

Public and Patient Involvement and Engagement (PPIE). A Practical Planning Guide for BTRU Researchers.

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Patient and Public Involvement and Engagement (PPIE) A practical planning guide for BTRU researchers

Understanding PPIE

A quick guide to PPIE, including key concepts and useful resources.

1

Our approach

Information about our PPI Strategy, Delivery Plan, and approach.

2

Planning PPIE

Information about how to plan, undertake and assess PPIE activities.

3

Evaluating PPIE

Information about how we will improve PPIE, through review, assessment, support and training.

4

PURPOSE OF THIS DOCUMENT

This document is designed specifically for researchers working in the Blood and Transplant Research Unit (BTRU) in Precision Cellular Therapeutics

Section 1 provides a brief overview of PPIE - with links to find out more.

Section 2 explains how you can work with the PPIE Team to (i) make an initial plan for PPIE and (ii) deliver and assess individual PPIE activities. It sets out processes to follow, with links to essential forms and templates.

The intention is to have a systematic approach that will help us to maximise the quality of the PPIE, whilst minimising the workload for everyone involved.



Indicates extra information

**Please contact us to discuss any aspect of PPIE. Your main contact is:
Dr Karen Shaw, PPIE Research Fellow, at k.l.shaw@bham.ac.uk**



Indicates action is needed

Working days are Mondays, Tuesdays and Thursdays. You can also leave a text message or ring on 07970 896336 (please note that calls may go to voice mail).

Section 1: PPIE

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N.B. Most forms and resources can be opened by clicking on the images or links

PPIE and the NIHR

"Public involvement is a required part of high quality research conducted by researchers and their institutions"

NIHR, Going the Extra Mile

The NIHR advocates that the public should be involved in:

- a. Identifying future research priorities and research questions
- b. Informing the design and development of innovations
- c. Participating in research studies
- d. Advocating for the adoption and implementation of research

The NIHR states this is important because:

- a. The public should have a say in the use of public funds
- b. It ensures that research focuses on issues that matter to society
- c. It leads to more effective research with better outcomes for patients
- d. It increases the likelihood that research findings will be used



Find out more about NIHR PPIE Strategy:

- NIHR (2015) [Going the Extra Mile](#)
- NIHR (2021) [Strategic Priorities for Public Partnership](#)



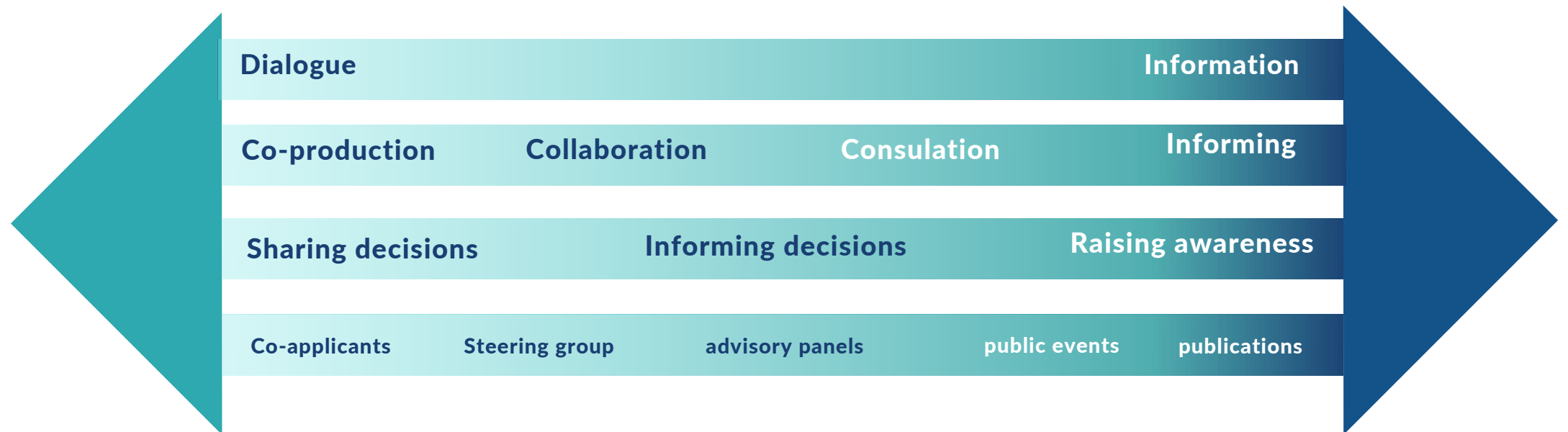
DEFINING PPIE

PPIE is about working with patients and the public to shape the work of the BTRU and communicating the research in ways that enable them to engage with it.

