# SOCIAL PARTICIPATION AND INDEPENDENT LIVING OF PEOPLE LIVING WITH A RARE DISEASE

## Questionnaire for a Rare Barometer survey

**July 2024**

The survey “Social participation and independent living of people living with a rare disease” will be conducted by EURORDIS-Rare Diseases Europe via its Rare Barometer programme.

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 1,000 rare disease patient organisations from more than 70 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families, and patient groups, bringing together stakeholders and mobilising the rare disease community, EURORDIS-Rare Diseases Europe strengthens the patient voice and shapes research, policies and patient services. eurordis.org

Rare Barometer is a survey initiative that robustly collects the experiences and opinions of people living with a rare disease and their close family members on topics that directly affect them. This programme is run independently by EURORDIS-Rare Diseases Europe and is a not-for-profit initiative. It conducts 1 to 3 studies annually and hosts a survey panel of more than 20,000 people who agreed to receive email invitations to participate in surveys and studies conducted by EURORDIS-Rare Diseases Europe. eurordis.org/voices
Rare Barometer is supported by the European Union, the AFM-Téléthon and the health industry: full list of partners accessible at tiny.cc/RBpartners

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# SURVEY PRESENTATION

## 1. OBJECTIVES OF THE SURVEY

The Rare Barometer survey on social participation and independent living of people living with a rare disease will allow to:

- Estimate the level of **participation in social activities** such as education, work or leisure.
- Identify **barriers or facilitators** in doing those social activities.
- Understand **preferences and needs** regarding **living arrangements and personal assistance**.
- Collect **experiences with disability assessment**.
- Identify the main difficulties in accessing **social and disability rights**.

## 2. HOW THE RESULTS WILL BE USED

**To advocate for all people living with rare diseases and disabilities to access:**

- adequate disability assessment and recognition
- adequate social protection and independent living

**To raise awareness of:**

- the diverse disabilities and barriers experienced by the rare disease community
- the social inequalities faced by people with rare diseases

## 3. SURVEY DESIGN

The questionnaire was written in English by the authors of this document based on a literature review identifying the main issues and topics of the survey (Faye 2024, to be published) and on the consultation of:

- 14 members of a Topic Expert Committee who contributed to clarifying topics to include in the questionnaire and on its final version.
- National alliances and European federations of EURORDIS-Rare Diseases Europe, representing a wide range of rare diseases in one country, on topics and criteria to be included in the questionnaire, and on its final version: https://www.eurordis.org/who-we-are/our-members/

The survey is available in the following 25 languages: Bulgarian, Croatian, Czech, Danish, Dutch, English, Estonian, Finnish, French, German, Greek, Hungarian, Latvian, Lithuanian, Norwegian, Polish, Portuguese, Romanian, Russian, Slovak, Slovenian, Spanish, Swedish, Turkish and Ukrainian.

It has been translated by professional translators specialised in health-related issues, and native speakers specialised in rare diseases or in social policies reviewed translations in 18 languages to check their cultural validity and consistency with the original English version.
To access the questionnaire in other languages, please contact the Rare Barometer team: rare.barometer@eurordis.org
Questions from the Rare Barometer framework are also available in 23 languages in the Rare Barometer question repository, available at this link: eurordis.org/publications/speak-up-listen-up-follow-up-guide-a-brief-guide-for-rare-disease-patient-organisations-on-how-to-listen-to-the-community/

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## 4. DISTRIBUTION

The survey is distributed online from 10 July to 8 September 2024. Respondents are contacted through the Rare Barometer panel and through social media, patient organisations, and EURORDIS' networks.

People living with a rare disease and their close family members can answer from any country in the world through the link: tiny.cc/RB_DailyLife

A communication toolkit is available in 25 languages at this link: eurordis.org/publications/rb-dailylife-toolkit/

More information, including link to the recording of the webinar for the survey launch: tiny.cc/RB_DailyLife_Info

Patient organisations that are members of EURORDIS-Rare Diseases Europe, as well as European Reference Networks, can contact the Rare Barometer team to access tailored online dashboards to follow the survey dissemination in their community: rare.barometer@eurordis.org

## 5. DATA PROTECTION

Rare Barometer complies with the General Data Protection Regulation (GDPR). Complete privacy notice available here: download2.eurordis.org/rarebarometer/Overview/Eng.pdf

## 6. RESULTS

The Rare Barometer team will ensure data management and curation, and will analyse the European results. European results will be available on the Rare Barometer website: eurordis.org/voices

Patient organisations that are members of EURORDIS-Rare Diseases Europe, as well as European Reference Networks, can contact the Rare Barometer team to receive their results: rare.barometer@eurordis.org

