

# Plan to develop the rare disorders strategy

## Scope

The scope of the rare disorders strategy seeks to identify and establish the main levers to influence and direct the health system to improve outcomes for people with rare disorders. Community aspirations underpin the scope.

### Key themes from the sector:

diagnosis	support	Pathways
medicines	information	Research
		Workforce

### Scope

Embedding recognition and understanding of rare disorders into health system

Enabling holistic person centred approaches for people living with rare disorders and whānau/supports

Identifying opportunities across health system to create equity for rare disorders community

Identifying health system settings to enable the system and influence outcomes

## Engagement

Active engagement with rare disorders communities, embedding voice across policy and strategy development.

### Pae Ora Strategies:

- New Zealand Health Strategy
- Women's Health Strategy
- Rural Health Strategy
- Health Of Disabled People Strategy
- Hauora Māori Strategy
- Pacific Health Strategy
- Health Workforce Strategy

July 2023

### Cross-strategy engagement

- Rare disorders priorities reflected across strategy spectrum
- Ensuring coherence across health system

#### Foundations:

Review of international literature and approaches  
 Review of local data and information  
 Long term insights briefing (precision health)

#### Opportunities and Options:

Policy pieces providing insights and advice on specific themes of interest to the rare disorders community and health system

### RARE DISORDERS STRATEGY:

The rare disorders strategy will be informed by the individual policy pieces, and provide a global strategic direction for the health system in supporting the rare disorders community.

## Outcomes

Establishing strategies in health system. Rare disorders strategy to build upon *New Zealand Health Strategy, other Pae Ora and Health Workforce Strategies*. Coherence between strategies extends to those already established and intended for refresh.

Existing and future health strategies

Government Policy Statement

National Health Plan

Interplay with key health agencies  
 Eg. Developing new models of healthcare

Community engagement

EOY 2023