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Combating the 'Silent Crisis' of the Donation Gap with 'Polyphonic Relatedness'

Jill Shepherd*
Joy Y Zhang**

Abstract: The UK has been a global leader in the development and regulation of biobanks and bio-databases that facilitate clinical and laboratory access to tissue, blood samples, DNA and data. Yet the persistent barrier to mobilise non-White communities into actively contributing to and, subsequently benefiting from structural and scientific advantages that the UK can offer constitutes a 'Silent Crisis'. This paper builds on ongoing research on stem cell donations carried out by the authors in the UK. We underline the centrality of the concept of 'relatedness' in donor recruitment, and the tricky role it has played, both as a uniting and an alienating force within and between different ethnic communities. We argue that the building of a thick societal relatedness or what we term as 'polyphonic relatedness' offers a constructive guidance to overcome the racial disparity in biomaterial donations.
Keywords: DNA, Data, access, bio-database

Introduction

> 'Rakesh [Shah], died from a blood disorder at the age of just 35. Due to Rakesh's Indian heritage, he struggled to find a donor with the 10 matching genes that would have helped ensure that his blood would accept the donor's cells.'
>
> — Mohammad Yasin. House of Commons, 2018

Rakesh Shah's tragedy opened the UK parliament debate on the chronic deficiency of blood, stem cell and organ donation from Black, Asian and minority ethnic (BAME) communities on 27 June 2018. The UK has been a global leader in the development and regulation of biobanks and bio-databases that facilitate clinical and laboratory access to tissue, blood samples, DNA and data. Yet there has always seemed to be a persistent barrier to mobilise non-White communities into actively contributing to and, subsequently benefiting from structural and scientific advantages that the UK can offer. This is due to a simple medical fact that donor-recipient capability is determined by their biological relatedness, or more precisely

* School of Biosciences, University of Kent
** School of Social Policy, Sociology and Social Research, University of Kent
Email: yz203@kent.ac.uk Zhang

put, by their human leukocyte antigen (HLA) similarities. One is more likely to find an HLA match among people of a similar ethnic background or ancestry. The racial disparity of donors and its immense health impact was characterised as a 'Silent Crisis' in a comprehensive review carried out by the Sheffield Street Company, commissioned by Member of Parliament Eleanor Smith (2018).

In the past few years, a number of scientific institutions and civic organisations, including high-profile individuals in the UK have been actively tackling this issue through education, targeted-campaign, and grassroots engagements. An economic calculation of using domestic stem cells which are cheaper than relying on an international market is an underlying policy rationale that encourages government-funded public bodies and health charities to join forces to improve service provision (Williams, 2015). However, a donor gap remains. According to the latest statistics released in May 2022, while the UK has reached a milestone of having more than two million people registered to become potential blood stem cell donors, the percentage of BAME donors remained at 13% (DKMS, 2022). Thus, little has changed with the dire disparity that patients from BAME backgrounds have a 20% chance of finding the best possible blood stem cell match from an unrelated donor, compared to 69% for northern European backgrounds (House of Commons, 2018; DKMS, 2022). Black donors make up only 1.2% of the British Bone Marrow Registry (Smith, 2018).

The persistence of the 'Silent Crisis' highlights an important yet often ignored pre-requisite for biomedical development to achieve the 'common good'. That is, equitable public health outcomes hinge not only on robust infrastructures of bioeconomy, policy framework and competitive innovation workforce but also on the quality of participation from diverse communities. To put it in another way, how people relate themselves to the importance and the implications of a medical practice (such as curating a stem cell registry) is a critical part of fully realising the promises of social good of biomedicine.

This paper builds on ongoing research on stem cell donations carried out by the authors in the UK, in which we explore more effective ways to address the 'Silent Crisis'. More specifically, we underline the centrality of the concept of 'relatedness' in donor recruitment, and the tricky role it has played, both as a uniting and an alienating force within and between different ethnic communities. The observed 'silence' from ethnic minority donors reflects an absence of a sense of relatedness to the biomedical agenda. We argue that the building of a thick societal relatedness or what we term as 'polyphonic relatedness' offers a constructive guidance to overcome the racial disparity in biomaterial donations.

