

Patient and Public Involvement and Engagement Strategy, 2022-2027

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Patient and Public Involvement and Engagement Strategy, 2022-2027



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 Research Unit (BTRU) in Precision Cellular Therapeutics.

The BTRU is undertaking research that will:

- Develop new kinds of cell therapies for blood disorders and blood cancer
- Improve systems to follow-up patients receiving treatment, to better support their care

We believe that it is right that people affected by our research should have a say in it. We also know that research is better when it involves individuals who have personal knowledge and experience of the issues being studied. This is why we have developed a PPIE Strategy. It is an action plan to guide PPIE at every stage of the research. It has been developed by patients, carers, public contributors, health professionals, researchers and other relevant groups. They have worked together to agree what we want to achieve and how to get there.

Important Definitions

Much of our Strategy is based on guidelines produced by the NIHR. We use their definitions for 'involvement', 'engagement' 'public' and 'public contributor'.

Involvement is research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. Examples include working with funders to decide what research is needed, offering advice to researchers, helping to make project decisions, undertaking research (e.g. interviewing participants), helping to share and communicate the findings.

Public engagement is where information and knowledge about research is provided and disseminated. Examples include sharing the study findings with people who took part, raising awareness of the research through television, publications or social media, or holding public events where people can find out about research.

Public includes patients, potential patients, carers and people who use health and social care services, as well as people from organisations that represent people who use services.

Public contributor is an umbrella term to describe members of the public who take part in patient and public involvement activities.

Our Purpose

Our purpose is to ensure that high quality PPIE is a central part of our research - for the benefit of patients, carers and the public. To achieve this, our approach is based on the important values of 'co-production'. According to the NIHR 'co-production' means:

Sharing of power – the research is jointly owned and people work together to achieve a joint understanding.

Including all perspectives and skills – make sure the research team includes all those who can make a contribution.

Respecting and valuing the knowledge of all those working together on the research – everyone is of equal importance.

Reciprocity – everybody benefits from working together.

Building and maintaining relationships – an emphasis on relationships is key to sharing power.

This means going beyond consultation (where public contributors are asked for their insight, ideas and advice). Instead, we will do things together to combine everyone's skills and expertise. We will follow [NIHR guidelines on co-production](#) to make sure that we work together in beneficial ways.

Our Aims

Our strategic aims are organised in relation to the [UK Standards for Public Involvement in Research](#). This sets out 6 Standards that describe what good public involvement looks like. We have described how we intend to meet these Standards below. However, this Strategy document is just a start. We will build on it throughout the research programme, as our learning grows. The next step is to develop a detailed Delivery Plan with our public contributors. This will describe the specific activities and resources needed to realise our vision – with milestones to keep us on track.

Contact Details

Contact **Dr Karen Shaw** (PPIE Research Fellow) or **Olalekan Lee Aiyegbusi** (PPIE Lead) at btruppi@contacts.bham.ac.uk or 07970 896336.

Or write to: The Centre for Patient Reported Outcomes Research, Murray Learning Centre, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

STANDARD 1: INCLUSIVE OPPORTUNITIES

What the Standard says.	<p>Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.</p> <p>Research to be informed by a diversity of public experience and insight, so that it leads to treatments and services which reflect these needs.</p>
To achieve this, we will:	<ul style="list-style-type: none">• Follow national recommendations such as ‘Strategies for diversity and inclusion in public involvement: Supplement to the briefing notes for researchers’• Have clear recruitment and selection processes for public contributors.• Work with our existing PPIE networks to ensure diversity among public contributors from the start of the research.• Widely share opportunities for involvement using a range of communication methods and appealing to different communities. These will be promoted through PPIE, community, charity and professional groups, using initiatives and materials co-designed with our public contributors.• Offer choice and flexibility about how people can be involved (e.g. virtual meetings, events at different times and places).• Identify and address barriers to engagement and involvement, ensuring appropriate payments, accessible methods and practical support.• Identify and address areas of underrepresentation by monitoring the characteristics of contributors, tailoring approaches, actively reaching out to underrepresented groups.• Engage with broad audiences by planning regular activities and one-off events that promote the research, highlight opportunities for involvement and share findings.

