

Annual ERN Patient-Clinician Feedback Session Guidance

Purpose:

There is a need to build and nurture a strong patient-clinician collaboration in the ERNs. Working together will contribute to improve the Networks' responsiveness to patient needs and will ultimately lead to better outcomes for all.

“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”. Rare2030 Recommendation 5

As one way to build rapport and to improve the collaboration between ePAG advocates and ERN clinicians, the ePAG Steering Committee recommends to organise regularly reflection sessions – at a minimum on an annual basis during the ERN annual meetings. The purpose of these sessions is to clarify shared purposes, and build a common understanding of roles and responsibilities. **As such, the purpose of the sessions is not to conduct a formal reporting on common activities but rather to use them as an opportunity to build rapport, common ground and exchange about the perceived quality of the collaboration.**

Since building an effective patient-clinician partnership is a shared responsibility, the idea is for ePAG advocates and clinicians to provide their perspectives and mutual feedback on different aspects of their collaboration.

The following document is meant to serve as a general guidance to organise these reflection sessions, providing an outline of its possible structure and content.

Target audience:

The target audience for the reflection session may include ePAG advocates and ERN clinicians actively collaborating in the different working groups and the board of the ERN. This may include the ERN coordinator and project manager as well as leads of ERN working groups and other relevant clinicians. We suggest to limit the number of participants to 10-15 and to create a trustful atmosphere where people will feel comfortable sharing and discussing, as in a team meeting.

Before the patient-clinician feedback session:

1. Identify 2 moderators who will prepare and moderate session (possibly one ePAG advocate and one clinician). Where needed, these facilitators may be supported by EURORDIS.
2. Request and confirm a 2 hour slot for feedback sessions during your ERN annual meeting (approx. 3 months in advance) or organise an ad-hoc meeting at another time throughout the year. If you organise it during the annual meeting, try to secure also a 15 min slot to report back in the plenary session – jointly ePAG lead+ERN Coordinator.

3. Discuss approach and structure of the session with ePAG leads and Project managers and/or ERN coordinator well in advance of the meeting (approx. 2 months) incl. who to invite to the session and how to approach the clinicians to make sure they will be interested by the session,.
4. Prepare agenda and timeline of session depending on the number of participants – calculate speaking time keeping in mind that each participants should be able to a) introduce themselves shortly and b) there should be enough time for everyone to express their views. c) there should be enough time to resume the session, agree on the outcome and next steps.
5. Ask ERN coordinating team to invite participants to the meeting and ask participants if they would like to include additional items in the agenda
6. Share the draft agenda and ask the participants to reflect on some questions ahead of the meeting. You may use the questions below:
 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? Why do you think this happened? What was the value of this collaboration – how would the result have been different if you would not have done it together?
 2. Recall a story of a challenge or failure in terms of team work that you want to learn from over this past year. When did something go wrong? When were you disappointed with the outcome of something you attempted? Why do you think this happened? What new challenges or opportunities did it create?
 3. The perceived level of satisfaction on how ePAG advocates and clinicians are working together as a team to advance ERN goals: strongly agree, disagree, agree, strongly agree.

Dynamics of the session:

- Tour de table: everyone should get the chance to introduce themselves shortly (1-2 minutes)
- Each person answers the questions sent ahead of the session (possibly try to identify 1 volunteer before the meeting that starts off as an ice-breaker)
- After each speaker allow for space to reflect on what has been said (1 / max 2 reflections). The discussion should allow you to assess where you are in terms of your collaboration, what works, what doesn't and identify misalignments in terms of purposes, roles and responsibilities.
- Going forward, reflect on the following questions:
 - Set one or more shared purposes for the year
 - Reflect on options available and/or necessary and sufficient conditions to reach the goals
 - Decide what you will do to reach goal
- Closing and follow-up: agree on key actions for collaboration for the year

As moderators,

- Make sure participants understand that feedback is a shared leadership responsibility
- Be clear on the process and objective of the meeting
- Keep the tone positive by encouraging ePAG advocates and clinicians to say what they appreciate about others' contributions
- Keep track of timing keeping in mind that each participant should be able to contribute
- Allow each participant to speak uninterruptedly
- Each speaker should be mindful of allowing time for everyone to speak – if necessary remind them

No pressure
to solve all
problems

- Help facilitate difficult conversations - don't avoid them because it might help to identify latent conflict that can be addressed on time before escalating- Try to identify the sources by asking the right questions, try to create options for agreement and get them to focus on common grounds.
- If needed, you may invite EURORDIS staff for support to facilitate the session
- Keep the session conversation going focusing always the discussion on the 2-side collaboration:
 - What are you the most proud of?
 - What are some of the obstacles you have faced?
 - What do you like most/least about your team work in the ERN?
 - How do think that collaboration could be supported more effectively?
 - What can be done to support team work more effectively?

After the session:

- If time allows, you could try to secure a 15 min slot to report back during the annual meeting plenary session – joint report by ERN Coordinator + ePAG lead
- Prepare a summary with key learnings and suggestions for future actions, share with ERN Coordinator and agree on a final version.
- Share with all ERN clinicians and patient advocates – for example via a joint email signed by the ERN Coordinator + ePAG leads.

Contact

For questions or comments please contact EURORDIS at Lenja.wiehe@eurordis.org