

STATE OF THE REGISTRY 2020–2021

The Anthony Nolan and NHS Stem Cell Registry Annual Review

The State of the Registry report has been compiled by the members of the Anthony Nolan and NHS Stem Cell Registry.

It highlights the work undertaken between April 2020 and March 2021 towards achieving our shared ambitions: providing donated stem cell products for UK patients in need of a lifesaving transplant, by recruiting stem cell donors; banking umbilical cord blood donations, and importing from international registries.

The Anthony Nolan and NHS Stem Cell Registry (known as the ‘aligned registry’) is formed of Anthony Nolan, DKMS UK, NHS Blood and Transplant (NHSBT), and the Welsh Bone Marrow Donor Registry. The aligned registry partners collaborate to streamline and accelerate unrelated stem cell provision and to increase the availability of unrelated donors and cord blood units in the UK.

Despite the challenges that the Covid-19 pandemic presented in 2020/21 the aligned registry grew to reach over 2.1 million stem cell donors, with over 232,000 new donors added to the register. This is approximately 95,000 fewer than in 2019/20. The decrease is directly related to the cancellation of face-to-face recruitment activity due to the pandemic.

The collection of umbilical cord blood units was paused for several months during 2020. The service was significantly limited in collection capacity while hospital clinical services responded to the pandemic. This resulted in 70% fewer cord blood units collected than in 2019/20. However, almost 550 new clinical grade umbilical cord blood units were collected, bringing the total cord bank to nearly 28,000.

The collaborative strength of the aligned registry has helped to meet many of the operational and logistical challenges faced this year. The aligned registry worked closely together to support one another during the pandemic and ensure continuity of service for UK patients.

The following charts and figures summarise key statistics related to the recruitment of stem cell donors to the aligned registry, cord blood donations, and provision of donated stem cells to patients in the UK in 2020/21.

STATE OF THE REGISTRY 2020–2021

The aligned registry is committed to improving access to optimum treatment options for patients from minority ethnic backgrounds. Diversifying the UK registry is one of the ways to support people who find it more difficult to find a matching donor or cord blood unit^{1,2}. However, the solutions go beyond donor recruitment in the UK and includes treatment options like cord blood, haplo-identical transplant and alternative therapies, along with international registry growth. Reflecting the commitment to improving access for patients, aligned registry partners are actively involved in the UK Stem Cell Strategic Forum. With a report expected to be published in Summer 2022, this initiative will make recommendations on all aspects of the patient journey from diagnosis through to treatment, including identification of a graft source, and recovery.

On the patient side, there is a significant lack of data available across all aspects of healthcare³, making it difficult to quantify the unmet need by ethnic group. Categorising ethnicities is also challenging, with inconsistencies in how ethnicity is recorded at the wider health system-level both in the UK and internationally, and no standard format of reporting ethnicity data.

While influencing the wider health-system data is a longer-term goal, the challenge of consistent categorisation is recognised by the aligned registry partners and work is ongoing to standardise how the ethnic diversity of the UK donor pool and recruitment activity is reported.

In this report, there are some interim changes in the way that the data is reported. They are:

- Consolidation and remapping of categories (i.e. combining African and African-Caribbean in the category Black / African / Caribbean / Black British; combining East Asian and South Asian under Asian / Asian British and including other Asian groups, previously under Other; Other European and Hispanic now sit under Other)
- Relabelling and remapping of categories (i.e. Northern European is now presented as White, Northern European and includes other White groups, previously under Other)
- Additional category (i.e. Mixed / Multiple has been added, where previously these numbers have been part of the Other category)

These interim changes provide the most accurate current picture of the UK aligned registry. However, in consultation with key stakeholders including the NHS, ONS and NBTA⁴, the aligned registry partners will propose and agree standard reporting and mapping of donor ethnicity data, to be in place for the State of the Registry 2022–2023. For any questions about categories or data mapping processes, please contact **stateoftheregistry@anthonymolan.org**

Please note: the use of the term ‘minority ethnic backgrounds’ in this report includes donors from the following groups: Asian/Asian British, Black/African/Caribbean/Black British, Jewish, Middle Eastern, Mixed/Multiple, Other.

