Decolonising Medical Knowledge - the case of breast cancer and ethnicity in the UK

# Abstract

National and global efforts have led to significant improvements in breast health and diagnosis, globally (Lukong, 2017). These achievements, however, are not even. Focusing on the case of breast cancer in the UK, we argue that enduring forms of medical racism leave Black women more vulnerable to advanced forms of the disease, explaining higher mortality rates and later-stage diagnosis. In particular, we show how a lack of dedicated policy, inadequate data collection, and a lack of representation conspire to place Black women at additional and unnecessary risk of worse breast cancer outcomes. We thus propose key recommendations to address the ethnic disparities in and make steps to decolonise breast cancer care. These are early screening for at-risk groups, community-led interventions, and more and better representation of Black women and their risks in breast cancer resources.

# Introduction

Globally, breast cancer is the most commonly identified malignancy found in women (Yin et al., 2020), but through national and global efforts to implement policies and interventions aimed to improve breast health and diagnosis, breast cancer deaths have stabilised globally since the turn of century (Lukong, 2017). These achievements, however, are not even. Focusing on the case of breast cancer in the UK, we argue that enduring forms of medical racism leave Black women more vulnerable to advanced forms of the disease, explaining higher mortality rates (ONS, 2021), and later-stage diagnosis (NCIN, 2010). We thus propose key recommendations to address the ethnic disparities in and make steps to decolonise breast cancer care.

In the UK, breast cancer deaths have fallen from 37.7/100,000 in 2001 to 27.9 in 2016 (The Nuffield Trust, 2018). These achievements are largely attributed to the NHS Breast Screening Programme (NHSBSP) and the work of UK breast cancer charitable organisations in advocacy and awareness building, and encouraging self-diagnosis and attendance of the screening programme (Gibbon, 2007). Since 1998, the NHSBSP, responding to evidence that early diagnosis of breast tumours increases the five-year survival rates by up to 90% (Youlden et al., 2012; see also Sun et al., 2017), invites all women aged 50-70 for screening (Public Health England, 2015). However, the successes in the UK are highly uneven. UK cancer registry data demonstrates that there are significant differences in incidence rates, stage of diagnosis, and survival rates across different groups of women. Here, women from ethnic minorities, lower socioeconomic status, and with existing comorbidities and/or disabilities are disproportionately at risk from late diagnosis and unfavourable survival outcomes. Notably, white middle class women in the UK have higher incidence rates than other groups, but are more likely to receive timely and satisfactory treatment. This therefore raises the question of why marginalised and disadvantaged groups face worse outcomes despite the improvements in screening and treating breast cancer.

To understand and address these inequalities of outcomes, we focus on the case of Black women in the UK, as this group appear to have benefited least from UK interventions in breast cancer care[[1]](#footnote-1). The median age for Black women to be diagnosed with breast cancer is more than a decade younger than White women (NCIN, 2010), and this has been the case since at least 1994 (Dewis & Gribbin, 2009). UK cancer registry data demonstrates that despite having lower breast cancer incidence rates than white British women, Black African women are more likely to be diagnosed with advanced disease and have poorer survival outcomes than White British women (Jack et al., 2009; ONS, 2021)[[2]](#footnote-2). Black women have also been found to have the lowest uptake of breast screening invitations of all groups (Bamidele et al., 2017). Even after allowing for potential confounders like age, women from Black backgrounds are at a greater risk of a breast cancer diagnosis with a more advanced staging and less favourable outcomes despite having a lower incidence rate than white and other ethnic minority women (Gathani, Reeves, et al., 2021).

Responding to calls ‘to tackle racism and discrimination within the [UK] health and care system’ (Public Health England, 2020), our aims are to investigate the mechanisms that lead to ethnic inequities in breast cancer diagnosis and outcomes in the UK for Black[[3]](#footnote-3) women, and to recommend policy interventions that would help address such disparities. By adopting a decolonial lens, we show that the worse outcomes for Black and other ethnic minority women in the UK are a form of systemic racism and violence.

We review existing literature concerning breast cancer and ethnicity in the UK and beyond, discussing the influence of genetics, the influence of environmental, lifestyle and socioeconomic factors, the influence of cultural background and beliefs, and systemic racism in the medical field. Then, using a case study approach that incorporates policy and media analysis, we examine how leading cancer organisations in the UK represent breast cancer and ethnicity. We reveal the UK breast cancer environment as exclusionary and violent by design, failing and systematically excluding Black women in particular. We finish by providing key recommendations to assist in the process of decolonising breast cancer.

