



CHANGING THE TRANSPLANT LANDSCAPE

**ANTHONY
NOLAN**

saving the lives
of people with
blood cancer

NHS
Blood and Transplant



**DELETE
BLOOD
CANCER**  **DKMS**

BACKGROUND

The third State of the Registry report has been compiled by the Anthony Nolan and NHS Stem Cell Registry. It showcases the impact of the work that has taken place in 2015.

Anthony Nolan

Founded in 1974, Anthony Nolan was the world's first bone marrow registry. Four decades later, the charity has expanded its reach, saving the lives of people with blood cancer and blood disorders across the UK and beyond. It does so with the help of groundbreaking research, dedicated patient support, and a register of almost 600,000 truly remarkable volunteer donors.

Delete Blood Cancer UK/DKMS

Part of the international DKMS family of organisations, Delete Blood Cancer UK/DKMS launched in 2013 as a registered UK Donor Centre. They support patients and their families and raise awareness of blood cancer and the UK Registry, through family appeals, donor recruitment events and focused campaigns.

NHS Blood and Transplant

NHS Blood and Transplant (NHSBT) is a Special Health Authority, responsible for providing a safe and reliable supply of blood, blood products and expertise to hospitals in England; for increasing the number of organs available for transplant in the UK; and for the provision of tissues and stem cells to the NHS. The British Bone Marrow Registry is a division of NHS Blood and Transplant. It holds details of stem cell donors and cord blood donations from England, Scotland and Northern Ireland.

Welsh Bone Marrow Donor Registry

Founded by the Welsh Blood Service in 1989 to provide high quality donor typing, the Welsh Bone Marrow Donor Registry has recruited almost 90,000 blood donors to its panel - incredible people who give hope and a second chance to patients throughout the world. The Registry is proud to be working with donors, patients, transplant physicians in Wales and centres across the globe.

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CASE STUDY

'It was such a simple, easy way to help save a life.'



Hayley's story

Hayley Reid gave birth to her daughter Abigail at King's College Hospital in 2015. She donated her cord blood to give someone with blood cancer or a blood disorder another chance at life.

I carried my baby for 41 weeks, anxious to keep him or her safe. And when I gave birth to a beautiful, healthy little girl, like all mothers, I knew I would do anything to protect her.

I can't imagine how hard it is being told your child has blood cancer, especially if there's no match. And that's why I donated my cord blood. The whole process is so easy, and if one sick little boy or girl could be helped from it, how amazing would that be?

The team at King's College Hospital were great. They made the whole process straightforward. I completed a form, signed it and agreed to give my cord blood. The rest was all taken care of by the team, and they even came to say thank you in the hospital after Abigail was born (and of course, to have a cuddle!)

All I can say is it was such a simple, easy way to help save a life. Why wouldn't you do it?

FOREWORD

The significant increase in the number of registered stem cell donors is a testament to the continued hard work of all the organisations recruiting donors. Only by continuing to expand and diversify the register will it be possible to offer the best chance to those many patients whose only option is to depend on the kindness of strangers to find a match. This has been demonstrated over the last few years through the fantastic results from targeting recruitment efforts towards young male donors. The growth of this 'fit panel' means clinicians have greater opportunity to select younger donors where the chances of a successful transplant are greatly increased.

Increased use of the latest and most accurate genetic testing techniques has made the identification of suitable donors a more accurate and rapid process. Quicker identification and selection of the best donors is essential if we want to continue to improve patient outcomes and these new technologies are a key advance.

Great strides have been made in improving the chances of patients from black, Asian and minority ethnic (BAME) backgrounds and for those with a mixed heritage of finding a suitable donor. I am committed to building on this success and doing all we can to ensure that more of these patients find a really good matching donor.

I know that the sustained progress described in this report has only been possible through close and collaborative working from all those committed to improving the treatment, care and support of people of all ages coping with the challenge of life-threatening conditions. It is a credit to all those involved and shows how working closely together with an increasing mutual understanding of each other's unique strengths continues to bring about positive change.

We should celebrate the good news in this State of the Registry review. It is an indicator of the progress made; it is also a benchmark for measuring further improvements and must spur us all on to achieve even more for patients.

Jane Ellison MP
Parliamentary Under Secretary of State for Public Health

INTRODUCTION: THE STATE OF THE REGISTRY IN 2016

The year 2015 has been an exciting time in the field of stem cell research and transplantation. Advances in technology and scientific research are leading to improved methods of treatment and care for patients. And all of us who make up the Anthony Nolan and NHS Stem Cell Registry have continued sharing insight, striving to recruit the best donors and working towards our common goal – saving as many lives as possible.

As of 31 December 2015, there are 1,138,564 potential donors on the register, a healthy increase of 11% since the year before.

A particular focus on recruiting more young male donors and people from black, Asian and minority ethnic (BAME) backgrounds has continued to produce encouraging results. In 2014, 108,163 donors were 16-30 year old males; this has now increased by 15% to 124,352. With more 16-30 year old men on the register, we can meet the transplant centres' preferred choice of donor more often. And with more BAME donors signing up than ever before, we can address the tragic inequality that too many patients from ethnic minority backgrounds face when looking for an HLA match.

