



# EURORDIS ePAG SUPPORT SATISFACTION SURVEY

## Results

December 2022

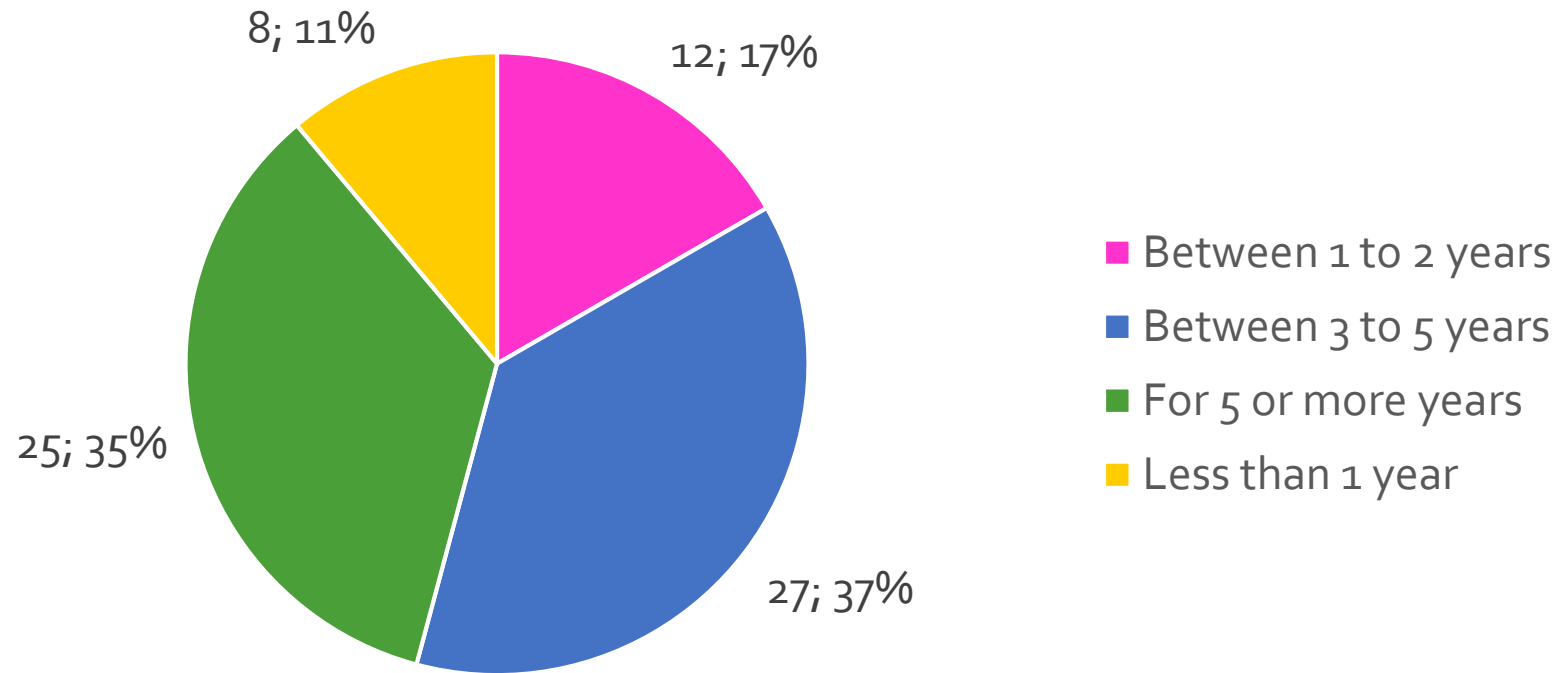
ERN ePAG Team

**EURORDIS.ORG**



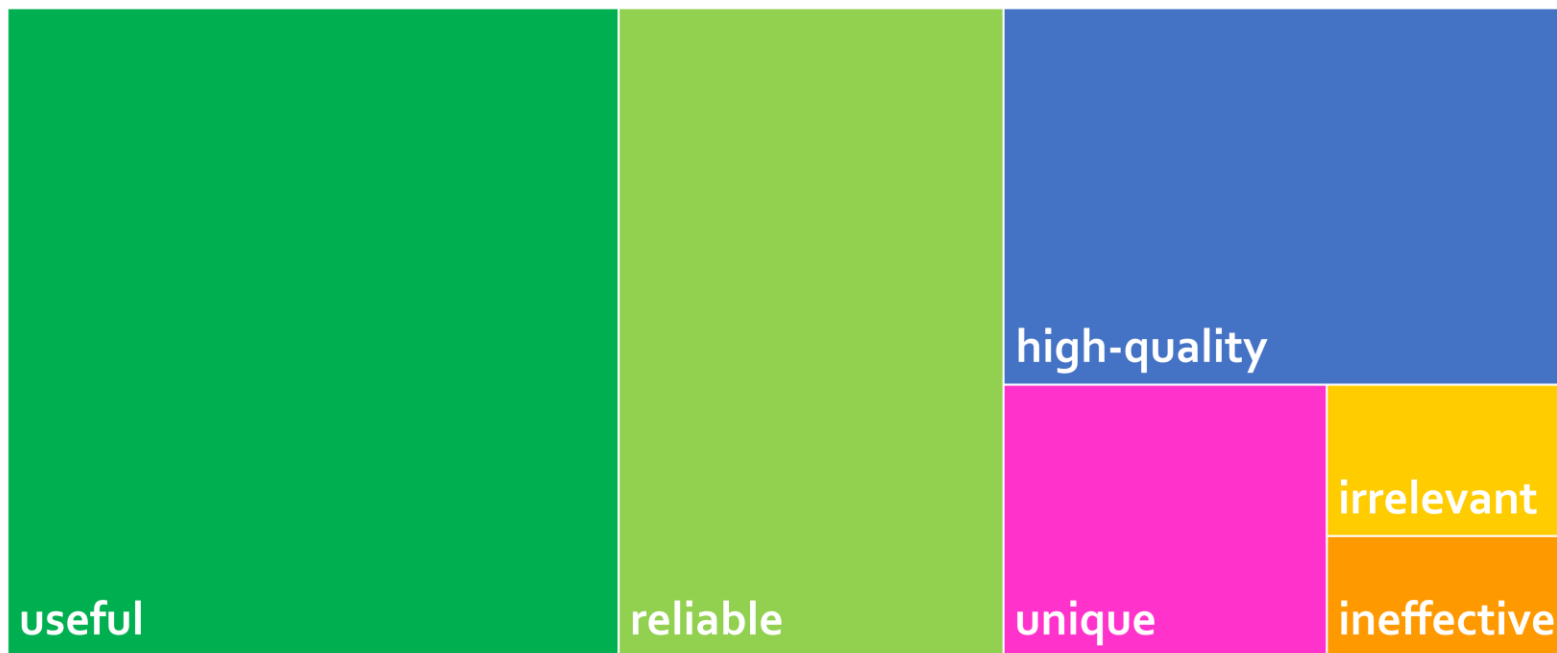
# 1. Time spent as ePAG advocates

71 total respondents



Out of the 71 total respondents 27, 37% had been ePAG advocates for between 3 to 5 years and 25, 35% for more than 5 years.

### 3. Which of the following words would you use to describe EURORDIS ePAG managers support to ePAG advocates



71 total respondents

Most of the respondents described EURORDIS support as useful, reliable and high-quality.

# 4. Overall assessment of EURORDIS ePAG managers qualities

A list of 7 qualities was presented to the respondents (multiple choice) so that they could identify the most valuable qualities of ePAG managers and the qualities they thought they were lacking. A final score was calculated by subtracting the to establish a ranking.

