



Public Involvement in Health and Social Care Research: an Introduction for Researchers

'I feel my input has had an impact because researchers often change their application or research documents after attending the panel. The researchers often say how grateful they are for our input.'
ARC NT Public Contributor

'I look forward to debating issues. I love a challenge. We all bring our 'passions' to the table. We are like a jigsaw puzzle, bringing our experiences together to influence the subject in a positive manner. I conclude we learn a lot from each other too.'
ARC NT Public Contributor

Prepared by [Dr Christine Smith](#) and Mrs Joyce Fox, March 2022

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Introduction

Patient and public involvement and engagement (PPIE), can have significant impact on the research, researcher(s), the patients/public involved, and more widely on organisations, systems, treatments, care, and wider. This guide aims to give you an overview of PPIE and how you might incorporate it into your research.

At its heart, PPIE is about having conversations and building relationships with the people who will be affected by the focus of your research (patients, carers, service users and the public) to ensure that all aspects of the research (its focus, research questions, conduct, and findings) address what is important to them.

People have various motivations for getting involved as public contributors in research. This may be because they have experienced great care and support and want to “give something back”; it may be that they have experienced difficulties, delays, safety incidents, or similar, and are keen to “make things better” or help ensure that in future others don’t have to experience what they did.

There is no one right way to do PPIE, however there are some important points to consider when planning and undertaking involvement or engagement activities. The way we engage with people sets the tone for how we go forward, and the way we involve people will underpin the development of trusted, collaborative, and productive relationships – or not.

Mrs Joyce Fox

Public Contributor

[NIHR ARC North Thames](#) is one of 15 ARCs across England, part of a £135 million investment by the NIHR to improve the health and care of patients and the public, by getting the results of research into practice. It is a collaboration between the public, researchers, and the people who plan and deliver health and social care services. Over six million people live in North Thames, an ethnically diverse population living in inner city, urban and rural communities across parts of London, Bedfordshire, Essex and Hertfordshire – a total of 26 boroughs. The neighbourhoods we cover range from the sixth most affluent in England to the third most deprived.

‘PPIE has changed the quality and impact of all our research. We could not do without them, and we are so grateful for the time of these really special people. They want to contribute to every stage of our research from, suggesting areas for study to teaching health and care professionals and Early Careers Researchers how to better do research.’

Professor Rosalind Raine, Director of ARC NT

Notes

This document is a summary of the National Institute for Health and Social Care Research (NIHR) [briefing notes for researchers in public-involvement](#), but also includes other sources of information. It is aimed at new researchers but will also be useful as an update for those who may want to refresh their knowledge.

Academia is full of technical terminology and acronyms. The NIHR glossary can be found [here](#). This document uses the acronym PPIE as an umbrella term for all things connected with public participation, involvement and engagement.

What is public involvement in research?

There are many different ways to talk about public involvement in research¹²³⁴. The NIHR classifies public involvement into three categories: engagement, involvement and participation⁵.

Involvement in research means research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research. This document will focus on involvement.

Engagement describes activities where information and knowledge about research is provided and disseminated. More information can be found here¹

Participation describes where people take part in a research study e.g. they are recruited to a clinical trial or other research study. More information is available here⁶

Who are ‘the public’?

In order for research to have an impact⁷ researchers must work with the people who are likely to use the research – the stakeholders. These might be the ultimate ‘end-users’ of the research – patients, carers, other members of the public, but they also might be professionals like advocates, commissioners of public services, clinicians, managers, educators or other researchers. Stakeholders come from many different sectors such as health and social care, academia, industry, the voluntary sector.

So why do we make such a fuss about PPIE?

Stakeholder engagement is common in health and social care research. However, traditionally researchers have only engaged with professional stakeholders, and the public or patient voice was not always present.

Why involve the public?

