Patient and public involvement: lessons from a research project

Patient and public involvement is an integral part of healthcare service delivery, development, evaluation and research. This article reflects on how planning, organising, running and evaluating PPI in a research environment can be a positive experience, as well as an approach that can be applied to care delivery projects.

Why PPI?
The fourth principle of the NHS Constitution for England (Department of Health, 2015) requires the NHS to: “actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services”. Similarly, the National Advisory Group on the Safety of Patients in England (2013) recommends that “patients and their carers should be present, powerful and involved at all levels of healthcare organisations from wards to the boards of trusts” (Box 1).

This guidance clearly tells us that PPI will improve patient safety and that we should be doing it at all levels of care delivery. Unfortunately, PPI is often seen as too difficult and time-consuming to implement, so people tend to shy away from it or, perhaps worse, rush it in a way that works badly for all those involved (Coulter and Ellins, 2006).

However, PPI in research is no longer optional – it is essential. Funding will not be allocated to research projects if PPI is not adequately addressed. There are resources available (Box 2) to guide and support PPI in research, which can also be applied to support it in direct care settings where such guidance is lacking. Not all are healthcare-specific but their principles can be applied in any setting.

Case study
Our case study comes from an initiative that involved patients in categorising patient feedback about safety during hospital stays. This was part of a randomised controlled trial (Wright et al, 2016; Sheard et al, 2014) funded by the National Institute for Health Research (NIHR). The trial tested a system called PRASE (Patient Reporting and Action for a Safe Environment) for collecting and using patient feedback from a safety questionnaire and a patient incident reporting tool.

Over 2,000 patients took part and they generated over 1,000 patient incident reports, which were collected from 33 wards in five hospitals across three trusts. The results were communicated...
Clinical Practice

Review

Box 1. What the National Advisory Group on the Safety of Patients in England says about PPI

The patient voice should be heard and needed at all times. Patient involvement means more than simply engaging people in a discussion about services. Involvement means having the patient voice heard at every level of the service, even when that voice is a whisper. Evidence shows that patient safety improves when patients are more involved in their care and have more control. Patient involvement is crucial to the delivery of appropriate, meaningful and safe healthcare and is essential at every stage of the care cycle: at the front line, at the interface between patient and clinician; at the organisational level; at the community level; and at the national level. The patient voice should also be heard during the commissioning of healthcare, during the training of healthcare personnel, and in the regulation of healthcare services.

The goal is not for patients and carers to be the passive recipients of increased engagement, but rather to achieve a pervasive culture that welcomes authentic patient partnership – in their own care and in the processes of designing and delivering care. This should include participation in decision-making, goal-setting, care design, quality improvement, and the measuring and monitoring of patient safety. Patients and their carers should be involved in specific actions to improve the safety of the healthcare system and help the NHS to move from asking, ‘What’s the matter?’ to, ‘What matters to you?’ This will require the system to learn and practise partnering with patients, and to help patients acquire the skills to do so.


Box 2. Resources to support PPI

Resources to support PPI in healthcare research include

- NIHR PPI handbook
  Bit.ly/NIHR_PPIHandbook
- INVOLVE resources and evidence
  www.invo.org.uk
- Public Involvement Impact Assessment Framework
  piiaf.org.uk
  Bit.ly/NHSEGuidancePPI
- NHS Health Research Authority. Patient and public involvement in research and research ethics committee review. Version 2
  Bit.ly/NPSA_PPI2009

Resources to support PPI in care settings include

- NHS England ‘involvement hub’ resources
  Bit.ly/NHSEResourcesPPI
- Participation toolkit from the Scottish Health Council
  Bit.ly/ScottishPPIToolkit
- National Institute for Health and Care Excellence PPI policy
  Bit.ly/NICEPolicyPPI
- ‘Working Together’ booklet from Plymouth University
  Bit.ly/PlymouthPPI

The right experience

The NIHR (2014) PPI handbook recommends using a role description as part of the recruitment process for PPI volunteers. The NIHR offers a range of resources, evidence and templates on PPI, which are available on the INVOLVE website (www.invo.org.uk).

