HOUSE KEEPING RULES

Please add your questions in the Q&A chat!

Use the "regular" chat to introduce yourself or make comments or suggestions!

Your microphone is going to be muted by default.

Use the “raise hand” button if you want to raise a question or share a point of view in public. The organisers will unmute you and give you the floor.
SOCIAl PARTICIPATION & INDEPENDENT LIVING FOR PEOPLE LIVING WITH A RARE DISEASE

A Rare Barometer Survey

Webinar for the survey launch
10/07/2024
OVERVIEW

1. SOME CONTEXT: EURORDIS’ ADVOCACY AND RARE BAROMETER

2. SHAPING THE QUESTIONNAIRE

3. INSIGHT INTO THE QUESTIONNAIRE

4. HOW TO ENCOURAGE PARTICIPATION IN THE SURVEY

5. SURVEY RESULTS - WHAT EURORDIS WILL PROVIDE

6. PATIENT ORGANISATIONS’ USE OF RESULTS
THE SURVEY IS LIVE!

10 JULY → 8 SEPTEMBER 2024

TARGET POPULATION
All people living with a rare disease and their family members

WORLDWIDE

25 languages

ALL rare diseases

tiny.cc/RB_DailyLife
SOME CONTEXT
EURORDIS-RARE DISEASES EUROPE

A unique, non-profit alliance of over 1000 rare disease patient organisations from 74 countries

- Data & Digital Health
- Development & Access to Diagnostic & Therapies
- Healthcare Policy & Services
- Social Policy & Services

**PEOPLE FIRST**

based on evidence and experience of unmet need and preferences

**EMPOWER**

To empower organisations and advocates to ensure that the rare disease community is well represented in policy discussions and decision-making at the EU level.

**PARTNER**

To establish and facilitate networks with strategic partners and key stakeholders.

**ADVOCATE**

To advocate for policies and innovative solutions driven by the needs of people living with rare diseases.

EURORDIS - Rare Diseases Europe

A unique, non-profit alliance of over 1000 rare disease patient organisations from 74 countries.
OUR VISION

EURORDIS’ vision is a world where all people living with a rare disease can have longer and better lives and can achieve their full potential, in a society that values their well-being and leaves no one behind.

Eddison, xeroderma pigmentosum
Achieving their full potential:

- Recognised as equal citizens with their rights fully respected
- Diagnosed timely and accurately
- Supported with state-of-the-art medical and social care, or cured
- Included in society in all aspects of life and enabled to live independently
Strategic Objectives: 2021-2030

2- Delivering on 6 priority areas

By 2030, EURORDIS will have made contributions to the goals of (Based on the Foresight Study Rare 2030):

- Integrated medical and social care with a holistic life-long approach and inclusion in society

Goal of reducing the social, psychological and economic burden [or negative impact] by one third by 2030
### Pillar 1

**Quality and adequate social services and policies**

### Pillar 2

**Integrated care: bridging health and social care**

### Pillar 3

**Equal rights & opportunities:**
- Disability rights, independent living
- Employment
- Non-discrimination

---

What are we advocating for?

**Position paper: holistic care**

Disability:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

UNCRPD Art. 1
Independent living:

- equal right to live in the community
- full inclusion and participation in the community
- Opportunity to choose where and with whom they live
- access to a range of in-home, residential and other community support services
- Community services and facilities available and responsive to their needs.
Evidence from a previous Rare Barometer Survey suggests that most people living with a rare disease face numerous barriers in their daily live and live with disabilities...

Now we need to know more about the many barriers they face to live to their full potential. And more about why their disabilities are often not recognised.
What we know about people with rare diseases:


More than 7 in 10 have difficulties with:
- Social life / relations
- Motor/ sensorial functioning
- Understanding & learning

40%

More than 4 in 10 have difficulties with:
- Daily activities & tasks
- Understanding & learning

More than 5 in 10 have difficulties with:
- Taking care of finances & everyday administrative tasks
- Personal care activities
- Controlling behaviour
- Communicating with others
- Daily activities & tasks
- Motor/ sensorial functioning
- Understanding & learning

More than 7 in 10 have difficulties with:
- Personal care activities
- Controlling behaviour
- Communicating with others
- Daily activities & tasks
- Motor/ sensorial functioning
- Understanding & learning

More than 4 in 10 have difficulties with:
- Social life / relations
- Motor/ sensorial functioning
- Understanding & learning

Disability Assessment is a barrier for 53%

34% report facing inadequate assessments. 19% do not receive an assessment at all but consider they would need one.

