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

267 participants in Europe

7 rare diseases represented

24 European countries

1 MOST PEOPLE LIVING WITH NEUROFIBROMATOSIS AND THEIR FAMILY MEMBERS REPORT POOR MENTAL HEALTH

7/10 people living with neurofibromatosis and their families report poor mental health

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

40% report moderate to severe **depression symptoms**

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

51% feel **lonely**

5-26 times higher than in the EU population (2-10%)[3]

45% report clinically significant **anxiety symptoms**

8 times higher than in the EU population (5.4%)[2]

34% report **suicidal thoughts** in the past 6 months

6-11 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 pandemic[5], or among **highly vulnerable populations**, including people living with HIV in Uganda[6], individuals treated in psychiatric hospital settings[7] or those living with severe mental disorders[8].

***70%** 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=267). **EU population** PHQ-8 ≥ 10[1]. **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=267). **EU population**: IHME estimation for WHO[2]. **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=241). **EU population**: systematic literature review[3]. **Suicidal thoughts**: percentage of participants who reported suicidal thoughts over the past six months. All participants except non-responses (n=228). **EU population**: systematic literature reviews[4]. **Note**: sample was self-selected and representativeness cannot be assessed because the characteristics of the rare disease population are largely unknown.*

2 PEOPLE WITH NEUROFIBROMATOSIS ENCOUNTER SEVERAL MENTAL HEALTH DIFFICULTIES

48% report at least **2 difficulties**

29% report at least **3 difficulties**

13% 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=267).

3 MOST OF THEM DO NOT RECEIVE PROFESSIONAL PSYCHOLOGICAL SUPPORT

While 73% report having needed professional psychological support in the past six months, only 53% received it from

28% **A general practitioner or a nurse**

23% **A Centre of Expertise** (multidisciplinary care teams specialised in the rare or undiagnosed condition)

22% **A non-reimbursed mental health professional** (psychologist, psychotherapist or psychiatrist paid by themselves or their family)

19% **A reimbursed mental health professional** (psychologist, psychotherapist or psychiatrist partially or totally reimbursed)

68% received community-based emotional support in the past six months, from

64% **Their family, friends, neighbours**

20% **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=240). 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 EHIS 2019: 6.1% depression symptoms - PHQ-8 ≥ 10. 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/fpsyt.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.

Rare Barometer
A EURORDIS INITIATIVE

Rare Barometer is a not-for-profit survey initiative run independently by EURORDIS-Rare Diseases Europe. It conducts regular studies to identify the perspectives and needs of the rare disease community and be their voice within European and international initiatives and policy developments. Rare Barometer brings together a panel of more than 25,000 people living with a rare disease or family members to make the voice of the rare disease community stronger.