

Patient and Public Involvement (PPI) Strategy for Oxford BRC-3

Summary

Building on the achievements of the PPI activities in previous Oxford BRCs, we aim to **strengthen and sharpen PPI activity across Oxford BRC-3**, and to integrate PPI in the overall governance of the BRC as a whole. We are doing this through a five-pronged strategy of:

- **streamlining** our processes and activities to align closely with NIHR and BRC priorities for PPI;
- **benchmarking** PPI performance across the BRC;
- **mainstreaming** PPI input to BRC governance and structures;
- **partnering** with other NIHR-funded research structures and other relevant networks in the Oxford region; and,
- **training** for researchers on how to undertake and evaluate PPI work.

Background

In BRC-2, PPI activity sought to focus on five things:

- [a] building strategic partnerships (academic-NHS-industry);
- [b] embedding PPI in governance (of BRC and of NHS trusts);
- [c] embedding PPI throughout the research cycle (including James Lind Alliance work);
- [d] public engagement (including links with theatre groups); and
- [e] research on the patient and staff experiences of taking part in PPI, and the impact of PPI.

Reports from BRC-2 describe successes in each of these activities while also identifying some areas for improvement. Whilst there are examples of good practice, the need remains to change attitudes across the BRC as a whole to make PPI an integral part of the research process.

To support this, we have sought to identify needs of BRC researchers through surveys of BRC theme leads as well as of PPI contacts across the BRC. An anonymous survey of Oxford's BRC theme leads undertaken in October-November 2016 identified their three key priorities:

- practical support for their **own efforts** to embed PPI in their theme (including finding patients to sit on steering groups);

- support to **evaluate** their PPI/E work and learn from models of good practice elsewhere; and
- closer **alignment** of PPI/E activity with other themes and activities in the BRC.

Initial discussions with patient representatives around the challenges of PPI in the BRC highlighted the continuing central difficulty of getting PPI mainstreamed throughout the BRC's work. We surveyed the liaison points for PPI in each of the themes across the BRC to assess PPI in practice. The overall picture was of PPI still not being well integrated:

- there was a **lack of understanding** about PPI, and the difference between involvement and engagement;
- PPI activity was **not well integrated** or visible in the overall BRC work
- and there was a **lack of resources** for PPI (time, funding and expertise).

In developing our PPI approach, we have involved patients; in particular, the Patients Active In Research (PAIR) group already established and experienced under BRC-2. As well as seeking input from across the BRC, we have also worked with other partner organisations in the area, including the Oxford Health BRC, the Oxford Academic Health Science Centre (AHSC), the Oxford Academic Health Science Network (AHSN), and the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Oxford. We developed the first outline of this strategy at the start of BRC-3, and have refined it over the first year. We expect the strategy to continue to evolve over the lifetime of BRC-3.

More widely, expectations of PPI have been raised throughout research. The NIHR's report on "Going the Extra Mile" sets out goals for public involvement to achieve reach (how far people and communities are engaged in research), relevance (how far public priorities for research are reflected) and refinement and improvement (models and methods for ensuring that involvement is adding value to research), and we have reflected these in our approach.

The NIHR's commitment to patient and public involvement is being taken up more widely. For example, the BMJ has launched a patient partnership strategy, requiring authors of research to set out how they have involved patients and including patients in the journal's review processes.

Strategy

Our aim is to make patient and public involvement an integral, routine part of research within the Oxford BRC partnership and to improve methods and tools for doing so; by doing this, we aim to help get the best value possible from the Oxford BRC. Our strategy to achieve this is built around five pillars of streamlining, benchmarking, mainstreaming, partnering and training.

Streamlining

We aim to simplify both processes and material for PPI within the BRC. This includes developing shorter, simpler ways of involving patients in priority-setting; in the first year, we are piloting a one-day workshop for patient involvement in developing a diabetes portal meeting both research and service delivery needs.

We are developing simpler materials for researchers to guide them in PPI, and shifted our focus to getting across the key messages of what PPI is and why it is important, with then follow-up targeted support for implementation in practice (described in more detail below).