¹ Lown, R. et al., (2013) Equality Of Access To Transplant For Ethnic Minority Patients Through Use Of Cord Blood and Haploidentical Transplants. *Blood*. 122(21). 2138. Abstract only. <https://doi.org/10.1182/blood.V122.21.2138.2138>

² APPG on Stem Cell Transplantation (2021, May 20). No Patient Left Behind: The Barriers Patients Face When Accessing Treatment and Care.

Accessible at: anthonymolan.org/sites/default/files/2021-05/no_patient_left_behind_final.pdf

³ Kapadia, D. et al., (2022) Ethnic Inequalities in Healthcare: A Rapid Evidence Review. NHS Race and Health Observatory. Accessible at: https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf

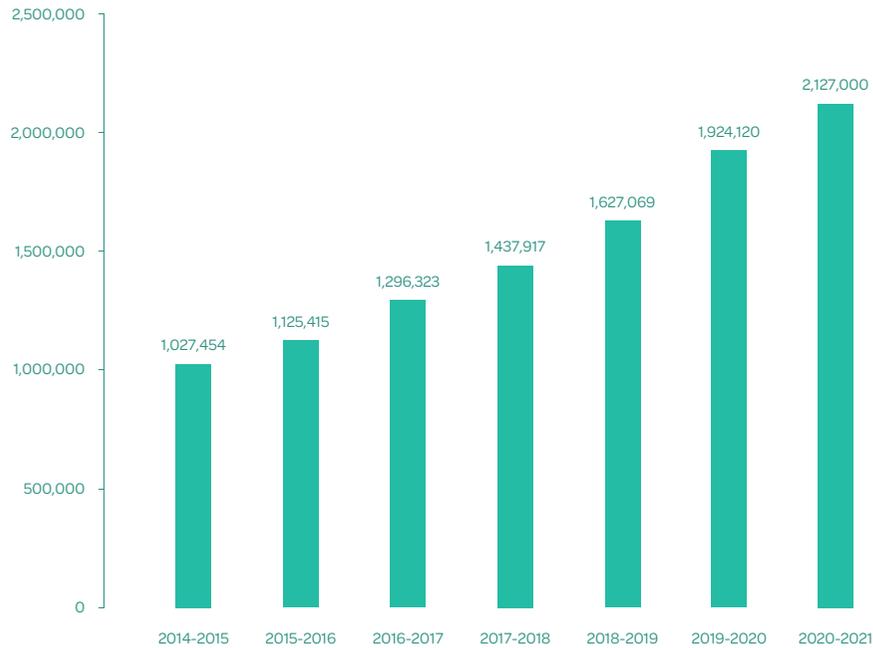
⁴ National Black, Asian, Mixed Race, and Minority Ethnic (BAME) Transplant Alliance

ALIGNED REGISTRY DEMOGRAPHICS 2020–2021

The aligned registry stands at over 2.1 million stem cell donors as of 31 March 2021. Passing the milestone of 2 million highlights the collective efforts of all the four organisations involved, along with the much-appreciated partners who support community donor recruitment efforts across the UK.

