

NIHR Blood and Transplant Research Unit in Organ Donation and Transplantation at Cambridge and Newcastle Universities

Patient and Public Involvement and Engagement (PPIE) Strategy (2022–2027)



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Introduction

Patient and public involvement and engagement are essential components of the work of the National Institute for Health and Care Research (NIHR) Blood and Transplant Research Unit in Organ Donation and Transplantation (BTRU in ODT) and will be critical in ensuring the unit addresses issues that are clinically, socially, and ethically relevant to individuals and the community.

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

Patient and Public Involvement and Engagement (PPIE) – a combination of the two definitions below

Patient and Public Involvement (PPI) – patients, carers and members of the public are actively involved in the activities, organisation and governance of research projects or themes

Patient and Public Engagement (PPE) – information and knowledge about research are provided and disseminated to the public¹

Along with our partner organisation National Health Service Blood and Transplant (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 objectives and an action plan for the lifetime of the Unit, 2022–2027.

Our Vision

The key objectives of the BTRU in ODT are to:

1. Establish the optimal use of novel perfusion technologies for the assessment and repair of donor organs prior to transplantation.
2. Improve donor organ utilisation rates and reduce variations in NHS (National Health Service) practice.
3. Improve long-term outcomes after organ transplantation and reduce the need for re-transplantation.
4. Evaluate and implement patient-reported measures to enhance the quality of life and patient experiences alongside graft and patient survival outcomes.
5. Increase organ donation from ethnic minority groups and increase access to transplantation within underserved communities.

Patients and the wider public are fundamental and integral partners in the work of the NIHR BTRU ODT. We aim to develop world-class high-quality research in the field of organ donation and transplantation but also to improve the well-being and quality of life for patients, reduce the barriers to and inequalities in organ transplantation experienced by ethnic minority communities and increase the number of individuals from underserved communities involved in our research.

The Unit will ensure:

- 100% of new research projects from across the BTRU ODT are presented to the Patient and Public Research Panel (PPRP) for their input.

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

- All BTRU in ODT projects are encouraged and supported to engage with patients and the public.
- All BTRU researchers are encouraged to present their projects to a non-scientific audience and participate in open Q & A.
- Feedback is collected after each internally organised event to ensure our engagement programme is relevant, impactful, informative, and tailored to the needs and interests of the OD&T community.
- It works with public contributors and researchers to develop toolkits which will record and measure the impact of PPI on BTRU research. Involvement will be assessed at the project, Unit, and panel levels to ensure it is embedded in a meaningful way.

The challenges experienced by the 2015–2022 NIHR BTRU in ODT have been learning opportunities, a way for us to improve and develop our PPIE activities.

- During the COVID-19 lockdowns panel meetings could no longer take place in-person and were moved to online communication platforms, i.e., Zoom. Although this was disappointing to our members, as online discussions can be challenging, it meant that panel members could meet more regularly and learn more about digital technologies and that meetings were environmentally friendly and more inclusive.
- The move to online working provided an opportunity for the Unit to engage with a wider audience. It meant those who are immunocompromised and self-isolating, who live outside of the local area, are experiencing ill health or have caring responsibilities could still connect with the Unit and be involved in research.
- Public contributors from non-Caucasian backgrounds have taken on roles within the BTRU's Independent Steering Committee and the Faculty of National Experts.
- Even though it was not mandated to do so in the application process, the Unit took the decision to include a public co-applicant who assisted in the writing of our Unit funding application. The public co-applicant is also a member of the Management Group and the Patient and Public Research Panel.
- The Unit is now a member of [Haref Allies](#), a network whose aim is to improve how health and well-being services are provided for ethnically minoritised communities in Newcastle and Gateshead. Through Haref Allies, northeast local communities have a platform to speak to mainstream services and affect change. Haref Allies also provides their members with networking and training opportunities which will enable the PPIE Lead to develop skills in, for example, engaging with and delivering health information sessions to diverse community groups.
- To date, the PPIE Lead has met with representatives from GOLD (Gift of Living Organ Donation) and South Asian Health Action to develop relationships and discuss how we might collaborate. We want to continue to take a proactive approach, going directly to organisations or through community gate-keepers and discussing what communities need from us to enable meaningful and non-transactional collaboration.
- The Unit has engaged with the National Innovation Centre for Rural Enterprise, and Centre for Rural Economy at Newcastle University to expand our links with rural community groups within the Northeast and Cumbria. The Unit is also reaching out to rural community groups throughout the UK to achieve its goal of diversifying the membership of the PPRP, reaching out to underserved communities in terms of ethnicity and geographical location.

