Q&As from Webinars

Is there going to be separate exclusive funding allocated for management of rare disorders?

The purpose of developing a strategy is to provide change and set the direction of the health system to support people and whānau with rare disorders. The strategy itself will not specify separate funding. This will be the role of the next Government Policy Statement, Te Pae Tata (the New Zealand Health Plan) and subsequent budget decisions by the Government of the day.

A rare disorders strategy will ride on the shoulders of the six Pae Ora strategies[1], and aims to bring focus on how the system should move to better support people and whānau with rare disorders over the next decade. Many barriers faced by people and whānau with rare disorders are common across the entire health system, especially barriers faced by people with disabilities. The priority areas outlined in the Pae Ora Strategies closely link with what we have heard as priorities for the rare disorders community. Achieving the vision for Pae Ora will also address wider system issues faced by those living with a rare disorder.

To what extent will medicines administration and (medical) device access issues be considered, e.g., issues with medicine compounding, accessing devices that fit, pharmacist knowledge around rare disorders etc.?

These issues could be considered as part of the critical health services aspect of the strategy. In particular, we note the new Therapeutics Products Act that aims to improve the health of all New Zealanders by providing for the:

- acceptable safety, quality, and efficacy of medicines
- acceptable safety, quality, and performance of medical devices
- acceptable safety and quality of Natural Health Products, and that any health benefit claims are supported by scientific or traditional evidence[2].

The new regime will be flexible enough to support innovation, while ensuring effective control over quickly evolving health technologies. It will also align with international standards and uphold the quality of regulation currently carried out by the Ministry.

As well as replacing and modernising the regulatory arrangements for medicines, the Act provides fit-for-purpose regulation of medical devices, as well as cell, gene, and tissue therapies, which are currently not fully regulated.

Although many of the provisions do not come into effect until mid-2026, the Manatū Hauora team implementing the Therapeutic Products Act are working hard to ensure the necessary rules and regulations are put in place to support the new therapeutic products regulatory regime.

[1] www.health.govt.nz/new-zealand-health-system/pae-ora-healthy-futures-all-new-zealanders
[2] www.health.govt.nz/our-work/regulation-health-and-disability-system/therapeutic-products-regulatory-regime

You can sign-up to receive updates on the implementation of the Therapeutic Product Act here: www.health.govt.nz/our-work/regulation-health-and-disability-system/therapeutic-products-regulatory-regime/subscribe-therapeutic-products-updates

Is there a list of rare diseases on the rare disorders website?

Attached is a list of rare disorders support groups from the RDNZ pamphlet. Many support groups cover a range of rare disorders.

Can you please clarify under the heading of Funding, assessment and prioritisation what medicines and medical devices have good assessment and prioritisation?

Currently, there is very good safety, quality and effectiveness assessment of medicines (by Medsafe) and value for money assessment and prioritisation of many medicines (by Pharmac). Both Medsafe and Pharmac have processes to make it easier for medicines used, only rarely to be assessed.

Assessment and prioritisation have been much less rigorous for medical devices, but improvements are being worked on both in implementing the new Therapeutic Products Act and by Pharmac and Te Whatu Ora working together.