

DKMS UK Submission for APPG Inquiry: Ensuring a resilient and sustainable UK stem cell supply for all

## Executive Summary

DKMS UK welcomes this important inquiry. The UK's increasing reliance on imported stem cells (76% in 2024–25 compared with 58% in 2017–18) understandably raises questions about the sustainability of the UK stem cell registry. Our evidence suggests three primary factors contributing to this trend:

- **Registry demographics and diversity:** The proportion of younger donors, who are most often preferred clinically, has declined (from 15.1% in 2019 to 10.1% in 2024)<sup>1</sup>. In addition, only 16% of the registry is made up of people from minority ethnic backgrounds, which contributes to the much lower match rate for minority ethnic patients (37% compared with 72% for patients of northern European heritage).
- **Operational pressures:** The availability of UK donors when called for confirmatory typing has reduced (62.4% in 2019 to 43.9% in 2024)<sup>2</sup>. Limited capacity in key services such as apheresis can also contribute to delays.
- **Registry growth:** While the registry continues to grow, the pace has slowed considerably. With only around 7% of the eligible population currently registered, there is still a significant pool of potential donors who have yet to be reached.<sup>3</sup>

At the same time, the selection of UK donors for international export has remained steady since 2019, demonstrating that UK donors remain highly valued and in demand by transplant centres abroad.

## 1. UK Stem Cell Supply

The UK Aligned Registry is a substantial national resource with more than 2.4 million registered donors. However, its composition has shifted in ways that do not always align with clinical preference. The proportion of younger donors, particularly those aged 16–26, has decreased, while the proportion of older donors has increased. Since transplant centres tend to prioritise younger donors, this demographic change may be contributing to fewer UK donors being chosen. Our figures show that for northern European patients, donors aged 18–25 are four to five times more likely to be selected, underlining the global demand for younger donors that the current UK donor pool does not fully meet.

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<sup>1</sup> UK Aligned Stem Cell Registry. State of the Registry Report/s 2018-2025

<sup>2</sup> DKMS UK Data

<sup>3</sup> UK Aligned Stem Cell Registry. State of the Registry Report/s 2018-2025

Diversity also remains a challenge for equity of access. Recruiting donors from UK minority ethnic backgrounds is more difficult, and availability at the confirmatory typing stage is often lower for these groups.

UK Aligned Registry growth figures show a steady increase, though at a slowing pace in recent years:

Fiscal Year	Registered Donors	Year-over-Year Increase %
2018/19	1,627,069	–
2019/20	1,924,120	18.25%
2020/21	2,127,000	10.54%
2021/22	2,233,254	5.00%
2022/23	2,317,065	3.75%
2023/24	2,374,212	2.47%
2024/25	2,441,358	2.83%

The overall growth of 50% between 2018 and 2025 is encouraging, but the slowdown in new registrations, particularly among younger age groups, could limit the system’s resilience in the future.

Across the DKMS group internationally, we have observed a wider societal shift that has affected donor availability across all age groups. Donors are less responsive and harder to contact when needed. To address this, we are working with behavioural scientists to adapt our processes and strengthen engagement with donors.

## 2. International Developments

International registries have also faced challenges in donor recruitment following the Covid-19 pandemic, but recent data from the WMDA indicates growth of around 4% in newly listed donors. In our own international network, we have found that recruitment through traditional channels has become more difficult, requiring adaptation and innovation.

## 3. Structural Challenges

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. In other countries within our network, we have successfully expanded capacity by operating our own collection centres. While we have explored this option in the UK, current demand levels do not make this feasible.

#### 4. Factors Influencing Donor Selection

DKMS donor centres are responsible for registering potential donors and supporting them before, during and after their donation. Our expertise does not extend to the clinical decisionmaking process, but we recognise the factors that influence donor selection and, by extension, guide our activities.

