



THE ROLE AND PARTICIPATION OF PATIENTS REPRESENTATIVES IN THE NETWORKS (ERNS)

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1. Necessity of patient involvement in ERNs

- The 2013 EUCERD ERN Recommendations (and Addendum, 2015), recognised the critical and integral role that patient representatives play as formal members of the decision and opinion making structures of ERNs.
- In 2016, EURORDIS, in collaboration with the European rare disease community, established 24 European Patient Advocacy Groups to optimise the involvement of patients in the ERNs. ePAGs were created to ensure **solidarity, inclusiveness and democratic representation**; this remains the case today, with a step wise and learning curve approach.



2. After one year, the number of patients involved in the ERNs is substantial

Over **300** patients are involved, including **255** patient advocates working together in the 24 European Advocacy Patient Groups



Over **1760** patient organisations involved in the 24 ERNs

3. ePAG advocates represent the wider patient community

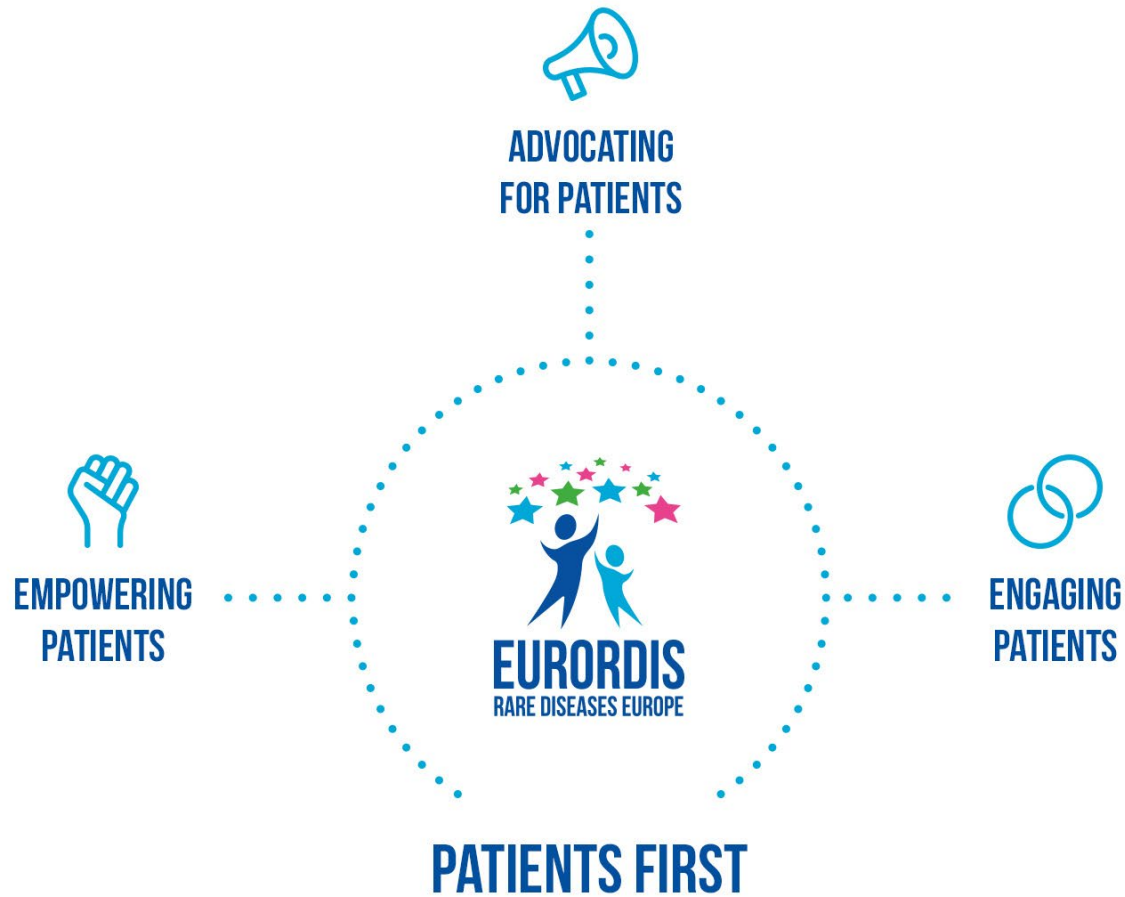


They represent the **voice of patients** within ERNs to ensure that the needs of people living with a rare disease are well understood and included in the strategic and operational delivery of the Networks



They create a bridge between the ERN and the **wider patient community**

4. How is EURORDIS supporting ePAG advocates



5. ePAG advocates role have a dual role

Macro level

Board and transversal groups

1. Ensure that the strategic and operational discussions are patient-centred
2. Provide advise on the ethics, quality and safety assurance of patient care and research
3. Contribute to raise awareness of ERNs activities
4. Help to identify alternative sources of funding

Micro level

Disease-specific networks

1. Inform the work of the ERNs by bringing the needs and experience of living with a rare disease to the core networks discussions
2. Prioritise, develop and disseminate clinical guidelines, scientific research, patient information and educational activities
3. Ensure transparency in quality of care, safety standards, clinical outcomes and treatment options in the different activities.

6. There has been good progress over the last year

- 1** The 24 ERN governing Boards include patient representatives.
- 2** ePAG Governance framework in place
- 3** Democratic representation of patients has been organised (bottom-up)
- 4** Cultural change and collaboration has gained traction, although some therapeutic areas are more mature than others and it will take time to get all of them to the same level

7. Good examples of meaningful patient involvement in ERN decision making processes and activities

Across different ERNs, patients and clinicians have worked together over the last year to:

1. Identify gaps/unmet needs of educational resources and Clinical Practice Guidelines
2. Develop healthcare pathways (patient journey) and Clinical Practice Guidelines
3. Review ontology and Orphanet coding
4. Develop the 3-year strategic plan for the ERN

8. Challenges for patient involvement in ERNs

- 1 Identify when and where patient involvement is more effective and provides the greatest **value**
- 2 Set up the mechanisms to liaise effectively with the **wider patient community**
- 3 **Improve knowledge management and exchange good practices**
- 4 Create a **patient-clinician partnership culture** that is similar across all ERNs and provide both parties with the soft skills needed to make this happen
- 5 **Funding** to sustain meaningful patient involvement

9. Priorities

1. ERNs operations should focus on those activities that can contribute to **improve health outcomes and wellbeing**
2. **Expand the expertise and geographic coverage to benefit all patients equally**, regardless of their condition and where they live
3. **Benefit the wider patient community**. ERNs create a clear governance structure for knowledge sharing and care coordination across the EU, but the system will fail to reach its full potential if it does not benefit the wider patient community.
4. Measure patient satisfaction through a standardised and **common patient feedback mechanism across the ERNs** to ensure robust and comparable data and results across all ERNs, all Member States and over the years.



Thank You

