NIHR | Blood and Transplant Research Unit in Data Driven Transfusion Practice at University of Oxford

Patient and Public Involvement and Engagement (PPIE) Strategy 2022

Summary

Blood and Transplant Research Units are academic partnerships between universities and NHS Blood and Transplant (NHSBT) aimed at advancing healthcare services for NHS patients through research. The Blood and Transplant Research Unit (BTRU) in Data Driven Transfusion Practice aims to improve transfusion practices using patient health data (details of health checks and conditions, medicines, treatments and records of contact you have had with doctors and other health and care workers such as blood tests and/or transfusions).

This research is to benefit NHS patients needing blood transfusions and public members generously donating blood and the PPIE strategy describes how we plan to include them as partners in research to make sure our work is relevant, acceptable and done in the best possible way to meet their needs.

Summarised at a high level, we will

1. **Involve patient and public members and third sector/community organisations in**
    - **Leadership and governance:** Senior management will actively promote and encourage involvement of patient and public partners. Two representatives of third-sector organisation sit in the Independent Steering Committee to steer and monitor our research
    - **Research:** Twelve patient and public members with diverse backgrounds are included in overarching activities and specific research projects
2. **Support researchers and patient and public members** to meaningfully and respectfully work together
3. **Reach out to partners and collaborators** using synergies and sharing expertise
4. **Resource** PPIE work appropriately with training, time and money
5. **Monitor and evaluate** to learn what went well, what we can do better and share the impact of our work

If you have any questions, please do not hesitate to get in touch.
You can find contact details at the end of this document.

What is the purpose of this strategy?

This strategy outlines how we intend to involve and engage public and patient partners in our NIHR funded Blood and Transplant Research Unit.

The health and wellbeing of people receiving blood transfusions in the UK is central to our work. This is especially important for our unit because our work focuses on the use of routinely collected NHS patient health data to improve blood transfusion practices. Patient health data represents a huge clinical resource for the recording of interventions (actions taken to improve a health condition such as a treatment or medicine). Meaningful Patient and Public Involvement and Engagement (PPIE) is vital to help shape our research ensuring that it is relevant, transparent, and trustworthy to create a lasting positive impact, which is what we aim to deliver through this work.

Why is the involvement of patient and public members important?

Patient and public representatives are experts in:

- Living with specific health conditions
- Experiencing healthcare of the NHS
- Caring for someone with health issues
- Supporting health services such as donating blood
- Contributing their information to healthcare data

Patient and public members bring valuable knowledge, experiences and skills that help to make sure that the research conducted speaks to the needs of specific communities, and fits with what they find socially acceptable and appropriate. Well designed and co-ordinated PPIE can make research more ethical and offers many benefits for people undertaking research to improve healthcare, including:

Patient and Public Involvement and Engagement

- Provides a **vital reality check about patient needs**
- Helps **better explain research** and **understand patient, carer and public perspectives**
- Leads to **new insights** that researchers may not have thought about
- Increases **public understanding, support and funding**
- **Develops networks** both inside and outside of academia
- Provides additional **motivation**

This document outlines our strategy for PPIE. It will be used to guide our work and to enable the steering committee, funders and wider community to monitor our progress. This strategy currently covers the first 36 months of our planned work from 1 April 2022 until 31 March 2025 and will be updated again as the award progresses.

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Definitions

In this strategy we use the following definitions:

Patient and Public Involvement (PPI): Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. (NIHR INVOLVE 2017). PPI is an active part of medical research were patient and public members give their views and perspectives on research to make sure it is relevant, acceptable and designed in the best possible way for those to benefit from it.

Public Engagement: Where information and knowledge about research is provided and shared with patients and members of the public.

PPIE: An abbreviation/acronym. Used to describe Patient and Public Involvement and Engagement (PPIE) work and projects, or activities that connect or encompass both.

Patient and public: In this strategy we use the term ‘patient and public’ to describe people affected by our research who do not have a professional role in health and social care services. The term

- Patients is used for people with lived experience of health conditions, service users, and
- Public is used for carers, family members, blood donors or members of the general population.

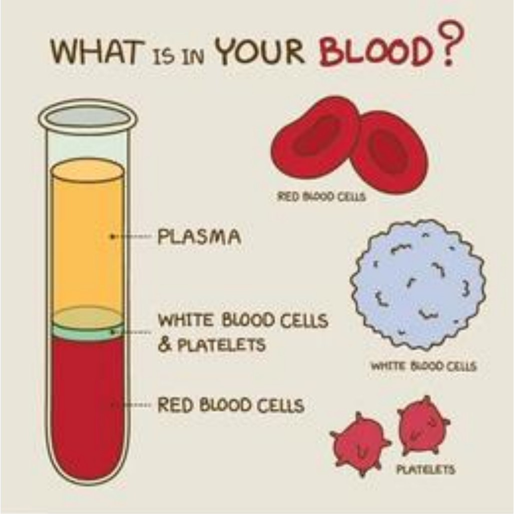
Co-production: Co-production is an approach to working together in equal partnership and for equal benefit. It is built on the principle that those who are affected by a service are best placed to help design it.