Benchmarking

We aim to support all those involved in research in answering a simple question; how well are we doing PPI? This simple question though is complex to answer in practice. There is no single standard for PPI, with many different frameworks available. In practice, too, a PPI framework that suits one area of research or one group of people does not necessarily suit another. An important part of the process of building engagement around PPI seems to be allowing researchers and patients to develop their own specific understanding of what the issues are and how they can work together.

We are therefore aiming to develop a different, more flexible and emergent approach to helping those involved in research to develop their own understanding of how well they are doing and how they could improve. We have carried out a systematic review of PPI frameworks, but rather than then choose one, we are working with patients, researchers and other stakeholders to identify building blocks from the most useful frameworks. Taking the NIHR's National Standards for Public Involvement as a starting point, we then aim to provide these as a 'toolkit' of ways of thinking about PPI, for each research community across the BRC to use as their own basis for developing their work on PPI and assessing they are performing in relation to others, and how to improve.

Mainstreaming

PPI is not the only part of the research process that researchers find difficult and do not always integrate. BRC researchers are typically specialised in biomedical or clinical issues, and frequently need support in other areas beyond that, such as statistics, economics, methodology, impact and ethics, as well as PPI.

We are establishing a Research Support Service to provide this kind of support for BRC researchers, with PPI support integrated within that. This is intended to provide a practical vehicle for mainstreaming PPI support into a wider engagement with BRC researchers. We are also doing research to better understand the experiences of being a research nurse (or other allied health professional) to help understand the overall research process and thus how to better integrate PPI within it.

More generally, we aim to include patients in the governance structures of the Oxford BRC. Our aim is to include patients to form part of reviewing plans and outputs for BRC themes and for the BRC as a whole. We have begun this with the Partnerships theme by creating an external Advisory Group and including patients and lay participants within that (including the chair).

We have integrated PPI into the main BRC website and are expanding our engagement tools, making theme-specific engagement platforms more centrally

visible, and working to better signposting patients and citizens to engagement opportunities in the areas of interest to them.

Key milestones for the future will be involving patients in the processes of annual and mid-term reviews of the BRC; and recruiting lay representatives for each of the governance bodies of the BRC overall.

Partnering

We collaborate with the other research structures and networks in the area (including the companion Oxford Health BRC, the AHSN, AHSC, CRN and CLARHC) in order to maximise synergies and take a coherent regional approach to PPI/E. To support this we, and the other infrastructure organisations mentioned, are members of the Thames Valley Patient Experience Operational Group, a forum for sharing expertise and developing joint work. The multiple and overlapping responsibilities of the different organisations involved in health research in the area are confusing to navigate, for both patients and professionals. We are working to develop a clearer understanding about the different roles and partnerships, though this is a constant process.

Training

An example of partnering is in training, where we have worked with the CLAHRC to provide a successful joint series of training events for patient participants in research, which we plan to continue in future years. We are working to develop a reference training programme for PPI through developing a masters' module on PPI; this will be available as a stand-alone course as well as being integrated into our existing masters in evidence based health care. We will work further with local partner organisations to develop a shared approach to training and development, capitalising on existing opportunities.

Progress so far

We acknowledge that there remain huge uncertainties about how PPI should be done and what impact it has. We will continue to contribute to these knowledge gaps through a programme of research which aims to assess the impact of PPI on the recruitment and retention of participants in clinical trials. We have completed a systematic review and meta-analysis on this topic, which demonstrated that on average, PPI has a positive impact on recruitment rates, and that PPI contributors having lived experience of the condition under study is an important factor contributing to this effect (to be published soon). A realist analysis of the included studies is now underway to further explore the mechanisms of impact of PPI and the conditions under which these are triggered.

We have also completed a four-stage project to develop a PPI intervention aimed at enhancing recruitment and retention in surgical trials. Further planned studies include refinement and feasibility testing of this intervention, analysis of UKCRN data to explore associations between PPI, recruitment success and recruitment-related impacts, critical analyses of the justifications for PPI and the distinctions between PPI and 'research on research'. The findings of this programme will inform our PPI strategy as well as contribute to the international evidence base around PPI.



We are continuing to work with patients, BRC colleagues and other partners to keep our PPI strategy under constant development throughout the duration of Oxford BRC-3.

This is a working strategy, which is being kept under review during the course of the Oxford BRC-3. It should also be read alongside the additional practical resources for PPI which are available from the Oxford BRC website.