

From: [Chris Higgins](#)
To: [Manager - MoH Policy team working on strategy](#)
Cc: [Redacted]
Subject: RE: Rare Disorders Strategy
Date: Monday, 31 July 2023 11:32:08 am
Attachments: [image001.png](#)
[image002.png](#)
[image003.png](#)
[image004.png](#)
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[image006.png](#)
[image007.png](#)
[image008.png](#)
[image009.png](#)

Thanks [Redacted] – it was good to talk on Friday, and the time frames work well for us given that we'll be commencing our own outreach to the rare disorders community from September in respect of our 2023/24 survey.

Looking forward to talking more on Thursday

Ngā mihi

Chris

Chris Higgins

Chief Executive

Rare Disorders NZ

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Email: [Redacted]@raredisorders.org.nz



[Manager - MoH Policy team](#)

From: [working on strategy](#) [Redacted]@health.govt.nz>

Sent: Friday, July 28, 2023 2:00 PM

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

Cc: [Redacted]

[MoH and RDNZ staff](#)

Subject: RE: Rare Disorders Strategy

Hi again Chris,

Thanks for the chat this morning – it was really valuable.

As discussed, we are planning on undertaking further engagement with the rare disorders community in August. I apologise it is a bit later than originally thought

(ie the July school holidays), but we want the engagement to be meaningful to the participants as well as useful to the development of the Strategy so timing is key. Our plan is to host 2 or 3 online hui towards the end of August once we have received and consolidated the feedback on the framework document we sent out in late June. We would like to use the hui as a way of gathering further feedback on the documents and making sure we continue to go in the right direction.

Our team is having an initial planning session on Tuesday next week, and we'll bring a draft plan to discuss with you on Thursday. We welcome all input!

Of course alongside all this, Te Aka Whai Ora are planning their engagement to gather the voice of our Māori whānau impacted by rare disorders. Our team, and yours at RDNZ meet with Te Aka Whai Ora regularly so are well connected with this important mahi.

I look forward to meeting with your team next week to continue this kōrero.

Warm regards

[REDACTED]

[REDACTED] [REDACTED]
Acting Manager, System Enablers
Strategy, Policy and Legislation

[REDACTED] [@health.govt.nz](mailto:[REDACTED]@health.govt.nz)
Manatū Hauora, 122 Malesworth Street Thorndon,
Wellington 6011

[REDACTED]



[REDACTED]



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

Sent: Tuesday, 25 July 2023 1:42 pm

To: Mānāger MoH Policy Teām [REDACTED] [@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>

Cc: MoH and RDNZ staff [REDACTED]

Subject: RE: Rare Disorders Strategy

H [REDACTED]

This is really appreciated thank you, and we'd definitely like to take you up on your offer of fortnightly meetings while the strategy is being developed. If it works for you Monday mornings in person will work best for us, any time after 9.00 am. If not, Thursday mornings is our second preferred option, starting as close to 9.00 am as your team can manage.

I'll arrange for the invoice to be sent under cover of a separate email, and in the meantime I'll give Andrew Cāmeron - HealthiNZ the green light to get things underway asap, and I'll look forward to talking more about alternative engagement approaches following your discussions with Allison Bennett.

Warm regards

Chris

Chris Higgins

Chief Executive

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[REDACTED]



[REDACTED]

[REDACTED]

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From: Manager MoH Policy Team <[REDACTED]@health.govt.nz>

Sent: Tuesday, July 25, 2023 11:57 AM

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

Cc: RDNZ and MoH staff <[REDACTED]>

Subject: RE: Rare Disorders Strategy

Hi Chris,

Thanks for your emails.

Firstly, absolutely agree that we should re-establish the monthly meetings – it was even something that came up in our team’s catch-up this morning. I think there is even utility in having them more regularly while the strategy is being developed; would you be interested in having them fortnightly? In any case, let us know what days of the week are good for you and Emma will set them up starting next week.

Andrew Cameron HiNZ

Secondly, if you send us an invoice based on the quote from [REDACTED] provided to you (attached) then we will organise to get that paid so the work can commence.

Lastly, thank you for letting me know about our previous commitments in regards to engagement with the support leads. These emails were useful as I was not in the team at the time. I do know that we have been hearing a lot about ‘engagement fatigue’ from communities recently and we are really cognisant of not adding to people’s burden by asking more of them. In particular when we have such a wonderful resource to collect the voices of the communities, via the free-form data from your 2021 survey, we wanted to be thoughtful before interrupting people’s lives to ask similar questions again. I do however hear your message that the leads would appreciate the opportunity to engage in ways that are not over email. I have a meeting with my GM, Allison Bennett (who was also in the email chain with Michelle Arrowsmith) this afternoon so will discuss this with her and get back to you in the next couple of days.

