Research Paper

How should we do racially just health research? Learning from a qualitative study on COVID-19 pandemic experiences in the UK

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Racialised social inequalities were exposed and exacerbated during the COVID-19 pandemic. The methods health researchers employ in designing and conducting research can replicate the same inequalities, with important implications for the creation of new knowledge. In this paper, we retrospectively and critically analyse the thinking and methods we employed during two qualitative studies about the diverse experiences of people and families during the COVID-19 pandemic in the UK. Set within a wider literature on engaging with race and ethnicity in health research, we present an analysis based on reflexive accounts and testimonies from researchers, and close-up examinations of different stages of the research. By illustrating these ideological, practical and interactional components of research, including some uncomfortable reflections, we hope to encourage more open conversations among researchers and research funders. Through this process, we can strengthen efforts that dismantle unhelpful historical research orthodoxies and move towards re-formulating ways of research practice that are more explicitly anti-racist and inclusive.

Introduction

Applied healthcare researchers in high income countries often struggle to recruit racially diverse research samples. Drawing on two recently completed UK-based qualitative projects about experiences of COVID-19 illness, this paper examines the intellectual, methodological, relational and practical work that

was needed at different stages of the research process in order to elicit and foreground racialised health experiences of the pandemic in the UK.

We begin with a short overview of the relationship between racialised identities and health, and how traditional health research practices can exacerbate these inequalities. We then briefly introduce the anti-racist scholarship that guided us, summarise the research projects this paper reports on, and proceed with a detailed reflexive analysis of our efforts to undertake anti-racist research. In recounting our experiences (both the good and the less satisfactory), we hope to stimulate more open conversations among funders and researchers about how to do this better.

Race and Health

The categorisation of people into races descends from European imperial projects, when it served as a way to dominate and control colonial subjects. Racism has been defined as "the state-sanctioned or extralegal production and exploitation of group-differentiated vulnerability to premature death" (Gilmore 2007, p. 28). Racially-determined and inequitable access to resources that affect health leads to racially-pattered health differentials (Came & Griffith 2018, Paradies et al. 2015, Williams et al. 2019), making racism a fundamental cause of health inequalities (Phelan & Link 2015). Social epidemiological theories have long explored how racism works at multiple levels - structural and institutional, cultural and interpersonal – to produce acute and longer term health disadvantages (Krieger 1999, Williams 1997). Camara Jones (Jones 2000) explained how racialised disadvantage, repeatedly reinforced across societal structures and institutions that people engage with through the life course (e.g. in education, housing, employment, healthcare), leads to poor health outcomes and that these effects accumulate over generations. It also leads to internalised racism, whereby members of stigmatised groups internalise negative messages about their own intrinsic worth and capabilities. Discrimination over time results in the *embodiment* of social disadvantage (Krieger 1999, 2012), taking the form of quantifiable differences in health between differently racialised groups (Geronimus 1992, Gravlee 2009).

The COVID-19 pandemic provided a vivid example of how racism affects health. In the UK, as in other White-majority countries, deeply entrenched structural racism leads to 'racialised capitalism' (Ganguli-Mitra et al. 2022, Laster Pirtle 2020), which means a disproportionate number of racialised minorities are employed precariously (with low pay and limited options for paid sick leave or home-working), often in public-facing roles (e.g. transport/postal workers, frontline healthcare staff) and living in cramped, overcrowded housing. Discrimination in healthcare access when they became unwell (either real or anticipated due to past experiences) also contributed to their disproportionately higher mortality and morbidity. All this combined to make them more exposed to the virus, and less able to support themselves when they became ill (Bambra 2022). In the backdrop to these events were vigorous media campaigns appearing to blame racialised minorities for spreading the virus (Dowrick et al. 2024), as well as suppression of a national report analysing these phenomena (Moore 2020) and a fierce denial of the existence of structural racism in the UK (Commision on Race and Ethnic Disparities 2021).

How Traditional Health Research Practices Reproduce Existing Racialised Inequalities

Despite the extensive literature within social epidemiology, medical sociology and anthropology (Hicken et al. 2018, Krieger 2012, Nazroo et al. 2020) that emphasise the importance of examining yet also problematising race/ethnicity in health research, mainstream disease-focused clinical and epidemiological publications remain chronically afflicted by either the non-use or problematic use of racialised categories (Krieger 2021). Even in June 2020, during the height of the COVID-19 pandemic, of 1518 COVID trials listed on ClinicalTrials.gov, only six studies reported data on ethnicity (Pan et al. 2020). Moreover, even when race/ethnicity data are reported, there is little theoretical reflection on the meaning of racialised

differences in risks and outcomes (Shannon et al. 2022, Stafford et al. 2020), and engage only with overly reductive 'risk factor' analysis using poorly defined measures of race/ethnicity.

