



All-Party Parliamentary Group  
**on Stem Cell Transplantation**

**ANTHONY  
NOLAN**

saving the lives  
of people with  
blood cancer

The Secretariat to the APPG on Stem Cell Transplantation is provided by Anthony Nolan

# **NO PATIENT LEFT BEHIND:** THE BARRIERS STEM CELL TRANSPLANT PATIENTS FACE WHEN ACCESSING TREATMENT AND CARE

---

# CONTENTS

Foreword	4
Executive Summary	5
Introduction	6
Diagnosis and referral	10
Access to treatment	12
Post-transplant recovery	15
Access to clinical trials and new treatments	18
Recommendations	20
Appendix 1: People who gave evidence	23
Appendix 2: Methodology	24
Appendix 3: Terms of Reference	25
References	26

# FOREWORD

On behalf of the All-Party Parliamentary Group (APPG) on Stem Cell Transplantation, I am delighted to present this report of the APPG's Inquiry into the barriers patients face when accessing treatment and care across the UK.

We are grateful to the patients, family members, clinicians, charities, and researchers who took time to contribute over 40 pieces of insightful written evidence to the Inquiry. This wide range of evidence was built on during an oral evidence session, where four witnesses spoke in a knowledgeable and often moving way about their personal and professional experiences of the barriers patients can face. We saw many of the same barriers and inequalities being highlighted within the written and oral evidence of this Inquiry.

We also heard how the COVID-19 pandemic has exposed and amplified existing health inequalities. This means that exploring barriers to treatment and care in all sectors of health care, including the field of haematopoietic stem cell transplant,

is more important than ever. This insight has raised many important questions, none of which have easy answers. But we are confident this report will contribute to an important conversation around equity of access to treatment and care for stem cell transplant patients.

This report concludes with recommendations to address the inequalities highlighted. It is likely some of the issues outlined are also impacting patients with other cancers and complex conditions. We hope the findings from this report will act as a springboard to encourage more research and a renewed focus on understanding and overcoming barriers to accessing treatment and care, and I would welcome conversations with decision-makers in all four nations on their approach to tackling them.



**Mark Tami MP, Chair, All-Party  
Parliamentary Group on Stem Cell  
Transplantation**

---

# EXECUTIVE SUMMARY

A patient's access to the treatment, care and support their condition requires should not be hindered by the circumstances of their background. However, evidence from the health research literature shows that variation in access to treatment and care exists across the UK.<sup>1 2</sup> This Inquiry looked to identify the barriers that stem cell transplant patients might face, making recommendations to ensure that all patients have equitable access to treatment and care.

A stem cell transplant is a potentially curative option for patients with both cancerous and non-cancerous haematological disorders. However, it is a significant undertaking, requiring a long hospital stay and often protracted period of recovery for patients which in some cases can take years. Patients are likely to have a period of time out of work or study and will require the support of family or other carers.

This Inquiry heard evidence that patients from a minority ethnic background will find it harder than patients from white Northern European backgrounds to find an optimum donor source for their stem cell transplant. We heard that patients may be thrown into financial hardship as a result of long recovery times from transplant. And we heard that patients from a minority ethnic background, poor socio-economic status and women are less likely to be involved in clinical trials.

The report is split into four sections, looking at:

- How specific barriers can impact a patient's diagnosis and referral pathway
- Patients' access to treatment
- Post-transplant recovery
- Patients' access to clinical trials and new treatments

Throughout the Inquiry we have heard about the barriers patients face from their own perspective and that of their family members, and we have also heard from clinicians across the UK, researchers and third sector colleagues. This has painted a picture of barriers patients may face, which broadly fit into the following five themes:

- *Socio-economic barriers*
- *Complex health systems, health literacy and education*
- *Cultural barriers*
- *Race, ethnicity and discrimination*
- *Geographical barriers*

---

# RECOMMENDATIONS

Based on the evidence we have received and through review of existing literature, this report proposes nine recommendations. The recommendations are categorised into five areas for improvement, these are:

- *Personalising care*
- *Supporting patients emotionally and financially*
- *Better demographic data capture*
- *Improving outcomes through research*
- *Investment in the stem cell register*

## PERSONALISING CARE

1. The NHS in England, Scotland, Wales and Northern Ireland should maintain and embed innovation in digital care where it has worked effectively and made access to care easier for patients during the COVID-19 pandemic. This will enable joined-up care to be delivered more effectively. In doing so, the patient voice should be represented to ensure changes work for patients and inequalities in accessing digital care are recognised and tackled.
2. Stem cell transplant teams should receive training, for example through Health Education England or as part of Good Clinical Practice training, to provide treatment and care in a culturally appropriate way. This includes information being provided throughout the course of treatment, post-transplant and as part of any clinical trials, in both inpatient and outpatient settings, to overcome any language or communication barriers.

3. Hospitals should work on initiatives that can help recognise the circumstances and particular needs individual patients have going into transplant and beyond. For example, through “prehabilitation” services and “recovery summaries” that enable better joined-up care between the Transplant Centre, the patient, their GP and other relevant services. Initiatives should identify potential barriers a patient may face during their transplant journey and solutions to address these early on. Measures should be taken by healthcare teams to ensure the patient has adequate housing/accommodation and care outside of hospital, with the involvement of a social services team and/or additional support services as required.

