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Sociodemographic Variables in Canadian Organ Donation Organizations: A Health Information Survey

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Background. Health systems must collect equity-relevant sociodemographic variables to measure and mitigate health inequities. The specific variables collected by organ donation organizations (ODOs) across Canada, variable definitions, and processes of the collection are not defined. We undertook a national health information survey of all ODOs in Canada. These results will inform the development of a standard national dataset of equity-relevant sociodemographic variables. **Methods.** We conducted an electronic, self-administered cross-sectional survey of all ODOs in Canada from November 2021 to January 2022. We targeted key knowledge holders familiar with the data collection processes within each Canadian ODO known to Canadian Blood Services. Categorical item responses are presented as numbers and proportions. **Results.** We achieved a 100% response rate from 10 Canadian ODOs. Most data were collected by organ donation coordinators. Only 2 of 10 ODOs reported using scripts explaining why sociodemographic data are being collected or incorporated training in cultural sensitivity for any given variable. A lack of cultural sensitivity training was endorsed by 50% of respondents as a barrier to the collection of sociodemographic variables by ODOs, whereas 40% of respondents identified a lack of training in sociodemographic variable collection as a significant barrier. **Conclusions.** Few programs routinely collect sufficient data to examine health inequities with an intersectional lens. Most data collection occurs midway through the ODO interaction, creating a missed opportunity to better understand differences in social identities of patients who register their intention to donate in advance or who decline the donation. National standardization of equity-relevant data collection definitions and processes of the collection is needed.

(*Transplantation Direct* 2023;9: e1494; doi: 10.1097/TXD.0000000000001494.)

An understanding of the distributions of sociodemographic factors in the Canadian organ and tissue donation and transplantation (OTDT) population is necessary to ensure equity, diversity, and inclusion (EDI) in the field. Currently, in Canada

there is a lack of clarity on which sociodemographic data elements are collected by individual organ donation organizations (ODOs), including information on individual variable definitions, measurement standards during data collection, and how

Received 14 February 2023. Revision received 12 April 2023.

Accepted 13 April 2023.

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Supported by a grant from Canadian Blood Services. Canadian Blood Services is a national, not-for-profit charitable organization that manages the supply of blood and blood products in all provinces and territories in Canada (apart from Quebec) and oversees the Canadian Blood Services Stem Cell Registry. In 2008, Canadian Blood Services became responsible for national activities related to organ and tissue donation and transplantation (OTDT), which includes national system development and operation of interprovincial organ-sharing

programs. Canadian Blood Services is not responsible for the management or funding of any Canadian organ donation organization or transplant program. Canadian Blood Services works with the OTDT community to improve the system for all Canadians.

All authors participated in the research design, performance of the research, interpretation of the findings, and writing of the article.

Supplemental digital content (SDC) is available for this article. Direct URL citations appear in the printed text, and links to the digital files are provided in the HTML text of this article on the journal's Web site (www.transplantationdirect.com).

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The authors declare no conflicts of interest.

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ISSN: 2373-8731

DOI: 10.1097/TXD.0000000000001494

data are reported. At present, there are no Canadian national recommendations regarding the collection of sociodemographic variables for the OTDT health system despite a growing body of evidence identifying inequities in outcomes and access to donation and transplantation associated with race, ethnicity, sexual orientation, gender identity, age, and location of primary residence both in Canada¹⁻¹³ and globally.¹⁴⁻³² The Public Health Agency of Canada recently made a public call for the acknowledgment of existing health inequities and the prioritization of the collection and analysis of equity-focused data across the country.³³ The Canadian Institute for Health Information (CIHI) has also reported a need for individual Canadian jurisdictions to standardize core equity variable collection to measure inequity on the national level.³⁴ Canadian Blood Services (CBS) seeks to standardize data collection in the organ donation community in Canada through the identification of best practices and expert consensus. The ability to harmonize across health information systems through the use of standardized variable definitions will increase our capacity to characterize and mitigate health inequities.

The purpose of this Canadian ODO environmental data scan is to identify what sociodemographic data are currently collected for deceased organ donors by each of the ODOs in Canada, data definitions, and processes of collection. This data collection is a necessary first step to quantify inequities in organ donation and to inform the design of strategies to promote EDI in organ donation in Canada. The findings of this pan-Canadian data scan will inform the development of recommendations for standard minimum and enhanced national datasets of equity-relevant sociodemographic variables in organ donation in Canada.

MATERIALS AND METHODS

Study Design and Setting

We conducted a self-administered, electronic, cross-sectional, closed survey that we distributed to a representative

from each of the 10 provincial ODOs in Canada via email to collect information about their current data collection of sociodemographic variables. Survey domains included sociodemographic data collected by the ODO, variable definitions, patient populations represented, processes for collection, staff training, barriers and facilitators to the collection of equity-focused sociodemographic data, and feasibility of collection.

