NHS
Blood and Transplant

Supply and Demand of Ro Blood 2023

Contents

Calvin Campbell was diagnosed with sickle cell disorder at just six months old and has been in pain every day of his life. Regular red cell exchange transfusions are, in his words, probably the single most important thing keeping him alive.

"As a child and teenager, living with sickle cell was incredibly difficult," says Calvin. "It caused me no end of problems. I was always unwell, in constant pain. I spent huge amounts of time in hospital and, due to complications, came close to passing away on several occasions.

"The impact on my family when I was young was huge, but it didn't stop there: it has been devastating for my children and my partner, who have had to see me go through terrible things. I was sick so much while my children were growing up and they were unable to see me for long periods of time.

I spent almost three years in hospital when I had leg ulcers. Those leg ulcers lasted ten and a half years. For almost three years, I was paralysed from the chest down. Many years went by before I could do all the things I would normally be able to do.

"I had blood transfusions intermittently when I was very unwell as a child, then started having regular transfusions or exchanges when I was about 16 years old. Now I receive 10 to 11 units every four weeks – that's around 128 blood donations a year.

"Prior to my exchanges, I am very often extremely tired and in a lot more pain than usual, but I start feeling the benefits a few days afterwards. I get a boost in energy and most of the time a reduction in pain too.

"Were it not for the amazing blood donors I will never probably meet, I would not be here today. I owe my life to date to their incredible gifts.

"My family and I are so grateful for each person who donates and saves up to three adults, like myself, with each donation. Without their incredible donations, my children would not have a father and my grandchildren would not have a grandfather."

Introduction

Sickle cell disorder is a lifelong genetic condition. It is one of the most common conditions caused by a single genetic mutation in the UK.

Sickle cell disorder occurs when two copies of the genetic mutation are inherited – one from each parent – and results in abnormally shaped red blood cells. The shape of these cells can lead to episodes of severe pain, known as crises, as well as long-term damage to organs, such as the brain, lungs, and kidneys.

In addition, people with sickle cell disorder have low levels of haemoglobin, or anaemia, meaning their red blood cells aren't able to carry enough oxygen around the body – sickle cell disorder may indeed be referred to as sickle cell anaemia in certain cases.

Inheritance of only one variant gene is often termed 'sickle cell trait' and that person a 'carrier'. Most carriers of sickle cell trait do not have any symptoms of sickle cell disorder.

Sickle cell disorder is by far most prevalent in people of Black African and Black Caribbean heritage, although it can occur in people of any ethnicity.

The condition can vary in severity, with some patients requiring medical support every few years and others experiencing pain daily or weekly and requiring pain medication routinely. Patients can also develop severe life-threatening complications, such as acute stroke, acute chest syndrome and fat embolism syndrome, which require emergency treatment.

There are very few treatments available for patients living with sickle cell disorder, with a stem cell transplant being the only curative treatment. Two treatments are given to reduce the severity of sickle cell disorder: hydroxycarbamide, which is taken orally as a preventative medication, or blood transfusion therapy, which is used both as preventative and emergency life-saving treatment.

Blood transfusion practice for sickle cell disorder has improved in the last decade and can be undertaken in a variety of ways, including simple top-up transfusions, manual exchange transfusions, and the recently-developed automated red cell apheresis exchange transfusions.

Top-up transfusions simply dilute or reduce the number of sickle cells, but do not remove them. Both manual and automated red cell apheresis exchange transfusions, on the other hand, do involve the removal of the patient's red blood cells, which are replaced with donor red cells.

Manual exchange transfusion is a slow process and can take many hours, depending on the number of units of donor red cells used. It provides a less effective reduction in the number of sickle cells than automated red cell apheresis, which allows for a very low post-exchange sickle percentage, while also generally being completed in just a couple of hours.

Automated red cell apheresis transfusions, however, require between 8 to 10 units of red cells on average per apheresis, comparing to top-up transfusions, which may only need a couple of units of blood, and manual exchanges, which require around 3 to 8 units of red cells in an adult patient. Most patients will have an apheresis exchange transfusion every 4 to 8 weeks and on average will need around 100 red cell units every year.

The development of clinical care networks has allowed smaller clinical units treating sickle cell disorder to be linked in with specialist units, improving the care of patients even in areas where the condition is less prevalent. Since 2016, there has been a considerable increase in provision of red cell apheresis exchanges throughout England.

The additional units required by automated red cell apheresis exchange transfusions and their increased usage have combined to create a significant demand for donated blood.

More details can be found on the NHS website (Sickle cell disorder – NHS (www.nhs.uk)).

Prevalence

According to the latest Annual Data Report produced by the National Haemoglobinopathy Registry, there were 12,913 people living with sickle cell disorder in 2020/21 in England, with 63 per cent receiving treatment at hospitals in London (Foster, 2022).

In the UK, it is recommended that all new-born babies are tested for sickle cell disorder. In 2019/20, 245 of 614,694 (around 1 in 2,500) babies tested were born with the condition.

Around 1 in every 140 babies of Black African heritage and 1 in every 190 babies of Black Caribbean heritage were found to have sickle cell disorder.

The number of new patients with sickle cell disorder detected by new-born screening has remained stable in recent years (Sickle cell and thalassaemia screening: data report 2019 to 2020 – GOV.UK (www.gov.uk)).

