

# Involving patients and the public in research

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# Scope of talk

- What is Patient and Public Involvement (PPI)?
- The values that underpin PPI
- The diversity of involvement stories
- Theorising PPI
- Challenges to PPI
- Assessing and evidencing PPI



# What is Patient and Public Involvement?

- INVOLVE defines public involvement in research as research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them.
- When using the term ‘public’ we include patients, potential patients, carers and people who use health and social care services.
- Source [www.invo.org.uk](http://www.invo.org.uk)



# What is Patient and Public Involvement?



# What values underpin PPI?

- Values associated with public involvement might be **personal** (e.g. relationships between researchers and the public based on respect and trust), **organisational** (e.g. public involvement leading to research of greater quality and relevance to the healthcare system) or **societal** (e.g. accountability and transparency of research processes to the wider community)



# Typology of values

Using our definition of values we have identified three broad categories of values that are associated with public involvement:

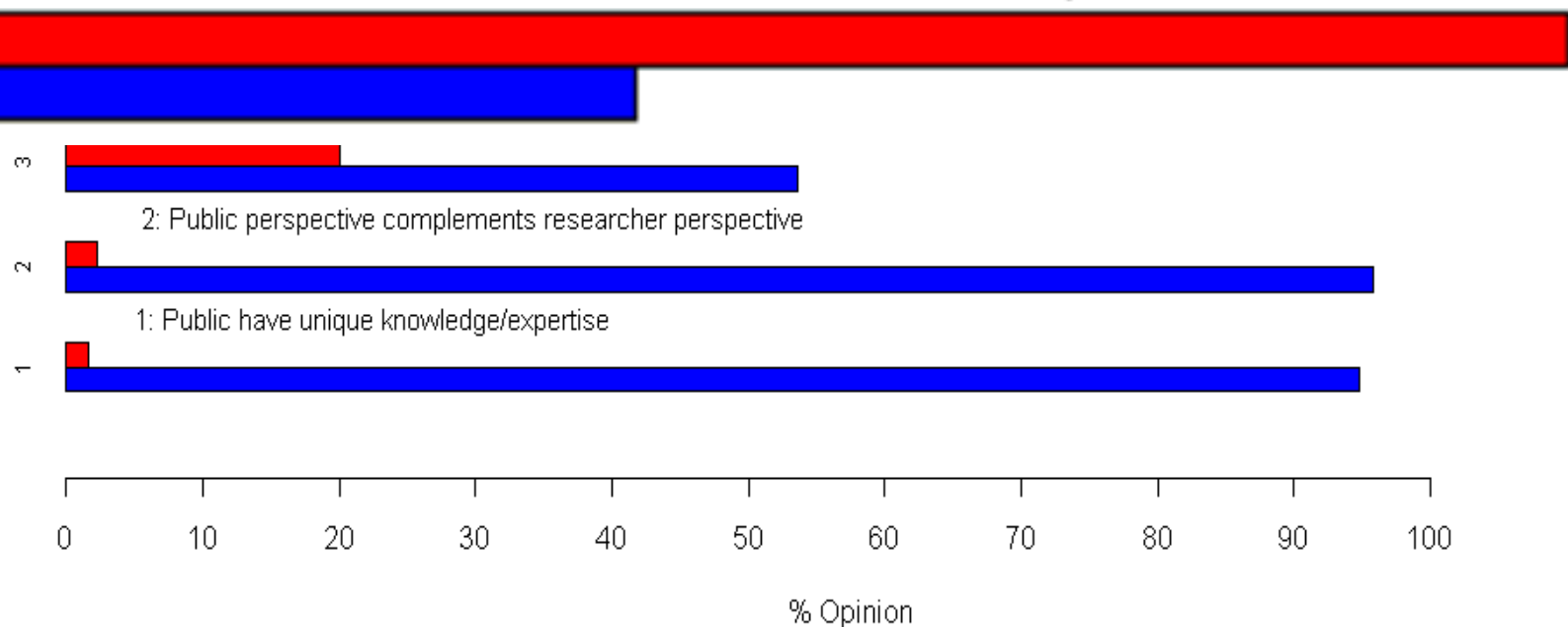
- Ethical and/or political concerns associated with public involvement in research – we call these *normative values*
- Concern with the consequences of public involvement in research – we call these *substantive values*
- Issues associated with the conduct of public involvement in research – we call these *process values*