In what follows, we will first unpack the role of 'biological relatedness' in stem cell research. We draw attention to the fine line between recognising genetic differences and not essentialising group identity or widening racial divides. We then provide an overview on how 'relatedness' is featured in existing initiatives in the UK and identity where there may be missed opportunities. Finally, we explain what we mean by 'polyphonic relatedness' and what it means for future research agenda.

The Role of Biological Relatedness in Stem Cell Research

Researching human genetic variation for biomedical research purposes is key to identifying risk factors and differentiated treatments (Risch et al, 2002). Biological relatedness is pertinent to stem cell research (Williams, 2021), especially research on translational medicine applications such as the focus of our ongoing work, the transplantation of donated haematopoeitc stem cells. The success of haematopoeitc stem cell transplantation depends on the type and degree of biological relatedness between donor and recipient; this 'matching' requirement between the donor and recipient is the same as that the principle applies to solid organ transplantation. In general terms, the higher the degree of this type of 'biological relatedness' between donor and recipient, the more likely it is the transplant will be successful. It is for this reason that siblings are usually the first port of call when a stem cell donor is needed. Where siblings are unavailable or not suitably matched, other relatives are explored as potential donors. Finally, if there are no suitable donors within the family, then national and international registries of stem cell donors are searched to find a matched unrelated donor (MUD).

A MUD is most likely to be found within the recipient's same ethnic group because people from the same ethnic group tend to display a greater degree of biological relatedness to each other than to individuals from outside. There are several different scientific techniques for measuring how well donor and recipient are matched, with modern genomics techniques being the newest gold standard.

In 2001 the Human Genome Project elucidated the sequence of the human genome; this was a first draft, a reference for use in comparison studies (Lander et al, 2001). Indeed, part of the 'grand vision' of The Human Genome Project was to improve our understanding of genetic factors influencing human health on a global scale. But despite the Human Genome Project being an international collaboration involving 20 research centres in six countries including China, France, Germany, the United Kingdom, Japan, and the United States, the reference genome produced was Euro-centric. This is not said to diminish the colossal achievements of the project but simply to introduce the historic under-representation of non-European ethnic groups in genomics datasets. The authors were more

than aware that obtaining a draft sequence of the human genome was the beginning of a new era of 'genomic medicine', including an explosion of work around the influence of genetic variation on human health and disease (Collins, 2003). The concluding thoughts of the original publication of The Human Genome Project state: 'Finally, it has not escaped our notice that the more we learn about the human genome, the more there is to explore' (International Human Genome Sequencing Consortium, 2001).

Since the Human Genome Project, there have been successions of efforts to genomic databases more representative of the diversity of global communities. The African Genome Variation Project (Gurdasani et al, 2015) and the GenomeAsia 100K Project (GenomeAsia100K Consortium, 2019) are two most well- known programmes that hope to address the chronic under-representation of non-European ethnic groups in genetic datasets. This important work recognises the genetic diversity of human populations and incorporates it into the body of scientific knowledge such that this fundamental, gene-level understanding of human health and disease is applicable to a larger proportion of the global population.

In short, the science of genomics, through measuring biological relatedness, can empirically describe the biological elements of ethnicity. But it must be reminded that the point of genetic *categorisation* for biomedical research purposes is to better *recognise* and *incorporate* diversity, so as to better *attend* to individual particularities. Good science necessarily takes into account multiple factors (biological and non-biological) in its understanding of a disease or of treatment, rather than seeing people as neatly demarcated groups. To put it in another way, the ethnic lens used in biomedical research and in stem cell sampling is to help map out human diversity rather than to reduce it to rigid conceptual boxes.

In fact, there has been a growing recognition on how international migration has blurred the lines of conventional categorisations of race. Similar to many other countries, 'multiracial populations' are the fastest growing ethnic group in the UK (Solomon, 2017; Henderson, 2022; Atkin et al, 2022). The number of Britons who self-identify as mixed-race almost doubled between the census of 2001 and 2011. Mixed-race people currently make up 16% of all non-whites in the UK, while the figure is 11% in the US (Nandi and Platt, 2020, 23). Mixed-race individuals often have much more difficulties in finding a donor (see ASCO, 2021 and the Mixed Match Project).