Migration also accounts for a small increase in the number of patients registered with a diagnosis.

Around 1 in 7 people of Black heritage (both African and Caribbean) are carriers of the sickle cell gene (sickle cell trait). Smaller proportions of people from Asian, mixed, and other ethnic backgrounds also have sickle cell trait. People with sickle cell trait are able to donate blood in the majority of cases.

Around 1 in 6 Black African and 1 in 10 Black Caribbean blood donors have sickle cell trait. This is similar to the national prevalence.

Table 1: Prevalence of sickle cell disorder and sickle cell trait among new-born babies in England, by ethnic group – data from the NHS new-born screening programme, 2019/20 (NHS England, 2022)

		Significant conditions (sickle cell disorder)		Carrier results (sickle cell trait)	
Ethnic group	Babies tested	N positive	%	N positive	%
Black African	21,257	156	0.73%	2,968	14.0%
Black Caribbean	5,412	28	0.52%	711	13.1%
Any other Black background	3,678	18	0.49%	403	11.0%
Mixed	41,170	16	0.04%	1,567	3.8%
Asian	71,643	17	0.02%	1,137	1.6%
White	433,652	1	< 0.01%	751	0.2%
Other	18,167	5	0.03%	230	1.3%
Unknown	19,715	4	0.02%	233	1.2%
England total	**614,694**	**245**	**0.04%**	**8,000**	**1.3%**

Table 2: Positivity rates for haemoglobin S (sickle cell trait) testing of blood donors in England, by ethnic group – donors registering to donate in the three-year period ending 30 April 2023

	HbS (sickle cell trait) testing		
Ethnic group	**Donors tested**	**N positive**	**%**
Black African	6732	1090	16.2%
Black Caribbean	3423	349	10.2%
Any other Black background	701	96	13.7%
Mixed	9,712	286	2.9%
Asian	22,553	49	0.2%
White	27,831	11	< 0.1%
Other	4,425	42	0.9%

It takes 100 blood donors per year to keep me alive, I am so grateful for everything blood donors do.

Demand

The demand for red blood cell transfusion for sickle cell disorder has increased greatly in the past few years, up by more than 50 per cent between 2016/17 and 2021/22, despite being slowed by the COVID-19 pandemic.

Provisional data from the National Haemoglobinopathy Registry annual report (2022) shows that 1,014 patients are currently on regular transfusion programmes and 774 are on regular automated exchange by red cell apheresis.

There has been a significant shift in transfusion practice, with 495 patients starting on automated red cell apheresis since 2020. Approximately 63,000 red cell units are used in total for transfusion in sickle cell disorder on an annualised basis. Of these, 61,300 units are used for patients on regular transfusion regimes. The average exchange uses 6 units (ranging from 1 to 12 and most commonly, 8 units), accounting for a predominantly adult population of patients receiving automated apheresis.

Certain requirements must be met when sourcing the blood with which to transfuse sickle cell disorder patients (Red Cell Transfusion in Sickle Cell Disease Part I (b-s-h.org.uk)). Of these criteria, matching blood groups is most crucial.

Most people are familiar with the ABO blood group system, in which every person has a blood group that is either A, B, O, or AB, but there are many more blood group systems. One such system is the Rh blood group system.

In patients with sickle cell disorder, it is important to match not only the ABO group, but also the Rh groups, otherwise patients can form antibodies and have reactions against future blood transfusions.

The Rh blood group system contains two main antigen groups: D and CE. Many people are aware of the D group, being familiar with descriptions of D positive or negative (D+ or D-), which respectively describe the presence or absence of the D antigen. These descriptions form the positive or negative part of a person's 'main' blood type description, i.e., the 'positive' in 'A positive' or the 'negative' in 'A negative'. Matching the Rh D group is important in any patient, as the Rh D antigen is highly immunogenic (meaning it is likely to create antibodies if transfused into an Rh D- recipient).

The other Rh antigens are described slightly differently: there are four antigens in two pairs – C/c and E/e. These antigens are less immunogenic than Rh D, but mismatches still have the potential to create antibodies, especially in patients with sickle cell disorder receiving multiple transfusions over time.

Each combination of D, C, c, E, and e antigens found in a patient or donor (the phenotype) is given a special name that is commonly used in transfusion practice, based on the most likely genotype corresponding to that phenotype. For example, the combination D+ C+ c+ E- e+ is known as R1r and is the most common phenotype in blood donors in England.

The most common Rh type found in patients of Black heritage is the combination D+ C- c+ E- e+. This phenotype is known as Ro (Ro blood – NHS Blood Donation (www.blood.co.uk)). As most patients with sickle cell disorder are of Black heritage, Ro phenotype blood is the type most commonly requested for transfusions treating it.

Given the D antigen is present (D+) in Ro, it may be seen in Rh D positive groups only. For example, an Ro donor may be A positive but cannot be A negative.

Aside from the Rh blood group system, other blood groups occur at varying frequencies between the generally White donor population and patients with sickle cell disorder (Table 12). Important blood groups where there is a high risk of antibody formation and transfusion reactions include Kell, Kidd, Duffy and the MNS blood group systems. These blood groups have different prevalence in Black heritage patients compared to White donors and better matching of blood also reduces the risk of antibodies developing against these groups.

