Together for rare and complex epilepsies

Meeting summary

31st of May from 6 to 8 pm CET

Together for rare and complex epilepsies meeting was organised after receiving positive feedback from patient organisations for different rare and complex epilepsies. The survey received 89 responses, and all the participants expressed their interest in joining the first online meeting with the patient community which was later held on May 31st 2024 from 6 to 8 pm CET.

During the meeting there was 55 participants that joined online on a Teams application. Moderator of the meeting was Nicola Openshaw-Lawrence, EpiCARE's Data Manager CPMS Coordinator. During the meeting Mentimeter questions was shared, and the results are available below.

Following the meeting agenda, please find below the meeting summary.

1. ***Prof. Alexis Arzimanoglou (EpiCARE ERN Coordinator): EpiCARE ERN and ePAG involvement***

The meeting commenced with a presentation on the European Reference Networks (ERNs), highlighting that there are currently 24 active ERNs. These networks have been operational since 2017 and are crucial for addressing rare diseases (RD) in the EU, which affect approximately 36 million people across over 6000 different rare diseases.

EpiCARE Overview

- EpiCARE encompasses 50 centres. The network also collaborates with centres from countries in the European region, irrespective of EU membership.
- EpiCARE working groups are divided into sections focusing on better practices, and healthcare policies and research. The structure and working groups are available at: https://epi-care.eu/european-core-programme/.
- He highlighted the complexities in diagnosing rare and complex epilepsies, often referred to as the diagnostic odyssey. There is a push for creating national networks to streamline diagnoses, as the European Commission does not fund individual centres within the network.
- He also noted that EpiCARE does not directly interact with individual patient cases, but supports individual centres through case discussions. EpiCARE directly collaborates with ePAGs involved in this network.
- EpiCARE also has education initiatives. Educations for young physicians and nurses were outlined, emphasizing the importance of continued learning and sharing knowledge to support future experts.

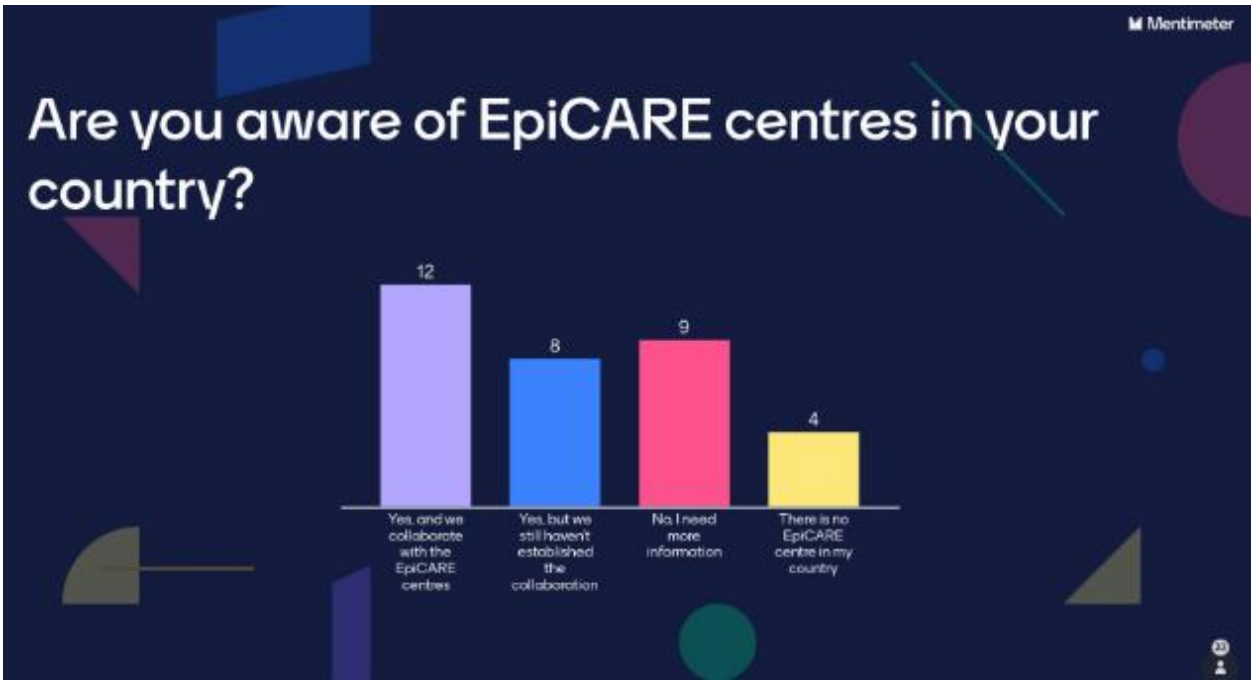
Next Steps

- Pathway Development
  - Recognizing the diverse healthcare pathways across countries, EpiCARE aims to facilitate collaboration between healthcare professionals (HCP) and patient associations (PA) to establish effective pathways on national levels.
- JARDIN Project (https://www.eurordis.org/jardin-101-explainer/)
  - This initiative focuses on developing national networks for better healthcare delivery.