These 'data' problems in mainstream medical research arise from racism that is present throughout the health research infrastructure. For instance, the lack of diversity within the leadership of academic institutions (Powell et al. 2022) is not just a matter of racial justice; it also builds institutional cultures that draw from a narrow breath of perspectives, biasing what research is commissioned and funded. The repeated use of non-diverse study samples (Montoya-Williams et al. 2022), in both qualitative and quantitative research stems from a mix of insufficient resourcing and outreach work and inadequate skillsets of research teams, alongside enduring methodological whiteness[1] (Bhambra 2017) in research designs, processes and tools, which normalise whiteness and subordinate the need to adopt race-conscious approaches (Rai et al. 2022).

Adopting Anti-Racist Methodologies for Our Work

Our work drew upon recent thought and writing exploring ways to disrupt traditional health research methodologies and replace them with ones that embed explicitly anti-racist and social-justice orientations (Came & Griffith 2018, Ford & Airhihenbuwa 2010, Krieger 2012). Anti-racism has been defined as "an educational or organising framework that seeks to confront, eradicate and/or ameliorate racism and privilege" (Came & Griffith 2018, p. 182). Notably, since the COVID-19 pandemic plunged the world into chaos, there has been a surge in publications within health research calling out racism and promoting anti-racist approaches in how research is generated (Amani et al. 2022, Cerdeña et al. 2020, Powell et al. 2022).

Anti-racist approaches to research praxes draw from a rich set of critical theories. Some (Smith 2012, Thambinathan & Kinsella 2021) use a decolonial lens (following authors such as Du Bois (1995 [1903]) and Mignolo (2009) to track how power relations today reflect the ossified structures and institutions established during colonial times and encompass a global and translational approach. Calls for transformative praxis come most powerfully from Indigenous and Black scholars and from the global South, who propose these approaches in order to "turn spaces of marginalisation into spaces from which resistance and hope flourish" (Thambinathan & Kinsella 2021, p. 1). Others (Ford & Airhihenbuwa 2010) use versions of critical race theory (Bell 1993, Crenshaw 1989) to study contemporary racism in specific national contexts and beyond its colonial foundations (Bonilla-Silva 2017). Both approaches require explicit rejection of a colour-blind ideology, which emphasises race neutrality and meritocracy as the organising principles of contemporary societies (Manning et al. 2015). They recognise that racism contributes not just to social and health inequities but also to diminishing the significance of racially-minoritised experiences/knowledges as 'marginal' and not worth knowing. Collectively, this literature proposes a set of fundamental practices that are relevant to qualitative research. They encourage critical reflexivity (within the research team and institution, as well as when interacting with public contributors and participants), understanding the ordinariness of racism, the need for reciprocity and respect in the generation of alternative knowledges, and centring the voices of people who are racialised as 'other'.

In UK health research, anti-racist research methodologies are still in development, making our work novel as it illustrates what and how much could be done within the relational particularities of who and where we were, the wider UK public discourse about race and ethnicity, as well as the pandemic-specific constraints that were placed upon us at the time. We now briefly describe the research studies that provide the context of this article, before moving on to a retrospective evaluation of the methods and thinking we employed for the work.

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[1] Gurminder Bhambra defines methodological whiteness as "a way of reflecting on the world that fails to acknowledge the role played by race in the very structuring of that world, and of the ways in which knowledge is constructed and legitimated within it" (Bhambra 2017).

The COVID-19 Interview Studies

This paper is based on a work package designed and led by study co-applicants TR, KQ and JD whose objective was 'to develop new approaches to engage with BAME[2] and other seldom heard communities in planning and conducting research' (we explain our discomfort with these terms below). This was situated within a research project (Study 1) titled 'Experiences of COVID-19 and recovery: learning from polyphonic voices for communities, policy makers and health and social care providers' (ES/V016032/1), for which qualitative interviews were conducted with 70 participants between March 2020 and September 2021. We drew on this experience to support a similar work package (led by the same team, among a wider group of co-applicants) for another project (Study 2) titled 'Understanding and using family experiences of managing Long Covid to support self-care and timely access to services' (COV-LT2-0005), with 72 participants interviewed between October 2021 and July 2022. Additional to academic outputs, study findings were disseminated via the public-facing health information and support website, hexi.ox.ac.uk.

