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# The role of Black-led community organisations in supporting Black mental health: a Black emancipatory action research project

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## ABSTRACT

**Objective:** To explore the role of Black-led community organisations in supporting Black mental health and wellbeing in the UK.

**Design:** A qualitative, Black Emancipatory Action Research Framework was adopted. Framework application involved adequately compensating community organisations for their consultancy role; having ‘research conversations’ rather than interviewing participants; and focusing outputs on community benefit. Eight individual and group research conversations took place with nine Black directors, employees and volunteers working with Black-led community organisations, aged between 19 and 62, living in the UK. Reflexive thematic analysis was used to analyse conversations.

**Results:** Three themes were developed in relation to what Black-led community organisations do for Black mental health. These are: identify and respond to mental health needs; selectively build relationships with mainstream services; and drive social and systemic improvements. Findings revealed that Black-led community organisations uniquely identify and address mental wellbeing by offering respite from racism, hosting activities, and meeting urgent needs. They navigate and facilitate access to health and social systems, protect communities from harmful services, and advocate for social and systemic change. Drawing on the study design, findings, and the broader literature, we propose three key changes to current funding, community, and research practices. These are a reconsideration of how Black-led organisations’ work is valued and measured, a forging of greater collaboration between these organisations, and bolder consideration of how research practice can benefit Black communities.

**Conclusions:** Black-led organisations play multiple roles in supporting individual and collective mental health, crucial for mediating the effects of racism and mitigating ethnic inequalities. To our knowledge, this is the first study to both illuminate the

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critical role of community organisations in promoting Black mental health in the UK and to prioritise participant, and community, benefit throughout the research process.

## Introduction

### *Black mental health inequalities*

In the United Kingdom (UK), people from Black<sup>1</sup> communities have a higher prevalence of mental health conditions including depression, panic disorder and psychosis (Bignall et al., 2019; Qassem et al. 2015). Higher rates of schizophrenia and suicide are found in Black Caribbean and African communities compared with South Asian, Chinese and white communities (Hunt et al. 2021). Despite worse mental health outcomes, evidence suggests that Black people are less likely to report or seek help for mental health conditions and when they do, are less likely to have their mental health conditions detected by health care professionals (Devonport et al. 2023). Black communities report experiencing racist mistreatment by mental health services. This leads to expectation of racist treatment, discourages early access, and leads to the perpetuation of mental health inequalities (Kapadia 2023).

### *Who is taking action on Black mental health inequalities?*

Since 2021, the UK's National Health Service (NHS) Race and Health Observatory have been taking significant action to challenge racism and the detrimental effects it has on mental health (Kapadia 2023). Initiatives aim to increase access to high quality and anti-racist mental health care and to reduce mental health inequalities. However, when scoping the academic literature on Black mental health, one could be forgiven for thinking that the NHS is the only organisation taking action on mental health inequalities. Community organisations often step in where statutory services, like the NHS, fail to provide appropriate mental health services, but their role is often underacknowledged. A scoping review explored the delivery of mental health services to Black youth in community, primary care, and educational settings (Martínez-Vega et al. 2024). Of the 54 included studies, only two focused on the role of communities. This underscores the paucity of evidence related to what community organisations contribute to Black mental health.

Internationally, there is growing recognition of the significance of community organisations, also called non-profit or voluntary sector organisations, as key actors in the provision of high-quality mental health services (Baskin et al. 2021; Karlsson and Markström 2012; Newbigging et al., 2020). Given current concerns about the ability of statutory services to provide timely mental health support, community organisations are increasingly expected to contribute to mental health care (Care Quality Commission 2015; Karlsson and Markström 2012). There is a historical precedence of communities stepping in where statutory services cannot, or will not, offer provision (Nelson 2011). Furthermore, there has long been consensus that in relation to health inequalities '... real change can come only from the local community itself by harnessing the energy, skills and commitment of local people, accessed through local community groupings ...' (Department of Health, 1999b, Section 10.22). However, there is a lack of evidence for the role of community

organisations in improving mental health outcomes and how organisations might best contribute.

### ***Historical and social context of Black communities in the UK***

The UK's history as a global colonial power has significantly shaped the demographics and health of its current Black population. The British Empire brutally exploited millions of Africans, forcibly transporting them across the Atlantic Ocean to the Americas as enslaved people. The abolition of slavery in British colonies occurred the nineteenth century, driven by economic factors and fear of rebellions by enslaved people (Andrews 2021). Despite abolishment, slavery's colonial legacy continued to influence migration patterns and societal attitudes. The post-World War II period saw significant migration to the UK, primarily from the Caribbean, Africa, and South Asia. These people were often recruited to fill labour shortages in the NHS and public transport sector. A notable group of people who migrated were those who arrived from the Caribbean between 1948 and 1971, the Windrush Generation. They were invited to the UK to help rebuild the nation after the war (Fitzgerald et al. 2020). Despite significant contributions, many faced systemic racism, discrimination, and social exclusion, resulting in barriers to housing, employment, and public services. See the Bristol Bus boycott (1963), Notting Hill Carnival begins (1966), Brixton uprising (1981), murder of Stephen Lawrence (1993) and the Windrush scandal (2018) for key movements in UK Black history over the past 60 years. Black communities in the UK continue to face health and social challenges related to systemic racism, and racial injustice.

