

Written evidence submitted to the All-Party Parliamentary Group on Stem Cell Transplantation's *inquiry into barriers to accessing treatment and care* from Mix and Match

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<http://mixandmatch.blog>

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Available online: <https://mixmatchsheffield.wordpress.com/outputs/>

Context for the written evidence

The All-Party Parliamentary Group (APPG) on Stem Cell Transplantation launched an inquiry on 5th August 2020 “[seeking to understand how a patient’s background can lead to barriers in accessing treatment and care.](#)” Anthony Nolan, one of the UK’s stem cell registries, and one of the most well-known and central charities for supporting patients in need or receipt of a transplant, is the APPG secretariat.

A year into the *Mix and Match* research project, I felt there were important contributions for the research to make to any discussion about this issue. The inquiry asked several open questions, and I felt the project was best placed to answer some specific ones amongst these:

- What barriers might patients with blood cancers and blood disorders face in accessing stem cell transplantation and post-transplant clinical care?
- What are the experiences of people and their families who have struggled to access treatment, care and support that meets the full range of their physical, psychological and practical needs?
- What national, regional and local levers would support improving access to the care and support stem cell transplant patients need? Do you have any examples of best practice in other areas of healthcare?

In this document, you can read the submitted evidence from *Mix and Match* to the inquiry.

It is important to note that at the time of submission, this project was at only a year into its research. More findings, and published peer-reviewed research outputs to support these, will become available as the project matures. These will all be published on the project website: <http://mixandmatch.blog>

Rationale for the research underpinning the evidence

From a sociological perspective, the project looks to learn how race may be being used to create community, and what the different outcomes of that use might be. Race is used in different ways to save lives, but biological racial difference may also be reasserted in the process. This project will make a major contribution to understanding how race and the specific category of mixed-race are being enacted in a biomedical context, whilst also providing valuable knowledge to those working to address the significant health inequality outlined above.

The project will ask the following research questions:

- To what extent, and in what ways, are racialised communities constituted through initiatives encouraging BAME people to register as stem cell donors?
- How are mixed-raced bodies understood, and mixed-raced communities constituted, in initiatives encouraging mixed-raced people to register as stem cell donors?
- What are the social, political and ethical implications of these initiatives, and how might sociological theories be further developed to help understand the use of race in biomedical contexts?

Methodology for the research underpinning the evidence

Using ethnographic and digital methods to explore donation drives and social media campaigns, this research looks at how racialised groups are being engaged with in a biomedical context. 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 three social media campaigns run by or for individuals looking for a match – including Tweets, Facebook posts, media coverage and their blogs and webpages.

Inquiry question:

What barriers might patients with blood cancers and blood disorders face in accessing stem cell transplantation and post-transplant clinical care? *This question is specifically about medical treatment. Are some patients less likely to be referred to transplant, to find a match, experience delays or to progress to transplantation for other reasons? This question also refers to follow-up treatments and care.*

I have spent a good deal of time with individuals who have themselves been seeking a stem cell match and have been unable to find one. This is as part of my ongoing three-year qualitative research fellowship with the Wellcome Trust (<http://www.mixandmatch.blog/>), as well as a previous social sciences PhD study focusing on related issues. I have been working with the African Caribbean Leukaemia Trust (ACLT) and Race Against Blood Cancer (RABC), and have undertaken significant amounts of social media data analysis looking at stem cell donor recruitment campaigns. I have also undertaken interviews with individuals who need a transplant and cannot locate one.

In this policy domain, it is frequently acknowledged that there remains a disparity in access to treatment that falls along racial lines. However, there is little to no acknowledgement that this produces a huge amount of work for individuals (often of BAME backgrounds) who then feel they have no option but to seek their own match and launch their own campaigns. These campaigns are relatively frequent, appearing in the news and so forth (participants have appeared on BBC Breakfast, Sky News, in print media like *The Telegraph* and *The New York Times*). Increasingly these campaigns avail themselves of social media connectivity to reach wider racialised audiences than their immediate social networks allow.

My research focuses in part on the substantial amount of work undertaken by donors and their families (with more and less formal levels of support from local registries like DKMS UK and Anthony Nolan) to locate matches whilst they are receiving treatments like maintenance chemotherapy and so on. Ultimately, as I describe in research that is currently in draft form but that will be available for circulation in the next year, this work is extensive:

It requires individuals having to “come out” with their diagnoses and prognoses to people they have never met via social media or even on national and international media when their stories are picked up by news outlets. Compare

this to most people who require a stem cell transplant for a haematological disorder. They will never have to do this because a match was more readily available within the UK aligned registries, or via the WMDA's global network of registries. This means sharing personal information that many of us would probably never conceive of sharing beyond close family, friendship and work networks.

