*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 (questionnaire for leadership team)**

We are interested in your views about patient partnership in [name of ERN]. **Patient Partnership in the Network can be defined as a mutual relationship between patients and health professionals where input from people living with a rare disease routinely and formally informs the Network’s collaborative activities and decision-making.**

The focus of this survey is to understand how patient partnership is carried out across the ERN and within the different areas of work. This questionnaire is targeted to assess the views of the ERN leadership team - staff in [ERN Name] Coordinating team, clinical leads and ePAG advocates who have a leading role (Chair or Co-Chair of ePAG and/or of ERN Working Groups), and ERN Board members.

The questionnaire includes 16 statements and questions. Please indicate your level of agreement with each statement and check only one box for each statement. Please provide additional feedback in the comment box provided. All information you provide will remain confidential.

Source: This questionnaire has been adapted by EURORDIS-Rare Disease Europe from the Public and Patient Engagement Evaluation Tool (PPEET) Organisation Questionnaire.

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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)

**BACKGROUND QUESTIONS**

**1. What is your role in the ERN?** \* (allow to choose several options)

* Patient lead ( e.g,. ePAG Chair, ERN Board member, ERN executive committee member, member of ERN Coordinating team, Co-chair of WG, etc.)
* Health professional lead (e.g. work package lead, ERN Board member, ERN executive committee member, etc.)
* ERN staff (project manager)
* Other

**1.1. If Other, please specify**\***:**

à If Patient representative à question 3b

à If Health professional à question 3a

à If ERN project manager à question 3a and 3b

à If Other à question 3a and 3b

**2. How would you rate your level of awareness of the Network overall approach to facilitate Patient Partnership? \***

* Completely unaware
* Low level of awareness
* Neither aware nor unaware
* Some level of awareness
* High level of awareness

**3.a How often do you interact with patient representatives involved in the ERN? \***

* Not at all
* Infrequently
* Sometimes
* Fairly frequently
* Very frequently

**3.b How often do you interact with clinicians involved in the ERN? \***

* Not at all
* Infrequently
* Sometimes
* Fairly frequently
* Very frequently

**4. In terms of maturity, at what stage would you say the ERN is when it comes to routinely engage patient representatives in its activities? \***

* Not yet started
* Just beginning
* Established/making some progress
* Well established

**Part A. Policies and Practices that support patient-clinician collaboration**

**5. The ERN has an explicit strategy or framework for Patient Partnership that guides its activities in this area. \***

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

**6. There are clearly identified resources allocated to facilitate Patient Partnership within the ERN.** \*

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

**7. The resources that are available to facilitate Patient Partnership are adequate. \***

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

**8. The ERN prepares reports that summarises the results of Patient Partnership i.e. the results of the collaboration between clinicians and patient representatives involved in the ERN. \***

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

**Part B. Participatory Culture**

**9. A commitment to Patient Partnership values and principles is found in key organizational documents (e.g., mission and vision, strategy, etc.). \***

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

**10. A commitment to Patient Partnership values and principles is demonstrated through the structure of the ERN (e.g., dedicated manager to support patient engagement, patient representatives in leadership positions as Chairs or Co-Chairs of ERN WGs). \***

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

**11. Responsibilities related to patient engagement are clearly articulated in the job descriptions of ERN staff who are leading and supporting these activities. \***

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

**12. Comprehensive training and materials on how to implement patient-clinician collaboration are available to support ERN staff who are managing the ERN activities. \***

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

**Part C. Influence and Impact**

**13. Clinical leads in the ERN demonstrate their commitment to incorporating the input provided by patient representatives in identifiable ways. \***

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

**14. I can think of instances where the input generated by patient representatives has influenced decisions within this ERN.** \*

* Never
* Rarely
* Some of the time
* All of the time
* Don’t know

**15. More specifically, I can think of instances where the input generated from patient representatives has influenced relevant governance decisions (i.e., at the Board level). \***

* Never
* Rarely
* Some of the time
* All of the time
* Don’t know

**16. Please use the following space to expand on your answers to the questions in this section, if you would like to do so.**

**Part D. Final Thoughts**

**17. Overall, I believe the ERN devotes an appropriate level of resources to support Patient Partnership. \***

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

**18. Please share any additional reflections about Patient Partnership within the ERN, if you would like to do so.**