

Patient and Public Involvement and Engagement (PPIE) Strategy (2015–2020)

Introduction

Patient and public involvement and engagement are essential to ensure that the Blood and Transplant Research Unit in Organ Donation and Transplantation (BTRU in ODT) addresses issues that are clinically, socially and ethically relevant, and this document sets out our strategy for delivery of this important component of our work.

For consistency throughout this document, we adhere to NIHR definitions as below:

Patient and public **involvement** – patients and members of the public are actively involved in the activities, organization and governance of research projects or themes.

Public **engagement** – information and knowledge about research is provided and disseminated to the public¹

Along with partner organisation NHSBT, the NIHR BTRU in ODT aims to develop appropriate networks to ensure a coordinated approach to PPIE.

This document sets out our approach to PPIE, the background objective and an action plan for 2015–2020.

¹ Further definitions: **participation** – people taking part in a research study as subjects/participants; **public** – inclusive term including all subgroups of population, community groups, ‘communities of interest’, ‘communities of place’, networks, organisations and healthy volunteers; **patients** – individuals receiving healthcare (NIHR, 2013, INVOLVE, 2014)



Our vision

Patients and the wider public are a fundamental and integral part of the work of the NIHR BTRU in ODT. We aim to develop world-class high quality research in the field of organ donation and transplantation. We want to bring research opportunities to patients and members of the public, to improve scientific and clinical understanding of organ donation, organ preservation and transplantation and investigate ways to improve the management of life-threatening conditions requiring organ support using technological interventions or organ replacement.

To achieve this aim, we want to work closely with patients and the public to create a dynamic research environment, with a shared commitment to the importance and value of research, the engagement and involvement of patients and the public and to the effective and timely translation of evidence into clinical practice, to make a real difference to people's lives.

A central aim is to develop a range of creative approaches to share and harness insights, experience and opinions of patients and the public, and to embed these within BTRU activity and decision making about research priorities in transplantation as well as in the subsequent dissemination and implementation of research findings about organ donation and transplantation.

Background

Strategic Approach

Patient and public involvement and engagement is both supported by and strongly encouraged within all NIHR funded activity (<http://nihr.ac.uk>) on the basis that this leads to better research that is more focused on the needs of patients and can accelerate timely and effective transfer of evidence into clinical practice.

The BTRU is committed to actively involving and engaging patients and the public as partners in the processes by which research is identified, prioritised, designed, conducted and disseminated. To achieve this, in collaboration with FMS (Faculty of Medical Science) Engage at Newcastle University, The Public Engagement Team, Cambridge University and relevant patient groups we will:

1. Build capacity and expertise in PPIE across the BTRU and in individual work streams
2. Establish mechanisms and standards for monitoring and reporting activity and embed evaluation of PPIE in order to maximise learning
3. Collaborate with key stakeholders in the local and national health economy and research community.

Implementation

Key objectives in these three strategic areas are listed below. We present an action plan for the delivery of these objectives in 2015–20. This encompasses PPIE actions at BTRU level, as well as within individual research projects and work streams. We present timelines for these activities in Appendix A.



Key objectives

Build capacity and expertise in PPIE across the BTRU and in individual work streams

- Develop organisational structure for PPIE across the BTRU
- Develop and introduce guidance, including rewards, payment, incentives and good practice guidelines, for involving patients and the wider public.

Build the evidence base around PPI and impact by embedding monitoring, reporting, evaluation and learning from PPIE activities

- Improve and facilitate awareness and understanding of PPIE by developing and delivering appropriate staff, patient and public activities
- Establish and improve processes to monitor, evaluate and review PPIE with a view to understanding its impact
- Share and learn from PPIE good practice and achievements

Collaborate with key stakeholders in the local and national health economy

- Ensure PPIE internal networking, partnership working and common strategies in research across the BTRU work streams
- Ensure PPIE external networking, partnership working and common strategies with local partners
- Ensure PPIE external networking and partnership working with appropriate national organisations

Action plan

Objective 1: Build capacity and capability to develop and deliver Patient and Public Involvement and Engagement (PPIE) in research around organ donation and transplantation

We will work together with patients and the public as a collective enterprise to embed their contribution in all aspects of BTRU research. Working closely with the School of Clinical Medicine (Cambridge University) and the Faculty of Medical Sciences (Newcastle University), and with support from the relevant NHS Trusts, we will develop and deliver robust mechanisms, including access to training and support, to enable researchers across the BTRU to undertake PPIE.

