



ERKNet

The European
Rare Kidney Disease
Reference Network

ePAG Exchange of Good Practices: *ERKnet Patient-Clinician Feedback Session*

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ERKnet Patient/Clinician Feedback Session: Objectives

Where do we stand right now?

Overall patient/clinician collaboration in ERKnet is quite okay.

Patients & clinicians have learned to work together in the last ePAG manager in the ERN coordination team,

Most ePAG advocates are involved in their WGs (this working best when strong relationships have been built already before the ERN)

Formalised processes of patient involvement are still missing and early involvement of patient in projects is “not a natural reflex” of the clinicians.

Cooperation is mostly asked in cases where patients are needed for e.g. guideline re-reading or when a project is almost finished. But there are good examples of cooperation as well.

Specific **aims** of the feedback session include:

- Build strong collaborative ties between ePAG advocates and clinicians in the WG
- Build rapport, common ground and exchange about the perceived quality of the collaboration
- Agree and set common goals for the next year in terms of collaboration

Participants: 3 ePAG advocates, 2 clinicians, 3 project managers, 1 EURORDIS facilitator

ERKnet Feedback Session - Personal Experiences (1)

2 questions to gain a better understanding of what participants are thinking:

1. Recall a story of success you were part of this past year in terms of cooperation — when was it and what did you and the team accomplish? What was the value of this collaboration – how would the result have been different if you would not have done it together?

Examples:

- The development of a guideline project and patient journeys were seen as a success of collaboration – better to say: it is a start, again relying on the work group members.
- Identifying the needs of the patient community to define and inform about the clinical pathway of patients with rare diseases was seen as a key collaborative area
Journeys can be used by both patients and clinical experts to explain the clinical pathway: professional experts can explain to newly identified patients how the clinical pathway generally looks like, whereas their patients can identify their specific needs within these pathways.
- Participants found that the ePAG contribution would need to be better mutually defined and early on i.e. well in advance of the beginning of the year or a project.

ERKnet Feedback Session - Personal Experiences (2)

2. Recall a story of a challenge or failure in terms of teamwork that you want to learn from over this past year. When were you disappointed with the outcome of something you attempted? Why do you think this happened?

Examples:

- A clinician expressed a challenge from the past year referring to a past guideline workshop known as [the], 'Best Practices of Success'. The clinician thought of the project as an ideal collaborative effort between patient and clinicians but experienced an extremely low response rate when trying to engage with the ePAG.
(Comment: ePAG couldn't find one patient with this disease willing to work with the clinicians.)
- Possible reasons for low engagement could include the fact that ePAG advocates do not know exactly what to do in the ERN – it is easier and more successful for them to participate in projects running outside this organisation. Clinicians and ePAG had the feeling, that PROMS have not been finally defined within the working groups which was perceived as another barrier for engagement.
- Some other challenges mentioned included: improving the exchange in working groups i.e discussing in advance what is important for the patients.
- Example: The 1st workgroup meeting this autumn happened to be not in reach for the patients, included in a big congress and wrong links sent out.

ERKnet Feedback Session: Objectives for the next year

- Define common short and long term objectives and scope the ePAG contribution for ERKNet in general and for each WG at the beginning of each year
- Conduct recurrent meetings at the beginning of the year and then after six month between clinical and patient lead of the WG to mutually define ePAG contribution to the yearly work plan of the WG
- Conduct Specialist-Webinars for patients with pre-collected questions and simultaneous translation
- Include patient's voice and knowledge in webinars for students and young clinicians, try to teach them early that patients are the experts (but not from day one after diagnosis)
- Disseminate Patient Surveys via patient associations -> patient centers research question to be discussed in the workgroup
- Check translation tools for particular conferences when involving patients
- Conduct another patient/clinician feedback session in about 6 months to see if we met our objectives
- The almost 35 new centers in ERKNet should be asked to introduce their patients /patient groups to the ePAG, so mor countries will be represented here.
- It is a good moment to have changes in the ePAG leading team – so the long time planned resignation of the ePAG chair and take over by another chair and vice chair with new ideas and a fresh portion of patience went smoothly.

Patient/Clinician feedback session – Lessons Learnt

- Overall the participants were satisfied with the outcome of the feedback session
- All Participants felt heard and had a fruitful discussion, but real trust will not be generated before it shows up that spoken words become reality in the future.
- Individuals who are willing to be open-minded and share ideas for the benefit of the team play a vital role in the success of these feedback sessions. Perhaps it could be a good idea to have meetings like this twice a year. Expectations and objectives may be aligned and clarified whenever problems come up and a common understanding of an ideal future collaboration can be built.
- Building good individual contact may set a precedent for other ERN teams and working groups. In this way, good practices in terms of collaboration can be made aware of and adopted by others.

Patient/Clinician feedback session - Top Tipps

- Make sure participants understand that feedback is a shared leadership responsibility
- Prepare participants ahead of the meeting by reflection on specific questions and making them aware of the process and objectives of this meeting
- Encourage people to contribute and allow time for reflections/appreciate contributions. This will show participants that their contributions are being heard and valued and it creates a positive atmosphere for all involved.
- Each speaker should be mindful of allowing time for everyone to speak and each participant should speak uninterruptedly.