

Importance of Public Involvement Research

No.1: Invisible Labour of Public Involvement

The first in a series of ARC National events on Patient and Public Involvement and Engagement (PPIE) research took place on Thursday 5 December 2024 with over 100 delegates, with most being public involvement leads/facilitators (33%) or researchers (36%) but there were a few PPI Public members and individuals who identified as having lived experience (2%) and 29% of delegates identified as being something else or a mixture of these roles.

The online event was hosted by the NIHR Applied Research Collaboration, East of England. Dr Elspeth Mathie, introduced the webinar series which hopes to create a space to discuss new emerging research evidence on Inclusive Involvement and Patient and Public Involvement. The series will aim to foster conversations and methodological development of patient and public involvement, inclusive involvement and co-production and is open to anyone interested or involved in supporting, facilitating or leading Patient and Public Involvement, and those undertaking and involved in PPIE themselves.

The event – Invisible labour of public involvement

Dr Stan Papoulias gave a very engaging and well received presentation based upon their recent [paper and blog post](#) written with Dr Louca- Mai Brady on the 'invisible labour of public involvement' and the role of the NIHR public involvement workforce (staff and researchers who support public involvement in research).

Stan spoke of the conflicting pull between the efficiency/quality drivers for getting the research completed to the necessary standards for funders and academic publication, and the empowerment agenda of service users having a real voice in decision making. Stan referenced the wide remit within a PPIE coordinator or lead's role and how the tensions are ever present as meaningful patient and public involvement needs time, commitment and resources, yet this is often within the landscape of inflexible research timelines, short contracts, and lack of adequate support and structures to facilitate the work.

Key Themes

Dr Kristin Liabo chaired a spirited discussion that identified PPI being undervalued in terms of expertise and skills. The importance of understanding the perspectives and needs of the workforce for embedding public involvement in health and care research, [NIHR requirements for inclusive research](#), and sustainable community engagement were explored. It was noted that presently as a large part of PPIE is done by researchers who may not be PPIE specialists there can be huge gaps in understanding the role, as well as the worry of burning out advocates

Two Mentimeters (an on-line way of capturing audience reactions) were launched during the webinar (see below); the first asked about challenges for the PPIE workforce and which identified **time, funding, capacity, resources and support**. The second mentimeter asked about the priorities and future directions for the PPIE workforce and **sustainability, recognition, support, and training** were the main responses.

Speakers

Dr Stan Papoulias is Research Fellow at the [Service User Research Enterprise](#) (SURE) a unit comprised of researchers with direct experience of neurodiversity, trauma and mental distress at King's College London. Stan uses qualitative and participatory methods to explore lived experience as a form of knowledge and the ways in which working conditions of staff shape research. Stan's work has included evaluating public involvement [in different research organisations](#) and they have collaborated in the production of [a competency framework](#) for the public involvement workforce. Stan is also involved in developing a [community based model for ethical research](#) and is one of the commissioners in the Lancet Psychiatry Commission on [Lived Experience in mental health research](#).

Dr Louca-Mai Brady is a Reader in Youth Involvement and Health at the [Centre for Public Health and Community Care](#), University of Hertfordshire, UK. Her research focuses on children and young people's participation in health and care services, co-production and public involvement, and qualitative, participative and creative research methods. As well as leading the Herts [young people's research advisory group](#) and a participative project on young people's participation in an Integrated Care System, she also supports young people's involvement in research including a study on [young Muslim women's mental health](#), [food in special schools](#) and a [Europe-wide study on problematic internet use amongst teenagers](#).

https://go.herts.ac.uk/loucamai_brady <https://bsky.app/profile/louca-mai.bsky.social>

Dr Elspeth Mathie is Assistant Director, Centre of Research in Public Health and Community Care (CRIPACC), University of Hertfordshire and Lead of Inclusive Involvement in Research theme, NIHR Applied Research Collaboration (ARC), East of England.

Dr Kristin Liabo is an Associate Professor and Deputy Director of PenARC and leads PenARC's Patient and Public Involvement Team.

The presentation slides are available below as a pdf

A recording of the presentation is below

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