

Rare Disorders New Zealand response to the Manatū Hauora Rare Disorders Strategy updated Framework document¹

Thanks for the opportunity to provide feedback on the revised RDS framework document, and we appreciate and acknowledge the amendments that have been made in response to our (and others') comments on the original draft. In respect of the second draft our comments are as follows:

1. There should be a reference to the recent Cabinet paper which sets out a mandate for reviewing how primary health care services are to be delivered in the future. Although the Cabinet paper omitted to include people with rare disorders as a vulnerable population group, and also omitted to emphasise the importance of primary health care practitioners having access to external sources of knowledge and expertise (which we interpret as errors of omission rather than commission), the fact that the Cabinet paper instructs Manatū Hauora to carry out a primary health care review creates an opportunity for future primary health care delivery to have a more focussed approach to delivering services to people with rare disorders. We specifically recommend that the RDS include a comment to the effect that the forthcoming primary health care review will include a focus on rare disorders, and RDNZ therefore recommends that this also be foreshadowed in the framework document.
2. The proposed principles should include a reference to and acknowledgement of the specific role of Rare Disorders New Zealand and rare disorders support groups in: supporting people with rare disorders to navigate their way through health, education, justice and other social support systems; providing information and advice to people with rare disorders, their whanau/family, their health professionals, other cross-sectional professionals, and cross-sectional policy makers; and facilitating implementation of the strategy upon its completion
3. As we've commented in our submission to the first framework document addressing equity for people with rare disorders should be rare disorders specific and go beyond the equity issues that arise from being Māori or from being disabled (albeit that we fully support the inclusion of these elements). The poor health outcomes experienced by people with rare disorders are the result of the combination of the rare disorder itself and how they are addressed by the New Zealand health and other systems. Inequity of outcomes for people with rare disorders is represented by the outcome differences experienced by people who receive a full suite of planned and coordinated evidence-based services compared with those who don't. These outcome inequities are exacerbated for people with rare disorders who are disabled and/or Māori.

¹ Framework document: A rare disorders strategy for Aotearoa New Zealand. Manatū Hauora. 24 August 2023



4. We don't agree with the statement "In New Zealand, we have good assessment and prioritisation of individual products (such as medicines and medical devices)". We recommend that this be amended to "In New Zealand, we assess and prioritise individual products (such as medicines and medical devices) in ways that often disadvantage people with rare disorders, both in comparison to citizens of other OECD countries and as a result of being denied access to potentially life saving products."
5. The framework document should acknowledge that the wellbeing needs of people living rare disorders are not confined to the health sector, and that the scope of the strategy will be extended to other sectors including disability/whaikaha, education, justice, social welfare etc
6. There should be explicit acknowledgment that people with rare disorders comprise a "priority" or "vulnerable" population
7. In addition to articulating RDNZ's seven points in section six the framework document should also articulate our view that effectively addressing the seven points will be facilitated by a "rare and undiagnosed disorders centre of expertise" (previously referred to by RDNZ as a "rare disorders centre of excellence")
8. It would be helpful for section 1 of the framework document to more clearly express what the strategy will and won't do, and to identify which agencies will be accountable for addressing the RDS's implementation, and which agencies will be expected to address anything that the RDS states that it won't do

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Chief Executive

6 September 2023