

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



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)



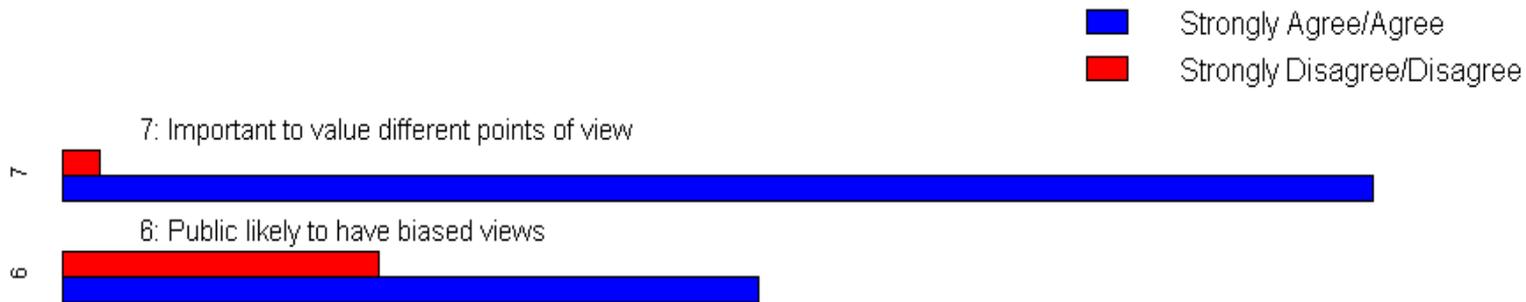
Typology of values

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

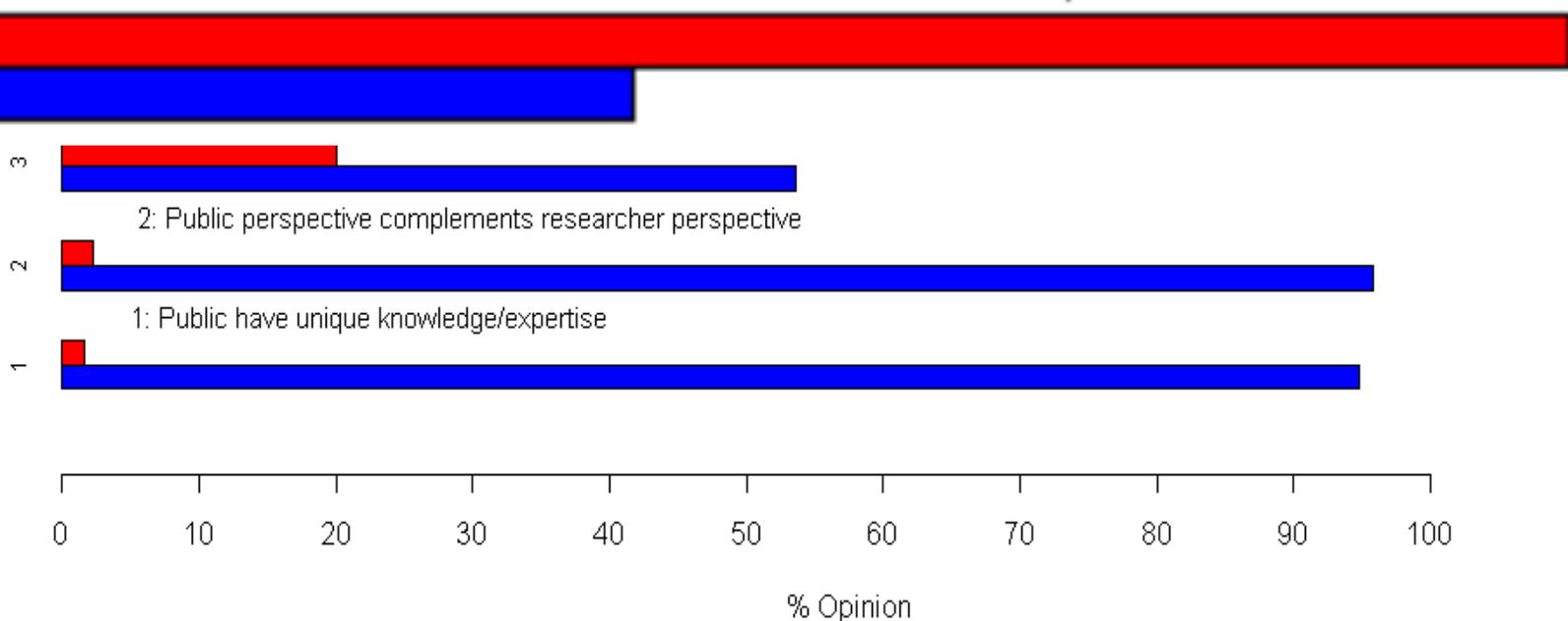
- Ethical and/or political concerns associated with public involvement in research – we call these *normative values*
- Concern with the consequences of public involvement in research – we call these *substantive values*
- Issues associated with the conduct of public involvement in research – we call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