Matching is optimised for Rh and Kell blood groups (table 10 and 11), with more than 99 per cent of all requests for Ro blood also specifying the Kell negative (K-) phenotype. Further matching may be required for other blood groups if a patient develops antibodies. Once a patient has developed an antibody, their risk of developing more antibodies increases.

Exposure to blood containing antigens that these antibodies have developed in response to may cause life-threatening transfusion reactions. It may also make it very difficult to give the patient transfusions in future, due to the complexity of the antibodies.

Hospitals in London, due to its large population of patients with sickle cell disorder, were among the first to establish automated red cell apheresis services. London hospitals account, hence, for a large majority of requests for both Ro blood and blood for patients with sickle cell disorder more generally: in 2021/22, 80 per cent of orders for Ro red cell units came from London hospitals, as did 76 per cent of those being used for sickle cell disorder patients.

Table 3: Requests from English hospitals for red cell units with the Ro phenotype and/or for transfusion to patients with sickle cell disorder, 2016/17 to 2022/23

	Red cell units requested, where the order specified:						
Financial year	Ro only (not intended for sickle cell disorder patients)	Both Ro and intended for sickle cell disorder patients	Intended for sickle cell disorder patients only (not Ro)	Total Ro units requested	% change from previous year	Total units requested for sickle cell disorder patients	% change from previous year
2016/17	16,842	30,374	25,278	47,216	-	55,652	-
2017/18	22,367	31,164	24,742	53,531	+13.4%	55,906	+0.5%
2018/19	25,106	35,542	27,009	60,648	+13.3%	62,551	+11.9%
2019/20	24,682	41,454	32,940	66,136	+9.0%	74,394	+18.9%
2020/21	23,655	42,696	33,784	66,351	+0.3%	76,480	+2.8%
2021/22	27,452	47,090	37,399	74,542	+12.3%	84,489	+10.5%
2022/23	27,910	47,614	38,966	75,524	+1.3%	86,580	+2.5%

Note: More than 99 per cent of all Ro requests also specified the K- phenotype.

Red cell unit requests for Ro blood likely reflect both the numbers of patients with sickle cell disorder and the demographics of the local population. As expected, most of the top 20 English hospitals requesting units for sickle cell patients are in London or the home counties (14 out of 20, according to 2021/22 data).

Other centres in the top 20 but outside of London include hospitals in Manchester, Nottingham, Birmingham, Oxford, Leeds, and Leicester. All but one of these hospitals are also in the top 20 requesters of Ro units overall (for both sickle cell disorder and non-sickle cell disorder patients).

Collectively, the top 20 hospitals accounted for 87 per cent of red cell unit requests for sickle cell disorder patients in 2021/22, and the same proportion of Ro requests.

Table 4: Requests from English hospitals for red cell units with the Ro phenotype and/or for transfusion to patients with sickle cell disorder in 2022/23, by location of requesting hospital

	Red cell units requested, where the order specified:				
Location (city) of requesting hospital	Ro only (not intended for sickle cell disorder patients)	Both Ro and intended for sickle cell disorder patients	Intended for sickle cell disorder patients only (not Ro)	% of all Ro units requested here	% of all units for sickle cell disorder patients requested here
London	23,236	35,191	28,369	77%	73%
Manchester	575	2,502	1,117	4%	4%
Birmingham	354	1,470	1,983	2%	4%
Bristol	72	710	448	1%	1%
All others	3,673	7,741	7,049	15%	17%]

Total Ro demand is the sum of the second and third columns (e.g. Bristol = 782 units); total demand for blood to treat sickle cell patients is the sum of the third and fourth columns (e.g. Bristol = 1,158 units).

Table 5: Requests from English hospitals for red cell units with the Ro phenotype and/or for transfusion to patients with sickle cell disorder in 2016/17, by location of requesting hospital

	Red cell units requested, where the order specified:				
Location (city) of requesting hospital	Ro only (not intended for sickle cell disorder patients)	Both Ro and intended for sickle cell disorder patients	Intended for sickle cell disorder patients only (not Ro)	% of all Ro units requested here	% of all units for sickle cell disorder patients requested here
London	13,417	26,307	19,778	84%	83%
Manchester	1,161	667	519	4%	2%
Birmingham	157	973	1,022	2%	4%
Bristol	74	238	168	1%	1%
All others	2,033	2,189	3,791	9%	11%

Supply: issues and substitutions for Ro requests

As described in the previous section, just over half of the red cell units requested for patients with sickle cell disorder are Ro. These patients, however, also require a match for their ABO group, as well as for other lesser-known antigens to which they have already developed an antibody.

It can be difficult to match for all the different requirements and substitutions must be made. All substitutions of the ABO and Rh D subtypes that are made by NHS Blood and Transplant are safe substitutions.

For example, a patient with group A blood can receive blood from a group O donor. Similarly, patients who are Rh D positive can receive blood from an Rh D negative donor. The combination of group O and Rh D negative – O negative – is often described as the 'universal donor'.

Our records allow us to retrospectively identify requests for Ro red cells where only the ABO and/or Rh D group have been substituted (table 4). In more complex requests, where the complete set of requirements involving antigens outside of the ABO and Rh systems could not be met, the original order would be amended after discussion between NHS Blood and Transplant and the requesting hospital. These "substitutions" are not identifiable as such in retrospect.