## SUPPORTING PATIENTS FINANCIALLY AND EMOTIONALLY

4. The UK Aligned Stem Cell Registry and the NHS across the UK should work to understand more about the challenges faced by related donors who are asked to travel to the UK from overseas, in terms of border restrictions, visas and costs. This work should scope how certain costs could be covered by the NHS to avoid it falling to patients and their families.

- 
5. The Department for Work and Pensions should review how much existing benefits, such as Employment Support Allowance and Statutory Sick Pay, are able to meaningfully alleviate the financial impact long-term recovery from a treatment like stem cell transplantation can have on patients.
  6. Across the UK, the NHS should commit to reviewing what psychological support is available and should ensure appropriate psychological support is available for all stem cell transplant patients.
  9. More research is required to gain a better understanding of how factors such as income, education level, social marginalisation, poor quality housing and health literacy affect access to treatment and outcomes; impact stem cell transplant patients' quality of life and wellbeing; and the unmet needs of these groups.
  10. The Government should invest in programmes helping to increase stem cell transplant patients' participation in clinical trials, such as the IMPACT clinical trials network, and make compliance with the NIHR "INCLUDE" principles mandatory for all Government-sponsored research.

#### **BETTER DEMOGRAPHIC DATA CAPTURE**

7. Every effort should be made by hospitals to provide data registries with accurate patient demographic data (with patient consent). Whilst NHS England are working with specialised services' data registries to capture ethnicity data from April 2021, other demographic data like socio-economic status and language also needs to be considered in order to better understand differences in outcomes.

#### **IMPROVING OUTCOMES THROUGH RESEARCH**

8. Further investment is needed in research to improve the use of, and outcomes from, stem cell transplants using haploidentical stem cell donation and cord blood stem cell donation, helping to contribute to better outcomes globally for patients from African, Caribbean, Asian and middle eastern and mixed ethnicity descent.

#### **INVESTMENT IN THE STEM CELL REGISTER**

11. The Department of Health and Social Care should continue to invest in initiatives to increase engagement with minority ethnic communities, encourage them to sign up to the stem cell register and work to improve retention. There may be particular lessons to be learnt from approaches engaging with faith and minority ethnic communities for organ donation.
12. The Department of Health and Social Care should invest in widening the global pool of donors, including strengthening stem cell registers in other countries, and should also support global partnerships to develop capacity for blood cancer and blood disorder care more generally too.

---

# INTRODUCTION

A stem cell transplant is a potentially curative option for patients with both cancerous and non-cancerous haematological disorders. During a stem cell transplant the medical team will put new, healthy stem cells into a patient's bloodstream. A stem cell transplant can be autologous, meaning the patient is their own donor, or it can be allogeneic meaning someone other than the patient is the donor. After a period of time the new stem cells will attach to the bone marrow, called engraftment, and start to make new blood cells. Stem cells are selected from a donor that is closely matched to a patient, giving them the best chance of overcoming their condition. However, it is a significant undertaking, requiring a long hospital stay and often a protracted period of recovery for patients which in some cases can take years. Patients are likely to have a period of time out of work or study and will require the support of family or other carers. Medical teams must perform a careful assessment to balance the potential benefits for patients versus the risks of the procedure and post-transplant recovery.<sup>3</sup>

More generally, medical research literature shows that social, cultural, economic and geographic factors can impact on a patient's access to healthcare and health outcomes.<sup>4,5</sup> Therefore, it is crucial to review how a patient's background and personal circumstances might impact their access to stem cell transplantation and related treatment, care and support. The following section provides an overview of the general barriers that are known to impact access across the health system, not just for stem cell transplant patients. Equity of access in healthcare refers to how easy it is for patients of different groups to get the treatment, care and support relevant to their disease. This inquiry sought to understand how these factors are relevant for stem cell transplant patients and where policy on health inequalities might not be adequately addressing these barriers.

---

## WHAT BARRIERS MIGHT PATIENTS FACE?

The reasons not all patients have equity of access and do not have equal health outcomes in the UK despite having access to the NHS are complex, and many are due to deep-rooted inequalities in society as well as the way that healthcare is delivered in the UK.<sup>6</sup> Some of the issues that patients might face were drawn out in this Inquiry and are listed below in broad themes. It should be noted that a patient may well face more than one of these barriers when trying to access the treatment, care and support they need, and many of these factors are inter-related.

### *Socio-economic barriers*

There is evidence from across different areas of healthcare that a patient's socio-economic status makes a difference to their health outcomes.<sup>7</sup> The reasons for this are complex and multifaceted but contributing factors include education and health literacy (see below), income and the lifestyle that someone can afford, and their relationship with the healthcare system. People living in lower income households are more likely to suffer from certain health issues, for example those associated with being unable to afford healthier lifestyles or being forced to live in poor housing conditions.

Studies have also shown people with lower socio-economic backgrounds are more likely to get certain cancers, however this does not appear to be the case for blood cancers.<sup>9,10</sup>

### *The complexity of healthcare systems and health literacy*

A patient's understanding of health and the healthcare system makes a difference to how easy it is for them to access treatment and care.<sup>11</sup> For example, if someone who is aware of the symptoms of cancer and understands how referrals from the GP work, they may be more likely to communicate their needs to the GP to refer them to the hospital for tests. Patients with good health literacy can navigate the health system more effectively and with greater assertiveness.

