Yorkshire and Humber Patient Safety Translational Research Centre

Patient and Public Involvement and Engagement Strategy 2017−2019
This document sets out the Patient and Public Involvement and Engagement (PPIE) Strategy for the NIHR Yorkshire and Humber Patient Safety Translational Research Centre (Yorkshire and Humber PSTRC) between August 2017 and December 2019. The strategy has been co-developed with our PPIE lay leaders for the centre, researchers from across the themes and partner organisations for the centre. This plan will be monitored and formally reviewed annually by the PPIE strategy development group.

1.0 Background

The overall vision of the National Institute for Health Research (NIHR) is to improve the health and wealth of the nation through research. The NIHR PSTRC scheme was set up in 2007, with the aim of bringing advances from basic research related to patient safety into an applied health services research setting (NIHR, 2017). PSTRCs in England include Imperial PSTRC (College Healthcare NHS Trust and Imperial College London) and the Greater Manchester PSTRC (Salford Royal NHS Foundation Trust and the University of Manchester).

The Yorkshire and Humber PSTRC is the newest centre, established in August 2017 and represents a partnership between Bradford Teaching Hospitals NHS Foundation Trust and the University of Leeds, working collaboratively with the University of Bradford. The aim of the Yorkshire and Humber PSTRC is to conduct high quality research that makes patient care better and safer. Awarded £3 million over five years, the centre focuses on the following four research themes:

- The central role of patients and their carers
- Creating workplaces that people want to work in
- The safer use of medicines
- Using digital technology to improve safety
2.0 Purpose of Patient and Public Involvement and Engagement – Yorkshire and Humber PSTRC

A central aspect of the work conducted in Yorkshire and Humber PSTRC is a strong commitment to active patient and public involvement and engagement throughout the research process, from early development of research ideas to dissemination activities (See Figure 1). This is to ensure that patients, carers and the public help to shape the research conducted within the Centre.

Figure 1: The research process and potential opportunities for PPIE (adapted from NIHR, 2018)
We are guided by the NIHR INVOLVE definitions of public involvement, participation and engagement activities. This considers differences between public involvement in research which is research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them (INVOLVE, 2012). Participation considers people taking part in research studies and engagement activities include providing and sharing information and knowledge about research with the public.

2.1 Aim and objectives

We aim to meaningfully involve and engage patients and the public in the research conducted within the PSTRC. To achieve our overarching aim we will:

- Actively involve patients, carers and the public in the research conducted within the Centre, ensuring that opportunities are accessible to all and meet research needs
- Provide a mutually supportive and respectful environment for patients, carers and the public and researchers to develop collaborative relationships
- Develop PPIE skills, knowledge and experience for researchers, patients, carers and the public working with the Yorkshire and Humber PSTRC
- Provide a way for PPIE members and groups to contribute to research governance and leadership issues
- Capture and report examples of PPIE impact within the Yorkshire and Humber PSTRC
- Work collaboratively with partner and key organisations in order to optimise opportunities to engage with members of the public and disseminate research findings
- Contribute towards the evidence base for quality PPIE in translational health service research

Each objective is expanded below:

Objective 1: Actively involve patients, carers and the public in the research conducted within the centre, ensuring that opportunities are accessible to all and meet research needs

To meet this objective we will:

- Recruit PPIE lay leaders to work within research and across research themes
- Create a Citizen Participation Group (CPG) to engage with the local population and develop participation and engagement activities to meet the on-going needs of research themes and projects
- Provide patient and public involvement opportunities that reach people and groups related to research needs
- Explore the best ways to engage patients, carers and the public to improve the way research is conducted and disseminated
Objective 2: Provide a mutually supportive and respectful environment for patients, carers, the public and researchers to develop collaborative relationships

To meet this objective we will:

- Provide dedicated support for all stakeholders via a PPIE leader for the Centre
- Develop terms of references for PPIE groups to ensure a respectful partnership between all stakeholders
- Recognise people as individuals who have strengths and preferences, in order to support personalisation within the context of a health research setting