Warm regards

[REDACTED]

[REDACTED]
Acting Manager, System Enablers
Strategy, Policy and Legislation

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[REDACTED]

[REDACTED]

[REDACTED]

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

Sent: Monday, 24 July 2023 1:15 pm

To: Manager MoH Policy Team <[REDACTED]@health.govt.nz>

Cc: Kim McGuinness <[REDACTED]@health.govt.nz>; lewanna

<[REDACTED]@health.govt.nz>

Subject: RE: Rare Disorders Strategy

Hi again [REDACTED]

My earlier email below has generated quite a bit of discussion among the RDNZ team and I need to

add the following:

Our understanding from prior RDNZ/Manatū Hauora meetings held in March and April this year is that Manatū Hauora indicated that its RDS team would work with RDNZ to engage people and whanau living with a rare disorder through a variety of accessible avenues, and wouldn't be relying solely on RDNZ's engagement with its support group leads through email. The forms of engagement discussed in March and committed to via email (copied and highlighted below) included face to face and online hui (at the time indicated to occur prior to the July School holidays), and then at the meeting in April discussion included the idea of engagement through Tātou, joint RDNZ and MoH interactive webinars as trialled for the Pae Ora strategies, and face to face or online hui. The likelihood of this style of engagement was communicated, in good faith, to our support group leads.

RDNZ is now receiving feedback from many support group leads that they are unhappy with the engagement to date and feel it is simply 'ticking a box'. Many of our support group leads have expressed frustration and concern about the style of engagement being limited to email which is not accessible to all of them due to disabilities, as well as feeling uninvolved in the work leading up to this point, and unsure about what further opportunities will be available.

We recognise that plans may have changed but we are concerned that the current engagement is putting RDNZ's credibility and reputation at risk and would appreciate the Ministry sharing with us the proposed schedule or plan for consultation and engagement with the rare disorders community, and what form this is to take, so we can reassure our community that the engagement is genuine and there will be opportunity for their valuable input to be heard in a variety of formats.

I need to emphasise therefore that my points below in my earlier email about regularly meeting with RDNZ, and meeting directly and face to face with members of the rare disorders community, will be essential components of the RDS development process if we're to have a document that has the buy in of, and will make significant differences for, the rare disorders community.

If Manatū Hauora declines or delays responding to these concerns we'll be telling any disaffected support group leads and representatives that the current engagement with the community is not what RDNZ advocated for and that it does not align with prior agreement we have had with the Ministry, and that RDNZ is not happy with how the Ministry is engaging with our community.

As always I welcome an opportunity to discuss and work through these issues constructively and collaboratively.

Ngā mihi

Chris

Chris Higgins

Chief Executive

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From: [REDACTED] Principal Policy Analyst MoH, [@health.govt.nz](mailto:[REDACTED]@health.govt.nz)>

Sent: Friday, 3 March 2023 3:09 pm

To: Michelle Arrowsmith <[\[REDACTED\]@raredisorders.org.nz](mailto:[REDACTED]@raredisorders.org.nz)>; Kim McGuinness

[redacted]@raredisorders.org.nz>

Cc: Maree Roberts [redacted]@health.govt.nz>; Alison Bennett

[redacted]t@health.govt.nz>; [redacted]@health.govt.nz>; [redacted]

[redacted]@health.govt.nz>

Subject: RE: Urgent dates for Rare Disorders Voice into Pae Ora Strategies, Precision Health LTIB and National Strategy for Rare Disorders

Thanks very much for that record Michelle.

We were also to provide Kim with some potential newsletter content highlighting opportunities open to everyone to input to the strategic direction for the health system (I've sent this earlier this afternoon). The lines highlighted the Tātou discussions that people can input to right now, and that they will be changing up in coming weeks/months.

Some notes on your points:

1. [redacted] will respond on this.
2. Confirming that are working to set up these two events, your suggested dates look feasible however we will need to confirm tech support before finalising dates and times. Confirming the tech support will take at least until Tuesday. Sorry if that is a holdup for you. I will let you know as soon as we have that confirmed. We will also be in contact to discuss some of the planning on Tuesday or Wednesday next week.
3. At the meeting we agreed we would explore the possibility of a Tātou discussion focused on rare disorders and/or high health needs and what would be possible timing-wise, noting that something starting or that could be announced during March (Rare Disorders Month) would be aimed for if possible. We've started the discussion internally but are waiting on key people's availability to get an idea of how/when this might be possible. We will keep in touch.
4. Yes, we are committed to some face to face and further online hui, that will be before the July school holidays – we could possibly start these in May, agree that we will work on these after the above points.

Thanks again, ngā mihi, [redacted]

[redacted] (she/her)

Principal Policy Analyst
System Enablers

[redacted] n | Te Pou Raukawa

[redacted]
Manatu Hauora, 133 Molesworth Street Thorndon,
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[redacted] ?

[redacted] ?

[redacted] ? ? ? ?

