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Registration and Familial Consent for Deceased Organ Donation Among Ethnic Minorities in Ontario, Canada: Opportunities for Improvement

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Abstract

Canadians on the transplant waiting list are dying every day because there are not enough available solid organs for transplantation. An important aspect of addressing this problem is to increase deceased organ donation consent rates. Consent rates are, in part, affected by the number of adults registering their commitment to deceased organ donation in the event of their death through a donor registry. In provinces such as Ontario, approximately 30% of the population is registered for deceased organ donation and approximately 60% of families consent to organ donation. These low figures have been attributed, without evidence, to the relatively high proportion of immigrants or ethnic minorities living in Ontario.

This research uses Ontario's large administrative databases to examine organ and tissue donor registration in the general population and familial consent among those referred for organ and tissue donation. Modified-Poisson regression was used to identify characteristics associated with donor registration and familial consent.

The first manuscript examines deceased organ donor registration and familial consent among Chinese, South Asian and the remaining general public. Chinese and South Asian individuals registered and their families consented less for deceased organ donation than the general public.

The second manuscript examines deceased organ donor registration among immigrants compared to long-term residents and identifies and quantifies characteristics associated with organ donor registration. Compared to long-term residents, immigrants as a group were much less likely to register for organ and tissue donation. Characteristics among the immigrant population associated with a higher likelihood of registration included economic immigrant status, living in a rural area (population < 10 000), living in an area with a lower ethnic concentration, less material deprivation, a higher education, ability to speak English and French, and more years residing in Canada.

The third manuscript examines familial consent among immigrants and identifies and quantifies characteristics associated with familial consent. Compared to long-term residents, families of immigrants as a group were less likely to consent for deceased organ donation. However, there was no statistical difference in consent rates among immigrants and long-term residents who had registered for organ and tissue donation.

The information gained from this study will guide organ procurement organization’s strategies and approaches to organ and tissue donation. These results can be used to implement and design donor awareness campaigns targeted at groups with lower donor registration and consent rates that are culturally sensitive and effective.

Co-Authorship Statement

All manuscripts contained in this thesis were primarily conceived, designed, executed and written by Alvin Li for his PhD thesis. Mr. Li is the primary and corresponding author of all manuscripts. He also participated in the writing of funding proposals, facilitated data transfers and completed ethics board submission. He wrote the initial drafts, integrated feedback from co-authors and responded to reviewers for manuscripts that have been accepted for publication. Regular feedback was provided by the supervisory committee as well as each of the co-authors. Other research team members provided data cuts (as per ICES regulations), statistical support, or content expertise (as needed) and were listed as co-authors on the studies for which adequate contributions were made. All co-authors provided feedback and approved the final manuscript. The co-authors are recognized for each manuscript.

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CHAPTER 1: Introduction

1.1 Introduction and Overview

Canadians on the transplant waiting list are dying every day because there are not enough available solid organs for transplantation. An important aspect of addressing this problem is to increase deceased organ donation consent rates. Consent rates are, in part, affected by the number of adults registering their commitment to deceased organ donation in the advent of their death through a donor registry. In provinces such as Ontario, 30% of the population is registered for deceased organ donation and approximately 60% of families consent to organ donation. These low figures have been attributed, without evidence, to the relatively high proportion of immigrants or ethnic minorities living in Ontario. To improve these statistics, this thesis takes an integrated knowledge approach by collaborating with knowledge users from Trillium Gift of Life Network, to better understand the proportion and determinants of donor registration and familial consent for deceased donation among immigrants and ethnic minorities.

1.2 Trillium Gift of Life Network

Trillium Gift of Life Network (TGLN) is Ontario’s organ procurement organization. They are responsible for the planning, promotion, coordination and support of activities relating to organ and tissue donation. TGLN uses social media, earned media, advertising, volunteers and community events to raise awareness and promote donor registration. For example, TGLN helped develop the “One Life.. Many Gifts” program to increase awareness of organ and tissue donation among Ontario high school students.(1)

1.3 Current Knowledge of Donor Registration and Familial Consent to Organ Donation from Trillium Gift of Life Network

Currently, the Ministry of Health and Long-term Care only sends TGLN aggregated data on age, sex, and first three characters of the postal code of organ donor registrants in the province. TGLN then reports data on donor registration rates by calculating the proportion of registered donors among the total number of health card holders that are of eligible age (i.e., ≥16 years old) to register as a donor. At best, TGLN is able to identify which age, gender, and geographic areas have lower registration rates.

After much effort and support from TGLN, the Ontario Ministry of Health released the organ donor registration status field to the Institute of Clinical Evaluative Sciences (ICES), the repository of Ontario's large healthcare databases. The organ donor registration status field contains the donor status of everyone in Ontario with a valid health card. Within ICES we have now linked this field to all the other large healthcare databases in Ontario, including the Immigration, Refugees and Citizenship Canada's Permanent Resident Database. Similarly, TGLN has data on patients approached for organ donation, but not their ethnicity. These linked datasets will be invaluable in understanding socio-demographic factors that influence donor registration status and familial consent to organ donation.

To demonstrate the feasibility and potential impact of this thesis work, the following is an example of a study we conducted using the organ donor registration status field linking with other healthcare databases. I published this as study as first-author in the Journal of American Medical Association (JAMA).(2)

Introduction and objective: One common myth, especially among ethnic minorities, is that healthcare professionals will provide suboptimal care if they find out that the individual is a registered organ and tissue donor.(3) A way to dispel this myth would be to share with the public that many physicians have registered for organ and tissue donation. While most physicians in surveys indicate their support for organ donation(4–7), whether they have actually registered remains unknown. Therefore, we conducted a study to determine the proportion of physicians who are registered, and compared this value in both the general public and citizens from the general public matched on similar socio-demographic characteristics as physicians. We also investigated the characteristics associated with registration, and determined the proportion of registrants in each of the three groups who selected the option to exclude certain organs or tissues from donation (e.g. cornea, heart). ***Data Sources:*** We obtained the information used in this study from four linked databases: (1) a list of active physicians practicing in Ontario from the College of Physicians and Surgeons Ontario(8) (approximately60% of all Ontarian physicians); (2) their specialty from the Institute for Clinical Evaluative Science Physician Database; (3) the Ontario Registered Persons Database to identify citizen demographics, vital statistics, and information on deceased organ donor registration; (4) obtained information on physician billings from the Ontario Health Insurance Plan. ***Results:*** We found that 6596 physicians (43.3%; 95% CI, 42.5%-44.1%) were registered, a significantly higher proportion than matched citizens (17 975 [29.5%; 95% CI, 29.1%-29.7%]) or the general public (2 596 766 [23.9%; 95% CI, 23.9%-23.9%]). Women were more likely to be registered in all three groups, as were those of younger age, and rural residence. Amongst physicians, emergency room physicians and pediatricians were more likely to register when compared to general physicians. When registered for donation, 11.7% (95% CI, 10.9%-12.5%) of physicians selected the option to exclude at least one organ or tissue from donation (e.g. eyes, heart), a proportion lower than citizens with similar sociodemographic characteristics 14.3% (14.3%; 95% CI, 13.9%-14.7%) and the general public (16.8%; 95% CI, 16.7%-16.8%). ***Conclusion:*** We concluded overall that physicians are more likely to register for deceased organ and tissue donation than the general public. Our findings can be used to allay existing misconceptions about the care physicians provide organ donor registrants.

This study received substantial media attention(9) and TGLN reported they received a five-fold increase in online registrations the following day the study was published. However, there are opportunities to increase registration rates among physicians given that less than half have registered.

1.4 Study Rationale

In order for TGLN to effectively fill Ontario's organ donor registry, they must fully understand their target audiences or potential registrants (Figure 1-1). In 2015, TGLN set an ambitious goal to sign 1 million new registrants in the "Inner Greater Toronto Area", an area with lots of ethnic diversity.(10) Having a better understanding of the relationship between ethnicity and deceased organ donation is important because ethnicity plays a significant role at every stage of the transplant process.(11) First, race and culture is associated with the prevalence of many end-stage organ diseases.(12,13) Second, many ethnic minorities have been shown to spend longer time on the transplant waiting list.(14) Third, post-transplant outcomes, including higher graft failure and mortality, have also been shown to be poorer for some ethnic groups.(15,16)

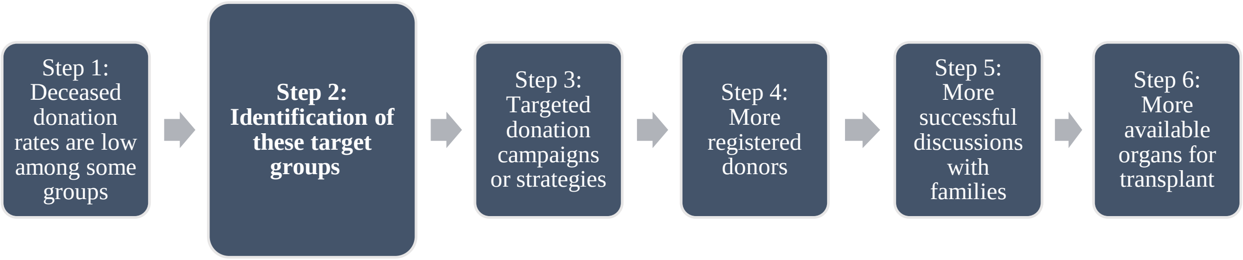
Some researchers argue that race is a crude explanatory variable that is actually a surrogate measure of income, education and access to healthcare, which are the variables that truly account for the observed racial disparities in health.(17,18) However, Kaufman et al. found that even after controlling for socioeconomic status and access to health care, the odds ratio of consenting to organ donation for Caucasians compared to African Americans increased from two to four fold.(18)

The overall benefit of increasing the number of deceased donor registrants and number of families consenting for deceased organ donation is plentiful. Increasing registration may increase the likelihood of families consenting to deceased organ donation, which in turn increases the number of available of organs for transplantation. Finally, having a high organ donor registration rate will be proof of Canadians willingness to become deceased organ donors.

In order to create effective and culturally-sensitive interventions to increase organ donation, there needs to be a better understanding of the target audiences and potential registrants (Figure 1-1; Step 2). The overall aim of this thesis is to conduct <u>three population-based studies</u> using Ontario's large administrative databases to help better understand organ donation among ethnic minorities in Canada. Although large survey studies may provide more information on reasons in differences in registration rates among ethnic minorities, there may be social desirability bias and low response rate given the sensitivity of the topic. Further, survey studies would rely on individuals to self-report their registration status which may be inaccurate.

This dissertation is presented in an integrated-article format consisting of three manuscripts. Chapter 4 compares the prevalence of deceased organ and tissue donor registration and familial consent rates between Chinese, South Asians and the remaining general public. Chapter 5 compares the prevalence of deceased organ and tissue donor registration between immigrants and long-term residents. Chapter 6 compares the relative rates of familial consent to deceased organ and tissue donation between immigrants and long-term residents. The figure below illustrates Chapter 4-6's aim to identify target groups who may benefit from strategies promoting organ donation (Figure 1-1; Step 2). This is a key step to increase the number of available organs for transplantation. Strategies such as print, television or web-based media can then be designed and targeted at well-defined groups (Figure 1-1; Step 3).

Figure 1-1: Pathway to Increase Organ Donation



1.5 Study Objectives and Hypotheses

Objective 1a: To compare the prevalence of organ and tissue donor registration among Chinese, South Asians and the general public

Objective 1b: To compare the rate of familial consent to deceased organ donation among Chinese, South Asian and the general public individuals

Secondary Objectives:

i) Identify the proportion of Chinese, South Asian and the general public individuals that excluded specific organs (kidney, heart, liver, lung small bowel or pancreas) or tissues (eyes, bone, skin)

ii) To compare the prevalence of organ and tissue donor registration in a large metropolitan area (Greater Toronto Area) to the rest of the province

Hypotheses: Chinese and South Asian individuals will be less likely to register for organ and tissue donation compared to the general public. Families of Chinese and South Asian decedents will be less likely to consent to deceased organ donation. The proportion of Chinese and South Asian individuals excluding specific organs will be higher than the general public. The organ donor registration rate in a large metropolitan area (Greater Toronto Area) will be lower than the rest of the province.

Objective 2a: To compare the prevalence of organ and tissue donor registration among immigrants and long-term residents. Identify the 5 countries of birth with the largest absolute numbers of unregistered people.

Objective 2b: Identify socio-demographic or migration-related factors associated with donor registration

Secondary Objectives:

i) Examine the consistency of the associative relations of identified factors by conducting the analyses stratified by the country of origin of the 5 largest groups of immigrants who had not yet registered for organ and tissue donation.

ii) Identify the proportion of registrants by world region of birth that excluded specific organs (kidney, heart, liver, lung small bowel or pancreas) or tissues (eyes, bone, skin)

Hypotheses: The prevalence of donor registration among immigrants is low (<10%). Immigrants are less likely to register for organ and tissue donation compared to long-term residents. The 5 countries with the largest absolute number of unregistered people will be predominately from East Asia and South Asia. The identified factors will be consistent across the 5 largest groups of immigrants. Among immigrants, an individual's country of birth and time spent in Canada will be the strongest factors associated with being a donor registrant. Of those registered for organ and tissue donation, immigrants are more likely to exclude tissues (corneas, skin, bone) compared to organs.