The group most often substituted among Ro requests is B positive, where over half of requests are met with B negative instead. B negative blood is highly likely to come from White donors, meaning there is greater potential for substitutions to be required in other blood grouping systems (Kidd, Duffy, etc.) as well.

> *My pain is like a hammer breaking my bones when I am in a crisis.*

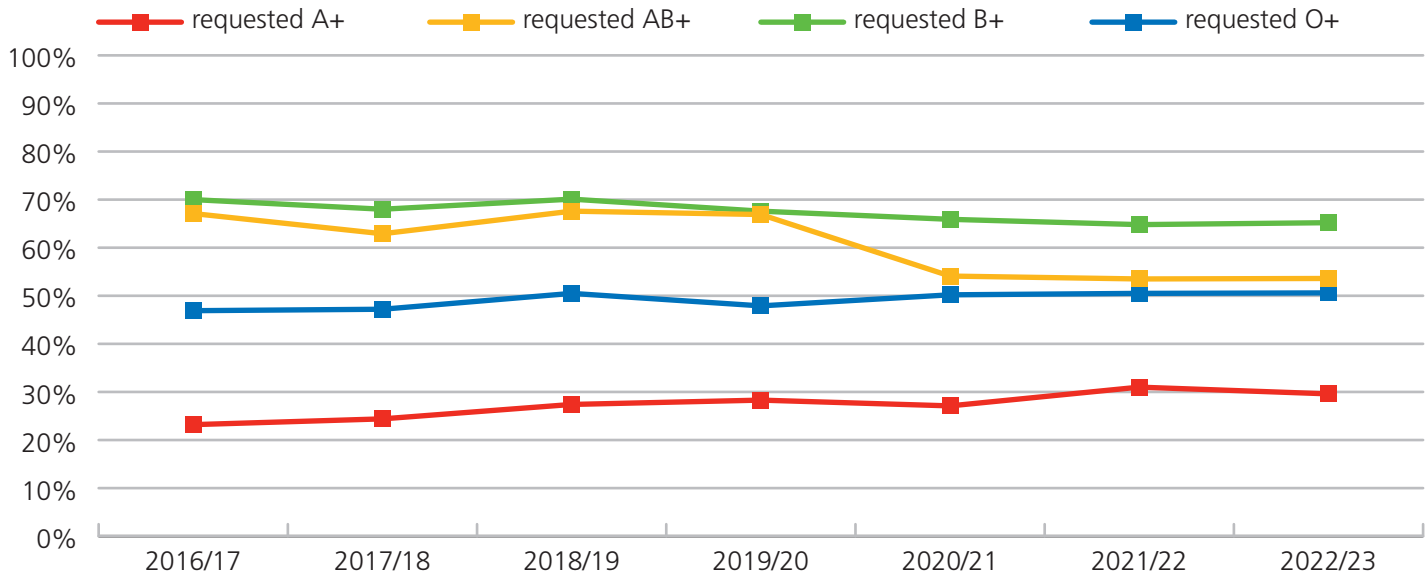
Table 6: ABO and Rh D substitutions applied to all Ro red cell requests from English hospitals in 2022/23 (green shading = no substitution)

Requested group	Total units requested	Issued group (% of requested units): O+	O-	A+	A-	B+	B-	AB+	AB-	not fulfilled*
O+	39,556	49.0%	50.6%							0.4%
A+	19,786	0.4%	1.0%	70.2%	28.1%					0.2%
B+	14,182	1.5%	7.0%			34.7%	56.7%			0.1%
AB+	2,000	0.4%	1.3%	18.3%	18.5%	0.3%	0.1%	46.0%	14.8%	0.5%

* Not *fulfilled* indicates cases where no suitable blood could be identified, requiring careful discussion about alternative management, such as postponing or cancelling the transfusion, or relaxing criteria on sickle cell requirements, such as the age of units.

The percentage of requests with ABO and/or Rh D substitutions has not changed significantly in the past three years (Figure 1).

Figure 1: % of requests with ABO and/or Rh D substitutions, by requested group – all requests from English hospitals for Ro red cell units, 2016/17 to 2022/23



For the subset of Ro units requested for patients with sickle cell disorder, the pattern of substitutions was similar to Ro units in general (Table 5) and has remained stable in recent years (Figure 2).

For example, for Ro units overall, 49.0 per cent of O positive requests were fulfilled with O positive units. For Ro units specifically required for sickle cell disorder patients, the corresponding figure was 51.3 per cent.

Once again, more than half of B positive Ro requests for sickle cell patients were instead substituted with B negative units.

Ensuring red cells transfused to patients with sickle cell disorder are closely matched is critical in improving health outcomes and reducing complications for patients. There are patients who have developed significant antibodies that make transfusion a high-risk intervention and there therefore may only be a limited number of units available that are suitable for transfusion.

