SHORT GUIDE: Assessing Patient Partnership Implementation in the ERNs

In order to understand the impact of patient partnership in each individual European Reference Network (ERN) and continue improving it, it is important to regularly assess its implementation. The Public and Patient Engagement Evaluation Tool (PPEET)[1] was developed in 2018 as a set of three questionnaires intended for use by a wide range of healthcare settings to assess the quality and impact of patient engagement. EURORDIS adapted two of these questionnaires to assess the implementation of patient partnership in the ERNs. This factsheet describes 4 key steps to help you administer these two questionnaires and includes a checklist to prepare a reflection session to provide mutual feedback on patient partnership in the Network collaboration and agree on follow-up actions.

Step 1. Prepare

The ERN Coordination team uses the downloadable template's documents with the questions & questionnaire logic to create two online questionnaires. The ERN Coordination team will be responsible for storing the responses. EURORDIS discourages the removal or complete re-wording of questions.

Step 2. Circulate

The ERN Coordination team circulates them once a year, for example at the time where the ERN monitoring indicators are collected, or every two years. The two questionnaires complement each other; both evaluate the implementation of patient partnership from a different perspective, so it is recommended to use both of them together. The Coordination team may launch the two questionnaires simultaneously or in a staggered manner. Please refer to Annex I for more details about each questionnaire, including the templates.

- **Patient Partnership implementation in the ERN (ePAG).** To be filled in by all ePAG advocates, including the ePAG Chairs and other ePAG advocates in leading positions.
- **Patient Partnership implementation in the ERN (leadership team).** To be filledl by ERN Leadership team (i.e. Coordinating team, clinical leads and ePAG advocates in leading positions, ERN Board).

Step 3. Analyse

The ERN Coordination team prepares a report with the main findings and results and shares it with the ERN leadership team (i.e. clinical leads and ePAG advocates who are Chairs or Co-Chairs of ERN Working Groups & ERN Board members) and with the ePAG.

Step 4. Discuss and agree on follow-up actions

The ERN Coordination team organises a reflection session where patient representatives and clinicians involved in the ERN can discuss the results, provide mutual feedback on their collaboration and agree on follow-up actions to improve their partnership. You may use the checklist in Annex II to prepare the session.

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[1] Abelson J, PPEET Research-Practice Collaborative. The Public and Patient Engagement Evaluation Tool. https://ppe.mcmaster.ca/resources/public-and-patient-engagement-evaluation-tool/

Annex I - Basic Information on the Questionnaires

	Patient Partnership implementation in the ERN (ePAG Questionnaire)	Patient Partnership implementation in the ERN (Leadership team Questionnaire)
Objective	This questionnaire collects feedback from ePAG advocates on their involvement in the ERN, providing insights into key features of their partnership with health professionals.	The focus of this questionnaire is to understand how patient partnership is carried out and supported across the ERN.
Template	Download templates in Word format (ERN leadership) or download and import to your EU survey dashboard.	Download templates in Word format (ERN leadership) or download and import to your EU survey dashboard.
Target Respondents	ePAG representatives in the ERN	ERN Coordinating team, clinical leads and ePAG advocates who Chairs or Co-Chair ERN Working Groups, and ERN Board members
Format	This survey includes 20 questions of 2 types: a) closed questions where respondents may include their level of agreement with each statement and check only one box for each statement b) open questions for comments & feedback Estimated time: 20 minutes	It includes 16 statements and questions, where respondents may include their level of agreement with each statement and check only one box for each statement. They may provide additional feedback a comment box. Estimated time: 5 minutes
Recommendation	ePAG advocates are encouraged to use a simple system to capture on a regular basis their activities in the ERN. This will allow faster completion of this annual survey faster. You may use for this purpose the "My impact as an ePAG advocate" notebook or any other system.	Adapt the target audience to the governance structure of each ERN.
When to use it	It is suggested to administer the surveys once a year, for example at the time where the ERN monitoring indicators are collected, or every two years.	
Use of results	Results can be used by ERNs to monitor progress, and identify strengths as well as areas of improvement in the implementation of patient partnership. By analysing and discussing the results, patient representatives, healthcare professionals involved in the Network, and ERN staff can co-create a roadmap for continuous improvement based on shared insights.	

Annex II – Checklist to prepare an ERN Reflection session

	Action	Tips and suggestions
Before the session	**Identify who will plan it and agree on the format**	One of the ERN Project Managers supporting patient partnership or in charge of the monitoring indicators in the ERN. You may consider running an online session (1.5h) or f2f 2 hours.
	Invite participants	ERN Patient Partnership working group, if the ERN has one. Alternatively, participants should be the ERN leadership team (ERN Coordinating team, clinical leads and ePAG advocates who are Chairs or Co-Chairs of ERN Working Groups & ERN Board members). Ask for their availability in order to find a suitable date and time for the session.
	To select a date and time	This sessions should be run once the ERN Coordination team has run an analysis of the results from both or one questionnaires.
	To prepare and Agenda	The objective is to discuss the results from both questionnaires to identify areas of improvement and celebrate achievements. Ask participants for feedback on the draft agenda. Engaging participants early on will ensure their commitment to participate to the session and contribute to a productive outcome. Based on the questionnaire results, you may want to include in the agenda: · What are you the proudest of? · What are some of the obstacles you have faced when collaborating (or not)? · What do you like most/least about your teamwork in the ERN? · How do think that collaboration could be supported more effectively? · What can be done to support team work more effectively?
During the session	**To facilitate the session and take notes**	Identify 1 facilitator, for example a member of the ERN coordination team. The facilitator should be someone able to facilitate difficult conversation and should keep the session conversation going always focusing the discussion on the 2-side collaboration. Another member of the ERN Coordination team should be the note taker.
After the session	**To debrief after the session**	The ERN Coordination team put togethers a list of action points and responsibles and organises a 45 min debriefing call with the reflection session participants to review the conclusions and action points.
	To draft an improvement plan and follow-up	The ERN Coordination team develops an improvement plan for the next 6-12 months based on the outcome of the questionnaires and the discussions of the reflection session. The plan should identify in the actions and responsibles.. The ERN Coordination team shares improvement plan with all participants and follows-up on implementation.