But we need more evidence on...

The barriers to social participation and independent living, and their preferences.

Types of disabilities people with a rare disease live with

What is going wrong with the recognition of their disabilities.

How is their access to the support they need.
The human rights perspective

The problem is not our diseases and disabilities, but a society and a system that poses barriers and leaves out people with rare diseases. There is nothing wrong with us. It’s up to society to change.

Goes further than the social model. There is no excuse to discriminate or deny access to equal opportunities.

Robustly collects experiences and opinions of people living with a rare disease and their close family members, on topics that directly affect them.

Transforms those experiences and opinions into facts and figures to feed the advocacy work of the rare disease community.

**WHAT**
Not-for-profit initiative

**WHO**
Run independently by EURORDIS-Rare Diseases Europe

**WHEN**
Created in 2016

**WHY**
Evidence-based advocacy
THE RARE BAROMETER PROGRAMME

EURORDIS’ survey initiative to support evidence-based advocacy

Surveys

People living with a rare disease & family members

1-3 studies per year

25 languages

Worldwide

Up to 13,000 respondents to our surveys

Panel

20,000+ people living with a rare disease registered

2,300+ rare diseases

120+ countries

People DO NOT have to register to participate in surveys

Make your voice heard!

Collective results shared with participants, patient organisations, decision makers and the wider public

Information is only accessible to the Rare Barometer team, saved on a secured server in Europe

