



For the rare disease sector, *by* the rare disease sector.

Co-design and the person-centred approach

Including lived experience in the **co-design and continual improvement** of health care is vital to ensuring health care is **effective and appropriate** for the individual or community of its intended use. The National Safety and Quality Primary and Community Healthcare Standards (2021) mandate health services to **“work in partnership with patients, carers, families, and consumers to seek and incorporate their views and experiences into the planning, design, monitoring, and evaluation of services.”**¹

“ We are people, there is the sector and the dollars, there’s diagnosis and there’s research. There’s all these things, but it really often forgets, I think, the human experience.”

Person living with a rare disease



“ Stories of someone’s diagnostic journey and experience managing their condition could be beneficial to clinicians and other health professionals to identify symptoms, make a prompt diagnosis and optimise treatment.”

Person living with a rare disease



The importance of storytelling

Storytelling can foster a **better understanding of the experiences** of people living with a rare disease (PLWRD), including families and carers, and is integral to the inclusion of people living with a rare disease in **decisions that impact them**.

Health professionals can also offer their professional experiences of caring for PLWRD. This can **highlight the needs, systemic barriers, gaps and solutions** needed to enable better care and support for people living with a rare disease.

Each person’s **medical journey** is often very **personal** and sometimes **traumatic**. Stories may contain sensitive information, and therefore, must be handled **carefully and respectfully**.²

Storytelling can also offer **insights into cultural practices**, beliefs and nuances that can help inform culturally safe and appropriate ways to co-design and collaborate.

1. Australian Commission On Safety And Quality In Health Care. National Safety and Quality Primary and Community Healthcare Standards. Accessed <https://www.safetyandquality.gov.au/standards/primary-and-community-healthcare> on 11 October 2023.

2. Medics 4 Rare Disease. Rare Disease 101 - Australia: Respectful and Effective Communication. Accessed <https://learn.m4rd.org/> on 11 October 2023.

The information in this factsheet includes authentic quotes from people within the rare disease community. Their permission has been granted to include these quotes for public display.

