generally able to access healthcare services at least at a similar rate to non-Māori.

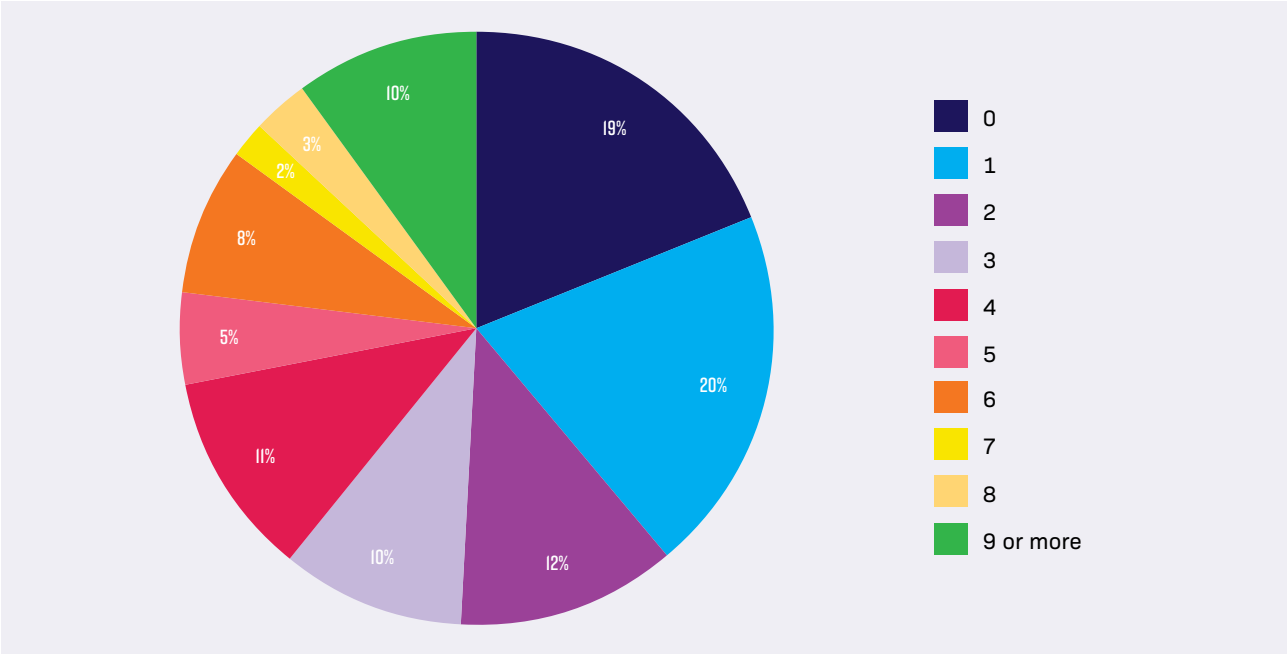
7 Graham R, Masters-Awatere B. Experiences of Māori of Aotearoa New Zealand's public health system: a systematic review of two decades of published qualitative research. Australian and New Zealand journal of public health. https://www.sciencedirect.com/science/article/pii/S1326020023005484

Medicines and Treatments

The range of treatments people reported taking were mainly focused on reducing pain or inflammation, not treatment of the rare disorder itself.

81% of Māori were taking at least one medicine (see Figure 15) however in the majority of cases this was not a modern medicine[8] indicated specifically for treatment of their rare disorder.

Figure 15: Number of medicines taken by people with rare disorders



There were more than 136 different medicines listed and 499 medicines listed in total. This equates to 3.5 medicines on average being taken per person. It was noticeable that the most common medicines prescribed and publicly funded were for conditions suffered as a consequence of having a rare disorder (e.g. pain and inflammation), rather than being a medicine for direct treatment of the rare disorder itself.

The most commonly reported medicines were ibuprofen for 49 people (34%), melatonin for 29 (20%), prednisolone for 20 (14%), salbutamol for 19 (13%), hydrocortisone for 17 (12%), gabapentin for 14 (10%), paracetamol for 14 people (10%). There were a number of people taking a broad range of different treatments, including antibiotics, antipsychotics, antidepressants, and vitamins (C, D, E). These were similar to non-Māori.