Survey Instrument

The design of our survey tool was consistent with evidence-based survey science recommendations.³⁵⁻³⁸ We generated survey questions iteratively using a process informed by literature review and discussion with content experts and a diverse group of collaborators until we achieved thematic saturation, which was determined by collaborators. We then reduced items iteratively using a modified Delphi approach with 2 rounds of item rating until we had an appropriately concise survey; there were no formal criteria for consensus. Individual survey items were focused on single constructs. Attention was paid to making question stems brief and written for easy understanding in a neutral tone to minimize bias.³⁹ Absolute terms (ie, never, always), abbreviations, or complex terminology were avoided. We anticipated that some concepts and definitions (ie, “self-identification” for sociodemographic variables, definitions of gender, and sexual orientation) may be fluid or have an inconsistent understanding of their meanings so definitions were included for survey respondents (Table 1). When a specific perspective was sought from a respondent, this was made explicit in the question format.⁴⁰ Before dissemination the survey tool and electronic platform were pilot tested by collaborators (organ donation and transplant physicians, organ donation coordinators, CBS health systems analysts, and health equity specialists). The survey tool was examined for clinical sensibility and content validity. Our collaborators examined the tool for face validity, comprehensiveness, and clarity. The survey was translated and back-translated from English to French using a professional translation service and

TABLE 1.
Sociodemographic variable definitions

Variable	Variable definition
Age	Age in years
Sex	Sex assigned at birth based on physical reproductive organs (ie, male, female, intersex)
Gender	The gender that a person internally feels (gender identity) and publicly expresses (gender expression). A person's gender may differ from the sex a person was assigned at birth and it may change over time. Gender may be categorized as man, woman, gender diverse, nonbinary, or in other ways
Income level	Relative income refers to an individual's income compared with others in society. It is often expressed in terms of income quintiles
Education	An individual's highest level of educational attainment
Race	A social construct used to categorize people based on skin color and other physical features
Ethnicity	Refers to the cultural group that an individual belongs to (may be connected to race, nationality, language, religion)
Indigeneity	Refers to membership in First Nations, Metis, or Inuk/Inuit populations
Religion	Refers to self-identified affiliation with a religious ideology or group
Immigrant status	Length of time an individual has lived in Canada, including whether they are a refugee, immigrant, or Canadian-born
Primary language	The language(s) that an individual feels most comfortable speaking or reading fluently
Sexual orientation	An individual's romantic or physical attraction to a specific sex or gender
Housing	The housing situation of an individual, which could include housing tenure (own home, rent, homeless, etc) or inadequate housing (ie, overcrowded, damp)
Disability	Refers to whether an individual has a long-term or recurring physical, mental, sensory, psychiatric, or learning impairment that is considered to be a disadvantage
Health insurance	The extent of an individual's insurance coverage for prescription drugs, dental care, or other health services
Occupation	What job(s) an individual has to support themselves and their dependents financially

rechecked by a bilingual physician (C.L.R.). Electronic surveys in both English and French were created and disseminated using Interceptum (Interceptum.com). The electronic survey typically featured 1 item per page and contained 24 items. Respondents were able to review and modify their responses until the survey closed. The survey tool is appended (Appendix).

Recruitment

We used a purposive sampling technique using CBS contacts to target key knowledge holders with awareness of the data collected by their organization from each of the 10 existing ODOs in Canada who manage potential organ donors to the point of donation. ODO representatives were asked to answer questions on behalf of their organization and to consult with other staff as needed if there was any uncertainty. Our sample frame consisted of the following ODOs: British Columbia Transplant, Human Organ Procurement and Exchange Program, Southern Alberta Organ and Tissue Donation Program, Saskatchewan Health Authority Donation Program, Transplant Manitoba Gift of Life, Ontario Trillium Gift of Life Network, Transplant Quebec, Nova Scotia Legacy of Life, New Brunswick Organ Donation Program, and the Organ Procurement Exchange of Newfoundland and Labrador. Survey completion was entirely voluntary, and completion of the survey was taken as consent. No survey incentives were offered. Each respondent received a unique link to the electronic survey. We recontacted 3 programs after survey completion to obtain missing data.

Statistical Analysis

We targeted a response rate of 60% which compares with response rates of 55%–70% achieved in surveys of similar populations of healthcare workers using evidence-based survey science strategies.^{41–43} We have presented categorical item responses (ie, Likert scales) as numbers and proportions.

Outcomes

Our outcomes included the deceased donation patient population for which each ODO collects sociodemographic variables, the modalities by which they are collected, which

staff collect these data, methods of collection, the process of self-identification for variable disclosure, and barriers or facilitators to the routine sociodemographic variable collection in ODOs.

Ethics Approval

Ethics approval was not required for this quality improvement data scan according to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans.⁴⁴

RESULTS

We sent invitations to the 10 Canadian ODOs to respond to our survey. We received 10 complete responses representing a response rate of 100%. All surveys were completed, and none were excluded; we analyzed responses from all 10 completed surveys.