In addition, being able to understand health information and act on it makes a difference to health outcomes.<sup>12</sup> Patients for whom English is a second language might be at a disadvantage because it may be harder for them to understand health information and to navigate the healthcare system when information is not readily available in their first language.



---

### *Cultural barriers*

Language and culture are important aspects of health communications that affect healthcare access and quality.<sup>13</sup> Cultural differences can impact the relationship between patients and doctors, and potentially cause misunderstandings. Understanding how culture can influence a person's perceptions of health and medicine can make a difference in understanding a person's medical needs and how to communicate with them.

### *Race, ethnicity and discrimination*

There is evidence, most recently from the COVID-19 pandemic as well as the latest UK maternal mortality data,<sup>14,15</sup> that patients from different ethnic groups have different health outcomes and part of this is to do with a different experience of accessing and receiving treatment and care.

Historically, minority ethnic groups in the UK have faced systemic discrimination as well as a deeply troubling history of eugenics and discriminatory medical research globally. Not surprisingly, that means different ethnic groups may have different relationships with the healthcare system and understandably some groups are more likely to have a lack of trust in the medical establishment.<sup>16</sup>

The COVID-19 pandemic is an important example of how ethnicity might interact with other factors to result in poorer health outcomes. Some patients from minority ethnic backgrounds have been shown to have worse outcomes from COVID-19 than their white counterparts.<sup>17</sup> This is believed to be largely due to: increased exposure to the virus through living in a deprived area, larger households and job type; and the other health issues they are more likely to have which put them at greater risk.

There are many reasons for these disparity in outcomes,<sup>18</sup> whilst inherent biological differences may play a role, it is more likely that this interplay of race and ethnicity with other socio-cultural, political and economic factors, and discriminatory practices, may cause inequity within healthcare systems.

This is believe to be largely due to **1)** increased exposure to the virus through: living in deprived areas, larger households and job type and **2)** the other health issues they are more likely to have which put them at greater risk.

---

### *Geographical barriers*

Although the health service is national, it is different across the four nations of the UK and there are differences between areas within nations too. That is because much of the healthcare system is run by regional and local groups who decide what healthcare is required in their area. That means a patient living in one area might have access to a treatment option that a patient in a next-door area might not.

The following sections of this report will show how these identified barriers impact stem cell transplant patients' treatment and care at different stages of their pathway, informed by both review of existing literature and the submissions, both written and oral, to the Inquiry.

---

# DIAGNOSIS AND REFERRAL

To have the opportunity for a stem cell transplant, a patient will first need to be diagnosed with blood cancer or a blood disorder for which transplant is a viable and evidenced based treatment option for their disease and then be referred to a specialist transplant centre.

Some blood cancer and blood disorder patients might end up being diagnosed later than others as a result of the inaccessibility of the healthcare system and their health literacy; variation in diagnosis and referral practices across the country; and/or the bias of healthcare workers. As we included above, understanding how the healthcare system works could mean a patient gets access to a test more quickly or presents to the healthcare system with symptoms earlier. For many conditions, a longer period of time between diagnosis and receiving a transplant has been recognised to adversely affect patient outcomes.<sup>19</sup> However, while we know that blood cancers are more likely than other cancers to be diagnosed in an emergency setting,<sup>20</sup> there is currently a lack of research exploring if some blood cancer and blood disorder patients are more likely to have late diagnosis than others.

There is also a lack of research into whether some patients face barriers in being referred for a stem cell transplant. The presence of co-morbidities can affect whether someone is a suitable candidate for a stem cell transplant, and research has shown that lower socio-economic status is associated with a 50% increased prevalence of co-morbidities in those with cancer.<sup>21</sup> That means it is possible that patients from lower socio-economic backgrounds may be less likely to be referred for a stem cell transplant due to their co-morbidities.

**‘IT IS NOT UNCOMMON FOR US TO HAVE TO CONSIDER POST-TRANSPLANT LIFESTYLE UPFRONT, THINGS LIKE POOR QUALITY OR UNSTABLE HOUSING ARRANGEMENTS IS OFTEN A CONCERN DUE TO INFECTION RISK’.**

**A clinician giving written evidence**

---

Submissions to the inquiry also noted that a less widely studied area is whether patients with poor housing, no fixed abode or socially marginalised groups face delays or referral bias to transplant, due to concerns about post-transplant infection or ability to access post-transplant care. Measures can be taken to ensure involvement of a social services team and additional support staff, and access to housing including access to temporary accommodation close to the hospital. The availability of such services for transplant centres across the UK, provided by their NHS trust or affiliated charities should be reviewed.

---

# ACCESS TO TREATMENT

One widely recognised barrier to accessing a stem cell transplant for patients from minority ethnic groups is the availability of an unrelated donor.

