



DESTINATION  
**CURE**

**Arriving at a better  
future for people  
with blood cancer**

**ANTHONY  
NOLAN**

saving the lives of  
people with  
blood cancer



DESTINATION  
**CURE**

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# FOREWORD

**We're looking ahead to a future when the destination for every patient is a cure.**

We've come a long way since Shirley Nolan started the world's first bone marrow donor register over 40 years ago. We're proud of what we've achieved in that time and of the challenges we've overcome, and proud that in the next five years we will help over 6,000 people receive a potentially lifesaving stem cell transplant from a stranger. But we also know that, despite the progress we've made, there is still a lot more to do.

## DESTINATION: CURE

A stem cell transplant can be a lifesaving milestone for someone with blood cancer, but it isn't the end of the road. Most patients face long-term health complications and tragically, one third do not survive their first year post-transplant.

At Anthony Nolan we're working hard to improve the prospects for people at every stage of this journey. By identifying the best possible donors, carrying out pioneering research and offering support to patients and their families, we aim to continually improve the outcomes and quality of life for every person in need of a stem cell transplant.

## THE CHALLENGES AHEAD

In each of these areas, however, there are formidable challenges.

We know that 1 in 8 people still fail to find the donor they need – odds that drop dramatically for patients from ethnic backgrounds. Even for those who do receive a transplant, the future is far from certain: over a third of adults and almost a fifth of children will not survive their first year. And because funding for post-transplant care continues to fall short, patients are not guaranteed the support they need to return to an active life.

The need for action is clear, but we can only succeed with strong support from the Government. Through collaboration and hard work we can achieve our three ambitious aims:

- **A stem cell donor for every person who needs one**  
By maintaining investment to support the stem cell registry and the growth of the cord blood inventory, the Government can help us to find the best possible donor for every person.
- **A successful transplant for every patient**  
By creating the right research environment the Government can put us in pole position to make the breakthroughs that will improve transplant outcomes.
- **The right post-transplant care for every patient who needs it**  
By establishing a fully-funded care pathway for transplant patients the NHS can ensure that all post-transplant patients return to good health and a good quality of life.

## FIVE IMPORTANT YEARS

The new Government has a term of five years to make a life-changing impact for stem cell transplant patients. Five years which could, if action is taken, leave a legacy of ensuring that every patient can look forward to a full recovery.

Our journey as a charity has always been one of forward progress – and, with so many lives at stake, this idea is more important now than ever before.

We know we can achieve our vision – but we can't do it alone. We need strong and unwavering support from the Government. And, only then, can we ensure that every patient reaches their destination: cure.

Henny Braund  
Chief Executive,  
Anthony Nolan



## A stem cell donor for every person who needs one

Between 2015 and 2020, over 11,000 people with blood cancer or a blood disorder will need a curative stem cell transplant.<sup>1</sup> Of these, 1 in 8 people will not receive the lifesaving transplant they need because either there is no donor available for them, or because a donor cannot be found quickly enough.<sup>2</sup>

The fact that many patients will not receive the transplant they need is unacceptable. But we can meet this challenge.

For 40 years we have helped facilitate stem cell and bone marrow transplants, and we know that the most effective way to provide a transplant for every person who needs one is to recruit more of the best potential donors. We therefore need to build a UK donor register which is not just larger, but better.

There is a particular need for younger people to sign up to become potential donors. Young people are less likely to experience health complications which could delay or prevent their lifesaving donation from taking place. For this reason Anthony Nolan's joining policy invites people aged between 16 and 30 to join the register (though all those on the register can donate until the age of 60), in recognition of the recommendations of the UK Stem Cell Strategy 2014.<sup>3</sup> There is also mounting evidence that younger donors offer the best chance of survival for patients who receive a transplant.<sup>4</sup>

The UK Stem Cell Strategy 2014 also highlights the need to recruit males to the stem cell registries, who are more likely to be picked as viable donors. Anthony Nolan places a focus on the recruitment of young male potential donors for high-resolution genetic typing, known as a 'fit panel'. This means that those who are most likely to be chosen as donors are more available, and in some cases, able to donate more quickly

because more is known about their genetic compatibility with patients.

