Project Title: Partnership for Black People's Health: involving Black communities in addressing health inequalities

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Plain Language Summary

Background

The Partnership for Black People's Health (P4BPH) is an academic-community partnership established to engage Black African and Black Caribbean communities in the UK in discussions about their health and healthcare needs and experiences in the context of stark health inequalities.

Original objective(s)

The key aim of P4BPH is to build on and expand a community of practice able to address health inequalities through community engagement and leadership, disproving perceptions about 'hard to reach' communities, and with the following objectives:

- regular and structured exchange about methods to use in a deliberative process with different communities
- involvement of different groups to interrogate together their understandings and experiences of health, health care and inequalities, and to identify priorities for research and interventions
- assessment of the most successful methods of involvement
- a community-driven research agenda and research funding applications to deliver it
- a case study to inform similar partnerships

Methods

The project was led by 19 Partners (8 clinical and social science academics and 11 community mobilisers). Over 18 months, we hosted 16 public engagement events with Black African and Black Caribbean members of the public, with variation by age (15-80 years old), sexuality, gender, health condition, migrant status, and ethnicity. We employed focus group, photovoice, body mapping, world cafe, and arts and theatre-based techniques. The engagement activities covered issues from specific health conditions to broader health and equity concerns. Events were led by Black facilitators, in community or public spaces, at accessible times, and with culturally appropriate food. All participants were reimbursed for their time. In total, we engaged with 207 community members.

Key findings

The project allowed us to improve understanding about: how partnerships are built and sustained; the challenges and needs for authentic collaboration (including systemic and institutional challenges); the common experiences of institutional racism in healthcare, lack of opportunities for collective exchange and action on health, but also strategies for support and self care amongst very heterogeneous Black communities. Our approach sought to center Black leadership and break away from extractive practices of historical and colonial research.

Outputs, impact and dissemination

1. a community-facing report for all participants and their networks (available here: https://www.qmul.ac.uk/wiph/centres/centre-for-public-health-and-policy/global-public-health-unit/p4bph/);
2. four funding applications by Partnership members - one under review by NIHR and three awarded for linked projects
3. An ongoing dissemination strategy including media and social media outputs (infographic; podcast)

4. Presentations at academic and NIHR meetings and the Black Health Inequalities Summit.

Conclusions

Despite institutional challenges to authentic power-sharing, building meaningful partnerships is achievable. Black communities have not been adequately represented in research and intervention and there are severe health inequalities across populations. Community-led projects that intentionally and meaningfully engage the public in setting frameworks for understanding problems and solutions to the health challenges they face are paramount to work towards achieving equity.

Future plans

A further funding application is currently in preparation for submission to NIHR to continue to strengthen the Partnership and co-conduct research studies with all Partners. We will also produce publications and presentations to different audiences to share learning from this successful project.

Summary of Research:

Background

It is widely recognised that health inequalities are best addressed with the involvement of those communities who bear the burden of poorer health access and outcomes in society, and that interventions are best co-produced with those they are targeted at (NIHR, 2020; NIHR, 2021). The traditional gap between those conducting research and those for whom research is done 'about' represents a limitation in the accuracy, application, relevance and utility of the knowledge produced (NIHR, 2020; Treweek et al, 2020). Moreover, a redistribution of power in the form of knowledge co-production (and not merely implementation or translation) has long been called for by many activist communities asking for a driving seat in the generation of evidence, interventions, and policies that can more directly benefit them (NIHR 2020, UNAIDS, 2007). Multiple, intersectional forms of discrimination are often carried through into processes and practices of health knowledge production (Bowleg, 2012), contributing to exclusion, disengagement, unfair treatment, silencing as well as misrepresentation in what is considered 'evidence' (Dhairyawan, 2020). Through this partnership development grant we came together as a community of practice to establish a set of techniques and principles to underpin engagement and research infrastructure capable of realising the 'nothing about us without us' approach to which we are all committed (NIHR, 2020; UNAIDS, 2017). Through our work we have observed, experienced and highlighted how key and interlocking systems of discrimination based on racialisation, gender, sexuality, and socio-economic status (including importantly citizenship status), contribute to health inequalities (Bowleg, 2012; Collins, 2019). These observations are well supported by an extensive, heterogeneous, interdisciplinary, robust and reliable academic literature that also shows how the multiple and intersecting pathways of these various forms of discrimination interact. Evidence shows that discrimination operates at individual, organisational and structural levels, and that different kinds of discrimination experienced at different time compound one another (Marmot et al, 2020; Gee et al, 2012, Bauer et al, 2019; Krieger, 2012). In particular, helpful theoretical frameworks (e.g. life course, intersectionality, eco-social, social determinants and critical race theories) support an assertion that racialisation matters to health inequalities and racism is a specific driver of poorer health outcomes (e.g. Bailey et al, 2017; Bowleg, 2012, Collins, 2012; Krieger, 2012; Nazroo, 2003). In this partnership we thus wish to focus specifically on Black People's Health – by which we mean the health of people of Black African and Black Caribbean heritage.

