

12 November 2024

Health New Zealand  
Te Whatu Ora

Tēnā koe [REDACTED]

### Your request for official information, reference: HNZ00069614

Thank you for your email on 23 October 2024, asking Health New Zealand | Te Whatu Ora (Health NZ) for the following under the Official Information Act 1982 (the Act):

*Can Rare Disorders NZ please have a copy of the paper on the rare Disorders Strategy and implementation options you mention in the email below as well as the relevant part of the minutes from the meeting where the ELT discussed this paper?*

### Response

Please find attached as **Appendix 1**, a copy of the paper on the Rare Disorders Strategy and Implementation Options (10 July 2024) which was considered by Health NZ's Executive Leadership Team (ELT), (as referred to in my email on 14 August 2024 to your colleague Chris Higgins at Rare Disorders NZ).

I have also included the excerpt from the ELT meeting minutes from 6 August 2024, Point 6 where ELT discussed this paper.

### How to get in touch

If you have any questions, you can contact us at [hnzOIA@Tewhatora.govt.nz](mailto:hnzOIA@Tewhatora.govt.nz).

If you are not happy with this response, you have the right to make a complaint to the Ombudsman. Information about how to do this is available at [www.ombudsman.parliament.nz](http://www.ombudsman.parliament.nz) or by phoning 0800 802 602.

Nāku iti noa, nā



**Tim Wood**

Group Manager Planned & Unplanned Care,  
Commissioning Living Well

# APPENDIX 1

## Executive Leadership Team

### Rare Disorders Strategy

<b>Date:</b>	10 July 2024	<b>Author:</b> Tim Wood, Group Manager Planned & Unplanned Care, Living Well, Commissioning	
<b>For your:</b>	Approval	<b>Approved by:</b> Richard Sullivan, Chief Clinical Officer Sarah Clarke, National Clinical Director, Primary & Community Care, Commissioning	
<b>Seeking funding:</b>	Yes-/ No	<b>Funding implications:</b>	Yes-/ No
<b>To:</b>	ELT		

### Purpose

1. The purpose of the paper is to advise the Executive Leadership Team (“ELT”) of the development of a rare disorders strategy by Manatū Hauora and identifies the opportunity to proactively to establish an advisory group and develop a response to the Strategy.

### Recommendations

2. The ELT is asked to:
  - a) **note** the development of the rare disorders strategy by Manatū Hauora.
  - b) **note** Rare Disorders New Zealand have published two white papers.
  - c) **endorse** the appointment of Dr Richard Sullivan, Chief Clinical Officer as sponsor.
  - d) **endorse** the establishment of an advisory group.
  - e) **endorse** the development of a response to the strategy.

### Rare Disorders Strategy

3. Aotearoa New Zealand lacks a cohesive approach to rare disorders that negatively impact the lives of those with, and those caring/supporting someone, with a rare disorder.
4. Health New Zealand has an opportunity with the development of a rare disorders strategy to determine a response that improves the healthcare systems ability to provide care, treatment and advice to people with a rare disorder.
5. Manatū Hauora have released an Aotearoa New Zealand Rare Disorders Strategy (the Strategy) (Appendix 3).

6. The Strategy provides a framework and long-term priorities that will guide health entities in improving health and wellbeing outcomes for people and their whānau with rare disorders over the decade of 2024 to 2034.
7. The Strategy has five objectives:
  - a) Gearing the system for quality care – there are three components to this objective: (i) building leadership and coordination, (ii) introducing new capabilities to speed up diagnosis and allow earlier preventative care, and (iii) giving consideration to rare disorders when investing and prioritising.
  - b) Learning and sustaining progress – there are four components to this objective: (i) collection of rare disorder information, (ii) using information to support provision of care, (iii) using information to monitor and improve care, (iv) using information to decide on priorities, and (iv) supporting research and evaluation.
  - c) Equipping the health workforce to provide quality care for rare disorders – this includes health practitioner education, clinical guidelines and pathways, and practitioner support.
  - d) Giving voice to people and their whānau living with rare disorders.
  - e) Joining up to achieve more through partnerships with other countries, joining clinical trials, and better regulation and standards.
8. There are many patient advocate groups for rare disorders. Rare Disorders New Zealand is an umbrella group advocating for all people and whanau with a rare condition.
9. Rare Disorders New Zealand with Health NZ have published (2024) a white paper “Impact of Living with a Rare Disorder in Aotearoa New Zealand” and a companion paper “Impact for Whanau Māori of Living with a Rare Disorder in Aotearoa New Zealand”. These papers highlight that for people with rare disorders and their whanau:
  - a) A picture of isolation, lack of timely diagnosis, high utilisation of healthcare services, poor treatment access, lack of coordinated care, significant carer impact, lack of care services including mental health and wellbeing.
  - b) Few accessible medicines and only a few gained access through the Named Patient Pharmaceutical Assessment (NPPA) process.
10. The Rare Disorders New Zealand white paper proposes the establishment of a Rare and Undiagnosed Disorders Centre of Expertise. This is a model that has been implemented internationally in some jurisdictions, for example the Western Australia Child and Adolescent Rare Care Centre.
11. Rare Disorders New Zealand proposes that they are considered as a valued enabler in developing and implementing a response to the Strategy.
12. The development of the Strategy provides an opportunity for Health New Zealand to:
  - a) Appoint an ELT sponsor
  - b) Set up an advisory group