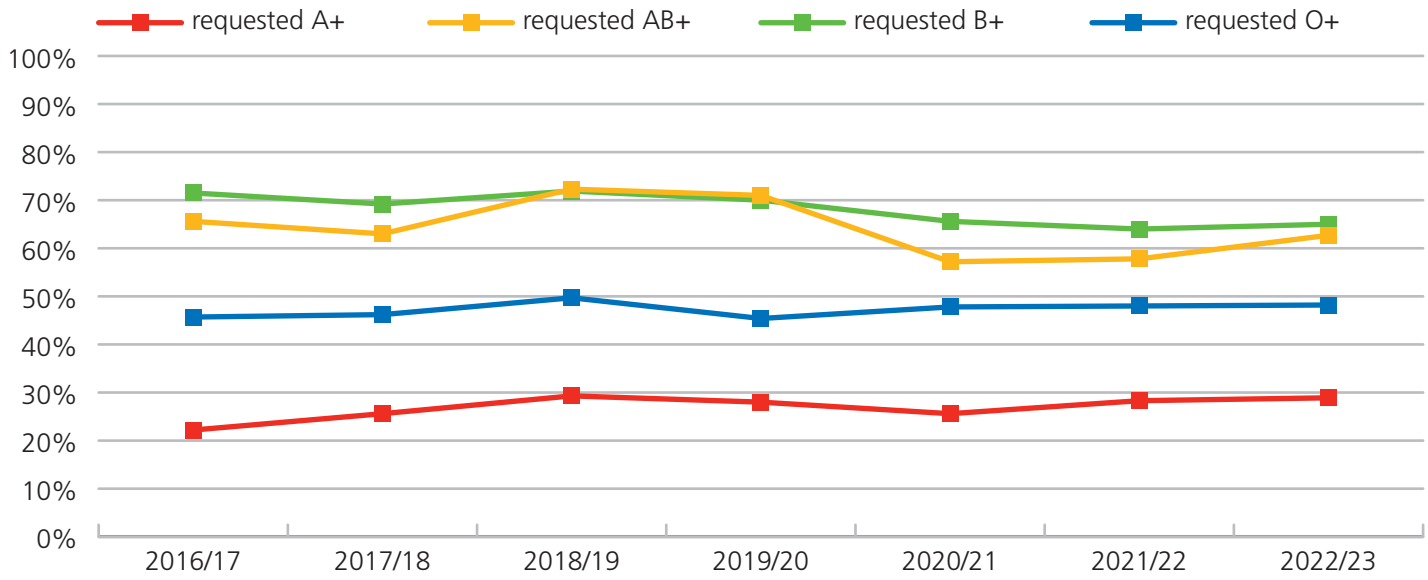
Ideally, fresh units will provide the best source of red cells, but when they are not available, the National Frozen Blood bank is a valuable resource for rare units.

As of July 2023, the National Frozen Blood Bank contained 1,072 frozen red cell units, the oldest red cell units having been collected in 2004.

Table 7: ABO and Rh D substitutions applied to all Ro red cell requests from English hospitals in 2022/23 for treatment of patients with sickle cell disorder (green shading = no substitution)

		Issued group (% of requested units):								
Requested group	Total units requested	O+	O-	A+	A-	B+	B-	AB+	AB-	not fulfilled
O+	24,413	51.3%	48.2%							0.5%
A+	13,105	0.3%	0.9%	70.9%	27.7%					0.2%
B+	8,982	1.8%	5.9%			35.0%	57.3%			< 0.1%
AB+	1,114	0.7%	0.5%	19.6%	24.8%	0.0%	0.0%	37.1%	17.1%	0.3%

Figure 2: % of requests with ABO and/or Rh D substitutions, by requested group – all requests from English hospitals for Ro red cell units for treatment of patients with sickle cell disorder, 2016/17 to 2022/23



Regular blood transfusions have given me back my life.

Donor base and donations

The Office for National Statistics has released Census data (Table 6) on the resident population in England by ethnic group and age group, as of 21 March 2021. People from Black African, Black Caribbean, or other Black backgrounds made up approximately 4.4 per cent of the total population of England in 2021. The proportion was very similar (4.9 per cent) in the subset of the population aged 17-65 (the age range within which people are eligible to start donating blood).

In 2017/18, people of Black heritage made up 2.1 per cent of those making their first donation (Table 8). By 2022/23, this figure more than doubled to 4.7 per cent of first-time donors being of Black heritage – closely matching the level of representation in the population.

Multiple NHS Blood and Transplant initiatives have contributed towards the increase in recruitment of Black donors. These include focused marketing activities, partnerships, media outreach and sustained drives from charities and community organisations. NHS Blood and Transplant also deliver a Community Grants Programme, which funds community organisations to promote blood donation in key geographical areas. In addition, there have been changes to policies on donation selection, which no longer automatically exclude donors who have had partners from sub-Saharan Africa (Landmark donation eligibility change for Black African heritage donors (www.blood.co.uk)).

The number of people of Black heritage among the NHS Blood and Transplant donor base (the number of people donating blood at least once in a year) has grown from 5,841 in 2016/17 to 12,872 in 2022/23 (Figure 3). Just under 800,000 people in total gave blood at least once in 2022/23, meaning Black donors made up 1.6 per cent of the overall donor base.

This group of donors tend to be relatively young (in 2022/23, 16 per cent of Black heritage donors were aged 17-24 and another 36 per cent were 25-34) and live mostly in London (52 per cent), the South East (10 per cent) and the West Midlands (10 per cent).

The number of Black heritage Ro blood donors donating for the first time has tripled, from 1,035 in 2016/17 to 3,012 in 2022/23 (Table 11). The size of the Black Ro donor base as a whole increased by around 50 per cent over the same period – from 3,047 to 7,223 (Table 12; Figure 4).

