

Patient and Public Involvement and Engagement Delivery Plan, 2022-2027

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Patient and Public Involvement and Engagement

Delivery Plan, 2022-2027



Introduction

This document sets out the Patient and Public Involvement and Engagement (PPIE) **Delivery Plan** for the National Institute for Health and Care Research (NIHR) Blood and Transplant Research Unit (BTRU) in Precision Cellular Therapeutics.

The Delivery Plan describes the steps that will be taken to achieve our ambitions for PPIE over the duration of the research programme. It builds on our PPIE Strategy Document and is organised to reflect the UK Standards for Public Involvement. These Standards set out 6 areas for developing and assessing high quality PPIE. The Delivery Plan is also based on co-production - an approach where 'researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge' (NIHR) .

The Delivery Plan was developed by public contributors, researchers and health professionals who worked together to produce this final version. The process began in October 2022 with a joint meeting to introduce the research and discuss PPIE. Ideas from this meeting were further developed by the 9 public contributors who formed the PPIE Strategy Group at that time. They took part in individual and group activities to produce an initial plan. This was sent to BTRU staff for further input - with the final version agreed in February 2023. Our approach was also shaped by best practice guidelines in PPIE, listed at the end of this document.

The Delivery Plan is presented in 6 Tables - one for each UK Standard for Public Involvement in Research. These Tables describe the Standard, what we will do to achieve it, what it will involve or require, when it will happen, who will be responsible and how we will assess progress. We will review and update the Delivery Plan every year, as we make progress. This will involve responding to regular feedback and incorporating other new learning about PPIE.

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STANDARD 1: INCLUSIVE OPPORTUNITIES

- Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.
- Research to be informed by a diversity of public experience and insight, so that it leads to treatments and services which reflect these needs.

What will we do?	What will this involve or require?	Who is responsible & time-frame?	How will we assess progress?
Have a clear structure for PPIE that supports equality, diversity and inclusion (1a)	The co-produced PPIE structure includes 2 groups to support different functions and preferences: (i) <i>PPIE Strategy Group</i> . 12-15 public contributors who will meet regularly to review PPIE strategy and support the Research Themes and (ii) a <i>Patient and Public Advisory Mailing Group</i> to widen involvement. The intention is to recruit public contributors who reflect the diversity of people to whom the research is relevant.	PPIE Leads/Strategy Group. Groups to be set up in Year 1.	Evidence of membership & diversity.
Have transparent recruitment processes (1b)	We will co-produce transparent recruitment strategies and processes. This will include role descriptions to clarify what is involved and self-referral processes for the public to contact the BTRU. We will also use targeted approaches to reach specific or under-represented groups.	PPIE Leads/Strategy Group. Year 1 & ongoing.	Evidence of recruitment processes & effectiveness.
Advertise opportunities for involvement that promote equal access (1c)	We will co-produce strategies and templates to advertise opportunities for involvement. These will be suitable for a wide range of contexts, formats and audiences, and promote equality, diversity and inclusion. They will follow best practice in accessible, inclusive communication.	PPIE Leads/Strategy Group. Year 1.	Evidence of templates, design strategy & effectiveness.
Have fair and transparent selection processes (1d)	We will understand what groups of people are affected by blood disorders and blood cancers and develop selection criteria to optimise representation. These criteria will be transparent and included when advertising opportunities for involvement or reporting PPIE activity.	PPIE Leads/Strategy Group/Researchers. Year 1 & ongoing.	Evidence of criteria & selections made.
Ensure people's financial circumstances do not act as barriers to involvement (1e)	We will offer payments for involvement and out of pocket expenses. The policy and process for payments will be made clear to public contributors. Payments offered for PPIE activities will be made clear in invitations and advertisements. Payments will be made in a timely manner.	PPIE Leads/ Researchers. Year 1 (policy) & ongoing.	Evidence of policy & payments.
Have networks and routes to promote PPIE (1f)	We will compile a list of national and community organisations, and build relationships with them to promote PPIE - based on mutual interest, support and collaboration.	All. Ongoing.	Evidence of network, reach & outcomes.
Have a calendar of events to promote PPIE (1g)	We will compile a list of anticipated events to showcase the work of public contributors, promote opportunities for involvement and engage with the public.	All. Ongoing.	Evidence of calendar, activity & responses.
Prioritise under-represented groups in research (1h)	We will monitor the characteristics of public contributors to identify and address areas of under-representation - following best practice guidance.	PPIE Leads/Strategy Group & ongoing.	Demographic data & trends.
Take the research into communities (1i)	Opportunities for involvement will be taken into communities, particularly to reach under-represented groups. This will involve understanding what communities seek or value in their relationships with the BTRU and working in mutually beneficial ways.	PPIE Leads. Ongoing.	Evidence of activity & response.
Offer appropriate choice for involvement (1j)	Opportunities for involvement will cater for different preferences and personal contexts, including individual/group activities (remote, in-person, hybrid) that are researcher/patient led, using different methods and ways to contribute, at different locations/times.	All. Ongoing.	Evidence of preferences, choices & impact.

