


Patient and Public Involvement in Research

Ailsa Donnelly (Public contributor in Research)

Heather Bagley (Patient and Public Involvement Co-ordinator, Dept of Biostatistics, University of Liverpool)

Carrol Gamble (Professor of Medical Statistics, Dept of Biostatistics, University of Liverpool)

- 
- Patient and public involvement (PPI) in research is where research is “being carried out ‘with’ or ‘by’ members of the public” not just “‘to’, ‘about’ or ‘for’ them”


INVOLVE – What is public involvement in research?

<http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>

Definitions



Image provided by PRIMER



"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"

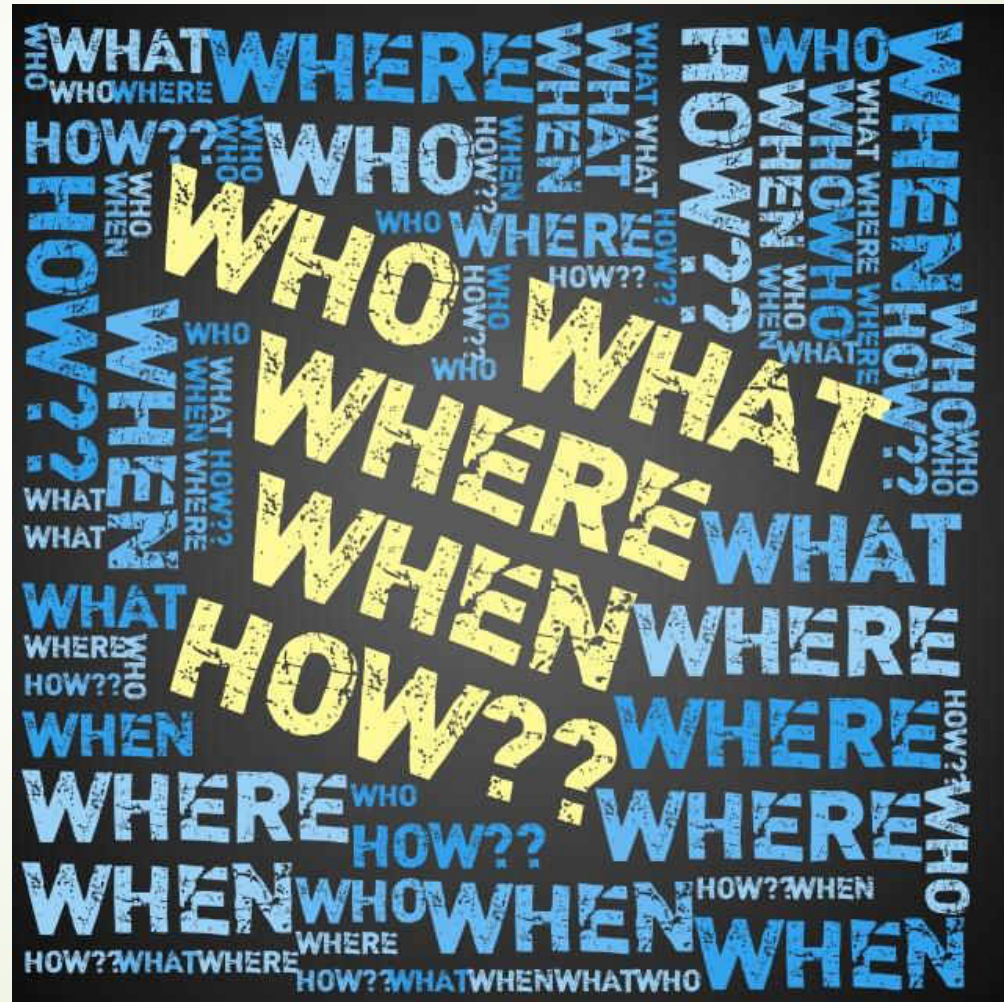
Professor Dame Sally Davies (Chief Medical Officer England, Foreword in Staley report, 2009)

