

# State of the Registry 2018-2019

The Anthony Nolan and NHS  
Stem Cell Registry Annual Review



Jon, stem cell donor

**ANTHONY  
NOLAN**

saving the lives  
of people with  
blood cancer

**DKMS**  
WE DELETE BLOOD CANCER

**NHS**  
*Blood and Transplant*

  
Welsh Blood Service



## CONTENTS

INTRODUCTION: THE STATE OF THE REGISTRY IN 2018-2019	5
KEY STATISTICS IN 2018-2019	6
ALIGNED REGISTRY DEMOGRAPHICS 2018-2019	8
NEW DONORS MADE ACTIVE 2018-2019	10
STEM CELL PROVISION 2018-2019	12

### Anthony Nolan

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75-87 Agincourt Road  
London  
NW3 2NU

[anthohnolan.org](http://anthohnolan.org)  
0303 303 03 03

Registered charity no  
803716/SC038827

1969CM

### DKMS UK

Ashburnham House  
Castle Row,  
Horticultural Place,  
London W4 4JQ

[dkms.org.uk](http://dkms.org.uk)  
020 8747 5620

Registered charity no  
1150056

### NHS Blood and Transplant

Oak House,  
Reeds Crescent  
Watford, Hertfordshire  
WD24 4QN

[nhsbt.nhs.uk](http://nhsbt.nhs.uk)  
0300 123 23 23

### Welsh Blood Service

Ely Valley Road,  
Pontyclun,  
Mid Glamorgan  
CF72 9WB

[welsh-blood.org.uk](http://welsh-blood.org.uk)  
0800 252 266



Rayhan, transplant recipient

## INTRODUCTION: THE STATE OF THE REGISTRY IN 2018-2019

The **State of the Registry** report has been compiled by the **Anthony Nolan and NHS Stem Cell Registry** – the aligned UK registry formed of **Anthony Nolan, DKMS UK, NHS Blood and Transplant, and the Welsh Bone Marrow Donor Registry**.

For the first time, this report showcases the work that has been undertaken in the 2018-2019 financial year, rather than calendar year, in line with other aligned registry reporting. In the following pages, the report covers the recruitment of stem cell donors to the aligned registries, umbilical cord blood donations, and provision of donated stem cells to patients in the UK in need of a lifesaving transplant.

The aligned registry has reached an incredible milestone – there are now **1.6 million potential donors** ready and waiting to save someone's life. This came after the combined registries saw the most people added in a single year, with over **205,000 new people recruited**.

It's also incredibly encouraging to see that **49% of those added were aged between 16 and 30 years old**. This is vital to meeting the demand of transplant centres, as **75% of UK donors selected for UK patients were in this age category**, the vast majority of which were also male. This targeted recruitment is also proactively responding to international research that shows that the younger a donor is, the better the outcome for the patient.<sup>1</sup>

However, although recruitment trends are encouraging, more needs to be done to lower the **average age, which was 32 for those recruited in 2018-2019, and 38 for the registry as a whole**.

There has also been an increase in imports for UK patients, with **63% of UK patients receiving cells imported from an overseas donor or cord blood unit (CBU)** compared to 58% in 2017-2018. There is an evident need to continue improving the quantity and quality of UK donors for UK patients.

There has been positive progress in the typing level of potential donors, which now stands at **half of all people on the aligned registry being typed to six loci**. International research published in the last year has shown that the ability to match at this level, and provide patients with a 12/12 match, increases their chance of survival.<sup>2</sup>

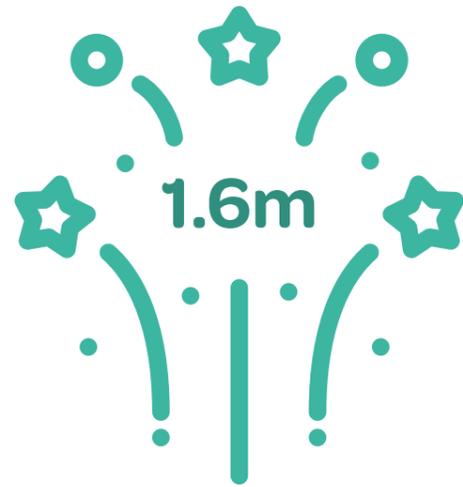
While matching to this level could change patient outcomes, there are still patients who struggle to find any kind of match. This is particularly true for patients from a Black, Asian or minority ethnic (BAME) background, with **donors from these backgrounds making up only 14% of the aligned registry and 22% of recruitment this year**.