We complemented the role description with a simple application form and our PPI facilitator circulated them both to existing hospital volunteers, people who had previously taken part in PPI, foundation trust members and a range of community groups. Interested parties were asked to return the application form to us via email or post. We then used the role description to decide whether respondents met the requirements of the role.

In total, 10 people responded to our request for volunteers. Eight – seven women and one man – were available to come to our first meeting. The mean age among these eight volunteers was 59 years; five were white British, one was white European, one was of mixed race and one was British Pakistani; and four declared a disability.

There were many reasons why people chose to volunteer, such as: having experienced a safety incident themselves as carers or patients; wanting to make sure their trust was as safe as possible; being interested in safety generally; and wanting to use their life skills in a positive way.

Remuneration

Should PPI volunteers be paid? There is no correct answer to this question, it is up to you and your trust, but any out-of-pocket expenses (travel, parking) should certainly be refunded. Most trusts rely on voluntary participation for PPI.

As a research team, we follow the NIHR advice on budgeting for involvement (NIHR, 2013), which suggests a remuneration of...
“Communicating regularly with volunteers meant that everyone understood what they needed to do and worked hard to complete the task”

Managing expectations
We decided to hold a first meeting where we would outline our project to the volunteers and give them an opportunity to ask questions. It was made clear to them that if they decided the project was not for them, they could leave before the actual work started. We explained that, should they have any worries or concerns, they could contact us at any time via email or telephone. As a result, all parties were clear about what was expected of them from the outset. During this planning session, we showed them an animated film that gives an overview of PRASE and the incident reporting process used to generate the patient incident reports (Yorkshire and Humber Improvement Academy, 2014).

What did volunteers do?
The volunteers were asked to sort 1,155 patient incident reports and devise categories that meant something to them as patients/carers. They worked well together as a team and were extremely professional. When there was disagreement about how to categorise a patient incident report, they discussed the options, everyone was listened to, all views were respected and consensus was eventually reached. Little facilitation was required, except to clarify some of the terminology used in the patient incident reports.

How did it work for them?
All of the volunteers attended every session they had agreed to attend at the planning session. There were seven three-hour sessions in total, with each volunteer attending five sessions on average. At the end of the process, they all said they had found the experience interesting and positive. Overall, volunteers felt that the job description had been accurate and clear about what they wanted to do and the information they had received about PRASE was just right to give them a broad understanding of the research. There were no negative responses or comments.

How did it work for us?
The whole project worked well for us. Being clear and communicating regularly with volunteers meant that everyone understood what they needed to do and worked hard to complete the task. The result of the exercise is a taxonomy developed by non-health professionals that is meaningful to them and reflects their experiences.

Box 3. Quotes from volunteers about their experiences

- “I think you needed people who could give objective input, but had to be careful that your recruits were not coming with a bias towards their own negative experiences. I don’t know how you managed to do that, but you did!”
- “I think the strength was that we were a mature bunch of people, who were clearly very task orientated. This may be because we are all volunteers with the trust or with our own GP practices. The maturity (in years) was a strength, but could also be a weakness, as we probably only had one participant younger than 40, so [we] may, unwittingly, not have been as representative of service users as we might have been with some younger recruits. However, as older people make up a large percentage of service users, maybe the group was representative.”
- “It was very helpful to have some knowledge of the job before applying to do it. The job description was thoroughly explained.”
- “Variety of experiences, focused and committed people; good communication skills.”
- “The group were from all walks of life.”
- “Having a small group helped the process to work well compared to other work with the hospital where large groups have been selected.”
- “It was really amazing. Maybe because we all were doing it for the benefit of others?”
understanding of the safety of patients in the hospital environment (O’Hara, 2018), rather than the values of health professionals involved in care management (Table 1).

