ADDRESSING RACIAL DISPARITIES
IN REPRESENTATION ACROSS BLOOD, STEM CELLS, AND ORGAN AND TISSUE DONOR POOLS

Developed in partnership with:

stem cell club

The Canadian **Donation and Transplantation** Research Program
Programme de recherche en **don et transplantation** du Canada

ROYAL COLLEGE OF PHYSICIANS AND SURGEONS OF CANADA
COLLÈGE ROYAL DES MÉDECINS ET CHIRURGIENS DU CANADA

OVERVIEW OF UNDERREPRESENTATION IN DONATION

There is an underrepresentation of diverse donors across blood, stem cell, and kidney donation products, which has various impacts on patient care.

	WHY DIVERSE DONORS ARE NEEDED	LACK OF REPRESENTATION IN DONOR POOLS	IMPACT ON PATIENT CARE
BLOOD	People from different ethnic backgrounds have **differences** in **red blood cell minor antigen**[a] expression. For patients with **sickle cell**[b] disease, guidelines recommend **extended phenotype matching**[c] across these minor antigens. Individuals from specific racial and ethnic groups are also more likely to have sickle cell disease, requiring frequent transfusions.	In Canada and other western countries, people of African ancestry are underrepresented in donor pools. Individuals from these populations are also less likely to become repeat donors.	Without a diverse donor pool, it may not be possible to transfuse patients with minor antigen-matched blood. This could put them at an increased risk of **alloimmunization**[d] and other complications.
STEM CELLS	Patients are more likely to find an **HLA-matched**[e] unrelated donor from within their own racial and ethnic group.	**Racialized**[f] populations are underrepresented as donors. This is seen within individual registries and across worldwide stem cell donor pools. High **attrition rates**[g] also decrease the availability of donors for them.	Patients from underserved racialized and ethnic populations are less likely to have an available, fully matched unrelated donor.
ORGANS (KIDNEY)	Individuals from specific racial and ethnic populations are more likely to require a kidney transplant, due to disproportionately higher rates of end-stage renal disease. Patients are more likely to find HLA matched kidney donors from within their own racial and ethnic group.	Racialized populations are underrepresented in the pool of donors, both living and deceased.	Patients from underserved racialized and ethnic populations face longer waiting times and lower transplantation rates.

STRUCTURAL RACISM[h] IN DONATION POLICIES

These factors affect donors and patients across blood, stem cell, and kidney donation products.

EXAMPLES OF POLICIES THAT IMPACT DONORS

DISCRIMINATORY SCREENING QUESTIONS

These are questions related to **donor eligibility** or **infectious disease risk.** E.g. asking about a person's associations with the continent of Africa or people who are African.

These can sometimes stigmatize peoples of African descent.

INEQUITIES IN DONOR ELIGIBILITY CRITERIA:

Travel Restrictions:

Deferral of donors who travel to **malaria-endemic countries** for a period of months to years. Such policies **disproportionately affect ethnic donors**, who are more likely to have **ancestral ties** to regions with a higher prevalence of malaria.

Laboratory requirements:

Deferral of donors for **low hemoglobin levels** based on a single value hemoglobin cutoff will **disproportionately impact specific ancestral populations** (e.g. African, Middle Eastern, Southeast Asian populations) due to **increased risk of sickle cell and/or thalassemia trait**.[i, j, k, l]

EXAMPLES OF POLICIES THAT IMPACT PATIENTS

REFERRAL BIAS

Lack of referral of patients from ethnic/racial minority groups for stem cell or kidney transplantation evaluation.

PATIENT EVALUATION

The use of **race specific glomerular filtration rates (GFR) estimates**[m] in kidney transplantation can unfairly impact transplantation access for patients from specific racial and ethnic groups.

DONOR SELECTION PROCESS

Failure to prioritize patients with poor unrelated donor search prognosis scores for alternative donor sources in stem cell transplantation.
This can lead to **missed opportunities** for timely stem cell transplantation, particularly for racialized and ethnic groups.

SOLUTIONS TO ADDRESS RACIAL DISPARITIES IN DONOR REPRESENTATION

ADDRESS BARRIERS RELEVANT TO MULTIPLE RACIALIZED GROUPS

Identify and address the common barriers faced by various racialized groups, including historical mistrust of healthcare, lack of knowledge, and sociocultural beliefs and views.

