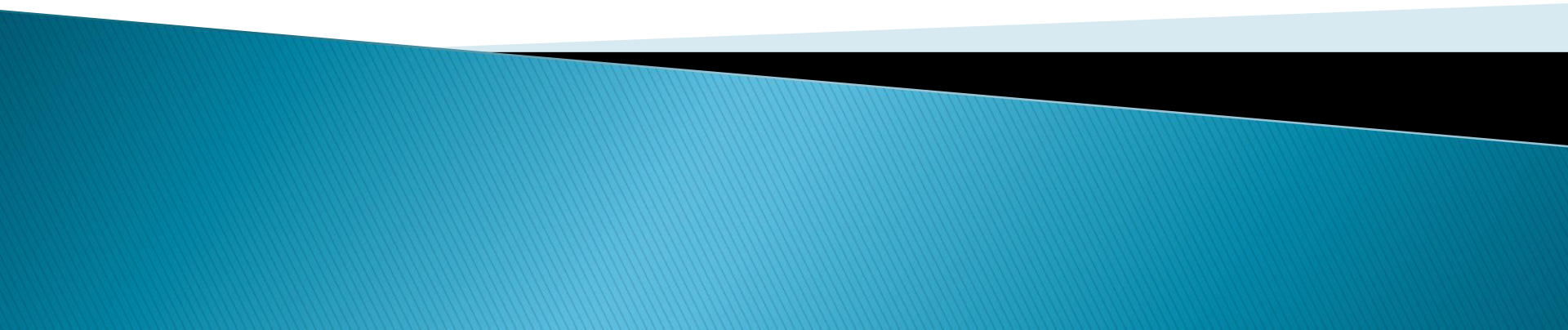


# Patient and Public Involvement – approaches and techniques

Workshop 30th May 2017



# Today is a collaboration....

Collaboration for Leadership in  
Applied Health Research and Care  
Oxford



**NIHR Oxford Health Biomedical Research Centre &  
Cognitive Health Clinical Research Facility**



**Evidently Cochrane**  
Sharing health evidence you can trust

**NIHR Clinical Research Network  
Thames Valley and South Midlands**



# Housekeeping

Timings



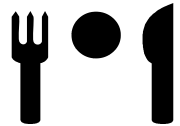
Phones



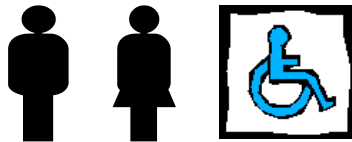
Refreshments



Lunch



Facilities



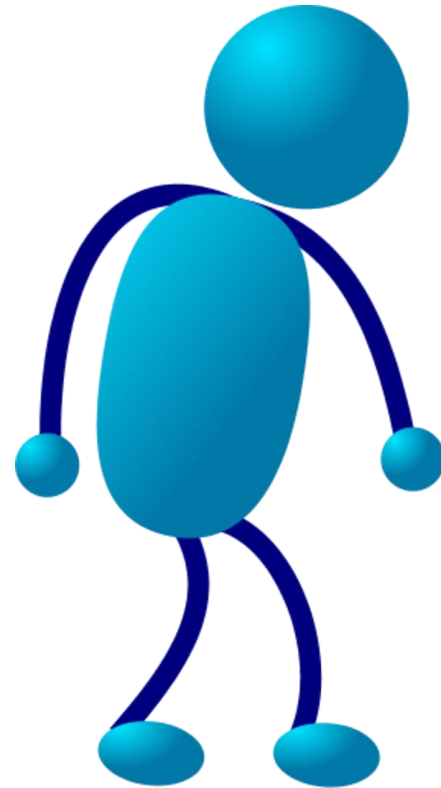
Expenses



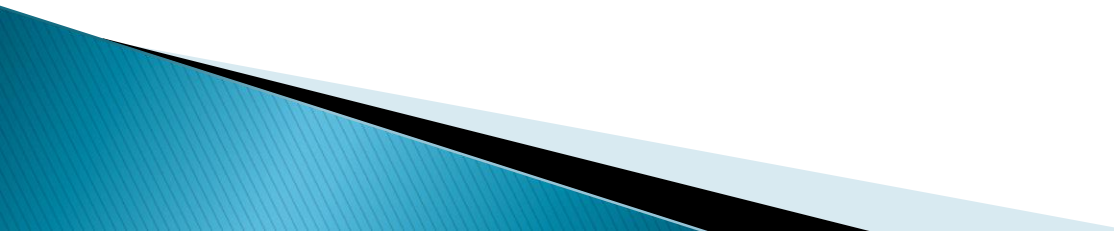
**#PPIMethods**

# Taking time out

- ▶ If you need to take a breather or 'duck out' for a bit that is fine.....
- ▶ Cafe over the way....

