

## **Patient and Public Involvement and Engagement - Resources for Researchers**

Members of the public (including patients, potential patients, carers and health advocates) are getting involved and fulfilling crucial roles throughout the whole research process. **Patient and public involvement (PPI)** in research is 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. Below you will find useful links to help you engage and involve patients and members of the public in your research:

### **1) Introduction to PPIE**

**Briefing notes for researchers** on how to involve members of the public in research includes detailed information on public involvement, case studies showing how the public have been involved in research projects and templates of useful documents. This [guidance](#) will help you to plan, resource and support public involvement in research.

**A Plain English Summary** is a brief summary that has been written for members of the public, rather than researchers or professionals. It should be written clearly and simply, without jargon and with an explanation of any technical terms that must be included. Click [here](#) to see the guidance on making sure your research study has a clear and concise plain English summary.

**The NIHR Learning for Involvement website** offers a range of resources for researchers who want to increase their knowledge of PPIE within research. [Here](#), you can search, complete and recommend resources you found useful.

[Involving children and young people as advisors in research](#) is a short overview of the key issues on involving children and young people in NHS, public health, and social care research. Developed by several Young People's Advisory Groups (YPAG) and members of the INVOLVE Children and Young People's working groups, it provides researchers with practical information on what they need to consider when involving children and young people in research.

**Young Person's Advisory Group – Online Toolkit:** The toolkit is designed to take you through each part of the process of setting up a YPAG and is split into four sections recommended by our users: understanding why it is important; getting started; delivering a meeting; evaluating the work, and the impact a YPAG can have on both the participants themselves and on child health research. Link [here](#).

The [UK Standards for Involvement](#) provide a framework for reflecting on and improving the purpose, quality and consistency of public involvement in research. They describe the building blocks for good public involvement and provide a baseline of expectations. This helps the public know what to expect when involved in research, and researchers know what needs to be done.

The [Research Design Service PPI Handbook](#) helps you better plan, manage, and carry out meaningful patient and public involvement (PPI) during your research. The handbook addresses the most common questions and misunderstandings about PPI that we have come across while advising researchers.

**PPIE in commercial research:** [How to involve and engage patients in digital health tech innovation](#) was developed by Boehringer Ingelheim and the University of Plymouth and published by the AHSN Network. This evidence-based guide is a review of best practice in patient and public involvement and engagement (PPIE), providing valuable advice and resources to digital health innovators and allowing for the development of digital products with patients front of mind.

[PPIE in lab-based research:](#) this web-based resource provides practical and accessible guidance for lab-based researchers at all stages of their careers on involving patients and the public in their research.

## 2) Payment and recognition for involvement

We have tailored guidance on reimbursing expenses and payments for involvement and participation in research for Barts Health and Queen Mary researchers on the [JRMO webpage](#). Here you will find more information on making payments to public contributors who are actively involved in health and social care research as well as reimbursing the expenses to people who are taking part in research as participants. Additionally, the page includes links to the NIHR's guidance on paying for involvement.

There are several ways to recognise the contributions of members of the public who are actively involved in research. The **NIHR INVOLVE** page provides practical advice on payment and non-monetary methods for recognising the time, skills and expertise provided by members of the public. This [page](#) also provides a link to the [involvement cost calculator](#), a tool which allows you to work the actual costs of involving people in your study. Further guidance can be found on the NIHR website [here](#).

## 3) Reaching underserved communities

**NIHR INCLUDE Guidance:** This guidance summarises what an under-served group is, provides a roadmap suggesting intervention points to improve inclusion, examples of under-served groups and example barriers to inclusion. Read the full guidance [here](#).

**Being inclusive in public involvement in health and social care research** is an [NIHR guidance document](#) which provides a helpful series of prompts for researchers and practitioners whose job it is to support public involvement in research (practitioners). To accompany this guidance, the NIHR have also published their [Reaching Out programme](#): a practical guide to being inclusive in public involvement in health research. Together, these provide key learning points, tips, and examples for each of the 12 prompts for delivering inclusive public involvement.

The Centre for Ethnic Health's [toolkit for increasing participation of Black Asian and Minority Ethnic \(BAME\) Groups in health and social care research](#) aims to capture best practice and provide researchers with a framework on how to improve the participation of BAME groups in research. The suggestions, strategies, and tips in this document will help researchers

## 4) Funding opportunities

### Centre for Public Engagement (CPE)

The CPE's [Small Grants](#) are a monthly funding scheme, providing up to £1,000 of funding for Queen Mary staff and students to deliver small-scale projects which engage with the public. Three categories of award are available (Public Engagement, Patient and Public Involvement, and Community Engagement), and the scheme is open with a rolling deadline of the 15th of each month. See website for further details of these funding schemes plus larger grants schemes.