The cord blood programme has also seen marked successes over the course of the year, with 16,909 clinical grade UK cords now available; a 17% increase on the previous year. The programme is particularly

important for BAME patients, as it offers a valuable alternative for those who can't find a match on the adult register. This has meant that the number of cord blood transplants provided for UK patients from banks in the UK has also increased overall for 2015.

Pioneering research by leading experts has also led to the launch of exciting new technology, designed to type donors to the highest level of resolution. By analysing an entire gene in one go, better matches can be made between patients and donors. It is hoped this will lead to improved survival rates and help reduce post-transplant complications.

The progress made in 2015 has been positive, but we still have so much to do. There are still too many patients dying because of post-transplant complications. There's also more work to be done to diversify the register. Unfair survival odds still hamper people from BAME backgrounds and we need to continue to inspire and engage these communities, as well as more young men, to join the register.

As we continue to strive forwards together, this report offers a chance to reflect over the successes of the past year, as well as the areas that still require our attention. It is clear that there is still more to accomplish. But, united in our common goal to save and improve the lives of our patients, we know we have the determination and impetus to succeed.



Henny Braund

Henny Braund
Chief Executive,
Anthony Nolan



Ian Trenholm

Ian Trenholm
Chief Executive,
NHS Blood and Transplant



Cath O'Brien

Cath O'Brien
Director,
Welsh Blood Service



Peter Mas-Mollinedo

Peter Mas-Mollinedo
Chief Executive,
Delete Blood Cancer UK

CASE STUDY



Judy's story

Judy Leden MBE is the three times World Hang Gliding and Paragliding champion and world altitude record holder. She donated her stem cells via PBSC in 2015.

I joined the register after seeing the campaign to find little Margot Martini a donor. It was such a powerful piece and as a result I registered right away.

Then, just 18 months later, I got a call out of the blue to say I was a match for a patient with blood cancer. I was amazed and delighted to be able to donate my stem cells, especially as I am in my fifties, so at the upper end of the age range for donation.

The donation itself was a negligible four hours by comparison to what my recipient was going through. While I was donating, I was visited by Jayne Snell – a lady who had received a lifesaving stem cell transplant three years ago. I was very moved by her tale as her children are the same age as mine. We decided then and there to go hang gliding together. Jayne's new lease of life has given her a taste for adventure and it was a joyous way to celebrate as well as raise funds.



'To think that this lady saved my life not once but twice is pretty amazing.'

Patrick's story

Patrick Shaughnessy was diagnosed with a rare blood disorder, CD40 ligand deficiency, when he was born. Tragically the disease claimed the lives of his two older brothers and two of his cousins.

I was just six years old when a donor was found for me. My family and I travelled from Ireland to the Great North Children's Hospital in Newcastle for my bone marrow transplant and I lived in a bubble of sterilised air for nearly four months afterwards. Three years later, when I returned for a check-up, I was told I would need a top-up transplant. Thankfully my donor was happy to donate again, and I became determined to find out who they were so I could thank them.

My illness has definitely informed my career choice. After finishing school I moved to the UK to study physiotherapy from the University of Central Lancashire. I went back to visit my consultant at Newcastle; he was so surprised and happy to see me in my student physio uniform. It was amazing to be able to chat with parents, and reassure them that I had been as sick as their children, but look at me now.

While I was over in the UK I finally got to meet my donor – Bernadette Dodds. My parents and sister flew over from Ireland for the occasion as they are as grateful to her as I am. To think that this lady, who has two children of her own, saved my life not once but twice is pretty amazing. I wanted to let her know what her generosity and bravery has allowed me to do.

THE REGISTRY TODAY

In 2013, the UK's stem cell registries aligned to create the Anthony Nolan and NHS Stem Cell Registry, a single collaborative approach to the provision of stem cells from unrelated donors. Three years on, we reflect on the registry today; the positive changes made through our partnership, as well as the areas that still require improvement.

Over the past three years, the number of donations provided for UK patients has remained relatively consistent, going from 1,011 in 2013, to 1,064 in 2014, to 977 in 2015. The Anthony Nolan and NHS Stem Cell Registry received 2,150 search requests in 2015 – an increase of 13% from 2013 – indicating that the need for stem cell transplants is not abating. Though the overall number of unrelated transplants declined this year, the data reflects the UK transplant centres' increasing preference for UK donors as a cost-effective, and more importantly, time-efficient means of facilitating transplants. The proportion of UK patients helped by UK-sourced unrelated transplants has grown from 38% in 2013 to 42% in 2015.

Transplant centres prefer to select young male donors. Accordingly we have targeted our recruitment at men under 30 to provide the transplant centres with the donors they prefer for patients. In 2013 there were 87,358 male donors aged 16-30 on the register. Notably, in just three years this has increased by 42% to 124,352 in 2015. Our data also indicates that:

- The most common age of joining in 2015 was 20
- 28% of those on the register are now aged 16-30

Patients from black, Asian and minority ethnic (BAME) backgrounds continue to face significant challenges finding a suitable match, underlining the importance of diversifying our pool of potential donors. Throughout 2015, patient appeals continued to capture the attention of social media and the press, leading to significant spikes in those applying to join the register. Sharing these stories and the challenges BAME patients face remains one of the most effective ways to raise awareness and to motivate individuals from BAME communities to join the register.