Around one in six people believed they were missing out on some medicines. Of those listed, the most frequent were for CBD, Kuvan and ERT.

> **"Trying to get effective pain relief is another massive hurdle. Being made to feel like a drug addict because Panadol doesn't work for severe pain. I am extremely sensitive to medication and have had multiple anaphylactic reactions. Which leaves me very little options for effective pain relief.**
>
> **Person with rare disorder**

Only 6% had attempted to gain access to medicines through the Named Patient Pharmaceutical Assessment (NPPA) process, funding a treatment for an individual patient whose clinical circumstances are exceptional. Where an application had been made though, for 38% it had been successful, 19% lower than for non-Māori.

8 Per Medicines NZ, a modern medicine is defined as "an innovative pharmaceutical medicine (including biologic medicines) that contains a new molecule that has not been previously approved in these countries before."

Almost one in three people obtain at least some of their current medicines through private/ out-of-pocket means and, for those taking this approach, almost all were self-funding (85%), with financial impact and related consequences. It is anticipated that this could lead to inequity in medicine access.

In addition, one in two Māori reported taking or having at least one other treatment in the last 6 months, with the most commonly reported being a natural health product bought from a supermarket, health shop, chemist (29%) and other alternate or complementary medicine not prescribed by a doctor or nurse (34%). In addition 19 (14%) Māori participants reported having Rongoā Māori in the last 6 months.

Of those Māori who had thought about it, almost eight in ten (79%) were either worried or very worried that promising future treatments and medicines (e.g. gene therapy/CRISPR) will not be funded by New Zealand's public health system.

> **"The biggest help in getting my diagnosis was having CT and MRI scans. The wait time for public health was just unacceptable due to the amount of constant pain I was in, although I was deemed as not urgent so was looking at 6+ months of waiting. I had to crowdfund to pull the money together.**
>
> **Person with rare disorder**

Concluding Comment

These results point to the need for improvements in how people with rare disorders get access to the medicines they need.

Conclusions

The impact for Māori living with a rare disorder in NZ is significant for all dimensions in the survey including; level of care required, healthcare services utilisation and access to treatments, coordination of care, overall costs, employment, education, care services, family life, stress and wellbeing. For Māori living with a rare disorder today, the impact was similar to, or sometimes greater, compared with non-Māori.

The overwhelming findings for the 2023 New Zealand Voice of Rare Disorders Survey show that over the last four years better understanding how to best support people with rare disorders has not translated into better outcomes for New Zealanders. This needs to change.

Given this, the results for Māori have been considered in the context of the four essential priority actions Rare Disorders NZ (RDNZ) have identified to drive needed changes. These essential actions, if fully implemented, will be important changes to improve outcomes for all people, including for Māori, living with a rare disorder in Aotearoa.

Need to close healthcare service & support gaps in New Zealand's health systems

Results paint a picture for Māori of isolation, lack of timely and accurate diagnosis, high utilisation of healthcare services, poor treatment access, lack of coordinated care, significant carer impact, lack of access to care services including suitable mental health and wellbeing support, and for many, being lost in the system.

- The majority of Māori with a rare disorder do not receive a timely or accurate diagnosis.
- Māori living with a rare disorder have high utilisation of healthcare services including specialist, GP visits, diagnostic tests and inpatient services.
- Coordinating care is challenging for Māori with rare disorders, which can then be further complicated by healthcare teams.
- Access to culturally safe care services was often variable for Māori living with a rare disorder, including suitable hinengaro ora/mental health and wairua ora/spiritual health support.

These results point to the need for improvements in how healthcare services are delivered to Māori with rare disorders.

The survey findings suggest Māori were generally able to access healthcare services at least at a similar rate to non-Māori, noting however that there is also evidence from the wider literature which shows that Māori experience barriers to accessing healthcare in Aotearoa. These barriers can manifest in the form of organisational structure, staff interactions and practical barriers to receiving care[9].

There is a critical need to close healthcare services and support gaps in health and other systems for Māori in Aotearoa.