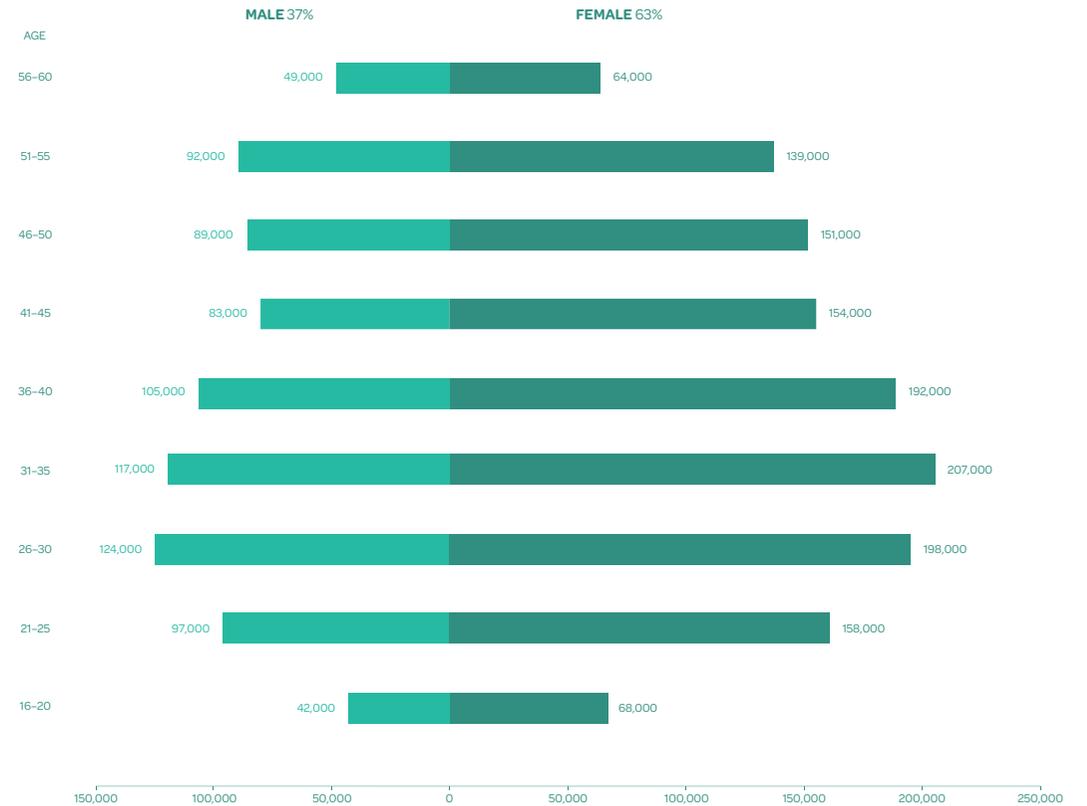
The cord blood bank has grown to almost 28,000 searchable clinical grade cord blood units.

