



Re: Putting Patients First: Modernising health workforce regulation consultation

To: workforceregulation@health.govt.nz

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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 the Ministry of Health's Putting Patients First: Modernising health workforce regulation consultation

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.

A rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 2,000 people in Aotearoa New Zealand. Rare disorders include, but are not limited to, rare conditions among genetic disorders, cancers, infectious disorders, poisonings, immune-related disorders, idiopathic disorders and various other rare undetermined conditions. An ultra-rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 50,000 people in Aotearoa New Zealand.



Our Submission

Rare Disorders NZ welcomes the opportunity to respond to the Ministry of Health's consultation on modernising health workforce regulation. We support the proposed purpose of this review: *"to ensure timely, quality access to healthcare for all New Zealanders."*

We agree with the assertion that *"in the near-term, we need to improve accessibility, timeliness, quality, and choice of health services to better meet people's immediate health needs."* However, regulation alone is not the key mechanism to achieve these outcomes. Regulatory reform must not be considered in isolation. Systemic issues such as long-term workforce planning, training capacity, and sustainable resourcing need addressing and there is little value in revising regulatory frameworks if they are not supported by sufficient investment in workforce development and retention.

Credentialling and Micro-Credentialling

Rare Disorders NZ supports the implementation of credentialling and micro-credentialling, particularly where these initiatives support care for people living with rare disorders. We have seen positive outcomes from specialist nurses in the community (often charity funded) and nurse specialists in rare disorder specific clinics where these have been appropriately resourced and integrated into care models. We see the potential to develop roles that can reduce wait times for essential services, such as genetic testing and genetic counselling, and to support multidisciplinary care teams managing complex or rare conditions. We also see room for roles that support care coordination and navigation of the health system for those living with rare disorders and other complex chronic conditions.

Future-Proofing Regulation

Rare Disorders NZ agrees that health workforce regulation should be future-proofed. International collaboration is needed when relevant expertise may not exist within New Zealand for specific rare disorders. Regulatory frameworks must not create unnecessary barriers to involving overseas experts in the care of patients, provided there is appropriate oversight to maintain New Zealand's safety and quality standards. We recommend the creation of a pathway to allow temporary registration or credentialling of international experts to contribute to the management of individual cases or provide short-term services either in New Zealand or remotely.

Cultural Safety as a Core Component of Clinical Safety

We strongly support the inclusion of cultural safety as an integral component of clinical safety. Cultural safety should not be seen as an optional or secondary consideration; it is essential to ensuring quality care for all patients. In our 2023 *Voice of Rare Disorders* survey, 19% of Māori living with a rare disorder reported that they experienced health services as culturally unsafe. Removing or weakening cultural safety requirements would risk further marginalising these communities and undermining trust in the health system. We therefore recommend that regulators be mandated to uphold and promote cultural safety as part of their core function.

Additional Considerations

We are concerned about the lack of discussion in the consultation document regarding the potential risks to patient safety posed by deregulation, particularly where there is an expansion of scopes of practice or the introduction of new health professions. These changes must be carefully assessed for their impact across the system – including on supervising clinician time, diagnostic accuracy, appropriate use of clinical tests and resources and the training pipeline for medical specialists.

The consultation would benefit from a comparison with international best practices. Lessons could be drawn from countries with similar healthcare systems to understand what approaches have been effective or problematic in regulating health workforces, as well as the positive and negative impacts of introducing new professions and increasing scope of existing professions on the wider health system.

Conclusion

Rare Disorders NZ supports the goals of ensuring a high-quality, responsive, and sustainable health workforce. We see a lot of potential here to build workforce capacity and capability in relation to rare disorders, as well as a more coordinated health system.

However, regulatory reform alone is not enough. It must be paired with sufficient investment in workforce development and retention. There also needs to be consideration of the evidence base for changes and the flow on effects of regulation changes on the wider health system and patient safety.