European Patient Advocacy Groups (ePAGs) Annual Meeting

4 & 5 November 2021

Meeting Report

November 2021

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The European Patient Advocacy Groups (ePAGs) meeting took place online on 4 & 5 November 2021. The meeting was organised around the theme of making shared patient-clinician partnership, more like `'business as usual" in the ERNs. It was the occasion for ePAG advocates and ERN clinicians and project managers to exchange about patient-clinician partnerships, learn about inspiring examples of collaboration and explore the development of common practices, behaviours and processes to champion patient-clinician shared leadership partnership. **103 participants (ERN clinicians & project manager and ePAG advocates) attended the first day and 45 ePAG advocates participated in the second day.**

Day 1, 4th Nov 2021

"You are the innovators. You are the social reformers of care not only by voicing it at the European level, but by changing that relationship. And I know it's difficult. I know it's tricky. I know it can be exhausting, but because you're doing something fundamental, you're changing the lines. You're changing the system, which will progressively translate into something more formal and routine in the coming years with regards to the partnership"- Yann Le Cam, EURORDIS' Chief Executive Officer

The objective of the first day was to build a ***common understanding of shared leadership in the ERNs and celebrate good examples of patient-clinician partnership***. The meeting kicked off with an introduction and an interactive session, followed by a keynote speech by Nick Sireau and panel discussion. In the afternoon, participants learned about and discussed concrete examples of shared leadership, during 4 parallel sessions titled: 1) Structuring patient involvement in the ERN Governance, ePAGs as associated partners in the ERN EURACAN 2) Partnering in the development of clinical decision support tools: ADKP in children consensus statement 3) Partnering to set up the NMD registry, and 4) Partnering in the production of good quality information: The VASCA Magazine.

Introduction

Yann Le Cam opened the meeting by giving insight into the ambition of an **'EU health system for rare diseases (RDs)'**, and the role of the ERNs as the operational arm of this system. Specifically, the ERNs will be instrumental to define and deliver a full basket of cross-border healthcare services for RDs and advance research. . Due to their critical role in the years to come, he emphasised the importance of getting the patient-clinician partnership dynamic right within the ERNs. He reminded the audience of the Rare2030 Recommendations that define patient partnership as 'a mutual relationship between all stakeholders, one that goes beyond involvement, engagement, and empowerment, where people living with a rare disease routinely and formally inform policy reflections and decisions'.

You may access the transcript of Yann Le Cam full speech **here**.

Panel discussion: How can we make shared patient-clinician leadership "business as usual" in the ERNs?

Nick Sireau from the AKU Society introduced the session with a keynote speech about his leadership journey as a patient advocate, and was then joined by Silvia Aguilera (ReCONNET ERN), Alexis Arzimanoglou (EpiCare ERN), Michelle Battye (eUROGEN ERN) and Yann Le Cam (EURORDIS). Throughout the discussion, participants learned from the panelists important insights into what shared leadership means in practice. Specifically, it was stressed that, in order to create a collaborative working environment, patients and clinicians involved in the ERNs need to have opportunities to meet regularly to plan, set goals and assess progress together in order to be able to **build a space where shared leadership can be nourished.**

All speakers mentioned that insufficient funding, time constraints and communication were the main barriers to making patient-clinician leadership, "business as usual" in the ERNs. Enhancing **equal access to information**, e.g., through common workspaces was seen as critical in order to increase trust and improve collaboration. **Respecting the knowledge** and valuing the contribution that each one brings to the table as well as letting people lead in the areas where they are experts was seen as key while, at the same time, acknowledging that shared leadership does not mean that patients and clinicians have the same roles and responsibilities in the ERNs.

