

NIHR North West London Patient Safety Research Collaboration

Patient and Public Involvement and Engagement Advisory Board

Terms of Reference v9 – March 2023

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:

1. **Theme 1** - Influencing patient and healthcare worker behaviours to optimise safety and minimise risk.
2. **Theme 2** - Developing and testing technologies that enhance medication safety.
3. **Theme 3** - Using integrated care data to address patient safety challenges.
4. **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 existing PSTRC PPIE Advisory Board will roll into the new five years of funding and become the PSRC PPIE Advisory Board. It is co-chaired by a public partner (a patient or carer representative) and the PSTRC PPIE Academic Champion and will report directly to the PSRC Executive Board. These Terms of Reference will be kept under review. The PPIE Advisory Board will promote the values set out by NIHR¹, including: respect, support, transparency, responsiveness, fairness of opportunity, openness, clarity and accountability.

2. Purpose of the Board

The PPIE Advisory Board will have three major functions:

- To guide and oversee the implementation and further development of the PPIE strategy across the PSRC and advise the PSRC Executive Board on PPIE matters, to help to ensure that:
 - The PSRC is involving and engaging a diverse group of patients, carers and the public.
 - PPIE is embedded across the PSRC.

¹ <https://www.invo.org.uk/wp-content/uploads/2017/08/Values-Principles-framework-Jan2016.pdf>

- All PSRC researchers have the training and resources to be able to effectively carry out PPIE.
- All patients, carers and the public who are involved are properly supported, rewarded and remunerated as per NIHR's guidance².
- Impact measures are defined to assess the implementation of the strategy and to capture the impact of PPIE.
- Learning about PPIE is shared through links with other research programmes and organisations.
- The PSRC is effectively communicating about its research and PPIE programme, including opportunities for patients, carers and the public to be engaged and involved.
- To provide assurance through updates to the PSRC Executive Board that:
 - Patients, carers and the public are appropriately engaged and involved in the PSRC research programme.
 - Action is taken when any problems are identified.
- To oversee the work programme of the Research Partners Group (RPG)³.

The PSRC budget, including the resources for PPIE, is overseen by the PSRC Executive Board, and managed by the PSRC Centre Manager. The PPIE Advisory Board will not hold any budgetary responsibilities.

3. Membership

See Appendix 1 for full membership. The PPIE Advisory Board will be made up of up to 10 members in total, including:

- Three public partners (one to be drawn from the RPG) – including a non-RPG public co-chair
- PSRC PPIE Academic Champion – the co-chair
- At least one other PSRC Theme Lead (other than the co-chair) representing researchers from the PSRC
- Two experts in PPIE from other organisations
- PSRC PPIE Lead – the secretariat
- PSRC Centre Manager
- PSRC PPIE Officer – the secretariat

One of the existing members must also be a clinician from within the Imperial Academic Health Science Centre.

Members will be expected to:

² <https://www.nihr.ac.uk/documents/centre-for-engagement-and-dissemination-recognition-payments-for-public-contributors/24979>

³ The Research Partners Group is a diverse group of patients, carers and the public who will advise researchers and clinicians on their research ideas and activities

- Know which role above they are fulfilling.
- Promote the values set out by NIHR (see reference 1), including: confidentiality, respect, support, transparency, responsiveness, fairness of opportunity, openness, clarity and accountability.
- Represent their views as individuals with an interest and expertise in PPIE, not those of their organisations.
- Preferably attend in person, and otherwise dial in to meetings.
- Respond within agreed timelines.

To note:

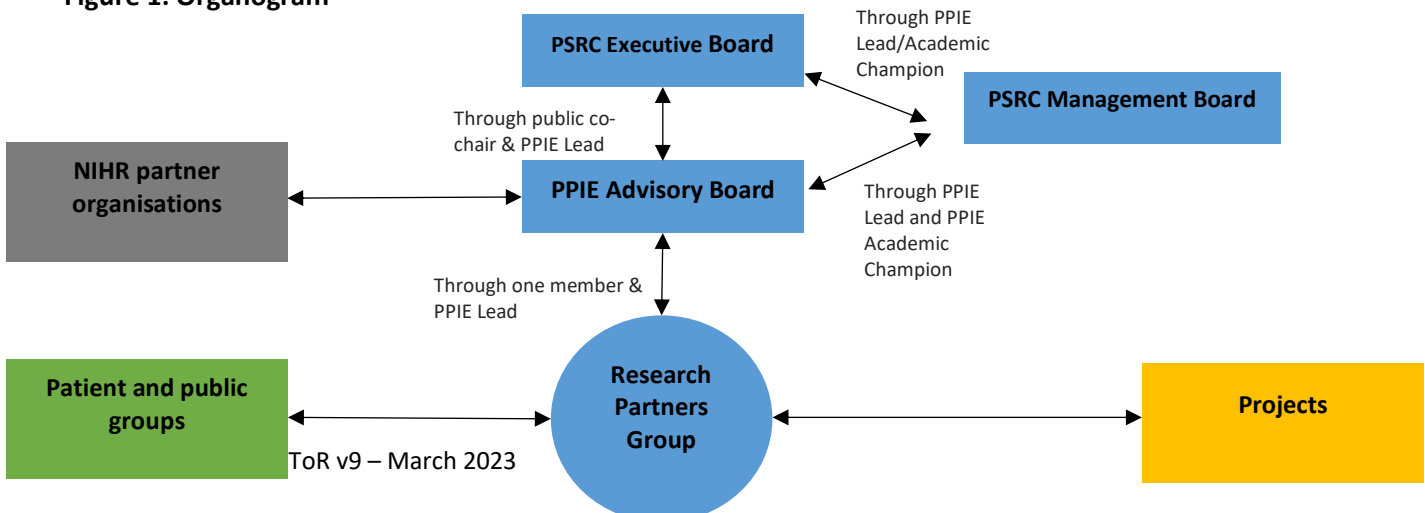
- The PSRC researcher and clinical representatives will rotate at the mid-point (2.5-3 years), with at least one theme lead remaining for continuity, unless otherwise agreed by the co-chairs.
- Three public partners were invited to serve on the PPIE Advisory Board (one from the RPG).
- To ensure there is a link between the RPG and the Board, another RPG member will be invited to the PPIE Advisory Board meeting if the RPG member (Sandra) cannot attend. Also, to invite the non-RPG members of the Board to one RPG meeting a year.
- Members will be invited to serve on the Board for one year in the first instance, renewable for two further periods of two years, subject to review.
- If members cannot attend, it is not expected that alternates will attend in their place, unless in specific circumstances, as agreed with the co-chairs.