A stem cell transplant relies on matching the tissue type of the patient to the tissue type of the donor, and a person's tissue type is related to their ethnicity. Around 30% of patients have a sibling who is a "full match".<sup>22</sup> A transplant from a fully matched sibling is the preferred donor source. For those who do not have a fully matched sibling, other types of transplant are available. These are a transplant from an unrelated donor, where 10/10 matches provide increasingly nearing equivalence in outcomes as a matched sibling, a one allele mismatched transplant (9/10), a cord blood transplant, or a haploidentical transplant where a patient receives cells from a relative who is half-matched to their tissue type.

In terms of finding a match for minority ethnic patients, recent (not yet published) analysis by Anthony Nolan has shown that although patients of all ethnicities have a roughly equal (95%) chance of accessing at least one type of donor for stem cell transplant

(when taking into account all possible donor sources including 9/10 unrelated donor, umbilical cord blood and haploidentical transplants), patients from a minority ethnic background have only a 37% chance of finding the optimal match (10/10 matched) from an unrelated donor, compared to 72% chance for patients from a British, Irish or Northern European ethnic background.

**'AS BAD AS I FELT PHYSICALLY, IT WASN'T THE TREATMENT THAT OCCUPIED MY MIND MOST... IT WAS THE SEARCH FOR A DONOR'**

**A patient giving oral evidence**

We heard in the Inquiry that for some patients who have moved to the UK from other countries with family members still living overseas, the logistics of arranging tissue-typing abroad can be time consuming. It can also sometimes incur additional expenses born by the patient and family members for use of hospitals and services in overseas countries to facilitate this testing. If siblings do need to travel for donation to a UK hospital this cost is not always covered by the hospital and therefore can become expensive for the family.

---

There is still, therefore, more to be done. In 2018 a Labour Party review, led by Eleanor Smith MP,<sup>23</sup> was undertaken to understand why over several years, the number of suitable donors for patients from minority ethnic backgrounds fell, while patients from these backgrounds in need of blood, stem cell and organ donation rose. Recommendations included a strategy to promote increased collaboration between local, national and international organisations as well as the need to create a culture of normality around donation, which is crucial to raising donor rates.

We heard in the Inquiry about successful initiatives within the organ donation community to increase sign ups from minority ethnic donors. This recent positive trajectory in the numbers of organ donors and transplants from minority ethnic communities cannot be attributed to a single intervention but points to the emerging policy recognition, over the last 20 years, that organ donation and transplantation inequalities exist in the UK, and that they need to be addressed. Recommendations from the *Taking Organ Transplantation to 2020*

*Strategy* demonstrate national policy recognition of the need for meaningful engagement with faith groups regarding the issue of organ donation. This has been translated into tangible action with funded community programmes, such as the Community Investment Scheme and the Living Transplant Initiative.

**‘WE NEED TO THINK ABOUT A GRASSROOTS APPROACH TO BUILD TRUST AND CONFIDENCE IN STEM CELL DONATION.’**

**Professor of Diversity in Public Health giving written evidence**

For patients from a minority ethnic background, improving access to unrelated stem cell donors is important because every donor from a minority ethnic background could be the best possible match for a patient in need. Equally important is improving the outcomes of haploidentical and cord blood transplants, as patients from a minority ethnic background are more likely to rely on these alternative sources of donor cells.<sup>24</sup>

---

As well as the difficulties in finding a match, some respondents told the Inquiry about a lack of communication from medical teams with regard to trying to find a potential donor, leaving the patient to contact a relevant charity directly to work on their behalf. These families report feeling helpless and unsupported at a critical time.

The Inquiry learnt how the inability to find a match can mean patients from a minority ethnic background spend a substantial amount of time undertaking a patient appeal to encourage more people to join the register, in the hope they will be able to locate a match. This can be a huge emotional undertaking, with patients and their families having to talk about their diagnosis publicly, which might be taking place while they are receiving physically demanding treatments like maintenance chemotherapy.<sup>25 26</sup>

Another barrier that can potentially impact access to treatment is a patient's geographical location. To ensure standardisation and best possible care, all transplants take place in specialist centres which are The Joint Accreditation Committee ISCT-Europe & EBMT (JACIE) accredited.<sup>27 28</sup> There are 35 allograft centres across the UK, which means whilst patients will have a centre in their region, it may not be their local hospital.<sup>29</sup>

In light of this, we heard that many patients have to travel significant distances to their nearest transplant centre. Concerns were raised in the Inquiry that longer distances, and increased travel, impact on both access to transplant and post-transplant care and follow up. Whether this has an impact on clinical outcomes will be an important area to review in the UK setting. It is important to assess patient-reported outcomes, quality of life and impact on well-being of family and carers, to understand the real-life impact of a patient's distance from their Transplant Centre.

Geographical barriers are particularly felt in the devolved nations where there are fewer transplant centres, meaning that patients will have to travel greater distances for their transplant and may even be referred to a transplant centre in England. It also impacts on the availability of certain types of transplant such as ambulatory (outpatient) autologous transplants, where the patient must live within a certain radius of the Transplant Centre should emergency care be needed.