# QUESTIONNAIRE

**Text in orange won't be displayed in the questionnaire but featured in the software system.**

**Text in blue comes from other surveys and could be used for comparison.**

**Text in purple is part of the Rare Barometer framework.**

## Presentation page of the survey

*Do you have a rare disease or a rare cancer?*

*Do you have a family member living with a rare disease?*

*How are you or your family member participating in social activities, such as school, leisure and work? What does living independently mean to you? What would you need to participate in society to your full potential?*

*This survey will take around 20 minutes to complete. It will help EURORDIS-Rare Diseases Europe, a non-profit alliance of 1000+ patient organisations, to work towards and advocate for advocate for people with rare diseases to access their rights and participate in society on an equal basis with others.*

*You will receive the global survey results, which we will share with decision-makers. Your answers will be kept in secure storage, which only the research team can access.*

*If you have any questions, you can contact the Rare Barometer team at rare.barometer@eurordis.org*

*By clicking "Next", you agree to our privacy notice*

When answering this questionnaire, please share the experience and opinion of ONE INDIVIDUAL - either yourself or your family member. If you want to share the experience and opinion of someone else in your family, you can take the survey again by following the link that will appear after clicking on the "save" button.

**Q1. Are you answering the questionnaire as a...**

1. Person living with a rare disease yourself
2. Former or recovering patient (e.g. cancer survivor)
3. Parent of a person living with a rare disease
4. Grandparent of a person living with a rare disease
5. Spouse of a person living with a rare disease
6. Uncle/aunt of a person living with a rare disease
7. Sibling of a person living with a rare disease
8. Other, please specify

**Q2. Are you also a patient representative, i.e., involved in voluntary and/or policy activities to support the cause of rare diseases?**

1. Yes
2. No
3. I am not sure

# DIAGNOSIS

**Q3. Please select your current situation:**

a. I know the NAME of the disease, syndrome or malformation, and it has been CONFIRMED by appropriate genetic, clinical, medical imaging, molecular or biochemical tests (for example, biopsy, blood or urine test) (confirmed diagnosis)
b. I know the NAME of the rare disease, syndrome or malformation but it has NOT yet been confirmed by appropriate genetic, clinical, medical imaging, molecular or biochemical tests (initial diagnosis)
c. I only have PARTIAL information on the name of the rare disease, the gene involved, or the type of disease (partial diagnosis)
d. I know the disease is rare, but the name or the cause has NOT BEEN IDENTIFIED (unsolved case)
e. Other, please specify

**Q4a,b & c (name of the rare diseases) are at the end of the section on independent living…**

**Q5a. As far as you remember,** how long has it been since you first knew the NAME of the rare disease, syndrome or malformation? **(if Q3b and Q3c)**

1. Less than 6 months
2. 6 to 23 months
3. 2 to 4 years
4. 5 years or more

**Q5b.** …how long has it been since the name of the rare disease, syndrome or malformation was CONFIRMED by appropriate genetic, clinical, medical imaging, molecular or biochemical tests (e.g. biopsy, blood or urine test)? **(only if Q3a)**

1. Less than 6 months
2. 6 to 23 months
3. 2 to 4 years
4. 5 years or more

# DAILY DIFFICULTIES

*The next questions are about difficulties you may experience doing certain daily activities.*
*The next questions are about difficulties your family member living with a rare disease may experience doing certain daily activities.* ***(For family members)***

**Q6a to Q6f are based on the short set questions on functioning from the Washington Group questionnaire, available at https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/**

**Q6a. Do you have difficulty SEEING, even if wearing glasses? Would you say…**
***(If family members)*** **Do they have difficulty SEEING, even if wearing glasses? Would you say…**

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

**Is the difficulty…** **(if Q6a is 2,3 or 4)**
*Please select all that apply.*
**1.** Permanent
2. Transient (occurs during acute episodes, periodic crises or relapses) **(if Q6a is 1, 2, or 3)**
3. Worsening
4. Improving

**Q6b. Do you have difficulty HEARING, even if using a hearing aid(s)? Would you say…**
***(If family members)*** **Do they have difficulty HEARING, even if using a hearing aid(s)? Would you say…**
1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

**Is the difficulty…** **(if Q6b is 2,3 or 4)**
*Please select all that apply.*
**1.** Permanent
2. Transient (occurs during acute episodes, periodic crises or relapses) **(if Q6b is 2, or 3)**
3. Worsening
4. Improving

**Q6c. Do you have difficulty WALKING or CLIMBING STEPS? Would you say…**
***(If family members)*** **Do they have difficulty WALKING or CLIMBING STEPS? Would you say…**
1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