# Risk factors of breast cancer and ethnicity

As the most commonly identified malignancy found in women, since the 1970s, particularly in the global north, there has been increasing pressure to improve understanding of breast cancer risk-factors and develop treatments (Lukong, 2017). Breast cancer is now one of the world’s most researched cancers (Carter & Nguyen, 2012). However, this knowledge is mainly derived from research of white middle class women in the global north (Hirko et al., 2022; Yedjou et al., 2019). Although it is only since 2010 that ethnicity data has been routinely collected for breast cancer patients in the UK (Gathani, Chaudhry, et al., 2021), data suggests that in the UK and other global north settings (see Hirko et al., 2022) ethnicity correlates with differing presentations and development of the disease (NCIN, 2010), rates of education about self-help and screening (Jones et al., 2015), and mortality rates (ONS, 2021). Drawing on research from the UK and other global north locations, we review key debates concerning ethnicity as a risk factor for breast cancer. We examine the role of genetics and epigenetics, environmental, lifestyle and socioeconomic factors, the role of cultural background, and the role of societal and medical racism. Ultimately, we argue that breast cancer knowledges and practices are incomplete, colonial, and racist.

## Genetic risk factors

Although much is known about the genetic risk factors of breast cancer more broadly (van der Groep et al., 2011), relatively little is known about whether and to what extent genetic and epigenetic factors explain ethnic variations in breast cancer rates and outcomes. Recent research suggests there may be a connection, particularly with certain types of breast cancer, but warns that environmental and socioeconomic factors can influence the expression of genetic and epigenetic markers (Hirko et al., 2022; Salas et al., 2021; Joshi et al., 2022). Furthermore, without sensitive interpretation of findings, genetic evidence can itself be antithetic to care. Jones et al. (2015), for example, in their UK-based study that sought to understand barriers to early diagnosis in Black African and Black Caribbean women, found that messages about genetic risk factors had been misunderstood. There is also no evidence that positive correlations result in behaviour change in relation to smoking, physical activity and diet (Hollands et al., 2016). Additionally, while further genetic research could prove useful, the quantification of ethnic risk can lead to further exclusions and can lead to the misappropriation of genetic data in what has been termed ‘genetic supremacy’ (Cerdeña et al., 2022).

## Environmental, lifestyle and socioeconomic factors

Environmental factors such as air pollution and radiation are identified as risk factors for breast cancer, as are lifestyle factors such as weight, alcohol consumption, smoking status, diet, and existing health conditions (Momenimovahed & Salehiniya, 2019). Many of these connect to socioeconomic status. Additionally, housing and neighbourhood quality, and employment and education levels are also identified as risk factors as they limit an individual’s ability to live in less polluted areas, access nutritious foods or safe housing (Wiese et al., 2019; Freeman & Chu, 2005; Goel et al., 2022; Pancholi, 2021). Across the global north, including the UK, socioeconomic status frequently intersects and overlaps with ethnic status (MHCLG, 2020), placing Black women at heightened risk of developing breast cancer.

Socioeconomic factors also influence the care available to women and their likelihood of engaging with it. Lower socioeconomic status has been associated with decreased likelihood of diagnosis, and increased risk of mortality, while better access to healthcare and higher education levels correlate with improved survival outcomes (Sakellariou & Rotarou, 2019; Aleshire et al., 2021). Variations have also been explained by inequalities in access to and quality of diagnostic services (Bamidele et al., 2017; Ahmed et al., 2017; Masi & Gehlert, 2009). Unmet healthcare needs in the UK, for example, have been directly attributed to patients not being able to afford transportation or medical examination costs (Bonevski et al., 2014). Factors such as changing of addresses associated with living in temporary or rented accommodation, poor access to transportation, a lack of childcare provision, or being unable to afford leave from work are further breast cancer risk factors in the UK and US (*Ibid.*).

## Cultural background and beliefs as risk factors

In global north settings, it is thought cultural background may correlate with increased risk of non-diagnosis and mortality, although not of acquiring breast cancer. Indeed, Miller et al. (2019) go so far to suggest that “cultural/immigration-related barriers may be the only barrier type that is unique to racial/ethnic minority women” in attending breast screening in the UK[[4]](#footnote-4). Language can become a key barrier – preventing both access to healthcare and the ability to describe or explain symptoms – as can fears of immodesty in screenings (*Ibid.*). Further, research by Masi and Gehlert (2009) of women in Chicago found avoidance due to mistrust, concerns about racism, and the impact treatment might have on intimate relationships.

