

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



87 participants for ERN EuroBloodNet



27 rare hematological diseases represented



25 European countries

1 MOST PEOPLE WITH RARE HEMATOLOGICAL DISEASES REPORT POOR MENTAL HEALTH



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

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

37%



report moderate to severe depression symptoms

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

38%



feel lonely

4-19 times higher than in the EU population (2-10%)³

33%



report clinically significant anxiety symptoms

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

26%



report suicidal thoughts in the past 6 months

4-9 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.

59% 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=87). 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=87). 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=84). 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=80). 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

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=87).

3 MOST OF THEM DO NOT RECEIVE PROFESSIONAL PSYCHOLOGICAL SUPPORT

While 74% report having needed professional psychological support in the past six months, only 45% received it from



31% A general practitioner or a nurse



18% A reimbursed mental health professional (psychologist, psychotherapist or psychiatrist partially or totally reimbursed)



16% A non-reimbursed mental health professional (psychologist, psychotherapist or psychiatrist paid by themselves or their family)



15% A Centre of Expertise (multidisciplinary care teams specialised in the rare or undiagnosed condition)

67% received community-based emotional support in the past six months, from



61%

Their family, friends, neighbours



28%

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=85).

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/fpsyg.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.