The Unit aims to conduct research that helps NHSBT achieve its overarching mission to increase organ donation and donor organ utilisation, perform more transplants and improve long-term outcomes and hence realise the objectives in the [ODT 2030 vision documents](#).

To achieve our aims, we will work with patients, the public and industry to develop and deliver a comprehensive research programme that facilitates rapid translation of new developments into clinical practice. The focus will be on benefitting patients, especially those from underserved communities. Early public and patient involvement and a co-production approach will remain central to the work of our BTRU.

We wish to develop a range of creative approaches to share and harness the insights, experiences and opinions of patients, carers, and the public, and to integrate these within BTRU activity and influence decision-making about research priorities in organ donation and transplantation as well as in the subsequent dissemination and implementation of any new research findings generated.

Background

Strategic Approach

Patient and public involvement and engagement are both supported by and strongly encouraged within all NIHR-funded [activities](#) on the basis that this leads to better research that is more focused on the needs of patients and can accelerate the timely and effective transfer of evidence into clinical practice.

The BTRU is committed to actively involving and engaging patients, carers, and the public as partners in the processes by which research is identified, prioritised, designed, conducted, and disseminated. To achieve this, and in collaboration with [Engage FMS \(Faculty of Medical Science\)](#) at Newcastle University, the University of Cambridge, the NIHR BTRUs, [NHSBT](#), Charitable organisations, [NIHR RDS NENC](#) and patient groups we will:

1. Continue to build capacity and capability to develop and deliver Patient and Public Involvement and Engagement (PPIE) in BTRU organ donation and transplantation research.
2. Build the evidence base around PPIE and impact by embedding monitoring, reporting, evaluation and learning from PPIE activities.
3. Collaborate and share best practice with key stakeholders within the local, national, and international health economy and research community including all NIHR BTRUs, [NHSBT Patient and Public Advisory Group \(PPAG\)](#), UK Organ Donation and Transplantation Research Network ([UKODTRN](#)) and patient groups to ensure a coordinated approach.

Implementation

The key objectives within these three strategic areas are listed below. We present an action plan for the delivery of these objectives in 2022–2027. The plan encompasses PPIE actions at BTRU level, as well as within individual research projects and themes. We present timelines for these activities in Appendix A.

Key Objectives

Continue to build capacity and capability to develop and deliver Patient and Public Involvement and Engagement (PPIE) in organ donation and transplantation research:

- To build upon and improve the existing structure of PPIE activity across the BTRU through the implementation of the UK Standards for Public Involvement.

- To ensure PPI is inclusive, that all contributions are valued and that patients and the public have a voice which can influence research.
- To improve the equality, diversity, and inclusion of underrepresented groups within BTRU in ODT research.
- To listen to and learn from individuals and communities of experience.
- To develop and introduce guidance, including training and sharing of good practice guidelines, for involving patients, carers and the wider public in BTRU in ODT research.
- To support all BTRU in ODT colleagues to implement PPIE within research in a meaningful way.

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

- Build and share evidence of how to involve patients and the public and demonstrate its impact on BTRU in ODT research.
- Establish and improve processes to monitor, evaluate and review PPIE with a view to understanding its impact.
- Build a culture of continuous reflection and improvement for all BTRU ODT stakeholders.
- Share and learn from PPIE good practice and achievements.

Collaborate and share best practice with key stakeholders within the local, national, and international health economy and research community to ensure a coordinated approach:

- Ensure PPIE internal networking, partnership working and common strategies in research across the BTRU in ODT themes.
- Ensure PPIE external networking, partnership working and common strategies with local partners.
- Liaise with local, national, and international organisations including the UKODTRN and NHSBT PPAG to ensure a coherent national strategy for PPIE around organ transplantation.
- Continue to work with international networks and organisations, for example, the Canadian Donation and Transplantation Research Program, to ensure collaboration on PPI activities for patient and researcher benefit.

