

Where are our Nation's Donors?

ALL-PARTY PARLIAMENTARY GROUP:

Ethnicity Transplantation and Transfusion

Advocating equitable access to treatment for mixed heritage and ethnic minority patients

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All-Party Parliamentary Group: Ethnicity Transplantation and Transfusion

Purpose

Highlighting how the lack of donor participation affects patients with ethnically diverse backgrounds. Raising awareness of health inequalities faced by mixed heritage and ethnic minority patients requiring an organ or stem cell transplant or a blood transfusion. Advocating equitable access to treatment for mixed heritage and ethnic minority patients.

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Contents

EXECUTIVE SUMMARY AND RECOMMENDATIONS	PAGE 4
I BACKGROUND TO THE APPG AND INQUIRY:	PAGE 8
<ul style="list-style-type: none">• About the APPG• Terms of reference• Written evidence• Oral evidence	
II INTRODUCTION: WHAT'S THE PROBLEM?	PAGE 10
<ul style="list-style-type: none">• Box A – Finding matched stem cells for UK mixed heritage and ethnic minority patients• Box B – Case study: Daniel's story	
III WHAT'S BEHIND THIS INEQUITY?	PAGE 18
<ul style="list-style-type: none">• The need for better data, to drive informed strategies• The need for cultural competence in healthcare• Box C - Culturally competent communication along the patient pathway• The need for trusted messengers to encourage a culture of donation• The need for education• The need to build equality into research infrastructure, new treatments and technologies• The need to ensure accountability	
IV HOW TO TACKLE THIS INEQUITY	PAGE 32
V CONCLUSION	PAGE 34
VI RECOMMENDATIONS AND NEXT STEPS	PAGE 36
<ul style="list-style-type: none">• Box D – The imperative for action now• Box E – Who's who in registering and administering donors	
GLOSSARY	PAGE 42
APPENDIX – LIST OF EVIDENCE RECEIVED	PAGE 54

Executive summary

WHERE ARE OUR NATION'S DONORS?

We ask because lives are being lost. Every patient needing a blood transfusion, stem cell treatment or organ transplant relies on a donor being available to match their need. And as many families tragically testify, donors aren't always found. This is particularly, and disproportionately, true for the UK's mixed heritage and ethnic minority communities.

Our All-Party Parliamentary Group (APPG) was launched in December 2022 to focus attention on this known and growing problem. This is our first inquiry, and it confirms that there is a moral imperative for action. The National Health Service (NHS) is bound to provide equality of access, but a patient's chance of surviving diseases such as blood cancer, and chronic conditions such as kidney disease, are heavily swayed by their ethnicity: mixed heritage and ethnic minority communities wait longer for diagnosis, and longer for the best donor to be found for their treatment.

The UK's mixed heritage and ethnic minority population face a double whammy of inequity:

- they are more likely to need donors - due to diseases such as sickle cell and kidney disease, which disproportionately affect them
- they are less likely to find well-matched donors on the blood, stem cell and organ donor registers.

This is particularly true for patients in need of stem cell transplants, where matched tissue type (most often found in donors from similar ethnic backgrounds) is critical to successful outcomes.

It's a known problem, and it's a growing problem: currently, one in five adults are mixed heritage or ethnic minority, but this increases to one in three school age children. It's a ticking time bomb if left unaddressed.

This inequity has significant implications for patients, their families and carers, the NHS and the economy. It's known that we need more donors, it's also known that we need more donors who are more likely to match the tissue and blood types of mixed heritage and ethnic minority patients.

Despite this having been acknowledged for many years, it has not been effectively addressed.

We sought to discover why:

- **our most startling discovery is how little hard data is available and the lack of progress in getting it.** Our healthcare systems don't currently record ethnicity with the consistency, nor the granularity, to be clear about the gaps in need and the outcome of treatments. We fail to understand how meaningful strategies can be set without this information. Our witnesses were unanimous in agreeing that better ethnicity data is needed, and while we appreciate the significant challenge involved in establishing national sets of ethnicity categories, we are astounded by how little progress has been made since this was recommended in 2010, this time by the UK Stem Cell Strategic Forum (UKSCSF). We ask for immediate ministerial attention as this lack of data has clear and present implications for setting and monitoring strategy, for accountability and ultimately for patients' lives.
- **we were also struck by how deeply inequity is baked in.** We heard compelling evidence of poor cultural competence within our healthcare systems – set up post war for a white population – with people and structures failing to meet the social, cultural and linguistic needs of all donors and patients. Distrust in 'the system', cultural and religious barriers and poor communication are contributing to delays in diagnosis and referral for mixed heritage and ethnic minority patients, harming the chances of successful treatment. The trusted messengers and tailored messaging that research evidence, community campaigns and charities have shown will overcome these barriers are not being properly resourced. Limited funding is impeding efforts to build a culture of donation among mixed heritage and ethnic minority communities. We recommend a review of the whole transplant care and transfusion pathway, with an equality tsar appointed to galvanise action, and inter alia, to ensure all organisations in England that receive public funds are clearly accountable for their progress in improving outcomes. We cannot allow this to drift a moment longer.
- **we heard particular concerns about the scrutiny and accountability of the stem cell registries – the organisations responsible for finding unrelated stem cell donors.** It's a curiosity in our healthcare system that the NHS is responsible for performing stem cell transplants but the responsibility for stem cell searches and imported stem cells for UK patients rests with and is led by an organisation that sits outside the NHS. This in itself causes issues with regards access to data. The stem cell registries each set their own strategies for recruiting donors, having regard to the recommendations from the UKSCSF. Evidence points to inadequate recruitment targets for mixed heritage and ethnic minority donors. The stem cell registries are remunerated by the NHS for the provision of clinically suitable donors for NHS patients. The stem cell registries have consistently failed to improve self-sufficiency in providing UK stem cells for UK patients, with a continuing and increasing over-reliance on imported stem cell donors. We ask for improved transparency; in reporting, to understand where interests lie and how strategy is set, and ask whether structural reorganisation could lead to consistent policy, help longer term strategic planning and ultimately save more lives.

- **we need better overall education about donation and cultural awareness within training**, for which we suggest a number of quick fixes. We also ask for immediate action to ensure research and clinical trials are inclusive of mixed heritage and ethnic minority communities, to ensure further inequity isn't baked in.

What do we want to come out of our inquiry? More donors in general, more donors from mixed heritage and ethnic minority communities in particular, greater visibility of donors within UK society, and for our healthcare services to be attuned to the needs of our whole population.

However, given the shocking lack of progress in the last few decades, we have no hope that the necessary change will be delivered without significantly strengthened governance and accountability. We consider this to be particularly true for stem cells. We look to see a minister for transplant and transfusion health inequalities appointed, a ministerial review, and an equality tsar to spearhead action.

Lives are being lost. We cannot, morally, ignore this known problem a moment longer.

Summary of main recommendations:

RECOMMENDATION 1: IMPROVED GOVERNANCE AND ACCOUNTABILITY

- A minister to be appointed for transplant and transfusion health inequalities**, with cross-departmental responsibility for improving outcomes.
- An equality tsar appointed** to galvanise action.
- A ministerial review of all organisations and national charities in England along the transplant and transfusion pathway** receiving public funds for services they provide to the NHS. The review should cover governance and accountability, and include plans to improve diversity within governing groups, plans to include patient and donor groups, patient voices and the effectiveness of the organisations in fulfilling their public sector equality duty.
- Terms of reference and governance for blood, organs and of the UK Stem Cell Strategic Forum (UKSCSF) to be strengthened** for greater accountability.

RECOMMENDATION 2: IMPROVED DATA, REPORTING AND TRANSPARENCY

- a. **A roundtable to be convened by the Race Health Observatory (RHO) to consider data**, inter-alia, the different data sets held and used by the registries and NHS Blood and Transplant (NHSBT), the options for matching patient and census data, the public interest in recording ethnicity at birth, and the accompanying public education campaigns required to engender trust in the process.
- b. **Department of Health and Social Care (DHSC) review of the strategic objectives and financial imperatives behind the targets for all forms of donor recruitment**, including plans to improve UK self-sufficiency in stem cells and reduce the reliance on international stem cell donors; annual targets to be set and reported to the minister for transplant and transfusion health inequalities.
- c. **Review of the Organ Donation (Deemed Consent) Act 2019** to understand the impact of family's rights to overturn donors wishes, with particular focus on the impact on mixed heritage and ethnic minority donations.

RECOMMENDATION 3: IMPROVED EDUCATION, AWARENESS AND ACTIVITY

- a. **NHSBT review of funding for charities and community campaign groups** to include a broad assessment of the economic and health benefits derived from improving mixed heritage and ethnic minority engagement with health services, alongside their impact in raising awareness of donations. If the case for greater devolution to these organisations is made, increased and longer term funding must follow.
- b. **Wide action to build a culture of donation across the whole UK population**, including:
 - amended Personal Social Health and Economic (PSHE) guidance to schools to cover blood, organ and stem cell donation at both primary and secondary level.
 - a long term public information campaign – akin to the FAST stroke campaign – to raise awareness about donation.
 - all forms of donation to be included in future initiatives; adding stem cell and blood donation alongside organs on the Driver & Vehicle Licensing Agency (DVLA) application form and also on passport applications and renewals; including stem cell donor prompts on the NHS App alongside organ and blood donation.
 - making organ donors - living donors and donor families – and their life-saving stories more visible through the concerted efforts of policy makers, opinion formers, media and wider influences and influencers.

I. Background to the APPG and inquiry

ABOUT THE APPG

The purpose of the APPG is: to highlight how the lack of donor participation affects patients with ethnically diverse backgrounds; to raise awareness of the health inequalities faced by mixed heritage and ethnic minority patients requiring an organ, stem cell transplant or a blood transfusion; and to advocate equitable access to treatment for mixed heritage and ethnic minority patients. APPGs are informal groups of members of both Houses with a common interest in particular issues. The views expressed in this report are those of the group. The APPG is chaired by Sarah Olney MP, (LibDem, Richmond Park) with a secretariat provided by Team Margot Foundation. This report is not an official publication of the House of Commons or the House of Lords.

TERMS OF REFERENCE

The APPG launched this inquiry on 12 May 2023 with a call for evidence from organisations and individuals addressing any, or all, of the following points:

- The scale of the problem:
 - a. What are the most significant barriers to addressing the shortfall in organ, stem cell and blood availability for ethnic minority and mixed-race patients?
 - b. What data/evidence is lacking and how can this be addressed?
- Strategies to tackle the issue:
 - a. What initiatives and strategies have been tried and are now in place to increase the diversity of donors, with what impact on ethnic minority and mixed-race donations?
 - b. What initiatives and strategies are planned – short, medium and long term – which specifically address donations from the ethnic minority and mixed-race communities?
- What further changes are required to ensure that the health system can meet the needs of mixed heritage and ethnic minority patients with regards to organ, stem cell, and blood availability? Resource, restructure, or other?

As a Westminster All-Party Parliamentary Group, the inquiry did not cover devolved matters but evidence from the devolved administrations and internationally was welcomed and gratefully received.

WRITTEN EVIDENCE

Written evidence was received from more than 50 individuals and organisations, and is published on the Team Margot website <https://www.teammargot.com/all-party-parliamentary-group-inquiry/>. We would like to thank everyone who took the time to write in with a wealth of data, information, personal experience and opinion; all contributions were invaluable in shaping this report. The appendix to this report lists all written submissions.