STANDARD 2: WORKING TOGETHER

- Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.
- Public involvement in research is better when people work together towards a common purpose, and different perspectives are respected.

What will we do?	What will this involve or require?	Who is responsible & time-frame?	How will we assess progress?
Support understanding around co-production (2a)	We will ensure the concept, values and methods of co-production are understood by all involved in the BTRU, and offer support and training to researchers and public contributors.	PPIE Leads. Year 1 & ongoing.	Evidence of materials & support.
Ensure roles and responsibilities are clear (2b)	We will co-produce Terms of Reference, Working Agreements, Role Descriptions - to ensure that roles and responsibilities of public contributors and those supporting them are clear.	PPIE Leads/Strategy Group. Year 1.	Evidence of materials.
Welcome and support new public contributors (2c)	We will co-produce a formal Welcome Pack for public contributors. We will also offer a brief one-to-one meeting (usually by phone or zoom) to support induction.	PPIE Leads/Strategy Group. Year 1 & ongoing.	Evidence of materials & induction.
Support involvement in ways that respect preferences and competing demands (2d)	We will clarify expectations about involvement, including the importance of public contributors being able to make choices based on their preferences and competing demands. This will include clear processes to confirm involvement, attendance, changes to roles or withdrawing.	PPIE Leads/Strategy Group. Year 1.	Evidence of processes.
Develop a sense of belonging and community among public contributors (2e)	We will provide opportunities for public contributors to network with each other and share progress through regular events and updates.	PPIE Leads. Ongoing.	Evidence of networking activities.
Support partnerships between researchers and public contributors (2f)	Public contributors will be invited to key events in the BTRU Calendar. Relationship building will also be supported through events and materials that highlight roles, offer opportunities to work together, and learn more about the research and one another.	All. Ongoing.	Evidence of materials & events.
Develop shared research plans (2g)	We will hold joint meetings between researchers and the PPIE Strategy Group - as soon as practicable. These will give opportunities to understand the research, identify how public contributors can add value, and agree PPIE strategies for the BTRU and individual studies.	Researchers. Year 1.	Record of meetings, plans, notes & outcomes.
Proactively undertake research involvement activities (2h)	We will carry out the PPIE plans, ensuring that public contributors have adequate information and time to make informed decisions about being involved, and the necessary materials and resources to undertake activities. We will ensure that public contributors can see the impact of their involvement (ideally in real time), and provide progress updates to them and PPIE Leads.	Researchers. Ongoing.	Record of invitations, meeting notes & output.
Shared workspaces and communication methods (2i)	We will develop shared (digital) workspaces and communication methods where public contributors and researchers can work together.	PPIE Leads. Year 1.	Evidence of workspace & use.
Recognise contributions (2j)	We will acknowledge the individual and collective contributions that public contributors have made to the BTRU and research.	All. Ongoing.	Evidence of acknowledgements.
Celebrate success (2k)	We will regularly show the impact of PPIE and celebrate success. This will include an annual 'celebration event' and opportunities to showcase the results of co-production.	All. Ongoing.	Feedback from events.

