



**ERN RARE-LIVER
PATIENT ADVOCACY GROUP**



Named Patient Representatives



**European
Reference
Network**

**Hepatological Diseases
(ERN RARE-LIVER)**

ePAG Exchange of Good Practices: *ERN RARE-LIVER Patient-Clinician Feedback Session*

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EURORDIS.ORG



Introduction: Developing a Patient/Clinician collaboration culture

- ERNs transform partnerships comprised of clinicians & patient representatives (and other stakeholders) responsible for managing resources, delivering standards and improving the health of the rare disease community.

*“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)*

- In 2021, ERN RARE-LIVER and ERKnet, piloted patient/clinician feedback sessions as a tool to improve the collaboration between ePAG advocates and ERN clinicians.

Introduction: Feedback Session - an important tool

EURORDIS

The overall aim of the feedback session 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

Specific aims include:

- Clarify shared purposes in order to build a common understanding of roles and responsibilities
- 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

ERN RARE-LIVER: Engaging in a successful partnership

Goal: to improve collaboration between patients reps and clinicians inside ERN RARE-LIVER

The keys of success:

1. Project definition and Survey design – Precise clearly where to go, objectives to match
2. Deployment with the help of ERN office – online during 30 days but sending reminders
3. Analysis and Synthesis – Preparation of a document showing the present situation
4. Meeting with WGs Leads and ePAG Named Patient Reps to present the results
5. Organisation of Feedback session with EURORDIS and ERN LIVER coordination office help
6. Building a mutually agreed concrete plan for 2022 (fruit of survey + feedback session)
7. Presentation during the ERN LIVER annual meeting

Next steps: monitoring progress and follow up survey after 1 year

Project Form ERN RARE LIVER



Hepatological Diseases
(ERN RARE-LIVER)

Project Form

Date: April 2021

Name of the project: Patient Representative and Healthcare Professionals (HCPs) Survey for a better collaboration in ERN RARE-LIVER

Name of requester	Leads Patients Representatives	Working group/Pillar	Transversal Project
Definition	Ask Patients and Health Care Professionals how they respectively see patients' role, and which are possible threats and ways to improve collaboration	Objective	Understand difficulties and positive points, quantify them. Final objective: Improve Patients and HCPs understanding, working together, collaborating, leading to better results, realize projects that make sense and build a mutual sense of motivation. Ultimately better outcomes for patients

1. Description

Online Survey prepared by Lead Patients, asking about the role of Patients Representatives, most important qualities of both patients and HCPs, other qualities, the principal difficulties for cooperation from both sides, other issues, and how mutual involvement should be.

From the analysis of the results, concrete actions will be defined and proposed (education, communication, etc). This allows to define a comparison parameter, enabling to check if the actions led to situation improvement – by April 2022 – and what should be still implemented.

2. Estimate timescales

1 month online at EU website. Until April 30th, 2021

Final analysis: June

Restitution + Synthesis meeting: June 10th

Connect meeting: June 30th (1H30meeting) – Present the analysis, exchange between Patient Reps & HCPs and establish a progress plan

3. Support from: ERN Project Manager (Aileen)

Make available the Survey online, send the Survey link to all participants, send reminders.

Participate of the restitution + synthesis meeting

Prepare some graphs with the answers – validate which will be presented

Co-organise the meeting between Patient Reps and HCPs

4. Support from EURORDIS (Lidia)

Participate of the restitution + synthesis meeting

Co-organise the meeting between Patient Reps and HCPs

Bring tools to help the meeting

5. Concrete actions to be defined:

They will be defined after the restitution, for example education, communication, definition of good practices, etc

