

From: [Chris Higgins](#)
To: [Manager and Principal Policy Analyst MoH](#)
Cc: [Kim McGuinness](#); [lewanna](#); [REDACTED]
Subject: RE: Input to a rare disorders strategy for New Zealand
Date: Thursday, 6 July 2023 3:13:11 pm
Attachments: [image001.png](#)
[image002.png](#)
[image003.png](#)
[image004.png](#)
[image005.png](#)
[image006.png](#)
[image007.png](#)
[image008.png](#)
[image009.png](#)
[image010.png](#)

Kia ora [Manager Policy Team at MoH working on the strategy](#)

This is very helpful thanks, and understood. We'll endeavour to reach out to the rare disorders support group leads early next week. We'll keep Manatū Hauora and Te Aka Whai Ora informed, and will look forward to seeing you on Monday with the Minister

Ngā mihi

Chris

Chris Higgins

Chief Executive

Rare Disorders NZ

PO Box 14-313, Kilbrnie, Wellington, 6241, NZ

Mobile: [REDACTED]

Office: +64 4 385 1119

Email: [REDACTED]@raredisorders.org.nz



Follow us on [Facebook](#), [LinkedIn](#) and [Twitter](#)

From: [Manager MoH Policy Team](#) [REDACTED]@health.govt.nz>

Sent: Thursday, July 6, 2023 3:04 PM

To: Chris Higgins [REDACTED]@raredisorders.org.nz>; [REDACTED]@health.govt.nz>

Cc: Kim McGuinness [REDACTED]@raredisorders.org.nz>; lewanna

[REDACTED]@raredisorders.org.nz>; [REDACTED]@health.govt.nz>

Subject: RE: Input to a rare disorders strategy for New Zealand

Kia ora Chris,

Thanks for checking in with us about how best to ensure good input to developing a rare disorders strategy from RDNZ's member organisations, while supporting us in fulfilling our public sector agency responsibilities in the period leading up to the general election and government formation after that.

[REDACTED] has worked with our integrity team within the Ministry to provide the following advice.

For your information, and to assist in responding to any questions that may arise, our responsibilities are set out in the Public Service Commission's [General Election Guidance 2023](#). The guidance supports agencies, including Manatū Hauora, to maintain political neutrality in the pre-election and government formation period and, importantly, to prevent any possible perceptions of using public funds or resources for party political purposes. In particular, the section on [Public sector advertising, publicity and the media](#), and the [Guidelines for Government Advertising](#) apply to policy communications and discussion and consultation documents and materials.

In applying this guidance, we are continuing with strategy development with targeted consultation with those affected, not with general consultation with the wider public. Our targeted consultation includes limited distribution of discussion documents and materials, such as the reference group document currently circulated to reference group members. Distribution is limited to reference group members, government agency representatives and, via RDNZ, support group leads for your member organisations.

Support group leads may wish to discuss the content of such documents with key informant members or their board, in order to best provide input. We are happy for limited discussions to occur with a few key people, and for key document content to be shared, such as verbally or on screen, during the discussions only. All participants of such discussions need to know that their involvement is important to strategy development that, because it is happening around the time of a general election, is occurring with input from key affected people rather than the wider public. Any information being discussed with them is provided in strict confidence, for the purpose of their contribution to strategy development.

Discussion documents provided to support group leads are not for further distribution – that is, not to be emailed, copied or otherwise passed on and in no circumstances to be posted on websites, noticeboards, platforms or social media.

We thank you for supporting Manatū Hauora in maintaining political neutrality and avoiding any potential perception of public resources being used for party political purposes during this next several months.

Here is some suggested text for your emails to support group leads:

IN-CONFIDENCE – Not for wider circulation

As a support group lead, you have important expertise to contribute to the development of a rare disorders strategy for New Zealand. Manatū Hauora | the Ministry of Health is leading development of the strategy and sending out a series of documents and other materials to a reference group of sector experts and agency representatives, including Rare Disorders NZ. We have offered to collect and co-ordinate input from our large number of support groups through support group leads.

Attached is the first document from Manatū Hauora. Their team welcome your feedback on as much or as little of the content as you prefer. Please reply with your feedback by ...[RDNZ timeframe]. Note that if you are not able to meet this timeframe, there will be future opportunities for input.

IMPORTANT:

This document is not for further distribution – that is, not to be emailed, copied or otherwise passed on and in no circumstances to be posted on websites, noticeboards, platforms or social media.

The reason for this is that work on a rare disorders strategy is happening around the time of a general election. During this time, input needs to be from key affected people rather than the wider public.

If you wish to check with another key person in your support group, it will be okay to discuss parts of the document or show it on screen during the discussion only. Make sure they know it is in strict confidence, and only because their input to strategy development is important.

