

IMPROVE OUR MENTAL HEALTH!

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

June 2026



1 MOST PEOPLE WITH RARE NEUROMUSCULAR DISEASES REPORT POOR MENTAL HEALTH



7/10

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

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

46% 

report moderate to severe
depression symptoms

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

42% 

feel lonely

4-22 times higher
than in the EU
population (2-10%)³

39% 

report clinically significant
anxiety symptoms

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

26% 

report suicidal thoughts
in the past 6 months

4-8 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=604). 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=604). 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=574). 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=547). 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 NEUROMUSCULAR 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 ≥ 10), anxiety symptoms (GAD-2 ≥ 3), loneliness (UCLA ≥ 9) and suicidal thoughts in the past 6 months. All participants (n=604).

3 MOST OF THEM DO NOT RECEIVE PROFESSIONAL PSYCHOLOGICAL SUPPORT

While 68% report having needed professional psychological support in the past six months, only 44% received it from



24%

A general practitioner or a nurse



18%

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



17%

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



14%

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

72% received community-based emotional support in the past six months, from



69%

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=577). p-values <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 EHIS 2019: 6.1% depression symptoms - PHQ-8 ≥ 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 ≥ 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