TEAM MARGOT SUBMISSION to the Ethnicity Transplantation and Transfusion APPG Inquiry 2025 'Ensuring a resilient and sustainable UK stem cell supply for all'

Objective

Lives are being lost. Our objective is to save more lives and achieve better equity of access and outcomes of stem cell transplantation, particularly for ethnic minority and mixed heritage patients.

Introduction

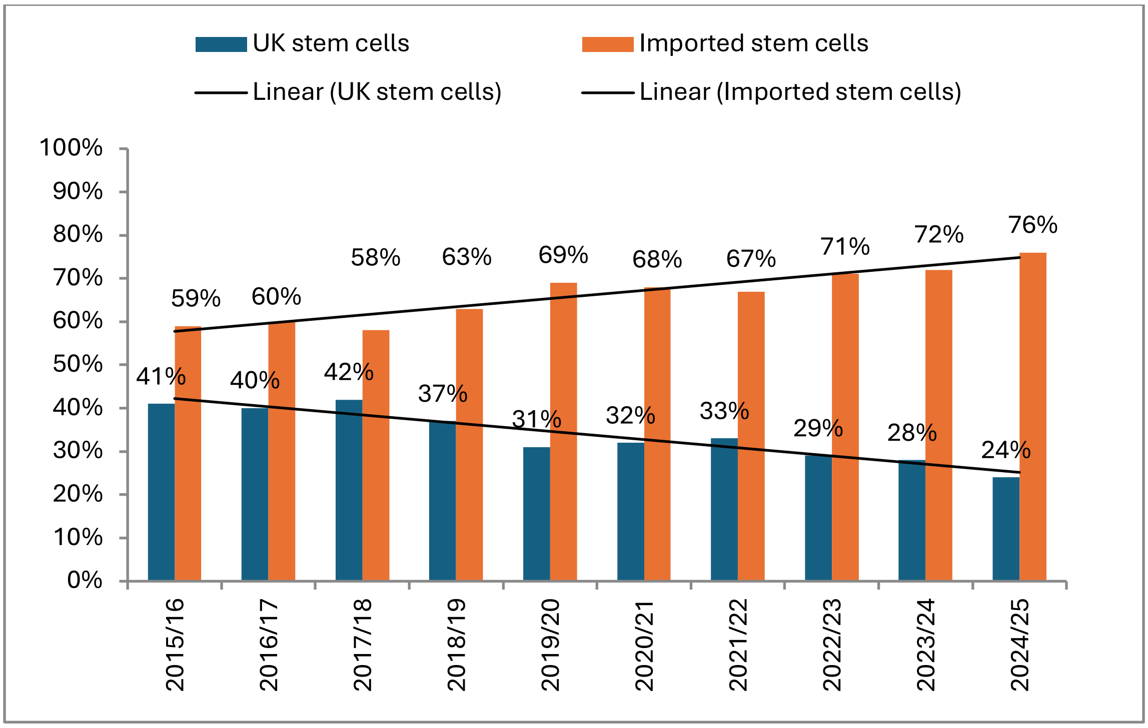
Stem cell transplants are used to treat some blood cancers and blood disorders including Myeloma, Leukaemia, Lymphoma, and sickle cell anaemia. This is life saving treatment.

When a patient needs a stem cell transplant, the donation must come from a good genetic (HLA) match. There is a 1:4 chance of a sibling being a match but if one is not available a search is made of the stem cell registries.

In the UK, there is a 72% chance of identifying a good match if you are white North European. Those chances are just 37% if you are from an ethnic minority community. Those with a mixed ethnic heritage find it even more difficult to find a match.

If there is no appropriate donor on the UK registry an international search of the global registries is performed. In the UK we rely heavily on imported donations. This dependence is increasing.

In 2024-2025 in the UK, 76% of transplants used an unrelated stem cell donation imported from overseas. This contrasts with 58% in 2017 – 2018.