PPIE is relevant throughout the research cycle



A range of PPIE approaches exist
Activities can be done in many ways, at different levels, for different purposes



Key organisations related to PPIE in the context of the BTRU include:

- [National Institute of Health and Social Care Research](#)
- [National Co-ordinating Centre for Public Engagement](#)


DEFINING THE PUBLIC

The NIHR uses the following terms:

Public Partnerships: collectively describe ways in which patients, service users, carers and members of the public work with researchers, and health and care professionals, in the creation and use of health and care research. Public partnerships encompasses participation, involvement and engagement.

Public Contributors: an umbrella term used to describe members of the public who take part in patient and public involvement activities.

In the context of the BTRU in Precision Cellular Therapeutics, this might include:

- 
- Patients with experience of blood disorders or blood cancer
 - Patients with experience of advanced cellular therapies
 - Family members - including parents and carers
 - Donors and potential donors
 - Organisations representing patients or service users
 - Members of the general public with an interest

DEFINING INVOLVEMENT

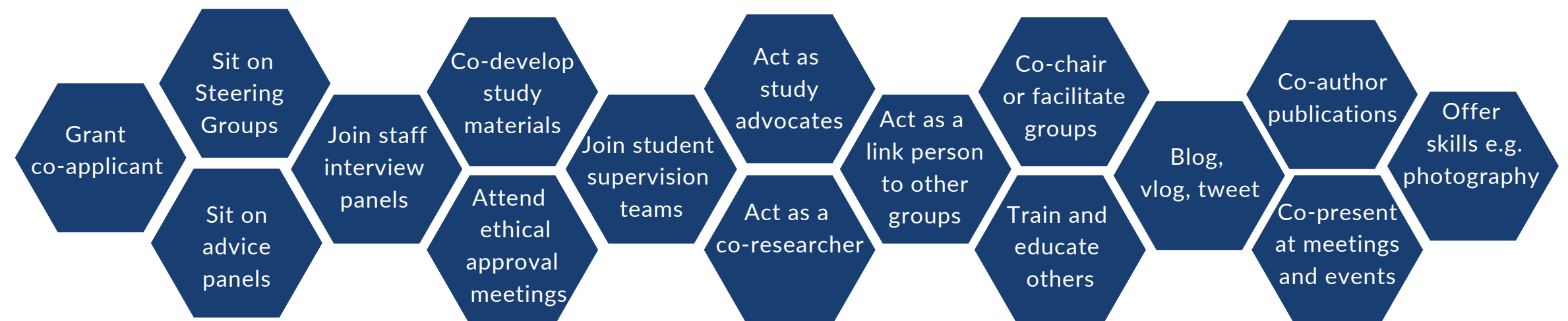
The NIHR defines involvement as 'Research done with or by patients and the public, not to, about or for them. It is about working collaboratively with patients and the public and sharing decision-making'



Patient and public involvement can help researchers to:

- Confirm and demonstrate the relevance of their work
- Choose between options and prioritise what matters most to patients
- Understand how the public perceives the benefits, risk and ethics of their research
- Avoid bias, incorrect assumptions and unintended consequences
- Develop effective research plans and methods, such as successful recruitment strategies
- Choose relevant outcomes measures and end points
- Communicate their research and findings in ways that are easily understood
- Develop new ideas and increase buy-in from funders, industry, care providers and patient groups

Patients and the public can be involved in different ways, with varied roles:



Introductory reading: NIHR (2021) [Briefing notes for researchers](#)

Detailed information: NIHR Oxford BMC (2021): [Researcher guidance](#)

Video training: Cochrane Training (2019) [Patient and public involvement in research: What, why and how?](#)

INVOLVEMENT IN BASIC AND TRANSLATIONAL RESEARCH

Involving patients and the public in laboratory-based research can be challenging. However, it can have important benefits, especially if started early.