eurordis.org/voices
RARE BAROMETER PANEL

Over 21,300 participants
RARE BAROMETER PANEL

Over 21,300 participants
Rare Barometer Panel

Orphanet disease classification (number of participants)
<table>
<thead>
<tr>
<th>Disease</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cystic fibrosis</td>
<td>590</td>
</tr>
<tr>
<td>Hypermobile Ehlers-Danlos syndrome</td>
<td>505</td>
</tr>
<tr>
<td>Hereditary haemorrhagic telangiectasia</td>
<td>464</td>
</tr>
<tr>
<td>Neurofibromatosis type 1</td>
<td>276</td>
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<tr>
<td>Sarcoïdosis</td>
<td>268</td>
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<tr>
<td>Tuberous sclerosis complex</td>
<td>186</td>
</tr>
<tr>
<td>22q11.2 deletion syndrome</td>
<td>183</td>
</tr>
<tr>
<td>Systemic sclerosis</td>
<td>174</td>
</tr>
<tr>
<td>Myasthenia gravis</td>
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<tr>
<td>Duchenne muscular dystrophy</td>
<td>151</td>
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<tr>
<td>Williams syndrome</td>
<td>150</td>
</tr>
<tr>
<td>Common variable immunodeficiency</td>
<td>125</td>
</tr>
<tr>
<td>Addison disease</td>
<td>114</td>
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<tr>
<td>Perineural cyst</td>
<td>110</td>
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<tr>
<td>Behçet disease</td>
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<tr>
<td>Rett syndrome</td>
<td>107</td>
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<tr>
<td>Arnold-Chiari malformation type I</td>
<td>106</td>
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<tr>
<td>Osteogenesis imperfecta</td>
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<tr>
<td>Autosomal systemic lupus erythematosus</td>
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<td>Classical Ehlers-Danlos syndrome</td>
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<td>Primary sclerosing cholangitis</td>
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<td>Fragile X syndrome</td>
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<td>Granulomatosis with polyangiitis</td>
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<tr>
<td>Phenylketonuria</td>
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<td>Marfan syndrome</td>
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<td>Fabry disease</td>
<td>81</td>
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<td>Gaucher disease</td>
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<tr>
<td>Idiopathic pulmonary arterial hypertension</td>
<td>77</td>
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<tr>
<td>Chronic inflammatory demyelinating polyneuropathy</td>
<td>73</td>
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<tr>
<td>Proximal spinal muscular atrophy</td>
<td>69</td>
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<tr>
<td>Angelman syndrome</td>
<td>66</td>
</tr>
<tr>
<td>Dravet syndrome</td>
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<tr>
<td>Wilson disease</td>
<td>63</td>
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<td>Interstitial cystitis</td>
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<tr>
<td>Prader-Willi syndrome</td>
<td>62</td>
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<tr>
<td>Facial dysmorphism-development delay</td>
<td>60</td>
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<tr>
<td>-behavioral abnormalities syndrome due to</td>
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<td>10p11.21p12.31 microdeletion</td>
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<tr>
<td>Idiopathic intracranial hypertension</td>
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<td>Autoimmune hepatitis</td>
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<td>Facioscapulohumeral dystrophy</td>
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<td>Friedreich ataxia</td>
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<tr>
<td>Hereditary spastic paraplegia</td>
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<td>Hereditary angioedema</td>
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<td>Diffuse cutaneous systemic sclerosis</td>
<td>52</td>
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<tr>
<td>Familial Mediterranean fever</td>
<td>52</td>
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<tr>
<td>Neurofibromatosis type 2</td>
<td>51</td>
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<tr>
<td>Glycogen storage disease due to acid</td>
<td>49</td>
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<tr>
<td>-maltaise deficiency</td>
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<tr>
<td>Classical-like Ehlers-Danlos syndrome type 1</td>
<td>48</td>
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<tr>
<td>Alpha-1-antitrypsin deficiency</td>
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<tr>
<td>Huntington disease</td>
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<tr>
<td>Primary ciliary dyskinesia, Kartagener type</td>
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<tr>
<td>Scleroderma</td>
<td>46</td>
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<tr>
<td>Pulmonary arterial hypertension</td>
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<td>Turner syndrome</td>
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<tr>
<td>Acute inflammatory demyelinating polyneuropathy</td>
<td>44</td>
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<tr>
<td>Desmoid tumor</td>
<td>44</td>
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<tr>
<td>Acromegaly</td>
<td>43</td>
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<tr>
<td>Narcolepsy type 1</td>
<td>43</td>
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<tr>
<td>Large congenital melanocytic nevus</td>
<td>41</td>
</tr>
<tr>
<td>Non-acquired panhypopituitarism</td>
<td>41</td>
</tr>
<tr>
<td>Pseudomyxoma peritonei</td>
<td>41</td>
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<tr>
<td>Pulmonary arterial hypertension associated</td>
<td>41</td>
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<tr>
<td>-congenital heart disease</td>
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<tr>
<td>Vascular Ehlers-Danlos syndrome</td>
<td>41</td>
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<tr>
<td>Idiopathic/heritable pulmonary arterial</td>
<td>40</td>
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<tr>
<td>hypertension</td>
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<tr>
<td>Noonan syndrome</td>
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<tr>
<td>Atypical Rett syndrome</td>
<td>39</td>
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<tr>
<td>Polycythemia vera</td>
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<tr>
<td>Acute intermittent porphyria</td>
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<tr>
<td>Classic phenylketonuria</td>
<td>37</td>
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<tr>
<td>Cushing disease</td>
<td>37</td>
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<tr>
<td>Eosinophilic granulomatosis with polyangiitis</td>
<td>37</td>
</tr>
<tr>
<td>Idiopathic pulmonary fibrosis</td>
<td>37</td>
</tr>
<tr>
<td>Mixed connective tissue disease</td>
<td>37</td>
</tr>
<tr>
<td>Lupus erythematosus panniculitis</td>
<td>36</td>
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<tr>
<td>MeniÂže disease</td>
<td>36</td>
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<tr>
<td>Charcot-Marie-Tooth disease type 1A</td>
<td>35</td>
</tr>
<tr>
<td>Paroxysmal nocturnal hemoglobinuria</td>
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**TAILORED RESULTS**

Collective results shared with EURORDIS members and ERNs if respondents’ anonymity is ensured

<table>
<thead>
<tr>
<th>EURORDIS European &amp; international Federations</th>
<th>Results for one country on all rare diseases</th>
<th>Specific results (one group of diseases in one country...)</th>
<th>European results for diseases of each ERN</th>
<th>European results</th>
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<td>EURORDIS National Alliances</td>
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<td>Other EURORDIS members</td>
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<td>European Reference Networks (ERNs)</td>
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<td></td>
</tr>
<tr>
<td>Anyone (EURORDIS website)</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

rare.barometer@eurordis.org
SHAPING THE ONLINE QUESTIONNAIRE
OBJECTIVES OF THE SURVEY

• 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.
OBJECTIVES OF THE BACKGROUND DOCUMENT:

• Reviewing the literature on disabilities among people living with rare diseases.
• Identifying determinants of social participation at work and among children living with a rare disease and/or disabilities.
• Identifying determinants of some elements of independent living, such as housing and housing preferences, access to personal assistance or assistive devices.
• Analyse disability frameworks, including disability measurement and disability assessment methods throughout Europe.
• Identify existing questions and surveys that could be used for comparison with other populations.
DESIGNING THE QUESTIONNAIRE

Background
document

Topic Expert
Committee

Writing the
questionnaire

Testing the
questionnaire

Translating the
questionnaire

Reviewing the
translations

Adéla Odrihocká, Patient representative, Rare Diseases Czech Republic

Ariane Weinman, Public Affairs Senior Manager, EURORDIS-Rare Diseases Europe, France

Dorica Dan, Patient representative, Romanian National Alliance, Romanian Prader-Willi Association, Romania

Gavin McDonough, Orphanet Disability Project Manager, France

Haydn Hammersley, European Disability Forum, Social Policy Coordinator,

Jakub Gietka, Patient representative, Aiming for the Future Foundation

Kirsty Hoyle, Patient representative, Metabolic Support UK

Maria Montefusco, National competent authority, patient representative, Sweden

Pauline McCormack, Medical Sociologist, Newcastle University, UK

Petra Bruegmann, Patient representative, European MEN Alliance e.V., Germany

Petra Rantamaki, European Association of Service Providers for Persons with Disabilities, Finland

Sara Rocha, Women's Committee of the European Disability Forum, European Council of Autistic People, and President of the PT association Voz do Autista, Portugal

Stavros Goulidis, Ministry of Labour and Social Affairs, responsible for personal assistance reform, Greece

Valentina Bottarelli, Public Affairs Director & Head of European and International Advocacy, EURORDIS-Rare Diseases Europe, Belgium
DESIGNING THE QUESTIONNAIRE

Background document
Topic Expert Committee
Writing the questionnaire
Testing the questionnaire
Translating the questionnaire
Reviewing the translations

Rare Barometer team
Accessibility: wording adapted to people living with a rare disease and to family members, presentation, colours.
DESIGNING THE QUESTIONNAIRE

- Background document
- Topic Expert Committee
- Writing the questionnaire
- Testing the questionnaire
- Translating the questionnaire
- Reviewing the translations

Topic Expert Committee, EURORDIS’ Council of national alliances and Council of European Federations
DESIGNING THE QUESTIONNAIRE

Background document
Topic Expert Committee
Writing the questionnaire
Testing the questionnaire
Translating the questionnaire
Reviewing the translations

Professional translators specialised in health

Survey available in 25 languages:
Bulgarian, Croatian, Czech, Danish, Dutch, English, Finnish, French, German, Greek, Hungarian, Italian, Latvian, Lithuanian, Norwegian, Polish, Portuguese, Romanian, Russian, Slovakian, Slovenian, Spanish, Swedish, Turkish, Ukrainian
DESIGNING THE QUESTIONNAIRE

Background document

Topic Expert Committee

Writing the questionnaire

Testing the questionnaire

Translating the questionnaire

Reviewing the translations

THANK YOU to all our reviewers!

Mária Ábele (Hungarian), Jurn Anthonis (Dutch), Petra Brugman (German), Dorica Dan (Romanian), Jessie Dubief (French), Stavros Gouildis (Greek), Malin Grande (Swedish), Gulcin Gumus (Turkish), Lene Jensen (Danish), Stephanie Juran (Swedish), Anja Helm (German), Jelena Malinina (Lithuanian), Martina Bergna (Italian), Judit Baijet (Spanish), Maria Montefusco (Swedish), Adéla Odríhocká (Czech), Oleksandra Olinyk (Ukrainian), Hüseyin Örün (Turkish), Cindy Penningnieuwland (Dutch), Claudio Pirola (Italian), Veronica Popa (Romanian), Alba Parejo (Spanish), Petra Rantamaki (Finnish), Rebecca Skarberg (Norwegian), Zuzana Smith (Slovakian), Tanja Zdolsek (Slovenian), Hrvatski savez za rijetke bolesti/ Croatian Association for rare disease (Croatian)
INSIGHT INTO THE ONLINE SURVEY
THE SURVEY TOPICS

1. DISEASE CHARACTERISTICS & DAILY DIFFICULTIES

2. PARTICIPATION IN SOCIAL ACTIVITIES

3. DISABILITY ASSESSMENT & INDEPENDENT LIVING

tiny.cc/RB_DailyLife_questionnaire
DISEASE CHARACTERISTICS & DAILY DIFFICULTIES

• **Status**: person with rare disease/family member; confirmed diagnosis, initial diagnosis, partial diagnosis, unsolved case, other.

