

## ***“They say it’s more aggressive in black women”*: Biosociality, breast cancer and becoming a population ‘at risk’**

### **Abstract**

Recent geographical scholarship has drawn attention to the ways in which the practice of public health constructs particular bodies and populations as ‘risky’. From a biopolitical perspective this status of being ‘at risk’ offers the basis for an emergent biosociality; groups brought together by a shared vulnerability to disease, which then forms the basis for both state-led public health interventions and community driven advocacy and support. Critics, however, suggest a focus on biosociality can act to obscure other dimensions of individual and community identity, dimensions that can play a key role in determining both health status and the success of healthcare interventions. This paper draws together insights from geography, anthropology and sociology with empirical evidence from focus groups collected as part of an evaluation of a breast cancer awareness DVD distributed in the London borough of Hackney. We explore the extent to which the DVD, by defining a specific group (black women aged 25-50) as being at increased risk of developing more severe forms of breast cancer at a younger age, led to the formation of a biosocial community. Themes emerging from the analysis of focus group transcripts present a complex picture. At times our participants clearly aligned themselves with this biosocial collective, drawing on a shared Black political identity, assumptions of a common African genetic heritage, experiences of diaspora and

perceived similarities in lifestyles and bodily norms. At other times, however, this shared sense of belonging fragmented in light of perceived differences in culture, lifestyle and community which nuanced both participants' sense of being 'at risk' and how they might seek to manage (or not) that risk. Our findings suggest that biosociality is a fragile and heterogeneous accomplishment, with implications for the way we practice medical and social science research, design community-targeted public health interventions and conceptualise risk.

## Introduction

‘Modern prevention is above all the tracking down of risks [...], we are particularly moving away from the older face-to-face surveillance of individuals and groups known to be dangerous or ill (for disciplinary or therapeutic purposes), toward projecting risk factors that deconstruct and reconstruct the individual or group subject.’ (Rabinow 1996: 100)

For some time now geographers working on health, disease and biopolitics have drawn attention to how the practice of public health necessitates the definition and construction of particular bodies and populations as ‘risky’ (T Brown 2000; T Brown and Duncan 2002). For example, Michael Brown (2006, 2009) has focused upon the ways in which particular communities (women engaged in sex work, homosexual men) have been characterised as the bodies most at risk of contracting and spreading sexually transmitted diseases, while Bethan Evans and Rachel Colls show how yet other bodies, those identified as overweight or obese, are problematised because they are perceived to be deliberately putting themselves at risk through their refusal to conform to bodily (mass) norms (Evans and Colls 2009; Evans 2010). Added to accounts such as these is the work of historical geographers who have variously described the ways that populations associated with disease outbreaks – often defined in terms of their class position, racial categorization or status as immigrants – are socially constructed and marginalised through the discourse and practices of public health authorities (e.g. Craddock 1999; McFarlane 2008). It is not only people who are rendered riskier and/or more threatening in this discourse.

Assumptions are also made about the risks of (too) close interconnections between humans and non-humans, as the work of Stephen Hinchliffe and Nick Bingham highlights with its focus on the particularly 'risky' configurations of Egyptian low-income urban dwellers and their backyard poultry during the 2005 avian influenza outbreak (2008a, 2008b).

While there is considerable divergence in the focus of these papers, one area that connects them is their engagement, whether acknowledged or otherwise, with epidemiological notions of risk. As Dean (1999) suggests, epidemiological risk is one amongst a number of risk rationalities that emerged over the course of the nineteenth and twentieth centuries. As with other such rationalities, epidemiological risk, whose principal focus is health, disease and illness, represents a way of (re)ordering reality into a form that is not only calculable but open to intervention; in Foucauldian terms, it is made governable (see Foucault 2007 [1978]). The risk factors that render a population or individuals within a population vulnerable to disease and illness vary; as do the techno-scientific techniques used to identify or trace these factors to risky individuals or population sub-groups. For example, in the nineteenth century a combination of field observations and medical statistics were used to identify risk, whereas in the twentieth century field observations were increasingly replaced by bacteriology and laboratory medicine. The molecularization of medicine, especially following the mapping of the human genome in the late twentieth and early twenty-first centuries, has added further complexity to this picture (Rose 2006). At risk individuals and populations are increasingly defined as such by variation, mutation and change at the molecular level, resulting in

what Rose and Novas (2005) referred to as the emergence of ‘genetic risk’ (*cf.* Armstrong 2017).

Evolving conceptions of epidemiological risk are central to our paper, with its focus on biosociality, breast cancer and risk, in part because it was through a combination of clinical observation, epidemiological tracing and laboratory research at the molecular level that our population of women was codified as a specific ‘at risk’ group. However, in contrast to some of the geographical scholarship that we have already referenced, this construction of risk was not regarded as controversial because it acted to reinforce social anxieties around particular behaviours, practices or human-animal relations such as homosexuality or backyard chicken keeping. Nor were the behaviours, practices or relations of individuals within our sub-population associated with notions of danger or dangerousness (Douglas 1966; Douglas and Wildavsky 1982). Put simply, the women in our study were not perceived as a threat to the health and wellbeing of others. Yet, it became apparent that many of the women, all of whom were black women aged between 25 and 55, *did* regard their definition as an ‘at risk’ population as challenging and in some instances even contentious.