However, with the growth of the cord blood bank – which now stands at more than **25,000 searchable clinical-grade CBUs** – it is noticeable that many of the cords were donated by mothers from BAME backgrounds. This has resulted in **38% of CBUs on the registry being of BAME parentage**.

The aligned registry will continue to grow and develop to meet the needs of patients now, and in the future, as research continues to inform recruitment of the best possible donors to improve transplant outcomes.

<sup>1</sup> Shaw, B. et al. (2018). Development of an Unrelated Donor Selection Score Predictive of Survival after HCT: Donor Age Matters Most. *Biology of Blood and Marrow Transplantation*, 24(5), pp.1049-1056.

<sup>2</sup> Mayor, N. et al. (2019). Recipients Receiving Better HLA-Matched Hematopoietic Cell Transplantation Grafts, Uncovered by a Novel HLA Typing Method, Have Superior Survival: A Retrospective Study. *Biology of Blood and Marrow Transplantation*, 25(3), pp.443-450.



There are now over **1.6 million** potential stem cell donors on the UK's aligned registry.



Over **205,000** people were added to the aligned registry last year.



**2,355** searches took place for a UK donor for a UK patient.

**75%** of UK donors for UK patients were aged 16–30.

**63%** of UK donors for UK patients were men aged 16–30.

**81%** of UK donors for UK patients were male.

**37%** of UK patients received a UK donor or CBU.



There are now more than **25,000** searchable clinical-grade cord blood units (CBU) banked after **2,216** cords were added in the last year.



**1,079** individual patients were helped in the last year.



The aligned registry saw a **13%** growth in the last year.

**49%** of those added to the aligned registry were aged under 30.

**39%** of those added were male, but only **20%** of those added were men aged 16–30.

**22%** of new potential donors are from black, Asian or minority ethnic (BAME) backgrounds.

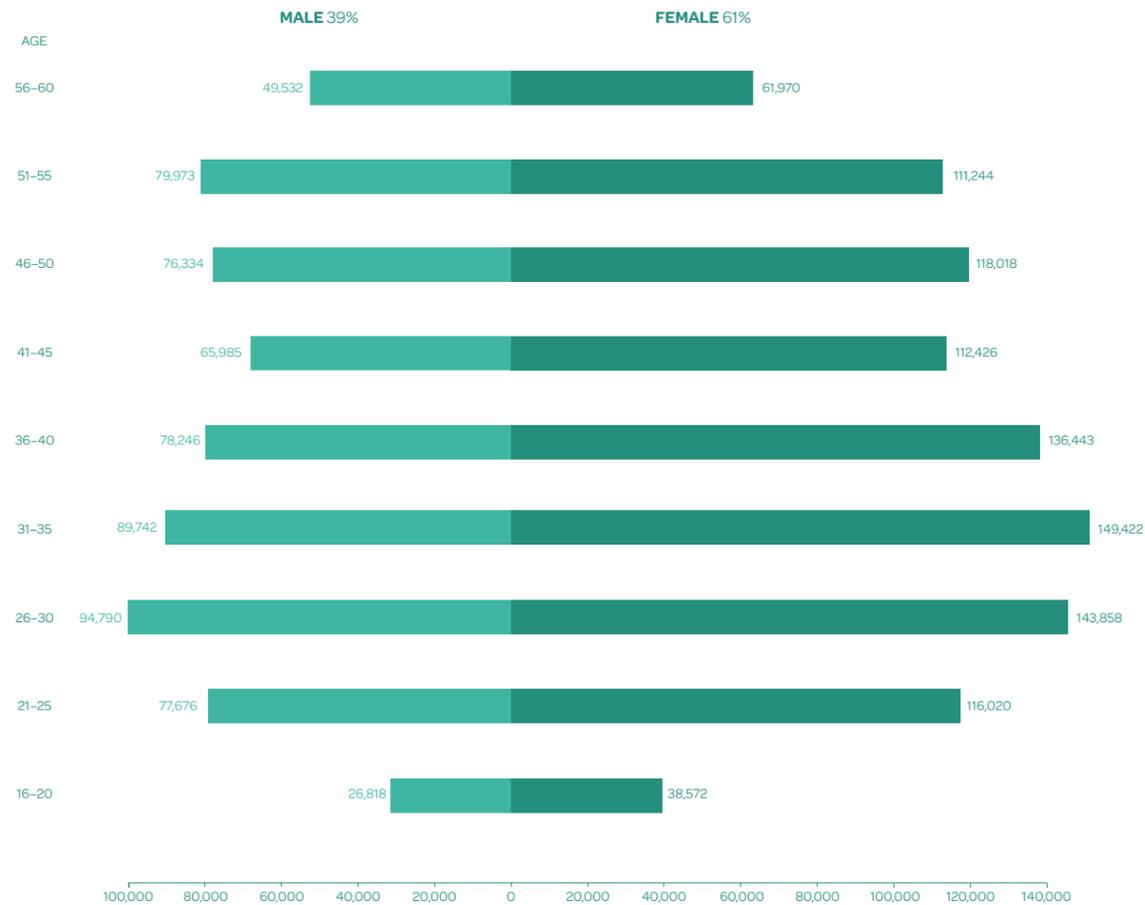
# ALIGNED REGISTRY DEMOGRAPHICS 2018-2019

