NIHR Imperial Patient Safety Translational Research Centre
Patient and Public Involvement and Engagement Advisory Board
Terms of Reference v4 – September 2017

1. Background

The National Institute for Health Research (NIHR) Imperial Patient Safety Translational Research Centre (PSTRC) is a partnership between Imperial College Healthcare NHS Trust (ICHNT) and Imperial College London (ICL). It has been funded by the NIHR for 10 years and has recently been awarded a further £7 million from NIHR for the next five years, through a competitive bid process.

The PSTRC 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 in themes such as: safety information and data; design and technology; involving patients/carers/family members; teamwork; safer systems; diagnosis; economics and policy.

Patients, carers and members of the public are central to our work, and with their input we have recently reviewed our Patient and Public Involvement and Engagement (PPIE) strategy of which the PPIE Advisory Board is a core part.

The PSTRC PPIE Advisory Board is established to cover the 5 year funding period to July 2022. It will be Co-Chaired by a lay partner (drawn from patient, carer and public members) and the PSTRC PPIE Researcher Champion; will ensure implementation and further development of the PPIE strategy; will establish and oversee the work of the Research Partners Group; and will report directly to the PSTRC Executive Board. These Terms of Reference will be kept under review. The PPIE Advisory Board will promote the values set out by INVOLVE1 and 4PI2, 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 PSTRC and advise the PSTRC Executive Board on PSTRC matters, to help to ensure that:
  - The PSTRC is involving and engaging a diverse group of patients, carers and the public.
  - PPIE is embedded across the PSTRC.
  - All PSTRC 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 recognised, rewarded and remunerated as per the PSTRC’s Patient and Public Recognition, Rewards and Remuneration policy3.
  - Impact measures are defined to assess the implementation of the strategy and to measure the impact of PPIE.

3 NIHR Imperial PSTRC Recognition, Rewards and Remuneration Policy - January 2017
Learning about PPIE is shared through links with other research programmes and organisations.

The PSTRC 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 regular reports to the PSTRC Executive Board that:
  - Patients, carers and the public are appropriately engaged and involved in the PSTRC research programme.
  - Action is taken when any problems are identified.

- To oversee the establishment and the work programme of the Research Partners Group (RPG)\(^4\).

The PSTRC budget, including the resources for PPIE, is overseen by the PSTRC Executive Board, and managed by the PSTRC 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 12 members in total, including:

- Three lay partners (drawn from the RPG in due course) – John Norton will Co-Chair the PPIE Advisory Board for the first year.
- The PSTRC PPIE Researcher Champion, Steph Archer – who will Co-Chair the PPIE Advisory Board.
- Two PSTRC Theme Leads representing researchers from the PSTRC.
- One clinician from within the Imperial Academic Health Science Centre.
- Four experts in PPIE from other organisations.
- The PSTRC PPIE Manager, Anna Lawrence-Jones - who will also act as the secretariat.

In addition the Senior Programme Manager Patient and Public Involvement, NIHR Central Commissioning Facility, will be invited as an observer occasionally.

Members will be expected to:

- Know which role above they are fulfilling.
- Promote the values set out by INVOLVE\(^5\) and 4Pi\(^6\), including: 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.
- Sign a confidentiality agreement on joining the group\(^7\).

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\(^4\) 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


\(^7\) This is because there may be sensitive information discussed including patient information and new research ideas
To note:

- PSTRC researcher and clinical representatives will rotate on an annual basis, unless otherwise agreed by the Co-Chairs.

- Initially, three interim lay partners have been invited to serve on the PPIE Advisory Board until the RPG is established and members can be appointed from this.

- Sheila Adam, PSTRC external consultant, will initially Co-Chair the PPIE Advisory Board, whilst Steph Archer is on maternity leave (from August 2017).

- Members will be invited to serve on the board for one year in the first instance, renewable for two further periods each 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

The PPIE Advisory Board will:

- Promote the values set out by INVOLVE\(^8\) and 4Pi\(^9\), including: respect, support, transparency, responsiveness, fairness of opportunity, openness, clarity and accountability.

- Report directly to the PSTRC Executive Board through the Co-Chairs (Anna Lawrence-Jones will represent Steph Archer on the Executive Board, whilst on maternity leave).

- Provide updates to PSTRC Management Board through the PPIE Manager.

- Be responsible for the RPG (three members of the RPG will be members of the PPIE Advisory Board).

