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Ending discriminatory practices in organ and tissue donation and transplantation (OTDT)

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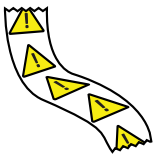
Issue

Gay, bisexual, and queer men—including Two-Spirit, trans, and gender diverse people (2S/GBTQ+) have long experienced discrimination in the process of blood, organ, and tissue donation. In response to HIV, donation policies that treat 2S/GBTQ+ people differently were introduced in Canada and many other countries. However, many policies have not evolved with our growing understanding of HIV transmission, treatment, and prevention and continue to exclude people from the donor pool based on sexual contact between men, rather than evidence-based behavioural risk factors for HIV. These policies are stigmatizing and harmful to 2S/GBTQ+ people and continue to reinforce negative stereotypes. These policies also result in a smaller donor pool with fewer available organs and tissues for all Canadians who need them.

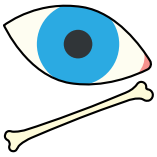
Health Canada recently revised Canadian blood donation eligibility criteria to reduce discrimination; however, there are many inequities that must still be addressed, particularly in regard to organ and tissue donation and transplantation (OTDT).

Opportunities To Enhance Equity

Aspects of OTDT that continue to discriminate and perpetuate stigma against 2S/GBTQ+ people include:



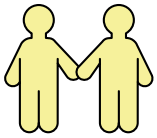
"Increased infectious risk" designation. Under current policy, solid organs (i.e. heart, lungs, kidneys, liver, pancreas) donated by men are labelled as coming from "increased infectious risk donors" if the donor has had sex with a man in the last year. This label perpetuates stigma against 2S/GBTQ+ people and false ideas about HIV transmission.



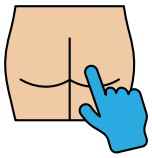
Reduced opportunity to donate tissues. When it comes to tissue donation (i.e. bones, skin, corneas and other tissues), 2S/GBTQ+ tissues are routinely rejected in Canada if the donor has had sex with a man in the last year. These donation criteria perpetuate stigma and needlessly exclude 2S/GBTQ+ people as tissue donors.

Inadvertent outing. As a result of being labelled "increased infectious risk", living 2S/GBTQ+ organ donors (who are most often considering donation to family members or people they know personally) may be outed. This is because the transplant team is required to inform potential organ recipients that the organ they are being offered is from a donor with an increased risk of passing on HIV, hepatitis B or hepatitis C. There is no standard process for ensuring potential donors consent to this disclosure or understand the risks to their privacy after disclosure.

Incomplete data collection. Current policies do not adequately document gender or account for transgender identities in the way data is collected, or in the way eligibility for donation is determined. This leaves transgender and gender diverse people vulnerable to misapplication of sex or gender-based policies and upholds a system that is inherently non-gender-affirming.



Serodiscordant partners. Seronegative sexual partners of people living with HIV are also marked as 'increased infectious risk' potential organ donors if they have been sexually active within the last 12 months. This doesn't account for the type of sex acts, HIV prevention mechanisms (like condoms and PrEP) or whether the partner living with HIV has an undetectable viral load (in which case HIV could not be passed through sex). This policy doesn't take into account current evidence on HIV transmission and perpetuates HIV stigma.



Invasive and unjustified physical exams. For deceased organ donors, standardized physical exams in some jurisdictions include an examination of the rectum to identify "evidence" of receptive anal sex.[1] This practice is not a reliable or evidence-based method to assess risk of HIV and perpetuates false and stigmatizing assumptions about 2S/GBTQ+ peoples' sexual lives. Perhaps more concerning, there is no standardized informed consent process for this specific invasive element of the physical exam.

Sex-based calculations in clinical care. Some calculations that impact clinical care pre- and post-transplant—for example, calculations related to kidney function—are based on patient sex. But, much is unknown when it comes to interpreting these calculations for trans and gender-diverse transplant patients.[2] Overall, there has been insufficient consideration of how transgender and gender diverse patients experience care in the organ donation and transplantation system.

Recommendations

We make the following recommendations to Health Canada:

1. Strike a working group with researchers, clinical and ethical experts, and 2S/GBTQ+ community members to critically review inequities facing 2S/GBTQ+ people in the OTDT system.

2. Remove the 12-month sexual contact criteria for 2S/GBTQ+ organ donors and revise current eligibility for organ and tissue donation to screen for evidence-based behavioural risk factors for HIV and hepatitis exposure. Eligibility criteria should be behavior-based and not identity-based. New eligibility criteria should both affirm and include people who are not cisgender or heterosexual and reflect current evidence regarding HIV transmission so as to reduce stigma.