## ALIGNED REGISTRY OVER TIME



## ALIGNED REGISTRY DEMOGRAPHICS

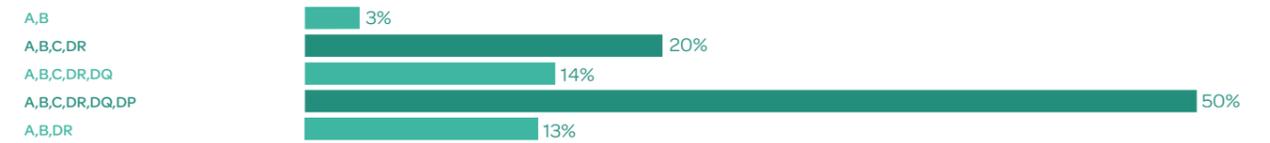
LAST YEAR 1,437,917  
**TOTAL 1,627,069**



## SUMMARY OF ALIGNED REGISTRY

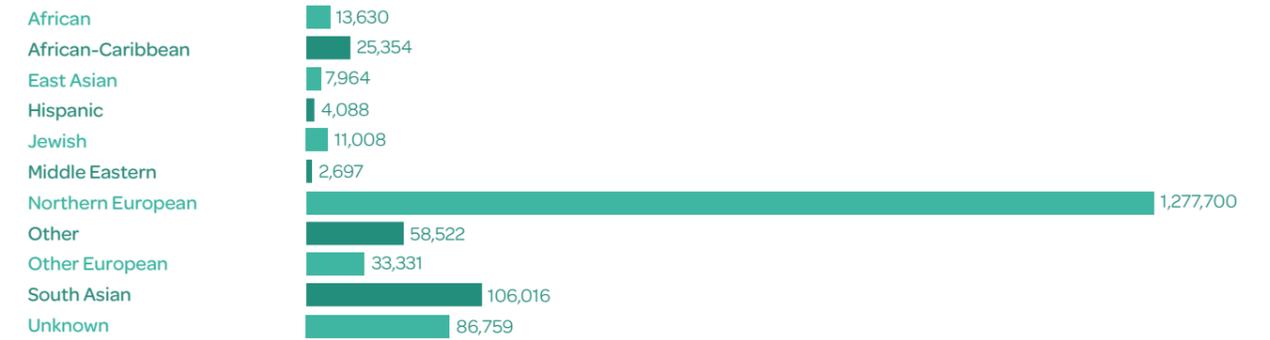


## ALIGNED REGISTRY BY HLA TYPING



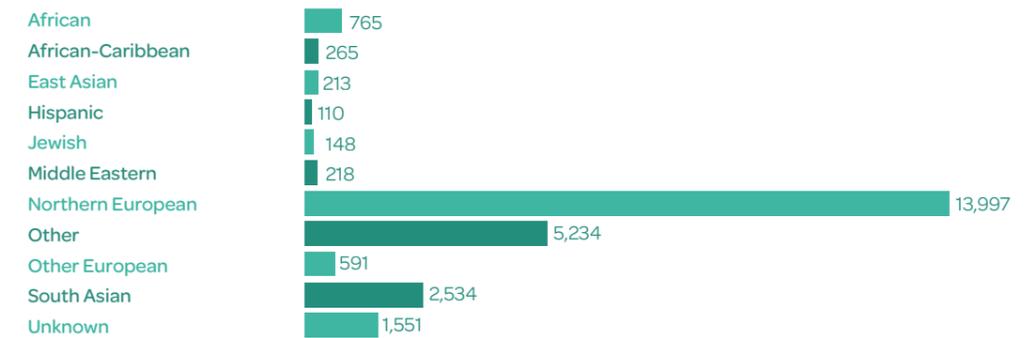