---

# POST-TRANSPLANT RECOVERY

Advances in stem cell transplantation have resulted in significant increases in the number of patients surviving the procedure.<sup>30</sup> Whilst this is very positive, increased survivorship means that more patients need support to deal with physical and psychological late effects but there is still a lot of variation in access. Despite robust evidence and consensus highlighting the importance of long term follow up, there is significant variation across the UK, with many areas not having access to the appropriate health screening or support services required.<sup>31 32</sup>

Recovery from transplant can be a lengthy process, and patients may require long stays in hospital, several trips a week back to their Transplant Centre in the weeks and months following the transplant, or a long time recovering at home when they are unable to work. This means a stem cell transplant can place a significant financial burden on patients, and patients with a lower income may face more financial strain. A lot of patients responding to this Inquiry voiced concerns about the financial burden of having a transplant. Patients flagged that employment can be put at risk through time off work and payment for basics, like parking and laundry, become overwhelming.

In addition, submissions to the Inquiry highlighted issues for patients with poor housing, no fixed abode or from socially marginalised groups. Recovery from transplant can be a lengthy process, and continuation of immunosuppressive medications, for example, in treating graft versus host disease can mean the patient remains immunocompromised for some time post-transplant. In light of this, a healthy lifestyle post-transplant is vital to the patient's recovery. Stable housing and adequate care arrangements are also crucial to reducing infection risk.

We heard that travel can become a huge concern to patients and their families, especially with regards to post-transplant care. Patients have to uproot their lives and sometimes separate themselves from family for several months which becomes a huge burden on their emotional and psychological well-being and post-transplant recovery. Throughout the pandemic, more care has been provided virtually with appointments being held over video call or telephone where possible. This has gone some way to address the issue of distance a patient may be from a Transplant Centre. However, another barrier emerges as quality of internet connection varies across the UK and patients and their families may not have access to the necessary equipment required for these virtual appointments.



---

One respondent remarked that since returning to Northern Ireland following treatment at a Transplant Centre in London, there had been no input from the transplant coordinator or nurse specialist, meaning some patients can feel they are left to manage alone. This issue is particularly acute when patients are a significant distance away from Transplant Centres. Another patient, who resides in a rural area, told us that they were unable to attend holistic care and support groups as they were too far from home and couldn't afford any extra petrol costs.

'I FOUND THAT THERE WAS AN ASSUMPTION THAT YOU WOULD BE ABLE TO GET TO HOSPITAL THREE TIMES A WEEK POST TRANSPLANT AND THAT SOMEONE ELSE WOULD TAKE YOU, IF MY FATHER'S WORK HAD NOT BEEN SO UNDERSTANDING I WOULD HAVE STRUGGLED TO MAKE THE APPOINTMENTS.'

**A patient giving written evidence**

Post-transplant recovery involves a number of follow-up appointments after discharge from the hospital. The Inquiry heard evidence that young men, particularly those from socio-economically deprived backgrounds, are often less likely to fully engage with the transplant process. This can result in missed clinic appointments and being non-compliant with the post-transplant medication regime. Submissions from the clinical community emphasised that conversations must start from diagnosis about how the patient would like to engage with the process and whether being able to communicate with other patients from a similar background who have been through a similar process could help with engagement.

Communication is of paramount importance throughout the transplant pathway. It is essential to obtaining valid consent, updating on progress, ensuring compliance with treatment and answering any patient concerns.<sup>33 34</sup> If a patient is unable to process the vast amount of information that comes with a blood cancer or blood disorder diagnosis and beyond, every effort should be made to ensure written and spoken communication is in a patient's first language throughout the transplant journey. The degree to which this is available in UK Transplant Centres,

---

in both outpatient and inpatient settings, and the impact this has on compliance with treatment and patient reported outcomes post-transplant, such as psychological wellbeing, is not well evidenced.

Submissions to the Inquiry highlighted the need to ensure that all care and support is provided in a culturally competent manner, meaning healthcare professionals have the ability to understand, communicate with and effectively interact with people across cultures. This means care and support that will take into account the individual patient and family needs, in terms of their socio-economic status, age, education, ethnicity, language needs and religion.

---

# ACCESS TO CLINICAL TRIALS AND NEW TREATMENTS

Clinical trials are a fundamental way of offering patients access to the latest medical advances and could potentially improve quality of life or even extend survival. However, many groups are under-represented, including people from minority ethnic backgrounds and lower socio-economic status, in clinical research.<sup>35 36</sup> The most socio-economically deprived people receive just half the number of referrals to early phase cancer clinical trials compared to the least deprived.<sup>37</sup>

Patient and public involvement in research is rarely designed to address the needs of all groups or the entire research process, and it often attracts particularly motivated community members, which can limit diversity and equitable representation from seldom-heard communities.<sup>38</sup> To involve patients from an minority ethnic background, clinical trials need to go beyond just inclusion in research design, but to encompass active involvement in setting research questions, helping shape study design, and actively informing study implementation, data analysis and interpretation, and dissemination of findings.<sup>39</sup>

This means some patients are missing out on the benefits that being part of clinical research can bring. It potentially limits the validity and applicability of the research to the UK's diverse population. Women

have also historically been excluded from clinical trials and as a result, data derived from a predominantly male population are commonly and perhaps inappropriately extrapolated for clinical use in women.<sup>40</sup>

The explanation for this under-representation is complex, with reasons including reluctance or mistrust from participants, lack of inclusion by researchers, structural inequalities, or perceived barriers such as language, cultural values, or geographical inaccessibility.<sup>41</sup>