**Is the difficulty…(if Q6c is 2,3 or 4)**
*Please select all that apply.*
**1.** Permanent
2. Transient (occurs during acute episodes, periodic crises or relapses) **(if Q6c is 2, or 3)**
3. Worsening
4. Improving

**Q6d. Do you have difficulty REMEMBERING or CONCENTRATING? Would you say…**
***(If family members)*** **Do they have difficulty REMEMBERING or CONCENTRATING? Would you say…**
1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

**Is the difficulty…** **(if Q6d is 2,3 or 4)**
*Please select all that apply.*
**1.** Permanent
2. Transient (occurs during acute episodes, periodic crises or relapses) **(if Q6d is 2, or 3)**
3. Worsening
4. Improving

**Q6e. Do you have difficulty with SELF-CARE, such as washing all over or dressing? Would you say…**
***(If family members)*** **Do they have difficulty with SELF-CARE, such as washing all over or dressing? Would you say…**
1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

**Is the difficulty… (if Q6e is 2,3 or 4)**
*Please select all that apply.*
1. Permanent
2. Transient (occurs during acute episodes, periodic crises or relapses) **(if Q6e is 2, or 3)**
3. Worsening
4. Improving

**Q6f. Using your usual language, do you have difficulty COMMUNICATING, for example, understanding or being understood? Would you say…**
***(If family members)*** **Using your usual language, Do they have difficulty COMMUNICATING, for example, understanding or being understood? Would you say…**
1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

**Is the difficulty… (if Q6f is 2,3 or 4)**
*Please select all that apply.*
1. Permanent
2. Transient (occurs during acute episodes, periodic crises or relapses) **(if Q6f is 2, or 3)**
3. Worsening
4. Improving

***The following questions are about the frequency of physical difficulties you may experience.***
***The following questions are about the frequency of physical difficulties your family member living with a rare disease may experience.***

**Q7a and Q7b are from the extended version of Washington Group questionnaire to better capture difficulties encountered by people with invisible disabilities: https://www.washingtongroup-disability.com/question-sets/wg-extended-set-on-functioning-wg-es/**

**Q7a. In the past three months, how often did you have PAIN? Would you say…**
***(If family members)*** **In the past three months, how often did they have PAIN? Would you say…**
1. Never
2. Some days
3. Most days
4. Every day
5. I don't want to answer
6. Don't know *(only for family members)*

**Q7b. In the past three months, how often have you felt VERY TIRED OR EXHAUSTED? Would you say… *(If family members)* In the past three months, how often have they felt VERY TIRED OR EXHAUSTED? Would you say…**

1. Never
2. Some days
3. Most days
4. Every day
5. I don't want to answer
6. Don't know ***(only for family members)***

**Q8 is from the GALI questionnaire:** https://ec.europa.eu/eurostat/documents/17847228/17905408/GALI-implementing-guidelines.pdf/1f5edb44-7444-a3b2-e6cf-1abba2492ca4?t=1700132867646

**Q8. During the last 6 or more months, have you been limited in performing activities that people usually do because of a health problem? Would you say…**
***(If family members)* During the last 6 or more months, have they been limited in performing activities that people usually do because of a health problem? Would you say…**

1. Severely limited
2. Limited but not severely
3. Not limited at all
4. Don't know ***(only for family members)***

**Q9. Do you consider yourself as a person with…**
***(If family members)* Do they consider themselves as a person with…*(for family members)***

1. a visible disability
2. an invisible disability
3. both visible and invisible disabilities
4. no disability
5. Don't know ***(only for family members)***

**Q10.How difficult do you find to obtain support such as attendant care support, home support, financial support, assistive technology, mobility aids, etc.?**
**How difficult do they find it to obtain support such as attendant care support, home support, financial support, assistive technology, mobility aids, etc.? *(for family members)***

1. Very difficult
2. Difficult
3. Neutral
4. Easy
5. Very easy
6. Not applicable
7. Don't know ***(only for family members)***

**Q11.What barriers are you facing in obtaining support, such as attendant care support, home support, financial support, assistive technology, mobility aids, etc.? (If Q10 is not 6; randomised response items)**
***(If family member)* What barriers are they facing in obtaining support, such as attendant care support, home support, financial support, assistive technology, mobility aids, etc.? (If Q10 is not 6, randomised response items)**
***Please select all that apply***

1. The eligibility criteria (age, residency, nationality, history of contribution, income) were unmet.
2. The disability was not considered severe enough.
3. The rare disease was not on the list of diseases eligible for benefits.
4. Difficulty in providing the medical evidence requested (medical records, diagnosis)
5. The support or services needed are unavailable in the country/region

