



**Submission to the New Zealand Royal Commission COVID-19 Lessons Learned Te Tira Ārai Urutā public consultation**

**To:** [InquiryintoCOVID-19lessons@dia.govt.nz](mailto:InquiryintoCOVID-19lessons@dia.govt.nz)

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**Submitted by:** Rare Disorders NZ

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**Declaration of interest**

Rare Disorders NZ works with clinicians, researchers, allied health professionals, academia, government and industry to achieve better outcomes for people with a rare disorder in New Zealand and their whānau. We are funded by grants, donations, fundraising events, Pharma roundtable and a small Te Whatu Ora contract.

**Rare Disorders NZ**

Rare Disorders New Zealand is the respected voice of rare disorders in Aotearoa. We are the national peak body organisation, supporting the 300 000 New Zealanders with rare disorders and the people who care for them. We help those affected by rare disorders navigate the healthcare system, find information and resources, and connect with support groups specific to their condition.

We proudly advocate for public health policy and a future healthcare system that works for those with rare disorders – using a strong and unified voice to collaborate with Government, clinicians, researchers, and industry experts, to promote diagnosis, treatment, services, and research.

Our vision is for New Zealand to become a country where people living with a rare disorder are fully recognised and supported with equitable access to health and social care.



## **Submission**

Rare Disorders NZ commends New Zealand's public health response to the COVID-19 pandemic that meant mortality from Covid-19 in New Zealand has been kept relatively low compared to other similar nations<sup>i</sup>. New Zealand's initial elimination and later minimisation response allowed a large majority of people to be vaccinated, and many boosted prior to the country experiencing its peak of infections. This approach helped minimise the risk for those more vulnerable in our communities, including many with rare disorders. We would hope for a similar evidence based and risk informed public health response if or when the next infectious disease pandemic occurs, albeit one that is finessed by what we can learn from the past.

To perform better in any future pandemic or health crises, it is crucial to acknowledge that individuals within the rare disorder community have encountered significant challenges from the onset of the pandemic until today. These challenges are likely to persist in the future, both concerning COVID-19 and beyond.

Below we have highlighted some areas of New Zealand's COVID-19 response that created concerns and challenges for the rare disorder community.

### **1. Disruption to medical services**

Our 2021 Voice of Rare Disorders Survey found that the majority of respondents (58%) felt there was some or significant impact of COVID-19 on their healthcare services. The main effects were through cancellation or postponement of appointments, delays in screening, tests or surgery<sup>ii</sup>. The pandemic highlighted the need for a better baseline of health workforce planning, retention, and resourcing.

### **2. Underlying need for better access to medicines and treatment pathways**

The pandemic has underscored the urgent need for equitable access to life-changing therapies and optimal management processes for individuals with rare disorders in New Zealand. Limited access to gold standard treatments and inadequate implementation of best practice care have left many more medically fragile than if they were receiving a higher standard of care and treatment, thus unnecessarily susceptible to both severe COVID-19 complications and the broader health system delays that followed.

### **3. Initial lockdown and ongoing pandemic fears, exacerbated by lack of care coordination, data and pathways**

The initial lockdown and ongoing pandemic have been particularly frightening for the rare disorder community. The lack of specific pathways and advice, especially for the vulnerable in the rare disorder community and for carers, has compounded existing challenges they face, including that people living with a rare disorder already experience higher levels of tension, isolation, depression and hopelessness than the general population<sup>iii</sup>.



Guidance issued to the public often failed to consider or address the situations people with rare disorders and their carers were in, leaving them directionless and anxious.

The majority of people living with a rare disorder in New Zealand do not have a care coordinator<sup>iii</sup>, care plan, or process to follow when they become unwell. This is despite their disorder often meaning that standard advice is not applicable or even dangerous for them to follow.

There are also a very limited number of registries of people with different rare disorders as well as a paucity of data and as such, contacting people or their General Practitioner to provide advice specific to their disorder would be a near impossible task, as would determining the number of people with specific disorders who may be affected. This is a huge gap in our health system that needs addressing in order to be better prepared for any future pandemic or large health event.

