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## **'We all have a responsibility to each other': valuing racialised bodies in the neoliberal bioeconomy**

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### **Abstract**

In neoliberalism, human tissue has been targeted as a novel source for the extraction of surplus value. Entire new markets for human biomaterials such as reproductive tissue, organs and clinical data have emerged. Commercial attention has also turned to ethnic and racial minorities, resulting in myriad products and services specifically developed for them. In this paper, we focus on this market interest in racialised tissue by exploring two contested empirical examples: clinical trials for pharmaceuticals in the United States and stem cell transplantation in the United Kingdom. Both examples use racial taxonomies as useful tools in discerning human biological difference to draw conclusions about the economic potential of donors' and participants' genetic constitutions. We will show, first, how they do so by appealing to racialised minorities' sense of responsibility toward 'their' communities, not only actively buttressing the conflation of the social and biological registers of human variation but also demonstrating neoliberalism's mobilisation of discourses of community. However, while the inclusion of racialised minorities is hoped to bring economic benefits, it also aims to work towards the beneficent ends of addressing racial inequalities in healthcare provision. Drawing on debates in Science and Technology Studies, we argue, second, that in our examples, economic, social and cultural values cannot be disentangled. This compels us to complement narratives of the commodification of racialised difference in neoliberal (consumer) culture, and focus on the intersections between different values pertaining simultaneously to economic and ethical realms. Ultimately though, we find that whilst important work is being done to ameliorate racial inequities, the broader socio-economic and

political inequalities minority communities face go unaddressed, likely precluding the realisation of bioscience's promise of health equality.

**Keywords:** race; neoliberalism; science and technology studies; clinical trials; stem cell donation

## **Introduction**

Over the past three decades or so, new biomedical technologies have, through licensing agreements, patenting, and innovation monopolies, become the basis for a plethora of lucrative investments. From the development of powerful immunosuppressants that revolutionised transplant medicine, to sophisticated assisted reproductive technologies, fundamentally transforming our understanding of human reproduction, it is increasingly the molecular qualities and regenerative capabilities of the human body that are being put into the service of both bioscientific endeavours and commercial exploitation (Cooper, 2008; Cooper and Waldby, 2014; Lock, 2001; Rose, 2006; Scheper-Hughes, 2001).

Such scientific practices have also re-established the discussion of meaningful human differences along racial lines. Though race has, since the horrors of World War II and Nazi science, been discredited as a biological category and shown to lack any scientific credibility (but Reardon, 2005), entire new industries have been built around the idea that the category can be determined at the minuscule level of DNA. From genetic ancestry testing (Nelson, 2008; Bolnick et al. 2007) to race-specific medicine (Kahn, 2012; Roberts, 2010; Inda, 2014) we can find numerous examples of how science produces opportunities to make racial difference economically valuable. In line with neoliberalism's creation of new racialised markets – advertising, cars or sports clothing are only a few examples (Whitmarsh and Jones, 2010) – the mutually constitutive practices of the life sciences and the tenets of market stratification and product differentiation have also produced novel markets in racialised human tissue.

In this context, this paper examines two empirical examples, clinical drug trials in the United States and umbilical cord blood stem cell banking in the United Kingdom, that centre on the enrolment of racial and ethnic minorities, aiming to generate economic benefits from racialised tissue. Emerging out of larger research projects in which we have each investigated

specific aspects of the complex entanglements of race, bioscience and the creation of new markets – the relations between research on human diversity and the globalisation of clinical trials (Author’s name removed), and the processes of encouraging potential minority ethnicity donors to participate in umbilical cord blood banking in UK stem cell governance (Author’s name removed) – we empirically investigate how, as Paul Gilroy puts it, “[n]eoliberal culture and economic habits unearthed the value in previously abjected black life” (Gilroy, 2013: 36). In neoliberal consumer culture, racial difference or ‘diversity’ has undergone a valuating process, shifting representations of race associated with crime or poverty to making it the locus of ‘positive’ markers such as uniqueness, creativity, and rarity. Bioscientific products such as BiDiL, the world’s first so-called ethnic drug (Kahn, 2012), or personal genomics company 23andMe’s African Ancestry Project (Merz, 2016) are expressions of such a new valuing of racial difference, not least for its commercial appeals.

However, in this paper we seek to problematise the assumption that such markets are merely another expression of the commodification of racial difference, or an extension of the historical extraction of surplus value from racialised bodies to racialised cells. Though authors such as Dorothy Roberts (2011) aptly emphasise the enduring entanglements of race, commerce and conquest since the era of enslavement and colonial violence, we suggest that the economic attractiveness of racialised tissue can only be understood in relation to the various contemporary social, moral and cultural systems of meaning-making that co-produce, and sometimes contradict, it. Important historical, institutional, cultural differences between our two cases aside, this value cannot be understood purely in terms of the commodification of racialised lives but enfolds economic, ethical and vital value in that money might be made (through private drug trials) or saved (through public stem cell banks) but lives also lengthened or improved, and historical wrongs addressed (Dussauge et al., 2015). What Nikolas Rose has called the “biology of the present” (2006: 160) cannot be comprehensively understood within the trajectory of nineteenth century race science or as merely the latest expression of the biogenetic legitimation of social health disparities. Rather, it is part of the larger “economy of hope” (Rose, 2006: 167) that characterises contemporary biomedical practices. We suggest that though problematically reifying and mobilising racialised difference as biological by phenotypically matching individuals with their presumed communities, present-day bioscientific practices disrupt tidy accounts of economic exploitation. We therefore argue for a more nuanced account that acknowledges that practices

which operate within market principles to enrol racialised life also portend beneficent health outcomes and aim to address historical exclusions.