As we shall go on to discuss in more detail, biomedical expertise and its constitutive properties bring into the foreground important questions about what being a ‘body at risk’ entails. Specifically, how being constructed as a population ‘at risk’ often prompts the formation of what Paul Rabinow (1996) termed ‘biosocial communities’, which according to Rose and Novas (2005) are the collectivised form of biological citizenship. Biosociality is also a particular rendition of a familiar move in social and

cultural geography and Science and Technology Studies (STS), seeking to dissolve the boundaries between nature and culture (Lemke 2015), and therefore respectively of the science of biomedicine and the practice of healthcare. Geographers too have already begun to engage critically with this concept (see for example Greenhough 2011; Kearns and Reid-Henry 2009), but its relevance to the argument presented in this paper lies with the recognition that biological citizenship requires all individuals, though especially those identified as being at heightened risk for future ill-health, to take responsibility for their self-care; a manoeuvre that Bethan Evans has quite astutely referred to as ‘pre-emptive biopolitics’ (2010: 21). Furthermore, where to date much of the empirical work on biosocial communities has focused ‘on processes of subjectification “from below”’ (Lemke 2015: 196), here we turn our attention to the ways in which empirical work in geography, epidemiology and public health also plays a role in the ‘constitution of individual and collective identities by expert discourse and medical authorities’ from above (ibid.), responding in part to Legg’s (2005) call for geographers to engage critically with the way in which they define populations in and through their research.

As much of the work mentioned previously reminds us, identifying with a biological community and/or being constituted as one is not to suggest that other aspects of a person’s identity are somehow lost or even submerged. As Tulloch and Lupton (2003:7) argue, understandings of risk are both ‘historical and local’ and ‘subject to disputes and debates over their nature, their control and whom is to blame for their creation’. Tulloch and Lupton (2003: 6) draw on Lash’s (1993) concept of risk cultures to emphasise ‘fluid and interchanging ways of viewing risk, drawing on habitual, embodied

and affective judgements which are subjective rather than objective' as well as the work of Mary Douglas (1992) which emphasizes how cultural dispositions shape the ways in which risk is identified and understood. Similarly, in the same essay where he first proposed the concept of biosociality, Rabinow (1996) cautions that emerging biosocial communities will not supplant older forms of social organisation. As we know, identity is multi-faceted and shaped by multiple oppressions experienced because of a person's gender, class position, ethnicity/race, age, sexuality and so on.

Such moves are important in light of the post-WW2 schism Rabinow and Rose (2006: 205) note between ideas of race in policy discourse, where it is strongly stated that race is not to offer a biological basis for discrimination, and the technical discourses of medical practice where 'many biologists still believed they encountered such differences, not least in examining the prevalence of particular diseases in different regions or the efficacy of medicines in different national populations' (ibid. 207, see also Rose and Novas 2005). The persistence of racial determinism that Rose and Novas highlight in the biological sciences (see also Krieger 2000) is to an extent evident in the on-going search for causality as it relates to black women's risk status relating to breast cancer. Specifically, black women in the UK, similarly to women of African heritage living in other majority white, multi-ethnic nations, are more likely to present with breast cancer at a younger age (typically under the age of 50) and with basal and/or triple-negative status tumours whose characteristics are associated with poorer prognosis; and notably, significantly higher mortality when compared with women of European ancestry. While there are strong arguments made for socio-environmental explanations for these

inequalities, the search for biological answers, and notably genetic ones, persists. This leads to a risk of 'ethnic medicalisation'; 'medical research that accepts race as a reporting category, for example, can imply that the differences between races have to do with biological inheritance and are not, say, a consequence of geographical origins or patterns of endogamy' (Kearns and Reid-Henry 2009: 558, see also Epstein 2004).

There is then, to our minds, a crucial tension when dealing with biological difference and social categories widely used in research and health promotion initiatives. Indeed, as Ehiwe et al (2013: 115) observe, '[t]here is a need to critically review the generalisation of the perceptions used to describe people of black African origin from studies undertaken in both the USA and the UK'. Sheppard et al (2010) highlight that differences exist between African-born black women and those born elsewhere, but these can be missed during the implementation of health services and during health promotion. Geographers have for some time acknowledged that not only are racial categories social constructs, health promotion discourses often perpetuate uncritical medicalized interpretations which are infused with cultural determinism and which can conflate analytic categories such as race, culture and ethnicity (Ortega-Alcázar & Dyck, 2011: 3). There is a critical need, therefore, to offer a counterpoint to discursive constructions of 'othered' groups, which can perpetuate essentialised categorisations on which public health initiatives often rely (Grove and Zwi, 2006).

One key counter discourse can emerge from the 'othered' groups themselves. While the delineation of 'at risk' groups often draws on scientific expertise, biosocial communities may then turn to challenge the expertise and knowledge which first defined



them as being 'at risk'. For example, Steve Epstein (1995: 408) used his empirical study of HIV-AIDs activists in the US to demonstrate how these groups effectively 'constituted themselves as credible participants in the process of knowledge construction, thereby bringing about changes in the epistemic practices of biomedical research'. His paper compellingly shows how AIDs activists were able to engineer a shift in the discourse, moving from a position where risk was something the public should be protected from (as seen in Beck's (1992) *Risk Society* thesis) to an emphasis on an individual's rights to take risks, through, for example, participating in clinical trials for new experimental treatments. This led to the development of new forms of biological citizenship, what Epstein (1995: 428) describes as an upsurge of health-related activism involving, 'the formation of groups that construct identities around particular disease categories and assert political claims on the basis of those new identities', challenging hierarchical relationships between biomedical experts on the one hand and lay people/patients on the other.

