Fit for Everyone: Rebuilding a Resilient and Equitable UK Stem Cell Supply

An interim report of the APPG inquiry into the unrelated Haematopoietic stem cell system

May 2026

All Party Parliamentary Group
on Ethnicity, Transplantation
and Transfusion

May 2026

The APPG Secretariat support is provided by National Black, Asian, Mixed Race, and Minority Ethnic Transplant Alliance (NBTA).

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Addendum (April 2026)

Since the completion of this report the Department of Health and Social Care (DHSC) has commissioned an independent review of the UK Haematopoietic stem cell (HSC) supply. This report was prepared in advance of that decision and includes a recommendation calling for such a review. The All Party Parliamentary Group for Ethnicity, Transplantation and Transfusion (APPG) welcomes this important development.

References requesting the commissioning of a review remain within the report should now be read in the context that such a review will take place. The APPG believes that the evidence and findings presented here provide both a timely and relevant contribution to the review process. It therefore presents this report as an interim submission to support and inform the work of the DHSC HSC supply review.

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Foreword

From the Chair of the All-Party Parliamentary Group on Ethnicity, Transplantation and Transfusion

Haematopoietic Stem Cell (HSC) transplantation is a life-saving treatment for patients with blood cancers and other serious conditions. This inquiry sought to understand the issues behind the declining use of UK unrelated HSC donors and cord blood HSC in providing life-saving transplants for UK patients. The UK has a global reputation for clinical expertise and innovation in this field which must be continued. Ensuring that all patients can access these treatments when they are required relies heavily on the resilience, sustainability, accessibility and equality of all aspects of the transplant pathway.

The All-Party Parliamentary Group on Ethnicity, Transplantation and Transfusion (APPG) established this inquiry to examine the long-term sustainability and resilience of the UK's HSC supply; to understand how current pathways affect patients, clinicians, recruiters, and donors. In particular, the APPG sought to explore the implications for patients from minority ethnic and mixed-heritage backgrounds, who continue to face significant inequalities in access to transplants with well-matched HSC donors to all aspects of the transplant pathway. It is greatly concerning that in 2026, we still don't know how big a problem this is; by some estimates, thousands of people have already died for lack of a suitably matched donor.

The APPG wants this to stop. Lives are being lost due to systemic shortcomings. What is clear is that the current system isn't working for potential HSC transplant patients from ethnic minority and mixed heritage populations. This report is a call to action for system change.

Written submissions were received from UK stem cell registries, government arm's length bodies and DHSC, NHS England, patient organisations, and community representatives and an oral evidence session was held where the APPG heard from attending clinicians and a donor recruitment expert, with direct experience of the system. Both provided detailed evidence for the inquiry. The oral evidence revealed a high level of commitment from across the sector, with individuals going far beyond their formal responsibilities to ensure patients and donors receive the care and support they require. The APPG notes that the four UK stem cell registries were invited to provide oral evidence to the inquiry, but declined.

The evidence also points to systemic challenges relating specifically to resilience, sustainability, data, commissioning, and accountability, all of which cannot be addressed by the current legacy system. A recurring theme was that the system currently depends on the commitment of individuals and organisations to compensate for structural gaps, rather than there being clear accountability, long-term planning, aligned investment and making the most of what technology offers today. These are all key aspects of the Government's "Fit for the Future: 10 Year Health Plan for England" and addressing these issues for HSC transplantation could provide insights to tackling these same issues in the wider NHS.

This, the second inquiry report published by this APPG, brings together evidence, clearly setting out the key issues facing the UK's HSC supply for UK patients and identifies areas where further consideration is urgently required. It concludes that HSC supply should be regarded as a strategic national capability – comparable to that of blood and organ donation, requiring accountable leadership, oversight and resilience planning. We welcome the recently announced review of HSC supply and strongly advise that the review takes due note of the APPG's recommendations to ensure that the UK's HSC transplantation system is fit for the future.

The APPG is grateful to all those who contributed their written evidence submissions[1], and time and expertise to the oral evidence session. We hope that the findings will galvanise action and the system change required to strengthen the UK's approach to HSC supply so that more lives can be saved and that it better serves all UK patients more effectively, equitably and sustainably well into the future as well as delivering value for money whilst continuing to support world-leading research in the delivery of new treatments.

Bell Ribeiro-Addy MP for Clapham and Brixton Hill
Chair APPG on Ethnicity,
Transplantation and Transfusion

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[1] These can be viewed at: https://www.nbta-uk.org.uk/all-party-parliamentary-group-for-ethnicity-transplantation-and-transfusion/

Executive Summary

Haematopoietic stem cell (HSC) transplantation is a life-saving treatment for patients with blood cancers, blood disorders and some auto-immune conditions. The UK has internationally recognised clinical expertise in this field and, historically, the UK has played a leading role in innovation in treatment and donor provision. Evidence gathered by the APPG on Ethnicity, Transplantation and Transfusion's (APPG) inquiry, including submissions and oral evidence indicates that many aspects of the UK's system for supplying unrelated HSC is now no longer resilient, sustainable nor equitable and system change is required to ensure patients' needs in the future are met.

Evidence also indicates that unmet need is not fully visible within the current system. Without action, the UK is likely to become increasingly reliant on importing HSC from overseas registries, creating greater cost pressure and risks to long-term supply, adding risks to patient outcomes and the efficient use of public resources.

Strengthening the UK's ability to operate within a global HSC ecosystem is essential to improving patient outcome and therefore ensuring international registry interoperability and global collaboration to support equitable access to optimal donors is important.

Resilience and sustainability

The APPG called for this inquiry to examine the sustainability and resilience of the UK unrelated HSC supply, and to additionally provide evidence to understand the persistent and unacceptable inequalities that are being faced by minority ethnic and mixed heritage patients. Written submissions from UK stem cell registries, government arm's length bodies, DHSC, NHS England, patient organisations and community representatives, alongside oral evidence from clinicians and donor recruitment representatives, has confirmed that the unrelated HSC transplantation system has fragmented accountability and governance, in contrast with the coordinated models used for blood and solid organ donation.

As a result, threats to the resilience and sustainability of the UK HSC supply are not being addressed. The APPG notes that ushering in a new era of transparency, resilience, accountability and reduction in health inequalities are key elements of the Government's "Fit for the Future: 10 Year Health Plan for England" and strongly believes these principles should apply to HSC transplantation.

Evidence also highlighted the underutilisation of umbilical cord blood HSC in the UK. A national strategy is required to ensure this resource is properly implemented within clinical pathways, supporting better patient outcomes and preventing avoidable loss of life.

In the absence of such structural reform, the UK risks further decline in domestic HSC capability and a growing dependence on international supply.

The paucity of evidence submitted to the inquiry on costs associated with domestic and imported HSC donations highlighted that there was a lack of transparency in this area. A clearer understanding of the full costs of unrelated HSC transplantation, including international procurement is required to support effective planning and value for money, particularly if there remains a growing dependence on international supply.

Strengthened accountability, governance and transparency in the pricing of these products is required, supported by clear oversight from the DHSC, NHS England or the NHS commissioners to ensure consistency, value for money and effective stewardship of public funds.

Health is a devolved responsibility

Recommendations in this report are made in the context of health being a devolved responsibility and the APPG recognises that the Devolved Administrations hold overall responsibility for patients in their countries who require an HSC transplant. The APPG has written to the Devolved Administrations and received supportive feedback that Scotland and Wales would engage with any review commissioned by the Department of Health and Social Care (DHSC).

Commission an independent review

The many issues that this report sheds light on need to be addressed in a holistic manner. The APPG recommends that the DHSC, in conjunction with the Health Ministers of Scotland, Wales and Northern Ireland, should commission an independent review of the supply and use of UK unrelated HSC. This will ensure investments are used effectively, particularly the costs associated with international procurement of HSC, reduce duplication and inefficiencies within the current system, and deliver the improvements to sustainability and resilience so desperately needed to save more lives.

Accountability and transparency

Having an accountable, transparent organisation that is given the responsibility for ensuring the resilience and sustainability of the UK HSC supply is critical for making the system fit for the future. The APPG recommends that a ministerially accountable body with the necessary experience, skills and resources should be charged with coordinating a new UK model. The APPG believes that the organisation that best fits the mix of experience, skills and accountability to ministers is NHS Blood and Transplant (NHSBT). NHSBT is already accountable for blood supply in England and solid organs for the UK, making it logical that they also have this role for the nation’s HSC supply.

Address health inequalities

Whilst these challenges are acknowledged as critical for all patients, the disproportionate impact that they have on minority ethnic and mixed heritage patients is clear. Evidence confirms that these patients are significantly less likely to find an optimal donor (or even a donor at all), more likely to experience delays and have significantly less successful clinical outcomes. The absence of a single organisation accountable for improving equity compounds the problems already identified around data gaps, lack of visibility of unmet need, and actions to improve equity, particularly around recruitment. The APPG is calling for a new approach to community engagement that brings together recruitment, involvement in research and health. This investment could pioneer a new form of Digital Neighbourhood to support the aims of the Government’s “Fit for the Future: 10 Year Health Plan for England”.

Support clinical innovation

Clinical innovation, including the use of post-transplant cyclophosphamide (PTCy), and advances in the use of HSC from cord blood, highlight important opportunities for improving access and outcomes of HSC transplantation. To realise these opportunities a coordinated national leadership, improved data and investment are needed. To make the most of these opportunities, the APPG concludes that a review and appointment of a single responsible body for HSC transplantation to ensure its long-term sustainability and, resilience, value for money and equity of access for all patients.

Opportunity

Whilst the report identifies systemic challenges, the evidence also highlights an opportunity for collective progress. The recommendations, in seeking to address the structural barriers in the HSC transplantation system in the UK, also highlight the shared opportunities for growth, innovation and impact across the UK HSC community that can only be fully realised by working more effectively together.

Recommendations

The key finding of our inquiry is that systemic issues in the UK's system for supply and use of HSC need to be addressed. This is despite the efforts of dedicated individuals and organisations whose commitment often going beyond their formal responsibilities to support patients and improve the system for the benefit of patients. The following recommendations are intended to address identified systemic issues to ensure the resilience and sustainability of this life saving treatment for all patients.

Recommendation 1: Commission Independent Review

That the Department of Health and Social Care, engaging with Health Ministers for Wales, Scotland and Northern Ireland, commission an independent review of use, supply and funding of haematopoietic stem cell transplantation in the UK.

The review should have the aims of:

a. ensuring the resilience and sustainability of the UK HSC supply,

b. delivering value for money,

c. addressing health inequalities as its main priorities.

Recommendation 2: Assigning Responsibility for Accountability, Resilience and Sustainability for the UK Haematopoietic Stem Cell Supply

That a single organisation is appointed by the Secretary of State for Health and Social Care and Health Ministers for Wales, Scotland and Northern Ireland with the overall responsibility for the UK haematopoietic stem cell supply.