Who We Are

Research funded through urgent COVID-19 streams during 2020/21 needed to adhere to tight timelines, necessitating a larger team of research interviewers than is usual in qualitative interview research. Interviews for Study 1 were conducted by AD, TR and KQ, with an additional four interviews conducted by HM. For Study 2, CW was the main researcher alongside three others, with TR and AD contributing a few interviews. The core research team are all highly educated, middle class academics based at prestigious institutions. We describe ourselves further in our own words as follows:

> *TR is an Indian, cis-gendered woman and first generation immigrant to the UK (arrived on an academic scholarship in 1998). She is in her 40s and speaks Urdu/Hindi.*
>
> *AD is a White British cis-gendered woman from the north of England. She is in her 30s with Irish family heritage.*
>
> *KQ is a White British cis-gendered woman from the south of England. She is in her 40s. Her name, changed upon marriage, obscures her English family heritage.*
>
> *JD is an African-Caribbean woman, born to Jamaican parents who migrated to the UK in the 1950s. She has lived in the West Midlands for most of her life and has a lot of personal networks in the African-Caribbean community.*
>
> *HM, is a White, Ashkenazi Jewish, cis-gendered woman, originally from the United States. She is in her 30s and speaks Yiddish. Her name obscures her Jewish identity, and highlights her Scottish ethnicity.*
>
> *CW is a White, cis-gendered woman from New Zealand in her late 20s with British, Irish and Middle Eastern heritage. She arrived in the UK in 2021.*
>
> *SZ is a White British, cisgender woman in her 60s, a sociologist with interest in the social determinants of health.*

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[2] BAME stands for Black, Asian and Minority Ethnic, and is a term commonly used in UK government and other institutional reporting to mean everyone who is not White.

For both projects, we also identified patient and public involvement (PPI) co-applicants from racialised minorities (as part of a larger PPI panel), who shaped our approach to recruitment, data collection and analysis, and the presentation and dissemination of study findings on the website.

Study Sample and Recruitment

We adopted an intersectional lens (Crenshaw 1989, Douglas 2023) to inform our planning and recruitment, attending to how other axes of difference such as social class, gender, occupation and migration status intersect with race/ethnicity at the level of individual experience to "reflect interlocking systems of privilege and oppression (i.e. racism, sexism, heterosexism, classism) at the macro social-structural level" (Bowleg 2012, p. 1267) and produce particular health inequities. Occupation in particular was relevant since we were interested in identifying people with public-facing, 'essential worker' roles during the pandemic.

Community-based recruitment is known to facilitate samples that resemble wider population demographics (Campbell & McLean 2003), but pandemic social distancing necessitated the use of remote methods. We therefore planned all initial contact through phone calls, social media and emails. Following our PPI co-applicants' suggestion that some participants might not have electronic devices or hi-speed internet, we built in capacity to courier data packages and tablet computers to those who needed it. We initially drew on our own and our PPI co-applicants' personal and professional networks. This was later extended to intermediaries to reach a wider network of potential participants (Table 1).

As promised in our funding application, more than two-thirds of our participants were from racially minoritised groups, the majority working in public-facing, frontline jobs and/or from financially precarious households. In what follows, we look closer at different stages of the research, distinguishing between aspects of research that we had planned for at the grant writing stage, and those that were unanticipated and required innovation or creative modifications as we progressed.

Points of contact	Methods used
Across personal and professional networks and relationships (friends, colleagues, students, neighbours, parents' groups, school networks)	Using word-of-mouth, study posters and leaflets, WhatsApp, twitter and other social media
Through our own research networks	Rekindling participant and recruitment contacts made through earlier research projects
Connections and snowball chains across participant networks	Through second and third degree connections, such as friends of friends, students and colleagues, contacting their own networks and posting our study information on their WhatsApp groups and social media sites
Individuals and organisations identified via google searches	Mapping and contacting community support groups and organisations based in areas badly affected by COVID-19 and located in ethnically-diverse, socially-deprived geographical locations, or finding prominent spokespersons from minoritised groups, 'gate keepers' cited on the news or amplified through relevant social media channels

Table 1: Methods employed for participant recruitment

We use case examples to illuminate three main methodological reflections upon the study. First, we describe how we built trust within the team and with our participants such that all intuited a common cause with the study concerns. Second, we examine how our approaches to interviewing and to

researcher-participant positionalities affected the interview narratives. And finally, we explore why some of our efforts were more and some less successful, and what can be learnt from those experiences.

