

The Impact of Living with a Rare Disorder in New Zealand 2020

For New Zealanders living with a rare disorder today, the impact is significant, affecting not only themselves but extending to affect families and carers, the health system and society.

In the largest survey of its kind ever conducted in this country, the 2019 NZ Voice of Rare Disorders Survey provided an opportunity to understand the real impact of living with or caring for people with rare disorders. This survey not only improved our evidence-base in this area but also provides an impetus for demanding changes that deliver sustainable improvements in health outcomes.

Key findings from survey:

- For 60-75% of people and their families surveyed, their **rare disorder makes a number of everyday activities difficult**.
- The time burden is substantial for people living with a rare disorder and their carers; the **majority requiring over two hours per day for care and coordination**.
- High utilisation of healthcare services including specialist and GP visits, and diagnostic tests. **One in three people were in hospital for an average of 16 days per year. One in twenty people were in ICU for an average of eight days per year.**
- There were **almost no effective treatments accessible** for the majority of people other than for reducing inflammation.
- Most people living with a rare disorder and their carers consider that **professionals are poorly prepared to support them** and that there is a **clear lack of communication between service providers**.
- **Full employment and education are a challenge** for people living with a rare disorder and their carers: this may require modifying work arrangements through part-time contracting; or continuing absence from school for children.
- The disorder has **serious effects on social and family life, increasing tension** with family members and **triggering isolation** and feelings of being **neglected**.
- Mental health of people living with a rare disorder is worse in comparison with the general population with **one in three often unhappy and depressed** and **feeling they cannot overcome their problems**.

The results painted a picture of isolation, poor treatment access, lack of coordinated care, significant carer impact and for some, being lost in the system. It highlights the need for changes and several recommendations have been made:

- Develop an inclusive **consistent definition for rare disorder**. This is essential in order to enable policymakers to develop a national plan for rare disorders.
- Build a collective voice for people living with rare disorders through **wider community engagement**, in particular to include Māori, Pacific and ethnic minorities
- Greater collaboration amongst different stakeholders to **implement patient centric co-ordinated models of care** for better quality life for people with rare disorders.
- Ensure funding mechanisms for medicines for rare disorders use an economic evaluation method that not only considers direct medical costs and medicine costs but other societal costs.
- Develop a **NZ Rare Disorders Framework and Action Plan**.