1. The organisation does not have to carry out all functions needed for a resilient and sustainable haematopoietic stem cell supply but would be responsible and accountable for putting into practice the recommendations of the independent review.

2. The organisation should be accountable to ministers, have the ability to plan for the long-term, including investing in the UK HSC supply to ensure resilience, sustainability and value for money. Experience in working with all UK Governments and having a national presence are also important.

3. The APPG believes that the NHS Blood and Transplant is the most appropriate organisation that meets these criteria.

Recommendation 3: Address Health Inequalities

Invest in recruitment of minority ethnic donors to:

1. Increase ethnic diversity in the UK Aligned Stem Cell Registry, and improve access to transplantation for minority ethnic patients, including increasing the availability of donors suitable for post-transplant cyclophosphamide and mismatched donor transplantation.
2. Trial a new approach to engagement with potential donors using modern communication technologies, creating opportunities in health research, health prevention and health promotion to further address health inequalities, pioneering a new form of Digital Neighbourhood to support the Government's "Fit for the Future: 10 Year Health Plan for England".

Research Recommendation 1

To inform the DHSC commissioned independent review, the APPG believes that modelling should be carried out to understand:

1. How investment in UK donor recruitment could increase the use of UK donors and deliver cost savings to the NHS,
2. How the introduction of post-transplant cyclophosphamide may affect the use of UK donors, and the implications for recruiting donors from minority ethnic communities to improve access to HSC transplantation for minority ethnic patients.

Research Recommendation 2

The introduction of post-transplant cyclophosphamide represents a possible opportunity to improve access and clinical outcomes of HSC transplants using mis-matched and multiple mis-matched donors. It is very important to gain an understanding as to which HLA mismatches lead to clinical complications and which do not.

1. NIHR should fund a call to explore this and the APPG notes that many stem cell transplant patients have whole genome sequencing.
2. Whole Genome Sequencing of patients receiving mismatched HSC transplants and their donors should be undertaken, with informed consent.
3. UK expertise in genomics and AI should explore linking HLA, genetics, and clinical outcomes to allow clinicians to make better decisions for patients undergoing a mismatched HSC transplant.

1. Purpose of the Inquiry

This inquiry sought to understand the issues behind the declining use of UK unrelated HSC donors and cord blood HSC in providing life-saving transplants for UK patients. Since the APPG responded to the “Change NHS: help build a health service fit for the future”[2] consultation in November 2024 with a call for the DHSC to commission an independent review of UK HSC transplantation, there has been widespread support from stakeholders, including those who provided evidence to this inquiry.

The APPG believes that the evidence gathered here further supports our call for the independent review and contributes to a wider understanding of issues such as:

- In 2024-25 the UK imported 76% of the unrelated HSC donations used in transplanting UK patients. The UKSCSF “A 10 Year Vision for Stem Cell Transplantation and Cellular Therapies, July 2022[3] “recommends a resilient and sustainable UK HSC supply of 45% UK donors for UK patients. Currently, the UK HSC supply is at 24%, around half the recommended level.
- HSC imports cost more than UK donors, introduces supply chain risks and diverts support from UK registries and UK expertise.
- Rebuilding a sustainable and resilient HSC supply as a national asset is long overdue and understanding the reasons for the decline is the first step.
- The extent and drivers of unmet need for HSC transplantation in the UK are not sufficiently understood or quantified, limiting the ability to address health inequalities.

This issue is of particular concern to this APPG because of the significant health inequalities facing minority ethnic and mixed heritage patients needing an HSC transplant in the UK.

Minority ethnic patients only have a 37% chance of getting a well-matched donor compared with 72% of patients of Northern European heritage.

The odds for mixed heritage patients are even lower.

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[2] NHS 2024 Change NHS: help build a health service fit for the future

[3] The UK Stem Cell Strategic Forum ‘A 10 Year Vision for Stem Cell Transplantation and Cellular Therapies, July 2022

1.1 The Time for Action is Now

Sustainability and resilience

There are major question marks about the resilience and sustainability of the UK HSC supply and unlike blood and organs, no single organisation has responsibility for this supply chain. In 2024/25, only 24% of HSC transplants in the UK used a UK donor. In contrast, Germany supplied 42%[4] of the UK's HSC donations in that period. This is the level of UK self-supply recommended by the UKSCSF, a DHSC advisory body. It is not hard to see how a combination of supply chain risks could seriously impact patients.

Changes within the NHS are happening – time to make them effective

The inquiry heard that without clear national oversight, there is a risk that existing challenges relating to resilience, data and long-term planning may persist.

However, significant changes are taking place across the NHS that are relevant to the future of HSC transplantation in the UK. In England, specialised services are increasingly being commissioned through Integrated Care Boards (ICB) as part of reforms that are being aimed at improving the integration of services, addressing health inequalities and ensuring resources are used more effectively across different patient pathways.

These developments present an important opportunity to position HSC transplantation as a strategic national capability. The infrastructure required to support and coordinate the HSC transplantation system should be part of wider efforts to ensure national capabilities are best supported and sustained in the long term.

Address existing health inequalities facing minority ethnic and mixed heritage patients

There are exciting changes to clinical practice that have long term implications for access to a HSC transplant for patients who do not have a good match, especially minority ethnic and mixed heritage patients.

Advances in clinical practice are changing approaches to treatment and what is possible for patients who do not have a fully matched donor. These expanding treatment options may potentially have significance for patients from minority ethnic and mixed heritage backgrounds who are less likely to find an optimal match through traditional pathways. Likewise, the inquiry also highlighted the potential role of umbilical cord HSC in improving access to transplantation for some patients. Whilst these opportunities are not being realised consistently, improvements could be made if a clear strategy, coordination and investment was made to ensure that the opportunity these developments could provide are realised.

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[4] NHSBT written submission

Use technology to advance understanding

There is significant opportunity to use UK expertise in AI and genomics to identify which mismatches have clinical consequences, to enable better selection of mismatched donors and improve patient outcomes, thereby delivering benefit to HSC patients. The UK is investing significantly in genomics and data infrastructure across the NHS. The NHS Genomics Strategy (2020)[5] aims to integrate genomic medicine within healthcare and link genomic data with wider clinical datasets to help improve patient outcomes. This is the opportunity for HSC transplantation, by linking HLA data, genomic information and transplant outcomes more effectively to facilitate a better understanding of risk around donor-patient mismatches. The APPG heard that relevant data is fragmented and needs to be brought together to fully support clinical decision making and planning within the HSC supply and transplant system.

There are also national initiatives that are exploring the use of AI in genomic medicine and clinical datasets within the NHS. By applying these capabilities to HSC transplantation, clinicians could be better supported in donor matching decisions and particularly in mismatched situations.

Therefore, with appropriate coordination and leadership, the UK has the potential to build on its existing structure as part of the changes taking place within the NHS, but further develop UK HSC transplantation by ensuring these changes support long term resilience, sustainability and equity.

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[5] DHSC (2020). Genome UK: the future of healthcare. London, DHSC

2. Methodology

On the 29th August 2025 the APPG released the following call for written evidence on:

1. UK HSC supply,
2. Factors influencing decisions about donor selection – clinician's and commissioners' perspective, with a closing date of noon on Wednesday 24 September 2025.

2.1 Written Evidence: UK HSC supply

Areas that the APPG wished to address were provided (as below) in addition to welcoming any other relevant contributions:

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

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

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

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

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

f) The UK system for HSC 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?

2.2 Written Evidence: Factors influencing decisions about donor selection – clinician's and commissioners' perspective.

The APPG understood that clinicians make decisions based on what is best for their patients. However, the reasons why fewer UK donors are being chosen have not been widely discussed. This call for evidence provided an opportunity for organisations and individuals with insight into why this is happening to share their experiences so that factors impacting donor selection decisions can be clearly identified.

Written evidence was also welcomed from HSC patients or patient groups. Suggested areas to address were:

a) Timeliness and reliability of UK stem cell donations,

b) Quality of UK stem cell donations,

c) Changes to transplantation processes,

d) Any other factors relevant to this inquiry.

Evidence submissions were received from the following and can be viewed on the APPG website:[6]

African Caribbean Leukaemia Trust

Anthony Nolan

BSBMTCT

Department of Health and Social Care

DKMS UK

Dr James Griffin[7]

Dr Kanchan Rao[8]

NHS Blood & Transplant

NHS England

Regenerative and Cellular Medicine Registry

Sabrina Jarrett[9]

Team Margot

UK Stem Cell Strategic Forum

Welsh Bone Marrow Donor Registry

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[6] These can be viewed at: https://www.nbta-uk.org.uk/all-party-parliamentary-group-for-ethnicity-transplantation-and-transfusion/

[7] Submission provided in a personal capacity

[8] Ibid

[9] Ibid

3. Ensuring Sustainability, Resilience and Value for Money for All Patients

The UK Aligned Stem Cell Registry is an important national asset that provides life-saving HSC transplants to patients with blood cancer and other conditions. A similar number of patients have HSC transplants from either related or unrelated donors, as do those who have a solid organ transplant every year. However, the APPG has heard evidence that support and investment in this vital treatment pathway is lacking, and that HSC donation services are 10 years behind in development compared to solid organs and blood.

3.1. Sustainability

Sustainability is the ability to function effectively over a long period of time. 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. The table below shows a sustained deceleration in growth of the registry year on year, with only a marginal percentage increase in the last year.

Fiscal year	Total registered donors	Increase in the size of the Registry	Increase in the size of the Registry as a %	Change in increase %
2018/19	1,627,069	189,152	-	
2019/20	1,924,120	297,051	18.25	
2020/21	2,127,000	202,880	10.54	-7.71
2021/22	2,233,254	106,254	5.00	-5.54
2022/23	2,317,065	83,811	3.75	-1.25
2023/24	2,374,212	57,147	2.47	-1.28
2024/25	2,441,358	67,146	2.83	+0.36

Table 1. The number of registered donors on the UK Aligned Stem Cell Registry from 2018-2025[10]

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[10] Written submission

3.1.1 Written Evidence on Sustainability from the UK Aligned Stem Cell Registry Members

The APPG Inquiry asked members of the UK Aligned Stem Cell Registry if ***"the reduction in income from UK donor to UK patient provision was impacting on their organisation's investment in the Registry?"***:

The NHSBT, Anthony Nolan, DKMSUK and WBMDR written answers were:

Written Evidence NHSBT: *"A fall in total provision inevitably reduces income and therefore constrains discretionary investment. While NHSBT has protected core operations donor search, testing (through Grant in Aid Funding), and collection capacity a decline in total provision from our registry would limit reinvestment in digital upgrades, donor recruitment, and diversity initiatives.*

Currently, export income is sufficient to cross subsidise these functions even though UK to UK provision has fallen; if overall provision declines, reinvestment capacity will erode."