Underserved groups: A group of people that the research community needs to provide a better service for. The lack of inclusion is not due to any fault of the members of these groups.

Please see glossary for specific terms used in this document.

Background Information

About Blood Transfusions



Every year approximately 2.5 million units of blood or its constituents are transfused in the UK at a cost of over £300 million. Overall costs are likely to be higher, given these costs do not include the processing, storage and safe administration of blood in hospitals.

Blood transfusions play a vital role in saving lives, for example for patients with major bleeding. Many blood transfusions are also given to non-bleeding patients, like those with anaemia, sickle cell disease, cancer or kidney disease.

However, repeated studies have shown large gaps between what is recommended for when to use transfusions and actual practice. This means that patients may be receiving blood transfusions when they were not needed or necessary. Scientific reports (National Comparative Audit of Blood transfusion programme and the SHOT haemovigilance scheme, see references) and collaborative work with patient and public groups highlights that unnecessary transfusions put patients at risk of adverse effects.

In addition, blood services across UK (e.g., NHSBT in England) find it difficult to predict how much blood hospitals may need, and they would benefit from better access to timely patterns of blood usage to ensure supply meets demands. The lack of real-time information on the blood supply chain can mean both wasted blood as well as a risk that the best blood components may not always be available to the patients at greatest need.

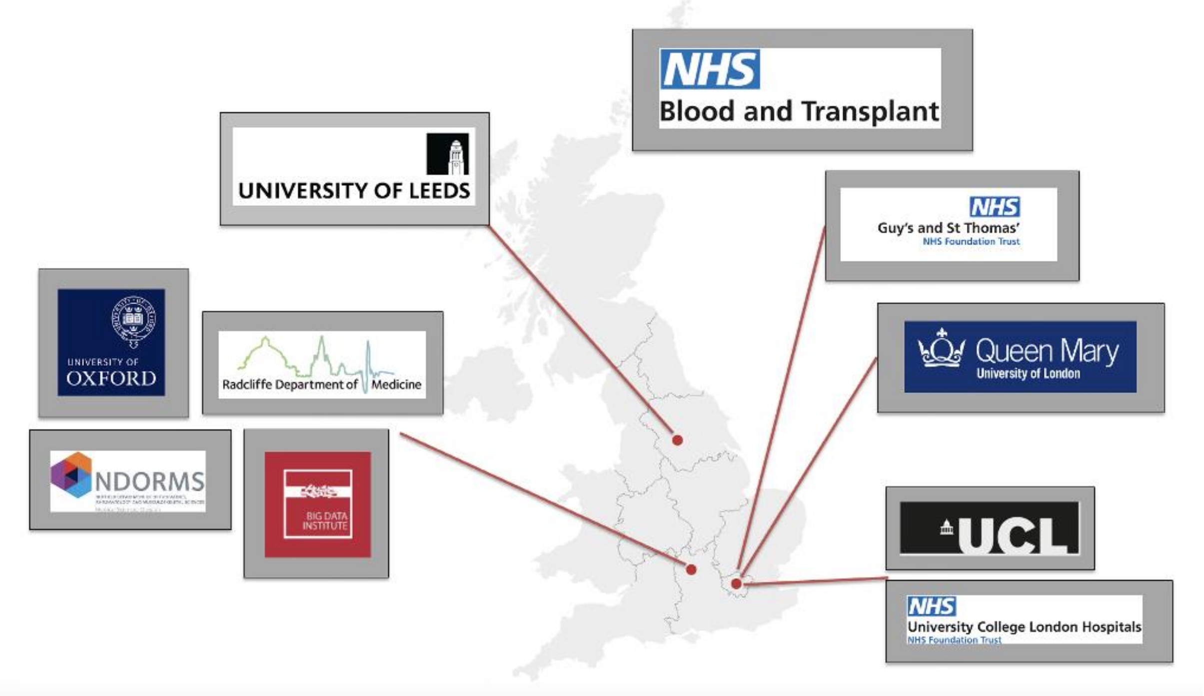
These issues of safe and reducing unnecessary use of blood has a high priority for the NHS and the James Lind Alliance (an organisation working with patients and clinicians to identify areas of immediate priority within the NHS) identified this in the top 10 research priorities for transfusions (see references).

The patient and public members who have already been involved in our work have also raised important questions around health equality and equity, asking if demographic data e.g., socio-economic status, geographical location and ethnicity have an impact on the availability of transfusion treatments or patient outcomes. There is a clear opportunity to improve the use of blood products in clinical care leading to better outcomes for patients and cost savings for the NHS.

About the Blood and Transplant Research Unit in Data Driven Transfusion Practice

Our Blood and Transplant Research Unit (BTRU) aims to speed up the development of data-driven methods to optimise blood use and integrate them within routine clinical practice to improve patient outcomes.