Black people have a long history of fighting for racial justice, organising and advocating for improved housing, education and health care in the UK (see Metropolitan People's Housing Association and the Liverpool Black Sisters). These initiatives have played vital roles in basic survival, challenging racism and promoting mental health (Lateef and Androff 2017). Black and 'minority ethnic'<sup>2</sup> community-led groups have long recognised the importance of spaces where health and social issues can be addressed collectively, relieving the burden from the individual, learning from the experience of others and developing creative strategies for overcoming racism and inequality (Tilki et al. 2015). Yet there has been limited acknowledgement in research or policy spheres of the role that Black-led community organising has played in promoting mental health and well-being.

Within the UK, information about the number and contributions of Black-led community organisations is piecemeal. The recent development of a national Directory of Black-led community organisations aimed to address this gap, facilitating connections and highlighting the extensive work undertaken by and for Black communities (Ejegi-Memeh and Makinta 2024). While the Directory currently features 165 organisations, this paper responds to the need for a more nuanced understanding of the contributions of Black-led mental health organisations.

### ***Creating action research***

Whilst a deeper understanding of contributions is important, there is a need to conduct research which takes action as it discovers. Action has been called for by a number of racial and global health inequalities researchers (Büyüm et al. 2020; Kapadia 2023; Razai et al. 2022). In 1991, Connolly & Torkington published a strongly worded paper

arguing that the extensive amount of research conducted on Liverpool's Black communities had failed to improve discrimination and disadvantage faced in employment, education, housing and health care. Their response was:

... refusing to participate in investigations which many now see as using black people as the topic of academic papers and reports which ultimately serve only to further the academic prestige of those who write them.

They instead promoted participatory, action-focused community-led research that produced very tangible outputs. These outputs included setting up local sickle cell units and sending discrimination notices to the city council. Their Health and Race Action Research project contributed to the establishment of Mary Seacole House, a mental health charity for racially minoritised people (Wainwright and McKeown 2019). The current project was borne of a similar frustration at the futility of health inequalities research that is not tied to direct action and impact.

Given the persistent global prevalence of anti-Black racism and the disproportionate burden of poor health outcomes among Black communities, coupled with the underrecognition of community-led initiatives, this paper seeks to report strategies for enhancing mental health outcomes for Black individuals. Specifically, we aim to examine the contributions of Black-led organisations in promoting mental health and explore the potential for research practices to positively impact Black communities.

## **Materials and methods**

### ***Design***

This 18-month project was an Individual Career Development grant awarded to SEM. The research proposal was designed collaboratively by SEM, leaders of Black-led organisations and academics.

Professor Sarah Salway and Dr. Ros Williams, experts in racialised health inequalities and the sociologies of ethnicity, respectively, provided academic guidance and mentorship. Regular meetings were held to facilitate project development. Community organisation project development and mentorship were overseen by David Bussue, Ursula Myrie, and all research participants. The project design was iterative, incorporating feedback from the community throughout.

### ***Black emancipatory action research***

Black Emancipatory Action Research (BEAR) was developed to integrate race theory into qualitative methods (Akomo 2009). It uses research as a theoretical and methodological tool to challenge racism, sexism and classism, with an aim to contribute towards social justice. The principles articulated within the Black Emancipatory Action Research (BEAR) approach underpinned project development at all stages. Theoretically, BEAR draws on Critical Race Theory, Critical Afrocentricity, participatory action research and feminist scholarship to address unique experiences and challenges faced by Black communities. Critical Race Theory examines how systemic racism is embedded in laws, policies, and institutions arguing that race is a social construct and that racism is

a normal part of Western society (Rollock and Dixson 2016). Critical Afrocentricity focuses on the experiences and perspectives of African people and the African diaspora. It emphasises the importance of centring Black voices and knowledge in research (Asante 2020). Participatory action research is an approach involving collaboration between researchers and community members. It emphasises the importance of empowering communities to identify their own problems and to develop solutions (Bradbury and Reason, 2003). Feminist scholarship examines gender inequality and the ways in which gender intersects with other social categories like race, class, and sexuality (hooks, 1984). In the context of BEAR, these four frameworks are combined to create a critical methodology which allows the researchers to examine the ways in which racism, sexism and classism affect Black communities while centring the needs of community members in the research process. Methodologically, BEAR draws on ethnography, autoethnography and narrative enquiry (Akom 2009). This involves immersing oneself in the research environment, using personal experience and reflection to explore broader social issues. By drawing on these theoretical and methodological traditions, BEAR offers a powerful framework for conducting research centred on Black communities that is both rigorous and transformative.

