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Te Kāwanatanga o Aotearoa

MINISTRY OF HEALTH
MANATŪ HAUORA

Aotearoa New Zealand Rare Disorders Strategy 2024 – 2034

Implementation Plan 2026-27

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Purpose

Following on from the Aotearoa New Zealand Rare Disorders Strategy 2024 – 2034 (the Strategy), the Rare Disorders Strategy Implementation plan (the plan) outlines the first coordinated plan of how agencies working together across the health system will action the Strategy. It follows an initial period of largely independent action by each health agency towards the strategy.

Vision and outcomes

The implementation plan seeks to support achieving the vision of the Strategy that:

All people and their whānau living with rare disorders share in pae ora (healthy futures) and live fulfilling lives.

This vision will have been achieved when:

- people and their whānau living with a rare disorder have a better quality of life.
- the health system is responsive to people whose needs or situation are uncommon, unusual or unclear.
- designing, commissioning or providing new policies or services routinely consider the needs of people with rare disorders.

Governance and accountability

Implementation of the plan will be overseen through a shared accountability model across health agencies, convened and supported by the Ministry of Health.

Key components include:

- designation of agency leads responsible for delivery of and progress reporting on specific actions
- regular bi-annual cross-agency forums (including the Ministry of Health, Health New Zealand, Pharmac, HQSC, and Rare Disorders New Zealand) to review progress, identify emerging issues and agree priorities for future action
- ongoing engagement with people and whānau living with rare disorders to inform implementation, facilitated through Rare Disorders New Zealand.

Governance arrangements will ensure that:

- responsibilities are clearly defined and documented
- progress is regularly reviewed and reported annually
- decisions are informed by evidence, including system data when available and lived experience.

Figure 1: Strategic Framework for actioning the Strategy

Vision	Outcomes	Priorities
"All people and their whānau living with rare disorders share in pae ora (healthy futures) and live fulfilling lives"	**Quality** People and their whānau living with a rare disorder have a better quality of life. **Responsive system** The health system is responsive to people whose needs or situation are uncommon, unusual or unclear. **Considers needs** Designing, commissioning or providing new policies or services routinely consider the needs of people with rare disorders.	Gearing the system for quality and timely care. Learning and sustaining progress. Equipping the health workforce for quality rare disorders care. Giving voice to people and their whānau living with rare disorders. Joining up internationally to achieve more.
Implementation Plan [applicable time period]	**Monitoring and Governance**	**Reporting**
The Ministry of Health produces an implementation plan for each period with input from a cross-agency Monitoring and Governance Group. The plan outlines the actions to be undertaken during the applicable period, along with their strategy priority area, the most aligned strategy outcome and the responsible lead agency. Actions will adhere to the **principles to uphold in actioning the strategy**: • build on and draw from the Pae Ora Strategies, the New Zealand Disability Strategy and the Child and Youth Wellbeing Strategy • honour Te Tiriti o Waitangi and work towards achieving equity for Māori • give voice to people and their whānau living with rare disorders • support health practitioners and providers to deliver high-quality care • be informed by and seek out evidence • be collaborative and build on partnerships • support pae ora for all while focusing on the health system challenges that come with rarity.	A governance group oversees and monitors implementation of the Strategy including development and monitoring of successive implementation plans. The group: • meets formally every six months, chaired by the Ministry of Health Chief Medical Officer • includes representatives of Health New Zealand, Pharmac, the Health Quality and Safety Commission and Rare Disorders New Zealand.	Progress against the plan is published annually by the Ministry of Health, in addition to more detailed reporting by each agency on actions they include in their annual reports and other documents.

Implementation progress 2024 - 2026

Since the publishing of the Strategy in July 2024, the health system has progressed a series of initiatives to implement the Strategy. The progress, reported below, will increase in visibility with annual reporting under the new joint oversight approach to planning, monitoring and reporting.