Graph 1: Number of UK transplants using stem cells from UK versus imported donor

The UK is becoming increasingly less self-sufficient. The UK Stem Cell Strategic Forum (UKSCSF) recommendation is that 45% of UK patients should receive stem cells from a UK donor. We welcome that the need to reverse and improve the direction of travel has been identified, however ever since this recommendation was made, the proportion of UK-sourced stem cells for transplants has continued its downward trajectory – see graph 1 - exacerbating reliance on costly and logistically vulnerable imports that now account for 76% of supply. This stark trend underscores the urgent need for accelerated action on donor recruitment and registry expansion to meet the 45% self-sufficiency target and safeguard patient access.

This point has been highlighted by the All-Party Parliamentary Group for Ethnicity Transplantation and Transfusion during its 2025 Inquiry, where the recommendation of 45% UK donors for UK patients was re-iterated by clinicians, including the Chair of the UKSCSF, with one clinician advocating a figure of 50% or more.

Whilst no country can be totally self-sufficient in providing stem cells for its patients, we believe that the UK should have the ambition to become far more self-sufficient. In the face of our plummeting domestic supply, which leaves patients perilously exposed to a fragile import chain that could shatter under the next global crisis; we must aspire to forge a more resilient, home-grown UK Stem Cell registry for every UK life in need of a transplant. This makes ethical, moral and financial sense.

If we want all patients to have access to the *same standard of treatment* when they need it, then we must increase the number of ethnic minority and mixed heritage donors on the register.

New transplant strategies like post–transplant cyclophosphamide may enable patients without a well-matched donor to be transplanted with a multiple mismatched donor. Yes, these patients will be getting a transplant, which could be argued as addressing inequality, but it is not the same standard of treatment as a patient with a well-matched donor.

Unless there is a focus on increasing appropriate recruitment, this new strategy will mean ethnic minority and mixed heritage patients will still not get a well-matched transplant – so inequity would be “baked” into the healthcare system.

A strategy to increase registrations will save more lives. We set out the following asks which we believe will deliver better outcomes for all in need of a stem cell transplant and address the inequity which currently exists for mixed heritage and ethnic minority patients.

Recommendations

Our recommendations for the Ethnicity Transplantation and Transfusion APPG Inquiry 2025 ‘Ensuring a resilient and sustainable UK stem cell supply for all’, are as follows:

1. **Specifically target ethnic minority and mixed heritage donors to join the register.**
2. **Educate the public about the need to join the register and the process of donation.**
3. **Examine fairness and equity through a ministerial commissioned independent review of the management of the UK Stem Cell and Cord Bank registries and the role of NHSBT.**
4. **NHSBT to reverse the reduction in donor recruitment to the register through more active enlistment.**
5. **NHS should improve ethnicity data collection and make better use of it.**
6. **Assess whether current apheresis capacity is constraining greater use of UK donors for transplant and if so, address it.**
7. **NHSBT should roll out the approach adopted in Wales with buccal swab testing and facilitate individuals registering as stem cell donors, without the requirement to be a blood donor.**
8. **Review the national usage of cord blood transplantation to ensure the full transformational potential of cord blood is being realised.**

1. Specifically target ethnic minority and mixed heritage donors to join the register

Between 2017 and 2019 there was a heightened emphasis on ethnic minority recruitment to organ and blood donor registers as there was a focus at the time on tackling racial disparities in healthcare. The same cannot be said with regards to stem cells. This focus needs to be reset if there is to be a suitably mixed ethnic profile on the register which increases the chances for everyone having an equal chance of finding a well-matched donor.

There is considerable disparity in the preparedness of different communities to engage with donation.

While over 43% of the UK population is currently registered as organ donors, only 4.4% are from a mixed heritage or ethnic minority community.

For blood, just 1.4% of the population are active blood donors with only 0.1% of the ethnic minority population being blood donors.

In respect of stem cells, less than 3.3% of the UK population are on the stem cell register. This falls to just 0.5% of the ethnic minority and mixed heritage communities.

This is against a background whereby there are health inequalities facing those from ethnic minorities needing a stem cell transplant. Firstly, ethnic minority populations disproportionately suffer from conditions which can be treated by stem cell transplants.

Secondly it is more difficult to identify a match where the patient is from an ethnic minority or is mixed heritage. Over 80% of donors on the global stem cell registries are white, even though the white population is less than twenty percent of the world's people. This means that there needs to be a higher number of donors from ethnic minority populations, if we're ever going to level the playing field for treatment.

