
Patient and Public Involvement (PPI) working group

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PPI WORKING GROUP BACKGROUND AND OBJECTIVES

OBJECTIVES

- To **map existing PPI capabilities in paediatrics**: Number of existing groups, level of development/expertise, type of expertise (YPAGs, disease groups, POs, ERNs, umbrella organisations...), existing resources...
- To evaluate **the needs of PPI** groups/people in terms of **training, resources**...
- As a perspective, to develop appropriate framework to involve children and young people and parents.

PPI WORKING GROUP – QUESTIONNAIRE

- Questionnaire currently under review by group members
- Expected to be sent by end of November 2025

CONTENT OF THE QUESTIONNAIRE

- **Information on the person completing the questionnaire:**
 - Individual or structure, position
 - Background
 - Position
 - Training received in PPI

PPI WORKING GROUP – QUESTIONNAIRE

- **PPI activity:**

- Therapeutics area
- Type of PPI activity
- Type of groups/individuals (years of activity, size of the group, age of the members, age range input, type of PPI activities, language used)
- Description of activity

- **PPI in the respondent country:**

- Description of recommendations/laws/guidance existing
- Need for ethical approval
- Facilitation for PPI activities/Difficulties

PPI WORKING GROUP – QUESTIONNAIRE

- **Training in PPI activity:**

- Type of training provided already, to whom?
- Need for more training, for whom? Which focus? How to deliver it?

- **Any other suggestions**

Questionnaire to be sent to:

- UK + EU
- EnprEMA networks, ERNs, Eurordis, local networks, university hospitals.

PPI WORKING GROUP – NEXT STEPS

- **Questionnaires opened for answers until end of March 2026?**
 - To be reevaluated if needed
- **Review of Questionnaires received**
 - After a few are received, January 2026
 - Adjustments possible
 - Preparation of analysis
- **Analysis of the questionnaire (3 months)**



Thank You