Objective 3: To compare the rates of familial consent to deceased organ donation among immigrants and long-term residents

Secondary objectives:

i) Evaluate the association between immigrant status and familial consent in four subgroups: age, sex, hospital type, and cause of death

ii) Assess whether being registered for organ donation modified the likelihood of obtaining final consent from families among immigrants and long-term residents

Hypotheses: Familial consent among immigrant decedents is low (<50%). Families of immigrants are less likely to consent for organ and tissue donation compared to long-term residents. Familial consent among immigrants will be lower in all four subgroups compared to long-term residents. Families of immigrants registered for organ donation will be less likely to consent to deceased organ donation compared to families of long-term residents.

1.6 Integrated Knowledge Translation

I adopted an integrated knowledge translation approach to this thesis work. As Canadian of Institutes for Health Research describes, “The central premise of integrated knowledge translation is that involving knowledge users as equal partners alongside researchers will lead to research that is more relevant to, and more likely to be useful to, the knowledge users”.(19) I involved knowledge users from TGLN to help refine the research questions, acquire data, review methodology, interpretation and dissemination of study results. The research questions described in this thesis have been identified by TGLN as important information for them to improve organ donor registration and consent rates.

1.7 Structure of the Thesis

Chapter 2 presents a review of the relevant literature on deceased organ donation and ethnicity. Chapter 3 presents more detailed information on the databases used for this thesis. Chapter 4 addresses Objective 1, and is published in PLoS One. Chapter 5 addresses Objective 2 and is published in CMAJ Open. Chapter 6 addresses Objective 3 and is ready for submission in Journal of Critical Care. Chapter 7 concludes the thesis with an integrated discussion of this thesis and opportunities for future research. Other relevant information is provided in the appendices.

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Chapter 2: Literature Review

2.1 Literature Review

This section provides a review of the literature relevant to the study objectives of this thesis. I conducted a comprehensive search of the literature using electronic databases such as PubMed and Google Scholar. The following keywords were used: “organ donation”, “consent”, “registration”, “attitudes”, “survey”, “ethnicity” and “immigrants”.

2.2 Shortage of Solid Organs for Transplantation

There is a worldwide shortage of available organs for transplantation and most patients rely on organs becoming available from deceased donors.(1) Unfortunately, the waitlists for deceased organs continue to grow in many nations around the world.(2–4) This disparity between need and availability means that patients die every day while waiting for a life-saving organ. In 2012, 285 Canadians died while waiting for an organ transplant.(5) In 2004, Canada had a deceased donor rate per million (DRPM) of 13.2, which is lower compared to other countries such as France (20.9 DRPM), United States (20.2), Italy (21.1 DRPM), and Spain (34.6).(6) In 2013, Canada’s DRPM increased to 15.7.(7) The shortage of available organs for transplantation has prompted major concerns that some Canadians will seek commercial organ transplantation overseas.(8)

2.3 Benefits of Organ Transplantation

Organ transplantation has been heralded as one of the key scientific contributions in recent history, adding millions of years of life to recipients worldwide.(9) One organ donor can save up to eight lives and improve the quality of life for as many as 75 people via tissue donation.(10) There are many publications on the benefits of organ transplantation.(9) Schnitzler et al. estimates that using all solid organs from a single deceased donor provides an additional 56 life-years spread among six transplant recipients.(11)

Kidney transplant recipients have a lower risk of mortality and cardiovascular events and higher ratings of quality of life compared to dialysis patients.(12) Under the Canadian healthcare system, Whitby et al. estimates that kidney transplantation results in a gain of 1.99 quality adjusted life years and a cost savings of $104,000 over a 20-year time frame compared to dialysis treatment.(13)

For heart transplantation, the relationship between transplant benefit and heart failure severity is complex and unknown.(14) Nonetheless, heart transplant is considered the “gold standard” in certain patients with low survival probabilities.(15)

Lung transplantation can extend and significantly improve quality of life in certain patient populations, especially among patients with cystic fibrosis.(16) There is a 69% reduction in the instantaneous risk of death in patients with cystic fibrosis compared to being on the waitlist.(16)

Liver transplantation is the only option for patients with end-stage liver disease.(9) Deceased liver transplant recipients have a 79% reduction in mortality risk at one year compared to being on the waitlist.(17)

Benefits of organ donation extends beyond the transplant recipients. For example, bereaving families who consent to organ donation derive emotional benefits from saving a life.(18) For example, one family member noted, “I was happy to hear that a young boy can now lead a normal life with a new kidney; this made the decision worthwhile”.(18,19) In addition, patients on dialysis often rely unpaid caregivers (i.e. family members).(20) Caregiving for these patients may cause anxiety, fatigue, and deterioration in family relationships resulting in overall lower physical and general health.(21,22)

2.4 Organ Donation Process

Organs that can be transplanted are the lungs, heart, kidneys, liver, pancreas and bowel.(23) Tissues that can be donated include eye tissue, heart valves, bones, tendons, arteries, veins and ligaments.(23) However, before someone can become a donor, they must undergo strict medical testing to ensure that neurological death has occurred or whether to continue with donation after cardiac death.(23) Only a small percentage of decedents can become actual donors. In 2014, organ procurement organizations in the United States only reported 9252 eligible deaths.(24) In Canada, decedents and their families cannot choose who will receive their organs.(23) Organs and tissues are allocated based on an organ allocation criteria managed provincially. Due to Canadian law, recipients are not permitted to know the donor’s identity.(23)

Race or ethnicity is not used as a determining factor for transplant recipients to match with an organ donor.(25) Recipients from all ethnic backgrounds can and commonly do receive organs from other donors of different backgrounds.(25) However, compatible blood types and tissue markers are more common among those with the same ethnic background, which may improve transplant outcomes.(25) For example, one US study reported that black kidney recipients who received kidneys from black donors had better long-term graft and survival compared to those who received kidneys from white donors.(26)

2.5 Becoming an Organ Donor after Death: Donor Registries

Organ donor registries record an individual's preference on organ donation after death.(27) The registry is then accessed at the time of death, for the purpose of communicating the deceased's wishes regarding organ donation. In Canada, the next-of-kin makes the final decision to proceed with deceased organ donation at the time of death of a loved one. The intense grief surrounding the death of a loved one can often make the decision to donate organs very difficult for family members.(28) However, if the patient has previously registered as an organ donor, this information can ease the burden on the family. As of 2016, 30% of the adult population in Ontario has registered a wish to donate.(29) This proportion is far less than many states in the United States where registration rates exceed 80%.(30)

In 2012, we published a CIHR-funded knowledge synthesis review in partnership with Trillium Gift of Life Network (Ontario's organ and tissue donation agency), other provincial organ and transplantation agencies and the Canadian Blood Services.(27) For this project, we collected information relevant to the design and use of every registry worldwide including: implementation date, operation level (national or regional), minimum eligible age, available methods of registration, and registrant values.(27) We found that these characteristics varied greatly across registries worldwide.(27) There are two main types of registries: donor and non-donor registries. Countries with an explicit consent law ("opt-in", requires an individual to express their consent to organ donation in advent of death) mostly use donor registries to promote deceased organ donation and enroll individuals to register their preference towards organ donation. On the other hand, countries with presumed consent law ("opt-out", assumes everyone consent to organ donation unless specified otherwise in advent of death) will use nondonor registries as a legal means for individuals to register their objection to being a deceased organ donor.(27) Nineteen countries operate deceased organ donor registries where the stated goal is to maximize the total number of affirmative registrants.(27) In most states, registries operate under a “first-person consent” system where the registration is legally binding.(27)

Even within Canada, characteristics of donor registries vary (Table 2-1). In 2012, Nova Scotia had the highest proportion of citizens registered (65%), followed by New Brunswick (42%), Ontario (18%) Yukon (16%), Quebec (10%) and British Columbia (8%).(27) Ontario is the only province that reports the proportion of individuals registered for organ donation online. Since our publication, Alberta and Manitoba have also implemented a donor registry. In total, eight provinces now incorporate a deceased organ donation registry as a key aspect of their strategy to increase the number of organs available for transplant. Since December 2008, Ontario’s organ donor registry became ‘affirmative only’, meaning that only ‘yes’ responses in favour of becoming a donor after death are being collected. In Ontario, individuals can register in-person at government agencies that administer vehicle registration and driver licensing, online and by mailing in a consent form. When registering through online or mail, individuals can select any number of organs and tissue that they wish not to donate. These organs and tissue include kidneys, eyes, liver, skin, heart, lungs, bone and pancreas.

Table 2-1: Characteristics of Donor Registries Operating in Canadian Provinces

Province	**Implementation Date**	**Registration Choices**	**Minimum Age**	**Can registrants specify which organs to donate? If yes, are specified organs to be included or excluded from donation?**	**Registration Modalities**				**Additional Details**
					Online	**Paper**	**Telephone**	**In Person**	
Alberta	2014	Yes only	18	Yes, Include	Yes	Yes	No	Yes	Registrants must also mail or fax in a copy of their consent forms.
British Columbia	1997	Yes & No	None	Yes, Exclude	Yes	Yes	No	No	Registrants below the age of majority (19 years) must have their registration signed by a parent or guardian.
Manitoba	2012	Yes only	18	Yes, Include	Yes	No	No	No	None
New Brunswick	2007	Yes & No	None	No	No	Yes	No	No	Registrants below the age of majority (18 years) must have their registration signed by a parent or guardian. Registration must be renewed every 3 years when the provincial health insurance card expires.
Nova Scotia	1999	Yes Only	16	Yes, Include	No	Yes	No	Yes	Registrants between the ages of 16-18 must have their registration signed by a parent or guardian until the age of majority (19 years). Registration must be renewed every 4 years when the provincial health insurance card expires. In person registration is available at awareness events.
Ontario	1995	Yes Only	16	Yes, Exclude	Yes	Yes	No	Yes	In person registration is available through ServiceOntario. It is also mandatory to ask any person not previously registered if they would like to be an organ donor during an in-person provincial health insurance card transaction. Online registration was implemented June 14th, 2011.
Quebec (Notary Public registry)	2005	Yes & No	18	No	No	No	No	Yes	In person registration is available through the Notary Public via a registered will or mandate for anticipated incapacity.
Quebec (RAMQ registry)	2011	Yes	14	No	No	Yes	Yes	Yes	Registrants below the age of 14 must have their registration signed by a parent or guardian. In person registration is available through Régie de l'assurance maladie du Quebec with renewal of the health insurance card.
Yukon	2000	Yes Only	None	Yes, Exclude	Yes	Yes	No	Yes	Registrants below the age of majority (18 years) must have their registration signed by a parent or guardian. Registration must be renewed every year when the provincial health insurance expires.

Table adopted from Rosenblum AM, **Li AH,** Roels L, Stewart B, Prakash V, Beitel J, et al. Worldwide variability in deceased organ donation registries. Transpl Int . 2012 Apr 16

2.6 Benefits of a Registry

The most common reason to promote organ and tissue donor registration is that families can know the decedent's wishes at the time of death and increase the likelihood of consenting to donation.(31) In addition to donor registries, people can also sign a donor card or their drivers' license indicating that they would like to be a donor or discuss their preferences with their family members.(31) However, this information may not always be available to healthcare providers or transplant coordinators when decisions to proceed with donation need to be made.(31) Therefore, the availability of donor registry information online can facilitate the donation decision that healthcare providers or transplant coordinators need to the available family members of the decedent.(31)

In Ontario, families consent to donation approximately 90% of the time when the deceased is registered, compared to approximately 50% when not registered.(32) Siminoff and Lawrence found that families were seven times more likely to consent to deceased organ donation when they knew the decedent's preferences compared to not knowing after adjusting for important sociodemographic characteristics.(33) In the United Kingdom, almost 90% of families consented to organ donation when the decedent had registered for organ donation.(34)

In cost effectiveness analyses conducted in 1999, Beasley et al. estimated that approximately 83,000 individuals need to register for organ donation in the United States in order to realize one new potential donor within a year.(35) The authors questioned the cost-effectiveness of these registries to increase the supply of organs.(35) However, using more recent data (2006), Howard and Byrne estimates that under a "first-person consent" system, the average value of a young adult registrant to society (ages 18 to 32) is $1900USD.(36) In Canada where families have the right of refusal, the value of a young adult registrant (ages 18 to 34) is approximately $840USD.(36) They did not have concrete data on the costs of operating registries and attracting new registrants. Nonetheless, they concluded that donor registries may be cost-effective assuming they have fairly limited operations.(36) Another study from the United States estimated that the implementation of an organ donor registry led to an 8-10% increase in donation rates.(37) Finally, in a cost-outcome analysis, Razden et al. reported that donor registries have a positive return on investment because the cost of registering an individual and securing a donor is not higher than the value of a registrant and a donor (i.e. benefit to society).(38)

Donor registries can also be used to promote public awareness of organ donation and to evaluate public campaigns.(39,40) The American Society of Transplantation, Kidney Foundation of Canada, and the general public in many nations support registry use.(27,41)

2.7 Criticism of Donor Registries

Many countries with high organ donation rates do not have an active donor registry. For example, Spain has the highest rate of deceased organ donation and does not maintain a donor registry.(42) They attribute their success to the "Spanish Model for Organ Donation and Transplantation" which includes the development of a network of highly motivated physicians specifically responsible for the organ donation employed within the hospital.(42) Another criticism of donor registries is that the web sites of these donor registries do not fulfil the requirements for informed consent.(43) Most web sites provided positive reinforcement rather than disclosing important information regarding the organ donation process.(43) Another important criticism of donor registries is that some families may interpret a lack of donor registration as a "No" statement (preference to not become a donor).(37,44) However, the decedent may have simply been undecided about organ donation or have not taken the time to register yet. Others argue that the ethics of asking individuals to make a theoretical decision in advance and holding their loved ones to them questionable given that this decision does not necessarily hold true years later.(45)

