

PPI – 10 tips to make it easier

Lynne Maddocks

Patient & Public Involvement Coordinator,
University of Oxford, member department of
School for Primary Care Research

SPCR 2016 Annual Trainees' Event

19 -20 September 2016

Queen's College, Oxford

PPI – 10 tips to make it easier



1 Know what it is and what it is not

Participation = where people take part in a research study or clinical trial.

Engagement = where information and knowledge about research is shared with the public, with some interaction and listening to the public.

Involvement = where people are actively involved in research projects and in research organisations, planning what should be researched and how it should be done.

PPI – 10 tips to make it easier



2 Be clear with yourself about why you are doing it.

Philosophical impetus;

- a) public right as public money
- b) it will improve the research

Avoiding the tokenism cycle

PPI – 10 tips to make it easier

3 Understand how PPI Contributors perceive their role

Perceived role	Proposed mechanism of impact
The expert in lived experience	Through their lived experience of a condition, PPI contributors are able to consider the acceptability and feasibility of research proposals for the target population
The creative outsider	PPI contributors bring a fresh perspective from outside the research system, and can help to solve problems by thinking 'outside the box'
The free challenger	PPI contributors are able to challenge researchers without fear of consequences
The bridger	PPI contributors bridge the communication gap between researchers and patients or the public, making research more relevant and accessible
The motivator	PPI contributors increase researchers' motivation/enthusiasm, for example by emphasizing how the research will benefit people.
The passive presence	PPI contributors can change the way that professionals think just by being present at meetings.