In short, our biological differences are both real and messy. For stem cell registries to generate equitable health benefits for all citizens, it requires diversified profiles of donors. This point is important. As the next sections demonstrate a common approach to drive up stem cell donation capitalises on biological relatedness and relies on an 'ethico-racial imperative' rhetoric

(Williams, 2021). While such an approach has shown some effect in the short run, we argue that the 'ethics-racial imperative' framing alone is misleading and could be counter-productive in the long run. What lies at the heart of the Silence Crisis is not a competition between different races and ethnicities but is part of a larger disjointedness of contemporary bioscience with minority groups. Its solution also calls for attentiveness to another type of relatedness, that is, the social relatedness of bioscience to citizens from diverse ethnic backgrounds.

Existing Approaches to the Silent Crisis and Their Limitations

It is safe to say that the aforementioned 2018 review of donor disparity commissioned by the British MP Eleanor Smith not only renders better visibility to the donation disparity, but it also encompasses a general framework for how this disparity is analysed and addressed. The review identified three factors as the main reasons for low participation from BAME communities (Smith, 2018, 8). They are: 1) lack of awareness or of access to information on donations, 2) religious permissibility and 3) lack of trust in medical institutions and a fear of medical exploitation along class and ethnic lines. Correspondingly, the 2018 review made a comprehensive list of suggestions, such as creating a culture of donation through public campaigns, integrating information about donation into school curriculums, normalising collaboration between medical institutions and local faith leaders, targeting engagement with grassroots BAME communities, and increasing ethnic diversity in NHS staff (Smith 2018, 12-7).

Two general rationales can be seen across different initiatives that have been carried out in the UK. One is a focus on reaching out to young people through education and targeted campaigns. Following the parliament debate, the UK Department for Education introduced guidelines for secondary schools to teach their pupils 'about the science relating to blood, organ and stem cell donation' (DfE 2018, 2019, p. 37). Anthony Nolan (https://www.anthonynolan.org/), a blood cancer charity, hosts a registry for donors until the age of 61. But its recruitment is focused on healthy individuals aged between 16 and 30. The focus on younger generations has at least two advantages. One is that it helps to cultivate cultural change through upcoming generations in different communities. The other is that donations from young healthy individuals have higher clinical success rates for patients.

The second general rationale is working from inside ethnic minority communities. The UK's National Health Service (NHS) hosts the Community Grants Programme (formerly the Community Investment Scheme) dedicated to 'build[ing] support for donation amongst Black, Asian, mixed heritage and minority ethnic communities'. In their latest call

launched in December 2022, a total of £700,000 was committed to support community-based projects across England and Wales to raise awareness of donations. Individuals of influence (e.g. community leaders, elderly people, or celebrities of colour) are often considered key in mobilising stem cell donations within the ethnic community they resemble. It is also not uncommon for civic initiatives to be developed through racial lines. For example, the Iman Hussain Blood Donation Campaign in Manchester is focused on Muslim communities, while the African Caribbean Leukaemia Trust focuses on black communities. Ethnic narrative is embedded in many media campaigns as well, such as Dev Patel, the Slumdog Millionaire actor's public appeal for stem cell donors to save the life of a young British South Asian boy (https://fb.watch/i96IIuX0aS/).

However, this is also where a paradox seems to arise. That is, while ethnic specific initiatives may help incentivise donations from an immediate community and establish islands of specialised registry, it also amplifies the *social* construct of racial difference and thus aggravates a *social racialisation* of biomedicine, which was, arguably, a major cause of ethnic minority groups' non-engagement in the first place.