Written Evidence Anthony Nolan: *"The register remains a key organisational priority and our investment in it has grown significantly over the past five years."*

Written Evidence DKMS UK: *"DKMS UK remains fully committed to its mission and continues to increase investment in donor recruitment and engagement year on year regardless of fluctuations in domestic provision.*

It is important to emphasise that UK donor exports to international patients remain stable. UK donors continue to be selected globally providing a reliable revenue stream that supports our long-term operational sustainability."

Written Evidence WBMDR: *"The WBMDR has made great strides in increasing its donor panel especially the 'fit' panel of donors between 17 and 30 which are most frequently requested by transplant clinicians. The WBMDR also has an excellent reputation for reliability and efficiency that rivals their larger international partners. Essentially the WBMDR is playing a significant role in increasing the UK donor panel but the final donor selection decision lies with the transplant centre and that may be where this reduction in UK donor utilisation needs to be addressed."*

The impact of these positive responses should be seen in the data for 2025-2026 when available and it will be interesting to see the scale of the uplift in the number of donors on the UK Aligned Stem Cell Registry.

It was also highlighted by both Anthony Nolan and NHSBT that there are long term risks and a need for further investment, the relevant paragraph from NHSBT is quoted below:

> **Written Evidence NHSBT:** *"If domestic provision continues to decline, the UK risks a self-reinforcing downward cycle: fewer UK donations → lower income → reduced investment → further decline. Given the large differential between export (£29k) and domestic (£5k) income, the Registry's sustainability depends on maintaining both export competitiveness and UK utilisation. NHSBT's position is that targeted reinvestment now is essential to reverse this trend – focusing on younger, diverse, high-availability donors and digital engagement tools that improve readiness and work-up success."*

Anthony Nolan's response highlighted the importance of donor availability, as well as recruitment:

> **Written Evidence Anthony Nolan:** *"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."*

Overall, it seems that each member is doing what it can to contribute to the UK Aligned Stem Cell Registry within the limits of their own business plans. However:

APPG Insight
The APPG finds that:

1. the big picture is one of stasis and is likely to remain so until a single body is given the overall responsibility for ensuring a growing UK Aligned Stem Cell Registry that reflects the needs of UK patients,
2. the need for further investment is also clear and how this can be achieved is discussed in the Value for Money section below,
3. increasing the UK donor pool will only translate into increased UK donor provision to UK patients and deliver the costs savings to the NHS, if issues in delivering UK HSC donations in a clinically relevant timeframe are identified and addressed.

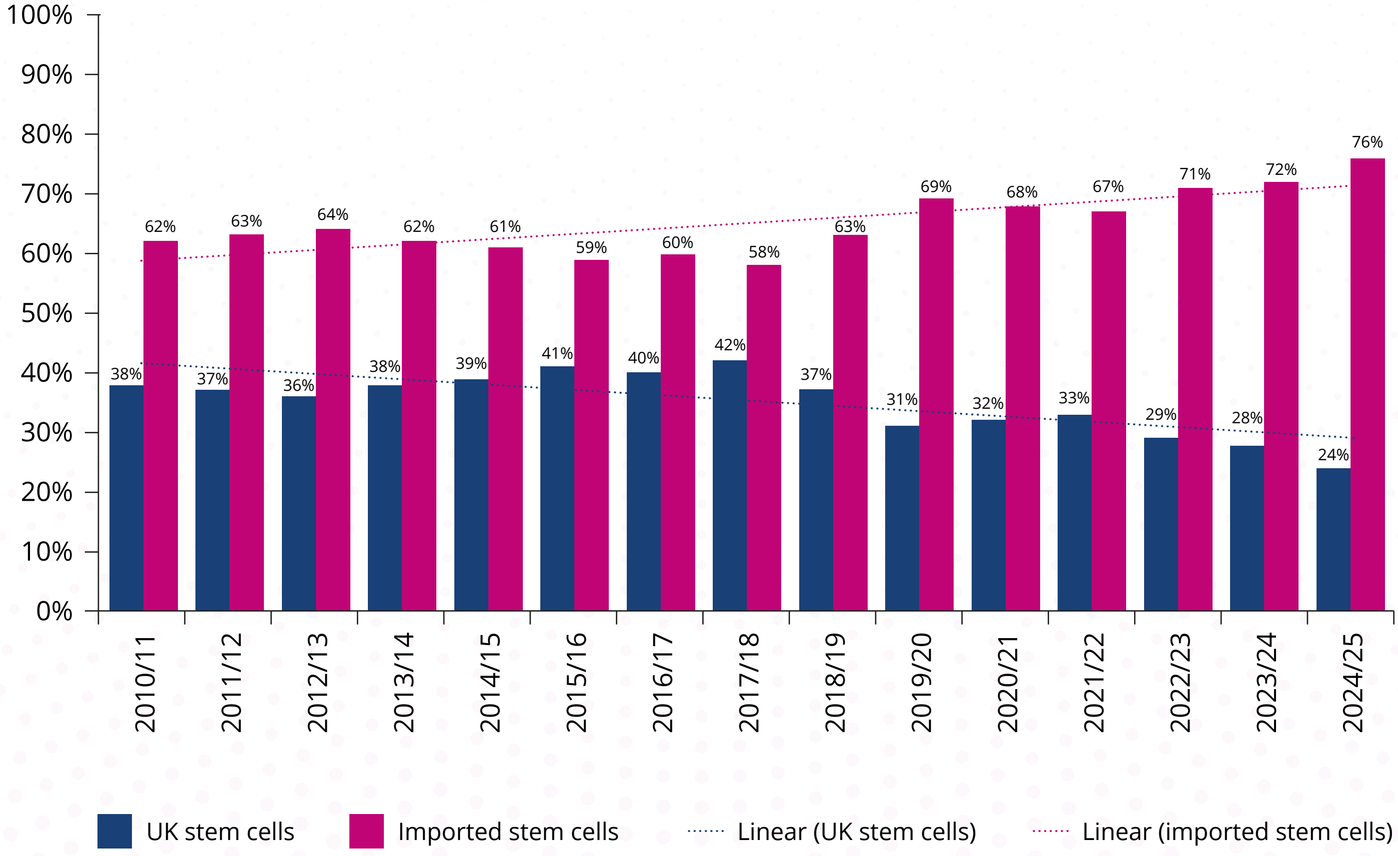
3.2 Resilience

Resilience is the capacity to withstand or recover in a timely manner from adverse events. The UK is currently providing only 24% of unrelated HSC donations used for transplant, against a recommendation by the UKSCSF of 45% with the trend being one of continued decline. At the APPG oral evidence session the clinical panel were asked if they prioritise use of UK donors and it was confirmed that they prefer to use a UK based donor if available in a clinically relevant timeframe.

We live in an increasingly unstable world with recent examples of disruption or potential disruption including Brexit, the COVID-19 pandemic, war in Ukraine and continuing cyber-attacks on supply chains and healthcare systems.

APPG Insight:

The increasing lack of availability of UK donors for UK patients is a very real resilience risk.



Graph 1 Percentages of UK sourced and imported HSC donations 2011-2025 (with UK and Imported HSC trend line)[11]

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[11] Written submission

APPG Insight:

Just before the pandemic in 2018-19, the UK supplied 37% of its needs rather than the current 24%. This increased reliance on imports is likely to impact resilience to supply chain shocks.

The APPG recommends:

As the impact of the pandemic was referenced in the submissions, any data on availability and outcomes of HSC transplants carried out over this period should be part of any independent review of UK HSC provision and use.

The APPG asked:

"With Germany now supplying 42% of UK stem cell transplants and the US also providing significant volumes, are contingency plans in place for potential disruption to this supply?"

What was clear from the replies (below) was that although each organisation has its own plans no one has responsibility for the system as a whole."

The APPG recognises:

The importance of international co-operation in the supply of HSC and that some level of imports will always be needed. Indeed, the cooperation in providing HSC donations wherever needed is a great example of organisations and countries co-operating with each other and should be applauded.

Written Evidence Anthony Nolan: *"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."*

Written Evidence DKMS UK: *"The global registry system is intentionally designed for resilience. No national registry can meet all domestic patient needs; the strength of the system lies in its international interconnectedness, supported by WMDA standards, global courier networks, and long-standing cooperation between donor centres."*

Written Evidence WBMDR: *"We are required to have contingency plans in place for the delivery of stem cells, and this includes gaining evidenced assurances of contingencies provided by overseas registries under their local regulations."*

Written Evidence NHSBT: *"The COVID pandemic provided a very robust test of our ability to handle major supply chain disruption and logistical hurdles to the international exchange of stem cell products. We are very proud that despite all the challenges, in partnership with our Aligned Registry partners, we were still able to facilitate export and import of stem cell products."*

Impact of the COVID-19 Pandemic

The COVID-19 pandemic was a recent test of system resilience for HSC transplantation. It had a significant impact on availability of HSC donors, disrupting both international and UK donor availability as well as the ability to perform the transplants themselves. As noted in written submissions, there was considerable effort to introduce mitigations to support the supply and use of HSC transplantation in the UK.

APPG Insight:

The APPG is not aware of any published study on the impact of access to or outcomes of HSC transplantation in the UK during this period. An evidence-based understanding of the impact of COVID-19 would be very useful for the resilience planning for HSC transplantation.

APPG Insight:

The UK supply from UK donors was around 42 % in 2017/18 and is now down to 24% which may impact resilience.

3.3 Value for Money

An important source of funding for the members of the UK Aligned Stem Cell Registry comes from supplying the NHS with HSC donations for UK patients. If that funding is being reduced this raises questions of sustainability and resilience. Imported donations are more expensive than the domestic supply, so reducing the reliance on imports could free resources to improve UK domestic supply and address health inequalities facing HSC transplant patients.

The APPG asked the members of the UK Aligned Stem Cell Registry if "any modelling had been carried out to understand the potential impact of investment in the UK Aligned Stem Cell Registry on costs to the NHS?"

NHSBT confirmed that it and other members of the UK Aligned Stem Cell Registry have modelled the financial impact of improving UK self-sufficiency and these have been reported through the UKSCSF. The findings formed the basis of the business case for the DHSC Stem Cell Programme funding.

Written Evidence NHSBT: *"imported donations cost 30–50% more than equivalent UK products once transport, insurance, and coordination costs are included. Raising the UK-sourced share of transplants by even 5–10 percentage points could yield annual savings to the NHS in the low millions."*

This modelling underpins the UK Aligned Stem Cell Registry sustainability business case, linking reduced import dependency and sustained export revenue to long-term financial stability. Whilst the UK Aligned Stem Cell Registry will never be 100% self-sufficient in providing HSC to all UK patients, the UKSCSF recommended in their 10 Year Vision for HSCT and Cellular Therapies (July 2022) that the UK should provide a minimum of 45% of unrelated stem cell donations.

