

The rights and interests of First Nations, Métis, and Inuit in debates over deemed consent legislation for deceased organ donation in Canada: calls to action

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Summary

Nova Scotia, Canada is the first jurisdiction in North America to pass deemed consent legislation for organ donation. Individuals medically suitable to be deceased organ donors are considered to have authorised post-mortem organ removal for transplantation unless they opt out of the system. While governments do not have a legal duty to consult Indigenous nations before passing health legislation, this does not diminish Indigenous interests and rights in relation to the legislation. This analysis discusses impacts of the legislation, specifically intersectionality with Indigenous rights, trust in the healthcare system, transplant inequities, and distinctions-based health legislation. How governments engage Indigenous groups about the legislation is yet to unfold. Consultation with Indigenous leaders and engagement and education of Indigenous peoples is, however, key to moving forward legislation that respects Indigenous rights and interests. What happens in Canada is being watched globally, as deemed consent is debated as a solution to organ transplant shortages.

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The province of Nova Scotia, Canada is the first jurisdiction in North America to pass deemed consent or “opt out” legislation for deceased organ donation¹ Deemed consent legislation (DCL) means “competent members of a jurisdiction are assumed to have given their consent for deceased organ donation unless they have explicitly registered otherwise.”^{2(p.E1008)} Nova Scotia, enacted DCL on January 18, 2021, to address an increasing shortage of organs available for transplant. Simultaneously the province introduced frontline resources and infrastructure to further support a “culture of organ donation.”^{3(p.211)}

Canada faces a growing shortage of organs for transplant. In 2021, 2782 organ transplants were performed in Canada and 4043 people were on the organ transplant waitlist (57% were active on the waitlist and 43% were on hold due to medical or other reasons).⁴ The same year, 652 patients were removed from the transplant waitlist; 238 patients (38%) died while waiting for a transplant.⁴ Considerable debate exists between Canadian transplant decision-makers about whether DCL is the optimal approach for improving donor rates.^{3,5–7} Countries such as Spain (1979), Brazil (1997), and Wales (2013) have enacted DCL with differing

success.^{8,9} While in Nova Scotia it is too soon to know whether DCL is having the desired outcome, other Canadian provinces are considering adopting similar legislation.^{3,5,6,10}

A consideration missing from discussions in Canada is the interests and rights of Indigenous peoples—First Nations, Inuit, and Métis (FNIM). While governments do not have a legal duty to consult Indigenous nations before passing health legislation, this in no way diminishes Indigenous interests and rights in relation to DCL, nor does it lessen the value of engaging the respective Indigenous nations in meaningful consultation as a matter of policy and good government. The marginalization of Indigenous voices in designing organ donation and transplantation (ODT) services, policies, and legislation in Canada is reflective of the lack of Indigenous engagement globally on ODT issues, including addressing equity issues specific to Indigenous populations.¹¹

In drafting and passing DCL, Nova Scotia moved forward without consulting Indigenous groups, instead opting to engage Indigenous and other “historically underrepresented communities” through evaluation of the legislation.^{7(p.4)} As of 2022, Indigenous groups in Nova Scotia hold limited knowledge of the legislation and its potential impact upon their people. With other Canadian jurisdictions, and potentially other countries, considering DCL, this paper draws attention to the

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interests and rights of Indigenous peoples and the intersections with healthcare equity and public trust. “Calls to action” aimed at Indigenous, government, and ODT decision-makers are provided as initial steps for meaningful engagement and consultation with Indigenous peoples as DCL is debated in Canadian jurisdictions.

Canadian Indigenous peoples and organ donation and transplantation

Indigenous peoples make up 4.9% of the Canadian population, with First Nations making up 2.8%, Inuit 0.2%, and Métis 1.5%.^{12,13} Provincial, territorial, and federal governments share jurisdiction in the provision of healthcare for Indigenous peoples. The Canadian health system consists of intersecting agreements, policies, and legislation falling under federal and provincial/territorial control. Métis, Inuit, and First Nations are included in per capita funding allocations from federal fiscal transfers to provinces/territories and are entitled to access insured provincial/territorial health services as residents. Indigenous Services Canada’s (ISC), First Nations and Inuit Health (FNIH) provides federal funds and directly provide health services for status-First Nations living on reserve, and Inuit living on their traditional territories in Quebec and Labrador. These services supplement provincial/territorial healthcare, including primary healthcare, health promotion and supplementary health benefits.¹⁴

“Status Indian” is a legal identity of First Nations registered under the Indian Act. The federal government’s obligations to status-First Nations and Inuit for healthcare are described in Section 73 of the Indian Act. Not all First Nations are registered under the Indian Act. These individuals are called non-status Indians by the Federal government. Non-status First Nations are individuals who identify as First Nations but they or their ancestors were denied or lost their Indian status through processes of the Indian Act. For jurisdictional purposes, healthcare provided to status-First Nations living off reserve, non-status First Nations, Métis, and Inuit living away from their traditional territories all fall under provincial/territorial health jurisdictions.