Thirdly, the challenge of finding a donor intensifies for individuals of mixed heritage. Finding a precise match is markedly harder still - hence the heavier reliance on international registries, which frankly aren't diverse enough.

An additional, longstanding problem is that the ethnic profiles of patients requiring a stem cell transplant, but who do not have a donor, is not known – the so called ‘unmet need’.

The most important factor for successful stem cell transplantation is genetic or HLA match. This demands recruitment that mirrors the UK's diversity. Nevertheless, it is considered that the best donors are younger men primarily because they produce a higher overall number of stem cells for donation than women and older men. Consequently, the NHS Stem Cell Registry (formerly known as the British Bone Marrow registry) restricts registrations to potential donors between the ages of 17 and 40.

However Anthony Nolan restricts registration to between 16 and 30 years old, whilst DKMS recruit from 17 to 55 and the Welsh Bone Marrow Donor Registry (WBMDR) recruits between 16 to 45 year old. Yet people remain on the register and stand ready to donate stem cells until aged 61. This emphasis on youth is unlikely to deliver the 45 percent self-sufficiency target set by the UK Stem Cell Strategic Forum.

And whilst stem cells from younger donors may yield better outcomes, the overriding reality is that a donor must be an HLA match first. Age is secondary.

Whilst NHSBT ask blood donors to consider joining the stem cell register, it is very clear that relying on the blood donor population will not generate a register of sufficient diversity to satisfy demand, as most blood donors are white. Unless the ethnic diversity of those on the registers matches the diversity of patients needing a transplant, then there will be ‘baked in’ inequity in the access to treatment for ethnic minority and mixed heritage patients.

Given the growing diversity of our population this is a problem which is only going to get ever more challenging. Today 1 in 5 of our adult population identify as being mixed heritage or ethnic minority. For school age children this is 1 in 3. The UK's mixed heritage population is the fastest growing population.

Distrust of the medical profession is often cited as a reason for lower rates of engagement. We do not think it helpful to make the ethnic communities the problem here. When failings in how the medical profession was treating women was identified, a woman’s health ambassador was created to tackle these issues. The complaints offered by women were not dissimilar. They felt belittled or that they were not being listened to. We think a similar role could be created to advocate for ethnic minority communities and ensure that the NHS and NHSBT is not failing in its obligations to give them the best possible care consistent with the Public Sector equality duty.

We recommend that the focus of recruitment directed by the DHSC should be made on increasing the quantum of registrations by specifically targeting ethnic minority and mixed heritage donors to join the register.

2. Educate the public about the need to join the register and the process of donation

We believe that the British public are generous and inclined to register when prompted about the need. This is why patient focused appeals are so successful in recruiting donors.

What is clear is that stem cell donation is an area of medicine which is not widely understood. Education and public information needs to be deployed to encourage more registration. Given that blood cancers are becoming more common and there is an ever increasing number of conditions that a stem cell transplant can be used as treatment, the need for donors is only going to become greater. On average, only one in twelve hundred registered donors will ever be selected - so the priority must be education that builds lasting commitment, not fleeting enthusiasm.

The DVLA has been a very successful recruiter of people to the Organ Donor Register. We recommend that stem cell (and blood) donation is added to it and that a stem cell donor registration question is added to the NHS app.

We recognise that the NHS and DHSC have made resources available for education. We would ask that these initiatives are reviewed and measured against whether they are genuinely delivering outcomes. This should be particularly focused at ethnic minority and mixed heritage audiences. In particular, examination ought to be made as to whether tools and materials need to be more culturally sensitive. In particular, those ethnic groups least represented on the register tend to be more likely to be influenced by matters of faith and this needs to be respected and taken into account by the systems for recruitment.

People need to understand the process of donation and what it is for. Many people are not aware of how stem cells are collected.