The APPG heard evidence that this is still an achievable and desirable level of domestic supply.

APPG Insight:

This evidence shows that the current system is unsustainable; buying expensive imported HSC donations means that NHS funds are used to support the infrastructure and expertise of HSC registries in other countries (Germany provided 42% of unrelated HSC donations for UK patients in 2024). This deprives the UK based registries of resources needed to expand the number of UK registered HSC donors with recruitment tailored to better meet the needs of UK patients.

The APPG also received evidence that highlighted the UK as an important international source of HSC[12], partly due to our relatively diverse ethnic population. Evidence provided by NHSBT indicated that UK exports are currently subsidising other activities of the members of the UK Aligned Stem Cell Registry.

APPG Insight:

Supporting a resilient and sustainable UK supply would not only benefit UK patients but could help more patients internationally. Generating income by providing life-saving HSC donations is not in itself a problem. However, relying on this to underpin the UK HSC supply leaves the UK vulnerable to the abovementioned risks.

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[12] NHSBT written submission

3.4 Barriers to providing UK HSC donations in a clinically relevant timeframe and ensuring value for money

The APPG is grateful for the clinicians who provided written submissions and attended the evidence session in person. The aim was to understand the transplant clinician's perspective as this part of the process is not well understood outside the clinical HSC transplant community. We hope these insights provide clarity for non-specialist policy makers and other interested parties.

The APPG heard that clinicians usually select donors as part of Multi-Disciplinary Team (MDT) meetings, which includes guidance from tissue typing (HLA matching) experts. The two principal criteria used to select a donor are:

1. The HLA or tissue match, between the patient and the donor,
2. Donor availability to donate at a clinically relevant time.

Other factors that need to be considered are donor gender, age, blood group and CMV status.

Donor availability is critically relevant in relation to the date that the patient clinically requires the transplant which includes the preparation of the patient for transplant – the pre-conditioning of the patient. The preparation of the patient for transplant is variable depending upon the regime used. If there is a well-matched donor but they are unable to donate when the patient requires the transplant, then this donor will not be selected.

The inquiry heard examples of good practice, including:

- **the early involvement of HSC transplant clinicians in MDT meetings in secondary blood cancer units.** Referred blood cancer patients are discussed and those suitable for transplant are identified. It is at this stage that family members are investigated for suitable donors and if none are available a search for an unrelated donor is initiated.

The inquiry was also made aware of some concerns in:

- **delay in referral of patients from primary to secondary care centres for some blood cancer patients.**[13]

The APPG recommends:

The delay in referral of patients from primary to secondary care centres should be a consideration for the DHSC commissioned independent review.

The potential barriers between a donor being selected and a donation taking place were highlighted in evidence as risks that can impede a transplant taking place. Apheresis capacity (the procedure used to collect the HSC from the donor), both in terms of equipment and clinical personnel was highlighted as one such issue. At the time of writing, a DHSC sponsored review of apheresis capacity in the UK is underway. The APPG welcomes this review and sees it as an opportunity to address a key constraint in the HSC donation pathway.

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[13] Oral evidence

Other contributing factors that cause delays and negatively influence the selection of a UK donor include the lack of clinical or laboratory personnel and equipment.

DKMS UK, NHSBT and Anthony Nolan highlighted this in their written evidence:

Written Evidence DKMS UK: *"Practical challenges within the UK also play a role. Timeliness is essential, and clinicians often highlight that the speed of confirming a donor's health status and availability is a major factor in the selection process. The UK system has many strengths, but aspects of its structure and composition could be further optimised to respond more rapidly to urgent patient need.*

The availability and geographic spread of collection services, including apheresis and bone marrow harvests, also affect timeliness. Where timelines do not align with patient requirements, clinicians may turn to overseas registries. At DKMS UK, we also face challenges meeting transplant centre timelines because of limited capacity at contracted collection centres."

Written Evidence NHSBT: *"NHSBT Therapeutic Apheresis Services has experienced steadily increasing cell collection demand for registries over the last 10 years, however continued UK wide apheresis capacity pressures can impact the availability of stem cell donation slots. This is not just due to available apheresis slots, but also donor medical assessment capacity and stem cell lab support."*

Anthony Nolan also noted the same issue and have obtained philanthropic funding for a new cell collection centre in Nottingham which is a welcome addition, but does not address the general lack of UK capacity for HSC collection.

Recommendation Link

Ensuring the timely delivery of HSC donations for transplant is critical for improving the sustainability and resilience of the UK HSC supply and should be a focus of the DHSC commissioned independent review and acknowledge the findings and recommendations of the DHSC apheresis review.

3.5 Addressing health inequalities facing minority ethnic and mixed heritage patients needing a life-saving HSC transplant

Minority ethnic and mixed heritage patients needing an HSC transplant are at a disadvantage compared to patients needing blood products or a solid organ transplant. Real and severe problems still face those needing blood products or solid organs but there are clear lines of responsibility and accountability as well as far better granular patient and donor data available. Understanding the issues and formulating policies to address them for UK patients requiring an HSC transplant is much further behind that for blood and organs.

At the APPG's clinical evidence session, it was noted that UK HSC transplant system is considered to be 10 years behind the systems in place for blood and solid organs.

Recommendation Link

Urgent action is needed to change this situation and the APPG strongly recommends that this should also be a focus of the DHSC commissioned independent review.

Health inequalities that affect access to HSC transplantation for minority ethnic and mixed heritage patients are complex. The history in the UK of political and social discrimination has wide ranging impacts on interactions within the health and care system. For example, as minority ethnic and mixed heritage people experience socio-economic disadvantage in the UK, this also impacts on the likelihood of them receiving an HSC transplant. Patients with socio-economic disadvantages have higher levels of co-morbidities which can be a contraindication for receiving HSC transplants. Socio-economic circumstances also affect the chances of having a successful HSC transplant as it puts intense pressures on a person, their support network and their resources. The Government's *"Fit for the Future: 10 Year Health Plan for England"* has a clear commitment to reduce ethnic health inequalities.

3.5.1 Unmet Need

The 2022 report *"A 10 year vision for stem cell transplantation and cellular therapies"* by the UKSCSF stated:

> *'The UK Aligned Stem Cell Registry now provides a substantial searchable pool of over two million adult stem cell donors and cord blood stem cell units. The registry also has the capability to search overseas registries to provide cells to UK patients.*
>
> *Despite this, there remains a substantial degree of unmet patient need for optimal 10/10 HLA-matched donors, and a reliance on overseas donors to provide cells for UK patients." (UKSCSF, 2022)*

The unmet need in terms of patients who could benefit from an HSC transplant but do not receive one are:

- patients that do have a well-matched donor, but the donation cannot be made within the clinical time frame for the patient.

This may be due to limitations in donor availability, timeliness, or system design rather than clinical choice; it is not just a capacity issue but also an equity issue.

- patients that do not have a well-matched donor – a 10/10 as described by the UKSCSF above.

Patients that do not have a well-matched donor may, depending upon their age and diagnosis, have alternative options:

1. Receive HSC from a mismatched adult donor or cord blood unit,
2. Receive HSC from a haplo-identical donor (often a parent or sibling).

These patients that take alternative options together with those patients who have no donor and therefore no transplant, constitute the unmet need.

Whilst these alternative donor options do enable the patient to have a transplant and so to some degree addresses the inequality, it is not an equitable transplant comparable to patients that had a well-matched donor. These alternative donor options do not address the root cause of the inequality – namely a well-matched donor for all patients.

From the evidence session it was confirmed that the unmet need was still not well understood, although examples of good practice were heard which included:

- early involvement of HSC transplant clinicians in MDT meetings discussing treatment for cancer patients,
- early identification of patients and early investigations for a family or unrelated donor.

However, it was noted that this did not happen everywhere and such early interventions in the process involves more clinical time.

Calculation of unmet need

In 2010, the UKSCSF report the unmet need was calculated from surrogate data of a transplanted group of patients and this determined the UKSCSF recommendation that a cord bank of 50,000 units was required to provide cord units to patients who did not have a well-matched unrelated donor.

In 2014 the unmet need was calculated (from unpublished data) using a different formula which had been presented at an international meeting. This was based on a small cohort of 228 patients out of 401 across four transplant centres.

This calculation determined the revised UKSCSF recommendation that a UK cord bank of 30,000 units was required to provide cord units to patients who did not have a well-matched unrelated donor.

The APPG noted:

That the UK Aligned Stem Cell Registry report (2024/25) stated that the UK cord bank was 28,418 units, showing that a decade after of the recommended size of 30,000 units had been made this target still had not been met.

The unmet need can only be determined by collecting data on all patients, together with their ethnicity, at the time an unrelated search has been requested. Data must confirm if a donor was identified or not, and record those who did have a donor but did not go to transplant.

APPG Insight:

Understanding the reasons why identified donors do not proceed to transplant needs to be systematically addressed and recorded.

The APPG notes that in the report “A 10 year vision for stem cell transplantation and cellular therapies” (UKSCSF,2022) it was stated:

> *“The aligned registry should then publish annual minority ethnic donor recruitment targets each year, with supporting contextual information on unmet need, recruitment strategies, and progress against targets.” (UKSCSF, 2022)*

Whilst patient ethnicity data is collected by the UK Aligned Stem Cell Registry at time of search (mandated since 31st October, 2022) **the APPG is unaware of:**

- **any of this ethnicity data being available,**
- **any annual supporting contextual information on unmet need being available.**

Reasons for measuring and addressing the unmet need:

- improving and addressing an understanding of unmet need is essential to address health inequalities regarding access to transplantation, particularly for minority ethnic and mixed heritage patients, as well as to inform strategic policy to UK recruitment,
- calculating unmet need provides data on potentially avoidable mortality and morbidity inefficiencies and waste of resources in the NHS from avoidable use of alternative treatments / therapies; it additionally highlights / quantifies systemic inequity,
- calculating unmet need is key to understanding if the recruitment of HSC donors is efficient and equitable.

Recommendation Link

Ensuring data is available to define the unmet need is essential to inform recruitment policies and strategies. It should be a focus of the DHSC commissioned independent review.

3.5.2 Access to an HSC transplant

This APPG's previous report "Where are our nations donors" highlighted the health inequalities faced by mixed race and ethnic minority patients needing a transplant or blood transfusion. A mixed race or ethnic minority blood cancer patient requiring an HSC transplant has a 37% chance of getting a well-matched donor compared 72% for a northern European heritage patient. This data is from an analysis by Anthony Nolan and is quoted in the 2022 report "A 10 year vision for stem cell transplantation and cellular therapies" by the UK Stem Cell Strategic Forum (UKSCSF). This was based on data from a small group of transplant centres and is clearly out of date.