The democratic and moral argument for PPIE - ‘Nothing about us without us’

The fundamental reasons for involving members of the public in research are based on broader democratic principles of citizenship, accountability and transparency. These reasons connect with

¹ [National Coordinating Centre for Public Engagement](#);

² [Wellcome Trust](#)

³ [NIHR INCLUDE Framework](#)

⁴ [Research Excellence Framework](#) & [Who defines impact?](#)

⁵ [NIHR PPIE definitions](#)

⁶ <https://bepartofresearch.nihr.ac.uk/>

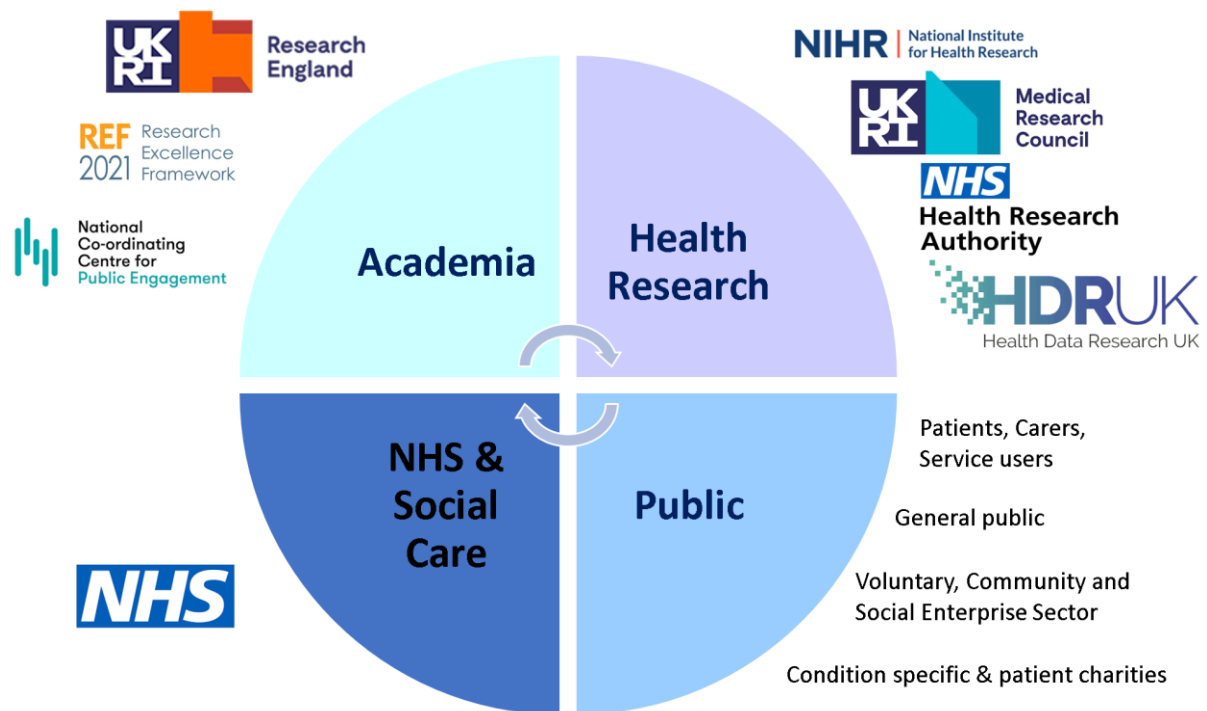
⁷ [Impact is defined](#) as the demonstrable contribution that research makes to society and the economy, of benefit to individuals, organisations and nations.

the notion that any research, especially that paid for through taxation via the NIHR, should not disadvantage anyone, particularly individuals or groups who are underserved or who have a protected characteristic as defined by the Equality Act 2010⁸

The expectation of PPIE in research⁹

All of the stakeholders (See Figure 1.) in health and social care research hold an **expectation of PPIE in research**, including the partner organisations of NIHR ARC North Thames¹⁰.

Figure 1. Organisations involved in Health and Social Care Research



The NHS Constitution states that research is a core part of the NHS. Research has shown that not only do research-active institutions help improve patient care¹¹, but that institutions that engage in research show improvements in their performance¹². The NIHR emphasises the importance of PPIE in its funding criteria¹³. High quality PPIE is an expectation within its projects, programmes, infrastructure and at a strategic level. In addition, PPIE is a core component of Health Research Authority approval processes, as it can help ensure that research is ethical, relevant and acceptable from a public perspective¹⁴.

⁸ [Easy Read: The Equality Act - making equality real - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/news/easy-read-the-equality-act-making-equality-real)

⁹ https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371#Briefing_note_three:_why_involve_members_of_the_public_in_research?