There is also evidence that some migrant groups have limited understanding of breast cancer where it has not been a priority health issue in their previous country, and/or have a lack of knowledge and misinformation about screening initiatives (Kwok et al., 2022). In Australia, risk perception among Black African migrant women remains low with more than 34% not attending regular screening invitations as recommended (Ogunsiji et al., 2017). Studies by Banning (2011) and Jones et al. (2015) that address views of Black British women from a variety of backgrounds demonstrate many women had low breast health awareness, did not possess risk awareness, or practice self-examination. First generation Black African women experience the most barriers to early diagnosis, with some only becoming familiar with breast cancer upon their relocation. Study participants gave varying reasons for poor attendance such as low risk perceptions, anxiety about a diagnosis, fearful associations with breast cancer, and a reliance on religious or spiritual beliefs (Bamidele et al., 2017; Baird et al., 2021). Such behaviours may carry through the generations (*Ibid.*). Institutional mistrust has also been identified in mental health patients from Black ethnic groups, who have described experiencing institutional injustice (Hui et al., 2021).

In efforts to increase participation and close outcome gaps in minority groups, community-led breast screening initiatives have gained traction. A systematic review by Bonevski et al (2014) analysed healthcare initiatives from twenty-six studies and six reviews for socially disadvantaged groups in Canada, Australia, the USA and UK, concluding that successful community engagement and increased trust in initiatives occurred when community representatives were involved in the health design and delivery (see also Ehrlich et al., 2016). While little research exists concerning interventions in breast cancer in the UK in this regard, Garcia, Ali, Papadopoulos and Randhawa (2015) in examining antenatal care note that trust, lack of informed choice, and previous bad experiences of healthcare services are powerful barriers to positive health outcomes.

The use of community-led interventions can prove a successful aid in bridging cultural gaps and increasing trust in the medical profession in community settings (Bonevski et al., 2014; Pilkington et al., 2017). However, it is important to recognise that Black and other minority groups may not live in certain areas or engage with members of their ethnic group and may not benefit from such targeted interventions. This has long driven calls for better inclusion, diversity, and representation of marginalised groups in national health promotion activities (Lupton, 1994; Myers et al., 2019). A recent survey, for example, found that 96 out of 100 women of Black ethnicity living in the UK with a breast cancer diagnosis felt Black women are not adequately represented in breast screening literature or media campaigns relating to breast cancer (Black Women Rising, 2018). It is thus important to understand when and how literature and media campaigns represent Black women.

## Medical /systemic racism

As alluded to throughout, despite being one of the most researched cancers, there remains significant gaps in understanding the role of ethnicity as a risk of factor of breast cancer. Although well-established that Black women are at higher risk than many other ethnic groups in the global north, it is not known why. Increasingly, however, scholars and activists are drawing attention to how this lack of understanding, among other things, is a result of systemic racism in medical research, education, and practice (Evans et al., 2020; Carlos et al., 2022). In this sense, racism itself becomes a cause of a variety of diseases, conditions, and mortality, ‘structural racism can kill cancer patients’ in ways that are ‘ingrained but not inevitable’ (Nelson, 2020, p.83).

Knowledge has been a tool and instrument of colonisation and imperialism, and building on the last 500+ years of western invasion and influence, knowledge continues to be a weapon for oppression, control, and discrimination, reinforcing the status quo (Mignolo, 2007). As historian Dipesh Chakrabarty (1992) tells us, for generations, those shaping the very nature of knowledge ‘have produced theories embracing the entirety of humanity’ but which are ‘produced in relative, and sometimes, absolute ignorance of the majority of humankind’. And as it is in Social Sciences, so it is in the Medical Sciences where a very narrow segment of society shapes knowledge, and then makes universal claims about that knowledge.

Medical knowledge has long been part of this colonising logic, structure, and discourse and was founded on the colonising logic that discriminated against people of colour and the colonised races. In observing India’s relationship with western medicine, for example, Kalindi Vora notes that ‘the historical role of Western medicine was as a tool of colonial subjectification and the British civilising mission’ (2015, pp.89–90). Today, Towghi and Vora (2014, p.11) observe how ‘biomedical science can be colonizing in spaces that are not recognized as colonial’. Colonialism and later neoliberalism have meant that ‘the relationship between Western medicine, power, and the body has been cast and recast” (Vora, 2015, p.90). Here, the body (especially the female body, the abject body, the othered body), and the discourse and narrative about the body, metanarratives, myths, and assumptions about the body, have been battlegrounds, sites of ‘colonisation, conquest, and contestations of power’ (*Ibid.*).

It is important to understand, then, that western medical knowledge, like other dominant knowledges, is neither neutral nor necessarily benevolent or benign (Pete in Bhambra et al., 2020). When that which is constructed, validated, and legitimised as ‘knowledge’ sidelines, marginalises, erases and silences certain groups, there is a cost to many minorities and colonised peoples. This process of colonising medical and care spaces others and subalternises and otherwise perpetrates violences, epistemic and non-epistemic, onto minority groups (Rudolph et al., 2018). However, by claiming to produce knowledge which is ‘universal and independent of context’ (Mbembe, 2016, p.32), western modern science sets itself up as ‘the only valid way of coming to know’ (Boisselle, 2016, pp.4–5).