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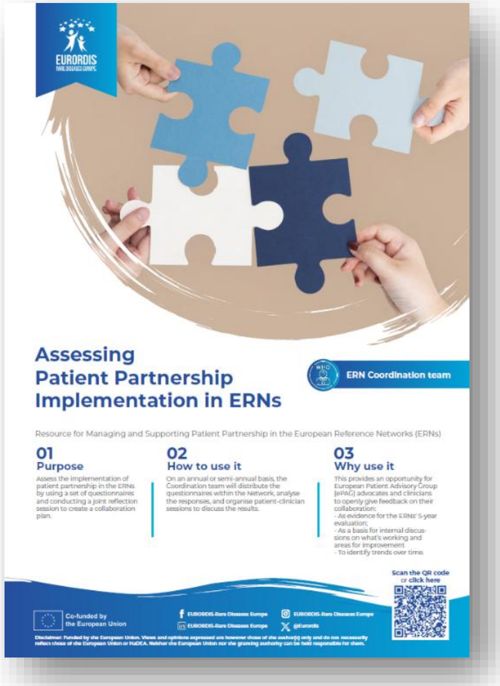

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Assessing Patient Partnership Implementation in ERNs

ERN Coordination team

Resource for Managing and Supporting Patient Partnership in the European Reference Networks (ERNs)

01
Purpose
Assess the implementation of patient partnership in the ERNs by using a set of questionnaires and conducting a joint reflection session to create a collaboration plan.

02
How to use it
On an annual or semi-annual basis, the Coordination team will distribute the questionnaires within the Network, analyse the responses, and organise patient-clinician sessions to discuss the results.

03
Why use it
This provides an opportunity for European Patient Advisory Group (ePAG) advocates and clinicians to openly give feedback on their collaboration:
- As evidence for the ERNs' 5-year evaluation;
- As a basis for internal discussions on what's working and areas for improvement
- To identify trends over time.

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Assessing Patient Partnership Implementation in the ERNs

Patient Partnership in the European Reference Networks (ERNs) can be defined as a mutual relationship between people living with a rare disease (PLWRD) and health professionals involved in an ERN where input from PLWRD routinely and formally informs the Network's collaborative activities and decision-making[1].

To understand the impact and continuously improve Patient Partnership in each individual ERN, it is crucial to assess its implementation regularly. To support ERNs in this process, EURORDIS has adapted **two questionnaires** developed at McMaster University in Canada to assess patient and public engagement in a wide range of health system organisation settings[2][3].

The questionnaires can be used by ERNs to monitor progress, and identify strengths as well as areas of improvement in the implementation of patient partnership. By analysing and discussing the results, patient representatives, healthcare professionals involved in the Network, and ERN staff can co-create a roadmap for continuous improvement based on shared insights.

Questionnaires for Assessing Patient Partnership in the ERNs

Questionnaire for ERN patient representatives (ePAG)

This questionnaire collects feedback from ePAG advocates on their involvement in the ERN, providing insights into key features of their partnership with health professionals.

- **Duration:** Approximately 20 minutes.
- **Format:** 20 or 21 statements and questions.
- **Recommendation:** ePAG advocates are encouraged to use a simple system to capture on a regular basis their activities in the ERN. This will allow faster completion of this annual survey faster. You may use for this purpose the "My impact as an ePAG advocate" notebook or any other system.

Download templates in Word format (ePAG) or download and import to your EU survey dashboard.

Questionnaire for ERN leadership team

This questionnaire evaluates how patient partnership is integrated across various aspects of the ERN's work. It is intended for the ERN Coordinating team, clinical leads, ePAG representatives who Chair or Co-Chair ERN Working Groups, and ERN Board members.

- **Duration:** Approximately 5 minutes.
- **Format:** 16 statements and questions.
- **Recommendation:** Adapt the target audience to the governance structure of each ERN.

Download templates in Word format (ERN leadership) or download and import to your EU survey dashboard.

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My impact as an ePAG advocate

ePAG advocates

Resource for Managing and Supporting Patient Partnership in the European Reference Networks (ERNs)

01
Purpose
Regularly capture and monitor the contributions and impact of patient representatives in ERN collaborative activities.

02
How to use it
This template enables the European Patient Advisory Group (ePAG) advocates to routinely record details of their participation in ERN projects and the impact of their involvement. It is recommended that the ERN Project Manager shares this template and explains how the information will be used to support the ERN monitoring system.

03
Why use it
The information compiled in these notebooks can be integrated into your ERN's annual reporting and/or monitoring system as evidence of patient involvement and the impact of their contributions.

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