

PPI AND PES: ARE THERE LINKS? IS THERE SOMETHING TO LEARN?

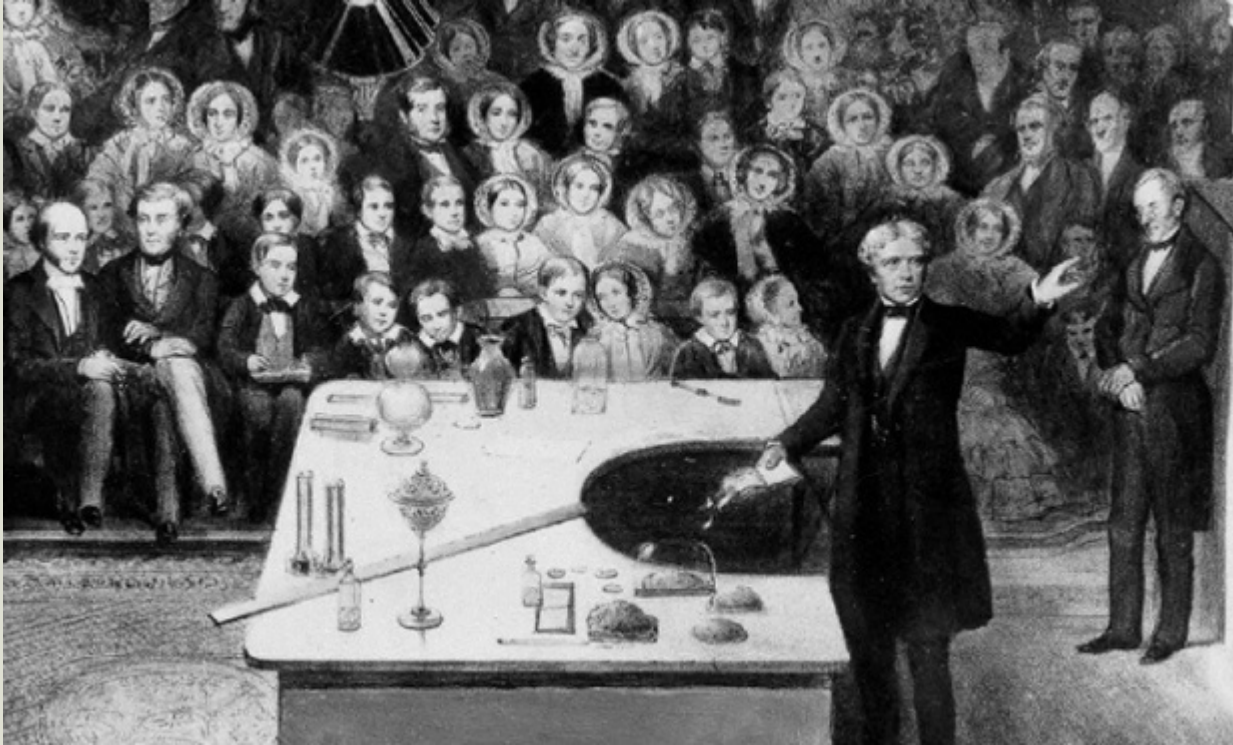


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Background

- Patient and Public Involvement (PPI) and Public Engagement in Science (PES) – independent arenas
- INVOLVE’s distinction between PPI and PES:
 - “When we (INVOLVE) use the term ‘public involvement’ we are not referring to researchers raising awareness of research, sharing knowledge or engaging and creating a dialogue with the public. We are also not referring to the recruitment of patients or members of the public as participants in research. However, these different activities – involvement, engagement and participation – are often linked and, although they are distinct, can complement each other.” (Involve, 2012)
- Two models of engagement in research parallel but distinct

Public engagement in science



Michael Faraday's 1856 Christmas Lecture at the Royal Institution.