Update : June 14th 2021

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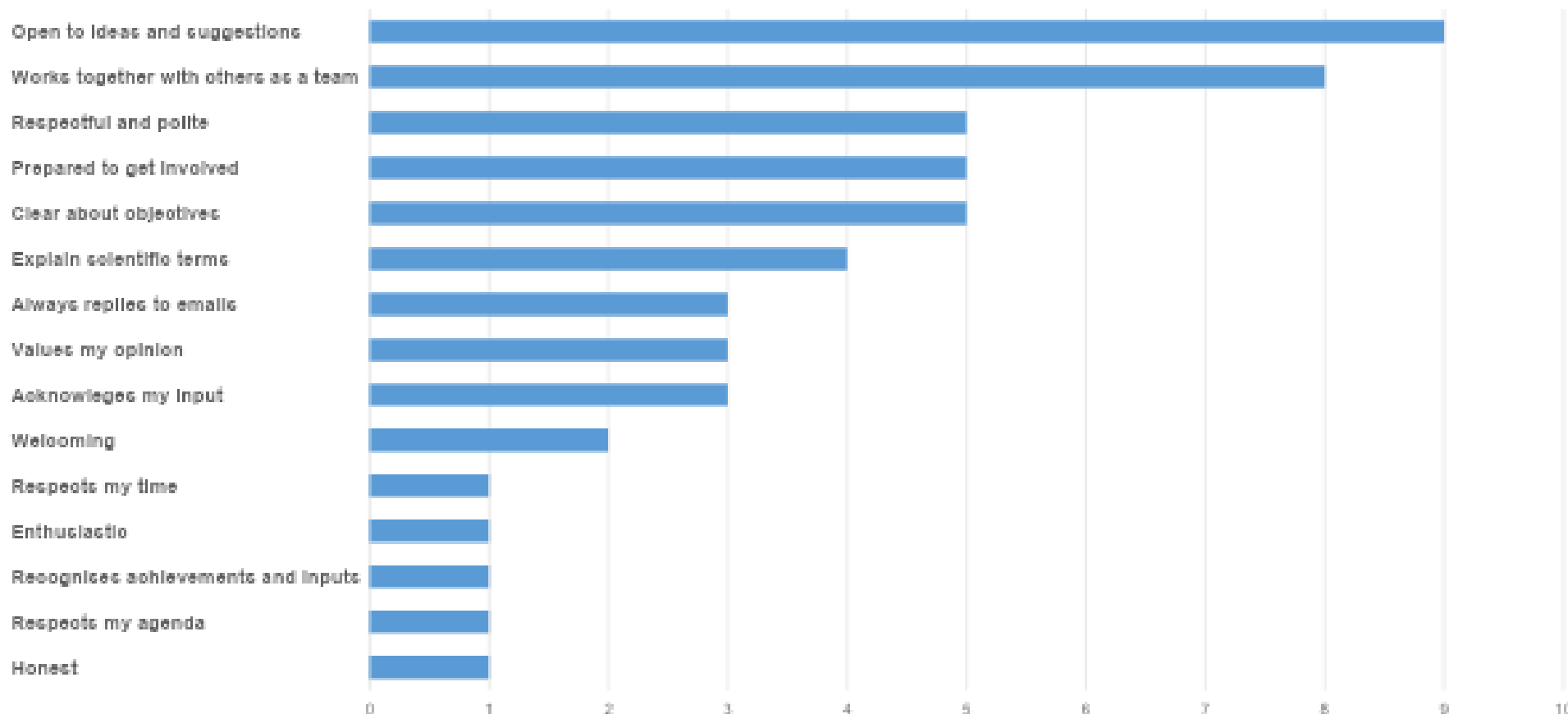
ERN RARE-LIVER: Engaging in a successful partnership

- A patient/clinician **Collaboration Survey** to detect areas of progress. The results were presented in a meeting, which took place at the end of June.