3. Mandate Nucleic Acid Testing (NAT) be used for any donors at "increased infectious risk" (based on *updated*, evidence-informed, risk-based criteria as per Recommendation 2 above).

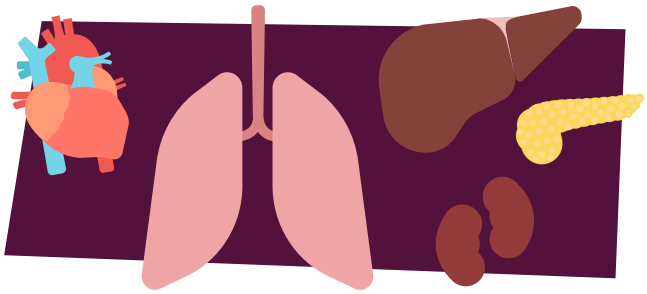
4. Given the risk of a missed window period infection in 2S/GBTQ+ organ donors is small after NAT testing, conduct a multi-disciplinary forum to evaluate the risks and benefits of consenting all potential transplant recipients for the risks associated with "increased infectious risk" organs.

5. Immediately call on provincial organ donation organizations to remove routine rectal examinations to screen for evidence of receptive anal sex and directly engage clinical networks to denounce this practice. Revise the Canadian Standards Association guidance document to remove the recommendation for routine rectal examinations for deceased male donors.[1]

6. Mandate the development of standardized informed consent materials for (A) any sensitive or invasive examinations required of organ donors, and (B) any donors whose organs and tissues will be labelled "increased infectious risk". Scripts should be developed to support this process.

Organ and tissue donation for 2S/GBTQ+ people in Canada

Organ Donation

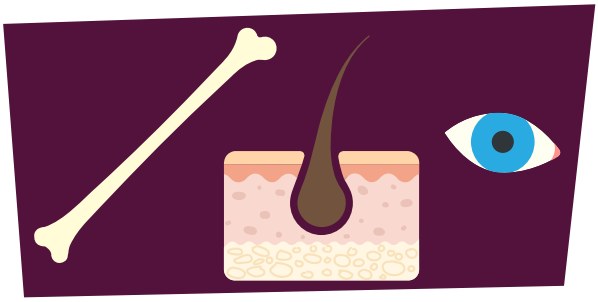


Donated organs can include the heart, lungs, kidneys, liver, and pancreas

Current Rules for Donation

Male organ donors who have had sex with another man in the last year cannot donate organs, except through an "exceptional distribution" process. This means that their organs are labelled as higher risk for HIV and other infectious diseases, purely because they have had sex with another man.

Tissue Donation



Donated tissues can include bones, skin, corneas and other tissues

Tissue donation is legal for 2S/GBTQ+ people, but in practice, these tissues are rejected by tissue banks before even being tested for HIV as there is no "exceptional distribution process" for tissues (unlike for organs).

Background: "Increased Infectious Risk" Organs and a Ban On Tissue Donation

Policies that treat 2S/GBTQ+ people differently in organ and tissue donation were implemented as a result of the AIDS crisis due to a higher incidence of HIV and other viruses like Hepatitis C and B among 2S/GBTQ+-identifying populations. **While it is important to prevent these types of infections wherever possible, Canada's policies for OTDT discriminate against 2S/GBTQ+ people based on sexual contact between men, rather than actual risk-associated behaviors and are not supported by current evidence. Developing true risk-based donation eligibility criteria would reduce homophobia, transphobia and HIV stigma that are perpetuated by current policies**.

Currently, men who have had sex with another man in the last 12 months are considered "increased infectious risk" donors when donating organs. Certain other groups are also considered "increased infectious risk" including non-male sexual partners of men who have sex with men, sexual partners of people living with HIV, sex workers, and incarcerated people. However, these criteria mean many people are considered "increased infectious risk" without ever engaging in behaviours that would put them at risk for HIV. For 2S/GBTQ+ donors, current screening procedures do not take into account HIV prevention methods, like condoms, pre- and post-exposure prophylaxis (PrEP and PEP), or the type of sexual behaviours associated (or not associated) with transmitting HIV. The importance of the Undetectable = Untransmittable (U=U) message—the fact that people living with HIV who have an undetectable viral load can't transmit the virus via sexual contact—is ignored by these eligibility criteria, which continue to consider sexual partners of anyone living with HIV "increased infectious risk." This unecessarily restricts donation from HIV seronegative sexual partners of people living with HIV (who may have a lower risk of transmitting HIV than the general public). The risk of transmission of HIV via organ or tissue donation from a person living with HIV with an undetectable viral load is not known and is an important area of further research.

