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How the Anthony Nolan charity is addressing haematopoietic cell transplant inequities from all angles

Dr Neema Mayor and Caitlin Farrow explore solutions in transplant inequity.

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The UK stem cell charity Anthony Nolan is uniquely placed to bring together patients, researchers, funders and healthcare providers to identify and resolve inequities in haematopoietic cell transplants (HCTs).

Patients undergoing HCT – the primary focus of Anthony Nolan – can experience disparities in outcomes based on their ethnicity. Despite the lifesaving potential of HCT for patients with haematological malignancies or immunological disorders, not all patients have the same chance of positive outcomes after HCT. This is something we are determined to change.

Identifying inequities in HCT

In 2024, research from Anthony Nolan in collaboration with the British Society of Blood and Marrow Transplantation and Cellular Therapy revealed significant disparities in HCT clinical outcomes – including transplant-related mortality (TRM) – correlating to patients' self-described ethnicity.[1] This was the first study on ethnicity and HCT clinical outcomes in the UK.

The study analysed data from over 30,000 HCTs from 2009–2020, including 14,000 allogeneic transplants. The data showed that Black and Asian patients undergoing allogeneic transplant had significantly higher risk of TRM at 100 days, and of death by any cause at 5 years, compared to White patients. Hazard ratios reached 1.5 or higher in the most significant comparisons.

Since the release of these results, we have been reflecting on the impact of these findings and where they should take us next.

A unique opportunity

As a research organisation as well as a healthcare charity, Anthony Nolan has strong relationships with patients, donors, transplant centres and other research groups. This allows us unique oversight and integration of the research process – from the initial identification of issues, through to the development of interventions with the potential to effect real change.

Our in-house policy and influencing team work directly with policymakers and key partners in the HCT landscape to make sure those evidence-backed changes are effectively put into practice on a national level.

Revealing the causes of inequities

One of the areas we are keen to focus on is the prevalence of inequities in paediatric HCT. Our 2024 study found the most pronounced disparities in paediatric outcomes – especially for Asian paediatric patients, who experienced a 32% risk of TRM compared to 15% for White paediatric patients.[1] Working together with paediatricians in the UK, we are developing new research that will expand upon these findings and help us determine the cause of outcome disparities in paediatric HCT patients.

We are also planning a 'State of the Nation' paper: an audit of the types of HCT that different patient groups typically receive in the UK. This would add to our foundational knowledge about factors in the clinical environment that could be contributing to inequities in HCT outcomes, and help us identify inequities in data reporting.

On this note, our research has identified major inadequacies in ethnicity data across the UK. Incomplete or absent ethnicity data for patients can limit the impact of research – and ethnicity data capture only became mandatory within the NHS in the past few years. Our 2024 study showed that, of 35,921 UK patients receiving an autologous or allogeneic HCT between 2009 and 2019, 1,824 patients (5%) had missing ethnicity data.[1]

We believe that mandatory ethnicity data capture should improve data availability; but issues of data quality may still remain. Our Research Data Manager Project aims to provide funding for embedded research data managers within transplant centres and seeks to improve the quality of ethnicity data for HCT patients across the UK.

Anthony Nolan's research has uncovered major inadequacies in ethnicity data.

Diversifying the donor pool

We know people from minority ethnic backgrounds in the UK have a lower chance of finding a fully matched donor, due to greater HLA type diversity within populations not described as White Northern European.[2] While the Anthony Nolan register is broadly representative of the UK population, we are determined to improve our register's diversity by recruiting more donors from minority ethnic backgrounds.

Our research initiatives also seek to utilise bioinformatics tools to identify regions of the world where targeted recruitment could produce more donors with sought-after HLA types among minority ethnic populations. Our pilot study with Indian stem cell register DATRI has produced promising initial results.[3]

International collaborations like this are crucial in maximising the impact of recruitment strategies – but recruitment initiatives alone are not enough to solve inequities in transplant outcomes.[4] This is why our research also expands beyond recruitment to alternative donor options and novel clinical strategies.

Anthony Nolan uses cutting-edge bioinformatics research to identify populations underrepresented in donations.

Finding all patients an acceptable match

Our long-running Patient/Donor Project continues to identify more permissive mismatches that could further expand the donor pool, with the potential to be especially impactful for patients from minority ethnic backgrounds. This project has, over the past 30 years, encouraged significant changes in donor selection processes across the UK – including an emphasis on the consideration of cytomegalovirus matching status alongside HLA match,[5] and the implementation of HLA-DPB1 matching.[6]

Elsewhere in the field of HCT research, one of the most promising advances is the use of cyclophosphamide post-transplant (PTCy) in mismatched unrelated donor transplants. This has shown efficacy in reducing the risk of major HCT complication graft versus host disease (GvHD) in US trials.[7] By reducing the risk of GvHD, the use of PTCy could expand donor options for patients without access to a fully matched donor; an advancement that could particularly benefit patients from minority ethnic backgrounds. As a key influencing body for HCT patients in the UK, Anthony Nolan's focus on PTCy is to help answer questions around its potential use in the UK and facilitate its uptake by clinicians, where appropriate.

Access for all

Beyond research, general equity of access is a priority across our organisation, including the way our website accommodates accessibility needs and our efforts to provide effective translation services for our patient information. Our Equity, Diversity and Inclusion strategy outlines the steps we are taking as an organisation to improve access and equity both within Anthony Nolan and in the wider community.

We also campaign for wider policy change in the UK regarding cell and gene therapies. As well as the potential to save the NHS hundreds of millions of pounds in projected costs,[8] novel cellular therapies such as 'off-the-shelf' allogeneic CAR-T could preclude the need for stringent patient/donor matching.

We will build on the momentum from the success of the Casgevy campaign for beta-thalassaemia and sickle cell disorder to illustrate the need for and impact of wider access to breakthrough cell and gene therapies, especially for patients from minority ethnic backgrounds who may have more limited treatment options.

Work with us to stay proactive towards the goal of healthcare equity

Undeniably, more needs to be done to address HCT inequities. With equity research in the US suffering a major blow from sweeping funding retractions,[9] preserving global scientific collaboration and resilience is more important than ever.

We now have the opportunity to set the standard for healthcare inequity investigation and intervention in the UK – but it will rely on open channels of communication and collaboration. Don't hesitate to reach out to our teams to find out how we could work together, towards a future where every patient in need of a transplant can survive and thrive.

References available on our website.

Meet the authors

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