Exploring the role of patient and public involvement (PPI) in healthcare realist reviews: a review in progress

J. Rastogi, R. Abrams, G. Wong, J. Hamer-Hunt, B. Gudgin, M. Petrova, S. Tierney, S. Dawson, A-M. Boylan and S. Park

Department of Primary Care and Population Health, UCL



BACKGROUND

"Patient and public involvement (PPI) in research refers to research carried out with and by members of the public" NHS Involve (2014)



- Patients and the public have been involved in a variety of ways within evidence synthesis. However PPI within realist reviews has received less attention.^{1,2}
- PPI is described as transforming the way in which healthcare research is undertaken – it improves efficiency, accountability and balances the power dynamics of healthcare research through a democratic dialogue.³
- o PPI is often an essential requirement for research funding. However there is limited evidence on the impact of PPI on research and clear standards for PPI reporting.4

AIMS

This literature review explores the ways in which contributors are involved within healthcare realist reviews published since the release of INVOLVE guidance on PPI in evidence synthesis.5



- To understand the different ways in which researchers broadly involve contributors in realist reviews
- To look specifically at how PPI is reported within realist reviews.

METHODS

- A search of electronic databases (CINAHL, Embase, PsychINFO and Medline) was undertaken.
- 448 papers published between 2014-2019 were screened.
- Papers were included if they were realist reviews and made reference to terms for contributors such as: stakeholder, PPI, patient and public involvement, expert panel and advisory.

Framework analysis

- Data was analysed using a framework analysis.⁶
- Framework analysis followed a six stage process including familiarisation, coding, developing an analytical framework, application of the analytical framework, charting the data in a framework matrix and interpreting the data.



What reference do the authors make to contributors in the review?



How do contributors relate to the review?



How is their involvement reported/recorded in the paper?



What impact is mentioned in relation to contributions?



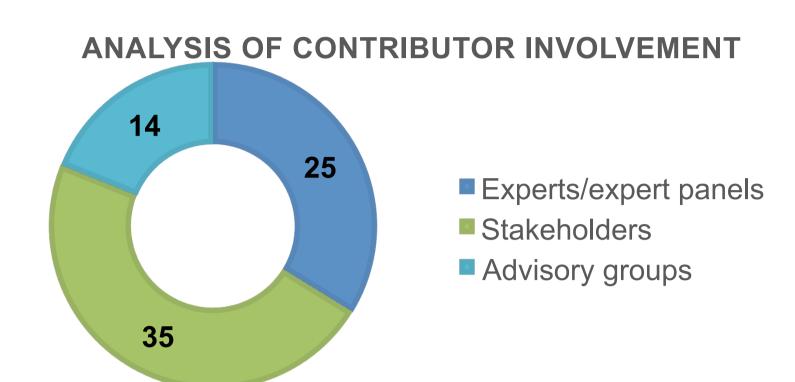
What were the stated motivations/intentions for contributions in the review?

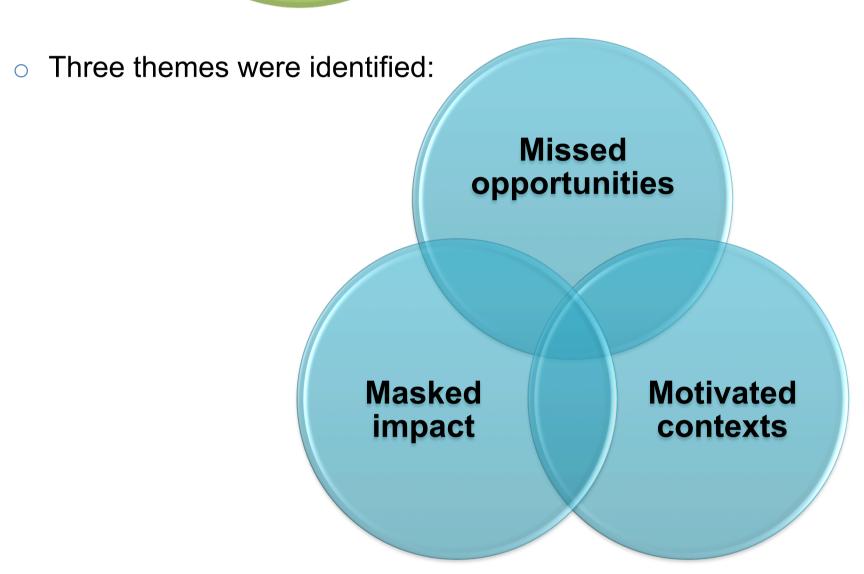


This research was part of the Evidence Synthesis Working Group, which is funded by School for Primary This research was part of the Evidence Synthesis Working Group, which is funded by the National Institute for Health Research School for Primary Care Research (NIHR SPCR) [Project Number 390]. The views expressed are those of the author(s) and not necessarily those of the NIHR, the NHS or the Department of Health

RESULTS

- 74 articles were included in this review.
- Contributor involvement across each review has been analysed using the framework analysis.





DISCUSSION

- The majority of reviews demonstrate that a range of contributors are involved in realist reviews but that involvement is not always clearly reported.
- Specifically, PPI is often not clearly defined and little information is reported on the exact contributions of PPI.
- Our review findings will contribute to future recommendations on the role of PPI in realist reviews and provide guidance to support researchers in their future collaboration with PPI participants.
- These findings will contribute towards creating a series of reflexive questions for researchers to consider when using PPI in realist reviews.
- Reasons for limited use/reporting of PPI in realist reviews:
 - Word count restrictions
 - Conflicting interests
 - Experience of the researcher

PATIENT AND PUBLIC INVOLVEMENT

This review sought the perspective of two patient contributors who had experience of being involved in various different stages of a research cycle including evidence syntheses. Their involvement shaped the types of questions we asked of our data and framed our findings, ensuring that the patient perspective was accounted.

REFERENCES

- Harris J, Croot L, Thompson J, Springett J. How stakeholder participation can contribute to systematic reviews of complex interventions. J Epidemiol Community Health. 2015;70(2).
- Kreis J, Puhan MA, Dickersin K, Schünemann HJ. Consumer involvement in systematic reviews of comparative effectiveness research. Health
- Andersson E. Healthy Democracy The future of involvement in health and social care. INVOLVE: The National Centre for Involvement; 2017. Crocker JC, Boylan AM, Bostock J, Locock L. Is it worth it? Patient and public views on the impact of their involvement in health research and its
- assessment: a UK-based qualitative interview study. Health Expectations. 2017;20(3):519-28. Vale C. Public involvement in systematic reviews: Supplement to the briefing notes for researchers. INVOLVE: National Institute for Health Research; 2014.
- Ritchie J, National Centre for Social R, Social and Community Planning R. Qualitative research practice: a guide for social science students and researchers / [edited by] Jane Ritchie ... [et al.]. 2nd edition ed. Los Angeles ; London: Los Angeles ; London : SAGE; 2014.