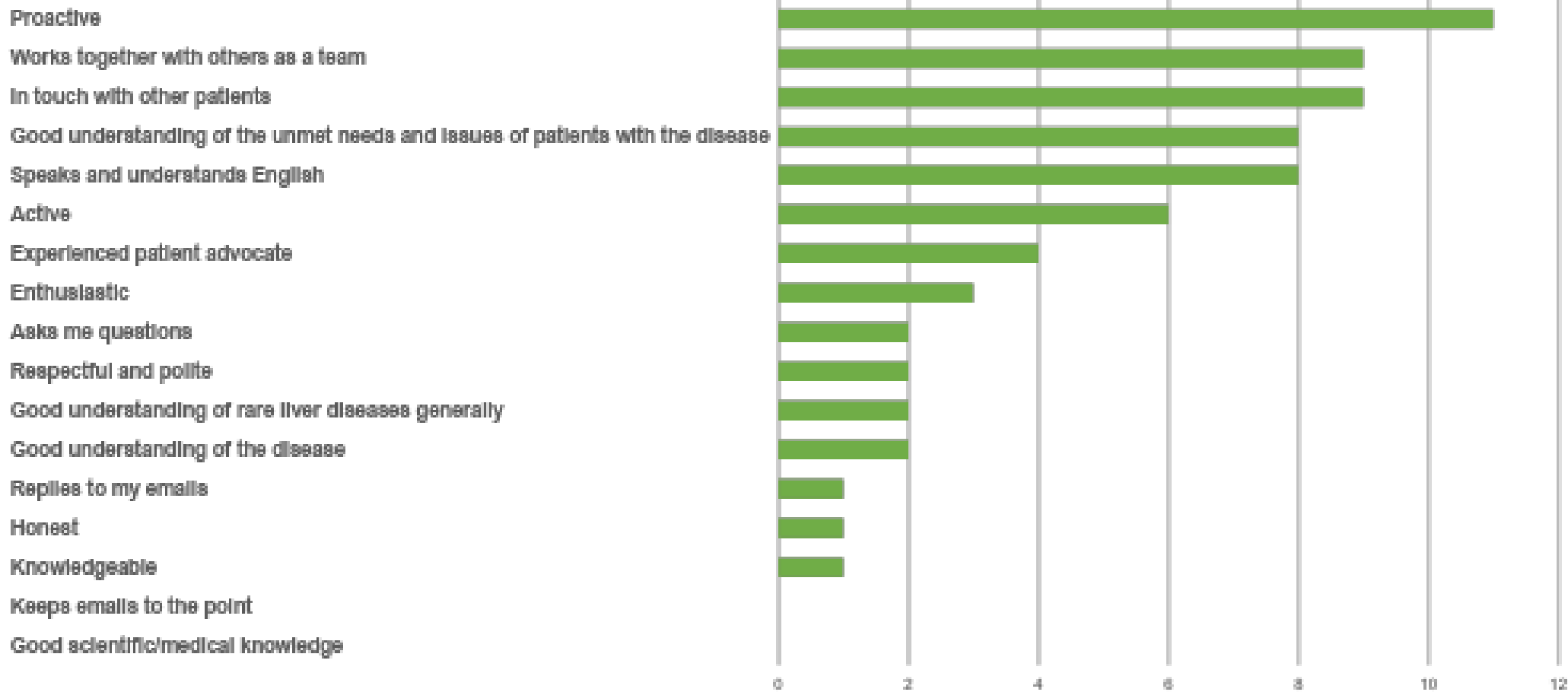
ERN RARE-LIVER Survey results- answers from patient representatives:

The most important qualities of the ideal HCP when collaborating with a NPR ?



ERN RARE-LIVER Survey results- answers from healthcare professionals:

The most important qualities of the ideal ePAG NPR when collaborating with a HCP?



ERN RARE-LIVER Feedback Session – the Agenda

Introduction

2-3 min.

Welcome, purpose of the meeting, agenda (Lenja and Aileen)

Tour de Table

max. 1 min. per participant

Please state your name, country, organisation/centre, and ERN working group(s)

Your Personal Experiences

6 min. per participant + 1-2 reflections

Please answer the questions sent ahead of the session:

1. How satisfied are you with the way in which patient representatives and clinicians are working together to advance the goals of ERN RARE-LIVER? (max. 3 sentences)
2. 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?
3. 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?

Goals for The Next Year

15 min.

The participants discuss among each other 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 the goals. Agree on key actions for collaboration for the year.

Closing

2 min.

Final Remarks, Conclusions (Lenja and Aileen)

ERN RARE-LIVER Feedback Session - Personal Experiences:

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

1. How satisfied are you with the way in which patient representatives and clinicians are working together to advance the goals of ERN RARE-LIVER?
2. 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?
3. 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?

Personal Experiences: Reflections on Question 1

1. How satisfied are you with the way in which patient representatives and clinicians are working together to advance the goals of ERN RARE-LIVER?

- A lot of progress has been made but many things need to be improved. We need to have a clear communication of goals and objectives i.e. WGs need to be well organized and communication must work well so needs can be addressed to the ERN.
- It is important to extend the network to more countries and their patients to reach patients independent of where they live.

Personal Experiences: Reflections on Question 2

2. 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?

- In most working groups patient involvement works well and there are at least a few successes to report i.e. disease information on the website, translated leaflets, educational videos, surveys.
- We are progressing in the right direction i.e. Transition WG & Unmet Clinical Needs project. Some patient representatives have built stable communication with the clinicians/ lead. Quality of life, guidelines, best practice, surveillance are good transversal topics for a patient/clinician collaboration.
- There are very good examples of dissemination of a survey by patient representatives multiplying the communication to their stakeholder group who then distributed the information to their members.
- There has been a very fruitful experience for clinicians to invite local patient representatives to their centre and involve them in project through the personal contact.

