

All-ePAG meeting

2022

Meeting Report

November 15-21, 2022



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Introduction

The all-European Patient Advocacy Groups (ePAG) meeting is a unique annual networking and peer-learning event for European Reference Networks (ERNs) patient representatives. The **theme** of this year's all ePAG meeting was '**listening to your patient community**'. The meeting aimed at supporting patient representatives, ERN clinicians and network managers to build a clearer understanding of how-to best capture and act on the insights of the rare disease patient community by listening to them, analysing their feedback, and acting on it, using the collective feedback to guide the strategic vision and concrete projects carried out by the ERNs.

A lot can be achieved if the rare disease community uses adequate methodologies to systematically capture patients' voice and to analyse the findings and information gathered. Bringing the voice of the patient community is a core task for patient representatives in the ERNs; if this task is performed with the right tools and methods, it will:

- make the patient voice stronger in the ERNs;
- ensure that the ERNs' work priorities and outcomes meet the needs and address the priorities of people living with a rare disease, and
- strengthen the collaboration between patients and clinicians in the ERNs.

To support patient representatives and patient organisations in this effort EURORDIS has developed a [practical guide](#) on tools and methods to capture the views, needs and preferences of the rare disease patient community.

On the other hand, just as important as using good methods to capture the patient community's voice, is the existence of **processes to incorporate this voice in a consistent and transparent manner** in the ERNs collaborative activities. At the same time, these processes should enable a well-functioning partnership between patient representatives and clinicians involved in the Networks.

'ERNs are a revolution in taking patients seriously' – Allison Watson, Ring20 co-founder, Trustee/CEO and ePAG EpiCARE

Therefore, applying good methods to gather the views of the rare patient community and having effective processes to incorporate their voice in the ERNs strategic discussions and projects are strongly complementary dimensions that may contribute to build patient-centred ERNs; both dimensions were the common thread that run through the sessions and discussions of this year's all-ePAG meeting.

Attendance and participants' feedback

The meeting was structured around 1-hour online sessions organised throughout 5 days. It gathered 139 participants (ePAG advocates, ERN clinicians & project managers) from 23 ERNs (**Table 1**).

Table 1: All-European Patient Advocacy Groups (ePAG) meeting attendance

Stakeholder	No	No of ERNs represented
ePAG advocates	103	21
ERN managers	20	15
ERN clinicians	3	3
EURORDIS Staff	12	NA
Other	1	
Total	139	23

Regarding the feedback on the format, some participants would have liked to have longer sessions; others would have preferred to have a full day online meeting rather than different sessions over several days as 'having to keep switching on and off' from ePAG mode over several days was tiring and was perceived as being less productive than attending a daylong meeting. However, with regards to the content, on average, **79%** of the participants rated the sessions as **useful** and **76%** were **satisfied with the sessions' content**.

Overall, the feedback received from the participants was very positive with many highlighting the interactivity of the sessions. Alongside ePAG advocates, 20 ERN managers joined the different sessions (**Table 1**). This indicates that the ERN community at large values this event and is interested in coming together to exchange and discuss patient partnership.



“
The 2022 All ePAG meeting has made 2 important steps:
1) towards the improvement of the collaboration between the ERN clinicians and ePAGs and
2) towards the enhancement of the ePAG voices at national level by supporting national alliances in their efforts to promote the ERNs.
“

Petia Stratieva, MD/Ph.D.,
ePAG Advocate at ERN-EYE,
Chairperson of Retina Bulgaria



“
It was fascinating to hear the perspectives of other ERNs and ePAGs and the meeting clearly underlined the value and importance of clinicians and ERNs listening and responding to the patient needs.
“

Michelle Battye,
ERN eEUROGEN Programme Manager



“
The session prompted me to reflect on what successful patient partnership looks like, how it can be achieved and how we can continue to build this within the ERNs.
“

Olivia Spivack,
ERNICA Project Manager



“
It is always incredibly inspiring to learn from other patient representatives and share best practices. Without EURORDIS and the ePAGs, I would not be where I am now.
“

Ruth Biller,
ePAG Advocate at ERN GUARD-Heart

Session 1. European Reference Networks and ePAGs 101

When: 21st November 2022 (9 to 10 am CET)

Background: The objective of this networking session was to bring together more seasoned and newer ePAG advocates to promote open dialogue and exchange, including on any practical matters related to their role as an ePAG advocate.