Action Plan

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

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

Organisational Structure

Governance

The Unit's Independent Steering Committee includes an independent public representative. The Management Group includes our Public Co-applicant who is a pivotal part of our team and a

member of our PPRP. She has provided guidance on our teaching activities, engagement events, impact evaluation, communication strategy, and recruitment of new members to our panel.

NIHR BTRU in ODT Patient and Public Research Panel (PPRP)

The PPRP was established in 2015 under the 2015–2022 NIHR BTRU in ODT to ensure that the patient and public voice was embedded and involved in all aspects of the BTRU ODT research. The membership of the panel comprises of patients, carers, living donors and members of the public who bring their unique perspectives and lived experiences to our research.

The panel currently has 11 members who meet on a quarterly basis, via Zoom, to support the delivery of the Unit's PPIE Strategy, to provide insight and opinion on new projects or topics of research and to impart their thoughts relating to broader ethical and psychosocial issues.

Researchers who wish to obtain feedback from the panel must first complete the Panel Feedback and Evaluation document (Appendix B). The document outlines, in plain English, questions the research team has for the panel, the clinical problem that they hope to solve within the project, why the project is important and the methods to be used. Panel members are emailed the document and have two weeks to prepare their comments and questions. Once the meeting has concluded the document is returned to the research team with a summary of the discussion and a full transcript of the feedback offered by the panel. Researchers are also asked to give their feedback on the discussion, describing which elements of the feedback they included in their research/funding application, the outcome of their application and if they require further support from the panel or PPIE Lead.

The BTRU ODT is aware that more action is needed to expand the diversity of the panel membership and we are already taking steps to ensure the panel represents as wide and varied a patient/public view as possible.

The Unit will:

- Take a proactive approach and reach out and engage with individuals/groups from ethnically minoritised communities, lower socioeconomic backgrounds, rural communities, students, and young people (18–25) to build relationships, communicate our vision and research, dispel myths, and support future involvement in our research.
- Reach out to community gatekeepers and organisations to seek their advice on the best way to engage with underserved communities and be led by their expertise, not dictating our needs and expectations.
- Go out into local communities in person to support the building of relationships, trust and networks.
- Offer remuneration to panel members for their time in line with NIHR guidance.
- Make practical adjustments to increase accessibility to PPRP meetings, e.g., holding meetings in the early evening or at weekends.
- Provide a digital exclusion subsidy to assist panel members with digital attendance costs of PPRP meetings.
- Enable the PPRP to continue to support the research activities of the BTRU by meeting on a quarterly basis, mostly via Zoom, to provide feedback on proposed research and engagement activities. Meeting online via Zoom will increase inclusion and allow the Unit to recruit panel members and public co-applicants from across the UK.

- Continue to support PPRP members in their roles and offer the opportunity to attend any relevant training and workshops.
- Work with PPIE networks and colleagues to ensure a collaborative approach.

Inclusion of Public Co-Applicants within BTRU Research

Improving the understanding of PPIE and its implementation within the research cycle will be reinforced by training and the development of hardcopy resources in collaboration with our partners.

All BTRU colleagues are encouraged and supported to work with the public/patients from an early stage to develop organ donation and transplantation research projects.

The Great Expectations project, which examines the role of the public co-applicant within research, was led by the 2015–2022 NIHR BTRU in ODT in 2021. A workshop was held that sought to understand the challenges and barriers to the effective inclusion of public co-applicants in research projects. All stakeholders, including researchers, PPIE professionals and public contributors, were invited to share their views and the lessons learnt have been summarised and turned into an educational animation.

The animation now forms part of the tools available on the NIHR Research Design Service (RDS) Resources website (<https://www.rdsresources.org.uk/great-expectations-inclusion-of-public-co-applicants>).

The further development of the Great Expectations project will be continued by the PPIE Lead of NENC RDS, with support from the BTRU in ODT. The animation will form part of a wider training programme to be developed for researchers. The BTRU will also work with RDS NENC, NIHR BTRUs, NHSBT and the UKODTRN to develop a network of public co-applicants who can provide support to prospective and experienced co-applicants and researchers.

Communication

The BTRU in ODT will continue to communicate with ODT stakeholders providing updates on our research, advertising events and involvement opportunities and reporting on our progress.

We will maintain a contacts spreadsheet of all individuals who wish to be kept informed of the Unit's research, publications, and upcoming events. We will continue to advertise our involvement opportunities and encourage individuals to contact us if they are interested.