Our funding began in April 2022 and will run for 5 years until 31 March 2027. Our lead site for this research unit is the University of Oxford (Radcliffe Department of Medicine) and we work with collaborators across the UK. The main partnership sites are:



BTRU collaborators	Description
Guy's and St Thomas' NHS Foundation Trust	Guy's and St Thomas' NHS Foundation Trust have a long history of collaborating in transfusion research to drive good transfusion practice.
University College London Hospitals NHS Foundation Trust (UCLH) and University College London (UCL)	University College London Hospitals NHS Foundation Trust (UCLH) and University College London (UCL) have developed an Experimental Medicine Application Platform that intercepts standard 'messages' between electronic health records and Laboratory Information Management System to create a live operational database of patient health data for research and has extensive experience and expertise in PPIE.
University of Leeds	University of Leeds have developed live linked records across primary and secondary care, as well as secure research facilities for real world data analytics and are leaders in the field of implementation research.

University of Oxford: • Redcliffe Department of Medicine • Nuffield Department of Clinical Laboratory • Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences • The Big Data Institute	The Nuffield Department of Clinical Laboratory and Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences are part of the Redcliffe Department of Medicine at University of Oxford. The Big Data Institute is a purpose-build facility bringing together machine learning, computer science, ethics, epidemiology and translational research.
Queen Mary University of London	Queen Mary University of London has extensive expertise in the area of health economics and will help to calculate the economic implications of our findings.

We also work with international partners including members of the Synergy Blood group in Australia as well as researchers in Canada and US to share practices within the international field. This helps ensures lessons learnt can be shared and passed around.

Overall, we intend that our collaborative work with cross cutting expertise means we will be able to guide real change in this field and produce patient focused solutions.

Our Vision, Objectives and Aims

Our vision is to use routinely collected patient data from a large diverse patient population to identify changes in transfusion practice which can improve outcomes for patients. We will work to communicate these findings effectively to the clinical teams delivering care to drive improvements for patients in the UK.

We will deliver this in partnership with the public and patients so we can better understand and improve how we:

- Deliver the right (or best matched) blood transfusions from donor to patient
- Use data in transfusion research to set standards for research in this field
- Increase awareness of the importance of using routinely – available patient data to improve health equality and build trust
- Involve and engage a diverse group of patients and public members in setting what research is done

The vision is to create sustainable and lasting improvements, and impact beyond the funding for this unit.

Our objectives are to:

1) Build on meaningful patient and public input at every step as we develop systems for the use of patient data
2) Continue to identify and prioritise patient-focused research questions
3) Ensure there is strict information governance for the use and sharing of data
4) Be transparent about the use of data and research

We will involve patients and public members in the strategy, direction and research carried out by this research unit to ensure the results are relevant to patient needs, applicable to clinical practice and make a major contribution towards health inclusion and equality in the UK.

Our aims

Our overarching aims are aligned with the UK Standards for Public Involvement, as follows:

1. **Inclusive Opportunities:** Listen to voices relevant to our research priorities that reflect the diversity of our populations, making sure we include the views of underserved communities.

2. **Working Together:** Build a culture that respects different perspectives, values contributions and supports mutually respectful and productive relationships.

3. **Support and Learning:** Provide training and support to researchers, patient, and public members.

4. **Governance:** Involve patient and public partners at strategic and operational levels, ensuring best practice and supporting research transparency.

5. **Communications:** Use innovative approaches and good communication to maximise the reach of our activities, and to ensure knowledge and interest in our research is widely spread.
6. **Impact:** Capture, monitor and share learnings, impact and best practices to feedback to those involved, avoid duplication, and contribute to the knowledge base of PPIE.

Image credit: NIHR, https://sites.google.com/nihr.ac.uk/pi-standards/home

We would like to thank members of the Oxford Blood PPI group and the NHSBT donor panel for contributing to the initial research questions for the BTRU application, and to our newly formed BTRU Patient and Public Panel for their additional input on this strategy. We will continue to include their views and opinions at all levels within our research unit through this programme of work and we are grateful for their time and expertise.

Organisational Structure and Leadership

Organisational Structure

An independent steering committee oversees all work of this BTRU. The committee is made up of research experts and leading public/patient representatives from third-sector organisations.

Individual research project co-leads from our various partner organisations will work with the Director in each of our Work Packages (WPs). This includes cross disciplinary teams of surgeons, anaesthetists, critical care specialists, haematologists, research nurses, GP's, translational scientists, public and patient members, statisticians, health economists and others from universities and hospitals across the UK. We recognise that many of our work package leads are clinicians with major service responsibilities.

WPs focus on the following areas:

- **Work Package 1 (WP1) looks at understanding and reducing inappropriate variations in blood use.** WP1 aims to use electronic health records to improve understanding of blood use and explore how we might address persistent inappropriate variations in blood use.

- **Work Package 2 (WP2) is about generating new data linkages for example to NHSBT, to improve the efficiency of the blood supply chain and blood stock management.** WP2 aims to improve the connectivity between hospitals and NHSBT to improve the management of blood reserves. Data linkages will also be explored to other organisations for example primary care and hospital episode statistics (HES).