There is a significant evidence base that shows that most clinical trials and research programmes do not take a culturally competent approach to research design and participant recruitment.<sup>42</sup> This means having a skilled team to recruit study participants from diverse patient groups and even co-designing studies in partnership with representatives from different communities. In the UK, there is no obligation to include or report on ethnicity data in clinical research<sup>43</sup> and in the UK policy framework for Health and Social Care research there is limited specific guidance on ensuring inclusion on the basis of gender, ethnicity, socio-economic status, disability or culture.<sup>44</sup>

---

Submissions to the Inquiry noted that language and educational barriers can impact a patient's ability to take part in a trial. If someone's first language isn't English this could lead to recruiter bias, and those working on the trial being less likely to recruit the individual as it may be more difficult to gain consent. Information on clinical trials often involves a lot of information and clinical jargon, therefore unless time is taken to explain the trial clearly, it can be difficult to comprehend and patients may be less willing to take part. Clinicians told us that it would be helpful to have standard patient information sheets in the other languages common to immigrant communities in the UK to address these difficulties.

**'CLINICAL TRIALS TAKE AN ENORMOUS AMOUNT OF TIME TO ORGANISE AND TAKE A LOT OF CLINICIAN TIME. THEY CAN BE EXTREMELY COMPLICATED TO DELIVER AND DIFFICULT FOR PATIENTS TO UNDERSTAND. IT CAN BE TOO MUCH INFORMATION FOR PATIENTS TO TAKE IN'.**

**A clinician giving written evidence**

Patients spoke about geographical barriers in their access to clinical trials. Taking part in a trial can mean needing to be able to attend more appointments, give more time and do more tests. For those patients who are already struggling with distance and the number of hospital visits, they may find this difficult to commit to. If a patient and their family are already struggling financially with hospital visits, this may add to their financial worries. Whilst some clinical trials do reimburse travel costs, this is not the same for all.

The Inquiry heard from clinicians and researchers about the benefits of including a diverse population in clinical trials. There are several reasons to prioritise more equal access to clinical trials. It ensures people have equal chance to access new treatments that may have clinical benefit; and improves data quality on how different treatments can benefit different patients. In these cases, all efforts should be made to ensure that clinical trials are as culturally competent as possible to appeal to, and successfully recruit, a diverse range of participants. One important initiative highlighted in the Inquiry to improve this is the National Institute for Health Research (NIHR) INCLUDE project which has the aim of widening inclusion to underserved groups.

---

# RECOMMENDATIONS

Through analysis of oral and written evidence, several key challenges emerged where the APPG on Stem Cell Transplantation believes further action is needed to tackle the barriers patients face when accessing a stem cell transplant and the care associated with it. Below we set out these recommendations and where possible, indicate where responsibility for taking a recommendation forward should lie.

## PERSONALISING CARE

1. The NHS in England, Scotland, Wales and Northern Ireland should maintain and embed innovation in digital care where it has worked effectively and made access to care easier for patients during the COVID-19 pandemic. This will enable joined-up care to be delivered more effectively. In doing so, the patient voice should be represented to ensure changes work for patients and inequalities in accessing digital care are recognised and tackled.
2. Stem cell transplant teams should receive training, for example through Health Education England or as part of Good Clinical Practice training, to provide treatment and care in a culturally appropriate way. This includes information being provided throughout the course of treatment, post-transplant and as part of any clinical trials, in both inpatient and outpatient settings, to overcome any language or communication barriers.
3. Hospitals should work on initiatives that can help recognise the circumstances and particular needs individual patients have going into transplant and beyond. For example, through “prehabilitation” services and “recovery summaries” that enable better joined-up care between the Transplant Centre, the patient, their GP and other relevant services. Initiatives should identify potential barriers a patient may face during their transplant journey and solutions to address these early on. Measures should be taken by healthcare teams to ensure the patient has adequate housing/ accommodation and care outside of hospital, with the involvement of a social services team and/ or additional support services as required.

---

## **SUPPORTING PATIENTS FINANCIALLY AND EMOTIONALLY**

- 4.** The UK Aligned Stem Cell Registry and the NHS across the UK should work to understand more about the challenges faced by related donors who are asked to travel to the UK from overseas, in terms of border restrictions, visas and costs. This work should scope how certain costs could be covered by the NHS to avoid it falling to patients and their families.
- 5.** The Department for Work and Pensions should review how much existing benefits, such as Employment Support Allowance and Statutory Sick Pay, are able to meaningfully alleviate the financial impact long-term recovery from a treatment like stem cell transplantation can have on patients.
- 6.** Across the UK, the NHS should commit to reviewing what psychological support is available and should ensure appropriate psychological support is available for all stem cell transplant patients.

## **BETTER DEMOGRAPHIC DATA CAPTURE**

- 7.** Every effort should be made by hospitals to provide data registries with accurate patient demographic data (with patient consent). Whilst NHS England are working with specialised services' data registries to capture ethnicity data from April 2021, other demographic data like socio-economic status and language also needs to be considered in order to better understand differences in outcomes.