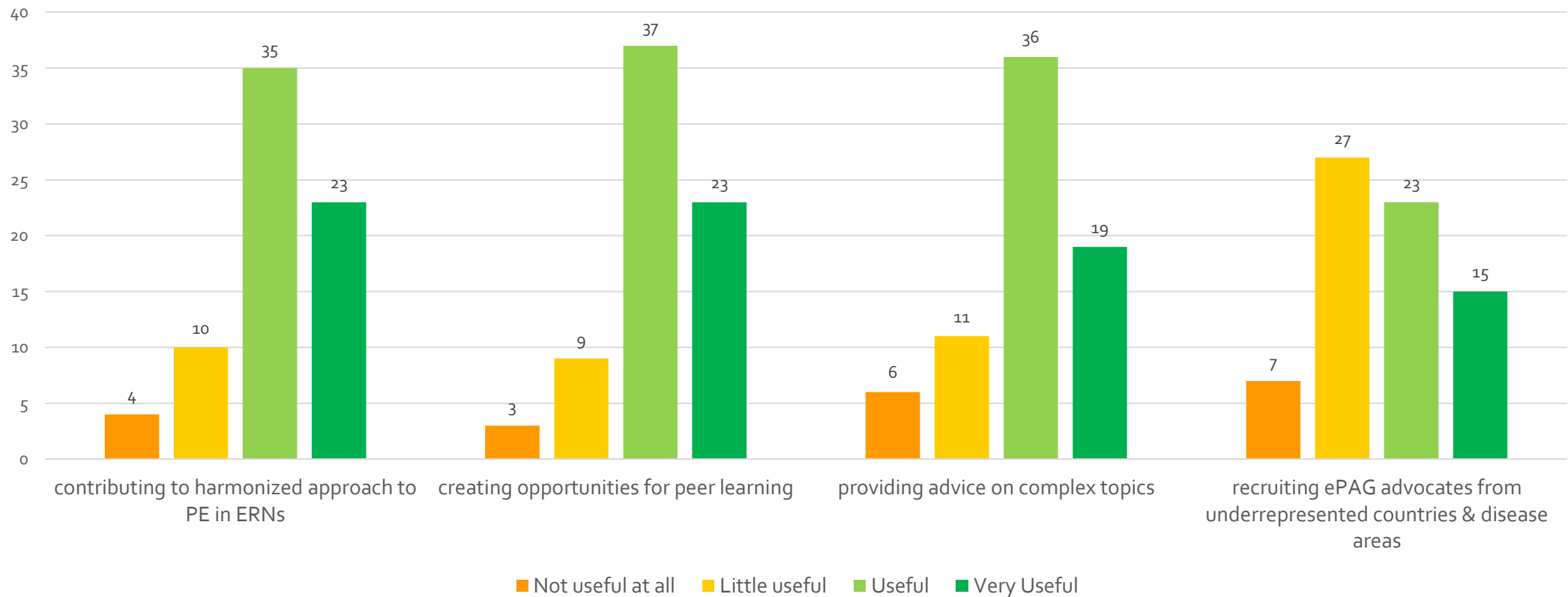
Out of 71 people	ePAG managers lack this quality (number of respondents)	ePAG managers most valuable quality (number of respondents)	Final Score	Ranking
Openness	6.4	14.2	7.8	1
Easy to reach	7.1	13.5	12	2
Responsiveness	7.1	10.7	3.6	3
Ability to share knowledge in simple terms	12.1	10.7	-1.4	4
Help to resolve problems	12.1	9.9	-3.0	5
Proactive	11.4	7.8	-3.6	6
Innovative	14.9	4.3	-10.6	7

Limitations: There were some problems with these 2 questions:

- Not everyone was able to identify who were the ePAG managers: only Lenja,Rita,Ariane or also Matt & Ines?
- Some people responded to the question on lacking qualities because it was mandatory, but they struggle to pick up the lacking qualities
- We did not explain what we meant by innovative, so each respondent was forced t