We will continue to communicate with the wider OD&T community through our quarterly 'Get Involved' newsletter and the Unit's Twitter account, https://twitter.com/BTRU_ODT

The 'Get Involved' newsletter was relaunched in 2021 and has received a very positive response from readers. Changing the format from PDF to Microsoft Sway has created a newsletter which is now more dynamic, interactive, and eye-catching. <https://odt.btru.nihr.ac.uk/get-involved/get-involved-newsletter/>

PPIE Guidance

Standardisation is crucial for both the public participants and the BTRU to guide planning, avoid tokenism and ensure a better understanding of how PPI adds value to BTRU research. We will co-develop and make available guidance for PPIE activities to support the standardisation of approach across the BTRU. This will include:

Policies and procedures on:

- PPRP Terms of Reference and Code of Conduct.
 - Template Role Description for panel members and public co applicants.
 - Accessing patients/members of the public for PPIE activities via the Patient and Public Research Panel.
 - Payments, rewards and incentives for patients and members of the public who are involved in specific research projects as members of panels or as co-applicants, including certificates of participation or letters of acknowledgement for use in education or employment.
 - Health and safety, public liability, and insurance issues
-
- Confidentiality or non-disclosure agreements.
 - Guidelines on PPIE, including definitions, values, and models.
 - Good practice examples for both engagement and involvement.
 - Training for members of the PPRP to promote research literacy and stimulate debate on research evidence, interpretation, and translation.
 - Signposting colleagues to external partners who can provide further guidance or support.

Improve awareness of patient and public involvement and engagement opportunities

We will develop a programme of awareness-raising events to inform and engage patients and members of the public in ongoing and future research. Events targeted at 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 directed towards patients and members of the public will be facilitated in collaboration with Engage FMS (Newcastle University), Public Engagement at University of Cambridge, NHSBT and other partners of collaboration as appropriate. Seminars, workshops, and 'drop-in' events will be offered.

BTRU colleagues will attend externally organised events, including Cambridge Festival, formerly Cambridge Science Festival, and Big Biology Day.

Pages of the [BTRU in ODT website dedicated to PPIE](#) will also include links to national resources, examples of good practice across BTRU work streams, details of PPIE news and events, copies of the 'Get Involved' newsletter, a list of useful contacts and guidance (as described above).

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

Monitoring, evaluating, and reviewing processes

Pilot PPI Standards

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

Sharing good practice

We will work closely with the other BTRUs, the University of Cambridge, Newcastle University, NHS Trusts, NHSBT and NIHR organisations to effectively share best practices and expertise, reduce duplication and enhance the effectiveness of patient and public involvement and engagement.

We are committed to working with our BTRU colleagues, both internal and external, and public contributors to develop and implement an effective PPIE impact assessment and monitoring strategy.

It is important that the impact of PPIE on BTRU in ODT research is assessed and evaluated to:

- Ensure members of the PPRP can see the difference their input has made to research activity and applications for funding.
- Ensure both public contributors and researchers feel their input is valued.
- Ensure BTRU researchers commit to implementing PPIE throughout their research lifecycle.
- Improve the quality of the Unit's PPIE output and in turn the quality of its research.
- Improve communication between researchers and public contributors.
- Encourage a process of reflective practice and an appreciation of the emotional and psychological toll placed upon public contributors and researchers, particularly when discussing distressing or upsetting experiences or scenarios.
- Assist BTRU researchers in writing their annual funder reports.

BTRU patient and public involvement within the BTRU is implemented in two ways:

1. The Patient and Public Research Panel (PPRP).
2. Members of the public/patients/carers can become part of a working or advisory group or public co-applicants within individual Unit research projects.

In accordance with NIHR guidance, a project has been created to measure the impact of PPI activities on BTRU research. The project has been divided into three stages: Design, Pilot and Roll-out.

Stage 1: Design

Expertise in impact evaluation has been sought from multiple sources including [RDS NENC](#), NIHR BTRU's and BTRU researchers and public contributors.

An impact assessment subgroup, comprising volunteers from the Unit's Patient and Public Research Panel, has been formed. Its role is to assess existing PPIE impact evaluation models/frameworks, to provide a public perspective on the process and importance of impact assessment and provide insights on the information they feel should be captured by BTRU researchers.

