Reumatiker
förbundet

Evaluation of patient and public involvement in research project

The following questions and tools are intended to support researchers and patient research partners (PRPs) in discussing and evaluating patient and public involvement (PPI) in their research projects.

We encourage you to use this material during, as well as at the end of, the project so that you have the opportunity to act on any points that are raised. We suggest completing the questions separately and then jointly discussing the answers.

The tools can also be used to collect PRPs' contributions to the research in a structured way, which facilitates PPI reporting in journal articles and grant applications.

Discussion questions

1. How have you collaborated, and has it worked well for you?

Has the PRP had the necessary support/conditions to contribute to the project? Did they receive sufficient information and support to contribute? Do they have a relevant background or the necessary experience for this specific project? How has your relationship been? Have you felt respected, included, safe, etc.?

2. How has the collaboration been in relation to your expectations and plans?

Has the PPI taken place as initially discussed? For example, in terms of time commitment, activities, and collaboration methods.

What level of involvement has taken place in the project and how does it relate to your expectations? You can use the Involvement Matrix to document this by ticking the level of involvement at different stages of the research process. You can also add other activities that are relevant to your project.

3. What has the collaboration led to?

What difference has PPI made – for the research, for you as individuals (researchers/PRPs), and more generally? You can use the Impact Log (page 3) to record specific examples of PPI impact in your project.

4. What are your plans and lessons learned for the future?

What has worked well and what should you continue doing? What can be improved in the future? Do you have other reflections regarding PPI in your project?

Involvement matrix

		Patient research partner’s role				
		PRP is given information	PRP’s opinion is sought	PRP gives solicited advice	PRP contributes as an equal partner	PRP takes initiative and makes the final decision
		Listener	**Co-thinker**	**Advisor**	**Partner**	**Decision-maker**
Stage of research process	Identifying research question/problem					
	Study planning and design					
	Development of information sheets and questionnaires					
	Data collection					
	Data analysis/interpretation					
	Manuscript writing					
	Dissemination of findings					
	Other (fill in your own areas)					

Based on **Involvement matrix**: Smits D.W., van Meeteren K., Klem M. Alsem M. and Ketelaar M. (2020) Designing a tool to support patient and public involvement in research projects: the Involvement Matrix. *Research Involvement and Engagement* **6**:30. https://doi.org/10.1186/s40900-020-00188-4

Impact log

Involvement	Feedback	Outcome	Impact		
			For the research	For the person	Other

Involvement: How was the PRP involved – via email, online meeting, etc?
Feedback: What feedback or input was raised by the patient research partner during this contact?
Outcome: What did the research team do with the feedback/input? Have any changes been made? What did the feedback result in?
Impact, both positive and negative:

- **For the research** – how has the involvement affected the research project?
- **For the person** – how has the involvement impacted you as a researcher / you as a patient research partner?
- **Other** – how has the involvement impacted on other aspects, for example on implementation or dissemination?

Impact log, based on: **Public involvement Log** (People in Health West of England (PHWE), available at: https://www.bristolbrc.nihr.ac.uk/patient-public-involvement/patient-and-public-involvement-impact-log/