NHSBT Patient and Public Involvement and Engagement (PPIE)
Patient and Public Advisory Group (PPAG)

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Author: Yomi Adegbaju (National Research Manager) with input from NHSBT PPIE Working Group
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1. Introduction

NHS Blood and Transplant (NHSBT) has the responsibility for optimising the supply of blood, organs, tissues and raising the quality, effectiveness and efficiency of blood and transplant services for the public. One way that NHSBT achieves this is by commissioning and conducting research and development (R&D). Working in collaboration with leading universities, public and private industry, the R&D programme guides international transfusion and transplantation practice to benefit healthcare in the UK and beyond. Within the public, private and academic sectors in the UK, there are no other organisations capable of delivering an R&D programme that spans our range of products and services.

Our current research consists of a portfolio which is funded across a number of themes (Appendix 1), both internal and external to NHSBT. Each project is aligned with one of our nine research themes. We are also supported by the National Institute for Health Research Blood and Transplant Research Units (NIHR BTRUs) for research to improve the supply of blood, blood products, stem cells and tissues.

We also provide core funds to our Principal Investigators for research prepared in conjunction with NHSBT Research Strategy Groups. This approach has increased alignment with operational requirements and improved translation of results into service delivery.

More people than ever before are taking part in research studies. New and better treatments and services become available because people take part in our research. Members of the public are also getting involved in advising us about what research should be funded and helping to design research studies.

Public involvement in research is defined as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials.

The term ‘public’ includes patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. There is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

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The role of the group is to bring together expertise, insight and experience in the field of public involvement in research, with the aim of making it an essential part of the process by which NHSBT research is identified, prioritised, designed, conducted and disseminated.

2. The need for Patient and Public Involvement and Engagement (PPIE)

NHSBT does not currently have a central Patient/Public Advisory Group (PPAG) that could provide the support our researchers need to fulfil the PPIE requirement in their research. PPIE support includes:

- Patient and public involvement (PPI) in study design;
- Implementing managing the study with patient and public engagement (PPE);
- Disseminating research results to the public;
- Funding opportunities and resources available when PPIE is incorporated in research development and delivery.

PPIE is important to ensure research quality and relevance as well as being part of public accountability and transparency.

A recent article shows how researchers seem to misunderstand what involvement means and its purpose at different stages of research (Staley and Elliott, 2017)*. Some of the more prominent statements from the article are listed below:

“UK research organisations have a strategic commitment to public engagement.”

“Researchers are recognised and valued for their involvement with public engagement activities.”

“The epistemological argument: patients and the public have knowledge of their own illness, disease or health condition that can be of benefit to researchers, who may not have first-hand experience themselves of the issue they are researching.”

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“The moral imperative: patients and the public have the right to be involved in any publicly-funded research that may impact on their health status or the services that they receive.”

“The consequentialist argument: PPI has the potential to improve the quality, relevance and impact of health research, whilst also improving the transparency of the process and the accountability to the wider community of the researchers themselves.”

“The policy imperative: PPI is currently Department of Health and NIHR policy, so funding often depends on getting PPI right at the grant application stage.”

The impact of creating and sustaining an NHSBT PPAG will be to actively support patient/public involvement and engagement in NHS Blood and Transplant research activities.

3. PPAG Member role description

A diverse PPAG will ensure that patients and the public are systematically involved and embedded in all aspects of the research process. This group and list of contacts will be a resource for NHSBT researchers to draw upon to support them with research questions or tasks (Appendix 2). A range of patient and public representatives will be invited to join. The role and structure of this group is dynamic and fluid and may consist of:

- A database of already established patient groups willing to be contacted to offer support to NHSBT researchers;
  - 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.

- A register of patients and members of the public willing and able to meet either physically or virtually to discuss strategic issues and to support research at various stages. These volunteers will be drawn from across the country.

