

TOGETHER FOR BETTER

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The very first State of the Registry review showcases the work, achievements and impact of the alignment of all the UK registers for UK transplant centres: a single registry known as the Anthony Nolan and NHS Stem Cell Registry.

This alignment was part of delivering recommendations from the UK Stem Cell Strategic Forum in July 2010. The final piece of the jigsaw was completed in September 2013 when the Welsh Bone Marrow Donor Registry (WBMDR) came on board.

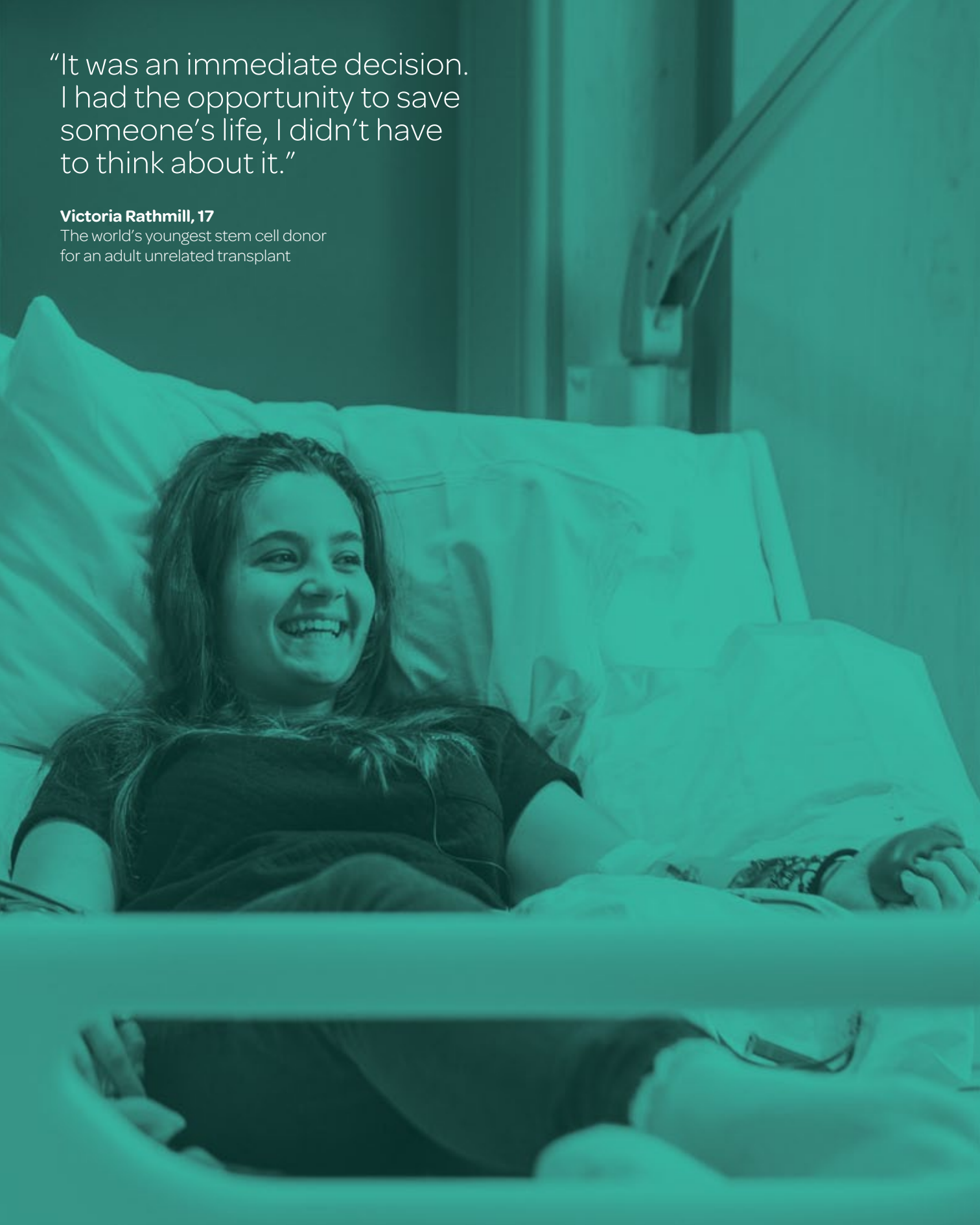
This report, aimed at internal and external audiences such as UK transplant centres, policy decision makers, potential funders and the media, is the first publicly available material to promote the collaboration and the first time the data from 2013 will be published. It is intended that this will be an annual publication.

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“It was an immediate decision. I had the opportunity to save someone’s life, I didn’t have to think about it.”

Victoria Rathmill, 17

The world’s youngest stem cell donor for an adult unrelated transplant



FOREWORD

The progress of stem cell transplantation is a major medical achievement, offering hope to patients with blood cancers and other blood disorders where other treatments have failed. The science enables the damaged immune system to be wiped out and a healthy immune system regrown from the building blocks in bone marrow or cord blood. But the transplanted cells must be a match for patients – and with our genetic code meaning that there are millions of differences between our blood stem cells, finding a compatible type is challenging.

Around a third of patients in the UK are able to secure a transplant from a close relative. The rest rely on the kindness of a stranger and the Anthony Nolan and NHS Stem Cell Registry to support their clinical team in finding that precious match. For many patients, speed is absolutely vital: we know that accelerating the process is critical to improving transplant outcomes.

A single search of the Anthony Nolan and NHS Stem Cell Registry now covers every stem cell donor and publicly banked cord blood unit available for transplant in the UK. Furthermore, the journey to transplant is becoming more rapid thanks to greater investment in detailed typing of high-demand donors as they are recruited to the Registry.

Each organisation is using its unique strengths to continue to recruit donors and collect cord blood units to meet the current demand, so that we can have equal access to transplants for all patients in the UK delivered through a sustainable, affordable and effective care pathway.

The partnership between the NHS and the voluntary sector that is making this possible should be celebrated. I warmly welcome this State of the Registry review, both as a marker for what we are able to offer patients in the UK today and as a measure of further progress we can make in saving even more lives in the future.

Jane Ellison MP
Parliamentary Under Secretary
of State for Public Health

INTRODUCTION: THE STATE OF THE REGISTRY IN 2014

We are delighted to publish this first State of the Registry review: a milestone on our journey towards being able to provide a stem cell transplant for every patient in the UK who needs one.

The historic collaboration of all the partner organisations in stem cell provision, across sectors and locations, is a great example of what can be achieved when people work together towards a shared goal.

In September 2013 we were able to put the final pieces of the jigsaw in place to fully align all our UK registers: Anthony Nolan, NHS Blood and Transplant and the Welsh Blood Service. This means that when a sick patient urgently needs an unrelated stem cell transplant, doctors in any UK stem cell transplant centre can search all the UK registered donors and cord blood units for matching stem cells at once, saving time and avoiding duplication.