¹⁰ <https://www.arc-nt.nihr.ac.uk/about-us/partners/>

¹¹ <https://www.rcplondon.ac.uk/news/recognising-research-how-research-improves-patient-care>

¹² <https://bmjopen.bmj.com/content/bmjopen/5/12/e009415.full.pdf>

¹³ <https://www.nihr.ac.uk/researchers/apply-for-funding/how-to-apply-for-project-funding/make-a-strong-application.htm>

¹⁴ [New best practice principles for public involvement - Health Research Authority \(hra.nhs.uk\)](https://www.nhs.uk/health-research-authority/public-involvement/new-best-practice-principles-for-public-involvement/)

Benefits for Research

Incorporating PPIE in your research can **improve its relevance**, by helping researchers identify research that matters and by bringing **expertise by experience** into the research team. It can improve **research quality** by ensuring that methods are acceptable and logistically feasible; and by providing appropriate oversight - offering transparency and accountability to the ultimate funders of our research (the taxpayer) thereby **adhering to democratic principles** and **improving public confidence and trust**. Finally it can **increase the impact of research**, by identifying potential 'real-world' impact, and helping to disseminate research findings that matter and implement change.

“For me the main contribution is that they remind us all the time what it’s about. So we don’t lose touch with what our patient population is or what the trial’s about actually.”

“it probably made some of the questions easier to understand [...] and therefore it would have improved the data collection”¹⁵

Benefits for the Researcher

Incorporating PPIE into your research has positive benefits for you as a researcher. By asking the right questions, through working with your end user, you are increasing the chances that your research will make a difference.

Researchers have described how they and their research were influenced, and their thinking changed, by including public contributors as part of the team such as:

- increased researchers’ empathy and understanding
- improved quality and relevance of decision making within projects so that recruitment and retention were enhanced

Ultimately these improvements led to increased grant capture and publications

*Past challenges raised against involving patients included “we haven’t got time to talk to patients, we’ve got very tight timelines and need to get the study set up quickly”.. and “you only need to talk to doctors because they’ll tell you what the patients will have said”. However, **if you only talk to health professionals you will completely miss some really important insights.** Researcher*

Benefits for the Public Contributor

The following reflections were shared by public contributors who were asked what benefits they had gained from their involvement in healthcare research:

- With certain conditions you become **isolated**, by taking part it makes my time meaningful and it has increased my social network

¹⁵ <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0128817>

- It gave me an opportunity to do presentations to groups; I **gained confidence** generally and in public speaking
- In addition to using my experience of my health condition, I've been able to use skills from my **professional** life again. I felt **valued** and the **work felt meaningful**
- It's given me back a **sense of worth that [my illness] stripped away**
- Everything I was and identified with was taken away from me by my illness. By becoming involved, it has helped me recognise who I am and helped me understand that my experiences are important and **I can help to make a difference.**

Additional benefits of PPI are included in a short [video](#) about PPI in research by ARC North Thames.

Where/when/how do I involve the public?

Not all research is the same. The way that you approach PPIE for your project will depend on many factors, such as the context and aim of your research and your resources. However, the basic principles of PPIE apply across the whole spectrum of research.

UK Standards for Public Involvement

The UK Standards for Public Involvement (UKSPI)¹⁶ were launched in 2019 and form the framework that underpins PPIE within the NIHR. They evolved out of the 2015 Going the Extra Mile¹⁷ report of the 'Breaking Boundaries' strategic review of public involvement in the National Institute for Health Research (NIHR). They are a description of what good public involvement looks like and are designed to improve the quality and consistency of public involvement in research by encouraging reflection and learning.

The six dimensions of UKSPI are [inclusive opportunities](#), [working together](#), [support and learning](#), [governance](#), [communication](#) and [impact](#).

Any researcher within the NIHR is expected to reference the standards in relation to their work and should be able to demonstrate that they are working towards them.

How and where do I find people to involve them?^{18, 19}

Principles

Before you start to look for people to involve in your research you need to consider what perspectives you are looking for. There are a few broad rules to follow:

1. Involve more than one person. This increases the range of perspectives influencing your work, makes you team more resilient to absences and, crucially, provides the opportunity for your public contributors to support each other.