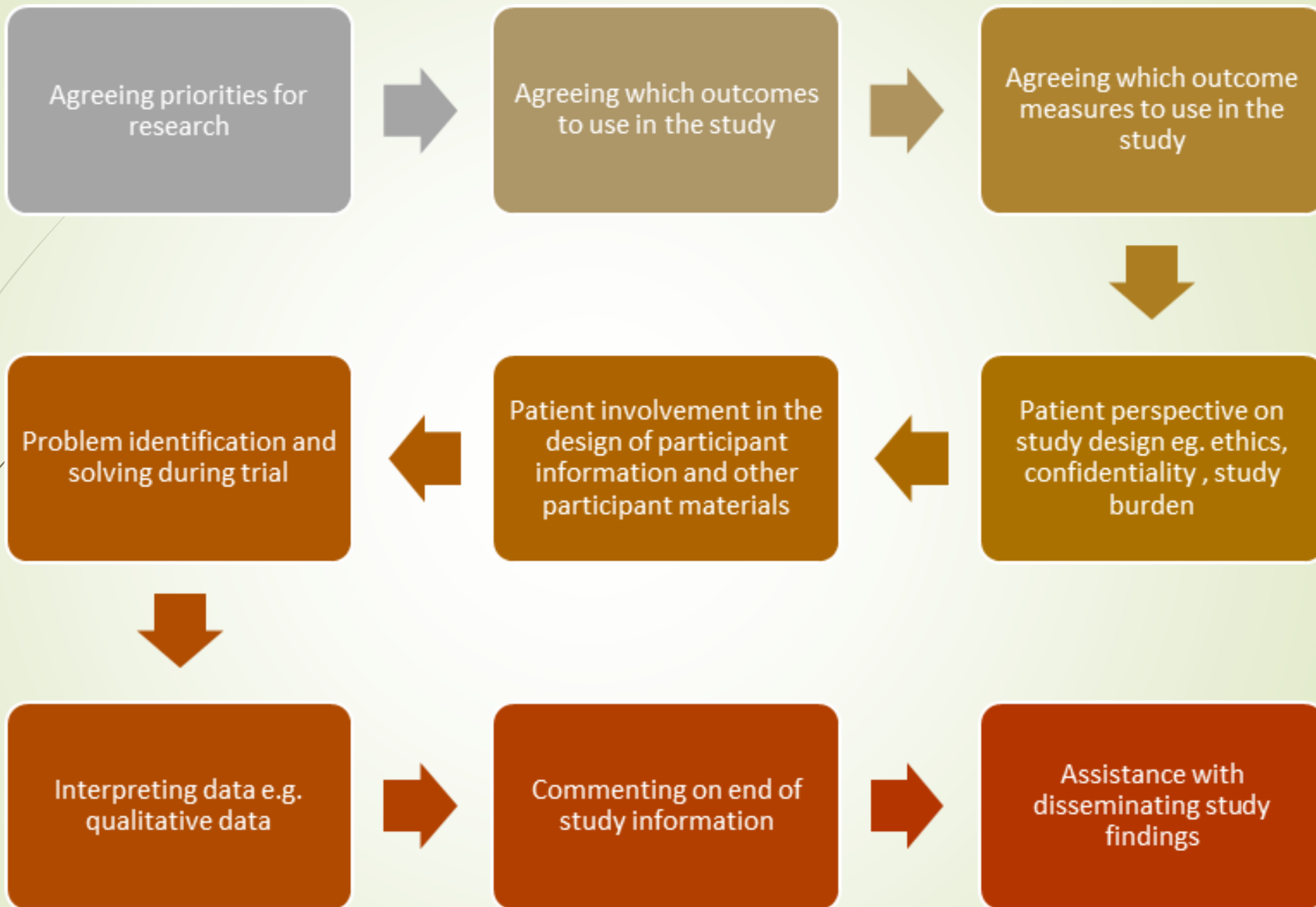



**Where can patients input into
research?**



Plan!

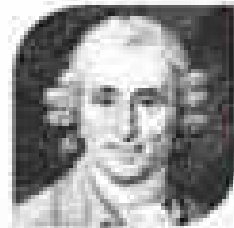






Are we asking a relevant and important research question?