Reflections

Building Trust, Establishing a Connection

Working With Our PPI Co-Applicants

The PPI co-applicants for both studies were Black and Brown women who had experienced COVID themselves. For Study 1, they were enlisted rapidly (identified from PPI participation in previous research) enabling us to make the urgent funding deadline. For Study 2, we invited three participants from Study 1 (who had subsequently developed Long Covid) to be our PPI co-applicants.

The difference was palpable. In Study 1, the lack of lead time meant that beyond the initial meeting, our engagement with them was scattered and thin as we scrambled to mobilise our recruitment and data collection (we had been allocated just 12 months to collect 70 interviews despite being in national lockdown for much of that year). In contrast, we developed sustained long term, active working relationships with our PPI co-applicants for Study 2, which built upon the initial rapport established during the Study 1 research interview. Despite the same financial reimbursement across both studies, PPI co-applicants in Study 2 demonstrated collective ownership and investment in the research, attending team meetings regularly and frequently making recommendations, confident their voice would be valued. These contrasting experiences align with Mackenzie et al.'s (2007) ethical reflections based on their work with refugees, on the nature of consent-taking, where having iterative research processes which allow multiple contacts, and therefore continuous opportunities for negotiating trust, are essential to enabling people's capacity for self-determination.

Critical Reflexive Conversations within the Research Team

For research to achieve anti-racist goals, researchers need to remain attentive to the epistemological assumptions informing the research plan, ready to make informed adaptations when more conventional methods prove inappropriate (Datta 2018, Taha 2018). Our research team was racially diverse and shared the intended goals for the project. However we still needed to confront, clarify and consolidate certain issues, two of which we now discuss.

Keeping in mind that our study was not specifically about race or racism, we still wanted to 'make space for race' in the interviews. Avoidance of talk about race and racialised inequality can silence challenge or dissent to the normalised (White) mainstream narrative, thereby indirectly legitimising and normalising racialised injustice (Evered et al. 2023, Gast et al. 2022, O'Brien 2011). Thus, while our topic guide was organised to elicit free-flowing accounts about participants' COVID-19 experiences from the point at which they first heard about the virus, we deliberately included specific questions about participants' social identities (specifically, ethnicity and occupation) and whether and how these had affected their experiences. Later on we address the interview tool in relation to reflexivity about the interview process, but here we emphasise how this became a pivotal moment for political discussion among the team, about our respective positions on 'race talk'.

On mentioning this to a (White) colleague working on different project, her initial response was that if participants' felt racism had been an issue for them, they would volunteer it themselves, so we did not need to ask specifically. Her concern was with avoiding leading questions, however this response illustrates a conflation, seen frequently in research and in institutional life, between achieving 'diversity' and doing anti-racist work. In this context, the implication was that having racially diverse participants

(and indeed, racially diverse researchers) was *in and of itself* proof that our research was anti-racist (Ahmed 2006). It also ignores how difficult it is for racially minoritised people to discuss racism, particularly in the context of the immense power asymmetry of a researcher-participant interaction. We discussed this at length, feeling grateful for how it had pushed us to reflect more deeply on the matter, and felt convinced of the need to actively create opportunities for race talk.

We anticipated that participant trust in our research would be influenced by how it was presented. This included acknowledging our own racialised identities within the group and how that shaped the contours of what each of us might accomplish. The use of cultural 'insiders' or brokers, particularly through membership of that group is common when working across cultures (Trimble & Fisher 2015). Although JD did not conduct interviews herself, her involvement with the study, as a Black woman with a lifetime of academic and policy work on Black people's health (Douglas 1992, 1998, 2023), contributed to significant buy-in from the communities to which she was connected. For example, AD interviewed a Black participant who was strongly mistrustful of medical research, particularly its racist origins. However, having heard of our study through one of JD's networks had reassured her. AD recalls her saying:

> Well somebody rang me and said, "You must take part in this because they need to hear Blacks." So I wouldn't have done it otherwise, [but] it's someone that I respect that said "they need to have a Black perspective."

