EURORDIS
RARE DISEASES EUROPE

Rare Barometer

RECOGNISING DISABILITIES AND BARRIERS!

Key findings from a Rare Barometer survey on the impact of living with a rare genetic tumour risk syndrome

February 2025

10 July
8 Sept. 2024

133
respondents
in Europe

9 rare genetic tumour risk syndromes represented

22
countries

1 MOST PEOPLE WITH RARE GENETIC TUMOUR RISK SYNDROMES LIVE WITH DISABILITIES

8/10 people with rare genetic tumour risk syndromes live with disabilities

Q *Washington Group Short Set on Functioning (WG-SS): 83% of the participants had 'some difficulties', 'a lot of difficulties' or 'could not at all' see, hear, walk, remember/concentrate, selfcare (dressing or washing over) or communicate; Global Activity Limitation Index (GALI): 63% of the participants were limited or severely limited in performing activities that people usually do because of a health problem during the last 6 or more months; self-identification: 72% of the participants considered themselves as a person with a visible disability, an invisible disability or both. All participants (n=133).*

2 A MAJORITY LIVE WITH DIVERSE AND COMPLEX DISABILITIES

66% had difficulties with at least 2 activities :

- Seeing
- Hearing
- Walking or climbing stairs
- Remembering or concentrating
- Selfcare
- Communication

Q *Percentage of people with rare diseases who had 'some difficulties', 'a lot of difficulties' or 'could not do at all' in at least 2 domains of the WGSS - All participants (n=133); The six domains of the Washington Group Short Set on Functioning (WGSS).*

3 PEOPLE WITH RARE GENETIC TUMOUR RISK SYNDROMES DO NOT RECEIVE ADEQUATE SUPPORT...

36% **found it difficult or very difficult to obtain publicly funded support** such as attendant care support, home support, financial support, assistive technology, mobility aids or other support.

Q *'How difficult do you find it to obtain State support such as attendant care support, home support, financial support, assistive technology, mobility aids, etc.?'– All participants (n=133).*

4 ...AND THEY DO NOT TAKE PART IN SOCIETY ON AN EQUAL BASIS WITH OTHERS

Most people with rare genetic tumour risk syndromes experienced discrimination:

51% **experienced discimination related to the rare disease or disability** in healthcare, in employment, in education, in housing, in public accomodations or in other places.

Q *Percentage of participants who answered 'In healthcare', 'In education', 'In employment', 'In housing', 'In other public accomodations (hotel, restaurants, transport, museums, etc.)' or 'other' to 'Have you ever experienced discrimination related to the rare disease or disability?' - All participants (n=133).*

Unemployment of people with rare genetic tumour risk syndromes is higher than in the general population:

17% of people with rare genetic tumour risk syndromes are **unemployed**

Comparison: the unemployment rate in the general population of the European Union was **6.1%** in 2023[1].

Q *Percentage of participants aged 16-64 who answered 'Unemployed' or 'Cannot work because of a disease' to 'What is your current situation?' (n=84).*

More information: eurordis.org/voices or rare.barometer@eurordis.org
Full report in English: tiny.cc/survey/RB_DailyLife

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

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[1] Unemployment rates by sex, age and citizenship, Eurostat (https://ec.europa.eu/eurostat/databrowser/view/lfsa_urgan__custom_15225487/default/table?lang=en), consulted February 3rd 2025.

Rare Barometer
A EURORDIS INITIATIVE

Rare Barometer is the survey programme run independently by EURORDIS-Rare Diseases Europe and is a not-for-profit initiative. It conducts regular studies to identify the perspectives and needs of the rare disease community in order to be their voice within European and International initiatives and policy developments. Rare Barometer brings together more than 20,000 people living with a rare disease or family members to make the voice of the rare disease community stronger. For more information please visit eurordis.org/voices