Careful attention was paid to BEAR's principle of healing and social justice as authors felt that this was often lacking in academic research practice. To uphold BEAR's principles of healing and social justice, the research centred the needs of Black-led organisations while also generating new knowledge (Akom 2009). We actioned this more holistic approach in several ways. First, data generation formed one part of this project but we wanted to challenge extractive models of research which prioritise data generation to the detriment of all else. Other ways we enacted a healing approach included adequately compensating community organisations for their consultancy role (organisations were paid £1000 each for their role as research consultants, and individuals were paid £25 each); having 'research conversations' rather than interviewing participants; and focusing outputs on community benefit. Furthermore, all participants were invited to be co-authors on this paper. They were provided with the option to contribute to manuscript writing but this was not obligatory to be named as a co-author. The participants' words and experiences form the foundation of this paper. Without their time, labour and expertise, this paper would not exist. By including participants as co-authors, we affirm the participatory, reciprocal nature of this research and depart from traditional, extractive research paradigms. Please see [Box 1](#) for our joint positionality statement. Quotes in the Results section are labelled as 'director', 'employee', or 'volunteer' to ensure appropriate levels of anonymity.

**Box 1: Joint positionality statement.**

Co-authors are a diverse cohort of Black individuals residing in the United Kingdom. We bring a range of lived experiences to this research. Our ages span from early 20s to mid 60s. We identify across diverse sexual orientations and socioeconomic classes. We have distinct religious beliefs. Our professional backgrounds encompass various sectors, including public, private, and voluntary organisations.

Central to our collective identity is our engagement with Black-led community initiatives. We have histories of volunteering, working, and leading within these organisations. Additionally, some of us have personal experiences with mental health conditions. This joint statement underscores the multifaceted nature of our identities and lived experiences, which inform our perspectives and contributions to this research.



Research ethics approval was obtained from the University of Sheffield Ethics Committee (052428) prior to beginning data collection. All participants were provided with an information sheet with study details and gave written and/or verbal informed consent prior to taking part in research conversations. Furthermore, ethical guidance from Black emancipatory and Black community-empowering research literature was consulted throughout the research to prevent inadvertently harmful practices (Boat-swain-Kyte et al. 2022; Jean-Pierre, 2024).

### **Recruitment**

Participants were recruited during earlier stages of the project which involved volunteering with community organisations and creating a Directory of Black-led mental health organisations in the UK. Black-led organisations were defined as organisations, of any size, where Black individuals held leadership roles (Trustee, Director, or Executive Officer) and at least 50% of the workforce was Black staff and/or volunteers. Organisations were purposively approached to ensure a range of social identities and characteristics, including geographic location, sexuality, gender and ages of the community they serve. Organisations were contacted via email, provided with the information sheet and invited to take part in this project. Volunteers, employees and directors were invited to directly contact SEM by email or phone if they were happy to take part in a research conversation. A preliminary call with potential participants was then arranged to provide further information on the project and to go through ethical commitments and procedures. Interested participants were sent a consent form to complete by email.

### **Data collection**

SEM had a series of individual and group research conversations with Black people aged between 19 and 62 living in the UK. The semi-structured research conversation guide focused on the experiences of working with Black-led community organisations. The term ‘research conversations’ was chosen over ‘interviews/focus group’. ‘Research conversation’ is becoming more commonly used in research which aims to shift from traditional data extraction methods to ones which reflect the dual-reality making of conversations (Mwale and Williams 2023). In research conversations, SEM shared her own thoughts and opinions. Rather than this ‘leading’ the other party in the research conversations, the purpose was to create a more honest and deep conversation than would usually occur. Evidence of this is shown in the participants’ willingness to disagree with SEM and provide counter perspectives. Furthermore, as SEM is a Black person working and volunteering within Black community organisations, it was important to acknowledge her own political position and experience in regard to how research has historically been extractive to Black communities. Recognition of this insider position was important to promote an honest dialogue and to transparently report the research findings. Eight conversations (seven individual, one dyad) lasted approximately an hour each. These were held with three directors, four employees and two volunteers. All research conversations were recorded and transcribed verbatim. During and after each research conversation, SEM made field notes.



## Data analysis

Braun and Clarke's six phases of reflexive thematic analysis (familiarisation with the data, generating initial codes, searching for themes, reviewing potential themes, defining and naming themes and producing papers/reports) were used to analyse the research conversations (Braun and Clarke 2006, 2019). Given the sensitive nature of the work and SEM's extensive personal and professional experience in this area, reflexive thematic analysis was chosen. This approach acknowledges the researcher's inherent involvement in the data interpretation process (Braun and Clarke 2021).

