



Below are All.Can International's responses to the European Parliament's consultation on rare diseases.

Question: Are you are replying as:

- An individual
- A patient/support group
- A healthcare professional, researcher, healthcare provider, research institute or university
- An international organisation, government or other public body
- A stakeholder or interest group

Question: What is the name of your organisation? (100 characters max)

All.Can International

Question: How many employees/volunteers does your organisation have?

1-9 / 10-49 / 50-249 / 250-499 / 500 or more

Question :Where is your organisation based?

Austria / Belgium / Bulgaria / Croatia / Cyprus / Czechia / Denmark / Estonia / Finland / France / Germany / Greece / Hungary / Ireland / Italy / Latvia / Lithuania / Luxembourg / Malta / Netherlands / Poland / Portugal / Romania / Slovakia / Slovenia / Spain / Sweden / Outside the EU

Question: Is your organisation registered in the EU Transparency Register? <https://transparencyregister.europa.eu/>

Yes / No

Question: Has your organisation received funding from the EU in the last five years?

Yes / No

Question: Is your organisation mainly focusing on:

Patients of all needs / Patients with rare diseases / Other specific group of patients

Question: Is your organisation active in:

One of the EU Member State / In multiple (or all) EU Member States / Not active in any EU Member State

Question: What are the major issues of rare disease patients according to your organisation?



- Difficulty in accessing care
- Hinders for accessing cross-border healthcare
- Difficulty in diagnosis
- Limited access to treatments
- High cost of care
- High cost of treatment
- High costs of accessing care (travel costs, etc)
- Access to support in the daily life
- Access to psychological support
- Other

Question: Do you take actions to raise awareness about rare diseases and if so through which means?

- We do not take such actions
- Off-line promotion campaigns
- Off-line promotion campaigns
- TV or radio awareness
- Conference speeches
- Studies and publications
- Press articles
- Organising events
- Trainings
- Advertisements
- Presentations in schools
- Gadgets distribution
- Other

Question: What are the major issues that your organisation faces?

- Reaching patients
- Raising awareness on the importance of rare diseases
- Raising funds
- Mobilisation of volunteers
- Finding staff with adequate knowledge about rare diseases
- Other

Question: Do you collaborate with other stakeholders?

- We do not collaborate with other stakeholders
- Public entities in your country
- Public entities outside your country
- International bodies (including the EU)
- Patient and support groups
- NGOs/Charity organisations
- Healthcare institutions (hospitals, clinics...)
- Health professionals organisations
- Industry
- Media
- Other



Question: What types of resources helpful for rare disease patients?

or support services do you find most

- Rare disease registries and databases
- Specialised centres and networks
- Telemedicine and digital health tools
- Multidisciplinary care teams
- Mental health and social support services
- Patient support groups
- Single contact points for all medical and administrative needs
- Information on ongoing and new clinical trials for patients and doctors
- Access to clinical trials

Question: In your opinion, what types of resources or support services for rare disease patients need improvement?

- Rare disease registries and databases
- Specialised centres and networks
- Genetic testing
- Telemedicine and digital health tools
- Multidisciplinary care teams
- Mental health and social support services
- Patient support groups
- Single contact points for all medical and administrative needs
- Information on ongoing and new clinical trials for patients and doctors
- Access to clinical trials
- Other

Question: In your opinion, in which fields can EU improve its actions?

- Level of EU funding for research
- Time necessary for approval of new treatments/therapies
- Access to cross border healthcare
- Collaboration and coordination between healthcare professionals
- Collaboration and coordination between healthcare institutes/centres
- Patient engagement
- Specialised centres for rare disease
- Support networks
- Harmonisation of Member States' legislation
- Coordination of multinational research
- Other
- No need for improvement

Question: In your opinion, in which fields can EU intervene more efficiently than the Member States alone?

- Support for research networks
- Support for development of database for research
- Support for development of database (information repository) for patients
- Coordination of national legislation
- Regulating the market



- Increased international cooperation
- Funding for research/medicines/treatments
- Awareness raising
- Other

Question: Are you aware of EU actions in the area of rare diseases?

- I am not aware of any EU action in the area of rare diseases
- European Experts group on rare diseases
- Screen4care project
- European Reference Networks
- EUROCAT network
- Funding for R&D
- EU RD Platform
- European Rare Diseases Research Alliance (ERDERA)
- Other

Question: Is there anything else you would like to share regarding your views on care for rare diseases? 350 character(s) maximum

Rare cancers account for approximately 24% of all new cancer diagnoses in Europe, with 650,000 new cases annually. Delays in diagnosis & lack of specialised care lead to poorer outcomes & higher healthcare costs. For efficient care, the EU must ensure sustained funding for early diagnosis, research & specialised centres, including equitable access to clinical trials, while strengthening cross-border collaboration & data integration to improve access to high-quality, cost-effective care. Appropriate metrics to measure the efficiency of the care systems and of patients' outcomes and experiences are also key.

Contribution code

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