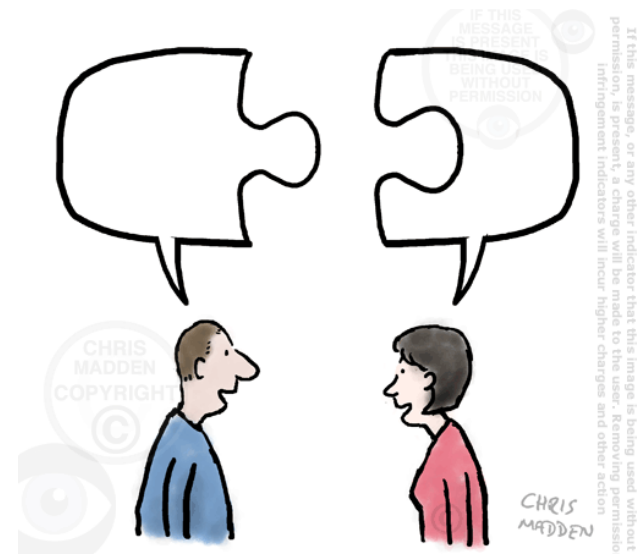


# Overview

- ▶ Some introductions, sharing experience and Bingo!
  - ▶ Overview of PPI and considerations for methods and approaches
  - ▶ Overview of four method areas
  - ▶ Afternoon group work – discussion and task focussed
  - ▶ Wrap up and reflections
- 

# Getting to know each other

- ▶ Introduce yourself
- ▶ We sent you some questions before you came today....please share any aspect of these...
- ▶ If you have not had a chance to reflect on these then your experiences in PPI with your colleagues



# Whilst you are chatting....

- ▶ Please complete the **PPI BINGO** sheet on your table
- ▶ Once you have crossed off all of the Bingo items – someone shout **‘HOUSE’** and there is a prize.





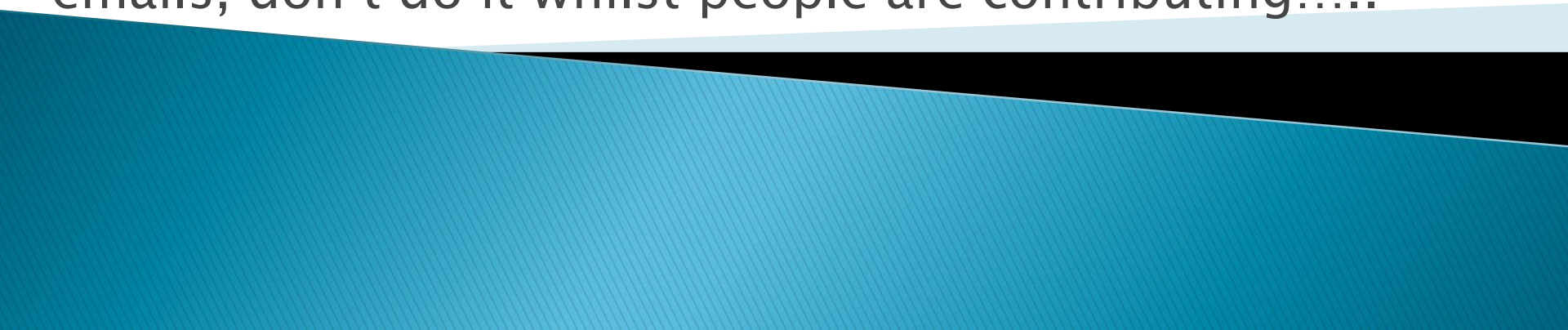
# How best to work together?

Equity of voice – all participants have something of value to contribute to this workshop

Respectful & active listening throughout

Jargon watch

Please mute your phones, if you need to check your emails, don't do it whilst people are contributing.....