STANDARD 3: SUPPORT AND LEARNING

- We will support learning and skill-building in relation to PPIE.
- We seek to remove practical and social barriers that stop members of the public and research professionals from making the most of public involvement

What will we do?	What will this involve or require?	Who is responsible & time-frame?	How will we assess progress?
Ensure that public contributors are involved according to their preferences, interests and experiences (3a)	Information about the research involvement opportunities will contain sufficient information for public contributors to make an informed choice about involvement. Preferences for involvement will be routinely assessed. We will make sure that public contributors understand their rights to decline invitations and change their minds with 'no judgment' or negative consequences.	PPIE Leads. Ongoing.	Evidence of choices offered & made.
Ensure that public contributors 'get something back' for involvement (3b)	Public contributors will receive appropriate reward and recognition for their contributions. This will include financial and non-financial forms of reward to demonstrate that we value their input. This will involve identifying and supporting opportunities for personal development.	PPIE Leads/Strategy Group. Ongoing.	Evidence of reward & recognition.
Identify and address the learning and support needs of public contributors (3c)	We will assess the learning and support needs of public contributors and make personal development plans where required. We will tell them where to go for information and support, offer training and seek regular feedback on the quality of support provided.	PPIE Leads. Ongoing.	Evidence of needs assessment & response.
Develop a resource hub for PPIE (3d)	A digital resource hub will be developed to include useful resources for public contributors and researchers. These will also be available in hard copy where requested.	PPIE Leads. Ongoing.	Evidence of resources & use.
Have a central contact for help and support (3e)	The PPIE Leads will act as a central place for support, offering individual or group advice as needed to both public contributors and researchers.	PPIE Leads. Ongoing.	Evidence of contact & support requests.
Deliver formal training (3f)	We will deliver formal training to public contributors and researchers through workshops or presentations - to help them develop their knowledge, skills and confidence in PPIE. Public contributors will also be given opportunities to increase their understanding of the research topics and methods.	PPIE Leads. Ongoing.	Evidence of training & impact.
Have feedback mechanisms (3g)	We will use feedback forms from PPIE activities, informal feedback and other learning opportunities to improve future training and support.	PPIE Leads. Ongoing.	Record of feedback & response.
Discuss training and support in meetings (3h)	We will create a culture of learning by regularly discussing training and support for PPIE in strategy and management meetings, and acting on the decisions made.	All. Ongoing.	Meeting records.
Develop a PPIE Network (3i)	We will attend and actively participate in external PPIE related events and networks to contribute to, and learn from, national and local initiatives.	PPIE Lead. Ongoing.	Evidence of networks & meeting records.
PPIE groups to support education of the next generation of researchers and health professionals (3j)	We will integrate public contributors into educational events, PhD supervision, clinical training. This will include using (or developing) processes and materials to support and evaluate these activities.	All. Ongoing.	Evidence of integration & impact.

STANDARD 4: GOVERNANCE

- Involve the public in research management, regulation, leadership and decision making.
- Public involvement in research governance can help research be more transparent and gain public trust.

What will we do?	What will this involve or require?	Who is responsible & time-frame?	How will we assess progress?
Public contributors will co-produce the PPIE strategy and Delivery Plan (4a)	Members of the PPIE Strategy Group, researchers and health professionals will co-produce the PPIE Strategy and Delivery Plan, which will be reviewed and updated every year.	PPIE Leads/Strategy Group. Year 1 & ongoing.	Meeting records & evidence of strategy development.
Public contributors will be included in the Project Management Group (4b)	Members of the PPIE Strategy Group will represent the PPIE Groups on the Project Management Group. Other members of the PPIE Strategy Group will have opportunities to attend Project Management Group meetings as observers (1 per meeting).	PPIE Leads/Strategy Group, BTRU Director. Ongoing.	Attendance & impact (e.g. meeting records).
PPIE will be organised in fair and equitable ways (4c)	We will work together to ensure that PPIE activity is fair and equitable across the different studies in the BTRU. PPIE Leads need to have reasonable time and resources to organise activities and to provide public contributors with sufficient time to make informed choices.	All. Ongoing.	Evidence of the distribution & scheduling of PPIE activities.
PPIE will be represented in formal reports and publications (4d)	Public contributors will co-author and/or review appropriate sections of annual reports and publications to funders and other important organisations (e.g. submissions for ethical approval).	PPIE Leads/Strategy Group, BTRU Director. Ongoing.	Evidence of materials.
Transparent information about payment for involvement (4e)	Public contributors will be given clear information about the payments available for involvement and 'out of pocket' expenses, including the implication of these and the processes to claim payments.	PPIE Leads. Year 1 and ongoing.	Evidence of payment policy.
Transparent information about financial budgets for PPIE (4f)	Public contributors will be given clear information about the budget available to support PPIE. Public contributors will be involved in decisions about PPIE expenditure and spending priorities.	PPIE Leads, PPIE Strategy Group, Researchers. Ongoing	Evidence of budget decision-making & use.
Adhere to data protection regulations (4g)	We will adhere to UK Data Protection Laws and guidance. This includes ensuring that privacy notices for collecting, storing and using data are clear to public contributors and appropriate consents are sought/given. It also includes information about the 'right to be forgotten'. We will follow national and local policies for setting-up and keeping databases and mailing lists.	PPIE Leads. Ongoing.	Evidence of compliance.
Adhere to organisational health and safety policies when conducting PPIE activities (4h)	We will identify and adhere to local governance and safety arrangements when conducting PPIE activities at internal and external sites (e.g. national/local infection control, health and safety risk assessments).	PPIE Leads. Ongoing.	Evidence of compliance.
Have a process for concerns and complaints (4i)	The process to raise concerns and make complaints about PPIE will be made clear. This will include information about the rights of public contributors and who to contact to discuss concerns, This will include a contact who is independent of the BTRU.	PPI Leads will provide details on complaints process.	Evidence of complaints process, complaints made (anonymised) & resolutions/learning.

