

# NIHR North West London Patient Safety Research Collaboration

## Patient and Public Involvement and Engagement

### Research Partners Group

#### Terms of Reference – June 2023 v5

#### 1. Background

The National Institute for Health Research (NIHR) North West London Patient Safety Research Collaboration (PSRC) is a partnership between Imperial College Healthcare NHS Trust (ICHT) and Imperial College London (ICL). It has been funded by the NIHR for 15 years, as the NIHR Imperial Patient Safety Translational Research Centre. It was awarded approximately £2.5 million from 1 April 2023 - 31 March 2028, through a competitive bid process.

The PSRC aims to deliver sustainable long-term, high impact programmes of translational research in patient safety in the NHS and internationally. With its multidisciplinary team and in collaboration with partners (e.g. patients, carers and the public; other academic institutions; and industry), it carries out research across four themes:

**Theme 1 - Influencing patient and healthcare worker behaviours to optimise safety and minimise risk.**

**Theme 2 - Developing and testing technologies that enhance medication safety.**

**Theme 3 - Using integrated care data to address patient safety challenges.**

**Theme 4 - Evaluating and integrating patient safety in the design of new service delivery models.**

Patients, carers and members of the public are central to our work. Members of the public are involved in the PSRC Executive Board, the PSRC Patient and Public Involvement and Engagement (PPIE) Advisory Board and the Research Partners Group. Each research project will also have a PPIE plan and involve appropriate public members. The RPG will help to ensure that researchers are involving patients, carers and the public appropriately in all stages of the research cycle. These Terms of Reference and the role of the RPG will be reviewed by the PPIE Advisory Board<sup>1</sup> every two years.

The RPG will promote the values set out nationally by the NIHR<sup>2</sup> and 4Pi<sup>3</sup>, including:

- **Respect** – e.g. to listen and respect everyone's comments in meetings
- **Support** – e.g. to support each other to contribute to the discussion
- **Transparency and clarity** – e.g. to be open, have open processes and avoid jargon
- **Responsiveness and flexibility** – e.g. to respond to expectations and the evolving RPG role
- **Fairness of opportunity** – e.g. being mindful of diversity and holding everyone in equal regard
- **Accountability** – e.g. to be accountable for the recommendations and the researchers to report back on their actions

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<sup>1</sup> PSRC PPIE Advisory Board: The membership includes three lay partners (two patients/ carers/publics drawn from the RPG), researchers, clinicians and PPIE experts to guide and oversee the implementation and further development of the PPIE strategy across the PSRC

<sup>2</sup> <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>

<sup>3</sup> <http://www.nsun.org.uk/assets/downloadableFiles/4PiNationalInvolvementStandardsFullReport20152.pdf>

- **Confidentiality** – *e.g. to maintain the privacy of personal experiences and safeguard intellectual property.*

### 1. Purpose of the RPG

The purpose of the RPG will be:

- To review the plans for PPIE in all new projects within the PSRC to ensure that patients, carers and the public are appropriately involved across the research cycle (e.g. in developing the proposals for research, conducting the research, and disseminating the results), including where appropriate to comment on the research project design itself
- To act as a link to networks of patients, carers and members of the public, to advise who might be involved in projects, and to help researchers to make contact
- To provide a portal for advice on PPIE for the individual research teams at any stage of a project
- To help evolve the RPG, by:
  - Giving feedback as to what is working well and how the RPG could work more effectively;
  - Reaching out to new communities, who may not have done PPIE in research before;
  - Mentoring and supporting new RPG members, who may have less experience of PPIE in research.

Members of the RPG are not expected to also be the long-term lay partner to any specific research project. However, members can be involved in a maximum of two PSRC research projects, overseen by the PPIE Manager, to ensure the centre is involving a diverse group of patients, carers and members of the public in its projects.

### 3. Membership

Members were appointed through an application process in July 2017 and October 2019 including an informal face-to-face interview with members of the PPIE Advisory Board (including a lay partner). Please see the role description for details of the skills and experience required in this first round of recruitment (Appendix 1). Members must be based in London and will continue to reflect the diversity of our local community.

The members' biographies can be found on the PSRC [website](#).

These initial appointments were for the five year period of funding, with potential to renew, subject to review. Alternates cannot attend meetings.

### 4. Meetings and ways of working (see Appendix 2 for an example)

The PPIE Lead and PPIE Officer will provide support for the RPG including:

- Timetabling meetings (as far in advance as possible)
- Circulating papers electronically (at least one week before the meeting)
- Liaising with researchers and healthcare professionals with regard to individual projects
- Facilitating the meetings
- Documenting recommendations, decisions and ensuring the feedback loop to RPG members in complete
- Collating feedback and learning

- Organising induction, training, development and support for RPG members.

