

Patient and Student Partnership.

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Patient and Student Partnership

A guide for patients, students and supervisors



Introduction

This document describes the **Patient and Student Partnership**, called the **PSP** from this point forward. It explains why it is important to involve patients in student research and what you can expect. It is part of a set of resources that also include:

- A *Role Description and Working Arrangements Template* that can be tailored to individual projects. This should be made and agreed with Patient Partners.
- An *Activity Log* to record patient and public involvement or engagement.

Our approach has been informed by the successful Student Patient Alliance developed by the *Rheumatology Research Group* and the *Rheumatology Research Patient Partnership* at the University of Birmingham. We ask that this is fully acknowledged when using this document (see publication details).

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What is the Patient and Student Partnership?



The PSP is a partnership between research students and patients (or other relevant members of the public, such as carers). It involves working together on a research project to make sure that it addresses issues that matter to patients, their families, communities and wider society.

The PSP is part of the *Patient and Public Involvement and Engagement (PPIE) Strategy for the Blood and Transplant Research Unit in Precision Cellular Therapeutics (BTRU-PCT)*.

The BTRU-PCT is a collaboration between Oxford and Birmingham Universities and 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.

The PSP is also designed to offer mutual benefit:

- Many research students do not have a clinical background or personal experience of the disease they are studying. Patient Partners can help them understand the relevance of their research and develop patient-focused approaches. Working with patients can also support their skill development, such as learning how to talk to public audiences.
- Patient partners can learn about cutting edge research that is relevant to their condition and shape it in ways that will improve patient benefit. They may also develop new knowledge and skills that are useful beyond the PSP.

What type of research is involved?

The PSP is concerned with doctoral research. This is research done after a student has gained a degree from a university. Students in the BTRU are most likely to be undertaking a PhD (sometimes called a DPhil). This is short for Doctor of Philosophy. It is the highest level of academic qualification that a person can achieve and normally takes between 3 or 4 years of full-time work to complete. The student usually needs to undertake research that is new and original, and write this up in a large document (“thesis”).

A PhD (or DPhil) can involve all types of research from laboratory studies, to working with medical data, clinical trials or collecting people's information using surveys or interviews.

Students doing a PhD (or DPhil) work very independently. However, they are supported by a supervisory team (usually staff at the University) and are formally monitored to check they are making progress.

Students can also benefit by involving experts outside the University. This includes **patients who are ‘experts by experience’**. This helps students to access a wider set of knowledge and skills.

Why involve patients?

The BTRU is funded by the *National Institute of Health and Social Care Research (NIHR)*. The NIHR, like many other funders, believes that patients and the public should have a say in research that affects them. The aim is to produce high quality research that solves problems that matter to the public. For example, patients and members of the public can help researchers to develop important research questions, choose between options, design effective methods to collect data, understand their results and communicate findings in ways that are easily understood.

You can find out more about Patient and Public Involvement and Engagement (PPIE) here:



Researchers: NIHR briefing notes on public involvement for researchers: <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>

Patient Partners: NIHR Starting out guide - why and how to get involved in research <https://www.nihr.ac.uk/documents/Starting-Out-Guide/30145>

Who can be a Patient Partner?



The role is open to patients with blood cancers and blood disorders who have experience or personal characteristics that are relevant to the research study. Depending on the project, the role may also be open to family members, carers and other members of the public who have an interest in the research or represent patient or carer organisations.

Patient Partners are not expected to have any specific knowledge, understanding or research skills. **It is their experience that counts.** However, being a Patient Partner does require a commitment to a student that may involve regular communication or meetings over several years. It also requires a willingness to learn, share opinions and respond to reasonable deadlines.

Patient Partners will normally be paired with one student, but this will depend on the needs of the study and the Patient Partner.

Our research aims to be equitable, diverse and inclusive. Involvement is therefore open to all, regardless of gender, ethnicity, religion, disability, sexuality or background. However, opportunities for involvement in specific studies may be targeted at specific groups - but only where this is necessary and justified by the research questions. Any selection processes will be clear and transparent.

