Better public involvement for better research

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SPCR Conference: Annual Trainees’ Event
25 September 2018
Case for introducing standards

1. High quality public involvement can make a real difference to research and to its beneficiaries - but **what does it look like?**

2. Growing body of case studies, toolkits, guidance and other resources but **no clear, concise benchmarks for effective public involvement** alongside indicators against which improvement can be monitored.

3. Strong basis to build on INVOLVE’s Values and Principles Framework for Public Involvement in Research
Recommendation 2 – Culture
The NIHR should commission the development of a set of values, principles and standards for public involvement:

- Co-produced with the public and other partners.
- with a clear set of self-assessment criteria, so that organisations across the NIHR see their adoption as integral to their continuous improvement in public involvement.

https://www.nihr.ac.uk/patients-and-public/documents/Going-the-extra-mile
Our partners & stakeholders

DEVELOPMENT PARTNERSHIP

- Members of the public
- Charities
- Public involvement practitioners
- Involving People Network, Wales
- Industry e.g. PFMD
- Health & Social Care Administrations
- INVOLVE members and associates
- Universities

....and public contributors
Draft and consult widely

DEVELOPMENT

• Built on INVOLVE’s values and principles for public involvement in research framework
• Drawing from relevant standards developed by others
• Iterative writing to draft standards, rationale, indicators, examples

CONSULTATION

• 670+ responses / 50+% members of the public
• Broad support for standards across all stakeholder groups
• More contextual info needed – how to implement, resource, monitor, evaluate
• Plain language!!!
Launch: March 2018

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

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

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

COMMUNICATIONS: We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

IMPACT: To drive improvement, we capture and share the difference that public involvement makes to research.

GOVERNANCE: We involve the public in our governance and leadership so that our decisions promote and protect the public interest.
How did we get here?

2013-15 & before
Identified need – why standards?

2015 & ongoing
Establish & maintain buy in

2016 & ongoing
Mobilise partners & s’holders

2017
Draft and consult widely

2017/18
Revise and launch standards

2018/19
Test standards

2019/20
Roll out

Sept 2018
Who are they for?

The standards are for people and organisations that do research, support research and do public involvement to improve research.

The standards can be used in different ways by different people, for example:

• Members of the public and community groups can use the standards to assess the strengths and weaknesses of their involvement in a research project or organisation and identify how to improve that involvement

• Researchers and research organisations can use the standards to assess their plans for public involvement and identify how to improve those plans
What are the standards?

The standards are:

• a description of what good public involvement in research looks like
• designed to encourage self reflection and learning, including where lessons have been learned when public involvement has failed to lead to expected outcomes
• a tool to help people and organisations identify what they are doing well, and what needs improving
• intended to be used with any method or approach to public involvement in research
• adaptable to your own situation and can be used alongside other resources such as case studies, public involvement checklists, and toolkits.
STANDARD 2: WORKING TOGETHER
We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

We deliver better research when we work together for a common purpose. Different perspectives are respected and embraced through clearly defined roles and responsibilities.

INDICATOR 2.1
We jointly define and record the purpose of our public involvement activity

INDICATOR 2.2
We develop public involvement plans and activities together

INDICATOR 2.3
We ensure there is shared understanding of roles, responsibilities and expectations, which may evolve over time

INDICATOR 2.4
We recognise individual ideas and contributions and uphold decisions together

A standard is a statement of good practice that describes one of six core elements in public involvement in research

An indicator is a statement of good practice that describes what is needed to demonstrate meeting the standard. Plus examples and links to resources
Piloting the standards

- **10 Test bed projects** – reflecting geographical spread, different types of organisations, experience of public involvement, research interests

- **40+ Freestyle projects** – broad range of groups, organisations and activities, public register, pre/post surveys

[https://sites.google.com/nihr.ac.uk/pi-standards/test-beds](https://sites.google.com/nihr.ac.uk/pi-standards/test-beds)
Profile of PI Standards Test Bed Projects (2018-19)

- Cerebral Palsy
  - Developing a confidential register of children

- Speech and Language, Women’s Health, Research Innovation
  - Research priority setting, comms and diversity

- Translational Research, Experimental Medicine, All Health Areas
  - Working with creative disciplines for public involvement in research

- Kidney Disease and Asthma
  - Research partnerships of charity, patient groups, and researchers

- Aging and Dementia, Social Care Research, All Health Areas
  - Embedding and assessing public involvement across existing programmes

- End of Life and Palliative Care
  - Strategy and planning, building a Team

Scotland, Wales, England and Northern Ireland
Putting the standards into practice - 2

An idea!

NIHR People’s Scorecard

Based on your experience of the NIHR over the last year, are we meeting the national standards for public involvement in research?

- Inclusive opportunities
- Working Together
- Learning and support
- Communications
- Impact
- Governance

26% 62% 12%
Putting the standards into practice - 3

CCF projects include

- Writing the CCF PPI team’s annual highlights report against the standards
- Research Design Service piloting reporting against the standards for 2017/18 annual reports
- Inclusion of the standards in the NIHR Applied Research Collaborations competition
Thank you!

Join the conversation by using #PPIStandards @CSO_Scotland, @NIHRINVOLVE, @OfficialNIHR, @publichealthni, @ResearchWales, @sally_crowe

https://sites.google.com/nihr.ac.uk/pi-standards/home

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