ePAG Involvement in EpiCARE ERN

- Materials
  - The use of leaflets and Patient Journeys was discussed to improve HCP and patient education and engagement.
- Collaboration Expectations
  - HCPs expect regular and strong collaboration with PAs to better understand and address patient needs.
- Guideline Preparation and Implementation
  - Ensuring that guidelines are applied uniformly across countries to standardize care.
- Webinars
  - Organised to educate HCPs on the needs of various epilepsies and their diagnosis, which will also benefit patients. Webinars tend to include the patients' perspective as well, when possible.

This topic was closed with a consensus on the importance of collaboration, education, and standardized guidelines to improve the management of rare and complex epilepsies. Further steps were outlined to develop national networks and enhance patient involvement.



Conclusion of the Mentimeter results were to work on dissemination about the EpiCARE ERN, as well as encouraging collaboration among EpiCARE centres and PAs.

2. *Isabella Brambilla (ePAG EpiCARE Chair): ePAG EpiCARE activities*

The meeting continued with a presentation on the activities of the ePAG EpiCARE group, which includes ePAGs and patient representatives (https://epi-care.eu/epicare-patient-representatives/).

ePAGs are involved in majority of EpiCARE ERN Working Group providing their input from a patient perspective. There is also an existing collaboration with external organizations like the International Bureau for Epilepsy (IBE) and the Rare Epilepsy Network (REN). Within the ERN

EpiCARE network there was an establishment of a Working Group dedicated to Patient Advocates, and the activities of this WG were shared later in the agenda.

ePAGs tend to participate in congresses which was noted as a crucial activity for fostering collaborations and sharing knowledge.

In the networking part, a significant gap identified is the language barrier, especially given that there are over 280 associations for different rare and complex epilepsies from various countries across Europe and globally. Some countries have numerous associations, while others have very few. It is essential to address these language barriers to facilitate better communication and collaboration.

Emphasis was also placed on the importance of working together to build a robust network.

Collaborative efforts on various projects were encouraged to strengthen the network and enhance patient support.

The topic concluded with a reaffirmation of the need for enhanced collaboration, particularly in overcoming language barriers, to ensure effective communication and project execution. Building a strong network through cooperative efforts was deemed crucial for advancing the objectives of rare and complex epilepsy patient community.

3. ***Vedrana Bibić (ePAG EpiCARE Secretary): Patient Journey and leafets***

The Patient Journey is a project developed by EURORDIS, and implemented within the all ERNs, that aims to map the patient journey through various stages of rare and complex epilepsy, highlighting key areas of patient and family needs.

Key Stages of the Patient Journey include prenatal/presymptomatic when possible, first symptoms, diagnosis, treatment, follow-up – childhood and follow-up – adulthood.

Focus areas in the Patient Journey are patient needs, as each stage focuses on identifying and addressing patient needs to achieve ideal outcomes which are also highlighted.

Leaflets are the EpiCARE initiative and present informative documents in a Q&A format. They are divided into two parts: one for healthcare providers (HCPs) and another for patients and caregivers, using lay language.

Translations of these documents are crucial to ensure greater visibility, availability, and impact within the community, making these resources accessible to a broader audience.

Published documents and translations are available at: https://epi-care.eu/patient-and-caregiver-leaflets/.

She shared the values of these documents as well that include: providing up-to-date information to HCPs and patients and families, sharing knowledge and educating about different rare and complex epilepsies, highlighting and addressing patients' needs, guiding through the complexities of care, recognizing common needs among various conditions, and offering information to HCPs and neurologists in areas with limited resources or knowledge.

The topic was concluded with the affirmation that these projects are a vital initiative, aiming to support patients and families by providing comprehensive, accessible information and addressing the complexities of rare and complex epilepsies. She finished by thanking all the PA that have contributed so far, and with an open call for others to get involved.

Mentimeter results confirmed the shared views on the use of these documents, and showed a great interest from PAs in developing them.