This paper focuses on black women's constitution as a population at risk for breast cancer; here associated with a specific public health intervention. Importantly, though, the origins of this paper's critique begin not with the researchers' reflexivity, but with the ways in which our participants contested and engaged critically with their designation as a population 'at risk'. Our participants challenged the lay-expert divide in a manner reminiscent of, but also distinctive from, Epstein's account of AIDs activists. While Epstein focused on how activists renegotiated the right to take risks, in the sections that follow we consider how the construction of the women as a population 'at increased risk of

breast cancer’ was contested and negotiated by them. As we argue, it was not only the women’s perceptions of breast cancer as a disease of white, rather than black, women that mattered here; nor their criticism that the project’s majority white researchers had unthinkingly constructed them as a coherent group whose difference was ignored in favour of ideas about their sameness, although we learnt a great deal from their observations. Rather, we draw attention to the ways in which different aspects of the women’s identities were drawn upon in wide-ranging discussions that at times foregrounded ideas about a shared biological inheritance and at others highlighted differences in their socio-cultural norms. The women who participated in our research at times *identified* as a collective and at others *(dis)identified* with it. We raise questions about the possibility of an emergent biosocial citizen community cohering around the risk for breast cancer amongst this epidemiologically conceived population of black women, and examine how the women’s refusal to uncritically accept racially-defined categorisations challenges the ways in which epidemiological risk is constructed.

### Intervening in a population ‘at risk’

Before outlining in more detail the study upon which this paper is based, it is worth noting that we are an interdisciplinary team of researchers, combining approaches and insights from the disciplines of geography, epidemiology, anthropology and oncology. Collectively we were involved with a public health intervention evaluating the effectiveness of an educational DVD relating to breast cancer awareness, in a cohort of black women aged between 25 and 55 living in the east London borough of Hackney. The DVD was created

in collaboration with Homerton Hospital and featured a well-known, local black female TV presenter who acted as the narrator. Opening with a discussion between three women, one of white ethnicity, the audience is asked to identify which of them has breast cancer. Staged to challenge the common perception that breast cancer is a disease that primarily affects white women (Phillips, Cohen and Moses 1999), the DVD moves on to focus on a local street scene as a prompt for communicating the scale of women's risk and the general level of awareness amongst the population before focusing on the issue of race. Questioning a young black woman, the narrator asks whether race matters: 'Do you think it matters what race you are? Black, White, Asian'. The young woman's reply, which expressed her general awareness of the condition but desire to know more, is used as a further staging point; one that introduces the authoritative figures of biomedical expertise, in this instance represented by white male and Asian female oncologists.

Having set the scene, the DVD moved through a series of additional encounters, all staged at different locations within the hospital setting, each of which was designed to promote breast awareness amongst black women, advise on the practice of self-examination and to encourage early presentation at relevant health care services. Each of these messages was reinforced in a final scene, which involved a group discussion between women living with breast cancer and the two expert figures. These women, like those watching the DVD, were represented as individuals from a collective black community seeking information about a shared risk for breast cancer. Put differently, they were being constituted in the DVD as a distinct biosocial community. In order to evaluate the effectiveness of this public health intervention, at least in terms of the

messages it communicated and the biosocial practices that it engendered, a mixed-methods study involving fourteen general practices was conducted across the borough between January and June 2013 (pilot phase) and June to November 2014 (main phase). In keeping with the interdisciplinary nature of the team, the study was organised around the principles of a randomised control study with seven GP practices identified as 'control practices' and seven as 'intervention practices'. All patients registered in the intervention practices who fell within the study's inclusion criteria (black women aged between 25 and 50) received a copy of the DVD by post; those in the control practices did not receive the DVD.

The principal aim of the study was to determine whether receipt of the DVD encouraged women to present at their GP practices for breast cancer diagnostic services; that is, if the DVD prompted them to be breast aware and, where change in their breasts was noticed, to seek appropriate medical advice. To obtain feedback on the women's response to the DVD and the messages conveyed within it, as well as to ascertain the level of breast cancer knowledge and breast awareness in the local population, focus group discussions were conducted at each of the control and intervention practices across the pilot and main stages of the study (for more detail on the findings of other elements of the research see Brown *et al* 2017; Greenhough *et al* 2016). Women were contacted directly through the GP practices with which they were registered with the aim of recruiting between 8 and 10 women per focus group; practices and participants were reimbursed for their time commitment and related expenses. Prior to each discussion, all the women of a group completed a version of the Cancer Awareness Measure survey,

which combines basic demographic data with questions relating to previous knowledge of cancer (Cancer Research UK 2011). The DVD was then screened (particularly important for those women who had not received the DVD). Following this a focused discussion aimed to draw out the women's responses to the DVD. As Table 1 highlights, the focus groups varied in size and self-identified ethnicity, with some groups including relatively small numbers of participants and with some being more homogenous than others in terms of the women's ethnicity. The small size (two or three women) of five of the focus groups meant they were less helpful in drawing out some of the diversity and complexity found in other groups, but were included for completeness of data.<sup>1</sup>

*[insert table 1 about here]*

Originally designed as a two-stage investigation (a pilot study and main study, with the pilot data refining the guiding questions and direction of the focus group discussions), an additional phase was added to follow-up on several key themes that emerged from initial analysis of the focus group discussions. To this end, a further six focus group discussions were undertaken with thirty-three women recruited through a range of local

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<sup>1</sup> The focus groups were intended to provide a safe physical and emotional space for sharing views and experiences, and the method also aims to reduce the hierarchical relationship between researched and 'researched' through the participants' ability to have control over the direction of discussion. It is also through the social interaction of such discussion that knowledge is constructed and awareness of particular issues may be promoted. There are considerable challenges in using focus group methods, particularly with immigrant and minority groups, which are addressed in the methodological literature (Pratt 2002). For the purposes of this research focus groups were considered the most appropriate for the addressing the research problem, as well as for working with the women participants (Greenbaum 1996; Hay 2000; Kreuger 2000).

community organisations (Table 1). In these later groups additional questions were added to the focus groups discussions to draw out women's experiences of being constructed as a population 'at risk' based on the analysis of data from the two earlier phases. As with the previous phases of the study, many, though not all, of the groups included women from different ethnic backgrounds and with varying periods of time spent in the UK (from birth to less than one year); the exception was one focus group (E01) which was made of women all of whom identified as being of Sierra Leonean origin. While there is a suggestion from researcher notes that group dynamics were affected by the size and ethnic make-up of the focus groups, the 'liveliness' of the discussions, to use a term applied to focus group research by Mike Crang and Ian Cook (1995), varied in ways that cannot be solely attributed to this. Yet, it is important that we acknowledge discussion was most evident in groups that were either more diverse or included women of African-Caribbean heritage or identified as Black other, especially around the question of the women's labelling as 'black women' and as a distinct 'at risk' population. It was from these groups that the women's ascribed identity was initially contested: as one participant remarked, 'Yeah, but what type of Black women?' (E05).