- **Work Package 3 (WP3) looks at delivering real time feedback about the effectiveness of using blood.** WP 3 aims to establish an infrastructure for clinical, epidemiological and quality improvement research in the field of transfusion medicine.

- **Work Package 4 (WP4) is about analysing and understanding the cost effectiveness of blood management at all stages-** WP4 aims to deliver cost-effectiveness of automated systems from supply-demand and clinical practice perspectives.

Leadership

The data driven BTRU is directed by Prof. Simon Stanworth, a consultant haematologist at the University of Oxford who has spent his career working to improve transfusion outcomes for patients in the UK. The Director will be supported by the Programme Manager who will ensure that PPIE remains high on the agenda throughout the duration of this award. The appointment of a specific PPIE Manager has also strengthen this, providing a specific contact for our patient and public partners and PPIE Leads in WPs.

Equality, Diversity and Inclusion

'Diverse and inclusive public involvement is essential if research is to be relevant and provide better health outcomes for all.' (Knowles et al.) Recent reports on COVID-19, medical equipment, sickle cell disorder and delays in cancer diagnosis for Black, Asian and other ethnic minorities highlighted health(care) inequalities linked to race and ethnicity, in addition to socio economic status and location of treatment. Patient and Public Involvement in research highlights the most pressing areas and helps to find meaningful solutions for change.

We will create and build upon the following inclusive opportunities for patient and public partnership work to make sure research is 'informed by diversity of public experience and insight' (UK Public Involvement Standards):

1. Capture diversity data in research and ensure that we work with our patient and public partners to gain diverse perspectives and views on research

2. Set up and maintain a patient and public panel with lived experience of transfusion for different health conditions, their carers and blood donors with a good gender balance and high representation of Black, Asian and Ethnic Minority backgrounds

3. Secure input from Independent Steering Committee members representing underserved communities including Black blood donors and people in need of regular transfusions for health conditions such as sickle cell

4. Co-design ways of working to enable patient and public contributors with diverse needs and experiences to be involved our work

5. Deliver innovative and community-focused approaches to our research working with third-sector organisations for underserved communities

6. Use NIHR training and the Race Equality Framework to encourage BTRU researchers, staff and patient and public partners to learn how they can act to improve racial and cultural competencies in addition to trainings on inclusive leadership and cultural awareness

PPIE activities

We have planned the following PPIE activities with patient and public partners:

1. **BTRU PPIE Working Group** (Month 3 onwards)

We will ensure that our PPIE work is strongly lead and that we make best use of existing expertise and experience.

The unit has a dedicated PPIE team, who actively encourage and support researcher, patient and public partnerships:

- Prof. Simon Stanworth is the BTRU Director overseeing the unit's work and a consultant haematologist at the Redcliffe Department of Medicine, University of Oxford. Simon has spent his career working to improve transfusion outcomes for patients in the UK.

- Dr Wai Keong Wai is the clinical BTRU PPIE Lead at UCLH. Dr Wong is a Consultant Haematologist and Chief Research Information Officer at UCLH. At UCLH he is responsible for digital aspects of running clinical trials, making available routinely collected clinical data for research and identifying opportunities for using electronic health record systems as a form of health intervention.

- Dr Hayley Evans is the BTRU Programme Manager. Hayley is based at University of Oxford and manages the programme of BTRU research activities working across all the BTRU partner sites. Hayley was previously a postdoctoral research scientist and is keen to promote equality, diversity and inclusion in research.

- Linda von Nerée is the BTRU Patient and Public Involvement and Engagement (PPIE) Manager. She sits at UCLH, and her role includes building and supporting relationships between researchers and patient and public members. Linda brings great expertise from previous PPIE roles including a former BTRU.

The Director, Clinical Lead, Programme Manager and PPI Manager with the Steering Committee will ensure Work Package Leads and all BTRU activities are recognised and will be actively promoted with patient and public partners in their work.

The Programme Manager will take an active role in supporting the delivery of PPIE elements and will ensure researchers understand the advantages and impact well-designed PPIE can bring to their work. The PPI Manager will oversee and run PPIE activities, sitting in the PPI team at UCL Hospitals Biomedical Research Centre who have extensive experience in the delivery of effective PPIE.

The PPIE Manager will

- Deliver overarching PPI activities and support Work Package Leads to actively work with patient and public partners using best practices.

- Provide training and assist setting up and facilitating work between researchers and patient and public members. We will ensure all work packages include a discussion of PPIE as a standing item on their agendas to ensure it is always at the forefront of researchers' minds.

The unit will seek assistance from UCL's Co-Production Collective, which provides support to co-produce research. Additionally, we will work with the PPI team at University of Oxford, attending seminars and University-wide trainings and outreach days to ensure we are use resources available and improving our PPIE work.

2. Cross NHS Blood and Transplant and BTRU PPIE Working Group (Month 3 onwards)

We will learn from NHS Blood and Transplant and other BTRU's to improve and shape our practice working with patient and public partners and share our learnings in return.

