

Patient and Public Involvement and Engagement (PPIE) Strategy (2018–2020)

Introduction

We actively involve patients and members of the public to deliver ground breaking research that is driven by the demands of patients for better outcomes and treatment options. We engage the public in the work of the [UCL Blood and Transplant Research Unit](#) (UCL BTRU) to increase science education and public support for future funding. We adhere to NIHR definitions for Patient and Public Involvement and Engagement (PPIE), which can be found in the glossary (see Appendix I) explaining key technical terms and abbreviations.

PPIE has been addressed by the UCL BTRU as part of its research from the beginning of funding in 2015. In 2018 a PPIE Coordinator was recruited to revise and implement an overarching structure as laid-out in this document. The PPIE strategy 2018-2020 sets out our approach to PPIE focussed on research undertaken at the UCL BTRU until the end of the funding period on 30 September 2020. The strategy is based on the NIHR National Standards for Public Involvement in Research (March 2018, see summary in Appendix II) and was developed involving patients and public members.

Background

The UCL BTRU is one of four BTRUs funded by the National Institute for Health Research (NIHR). BTRUs are research partnerships between universities and NHS Blood and Transplant (NHSBT) to support the need for research to improve the supply of blood, blood products, stem cells, tissues and organs for transplantation. Research at the UCL BTRU is focused on

- **Haematopoietic Stem Cell Transplantation** (transfer of stem cells which lead to new blood cells in the recipient) and
- **Immune Therapies** (approaches designed to replace, repair or enhance the immune systems response to infection or disease).

Stem Cell Transplantations and Immune Therapies are often the only way to treat inherited genetic disorders or cancers of blood and lymph nodes, but carry significant risks. The main risks for failure of the current therapies are relapse of the underlying cancer, death related to infection or a harmful immune response of the recipient to donor cells which is called graft-versus-host disease (GvHD). The UCL BTRU aims to minimise these risks by harnessing technological advances. It consists of four individual but complementary research areas called Themes:

- **Theme 1:** Improving donor selection or cellular composition of the tissue donation for transplantation (Theme Lead: Prof Stephan Beck)
- **Theme 2:** Developing and evaluating approaches to gene modification of haematopoietic stem cell transplants in malignant or inherited genetic disorders (Theme Lead: Prof Amit Nathwani)
- **Theme 3:** Developing and evaluating cellular therapies to prevent or treat post-transplant relapse (Theme Lead: Prof Karl Peggs and BTRU Director)
- **Theme 4:** Optimising and automating cell production processes for transplants (Theme Lead: Prof Adrian Thrasher)

Our Vision and Objectives

Our vision is to fully involve patients and the public at all levels in our work at the UCL BTRU to support planning, delivery and communication of results to maximise patient benefit. The following five objectives will guide our work to turn our vision into reality:

- 1. Patient and public involvement to ensure high quality research**
- 2. Capturing patient experiences to inform future standards**
- 3. Public engagement to build science education and support**
- 4. Collaboration with key stakeholders in health research to use synergies**
- 5. Implement standards and assess impact of PPIE**

Action Plan

The action plan outlines how we aim to reach each of our objectives. A more detailed version of the action plan is shown in the table 'PPIE activities 2018-2020' in Appendix III.

1. Patient and public involvement to ensure high quality research

We will work closely with patients, carers and members of the public harnessing their expertise and experience to guide and improve our research. We will involve patients and the public as active members early and at different stages in the research cycle to make our research more relevant to patient needs, enhance its quality and increase chances of future funding. We will seek a flexible approach to work with patients, carers and public members of established Patient Advisory Groups (PAG) with relevant health care experience and patients who have received UCL BTRU aligned treatment. We will achieve this objective by:

- Involving two patients or members of the public working closely with the PPIE Coordinator on PPIE related strategic planning and decision-making
- Including PPIE input early for future research planning and at relevant stages in ongoing research
- Developing public engagement and communication materials with patients and members of the public, to share UCL BTRU activities and research findings with the public

These milestones will allow us to routinely work with patients and the public in governing, planning and delivering research.