From: Michelle Arrowsmith [redacted]@raredisorders.org.nz>

Sent: Friday, 3 March 2023 2:12 pm

To: Principal Policy Analyst MoH [redacted]@health.govt.nz>; [redacted]@health.govt.nz>;

[redacted]@health.govt.nz>

Cc: Maree Roberts [redacted]@health.govt.nz>; Allison Bennett

[redacted]@health.govt.nz>; Kim McGuinness <[redacted]@raredisorders.org.nz>

Subject: Urgent dates for Rare Disorders Voice into Pae Ora Strategies, Precision Health LTIB and National Strategy for Rare Disorders

Importance: High

Kia Ora Principal Policy Analyst MoH [redacted]

Thanks for your time on Wednesday to discuss the Rare Disorders Community Voice into the Pae Ora Strategies, Precision Health LTIB and National Strategy for Rare Disorders.

We agreed the following;

1. For Precision Health a roundtable focused on Precision Health through the lens of Rare Disorders. – We agreed a 2 hour virtual meeting, led by MoH supported by RDNZ. We will provide the attendee names and details. We can also do invites etc, let's discuss practicalities Alex once the date is fixed. **We are suggesting either 23rd March or 27th March 2023.** Time to be agreed. We will include some lived experience experts around the table but in the main this will be relevant professional experts.
2. For the rare community voice for the Pae Ora Strategies – We agreed 2 virtual events for an hour each led by MoH supported by RDNZ, for the rare community to input their lived experience and views. We will do the advertising and support the community to attend once we have fixed a date. We would like to work with you to feedback on your suggested content and process for these sessions once you have the content defined. **We are suggesting 27th or 29th March for an evening session and then 3rd or 4th April for a lunchtime session.**
3. For the rare community voice for the Pae Ora Strategies using the Tatou Portal – we agreed that MoH team to produce some content/questions specifically focused around rare disorders. RDNZ then can provide feedback on this content. This will be **posted at an agreed date and time to the portal** so we can support our community to voice their experience and views via the portal.
4. **We agreed there will need to be further engagement and especially some face to face engagement for the national strategy for rare disorders. We agreed this will likely take place June/July time before election time and after the Pae Ora strategy work. We at RDNZ have some ability to support some hui's across the country and also have support we can engage to do some of this through using SenseMakers. We would like to discuss this further with you in due course after we execute the first 3 points above.**

We look forward to fixing these dates in the diaries asap and working with you to ensure and deliver the voice of the rare disorders community into these important strategies and insights briefings. We would be looking to put these dates out on Monday or Tuesday next week if you are able to let us know the agreed dates, thanks.

Ngā mihi

Michelle

Michelle Arrowsmith

Chief Executive

Rare Disorders NZ

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From: Chris Higgins

Sent: Monday, July 24, 2023 11:14 AM

To [REDACTED]@health.govt.nz > **Manager Policy Team MoH**

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

Subject: Rare Disorders Strategy

Kia ora [REDACTED]

Andrew Cameron emailed me last week as to whether there's been any movement on Manatū Hauora contracting with RDNZ re the Qualitative Survey Analysis – he's ready to go when we are. We've been receiving a number of submissions from support groups re the Rare Disorders Strategy document, and we're working on pulling all of them together into a combined submission from them

and us (including the RDNZ Board) which we'll have to you by 4th August. I'm told that the Manatū Hauora RDS team and RDNZ were meeting semi-regularly prior to my becoming CE, and I'm thinking that it might be timely to reinstate these as monthly meetings commencing in August as I imagine there'll be much work to do as the strategy takes shape between now and the end of the year. Also, given the level of engagement that we've been having with the support group leads, Manatū Hauora may wish to consider reaching out directly to people living with rare disorders, in a way that's similar to how Te Aka Whai Ora is reaching out to Māori and whanau with a rare disorder. This could be a useful way of complementing the current approaches of analysing the qualitative survey data, and considering the collective RDNZ view of the strategy document.

I hope all's well

Ngā mihi

Chris

Chris Higgins

Chief Executive

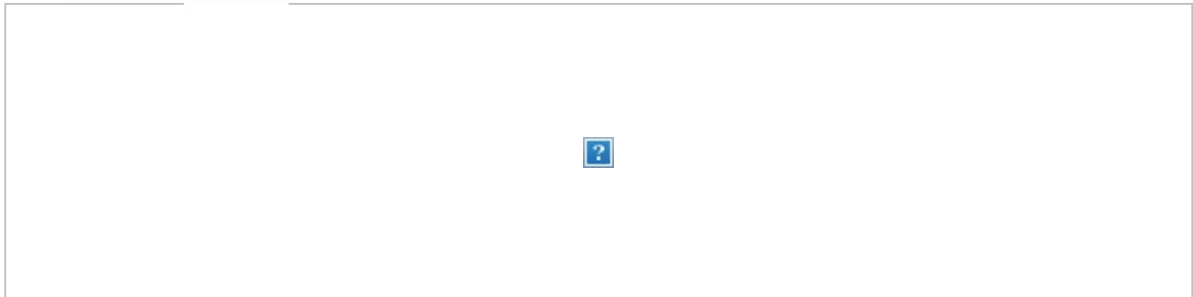
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