



Is your organisation ready to co-design

Strongly agree Agree Unsure Disagree Strongly disagree

Co-design is central to our organisation and is supported at all levels.

Our approach to co-design is iterative - priorities, focus and tasks can change or evolve.

We are aware of the unique challenges of living with a rare disease and value the expertise people living with a rare disease offer.

We do, or are open to, co-designing with everyone in the rare disease sector, understanding that solutions to complex issues require many people or groups.

We involve or plan to involve people living with a rare disease in the design, delivery and evaluation of policies, services, medications, or therapies that impact them.

When planning our co-design approach, we budget for remuneration, and consider the timing needed for storytelling.

When we plan to co-design with the rare disease community (including rare disease organisations), we are aware of, and sensitive to, the challenges of living with a rare disease and make adjustments accordingly.

When we co-design or plan with the rare disease community, we authentically and meaningfully consider those in the community from Aboriginal and Torres Strait Islander backgrounds, culturally and linguistically diverse communities, and other priority populations. We ensure relevant expertise is sought to help us engage.

We have appropriate mechanisms and/or a staff member to support people before, during or after sharing their story, and for those listening to stories.