2. Capturing patient experiences to inform future standards

Many of the clinical trials at the UCL BTRU are the first in their speciality area performed in the UK. Therefore, it is of great importance to learn from patients and their views on their general medical and health experiences to inform future studies. This is delivered through:

- Capturing and sharing the experiences of patients and their carers to inform future studies and national delivery of these therapies in the form of a patient led documentary, patient stories and patients giving talks alongside researchers
- Involving patients and carers in questions around current studies and in future research design

The experiences of patients are a great asset, which we are feeding into expertise applied to future work in the field both within clinical trials and to help inform

government thinking about standards of care once treatments have regulatory approvals.

3. Public engagement to build science education and support

We will embrace opportunities offered locally within UCL, collaboratively with the other BTRUs and beyond to engage with patients, members of the public, clinical and academic researchers to increase the understanding of our research and to secure public support for future funding. This will consist of:

- Engagement in two or more public engagement events with interactive activities to create dialog about our work
- Science education in the form of at least one school visit and one short film co-produced with public members
- Talks presenting UCL BTRU research to a broad spectrum of audiences

The Theme Leads, as leaders in their fields, will present their research to allied professionals, patient organisations and charities.

4. Collaboration with key stakeholders in health research to use synergies

We will work collaboratively across all themes within UCL and with other universities and NHS organisations to coordinate PPIE activities, share best practice to improve PPIE expertise and reduce duplication. This includes the following collaborations:

- Internally across all UCL BTRU themes to share best practices and learning
- Locally working particularly closely with members of the UCLH Biomedical Research Centre (UCLH BRC) Cancer Lay Panel, patients that have undergone a haematopoietic stem cell transplant or immune therapy and/or their carers, the UCL BRC PPIE team, the UCL Public Engagement department and other local PPIE leads, networks and affiliated institutions
- Nationally establishing links to the NHSBT PAG, other advisory groups as appropriate and continuing to work with NHSBT, the other BTRUs, NIHR organisations, PPIE networks and national groups

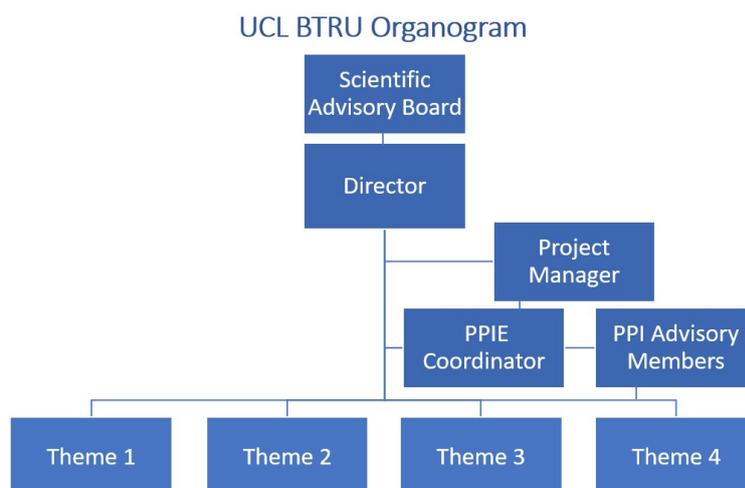
5. Implement standards and assess impact of PPIE

We work with the UCLH BRC who provides PPI training to researchers and the UCL Public Engagement unit to increase knowledge and skills to routinely embed PPIE in research planning and throughout the research cycle. The PPIE Coordinator will provide an introduction to PPIE, individual advice and guidance to researchers and bespoke PPIE training and support to patients and members of the public. For each specific project, patients and members of the public will be introduced to the research aims by UCL BTRU research staff using lay language.