While donated organs from "increased infectious risk" groups are permitted by Health Canada under an exceptional distribution program, tissues like skin, tendons, corneas and bones are rejected by tissue and eye banks from men who have had sex with a man in the last 12 months. The exceptional distribution process by which 2S/GBTQ+ organs can be donated is not applied to tissue donation in Canada because the need for tissues is viewed as less immediate and less likely to be lifesaving as compared to organ donation.

The exceptional distribution process and functional ban on tissue donation are discriminatory and harm 2S/GBTQ+ and people living with HIV by perpetuating stigma. Needlessly restrictive policies, including the 12-month abstinence period required for 2S/GBTQ+ to donate organs without an "increased infectious risk" label (or to donate tissue at all), reinforce false perceptions about 2S/GBTQ+ people and HIV risk. These policies incorrectly suggest to the public and to medical professionals that sex among 2S/GBTQ+ is inextricably linked to HIV exposure and that HIV transmission is a threat, regardless of efforts to test, treat, or prevent exposure to HIV.

Creating Vulnerabilities and Outing 2S/GBTQ+ People

Under the exceptional distribution program—applied to all 2S/GBTQ+ people who have had sex with a man in the last 12 months—potential transplant recipients are informed that the organ they are being offered is from an 'increased infectious risk' donor and has an increased potential to expose them to HIV or other viruses. While 2S/GBTQ+ identity isn't disclosed specifically, this process creates vulnerabilities for 2S/GBTQ+ in living donation programs who aren't out but may have taken initial steps in being worked up as a potential organ donor for friends, family or other individuals known to them. Even if the potential donor declines to donate out of fear of being outed, if the potential recipient was known to them (as is the case in most living donations) donors may be forced to out themselves or lie about why the donation did not proceed. There is no standardized or structural protection in the health system for this eventuality. Potentially outing a donor to their family and loved ones could have irreversible outcomes for these relationships. This lack of consideration and planning may also result in potential recipients not receiving needed organs.

Throughout this process, there is no standardized method for obtaining informed consent from the potential living organ donor regarding the "increased infectious risk" label. While living donors are typically told about the

implications of the label, this conversation is not standardized and may not happen in every case. If the donor is deceased, a substitute decision maker (typically a family member or loved one) is consulted, but not always told about the "increased infectious risk" label and the fact that it is being applied based on 2S/GBTQ+ identity of the deceased. This disclosure may be highly relevant to members of systemically oppressed and marginalized populations. Introducing a standardized method to obtain informed consent specific to this exceptional distribution program is a vital and necessary step to establish respect, dignity and autonomy of 2S/GBTQ+ donors.

Rigorous Testing Means a 1 Year Ban is Unwarranted

While it is important to prevent transmission of HIV and other viruses through medical procedures, testing for HIV and other transmissible viruses is available for any organ or tissue donor regardless of the response to screening questions.

Screening potential donors for risk factors for transmissible infections is still important since there is a 'window period' in which the results of HIV (or hepatitis C and B) tests can be falsely negative (missing a true infection). This window period can be reduced to about 7 days using nucleic acid tests.[3] This means that screening based on a 1-year window of abstinence should be shortened dramatically. A screening questionnaire using evidence-based questions on HIV risk would reduce discrimination and stigmatization against 2S/GBTQ+ people and those living with HIV and increase the donor pool.

	HOW EARLY CAN HIV BE DETECTED?	AVAILABILITY
Nucleic Acid Test (NAT)	In most cases, HIV can be detected around 7 days after someone is exposed to HIV.	NAT is available across Canada, but is not routinely offered in every case due to an increased cost compared to other tests. NAT is currently mandated for 'increased infectious risk donors' in Canada.
Antibody/Antigen combination test (4th generation HIV tests)	In most cases, HIV can be detected 35 days after someone is exposed to HIV, but it is possible for HIV to be undetected for up to 12 weeks after exposure.	Antibody/Antigen combination tests are the standard test available in Canada and are routinely used to screen for HIV.

Understanding of Risk is Dynamic

HIV, like other infectious diseases, is distributed differently across many sociodemographic factors including not just sexual orientation, but sex, age, ethnicity, location, and other factors. However, most of these factors are not incorporated into organ and tissue donation screening and eligibility criteria. Rather than excluding certain demographic groups from organ and tissue donation—which is inherently discriminatory—we should determine eligibility based on known, evidence-informed risk behaviours. This is particularly true now, since our understanding of HIV transmission has grown dramatically since bans on blood, organ, and tissue donation were first introduced for 2S/GBTQ+ people.

Health Canada has recognized that eligibility criteria for blood donation based specifically on sex between men is a discriminatory process and have shifted their screening questions for potential blood donors to focus on higher-risk sexual behavior for all donors regardless of their gender or sexual orientation. The organ and tissue donation and transplantation system should be similarly updated.

