

## GUIDANCE ON THE APPROPRIATE USE OF PPI (PATIENT/PERSONAL & PUBLIC INVOLVEMENT) EVENTS RELATING TO RESEARCH

**PPI is** Patient/Personal & Public Involvement. It is intended as a mechanism to guide researchers in establishing priorities by including service users and others in the design of research studies and in the dissemination of outputs.

NHS guidance [INVOLVE](#) described this as: “research being carried out *with* or *by* members of the public rather than *to* or *about* them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group [and] commenting on and developing research materials...” Detailed guidance and briefing notes on public involvement in health and social care research is available from the [NIHR website](#).

For specific queries relating to PPI, please visit the [QUB Personal and Public Involvement \(PPI\) Network website](#), replete with resources, news items, events and case studies, or consider contacting the Network directly on [ppihub@qub.ac.uk](mailto:ppihub@qub.ac.uk). Please note, for PPI undertaken at QUB, remuneration of PPI contributors must abide by [NIHR directives](#), which are endorsed by the QUB PPI Network.

**PPI is not** a way of conducting research involving individuals as research participants or potential recruits without going through appropriate ethical and governance procedures. It is appropriate to ask people involved in PPI events to comment on their experiences of or views on your research, but not on their own health, condition or personal situations. In other words, PPI events cannot be used to collect research data relating to the participants.

**The “about whom” principle** can help us to differentiate between research and other related activities, including PPI.

If you are obtaining specific information *about an individual*, that is likely to be research.

If you are obtaining opinions, views or information *about your research* - whether proposed, in progress or complete - or about a process, then that might be classified as PPI, audit or service evaluation/development.

### **Can I publish outputs from PPI events?**

Yes, but it needs to be clear that you are not publishing the results of research.

### **Do I need ethical approval to carry out PPI?**

No. As referenced in the [PPI Ignite Network statement](#) ‘Approval from a research ethics committee is not required for public and patient involvement (PPI) in the idea generation, planning, design, interpretation of findings, or dissemination stages of research.’ If you intend to use PPI events to inform your research or to discuss your findings, you should mention this in your ethics application. IRAS, for example, asks researchers (section A14-1) to comment on any PPI involvement in framing or designing the research. The Health Research Authority also makes clear the importance of including PPI in their [Participant Information Quality Standards](#) and [Participant Information Design and Review Principles](#) in order to obtain an NHS/HSC Research Ethics Committee approval.

Although specific ethical approval for PPI events is not required, you should always consider the broader ethical implications. For example, if you are including certain populations (children, vulnerable adults, patients) in a PPI event, you need to bear in mind risk, access, consent and other issues.

### **Do I need permission?**

That depends upon where the event is being held. If you intend to use third party premises – for example, hospital or community premises, then yes. You will need to be aware of insurance, health & safety, transport, parking and other considerations.