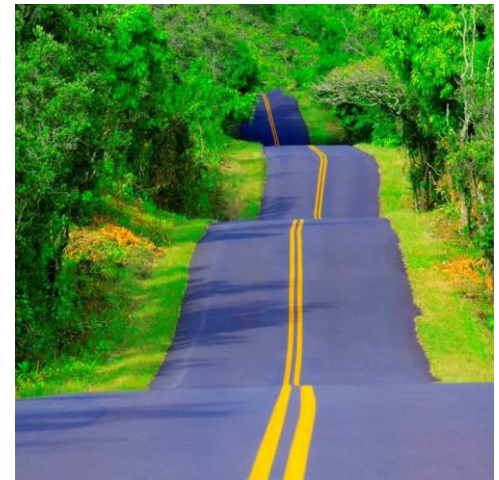


# Help is at hand!



# Starting as we mean to go on...

- ▶ Values and principles in Patient and Public Involvement?
- ▶ Minimum expectations of each other?
- ▶ What do we mean by Patient and Public Involvement?



Whatever PPI methods or approaches  
we use.....

What should we consider in our work  
together?

Chat for 5 mins please...



# Lots of examples for you to use

- ▶ INVOLVE (handout)
- ▶ Healthcare Quality Improvement Partnership (handout)
- ▶ National Voices and TLAP (Think Local Act Personal)
- ▶ NICE
- ▶ Heathwatch UK



# Not forgetting....

- ▶ That good PPI is as much about human relationships and interactions as well as methods



# Standards are the next logical step..

- ▶ Considered by many groups in Northern Ireland (Health and Social Care), Scotland (Community Engagement) 4PI (Mental Health) and Global (Health Technology Appraisal)

<https://sites.google.com/nihhr.ac.uk/pi-standards/resources/examples-frameworks-and-user-guides>