For clinicians, timeliness, reliability and viability of the donor are paramount. Declining availability and service capacity are important considerations. Importantly, the quality of UK donations is not in question. UK donors continue to be highly valued internationally, as reflected in the steady rise in exports to patients abroad since 2019. This indicates that the challenge is one of demographics, availability and infrastructure, rather than donor quality.

#### Conclusion

The decline in the use of UK donors appears to result from a combination of demographic shifts, limited diversity, structural challenges and the continued expansion of international registries. DKMS remains committed to working collaboratively with the APPG, government and the wider transplant community to enhance the UK registry and ensure that patients of all backgrounds have the best possible chance of finding a life-saving match.

Peter McCleave

DKMS UK Managing Director



## DKMS UK – Responses to APPG Supplementary Questions

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

Reduced domestic provision naturally reduces one of our revenue streams. However, this has not resulted in any reduction to our overall investment in donor recruitment or registry development.

For DKMS UK, our primary priority is maintaining a resilient, diverse, and high-quality donor pool to support optimal matching outcomes for patients. While income from UK-to-UK provision has declined, our commitment to investing in the UK donor base and the wider registry system remains unchanged.

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

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.

Engaging potential donors, particularly younger individuals, has become increasingly challenging and comparatively costly across all international registries. In response, DKMS continues to invest in research, behavioural insight, and more targeted communication models to better understand barriers to registration and to develop more effective outreach approaches.

3. If UK donor-to-UK patient provision continues to decline, will further reduction in income lead to a lack of investment in donor recruitment and threaten the sustainability of the Registry?

No. 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. From DKMS UK's perspective, reduced domestic utilisation alone does not impede our ability to invest in donor recruitment, nor does it jeopardise the sustainability of the UK Aligned Registry.

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

We have not undertaken modelling based on the assumption that reduced importation would generate sufficient financial savings to support additional investment.

It is important to clarify that we at DKMS UK do not determine the cost of imported products in the UK market, nor do we have any knowledge of how the costings of imported products are formulated. Furthermore, it is not evident that imports should inherently increase overall transplant costs. In several countries, donor centres operate highly professionalised, specialised, and scaled systems that may be as cost-efficient, or in some cases more efficient, than domestic alternatives. For this reason, the proposition that reducing imports would directly generate net savings that could be reinvested is not straightforward.

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

Supporting minority ethnic and mixed-heritage patients is a long-standing organisational priority for DKMS. This focus underpins our strategic expansions into countries such as South Africa, India, and Chile, and is reflected in our sustained investment in UK community partnerships, tailored outreach, and targeted recruitment initiatives aimed at improving representation and access.

However, recruitment is only one part of the challenge. Ensuring availability and eligibility at the point of need is often constrained by external regulatory factors, for example, travel-related deferral rules for individuals visiting malaria-endemic countries. These measures disproportionately affect communities we most need to reach, creating structural barriers that lie beyond the control of donor centres or the registry.

Additionally, historical health inequalities have fostered a degree of scepticism in some communities toward healthcare systems and requests involving personal or genetic materials. Concerns around potential misuse or misunderstanding of genetic information remain a significant communication barrier. DKMS UK continues to work closely with trusted community voices to address these concerns through transparent dialogue, culturally tailored messaging, and long-term relationship-building.

6. 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?

This is an important and valid question. A significant proportion of UK patients, especially those from minority ethnic and mixed-heritage backgrounds, rely on international donors to secure the best possible match.

However, 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.

German and US donor centres, including those operated by DKMS, have demonstrated exceptional operational stability, even during major disruptions such as the Covid-19 pandemic. Throughout that period, the global transplant community collaborated effectively to maintain uninterrupted provision.

While contingency planning is essential and should remain a shared responsibility, the key issue is not the volume of provision from any single country. It is ensuring that UK patients, especially those with rarer genetic profiles, can continue to access the best available match globally. WMDA data consistently shows that many UK patients rely on international donors each year. Strengthening global collaboration, therefore, remains the most effective longterm strategy for safeguarding patient outcomes.

Peter McCleave

DKMS UK Managing Director