## What kinds of knowledge should inform health and social care research?



## 4: Professionals are also users, so can represent user issues effectively







# Involving the Public in Health Services Research

NIHR CLAHC for the South West Peninsula

**NHS**

National Institute for  
Health Research



## Peninsula Public Involvement Group



Management  
Board



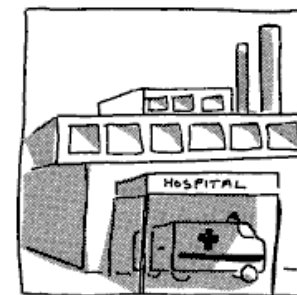
Working with other organisations in  
the South West



Generating  
research questions



Academic  
outputs



Improved  
services and  
treatments



Doing research



Providing  
information



Training

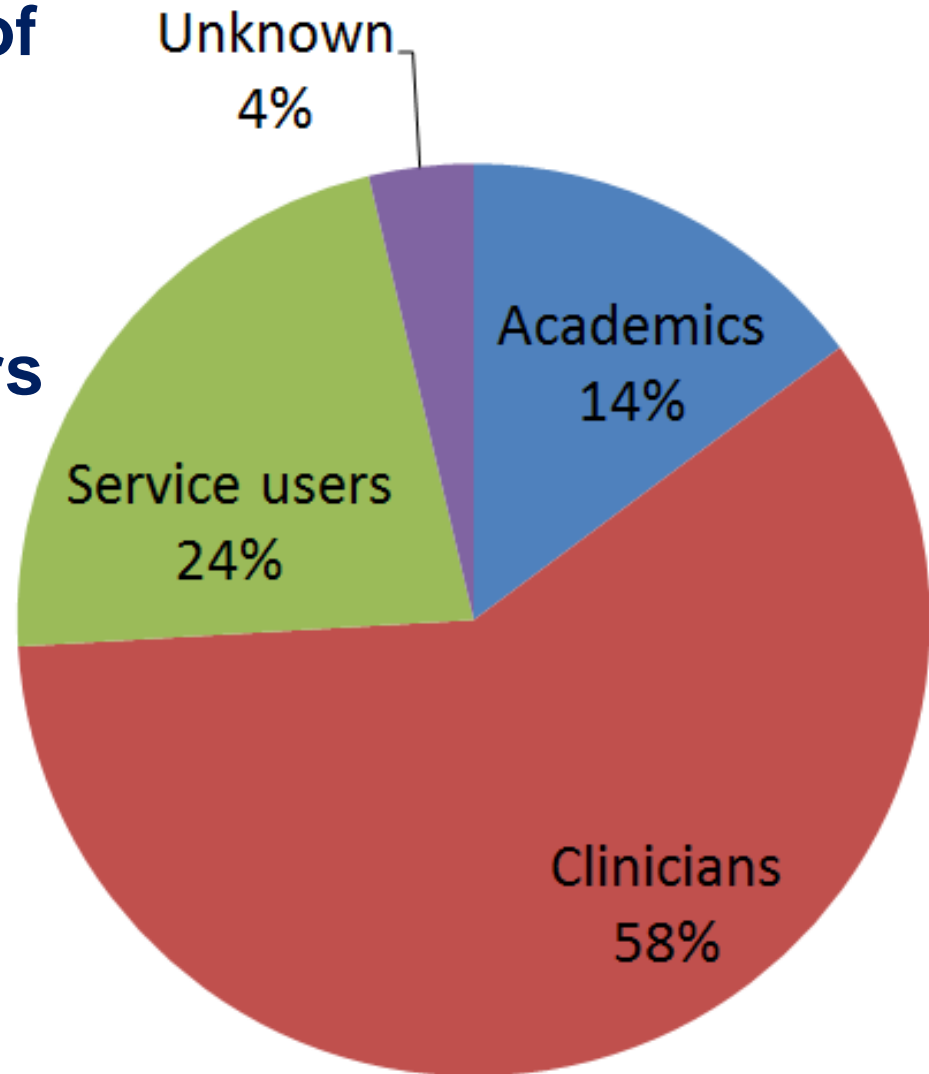


Prioritisation

# Involvement in the research cycle



**In previous rounds  
almost a quarter of  
PenCLAHRC's  
prioritised  
questions came  