STANDARD 5: COMMUNICATIONS

- Use plain language for well-timed and relevant communications, as part of involvement plans and activities.
- Communicate with a wider audience about public involvement and research, using a broad range of approaches that are accessible and appealing.

What will we do?	What will this involve or require?	Who is responsible & time-frame?	How will we assess progress?
Have a central contact point for PPIE (5a)	We will have a named individual who will act as the main contact for PPIE – plus a dedicated contact address for all PPIE enquiries and correspondence. There will be mechanisms in place to provide cover for any absences etc.	PPIE Leads. Year 1.	Evidence of contact processes & their use.
Have multiple ways to contact the BTRU and PPIE teams (5b)	Although there will be a central contact point for PPIE, there will be multiple ways for individuals to contact the PPIE and BTRU teams (e.g. by post, phone, email, social media, web forms).	PPIE Leads/BTRU Director. Year 1.	Evidence of contact routes & their use.
Communicate in ways that are timely and responsive (5c)	We will be clear about response times and respond as early as possible, using plain language and personalisation where possible and appropriate. This includes providing agendas, summaries and feedback in a timely fashion – and escalating responses where issues have personal or reputational risk.	All. Ongoing.	Communications & audit trails for escalations.
Meet communication needs of public contributors (5d)	We will identify and address the communication preferences and support needs of public contributors. This includes communication related to routine correspondence and support for involvement in PPIE activities.	PPIE Leads. Ongoing.	Evidence of assessment & responses.
Support researchers to communicate their involvement opportunities to public contributors and wider public (5e)	We will develop a template for researchers to promote opportunities for involvement, with guidance about plain language and accessible communication methods. We will also provide a template for researchers to support meaningful feedback about the results of PPIE activities to public contributors and PPIE Leads.	PPIE Leads/Strategy Group. Year 1	Evidence of templates, guidance & use.
Use accessible communication to engage with the Public (5f)	We will co-produce public facing materials, following best practice guidance for accessible communication and suitable for a broad range of audiences. This may include different communication formats and routes such as websites, posters, flyers, social media. Information will be shared with the Public in a range of ways, such as infographics, animations, videos with closed captions, accessible versions of documents e.g. available in other languages or suitable for those using screen readers.	All. Ongoing	Evidence of communications & impact.
Have plans to share information about the BTRU, including the study findings (5g)	We will co-produce plans to share the research with the Public. This may include identifying target audiences and appropriate methods of communication. It may also include hosting or attending large and small events, writing publications, or using social media, creative media, art and performance.	All. Ongoing.	Evidence of engagement, dissemination plans & activities.
Involve public contributors in activities to help others use the research findings (5h)	Public contributors will be invited to be directly involved in activities to help others to make use of the research findings. For example, talking at conferences, co-authoring press releases, talking to the media, co-leading workshops.	All. Ongoing.	Evidence of activities.