Quirkos, computer-assisted qualitative data analysis software was used to support analysis. Themes were developed in relation to the research question of 'What contributions do Black-led mental health organisations make to Black mental health and well-being?' A flexible coding processes was adopted with codes added, merged and split throughout the analysis process. Semantic-level (descriptive) approaches to coding and theme development were used to capture and stay close to participants' verbatim statements. Initial codes were developed by SEM. A preliminary list of 42 initial codes were subsequently merged into 30 codes. Themes were generated by SEM identifying patterns of shared meaning in the codes and data, united by the central idea of contributions of Black-led community organisations. The final themes are the result of extensive discussions with and contributions from project mentors and co-authors.

## Results

Three overarching themes were developed regarding what community organisations do for Black mental health and wellbeing. These were: identify and respond to mental health needs; selectively build relationships with mainstream services; and drive social and systemic improvements.

### *Identify and respond to mental health needs*

Community organisations were described as uniquely positioned to understand and address local needs. They often respond directly to community requests or seek support to fulfil them. These organisations, particularly those predominantly or entirely Black, offer spaces of cultural familiarity, refuge from racism, and a sense of purpose.

Through working within and forming a part of the communities they served, directors and employees were particularly attuned to the needs of Black communities. The exchange below demonstrates how the director of an organisation for Black queer men identified where the knowledge, and action, gaps were in terms of supporting Black queer men's health:

- Director: [Black queer men] never get to say about what the [NHS health] programme should be. What the actual need is. So it's not that much of a surprise that we still have no work on employment, no real work on domestic violence, no work on drug use from our perspectives ...
- SEM: And those are the things that you would like to pursue? Those are the things that need to happen?

Director: Well, those are the things that the guys are telling me they want, that they need. So finally we've done some research which says ... the guys are particularly vulnerable to loneliness.

Those who worked in and with community organisations were able to identify groups within the Black community that were more 'vulnerable' to social exclusion than others. Examples included African people who had recently migrated, queer communities, elders, and people with a history of mental health conditions. Black-led community organisations are uniquely placed to identify, and contribute to addressing these intersections:

I knew that there was a need for supported living for our Black elders and for people with a mental health conditions [...] There's no doubt that because of who we are and where we are as an organisation, we've got a really, really good grasp of what the community is saying and what the community wants and what the community needs. Director.

Some organisations responded to time-sensitive, mental health emergencies. One director reported attending to the immediate needs of community members in need of urgent mental health, and in this case financial, support:

... they were in the middle of cooking [when the electricity cut out] and that was the straw that has broken the camel's back. On top of the child coming home from school this week with the shoe open ... and I've just bought those shoes, I don't have money and they've sent me a letter saying I've got to come in to talk about whether or not I can still get benefits ...

I can either say I'm really sorry to hear that and here's [City Council]'s number, because they have an emergency out of hours service that can get you some money to top up your thing, or I can think, [organisation's] got money in its reserves. Now that you've finished pouring, let's get off the floor, let's walk down to the corner shop together and put some money on that electric. Director

This is a powerful example of two things. First, that smaller community organisations can be more rapidly responsive to challenges faced by individuals when compared with statutory services. Second, it demonstrates how mental health is connected to a wider life context, in this case significant financial challenges led to mental distress.

As well as providing financial support, social support was also reported as key. Providing spaces to connect with other Black people was reported as, often happening through culturally focused food, music or events:

... there were people with a mental health difficulties, and [name], one of our tenants, was stood there washing up at the sink. I don't know who'd embrangled him to do that. There was [name], another one of our tenants, sat there knocking a tambourine because they were having a music workshop and there were older people there and people clearly with disabilities. And the peer element of that was that they were all African Caribbean. The food smelt like they recognised, they recognised the food. Director.

Providing cultural familiarity and being around other Black people generated a sense of safety. Nearly all research conversations described the importance of creating spaces where people felt able to express themselves freely and honestly. This included both online (e.g. therapy, women's/men's groups) and in-person activities (e.g. a spa day, lunch clubs). It was challenging to define the components that made these spaces important but they were reported as crucial to making people feel 'heard

and seen' and cared for, key aspects of creating and maintaining mental health and well-being:

I've seen people come in a really bad state and just need someone to show them a little bit of affection and a little bit of care and understanding and come out the other end. There are a lot of testimonials [...] people would say they came in one way and left another. Volunteer/service user.

... we have a website in part just so that we can start a conversation. So that people can see that there are others who are having similar experiences [...] it's valid in a public space to talk about your experience. Director.