RECRUITMENT AND RETENTION PROGRAMS TAILORED TO SPECIFIC POPULATIONS

Develop targeted recruitment and retention programs that maintain regular engagement with diverse donor communities.

These programs should include education, personal stories from diverse donors, and highlights of the impact of donation on specific individuals and communities.

PARTNER WITH ADVOCATES FROM DIVERSE POPULATIONS

Collaborate with advocacy groups and community leaders from diverse racialized and ethnic backgrounds to design recruitment, education, and policy initiatives that meet the specific needs of these populations, ensuring their involvement at every stage of the process.

EDUCATION AND TRAINING

Invest in ongoing education and training for healthcare providers and trainees, policy makers, and the general public, including conferences, workshops, and multimedia campaigns to raise awareness of racial **disparities** in donation.

ADDRESS SYSTEMIC RACISM AND ITS AFTERMATH

Recognize and address systemic racism in the donation process to rebuild trust with racialized communities by:

- Acknowledging and formally apologizing for past harms and their consequences to today
- Revising discriminatory policies
- Correcting biases in donor eligibility and treatment
- Improving access to optimal donation products for all patients

APPENDIX

A. RED BLOOD CELL MINOR ANTIGENS
In addition to the major ABO and Rh blood group antigens, red blood cells express many other surface proteins known as minor antigens. If a person receives blood containing mismatched minor antigens, their immune system may produce antibodies against these antigens, increasing the risk of alloimmunization and transfusion complications.

B. SICKLE CELL ANEMIA
A genetic blood disorder in which red blood cells become rigid and crescent-shaped, blocking blood flow and causing pain, fatigue, and organ damage. It mostly affects people of African, Caribbean, Middle Eastern, and South Asian descent, and often requires regular, closely matched transfusions.

C. EXTENDED PHENOTYPE MATCHING
The practice of matching blood donors and recipients for a wider set of red blood cell markers (beyond just ABO and Rh types). It helps reduce the risk of immune reactions in patients who need frequent transfusions, such as those with sickle cell disease or thalassemia.

D. ALLOIMMUNIZATION
When a person's immune system forms antibodies against foreign proteins (antigens) found in transfused blood or transplanted tissue. This can make it harder to find compatible donation products and increase the risk of transfusion or transplantation.

E. HLA-MATCHED
Human leukocyte antigen (HLA) matching compares immune-related proteins on the surface of cells to assess compatibility between a donor and recipient, especially for stem cell or organ transplants. A close HLA match lowers the risk of rejection and improves transplant success.

F. RACIALIZED
Describes people who are socially categorized and treated differently based on their perceived racial or ethnic identity.

G. ATTRITION RATES
The percentage of people who register to become donors (e.g., for stem cells or organs) but are then found to be unavailable to donate when asked (due to medical ineligibility or being unreachable or unwilling to donate).

APPENDIX

H. STRUCTURAL RACISM
Refers to the system of public policies, institutional practices, and cultural norms that perpetuate racial inequity. It impacts access to healthcare, education, housing, and employment, and contributes to ongoing health disparities.

I. SICKLE CELL DISEASE/ANEMIA
A genetic blood disorder in which red blood cells become rigid and crescent-shaped, blocking blood flow and causing pain, fatigue, and organ damage. It mostly affects people of African, Caribbean, Middle Eastern, and South Asian descent, and often requires regular, closely matched transfusions.

J. SICKLE CELL TRAIT
Occurs when a person inherits only one copy of the gene that causes production of sickle cell hemoglobin . People with the trait usually do not have symptoms of sickle cell disease but can pass the gene on to their children.

K. THALASSEMIA
An inherited genetic disorder that reduces the body's ability to make hemoglobin, the protein that carries oxygen in red blood cells. People with thalassemia often need regular blood transfusions to manage their symptoms.

L. THALASSEMIA TRAIT
Occurs when a person carries at least one copy of a specific mutation in the gene that directs hemoglobin production but still makes normal hemoglobin. While they usually have no symptoms or only mild anemia, they can pass the gene to their children.

M. EGFR
The estimated glomerular filtration rate (eGFR) is a calculation that estimates how well the kidneys are filtering the blood. It helps diagnose and monitor kidney disease.
Older formulas included a race-based correction for Black patients, which may have contributed to delayed diagnoses or treatments.

N. DISPARITIES
Differences in health outcomes, access to care, or quality of treatment that are closely linked to social, economic, and/or environmental disadvantages. These are often due to systemic inequities related to race, ethnicity, income, gender, or geographic location.

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