Making clear that Black voices were being foregrounded, and having this conveyed by someone she trusted, was central to her participation. Once past this stage, she agreed to be interviewed by AD, and offered one of the most searing critiques of the racialisation of the pandemic response, building connections with broader structural racism in Britain. Additional to valuing JD's implicit legitimisation of the process, we also see AD's act of seeking JD's authority to provide authenticity as a proactive methodological step towards decentring whiteness, and of respecting and legitimising racialised distrust in research in order to make room for the elicitation of other(ed) ways of knowing (Taha 2018).

Research Can Be Hard-To-Trust

Terms such as 'hard-to-reach' or 'seldom heard', often used to explain low recruitment of racialised populations in research, can suggest that those labelled in this way choose to abstain from activities for the 'common good'. Like Islam et al. (2021), we suggest a reframing that positions *research itself* as 'hard-to-trust'. What university-based researchers see as 'standard' research practice may be viewed differently by people who are not part of these traditions and institutions. The odious legacy of medical experimentation, non-consensual treatments and medical malpractice (Ojanuga 1993, Scharff et al. 2010), Western universities' contributions to the maintenance of racialised disadvantage and the concentration of privilege (see epistemic violence (Spivak 1988 and, more recently, Bhopal 2017 and Godoy 2020) and the wider impact of structural racism in daily life and health care (Obermeyer et al. 2019, Sowemimo 2023), makes many racially-minoritised publics living in White-majority countries feel distrustful of health research (Bécares et al. 2022). PPI discussions reinforced our anticipation that people who feel marginalised in British public life might be guarded when contacted by university researchers such as ourselves.

To this end, we created a one-page full-colour study recruitment poster, in electronic (WhatsApp-able) and paper form, with text emphasising our commitment to speaking with people from racially minoritised groups and included photographs of the field researchers (making their racialisation visible). We had this poster translated into Arabic, Urdu and Gurmukhi through students and researchers based at the lead university (more on this later, in 'The limits of our work'). We also arranged, at their convenience, multiple pre-interview conversations with potential new participants, often at evenings and weekends. By the time they were interviewed, participants had been through an informal consenting

process negotiated over several contacts, rather than at a single time (Thambinathan & Kinsella 2021), which created space for them to be comfortably 'suspicious' of us, ask questions and set mutual expectations. For example, TR recalls chatting with a participant about how journalism compared with academic research, and about managing a career alongside family responsibilities, long before discussing the actual research.

Our efforts did falter sometimes – for example, we were uncomfortable using 'BAME' and 'seldom heard' in our *named* work package, but were responding to the inertia within institutional cultures in the adoption of anti-racist vocabulary (such as 'racially/ethnically minoritised' (Gunaratnam 2003)). To ensure our funders understood us, we strategically acquiesced to using these problematic terms in our proposal, which unfortunately promotes the reductive, racist categorisations that we were striving to resist.

Reciprocity

As part of the funded plan, we offered financial reimbursement to those helping with participant recruitment. Appreciating the inherent inequality in research relationships (von Vacano 2019) and as a gesture to compensate for this, we sometimes also agreed reciprocal favours to the people or institutions we reached out to, such as by giving scientific presentations at community gatherings and reviewing formal documentation for them (e.g., an application for local council funding). For instance, KQ had approached the organisation that ran her children's day care, which eventually yielded several study participants. However, the momentum for this came because KQ paid attention to the director's disenchanted response when she had initially asked for help with recruitment, as KQ's notes explain:

> the director of [organisation] was weary of researchers approaching them for help with studies
> and spoke critically about researchers (who were being paid well, she thought) burdening them
> with invisible work (of discussing the project with case workers and clients) and then leaving
> without so much as a how'd-you-do.

KQ enquired how she could contribute to the organisation, and following a few conversations, she delivered five online workshops about COVID-19 vaccines, for which she spent time updating her own knowledge. Chronic underfunding of publicly-funded organisations (like this one) means they often run on the fundamental goodwill of their (underpaid) employees. In order to dilute the extractive nature of our request we offered something in return, and this was ultimately beneficial to our research aims. However, the lack of research metrics for such community-based 'giving back' activities places the burden of responsibility upon individual researchers who are "motivated to step outside the academic industrial complex" (Tuck & Yang 2014, p. 238). The opportunity costs of doing this kind of work may take the form of reduced time spent writing or presenting to academic audiences (Nagar 2014, Smith 2012), which over time may have implications for researcher career development.

In the next section, we reflect on the interviews, how the interactions between researcher and participants affected the content of the narratives, and how participants reflexively composed their responses.

