

PATIENT AND PUBLIC INVOLVEMENT IN RESEARCH
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What are the questions to be asked?

When did it start? PPI started at HTA (Human Technology Assessment?) in 1993 and INVOLVE in 1996

What is it now? "PPI has now become part of the Zeitgeist and is included in all stages of research"

How is it monitored? Complementary framing is used in three primary areas namely Efficiency, Accountability and Power

To what extent is PPI now Tokenistic, Unrepresentative, Manipulative and Exploitative?

Power Framing involves the "Unbearable lightness of citizens in the public deliberation process"

Authentic involvement is difficult because patients don't have PhD's

Patients are simultaneously asked to be nobody (unbiased) and everybody (represent all) at the same time. Patients achieve some but not all key characteristics

Engaging patients and members of the public results in better research

"The nature and quality of the research did not reflect the priorities of those who took part"

"The idea of meaningful PPI in research is often problematic"

"More democratic research results in continuous dialogue between 'research actors' and 'research professionals'"

How do we assess the efficiency of PPI? It is possible to quantify how democratic the PPI involvement is by checking hardware wants (how accurate is the Information about research project) and software wants (check on the value added by the PPI participants). The public do often complain about the basic practicalities i.e. how they get their expenses and honoraria paid?

Real progress is achieved when there is less "them" and "us"

"Conflict is inherent and can be quite productive"

"Agonistic Pluralism" can be obtained when there is less "Antagonism" (conflict between enemies) and more "Agonism" (when all parties engage by sharing the commitment to address issues via discussion)

Conclusion: "It seems to be agreed that we will never eradicate conflicts and contradictions in PPI as they are inherent in the process"

Paul Osman 21st November 2018