Whether or not these efforts will result in actual improvements in health remains highly uncertain of course. The health inequalities often pitched as the focus of scientific effort are but part of a broader tapestry of socio-economic and political inequalities. These preclude the realisation of bioscience's lofty promises to improve health equity, and prompt a broader question that needs to be asked about when and why certain lives do, or do not, come to matter. We conclude by suggesting that our vignettes propose technological fixes that are likely to leave unaddressed the much larger social and economic problems reproducing racial health disparities.

### **Neoliberal bioscience and the valorisation of vitality**

Neoliberalism, understood here as both a set of governing practices and distinct economic policies characterised by a preference to marketplace mechanisms, trade liberalisation and the individualisation of risk and responsibility (Moore et al., 2009), has had a concrete impact on bioscientific practices in the US and UK. This is evident through the privatisation of biotechnology, the commercialisation of life processes and the establishment of rigorous patent laws to secure intellectual property (Lave et al., 2010; Moore et al., 2009). The growth of post-Fordist modes of production, at least in the Global North, saw a rise in innovation-driven models of growth in which bioscientific discoveries took centre stage. In the US, Reagan-era science policy incorporated massive cutbacks in government services, most notably public health, and witnessed large-scale public investments in new technologies as well as their commercialisation (Cooper, 2008). The Bayh-Dole Act of 1980, for instance, facilitated university ownership of intellectual property; more and more universities began to hold patents and cooperate with private companies to develop new products based on their findings. In the UK, Thatcher's market-driven ideologies meant a 25% cut in project grants, and the value of scientific research was increasingly measured by its potentials for commercialisation and profit maximisation (Noble, 2013). The tenets of neoliberalisation deeply permeated scientific practice, increasingly determining how research targets were defined, where research was conducted and who was to benefit from its results (Loepky, 2004).

Not merely coinciding with the advent of neoliberalism as a politico-economic project, discussions in Science and Technology Studies have argued that the development of the contemporary biosciences and neoliberal political economy are mutually constitutive. Melinda Cooper, for instance, notes that neoliberalism and the biosciences stand in a productive dialogue with each other, reworking the relation between life and debt and pushing the boundaries of both economic and biological productivity (2008: 10). Following Foucault's assertion that the development of the modern life sciences and classical political economy need to be understood as intrinsically entangled phenomena, she demonstrates how the realms of biological (re)production and capital accumulation have jointly evolved. Cooper points to the ways in which the biotech revolution has emerged out of a series of "legislative and regulatory measures designed to relocate economic production at the genetic, microbial and cellular level" (2008: 19). Commercial processes have firmly expanded into the sphere of what Rose similarly calls "life itself", the increasing concern with "our growing capacities to control, manage, engineer, reshape, and modulate the very vital capacities of human beings as living creatures" (2006: 7).<sup>1</sup> In other words, the lab and the factory have become intrinsically interlinked; today, companies do not simply apply or market novel scientific findings but are themselves at the forefront of innovative research in the life sciences and beyond.

These entanglements illustrate how the molecular scales of the body have been opened up for scientific scrutiny as well as capital accumulation. The oocyte, the stem cell and the microbe have become the raw material of the capitalist production of value or, indeed, of "biovalue", defined as the "yield of vitality produced by the biotechnical reformulation of living processes" (Waldby, 2002: 310). More broadly, biovalue refers to the ways in which vitality has become a potential source of value, extracted from the very vital and self-reproducing properties of human life. As Catherine Waldby (2002) argues, there are two incentives for the creation of biovalue. The public incentive is motivated by the hope that new technologies will unearth some kind of viable contribution to health, or use value, from human tissues. The vitality of the stem cell, for instance, is charged with lessening debility and the improvement of overall well-being (*ibid.*). The second, commercial incentive, aims at the creation of

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<sup>1</sup> Of course, we must not overemphasise the novelty of these phenomena. The very development of capitalism has been premised on the insertion of life (human, animal, plant) into the capitalist mode of production, and the adjustment of "the phenomena of population to economic processes" (Foucault, 1998: 140-1), but due to the limited scope of this paper, we cannot address the question of whether biocapitalism is truly a novel phenomenon or an intensification of existing processes of accumulation.

exchange value from human materials, producing biological commodities that can be bought and sold. Profitable drugs and medical devices are only one example illustrating the bond of scientific knowledge creation and its commercialisation.