This kind of power or dominant knowledge performs epistemic violence, as Gayatri Spivak (1988) puts it, by othering, marginalising, even silencing and subalternising other forms and sources of knowledges. This is the reason there are such large and problematic data gaps for minorities, whose life experiences and medical experiences are not account for, because the largely white, western conditions and experiences have been regarded as universal, peripheralizing all ‘others’. Indeed, it is only within the last 30 or so years that Black women have been included as participants in breast cancer research, and even then, they remain a minority, as do other marginalised groups (Gathani, Chaudhry, et al., 2021). This limited and silencing knowledge means that minority groups experience exclusion at various levels, from how their health is taught and studied, right up to how they are diagnosed and treated. As Bozalek (2011) tells us, exclusion de-centres or marginalises people, giving them even less access to resources. Moreover, the further one is from the Centre where knowledge is produced and legitimised, the further one is not only from resources, but from being included in that knowledge production process, and as a result, from being represented in it.

Indeed, where higher education and training of healthcare professionals are concerned, it would be understating the case to say that particularly in previously colonising countries of western Europe and North America, curriculums and syllabi (read sanctioned knowledges) were and remain ‘designed to facilitate and entrench the power and privilege of the dominant white majority, often at the expense of ethnic minorities that continue to remain on the periphery of the Academy’ (Heleta 2016 cited in Arday et al., 2021). Kamola (2020, p.21) indicts universities as places that are ‘organised by racism, Eurocentrism, coloniality, white supremacy, patriarchy, neoliberal capitalism, and remain complicit in Empire’, and that rationalise ‘genocides, ontolocides, epistemicides, culturecides and linguicides’ (24). Seen from these angles, and contextualising western medical knowledge and Western modern sciences, knowledges validated and used within the UK healthcare system are unlikely to be neutral, representative, diverse, or inclusive, because the very education and research systems which produced those knowledges, were none of the above.

Racism explains why Black women are disproportionately of lower socio-economic status and located in more deprived and polluted places than white women (Ali et al., 2021). Racism explains why less is done to engage Black women in health promotion campaigns and self-care activities and breast cancer research, and why Black women are routinely dismissed and disbelieved in medical examinations (Hoffman et al., 2016). Thus, in what follows, addressing the gap in work that explicitly seeks to decolonise breast cancer care, we demonstrate how this colonial and racist legacy plays out in contemporary breast cancer policy and advocacy in the UK through our analysis of relevant media, advocacy and policy documents.

# **Methods**

To investigate the mechanisms that lead to ethnic inequalities in breast cancer diagnosis and outcomes in the UK for Black women and to recommend policy interventions to help address such disparities, we adopted a case study approach. A case study approach offers a level of flexibility and adaptability to address a case such as breast cancer care and ethnicity in the UK (Hyett et al., 2014).

We collected evidence concerning ethnicity from across the UK breast cancer landscape between the years of 2007-2022. As the use of healthcare promotion materials are key factors in improving engagement with health services and in providing patients and healthcare professionals with knowledge about conditions, self-care, and diagnosis (Myers et al., 2019), it is important to pay attention to publicly available health literature. Accordingly, data of publicly available UK health information concerning breast cancer was collected from five sites (see Table 1). Further, we draw on ethnographic observations from Author A’s time working in radiology and with radiologists and other breast cancer screening specialists in the NHS, primarily in South England, as well as personal correspondence (with permission).

The NHS was chosen as it is the UK’s primary provider of healthcare information with around 50 million visits to the NHS website made each month (NHS, 2018). As noted, the NHSBSP is the key actor in the UK breast cancer environment, due to its role in early detection measures. The NHS breast cancer information page advises the other three organisations – Breast Cancer Now, Macmillan Cancer Support and Cancer Research UK as recommended sites for further information (NHS, 2017). Such organisations engage in a combination of research activities, providing advice and developing resources, providing and/or supporting NHS support services, and advocacy work. NICE was later added due to its importance in developing and setting UK health policy and standards.

Using Google’s site search function, two authors independently searched for references to ‘ethnicity,’ ‘Black women,’ ‘race’ and ‘racism’ across all sites. The authors also reviewed pages including key information on breast cancer, such as risk factors and screening information, of visual materials displayed on website home pages and pages related to diagnosis and symptom checking regardless of if the page discussed ethnicity. Author A conducted searches in May 2020 as part of a Master’s dissertation and Author B refined and repeated the searches in December 2021, adding NICE. Policy documents and directives, national statistics, self-help guides, educational resources, and information about screening and treatment were included for analysis. Data was collated on Excel and inductively coded. The key nodes align with the sections presented in the findings.