¹⁶ <https://sites.google.com/nihr.ac.uk/pi-standards/home>

¹⁷ [Going-the-Extra-Mile.pdf \(nihr.ac.uk\)](#)

¹⁸ [Briefing note 5: how to involve members of the public in research](#)

¹⁹ [Briefing note six: who should I involve and how do I find people to involve?](#)

2. Consider which individuals, communities or wider populations might be most impacted by, or relevant to your research and work specifically to involve them. An Equalities Impact Assessment may prove useful^{20, 21}.
3. Be aware of the principles of equality, diversity and inclusion but try to not be paralysed by the fact that you cant do everything
4. Plan your resourcing for PPIE²², including reimbursement for your public partners, but also considering the time it will take to undertake meaningful PPIE

Once you have identified who you want to involve you need to consider how you will find and make contact. Each ARC is part of local, regional and national PPIE networks. The ARC North Thames PPIE Lead²³ can advise on local PPIE resources but you might need to consider recruiting nationally for your PPIE if your research population is a national one. Your public contributors need to be aligned with your research population. The NIHR's Reaching Out programme sought to understand how best to work with underserved communities and has produced this guide to being inclusive²⁴.

Practicalities

Equality Impact Assessment

An Equality Impact Assessment, or EIA, is a mechanism to incorporate equality and diversity into your research, to understand how your research might impact on different groups or individuals. These individuals and groups might be underserved or have a protected characteristic, as defined by the Equality Act 2010²⁵. By undertaking an EIA during the first, planning stage of your research you can ensure that you consider issues of fairness so that your research meets the needs of a wider range of end-users. An EIA can also help you identify who you want to involve in your research.

There are several toolkits to support your EIA²⁶.

Resourcing Public Involvement

The NIHR expects to see that PPIE is properly costed within research proposals, in terms of both the budget and the additional time needed. Guidance can be found here²⁷. It is worth noting that this can be quite complex and discussion with the ARC North Thames PPIE team²⁸ is recommended.

Ethics

There is sometimes confusion concerning ethical approval for PPIE. The NIHR website²⁹ states that 'Ethical approval is not needed where people are involved in planning or advising on research, for

²⁰ <https://arc-em.nihr.ac.uk/clahrcs-store/equality-impact-assessment-eqia-toolkit>

²¹ <https://arc-nwc.nihr.ac.uk/wp-content/uploads/2021/12/Introduction-to-The-FOR-Equity-221121-3.pdf>

²² <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>

²³ See Contacts for Further Information, pg 13

²⁴ <https://www.learningforinvolvement.org.uk/?opportunity=nihr-reaching-out-a-practical-guide-to-being-inclusive-in-public-involvement-in-health-research-lessons-learnt-from-the-reaching-out-programme>

²⁵ <https://www.legislation.gov.uk/ukpga/2010/15/contents>

²⁶ Centre for Ethnic Health Research; <https://forequity.uk>; UK Research and Innovation