Respondents

Survey respondents were representatives of the ODOs across Canada known to CBS and were ODO managers and ODO coordinators with the expertise and scope of practice required to be knowledgeable about their ODO's sociodemographic data collection. Respondents completed our questionnaire (SDC, <http://links.lww.com/TXD/A536>) in English (n = 9) and French (n = 1).

Respondents from ODOs reported varying practices with respect to the collection of sociodemographic variables at different points for patients as they transition through the deceased organ donation system. Definitions of each sociodemographic variable as provided with our survey tool are included (Table 1). In general, there were little sociodemographic data collected on individuals registering their intention to donate organs via organ donation cards or electronic registry platforms (ie, signupforlife.ca) with respondents identifying postal code (1 of 10), city/town of primary residence (2 of 10), age (2 of 10), and gender (1 of 10) being the only identified sociodemographic variables collected by these registries (Table 2). Additionally, only 3 of 10 programs reported collecting sociodemographic information on the substitute decision-maker (SDM) of potential deceased organ donors.

TABLE 2.
Patient population for which each ODO collects each sociodemographic variable

	Referred potential donors	Approached eligible donors	Consented donors	Other	Not collected
Race	3 of 10	1 of 10	3 of 10	1 of 10	2 of 10
Ethnicity	2 of 10	–	2 of 10	1 of 10	5 of 10
Indigeneity	1 of 10	–	3 of 10	–	6 of 10
Migrant status	–	–	5 of 10	–	5 of 10
Primary language	–	1 of 10	2 of 10	1 of 10	6 of 10
Religion	–	–	–	1 of 10	9 of 10
Age	9 of 10	–	–	1 of 10	–
Occupation	–	–	7 of 10	–	3 of 10
Disability	1 of 10	–	3 of 10	–	6 of 10
Postal code	1 of 10	–	5 of 10	2 of 10	–
City/town	3 of 10	–	5 of 10	–	2 of 10
Sex	6 of 10	1 of 10	1 of 10	1 of 10	1 of 10
Gender	4 of 10	1 of 10	–	2 of 10	3 of 10
Sexual orientation	–	–	1 of 10	3 of 10	6 of 10

“–” indicates 0 of 10 (0%), “other” was specified by 1 program as retrospective data collected for “all deaths in ventilator units.” ODO, organ donation organization.

With respect to sociodemographic variable collection on deceased organ donors, respondents, reported age and postal code were uniformly collected (10 of 10 each). Sex was more commonly collected than gender (9 of 10 versus 7 of 10 programs) and much more so than sexual orientation (4 of 10 programs). Patient race was more commonly collected than ethnicity or Indigeneity (8 of 10 versus 5 of 10 versus 4 of 10, respectively). No ODOs collected data on education, income, health insurance, or housing status (Table 2).

There was considerable variation in the modality by which sociodemographic variables were collected. Free text, multiple choice, and extraction from other parts of the health record were described with some programs using multiple modalities. Race and ethnicity were poorly differentiated by programs with multiple-choice response options that included a combination of racial and ethnic identities. When collected, race, ethnicity, and indigeneity were collected via multiple-choice formats (4 of 10, 4 of 10, and 3 of 10, respectively) more commonly than free text (4 of 10, 3 of 10, and 2 of 10, respectively). Response options used for the multiple-choice format by which ODOs collect the race/ethnicity variable included “Aboriginal/First Nations, Arab, Black, Chinese, Filipino, Japanese, Korean, Latin America, South Asia, Southeast Asia, West Asia, White, Other, multiple visible minorities, next of kin (NOK) declines to answer, NOK not asked, unknown” in 2 programs, “Aboriginal, African/Black, Asian, Caucasian/White, Indian Subcontinent, Latin American, Middle Eastern, Multiracial, Pacific Islander, other, not documented, unknown” in one program and the fourth reported obtaining race/ethnicity from the kidney donor profile index calculation (with race categories of American Indian/Alaskan Native, Asian, Black/African American, Hispanic/Latino, Native Hawaiian/Other Pacific Islander, White, or multiracial).^{45,46} No ODOs used a distinctions-based response option for identification of indigeneity (ie, First Nations, Inuit, or Metis), rather, all programs that collected indigeneity (4 of 10) reported a single summary identifier to capture all indigenous peoples. The response option used to identify indigeneity was reported by 3 ODOs as “Aboriginal/First Nations” and 1 ODO collected “Aboriginal” (Table 3).

Ability (often called “disability”) was collected via free-text (4 of 10) and multiple choice (1 of 10) with 1 ODO reporting the question: “Did he/she have any physical limitations requiring assistive devices, such as a: cane, walker, or wheelchair?” and response options “no, yes (please explain), unknown” (Table 3).