Need for better access for rare disorder medicines

The current one-size-fits-all model under Pharmac's pharmaceutical schedule simply does not work for low volume, high-cost medicines for rare disorders. The survey results confirmed that there were few accessible effective modern medicines available for the majority of Māori. It was also noticeable that the most common medicines prescribed and publicly funded were for conditions suffered as a consequence of having a rare disorder (e.g. pain and inflammation), rather than being a medicine for direct treatment of the rare disorder itself.

- Only a few had successfully gained access to medicines through the Named Patient Pharmaceutical Assessment (NPPA) alternative process.
- Almost one in three people obtain at least some of their current medicines through self-funding, with financial impact and related consequences. It is anticipated that this could lead to inequity in medicine access.

Importantly, most Māori were worried that promising treatments and medicines (e.g. gene therapy/CRISPR) will not be funded by New Zealand's public health system in the future.

These results were consistent for all people with rare disorders, generally being similar for Māori and non-Māori. These point to the need for improvements in how Māori with rare disorders get access to the publicly funded medicines they need.

9 Graham R, Masters-Awatere B. Experiences of Māori of Aotearoa New Zealand's public health system: a systematic review of two decades of published qualitative research. Australian and New Zealand journal of public health. https://www.sciencedirect.com/science/article/pii/S1326020023005484

Understanding similarities and differences between Māori and non-Māori experiences as a focus for future research.

The survey findings suggest Māori with a rare disorder were generally able to access healthcare services at least at a similar rate to non-Māori. However this is inconsistent with the evidence from the wider literature which shows that Māori will often experience barriers to accessing healthcare in Aotearoa. These barriers can manifest in the form of organisational structure, staff interactions and practical barriers to receiving care[9].

Given the limited number of Māori participants and their differing demographics from non-Māori, it's important to recognise potential limitations in conclusively determining whether Māori and non-Māori with rare disorders experience similar healthcare access in Aotearoa. Exploring qualitative responses from the survey could enhance understanding of both the similarities and differences between Māori and non-Māori experiences, which should be a focus for future research. Moreover, increasing Māori engagement in future iterations of the Voice of Rare Disorders survey would allow for more direct comparisons, such as between the experiences of Māori and non-Māori adults with rare disorders and caregivers of children with rare disorders, providing valuable insights into healthcare access disparities among various demographic groups.

Accordingly Rare Disorders NZ intends to produce a further document which brings together Te Aka Whai Ora's Whānau Voices paper reporting on their Rare Disorders Strategy consultation with Māori, key findings from this White Paper, further quantitative analysis of Māori and whānau survey responses, and fuller inclusion of the qualitative responses to the survey. Rare Disorders NZ advise that this document is intended to inform their advocacy positions for achieving better outcomes for Māori and whānau living with a rare disorder, what it means for RDNZ to be a better Tiriti partner, and how to better represent itself in a way that's more consistent with te ao Māori.

Need for RDNZ to continue to improve community engagement with Māori

Rare Disorders NZ is the only national organisation supporting all New Zealanders, including Māori, living with a rare disorder and their carers. It has been valued as a key partner with Manatū Hauora and Te Aka Whai Ora in the development of the Rare Disorders Strategy and is intended to continue with its implementation. In addition, it continues to provide the most representative and collective voice for people with rare disorders including for Māori.

There is a key need for RDNZ to continue on its journey to being a culturally safe Tiriti partner and improve its engagement with whānau Māori. For any future survey to increase whānau Māori engagement further, inclusion of, for example, Kaiāwhina and Kaitakawaenga throughout the process is imperative so that pātai/questions for this survey are relatable to Māori.

Full implementation of these recommendations is essential to improve outcomes for Māori living with a rare disorder in Aotearoa.

He aha te mea nui o te ao? He tāngata, he tāngata, he tāngata

What is the most important thing in this world/ it is people, it is people, it is people

About Rare Disorders New Zealand

Rare Disorders NZ is the national peak body organisation, supporting the 300,000 New Zealanders living with a rare disorder and the people who care for them.

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This white paper was written by HealthiNZ

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Advancing life-changing solutions