

EVALUATING THE IMPACT OF PATIENT AND PUBLIC INVOLVEMENT

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PATIENT AND PUBLIC INVOLVEMENT (PPI) IS RESEARCH CARRIED OUT WITH OR BY THE PUBLIC. RATHER THAN TO, ABOUT OR FOR THEM

PPI is an important aspect of health research and a requirement by many funders including the NIHR and involves a diverse range of activities as shown.

Evaluating PPI is important to:

- improve the quality of PPI and research
- justify funding and support for PPI
- provide feedback to public contributors on their contributions
- grow the evidence base of PPI to encourage wider adoption

Both the process and impact of PPI can be evaluated. A simple impact log can be used to capture the impacts of PPI and the main recommended framework for evaluating these impacts is the Public Involvement Impact Assessment Framework (PiiAF).

Here, I will focus on the impacts of PPI and how these can be evaluated as well an introduction to research capturing perspectives on these issues from an underserved community.



IMPACTS OF PPI

IMPACT ON RESEARCH

- Improved recruitment rates in clinical trials
- Increased clarity of patient information documents
- Developing coding framework for interview transcripts
- Homogeneous participants encouraged to participate by public contributors

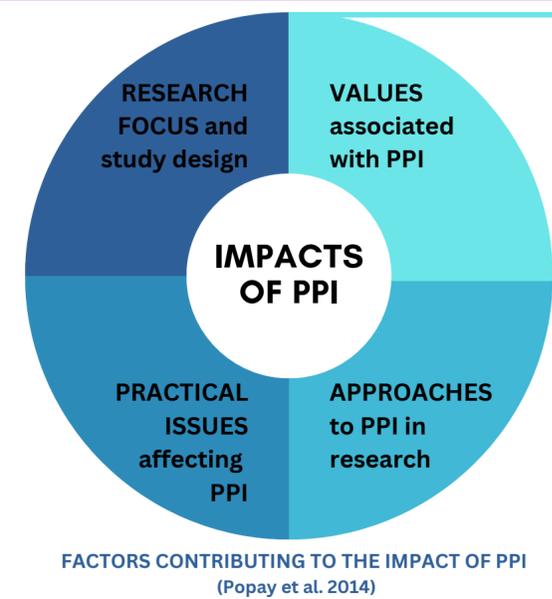
IMPACT ON INDIVIDUALS

- Improved confidence and practical skills for public contributors
- Better understanding of patient experiences and perspectives for researchers
- Feelings of isolation as only public contributor within a team
- Burden of representing their community as public contributors from underserved groups

IMPACT ON COMMUNITIES

- Improved trust and acceptability in research
- Improved relationships between communities and researchers
- Changes to practices/services

Modigh et al. 2021



- **Normative values** - moral, ethical and political concerns e.g. empowerment, rights and accountability
 - **Substantive values** - concerns about the consequences of PPI e.g. generalisability, validity and evidence base
 - **Process values** - concerns about the conduct of PPI e.g. equality, trust and independence
- Gradinger et al. (2015)



These values, along with the additional three factors, can affect the impacts of PPI. In line with the PiiAF, these should be acknowledged at the beginning of the project and used to guide a plan for evaluating the impacts of PPI.

MY RESEARCH

I aim to build on the work around the impacts of PPI and the values associated with PPI. While there has been research in these areas, none has looked specifically at the views of Black public contributors and those wider communities.

I seek to explore views on:

- their values and motivations for getting involved in research
- the impacts they'd like to have on research (and how this compares to the existing perceived impacts)
- how they would like these impacts to be captured and evaluated

REFERENCES

Gradinger, et al. (2015). Health Expectations: An International Journal of Public Participation in Health Care and Health Policy, 18(5), 661.

Modigh, et al. (2021). Health Policy (Amsterdam, Netherlands), 125(9), 1208-1221.

NIHR RDS West Midlands. (2022). Public Involvement Research Cycle

Popay, et al. (2014). The Public Involvement Impact Assessment Framework Guidance.



PPI IN THE PROJECT

An advisory group including Black African and Caribbean public contributors will support the work throughout, particularly at key stages including interview schedule development; interview transcript coding; and developing outputs from the project such as recommendations.