



Re: Proposal to fund recombinant varicella zoster virus vaccine (Shingrix®) for the prevention of shingles in immunocompromised people

To: consult@pharmac.govt.nz

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Submitted by: Rare Disorders NZ

Contact person: Chris Higgins (CE)

Email: Chris@raredisorders.org.nz

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 fund recombinant varicella zoster virus vaccine (Shingrix®) for the prevention of shingles in immunocompromised people.

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 supports the principles behind the proposal to widen the access for recombinant varicella zoster virus vaccine (branded as Shingrix) for prevention of shingles in immunocompromised people from 1 July 2024. This is an important step for immunocompromised people who are at both a higher risk of shingles and cannot receive the live vaccine.

However, we find the criteria very narrow and are extremely concerned by the exclusion of patients on immunocompromising therapies, except the three named conditions in receipt of DMARDs (polymyalgia rheumatica, systemic lupus erythematosus or rheumatoid arthritis).

It is frustrating to see that while the Immunisation Advisory Committee noted that individuals receiving regular high doses of systemic corticosteroids, disease modifying anti-rheumatic drugs, or chemotherapy are at high risk of shingles, people with rare disorders who fit this description and would benefit greatly from receiving Shingrix are excluded from the proposed Special Authority criteria. Examples of this situation include individuals with EGPA, Multiple Sclerosis (rare forms) and ANCA vasculitis.

In instances such as these, Special Authority 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 rare disorders be listed in such criteria.

We ask Pharmac consider utilising wording it has previously, for instance in regard to who is immunocompromised for the purposes of access to COVID-19 antiviral treatments, including the criteria “is considered otherwise severely immunocompromised”.

Going forwards we urge Pharmac to consider how to include the rare disorder population in the drafting of Special Authority criteria containing lists of specific conditions and medicines, as such lists may unintentionally exclude people with rare disorders.

ENDS

Rare Disorders NZ

6 March 2024