

# Patient and Public Involvement (PPI) and Public Engagement (PE) in Research



## **NIHR Imperial Biomedical Research Centre (BRC) and Patient Experience Research Centre (PERC)**

- Dr Markella Boudioni, Patient and Public Involvement Manager

## Overview of presentation

- Definitions and strategy:
  - Patient and Public Involvement (PPI)
  - Public Engagement (PE)
  - Participation
- Research funding bodies PPI/PE requirements
  - NIHR
  - Other
- PPI in research – Benefits
- Advice, information and support for PPI

## Definitions (NIHR BRC requisites)

### Patient & Public Involvement (PPI)



- *Patients and the public being actively involved in the activities, organisation and governance of specific research projects or research in general.*

### Public Engagement (PE)



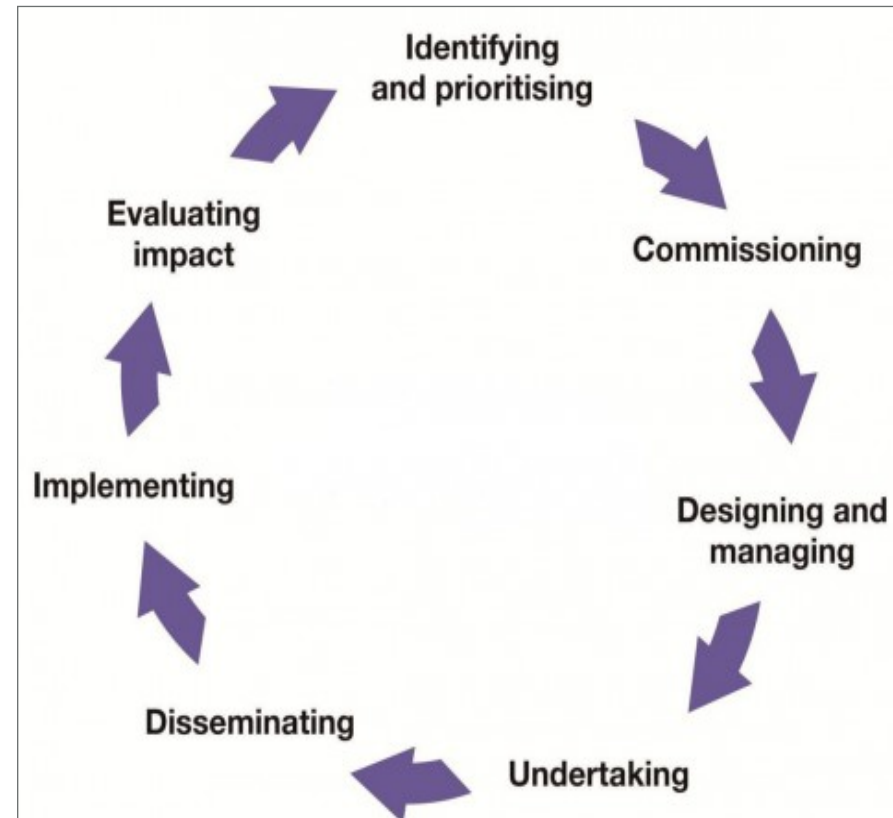
- *Providing and disseminating information and knowledge about research to the public; discussing, consulting the public.*

***Not to be confused with Participation in Research (as subjects/research participants)***

## PPI/PE Strategy (2014-2017)

### Overall aims

- Embed patient and public involvement (PPI) across the whole organisation with active consultation and collaboration in research projects, research themes and board level, and where feasible user-led projects
- Active public engagement (PE) with a proactive approach to make our work accountable, transparent and relevant to the public



### The research cycle

(INVOLVE Briefing note eight: Ways that people can be involved in the research cycle)

## PPI/PE Achievements

1. Building capacity and expertise
  - BRC PP panel
  - Rewards and recognition guidance
  - PPI Grants
2. Monitoring and learning
  - Training/resources for researchers, patients, public
  - Monitoring of activities, sharing good examples
3. Collaborating
  - Imperial BRC PPI/PE Virtual Network
  - Imperial & Partners PPI Research Forum
  - BRC PPI Network
  - 100,000 Genomes PPI Network
4. Assessing the impact of PPI/PE
  - 100,000 Genomes Project National Service Evaluation
  - Number of projects / teams / themes
  - Level of involvement / engagement
  - PP co-design & co-production of BRC Open Day
  - PP co-reviewing Grants



## PPI/PE Requirements – NIHR Funding

- The NIHR
  - expects the active involvement of patients and the public
  - recognises that the nature and extent of active PPI is likely to vary depending on the context of each study award
  - expects full proposals to demonstrate **substantial, convincing engagement with patients and the public** at every stage of the research project, from early design through to publication
- Planning public involvement
- Ongoing public involvement