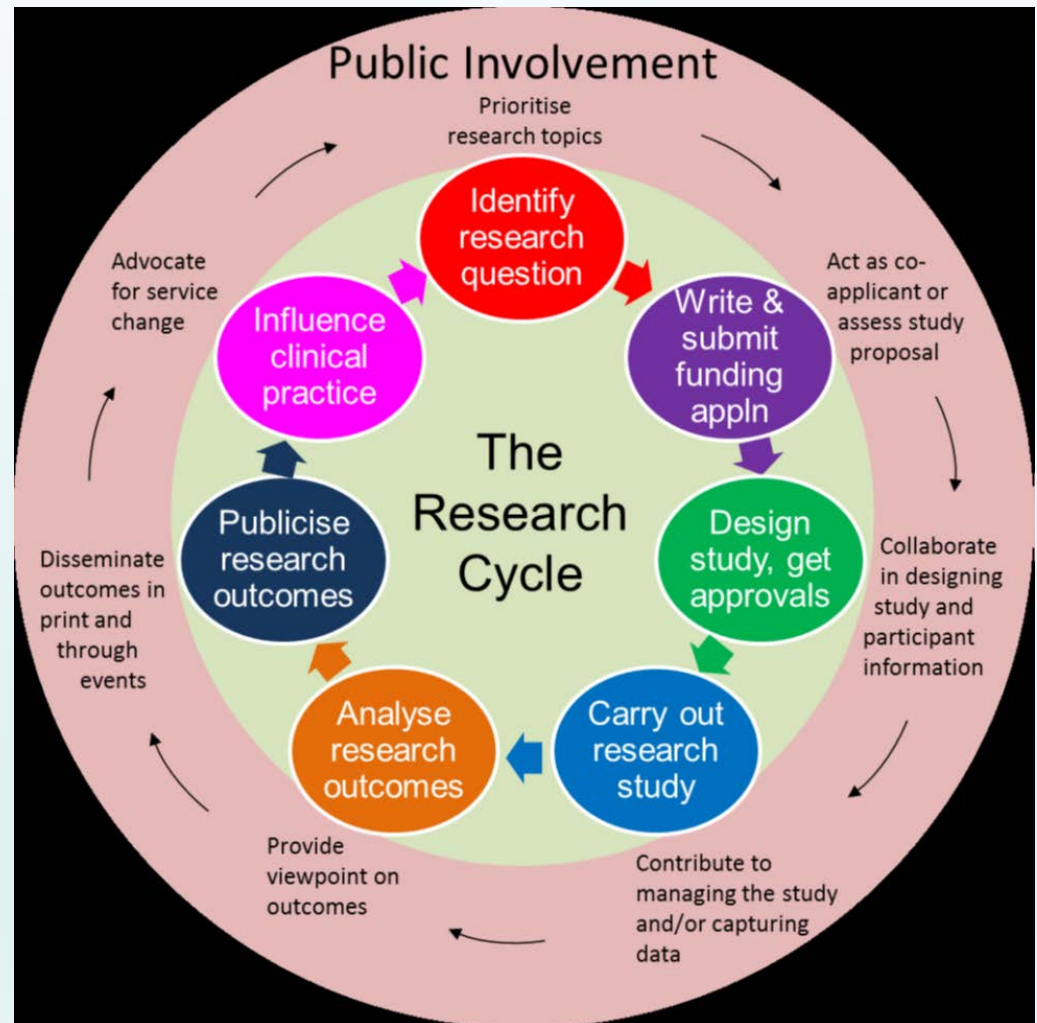
PPI – 10 tips to make it easier



- 4 Be clear about which type of involvement will work best for what you want to achieve?
 - ? Trial steering committee
 - ? Advisory or focus group
 - ? Stakeholder group
 - ? One to one interviews
 - ? Visit to an existing group
 - ? Virtual panel
 - ? Social media
 - ? Combination of any or all of the above (or others you invent!)

PPI – 10 tips to make it easier

5 Be clear about when to do it.



PPI – 10 tips to make it easier

6 Plan an adequate budget in detail

Travel
expenses

Payment
for time

Training
costs

Advertising
to recruit

Hire of
meeting
rooms

Refreshments
at meetings

Payment to enable involvement such as
respite care or personal assistance costs

Translation
or
interpretation

PPI – 10 tips to make it easier



7 Recruit appropriately

It is important that both you, as a researcher, and the people you involve have a shared and clear understanding of what they are being invited to do:

- ✓ Explain why you want them involved
- ✓ Be clear about whether you need someone to have ‘lived experience’
- ✓ Develop a role description
- ✓ Be clear about the time commitment
- ✓ Be clear about what they can expect from you
- ✓ Be clear what the aims of your research are
- ✓ Be clear which aspects of the research have scope for people to influence and how much influence they will be able to have (including where there is no scope to change the research)
- ✓ Develop principles of how you will run any meetings that have the public in them
- ✓ Be clear about what reimbursement and payment they can expect

PPI – 10 tips to make it easier



8 Put time and effort into supporting your PPI Contributors and expect to have to adjust to fully include them

Remember some of the basics;

- Meeting papers to be sent 1 – 2 weeks in advance. If necessary write summaries and present information differently.
- Phone contact before and after meetings to answer queries
- Help with claiming expenses & payment and recording what they claim & receive
- Tell them about any training that is available
- Regular feedback so that they know what progress is being made on the project. Wherever possible include feedback on how their impact has made a difference to the work.

PPI – 10 tips to make it easier

9 Make use of the resources available to you

INVOLVE	Briefing notes for researchers	http://www.invo.org.uk/resource-centre/resource-for-researchers/
Healthtalk	Range of interviews of patients and researchers on all aspects of PPI	http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics http://www.healthtalk.org/peoples-experiences/medical-research/researchers-experiences-patient-public-involvement/topics
James Lind Alliance	Learn about what researchers and the public working together decide are the top research questions in your field	http://www.jla.nihr.ac.uk/
People in Research	Find recruits for PPI nationally	http://www.peopleinresearch.org/
Research Design Service	Range of advice prior to grant funding including on PPI	http://www.rds.nihr.ac.uk/ follow links to find your regional office

PPI – 10 tips to make it easier

10 - There are specialists in each member department who can help you and many have additional resources;

Bristol	Catherine Jameson	cdzclc@bristol.ac.uk
Cambridge	Stephen Barclay	sigb2@medschl.cam.ac.uk
Keele	Krycia Dziedzic	k.s.dziedzic@keele.ac.uk
Oxford	me!	
Manchester	Claire Planner	Claire.planner@manchester.ac.uk
Newcastle	Richard Thomson	richard.Thomson@Newcastle.ac.uk
Nottingham	Christina Brindley	Christina.Brindley@nottingham
Southampton	Clare McDermott	crm20@soton.ac.uk
UCL	Fiona Stevenson	f.Stevenson@ucl.ac.uk

PPI – 10 tips to make it easier

Finally, keep calm
and don't panic

Any questions?