Table 1: List of sites and search results

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **National Health Service (NHS)** | **National Institute of Clinical Evidence (NICE)** | **Breast Cancer Now (BCN)** | **Macmillan Cancer Support (MCS)** | **Cancer Research UK (CRUK)** |
| **Homepage** | [www.nhs.uk](http://www.nhs.uk)  | [www.nice.org.uk/](https://www.nice.org.uk/)  | [www.breastcancernow.org/](http://www.breastcancernow.org/)  | [www.macmillan.org.uk/](https://www.macmillan.org.uk/)  | [www.cancerresearchuk.org/](http://www.cancerresearchuk.org/)  |
| **Role and scope** | Screening, diagnosis, care, support, health promotion | Sets clinical standards and guidelines and provides advice to practitioners about diagnosis and treatment | Research, care and support services, and advocacy. | Fundraising and awareness, research, staff development, and services for patients.  | Fundraising, research and lobbying for policy change. |
| **Search terms** | Ethnicity OR “Black women” OR race OR racism AND“Breast cancer”  | Ethnicity OR “Black women” OR race OR racism AND“Breast cancer” | Ethnicity OR “Black women” OR race OR racism | Ethnicity OR “Black women” OR race OR racism | Ethnicity OR “Black women” OR race OR racismAND “breast” |
| **Included results from text search** | 4\*\*Additionally, local trusts occasionally publish information. Local interventions were by nature excluded from our national case study approach.  | 15Reports and summaries of evidence = 10Guidance and advice = 2Equality assessments = 3 | **28**Personal stories = 13General breast cancer information and resources = 4Reports and summaries of evidence= 8Black women event and support group info = 3 | **10**Reports and summaries of evidence = 7General breast cancer information and resources = 1Personal stories = 1Event info = 1 | 15Reports and summaries of evidence = 9EDI statements = 1General information pages = 4 |
| **Additional pages included for analysis** | nhs.uk/conditions/breast-cancercausessymptomsdiagnosis | [nice.org.uk/guidance/conditions-and-diseases/cancer/breast-cancer](https://www.nice.org.uk/guidance/conditions-and-diseases/cancer/breast-cancer)  | breastcancernow.org/information-support/have-I-got-breast-cancer And all pages linked | macmillan.org.uk/cancer-information-and-support/breast-cancer  | cancerresearchuk.org/about-cancer/breast-cancerAnd all pages linked |

# Findings

## Knowledge of ethnicity and breast cancer

Faced with evidence that Black women and other ethnic minorities face differing risks in terms of delayed diagnosis, more aggressive presentation, and worse mortality rates, we examined how the UK breast cancer landscape presented this information. Notably, neither the NHS, NICE nor Macmillan provided information surrounding risk factors associated with breast cancer and ethnicity on key pages. Indeed, the NHS provided no relevant information across its site concerning additional risks for Black women and did not present ethnicity data in its 2018-9 Breast Screening Programme Report (Screening & Immunisations Team, 2020). CRUK noted ‘A large report found that the risk of breast cancer is higher in white women than any other ethnic group. This is at least partly due to lifestyle factors’ but provided no additional information. CRUK also stated minorities had a lower mortality rate but did state Black women are at greater risk of certain breast cancers.

Breast Cancer Now most visibly and in detail provided data and risk factors associated with ethnicity, across its website and was the only site to include a dedicated page to breast cancer and ethnicity. BCN clearly stated that although Black women have a lower incidence of breast cancer that they ‘experience differences in breast screening attendance, the stage and age of diagnosis, survival outcomes, and experiences of care and treatment’. BCN further included links to external research, as did Macmillan, which offered more critical and in-depth information as to the link between ethnicity and breast cancer. Macmillan hosts a variety of reports examining BAME experiences of cancer broadly that generally include breast cancer sections, while BCN refers to extensive research and appears to make a conscious effort to include ethnicity throughout its research endeavours. Additionally, in 2020, CRUK various commitments to EDI and decolonisation of cancer research more broadly including in allocation of research funding.