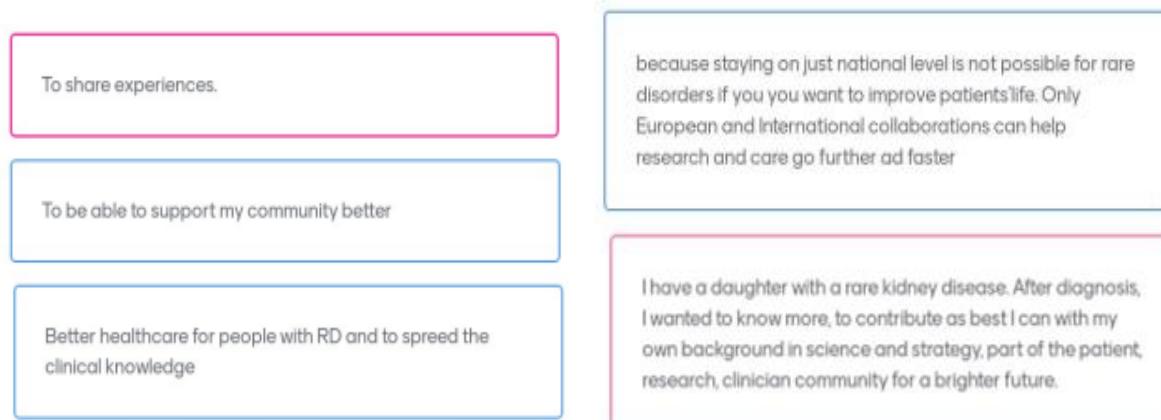
Speakers: Dorica Dan (ePAG ERN ITHACA), Graham Slater (ePAG ERN ERNICA), Isabella Brambilla (ePAG ERN EpiCARE), Simone Louise (ePAG ERN GUARD-HEART)

No of attendees: 44 participants. The large majority of the participants to this session (70%) reported having been involved in the ERNs as ePAG advocates for more than 2 years.

Key takeaways¹:

- Participants shared their reasons for getting involved in the ERNs as patient representatives. A variety of reasons were mentioned (**Figure 1**), from the willingness to serve the rare disease community to the importance of tackling rare diseases challenges at the European level or the value of sharing experiences.
- The session also served to identify challenges related to volunteering in the ERNs as a patient representative, such as the difficulties to commit the time required, difficulties to find new volunteers and onboarding new ePAG advocates. Additionally, ePAG advocates who have a leadership role within their ePAG reported other challenges linked to priority-setting and team management.

Figure 1: Patient representatives' reasons for becoming involved in the European Reference Networks.



¹ Since this was a networking session, it was not recorded

Session 2. Why Listening to Your Community Matters

When: 15th November 2022 (10-11 am CET)

Background: The objective of this session was to offer different perspectives around the need to listen to the rare disease patient community as a key component for the strategic planning and operational delivery of the ERNs.

Speakers: Nico Wulffraat (ERN RITA Coordinator), Olivia Spivack (ERN ERNICA Project Manager) and Petia Stratieva (ePAG ERN EYE). The session was moderated by Rita Francisco (EURORDIS).

No of attendees: 84 participants

[Watch the recording here](#)

[Find the slides presented by the speakers here](#)

Key takeaways:

- Defining and spreading awareness on how good patient partnership² in the ERNs looks like in practice, as well as creating metrics to capture and assess patient involvement and experience were highlighted as important measures to promote a patient-clinician partnership culture.
- The competencies considered by the participants as the most important to build and maintain successful patient-clinician partnership included respect, trust, empathy, collaboration and listening (skills) (**Figure 2**).