- ▶ Ongoing work –register for the standards network here

<https://sites.google.com/nihhr.ac.uk/pi-standards/standards-network>



# What do we mean by Patient and Public Involvement?



**SUPPORT**



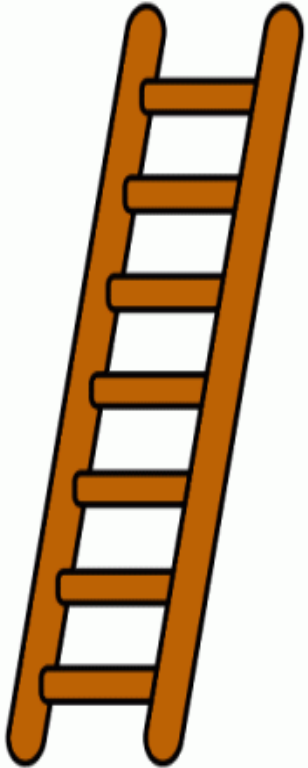
empower  
yourself

**GET INVOLVED**



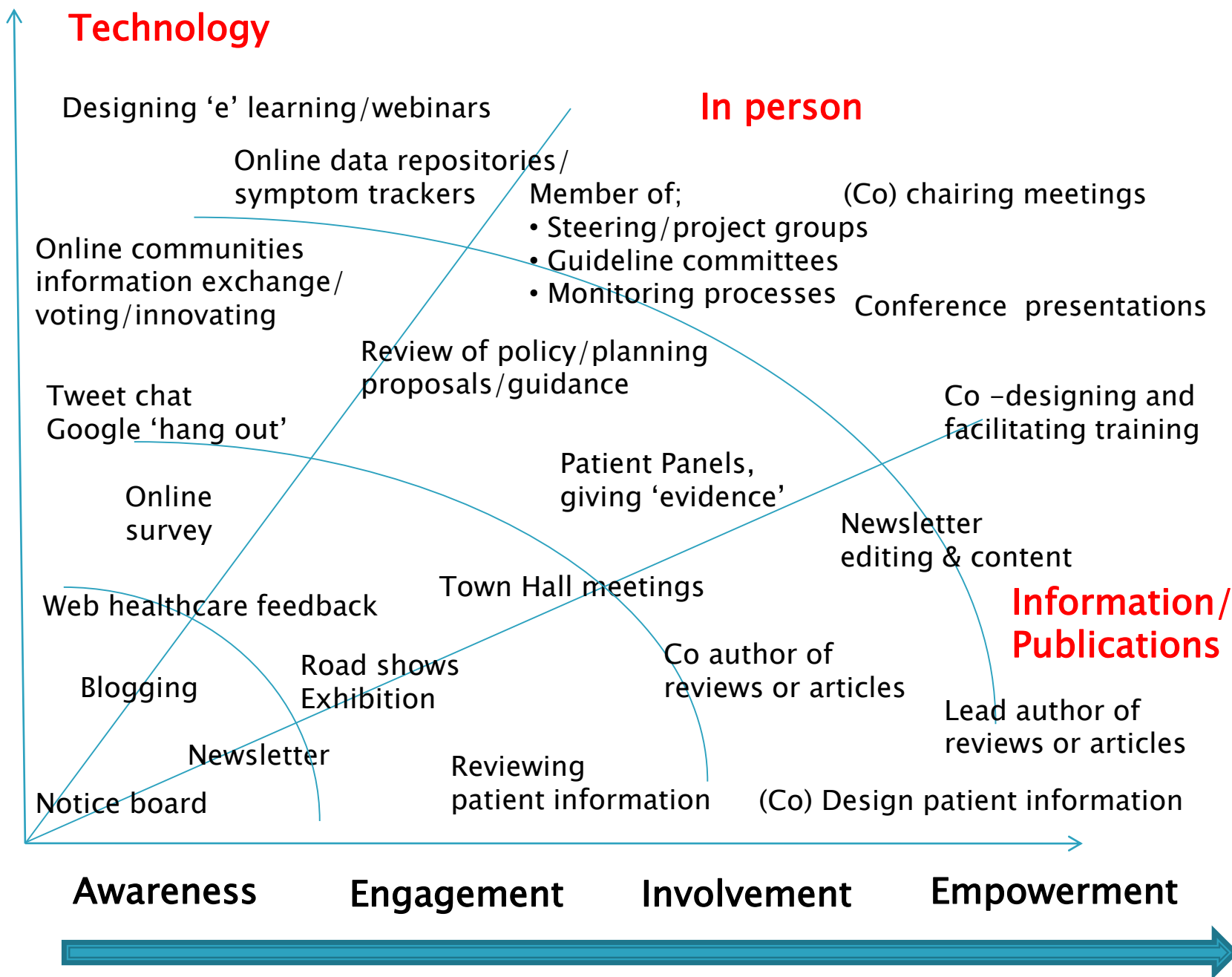


# A ladder of participation (Arnstein's ladder of citizen participation 1969)



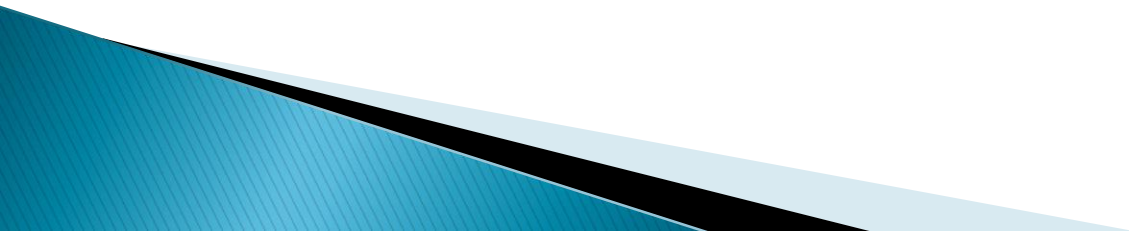
- ▶ **Level 5:** 'You do what is important and needed, and we will support you'
- ▶ **Level 4:** 'What do you think we should be doing? OK let's do it together, and we will support you'
- ▶ **Level 3:** 'Please get involved in what we are doing, and we will support you'
- ▶ **Level 2:** 'What do you think about what we are doing?'
- ▶ **Level 1:** 'Here's what we are doing'

Thanks to e-Patient Dave deBronkart

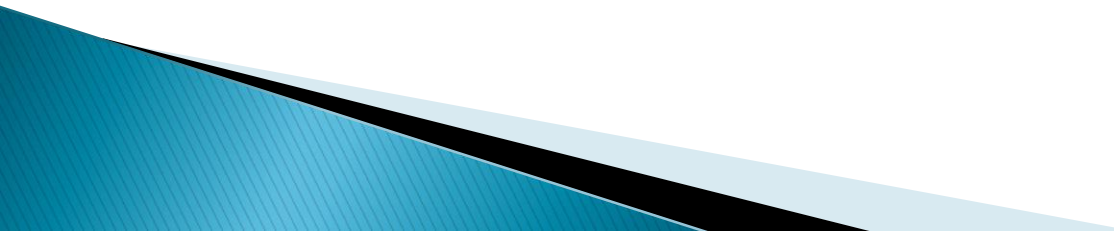


**Four approaches and techniques –  
overview;**

**Sarah, Sian, Sally, Sandra**



# Public Involvement and Priorities

- ▶ Recent history in health/social care, much more embedded in local government, system design
  - ▶ Advent of internet and social media – a game changer
  - ▶ Rise of ‘populism’ brings advantages and challenges!
- 

