



Patient and Public Involvement and Engagement Strategy, 2022–2027

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Introduction

About this strategy

This document describes the Patient and Public Involvement and Engagement (PPIE) Strategy for the National Institute of Health and Care Research (NIHR) Blood and Transplant in Genomics to Enhance Microbial Screening (BTRU-GEMS).

BTRU-GEMS research aims to

- Advance the safety of donated blood and organs for transplantation, by developing better tests for pathogens using genomic methods
- Understand more about viruses that can infect humans and pose a risk for transmission via donated blood and organs
- Be prepared for emerging pathogens, threats to the safety of blood in the UK

This strategy was developed because research is better when it involves individuals who have personal knowledge and experience of the issues being investigated. It is right that those who will be affected by this research have a say in how it is conducted, embodying the quote 'nothing about me without me'. Furthermore, we recognize the benefits that collaboration can bring to public contributors and researchers, in terms of wellbeing, impact and skills-building.

Version 1.2

Version includes feedback from researchers, PPI committee.

Our Vision

To combine the voices of researchers, patients, and the public to work together to shape innovative, evidence-based practices that enhance and transform the safety of blood and transplantation services.

Our aims

To enable our vision, we have developed five aims. These aims are organized according to themes from UK Standards for Public Involvement and the recent NIHR public partnerships strategic update.

Theme	Our aims
INCLUSIVE OPPORTUNITIES and EMBED RESEARCH INCLUSION	1. We will develop public involvement partnerships that are accessible and include a diverse range of individuals, communities and patient groups that stand to benefit from our research.
WORKING TOGETHER and STRENGTHEN PARTNERSHIPS	2. We will jointly develop a shared vision, and work towards that vision in a way that values all contributions, and that builds and sustains relationships. We will co-develop a work plan for the remainder of the grant.
SUPPORT AND LEARNING and STRENGTHEN CAPABILITY AND CAPACITY	3. We will work to understand the support required to enable our vision, and provide support and learning that builds confidence and skills for PPIE

GOVERNANCE	4. We will involve the public in research management, regulation, leadership and decision making.
COMMUNICATION	5. We will use plain language for well-timed and relevant communications for patients and the public, and do so using a range of approaches, informed by a co-developed communications plan.
IMPACT and REQUIRE FEEDBACK	6. We will identify the difference PPI makes, and listen to the benefits and learnings shared by researchers, patients, public contributors and implementors.

Our objectives and associated activities

To break down each aim we have created several objectives and associated activities.

1. INCLUSIVE OPPORTUNITIES

Aim	To enable this aim, our objectives are to:	Timeframe
We will develop public involvement partnerships that are accessible and include a diverse range of individuals, communities and patient groups that stand to benefit from our research.	Map out the stakeholders relevant to BTRU-GEMS research (deliverable 1)	Short-term
	Recruit a PPI committee that reflects the wide variety of experiences relevant to BTRU-GEMS (deliverable 2)	Short-term (mostly complete)
	Create an engagement plan that targets our key groups, and does so in a way which is brings research to life and is relevant to the groups (deliverable 3)	Short-term
	Review engagement plan with PPI committee and PPI professionals to identify ways of building relationships with underrepresented communities affected by BTRU-GEMS research (deliverable 3)	Mid-term
	Review the strategy annually to understand the barriers to involvement and implement changes (deliverable 3)	Throughout the grant

Deliverables

1. Stakeholder map – to be added to our strategy, engagement and communications plan
2. Recruit a PPI committee and commit to regular engagement
3. Engagement plan

2. WORKING TOGETHER and STRENGTHENING PARTNERSHIPS

Aim	To enable this aim, our objectives are to:	Timeframe
We will jointly develop a shared vision, and work towards that vision in a way that values all contributions, and that builds and sustains relationships. We will co-develop a work plan for the remainder of the grant.	Agree on our shared vision, with PPI committee members and researchers – to ensure it reflects everyone's perspectives (deliverable 1)	Short-term
	Solicit feedback on this PPI strategy with the PPI committee, from at least 3 contributors and 3 researchers. Including developing our objectives and prioritizing them (deliverable 1)	Short-term
	We will work closely with researchers at BTRU-GEMS to understand where they are in their research process and identify solid opportunities for PPI, mapping them to our work plan (deliverable 3)	Mid-term
	We will develop a shared understanding of roles, responsibilities and expectations of involvement – captured in our Terms of Reference (deliverable 2)	Short-term
	While developing our work plan, we will find ways to capture individual's influence, ideas and contributions and ensure that individuals are recognised for their contributions, as evidenced by using at least 3 different methods to capture feedback per year (deliverable 3 and 4)	Throughout the grant