A further point of methodological significance is that although the focus groups were conducted according to the same research protocols, the identity of the researcher moderating them changed across the study. Here, we should also note that the researchers were all women with considerable experience of working across a range of non-white ethnic groups, but there was no deliberate attempt to match them to the ethnicity of the participants. Of the three researchers that moderated the focus groups,

two were of white European ethnicity and a third of white-Asian ethnicity. This may be perceived as an oversight – and we acknowledge that there is some suggestion that matching for ethnicity is beneficial; however, the women’s participation in the discussion was not overtly constrained by the researchers’ ethnicity. Indeed, it might be argued that the difference in ethnicity provided an opportunity for the women to question what they regarded as the study’s (mis)representation of them as a coherent, homogenous collective (see Ortega-Alcázar and Dyck 2012). Perhaps the women also sought to counter what they perceived as their being rendered as ‘conspicuous “objects-in-place”’ (McKittrick and Woods 2007: 4). As we go on to demonstrate, the women’s response to this perceived misrepresentation was to reveal their multiple and at times contested subject positions.

### **On blackness: diversity, socio-political identity and constructions of risk**

In this section, we explore a key theme that developed to differing degrees during all focus group discussions; how the women made sense of what being a ‘black woman’ meant. As mentioned, the educational DVD was viewed by all the participants during the focus groups. Although some of the women had received a copy in the post as a part of the intervention, for many women this was the first time they heard about the elevated risk associated with breast cancer faced by younger black women, and the extent to which the women accepted the risk posed to them as a collective varied. There were some women who were sceptical because they had not personally seen ‘evidence’ of breast cancer, others received the news with some anxiety but accepted it and were keen to explore the risks and to seek answers.

In addition to these anticipated responses though, some women directly drew attention to what they perceived as an unproblematised notion of 'blackness' that underpinned the message of the DVD and the wider project. The complicated nature of blackness, subjectivity and gender draws attention to the 'politics of diversity among women', but also to 'the uneasiness of being black and gendered' (McKittrick 2010: 128, see also Blunt and Rose 1994; Bhabha 1994; Mercer 1994). There was a sense for some that the definition of black women as a community 'at risk' was not one that they had chosen but was one conceptualised outside of *their* community by external agencies, including medical and academic institutions. As one woman observed; '[t]hey say it's more aggressive in black women' (M04, emphasis added)<sup>2</sup>. This participant, who was one of a number of African-Caribbean women in a group including women of white and African-Caribbean heritage, continued by stating that 'it's almost alienating, just targeting one kind of black woman.'

Unsurprisingly perhaps, there was evidence throughout the focus group discussion of participants responding to collective notions of 'blackness' in diverse ways; and not always in the same questioning terms highlighted above. Some appeared to accept their identification with an inclusive 'black woman' category, adopting the same language during their discussion. In this case, the women used a mixture of personal and possessive pronouns to identify risk for breast cancer as something that was collectively shared. For example, phrases such as 'we black women', 'us black women', 'our women'

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<sup>2</sup> Focus groups are identified by a single code for each group. Codes beginning P refer to the pilot study (June-July 2013), those beginning with M the main study (November 2014-February 2015) and those beginning with E to the extended study (October-December 2016).



and 'our people' were used across the focus group discussions. As a woman in a large group of mixed participants stated: 'Seeing a sister on the face [Facebook], I'll tell it to all *my other black women*' (M01, emphasis added). Yet, despite articulating a clear sense of their shared identity as 'black women' this was cut through with ideas about home and place, origins and locations reflecting the 'entanglements of genealogies of dispersal' (Brah and Phoenix 2004: 83). This difference was never articulated in oppositional terms, but, like other markers of identity, did serve to render the term 'black women' open to scrutiny. When prompted to consider what the term 'black women' meant to them in later focus group discussions, some participants returned to questioning this form of labelling. Responding to a question about the project's use of the term and whether it was helpful, one participant responded: 'No. We're actually the African heritage community. We're not black, we're African, whether in the mainland or the diaspora' (E05). Another participant in this group, suggested that while she did not mind the label it was 'not a respected term' and that it had a lot of 'negative connotations about it'.

These multiple, overlapping and sometimes messy constructions of themselves appeared both a challenge and reconciliation of the homogenisation implicated through the use of the term 'black women'. As a participant in the main phase of the study articulated, 'it doesn't even sound like they're saying, well black women from the West Indies or black women from Africa or black women from here, it just seems like black women... in general' (M03). One key response to this perceived problem of the homogeneity inherent in the category 'black women' was an acknowledgement of their great diversity; both of those women participating in the research and of the wider

community. As another participant suggested, the term 'black women' was unclear because 'we would have a black African and have black Caribbean. But we also have 52 countries in Africa' (E02). This picture of a diverse rather than homogenous group identity was reflected elsewhere: 'sometimes when they say black, it's like, there's the black African, there's the black Caribbean and Afro Caribbean and maybe there's like other browns' (E06). Yet, another participant stated that she preferred 'something a bit more multicultural because black women encompasses not just Afro Caribbean ... But then you've got African community and everything like that and I think it should be a bit more multicultural, mixed race' (M04). Divergence was also evident between focus groups, particularly those in the second phases of the study that focused more explicitly on questions of ethnicity. For example, the focus group involving a community action group of women all originally from Sierra Leone (EO1) shared a reluctance to question difference within the black community, perhaps not only due to their shared heritage but also the political nature of their work, while another group of charity workers who had links to a range of different African countries (EO2) seemed keen to emphasise the diversity between them.