## PPI/PE requirements – NIHR funding

### Planning public involvement

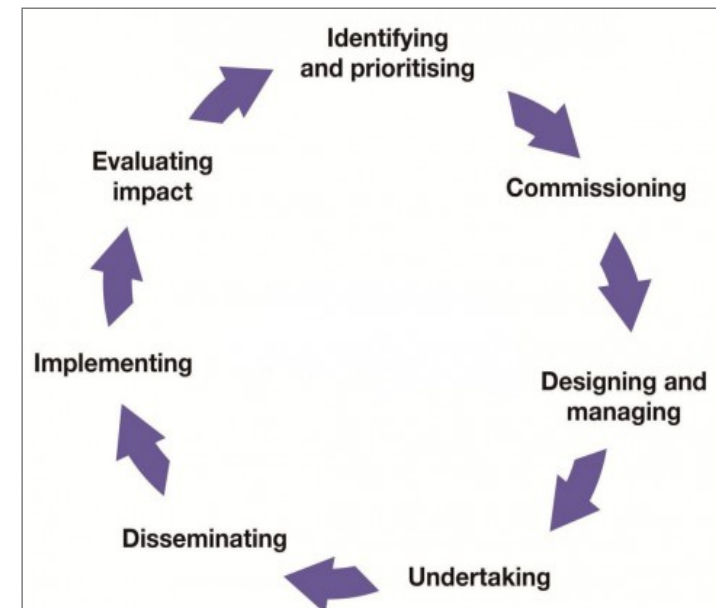
- Were patients and the public actively involved in **identifying the research topic or prioritising the research questions**?
- Were patients and the public actively involved in **preparing the application**?
- **If YES to either or both** questions, give details. Describe:
  - **how** PPI has informed and/or influenced the development of the application
  - **how** patients and the public have been involved
  - provide names of individuals and/or groups,
  - outline the **activities** they have been involved in and
  - how this involvement has or has not, **influenced or changed this research application**.
- **If NO to either or both** questions please explain **why** patient and public involvement was not necessary

## PPI/PE Requirements – NIHR Funding

### Ongoing public involvement

- Please indicate **the ways in which patients and the public will be actively involved** in the proposed research.
- If active involvement is planned, please give more details, including:
  - **how** it will benefit the research,
  - **the reasons (why)** for this approach and
  - arrangements for **training and support**
- Describe the **way** the public will be involved
- Provide names of individuals and/or groups
- Outline the **activities** they will be involved in
- Explain **how** it will **benefit** the research.

### The research cycle





## PPI/PE Requirements – MRC

- **MRC Clinical Trials Unit**
  - Guidance for cancer trial managers about PPI
  - Guidance about PPI in clinical trials
  - Guidance about PPI in systematic reviews
  - Policy about PPI in systematic reviews
- **MRC Guidance for applicants**
  - Public Engagement in Research
  - Pathways to Impact



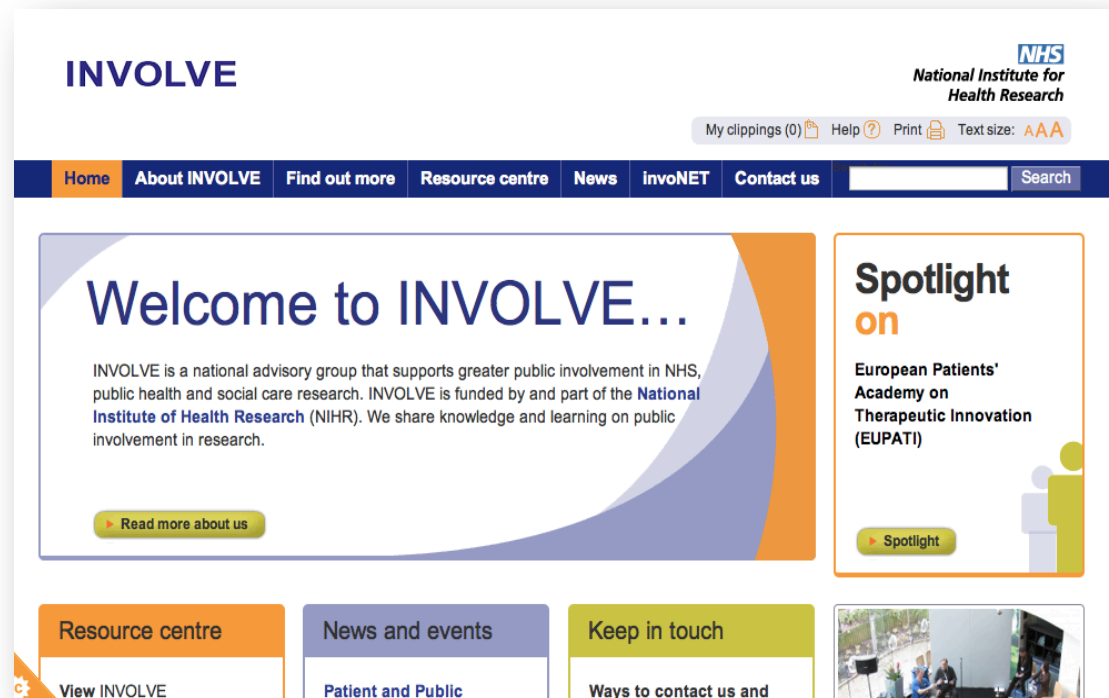
## PPI in Research: Benefits

- Democratic Principles
- Health and social care policy commitment and initiatives
- Research Quality and Relevance
- Interests of research funders and research organisations



# Advice, information and support

- INVOLVE
- Research Design Service



## Advice, information and support

- BRC & PERC PPI Manager
- PERC PPI Officer for HPRUs and DEC
- Imperial PPI/PE Virtual Network
  - PPI/PE Champions within each team
- PPI Training/Workshops
- Individual support and advice
- PPI Resources
  - Rewards and recognition guidance
  - PPI Grants
- BRC PP Panel
- Wider PP Panel



## Thank You & Questions



Please contact:

Dr Markella Boudioni,  
Patient and Public Involvement Manager  
NIHR Imperial BRC and PERC  
Email: [mboudion@imperial.ac.uk](mailto:mboudion@imperial.ac.uk)  
[ppi@imperial.ac.uk](mailto:ppi@imperial.ac.uk)