Patient and Public Involvement (PPI) Network Policy and Information Document

Welcome to York St John University's PPI Network

This document outlines the aims of the network, provides policy information to both researchers and the public, and includes links to further information.

1. What is Patient and Public Involvement (PPI)?

Patient and Public Involvement (PPI) is a collaborative approach that involves patients, service users, and the public in the research process. It goes beyond the traditional model where researchers conduct studies in isolation, recognising the valuable contributions that individuals with lived experiences can bring to the design, conduct, and dissemination of research.

The National Institute for Health and Care Research (NIHR) define PPI as:

"Research being carried out 'with' or 'by' members of the public rather than 'to,' 'about,' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.

The NIHR outline, broadly, three types of PPI:

Consultation

This is when researchers gain feedback from patients and the public on research plans, materials, or findings. It is used to make sure information is appropriate for the audience, and that researchers aren't using jargon or complicated terms. They might also be gaining feedback about the characteristics of a particular group. This type of PPI can take the form of surveys, questionnaires, reviewing documents, or one-off sessions.

Collaboration

This is more involved than consultation and is when researchers gain input on research design from the outset. This includes specifics, such as recommended outcomes that are important, or what health/care interventions should consist of. The public have a say and are normally formally involved in the form of a patient advisory group or panel, or a named PPI representative on a project. This has overlap with 'co-production'. The key difference between collaboration and co-production is that in co-production, everyone in the partnership has the same amount of power – the research is jointly owned, and everyone is of equal importance. This may or may not always be in the case when collaborating.

User-controlled

This is when research is actively controlled, directed, and managed by service users and their service user organisations. Service users decide on the issues and questions to be looked at, as well as the way the research is designed, planned, written up and disseminated. The service users will run the research advisory group and carry out the research. The researchers get involved via training, support, or conducting parts of the research.

2. Why is PPI Important in Research?

Research is most effective when it reflects the needs, preferences, and priorities of those it aims to benefit—patients and the public. PPI ensures that research is more relevant, ethical, and accountable.

Key reasons for incorporating PPI in research include:

Ethical Considerations

PPI helps to ensure that research is conducted ethically, with due consideration for the rights and wellbeing of participants.

Enhanced Relevance

PPI helps align research objectives with the real-world needs and concerns of patients and the public, ensuring that the research is meaningful and applicable. It helps to formulate future recommendations for research.

Improved Quality

Involving individuals with diverse perspectives enhances the design, methodology, and interpretation of research, contributing to its overall quality.

Increased Accountability

Including patients and the public in decision-making processes increases transparency, accountability, and public trust in research.

Through our PPI Network, we aim to create a collaborative environment where researchers and the community work together to drive impactful and patient-centred research.

3. Aims of the Network

The aim of our network is to create meaningful, impactful research in collaboration with our communities. This incorporates the objectives outlined above, ensuring research is conducted to a high standard in accordance with the rights and wellbeing of participants, and enhancing the relevance and quality of our research, increasing accountability, transparency, and trust in our research processes. We also aim to provide opportunities for engagement, learning, and development for those members of the public that are interested in becoming involved with research.

Our network aims to align with the UK Standards for Public Involvement. These are a set of six standards, developed in partnership with the NIHR. They are a framework for what good public involvement in research looks like. The process of aligning our network with these standards is an ongoing goal that will include regular review.

The standards are:

Communications

This involves making sure the communication methods we use are appropriate for our target audience and are as inclusive as possible. We aim to use a range of approaches that are appropriate for different audiences.

Inclusive Opportunities

This involves making sure partnerships are accessible and include as diverse a group as possible, informed by community and research needs. We aim to involve the people and groups most affected by the research from the earliest stages.

Working Together

This involves making sure our PPI work is more than a tokenistic gesture; we value all contributions and aim to build mutually respectful and productive relationships. We aim to work together towards a common purpose.

Support and Learning

This is about making sure our contributors have opportunities to learn about public involvement; to develop skills and confidence and to make the most of their involvement in research. We aim to provide opportunities for learning and development where possible.

Governance

This involves making sure our practices align with relevant data and research governance. We aim to be transparent about our policies and ensure all of our work aligns with GDPR and other data protection laws.

Impact

This standard is about continually seeking improvement and sharing the difference that public involvement makes to research. We aim to gather and share our learning from the insights and experiences of patients, carers, and the public.

4. Participation, Recognition and Accessibility

People who sign up to the PPI Network will become collaborators and receive information about PPI opportunities via email, approximately once per month. These emails will outline the specific project details and details of the activity for which representatives are being sought. Collaborators can indicate their interest in a particular opportunity by replying to these emails. We will then seek consent to pass the member’s contact details to the lead researcher who is organising the project. If collaborators are not interested in a particular opportunity, they do not have to do anything, and we will not assume interest in or availability for the activity.

We understand that individuals have varying levels of availability and interest. Therefore, there is no minimum or maximum amount of participation required. Collaborators can "dip in and out" according to sessions and research projects that align with their interests and availability.

We recognise and value the time and expertise our collaborators invest in the PPI Network. When possible, collaborators will be compensated for their time in accordance with fair and transparent reward and recognition policies. More information on the reward and recognition policy can be found in section 6.

We are committed to ensuring that our PPI Network is accessible to a diverse group of individuals. We will actively work to overcome barriers to participation, considering various communication methods, venues, and formats to engage a wide range of voices.