6. The support or services exist in the country, but there is a lack of personal/ human resources
7. Lack of information about the process
8. The process is complex and lengthy
9. A fear of discrimination
10. It is possible to access the support by my own means
11. Undiagnosed or SWAN and therefore not eligible for benefits
12. Not facing any barriers
13. Other

# PARTICIPATION IN SOCIAL ACTIVITIES

*The following questions are about involvement in various activities, such as at school/university, work, and cultural or sports events. It also concerns interactions with others, including family members, friends, coworkers, neighbours…*

**Q12. What is your current situation?**
***(If family members)*** **What is their current situation?**
***Please select only the activity that takes up most of the time***

1. Employed (or partially employed)
2. Unemployed
3. Retired
4. Student/pupil
5. Homemaker (e.g. stay-at-home mum or dad)
6. Self-employed
7. Other

- SCHOOL PARTICIPATION

**Q13. Do you attend… (if Q12 is 4)**
***(If family members)*** **Do they attend…?**

1. Mainstream school without accommodations or adaptations
2. Mainstream schools with accommodations or adaptations
3. Specialised school for children with disabilities
4. Homeschooling
5. A combination of mainstream school, specialised school, and homeschooling
6. University
7. Not of school age yet
8. Other, specify

**Q14a to Q15c are extracted from the Children and Adolescent Scale of Participation (CASP) questionnaire, designed for 5-24 years old:**

- **Youth revised version: https://sites.tufts.edu/garybedell/files/2012/07/CASP-Youth-Version-Revised-12-29-11.pdf ;**
- **Original version (directed to family members): https://sites.tufts.edu/garybedell/files/2012/07/CASP-Administration-Scoring-Guidelines-8-19-11.pdf**

**Q14. Compared to other people the same age, what is your current level of participation in the following activities: (If Q13 is 1, 2, 3, 5, 6,7)**
***(If family members)*** **Compared to other people the same age, what is their current level of participation in the following activities? (If Q13 is 1, 2, 3, 5, 6,7)**

> **Q14a. Using educational materials and equipment that are available to other students in the classroom/s or that have been modified for you (e.g., books, computers, chairs and desks)?**
> 1. Full participation
> 2. Somewhat limited

3. Very limited
4. Unable
5. Not applicable
6.Don't know *(only for family members)*

**Q14b. Communicating with other students and adults at school/university?**
1.Full participation
2.Somewhat limited
3.Very limited
4.Unable
5.Not applicable
6.Don't know *(only for family members)*

**Q14c. Educational (academic) activities with other students in the classroom?**
1. Full participation
2. Somewhat limited
3. Very limited
4. Unable
5. Not applicable
6.Don't know *(only for family members)*

**Q14d. Social, play and recreational activities with other students at school (e.g., "hanging out", sports, clubs, hobbies, creative arts, lunchtime or recess activities)**
1. Full participation
2. Somewhat limited
3. Very limited
4. Unable
5. Not applicable
6.Don't know *(only for family members)*

**Q14e. Moving around at school/university (e.g., to get to and use the bathroom, playground, cafeteria, library or other rooms and things that are available to other students of the same age)?**
1. Full participation/ Age expected (for carers)
2. Somewhat limited
3. Very limited
4. Unable
5. Not applicable
6.Don't know *(only for family members)*

## LEISURE AND SOCIAL LIFE

**Q15. Compared to other people the same age, what is your current level of participation in the following activities:**
***(If family members)*** **Compared to other people the same age, what is their current level of participation in the following activities:**

**Q15a. Social, play, or leisure activities with friends in the neighbourhood and community (e.g., casual games, "hanging out," going to public places like a movie theatre, park or restaurant)**
1. Full participation
2. Somewhat limited
3. Very limited
4. Unable
5. Not applicable
6.Don't know *(only for family members)*

**Q15b. Structured events and activities in the neighbourhood and community (e.g., team sports, clubs, holiday or religious events, concerts, parades and fairs)**
1. Full participation
2. Somewhat limited
3. Very limited
4. Unable
5. Not applicable
6. Don't know ***(only for family members)***

**Q15c. Moving around the neighbourhood and community (e.g., public buildings, parks, restaurants, movies)**
1. Full participation
2. Somewhat limited
3. Very limited
4. Unable
5. Not applicable
6. Don't know ***(only for family members)***

**Q15d. Communicating with others in the neighbourhood and community**
1. Full participation
2. Somewhat limited
3. Very limited
4. Unable
5. Not applicable
6. Don't know ***(only for family members)***