> *"I struggle to plan things in my life as I don't know when I will have the next crisis. It is so unpredictable: I will be fine then the next minute the pain will start."*

Meanwhile, the number of Ro donors from other ethnic backgrounds has remained relatively stable. Black Ro donors accounted for around 23 per cent of all Ro donations collected in 2022/23, up from 14 per cent in 2016/17. This increase in the proportion of Ro units coming from Black donors is important as these units are more likely to match for other blood group systems and could prevent future antibody formation and transfusion reactions, potentially benefitting all Black heritage patients as well as those with sickle cell disorder.

While this is encouraging, these findings should be interpreted with caution. Black donors tend to donate less frequently than other blood donors (typically, 1.5 donations per year, compared with 1.9 for Ro donors from other ethnic backgrounds), and the retention rate of first-time donors is lower – 44 per cent of Black Ro donors who donated for the first time in 2021/22 returned to donate again within 12 months, compared with 59 per cent of first-time Ro donors from the same period who were not Black.

The reasons that Black donors do not return are complex and include factors such as being more likely not to meet the haemoglobin (Hb) threshold. This experience can make Black donors reluctant to return. Other issues may include recent staffing challenges and late cancellations which may be discouraging for new donors.

Increasing blood donation from Black donors is critical for patients living with sickle cell disorder and gives access to red cells that are better matched for Ro and for the other high-risk blood groups that have a different prevalence in the generally White donor population. Despite successes in recruitment, NHS Blood and Transplant still needs an additional 12,000 new Black blood donors in 2023/24 to meet demand.

Table 8: ONS Census 2021 data on residents in England describing their ethnic group as "Black, Black British, African or Caribbean", by age group (ONS, 2023)

Age (years)	Black African	Black Caribbean	Other Black background	% of all residents in England
0 – 16	409,500	90,345	130,740	5.7%
17 – 25	225,615	71,275	39,305	5.6%
26 – 35	222,680	84,820	28,700	4.8%
36 – 45	248,025	77,425	26,565	5.3%
46 – 55	212,015	103,385	31,160	5.1%
56 – 65	104,215	108,345	26,705	3.8%
66 and over	46,425	83,845	10,640	1.4%
Adults aged 17 – 65	**1,012,550**	**445,250**	**152,435**	**4.9%**
Total, all ages	**1,468,475**	**619,440**	**293,815**	**4.4%**

Table 9: New Black donors donating for the first time, 2016/17 to 2022/23

Financial year	New Black donors making their first donation in this FY: Black African	Black Caribbean	Other Black background	Total new Black donors	Total new donors donating (all ethnic backgrounds)	Black donors as % of all new donors donating
2016/17	1,087	732	187	2,006	143,012	1.4%
2017/18	1,751	1,207	254	3,212	150,067	2.1%
2018/19	1,430	1,077	232	2,739	158,895	1.7%
2019/20	1,818	1,189	296	3,303	131,626	2.5%
2020/21	1,646	960	224	2,830	132,335	2.1%
2021/22	3,092	1,769	330	5,191	131,590	3.9%
2022/23	3,524	1,731	329	5,584	118,268	4.7%

Note: a small number of new Black donors donating in 2020/21 and 2021/22 may have donated plasma instead of whole blood as their first donation.

Table 10: Black whole blood donors – size and donation frequency of the donor base, 2016/17 to 2022/23

Financial year	Black African		Black Caribbean		Other Black background		Total Black donor base
	Donor base	Frequency	Donor base	Frequency	Donor base	Frequency	
2016/17	2,222	1.45	3,085	1.72	534	1.63	5,841
2017/18	2,980	1.40	3,560	1.65	653	1.62	7,193
2018/19	3,040	1.40	3,748	1.62	688	1.58	7,476
2019/20	3,686	1.42	4,043	1.63	775	1.56	8,504
2020/21	3,442	1.44	3,680	1.66	699	1.60	7,821
2021/22	5,424	1.41	5,088	1.63	904	1.54	11,416
2022/23	6,433	1.35	5,484	1.58	955	1.53	12,872

Donor base = the total number of donors donating at least once within a given period.
Frequency = average donations per donor during the period.

Table 11: New Ro Kell negative (K-) donors donating for the first time, 2016/17 to 2022/23

Financial year	New Ro K- donors making their first donation in this FY: Black African	Black Caribbean	Other Black background	Total new Black *Ro* K- donors	Total – all new *Ro* K- donors
2016/17	617	352	66	1,035	3,614
2017/18	999	535	115	1,649	4,266
2018/19	800	504	94	1,398	4,072
2019/20	1,056	581	140	1,777	4,177
2020/21	931	439	100	1,470	3,977
2021/22	1,788	851	134	2,773	5,261
2022/23	2,071	801	140	3,012	5,218

