

IMPROVE OUR MENTAL HEALTH!

Key findings from a Rare Barometer survey on
the mental health of people with rare diseases

June 2026



11 Sept.
14 Dec. 2025



125
participants
in Australia



66
rare diseases
represented

1 MOST PEOPLE LIVING WITH A RARE DISEASE AND THEIR FAMILY MEMBERS REPORT POOR MENTAL HEALTH



8/10

people living with rare
diseases and their families
report poor mental health

People experiencing poor mental health report at least one of the following difficulties

59%



report moderate to severe
depression symptoms

12 times higher
than the Australian
population (4.9%)¹

55%



feel lonely

4 times higher than
the Australian
population (15%)²

45%



report clinically significant
anxiety symptoms

12 times higher
than the Australian
population (3.8%)¹

39%



report suicidal thoughts
in the past 6 months

12 times higher than
the Australian
population (3.3%)¹

Levels of psychological distress are comparable to those observed in **exceptional contexts** such as the COVID-19 pandemic³, or among **highly vulnerable populations**, including people living with HIV in Uganda⁴, individuals treated in psychiatric hospital settings⁵ or those living with severe mental disorders⁶.

76% of participants reported at least one of the following mental health difficulties: **Depressive symptoms (PHQ-8)**: percentage of participants with a score of 10 or more to 'Over the last two weeks, how often have you been bothered with the following problems?' (i) interest/pleasure in doing things, (ii) feeling down, (iii) sleeping, (iv) energy level, (v) appetite, (vi) feeling bad about oneself, (vii) concentrating, (viii) moving or speaking. 0=not at all; 3=nearly everyday. All participants (n=125). Australian population PHQ-9 over 12 months¹. **Anxiety symptoms (GAD-2)**: percentage of participants with a score of 3 or more to 'Over the last two weeks, how often have you been bothered with the following problems? (i) Feeling nervous, anxious or on edge; (ii) Not being able to stop or control worrying'. 0=not at all; 3=nearly everyday. All participants (n=125). Australian population Generalised Anxiety Disorder over 12 months¹. **Loneliness (UCLA loneliness)**: percentage of participants with a score of 9 or more to 'Over the past six months, how often have you [felt] (i) that [you] lacked companionship, (ii) left out, (iii) isolated from others'. 1=never; 5=very often. All participants except non-responses (n=109). Australian population loneliness ≥ 5². **Suicidal thoughts**: percentage of participants who reported suicidal thoughts over the past six months. All participants except non-responses (n=109). Australian population serious thoughts about taking one's own life in the last 12 months¹. **Note**: sample was self-selected and representativeness cannot be assessed because the characteristics of the rare disease population are largely unknown.

2 PEOPLE WITH RARE DISEASES ENCOUNTER SEVERAL MENTAL HEALTH DIFFICULTIES



report at least 2 difficulties



report at least 3 difficulties



report all 4 difficulties

Percentage of participants reporting several mental health difficulties among depressive symptoms ($PHQ-8 \geq 10$), anxiety symptoms ($GAD-2 \geq 3$), loneliness ($UCLA \geq 9$) and suicidal thoughts in the past 6 months. All participants ($n=125$).

3 MOST OF THEM DO NOT RECEIVE PROFESSIONAL PSYCHOLOGICAL SUPPORT

While 78% report having needed professional psychological support in the past six months, only 54% received it from



32%

A general practitioner or a nurse



27%

A non-reimbursed mental health professional (psychologist, psychotherapist or psychiatrist paid by themselves or their family)



17%

A reimbursed mental health professional (psychologist, psychotherapist or psychiatrist partially or totally reimbursed)



10%

A Centre of Expertise (multidisciplinary care teams specialised in the rare or undiagnosed condition)

82% received community-based emotional support in the past six months, from



74%

Their family, friends, neighbours



24%

A charity or NGO (advocacy organisation, helpline...)

'Over the past six months, did you receive emotional or psychological support from...'. Support needed: percentage of participants who answered 'yes and enough to cover my needs', 'yes but not enough to cover my needs' or 'no but it was needed'. Support received: percentage of participants who answered 'yes'. All participants except non-responses ($n=108$). p -value <0.01 .

THANK YOU

to all the people with rare diseases and family members who participated in the survey, and to Rare Barometer partners!

More information: eurordis.org/voices or rare.barometer@eurordis.org; Full report in English: tiny.cc/RB-MH



If you have suicidal thoughts, you can contact someone anonymously by phone or chat in your country: blog.opencounseling.com/suicide-hotlines or befrienders.org

1. Australian Bureau of Statistics, 2021 Census: 4.9% depressive episodes over 12 months ($PHQ-9$); 3.8% Generalised Anxiety Disorders over six months; 3.3% had serious thoughts about taking their own life in the last 12 months. <https://www.abs.gov.au/methodologies/national-study-mental-health-and-wellbeing-methodology/2020-2022>; 2. 2024 HILDA survey: 15% loneliness ≥ 5 . <https://www.aihw.gov.au/mental-health/topic-areas/health-wellbeing/social-isolation-and-loneliness>; 3. Delpino et al. 2022: 35% anxiety symptoms - GAD and other scales. doi.org/10.1016/j.jad.2022.09.003; 4. Kaggwa et al. 2022: 8-67% depression symptoms - $PHQ-9 \geq 10$. doi.org/10.3389/fpsyg.2022.781095; 5. Plummer et al. 2022: 30-50% anxiety symptoms - GAD-2 and GAD-7. doi.org/10.1016/j.genhosppsych.2015.11.005; 6. Bai et al. 2021: 30% point prevalence of suicidal ideation. doi.org/10.1038/s41398-021-01671-6