Agreeing priorities for research



James
Lind
Alliance

Priority Setting Partnerships

<http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/>



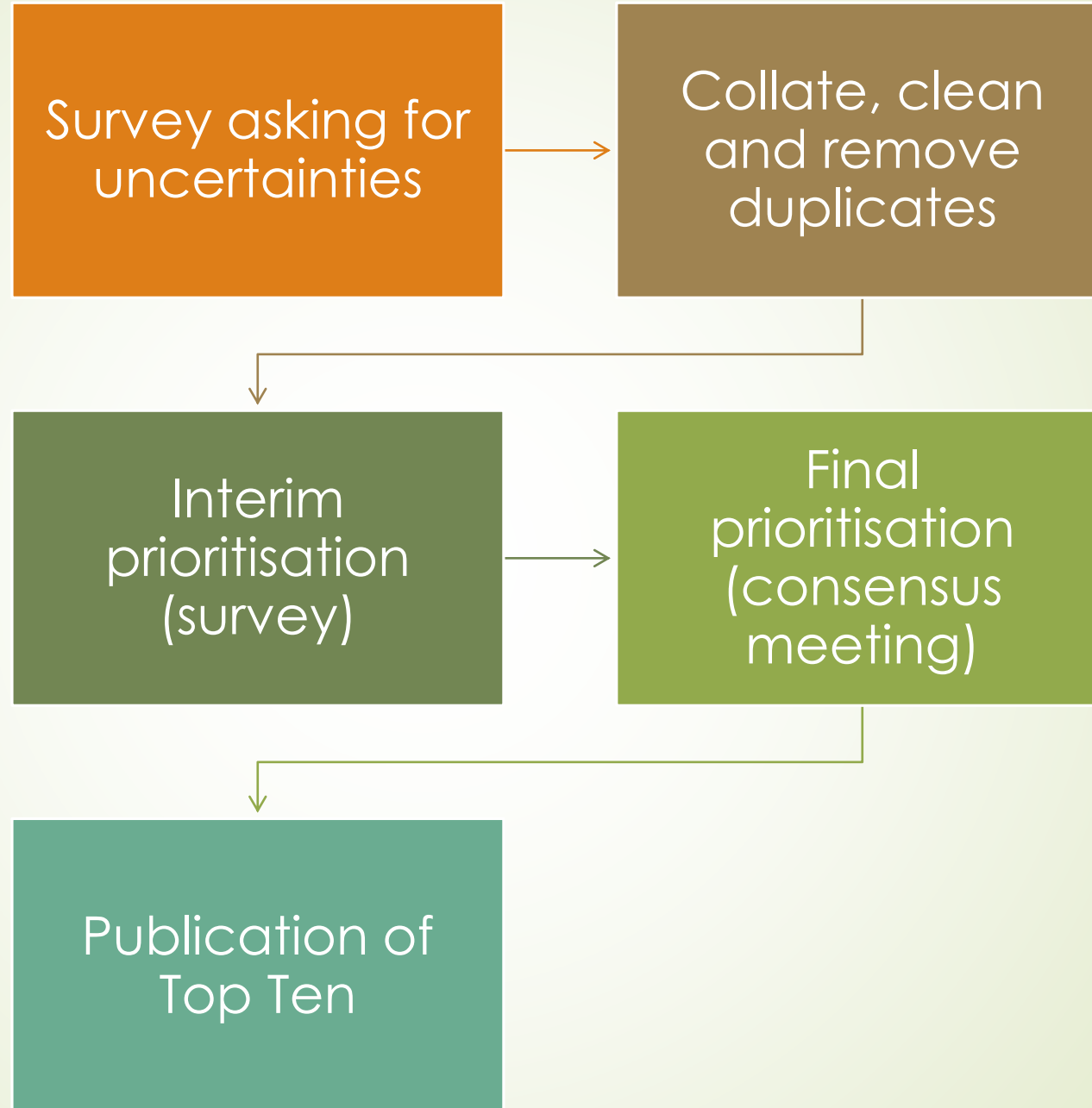
Survey asking for
uncertainties

Collate, clean
and remove
duplicates

Interim
prioritisation
(survey)

Final
prioritisation
(consensus
meeting)

Publication of
Top Ten



Agreeing patient important outcomes for research


Agreeing which outcomes
to use in the study



<http://comet-initiative.org/>



Agreeing how to measure the outcomes



Agreeing which outcome
measures to use in the
study



Is the study well designed from the perspective of a potential participant?




Patient perspective on
study design eg. ethics,
confidentiality , study
burden

Will potential study participants understand the study information?

Patient involvement in the design of participant information and other participant materials






What do you think we should do about
this?



**Problem identification and
solving during trial**



What are your views on the data?



Interpreting data e.g.
qualitative data



Data


What do you think about what how we will present the results to participants?

Commenting on end of study information





Disseminating the findings



Assistance with
disseminating study
findings



What ways do patients get involved?



Examples of potential public contributor roles

- Advisory groups
- Public panel
- Priority setting partnerships
- Trial management groups
- Co-applicants
- User led research

Different roles /
different
experience &
skills



What are the benefits of patient involvement?



Impact of PPI on research – some examples

- Identifying topics for research
- Making the research design more relevant and accessible
- Improving the consent process by producing clearer, more accessible information
- Enhancing the ethical acceptability of research
- Increased participation and response rates
- Identify research themes that researchers may miss
- Make research findings more accessible and messages more powerful


<http://www.piaf.org.uk/documents/impacts-summary-1113.pdf>



Impact on the patient

- Increased knowledge and skills
- Personal rewards (eg. making friends, feeling of making a difference)
- Financial reward

<http://www.piaf.org.uk/documents/impacts-summary-1113.pdf>

- 
- “You're doing something valuable; you're contributing to society in some way. And I suppose, at some level, you feel as though you're kind of trying to exert some control over the future. Having had a disease over which you had no control and was very random, you are now in a position where, well OK, maybe by doing something around PPI I might get some control and help other people in the future”.


