*Template questionnaire*

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*Learn more about this questionnaire and how to administer it in the* [*EURORDIS website*](https://www.eurordis.org/publications/assessing-patient-partnership-implementation-erns/)*.*

**Assessing Patient Partnership in the ERN (ePAG)**

We are interested in your feedback about your participation in [insert name of ERN].

This survey includes 21 questions – some questions ask you to rate your level of agreement in response to a statement and others ask for you to provide your comments and feedback. You are encouraged to share your experiences and any information you feel is relevant and will help us to improve our engagement processes.

Please be aware that all the information you provide will be confidential. Should you have any questions about this questionnaire, please contact [name] at [phone] or [email].

Thank you for your participation!

*Source: This questionnaire has been adapted by EURORDIS-Rare Disease Europe from the Public and Patient Engagement Evaluation Tool (PPEET) Participant Questionnaire for ongoing/long-term engagement initiatives.*

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*Abelson, J., Li, K., Wilson, G., Shields, K., Schneider, C., & Boesveld, S. (2016). Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Evaluation Tool. Health Expectations, 19(4): 817-827.* [*https://doi.org/10.1111/hex.12378*](https://doi.org/10.1111/hex.12378)

*Additional questions were added from Evaluating the Impact of Patient Partnering, Ontario Health Quality: https://www.mcmasterforum.org/docs/default-source/rise-docs/partner-resources/3-evaluation-guide-eng-(002).pdf?sfvrsn=82ecaebe\_5*

**Background question**

**1. How long have you been involved in the ERN as an ePAG advocate? \***

* Less than 6 months
* 6 – 12 months
* 1 – 2 years
* 3 – 4 years
* 5 years or more

**Part A. Communication and Support for Participation**

Please indicate your level of agreement with each of the statements below.

**2. I have a clear understanding of the purpose of the ERN. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**3. The support I need to participate in the ERN is available (e.g. online meetings, travel, support from ERN Coordinating team, support from EURORDIS, etc.) \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**4. I have enough information to be able to carry out my role. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**5. What else would you like us to know about how your participation in the ERN is supported?**

**Part B. Sharing Your Views and Perspectives**

**6. I am able to express my views freely. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**7. I feel that my views are heard. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**8. A wide range of views on discussion topics is shared. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**9. The individuals participating in the ERN represent a broad range of perspectives. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**10. What else would you like us to know about how you are able to share your views?**

**Part C. Impact and Influence**

**11. I can identify examples of where my input has influenced the direction of an initiative or a project in the ERN. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

à If Strongly disagree, Disagree, Neither agree nor agree à question 12

à If Agree or Strongly Agree à question 13 and 14

**12. Can you tell us more about why you think your input did not influence the project?**

**13. In what way have you influenced a project? Please choose all that apply. \***

* Contributed to the initial focus of the project
* Contributed to project meeting discussions
* Helped others working on the project to focus on patient/caregiver needs
* Contributed ideas to the project as it evolved
* Contributed to recommendations or decisions made as part of the project
* Other

**14. For each of the items selected in question 13, please share examples of how your influence made a difference. \***

**15. I am confident that the ERN takes the feedback provided by ePAG advocates into consideration. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**16. I think that the involvement of ePAG advocates makes a difference to the work of the ERN. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**17. What else would you like us to know about the influence you think ePAG advocates have had in the ERN?**

**Part D. Final Thoughts**

**18. Overall, I am satisfied with the collaboration between ePAG advocates and clinicians in the ERN. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**19. Overall, I am satisfied with the collaboration between ePAG advocates and clinicians in the working group(s) I am part of. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**20. Participating in the ERN is a good use of my time. \***

* Strongly Disagree
* Disagree
* Neither agree nor disagree
* Agree
* Strongly agree

**21. What else would you like us to know about your experience with the ERN?**