## WORK LIFE

**Q16. What type of work contract do you have?** ***(if Q12 is 1)***
*(If family members)* **What type of work contract does your family member with a rare disease have?** ***(if Q12 is 1)***

1. Full-time contract, fixed-term
2. Full-time contract, permanent
3. Part-time contract, fixed-term
4. Part-time contract, permanent
5. Other, specify

**Q17. Do you work?** ***(if Q12 is 1 or 6)***
***(If family member)*** **Do they work?**

1. In regular employment (working at an organisation employing people with and without disabilities, without support or workplace accommodations)
2. In regular employment with support or workplace accommodations (working at an organisation employing people with and without disabilities, with support or workplace accommodations according to my personal situation).
3. In sheltered employment (organisations employing mostly people with disabilities)
4. Don't know **(only for family members)**

**Q18. Would you prefer to work…** **(if Q12 is 1, 2 or 6)**
***(If family member)*** **To your knowledge, would they prefer to work?**

1. In regular employment (working at an organisation employing people with and without disabilities, without support or workplace accommodations)
2. In regular employment with support or workplace accommodations (working at an organisation employing people with and without disabilities, with support or workplace accommodations according to my personal situation).
3. In sheltered employment (organisations employing mostly people with disabilities)
4. No preference
5. Don't know **(only for family members)**

**Q19. What is your current level of participation at work?** **(If Q12 is 1)**
***(If family members)*** **What is their current level of participation at work?**

1. Full participation
2. Somewhat limited
3. Very limited
4. Don't know **(only for family members)**

**Q20.Which employment support and workplace accommodations do you think can improve your work life?** Please select the 3 most important to you. *(if Q12 is 1 or 6)*
***(If family members)*** ***To your knowledge, which employment support and workplace accommodations do you think can improve their work life?*** Please select the 3 most important to you.

1. Work accommodations such as adequate work settings, flexible schedules, remote working, possibility of being absent from work for treatments or therapies
2. Support for transportation
3. Personal assistant
4. Adequate training, career counselling or job guidance
5. Inclusion and positive attitudes from colleagues and or employers
6. Don't know **(only for family members)**

**Q21. What type of work contract would you prefer if you became employed?** ***(if Q12 is 2)***
*(If family members)* **To your knowledge, what type of work contract would they prefer to have if they became employed?** ***(if Q12 is 2)***

1. Full-time contract
2. Part-time contract
3. None, not looking for a job
4. Don't know **(only for family members)**

**Q22. What are the reasons for being currently unemployed?** **(if Q12 is 2; randomised response items)**
***(If family members)*** ***To your knowledge*****, what are the reasons for him/her being currently unemployed?** **(randomised response items)**

1. Discouragement from family
2. Fear of losing financial benefits
3. Caregiving responsibilities
4. Difficulty in managing symptoms/medical appointments
5. Lack of adequate training, career counselling or job guidance
6. Lack of work accommodations such as adequate work settings, flexible schedules, support for transportation or personal assistant
7. Negative attitudes and stigma from potential or previous employers
8. Difficult labour market
9. Don't know **(only for family members)**

- **SOCIAL SUPPORT**

**Questions on social support are extracted from the EHIS (European Health Interview Survey). Comparisons are possible, including per level of disability (as measured with GALI).**
**Last data accessible here:**
**https://ec.europa.eu/eurostat/databrowser/view/hlth_ehis_ss1d/default/table?lang=en&category=dsb.dsb_lsp.dsb_lspi**

**Q23.How would you qualify your overall perceived social support (close people to count on, concern shown by other people, practical help from neighbours in case of need)?**
***(If family members)*** **How would you qualify their overall perceived social support (close people to count on, concern shown by other people, practical help from neighbours in case of need)**

1. Poor
2. Intermediate
3. Strong
4. Don't know **(only for family members)**

## VOLUNTARY WORK

**Q24 based on SILC (Statistics on Income and Living Conditions): https://ec.europa.eu/eurostat/web/microdata/european-union-statistics-on-income-and-living-conditions**

**Q24. Did you do any unpaid, non-compulsory work or informal activities (e.g., helping other people, helping animals) for an organisation during the last 12 months?**
***(If family members)*** **Did they do any unpaid, non-compulsory work or informal activities (helping other people, helping animals, etc.) for or through an organisation, a formal group, or a club?**

1. Yes
2. No
3. Don't know **(only for family members)**

> **Q25. Why not? Please give only the most important reason**
> 1.Too young to volunteer
> 2.Lack of interest
> 3.Lack of time
> 4.Health issues
> 5.Inaccessible built environment
> 6.Fear of losing disability benefits if volunteering
> 7.Other reasons
> 8.Don't know **(only for family members)**