Science literacy:
increasing scientific
literacy



**Public Understanding
of Science:** promoting
engagement



Science and Society:
changing science,
citizen science

Patient and Public Involvement



Professor Dame Sally Davies, Chief Medical Officer

“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 effective.” (Staley, 2009)

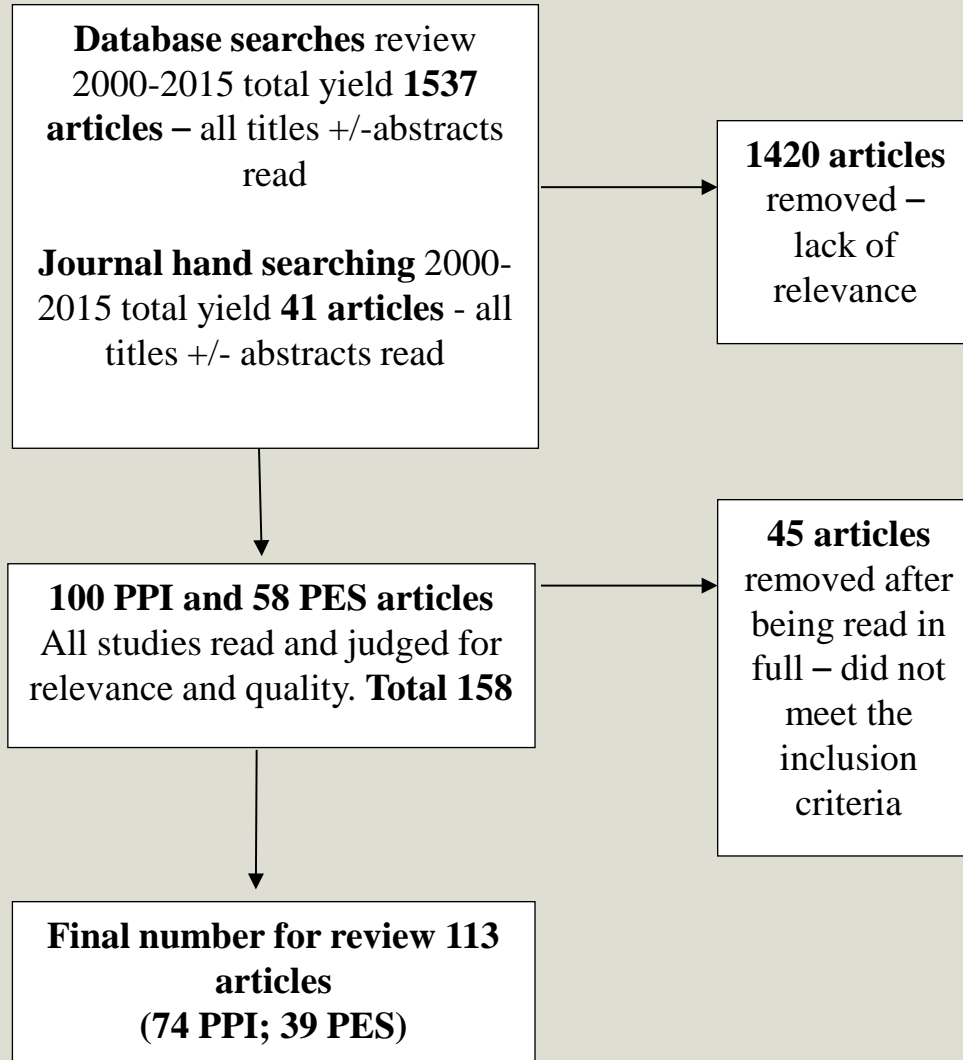
Review questions

- Review the two fields of PPI and PES together in order to:
 - Identify their commonalities and differences
 - Identify opportunities for one to learn from the other

Review methods

- Review of existing literature on PPI and PES including reviews and conceptual papers
- Search terms and timeframe defined
- Databases searched: ASSIA, Web of Science, SCOPUS, PubMed and Psychinfo
- Data extraction sheets: concepts, objectives, methods, impacts
- Narrative synthesis
 - Stage 1 - tabulation & thematic analysis to categorise findings.
 - Stage 2 - explore the relationships in the data