It often requires recourse to a range of skills that one might more likely expect to see in a marketing agency than a patient campaign. A campaign might establish its own hashtag (e.g., I would call mine #Match4Ros) and develop a website and a social media presence; branding and logo development; the production of charity events, wrist bands and other ephemera; the cultivation of attractive "clickbait" content to "game" social media algorithms using images of themselves and their families. This work necessarily makes estimations about what will provoke more sympathy (and therefore action in the form of donation) in audiences.

This work also includes spending time at in-person donor drives (interviewees have had much assistance from Anthony Nolan and DKMS in doing this work). Running these might involve telling their story to all who will listen, often involving their own children in their activities (with a view to demonstrating the value of registering to donate for a parent who might otherwise not be around to their raise their children). Interviewees from my research have described finding this work physically exhausting. Their campaigning doesn't give them time to convalesce as they ought to from gruelling treatment regimens for their illnesses.

This work is being done by a range of individuals and seems to be becoming more common. I would also note that it seems far more likely to be done by minoritized persons who are necessarily less likely to find their match on donor registries (as per the statistics first laid out some ten years ago in the *Stem Cell Strategic Forum* report, but which still bare out in my anecdotal conversations with people working in this area).

Ultimately, this is work that we can all agree they oughtn't to have to do. Were registries more representative, these individuals could focus more on staying well and healthy and living with cancer as they manage their treatment protocols.

This is further compounded by the fact that much blood cancer patient support assumes people will have found their match (if they require a transplant) from the outset. The resources and support for scenarios where this isn't the case, beyond patient support from the registries and of smaller charities like ACLT and RABC, doesn't exist. My research intends to fill this gap through the development of resources. I am happy to share my plans with the APPG and present findings if this is useful.

**MIX +
MATCH**

CONSTITUTING RACIALISED
COMMUNITIES IN
UK STEM CELL DONATION



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Inquiry question:

What are the experiences of people and their families who have struggled to access treatment, care and support that meets the full range of their physical, psychological and practical needs? Please use this question to highlight examples of what may have been relayed to you by patients and families you work with or represent and their struggles in accessing treatment, care and support.

Patients with whom I have spoken describe being confronted with odds that many of us would consider insurmountable. “Your chance of finding a match is 1 in 24 million”, for instance. Or being told that one’s odds are so small, they may as well go home and enjoy the time they have left with their family. The psychological trauma of this news, which continually ends up with patients becoming the invaluable person-focused campaigns that win registries large spikes in donors, is not really acknowledged in policy.

Further consideration ought to be given to how we as a wider public, and the global stem cell infrastructure (particularly clinicians and registries) can most fruitfully support this work, whilst acknowledging that the beneficiaries of it are likely never to be the individual campaigner, but unknown strangers. Those few registered stem cell donors who do actually go on to donate, will never have met their recipients nor have registered in their name. It is in this sense that the work that individual patient campaigners do cannot be calculated: its ultimate list of beneficiaries stands to be very long and international.

Both more widely acknowledging this labour and thinking of ways to support it (as well as focusing on trying to make sure it doesn’t need to happen, e.g. through supporting BAME recruitment initiatives) is necessary. A nice example is in Anthony Nolan’s awards ceremony, or Race Against Blood Cancer’s annual gala dinner, which acknowledges individual patients who have done important recruitment work. That said, there is more yet to do to ensure that patients who share their stories for the benefit of expanding and diversifying the registry are supported to do so, and feel properly acknowledged and appreciated for having done what is realistically (and sadly) likely to be quite selfless work.

Inquiry question:

What national, regional and local levers would support improving access to the care and support stem cell transplant patients need? Do you have any examples of best practice in other areas of healthcare? This question is mainly directed at policymakers, healthcare professionals and commissioners but other insights are welcome.

My research suggests that there need to be clearer resources for blood cancer patients for whom a match has not been located. This would include making sure clinicians are well-versed in how to signpost their patients to support with registries and smaller recruitment charities. It shouldn't be limited to this, however. The statutory healthcare system has a duty to serve its entire public. Currently, those who need help too often rely on the support of a stretched third sector (registries and recruitment charities) who have a range of commitments and limited resources.

My own research is currently focused on considering the most effective routes and resources to improve care and support for would-be transplant patients who cannot find, but desperately need, a match. I would welcome an opportunity to work with the APPG in this endeavour or discuss this work with them in oral evidence.