We would like to thank everyone involved in making this possible, but we especially want to recognise the generosity of the many healthy men and women who last year helped to save the lives of hundreds of strangers following selection from the Registry. They truly are heroes.

The UK Stem Cell Strategic Forum set out a range of measures in 2010 to improve the performance of UK registers, meeting the needs of UK patients and saving an extra 200 lives each year through stem cell transplant.

This alignment of the registers, now known as the Anthony Nolan and NHS Stem Cell Registry, allows us to see the full picture of potential donors in the UK today, vital in ensuring the optimum composition of the Registry matching the UK population as a whole. It is also crucial in

helping each recruiting organisation use its unique position to best direct its resources where there is further potential for the Registry to grow.

Investing in a sustainable UK source of donors means that bone marrow and cord blood stem cell transplants are becoming much better value for the NHS and the taxpayer. Our commitment to reducing the time between a search and a transplant going ahead is making a significant difference.

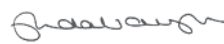
We are giving transplant centres every reason to 'buy British', reducing our need to import more expensive stem cells. Sharing donor information will help us learn more about genetic patterns that help us recruit the right selection of potential donors, and will make finding a match much easier.

While this is real progress, we must not lose momentum. Patients still die because a donor match cannot be found in time to offer them a transplant. And we know that this tragic outcome disproportionately affects patients from black, Asian and minority ethnic (BAME) backgrounds.

We look forward to a time when, thanks to the success of this collaboration in creating a single Registry for UK transplant centres to access, even more lives will be saved.



Henny Braund
Chief Executive
Anthony Nolan



Lynda Hamlyn CBE
Chief Executive
NHS Blood and Transplant



A BRIEF HISTORY OF STEM CELL TRANSPLANT

Around 1,800 people in the UK need a bone marrow or stem cell transplant each year. This is usually their last chance of survival.

Bone marrow transplant is used to treat:

- Severe aplastic anaemia (bone marrow failure)
- Leukaemia (cancer of the white blood cells)
- Non-Hodgkin's Lymphoma (cancer of the lymphatic system)
- Certain genetic blood and immune system disorders (e.g. sickle cell anaemia, thalassemia, and some severe immune system diseases)

Stem cell transplants are usually recommended for patients whose disease has not responded adequately to other forms of treatment, or has a low probability of long-term cure with other treatment alone. In each individual case, the decision to transplant is based on the risks of the disease weighed against the risks of transplant complications.

In the earliest days stem cell transplants were only undertaken in children and younger adults due to the high risk of complications in older transplant recipients. However, advances in several aspects of transplant care now mean that age is no longer a defining factor, and older patients can now be offered a stem cell transplant providing they are in good general health.

SOURCES OF STEM CELLS

Clinicians assess a wide variety of factors when considering a patient's treatment options with haematopoietic stem cell transplant (HSCT). This includes the patient's disease indication, how advanced or aggressive their disease is, the patient's general health and suitability for transplant, and how quickly the transplant needs to take place. These factors will also influence where clinicians will choose to source the stem cells for the transplant.

Each year, around 60% of all HSCT are autologous – using the patient's own stem cells. The other 40% of transplants are allogeneic, using stem cells from a related donor (30%), or in the majority of cases (70%) from an unrelated adult donor or cord blood unit (CBU).

When an unrelated donor or CBU is required, the patient's team initiates a search through the Anthony Nolan and NHS Stem Cell Registry. The Registry accesses the combined database of the Anthony Nolan, British Bone Marrow Registry, Welsh Bone Marrow Donor Registry, Delete Blood Cancer, Scottish National Blood Transfusion Service and Northern Ireland Blood Transfusion Service adult volunteer donors and CBUs. Anthony Nolan will also conduct a search of international registers, representing a global donor database of over 22 million adult donors and around 500,000 publicly available CBUs.

Adult stem cell donations are collected from the blood or bone marrow of registered volunteers as need occurs, while cord blood units are preserved from the collection shortly after birth of the stem cell rich blood drained from the umbilical cord, which is usually discarded. Stem cell transplants are only available thanks to the generosity of donors and the trust they place in Anthony Nolan and the NHS to use their gift well.

Choosing between an adult donor and cord blood depends on a number of factors. In most cases, a suitable matched adult donor will be preferred, particularly for adult patients. This is because a donation from an adult donor will normally provide a larger cell dose, helping to speed up the engraftment process. However, if a matched adult donor is not found, the transplant needs to take place very quickly or the outcome may be judged to be better, a CBU may be selected.

CBUs are available off the shelf, and good patient outcomes can be achieved even if the CBU and patient are not perfectly matched.

RECENT HISTORY OF UK STEM CELL SUPPLY

In 2010, the Health Minister asked NHS Blood and Transplant to bring together a wide group of stakeholders to form the UK Stem Cell Strategic Forum, to consider the future of unrelated donor stem cell transplantation in the UK. The Forum's report was endorsed and published by the Department of Health in July 2010.

The report set out a strategy to save an additional 200 lives each year by increasing the UK inventory of cord blood donations, and by improving the performance of the UK-based stem cell registers to match the best in the world. It was noted that this bold vision would take time to realise, but that the recurring clinical and economic benefits would be substantial.

Among the recommendations of the 2010 Stem Cell Strategic Forum (SCSF) Report, there was recognition of the need to:

- Shorten the time from donor search to transplant to improve patient survival
- Increase access to treatment and address the unmet need for transplant, particularly in the black, Asian and minority ethnic (BAME) population, by increasing the availability of stem cell donations
- Reduce the cost to the NHS of procuring stem cell donations.

ACHIEVEMENTS SO FAR

Following the publication of the 2010 SCSF report, the ongoing strategic implementation of the report's findings has been overseen by the UK Stem Cell Oversight Committee, with a number of working groups supporting the implementation of the recommendations. The original call for funding in the 2010 report was for £50m to achieve all the aims of the report.

Since 2011-12, £4m a year has been committed by the Department of Health. This has been invested in the alignment of the registers, better tissue typing of those on the Registry and an acceleration of cord blood collection and banking. The principal achievements to date are:

- The alignment of all the UK registers, to create the Anthony Nolan and NHS Stem Cell Registry. The joint working that brought together the registers have enabled best practice to be shared and a focus on improving turnaround times, provision of typing samples, better donor retention plus lower attrition rates and updating donor contact details. We have collectively been able to improve on our key performance indicators so that the UK Registry is now equal to or better than the best registries in the world. Together with other achievements, this has resulted in a reduction in the time from search to provision: a critical factor in improving patient survival rates.
- Increased quality of donor panels, by expanding the Fit Panels of younger male donors (who are preferred by transplant centres) typed to a very high resolution. These panels consist of people who are likely to be able to donate and are prospectively tissue typed to high resolution, enabling the closest match for a patient to be selected sooner (saving time in the lead up to transplant). This panel is currently 50,000 strong and growing, and such donors are eight times more likely to go on to be a final donor for a patient than the rest of the donor panel. Before 2011, UK donor registers were losing out to overseas registers in the provision of unrelated donors to UK transplant centres, with a year on year declining market share.

