'It's in the data': How health data gaps are failing Black British people.

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Abstract

Data gaps have continued to persist within healthcare, especially for Black British people. This has had dire impacts on their health outcomes and made it harder to provide interventions that meet their needs. This article assesses the problem of data gaps, the impact of these gaps on our health and why we need better data practices. I argue that current data is too homogenised. We need specific and nuanced data that accurately captures how inequalities impact the health of Black British people. My vision is one where health data is readily available on all issues affecting Black people, and that it helps accurately challenge racism at every level: individual, collective, structural and institutional. To achieve this, I suggest that we critique and interrogate all forms of data in global health. Ultimately, improving data practices for Black British people and their health inequalities will reduce all health inequalities.

Keywords: Data, health inequalities, global health, interventions, racial inequality, Black British.

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The Problem of Data Gaps

There are many different definitions of global health, and it continues to be a hotly contested topic. At its core, however, it is an aspirational field that aims to achieve 'health equity' for all. As I continue to learn more, I realise what I am interested in is critical global health. Critical global health forces you to be critical about the concepts and theories used in the field, critical about your way of engagement with other ways knowing; critical about everything within the field and being comfortable with questioning things. The aim is that being critical will lead to better practices in the field. One way this has evolved, is through the digitisation of healthcare during the COVID-19 pandemic. Digitisation has meant that the breath of health-related data has rapidly expanded, which has meant its role has risen in significance to delivery of care, case predications, targeting of resources and ultimately our health outcomes.

As a Black British woman, with chronic illnesses, I have always been interested in the global health issues that Black people face. It is widely known we have some of the worse health outcomes, this is certainly the case for the health conditions I have experienced. However, a lack of data has meant that addressing health conditions in a way that would suit my needs is non-existent. Doing this is not as easy as people think – and no, it's not because of the myth that Black people are a ''hard to reach group" – or even the very valid reasons many of us have for mistrusting global public health systems and their research agendas [1]. But because we are invisible in the data.

This is not just an issue that has followed me around recently, as a scholar, a health journalist or even when accessing healthcare. It became apparent when I was a student. Most of my interests as a global health student sat at the crossroads of Black and gendered health which is the differences in accessing resources, the distribution of labour and domestic roles, social norms and values, and decision-making based on gender; our social realities and resulting social injustices such as where we work, study, live, what we eat, how we experience joy especially how it impacts us, and I always wanted this to be present in my work. However, it was hard to ever write about these issues without the data to support my arguments and without physical, emotional and social separation from these issues, even though I knew from conversations within my community, with friends, family and even lived experiences the real-life implications of these issues.

'London BLM March'by Jai Toor, 2020
Protestor with 'Black Lives Matter' on his back

It was made even more difficult when I would go to office hours and speak to my lecturers, and they would tell me what excellent ideas I had but they always wanted me to validate them with 'evidence'. I know from their lectures a hierarchy of evidence existed, where quantitative studies were needed for my claims to be considered reliable. However, I always wondered how the issues I knew my community to go through, such as racism and especially its impacts, could be quantified. These were qualitative realities and should validated through other ways of knowing.

The Impact of Data Gaps on Health Inequalities

It is hardly a surprise that data has never mattered more, in a

field such as global public health – our lives are increasingly shaped by it, how it is defined, collected and utilised [2]. For example, during the monkeypox outbreak it has been imperative to understand how and where cases were rising, to adequately direct the limited vaccines that were available [3].

This only tells half the story. We also need to know whose data is collected, analysed and applied. The intersection of racial, class and gendered inequality is an underlying condition that has been festering in our healthcare systems globally, for decades [4]. Its effects are wide-ranging, impacting patients, carers, healthcare workers, and any Black person interacting with the system.

A study commissioned by the NHS Race and Health Observatory [5], revealed that 'ethnic inequalities in health outcomes are evident at every stage throughout the life course, from birth to death.' From new mothers to the elderly, cancer patients to Covid patients – research has found that if you are Black, you are more likely to have negative experiences within the healthcare system, more likely to experience medical racism, more likely to be ignored and denied access to lifesaving medication, more likely to be sanctioned as a Black healthcare worker,[6][7] and more likely to die.

