

# Evidence Response to the Commission on Race and Ethnic Disparities' Open consultation on "ethnic disparities and inequality in the UK"

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Responding on behalf of research project *Mix and Match: Constituting racialised communities in UK stem cell donation*

<http://mixandmatch.blog>

This evidence was produced through research funded by a Wellcome Trust Social Science and Humanities Research Fellowship (Grant number 212804/Z/18/Z), and a UKRI/Economic and Social Research Council doctoral training grant (award reference: 1221214). Research spans from 2012 and is ongoing.

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## Context of the Commission's consultation

After establishing a new [Commission on Race and Ethnic Disparities](#) in July 2020, the UK government asked the Commission to undertake a review of ethnic disparities and inequality in the UK. The Commission's terms of reference, and its consultation's focus, is on education, employment, health, and crime/policing.

From the 26th October to 30th November 2020, the Commission [invited responses](#) from the public/local communities, organisations in the public, private and third sectors, and researchers and academics.

The questions asked ranged from the general to the specific, and included two that were directly related to health:

- Question 6: Which inequalities in health outcomes of people in different racial and ethnic groups are not (wholly) explained by inequalities in underlying determinants of health (for example, education, occupation or income)?
- Question 7: How could inequalities in the health outcomes of people in different ethnic groups be addressed by government, public bodies, the private sector, and communities?

The below sections of this document provide a copy of the response I sent to these two questions, drawing on my expertise in relation to the sociology of human tissue donor recruitment. The response is intended to flag the topic of stem cell, blood and organ donation as key for thinking through the issues of (mis)trust, (dis)engagement, and fair service provision for minoritised ethnic groups.

Question 6: Which inequalities in health outcomes of people in different racial and ethnic groups are not (wholly) explained by inequalities in underlying determinants of health (for example, education, occupation or income)?

Key points:

- Human tissue donation (stem cell, blood, organ) is a key example of how racial/ethnic health differences are linked to more than individual/community determinants of health. Historical exclusion must be acknowledged and explored.
- Historical patterns in donation have seen large uptake in white British groups, but far less in minoritised groups. This is thought to be partly down to issues related to lack of trust in health systems and in statutory actors. This has led to longer waiting times and worse outcomes for many minority ethnic patients requiring transplants and transfusions.

Whilst many inequalities in health outcomes can be partially explained by underlying determinants of health, there are certain contexts where inequalities in outcomes have to be understood as emerging from a much broader, historical context than a social determinants model allows. A clear and consequential example of this is when patients require treatments including blood transfusions and stem cell or organ transplantations, but cannot access them because of their ethnicity.

Compatibility between donors and recipients is decided by blood type (in the case of blood transfusion and most organ donation) and HLA type (in the case of stem cell and some organ donation). These types are understood to be more frequent in certain ethnic groups. As such, when an ethnic group is less numerous in blood stocks and on organ and stem cell registries, this can lead to worse outcomes for patients from that group who require, but cannot access, these human tissues for treatment. Consider blood and stem cell donation. In the UK, minority ethnic groups are significantly underrepresented across these contexts:

- For example, *NHS Blood and Transplant* note<sup>i</sup> a continual lack of black blood donors because they are understood as more likely to have a specific blood type that is more common in patients with sickle cell (who are also more likely to be black).
- Additionally, there is ongoing underrepresentation of minority ethnic donors on bone marrow registries in the UK<sup>ii</sup>—remarkably, whilst white patients requiring a stem cell transplantation (a standard treatment for cancers like leukaemia, lymphomas and myelomas) have around a 90% chance of finding a match, minority ethnic groups are believed to have far lower odds of between 20-40%<sup>iii</sup>.

Why is this the case? It is not simply because of the social determinants of health (e.g., individual lifestyles factors, or even contemporary socio-economic factors) – i.e., being

poorer, or working in a particular industry, does not account for this. Rather, we must look to history.

