

# Public Involvement and Engagement in Identifying, Designing, Delivering and Disseminating Research in Infectious Diseases

19<sup>th</sup> March 2014

## Definitions

- Public – Patient – Layperson
- Engagement – Involvement → PPI and PPE
- “Research being carried out **‘with’** or **‘by’** members of the public, rather than **‘to’**, **‘about’** or **‘for’** them”

NIHR INVOLVE: [invo.org.uk](http://invo.org.uk)

- Acronyms aplenty!

## Why involve patients?

- “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”

– Dame Sally Davies, CMO

- It is ‘right’
- Common sense
- Enriches society

## Whom? When? How?

- Who?
  - Us
- When?
  - Now and continuous
- How?
  - Now... there’s a question
  - OxBRC – PPI/PPE director support
  - INVOLVE - national advisory group supporting PPI
  - PIIAF – Patient information advisory forum
  - James Lind Alliance – patients and clinicians collaborating to identify and prioritise unanswered questions...

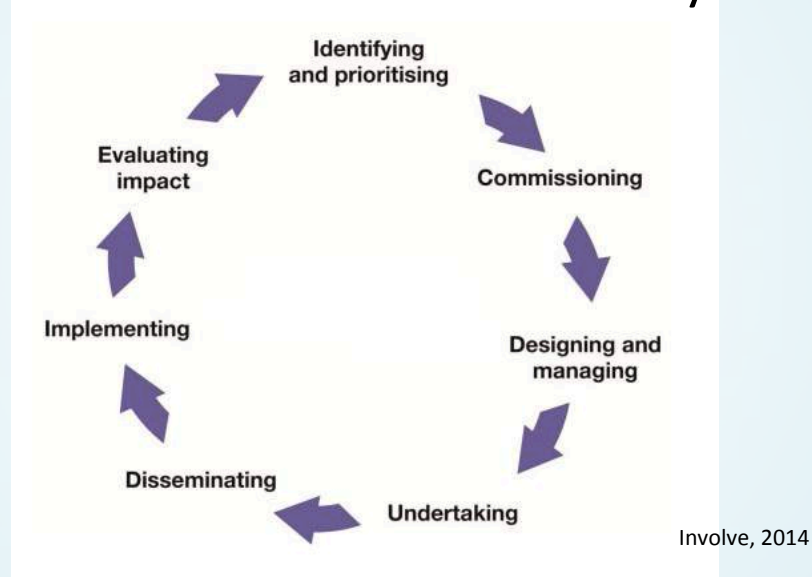
## Why might the JLA method lead to better research?

- Research often overlooks what matters to patients and clinicians
- The drug and technology industries may have priorities that differ from those of patients
- JLA-identified priorities increasingly of interest to research funders
  - Healthtalkonline modules
  - [www.lindalliance.org](http://www.lindalliance.org)

## Simon Denegri: INVOLVE Chair

- The UK is unique in having a publicly funded body for the promotion of public involvement in research and we should be proud of it.
- UK is a world-leader in public involvement in health research
- Public involvement is about design and effectiveness and quality. Not PR.

## Involvement in the Research Cycle



## PPI has an impact ...

- Changes trial design/improves recruitment
- Makes outcome measures meaningful/relevant
- Improves ethical acceptability
- Widens research topics
  
- Impacts?

## Why evaluate the impact of PPI?

- Effectiveness case: what works, for whom, and in what circumstances?
- Ethical case: might PPI have harmful impacts - the research community has a duty of care.
- Economic case : PPI takes time and money – is it a good use of (scarce) resources?

## How to evaluate the impact of PPI

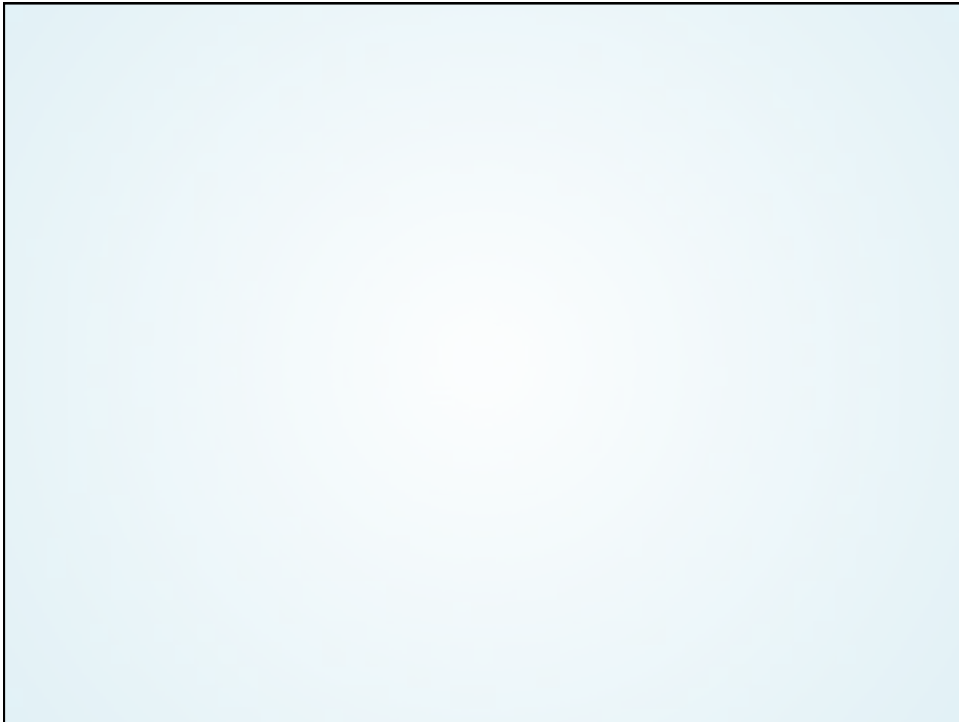
- Evidence
  - Quantitative?
  - Qualitative?
  - At what stage?
- Many groups are working on this
  - GRIPP - Guidance for Reporting Involvement of Patients and Public
  - PiiAF - Public Involvement Impact Assessment Framework
- Which “stakeholders” should and can evaluate involvement.....?