Objective 3: Work collaboratively with partner and key organisations in order to optimise opportunities to engage with members of the public and disseminate research findings

To meet this objective we will:

- Develop ways of communicating in a timely and responsive manner with PPIE groups within the centre
- Explore and expand existing partnerships with local and regional community groups
- Capitalise on the experience of existing PPIE knowledge and experience with current and existing networks and individuals within the centre, i.e. PPIE lay leaders, Yorkshire Quality and Safety Research group patient panel
- Use plain language to communicate with patients, carers and the public in a timely and accessible way as guided by the NHS England Patient and Public Participation and Insight Group, 2006
- Work with PPIE groups to help develop a language and understanding about the work being carried out within the centre for the public
- Actively involve PPIE lay leaders with grant applications and writing for publication, dissemination activities
- Develop co-production working practices between research teams and PPIE groups

Objective 4: Develop PPIE skills, knowledge and experience with and for patients, carers and the public working with Yorkshire and Humber PSTRC research teams

To meet this objective we will:

- Provide accessible and relevant training opportunities for PPIE lay leaders, the CPG and Q&S patient panel
- Provide opportunities for PPIE groups to share skills, knowledge and experience within and across themes and other PSTRCs
Objective 5: Provide a way for PPIE members and groups to contribute to research governance and leadership issues

To meet this objective we will:

- Attend and verbally report to the PSTRC executive group and advisory board as required
- Provide opportunities to feedback experiences concerns, informally and formally through the PPIE research lead
- Co-produce the NIHR annual report for PPIE activities
- Representatives from all the PPIE groups to meet on a quarterly basis to review and monitor progress and discuss any concerns or issues that have been raised with the PPIE research lead.

Objective 6: Capture, identify and report examples of PPIE impact

To meet this objective we will:

- Develop an activity tracker for PPIE lay leaders to track and monitor progress
- Formally record PPIE activities
- PPIE lay leader to assess PPIE activities undertaken at an individual level with PPI research lead on a three monthly basis
- Use the NIHR national standards (NIHR, 2018) for public involvement to assess the success of PPIE plans and as improvement measures

Objective 7: Contribute towards the evidence base for quality PPIE in translational health service research

To meet this objective we will:

- Contribute to the design and implementation of a formative evaluation of PPIE impact
- Co-produce, write and publish impact findings across a variety of ways, such as, peer-reviewed journals, newsletters, blogs, social media and the PSTRC website.
- Work with other PSTRCs to develop joint dissemination plans for PSTRC PPIE activities
2.2 Programme of projects and activities

The following PPIE activities planned for the duration of the current PPIE strategy (Aug 2017- Dec 2019) are presented in Table 1. These are aligned to the aim and objectives of the strategy with an indication of milestones to provide a framework to measure achievements. The PPIE programme of activities will be reviewed at a mid-point (November 2018) in order to review planned activities and the addition of emergent PPIE opportunities and activities.

