

Public involvement, engagement and participation (PPIE) in research strategy 2017 – 2020

Introduction

Royal Brompton & Harefield NHS Foundation Trust (Trust/RB&HFT) is a partnership of two specialist hospitals which are known throughout the world for their expertise, standard of care and research success.

Patients are central to the work of the Trust and this document sets out our strategy for ensuring effective patient and public involvement, engagement and participation. As a Trust and a research organisation we believe that involving patients and members of the public in developing, designing and implementing research ensures that the research is:

- relevant to the people it is trying to help
- beneficial in terms of delivering meaningful outcomes for patients
- conducted in a way that is sensitive to the needs of the participants and their friends/family – through better patient information, recruitment processes and general management of the project and the project outcomes.

We will continue embedding patient and public involvement, public engagement and patient participation across the whole organization with active consultation with patients, carers and members of the public in research projects across the Trust.

Background

The former National Institute for Health Research (NIHR) cardiovascular and respiratory Biomedical Research Units (BRU) have been running an active public involvement and engagement programme since 2008. This was underpinned by the previous Public Involvement and Engagement Strategy 2013 – 16. Funding for the BRUs ended on March 31st 2017

The Trust applied for funding for an NIHR Biomedical Research Centre (BRC) which would have provided funding until March 2022, but was unsuccessful. The Trust also applied for NIHR Clinical Research Facility funding which partly funds the Respiratory Clinical Research Facility.

The Trust has provided initial infrastructure funding to the two former BRUs, now referred to as research centres.

Patient and public involvement in research is supported by 0.5FT salary and budget to cover costs. This is covered jointly by the Trust and the NIHR CRF award.

Definitions

Throughout this document the following terms will be referred to:

Involvement: An active partnership between patients, the public and researchers in the research process, rather than the use of people as 'subjects' of research.

Engagement: Describes activities that involve raising public awareness and interest in research and providing opportunities for researchers to hear public views on their work.

Participation: Where people take part in a research study such as taking part in clinical trials, completing a questionnaire or participating in a focus group as part of a research study.

When the above terms are referred to collectively the term PPIE (patient and public involvement, engagement and participation) will be used.

Strategic context

PPIE in research within the Trust is underpinned by the following Trust and government policies:

Trust strategies

The Trust supported patient and public involvement through the RB&HFT Research Strategy (2012 – 15) to promote patient, carer awareness of the Trust as a research active organisation amongst patients, carers, friends and family. The Trust will be developing a new research strategy which will include PPIE.

The RB&HFT Membership Strategy (2015 – 17) provides opportunities for members to take part in public involvement and engagement in the Trust.

Government policy

The public sector is committed to public involvement and the duty to consult service users in the development of health services is a legal requirement under the Health and Social Care Act 2001, Part 1, Section 11.

In the white paper “Equity and excellence: Liberating the NHS” (July 2010), the Government has also expressed its commitment to increasing patient choice and control in research. This can be achieved by giving patients “more information on research studies that are relevant to them and more scope to join in if they wish”.

The Health and Social Care Act 2012 introduced a duty on the health secretary, NHS England and Clinical Commissioning Groups, to promote research and the use of research evidence.

Regulatory bodies

Higher Education Funding Council for England (HEFCE)

The Research Excellence Framework (REF) requested academic bodies to demonstrate measurable research impact, including that resulting from public engagement. This applies to the last REF exercise in 2014 and the next exercise planned for 2021, in which the proportion of public engagement is set to increase.

National Research Ethics Service

The National Research Ethics Service (NRES) value the importance of active public involvement to the role of research ethics committees. It supports the premise that high quality public involvement in research is more likely to result in ethical research.

Funding bodies

National Institute for Health Research

The Respiratory Clinical Research Facility is part-funded by the NIHR. The NIHR states that “involving patients and members of the public in research can lead to better research, clearer outcomes, and faster uptake of new evidence.”

Other funding bodies

Several funding bodies, such as the Medical Research Council (MRC) and Research Councils UK fund research and expect the inclusion of certain elements of PPIE in funding applications.

Charities

An increasing number of health charities such as the British Heart Foundation, British Lung Foundation, Wellcome Trust and Asthma UK now request the inclusion of public involvement and engagement in their research funding applications.