'Realising that everyone has different expertise, coming together, and building something together that is better than what was there before.' – Rita Francisco, EURORDIS

² 'Patient partnership is a mutual relationship between all stakeholders, including patients, where input from people living with a rare disease or caring for someone with a rare disease routinely and formally informs policy reflections and decisions. Patient partnership implies going beyond empowerment and engagement but considering people living with a rare disease and their advocates as equal partners and actors in policy and programme design and evaluation.' – source: Rare 2030 Recommendations ([Recommendation 5](#))

Figure 2: Competencies required for successful patient-clinician partnerships in the ERNs.

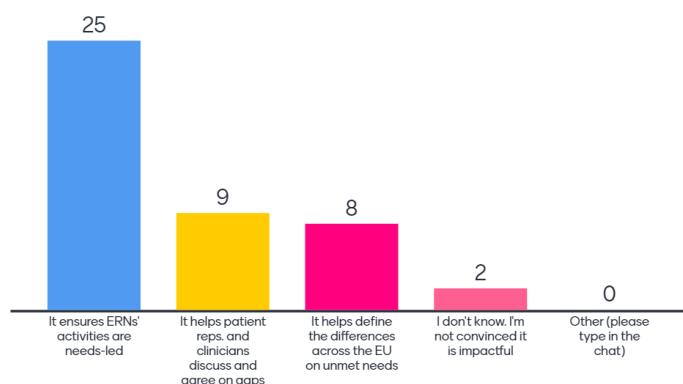


- Providing patient representatives with the space to get actively involved in the ERNs and improving existing mechanisms to listen to the patient voice were considered crucial e.g., to consult and capture patient representatives' views when ERNs are drafting their annual action plans and objectives. These mechanisms should promote early, continuous, and proactive patient involvement.

'Most projects are clinically-led, they are of interest within the clinical remit. They will ultimately have positive consequences for the patients. But listening to the patients is not that easy or common.' – Julie Power, ERN RITA ePAG advocate

- Patient involvement, as well as collecting the views of the wider patient community, were perceived as positively impacting the ERNs performance, especially because doing so 'ensures that ERNs activities are needs-led' (Figure 3).

Figure 3: Views on the impact of listening to the wider patient community on the European Reference Networks (ERNs) activities.



- Most attendees reported their ERNs had performed between 1 to 5 projects to collect the needs and priorities of the wider rare disease patient community. Various solutions were put forward to increase the number of projects, including: (i) giving the necessary tools and empowering patient organisations to collect the views of their community in a robust manner and (ii) setting up an ERN governance framework to systematically involve patient representatives as equal partners in the Networks.

'We need to move from a reactive interaction mode to an active interaction mode' –
Petya Statieva, ERN EYE ePAG advocate

Session 3. How Can I Best Capture My Community's Voice

When: 16th November 2022 (10-11 am CET)

Background: The objective of this hands-on session was to discuss how to best capture the rare disease community's voice and to share good examples of community involvement in different projects. Participants exchanged about different ways and methods to capture the voice and act on the insights of the rare disease community.

Speakers: Angela Leburgue (ePAG ERN RARE-LIVER), Jessie Dubief (EURORDIS) and Simon Eaton (ERN ERNICA & University College London). The session was moderated by Jessie Dubief (EURORDIS).