'Bench to bedside' should be a two-way process

Early involvement of patients and the public helps identify patient priorities, leading to more acceptable and beneficial treatments. Avoids developing interventions with no guaranteed market.



It may identify real world factors that shape translation

Public contributors can provide valuable information about how and why interventions reach the bedside. Supports uptake at the clinical and community level.



It can be a good financial investment

Early involvement may support quicker routes to market, by avoiding costly changes in direction, wasted resources and unintended consequences.



It can add credibility and trustworthiness

Public involvement can help understand the range of attitudes held towards your work, and support transparent and effective communication, This is important given the world of fake news and misinformation!



Infographic: [Accelerate. Why is stakeholder engagement important for translational research?](#)

VIDEO: [Accelerate. Engaging patients, public & healthcare professionals in translational research](#)

VIDEO: [Dr Emma Dorris: PPI in pre clinical and basic life sciences research](#)

DEFINING ENGAGEMENT

The NIHR defines engagement as:

The ways in which research can be shared with the public in a two-way process. Engagement encourages researchers to listen and interact with the general public, for example, via science festivals, open days, media coverage.

Raise awareness

Engagement offers opportunities to raise awareness about the BTRU, opportunities for involvement and the needs of patients



Build trust

Transparent dialogue builds understanding and appreciation of your work and helps you to align it to wider society



Inspire and promote

Motivate researchers in your teams and inspire young people to get involved in STEM education and become the next generation of researchers



Provoke discussion

generate conversations and debate about the social and ethical implications of research, healthcare and treatments



Some great examples of engagement

- [The Francis Crick Institute](#)
- [National Co-ordinating Centre for Public Engagement](#)

PERSONAL BENEFITS OF PPIE

High quality PPIE takes significant work to plan, deliver and evaluate. However, it has many personal rewards.



RESEARCHERS

Develop skills

Such as increased confidence and communication skills when dealing with patients and the public.

Enhance your reputation and profile

For example, PPIE can provide an additional way to showcase your work internally and externally.

Widen partnerships and networks

for example, PPIE can help you develop relationships that may support your research and future opportunities.

Be more motivated and inspired

PPIE can remind you about the value of your work and inspire you to take new directions.

PATIENTS AND PUBLIC

Opportunity to make a difference

For example, people describe PPIE as an opportunity to shape future care or 'give something back'.

Meet others

For example, PPIE offers opportunities to meet others with shared experiences, interests or goals.

Represent others

For example, PPIE offers opportunities to ensure that groups have a voice, especially underserved communities.

Learning and skills

Such as learning more about research, sharing existing skills and developing new ones.



RCUK: What's in it for me? [The benefits of public engagement for researchers](#)

HealthTalk videos: Different patients talk about their reasons for being involved in PPIE: [here](#)

OUR PPIE STRATEGY

We have produced a:

- [Strategy Document](#) that outlines our ambitions for PPIE.
- [Delivery Plan](#) that describes our planned actions to achieve these.



Please read - The Delivery Plan forms the framework by which we will evaluate PPIE activity in each research Theme.

They are organised in relation to the: [UK Standards for Public Involvement in Research](#) and cover 6 areas of good practice: *inclusive opportunities, working together, support and learning, governance, communications and impact.*

PUBLIC CONTRIBUTORS IN THE BTRU

We have two different involvement groups to support inclusion, choice and capacity

Our PPIE is also supported by a wide number of partnerships (e.g. charities)

PPIE STRATEGY GROUP

A group of up to 15 people who meet regularly (remotely and in person) to work with the Themes and develop the BTRU PPIE Strategy.



PATIENT AND PUBLIC ADVISOR MAILING GROUP

A wider group of people who have agreed to receive regular newsletters (by email or post) that advertise opportunities for involvement. There are no expectations about the level of commitment and activities will usually involve short home-based tasks.

CO-PRODUCTION

Our PPIE Strategy is based on Co-production

This 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'. (NIHR INVOLVE)

While the PPIE team can do much on your behalf, it is important that researchers build genuine relationships with the PPIE groups to ensure meaningful partnerships.