Recognising rare disorders and the voices of people and their whānau living with rare disorders

- Pharmac's establishment of the Consumer and Patient Working Group and the stronger transparency and consuming engagement through the Rare Disorders Advisory Committee
- Pharmac updating its definition of 'rare disorders' to a medical condition that affects fewer than or equal to 1 in 2,000 people
- introducing regular and scheduled calls for funding applications for rare disorders medicines aligned with scheduled Rare Disorders Advisory Committee meetings
- increasing transparency through routinely publishing agendas for Rare Disorders Advisory Committee meetings on Pharmac's website
- policy development and implementation planning for the National Genomics Operational Strategy has included considering benefits to people with rare disorders
- initial steps to establish a Health New Zealand clinical reference group on rare disorders.

Improving diagnostic and primary care services

- commencing a two-year Whole Genome Sequencing clinical pilot to deliver faster diagnoses and results to people with rare disorders
- commencing the Diagnostic Improvement Plan in September 2025 to deliver an additional 74,950 procedures in 12 months (although not designed specifically for people with rare disorders, benefits for this group are likely)
- upgrading to diagnostic infrastructure to deliver 32 new and replacement CT, MRI, and SPECT scanners and boost imaging capacity by 6% (although not designed specifically for people with rare disorders, benefits for this group are likely)
- improving access to medicines by introducing new regulations to support 12-month prescriptions (although not designed specifically for people with rare disorders, benefits for this group are likely).

Monitoring and governance initiatives to support the implementation of the plan and the Strategy

- health agencies appointing implementation leads to hold accountability for the development and delivery of implementation actions
- health agencies and Rare Disorders New Zealand to meet twice a year commencing in May 2026 to discuss and plan implementation of the Strategy and review progress

Implementation Actions 2026-27

The implementation actions are detailed below, categorised by their strategy priority area and the most aligned strategy outcome. The plan and its implementation actions will commence on 24 July 2026 and progress over 12 months.

Gearing the system for quality and timely care

The health system builds towards a system that delivers coordinated, timely and high quality care for people and whānau living with rare disorders, regardless of where they live.

Actions	Lead	Outcomes
• Health New Zealand will establish its Rare Disorders Clinical Reference Group to identify Health NZ initiatives and areas of clinical improvements with Rare Disorders NZ. Milestone steps include: – Health NZ will consult with Rare Disorders New Zealand on roles and functions by July 2026. – Recruit and establish an advisory panel of clinical experts with a supporting Terms of Reference by October 2026. – Engage with Rare Disorders New Zealand for areas of clinical improvement through periodic meetings (ongoing).	HNZ	Responsive system
• Health NZ will continue with the delivery of its two-year clinical pilot of Whole Genome Sequencing of patients with rare diseases. • Health NZ will complete the delivery of its Diagnostic improvement programme 30 June 2026 and integrate improvements into BAU.	HNZ	Quality of life
• Health NZ will continue development of a National Clinical Network for Radiology workplan that considers the Strategy outcomes and inclusion of rare disorders. • Health agencies consider rare disorders and the Strategy in the planning, policy and delivery related to genetic and genomic testing services.	HNZ	Responsive system
• Pharmac will complete its review of the Exceptional Circumstances Framework. This includes the Named Patient Pharmaceutical Assessment (NPPA) policy and other ways Pharmac can fund medicines for individuals in special or exceptional clinical situations. • The Framework recognises that different funding pathways serve different purposes. The Schedule process supports access for population groups, while other pathways exist to respond to exceptional situations. Together, these processes are designed to work alongside each other so that people can achieve the best possible health outcomes.	Pharmac	Considers need