National Institute for Health Research



Peninsula Public Involvement Group



Working with other organisations in the South West



Management Board



Generating research questions



Training



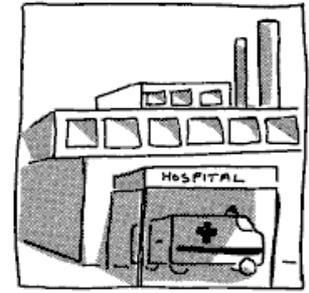
Prioritisation



Doing research



Academic outputs

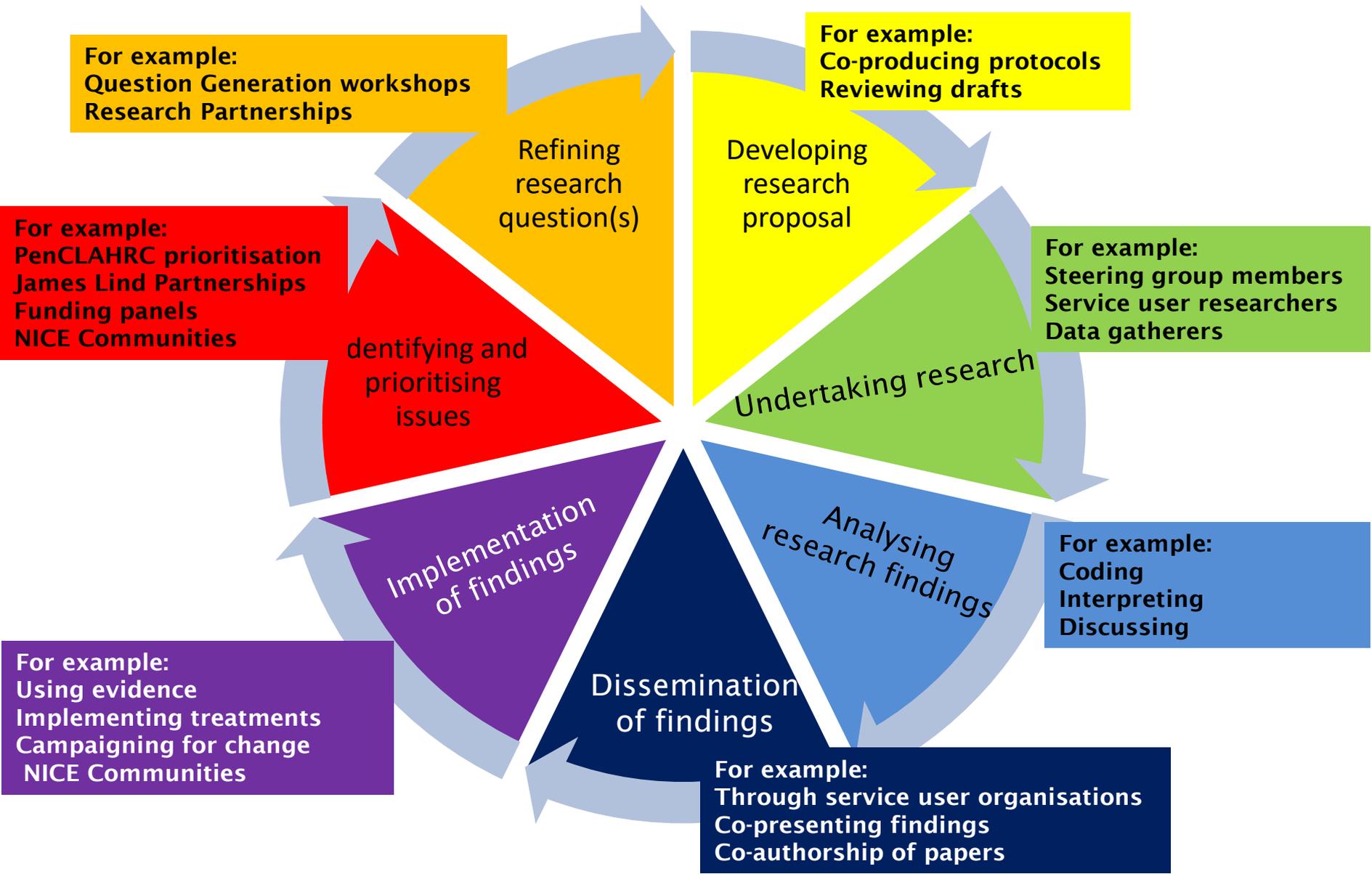


Improved services and treatments

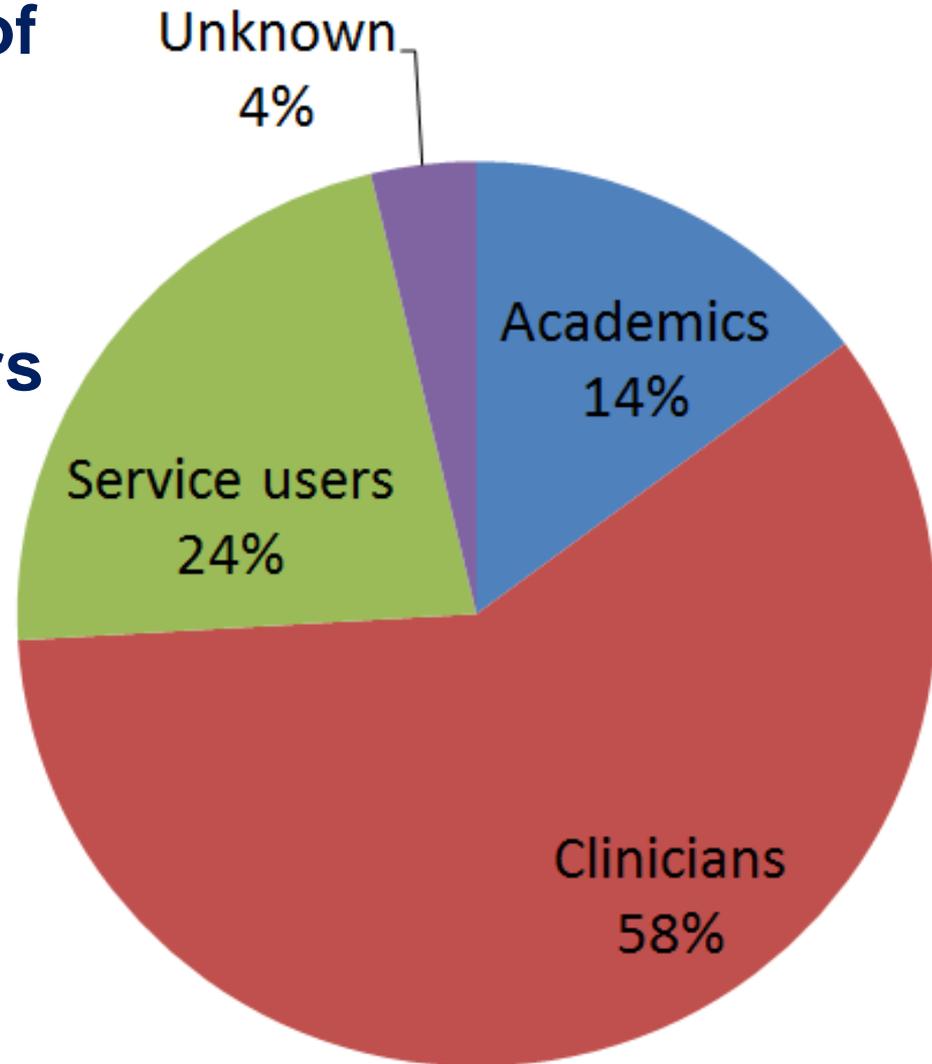


Providing information

Involvement in the research cycle