> *"As a patient advocate, in part it is our fault that we have not yet fully achieved shared leadership. It is our job to show what our added value is and it doesn't have to be any special skill or if you have a PhD or if you understand something about medicine in particular. You are the representative of the disease and that is already an added value that should be taken into consideration. But it is our job to bring it to the table and tell the HCPs that we are there to help them. It does take time, but we should be insisting to them that we are to make ourselves known to coordination teams"- Silvia Aguilera, ePAG advocate ReCONNET*

Parallel session 1: Structuring patient involvement in the ERN Governance. ePAGs as associated partners in the ERN EURACAN

This session was presented by Kathy Oliver and Muriel Rogasik from EURACAN. The speakers explained the governance of EURACAN and presented their Terms of Reference which govern all EURACAN members and partners. ePAG advocates are considered "Associate Partners" of the Network, along scientific societies, and other ERN stakeholders. The speakers explained how their model considers patient organisations to be on an equal footing with any other Associate partners and how ePAG advocates are involved in the decision-making processes. This led to a conversation about what other ERNs are doing to be more inclusive of ePAG representatives in their own decision- making processes. The speakers explained how an adequate governance structure is one of the key features needed to achieve successful patient engagement.

> *"All ePAGs are very involved in all clinical domains, we need them, so it's normal that they have the same status as other members. The term" Associated Partner" was defined at the very beginning of the establishment of EURACAN to ensure every member has the same rights and obligations"-Kathy Oliver, ePAG advocate EURACAN*

Parallel session 2: Partnering in the development of clinical decision support tools: ADKP in Children consensus statement

Tess Harris and Djalila Mekahli from ERKNet led this session and stressed that the main challenge in developing ADKP in Children consensus statement is the perception that ADKP is an adult disease. They explained the controversy surrounding testing for ADKP in children as there is no effective treatment to help them and if diagnosed early, they will be medicalised very early on in life, which could cause stress in the families. They went on to emphasise the importance of the role of patient representatives in changing the way ADKP is perceived and the need to include the voice and experiences of children and their parents in relative discussions to help with dissemination of information. Healthcare professionals need to take lead from patients with a good knowledge and understanding of the disease so that the clinical guidelines can be developed accordingly.

> *"Perfect partnership is founded on establishing a shared understanding and common goals. Invest time in building personal relationships with the clinicians, through any and all face-to-face opportunities. Patient leads must secure and maintain an up-to-date knowledge and be recognised as an expert".- Djalila Mekahli, UZ Leuven*

Parallel session 3: Partnering to set up the NMD ERN registry

François Lamy and Teresinha Evangelista from EURO-NMD spoke about how they worked together to ensure that the patient perspective was included in the development of the NMD ERN registry. They stressed that clinicians and all other relevant stakeholders should ensure patient involvement from the beginning, in the elaboration and implementation of the registry development process. They explained that a collaboration from the onset of the project came naturally to them as patient advocates are embedded in the governance and decision-making structures of EURO-NMD. However, they explained how a lack of funding is one of the main barriers to developing the registry, therefore patients and clinicians need to take it upon themselves to achieve a successful registry. They concluded that engagement from both sides, trust and open discussions are key to succeed in the collaboration.

> *"The NMD registry is a collaborative effort and represents a unique opportunity to the NMD communities to communicate and exchange knowledge, experience and news". - Teresinha Evangelista, ERN NMD Coordinator*

Parallel session 4: Partnering in the production of good quality information: The VASCA magazine

Petra Borgards and Leo Shultz Kool explained how patient representatives and clinicians in the VASCA sub-network that belongs to VASCERN had collaborated to develop the VASCA magazine. The project was led and managed by the patient representatives, the clinicians accepted this leadership role and were responsive and engaged to ensure the good quality of the magazine. The VASCA sub-network has put in place the tools and processes to facilitate regular collaboration between ePAG advocates and clinicians on different activities, also an ePAG lead attends the monthly meetings held by the clinicians. The group has managed to create a climate of good collaboration and trust enables a climate where people feel free and comfortable to take initiative and lead on assignments. The speakers underlined that they build on each other's strengths – each leading on different areas where we are stronger. They went on to stress the importance of clinicians being open to listen to the patients' thoughts and ideas.