The initial funding for BTRUs started in 2015 and much experience has already been gathered around creating a successful partnership with patient and public members. We will set out to learn from PPIE in the NHS Blood and Transplant (NHSBT) and other BTRUs to make the most of the knowledge and experience and continue to exchange learnings and best practice in a cross NHSBT and BTRU PPIE working group.

The NHSBT and BTRU PPIE working group will meet quarterly and brings together PPIE Managers/Leads from NHSBT, NIHR and current BTRUs, as well as public and patient partners from each unit to share best practices, ideas, experiences and opportunities for collaborations.

Further cross BTRU collaborations are being discussed currently and we plan to work closely with the BTRU in Cambridge and Newcastle as well as those at Oxford to carry out some join PPIE activities.

3. Representation of patient and public partners in BTRU research (Month 3 onwards)

We will work with representatives of other community organisations and patient and public panels and members as active partners in our research. Examples include PPI panels for implementation research (Leeds) and BTRU in blood donation (Cambridge University /NHSBT).

a. Independent Steering Committee

We are also fortunate to be able to appoint both Beverley De-Gale OBE and Tracy Williams to our Independent Steering Committee.

- Beverley De-Gale is co-founder and Director of Operations of the African Caribbean Leukaemia Trust (ACLT) which has been running for over 26 year's campaigning to increase the diversity of donors listed on the Bone Marrow Registry as well as encouraging members of the Black community to donate blood to help meet the need for well-matched blood products in the UK.

- Tracy Williams is the Project Manager at the Sickle Cell Society working on blood donations and brings a wealth of experience working with donors and recipients.

The involvement of two such experienced members on the steering committee will help ensure that our PPIE work as well as our research is well monitored and challenged.

Steering Committee members will represent their own and/or other patient and public perspectives on blood donation/transplantation from underserved communities. This ensures learning from and embedding these valuable views in the unit's research direction. Steering Committee members were selected on the basis of their expertise and personal experience as well as their enthusiasm to shape and steer BTRU research and confidence to provide robust challenge and governance. The Steering Committee role description and Terms of References provide more detailed information.

b. Patient and Public Panel

We will set up a group of about twelve patient and public partners to form a dedicated BTRU Patient and Public Panel. Panel members are involved in overarching PPIE activities and aspects of specific work packages depending on their interest and experience. The panel will contribute to research design, implementation, interpretation and publication.

Patient and Public Panel members will bring experience of blood donation/transplantation as patients or carers for different health conditions. We will invite patient and public panel from different ages, gender, ethnic and socio-economic backgrounds to include diverse views and perspectives. In specific, we will reach out to patient and public members from underserved communities with experience of donating blood and needing frequent transfusions including those with no or little experience of PPIE and research.

The PPIE Manager will provide training and support individual needs of Patient and Public Panel members to make sure they feel confident to provide input to research and voice questions and areas of concern. They will work with the PPIE Manager to finalise, update and monitor the PPIE strategy, making sure that the unit delivers in a timely and effective manner.

Panel members will be invited to pair with researchers in our wider programme and are invited to different work package projects and meetings on a regular basis. This will make sure they are informed and active partners to monitor progress and contribute to research at all levels. Panel members will be invited to work on overarching projects such as co-produce literature reviews and protocol papers, and to join the cross BTRU working group. We will work with additional patient and public panels, networks and partners when appropriate. The Patient and Public Panel role description and Terms of References provide more detailed information.

4. **Training and support** (Months 6 onwards)

We will provide training and support for researchers and patient and public partners to work as a confident and effective team.

The unit has a dedicated PPIE team (Director, Programme Manager and PPIE Manager) and budget to support PPIE elements and pay patient and public partners for their time and expenses.

The PPIE team will ensure the following support, advice and training:

a. Training and support for patients, community and public partners

- Introduction and training about BTRU research, PPIE, health care data use in research and the NHS, transfusion practices and other identified interests and needs to confidently contribute to BTRU research
- Opportunities for face-to-face meetings between researchers and patient and public partners to enable casual conversations over a cup of tea in addition to research focussed discussions
- Pre-meeting briefings and support for patient and public partners involved in decision making such as the Steering Committee, work package meetings, and quarterly meetings with NHSBT and other BTRUs following the guidelines for ‘Involving public and patients in decision making’ (see link in references)
- Resources to support needs of patient and public partners to give their views on BTRU research (childcare, carer, IT, translation, accessibility or other needs)
- Dedicated contact for patient and public partners to support them grow their skills, confidence and signpost them to other involvement opportunities aligned to their interests

b. Training, support and advice for researchers and BTRU staff

- Introduction to PPI training and other trainings supporting patient and public partnership work. This includes an initial bespoke PPI training for BTRU staff complimented with PPI trainings for all BTRU staff making use of training programmes at UCLH and Oxford BRCs, inclusive leadership and cultural awareness trainings
- Advice and support for researchers to meaningfully involve patient and public partners

5. Review of the PPIE literature in the context of the use of data and transfusion (Months 6-12)

We will look at published literature about PPIE in transfusion research to ensure we are learning from and building upon it.