Sex and gender were more commonly collected via multiple-choice questions (5 of 10 and 4 of 10, respectively) compared with free-text formats (3 of 10 each). Response options for sex when collected via multiple choice included male/female (x2), male/female/unknown (x2), and male/female/other (x1). Response options for gender when collected via multiple choice included “Agender, Bigender, Cisgender, Gender Fluid, Non-binary, Transgender, Two-Spirit, Unknown” at one site with the remaining 3 ODOs using “male, female, unknown, other” response options. One ODO highlighted that at the point of initial referral and registration, they had only 2 options for gender (male/female) but once the patient became a consented donor, they were able to access 4 response options (male/female/unknown/other). Sexual orientation was reportedly collected via free text by 4 of 10 programs, although 2 programs indicated this variable came from a standard donor screening questionnaire (SDC, <http://links.lww.com/TXD/A536>) in which there are questions about sexual behaviors but not sexual orientation (Table 3).

ODO coordinators collected most of the sociodemographic information from patients or their SDMs with a minority of sociodemographic information coming from allied healthcare staff. No demographic data were reported as collected by physicians. Only 1 program reported an integrated data system in which sociodemographic variables were “auto-populated” from other parts of the medical record (Table 4).

Regarding the method of sociodemographic variable collection used by each ODO, race, ethnicity, and indigeneity were collected by ODOs via self-identification (4 of 10, 3 of 10, and 4 of 10, respectively) and data collector impression (4 of 10, 1 of 10, and 1 of 10, respectively). Sex and gender were commonly collected indirectly from the medical record or a referral form (7 of 10 and 4 of 10, respectively) otherwise via self-identification (2 of 10 and 3 of 10, respectively) or data collector impression (2 of 10 and 1 of 10, respectively). Sexual

TABLE 3.**Modality by which sociodemographic variables are collected by each ODO**

	Not collected	Free text	Multiple choice	Hospital chart/other/unknown
Race	2 of 10	4 of 10	4 of 10	–
Ethnicity	5 of 10	3 of 10	4 of 10	–
Indigeneity	5 of 10	2 of 10	4 of 10	–
Migrant status	5 of 10	3 of 10	1 of 10	1 of 10
Primary language	6 of 10	1 of 10	–	3 of 10
Religion	9 of 10	1 of 10	1 of 10	–
Age	–	6 of 10	–	5 of 10
Occupation	3 of 10	6 of 10	–	1 of 10
Ability	6 of 10	4 of 10	1 of 10	–
Postal code	–	7 of 10	–	4 of 10
City/town	2 of 10	7 of 10	–	3 of 10
Sex	1 of 10	3 of 10	5 of 10	2 of 10
Gender	3 of 10	3 of 10	4 of 10	–
Sexual orientation	6 of 10	4 of 10	–	–

Rows were not mutually exclusive, may not sum to 10; “–” indicates 0 of 10 (0%). ODO, organ donation organization.

TABLE 4.
Staff who collect sociodemographic variables

	Not collected	ODO coordinator (program-based)	ODO coordinator (hospital-based)	Allied healthcare staff/other
Race	4 of 10	5 of 10	1 of 10	1 of 10
Ethnicity	5 of 10	3 of 10	1 of 10	1 of 10
Indigeneity	6 of 10	4 of 10	–	–
Migrant status	5 of 10	4 of 10	2 of 10	–
Primary language	6 of 10	4 of 10	1 of 10	–
Religion	9 of 10	–	–	1 of 10
Age	1 of 10	5 of 10	3 of 10	4 of 10
Occupation	4 of 10	4 of 10	3 of 10	–
Disability	6 of 10	3 of 10	1 of 10	–
Postal code	–	6 of 10	3 of 10	2 of 10
City/town	1 of 10	6 of 10	3 of 10	1 of 10
Sex	1 of 10	5 of 10	2 of 10	3 of 10
Gender	3 of 10	5 of 10	1 of 10	3 of 10
Sexual orientation	6 of 10	2 of 10	1 of 10	–

Rows were not mutually exclusive, may not sum to 10; "–" indicates 0 of 10 (0%); program-based ODO coordinators are based in ODOs, hospital-based ODO coordinators are primarily based in individual hospitals with training in the OTDT health interaction. ODO, organ donation organization.

orientation was reported as collected via self-identification by 4 of 10 programs, whereas 6 of 10 programs did not collect this variable. Of the 4 programs that collected sexual orientation, 2 of 4 specified the variable came from the donation screening questionnaire (SDC, <http://links.lww.com/TXD/A536>) (which asks about sexual behaviors, not sexual orientation) (Table 5).

For those ODOs that endorsed variable collection via self-identification, it was uncommon for programs to endorse specific training for data collectors in how to collect sociodemographic variables in a culturally sensitive way. Few programs employed a script explaining why sociodemographic data were being collected and what the data would be used for. It was rare for programs to employ self-identification for disclosure via a structured interview wherein interviewers read categories and response options from a list (Table 6).