ORAL EVIDENCE

An oral evidence session was held for invited witnesses on 29 June 2023, by Zoom, and is available to view on the above-mentioned APPG webpage. This session was chaired by **Sarah Olney MP**, (Lib Dem, Richmond Park), alongside **Jackie Doyle-Price MP** (Con, Thurrock) and **Rt Hon Mark Tami MP** (Lab, Alyn and Deeside). The Department of Health and Social Care (DHSC) was invited to attend the session but declined, stating that NHS Blood and Transplant (NHSBT) could respond to questions on their behalf. There was thus no opportunity to address questions of overarching healthcare strategy. We are extremely grateful to all witnesses who did attend, for taking time out of their busy schedules, and for giving us such clear insights into the problems, practice and potential solutions: **Orin Lewis**, OBE, CEO African Caribbean Leukaemia Trust (ACLT), co-Chair of National BAME Transplant Alliance (NBTA); **Prof Gurch Randhawa**, PhD FPH DL, Professor of Diversity in Public Health and Director, Institute for Health Research, University of Bedfordshire; **Dr Delordson Kallon** PhD FRCPATH, Head of Clinical Transplantation Laboratory, Barts Health NHS Trust; **Mr Rajesh Sivaprakasam** MBBS, MRCS, M.Phil, FICRS, FACS, FRCS Consultant in Transplant, access and general surgery, lead for robotic renal failure surgery & research, Barts Health NHS Trust; **Michele Salter**, CFPA (Hons), Chair, Sickle Cell Society; **Dr Gail Miflin**, Chief Medical Officer and Director of Clinical Services, NHS Blood and Transplant; **David Rose**, Director of Donor Experience and Communications, NHS Blood and Transplant; **Henny Braund** MBE, Chief Executive Officer, Anthony Nolan (supported by **Dr Robert Danby** and **Prof Steven Marsh**); **Prof Smeeta Sinha**, National Clinical Director for Renal Services, NHS England; **Prof John Snowden** BSc, MBChB, MD, FRCP (London), FRCP (Edin), FRCPATH, DTM&H Consultant Haematologist, Director of Blood and Marrow Transplantation Programme, Sheffield Teaching Hospitals NHS Foundation Trust.

Note that this report has attempted to use consistent terminology throughout, with the glossary at the end explaining the abbreviations or shorthand used. Where witness evidence has been quoted, this is in the terms expressed by that witness.

II. Introduction: What's the problem?

“There is no doubt that minority ethnic and mixed heritage blood cancer patients in need of a suitable unrelated stem cell donor continue to face a massive health inequality in comparison to their white counterparts... it is shocking that so little progress has been made in the last 13 years.”

Lionel Salama, Co-founder and Secretary, Sue Harris Trust

1. As constituency MPs, we're regularly confronted with inequalities in health: from the postcode lottery in accessing care to the multiple social inequalities affecting health. There's also a wider injustice: the layer of inequality in health that comes into play through ethnicity. And in particular, the impact that ethnicity has on those needing organ, blood and stem cell treatments.
2. Every patient awaiting a blood transfusion, organ transplant or stem cell treatment needs a donor. Despite the best efforts of the National Health Service (NHS), NHS Blood and Transplant (NHSBT), campaign groups, charities and the donor registries, there are still insufficient blood, organ and stem cell donors to meet demand. This means that whilst we could all benefit equally from these treatments, we won't. And this is particularly and disproportionately true for mixed heritage and ethnic minority patients.
3. The UK's mixed heritage and ethnic minorities are both more likely to need these treatments, because of diseases that disproportionately affect them and, to compound matters, are less likely to find the best options for treatment available, because donors of the right blood or tissue type matches can't be found. This matching is important, and sometimes critical, to successful treatment and outcomes. Despite clinical advances, organs, stem cells and blood are not universally transferable:
 - For blood transfusions, whilst it's relatively simple to find a match across the major ABO groups, for patients needing the limited supplies of Ro blood available (part of the rhesus system) there's a disproportionate ethnic disparity. People of Black African or Black Caribbean heritage are ten times more likely to have the Ro subtype as white northern Europeans.¹

1 NHSBT written evidence explained it can provide matched blood for just over half of all hospital requests with the rest treated with the universal blood type O negative. This is a clinically safe alternative but could mean, long term, that patients develop antibodies

- For organ transplants, and for kidney transplants in particular, matching tissue type reduces the risk of sensitisation and complications for follow-on treatments. The law for deemed consent for organ donation² came into effect in May 2020, but the overall consent rate for deceased donation remains low with large disparities in lower socio-economic groups, older groups, geographically and, so far as it's possible to ascertain, by ethnicity.³
- For stem cell transplants – needed, for example, for treatments for cancers such as leukaemia – a good tissue type match is critical to successful outcomes. As tissue type is influenced by ethnic origin, an unrelated donor match is more likely to be found within the same ethnic community as the patient. Globally, 88% of the world's population is non-white whereas 70% of registered stem cell donors are of white background.⁴

4. The consequent disparities are stark:

- One year after being listed for a kidney transplant, 81% of mixed heritage and ethnic minority patients will be awaiting a transplant compared to 65% of white patients;⁵
- For those needing stem cell transplants, there's a 37% chance of a minority ethnic patient finding a well-matched unrelated donor – compared to the 72% chance for white patients;⁶
- 35% of those still waiting for kidney transplants a year after being listed are from ethnic minorities (compared to the UK population of 18% ethnic minority);⁷
- The overwhelming majority (99%) of active blood donors in England are white – which heavily influences the supply of Rh blood available. The demand for Rh blood is projected to double from 2016/17 levels by 2025/26, with sickle cell the fastest growing genetic blood disorder, mostly affecting people of Black ethnicity. An estimated 40,000 donors of Black heritage are needed⁸ each year.

2 Organ Donation (Deemed Consent) Act 2019; in 2020/21 69% of those approached consented; by 2022/23 this had declined to 61%.

3 NHSBT written evidence: “there is no true picture of how many Black, Asian and Mixed ethnic group people have registered their decision.”

4 <https://swabtheworld.com/en/>

5 Tackling organ donation among minority ethnic communities in the UK-a whole systems approach
<https://academic.oup.com/bmb/article/142/1/4/6562918>

6 <https://www.anthonynolan.org/front/facts-and-stats>

7 Key Stats from the BAME Supplementary Report 2017-18 (NHSBT)
<https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/12164/bame-transplant-activity-report-stats.pdf>

8 NHS Blood and Transplant Annual Report and Accounts 2021-22
<https://bit.ly/45qC4ug>

5. While the statistics make harsh reading, they don't begin to convey the human stories behind them. For these, we thank our witnesses for shedding light on what's involved in waiting to find organ, stem cell and blood donors; the disruption caused to the everyday lives of patients and their families; a wait that adds to costs for the NHS; a wait that disproportionately hits family income of mixed heritage and ethnic minority patients; a wait that affects the eventual success of treatment outcomes for those patients.

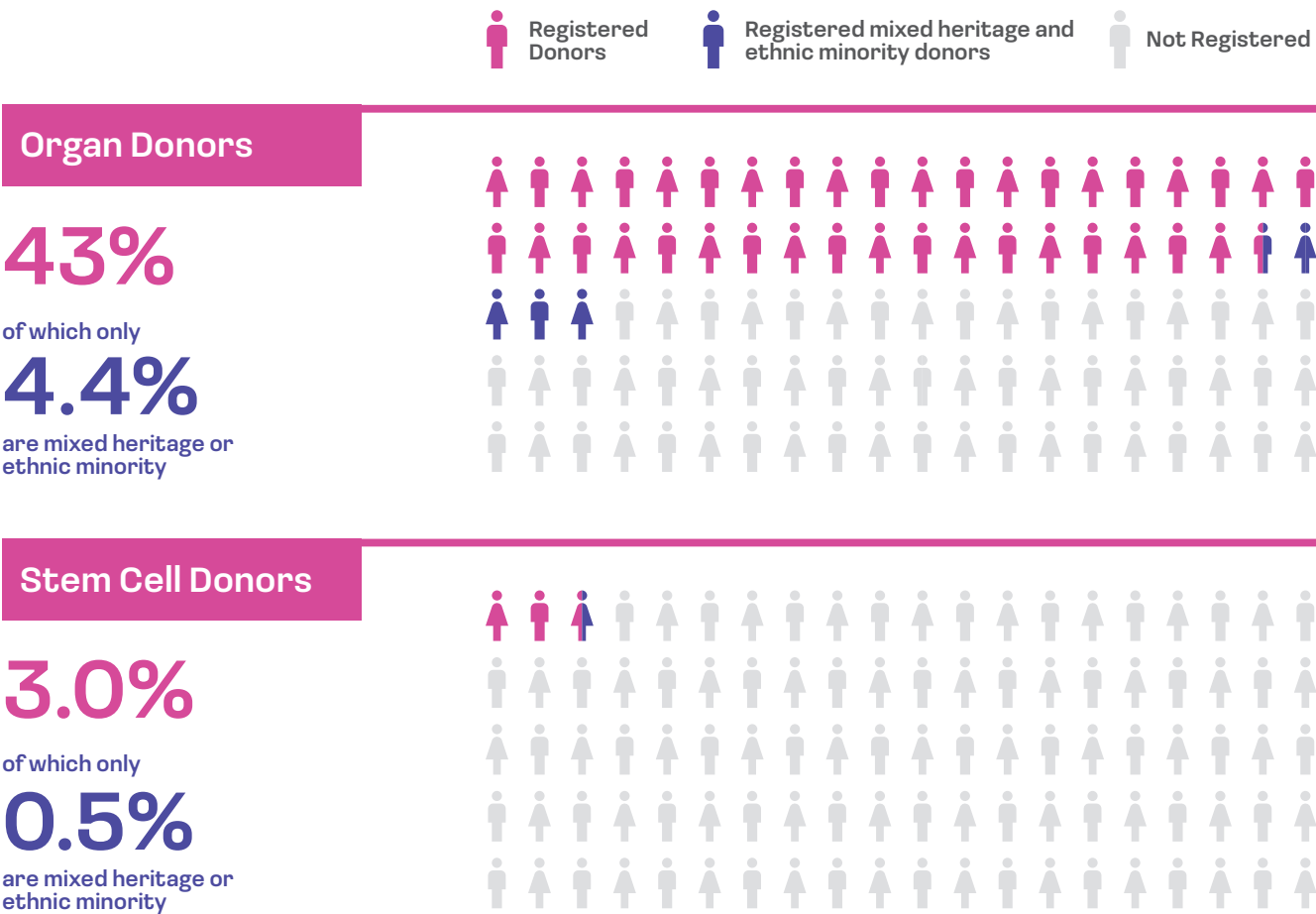
6. **While our inquiry covered all three forms of donation namely, blood, organ and stem cell, progress has lagged most obviously with stem cells.** All the evidence we received, and heard, was clear on the need for more donors, for more donors from mixed heritage and ethnic minority communities, and for this deficit to be addressed as a priority because: "The ethnic diversity of the country is growing, creating a health time-bomb if left unaddressed"⁹. How this need is accurately assessed and best addressed are taken up in this report.

7. Our main concern is the lack of progress. This health inequality has been well known for decades, but rather than hearing hope of reduced inequity we've been shown real risk that it will become worse. Swift action is needed now to ensure the needs are met of an increasing, and increasingly diverse, mixed heritage and ethnic minority population – 34.5%¹⁰ of children in primary and secondary school are from non-white backgrounds - and to ensure that future technologies, cell and gene therapies don't 'bake in' further inequity. We examine below the systemic change needed, and how governance and structures should be revised to ensure accountability for action and progress.

9 Jacob Knox-Hooke, Race Against Blood Cancer

10 <https://explore-education-statistics.service.gov.uk/find-statistics/school-pupils-and-their-characteristics>

Percentage of UK population registered as organ & stem cell donors



BOX A:

Finding matched stem cell donors for UK mixed heritage and ethnic minority patients

“Whilst we know that huge progress has been made, there is still and we know this, inequity in access to well-matched unrelated stem cell donors for people from a minority ethnic background”.

Henny Braund MBE, CEO Anthony Nolan

We have no way of knowing how many patients of mixed heritage and ethnic minority are failing to find suitable stem cell donors.

In part, this is because there are significant gaps in the ethnicity data being collected in the health service and by the stem cell registries. In part, it is because where well-matched donors can't be found, other options – quite possibly second best for that particular patient – disguise the level of unmet need and the inequity in outcomes.

The key to successful treatment is finding a stem cell donor with a well-matched tissue type - Human Leukocyte Antigen (HLA).

The best options for patients are a HLA matched related donor (usually a sibling) or a well-matched unrelated donor from the stem cell registries. Ethnicity comes into play because this HLA matching is more likely to be achieved from donors with the same ethnic heritage. Other alternatives include the 'long stop' insurance to find a cord blood bank donation (umbilical cord blood stem cells donated after birth), where the degree of matching is less critical and haploidentical transplants. See Box E for how these donor searches are coordinated.