> *"In any ERN related activity, the clinicians can speak for themselves but when you represent a patient group, that's different, one has to express the consensus view, hence we need more time to get back to the community and then convey agreed messages from that group. So, this must be taken into consideration when planning any activity" Claudia Croccione, ePAG advocate VASCERN*

Please see below the presentation for Day 1, incl. presentations of the parallel sessions as well as the common note taking document:
http://download2.eurordis.org/epag/FINAL%20Day%201%20all%20ePAG%20meeting%20full%20presentation.pdf

https://download2.eurordis.org/epag/Day%201-All-PAG%20meeting-%20%20Common%20Note%20Taking%20Template%20%282%29%20%281%29.pdf

The recordings for three of the four parallel sessions can be found below:

1. Structuring patient involvement in the ERN governance: ePAGs as Associated Partners in the ERN EURACAN
https://drive.google.com/file/d/1CT3uLCyZ9T3A99Uks4Fu45xsVv2xhaVg/view?usp=sharing

2.Partnering in the development of clinical decision support tools: ADKP in Children consensus statement
https://youtu.be/7BYHOKwupXM

3.Partnering to set up the NMD ERN registry
https://youtu.be/oFoT_JYnaWQ

Day 2, 5th Nov 2021

The objective of the second day of the all-ePAG meeting was **to *give ePAG advocates enough time to reflect together on the takeaways from Day 1 and share what specific steps could be taken to improve collaboration*.** During multiple breakout discussions, participants explored what good, shared leadership practices and behaviours look like, what is already in place, and what is more challenging to implement as well as what steps are needed to turn these into practical action in the ERNs. We highlighted some of the main themes alongside corresponding activities and/or behaviours below:

Key takeaways from Day 2 (emerging themes)	**Activities and/or behaviours needed to implement shared leadership in the ERNs (proposals)**
Creating a shared leadership agreement	• Identify **ground rules** for patient-clinician collaboration e.g. identify together shared goals, agree on how to assess progress, distribute responsibilities, be clear about who brings what. • Develop Patient Engagement (PE) **guidance** e.g. In defining how patients & clinicians can work together

	on certain activities such as in clinical practice guidelines development or others. ● Explore possibility of establishing a **cross-ERN joint working group on PE** with ePAG advocates, ERN clinicians and project managers so that exchanges can happen more regularly and informally. ● Define **measures of success** and ensure that the patient-clinician collaboration is embedded in the assessment, monitoring and evaluation pillars of the ERNs as well as regular surveys on perceived quality of collaboration to ePAG advocates and clinicians.
Direct communication and Relationships	● Create **opportunities** for ePAG clinicians and patients to meet to share observations, comments and thoughts in order **to advance towards achieving common objectives** (in-person meetings would be preferable!). ● Agree on processes for **information sharing** to ensure equal access to information e.g. Patients and clinicians use the same workspaces and tools. ● Improve **communication** around patient-clinician collaboration through **different tools** e.g. magazines, newsletters, videos, connecting platforms/forum, virtual/face-to-face meetings and animation video, explaining how clinicians and patients can contribute in different ways to achieving ERN objectives. ● Establish the communication around the **value** of the ePAGs as a resource to of the ERNs (and demonstrate the added value).
Building trust and active listening	● Build trust by **active listening** e.g. Clinicians need to acknowledge and respect the expertise of the ePAG leads and express support for their work. They need to acknowledge the **expertise of ePAG advocates**, exhibiting curiosity, with the intent to learn and involve ePAGs in all aspects of their medical 'journey' (e.g. treatments, research findings etc). ● Create a **transparent work environment,** allowing open communication which encourages contributions and encourages patients to lead on projects where adequate (e.g. VASCA magazine).

Training and peer learning	- Develop a more structured **induction** for ePAG advocates and clinicians e.g. Governance, organisation of the Network and ePAG advocate roles. - Organise mentoring for new clinicians and ePAG advocates by experienced ePAGs and clinical leads. - Increase **peer to peer learning** e.g. By sharing good practices of joint patient clinician collaboration in smaller groups. - Joint patient-clinician **training** to improve the collaboration and communication.

You may find the notes from the 4 breakout discussions and the recording of the reporting back from the group discussions here:

http://download2.eurordis.org/epag/Day%202%20note%20taking%20template.pdf

https://youtu.be/7Bn6QmEvd40

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