We will capture and share the difference that PPIE makes to research, patients and the public. This focusses on outcomes, skills gained, lessons learnt and the long-term impact of PPIE to grow its capability and capacity. All UCL BTRU researchers who involve patient and public members will be asked to provide a brief summary of changes made to their work as a result of input of lay members, or reasons why suggestions were not acted upon. This, in addition to skills gained and lessons learnt from public involvement will be fed back to the PPIE Coordinator, patients and members of the public. For Public Engagement, general assessment measures include, but are not limited to, number of people reached, participant feedback and learnings from activities. Measures and processes to capture outcomes and impact will be revisited and modified as needed. This PPIE strategy will be reviewed annually and changes will be made as necessary.

Reporting

The Director of the UCL BTRU has oversight for all research including PPIE activities taking place at the unit. The PPIE Coordinator is responsible for driving the delivery of the PPIE strategy and collating outputs and impact from PPIE across the UCL BTRU. Additional support will be provided by the Project Manager. The PPIE Coordinator works closely with two patients and/ or public members on PPIE and UCL BTRU research at a governance level and facilitates dedicated PPIE meetings with relevant messages being presented at the Theme Leads meetings. In turn the conclusions of the Theme meetings are reported back to involved patients and members of the public. Theme Leads inform their team members about PPIE outputs. The organogram shows the interaction of key personnel at the UCL BTRU:



The UCL BTRU provides summary reports on progress and outcomes on PPIE to the NIHR annually. These are publicly available via the [NIHR website](#). The PPIE Coordinator is responsible for collating and summarising this information with input from Theme Leads, involved patients and public members and other research team members. Information on PPIE activities and opportunities will be communicated regularly to the public via the UCL BTRU website and through other relevant communication channels.

Resources

Dedicated funds are allocated within the UCL BTRU to support PPIE activities, in addition to support from a 0.6 Full Time Equivalent (3 days per week) PPIE Coordinator in place since October 2018. Funds will be used to support PPIE training and other related activities required by Theme Leads, their groups and the PPIE Coordinator. In addition, patients and members of the public will be reimbursed for their travel and time when involved in UCL BTRU research in accordance either with PAG terms of reference or with [NIHR INVOLVE guidelines](#).

Appendix I: Glossary

Blood and Transplant Research Unit (BTRU) - research partnerships between universities and NHS Blood and Transplant (NHSBT)

Haematopoietic Stem Cell Transplantation - transfer of stem cells which give rise to blood cells from one person to another

Graft-versus-Host Disease (GvHD) - harmful immune response of the donor cells against the patient

NHS Blood and Transplant (NHSBT) - NHS organisation that manages blood and platelet donation, and organ, stem cell and tissue donation and transplantation.

Patient and Public Involvement (PPI) - research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them ([NIHR 2013](#))

Public Engagement (PE) - sharing information and knowledge about research with the public ([NIHR 2013](#))

Participation - people taking part in a research study as subjects/participants ([NIHR 2013](#))

Patients - individuals receiving healthcare (NIHR 2013)

Patient Advisory Group (PAG) - patient forum that embeds the patient and public voice in research

Patient Experience - range of interactions that patients have with the health care system

Public Members - inclusive term including all subgroups of population, community groups, 'communities of interest', 'communities of place', networks, organisations and healthy volunteers ([NIHR 2013](#))

Research Cycle – different stages of research from identifying research to evaluating its impact

University College London Blood and Transplant Research Unit (UCL BTRU) - research partnership of UCL and NHS Blood and Transplant (NHSBT) to advance research related to blood and transplantation

University College London Hospital (UCLH) - teaching hospital located in London, which is part of the University College London Hospitals NHS Foundation Trust and closely associated with University College London

University College London Hospital Biomedical Research Centre (UCLH BRC) - a partnership between UCLH and UCL to support world leading clinical translational research and continued growth in experimental medicine

Stem cells - cells that have the ability to develop into a variety of different specialist cells within the body

Stem cell transplantation - Transfer of new stem cells which lead to new cells in the recipient

Appendix II: NIHR National Standards for Public Involvement in Research, March 2018



Standard 1: INCLUSIVE OPPORTUNITIES

We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

Standard 2: WORKING TOGETHER

We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Standard 3: SUPPORT & LEARNING

We offer and promote support and learning that builds confidence and skills for public involvement in research.

