

Patient and Public Involvement (PPI) in Research – Case Study

Provided by:

Dr Liz Ormondroyd. Heart/Genomics. Division of Cardiovascular Medicine.

How patients and the public were involved

NIHR Oxford Biomedical research Centre (BRC) open days; received input from Genetic Alliance UK re Patient information sheets and consent forms. My research interests include psychosocial and ethical implications of genetic technology, so is concerned with patient experience of genetic conditions and interactions with genetics research.

The impact of involving patients and public in the study

We work with patients in clinic, so have a reasonable idea of patient concerns and expectations. It is clear that a number of people are interested and informed, the challenge is how to extend and engage with more people.

The importance of involving patients and the public in research

We need to make sure participants have fully understood the research so that they can consent appropriately – this is especially important with genetics research where the outcomes are unpredictable.

The biggest challenges in PPI and what might help to overcome them

Engaging more widely.