Personal Experiences: Reflections on Question 3

3. Recall a story of a challenge or failure in terms of team work 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?

- There are some groups that are not active at all or that have not defined their goals. Some groups have a focus on scientific topics, while patient centred topics seem not to be of much interest.- This makes it difficult for patients to know how they can contribute.
- Patients are outnumbered by clinicians, which makes in an even bigger challenge to dare involve themselves and speak up in meetings, etc.
- Patients who are active and well involved are still rare. We need to be aware that for most patient representatives and clinicians, work for ERN is voluntarily, which puts a limit to what they can contribute.
- Patients have frequently stated that they felt they were not involved. Therefore, their request is to be involved in projects from the beginning and to be involved throughout the project as much as possible- requests are also not handled satisfactorily in the Hamburg office.
- Clinical care pathways: practical integration support is missing in those pathways or just alluded to. An open question is how we can address the concerns of patients with the other rare conditions that are not covered by the ERN.

ERN RARE-LIVER

Concrete results: Objectives for 2022

- **Each working group appoints 2-3 leads:** 1 adult clinician and/or 1 paediatric clinician as appropriate and 1 patient representative.
- In the beginning of the year: **the ERN coordination team will present the annual work plan of the ERN including the objectives of the year and all working group leads and patient reps need to attend.**
- **Each disease working group must set out clear, short and long term goals, and set up a work plan with tasks for each person in the group to do.** The WG leads should organise separate meeting with their group's patient reps to **discuss the work plan** and where they can contribute. They should **discuss expectations from both sides** and assess the unmet clinical needs of their disease in collaboration with clinicians and patient representatives.
- Patient leads and EURORDIS **must inform patient reps about what is their role in the working groups. Mentoring and/or coaching might be helpful for patient representatives** to find their way into working for the ERN .

and the last but not the least:

- It is important to **extend the network to more countries**, more patient groups with patient representatives. We also need to have the ability to reach patients, independently of where they live.
- The ERN LIVER patient representatives and clinicians **can help patients to create patient organisations locally**.
- **Quality of life, unmet clinical needs, guidelines, best practices, surveillance etc. are good transversal topics** that patient representatives and clinicians can **cooperate within their disease working group**.
- An **“unmet clinical needs” project/group is newly created** and had its first meeting September 3rd, 2021
- The great majority of patient representatives and clinicians work for ERN in a voluntary basis. There is a **need to have motivation**, this, being helped with: valuable and clear objectives, precise goals, as well as **having a pleasant and NO STRESS ambience**.

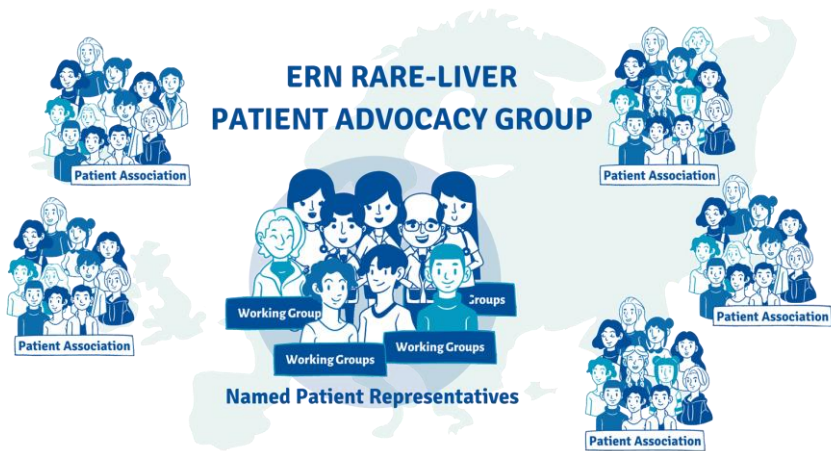
Patient/Clinician feedback session - Top Tipps

- Make sure participants understand that **feedback is a shared leadership responsibility**.
- **Prepare participants ahead of the meeting by asking them a reflection on specific questions** and making them **aware of the process and objectives** of the 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. **The role of moderation is very important as well as taking notes**

Patient/Clinician feedback session – Lessons Learnt

- **Participants needs to agree on common objectives**, leading to a **higher commitment with the team**, generating greater levels of trust and mutual respect. This is particularly useful for clinicians and patient representatives who frequently experience tension due to divergent skills and ways of thinking.
- 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. **Positive and Constructive participants, even if they disagree.**
- This methodology and the experience can help other ePAG advocates to improve the relationship leading to a better collaboration

Thank you!



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