• **Diagnosis**: name of the disease(s) (Orphanet list)

• **Diagnosis journey**: time since the diagnosis (initial or confirmed)

• **Types & frequencies of daily difficulties based on the Washington Group Questionnaire**: seeing, hearing, walking or climbing steps, remembering or concentrating, self-care (washing, dressing...), communicating, pain, fatigue

• Adapted question from the GALI questionnaire

• **Self-definition of person with disability**: visible/invisible

• **Support**: access, barriers

[tiny.cc/RB_DailyLife_questionnaire]
PARTICIPATION IN SOCIAL ACTIVITIES

- **School / higher education (for students / pupils):**
  - **Type of school:** mainstream school with or without accommodation or adaptations, specialised school, homeschooling, higher education
  - **Level of participation:** activities with other students, recreational activities, moving around at school, using educational materials and equipment, communicating with other students/pupils and adults at school. Based on the CASP questionnaire.

- **Neighborhood and community participation:** leisure activities with friends, structured events (e.g. team sports, clubs, holiday of religious events, concerts, parades and fairs), moving around the neighborhood and community, communicating with others

[tiny.cc/RB_DailyLife_questionnaire]
PARTICIPATION IN SOCIAL ACTIVITIES

• Work participation:
  • **Employed**: type of work contract (full time/part time, fixed-term/permanent); specific support or workplace accommodation / sheltered employment, preferences in this regard and possible improvements;
  • **Unemployed**: preferred type of contract, reasons for unemployment (linked to the symptoms of the rare disease, lack of work accommodation, caregiving responsibilities, fear of losing financial benefits, others).

• **Social support**: Adapted from the **EHIS questionnaire** (European Health Interview Survey)

• **Voluntary work**: involved or not, why and why not (Adapted from the **SILC questionnaire** - Statistics on Income and Living Conditions)

• **Discrimination**

tiny.cc/RB_DailyLife_questionnaire
**DISABILITY ASSESSMENT & INDEPENDENT LIVING**

- **Disability assessment**: already went through the process or not, for which purpose(s), type of information required during the assessment, type of professionals involved, results of the assessment, difficulties and dissatisfactions, open question.

- **Living arrangements**: types of benefits accessed, housing arrangements (type, satisfaction, preferences), with whom they spend most of their days with (other family members, people with disability).

- **Personal assistance**:
  - **When access to a personal assistant**: how he/she was chosen, possible difficulties, number of days of PA and number of hours per day, types of tasks covered and needed but not covered
  - **When no access to but need of a personal assistant**: reasons for not having one, which types of tasks they would need assistance with

*tiny.cc/RB_DailyLife_questionnaire*
3 SHARE THE WORD!
SURVEY DISSEMINATION

Survey open until 8 September

Invitations sent to participants in the Rare Barometer panel

- Already 500+ respondents!

Global communication

- From July 10th, use the communication toolkit to encourage participation in your network! euordis.org/voices

Follow dissemination

- EURORDIS members & ERNs can request a dashboard to follow the survey participation in their community! rare.barometer@eurordis.org

Reminders

- Send reminders to your network!
- Check our social media!

Final reminder

- Send a last reminder a week before the survey closes!
HOW TO COMMUNICATE ABOUT THE SURVEY?

Spread the word in your network!

• Send an email to your community – still the most efficient communication action!

• Share the survey on social media

• Host a webinar or Facebook live session

• Link the survey to a local/national/international campaign or awareness day

• Invite the Rare Barometer team to come and speak in your community!

#RareBarometer

tiny.cc/RB_DailyLife
COMMUNICATIONS TOOLKIT

eurordis.org/voices

- Available in 25 languages
- Social media images, suggested social media messages, email template, logos
- Possibility to add your organisations’ logo
- Blank versions of social media images available to adapt messages in your native language
Communications toolkit in 25 languages

Suggested email & social media

Subject: Make your voice heard: take the new Rare Barometer survey on the impact of rare diseases on everyday life!

The new Rare Barometer survey on the impact of rare diseases on everyday life is now live! By asking questions on your participation in daily activities, such as school, leisure and work, and on what you would need to live life at its fullest, we will be able to advocate for people with a rare disease to better defend their rights and participate in society on an equal basis with others.