Ironically, the focus on the molecular qualities of the human body, alongside its commercial appeals, has also reinvigorated the idea that human biological difference can be defined along racial lines. Despite the findings of the Human Genome Project that human beings share 99.9% of their genetic code with one another, the 0.1% that distinguish us have rapidly been translated into human variation that neatly maps onto what have previously been understood as races. Despite Gilroy's hope that though "Genomics may send out the signal to reify 'race' as code and information, [but] there is a sense in which it also points unintentionally towards 'race's' overcoming" (Gilroy, 2000: 37), race has been firmly re-established as a meaningful marker of human variation (Fullwiley, 2007; Roberts, 2010; Whitmarsh and Jones, 2010). This interest in racial difference at the level of DNA cannot, of course, be attributed to the racist assumptions of bioscientific research alone but must be located on a complex grid of scientific, economic and political objectives. The use of social groupings to define sample populations mandated by policy and often stemming from genuine concern over racialised health disparities by both politics and activism; the incentives generated by the patent system; and the commercial appeals of racialised niche-markets, as we will explore, have all significantly contributed to the re-establishment of racial classifications in the life sciences. Through a constant "back and forth between physical world referents and social structure", as American sociologist Duana Fullwiley (2007: 8) puts it, race has been reified as an organising principle not only of society, but also of nature. Today, bioscientific practices of recruitment, storage, organisation and reporting, as Fullwiley argues, firmly rely on population differences described as racial.

Reaffirmed as existing at the molecular level and moulded with social and political concerns, race has therefore also opened up myriad possibilities for commercialisation. The well-rehearsed story of the making of BiDil, the world's first so-called ethnic drug (Inda, 2014; Kahn, 2012; Pollock, 2012; Roberts, 2011), is an indicative but not isolated example. Overall, 26 drugs approved by the US Food and Drug Administration (FDA) between 2008 and 2013 report potential ethnic and racial difference in the labelling (Ramamoorthy et al., 2015). Genetics company Myriad Genetics has modified its patent related to the testing of mutations of the breast cancer gene BRCA2 specifically to Ashkenazi Jewish women (Abbott, 2005). In

the realm of stem cell science, as we will show, public stem cell banks are increasingly looking to recruit ethnic and racial minorities to improve their chances for a suitable match, but also to realise economic benefits. In short, not only do new biotechnologies read race at the minuscule level of DNA, but the very vitality of racial minorities has become a potential source of biovalue, fuelled by both the hope for actual improvements in racial health disparities and the incentive of creating exchange value out of racialised tissue.

### **Racialised bioscience: Drug trials and stem cells**

In the remainder of the paper, we demonstrate how, in our two empirical vignettes of the clinical drug trial and the public stem cell inventory, bioscientists and recruitment agencies shuttle between social identities and biological processes by appealing to future participants' and donors' sense of responsibility for their respective communities in the hope for tangible economic benefits. However, we also argue that the value located in racialised tissue cannot be measured in economic terms alone but is equally driven, as Waldby puts it, by the wish for an "improvement in functioning and well-being" (2002: 310). Whether or not the bioscientific practices we discuss are suited to meet this aim remains, of course, highly contested.

To situate this discussion, the following section briefly introduces our two vignettes to provide some context to these bioscientific projects. Both are taken from our respective PhD projects in which we have, in our own ways, explored different aspects of racialised bioscientific practices. (Author's name removed) has, in her qualitative study of the convergence of postgenomic bioscience and clinical trial outsourcing, interviewed 42 scientific experts and policy makers working for multinational pharmaceutical companies, Contract Research Organisations (CROs) and regulatory authorities across Switzerland, the UK, India, Australia, Singapore, Hong Kong and the US. In addition, she has consulted a variety of published and unpublished materials such as company reports, proceedings of scholarly conferences, interviews with key actors in popular magazines and scientific journals as well as media representations such as the *I'm in* campaign analysed in this paper. (Author's name removed) research included analysis of key public-domain material produced by national and international charities and non-profit organisations, including UK charities involved in encouraging minority ethnicity stem cell donation. Other outputs from the UK's Department of Health and the UK's parliamentary All-Party Parliamentary Group on Stem Cell Transplantation were also analysed. The All-Party Parliamentary Group was used to locate 19 interviewees for qualitative interviews with those involved in the production of policy relating

to the UK's public stem cell collection arrangement. These individuals included stem cell banking personnel, recruitment and collection personnel, clinical professionals, health activists and policy-makers. In the case of both projects, most interviews were recorded and transcribed, and all materials were coded and memoed using the qualitative data analysis software NVivo.

### *The Clinical Drug Trial in the USA*

The concern over ethnic and racial variability in drug research, understood as both intrinsic (genetic) and extrinsic (socio-cultural, environmental) differences, has resulted in what Steven Epstein (2007) has called an “inclusion-and-difference paradigm”, the simultaneous inclusion of minorities and their reproduction as biologically distinct. While there is no coherent definition of the terms racial and ethnic – races *tend* to be defined as sharing biogenetic characteristics or geographical origins, and ethnicity *usually* refers to a social group with shared cultural values and lifestyle patterns (Ramamoorthy et al., 2015) – this new approach in science policy aims at “the inclusion of members of various groups generally considered to have been underrepresented previously as subjects in clinical studies; and the measurement, within those studies, of differences (by sex, race, ethnicity, and age) with regard to treatment effects, disease progression, or biological processes” (Epstein, 2008).