In her series of discussions on UK stem cell donation strategies, Ros Williams has pointed out how the idea of 'relatedness' was exploited in the context of race, in which 'racialised suffering' is used to invoke 'racialised obligation' of donation (Williams, 2021, 482, 486). The pursuit of diversifying samples for stem cell banks has effectively resulted in British scientific communities aligning one's HLA type with their ethnic identification, a practice that Williams considered as 'alarming' for it reinforces the racial divide (Williams, 2015). Existing norms of community-engagement and their varied success also raises 'an uncomfortable and not easily answerable question': 'What does it tell us that so much of the ongoing and difficult work to ameliorate health inequalities is actively placed in the hands of racialised communities themselves, rather than framed as a collective onus borne by us all, regardless of how we identify or are read, to address the historical striations of inequity that our health systems so urgently need addressed?' (Williams, 2021, 488). In addition, an 'ethics-racial imperative' rhetoric has its limit. In particular, why minority individuals may 'elect not to engage with biomedical projects' (Williams, 2021, p. 487) remains under-explored (see also Amendola, et al 2018).

We hope to address questions provoked by Williams' research. While we consider both reaching out to younger generations and purposeful grassroots engagement as critical, we also argue that reflecting on the purpose and on what it means to engage with ethnic minority communities is vitally important.

Studies have suggested that the concern over race and ethnicity as a barrier to biomedical participation itself has been treated uncritically

(Hartigan, 2008; Landry, 2021; Young et al, 2022). Race and ethnicity could be confounding factors that are wrongly used to 'blackbox' a number of issues that distance non-white communities from actively participating in donations. The point here is not to underplay the value of targeted engagement with minority communities but to highlight that the substance of the engagement (e.g. how we engage and what the goals should be) cannot be taken for granted and requires further empirical investigation.

For example, uncritical reiteration of the correlation between mistrust in medical institutions and a particular race could create a false perception of that ethnic community as non-trusting or could underplay more systematic problems. A large-scale study on decisions about unrelated hematopoietic stem cell donation among White, Asian/Pacific Islander, Hispanic and African-American populations showed that 'doubts and worries' was 'the most consistent factor associated with opting out of the registry across all race/ethnic groups' (Switzer et al, 2013, 1469). Another recent study on Hispanic, non-Hispanic White, Asian, and biracial families' rationales in participating clinical genomics research found that, contrary to conventional impression, Hispanic families have shown more trust in providers than parents from other ethnic background (Young et al 2022, 6). This is of course not to negate a general scepticism and distrust that historically exploited and excluded ethnic groups have towards (Western-dominant) modern medicine, but to underline the often-ignored fact that how one relates to the health system is not dictated by one's genetic heritage, but is situational, empirical and always evolving (Gaskell et al, 2013, Passmore et al, 2019).

A reflexive and non-essentialist approach to minority communities is especially pertinent for any future-oriented engagement work with potential donors from varied sociodemographic backgrounds to be effective. As the future population is increasingly mixed-race, conventional boundaries of identity politics are increasingly difficult to hold (Solomon, 2017; Nandi and Platt, 2020). To improve diversity in biomedical research, rhetoric and strategies rooted in reinforcing rigid regimes of *biological relatedness* are short-sighted and could be counter-productive in the long run. The chronic shortage of stem cell donors from diverse sociodemographic backgrounds underlines a broken societal connectedness between the field of stem cells and non-White communities. We need to address the Silent Crisis by building '*polyphonic relatedness*' that creates a deep and sustained connection between ethnic minorities and (individual and collective) future health.

Polyphonic Relatedness and An Agenda for Future Research

A polyphony refers to a rich texture of music in which two or more independent melodies are simultaneously present. By building 'polyphonic relatedness', we mean the creation and curation of biological and socio-

political connectedness between individual citizens (especially those from ethnic minority backgrounds) and biomedicine through the interblending of different voices. We argue for methodological innovations in how we engage with ethnic minority communities and a re-orientation of what engagements such as donor campaigns should be aiming to achieve.