The subgroup evaluated multiple models/toolkits including [the Public Involvement Impact Assessment Framework \(PiiAF\)](#) and an [impact logbook to record PPI outcomes](#). It became clear that no one model could be used by all projects/themes within the BTRU. The subgroup will conduct a prioritisation exercise establishing a list of the most important elements from multiple models to create a hybrid. The new toolkit will capture the impact a PPI contribution has made to a research project or funding application, how heard and valued PPI contributors feel, and the researchers' views on the usefulness of the toolkit. The toolkit will also include questions which encourage continual reflective practice. The regular consideration of PPI activities, for example, the impact of discussing emotive topics, monitoring levels of communication, and working with public contributors to assess their needs, training requirements, and ensuring they have a clear role description, will ensure a process of continual learning and refinement.

Advice will be sought from BTRU researchers to ensure their concerns, ideas and comments are recorded and incorporated into the selection and design of the new evaluation toolkit.

Our approach will be flexible, allowing individual researchers and projects to decide how they will record and evaluate the impact of PPI on their work, selecting tools from those recommended by the subgroups of public contributors and researchers. It is important to capture the impact the PPI contribution had on research, to know how heard and valued the public contributors felt and what the researchers' views are towards the usefulness of the process and the methods of data capture suggested.

Stage 2: Pilot

A small number of priority projects will be identified, for example, [E-CLAD](#), an NIHR EME Clinical Trial that arose from the 2015–2022 NIHR BTRU in ODT, which will be asked to record impact within the nominated toolkit and assess its effectiveness in capturing the impact and effecting change within the project.

Once the pilot has concluded, after a period of 6 months, we will conduct an evaluation, assessing the data collected, the ease with which the data was collated, the performance of the model/toolkit and adjust the initiative based on the feedback we receive from PPIE coordinators, researchers, and public contributors.

The results will be presented to BTRU colleagues, and the process of rollout will begin in years 2–3. The aim of the initiative is to have at least 50% of BTRU projects capturing and evaluating impact by year 4.

Those researchers who participated in the pilot will be asked to act as 'Research Champions' encouraging BTRU colleagues to support the initiative and take example from their experience within the pilot.

Stage 3: Roll out

We will support all BTRU in ODT researchers and public contributors throughout the process.

We will create training videos which will outline how to complete the impact evaluation toolkit, provide examples of the information required and share good practice. Providing training in this way ensures accessibility for all at a time which is convenient to the individual.

We will cultivate a culture of continuous reflection which asks that all stakeholders, BTRU researchers and public contributors, consider their activities, answer fundamental questions with a critical eye, and implement change that will improve PPI processes within BTRU research and individual projects.

Theme leads and those responsible for PPIE on a project level will be contacted twice per year to ensure they are engaging with the initiative and provide any support or training required.

The initiative will be reviewed annually to ensure meaningful engagement by all stakeholders and what changes, if any, could be made to improve the process.

The initiative will be coordinated and overseen by the PPIE Lead.

Objective 3: Influence policy and practice by collaborating with key stakeholders in the local, national, and international health economy and research community to ensure a coordinated approach:

The BTRU in ODT PPIE strategy aims to promote collaborative working across universities, NIHR and NHS organisations to facilitate coordination of PPIE activity as well as sharing best practices and

expertise to reduce duplication of effort and enhance the effectiveness of PPIE. We will continue to work with our partners and seek new alliances with organisations locally, nationally, and internationally.

Internal Collaboration

Internal collaboration will build upon the 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 the BTRU PPIE Lead and BTRU work streams.

Opportunities to attend training and increase knowledge of important elements of PPIE will be shared and advertised to all BTRU colleagues and public contributors by the BTRU PPIE Lead. Through our connections with [RDS NENC](#) and Connected Voice we have already been able to offer BTRU colleagues training in cultural competency and the writing of English lay summaries.

Local Collaboration

We will continue to work closely with Newcastle University's Faculty of Medical Science Engagement Group and Biomedical Research Centres at both Cambridge and Newcastle as well as existing patient organisations – both generic and those pertaining specifically to organ transplantation/donation, taking advantage of existing PPIE networks and collaborations.