The growing awareness of ethnic and racial differences culminated in the National Institutes of Health (NIH) Revitalization Act in 1993, a piece of legislation that made the inclusion of women and ethnic minorities mandatory for all NIH-funded studies. The Act sought to ensure that clinical trials were designed in a way that allowed separate analyses of whether the variables under study affected women and ethnic or racial minorities differently than the hitherto largely white, male, middleclass and heterosexual body as the standard of biomedical research (for a more comprehensive genealogy of the Act, see Epstein, 2007). As critics of the new policy, and of the renewed focus on race more generally, have warned, conflating bureaucratic and scientific categories of difference has given race new salience as a biological rather than a social unit of analysis, potentially opening up a return of eugenics ‘through the backdoor’ (Duster, 2006; also Bliss, 2012; Epstein, 2007; Fullwiley, 2007; Roberts, 2011).

Over two decades after the Act, the recruitment of racial and ethnic minorities into clinical trials has remained a central focus of state-sponsored biomedical research and regulatory



approval. A recent study by researchers at the University of California at Davis found that racial and ethnic minorities constitute less than 5% of trial participants, with less than 2% of cancer research focusing on cancer subtypes disproportionately affecting minorities (Moon et al., 2014). A leading NIH expert on inclusion policies interviewed for this research confirmed that there is “a kind of re-emergence of that [the Revitalization Act]...we’ve been under a lot of effort over the past year or two to enhance the rigour and reproducibility of NIH results and NIH research. And one piece of that has relevant biological variables like sex or age or other factors [like race and ethnicity]” (interview with the author). Despite concerted efforts to improve minority representation, she admitted, these have so far failed to achieve their objective of a more equitable distribution of the burdens and benefits of clinical research.

Responding to such enduring inequalities in biomedical research participation, the US Pharmaceutical Research and Manufacturers of America (PhRMA), representing the country’s leading research-based pharmaceutical companies, has joined forces with the National Minority Quality Forum (NMQF), an educational organisation dedicated to improving health care for racial and ethnic minority populations, to encourage minority participation in clinical trials. In 2014, they launched their campaign titled *I’m in*, consolidating existing efforts to increase diversity by individual companies and charities, and push for greater awareness of clinical trials as tomorrow’s medicines. The campaign aims at reaching African American, Asian American and Hispanic communities which, according to latest estimates, make up only 5%, 1-2% and 1% of all clinical trial participants despite representing 12%, 5% and 16% of the overall population respectively (PhRMA, 2014; for a critical discussion of the well-founded refusal to participate in studies see Benjamin, 2016).

The campaign’s short recruitment video shows a young, male, African American runner, jogging on a tree-lined and picturesque country road. A male voice-over narrates as lines of text fade in, detailing differential health risks for minorities and their marginal involvement in clinical trials. As the camera tracks the runner, the narrator describes how biomedical science is actively researching innovative medicines to solve these disparities through clinical trials. Suddenly though the runner begins to slow, his once effortless gait now appears laboured, and he is overtaken by another runner. The camera zooms in with a close-up on the actor’s face and the narrator returns to inform us that something is missing from this life saving project: “you”. A group of other, racially diverse joggers begin overtaking him; with each passing and racially marked jogger, an accompanying text offers more information about that specific at-

risk population the jogger supposedly represents. For example, as a young Asian woman steadily jogs past, we learn that “only 2.8% of cancer clinical trial participants are Asian American” (0:58:00) Ultimately though, the runner rediscovers his stride and, smiling proudly, triumphantly leads the group while the campaign’s slogan *I’m in* appears.

The video, akin to the campaign as a whole, directly links identity politics and phenotypic representations with differential disease risks and genetic constitutions, as discussed earlier. Racial and ethnic identification are presented as constituting different biological properties that signal heightened susceptibility for a specific disease or adverse drug reaction. As other critics have warned, by rendering scientific and bureaucratic categories of difference functionally equivalent, racial and ethnic categories are firmly re-established as meaningful markers of human variation at the level of DNA.

Drawing on such geneticised understandings of racial groupings, specific Contract Research Organisations (CROs) have specialised in the recruitment of racial and ethnic minorities. Private firms such as Bridge Clinical Research brand themselves as “the premier clinical research organization dedicated to providing all your diversity research needs”<sup>2</sup>, or promise to “end health disparity for Latinos, African Americans and women in the USA”<sup>3</sup>. A distinctive regime of, as Epstein has called it, “recruitmentology” re-emerges as an auxiliary science which “evaluates the efficacy of techniques necessary to get bodies into a trial in the first place, and to keep them there throughout the life of the experiment” (Epstein 2008: 803). Ironically, demands for greater equity and representation codified in the Revitalization Act have also made the hunt for racialised bodies into a lucrative industry. A pharmaceutical executive at a multinational drug company interviewed for this research notes that “the FDA tells me in my previous clinical trial, I didn’t have adequate representation of African-Americans. So what do I do next time? I go to Georgia, or places like that, where I’ll have more chances of getting some African-Americans”. ‘Places like that’, that is, places worst affected by enslavement and its contemporary legacies, have become attractive locations for drug companies seeking to increase their representation of ethnic and racial minorities. This demonstrates the economic potential pharmaceutical companies locate in racialised and impoverished Americans, if not for the production of race-specific products, then at least for

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<sup>2</sup> <http://www.bridgeclinical.com/>

<sup>3</sup> <http://www.lanzargroup.com/count>

ensuring the approval of pharmaceuticals for the general population by a regulatory body eager to redress existing discrepancies. Whilst, at first sight, pharmaceutical companies' strategies targeting the bodies and spaces most scarred by centuries of racism and its contemporary legacies appears to carry forward the long history of racial exploitation, we contend that the logics at play here cannot be fully captured by such lines of argumentation. We will provide a more comprehensive analysis after briefly considering the case of the UK public stem cell bank to draw out important analogies and differences.

### *The Blood Stem Cell Inventory of the UK*

The UK's public blood stem cell inventory comprises both the nation's bone marrow registries and umbilical cord blood banks, and acts as a window through which UK-based transplant clinicians might locate stem cell tissue for patients requiring a blood stem cell transplant (Anthony Nolan 2015). This inventory operates partly through revenue from the state, but also on the sale of its stem cells to requesting health services. For example, in the UK an individual umbilical cord blood (UCB) unit might be sold for around £17,000 either to a UK NHS hospital or to a foreign hospital. Likewise, UK NHS hospitals might purchase units from abroad if they cannot find a suitable one in the UK (different inventories charge different amounts). Elsewhere, Williams (2015) has explored how these economic mediations are important in understanding why and how the UK's public inventory is trying to develop itself as a self-sufficient provider of stem cells that will eventually preclude foreign (and potentially expensive) import.

Race plays an important role in these mediations. It is understood that each individual's cell surfaces are composed of various proteins or alleles—our own tissue type. This is how our bodies determine which matter within us is our own, and which is potentially harmful and therefore in need of rejection (Erlich, 2012). Individual cell composition is directly related to one's parentage, which is why most transplants take place between related individuals like siblings. When an appropriate related donor cannot be found for a patient however, clinicians can use resources like the UK's stem cell inventory where a large pool of stem cells may be searched for tissue with cell surfaces as similar to the patient as possible (Brown and Williams, 2015).

Scientific understandings of this process invoke an explicitly racialised register of language. As explained above, stem cell inventories rely on locating similarity between bodies that are not related. Through the development of immunological and population genetics research

through the 1960s and 1970s, it is now understood that particular allelic structures of cell surfaces (the basis of locating a suitable donor for oneself) are more frequent in certain ‘populations’. This understanding had a profound impact on early transplant science (Thomas, 1994; Williams, 2017a), such that the notion of race often becomes interchangeable with genetic population in this scientific community; as with the pharmaceutical drug trial, categories of difference used in scientific and social practice are rendered equivalent, reinforcing socially salient categorisations through the assertion of biological facticity, which can be mobilised, as we will see, to encourage minority participation.

Mirroring efforts to incorporate ethnic minorities into drug trials, there is an ongoing call to increase ethnic minority stem cell donation to the UK stem cell inventory. If a Black patient is indeed more likely to find a match from a Black donor, it *matters* that in the UK, the composition of the public stem cell inventory is saturated with self-identified white donors, but proportionally underrepresents non-white donors in relation to the UK population (see Anthony Nolan, 2015). Alongside this is the important issue of the NHS needing to avoid costlier interventions, like the importation of non-domestic stem cells. Ultimately, then, addressing what is seen as a dearth of Black donation stands to save more lives, and save money (Williams, 2015). This call has had significant uptake, with the UK’s stem cell inventory having a mandate since 2010 to actively increase UCB donation and stem cell registrations amongst minorities.

The effort to maximise acts of donation from minorities is, for example, instructive in where UCB is collected. As two individuals involved in the All-Party Parliamentary Group (APPG) on Stem Cell Transplantation described during interviews:

*“A petition went on in Manchester by the MP ... to have a collection site opened there and that’s why we’ve ended up in Manchester. Again, another place with lots of babies and good diversity.”*

*“...we collect at King’s...because King’s has a huge number of ethnic minorities...You basically target the region because that’s where there are lots of mothers of ethnic minority groups.”*

In the first quote, the interviewee explains that a collection site in Manchester is a rational choice not only because of the density of births – ‘lots of babies’ – but also the high numbers

of women coming from ‘ethnic minority groups.’ Echoing this, the second quote notes that King’s College Hospital (one of the London collection sites) is similarly attractive, with its catchment areas of Lambeth, Southwark and Lewisham, the three London boroughs with the highest density of Black residents, according to the 2011 census (Office for National Statistics, 2013). This focus on ethnic minority donors again reveals an acknowledgement of the perceived vital potential of their bodies, relatively rare as they are in comparison to white bodies. Such opportunities are thus seized to maximise opportunities for donation. This is perhaps most starkly evident in the account of another individual involved in the APPG. They described in an interview how there has been a:

*“focus on hospitals which have a high birth rate. Preferably a high birth rate of diverse ethnic mothers and that’s what we’re focused on. So Mrs Jones out in little Bollock-on-the-Wold going into her local maternity hospital? She doesn’t have access to that.”*

The hypothetical Mrs Jones resides in the fictional Bollock-on-the-Wold (reminiscent of the similarly hyphenated rural Cotswolds town of Stow-on-the-Wold). Mrs Jones – her whiteness inferred by one of the most common British surnames in the UK census (McElduff et al., 2008) and a rural (and thus predominantly white) residence (Parkinson et al 2006) – is not in the scope of ‘focus’. Instead, the focus is placed on hospitals where there are ‘diverse ethnic mothers’. Just like the multinational drug company explicitly focuses on Georgia to recruit African American research subjects, the UK stem cell inventory targets its donation in areas with more non-white people. Such a tacit acknowledgement of the precedence of non-white over white donors reveals how the vital potential of non-white bodies is recognised and tapped into through practical means.

### **Discussion: the value of racialised communities**

The construction of rarity in minority ethnicity is rooted in a particular and deeply problematic history. Richard Titmuss, author of *The Gift Relationship*, was attuned to it, cautioning his readers to remember the “contemporary world-wide phenomena of racial prejudice and its association with concepts of blood impurities, ‘good’ blood and ‘bad’ blood, untouchability and contamination” (1970: 20). However, as we have outlined earlier in the paper, we argue that our examples present almost an inversion of this logic. In both cases, the construction of rarity in racialised tissue stands to produce tangible economic benefits. In line

with the discovery of previously marginalised populations as sources for the creation of profit (Gilroy, 2013), the convergence of bioscientific interrogations of racial difference and market principles has conferred a certain value on race. But, in both cases, recruitment agencies and collection managers also attempt to combat the underrepresentation of minorities, focusing more intensely on those bodies previously excluded from biomedical attention and care.

Both vignettes illustrate how bioscientific practices deploy racialised minorities' collective social identities, drawing heavily on an affective repertoire of community responsibility to engage racialised groups in acts of participation and donation. Pharmaceutical companies, CROs, and organisations involved with the stem cell inventory aim to remind trial participants and stem cell donors of their collectivised responsibility towards one another. They thereby reframe the obligation of their racialised audiences as an ethical self-fashioning to eliminate health inequalities. For example, both the *I'm in* campaign and stem cell collection registries deploy community outreach workers and advocates, sometimes themselves former participants or stem cell recipients' family members, who explicitly use their racial identity to attract potential participant-donors. The *I'm in* website features testimonies of patients and participants such as the following by a nurse practitioner, who argues that in order "to get more people of color open and willing to participate, you have to have somebody who *looks* like them." Similarly, the bone marrow patient activist cited above acknowledges a need for his organisation, which encourages Black stem cell donation, to adopt a particularly 'Black mode of communication': "We're taking the generic message... and we couch it in a frequency, in a way that suddenly our people recognise 'now I hear you!'" In both cases, the delineation of 'our people', or of people 'who look like them' highlights how what Rogers Brubaker (2002: 166) terms "ethnopolitical entrepreneurs", specialists who live 'off' as well as 'for' race or ethnicity, work to attract participants or donors through affectively invoking a mutual objective qua shared racial identification.

Both projects foster a moral appeal to community that looks to create an active sense of solidarity with a community of suffering that has long been the subject of both biological damage and biomedical neglect (Inda, 2014; Nelson, 2012). Towards the end of the *I'm in* recruitment video, for instance, the unseen narrator emphatically appeals to the viewer's sense of responsibility for their own health and – crucially that of the identities actors and consumers presumably share: "It's not enough to wait for someone else to act. We all have a role to play. We all have a responsibility to each other, and future generations", he declares.

The campaign centrally draws on the neglected or wounded body as a powerful metaphor around which ethnic and racial minorities have historically organised (Nelson 2012), directly appealing to a sense of common responsibility. This point is also present in the case of public stem cell provision. Discussing blood donation systems nearly fifty years ago, Titmuss recognised the possibility “that because one’s blood is rare or unique”, an individual might be made to feel a “particular responsibility to make it available to others who may need it” (1970: 263). Although Titmuss was discussing blood rather than stem cell donation, the point is echoed in a quote from an individual involved in an organisation that encourages ethnic minority stem cell donation.

*... we are the vanguard of this movement of getting ethnic minorities, especially Black and mixed raced people to realise: take your health seriously, especially when it comes to cancers and especially when it relates directly to race. You need to be ready to try and help someone else because you never know when you might need it yourself ... That’s a very specialised message that’s got to be ... couched in a way that will resonate with families and mothers-to-be when they hear it.*

The militaristic inference of a ‘vanguard’ is suggestive of being on the frontline of a battle in bringing ethnic minorities to a realisation of the sharedness of their community and the mutuality of their responsibility toward one another. The participant puts this quite bluntly, stating that one must be ‘ready to try and help someone else because you never know when you might need it yourself’, drawing on the same tone of obligated reciprocity that underwrites the *I’m in* video campaign explored above. This obligation to others in the group must be ‘couched’ so that it will ‘resonate’ with the potential donors. This affective resonance is a central element in the augmentation of donation. Awareness raising is therefore not simply about highlighting the illness and the statistical probabilities of locating a match, but of highlighting potential donors’ responsibilities to their community.

In this sense, the reinforcement of biological affiliation and mutual responsibility serves to mobilise participating individuals to themselves encourage participation from others. Participant testimonials and patient activists might thus be read as evidence of individuals’ recognition of their own subjectivity. The techniques and languages deployed in our examples not only shape participants’ self-understandings vis-à-vis ‘their’ racialised communities, but

also activate their sense of responsibility for their fellow group members, while at the same time distinguishing themselves from other, non-group members predominantly in somatic terms. As such, this collective self-governance resonates with what Rose has termed projects of biological citizenship in which “biological senses of identification and affiliation made certain kinds of ethical demands possible: demands on oneself; on ones’ kin, community, society” (Rose, 2006: 133). Within this normative ethical framework, it is possible to participate and be a good biological citizen, or refrain and be a bad one. This logic also plays out in Ruha Benjamin’s (2013) analysis of African American sickle cell disease activism in the US: The community of a potential illness (sickle cell is cast unquestioningly as a ‘Black’ disease) is a powerful tool to mobilise action – and to castigate inaction. Just as there can be good and bad biological citizens, the refusal to express solidarity in the pursuit of a cure for sickle cell amounts, as Benjamin highlights, to a kind of ‘civic defection’. Amongst Black donors and recipients, or participants and future consumers, made into a community because of the allusion to their cellular compatibility, to not participate is anathema. Likewise, in our own examples, minoritised peoples are compelled to engage in helping to improve or even save the lives of others in their communities qua their historical relationship through shared suffering.

Despite their progressive intentions, we find these appellations to a particularly racialised obligation to participate or donate to be highly problematic. They affirm the legitimacy of groupings based on biological understandings of race, breaking with the trend towards personalised treatment based on the calculation of individual risk factors. As other critics have warned, deploying race-based markers in the ‘meantime’ between today’s one-size-fits-all model and tomorrow’s practice of personalised medicine risks reconfiguring race from a rather crude proxy for genetic variation to an increasingly viable, and widely used, placeholder (Kahn, 2012). At the same time, the practices in our examples also appear to incentivise responsibility only within one’s racial group, racialising the responsibility to donate itself. Such attempts amplify, as Kierans and Cooper (2011: 14) note, “the idea that donation is the collective responsibility of biologically, socially and culturally distinct and distinguishable communities”. As projects of biological citizenship, they not only proclaim membership to particular biological groups but also demarcate non-membership. Consider, for example, this excerpt from a media interview with campaign co-founder and NMQF CEO Gary A. Puckrein: “If people who don't look like you aren't in clinical trials”, he notes, “when the time comes we’ll be playing Russian roulette with your health because we don’t have the



science” (Colliver, 2014, emphasis added). Illustrating not only the superimposition of identity politics and genetic variation, Puckrein also suggests it is only people who share phenotypic representations that can exercise care towards, or stand in a reciprocal relationships of responsibility with each other. Patients who do not ‘look like’, that is, racially identify with the minorities portrayed in the video, are exempted from their responsibility to enrol themselves in clinical trials for the next generation of patients-to-be. This suggests a particular, racialised dimension of the “responsibilization” of and through neoliberal markets (Shamir, 2008).

The centrality of particular groups also speaks to how in neoliberalism, the discourse of community directly feeds into the operations of capitalism. Writing against ‘the romance of community’, Miranda Joseph argues that the modern creation of identity-based communities directly benefits capitalist production. The “indeterminateness of capital”, she writes “its openness to determination by use-value, is an opening to ‘community’, to determination by social relations and ‘values’ in exchange, production and consumption” (2002: 14). The neoliberal utilisation of diversity, for her, is a direct outcome of this discourse of community that today is no longer centred on a specific national but on various social identities. The production of economic value is predicated on the production and consumption of community, and often particular racialised communities, as we aimed to illustrate through our empirical examples. In both our vignettes the narrative of community responsibility functions as a regime through which racialised communities are invoked for the creation of new markets in human tissue. These communities are thereby actively (re)produced as racial through the somatic connections established by the scientific reification of racial categories. While immediate commercial incentives can be more clearly located in the case of clinical drug trials, public stem cell banking initiatives, as Nik Brown (2013) notes, also take on substantial symbolical *and* economic attributes in their constitution as systems of exchange value – not least because these stem cells are bought and sold potentially internationally by public and private health providers for their patients (Williams, 2017b)

The highly affective efforts to cultivate attachment between the participant-donor and their obligation to a particular racialised community exemplify the ways in which the creation of such communities is central to the creation of value, in the double sense of tangible profits to be derived and the social values to be realised. The potential economic surplus (we emphasise *potential* as both pharmaceutical development and stem cell banking are highly speculative

practices in that they could well never lead to a new drug or an actual tissue transplant) cannot be disentangled from the social values of accessibility of care, amelioration of health inequalities and improving quality of life. The generation of economic value in health markets is always also tied to the cultivation of vitality and well-being (Rose, 2006; Inda, 2014; Waldby, 2002). In other words, despite their racialising functions, we locate both stem cell banking and drug trials at the life-affirming pole of twenty-first century biopolitics (Rose, 2006; Rabinow and Rose, 2006). Though they are firmly embedded in market frameworks and the pursuit of profits, the vital politics exposed in our examples also aim at nurturing and extending rather than limiting life at the genomic level.