The quotes above demonstrate how Black-led organisations provide healing spaces where people can seek refuge and connect with others who have had similar experiences. The focus on public conversations in the latter quote reflects the importance of visibilising experiences as part of that healing process. It was reported that this '*having space to talk*' with others with similar lived experiences was essential, but often lacking in mainstream mental health services.

The Eurocentric mental health paradigm was framed as overly pathological and medical and this was considered problematic and incongruous with participants' day to day experiences of mental health. Black-led organisations were reported to provide a unique space where Eurocentric conceptions of psychology were challenged and more holistic mental health provision was provided:

I volunteered before in other mental health spaces and I just really wanted to do something that wasn't ... that was conscious enough about how Westernised and how Eurocentric the field is [...] I think it's very important that we recognise the damage that Eurocentric psychology has done and continues to do for a lot of people [...] I think that also then really does highlight that it is the work of [organisation]. Where else are you going to be able to have these open and honest conversations? Employee.

... we need to reframe what mental health means and it can't just be from a Western perspective of what mental health is. There are a lot of African scholars, a lot of Caribbean scholars, a lot of Asian scholars who write about mental health in a more holistic way and it is beyond this heavily pathologised style that we see here. Employee.

However, the value of mental health support via talking therapy was frequently discussed as useful, particularly around racial trauma. It was again highlighted that Black-led community organisations are appropriately placed to deliver this type of therapy, rather than mainstream organisations who it was reported often did not recognise racism as traumatic:

... we [Black-led organisation] recognise racism as traumatic. Not a lot of mainstream bodies have [...] Trying to access support for specific things such as racial trauma, which you would only experience as a racialised person, in the mainstream environment that caters specifically to white people, that's not going to happen. Employee

We [all non-white communities] don't experience racism in the same ways, not to minimise anyone one else's experiences, but it's just ... we all experience racism, just differently. There are hierarchies to this too so those who experience things in a very specific way need to be able to come together. I think it's really important to hold a specific space for specific people and that's what [organisation] does. It's very important, yeah. Employee.

These two quotes reflect how racism is productive of mental health problems, and how a lack of understanding of what that means and how people can be helped in that context, is so pivotal to understanding the role of these organisations and how they can contribute to mental health services. Refuge from anti-Black racism was also reported to be a role of Black-led community organisations.

Working and volunteering within Black mental health organisations contributed to Black mental health. The positions of service user, volunteer and staff member blurred in significant ways. For example, some employees had begun working with community organisations as service users and then become volunteers. Others had personal experience of mental illness. They reported that volunteering or working within Black-led organisations had provided them with a sense of purpose. Volunteers reported that their roles helped manage previous diagnoses of depression and PTSD:

At [organisation], I have people I can speak to. I have friends in there. I have [Director of organisation]. And also, the volunteering and being asked to come to events, or being asked to come and participate in things, it helps pull me out of my seclusion.' Volunteer

SEM: It sounds like doing stuff for other people is what brings you ... what word would you use? Peace, joy, stability?

Volunteer: Complete, well basically, complete, I guess.

The data reflected that the mental health impact, for individuals, of contributing to Black mental health organisations should not be underestimated and that this may contribute to both healthier individuals and communities. The data indicates that organisations provide spaces where individuals are empowered with confidence, agency, and the ability to take action, both for their individual mental health and that of broader communities.

### ***Selectively build relationships with mainstream services***

While Black mental health organisations make important contributions within their communities, creating links between community members and mainstream health, education, and housing services is a second role played by Black-led organisations:

... they've linked me with people that have been able to help me with setting up my uni, being able to clear my debt [...] If it wasn't for the person that [Organisation] linked me with, I wouldn't have been able to attend uni. And [Organisation] has also helped me with housing. Volunteer

Some organisation directors and employees were more open to close relationships with mainstream systems than others, but all could see the value in their existence. One director who expressed distrust of mainstream services, having experienced significant harm at their hands, reported that when required, they would provide a link to mainstream services. However, they were confident that they often, could provide the mental health support required by service users:

SEM: Is there ever a point you need to refer to psychiatric mainstream services or is that not your role?

Director: It is my role because we have a duty of care, If we go and see that somebody's in proper crisis then that is my role but I always say to people and you've heard me

say this before, that in the [over a decade] years we've been going we've never lost one of our service users to the PCP, the prison, the cemetery or the psychiatric ward, because we've never allowed them to reach crisis point.

While organisations create links with outside organisations, they also see their role as protecting Black service users from harm from state services or larger mainstream community organisations. This is in the context of a long history of harmful, even deadly, outcomes for Black people within these services (see the case of Colin Holt and the Home Office statistics (2023) reporting the number of Black inpatients injured while being restrained by police in mental health units). Conversations focused on the need to develop relationships with statutory services with care in order to both reassure and protect community members:

- Employee: If we announce it [collaboration with the police] today, with what the community thinks, the vast majority of our service users will straightaway start to get paranoid.
- SEM: About involvement with the criminal justice system?
- Employee: With the police, yeah. So, that's why I'm saying, we want to do it but it has to be done very very carefully.