Blood donation systems, emerging in the early 20th century in response to war-time injury, are entangled with ideas of nation and national belonging<sup>iv</sup>. In the US, people of colour were initially banned from donating blood. When they were finally allowed in the late thirties and early forties, their blood was marked C for “coloured”, so practitioners knew not to give it to white people – this was for pseudoscientific “racial hygiene” purposes, rather than anything to do with blood type compatibility<sup>v</sup>. If practices of donation are embedded in families and communities (with one learning about it, and engaging in it after learning from their parents, for example), we begin to see the effects of racism long ago having an impact on contemporary practice. In the UK, where blood donation is intrinsically tied to national health (Britain’s blood transfusion service predates the NHS), statutory bodies’ recruitment practices have had a ‘strong historical penetration amongst advantaged middle class blood donors’ and a lack of capacity to recruit ‘beyond the mainstream demographic’<sup>vi</sup>.

It should not, then, surprise us that some minority ethnic donors would say that donation is something that “white people do”<sup>vii</sup>. For example, in a recent promotional video<sup>viii</sup> from *NHS Blood and Transplant* and the *African Caribbean Leukaemia Trust* to encourage black British organ donation, DJ Ace from BBC 1xtra, who is waiting for a kidney donor, says:

*“when I was 17 and I was filling out my driver’s licence form and you get down to the part that asks you if you want to be an organ donor... [My mum said] no, we don’t do that... it could be religious, it could be cultural. I know that there is a real lack of trust from the black community when it comes to just authority”.*

In my own research with organisations encouraging stem cell donation amongst minority ethnic communities, I have spent time with recruiters. I have witnessed, as part of qualitative ethnography, that just because donation is linked to the NHS does not guarantee that people will buy-in, because many minority ethnic individuals have very different (and not necessarily positive) relationships with the NHS.

**As such, it is not simply because minority ethnic people cannot access donation because of individual factors (like income or occupation). One must rather situate a lack of uptake in a broader history in which healthcare systems have not always been accessible, even when they claim to be universal.** It is only in the past two or three decades that statutory actors have begun to address low uptake in the context of human tissue donation. Additionally, as my published research with colleagues notes<sup>ix</sup>, even the contemporary context of health care (for example the Windrush scandal and its impact on health access, or the NHS surcharge for ethnic minority healthcare workers from abroad) doesn’t necessarily foster the trusting relationships on which engagement in something as important as human tissue donation would need to be founded.

Question 7: How could inequalities in the health outcomes of people in different ethnic groups be addressed by government, public bodies, the private sector, and communities?

Key points:

- Currently, work to address ethnic minority underrepresentation in human tissue provision (blood, organ and stem cell), which leads to inequality in health outcomes, is a mixture of statutory actors and large third-sector organisations like stem cell registries, along with small minority ethnic-led organisations.
- This model of operation suggests that minority ethnic people are best placed to make appeals to their own communities. However, it also risks a discourse of “blame” and “responsibility” of something for which both the state, and we as a larger multi-ethnic national community, share an onus to correct.
- My research suggests problems of low engagement of minority ethnic individuals requires a serious re-evaluation of the relationship between statutory actors like the NHS and minority-led third sector organisations to whom ‘engagement’ work is effectively outsourced. Significant and long-term financial support from the state is important and should be seriously considered. But the NHS must also consider why it is in a position that its voice is considered less trustworthy than that of minority community spokespeople.

In my answer to question 6, I noted that minority ethnic people are less engaged in potentially life-saving activities like blood, organ and stem cell donation. This has direct impacts on health outcomes for minority ethnic patients who need, but cannot access, transfusions and transplantations. The question of how to address this problem is not easily resolved. Stem cell donor recruitment, which I am currently researching, offers a useful example of these challenges in practice:

*NHS Blood and Transplant* has increasingly centred minority ethnic underrepresentation since the 1990s<sup>x</sup>. Yet it is telling that this is some thirty years after the establishment of the UK’s first stem cell registry. What’s more, this concerted formal effort to recruit minority ethnic stem cell donors wasn’t driven by statutory bodies, but the third-sector (e.g., the *African Caribbean Leukaemia Trust*, established by the parents of a black teenage boy unable to find a stem cell donor).