As described above, Indigenous peoples in Canada have unique and complex relationships to healthcare access. This results in Indigenous patients and families commonly navigating multiple health jurisdictions complicated by the decentralised nature of the Canadian healthcare system. Inter- and intra-government coordination of healthcare responsibilities is disjointed particularly for status-First Nations and Inuit whose healthcare falls under both federal and provincial/territorial jurisdictions. Disputes between or within Federal and provincial/territorial governments about which government is responsible for costs associated with patient assessments, treatments, and other

healthcare costs, are not uncommon. Jurisdictional barriers prevent some Indigenous people from accessing government-funded supports such as medical transportation that are provided to other Indigenous people in the same geographical region. Navigating jurisdictional challenges adds additional stress to already complex medical circumstances, specifically for patients living in remote, northern, reserve, and rural (RNRR) areas.¹⁵

The Canadian public remain relatively uninformed about jurisdictional and other challenges faced by Indigenous patients when accessing healthcare.^{16,17} Widespread misconceptions that FNIM receive special healthcare privileges not afforded to other Canadians are indicative of a general unwillingness of Canadians to learn about and accept the legitimacy of Nation to Nation, Inuit to Crown, and government-to-government relationships with FNIM nations. The Truth and Reconciliation Commission of Canada,¹⁸ which operated between 2008 and 2015, made some progress in advancing public education and “calls to action” to address historical injustices experienced by Indigenous peoples; however transformational change remains slow. Racist thinking permeates healthcare delivery in Canada. This is fuelled by misperceptions that Indigenous people place a significant and unnecessary burden on the healthcare system largely due to poor lifestyles choices.^{19,20} ODT healthcare providers and systems are not immune to acts of individual and systemic racism which can disadvantage Indigenous patients. In the absence of Indigenous distinctions based ODT data that tracks FNIM patients moving through ODT systems, including lived experience data, there is no avenue to identity, name, and address racism.¹¹

Indigenous people in Canada experience poorer health outcomes as compared to the general population.²¹ In relation to end-stage organ failure and transplantation, Indigenous people have higher rates of acute and chronic illness contributing to organ failure, and they are likelier to face multiple barriers when accessing transplant waitlists.¹¹ Health inequities are accentuated among Indigenous populations in RNRR areas due to intersecting factors, including, inter-generational colonial impacts, geographical remoteness, a lack of local healthcare, poverty, and, food and housing insecurities.¹¹ Across Canada, inequities in ODT are downplayed or ignored because transplant programs and services operate in large urban hospital settings that are faced with a shortage of organs for transplantation. Addressing the complex needs of Indigenous patients living in RNRR settings for treatment of end-stage organ failure and transplant is complicated because many needs of patients fall outside of the mandates of transplant programs. Factors such as travel costs, a lack of local primary healthcare, jurisdictional disputes between and within governments about healthcare coverage, and inadequate supports for Indigenous patients who

relocate, are some of the challenges Indigenous patients face.^{5,11,22}

In the context of receiving ODT services, Indigenous people, no matter their circumstances or where they live, are understood to either comply or not comply to ODT assessment and treatment regimes, whether the circumstances they face are within their control or not.¹¹ While transplant programs aim for equity in organ allocation, they also place significant weight on utility considerations; given the shortage of organs, each organ should be transplanted into the recipient in which it will survive the longest. A chronic shortage of organs means placement of patients on transplant lists and the allocation of organs is ultimately about managing a scarce resource—organs. A patient who struggles to comply with pre-transplant requirements, such as missing medical appointments, even when the circumstances are beyond their control, is likely to be viewed as equally at risk of medical non-compliance post-transplant. This can disadvantage Indigenous patients, particularly those living in RNRR regions where a lack of local healthcare and geographical remoteness can impact a patient's ability to comply with medical requirements. When issues of utility are considered for either placement on a transplant list or in patient selection for available organs, Indigenous patients who face compliance challenges, risk exclusion.^{11,23} Similar concerns exist for Indigenous Australians, where a chronic shortage of organs, compliance labelling, and a dearth of evidence about post-transplant compliance, systematically disadvantages Indigenous patients who require a transplant.²⁴