Participants expressed entering relationships with large, mainstream organisations very cautiously as in the past, they had invested significant energy into research projects and initiatives led by mainstream organisations which had resulted in '*fart to show for it*'. However, despite cynicism about partnerships with statutory services, academic institutions and larger mainstream community organisations, there was a concerted effort to feed information about the needs of Black communities into these services to improve the provision of care:

The whole agenda of research and engagement and working in partnership with the [Universities], that's core business for us. Why? Because it's about achieving better outcomes and better understanding for our community. Director

... we did a session once for a local council. How race-based trauma has similarities to PTSD and so by educating people about these things they have a better understanding of the world around them and how they then interact with the Black people that they worked with [...] they were social workers. Director

Alongside providing larger and statutory organisations with information, sometimes calling out these organisations on their poor or ineffective practice was required. These challenging conversations between community and mainstream organisations were key to developing better ways of working and serving communities:

... the only reason we found out [about a funding call] was they sent an email out two days before the deadline and I ranted at them [...] so then they came back to say, okay, fine, we've got an extension. Let's work properly together. Employee

I was saying to them in the tender for our community you can't just be locality based, because we'll continue to be ignored and overlooked because we are very geographically diverse. I'm meeting with [council leader], who's one of the key commissioners around this, and just reinforcing this and saying, [...] if you continue with that methodology, our community is going to continue to fail to get over the line with these tenders. And that's not a sustainable position for the city. Director

In the UK, services targeted at ‘diverse’, or ‘minority’ populations tend to work on the basis that people live clustered together in diaspora and migrant neighbourhoods. However, this systematically excludes Black communities in the UK which tend not to be geographically clustered. Sharing this knowledge (e.g. Black people in a city are geographically disperse) has the power to influence the development of more appropriate provision by mainstream services. However, this depends on the ability and willingness of mainstream services to respond to community knowledge and need. The significant work undertaken by Black-led community organisation to shift the rules of engagement with mainstream and large funders often goes unrecognised.

### ***Drive social and systemic improvements***

Most participants were keenly aware of the link between mental health and wider social issues, such as poverty and insecure housing. They understood that if people’s material conditions were to improve, that mental health would likely improve alongside it, and this led them to push for systemic change:

I think there’s definitely potential for improved wellbeing. [...] we see it even in the way that in parks they’ll build benches and seats in a way that prevents homeless people from sleeping on them. That is so cruel [...] You will find that if people’s basic needs are met, we would see a sharp decline in depression, a sharp decline in anxiety, a sharp decline in many other indicators of [poor mental health]. Employee

... the health advisers prove the fact that we know that physical health can very much lead to mental health issues and the other way around. Housing, we know that being in a place where you’re not guaranteed that the landlord’s going to treat you right, all of that [impacts on mental health]. Director

Conversations reported the need for allies from both other racially minoritised communities and the white community to challenge these wider social issues:

... when it comes to organising and doing activism work, showing solidarity can definitely exist within our communities because we’re fighting a higher white supremacy which we all experience. Employee

As well as recognising the need to push for agency and solidarity for marginalised communities, it was acknowledged that large-scale change required decisions and a willingness to act from senior leaders in statutory organisations:

I think that in terms of the system it does need to be those leaders, those decision makers that are at senior levels and who can influence and make change. And it’s got to be change. I’m not just talking about the usual health [organisations], the council, the NHS, all the rest of it. There’s definitely a role for the universities. Director

Research conversations highlighted that being included in meetings with key stakeholders was important for generating change and there was a general feeling that progress was being made:

... we should try and be at every table [...] At every table and advocate for ourselves. That’s why I have the speaking stuff. The meetings can get annoying. But if they don’t value you by yourself and then scream about what you’re doing every chance you get, so that they can’t forget you when the money comes or when the policy comes, or whatever comes, so that we are everywhere where decisions are being made – and I think we’re getting there. Employee

However, participants identified superficial inclusion efforts as a significant barrier to addressing racialised health inequalities, as they consumed community organisers' time without yielding concrete outcomes. Two accounts explicitly labelled this as a form of racism:

I used to chase purse string holders, policy writers. Be a yes ma'am, no ma'am, three bags full ma'am, type of person. Go to all these big meetings in the town hall. Speak to Lord Mayor, High Sheriff, them sitting nodding and patting me on the shoulders means I'm really making a difference and they're really listening and they're going to go away and do something and then I'd be chasing them up and they would be blowing smoke up my arse and saying, yeah, we're going to and I learned that actually this is how they waste our time. Speaking to people that are saying they're going to do things for you and do absolutely nothing. You get to the stage where you recognise that is racism. Director