4. *Małgorzata Kośla (ePAG member): Survey for rare and complex epilepsies*

The survey aims to address gaps in the care of patients with rare and complex epilepsies by understanding patient demographics, needs, and struggles across different disorders and countries. The ultimate goal is to improve care for these patients throughout Europe.

Throughout our work and conversations, we have identified the gaps in patient care among the different countries. There is also a highlighted the need to know how many patients are there and what they struggle with.

Goals of the Survey

- Gain a deeper understanding of both common and specific needs across different disorders and countries.
- Strengthen the voice of connected patient organizations.
- Ultimately, aim to achieve better care for rare and complex epilepsies across Europe.

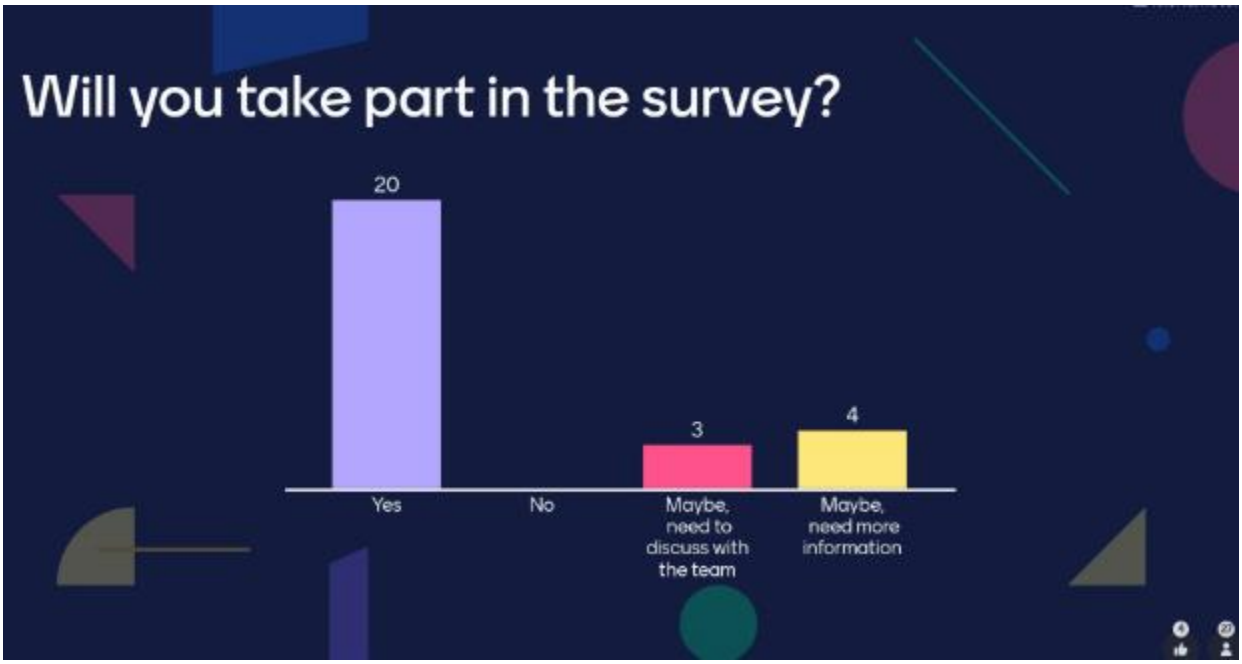
Timeline of survey development:

- The survey draft was finalized in April.
- A working group with physicians is being established.
- Next steps include translation and dissemination of the survey, for which support is needed.
- The survey will be open for 3 months.
- Preliminary results will be shared at a face-to-face meeting.
- Publications will be prepared.

Survey sections include: demographic data, birth information, diagnosis, epilepsy presence, epilepsy treatment, standard of care, comorbidities, non-antiepileptic drugs and food supplements, rehabilitation, autonomy and expenses.

For dissemination the plan is to create a campaign in different languages to support survey distribution. Assistance from all stakeholders is desirable for the dissemination process.

The survey is a critical tool to identify and address the needs of patients with rare and complex epilepsies. The collaborative effort in developing, translating, and disseminating the survey is essential to achieve the ultimate goal of better care across Europe.



Mentimeter results showed great interest of participants in taking part in the survey, as well as supporting dissemination among their patient community, and country.

5. ***Irena Bibić (ePAG EpiCARE Co-chair), Matt Bolz-Johnson (EURORDIS Mental Health Lead and Healthcare Advisor): Face to face meeting 2025***

Irena presented the initiative of organising a face-to-face meeting with patient community that fall under the scope of a working group dedicated to patient advocates. As there are over 250 Pas identified, with many new, young PAs, and many common needs this group started to plan a face-to-face meeting.

