NIHR Imperial Patient Safety Translational Research Centre
Patient and Public Involvement and Engagement
Research Partners Group: First Phase
Terms of Reference – January 2018 v2

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 was awarded a further £7 million from NIHR from 1 August 2017 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 (including patients, carers and the public; other academic institutions; and industry), it carries out research across six themes:

1. Safer systems across the continuum of care
2. Partnering with patients for safer care
3. Avoiding deterioration and delays in the care of patients with complex needs
4. Enhancing the safety of medication and technology
5. Improving diagnostic accuracy and decision-making
6. Ensuring value for money in patient safety.

Patients, carers and 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 Research Partners Group (the RPG) is a core part. The RPG will be established to cover the five year funding period from August 2017 to July 2022. It will help to ensure that researchers are involving patients, carers and the public in all stages of the research cycle. These Terms of Reference and the role of the RPG will be reviewed on at least an annual basis by the RPG and PPIE Advisory Board1.

The RPG will promote the values set out nationally by INVOLVE2 and 4Pi3, 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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1 PSTRC PPIE Advisory Board: The membership includes three lay partners (patients, carers, and the public drawn from the RPG), researchers, clinicians and PPIE experts to guide and oversee the implementation and further development of the PPIE strategy across the PSTRC
Confidentiality – e.g. to maintain the privacy of personal experiences and safeguard intellectual property.

Although the intention is to recruit up to 30 members of RPG, we have begun by appointing eleven members, all bringing experience of and expertise in PPIE in health research. The reasons for this are two-fold. First, in order to ensure that all projects starting from 1 August 2017 can be reviewed by experienced RPG members without any delay to the researchers. Second, to have an expert cadre of RPG members to co-produce the full RPG.

2. Purpose of the first phase of the RPG

The purpose of the first phase of the RPG will be:

- To scrutinise the plans for PPIE in all new projects within the PSTRC 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
- 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 first phase of the RPG and develop a larger 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, if there is a research project where an RPG member would make a particularly suitable lay partner, then this can be considered, as long as it does not impact their availability to be part of the RPG. The PPIE Manager will maintain a register of all PSTRC projects which have been reviewed by RPG, to ensure that we are involving a diverse group of patients, carers and members of the public.

3. Membership

Members have been appointed through an application process in July 2017 including a face-to-face interview with members of the PPIE Advisory Board. Each panel included a lay partner. Please see the role description for details of the skills and experience required in this first round of recruitment (Appendix 1).

The members from 1 August 2017 are:

- Charity Gondwe
- Maurice Hoffman
- Sandra Jayacodi
- Jill Lloyd
- John McNeill
- Helen Miller
- John Norton
These initial appointments are for one year in the first instance, renewable for one or two further periods of 2 years subject to review. It is not expected that alternates will usually attend meetings.

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

The PPIE Manager 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 and decisions, and collating feedback and learning
- Organising induction, training, development and support for RPG members.

It is envisaged that:

- Meetings will take place in central London
- The RPG will meet 6 monthly as a full group for a few hours business/development session
- A smaller number of RPG members (between 3-6 members) will meet on an approximately monthly basis with researchers to discuss individual research projects:
  - The PPIE Manager will convene these meetings and members can sign up to the meetings at their convenience; they are expected to attend on average 1 in 2 meetings i.e. up to 6 meetings per annum
  - Prior to the meeting, two lead speakers will be nominated by the PPIE Manager to lead the discussion with the researcher at the meeting; RPG members will be invited to say whether there are specific projects which they would like to review, and whether they would be willing to take the lead in doing so
  - The researcher will present for 10 minutes on their project; there will be 5 minutes for questions for clarification and approximately 20 minutes for discussion (led by the lead speakers); then 10 minutes for summing up and agreement of key recommendations.
- 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 RPG and its Terms of Reference will be reviewed at least on an annual basis by the RPG and the PPIE Advisory Board. The first review is planned for October 2018, 12 months after the first full meeting of the RPG.

The PPIE Advisory Board, which will include three members of the RPG, will oversee the work of the RPG. One of these three members will co-chair the PPIE Advisory Board (with the PSTRC Researcher

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4 Each lead speaker will read the project documentation before the meeting with the researcher, and then lead the discussion. They will set out their views about the proposal first, and pose any questions to the researcher. After this they will invite the other members of the RPG to give their views, and the researcher to respond.
Champion). The co-chairs of the PPIE Advisory Board will report on PPIE progress to the Executive Board (who meet six monthly), and to the PSTRC Management Board (via the PPIE Manager).