Methods

The project was led by 19 Partners (8 clinical and social science academics and 11 community mobilisers). Over 18 months, we hosted 16 public engagement events with Black African and Black Caribbean members of the public, with variation by age (16-80 years old), sexuality, gender, health condition, migrant status, and ethnicity. We employed focus group, photovoice, body mapping, world cafe, and arts-based techniques. The engagement activities covered issues from specific health conditions to broader health and equity concerns. All events were led by Black facilitators, all participants were reimbursed for their time, and all sessions were held in community or public spaces, at accessible times, and with culturally appropriate food. In total, we engaged with 207 members of the public, as per

Table 1: P4BPH public engagement activities:

Activity, Demographics, Numbers attending
Black men and the NHS (Hackney meeting), Black men; 50 – 60s; Caribbean; East London residents, 10 attendees

Black men and the NHS (Tottenham), Black men; 50 – 60s; Caribbean; North London residents, 10 attendees

Elderly Black Individuals 1 (lunch club), Elderly Black Caribbean & African individuals; 55+; North London, Finsbury Park, 12 attendees

Elderly Black Individuals 2 (lunch club), Elderly Black Caribbean & African individuals; 55+; North London, Finsbury Park, 12 attendees

Re-imagining Pain Care for Black People, Black African & Caribbean individuals with different conditions (including MS, SCD, wheelchair user(s); range of ages, 13 attendees

Factors that influence treatment adherence among Black African women in London, Black women; 26 – 65; African; Living with HIV; Presently on medication, 12 attendees

HIV/STI testing – Barriers to accessing SH services in relation to HIV/STI, Black African and Caribbean men & women, 8 attendees

ALIVE Brunch, Black; African & Caribbean women; from East London; 25 – 60 years of age, 19 attendees

Black women's wellbeing & celebration dinner, Black Caribbean women;18 - 65, 7 attendees

Black Women's Maternity Experiences, Somali women; 18 -55, 23 attendees

Black Peer/Co/Community researchers Workshop, Black, Black British, Black Caribbean, Black African and Somalian; 17 – 52, male & female,

8 attendees

Black women living with HIV, Black Women; Living with HIV; 18 – 60+; African and Caribbean descent; Cisgender, 19 attendees

Careers & Wellbeing Workshop, Youth; 15 – 19 years of age; African & Caribbean, 12 attendees

Black Queer Men's Dinner, age 22 – 59; men (including trans men); African and Caribbean descent, 26 attendees

Black Migrant women's dinner, African and Caribbean, 4 attendees

Black Migrant men's dinner, African and Caribbean, 5 attendees

An inside issue: Black women with painful gynaecological condition(s), African; age 21-29; debilitating/ chronic gynaecological pain, 7 attendees

Partners met every 3 weeks for the first 12months of the project, then every month. At each meeting, Partners that had led on involvement activities (referred to as 'Involvement Leads') detailed in Table 1 discussed feedback from their events and/or plans for future events. In this way, over the course of the project, Partners shared learning about methodologies, challenges and opportunities, and issues discussed by public participants. Some of the Partners joined up together to carry out some of the engagement events together. Involvement Leads completed a feedback and reflection form for their activities which included questions on what public participants had raised in engagement discussions, but also prompted reflection on methodology and experience of the Involvement Lead. Once all events were completed, a theme of five Partners (two academics and three community Partners) carried out an analysis workshop to synthesise findings from participants. These were then shared and refined with the whole Partnership across three grant development workshops aimed at co-producing a research and intervention agenda to form the basis of additional funding applications.

Results and Discussion

As this was not a research study, the following Results and Discussion should more accurately be read as calls for action and improvement to practice emerging from engagement with the public and, importantly, engagement between academics and communities as Partners.

What the public raised:

1. The NHS is 'falling apart': Participants expressed deep concerns about the decline of the NHS, particularly among older generations who feel they contributed to its creation. This deterioration is felt by all, but Black communities experience it differently from their ethnic counterparts because of historical and ongoing inequalities. The unique challenges they face within the crumbling healthcare system amplify the existing inequalities and create further disengagement and exclusion.

2. Health care outside the NHS: Health should be seen as more than just the absence of illness. Many Black communities have developed alternative ways to support their health and manage illness, turning to digital media, community groups, and safe spaces for education, support, and healing. Yet, these efforts are often unrecognised or dismissed by traditional healthcare providers, preventing dialogue and reducing chances for good quality care.

3. Black Women's Health: Black women bear the burden of healthcare discrimination, especially in areas such as gynaecology, pain management, and maternal care. Throughout this project, many participants shared experiences of not being believed when they expressed pain or concerns, resulting in delayed or inadequate treatment. Despite these challenges, Black women are highly active in educating and advocating for themselves and their peers, creating support networks to fill the gaps left by the healthcare system.