The goals of the meeting are: encouraging collaboration between PAs, create opportunities for these PAs to meet face to face and exchange information, practices and work on common projects, and build a collaborative network to support shared goals and initiatives.

Upcoming meeting in 2025 will be a **hybrid event**, with the place to be confirmed, and the date to be confirmed as well (but probably in May/June 2025). The event will be held in conjunction with the EpiCARE Annual General Meeting (AGM), as we are aiming for better availability and participation of physicians.

Survey results were shared with responses received from 25 countries, covering over 30 rare and complex epilepsies, and 60% of respondents showed interest in participating onsite, with 37% preferring online participation.

The face-to-face meeting and the establishment of the new EpiCARE working group mark significant steps towards enhancing collaboration among PAs. The hybrid event scheduled for May/June 2025 aims to bring together stakeholders to share insights, discuss common challenges, and work towards improving care for rare and complex epilepsies.

To ensure that the aims are met, Matt shared the proposed workshop topics for the face-to-face meeting.

The upcoming face-to-face meeting will focus on 2 main areas: Patient Partnership and Quality of Life. Key topics will include the integration of patients and health professionals as equal partners, effective communication strategies, and tools to enhance knowledge about rare and complex epilepsies, transition i.e. continuity of care, and mental healthcare.

- Patient Partnership: ensuring People Living With Rare Diseases (PLWRD) and HCPs are involved as equal partners in all ERN activities and domains.

- Communication: Developing effective communication messages and channels to address the needs of patients with rare and complex epilepsies. Strategies to improve awareness and understanding of these conditions among the broader community and healthcare providers.

- Tools: Introducing tools to enhance the knowledge of rare and complex epilepsies among health professionals and patient organizations. Utilizing digital platforms, educational materials, and workshops to disseminate information.

- Transition: Addressing the challenges patients face during the transition from paediatric to adult services, which often results in a lack of continuous care and support. Discussing the need for integrated education, adequate rehabilitation, and support for future adults in protected working environments. Emphasizing the importance of adult services understanding rare and complex epilepsies and their related comorbidities, and adopting novel treatment options to manage syndromes, not just symptoms.

- Mental Health and Wellbeing: Recognizing that mental health needs can have a more significant impact on families than physical health needs. Promoting a holistic approach to care that goes beyond seizure control to address the overall needs and care

coordination throughout the patient's life journey. Integrating psychosocial support as a standard part of care for both children and their parents. Empowering families with skills to manage daily challenges and providing support to cope, manage, and stay flexible. Sharing practical strategies and 'secrets' for managing rare and complex epilepsies effectively.

The sessions aim to foster collaboration, enhance communication, and develop tools to improve the quality of life for patients with rare and complex epilepsies. By addressing both medical and psychosocial needs, the meeting will pave the way for better care and support for these patients and their families.

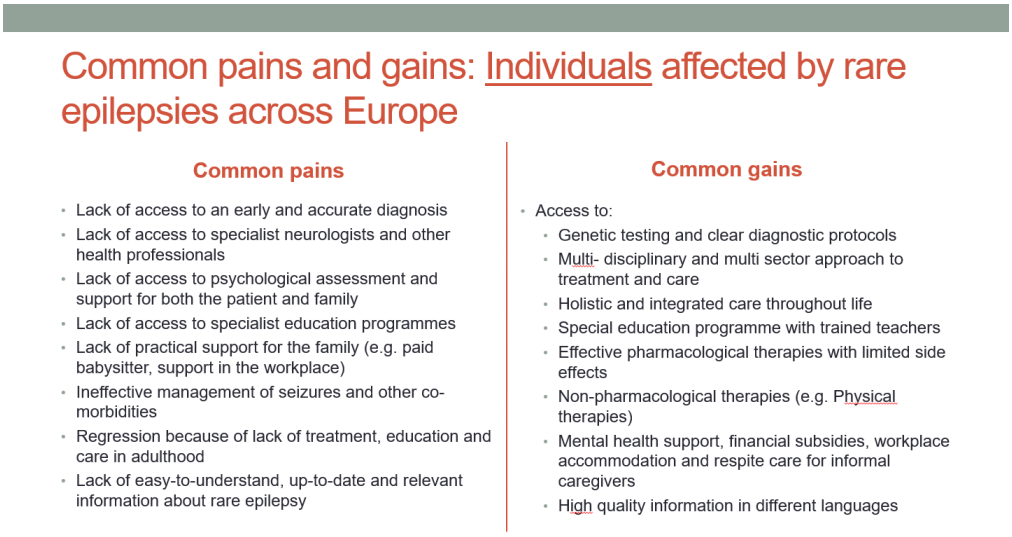
6. *Kathy Redmond (Redmond Consulting): Creating a network*

Kathy shared information about the importance and structure of building alliances among patient organizations, in this case focusing on rare and complex epilepsies. This topic highlighted essential building blocks, common goals, shared values, and the core purpose of the alliance.