It is important to acknowledge that families may still decline consent if the patient has registered in countries that do not have 'first-person authorization'.(46) For example, from 2011 to 2016, The National Health Services Blood and Transplant from the United Kingdom reported that 547 families refused to consent to organ donation, despite their loved ones being on the registry which resulted in an estimated 1200 wait listed patients missing out on a transplant.(46)

2.8 Discrepancy between Support for Organ Donation and Registration.

In a 2010 survey study conducted in Edmonton, Canada, over 90% of participants supported organ donation but only 26% had signed donor cards.(47) Other Canadian surveys have also reported similar discrepancies.(48,49) This discrepancy has also been seen in the United States where over 95% in Gallup polls reported they support organ donation.(50) Siegel et al. explains that the “principle of compatibility” may help partially explains this discrepancy. This theory specifies that “measuring the attitude and the behavior at the same level of specificity can maximize the predictive power of attitude”.(50) They conducted two experiments and found that attitudes toward organ donor registration explained 70% more variance in registration behaviors compared to general attitudes toward organ donation.(50) Understanding differences in donor registration behavior is just as important as understanding differences in attitudes towards organ donation. There may be some specific barriers to donor registration behavior such as placing one’s name in a computerized database.(51)

2.9 Becoming an Organ Donor after Death: Consent for Organ Donation

Obtaining consent from families of potential organ donors is considered one of the most important elements of a successful organ and tissue donation program.(52) Families are highly involved in the organ procurement process worldwide regardless of the country’s consent principle (explicit or presumed) and whether the decedent’s wishes were expressed or unknown.(53) Simpkins et al. interviewed US families of potential organ donors and found that 58% of families were favorable towards donation, 17% were unsure, and 26% were unfavorable.(54) Although limited by small samples, Baker et al. reported the conversion from brain deaths to realized organ donor ranged from 20% to 86% in three different Canadian hospitals, attributing most of the variation due to family refusal.(55) To meet the demand for organs, the challenge moving forward is to secure consent for donation from favourable families, and to provide relevant information to those unsure and unfavourable towards organ donation.(52) Despite the importance of the family role in organ donation, few families report ever discussing organ donation.(54) One study found that half of families (36/69; 52%) who refused deceased organ donation would consent to donation in a new situation.(56)

2.10 Ethnic Minorities in Canada: An opportunity to improve donation

Approximately 250,000 individuals immigrate to Canada annually, with the largest proportion of immigrants coming from Asia, Africa, and the Middle East.(57) Further, 20% of the Canadian population identifies themselves as a member of a visible minority group.(57) In a country as ethnically and culturally diverse as Canada, programs and policies for increasing organ donation will benefit from a greater understanding of which ethnic and immigrant groups register, as well as consent, for organ donation. The two largest ethnic groups in Ontario, Canada are Chinese and South Asian. Therefore, there will also be two sections in this literature review summarizing their attitudes towards deceased organ donation.

2.11 Determinants of Willingness to Donate

There is a wealth of information on determinants and attitudes of organ and tissue donation including five systematic reviews.(18,58–61) An important consideration to make when reviewing the literature is to distinguish between determinants of: 1) positive attitudes towards organ donation; 2) willingness to become a deceased organ donor; 3) donating organs to family/friends; 4) willingness to consent their family (including perceived willingness) and 5) registering (via a donor registry or signing donor cards) for organ donation. It is also important to acknowledge that determinants of organ donation indicators may vary depending on the population studied (e.g. medical students, ethnic minorities, general public, adolescents). Unless stated otherwise, the following sections will focus on verified donor registration which is the gold standard because people may over report their intention to register or donor registration status.(62) However, there is limited literature on verified donor registration. As discussed previously, there is only a moderate relationship between intention to become a donor and actual donor registration behavior.(58,63)

2.11.1 Age

In general, there appears to be a quadratic relationship between age and donor registration.(58,61) Middle aged appeared to be more likely than younger age and older age to register for deceased organ donation.(58,61) In multivariable analyses, Sieghal et al. found that those aged greater than 55 were less likely to be registered compared to those aged 35-54 but no difference compared to those aged 18-34.(64) One recent survey from England found that age groups 18 to 24 (OR, 0.3l 95% CI: 0.20-0.50) and 25 to 34 (OR, 0.4; 95% CI: 0.30-0.60) were negatively associated with a definite desire to donate all organs compared to older age groups.(65) A Canadian Ipsos Poll reported older Canadians were more likely to mention signing a donor card.(66)

2.11.2 Gender

Most studies find that females are more likely to be registered and support organ donation compared to males.(61) In one survey, 70% of teenage girls compared to 40% of teenage boys reported that they were willing to sign a donor card when they apply for their driver's license.(67) Among medical professionals, there was no difference in holding a donor card in female compared to men.(68) One study examining the role of gender as a moderator in the attitude-behavior relationship in organ donation found that women did indeed showed overall higher positive attitude but there was no difference between men and women in intention to signing a donor card. In fact, they found that the link between attitudes and intention to signing a donor card was stronger for men compared to women.(69)

2.11.3 Knowledge

Many studies showed a positive association between having a higher knowledge or awareness of organ donation and willingness to donate.(58,61) This association is also apparent among medical professionals, where medical professionals with higher knowledge (e.g. about brain death criteria) have more positive attitudes towards organ donation.(70) A common knowledge gap among ethnic minorities is the need for organ transplants (i.e. the number of donors compared to the number of individuals on the transplant waitlist).(59) Other issues related to knowledge of donation that is associated with poorer attitudes towards organ donation include “medical mistrust” and “bodily concerns” about organ donation.(59) Two qualitative studies found that Chinese and Indo-Asian Canadians were unaware that a donor registry existed.(71,72)

2.11.4 Ethnicity

A lot of the research in the United States have focused on African Americans and Hispanics and found that in general, they are less likely to support organ donation.(61) In a sample of young adults in a minority-majority state (New Mexico), Ginossar et al. found that Non-Hispanic whites were more likely to be registered as donor compared to American Indians and Hispanics.(73) There was no significant difference between Non-Hispanic whites and Asians or Pacific Islanders.(73) In another study of undocumented Hispanics, they found that most (74%) are willing to donate their organs.(74)

In a study of 600 Chicago residents (equal groups of African Americans, Caucasians, and Latinos), Quick et al. found that African American and Latino participants were less likely to be registered than Caucasians.(25) They studied four ‘non-cognitive factors’ that are key determinants of donor registration: bodily integrity, disgust, medical mistrust and superstition. African Americans scored higher on all four factors compared to Caucasians.(25) Latinos scored higher on bodily integrity and superstition than Caucasians.(25) African Americans scored higher in medical mistrust and disgust compared to Latinos.(25) Bodily integrity was the only ‘non-cognitive factor’ that was significantly negatively associated with donor registration status in adjusted analyses.(25)

One Canadian study from Edmonton, Alberta found that factors negatively associated with willingness to donate included being of East-Asian descent (odds ratio (OR) 0.52, 95% confidence interval (CI) 0.27 – 0.99) and Indo-Asian descent (OR 0.49, 95% CI 0.25-0.95) (the reference group in both cases was Caucasian).(47) These finding are similar to older Canadian studies published in the 80s.(75,76) Many studies focused on specific ethnic or cultural collectives such as Hispanics, African Americans, Asians and Arabs. Only one study examined the willingness to donate among the entire immigrant population of a national state (Spain).(77)

These researchers found that immigrants from East Europe and North African are more reluctant to donate their own organs compared to other immigrant groups.(77)

2.11.5 Socio-economic status and Marginalization

In general, individuals with a higher socioeconomic status have more positive attitudes towards organ donation.(61) Irving et al. also found in their review of qualitative studies that minority population groups whom may feel a greater sense of marginalization from the healthcare system had more negative attitudes towards organ donation.(60) Marginalization can be defined as the "process by which individuals and groups are prevented from fully participating in society".(78) One measure of marginalization is Matheson et al.'s Canadian Marginalization Index, which is related to socio-economic status and is used to understand inequalities in health and other social problems.(79) This measure consists of four dimension of marginalization: residential instability, ethnic concentration, dependency and material deprivation.(79) No studies have used this measure of socio-economic status as a predictor of organ donation. However, this measure has been used to show that living in more deprived neighborhoods was associated with greater use of mental health services.(80) In another study, using cluster analysis, Riebel et al. also found that areas with high minority/immigrant areas and lower income have lower registration counts.(81) However, they also noted that in the very highest areas of socioeconomic status, there were very high levels of donor registration despite high racial diversity.(81)

2.11.6 Other Determinants of Donor Registration / Intent to Register

Sehgal et al. hypothesized that there may be a relationship between signature size and organ donor designation because previous literature found that a large signature size was associated with narcissistic characteristics.(82) However, they found no relationship between signature size and verified donor designation.(82) In another study, they found that having fewer comorbid conditions was associated with more donor registration.(83) This may be related to the common myth where some people feel they are not healthy enough to register for organ donation. One survey of 255 waitlisted transplant recipients found that approximately 40% of respondents felt that they were not healthy enough to become donors.(84) In addition, 20% felt their treatment plan would change if they became an organ donor and 7% reported that registering for organ donation would affect their likelihood of receiving an organ.(84) In another study, Cohen and Hoffner found that perceived self-benefit (i.e. those who saw the benefits of becoming a donor such as adding extra meaning to life) predicted registering for organ donation but not perceived benefit for others.(85)

2.12 Familial Consent to Organ Donation

In the United States, Goldberg et al. analyzed 35,823 eligible deaths and found that consent for organ donation was obtained on approximately 70% of all cases.(86) They confirmed that there were substantial differences in consent rates among ethnic groups: 77% in Whites, 68% in Hispanics, 55% in Blacks and 48% in Asians. They also reported that consent for donation was less likely to be obtained among older donors (age group 55-64 [OR: 0.72; 95% CI: 0.67-0.77], age group ≥65 [0.58; 95% CI: 0.52-0.64), the reference group was age group 18-39).(86)

In the United Kingdom, Hulme et al. found that patient ethnicity and involvement of a nurse specialized in organ donation were strongly associated with consent. Families of Asian decedents (OR: 0.20; 95%: 0.12-0.34) and Black decedents (OR:0.31; 95%: 0.31-.53) were less likely to consent compared to White families. Following risk adjustment, the patient’s age and sex was not associated with familial consent.

2.13 Consent to Tissue Donation among Ethnic Minorities

Consent towards tissue donation among ethnic minorities is poorly understood.(87) Siminoff et al. suggest that individuals willing to consent to tissue donation are similar to those willing to consent to organ donation.(87) However, organ and tissue donor researchers often assess attitudes towards organs and tissue donation as a single phenomenon. Only 50% of families who consent to donation were able to distinguish tissue donation from organ donation.(88) The largest study of potential tissue donors from the United States found that whites were more likely to donate compared to nonwhites (92.3% versus 69.2% respectively, p<0.001). A Canadian report found that 55% would actually donate an organ but only 39% would consider the possibility of tissue donation.(89)

2.14Attitudes towards Organ Donation among Chinese

In China, there are over one million patients waiting for a transplant but less than 1% receive an organ.(90) A survey of individuals in China (n=2930) reported high awareness and favourable attitudes towards organ donation.(91) They reported that over 95% knew about organ donation and almost 90% supported deceased organ donation.(91) Fewer supported living organ donation (65%).(91) Another survey of Chinese medical students (n=320) revealed that 82% would consider live donation and 82% would consider deceased donation.(92) There were no gender differences but religious commitment and socioeconomic status were significantly associated with willingness to donate a living or deceased kidney.(92) In another survey (n=174) on attitudes toward donation after cardiac death in China, 82% of participants believed that the donor is a “hero”.(93) However, another survey of health professionals in China (n=400) revealed that only 60% supported deceased donation and 49% supported living donation.(94) These surveys support that there is general positive attitude towards organ donation in the public but mixed attitudes among healthcare professionals. One major criticism of China is their use of organs from executed prisoners and prisoners of conscious as the primary source of organ transplants.(95) Lavee et al. suspects that this usage of organs is an understudied but major factor for the low deceased organ donation consent rates in China.(96)

Molzahn et al. conducted a qualitative study of 15 interviews to explore the values and beliefs regarding organ donation among Chinese Canadians.(97) They found that the major themes were “lack of communication” and “need to preserve an intact body” in relation to death.(97) Participants discussed how speaking about death is not appropriate in their culture.(97) In addition, another participant said that “people don’t want to give up their own parts of the body”. Another important finding of this study was that few individuals knew about the donor registry and did not know how to donate their organs. Finally, participants also discussed about how making decisions as a family was important for their culture. However, in another study of Chinese young adults, they found that almost 90% were reluctant to discuss organ donation with their families.(98)

2.15 Attitudes towards Organ Donation among South Asians

South Asians, also frequently referred to as Indo-Asians, originate from the Indian subcontinent.(99) A survey of South Asians in the United Kingdom reported that 69% supported organ donation but only 13% were registered for organ donation.(99) Factors associated with supporting organ donation included younger age, non-Muslim, knowledge about organ donation, knowing someone who is a registered donor and more liberal degree of religious beliefs.(99) Another survey conducted of medical students in India revealed that there was general low attitudes towards organ donation.(100,101)

Molzahn et al. conducted interviews and focus groups with 40 Indo-Canadians to understand their beliefs regarding organ donation.(102) Similar to their study of Chinese Canadians, they found major themes of organ donation included the role of family, religion, knowledge about organ donation and beliefs about death and dying.(102) They also found that community members were reluctant to discuss death and organ donation. However, they do conclude that the beliefs about organ donation varied significantly across participants and that it is not appropriate to assume the beliefs of any one individual based on their ethnicity.(102)

2.16 Limitations of Existing Literature

There are several limitations in the existing literature on ethnic differences in organ donor registration and familial consent.