When discussing widening participation and engaging with marginalised or disadvantaged groups, we often talk about 'voice'. In widening stem cell donations, it is essential to listen to communities' needs and cultural and religious particularities. But what if a community does not have a *coherent* voice? What if there are different voices within the same community? To further complicate the scene, 'community' is also a social construct. Membership to a community can be assigned, bestowed, or self-identified. One's relationships with different communities are always overlapping and forever evolving. Few would dispute that good engagement is to enable new communities and new relatedness to emerge. But how do we avoid the reductionist temptation of rectifying racial divides, so that we can still purposefully identify social groups to diversify donors but not lose sight of in-group diversity and the necessary fluidity of its composition? When we reach out and try to build connections with ethnic minority communities, how we can better encourage and make sense of different voices?

Answers to these questions may be contextual. Racial disparity in stem cell donations is a global problem with community level solutions (APPG, 2021). Purposeful engagement necessarily needs to start with the engagement of a particular group of individuals (for example, our ongoing research focuses on black communities). But it should bridge rather than reinforce racial divides. Building polyphonic relatedness offers an effective and sustainable framework for finding solutions to the Silent Crisis for the following reasons:

1) At a basic level, building polyphonic relatedness is enhanced listening and enhanced articulation. By enhanced articulation, we mean going beyond a simple framing of 'racialised suffering', to integrate different accounts of the multi-layered interdependence and interrelatedness that is embodied in the registration, participation and utilisation of stem cell registries. It also requires giving a clearer account of the short term and long term impacts of building diverse stem cell registries. Only through providing a more comprehensive account can biomedical institutions become more 'account-able' to ethnic minority groups. It also helps to shift the narrative from calling upon ethnic minorities to solve a crisis to bolstering their readiness to join collective scientific endeavours. Culturally sensitive articulation requires enhanced listening, which does

not treat 'what we hear' as static and dogmatic. Polyphonic listening is to appreciate in-group diversity, such as generational differences, socioeconomic differences and to recognise cross-group memberships.

2) Building polyphonic relatedness is to co-narrate and co-discover the importance of stem cell donation. Relatedness should be two-way. Engagement and collaborations with local communities should focus both on educating how stem cell registries *relate to them*, and on learning how they *relate themselves to* (or would like to relate themselves to) biomedical research. This is a necessary step to allow new relatedness to be discovered and to be developed. However, currently, most research on mobilisation of minority donors has mainly focused on how to adapt recruitment messages to fit in with particular cultural norms (i.e. how to relate recruitment goals to local communities), rather than evoking a sense of partnership and vision of biomedical development from minority communities (i.e. how they (wish to) relate themselves to biomedical development).
3) Building polyphonic relatedness enables an active form of biological citizenship. Bio-citizenship is a concept first coined by Andriana Petryna (2002) to describe a somewhat passive right, that is the state's obligation towards welfare claims made by a biologically damaged population. Nikolas Rose and Carlos Novas (2005) later extended this concept by highlighting the unavoidable entanglement of one's identity and biotechnology, and how this gave rise to new forms of subjugation as well as public participation in socio-political domain. Biomaterial donation could rely on the rhetoric of passive biological citizenship (e.g. it's one's duty to save the life of an ethnic peer), or it could rely on an active form of biological citizenship (e.g. it's one's choice or preference). These two forms of bio-citizenship are not mutually exclusive. But arguably, a fairer and more sustainable bioeconomy would benefit from more practice of active biological citizenship. This requires policy and structural support that can help reduce socio-economic, geographic barriers to participation (APPG, 2021). But it also requires a cultural change. That is, in addition to enhancing scientific literacy itself, more individuals could relate themselves to biomedical advancement, and actively reflect on and contribute to its development. This is where community level engagement makes a difference.

The framing of 'relatedness' lies at the heart of the chronic problem of under-recruitment of ethnic minority donors. We've demonstrated that

a conventional approach of mobilising minority donors often over-relies on biological relatedness, which paradoxically aggravates rather than bridges racial divides. What has been overlooked is curating 'polyphonic relatedness' between disadvantaged groups and biomedical institutions, through enhanced articulation and listening, evoking partnership, and enabling active biological citizenship. In short, polyphonic relatedness enables a constructive and liberal realm for conversation and collaboration where, as poet W. H. Auden elegantly put:

> Our several voices
> Interblending,
> Playfully contending,
> Not interfering
> But co-inhering.

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