In the interim, three lay partners have agreed to serve on the PPIE Advisory Board until the RPG is fully established. Members will then be invited to express an interest in one of the three places for patients, carers and the public on the PPIE Advisory Board.

At any point, members of the RPG can ask to receive or give feedback to the PPIE Manager (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 of PSTRC structure

6. Remuneration and expenses

All members will have their public transport travel expenses reimbursed, and will be remunerated £20 per hour, as per the PSTRC Patient and Public Recognition, Rewards and Remuneration Policy4.

7. Future vision

The RPG will “launch and learn”, “learning by doing” to co-produce the full RPG with the PSTRC. The group will evolve over time working with feedback from members and researchers. Over the next 12 months we will look to expand the RPG to up-to 30 patients, carers and members of the public (by Winter 2018). The membership will continue to reflect the diversity of our local community.

We intend to reach out to and recruit members with less experience of working in this type of setting, and who may be seldom heard. The PSTRC will work with RPG members and local communities to ensure the application process is appropriate and people are sufficiently supported to apply and to be active, integrated members.

4 NIHR Imperial PSTRC Patient and Public Recognition, Rewards and Remuneration Policy, January 2017
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.

A proportion of those appointed in Phase 2 may not have previous experience in PPIE in health research to widen community involvement. If this is the case the PSTRC will ensure that new members each have a development plan, which may include mentoring by a more experienced RPG member.
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:

<table>
<thead>
<tr>
<th>RPG concerned that</th>
<th>RPG suggests</th>
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<tbody>
<tr>
<td>Patients and carers were not involved in the design of the study</td>
<td>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</td>
</tr>
<tr>
<td>Patients who the team have begun discussions with have early Parkinson’s with relatively mild symptoms</td>
<td>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</td>
</tr>
<tr>
<td>The team are not offering to remuneration and reimbursement to lay partners</td>
<td>To remunerate lay partners £20 per hour, as per Imperial’s policy</td>
</tr>
<tr>
<td>The team are finding it difficult to find appropriate lay partners</td>
<td>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</td>
</tr>
<tr>
<td>The team are not sure how to advertise involvement opportunities</td>
<td>The team looks at the Research Design Service PPI Handbook5, 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</td>
</tr>
<tr>
<td>There are no plans for patients and carers to help with the dissemination of the results</td>
<td>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</td>
</tr>
</tbody>
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## Appendix 3

### Glossary

<table>
<thead>
<tr>
<th>Patient and public involvement in research</th>
<th>Research being carried out <em>with</em> or <em>by</em> patients, carers and members of the public in partnership with researchers and clinicians rather than research being <em>to</em>, <em>about</em> or <em>for</em> them.</th>
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<tbody>
<tr>
<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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<tr>
<td>Patient</td>
<td>Or service user is someone who is currently receiving healthcare or has recently completed an episode of care.</td>
</tr>
<tr>
<td>Carer</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).</td>
</tr>
<tr>
<td>Member of the public/Citizen</td>
<td>Or citizen, includes potential users of the healthcare system and carers.</td>
</tr>
<tr>
<td>Lay partner</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.</td>
</tr>
<tr>
<td>Clinician/healthcare professional</td>
<td>A healthcare professional e.g. GP, doctor or nurse, who has direct contact with patients.</td>
</tr>
<tr>
<td>Researcher/academic</td>
<td>An academic, someone who is currently carrying out research, in this context: health.</td>
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<tr>
<td>PSTRC Executive Board</td>
<td>The key oversight body for the Centre. 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. Meets six monthly.</td>
</tr>
<tr>
<td>PSTRC Management Board</td>
<td>Responsible for overall management of the Centre and for major operational decisions and direction. It includes: the PSTRC Director, Centre Manager, Scientific Theme Leads and PPIE Manager. Meets bi-monthly.</td>
</tr>
<tr>
<td>Research ethics</td>
<td>The name given to the code of practice based on a set of decent, fair and moral principles and guidelines that researchers should abide by. Research that will seek to gain personal confidential information or to test a new intervention on people must get ethical approval from a Research Ethics Committee (REC).</td>
</tr>
<tr>
<td>Secretariat</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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