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Interested parties will register via Cognito forms, which is a password protected site with limited access. The PPAG contacts database will be developed and maintained with appropriate permissions, to enable virtual interaction and electronic communication between PPAG members and NHSBT researchers. Compliance with the Data Protection Act 2018 will be achieved via Informed consent and R&D Office Privacy Policy at registration on Cognito (approved by NHSBT Information Governance).

Confidentiality or non-disclosure agreements (where applicable) may be required; this will be managed by the R&D Contracts Manager.

We will develop and make available guidance for PPIE activities, which will include:

- Guidelines on PPIE, to include definitions, values, different approaches, methods;
- Leadership development among patients and the public to promote research literacy and stimulate debate on research evidence, interpretation and translation;
- PPAG member role description (please see below)

**Responsibilities**

- Attendance at research team meetings, which will be held at regular times throughout the year (decided on a project by project basis). This will include a yearly PPAG Management Group meeting hosted by the R&D Office (held on a working day);
- Review research related documents/paperwork to provide feedback at meetings or electronically;
- Support the R&D Office in developing web or social media resources;
- Completion of questionnaires;
- Prepare in advance for meetings;
- Respond in a timely manner to all email communication between from R&D Office and NHSBT researcher as required.

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You may be asked to:

- Share your views in a considerate and constructive manner;
- Treat all research related documents that you review as confidential (except already published materials);
- Provide ongoing feedback to help further develop and refine the process for involving patients in the review of clinical research.

Skills and Experiences required:

- Ability to listen and to express own views about issues concerning research;
- Ability to work as part of a group with people from a wide range of different backgrounds;
- A commitment to diversity and equality;
- A commitment to seeking the views of a range of stakeholders and an ability to bring perspectives beyond personal experience.

Person Specifications:

- Be enthusiastic about research, and willing to familiarise yourself with medical and research language;
- Good communication skills with an ability to listen to and to respect differing opinions, and to express your own view clearly and appropriately.

Please note is desirable although not essential that some PPAG members have experience of taking part in a clinical trial/research.

Length of membership

- Membership to PPAG is for 1 year, after which the membership will be reviewed.

Time commitment and dates

- Online registration;

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• PPAG Management meeting (once a year);
• The time it takes to prepare and review research documents as applicable (this must be decided in advance with researcher).

Expenses

Expenses for NHSBT activities will be covered either by the R&D Office when attending events organized by us or you will be reimbursed directly by the research team that you are supporting (please agree with research team in advance).

Accountability

Members of the PPAG are accountable to the NHSBT PPAG management group (please see below).

4. NHSBT PPAG management group

<table>
<thead>
<tr>
<th>Chair</th>
<th>Oluwayomi Adegbaju (National Research Manager – R&amp;D Office)</th>
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<tr>
<td>Deputy Chair</td>
<td>Sarah Wills (Research Governance Manager - R&amp;D Office)</td>
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<td>Secretariat</td>
<td>Alice Bell (R&amp;D Administrator - R&amp;D Office)</td>
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<tr>
<td>Contributors</td>
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<td></td>
<td>• Dr Lise Estcourt (CTU – Medical Director of CTU)</td>
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<td></td>
<td>• Heather Smethurst (Trial Manager/Research Nurse)</td>
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<td>• Rebecca Mellor (Component Development Scientist)</td>
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<td>• Susan Brunskill (Senior Information Scientist)</td>
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<td>• Dr Johannes (Muller Specialty Doctor Manchester)</td>
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5. Appendices

Appendix 1: NHS Blood and Transplant Research Themes

1. Blood Donor Health
2. Transfusion/Transplantation Virology and Microbiology
3. Patient Blood Management
4. Advanced Blood Components
5. Organ Donation and Transplantation
6. Stem Cells and Immunotherapies
7. Tissue Engineering
8. Behavioral Research
9. Translational Data Science

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Appendix 2: Process flow chart for requesting PPAG member for research related work

*PPAG member will be asked to sign a Confidential Disclosure Agreement if appropriate

Additional information

NHSBT is committed to being inclusive in all that we do and we will therefore make any reasonable adjustments required to enable you to fulfil this role.

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