ALIGNED REGISTRY OVER TIME



ALIGNED REGISTRY DEMOGRAPHICS

LAST YEAR 1,924,120
TOTAL 2,127,000*

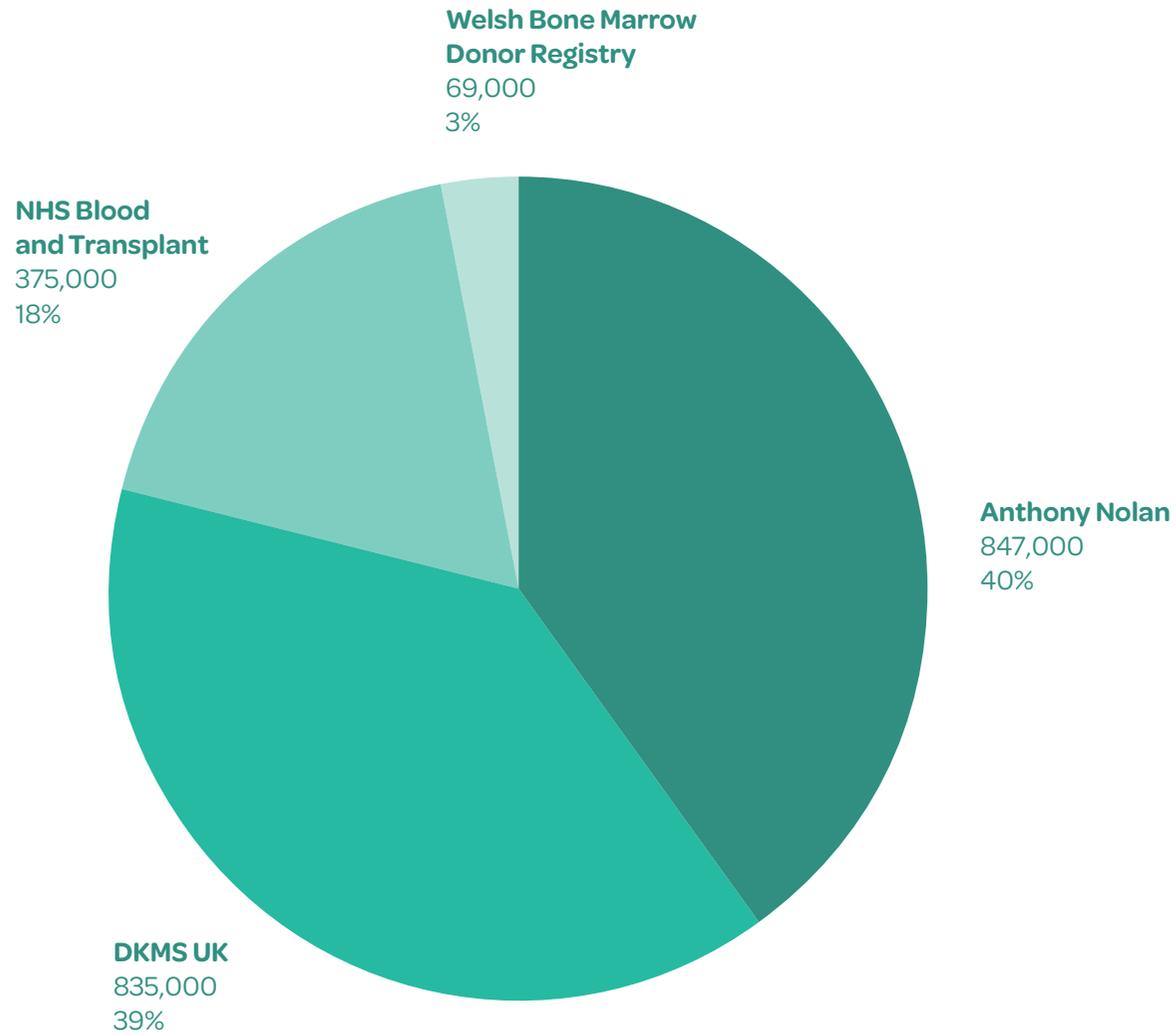


* The total aligned registry for 2020/21 is 2,127,000 – rounded to the nearest thousand. However, the rounding of data presented in this graph will cause a small deviation in the calculated total.

ALIGNED REGISTRY DEMOGRAPHICS 2020–2021

ALIGNED REGISTRY BY REGISTER

TOTAL 2,127,000*



* The total aligned registry for 2020/21 is 2,127,000 – rounded to the nearest thousand. However, the rounding of data presented in this graph will cause a small deviation in the calculated total.

ALIGNED REGISTRY DEMOGRAPHICS 2020–2021

ALIGNED REGISTRY BY ETHNICITY

LAST YEAR 15% **
MINORITY ETHNIC 15%



CORD BANK BY ETHNICITY

LAST YEAR 35% **
MINORITY ETHNIC 36%

LAST YEAR 27,261
TOTAL 27,714



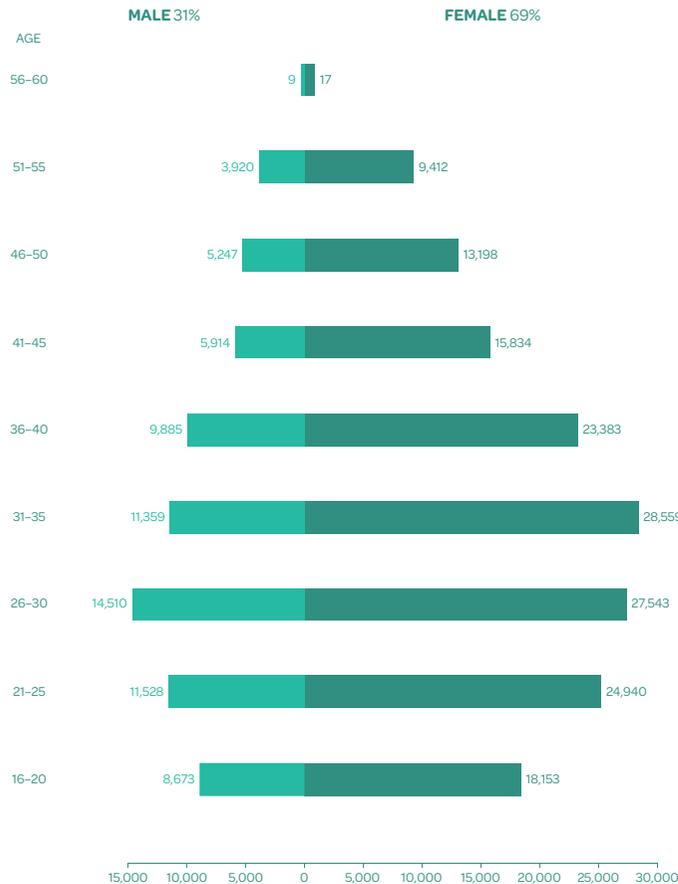
** This is based on the percentage of people from a minority ethnic background using the ethnicity categorisation presented in this year's report. Where possible, data has been partially remapped to allow for broad comparison. As such, this does not directly match the percentage quoted in the State of the Registry 2019-2020.

