

Summary from Whiteboard session meeting between Ministry of Health and Rare Disorders NZ 15 May 2023

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Sent: Monday, May 15, 2023 1:24 PM

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Subject: Rare Disorders Engagement Planning Meeting - 15 May

Kia ora koutou,

Thanks for meeting with us this morning for further discussions regarding a rare disorders definition and future engagement planning.

Please see below notes taken from our whiteboard session.

Definition

Why?

- Access to funding, supports, treatments, research
- Connections with other accepted / standards of care etc

It was noted that a definition for Rare Disorders will be widely linked to many of the prominent priorities such as:

Diagnosis

- Access to services: paediatrics, genetics, general medicine, endocrinology, neurology, rheumatology, musculoskeletal (orthopaedics, physio).
- Genetic testing (number of geneticists) -> patient could get test, but not reported or may not be ordered.

Pathways

- GPs don't know where to refer or what to do next
- Standard pathways useful for people + workforce
- Care coordination - few people have, but it is life changing for those who do have it. This can include both traditional nursing and system navigation roles in one. (nurse prescribing)
- ERNs (Starship and Youth Clinical Networks)

Access to Supports

- Education/Whaikaha/health

Health and Disability

- Barriers; people may qualify for support but don't know that they can access the services, or in some cases that they even exist.
- Hidden disabilities (survey - 70% don't know about supports)

Mental Health

- Higher rates compared to wider disabled groups
- Support for carers (for some, supports are very complex)

Medicines

- Pharmac; (RDNZ medicines access group) e.g., have only 3 people in NZ.
- May know medicines in stage 3 clinical trials

Research

- e.g., Fragile X Education
- Collective experiences (effective and pathways)
- Partnerships; international, between patients and workforce, need to use the same coding

Info/data

- Clinical information
- Registry = data coded (code for suspected undiagnosed rare disorders)
- Support and advice

Workforce Development

- Clinic; clinical advisory panel
- Guidelines and standards of care
- Future proofing; what will be identified
- Pathway for suspected undiagnosed
- Resources used where they are available; often overseas resources adopted
- Expertise may exist but not known about

Ngā mihi,



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