

Public Involvement in Research

Clinical Research Network
West Midlands

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Aims

- Understand the different ways in which the public can support research
- Explore the meaning and importance of public involvement in research
- Identify what challenges, apprehensions and expectations:
 - The public may have about getting involved in research
 - A researcher may have about involving the public in their research
- Identify the support you may need to manage these challenges, apprehensions and expectations if you decide to involve the public in your research

Workshop outline

- Overview of:
 - what we mean by the term ‘public’ in this context
 - what ‘public’ involvement’ means
 - the different ways in which the public can get involved in research
- Discussion “why public involvement in research is important”
- Discussion “what expectations research place on the public who want to get involved”
- Talk from Jacky Antcliff
- Discussion “why the public get involved in research”
- Talk from Brin Helliwell
- Summary and Questions

What we mean by...

The term “public”

- **INVOLVE:** <http://www.invo.org.uk>
 - Funded by and part of the National Institute of Health Research
 - A national advisory group that supports greater public involvement in NHS, public health and social care research.
- Refer to the term “**public**” as:

“Patients, potential patients, carers and people who use health and social care services”

“Public Involvement in research”

- **INVOLVE** define this as:

“... research being carried out ‘with’ or ‘by’ members of the public rather than...”

Research being carried out “...to’, ‘about’ or ‘for’ them.”

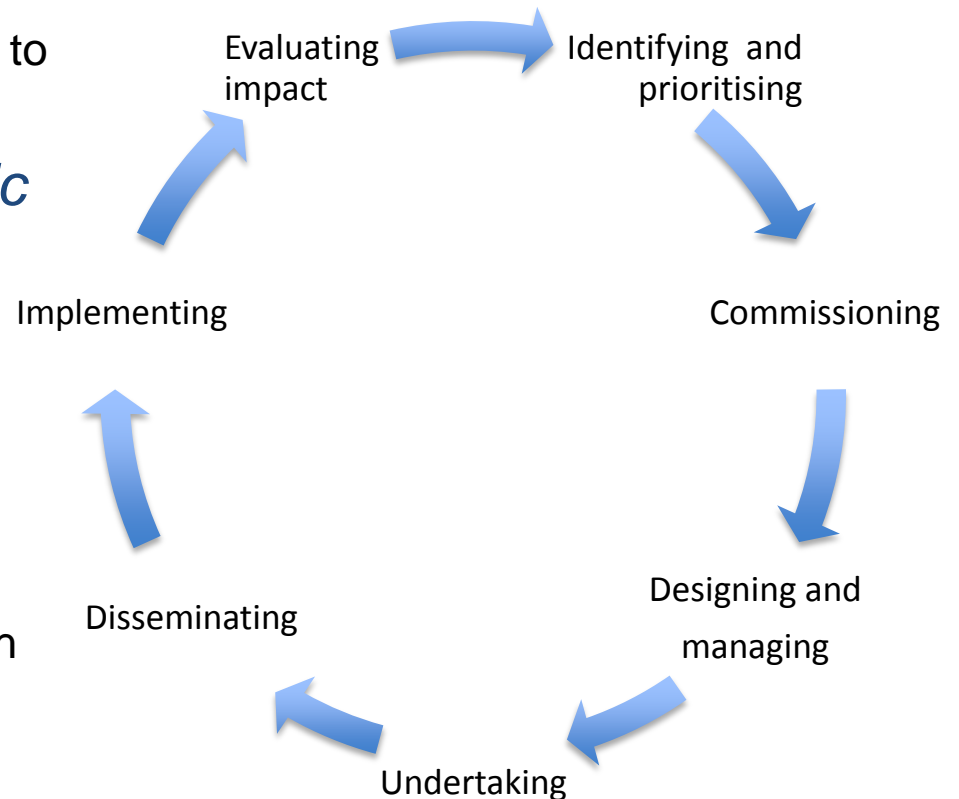
Public Involvement

INVOLVE uses the following term to describe involvement:

“Where members of the public are actively involved in research projects and organisations”

INVOLVE has identified when people can be involved in the research cycle

**Briefing notes for researchers,
February 2012**



Public Engagement



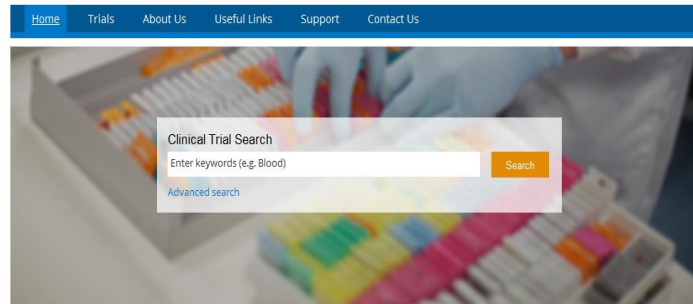
Public Participation



Examples of involvement and engagement



UK Clinical Trials Gateway



Welcome to the UK Clinical Trials Gateway



OK to ask <http://www.nihr.ac.uk/awareness/Pages/OKtoask2014.aspx>

Research Changed My Life <http://www.crn.nihr.ac.uk/ppi/rcml/your+stories/your-stories>

UK Clinical Trials Gateway <http://www.ukctg.nihr.ac.uk/default.aspx>

Involvement 4 Access http://www.crn.nihr.ac.uk/ppi/why_is_research_important/involvement4access/tell_us_about_your_initiative.htm

James Lind Alliance http://www.lindalliance.org/Current_Projects.asp

Discussion 1

- Why is public involvement in research important?

Why have public involvement

*“No matter how complicated the research, or how brilliant the researcher, **patients, and the public always offer unique, invaluable insights.** Their advice when designing, implementing and evaluating research **invariably makes studies more effective more credible and often more cost efficient as well.**”*

Professor Dame Sally Davies, Chief Medical Officer
(forward in Staley, 2009)

The NHS Constitution

- Patients have the right to find out about the research opportunities suitable for them.
- NHS health practitioner should inform you of any studies for which you may be eligible.



THE NHS
CONSTITUTION
the NHS belongs to us all

Discussion 2

- Put yourself in the position of a researcher
- Discuss what challenges, apprehensions and expectations they may have around involving patients, carers and members of the public in research
- How would you overcome these?
- What support would you need?

Welcome

- Jacky Antcliff

Discussion 3

- Put yourself in the position of a patient, carer or member of the public
- Discuss what challenges, apprehensions and expectations they may have around being involved in research
- How would you overcome these?
- What support would you need?

Patient and Public Opinion

<http://www.crn.nihr.ac.uk/can-help/patients-carers-public/why-research-is-important/>

According to a poll in June 2011:

- 97% of the public believe it's important for the NHS to support research into new treatments
- 93% want their local NHS to be encouraged or required to support research
- 72% would like to be offered opportunities to be involved in trials of new medicines or treatments, if they suffered from a health condition that affects their day-to-day life.

Why people get involved

People get involved for many reasons:

- Personal and/or Social
- Sometimes these are linked to:
 - personal experiences of a health or social care service
 - a desire to bring about change in the quality of care
 - a desire to improve treatments either for themselves or for others with a similar condition
- To have a “voice”, to “influence” the process that affects people’s lives
- Giving something back and helping other’s through their involvement

Welcome

- Brin Helliwell

Closing Comments

- Further support:
 - INVOLVE resources <http://www.invo.org.uk>
 - NIHR Patient and Public Awareness
<http://www.nihr.ac.uk/awareness/Pages/default.aspx>
 - Research Design Services
<http://www.nihr.ac.uk/research/Pages/ResearchDesignService.aspx>

- Thank you

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