Academic partners

National Heart & Lung Institute (NHLI), Imperial College London

The NHLI is one of the largest heart and lung departments in the world. It maintains close links to the Royal Brompton and Harefield NHS Foundation Trust with many researchers and clinicians working across the two organisations. The Trust also collaborates closely with other departments and faculties within Imperial College including the Faculty of Medicine.

Imperial College Academic Health Science Centre (IC AHSC)

This is a partnership between Imperial College London, Imperial College Healthcare NHS Trust, Royal Brompton & Harefield NHS Foundation Trust and the Royal Marsden NHS Foundation Trust. The aim is to improve the quality of life of patients and populations by taking new research discoveries and translating them into new therapies as quickly as possible. The IC AHSC is focused on research and education as the key drivers to better patient care. Patient experience is one of the key priority areas.

Institute of Cardiovascular Medicine and Science

The Institute of Cardiovascular Medicine and Science (ICMS) is a joint venture between Royal Brompton & Harefield NHS Foundation Trust and Liverpool Heart & Chest Hospital NHS Foundation Trust. A patient ambassador role is currently being developed as part of the collaboration.

Strategic aims

The Trust is committed to actively involving patients and the public in our research to ensure we produce high quality research focused on patient benefit, and increase public awareness and interest in our heart and lung research. This will be achieved through the following aims:

1. Develop **infrastructure** to support and **deliver** PPIE across Trust research activities
2. Ensure consistently high standards in PPIE through **education** and **training**
3. Develop and maintain **collaborations** across local and national organisations to deliver PPIE
4. **Evaluate** PPIE to capture impact and continue to develop and improve

Key objectives

1. Develop infrastructure to support and deliver PPIE across Trust research activities

- 1.1 Identify PPIE research champions to help promote strong leadership and corporate culture and embed research PPIE across the whole organisation
- 1.2 Provide support and guidance on PPIE activities to researchers and healthcare professionals by embedding PPIE within research grant applications
- 1.3 Increase and diversify the approaches to PPIE so as to attract a wider range and number of patients, carers and public (across age, sex, ethnicity, ability etc.) to take part in PPIE activities
- 1.4 Schedule regular public engagement activities to raise awareness and interest of research, highlighting opportunities for involvement

2. Ensure consistently high standards in PPIE through education and training

- 2.1 Develop PPIE guidelines, protocols and standards to ensure shared good practice in research PPIE occurs across the Trust
- 2.2 Role development for both the public and researchers by providing and signposting to training and education opportunities

3. Develop and maintain collaborations across local and national organisations to deliver PPIE

- 3.1 Maintain and increase the number of links with relevant research organisations both locally and nationally by attending events related to PPIE and research
- 3.2 Maintain and increase links with non NHS partners, including training providers, patient representative bodies, schools, museums and public event organisations

4. Evaluate PPIE to capture impact and continue to develop and improve

- 4.1 Capture all PPIE activities and systematically evaluate to identify improvements and measure impact/outcomes
- 4.2 Gather research participation feedback to improve patient experience and encourage more patients to be involved in research in the future

Reporting

Regular meetings with the Research Office will be used to monitor activities including measuring, monitoring and evaluating PPIE. These meetings will also be used to review progress against the objectives outlined (meetings every 3-4 months).

Oversight of this strategy, and evaluation of progress against the strategic goals, will rest with the Trust Research Management Committee (RMC). By having RMC oversight it is anticipated that Trust and Imperial College clinicians and researchers will view this strategy as a high priority for the Trust, and will therefore be more willing to engage in PPIE activities.

The NIHR Respiratory Clinical Research Facility reports annually to the NIHR. As part of this a summary of the PPIE activities will be collected and reported on.

Contributors

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Appendix

Traffic Light System

Tool to assist patient reviews of biobank access applications and patient involvement reviews of research studies. The form was created by the respiratory patient representatives group to allow them to provide better feedback on research proposals. The form is in the style of a traffic light system, the reviewers address key questions such as key patient benefits and then award the project with red, green or amber.

INVOLVE

INVOLVE is part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research. More information is available here: www.invo.org.uk/about-involve/