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



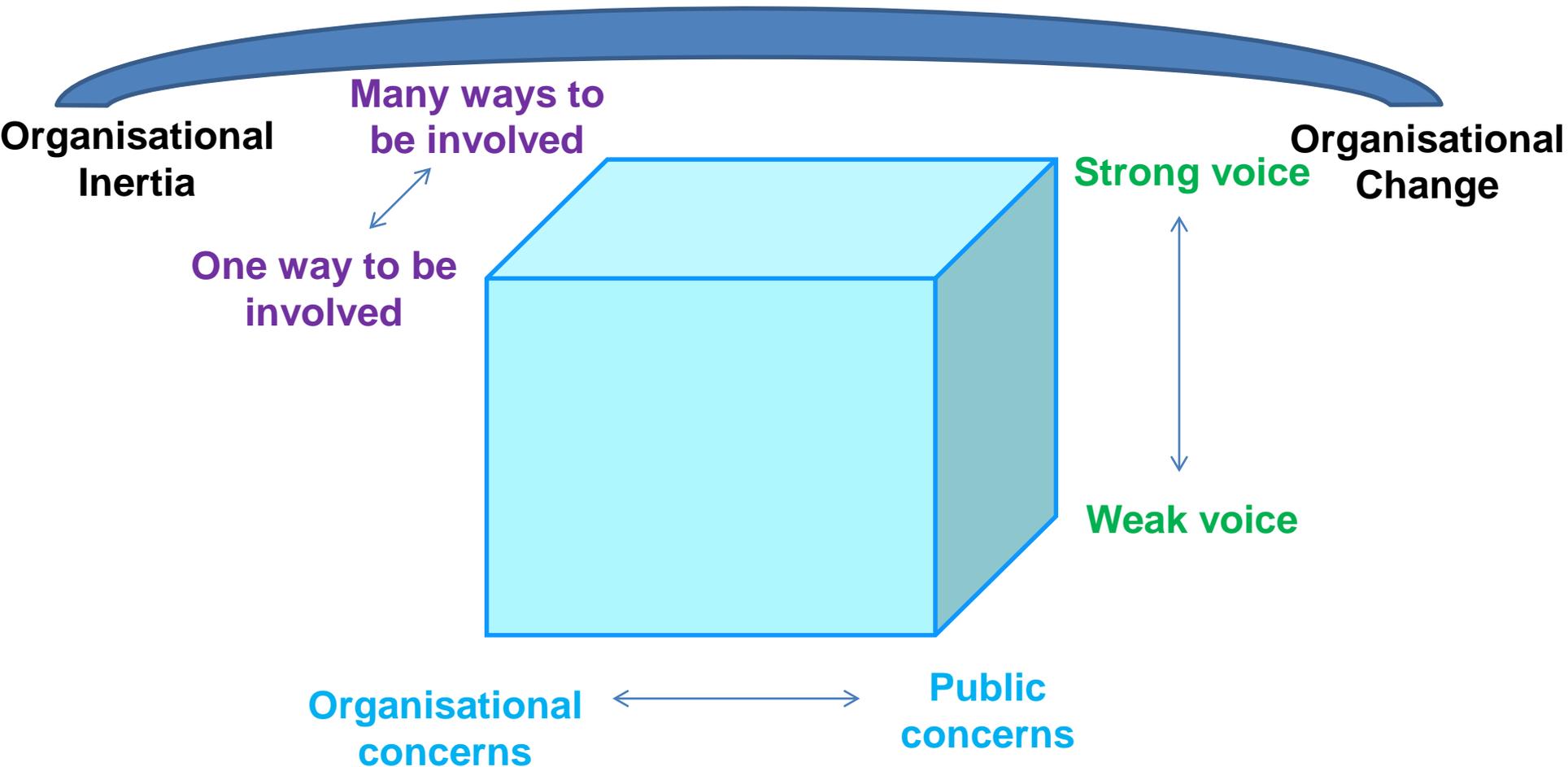
Involvement stories



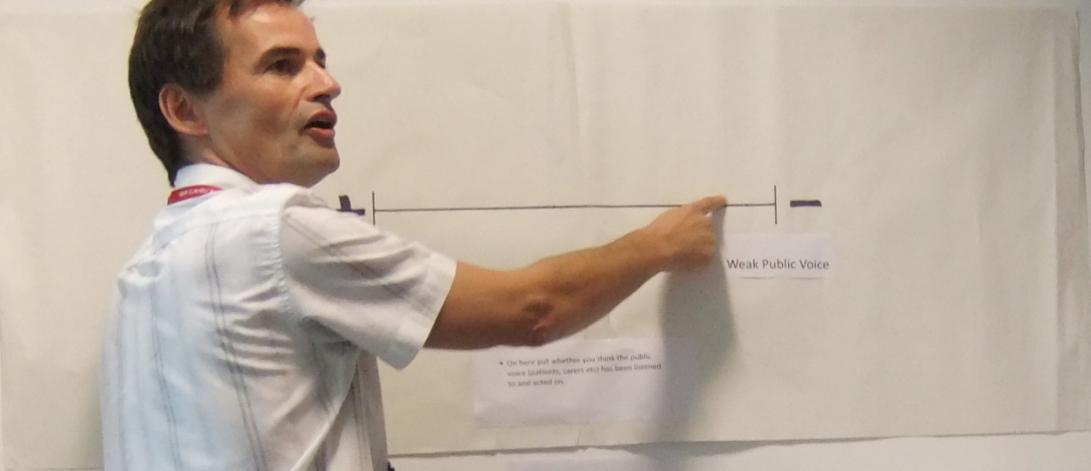
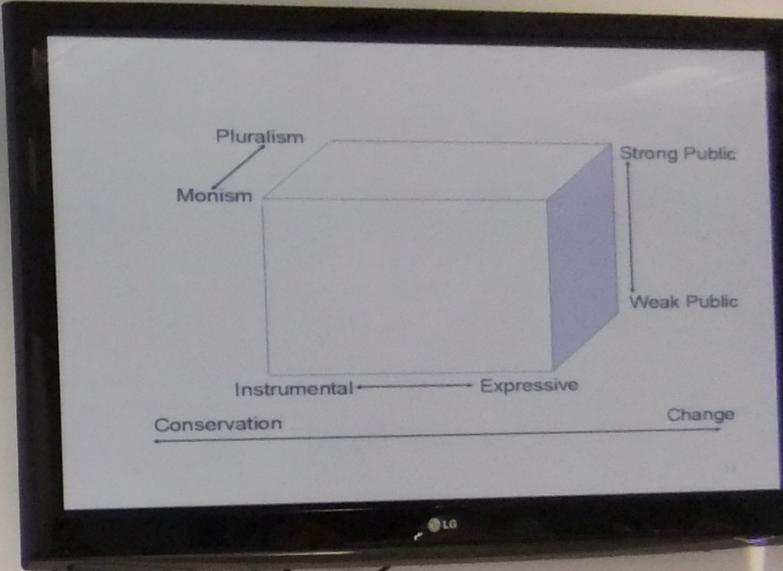
Liraglutide



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

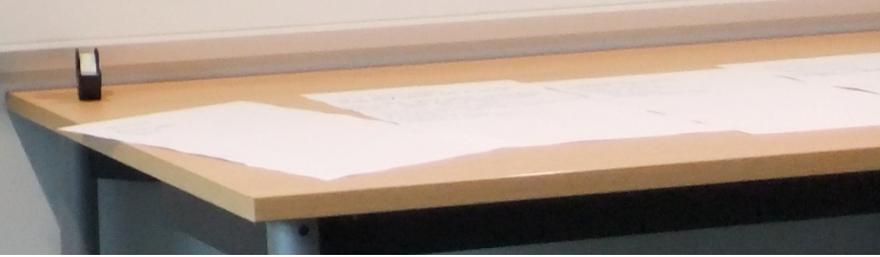


*Adapted from Gibson et al., Theoretical dimensions for an emancipatory concept of patient and public involvement. *Health*, 16: 531–547, 2012.