Increasing the number of potential donors on the register is important, but we must also ensure that our donors are eligible, committed and contactable. Each organisation continues to work to maintain an engaged panel of potential donors and to reduce unavailability.

In 2015, there were 16,909 clinical cord blood units available in our cord blood banks – up 17% since 2014. The cord blood programme is particularly important for BAME patients who have less chance of finding a match from an adult donor. This year, the NHS cord blood bank, the first public cord blood collector in the UK, will celebrate its 20th anniversary; an important milestone in the provision of stem cells for UK patients. We will encourage the transplant community to continue to utilise the UK's cord blood banks whenever clinically appropriate.

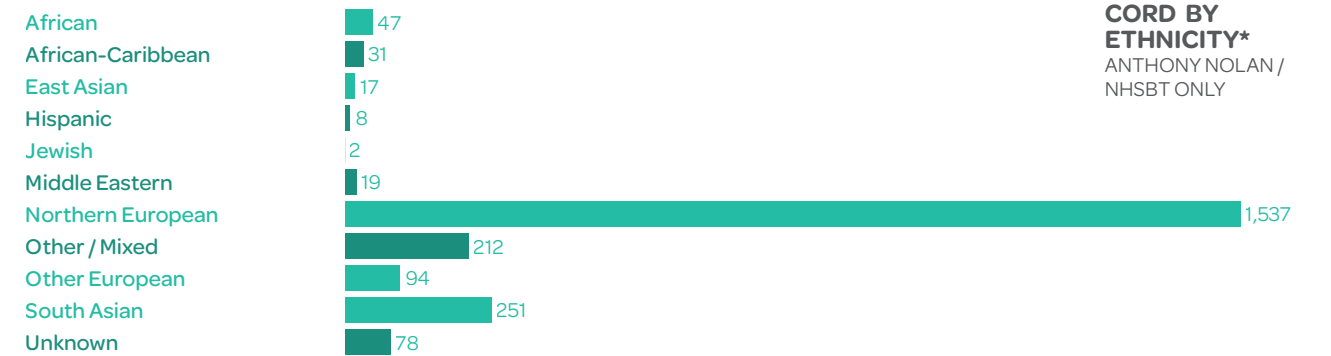