I hope you find that information useful, but please feel free to contact me if you have any further questions. We will look to address other points in your email in the next day or so.

Warm regards



██████████ ██████████
Acting Manager, System Enablers
Strategy, Policy and Legislation

██████████ [@health.govt.nz](mailto:██████████@health.govt.nz)

Manatū Hauora, 133 Molesworth Street Thorndon,
Wellington 6011



From: Chris Higgins ██████████ [@raredisorders.org.nz](mailto:██████████@raredisorders.org.nz)>

Sent: Wednesday, 5 July 2023 3:24 pm

To: [Principal Policy Analyst MoH ██████████ @health.govt.nz](mailto:██████████@health.govt.nz); [Policy Manager MoH ██████████ @health.govt.nz](mailto:██████████@health.govt.nz)>

Cc: Kim McGuinness ██████████ lewanna

██████████ [@raredisorders.org.nz](mailto:██████████@raredisorders.org.nz); ██████████ [@health.govt.nz](mailto:██████████@health.govt.nz)>

Subject: RE: Input to a rare disorders strategy for New Zealand

Hi [MoH Principal Policy Analyst and Policy Manager ██████████](mailto:██████████@health.govt.nz)

Thanks for the response below, the follow up discussion yesterday afternoon, and your understanding of the issues relating to consultation with the rare disorders support group leads. My recollection is that we agreed as follows:

You will provide us with us some more nuanced wording around the reasons and context for wishing to limit how the draft rare disorders strategy document while balancing that with the need for wide consultation, which we will use when we send the document to the approximately 300 support group leads.

When we send the document out we'll invite feedback on both its content as a whole and on specific components which will include access to diagnostic testing, medicines, specialist clinical services, and support services; we're also thinking about using the prompts being developed by Te Aka Whai Ora to assist with their engagement with Māori and whanau. We'll also ask if they'd prefer to receive a shortened summary version of the document, and if they wish to be engaged with in a different way (which could be similar to the approach being adopted by Te Aka Whai Ora)

We'll ask for feedback to be sent to RDNZ for collating into an overall RDNZ response, but we'll also let the support groups know that they also have the option of providing feedback directly to the generic strategy email

You explained your hesitancy around identifying the other members of the reference group. RDNZ is happy for our details to be made available to all reference group members, and we'd appreciate it if you could let them know that we're happy to be contacted should any of them choose to do so.

We'd be grateful if we could receive the key action points from the 13th June meeting

There's a number of bullet points in the fourth section of my email below, many of which have now been covered off, and I'm thinking that it might be helpful to schedule a follow up meeting between Manatū Hauora's strategy team and RDNZ to discuss the remainder and ensure that we continue to be on the same page

Thanks again

Ngā mihi

Chris

Chris Higgins

Chief Executive

Rare Disorders NZ

PO Box 14-313, Kilbrnie, Wellington, 6241, NZ

Mobile: + [REDACTED]

Office: +64 4 385 1119

Email: [REDACTED]@raredisorders.org.nz



Follow us on [Facebook](#), [LinkedIn](#) and [Twitter](#)

From: Principal Policy Analyst MoH [REDACTED]@health.govt.nz>

Sent: Monday, July 3, 2023 5:29 PM

To: Chris Higgins [REDACTED]@raredisorders.org.nz>

Cc: Kim McGuinness [REDACTED]@raredisorders.org.nz>; lewanna

[REDACTED]@raredisorders.org.nz>; Policy Manager MoH [REDACTED]@health.govt.nz>; [REDACTED]

[REDACTED]@health.govt.nz>

Subject: RE: Input to a rare disorders strategy for New Zealand

Thanks Chris, that is a lot. I will try to answer as briefly and quickly as possible, starting with your earlier points.

- Timeframe for comments - we don't have a firm deadline for feedback on the document sent out on Friday. We didn't want to put pressure on anyone, rather to welcome input when received. It will be some time before we have, for example, Māori input from the engagement that Te Aka Whai Ora is leading, with your people's involvement. We have planned to send out further iterations, say, monthly or thereabouts so people can see where things are heading. That still allows for their input over time. Though, of course, receiving it earlier does mean it can be considered earlier and that is helpful with progressing the work.
- Who it's been sent to – it has been sent to our reference group as per the earlier emails. This includes a range of clinical and other health sector experts and agency representatives, with RDNZ people being the only non-government recipients apart from some academics including Australian. The reference group includes a range of sector experts that RDNZ had nominated earlier – though this is not as extensive a list as you have attached today, I note that many of the people on that list are included, for example that may have been nominated by their employer or others.
- Seeking feedback from support group leads – our understanding has been that support group leads are in touch with what their membership are really needing to be addressed and able to pinpoint solution-focused feedback in a way that will be most useful for strategy development, and not place too much burden on members who already have significant stressors in their lives. Your highlighted passage from the support group leads newsletter is aligned with that understanding, and you sharing the reference group document with those support group leads is, as we understand it, following through on that.