4. The need for advocacy: Black communities recognise the critical importance of advocacy when navigating the healthcare system and wider. There is a strong demand for peer navigations systems or similar models, to help individuals navigate the complex healthcare landscape. This is especially true for those who need language support, assistance with digital health tools, or face-to-face guidance. Diverse advocacy is needed, including for groups like older men, queer men, and neurodivergent individuals within the Black community.

5. Changing the NHS: There is an urgent need for anti-racist and culturally sensitive at all levels of the NHS. It is not enough for these efforts to be superficial – participants stressed the importance of building genuine connections between healthcare professionals and Black communities. This includes understanding the local context and identities that shape people's relationships with the NHS, particularly for those who have deep ties to specific areas. Collaborative research with communities is essential for developing education and training that truly meets needs.

What the Partnership approach showed:

Effective engagement with Black communities has been the cornerstone of the Partnership's approach. By creating a safe and caring environment where individuals feel heard and valued, we have been able to [re]build trust, especially given the history of negative experiences many have had within the healthcare system. Additionally, fostering confidence and trust through authentic social interactions that did not approach participants as 'research

subjects' but as interlocutors in dialogue, has been crucial to the Partnership's effectiveness. With facilitators who share the community's experiences and a commitment to building genuine relationships, our activities have empowered individuals to identify and articulate their health needs. The use of relatable engagement tools, including arts based approaches and open-ended discussions, and the development of long-term community champions are also vital for sustained involvement and advocacy. Furthermore, it is important to note and highlight that engagement must be designed to resonate with participants, considering practical aspects such as timing and location, and avoiding traditional research methods that can exclude some people depending on their situations. The easier it is to access and the more culturally appropriate the research engagement is, the more likely community members are to attend and fully participate.

Issues raised for the Partnership itself:

A key strength of the Partnership lies in its shared values and commitment to addressing health inequalities in Black communities. Despite coming from diverse professional backgrounds, partners are united in wanting to improve health outcomes and emphasise the redistribution of power and resources from academic institutions to the community as a necessity. This collective commitment helps challenge the notion of a singular Black experience, fostering a richer, more inclusive dialogue. Furthermore, through its regular meetings where partners share experiences and strategies, the Partnership has provided valuable opportunities for mutual learning. However, there is a clear need for greater integration and collaborative working, which could be facilitated by additional funding.

Institutional barriers, such as bureaucratic delays and complicated payment processes, have posed significant challenges, impacting morale and trust within the Partnership. As the Partnership continues to develop, clarity on its strategic aims and leadership structure will be crucial.

Whether we have met our objectives:

- *To convene a community of practice of community organisations, community members, lived experience experts, clinicians, researchers, policymakers, and practitioners working on Black People's Health* - this objective was met both in convening the Partnership and in collaborating with new members

- *To have regular and structured exchange where we share methods that the group can discuss and the take away to use in a deliberative process with different communities* - this objective was fully met

- *To run a series of public deliberations and community involvement activities with different Black African and Black Caribbean heritage groups to interrogate different understandings of health and experiences of health care and inequalities, and to identify priorities for health research and interventions* - this objective was fully met

- *To explore and assess the preferred and most successful methods of involvement to be tailored to different groups and their health priorities* - This objective was fully met

- *Based on the above, to co-produce a community-driven research agenda and research funding applications to deliver it* - this objective was met as members of the Partnership have submitted four grant applications: one to NIHR Digital Inequalities call (awaiting response), three to Centre for Public Engagement of Queen Mary University of London (all awarded) to extend work on Black Men's Health and for a full evaluation of the P4BPH project and process undertaken

independently by two academics at QMUL in collaboration with all Partners. Moreover, the Partners are currently working on a further submission to NIHR PDG for a subsequent linked project.

- *To produce a case study that can be used by other similar partnerships in the future* - this objective has only been partially met as we have not yet prepared a publication for peer-reviewed publication.

Conclusions

Our insights provide a clear and urgent call to action:

- to improve health outcomes for Black communities, the healthcare system must listen, adapt, and make space for Black voices and leadership.

- there is no such thing as 'hard to reach' communities when research and engagement are community-led and co- produced

- authentic power-sharing in Partnership is achievable but currently hampered by institutional and systemic infrastructures that create unnecessary hierarchies and obstacles to equitable practice in collaboration.

Disclaimer

This project is funded by the National Institute for Health and Care Research (NIHR) under its Programme Development Grant Programme (Grant Reference Number NIHR205178). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

This project was carried out between April 2023 and October 2024. This final report has not been peer-reviewed. The report was examined by the Programme at the time of submission to assess completeness against the stated aims. These reports do not undergo a peer review process.

Data Sharing Statement:

[https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253] for the NIHR position of the sharing of research data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to patients and the wider public, the health and care system and which contributes to economic growth in the UK. All requests for data should be directed to the award holder and managed by the award holder.

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