Such fluctuating subjectivities echo Aspinall's (2002) observations that terms used to define both individual or group identities are always problematic because they remain context specific and fail to represent the true diversity of identity. Moreover, there were notable differences with how inscriptions of blackness were perceived, experienced and reconciled by the women. As one woman said, 'I'm very proud to be black. That's not the problem. I think it's the problem for other people when they look at black women in the

black community, they have the problem' (E05). A significant consequence of the perceived homogenised racial constructions of blackness was concern that public health initiatives targeted at black women might be sabotaged. As the same woman went on to explain, 'I think using black women as the term might shut opportunities off for us because some people, as soon as you say 'black', they don't want to know' (E05). She went on further to remark that 'if it's segregated to a black problem, I don't know if you'd get as much help with the movement'. In making this statement, this participant questioned whether it was possible to cohere as biosocial community around this issue.

The significance of this contested 'black' identity emerges in relation to the anticipatory logic of a pre-emptive public health which aims to nudge a population towards idealised biosocial subjectivities (see Carter 2015). It is now widely acknowledged that an 'ethic of active citizenship' shapes contemporary subjectivity in advanced liberal societies. The women in our study were obviously not compelled to perform the kinds of self-care regime proposed in the educational DVD used in this intervention; however, they like the rest of us *are* expected to 'adopt an active, informed, positive, and prudent relation to the future' (Rose 2006: 28). As this research demonstrates, many of the participants in the study acknowledged their lack of awareness of breast cancer symptoms and many admitted to adopting very irregular self-care regimes. Here, the women's complex interpretation of their own bodies (as biological, cultural, social and political entities) and how they responded to their being labelled as at risk 'black women' appears to have profound implications for their embodiment of self-care practices that many associated with 'white' bodies at greater risk than their own (Robertson 2000).

These concerns speak to Craddock's (1999) observations about how the body, as a site of power relations, is simultaneously pathologized and racialized through medical inscriptions of disease or illness. Indeed, the women's participation in the research may even be seen as part of that labelling process. Mirza (1997 cited by Maylor 2009) describes 'black' as being '[a]bout a state of 'becoming' (racialised); a process of consciousness, when colour becomes the defining factor about who you are'. The concerns expressed by our respondents about the potential consequences of initiatives which target black women indicates perhaps a fear of being overtly 'othered' through collective identification as an 'at risk' group. While this may be so, other women articulated very different challenges to their constitution as a homogenous group of 'black women'. For example, for women born outside of the UK other markers of difference (and similarity) such as social class were more pertinent: 'Because here, it's either you are black or you are white. Where I am from, it's either uptown or downtown. We left from one island to a much bigger island, and we are all swimming with the sharks and surviving' (E06). In another illustration, a participant simply stated that her ascribed identity was not one that she readily acknowledged: 'I do not refer to myself as anything because when I wake up in the morning I don't say, "Oh, I'm black." But if I have to fit into one of those categories I tend to say I'm from the Caribbean and that's that' (E05).

As our focus group discussions revealed, there was a complex and diverse picture that emerged around the constitution of these women as an 'at risk' group. Despite the women's mixed response, being constituted as such did lead many women to question what it was that placed them at collective risk:

‘So what is about our colour, you know, and genetics that makes us, considering we’re all different – my dad’s Jamaican and I’m mixed race, this lady’s Somalian, yeah, Africa, see, so – but we’ve all got the same high risk of having an aggressive cancer. (M03)

As this suggests, there was great interest in what it was about being black that put the women at risk. This response was partially shaped by the DVD, which had alerted the women to their risky subjectivity. Although the focus groups included women whose close family or friends had been diagnosed with or had died from breast cancer, many were completely unaware of their risk status prior to participation in the study. As one participant stated, ‘I didn’t have a clue what breast cancer was and I’m 40 but I didn’t have a clue and I didn’t think it was going to affect me’ (M04). Another common response is reflected in this participant’s statement that she had ‘never heard of any black people with cancer’ (M06). As we have reported elsewhere, this lack of awareness prompted many of the women to want to know more about the condition and how it affected them (Brown *et al* 2017). Rather than focus on this aspect of the women’s discussion here, we turn our attention here to the ways in which they negotiated their risky status and especially how they came to understand the interconnections between their embodiment as black women and their heightened risk for specific types of breast cancer.

### On being a population at risk, individual identity and the everyday

The women's understanding of their *being* a population at risk drew on ideas about shared black identity and how this was bound up with their physicality and embodied experience. Shared physical characteristics were, for example, perceived as grounds for collective notions of blackness. As one woman observed, 'as black women we're blessed as other people sort of say we have got big bum[s] or we've got big breasts. We live with it, in fact we're *proud* of it' (P04, emphasis added). Outside of their preparedness or otherwise to embody what might be regarded as racialized representations of black identity (McKittrick 2000), the women's understanding of their being an 'at risk' population also referred to highly spatialised notions of their biological, cultural, social and political identities which at one and the same time connected and differentiated them. Central to this aspect of their discussions were ideas about genetics and relatedness, lifestyle and difference, as well as observations regarding bodies in space and place. We focus on these three aspects of being a population at risk in the following section.