**“It’s usually people of prestige  
and affluence who advise  
people of influence”**

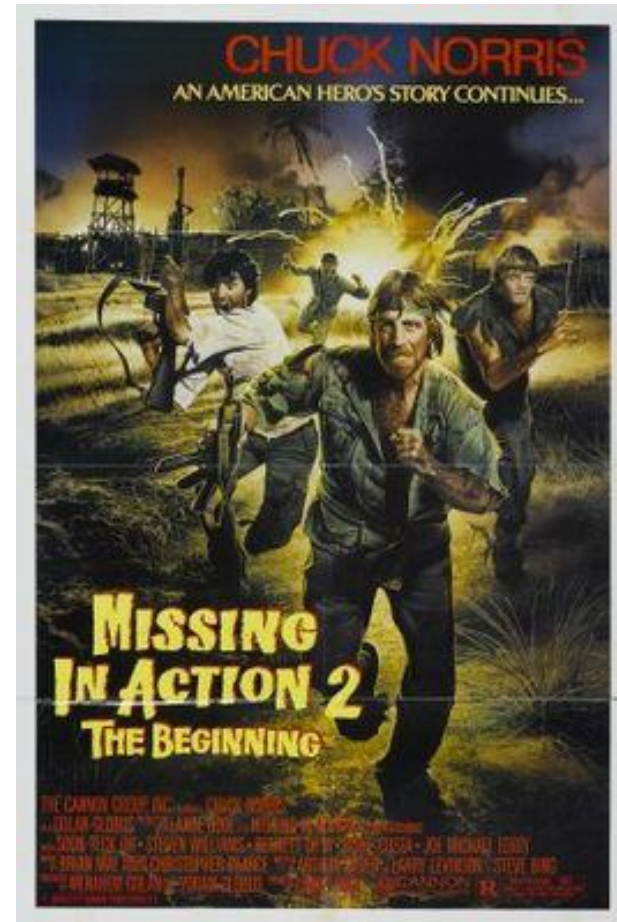
John Bell (Iona Community) – Thought for the day – BBC Radio 4  
18/03/13