Despite there being data collected to document the issues Black British people, including those of African, Afro-Caribbean and mixed descent face, the data that's collected are often too vague to be of much use. One haunting example of this is maternal inequality for women in prison. Tables 1 and 2 show that there were a greater number of women from white backgrounds than from minority ethnic backgrounds to have applications approved to be placed in Mother and Baby Units (MBU) [8]. White women comprised 34 (77%) of the 44 approved applications in the latest year, while applications from women with a minority ethnic background made up 15% (5) of the total number of approved applications. 63% of applications from women of a minority ethnic background were approved by the Board, compared with 72% of applications from women with a white background. This generalised data highlights the government's piecemeal approach to racial health inequalities.

Table 1: HMPPS Offenders Equalities Report 2021/22 findings on disparities existing between the number of applications by protected characteristics, approved and refused to an MBU in England and Wales, the 12-months ending March 2022
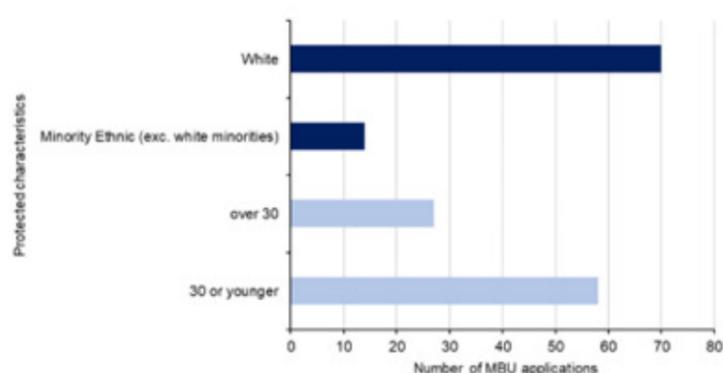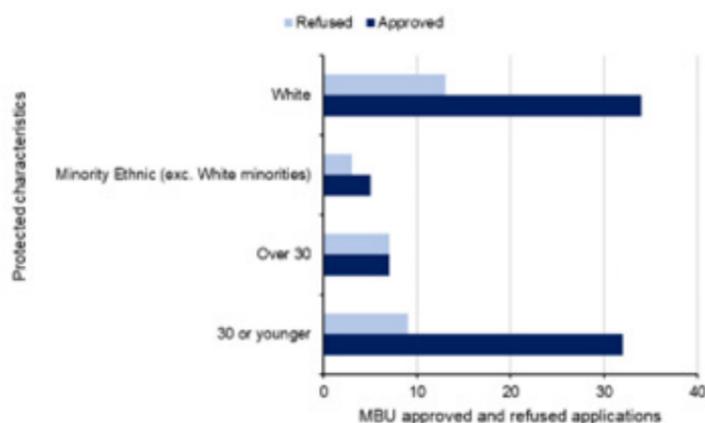

Table 2: Source: HMPPS Offenders Equalities Annual Report for 2021/22 findings on disparities existing between the number of applications received to an MBU, by protected characteristic, England and Wales, the 12-months ending March 2022

Many organisations such as Nuffield Health Trust have lobbied more nuanced data such as who has access to services, who gets to be seen, what this means for their experience of pregnancy to term, and to raise awareness of the number of pregnant women in prison which would in turn advocate for appropriate services to be in place to meet their distinct health care needs [9]. This is particularly important given the tragic deaths of two new-born babies, one at Her Majesty's Prison (HMP) Bronzefield [10] and the other at HMP Styal [11] in 2019 and 2020 respectively.

The Violence of Homogenisation

The lack of nuance in the prisons data exemplifies the violence of data invisibility. The manufactured metrics are so poor that it generalises minoritised people to tell us what we already know; that these things keep happening. Homogenisation fails to answer how and why these things keep affecting us and how we can stop it from happening altogether. This is the context for our imperial, colonial and white supremacist world order. The data we do have posits the experiences of non-minoritised, especially Black people, as the norm.