STANDARD 2: WORKING TOGETHER

What the Standard says.	<p>Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.</p> <p>Public involvement in research is better when people work together towards a common purpose, and different perspectives are respected.</p>
To achieve this, we will:	<ul style="list-style-type: none">• Have a Public Contributor Strategy Group that meets regularly to co-develop and deliver the PPIE strategy. It will develop its own Terms of Reference and be involved in BTRU decision-making.• Ensure shared understanding of the purpose, roles, responsibilities and expectations related to PPIE.• Work together to develop a Delivery Plan that will include different ways for people to contribute their expertise.• Identify what practical arrangements are needed for joint working and address support needs.• Promote Responsible Research and Innovation. This means acknowledging controversies, dilemmas and different views related to science and innovation – and creating safe ways to discuss them.• Show how people’s contributions have been recognised, addressed and influenced the research.

STANDARD 3: SUPPORT AND LEARNING

What the Standard says.	<p>We will support learning and skill-building in relation to PPIE.</p> <p>We seek to remove practical and social barriers that stop members of the public and research professionals from making the most of public involvement in research.</p>
To achieve this, we will:	<ul style="list-style-type: none">• Regularly discuss and assess learning needs related to PPIE – and develop plans to address them.• Have dedicated staff responsible for supporting PPIE knowledge and skill development.• Have a range of resources to support the learning and development needs of public contributors, researchers and the public. This will involve signposting existing resources and developing training or support where needed.• Help the public to find information about PPIE, including a PPIE section on the research website.

STANDARD 4: GOVERNANCE

What the Standard says.	<p>Involve the public in research management, regulation, leadership and decision making.</p> <p>Public involvement in research governance can help research be more transparent and gain public trust.</p>
To achieve this, we will:	<ul style="list-style-type: none">• Have leadership for PPIE. This includes Dr Lee Aiyegbusi who has overall responsibility for PPIE and Dr Karen Shaw who has operational responsibility for developing and implementing the Strategy.• Have realistic resources for PPIE. This includes a budget based on NIHR guidelines to ensure that cost is not a barrier to being a public contributor.• Ensure that PPIE plans are regularly monitored, reviewed and reported. PPIE activity will be reported to the Research Management and Steering Committees. Public contributors will be represented on these. PPIE Leads and public contributors will also complete the PPIE Section of the annual report sent to the NIHR.• Follow strict rules to ensure personal data related to PPIE is kept safe and used fairly, lawfully and transparently.

STANDARD 5: COMMUNICATIONS

What the Standard says.	<p>Use plain language for well-timed and relevant communications, as part of involvement plans and activities.</p> <p>Communicate with a wider audience about public involvement and research, using a broad range of approaches that are accessible and appealing.</p>
To achieve this, we will:	<ul style="list-style-type: none">• Work together to develop communication plans to support PPIE.• Use a broad range of inclusive and flexible communication methods to meet the needs of different people.• Ensure that people are given information that they can understand and have access to communication support.• Identify, respect and meet the communication needs and preferences of public contributors.• Have a broad range of methods for the public to contact us.

STANDARD 6: IMPACT

What the Standard says.	<p>Seek improvement by identifying and sharing the difference that public involvement makes to research.</p> <p>Understand the changes, benefits and learning gained from the insights and experiences of patients, carers and the public.</p>
To achieve this, we will:	<ul style="list-style-type: none">• Work with our public contributors to define and assess the impact of PPIE.• Review the PPIE Delivery Plan (at least once a year) so that new learning can support better impact.• Have processes in place to capture the impact of PPIE. This will involve collecting routine data (e.g. notes from meetings) and using assessment and reporting tools (e.g. Public Involvement Impact Assessment Framework, Guidance for Reporting Involvement of Patients and the Public).• Share our learning widely to improve the future impact of PPIE. This will use established frameworks to guide how we exchange and transfer knowledge about PPIE impact.

Publication information

This document was informed by NIHR best practice documents and researcher guidance [available here](#)

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