Standard 4: COMMUNICATIONS

We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

Standard 5: IMPACT

To drive improvement, we capture and share the difference that public involvement makes to research.

Standard 6: GOVERNANCE

We involve the public in our governance and leadership so that our decisions promote and protect the public interest.

For full version please visit: [https://www.nihr.ac.uk/news-and-events/documents/Public Involvement Standards March%202018 WEB.pdf](https://www.nihr.ac.uk/news-and-events/documents/Public%20Involvement%20Standards%20March%202018%20WEB.pdf)

Appendix III: Action plan of PPIE activities 2018-2020

1. Patient and public involvement to ensure high quality research		
Action	Measures of success	Timeframe
a. Patients and public members involved in strategic decisions		
Delivery and review of PPIE strategy 2018-2020	Gaining feedback and including insights of lay members to inform the delivery and review of the PPIE roadmap until end of funding period	Dec 2018 – Feb 2019
Lay members advising on BTRU PPIE decision-making	Two lay members to plan, oversee and assess PPIE activities with the PPIE Coordinator	Mar 2019 – 30 Sep 2020
NIHR BTRU annual progress report - PPIE section	Lay members (supporting strategic planning) co-writing the PPIE section of the annual progress report	Apr – May 2019, 2020
NIHR BTRU and NHSBT PPIE meetings	Lay members (supporting strategic planning) to attend meetings and to be involved in the discussions	Feb 2019 – 30 Sep 2020
Funding applications	Lay summary and PPIE informed by lay members	Needs to be defined
b. Patient and public involvement in lab-based research projects		
Educational video about gene editing for therapeutics	Increase understanding of the scientific technique and its benefits for treatment in a lay friendly format co-produced with lay members	Spring – Autumn 2019 (TBC)
c. Patient and public involvement in clinical trials		
Clinical trial design	Improved study design by including patient and public perspectives	For clinical trials to open during BTRU funding period
Clinical trial management committee	Active involvement of patients and public members in making decisions	Dec 2019 until the end of the trial (beyond Sep 2020)
Review study materials	Discussion with patients and public members to produce clear study materials e.g. patient information sheets, consent forms and other materials	For clinical trials that open during the UCL BTRU funding period – TBC
d. Patient and public involvement in public engagement activities		
Input into activities for public engagement events	Develop at least one activity with support of lay members around UCL BTRU research	Mar – Jun 2019
Support the delivery of public engagement activities	Involve patients and the public in UCL BTRU activities at research engagement events	Jul 2019 – 30 Sep 2020
e. Communication to patients and members of the public		
UCL BTRU website	New content development and updates to the website using plain English to inform about the research and PPIE activities	Feb – Jun 2019 plus ongoing updates

Additional communication channels	Identify and utilise other communication channels as appropriate, to disseminate outputs from the research and PPIE activities	Feb 2019 onwards
Public access to lay summary of selected research findings	Developing a lay summary of research findings with support of lay members made accessible on the UCL BTRU website and other appropriate communication channels	Until 30 Sep 2020
Stories of involvement and engagement	Creating and sharing stories around PPIE of lay members and researchers	Feb 2019 – 30 Sep 2020
Speaking engagements	Giving patients and public members a voice at research and public events to communicate their perspective relating to the work of the UCL BTRU	Jan 2019 – 30 Sep 2020

2. Capturing patient experience to inform future standards

Action	Measures of success	Timeframe
Patient driven documentary on T-cell trial 'War in the blood' produced by Minnow films for BBC Two	Documentary broadcast sharing experiences of patients taking part in early clinical trials in support of the development of pioneering new treatment options	Spring 2019
Raising awareness about the documentary	Referencing the documentary through the UCL BTRU website and informing UCL BTRU stakeholders	Spring 2019 onwards
Patient stories and capture patient experience in clinical trials and general medical and health practice around it	Implementing ways to capture and share patient experiences that inform future research and its standards	Mar 2019- 30 Sep 2020
Patient voices at speaking engagements	Patients sharing their experiences taking part in UCL BTRU clinical trials alongside Principal Investigators	TBC