Anthony Nolan told us that 15% of donors signed up to the stem cell registries are from minority ethnic backgrounds.¹¹ Their target (20%), set in 2022, appears to proportionately reflect the diversity of the UK population¹². However, the relevance of this target is complicated: first because population diversity doesn't equate to patient need by ethnicity, and secondly, because

11 Anthony Nolan and NHS Stem Cell Registry Annual Review: State of the Registry 2020/21

<https://www.anthonynolan.org/sites/default/files/2022-06/State%20of%20The%20Registry%202020-2021.pdf>

12 The UK minority ethnic and mixed heritage population is 18.1% (Office for National Statistics: Census 2021)

mixed heritage and ethnic minority groups have a significantly more diverse range of HLA types, and a greater number of unique HLA types, than is found in white ethnic groups.

Anthony Nolan said that even if they were to recruit every person from a minority ethnic background in the UK to the donor register, the odds of patients finding a highly-matched donor would not materially change due to increased genetic diversity amongst this patient group.

Professor Steven Marsh explained at our hearing that for every 100 donors recruited from the UK white population, 40 will bring unique tissue types; this compares with 90 new variants in every hundred donors from the UK African population and 60 in every hundred Asian Indian donors.

This has contributed to the view that the mixed heritage and ethnic minority transplant imbalance cannot solely be addressed by recruiting more mixed heritage and ethnic minority donors in the UK: that the gap should also be met through global recruitment, and through investment in new therapies and cord blood transplants. What's critical, is that this shouldn't be at the expense of domestic donor recruitment.

The current UK strategy focusses efforts on recruiting younger male donors, as they tend to provide a higher number of stem cells than female and older donors.

We have sought to understand how commercial imperative influences this strategy. NHS Blood and Transplant told us in written evidence that the stem cell registries need to ensure they have service provision income to support growth ('service provision' is the 'fee income' paid by the NHS for every donation) and "to ensure they have a balanced strategy to support all patients." However, "donor provision rates from [ethnic minority background] donors is still proportionately, significantly below the level of white ethnic group donors, especially for UK patients. A donor strategy that is disproportionately biased to ethnic minority recruitment in percentage terms would be financially unsustainable."

This strongly suggests that financial strategy - ultimately money - is making proportionate mixed heritage and ethnic minority recruitment unviable. If so, this raises some very significant questions about how strategy is being set for achieving equity, where the accountability for this lies, and whether greater resource or systemic change will be needed to achieve equity.

BOX B

Orin Lewis OBE: Daniel's story

"After numerous misdiagnoses, my ailing step-son Daniel De Gale was finally, correctly diagnosed with acute lymphoblastic leukaemia on the 7th April 1993 when he was just six years of age. He initially went through two years of highly intensive chemotherapy, numerous blood transfusions and other toxic treatments to firstly get him into remission in order to ultimately beat the blood cancer.

However, after 9 months of remission Daniel sadly relapsed in December 1995 when the leukaemia came back. Beverley and I were told the devastating news that Daniel would need a life-saving stem cell, or the other terminology bone marrow, transplant, from either a matching sibling, his younger sister Dominique, or an unrelated donor, if he was to beat the illness. Dominique was initially tested but she wasn't found to be a match because siblings only have a 1 in 4 chance of being a perfect match. So then we got family members tested but nothing happened there. It was at this point that the doctors at Great Ormond Street Hospital said to us that they needed to search the world wide register to see if a donor was there for Daniel. They said that the chance of finding a donor for Daniel was astronomical, simply because so few Black and mixed race people had registered, especially on to the UK Anthony Nolan register which had been going for 23 years by that time. A match is when the patient and the donor is from the same ethnicity, and Professor Paul Veys who was personally treating Daniel, said Daniel had a 1 in a quarter of a million chance of finding his donor because of his ethnicity and lack of donors. Whereas if he was white British the chances would be much closer to 1 in 4 or 1 in 5. That is not to say that every white person finds a donor, but they were the odds we were facing. So that was the tipping point for me and Beverley to start the ACLT, African Caribbean Leukaemia Trust, and to put Daniel's future in the hands of our community in this country and around the world. We also started working with many, many other families along the way, who were in a similar situation to us and started an international media campaign.

Daniel meanwhile finished two more years of treatment and had a second relapse in September before, miraculously, a 45 year old African-American woman called Doreene Carney, was found to be Daniel's life saving donor, months after registering on the American register. On 16th June 1999, Daniel touched the hearts of the United Kingdom. His story was covered nationally and internationally as he received Doreene's donated bone marrow cells. At 6:45pm that Wednesday evening, he became the first Black individual to receive a life-saving stem cell transplant from an unrelated donor. Allowing Daniel, six months later to go back to school, and go from strength to strength gaining 12 GCSEs, 3 A levels and then off to university to study sports physiotherapy.

He wanted to become a fully trained physiotherapist and to get his Masters in time for the 2012 London Olympics. So Daniel was finally able to beat his leukaemia and relatively speaking was able to finally to start to live his life to the full, and enjoy family time and family. But tragically, on the 8th October 2008, we lost our Daniel, at the age of 21 due to multiple organ failure. Now this was due to complications with his health having received well over six years of chemotherapy, radiotherapy, the toxicity of it, whilst waiting for that match and the numerous blood transfusions he was having. Beverley and I are convinced that Daniel waited far too long for his donor to be found. Because of lack of access, the lack of urgency and many other reasons why it took so long. In the end, near the end, he was needing, urgently on a weekly basis needing three to five units of blood transfusions to live. But ultimately, multiple organ failure, his kidneys and liver were devastated, and he needed an organ transplant. So Daniel was touched by all three forms of donation. And following Daniel's passing our charity, the ACLT, has continued to provide hope and support to patients living with illnesses where a matched donor is much needed.

We don't want people to wait like Daniel waited. Like we as parents had to wait. And so as I come to the end of this statement, since 1996 when we started we found well over 200 actual life-saving blood cancer patients, stem cell donors. Tens of thousands of people, especially those from the Black and mixed race community have been registered on to the Aligned Registry. Thousands to start to giving blood, and many others to start registering and stay on the organ donor register.

However, we still recognise that a Black or mixed-race individual living with a blood cancer like leukaemia still, at best, has a 37% chance of finding a well-matched unrelated stem cell donor in comparison to their white counterparts, who at best have a 72% chance of finding a life-saving stem cell donor. Less than 1% of blood donors are Black and similar figures for organ donation. So we the ACLT, alongside those on this great initiative that has been put together today, are fighting to make sure that access to treatment, and to transplant and to transfusions for people of diverse backgrounds is going to get better because of what's going to be debated, and the results and inquiry findings that come out of this.

And so in closing, Beverley, me and our small but dedicated African Caribbean Leukaemia Trust, ACLT, team and volunteers continue to be multifaceted and inspire many others in this country to become potential stem cell donors, to give blood and stay locked in to and opt-in to the organ donor register in order to inspire others to give the gift of life through donation and transplantation."

Orin Lewis OBE, CEO ACLT (African Caribbean Leukaemia Trust)

III. What's behind this inequity?

“It is important to recognise that transplantation has the potential to benefit people from all socio-economic, age, gender, cultural, faith and ethnic backgrounds but our challenge is, just like many other areas of health, the benefits are not actually currently evenly distributed within our society and they don't reflect the diversity of the British population.”

Gurch Randhawa, Professor of Diversity in Public Health, University of Bedfordshire

“An unacceptably large number of people from Black, Asian, Mixed Race and Minority Ethnic backgrounds still spend far too long on the transplant waiting list because of a lack of suitable organs”.

DHSC written evidence

8. Our witnesses were unanimous that inequalities exist. Dr Gail Miflin, Chief Medical Officer at NHSBT, stated this was “unacceptable” and apologised for it. For stem cells, it has been nearly 50 years since Anthony Nolan launched the UK's first stem cell register, and it's now over 30 years since ACLT was founded and launched its campaign to raise awareness for more Black and mixed race donors and a similar period since the Sue Harris Trust first appealed for life-saving donors among the UK's Jewish community. But the problem persists.

Why?

It was put to us by Professor Gurch Randhawa¹³ that there's systemic failure; that the healthcare systems in place to meet the blood and transplantation needs of the whole UK population need overhauling from top to bottom, to ensure equity of access for all ethnic groups. We point to the following key needs:

¹³ and by others in written evidence including Dr Ros Williams and Action on Blood

THE NEED FOR BETTER DATA, TO DRIVE INFORMED STRATEGIES

“There is no one consistent way to record ‘race’ or ‘ethnicity’ in the UK.”

**Dr Ros Williams, Senior Lecturer and Deputy Director of Research,
University of Sheffield**

9. Possibly our most startling concern is how little is known about the scale of the problem. Our healthcare systems don’t currently record ethnicity with consistency, nor with sufficient granularity, to be clear about the gaps in need and outcome for mixed heritage and ethnic minority patients. Without this data, issues cannot be understood, strategies cannot be agreed, and key metrics cannot be set and measured to ensure equity of access.

“Very little is known about how a person’s ethnicity impacts their chances of accessing a transplant and surviving it”.

Henny Braund MBE, CEO Anthony Nolan

10. For organs, whilst there is good data on outcomes from transplantation, this only gives a partial picture as hundreds of patients die every year while waiting for a donor, or within a year of being removed from a waiting list due to ill health, without their ethnicity being consistently recorded¹⁴. NHS England’s National Clinical Director for Renal Medicine, Professor Smeeta Sinha, told us of the need for “more granular data so we know who to target interventions with”. Kidney Research UK explained in written evidence: “There is not a clear pathway to capture data for those transferred from primary to secondary care around chronic kidney disease. Moreover, not dissimilar to other areas of healthcare, ethnic and faith data monitoring is not captured completely on the organ donation register or at time of donation or refusal”.

“The registries have tried their best to accommodate data from ethnic minority communities, but more resource needs to be put into this if we’re to provide high quality treatments such as transplants in an equitable way”.

**Professor John Snowden, Consultant Haematologist,
Sheffield Teaching Hospitals NHS Foundation Trust**

14 Dr Delordson Kallon, oral evidence

11. Dr Delordson Kallon, Head of the Clinical Transplantation Laboratory at Barts NHS Trust explained at our hearing: “We have a lack of insight as data isn’t collected nationally at UK level. It’s anecdotal, but ethnic minority groups are disproportionately removed from transplant waiting lists because we can’t find matched donors. In my centre, in a one-year period, 38% of those removed from lists were Black – this doesn’t include other ethnic minority and mixed race patients.”
12. While data may provide sufficient insight for organ transplant and donation strategy, we’re unclear how the lack of and incomplete data sets available on stem cells can meaningfully be used to determine the UK’s stem cell strategy. Here anecdote – and one small study of four transplant centres¹⁵ - appear to be the best guide. Worryingly, we’re not the first to raise this concern. In 2010, the UK Stem Cell Strategic Forum (UKSCSF) recommended: “standardised data collection and outcome monitoring should be integrated into every stage of the patient pathway so that reliable outcome data can be used to benchmark individual performance and promote best practice.” Evidence provided to the inquiry reveals that this has not been actioned nor achieved.
13. In oral evidence, Henny Braund, Chief Executive of Anthony Nolan, endorsed the need for better ethnicity data for patients in the NHS. Dr Gail Mifflin, Chief Medical Officer for NHSBT, also expressed concern about the gaps in data: “We have very good outcome data for solid organ transplants, but not for stem cell transplantation to help inform strategies.” She explained that for transfusion, “there’s good data for when things go wrong but not for understanding outcomes following transfusions generally which would be helpful to treatment of sickle cell”. But to obtain this “would require the linking of many different data sets and systems.” Anthony Nolan’s written evidence pointed to similar lack of joined-up insight, referring to “using the limited data that we as an independent charity operating outside of the NHS are able to access.”
14. NHSBT sponsor the UK Stem Cell Strategic Forum (UKSCSF) which was established in 2010 as an independent advisory group. NHSBT explained they, and others including Anthony Nolan, are working with the UKSCSF to address the lack of data. Since autumn 2022 Anthony Nolan made it mandatory for transplant centres to provide ethnicity when they make a search request. But we heard the submission of this data from transplant centres is poor¹⁶ and we understand that it doesn’t align with the classifications used for the recruitment of donors¹⁷. Information from Anthony Nolan suggests only 60% of patient ethnicity is being recorded at time of search. There has also been

15 Anthony Nolan, written evidence – 2017-18 study of 4 transplant centres

16 Briefing from Dr Delordson Kallon

17 Written evidence from Sue Harris Trust

no mechanism for recording whether or not a search has successfully identified a well-matched unrelated stem cell donor for a UK patient. A three-year retrospective study has now been initiated by NHSBT.