Since the alignment this loss of market share has been halted and gradually reversed, as UK transplant centres increasingly recognise the improved quality of the UK donor panel. This is good news, as UK donors are more affordable and are making a valuable saving for the NHS.

- The acceleration of cord blood collection. A UK inventory of 50,000 CBUs suitable for transplant, as recommended in the SCSF report, will enable matches for over 90% of the population. Funding has been used to expand to 24/7 collections in eight existing collection sites and open an additional site at University College Hospital. All sites were selected for their high birth rate and diverse ethnic population, ensuring the greatest tissue type diversity of the cord blood collections.

The rate of cord blood collection has tripled compared to the steady state in 2011. The rate of patient use has increased as the quality of the inventory has improved. In 2011 the UK accounted for less than 5% of the cords used in UK transplants with the rest being imported, at great expense to the NHS, from overseas public cord banks. This year (2014) over 25% of UK cord provision will come from the UK. This benefits patients as UK supply is quicker and more reliable, and benefits the NHS as UK CBUs are on average less than half the price of imported CBUs.

TURNAROUND TIMES

For patients, speed matters. We know that for many people requiring a stem cell transplant, especially those with acute leukaemia, days count. That is why the partners in the Anthony Nolan and NHS Stem Cell Registry have worked hard to identify how to speed up our service and reduce the turnaround time between the search for a donor and stem cells being available and ready for transplant. It's a genuine collaboration, combining the strengths and diversities of our organisations to find the best solutions to the challenges we face.

STAYING IN TOUCH

Both our organisations are about partnership on many levels: the relationship between potential donors and their respective registers is a vital one that both organisations have worked to strengthen. We want all donors to be aware of the life-enhancing and lifesaving gift of donation they may be called upon to give, and to be ready for that letter or call when we have found them to be a successful match. "Update your details" campaigns have seen very high response rates.

PROGRESS IN PROVISION AND RECRUITMENT

Blood sample provision, the essential precursor to any unrelated blood stem cell transplant, is nine days faster today than in 2010. NHS investment in creating a Fit Panel of donors (discussed in more detail elsewhere in this report) focuses on recruiting the right donors to the register.

In 2010, Anthony Nolan revolutionised the way potential donors can sign up to the register by introducing a quick and simple saliva test. A high quality sample for tissue typing offered an additional benefit in that it did not need to be processed as quickly as a blood sample.

NHS Blood and Transplant and the Welsh Blood Service make it simple for those who have already committed to donating blood to join a bone marrow register by taking an extra blood sample for typing from interested volunteers during their usual blood donation session. Recruitment information is targeted towards donors whose information suggests they are most likely to meet unmet need for transplant in the UK.

MOVING FORWARD

The future of stem cell therapy is very exciting, with considerable advances in technology made in just the last few years. The potential for cord blood stem cells continues to increase; a number of clinical trials on cord blood expansion are coming to fruition, addressing the major challenge of cell dose and speed of engraftment in cord blood transplants.

Advance cellular molecular therapies using cord blood and adult derived stem cells for regenerative medicine, immunotherapy and tissue repair are also developing rapidly. Next Generation Sequencing (NGS) is now being rolled out, allowing molecular level high resolution and high speed HLA tissue typing, which results in better matching between donor and patient and improved speed to transplant as well as better transplant outcomes.

Together we have made real and quantifiable progress on the original recommendations of the 2010 SCSF Report, which is translating into more lives saved. However, in a fast moving landscape of clinical advances and better understanding of the strategic developments in the field of HSCT, the Stem Cell Oversight Committee recognises the need to refresh areas of the original strategy. In particular there is a need to revisit the stem cell supply side, and consider the size and composition of both the adult unrelated donor panel and the cord blood inventory. Since the 2010 report, the cell dose threshold of cords we process for patient use has been raised to match our supply to clinical demand. This was in recognition of the fact that over 75% of cords being used globally are selected from the top 25% of the inventory measured by cell dose.

The success of the Fit Panels has also exceeded expectations, and we recognise the critical importance of recruiting young donors and typing them to high resolution. The development of high quality donor panels and cord inventory is more expensive, but the evidence is clear that the utilisation rate increases with quality. Therefore the Stem Cell Supply Working Group, in partnership with a team of Department of Health analysts, is currently refreshing the strategy for stem cell

supply with a comprehensive review of the health economic analysis. The group expects to report by June 2014.

It is anticipated the report will recognise the importance of investment in refreshing the existing donor panel with young donors, typed to a high resolution, to improve the overall quality of the UK Registry. To achieve this, we need to invest in NGS to allow high volume molecular level typing of our donors; continued targeted recruitment of young diverse donors; better retention strategies to reduce donor attrition and ensure donor availability; and to continue development of our IT infrastructure.

The report will also consider carefully the balance between the size and quality of the cord blood inventory to help reduce the unmet need, and reduce the reliance on overseas cord imports.

The number of unrelated HSCT taking place in the UK is increasing year on year. As clinical techniques improve and we have a better understanding of the critical factors in selecting the best stem cell source for a patient, we can see a widening of access for more patients. The numbers of adult patients receiving cord blood grows steadily as conditioning regimes improve and cell dose is increased through the use of double cord transplants.

Patients who would not have previously been considered eligible for transplant are now being successfully treated. There is growing evidence that BAME patients' chances of receiving a transplant have increased substantially since 2011. The range of disease indications that are now being successfully treated through stem cell transplantation has also increased.

We have improved considerably on the data gathering of transplant outcomes which helps us develop our future strategy, but we still have a long way to go. Currently most of the data we have is based on patients who have been selected for transplantation and the outcome of their transplants. We need to develop better data capture to understand the earlier stages of the patient pathway so we can better understand the unmet need.

A BRIEF HISTORY OF STEM CELL TRANSPLANT



“I would 100% recommend it to other people. It’s comfortable, painless and so worthwhile.”

Zachary Hughes, 23

A Fit Panel member in Leicester



THE REGISTRY TODAY

The demographic data for 2013 paints an interesting picture of the year, and of the Anthony Nolan and NHS Stem Cell Registry to date.

In 2013, 367 UK patients were helped by UK donors. This is a 7% increase when compared to the previous year when 343 were helped. It also shows that UK transplant centres have access to, and are choosing, well-matched home-grown donors for those in need.

Among the key statistics relating to potential donors added to the Registry during this year (NHSBT and AN figures):

- 41 % of potential donors were male and 59 % female
- The most common age of new recruits to the Registry was 19 years old
- A total of 60% of umbilical cords banked were from Northern European mums, and 40% of those were from mums from ethnic minorities.