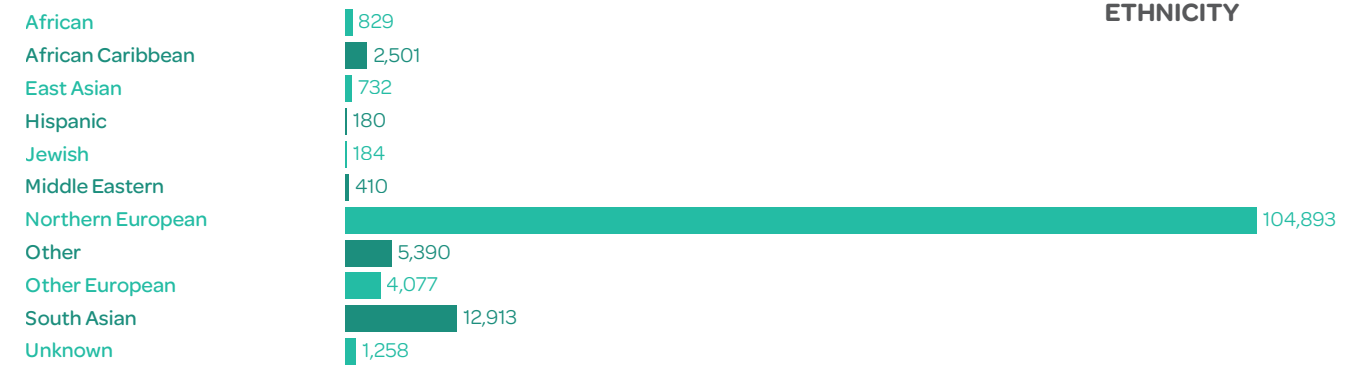
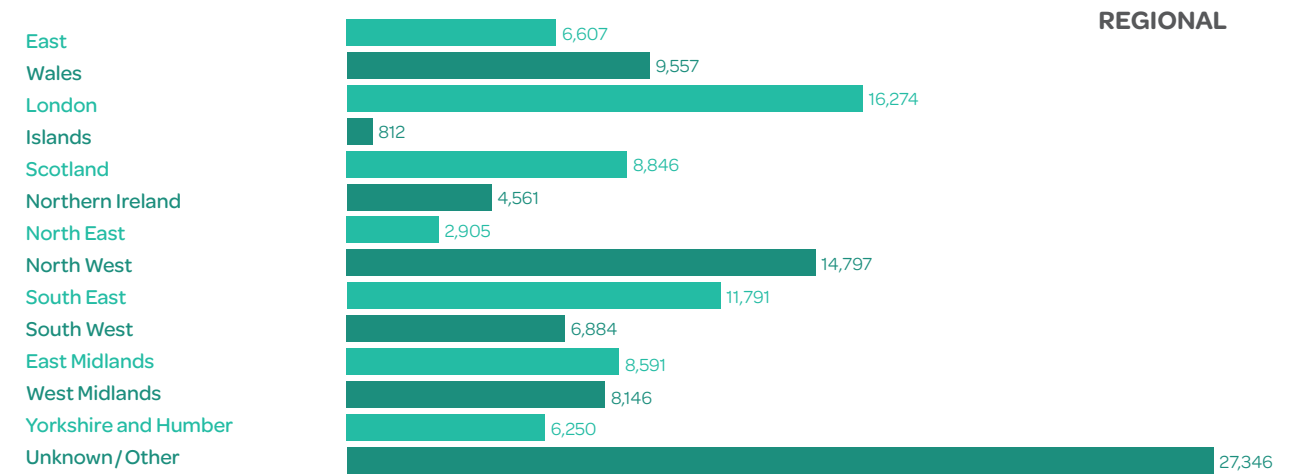
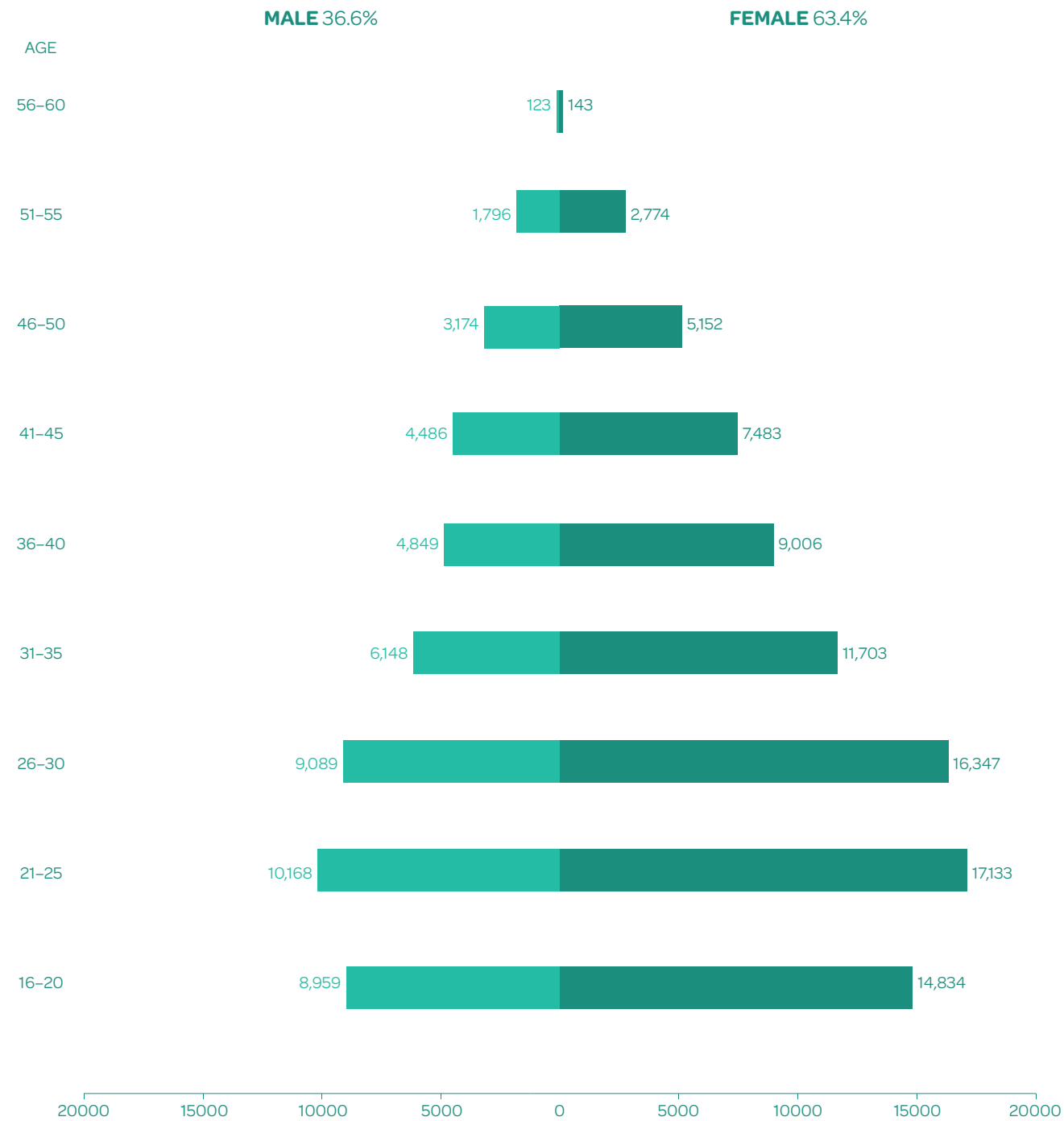
A big challenge for the Anthony Nolan and NHS Stem Cell Registry has been aligning our combined data. We continue to work as individual organisations to improve how we collect and report our data, whilst collaborating to present this information in the best and most consistent way.

Since the registries aligned three years ago, the Anthony Nolan and NHS Stem Cell Registry has made encouraging strides forward. We will continue to focus on recruiting committed young males and BAME donors, as well as typing as many donors as feasible to a higher level. By doing so we hope to strengthen and diversify the register, so that every person in need of a stem cell transplant finds their lifesaving match.