Potential donors recruited to the 'fit panel' are now eight times more likely to go on to donate, compared to others on the register. We now need to extend the size of this panel of young male donors from around 60,000 to 150,000, a move which would save an additional 90 lives each year.<sup>5</sup>

Building a better register also means building a more ethnically diverse register. Whereas 96% of patients from a white northern European background in need of a stem cell transplant can find a suitably matched donor, only 61% of patients from a black, Asian or minority ethnic (BAME) background are able to do so.<sup>6</sup>

This is due to the fact that patients from a BAME background are likely to have a more diverse genetic heritage – especially if they are mixed race – which makes it harder to find a suitable donor. The problem is compounded by the fact that UK and overseas registries do not adequately cater for these communities.

Crucially, this disparity is even more pronounced when it comes to finding the best possible genetic match. The extent to which a donor's stem cells match those of the recipient has an important bearing on the outcome of the transplant. Patients receiving stem cells that are the best possible match – known as a 10/10 match – do better after their transplant than patients receiving cells which are not matched to this degree.

Of patients with white northern European genetic heritage, 69% will receive cells which are a 10/10 match. In stark contrast, only 21% of BAME patients will find an equivalent match.<sup>7</sup> This inequality of access underlines the importance of building a diverse register by recruiting people from

<sup>1</sup> Anthony Nolan projection based on BSBMT transplant figures 2001-2013 and estimates of unmet need calculated by the Stem Cell Strategy Oversight Committee, November 2014

<sup>2</sup> Anthony Nolan projection based on BSBMT transplant figures 2001-2013 and estimates of unmet need calculated by the Stem Cell Strategy Oversight Committee, November 2014

<sup>3</sup> Stem Cell Strategy Oversight Committee Report, November 2014

<sup>4</sup> Kollman C. et al, *Blood* (2001) 98 2043-2051

<sup>5</sup> Stem Cell Strategy Oversight Committee Report, November 2014

<sup>6</sup> Lown, RN. et al. (2013) Equality of Access to transplant for ethnic minority patients through the use of cord blood and haploidentical transplants. Abstract. American Society for Haematology.

<sup>7</sup> Lown, RN. et al. (2013) Equality of Access to transplant for ethnic minority patients through the use of cord blood and haploidentical transplants. Abstract. American Society for Haematology

a wide range of ethnic backgrounds to become potential donors. We must continue to build and diversify the Anthony Nolan and NHS Stem Cell Registry to ensure that 10/10 matches are the standard for patients in need of a transplant in future.

Another important strategy to help address this inequality is the use of umbilical cord blood. Stem cells taken from umbilical cords can be used in transplant with a greater degree of flexibility, because these cells can tolerate a higher degree of genetic mismatch. Furthermore, the long-term outcomes for patients undergoing cord blood transplants have substantially improved in recent years and are now similar to those receiving stem cells from an unrelated adult donor.<sup>8</sup>

This means that cord blood is particularly important for meeting the needs of patients who are unable to find a suitable match from an unrelated adult donor. Research shows that the needs of 21% of BAME patients are currently being met by a cord blood transplant. In comparison, cord is used for around only 4% of white northern European patients, as their needs are better catered for from adult donors in stem cell registries.<sup>9</sup>

As a result, advances in the collection and banking of umbilical cord blood have contributed significantly to the improvement in the number of BAME patients receiving transplants. But with nearly 2 in 5 BAME patients still unable to find a suitable donor, there is clearly still more work to do. The NHS Stem Cell Registry and Anthony Nolan currently have 15,000 cord blood units banked and available for patients in

need of lifesaving cells. We need to double that number in order to address unmet patient need.

We are working towards a future in which we can find a well-matched stem cell donor for every person that needs one. To do so requires the Government to commit long-term funding to support both the ongoing recruitment of young, male and ethnically diverse donors, and continued growth in the provision of cord blood cells.