15. This lack of data has implications for strategy and for accountability. For example, the Sue Harris Trust pointed us to opaque decisions taken for the UK's cord blood bank strategy. In 2010 the UKSCSF recommended the UK cord bank inventory should be set at 50,000 collections, as this offered a cost-effective means to address health inequalities for mixed heritage and ethnic minority patients in particular, where well-matched stem cell donors can't be found. In 2014, it was reduced to 30,000, however at no time have either of these targets ever been met. Notwithstanding, in the last 10 years and in spite of substantial investment, the total UK cords provided for UK transplant patients stands at just 251 – with no data to say if they were used for a single mixed heritage or ethnic minority patient¹⁸.

16. This is too important a need to be ignored any longer. Paucity of data should be addressed as a priority, with nationally agreed and used sets of ethnicity categories. It has been suggested that overlaying anonymised NHS health data with the Office for National Statistics: Census 2021 data could provide helpful insights to enable progress on these issues.

THE NEED FOR CULTURAL COMPETENCE IN HEALTHCARE

“There isn’t cultural competence to understand needs of people from a different background; without an element of familiarity there isn’t the trust in what’s being offered”.

Mr Rajesh Sivaprakasam, Consultant in Transplant, Barts NHS Trust

17. Ethnicity affects demand as well as supply. It's not just that there are fewer ethnic minority donors on the registers, but that there is also proportionately greater need from the UK's mixed heritage and ethnic minority patients. As Professor Smeeta Sinha explained at our hearing: “Some ethnic minorities have a different disease burden, which needs to be accounted for.”

18 Cumulative data published by the Anthony Nolan and NHS Stem Cell Registry, State of the Registry reports

18. Ethnicity plays a part in a number of conditions – including diabetes, hypertension, kidney disease and sickle cell - all of which increase the likelihood of needing a transplant or blood transfusion. But exacerbating this, ethnicity appears to affect speed of diagnosis and referral. We heard from leading renal experts that mixed heritage and ethnic minority patients are more often referred with advanced conditions than white patients, which plays a critical part in successful outcomes. A number of explanations for this were put to us, including cultural barriers to engaging with health services; for example: “Black men have a fear of doctors or are more likely to be hesitant to discuss certain personal issues. This means there is often a delay in assessment, diagnosis or treatment”¹⁹.
19. Cultural barriers can present very practical problems for treatment. We heard of matched family members living overseas, being refused visas to fly into the UK to donate through concern about them being a drain on the NHS²⁰. And cultural competence is providing significant barriers to tackling concerns about donating or receiving treatment. Mr Rajesh Sivaprakasam and Professor John Snowden both provided evidence on this point, explaining the need for information tailored to meet cultural and religious needs in place of today’s ‘one size fits all’. (See Box C)
20. These barriers all contribute to more mixed heritage and ethnic minority patients suffering end stage kidney disease or organ failure than need have occurred. We were told by Professor Smeeta Sinha that the ‘gold standard’ for renal services is pre-emptive transplants – a transplant before dialysis is required – but the UK renal registry data audit of 2017-19 showed those from Black ethnic backgrounds are significantly less likely to be pre-emptively listed (let alone get a transplant), and those from a Black or Asian ethnic background are less likely than those from white backgrounds to have a transplant two years after being on dialysis.
21. As our witnesses testified, the consequences are heart breaking. On top of the human costs and hurt to the patients and their families, there are very clear economic costs arising: additional costs to the NHS, costs to the economy as patients and their carers are unable to work, costs as children drop out of education.

19 Carol Burt (SCIPE CIC) written evidence

20 Dr Delordson Kallon - oral evidence

BOX C

Culturally competent communication along the patient pathway

Professor John Snowden, consultant haematologist and director of blood and marrow transplantation at Sheffield:

“The first step is to identify the donor, and the better the match, usually the better the outcome. That’s important. Also the speed at which donors can be identified, worked up and can give their donation is important in many diseases.

The patient has to be in the right condition, fit and able to go through the toughness of the procedure. Also the patient has to understand all the phases of the transplant - why we’re doing it; the underlying disease has to justify it and balance the risks of the underlying disease, the threat of the underlying disease verses the inherent risks of the transplant.... and that their life thereafter is never the same again. I describe it to my patients as like walking a tight rope. You’re an inpatient for a month. You get chemotherapy, possibly radiotherapy and then you get your stem cell donation, like a transfusion, and often that is the easy bit. But it’s that period thereafter where you are exchanging somebody’s normal immune system for a donated immune system - so life is never the same again. The patient will stay probably for another month in hospital until their blood counts recover. Their immune system is frail; they are recovering from all the chemotherapy and radiotherapy...and the new immune system can also attack the patient. That’s called graft versus host disease.

This tight rope walk remains until their immunity is more normal, and their disease stays in remission and they are hopefully cured of disease – it’s a process of years, not just the 4-6 weeks of being in hospital, and is a period needing full family support.

In this process, communication with patients is of huge importance, particularly mixed and ethnic heritage patients, and includes a team of clinical nurse specialists, social workers, psychologists, physiotherapists, with extra resource if the patient’s first language isn’t English. For the best outcomes, patients need full understanding of the disease and transplant – not for the first month but for years.”

THE NEED FOR TRUSTED MESSENGERS TO ENCOURAGE A CULTURE OF DONATION

“The UK has historically framed the communities as having the problem... communities are very willing to engage with the whole conversation and action, but this has to be led by trusted messengers with tailored messages which requires resource.”

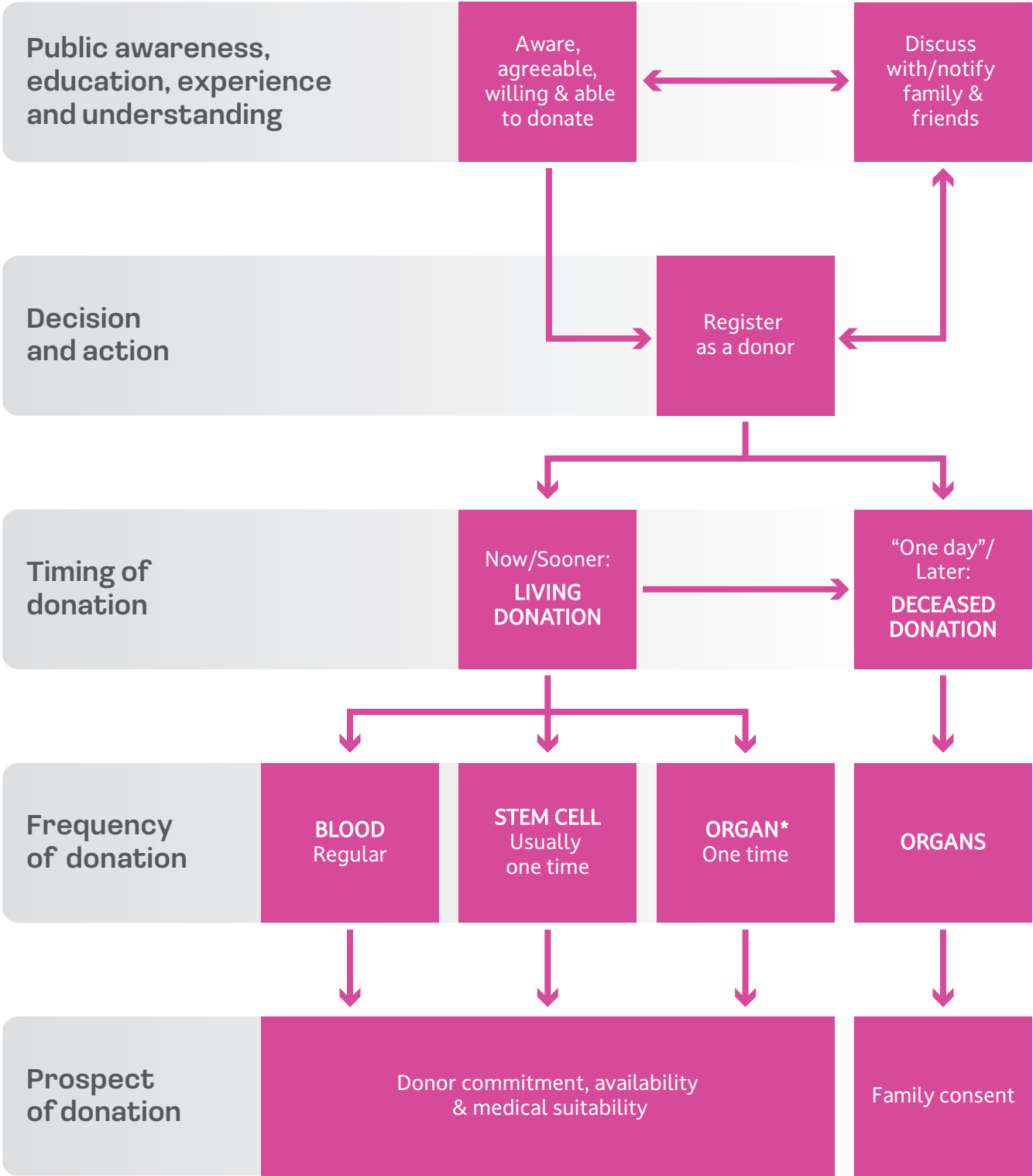
Gurch Randhawa, Professor of Diversity in Public Health, University of Bedfordshire

- 22.** In addition to the cultural competence needed to address mixed heritage and ethnic minority access to healthcare, our witnesses flagged the importance in building trust to encourage donations. Race Equality Foundation wrote: “Lack of trust in clinicians and the system as a whole tends to be higher among groups that are marginalised in society... Contributing to that is a lack of information and education around the issue of donation. While the need for donation in BAME communities is higher, it is still a relatively uncommon experience, and as such people do not know anyone who has been directly affected by it or feel the motivation to find out more. Similarly, people of faith believe there is a conflict between those values and donation (Ali et al, 2022), whereas religious scholarship and interpretation have significantly moved on in recent decades.”
- 23.** The importance of using trusted messengers and tailored messages was emphasised time and time again in evidence: empowering those from the relevant communities to promote to their peer networks the opportunity to register as a potential lifesaver. “It isn’t true that Black people won’t donate. Rather, more needs to be done to empower and enable them to do so.”²¹ And: “where there is the will, it is possible to develop and implement a comprehensive strategy for growing the number of minority ethnic stem cell donors.”²²

²¹ Action on Blood, written evidence

²² Sue Harris Trust written evidence

The donor journey and the process to donation



*Regarding living organ donation: a healthy person can lead a normal life with only one functioning kidney so is able to donate the other to help someone in need of a kidney transplant. Part of a liver can also be transplanted from a living donor to help someone in need of a liver transplant.

