Aide-Mémoire

Roundtable on progress with Rare Disorders Strategy implementation

Date due to MO:	6 November 2025	**Date of Event:**	11 November 2025
Security level:	IN CONFIDENCE	**Reference:**	H2025073318
To:	Hon Simeon Brown, Minister of Health		
Consulted:	Health New Zealand: ☐ Pharmac: ☐ Rare Disorders New Zealand: ☐		
Proactive release:	This **title** is proposed by the Ministry of Health for proactive release: ☐		

Contact for telephone discussion

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Alison Cossar	Manager System Enablers, Strategy and Policy	

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This aide-memoire is proposed for proactive release, subject to redaction as appropriate under the Official Information Act 1982.

About the Event

Purpose of Event: You are hosting a roundtable to bring together agencies and discuss the implementation of the Rare Disorders Strategy.

Details of Event:

Date:	Tuesday 11 November
Time:	5.15pm-6.15pm
Venue:	6.6EW

Attendees:

Rare Disorders NZ	Chris Higgins, Chief Executive Kim McGuinness, Relationship Manager Lewanna Pentecost, Navigator (Observer)
Health NZ	Rachel Haggerty, Director Funding - Hospitals, Planning, Funding and Outcomes Mary Cleary-Lyons, Director National Clinical Networks Nicky Plant, National Services Manager (Observer)
Pharmac	David Hughes, Chief Medical Officer Hannah Burgess, Principal Policy Advisor (Observer)
Health Quality & Safety Commission	Carlton Irving, Director Māori Health and Consumer DJ Adams, Senior Consumer Advisor

Ministry representatives: Dr Joe Bourne, Chief Medical Officer
Allison Bennett, GM Health System Settings, Strategy and Policy
Natalie Welch, Policy Analyst (Observer)

Comment/ Summary:

- Background information on RDNZ and updates on the Rare Disorders Strategy have been provided to support the meeting.
- A draft meeting agenda is attached as appendix one.
- Profiles of attendees from RDNZ are provided as appendix two.
- A draft 12-month implementation plan is attached as appendix three.

Background and context

1. A rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects less than 1 in 2,000 people in Aotearoa New Zealand.
2. Rare Disorders New Zealand (RDNZ) estimate there could be over 300,000 people living with a rare disorder in New Zealand.
3. There are approximately 7,000 known individual rare disorders. Rare disorders generally manifest during childhood and can be chronic and severe. Many people with a rare disorder live with a disability or impairment and face challenges such as limited treatment options and lack of timely diagnosis.

About Rare Disorders NZ

4. RDNZ was established in 2000 and is a non-government organisation that works to support and advocate for all New Zealanders who live with a rare disorder, and the people who care for them.
5. RDNZ facilitates access to support groups for individual rare disorders and provides a contact point for families who are affected by conditions so rare that they do not have their own support group.
6. RDNZ maintains a website, social media platforms and other information services to enable people with rare disorders to navigate the health care system, and to support people and whānau who are unsure about whether they have a disorder.
7. You attended a parliamentary roundtable organised by RDNZ in May 2025, attended by Health NZ, Pharmac, the Ministry of Health (the Ministry) and various consumer groups and stakeholders. At an introductory meeting following this, you agreed to host the current roundtable to follow up on implementation of the Rare Disorders Strategy.
8. RDNZ is currently inviting responses to its biennial Voice of Rare Disorders survey and expects to launch the 2025 survey results around March 2026. You will be invited to speak at the launch.

The Rare Disorders Strategy

9. In July 2024, the Ministry released New Zealand's first Rare Disorders Strategy. It sets the direction for how the health system will change for people and whānau living with rare disorders over the next 10 years and was developed with the support of RDNZ, health sector agencies and representatives of clinical, community and other interest groups.
10. The Rare Disorders Strategy provides a framework with long-term priorities and guides health entities in improving health and wellbeing outcomes. The implementation focus is therefore on gradual and sustainable improvements through which achievement will become evident as activity builds. The five priorities are:
    i. Gearing the system for quality and timely care
    ii. Learning and sustaining progress
    iii. Equipping the health workforce for quality rare disorders care
    iv. Giving voice to people and their whānau living with rare disorders
    v. Joining up internationally to achieve more

11. RDNZ has raised concerns with a lack of cohesion between agencies in implementing the Strategy.

12. RDNZ would like to see clear leadership and coordinated implementation of the Strategy, with senior leads appointed from the Ministry and Health NZ, and each agency developing its own implementation plan. They also seek ongoing collaboration through a six-monthly cross-agency forum and regular reporting on progress via existing accountability mechanisms.

13. The Ministry has met with RDNZ, Health NZ and Pharmac in the lead up to this roundtable to identify areas of progress and issues impeding progress on the Strategy.

Progress to date on the Strategy

14. Over the past year, the health system has been focused on shoring up health service delivery and managing budget constraints. There have been important gains that will benefit people with rare disorders in line with the Strategy.

Pharmac

15. This year, Pharmac has set up a Consumer and Patient Working Group to ensure that the Pharmac reset programme is designed in a way that values and reflects the needs and perspectives of consumers and patients. Chris Higgins, CE of RDNZ, is a member of this working group.

16. In October 2025, Pharmac announced that they will update their rare disorders policy principles by broadening the definition of a rare disorder from conditions affecting 1 in 50,000 to 1 in 2,000. In doing this, Pharmac will better align with the Rare Disorders Strategy and enable earlier assessment of more medicines for funding.

17. Pharmac also has a Rare Disorders Advisory Committee which most recently met in June 2025. A month later, they shared the meeting agenda to offer more transparency to those with rare disorders looking for updates on specific medicines. Pharmac are also working alongside RDNZ to make sure the right voices are heard in these meetings.