Co-production is both an approach and ethos based on:



Collaboration



Equality



Combining different types of expertise



Creating new knowledge and shared understandings



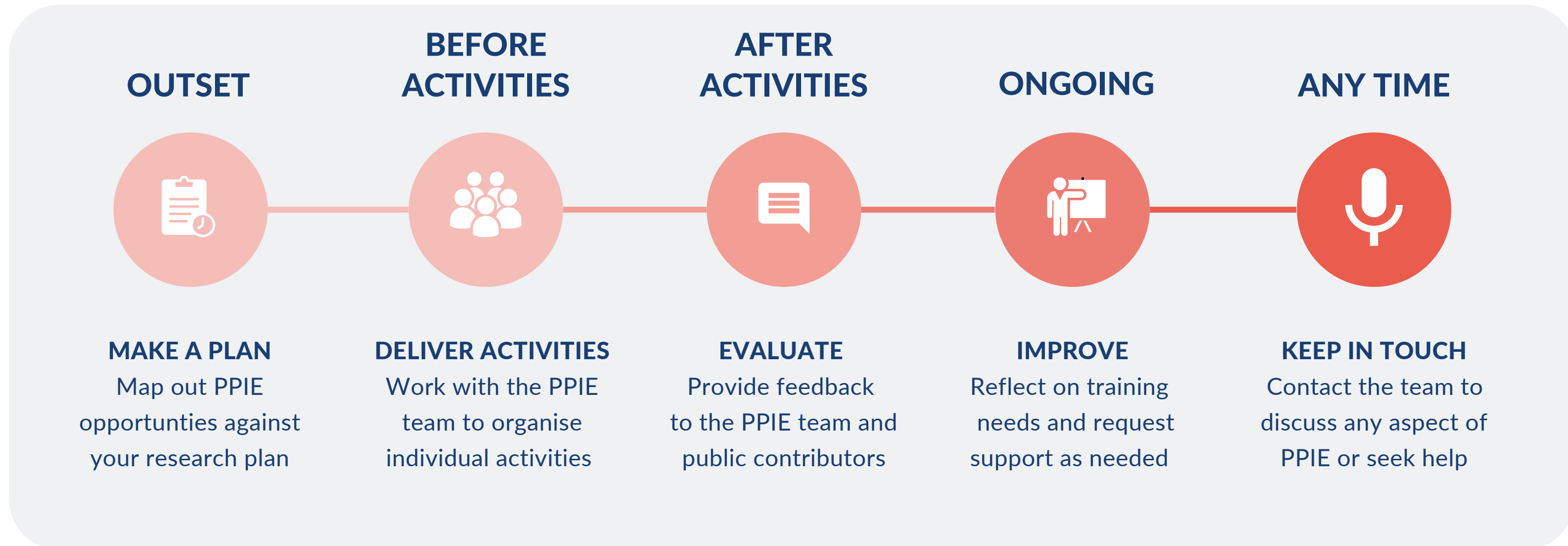
Building a legacy



Important reading and resources: NIHR (2021) [Guidance on co-producing a research project.](#)

SECTION 2: PLANNING PPIE

To ensure high quality PPIE, we ask that you follow best-practice processes



Each stage is supported by guidance, templates and forms - outlined in the following pages.

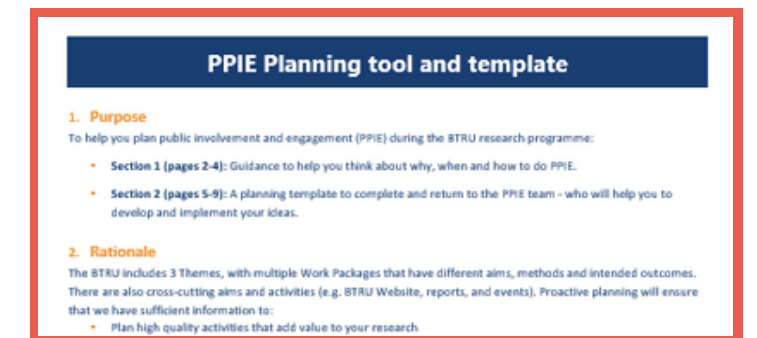
MAPPING PPIE TO YOUR RESEARCH

PPIE should be an integral part of your research - not an afterthought!

We therefore ask each Work Package to make a **PPIE Plan** at the **start** of their research.



