Ethnicity and Transplantation APPG Inquiry September 2025

Introduction

Anthony Nolan welcomes the opportunity to respond to the APPG's questions about the drivers of the fall in UK-to-UK provision of stem cells. We have focused our response on the first part of the Call for Evidence (Stem Cell Supply).

Every year, around 1,075 people in the UK receive a life-saving stem cell transplant from an unrelated donor. For these patients, a stem cell transplant represents hope where other treatments have failed. It is vital that the UK's stem cell supply system is working in the best possible way to meet the requirements of every patient in need, regardless of their ethnicity, background or circumstance.

As more patients need a stem cell transplant or cell therapy, it is important to meet as much of the UK's demand for cells as possible from UK donors. This will help to protect the system from global disruptions and deliver the best value to the NHS.

However, providing stem cells to UK patients will always require international cooperation and the ability to import cells from abroad is vital for UK patients – particularly those UK patients from a minority ethnic background.

The growth of donor registers around the world is also important for the global population. Donors recruited from South Asian and sub-Saharan African countries are the most likely to match the needs of patients in the UK and globally who currently struggle to find a 10/10 donor match.[1] Yet, these are the regions with the fewest donor registers.

Responses to questions

[1] Maiers et al. The Registry of Unmet Need: A World Marrow Donor Association Analysis of Patients Without an HLA Match. HLA. 2025 May 22;105(5):e70255. doi: 10.1111/tan.70255

a) Does the size, composition, or quality of UK registries, or strategies for donor recruitment mean UK donors are less likely to be chosen?

Factors that influence donor selection

The choice of donor is made by the patient's medical team and involves numerous considerations, including the type of disease, age of the patient, availability of a family donor etc.

The key points we believe are important when thinking about how the composition of the UK Aligned Registry relates to the proportion of UK-UK provisions are:

1. How representative the UK Aligned Registry is of the range of HLA patterns found in the UK patient population
2. How quickly the UK Aligned Registry can manage the process of contacting a matched donor, collecting their cells, and delivering them to the patient
3. How many young donors there are on the UK Aligned Registry

The UK Aligned Registry consists of over 2.4 million individuals registered across four donor registries: Anthony Nolan, DKMS UK, NHSBT, and WBMDR. Each individual register has a different composition. We have provided information on Anthony Nolan as an individual member of the UK Aligned Registry below, as this is where we have access to the most data.

Representation of UK patient HLA types on the Anthony Nolan register

There are 920,000 people on the Anthony Nolan register as of end FY 2024/25.

The Anthony Nolan register includes common HLA types found in the UK population, as well as less common HLA types. The most common HLA types on the register are those predominantly found in people of White European heritage.

Less common HLA types on the Anthony Nolan register can be, but are not exclusively, associated with people who have non-White European heritage. To illustrate, a study we published in 2019 reported that 35.5% of people with White self-disclosed ethnicity on the Anthony Nolan register in 2019 (based on a random sample) had a unique HLA phenotype (the individual's combination of HLA genes), whereas a much higher proportion of non-White donors had a unique phenotype – e.g. 92.1% of East Asian, 95.7% of African and 98.3% of Middle Eastern individuals on the register had a unique phenotype within their subpopulation.[2]

The size of the UK Aligned Registry has an impact on how well it can cater to the UK population's needs. UK patients who have the most common HLA types within the UK

are very likely to already have multiple matches on the UK register at its current size, and this means it is more likely that one of those matches will be contactable, willing and able to donate. If the register were increased in size, even more UK donors would likely be available to UK patients, increasing the chances of a UK provision.

[2] Leen G, Stein JE, Robinson J, Maldonado Torres H, Marsh SGE. The HLA diversity of the Anthony Nolan register. HLA. 2021 Jan;97(1):15-29. doi: 10.1111/tan.14127. Epub 2020 Nov 16. PMID: 33128327; PMCID: PMC7756289.

Increasing the size of the UK register, while very important, needs to be done as part of a careful strategy that also considers the type of donors being recruited in terms of their ethnicity, age, and willingness to remain on the register and go on to donate if asked.