There are 894,714 potential donors listed on the Anthony Nolan and NHS Stem Cell Registry. The age data is divided into two categories: 16-30 and 31-60. Those under the age of 30 are preferential for transplant centres, so their recruitment is measured as a key performance indicator. Those on the Registry range in age from 16-60, with the average age being 40. Encouragingly, the average age of new donors added to the Registry in 2013 was 24.

Across the Registry young men aged 16-30 made up 10% of the potential donors, with women aged 31-60 making up 45%. There is still a need to focus on actively recruiting men, as we know that they are most likely to be chosen by transplant centres. While recruitment of male potential donors in 2013 was strong, there is still work to be done.

As would be expected, the ethnicity data reveals that the majority of potential donors on the Registry fall into the Northern European category.

Almost 25% of potential donors are from ethnic minorities: but there is still progress to be made in this area, as there remains a gap between the provision of cells for Northern European patients and those patients from ethnic minorities.

In terms of a regional spread, the Registry is generally in line with the most recent census breakdown (2011). It is clear that there is a large proportion in the North of the country (a remnant of historic donor recruitment activity), but this is being addressed with more balanced recruitment activity.

The demand for cord blood stem cells continues to increase, with 2013 seeing a 20% increase in the use of cords for UK patients in comparison to 2012.

Over the years, potential donors on the Registry have been tissue typed (HLA typed) to varying levels. The highest level of typing (with a combination of six HLA alleles) makes up 6.7 % of the total Registry. However, with the next level of five combinations at 21.7%, well over a quarter of those on the Registry are well-typed.

Out of nearly 2,000 searches conducted, around 50% of searches result in a patient receiving a donation of bone marrow, peripheral blood stem cells (PBSC) or cord blood.

The success of the donor Fit Panels, one of the key recommendations of the UK Stem Cell Strategic Forum, has exceeded expectations. The panels have grown, and these donors have been typed to a very high level. A third of all UK donors to UK patients in 2013 were Fit Panel members, despite only representing one-fifth of the Registry.

Overall, this data demonstrates how the Registry is developing by increasing the recruitment of young people who are more likely to be called upon to donate, addressing the need for more BAME donors and growing the potential of the relatively new area of cord collection.

CASE STUDY

“I would do it again. It’s something people should get involved in – they might never get the call but if they do, they could be saving someone’s life.”

Andrew

Andrew Parry, 23, is a Survival Equipment Fitter at RAF Brize Norton and a Fit Panel member. He signed up in July 2011 and donated in August the same year.

“A sergeant here at Brize Norton had had cancer and needed help from Anthony Nolan. He held a recruitment event, and that’s how I got involved.

“I just thought it could be my chance to save someone’s life... I thought, I can do something above and beyond and actually help someone.

“It was only a couple of months after that I got the letter through saying I was a match. My first reaction was, ‘Oh God’. There was a little bit of shock – not because I didn’t want to do it, but because I just wasn’t expecting it.

“Anthony Nolan asked me if I wanted to continue and said that I needed to go through more tests to see how much of a match I was.

“I spoke to the sergeant here and told him what had happened. He said ‘Look, it’s completely up to you, but I got help through [Anthony Nolan] and I’m still alive now because of someone else who was in your position’. I thought ‘well, I might as well go through with it and see what happens next’.

“After giving some blood samples I got another letter from Anthony Nolan saying I was enough of a match, and that if I was still prepared to go ahead they would arrange for me to go down to London. Work gave me light duties either side of the donation to make it easier for me and let my body recover.

“The sergeant was really supportive. He gave me loads of advice and helped me get the time off I needed to donate. While I was getting my fourth injection I was thinking: this is it, tomorrow I’m donating!

“The donation itself was a bit nerve-racking. It isn’t too painful, but the problem is that I have a fear of needles!

“I would do it again. I think it’s a worthwhile thing to do. It’s something people should get involved in – they might never get the call but if they do, they could be saving someone’s life.

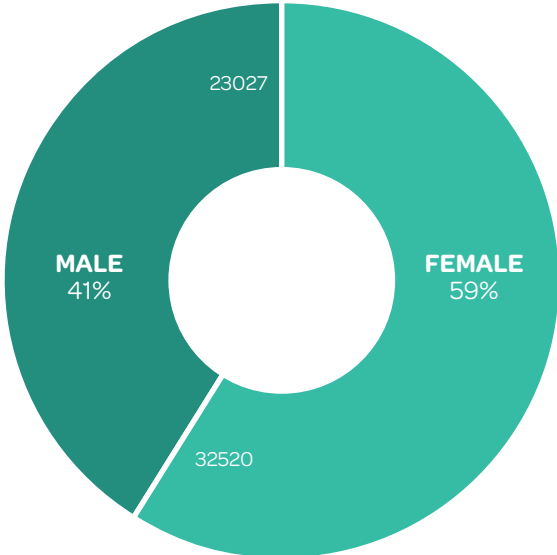
“People should definitely do it. Even with a fear of needles, it’s pretty painless. And afterwards you get some scones, which is nice.”