NICE also housed a variety of reports and summaries of evidence that provide some information as to ethnic inequalities in breast cancer statistics. Such documents were generally difficult to find from standard searches and were not easily visible from key landing pages. Reports and summaries are mostly dense with limited space given to ethnicity. Of those available via NICE, eight (dating from 2009-2018) state not enough is known about ethnicity and breast cancer, while an evidence report notes that breast cancer research participants are primarily white middle class, educated and married (National Collaborating Centre for Cancer 2009). Further, in examining the use of a screening tool, NICE (2018) suggest that US data is incomparable to UK data due to ethnic differences, and considering evidence that “bevacizumab in combination with a taxane may be particularly effective in African-American women" NICE state that:

Clinical specialists indicated that they considered that this might be because of increased incidence of aggressive disease, and that this might be due to genetic factors or other disease factors rather than ethnicity. It was agreed that this was not an issue that needed to be included in the scope." (NICE, 2011, p.3)

Across other reports found across the sites, key evidence is repeated (see Table 1). In particular, that women born in West Africa were significantly younger at diagnosis and had more aggressive tumours than white women, and have an increased risk of death from breast cancer is repeated across the sites following a 2009 NICE report (Dewis & Gribbin, 2009). All sites except the NHS included multiple references to triple negative breast cancer and noted that it affects Black women most. NICE recommend progesterone receptor testing for all women, but there are still no dedicated policies or guidance for Black women.

Table 2: Evidence about risk factors of Black women and breast cancer found on each website

|  |  |
| --- | --- |
| **Black women and breast cancer risk factors**  | **Sites that noted data** |
| Younger at diagnosis | BCN, CRUK, Macmillan, NICE |
| increased risk of mortality | BCN, Macmillan, NICE,  |
| Later stage diagnosis | BCN, CRUK, Macmillan, NICE  |
| Language/culture/trust as diagnostic barrier | BCN, CRUK, Macmillan, NICE, NHS |
| Different care experiences | BCN |
| Limited data / need more data | BCN, Macmillan, NICE |
| Triple negative and Black women | BCN, CRUK, Macmillan, NICE |

## Policy interventions

We found there are no national policy interventions targeted towards improving engagement of hard-to-reach groups, including ethnic groups, within breast cancer screening and education. Nonetheless, anecdotal evidence from author A, as well as summaries of local-based interventions found in evidence reports across the five sites, suggests that on a local level, certain areas are inviting Black women to earlier-than-usual breast screening. In this case, where individual GPs or local health groups recognise that ethnicity may be a risk factor of earlier onset of disease, *some* Black women may get access to earlier screening. Similarly, a 2015 report by NICE suggests that in some settings, local public health projects are seeking to organise community-based information and screening sessions (Bagnall et al., 2015).

Notably, from 2008-2013 there was a spike in calls for targeted interventions for ethnic minorities from both charities and NICE. These calls include taking cultural factors into account in diagnosis (NICE 2013), creating targeted messages (CRUK 2009), raising awareness in minority communities’ (CRUK 2008). Nonetheless, the only way in which considerations around ethnicity appear to impact NICE guidance in relation to diagnosing breast cancer is because “issues of language may correlate with ethnicity”.

## Representation in healthcare promotion and education materials

In analysing the types of images and language used to teach patients and healthcare professionals about self-examination and information on accessing diagnostic services we found that all charities included photos of Black and other ethnic minority women. NICE and the NHS did not, the NHS only included a video with a white woman attending a screening (Figure 1), but both have few images on their websites. BCUK on included Black women as general images such as on the homepage. BCN, however, included thirteen stories of Black women with breast cancer with accompanying photos (see Figure 2), and Macmillan included one personal story, although as noted included broader reports on BAME experiences of cancer. BCN also included significant coverage of Black Women Rising – a charity focused on Black women with cancer.



Figure 1: The only image of breast cancer on the NHS website, NHS 2021



Figure 2: Example of a personal story featuring a Black woman on Breast Cancer Now

No website featured photographs of Black breasts or provided specific information as to how cancer may present on non-white bodies. BCN did, however, feature illustrations of cancer on Black skin (see Figure 3). Other websites provided no illustrations of symptoms. Following this, we also searched for breast cancer images in Black and Brown Skin: Mind the Gap, a website specifically dedicated to creating an archive of images from medical cases to demonstrate conditions and how they appear on Black and Asian skin tones. In light of no results, we contacted Mind the Gap who confirmed that “information about breast cancer however it is quite difficult to find.” (Author A personal communication, 9th July 2021).



Figure 3: Illustrations of Black breasts on Breast Cancer Now (2021)

# Discussion

Our analysis of the UK breast cancer landscape clearly demonstrates that ethnic minorities, specifically Black women are under-represented in knowledge production of breast cancer, in health promotion and health educational materials, and despite recognition of inequalities in diagnosis and outcomes, there are no dedicated policy interventions or recommendations aimed towards Black women. Except for Breast Cancer Now, who it must be noted provide detailed, contextualised, and relevant knowledge and resources for Black women, knowledge of Black women’s and other ethnic minorities relationship with breast cancer are systematically erased at worst and presented as tokens at best. This is an epistemic violence. Here, we chart two ways this epistemic violence is evident.

