



Re: Proposal to fund continuous glucose monitors, insulin pumps, and insulin pump consumables

To: consult@pharmac.govt.nz

Date of Submission: 24 April 2024

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 continuous glucose monitors, insulin pumps, and insulin pump consumables.

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

We welcome the inclusion of pancreatogenic diabetes mellitus in the conditions that these products are proposed to be funded for, and appreciate that the definition used includes rare causes of pancreatogenic diabetes like Cystic Fibrosis and Permanent Neonatal Diabetes Mellitus.

We were disappointed to see the *Summary of Consultation* for this proposal (here: <https://pharmac.govt.nz/news-and-resources/news/summary-2024-03-28-cgm>) only included reference to the proposal being for those with type 1 diabetes. We do not want to see the same occur as this work progresses and stress that it is important that the 'support for people with type 1 diabetes' and the 'support for healthcare professionals' outlined in the proposal is also inclusive of those with pancreatogenic diabetes and not solely targeted at those with type 1 diabetes. This would include consideration of the different clinician and allied health groups that may need to be targeted and different consumer information, education and support that may need to be generated. Too often people with rare disorders and their needs are overlooked and it is important that this does not happen here.

We do not have the expertise to comment on the choice of brand or products proposed for funding but as people with rare disorders often have unique needs, we are pleased to see Pharmac are proposing to manage the funding of alternative brands via Pharmac's Exceptional Circumstances framework and that applications would be different to Named Patient Pharmaceutical Applications (NPPA). We encourage Pharmac to follow the advice from the Diabetes Advisory Committee to provide greater flexibility than a strict predefined exception criteria, instead allowing clinicians to identify these exceptions as they arise.

We also are pleased to see that Pharmac intend to include more details on how to apply to their Exceptional Circumstances Framework if this proposal is approved and urge Pharmac to ensure that instructions are user-friendly and that the pathway is well known about and understood.

ENDS

Rare Disorders NZ

24 April 2024