Anthony Nolan's strategy for the register

When growing the register we need to consider:

- The need to replenish the register with younger donors to replace those who "age out"
- The need to continue diversifying the ethnicity of the donor register
- The need to improve donor commitment and availability

Anthony Nolan's recruitment strategy focuses on recruiting young donors and donors from a minority ethnic background. However, we recognise that recruitment in the UK alone will not solve the disparity on access to unrelated donors for patients from a minority ethnic background.

To make the most difference for patients from a minority ethnic background in the UK and around the world, donors must also be recruited from countries that are currently under-represented, particularly countries in sub-Saharan Africa and South Asia. There are operational, ethical and financial challenges to global recruitment but members of the UKAR are actively supporting international donor registry growth. For example, DKMS has established registers in South Africa, Chile and India, and Anthony Nolan is partnering with the Indian register DATRI, thanks to funding from the NIHR, to recruit more donors in India.

Donor availability and efficiency of UK donor provision

As described above, a larger UK Aligned Registry would offer an increased likelihood of UK patients being matched to UK donors and would increase the likelihood that at least one matched donor would be available or able to donate.

By a donor being "available" we mean: contactable, willing and able to go on to provide a blood sample and have medical tests performed on them, and then go ahead with cell collection.

The decline in donor availability

Donor availability is a key concern for members of the UK Aligned Registry. We have all seen donor availability decline since the pandemic – i.e. registered donors in the UK are more frequently uncontactable or are unwilling or unable to go through the donation process.

Other registers across the world have also experienced this challenge, although some registers abroad have better donor availability than others.

Other factors that impact on UK donor availability

Another key limit to UK donor availability is cell collection centre (apheresis) capacity. We describe this in more detail in answer to question c.

Usage of German donors in the UK

In 2024-25, 42% of provisions for UK patients were from German donors.

In 2024-2025, German registries provided blood samples for "verification typing[3]" (VT) for UK patients from 69% of all requests sent to them. In contrast, the Anthony Nolan register delivered verification typing for 47% of requests, similar to DKMS in the UK. Our answer to question (e) provides more information on the challenge of availability of donors.

While the evidence we have is anecdotal, it appears that a combination of size, cultural and system factors contribute to the relatively higher donor availability in Germany. Germany's large donor registers (over 10.5 million people) also contain a large proportion of young people and young men. From conversations with our international peers, it seems Germany has cultural attitudes that encourage donation, and wellfunded, efficient systems for keeping donor information up to date.

The age profile of the UK Aligned Registry

Donor age matters because there is extensive research from Anthony Nolan and others that younger donors (under the age of 30) are strongly correlated with improved patient survival. [4] Most (82%) of UK:UK provisions are from a donor under the age of 35.[5] So, to increase the proportion of UK:UK provisions, the UK Aligned Registry must also be able to offer young donors.

In 2012, Anthony Nolan proactively shifted focus to recruiting 16-30 year-olds to the register and therefore has a high proportion of young donors. For this reason,

proportionally, the Anthony Nolan register performs well (50% of UK:UK provisions) in terms of how likely its donors are to be selected in comparison to other registers in the UK and abroad.

Another reason why the recruitment of young donors is important is the potential emergence of multiple mis-matched transplant with post-transplant cyclophosphamide, which may mean that transplant centres place even more of a priority on the age of a donor.

In summary, it is important that growth in the size of the register is fuelled by the right type of donors and focus given to those donors being supported and engaged, to ensure that growth directly results in more UK donors for UK patients.

b) Have there been changes in overseas registries that increase their chances of being chosen as suppliers?

[3] A Verification Typing test request is when a medical team asks the donor register to request blood samples from a potential donor who may be a suitable match for their patient. This is an essential step in selecting a donor and includes up-to-date HLA testing to confirm the match. Prospective donors must be contactable, medically fit and willing to provide a blood sample to proceed with verification testing.

[4] Shaw, Bronwen E. et al. Development of an Unrelated Donor Selection Score Predictive of Survival after HCT: Donor Age Matters Most, Biology of Blood and Marrow Transplantation, 24, 5 (2018) 1049 – 1056 Vale, C., Langston, A.A. (Donor) age is more than just a number…., Bone Marrow Transplant 60, 1–2 (2025). doi.org/10.1038/s41409-024-02420-1

[5] State of the Registry (UK Aligned Stem Cell Registry Annual Data 2024/25), Available at https://www.anthonynolan.org/sites/default/files/202506/State%20of%20the%20Registry%202024-2025.pdf

There are over 100 registers across the world and lots of changes will have taken place since 2017. It is hard to pinpoint any one single change made by other registers which would explain the drop in transplant centres selecting UK donors for UK patients.