Barriers to Routine Sociodemographic Variable Collection

Respondents endorsed a number of barriers to the routine collection of sociodemographic variables as a part of the clinical organ donation interaction (Table 7).

Facilitators of Routine Sociodemographic Variable Collection

Respondents identified a few facilitators of the routine collection of sociodemographic variables currently present within their ODOs (Table 8).

Feasibility

Respondents rated each sociodemographic variable in terms of the feasibility to collect for donors routinely on a 5-point Likert scale ranging from least feasible to most feasible (Figure 1). A slight majority of respondent ODOs endorsed donor race and indigeneity as being feasible to collect, although a minority felt donor ethnicity would be feasible. A larger margin felt that donor sex and gender would be feasible to collect with a slight minority endorsing donor sexual orientation as being feasible. Less sensitive demographics like donor postal code, city/town of primary residence, occupation, and age were all favored by the majority to be feasible to collect by ODOs. Donor income level, housing, education, and health insurance were all rated as less feasible for collection by ODOs.

With respect to sociodemographic variable collection on the SDMs of deceased organ donors, all 10 ODO respondent

TABLE 5.
Method of sociodemographic variable collection

	Not collected	Self-identification	Data collector impression	Medical record or referral form
Race	2 of 10	4 of 10	4 of 10	2 of 10
Ethnicity	5 of 10	3 of 10	1 of 10	1 of 10
Indigeneity	6 of 10	4 of 10	1 of 10	1 of 10
Migrant status	6 of 10	4 of 10	–	–
Primary language	6 of 10	4 of 10	–	–
Religion	9 of 10	–	–	1 of 10
Age	1 of 10	3 of 10	–	9 of 10
Occupation	5 of 10	5 of 10	–	–
Disability	6 of 10	3 of 10	–	2 of 10
Sex	2 of 10	2 of 10	2 of 10	7 of 10
Gender	3 of 10	3 of 10	1 of 10	4 of 10
Sexual orientation	6 of 10	4 of 10	–	–

Rows were not mutually exclusive, may not sum to 10; "–" indicates 0 of 10 (0%); self-identification occurs when the patient tells the data collector which category they identify as; data collector impression occurs when the data collector makes an assumption about which category the patient belongs in and classifies them accordingly.

TABLE 6.
Process of collecting sociodemographic variables via self-identification (or SDM-identification)

	Interviewers read categories and answer options from a list	Interviewers follow a script that explains why these variables are being collected and what they will be used for	Interviewers have specific training in how to collect this variable in a culturally sensitive way
Race	1 of 10	–	1 of 10
Ethnicity	2 of 10	1 of 10	–
Indigeneity	2 of 10	–	1 of 10
Migrant status	–	1 of 10	1 of 10
Primary language	1 of 10	–	–
Religion	–	–	–
Age	–	1 of 10	2 of 10
Occupation	–	1 of 10	1 of 10
Disability	1 of 10	1 of 10	2 of 10
Sex	–	1 of 10	2 of 10
Gender	1 of 10	1 of 10	1 of 10
Sexual orientation	–	2 of 10	1 of 10

SDM, substitute decision-maker.

TABLE 7.
Barriers to routine sociodemographic variable collection

Barriers to routine sociodemographic variable collection	Present
Lack of cultural sensitivity training	5 of 10
Lack of training in sociodemographic variable collection	4 of 10
Competing priorities having to gather other workups during the organ donation workup	4 of 10
Discomfort asking patients sensitive questions	3 of 10
Discomfort asking SDMs sensitive questions	3 of 10
Concern that asking sensitive questions could degrade trust in the therapeutic relationship	3 of 10
Sociodemographic variables not being relevant to the clinical care of the patient or potential donor	3 of 10
Concern that asking sensitive questions could decrease the likelihood of consent for donation	1 of 10
Lack of involvement with patient advocacy services during the organ donation interaction	1 of 10
Insufficient privacy in the clinical environment for sensitive questions	1 of 10
Discomfort asking about equity-focused demographics in systematically oppressed or equity-deserving groups because healthcare team members represent privileged groups	1 of 10
Increased burden of time spent collecting sociodemographic variables	1 of 10
Nonrelevance of sociodemographic variables to performance metrics	1 of 10

SDM, substitute decision-maker.