#### *Relatedness and genetic inheritance*

There is longstanding recognition that breast cancer risk has a genetic component, with two 'breast cancer genes', BRCA1 and BRCA2, identified in 1994 and 1995 respectively (Couch, Nathanson and Offit 2014). It is now understood that up to fifteen per cent of patients with invasive breast cancers are the result of inherited genetic events; not all of which result from mutations of these two particular genes. Given the high-profile media reporting of genetic causes for breast cancer (Henderson and Kitlinger 1999), especially

since the unveiling of the human genome in 2000, it is not surprising that ideas about inherited risk featured strongly in the women's discussions. When questioned why they thought they might be at heightened risk, many women concurred with the idea that it was related to genetics: 'I think it's genetics', 'I think it's genetic', 'I think genetic ... cancer is genetic' (E06). The women in this focus group discussed genetics, blood and DNA as interchangeable risk factors and drew them together:

V5: When it is genetic, it can come in the blood.

V3: It's in the blood, in the genes, in the DNA, yes, yes.

V5: And you will get it. In the blood. Your grandmother had it or your father had it, well then it is in the blood. One day, one time it will come.

(E06)

Importantly, the idea that genetic inheritance was responsible for their collective status as being at risk for breast cancer was not limited to the women's discussions of direct family members; a much broader conceptualisation of relatedness was also evident (see Nash, 2005, 2012). As one participant suggested, 'if I tested my genetics it would go back to Africa anyway'. Going further, she noted, that 'it doesn't matter how filtered your blackness is within you [...] there's still that one dot [...] that says your ancestors came from' (M03). The acceptance here of a shared genetic heritage – which manifests as a propensity to developing particular forms of cancer – reflects equally unquestioned assumptions within genetic medicine that race can act as a proxy for biological differences

in both the presentation of disease and responses to treatment. The most well-known example of this form of stratified medicine is the approval granted by the Food and Drug Administration in the United States for the use of BiDil, a drug for congenital heart failure to only be used in African-American populations (Inda 2014; Kahn 2013). While for some this move is a positive one – facilitating the targeting of resources towards marginalised communities – critics point to concerns that a focus on genetics can act to obscure and direct attention away from very real categories of shared social and economic disadvantage. Similar dilemmas arguably arise in Hackney, which was ranked as the eleventh most deprived local authority overall in England in 2015 (London Borough of Hackney Policy Team 2016). Especially given there is, as yet, no scientific or medical explanation of the propensity for Black women to present with breast cancer less often but at a younger age and with more severe prognoses. Furthermore, this lacuna around the impact of political economy on public health is one critics suggest is echoed in the biosociality literature (Kearns and Reid-Henry 2009; Lemke 2015; Sunder-Rajan 2008).

### *Lifestyle as difference*

Attempts to reconcile a collective risk profile through a genetic discourse were juxtaposed against ideas of individual choice and varying lifestyles, some of which reflected the challenges of social and economic marginalization described above. Here, it was notable that the explanations the women themselves proposed were often in line with more



generic public health messages about the links between lifestyle and cancer; as this participant questioned when discussing a friend's diagnosis with breast cancer:

I mean I've sat down with [my friend] and it's why me, why me, is it 'cause I smoked, is it 'cause I raved, is it 'cause I've done this, is it 'cause I've puffed [...] is it 'cause I ate too much rubbish? (M10)

However, this understanding of lifestyle risk factors was itself highly nuanced in other aspects of the women's discussion. As one woman observed, 'because if you consider it, even though we are all black women we are still not a homogenous group, so we have different diets, we have different cultures, we have different lifestyles' (M02). Participant's acknowledgement of their socio-cultural difference was also reflected elsewhere in the focus groups. As another participant stated, 'we all have different lifestyles, like West Africa they would have a diet which is very full of like hot food. And they eat a lot of fish, they eat a lot of that. When you come to East Africa for example it will be more of meat and starch' (E02).

The importance of such reflections on socio-cultural difference lies in the fact that they were mobilised in response to what the women perceived as the homogenising nature of their categorisation as black women at risk. Perhaps even more significantly, the space the focus group offered the women to discuss their cultural differences also presented some of them with the opportunity to reflect on how their lifestyles had changed. Though there were some positive voices, many more women highlighted the

negative consequences of life in Britain. Echoing work by other authors, women felt that they worked harder, longer hours in low skilled, poorly paid jobs whilst also caring for children, husbands and elderly parents (Remennick 2006; Moorley et al 2013). Time pressures allowed less time for exercise as part of everyday life: 'I think a lot of it is to do with the lifestyle, as I said a lot of us work a lot. And lots are full-time mum ... if you go to the gym for example, the local gym you are rarely going to find proper black African women. Yes, actually find more white people' (E02). This also highlights issues with regards cultural practices around formal exercising which act as markers of difference; not just between 'proper black women' and 'white people', but through the exclusion of other 'kinds' of black women. This further alludes to fractures within the 'black woman' category. A complex picture emerges which points to intersecting shared experiences of a diasporic identity and social and economic marginalisation, but also highlights differences and multiplicities in both lifestyles and the social and cultural discourses and experiences which shape them.

### *Bodies in space and place*

These intersecting axes of similarity and difference also emerge in diverse ways across a range of sites and spaces, from intimate corporeal experiences, to the histories and geographies of East London, to the global Africa diaspora. As McKittrick (2010: 127) asserts, 'different femininities, or racialised subjectivities, are produced in different geographical and historical spaces'. These observations resonate with the views of the

women in our study, in that they interpreted their risky bodies and identities in distinctly spatial terms. This included their relationships and experiences of everyday places in East London and places that they were connected to in the Caribbean and in Africa. Perhaps because of this, considerations about the amplified risk of breast cancer were understood within the context of everyday life in the UK and in contrast with places elsewhere. Not only did women contextualise their explorations of risk through past experiences of living abroad, they also spoke about on-going contact through visits 'back home', and their belonging to a UK-based diaspora. This further highlights the women's fluid negotiation of collective and individual identity, moving back and forth between talking as 'black women', being of 'black culture', associating (or not) with being of African and Caribbean heritage and so on.