2.16.1 Studies on Donor Registration

i) Convenient sampling: Many studies use convenience sampling to survey a group of individuals, which may not be representative of the population being studied.(103) For example, Lee et al's Canadian survey study approached adults attending a university's union building, supermarket and soccer games.(47) The authors noted that their respondents may be more interested and educated about organ donation because a high proportion of their participants were blood donors.(47)

ii) Non-validated measures: Most studies used a self-administered survey to ask participants a variant of, "Would you be willing to become an organ donor?"(103) Surveys are effective in that they can collect a wide range of information such as attitudes, values, knowledge and beliefs surrounding organ donation. However, support for organ and tissue donation is a sensitive topic and therefore the reliability of the survey data depends on the respondents' motivation and honesty to respond. There may be a 'social desirability' bias, where respondents feel they will be viewed more favourably if they say they are willing to become an organ donor, when in truth they have no intent to register for organ donation.(104)

iii) Low response rate: Given the sensitivity of this topic, many individuals may not feel comfortable completing the survey. One Canadian report (2005) on attitudes towards organ and tissue donation by the Canadian Blood Services only had a 13.5% response rate.(49) Another Canadian poll conducted by Ipsos Reid (2011) reported a 8% response rate.(66)

iv) Tissue donation: Some studies and reports indicate that individuals prefer to donate organs compared to tissues.(105) However, few studies exist looking at ethnic differences in tissue donation.(105)

2.16.2 Studies on Familial Consent

i) Control for confounding: Of the studies that examined ethnic differences in consent rates among eligible deaths, they failed to adjust for important confounders such as socio-economic status.(86)

ii) Single centers / small samples: Previous studies examined donors from single centers with limited number of patients.(106,107) Furthermore, these studies examined only the profiles of actual donors rather than all potential donors.

iii) No Canadian studies: A recent US study published in 2013 was the first to publish analyses of consent rates among all eligible deaths examining ethnic differences.(86) However, results from the US may not generalize to the Canadian population. There are important differences in access to healthcare and the ethnic makeup of the population in both countries. Only one Canadian study from British Columbia examined the racial differences in deceased organ donors but lacked data on eligible deaths and those whose consent was refused.(108) In an updated report from 2005 to 2009, they found that Caucasians represented the majority of donors (89%), followed by Pacific Asians (4%) and Asian Indians (1%).(109)

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CHAPTER 3: Methods

3.1 Introduction

This chapter describes administrative database research, its limitations and strengths and the primary databases used in this thesis. The Institute for Clinical Evaluative Sciences (ICES) houses multiple databases that can be linked together via an encoded identifier. Appendix A summarizes the variables used for this thesis.

3.2 Administrative Database Research

Administrative database research refers to the use of routinely collected data in health services and clinical research. These databases may include administrative data collected during hospitalization that describes a patient's course through the healthcare system.(1) However, there are important limitations to consider in these databases given that they were not designed for research purposes.(1)

Ontario, Canada has a population of approximately 13 million. Ontarians have universal access to health care services. This publicly funded system collects comprehensive data via multiple databases. To be eligible for healthcare services, Ontarians are issued a unique Ontario Health Insurance Plan (OHIP) number. This number can be used to produce a unique number which can then be linked to multiple administrative data and registries to produce a comprehensive database. In Ontario, the organ donor registration status information of all residents is maintained by the Ministry of Health and Long-term Care.

3.2.1 Advantages and Limitations

Administrative databases provide relatively easier and cheaper access to large numbers of patients over large geographic regions.(2) The large number of patients included in these databases are considered to represent the population of interest.(2,3) The limitations of administrative database include the limited detailed data and inaccuracies of coding.(4) Previous studies show that coding wasaccurate for some diseases(4,5) but not for all.(6)

The following is an example of a validation study I conducted to help illustrate potential disadvantages of administrative database research.(7) Organ procurement organizations collect their own data using manual chart abstractions at multiple hospitals. However, obtaining this information from healthcare administrative databases may be an alternative cost-effective approach. I analyzed all deaths registered in Ontario administrative databases and compared the performance of an algorithm consisting of physician billing claims to identify deceased organ donors with manual chart abstractions (commonly used as a gold standard(8)). An example of a billing code is “M157” which is described as “Donor Heart – Lung removal”. The best performing algorithm was mediocre and had a sensitivity of 75.4% (95% CI: 72.6% to 78.0%) and a positive predictive value of 77.4% (95% CI: 74.7% to 80.0%) for identifying deceased organ donors. I found that the algorithms were suboptimal in identifying organ-specific donors. For example, physician billing claims were not able to identify any pancreatic and small intestine donors. Overall, I concluded that researchers should use primary data abstraction compared to administrative data to identify deceased organ donors in large healthcare databases. Although the data did not permit us to study why the algorithm had poor performance, we hypothesize that some surgeons may receive funding from alternative payment program (rather than reimbursement from billing claims) and billing the recipient rather than the donor.

3.3 Data Sources

3.3.1 The Registered Persons Database

The Ontario Registered Persons Database is a registry of all individuals who have ever been issued an Ontario Health Card. This database is maintained by the Ministry of Health and Long-term Care. This database contains demographic information of all these individuals including date of birth, sex, date of death and residential postal code. The health card number of all individuals is encoded using an ICES key number, which is used as a common identifier to link to other databases housed at ICES.

The Organ Donor Registry is part of the Registered Persons Database. It is brought in separately from the Ministry of Health and Long-term Care and a data request must be sent to the Ministry to receive an update. This data includes individuals who have registered for deceased organ donation, their data of registration and if so, any organs or tissue that they excluded.

The main limitations of this dataset is that it is not mandatory for individuals to inform the Ministry if they move to a new residence. Individuals may reside outside the province but still hold their Ontario health card. In addition, data such as neighborhood income quintiles that requires linkage of the residential postal code in the Registered Persons Database may be outdated and unreliable if the individual moves to a new neighborhood without updating their address or have multiple residences.

3.3.2 Trillium Gift of Life Network Database

Trillium Gift of Life Network provided us with data on everyone referred for deceased organ donation from 2008 to 2013. Patients who meet any of the following are referred for potential organ donor consideration: 1) Glasgow Coma Scale score of 3; 2) injured brain or non-recoverable injury or illness; 3) family initiated discussion of organ donation with the healthcare team or withdrawal of life sustaining therapy and/or 4) planned discussion of therapy limited, de-escalation of treatment or withdrawal of life-sustaining therapy. All patients referred for organ donation are then evaluated for medical suitability. This dataset also contains information on whether the family was approached for donation and if consent from their family was obtained. These data are recorded on a real-time basis by a call center.

3.3.3 Canadian Institute of Health Information (CIHI) - Discharge Abstracts Database (DAD)

The CIHI-DAD describes patient-level data for acute care, chronic care, rehabilitation hospitals and day surgery clinics.(9) Each single record represents a hospitalization encounter. Starting in 2002, diseases are coded using the International Classification of Diseases, Version 10 and procedures are coded using were coded using the Canadian Classification of Interventions system. This database was used for Chapter 6 to classify cause of death for patients. While the Office of the Registrar General – Deaths (ORGD) database may have more accurate cause of death information available at ICES, this dataset did not have the up to date information that I required at the time. Using CIHI-DAD to classify cause of death has also been used in a previous Canadian study to compare rates of deceased organ donation in transplant hospitals and general hospitals.(10)

3.3.4 Chinese and South Asian surname database

Surname analysis involves using an individual’s surname (and/or given name) to derive an individual’s race and ethnicity.(11) Surname algorithms exist for many groups including Hispanics(11), Vietnamese(12), Koreans(13), Chinese(14) and South Asians.(14) The performance of surname algorithms depends on the distinctiveness of the surnames and may not be accurate for those with spouses of a different ethnic group. For Chapter 4, we used the Chinese and South Asian surname database which compromises a list of 9,950 South Asian surnames and 1,133 Chinese surnames.(15) This list was developed by reviewing comprehensive lists of South Asian and Chinese surnames that are unique and excluding surnames that may be common in other population. For example, “Lee” is is a very common Chinese surname in America.(16) However, it is also commonly shared with Europeans, Koreans and Vietnamese individuals.(16) Therefore, to increase the positive predictive value of the Chinese list, “Lee” is excluded as a Chinese surname in this database and anyone with the last name “Lee” would be in the general population group.(15) This list was validated with the self-reported ethnicity data from Canadian Community Health Survey and has a positive predictive value of 89% for the South Asian list and 92% for the Chinese list. However, the South Asian and Chinese list only has a sensitivity of 50% and 80%, respectively.

3.3.5 Immigrant Database – Permanent Resident Database

The Permanent Residence Database is maintained by Immigration, Refugees and Citizenship Canada. Information is gather about these immigrants at the time they receive their landed resident status. This information includes date of landing, country of birth, marital status, language ability and type of immigration (e.g. economic, refugee). The primary limitation of this dataset is that information is collected at time of immigration and certain characteristics, such as marital status and language ability may change over time. This database has been used previously in diabetes research and mental health research.(17,18) For Chapters 5 and 6, we used world region of birth to categorize the country of births.(Appendix B). This grouping was chosen because I hypothesized that differences in organ donation would be primarily due to cultural differences, which may be more similar within world regions. However, I do recognize that important cultural differences may also exist within world regions. For example, South Asia region compromises of many countries with different majority religions which may differ in attitudes towards organ donation.

3.3.6 Marginalization Database

As described in the literature review, marginalization is defined as the “process by which individuals and groups are prevented from fully participating in society”.(19) We used Matheson et al.’s Canadian Marginalization Index to assign marginalization quintiles based on an individual’s area of residence.(20) These marginalization quintiles reflect measures of socioeconomic status and is used to understand inequalities in health and other social problems.(20) The four dimensions of marginalization include residential instability, ethnic concentration, dependency and material deprivation.(20) These index was developed using a theoretical framework.(20) The quintiles was created using factor analysis of census indicators.(20) The quintiles were then sorted into five groups (1 - least marginalized; 5 – Most marginalized) and each of these groups represented a fifth of the geographic units. For example, if an area had an ethnic concentration quintile of 5, it means it represents the 20% most ethnically concentrated area of areas in Canada.

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CHAPTER 4: Deceased Organ Donation Registration and Familial Consent among Chinese and South Asians in Ontario, Canada[a]

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[a] A version of this chapter has been published elsewhere as: Li AH, McArthur E, Maclean J, Isenor C, Prakash V, Kim SJ, Knoll G, Shah B, Garg AX. Deceased Organ Donation Registration and Familial Consent among Chinese and South Asians in Ontario, Canada. PLoS ONE 10(7): e0124321.

4.1 Introduction

There is a worldwide shortage of organs available for transplant. In 2012, almost 4000 Canadians were on a waiting list for an organ transplant and 230 died while waiting.(1) An immediate solution to this problem is to increase deceased organ donation consent rates, which in part is affected by the number of individuals registering their commitment to deceased organ donation in the event of their death.(2) In Ontario, when the decedent is eligible, approximately 60% of families consent for deceased organ donation, and 23% of the population is registered for deceased organ donation.(3) Other provinces such as British Columbia and Quebec have less than 10% registered for deceased organ donation.(2)

While U.S studies have demonstrated that attitudes towards organ donation and consent rates are lower in black, Hispanic, Asian and older potential donors (4–7), these data may not generalize well to Canada's population. In Canada, people of Chinese (China, Hong Kong, or Taiwan) and South Asian (Indian subcontinent) ancestry represent the two largest visible ethnic minority groups.(8) Previous studies from British Colombia and Alberta have suggested that these two groups are less likely to become deceased organ donors.(9–11) However, limitations of these studies include measuring support rather than actual registration, potential biases associated with survey design, and measuring ethnic differences in realized rather than eligible deceased organ donors.

We conducted two studies to test the hypotheses that Chinese and South Asians individuals in the province of Ontario, Canada are less likely to register for organ donation than the remaining general public (a cross-sectional study) and their families are less likely to consent to deceased organ donation at the time of death (a cohort study).

4.2 Subjects and Methods

4.2.1 Study design and setting

Using the large healthcare databases of Ontario, Canada, we conducted two population-based studies on Ontario citizens with a valid provincial health card number: 1) a retrospective cross-sectional study to examine the proportion of deceased organ donor registration and 2) a retrospective cohort study to examine rates of familial consent to deceased organ donation among South Asian individuals, Chinese individuals and the remaining general public. We conducted both studies at the Institute for Clinical Evaluative Sciences (ICES) according to a pre-specified protocol that was approved by the research ethics boards at Sunnybrook Health Sciences Centre (Toronto, Canada). This study follows reporting recommendations in the STROBE statement for observational studies (Appendix C).

As of 2008, Ontario's organ and tissue donor registry became affirmative only (i.e. recording only 'yes' responses).(2) Individuals 16 years of age and older can register online or can mail in a consent registration form. It is also provincially mandated that individuals are asked about organ and tissue donor registration with all health-card related transactions, driver's license renewals and Ontario photo ID applications at Service Ontario centres. Those who choose to register can select the option to exclude certain organs or tissues from donation.

4.2.2 Data sources

We obtained the information used in both studies from three linked databases using coded identifiers.

