

# The need for data on rare disorders in NZ

## At a glance

There are estimated to be around 300,000 New Zealanders living with a rare disorder.

This estimate is based on international data, because in the New Zealand health system data on rare disorders is not being captured.

## Key stats

A 2023 insights report on the prevalence of rare disorders in New Zealand found



The quantity of data available on rare disorders in New Zealand is strikingly low.



The classification system for diseases that New Zealand uses does not include most rare disorders.

Rare Disorders Insights Report: Pathways Towards Better Health Outcomes  
<https://www.raredisorders.org.nz/about-rare-disorders/rare-disorders-in-new-zealand/berl-insights/>



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[www.raredisorders.org.nz](http://www.raredisorders.org.nz)

## CHALLENGES

New Zealand has no official process for collecting data on rare disorders. This means this sizeable population group and their health needs are invisible and not being factored into decisions by policy-makers, nor receiving adequate Government funding and resource allocation, despite often being high-cost and high-needs patients.

## SOLUTIONS

An integrated, centralised and accessible data patient registry which uses the Orphanet classification system would improve data collection and accuracy, and benefit international collaboration on research.



Develop a rare disorder patient registry



Establish an official definition of what is considered a rare disorder in NZ



Adopt the Orphanet classification system for rare disorders

## BENEFITS

### Benefits One

1

Better communication between care providers, improving diagnosis and treatment.

### Benefits Two

2

Government funding and resources more adequately allocated to meet the needs of rare disorder patients.

### Benefits Three

3

Valuable information for researchers and policymakers to inform inclusive policy and improve the lives of people living with a rare disorder.