If you're not committed to [anti-racism] personally and professionally, it's a complete waste of everybody's time. You can make all the right noises. You can say all the right things but in truth I would rather the person call me a Black bastard to my face rather tell me how important it is in all the rest of it and then they don't engage with Black people. Director

Co-production, collaborations between mainstream and Black-led organisations, was proposed as a solution to ineffective, superficial inclusivity. This approach, from idea inception to project delivery, was reported as successfully creating initiatives that genuinely benefitted Black communities:

I think the co-creation type work that they're doing is much better than it was before, because in the old days it used to be that they designed the whole thing and then came to you again to say, we've got five options, which one do you want? Employee

What [National Health Service Trust link worker] said is 'I've got this pot of money that I want to spend to address racialised inequities.' She hadn't come with this preconceived idea of how she was going to spend the money and so out of that conversation we learnt that key issues for them were around restrictive practice on the wards, that the data was telling them particularly African Caribbean men were heavily overrepresented in isolation and in restrictive practice at whatever level so we agreed that the money would fund [a role focused on health and racism in hospital settings]. Employee

Sustainable funding was reported as key to supporting community organisations to drive social and systemic change, but securing funding for some of the more intangible work (e.g the provision of safe spaces, events for wellbeing) was reported as challenging. Frustration at their worth not being recognised or adequately and sustainably funded by mainstream was expressed:

... social care is always going to be needed. So why can't we just make that commitment? And organisations like ours are always going to be needed. Why? Because there are some people who they just feel more relaxed, they feel better served when there are people who look like them and they don't have to explain. Director

Donations, unrestricted funding, core funding or '*rolling funding without any strings attached*' were suggested as better models to sustain both the drive for social change and the community building and caring work undertaken by community organisations, both of which are crucial to wellbeing but challenging to define or measure impact.

A step towards measurement of impact is noticing that a reduction has taken place. One participant visited mental health wards and had discussions with Black people on



the wards. Since they had been going into the wards, a marked reduction in restrictive practices occurred suggesting that their work had contributed towards prevention of restrictive practices. Documenting social and systemic improvements is key to demonstrating the effectiveness of community-led work and advocating for informed decision-making and policy changes.

## Discussion

This article introduces the crucial role of Black-led mental health organisations in the UK. We highlight their work in healing historical and ongoing injustices and challenging systemic harms. We also demonstrate a BEAR-informed methodology designed to achieve this goal. However, our research has limitations. Given that conversations were had with only 10 people (including SEM) from six organisations, there is a significant amount of work being undertaken that has not been captured in this paper. Secondly, our findings are reflexive but not critical. We acknowledge that Black-led organisations and communities are also capable of doing harm through stigma and religious beliefs around mental ill health (Shocka 2023). Whilst acknowledging these limitations, we now draw on the findings above and the wider literature to argue for three key changes to current funding, community, and research practices. These are a reconsideration of how Black-led organisations' work is valued and measured, a forging of greater collaboration between these organisations, and bolder consideration of how research practice can benefit Black communities.

### *Reconsideration of how Black-led organisations' work is valued and measured*

Community-led initiatives can provide vital spaces for connection, joy, and respite from racism (Salami 2020). Our research, and that of others, suggests that volunteering can boost well-being and a sense of purpose (Fegan and Cook 2014; Thoits 2012; Tierney et al. 2022) and there is a long history of Black people volunteering both in the UK and elsewhere (Cash 2001; Mayblin and Soteri-Proctor 2011). These positive effects may be accentuated for Black people who are more exposed to microaggressions and systemic racism, contributing to significant psychological distress (Mclean et al. 2003; Rollock 2022; Williams, Lawrence, and Davis 2019). The existence of Black-led organisations as avenues for volunteering and the associated positive mental health benefits should be more carefully considered.

Our findings highlight the crucial role Black-led organisations play in providing access to mental health support, including therapy, safe spaces, emergency funds, and navigation of complex statutory systems. A mapping exercise by Mwale and Williams (2023) documented the activities of 21 Black-led organisations in the UK, these ranged from combating discrimination to addressing social and educational challenges. Protection from harm was also a key focus of these organisations, aligning with our findings. These 21 organisations, and the ones included in our research, often served as valuable bridges between Black communities and statutory services, mitigating issues of mistrust and stigma (Butt 2001; Memon et al. 2016).

As well as linking to statutory services, Black-led community organisations have a rich history of innovative, emancipatory approaches to addressing health disparities. Examples include Black Supplementary Schools (Andrews 2013), Black women's

health movements (Douglas 2019), and the recognition of Black barbershops as spaces for mental health (Wippold et al. 2023). While the impact of such approaches may be difficult to quantify using conventional academic metrics, their value should not be underestimated. Providing volunteering opportunities, bridging communities with statutory services and building alternative health provision requires significant effort. Yet, funding mechanisms frequently fail to recognise the transformative impact of Black-led organisations on people's lives. We advocate for greater trust and flexibility from funders and policymakers. By acknowledging the critical role of these organisations, trusting them, and simplifying funding and evaluation processes, decision-makers and funders can return time and space to these organisations allowing them to focus on their core mission: improving the health and well-being of Black communities.