I hope that at least addresses some of your questions and we can continue tomorrow (or it may perhaps be quicker to discuss).

Ngā mihi nui, [REDACTED]

[REDACTED]
Principal Policy Analyst
System Enablers
Strategy, Policy and Legislation | Te Pou Raukawa

[REDACTED]
Manatū Hauora, 133 Molesworth Street Thorndon,
Wellington 6011



From: Chris Higgins [REDACTED] <[\[REDACTED\]@raredisorders.org.nz](mailto:[REDACTED]@raredisorders.org.nz)>
Sent: Monday, 3 July 2023 4:43 pm
To: Principal Policy Analyst MoH [REDACTED] <[\[REDACTED\]@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>
Cc: Kim McGuinness [REDACTED] <[\[REDACTED\]@raredisorders.org.nz](mailto:[REDACTED]@raredisorders.org.nz)>; lewanna [REDACTED] <[\[REDACTED\]@raredisorders.org.nz](mailto:[REDACTED]@raredisorders.org.nz)>
Subject: RE: Input to a rare disorders strategy for New Zealand

Kia ora [REDACTED]

Firstly, thanks for the initial proposed content and points to consider and provide feedback on for the rare disorders strategy which we received last Friday. The RDNZ team will review the document and come back to you and your team with our comments. We'll do this as soon as we can, but would be grateful if you could let us know if you have any particular deadlines for responses. We'd also appreciate knowing whether the document has been sent to RDNZ only in the first instance for initial review, or whether it has been sent to others (and if so who?). If it has been sent to others we'd appreciate it if the circulation list could include specialist clinicians and others with rare disorders expertise including those on RDNZ's attached work-in-progress proposed list of experts. I also note that in the meeting on 19 April 2023, RDNZ representatives shared that to achieve maximum engagement it is important that it is communicated to the rare disorders community what will be happening with the information and feedback they provide and that a sense of progress is communicated to maintain engagement. We trust that this information will be included in the invitations for feedback and hui.

Secondly, I'd like to acknowledge the 27th June email from MoH Policy Analyst [REDACTED] (attached), which we're assuming extends to last Friday's strategy document. We are very happy to facilitate sharing opportunities for feedback with our support group leads and we appreciate that any documents shared are in confidence. However, many if not all of the support group leads will wish to communicate and consult with their specific member and whānau stakeholders and it won't be practical (nor desirable from our point of view) for RDNZ to require that further distribution does not extend beyond them. We'd very much appreciate it if the requirement in [REDACTED]'s email (and the rare disorders strategy one below) could be extended to support group leads and members/stakeholders, and if consideration be given to reaching out to those living with rare disorders which are not covered by a specific group. A framework for providing feedback could be a helpful enhancement, which could perhaps reflect the yellow highlighted bullet points below, which were included in Manatū Hauora's contributed content to RDNZ's May 2023 newsletter to support group leads:

"Manatū Hauora is working closely with RDNZ to ensure rare disorders voices are heard effectively and with minimal extra burden. We will be seeking your input progressively as elements of the strategy unfolds, and this input will be fed into the cross-agency group as the work is progressing. Early topics to hear about include:

- *Who are people with rare disorders, how do we describe and define who the strategy is for? Manatū Hauora is working on a paper to define a rare disorder and will be seeking feedback on this in the next month.*
- *Who are the different communities of people with rare disorders and how can we provide for different approaches, cultures, needs or ways of having a voice? This includes what are the*

perspectives and aspirations of Māori whānau and Pacific peoples with rare disorders.

- *What effective innovations are already working somewhere in New Zealand or with some rare disorders communities that could be learned from or built on?*
- *Are there people or whānau with rare disorders who have good experiences of the system, who can share what was good, why it worked well and how they benefitted?*
- *Are there people or whānau with rare disorders who found people or things that helped outside the system, who can share what worked for them and how they found it?*

RDNZ and Manatū Hauora will work together to collect this input in ways that are effective and respect people's time and energy. For example, surveying support group leads or having a paper or presentation developed in advance for people to react to. Some topics might need one round of input, others to be heard from in stages. We will keep support group leads informed of what's coming up. In the meantime, please feel free to indicate what topics on this list you are particularly keen to provide input for."

We'd also appreciate clarification as to who/which organisations will be represented on the strategy's reference group along with RDNZ, including rare disorders support groups representatives.