Reflexivity and Negotiation in Building the Interview Narrative

Qualitative interviews involve the co-production of knowledge, making it vital to consider the details of research interaction (Gunaratnam 2003). In our research, the power asymmetries between the researcher and participant were sometimes in terms of racial identity but also across gender, social class, age and other axes. Riach (2009) advises that reflexivity should not just be undertaken retrospectively after the interview, but pursued *actively during* the interview. We also embraced McDermott (2014)'s invitation to listen *affectively*, such that we were not just passively noting what participants said but allowing the

possibility of being *transformed* by it, in our hearts and minds (Thambinathan & Kinsella 2021). This kind of embodied praxis is not just individually transformative, but given our status as university-based researchers, it holds the prospect of transforming the university into a space where anti-racism can happen (Came & Griffith 2018). We now explain what we did in order to achieve this.

Creating Space for 'Race Talk' With Participants

As noted above, we committed to creating space for race talk right from our earliest interactions with participants; therefore, in our pre-interview conversations, we often initiated discussion about racialised inequalities in COVID-19 infection and why our work needed to include accounts from people most impacted.

We also used critical storytelling (Ford & Airhihenbuwa 2010), for example relating how research has historically sidelined racialised experiences, to reduce the social distance between us, and explained how our work would be different. As well as communicating an anti-racist cause, we believe that these sounding-out conversations eased participants' comfort in talking plainly without needing to minimise their identities as members of racialised groups. Our fieldnotes describe the comfortable, free-flowing conversations we had with them, much after the interview ended. In the topic guide, we included questions such as:

- *Did you have worries/concerns when you first began to hear about Covid-19? (Prompt as appropriate)*
  - *as a Black/Asian/minority/migrant person?*
  - *Other relevant circumstances e.g. work, household, age, other conditions/illnesses*
- *Did you have any concerns about the decisions made about your treatment because of your particular circumstances (as appropriate: being black/Asian/minority/migrant person, work, household, comorbidities age etc)*
- *Did you feel you were treated fairly, in the same way as everybody else?*

We recognise these questions were sometimes 'clunky' and put the researcher, and sometimes also the participant, in some discomfort. We persisted with them because we found them necessary and very generative. The awkwardness did not last, and opening this space often released the flow of conversation as participants felt free(r) to speak without needing to censor their responses.

Navigating Racialised Identities During the Research Interview

We remained attentive to the researcher-participant relational identities and power dynamics (Gast et al. 2022, Gunaratnam 2003), and how the interaction evolved as the researcher and participant became better acquainted. We explore this through two case examples; this first one illustrates how TR enlisted her own non-White racialised insider identity (Gunaratnam 2003, Trimble & Fisher 2015) to ease participants' comfort:

> I found the Bangladeshi Muslim participants, Shabnam and Mohammed, through cold calling a health organisation within one of the 'epicentre' areas of the UK pandemic. … Over that initial phone conversation, Shabnam and I established our shared (South Asian) heritage, and I felt the warmth of her approval especially when she realised I was a first-generation adult immigrant like herself. In the recorded interview, Shabnam and her husband recounted in vivid detail, episodes of racial discrimination in their social and working lives, and how it influenced their hospitalisation experience.

TR was taken aback by how spontaneously they had talked about these painful subjects. Her shared cultural/ethnic identity with the participants earned trust more quickly and eased the communication process, but simply creating a supportive environment to talk about these issues felt like the fundamental process that allowed certain conversations to occur.

Silence around whiteness as a racialised identity is recognised as critical to social and intersubjective power relations and positionings (Gunaratnam 2003). With this in mind, in the next example, we illustrate how AD acknowledged her own position as a White woman when interviewing a Black participant:

> Some of my interviews were with people I hadn't personally recruited. In these instances, some of the trust in the process was transferred across from other members of the team. TR had interviewed a participant, a Black woman, who recommended to her cousin that he participate too. This man, a queer Black refugee, contacted the study contact number from the recruitment poster, which took him to me. When we first interacted over the phone, he asked if he was speaking to the 'Indian lady from the poster'. I responded with humour, 'unfortunately not, I'm one of the White researchers'.