However, some key drivers are likely to be:

- Some registries abroad, with similar genetic representation as the UK population, have better donor availability in comparison to UK donor availability, which has declined since the pandemic (as we have detailed above with the registers in Germany)
- Registries abroad continue to grow significantly in size – notably, Germany and the USA
- Another potential factor is that apheresis capacity is less of a problem abroad than it is in the UK – we have explained the UK apheresis capacity challenge further below.

c) Does the availability of key UK support services for stem cell donation such as apheresis (there is a DHSC review being undertaken of apheresis services) affect the likelihood of UK donors being chosen?

UK apheresis capacity has been a major limitation in our ability to deliver UK donor cells to patients within the timeframe required. That is why this year Anthony Nolan opened a new Cell Collection Centre in Nottingham to increase apheresis capacity across the country. The cell collection centre will eventually have capacity for 1,300 slots per annum and will help us to better meet the first-time date requested by the clinical team, which prior to the cell collection centre opening was only at 20%. An increase to 50% within five years will mean an additional 200 patients receiving their cells on the date requested.

The Anthony Nolan Cell Collection Centre has not received any government funding and has instead been funded by our fundraising efforts.

d) Is availability and training of key staff that support the UK stem cell transplantation pathway influencing choice of donor?

Transplant centre staff will be best placed to answer this question, however there are two areas of availability and training of staff that we are aware pose challenges.

1. <u>Workforce pressures</u>
   Transplant centres across the UK are facing staffing shortages in both clinical and non-clinical roles, including apheresis (cell collection). Hiring freezes are widespread due to financial constraints. Meanwhile, transplant activity is rising yearon-year, placing increasing demands on an overstretched workforce. Without intervention, there is a risk of insufficient expertise to support complex decisions and specialist procedures.

2. <u>Variation in the cell sources used in transplant centres</u>
   There is variation in the use of cell sources across UK centres — some have expertise in using cord blood units, others in haploidentical transplants. While patient and disease factors play a role, staff training and familiarity also influence practice. Not all hospitals have the expertise to use cord blood, potentially disadvantaging patients. To address this, Anthony Nolan and NHSBT are investing in clinical education through the Cord Support Programme, offering free training and guidance. Anthony Nolan also chairs the UK Cord Blood Initiative, a collaborative group

promoting cord blood use through education and shared expertise. Anthony Nolan, with UK Aligned Registry partners, also host the annual Graft Selection Strategy Workshop to provide an independent, impartial education and networking opportunity for clinical and laboratory staff in transplant centres.

e) Have there been changes in behaviour of UK adult stem cell donors on the UK Aligned Registry that make them less likely to donate?

Since the Covid-19 pandemic, we have seen an increase in donors who are less likely to donate. This is both a problem in the UK and globally.

Fulfilment of VT requests from UK donors has dropped from 63% in FY18-19 to 47% in FY24-25. For comparison, below are the same figures from the UK's top 5 countries of import, from Anthony Nolan data of VT requests fulfilled for UK patients:

Country	FY18-19	FY24-25
Germany	74%	69%
USA	48%	38%
Poland	67%	57%
Netherlands	68%	62%
Israel	74%	56%

Anthony Nolan is committed to improving donor availability by building strong, tailored engagement with our community—particularly younger donors and those from minority ethnic backgrounds—so they feel informed, supported, and ready to donate when called upon. To achieve this, we are investing in personalised communications, data quality, technical innovations, and dedicated support services that make it easier for donors to stay connected, confident, and prepared.

f) The UK system for stem cell provision has evolved over decades. What are the pros and cons of the current system and what system changes could provide a more resilient and sustainable stem cell transplant system?

The UK was the first country to establish an unrelated stem cell donor registry, founded by Shirley Nolan as she searched for a match for her son Anthony. Since then, over 28,000 transplants have been facilitated in the UK and globally by the organisation.

The four members of the UK Aligned Registry have delivered key system improvements — including donor register growth, a national cord blood bank, and a unified search to provision pathway for transplant centres.