#### **4. Education access**

Schools were poorly set up to manage the pandemic. Creating a safe classroom for many children with rare disorders was difficult due to limited options to create and monitor air flow and a lack of equipment to improve this situation. Restrictions lifting allowing COVID-19 positive students, teachers and support staff into the classroom without adequate mitigations in place for these students did not, and continues to not, protect this vulnerable population. For some in the rare disorder community, we have heard that this limits their ability to attend school due to risk of infection.

#### **5. Initial limited and inequitable anti-viral access**

Many people with rare disorders have high health needs. In our 2023 Voice of Rare Disorders Survey, we found that in the preceding 12 months more than one in three (39%) respondents were in hospital for an average of 12 days as an inpatient, and one in 13 were admitted to ICU for an average of 4.6 days<sup>iii</sup>.

Until the 1 October 2023 widening of anti-viral access criteria, many in the rare disorder community struggled to access Covid 19 anti-virals despite in some circumstances a significant increase in risk to their health and outcomes from Covid 19, and similar if not greater health need than some conditions listed (for instance Down Syndrome was on the criteria but many rare neurodevelopmental disorders associated with moderate to severe intellectual disability and increased health needs were not).

Criteria containing lists of specific conditions are not equitable for people with rare disorders. Due to the vast number of rare disorders (>7,000), and that specialists will not be familiar with many of them due to their rarity, it is not feasible that all relevant rare disorders be listed in such criteria. Going forwards we urge Pharmac and other bodies to consider how to include the rare disorder population in the



drafting of criteria containing lists of specific conditions, as such lists may unintentionally exclude people with rare disorders. Allowing prescriber discretion or more inclusive criteria such as that eventually reached in October 2023, is much more equitable for those with rare disorders.

We heard from our community, and agree, that the driver for access to anti-virals seemed to mainly be about reducing hospitalisations and not in any way focused on the factors that might lead to long term health detriment for those with a rare disorder, which would impact on health needs and burden on healthcare services. We believe this approach was short-sighted and would urge that an approach aimed at reducing long term morbidity also be included in any future instance.

#### **6. Antiviral access not widened until after restrictions dropped**

Rare Disorders NZ was extremely frustrated that the Government removed the final COVID-19 restrictions on 15 August 2023, while Pharmac was still in the process of deciding whether to widen the access criteria for COVID-19 antivirals. The criteria in place at the time excluded many groups of people who would be vulnerable to severe illness from COVID-19, including many in the rare disorder community. The eventual widening of access to anti-virals was implemented on 1 October 2023.

It was very concerning to us that the decision to lift restrictions was not postponed for a few more weeks to ensure the most vulnerable groups had access to the protection they needed before they were put at increased risk of exposure.

These challenges identified highlight the importance of proactive measures to address the needs of individuals with rare disorders prior to and during health crises. Moving forward, Rare Disorders NZ urges policymakers and officials to prioritise elevating the standard of care those with rare disorders experience to be better prepared for a future event of a similar nature, and to include consideration of how to treat individuals with a rare disorder equitably when responding to such events.

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<sup>i</sup> Cases and mortality by country, John Hopkins Coronavirus Resource Centre, last updated 16 March 2023, accessed here: <https://coronavirus.jhu.edu/data/mortality>

<sup>ii</sup> Impact of Living with a Rare Disorder in Aotearoa New Zealand, 2022, [www.raredisorders.org.nz/about-rare-disorders/rare-disorders-in-new-zealand/nz-voice-of-rare-disorders-white-paper-2022/](http://www.raredisorders.org.nz/about-rare-disorders/rare-disorders-in-new-zealand/nz-voice-of-rare-disorders-white-paper-2022/).

<sup>iii</sup> Impact of living with a rare disorder in Aotearoa New Zealand, 2024, [www.raredisorders.org.nz/about-rare-disorders/impact-of-living-with-a-rare-disorder/](http://www.raredisorders.org.nz/about-rare-disorders/impact-of-living-with-a-rare-disorder/)