#### **BETWEEN NOW AND 2020 THE GOVERNMENT SHOULD:**

1. Maintain investment to support the work of the Anthony Nolan and NHS Stem Cell Registry to expand the number of young, male and ethnically diverse donors between the ages of 16 and 30. Investment should support the expansion of the 'fit panel' to 150,000 donors, as recommended by the UK Stem Cell Strategy.
2. Maintain investment to support the Anthony Nolan and NHS Cord Blood Bank to grow the UK's umbilical cord blood inventory. Investment should achieve an inventory of 30,000 units by 2018, in line with the recommendation of the UK Stem Cell Strategy, to ensure a self-sufficient inventory which meets patient need.

By supporting the UK Stem Cell Strategy 2014 and investing in the growth of the UK's adult donor and donated cord blood stem cell supply, the Government can help us reach our goal of finding the best possible donor for every patient in need of a lifesaving transplant.



<sup>8</sup> Overall survival rate at 5 years is 34% for umbilical cord blood transplants and 41% for voluntary unrelated donor transplants. British Society of Blood and Marrow Transplantation Annual Report 2012, p. 64.

<sup>9</sup> Lowm, RN. et al. (2013) Equality of Access to transplant for ethnic minority patients through the use of cord blood and haploidentical transplants. Abstract. American Society for Haematology.

A stem cell transplant is often the last chance of life for a person with a blood cancer or a blood disorder. However, it remains a complex procedure.

Patients can suffer a number of complications during the post-transplant period, including relapse, infection and Graft versus Host Disease (GvHD) – a complication that sees the transplant patient’s new immune system attacking existing organs in the body. The major cause of treatment failure remains disease relapse, which in most patients is untreatable. Such complications mean that there is still urgent need for significant improvement in transplant patient outcomes.

Over 9,800 people will receive an allogeneic<sup>10</sup> stem cell transplant in the next five years. Of these, over 3,500 will receive stem cells from a sibling donor. Of the remaining 6,300 patients who will receive a stem cell transplant from an unrelated donor, over a third of adults and almost a fifth of children will not survive their first post-transplant year.<sup>11</sup> Furthermore, fewer than half of patients will live beyond their fifth year, underlining the urgent need for improvements in transplant outcomes.<sup>12</sup>

Innovations in transplant medicine, clinical practice and patient care, combined with improved genetic matching of patients and donors, are the key to improving these outcomes and saving more lives of people with blood cancers and blood disorders.

At Anthony Nolan we are consistently working towards improving stem cell transplantation survival rates.

Our Research Institute carries out pioneering research into stem cell transplantation techniques and the matching process to try and pinpoint the unknown variables that may influence the chances of a successful transplant outcome.

We are the world’s first organisation to invest in Third Generation Sequencing technology, which allows us to type and match the genes of donors and patients with far higher accuracy and detail. This helps us determine which genes affect the chances of a successful transplant, which lowers the risk of unknown mismatches and can improve patient outcomes.

In the clinical setting, processes and procedures have advanced to minimise the risks faced by patients undergoing pre-conditioning therapies prior to their transplant. This helps to ensure that every patient is in the best possible condition to receive their transplant.

However, much more must be done to improve patient outcomes and translate innovative research into clinical practice, to ensure that patients can access new, potentially lifesaving therapies and treatments. To reach our goal, we must overcome a number of barriers to progress.

It is crucial that best practice techniques for stem cell transplantation are identified and applied across all transplant centres to ensure positive patient outcomes, but a lack of harmonisation of transplant protocols across UK clinical practice makes it difficult to determine the optimal means of conducting transplants and assessing which factors may influence outcomes.

Medical research and clinical trials are essential in developing a consensus on the most effective transplant care protocols, as well as in assessing the safety and efficacy of a new therapy before it is deemed suitable for clinical use. However, due to small patient cohorts and a complex regulatory environment, researchers and transplant centres find it difficult to recruit sufficient numbers of patients to clinical trials. Currently, fewer than 5% of transplant patients are entered into prospective clinical trials of any kind.<sup>13</sup>

These issues are compounded by a lack of infrastructure, resource and capacity within individual transplant centres to support clinical trials and research. Transplant centres are not currently well-resourced to develop effective data collection. Not only is this a significant obstacle to the implementation of clinical trials, but it also hampers the retrospective analysis of patient outcomes data, which can often provide important insight into the factors that determine transplant outcomes.