# DISABILITY ASSESSMENT

*National or local authorities use disability assessments to determine disability, grant benefits, and provide social protection to citizens with disabilities. The following questions are about your experience with access to social rights and disability assessment.*
***(If family members)*** *Your national or local authorities use disability assessments to determine disability, grant benefits, and provide social protection to citizens with disabilities. The following questions are about your experience with access to social rights and disability assessment for your family member.*

**Q26. Have you ever undergone a disability assessment, which aims to assess and recognise disabilities?**
***(If family members)*** **Have they ever undergone a disability assessment, which aims to assess and recognise disabilities?**

1. Yes
2. No, but it is/was needed
3. No, it is/was NOT needed
4. No, I chose not too
5. Don't know **(only for family members)**

**Q27. How many disability assessments have you undergone?** ***(if Q26 is 1)***
***(If family members)*** **How many disability assessments have they undergone?**

1. One assessment
2. More than one assessment
3. Don't know **(only for family members)**

**Q28.Was (or were) the purpose(s) of the disability assessment(s) to obtain… (If Q26 is 1; randomised response items)**
***Please select all that apply***

1. A disability status, a "disability certificate" or to be registered as a person with disability
2. A disability pension
3. A pension for permanent incapacity to work
4. A pension for family members with caring responsibilities
5. Other cash benefits for persons with disabilities
6. Personal assistance
7. Support to adapt to the home or to access housing
8. Employment or education accommodations
9. Mobility aids, assistive technology or devices
10. Referral to other community services
11. Other
12. Don't know **(only for family members)**

**Q29. During the assessment, were you required to provide information on…? (if Q26 is 1)**
***Please select all that apply***

1. Health status (medical examination or reports)
2. Daily activities
3. Care and support needs
4. Financial resources
5. Other, specify…
6. Don't know **(only for family members)**

**Q30. What kind of professionals were involved in the assessment? (if Q26 is 1)**

1. Medical doctors only
2. Several healthcare professionals (doctors, nurses, therapists…)
3. Healthcare professionals (doctors, nurses, therapists…) and non-healthcare professionals (social workers…)
4. Non-medical staff hired by private companies
5. Don't know **(only for family members)**
6. Other, specify…

**Q31. Was the result of the assessment as expected? (if Q26 is 1)**

1. Yes
2. No
3. Unsure

**Q32. In your opinion, was it because …? (if Q26 is 1 and Q31 is 2 or 3; randomised response items)**
***Please select all that apply***

1. The disability was not recognised
2. A lower percentage or grade of disability than expected was assigned
3. Access the support needed was denied
4. The rare disease was not on the list of diseases eligible for benefits
5. Difficulties to work or to perform daily activities that were underestimated
6. The ability to work or perform daily activities was underestimated
7. Needs were underestimated
8. Don't know **(only for family members)**
9. Other, specify…

**Q33.At the end of the disability assessment, did you have access to the expected rights and support? (if Q26 is 1)**

1. In full
2. Partially
3. No access
4. Don't know **(only for family members)**

**Q34. During the assessment did you have DIFFICULTY or DISSATISFACTION in (randomised response items): (if Q26 is 1)**

1. The ease of the application process
2. The knowledge and understanding of people conducting the assessment demonstrated regarding the rare disease
3. The required information and documents
4. The way people conducting the assessment treated you
5. The way your needs were assessed
6. The way your opinions were sought and considered during the process
7. NO difficulty nor dissatisfaction
8. Don't know **(only for family members)**

**(for family member)** During the assessment and to your knowledge, did they have DIFFICULTY or DISSATISFACTION in **(randomised response items)**: **(if Q26 is 1)**

1. The ease of the application process
2. The knowledge and understanding of people conducting the assessment demonstrated regarding the rare disease
3. The required information and documents
4. The way people conducting the assessment treated him/her
5. The way their needs were assessed
6. The way their opinions were sought and considered during the process
7. No DIFFICULTY or DISSATISFACTION
8. Don't know

**Q35. Please tell us more about your experience with disability assessment: What went wrong? What went well and why? How could it have been better? What improvements would you suggest for the process? (if Q26 is 1)**
*Please type your answer here*

# LIVING ARRANGEMENTS AND PERSONAL ASSISTANCE

The following questions aim to assess your preferences and needs regarding living arrangements and personal assistance.

*(If family members)* The following questions aim to assess the preferences and needs of your family member living with a rare disease regarding living arrangements and personal assistance.