Organisational structure

NIHR BTRU in ODT Patient and Public Research Panel

We will establish and support a generic patient and public research panel to ensure that patients and the public are systematically involved and embedded in all aspects of the research process. This group will be established at the outset of the BTRU and will support delivery of the other activities. It will provide a resource to draw upon in relation to particular questions or tasks and



will provide PPIE input relating to broader ethical and psychosocial issues. A range of patient and public representatives will be invited to join. The role and structure of this group is dynamic and fluid and currently comprises:

- A register of 30 patients and members of the public willing and able to meet either physically or virtually every 4–6 months to discuss strategic issues and to support research at various stages. These volunteers are drawn from across the country.
- Sub-groups drawn from this register who will meet quarterly (physically or virtually, for example via social media such as Facebook and Twitter) to review specific proposals or requests for support. These sub-groups may include: (a) people with specific expertise/experience or medical conditions; (b) people willing to support research but with less time available; (c) representatives of charities or local communities/networks.

In addition and as required for the support of specific projects, individuals from this register or from collaborating groups and organisations will be invited to contribute to Study Advisory Groups, Trial Steering Committees, etc.

We will maintain a contacts database for all aforementioned individuals and their organisations, with appropriate permissions, to enable virtual interaction and electronic communication.

PPIE Guidance

We will co-develop and make available guidance for PPIE activities to support standardization of approaches across the BTRU. This will include:

- Policies and procedures on:
 - Accessing and recruiting patients/members of the public for PPIE activities
 - Payments, rewards and incentives for patients and members of the public, including various types of contracts, e.g. consultancy agreements
 - Job descriptions for PPIE representatives
 - Health and safety, public liability and insurance issues
 - Confidentiality or non-disclosure agreements
- Guidelines on PPIE, to include definitions, values, different approaches, methods.
- Good practice examples for both engagement and involvement.
- Leadership development among patients and the public to promote research literacy and stimulate debate on research evidence, interpretation and translation

Objective 2: Build the evidence base around PPI and impact by embedding monitoring, reporting, evaluation and learning from PPIE activities

Improve awareness of patient and public involvement and engagement opportunities

Develop a programme of awareness raising events in order to inform and engage patients and members of the public in ongoing and future research. Events targeted towards



researchers/scientists, clinical academics, research managers and other staff will aim to promote early and active involvement of patients and members of the public. Other events will be directed towards patients and members of the public and will be facilitated in collaboration with FMS Engage, NHSBT and other partners of collaborators as appropriate. Seminars, workshops and 'drop-in' events will be offered.

Understanding of PPIE will be reinforced via various resources and media such as online and hardcopy resources for ease of access and distribution.

The BTRU in ODT PPIE webpages at <http://odt.btru.nihr.ac.uk/get-involved/> will also include links to national resources, examples of good practice across BTRU work streams, details of PPIE news and events, lists of PPI leads and contacts, guidance (as described above).

Monitoring, evaluation and review processes

Pilot PPI Standards

In order to ensure clear reporting, monitoring, evaluation and learning we will adopt a common approach to PPIE standards and categories, and develop resources and educational activities to support their implementation.

Share good practice

We will work closely with other university, NHS and NIHR organisations to effectively share best practice and expertise, and to reduce duplication and enhance the effectiveness of patient and public involvement and engagement.

Objective 3: Influence policy and practice by collaborating with key stakeholders in the local and national health economy

The BTRU in ODT PPIE strategy aims to promote collaborative working across other university and NHS organisations in order to facilitate coordination of PPIE activity as well as sharing best practice and expertise to reduce duplication of effort and enhance effectiveness of PPIE. We will establish collaborations internally, locally and nationally.