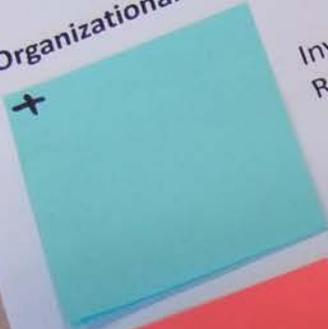
• Do have got whether you think the public voice (customers, carers etc) has been listened to and acted on.

- involvement in Research/Innovation
- involvement in Prof/PD
- involvement in Research/Projects

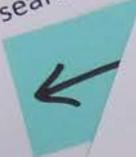


Organizational Concerns vs. Public Concerns

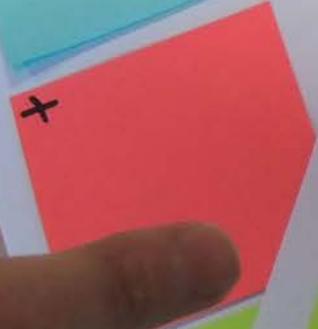
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Involvement in
Research Prioritization



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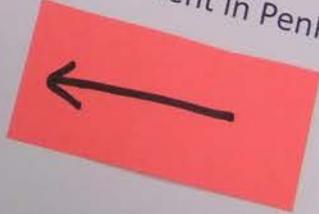


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Involvement in PenPIG



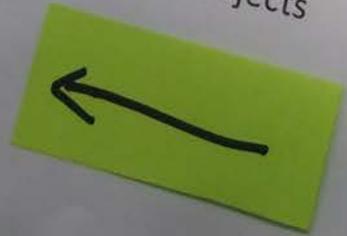
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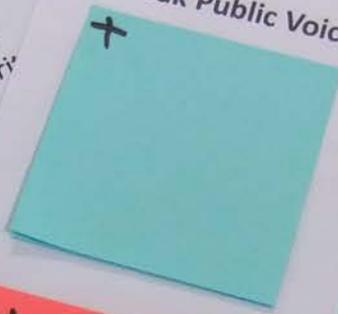