²⁷ <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>

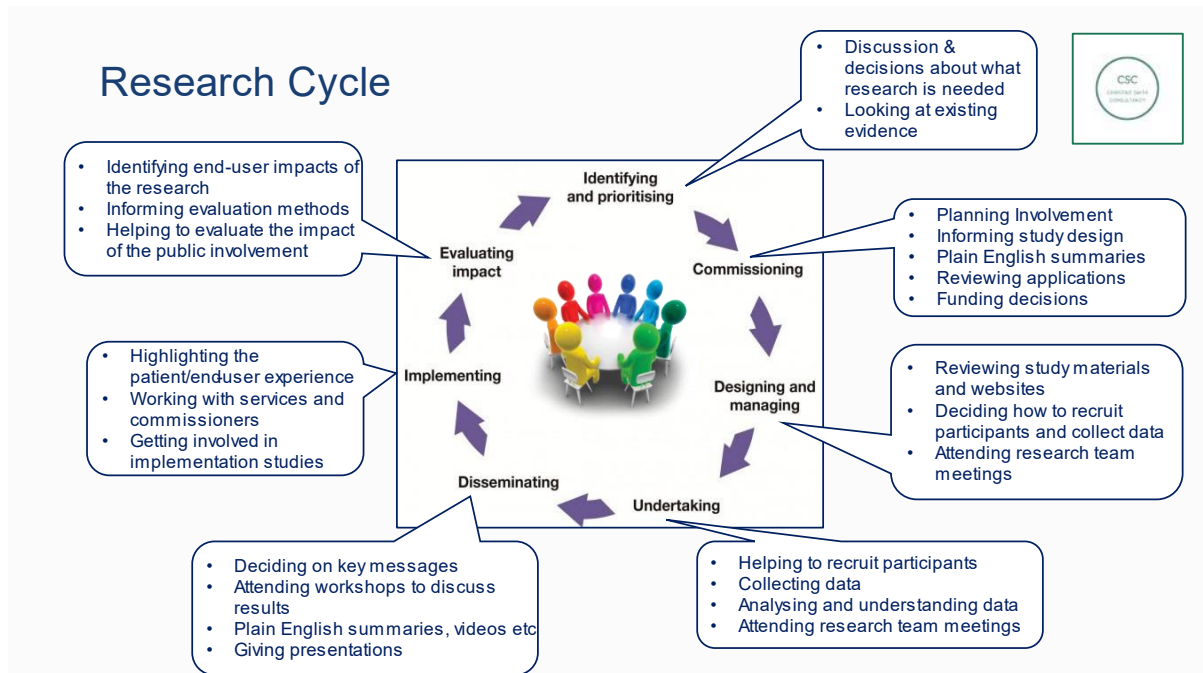
²⁸ See page 13

²⁹ <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371#Ethics>

example as a co-applicant on a research grant, a member of an advisory group or in developing a questionnaire. It recommends this³⁰ further reading. It is worth noting that this can be quite complex and discussion with the ARC North Thames PPIE team³¹ is recommended.

When do I involve people?

The easiest way to think about when to involve the public in your research is to think about the research cycle³².



You need to decide where PPIE will be most effective in your project and plan accordingly, remembering that while the NIHR expects to see evidence of meaningful public involvement and progression towards the UKSPI, this needs to be feasible within your resources and will depend on where you are in your personal PPIE 'journey'.

There are key areas where historically researchers have been criticised for their approach to PPIE.

Feedback

Standard 4 of the UKSPI is communications and this is a traditionally weak area for researchers.

Specific [guidance](#) has been developed by the Centre for Research in Public Health and Community Care.

³⁰ [Qualitative research and patient and public involvement in health and social care research: What are the key differences?](#) and [Patient and public involvement in research and research ethics committee review. \(.PDF\)](#)

³¹ See page 13

³² [https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371#Briefing note eight: ways that people can be involved in the different stages of the research cycle](https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371#Briefing%20note%20eight:%20ways%20that%20people%20can%20be%20involved%20in%20the%20different%20stages%20of%20the%20research%20cycle)

Evaluation and impact

As researchers it is crucial that we reflect and evaluate PPIE, so that we can articulate its impact – the difference it makes. The University of the West of England has produced [guidance](#) that presents different approaches.

Reporting

The way that PPIE is discussed in publications is quite inconsistent. The [GRIPP2](#) (Guidance for Reporting Involvement of Patients and the Public) reporting checklists were developed to improve the quality, transparency and consistency of the PPIE evidence base.

How do I involve people?

There are different ‘levels’ or approaches to PPIE that correspond to increasing levels of power sharing. Projects can include a combination of any or all of these.

[Consultation](#) - is when you ask members of the public for their views and use these views to inform your decision making. Consultation can be about any aspect of the research process – from identifying topics for research through to thinking about the implications of research findings. From a public contributor point of view, this is quite passive, they have no power in the decision-making process.

[Collaboration](#) – Collaboration involves an ongoing partnership between you and the members of the public you are working with, where decisions about the research are shared. For example, members of the public might collaborate with the researchers on developing the research grant application, be members of the study advisory group and collaborate with researchers to disseminate the results of a research project.

[Coproductio](#)n – The concept of coproduction, which means different things to different people³³. Coproduction is a specific methodology, which is very involved and rigorous. It is also a set of principles. The NIHR, in Going the Extra Mile Recommendation 6, expects that The public, researchers and health professionals should be empowered and supported better to work together in the future...”. It has produced guidance³⁴ on coproduction that describes the five key principles of coproduction:

- Sharing of power
- Including all perspectives and skills
- Respecting and valuing the knowledge of all those working together on the research
- Reciprocity
- Building and maintaining relationships.