First, although the UK cancer landscape recognises that Black women face certain inequities in breast cancer diagnosis and outcomes (even if accessing such information may be difficult), this recognition does not translate into targeted policy interventions or guidelines. In the USA, conversely, following the identification that African American women are more likely than White women to be diagnosed with stage IV breast tumours and less likely to be diagnosed with Stage I at presentation (Ahmed et al., 2017), recommendations were made to move Black women onto a ‘high risk’ register in 2018 for priority breast screening at age 40 (Monticciolo et al., 2018). The programme has been a success, as has the African American Women and Mass Media campaign in improving Black women’s awareness of screening through targeted radio and print materials (Hall et al., 2012). Similarly, in response to inequities in breast cancer outcomes between white and Aboriginal women, New Zealand and Australia implemented BreastScreen, a programme that uses local workers to deliver training and awareness sessions and offers transport to women who live remotely (Pilkington et al., 2017). In its 15 years, BreastScreen has successfully increased the attendance of indigenous groups, in some cases to over 90% (Tapia et al., 2019).

The failure to enact similar national policies or guidelines in the UK is racism in action. While NICE cite differences in populations to justify the dismissal of US data, other evidence from the US and UK demonstrates similar findings regarding ethnicity and breast cancer. This is even more astounding when NICE and other groups have since at least 2009 recognised that Black women face worse outcomes and younger age of diagnosis in the UK, and have called for more data on ethnicity since at least 2007 (although have done little to address the paucity of data). Here, the lack of data further justifies non-action – not knowing means nothing can or should be done. Further, although our evidence shows that some women may be benefiting from local-scale targeted interventions to improve engagement with breast screening services, this leads to a postcode lottery in access to care without a national commitment.

Second, in the case where Black women in the UK are less likely to attend screening, more likely to suffer worse outcomes, and have already voiced that they are not adequately represented, the omission of Black women’s bodies and information about Black women’s risks becomes another form of epistemic violence that perpetuates dominant understandings of breast cancer as a white woman’s disease. Although some of the UK’s national breast cancer organisations are beginning to make it more visible that breast cancer is not just a white woman’s disease, largely this is done through tokenistic acts of including Black bodies without context as to the connections with ethnicity and risk. Indeed, it is important to note that the time of initial review (May 2021) followed the global rise of Black Lives Matter during 2020 and 2021 and increasingly strong calls globally to address systemic forms of racism including by decolonising global health institutions (Olusanya et al., 2016). Organisations thus had a stronger impetus to look as though they cared (see also Liu, 2020). Such tokenistic attempts, however, continue to silence and cause violence to non-white women. This is particularly the case where organisations such as CRUK continue to state that Black and other ethnic minority women are at lower risk, despite knowledge that Black women are already less likely to engage with screening and self-care practices (Bamidele et al., 2017). Unless Black women are lucky enough to choose or be referred to a site with adequate ethnicity-related information, their ethnicity-related risks are not communicated. This in itself becomes another risk.

We contend that the exclusion non-white bodies in visual representations of breast cancer diagnostic images is a clear form of epistemic violence that leads to non-diagnosis and/or misdiagnosis, preventing patients from accessing appropriate and timely care and treatment and impacting the ability of healthcare professionals to accurately diagnose patients and organise their care. That Mind the Gap cannot source images demonstrates they are unlikely to exist in medical textbooks. That the NHS does not discuss links between ethnicity, NICE makes it difficult to find, and charity organisations apart from BCN, provide little and/or contradictory information, gives patients and healthcare workers alike little chance in finding the information. That Black women are more likely to receive delayed non-diagnosis, and mis-diagnoses than other ethnic groups when they seek care, is perhaps, then, not surprising in the face of systemic exclusion of representations of Black women in resources (see also Pallok et al., 2019).

# Moving forwards

Radical change is required to decolonise breast cancer practice in the UK (and elsewhere) and to ensure that Black women and other minority groups are not subjected to additional and preventable risks or epistemic violences. The importance and urgent necessity for decolonising medical knowledges cannot be overstated, particularly whilst the UK breast cancer environment is flooded by harmful and partial knowledges that are perceived as ‘natural’ ‘apolitical and ‘rational’ and which do not ‘need to be scrutinised’ (Gebrial in Bhambra et al., 2020, pp.25–6). Addressing the inequities facing Black women with breast cancer in the UK is a large task that requires the engagement of the entire medical and allied health education system and research systems in the UK, but this research has shown there are three key issues to address as urgent priorities.