24. In oral evidence, David Rose told us how NHSBT continued to adapt donor recruitment for blood donors. But perceptions vary. For example, Action on Blood explained how this had “hardly changed” since the Second World War, “unlike other countries that use travel vouchers, tax incentives, time off from work... UK donors receive biscuits and squash as their only reward for a lifesaving donation. Appointments during the working day, in inconvenient locations and set far into the future when the urge to donate has long since evaporated favour those with the affluence, time or historical and/or familial connection to donate.” They pointed to the need to locate donation centres in areas with large ethnic minority communities - such as the success of a centre in Stratford, East London, in recruiting donors. They also suggested that recruitment campaigns learn from commercial organisations expert in engaging mixed heritage and ethnic minority youngsters, to win hearts and minds over to blood donation as effectively as to sports shoe brands.
25. For organs, messaging on donation faces two hurdles: first, encouraging people to register their decision to donate, and informing family members about it, and then gaining consent from those family members at time of death. NHSBT’s written evidence explained there is a lower opt in rate for minority ethnic people – 65% Black and Asian against 75% white. This gap is then exacerbated by decisions not to consent to donations²³ - which run at almost twice the pace for ethnic minority families as for white families (consent is 40% for Black and Asian families against 71% for white families).
26. Lhiza Smith, Specialist Requestor/Specialist Nurse for Organ Donation (SR/SNOD), in a London team illustrated this in written evidence: “...when approaching families belonging to the BAME group, I always have this reservation and doubt in obtaining consent ...culture, religion and myths... misconceptions and gaps in understanding organ donation all result in inequitable access to transplantation as a treatment for end stage organ failure. Religion also ranks highly... as most of them refuse consent due to their belief that OD [organ donation] is contradicted with their religion”. Written evidence from Sophia Iman Ali²⁴, (whose father was instrumental in Mufti Zubair’s updated Fatwa on organ donation in Islam) explained conversations on donation and transplantation in Muslim and South Asian families typically only take place should a family member become ill, when they were not helped by lack of information in Urdu and Arabic. The Vanik Council pointed to lack of awareness within the Jain and Hindu communities about being a living donor, about the

23 The Organ Donation (Deemed Consent) 2019 Act allows families to decline to give consent or authorisation for donations

24 Sophia Iman Ali, written evidence: “The result of this was that living donations are permissible if the harm to the donor is minimal. However, deceased donations have yet to be discussed due to lack of knowledge on when the Rūḥ (soul) has left the body.”

deceased donor process and the need for producing culturally competent communication, through collaboration with community organisations, to foster a culture of donation.

27. NHSBT's faith and organ transplant plan recognises the need for better resourcing for staff training, to build familiarity with faith and cultural issues relating to death and consent. Alongside this, David Rose told us NHSBT recognises the importance of trusted messengers in donor recruitment, and that NHSBT is reviewing its community grants programme. This currently funds 50 groups across England and Wales sharing £685,000 – with grants from £50 to a maximum of £20,000. As one example, Action on Blood pointed to a Nollywood film they had funded through a NHSBT grant, where one of the Nigerian celebrities involved went from being against organ donation to getting an organ donor card and encouraging her followers on social media to consider doing likewise. The imperative for a rethink of this resource was raised repeatedly, including:

- Race Against Blood Cancer, who asked for: “a devolution of ethnic minority donor recruitment to smaller charities with stronger genuine links into communities. This would need consistent and long term funding and support to allow the recruitment to scale effectively.” They pointed to the 35%+ ethnic minority sign ups they had gathered since 2015 – beating the 20% targets set by NHSBT, Anthony Nolan and the UKSCSF – and explained the transformational impact of hiring a “geography and community-targeted community engagement manager, to professionalise the key tasks of connecting with the community, educating people especially young people, and signing up more donors.” They saw funding roles of this type as fundamental to embedding people in key minority communities with the “remit and mandate to bring about culture change and behavioural change, as well as saving lives by signing people up”.²⁵ In written evidence, Alan Miller suggested that for stem cells this could be funded through registries sharing the fee they receive for providing a donor with the organisation instrumental in registering the donor.
- ACLT pointed to what they could achieve if they had funding to provide hubs in all the UK's main cities with large populations of Black and mixed heritage communities.
- The Sue Harris Trust explained how they had developed a successful model for proactive stem-cell recruitment. Taking their proven programme for Jewish Swab Week to Luton's super-diverse communities, they had run the UK's first town-wide stem cell donor recruitment campaign. It was organised in partnership with Luton Council, Luton Sixth Form College, the University of Bedfordshire, Anthony Nolan, the National Black, Asian, mixed heritage and minority Ethnic Transplant Alliance, Luton Rising, Cricket East, Wicketz, Streets and

25 Jacob Knox-Hooke, Race Against Blood Cancer, written evidence

Macmillan Cancer Support. The goal was to establish an easily replicable model for donor recruitment, that is not dependent on patient-led campaigns, and is driven by the most appropriate individuals who are culturally sensitive and know the best means to secure community engagement.

28. We are unclear how the full impacts of these measures are evaluated by NHSBT and DHSC. How is the cost of the £685,000 grants programme assessed against success in encouraging – and enabling – a culture of donation? Is any reckoning made of the benefits of patients being able to access donors more readily, and the economic, social and personal value gained from them quite possibly being back at work within a year of a transplant?

THE NEED FOR EDUCATION

29. The evidence we received was clear on the importance of building a culture of donation, so we were surprised to find that NHSBT’s strategy is silent on education. Action on Blood explained in written evidence: “The general public has no concept of the urgent need for them [blood, organ and stem cell donations], that they must be donated by others, or the science behind how they are matched to recipients and transplanted, and the link to ethnicity.” Other evidence stated the importance of “Incorporating donation education in the school curriculum across multiple age groups as well as appealing to college/university students”²⁶. It was explained the imperative behind this is that: “the younger generations are aware and are comfortable with donation so that they automatically register as donors when they come of age. They will also have an influence on their family, encouraging discussion about the various forms of donation within the family and wider community.”²⁷

The current NHSBT and Department for Education (DfE) strategies do not prioritise education about donation. The DfE’s PSHE guidance is under review, and we ask NHSBT, DfE and DHSC to reconsider this point.

30. We also highlight here the importance of workforce education. Aligned to our comments above on building cultural competence, action is needed to address concerns about racial stereotypes in training. As stated by Medics4RareDiseases: “We need to start talking about racism in undergraduate training”.

26 Kate Rynberg, written evidence

27 Dr Daniel J McCloskey, written evidence

NEW TREATMENTS, TECHNOLOGIES, CELL AND GENE THERAPIES AND THE NEED TO BUILD EQUALITY INTO RESEARCH INFRASTRUCTURE

- 31.** Developments were outlined by witnesses at our oral evidence sessions. Dr Robert Danby told us: “The rate of development of new medicines is astronomical at the moment, and it is important that we bring these through to the UK to help our patient population, as I think they will have a benefit in minority ethnic patients who are less likely to find an HLA-matched unrelated donor”. These include:
- Post-transplant cyclophosphamide – chemotherapy after transplant to avoid the complication with graft vs host disease. Dr Danby said this is being used in up to 50% of transplants in the US using an HLA-mismatched donor and could be “pivotal going forward being able to deliver more transplants for patients that don’t have a traditional HLA-matched unrelated donor”. He explained the success of the treatment was contributing to more donors being utilised as more mismatched donations are being used for transplant in the US.
 - Cell and gene therapies – including those currently awaiting the National Institute for Health and Care Excellence (NICE) approval, will be ‘particularly important for sickle cell’ and for patients in whom a stem cell donor is not available or suitable. These treatments have the potential to offer curative therapy and may have fewer side effects compared to stem cell transplant.
- 32.** Professor John Snowden told us: “Outcomes of some diseases behave differently between different groups – some highly prevalent among some groups, such as sickle cell disease, but also leukaemia and other cancers. So we’re in an era of personalised medicine, but the majority of genetic and clinical trial data is conducted in the white populations. Research needs to be relevant to ethnic minority populations and trials inclusive of them.”
- 33.** DHSC’s written evidence outlined the National Institute for Health and Care Research (NIHR) strategy for more inclusive research and for widening participation in clinical trials. The NHSBT’s evidence explained it was committed to innovation and trials “improving outcomes for all patients but particularly where we recognise health inequalities exist”.
- 34.** We were pointed to Lord O’Shaughnessy’s²⁸ report which echoes calls from our witnesses for the UK’s trial infrastructure to be broadened, consistently to ensure research trial sponsors and researchers include all patient communities. This may mean changing structures and extending timeframes to

28 Commercial clinical trials in the UK: the Lord O’Shaughnessy - review:
<https://bit.ly/48Pl57S>

ensure mixed heritage and ethnic minority patients are found; it may mean greater investment in attracting and recruiting participants; it may mean legislative compulsion for publicly funded research to be representative, as in the United States²⁹. Currently, there's no such obligation in the UK.

THE NEED TO ENSURE ACCOUNTABILITY

“The general health bodies should constantly be reminded of these inequality issues”

Melvyn Quartey, Trustee, DWIB (Daniel Whyte Ivor Burford) Leukaemia Trust

35. There are clear moral imperatives for action. We think that the lack of progress raises significant questions for those responsible for setting strategy for donor recruitment targets, for resourcing and running community campaigns, for designing research infrastructure and trials including cell and gene therapies, and for adapting and resourcing workforce training and wider education.
36. Box E (page 40) outlines the framework of the stem cell, blood and organ registries. We received several submissions questioning how the stem cell registries, in particular, were accountable for their strategy, and calling for greater transparency in their funding arrangements. There are certainly some distinct curiosities requiring explanation. For the stem cells registries, there are four independent organisations with four different recruitment and exclusion criterion and two different methodologies for providing samples for those registering as a potential stem cell donor. Anthony Nolan is focussed on recruiting males between 16 and 30, and while we are told this target group provides the best quality stem cells in terms of cell count, it doesn't necessarily improve the quest for donor diversity. Calls for a target for ethnic minority recruitment were only answered in 2022, when 20% was proposed for that one year. But this target reflects the overall population (18% ethnic minority³⁰), rather than the relevant percentage of all mixed heritage and ethnic minority patients in need of a stem cell transplant – data which is not available or not being collected. David Rose confirmed in oral evidence that the expectation was for targets to reflect the UK general population, as a minimum.
37. NHSBT's written evidence explained that the large diversity of HLA types meant that a donor strategy “disproportionately biased to ethnic minority recruitment in percentage terms would be financially unsustainable.” However, it is not clear how the “service provision” (fee arrangements) - the registries are paid by the NHS for each donation - influences this strategy. We would like a better

29 NIH Revitalisation Act 1993 - <https://www.ncbi.nlm.nih.gov/books/NBK236531/>

30 Office for National Statistics: Census 2021

understanding: does the imperative to fund growth drive the UKSCSF's strategy, set in 2014, to focus on 'donors most likely to donate' – as this arguably contributes to inequity of access?

And do the higher fees payable for imported stem cells influence strategy for global vs UK recruitment? In the last 13 years, the UK has remained heavily and increasingly reliant on imports, despite the UKSCSF's recommendations for increased self-reliance, not to mention the UK Government's wish to reduce reliance on imported stem cells.

38. Transparency is also lacking in how targets are set for cord blood - and the accountability for those targets. The Sue Harris Trust wrote: "the much-touted insurance policy of the umbilical cord blood inventory for minority ethnic patients has sadly not proven to be the case: In the last decade, the total UK cords provided for UK patients stands at just 251."
39. Further scrutiny is also needed of the overall strategy for donation. Where does accountability lie for encouraging a UK culture of donation? Largely thanks to the Driver & Vehicle Licensing Agency (DVLA), 43% of the UK's population has opted into the NHS organ donor register. The DVLA campaign for organ donation doesn't promote blood and stem cell donation and in contrast, only 1.4% of England's population actively give blood and just 3% of the UK population are on the stem cell register. The NHS App refers to organ and blood donation but not stem cell donation. Written evidence ³¹ suggested DVLA should encourage organ donors to join other registries. When we asked David Rose of NHSBT about this, he suggested common messaging wasn't the best way to engage all communities, although he pointed to NHSBT's broad campaign on 'Giving Types'.

Evidence we received from Nishtha Chugh suggests there is much to be learnt from how other countries, ethnically similar to the UK's minority communities, have increased organ donor rates.

31 Nadia Martini, written evidence

IV. How to tackle inequity

40. Our witnesses identified a raft of issues to be addressed - many being longstanding and widely acknowledged. This persistence suggests a 'whole systems approach' is needed to address inequity - encompassing prevention, management, treatment of long-term conditions that lead to organ failure, organ donation and transplantation and blood transfusion.