Working closely with Engage FMS and the Newcastle University Health and Wellbeing committee the Unit will find opportunities to engage with non-academic employees and students leveraging existing resources to build our networks, share our research and increase and diversify the membership of the PPRP.

We will strengthen and build strong relationships with organisations relevant to BTRU in ODT research themes and those focussed on public engagement, specifically Voice but also considering others such as Tyneside Kidney Patient Association, Freeman Heart and Lung Transplant Association, LIVErNORTH, TransplantTV, Kidney Research UK, 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.

Strong links will continue with other NIHR infrastructures including the NIHR Research Design Service Northeast and North Cumbria. The PPIE Lead will manage and promote effective engagement and involvement for and beyond the Unit, including the coordination and administration of an informal peer support network for public co-applicants in conjunction with NIHR Research Design Service Northeast and North Cumbria and the UKODTRN.

Collaboration on public engagement will also take place through the attendance of externally organised events such as Cambridge Festival, Newcastle FMS Mini Medical School (FMS), European Researchers Night, TEDx and internally organised events when considered appropriate and timely.

Twice per year, the BTRU will host a 'Research Explained' webinar. Four BTRU researchers, two from the University of Cambridge and two from Newcastle University, will spend 10 minutes outlining their research to a public, non-scientific audience. The event is hosted by either the BTRU Director or the Co-Director and is an excellent opportunity for the public to ask questions and learn more about what the BTRU does. The webinar is also a chance for our researchers to gain experience in public speaking, communicating complex ideas to a lay audience and responding to criticism and challenge.

We will engage with a creative practitioner to undertake co-production activities to generate content that communicates the public and patient perspective in donation and transplantation research. These activities will build on the success of our previous Haiku poetry project in the 2015–2022 NIHR BTRU in ODT and will upskill both researcher and public/patient contributors in reflection to capture impact.

National Collaboration

We will work with key NIHR organisations to support public and patient involvement and engagement in research, including Clinical Research Networks and other NIHR-funded organisations, such as the Creating Connections network within the Northeast and North Cumbria 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 coordination of PPIE and the timely translation of research evidence to maximize impact. We will also collaborate with charitable organisations and businesses/industries where appropriate.

We will hold an annual online workshop to explore a different UK Standard for Public Involvement. PPI feedback will be gathered at each one, enabling the Unit to identify ways to improve across the lifespan of the BTRU. Emoluments for public contributors in line with NIHR guidance reflect the Unit's recognition of the input of our contributors.

The Faculty of Medical Sciences at Newcastle University and the School of Clinical Medicine at University of Cambridge will continue to participate in national campaigns such as NHSBT blood and organ donation campaigns. We are committed to including and working with people from underserved communities, including black, Asian and minority ethnic groups, given the inequalities in waiting times for patients from such communities, and underrepresentation on the organ donor register. We will deepen our links with communities of experience who can increase our understanding and build relationships with regional and national community groups (e.g., South Asian Health Action and Health and Race Equality Forum) to increase participation in our work.

We will work with other BTRUs, including the BTRU in Donor Health and Behaviour, and NHSBT on a PPI collaboration activity, in year 3, reflecting our commitment to diversity.

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

Events Calendar

An events calendar will be developed to harness synergies with national campaigns beyond the donation and transplantation field (e.g., Mental Health Awareness week, International Clinical Trials Day, WearRed4Research day). BTRU colleagues will be encouraged to participate in social media campaigns, using the Unit Twitter account to raise awareness and highlight important causes for organ donation and transplantation stakeholders.

The calendar will be published on the BTRU in ODT website (<https://odt.btru.nihr.ac.uk/>).

International Collaboration

We will identify international organisations, for example the Canadian Donation and Transplantation Research Program, with whom we can develop collaborative PPI activities for patient benefit and

projects aimed at increasing researchers' knowledge and skills in PPIE related activities, e.g., inclusion of public co-applicants or writing English lay summaries.

We have established partnerships with [The European Society of Organ Transplantation \(ESOT\)](#) which will lead to further engagement and involvement training opportunities.

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 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 the Patient and Public Research Panel Members (PPRP), is responsible for collating and summarising this information.