Here the emphasis accorded to everyday places contrasted with the institutional settings and local venues depicted in the DVD, representing an attempt by the women to make sense of their being at risk in terms which were more relevant to their quotidian lives. Some women framed their collective identity through being better informed about health risks than those still living in the Caribbean and in Africa, citing practices and knowledge acquired by life in the UK. These accounts were juxtaposed, however, against numerous accounts of women avoiding medical interventions and returning home to seek alternative treatment. The negotiation of risk and identity can be further exemplified through the interface between food, diet and place. Contrary to well versed insecurities about the global North facing attack from the spread of disease from the global South (Braun 2007), the women wondered if their health was at risk in the UK from consuming

food which was subject to the processes of global mass production. As one woman explained, 'we don't know where our food comes from, when at home, you know actually your food where it comes from. It is localised' (E06). Life in the UK, in contrast to life in the Caribbean or in Africa, meant a reduced familiarity with how and where food is produced. At the root of these explanations was a sense that conditions in the UK were less favourable than those they had been accustomed to, placing women at greater collective risk. Indeed, life in the UK was seen as more stressful than life 'back home' and was regarded as a trigger for breast cancer: 'What is stress? Before you came to England, did you know the word stress?' (E06).

Interestingly, while ideas of a shared genetic susceptibility emerged in a largely consistent and uncontested manner (reflecting more general hierarchies in the discourses of health, which emphasise genetic over other causes), the discourse about a shared environmental vulnerability was accompanied by debate and speculation that sought to unpack and anecdotally evidence environmental causes of disease. The distinctive geographies of East London and the African diaspora were highlighted as factors the women saw to be placing them both individually and collectively 'at risk' (or in some cases protecting them from risks), reflecting the ways in which spaces and biosocial identities are co-implicated. These perceptions reflect a critical engagement with a form of biosociality 'understood as rooted in biology and not in social or geographical context' (Kearns and Reid-Henry 2009: 557, see also E Hall 2005). Some of the factors participants identified – particularly around diet and lifestyle – reflect the influence of state-directed biological citizenship in the form of public health campaigns encouraging 'care of the self'.

Others, for example the ways in which some of the participants linked their 'at risk' status to the challenges of living in one of the most deprived local authorities in England, reflect Kearns and Reid-Henry's (2009) call for a greater attention to the ways in which biological citizenship is conditioned by wider political economic factors.

## Conclusions

In his classic essay on the emergence of biosociality, anthropologist Paul Rabinow (1996: 101) cites a genetically inherited propensity to develop breast cancer as one form of biosocial knowledge around which new individual and group identities may emerge. At one level, the findings of our focus group work supports this. Biosociality, distinct from biological citizenship writ more broadly, involves the active formation of collectives around biosocial groupings, a citizenship which manifests 'in a range of struggles over individual identities, forms of collectivisation, demands for recognition, access to knowledge and claims to expertise' (Rose and Novas 2005: 442). These forms of biosocial struggle are evident in our participants' critical engagement with the intersection of biological and racial categories (struggles over individual identities), a response to a shared designation of being 'at risk' through a desire to educate themselves and others (forms of collectivisation), and a demand for access to more knowledge about exactly how to be breast aware and how to mitigate against the risks of disease (access to knowledge).

Yet the story is also a more complex one. We opened this paper by considering questions of risk and how it is encountered, embodied and resisted as public health discourses transform the futures for people who had perhaps presumed

themselves to be otherwise healthy, (as Armstrong (1995: 400) argued some time ago now, epidemiological risk points to 'some future illness'). Many of the women in our study were aware of breast cancer, knew some, if not all, of the signs and symptoms that they should check for in their breasts and were generally knowledgeable about the self-monitoring techniques they should practice; even if this knowledge was only irregularly put into practice. In this regard, many of them did conform to contemporary expectations regarding health, risk management and the governmental desire for prudential subject-citizenship. However, it was also apparent that the women's prior encounters with breast cancer were mediated by a widely shared belief that their ethnicity was in some ways protective; that breast cancer was primarily a disease that affected women of white ethnicity. In foregrounding the women's blackness and rendering this as the principal reason for their increased risk for more aggressive forms of breast cancer, the DVD prompted the women to not only challenge the deterritorializing and reterritorializing of their bodies by expert discourses, but also to look beyond the explanations that were offered to them. This has implications for the extent to which, in this case, shared disease risk offers shared ground for the formative of biosocial collectives.

Despite Rabinow's (1996: 103) early insistence that new forms of biosociality do not supplant other forms of identification, 'but rather co-exist with older cultural grids – or even at times reaffirm them' (as is the case with BiDil), Lemke (2015) suggests that much of the subsequent empirical work on biosociality has tended to treat the biological basis of shared group identities rather uncritically. This is in marked contrast to the women in our study who, while ready to speculate on the 'genetic' basis of a shared risk

of breast cancer, none-the-less remained puzzled by their grouping as a collective biomedical entity. In particular the category black, while reflecting a long biopolitical history of the classification of populations along ethnic lines, and forming an enduring point of political identification for some participants, was in tension with the ways in which the women differentiated themselves from each other. These struggles in turn reflect the ways in which biological designations of 'communities of interest' pose distinctive challenges for community identity also seen in work on biomedical research with indigenous and marginalised populations (Reardon and TallBear 2012; Kowal 2013). Therefore, while at times politically powerful – as was clearly the case for Epstein's (2004) work on HIV-AIDs activists and Petryna's (2004) work on those impacted by a nuclear disaster – attempts to intervene in order to generate a shared sense of community 'at risk' need to be sensitive to heterogeneity within the communities so-defined. While within our study population a shared black political identity, assumptions of a common African genetic heritage, experiences of diaspora and perceived similarities in lifestyles and bodily norms which acted as unifying factors, differences in culture, lifestyle and community suggest we need to act with caution when seeking to adopt a one-size-fits-all approach.