We've reached a tipping point where **systems-wide change** is needed to address inequity, rather than tinker with 'add-ons' to existing strategy. The healthcare systems set up post war, to cater for a white population, need to be rethought to ensure they are meeting the blood and transplantation needs of an increasing, and increasingly diverse mixed heritage and ethnic minority population.

41. We heard and have seen compelling evidence of the need to improve **cultural understanding and competence**: to build awareness for disease prevention and treatment, to engender trust for donor recruitment, to ensure equity in research trials including cell and gene therapies. For example, as Mr Rajesh Sivaprakasam pointed out, there's no ethnic minority representation on the NHSBT executive board, and in the wider NHS it would be good to have someone from an ethnic minority to address chronic diseases. We recommend this should be reviewed from the top down.
42. Everything we have heard suggests that more **effective collaboration** is needed. Community campaigners – the trusted messengers with effective messages – need to be properly resourced to help engage donors and demystify disease. David Rose told us that NHSBT is exploring increased funding and longer-term grants. We urge this as a priority, informed by evidence of the cost-effectiveness of these campaigns.
43. We support witnesses' calls for improved trust and **collaboration between the NHS, industry and the third sector**, allowing each party to do what they do best, allowing successful pilots - such as the peer educator programme from Kidney Research UK – to be scaled up to benefit wider donation.
44. **In view of the particular issues raised for stem cell donations, we recommend reviewing the accountability of the stem cell registries.** We ask whether a structural reorganisation could lead to consistent policy and help longer term strategic planning. We've raised questions about the balance of interests in the strategy to target those donors most likely to donate, rather than those most likely to address the imbalance in patient need. We need greater clarity to understand this, and to explain where interests lie in servicing demand for stem cells from outside the UK. Where does strategy – and responsibility – rest for improving UK self sufficiency?

45. We understand that **international collaboration and recruitment is a necessity**, but this should not be to the detriment of domestic activity. The UK registries and charities are actively working with Chile, Germany, India, Israel, Poland, South Africa and USA (in addition to working with the World Marrow Donor Association), and we agree there is a moral obligation to help other countries establish registries, for their own and mutual benefit. Currently, 70% of the global stem cell donors are of white background whereas 88% of the world's population is of a non-white background³². But we are unclear where overall accountability for stem cells rests in the UK for this multi-track approach.
46. Perhaps the most pressing need is for **better, more granular data** on patient and donor ethnicity and treatment outcomes to help drive strategy and improve accountability. This need has been known for at least 13 years. The UK Stem Cell Strategic Forum (UKSCSF) recommended in 2010: “standardised data collection and outcome monitoring should be integrated into every stage of the patient pathway so that reliable outcome data can be used to benchmark individual performance and promote best practice.”
47. Our witnesses have asked for all hospitals, NHS and private, to log the ethnicity and religion of all patients to reveal how many are diagnosed annually; how many need organ transplants, blood donations and stem cell transplants; the ethnic minority breakdown in percentages for patients awaiting them; how many receive transplants in time and how many don't. This should be at a sufficiently granular level to ensure multiple ethnicities and mixed-heritage are recorded. We're aware of the complexities involved in agreeing – and setting – a standardised set of ethnicity categories and the educational campaign that would need to be run alongside this development, but we consider change is essential to developing informed, actionable strategy for equity.
48. NHSBT explained they recognise the importance of investing in data and are looking to ‘consider the feasibility and means of improving the collection, analysis and publication of data by ethnicity and religion’³³. Whilst NHSBT have full responsibility for blood and organ, this is not the case for stem cells. This is owing to some of the organisational processes, as well as the operational responsibility for stem cell searches for UK patients resting with an independent charity, operating outside of the NHS.

32 Swab the World – <https://swabtheworld.com/en/>

33 NHSBT written evidence

49. Which leads us to conclude that progress in all this is unlikely unless and until we have clearer channels of accountability and oversight. Mr Rajesh Sivaprakasam explained in oral evidence how appointing a national lead for gun crime had catalysed action. A similar convening figure could help drive a review of the organisations, the processes and procedures, the governance and accountability to ensure equity of access to treatment for all ethnic groups in the UK population.

We suggest that the Race Health Observatory take a lead in this and that a Transplant and Transfusion Health Inequalities Minister be appointed for ultimate accountability.

V. Conclusion

50. We conclude that there are serious issues to be addressed which, morally, cannot be ignored a moment longer. We have found that there are evident, basic inequalities in access to transplant and transfusion treatments for mixed heritage and ethnic minority patients in the UK, with significant implications for patients, their families, communities and the economy, with some serious questions raised about trust in the systems administering them.

51. Tragically, these are not new findings, which is why we have no confidence that they will be resolved through amendment and add-ons to existing strategy and structure. We need urgent action and systemic change to ensure accountability and progress:

- We need a minister with overall responsibility for catalysing action across government departments and agencies, and a ministerial review of the systemic change needed to drive the immediate and short-term need to increase donors from mixed heritage and ethnic minority groups, and the longer term focus to decrease the number of mixed heritage and ethnic minority patients requiring treatments.
- We recommend drawing on the lessons learnt from the UK Organ Donation Taskforce³⁴.
- We recommend that DHSC take a hard look at building cultural competency in four core areas: transplant and transfusion services; workforce and staff training; trials and research, including cell and gene therapies; and public engagement.
- Responsibility must be clearly assigned within government, NHS England, NHSBT and then to the community for an integral strategy for equity. We suggest this is galvanised by an equality tsar.

34 Professor Gurch Randhawa written evidence

Future technologies may provide solutions, but this potential prospect can't be used to kick the issue down the road any longer. We need only look back 13 years to the promise of cord blood and how it was believed to be the panacea for mixed heritage and ethnic minority stem cell transplantation. We need more donors from more ethnically diverse backgrounds and to deliver this, we need our relevant healthcare services and registries set up to deliver equitable standards of care, access to care and outcomes.

We note that this is an area of constantly changing dynamics, with an ever-developing evidence base³⁵. As an APPG we intend to be dynamic in monitoring developments whilst continuing to push for the change needed to ensure equity.

35 At time of going to press:

- The State of the Registry report on stem cells (2022 - 2023) was awaited;
- Professor Randhawa's latest research has since been published: Taking a "Care Pathway/Whole Systems" Approach to Equality Diversity Inclusion (EDI) in Organ Donation and Transplantation in Relation to the Needs of "Ethnic/Racial Migrant" Minority Communities: A Statement and a Call for Action;
- NHSBT's latest report into Ethnicity Differences in Organ Donation and Transplantation was published in October 2023

VI. Recommendations and next steps

RECOMMENDATION 1: IMPROVED GOVERNANCE AND ACCOUNTABILITY

- a. **A minister to be appointed for transplant and transfusion health inequalities**, with cross-departmental responsibility for improving outcomes.
- b. **An equality tsar appointed** to galvanise action.
- c. **A ministerial review of all organisations and national charities in England along the transplant and transfusion pathways** - prevention, management, treatment, donation - receiving public funds for services they provide to the NHS. The review should cover governance and accountability, and include plans to improve diversity within governing groups, plans to include patient groups and patient voices and assess the effectiveness of the organisations in fulfilling their public sector equality duty. All of the research evidence highlights the importance of building trust among ethnic minorities – something which can be delivered by developing a culturally competent approach to policy making.
- d. **Research funding** for ‘demand’ and ‘supply’ side transplant issues should be conditional on taking a culturally competent approach to research design and participant recruitment, encompassing diseases disproportionately affecting ethnic minorities. We cannot allow further inequity to become baked in.
- e. **Terms of reference and governance for blood, organs and the UK Stem Cell Strategic Forum to be strengthened** for greater accountability. Since the formation of the UKSCSF and the Aligned Registry, the progress made in stem cell and cord provisions for mixed heritage and ethnic minority patients has lagged behind the advances made in blood and organ in terms of equity.

RECOMMENDATION 2: IMPROVED DATA, REPORTING AND TRANSPARENCY

- a. **A roundtable to be convened by the Race Health Observatory to consider data**, inter-alia, the different data sets held and used by the registries and NHSBT, the options for matching patient and census data, the public interest in recording ethnicity at birth, and the accompanying public education campaigns required to engender trust in the process. Strategy for tackling health inequalities is being developed and monitored with poor and incomplete data about ethnicity. Agreement is needed for a consistent way to record ethnicity and religion in the UK with sufficient granularity to ascertain patient need and provide insight to patterns, barriers and outcomes to guide strategies and interventions.

Recommendations Include:

- Improve the collection of ethnicity coding in health service datasets, as recommended by the Nuffield Trust report (June 2021) to give better coverage, consistency, and quality.
 - Commission an analysis now of existing health service datasets to answer the question: “Are patients needing stem cell, organ transplants, or blood, equally able to obtain donations regardless of their ethnicity?”
 - If existing health service datasets prove to be deficient in their coding of ethnicity (coverage, consistency, and quality), records should be matched anonymously by the Office for National Statistics to their high quality 2021 Census records in a secure laboratory to link ethnicity, religion, and other variables to enable the above analysis, and also analysis of donor populations.
- b. DHSC review of the strategic objectives and financial imperatives behind the targets for all forms of donor recruitment**, including plans to improve UK self-sufficiency in stem cells and reduce the reliance on international stem cell donors; publicly available annual targets for mixed heritage and ethnic minority donors to be set and reported to the minister for transplant and transfusion health inequalities.
- c. Review of the Organ Donation (Deemed Consent) Act 2019** to understand the impact of family’s rights to overturn donors wishes, with particular focus on the impact on mixed heritage and ethnic minority donations.

RECOMMENDATION 3: IMPROVED EDUCATION, AWARENESS AND ACTIVITY

- a. NHSBT and DHSC review of funding for charities and community campaign groups** to include a broad assessment of the economic and health benefits derived from improving mixed heritage and ethnic minority engagement with health services, alongside their impact in raising awareness of donations. If the case for greater devolution to these organisations is made, increased and longer-term funding must follow. While the registries are paid a fee for each stem cell donation delivered, there’s no equivalent recompense for the campaigners behind their recruitment.
- b. Wide action to build a culture of donation across the whole UK population**, including:
- amended PHSE guidance to schools to cover blood, organ and stem cell donation at both primary and secondary level.
 - a long term public information campaign – akin to the FAST stroke campaign – to raise awareness about donation.

- all forms of donation to be included in future initiatives; adding stem cell and blood donation alongside organs on the DVLA application form; including stem cell donor prompts on the NHS App alongside organ and blood donation.
- making organ donors - living donors and donor families – and their life-saving stories more visible through the concerted efforts of policy makers, opinion formers, media and wider influences and influencers.

We intend to undertake a further inquiry as an APPG if progress hasn't been made on this in a year's time.

BOX D

The imperative for action now:

Michele Salter, chair of the Sickle Cell Society, outlined the specific challenges for Black communities in building awareness of the needs for donation and treatment of sickle cell.

“Sickle cell is a condition associated predominately with Black communities; not everyone requires blood transfusions – some only need them after a sickle crisis but some need them every three weeks to sustain life. If the blood is not ethnically matched transfusions antibodies can arise, or necessitate further transfusions with risks of iron-overload which can lead to organ failure.

The main issues are the numbers involved – we need 40,000 additional Black heritage donors [per annum]. Trust is an issue in recruiting donors, as is flexibility around where blood donation centres are located and their opening times. NHSBT is investing in community groups such as the Sickle Cell Society to get community buy in – but we [SCS] only receive £20,000 a year. We need adequate resources for NHSBT to appropriately fund projects which are proven to work. The Sickle Cell Society ran the first successful pilot, and this has subsequently been rolled out, but without adequate resources. There are overall economic benefits when considering the full economic spectrum: timely treatment ensures children remain in school, people gain employment, patients spend less time in hospital. This saves money and also ensures the human cost of people fulfilling their potential.

Sickle cell crisis can result in unbelievable pain, which are not necessarily understood or believed by emergency services. In 2019 Evan Nathan Smith had complications following general surgery, and experienced a sickle cell crises, but the ward staff did not recognise he was in crises. The coroner identified that a blood transfusion earlier would have saved his life. This isn't a unique case - blood transfusions are not being used quickly enough to save lives or avoid complications.”