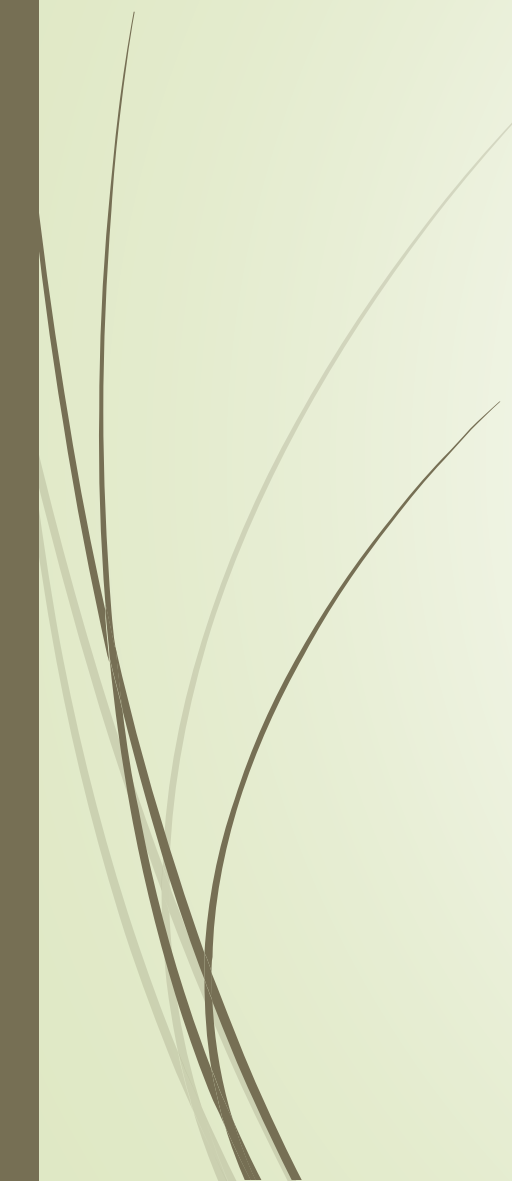
<http://www.healthtalk.org/peoples-experiences/improving-health-care/patient-and-public-involvement-research/reasons-staying-involved-and-wider-benefits>



Impact on the researcher

- Fresh insights into the issues of the study
- Better understanding of and relationships with the community
- Potentially enhanced career benefits
- Positive challenges to beliefs and attitudes

<http://www.piaf.org.uk/documents/impacts-summary-1113.pdf>

- 
- 
- “I think the biggest impact that their involvement has had is to keep the group of methodologists constantly aware of the patient and public perspective during our discussions and our work.”
Methodology researcher
 - “I can easily list things such as commenting on PIS and topic guides etc and that has been really useful. But a list like that would hardly begin to capture the ways that working with research partners has changed how I think about my research, the questions it asks, how I do studies and how I understand the purpose of the work. Everything really – plus keeping me orientated and grounded in what really matters”.
Qualitative researcher.



Assessing impact resources

- Public Involvement Impact Assessment Framework (PiiAF): <http://piiaf.org.uk/>
- Guidance for Reporting the Involvement of Patients and the Public (GRIPP) Staniszewska, S, Brett, J, Mockford, C, & Barber, R n.d., 'The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research', *International Journal Of Technology Assessment In Health Care*, 27, 4, pp. 391-399,



How can you support and resource patient involvement in research?

Facilitating good PPI

- Offering support to patients who are involved
- Effective communication, so people understand what, where, how and when they might be involved
- Providing acknowledgement for involvement
- Appropriate funding for PPI
- Adequate resources for PPI (especially time)
- Using existing resources to support PPI (not reinventing the wheel) Eg. INVOLVE, PPI Toolkit, PRIMER resources)

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

PPI Toolkit - <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0029-8>

Primer resources: <http://research.bmh.manchester.ac.uk/PRIMER/downloads/>

Challenges of PPI





Final thoughts

- ▶ Both researchers and PPI partners must:
 - ▶ Be committed to making PPI work
 - ▶ Communicate freely and frequently
 - ▶ Have clear and realistic expectations
 - ▶ Respect each other: remember that a meeting between a researcher and a PPI partner is a meeting between experts with different areas of expertise