

# Public and Patient Involvement in Research

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“People-focused research in the NHS simply cannot be delivered without the involvement of patients and the public. No matter how complicated the research or how brilliant the researcher, patients and the public always offer unique, invaluable insight.”

*Professor Dame Sally C Davies, Chief Medical Officer and Chief Scientific Adviser, Department of Health*

<http://www.nets.nihr.ac.uk/ppi/resources-for-researchers>

## **What is Public and Patient Involvement (PPI)?**

Health Research Authority:

“Public involvement means that work is undertaken ‘with’ or ‘by’ patients and the public rather than ‘to’, ‘about’ or ‘for’ them.”

<http://tinyurl.com/o7yocp4>

■ **Involvement**

- Members of the public or patient groups active in research groups or research organisations to further any or all stages in the research process

■ **Engagement**

- Raising awareness of research, sharing knowledge or creating a dialogue with the public (led by researchers or members of the public)

■ **Participation**

- Recruitment of the public and/or patients to take part in a research study or trial

## **Public and Patient Involvement in research can include:**

- Advice on focus of research
- Co-applicants on grants
- Advice on research procedures
- Advice on wording and content of patient information leaflets and consent forms
- Advice on questionnaire or interview formation
- Advice on appropriate reimbursements
- Advice on implementation of research
- Involvement in analysis and dissemination of research findings

## Why consult with patients and the public?

### ■ Ethical / moral

- Research beneficence: do no harm; maximize possible benefits / minimize possible harms of research activities
- Seeks to balance power between researcher and participant

### ■ Pragmatic

- Funders increasingly request and/or mandate PPI

### ■ Empirical

- Improve relevance, impact and quality of research

## **INVOLVE systematic review:**

“...the benefits and costs [of patient and public involvement in research] are being consistently reported.”

- improved clinical trial design
- increased confidence in the use of relevant outcome measures and thus the scientific validity of results
- increased patient satisfaction
- improved understanding and view of research among participants

■ Accessible explanations of key research methods:

- Equipoise
- Randomisation
- Blinding
- Consent

■ Locally relevant research procedures:

- Timing of research implementation
- Topics, questionnaire and methods

INVOLVE. Exploring the impact of public involvement on the quality of research: examples. July 2013  
<http://www.invo.org.uk/wp-content/uploads/2015/07/INVOLVEExploringImpactQualityResearchExamplesUpdatedJuly2014.pdf>

Donovan, J; Mills, N; et. al. *Improving design and conduct of randomised trials by embedding them in qualitative research: ProtecT (prostate testing for cancer and treatment) study*. BMJ. 2002 Oct 5; 325(7367): 766–770.



## How to start?

- Identify relevant patient / public group(s)
  - Speak to stakeholders
- Determine objectives of involvement
  - Specific or general; directed or exploratory
- Identify appropriate level of involvement
  - Dependent on research aims and methods
- Determine methods of involvement
  - Patient advisory group; community advisory board; steering committee membership
  - Website; posters; face-to-face

## PPI activities matched to research topics

- Non-stigmatising conditions
  - Potential for research implementation by patients and public
- Stigmatising / sensitive personal topics
  - Usually should **not** be public and patient led research implementation
  - Other stages in the research cycle may greatly benefit from PPI
- Laboratory / basic science / medical device research
  - Highly dependent on focus of research: will this potentially produce changes in patient care? Are you using patient-consented samples? If so, PPI **is** relevant!

## Practical considerations

- Allocate funding for PPI in grant applications
  - PPI programmes should be zero-cost for participants
  - Include staff time as well as reimbursements and consumables: will this require a full time staff-person to implement? Will you need to train PPI members?
  - Major funders **expect** a fully-costed PPI programme – don't be shy to ask for funds!
- Decide purpose and parameters for involvement at the outset
  - Clear goals allow individuals to decide if the programme is a good fit for them
  - Vaguely stated programme purposes invite questions of authenticity and discourage active involvement
- Allow some room for change / improvements / suggestions to programme by participants
  - Increases patient ownership / buy-in of programme

## **PPI Resources: guidelines**

- **NIHR - INVOLVE**

- <http://www.invo.org.uk/>

- **Research Design Service (RDS)**

- <http://www.rds-london.nihr.ac.uk/Patient-Public-Involvement.aspx>

- **National Institute for Clinical Excellence (NICE) Patient and Public Involvement**

- [www.nice.org.uk/about/nice-communities/public-involvement](http://www.nice.org.uk/about/nice-communities/public-involvement)

## **PPI Resources: patient identification**

- People in Research (MRC/NIHR)

- [www.peopleinresearch.org](http://www.peopleinresearch.org)

- Local resources:

- <https://www.stgeorges.nhs.uk/patients-and-visitors/get-involved/patient-and-public-involvement/>
- <https://www.facebook.com/wandsworth.ppitem?ref=nf>
- <http://www.healthwatchwandsworth.co.uk/>

## **National Institute of Health Research (NIHR):**

“Public involvement is an essential part of the development of modern health and social care services. Research that reflects the needs and views of the public is more likely to produce results that can be used to improve health and social care.”

Thank you!