### Research Design Service (RDS)

Diversity and Inclusion (EDI) in research fund pilot to health and social care researchers across London. Researchers may receive up to £300 towards activities that will help improve your grant application from the perspective of EDI. Applications are accepted on a rolling basis. More information and guidance can be found [here](#).

The RDS' [Public Involvement Fund \(PIF\)](#) is designed to help researchers implement public involvement as early as possible in their research design. You can apply for the PIF when you are planning to submit to any peer-reviewed applied health and social care research funding streams based in England. The maximum amount awarded is £350. **PIF Plus** offers up to £750 to those submitting to the NIHR Programme Development Grants call for Developing Innovative, Inclusive and Diverse Public Partnerships. This fund is designed to help facilitate the involvement of under-served groups.



## 5) Local support for PPIE

The **Barts Health Trust Research Engagement team** works with researchers, patients, and the public to build stronger partnerships in research development and delivery and encourage greater levels of *engagement*, *participation* and *involvement* in our research amongst patients and local residents. The team provide a wide range of services, which include:

- advising on inclusive patient and public involvement for research (e.g. grant applications)
- providing a forum for sharing best practice and problem-solving: Barts Health Patient and Public Involvement in Research (PPIR) Working Group
- providing access to community organisations and local residents who want to get involved in healthcare research
- organising research dissemination activities and events
- coordinating the NIHR Patient Research Experience Survey across all Barts Health hospitals
- managing the Patient Research Champions volunteer initiative.

For more information, contact the Research Engagement team at [patientsinresearch.bartshealth@nhs.net](mailto:patientsinresearch.bartshealth@nhs.net) or visit our [Public Involvement](#) pages on the JRMO website (for researchers). Our public-facing research pages can be found on the [Barts Health](#) website.

[The Centre for Public Engagement \(CPE\)](#) advises and supports engaged activity, working to embed public engagement further within the university. Their aim is to build on Queen Mary's strong history of public engagement to help support all staff in developing new activity and sustaining and strengthening existing projects. The Centre for Public Engagement runs regular public engagement surgeries where you can pick the team's brains about projects, funding, logistics and more.

The [NIHR Research Design Service \(RDS\) London](#) network provides help for researchers to prepare proposals for submission to NIHR and other national, peer-reviewed funding competitions for applied health or social care research by providing expert advice on research design and methodology. The RDS also offers bespoke advice and support regarding how to embed Public Involvement in research, information and guidance, including information on relevant groups and networks who may be interested in collaborating. RDS London also produces a monthly e-bulletin with the latest news and events. Click [here](#) to subscribe.

**Christine Menzies** is the Patient and Public Involvement and Engagement (PPIE) Manager for Clinical Research Network - North Thames. Within this role she provides PPIE support to staff within the 20 Partner Organisations around North Thames and delivers several national projects including the Research Ready Community Champions programme, the Participant Research Experience Survey (PRES) and the Public Research Champions programme. To find out more about any of these national projects or to speak to Christine about PPI support and training taking place in North Thames or nationally, email Christine on [christine.menzies@nihr.ac.uk](mailto:christine.menzies@nihr.ac.uk)

[UCLPartners](#) work closely with partner organisations, NIHR ARC North Thames and NIHR CRN North Thames to support applied health research and clinical trials across North Central London, North East London, and Mid and South Essex. They provide PPIE support to academics, researchers and allied health professionals by helping them understand what involvement is and why it's so important, building their knowledge and skills to make it a core part of their work. Click [here](#) to join the mailing list for their newsletter, or get in touch via email at [contact@uclpartners.com](mailto:contact@uclpartners.com) to find out more about working with UCLPartners.

## 7) Miscellaneous

**Research Involvement and Engagement** is an interdisciplinary, health and social care journal focussing on patient and wider involvement and engagement in research, at all stages. The [BioMed Central \(BMC\) journal](#), which is free to use with open access, is co-produced by all key stakeholders, including patients, academics, policy makers



and service users. Researchers can search for papers and articles, sign up for article alerts or submit their own manuscripts.

**People in Research** enables researchers to advertise opportunities for the public to get involved in research, such as joining a patient panel group or taking part in a workshop. [www.peopleinresearch.org](http://www.peopleinresearch.org)