Unaddressed inequities in public health and healthcare are directly linked to elevated rates of end-stage organ failure among peoples living in RNRR regions of Canada.^{24,25} For example, a lack of dialysis has led some ODT experts to call for prioritization of individuals living in these regions for deceased kidney transplant.²⁵ Research in the province of Ontario comparing demographic and clinical characteristics of northern Indigenous and non-Indigenous people found Indigenous peoples were notably overrepresented among patients requiring dialysis and a kidney transplant, with a younger age of disease onset and more rapid illness advancement.²⁶ Similarly, the average age of death for First Nations in the province of Saskatchewan living with chronic kidney disease, is approximately 14 years earlier than their non-First Nations counterparts, largely due to inadequate and inaccessible dialysis options.²⁷ According to Statistics Canada (2006–2016), the age-standardised mortality rate for First Nations living on reserve due to kidney disease was 9.6/100,000, as compared to 6.5/100,000 for First Nations living off reserve, and 4.3/100,000 for the non-Indigenous population.²⁸

A shortage of healthcare services treating end-stage organ failure in RNRR regions contributes to urban migration of Indigenous patients who are either forced

to travel long distances for frequent treatments or to relocate as individuals or families. The FNIH federal Non-Insured Health Benefits (NIHB) program covers some of the costs for status-First Nations and Inuit, such as medical transportation and accommodation. For Indigenous people who do not fall under federal jurisdiction (non-status First Nations, Inuit, and Métis), these patients are responsible for all costs associated with travel and relocation. The burden experienced by Indigenous patients and families, whether under federal or provincial/territorial jurisdictions, brought on by frequent, long-distance travel or negative experiences associated with relocation (e.g. long hotel stays, being away from family, additional living expenses), contributes to poor patient health outcomes.^{11,25} Even when Indigenous people live in urban centres where it is easier to access treatments for organ failure and transplantation, issues of poverty, racism, food and housing insecurities and overall poor physical and mental health, act as barriers to some patients receiving the care they need.

As stated above, a paucity of data documenting rates of end-stage organ failure, and ODT in FNIM populations masks how equity and utility issues intersect in the care of Indigenous ODT patients.¹¹ Currently, transplant programs across Canada have no way to determine how many Indigenous people requiring an organ transplant are: 1) refused placement on transplant wait lists, including the reasons why; 2) the number of Indigenous patients placed annually on transplant waitlists; 3) the length of time before they receive a transplant; 4) the number who die annually while waiting for a transplant; and 5) the number of Indigenous patients who decide against lifesaving treatments, including transplantation.¹¹ Of the few studies that exist, most involve status-First Nations because their status numbers are currently the only way in most regions of Canada that Indigenous patients can be identified in hospital utilization data. A 2021 systematic review of postoperative outcomes found Indigenous patients (namely status-First Nations) living with end-stage renal disease experience longer wait times to receive a transplant and have much lower rates of transplantation than non-First Nations people.²⁹ A second study found that First Nations are twice as likely to die while waiting for a liver transplant (10.6%) as compared to other wait-listed patients (5%).³⁰

Even less data exists documenting rates of organ donation in FNIM populations. Studies examining attitudes of Indigenous peoples about ODT report less willingness among Indigenous peoples to consider being an organ donor when they lack knowledge or direct experience about ODT.³¹ While cultural values are seen as both supporting or discouraging ODT, pragmatic and immediate needs of family members largely eclipse cultural and other beliefs such as mistrust in the healthcare system, when the viable lifesaving measure is

transplantation.³² Like other groups, FNIM have varying and complex understandings of ODT, based upon cultural values, where they live, knowledge of ODT, age, gender, and direct experience with ODT.^{11,32}