Each member contributes unique expertise in histocompatibility, immunogenetics, and clinical support, operating on a non-profit basis and investing in research, infrastructure, and patient services to benefit the NHS.

The challenges we face are around: responding to the increasing diversity of the UK population; growing engagement in the register amongst young people and strengthening the global technological and logistical operations that connect patients and donors across the world.

To meet rising demand, increasing complexity and to tackle persistent inequalities, the UK stem cell system needs targeted support. We're calling for:

- Government investment in UK Aligned Registry projects to deliver UK register growth and improve donor availability.
- Investment in global donor recruitment, especially in countries with high potential to support patients from Asian and African heritage.
- Better NHS data on ethnicity and patient characteristics, to improve our understanding of inequities and deliver informed national policy on inequities.
- Commitment from the UK Government to strengthen the education on stem cell donation for young people, building the next generation of lifesavers.
- Funding of the cell therapy workforce and infrastructure, to ensure the system is future-ready and can respond to the growing numbers of cellular therapies patients.
- Support to improve patient care and experience, across stem cell transplant and emerging cell and gene therapies.

Ethnicity and Transplantation APPG Inquiry

Anthony Nolan response to follow up questions

November 2025

It was highlighted in the written evidence to our Inquiry that there has been a marked reduction in the numbers of donors recruited to the UK Aligned Stem Cell Registry since 2018-19.

We would like to understand the implications for sustainability of the UK stem cell supply for transplant and would like to ask these follow up questions.

1. Reduced provision leads to a reduced income, is that impacting on investment in the Registry from your organisation's perspective?

The register remains a key organisational priority, and our investment in it has grown significantly over the past five years. We would welcome further investment from government to support continued expansion in this area. Alongside donor recruitment, it is vital that we also focus on donor availability — ensuring that those on our register remain engaged and ready to donate when patients need them.

2. If not, what are the reasons for the reduction in recruitment?

We have not reduced investment in the register. There are a number of reasons for a reduction in the number of people we have been able to recruit year on year.

A post-pandemic behavioural shift at a global level appears to have reduced individuals' willingness to participate in altruistic health initiatives such as stem cell donor registration. It has also become harder to reach and convert people online because digital spaces are now more crowded, fragmented, and saturated with competing messages than they were five years ago. Changes to social platforms also mean its harder to target key audiences than it was in the past. The initial drop post covid was also due to having to rebuild our programmes for face-to-face recruitment. Since then, the trend for Anthony Nolan event recruitment has been one of growth.

3. If UK donor to UK patient provision continues to decline, will further reduction in income lead to continued lack of investment from your organisation's perspective in new donor recruitment and threaten the sustainability of the Registry?

Sustained and increased investment in the register is essential to meeting patient needs. While we remain committed to prioritising this area, additional funding is critical to accelerate growth and strengthen impact. Investment must support not only donor recruitment but also donor availability — ensuring that every person on our register is engaged, committed, and ready to donate when called upon. Investment should also be directed at supporting the registry's search and provision infrastructure, including the vital technology that supports efficient communication between transplant centres and the registry, UK and global search ability, and the quality of data available to and from the registry.

4. Has your organisation done any modelling to support a business case for investment in the UK Aligned Registry using the cost savings driven by reduced imports to pay for this investment?

Yes, we have done some modelling in the past to show how increased investment in the register could result in cost savings from increased UK to UK provision. Please refer to Appendix 3 of the 2022 UK Stem Cell Strategic Forum Report for more information.

5. Was any mitigation for the continuing health inequity faced by minority ethnic and mixed heritage patients included in a business case?

Every recent funding bid we've submitted has had a major focus on reducing health inequality. Driving greater equity is a fundamental pillar of Anthony Nolan's fiveyear strategy.

6. With Germany now supplying 42% of UK stem cell transplants and the US providing a significant number of stem cell provisions are contingency plans in place by the UK Aligned Stem Cell Registry for disruption to this supply of life-saving transplants?

We have business continuity plans in place for any disruption, such as a global pandemic, which may impact the continuity of cell supply for UK patients. These plans include our donor & transplantation services, donor recruitment and other essential functions. Business continuity plans are reviewed annually.