

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



9897
participants
in Europe



1657
rare diseases
represented



45
European
countries

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



7/10

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

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

44%



report moderate to severe depression symptoms

7 times higher than in the EU population (6.1%)¹

45%



feel lonely

4-20 times higher than in the EU population (2-10%)³

42%



report clinically significant anxiety symptoms

7 times higher than in the EU population (5.4%)²

31%



report suicidal thoughts in the past 6 months

5-10 times higher than in the EU population (3-6%)⁴

Levels of psychological distress are comparable to those observed in **exceptional contexts** such as the COVID-19 pandemic⁵, or among **highly vulnerable populations**, including people living with HIV in Uganda⁶, individuals treated in psychiatric hospital settings⁷ or those living with severe mental disorders⁸.

68% 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=9897). EU population PHQ-8 ≥ 10¹. **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=9897). EU population: IHME estimation for WHO². **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=9277). EU population: systematic literature review³. **Suicidal thoughts**: percentage of participants who reported suicidal thoughts over the past six months. All participants except non-responses (n=8676). EU population: systematic literature reviews⁴. **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=9897).

3 MOST OF THEM DO NOT RECEIVE PROFESSIONAL PSYCHOLOGICAL SUPPORT

While 73% report having needed professional psychological support in the past six months, only 49% received it from



28%

A general practitioner or a nurse



19%

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



18%

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



16%

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

70% received community-based emotional support in the past six months, from



65%

Their family, friends, neighbours



25%

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=9265). 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. Eurostat EHS 2019: 6.1% depression symptoms - PHQ-8 \geq 10. [ec.europa.eu/eurostat/databrowser/product/page/hlth_ehis_mh2e\\$defaultview](https://ec.europa.eu/eurostat/databrowser/product/page/hlth_ehis_mh2e$defaultview); 2. IHME estimates in WHO 2018, 5.4% anxiety symptoms. doi.org/10.1787/health_glance_eur-2018-en; 3. Surkalim et al. 2022: 2-10% loneliness depending on country and age. doi.org/10.1136/bmj-2021-067068; 4. Castillejos et al. 2020, Liu et al. 2020: 3-6% 12-months prevalence of suicidal ideation. doi.org/10.1017/S003329171900391X, doi.org/10.1080/13811118.2020.1765928; 5. Delpino et al. 2022: 35% anxiety symptoms - GAD and other scales. doi.org/10.1016/j.jad.2022.09.003; 6. Kaggwa et al. 2022: 8-67% depression symptoms - PHQ-9 \geq 10. doi.org/10.3389/psyt.2022.781095; 7. Plummer et al. 2022: 30-50% anxiety symptoms - GAD-2 and GAD-7. doi.org/10.1016/j.genhosppsych.2015.11.005; 8. Bai et al. 2021: 30% point prevalence of suicidal ideation. doi.org/10.1038/s41398-021-01671-6