Access to better data would also cut through the veneer of generalisations. For example, if we know black women are three times more likely to die from maternal inequalities, how does this differ between Black Caribbean, Black African, Black Mixed or Black British women? How are these ethnicities being defined? The current use of census data – a construct that lumps arbitrary demographic racialisations only leads us to conclusions that are half-truths [12]. This is because census data cannot easily be transposed to the layered experiences of these constructed identities.

Even though the NHS does have some of these racial categories, poor data practices from staff including not explaining what data will be used for (especially explaining that it would not be used to discriminate against them) continues to fail us. [13] The reality is, that the list of disciplines where race and ethnicity-based data could reveal uncomfortable truths is extensive, but it is needed if we will achieve real equity. Data gaps keep people in the dark about their health and environment, stifle innovation in solutions and prevent governments and healthcare institutions from truly understanding the impact of their policies and practices [14].

There is value in discussing the terms and languages used to homogenise us, such as 'People of Colour', 'Black and Minoritised Ethnicities (BME)'. However, these debates also serve as a distraction. This is because the terms and language will always be present, and they will only keep evolving with socio-political, geographic and historical contexts. What matters most is the nuances in the data.

The Need for More Holistic data

Ultimately, what we choose to measure (or not to measure) has significant implications on the narratives used to talk about the health of Black communities. It is especially important to stop pathologising Black people. The issues do not lie with us, but the people that construct, lead and maintain the status quo of these systems.

Data must stop measuring and qualifying our pain in singular forms of knowing. Within healthcare, quantitative data through surveys and standardised instruments serve as the pinnacle of truth. But how can you quantify our pain? Why are we constantly trying to prove that racism exists? Why is what a Black person says not enough? Does the data collected enable us to fully evaluate equity and identify where and why inequities exist in health and healthcare?

As Da'Shaun L. Harrison writes in Belly of the Beast: The Politics of Anti-fatness as Anti-Blackness [15] in relation to anti-fatness as anti-blackness within medical, policing and public health systems 'the personal is political, but the political has not

made room for data beyond the personal. It is not enough to have data on direct health issues but also our social realities - housing, environment, gender, class, our jobs all impact our health and consequently, any health data we may collect.

We need to move past focusing only on equality rather than equity. This will stop a blanket approach to just looking at the language we use, or solely the data, or one area of Black health we know to be an issue, instead of focusing on what this data does. Looking deeper into the rest of the data or nuances within the data will aid in addressing the issues in terms of equity and individual experiences – which in turn will allow us to address these issues at institutional, community and society levels.

Scholars such as Malone Mukwende, Annabel Sowemimo and Seye Abimbola are all working on research that champions different ways of knowing in global health. However, these scholars can be difficult to cite as some ways of knowing, such as peer-reviewed journals, are elevated over others. This makes it near impossible to cite Black scholars –especially Black scholars from African, Caribbean and Latin American countries, and those who choose not to be published in glorified scholarly, academic journals [16].

Conclusion

Current data practices reflect and sustain an incomplete account of Black lives, their health and healthcare. The data we have now continues to delegitimise the everyday experiences of Black people. Health data must be readily available on all health issues affecting Black people. This will help to challenge racism at every level: individual, collective, structural and institutional. The biggest problem is having generic data on minoritised people. There needs to be a more nuance to reflect the true extent of these inequalities i.e., a working-class Black woman and a rich Black woman will experience navigating the healthcare system differently.

The problem of data gaps and their impact can only be solved by better data practices. The ideas I am proposing in this article are hardly new or radical. However, I hope this article can encourage readers to critique and interrogate of all forms of data for those working within, and across health. I want you to start asking all the hard questions: what is being collected and considered as data? Who is collecting the data and why? Which forms of data are validated? What impact does that data have on the field? What is the data trying to tell us and most importantly, what are we going to do about it?

The specificity of these issues cannot just be a Global North versus Global South or Black versus White, because that is how the most marginalised within minoritised communities get left behind. Arming us with disaggregated and nuanced data will equip us with a tool for action. It can better inform resource allocation within services, changes in legislation and structural realities, gaps in accessing services, representation, our visibility in the data and ultimately – it can save our lives.

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