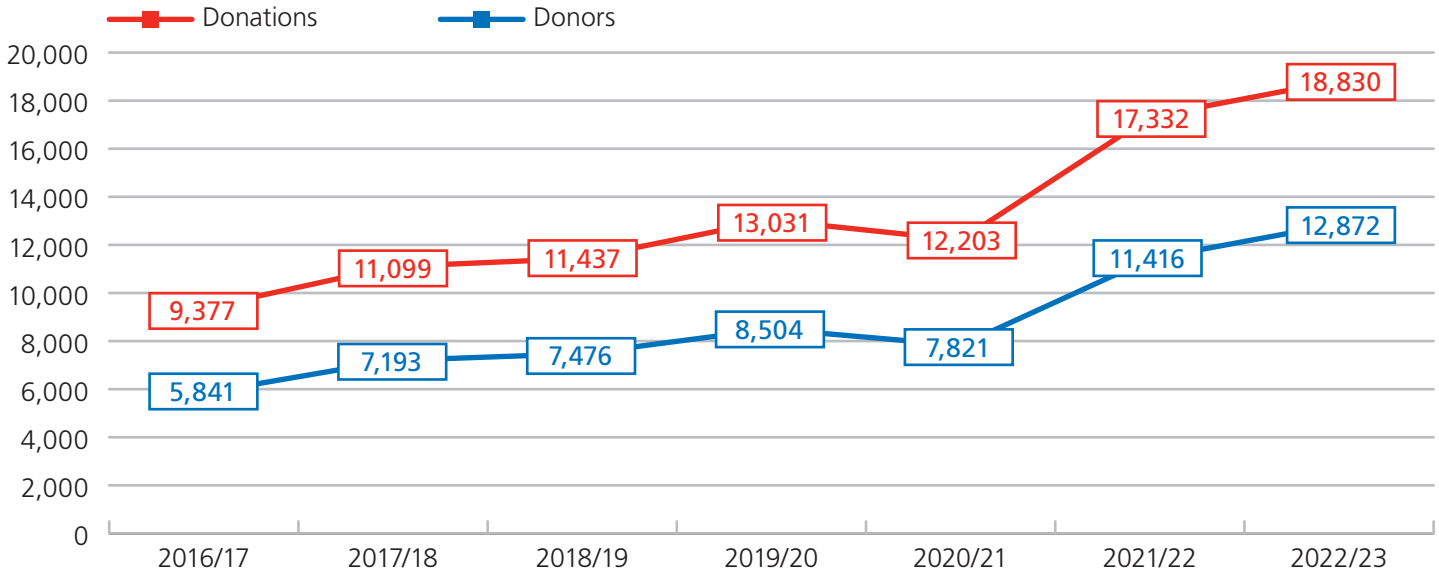
Note: a small number of new Ro K- donors donating in 2020/21 and 2021/22 may have donated plasma instead of whole blood as their first donation.

Table 12: Ro K- whole blood donors – size and donation frequency of the donorbase, 2016/17 to 2022/23

	Black *Ro* K- donors		All other *Ro* K- donors		% of all *Ro* K- donations given by Black donors
Financial year	Donor base	Frequency	Donor base	Frequency	
2016/17	3,047	1.62	15,626	1.94	14%
2017/18	3,794	1.57	15,561	1.91	17%
2018/19	4,040	1.54	16,677	1.86	17%
2019/20	4,788	1.56	18,053	1.91	18%
2020/21	4,451	1.59	17,631	1.95	17%
2021/22	6,303	1.56	18,538	1.92	22%
2022/23	7,223	1.49	18,991	1.94	23%

Donor base = the total number of donors donating at least once within a given period.
Frequency = average donations per donor during the period.

Figure 3: Black whole blood donors and donations – trends from 2016/17 to 2022/23



> *I had had three miscarriages and going onto an exchange transfusion programme for my last pregnancy has allowed me to have my baby.*

Figure 4: Black Ro K- whole blood donors and donations – trends from 2016/17 to 2022/23