Foregrounding these racialised differences (or overlaps) between researcher and participant was a way to recognise the possibilities of different research encounters, acknowledging that the interview might go differently with Asian or White researchers. But equally, this example shows the importance of signalling to the participant, in this case by way of the (White) interviewer's light-hearted remark, a rejection of a colour-blind approach. Similar to the earlier example of having JD as a study team member, TR's interview with his cousin, along with further informal conversations before the interview, enabled AD to open up dialogue that actively engaged with race and racism, including a rich discussion of how racism had affected care for his dying father during the pandemic. This necessitated a Black participant critiquing whiteness with a White researcher, which may have been more difficult without the 'distributed' trust facilitated by differently racialised team members. However, it would have been *impossible* if AD had not equipped herself with the necessary skills and experience to develop relationships across different social identities and facilitate open discussions about racial injustice, through several years of involvement in anti-racist research practice networks. Ahmed (2006) warns us that declarations of whiteness or privilege *on their own* are just non-performative speech acts: they do none of the anti-racist work they intend and may in fact reinforce white privilege instead of challenging it. AD and the team understood this and that anti-racist allyship is a lifelong project.

Metalanguages of 'Race'

For the most part, the content of interviews with participants racialised as non-White were similar to that of White participants. They were largely about managing the different personal, financial or work challenges during the pandemic. Indeed, Gunaratnam (2003) encourages researchers to problematise our "own analytical reliance upon the need for ethnic and racial identifications to be made explicit throughout the narratives of minoritised participants" (p.133). However, some of these accounts were tinged with racialised specificity – for example, a Muslim respondent describing her sadness when family gatherings were denied during Eid in 2021, while observing that social mixing rules were relaxed later on, for Christmas day, despite daily infection rates being even higher then.

Keeping the space actively open to race talk also allowed the elicitation of racialised narratives that participants themselves may not explicitly see as being *about* race (Gunaratnam 2003). For example, TR interviewed a Black participant who worked as a community nurse, visiting patients at home to deliver care. He recalled being issued insufficient protective equipment and being instructed by his bosses to turn off the 'Track-and-Trace' app on his phone when making home visits (and hence unable to check if he was visiting someone with an active infection). It was due to a home visit that he had acquired COVID-

19, which had led to severe illness. When TR asked him if he felt that his race had influenced his experience, he denied it. However, later in the interview he reflected that most of his colleagues doing the same job were "from my [Black] community". This account resonated with KQ's interview with a Pakistani participant who focussed on the extra COVID-19 exposure for *taxi drivers;* in that city, taxi drivers are disproportionately from Pakistani backgrounds, although the participant did not mention this.

Structural racism, as opposed to direct or interpersonal racism (Nazroo et al. 2020) may not appear to everyone as a justifiable and valid explanation for discriminatory treatment. As mentioned before, racially-minoritised people may have internalised stigma regarding racialised inequities encountered over their lives, such as in school, employment, housing, etc. (James 2022, Jones 2000). People may also wish to protect themselves from experiencing testimonial injustice (Fricker 2007) of not being believed. Agreeing with mainstream colour-blind discourses can also be a defence mechanism, for example Mexican Americans embracing colour-blind and 'American dream' rhetoric to cope with the discrimination they face (Garbow 2015).

The Limits of Our Work

Despite our efforts, sometimes our approaches produced unanticipated and/or suboptimal outcomes, and we now turn to these reflections.

Extending Our Reach, Success and Disappointment

KQ met HM in another research context and on hearing that she was already researching Orthodox Jewish experiences of COVID-19 in the USA, we employed her with the specific brief of recruiting and interviewing Orthodox Jewish participants in the UK. As she was already on the lead university's payroll, we could circumvent time-consuming bureaucratic procedures. Using her rich network of connections within the UK's ultra-Orthodox Jewish community she added four insightful interviews, which would be missed had we not involved her. HM adds more nuance to this:

> In many ultra-orthodox Jewish communities, use of the internet, even smartphones, is greatly or completely restricted. The inability to recruit or interview in-person [due to COVID-19] meant participants were from the most progressive and liberal ultra-orthodox communities. Despite these considerations, the inclusion of any ultra-orthodox Jews in this study can be seen as a real success.

This example provides an illuminating contrast to our less successful attempts to include participants who spoke little or no English. TR conducted a few interviews in Hindi and Urdu and HM employed a fair amount of 'Yinglish'[3] when called for. However this was the limit of languages at our disposal in the study team. The freelance researchers who had translated our study poster into other languages were untrained in our research methods, and therefore not equipped for conducting interviews. The value of having dedicated multi-lingual researchers, ideally within the core study team was therefore highlighted for us.

Additionally, our offer of data packages and tablets to participants who needed them was not taken up by anyone. We still believe this was an important resource to have on standby and have built this capacity in subsequent research projects.