- c) Develop a response to the strategy.

## Hauora Māori Services contribution

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**Contributed by:** Carlton Irving, Chief Clinical Officer – Allied Health

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13. HMS acknowledges the significant barriers faced by Māori living with rare disorders and emphasizes the importance of addressing these challenges to achieve health equity. By honouring Te Tiriti o Waitangi, we commit to ensuring that the voices of whānau Māori are central in the development and implementation of the rare disorders strategy. Our focus includes improving access to culturally appropriate care, enhancing data collection specific to Māori, and advocating for equitable resource allocation. We support the establishment of advisory groups with strong Māori representation and the integration of Māori health practices and values into care pathways. Through these efforts, we aim to enhance the quality of life for Māori living with rare disorders and ensure a responsive, inclusive health system. (More detailed advice on the approach for Maori is attached as Appendix 2).

## Discussion

14. We note that a rare disorders strategy and associated activity does not form part of the Health NZ work plan. Development of a response to the strategy could possibly be delayed until capacity and budget allow. If the recommended actions are not approved, there is a risk of concerns being raised from both the Ministry of Health who will expect actions as a result of this strategy, and Rare Disorders New Zealand who have been pushing for actions to address shortfalls in the care of this group for some time.
15. There is evidence that rare disorders have a significant burden on health systems, so this work could be aligned with the SSED and FSA shorter wait times targets. The Western Australia model suggests it reduces outpatient visits, inpatient admissions, bed days and ED visits.
16. We anticipate the costs associated with setting up an advisory group will be minimal, but this is yet to be costed as it will be dependent on the membership.
17. We also note the work required to support the strategy will need to be undertaken within existing resources.

## Next steps


18. Once the actions in this paper have been considered by ELT, if approved, we will undertake the next steps to establish the advisory group and response to the strategy document.

## Attachments

Appendix One – Background on rare disorders

Appendix Two – Specific advice on approach for Maori

**Document ownership**

Approved for submission	ABBE ANDERSON, NATIONAL DIRECTOR COMMISSIONING	
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## Appendix 1: Background on rare disorders

19. Rare disorders have widespread impacts on people living with them, their families, the health system and society. This can include significant impacts on mental, social and physical functions, household budget, employment and job careers, family life and well-being. Many of these conditions are life-long and debilitating and may lead to death at a young age.
20. A rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 2,000 persons in Aotearoa New Zealand.
21. Rare disorders include, but are not limited to, genetic disorders, cancers, infectious disorders, poisonings, immune-related disorders, idiopathic disorders, and undetermined conditions that are rare.
22. An ultra-rare disorder is one that affects fewer than or equal to 1 in 50,000 persons in Aotearoa New Zealand.
23. We do not have much specific information on how many people and what disorders are most prevalent in Aotearoa New Zealand. Very little rare disorders information is easily retrievable from health or statistical data.
24. There are over 7,000 rare disorders and more are being identified each year. Many are ultra-rare or extremely rare and may affect only one or a handful of New Zealanders. Yet overall, some 300,000 New Zealanders may live with a rare disorder.
25. Approximately 80% of rare diseases have genetic causes. Genomic data, coupled with phenotypic and clinical data, represents a treasure trove of information critical for shortening the diagnostic odyssey faced by rare-disease patients and for powering research and innovation in diagnostics and therapeutics.
26. The Horizon Scan January 2024, Genomic Medicine presented to ELT earlier this year has led to the establishment of a Genomic Strategic Group. This group and the development of a genomic strategy will be a critical enabler for a response to the rare disorders strategy.
27. Based on overseas studies:
  - a) around half of people with rare disorders are children
  - b) some 80% of rare disorders are genetic
  - c) rare disorders can occur in any family or population group in our country.
28. People and whānau living with rare disorders often face significant barriers in getting timely, effective, and equitable health care. Health practitioners may find it difficult to identify rare disorders or know how to respond to support health and wellbeing.
29. In 2021, the UN member states unanimously adopted an inaugural UN Resolution on “Addressing the Challenges of Persons Living with a Rare Disease and their Families”. It encourages countries to promote public policies, patient-centred programs, and initiatives

that would strengthen health systems and calls for action to address the specific challenges faced by people and their whānau living with rare diseases.

