## Evidence submission for the APPG on Ethnicity Transplantation and Transfusion – stem cell transplantation

### September 2025

#### The importance of a well-matched donor

Stem cell transplantation is used to treat forms of malignant and non-malignant conditions. For an effective donor stem cell transplant, it is important that the Human Leukocyte Antigens (HLA) of the donor and recipient are well matched. Often stem cells can come from a closely related family donor. When this is not possible, cells must be obtained from an unrelated donor, and it is important they are as closely matched as possible. Unrelated donors are found by searching the UK Aligned Stem Cell Registry and other stem cell registries around the world through the World Marrow Donor Association. The choice of donor is made by the medical team, who choose the donor they feel will be best for their patient, whether that is a donor available in the UK or one available overseas.

New clinical protocols are being adopted in the UK which will allow mismatched donors to be selected for harder to match patients. This will facilitate the use of more UK donors for UK patients and contribute to reducing health inequities related to ethnicity.

#### Health inequalities and stem cell transplant

Ethnic minority and mixed-race patients requiring a stem cell transplant from an unrelated donor are harder to match than white northern European patients within the UK population. This is because there are there are much smaller pools of potential donors registered globally and greater heterogeneity of Human Leucocyte Antigen tissue types. We know that patients with minority ethnicity backgrounds are less likely to find an unrelated donor with a good match than patients of European heritage, and the UK Aligned Registry members are updating their analysis to understand how access to unrelated donors for patients from a minority ethnic background has changed in recent years.

#### The importance of a UK stem supply for resilience, sustainability and cost effectiveness

An independent UK stem cell supply is important to reduce reliance on imported stem cells which rely on global supply chains that can be vulnerable to disruption. A greater domestic supply also provides clear cost savings and can help to retain and re-invest NHS financial resource in strengthening the stem cell and advanced therapy ecosystem.

To ensure sustainability and resilience of the UK stem cell supply the UK Stem Cell Strategic Forum<sup>1</sup>, which is responsible for providing expert advice to the department, recommends a 45% share for UK-to-UK donor to recipient provision. In 2024/25, UK-to-UK provision stood at 24%. DHSC's Stem Cell Programme (see below) has made progress on improving diversity and resilience of the registry, and we continue to work with NHS Blood and Transplant (NHSBT) and other registry members to meet the suggested target.

<sup>&</sup>lt;sup>1</sup> The UK Stem Cell Strategic Forum is a multi-disciplinary group formed in 2010 at the request of the Department of Health and Social Care. It is chaired by Professor Charles Craddock, and makes recommendations on improving outcomes for stem cell transplant recipients across the UK. The Forum's most recent report ('A 10-Year Vision for Stem Cell Transplant and Cellular Therapies') was published in 2022. In 2019, the Forum's remit was expanded to include advanced cellular therapies, given its potential to transform clinical outcomes.

## Steps to increase resilience and sustainability of UK stem cell supply and to address health inequalities

#### A) DHSC stem cell programme

- Between 2011 and 2023, the DHSC Stem Cell Programme has invested over £30 million to enhance clinical outcomes and access to stem cell transplants. This funding has facilitated the creation of a unified stem cell registry, a cord stem cell bank (see below), and a strategy for diverse donor recruitment, focusing on reducing health inequalities. The programme has been jointly delivered by NHSBT and Anthony Nolan.
- Between 2022 and 2025, the Programme has provided £2.4 million of funding to Anthony Nolan and NHSBT for a 3-year targeted stem cell donor recruitment campaign. The approach has focused on increasing sustainability and resilience of the UK stem cell supply by recruiting donors most likely to donate (male donors aged 16 to 30), and addressing health inequalities with targeted campaigns to recruit donors from ethnic minorities. Funding to both organisations has been extended by 1 year (2025/26).
- Examples of work undertaken through the programme include:
  - supporting specific patients from minority ethnic backgrounds through dedicated appeals, which helps to recruit ethnic minority donors more broadly (56% of those recruited through appeals events were from minority ethnic backgrounds), and running targeted campaigns through Ramadan
  - o an NHSBT pilot using event assistants, who are available to explain stem cell donation at blood donation sessions, which has a positive impact on recruitment
- Good progress has been made against recruitment targets, with NHSBT reporting a
  10 year high in stem cell donations from Black, Asian and mixed ethnicity donors in
  June 2025. In 2024/25, 29% of the people added to the Anthony Nolan register were
  from minority ethnic backgrounds showing significant investment in targeting diverse
  communities.
- By increasing the pool of potential donors, the programme seeks to improve the availability of matches in the UK, ultimately reducing waiting times for patients in need of stem cell treatment.

#### B) Anthony Nolan and NHS Cord Blood Banks

- £20 million of the funding for the DHSC Stem Cell Programme was invested to create the public UK Cord Blood Bank, a partnership between NHS Blood and Transplant and Anthony Nolan.
- Cord blood is the blood that remains in the placenta and umbilical cord, and is rich in blood stem cells, these stem cells can be used to treat many different cancers, immune deficiencies and genetic disorders.
  - A major benefit of cord stem cells compared to adult stem cells is that donors and patients don't need to be an exact match, as the stem cells in cord blood aren't mature and can develop to suit their recipient. Cord blood can be a great option for people from minority and mixed ethnic backgrounds, who it can be harder to find a match for on the stem cell register.

