

What is life like living with a rare disorder in Aotearoa New Zealand in 2022?

Our biannual Voice of Rare Disorders surveys fill a vital data-gap in our health system to understand the **impact** living with a rare disorder has on different areas of life, as well as where the **needs** are and what **barriers** exist that prevent people from accessing the care they need for a decent quality of life.

Our most recent survey in November 2021 had **718 responses**, making it the largest-ever survey of patient-reported outcomes for people with rare disorders in New Zealand. Anyone living with a rare disorder in New Zealand was strongly encouraged to take part, as well their whānau and carers.

The results paint a picture similar to our 2019 survey, of isolation, lack of timely diagnosis, poor treatment access, lack of coordinated care, significant carer impact and for many, being lost in the system. More than ever, the results clarify the need for a comprehensive plan to deliver sustainable improvements in health outcomes for the rare disorder community.

Key findings from the 2021 survey:

- Over half took longer than one year to get a diagnosis, and for one in five, it took over 10 years.
- For 60-75% of people, their disorder makes a number of everyday activities difficult.
- High utilisation of healthcare services, with 81-87% having seen a specialist or GP in the 70 days prior to survey, and 58% feeling these services have been impacted by COVID-19.
- Many have been in hospital over the last 12 months. One in three were in hospital for an average of 13 days, and one in 17 were in ICU for an average of 7 days.
- There were few accessible, effective modern medicines available for the majority of people, with most being used to relieve pain and inflammation.
- Over 50% felt that communication and information exchange between different service providers was poor and that professionals are poorly prepared to support them.
- 70% had a decrease in income and limited employment options due to their disorder.
- 57% have experienced increased tension between family members, and 69% experienced isolation from family and friends, amplified by or caused by their rare disorder.
- One in three often felt unhappy and depressed and felt they could not overcome their problems.

There is an opportunity to create a roadmap to improve health outcomes for people living with a rare disorder, but for this to occur rare disorders need to be specifically acknowledged within the Pae Ora (Healthy Futures) Bill. Other recommendations include:

- **Widen engagement** with communities of people living with a rare disorder to provide a unified, collective voice, in particular with Māori, Pacific and ethnic minorities.
- Create a clear national strategy for specific collaboration amongst different stakeholders to **implement person-centred co-ordinated models of care** for better quality of life for people with rare disorders, including those that are yet to be diagnosed. Enabling Good Lives model could be utilised as a basis.
- **Promote alternative assessment pathways and funding** to provide fair access to modern, life changing medicines for people with rare disorders.
- Continue to advocate for development of a **Health Strategy for Rare Disorders with priority actions for improved health and wellbeing.**