We will carry out a systematic review (a summary of the medical literature that uses explicit and reproducible methods to systematically search, critically appraise, and synthesize on a specific issue) of PPIE in transfusion medicine involving up to two patient and public partners as co-authors in the process from literature search to paper production.

First, we will do a scoping review of recent literature utilising the NHSBT Systematic Review Initiative (SRI) central support for systemic reviews to ensure our PPIE is informed by the most up to date learning and practices.

Secondly, we will review identified papers for relevance – for example, the outputs from consensus publications on PPIE roles in implementation research, and from an international group of stakeholders with expertise in public involvement and engagement relating to data intensive health research (Atken et al).

Lastly, we will write up findings and learnings from discussions to publicise it as a paper. If we fail to identify much relevant literature, we will explore how to widen the inclusion criteria to identify recent publications describing patient involvement in use of routine-data.

Finding will inform our work going forward, and we aim to write up and publish learnings and impact of PPIE in this unit.

6. Create transparency around the use of patient data in transfusion research (Month 12-36)

Working with the public, donors and patients we will co-produce information explaining the legislation and guidelines that exist around the use of data in research.

We are aware that there are many reasons people choose not to engage in blood donation or medical research, and we know from discussions with our patient and public partners that there is a lot of misinformation about the use of data, with concerns that information could be sold to companies or other organisation who might use it for unethical purposes.

To help address this we will

- Produce an overview of legislation and guidelines such as GDPR around the use of data in research and a lay summary of the recent Goldacre report on the use of data in research on our BTRU website. The Goldacre report sets out the way in which researchers should access and use data patient.
- Provide an explanation about the new Trusted Research Environments (TREs) and explain how using TREs will help keep patient data safe and anonymous whilst also allowing researchers to ask important research questions.
- Focus on the transparency of our own data and plan to generate an animation to explain how routinely collected NHS data can be used to improve transfusion medicine.
- Actively encourage and support our PPIE members to discuss our research with their communities. This could take the form of podcasts record by our PPIE members in their communities' common language to help build understanding and ultimately trust.

7. Active listening workshop about patient and public experiences and views on Data in Transfusion Research (Month 15-24))

In a full-day workshop, we will create a safe environment for researchers, patient and public members to talk about diverse views on using health data in transfusion research and ask difficult questions to understand and start acting on concerns expressed.

The workshop will be focussed on underserved populations to address issues highlighted in the ‘Diverse voices on data’ report from Understanding Patient Data and ClearView Research which aimed to understand the experiences, expectations and concerns of Black and South Asian people around patient data.

Findings from the report showed that many people with Black and South Asian backgrounds have low levels of trust in the NHS and are concerned about how their patient data will be protected. The key findings included:

- People believe data can be used to improve health outcomes in their communities, but they do not see this happening in reality
- Communities have negative experiences of the healthcare system and fear sharing their data will lead to racial discrimination and poorer health outcomes
- The current ‘tick box’ options are inadequate
- People want to be informed about how their data is influencing research, design and planning of healthcare services
- They want the opportunity to shape plans themselves

We will deliver a workshop that is

- Co-designed with our patient and public panel members from underserved communities, researchers and relevant third-sector organisations
- Inviting members of existing PPIE panels and people new to research advertising widely with the help of community organisations to reach people
- Actively listening to the experiences and views of attendees on using data for transfusion research
- Kickstarting a discussion about how we can better communicate and involve underserved communities in our research to create transparency about health data research

We will share a summary of our finding with attendees and a wider audience and take steps to address the opportunities identified in this workshop.

8. Develop a roadshow and toolbox to increase transparency and understanding of data driven transfusion research in schools and communities (Months 36 onwards).

We will co-produce a roadshow and toolbox for schools and communities to increase transparency and understanding about transfusion and big data research.

Building on the findings of our workshop, researchers and patient and public partners will work with an external engagement expert and young people from underserved communities to co-produce a roadshow and toolbox that can be used in schools and communities to explain how patient data is used in our research. We may explore this work with other interested partner organisations such as the Wellcome Trust.

We will focus on producing information for young people in secondary schools and communities as we believe that the use of routinely collected patient data will have a lasting impact on their future healthcare. Explaining the process may encourage future participation which is important to ensure that there is good quality data available to assess equality in transfusion care.

We aim to work with an organisation already established in this space, to ensure our work is relevant to the national curriculum to provide a valuable service to schools. In addition to educating young people about blood donation we will also aim to encourage them to consider being in involved in research in the future.

9. Information accessibility – Online Presence (Month 6 onwards)

We will use accessible online platforms including a website and Twitter to engage with people about our research.

a. **Website:** We are developing a website with information about our research programme, PPIE and outreach work with input from patient and public panel members. We will include a designated page for PPIE.

b. **Twitter:** We will use Twitter to develop an interactive presence on social media for regular updates about ongoing work and to network with a diverse range of people about our research. On this platform we will give both clinicians and the public opportunities to learn about and comment on our research and involvement work.