It also describes eight key features that you might expect to see in a coproduced project or initiative:

- establishing ground rules

³³ [Exploring the frontiers of research co-production: the Integrated Knowledge Translation Research Network concept papers | Health Research Policy and Systems | Full Text \(biomedcentral.com\)](#)

³⁴ [Guidance on co-producing a research project \(learningforinvolvement.org.uk\)](#)

- continuing dialogue
- joint ownership of key decisions
- a commitment to relationship building
- opportunities for personal growth and development
- flexibility
- continuous reflection
- valuing and evaluating the impact of co-producing research

The [Co-Production Collective](#) and the [NIHR](#) provide more guidance and resources about this way of working. There are also [books about coproduction in practice](#) that were produced during the COVID pandemic, and a series of [podcasts](#) produced by the Research Design Service in the South East. A recent NIHR initiative called Reaching Out produced [guidance on inclusivity](#). Finally, here³⁵ are some examples of coproduction in practice.

[User-controlled research](#) - is research that 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 or steering group and may also decide to carry out the research.

PPIE in ARC North Thames

[PPIE in ARC North Thames](#) is threaded throughout the programme from individual research projects to the Management Board. All PPIE is guided by the [PPIE Strategy](#). Your first point of contact for PPIE queries is the [PPIE Lead](#) in the ARC NT Core Team.

There are two key PPIE panels that guide and advise on all projects.

Panels

Both our panels (details below) are ethnically diverse and from a variety of personal and professional backgrounds.

Research Advisory Panel (RAP)

This group of local patient and public representatives, meets regularly and provides advice to ARC study teams at all stages of research, from inception to implementation. It reviews and advises on new ARC research proposals, potential ARC projects in development or at grant application stage, and existing research.

It is a diverse group with experience in the NHS, industry, social care. On average we hold a monthly RAP meeting which is normally for an hour and half and availability is scoped out with panel members about 6 months in advance.

³⁵ <https://journals.sagepub.com/doi/pdf/10.1177/1744987120914353> & <http://shura.shu.ac.uk/14627/1/Langley%20-%20How%20to%20engage%20people%20in%20co-production%20-%20%20Science%20of%20Improvement.pdf>

Once a researcher has expressed an interest in presenting, we endeavour to align the most appropriate RAP members to the topic area. We then work with the researcher to create a briefing document to share with the panel ahead of the meeting which normally takes the form of background of the project, outline of the aspect of the project they would like input on together with several questions (maximum of 6 normally) to help them think on the subject area ahead of time. If the researcher presenting to the panel is a PhD student, we often advise a supervisor who has knowledge of the subject area join the meeting.

The RAP sessions have a standard structure; welcome and brief reminders of the code of conduct, introductions, and then we hand over to the research team to give a brief overview of the project and address their questions, as facilitator we intervene when necessary. Following the RAP, we send on notes to the researcher and follow up with them a few weeks later once they have had time to digest the RAP suggestions so we can feedback how the panel had an impact. Often if further down the line the researcher wishes to present to the panel again on the same topic, we will endeavour to pull the same RAP members back together.

Virtual Document Review Panel (VDRP)

The VDRP provides a remote review service for patient-facing documents from studies, as well as providing PPI input to research funding applications. They review e.g. consent forms, patient information sheets, recruitment letters, patient surveys, plain English research summaries including those in grant applications, for plain English and accessibility.

When a researcher approaches us with an idea of a document they would like reviewed, we tend to prime the VDRP and ensure we have a maximum of 6 reviewers who are happy to review the document. We try to give them 2 weeks to review the document depending on the length and complexity of the document. Together with the researcher document we also send a review form which contains overall questions for the document. Again, once the researcher has had time to reflect on the suggestion we ask for feedback to share with the panel.

We reimburse the panel members' time in accordance with the NIHR CED guidance³⁶.

Contacts for further information

PPIE Lead: arc.norththames@ucl.ac.uk

ARC NT PPIE Webpage: <https://www.arc-nt.nihr.ac.uk/get-involved/patients-and-public/>

³⁶ <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>