The APPG notes that the UKSCSF's Data Commission is undertaking work to improve ethnicity data.

APPG Insight:

Bringing data on HSC patients up to the standard of data collected for patients receiving solid organ transplants or blood transfusions should be a high priority for change.

HSC taken from cord blood (cord blood units) are immunologically more naïve than from adult donor cells. It has been found that the tissue match (HLA match) between the patient and cord blood unit does not have to be as good as for adult donors, allowing for more mismatching. The NHS Cord Blood Bank was established in 1996 by NHSBT to make this source of HSC more widely available especially for patients who were not finding a matched related or unrelated adult donor. This was thought to be particularly applicable for minority ethnic and mixed heritage patients. Recently, the issuing of the 1000th unit from the NHS Cord Blood Bank was announced.

At the APPG evidence session Dr James Griffin discussed the current use of cord blood HSC:

Dr Griffin indicated that cord blood is currently underutilised in the UK, but highlighted that at his centre in Bristol many transplants had been performed.

He explained:

- the advantages of receiving cord blood for the adult patient when looked after in hospital (as there were complexities), and noted in particular the interesting data coming from its use in acute myeloid leukaemia paediatric patients (referencing the work of Professor Robert Wynn in Manchester),
- cell dose was sometimes a barrier to using cord blood units. In adults a double cord transplant would be required to obtain a sufficient cell dose[14]. This was less of an issue for paediatric patients,
- that the use of cord blood HSC has been reduced by the increased use of haplo-identical donors.

He stated that:

- there were units specialising in the use of cord blood, whilst there were others that were less confident in using cord blood units, noting the expertise in cord blood transplantation is not universal in the UK,
- the use of cord blood transplants is associated with longer in-hospital patient stays and the increased risk of infection,
- he expected that options for not fully matched donors would change in conjunction with the use of post-transplant chemotherapy. It was likely that this would be the area where changes would be seen.

APPG Insight:

Variation in clinical confidence and system capability limits the effective use of cord blood.

Recommendation Link

That the role and use of cord blood HSC transplantation in the UK should be evaluated by the DHSC independent review.

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[14] Cell dose is based on the patient's weight

3.5.3 Understanding disparities in HSC matching

Patients are more likely to find genetically well-matched HSC from unrelated donors who belong to the same or similar ethnic heritage. Large, established HSC donor registries are disproportionately located in Europe and North America, regions that have a majority white population. Although these regions contain less than 15% of the world's population, they account for around two-thirds of all registered HSC donors with 70 – 80% of donors being white.

Non-white ethnic groups represent around 80% of the global population and are genetically diverse as would be expected from the large number of racial groups. As a result, minority ethnic and mixed heritage patients have a significantly more diverse range of HLA types, and a greater number of unique HLA types, compared with those in patients of white ethnic heritage. This makes it harder to find a well-matched donor for minority ethnic and minority patients compared with patients of white European heritage.

These disparities are further compounded by imbalances in global registry representation. Minority ethnic and mixed heritage groups are underrepresented relative to need, limiting the probability of identifying well-matched donors and reinforcing structural inequities in access to transplantation.

3.5.4 Analysis of recruitment of minority ethnic and mixed heritage donors and impact of the DHSC stem cell programme 2022-2025

From the Team Margot evidence to the APPG Inquiry:

> **Written Evidence Team Margot:** *"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."*

The total number of **minority ethnic and mixed heritage donors** recruited in the 3 years between 2022-2025 by all four members of the UK Aligned Stem Cell Registry:

Year	Minority Ethnic and Mixed Heritage Donors Recruited	% Change
2022-23	24,815	-
2023-24	21,349	-13.97
2024-25	21,229	-0.56
Total 2022 – 2025	**67,393**	**-14.53**

Table. 2 Total number of minority ethnic and mixed heritage donors recruited 2022-2025 by all four members of the UK Aligned Stem Cell Registry (Anthony Nolan, State of the Registry Reports, 2025)

APPG Insight:

There has been a disturbing lack of investment in recruiting minority ethnic and mixed heritage HSC donors.

During 2022-2025, Anthony Nolan and NHSBT each received £400,000 per year from the DHSC Stem Cell Programme to support recruitment of minority ethnic and mixed heritage donors. To understand what the impact of the Programme had had, the APPG asked how many donors were recruited from this funding.

The DHSC provided the data shown in Table 3 that shows that DHSC is heavily supporting ethnic minority donor recruitment.

Organisation	Minority Ethnic	Northern European	Total	Minority Ethnic: Northern European Ratio	% Minority Ethnic
Anthony Nolan (DHSC Funded)	15,000	22,000	37,000	1 : 1.47	40.5
NHSBT (DHSC Funded)	3,000	13,800	16,800	1 : 4.6	17.9
Combined (DHSC Funded)	18,000	35,800	53,800	**1 : 2.0**	**33.5**
Anthony Nolan (Total)	23,000	37,000	60,000	1 : 161	38.3
NHSBT (Total)	13,500	36,000	49,500	1 : 2.67	27.3

Table. 3 Total numbers recruited by Anthony Nolan and NHSBT in the 3 years 2022-2025 highlighting numbers of donors recruited via the DHSC Stem Cell Programme (DHSC, 2026)[15]

APPG Insight:

Investment in the UK Stem Cell Registry is required to improve resilience, sustainability and value for money and to substantially increase recruitment of minority ethnic and mixed heritage donors.

The APPG recommends:

There should be a minimum matching amount of investment in minority ethnic and mixed heritage donors to that invested in northern European donors.

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[15] DHSC funds are allocated for the typing of the donor. Anthony Nolan and NHSBT have different costs for this.

Funding will increase the diversity of the Registry providing more donors for ethnic minority patients, including those who will be receiving a mismatched donor and cyclophosphamide as discussed in Section 4.1.1.

APPG calls for

a new approach to integrating donor recruitment to support delivery of the Government's "Fit for the Future10 Year Health Plan for England" (as set out in Section 3.5.7 below).

Recommendation Link

Funding to increase the resilience and sustainability of the UK HSC supply should include matched funding to support Recommendation 3 of this report.

3.5.5. Inequalities in outcomes for minority ethnic HSC transplant

Likelihood of fatal complications in cancer patients 5 years after transplant			
	All patients	**Adult patients**	**Paediatric patients**
White	29%	30%	15%
Black	37%	39%	16%
Asian	38%	39%	32%
Other	32%	30%	15%

Table 4: Inequalities in outcomes for minority ethnic HSC transplant patients (Source: Anthony Nolan, 2024)[16]

The above table shows the sobering reality of the health inequalities for minority ethnic patients having an HSC transplant. They are much more likely to have fatal complications after their treatment.

The APPG recommends:

That data on the impact of ethnicity on outcomes should be collected, curated and made available routinely to inform policies and ensure transparency.

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[16] The impact of patient ethnicity on haematopoietic cell transplantation outcome: a retrospective cohort study on the UK experience. Mayor, Neema P et al. The Lancet Haematology, Volume 11, Issue 12, e916 - e926 2024

3.5.6 Recruitment Activity

The APPG thanks Sabrina Jarrett for attending the oral evidence session and contributing by providing her experiences and thoughts on recruitment, especially minority ethnic and mixed heritage recruitment.

Sabrina Jarrett outlined the role of a recruiter, noting that it might seem very easy to recruit but that effective recruitment requires careful consideration of a range of factors for successful engagement, including:

- an understanding of medical, cultural and religious barriers to becoming a donor
- recognising recruiter to donor dynamics can influence engagement (e.g. female recruiters may find it more difficult to recruit men),
- adapting to changes in public behaviour following the COVID-19 pandemic,
- acknowledging and addressing the impact of systematic racism within healthcare.

Evidence presented to the inquiry emphasised how important culturally informed recruitment is in improving engagement with minority ethnic donors. She noted that recruiters who shared the same heritage as the communities they were engaging with were more effective as they could reduce cultural barriers and build trust, although this might not fully resolve challenges with gender imbalances.

It was highlighted that recruitment relies on empowering a wide network of partners including community groups, charities and patient families. Engagement through trusted intermediaries was identified as a key factor of successful recruitment.

However, the APPG heard that across all partnerships, often the relationship needed was not consistently developed or supported, with registries not sufficiently empowering their partners.

APPG Insight:

If recruiters do not have the support to sufficiently empower their partners, this limits the effectiveness of community-based recruitment efforts.

Examples were also provided of missed opportunities due to a lack of cultural confidence or training within recruitment organisations. Sabrina described engagement with community or faith groups were not pursued due to uncertainty about how to approach or engage in conversations around ethnicity, or belief. This lack of preparedness was identified as a barrier to recruitment and a contributor to donor attrition.

Concerns were also raised regarding the use of current incentives that could prioritise donor groups for commercial purposes rather than addressing patient inequalities. Comparisons were made with some international approaches that focussed on recruitment of underrepresented ethnic groups once sufficient donor recruitment had been achieved for majority populations.

Sabrina Jarrett also emphasised that signing up as a donor is a deeply personal and memorable decision for individuals. Therefore, when donors are subsequently contacted to donate, these memories and original motivations are still very relevant when triggered by this occurrence. The APPG heard that having support from someone who is additionally able to culturally understand the complexities of being called as a donor, can be invaluable in enabling them to proceed with donation.

Despite clear demographic trends, particularly in the primary school generations, it was noted that England's recruitment strategy has yet to adapt to reflect the increasing diversity of its population.

The APPG recognises that demographic trends in both primary and secondary school populations identify as minority ethnic or mixed heritage. This will shape future patient population and will have significant implications for donor recruitment strategies, which will need to evolve to support the demographic profile and future demand.

APPG Insight:

Recruitment is not a transactional process but a culturally and socially complex interaction. Current approaches do not consistently reflect the diversity of the population or adequately support the partnerships required to reach underrepresented groups.

APPG Insight:

Recruitment of minority ethnic donors is not supported by sufficient investment, resources, or effective recruitment approaches. This will be increasingly important as the impact of PTCy leads to increased demand for minority ethnic donors (see section 4.1.1 on PTCy).

Recommendation Link

Establishing a single organisation with a clear mandate for recruitment in order to diversify the UK Aligned Stem Cell Registry is needed. This must be supported by targeted investment and culturally competent training for campaigns to diversify the Registry.

3.5.7 A New Approach to Donor Engagement

Evidence to the Inquiry from some members of the Aligned Stem Cell Registry on the potential of improved recruitment to address health inequalities could be summed up as fatalistic and accepting. By contrast, a written submission from the Regenerative and Cellular Medicine Registry highlighted a more profound structural issue:

> **Written Evidence Regenerative and Cellular Medicine Registry:** *"The global ethnic majority – including African, Asian, mixed-heritage, and diasporic communities – remains largely invisible within both national and international donor databases, including the WMDA (World Marrow Donor Association) and the NMDP (National Marrow Donor Program). These communities together represent the majority of humanity, yet their genetic and cultural diversity is absent from the datasets that define global donor matching and treatment access.*
>
> *While NHSBT and ACLT have made efforts within their capacities, none of the existing frameworks have truly addressed the deep cultural and ethical disconnect that persists between donor organisations and diverse communities. There is no genuine strategy for engagement with faith-based or culturally distinct populations – Muslims, Jews, Christians of varying denominations, Hindus, and others – whose participation depends on trust, ethical clarity, and cultural resonance."*

Aligning with the ambitions set out in "Fit for the future: 10 Year Health Plan for England" (DHSC, 2025), the APPG is calling for a bold new holistic approach to donor engagement – one that:

- fosters long-term relationships benefiting individuals, families, communities, and society,
- builds on existing efforts to link recruitment for blood, organ, and HSC donors,
- develops a UK-wide digital-by-default model (with agreement from the Devolved Administrations).

The DHSC invests significantly in attracting minority ethnic and mixed heritage individuals to engage in health research, prevention and promotion activities and the digital-by-default approach offers a powerful opportunity to overcome historical exclusion for those facing compounded inequalities by:

- transforming engagement,
- reducing donor attrition,
- promoting healthier lives.

With tailored digital communications, relevant opportunities in health research, improvement, and protection could be seamlessly integrated.

APPG Insight:

A digital-by-default model would enable the creation of virtual “neighbourhoods” tailored to support potential donors throughout their lifelong health and care journey – particularly from minority ethnic and mixed heritage backgrounds. By addressing the root causes of inequality such as limited access to health promotion, prevention, and research participation, this approach has the potential to enhance equity, resilience, and sustainability in HSC provision.

APPG Insight:

This investment could pioneer a new form of Digital Neighbourhood, aligning with the Neighbourhood Health Service central to Fit for the future: 10 Year Health Plan for England (DHSC, 2025) that emphasises neighbourhood-based and digitally enabled models of care.

Recommendation Link

The APPG recommends exploring a UK-wide digital-by-default engagement model to support long term donor relationships.

3.5.8 Donor Recruitment and Attrition

Donor attrition, the proportion of potential donors on the UK Aligned Stem Cell Registry who are removed from the registry, has a significant impact on patients they are potentially matched to. It also impacts the reputation of the UK Aligned Stem Cell Registry on the global stage and additionally, has a silent impact on the sustainability and effectiveness of the UK Aligned Stem Cell Registry itself.

Donor attrition can be attributed to a number of causes:

- donors who cannot be contacted,
- donors who have decided not to be a donor at the stage of confirmatory typing,
- donors that fail the medical examination prior to donation,
- donors that decline donation after the medical examination,
- loss of donors to the register that have reached the age of 61 years.

Evidence across Anthony Nolan, DKMS UK and NHSBT showed a significant increase in donor attrition rates between 2019 to and 2024/25.

Written evidence from DKMS UK indicated that:

Written Evidence DKMS UK: *"UK donor availability at confirmatory typing decreased from 62% in 2019 to 44% in 2024/5. Reasons for this decrease are likely to be varied: not responsive to contact, the donor declines to proceed or is unavailable when approached. This decrease in donor availability has knock on effects related to a decrease in efficiencies due to repeated searches, delays, and consequential increased costs as well as possible clinical consequences for the patient."*

However, rising donor attrition rates are not exclusive to the UK; DKMS UK noted that:

Written Evidence DKMS UK: *"The decline in donor recruitment reflects global trends rather than UK-specific challenges. Registries worldwide are observing similar reductions in new sign-ups, driven by a combination of socio-economic pressures, behavioural shifts, and a degree of healthcare scepticism that developed following the Covid-19 pandemic."*

The APPG also heard that attrition is not an insoluble issue within HSC transplantation systems. System driven attrition refers to the loss of potential donors from the donation pathway due to issues within the systems and processes that support recruitment and follow-up. This can occur at different stages of the pathway and reflects how system design and operation can reduce the likelihood of a donor proceeding to donation.

Efforts to reduce attrition were highlighted and the APPG were informed that Anthony Nolan attrition rates had decreased from 43% to 17%; NHSBT rates decreased from 50% to 5% and DKMS UK decreased from 41% to 27%.[17]

APPG Insight:

Although how a decrease in attrition rates was achieved was not discussed or provided in the written evidence, these figures demonstrate that attrition rates can be addressed.

Table 5 shows the number of donors on the UK Aligned Stem Cell Registry in the different age categories, demonstrating the progressive aging of the donor pool in the registry. In the five years 2026 – 2030, 237,857 donors will be lost to the registry because they will reach the upper age limit for being a donor. Just to maintain the UK Aligned Stem Cell Registry at its 2025 size, 47,571 donors must be recruited each year for the next five years.

Currently all four UK registries have their own recruitment strategies based on their own priorities.

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[17] Oral evidence

APPG Insight:

This demonstrates the need for a long-term strategy for donor recruitment in the UK to ensure resilience and sustainability of the UK Aligned Stem Cell Registry. Identifying key areas will inform recruitment policies and strategies alongside any investment in the UK Aligned Stem Cell Registry.

Age Group	2021/22	2022/23	2023/24	2024/25
16 – 20	61,000	53,086	45,910	48,011
21 – 25	225,000	212,655	197,411	180,235
26 – 30	333,000	338,871	335,108	326,996
31 – 35	350,000	372,351	385,963	396,961
36 – 40	327,000	348,940	368,495	384,780
41 – 45	273,000	297,782	319,262	338,727
46 – 50	243,000	246,564	252,782	264,981
51 – 55	248,000	255,305	260,530	262,810
56 – 60	175,000	191,510	208,751	237,857

Table 5: Number of UK Aligned Stem Cell Registry donors in different age categories 2021-2025[18]

APPG Insight:

Whilst not all donor driven attrition can be prevented, a substantial proportion of attrition is caused or accelerated by system design. As system driven attrition is largely preventable, it represents an important opportunity for positively influencing registry sustainability, resilience, and equity. System driven attrition is a major driver of registry size.

Recommendation Link

Research into how attrition rates can be minimised is a key area that needs to be addressed and it should be a focus of the DHSC commissioned review.

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[18] DKMS UK written submission

4. Recommendations for Research

4.1 Post-Transplant Cyclophosphamide: Maximising Benefit for Patients

Cyclophosphamide is an anti-cancer drug that has been used for many years in a variety of cancers and used for over a decade in related haplo-identical HSC transplants to reduce post-transplant complications like GvHD. The new development is the use of post-transplant Cyclophosphamide (PTCy) – giving a small dose of the chemotherapy at specific days post – transplant, to patients receiving an HSC transplant from mismatched unrelated donors. This allows patients to have an HSC transplant when they would not otherwise receive one thereby, increasing patient access to HSC transplantation.

4.1.1 Post-Transplant Cyclophosphamide discussion at the APPG's Evidence Session

At the APPG's evidence session, Professor Charles Craddock highlighted PTCy as the most significant and recent advance in unrelated HSC transplantation. He indicated that the administration of a small dose of the chemotherapy following transplant was key in terms of increasing equity of access to transplant where there are significant health inequalities impacting minority ethnic and mixed heritage patients in need of an HSC transplant.

Professor Craddock referred the inquiry to recently published data by Al Malki et al. (2025) in the Journal of Oncology that demonstrated how the use of PTCy with mismatched, unrelated donors in the USA significantly improves transplant outcomes in these patients.

In the UK, a similar trail the 'Match of the Day' trial is progressing well. It is hoped the trial will show that the use of PTCy has substantial potential to increase the pool of viable donors for patients who do not have well matched unrelated donors, as it allows mismatched (9/10) or even multiple mismatched (8/10) transplants to be performed with good clinical outcomes.

Whilst Professor Craddock considers PTCy as the most important therapeutic advance in this field for the past 10-15 years, he also stressed the importance of ensuring a ***"consistent national approach to its adoption in order to address inequity in access."***

To ensure the need for consistency, the inquiry heard that in October 2025 a multi-stakeholder meeting was convened by the UKSCSF in London, bringing together UK transplant experts, HSC registry providers, relevant organisations and patients, to develop a national consensus on the adoption of PTCy. The newly agreed consensus is intended to establish a standard UK-wide approach to enable patients to proceed rapidly to transplant using mismatched donors with PTCy as standard treatment within clinical practice.

The APPG heard that conventional unrelated HSC transplant preferentially use a fully matched (10/10) donor. Some centres use a mismatched donor (9/10), but the clinical outcomes are inferior to using 10/10 donors. The use of PTCy hopefully will allow 9/10 or perhaps even 8/10 transplants to be performed with good clinical outcomes. The 'Match of the Day' trial will provide the clinical data to inform clinicians in its use. This will hopefully enable patients that do not have a well-matched donor to be transplanted with a mismatched or multiple mismatched donor.

The standardisation of this approach will improve the speed at which transplants can occur and should also increase donor availability for patients who don't have well managed disease, and improving equity of access particularly for minority ethnic patients.

Dr Deborah Richardson outlined the experience in Southampton where PTCy has been implemented in clinical practice. She highlighted how their matching capabilities have been optimised and how data have been used to track outcomes post-transplant, with positive results observed over the past 4 year period.

Dr Richardson emphasised that whilst results were promising, ***"the use of a well-matched donor remains clinically preferable to a multiple-mismatched donor using PTCy."*** With an increasing minority ethnic and mixed heritage population in the South Coast region, Dr Richardson expressed the need ***"to continue the expansion of donor recruitment across all ethnicities to better reflect the UK's population as a whole."***

In response to questions on the impact of PTCy on transplant availability, Dr James Griffin explained ***"that clinicians continue to prioritise donor matching, but what PTCy enabled were transplants with less stringent matching thresholds – making 9 or 8/10 viable rather than requiring 10/10."*** Dr Griffin referred to some modelling work that indicated that the probability of identifying an unrelated donor may be around 60% or lower in some populations, but that this rises to over 95% when one or two mismatches are permitted in combination with PTCy. This was of particular importance for certain ethnic groups. Whilst the use of PTCy could still not be considered a replacement for a fully matched donor, it had the potential to reduce disparities to transplant access, particularly for minority ethnic and mixed heritage patients. It however does not remove the basic inequality in that patients of minority ethnic or mixed heritage backgrounds are more likely, if transplanted at all, to be transplanted with a donor with an inferior match compared to their white counterparts.

The APPG welcomes the introduction of this new treatment which represents a significant clinical advancement, particularly as it has the potential to increase access to HSC transplants. The APPG commends the UKSCSF and the clinical community for working hard to standardise the treatment and ensure its rapid and consistent uptake in the UK.

APPG Insight:

Recognition that PTCy represents a significant clinical advance, particularly for patients from minority ethnic and mixed heritage backgrounds who are less likely to find well matched donors, is important. However, this does not remove the need for well-matched donors (the preferred clinical option). Since the probability of a patient finding a donor is highest within their own ethnic community, the increasing numbers of transplants enabled by PTCy is likely to also increase the demand for donors from diverse communities.

Recommendation Link

As the clinical panel were unanimous that using a well-matched donor remains the preferred option where available, increasing the targeted recruitment of donors from minority ethnic and mixed heritage backgrounds to meet growing demand associated with advances in transplantation is required.

4.2 UK Acute Myeloid Leukaemia (AML) Registry – MyeCare

Professor Craddock also provided an update on the development of the UK Acute Myeloid Leukaemia (AML) Registry, MyeCare, pioneered by Dr Priyank Mehta in collaboration with senior clinicians in the UK. He explained that AML accounts for approximately 70% of HSC transplants in the UK, making this initiative highly relevant to understanding transplant access and outcomes.

The MyeCare Registry operates as a prospective, sequential AML registry, collecting diagnostic, genomic, treatment and outcome data from newly diagnosed adults with AML across 18 major haemato-oncology centres across the UK. With anticipated recruitment of 700 patients a year over an initial 5-6 year pilot. Through collaboration with Genomics England, the MyeCare Registry will uniquely integrate clinical outcome data with next-generation sequencing data to provide unprecedented insights into AML disease biology.

Professor Craddock highlighted that a unique and valuable strength of MyeCare lies in its capacity to generate high-quality data on ethnic diversity and treatment outcomes. By linking clinical, genomic and transplant data, this will enable systematic analysis of equity of access to HSC transplantation by identifying how many diagnosed patients could benefit from allogenic HSC transplantation, whether eligible patients are being referred appropriately, whether there is under-referring and the reasons behind this.

APPG Insight:

The MyeCare registry plays an important part in improving understanding of access to transplant and outcomes of PTCy treatment in minority ethnic and mixed heritage patients.

Recommendation Link

Having data on non-AML patients considered for or receiving an HSC transplant is important and the DHSC review should consider, in collaboration with the clinical community and Genomics England how this could be achieved.

Research Recommendation Link

As some mismatches are likely to have a greater negative impact on clinical outcomes, NIHR should launch a call for AI research to analyse HLA, genomic and clinical data. This would identify which mismatches must be avoided and which are acceptable, thereby rapidly informing clinical practice to improve outcomes for HSC patients.

5. Data Gaps and Accountability

Addressing digital sustainability across all registries is central to operational efficiency, accountability, resilience and value for money. Evidence presented indicates that the monitoring of donor availability in real time, anticipation of donor attrition and the optimisation of end-to-end decision-making throughout the donor and patient pathway is limited. This is perpetuated by:

- **data gaps,**
- **fragmented accountability for data ownership,**

which collectively contribute to a:

- **reduction in transparency,**
- **limited performance oversight,**

which makes it harder to identify where there is capacity, process delays or where there are specific investment needs.

NHBT identified the need for continued investment in digital infrastructure to develop currently fragmented or outdated systems and enable international interoperability (including across the Devolved Administrations).

Outdated systems increase administrative burden; they do not optimally support donor tracking, availability and limit predictive planning. This impacts on current systems being able to proactively identify the most suitable and clinically optimal donors.

Data fragmentation should not be a limiting factor and a commitment to enabling data-driven healthcare supports the Government's "Fit for the Future: 10 Year Health Plan for England" (DHSC, 2025).

The UKSCSF Data Commission has been working to improve data on HSC availability and use, including data on ethnicity.

Expansion of end-to-end system integration, linking registry intelligence with clinical decision-making pathways is also required as this improved interoperability between donor registries, transplant centres and clinical data systems is required. This will enable both more timely and informed donor selection, reduce delays and support better patient outcomes across the HSC transplant pathway. This would additionally support a more predictive, data-driven system that would have the potential to align donor availability with clinical demand in real time.

Recommendation Link

The DHSC commissioned independent review should engage with the UKSCSF Data Commission and other stakeholders to make recommendations on data collection, curation and transparency.

6. Governance and Accountability

6.1 Strategic Oversight

The two main recommendations of the APPG are linked to the need for system change:

1. for an independent review to be commissioned by DHSC, in consultation with the Devolved Administrations, to examine the sustainability, resilience, governance, and equity of the UK HSC supply system,
2. for the appointment of a single organisation, namely NHSBT, with the overall responsibility for HSC supply, (taking into account that health policy is a devolved matter).

When compared to the situation with blood and solid organ donation it becomes clear that patient's requiring an HSC transplant are at a significant disadvantage. Ministers and others have no one accountable to turn to for answers to the glaring issues facing the UK stem cell system, or to take the lead in addressing them.

The responsible organisation should be set up with the appropriate governance structures and stakeholder participation to enable it to be directly accountable to ministers. It must be transparent in its use of public funding, be able to plan and budget over a period of at least five years to allow investment to produce the long-term cost savings to the NHS, and ensure consistent standards of resilience, equity and sustainability. Currently, Anthony Nolan is the only member of the UK Aligned Stem Cell Registry solely responsible for the supply and costing of all UK HST imports, which highlights the fragmented nature of current system responsibilities.

In addition, the accountable organisation should establish and maintain outward-facing collaboration with international registries, research programmes and global standard setting bodies. This will ensure that the UK remains an active and influential member of the global HSC network, supporting both domestic resilience and international best practice.

Recognition of the possible parallels with the 2006-2008 Organ Donation Taskforce approach and successful outcomes should be noted.

The APPG recognises

That the UKSCSF plays an important role in providing meaningful discussion by field experts that provide advice and recommendations to the transplant community and its stakeholders.

The swift action taken by the UKSCSF in convening stakeholders to ensure that the UK moves to make the most of the opportunities of PTCy for improving access to HSC transplants, highlights the important role UKSCSF will continue to have. However, its existence does not impact the need for a single organisation with responsibility and accountability for the resilience and sustainability of the UK HSC supply.

It is also important for those commissioning services involving HSC transplantation to have strong links with any organisation(s) responsible for HSC supply. This will ensure that any investment in the system is reflected in reducing the overall cost to the NHS relating to HSC supply.

Members of the UK Aligned Stem Cell Registry[19] provide the unrelated HSC donor provision across the UK. They work collaboratively but operate under different governance and accountability arrangements. Understanding these differing governance structures is important when considering issues of oversight, funding, performance, and strategic coordination across the UK. This is potentially an important element of the recently announced review.

6.2 National Resilience

Evidence highlighted that HSC supply in the UK is at increased vulnerability due to many factors, including a reliance on overseas donors. The UK's HSC system should therefore be viewed as an important part of the UK's health security and emergency preparedness capability. However, the UK Aligned Stem Cell Registry consists of one NHS organisation, two charities and a Welsh devolved organisation with no overall responsibility for resilience.

Having a single organisation strategically responsible and accountable for the UK HSC supply would aid mitigation of the UK's vulnerability to overseas risks (global disruption, geopolitical events, and international market systems) with a clear focus on maintaining it as a resilient national asset. If the single organisation is nominated for England only, their remit should include integration of cross boarder mechanisms with the Devolved Administrations to ensure supply during international disruption.

Recommendation Link

Investing in the development and long-term viability of the UK Aligned Stem Cell Registry should be regarded as a strengthening of national security and health system resilience.

6.3 Current Commissioning Structure

The APPG heard concerns about the proposed changes in England moving from the current National Commissioning model to NHS England Specialised Commissioning. Feedback from stakeholders highlighted concerns associated with failures in previous models that did not address fundamental issues affecting the HSC supply, unease about the absence of a national approach and noting a lack of clarity in current proposals.

Currently, in England, HSC transplantation for adults and children is a prescribed specialised service accountable to NHS England (NHSE). Donor HSC are part of the pathway, and the responsibility of providers. NHSE does not directly commission HSC services. The provision of donor HSC forms part of the HSC transplantation care pathway, and providers take local approaches in sourcing the most suitable HSC donations.

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[19] Members of the UK Aligned Registry: Anthony Nolan, DKMS UK, NHSBT, WBMDR

NHS England does not set any national standards for sustainability or resilience of supply for blood, HSC and organs. NHSE does however, have a national process for managing short-term supply issues. For example, NHSE/NHSBT put in place specific actions in 2022 in response to an amber alert regarding issues with type O blood stock shortages. Commissioning in the Devolved Administrations vary from those in England.

Recommendation Link

As part of an inquiry, differences within the Devolved Administrations to commissioning should be considered to assess impacts on equity, sustainability and innovation.

APPG Insight:

The changes to commissioning of HSC supply has the potential to ensure long-term sustainability and resilience whilst ensuring the efficient use of public funds, rather than relying on expensive imports.

With the agreement of all UK Governments, designating a single organisation whose responsibilities include sustainability and resilience of supply is essential to ensure patients receive the treatment they need uninterrupted by supply shocks and that public funds are used efficiently.

NHSBT manages the NHS Organ Donor Register and National Transplant Register for the UK. The APPG suggests that, with agreement of all four nations, NHSBT also be responsible for HSC supply for the UK.

Recommendation Link

The independent review should consider which organisations are best placed to carry out the various functions in the supply chain.

NHSBT is responsible for delivering blood products for England and the price for such products is agreed through the National Commissioning Group for blood. Prices are published annually on the NHSBT website ensuring transparency.

Recommendation Link

An independent review should consider a similar system for the UK HSC supply particularly for imported HSC provisions.

7. Why a DHSC Commissioned Review?

The evidence gathered by this APPG inquiry highlights that there are many challenges facing the UK's HSC transplantation system; cross cutting challenges that go beyond the remit of any of those organisations currently involved in HSC supply.

A holistic approach is needed to resolve these challenges that relate to sustainability, resilience, equity, accountability, workforce capacity, commissioning arrangements, and clinical practice that intersect between a complicated arrangement of different NHS organisations, arm's length bodies, and charities.

The DHSC is suitably placed to commission an independent review with the scope and neutrality required in the consideration of a national asset.

A review would provide ministers with the authoritative evidence base to inform policy decisions.

This would enable them to make the necessary changes to ensure sustainability, resilience, accountability, value for money and improve equitable access for all patients.

8. Conclusion

The UK's unrelated HSC transplantation system is at a critical juncture and requires structural reform to ensure resilience, equity and long term sustainability.

This inquiry finds that the UK's HSC transplantation system is at a critical juncture. Despite world class clinical expertise and dedication across registries, transplant centres and donor recruitment, the system as a whole lacks the structure needed to ensure long term resilience and equity. The system is fragile. Limited transparency in how funding and costs relating to donor recruitment, registry activity and international costs of HSC across the HSC system impedes long term planning and sustainability. Current arrangements leaves the UK heavily reliant on imported HSC and failing to provide the foundation or solutions to long term stability, resilience or equity.