First, we used the Ontario Registered Persons Database to identify the individual's demographics and information on deceased organ donor registration. We derived the individual's socioeconomic status using neighborhood income quintiles, (a household size-adjusted measure of income).(12)

Second, we obtained data from Ontario's organ procurement organization, Trillium Gift of Life Network on all potential donors referred for consideration for deceased organ donation. Not all patients who die in a hospital have the potential for organ donation. For example. in Ontario only hospitals with ventilator capacity can potentially make a referral. A ventilated patient who meets any of the following criteria is referred to Trillium Gift of Life Network to be considered as a potential organ donor: 1) grave prognosis or Glasgow Coma Scale score of 3; 2) injured brain or non-recoverable injury or illness; 3) family initiated discussion of donation or withdrawal of life sustaining therapy and 4) planned discussion of therapy limited, de-escalation of treatment or withdrawal of life sustaining therapy. All referred patients are then determined for medical suitability. This data is captured on a real-time basis by a call center. We did not include patients who were referred for tissue-only donation.

Third, we obtained information on diagnoses and procedures during hospitalization to ascertain the patient's cause of death from the Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD). We classified cause of death using International Classification of Disease codes. We used similar codes from a previous study on deceased organ donation.(13) With the exception of neighbourhood income quintile (which was missing in less than 1% for both cohorts), the databases were complete for all variables used in this study.

4.2.3 Individuals and outcomes

In the cross-sectional study, we studied Ontarians (>16 years of age and alive) as of May 17, 2013 to examine the proportion registered for deceased organ donation. In the cohort study, we studied all patients who died from October 25th 2008 to December 31st 2012 and all cases referred for deceased organ donation to Trillium Gift of Life Network to examine the rate of familial consent for deceased organ donation.

The primary outcome was whether the individual was registered for deceased organ and tissue donation (cross-sectional study) and whether the family provided consent for deceased organ donation (cohort study). In the cross-sectional study, we also examined the proportion of registrants that excluded specific organs (kidney, heart, liver, lung small bowel or pancreas) or tissues (eyes, bone, skin). In the cohort study, we assessed the primary outcome within 7 days of the decedent's family being approached for donation.

4.2.4 Ethnicity

We used a validated surname algorithm to identify individuals with South Asian or Chinese ancestry.(14) This algorithm has been used in several prior studies and demonstrates high positive predictive values when compared with self-reported ethnicity in a national survey (89.3% for South Asian and 91.9% for Chinese).(15–17) Among South Asians, the final list includes only names unique to South Asians (Hindu, Sikh and Sri Lankan surnames). Names used by South Asian Muslims or Christians were excluded because they could not be differentiated from people from other ethnic backgrounds such as Arab or Persian.(14). Individuals whose surnames were not classified as South Asian or Chinese were categorized as the remaining general public.

4.2.5 Statistical analysis

When the outcome is common, odds ratios estimated from cross-sectional and cohort data will overestimate the prevalence and rate ratio, respectively. Therefore, we used modified-Poisson regression to estimate prevalence (cross-sectional study) and rate ratio (retrospective-cohort study) along with their 95% confidence intervals.(18) We also used multivariable modified-Poisson regression to identify variables associated with organ donor registration, organ or tissue exclusion (among registrants only) and familial consent to deceased organ donation. We assessed baseline differences and compared proportions in deceased donor registration using standardized differences (cross-sectional study).(19) This metric describes differences between group means relative to the pooled standard deviation and is considered meaningful if a difference of greater than 10% is present. Deceased organ donor registration rates can vary by community, so we stratified the results according to whether an individual lived in the largest metropolitan area of the province (the Greater Toronto Area) or the rest of the province. We also assessed baseline differences of decedents whose family was approached for organ donation using an analysis of variance (ANOVA; retrospective-cohort study). We used the Wilson-score method to calculate 95% confidence intervals for proportions. We conducted all analysis with SAS software, version 9.3 (SAS Institute Incorporated, Cary, North Carolina, USA). In all outcome analyses, we interpreted two-tailed p-values <0.05 as statistically significant.

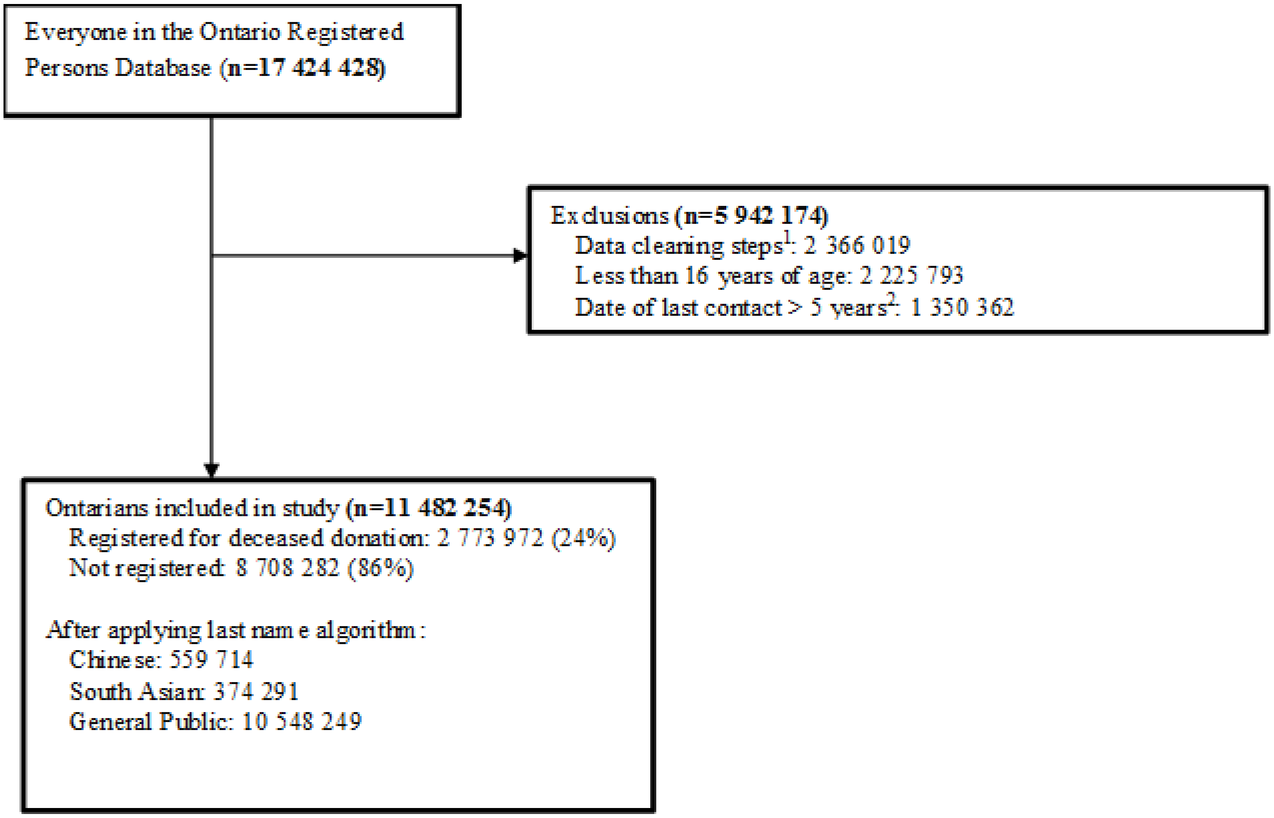
4.3 Results

4.3.1 Cross-sectional Study on Deceased Organ and Tissue Donor Registration

4.3.1.1 Baseline characteristics.

We identified 559 714 Chinese individuals, 374 291 South Asian individuals and 10 548 249 remaining general public who were eligible to register for deceased organ donation (S1 Fig). The characteristics of each group are listed in Table 4-1. Compared to the general public, Chinese and South Asian individuals were more likely to be from an urban city and of slightly lower socioeconomic status.

Figure 4-1: Selection of participants for inclusion in the cross-sectional study on deceased organ donor registration



[1] Data cleaning steps included invalid patient identifier, missing sex, non-Ontarian, death date prior to index date

[2] This exclusion was applied to ensure that the individual was living in Ontario

Table 4-1: Baseline Characteristics of Eligible Registrants (Cross-sectional Study)

Characteristic	**Chinese** (n=559 714)	**South Asians** (n=374 291)	**General public** (n=10 548 249)	**Standardized Differences[1]**	
				Chinese	**South Asians**
Mean age in years, (Standard Deviation)	42.2 (17.7)	40.5 (17.2)	44.0 (19.2)	10%	19%
Age					
16 – 29 years	157413 (28.1%)	116085 (31.0%)	3015548 (28.6%)	1%	5%
30 – 39 years	109123 (19.5%)	85222 (22.8%)	1676407 (15.9%)	9%	18%
40 – 49 years	114039 (20.4%)	63667 (17.0%)	1798314 (17.0%)	9%	0%
50 – 59 years	81263 (14.5%)	47989 (12.8%)	1671152 (15.8%)	4%	9%
60 – 69 years	50423 (9.0%)	36226 (9.7%)	1208621 (11.5%)	8%	6%
≥ 70 years	47453 (8.5%)	25102 (6.7%)	1178207 (11.2%)	9%	16%
Women	294580 (52.6%)	187563 (50.1%)	5402949 (51.2%)	3%	2%
Rural Residence[2]	3625 (0.6%)	2261 (0.6%)	1314886 (12.5%)	50%	50%
Income Quintile[3]					
Fifth (Highest)	93 488 (16.7%)	40735 (10.9%)	2169377 (20.6%)	10%	27%
Fourth	110 826 (19.8%)	60634 (16.2%)	2184138 (20.7%)	2%	12%
Third (Middle)	109 947 (19.6%)	88606 (23.7%)	2075976 (19.7%)	0%	10%
Second	132 330 (23.6%)	92741 (24.8%)	2045928 (19.4%)	10%	13%
First (Lowest)	110 181 (19.7%)	91015 (24.3%)	2031718 (19.3%)	1%	12%
Missing	2942 (0.5%)	560 (0.1%)	41112 (0.4%)	1%	6%

[1] Standardized Differences compared against the general public. Standardized Differences greater than 10% represent a meaningful difference between the two groups.

[2] Refers to areas with population less than 10 000.

[3] Categorized into fifths of average neighborhood income.

4.3.1.2 Organ donor registration.

A total of 49 938 of 559 714 Chinese individuals (8.9%, 95% CI: 8.8%-9.0%) and 47 774 of 374 291 (12.8%, 95% CI: 12.7%-12.9%) South Asians were registered for deceased organ donation. These proportions were lower than the general public (2 676 260 of 10 548 249 were registered, (25.4%, 95% CI: 25.4%-25.4%]) (Table 4-2). Chinese were almost three times (Prevalence Ratio [PR], 0.35; 95% CI, 0.35–0.35) and South Asian individuals were two times (PR, 0.50; 95% CI, 0.50–0.51) less likely to register for deceased organ donation compared to the general public. These results were virtually unchanged after adjusting for age, sex, socioeconomic status and residency (urban vs. rural). Other factors associated with a higher likelihood of registering for deceased organ donation included women (vs. men), younger age (vs. older age), higher income (vs. lower income) and living in a rural (versus urban) location (Table 4-2).

Table 4-2: Factors associated with Donor Registration (Cross-sectional study)

Characteristic	No. Registered (%)	Adjusted Prevalence Ratio[1] (95% CI)
Ethnicity		
Chinese	49 938 (8.9%)	0.35 (0.35 to 0.35)
South Asian	47 774 (12.8%)	0.50 (0.50 to 0.51)
General public	2 676 260 (25.4%)	1.00 [Reference]
Residence		
Urban	2 382 847 (23.4%)	1.00 [Reference]
Rural[2]	391 125 (29.6%)	1.25(1.25 to 1.26)
Age Category		
16 – 29 years	948 293 (28.8%)	1.00 [Reference]
30 – 39 years	558 946 (29.9%)	1.05(1.05 to 1.06)
40 – 49 years	496 331 (25.1%)	0.87(0.87 to 0.88)
50 – 59 years	394 863 (21.9%)	0.74(0.74 to 0.75)
60 – 69 years	246 021 (19%)	0.64(0.64 to 0.64)
≥ 70 years	129 518 (10.4%)	0.35(0.34 to 0.35)
Sex		
Men	1 250 333 (22.3%)	1.00 [Reference]
Women	1 523 639 (25.9%)	1.18(1.18 to 1.19)
Income Quintile[3]		
Fifth (Highest)	640 973 (27.8%)	1.16 (1.16 to 1.17)
Fourth	585 153 (25.1%)	1.04 (1.03 to 1.04)
Three (Middle)	553 545 (23.9%)	1.00 [Reference]
Two	522 224 (23.0%)	0.98 (0.97 to 0.98)
One (Lowest)	472 077 (21.1%)	0.88 (0.88 to 0.88)

[1] Adjusted for Sex, Residency, Age, Income Quintile. Unadjusted prevalence ratios were essentially unchanged

[2] Refers to areas with population less than 10 000.

The results were similar when stratified either for those living in the largest metropolitan area (Greater Toronto Area) or the rest of the province (Table 4-3). However, the absolute differences for deceased organ donor registration between the three groups was smaller in the Greater Toronto Area than the rest of the province (Greater Toronto Area: 8.0% [95% CI: 7.9%-8.1%] for Chinese and 11.8% [95% CI: 11.7%-12.0%] South Asian individuals were registered compared to 16.0% [95% CI: 15.9%-16.0%] for the remaining general public; Rest of the province: 12.9% [95% CI: 12.7%-13.1%] for Chinese and 17.0% [95% CI: 16.7%-17.3%] South Asian individuals compared to 30.1% [95% CI: 30.0%-30.1%] for the remaining general public).