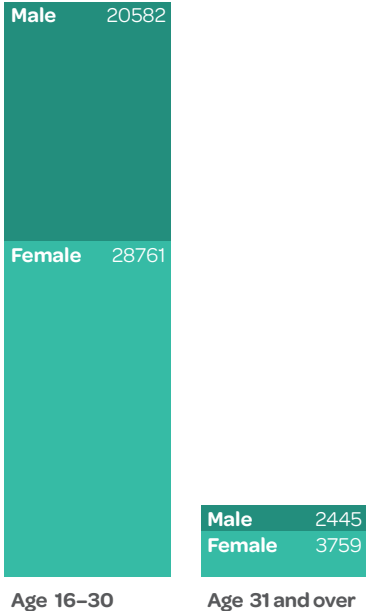
ALIGNED REGISTRY DEMOGRAPHICS

NEW DONORS MADE ACTIVE IN CALENDAR YEAR 2013 – ANTHONY NOLAN AND NHSBT FIGURES

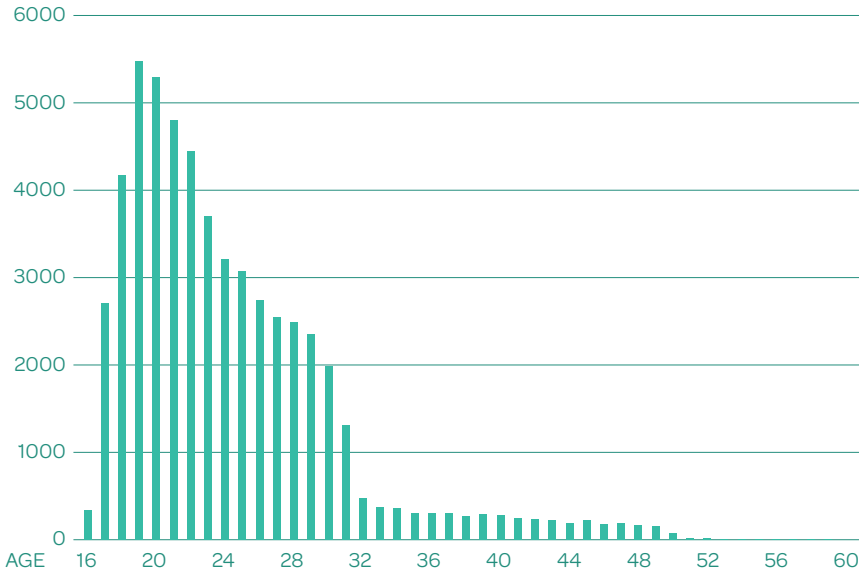
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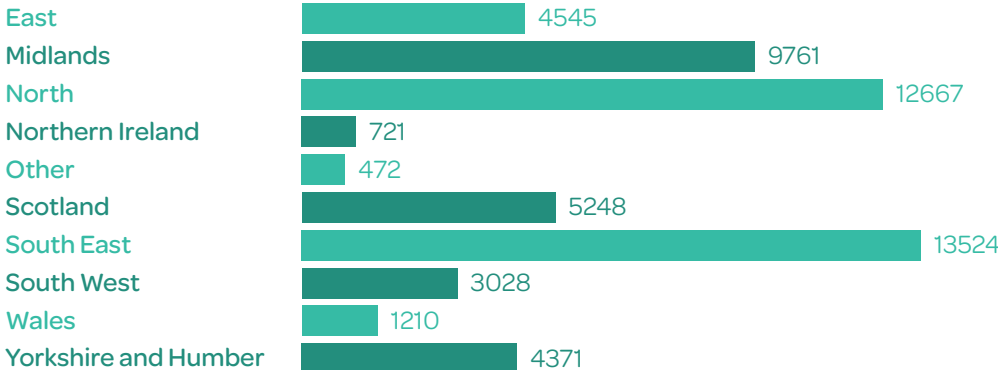
AGE & GENDER



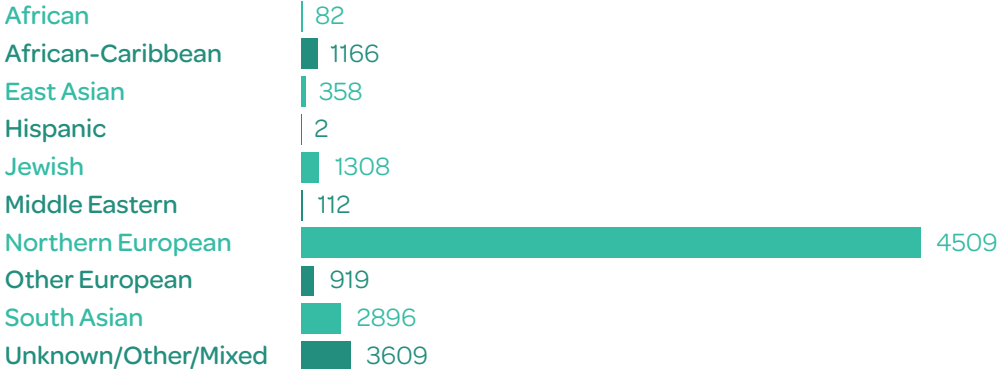
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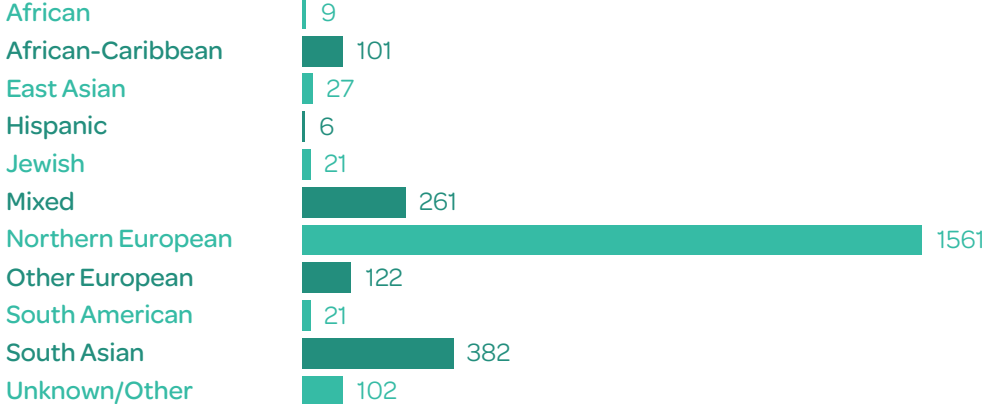
REGIONAL



ETHNICITY



AVAILABLE CORD BY ETHNICITY



“All I would say to other people is you should definitely sign up. I just hope I’ve helped – that’s the most important thing.”

Victoria

Victoria Rathmill, from Macclesfield, is the world’s youngest stem cell donor for an adult unrelated transplant at 17. Having signed up aged 16, she donated in November 2013.

“Anthony Nolan came into school and gave a presentation about how people need stem cell treatments. I was like ‘I’ll join when I’m 18, I’m not going to make any difference’. But then our family friend got leukaemia and it kind of hit home how serious it actually was, so I felt the need to join up.

“He was about 18 and managed to get a transplant from Germany, and he’s alright now. His family all know that he’s the reason I signed up.

“Before they came in I had the impression of, you know, ‘ooh, big needles, big operation’, but they spoke about doing it with stem cells instead and it didn’t seem that difficult.

“I signed up a few weeks later. I sent off a spit sample but for some reason my spit sample didn’t want to co-operate, so I had to send a blood sample off instead. So it was March or April by the time I was able to sign up and be placed on the register.

“After that I just stopped thinking about it. You know you’re on the register, but you don’t expect to get the phone call within six months of signing up. It just went to the back of my mind.

“My mum was taken aback initially, but she thought it was a nice thing for me to do, especially after what had happened with our family friend.

She also thought that it wouldn’t come up until some time in the future.

“I got the call around the beginning of October – a text asking me to ring them. I was in a history class, so for the rest of it I was panicking because I had an idea what it was about.

“The first person I called was my mum. Then I phoned Anthony Nolan, and the woman I spoke to said I might be a possible match and would I be willing to send a blood sample. I just said ‘yep, that’s fine’.

“It was an immediate decision. I had the opportunity to save someone’s life, I didn’t have to think about it. I wasn’t expecting it, and I was a little scared but I was excited for what it meant.

“I went down to London for a medical to make sure I was fit and healthy. It was my first trip to London without other people. Me and my dad got the tube map out and worked out exactly where I needed to go.

“All I would say to other people is you should definitely sign up. It’s not as difficult as you expect it to be and not as bad as some people make out.