Repairing Harm, Celebrating Outputs and Building Longer-Term Community Partnerships

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[3] The colloquial of ultra-Orthodox Jews which combines English, Yiddish, and Hebrew words.

One of the main outputs of our research studies is an online platform (Health Experience Insights, hexi.ox.ac.uk) featuring plain language summaries of the research findings and interview excerpts, in a format (video/audio/text) that participants choose themselves. Having such a visible and accessible output, that centred their experiences and could be shared with friends and family, was valuable to our participants (more than academic publications). It also required a longer term involvement in the research process from them, beyond the actual interview.

Repeated contact with participants (e.g. if participants want to review their transcript before giving permissions for use) helped reinforce friendly, trusting relations. This was particularly useful in a transcription-related situation we encountered where that trust was briefly compromised and needed to be repaired. Our pool of transcribers often struggled with non-English accents and cultural references (a product of their own socio-demographic homogeneity). Transcribing took longer than usual, and included a greater number of gaps and mis-typings, thereby making the transcript-checking process also very time-intensive for the researchers. As KQ recounts:

> Eileen, a Black, Caribbean-origin woman had mentioned using 'bay rum' during her recovery. However, in her transcript this appeared wrongly as 'beerum'. My heavy workload meant I asked a colleague to check the transcript before sending it to Eileen for review, instead of carefully checking it myself. I was mortified to see that Eileen had circled each instance of this term and crossed it out, writing in thick black capitals 'BAY RUM'. In contrast to their first conversations where I had talked about amplifying people's experiences and voices, I felt that this signalled 'I don't understand your voice'.

Distributing work across the research team had many advantages, however, in this instance, it produced an unfavourable outcome. KQ apologised to Eileen and a warm Christmas card in return provided reassurance that she had not borne any grudges. We felt this process of repair to be crucial, and were grateful for the long engagement of participants. Recognising how racialised issues can surface in the research process through the misrepresentation of speech into writing, this also highlights our need for seeking transcribers who could work across accents and cultures, as well as checking transcripts with extra care before sending to participants.

Following the launch of the websites to which all PPI co-applicants and participants were invited, we also collaborated with a PPI co-applicant and local council workers and charities to organise two public outreach-and-dissemination events in a high-deprivation and racially-diverse neighbourhood. Attended by >50 attendees each time, these meetings included discussions of Long Covid, and we invited representatives from the local Long Covid clinic to discuss available healthcare services. Although a relatively small impact, we felt glad that these events directly led to new referrals coming through the door, indeed referrals for their *first-ever* non-White patients.

Conclusion

In detailing our experiences in conducting this research, we wish to take stock of what we believe to be valuable experiences, but also acknowledge there is still a way to travel for making health research meaningfully inclusive and racially just. We wholeheartedly believe that "the praxis of anti-racist research should not be limited to health disparities scholars but applies to all researchers who study humans" (Montoya-Williams et al. 2022, p. 437). In a national (and to international) climate soaked in populist and extremist rhetoric, it seems an uphill struggle for academic researchers to insist that we must do better. The recent cancellation of the UK government's Heath Disparities Report (Nightingale & Merrifield 2023) shows a forceful resistance from political forces in engaging with the widening crisis of health inequalities, and this may also have implications for future health research funding. On the other hand, the COVID-19 experience and the unprecedented global swell of the Black Lives Matter movement, did

stimulate a shift among mainstream health discourses to develop more race-conscious research approaches (Flanagin et al. 2021, Powell et al. 2022, Stafford et al. 2020) and we hope other researchers will ensure that this momentum stays strong and moving in the right direction.

Our lessons from this work are as much about our struggles to expand and refine our qualitative research methods as they are about ways to create spaces within the academy where anti-racism can happen (Came & Griffith 2018). Building on the rich, theory-informed literature on anti-racist praxis in health, we have illustrated how this praxis may look when enacted through a research project, and where attention must be focussed. As we have noted throughout the paper, despite our efforts to resist mainstream health research orthodoxies, we were sometimes inconsistent and even contradictory. Meanwhile, our researcher and PPI teams were also personally affected by the pandemic during this research, leading to uneven working practices and periods where a re-distribution of work and priorities was needed. Despite these challenges, our work makes an important contribution to the urgent, ongoing dialogue about ways to operationalise racial equity in health research and we hope this paper provides some real world and relatable examples to other researchers wishing to undertake anti-racist qualitative research.

Conflict of interests

The authors report there are no competing interests to declare.

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