Deemed consent legislation

Increasing the number of available organs for transplantation is key to any transplant program. In North America, opt-in models are employed in all geographical regions except Nova Scotia, Canada. In Canada, affirmative or “opt-in” systems ask adults to register their intent for deceased organ donation generally through online registries which are linked to their healthcare identifier number, and which can be accessed by ODT organizations if the person becomes eligible to donate.⁵ Even when a person registers as an organ donor, family authorization is required post-mortem. This also applies to opt-out systems, and Canadian transplant programs strictly adhere to the wishes of the next of kin, who hold a legal right to make the final decision.⁵ In a DC system, “an individual deemed medically suitable to be a deceased organ donor has authorized post-mortem removal of their organs for transplantation unless the individual took a premortem action to register their dissent.”⁵ Tennankore and colleagues state that three factors influence whether rates of organ donation are likely to increase under an opt-out system: 1) next of kin post-mortem refusal rate; 2) the rate at which people in the jurisdiction opt-out of the system; and 3) the rate of eligible donors who normally do not consider donation nor hold discussions with their next-of-kin about their wishes, become donors under opt-out legislation.⁵ While there is considerable debate in Canada about the benefits of opt-in versus DCL opt-out systems, there is consensus that both systems require increased government investment. Enhancement of public awareness campaigns, health system transformations supporting donation, and increased investment in ODT infrastructure and personnel are arguably more important for increasing donor rates than if the system is opt-out or opt-in.^{3,5,7}

Deemed consent legislation and duty to consult with First Nations, Inuit, and Métis

Canada needs to move from seeing consultation as primarily a legal obligation to manage or a process to document concerns to instead seeing it as a valuable tool and opportunity to improve its relationship with Aboriginal groups and advance reconciliation and other shared objectives. Consultation and accommodation is a means to an end, not an end in itself.³³

Inuit, Métis, and First Nations are commonly considered special interest, cultural, or ethnic groups for

the purpose of designing healthcare strategies, policies, and legislation. Treating them as such is both a common practice of Canadian federal and provincial government decision-makers and medical experts.³⁴ Indigenous nations are rights holders. The rights they hold are embedded in section 35 of the Constitution Act, 1982³⁵ Treaty rights, and international rights, specifically the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP),^{35,36} for which Canada is a signatory. UNDRIP Article 19 declares: “States shall consult and cooperate in good faith with the indigenous peoples concerned through their own representative institutions in order to obtain their free, prior and informed consent before adopting and implementing legislative or administrative measures that may affect them.”³⁶

Across Canada, governments and ODT experts are debating the utility of DCL. In this debate, there is minimal discussion about the potential fallout for transplant programs if Indigenous health leaders and the people they represent are not consulted. Governments, however, do not have a legal duty to consult Indigenous nations before passing health legislation despite DCL directly impacting the interests and rights of Indigenous peoples. As a matter of policy and good government, meaningful consultation with FNIM is a key component for the development and success of the legislation. Consultation, including educating Indigenous health leaders and communities about the legislation, will address Indigenous mistrust of the legislation and associated healthcare, while shedding light on the lived experiences of Indigenous patients.

A touchstone of any strategy to increase the number of organ donors in Canada and elsewhere is patient and family trust and confidence in the healthcare system, and in transplant programs specifically. Transplant programs in Canada work hard to educate the public that the choice of organ donation ultimately remains the choice of potential donors.³⁷ A key principle used to encourage organ donation is free, prior, and informed consent, meaning once a person confirms their wishes to be an organ donor, consent can be withdrawn at any time prior to the procurement of organs. A deceased person’s next of kin play an important role in decision making because organ donation will not proceed without their consent. As a matter of respectful practice, ODT programs across Canada defer to the wishes of donor families.³⁸ While the goal of governments and ODT programs is to promote organ donation and reinforce free, prior, and informed consent, it is essential that ODT decision-makers consider how this goal might be undermined if DCL is enacted with limited public education and consultation.

Indigenous groups across Canada have a vested interest in ODT decision-making. The introduction of any new legislation, including DCL, applies to the population living in the jurisdiction where it is passed, and as

such the interests and rights of Indigenous groups living in the jurisdiction also apply. Free, prior, and informed consent is also a touchstone in Canada in building and maintaining trust between Indigenous nations and governments, institutions, and industry generally. In the example of DCL, the intersection of individual and collective rights and interests as they apply to FNIM nations respectively is key to understanding how Indigenous leaders and citizens are likely to consider the passing of the legislation. Decisions by governments and ODT decision-makers to invest in education and consultation aimed at FNIM peoples is also about protecting the integrity and public image of ODT. The level of mistrust in the healthcare system held by Indigenous peoples should be a key consideration in a government's decision to legislate DCL. Adopting this legislation without public education and consultation with Indigenous and other groups is a risky strategy, where potential negative outcomes for ODT generally, and transplant programs specifically could occur.⁵ The experience of countries such as Brazil,⁹ where DCL was passed in 1997 and quickly repealed because of public backlash, illustrates negative public perceptions, whether among Indigenous peoples or the broader society, can result in a public relations fall out for ODT systems.