It is envisaged that:

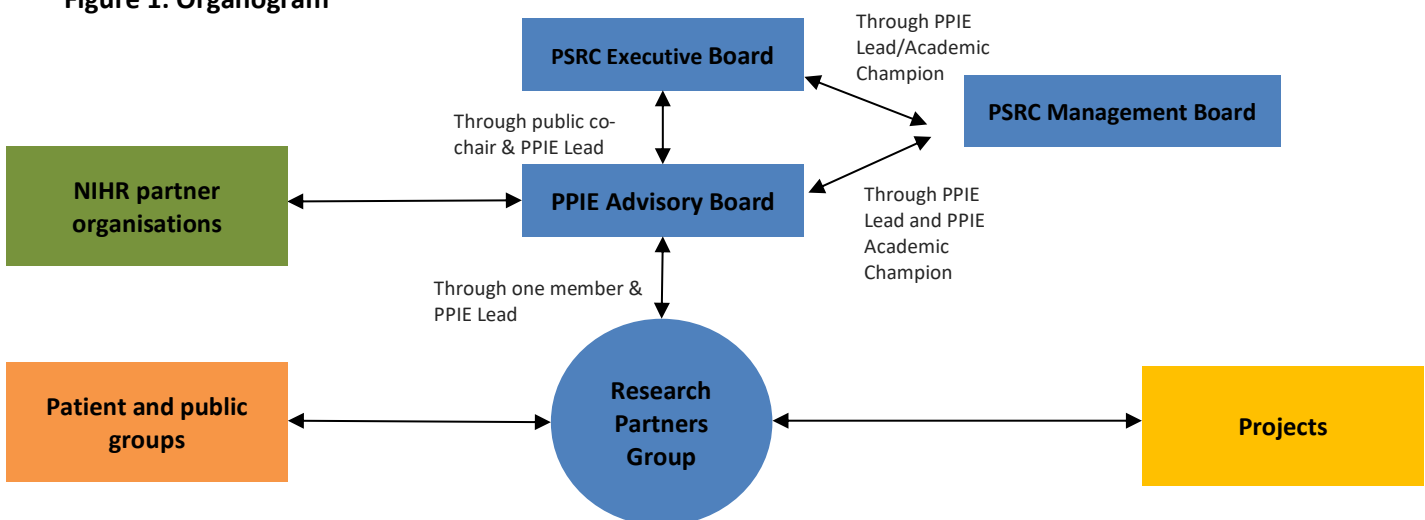
- Meetings will take place in central London or online
- The RPG will meet one a year in person for a reflection meeting and/or training
- A smaller number of RPG members (between 3-6 members) will meet on an approximately four times a year with researchers to discuss individual research projects:
  - The PPIE Lead and PPIE Officer will convene these meetings and members can sign up to the meetings at their convenience. Members are expected to attend on average half of the meetings
  - The researcher will present for 10 minutes on their project; there will be five minutes for questions for clarification; approximately 20 minutes for discussion, led by the lead speaker(s); 10 minutes for summing up and agreement of key recommendations; and, 15 minutes for group reflection at the end of each meeting (e.g. what worked well in the meeting).
- Some interaction may also happen over email (e.g. feedback on documents) and the RPG will explore other methods of communication (e.g. teleconferences and webinars).

## 5. Accountability and review

The PPIE Advisory Board will include at least one member of the RPG and one external lay partner, will oversee the work of the RPG. The external lay partner will co-chair the PPIE Advisory Board (with the PPIE Academic Champion). The lay co-chair of the PPIE Advisory Board will report on PPIE progress to the PSRC Executive Board (who meet six monthly), and to the PSRC Management Board (who meet every two months).

At any point, members of the RPG can ask to receive or give feedback to the PPIE Lead (or a different contact, if more appropriate) to improve the ways of working. If sensitive matters arise, the PPIE Manager may discuss a way forward with the co-chairs of the PPIE Advisory Board, if necessary.

Figure 1: Organogram



## 6. Remuneration and expenses

All members will be paid £25 an hour for their time and £5 working from home expense if online or their public transport travel expenses reimbursed with receipts.

## **7. Future vision**

The group will co-produce how to evolve over time, working with feedback from members, researchers and the PPIE Advisory Board, to address the changing needs of the PSRC. The PSRC will work with RPG members and local communities to ensure the process of appointing future members is appropriate, and people are sufficiently supported to be active, integrated members (e.g. being mentored by current members).