No of attendees: 78 participants

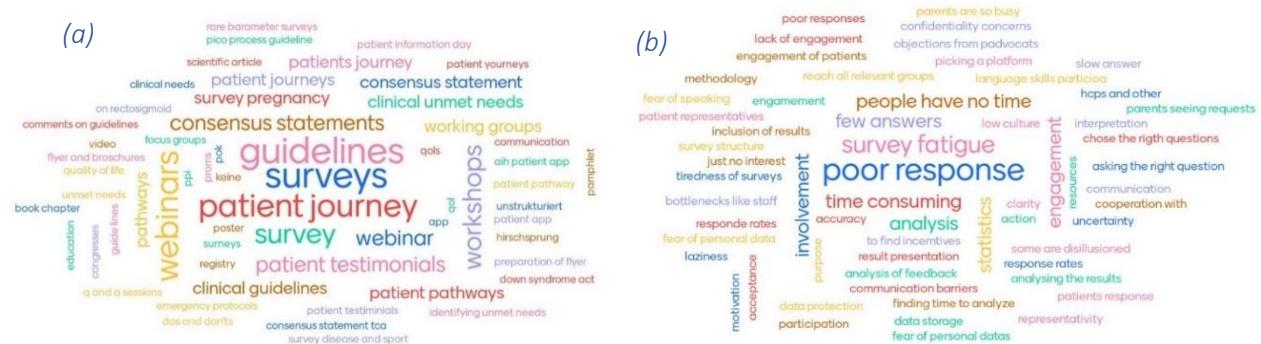
Watch the recording [here](#)

Find the slides presented by the speakers [here](#)

Key takeaways:

- Participants were asked to identify the types of projects developed within their ERNs to gather the experience and views of the wider rare disease patient community. The most frequently named were surveys, clinical practice guidelines and patient journeys (**Figure 4a**).
 - Challenges reported to capture patients' views referred to lack of or poor engagement of the community, including poor response and survey fatigue. Additionally, methodological aspects, such as analysis of results, platform selection, data protection and storage were also highlighted as hurdles (**Figure 4b**).

Figure 4: Main types of projects developed to capture the voice of the wider rare disease patient community within the ERNs (a) and the encountered challenges (b)



- Several case-studies to capture patients voices were presented, including an online survey to assess patients' medical visits to French Centres of Expertise, the development of a core set of indicators collected by a patient registry and a consensus conference (DELPHI process and workshops).
-

'To produce good evidence, you need to have a broad set of skills, but you don't need to master all of them. Teaming up with researchers or survey companies can help to analyse and publish results' - **Jessie Dubief, EURORDIS**

- Developing a culture for people to feel that their opinion matters and show that their voice is considered, was highlighted as a critical pre-condition for success. Approaches to foster this culture included:
 - **Involving the community early on** by taking their feedback into account when developing new projects.
 - **Using diverse communication channels and partners** to reach out a large population e.g., recruiting patients who are in contact with patient organisations and identifying patients with the help of ERN clinicians. Regarding under-represented population groups, other channels could be used e.g., Facebook groups.
 - **Following up regularly** by sharing updates and asking the community for feedback.
 - **Acknowledging contributions** by making participants feel listened to, addressing their comments and answering questions they share with you.
 - **Sharing project results** by sending the results to participants and explaining how those results are being or will be used by the ERN and/or other stakeholders.
 - **Putting your data into action** by using the results of the surveys to create concrete outcomes e.g., gain a better understanding of factors related to quality of life; provide feedback to clinicians on the assessment of their centres; guide policy action, etc.
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'We (clinicians and ePAG advocates) need to ensure that difficult to reach groups are not forgotten in our own processes.' - **Simon Eaton, ERN ERNICA**

Session 4. How Do I Communicate About ERNs' Added Value and Engage My Community

When: 17th November 2022 (10 to 11 am CET)

Background: The rare disease patient community is a diverse community organised around rare disease-specific local, national, European and international patient organisations as well as National rare disease Alliances. In this session participants listened to experiences from a national patient organisation and a National Alliance on the added value and benefits of the ERNs.

No of attendees: 66 participants

Speakers: Allison Watson (ePAG ERN EpiCARE) and Gabor Pogany (Rare Disease National Alliance of Hungary & ePAG ERN ITHACA). The session was moderated by Ariane Weinman (EURORDIS).