from service users**



# Involvement stories

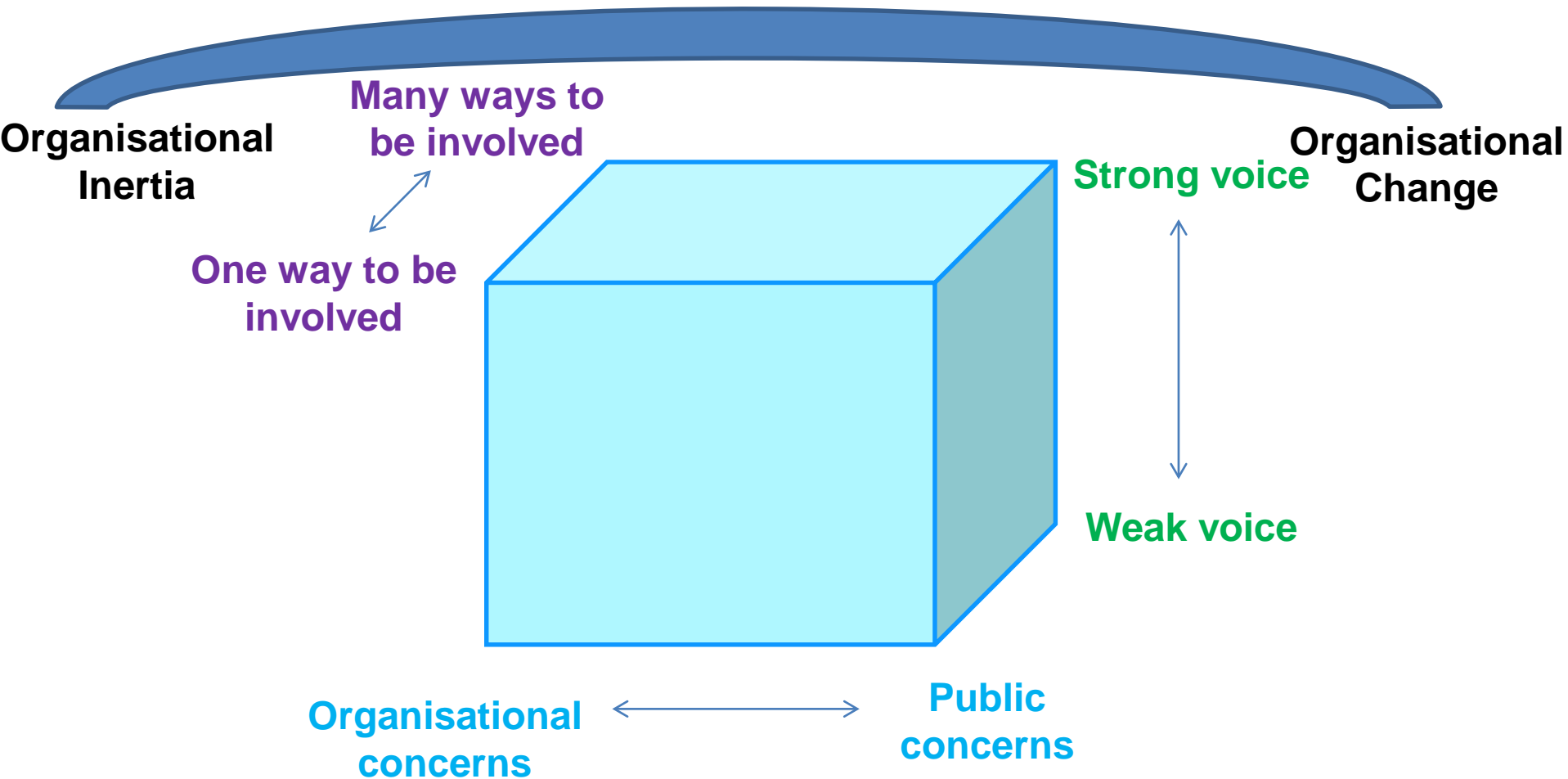




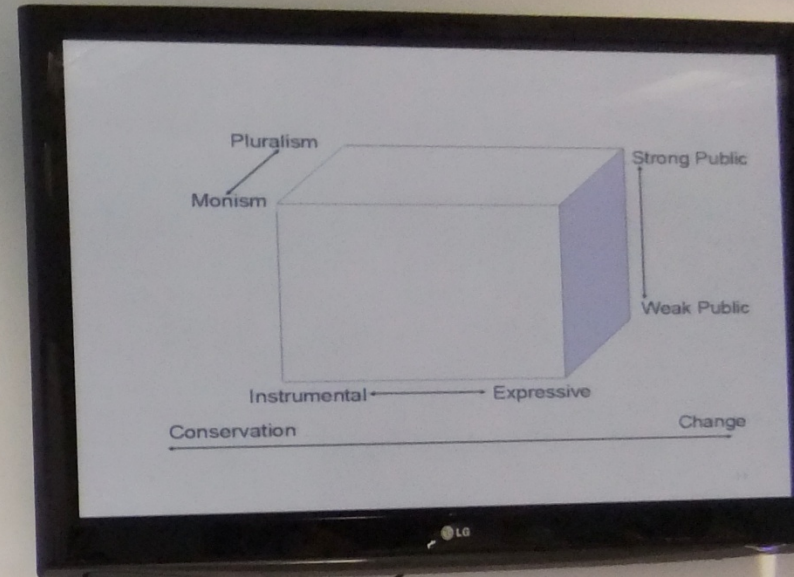
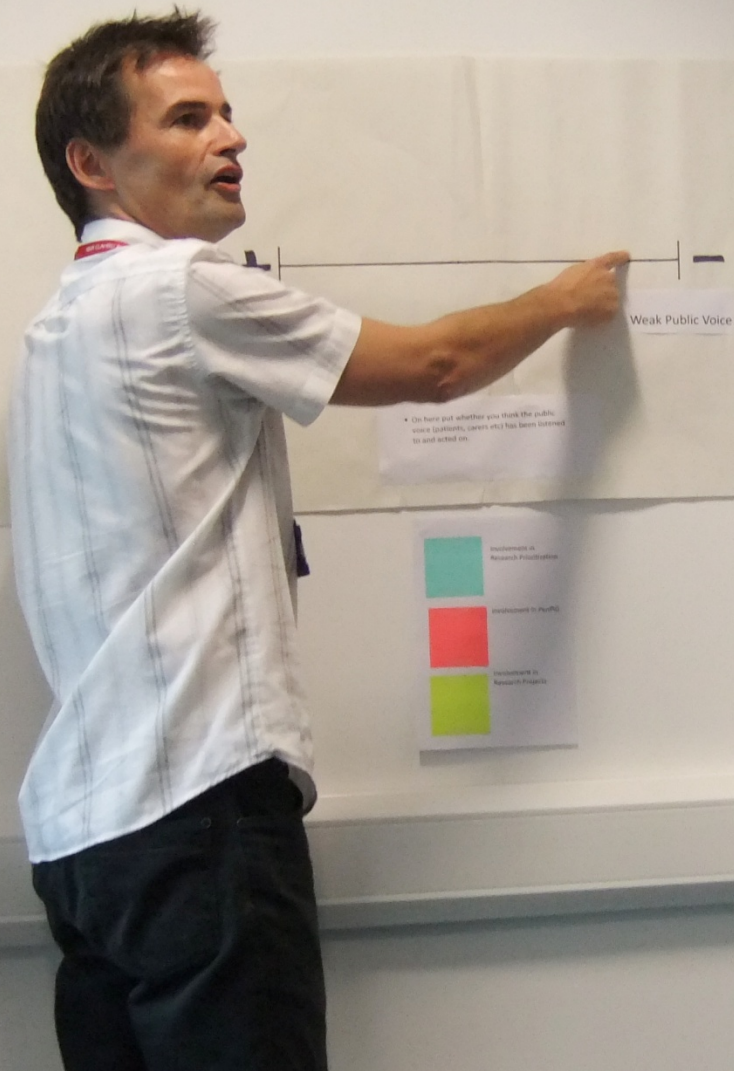
# Liraglutide



# How do we conceptualise such a diverse and complex phenomenon as PPI?



\*Adapted from Gibson et al., Theoretical dimensions for an emancipatory concept of patient and public involvement. *Health*, 16: 531–547, 2012.





