



Rare Disorders NZ submission on draft statement on disclosure of harm following an adverse event

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Submitted by: Rare Disorders NZ

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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 that is due to end June 2024. This submission is in response to the Medical Council of New Zealand's draft statement on Disclosure of harm following an adverse event closes on 22 September 2023.

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. All childhood cancers are rare. 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.

Response

Thank you for the opportunity to provide feedback on this draft statement.

Trust in the doctor-patient relationship is important for the rare disorder community who have high utilisation of healthcare services. Rare Disorders NZ supports the facilitation of honest communication, trust, accountability and transparency through open disclosure of adverse events.

We note the definition of harm is new to this iteration of the statement. We are concerned that the term harm is defined too narrowly and may not be seen to include delayed diagnosis or misdiagnosis.

The proposed definition of harm uses the words "situation where the patient has been injured..." but the term 'injured' is not defined in the statement. We would like to see this definition expanded



upon to clarify that injury means any harm to the body and includes mental injury, as defined in section 27 of the Accident Compensation Act 2001 as a clinically significant behavioural, cognitive or psychological dysfunction.

Why it is important that misdiagnosis and delayed diagnosis are recognised as causes of harm

The WHO lists diagnostic errors as a common source of patient harm noting that harmful diagnostic errors were found in a minimum of 0.7% of adult admissionsⁱ.

The results of Rare Disorder's NZ 2021 Voice of Rare Disorders surveyⁱⁱ found that 62% people with a rare disorder surveyed had been misdiagnosed at least once before their final diagnosis was confirmed while 10% were misdiagnosed at least twice. The results also showed that for over half of the people surveyed it took longer than one year to get a diagnosis, and for one in five the time taken to get a diagnosis was over 10 years.

It follows that some of the main adverse events that people with rare disorders experience when receiving medical care are misdiagnosis and delayed diagnosis. This can lead to people receiving inappropriate treatment and/or can delay treatment that otherwise would have prevented morbidity or mortality. This long 'diagnostic odyssey' in of itself can cause harm as it has a negative impact on mental health and wellbeing, with many being told it must all be in their head.

Rare Disorders NZ would like to ensure that delayed diagnosis and misdiagnosis are recognised as adverse events that can cause harm and require open disclosure. We believe this is vital to maintain trust in, and in some cases restore, the doctor-patient relationship. Open disclosure would also facilitate an environment where clinical teams can discuss misdiagnosis and delayed diagnosis and any adverse effect this had and disseminate learnings and improve processes to prevent similar situations occurring in the future.

ENDS

Rare Disorders NZ
14 September 2023

ⁱ Patient Safety, World Health Organisation, 11 September 2023, available here: www.who.int/news-room/fact-sheets/detail/patient-safety

ⁱⁱ Voice of Rare Disorders White Paper 2022, available here: www.raredisorders.org.nz/about-rare-disorders/rare-disorders-in-new-zealand/nz-voice-of-rare-disorders-white-paper-2022/