This has serious issues for recruitment to the register and for realisation of a transplant when a donor match is identified. On the one hand, many people believe that transplants can only be given by extraction from the bone. However this is just 10% of stem cell transplants, the vast majority, i.e. 90% are through apheresis. Whilst this is a less invasive procedure, it is still an onerous treatment. The donors are given a drug to stimulate the stem cells to go into the blood stream. The collection process involves the donor blood being circulated through a cell apheresis machine which separates the stem cells from the rest of the blood which is then returned to the donor. The collection process takes 5 to 6 hours, the stem cells are replaced within days. We are concerned that it has been characterised as being like a blood transfusion, the transplant is but the collection of stem cells is not. We understand that a contributing factor to the rate of attrition of those identified as a match who then subsequently do not donate, may be because they have not fully understood what the process entails until they are called to donate. Full disclosure of the collection process with all its pros and cons for the donor must be made at time of registration to ensure only donors most likely to donate.

DHSC and NHSBT need to take responsibility for educating the public on the need for more donors, particularly stem cell donors, and what it means for someone to be on the register.

3. Examine fairness and equity through a ministerial commissioned independent review of the management of the UK Stem Cell and Cord Bank registries and the role of NHSBT

It is for DHSC to ensure that all patients in need of treatment have fair equitable access. There is a clear inequity facing mixed heritage and ethnic minority patients and it is for DHSC to ensure that sufficient action is being taken to address and minimise this equality issue.

NHSBT as a matter of routine ask blood donors whether they are prepared to join the stem cell register. While this is a progressive move, the overwhelming majority of blood donors are white. Furthermore, NHSBT is primarily focused on managing the supply of blood for transfusion. Recruitment of new blood donors is focused on groups where there are supply issues. Where demand and supply are stable there is little incentive to recruit new blood donors.

We do not believe that this is an adequate approach to improve self-sufficiency in stem cell donation, because it renders stem cell donor recruitment a mere ‘add-on’ that piggy-backs on blood donation.

Ultimately, we know that certain life-threatening conditions - such as sickle cell disease, thalassaemia, and end-stage kidney disease - disproportionately affect ethnic communities. We would be failing in our duty if this known disparity were not actively reflected in NHS recruitment strategies for both organ and stem cell donors alike. We need to be doing more to make it easier for those who will consider becoming a donor to come forward.

NHSBT is fundamentally a logistics function. The responsibility for ensuring that arrangements are functional and delivering appropriate outcomes rests firmly with DHSC. We believe there should be a ministerial commissioned independent review of all organisations involved in the stem cell transplant pathway. This should include an assessment of unmet need. Ministers need to satisfy themselves that the system is fit for purpose and delivering what can legitimately be expected.

This review should include how the stem cell registries are governed and managed as well as the underlying financial structure of the transplant pathway. While the involvement of Anthony Nolan, DKMS UK, WBMDR and the NHS Stem Cell Donor Registry in managing the UK Stem Cell Registry is welcome, their operations remain trapped in unhealthily competitive silos, with no single entity held accountable for ensuring the demand for stem cell products - which continues to outstrip supply - is met.

Anthony Nolan co-ordinates searches of UK and international registries for UK transplant centres. They receive a facilitation fee from the transplant centre if an international donor is selected. Anthony Nolan, DKMS UK, WBMDR and the NHS Stem Cell Donor Registry receive a fee when one of their registered donors is selected and successfully donates.

Similarly, for cord blood transplantation, the UK cord banks receive a fee for cord units used by UK transplant centres and Anthony Nolan also receives a facilitation fee for any international cord blood units used.

The recruitment strategies of the stem cell registries have been shaped by the financial considerations detailed in the NHSBT written submission to the APPG's 2023 Inquiry – please see excerpt below from the "Where are our nation's donors?" 2023 inquiry report page 15:

"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."

This strategy is failing to serve all patients, because it inadvertently perpetuates inequities.

Ultimately it is the role of Government and the NHS to ensure that there is equity in health provision. This was a conclusion drawn by the All Party group report 'Where are our nation's donors?'

We recommend that the Secretary of State commissions an independent review and for specific consideration to be given to the economics and incentives behind the management of the stem cell and cord bank registers to be satisfied that they are addressing health inequalities.

