NIHR | Applied Research Collaboration South London

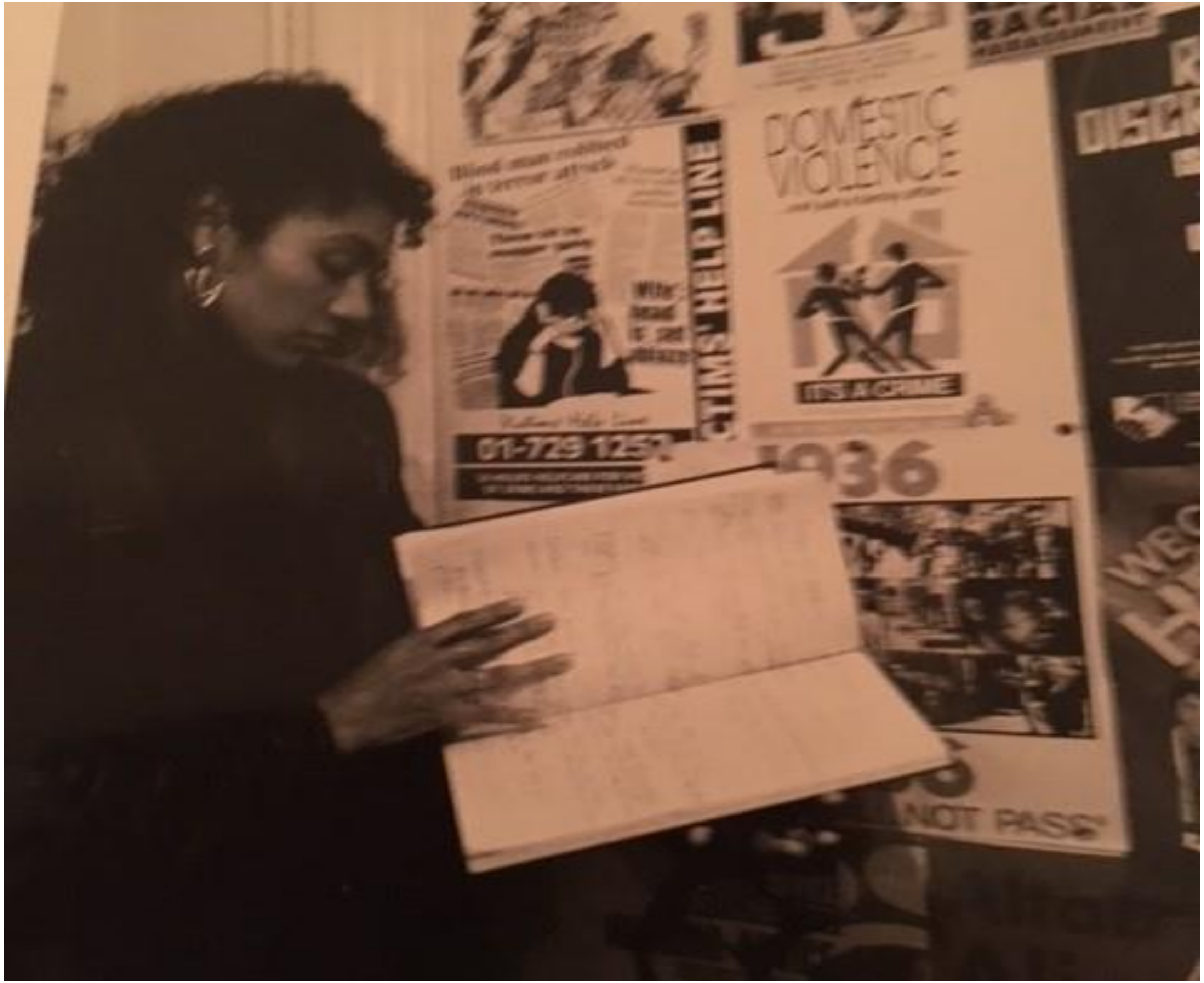
ARC South London Public Research Panel

Working together to build a community, diversity and participatory approach to research and practice

Leah Bedward [Public member on panel]
Rachael Buabeng [Public member on panel
Clare Coultas [ARC Public health researcher]
Josephine Ocloo [Senior Researcher/ARC EDI Lead]

Why is a Participatory Approach important?

‘*Participatory research is not something that was invented by researchers, educators or even community activists.* ***PR as a practice 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].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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

Why is a Participatory Approach so Important Now:

- We have seen the striking inequities that have impacted many groups with the pandemic:

- Black, Asian, and minoritised ethnic groups; people on low incomes, people in undervalued employment; people living in deprived areas, poor housing, and/or overcrowded or residential accommodation; older people; disabled people; people with learning difficulties; people with psycho-social disabilities; and people with long term conditions – especially those who rely on social care.