Table 4-3: Factors associated with Donor Registration in GTA and Rest of the Province (Cross-sectional study)

	Largest Metropolitan Area (Greater Toronto Area) (n=4 271 087)		**Rest of the Province** (n=7 211 167)	
Characteristic	**No. Registered (%)**	**Adjusted Prevalence Ratio**[1] (95% CI)	**No. Registered (%)**	**Adjusted Prevalence Ratio**[2] (95% CI)
Ethnicity				
Chinese	36 375 (8.0%)	0.50 (0.49 to 0.50)	13 563 (12.9%)	0.41 (0.40 to 0.41)
South Asian	36 352 (11.8%)	0.75 (0.74 to 0.76)	11 422 (17.0%)	0.53 (0.52 to 0.54)
General public	559 927 (16.0%)	1.00 [Reference]	2 116 333 (30.1%)	1.00 [Reference]
Residence				
Urban	Not applicable	Not applicable	1 750 193 (29.7%)	1.00 [Reference]
Rural[3]	Not applicable	Not applicable	391 125 (29.6%)	1.02 (1.02 to 1.02)
Age Category				
16 – 29 years	224 334 (18.5%)	1.00 [Reference]	723 959 (34.9%)	1.00 [Reference]
30 – 39 years	156 555 (19.7%)	1.08 (1.07 to 1.08)	402 391 (19.4%)	1.08 (1.08 to 1.08)
40 – 49 years	110 346 (14.5%)	0.79 (0.78 to 0.79)	385 985 (35.9%)	0.91 (0.91 to 0.92)
50 – 59 years	76 108 (12.0%)	0.63 (0.63 to 0.64)	318 755 (26.2%)	0.78 (0.78 to 0.78)
60 – 69 years	42 374 (9.6%)	0.50 (0.50 to 0.50)	203 647 (17.5%)	0.68 (0.67 to 0.68)
≥ 70 years	22 937 (5.4%)	0.28 (0.27 to 0.28)	106 581 (12.9%)	0.36 (0.36 to 0.37)
Sex				
Men	283 196 (13.8%)	1.00 [Reference]	967 137 (27.3%)	1.00 [Reference]
Women	349 458 (15.8%)	1.17 (1.16 to 1.17)	1 174 181 (32.0%)	1.19 (1.19 to 1.20)
Income Quintile[4]				
Fifth (Highest)	148 418 (20.3%)	1.39 (1.38 to 1.40)	492 555 (31.3%)	1.07 (1.07 to 1.07)
Fourth	127 352 (16.1%)	1.09 (1.09 to 1.10)	457 801 (29.3%)	0.99 (0.99 to 0.99)
Three (Middle)	131 547 (14.8%)	1.00 [Reference]	421 998 (29.5%)	1.00 [Reference]
Two	121 312 (13.1%)	0.90 (0.89 to 0.90)	400 912 (29.9%)	1.01 (1.01 to 1.02)
One (Lowest)	104 025 (11.2%)	0.74 (0.74 to 0.75)	368 052 (28.2%)	0.95 (0.95 to 0.95)

[1] Adjusted for Sex, Residency, Age, Income Quintile. Unadjusted prevalence ratios were essentially unchanged.
[2] Adjusted for Sex, Age, Income Quintile. Unadjusted prevalence ratios were essentially unchanged.
[3] Refers to areas with population less than 10 000.
[4] Categorized into fifths of average neighborhood income

When given the option to exclude certain organs and tissue (amongst those who had registered for organ donation), 9264 of 49 938 Chinese registrants (18.6%, 95% CI: 18.2%-18.9%), 11 889 of 47 774 South Asian registrants (24.9%, 95% CI: 24.5%-25.3%) and 412 487 of 2 676 260 general public registrants (15.4%, 95% CI: 15.4%-15.5%) excluded at least one organ or tissue (Table 4-4). When adjusted as above, Chinese individuals (PR, 1.11; 95% CI, 1.09–1.13) and South Asian individuals (PR, 1.52; 95% CI, 1.50–1.55) were more likely to exclude an organ and/or tissue compared to the general public. Other factors associated with excluding an organ and/or tissue included men (vs. women), older (vs. younger) age, higher (vs. lower) socioeconomic status and living in a rural (vs. urban) city. Across the three groups, eyes and skin were the commonly excluded tissues. A relatively high proportion of South Asian individuals opted to exclude skin (17.5%).(Table 4-4)

Table 4-4: Proportions of registered organ and tissue donors excluding organs and/or tissues

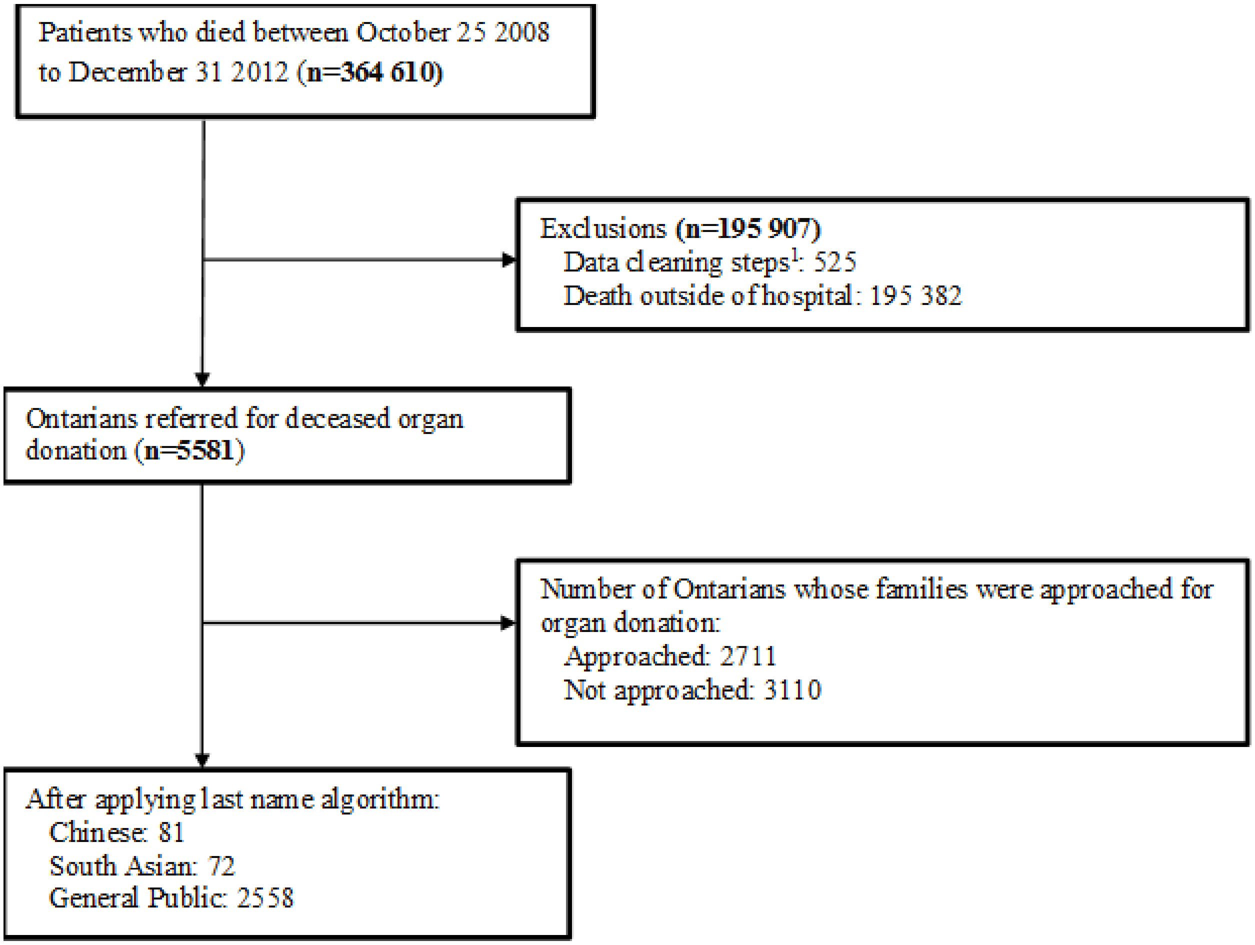
	Number of Registrants that opted-out:		
Organ and/or Tissue:	**Chinese**	**South Asian**	**General Public**
Kidney	947 (1.9%)	2381 (5.0%)	26 334 (1.0%)
Heart	1724 (3.5%)	2857 (6.0%)	43 496 (1.6%)
Eyes	5571 (11.2%)	5486 (11.5%)	270 430 (10.1%)
Bone	3754 (7.5%)	6121 (12.8%)	131 359 (4.9%)
Liver	1042 (2.1%)	2714 (5.7%)	28 399 (1.1%)
Lung	1102 (2.2%)	3037 (6.4%)	43 678 (1.6%)
Skin	5573 (11.2%)	8344 (17.5%)	242 573 (9.1%)
Pancreas	1529 (3.1%)	3887 (8.1%)	49 157 (1.8%)
Any of the Above	9264 (18.6%)	11889 (24.9%)	412 487 (15.4%)

4.3.2 Cohort Study on Familial Consent to Deceased Organ and Tissue Donation

4.3.2.1 Baseline characteristics.

From October 25 2008 to December 31 2012, a total of 168 703 Ontarians died in a hospital (Figure 4-2).

Figure 4-2: Selection of participants for inclusion in the Retrospective- cohort study on familial consent for organ donation



[1] Data cleaning steps included invalid patient identifier, missing sex, non-Ontarian, death date prior to index date
[2] This exclusion was applied to ensure that the individual was living in Ontario

A total of 5581 of these Ontarians were referred for deceased organ and tissue donation. Of those referred, the families of 81 Chinese decedents, 72 South Asian decedents and 2558 remaining general public decedents were approached to obtain familial consent for organ donation. The baseline characteristics of the decedents approached for donation are listed in Table 4-5. Compared to the general public, Chinese and South Asian decedents had significantly different causes of deaths

Table 4-5: Baseline characteristics of decedents whose family was approached for organ donation1 (Cohort study)

Characteristic	**Chinese** (n=81)	**South Asian** (n=72)	**General public** (n=2558)	***P***
Mean age in years, (Standard Deviation)	57.9 (19.27)	48.7 (18.72)	53.7 (18.75)	<0.05
Age				
0-44	15 (18.5%)	25 (34.7%)	662 (25.9%)	<0.05
45-54	13 (16.0%)	17 (23.6%)	481 (18.8%)	
55-64	21 (25.9%)	19 (26.4%)	587 (22.9%)	
65+	32 (39.5%)	11 (15.3%)	828 (32.4%)	
Women	29 (35.8%)	29 (40.3%)	1047 (40.9%)	0.65
Rural Residency[2]	<=5 (2.5%)	<=5 (6.9%)	334 (13.1%)	<0.01
Income Quintile[3]				0.23
Quintile 5 (highest)	17 (21.0%)	17 (23.6%)	571 (22.3%)	
Quintile 4	17 (21.0%)	24 (33.3%)	547 (21.4%)	
Quintile 3	19 (23.5%)	16 (22.2%)	516 (20.2%)	
Quintile 2	17 (21.0%)	9 (12.5%)	502 (19.6%)	
Quintile 1 (lowest)	11 (13.6%)	6 (8.3%)	422 (16.5%)	
Cause of Death				<0.01
Traumatic Brain Injury	16 (19.8%)	17 (23.6%)	435 (17.0%)	
Subarachnoid/Intracerebral Hemorrhagic event	35 (43.2%)	16 (22.2%)	620 (24.2%)	
Other damage to the brain[4]	17 (21.0%)	21 (29.2%)	643 (25.1%)	
All other causes of death[5]	13 (16.0%)	18 (25.0%)	860 (33.6%)	

[1] Cell sizes less than or equal to 5 are suppressed to protect confidentiality. Several categories were collapsed to protect confidentiality.

[2] Refers to areas with population less than 10 000.

[3] Categorized into fifths of average neighborhood income.

[4] Includes anoxic brain damage, cerebral edema, cerebral infarction, cerebral thrombosis and asphyxiation, and other disorders of the brain.

[5] Includes cardiac arrest and acute myocardial infarction

4.3.2.2 Consent for organ donation.

Overall, 68.3% (95% Confidence interval [CI]: 66.4%-70.0%) of general public families consented for deceased organ donation when approached compared to 40.7% (95% CI: 30.7%-

51.6%) of Chinese families and 54.2% (95% CI: 42.7%-65.2%) of South Asian families (Table 4). Families of Chinese decedents (Rate Ratio [RR], 0.60; 95% CI: 0.46–0.78) or families of South Asian decedents (RR, 0.79; 95% CI: 0.64–0.98) were less likely to provide consent for deceased organ donation compared to the general public. Results were not appreciably different after adjusting for sex, residency (urban vs. rural), age, socioeconomic status and cause of death (Table 4-6). When looking at the other factors associated with a higher likelihood of consent for deceased organ donation, families of older decedents (55+ years old) were less likely to consent compared to younger decedents (18–34 years old) (Table 4-6). Families of decedents with other causes of death were less likely to provide consent compared to those who died from traumatic brain injury (RR, 0.86; 95% CI: 0.80–0.92).