First, early screening for Black and other at-risk groups should become a standardised policy. We recommend the NHS follows the USA in lowering the age of breast screening to 40 years for women from minority backgrounds. While it may not be clear why Black women are at higher risk of earlier onset, we must respond to the evidence that they are. In line with this, we recommend that NICE updates breast cancer guidelines, making the differing and additional risks faced by Black and other ethnic minority women clear to healthcare professionals.

Second, recognising that early screening is insufficient if at-risk women do not feel able or safe to access care, more must be done to engage them. The current landscape of culturally tailored breast cancer care in the UK is highly piecemeal. A national programme aimed at improving participation, such as in New Zealand and Australia, would go some way to alleviating this issue for some women. Much as Census 2020 Community Advisors in the UK were recruited to teach minority communities about participation (The Race Equality Centre, 2021), a similar process can be employed to spread important health messages about breast cancer and other health issues. As Rose (1997) argues, an approach that uses sited, located, indigenous, local knowledges, that acknowledges subjectivity and particularity, taking all attempts to avoid the ‘God trick’ and claims of omnipotence and comprehensiveness is required to counter epistemic violence.

Third, there needs to better care taken to decolonise medical knowledges, education, practices, and languages to tackle forms of institutional racism that prevent women from accessing care when they seek it. Healthcare workers must understand ethnicity as a risk factors, be able to recognise how breast cancer appears on different skin types, and actively dispel previously held myths of breast cancer being a ‘white women’s disease.’ Improving the diversity of representation in healthcare resources, beyond tokenistic inclusions, must therefore be a priority. Black women and other marginalised groups will continue to face higher barriers to recognising that they should engage in self-care practices, be able access care services, and receive accurate and timely diagnoses when they remain invisible. Specifically, we urgently call for images of Black and other non-white breasts – not just faces and stories – to ensure that everyone can see what breast cancer looks like.

Overarching these recommendations, we have brought attention to the imperative for the field and practice of medical studies to become more self-aware of its colonising and racist logic and foundations, and to work actively to decolonise its curriculums and frames of references. The field needs to be wary of assumptions and taken-for-granted ground rules and precedents, and to make greater efforts towards being more inclusive, more representative, and more sensitive to ethnic minority differences, elisions, and excludedness. Indeed, while our focus here has been on the exclusion of Black women, it is important to note that in many contexts, breast cancer initiatives and knowledge also exclude other marginalised groups. Our analysis also demonstrated a lack of dedicated information and educational tools concerning other minority groups. Similarly, Black women face higher risks and barriers in relation to other health conditions such as antenatal care (Garcia et al., 2015). Thus, our findings and recommendations, whilst aimed towards decolonising medical practices to ensure Black women receive equitable access to care, are likely to have salience for other groups and conditions.

Finally, it must be clear that although such recommendations will go some way to alleviating the inequity in outcomes and ending enduring epistemic violences, that while Black women and other minority groups continue to live in worse conditions, have access to healthy food restricted, and are subjected to many of the risk factors associated with breast cancer, they remain at disproportionate risk of breast cancer. Further, increasing moves towards self-care and digital health in the NHS and elsewhere (Kent, 2021) alongside evidence that Black women and other minority groups have more limited access to or acceptance of digital health resources, means Black women may be facing further exclusions (see also Figueroa et al., 2021; Stone, 2021). Decolonising breast cancer involves recognising, teaching about, committing to implementing targeted policy initiatives, and representing the diversity of bodies that experience breast cancer. But it also involves ensuring that a decolonial attitude is adopted in the planning and adoption of new technologies and means of care. Without these steps, Black women with breast cancer in the UK will continue to face undue risk.

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1. It must be noted that other ethnic minorities (Farooq & Coleman, 2005), men (Quincey et al., 2016), transgender and gender diverse groups (Coad et al., 2021), and those from lower socioeconomic status (Smith et al., 2019)also face additional barriers to accessing and receiving decent breast cancer in the UK. Thus, while our research addresses the case of Black women, much of what we discuss will have salience for other groups. [↑](#footnote-ref-1)
2. diagnosis of breast cancer was established at stage I in 38% of White British women compared to 25% of Black African women living in the UK. Twice as many Black African women resident in the UK were diagnosed with stage III cancer than White British women (*Ibid.*) (ONS, 2021). The five-year survival outcomes in women diagnosed with stage III tumours drops to 72% from 98% compared to those with a stage I diagnosis (ONS, 2019). [↑](#footnote-ref-2)
3. Although we recognise contestations in definitions of ‘Black’ women and people, in this paper, our usage reflects categories used in UK health data collection. [↑](#footnote-ref-3)
4. Black women born in Africa, for example, are more likely than Black women born in Britain or the Caribbean to have later diagnosis and poorer outcomes (Miller et al. 2019) [↑](#footnote-ref-4)