## ALIGNED REGISTRY BY ETHNICITY

LAST YEAR 13%  
**BAME 14%**



## CORD BANK BY ETHNICITY

**TOTAL 25,626**

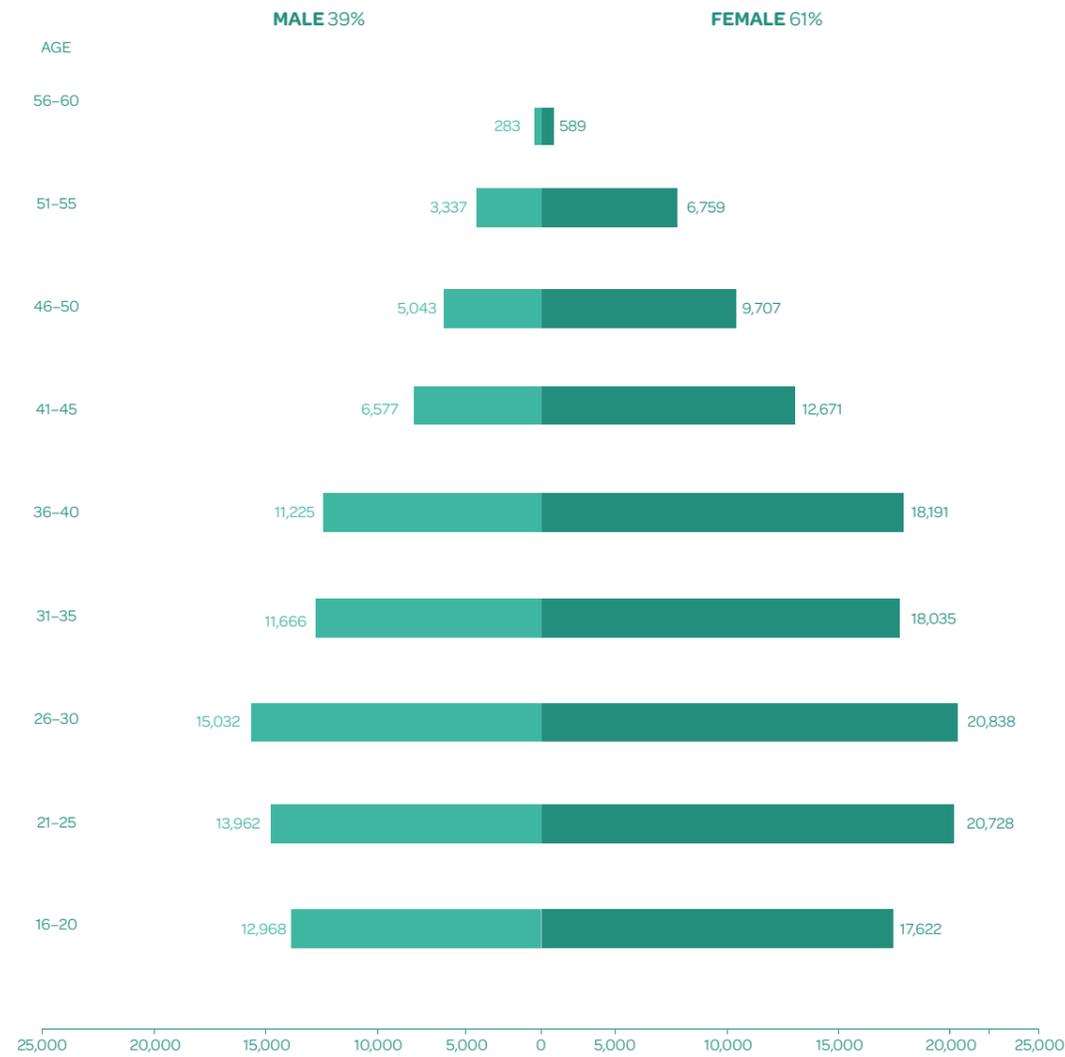


# NEW DONORS MADE ACTIVE 2018-2019

Donors added to the registry in the last financial year who are searchable for patients.