TABLE 8.
Facilitators of routine sociodemographic variable collection

Facilitators of routine sociodemographic variable collection	Present
Local legislation or health system policies regulating sociodemographic variable collection	0 of 10
Cultural sensitivity training for staff	3 of 10
Routine incorporation of patient advocacy services matched to the identity of the patient and SDM during the ODO interaction ^a	4 of 10
Specific staff recruitment or hiring strategies aimed at diversification of membership	0 of 10
ODO staff are sufficiently diverse to represent the population served	3 of 10 yes

^aOf the 4 respondents identifying routine patient advocacy services 3 were identified as pan-indigenous health advocacy services, 1 of 10 was nonspecific.
ODO, organ donation organization; SDM, substitute decision-maker.

representatives endorsed less feasibility for most variables compared with collection on donors. Most respondents reported that postal code and city/town of primary residence would, on balance, be more feasible to collect, but all other sociodemographic variables were rated as being less feasible to collect for SDMs of deceased organ donors (Figure 2).

Interpretation

In this environmental data scan of all Canadian ODO programs, a minority of programs routinely collect sufficient sociodemographic variables to examine health inequities with an intersectional lens.^{47,48} Intersectionality can be defined as a framework that recognizes human experiences are informed by complex interactions between each of our social positions in combination with forces of power and oppression⁴⁸—an intersectional analysis, then, often requires a large sample size to adjust for the interactions of multiple social identities.⁴⁹ Most of the data collected are done midway through the ODO interaction, specifically at the point where potential donors (or their SDMs) consent for donation. Data collection this late into the interaction creates a missed opportunity to better understand differences in social identities of patients who register their intention to donate in advance, or who are approached regarding donation and decline to donate. Previous research supports that there are select cultural, ethnic, and racial groups that are less likely to consent to organ donation.^{6,19,20,22,29,50,51} Understanding which intersecting identities are more or less likely to register to donate their organs or consent to donate organs once approached, would offer an opportunity to better understand the reasons why these groups are unlikely to donate, to design educational materials to enhance knowledge of the benefits of organ and tissue donation, and to inform strategies to disrupt barriers to accessing donation opportunities.

The social identities of the SDMs in deceased organ donation may also be highly relevant to their interaction with the ODO and their likelihood of consenting to organ donation. Only 30% of programs reported collecting information on SDMs, limiting our ability to evaluate inequities for this group. It is widely accepted that the ODO interaction with SDMs is a highly sensitive one and that expert training can improve

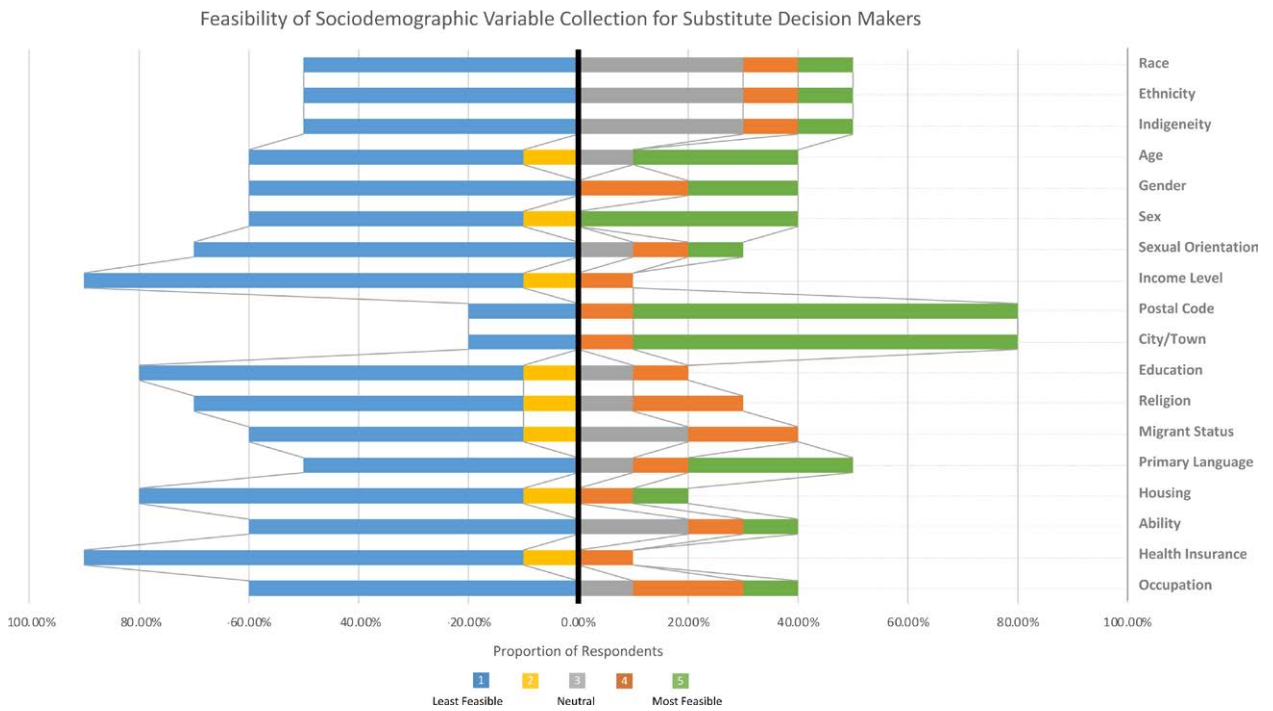


FIGURE 1. Feasibility of sociodemographic variable collection for donors.