## **Appendix 1**

### **Role description for the first phase of the Research Partners Group**

#### **Required skills and experience**

- Have knowledge and experience of the NHS, including as a patient or a carer.
- Have some experience in being involved in research e.g. as a lay partner on at least one research project or being involved in a committee that reviews research applications.
- Have some experience of how groups and committees work.
- Be able to promote the principles and values of PPIE.
- Be interested in improving patient safety and making it more focused on the needs of patients, carers and the public.
- Bring enthusiasm to the task.
- Have good communication skills.
- Be able to handle new ideas and information, and be willing to ask questions.
- Play an active part in their local community or in a relevant group or network (e.g. a charity).
- Have a commitment to continuous learning
- Be willing to work with us to develop the RPG and to improve PPIE in our research projects.
- Be willing to mentor RPG members, with less experience of involvement in research.

N.B. The process for Phase 2 recruitment will be developed with current RPG members.

## Appendix 2

### Example of how a small project meeting of the RPG works

A research team plans to evaluate the use of a home medication box which will hold a month's supply of drugs for patients with advanced Parkinson's. Members of the RPG will review the PPIE plans of the project with the research team. They will check whether patients with advanced Parkinson's and the carers of such patients:

- Have contributed to the study design
- Will be involved at relevant stages of the research cycle, for example helping to:
  - Recruit suitable patients and carers
  - Obtain consent
  - Collect and analyse data
  - Disseminate the findings
  - Consider whether, and if so what, further research is required in this area.

**Outcome 1:** RPG members consider that the project has a sound plan for PPIE and appropriate lay partners are already involved.

- No changes to the project required.

**Outcome 2:** RPG members have concerns with the lack of PPIE in the project so far and the plans for PPIE. The RPG suggests some changes. For example:

RPG concerned that	RPG suggests
Patients and carers were not involved in the design of the study	To hold a workshop as soon as possible to discuss the design of the project with appropriate patients and carers, before the team applies for ethical approval
Patients who the team have begun discussions with have early Parkinson's with relatively mild symptoms	To add two patients with advanced Parkinson's and their carers to the steering group throughout the project, as they are the appropriate lay partners for this project
The team are not offering to remunerate and reimbursement to lay partners	To remunerate lay partners £20 per hour, as per Imperial's policy
The team are finding it difficult to find appropriate lay partners	The team contact a charity that supports people with advanced Parkinson's and a Parkinson's nurse, who could be asked to advertise the involvement opportunity to their networks
The team are not sure how to advertise involvement opportunities	The team looks at the Research Design Service PPI Handbook <sup>4</sup> , with a Plain English template letter and suggest they advertise it on the <a href="http://www.peopleinresearch.org">www.peopleinresearch.org</a> website and on posters in their local area
There are no plans for patients and carers to help with the dissemination of the results	That lay partners could co-author an academic paper, co-present at a conference, write an article for the Parkinson's charity newsletter and hold a free event with all the participants of the research study and their families to tell them the findings

<sup>4</sup> [https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS\\_PPI-Handbook\\_2014-v8-FINAL-11.pdf](https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf)

### Appendix 3

#### Glossary:

<b>Patient and public involvement in research</b>	Research being carried out <b>‘with’</b> or <b>‘by’</b> patients, carers and members of the public in partnership with researchers and clinicians rather than research being <b>‘to’</b> , <b>‘about’</b> or <b>‘for’</b> them <sup>5</sup>
<b>Public engagement</b>	Refers to information and knowledge about research being shared and discussed with patients and the public, ideally as a two-way conversation e.g. events and social media
<b>Patient/ Service user</b>	A patient or service user is someone who is currently receiving healthcare or has recently completed an episode of care
<b>Carer</b>	Someone who cares for a person with health and/or social care needs, in this context usually an informal carer (family or friend) rather than a paid carer
<b>The public</b>	A member of the public or citizen, includes potential users of the healthcare system and carers
<b>Public partner</b>	Someone who represents the views of patients, carers or members of the public. They are working in partnership with professionals in a specific context. They do not represent the views of healthcare professionals or academics. They may have a particular role or task in different circumstances e.g. a member of a Board.
<b>Clinician/ Healthcare professional</b>	A clinician or healthcare professional e.g. GP, specialist doctor or nurse, who has direct contact in caring for patients
<b>Researcher/ Academic</b>	A research or academic, someone who is currently carrying out research, in this context: health
<b>PSRC Executive Board</b>	The key oversight body for the PSRC. It will meet twice a year and receive regular updates. It will provide feedback on outputs and provide input on future plans and strategic direction. It includes: the PSRC Director, the ICHNT Medical Director, the Vice Dean of the ICL Faculty of Medicine for research, a representative from NHS Improvement and the Co-Chairs of the PPIE Advisory Board
<b>PSRC Management Board</b>	Responsible for overall management of the PSRC and for major operational decisions and direction. It includes: the PSRC Director, Centre Manager, Scientific Theme Leads and PPIE Manager
<b>Remuneration</b>	Patient, carer and public members are paid for their attendance to meetings in line with national guidelines and are reimbursed for their travel costs
<b>Secretariat</b>	The person or group who support the administration of a group e.g. circulating papers and taking minutes