



Maree Roberts
Deputy Director-General, Strategy Policy and Legislation | Te Pou Rautaki
Manatū Hauora

13th November 2023

Dear Maree

Rare Disorders Strategy

This letter is to brief you on the development of Manatū Hauora's Rare Disorders Strategy (RDS).

Although on one level it's about the content of the RDS, on another level it's about the accompanying processes that we expect will be led by Manatū Hauora's senior executives, rather than by those directly involved in its development per se.

Firstly, we wish to commend Manatū Hauora's RDS team on how the strategy has been developed so far. RDNZ appreciates the acknowledgment as co-designing partners, the unique opportunity that has been extended to us as a member of the reference group including fortnightly meetings with the RDS team, the extensive efforts that have gone into ensuring full consultation with people living with rare disorders, the consultation that has occurred with rare disorders specialists and experts, and the partnering that has occurred with Te Aka Whai Ora to ensure that the voices of Māori living with rare disorders are heard.

One of the first points I emphasised to Manatū Hauora's RDS team shortly after becoming RDNZ's Chief Executive in June this year was the importance of producing a document that would be fully supported by rare disorders stakeholders, particularly RDNZ itself. All of us at that meeting concurred, and I remain hopeful that this is what will be achieved.

As we move towards the completion of the strategy, it is essential that it leads to concrete actions to ensure that the health system responds equitably to rare disorder patients and supports them to have the best possible quality of life, otherwise we will find it difficult to support.

This morning therefore we recommended to the RDS authors that they include the following as a minimum set of four actionable items in the next draft of the RDS, which we understand is due to be circulated this coming week:

1. Creation of a rare and undiagnosed disorders centre of expertise, modelled on Rare Disorders New Zealand's Rare Support Centre Aotearoa proposal presented in Appendix X (attached separately to this letter)
2. Full recognition of RDNZ as a key enabler for the Strategy's implementation
3. Incorporation of coding of rare disorders in the roll-out of the nationwide Electronic Medical Record (EMR) and other administrative data sets
4. Establishment of a single barrier-free pathway to enable people with rare disorders to access the medicines they need. Access will be consistent with or exceed best practice international norms.

Elaboration on these points is included in the attached BIM, and we've further elaborated to the RDS team on item 3 in respect of inclusion in particular of congenital anomalies register data, and outpatients' data.

We're asking Manatū Hauora to be aware that the four points above have been developed in close collaboration with a list of over 20 RDNZ identified specialists and experts and some 150 rare disorders support group leads. We believe that they were further reinforced during the clinical consultation sessions led by the Ministry's Hamish Gray.

As such they have wide sector support as having the best impact for patients and whanau/families. As part of our ongoing public advocacy campaign (boosted with TVNZ news items yesterday on the 6.00 pm news and this morning on Breakfast), we will during the course of the week make them widely available through our various communication and media channels. This may result in our recommending to Manatū Hauora's RDS team that they be further strengthened.

We're aware that consultation is occurring on the Strategy with both Te Whatu Ora and Pharmac. While it is important that these agencies have an opportunity to express their perspectives we think it important that the RDS in its final version is an aspirational yet actionable document which is not compromised by provider capture.

We'd also appreciate being advised as to what Manatū Hauora will be saying to incoming Ministers about the RDS in its own BIM. Feel free to draw on RDNZ's if you think that will be helpful.

We are encouraged to know that there will be other important elements to the RDS which will be or already have been identified by the Manatū Hauora Strategy team, and we look forward to contributing to their development as we see iterations of drafts over the next few weeks.

Kind regards



Chris Higgins
Chief Executive
Rare Disorders New Zealand
P: +64 27 292 8433
E: chris.higgins@raredisorders.org.nz

cc:

Dr Diana Sarfati, Director-General of Health and Chief Executive
Stacey Connor, Manager, System Enablers
James Mc Goram, RDNZ Chair