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5. Meetings

- Initially, the PPIE Advisory Board will meet every quarter at the St Mary’s Hospital campus, Paddington.
- Meetings are expected to last around 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.
- Lay partners will be remunerated as per the PSTRC’s Recognition, Rewards and Remuneration Policy\textsuperscript{10}.

7. Review

- The PPIE Advisory Board will keep its Terms of Reference under review during the first year and 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 Manager (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 Manager 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 and, in due course, a safe portal with documents will be shared with the group and owned by the secretariat.

\textsuperscript{10} NIHR Imperial PSTRC’s Recognition, Rewards and Remuneration Policy - January 2017
Appendix 1:

PPIE Advisory Board Members:

<table>
<thead>
<tr>
<th>Name</th>
<th>Role and Affiliation</th>
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<tbody>
<tr>
<td>Sheila Adam</td>
<td>PSTRC Consultant (Co-chair)</td>
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<tr>
<td>Steph Archer</td>
<td>PSTRC Research Fellow (Co-chair)</td>
</tr>
<tr>
<td>Paul Aylin</td>
<td>PSTRC Theme Lead and Professor of Epidemiology and Public Health at Imperial College</td>
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<tr>
<td>Charles Boucher</td>
<td>*Interim Patient, Carer and Public Representative</td>
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<tr>
<td>Linda Burridge</td>
<td>PPIE Manager, Imperial College NHS Healthcare Trust</td>
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<tr>
<td>Bryony Dean Franklin</td>
<td>PSTRC Theme Lead and Professor of Medication Safety at UCL School of Pharmacy</td>
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<tr>
<td>Sandra Jayacodi</td>
<td>*Interim Patient, Carer and Public Representative</td>
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<tr>
<td>Anna Lawrence-Jones</td>
<td>PSTRC PPIE Manager (Secretariat)</td>
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<tr>
<td>Rachel Matthews</td>
<td>PPIE Theme Lead, Collaborative for Leadership in Applied Health Research and Care Northwest London (CLAHRC)</td>
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<tr>
<td>Erik Mayer</td>
<td>PSTRC Theme Lead and Clinical Senior Lecturer in Urology at Imperial College</td>
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<tr>
<td>John Norton</td>
<td>*Interim Patient, Carer and Public Representative</td>
</tr>
<tr>
<td>Kay Ollivierre</td>
<td>Patient, Public and Professional Involvement Lead, Imperial College Health Partners</td>
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<tr>
<td>Kristina Staley</td>
<td>Director, TwoCan Associates</td>
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*Charles Boucher, Sandra Jayacodi and John Norton have agreed to act as interim Patient, Carer and Public Representatives until the Research Partnership Group is established and three representatives will be appointed from this.*

Appendix 2:

Glossary:

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>Patient and public involvement in research</td>
<td>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’ them¹¹</td>
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<td>Public engagement</td>
<td>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</td>
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<td>Patient/ Service user</td>
<td>A patient or service user is someone who is currently receiving healthcare or has recently completed an episode of care</td>
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<td><strong>Carer</strong></td>
<td>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</td>
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<td><strong>The public/ Citizen</strong></td>
<td>A member of the public or citizen, includes potential users of the healthcare system and carers</td>
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<td><strong>Lay partner</strong></td>
<td>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.</td>
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<tr>
<td><strong>Clinician/ Healthcare professional</strong></td>
<td>A clinician or healthcare professional e.g. GP, specialist doctor or nurse, who has direct contact in caring for patients</td>
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<tr>
<td><strong>Researcher/ Academic</strong></td>
<td>A research or academic, someone who is currently carrying out research, in this context: health</td>
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<td><strong>PSTRC Executive Board</strong></td>
<td>The key oversight body for the PSTRC. 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 PSTRC 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</td>
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<tr>
<td><strong>PSTRC Management Board</strong></td>
<td>Responsible for overall management of the PSTRC and for major operational decisions and direction. It includes: the PSTRC Director, Centre Manager, Scientific Theme Leads and PPIE Manager</td>
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<tr>
<td><strong>Remuneration</strong></td>
<td>Patient, carer and public members are paid for their attendance to meetings in line with national guidelines and are reimbursed for their travel costs</td>
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<tr>
<td><strong>Secretariat</strong></td>
<td>The person or group who support the administration of a group e.g. circulating papers and taking minutes</td>
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