- This impact has been more devastating because these groups were already disadvantaged by structural inequalities before the pandemic began.

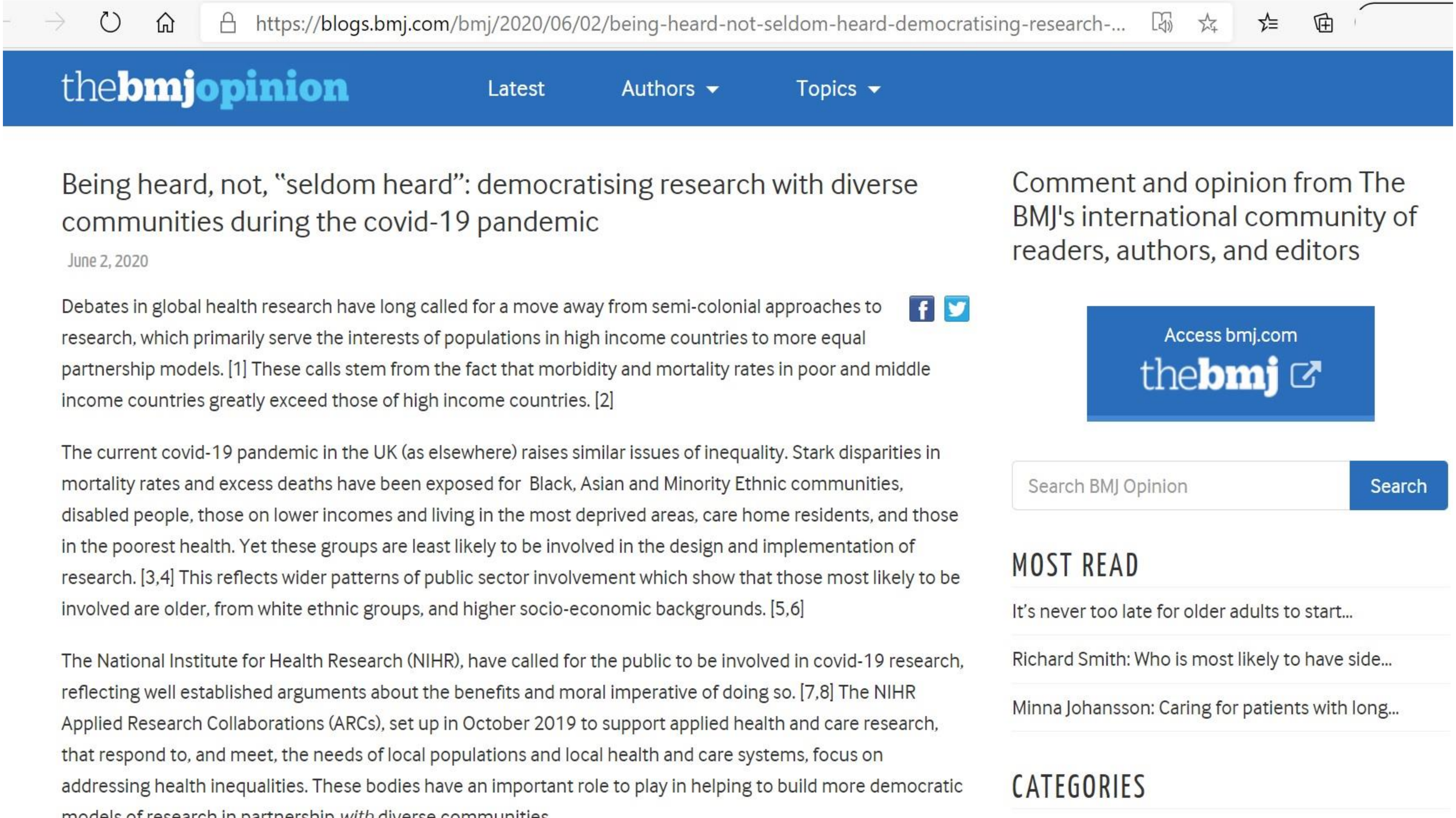
- The Black Lives Matter Campaign has also highlighted the huge impact of racism on Black & other minority ethnic groups

Why is a Participatory Approach particularly important now:

Despite this social & political context there are:

- Long-standing critiques about the limitations of patient and public involvement.
- Therefore an urgent need for more inclusive/co-produced approaches with patients/carers/the public in health/social care and research.