3. Public engagement to build science education and support

Action	Measures of success	Timeframe
Participation in public engagement events	Deliver public engagement activities at two or more public engagement events	Jul 2019 – 30 Sep 2020
Science education	Develop educational materials around BTRU research and deliver at least one engagement activity targeting school children	Jan 2019 – 30 Sep 2020
Speaking Engagements	Increase understanding of UCL BTRU research and receive public support from broad audiences	Jan 2019 – 30 Sep 2020

4. Collaboration with key stakeholders in health research to use synergies		
Action	Measures of success	Timeframe
a. Internal		
Shared PPIE learning across the themes within the UCL BTRU	UCL BTRU staff exchanging experiences and knowledge about PPIE	Oct 2018 – 30 Sep 2020
Lay advisory members to help inform PPIE activities	Two lay members actively involved in planning, overseeing and accessing PPIE activities together with the PPIE Coordinator	Mar 2019 – 30 Sep 2020
b. Local		
UCLH BRC Cancer Lay Panel	Support working relationship, collaborative projects and involvement of a subgroup of members in strategic planning	Dec 2018 – 30 Sep 2020
BTRU patients and carers	Capturing experiences and if appropriate involve in research and strategic planning	Oct 2018 – 30 Sep 2020
Other UCL affiliated research and staff	Identifying and using synergies to drive forward the PPIE strategy	Oct 2018 – 30 Sep 2020
Other UCL PPIE units (such as UCLH BRC PPIE team and UCL Public Engagement Unit)	Using and sharing of resources and exchange of best practices	Oct 2018 – 30 Sep 2020
UCL Partners Involvement Network	Expanded network and shared best practices	Dec 2018 – 30 Sep 2020
c. National		
NIHR BTRU PPIE Leads and NHSBT Research and Development Office	Joint activities and ongoing knowledge exchange	Oct 2018 – 30 Sep 2020
NIHR Central Commissioning Facility (CCF)	Reporting on PPIE activities and mutual sharing of challenges and learnings in PPIE	Oct 2018 – 30 Sep 2020
NHSBT Patient and Public Advisory Group and other Patient and Public Advisory Groups e.g. BTRU Bristol PAG	Good working relationship and collaborative projects	Feb 2019 – 30 Sep 2020
Other PPIE related organisations e.g. National Co-ordinating Centre for Public Engagement (NCCPE)	Sharing best practices, toolkits, PPIE opportunities and challenges	Oct 2018 – 30 Sep 2020

5. Implement standards and assess the impact of PPIE		
Action	Measures of success	Timeframe
a. Implement PPIE standards		
Signpost to PPIE training, bespoke advice and resources available	Enhanced PPIE knowledge and skills of UCL BTRU staff resulting in more PPIE activity and including it early in the planning process	Oct 2018 – 30 Sep 2020

Patient and lay member introduction training	Increased knowledge about PPIE / research and confidence to enable meaningful contribution	Dec 2018 – 30 Sep 2020
UCL PPIE network events	Exchange of best practices and discussion about challenges	Oct 2018 – 30 Sep 2020
PPIE in planning and implementation of research projects	Implementing processes to support PPIE planning and demonstrate changes made in BTRU research as a result of PPIE	Oct 2018 – 30 Sep 2020
Impact measures	Define impact measures and the process to capture these with lay members and researchers	Dec 2018 – 30 Sep 2020
b. Assess impact of PPIE		
Defined aims for public involvement	Clear objectives for PPIE activities	When planning research/ PPIE activity
Track outcomes and report back changes made to lay members	Summary of changes made, skills gained and learnings of all members involved in the activity; feedback of changes made to lay members	Directly after PPIE activity has been completed
Capture long term impact	Follow up and report on long term results of PPIE activities (e.g. outcome of funding application)	Shortly after PPIE activity
Impact report of PPIE activities and strategy	Review PPIE action plan and its impact as part of NIHR annual progress and final report	Apr – May 2019, 2020; end of funding cycle