Moreover, the central data registry in transplantation, the British Society of Blood and Marrow Transplantation (BSBMT), does not receive a sufficient or stable level of resources from the NHS or the Government to fully support the breadth of research needed to foster innovation and improve transplant outcomes.

Quality standards are also integral to achieving good outcomes in transplantations. All UK transplant centres have now achieved membership of the Joint Accreditation Committee (JACIE) of the International Society for Cellular Therapy (ISCT) and European Society of Blood and Marrow Transplantation (EBMT). Achieving the necessary standards to secure JACIE accreditation and membership has been found to improve transplant outcomes, and the UK is leading Europe in the number of transplant centres which have attained JACIE-accredited status. However, in the current financial context within the NHS, with pressure on resources such as data managers required to fulfil quality standard requirements, there is concern that retaining JACIE accreditation will prove challenging for UK centres, which may in turn affect outcomes.<sup>14</sup>

Every patient deserves to have the best possible chance of receiving a successful transplant. To ensure this, the Government and NHS England must promote and stimulate lifesaving research into best practice techniques and the factors affecting transplant outcomes, and must support the transplant community with the infrastructure and resource needed to translate research into clinical trials and practices, and retain high quality standards.

### OVER THE NEXT FIVE YEARS, THE GOVERNMENT AND NHS ENGLAND SHOULD:

1. Prioritise and support further research into stem cell transplantation so that the research community can continue their lifesaving work identifying the factors that affect transplant survival rates.
2. Establish a national stem cell transplantation trials network to ensure that innovative, potentially lifesaving new therapies are translated into clinical practice.

This network would allow for the rapid recruitment of participants across a number of transplant centres, and would help to standardise procedure and protocol. A trials network would also provide the necessary infrastructure and central data hub to manage, regulate and evaluate research and clinical trials for new transplant therapies. It is anticipated that such a network would be able to deliver 9-12 trials, across a number of locations, over a three-year period. Importantly, such a network must be sufficiently resourced to permit good access to clinical trials for patients irrespective of geographical location.

<sup>10</sup> An allogeneic transplant is one in which stem cells are donated by another person, either a voluntary donor or a sibling.

<sup>11</sup> British Society of Blood and Marrow Transplantation Annual Report 2012, p. 23.

<sup>12</sup> British Society of Blood and Marrow Transplantation Annual Report 2012, p. 64.

<sup>13</sup> Data provided by Professor C. Craddock, 2014

<sup>14</sup> Gratwohl, A. et al, Use of the quality management system “JACIE” and outcome after hematopoietic stem cell transplantation, *Haematologica*, 2014

3. Provide further funding for data resource to the transplant community to allow for the implementation of effective data collection and application in research and trials, and to meet JACIE requirements. Creating and stabilising this infrastructure would allow patients the opportunity to benefit from potentially lifesaving new therapies by participating in clinical trials, would improve the size and quality of patient outcomes data, and would maintain quality standards.

All political parties have expressed their desire to see cancer outcomes improved across the board. By taking these three steps, the Government and NHS can secure a research environment that will see us move towards significantly better outcomes for blood cancer patients undergoing stem cell transplantation.



**Over the next five years...**

**11,229**

people will need a transplant

**1,390**

won't receive the transplant they need

**6,297**

will get one from a stranger

**3,542**

will get one from a sibling

**2,224**

will NOT receive the best possible match

**4,073**

will have a 10/10 match

**567**

BAME patients will receive a transplant

**119** will have a 10/10 match

**119**

**448** will NOT receive the best possible match

**119** will receive cord blood cells

**119**

**6,297**

children and adults will get a transplant from a stranger

**1,042** will be alive at 100 days

**929** will be alive at one year

**1,133**

children

**4,596** will be alive at 100 days

**3,357** will be alive at one year

**5,164**

adults



**1,390** people  
won't receive  
the transplant  
they need.

Over the next  
5 years there will  
be an estimated  
**16,076** people  
living with  
the long-term  
effects of a stem  
cell transplant.