Common characteristics of over 130 rare and complex epilepsies were identified as following:

- Lifelong condition that is typically diagnosed at a young age
- Genetic aetiology (majority of cases)
- Frequent and complex to manage epilepsies (up to 500 seizures per year) associated with:
    - Need for combination drugs
    - Drug resistance
    - Burdensome side-effects
- Inability to be autonomous or live alone independently because of:
    - Intellectual disabilities
    - Behavioural difficulties
    - Communication difficulties
    - Motor difficulties/gait problems and other co-morbidities (e.g. eating difficulties)
- Need for 24/7 care from informal caregivers

The analysis of the common pains i.e. challenges and common gains i.e. how to address those challenges was done on 3 different levels: at an individual patient level, patient community level, and PAs level.



Common pains and gains: European Rare epilepsy patient community

Common pains

- Inequity in access to evidence-based treatments and care
- Lack of policy maker understanding of differences between common and rare epilepsies
- Lack of policy maker attention for rare epilepsies
- Challenges with the transition from paediatric to adult care
- Lack of pharmaceutical company interest in developing medicines for rare epilepsies
- Lack of investment in academic research for rare epilepsies
- Negative public perceptions about and understanding of epilepsy

Common gains

- Evidence on the burdens of living with rare epilepsy and gaps in access to optimal treatment and care
- More stakeholders awareness about the specific burdens associated with rare epilepsies and needs of people affected by the condition
- Consensus guidelines on seizure control and other aspects of treatment and care
- Change public perceptions about epilepsy to enable better integration of someone with epilepsy in daily life
- Better awareness of management of seizures in different contexts (e.g. Emergency room, school, sports etc.)

Common pains and gains: Rare epilepsy patient organisations across Europe

Common pains

- Lack of resources (financial and human)
  - Many are volunteer-run organisations with limited capacity and capability
  - Succession planning challenges
- Few opportunities to network and learn from the experience of other rare epilepsy patient organisations
- Challenging to stay up-to-date about scientific and medical advances in rare epilepsies
- Lack of opportunities to engage with influential stakeholders
- Stakeholders want a common and united voice (difficult to speak with many associations)

Common gains

- Information about scientific advances in rare epilepsies
- Build know-how on:
  - How to generate patient evidence
  - How health and social systems work
  - Evidence-based advocacy
  - Effective communications (e.g. Social media, website etc)
- Influential voice in:
  - Research on different aspects of treatment and care (pharma and academic)
  - Shaping healthcare, education and social services
  - Access decision making (e.g. HTA)
- Strategic alliances with other stakeholders with a shared purpose
- Leaders who can represent the community perspective

Throughout the conversation with patient advocates, besides the challenges, alliance value proposal was created as well, and goes as following:

1. Help make the different rare epilepsy communities stronger and more impactful
2. Co-ordinate joint action to address common problems
3. Provide a united and representative voice in all decisions that impact on people affected by rare epilepsies

Benefits for alliance members include:

- Have a structure to work together to address common problems
- Have the opportunity to:
  - Provide input into decisions that impact your community
  - Be involved in common projects
- Membership of the alliance will enable members to:
  - Increase their impact, influence and sustainability
  - Raise awareness about, give greater visibility to and attract more attention for their specific rare epilepsy
  - Reduce duplication of effort releasing resources for condition-specific activities

Again, Mentimeter results showed that majority of participants seed the need of a European Alliance for rare and complex epilepsies. As creating a new entity demand time investment, we understand that many discussions are yet to be done in order to make a decision in joining this Alliance.

Next steps

Establish a Steering Committee which will have the task of developing proposals for the Alliance's:

- Identity (core purpose, name, logo etc)
- Legal structure and governance framework
- Membership criteria and application process
- Roles and responsibilities
- Strategic objectives and action plan
- Resources

Hold a follow-up meeting with interested organisations to discuss proposals on **August 30th 2024.**

We'd like once again to thank all the participants and hope that this was only a first step in our future collaboration in creating better opportunities for rare and complex epilepsies.

If you have any questions or inquires, or wish to become an ePAG member or patient representative, please contact us at epag.epicare@gmail.com.