Involvement in
Research Projects

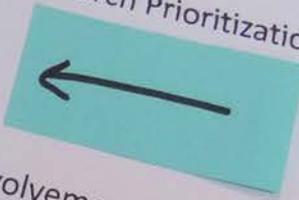


Weak Public Voice vs. Strong Public Voice

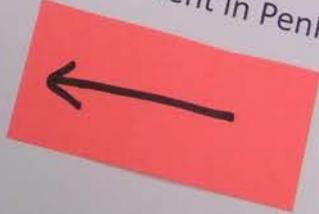
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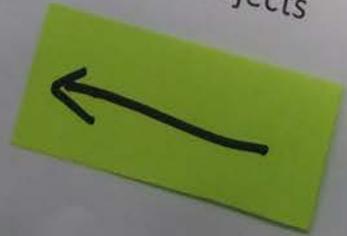
Involvement in
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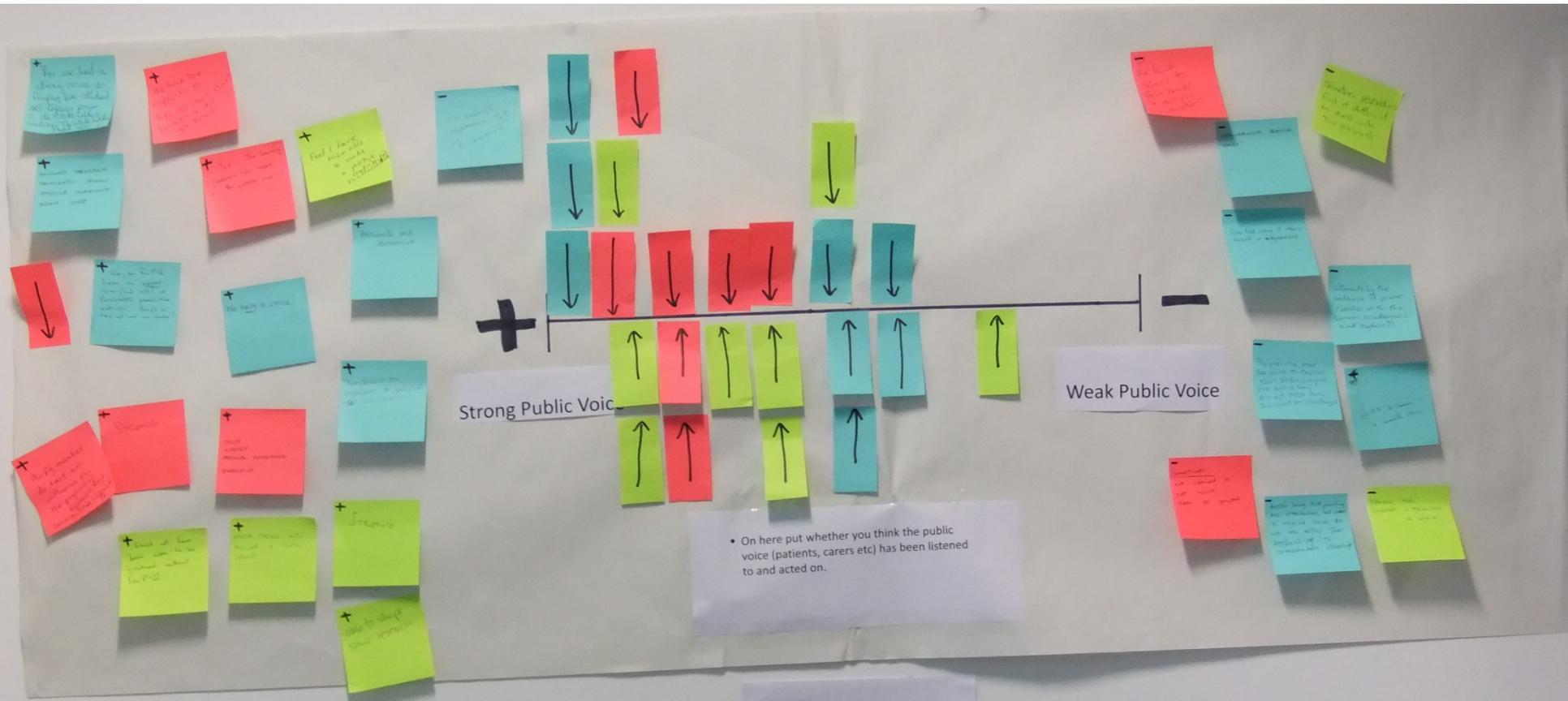