This survey is open to people living with a rare disease and their family members from any country in the world. It is translated in 25 languages.

To make your voice heard and share your experience, we invite you to take 20 minutes to fill out the survey by clicking here, before 8 September: [http://bit.ly/RB_DailyLife]

Overall results will be shared with everyone who responded to the survey, and communicated to patient organizations, policy makers, and the general public, in order to drive real change for the rare disease community. Rare Barometer complies with the General Data Protection Regulation (GDPR).

You can find more information on the survey here: [tiny.cc/RB_DailyLife_info]

If you have any questions while taking part in this survey, you can contact rare.barometer@eurordis.org

Thank you very much in advance for your participation.


Share your experience to help all people living with a rare disease live life to its fullest! Survey available in 25 languages [http://bit.ly/RareBarometer] #RareDisease #YoungAdvocates #MakeADifference EURORDIS

Final call: The #RareBarometer survey on the impact of rare diseases on everyday life closes on 8 September! Share your experience to help all people living with a rare disease live life to its fullest! Survey available in 25 languages: [http://bit.ly/RB_DailyLife]

eurordis.org/voices

Visuals for social media

QR code for printed materials
REACHING OUT TO YOUNGER PARTICIPANTS

Targeted social media posts included in the communication toolkit to encourage participation of young adults

You are between 18 and 30 years old and living with a rare disease?  
Tell us how your condition impacts your life!  
Share your experience to help all people living with a rare disease live life to its fullest!  
How is school/university with a rare condition?  
Your voice is powerful and can drive positive change!

🌍💬 #RareBarometer #RareDisease #YoungAdvocates #MakeADifference #EURORDIS

eurordis.org/voices
COMMUNICATION ACTIONS: GET PREPARED!

Theme - staying clear and relevant:

• **Everyday life / daily life**: avoiding conceptual terms, e.g. ‘social participation’, ‘independent living’

• **Impact** of the rare disease is clear but only refers to the ‘medical model’

• Mix with communications messages closer to a ‘human rights model’

• **Not focusing on disability**: avoid using *only* pictures of people living with a rare disease and a visible disability, to encourage everyone to participate

Example of suggested social media messages

How does your rare disease impact your daily life?
Tell us about it in the new #RareBarometer survey!
What would it take for you to live your everyday life to its fullest?
The #RareBarometer survey on the impact of rare diseases on daily life closes on 8 September!
Tell us how your rare disease impacts your life!
TAILOR YOUR COMMUNICATION TO YOUR NEEDS!

You do **not** have to **mandatorily** use the communications toolkit.

If you want to create communications material tailored to your needs, please make sure that you include:

- Survey link: tiny.cc/RB_DailyLife
- Rare Barometer logo (and the EURORDIS logo)
- #RareBarometer to your social media posts
- 20 minutes to fill and closes on September 8th
- Available in 25 languages, worldwide, to all people living with a rare disease & their close family members
- Survey results shared with participants & decision-makers
- How you intend to use the results of the survey
REQUEST TAILORED ONLINE DASHBOARDS
Available in all 25 languages

Follow your dissemination work and get a first insight into the results:

- COUNTRY
- DISEASE
- DISEASE GROUP
- DISEASE GROUP PER COUNTRY
- DISEASE GROUP BY REGION

Number of participants and sociodemographic information

Preliminary results for most questions

Example of online dashboard: https://www.sphinxonline.com/tiny/v/OD0blzqHVD

rare.barometer@eurordis.org
TAILORED DASHBOARD FOR DISSEMINATION

Follow responses in your community!

25 languages

Tailored for EURORDIS members & ERNs per country, geographical region, disease, group of diseases

Example of online dashboard: https://www.sphinxonline.com/tiny/v/OD0blzqHVD
SURVEY RESULTS - WHAT EURORDIS WILL PROVIDE
EUROPEAN RESULTS – END 2024

REPORT
available in English
30-50 pages

Example: eurordis.org/publications/rb-nbs-survey-results/
EUROPEAN RESULTS – END 2024

LONG FACTSHEET
4 pages
Available in English

SHORT FACTSHEET
2 pages, available in 15 languages + other languages on demand

Example: eurordis.org/publications/rb-nbs-survey-results/
EUROPEAN RESULTS – END 2024