Trust in Canadian healthcare

Considerable evidence exists documenting the experiences of Indigenous patients accessing Canadian healthcare. A central theme is the high level of mistrust of the healthcare system held by Indigenous groups.^{39–42} This finding is reinforced by egregious cases of racism reported in the media such as the case of Brian Sinclair in 2008⁴³ and Joyce Echaquan in 2020.⁴⁴ Inquiries into the treatment of Brian Sinclair, a 34-year old man who died of complications from a treatable bladder infection after being ignored by medical personnel for 34 hours while waiting in a hospital emergency room, and Joyce Echaquan, a 37-year old First Nations woman whose hours before her death livestreamed to Facebook healthcare workers verbally abusing her, paint a disturbing picture of racism in the Canadian healthcare system.^{43,44} Most recently, the results of a review commissioned by the B.C. Ministry of Health found similar problems existing in the province of British Columbia. The report states:⁴²

stereotypes of Indigenous patients being reluctant, mistrustful, or non-compliant made them [study participants] reduce their efforts to reach out. Others [study participants] discussed situations in which healthcare providers failed to give appropriate information to Indigenous patients, such as not properly explaining healthcare procedures or proceeding without informed consent...patients spoke of various other ways in which they had been “shut out” of care—from being physically locked out of buildings to being sent home without

assessment, treatment, or planning, leaving them to make repeated attempts to access care.^(p.45)

It is not surprising that procurement of organs for transplant is an area of healthcare where mistrust could be predictably high. While few studies have focused on the views of Indigenous peoples about ODT, of those that exist, fear that lifesaving care might be withheld so transplant teams can expedite procurement of an Indigenous patient's organs is a reoccurring theme.³¹ Fears of being an organ donor are directly linked to historical and contemporary experiences of Indigenous groups in Canada, where State leaders and supporting institutions, such as the Church or human service sector (health, education, justice and social welfare), failed to protect Indigenous peoples; failed to acknowledge and address abuses known to have been perpetuated against Indigenous peoples; and where evidence of abuses experienced by Indigenous peoples were deliberately covered up.^{11,23,31,45–47}

Mistrust of the healthcare system reaches far beyond the concerns Indigenous peoples have about racist attitudes held by non-Indigenous healthcare providers. Systemic racism refers to:²⁰

established laws, customs, or practices that are systematically reflected in and that produce racial inequities in society. Whether it is overt or unintentional or stems from oppressive or negative race-based policy, systemic racism contributes to health and socio-economic disparities, a greater exposure to risk, hazards, toxic environments, unfair perceptions, treatment, and injustices all of which ultimately influence health.^(p.03)

Systemic racism effectively operates through entrenched taken-for-granted assumptions that influence the decision-making culture of governments and related institutions. For example, if governments state publicly that equitable healthcare access for Indigenous peoples is an achievable goal of reconciliation but hold the belief this goal is practically unachievable, this is systemic racism. Additionally, if governments hold the belief that healthcare delivered to Indigenous peoples, particularly in RNRR areas is the best it can be given demands and constraints on healthcare systems, this too is systemic racism. While assumptions like these are not publicly stated as such, their entrenchment in the ways in which healthcare and related determinants of health are thought about is indicated by the persistent lower life expectancy of Indigenous peoples across Canada.^{19,48} The life expectancy of FNIM peoples has remained significantly and persistently lower than for other Canadians despite governments committing publicly to improving health outcomes and addressing determinants of health negatively impacting Indigenous populations.^{17,18,49,50}

The scepticism held by Indigenous peoples about healthcare systems is reinforced through their lived experiences.^{39–42} When considering DCL, a predictable

and reasonable concern is that the legislation could result in increased rates of organ donation among Indigenous populations, *but not* to equitable increases in the rates of Indigenous patients receiving organs.¹¹ Missing from discussions about DCL is the inclusion of mechanisms that identify, track and address inequities resulting from the legislation being enacted. Presently in Canada, governments and ODT decision-makers do not have processes to identify and track Indigenous patient populations in Nova Scotia to know if this is happening. As stated above, because health utilization data across provincial/territorial jurisdictions does not distinguish FNIM patient identities from other patient populations, it is impossible to know whether such a trend occurs when the legislation is implemented. The potential risk that Indigenous peoples could end up not benefiting from the legislation yet contributing through increased organ donation to the improvement of the health of the general population, suggests addressing equity issues for Indigenous peoples must be included within the scope of DCL.

