NIHR | Applied Research Collaboration South London

A few pointers on Patient and Public Involvement evaluation

Stan Papoulias
Service User Research Enterprise
King's College London

- **Intensifying interest on PPI evaluation**
- **Variance of models – emphasis on scientific rigour**
- **Contestation - over what evaluation should include and its purpose**

E.g.

Boivin A, L'Espérance A, Gauvin FP, Dumez V, Macaulay AC, Lehoux P, Abelson J. Patient and public engagement in research and health system decision making: A systematic review of evaluation tools. Health Expect. 2018 Dec;21(6):1075-1084

27 evaluation tools identified – 14 research specific
Mostly produced in UK, Canada and US

Centre of Excellence in Partnership with Patients and the Public

https://ceppp.ca/en/evaluation-toolkit/

Health Research

List view | Table view

All | Organization | Participants | Project

Scale

A Resource Toolkit for Engaging Patient and Families at the Planning Table

Survey

An Evaluation of In-Person and Online Engagement in Central Newfoundland

Questionnaire

Community Engagement and Participation in Research Measures

Objective

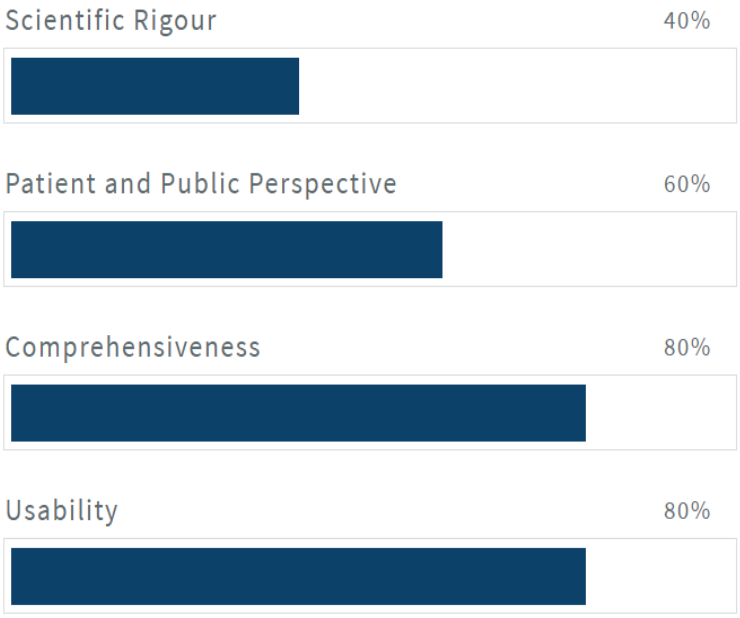
To help researchers assess the impacts of involving members of the public in health and social care research.

Reference

Popay, J., M. Collins, and with the PiiAF Study Group. "The public involvement impact assessment framework guidance." Universities of Lancaster, Liverpool and Exeter (2014).