NEW DONORS MADE ACTIVE 2020–2021

The data represents donors added to the aligned registry between 1 April 2020 and 31 March 2021, during which time over 232,000 new donors were added. The percentage of donors recruited from a minority ethnic background rose from 11%** (2019/20) to 14%. There has also been an increase in the proportion of younger donors recruited in 2020/21, with 63% of donors recruited aged between 16 and 35 this year, compared to 56% in 2019/20. The proportion of cord blood units donated by mothers from minority ethnic backgrounds has remained largely stable (35% 2020/21 vs 34%** 2019/20).

NEW DONORS MADE ACTIVE

TOTAL 232,084***



NEW DONORS MADE ACTIVE BY ETHNICITY

LAST YEAR 11% **
MINORITY ETHNIC 14%



CORD BLOOD UNITS ADDED BY ETHNICITY

LAST YEAR 34% **
MINORITY ETHNIC 35% LAST YEAR 1,794
TOTAL 542



** This is based on the percentage of people from a minority ethnic background using the ethnicity categorisation presented in this year's report. Where possible, data has been partially remapped to allow for broad comparison. As such, this does not directly match the percentage quoted in the State of the Registry 2019-2020.

*** As donors turn 60, or upon their request, they will be removed from the registry. This means that the total number of donors made active in the year does not equate to the year-on-year growth of the registry.

STEM CELL PROVISION 2020–2021

The aligned registry helped 1,013 UK patients in 2020/21, a 9% drop on the previous year. Pressures on cancer services during the pandemic impacted unrelated transplant activity, particularly in the first quarter when many non-urgent transplants were postponed. Provisions from UK donors were also heavily affected by the pandemic with the need to frequently update policies, provide extra support for donors, and implement Covid-19 testing. Despite the challenges, donor and cord blood provisions continued throughout, with somewhat of a recovery in the later months of the financial year.

The proportion of imported stem cell products remained stable at 68% (69% in 2019/20). The complexity of importing during the pandemic underlined the importance of meeting as much UK patient need as possible with UK donors and cord blood units. Increasing the usage of UK donors for UK patients helps to support a sustainable UK registry, reduces risk of international disruption and minimises cost to the NHS. However, this is only in the case that a suitable donor or cord blood option is available within the UK, as finding the best possible graft for patients remains the priority.

The number of cord blood units used to help UK patients increased this year. This can be seen for domestic provisions, which increased from 20 in 2019/20 to 32 in 2020/21 and international provisions, which increased from 59 in 2019/20 to 71 in 2020/21. Again, this shift in stem cell provision is connected to the pandemic. Cord blood units are protected from the risks around donor availability and international transport disruption, both of which were impacted by Covid-19.

Forty five percent of UK cord blood units used for UK patients in 2020/2021 were donated by mothers from a minority ethnic background. While this is a significant proportional increase on last year (24%** in 2019/2020), this change can be largely attributed to new, more accurate data processes and sourcing, which has helped to reduce the number of cord blood units where the mother's ethnic background was previously reported as Unknown. Donation via cord remains a vital method of meeting the needs of patients from minority ethnic backgrounds.

** This is based on the percentage of people from a minority ethnic background using the ethnicity categorisation presented in this year's report.

Where possible, data has been partially remapped to allow for broad comparison. As such, this does not directly match the percentage quoted in the State of the Registry 2019-2020.