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## Appendix 2: Specific Advice on approach for Maori

### a) Culturally Competent Care:

- **Training Programmes:** Implement training programmes for healthcare providers on cultural competence, focusing on Māori health practices and values. Ensure healthcare pathways incorporate traditional Māori healing practices such as rongoā Māori and mirimiri.
- **Integration of Māori Practices:** Encourage the integration of traditional Māori healing methods and culturally appropriate care into standard treatment protocols for rare disorders.

### b) Data Collection and Research:

- **Robust Data Systems:** Develop robust data collection systems to capture detailed information on rare disorders among Māori. Advocate for research funding focused on understanding genetic predispositions and the impact of socioeconomic factors on the prevalence of rare disorders in Māori communities.
- **Research on Genetic Factors:** Support research to identify any unique genetic factors within Māori populations that may contribute to rare disorders, leveraging genomic data to enhance diagnosis and treatment.

### c) Equity in Access:

- **Removing Barriers:** Prioritise equitable access to diagnostic, preventive, and treatment services for Māori with rare disorders. Work with healthcare providers to identify and remove barriers specific to Māori communities, such as geographical isolation and socioeconomic constraints.
- **Enhanced Accessibility:** Advocate for policies that improve accessibility to advanced diagnostic tools and treatments for Māori living in remote or underserved areas.

### d) Community Engagement:

- **Partnerships with Māori Organisations:** Foster partnerships with iwi, hapū, and Māori organisations to raise awareness about rare disorders and available resources. Support community-based initiatives and education programmes that are designed and led by Māori for Māori.
- **Inclusive Communication:** Ensure communication materials and outreach programmes are culturally tailored and available in te reo Māori to enhance engagement and understanding.

### e) Advocacy and Representation:

- **Advisory Groups:** Establish advisory groups with strong Māori representation to ensure that Māori voices are heard in all aspects of the strategy's development and implementation. Advocate for the inclusion of Māori perspectives in national and international rare disorders collaborations.



- **Policy Influence:** Influence policy to ensure Māori health needs and perspectives are central in the development of rare disorder strategies.

f) **Support Services:**

- **Tailored Support Services:** Develop and fund support services specifically tailored to the needs of Māori whānau affected by rare disorders. This includes mental health services, caregiver support, and navigation assistance within the healthcare system.
- **Comprehensive Care Models:** Promote the development of comprehensive care models that provide holistic support, addressing both medical and social needs of Māori patients and their whānau.

g) **Monitoring and Accountability:**

- **Regular Monitoring:** Implement mechanisms to regularly monitor and report on the progress of the rare disorders strategy in achieving equitable outcomes for Māori. Ensure accountability by setting clear targets and timelines for improvements in service delivery and health outcomes.
- **Transparency:** Ensure transparency in reporting and decision-making processes to build trust and maintain accountability to Māori communities.

### Appendix 3: Rare Disorders Strategy

[https://www.health.govt.nz/system/files/documents/publications/hp8873 - rare disorders v5.pdf](https://www.health.govt.nz/system/files/documents/publications/hp8873-rare-disorders-v5.pdf)

**Note: The above link has moved. This can now be accessed here:**

**[https://www.health.govt.nz/publications?keywords=rare+disorders&issued\\_from=&issued\\_to=&sort\\_bef\\_combine=search\\_api\\_relevance\\_DESC](https://www.health.govt.nz/publications?keywords=rare+disorders&issued_from=&issued_to=&sort_bef_combine=search_api_relevance_DESC)**

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## Executive Leadership Team

### Meeting Minutes 6 August 2024

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**Date** 6 August 2024

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**Chair** Margie Apa

#### 6. Rare Disorders Strategy Final

Tim Woods led discussion. Paper taken as read.

It was **noted** that will pause and review in the new year as no resource or budget available due to system reset. Margie to contact Di Sarfati about this strategy and if required provide a formal letter around agreed next steps.

The ELT -

- a) **Noted** the development of the rare disorders' strategy by Manatū Hauora.
- b) **Noted** Rare Disorders New Zealand have published two white papers.
- c) **Noted** that have constrained time and resources to do more than what the system currently does for Rare Disorders and will manage this as our clinical risk with clinical leaders.

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