

NIHR Barts Biomedical Research Centre

Public and Patient Involvement & Engagement Strategy

April 2017 - March 2022

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Introduction:

The NIHR Barts Biomedical Research Centre is a successful partnership between Barts Health NHS Trust and Queen Mary University of London and has been established to bring ~6m people (patients and the public) together with outstanding science enabling groundbreaking discoveries to be translated into life-saving pharmacological and device based therapeutics.

Barts is one of the largest NHS providers in the UK and has invested over £1.3bn in state-of-the-art new hospitals, including the Barts Heart Centre (BHC - £400m 2015) - one of the largest cardiovascular centres in Europe with ~80,000 patient episodes per annum. QMUL is part of the Russell Group of elite UK Universities with the 2014 UK Research Excellence Framework rating 90% of our research as world leading or internationally excellent and is host to Genomics England and the 100,000 Genomes project.

Having successfully delivered its aims and objectives as a cardiovascular-focused Biomedical Research Unit over the past decade in collaboration with the patients and public it represents, the BRC will support the continuation of this work with particular emphasis on world-leading translational genomics relating to inherited common and rare disorders and the development of diagnostic and therapeutic cardiovascular devices and innovative trials.

This strategy is a cornerstone of the BRC and demonstrates our vision, aims & objectives, and approach to ensuring that public and patient involvement/engagement (PPI/E) is at the heart of what we do now and in the future. The BRC actively involves patients and the public as partners in the processes, by which clinical research is identified, prioritised, designed, conducted, implemented, disseminated and evaluated.

The 2017-2022 PPI/E strategy has been developed in conjunction with the NIHR Barts BRC Patient & Public Advisory Group (PPAG), Patient Powerhouse UK (PPUK) and wider BRC Patient & Public Involvement/Engagement team.

Definitions: (source: Involve)

Involvement – Where members of the public are actively involved in research projects and in research organisations

Participation – Where people take part in a Research study

Engagement – Where information and knowledge about research is provided and disseminated (i.e. made available to a wider audience)

NIHR – National Institute for Health Research, part of the Department Health, which promotes understanding of medical research and a major funder of ours.

BRC – Biomedical Research Centre

NIHR define **public involvement** in research as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”. Examples of public and patient involvement activity include working with researchers to develop or comment on research materials, providing advice as members of a project steering group, and undertaking elements of research e.g. conducting interviews with participants.

NIHR define **public engagement** as “where information and knowledge about research is provided and disseminated”. Examples of public engagement activity include disseminating the findings of a study to research participants, colleagues or members of the public, raising awareness of research through media such as television programmes, newspapers and social media and open days at research centres where members of the public are invited to find out about research.

Vision:

To offer a comprehensive and inclusive range of opportunities to patients and members of the public so that they can engage with and get involved in areas of cardiovascular research of interest to them; such opportunities would also aim to be of interest clinicians, academics and society as a whole.

Strategic Aims & Objectives:

1. Maintain, develop and grow the inclusive, demographic richness of our patient, public and interested organisational memberships to best represent the aims and objectives of the BRC and associated research:
 - a) Direct and indirect advertising of the opportunities and benefits of PPI/E at internal/external events
 - b) Actively engaging with local, regional and national groups that offer access to such potential membership
 - c) Actively engage with areas of the research family that may not usually receive such engagement and/or feedback as to the impact of their work e.g. pharma teams et al
 - d) Work with other internal/external PPI/E focussed groups to explore areas of best practice and to identify opportunities for collaboration/shared learning
 - e) Enhance our on/offline capability and capacity to advertise, support and develop PPI/E opportunities at an individual level through to wider research community audiences e.g. enhanced web presence, targeted advertising, organising/attending internal/external events
 - f) Ensure that appropriate reimbursements are made available to those contributors to PPI/E activities

2. Promote the invaluable resource offered by PPI/E that is available for clinical and academic researchers to work together with in the development, delivery and evaluation of their research:
 - a) Liaising with key 'boards, clinicians, academics and associated staff to promote the PPI/E resource and to enhance their understanding of the value it may add to their research (including literature and training where appropriate)
 - b) Ensure that the PPI/E resource is easily accessible and responsive for researchers to utilise; developing and maintaining such to encourage i) their use of the resource and ii) their promotion of the same to internal/external colleagues/organisations
 - c) Invite professionals/organisational representatives to PPI/E meetings/events