LAST YEAR 156,012  
**TOTAL 205,233\***

## NEW DONORS MADE ACTIVE



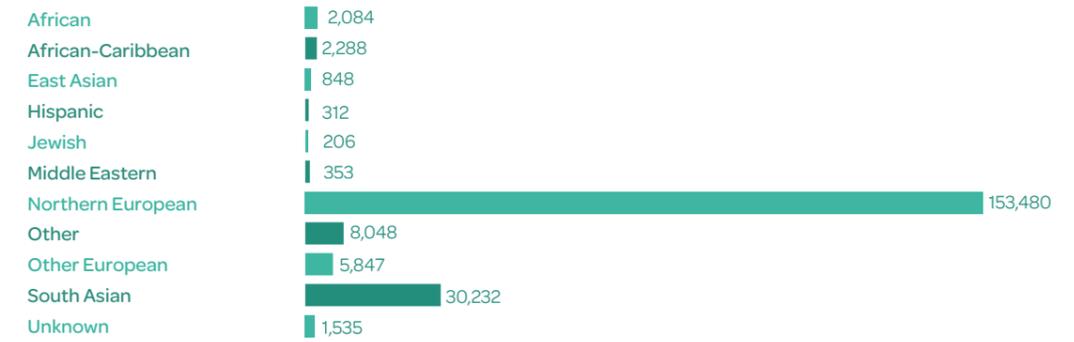
\*As donors turn 60, or upon their request, they will be removed from the registry. This means that the total number of donors made active in the year does not equate to the year-on-year growth of the registry.