# Organizational Concerns vs. Public Concerns

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Involvement in  
Research Prioritization



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# Weak Public Voice vs. Strong Public Voice

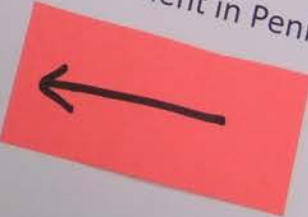
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Involvement in  
Research Prioritization



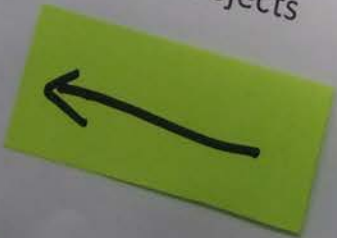
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Involvement in PenPIG

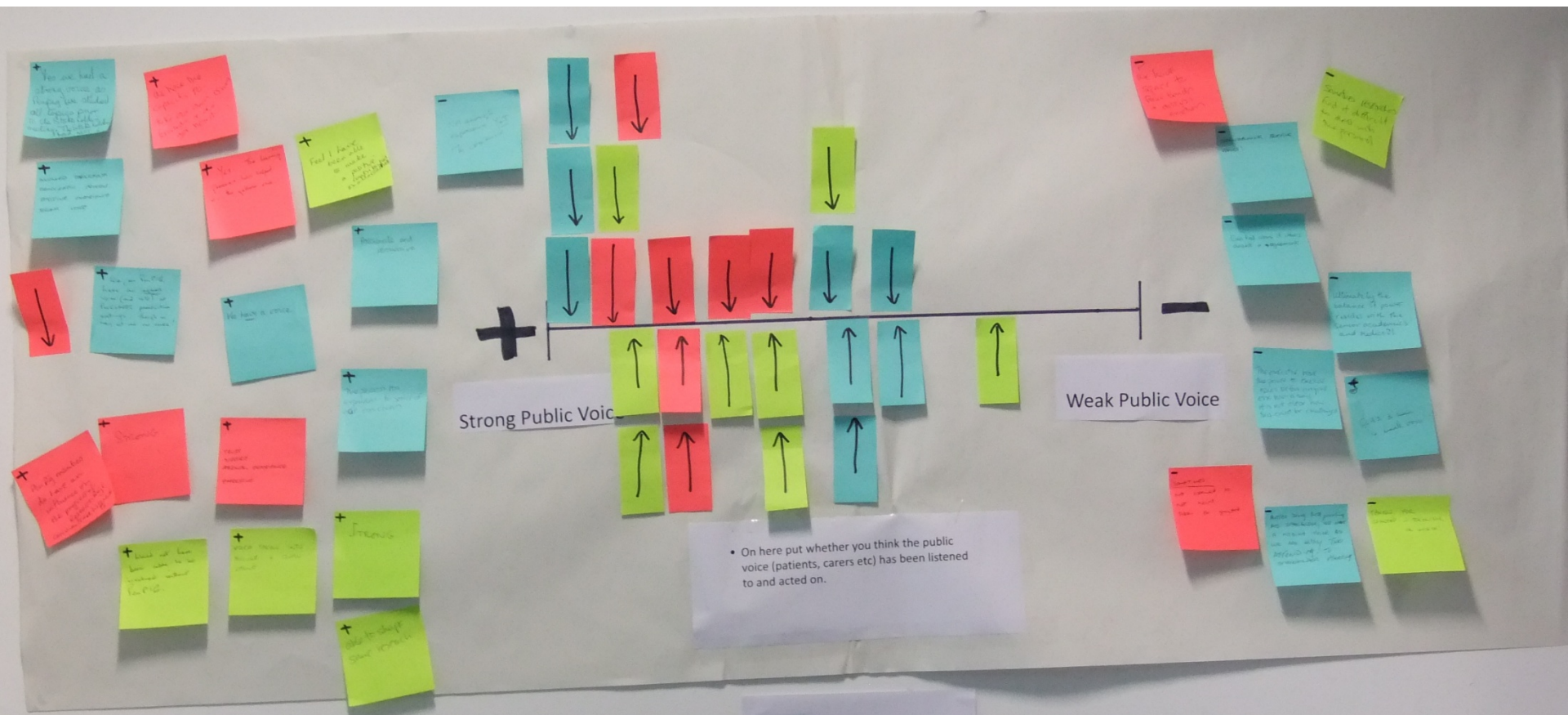


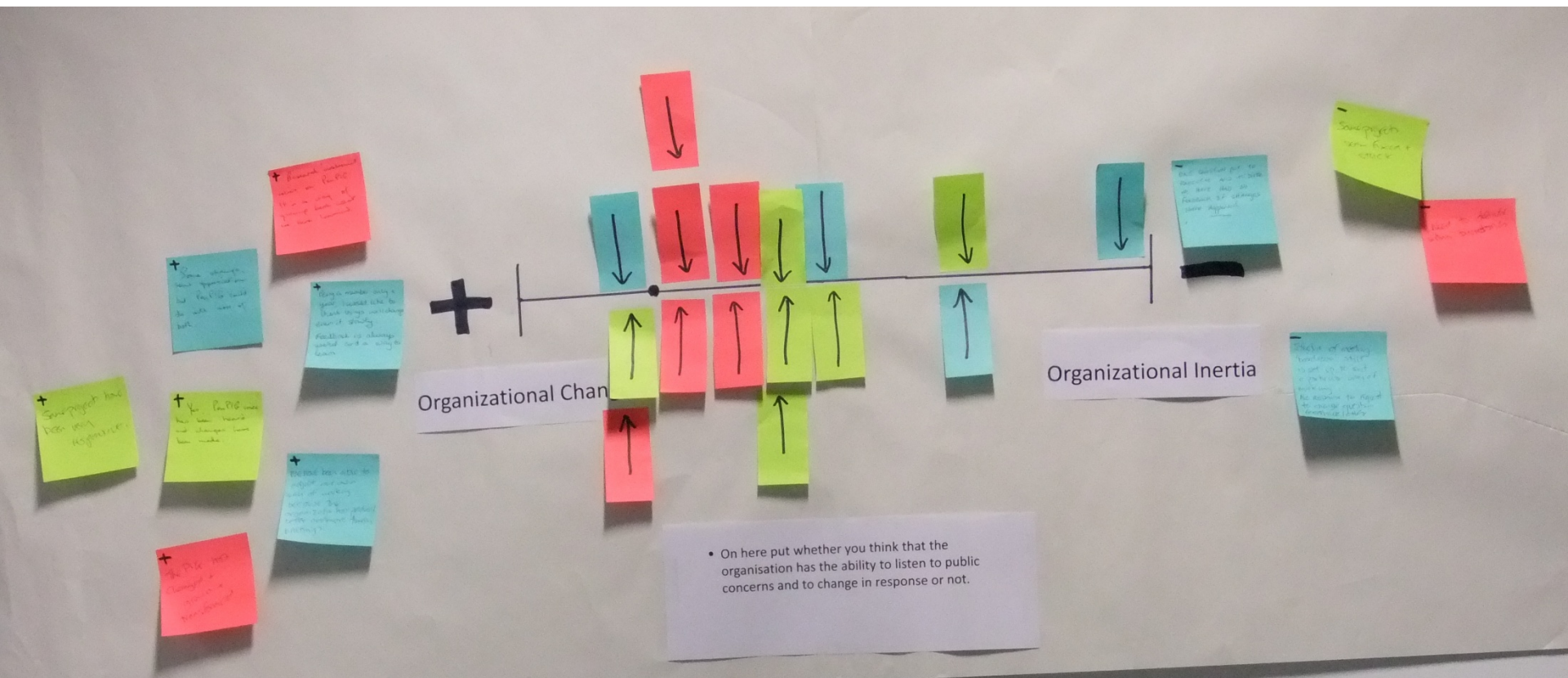
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Involvement in  
Research Projects