STANDARD 6: IMPACT

- Seek improvement by identifying and sharing the difference that public involvement makes to research.
- Understand the changes, benefits and learning gained from the insights and experiences of patients, carers and the public.

What will we do?	What will this involve or require?	Who is responsible & time-frame?	How will we assess progress?
Identify where public contributors can add value to the BTRU (6a)	We will work together to identify where public contributors can add value to the BTRU, research themes and individual studies. This will involve creating shared understanding about the priorities for involvement, including agreements about what activities are most required, for what purposes - and what approaches are most appropriate to achieve these aims.	All. Year 1 and ongoing.	Evidence of PPIE priorities & plans.
Develop pathways to impact (6b)	We will work together to identify potential impacts of PPIE. This will include defining short-term, medium-term and long-term goals, and making plans to achieve them.	All. Year 1 and ongoing.	Evidence of goal-setting & plans.
Record impact of involvement in meetings and activities (6c)	We will co-produce templates to ensure that we capture the contributions made in meetings and PPIE activities, and their impact.	All. Year 1.	Records & templates.
Support researchers to collect and use feedback (6d)	We will support researchers to collect, report and use feedback - to inform their PPIE activities and capture impact. This will include training, guidance and the development of feedback processes and templates.	PPIE Leads. Ongoing.	Evidence of support & processes.
Have formal and informal feedback processes (6e)	We will co-produce systems to seek, gain, record and address informal and formal feedback about PPIE activities. This will involve measuring experience and satisfaction with involvement, the production of new thoughts and knowledge, material outputs and changes in policy, practices and behaviours.	All. Year 1.	Feedback & responses.
Annual strategy review (6f)	We will meet every year to review the PPIE Strategy and Delivery Plan. This will involve reviewing our achievements against the criteria set out in this document to understand what has worked well and areas where improvement is needed. We will use this information to agree an action plan to build on this knowledge – and make revisions to core documentation, policies and practices.	PPIE Leads/Strategy Group. Ongoing.	Evidence of review & actions taken.
Annual reports (6g)	Public contributors will contribute to annual reports - co-authoring PPIE sections and plain English summaries.	All. Ongoing.	Evidence of contribution.
Use formal evaluation and reporting tools (6h)	We will use tools such as GRIPP2 to evaluate and report PPIE. This will include support for researchers to use these tools. We will also identify the most appropriate criteria to judge if we have achieved important goals in PPIE, such as equality, diversity. and inclusion.	All. Ongoing	Evidence of tools, use & evaluation findings.
Share learning (6i)	Information about the impact of PPIE will be shared widely to help others learn from our experiences. This may include co-authored research papers, case-studies, guidance documents, presentations, events, and use of social and creative media to widen reach. We will also share this learning through our PPIE and research Networks.	All. Ongoing.	Evidence of materials, reach & impact.

Resources

Resources that have informed the Delivery Plan

NIHR Applied Research Collaboration West Midlands Patient and Public Involvement and Engagement (PPI/E) Strategy 2019-2024. [Available here](#)

NIHR (2021) Guidance on co-producing a research project. [Available here](#)

NIHR UK Standards for Involvement. [Available here](#)

NIHR Oxford Biomedical Research Centre (2022) Patient and public involvement (PPI) Researcher Guidance. [Available here](#)

NIHR (2022) Payment guidance for researchers and professionals. [Available here](#)

NIHR (2022) Supporting equity and tackling inequality: how can NIHR promote inclusion in public partnerships?

An agenda for action. [Available here](#)

Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ 2017; 358 :j3453 doi:10.1136/bmj.j3453. [Available here](#)

NIHR definitions of important words in the Delivery Plan

Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge.

Involvement is research done 'with' or 'by' patients and the public, not 'to', 'about' or 'for' them. It is about working collaboratively with patients and the public and sharing decision-making.

Engagement focuses on raising awareness, sharing research knowledge and findings.

Public contributor is an umbrella term used to describe members of the public who take part in patient and public involvement activities. We use the definition of 'public' to include 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.

Equality is about the fair treatment of everybody and, for example, ensuring everybody has an equal opportunity and is not treated differently or discriminated against because of their characteristics.

Diversity is about the mix of people, taking account of the differences between people and groups of people, and placing a positive value on those differences.

Inclusion is about the culture in which the mix of people can take part and join in and be valued for being themselves.