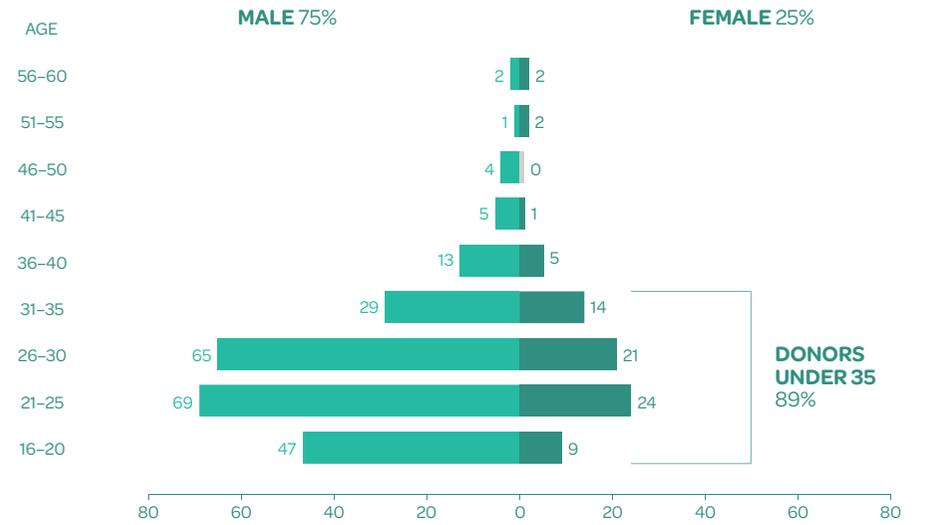
STEM CELL PROVISION 2020-2021

PROVISIONS FOR UK PATIENTS OVER TIME (IMPORTS VS UK)



UK DONORS FOR UK PATIENTS

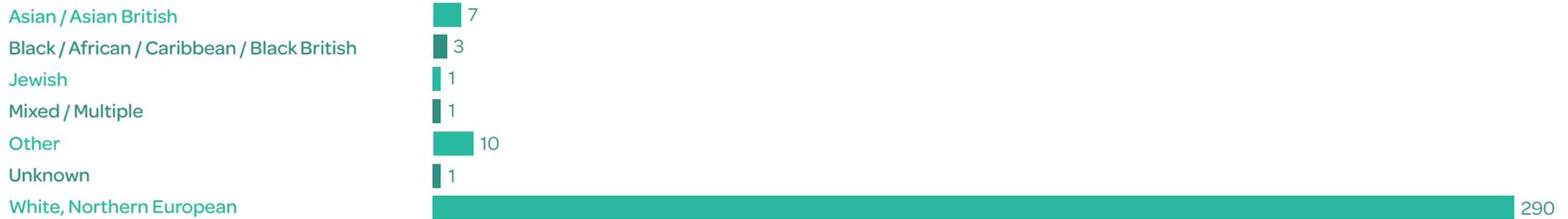
LAST YEAR 333
TOTAL 313



STEM CELL PROVISION 2020–2021

UK DONORS FOR UK PATIENTS BY ETHNICITY

LAST YEAR 5% **
MINORITY ETHNIC DONORS 7% **TOTAL 313**



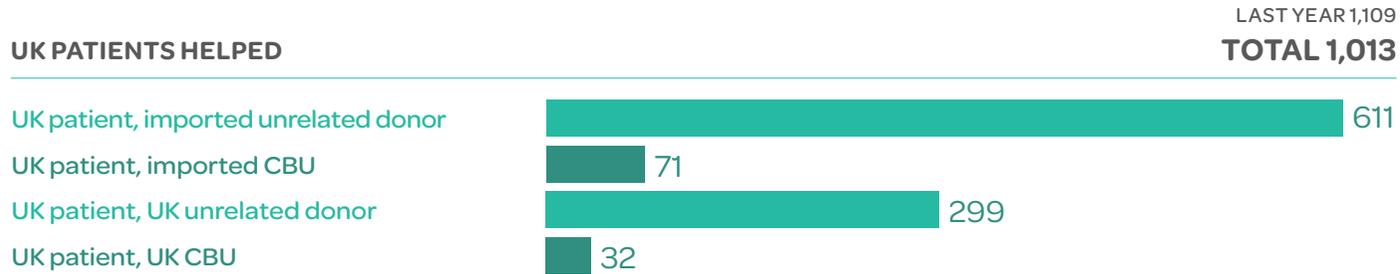
UK CORD FOR UK PATIENTS BY ETHNICITY

LAST YEAR 24% ** LAST YEAR 29
MINORITY ETHNIC 45% **TOTAL 38**



** This is based on the percentage of people from a minority ethnic background using the ethnicity categorisation presented in this year's report. Where possible, data has been partially remapped to allow for broad comparison. As such, this does not directly match the percentage quoted in the State of the Registry 2019-2020.

STEM CELL PROVISION 2020-2021



UK DONORS FOR UK PATIENTS (SEARCH REQUESTS VS BLOOD SAMPLES REQUESTED)