18. The inclusion of rare voices in Pharmac's work reflects the Rare Disorders Strategy priority of "*Giving voice to people and their whānau living with rare disorders*".

19. Pharmac has nominated David Hughes to be a senior lead to oversee the implementation of the Rare Disorders Strategy at Pharmac.

Ministry of Health

Genomics

20. The Ministry has an active work programme in precision health, which includes both genomics and AI. The work in this area aligns with the Rare Disorders Strategy priority "*Gearing the system for quality care*".

21. As part of our genomics work, we've worked alongside Health NZ to develop a National Genomics Operational Strategy. This includes testing for rare disorders as an area of focus and aligns with the Rare Disorders Strategy.

22. The Genomics Operational Strategy highlights:

a. The use of whole genome sequencing (WGS) to provide accurate diagnoses, reducing the diagnostic odyssey (lengthy time for diagnosis) for patients and their families with rare disorders.

b. Potential cost savings by using WGS to minimise unnecessary diagnostic investigations.

c. The potential to increase knowledge and understanding of rare disorders by gathering more information through genomic testing.

23. The issue of genetic discrimination by health and life insurance companies has also been a focus of our genomics work.

24. In late 2024, Ministry Officials worked with MBIE Officials to propose a regulation-making power to prohibit or restrict genetic discrimination to be included in the Contracts of Insurance Bill. This was passed in December 2024. The regulations are still to be made.

Health New Zealand

25. Health NZ has introduced a wide range of initiatives in the past year. Whilst these initiatives benefit all New Zealanders, not just those with rare disorders, they contribute to the Strategy's priority of *"Gearing the system for quality care"* in areas such as increasing access to diagnostics and primary care.

Increased access to diagnostics

26. In September 2025, it was announced that Health NZ will deliver an additional 75,000 diagnostic procedures this year through its $65 million Diagnostic Improvement Plan. This aims to reduce wait times for critical diagnostic procedures.

27. A $108 million upgrade to New Zealand's diagnostic infrastructure will also deliver 32 new and replacement CT, MRI, and SPECT scanners across the country. This investment is expected to boost the country's imaging capacity by approximately 6%, enhancing timely access to more precise medical imaging services for New Zealand patients.

Improving patient access to primary care

28. Health NZ is undertaking a comprehensive programme to strengthen primary and rural care through the Primary Care Tactical Action Plan which is a joint initiative with the Ministry. Within this, online 24/7 GP care launched in 2025 and new regulations to support 12-month prescriptions have been introduced.

Rare Disorders New Zealand

Rare disorders research network

29. In late 2024, RDNZ established the Rare Disorders Research Network which is a collaborative initiative aimed at strengthening research efforts across New Zealand to improve the lives of people living with rare disorders. It brings together researchers, clinicians, and community representatives to identify research opportunities and promote research that reflects the needs of the rare disorder community. The network currently has over 30 members.

30. RDNZ have also formed a Research Network Development Group which is tasked with guiding the research network's establishment and growth. This group provides strategic

oversight, helps shape the network's direction, and ensures that its activities reflect meaningful engagement with those affected by rare disorders.

31. RDNZ's work establishing a research network is relevant to the Strategy's priorities of "*Learning and sustaining progress*" and "*Joining up internationally to achieve more*".

Issues to be acknowledged

32. Strategic implementation of the strategy in its first year has been slower than was anticipated by RDNZ.

33. In that time, sector priorities have been on shoring up health service delivery including in health target areas, managing finances and assuring future workforce. These are important foundations without which progress for people with rare disorders would likely flounder.

34. There is now an opportunity to set an ongoing mechanism for collective implementation of the Strategy across organisations.

Next steps

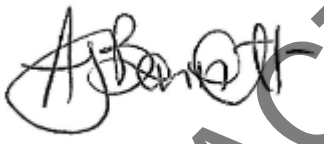
35. Work is underway to ensure the Ministry is overseeing the Strategy. Actions include:

    a. organising regular 6-monthly cross-agency leaders' meetings

    b. seeking named officials from each agency to act as senior leads on the Strategy

    c. directing agencies to each produce a 3-year plan for implementation of the Strategy

36. Current and planned work by each of the agencies is available in the high level 12-month plan attached in draft as Appendix 3. Officials are awaiting for input from Health NZ and will update ahead of the roundtable.



Allison Bennett
Group Manager
Strategy and Policy

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Appendix 2: Profiles of attendees from Rare Disorders New Zealand

Chris Higgins, Chief Executive

In May 2023, Rare Disorders NZ appointed Chris Higgins as Chief Executive.

Mr Higgins has extensive experience in the development of organisational change to achieve sustainable differences. Mr Higgins has over 10 years' experience leading several health and research organisations as CEO, bringing with him a passion for supporting the delivery of best practice.

Mr Higgins was previously a board member for Rare Disorders NZ from November 2014 to June 2018, and from December 2016 to June 2018 was Board Chair.

Mr Higgins holds a Master of Political Science, a Diploma in Health Services Management, and a Certificate in Business Excellence. Previously, he held several managerial roles within health service organisations and district health boards. He has also held the role of CEO for organisations such as the Northern Stewart Centre Trust, Headway – Brain Injury Association Auckland, Muscular Dystrophy Association NZ, Neuromuscular Research Foundation Trust, and New Zealanders for Health Research.

Kim McGuinness, Relationship Manager

Kim has a background in the not-for-profit sector and is a volunteer and past board member of Cystic Fibrosis New Zealand. Her role is to build strong sustainable relationships with clinical and non-clinical stakeholders to help deliver a wide range of projects and events that make a difference to patients' lives.

Lewanna Pentecost, Navigator

Lewanna has a background in the health sector and more recently in the social sector. She is passionate about health equity and reducing the barriers faced by people trying to access social and health support.

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