“I’d like to meet him or her one day. If they write a letter to me I’d be happy to write one back, but if they don’t that’s OK. I just hope they’re getting better and that I’ve helped – that’s the most important thing.”

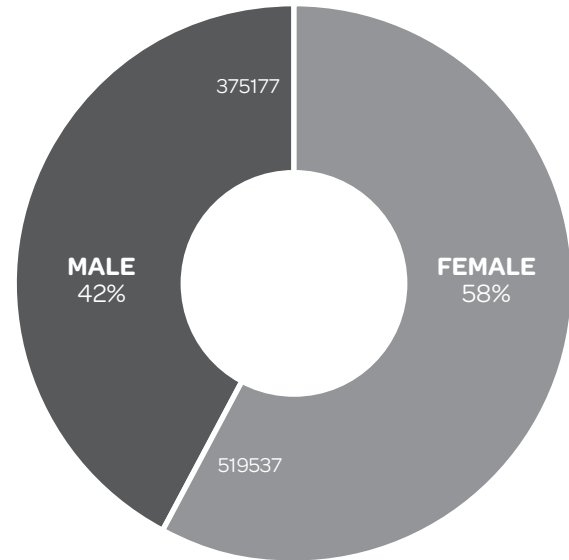


ALIGNED REGISTRY DEMOGRAPHICS

ANTHONY NOLAN / NHSBT / DBC / WBMDR REGISTER FIGURES AS OF 31/12/2013

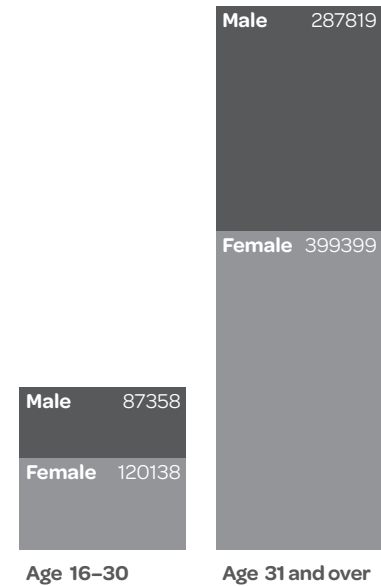
GENDER

ANTHONY NOLAN / NHSBT / DBC / WBMDR



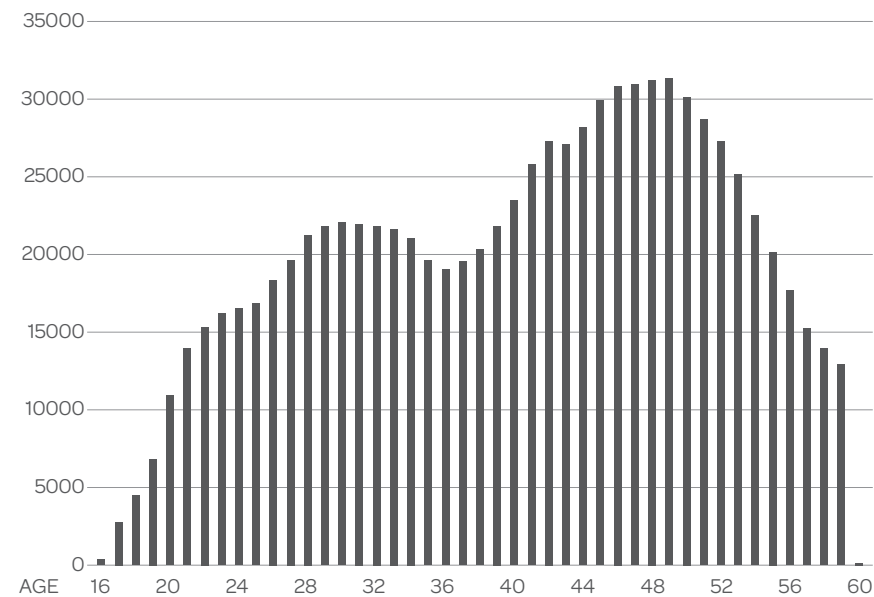
AGE & GENDER

ANTHONY NOLAN / NHSBT / DBC / WBMDR



AGE

ANTHONY NOLAN / NHSBT / DBC / WBMDR



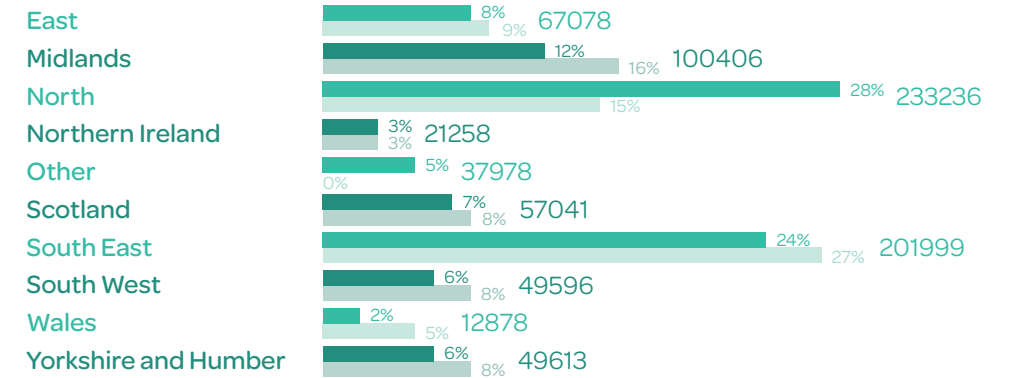
KEY

- ANTHONY NOLAN & NHSBT only
- All UK Registries
- UK census 2011

REGIONAL

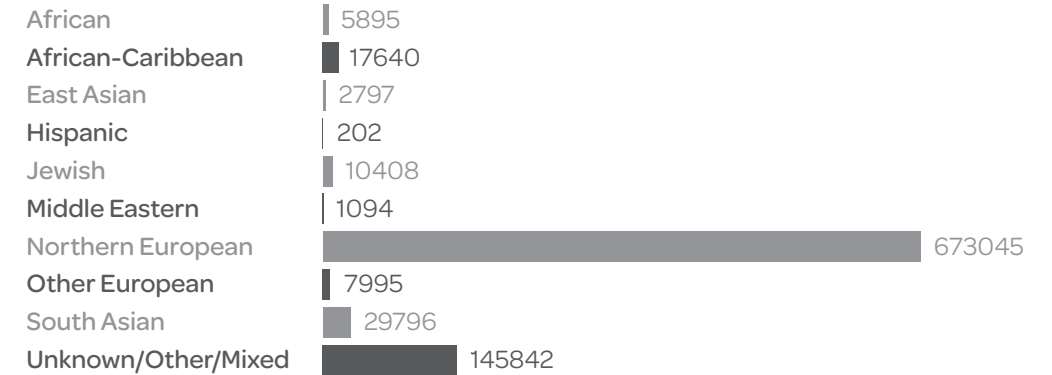
ANTHONY NOLAN / NHSBT

Compared with UK 2011 census for population spread



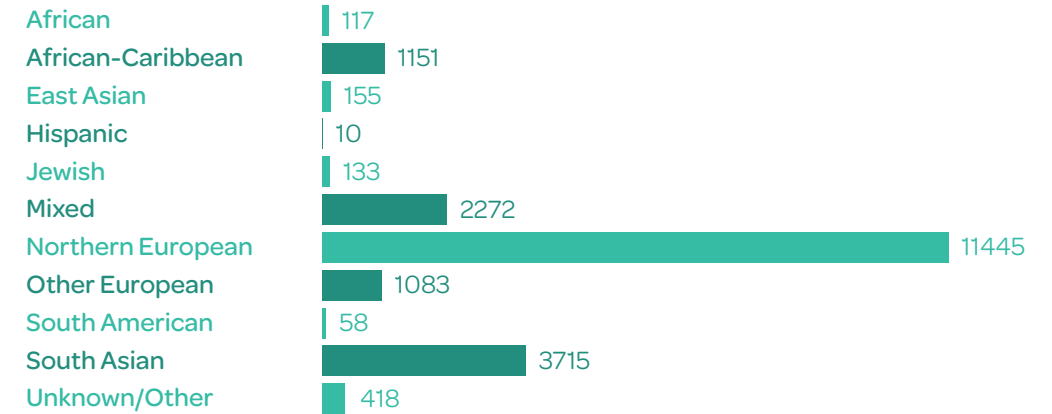
ETHNICITY

ANTHONY NOLAN / NHSBT / DBC / WBMDR



AVAILABLE CORD BY ETHNICITY

ANTHONY NOLAN / NHSBT



CASE STUDY

“My family and friends and work colleagues were very proud. Now I put it in my CV, because I think it’s one of the best things I’ve done and I want people to know about it and sign up themselves.”

Zach

Zachary Hughes, 23, is a Fit Panel member in Leicester. He signed up in September 2011 and donated at Easter 2012.

“I joined as part of a really big drive in Leicester for a little girl. My cousin was volunteering, taking samples at Leicester Tigers rugby ground, and I went along and signed up.

“I got a voicemail from Anthony Nolan and at first I didn’t think it was real, I was just amazed. But I rang back and they told me I was a close match.