## SUMMARY OF NEW DONORS MADE ACTIVE



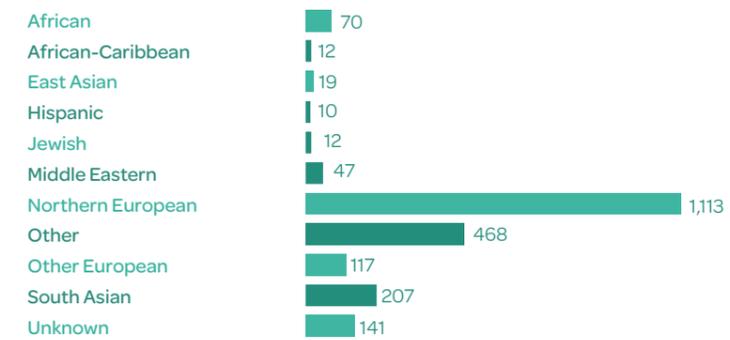
## NEW DONORS MADE ACTIVE BY ETHNICITY

**BAME 22%**



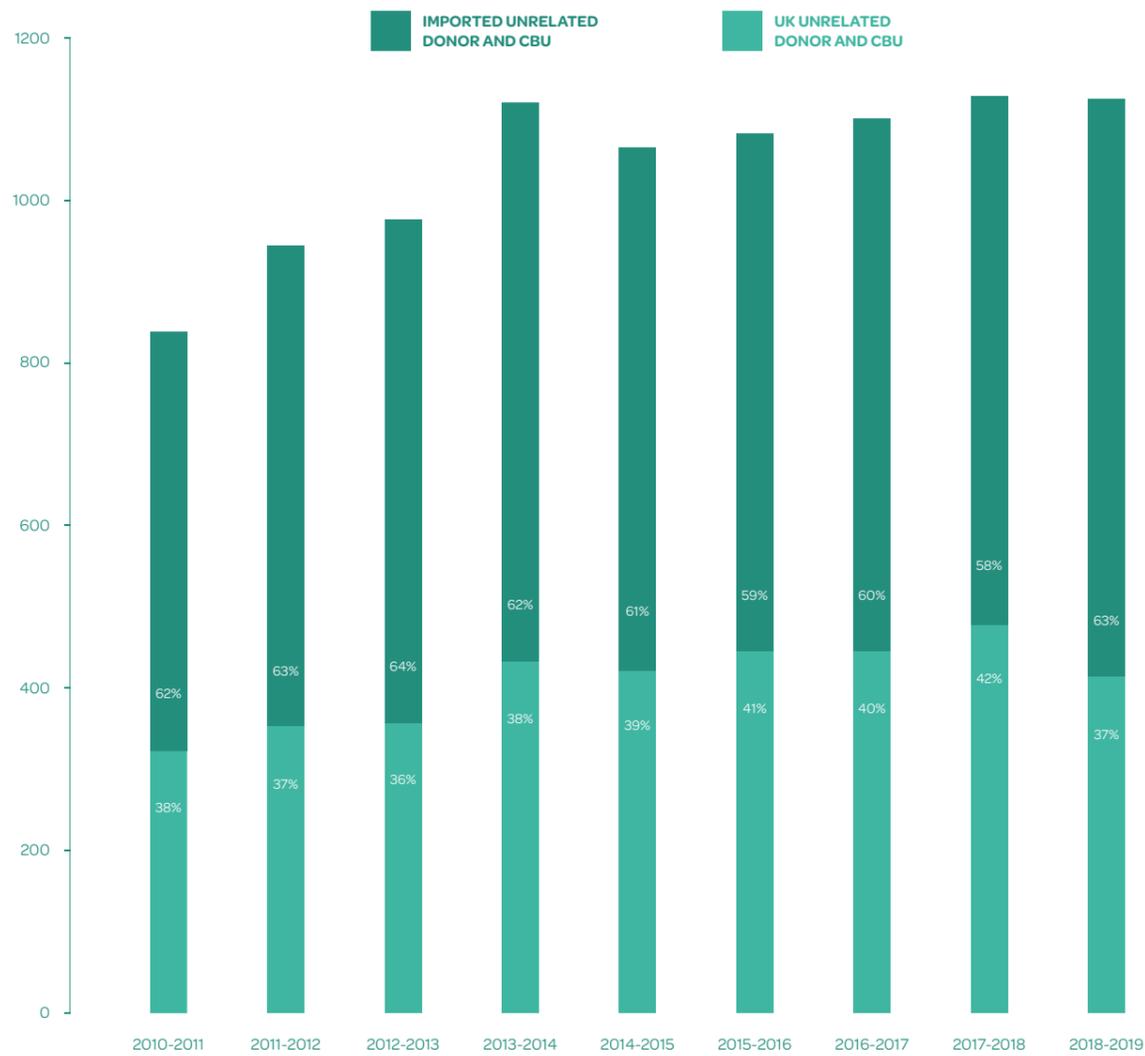
## CORD BLOOD UNITS ADDED BY ETHNICITY

**TOTAL 2,216**



# STEM CELL PROVISION 2018-2019

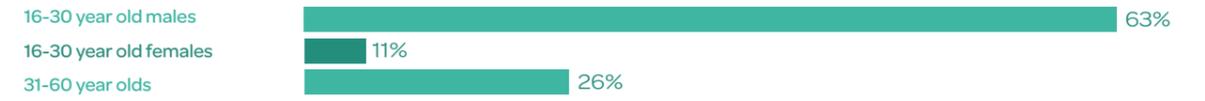
## PROVISIONS FOR UK PATIENTS OVER TIME (IMPORTS VS UK)



