

# Patient and public involvement in research

Isabelle Abbey-Vital

Patient and Public Involvement Manager

NIHR University College London Hospitals BRC



# What is patient and public involvement in research?

- Patients, carers and members of the public are **active partners** in research rather than the 'subjects' of research.
- It is about doing research **with** or **by** patients, carers and the public, not doing research to or about them.

# Participation, Involvement or Engagement?

1. Patients are invited to complete questionnaires to gather data about the frequency of symptoms
2. A patient reviews information gathered from telephone interviews.
3. A researcher hosts an open day at their university and invites patients to meet with the team to answer their questions.
4. Patient support groups review lay presentations about the research to help to disseminate findings
5. A researcher sends patients in their study a newsletter to update them on the project

Involvement

Patients, carers and/or members of the public are **actively** involved in research projects and organizations.

Engagement

Information and knowledge about research is provided and disseminated

Participation

Taking part in a research study (what used to be called a 'subject')

# Why is it important?

- Improves the **quality** and **relevance** of research by:
  - ✓ Making information about the research appropriate and accessible
  - ✓ Ensuring that research methods are acceptable and sensitive to the needs of participants
  - ✓ Identifying a broader range of research topics or new research questions
- Ensure accountability for public funding

# How to plan for involvement

Why?

What?

Who?

When?

Where?

# What methods will you use?



- One-to-one discussions
- Focus groups and discussion groups
- Advisory / reference groups
- Steering groups
- Co-researchers
- Research 'buddies'
- Pilot participants

# Budgeting for PPI meetings

According to INVOLVE guidelines, you need to:

- ✓ Reimburse people's travel expenses
- ✓ Consider the cost of babysitters/carers
- ✓ Provide a token of appreciation
- ✓ Budget for catering costs
- ✓ Prepare for unplanned circumstances



# In your grant application form..

- Be clear about distinction between PPI and public engagement
- Give some specific and detailed plans
- Consider involving patients/public at different points
- Detail how PPI will be supported
- Explain how PPI has already shaped research proposals
- Give realistic financial costing

How can we help?



# PPI workshops

- Since 2014, we have provided training for over 500 researchers, running workshops on the topics of:

- Introduction to PPI
- How to fill in the PPI section of a grant form
- Facilitation skills for PPI
- Finders- Keepers? How to access and sustain PPI
- Meaningful PPI – How was it for you?



<http://www.uclhospitals.brc.nihr.ac.uk/investigators/ppi-training>

# PPI Bursary Fund

Aim: to support researchers to actively involve patients and the public in their research.

- You can apply for a small amount of funding to support involvement in your research. Applications will need to demonstrate:

- ❖ how PPI will impact on a research study or research area
- ❖ how the impact of PPI will be recorded and evaluated
- ❖ how individual patients or members of the public will be identified and supported
- ❖ outline breakdown of likely costs and timetable

- In 2018, we will hold 4 calls for applications.

[www.uclhospitals.brc.nihr.ac.uk](http://www.uclhospitals.brc.nihr.ac.uk)

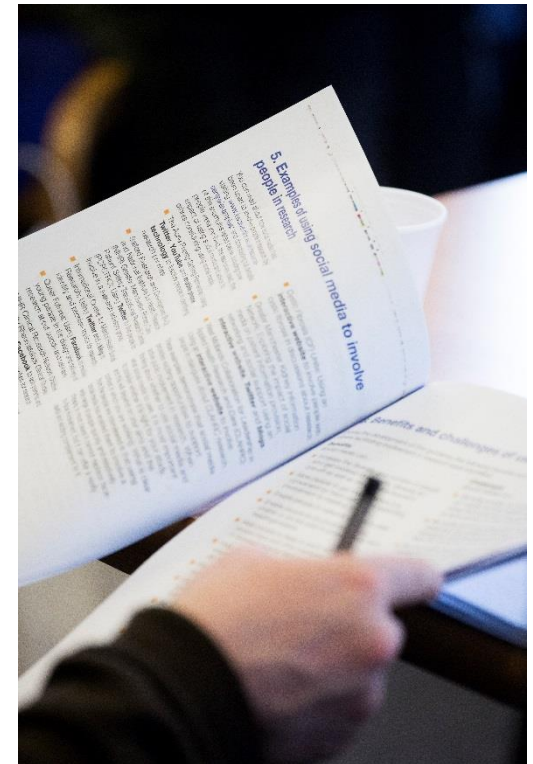


# Advice & support

We can help you:

- By providing advice on how to incorporate PPI into your research, including:
  - Understanding how you can involve people
  - Finding the right people to involve
  - Designing and planning PPI activities
  - Facilitating meetings
- Connecting you with our network of patients & lay panels

E: [ppihelpdesk@ucl.ac.uk](mailto:ppihelpdesk@ucl.ac.uk)



# Other support & resources



***National Institute for  
Health Research***

## **INVOLVE**

- Resources: <http://www.invo.org.uk/resource-centre/>
- InvoDIRECT: <http://www.invo.org.uk/communities/invodirect/>

## **Research Design Service London**

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

# Thankyou

Isabelle Abbey-Vital

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E: [i.abbey-vital@ucl.ac.uk](mailto:i.abbey-vital@ucl.ac.uk)

T: 020 3108 6952