5. Examples of PPI Activities in our Network

Our PPI Network engages collaborators in various meaningful activities to ensure their involvement throughout the research process. Here are some examples of PPI activities within our network:

- Research Prioritisation: Collaborators actively participate in discussions and workshops to prioritise research topics, ensuring that the studies align with the concerns and needs of the community. Individuals may then go to become PPI leads within a research group.
- Project Steering Groups: Members of our PPI Network may serve on project steering groups, providing valuable insights into study design, methodology, and ethical considerations.
- Reviewing Research Materials: Collaborators play a crucial role in reviewing and refining research materials, such as consent forms, information sheets, and questionnaires, to enhance clarity and accessibility. This could be for student research projects, such as PhD research, and staff research projects and funding applications.
- Dissemination and Communication: Collaborators will be involved in developing and implementing dissemination plans for research findings, ensuring that the outcomes are communicated in a way that is understandable and relevant to the wider community.
- Advisory Panels, known as ‘PPI Groups’: Our PPI Network establishes PPI groups where collaborators offer ongoing advice and feedback, guiding researchers in making informed decisions throughout the research lifecycle.

6. Reward and Recognition Policy

We will make clear what fees, if any, will be offered to collaborators when sending an invite to take part in any PPI opportunities. This information will include the exact rate and total amount that can be claimed by a collaborator for participating in a specific activity, i.e. attending a meeting or reviewing some documents. It is important to recognise that this is a form of reward as recognition for contribution and is not offered as a wage. Payments will be made as soon as possible after the activity has been completed, e.g. after we have received feedback on documents, or the collaborator’s attendance has been confirmed at a meeting. We take our rate guidance from the NIHR, but we also consider the budget available and the types of activities that are undertaken.

As a general guide, with effect from **1 August 2025**, we aim to offer £12.50 per hour of activity undertaken. We make it clear when we advertise the opportunity how much time we expect the activity to take and therefore how much monetary reward will be offered. This rate will be reviewed regularly.

At times, there will be opportunities to contribute formally to research projects that are funded through research grants. For example, collaborators might be a public member of a study steering committee, study management group, or a chair of a patient advisory group.

They may also be named as a co-applicant on a funding application. If this is the case, there may be a higher rate that reflects the size and complexity of the task and activity.

Compensation for PPI participation will be provided in the form of gift vouchers or if preferred an individual not employed by York St John University can ask to be setup as a creditor and paid via BACS. In exceptional circumstances cash may be paid to a collaborator where Finance has prior notice. Any collaborator that is also employed by York St John can be remunerated via gift voucher or as an additional non-taxable payment in their monthly payroll.

Sometimes there are other forms of recognition or reward that do not involve payment. These might be opportunities for learning and developing your knowledge, confidence, and skillset for being involved in PPI. If this is the case, this will be made clear when opportunities are advertised.

Expenses may also be payable according to the university's travel and expenses policy. If this is the case, the researchers will make this clear upon advertising and will provide guidance on how to submit a claim.

Welfare Benefits

If collaborators are receiving any form of state benefits, receiving payment for PPI activities may affect their claim. We cannot provide individual advice on benefits and highly recommend that collaborators seek expert advice from a benefits advisor, Jobcentre Plus, or Citizen's advice.

For more information, please refer to 'Section 8 – Welfare benefits' of the payment guidance for members of the public considering involvement in research.

Tax, and National Insurance

It is important to note that any payments made to collaborators may be subject to tax or National Insurance. Tax and National insurance contributions will not be deducted by York St John University. Collaborators will need to inform HMRC about the fees they receive for involvement if this takes their taxable income above their personal income tax allowance at the end of the financial year.

Collaborators are responsible for calculating whether they need to pay any tax or National Insurance. Advice is available from local HM revenue and Customs offices. More information can be found at Payment for public involvement in health and care research: a guide for members of the public on employment status and tax.

Choosing not to be Paid

Collaborators do not have to accept the fee offered for their contribution. It is possible collaborators to choose not to claim the fee and volunteer their time without any payment, for any reason.

7. Data Storage and Processing According to GDPR

We understand the importance of safeguarding personal data and are committed to complying with the General Data Protection Regulation (GDPR) in the UK. Any personal data collected through the PPI Network will be processed and stored securely, ensuring confidentiality and privacy. Our full privacy policy can be downloaded from the PPI Network webpage.

Key GDPR principles we adhere to include:

Consent

When collaborators sign up to the PPI Network, there is a clear option to indicate whether they consent to their data being processed for the purposes outlined in the privacy policy. In addition, if collaborators express interest in an opportunity, we will seek written consent before we pass their details on to the lead researcher of the project to facilitate their engagement.

Transparency

We process data transparently, ensuring fairness and legality in all data-related activities.

Purpose Limitation

Data collected will only be used for the specified purposes related to the PPI Network, and consent will be sought for any additional uses.

Data Minimisation

We collect only the necessary data for the PPI Network, ensuring that the information is relevant and not excessive.

Data Accuracy

We aim to keep data accurate and up-to-date, allowing individuals to rectify any inaccuracies.

Data Security

Robust security measures are in place to protect against unauthorised access, disclosure, alteration, and destruction of data.

Data Removal

Collaborators can be removed from the PPI Network list at any time upon their request or for any other reason. We respect the rights of collaborators to control their personal information.

8. Continuous Review and Collaboration

The objectives and processes involved in the PPI Network will be subject to continuous review and improvement. We value the input of our collaborators in shaping the direction of the network. Regular feedback, including surveys and collaborative discussions where necessary, will be conducted to ensure that the PPI Network remains dynamic, responsive, and aligned with the evolving needs of the community.

9. Relevant Links

Involve patients | NIHR

Public Involvement - Health Research Authority (hra.nhs.uk)

UK Standards for Public Involvement - The UK Standards (google.com)

Payment guidance for members of the public considering involvement in research | NIHR

Payment for public involvement in health and care research: a guide for members of the public on employment status and tax | NIHR