I am currently researching the work done to encourage minority ethnic stem cell donation. This is undertaken, in large part, by the third sector. By this, I refer not just to larger charities that operate stem cell registries, but to smaller charities such as the *African Caribbean Leukaemia Trust*<sup>xi</sup> or *Race Against Blood Cancer*<sup>xii</sup> which rely in large part on

grants, specific project funding from the NHS, and donations from members of the public. Similarly, as I have written about in more detail<sup>xiii</sup>, increasingly we see individuals launching appeals on social media to seek their own match or one for their child.

This work rests partly on the fact that non-scientific ethnic minority individuals/organisations are framed in policy as the most effective messengers in generating engagement of minority people. The latest parliamentary review on the topic, notes:

*The rate of donor recruitment by BAME grassroots and community organisations is high... Grassroots and community organisations' knowledge of respective target audiences, and their dissociation from governmental institutions, generate higher levels of trust from BAME groups. This allows them to reach under-represented communities more effectively.... The message or the framing might be accurate but its effectiveness is dependent on the messenger and mode of delivery. Due to their integration in local communities, BAME grassroots and community organisations are best placed to judge the types of approach that will work best for which topics<sup>xiv</sup>*

**If indeed minority ethnic-led organisations are most effectively positioned to generate trust, this does not abdicate statutory bodies of the responsibility to facilitate, encourage, and support this work.** It is crucial that these smaller charities and others like them<sup>xv</sup> are adequately financially supported to undertake long-term work in this area. This is not least because they help to limit the amount of more costly import of tissue from abroad, potentially helping to save the NHS money<sup>xvi</sup>.

As importantly, it is also vital that messages to minority ethnic would-be donors are not simply ones of 'blame' that responsabilise them for low uptake. This work, across organ, blood and stem cells, risks amplifying the idea that 'donation is the collective responsibility of biologically, socially and culturally distinct and distinguishable communities'<sup>xvii</sup> like 'black British' or 'British Asian' communities. **In fact, the onus to ensure an equitable system does not belong to an individual or an ethnic community, but to the state, and to the entire citizenry regardless of ethnic identity, who must between us give reason to minority ethnic groups to trust in health systems.**

If we are to truly acknowledge the historical and contemporary context from which disengagement and mistrust manifests, we must acknowledge that disengagement and mistrust are themselves legitimate reactions to statutory bodies like the NHS, and that the job of the NHS and the state more broadly is to work to ensure that mistrust of authority – as DJ Ace put it above – moves from being a legitimate reaction, to an unnecessary one that can be relegated to the past.



## Rationale and methodology for the research underpinning the evidence

Evidence from this research is linked to two projects undertaken by Dr Ros Williams as principle investigator. All research has been undertaken from a sociological, rather than a clinical, perspective

The first project was funded by the ESRC looking at practices of stem cell banking in the UK (award reference: 1221214). The study explored in part how minority ethnic stem cell recruitment was being undertaken in the context of umbilical cord blood banking. The project ran from 2012-2015 and culminated in a PhD thesis and several peer-reviewed academic articles. For the project, I undertook 19 semi-structured interviews with people involved in stem cell biobanking in the UK. Furthermore, I undertook significant amounts of analysis of grey literature and policy documents, including Hansard transcripts and APPG materials.