ALIGNED REGISTRY 2015 DEMOGRAPHICS

Due to challenges aligning our data, there are some small inconsistencies between this year's and previous year's data. We are working cross-organisationally to improve reporting consistency.

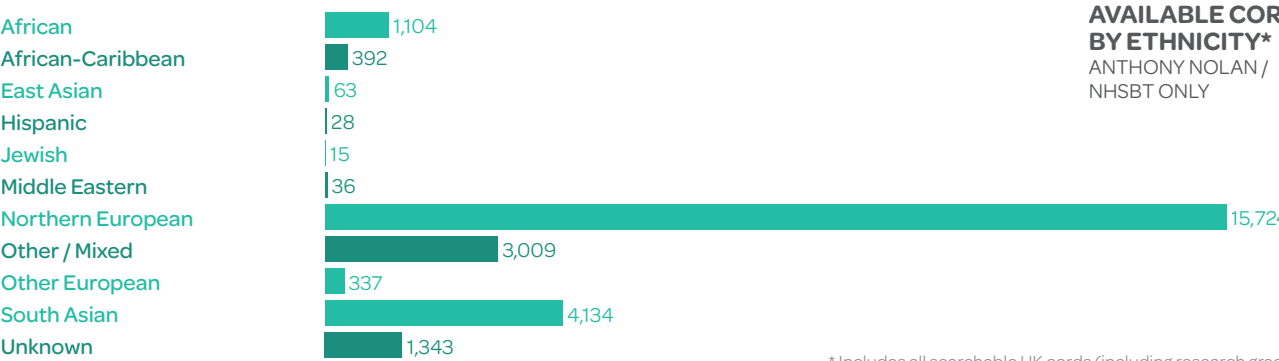
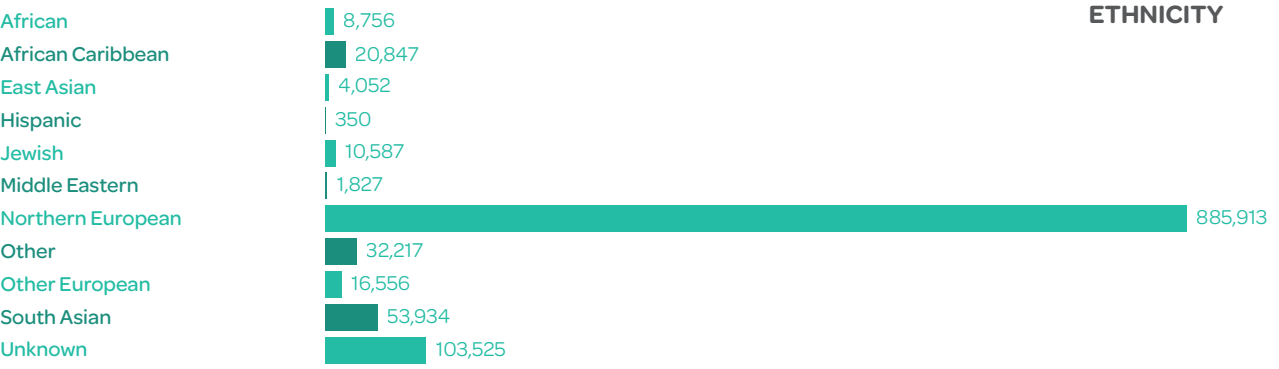
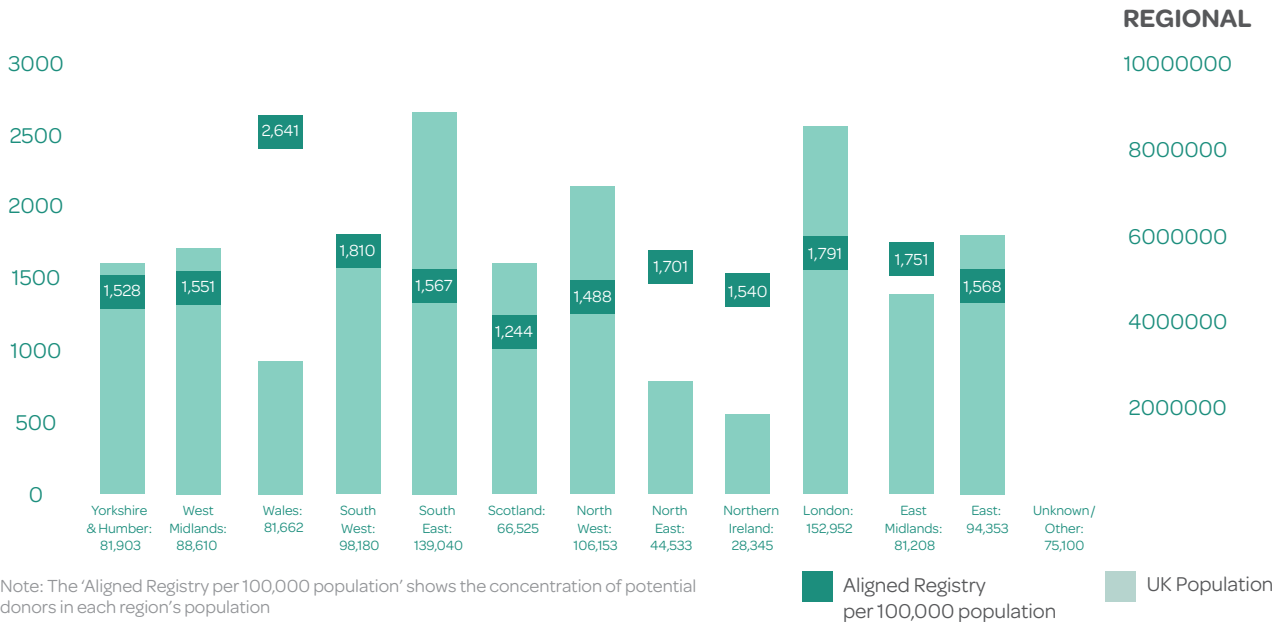
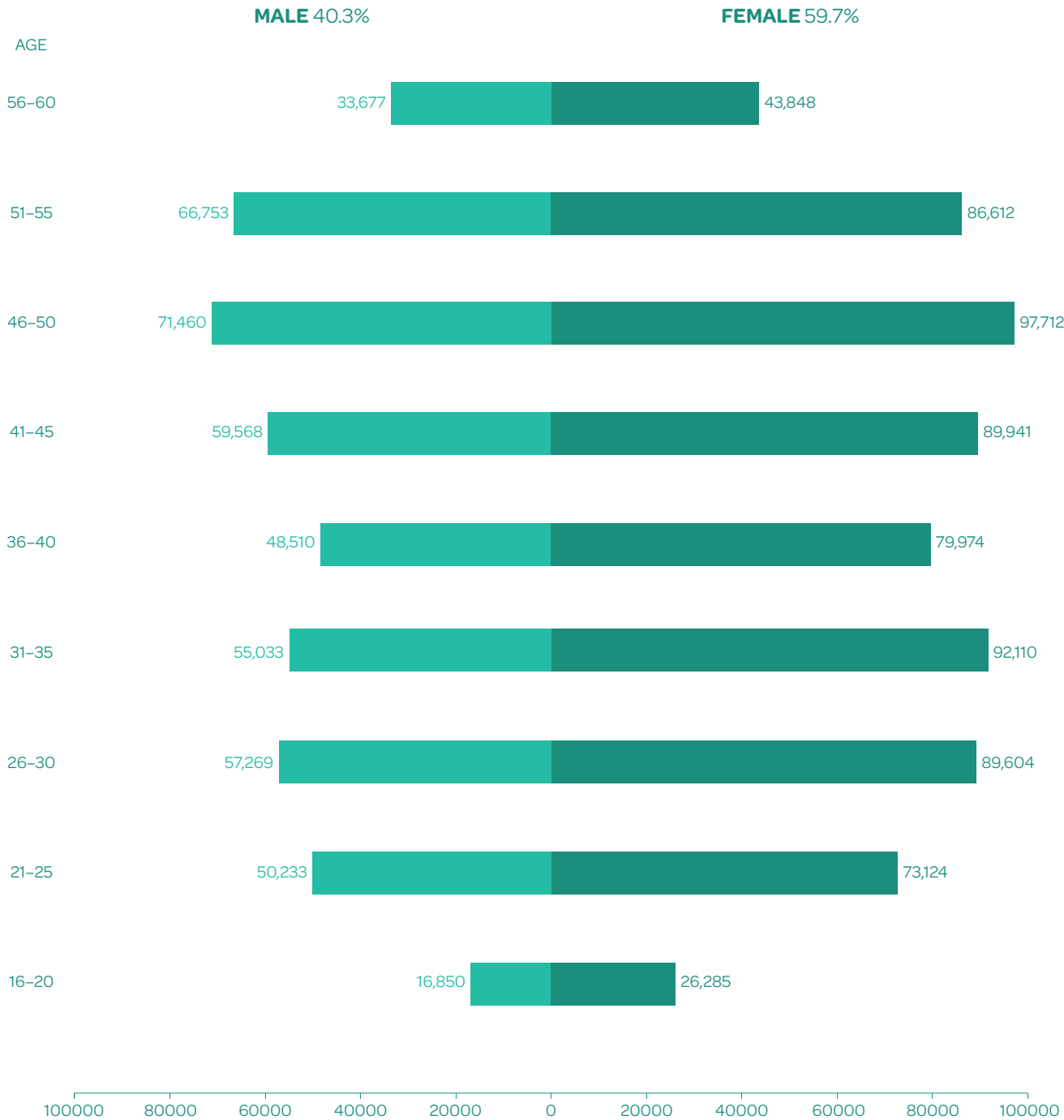
NEW DONORS MADE ACTIVE IN 2015