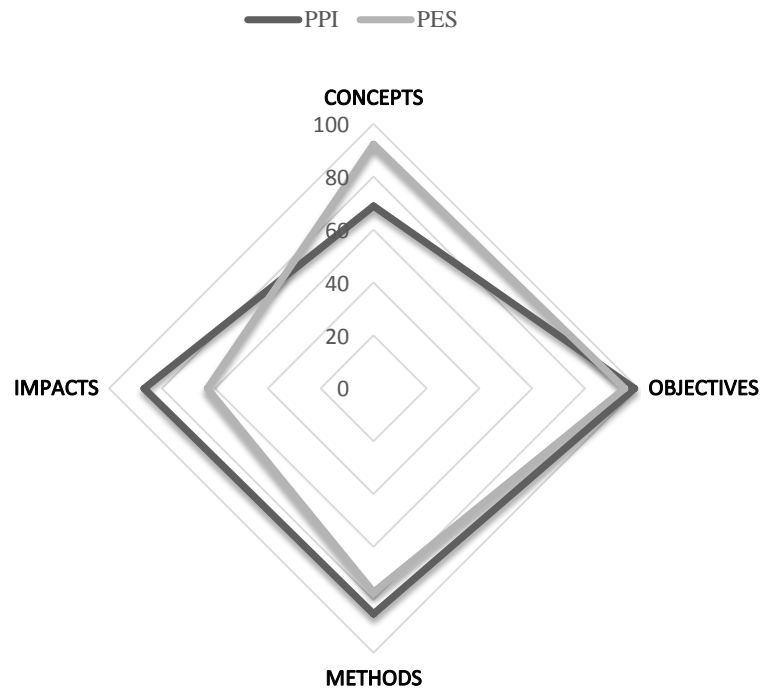
Review flowchart



Stage 1

- Concepts
- Objectives
- Methods
- Impacts

Radar chart representing the frequency of papers covering concepts, objectives, methods and impacts in PPI and PES (in %)



Conceptual basis of PPI & PES

PPI	Common features	PES
<ul style="list-style-type: none">• Democracy• Arnstein's continuum	<ul style="list-style-type: none">• Consumerism• Democratisation of science and civic life• Patients' or public's expertise	<ul style="list-style-type: none">• Deficit models<ul style="list-style-type: none">○ Scientific literacy paradigm○ Public Understanding of Science paradigm○ Science and Society paradigm

Objectives of PPI & PES

PPI	Common features	PES
<ul style="list-style-type: none">• Improve research quality• Improve quality of health care• Policy/funding requirement	<ul style="list-style-type: none">• Empower and educate the public• Change the model of knowledge production	<ul style="list-style-type: none">• Ensure public trust and win public support for science and technology

Methods of involvement and engagement

PPI	Common features	PES
<ul style="list-style-type: none">• Group meetings: focus groups; workshops; consumer panels; steering group; advisory group; seminars• In-depth interviews• Observation	<ul style="list-style-type: none">• Consultation exercises with limited interaction between researchers and the public: presentation on a research project, questionnaires.	<ul style="list-style-type: none">• Approaches to inform the public: conferences, forums, awareness events, citizens juries• Events using arts or novel technologies

Types of impact envisaged

PPI	Common features	PES
<ul style="list-style-type: none">• Research quality	<ul style="list-style-type: none">• Personal gains for those involved• Transform 'regime of truth': incorporate 'lay knowledge'• Increased visibility, accountability and transparency	<ul style="list-style-type: none">• Change the relationship between science and society

Stage 2

- Methods of involving/engaging
- Critical thinking in PES and PPI
- PPI & PES approaches to impact

Engagement practices: creativity and diversity

- In PPI - the public is incorporated into existing structures
- In PES - spectrum of methods much wider characterised by creativity
 - distinctive rationales of PPI and PES
 - different influences of policy on PPI and PES

Critical thinking in PPI & PES

- PES, unlike PPI, has a long tradition of critical thinking and self-reflection - is this discouraged in PPI?
- PPI literature a lot more focused on effectiveness and impact.
 - Lack of self-criticality to do with PPI's moral rationale
 - PPI implemented in a top-down approach

The importance of impact in PPI & PES

- PPI – search for measurable impact
 - PES – impact in relation to ideological/ philosophical questions
- Showing the impact of PPI is one way of establishing the legitimacy of this method of engagement
- The PPI field has strong links with clinical health research

Conclusions

- Two apparently different and independent fields have much in common, especially concepts and aims
- PES operates freely; PPI largely shaped by regulatory bodies – a constraining influence?
- PES: longer history, evidence of development and shifts in thinking
 - Could PPI learn from PES?

THANK YOU