The second, larger project, is ongoing from 2019-2022. It is funded by the Wellcome Trust (grant number 212804/Z/18/Z). The project explores how racialised communities are constituted through initiatives encouraging BAME people to register as stem cell donors. It also asks, what are the social, political and ethical implications of these initiatives? As of the evidence review, the project had undertaken:

- 4 months of ethnographic research with research partners *African Caribbean Leukaemia Trust*, and *Race Against Blood Cancer*. In March 2020 this part of the research was indefinitely paused because of the coronavirus pandemic.
- Interviews with 11 UK-based individuals involved in campaigning to locate stem cell donors for themselves for a loved one.
- In-depth analysis of five social media campaigns run by or for individuals looking for a match – including Tweets, Facebook posts, media coverage and their blogs and webpages.



## Endnote references

- <sup>i</sup> See <https://www.blood.co.uk/why-give-blood/demand-for-different-blood-types/ro-blood/>. Furthermore, organ transplant waits are also often significantly longer for minority ethnic would-be recipients too. See <https://www.organdonation.nhs.uk/helping-you-to-decide/organ-donation-and-ethnicity/> for further information about this.
- <sup>ii</sup> The UK's registries include several. These are run by charities like Anthony Nolan and DKMS, and statutory bodies like the British Bone Marrow Registry run by NHS Blood and Transplant. Latest data are available through the most recent aligned registries report. See [https://www.anthonynolan.org/sites/default/files/State\\_of\\_The\\_Registry\\_201819.pdf](https://www.anthonynolan.org/sites/default/files/State_of_The_Registry_201819.pdf)
- <sup>iii</sup> See NHS Blood and Transplant Stem Cell Strategic Forum (2010) <https://docplayer.net/7404866-Unrelated-donor-stem-cell-transplantation-in-the-uk.html>
- <sup>iv</sup> See Busby and Martin (2006) <https://www.tandfonline.com/doi/full/10.1080/09505430600890693>
- <sup>v</sup> See Lawrence Hill (2013) *Blood: The stuff of life*. London: Oneworld publications
- <sup>vi</sup> See Brown et al. (2011), quote from page 1877. <https://www.sciencedirect.com/science/article/pii/S0277953611000670>
- <sup>vii</sup> See Morris (2009), particularly page 187 <https://etheses.bham.ac.uk/id/eprint/552/1/Morris10PhD.pdf>
- <sup>viii</sup> See <https://aclt.org/bbc1xtradiacetosharehishealthstoryatacltgiftoflifeball/>
- <sup>ix</sup> See Fitzgerald et al. (2020) <https://journals.sagepub.com/doi/full/10.1177/0038026120914177> - *the point made in this paper is that the positive feelings many have towards the NHS is not universal. The Windrush scandal is a recent example of how people with legitimate entitlement to the NHS have been barred from its services because of state error.*
- <sup>x</sup> See Williams (2016), particularly page 136 <https://etheses.whiterose.ac.uk/12189/7/corrections3.pdf>
- <sup>xi</sup> African Caribbean Leukaemia Trust website <https://aclt.org>
- <sup>xii</sup> Race Against Blood Cancer website <https://www.raceagainstbloodcancer.com>
- <sup>xiii</sup> See my recent inquiry response to the APPG on Stem Cell transplantation here: <https://mixmatchsheffield.wordpress.com/2020/11/24/written-evidence-from-mix-and-match-provided-to-appg-on-stem-cell-transplantation-available-to-download/>
- <sup>xiv</sup> Ending the Silent Crisis review (2018) quote from page 10 <https://www.nbta-uk.org.uk/wp-content/uploads/2019/04/BAME-Donation-review-29.5.18.pdf>
- <sup>xv</sup> See National BAME Transplant Alliance, an important initiative amplifying the voices of a large number of organisations involved in this kind work across organ, blood and stem cells <https://www.nbta-uk.org.uk>
- <sup>xvi</sup> Williams (2015) <https://www.tandfonline.com/doi/full/10.1080/14636778.2015.1060116>
- <sup>xvii</sup> See Kierans and Cooper (2011) quote from page 14 <https://rai.onlinelibrary.wiley.com/doi/abs/10.1111/j.1467-8322.2011.00837.x>