[**Watch the recording here**](#)

[**Find the slides presented by the speakers here**](#)

Key takeaways:

- The ERNs were described as 'a new era of patient engagement', as they have been creating many avenues for involvement at the national but also at international level.
- Participants highlighted the potential of the ERNs to improve patient care through European cooperation in the development of clinical practice guidelines, patient registries, and virtual expert advice.
- Patient representatives and organisations were highlighted as an asset for the ERNs, as they bring a unique perspective and set of skills to the ERNs. The expectation is that they can contribute to map and identify common unmet needs to promote a more holistic approach to patient care. At the same time, patient organisations can also directly benefit from the network ePAG advocates create within the ERNs. The ultimate beneficiary of this virtuous circle is the wider rare disease patient community in Europe and eventually, beyond.

'No country is rich enough to deal effectively with all the thousands of rare diseases, to build enough knowledge and capacity for each of them. Cooperation at European level is a huge added value!' - **Gabor Pogany**, Rare Disease National Alliance of Hungary & ePAG ERN ITHACA.

- Several examples of patient-led national action to integrate ERNs into national healthcare systems and steer health decision-makers at local level were shared:

- **Romania:** The government has created a working group on rare and genetic diseases to transfer knowledge from the ERNs to the national context and work on the upcoming Joint Action for integration of the ERNs into the Romanian healthcare system.
- **Netherlands:** The National Alliance has been hosting meetings with Dutch patient representatives involved in the ERNs to share best practices, namely on how to work together, and disseminate information on the ERNs to the patient community. In 2022, they grouped their members into the 24 ERN disease groupings and launched a pilot project to foster knowledge and information sharing between Dutch ePAG advocates and the national patient organisations working in the same disease area. To do so they are using a digital platform (<https://huddle.com/>).
- **Italy:** ePAG Italia, a working group of Italian ePAG advocates and the Italian rare disease National Alliance (UNIAMO), was created in 2019 to collaborate with national stakeholders to raise awareness of the works of the ERNs in Italy

Conclusions

Session 1 revealed some of the challenges faced by ePAG advocates, such as the difficulties to commit the time required, difficulties to find new volunteers and onboarding new ePAG advocates. Additionally, ePAG advocates who have a leadership role within their ePAG reported other challenges linked to priority-setting and team management.

Session 2 focused on how patient partnership has been progressing in the ERNs. In this area, there is still room for improvement to ensure that patient representatives have an equal voice in the ERNs and are involved early on and in a systematic manner.

Developing the competencies to build a collaborative working environment between ePAG advocates, clinicians and ERN project managers is a pre-requirement to co-design activities that address the needs of the community. Everyone showed their commitment to work towards developing these competencies, although it was widely recognised that this will be a lengthy and complex process, requiring substantial resources.

Session 3 highlighted the need to develop tools and methods to systematically listen to the community to inform the ERNs priorities, as well as to monitor what is working and what could be improved. Additional insights shared around this topic were:

- Community's feedback about patients' experiences and needs are gathered in a wide range of ways within the ERNs, and there is no one-size-fits-all approach. Instead, continuously listening to people and communities using a combination of methods and tools can build a more comprehensive picture of people's needs and preferences.
- ERNs must invest in developing a systematic listening culture. To do so, they should develop efficient feedback, and where possible common, collection mechanisms across disease groups and ERNs to listen to and learn from communities.
- There are many communities that might not be reached through 'traditional' methods or communication channels, such as surveys or workshops. But involving them is relevant and can be made possible by using other means e.g., social media-led approaches.

Session 4 featured a general discussion on the value of ERNs for the patient community but, on a different note, a significant theme that emerged in the discussion referred to how patient representatives and organisations can be a critical asset for the ERN by contributing to map and identify common unmet needs to promote a more holistic approach to patient care.

'I hope that this new 5-year cycle (of the ERNs) will feature a clearer understanding of what each party brings to this partnership, clearer definition of roles, healthy teamwork dynamics and consolidate a culture of collaboration and trust.' – Yann Le Cam, EURORDIS CEO