### ***Forging greater collaborative networks between Black-led organisations***

The creation of spaces for connectedness between Black people and organisations, and the role that this type of activism can play in Black mental wellbeing has not been well discussed in the sociological and health literature (Douglas 2019). Our findings suggest that solidarity and increased connections can disrupt systemic oppression. A more coordinated approach is needed to strengthen the impact of organisations' work, nationally and internationally (Andrews 2021). The Directory of Black-led organisations was compiled to connect organisations working towards improved Black health (Ejegi-Memeh and Makinta 2024). The Black Mental Health Manifesto (Black Mental Health and Wellbeing Alliance, 2024) is another national effort to bring Black communities together and address pressing mental health issues. These initiatives aim to improve collaboration and more effectively address mental health inequalities.

We argue for organisations to set aside differences and coalesce around a common aim of challenging systems of oppression. When discussing community organising, Hayes and Kaba (2023) describe the need to engage and work with people with whom we may not fully align with ideologically, nor even like. They, and others, highlight the danger of not working in solidarity is that we will never build movements large and powerful enough to create systemic change (Ejegi-Memeh et al. 2023; Incite! 2007). Strengthening collaboration between Black-led organisations would create a more harmonious environment and amplify collective action against systemic injustices through the generation of a critical mass.

### ***Bolder consideration of how research practice can benefit Black communities***

Finally, we turn to the methods used to conduct research in this field. Co-production and co-creation have gained significant traction in public health research, enhancing inclusivity and improving research quality (Vargas et al. 2022). However, it is imperative to consider potential benefits for these newly included research populations. A growing body of scholarly work highlights the necessity of centering anti-racist practice in knowledge production (Ford 2016; Joseph-Salisbury and Connelly 2021). However, there remains a need for practical guidance.

This project, grounded in BEAR, aimed to shift the paradigm from research *about* Black communities, or even just *with* Black communities, to *research practice for* Black

communities. Despite limited funding (£25,000), the project yielded substantial benefits: over £80,000 in community funding, career development for 10 Black scholars, academic paper authorship for participants, a Directory of over 160 Black-led organisations, and a national networking event. Creating benefits for community of study throughout the research process should be the status quo for all researchers working with underserved communities. While changes to policy and practice resulting from research findings can often take years to materialise (Morris, Wooding, and Grant 2011), taking action throughout the research process can accelerate positive change.

This project demonstrates the potential for research to positively impact communities beyond traditional academic outputs. By prioritising community need and resisting institutional pressures, we can foster meaningful collaborations and contribute to social justice. We encourage other researchers to adopt similar approaches to create a more equitable research landscape. As Hollin and Williams (2022) note, even well-intentioned research can be co-opted. By prioritising community need, we can ensure that research processes and outcomes benefit underserved communities in new ways.

## Conclusion

This research provides a rich description of the contributions of Black-led community organisations in the UK. While their work is well-known within Black communities, this paper offers a significant and novel contribution to the academic literature. It is hoped that Black-led community organisations can use this paper as a tool to argue for increased funding from commissioning and statutory services that often require such ‘evidence’. It also hopes to contribute towards better understanding and recognition of the work of Black-led community organisations. However, this paper is also for Black-led community organisations. To visibilise their tireless work challenging systems of oppression, through whatever means necessary, and to let them know they are invaluable.

## Notes

1. Within this paper, the term ‘Black’ encompasses people of recent African and/or Caribbean descent. However, it is important to recognise the diversity within this population. Black people in the UK are a heterogeneous group, and their experiences are influenced by a range of intersecting social factors, including gender, class, sexuality, and ability. Within this paper we endeavour to reflect diverse experiences of Black people.
2. ‘Black and minority ethnic’ is the term used by Tilki et al. 2015. Authors acknowledge that terms such as ‘minority ethnic’, ‘racially minoritised communities’, and ‘marginalised communities’ have been subject to stringent critique for the ways in which they ‘other’ people (and undermine belonging). However, alternative terminology that accurately captures the complex social and political realities of these groups remains challenging. Where possible throughout this paper terms such as ‘minority ethnic’, ‘racially minoritised communities’ and ‘marginalised communities’ are avoided. However, we feel it important to acknowledge that a collective term that accurately captures the complex experiences of people disadvantaged by racism remains elusive.

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## Data availability statement

The data that support the findings of this study are available from the corresponding author, SEM, upon reasonable request.

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