



Submission to Pharmac on Proposal to change the access criteria for COVID-19 antiviral treatments

To: consult@pharmac.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. This submission is in response to Pharmac's proposal to change the access criteria for COVID-19 antiviral treatments

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.

Our submission

Rare Disorders NZ has been advocating for widening of access to COVID-19 antiviral treatment for some time. As you will be aware, the access criteria for COVID-19 antivirals as they currently stand have excluded many groups of people who would be vulnerable to severe illness from COVID-19, including many in the rare disorder community. We wrote to Pharmac in February requesting for a review to widen the access criteria, and we are pleased to see this finally coming to fruition.

We support the proposed changes to the criteria and would like to note the following:

- We are deeply concerned by the timing of the removal of the mandatory seven-day self-isolation period for those with Covid-19 as well as the removal of the requirement to wear masks in healthcare settings. It is disappointing that these measures have been relaxed before the proposed changes to antiviral access have been implemented. We therefore ask that this work is progressed under urgency to ensure that all people vulnerable to severe illness from COVID-19, including many in the rare disorder community, have access to antivirals given they are now at increased risk of exposure.



- The proposal states: “We are interested in feedback to help us understand how we could incorporate discretion within the access criteria. This is to make sure that people who meet the intent of the access criteria (they are at a similarly high risk of severe illness and death from COVID-19 infection as the groups identified in the criteria) but are not identified explicitly could access COVID-19 antiviral treatments”.

Rare Disorders NZ strongly agrees that discretion needs to be built into the access criteria.

In February 2023 Rare Disorders NZ wrote to Pharmac requesting that “Pharmac provides for an equitable situation and widens the access criteria to enable all people living with a rare disorder to have access to COVID-19 antivirals if their treating clinician considers it appropriate. This would not only reduce the need to access hospital services if they were to catch COVID-19 and for the treatment of post-viral exacerbations of their rare disorder, it would also help to prevent further clinical health decline”.

We continue to advocate for this degree of discretion and recommend that clinicians should be free to prescribe any of the antivirals they consider appropriate to anyone they consider would benefit from the treatment.

- The inclusion of criteria 4.9, “*Patient has pre-existing high risk due to a health condition and needs direct family, whānau or external disability care most days*”, is essential. This is because those described in criteria 4.8, “*Patient receives Disability Support Services funded by Whaikaha - Ministry of Disabled People*”, does not capture a large proportion of the rare disorder population, who have equivalent needs to those receiving Disability Support Services, on account of their disorder being defined as a ‘personal health condition’, making them ineligible for funding from Whaikaha.
- The COVID treatments advisory group recommended including, as a specific named group, those people who are considered clinically to have severe frailty, which the Group considered would likely encompass those people at highest risk of COVID-19 without needing to produce an exhaustive list of specific high-risk conditions. We see this reflected in criteria 4.10 “*Patient has pre-existing severe frailty and/or vulnerability due to a single severe chronic condition, including but not limited to: neurological, cardiovascular, renal and respiratory conditions*”.

We are concerned that this criteria states ‘single severe chronic condition’ as this may exclude people who are yet to have a unifying diagnosis for their co-presenting symptoms which combined cause severe frailty. This disadvantages people with an undiagnosed rare disorder. The majority of people in the 2021 ‘Impact of Living with a Rare Disorder in Aotearoa New Zealand’ survey conducted by Rare Disorders NZ had challenges in getting a diagnosis for their rare disorder: over half took longer than 1 year to get a diagnosis and for one in five the time taken to get a diagnosis was over 10 years.

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Rare Disorders NZ

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