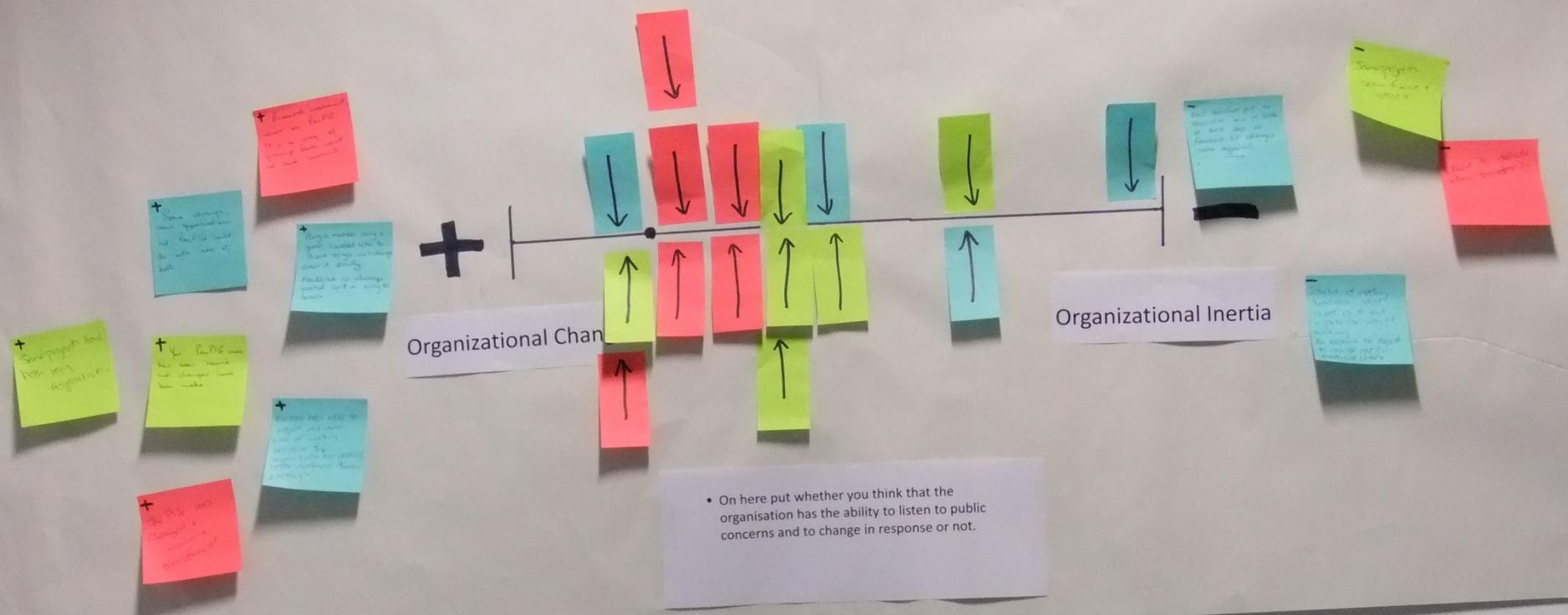
Involvement in PenPIG



Involvement in
Research Projects



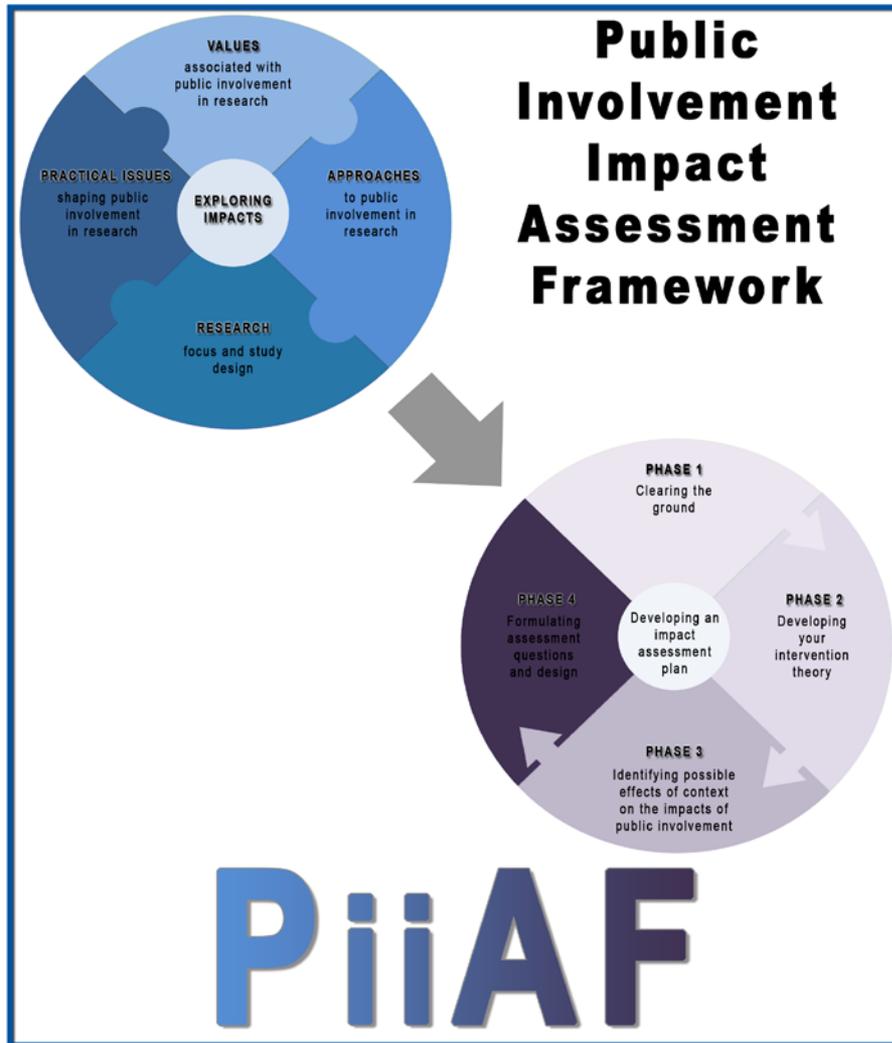




Challenges to PPI

- 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
- **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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