* Includes all searchable UK cords (including research grade)

ALIGNED REGISTRY 2015 DEMOGRAPHICS

ALIGNED REGISTRY DEMOGRAPHICS

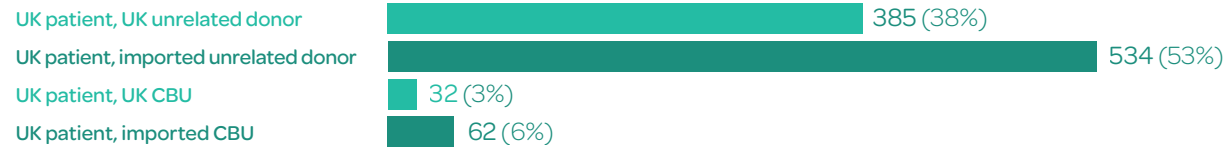


* Includes all searchable UK cords (including research grade)

ALIGNED REGISTRY 2015 SUMMARY

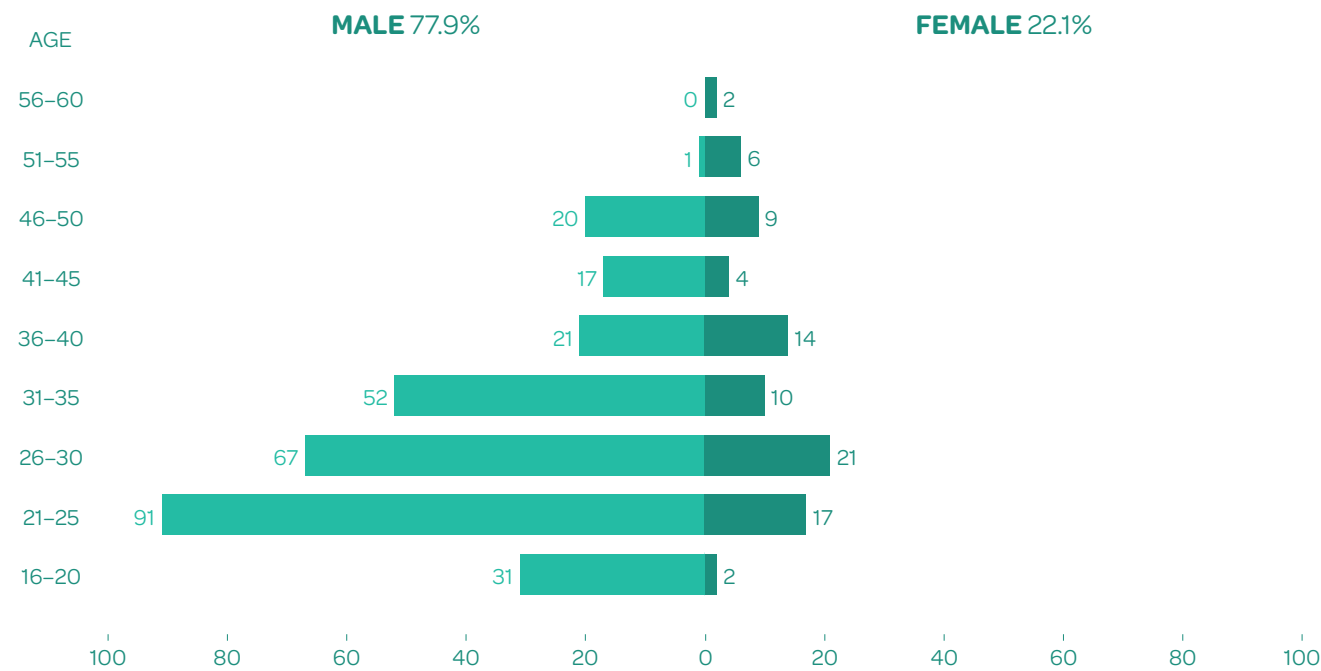
PROVISIONS FOR UK PATIENTS (MARKET SHARE)

TOTAL 1,035



UK DONORS FOR UK PATIENTS 2015

TOTAL 385



UK DONORS FOR UK PATIENTS 2015 BY ETHNICITY

TOTAL 385



UK PATIENTS HELPED 2015



UK DONORS FOR UK PATIENTS

SEARCH REQUESTS V MATCHES FOUND 2015

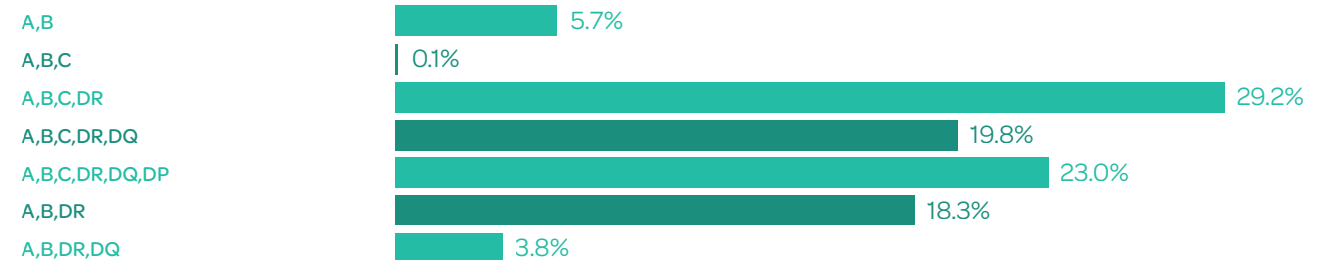


Note: around 50% of searches result in the patient receiving a donation from either an unrelated adult or cord blood unit. There is no correlation between the number of searches and donations in 2015.

