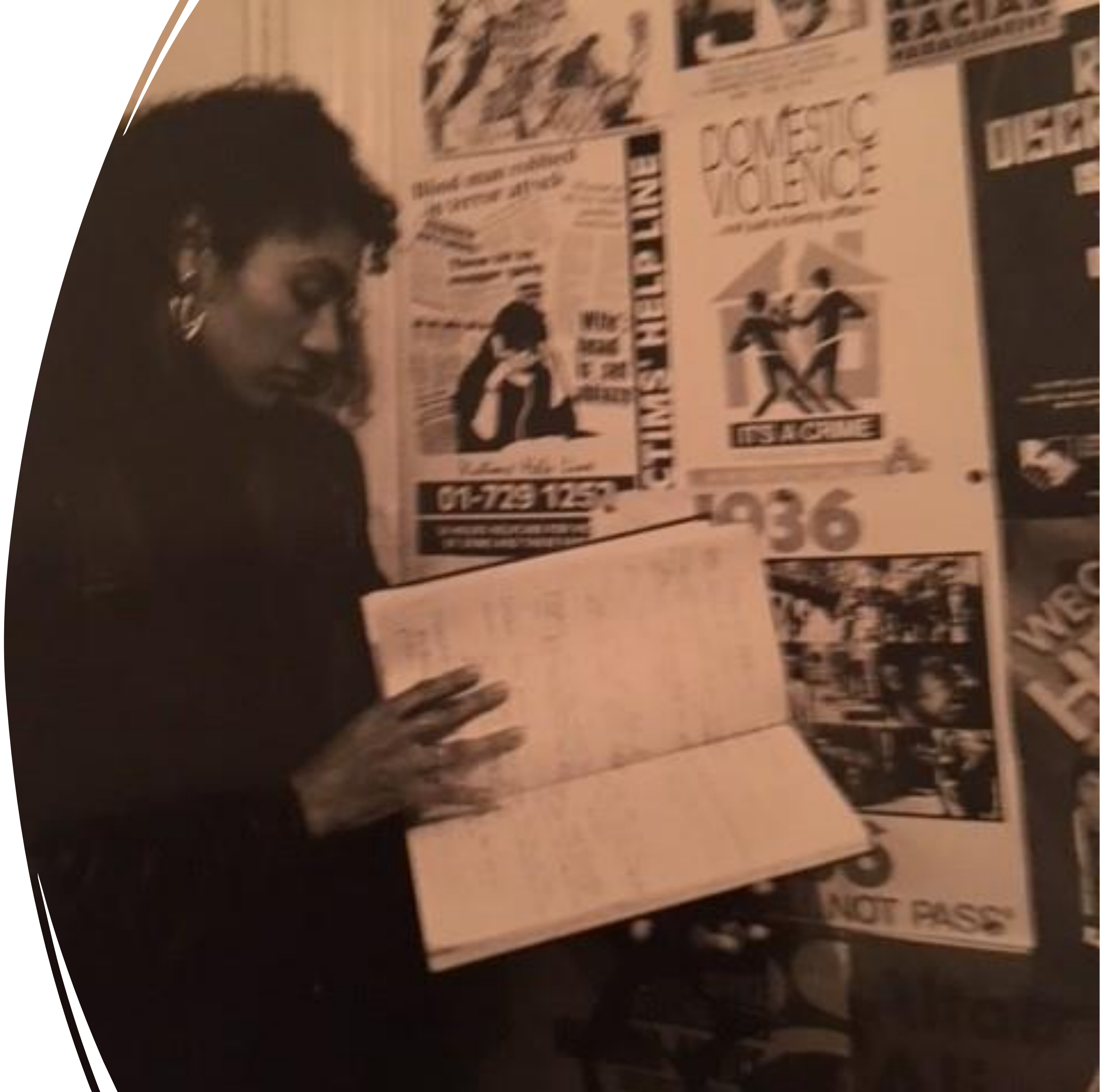
Building ongoing communication throughout the life cycle of research

Working together from start to finish in participatory action research

Josephine Ocloo

Why Participatory Research is important to me ?

- I am a social scientist and qualitative researcher with a long-standing interest in using participatory research methods.
- I also see myself as a harmed patient activist-scholar combining my research with activism.



Activist Scholarship:

- …. is concerned with the rights and lives of the oppressed and with marginalised forms of knowledge. Among its fundamental aims are to challenge power relations that lead to social, political and economic inequalities and to promote justice and equality

'This aligns with p*articipatory action research which was not invented by researchers….. But has always been in existence, wherever different oppressed and marginalised groups have struggled collectively to understand and to take action, often to tackle inequalities of power in their social worlds* [Hall: 2001: 174].

guardian.co.uk

WHO Patient Safety Champion - Driven by a personal tragedy, Josephine Ocloo campaigns to give a voice to those who feel they have been wronged by the medical profession and to make healthcare in Britain safer.

