



# ‘Trapped in the middle’: tracking the labour of the patient and public involvement workforce in health research

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## **A new workforce – that is devoted to patient and public involvement (PPI) – is being deployed in the National Institute for Health and Social Care Research (NIHR).**

This workforce is supporting the embedding of public contributions in research projects and – increasingly – delivering PPI strategy across research centres, NHS trusts and other stakeholders regionally.

### **What is the aim of the project?**

This project investigates the working

practices and concerns of the PPI workforce in optimising PPI in research and therefore, informing patient centred care. Despite the NIHR’s pioneering role in developing a robust PPI infrastructure for publicly funded health research in the UK, considerable barriers remain to embedding substantive and sustainable public input in the design and delivery of research.

Notably, researchers and clinicians report a tension between ‘organisational time’ and ‘PPI time’, that is - they consider PPI work as both time consuming and emotionally arduous and therefore potentially in tension with funder and organisational timescales, deadlines and deliverables.



## What did we do?

The research team conducted 21 semi-structured interviews with individuals holding NIHR-funded formal PPI roles across England. Interviews were analysed through reflexive thematic analysis with coding and framing presented and adjusted through two workshops with study participants.

## How did we involve people?

Researchers carried out a qualitative study with participatory elements, co-designed with PPI workers and public contributors. The study used purposive and snowball sampling and included regional and institutional diversity.

## What did we learn?

We generated five overarching themes which signal a growing tension between expectations put on staff in PPI roles and the structural limitations of these roles:

- the ambiguity of the 'support role'
- the invisibility of PPI labour
- the moral imperative of PPI work

- responsibility without control
- delivering change without change

## What next?

The team aim to disseminate these findings widely through a web-comic. They are also collaborating with NIHR Oxford Biomedical Research Centre (BRC) and ARC Oxford and Thames Valley, on a competency framework for the PPI workforce, funded by the Centre for Engagement and Dissemination. This work aims for a clearer understanding and better resourcing of the labour involved in undertaking PPI. However, their research also suggests that a broader institutional and epistemological transformation is necessary if we are to better integrate the expertise that both the PPI workforce and patients/service users bring to health research.

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## What is NIHR ARC South London?

The National Institute for Health and Care Research Applied Research Collaboration South London (NIHR ARC South London) is one of the 15 NIHRARCs.

NIHR ARC South London works with researchers, commissioners, health and social care practitioners, and local people to improve health and social care in south London.

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