SUMMARY OF DONORS SELECTED FOR STEM CELL DONATION 2015



ALIGNED REGISTRY BY TYPING LEVEL



SCIENTIFIC ADVANCES IN TISSUE TYPING

Over the last ten years, the field of stem cell research and transplantation has evolved, driven by initiatives which will ultimately improve patient outcomes.

The report of the UK Stem Cell Strategic Health Forum published in 2014 made 12 recommendations, including one regarding the typing of donors; namely that UK stem cell supply organisations should continue to implement next-generation DNA sequencing platforms for unambiguous HLA typing of selected adult donors and cord blood donations.

This work has progressed significantly over the last year, with NHSBT, Anthony Nolan and Delete Blood Cancer UK (part of the international DKMS group) investing in pioneering technology that could greatly improve stem cell transplant outcomes. These new methods, referred to as Third Generation Sequencing (TGS) by Anthony Nolan and Next Generation Sequencing (NGS) by NHSBT and DKMS, allow us to type donors to a higher allelic level than ever before. The Welsh Bone Marrow Donor Registry will also be moving to allelic level typing for all its donors at the time of registration within the next 12 months.

It is hoped that both NGS and TGS will provide further understanding of donor/patient compatibility, thus increasing survival rates and reducing post-transplant side effects such as graft versus host disease. Although only in the early stages, these processes have shown promising improvements in the time to transplantation for patients – a tangible benefit that should help to save even more lives. NGS and TGS should also reduce search times for donors, not to mention cut down on the time it takes to type each new register applicant. And with the ability to speed up typing, we hope to be able to add even more donors to the Anthony Nolan and NHS Stem Cell Registry than ever before.

Going forward, it's important that we invest time and resources into advancing our scientific research even further. By sharing insight and capitalising on what we already know, stem cell transplantation has the potential to be revolutionised and ultimately, save even more lives.

CASE STUDY

'The only painful part of the whole process was watching The Jeremy Kyle show!'

Mazhar's story

Mazhar Kusbeci signed up to the register after he saw a flyer appealing for more donors from Turkish and Cypriot backgrounds in his local fish and chip shop.

I was at my local chippy when I saw a flyer asking more people from Turkish and Cypriot backgrounds to sign up to the register. As I'm from Cyprus I was intrigued and ended up signing up. I donated exactly one year after that moment.

It was so simple. All the arrangements including transport and accommodation were sorted out. And the entire donation process took about five hours. In all honesty, the only painful part of the whole process was watching The Jeremy Kyle show!

In general, Cypriots are quite anxious when it comes to medical processes; they tend not to go to hospital unless they're really ill. The myths about big needles associated with bone marrow donation don't help either.

But I'd just say I'm so glad I did it. I got a thank you card from my recipient, and without a doubt, it's the best card I've ever received. It feels good to know you've helped, and that you've given someone another chance at life.



'I thank my lucky stars for being given a second chance.'

Sean's story

Sean McCabe was diagnosed with non-Hodgkin lymphoma in 2013, when he was just 28 years old. Sean was told he had months to live, unless a stem cell donor could be found.

Initially the chemotherapy looked like it was working and I was given the all-clear. But within a few months, my cancer returned and the doctor told me I only had a 20% chance of survival. It was heartbreaking. I even planned and booked my funeral so my girlfriend and children wouldn't have to go through the stress of doing it.

A worldwide search to find me a donor had been launched. Thankfully, an overseas donor was found in time and I had my transplant in February 2014. I waited five months, and then I cancelled my funeral and booked my wedding instead in the very same church. The experience has made me so passionate about raising awareness. I made so many friends in hospital, and not everyone survived. So I thank my lucky stars for being given a second chance.

EXECUTIVE SUMMARY

The year 2015 will undoubtedly be remembered as an important time for advances in stem cell transplantation and research. Our combined efforts to revolutionise the science behind our work, recruit more donors and improve post-transplant care across the UK have shown promising results. In 2016 and beyond we'll be striving to do even more to save the lives of every patient in need of a stem cell transplant.

This report has highlighted many encouraging achievements; from the 1,138,564 potential donors on the register, to the 15% increase in 16-30 year old men signing up to save a life. We are particularly pleased by the rise in young male sign ups, as transplant centres are increasingly showing a preference for these donors. Acquiring knowledge such as this is crucial to ensure that we invest our resources into recruiting those who are most likely to go on to donate.

The number of black, Asian and minority ethnic (BAME) donors on the register is growing, but more must be done to diversify the pool of donors, so every patient finds their lifesaving match. As a result, we must maintain our focus on recruiting donors from BAME communities, strengthen our cord blood programme and continue to educate as many young people as possible about the importance of stem cell donation.

Research has led to considerable progress in our work this year. However there is still more to understand when it comes to genetic matching, long-term complications and post-transplant side effects; all areas which require long-term investment to ensure the best possible outcomes. For the good of all our patients, supporting the type of groundbreaking research that has already saved and improved so many lives is vital.

With exciting new methods of tissue typing now being used, 2016 looks set to reinforce the achievements of our collaboration to date. While there will be further challenges, we pledge never to become complacent about striving to ensure that no one dies waiting for a stem cell transplant.

'I'm really happy to support the research and proud to be a part of the process to help patients.'

Lloyd Ellis, new generation lifesaver, pictured on the front cover

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