The HSC programme is not only a matter of national resilience, it provides a UK capability for lifesaving treatments. This is fundamental to the UK's health security and emergency preparedness, but it also plays a crucial role in protecting UK patients at an individual level.

For patients, the consequences of delay, sub-optimal donor matching and unmet need are very real. Patients from minority ethnic and mixed heritage backgrounds continue to face significantly lower chances of finding a well-matched donor and are more likely to experience unsuitable treatment pathways as a result of poor investment, lack of accountability and gaps in data and planning capabilities. Therefore, these inequalities are not inevitable.

However, whilst these challenges were already evident as contributors to rapid decline, dedicated leadership was identified as the enabler to recovery and a strengthening of the system. There was broad consensus across all stakeholders that changes to the UK unrelated HSC system, bringing it in line with the changes seen in blood and whole organ donation, would facilitate positive and sustained long-term change; requiring clearer accountability, improved data and use of data and investment that aligned with long-term outcomes, rather than in response to short term pressures. This included the embedding of clinical innovation and research as part of a properly governed and resourced system.

Action needs to be taken now to prevent further decline. With the right leadership, improved governance and accountability, the challenges facing the system can be removed and prevented, but an independent review commissioned by the DHSC is needed to confirm the system's weaknesses and opportunities. An independent review would allow ministers to take informed decisions on accountability, funding transparency, value for money and equity and resilience based on holistic assessment and ultimately appoint a single organisation to have overall responsibility for the UK unrelated HSC supply.

The APPG concludes that with timely and strategic action, the UK can build a sustainable and resilient domestic HSC capability that equally supports all its patients, the HSC transplantation system as a whole, and strengthens clinical and digital innovation, whilst providing long-term value for the NHS.

Background

Why HSC Supply is a National Issue

What is HSC Transplantation

A HSC transplant is a medical procedure that replaces an individual’s damaged or diseased blood-forming (haematopoietic) stem cells with healthy ones. It is often used to treat conditions that affect the bone marrow and blood cells, such as certain cancers and blood disorders. The healthy HSC, which can develop into red blood cells, white blood cells, and platelets, restore the individual’s ability to produce new, healthy blood cells and reconstitutes their immune system.

How an HSC transplant works

The process of a HSC transplant involves several main stages:

1. **Preparation (Conditioning):** The patient undergoes intensive treatment, typically with high-dose chemotherapy and/or radiation, to destroy the existing diseased cells and prepare the body for the new HSCs.
2. **Harvesting:** Healthy HSCs are collected either from the patient's own body or from a related or unrelated donor.
3. **Transplant (Infusion):** The harvested HSCs are infused into the patient's bloodstream, similar to a regular blood transfusion. This procedure is not painful and takes a few hours.
4. **Engraftment and Recovery:** After the infusion, the HSCs migrate through the bloodstream to the bone marrow and other tissues, where they begin to multiply and produce new, healthy blood cells. This process, called engraftment, takes several weeks. During this time, the patient's immune system is compromised due to the pre- transplant conditioning so they are at risk of infection and complications following the HSC transplant process.

Types of HSC transplants

There are two main types of HSC transplants, depending on the source of the cells:

- **Autologous transplant:** This type uses the patient's own healthy HSCs, which were collected and stored before the high-dose treatment. This is often used for certain lymphomas or myeloma.
- **Allogeneic transplant:** This involves using HSCs from a related or unrelated donor. The cells are usually collected from the donor’s blood but in some cases is taken directly from the bone marrow. The donor's cells must be a close genetic match to the patient to prevent rejection – this is referred to as the HLA match or tissue match. The donor may be a family member, but if one is not available, or a search of the UK and global HSC registries is conducted to identify a suitably matched unrelated donor. Other sources of allogeneic HSC are those collected from umbilical cord blood samples which are stored in liquid nitrogen in cord banks.

The APPG is holding this inquiry into the long-term resilience and sustainability of supply of unrelated HSCs for Allogeneic transplant.

Potential risks

HSC transplants are intensive and come with significant risks, including infection, bleeding, and other complications.

- **Graft-versus-Host disease (GvHD):** In allogeneic transplants, this serious complication can occur if the immune cells of the new donor (graft) attacks the patient's own cells (host). The closer the genetic match (HLA) between patient and donor the lower the risk of GvHD – but this does not eliminate the risk.
- **Side effects:** The high-dose chemotherapy can cause temporary side effects such as nausea, hair loss, and fatigue as well making patients vulnerable to potentially life-threatening infections.

After the procedure, it can take months or even a year for the immune system to fully recover. Patients require long-term follow-up care to monitor their recovery and manage potential complications.

Registry Structure

Global Network	WMDA	BMDW/Global Donor Database		
UK Aligned Stem Cell Registry	Anthony Nolan	NHSBT	DKMS UK	WBMDR
Collection and Processing	Collection Centres	Processing Labs	Cord Blood Bank	
Clinical Transplant Centres	NHS Transplant Centres			

The four UK HSC registries are aligned in that the transplant centres request an unrelated HSC donor search for their patients through the Anthony Nolan who co-ordinate the search process. Previously, transplant centres had to send a search request to all four registries. The four registries recruit their own HSC donors and form part of the global network of HSC registries, the majority of which are located in Europe and North America.

The process of identifying an unrelated HSC donor consists of the transplant centres sending their requests for a search to the Anthony Nolan. The combined HSC donor pool of the four UK HSC registries are assessed to identify suitably matched HSC donors. If no donors are found then the global HSC registries are assessed for suitably matched donors. For some patients the cord blood banks both in the UK and globally are assessed for suitably matched cord blood units.

If a suitably matched donor is identified after further testing and a medical examination, the donor HSC's are collected, processed and couriered to the transplant centre for infusion into the patient.

Cord blood units are stored frozen in liquid nitrogen and would be shipped to the transplant centre where they would be thawed before infused into the patient.

Methodology

Evidence sources: Written Submission

Written submissions and answers to follow-up questions were received from all who were invited to engage:

- African Caribbean Leukaemia Trust
- Anthony Nolan
- BSBMTCT
- DHSC
- DKMS
- Dr Mark Bale
- Dr Jonathan Graves
- Dr James Griffin
- Dr Daniel McCloskey
- Dr Deborah Richardson
- Dr Kanchan Rao, Specialist in Paediatric Bone Marrow Transplant
- NHSBT
- NHSE
- Orin Lewis OBE
- Regenerative and Cellular Medicine Registry

- Sabrina Jarrett
- Team Margot
- UK Stem Cell Strategic Forum
- Welsh Blood Service
- Yaser Martini BEM

We would like to thank everyone who took the time to write in, providing a wealth of data, information, personal experience and opinion; these contributions have been invaluable to the writing of this report.

Evidence sources: Oral Evidence

An oral evidence session was held on 27th October 2025 in the MacMillan Room, Portcullis House, London for invited witnesses.

The APPG is grateful for the clinicians who provided written submissions and attended the Evidence Session in person. The aim was to understand the transplant clinician's perspective as this side of the process is not as well understood nor discussed outside of those involved. We hope these insights provide help to inform non-specialist policy makers and Stakeholders.

Chair: Bell Ribeiro-Addy MP

APPG Member: Lord G Evans (Lord Evans) (online)

Expert Clinicians (Panel): Professor Charles Craddock CBE, Dr James Griffin, Dr Deborah Richardson

Donor Recruitment Expert: Sabrina Jarrett

APPG Secretariat: Orin Lewis OBE co-Chair of National BAME Transplant Alliance (NBTA)
Dr Jonathan Graves

Steering Group Chair: Dr Mark Bale,

Steering Group Members: Dr Daniel McCloskey, Yaser Martini BEM CEO Team Margot

Isabella Myers (Minutes)

Limitations

Absence of UK Aligned Stem Cell Registry organisations from oral evidence session:

Despite all members being invited, none of the members of the UK Aligned Stem Cell Registry felt able to attend the APPG's evidence session on 27th October. This may be because none of the member organisations have the overall responsibility and so cannot speak for nor answer on behalf of the system. This demonstrated to the APPG how fragmented and unaccountable the current system is, a system which requires one organisation to have the responsibility and accountability so as to ensure a sustainable and resilient domestic haematopoietic stem cell capability that equally supports all patients.

Appendices

Glossary and Abbreviations

ACLT	African Caribbean Leukaemia Trust
Anthony Nolan	Registry & Charity
APPG	All Party Parliamentary Group
BSBMTCT	British Society of Blood and Marrow Transplantation and Cellular Therapy
CMV	Cytomegalovirus – a virus that can become a problem when a patient's immune system is weak
Digital Neighbourhood	An approach where technology and data are used to move care from hospital settings into local communities and homes
DKMS UK	Registry & Charity
DHSC	Department of Health and Social Care
GvHD	Graft-versus-host disease
HLA	Human Leukocyte Antigen – markers to match a HSC donor with a patient used to reduce rejection of donor cells
HSC	Haematopoietic Stem Cell – immature cells that can grow into blood cells
NHSE	National Health Service England
NHSBT	NHS Blood and Transplant
NIHR	National Institute of Health Research
NMDP	National Marrow Donor Programme
PTCy	Post-Transplant Cyclophosphamide
RCMR	Regenerative and Cellular Medicine Registry
Team Margot	Unincorporated Association

UK Aligned Stem Cell Registry	Refers collectively to the four organisations that provide unrelated donor HSC provision across the United Kingdom: Anthony Nolan, DKMS UK, NHS Blood and Transplant, and the Welsh Bone Marrow Donor Registry. While these organisations work collaboratively, these registries are aligned only in that the transplant centres request a unrelated HSC search for their patients through the Anthony Nolan who co-ordinate the search process. Prior to the alignment transplant centres would have to send a search request to all four registries. They each operate under different governance and accountability arrangements: **Anthony Nolan and DKMS UK** • independent charities accountable to their respective Boards of Trustees. **NHS Blood and Transplant** • accountable to DHSC (England only). **The Welsh Bone Marrow Donor Registry** • accountable to the Welsh Government (Wales only).
UKSCSF	UK Stem Cell Strategic Forum – a DHSC Advisory Body
WBMDR	Welsh Bone Marrow Donor Registry

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Welsh Blood Service

About the APPG

The All-Party Parliamentary Group on Ethnicity, Transplantation and Transfusion highlights how the lack of donor participation affects patients with ethnically diverse backgrounds, raising awareness of health inequalities faced by mixed and minority ethnic patients requiring an organ, HSC transplant or a blood transfusion as well as advocating equitable access of treatment for mixed and minority ethnic patients.

Secretariat provided by the National Black, Asian, Mixed Race and Minority Ethnic Transplant Alliance (NBTA).

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Parliamentary Groups 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.

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