We believe that DHSC and NHSBT need to review what must be put in place to deliver more self sufficiency in stem cell donation and a UK Stem Cell Register and Cord Bank which better meets the likely demand. The Public Sector Equality Duty is a statutory responsibility that rests with public authorities and cannot be delegated. The Department of Health and Social Care must therefore take direct ownership of delivering a fully representative UK stem cell register.

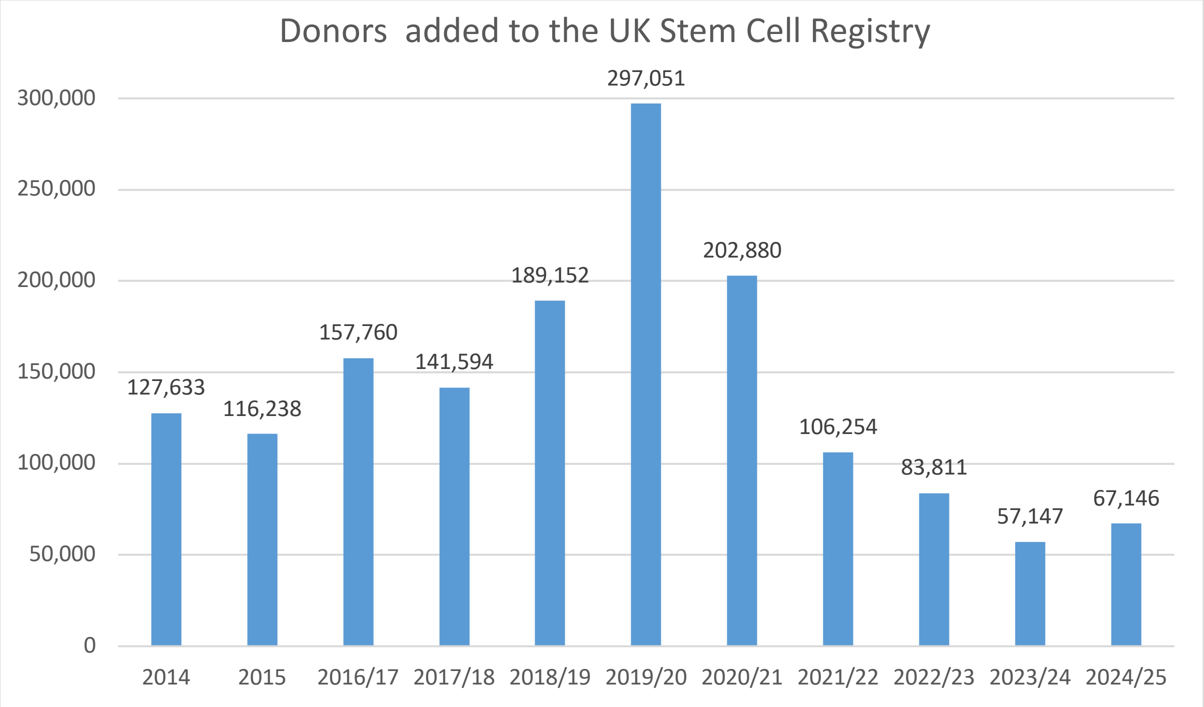
All patients are entitled to the same chance of a positive outcome. That will only be achieved if the UK Stem Cell Register and Cord Banks contains more diversity in its donor population.

The ministerial commissioned independent review should evaluate the incentives and structure, including funding, finance, governance and accountability of the UK Stem Cell Register and Cord Banks to ensure that they are delivering the optimal outcomes for UK patients of all ethnic groups.

4. Take action to reverse the reduction in recruitment to the UK Stem Cell register

During the pandemic focus on donation and transplantation was inevitably diminished as combating the pandemic consumed all the bandwidth of the Government and the health sector. But this now needs to be reset.

There are currently 2.4 million people on the UK Stem Cell Register, with over 1 million people registered with DKMS UK, 920,000 with Anthony Nolan's, over 75,000 with WBMDR and 400,000 with NHSBT. There has been donor decline since the pandemic with a year on year decline in recruitment (see graph 2).



Graph 2: Number of donors recruited year on year from 2014 to 2024/25

The decline in donor recruitment is exacerbated by donors becoming more unwilling or less able to go through with donation.