#### C) National Institute for Health and Care Research (NIHR) Stem Cell Research

• The National Institute for Health and Care Research (NIHR) currently provides £2.1 million for 4 research projects to improve access, better understand outcomes and improved delivery of stem cell transplants and advanced cellular therapies. Three of

these projects are relevant to the APPG. Led by NHS Blood and Transplant and Anthony Nolan, two projects will help better understand the impact of ethnicity on unmet need and outcomes of stem cell transplantation. The third project is piloting the concept of collaboration to recruit donors in India to match to UK patients of Indian ancestry as well as patients in India and elsewhere in the world. More detail on each of these projects is provided below:

# i) How to improve referral and access to stem cell transplantation through better understanding of inequity, barriers and unmet need, especially in the context of ethnic minority patients.

- This project aims to link relevant data to examine referral and access to transplantation to:
  - identify and evaluate any unmet need for stem cell transplantation (i.e. lack of referral where indicated), and
  - identify and evaluate any inequities in access to transplantation, considering type of transplant and the quality of the donor match
- Ethnicity and other factors such as gender, age, socio-economic status, education and location will be considered in these analyses.
- Improved understanding of unmet need and inequity of access to transplant will inform
  more effective targeting of resource to donor recruitment and cord blood collection, as
  well as enabling exploration of the national, regional and local changes required to
  level up equity of access for minority ethnic and other patients.

# ii) Prospective collection and analysis of demographic and patient reported outcome (PROM) data from patients receiving haematopoietic cell transplantation in the UK

- There is growing recognition that inequities in patient outcome and quality of life following haematopoietic cell transplant (HCT) may be due to social and demographic factors. To improve understanding about the impact of social determinants of health on patient outcomes, routine collection of patient demographic status (including age, gender, race, ethnicity, socioeconomic status) and patient-reported outcomes is required.
- This project is a national study, collecting demographic and Quality of Life (QoL) data among HCT recipients using a digital web-based tool hosted by Anthony Nolan.
- In this study, HCT patients are being invited to complete a brief demographic and QoL questionnaire at various timepoints in their transplant journey.
- The findings are intended to inform targeted service improvements to address inequity at both the individual patient level and the system level across NHS transplant services.

### iii) Research project to investigate a collaboration on donor recruitment between the Anthony Nolan and the Indian Stem Cell Donor Registry, DATRI

- The India Stem Cell Donor Collaboration is a new study piloting recruitment of stem cell donors in India.
- Recruitment is led by the Indian DATRI registry in partnership with Anthony Nolan.
   British Asians are the largest ethnic minority population in the United Kingdom (6.25% of the total population).

- The project is funding the recruitment and genotyping of 10,000 stem cell donors in regions of India that match the ancestry of the British Asian population.
- They will be available as donors in India, the UK and globally through the World Bone Marrow Donor Association.

#### D) NIHR Blood and Transplant Research Units

- The NIHR also co-funds 5 Blood and Transplant Research Units (BTRUs), partnerships between universities and NHS Blood and Transplant, which undertake research to improve the supply of blood, blood products, stem cells, tissues, and organs for transplantation.
- The Precision Cellular Therapeutics BTRU is conducting cord blood research to expand and gene edit the stem cells in cord blood, so they could be used with increased safety in a wider range of adults. This initiative will ultimately drive wider access to cord blood transplant.
- The Donor Health and Behaviour BTRU is researching the factors affecting blood donation behaviour. They have set up the Blood Donors Studies BioResource, a data set containing information about donation practices, patient characteristics and blood samples which can be accessed by other researchers. They are also developing strategies to increase blood donations from ethnic minority communities. This has led to NHSBT changing its messaging aimed at ethnic minority donors to increase awareness of the clinical need for ethnically matched blood.

#### Availability of key UK support services for stem cell donation

The availability of donors on the UK stem cell registry is only one factor which influences clinical decisions about whether to request a donation from a donor based in the UK. We are aware that limitations in apheresis capacity are causing challenges with stem cell donation and have begun a review to further understand the factors which underlie this. Anthony Nolan have recently opened a new Cell Collection Centre which is expected to significantly improve capacity for stem cell transplant cell collections.

#### **DHSC-led review of apheresis capacity**

- Apheresis is a procedure that uses a machine to remove, exchange, collect or treat a specific component from the blood. It is used to harvest stem cells for transplant, to treat conditions like sickle cell disease, and in the preparation of advanced cellular therapies.
- The Government is aware of issues around apheresis capacity within the NHS, impacting patient services including stem cell donations.
- A DHSC led working group has been set up to examine existing apheresis capacity and develop solutions. This working group includes members of the UK stem cell register, health professionals, and service providers, aiming to develop an evidence base by which strategic decisions around apheresis capacity can be established.
- The group has submitted an internal, interim report to ministers for consideration and is currently working to gather additional data and strengthen the evidence base of this report, before proceeding to publication.