10. Review and update the PPIE strategy (Month 30-36)

We will review this PPIE strategy with patient and public panel members to apply our learnings and set out activities for the second half of funding.

We will reflect on learnings from delivering elements set out in this PPIE strategy and apply learnings to update this document with continuing activities and new elements. Patient and public panel members will shape new elements and we will include key priorities and suggestions from Independent Steering Committee members.

PPIE elements in Work Packages

Specific PPIE elements in each Work Package (WP) will be discussed and developed with Work Package Leads, patient and public panel members with support from the PPIE Manager. PPIE will be proportionate to the sensitivity and scale of each project.

Each WP co-Lead and linked researchers will be responsible for actively working with patient and public partners in raising the need for designing, delivering and disseminating their research. The PPIE Manager will offer training and support.

Each WP will:

- Ensure all team members attend PPIE training when starting
- Have a dedicated PPIE Lead
- Involve a minimum of two patient and public partners in their research
- Include PPI as a standing agenda item and consider inviting patient and public partners to Work Package meetings following guidance for PPI in decision making (see references)
- Feedback the changes made because of input from patient and public partners, or if not why this wasn't possible
- Seek input from patient and public partners to improve PPI work practice
- Track learnings, outcomes and changes in the unit's impact log

Partners and Collaborators

We will work with the following partners and collaborators to deliver the aims of this strategy, to increase diversity of people involved in research, to share our learnings and to exchange best practices:

- Patient and public partners with relevant experiences from diverse backgrounds
- NHS Blood and Transplant and other Blood and Transplant Research Units
- NIHR organisations including NIHR Centre for Engagement and Dissemination, Biomedical Research Units at University of Oxford and University College London Hospitals
- Organisations working with patient and public members on use of data for healthcare and research
- UK third-sector organisations and charities working with underserved communities, with people in need of transfusions and to encourage blood donations
- Communities underserved in the UK health care system
- Schools in disadvantaged and/or ethnically diverse communities
- Other organisations as relevant to deliver this strategy and to increase diversity of patient and public partners in research

Resources

We will have a dedicated PPIE team that will deliver this strategy in partnership with researchers and patient and public partners. The PPIE Manager will oversee the delivery of this programme in collaboration with Programme Manager.

The dedicated PPIE budget will support:

- Expense and time reimbursement for patient and public partners.
- Training costs to ensure researchers and patient and public partners feel confident about PPIE and the research there are involved in.
- Facilities and other costs associated with the running of PPIE elements and outreach activities.
- Technological support for PPI members who do not have access to the equipment required to allow them to have involvement in our work.

Monitoring, Evaluating and Reporting

We will monitor, evaluate and report our PPIE activities and their impact to ensure that resources are being utilised effectively, and to share outcomes, learning and impact of PPIE.

a. Monitoring

We will monitor PPIE activities, and the delivery of this strategy as follows:

1. Regular PPIE work group meetings will set short term targets, monitor actions from previous meetings and ensure the work is progressing whilst also being responsive to the changing research landscape. These meetings will include the Director, Programme Manager and PPIE Manager.

2. PPIE will be added as a standing item to all work package meetings. PPIE Leads in each WP will regularly feedback on PPIE elements to the PPIE Manager, who will share updates with the PPIE working group.

3. The Independent Steering Committee will discuss PPIE in their meetings, monitor the delivery of this strategy and will advise on challenges and changes.

b. Evaluating

We will evaluate PPIE elements in our work as follows:

1. We set out success factors (see 'What success will look like and how we will measure it' below) as clear goals to measure specific PPIE elements in this strategy against.

2. The PPIE work group will use an online impact log to track activities, outcomes, learning and long-term impact, including input from researchers and patient and public partners.

3. The PPIE Manager will use mixed methods to evaluate specific, larger PPIE activities (e.g., qualitative interviews, quantitative surveys with researchers and patient and public partners).

4. We will continuously look to learn from experiences of the wider research community, liaising closely with other BTRU teams as well as University Teams to inform and improve our practice.

c. Reporting

We will work with patient and public partners on

1. An annual report that highlights progress, learnings and challenges addressing PPIE activities, aims and objectives.
2. Sharing evaluation and learnings of PPIE elements with stakeholders at internal and external meetings, via our website and social media.
3. Writing case studies and publications including PPIE and learnings to add to the wider evidence base.

d. What success will look like and how will we measure it

We set specific goals and how we will measure them for each proposed PPIE element:

Activity	What does success look like?	How will we measure it?
1. BTRU PPIE Working Group	Strong led PPIE making best use of existing expertise and experience.	The programme and PPIE Manager will work with at least two affiliated PPIE teams (UCLH and University of Oxford) to make use of synergies, expertise and available resources.
2. Participation in the cross BTRU Working Group	Learn from previous practice, work jointly with patient and public partners and other PPIE Leads to tackle challenges and share learnings of PPIE with NIHR, NHSBT and BTRUs.	a. Regularly attend quarterly BTRU-wide PPIE meetings with other units. b. Gain feedback from patient and public partners to ensure they meaningfully contribute to BTRU-wide PPIE meetings. c. Seek at least two opportunities to work in collaboration with other units
3. Representation of patient and public partners in BTRU research	Representation of patient and public partners or third-sector organisations on the Independent Steering Committee and a dedicated Patient and Public Panel working in partnership on BTRU research	a. At least two Patient and Public partners or representatives of third-sector organisations sit on the Independent Steering Committee b. Partnership work with a panel of about 12 patient and public members with diverse health experiences and backgrounds. We will monitor diversity of panel members via an expression of interest and use feedback forms to improve partnership work.
4. Training and support	Initial PPI training and identification of training needs and support for research staff	a. Deliver an initial PPI training for researchers and patient and public partners in autumn/winter 2022

	and patient and public members	b. Annually identify and act on training needs c. Assess need for support of patient and public partners and researchers in feedback surveys d. Monitor learning scoring knowledge before and after trainings and collect feedback for improvement/ follow up
5. Review of PPIE literature in the context of data and transfusion	We will produce a review paper with patient and public partners to inform best practice of PPIE in this field.	a. Work with 1-2 patient and public partners to publish a review paper b. Measure the impact of this publication by our ability to publish it and the engagement it receives from other researchers
6. Create transparency about the use of patient data in transfusion research	We will co-produce information to explain the current legislation and guidance around the use of data in research and how we will be applying this to our research programme with patient and public members.	Develop and publish easy-to-understand information for a patient and public audience on the BTRU website and promote it on Twitter, measuring engagement via google/twitter analytics
7. Workshop about Patient Data in Transfusion Research	We will bring researchers, patient and public members together to discuss the use of patient data in transfusion research in a safe environment, activly listening to patient and public views and experiences to inform future partnership work.	a. Co-design the workshop with at least one third-sector organisation and two panel members with Black and Asian backgrounds b. Invite equal parts of patient and public members with and without experience being involved in research c. Share findings and start acting on at least two identified opportunities within this award

8. Toolbox for school and communities	We will engage with secondary school age children from underserved communities about the use of data in research, blood transfusions and how they can play an active role in the research process.	a. Co-produce a roadshow for use in schools and community settings b. Collect feedback and questions from attendees c. Develop a toolkit for long-term use in UK secondary schools
9. Online Presence	We will have a vibrant and engaging online presence about our work designed with the help of patient and public partners.	a. A website will provide easy-to-understand information about research and PPI b. A Twitter account will provide regular updates c. We will monitor the reach via website visits and duration; re-tweets, engagement and followers on twitter
10. Review and update the PPIE strategy	We will review this PPIE strategy with patient and public panel members to apply our learnings and set out activities for the second half of funding.	a. Review this strategy collecting feedback and suggestions for future direction from researchers and patient and public partners in interviews and surveys b. Publish an updated PPI strategy on the BTRU website in Month 36 to set out and guide PPIE work until the end of this award.

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Glossary

Anonymised: Meaning identifiable information (such as name and address) is removed, so you have patient health data about without knowing who it belongs to.

Big Data – extremely large amounts of anonymised information which can be examined to reveal patterns, trends, and associations. This can be general information or information about a large group of patients with a specific characteristic such as a health condition like blood cancer.

BTRU: Blood and Transplant Research Unit, academic partnerships between universities and NHSBT for research to improve blood and transplant services for the NHS.

Interventions - actions taken to improve a health condition such as a treatment or medicine

NHS Blood and Transplant (NHSBT): National Health Service Blood and Transplant – our partner organisation which supports and carers for blood, organ, tissue and stem cell donors and patients. NHSBT are also funding part of this research unit.

NIHR: National Institute for Health and Care Research. The NIHR funds, enables and delivers world-leading health and social care research that improves people's health and wellbeing, and promotes economic growth. They are the funder for our research unit.

Patient Health Data - Patient health data is medical information about an individual patient. This may include information about past and current health or illness (e.g. blood tests and/or chronic health conditions), their treatment history (e.g. blood transfusions), lifestyle choices (e.g. smoking, diet and exercise) and genetic data (e.g. blood group, age and ethnicity). It may also include biometric data, which is any measurable physical characteristic that can be checked by machine or computer. This data is anonymised, if it is used for research and does not include names, addresses and other identifying information.

Routinely collected NHS patient health data: Details of health checks and conditions, medicines, treatments and records of contact you have had with doctors and other health and care workers such as blood tests and/or transfusions.

Systematic review - A systematic review is the process of bringing together all the evidence on a topic whilst also assessing how good each of the piece of evidence is to allow a wider conclusion to be drawn on the subject.

Transfusion – the process of transferring donated blood, blood products, or other fluid into another person.

UCLH BRC – University College London Hospital’s Biomedical Research Centre – which brings together a wide array of researchers to answer important translational research questions.

Contact details

For further information about our PPIE activities or to give us your feedback please feel free to get in touch with us:

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