We were sometimes surprised by the volunteers’ choice of categories for the patient incident reports. For example, as health professionals and researchers, we might have classified delays or cancellations into a ‘lack of resources’ category, but the volunteers often put them under ‘communication’. They explained to us that they understood the unexpected could happen and there could be emergencies, and that all patients needed to be told about any delays or cancellations in a timely manner.

Another example is of a patient who was not woken to be given epilepsy medication. This was classified as a medication safety incident by our team, but was classified as ‘staff to patient communication’ by the volunteers, as they felt the nurse should have woken and communicated with the patient to administer medication.

In another instance, a radiotherapy machine, which ran slowly so that patients were always waiting for their treatment, was classified as ‘staff to patient communication’ by the volunteers because they once again felt that the delay was acceptable if someone told them about it. However, as health professionals, we might have classified this as ‘equipment failure’ or ‘delay’.

**Conclusion**

PPI should not be ignored or pushed into the ‘too-hard-to-do’ category. It can give health professionals an insight into healthcare from the patient’s perspective, which is often very different to their own.

By listening and understanding, we can adapt and develop care delivery and services that meet everybody’s needs. To do this, we must be clear about what we need and who can help us; we must also be inclusive, reflecting our local population, and be prepared to support the volunteers (Wright et al, 2016).

Box 4 summarises some of the essential rules for conducting PPI initiatives. **NT**

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<thead>
<tr>
<th>Box 4. Some essential rules for PPI</th>
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<tr>
<td>- Be very clear about what you want from your PPI initiative</td>
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<td>- Be clear about time scales and commitment</td>
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<td>- Allow for flexibility and set ground rules for all parties at the start</td>
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<td>- Get the right people for the job</td>
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<td>- Be transparent about remuneration</td>
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**Table 1. Taxonomy of patient incidents reports (n=1,155) defined using PPI**

<table>
<thead>
<tr>
<th>Rank</th>
<th>Category</th>
<th>Number of patient incident reports</th>
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<tbody>
<tr>
<td>1</td>
<td>Communication</td>
<td>251 (21.7%)</td>
</tr>
<tr>
<td>2</td>
<td>Staff issues</td>
<td>153 (13.2%)</td>
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<tr>
<td>3</td>
<td>Environment</td>
<td>141 (12.2%)</td>
</tr>
<tr>
<td>4</td>
<td>Compassion/dignity/privacy/respect</td>
<td>135 (11.6%)</td>
</tr>
<tr>
<td>5</td>
<td>Medication issues</td>
<td>114 (9.9%)</td>
</tr>
<tr>
<td>6</td>
<td>Delay</td>
<td>102 (8.3%)</td>
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<tr>
<td>7</td>
<td>Staff training</td>
<td>63 (5.5%)</td>
</tr>
<tr>
<td>8</td>
<td>Food and drink/nutrition issues</td>
<td>54 (4.7%)</td>
</tr>
<tr>
<td>9</td>
<td>Ward management</td>
<td>44 (3.8%)</td>
</tr>
<tr>
<td>10</td>
<td>Equipment and systems failure</td>
<td>32 (2.8%)</td>
</tr>
<tr>
<td>11</td>
<td>Infection risk</td>
<td>27 (2.3%)</td>
</tr>
<tr>
<td>12</td>
<td>Health and safety</td>
<td>27 (2.3%)</td>
</tr>
<tr>
<td>13</td>
<td>Repeat procedure/complication</td>
<td>11 (1%)</td>
</tr>
<tr>
<td>14</td>
<td>Not a concern</td>
<td>1 (0.09%)</td>
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</table>

**References**


Wright J et al (2016) Improving patient safety through the involvement of patients: development and evaluation of novel interventions to engage patients in preventing patient safety incidents and protecting them against unintended harm. Programme Grants for Applied Research; 435