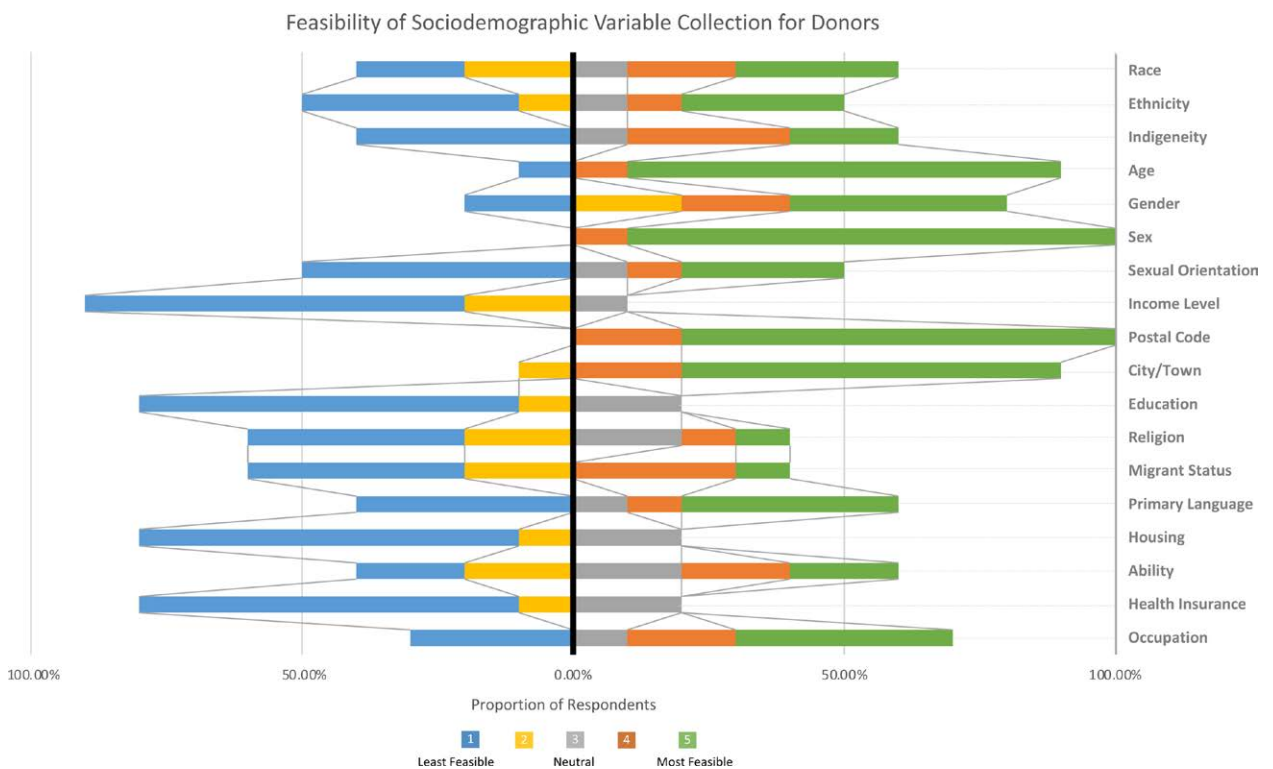


FIGURE 2. Feasibility of sociodemographic variable collection for substitute decision-makers of deceased organ donors.

consent rates and satisfaction with care.^{18,52-56} It would be reasonable to expect the addition of cultural sensitivity training and cultural support services into the ODO interaction with SDMs may have additional benefits and should be the focus of future exploration. Representation of SDMs in patient- and community-engagement processes should be explicitly sought to understand these perspectives.

Although predictors of consent for donation have been evaluated,⁵³ there remains a gap in understanding whether diversity of the ODO staff correlates with the likelihood of consent.

In considering which sociodemographic variables should be collected by the OTDT health system, one must balance the relative benefits with potential harms and costs. More

information on donor and SDM sociodemographic data will afford a greater ability to examine current inequities and monitor the effectiveness of interventions meant to mitigate them. It is now commonly held that self-identification, in which an individual is asked which of a given category they identify with, is a best practice when collecting sociodemographic variables (as opposed to assumptions made by the data collector).⁵⁷⁻⁵⁹ We identified a gap between current practice and best practice by identifying that equal proportions of programs still codified race and sex by data collector impression versus self-identification methods. This finding highlights an opportunity for the reformation of data collection processes with the benefits of gathering more accurate data and humanizing patients by respecting their lived experience through the data collection process—a benefit supported by the extant literature.⁶⁰ Simple educational interventions could facilitate self-identification as the primary mode for sociodemographic variable collection.⁶¹