“I was honestly just shocked that I was a match for someone. You just don’t expect it, especially as there are so many people on the register.

“I was a bit scared, because in my mind I thought I’d be doing the full bone marrow extraction. But at the same time I was never not going to do it. At the hospital they said that they could take the cells from the blood instead, so that reassured me.

“I did all the blood samples and then I was told that they had actually found a better match. And for a month I thought that was the end of it. Then I got a phone call saying the other match had fallen through for some reason and asking me whether I would still donate, and of course I said yes.

“I went down to London with my friend. We went out to Baker Street to get some lunch and as we were walking I felt a crunch under my feet. I looked down and I was standing on a crisp £50 note! I thought, well, that’s a little bit of karma for me!

“I was in hospital with my friend for pretty much the whole day. They told me they got double what they needed so I wouldn’t have to go back the next day. It was really comfortable, even though there was all this stuff sticking out of me.

“I’d do it again in a heartbeat. Although there were complications with the patient, the last update I got was that it eventually worked.

“I would 100% recommend it to other people. It’s comfortable, painless and so worthwhile.

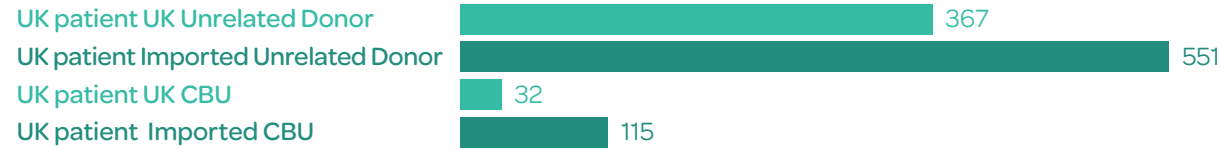
“My family and friends and work colleagues were very proud. Now I put it in my CV, because I think it’s one of the best things I’ve done and I want people to know about it and sign up themselves.

“I’ve been able to help someone get better and I had a great time in London, what more can I say? I loved it.”