Table 1: Programme of PPIE activities and milestones

<table>
<thead>
<tr>
<th>PPIE Activity</th>
<th>Milestones</th>
<th>Measure of success</th>
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<tbody>
<tr>
<td>1 PPIE Activity</td>
<td></td>
<td>▶ Appointment of PPIE lay leads for themes&lt;br▷ Establishing CPG group&lt;br▷ Workshop series co-developed with the CPG and researchers&lt;br▷ Promote and share PPIE knowledge and experience via social media, and the Yorkshire and Humber PSTRC website</td>
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<tr>
<td>2 PPIE Activity</td>
<td></td>
<td>▶ Mapping exercise with Q&amp;S patient panel to explore networks links with relevant organisations&lt;br▷ Introducing lay leaders at a routine panel meeting&lt;br▷ Routinely tabled agenda item at the Q&amp;S meeting</td>
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<tr>
<td>3 PPIE Activity</td>
<td></td>
<td>▶ Establish CPG group&lt;br▷ Workshop series co-developed with the CPG and researchers</td>
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<td>4 PPIE Activity</td>
<td></td>
<td>▶ Record PPIE activities within themes</td>
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<td>PPIE Activity</td>
<td>Milestones</td>
<td>Measure of success</td>
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<tr>
<td>5 PPI lead attending set up stages for all 4 research themes to support PPIE lay leaders and PPIE activity development</td>
<td>April – July 2018</td>
<td>▶ Provide a way of supporting direct PPIE activity within theme</td>
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<td></td>
<td></td>
<td>▶ Formally record activities</td>
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<td></td>
<td></td>
<td>▶ Identify and plan for any PPIE training needs</td>
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<tr>
<td>Meeting with Programme managers and PPIE leads for PSTRC’s - 16 May 2018</td>
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<td>6 Development of working practice guide for PPIE members and researchers - PPIE activity tracking guidelines share with PPIE groups and research teams for feedback and amendments</td>
<td>Completed and disseminated by 30 May 2018</td>
<td>▶ Working practice document disseminated across the centre for all stakeholders</td>
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<td>▶ Make widely available on Yorkshire and Humber PSTRC website</td>
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<td></td>
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<td>▶ Shared with PSTRC’s PPIE leads</td>
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<td>7 PPIE Strategy development</td>
<td>To be completed by 31 July 2018</td>
<td>▶ Face-to-face meetings with stakeholders, PPI Lay leads, researchers and collaborating organisation</td>
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<td></td>
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<td>▶ Discussion and consensus reached to co-develop the PPIE Strategy.</td>
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<td>8 PPIE priority setting exercise with all PPIE groups</td>
<td>Autumn 2018</td>
<td>▶ to be decided</td>
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<td>9 CPG workshops - developing a common and uniform language and understanding about patient safety translational research</td>
<td>June – August 2018</td>
<td>▶ A co-produced definition of the term patient safety</td>
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<td></td>
<td>▶ Co-creation of a poem capturing public perception of patient safety</td>
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<td>10 Joint meeting with PPIE leads and Centre managers, London</td>
<td>16 May 2018</td>
<td>▶ PPIE lead and centre manager attend meeting</td>
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<td></td>
<td></td>
<td>▶ Feed back to PPIE groups</td>
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<td>11 Training event for PPIE lay leaders and Q&amp;S patient panel members</td>
<td>May 2018 – September 2018</td>
<td>▶ 2 split day course for PPIE and research - delivered by the NIHR YH CLARHC</td>
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<td>▶ May - 5 attendees from the lay leaders and Q&amp;S patient panel</td>
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<tr>
<td>PPIE Activity</td>
<td>Milestones</td>
<td>Measure of success</td>
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<td>-----------------------------------------------------------------------------------</td>
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<td>12. Further outreach work with community groups in Leeds and Bradford, responsive to research needs</td>
<td>April 2018 – Dec 2019</td>
<td>➤ To be decided</td>
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<tr>
<td>13. Exploring the feasibility of a virtual PPIE group for research theme 4</td>
<td>May – July 2018</td>
<td>➤ To be decided</td>
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<tr>
<td>14. Developing an evaluative framework to measure the impact of PPIE activities on work within the centre</td>
<td>May-July 2018</td>
<td>➤ To be decided</td>
</tr>
<tr>
<td>15. Engagement work using blogs, videos twitter (refer to communication strategy)</td>
<td>May 2018 – December 2019</td>
<td>➤ Number of blogs, posts and twitter comments delivered, consider outcomes and impact of different communication and engagement activities.</td>
</tr>
<tr>
<td>17. Public and local Communities Engagement Event</td>
<td>Sept/Oct 2018</td>
<td>➤ Science and Media Museum, Bradford,</td>
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<td></td>
<td>‘A Night at the Museum’</td>
<td>➤ Priority setting work</td>
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<td></td>
<td></td>
<td>➤ Exploring what safer care means to people and an opportunity for sharing planned work/projects within themes</td>
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2.3 Resources

2.3.1 PPI Lead and Administration Support

The Yorkshire and Humber PSTRC has a dedicated PPI lead to support the research teams and members of the public involved in work within the centre, working two and a half days a week (0.5 WTE). The purpose of this role is to support and develop PPIE activity with a focus on active involvement, participation and engagement with patients, carers and the public underpinning all the work within the centre. Administrative support for the centre is also provided.

