

Patient and public involvement in clinical research

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Currently writing a grant proposal? Planning on applying for funding for anaesthesia or perioperative medicine-based research? Then we can help!

HSRC PPI Working Group members

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Patient and Public Involvement (PPI) is the creation of a partnership between patients and the public, and researchers, to try to make the research process more effective. INVOLVE (the national advisory group, funded by the National Institute for Health Research (NIHR), that promotes active public involvement in NHS, public health and social care research) defines patient and public involvement in research, as research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants.

‘No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.’

Professor Dame Sally Davies, Chief Medical Officer.¹

For some time it has been considered good practice to involve patients and the public in research. This involvement can lead to the development of more relevant research questions, and many funding bodies, in particular the NIHR, now require detailed information on patient and public involvement as part of the research funding process. Funders need to see how researchers have collaborated

with patients and the public and how patient needs and expectations have been incorporated into research plans. The National Research Ethics Service also asks for information about plans for public involvement during the application process for research ethics approval. This is important, not only to improve the experience of participants in the research, but also to ensure the research has real potential to deliver meaningful benefit for patients.

Whilst strong PPI has been an important feature of research in chronic disease management for some years, there has been less activity in research in more acute fields of medicine, where it can be difficult for clinical researchers to develop the kind of relationships with their patients that allow them to identify and invite suitable patients to take part. To help address the specific challenges of PPI in anaesthesia and perioperative medicine research, the NIAA Health Services Research Centre established a PPI Working Group in July 2013.

Who we are

The HSRC PPI Working Group consists of members selected from the RCoA’s Lay Committee who have an interest in clinical research, and is chaired by Professor Rupert Pearse, Consultant in Intensive Care Medicine, Barts and The London School of Medicine and Dentistry. The Group has received bespoke PPI training from an independent adviser and has had input from researchers from different fields, to better understand the research process and determine how we can be most effective with our support. We are very fortunate to have such a well-informed and enthusiastic group

of volunteers willing to help with this initiative.

What we can offer

We have developed a section with information and resources on PPI on the HSRC website. Researchers can use our online application tool to submit requests for PPI support here:

www.niaa-hsrc.org.uk/PPIRegister#pt

Each request for PPI support is reviewed independently by members of the Group, then, where possible, a group consensus is sought before delivering the final feedback to researchers.

We provide feedback and additional commentary on our understanding of the patient experience in the proposed study. Research proposals are reviewed under the following headings. We would encourage anyone intending to submit a research proposal for funding to consider these points when drafting the protocol:

- **Lay summary** – Is the explanation of the study in simple enough terms for the general public to understand? Effective communication increases the likelihood that patients will be more receptive to the research and participate in the study.
- **Impressions of the research** – The importance of the topic to patients and its value to future patient care. If the research topic is deemed important to patients, this is then a very strong statement to be able to include in a research application.
- **Consent** – When is the most appropriate time to talk to patients regarding this? We understand that consent is not always obtainable due to the nature of emergency procedures.
- **Communication** – Are there clear inclusion/exclusion criteria? Have the researchers consulted with their target group for input, and what

are the plans for dissemination of the results to both the research community and patients recruited into the study?

- **Patients** – Number required, age, distribution (is it a local or national study)? Is this achievable/realistic? Is there any evidence of prior discussions with any local PPI organisation or their target group of patients regarding the research?
- **Confidentiality** – Will Patient Identifiable Data be collected and if so, what will happen to this data?
- **Limitations** – Is what the research asking of patients reasonable? Would you agree to participate in the study? If not, why not?
- **Finances** – Is the research cost-effective/value for money? Is there any money allocated for PPI in the budget? No patient or member of the public should be out of pocket from participating in a research project.

We endeavour to provide PPI feedback in good time for applicants to make any necessary modifications to their proposals before the deadline of the identified funding organisation. The sooner you are able to submit your draft proposals to us the better. Two weeks' notice is the minimum we require to conduct a preliminary PPI review and provide basic feedback. The amount of PPI support we can offer to any one project is determined on a case-by-case basis and on the resources available to us at the time.

Although still in its infancy, the Group has already reviewed several applications for NIHR funding, providing initial feedback and comments with a provisional commitment to provide support tailored to the individual needs of the project (e.g. join a project steering group, be named as a co-applicant

on proposals etc.) We hope our PPI support will have a significant impact on the ability of UK anaesthesia and perioperative medicine researchers to develop proposals of the highest quality. Our aim is to help ensure that this area of research is focused on the public's interests and meets the needs and priorities of patients.

Further information

- www.invo.org.uk
- <http://piaf.org.uk/>
- www.niaa-hsrc.org.uk/PPI

References

- 1 Staley K. Exploring Impact: Public Involvement in NHS, public health and social care research. INVOLVE, Eastleigh 2009;4 (Foreword). (www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf).