Enactments of Race in the UK’s Blood Stem Cell Inventory

ROSALIND WILLIAMS

Department of Sociological Studies, University of Sheffield, Sheffield, UK

Recent sociological analyses of the intersections of race and science recognise race’s quality as an enacted object. Through this analytic lens, race is always materialising in the practices and processes that enrol it and therefore enjoys a kind of multiplicity. The context of blood stem cell transplantation, a scientific domain marked by a more and less explicitly racialised logic, offers an opportunity to see the conceptual assertion of race’s multiplicity play out. Indeed, an exploration of the UK’s stem cell inventory reveals—through analysis of interviews, policy and parliamentary meetings—how race materialises in the various practices that comprise this increasingly popular cancer treatment option. Looking at practices of recruitment, inventory management and tissue selection in particular provides an interesting window to look upon race and the many signifiers that implicate it. These cases reveal moments of race’s stabilisation and silencing; its oscillation between the status of vital information to the life of a public stem cell inventory, and of secondary data that provides little useful information to clinicians selecting tissue. Adopting an analytic lens that attends to race’s multiple enactments allows us to begin asking why enactments take the shape they do, and why the particular practices that mobilise them come to be.

KEYWORDS: bone marrow, umbilical cord blood, race, ethnicity, donation

Introduction

‘It’s incredible to think there could be someone on the register who is essentially your genetic twin.’ So said a UK stem cell donation charity spokesperson being interviewed in February 2016 (BBC News, 2016). They were talking about the small likelihood of being able to find a suitable stem cell donor for a stem cell
transplant patient. The donor would need an almost identical human leukocyte antigen (HLA) type to the recipient. The ability to speak of transplant at all is in no small part to the work of mid-twentieth-century immunologists like Jean Dausset, who discovered the first HLA in 1958. This triggered an effort to locate all the HLAs in the human body (Dausset, 1958). The donor’s HLA type is used to determine the suitability of a given unit of blood stem cells for the growing number of medical treatments that require transplantation of donor blood stem cells into the patient’s damaged immune system. The more alike the donor and recipient HLA, the better.

Normally, clinicians look to a patient’s siblings who may share an identical HLA type, and who might provide the stem cells required for transplantation. In cases where a sibling match is not possible, clinicians can turn to stockpiles of the ‘corporeal resource’ of stem cells (Brown et al., 2011). The two major stockpiles are bone marrow registries and umbilical cord blood (UCB) banks. The first, known as bone marrow or adult donor registries (herein, AD registries) have been in operation since the 1970s (see Pavlù et al., 2011). These registries retain HLA data of adult volunteers who may be called upon to provide cells at some point.

UCB banks are the second key resource for clinicians. After the first clinical intervention using UCB stem cells took place in 1988 (Gluckman et al., 1989), clinical scientists began collecting and storing UCB stem cells into ‘banks’. After the first was established in New York in 1993 (Rubinstein et al., 1995), the UK’s National Blood Service built its own UCB bank in 1995 (National Blood Service, 1997). Now, the World Marrow Donor Association (Petersdoorf, 2010) acts as an international standard-setting locus for banks and registries around the world, which clinicians can then search when looking for stem cells with HLA types compatible with their patients. In this paper I am interested in those moments in which a sibling match is not possible and an unrelated donor with an HLA type as similar to the patient as possible must be found.

Sociological attention to blood stem cells has looked at the various moral and economic tensions at play in the contemporary landscape of blood stem cell banking (Waldby, 2006; Dickenson, 2007; Martin et al., 2008; Waldby and Cooper, 2010), but these interventions have not focused on a crucial feature that figures centrally in this context: namely, ‘race’. In this paper, I want to ask, after Amade M’charek (2013), how race is variously enacted in the context of stem cell transplantation. How does it figure in the constitution of the stockpiling of stem cells—the very structure of AD registries and UCB banks? What shape does it take in reference to locating matches between donors and patients? What is the form of race when donors are asked to identify themselves? The asking of these questions relies on a conceptualisation of race as something beyond fact and fiction, but as an object that gains and loses visibility and traction through the practices of those who mobilise it.
To answer these questions, then, I explore a number of practices from the blood stem cell banking context: the recruitment of donors and the tools used to capture their ‘ethnicity’ data; the manner in which blood stem cell collection is strategised around comparing donor ethnicity information with census data; and some of the complexities of selecting tissue from AD registries and UCB banks for transplantation and how race figures in this practice. Looking at these different practices reveals race not as a singular thing but as a multiple object, taking on different shapes with the various practices that enact it. Through this, I seek to demonstrate how—even in the singular context of blood stem cell banking—the various practices that constitute it enact race in various ways. Thus, race is never just one thing, but has a quality of multiplicity to it, within, as well as between the particular contexts in which it emerges.

Analytic Perspectives: Theorising the Multiplicity of Race

A recent turn within the sociological study of race has been towards a more pronounced focus on the practices in which race appears in more and less recognisable forms. Significant work has been undertaken in trying to explain why it is that race sometimes feels like it is present in a context without being explicitly referred to (Wade, 2014; Schwartz-Marín and Wade, 2015). This literature suggests that the language of race is not simply being semantically sidestepped because of its historical and political baggage. Rather, the world of referents that hint towards race—for example, ‘population’, ‘ethnic group’, ‘ancestry’ and so on—speak to race’s multiplicity (M’charek, 2013).

That is to say, explicit and implicit acknowledgements of ostensibly racial logics of human difference take lots of shapes. This entails methodological and ontological implications both in how to find race (i.e. how are we to know when we have come upon race, and not something else), as well as in how to acknowledge race as an object that is enacted. Just as race can materialise as an object of concern, so too can it dissipate. To follow these moments necessitates us not to settle into a critical binary of existence versus inexistence. I explore these issues below to provide a conceptual foundation for the analytical work that follows.

Finding Race

One of the most striking things I found in beginning the project I discuss in this paper is how race felt like it was always there, and yet nobody really used the term. The point of race’s multiplicity resonates with recent conceptual discussion about scientific uses of race in the European context. Race in Europe has become something of an absent presence. It is at once something that people are not comfortable discussing, but which is central to public policy and different forms of personal, political and scientific practice. Race ‘oscillates between reality and
nonreality, because it is not a singular object but rather a pattern of various elements, some of which are made present and others absent’ (M’charek et al., 2014, p. 462).

M’charek et al. go on to suggest that the absences and presences of race in these different moments of oscillation are vital to recognising and to better understanding the variegated work that race is put to.

The absent presence issue, though, throws up something of an analytic challenge that we can frame as something like: when do you know you are looking at race, and not something else? This problematic sits at the heart of Peter Wade’s discussion, in which he suggests that there tend to be two give-aways that should alert us to the presence of race, even if the word itself is not being used:

What allows scholars to know when they are encountering something called race is a combination of these two features: a reference to a specific set of categories, located in a changing colonial history and geography, and an idiom of nature (bearing in mind the variable character of that concept) and more specifically ideas of heredity and transmission (bearing in mind these are historically relative). (2014, p. 592)

We can know race, he thus argues, but allusions to categories—the racialised apparatus of classification which, as Ian Hacking (2005) notes, sits at the heart of colonial practices of control. The ‘idiom of nature’, too, is key here, recognisable in the mobilisation of heredity. When people suggest that difference is biologically transmitted through generations, Wade argues, we can know that race is near. In this sense, like smoke implies fire, one can smell a racial logic in the mobilisation of terms like ‘ancestry’, which requires us to locate ourselves both spatially and temporally as individuals heralding from a certain place and point in time (Kahn, 2015).

My initial confusion that words like ‘ethnicity’ were everywhere and race nowhere made more sense, too, in light of the history of transplantation science, which is shot through with geography and heredity, but far less so with direct discussions of race. Mid-twentieth-century immunologists, busy working on tissue transplant treatments for leukaemia, were entertaining the idea that a human might have a particular expression of antigens across all their cells that could be either more or less compatible with another person’s body (Thomas et al., 1957; Ferrebee et al., 1958; Thomas et al., 1959).

It was the advent of ‘a deeper understanding of the molecular meaning of individuality’ (Anderson and MacKay, 2014, p. 117) based on distinguishing the autologous from the allogeneic, derived from the Greek autós (self) and állos (other). This distinction is still central to transplantation science and, according to a recent consensus paper, our HLA types are a combination of those of our parents (Erlich, 2012). Parentage and, through this, heredity are accordingly considered to be pertinent in the developing consensus around how tissue transplant practically works.
In the 1970s, immunologists and population geneticists began working together, becoming ‘obsessed with mapping patterns of HLA expression around the world’ (Anderson and MacKay, 2014, p. 129). In one well-known textbook from the field, scientists explain that some HLA alleles are ‘absent ... in East Asia and the Americas, Australia, New Guinea, and the Pacific islands and are therefore common only in Eurafrika (Africa, and Europe ...’) Still others that are ‘relatively rare in most of the world’ crop up in Australia and the surrounding islands, whilst other alleles reach their ‘highest frequencies in America’ (Cavalli-Sforza et al., 1994, p. 130).

Cavalli-Sforza et al., however, were reticent to speak of races exploring, at the start of their book, the ‘scientific failure of the concept of human races’ (1994, p. 19). Here, they noted that ‘The word “race” is coupled in many parts of the world ... with considerable prejudice.’ Fine-grained scientific analysis suggests finer gradients to distinguish between ‘clusters’ and ‘populations’ of people, the authors argue. A colour-coded map on the front cover depicts the spread of genetic difference around these clearly defined spatialities of the globe. Race as a term is disavowed whilst its signifiers (geography, heredity, classification) are still there. As Fausto-Sterling notes of scholarship that speak of and visually depicts human difference but does not say the word race—‘it stares out at us nonetheless’ (2004, p. 9). This is a point I have highlighted elsewhere in work mapping out the institutional context of UK stem cell donation in which overtly racialised language gets interchanged with descriptions of ‘genetic diversity’ as if they were metonyms (Williams, 2015).

In stem cell transplantation science today, the word race is often avoided altogether. Words of specific groups, like ‘Black’ or ‘Asian’, are common in the UK context to denote specific populations. This resonates with Catherine Bliss’ (2011) exploration of the conceptual slippage of racialised language in her systematic literature review of the use of race in genomic research. That these slippages exist reveals how these terms are not simply ‘out there’, but are always fashioned by us (Morning, 2014).

To speak of the HLA frequencies of Europe, for example, one might easily slip into speaking of Europeans which could have several synonyms. If you are ‘European’ in one instance, you could be ‘Caucasian’, ‘White’ or ‘Caucasoid’ in another even though each permutation bears a different etymology and application, not unsurprising given the intensely contextual nature of how we name and divide ourselves (see Hinterberger, 2012a). As readers will note below, other terms like ‘population’, ‘minorities’ or ‘ethnicity’, are called upon by interviewees to articulate those groups that can be differentiated by the likelihood of having particular HLA frequencies.

A term like ethnicity, argue sociologists of race Carter and Dyson, allow scholars to discuss fixed qualities in people ‘without using disreputable notions of race’ (2011, p. 966), whilst others suggest the notion of ‘ethnic minority’ carries with it its own baggage of racialising and racist consequences (see M’charek et al., 2014).
More than this, though, there are particular continuities between these different terms that give off the scent of race. In Peter Wade’s words, we can ‘detect when a discourse or practice that is not explicitly racial acts in a racializing way’ (2014, p. 588). For him, as for others (see Fujimura and Rajagopalan, 2011) combinations of human biology and geography (like that which we see in stem cell transplantation) share clear resonances with more familiar racial categories.

As such, I avoid participating in ‘the intricate and ever-recommencing definitional casuistry’ that Rogers Brubaker locates in scholarly commentaries on race and ethnicity (2004, p. 11). My suggestion here is that one need not use the word race (indeed, as we have seen above, some might actively not use it) to refer to the notion of biological heredity that we might recognize as racial. Indeed, it is perhaps even more important to seek out and interrogate race when it, to use Wade’s language, ‘hides in racialized concepts’ like ethnicity or population (2014, p. 594) given, the political tendency towards coding race into less problematic terminology that implies—without actually saying—race (Solomos, 1989).

Enacting Race

Having laid out what I mean by race as something that cannot necessarily be captured by the word, but which often is embedded in other racialised concepts like ethnicity, I want to flesh out the analytic attention I give to race as something enacted in various ways to different ends. It is useful here to mention Annemarie Mol’s ethnographic work on atherosclerosis, a disease that she argues takes on different permutations in different treatments, specialties and places. Her overarching point is that objects such as disease ‘come into being—and disappear—with the practices in which they are manipulated’ (Mol, 2002, p. 5). Her influential contribution to what she describes as medicine’s ontological politics, is instructive in how Amade M’charek develops her conceptual understanding of race.

In M’charek’s formulation, race is, just like disease, a contingent object that emerges through various practices. Its meanings and enactments are not stable, but multiple. For her, race is neither existent nor inexistent and, indeed, she eschews the common binary in which race is either a fact or a fiction, suggesting it simultaneously is both fact and fiction, in the sense that it does not have a singular location beyond the networks and practices that produce it. Rather than being ‘out there’, race is a ‘relational entity enacted “in here”’ (M’charek, 2013, p. 421). Different enactments produce different objects that do not necessarily look like one another.

Attending to the various enactments of race, as I seek to do in the following section of the paper, is a key way of showing how race, given its slippery multiplicity, cannot be forced into the positivistic box of provable biological fact, or explained away through social constructionism. We are better, as I seek to do
ahead, to plot out the practices through which race comes into focus and is—to use Mol’s parlance—enacted. Indeed, as M’charek notes, it is through the contrast of ‘different practices, that we come across different versions of an object—versions that do not easily add up to produce a whole and that may coexist in tensions or even clash with one another’ (2010, p. 309). Indeed, we can find interactions of the racial in which the word race is altogether absent.

The above conversation about finding race is entangled in the conceptual notion of enactment. Drawing on John Law, M’charek et al. note the increasingly ‘absent presence’ of race. State and institutional actors often seek to infer race (be they specific racial groups, or the notion itself) without actually using the word. Whenever race is mobilised in this more implicit way, it becomes impractical—perhaps impossible—‘to simply follow the explicit use of the race concept’. This highlights the need for analytic light-footedness in the sense of being attentive to moments in which biological heredity and human classifications which give off the scent of race, are folded into apparently less loaded terminology like ethnicity, population or otherwise.

M’charek analyses three cases—a near-diagnosis of Down’s syndrome, a murder case where suspects were identified through CCTV, and a thirteenth-century skeleton discovered and DNA typed who became the ‘face’ of a Dutch city. The cases highlight in a powerful way how race, so often black boxed as simply a locatable, biological ‘thing’ or an erroneous concoction of the social, is ‘made relevant and materializes in a variety of ways, from medical sensibility to legal arrangements and tactics in criminal investigation, to national identity and historic tie making’ (M’charek, 2013, p. 424). Taking my lead from this perspective, I consider how within one scientific context—blood stem cell transplantation—race again has a multiplicity of materialisations across a number of different moments, from recruitment of donors, to inventory management and tissue selection.

Its moments of enactment and silence—just some of which I want to trace here—are important in recognising that mobilisations of race in this context cannot be binarised as either fact/fiction, natural/social, existent/inexistent or—indeed—right/wrong. As Schwartz-Marín and Wade remind us, in noting the more and less malleable moments of race’s invocation, we do well to be attentive towards the ‘domains in which people are imagining and plotting relations of being and belonging’ (2015, p. 887). Race’s enactment in various contexts absolutely determines the shape it takes as an object and, indeed, the extent of its visibility.

Enacting Race in the Blood Stem Cell Inventory

The UK’s publically available AD registries and UCB banks are some of the most established in the world. The first AD registry was developed in the UK in the 1970s, whilst the UK was one of the first European countries to establish its own publically funded UCB bank. The network of banks and registries are
managed by a public body, the National Health Service Blood and Transplant Authority (NHSBT), and a charity called Anthony Nolan (see Anthony Nolan and National Health Service Blood and Transplant, 2014; Anthony Nolan, 2015). In 2014, governance of these different sources was combined into a single group, the Stem Cell Strategic Forum, which recommended shared funding and a more collaborative search mechanism across these geographically dispersed and managerially distinct entities. The period saw specific funding awarded by the UK Department of Health to this network of registries and banks, now called the UK’s ‘stem cell inventory’.

Empirically, the discussion I offer in this paper is informed by research undertaken between 2012 and 2015 which was granted relevant ethical approvals by the University of York, UK. The research included analysis of key public-domain outputs produced by national and international charities and non-profit organisations, the UK’s Department of Health and the UK’s parliamentary All-Party Parliamentary Group on Stem Cell Transplantation (herein, APPG). The APPG was also used to locate interviewees for qualitative interviews with those involved in the production of policy relating to the UK’s UCB collection arrangement (n = 19). These individuals spanned a number of different professional spheres, and included stem cell banking personnel, recruitment and collection personnel, clinical professionals, health activists and policy-makers. The span of interviewees across these different spheres reveals, as I parse through the following analysis, a number of distinctions and fissures between what race is useful for and how it is enrolled in various practices of the UK’s blood stem cell inventory.

**Basically Some Other Race—Race and Donor Recruitment**

In this first section, I explore how race materialises in the practice of donating stem cells. Specifically, individuals who want to donate are asked various questions, usually through a form that they have to complete. These questions include their gender, address, medical history and, via one term or another, some sense of their racial identity. A nice example of this is the ‘ethnic group’ classification scheme used by one AD registry and UCB bank (Anthony Nolan, 2013), which instructs the volunteer donor to ‘give the best description of your ancestors’ origin’ by ticking a box in a list of some 43 options under seven headings.

These headings are ‘United Kingdom & Ireland (White)’, ‘Europe (White)’, ‘Other (White)’, ‘Africa and Caribbean (Black)’, ‘Asia (Asian)’, ‘Other’ and ‘Mixed Ethnicity’. In bold, donors are asked to ‘Please tick only one’ option. One could not, for example, select both ‘Turkey’ (in the ‘Europe (White)’ section) and ‘Jewish’ (the ‘Other’ section). One could, however, select the ‘Mixed White & Other’ option from the ‘Mixed Ethnicity’ menu. Importantly, they also note that ancestry ‘is not necessarily your nationality’. This fascinating exercise where people are literally boxed into classifications based on their ancestry reveals a moment in which race is enacted with a certain amount of fixity.
A quote from a discussion with one of the individuals involved in designing the scheme is reproduced below. Here they provide a description of the meeting where it had been a topic of discussion. It reveals a significant amount of tension within the field about how much value lay in this ostensibly administrative tool. A particular tension apparent here is between different groups involved in recruitment, namely between the research scientists trying to guide recruitment practices, and the recruiters doing the practical work of converting people in adult donor registrants such as this interviewee, whose role is to encourage stem cell donation through national awareness campaigns and smaller donation drives across the country:

It was [the recruitment team] versus the researchers. We’ve got these major categories, and then we’ve got minor categories underneath them. So we’ve got mixed within each. British Irish, Asian, Northern European, and then mixed within that ... then we have also more major categories! And that was the bit where I was like ‘Look, we’re doing recruitment events here!’ ... In one of these meetings, we were talking about ‘what do you think is far enough back to get a true identity?’ and one of our medical people was like, ‘it’s grandparents’. I can’t run recruitment events where I say to people ‘where were your grandparents born?’ It’s just not feasible. That’s not the way that it works.(Adult donor registry administrator)

That racial classificatory schemes must be produced and agreed upon reveals in a very profound way Ann Morning’s point, in her exploration of the use of race in genetics, ‘that our categories are always ones that we fashion’ (2014, p. 1680). In this account, one’s ‘true’ racial positioning according to the scientist is somewhere in each person’s ancestral annals. A donor’s meaningful racial category can be pinned down with a box tick. And yet the above interviewee struggles with the impracticalities they see embedded in this scenario. They first describe with some exasperation the length of the form, explaining all of the different options and sub options within them. They also describe asking for guidance on ‘how far back’ into family histories they must venture.

One might see this as an attempt to understand how best to operationalise a nebulous term like ancestry which must be anchored down to a specific point for the purpose of data collection. This is an issue taken up by Jonathon Kahn who notes that ‘ancestry estimates implicate not only descent but also assumptions about time and space’—which is to say, mobilising ancestry requires one to decide when as well as where they are from (2015, p. 69). The answer, that they are best to ask people to think of their grandparents’ birth place, is seen as ‘just not feasible’, doubtless in part because recruitment events require the speedy conversion of many would-be donors into registered volunteers who would not necessarily know where their grandparents were born, or might not want to part with such information.
Tidy lists of ‘ethnic groups’ reveal race as a stable and durable object. This version of race ‘points in a different direction’ (M’charek, 2013, p. 423) from how the recruiter envisions the events where this form is deployed. This iteration is not feasible, its length and specificity renders it impractical to the work of recruitment. From the scientist side rather than that of recruitment, a similar amount of dissatisfaction with the manner in which the data are collected is apparent. Herein, they describe how different feelings and affiliations essentially get in the way of accessing the donor’s true race:

... it’s very hard to actually be sure that people know what ethnicities—in genetic ways—they actually belong to. You sometimes have the case that you have a great grandfather that was Chinese and due to that fact the whole family regards itself as being Chinese which is not necessarily true when all the other guys are basically some other race because after two generations, the racial indicator is gone ... then when people answer and say ‘ok, I belong to that ethnicity’ due to some cultural feeling which is not really reflected in their genes you get answers for the genetic way that do not necessarily really reflect the true ethnicity. (Data analyst at adult donor registry)

Tellingly, with reference to the vernacular slippage between different terms, this interviewee uses both the explicit language of race (‘racial indicators’) and ethnicity. Following Wade (2015), both terms here invoke the same racial logic of biological difference embedded in ideas of generational transmission. According to this data analyst, a person might struggle to ‘know’ their ethnicity ‘in genetic ways’. A great grandfather’s ethnicity is ‘not necessarily true’ for the generations that follow him because the ‘indicator is gone’.

There are threads of biological reductionism that might be picked up from this statement—particularly the idea that ‘some cultural feeling’ cannot be ‘reflected in their genes’ which equates to their ‘true ethnicity’. This speaks to an assumption that the social meaning of race is simply a misunderstanding of the actuality (i.e. the scientific meaning) of race. This is the view that ‘racial categories are what you get when social forces deform our apprehension of biological ancestry’ (Morning, 2014).

The jarring of the personal experience of race with this scientist’s view of what ‘true’ race is speaks to the complex intermingling of the different meanings attached to racial identity, and that scientists’ attempts to regulate ‘true’ race push against powerful familial and personal notions of identity. This is not to say that there are two versions of race—the scientific and the cultural—that can be, in different contexts, at odds and then in consensus. It is rather to suggest that the invocation of race need not be stable in either its meaning or its use.

Race—which appears deceptively stable when put into a list that permits only one selection—is not reducible to one thing. It is not always simply locatable in
one’s ancestry—this might be pinned down to grandparents’ place of birth, but even then, a person’s nationality, or a ‘cultural feeling’ might lead to an erroneous conclusion of race. Rather, race appears in this context as always ‘a configuration, an effect of relations between differences’ (M’charek, 2013, p. 435). The complex work of recruitment enacts race here as a stable, fixed entity that can be incorrectly communicated. And yet this conceptualisation of race sits uncomfortably next to the practical work of recruiters who do not necessarily have the luxury of tracing family histories, seeking out and challenging people’s racial affiliations.

Lots of Babies, Good Diversity—Race and Inventory Management

Stem cell donor recruitment reveals a rather complex materialisation of race. In the context of inventory management, race materialises in a very different way. Away from the context of individual donors who can confound data capture forms with conflicting cultural feelings, race becomes a descriptor of groups, a method through which to delineate different sections of the stem cell inventory. The practice of trying to measure the inventory in terms of race is done to give some sense of what the inventory contains now, and what it should aim to contain. This simultaneously produces race as a set of highly stable groups.

In 1999, 98% of UK stem cell registrants were classified as ‘European Caucasoid’ (Armitage et al., 1999). Looking towards the censuses on either side of this statistic reveals why the figure is so important. The census, itself noted as a conduit for the institutionalisation of racialised classification (see Hacking, 2005), is performed every decade in the UK and all households are obliged to complete it. The actual parameters of the UK population who are ‘white’ were 93% in 1991 and 87% in 2001. The 1999 figure of 98% white volunteer donors constitutes a clear skew.

As Brown et al. note, this is in part because AD registries enjoy ‘strong historical penetration amongst advantaged middle class blood donors but recruit less well beyond the mainstream demographic’ (2011, p. 1117). Many who are not from this mainstream (we might read, white) demographic are accordingly under-represented in the AD registry.

Since then, the composition of the registry has changed. Now, only around 76% of donors fall into the European Caucasoid category (Anthony Nolan, 2015). Why the change? Blood stem cell science has been caught up in a broader social discussion around health equity—that is, if recipients are more likely to match donors with similar ancestries, it is seen as incumbent upon this national health resource to provide a spread of ancestries to serve the various patients who might need them. This is evident in efforts to make the inventory more ‘representative’ in a bid to ameliorate health inequalities. Classifications like white, Black and Asian, have become a means through which one can measure whether or not the inventory ‘mirrors’ the public it serves.
This prioritisation is due to the contribution of large charities, like Anthony Nolan, and small charities working in tandem with them such as the African Caribbean Leukaemia Trust. Together, they have been trying to focus collection of AD volunteer details and saliva and blood samples in Black and Asian communities (see Merz and Williams, under review). But despite this, as of 2015, these groups remain ‘underrepresented’. This historic and continuing demographic deficit of individuals who do not self-identify as white on the AD registries in part explains the UK’s motivation to collect UCB.

Those professionally interested in UCB in the 1990s viewed it as having the capacity to penetrate particular demographics unaddressed by existing AD registries (Wagner et al., 1996). Indeed, UK policy explicitly highlights the role of UCB in addressing health inequality:

Patients from ethnic minorities are particularly disadvantaged. This is because HLA types are related to ethnicity and ethnic minority donors are underrepresented on registries...This impacts substantially on the prospects of ethnic minorities successfully locating a match...The banking of umbilical cord blood offers an opportunity to reduce this inequality. It is difficult to increase the representation of specific ethnic minorities on a volunteer donor panel, but considerably more practicable to focus collection of cord blood at hospital maternity units that serve populations with relatively high levels of ethnic diversity. (UK Stem Cell Strategic Forum, 2010, pp. 17–19)

It is instructive to pause and think specifically about how race is being enacted here as though it were a stable entity; ethnic minorities’ HLA types are ‘related’ to their ethnicity. Finding healthy ethnic minorities and placing their tissue into the inventory is an ‘opportunity’ to reduce inequality. During an APPG presentation on the composition of the UK’s UCB banks and AD registries, the speaker described ‘an element of underrepresentation on the larger registers [which] don’t necessarily...match the census data [on] the percentage of an ethnic minority in the UK population’ (APPG notes, September 2013).

The construction of a pie chart-like composition of the banks—so many white donors, so many Asians and so on—speaks to a particularly stable enactment of race wherein all Asian donors go in one sector, all Black donors in another. Here, we are not talking about fine-grained molecular analyses of HLA types, but simply of getting enough Asian and Black people in order to address the dearth of Asian and Black people. This becomes a game of probabilities playing out along distinct, racialised lines of difference. Maximising donations from particular groups heightens the chance of matches. This is not a question of specific donors, but of specific, raced groups of donors.

Emerging out of these accounts, too, is the importance of the specificity of the UK’s population. It should, for example, be noted that public funding sits behind
much of the public stem cell provision in the UK context, as well as the various practices I am exploring here—the funding awarded to Anthony Nolan and NHSBT was, for example, awarded by the UK state (NHS Blood and Transplant, 2011). In these accounts, we also see how the conceptualisation of a very ethnically diverse nation state produces a particular expectation of what the publically available stem cell collection should look like. This is an explicitly responsive effort, through purposefully inclusionary practices, ‘to concerns about the stigmatization and discrimination of groups’ (Hinterberger 2012b, p. 218).

Indeed, the inclusionary practice here is one of focusing UCB donation collection in specific places, a point I have explored in more depth elsewhere (see Williams, 2015). With the aim of redressing underrepresentation, it of course makes sense to question the spending of one’s resources on banking what are believed to be common, ‘white’ stem cells when there is a lack of rare, ‘minority’ stem cells that could be addressed through focused collection. A UCB collection coordinator, for example, described how ‘A petition went on in Manchester by the MP . . . to have a collection site opened there and that’s why [a collection site] ended up in Manchester. Again, another place with lots of babies and good diversity’ whilst an APPG contributor explained the decision to collect at a London site because it ‘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’.

The cities of Manchester and London are thereby framed as favourable collection sites because of the ‘huge number’ of ethnic minorities that live in them, a point that is explicitly highlighted in a central 2010 policy document:

Since 45% of ethnic minority individuals live in and around London . . . it follows that an ethnically diverse cord blood inventory may best be achieved by collecting cord blood units primarily from London hospitals with maternity units with over 5000 births per annum. (UK Stem Cell Strategic Forum, 2010, p. 35)

As is explained in this extract from the Stem Cell Strategic Forum report, commissioned by a parliamentary minister in 2012, nearly half of the ‘ethnic minority individuals’ of England live in London and its surrounding areas. To evidence this claim, it uses census data from the 2001 census (UK Stem Cell Strategic Forum, 2010). Through this, the collection managers attempt to focus more intensively on geographic areas with higher numbers of non-white people. By focusing in this way, their work actively excludes particular locations and the people in them. Being the rare, non-white body becomes an attractive property for inclusion in the bank.

A useful question to ask at this juncture is how race takes on such stability in its materialisation here. It is not contested, and becomes enrolled as a useful way of making strategic decisions. This, I suggest, is thanks partly to the scale of its enactment—here it is not individual donors being discussed, but an entire population
which is being regularly measured and classified (through censuses), and which is therefore rendered knowable and open to geographic focus. With a very straightforward focus on incorporating a broader racial mix, a clear path is trodden of selecting hospitals for collection based on census data.

When strategising with entire populations, race has a very different shape. It is no longer an impracticality (the lengthy form during a recruitment drive), nor is it something that people might misapply to themselves, classifying themselves incorrectly. In a different context of practice—the practice of strategic management—race has a very different tenor which is far more certain. In the move away from individuals to population statistics, race is not something being argued over between recruiters and scientists, but something that can be counted on as a useful and practical way of managing an entire inventory of human tissue.

**It Is Already There in the HLA—Race and Tissue Selection**

The point of tissue selection offers a different window from which to see race’s multiplicity and the work that it is doing. This time, race is not a box to be ticked, a misguided feeling, a grandparent’s birthplace, or a demographic reference point in the road to health equity. When a donor is being selected from the inventory for a patient in need of a tissue transplantation, race as accounted for by interviewees appears to recede in importance. For example, the quote below is from an interviewee responding to a question about whether clinicians would ever use donors’ race data when making a selection for their patient:

> No, because the ethnicity tends to be the thing that determines the HLA type ... the importance of ethnicity is only in the HLA type. So your HLA types are inherited, obviously, so certain populations have certain HLA combinations. So that’s why it’s so important. Um, but yeah, as soon as you—I’m not aware of any data, but as soon as you’ve the HLA match, it’s quite likely that they’re from the same ethnic group anyway. (Stem Cell Strategic Forum contributor and clinical practitioner)

In this account, the reason given for clinicians not using donors’ ethnicity data is ‘because the ethnicity tends to be the thing that determines the HLA type’. The interviewee conveys a surety that a match within an ‘ethnic group’ is ‘likely’ to be the case (whilst noting that there are no data confirming this). I asked a practitioner involved with the APPG the same question—would a clinician use such ethnicity data in making a tissue selection. They reflected on their own experience in response:

> So we would take it into account, but there are other things that matter before. So we’d match for HLA type ... We match for viruses they may have seen. We match for blood group. There’s all sorts of things we come
down. So ethnicity could be in there if we had the information. I have never had information, I don’t think, on the ethnicity.

RW: Ok, but if ethnicity is something that matters—

Well it’s already there.

RW: in the HLA?

Yeah, exactly.

This practitioner similarly notes that they ‘have never had information’ about donor race. If they did, they ‘would take it into account’ but this would be lower on the list of criteria considered in the process. Importantly, this account suggests that race (a datum that the practitioner never has) is not as important as HLA typology.

How the clinician chooses to describe this is telling. Ethnicity is ‘already there’ in the donor’s HLA type. In the preceding quote ethnicity ‘determines’ HLA. In the one just above, race is enveloped by HLA. HLA is crucial, and race takes on what I have described elsewhere as an almost metonymic position as HLA’s less specific stand-in (Williams, 2015). This reveals something of the ontological politics of the multiple views of the body at work here, as race oscillates ‘between presence and absence’ (M’charek, 2013, p. 436), in this absent moment embedded silently in the HLA of the individual donor. At another point, ethnic group is ‘so important’ whilst simultaneously ‘the importance of ethnicity is only in the HLA type’.

This brings into relief the contingency of the idea of race in this space. Its usefulness in the strategic domain of inventory management is plain, but its relevance in the clinic is less clear-cut. Race thus occupies, in the contemporary scientific domain, a complex position in which its usefulness is contextual, negotiated and far from guaranteed. This account demonstrates the complex variability of race, and reveals a moment where the relationality of race is laid bare. As M’charek notes, race never ‘materializes in the body but rather in relations established between a variety of entities, including bodies’ (2013, p. 434). This argument bears out in the moment at which a clinician assumes (‘it’s likely’) that donors and recipients share ethnicity if they match.

Race in this sense is wholly relational between donor and recipient—in their ‘match’. As an example, the interviewee below is a scientist who analyses the prevalence of different HLA types in registries across the world. I asked them whether they would find it useful to have donors’ racial data in stem cell collections around the world:

You might think ‘okay [donors’ race] data could be better for scientific evaluation,’ ... but I think this is a very luxurious demand in the context that we’re working in ... It would be nice to have them all always HLA typed at the best level ... which we try to do but of course it’s timely and a costly process.
RW: That’s a priority over having everyone’s ethnicity data?
Yeah, of course. I mean the ethnicity data is nice to have and if you could get it then it’s alright. But it’s not anything that I could imagine we would phone up someone and ask people for that.

This account and the one above it, with their allusions to ‘other things that matter before’, and the luxuriousness of demanding information on donor ethnicity, reveal that in the context of tissue matching race sits somewhere in the periphery. Clinical decision making focuses in on the level and quality of the match between donor and recipient, along with a variety of other cellular and disease-specific factors that figure into the protocols of tissue selection.

In this context, race seems almost irrelevant, a point that resonates with M’charek’s assertion that there is, in the contemporary moment, a broader phenomenon in which race does not just shuttle between presence and absence, but between occupying a central position to being rendered essentially irrelevant. We see this playing out in the stem cell context. Race becomes a key point of reference for constructing and maintaining the inventory, and tracing how representative of the UK population it can ever purport to be. Then it is important only insofar as it inheres in the HLA of a human body. It slips away into insignificance in the scientific work of tissue selection, when it is as if race’s job is done.

**Conclusion**

‘In practices’, Mol writes, ‘objects are enacted’ (2002, p. 31). Race is one such object, and M’charek’s invitation to recognise and trace race’s multiplicity as an object that materialises through its enactments in practice is one that this paper has taken up. Here, I have sought to parse some of these various enactments in a few of the practices of the blood stem cell inventory. Throughout practices of donor recruitment, of inventory management, and of the selection of tissue for transplantation, race is made relevant in a number of different ways.

In setting out to answer the question of how race is variously enacted in the context of stem cell transplantation, I have aimed to ‘denaturalize without dematerializing’ race (M’charek, 2013, p. 424). Whilst race is not an essential quality that inheres within an individual, it is mobilised through various practice in such a way that it has clear materiality—a data form, a decision to collect tissue in one place or not another, for example. In part, this effort is an attempt to address the dearth of critical focus on race in the context of blood stem cell science. The role of race has not been particularly prominent in a landscape of sociological scholarship that has attended to other questions of capitalisation, promise and futurity, and the gendered landscape of regenerative medicine (Waldby, 2006; Dickenson, 2007; Martin et al., 2008; Waldby and Cooper, 2010).

Race begins to emerge in studies focusing more specifically on the public and internationally networked initiatives to bank public stem cells in the manner
considered in this paper. Most prominently, concern tends to sit with how immunological difference becomes a corporeal resource through which immunities can essentially be stockpiled and exchanged (Brown et al., 2011; Brown and Williams, 2015). However, as this paper has sought to address, a sustained exploration of how race figures in this context has not been made a central element of discussion. In particular, by focusing on three different areas within this context, I have sought to bring into relief the multiple quality of the object of race.

In one case, it materialises as a datum that must be carefully captured early on in the recruitment phase. We see this emerge in devices like ethnicity data collection forms that invite stem cell donors to situate themselves within pre-given lists of ethnicity ‘options’. Yet even by anchoring a fuzzy notion like ‘ancestry’ into the specific question of the grandparent’s birthplace, race can confound and be confounded. It can easily get in the way of the practical work of recruiting volunteer stem cell donors (a list can be too long, a question can be too problematic to be feasible).

Race, too, can easily be mis-captured by a volunteer donor seen as too invested in their cultural identity of having a great grandfather from China to acknowledge their true ethnicity. But the language of ‘truth’ in this context should not lead us to assume that there is some reality of race that might be reached through the thicket of false enactments that conceal it. Instead, it is a case of recognising that race only appears here through the practices that mobilise it.

Away from the practical issue of recruitment, in the domain of managing the inventory, conceptualising it as a whole and comparing it to the national population, race becomes strangely stable and easy. The work of producing a useful inventory relies on clearly demarcated, racially identified donors. There are \( x \) number of Asians in the UK population, but only \( y \) number in the UK’s stem cell inventory. Boosting this number through the selective placement of UCB collection centres addresses this issue.

Race is a locus around which the strategic placement of collection centres is managed—more ethnic minority bodies around a maternity ward makes that ward more attractive as a UCB collection site. Race is, in the same vein, a means of determining how representative this stem cell collection is. The historic underrepresentation of minority ethnicity donors in the stem cell inventory has produced an active attempt to recruit more minority adult donors and encourage more minority UCB donation.

Race’s enactment during tissue selection reveals yet another materialisation of the object. In this practice, clinicians must lean on a great deal of information to make their clinical decisions. Race might not figure at all in this moment as clinicians do not see donors’ data (for instance, whichever box they ticked in the recruitment period). At most, race will be seen ‘in’ the HLA, enveloped in the very antigens that individuals inherit from their ancestors, revealing a stark difference in how different practices enact race differently; details of donors’ racial identities oscillate between important question and luxurious data.
Multiple as they are, what might be the political consequences of race’s enactments in blood stem cell science, a paradigm which is now inexorably connected with treatment provision for a growing number of treatment protocols? To be able to say that race is enacted through practices is a powerful conceptual tool against the reification of race as an inherent and essential human quality—the cases explored here demonstrate this in showing how difficult and contingent the pinning down of a donor’s race is, for instance. But the enactment of race for the purposes of producing a useful public health resource representative of those who may require it also reorients us towards asking other questions.

For instance, if ‘traces of races’ (Schwartz-Marín and Wade, 2015, p. 888) can be sniffed out in the decades-long history of blood stem cell science, why is it only towards the end of the twentieth century that practices of strategic management have been enacting race towards developing a maximally representative collection? Such a question, though it cannot be answered here, is a fundamentally political one produced by analysing race as a multiple object. Not only can we ask what enactments of an object materialise. We might also ask why enactments take the shape they do, and why the particular practices that mobilise them come to be.

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