Being a Patient Partner is a voluntary role and working relationships should be based on shared agreements about what is fair, appropriate and feasible. Importantly, Patient Partners can change their mind about their level of involvement or leave at any time. However, it is helpful to have notice of any changes, where this is possible.

Specific requirements

We want Patient Partners to feel able to contribute to the research. The PSP should therefore be inclusive, flexible and supportive to respect that everyone is a unique individual. People interested in the role should be given opportunities to discuss their needs and preferences at the outset, so we can identify the best way to meet these.

What does it involve?

The role of a Patient Partner is to provide a patient perspective on the student's research. They will be invited to join the student supervisory team as an external expert. This will involve taking part in:

- **A 'welcome' meeting** to meet the student, supervisors and PPIE team. This is usually a 1-hour meeting to give Patient Partners an opportunity to find out more about the research, ask questions and clarify preferences for being involved.
- **Important meetings.** This may include **supervision meetings** to review the student's progress and help them plan their next steps. It may also include **research-meetings**, such as helping the student to discuss their research with a group of patients. The number and format of meetings will depend on what is agreed, but it is expected that many will be held remotely. However, some may be in-person or hybrid meetings.
- **Activities at home** – such as reviewing and commenting on documents. Where possible, this should offer a choice of ways to be involved (e.g. by email, in writing, by video).
- **External activities (optional)** – such as going to a training session or conference with the student.



Patient Partners will also be invited to join the Patient and Public Involvement and Engagement (PPIE) Strategy Group. This is a group of patients, carers and members of the public who work more broadly with the BTRU-PCT. This will provide a wider support network and enable Patient Partners to help improve our approach by sharing their experiences at an annual review meeting.

Patient Partners generally work with the students to help them:

- **Communicate in ways that can be understood by the general public.** Such as helping the student to explain their research using common sense language, creative media or art-based approaches.
- **Plan and carry out their research.** Such as helping the student write patient information leaflets, design surveys or interpret findings.
- **Make decisions.** Such as helping the student to decide who needs to be told about the research or what research should be done in the future.
- **Stay motivated.** Doing a PhD can be challenging. It can be really helpful to remind students why their work is important.
- **Understand the impact of involvement.** Such as providing informal and formal feedback.

What can I expect?

Students, Patient Partners and supervisors are encouraged to think creatively about how they can work together to maximise the experience and impact of their partnership. However, as a minimum **it is expected that Patient Partners will:**

- Have a *Role Description and Working Arrangement*.
- Have regular opportunities for involvement. However, they should spend no more than 2-hours of their time on PSP activities per month. There may be exceptions (e.g. attending a conference), but this will need to be agreed with the Patient Partner and PPIE Team.
- Be paid for their involvement following *NIHR guidance* and the *BTRU-PCT payment policy*. This currently recommends £25 per hour, with payments made into people's banks or by voucher.
- Have opportunities to take part in select supervision meetings.
- Share decision-making on key patient/public-related issues (e.g. ethics, recruitment, PPIE)
- Co-produce a minimum of 1 patient/public-facing material (e.g. lay summary, patient survey).
- Co-produce a minimum of 1 research output (e.g. poster, presentation, journal article)
- Be acknowledged for their contributions.

What are my roles and responsibilities?