- Find the PPIE Planning Tool [here](#)
- Discuss it with your team as soon as possible
- Return to the PPIE Team so they can provide support



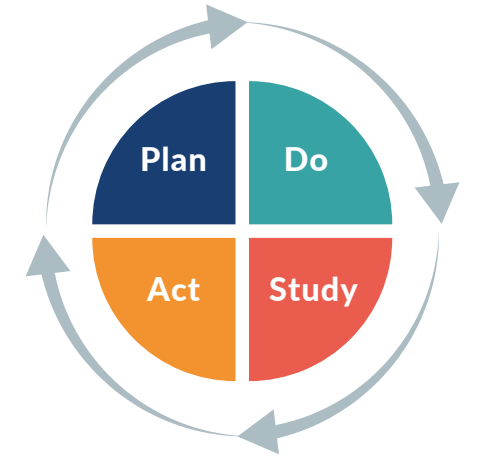
The PPIE Planning Tool:

- Provides guidance and templates to help you make a provisional plan for PPIE
- Directs you to think about the different stakeholders in your research and to map opportunities for PPIE against your research plan.
- Helps us to plan ahead - to ensure that we have the capacity to support PPIE activities, feasible scheduling and fair distribution of resources across the Themes and Work-packages.
- Is flexible. We know that plans may change as your research evolves and ad hoc requests for support are still welcome. However, having a plan will act as a useful conversation starter and create shared understandings.

DELIVERING INDIVIDUAL PPIE ACTIVITIES AND EVENTS

Your PPIE Plan will include many different opportunities for involvement and engagement.

Each one needs to be planned ahead of time. However, the process is always the same and based on the Plan-Do-Study-Act (PDSA) model recommended by [NHS England](#) and [NHS Improvement](#) to support continuous improvement.



The steps you need to follow are summarised below, with more information in the following pages

Plan

STEP 1: Decide what PPIE activity is needed

using the *Opportunities Template* - p.14

Do

STEP 2: Prepare and undertake the PPIE activity

using the *Pre-Activity Checklist* - p.15

Study

STEP 3: Measure the impact of the PPIE activity

by completing the *Feedback Survey* - p.16

Act

STEP 4: Improve our PPIE strategy and skills

via *Project Management, training* - p.17

STEP 1 - Deciding what PPIE activity is needed

Planning individual PPIE activities and events should start early:

- Planning can be time-consuming; especially in-person events that require rooms, travel and catering.
- Public contributors need sufficient time to consider invitations and prepare.
- We may also need time to address support needs (e.g. to book interpreters).

We therefore request that you use the following process to help us plan individual PPIE activities:



Contact the PPIE Team

Contact Karen Shaw at k.l.shaw@bham.ac.uk ideally 1-3 months before anticipated PPIE activities to discuss ideas and begin planning. Longer if possible, especially for in-person events.



Complete the PPIE Opportunities Form (right).

This form provides essential information about the activity and is used by the PPIE team to advertise the opportunity. It is usually started by the PPIE team, but can be used by researchers to request support from the PPIE team.

NIHR | Blood and Transplant Research Unit in Precision Cellular Therapeutics

Opportunity to be involved in:
[Brief title of activity]

Our research is... [provide some very brief context to help people understand what you are doing and why you have invited them and the impact]

Opportunity	To take part in a [remote/hybrid/in-person/home-based meeting/activity] to [develop, review, make ...]
Aim	The aim is to achieve [what?] by the end of the meeting/activity. This will be used to [what?]
When & where	This will take place on [] at [] (we will send more details if you decided to get involved including maps, directions, remote meeting links)
Who	It will be led by [] We expect XX people to attend and will introduce you to them before/during the meeting/activity.
Commitment	It will take [] of your time [Is any preparation need, how many others will be involved, is there a deadline]
Skills needed	You don't need any specific skills or knowledge. However, it will involve [what?]
Payments	TBC by PPIE team
Support	We can offer lots of different types of support – so please let us know what will make it easier for you to be involved or if you need this information in another format.
Feedback	[What type of feedback will be given, who is responsible, what is the timescale]
Information	Please contact Karen Shaw at btrppi@contacts.bham.ac.uk
RSVP	Please let us know if you want to attend (or not) at [form link]

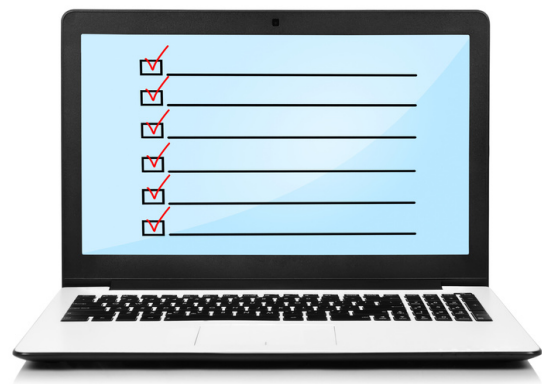
Include photos of meeting/activity leads or team members – and other relevant images.