Interestingly, this experience has not been shared in Germany. DKMS in Germany has 7.8 million donors on its register, 700,000 of which have been recruited in the last three years, equating to 10.5% of the population being on the register. As a nation, we ought to examine what can be learned that can be replicated here in the UK so that we can become more self-sufficient. German donors are currently supplying 42% of UK need.

We recommend that the DHSC take action to reverse the reduction in recruitment to the UK Stem Cell register.

5. NHS should improve ethnicity data collection and make use of it

The NHS needs to collect better data and, crucially, use it. Both sex and ethnicity have a profound influence on health risks and outcomes. Although these data are recorded, completeness remains poor (particularly for ethnicity), and they are used predominantly to monitor equity of access and to meet statutory equality duties rather than being routinely applied to improve individual patient outcomes or drive service improvement.

Much more could be done to collect better data that can be used to deliver better health outcomes. This includes educating patients why the sharing of information about their ethnicity is important, the benefits to them, their ethnic communities and the population as a whole in developing beneficial testing and treatments.

6. Assess whether current apheresis capacity is constraining greater use of UK donors for transplant and if so, address it

A frequently cited barrier to improving self-sufficiency is limited apheresis capacity within NHS Therapeutic Apheresis Services - both in terms of available sessions and appropriately trained staff - which can mean that even when a suitable UK donor is identified, collection is delayed or deemed impractical, leading transplant centres to request an overseas donor instead.

While total apheresis procedures have risen steadily (exceeding 13,000 in 2024 - 25), the great majority of these are for therapeutic patient treatments.. Unrelated donor collections remain a small fraction of overall activity (roughly 1,400 - 1,800 per year), yet scheduling conflicts and regional variation in capacity are repeatedly highlighted by clinicians and registries as reasons for turning to international donors who can often be collected more quickly.

Fresher cells from domestic donors are generally preferable for patient outcomes, and greater UK collection capacity would also support research and the development of new cellular therapies.

We welcome the Department's ongoing review of apheresis services. We ask that its findings - particularly any evidence of capacity constraints specific to unrelated stem cell donor collections - are published promptly, together with a clear action plan and timeline for resolving identified bottlenecks.

7. NHSBT should roll out the approach adopted in Wales with buccal swab testing and facilitate individuals registering as stem cell donors, without the requirement to be a blood donor.

Wales led the way in transplantation adopting the 'opt-out' registration system in 2013 for organs which was subsequently followed in England and Scotland. Similarly, Wales have adopted a more active system for stem cell donor recruitment. We recommend that England follow suit.

Prior to 2021, WBMDR recruited stem cell donors via blood donation. It recognised that in doing so it would only reach the 3% of the Welsh population who were regular blood donors. It consequently introduced collection of samples via buccal swabs, in order to expand the reach of donor recruitment beyond the blood donor population. WBMDR are now able to organise pop up occasions to disseminate and collect swabs and in so doing recruit more people to the stem cell register.

In Wales you are able to donate between the ages of 16 and 45 with 18% of total recruitment of individuals from ethnic minority communities.

We recommend that NHSBT should broaden recruitment of potential donors beyond the blood donation community by use of pop up events using buccal swabs. This will enable expansion of the UK Stem Cell Registry and the ability to target locations where the population is diverse. Specifically, we need NHSBT to enable the recruitment of potential donors at a scale not achieved by relying only on the blood donation community.

8. Review the national usage of cord blood transplantation to ensure the full transformational potential of cord blood is being realised.

Cord blood stem cells was seen as a more efficient way of accessing stem cells for transplantation. It is less critical for cords to be an exact HLA match due to the cells being immunologically immature. In addition the fact they are cryopreserved means they are a transplant resource that can be rapidly accessed. The development cell expansion technologies will make cord transplantation more accessible to adult patients and so indeed could be transformational. There is therefore real advantage in ensuring a greater supply of cords. The use of cord blood transplantation in the UK is lower than many other countries and we recommend that there is a ministerial independent review of the use of cord blood transplantation in the UK to ensure its full potential is being realised.