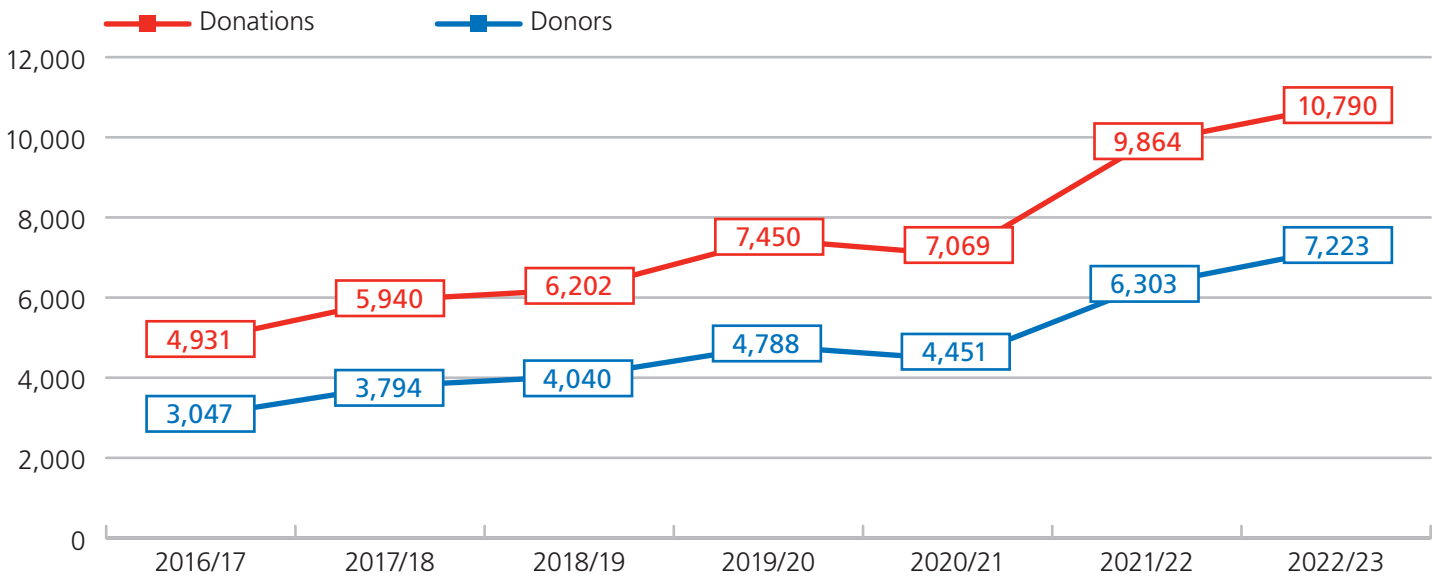


Table 14: Active donors with extended phenotyping information available, as of July 2023

	Black donors (N = 20,785)		All other donors (N = 1,420,921)	
Antigen	% of donors with known phenotype	% of tested donors who are negative for this antigen	% of donors with known phenotype	% of tested donors who are negative for this antigen
M	94.8%	26.6%	35.0%	19.7%
N	3.3%	23.9%	2.4%	29.9%
S	93.8%	72.1%	33.1%	48.9%
s	94.5%	7.2%	30.4%	9.5%
P1	1.4%	4.3%	3.4%	22.8%
Lua	25.3%	94.2%	6.9%	93.8%
Lub	5.4%	0.4%	11.9%	0.2%
K	99.9%	98.7%	99.9%	92.1%
k	2.8%	0.2%	7.2%	1.7%
Kp^a	28.8%	99.6%	8.3%	97.8%
Kp^b	6.8%	< 0.1%	14.8%	< 0.1%
Le^a	3.0%	80.3%	4.7%	77.6%
Le^b	3.0%	51.1%	3.5%	30.6%
Fy^a	94.4%	88.5%	28.1%	30.5%
Fy^b	94.3%	87.6%	27.0%	24.6%
Jk^a	95.1%	6.8%	35.7%	22.4%
Jk^b	95.0%	55.6%	35.5%	28.2%

Recruiting donors of Black heritage

People of Black heritage are much more likely to have the Ro blood type needed to treat the many people with sickle cell, which mostly affects people of Black heritage. With growing demand from hospitals, it is NHS Blood and Transplant's strategic priority to recruit more donors of Black heritage.

The shortage of Black donors means some Black patients may not always be able to get the best-matched blood. NHS Blood and Transplant needs donors from all ethnic backgrounds to come and donate, as patients of all blood types and subtypes will need blood at some point.

In the past, many patients with sickle cell had intermittent top-up blood transfusions. However, more patients have been identified as benefiting from regular full exchange transfusions. This is where all their deformed red blood cells are gradually filtered out and replaced with healthy donor blood. This complete blood transfusion requires a lot more blood, and that blood must be closely matched to prevent the risk of transfusion reactions building up over time.

Summary

Sickle cell disorder is a lifelong genetic condition that results in abnormally shaped red blood cells. The shape of these cells can lead to episodes of severe pain, known as crises, as well as long-term damage to organs, such as the brain, lungs, and kidneys.

It is by far most prevalent in people of Black African and Black Caribbean heritage, occurring in around 1 in every 140 and 1 in every 200 babies of Black African and Black Caribbean heritage, respectively, of those tested in 2019/20.

There are very few treatments available for patients living with sickle cell disorder, with blood transfusion therapy used both as preventative and emergency life-saving treatment.

Blood transfusion practice for sickle cell disorder has improved in the last decade and increased use and availability of automated red cell apheresis exchange transfusions have been among improvements made to blood transfusion practice for sickle cell disorder in the last decade.

These treatments, however, require a greater number of red cell units compared to other treatments and have led to a rise in demand for blood used in sickle cell disorder transfusion, with requests rising by more than 50 per cent between 2016/17 and 2021/22.

Ensuring red cells transfused to patients with sickle cell disorder are closely matched is critical in improving health outcomes and reducing complications for patients.

Just over half of the red cell units requested for patients with sickle cell disorder are Ro subtype, the most common subtype found in patients of Black heritage.

For other blood grouping systems, such as Kidd or Duffy, red cells from donors of Black heritage are more likely to match the patient's group, which should reduce the risk that new antibodies will be formed.

The number of Black heritage Ro blood donors donating for the first time has tripled, from 1,035 in 2016/17 to 3,012 in 2022/23, contributing to an increase of around 50 per cent in the size of the Black Ro donor base.

Increasing blood donation from Black donors is critical for patients living with sickle cell disorder and gives access to red cells that are better matched for Ro and for the other high-risk blood groups that have a different prevalence in the generally White donor population.

Donor story

Lloyd is one of London's most prolific Black blood donors, having donated more than 150 times. He carries the Ro subtype needed to help treat patients with sickle cell.

A coroner's officer and former detective, Lloyd started donating in 1976, at a session in the city of London.

He said: "I am aware there is a shortage of Black donors, particularly to help people with sickle cell disorder.

"I know some people are reticent and there is some fear of the needle and giving blood, but by donating you can save a life, plain and simple.

"You can give somebody else the opportunity you have got. It's also really interesting to get the text message saying where the blood has gone."

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