Physical Exams to Detect "Evidence" of Anal Sex

For deceased organ donors, an exam of the body is performed to identify diseases or infections that could impact the organ recipient. In Canada, this may include a rectal exam to identify "evidence" of anal sex and to identify donors as 2S/GBTQ+ on the basis of HIV exposure. In reality, this practice offers no clinically relevant indication of HIV status.

Not only are rectal exams ineffective in identifying sexual activity, they both rely on and perpetuate homophobic notions about 2S/GBTQ+ identity, sexual behaviours, and HIV risk. No reliable evidence supports this screening method, and donors (or their substitute decision makers) are not offered a standardized informed consent process explaining the reasons for this exam. Forced rectal examinations have been used by police and others to persecute 2S/GBTQ+ in countries where homosexuality is criminalized.[4 5] For many 2S/GBTQ+ in Canada, these practices are emotionally and politically charged, tied not just to persecution, but to experiences of stigmatization and mistreatment in the medical system.

Recognizing Trans, Gender-Diverse, and Intersex Lives in OTDT

Currently there is no standardized method for documenting gender or transgender identity within the OTDT system in Canada. This means the system is not gender-affirming, or inclusive. A lack of capacity for the healthcare system to differentiate sex assigned at birth from gender identity means that there is less transparency, and often less support, for transgender or gender-diverse people involved in OTDT. When donation eligibility criteria are based on rigid, binary categories for gender and sex, these can be misapplied, resulting in exclusion and harm for many 2S/LGBTQ+ people. Clear guidelines and inclusive health information systems would reduce barriers to donation experienced by our communities and provide an opportunity for clinicians and other health care staff to provide culturally competent, gender-affirming care.

Greater clinician awareness and clinical guidance is needed to support positive outcomes for trans and gender-diverse organ donors and recipients.[6] Gender affirming hormone therapy may influence serum creatinine levels (a test of kidney function); yet much is unknown when it comes to interpreting kidney function for trans and gender-diverse transplant patients pre- and post-transplant.[2] More research and clinical guidance to support trans and gender diverse patients is needed to improve health equity and ensure positive health outcomes during and after transplant surgery. People who have been intersexualized have unique considerations. The impact of intersexualization on the OTDT experience is not well known and warrants a distinct focus in future research.[7]

A need for better data on equity in OTDT

2S/GBTQ+ people are not the only groups to experience inequities in the process of OTDT. In Canada, multiple studies demonstrate that, among people who need a kidney transplant, White people are more likely to receive a kidney than non-White people.[8 9] Some suggested reasons for this include less awareness of organ transplant options, language barriers, and fewer donors among relatives of the person in need. However, this may also be linked to other systemic barriers, including a lack of culturally competent, anti-racist approaches to health services delivery. Indigenous people are also less likely to receive a transplant compared to the rest of the population.[10] More needs to be done to understand the reasons for racial inequities in OTDT, and actions required to reduce these inequities.

Generally, more needs to be done to understand other equity issues impacting OTDT in Canada too. Research in other countries suggests that other factors like geographical location and obesity (especially among women) can impact likelihood of receiving an organ in those contexts.[11] However, more research is needed to understand how these factors influence donation in Canada, and what can be done to improve health equity in OTDT.

All Party Support to End Discriminatory Donation Policies

The Standing Committee on Health is a group of elected Members of Parliament from all political parties who review and discuss issues that relate to Health Canada, including bills and regulations. In the summer of 2019, this Committee heard testimony from expert witnesses from across the country on how to improve health outcomes for 2S/LGBTQ+ Canadians. The Committee's final report, endorsed by its members, includes an explicit call to end discriminatory donation policies, specifically that "the Government of Canada end all discriminatory practices related to blood, organ and tissue donation for men who have sex with men and trans people and adopt donor screening policies that are evidence-based, gender-neutral and behaviour-based."

Conclusion

Current guidelines and practices for OTDT in Canada discriminate against 2S/GBTQ+ people and perpetuate false assumptions about 2S/GBTQ+ sexual identity and HIV risk. We call on Health Canada to re-evaluate their eligibility criteria in line with current evidence for HIV exposure and transmission, actively support the removal of routine screening rectal exams (or immediately institute appropriate standardized informed consent processes), establish mandatory informed consent processes for donors whose organs and tissues will be labelled increased-risk, and consult with trans and gender diverse communities to better understand and address the inequities that they face in the OTDT system. By making our OTDT system more inclusive and respectful we will ultimately help donors, donor families and recipients. Safe implementation of the proposed changes will broaden the donor pool for both organs and tissues, benefitting Canadians at large.

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