DASHBOARD
Each question of the questionnaire
Descriptive statistics
About 30 pages
25 languages

Example: eurordis.org/publications/rb-nbs-survey-results/
### TAILORED RESULTS

Collective results shared with EURORDIS members and ERNs if respondents’ anonymity is ensured

<table>
<thead>
<tr>
<th></th>
<th>European/ international results for one disease or group of diseases</th>
<th>Results for one country on all rare diseases</th>
<th>Specific results (one group of diseases in one country...)</th>
<th>European results for diseases of each ERN</th>
<th>European results</th>
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<tbody>
<tr>
<td>EURORDIS European &amp; international Federations</td>
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<tr>
<td>EURORDIS National Alliances</td>
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<td>Other EURORDIS members</td>
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<td>Anyone (EURORDIS website)</td>
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</tbody>
</table>

rare.barometer@eurordis.org
TAILORED RESULTS

FACTSHEET
2 pager
7 languages + on demand

Tailored for EURORDIS members & ERNs if more than 30 respondents:
per country, geographical region, disease, group of diseases

DÉPISTER LES MALADIES RARES À LA NAISSANCE!

En Europe, 5 569 personnes atteintes d’une maladie rare et les membres de leur famille ont exprimé leur avis sur le dépistage néonatal dans le cadre d’une enquête Rare Barometer menée entre le 24 mai et le 23 juillet 2023.

1 UNE VASTE MAJORITÉ DE PARTICIPANTS AURAIENT SOUHAITÉ ÊTRE DIASTOTIQUÉ DÈS LA NAISSANCE...

Specific key results

Comparison: the population concerned is more favourable to the neonatal screening (50%) than people with rare diseases and their families in the context of an on-demand study for a specific diagnosis.

1 Si c’était ou si c’était possible, faisons savoir que [la personne dont je m’occupe] soit diagnostiquée à la naissance.” - tous les participants (5 569)
ONLINE DASHBOARD

Each question of the questionnaire

Descriptive statistics

Possibility to filter crossings for:
- people living with a rare disease
- parents
- other family members

TAILORED RESULTS
PLEASE NOTE:

• People participating in our surveys **always receive the European results!**
  • Overall results will be shared with everyone who responded to the survey and will also be communicated to patient organisations, decision-makers and the general public.

• You do **not** need to register to the Rare Barometer in order to participate!
  • However, by registering to Rare Barometer, you will be the first to hear about new surveys, and the first to receive the results!

• We encourage you to **complete the survey to the end!**
  • We know it’s a long survey, but it’s very important to complete it to the end for us to take your answers into account!
USE OF RESULTS
European advocacy: 
Ongoing priorities

All people living with rare diseases and disability must access:

- Adequate disability assessment and recognition
- Adequate social protection and independent living support
European advocacy:  
Upcoming opportunities

**EU level:**

- Mid-term review of the EU Disability Strategy 2021-2030, to propose flagship initiatives.
- EC guidance on independent living and inclusion in the community.
- EU framework for Social Services of Excellence for persons with disabilities.
- EU Disability Platform discussions - aiming to present results in plenary.

**National level:**

- Guidance for Member States to improve disability assessment processes.
- Ongoing reforms of independent living and community-based services.
Raising awareness:

Of the diverse disabilities and barriers experienced by the rare disease community.

Of the social inequalities faced by people with rare diseases.
EXAMPLE OF HOW SURVEY RESULTS HAVE BEEN USED

Communicate about the results on your website

Analyse the targeted results yourself

Issue an academic publication
https://journals.sagepub.com/doi/full/10.1177/2397198321999927

Compare with your own past survey findings
THANK YOU FOR PARTICIPATING!

Share the link to our survey on your social media TODAY!

tiny.cc/RB_DailyLife

#RareBarometer
RESOURCES:

- PDF version of the questionnaire: tiny.cc/DailyLife_questionnaire
- Link to the survey: tiny.cc/RB_DailyLife
- Link to the communications toolkit: eurordis.org/voices
- Link to the page presenting the survey: tiny.cc/RB_DailyLife_Info
- Example of academic publication: https://www.nature.com/articles/s41431-024-01604-z
- Example of dashboard:  
  https://download2.eurordis.org/rarebarometer/Dashboards/DiagnosisOdyssey_results_Europe_EN.pdf
- Example of factsheet:  
Thank you! to the Rare Barometer participants, partners and corporate donors!

rare.barometer@eurordis.org