---

## IMPROVING OUTCOMES THROUGH RESEARCH

8. Further investment is needed in research to improve the use of, and outcomes from, stem cell transplants using haploidentical stem cell donation and cord blood stem cell donation, helping to contribute to better outcomes globally for patients from African, Caribbean, Asian and middle eastern and mixed ethnicity descent.
9. More research is required to gain a better understanding of how factors such as income, education level, social marginalisation, poor quality housing and health literacy affect access to treatment and outcomes; impact stem cell transplant patients' quality of life and wellbeing; and the unmet needs of these groups.
10. The Government should invest in programmes helping to increase stem cell transplant patients' participation in clinical trials, such as the IMPACT clinical trials network, and make compliance with the NIHR "INCLUDE" principles mandatory for all Government-sponsored research.

## INVESTMENT IN THE STEM CELL REGISTER

11. The Department of Health and Social Care should continue to invest in initiatives to increase engagement with minority ethnic communities, encourage them to sign up to the stem cell register and work to improve retention. There may be particular lessons to be learnt from approaches engaging with faith and minority ethnic communities for organ donation.
12. The Department of Health and Social Care should invest in widening the global pool of donors, including strengthening stem cell registers in other countries, and should also support global partnerships to develop capacity for blood cancer and blood disorder care more generally too.

---

# APPENDIX 1: TERMS OF REFERENCE

## **LISTED BELOW ARE THE TERMS OF REFERENCE SET OUT FOR WRITTEN SUBMISSIONS TO THE INQUIRY.**

We have learnt from conversations with patients and clinicians that patients can experience varying quality of care and access to treatment. The Inquiry aims to understand how a patient's background can lead to barriers in accessing treatment and care and will explore options for addressing the identified barriers. We would like to hear from a range of groups including patients and their families, clinicians and healthcare professionals, researchers, policymakers and charities.

Exploring barriers to accessing treatment and care is more relevant than ever. The COVID-19 pandemic has exposed and amplified existing health inequalities. The purpose of the APPG Inquiry is to gain a richer picture of the variations to treatment and care, and explore recommendations to address the barriers highlighted.

This Inquiry will be made up of qualitative responses and produce experiential evidence. The Inquiry will accept evidence from patients, their families, policymakers, clinicians, researchers and others involved in the provision of treatment and care for people with blood cancers and blood disorders who may require a stem cell transplant. We are also interested

to hear from those with experience in other disease or healthcare areas who may have interesting insights into health inequalities.

## **WHEN SUBMITTING WRITTEN EVIDENCE, STAKEHOLDERS WERE ASKED TO ANSWER ACCORDING TO THE FOLLOWING QUESTIONS:**

- What barriers might patients with blood cancers and blood disorders face in accessing stem cell transplantation and post-transplant clinical care?
- What barriers might stem cell transplantation patients face in accessing the care and support they need?
- What are the experiences of people and their families who have struggled to access treatment, care and support that meets the full range of their physical, psychological and practical needs?
- What barriers might stem cell transplantation patients face when accessing clinical trials and related research programmes?
- What national, regional and local levers would support improving access to the care and support stem cell transplant patients need? Do you have any examples of best practice in other areas of healthcare?



---

## APPENDIX 2: METHODOLOGY

The Inquiry was informed by desk research carried out by the APPG secretariat with the support of a Medical Officer at Anthony Nolan, this information fed into the literature review. The APPG also collected written evidence submissions and held one oral evidence session, details of participants can be found in Appendix 3. The information received across these channels has informed this report and its conclusions.

This Inquiry has not used quantitative data in its presentation of evidence within the final report. Whilst we understand the importance of data covering large numbers of the population, this Inquiry lends itself better to experiential evidence and will act a foundational piece of work to better understand barriers a patient may face.

---

## APPENDIX 3: PEOPLE WHO GAVE EVIDENCE

The APPG Stem Cell Transplantation would like to thank the 40 people and organisations who submitted written evidence, with particular thanks to the people with experience of stem cell transplantation who shared their personal experiences.

### THE APPG ON STEM CELL TRANSPLANTATION HELD ONE ORAL EVIDENCE SESSION ON 4<sup>TH</sup> FEBRUARY 2021.

#### WITNESSES:

- **Rik Basra**, patient representative
- **Dr Andrew Clark**, Consultant Haematologist, NHS Greater Glasgow and Clyde
- **Dr Angharad Pryce**, Medical Officer at Anthony Nolan
- **Professor Gurch Randhawa**, Professor of Diversity in Public Health and Director, Institute for Health Research