**Q36. Do you currently benefit from…?** **(randomised response items)**
*(If family members)* **Do they currently benefit from…?** **(randomised response items)**
***Please select all that apply***

1. A disability pension
2. A pension for permanent incapacity to work
3. A pension for family members with caring responsibilities
4. Other cash benefits for persons with disabilities
5. Personal assistance
6. Adapted housing or housing support
7. Employment or education accommodations
8. Mobility aids, assistive technology or devices
9. My family member does not have any benefits
10. Don't know **(only for family members)**
11. Other

- **HOUSING ARRANGEMENTS**

**Q37. Do you live…**
*(If family members)* **Do they live…**

1. Alone
2. With family
3. In an apartment with support services
4. In a smaller residential home with a private bedroom
5. In a residential institution with a shared bedroom
6. Don't know **(only for family members)**
7. Other, specify

**Q38. Are you satisfied with your current living arrangements?**
*(If family members)* **Are they satisfied with their current living arrangements?**

1. Very dissatisfied
2. Dissatisfied
3. Neither satisfied nor dissatisfied
4. Satisfied
5. Very satisfied
6. Don't know **(only for family members)**

**Q39. Would you prefer to live…** **(if Q39 is 1, 2, 3, 4)**
*(If family members)* **Would they prefer to live…**

1. Alone
2. With family
3. In an apartment with support services
4. In a smaller residential home with your own bedroom
5. In a residential institution with a shared bedroom
6. Don't know **(only for family members)**
7. Other, specify…

**Q40. Do you spend most of your day with…(only if consider themselves disabled: Q9 is 1, 2 or 3)**
***(If family members)*** **Do they spend most of their day with…**

1. Other family members
2. Other people with disabilities
3. Different people in the community
4. Alone
5. Don't know **(only for family members)**
6. Other, specify…

- PERSONAL ASSISTANCE

**Personal assistants are individuals providing direct, one-on-one support to disabled people, enabling them to achieve the same range of self-determination, opportunities, and activities as a nondisabled person, both at home and away, in the community. Please take some more time to answer additional questions about personal assistance. It could be very useful to shape upcoming European and national legislations.**

**Q41. Do you have a personal assistant to help you live independently?**
***(If family members)*** **Do they have a personal assistant to help him/her live independently?**

1. Yes
2. No, but it is/was needed
3. No, but it is/was not needed
4. No, I/they chose not to
5. Don't know **(only for family members)**

**Q42. Were you:** ***(If Q42 is 1)***
***(If family members)*** **Were they:**
***Please select all that apply***

1. Able to choose the personal assistant
2. Assigned a personal assistant
3. Having a family member acting as a personal assistant
4. Having a personal assistant employed by public services
5. Able to be the employer of the personal assistant using funding provided by public authorities.
6. Able to be the employer of the personal assistant using my / their own funds
7. Don't know **(only for family members)**
8. Other, specify…

**(Same modalities for patients and family members, except for 6)**

**Q43. How difficult do you find it to manage the personal assistant (hiring, managing, paying)?** ***(If Q42 is 1)***

1. Very Difficult
2. Difficult
3. Neutral
4. Easy
5. Very Easy
6. Don't know **(only for family members)**

**Q44. What are the difficulties faced managing the personal assistant?** ***(If Q42 is 1)***
***Please select all that apply***

1. The personal assistant is not adequately trained
2. The personal assistant does not accept to do all the tasks
3. The personal assistant is often unable to work and not replaced when not present
4. The personal assistant changes often
5. The personal assistant does not always respect [my] choices
6. It is hard to keep the personal assistant motivated
7. It is challenging to keep boundaries with the personal assistant

8. None
9. Don't know **(only for family members)**

**Q45. How many days of personal assistance do you/they currently have per week?**
***Please write your answer below.***

**Q46. How many hours of personal assistance do they currently have per day?**
***Please write your answer below.***

**Q47. What are the reasons for not having a personal assistant** ***(If Q42 is 2)***
***Please select all that apply***

1. The application process is unclear
2. The country/region does not have personal assistant
3. It was requested but denied / They requested it, but it was denied
4. It was requested, but I am on the waiting list / They requested it but are still on the waiting list
5. Requirements to access a personal assistant were not fulfilled
6. Don't know **(only for family members)**
7. Other

**Q48. How many days of personal assistance do you currently have per week?** ***(If Q42 is 1)***

*(If family members)* **How many days of personal assistance is your family member living with a rare disease granted per day?**
*Please, write down the number of hours here*

**Q49. Are you satisfied with the number of hours of personal assistance you have per day?** ***(If Q42 is 1)***
*(If family members)* **Are they satisfied with the number of hours of personal assistance they have per day?**