Table 4-6: Factors associated with Familial Consent (Cohort Study)

Characteristic	**Number of Individuals consented (%)**	**Rate Ratio (95% CI)**	
		Unadjusted	**Adjusted[1]**
Ethnicity			
General public	1746 (68.3%)	1.00 [Reference]	1.00 [Reference]
Chinese	33 (40.7%)	0.60 (0.46 to 0.78)	0.62 (0.48 to 0.80)
South Asian	39 (54.2%)	0.79 (0.64 to 0.98)	0.77 (0.63 to 0.96)
Sex			
Men	1083 (67.4%)	1.00 [Reference]	1.00 [Reference]
Women	735 (66.5%)	0.99 (0.93 to 1.04)	0.99 (0.94 to 1.04)
Residency[2]			
Urban	1578 (66.4%)	1.00 [Reference]	1.00 [Reference]
Rural	240 (71.0%)	1.07 (0.99 to 1.15)	1.03 (0.96 to 1.10)
Age			
0-18	103 (72.5%)	0.94 (0.83 to 1.05)	0.96 (0.86 to 1.08)
18-34	228 (77.6%)	1.00 [Reference]	1.00 [Reference]
35-44	198 (74.4%)	0.96 (0.87 to 1.05)	0.97 (0.89 to 1.07)
45-54	374 (73.2%)	0.94 (0.87 to 1.02)	0.96 (0.88 to 1.04)
55-64	427 (68.1%)	0.88 (0.81 to 0.95)	0.89 (0.82 to 0.97)
65-74	346 (60.8%)	0.78 (0.72 to 0.86)	0.80 (0.73 to 0.88)
75+	142 (47.0%)	0.61 (0.53 to 0.69)	0.62 (0.54 to 0.71)
Income Quintile[3]			
Quintile 5 (highest)	317 (72.2%)	1.08 (1.00 to 1.17)	1.08 (1.00 to 1.18)
Quintile 4	371 (70.3%)	1.05 (0.97 to 1.14)	1.05 (0.97 to 1.13)
Quintile 3	368 (66.8%)	1.00 [Reference]	1.00 [Reference]
Quintile 2	388 (66.0%)	0.99 (0.91 to 1.07)	0.99 (0.91 to 1.07)

Quintile 1 (lowest)	374 (61.8%)	0.93 (0.85 to 1.01)	0.93 (0.85 to 1.01)
Cause of Death			
Traumatic Brain Injury	348 (74.4%)	1.00 [Reference]	1.00 [Reference]
Subarachnoid Hemorrahage events	207 (77.5%)	1.04 (0.96 to 1.13)	1.05 (0.96 to 1.14)
Intracerebral Hemorrhage	253 (62.6%)	0.84 (0.77 to 0.92)	0.91 (0.82 to 1.00)
Other damage to the brain[4]	292 (68.2%)	0.92 (0.84 to 1.00)	0.92 (0.85 to 1.00)
Acute Myocardial Infarction, Cardiac Arrest	164 (64.8%)	0.87 (0.78 to 0.97)	0.90 (0.81 to 1.00)
All other causes of death[5]	554 (62.2%)	0.84 (0.78 to 0.90)	0.86 (0.80 to 0.92)

Note: CI= confidence interval

[1] Adjusted for Sex, Residency, Age, Income Quintile, Cause of Death

[2] Refers to areas with population less than 10 000.

[3] Categorized into fifths of average neighborhood income.

[4] Includes anoxic brain damage, cerebral edema, cerebral infarction, cerebral thrombosis and asphyxiation, other disorders of the brain

[5] Includes cardiac arrest and acute myocardial infarction

4.4 Discussion

We found that Chinese and South Asian Ontarians had lower deceased organ donor registration and consent rates compared to the remaining general public.

Our findings are consistent with other studies demonstrating that Chinese and South Asians are less likely to be organ and tissue donors. Although we found large differences in donor registrations between the three groups, differences in familial consent were smaller. The low organ donor registration may be in part due to the lack of awareness of the provincial donor registry.(20,21) Among ethnic minorities in North America and the United Kingdom, a recent review found that there was less favourable cultural/religious beliefs towards organ/tissue donation as well as less trust in healthcare professionals and the organ allocation system.(22) Further research on culturally-sensitive strategies to raise awareness and promote organ donation is warranted. For example, we found that many South Asian registrants opted to exclude skin for donation, which may have been affected by the myth that organ donation will disfigure the donor's body.(23) Finally, a US study revealed that most organ procurement organizations (90%) estimate that less than 10% of families of registered organ donors objected to deceased organ donation.(24) Therefore, increasing the number of registrants may be an important strategy to build support for organ and tissue donation and increase consent rates. Such a strategy has proven successful in other contexts. For example, in the United States, multiple educational campaigns including media campaigns, and educational programs at high schools and churches significantly improved the Hispanic American population's awareness, knowledge and intention to donate organs.(25) In addition, an aggressive outreach program implemented at high schools, churches, and medical clinics increased consent rate among Hispanic Americans from 56% in 2005 to 83% in 2011 (P = 0.004) (26). According to a recent review, community-based educational programs are more effective at increasing registration for organ donation among ethnic minorities compared to mass media campaigns.(27) To be successful, the program should be delivered by local community members in familiar environments and include a strong interpersonal element that addresses specific concerns of the community.(27) Giving the community ownership of the health issue may also be more effective than alternative approaches.(28)

4.4.1 Strengths and limitations

Our study examined deceased organ and tissue donor registration and familial consent among the two largest visible ethnic minorities in the entire province of Ontario, Canada. To our knowledge, our study is the first to document actual registration rates among ethnic minorities, rather than expressed support to donate. Further, we had data on all eligible deaths, referrals for deceased organ donation and whether the family was actually approached to obtain consent for deceased organ donation.

However, our study has some limitations. First, we did not identify any barriers to organ donation and had no information on the reasons why Chinese and South Asian individuals did not register for deceased donation or provide familial consent for organ donation, which would be useful to inform educational programs tailored for ethnicity. Second, we identified Chinese and South Asians based on a validated list of Chinese surnames with high positive predictive value but low sensitivity. There is the potential for misclassifying individuals whose surnames do not reflect their ethnicity. Third, this study focused only on Chinese and South Asian individuals. Future use of other data sources, including the immigration and First Nations databases, would provide opportunities to examine similar issues in other ethnic groups. Fourth, we were not able to distinguish whether patients were eligible for donation after brain death or donation after circulatory death. It may be possible that familial consent is influenced by cultural differences in the understanding of death. Finally, we estimate our general public group is made up of approximately 85% of individuals with European ancestry.(8) Aboriginal and Afro-Caribbean individuals share many surnames with the European population and are classified as the general public in this study.(22) Finally, we examined deceased organ donor registration for the Ontario population and stratified the results by the largest metropolitan area. Although ethnic communities have the same access to information about organ donation, registration rates can be influenced by level and type of organ donor registry awareness activities within each community. Further, other factors that could influence organ donor registration such as religious beliefs(29), education(30), medical mistrust(31,32), immigration status, and concerns about recording their identity in a government database were not measured in our study.

This study demonstrates that Chinese and South Asian Ontarians have lower deceased organ donor registration and familial consent rates compared to the general public. There is an opportunity to build support for organ and tissue donation in these large ethnic communities, which could help more patients receive a life-saving transplant and reduce their time on the waiting list.

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CHAPTER 5: Registration for deceased organ and tissue donation amongst new Canadians: a population-based cross-sectional study[a]

This Institute for Clinical Evaluative Sciences (ICES) project was conducted by the Kidney, Dialysis and Transplantation program at the ICES Western site. Parts of this material were based on data and information compiled and provided by the Canadian Institute for Health Information; however, the analyses, conclusions, opinions and statements expressed herein are those of the authors and not necessarily those of the Canadian Institute for Health Information. The authors thank Immigration, Refugees and Citizenship Canada for providing access to the databases used in this study. Core funding for ICES Western is provided by the Academic Medical Organization of Southwestern Ontario, the Schulich School of Medicine and Dentistry, Western University and the Lawson Health Research Institute. The ICES Kidney, Dialysis and Transplantation receives program operating grant support from the Canadian Institutes of Health Research. Aspects of this project were conducted in the Lilibeth Caberto Kidney Clinical Research Unit. The opinions, results and conclusions are those of the authors and are independent from the funding sources. No endorsement by these organizations is intended or should be inferred. The funders had no role in study design, data collection and analysis, decision to publish or preparation of the manuscript.

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The reporting guidelines for this study is in Appendix D.

5.1 Introduction

Increasing rates of organ and tissue donation in Canada could help save the lives of the thousands of Canadians with end-stage organ failure. One factor that can influence the family's decision to consent to organ donation is having knowledge of the potential donor's wishes in this regard.(1) Canada has an "opt-in" system, whereby citizens can record their donation wishes through a deceased organ donor registry, which can then be used to inform family members in the event of death.(2,3) Increasing the number of registered donors is a key strategy adopted by Canadian organ procurement organizations to improve organ and tissue donation.(2) An important step to increase the registration rate is to identify subpopulations that have lower donor registration rates, and to better understand the reasons for nonregistration.

Ethnic minority populations have greater concerns regarding organ donation compared with the general population, and these can be culture-specific.(4) Documented issues include medical mistrust among the Black population,(4-6) religious uncertainties among North Americans of the Islamic Faith,(4-6) donor registry unawareness among Chinese and Indo-Asians Canadians,(7-8) and lack of societal integration among Arab Americans.(9) In addition, a majority of new immigrants to Canada are from regions with less developed organ donation systems that lack donor registries, such as Asia, Latin America, and the Caribbean.(10) As rates of migration continue to rise in Canada and other countries, identifying immigrant groups with lower donor registration rates and understanding how sociodemographic factors can affect organ and tissue donor registration can inform culturally sensitive donation practice, public education and awareness campaigns.(4,11)

To better inform these issues, we conducted a population-based study in Ontario to determine the registration status for deceased organ and tissue donor for over 1 million recent immigrants from different countries compared with long-term residents. Our main outcome of interest was the proportion of immigrants and long-term residents of Canada who were registered deceased organ and tissue donors. For recent immigrants, we examined characteristics independently associated with registering for deceased organ and tissue donation. We also identified the 5 countries with the largest absolute values of unregistered people. Our secondary outcome was whether registered donors opted to exclude certain organs or tissues that they did not wish to donate.

5.2 Methods

5.2.1 Design and setting

We conducted a population-based cross-sectional study using linked healthcare databases in Ontario as of Oct. 22, 2013 via unique, encoded identifiers at the Institute for Clinical Evaluative Sciences (ICES) according to a pre-specified protocol. Ontario is Canada’s most populous province (approximately 30% of the Canadian population)(12), with about 11 million residents ≥16 years of age (the minimum age required to register for deceased organ and tissue donation) or more. In a 2012 study comparing characteristics and proportions registered of various registries worldwide, Nova Scotia had the highest proportion registered at 65%, followed by New Brunswick (42%), Ontario (18%), Yukon (16%), Quebec (10%), and British Columbia (8%).(2) In Canada, donor registries are “opt-in” registries that record only “yes” responses.

People can register for organ and tissue donation when they renew or apply for a new driver's licence or health card at ServiceOntario. Registration can also be completed online. Those who choose to register can select the option to exclude certain organs or tissues from donation. To register as an organ and tissue donor in Ontario, one must be at least 16 years old and have a valid health card (https:// www.ontario.ca/page/organ-and-tissue-donor-registration).

5.2.2 Data sources

We ascertained socio-demographic information and donor registration information from 2 main administrative databases: The Ontario Registered Persons Database and the Immigration, Refugees and Citizenship Canada's Permanent Resident Database. The former contains demographic information and donor registration for all residents of Ontario who have ever been issued a health card by the Ontario government. This captures everyone who has registered for organ donation. We derived income using neighbourhood income quintiles (a measure of income adjusted to household size).(14) Marginalization is the "process by which individuals and groups are prevented from fully participating in society".(15) We used Matheson and Colleagues'(16) Canadian Marginalization Index to assign marginalization quintiles based on an individual's area of residence on 4 components of marginalization: residential instability (a measure of turnover in the population), ethnic concentration (a measure consisting of the proportion of recent immigrants and proportion of people who self-identify as a visible minority), dependency (a ratio measure of the dependent population [i.e., seniors and children] to the working-age population), and material deprivation (a measure of inability to afford consumption goods or services). This index was developed with the use of a theoretical framework, derived from census indicators and created by sorting the data into 5 quintiles (from least marginalized to most marginalized).

The Immigration, Refugees and Citizenship Canada's Permanent Resident Database contains landing records for every permanent legal immigrant to Canada who arrived from 1985 onwards. Data are captured at the time of immigration application.(17) We used the Ontario portion of this database to ascertain immigration status and other migration-related variables. This database has been used previously to examine diabetes and cancer screening among immigrants.(18,19) The migration-related variables included time since arrival to Canada, immigration visa class (economic, family, refugees, or other), language ability (English, French, both, or neither), marital status (married, single, or separated, divorced, widowed) and education level at the time of immigration. "Economic" immigrants included those sponsored by the province, skilled workers, entrepreneurs, and investors. "Family" comprised those of family members of economic immigrants and those who arrived through family reunification. The "other" category included all other immigrant classes, such as live-in caregivers and those who arrived on humanitarian grounds.

5.2.3 Study population

We included all permanent residents of Ontario as of October 2013 and classified them as either immigrants or long-term residents based on their immigration status within the IRCC's Permanent Resident Database. Long-term residents were those who did not have a record in the IRCC's Permanent Resident Database. We excluded people who did not make at least 1 contact with the health care system in the 5 years before October 2013 to ensure we only included people in Ontario.

5.2.4 Outcomes

We used each immigrant’s country of birth to categorize most immigrants by world region of origin, according to the World Bank system: Western Europe; Eastern Europe and Central Asia; Middle East and North Africa; Sub-Saharan Africa; East Asia and Pacific; South Asia; Latin America and Caribbean; and United States, Australia and New Zealand.(20) Countries that did not fit into any of the world regions were categorized as “other.” We chose this grouping because we hypothesized that differences in donor registration were primarily due to cultural awareness and attitudes.

