Better public involvement for better research: putting the National Standards for Public Involvement into practice

Steven Blackburn
School for Primary, Community and Social Care, Keele University

Paula Wray & Hothan Esmael
UK Standards Partnership Team
Overview

- Background to the National Standards
- Keele INSPIRE test-bed project
- Putting the Standards into practice in studies
- Examples from the Test Beds
- Take home message
We all know why we do public involvement and why it is important.....or at least we should know?

- Accountability
- Ethical right
- Democratic right
- Adds value to research: Quality, Relevance, effectiveness
But.....how should we do public involvement?
To improve the **quality** and **consistency** of public involvement in research
UK Standards for Public Involvement

**INCLUSIVE OPPORTUNITIES:** Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

**WORKING TOGETHER:** Working together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

**SUPPORT & LEARNING:** Offer and promote support and learning that builds confidence and skills for public involvement in research.

**COMMUNICATIONS:** Use plain language for well-timed and relevant communications as part of involvement plans and activities.

**IMPACT:** Seek improvement by identifying and sharing the difference that public involvement makes to research.

**GOVERNANCE:** Involve the public in research management, regulation, leadership and decision making.
NIHR “Going the Extra Mile” recommends the development of a set of standards for public involvement.

UK Public Involvement Standards Development Partnership

UK-wide consultation on draft Standards

Draft Standards Launch & piloting phase

Standards revision

Formal launch
Pilot Sites

- Palliative and End of Life Care Research, Glasgow
- Northern Ireland Cerebral Palsy Register (NICPR), Queen’s University Belfast
- Kidney Patient Involvement Network (KPIN), Salford
- Public Programmes team, Manchester University NHS Trust
- Wales School for Social Care Research and The Centre for Ageing and Dementia Research, Swansea
- Asthma UK Centre for Applied Research, Edinburgh
- Sheffield Teaching Hospitals NHS Foundation Trust
- School for Primary Community and Social Care, Keele
- Royal College of Obstetricians and Gynaecologists’ (RCOG) Women’s Network
- Royal College of Speech and Language Therapists
INSPIRE
Implementing the National Standards for Public Involvement in Research Environments

Keele University
Audit and reflect on current practice

Implement all six National Standards

Assess improvement on the quality and visibility of public involvement

Ensure successes and learning are shared
### Audit Results

<table>
<thead>
<tr>
<th>Number</th>
<th>Standard</th>
<th>% Indicators rated High quality</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Initial Audit</td>
</tr>
<tr>
<td>4</td>
<td>Communications</td>
<td>38</td>
</tr>
<tr>
<td>5</td>
<td>Impact</td>
<td>44</td>
</tr>
<tr>
<td>6</td>
<td>Governance</td>
<td>50</td>
</tr>
<tr>
<td>1</td>
<td>Inclusive Opportunities</td>
<td>53</td>
</tr>
<tr>
<td>2</td>
<td>Working Together</td>
<td>58</td>
</tr>
<tr>
<td>3</td>
<td>Support and Learning</td>
<td>70</td>
</tr>
</tbody>
</table>

PPIE activity **not currently delivered**

PPIE activity delivered to **good level** of quality, but with **room** for improvement

PPIE activity delivered to a **high level** of quality
New resources and initiatives

**Inclusive Opportunities**
- Diversity & Inclusion Policy
- Recruitment Plan
- Good practice guide

**Working together**
- Role descriptions
- Good practice guide (TSCs, public co-applicants)
- PI Advisor role with RDS
- Co-develop PI Strategy

**Support & Learning**
- ‘RUG-Buddy’ support and mentoring
- New induction
- Introduction to email course
- Guide for supporting emotional needs

**Communications**
- Communications Plan
- Good practice guide for communication
- Improved Feedback process

**Impact**
- Brief guide for capturing impact
- Outcomes form
- Accessible annual report

**Governance**
- Reward & Recognition Policy
- Role of RUG Steering Committee letter
- TSC and public co-applicant guides
<table>
<thead>
<tr>
<th>Standards into practice</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inclusive Opportunities</strong></td>
</tr>
<tr>
<td>• Who are the intended end users of this research?</td>
</tr>
<tr>
<td>• How will you find them to involve them?</td>
</tr>
<tr>
<td>• What can you do to make it possible for people to be involved?</td>
</tr>
<tr>
<td><strong>Working Together</strong></td>
</tr>
<tr>
<td>• Are you clear about the purpose of planned involvement activities?</td>
</tr>
<tr>
<td>• Will everyone be clear about each other’s roles and how will you make decisions together?</td>
</tr>
<tr>
<td><strong>Support &amp; Learning</strong></td>
</tr>
<tr>
<td>• Will the people involved need any support (named contact in the team, etc) or training?</td>
</tr>
<tr>
<td>• Is there a budget to cover fees and expenses (including things such as carer costs where appropriate)?</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
</tr>
<tr>
<td>• How will you keep stakeholders informed about the project?</td>
</tr>
<tr>
<td>• What different methods of communication might you need to consider?</td>
</tr>
<tr>
<td>• How will public contributors feedback about their experience of being involved?</td>
</tr>
<tr>
<td><strong>Impact</strong></td>
</tr>
<tr>
<td>• What can/might change in the project and how do you intend to capture/monitor this?</td>
</tr>
<tr>
<td>• How might you learn from this experience?</td>
</tr>
<tr>
<td><strong>Governance</strong></td>
</tr>
<tr>
<td>• Do you have clear processes and policies to support the involvement?</td>
</tr>
<tr>
<td>• How are public contributors involved in decision making within your organisation/team/project?</td>
</tr>
</tbody>
</table>
Standards pilot projects – a variety of approaches
The Future of the Standards

• Improving PPIE practice, providing examples of good practice

• Supporting leadership and accountability for involvement within research organisations – ‘PPIE is everyone’s job’

• No single way of using the standards - how they are used will be influenced by many issues, such as the purpose of involvement and the amount of resources (money, people, skills) available.
Take home message

1. Don’t be afraid to use the standards – experiment and adapt to your research/project/context

2. Look for and use existing resources/materials – there are many online PPIE resources already available.

3. Seek support and advice from your organisation’s PPIE contact/team
Resources and information

• UK Standards for Public Involvement website: https://sites.google.com/nihr.ac.uk/pi-standards/home

• INVOLVE website: https://www.invo.org.uk/

• Learning for Involvement website: http://learningforinvolvement.org.uk/

• Health Research Authority – Public Involvement: https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/
Acknowledgements

The Keele INSPIRE project is funded by the National Institute for Health Research (NIHR) School for Primary Care Research (project reference 440). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Thanks to:
• The UK Partnership Development Team for their support and advice
• Carol Rhodes, PPIE Advisor at Keele University
• The Research User Group Steering Group for their great ideas, hard work and patience
• Versus Arthritis for their support of the Patient and Public Involvement and Engagement at Keele