Thirdly thanks for your contribution to our support groups newsletter (which went out last Monday) which we included in full, and there was also a message from me which included the following:

"One of the first issues I've been focusing on is the development of the rare disorders strategy (there's an update from the Ministry later on in this newsletter), and I know that support groups are expecting the Rare Disorders NZ team to be working with Manatū Hauora to expedite progress. In the immediate short term we've been pushing especially for a rare disorders definition and we're pleased to see that the Ministry has advised that something is to be drafted by the end of the month."

There's been no particular feedback so far on either your content or mine.

Fourth, and after having time to digest the 13th June strategy meeting, I've got some further requests and things that I'm wondering about as follows:

- Can we please receive an updated electronic copy of the rare disorders strategy – work plan document which was shared at the meeting, with the understanding that it is provided in confidence and we will not share it outside of our organisation?
- Should we expect to see minutes with action points from the meeting, together with planned next steps?
- The work plan document suggests that engagement with RDNZ and the rare disorder community ends in July. However RDNZ has accepted the strategy group's invitation to be part of the reference group, with a time frame for involvement extending from July to November, so presumably the engagement section is to be further fleshed out?
- Will the reference group be an/the opportunity for RDNZ and the rare disorder community to provide input on the "policy components"?
- We'd be grateful if we could be advised as to who else has accepted the invitation to be included on the reference group.
- Will there be only one reference group, or will this be split into subgroups to look at the different policy components?
- Is there a more comprehensive document that details the policy components that we can review? From what we can see there are some gaps for example data and digital in relation to ensuring rare disorders are captured in clinical coding (ICD10/11/ orphaned codes), and coordinated and integrated pathways for clinical care.
- Who are the initial discussions regarding the policy components with? Will RDNZ be involved in these discussions via the reference group?
- Will there be an action or implementation plan developed to accompany the strategy, or a date for review set?

Finally we're pleased to confirm that our Māori support group, Te Whānau Kōtuku (represented by [REDACTED] and our Māori Engagement Officer [REDACTED] have been involved in the Te Aka Whai Ora led work around gathering Māori perspectives and aspirations.

I appreciate that there's quite a few questions [REDACTED], and perhaps I've missed some things which ought to have been obvious, but I'll nevertheless look forward to you reply.

Ngā mihi

Chris

Chris Higgins

Chief Executive

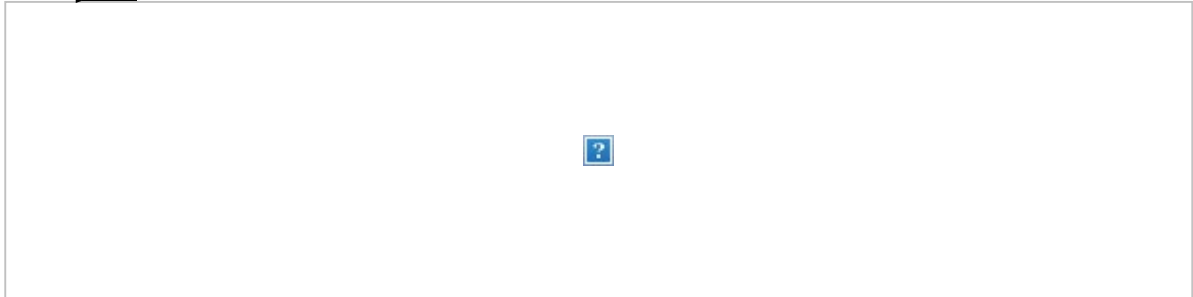
Rare Disorders NZ

PO Box 14-313, Kilbrnie, Wellington, 6241, NZ

Mobile: [REDACTED]

Office: +64 4 385 1119

Email: [REDACTED]@raredisorders.org.nz



Follow us on [Facebook](#), [LinkedIn](#) and [Twitter](#)

From: Rare Disorders Strategy <raredisordersstrategy@health.govt.nz>

Sent: Friday, June 30, 2023 3:42 PM

To: Rare Disorders Strategy <raredisordersstrategy@health.govt.nz>

Subject: Input to a rare disorders strategy for New Zealand

IN-CONFIDENCE – Not for wider circulation

Tēnā koe,

Thank you in anticipation for reviewing this first reference group document seeking your input to development of a rare disorders strategy. Your input is important to make sure the strategy is informed by a broad range of expertise from across the health and other sectors as well as from lived experience.

We welcome input but note that this document is for limited circulation only. Please let us know if there are others you would like to nominate to provide input.

Ngā mihi nui

raredisordersstrategy@health.govt.nz

Manatū Hauora, 133 Molesworth Street Thorndon, Wellington
6011