1. Very dissatisfied
2. Dissatisfied
3. Neither satisfied nor dissatisfied
4. Satisfied
5. Very satisfied
6. Don't know **(only for family members)**

**Q50. What tasks is the personal assistant currently assisting with?** ***(If Q42 is 1)***
***Please select all that apply***

1. Mobility around the place (transferring in and out of bed, from a position to another)
2. Personal care
3. Medical care
4. Household chores
5. Transportation
6. Social outings
7. At school
8. At the workplace
9. Extra school activities
10. Don't know **(only for family members)**
11. Other, specify…

**Q51. What tasks would you need assistance with and are not currently covered by the personal assistant?** ***(If Q42 is 1)***

***(If family members)*** **What tasks would your family member with a rare disease need assistance with and are not currently covered by the personal assistant?**

***Please select all that apply***

1. Mobility
2. Personal care
3. Medical care
4. Household chores
5. Transportation
6. Social outings
7. At school
8. At the workplace
9. Extra school activities
10. Don't know **(only for family members)**
11. Other

**Q52. What tasks would you need assistance with** ***(If Q42 is 1,2)***

***(If family members)*** **What tasks would your family member with a rare disease need assistance with?**

***Please select all that apply***

1. Mobility
2. Personal care
3. Medical care
4. Household chores
5. Transportation
6. Social outings
7. At school
8. At the workplace
9. Extra school activities
10. Don't know **(only for family members)**
11. Other

**Q53. WHAT DOES LIVING INDEPENDENTLY MEAN TO YOU?**

**Q54. Have you ever experienced discrimination related to your rare disease or disability?**

***(If family members)*** **Has your family member living with a rare disease experienced discrimination related to their rare disease or disability?**

***Please select all that apply***

1. In employment
2. In education
3. In healthcare
4. In housing
5. In other public accommodations (hotel, restaurants, transport, museums, etc...)
6. Never
7. Other

**If Q3a, Q3b or Q3c**

> *In order to create our questionnaire, we have used the most current and exhaustive list of rare diseases (orpha.net).*
> *If you have difficulty finding your rare disease or the rare disease of your family member, it might be a question of spelling or punctuation. Please check on the Orphanet website by typing in the name of your disease and let yourself be guided by the drop-down menu. The search engine will then take you to the name of the disease used by Orphanet; please use the spelling of your disease* ***as it appears on Orphanet*** *when selecting your disease.*
> **Q4a. To your knowledge, what is the name of the rare disease?**

*If you or your family member live(s) with several rare diseases, please specify the one you think has the biggest impact on everyday life.*
*Please start typing the disease below, select it, and then click outside the list to proceed to the next page. If you cannot find the rare disease in the list, please clear this field and select the option « The disease is not in the list ». Please type the name of the disease in the « Cannot find the disease » box.*

**Q4b.Cannot find the disease**
*If you still have problems finding your disease, please enter the name of your rare disease below:*

**Q4c. If you are living with other rare or non-rare diseases, please list them below:**

## More questions about you

*This information will allow us to analyse the data in more depth*

**Q55. Are you:**
- Female
- Male
- Other/Prefer not to say

**Q56a. How old are you?**

**Q56b. How old is the person living with a rare disease (for family members)**

**IF RESPONDENTS ARE UNDER 18 YEARS OLD**

*If you are younger than 18 years old, your legal representative´s consent is needed for your participation. Please ask your legal representative to respond to the following questions.*
**Please provide the first and last name of the legal representative**. Free text
I authorise the minor I represent to answer EURORDIS' surveys. I understand that these studies will deal with health-related issues and that EURORDIS guarantees strictly anonymous treatment of the responses to these surveys: Yes / No

**IF YES**
The minor can now continue to fill in the questionnaire.
**IF NO**
Thank you for participating in this survey, but only answers from people above 18 years old, or with parental consent, can be taken into account. Your answers and personal details will not be recorded. If you want to make the voice of people living with a rare disease stronger, you can share this survey link with other people living with a rare disease: tiny.cc/RB_DailyLife
If you have any questions, you can contact the team at: rare.barometer@eurordis.org

**Q57. How old were you when you stopped full-time education?**
- 15 y.o. or under
- between 16 and 19 y.o.
- between 20 and 23 y.o.
- 24 y.o. or above
- still studying

**Q58. In which country do you live?**

**Q59. Would you say that you (they) live in a:**

1. Rural area or village
2. Small or midsize city
3. Large cit

# THANK YOU

to all people living with a rare disease
who participated in Rare Barometer
surveys, and to Rare Barometer partners!

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