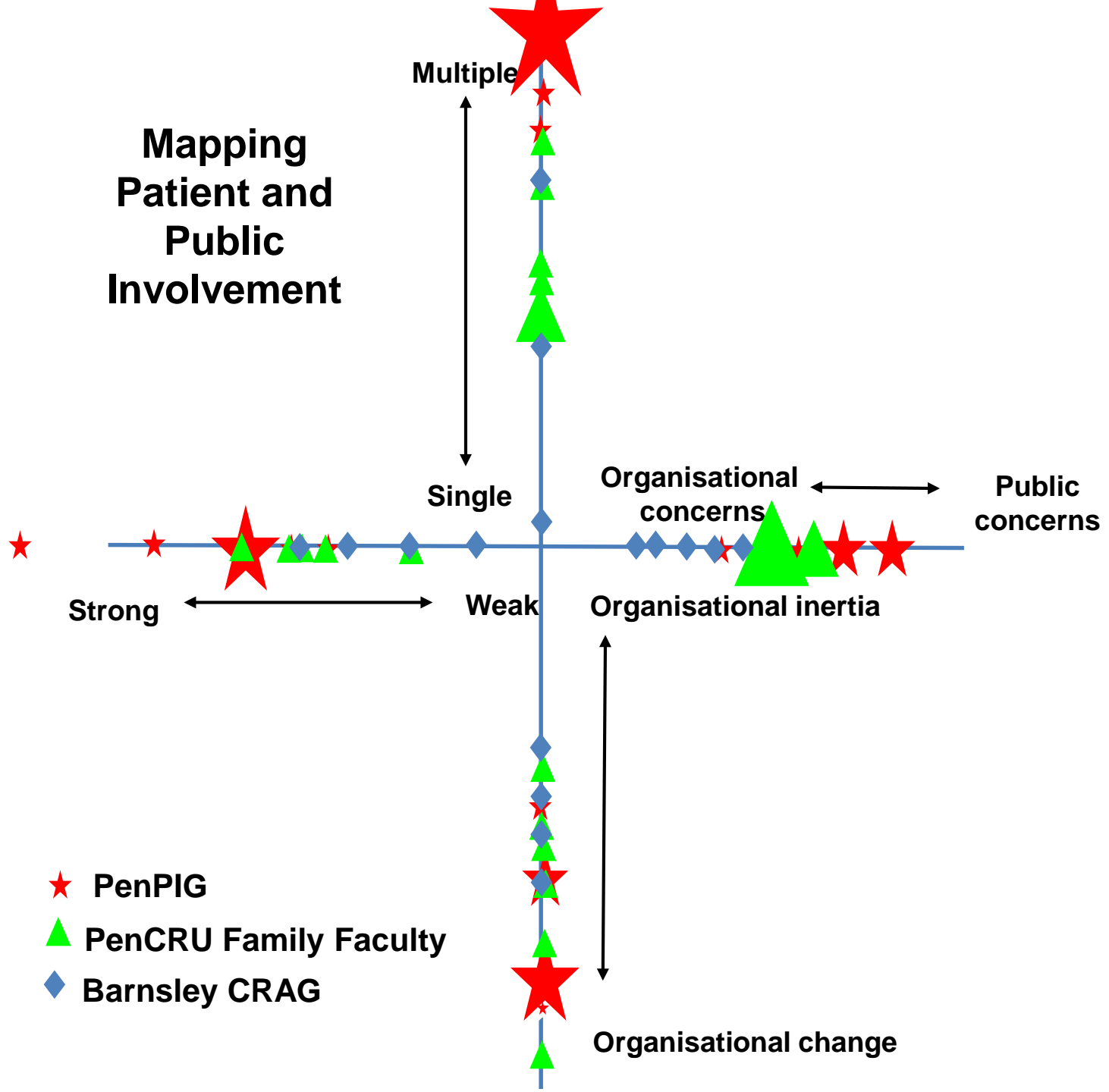








# Mapping Patient and Public Involvement

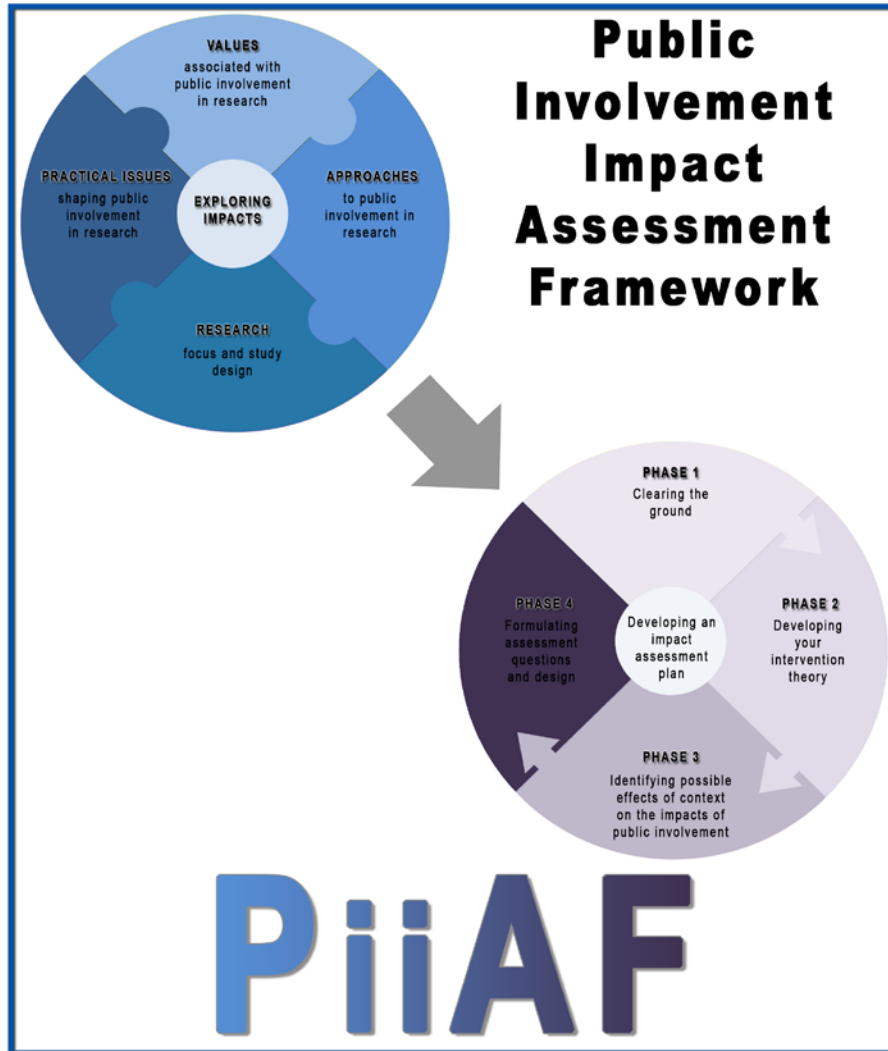


# Challenges to PPI

- Ives and Redwood critique
- Tokenism
- Austerity
- Commercial interests



# How can we assess the impact of Patient and public involvement?



<http://piiaf.org.uk>

# Guidance for Reporting Involvement of Patients and Public

- The GRIPP checklist. Staniszewska et al (2011)
- Gripp2 (Universities of Warwick and Oxford)
- Developing a reporting guideline, through expert consensus to improve the quality and transparency for reporting of PPI in health and social care research.



# Further information

- Gibson A, Britten N, Lynch J. (2012) **Theoretical Directions for an Emancipatory Concept of Patient and Public Involvement.** Health, 16(5) 531-547
- Staniszewska et al (2011). **The GRIPP checklist.** International Journal of Technology Assessment for Health Care, 27 (4):391-399PiiAF
- **Healthtalkonline :** <http://www.healthtalk.org/>
- **INVOLVE :** [www.invo.org.uk](http://www.invo.org.uk)
- **PenCLAHRC**
  - <http://clahrc-peninsula.nihr.ac.uk>
  - <http://clahrc-peninsula.nihr.ac.uk/patient-public-involvement-in-research.php>
  - <http://clahrc-peninsula.nihr.ac.uk/ppi-conference.php>
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