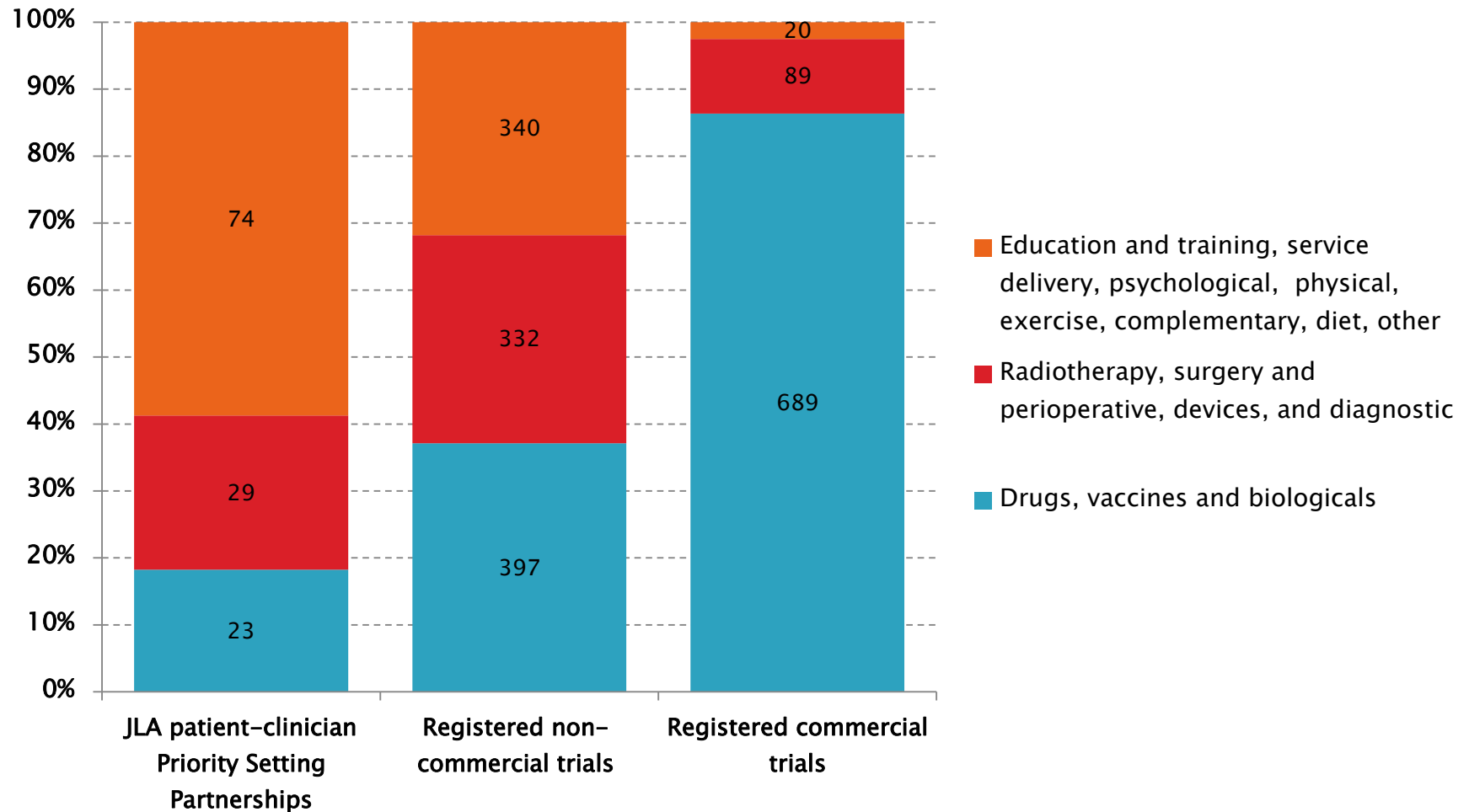
# Health priorities

- ▶ missing in action; not happening
- ▶ missing the mark; not resonating with our public
- ▶ missing the point; sometimes focusing on the wrong thing

▶ Adapted from [www.cruxcatalyst.com](http://www.cruxcatalyst.com)



# Interventions mentioned in commercial trials, non-commercial trials and research priorities identified by James Lind Alliance Priority Setting Partnerships, 2003–2012.

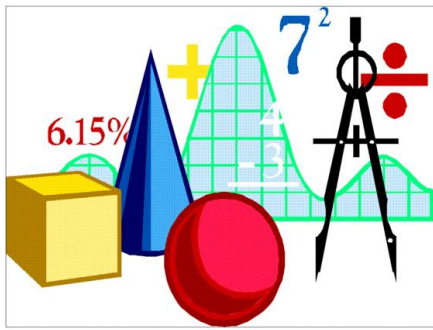


*Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch*

Crowe S, Fenton M, Hall M, Cowan K, Chalmers I

Research Involvement and Engagement 2015, 1:2 doi:10.1186/s40900-015-0003-x





## ► Technical

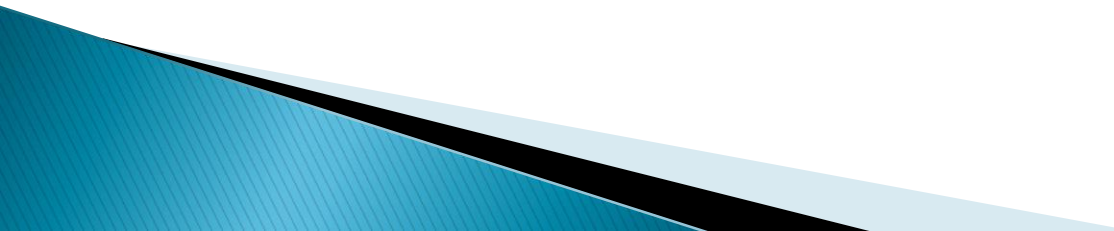
- use of existing data e.g. disease prevalence, economic burden, other measures
- Existing priorities?
- Expressed or identified need, guidance and policy plans, commissioning health services
- Use of criteria E.g. cost
- Horizon and environmental scanning