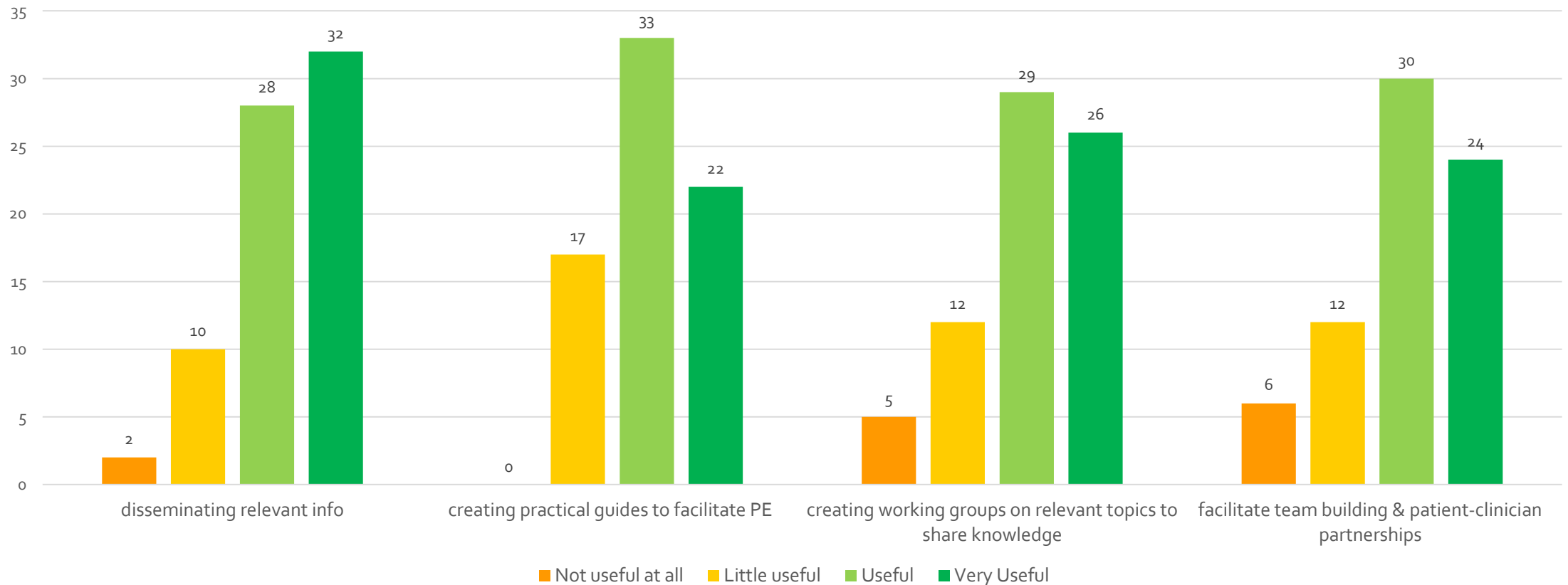


# 8. How useful are these activities for ePAG advocates:



71 total respondents

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71 total respondents

# 9. What are the main activities that you would like EURORDIS ePAG managers to focus on:

1. Facilitating **team building and partnership** approach in the ERNs between patient representatives and clinicians
2. Provide **advice on complex topics**
3. Helping **recruit new ePAG advocates**
4. Establish **clear communication** strategies (e.g. of concrete suggestions: Newsletter ePAG activities, central easily accessible repository of documents) without being overflowing
5. Improve **onboarding of ePAG newcomers** to help them navigate the system

Note: we were reminded to use accessible forms and formats! (e.g., visual impairment/blindness)

## 5. Comments

*'I have been involved prior to and since the formation of my ERN and have been very happy to have EURORDIS guide the ePAGs - bringing their expertise and patient focus approach to what has been a model that has been developed as it goes, without their involvement the ePAG/clinician element might well have been lost and whilst it is still early days for ERNs I see huge potential especially when one sees what certain individual ERNs have achieved.'*

*'As for the training: Ideally the training should be together with the clinicians so that we can hear each other and learn from each other.'*

*'I think that EURORDIS is a great organisation but the business model of the last years focusses too much on financing and getting the project of EURORDIS in shape by the power of voluntary contributions of patient advocates. I think long-lasting contributions of patients advocates should be rewarded financially.'*



## 6. Comments - cont'

*'Many opportunities are offered, but too little taken by us (no capacity, most of the times). I personally have had the chance of open dialogues, good and inspiring communication with EURORDIS managers. I am very grateful for that. But feel that building structures has led to demarcation kind of "against" patients. I would appreciate a closer contact with patients of various nations, low-threshold. We as patient advocates are not taken as we are; it seems we have to be educated (why? our core competency is being patients). I am dreaming of a culture of dialogue at eye level with all stakeholders.'*

*'I think that we should organize a WG on cooperation with the National Alliances on transfer of ERNs in the national health care systems'*

*'EURORDIS should focus more on legal aspects and involve lawyers esp. in questions of data protection. The new legislation planned is good for patients without diagnose but very arguable from diagnosed patients' point of view.'*

*'Question 6 was hard to answer, there was actually nothing I would willingly have marked! THANK YOU ALL!!!'*

*'I didn't feel that there was many support for the ePAGs from EURORDIS, at the exception of the EURORDIS academy and some webinars.'*

*'There are plenty of guides, webinars, but there are too much complex and too long to read or to follow. Most of ePAGS are engaged patient representative into their own country, with many local patient organisation activities. Very often, they didn't start to read documentation or to see webinars, due to lack of time.'*

# 7. Main Conclusions

- It is reassuring that “easy to reach” is the top 2 quality of ePAG managers. Even if we are not providing a 1 to 1 support to each group, they still find it easy to reach us and receive a response.
- The activities that the team is developing are perceived in general as useful or very useful. These confirms that we are on the right path and that the decision to provide more meaningful support, as opposed to administrative support is paying off.
- The lack of consensus regarding ePAG managers ability to share knowledge in simple terms could reflect the different levels of expertise and knowledge of the group, but also the lack of time to read what we produce, attend webinars and digest all the information that we share. In any case, the team needs to reflect on how to adapt our communication style to reach everyone.
- There appears to be a mismatch between how the team perceives itself as being innovative (doing new things, inventing ways to collaborate in the ERNs, coming up with new governance structures, etc) versus how the respondents perceive our activities.
- In future surveys, it would be important to pilot the questionnaire with a small group of participants to detect any shortcomings and refine the wording before sending it out to all ePAG advocates.