

Planning for Patient and Public Involvement

Reflect on patient and public involvement in your research. Consider the questions below and fill in the table on page 3.

WHAT & WHY

What –

- What would you like the patient research partners (PRPs) to contribute to?
Consider all stages of the research cycle and how PRPs could contribute at each stage. Examples of possible contributions are provided in the table below.

Why –

- Why are you involving PRPs?
- What do you hope to achieve through their involvement?
- How will their views and experiences be used and what difference will this make to your project?

Table 1. Examples of how PRPs can contribute at different stages of the research cycle

	Research activity	PRP contributions
PLANNING	Development of research question	Discussion of research needs
		Contribute ideas about what is important and relevant to patients
		Discussion regarding what aspects of disease research should focus on
	Questionnaire development	Choice of questions
		Wording of questions
		User-friendly formatting
		Estimation of time required to complete
	Interview guide development	Choice of questions
		Wording of questions
	outcome selection	Choice of outcomes, including PROMs
		Discussion about what is relevant to patients and what is feasible
	Intervention design	Focus on feasibility – how do you get the right balance of collecting data without overloading the patient
		Intervention's content/structure
	Recruitment	Recruitment strategy – where to recruit from, timing, practical aspects
		Design, wording, and content of recruitment material
	Development of materials for study participants - information materials, informed consent	Design, wording, and content of informed consent form, information material, and documents
	Choice of animal model	Discussion regarding how the model reflects the disease in humans

”DOING”	Focus groups or interviews	Leading focus groups/interviews together with researchers (peer-interviewer)
	Qualitative data analysis	Identification of themes based on their perspective as a patient
	Interpretation of results	Interpretation based on their perspective as a patient
		Discussion about which conclusions are most important to patients and should be highlighted

DISSEMINATING	Lay summaries	Wording and content
	Feedback text to study participants	Wording and content
	Dissemination via other media	Dissemination strategy to patients, healthcare, and the general public
		Wording and content

OTHER	Applying for research funding	Feedback on the application
		Plans for PRP involvement and contributions
		Wording of the lay summary
	Application to the ethical review committee	Feedback on the application
		Discussion of ethical aspects to consider
	Steering group	Participation in the steering group to ensure patients remain at the heart of the research
	Significance of the research	Conversations about how life is affected by the disease and what the research means for patients
	How the public perceives the research	Discussions about how patients and the public may view the research, e.g., justification of animal research, acceptability of a new treatment, etc.

HOW

- How will you involve PRPs? For example:
 - Inviting PRPs to research group meetings
 - Individual meetings with PRPs
 - Workshops with several PRPs
 - Communication via email to gather feedback and opinions
 - Involvement in a steering group
- What support do you need to provide for them in their role? For example:
 - Provide lay summaries
 - Provide background information on the research area
 - Offer opportunities to attend training courses
- In what role will PRPs be involved?
 - **Listener** – PRP is given information
 - **Co-thinker** – PRP is asked to give opinion
 - **Advisor** – PRP gives unsolicited advice
 - **Partner** – PRP contributes as an equal partner
 - **Decision-maker** – PRP takes initiative and may lead and make final decisions

PLANNING	WHAT & WHY <i>What should PRPs contribute to and what do you hope to achieve through their involvement?</i>	HOW <i>How do you plan to involve the PRPs and in what role?</i>
"DOING"		

	WHAT & WHY	HOW
DISSEMINATING		
OTHER		



WHO

Who will you involve? What background/experiences/interests should they have? Where will you recruit them from? How will you ensure diversity in experiences and perspectives?

WHEN

When should they be involved?

COSTS

What costs should be included in your budget? E.g., financial compensation, travel expenses, accommodation, conference costs. How will PRPs be compensated for their contributions? Is funding available and how will the payments be made?