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2.3.2 Training and support

Training needs for PPIE members will be continually assessed for the duration of the strategy in order to be responsive to on-going and new requirements.

A two day comprehensive training course run by the NIHR YH CLAHRC will be offered to PPIE groups. These are due to take place in May and September 2018.

Bespoke training may be developed to meet the needs of individuals within specific research projects.

Support will be provided by the PPIE research lead for the centre. It is the responsibility of the PPIE lead to record training provided, attended and developed.

2.3.3 Payment and recognition for public involvement

The payment structure for PPIE has been informed from current INVOLVE guidance and co-developed with the PPIE strategy development team (INVOLVE, 2018). Recognising the contributions of members of the public who are actively involved in work within the Yorkshire and Humber PSTRC is a vital aspect of PPIE in research. Everyone that is involved should be offered payment for their time and consider additional expenses, such as, meeting travel or child care costs.

The following payment structure recognises the different skills, knowledge and experience that different individuals and groups may bring to research process.
PPIE Lay Leaders

- £20.00 per hour - this includes work done outside formal meetings i.e. pre-reading for meetings, writing bids etc.
- Travel can be arranged for participants in addition to reimbursement for their time
- Reimbursement for any conferences, training or related PPIE events will be negotiated as required. Please contact PPIE Lead for support.

Citizen Participation Group members

- £20.00 per session (up to 2 hours)
- Travel costs will be met in addition to reimbursement for time

Q&S Patient Panel

- £25.00 per meeting (routine meetings every two months - YQSR PPIE budget)
- £20.00 per hour for additional PPIE activities related to the Yorkshire and Humber PSTRC work

2.4 Partners and collaborators

The Yorkshire and Humber PSTRC is collaboration between Bradford Teaching Hospitals NHS Foundation Trust, the University of Leeds and the University of Bradford. The Yorkshire and Humber PSTRC will also collaborate with the other NIHR PSTRC’s and local and regional public and community groups to help deliver the strategy.
2.5 Leadership and review

The leadership and lines of reporting for the PSTRC are illustrated in Figure 2. The PPIE lay leaders, members of the Citizen Participation group and the Quality and Safety patient panel are responsible to the PPIE research lead. The PPIE research lead is responsible to the Yorkshire and Humber PSTRC programme manager.

All PPIE groups and the PPIE research lead will be responsible for the annual report on PPIE involvement, engagement and participation work as required by the NIHR. The progress reported will be made against the agreed PPIE strategy and included changes or revisions to action plans.

The PPIE strategy will be reviewed on an annual basis with the PPIE Strategy and Monitoring group, who represent PPIE members, researchers and BTHFT within the PSTRC.

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Figure 2: PPIE structure and lines of reporting for the Yorkshire and Humber PSTRC. PPIE lay leaders and the PPIE research lead will report on patient and public involvement and engagement activities at Executive Group meetings and at the six monthly Advisory Board meetings.
2.6 Examples of impact

Examples of PPIE impact on research being conducted in the centre will be captured by the PPIE research lead via the PPIE activity tracker. This is in order to demonstrate impact for formal annual report requirements.

References


Glossary of terms

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<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>CPG</td>
<td>Citizen Participation Group</td>
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<tr>
<td>BTHFT</td>
<td>Bradford Teaching Hospitals NHS Foundation Trust</td>
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<td>NIHR</td>
<td>National Institute for Health Research</td>
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<td>PPIE</td>
<td>Patient and Public Involvement and Engagement</td>
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<td>PSTRC</td>
<td>Patient Safety Translational Research Centre</td>
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<tr>
<td>YH CLAHRC</td>
<td>Yorkshire and Humber Collaboration for Leadership in Applied Health Research and Care</td>
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<tr>
<td>YQSR</td>
<td>Yorkshire Quality and Safety Research group</td>
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