The University has clear responsibilities for supervisors and students in relation to PhD supervision. However, the role of a Patient Partner is more flexible and can be tailored to reflect the needs of the research and patient preferences. At a minimum, it is expected that:

- Supervisors will arrange for their student to be linked with one or more Patient Partner, with support from the PPIE Team.
- Students will ensure that a *Role Description and Working Arrangements Form* has been discussed and agreed with Patient Partners by (or at) the first meeting, with support from the PPIE Team.
- Students will take the lead in contacting Patient Partners and arranging meetings or activities. This should be done with enough notice for Patient Partners to make arrangements and prepare.
- Students will ensure that invitations for involvement clearly state the payment being offered and will make sure that all expense claims are sent to the PPIE team to be processed.
- Students will identify and address their own training/support needs for effective PPIE, with support from their supervisors and the PPIE Team.
- Students will support Patient Partners to identify and address any training/support needs for effective PPIE, with support from their supervisors and the PPIE Team.
- Students will routinely record PSP activity using the PPIE activity log.
- Students, Patient Partners and Supervisors will complete a PSP feedback form as requested by the PPIE team (at least annually).
- Everyone will respect one another's confidentiality, health and wellbeing.

Building effective partnerships



Set expectations at the beginning of the relationship. This should reflect the needs and preferences of Patient Partners, related to:

- Meetings and communication
- Working styles and training needs
- Personal requirements including:
 - Accessibility (e.g. disability or specific learning needs)
 - Culture or religion (e.g. religious observances, language)
 - Personal needs (e.g. work or caring commitments)
 - Personal goals (e.g. what do Patient Partners want to get out of the PSP)

N.B. They will also be invited to complete a confidential survey by the PPIE team.

Be inclusive and develop mutually beneficial ways of working

- Offer choice and flexibility where possible
- Provide timely information that helps people prepare for meetings/activities
- Provide timely feedback that explains how contributions have been used and next steps
- Think about what methods of working will support collaboration)

Plan your budget

- Check what funds are available with the PPIE Team.
- Think about what aspects of involvement are most likely to add value to your research and partnership.

Regularly review and record impact

- Log the activity after every meeting/activity and provide feedback as requested by the PPIE team
- Seek, and respond to, informal feedback
- Record impact formally and informally (e.g. take photos, personal reflections)
- Work together to refine your roles and working arrangements.

Respond to challenges

- Take note of people's concerns about the research. You don't always need to agree with them, but do need listen and genuinely consider their perspective.
- Discuss any development or support needs with supervisors and the PPIE team who can advise on the best way forward.
- Don't be afraid to admit mistakes, concerns or changes of mind. Early intervention is always best, so please seek support as soon as you may need it.

Resources

BTRU-PCT Resources

- **Website:** <https://www.rdm.ox.ac.uk/about/our-clinical-facilities-and-mrc-units/nih-btru-in-precision-cellular-therapeutics>
- **PPIE Strategy** <https://doi.org/10.48352/uobxbtru.0002>
- **PPIE Delivery Plan** <https://doi.org/10.48352/uobxbtru.0001>
- **Practical Planning Guide for BTRU Researchers** <https://doi.org/10.48352/uobxbtru.0003>
- **Planning Tool:** <https://doi.org/10.48352/uobxbtru.0004>

General PPIE Guidance:

- **NIHR briefing notes on public involvement for researchers:** <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>
- **NIHR Starting out guide - why and how to get involved in research** <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>
- **Guidance about PPIE in Advanced Therapies - including a guide to CAR T-Cell Therapy** (Advanced Therapy Treatment Centres) <https://www.theattcnetwork.co.uk/patients-and-public>

Specific Guidance for PPIE Activity

- **Plain English** (Plain English Campaign) <https://www.plainenglish.co.uk/index.php>
- **Providing feedback** (Centre for Research in Public Health & Community Care) https://www.clahrc-eoe.nihr.ac.uk/wp-content/uploads/2016/05/Guidance-for-Researchers-PPI-Feedback_2018.pdf
- **Writing a Lay summary** (NIHR) <https://www.nihr.ac.uk/documents/plain-english-summaries/27363>
- **Holding online meetings** (NIHR School of Primary Care Research) <https://www.spcr.nihr.ac.uk/PPI/resources-for-researchers/faq/how-do-i-hold-ppi-meetings-using-virtual-tools>
- **Group meetings, workshops, and consensus decision-meetings** (Seeds for Change) <https://www.seedsforchange.org.uk/resources>

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