Internal collaboration

Internal collaboration will build upon creation of a Cambridge/Newcastle BTRU PPIE Virtual Network comprising PPIE links or champions within individual BTRU work streams. This will facilitate communication, information flow, sharing of good examples, practices and innovation between BTRU PPI Lead and BTRU work streams.

Local collaboration

We will work particularly closely with Newcastle University's Faculty of Medical Science Engagement Group and Biomedical Research Centres at both Cambridge and Newcastle as well as existing PPIE organisations – both generic and those pertaining specifically to organ



transplantation/donation, taking advantage of existing PPIE networks and collaborations. We will strengthen and build strong relationships with organisations relevant to BTRU in ODT research themes and those focused on public engagement, specifically VoiceNorth, but also considering others such as Tyneside Kidney Patient Association, Freeman Heart and Lung Transplant Association, LIVERNorth, TransplantTV, Addenbrooke's Kidney Patient Association and Addenbrooke's Liver Transplant Association. We will meet several times a year to share examples of good practice, avoid duplication of effort and plan collaborative initiatives in terms of common PPIE approaches, goals and objectives.

Collaboration on public engagement will also take place through events such as the Cambridge Science Festival, Newcastle FMS MiniMedical School, 'It's OK to Ask' Campaigns, TEDEX and others where considered appropriate and timely.

National collaboration

We will also work with other key NIHR organisations to support public and patient involvement and engagement in research, including NIHR INVOLVE, Clinical Research Networks and other NIHR funded organisations, such as the Research Design Service, the Academic Health Sciences Network (AHSN), NIHR Innovation Observatory and NIHR Evaluation, Trials and Studies Coordinating Centre in order to support the effective co-ordination of PPIE and the timely translation of research evidence to maximize impact. We will also collaborate with charitable organisations and business/industry where appropriate. With NIHR support, we will participate in, and contribute to, the development and delivery of a workshop for all BTRU PPIE leads, focusing on: progress in developing PPIE strategies; approaches to monitoring strategic objectives for PPIE; clarification of the requirements for PPIE for the BTRU, including progress reports; sharing ideas and resources. The workshop will facilitate shared learning and ensure good practice.

The Faculty of Medical Sciences at Newcastle University and The School of Clinical Medicine at Cambridge will continue to participate in national campaigns such as NHSBT blood and organ donation campaigns and INVOLVE's 'It's Ok to Ask' Campaign.

We will also capitalize on other opportunities for networking within national involvement/engagement organisations, national and local groups and any relevant events they organize, e.g. INVOLVE, National Coordinating Centre for Public Engagement (NCCPE), Health Education Authority Lived Experience Network (HEA LEN), James Lind Alliance and HealthTalk Online.

Objective 4: Assess the impact of PPIE

We will implement data capture systems to monitor PPIE requirements and activity (Appendix B and Appendix C) with a particular view to demonstrating and recording impact. We will identify a small number of priority projects, and carry out detailed evaluation of PPIE activities in



collaboration with partners. We will also develop research to drive more embedded, better quality and more effective PPIE.

Reporting

Internal

Quarterly business meetings with the Theme Leads, which the PPI Lead attends, will continue to be used to monitor activities including reporting linked to PPI standards to facilitate additional procedures for good practice and for measuring, monitoring and evaluating involvement and its impact.

External

The NIHR BTRU in ODT will report annually to the NIHR. A summary of PPIE activities and their impact forms part of this report. The PPI Lead, with input from Theme Leads, PIs and P&P Research Panel members, is responsible for collating and summarising this information.



APPENDICES

Appendix A: PPIE Gantt chart showing timelines for activities

<http://odt.btru.nihr.ac.uk/wp-content/uploads/sites/3/2017/11/PPIE-STRATEGY-APPENDIX-A.pdf>

Appendix B: Patient and Public Research Panel feedback and evaluation form

<http://odt.btru.nihr.ac.uk/wp-content/uploads/sites/3/2017/11/PPIE-STRATEGY-APPENDIX-B.pdf>

Appendix C: Theme Lead PPI requirements questionnaire

<http://odt.btru.nihr.ac.uk/wp-content/uploads/sites/3/2017/11/PPIE-STRATEGY-APPENDIX-C.pdf>