Download : http://piiaf.org.uk/documents/piiaf-guidance-jan14.pdf

Assessment



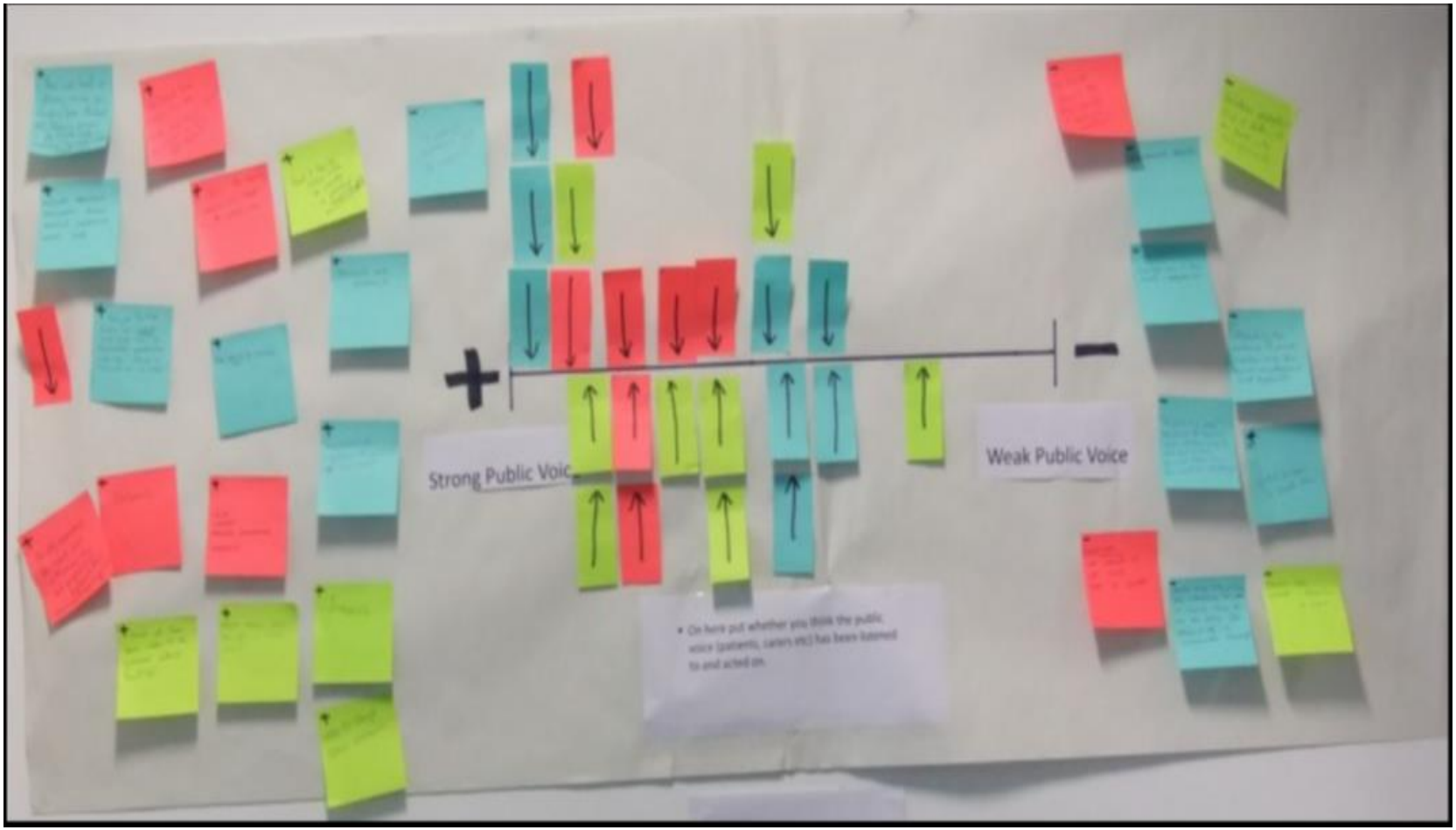
Issues to consider in PPI evaluation

- Ethical: what is valued and by whom (who matters)
- Methodological/Epistemological: what are the consequences of choosing a particular model of evaluation (what does it allow us to see and not see)
- Pragmatic: what is feasible?

What is valued and by whom?

"Evaluators need to be reflective about unspoken values and power imbalance underpinning patient and public involvement and its evaluation…. calls for evaluating the effect of PPI raise further questions about "effect on what and for whom"? While some researchers may involve patients and the public to increase study recruitment rates, patients and citizens may be more interested in ensuring that research answers questions and includes outcomes that matter to them and their communities."

Boivin A, Richards T, Forsythe L, Grégoire A, L'Espérance A, Abelson J, Carman KL. Evaluating patient and public involvement in research. BMJ. 2018 Dec 6



Gibson A, Britten N, Lynch J. Theoretical directions for an emancipatory concept of patient and public involvement. Health (London). 2012 Sep;16(5):531-47
Gibson A, Welsman J, Britten N. Evaluating patient and public involvement in health research: from theoretical model to practical workshop. Health Expect. 2017 Oct;20(5):826-835

what are the consequences of choosing a particular model of evaluation?

- E.g.
- A: PPI is a complex intervention
- B:PPI is ‘a conversation that supports learning’

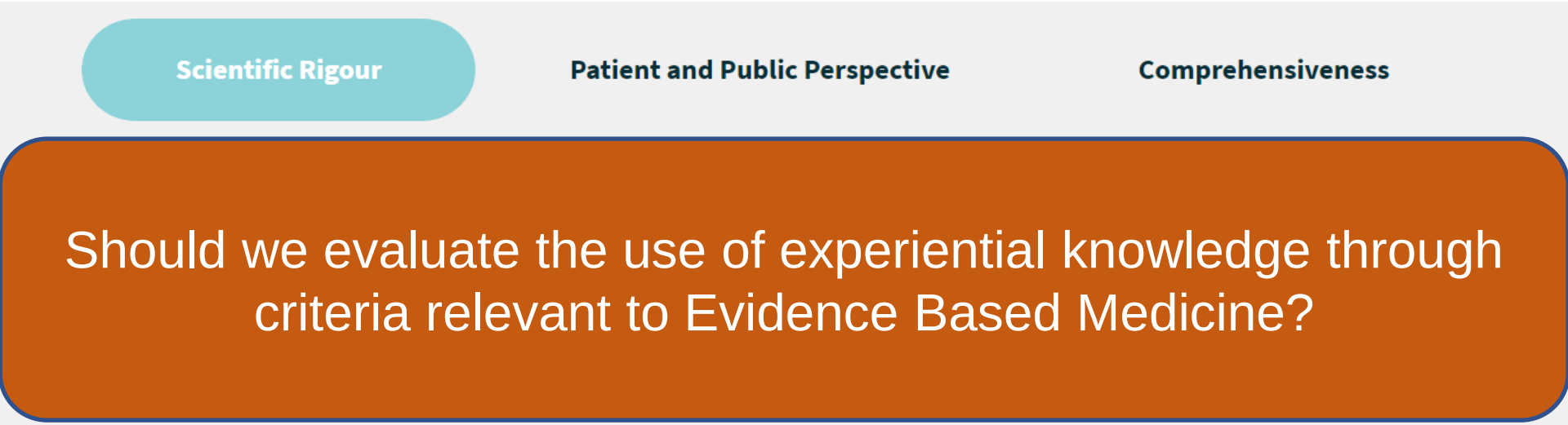
If A, then evaluation considers ‘do the public make a difference?’

If B, then evaluation considers ‘does the interaction between researchers and the public lead to a change?’

Staley, K., Barron, D. Learning as an outcome of involvement in research: what are the implications for practice, reporting and evaluation?. Res Involv Engagem ***5,*** *14 (2019).*

what are the consequences of choosing a particular model of evaluation?

- .
- A: PPI is a complex intervention



What is feasible?

- How will evaluation be resourced?
- (PPI as ‘invisible labour’)

- How will various stakeholders be motivated to participate?

- How can the diversity of organisational spaces be addressed?
- (ARC South London vs Cicely Saunders Institute)

NIHR | Applied Research Collaboration South London

Thank you
Over to you…