Actions	Lead	Outcomes
• The Framework includes the NPPA Policy for people with exceptional clinical circumstances, Special Authority waivers for people who broadly meet the intent of funded criteria but cannot meet every requirement, and other processes that allow Pharmac to consider unique or exceptional situations. These pathways aim to provide flexibility and clarity for people and their clinicians when standard funding rules do not apply. • The review will look at how the current Framework, including all the funding pathways, is working in practice and where improvements are needed. It will look at what is working well and what could be changed, removed or added, to make things better. • Funding of medicines to treat rare disorders is in scope for this review. At present, there is no specific pathway under the Exceptional Circumstances Framework for funding medicines for rare disorders. • Milestone steps include: – public consultation on discussion document – public consultation on proposed changes – publish final decision on review of changes.		
• Pharmac continues its annual invitation for applications of new rare disorders medicines. • Pharmac is always looking for new rare disorders medicines. As we learn of new information, we may approach suppliers or clinicians and encourage them to submit a funding application. On occasion we may start a funding application ourselves. • Our clinical advisers also stay up to date with the latest medicines on the market or in clinical trials through their professional practice.	Pharmac	Quality of life
• The Ministry will hold a cross-agency forum with Pharmac, Health New Zealand, HQSC and Rare Disorders New Zealand every six months. This will give stakeholders a formal opportunity to contribute to the implementation plan and to respond to new issues that occur during monitoring and evaluation of implementation.	Ministry	Considers need
• The Ministry will establish a process to integrate implementation of the plan with other relevant strategies, plans, and existing reporting and accountability cycles across implementation agencies.	Ministry	Considers need
• 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	Ministry	All

Learning and sustaining progress

Actions begin the development of a health system that has robust, usable information on rare disorders to support planning, care delivery, monitoring and investment decisions.

Actions	Lead	Outcomes
• Health New Zealand continues with primary care, hospital and specialist care coding improvements by: – publishing to the sector a SNOMED CT code set of all 7,000 approx. rare disorders covered in the Orphacodes. The code set would be distributed in the July 2026 release of the SNOMED CT NZ edition. Due date 20 July 2026. – providing guidance to software suppliers on how to use the code set (including how to map between SNOMED CT and Read Codes) September 2026 (ongoing).	HNZ	Responsive system
• Health New Zealand identifies and plans steps towards improving the continuity and coordination of care for people with rare disorders	HNZ	Responsive system
• HQSC plans to specifically include rare disorders in insights reporting.	HQSC	Considers need

Equipping the health workforce for quality rare disorders care

Actions that strengthen the health workforce to recognise, diagnose and manage rare disorders through education, guidance and pathways.

Actions	Lead	Outcomes
• Health NZ will develop new or improve its existing resources and information so the public and clinicians can navigate the system and find the rare disorders information they require.	HNZ	Responsive system
• Health NZ continues with its existing clinical improvements work programmes for rare disorders and establishes new areas for clinical improvement through the Rare Disorders Clinical Reference Group and with the input and consultation of Rare Disorders New Zealand.	HNZ	Responsive system

Giving voice to people and their whānau living with rare disorders

Actions that strengthen the role that people and their families living with rare disorders in shaping policy, services and decisions across the health system.

Actions	Lead	Outcomes
• Health agencies identify improvement work programmes where decision-makers have specifically considered impacts for people and whānau living with rare disorders.	All	All
• Pharmac's Consumer and Patient Working Group commenced June 2025 and operated until June 2026 with Chris Higgins, Chief Executive of Rare Disorders NZ, as a member of this group. • Lessons from this working group will inform the next phase of Pharmac's work to better incorporate consumer voices including a revised consumer advisory committee function.	Pharmac	Considers need
• Pharmac will continue its regular key stakeholder meetings (Rare Disorders Advisory Committee) to understand community priorities.	Pharmac	Considers need

Joining up internationally to achieve more

Actions that ensure New Zealand is better connected and learns from international partners to improve outcomes for people with rare disorders.

Actions	Lead	Outcomes
• Pharmac will establish an international review and collaboration mechanism to improve Pharmac processes for rare disorders assessment.	Pharmac	Responsive system
• The Ministry of Health will continue to identify and develop policy that supports rare disorders patients or related settings.	Ministry	Considers need
• RDNZ will contribute to the rare disorders research aspects of the Rare Disorders Strategy through its leadership of the rare disorders research network leadership group and the European Rare Diseases Research Alliance (ERDERA) affiliated New Zealand National Mirror Group. Through RDNZ these two entities will seek to both integrate rare disorders research with the Clinical Reference Group over time and contribute to the implementation of the RDS. • This will contribute to: – an expanded health research infrastructure that will support rare disorders research and evaluation (year 1) – people living with rare disorders participating in rare disorders research (year 2) – supporting clinical trials infrastructure to support participation by people with rare disorders from all parts of the country (year 3).	RDNZ	All