

## **Better public involvement for better research**

Paula Wray NIHR INVOLVE **SPCR Conference: Annual Trainees' Event** 25 September 2018









National Institute for Health Research

# **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

## Going the extra mile





Improving the nation's health and wellbeing through public involvement in research

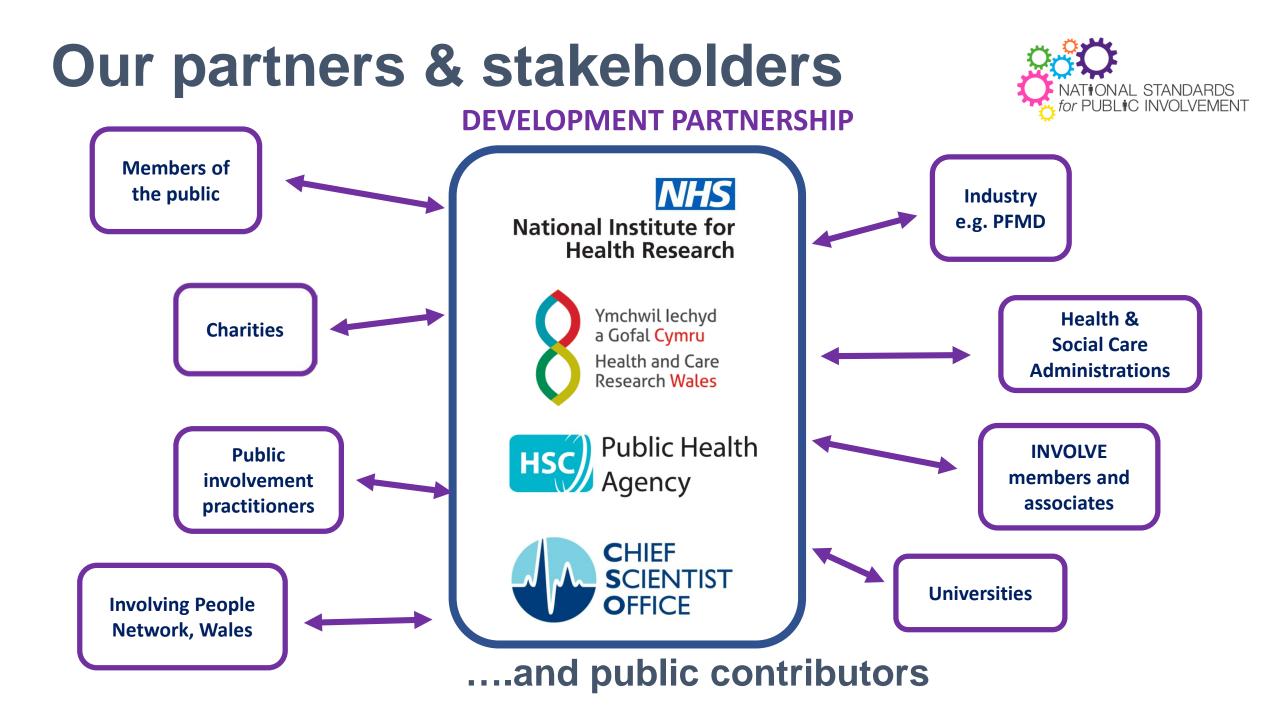
> The final report and recommendations to the Director General Research and Development / Chief Medical Officer (CMO) Department of Health of the "Breaking Boundaries" strategic review of public involvement in the National Institute for Health Research (NIHR)