PART  
**THREE**

**The right post-transplant  
care for every patient  
who needs it**

For patients with blood cancer and other blood disorders, receiving a transplant is an important milestone. However, for many, transplantation is only the beginning of the journey towards rebuilding their lives. Transplant patients often have long-term care needs for many years as a result of their treatment.

By 2020, there will be over 16,000<sup>15</sup> people living post-transplant. A significant proportion of these people will be experiencing the long-term health effects of their treatment, and will require specialist support.

The Government's National Cancer Survivorship Initiative Report, published in 2010, recognised that more support will be needed for people living with, or recovering from, cancer. This is particularly significant given that by 2030 we are likely to see four million people fall within this category in the UK.<sup>16</sup>

In transplant, this need for support is particularly acute. Of all cancer treatments, stem cell transplant patients experience some of the most severe long-term effects. Indeed, a transplant patient is often described as 'a patient for life'.

Of those people living with the long term effects of transplant, 45% will suffer from Graft versus Host Disease (GvHD).<sup>17</sup> In general, patients with GvHD require closer monitoring and more frequent readmissions to hospital as a result.

Notwithstanding GvHD, post-transplant patients can experience a number of physical health effects of their transplant to varying degrees of severity. These include infertility, premature menopause, sexual dysfunction, fatigue, and problems with eyes, bones, teeth, joints and muscles, and other major organs. Such patients are also at higher risk of infections, problems with the immune

system, and second cancers. For some patients, symptoms can be mild, but for others they can be extremely difficult and debilitating, requiring frequent hospital care and significantly impacting their quality of life. In some cases, they can prove life-limiting.

As well as experiencing physical health effects of transplant, it is also common for patients to experience psychological effects, ranging from depression to post-traumatic stress disorder.

While many patients will experience post-transplant complications within five years of receiving the therapy, patients can experience long-term complications for decades. Indeed, complications experienced as far along as 25 years post-transplant can be severe and require specialist care.

Given the potential severity of the physical and psychological implications of transplantation, patients should expect to be offered comprehensive care to help overcome them, including psychological support, rehabilitation services and access to social worker support if necessary. Such care should be coordinated by transplant specialists and should ensure that patients can rapidly access high-quality services that fully meet their care needs. A model that should be explored to achieve this is a Clinical Nurse Specialist-led long-term follow up service.

Increasing the availability of such services will not only reduce long-term dependence on the NHS, but should also see more post-transplant patients able to return to work and active life. A recent Anthony Nolan study found that returning to work is considered an important milestone for patients in their recovery, and is also a strong indication of a good quality of post-transplant life.<sup>18</sup>

<sup>15</sup> Data provided and analysed by the British Society of Blood and Marrow Transplantation  
<sup>16</sup> Living With and Beyond Cancer, MacMillan Cancer Support, 2013  
<sup>17</sup> British Society of Blood and Marrow Transplantation Annual Report 2012, p. 28.  
<sup>18</sup> Way Back to Work Report, Anthony Nolan and Justice Studio, February 2015

However, as research published by Anthony Nolan has found, current NHS provision of high-quality post-transplant care is not consistent across England.<sup>19</sup> This leads to an unacceptable postcode lottery for patients in terms of accessing comprehensive care for their long-term transplant-related conditions. Issues of inconsistent provision are also impacting paediatric transplant patients now needing to transition to specialist long-term post-transplant care in the adult setting.