Deliverables

1. Strategy plan, updated quarterly
2. Terms of reference [complete]
3. Work plan and project plan
4. Individual project outputs (to be defined in project plan)

3. SUPPORT AND LEARNING and STRENGTHEN CAPABILITY AND CAPACITY

Aim	To enable this aim, our objectives are to:	Timeframe
We will work to understand the support required to enable our vision, and provide support	We will identify learning and development needs with researchers at BTRU-GEMS to understand what their concerns and skills gaps are (deliverable 1)	Short-term
	We will develop and introduce clear processes for engagement and involvement, to ensure	Mid-term

and learning that builds confidence and skills for PPIE	researchers have a systematic means of engaging and involving patients and the public in their work (deliverable 2)	
	We will provide access to training and support which empowers our researchers and our contributors. All researchers have access to training from within the unit, across the University and elsewhere and are given time and support to engage with this training (deliverable 1)	Mid-term
	We will discuss training needs with public contributors. We will help members understand the research process and any specific strategies or goals of the group.	Mid-term

Deliverables

1. Training and development plan
2. PPI process documentation

4. GOVERNANCE

Aim	To enable this aim, our objectives are to:	Timeframe
We will involve the public in research management, regulation, leadership and decision making.	We will include public representation on the Steering Committee for the grant (deliverable 1)	Throughout the grant
	Public contributors will review and add to the annual report for NIHR (deliverable 1)	Throughout the grant
	We will discuss this objective with senior management other PPI leads to identify further opportunities to involve the public in research management	Short-term
	Information compliance and GDPR processes will be developed and adhered to (deliverable 2)	Short-term (completed)

Deliverables

1. Steering Committee review and report
2. DPIA – Data Protection Impact Assessment

5. COMMUNICATION

Aim	To enable this aim, our objectives are to:	Timeframe
We will use plain language for well-timed and relevant communications, and do so using a range of approaches, informed by a co-developed communications plan.	We will map out communications approaches for our target audiences, forming a communications plan alongside our PPI committee. This will include risk management strategies for various stakeholders (deliverable 1)	Short-term
	We will update our communications methods: website, newsletter and social media in collaboration with our PPI panel (deliverable 2, 3 and 4)	Short/medium-term

Deliverables

1. Communication plan
2. Updated website
3. Newsletter
4. Communications associated with our involvement activities, as defined in our communication plan

6. IMPACT

Aim	To enable this aim, our objectives are to:	Timeframe
We will identify the difference PPI makes, and listen to the benefits and learnings shared by researchers, patients, public contributors and implementors.	We will collect feedback following each PPI activity, initially using the Impact Log (deliverable 1)	Throughout the grant
	We will revisit how to assess impact with our PPI committee	Short-term
	We will develop case studies from our work (deliverable 2)	Throughout the grant
	We will embed periodic 'check-ins' to understand what is and isn't working	Throughout the grant

Deliverables

1. Impact Log (deliverable 1)
2. Case studies (deliverable 2)

Our Values

To enable our vision, we would like to promote our values related to NIHR 'co-production'.

- Share power
- Include all perspectives and skills
- Respect and value the knowledge of all those working together on the research
- Reciprocity
- Build and maintain relationships
- Stay curious
- Learning mindset

We recognize that finding opportunities to embed PPI in BTRU-GEMS may at times present challenges, but we commit to sharing our successes as a group and continuously improving

Glossary

Next generation sequencing	Laboratory methods for measuring a sample's genetic material.
Blood donation screening	The process of testing blood samples to detect specific conditions, diseases, or risk factors in individuals, often before symptoms appear. Blood screening helps identify potential health issues early, enabling timely intervention, diagnosis, or further investigation.
Involvement	Active collaboration with stakeholders, such as patients or the public, in the planning, design, implementation, and evaluation of research or projects. Involvement ensures their perspectives shape outcomes and decision-making.
Bioinformatics	Computer-based methods for analysing biological data, including genetic sequences.
Public engagement	The process of sharing information, fostering dialogue, and building understanding between researchers or organizations and the public. Public engagement aims to inform, inspire, and involve communities in ways that enhance mutual learning and trust.

Public or patient contributor	An individual who contributes lived experiences, insights, or feedback to research or projects as a representative of the public. Public contributors play a key role in ensuring that work remains relevant, accessible, and impactful to the wider community.
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