

Rare Disorder Centre of Excellence

At a glance

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

Rare disorders can be complex, debilitating and life threatening, and often require a broad range of services.

Key stats

Results from Rare Disease UK's (2018) *Rate your rare disease care survey* found



> 50%

of people who had access to a specialist centre rated their care as 'good' or 'excellent'

For those respondents who had none of their care provided at a specialist centre



< 25%

rated their care as 'good' or 'excellent'



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www.raredisorders.org.nz

CHALLENGES

People living with a rare disorder often report being lost in the health system, with a long pathway to diagnosis, and difficulties accessing information, treatments, specialists and healthcare services. Challenges surrounding coordination of care are common.

SOLUTIONS

Other countries have addressed these challenges by establishing Rare Disease Centres of Excellence that act as hubs of expertise, bringing together experts from multiple specialties to improve time to diagnosis, create effective referral pathways and coordinate multi-specialty clinical care.



Effective referral pathways



Network of expert healthcare professionals



A central hub for coordinating multi-specialty clinical care

BENEFITS

Benefits One

1

Time to diagnosis is reduced and patient experience, well-being and overall quality of life is vastly improved.

Benefits Two

2

Patients access appropriate care and treatment faster, lowering risk of becoming high-need, high-cost patients, and reducing the demand on health and social services.

Benefits Three

3

New Zealand delivers an equitable healthcare system that is able to keep pace with advances in genomics and precision medicine.