The PPIE team will collate & confirm responses

Invitations will include a RSVP survey link to confirm attendance and identify support needs. The PPIE team will confirm details with you. This will also be used to monitor involvement (e.g. inclusion and diversity)

STEP 2 - Preparing and undertaking individual PPIE activities



THERE ARE 2 PRE-ACTIVITY FORMS THAT NEED TO BE COMPLETED BEFORE ACTIVITIES OCCUR.

In most cases, we will send a **pre-activity reading pack** to public contributors.

We also complete a **pre-activity checklist** to ensure that all reasonable steps have been taken to create a positive experience that adds value to your research.

Your level of involvement in completing these forms will depend on the activity and your role within it.



The pre-activity reading pack is [here](#)

The pre-activity checklist is [here](#)

The aim of the checklist is to clarify:



Aims and outcomes

What is the aim, what do we want to achieve, what will be produced, etc?



Roles and responsibilities

Who is leading the event, who is attending, any training needs, etc?



Confidentiality issues

Are there any issues related to IP, confidentiality, competing interests, data protection etc?



Resource requirements

What are the anticipated costs, do we have a suitable venue, have we organised catering, travel, technology, etc?



Inclusivity

Do public contributors have the information and materials they need, have we addressed support needs, etc?



Recording and impact

How are the results and impact of the activity being recorded, how will this be fed back to contributors, etc?

STEP 3 - Measuring the impact of PPIE activities

After each PPIE activity, you will be sent a link to a **quick confidential feedback survey**.

The survey has four important purposes.

It is also used to record the impact of the BTRU's PPIE Strategy.

We therefore request that you return this promptly.



1

Thank contributors

Prompts are included to help you thank public contributors and explain how the results of the activity will be used. This information will be forwarded to public contributors by the PPIE Team and used to promote the research.

2

Identify risks

The survey provides an opportunity to flag any immediate concerns, seek personal debriefing or highlight issues that the PPIE Team need to address urgently or in the near future.

3

Support improvement

The survey asks you to rate the quality of the PPIE organisation and activity. You are also invited to make improvement suggestions and request training and support - for you, your team or public contributors.

4

Measure impact

Evaluating the impact of PPIE is essential. The survey therefore includes an 'impact log' to capture important features of the PPIE. You are also strongly encouraged to upload materials that provide evidence of your PPIE activities or outcomes.

STEP 4 - Improving our PPIE Strategy and Skills



PROVIDE FEEDBACK

Provide feedback about what works well and what could be improved using formal methods (such as the feedback survey) and informally. Please also think about what other evidence you could collect and share to show the impact of PPIE processes and outcomes.



INVEST IN PPIE

PPIE is everyone's business and while you are not expected to be an expert, it will be useful to reflect on how PPIE can become a routine feature of your work. Please discuss PPIE within your teams and let the PPIE team know how they can support you.




REFLECT AND REVIEW

Please make time to review your PPIE plans (at least annually) and build on your learning. Support the PPIE Team to develop the BTRU PPIE Strategy as part of Project Management Group and other governance structures.

Useful Resources

Resources to support communication and collaboration with patients and the public.




 [How to write in Plain English - by the Plain English Campaign.](#)

 [Writing Plain English Summaries - by the NIHR.](#)


 [Being inclusive in public involvement in health and social care research - by the NIHR.](#)


 [Online Engagement: A guide to creating and running virtual meetings and events - by the NCCPE.](#)

 [Partnership working principles - by the NCCPE.](#)

 [How to make information accessible. A guide to producing easy to read documents - by CHANGE](#)

 [Feedback from Researchers to PPI Contributors - by Cripacc.](#)

 [GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research - by S Staniszewska et al.](#)

 [What Works Engaging the public through social media - by the NCCPE.](#)

 [Panels and user groups - by the NCCPE](#)

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