## ► Interpretive

- Processes to generate, prioritize, and validate priorities
- Surveys (e.g. Delphi)
- Conversations and discussion with people (stakeholders); in workshops, meetings (e.g. Nominal Group Technique)
- Crowd sourcing, online exchange
- Access patient narratives, 'helpline' data and other proxy sources of perspectives

# Some methods/approaches

- ▶ **‘Q Sort’** – investigate perspectives of participants who represent different stances on an issue, participants rank and sort a series of statements.
  - ▶ **Delphi** – ‘experts’ answer questionnaires in two or more rounds, may conclude with a consensus workshop
  - ▶ **Consensus workshops** – consensus is reached when all participants are willing to move forward together, even if they do not agree on all the details.
  - ▶ **Citizen Panels** – large, demographically representative group of citizens used to assess public preferences and opinions
- 

# Small Group Work

- 1. Increasing awareness using social media – Sarah Chapman, Oliver Evans and Lynne Maddocks**
  - 2. Achieving a shared goal or strategic direction – Sian Rees**
  - 3. Developing priorities – Sally Crowe**
  - 4. Identifying and planning to reach target audiences – Sandra Regan and Alison Monk**
- 

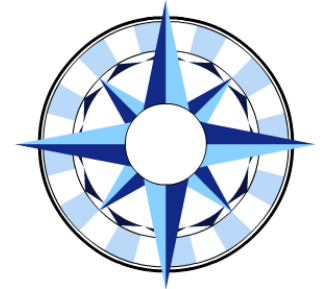
Research  
Involvement and  
Engagement



<http://www.nationalvoices.org.uk/>

**healthwatch**

<http://www.healthwatch.co.uk/about-us>



<http://www.researchinvolvement.biomedcentral.com>



**RESEARCH  
FOR ALL**

<http://www.ingentaconnect.com/content/ioep/rfa/2017/0000001/00000001>



**INVOLVE**

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

# Evaluation!

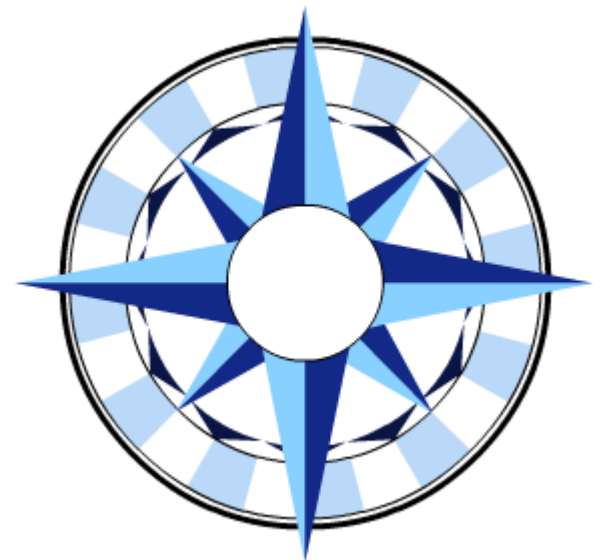
- ▶ Please fill in the form.....
- ▶ We can send it via email if you prefer....





# Participation Compass

- ▶ <http://participationcompass.org/article/index/method#5233>
- ▶ Fantastic and comprehensive overview of methods and approaches for participatory working





# Co Production

- ▶ *Co-production is not just a word, it's not just a concept, it is a meeting of minds coming together to find a shared solution. In practice, it involves people who use services being consulted, included and working together from the start to the end of any project that affects them.\**

\* Think Local Act Personal (2011) Making it real: Marking progress towards personalised, community based support, London: TLAP.



# Co production and other approaches;

- ▶ **Manage expectations;** relationships and outcomes
  - ▶ Check the **power dynamic and hierarchy**
  - ▶ **Value of the work and values that underpin the work** – share and debate
  - ▶ **Validity** – often the *‘stick that is shaken’* at PPI – intellectual openness, discuss hard and soft knowledge
  - ▶ **Pragmatism** – discuss what is feasible, achievable, and acceptable
- ▶ From: “Co-production: risks, limits, and how to overcome” Dr Matt Wood  
University of Sheffield Sir Bernard Crick Centre