Evan Nathan Smith’s tragic death featured in the APPG on Sickle Cell and Thalassaemia’s report ‘No one’s listening’, published in November 2021. The follow-on findings highlighted by Michele all resonate with the recommendations of our inquiry two years on: the need for appropriately matched blood to reduce antibody formation – antibodies which then work against future organ transplants; improved record keeping and data; improved access to appropriate and nationally recommended transfusion regimes; improved understanding and training in sickle cell in the wider NHS.

BOX E

Who's who in registering and administering donors?

NHS Blood and Transplant (NHSBT) is responsible for the supply of blood, organs, tissues and stem cells. It collects and supplies blood to hospitals in England and is the organ donation organisation for the UK. Total income in 2021-22 was £514.1m, around 72% of which came from sales of products and services to the NHS and the rest through grant in aid from the UK's government³⁶. NHSBT is solely responsible for recruiting all blood donors (1.4% of England's adult population actively gives blood) and all opting-in organ donors (43%); regarding stem cells (3%), this is not the case.

In the UK, there are four stem cell donor registries. In 2012, an **Aligned Registry** was formed which now comprises: Anthony Nolan, British Bone Marrow Registry (BBMR - managed by NHSBT), DKMS Foundation³⁷ and Welsh Bone Marrow Donor Registry (WBMDR). It is aligned only to the extent that transplant centres send in their requests to Anthony Nolan, which searches all UK donors on a single database. The Aligned Registry members do not have a united recruitment strategy, but instead, each runs their own independent recruitment strategy and has their own criteria for prioritising recruitment of donors. Each member of the Aligned Registry manages provision requests of their donor registers for transplant centres outside the UK.

The NHSBT is licensed to import stem cells but does not. Anthony Nolan imports international donor stem cells, receiving NHS funds for each imported donation. Reliance on imports is increasing: in 2022, 160 of the 926 patients receiving an unrelated stem cell transplant came from the UK; the rest were imported – a rate of 83%³⁸. In 2009, the UK stem cell registries provided 791 stem cell

36 NHS Blood and Transplant Annual Report and Accounts 2021-22

<https://bit.ly/45qC4ug>

37 DKMS is an international organisation for connecting patients with matching blood stem cell donors. Set up in 1991, DKMS had become the world's largest registry for stem cell donors by 1995 and in 2022 they accounted for 35% globally. Launched in the UK in 2013, 950,000 blood stem cell donors have been registered to date, helping give over 1,900 a second chance at life.

38 World Marrow Donor Association (WMDA) written evidence

donations: 41% were sourced from UK donors³⁹. In the thirteen years since, the use of domestic donors has decreased from 41%; the most recent available import data (2022) from WMDA states that domestic provision has fallen to a low of 17%.

The Aligned Registry sets the domestic fee schedules for stem cells – that is the charge paid by the NHS to the UK registries. As explained in oral evidence, the fee paid by the NHS is higher for imported stem cell donors than for UK donors. This fee for imported stem cells is set by one Registry.

39 The Future of Unrelated Donor Stem Cell Transplantation in the UK (Part 1) – Findings and Recommendations (July 2010)

<https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/29048/uk-stem-cell-strategic-forum-report-2010.pdf>

GLOSSARY:

Term	Definition
ACLT	African Caribbean Leukaemia Trust - a blood cancer/disorder charity dedicated to raising awareness of the severe shortage of donors on United Kingdom Stem Cell, Blood and Organ donor registers.
Action on Blood	Action On Blood - a charity that supports voluntary blood, organ and stem cell donors.
Acute lymphoblastic leukaemia	Acute lymphoblastic leukaemia (ALL) is a rare type of blood cancer where the bone marrow makes too many lymphocytes, a type of white blood cell.
Aligned Registry	The Anthony Nolan and NHS Stem Cell Registry (known as the 'aligned registry') is formed of Anthony Nolan, DKMS UK, NHS Blood and Transplant (NHSBT), and the Welsh Bone Marrow Donor Registry. The aligned registry partners collaborate to streamline and accelerate unrelated stem cell provision and to increase the availability of unrelated donors and cord blood units in the UK.
Anthony Nolan	Anthony Nolan is a UK stem cell registry. A charity that registers individuals willing to donate their bone marrow or blood stem cells to patients who desperately need life saving transplants.
Antibody	An antibody is a protein produced by the body's immune system when it detects harmful environmental components such as bacteria and viruses.
APPG	All-Party Parliamentary Groups (APPGs) are informal cross-party groups that have no official status within Parliament. They are run by and for Members of the Commons and Lords.
Asian	Asian is the collective term used for those individuals from East Asian, South Asian and Asian communities and countries.
Asian Indians	Asian Indians refers to individuals of Asian Indian heritage and descent.
Baked in	Something that is included in something else and inseparable from it.
BAME	Black Asian Mixed and Minority Ethnic

Term	Definition
Barts NHS Trust	A group of 5 hospitals providing a range of clinical services to people in east London and beyond.
BBMR	British Bone Marrow Register
Black	An ethnic group consisting of individuals with partial or total ancestry from any of the black racial groups of Africa.
Blood	Blood is comprised of plasma, platelets, and red and white blood cells that circulate through the veins, arteries, and capillaries of the body. It delivers essential substances, such as oxygen, nutrients and hormones, to the cells of the body and removes carbon dioxide and other waste products.
Bone marrow transplant	A bone marrow (or stem cell) transplant replaces unhealthy haematopoietic stem cells with healthy ones. It can be used to treat conditions affecting the blood cells, such as leukaemia, myeloma and lymphoma.
Bone marrow	Bone marrow is a spongy substance found in the centre of the bones. It manufactures bone marrow stem cells which produce the various cells and platelets found in the blood.
Cell and gene therapies	Cell and gene therapy are cutting-edge areas of medical development. These therapies are based on the idea that living cells or genetic material can be used to cure a wide range of acquired and inherited diseases, by altering the DNA or using them as a vehicle to deliver treatments. Gene and cell therapy can be used to treat illnesses such as leukaemia, haemophilia, autoimmune disorders, cancer, HIV, melanoma, and cystic fibrosis.
Cell Count	A cell count is a blood test that quantifies how many of the particular cell components in the blood.
Chemotherapy	Chemotherapy is a type of cancer treatment used to kill cancer cells. There are many different types of chemotherapy, but they all work in a similar way. They stop cancer cells reproducing, which prevents them from growing and spreading in the body.

Term	Definition
Chronic kidney disease	Chronic kidney disease (CKD) is a long-term condition where kidney function is impaired. It is a common condition often associated with aging and can affect anyone, but is more common in people who are black or of south Asian origin.
Clinical nurse specialist	A Clinical Nurse Specialist (CNS) is an advanced practice registered nurse that provides specialist care to patients in a variety of specialties, such as paediatrics, geriatrics, emergency care and oncology.
CMV	Cytomegalovirus (CMV) is a common virus. It does not usually cause any symptoms and most people do not realise they have it. Sometimes it causes problems for people with a weakened immune system.
Cord blood unit	A cord blood unit is the term used for the cord blood collected from the umbilical cord and placenta after a baby is born. Cord blood is rich in stem cells, which can be used to treat many different cancers, immune deficiencies and genetic disorders.
COVID	Coronavirus disease (COVID or COVID-19) is an infectious disease caused by the SARS-CoV-2 virus.
Crises	A crises is the term used to describe the painful episodes experienced by patients with sickle cell disease. These can be very severe and last for days or weeks, with an increased risk of serious infections and anaemia, which can cause tiredness and shortness of breath.
DATRI	DATRI is one of the largest unrelated stem cell donor registry in India, that helps patients with blood cancer and other fatal blood disorders to find a HLA matched stem cell donor.
Deemed consent	Deemed consent is when it will be considered that you agree to donate your organs when you die – if you are not in an excluded group, and have not confirmed that you do not want to be an organ donor - either by recording a decision on the NHS Organ Donor Register, or by speaking to friends and family.
DfE	Department for Education – the government department responsible for children's services and education, including early years, schools, higher and further education policy, apprenticeships and wider skills in England.

Term	Definition
DHSC	Department for Health and Social Care - the government department with responsibilities including the health and care framework: to make sure the legislative, financial, administrative and policy frameworks are fit for purpose and work together.
Diabetes	Diabetes is a lifelong condition that causes a person's blood glucose (sugar) level to become too high. There are two main types of diabetes – type 1 diabetes and type 2 diabetes.
Dialysis	Dialysis is a procedure to remove waste products and excess fluid from the blood when kidney function is not working properly.
DKMS	DKMS is an international stem cell registry. A charity that registers individuals in 6 countries, who are willing to donate their bone marrow or blood stem cells to patients who desperately need life saving transplants.
DNA	Deoxyribonucleic acid (DNA), made up of genes which are the basic physical and functional units of heredity material in humans.
Donor	An individual who gives an organ, tissue, blood, or stem cells to save or transform the life of someone else.
Donor registries	Organisations which hold and manage registers (lists) of individuals who are willing to donate stem cells.
DVLA	The Driver & Vehicle Licensing Agency (DVLA) holds UK driver and vehicle records.
DWIB Leukaemia Trust	DWIB (Daniel Whyte Ivor Burford) Leukaemia Trust was formed to increase awareness of leukaemia in the West African sub-region and create access to effective diagnostic and treatment resources.
Ethnic minority	The term refers to racial and ethnic groups that are in a minority in the population. In the UK, they usually cover all ethnic groups except White British.
Ethnicity	The social group a person shares with those of common and distinctive culture, religion, language and other factors including diet, ancestry and physical features.

Term	Definition
ETT	Ethnicity Transplantation and Transfusion
GCSE	General Certificate of Secondary Education. These are the qualifications obtained by fifteen and sixteen year olds (typically) at the end of their Year 11 schooling.
Gene	DNA is made up of genes which are the basic physical and functional units of heredity. Genes contain sets of instructions to produce the molecules in your body, usually a protein. These proteins control how our body grows and works; they are also responsible for many of our characteristics, such as our eye colour, blood type or height.
Genetic matching	Genetic testing – sometimes called genomic testing – detects changes in genes that can cause health problems. It's mainly used to diagnose rare and inherited health conditions and some cancers.
Graft vs host (GvHD)	Graft versus host disease (GvHD) is a frequent complication of stem cell transplantation using units from another person. GvHD happens when the transplanted stem cells produce white blood cells (T cells) that attack the patient's own tissues.
Haematologist	A haematologist is a clinician who diagnoses and treats patients with blood and bone marrow disorders.
Haploidentical	A donor that shares half their HLA with the patient. A parent is haploidentical, as are some siblings and unrelated donors.
HLA	Human Leukocyte Antigens are expressed on the surface of cells and are involved in the recognition of self and non-self and are integral to immune responses to infection, disease etc. HLA matching is used for organ, tissue and stem transplantation.
Hypertension	High blood pressure, also known as hypertension, is usually defined as having a sustained blood pressure of 140/90mmHg or above. Most doctors agree that the ideal blood pressure for a physically healthy person is around 120/80mmHg.

Term	Definition
Immune system / immunity	The immune system is the body's defence against infection and disease. The immune system produces antibodies (a type of protein) and T cells directed against the infection/ disease to get rid of it from the body. Immunity is the state where the immune system is primed to respond to a disease/ infection.
Immunotherapy	Immunotherapy is a drug treatment for some types of cancer. Immunotherapy uses your immune system to fight cancer. It works by helping your immune system to recognise and attack cancer cells. You might have immunotherapy on its own or with other cancer treatments.
Kidney Research UK	Kidney Research UK is a charity aiming to free lives from the restrictions, fear, anxiety and life limiting nature of kidney disease.
Leukaemia	Leukaemia is cancer of the white blood cells.
Living donors	A living donor is someone who has agreed to donate an organ, cells or tissue, for example a kidney or a lobe of their liver.
Lord O'Shaughnessy	A Member of the House of Lords since 2015, and former junior minister for health, where he led efforts to improve innovation within the NHS and to grow the UK's life science & healthtech industries. He recently undertook a review of the UK clinical trials landscape.
Match	HLA matching is used to match patients and donors for blood or marrow transplants. If two people share the same HLA type, they are considered a 'match'.
Matched sibling	A sibling that is a full HLA match to the patient.
Medics4RareDiseases	Medics4RareDiseases is a charity driving an attitude change towards rare diseases amongst medical students and doctors in training.
Mismatch donors	A mismatched donor is less than a full HLA match with the patient often described with the match out of 10 or 12 - eg 11/12, 9/10. A haploidentical match is 5/10, 6/12.
Mixed race / Mixed Heritage	An individual with more than one ethnicity.