Few programs reported incorporating specific training in culturally sensitive variable collection or the use of standardized scripts explaining why sociodemographic variables were being collected and how they would be used. Extant literature supports that concerns regarding privacy and discrimination can be major barriers to the disclosure of sensitive demographic information for patients.⁶⁰ Training in how to collect sociodemographic variables in a culturally sensitive way including standardized information about the reasons for collection, how the data will be used, and confirmation of privacy rules with respect to personal health information have been found to be effective facilitators of disclosure.⁶⁰ The organ donation system currently recognizes how emotionally charged the approach process can be and organ donation coordinators already receive training in the discussion of sensitive topics. These specialized staff would be well-positioned to offer culturally sensitive data collection with additional training. Our survey identified that ODO coordinators were the primary collectors of sociodemographic data in the Canadian organ donation system (as opposed to physicians or other allied health providers), making for an operationally simple target group for education about variable definitions and best practices for collection.

A lack of cultural sensitivity training was the most commonly identified barrier to the routine collection of sociodemographic data and an actionable target for interventions. Of the 4 programs that reported routine incorporation of patient advocacy services matched to the identity of the patient and SDM 3 of 4 identified these as indigenous-specific services without distinctions between First Nations, Metis, and Inuit populations. No programs reported having specific sexual identity or gender-diverse support services. Interestingly 4 of 10 programs reported collecting sexual orientation but 2 of 4 programs indicated this variable came from the donor screening questionnaire (SDC, <http://links.lww.com/TXD/A536>) in which there are questions about sexual behaviors but not sexual orientation, suggesting that complex nuances of the definition of sexual orientation may not be completely understood. Furthermore, some ODOs provided free-text examples of the classification systems they used to collect gender but the response options they provided reflected sex (male/female), and not gender (man, woman, nonbinary, etc). This is a common issue in health information systems and accurate use of the terms sex and gender has been identified by the Canadian Institutes of Health Research (CIHR) as a priority

area in their research action plan.⁶² Further exploration and action regarding inequities faced by sexual orientation and gender-diverse persons in the OTDT system are needed. To this end, we have formed a sexual orientation and gender identity OTDT patient and caregiver advisory team to codevelop community-informed priorities in both research and clinical services delivery for OTDT systems.

Limitations

Our findings are contextual and should not be extrapolated to other healthcare contexts wherein the costs and benefits of sociodemographic variable collection may differ or specific legislation or health policy exists to regulate this collection. However, by achieving a 100% response rate with this environmental data scan we were able to evaluate the policies of the Canadian ODO system comprehensively. Although these data scans explored the collection of a comprehensive set of sociodemographic variables, these did not explicitly explore the interactions between social identities and the factors used to determine when potential organ donors are categorized as increased risk donors (a designation given to donors deemed to be at increased risk for transmission of blood-borne infections). This designation disproportionately affects sexual orientation and gender-diverse populations. Differential treatment of these populations in the Canadian OTDT system requires further study. Health equity-focused data within transplantation programs were outside the scope of this project. Given the nature of the survey respondent biases must be considered as a potential limitation of our findings. Despite these limitations, this environmental scan of health equity-relevant sociodemographic data offers novel insight into the data currently collected by Canadian ODOs.

Conclusions

In this pan-Canadian environmental data scan, we found a minority of ODOs routinely collect sufficient data to examine health inequities with an intersectional lens.⁶³ Most data collection occurs midway through the ODO interaction, creating a missed opportunity to better understand differences in social identities of patients who register their intention to donate in advance or who decline the donation. To deliver OTDT health services equitably and accessibly for Canadians, it is imperative that sociodemographic data collection be accurate and comprehensive, both to identify opportunities for improvement and to monitor the effectiveness of interventions. A thorough understanding of sociodemographic variables that are properly collected, stored, and managed with the intent of enhancing health equity can enrich ODOs and the OTDT health system overall.

Future Directions

Standardization of health equity data practices through the development of a comprehensive minimum- and enhanced equity-relevant dataset including specification of which identities to collect, consideration of processes of data collection, and use of data is needed to provide equitable OTDT services across Canada. This collection should be standardized and harmonized in line with CIHI and CIHR recommendations. Culturally sensitive educational materials for OTDT health systems team members regarding best practices in the collection of sensitive sociodemographic information including standardized tools to facilitate collection would help address current barriers to the collection of sociodemographic data.

Equity-deserving populations should be engaged from the outset in the development of these materials. Tools developed and lessons learned should be translated to other healthcare contexts beyond OTDT to support the harmonization of sociodemographic variable collection across the health system. Further research is needed to understand the potential harms of expanded sociodemographic variable collection specific to OTDT patients, SDMs, and healthcare providers.

ACKNOWLEDGMENTS

Canadian Blood Services and Dr Christian LaRiviere for translation services.

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