3. Ensure that PPI/E outputs and outcomes are included as part of a continuous learning cycle that informs the development and delivery of the BRC's research direction and ongoing translation:
 - a) Maintain a log of PPI/E requests from researchers, any input they may offer and of any feedback subsequently received from researchers
 - b) Ensure that all PPI/E members are kept in the loop in respect of their input to any research they are involved with and the impact it has had/may have
 - c) Ensure that researchers are likewise kept informed of the PPI/E resource availability and activities that may be beneficial to their current or future areas of work
4. Work with an increasing base of internal and external organisations with an interest in the development and delivery of healthcare research:
 - a) Exploit the internal and external relationships in place that may offer access to such organisations
 - b) Involve the same in working with the public/patients
5. Ensuring ongoing financial and professional support to deliver the PPI/E strategy:
 - a) Identify and ring-fence a PPI/E budget
 - b) Ensure that appropriate staff and associated resources are made available to support PPI/E activities
 - c) Maintain the profile of PPI/E as an essential aspect of the BRC's research at senior levels e.g. BRC Executive Board

Governance:

Strategic Delivery

The BRC Executive Board, chaired by the BRC Director, is accountable for the implementation of the PPI/E strategy; membership of that board includes the Chair of the BRC PPAG and a representative of PPUK. The BRC Executive Board receives updates on PPI/E activity and provides advice, guidance and support to deliver the PPI/E strategy.

Operational Delivery

The operational delivery of the strategy is undertaken via a collaboration between expert patients and members of the public, the BRC PPI/E Lead and the wider BRC team; oversight of this delivery-focussed team is provided by the PPAG (Chaired by a PPAG member elected on an annual basis). Membership of the PPAG is formed from a wide-range of individuals and organisations with an open invite for new members to join (all members sign a confidentiality agreement as would be expected given the undertakings of the group) e.g. patients, public, staff, charities and other interested organisations.

At PPAG meetings, a structured agenda is agreed to in advance with the Chair receiving reports against the same from range of contributors; furthermore, this meeting is also available to offer and receive wider research updates, advice and guidance to and from research professionals and to consider requests for support to the research community.

Annex A: Examples of NIHR Barts BRC Participation, Involvement and Engagement Activities

Participation:

- The NIHR Barts BRC works in close collaboration with the Barts Cardiovascular Clinical Trials Unit and the William Harvey Research Institute's Clinical Trials Centre and often sees participation in research studies/trials from a wide-demographic population that often then participate in further PPI/E activities e.g.
 - The Barts City Lifesaver project: has extended free post-study basic life support training to over 115 patients
- Trial participants are also involved in actively shaping involvement and engagement activities (see below)

Involvement:

- Commenting on research proposals and patient information sheets
- Establishing true collaborations taking account of people's different expertise and life experience, making research accessible to everyone e.g.
 - Trials Connect: a BRC group harnessing patient stories to educate all ages about what it means to be involved in a clinical trial
 - Patient Powerhouse UK: members of the public and/or past/present patient volunteers with specialist skills and talents e.g. legal, regulatory, ethics, communications backgrounds and the creative arts; recently did a moving theatre event telling the story of how human experimentation during the Holocaust led to the code of ethics that is in use in clinical trials today.
 - Provided considered patient and public advice and guidance in respect of a recent (successful) application to Health Education England to become the academic host of a national Genomics Medicine course

Engagement:

- Year on year development of a range of community activities focused on science and medicine but shaped by the public and patient community e.g.
 - Teaching and Curriculum Development: patients have been and are engaged in the planning of relevant curriculum development, for example Trials Connect patients have directly been involved in training over 1000 students from 4 courses.
 - Annual Barts and Queen Mary Science Festival: PPAG members continue to take part and assist with this festival for schoolchildren; 2018 will see the 8th Annual festival, which will include a "Question Time" panel by Trials Connect about what it is like to take part in a clinical trial.