

ANNUAL ERN PATIENT-CLINICIAN FEEDBACK SESSION

GUIDANCE:

ERN LIVER AND ERKNET

DATE Wednesday 22nd September 2021

Area	ePAG Good Practice Call: Patient/Clinician Feedback session pilots: ERN RARE LIVER and ERKnet
Duration	90 minutes
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1. OVERVIEW OF GOOD PRACTICE

i Founded in 2017, European Reference Networks (ERNs) are currently consolidating their structures and transformation partnerships comprised of clinicians and patient representatives (and other stakeholders) responsible for managing resources, delivering standards and improving the health of the rare disease community. In doing so, ERNs rely on clinicians and patients working closely together, to help foster care tailored to the needs of the rare disease patient community. Therefore, there is a strong need to build and support patient-clinician collaboration within the ERNs. “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).

ERN RARE-LIVER and ERKnet are the first ERNs to pilot yearly patient/clinician reflection sessions as one of the main ways to build rapport and improve the collaboration between ePAG advocates and ERN clinicians. The aim of these sessions is to understand current attitudes, barriers and needs of patients and clinicians in terms of their collaborative efforts to advance the objectives of their ERN. Therefore, the feedback sessions are used to clarify shared purposes in order to build a common understanding of roles and responsibilities, to build rapport, common ground and exchange about the perceived quality of the collaboration. Finally, the sessions should be used to agree and set common goals for the next year in terms of collaboration. During the Good Practice call on 22 September, the lead patient representatives from ERN RARE-LIVER and ERKnet will

present their impressions and outcomes of the two pilot feedback sessions and provide top tips to other ePAG advocates in regard to how to prepare and conduct these sessions.

2. PATIENT ENGAGEMENT AND CONTRIBUTION TO IMPROVEMENT OF CARE

- i** One of the main ways in which we can improve the care of rare disease patients is through effective patient-clinician partnership and collaboration to advance the work and objectives of the ERNs. It fosters both task-related and social dimensions of group functioning, such as by having a shared purpose and social support, which, in turn, enhances productivity and organisational performance. A good patient-clinician collaboration will contribute to improve the Networks' responsiveness to patient needs and will ultimately lead to better outcomes for all.

3. SUCCESS FACTORS AND LESSONS LEARNED. SHARE YOUR TIPS!

- i** **Success Factors for the meeting:**
- 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.

Lessons Learned:

Participants of feedback sessions feel heard and agree on common objectives which, we believe, makes them committed to bring more resources to the task, share more information and experience higher commitment with the team, generating greater levels of trust and respect. This appears a valuable asset especially in managing multidisciplinary teams consisting of both clinicians and patient representatives who frequently experience tension due to divergent skills and ways of thinking.

Building good individual contact and tools and processes for collaborative efforts 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. Expectations and objectives may be aligned and clarified and a common understanding of an ideal future collaboration be built. This will be very helpful in moving forward to achieve success and fruitful discussion in ERN team meetings and other ERN initiatives. 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.

Selection criteria:

1. All sections are complete
2. The description of the good practice is clear
3. The good practice is innovative in terms of its impact and results
4. The good practice is easy to replicate