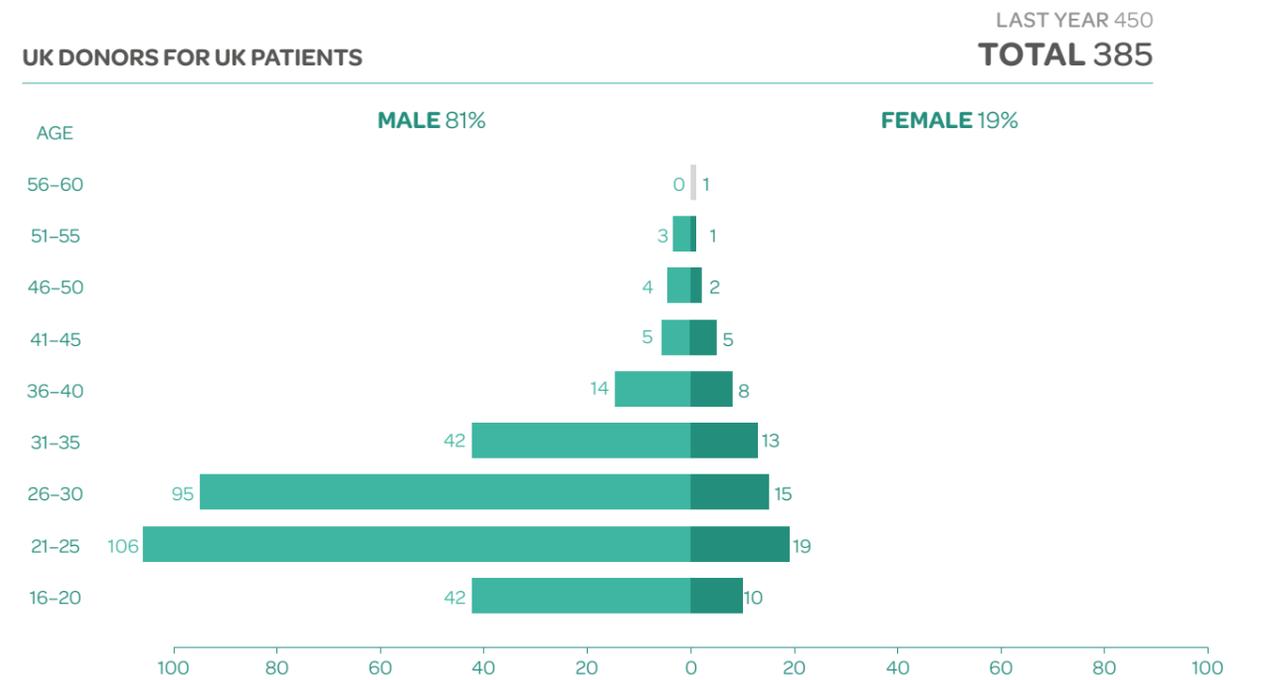
## PROVISIONS FOR UK PATIENTS (MARKET SHARE)



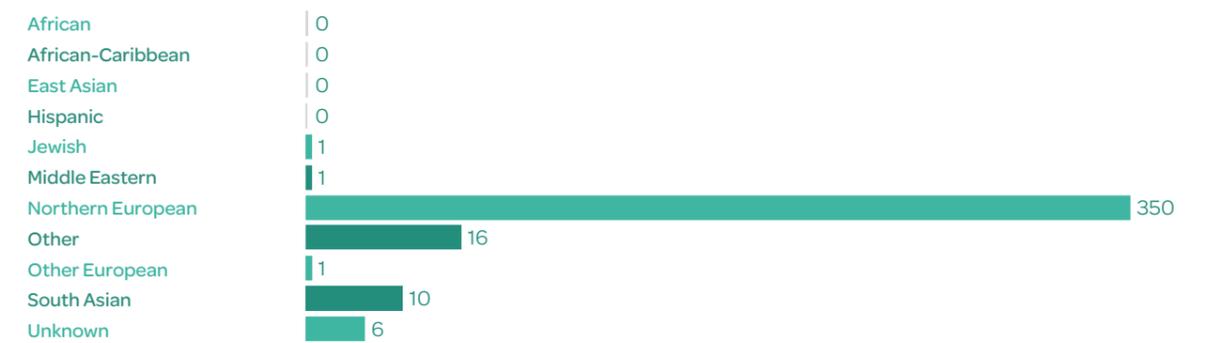
## SUMMARY OF UK DONORS FOR UK PATIENTS



## UK DONORS FOR UK PATIENTS

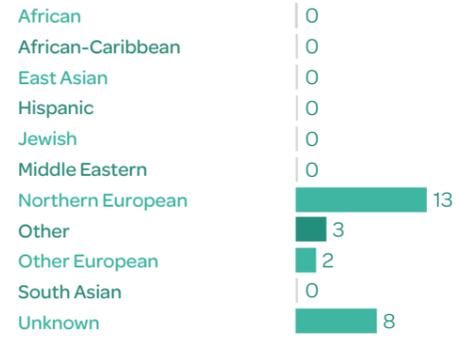


## UK DONORS FOR UK PATIENTS BY ETHNICITY



UK CORD FOR UK PATIENTS BY ETHNICITY

LAST YEAR 22  
**TOTAL 26**



UK PATIENTS HELPED

LAST YEAR 1,071  
**TOTAL 1,079**



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



Dolapo, cord blood donor

Over 205,000 new potential stem cell donors were made available for transplant patients in the UK and worldwide this year, bringing the total aligned registry to over 1.6 million potential donors.

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saving the lives  
of people with  
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