



European Patient Advocacy Group



European Patient Advocacy Groups (ePAGs)

European Reference Networks (ERNs) are virtual networks involving expert centres across Europe. They aim to improve patients' access to high quality diagnosis, care and treatment of complex or rare medical diseases that require highly specialised treatment and a concentration of knowledge and resources. There are 24 ERNs, each focusing on a particular disease area. **European Patient Advocacy Groups (ePAGs)** bring together rare disease patient advocates who are actively involved in the work of the European Reference Networks. Each ePAG corresponds to the scope of one of the 24 ERNs, aligning patient organisations and clinicians, experts and researchers working on the same rare or complex disease or highly specialised intervention.

Each ePAG has a number of 'ePAG advocates', who represent their disease area in the ERN. Some ePAG advocates also sit in the ERN Boards and horizontal working groups where they represent the broader rare disease patient community that falls under the scope of their ERN.

Mission of ePAG advocates

ePAG Advocates **represent the interests of the wider patient community** to ensure that the needs of people living with a rare disease are included in the strategic and operational delivery of the Networks.

Role of ePAG advocates

ePAG Advocates work in partnership with the clinicians and researchers in each European Reference Network. They are engaged at different levels and areas. **At an operational level** they provide the patient perspective in the development of registries, clinical practice guidelines, care pathways, information and dissemination or research priority setting. **At a global and strategic level**, they advise on overall planning, assessment and evaluation of ERNs' activities and have a shared leadership and responsibility in the decision-making.

To effectively perform this role, ePAG advocates must work and engage with their national and European networks and build a two-way communication between the ERN and the wider patient community to remain responsive to their collective needs.

ePAG advocates' contribution

ePAG advocates hold an important position in the ERNs and, as experts in their diseases and 'users' of the services that ERNs are working to provide, have a valuable contribution to make:

- They ensure that ERNs remain truly **patient-centric**, which is central to the achievement of the ERNs main goal: improving the quality of the care that patients receive and health outcomes.
- They hold the unique knowledge or **personal experience of a specific disease**, and can convey the needs and challenges of living with this disease into network discussions, decisions and activities.
- They also bring their **complementary skills and experiences outside the medical field** (legal, IT, training, communication, etc.) that can enrich network discussions and offer new and alternative perspectives.
- They have a **stake in every stage of the healthcare and research pathways**, from diagnosis, care and treatment through follow-up and from early research through to orphan drug authorisation, and as such they are in a **privilege position to have a holistic view of the whole process**.

Key messages

Below there is a selection of key messages that you might want to use when communicating about your role to different audiences, including your own patient community, clinicians, researchers and policy makers.

Raising awareness of ERNs and their potential

- ERNs have been set up to improve access to diagnosis, treatment and the provision of high-quality healthcare for rare disease patients, ultimately to improve health outcomes.
- They are also knowledge hubs for rare diseases functioning as focal points for medical training, research, information dissemination and evaluation.
- They facilitate the concentration of resources and expertise across Europe, but they will only deliver their full potential once each health system develops the mechanisms to anchor them into the national healthcare structures and care pathway.

Outreach is a critical element of the ePAG advocates role

- ePAG advocates need to work and engage with their national and European networks to build their legitimacy and authority. In their role as advocates they should bring to the table the collective needs and interests of the wider patient community. At the same time, they have an important role to disseminate the information and knowledge generated by the ERNs.
- They have the responsibility to partner with their national rare disease patient community and RD National Alliances to engage with a single voice in the conversation at national level on how to best integrate the Networks into their own national health system.

Opportunities and challenges of ERNs

- ERNs are networks of people that bring together medical experts and researchers from 900 centres and more than 300 patient advocates from 28 European countries, mobilizing a critical mass of expertise and data. They create an unprecedented opportunity to improve care delivery for rare disease patients, advance research and build the capacities of European health systems to deliver care for these patients.
- They create a new structure for cross-border networked care. They connect experts who are pioneering a new way of working across borders. To succeed they need sustained support and a protected environment for experimentation.
- We are already seeing pockets of good practices in different areas, learning and changes, but the scale of this initiative is such that it will take some time before we can see its impact in terms of improved health outcomes for rare disease patients.