Indeed, a recent survey of 27 UK allogeneic transplant centres found that while nearly all provided dedicated follow-up care for up to a year post-transplant, only half of them followed up with patients five years after transplant, when long-term and late complications may still arise. Moreover, while most transplant centres felt able to focus on physical complications of transplant, only 28% felt able to offer psychological screening to all patients. The most commonly perceived barriers to the provision of comprehensive long-term and late effects clinic services were a lack of funding for psychological support and the cost of staff.<sup>20</sup>

The care you receive should be determined by the condition you have, and not by the area in which you live. As rates of survivorship improve and the number of patients requiring long-term care increases in turn, we need to ensure appropriate services are not only in place but available to all.

The means of achieving that aim within the field of stem cell transplantation are right in front of us.

The NHS must ensure that all transplant patients can access the high-quality care they need, for as long as they need it. In order to accomplish this, the NHS should:

1. Establish a national care pathway for patients for at least five years after transplant, including guidance on the type and standard of care that providers must offer across this pathway.  
  
This would remove national variation in the current care services offered to patients recovering from their transplant. While a five-year pathway would represent a vast improvement to current provision, ideally the pathway will extend for as long as the patient needs specialist follow-up post-transplant care.
2. Ensure that the whole care pathway is fully funded to meet patient need, by reforming the commissioning of stem cell transplant. This would ensure that transplant centres are able to offer comprehensive long term clinic services to patients, including rehabilitation and psychological support services.

By taking these actions, the NHS can ensure that all post-transplant patients have timely access to high-quality care to meet their needs. This will see patients more rapidly returned to good health and a good quality of life, reducing long-term dependence on the NHS.

## CONCLUSION

While significant progress has been made in stem cell transplantation over the last 40 years, there remain considerable challenges to overcome in the next five.

We have yet to ensure that every patient in need finds the best possible donor. A third of patients still do not survive their first year after transplant. And patients are still not guaranteed the long-term care and support they need to make a full recovery.

The Government has a term of five years to leave a strong legacy for blood cancer patients by working with us to improve stem cell transplantation. It can secure this legacy by taking the steps outlined in this report.

## OUR VISION IS CLEAR. WE NEED TO ACHIEVE:

- Continued growth of the UK's adult donor and donated cord blood stem cell supply.
- A research infrastructure that drives improvement of outcomes for all patients undergoing stem cell transplantation.
- Guaranteed access to high-quality care for every patient which meets their long-term needs after transplant.

By taking action in each of these areas, the Government can help us secure a future in which the destination for every patient is a cure.

## SUMMARY OF RECOMMENDATIONS

Between now and 2020 the Government should:

1. Maintain investment to support the work of the Anthony Nolan and NHS Stem Cell Registry to expand the number of young, male and ethnically diverse donors between the ages of 16 and 30.
2. Maintain investment to support the Anthony Nolan and NHS Cord Blood Bank to grow the UK's umbilical cord blood inventory.
3. Prioritise and support further research into stem cell transplantation so that the research community can continue their lifesaving work identifying the factors that affect transplant survival rates.
4. Establish a national stem cell transplantation trials network to ensure that innovative, potentially lifesaving new therapies are translated into clinical practice.
5. Provide further funding for data resource to the transplant community to allow for the implementation of effective data collection and application in research and trials, and to meet JACIE requirements.
6. Establish a national care pathway for patients for at least five years after transplant, including guidance on the type and standard of care that providers must offer across this pathway.
7. Ensure that the whole care pathway is fully funded to meet patient need, by reforming the commissioning of stem cell transplant.

<sup>19</sup> Roadmap for Recovery, Anthony Nolan and 2020Health, 2013

<sup>20</sup> Provision of Long-term Monitoring and Late Effects Services Following Allogeneic HSCT in Adults: A British Society of Blood and Marrow Transplantation Survey of UK NHS-Based Programmes, Hamblin, Snowden et al, 2015

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**Gillian Adams**, Patient Representative

**Louise Hannard**, Patient Representative

**Jane Woodward**, Patient Representative





DESTINATION  
**CURE**

**ANTHONY NOLAN**  
2 Heathgate Place  
75-87 Agincourt Road  
London NW3 2NU

**anthynolan.org**  
0303 303 0303

 @anthynolan  
 anthynolan

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NOLAN**

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