Indigenous distinctions-based health legislation

In January 2021, Indigenous Services Canada (ISC), led by Federal Minister Marc Miller, launched a national distinctions-based Indigenous health legislation initiative. The initiative was mandated by Prime Minister Trudeau in 2019 and affirmed in the September 2020 *Speech from the Throne*.⁵¹ According to Miller, distinctions-based health legislation, “serves to improve access to high-quality, culturally relevant health services...that is responsive to the distinct needs of all Indigenous people, no matter where they live.”⁵² According to ISC, distinctions-based health legislation will provide a concrete framework in which “agreements and partnerships can occur, across the country, according to communities’ distinct needs, with the backing of stable resources”; have “deep” symbolic value, “that could incorporate the shared values and aspirations that emerge from engagement and the co-development process”; and “provide an opportunity to seek to address systemic issues in a positive, lasting way to create solutions to be put forward in collaboration with First Nations, Inuit and Métis to ensure health services meet their needs.”⁵²

As DCL is considered across Canada, it will be debated and decided upon at the same time distinctions-based Indigenous health legislation is being enacted. While ODT decision-makers may feel DCL exists separate and apart from distinctions-based Indigenous health legislation, it is important they consider the following: does DCL have the potential to contribute to systemic discrimination against Indigenous peoples? Does DCL contribute to “high-quality”, “culturally relevant” health services that are responsive to the distinct

needs of Indigenous peoples, no matter where they live, or will it potentially undermine this goal? Does DCL support the transformation of healthcare delivery through collaboration with Indigenous peoples in the development, provision, and improvement of services? And will DCL advance reconciliation with FNIM partners “based on the recognition of rights, respect, co-operation and partnership”?⁵²

Conclusion

The goal of DCL is to increase the number of organ donors and save the lives of more patients who require an organ transplant. While the goal and predicted outcome of the legislation appears to be straightforward, DCL is not being debated and passed in a societal context free of Indigenous rights and interest, health inequities and racism. Predicting harm to Indigenous groups or to public perceptions of ODT if Indigenous groups push back against the legislation, needs to be part of discussions about the societal value of the legislation. Addressing and avoiding potential harms is best approached through the involvement of FNIM health leaders and their communities. Public education and consultation in which government and ODT decision-makers are open to listening to the perspectives and experiences of Indigenous peoples is the basis for good policy and decision-making and protects the integrity of ODT programs across the country. How governments and ODT decision-makers proceed in engaging Indigenous groups across Canada on this issue is yet to unfold. However, decision-making, whether inclusive of Indigenous peoples or not, will ultimately lead to a response by Indigenous communities about the legislation. What the respective responses are of Indigenous groups will inform other Indigenous groups as they too consider the legislation at local, regional, and national levels.

The following “calls to action” are provided for Indigenous healthcare leaders, and government and ODT decision-makers:

1. Government investment to support FNIM involvement in ODT decision-making, including decision-making about DCL.
2. Creation of a national funded Indigenous-led working group focused on ODT and Indigenous peoples. The working group will serve as an advisory body to FNIM health leaders and government and ODT decision-makers.
3. Prior to further passing of DCL, governments invest resources to support FNIM healthcare leaders to develop culturally appropriate public education and consultation strategies aimed at informing FNIM about opt-in and opt-out ODT systems.
4. Respecting Indigenous data sovereignty principles, governments and ODT decision-makers partner

with FNIM health leaders to design data collection strategies that track distinction-based FNIM ODT data, including tracking the impact of opt-in and opt-out ODT systems.

- ODT programs invest in cultural safety training for administrators, clinicians, nurses, and patient and family support workers, including education about the intersections between health inequities and barriers preventing FNIM peoples from receiving and donating organs.

Contributors

Caroline L. Tait: Author, created the concept for the manuscript, writing, interpretation, literature search, and revisions.

Declaration of interests

No interests to declare.

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