Useful Definitions Document for NIHR Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology

The NIHR (and indeed all funding bodies) expect patients and the public to be involved in research before you submit for funding through to the dissemination of results. This is widely known as Patient and Public Involvement (PPI). The NIHR and Higher Education Institutions also expect you to convey and inform the wider public about the findings of your research and current work taking place within your institution. This can result in confusion about terms and terminology in this area for you, your teams, and patients and the wider public that you involve.

Public Engagement "describes the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit. "(National Coordinating Centre for Public Engagement NCCPE). These may be events where you present research findings to patient groups, disseminate results of work or organise events for local schools about research or the work of the hospital or Trust.

Public engagement events are not the same as Patient Public Involvement. Public engagement events are a good way of engaging with local people and patients and building relationships which may lead to these people then being involved in advising your research in a PPI capacity.

Patient and Public Involvement (PPI) in research also known as user / lay involvement is the development of an active partnership between patients and / or members of the public and researchers.

PPI is the term used to describe researchers and patients and the public working together to develop research which is relevant to patient needs and beneficial to patients.

What PPI is not

- PPI is not about researchers using people as subjects of research
- It is not about users filling in questionnaires or being interviewed
- It is not about patients giving samples
- It is not about recruitment of people to a clinical trial
- It is not the same as qualitative research and cannot replace qualitative research

What PPI is

Principally PPI tries to use the direct experiences of patients to produce results from research that may be more reliable and credible. Pragmatically this involves;

- Working with members of the public to refine research questions
- Working with patients to produce easily understandable materials for your research project, including consent forms, patient information packs and summaries of your findings
- Using patient experience to help you develop a recruitment strategy that works for participants and may make people more inclined to agree to take part
- Using patients and their informal networks to disseminate information

Patient involvement in a clinical trial – you may be recruiting patients to your trial or study via clinics and appointments. This is recruitment of participants to your trial and is entirely separate to patient and public involvement and public engagement. Public engagement events are a good way to publicize current trials or findings from a completed trial which may encourage those attending to take part in future trials.

Patient involvement in a clinical trial may be (for example) involvement in a trial steering committee, creating information sheets and consent forms, developing any qualitative components. In the case of interviews and focus groups, this may be assisting in creation of vignettes or interview schedules, help in analysing initial findings and disseminating results.

Ethics & Consent:

You do not need to obtain formal consent to undertake PPI and to involve people in your research as users. For more information about this the National Research Ethics Service and INVOLVE have written a statement to clarify the position of ethics and PPI.

“The active involvement of patients or members of the public does not generally raise any ethical concerns for the people who are actively involved, even when those people are recruited for this role via the NHS. This is because they are not acting in the same way as research participants. They are acting as specialist advisers, providing valuable knowledge and expertise based on their experience of a health condition or public health concern. Therefore ethical approval is not needed for the active involvement element of the research, (even when people are recruited via the NHS), where people are involved in planning or advising on research e.g. helping to develop a protocol, questionnaire or information sheet, member of advisory group, or co-applicant.”

You can find the full NRES INVOLVE Statement here: www.conres.co.uk/pdfs/INVOLVE_NRESfinalStatement310309.pdf

However If you plan to undertake interviews or analyse data from a Patient Day, you will need ethical approval for this.

In addition if you wanted to use patients as interviewers or if they would be seeing any patient identifiable data then you would need ethical approval and NHS permissions. Please speak to the Ethics Committee (details)

If you wish to discuss these definitions any further, please contact Carol Porteous, Research Associate for Patient Public Involvement in Research for the NIHR Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology at

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