## Who...?

- Who can/should be involved?
- How best to do so?
- What about the rest?
  
- Not personal – imperative to get broad input
- Might not be able to enact some suggestions
  - Ethical, economic, effectiveness reasons
  - But all suggestions will be objectively appraised

## Continued engagement and involvement

- Working groups
- Oxford BRC open day
  - Monday 19<sup>th</sup> May, West Wing entrance foyer
- PHE seeking a new Lay Member to join advisory committee on Antimicrobial Resistance and Healthcare Associated Infections
  
- Contact us
  - Email
  - Phone
  - Twitter - ModMedMicro



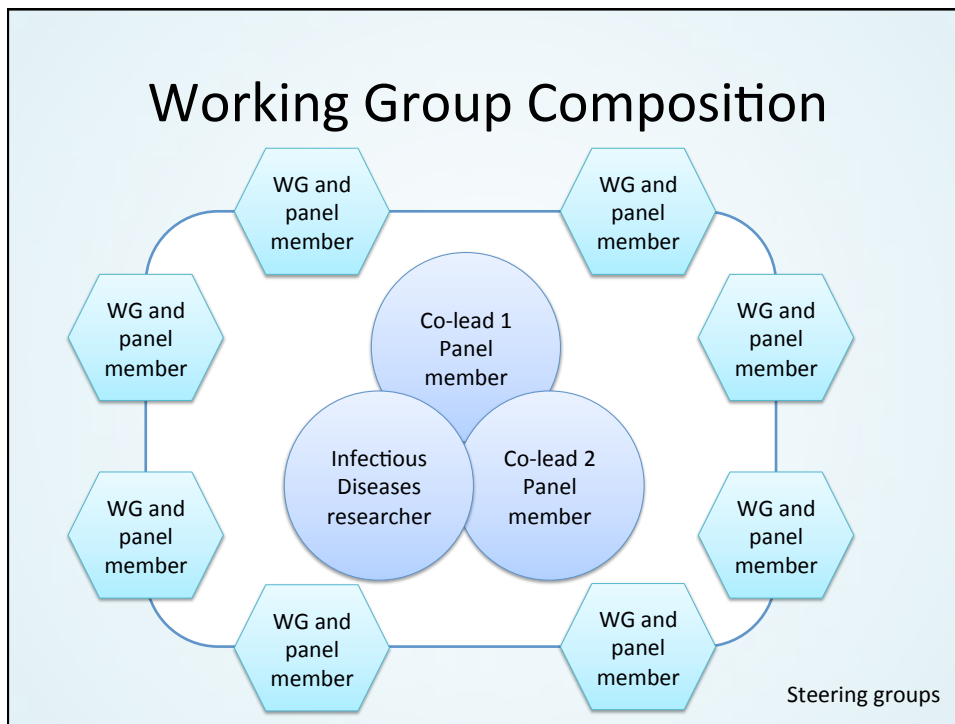
Next Steps & Working Groups

Working Groups	Facilitators
<p><b>1) Generating and reviewing public information and grants (Here)</b></p> <ul style="list-style-type: none"> <li>Rapid impact activities: including designing engaging public information and ensuring that grant proposals are summarised in a public-friendly way.</li> </ul>	<ul style="list-style-type: none"> <li>Ali Vaughan, Derrick Crook &amp; Cliff Gorton</li> </ul>
<p><b>2) Designing research studies and trials (Foyer)</b></p> <ul style="list-style-type: none"> <li>Medium term activities: generating proposals for how current research may be delivered more effectively.</li> </ul>	<ul style="list-style-type: none"> <li>Claire Gordon, Amy Mason &amp; Tim Peto</li> </ul>
<p><b>3) Identifying research priorities (Foyer)</b></p> <ul style="list-style-type: none"> <li>Longer term activities: looking into identifying gaps in the current research, ensuring that future proposals for work address public concerns.</li> </ul>	<ul style="list-style-type: none"> <li>Helen Barker, Nicole Stoesser &amp; Bernadette Young</li> </ul>

## Working Groups

- Assigned on the basis of questionnaire responses, if available
- Mirror groups from next week
- Remit for today:
  1. Introductions and background
  2. Nominate balanced co-chairs
  3. Propose 5 keys topics
  4. Share contact details?





## Working Groups - Next Steps

- Blend WGs from two face to face sessions
  - Integrate others
- Identify balanced Working Group (WG) co-chairs
- Arrange blended WG interactions
- Define key topics/actions for the WG
- Propose additional WGs
- Evidence measures



Thank You!