---

# REFERENCES

- 1 World Health Organisation, Closing the gap in a generation: health equity through action on the social determinants of health - Final report of the commission on social determinants of health (2008)
- 2 The Marmot review, Fair Society, Healthy Lives. Strategic Review of Health Inequalities in England post-2010. (2010)
- 3 NHS England, 2013/14 NHS Standard Contract for Haematopoietic Stem Cell Transplantation (Adult). ([www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/f01/](http://www.england.nhs.uk/commissioning/spec-services/npc-crg/blood-and-infection-group-f/f01/) accessed February 2021)
- 4 World Health Organisation, op.cit.
- 5 The Marmot review, op.cit.
- 6 The Marmot review, op.cit.
- 7 The Marmot review, op.cit.
- 8 The Marmot review. op.cit
- 9 Mihor et al, Socioeconomic inequalities in cancer incidence in Europe: a comprehensive review of population-based epidemiological studies. *Radiology and Oncology*. 54(1):1-13 (2020)
- 10 Pearce et al. Are Transplants truly available to all, regardless of geography, socioeconomic status and ethnic group. The 46th annual meeting of EBMT Poster. *Bone Marrow Transplantation* (55)774-776. (2020)
- 11 JACIE Standards. EBMT ([www.ebmt.org/accreditation/jacie-standards](http://www.ebmt.org/accreditation/jacie-standards) accessed February 2021)
- 12 National Voices. Improving information and understanding: summarising evidence from systematic reviews. (2014)
- 13 National Voices, op.cit.
- 14 Public Health England. Disparities in the risk and outcomes COVID-19. (2020)
- 15 Knight M et al. Saving lives, Improving Mother's Care. Lessons learned to inform maternity care from UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2015-2017 (2019)
- 16 Public Health England. Beyond the data: Understanding the impact of COVID-19 on BAME groups (2020)
- 17 Public Health England. (2020) op.cit.
- 18 Public Health England. Public Health Outcomes Framework: Health equity report (2017)
- 19 Lown et al. Beating the odds: factors implicated in the speed and availability of unrelated haematopoietic cell donor provision. *Bone Marrow Transplantation*.48:210-219. (2013)
- 20 Blood Cancer UK. Delays Expected: The Current State of Blood Cancer Diagnosis in England (2019)
- 21 Louwman et al. A 50% higher prevalence of life-shortening chronic conditions among cancer patients with low socioeconomic status. *British Journal of Cancer*. (103):1742-1748. (2010)
- 22 Lown et al. op.cit.
- 23 Eleanor Smith MP. Ending the silent crisis: a review into black, Asian, mixed race and minority ethnic (BAME) blood, stem cell and organ donation (2018)
- 24 Lown et al. Beating the odds: factors implicated in the speed and availability of unrelated haematopoietic cell donor provision. *Bone Marrow Transplantation*.48:210-219. (2013)

- 
- <sup>25</sup> Williams, R “Everything to gain, nothing to lose?”: Patient campaigners, racialised inequity, and stem cell donor recruitment, British Sociological Association 70th Annual Conference. 13-15 April. (2021)
- <sup>26</sup> Williams, R. Mix and Match: Constituting racialised communities in UK Stem Cell donation, Wellcome Trust Research Fellowship. ([www.mixmatchsheffield.wordpress.com](http://www.mixmatchsheffield.wordpress.com) accessed February 2021)
- <sup>27</sup> JACIE Standards, op.cit.
- <sup>28</sup> NHS England, op.cit.
- <sup>29</sup> BSBMCT Transplant Centre List ([www.bsbmct.org/uk-transplant-centre-list/](http://www.bsbmct.org/uk-transplant-centre-list/) accessed January 2021)
- <sup>30</sup> Anthony Nolan. A pathway for post-transplant care (2019)
- <sup>31</sup> Hamblin et al. Provision of long-term monitoring and late effects services following adult allogeneic haematopoietic stem cell transplant: a survey of UK NHS-based programmes. *Bone Marrow Transplantation*. (52) 889-894. (2017)
- <sup>32</sup> Anthony Nolan. op.cit.
- <sup>33</sup> JACIE Standards, op.cit.
- <sup>34</sup> NHS England, op.cit.
- <sup>35</sup> Smart et al. The under-representation of minority ethnic groups in UK medical research. *Ethn Health*. 22: 65-82. (2017)
- <sup>36</sup> Ford JG et al. Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review. *Cancer*. 112(2):228-242. (2008)
- <sup>37</sup> Mohd Noor et al. Effect of patient socioeconomic status on access to early-phase cancer trials. *J Clin Oncol*. 31(2):224-30. (2013)
- <sup>38</sup> Ekezie et al. Patient and public involvement for ethnic minority research: an urgent need for improvement, *Journal of the Royal Society of Medicine* (2021)
- <sup>39</sup> Ekezie et al, op.cit.
- <sup>40</sup> Duma et al. Representation of Minorities and Women in Oncology Clinical Trials: Review of the Past 14 Years, *Journal of Oncology Practice*. 14:1, e1-e10. (2018)
- <sup>41</sup> National Institute for Health Research. Improving inclusion of under-served groups in clinical research: Guidance from the NIHR INCLUDE project. UK: National Institute for Health Research. (2020)
- <sup>42</sup> The BMJ. Racism in medicine ([www.bmj.com/racism-in-medicine](http://www.bmj.com/racism-in-medicine) accessed February 2021)
- <sup>43</sup> Treweek et al. COVID-19 and ethnicity: who will research results apply to? *Lancet*. 395(10242):1955-1957. (2020)
- <sup>44</sup> NHS Health Research Authority. UK Policy Framework for Health and Social Care Research ([www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/](http://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/) accessed January 2021)

---

**NO PATIENT LEFT BEHIND:**  
THE BARRIERS STEM CELL  
TRANSPLANT PATIENTS  
FACE WHEN ACCESSING  
TREATMENT AND CARE



All-Party Parliamentary Group  
**on Stem Cell Transplantation**

The Secretariat to the APPG on Stem Cell Transplantation is provided by Anthony Nolan



saving the lives  
of people with  
blood cancer