Term	Definition
Moral imperative	When compelled to act on an issue because it is the right (moral) thing to do.
National BAME Transplant Alliance	A coalition of organisations which seeks to promote awareness of organ, blood and stem cell donation amongst BAME communities and to increase the number of donors from these communities.
National Institute for Health & Care Research (NIHR)	Working in partnership with the NHS, universities, local government, other research funders, patients and the public, NIHR funding enables and delivers world-leading health and social care research that improves people's health and wellbeing and promotes economic growth.
NHS	National Health Service
NHS England	NHS England provides national leadership for the NHS. It promotes high quality health and care for all, and supports NHS organisations to work in partnership to deliver better outcomes for patients and communities, at the best possible value for taxpayers and to continuously improve the NHS.
NHSBT	National Health Service Blood and Transplant is responsible for the supply of blood, organs, tissues and stem cells. It collects and supplies blood to hospitals in England and is the organ donation organisation for the UK.
NICE	The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care.
O negative blood	There are four major blood groups, A, B, AB and O and an individual is either Rhesus (Rh) positive or negative. O negative blood is often called 'universal' because anyone can receive the red blood cells from these donations. Although about 8% of the population has O negative blood, it accounts for around 13% of hospital requests for red blood cells.
Opt out / in	Opt out/ in is the decision by an individual to opt in or out to donating organs / cells / tissue after their death. Individuals are encouraged to record their decision on the Organ Donor Register.
Organ	A natural part or structure of the body, capable of performing a special function which is essential to the life or well-being of the body, i.e. kidney, heart, lungs, etc.

Term	Definition
Organ donation (OD)	Organ donation is the gift of an organ to help someone who needs an organ transplant.
Organ Donation Register (ODR)	The NHS Organ Donor Register (ODR) is a confidential record of individual organ donation decisions. It is managed by NHSBT and records an individual's choice whether to become an organ donor or not.
Organ failure (multiple)	Failure of a single (or multiple) organs in a patient who is unwell.
Personalised medicine	Personalised medicine is a medical model of treatments that separates people into different groups—with medical decisions, practices, interventions and/or products being tailored to the individual patient based on their predicted response or risk of disease.
Post-transplant cyclophosphamide	The use prophylactically of the drug cyclophosphamide after a stem cell transplant to reduce post-transplant complications.
Primary care	Primary care services provide the first point of contact in the healthcare system, acting as the 'front door' of the NHS. Primary care includes general practice, community pharmacy, dental, and optometry (eye health) services.
Race	The concept that the human species is divided into distinct groups on the basis of inherited physical and behavioural differences.
Race Against Blood Cancer (RABC)	Race Against Blood Cancer is a non-profit charity whose goal is to increase the volume and diversity of people who register as potentially life-saving donors.
Radiotherapy	Radiotherapy is a treatment involving the use of high-energy radiation. It's commonly used to treat cancer. Almost half of all people with cancer have radiotherapy as part of their treatment plan.
Red blood cells	Red blood cells contain a substance called haemoglobin, which transports oxygen around the body. The amount of oxygen that's delivered to your body's tissues depends on the number of red blood cells you have and how well they work.

Term	Definition
Register	A list of potential donors of blood, organ, bone marrow or stem cells for the benefit of patients.
Relapse	The return of symptoms of a disease or illness after temporary improvement following treatment.
Related donor	A relative who donates an organ, cells or tissue, for example, a parent, sibling or child.
Remission	A temporary or permanent reduction in the signs and symptoms of a disease usually following treatment.
Renal Medicine	The diagnosis and treatment of diseases of the kidneys.
Ro	The Ro subtype is a variation of the Rh (rhesus factor) positive blood type. Rh subtypes are important if you are receiving regular transfusions and need blood that's compatible with both your blood type and your Rh subtype.
Search(es)	A request to search the national and international stem cell registries for potential donors.
Secondary care	Secondary care is healthcare provided by hospitals and specialists.
Sequences	Sequences are the order of the four chemical building blocks - called "bases" - that make up DNA.
Sickle Cell Society	The Sickle Cell Society is a charity that supports and represents people affected by sickle cell disorder to improve their overall quality of life.
Sickle cell	<p>Sickle cell disease is the name for a group of inherited health conditions that affect the red blood cells. Sickle cell disease is particularly common in people with an African or Caribbean family background.</p> <p>People with sickle cell disease produce sickle shaped red blood cells that can cause problems because they do not live as long as healthy blood cells and can block blood vessels.</p>
SNOD	Specialist Nurse Organ Donation

Term	Definition
SR	Specialist Requestors (SR) are a specialist branch of SNOD. They are deployed to donor referrals first, to support and approach families for donation.
Stem Cells	Stem cells are the body's raw materials — cells from which all other cells with specialised functions are generated.
Haematopoietic stem cells	Stem cells are special cells produced by bone marrow (a spongy tissue found in the centre of some bones) which turn into the different types of blood cells; red cells, white cells and platelets.
Stem cell transplant	A stem cell transplant replaces defective stem cells with healthy ones. It can be used to treat conditions affecting the blood cells, such as leukaemia, myeloma and lymphoma.
SHT	The Sue Harris Trust is a charity that helps save the lives of patients suffering with a blood cancer and works to increase the number of donors of Jewish heritage.
Team Margot Foundation	<p>Team Margot Foundation is named in memory of Margot Martini and to honour her legacy.</p> <p>Team Margot's mission is to help save and improve lives by educating, inspiring and motivating people, especially from ethnically diverse communities, to register as blood, organ, stem cell and bone marrow donors and to provide a range of support to families caring for child cancer patients. Team Margot Foundation (registered Charity Number: 1160236) provides secretariat support to the All-Party Parliamentary Group for Ethnicity Transplantation and Transfusion.</p>
Terms of reference	Terms of reference (TOR) define the purpose and structures of a collection of people who have agreed to work together to accomplish a shared goal.
Thalassaemia	Thalassaemia is the name for a group of inherited conditions that affect a substance in the red blood cells called haemoglobin which carries oxygen around the body. People with thalassaemia produce too little haemoglobin. It mainly affects people of Mediterranean, south Asian, southeast Asian and Middle Eastern origin.

Term	Definition
Third sector	The Third Sector includes charities, social enterprises and voluntary groups, delivers essential services, helps to improve people's wellbeing and contributes to economic growth.
Tissue type	Tissue type is the term used to describe an individual's combination of HLA (Human Leukocyte Antigens) genes.
Transfusion	The act of taking blood cells from one person (a donor), processing it, then giving it (transfusing) to someone else (a patient). A transfusion can be for red or blood cells, platelets or stem cells.
Transplant	The transfer of a healthy organ, stem cells or tissue from one person into the body of another person.
Transplant waiting list	A list of all the people in the UK who are waiting for an organ from a deceased donor.
Trials	Research studies involving patients or healthy people and are designed to test new treatments.
UK	United Kingdom
UKSCSF	The UK Stem Cell Strategic Forum is a multi-disciplinary expert group formed in 2010 at the request of the UK Government Department of Health and Social Care. The Forum was established to make recommendations on improving outcomes for stem cell transplant recipients across the UK.
Umbilical cord blood stem cells	See 'cord blood unit'.
Unrelated donor	A potential donor who is not related to the patient. The donor may be known to the patient, for example spouse, or not known to the patient.
Vanik Council	A charity providing shared services to affiliated organisations (many of which are also registered charities) at a national level for the advancement people of Jain and Vaishnav faiths.
WBMDR	Welsh Bone Marrow Donor Register
WBS	Welsh Blood Service

Term	Definition
White Northern European (white)	A Caucasian person originating from Northern Europe.
WMDA	World Marrow Donor Association - a global society of registries, cord blood banks, donor centres, collection centres, HLA-experts, regulators, researchers, technologists, and industry partners with a shared vision to strive for a world where access to life-saving cellular therapies for all patients is assured and donor's rights and safety are protected.
Younger male donors	Young males between the ages of 16 to 30.

Appendix

The following individuals and organisations submitted written evidence. These are all available to read and download from the APPG website (<https://www.teammargot.com/all-party-parliamentary-group-inquiry/>)

- Abiola Okubanjo, Action On Blood
- Alan Miller
- Alexander Wood PhD, Network Manager Renal Operational Delivery Network, North East and North Cumbria
- Anthony Nolan
- Beverley De-Gale OBE, Co-Founder ACLT (African Caribbean Leukaemia Trust)
- British Society for Histocompatibility and Immunogenetics (BSHI)
- Carol Burt, SCIPe CIC
- Chanel Taylor, Unsickle My Cells
- Professor Charles Craddock CBE, Professor of Haemato-oncology, University of Warwick, Chair of UKSCSF
- Dr Daniel J McCloskey
- Dela Idowu, Founder of Gift Of Living Donation (GOLD)
- Department of Health and Social Care (DHSC)
- DKMS Foundation
- Emma Wynn, Specialist Nurse Organ Donation
- Feyona Daley, Sick Cell Patient
- Georgelene Elliott, Founder of Black Blood Matters
- Gideon Hammond, Blood donor
- Professor Gurch Randhawa PhD FFPH DL, Professor of Diversity in Public Health & Director, Institute for Health Research, University of Bedfordshire
- Ivan Greenhill, Blood donor
- Ivor Burford, DWIB (Daniel Whyte Ivor Burford) Leukaemia Trust
- Jacob Knox-Hooke, Race Against Blood Cancer
- Judy Leden, Stem cell donor
- Kate Rynberg, Blood donor
- Kidney Care UK
- Kidney Research UK
- Kirit Modi MBE, Jain and Hindu Organ Donation Alliance (JHOD)
- Lhiza Smith, Specialist Requestor, Specialist Nurse Organ Donation
- Lisa Silas, Advanced Nurse Practitioner
- Dr Lucy McKay, Medics4RareDiseases

- Manhar Mehta, Vanik
- Melvyn Quartey, DWIB (Daniel Whyte Ivor Burford) Leukaemia Trust
- Nadia Martini, Patient family
- NHS Blood and Transplant (NHSBT)
- Nishtha Chugh, Churchill Fellow 2016, Global Development and Environment journalist
- Orin Lewis OBE, Co-Founder ACLT (African Caribbean Leukaemia Trust) / National Black, Asian, Mixed Race and Minority Ethnic Transplant Alliance (NBTA)
- Peter May, Department of Health Permanent Secretary and HSC Chief Executive, Northern Ireland
- Peter McCleave, Patient, 10,000 donors
- Poonam Chauhan, Stem cell donor
- Prafula Shah, Living kidney donor
- Race Equality Foundation
- Ricky Cheema, Stem cell donor
- Ros Mafi, Stem cell donor
- Dr Ros Williams FHEA, Associate Director, ESRC Digital Good Network Executive Committee, iHuman institute Associate Editor, New Genetics and Society
- Roydon Turner, Founder and CCO of the Orgamites: Organ Donation Education and Awareness for Kids
- Sickle Cell Society
- Sophia Iman Ali, daughter of late Amjid Ali
- Dr Stefano Casalotti and Supanya Casalotti, Patient family
- Sue Harris Trust
- Terry Archbold, Beatrix Heart (video evidence)
- Vivian Osho, Community Advocate Sickle Cell Society UK
- Webber Phillips
- Welsh Blood Service
- World Marrow Donor Association (WMDA)
- Yaser Martini BEM, Patient family

The purpose of the All-Party Parliamentary Group for Ethnicity Transplantation and Transfusion is to:

- Highlight how the lack of donor participation affects patients with ethnically diverse backgrounds
- Raise awareness of health inequalities faced by mixed heritage and ethnic minority patients requiring an organ, stem cell transplant or a blood transfusion
- Advocate equitable access to treatment for mixed heritage and ethnic minority patients



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