Through the scientific work of locating racial or ethnic, read, genetic ‘populations’ who might find their tissue match from another within that population, we simultaneously witness the assembling of a public with all its “symbolic and discursive appeal” (Hinterberger 2012: 530). This invocation of a public has more than one purpose. The *I’m in* campaign seeks to engage participants in a project that could produce new pharmaceuticals and thus profit for private drug companies. But the engagement, often fuelled by political incentives, also has the purpose of *maybe* saving the lives of some individuals in the community the participant is reaffirmed as existing within. Likewise, the public animated in the stem cell case is engaged specifically with the purpose of participating in a medical effort to save lives of patients needing transplants. Implicit in this is the requirement of a struggling health service to ensure the treatments that are commissioned are affordable. A domestic stem cell unit is likely to be much cheaper than an imported one, and mobilising a public seeks to make the domestic stem cell inventory more able to serve UK clinical requirements.

This highlights, for us, how these different tenors of value, economic and ethical, are co-constituted. The profits portended by drug development, and the savings anticipated by domestic stem cell provision, cannot be understood without the more ethical framing of value as the capacity for these drugs and stem cells to become lifesaving medical interventions, particularly for racially marginalised bodies and groups. In the life sciences, value itself does not only imply material valuation by the market but also suggests a genuine concern with the meanings and practices of ethics (Rajan, 2006). Far from obfuscating the bare economics of exchange that contemporary bioscience entails (Birch and Tyfield, 2012), we argue that the intangible mobilisation of responsibility towards one’s community and the evocation of an ethical self-fashioning sit at the epicentre of value production vis-à-vis racialised biological

difference. The value produced here cannot be viewed purely through the lens of life's commodification, but also its improvement and extension.

Of course, though, such goals as the improvement and extension of life are important to scrutinise. This is particularly so in the two contexts we have analysed in this paper. In the US, the Affordable Healthcare Act hangs perilously in the balance, with the mooted replacement legislation ready to increase the number of those without basic health coverage by some 22million (Congressional Budget Office, 2017). The UK's National Health Service, beset by political demands to become more 'sustainable' in the context of a slowing rate of growth in its funding (King's Fund, 2017a), is regularly described as in crisis, with increased waits for treatments (King's Fund, 2017b). It is in the shadow of this state of affairs that Benjamin's words about investments in biological research are insightful. One can sense, she aptly suggests, a 'social dissonance' in investing money in experimental research (we might also extend this to relatively rare treatment protocols like stem cell transplantation) when so many in the US (and we might extend this to the UK) struggle to access more basic forms of healthcare. The focus on rarer treatments and speculative research is "comparable to sweeping up broken glass while the more pressing flames ... are left to wreak havoc" (Benjamin, 2013: 124).

## **Conclusion**

Examining two different bioscientific contexts, US clinical drug trials and UK public stem cell donation, in this paper we have suggested that racial difference stands to be highly valuable in the neoliberal bioeconomy. We have argued that this value cannot be purely understood as the commodification of racial lives though; rather, analyses need to be attentive to the social, medical and ethical registers enmeshed in value production. We have shown how the mobilisation of a discourse of mutual obligation within racialised communities, itself both tied to economic and moral imaginaries, functions as a central theme in attaching the participant-donor to a particular racialised community. Our analysis suggests that it is wise not to capitulate to the label 'commodification' in this scenario; though the term is befitting of those cases where an unabashed profit motive reveals itself, for the cases we have examined it would be analytically remiss to disentangle the projects' capacities for the derivation of capital from the health benefits that their strategic successes as private and public initiatives might unlock.

However, we suggest it is necessary, in the contemporary political moment, to critically interrogate a system that valorises the communities of Black folks while still firmly prioritising white folks in most other areas of life. As the case of BiDil, the first ‘race-specific’ drug, has made ironically clear, products or services targeted at historically disenfranchised groups may well fail to reach their markets because these groups cannot afford to buy them (Pollock, 2012). More destructive still, such efforts can quite easily distract from the larger, structural issues that condition the very racial inequalities and underrepresentation to which these solutions respond. The logic of fostering racial vitality through pharmaceuticals or other biotechnologies is not so obviously at work outside the clinic or lab where potentially profitable products may be derived. Again, Benjamin highlights this deep asymmetry between scientific and political life today, arguing that “our investment of both time and money in reengineering biological life far exceeds our collective will to transform *social life*” (2013: 176). The rise of the Black Lives Matter movement illustrates that establishing more equitable social conditions requires much more – of all of us – than participation in clinical trials and tissue donation. Analyses of how race is put to work for the production of value in biomedicine must be attuned to this political and social reality. Racialised bodies *do* matter in the lab and the clinic; beyond this domain, however, the value of these same bodies remains firmly in question.

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