#### **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-



## 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.



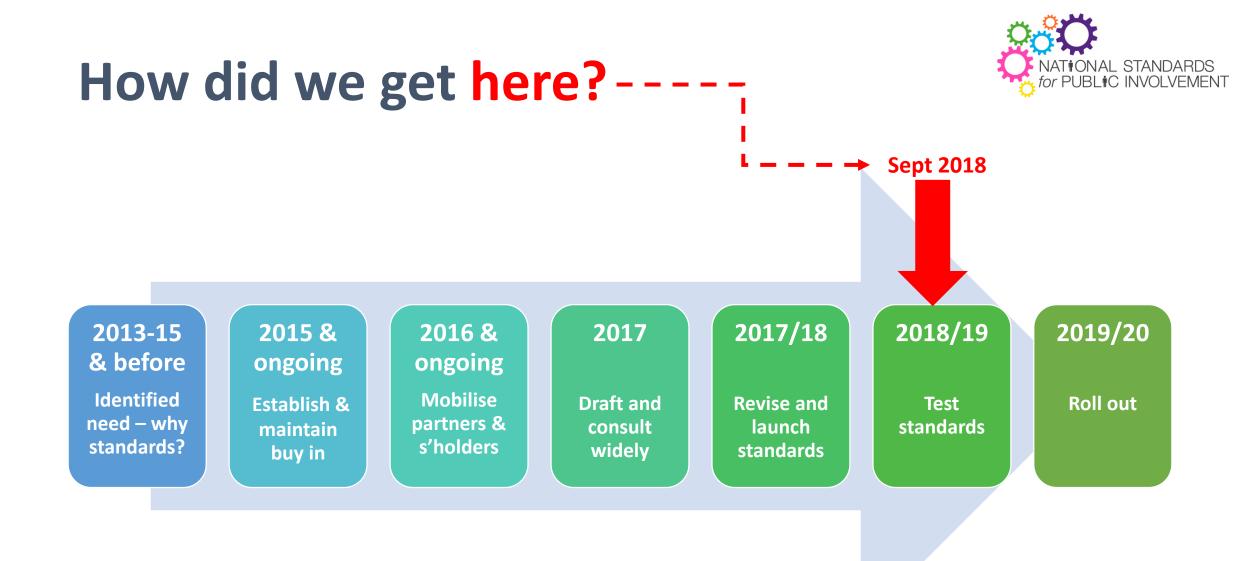
**WORKING TOGETHER:** We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

**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.



## 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.



## Putting the standards into practice - 1

#### **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.

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

**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

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**

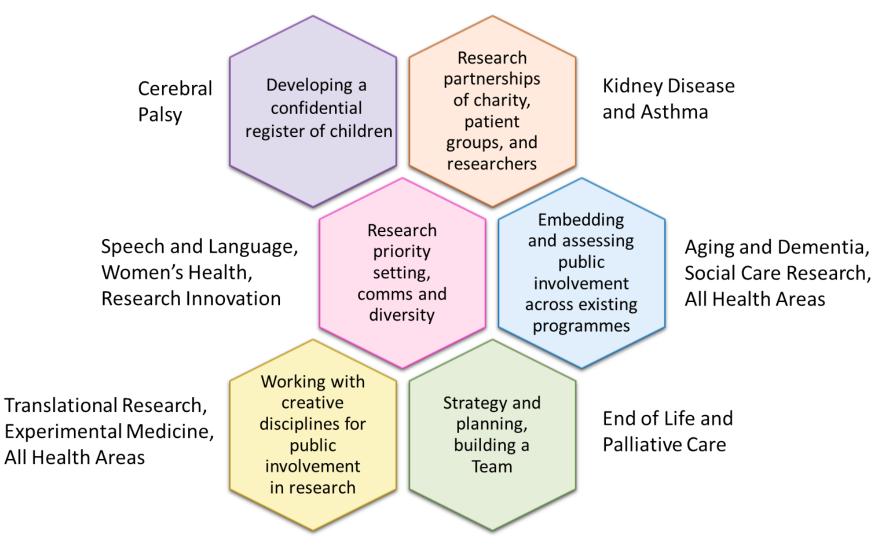


- 10 Test bed projects reflecting geographical spread, different types of organisations, experience of public involvement, research interests
- 40+ Freestyle projects broad range of groups, organisations and activities, public register, pre/post surveys

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

#### Profile of PI Standards Test Bed Projects (2018-19)





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?

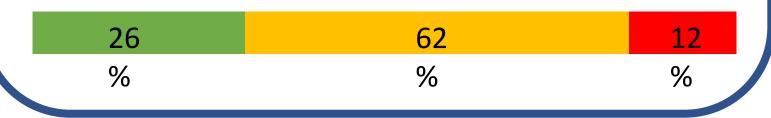


Inclusive opportunities 🐞 Communications Working Together

Learning and support

Impact

Governance



# 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







Join the conversation by using <u>#PPIStandards</u> @CSO\_Scotland, @NIHRINVOLVE, @OfficialNIHR, @publichealthni, @ResearchWales, @sally\_crowe



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

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