Acknowledgements and Authorship

This strategy was written by Hannah Murray (PPIE Lead, BTRU in ODT), Dr Bill Scott (Scientific Director of Transplantation and Regenerative Medicine Laboratory at Newcastle University, BTRU in ODT), Professor Andrew Fisher (Co-Director, BTRU in ODT), Professor Mike Nicholson (Director, BTRU in ODT), Dr Siân Russell (Theme 6, BTRU in ODT), Rachel Brown (Project Co-ordinator, BTRU in ODT) with extensive review by the Unit's PPI Co-applicant.

We would like to thank all public collaborators and researchers throughout the BTRU who have supported the writing of this strategy.

Key Contacts

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Appendix A

Appendix A. Patient and Public Involvement and Engagement Strategy - Gantt Chart

Key																				
Scheduled and Completed																				
Scheduled and not completed																				
Planned																				
Planned and Ongoing																				
	Q1 APR/JUN	1: 2022/23 Q2 JUL/SEP	Q3 OCT/DEC	Q4 JAN/MAR	Q1 APR/JUN	2: 2023/24 Q2 JUL/SEP	Q3 OCT/DEC	Q4 JAN/MAR	Q1 APR/JUN	3: 2024/25 Q2 JUL/SEP	Q3 OCT/DEC	Q4 JAN/MAR	Q1 APR/JUN	4: 2025/26 Q2 JUL/SEP	Q3 OCT/DEC	Q4 JAN/MAR	Q1 APR/JUN	5: 2026/27 Q2 JUL/SEP	Q3 OCT/DEC	Q4 JAN/MAR
ENGAGEMENT																				
Cambridge Festival																				
Participating in engagement events hosted by Newcastle and Cambridge Universities																				
MRes PPIE Lecture (Annual)		Sept					Oct				Oct				Oct				Oct	
Research Explained online webinar series		Sept		Jan		July		Feb		July		Feb		July		Feb		July		Feb
PPI/E Newsletter	April	Sept	Dec	Feb	April	July	Oct	Jan	April	July	Oct	Jan	April	July	Oct	Jan	April	July	Oct	Jan
PPI/E Induction Session																				
UK Standards for Public Involvement Annual Workshop (Online)			Nov				Nov				Nov				Nov				Nov	
Communicating the public and patient perspective in donation and transplantation research						Sep								Sep						
Events calendar to harness synergies with national campaigns		Sep																		
INVOLVEMENT																				
Patient and Public Research Panel - Increase and Diversify membership																				
Update PPRP Glossary of Terms		Sep				Sep				Sep				Sep				Sep		
Update PPRP Terms of Reference		Sep				Sep				Sep				Sep				Sep		
Public and Patient Involvement and Engagement (PPIE) Strategy		Sep																		
Develop/Collate PPI Resources			Dec																	
Proposal Review Meetings	June	Sep	Dec	Mar	June	Sep	Dec	Mar	June	Sep	Dec	Mar	June	Sep	Dec	Mar	June	Sep	Dec	Mar
Ad hoc proposal meetings	June/Jul																			
BTRU Trainee Days - PPI presentations and feedback				April																
Review of PPI documentation	June			June					June				June				June			
Panel contribution of further NIHR/NHSBT funding application																				
P & P Research Panel Member attendance at management group meetings		Oct		April					April				April				April			
Informal Peer Support Network for lay co-applications in conjunction with NIHR RDS NENC																				
PPI Collaboration activity with other BTRUs focussing on Diversity																				
Identify international organisations to develop up to two collaborative PPI activities for patient benefit.																				

Appendix B

Public and Patient Research Panel Feedback and Evaluation Document

COMPLETE BEFORE PANEL REVIEW (NB: Max page length 3 pages)
Research title
Researcher(s) – team and organisations
Reviewed by: Full Panel <input type="checkbox"/> Sub-group <input type="checkbox"/>
Questions for Panel discussion/feedback (Please indicate specific issues that you would like the panel to focus on)
Stage of research cycle (e.g. prioritising, designing, undertaking, disseminating results, promoting implementation of findings)

Research summary:

Background:

Clinical problem:

What we already know:

What we hope to find out:

How we will do this:

Why this is important:

COMPLETE AFTER PANEL REVIEW

Summary of panel feedback

What difference has panel input made to your research?

(Please give examples of any changes, explanation of any panel feedback you decided not to act upon)

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<p>What was your experience of working with the Patient and Public Research Panel? (Please give examples of any challenges and any benefits)</p>
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Meeting date	Name of person completing this form
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