4. Accountability

See Figure 1 organogram below. The PPIE Advisory Board will:

- Promote the values set out by NIHR (see reference 1).
- Report directly to the PSRC Executive Board through the public co-chair and the PPIE Lead.
- Provide updates to PSRC Management Board through the PPIE Lead.
- Be responsible for the RPG (one member of the RPG and the PPIE Lead will represent the RPG to the PPIE Advisory Board).

Figure 1: Organogram



5. Meetings

- The PPIE Advisory Board will usually meet twice a year at the St Mary's Hospital campus, Paddington or online.
- Meetings are expected to last up-to two hours.
- The secretariat will organise the meetings; circulate papers at least one working week before the meeting; take minutes; and provide general support to the PPIE Advisory Board.
- All views will be minuted and minutes will act as an audit trail of the discussions and decisions that were made. All members will have an opportunity to comment on draft minutes and final minutes will be signed by the co-chairs at the subsequent meeting.
- Agenda items for future meetings will be discussed at the meeting. Items can be suggested by members and will be coordinated by the secretariat.
- External speakers may be invited to meetings.

6. Remuneration and expenses

- All members can have their travel expenses reimbursed.
- Public partners will be remunerated as per the Centre for Engagement and Dissemination guidelines (see reference 2).

7. Review

- The PPIE Advisory Board will keep its Terms of Reference under review annually. The format, frequency and arrangements for meetings will be reviewed on an annual basis.
- At any point, members can give feedback to the PPIE Lead (or a different contact, if more appropriate) to improve the ways of working. It is also noted that members can ask for feedback from the PPIE Lead or the Co-Chairs. If sensitive matters arise, the Co-Chairs will discuss a way forward with the PPIE Manager.

8. Sharing of information and resources

- Papers will be circulated by email.

Appendix 1:

PPIE Advisory Board Members:

Charles Boucher	Patient, Carer and Public Representative
Linda Burridge	PPIE Manager, Imperial College NHS Healthcare Trust
Jodie Chan	PSRC PPIE Officer (Secretariat)

Dorota Chapko	PPEI Theme Lead, Applied Research Collaboration Northwest London (NIHR ARC NWL)
Eleni Daniels	PSRC Centre Manager
Bryony Dean Franklin	PSRC Director and Professor of Medication Safety at UCL School of Pharmacy (Academic Co-Chair)
Sandra Jayacodi	Patient, Carer and Public Representative (RPG member)
Anna Lawrence-Jones	PSRC PPIE Lead (Secretariat)
Sarah Kinsella	Patient, Carer and Public Representative (Public Co-Chair)
Olga Kostopoulou	PSRC Theme Lead
Kay Ollivierre	Patient, Public and Professional Involvement Lead, Imperial College Health Partners

Appendix 2:

Glossary:

Patient and public involvement in research	Research being carried out ‘with’ or ‘by’ patients, carers and members of the public in partnership with researchers and clinicians rather than research being ‘to’ , ‘about’ or ‘for’ them ⁴
Public engagement	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
Patient/ Service user	A patient or service user is someone who is currently receiving healthcare or has recently completed an episode of care
Carer	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
The public	A member of the public or citizen, includes potential users of the healthcare system and carers
Public partner	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.
Clinician/ Healthcare professional	A clinician or healthcare professional e.g. GP, specialist doctor or nurse, who has direct contact in caring for patients
Researcher/ Academic	A research or academic, someone who is currently carrying out research, in this context: health

PSRC Executive Board	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
PSRC Management Board	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
Remuneration	Patient, carer and public members are paid for their attendance to meetings in line with national guidelines and are reimbursed for their travel costs
Secretariat	The person or group who support the administration of a group e.g. circulating papers and taking minutes