

# Patient and Public Involvement and Engagement Guidelines

World Cancer Research Fund strongly encourages active public and patient involvement in the design and assessment of clinical research. The expectation is that your research will be “co-produced” with patients or members of the public as partners, with direct relevance to the project. Public and patient involvement in this context does not include being a research participant, but does include:

- Being consulted on setting research priorities.
- Defining research objectives and outcome measures.
- Providing other input into study design, conduct, and monitoring.
- Evaluation and the dissemination of results.

Please note that applicants are required to provide details on Public and Patient Involvement as part of their application.

When putting together your proposal, please consider the following questions, which are based on the Guidance for Reporting Involvement of Patients and the Public (GRIPP):

- How was the development of the research question and outcome measures informed by patients’ priorities, experience, and preferences?
- How did you involve patients in the design of this study?
- Will patients be involved in the recruitment to and steering of the study?
- How will the results be disseminated to study participants and the public?

For more information on public and patient involvement and engagement in research, visit <https://www.amrc.org.uk/guidance-and-tools-for-public-involvement>

## Definitions

**Public involvement** describes when members of the public use their views and personal experience of illness and treatment to help to prioritise, plan, deliver, evaluate and share health and social care research.

**Public engagement** refers to activities or events where information about, and findings from, our research are shared with the public.

Term	Examples	Relevant PPIE?
<b>Patient involvement</b>	<ul style="list-style-type: none"><li>• Patients are active collaborators throughout the research process</li><li>• Patients may be co-applicants or on the project team</li><li>• Patients are involved in discussion around project planning, design, feasibility and predicted outcomes</li></ul>	Yes
<b>Patient engagement</b>	<ul style="list-style-type: none"><li>• Patients consulting throughout the course of the research project, providing feedback on planning and execution</li><li>• Patients engaged through workshops, interviews, focus groups, surveys and patient advisory groups</li><li>• Patient opinion is actively sought out and communicated to the research team</li></ul>	Yes
<b>Patient or public participation</b>	<ul style="list-style-type: none"><li>• Patient and healthy individuals participating in a research study</li></ul>	No

## PPIE Throughout the Research Process

Patients and public involvement and engagement (PPIE) is vital across all stages of the research process. PPIE representatives have a unique and valuable perspective that has been shaped by their experiences of being a patient, carer or supporter of those affected by cancer. Some examples of how PPIE contribution can help shape research at every step of the way:

### Research Priorities

- Determine the gaps in research and understudied areas.
- Share views on what patients want to know.
- Express what areas of research may be most important to people affected.

### Research Design

- Ascertain that the researchers have consulted with appropriate patient groups with lived experience, and determined their priorities and needs.
- Comment on feasibility of the study design in relation to patients. Consider any limitations that may hinder recruitment or adherence to the study.
- Ensure clear and understandable lay summaries and other patient-related information and the dissemination of the research study to a wide audience, including patients.

### Research Study

- Assist in promotion of the study.
- Liaise with patient network groups and assist with patient recruitment if needed.
- Communicate with patient community on useful interim results of the research study.
- Encourage others to support the research.

### Research Dissemination

- Disseminate research findings to patient groups and relevant networks.
- Contribute to discussions about translatable aspects of the results.
- Suggest methods to ensure any useful novel information reaches the relevant patient and healthcare professional audiences.
- Contribute suggestions of specific audiences that may want to know about this research.

## Describing PPIE in your Research Proposal

Please consider the following aspects when describing the PPIE components of your proposed study.

- Ensure that PPIE is described in simple, lay language as this part of the application will be assessed by the Lay Panel Members who may not have technical scientific expertise.
- If you have to use scientific terms and acronyms, make sure they are clearly explained.
- Outline the relevance of your research to the clinical setting.
- Demonstrate an understanding of the distinction between patient involvement and patient engagement.
- Describe strategies for PPIE representative recruitment, the category of PPIE expertise (e.g. relevant patients, family members, carers) and process to ensure diversity.
- Name the PPIE members involved with the research proposal, outlining their expertise and interest in the research.
- Ensure that PPIE is a part of the entire cycle of the study (concept, design, development) and give details of how PPIE is integrated into the co-design and on-going collaboration.
- Outline any support, training or education for PPIE members to better understand the research objectives.
- Specify any PPIE budget if applicable and provide details of the predicted costs.