Mark Gould reports.

[The Guardian]

Wednesday June 25, 2008

Health Services Research UK Conference 2022

Why participatory Approaches that involve diverse groups are particularly important now:

- A long standing NIHR strategic objective to ensure patients and the public are **involved in all stages of the research process, because this is considered to lead to better research, that is more relevant and likely to be implemented** (Dept. of Health, 2006:34).

- Evidence has shown those tending to be involved in research have come from a narrow section of the population (INVOLVE, 2012:3), from older age groups, white ethnic and higher socio-economic backgrounds (Beresford, 2013; NIHR, 2015; Ocloo & Matthews, 2016).

- This stands in contrast with those who are most likely to use health & social care services, or who are often the target of public health initiatives.

Ethnic inequalities in mortality and service use in people with multiple mental and physical long-term health conditions during the COVID-19 pandemic

Qualitative Elements to the Study

Dr Jayati Das-Munshi (principal investigator)

Clinician scientist/ senior lecturer (IOPPN/ KCL)/ Honorary consultant psychiatrist (SLAM)

Dr Josephine Ocloo, (Co-Investigator) and senior researcher in the IoPPN and Equality, Diversity and Inclusion lead for the NIHR Applied Research Collaboration, South London.

Aims of the Project

- To assess whether changes to health services as a result of COVID-19, magnified ethnic inequalities in care pathways & were associated with more deaths, in people with serious mental and physical long-term health conditions.

- To explore through online qualitative interviews the experiences of people from Black African, Black Caribbean, Indian, Pakistani & Bangladeshi backgrounds [service users/carers] in partnership with mental health trusts in 3 geographical regions [South London, Birmingham and Manchester]. All of the Trusts were piloting the new Patient & Carer Race Equality Framework about to be rolled out nationally in mental health trusts.

- A participatory action research [PAR] approach was used: PAR is relevant to the development of co-produced research with patients, the public and communities as **it seeks to challenge the control of how knowledge is defined, to create more equal partnerships.** We particularly drew upon community peer research methods in which members of the community being researched take part in **designing, conducting, analysing, and disseminating the research.** Peer research models have long been used to enable those with lived experience of using mental health services to be involved in research and practice. **This methodology goes beyond a PPI Model to challenge power inequities.**

Designing, conducting, analysing, and disseminating research with Peer Researchers

- **We worked throughout with 4 peer researchers** [Black & Asian public members with lived experience of using Mental Health services] They were recruited via study contacts on the Steering Group [SG]/connections with the partner PCREF sites. Peer Researchers [PRs] were generally paid £25 per hour including payments for preparation or £35 per hour [Steering Group]. **Budgeting for coproduction throughout the lifecycle of research is absolutely crucial.**

- **Starting point: Design of the study** - PRs were recruited onto the SG & fed into all aspects of the study design before it was submitted for ethics. PRs were named as part of the study team in ethics.

- **Conducting - participant recruitment strategy & diversity -** PRs helped with disseminating study materials to their patient & public involvement [PPI]/community contacts - phoning/emails/directly taking written materials to community organisations to encourage participation.

- **Training** – workshops were held for PRs on Qualitative Research /Participatory research/conducting interviews which included time for them to practice with researchers so they felt comfortable.

- **Reflective logs –** Researchers kept reflective logs. PRs were supported with this & with notes being typed up if requested.

Designing, conducting, analysing, and disseminating research with Peer Researchers

- **Conducting interviews** – [myself and 4 PRs]. University researchers contacted participants & set up the interviews online. PRs were supported online by a university researcher present but on mute with their camera off. The researcher dealt with all technology aspects [recording consent, interviews/uploading recordings onto a secure database/filling data into an excel spreadsheet on demographic characteristics/payments e.g. voucher/bank transfer]. University researchers could intervene if there were any concerns or if PRs had questions they couldn't answer. Topic guides were used as a supportive tool with prompts/statements to support the PRs in conducting the interviews.

- **Analysing - developing the coding framework -** PRs were involved in reading a selection of transcripts/then discussing/agreeing key themes & the final coding framework with university researchers.

- **Analysing - meetings held to discuss preliminary findings with PRs –** they have been asked to comment on the draft paper for publication if they wish to be authors. University researchers will support them in this process.

- **Dissemination - co-presenting findings** - PRs have been involved in presenting findings at an international conference/helping to co-facilitate breakout sessions in an online event to feedback findings to study participants and community organisations.

- **Building in extra time & support for the peer researchers has been fundamental to co-producing the study.**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