Community Zoom Event: Listening to the voices of diverse communities



Being heard, not, "seldom heard": democratising research with diverse communities during the covid-19 pandemic

June 2, 2020

Debates in global health research have long called for a move away from semi-colonial approaches to research, which primarily serve the interests of populations in high income countries to more equal partnership models. [1] These calls stem from the fact that morbidity and mortality rates in poor and middle income countries greatly exceed those of high income countries. [2]

The current covid-19 pandemic in the UK (as elsewhere) raises similar issues of inequality. Stark disparities in mortality rates and excess deaths have been exposed for Black, Asian and Minority Ethnic communities, disabled people, those on lower incomes and living in the most deprived areas, care home residents, and those in the poorest health. Yet these groups are least likely to be involved in the design and implementation of research. [3,4] This reflects wider patterns of public sector involvement which show that those most likely to be involved are older, from white ethnic groups, and higher socio-economic backgrounds. [5,6]

The National Institute for Health Research (NIHR), have called for the public to be involved in covid-19 research, reflecting well established arguments about the benefits and moral imperative of doing so. [7,8] The NIHR Applied Research Collaborations (ARCs), set up in October 2019 to support applied health and care research, that respond to, and meet, the needs of local populations and local health and care systems, focus on addressing health inequalities. These bodies have an important role to play in helping to build more democratic models of research in partnership *with* diverse communities

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CATEGORIES

ARC Covid Research Panel for the Public

Exchange

COVID Research Panel for the Public

Embedding Inclusivity and Public Participation in COVID Research through a COVID Research Panel for the Public

Key presentations to the Covid Panel to date:

- **General practice service use towards end-of-life among patients** during the pandemic
- **Disrupted bereavement among the Muslim Community**
- **Covid-19 vaccination intention in the UK**: a national cross-sectional survey
- Priorities for research: **Black, Asian & Minority Ethnic people hospitalised with Covid-19**
- **Learning from the Covid-19 Health System Shock**: building resilient health systems
- Co-design/evaluation of **personalised self-management for people with Long Covid**
- Mixed methods **evaluation of the shift to remote consultation in primary/secondary care**

Some of the Feedback from research presenters to the panel:

- The panel offered **“thoughtful and novel suggestions”** for studies.

- Feedback was given in a **“constructive and helpful way – direct and to the point”.**

- The experience **“was very easy & a rich discussion happened, with no prompting ”.**

- “**Constructive challenges & practical suggestions for recruitment were offered.”**

- **Verbal feedback as well as written feedback** was seen as particularly beneficial.

- Presenters felt able to explain flaws in their grant/ engagement processes without feeling defensive - but are **“learning more about participatory and inclusive methods”**

Feedback from research presenters on the panel experience:

"I wanted to let you know the good news that our bid was successful. I really do think that the input from you and the PPI panel and our other stakeholders helped shape the bid- and our ultimate success. Please can you pass on my heartfelt thanks to all of the panel for their insightful and helpful feedback. I also wondered if it would be possible to attend another panel meeting at some time in the future to share progress and to discuss our inclusion and diversity strategies".

Why do we need a diversity, community-based approach?

- Community engagement as a strategy for research allows us **to reach the people who are using the services & experiencing the things that we are researching**
- Early community engagement ensures the **research objectives are in line with what the community needs**
    - What is impacting them?
    - How can research be used to improve this?
- Working with community groups & community leaders helps **reaching marginalized communities** that are often referred to as "hard to reach"
    - **Builds trust** within these communities and **raises the profile of the research** being carried out

Why do we need a diversity, community-based approach?

- **Co-production and peer-led approaches** between researcher and community leaders/members create a **sense of ownership**
- Working with grassroot organizations needs to be a **two-way street**: they want to be kept informed and they want to see the **outcome benefitting their community**
- **Factoring in finances** is vital for grassroot organisations/community members who are **often underfunded** → shows respect for their work, time and knowledge

Reflexivity is key to systemic change, inclusion & diversity

- Questions to ask:
    - **How** and **why** are you doing this?
    - How can you **keep diversity on the agenda** at every meeting?
    - If you identify 'challenges’: **open reflective conversations** that recognise the way in which systemic inequality may be **impacting on research development**, with a view to **developing a strategy** to overcome those 'struggles’
    - How much have you thought about the community you're trying to reach? **Mapping exercising** can be used to **identify groups to contact**

Reflexivity is key to systemic change, inclusion & diversity

- **Peer-led research & evaluation approaches** can enable to:
  - Get better access to data and narratives
  - Build long lasting relationships with community members

- **Training communities** to facilitate research helps create and maintain meaningful contacts

ARC South London Public Research Panel aims, objectives and functions

This independent Experts by Experience panel aims to support the building of meaningful engagement & partnerships between researchers & members of the public by:

1. Developing a broader model of patient/public involvement in research, grounded in principles of diversity and inclusion.
2. To work with members from diverse communities in a democratic process to co-produce, co-evaluate and theoretically inform key values for research and the delivery of services.
3. To work in partnership with ARC South London researchers to build a community, diversity and participatory approach to research and practice within the ARC.
4. To bridge the gap between researchers and the subjects of research to support researchers in their communication with research participants and to amplify the voices of service users.
5. To provide a forum for facilitating wider community research engagement events on specific topics that are important and relevant to the research work of the panel.