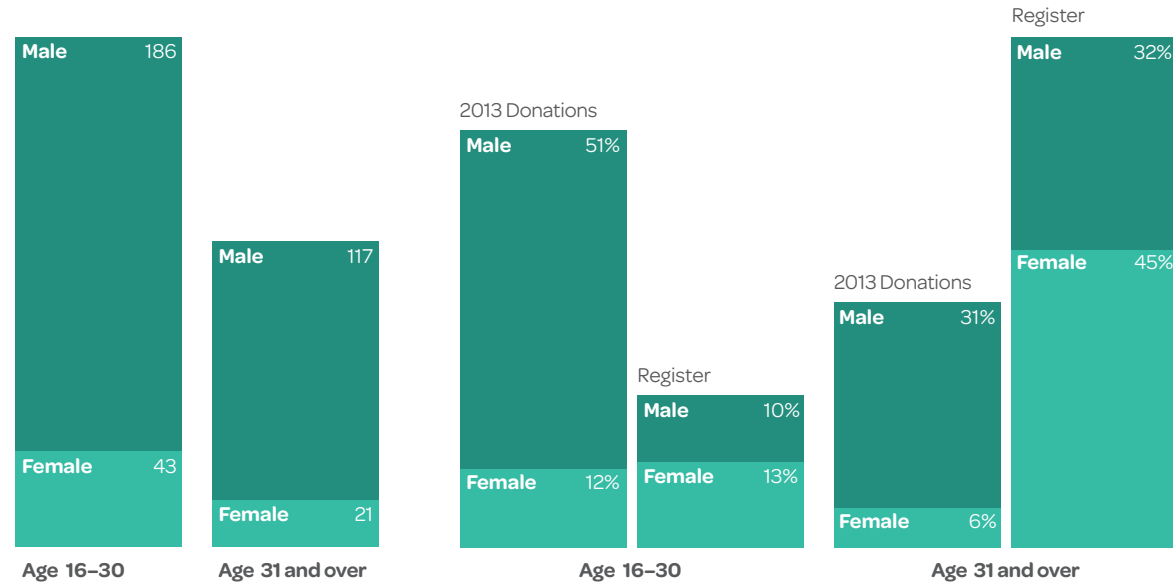


ALIGNED REGISTRY SUMMARY

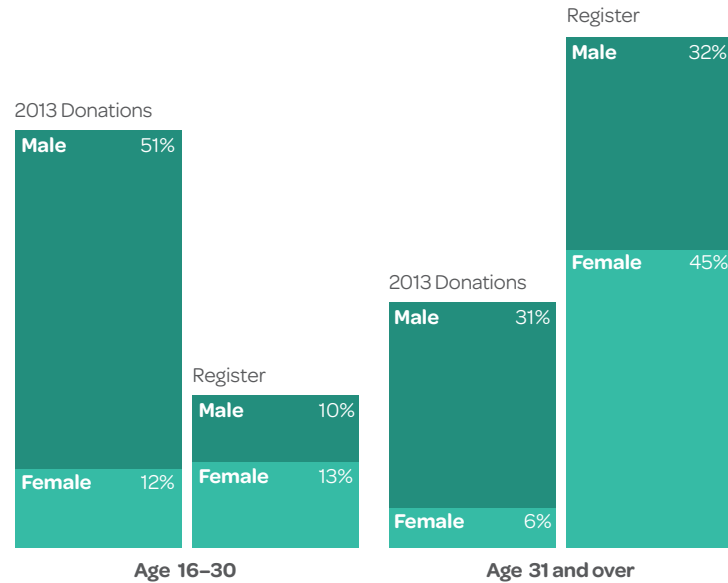
PROVISIONS FOR UK PATIENTS (MARKET SHARE)



UK DONORS FOR UK PATIENTS 2013



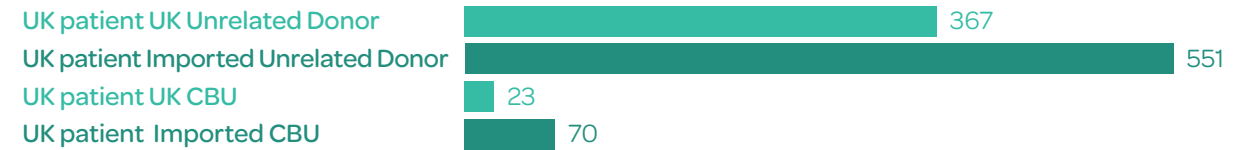
UK TO UK DONATIONS 2013 COMPARED WITH WHOLE OF REGISTER



UK DONORS FOR UK PATIENTS 2013 BY ETHNICITY



UK PATIENTS HELPED 2013



UK DONORS FOR UK PATIENTS

SEARCH REQUESTS V MATCHES FOUND 2013



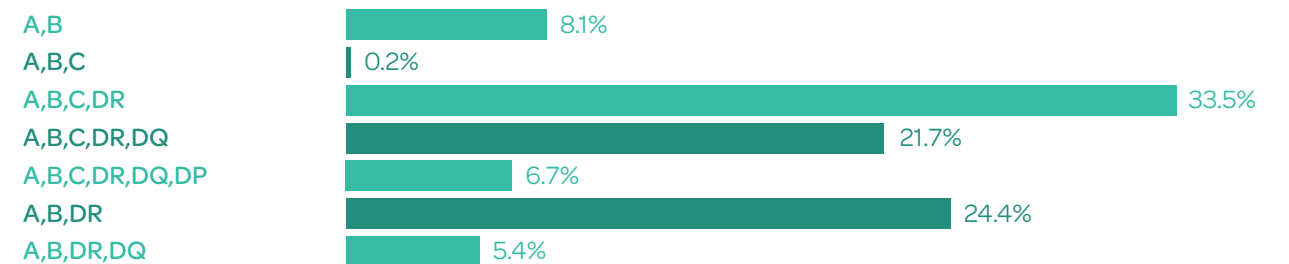
Note: circa 50% searches run result in patient receiving a donation either adult unrelated or CBU. There is no correlation between the number of searches and donations in 2013.

DONORS SELECTED AT WORK-UP / FIT PANEL

V REST OF REGISTER 2013



ALIGNED REGISTRY BY TYPING LEVEL



CASE STUDY

“I’d definitely recommend becoming a donor to anyone. I’ve got nothing but praise for everyone involved – the procedure from start to finish was very professional and transparent.”

ROSS

Ross Kirk, 31, is a physics teacher from Mansfield. He became a stem cell donor in June 2012.

“When I was asked to donate, I expected to have to undergo a procedure to remove stem cells directly from the bone. But I was pleasantly surprised to find it would be done by peripheral blood stem cell collection. This is how most stem cell donations are now done.

“It just takes around four injections to stimulate the cells before they’re removed from the blood. They use a specialist apheresis machine to extract the stem cells, and it takes four to five hours.

“After the procedure, I got out of bed and felt absolutely fine. I felt a bit more tired than usual for a couple of days afterwards, but that was it and I went back to work a few days later.

“I’ve always been one of those people that just shrugs things off and gets on with things, but I’d definitely recommend becoming a donor to anyone. I’ve got nothing but praise for everyone involved – the procedure from start to finish was very professional and transparent.

“I know the recipient of my stem cells is doing well. I’d like to meet him or her if the chance ever arose.

“I’ve helped to promote stem cell donation through Anthony Nolan recruitment events at my secondary school. I’m also donating blood every ten weeks as part of the INTERVAL study.”

INTERVAL is an NHSBT and Oxford University study into frequency of blood donation.



EXECUTIVE SUMMARY

The collaboration behind the Anthony Nolan and NHS Stem Cell Registry will help save thousands of lives in the UK and abroad by making finding a match easier, faster and more cost-effective.

As this report shows, we grew the Registry by 55,547 people last year*, focusing on recruiting the type of people transplant centres are likely to choose for stem cell matches: younger males. The good news is that as a result, 367 UK patients had a transplant from a UK adult unrelated donor last year – a 7% increase on the previous year.

We are confident that the alignment and expansion of the Registry will help us deliver even better outcomes.

Sadly, even today, it is not possible to find a suitable match for every person who needs a life-saving transplant. It is essential that we keep expanding the donor registers and the cord blood bank, to ensure that every person in need of a transplant has the best possible chance of survival.

We are also focusing on diversifying the Registry to ensure that every patient has the best possible chance of finding a matching donor, regardless of their ethnic background.

There have been considerable advances in our understanding of how to optimise the matching of donors and patients. As a result, significant progress has been made in identifying the best donor for patients, and this has reduced major transplant complications such as Graft versus Host Disease (GvHD).

However, it remains that for a significant number of patients, transplants are not curative. There is much still to be done to develop new transplant strategies which reduce the risk of disease relapse – the major cause of transplant failure. The next challenge is therefore to ensure that every patient undergoing a transplant is cured and can live the rest of their life to its maximum potential.

Research has also shown that blood stem cells have the potential to treat degenerative diseases such as Alzheimer's disease and arthritis. While it is very early days in this field, it could open up a world of new opportunities to treat some of the most difficult and destructive diseases which we are currently unable to tackle effectively. One day we hope we can offer hope – and cures – to all blood cancer patients, and possibly even those with other conditions.

The powerful partnerships behind the Anthony Nolan and NHS Stem Cell Registry, now and into the future, will help ensure that no patient in need of a transplant dies before a suitable donor can be found.

*Anthony Nolan and NHSBT figures only