Furthermore, the negotiation of a collective risk profile was often in tension with individual identity and everyday experience. In addition to factors such as genetic differences and lifestyle choices, we argue that participants interpreted their (black) bodies 'at risk' in distinctly spatial terms. Our data offers a view of biosocial communities as heterogeneous and performative, not only in terms of particular cultural/social

categories (race, gender, dis(ability)), but also in terms of the scales and temporalities over which those identities are expressed. Knowledges of health risks are 'produced and circulate within circumscribed spaces' (Kearns and Reid-Henry 2009: 557, see also E Hall 2005), but attempts to circulate these beyond the biomedical context within which they are developed produce new configurations of knowledge, power, authority and understanding, whereby biomedically-defined and other types of identity intersect. Where previous work on risk has emphasised that risk is 'contextualised' (Tulloch and Lupton 2003) and that individuals have a right to place themselves at risk (Epstein 1995), here the women sought to better understand – and ideally have a stake in (re)defining – what placed them at risk. They critically interrogated the ways in which standardised (even if self-reported) ethnic categories offered a questionable proxy for complex, situated, embodied and highly differentiated experiences of being a black woman in East London, articulated through contrasts drawn with places elsewhere, particularly Africa and the Caribbean. This underscored a tension between how breast cancer is understood and managed in everyday life and the actions of the 'ideal patient' or biological citizen as depicted in the DVD; someone who uncritically adopts health information and routinely self-examines, takes up screening, and on the discover of breast cancer symptoms seeks timely help from healthcare professionals (Granek and Fergus 2012).

We contend critical engagement with the kind of 'pre-emptive biopolitics' (Evans 2010) which sees race as a basis for targeting healthcare interventions has implications for the ways in which geographers, anthropologists, epidemiologists and oncologists and others define, understand and engage with what have been described as hard to reach,



marginalised and disengaged populations. An uncritical acceptance of race as a proxy for biosocial risk factors (*cf.* BiDil) can lead to a confusion of correlation and causality, where selected commonalities (e.g. race, genetics) within a group are assumed (arguably by both health and medical professionals and community members) to be the factors placing them 'at risk', perhaps obscuring the role of other elements (lifestyle, environment), or more accurately the complex interplay between a wide range of factors. As Adriana Petryna notes in her influential work on biological citizenship, (2004: 257) 'definitions of health and illness are embedded within spheres of politics and economics and are almost always connected with dimensions that go beyond the immediate body, such as interpersonal and domestic relationships'. If to be 'at risk', as it is conceived in epidemiological and genetic terms, is not enough to constitute a shared identity, nor is it enough to inform the effective targeting of public health interventions. Rather, it is a shared understanding of the factors that place a group at risk (genetics, identity, lifestyle, health-seeking (or avoiding) behaviours) that offer the strongest basis for effective, targeted and hopefully collaborative intervention.

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**Table One**

*Summary of focus group location, size and composition. Note the change in the way in which ethnicity is recorded between the pilot and main study and the extended study, where we sought to better capture ethnic diversity and difference in the latter.*

	CODE	VENUE	NUMBER OF PARTICIPANTS	AGE RANGE	SELF-REPORTED ETHNICITY			
					Black African	Afro-Caribbean	Other black background	Refused
PILOT STUDY: Focus groups at GP Surgery's as part of wider study evaluating a DVD to raise awareness of increased risk of breast cancer in younger Black British women	P01	GP PRACTICE	9	28-49	6	2		1
	P02		4	31-37	3			1
	P03		6	29-47	1	4		1
	P04		7	30-58	1	3	3	
MAIN STUDY: Focus groups at GP Surgery's as part of wider study evaluating a DVD to raise awareness of increased risk of breast cancer in younger Black British women	M01	GP PRACTICE	7	34-50	1	6		
	M02		2	50	1	1		
	M03		5	no data	2	3		
	M04		5	40-51		3	2	
	M05		4	25-35		4		
	M06		3	30-45		3		
	M07		3	28-45	2			1
	M08		6	20-50	3	1	1	1
	M09		8	30-61	4	4		
	M10		3	36-45		1	2	
EXTENDED STUDY: Focus groups with pre-established local community groups to explore emerging themes from phase around identity and risk	CODE	VENUE	NUMBER OF PARTICIPANTS	AGE RANGE	SELF-REPORTED COUNTRY OF ORIGIN / ETHNICITY			
	E01	Community Centre	6	no data	Sierra Leone (6)			
	E02	Community Centre	7	35-56	Uganda (2); Kenya (2); Sudan (1); Rwanda (1); Congo (1)			
	E03	Catholic Church	2	41-50	UK (Nigerian parents, 1); Ghana (1)			
	E04	Catholic Church	5	31-51	UK (Caribbean parents) (1); Congo (1); Ghana (1); Nigeria (1); Ivory Coast (1)			
	E05	Catholic Church	8	26-42	Nigeria (1); Congo (1); Ghana (1); African Caribbean (2); Black British (3)			
	E06	Community Venue	5	20-50	Uganda (2); Jamaican (2); Rwanda (1)			