ARC Public Research Panel: Available dates:

- 24th Nov - 4-6pm
- 15th Dec – 4-6pm
- 26th Jan – 4-6pm
- 23rd Feb – 4-6pm
- 23rd March – 4-6pm

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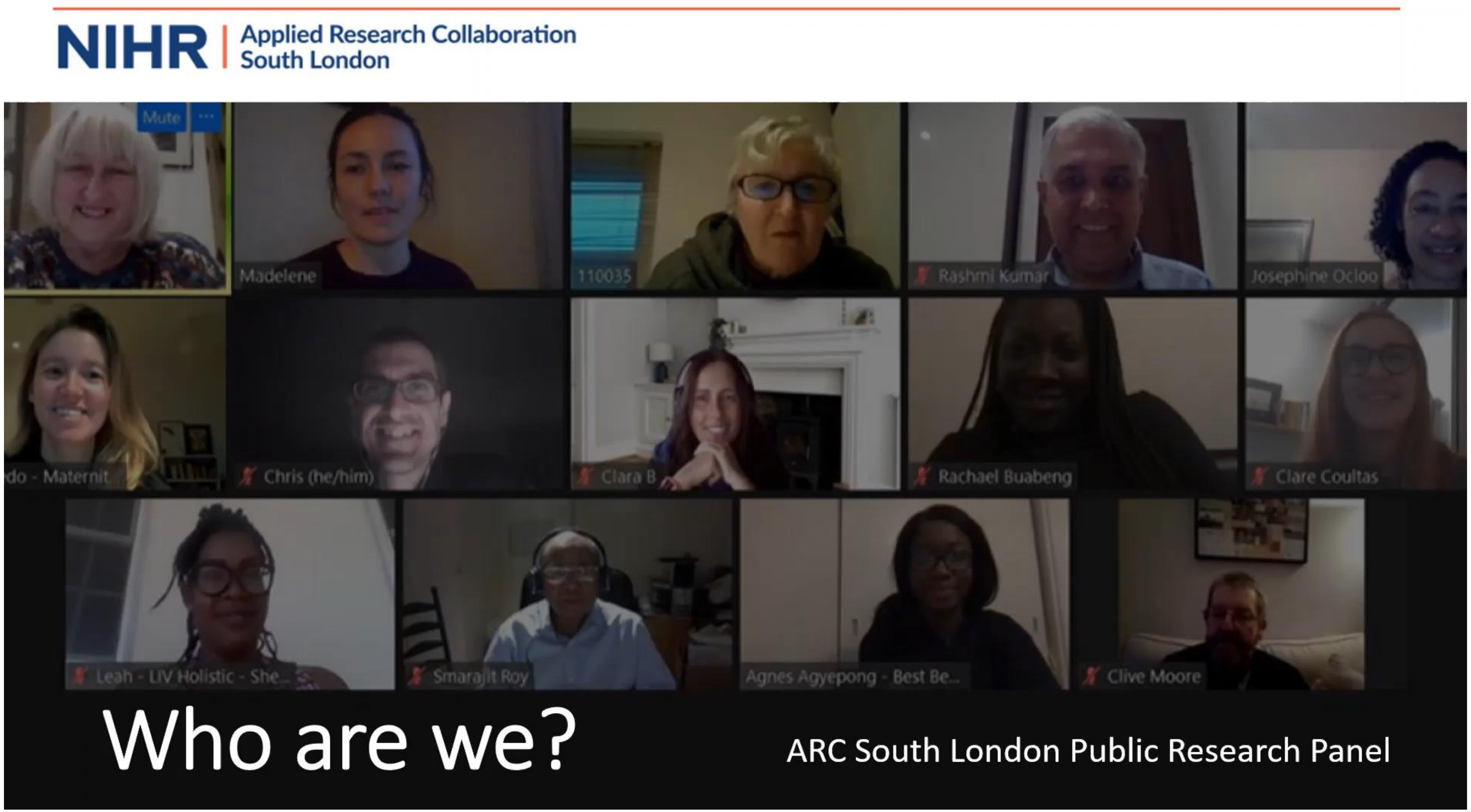

Who are we?

ARC South London Public Research Panel

Thank You

Public Members

- Clive Alan Moore-Ceaton
- Katherine Barrett
- Rashmi Kumar
- Smarajit Roy
- Clara Martins de Barros
- Agnes Agyepong
- Leah Noel
- Lana Samuels
- Chris Pavlakis
- Leah Bedward
- Vita Moltedo
- Rachael Buabeng

ARC Members

- Madelene Boyton
- Hannah Dasch
- Clare Coultas
- Josephine Ocloo