5.2.5 Statistical analyses

We compared sociodemographic characteristics and the proportion registered for organ and tissue donation between immigrants and long-term residents using standardized differences, for which a value greater than 10% indicates a meaningful difference.(21) We used modified-Poisson regression to estimate the prevalence rate ratio and 95% confidence intervals (CI) of organ and tissue donor registration for immigrants relative to long-term residents.(22)

We also used multivariable Modified-Poisson regression to identify variables independently associated with organ donor registration among immigrants and long-term residents, as well as for the immigrant group only.(22) We adjusted for variables chosen a-priori based on the findings of previous studies (e.g., age, sex, income quintile).(23) We used the Wilson-score method to calculate 95% CI for proportions. We conducted complete case analysis (without multiple imputation) for the multivariable analysis because the amount of missing data was low (less than 1.3% of residents were excluded due to missing data). We conducted all analysis with SAS software, version 9.3. Finally, we examined the consistency of the associative relationships by conducting the analyses stratified by the country of origin of the 5 largest groups of immigrants who have not yet registered for organ and tissue donation.

5.3 Results

5.3.1 Baseline characteristics

We identified 1 947 646 immigrant and 9 244 570 long-term residents (i.e., non-immigrants) (Figure 5-1). Compared to long-term residents, immigrants were more likely to be younger (mean age 44.1 v. 47.3 year), from urban areas (98.7% v. 90.6%), from lower socio-economic neighbourhoods, and areas with a higher ethnic concentration; they were less likely to be from rural areas (Table 5-1). Half of all immigrants were from the East Asia and Pacific Region (25.6%) or South Asia (24.3%).

Figure 5-1: Selection of participants for inclusion in the cross-sectional study on deceased organ donor registration

[1] Data cleaning steps included invalid patient identifier, missing sex, non-Ontarian, death date prior to index date

[2] This exclusion was applied to ensure that the individual was living in Ontario

Table 5-1: **Baseline characteristics of immigrants and long-term residents**

Characteristic	Immigrants (*n* = 1 947 646) (%)	Long-term residents (*n* = 9 244 570) (%)	Standardized differences (%)*
Mean age, yr (standard deviation)	44.1 (15.5)	47.3 (19.2)	17
Age category, yr			
16–19	76 073 (3.9)	599 264 (6.5)	12
20–29	290 314 (14.9)	1 510 757 (16.3)	4
30–39	419 949 (21.6)	1 380 229 (14.9)	17
40–49	493 544 (25.3)	1 498 785 (16.2)	23
50–59	370 569 (19.0)	1 657 095 (17.9)	3
60–69	163 899 (8.4)	1 301 436 (14.1)	18
70–79	86 024 (4.4)	775 156 (8.4)	16
≥ 80	47 274 (2.4)	521 848 (5.6)	16
Women	933 639 (47.9)	4 841 077 (52.4)	9
Rural residence†	24 848 (1.3)	1 243 904 (13.5)	48
Income quintile‡			
First (lowest)	493 294 (25.3)	1 618 342 (17.5)	19
Second	428 901 (22.0)	1 760 076 (19.0)	7
Third (middle)	409 244 (21.0)	1 864 728 (20.2)	2
Fourth	368 900 (18.9)	1 984 856 (21.5)	6
Fifth (highest)	247 307 (12.7)	2 016 568 (21.8)	24
Instability§			
First (lowest)	604 813 (31.1)	2 350 648 (25.4)	13
Second	350 284 (18.0)	1 969 402 (21.3)	8
Third (middle)	207 937 (10.7)	1 542 066 (16.7)	18
Fourth	335 781 (17.2)	1 636 146 (17.7)	1
Fifth (highest)	433 725 (22.3)	1 615 948 (17.5)	12
Missing	15 106 (0.8)	130 360 (1.4)	6
Ethnic concentration¶			
First (lowest)	40 269 (2.1)	1 280 350 (13.8)	45
Second	73 994 (3.8)	1 620 959 (17.5)	46
Third (middle)	125 735 (6.5)	1 749 603 (18.9)	38
Fourth	294 318 (15.1)	1 963 863 (21.2)	16
Fifth (highest)	1 398 224 (71.8)	2 499 435 (27.0)	100
Missing	15 106 (0.8)	130 360 (1.4)	6
Dependency**			
First (lowest)	663 665 (34.1)	1 977 392 (21.4)	29
Second	529 973 (27.2)	2 034 206 (22.0)	12

Third (middle)	335 353 (17.2)	1 815 183 (19.6)	6
Fourth	214 055 (11.0)	1 609 352 (17.4)	18
Fifth (highest)	189 494 (9.7)	1 678 077 (18.2)	24
Missing	15 106 (0.8)	130 360 (1.4)	6
Material deprivation††			
First (lowest)	502 397 (25.8)	2 461 225 (26.6)	2
Second	402 011 (20.6)	2 135 074 (23.1)	6
Third (middle)	377 933 (19.4)	1 825 100 (19.7)	1
Fourth	331 916 (17.0)	1 488 359 (16.1)	2
Fifth (highest)	318 283 (16.3)	1 204 452 (13.0)	9
Missing	15 106 (0.8)	130 360 (1.4)	6
World region of birth			
East Asia and Pacific Region	499 533 (25.6)		
South Asia	474 101 (24.3)	–	
Latin America and Caribbean	269 170 (13.8)	–	
Eastern Europe and Central Asia	215 856 (11.1)	–	
Middle East and North Africa	181 565 (9.3)	–	
Western Europe	153 259 (7.9)	–	
Sub-Saharan Africa	115 371 (5.9)	–	
USA, Australia and New Zealand	38 014 (2.0)	–	
Other	777 (< 0.1)	–	
Educational qualification			
University degree or higher	502 234 (25.8)	–	
Some university	80 655 (4.1)	–	
Non-university qualifications (e.g., college diploma)	277 160 (14.2)	–	
Secondary or less	923 002 (47.4)	–	
No education	164 521 (8.4)	–	
Missing	74 (< 0.01)	–	
Time since arrival in Canada, yr			
≥20	512 570 (26.3)	–	
15–19	379 567 (19.5)	–	
10–14	453 966 (23.3)	–	
4–9	518 677 (26.6)	–	

< 4	82 866 (4.3)	–	
Canadian language ability			
English	1 149 609 (59.0)	–	
French	16 612 (0.9)	–	
Both	49 192 (2.5)	–	
Neither	732 166 (37.6)	–	
Missing	67 (< 0.01)	–	
Marital status			
Married	1 035 265 (53.2)	–	
Separated, divorced, widowed	74 680 (3.8)	–	
Single	837 396 (43.0)	–	
Missing	305 (< 0.1)	–	
Immigrant class		–	
Economic	899 634 (46.2)	–	
Family	685 080 (35.2)	–	
Refugee	312 174 (16.0)	–	
Other	50 750 (2.6)	–	
Missing	8 (< 0.01)	–	

Note: “– “ represents data is not available among long-term residents.

*Standardized differences compared against long-term residents. Standardized differences greater than 10% represent a meaningful difference between the 2 groups.

†Refers to areas with population less than 10 000.

‡Categorized into fifths of average neighbourhood income.

§Measure of the turnover in the population.

¶Measure of the proportion of recent immigrants and those who self-identify as visible minority.

**Measures the size of the “dependent” population (i.e., seniors and children) in relation to the “working age” population who provide social and economic support.

††Measure of inability to afford consumption goods or services.

5.3.2 Registration for organ and tissue donation

A total of 231 180 immigrants (11.9% registered; 95% CI 11.8–11.9) were registered for deceased organ and tissue donation, compared with 2 453 116 long-term residents (26.5%; 95% CI 26.5–26.6) (Table 5-2).

Table 5-2: Characteristics associated with donor registration among immigrants and long-term residents (n= 11 192 216)

		Prevalence ratio (95% CI)	
Characteristic	No. registered (%)	Unadjusted	Adjusted*
World region of birth			
Long-term residents	2 453 116 (26.5)	1.00 [Reference]	1.00 [Reference]
Immigrants	231 180 (11.9)		
East Asia and Pacific Region	41 752 (8.4)	0.31 (0.31–0.32)	0.39 (0.38–0.40)
South Asia	53 077 (11.2)	0.42 (0.42–0.43)	0.53 (0.52–0.54)
Latin America and Caribbean	41 006 (15.2)	0.57 (0.57–0.58)	0.68 (0.67–0.69)
Eastern Europe and Central Asia	20 222 (9.4)	0.35 (0.35–0.36)	0.38 (0.37–0.40)
Middle East and North Africa	19 059 (10.5)	0.40 (0.39–0.40)	0.47 (0.46–0.49)
Western Europe	31 637 (20.6)	0.78 (0.77–0.79)	0.79 (0.78–0.81)
Sub-Saharan Africa	9 080 (7.9)	0.30 (0.29–0.30)	0.35 (0.33–0.36)
USA, Australia and New Zealand	15 209 (40.0)	1.51 (1.49–1.53)	1.40 (1.36–1.43)
Other	138 (17.8)	0.67 (0.58–0.78)	1.01 (0.74–1.36)
Age category, yr			
16–19	107 575 (15.9)	1.00 [Reference]	1.00 [Reference]
20–29	406 873 (22.6)	1.42 (1.41–1.43)	1.45 (1.43–1.47)
30–39	526 486 (29.2)	1.84 (1.83–1.85)	1.96 (1.94–1.99)
40–49	556 450 (27.9)	1.75 (1.74–1.76)	1.85 (1.82–1.87)
50–59	502 942 (24.8)	1.56 (1.55–1.57)	1.54 (1.52–1.56)
60–69	349 575 (23.9)	1.50 (1.49–1.51)	1.41 (1.39–1.43)
70–79	165 279 (19.2)	1.20 (1.20–1.21)	1.11 (1.10–1.13)
≥80	69 116 (12.1)	0.76 (0.76–0.77)	0.69 (0.68–0.70)
Sex			
Women	1 495 776 (25.9)	1.00 [Reference]	1.00 [Reference]
Men	1 188 520 (21.9)	0.85 (0.85–0.85)	0.83 (0.83–0.83)
Residence			
Urban	2 306 304 (23.2)	1.00 [Reference]	1.00 [Reference]
Rural†	377 992 (29.8)	1.28 (1.28–1.29)	0.97 (0.96–0.98)
Income quintile‡			
First (lowest)	430 400 (20.4)	0.86 (0.86–0.86)	1.03 (1.02–1.04)
Second	491 648 (22.5)	0.95 (0.95–0.95)	1.00 (0.99–1.01)

Third (middle)	537 122 (23.6)	1.00 [Reference]	1.00 [Reference]
Fourth	588 534 (25.0)	1.06 (1.05–1.06)	1.00 (0.99–1.00)
Fifth (highest)	636 592 (28.1)	1.19 (1.18–1.19)	1.02 (1.01–1.02)
Ethnic concentration§,¶			
First (lowest)	417 114 (31.6)	1.08 (1.08–1.08)	1.11 (1.10–1.11)
Second	524 728 (31.0)	1.06 (1.06–1.06)	1.07 (1.06–1.07)
Third (middle)	548 379 (29.2)	1.00 [Reference]	1.00 [Reference]
Fourth	582 938 (25.8)	0.88 (0.88–0.89)	0.89 (0.89–0.89)
Fifth (highest)	575 086 (14.8)	0.50 (0.50–0.51)	0.58 (0.57–0.58)
Material deprivation§,**			
First (lowest)	772 427 (26.1)	1.11 (1.10–1.11)	1.10 (1.10–1.11)
Second	625 442 (24.7)	1.05 (1.04–1.05)	1.02 (1.01–1.03)
Third (middle)	519 271 (23.6)	1.00 [Reference]	1.00 [Reference]
Fourth	414 418 (22.3)	0.97 (0.96–0.97)	1.00 (0.99–1.01)
Fifth (highest)	316 687 (20.8)	0.88 (0.88–0.89)	0.99 (0.98–1.01)

Note: CI = confidence interval.

Total immigrants and long-term residents registered were 2 684 296 (24.0%).

*Adjusted for world region of birth, sex, residence, age category, neighbourhood income quintile, material deprivation, and ethnic concentration. Adjusted analysis based on a random sample of 20% (*n* = 2 238 443).

†Refers to areas with population less than 10 000.

‡Categorized into fifths of average neighbourhood income.

§Missing data on material deprivation and ethnic concentration on 145 466 individuals, of which 36 051 were registered (1.3% missing).

¶Measure of the proportion of recent immigrants and those who self-identify as visible minority.

**Measure of inability to afford consumption goods or services.

When we assessed the proportion of immigrants registered for deceased organ donation according to the world region of birth, the highest proportion of registered donors were from the USA, Australia and New Zealand (40.0% of immigrants born in this region were registered; 95% CI 39.5–40.5) followed by Western Europe (20.6%; 95% CI 20.4–20.9), and Latin American and the Caribbean (15.2%; 95% CI 15.1–15.4). Less than 10% of immigrants from Eastern Europe and Central Asia (9.4%; 95% CI 9.2–9.5), East Asia and Pacific Region (8.4%; 95% CI 8.3–8.5), and Sub-Saharan Africa (7.9%; 95% CI 7.7–8.0) were registered. Immigrants born in the USA, Australia and New Zealand region had a higher proportion of registrants than long-term residents.

5.3.3 Characteristics associated with donor registration

For the combined immigrants and long-term residents, the 30–39 year age group had the highest donor registration rates (29.2% were registered; adjusted prevalence ratio (PR), 1.96; 95% CI 1.94–1.99; referent 16–19 year) (Table 5-2). In adjusted analyses, we observed no association between income and registration rates. Individuals living in higher ethnically-concentrated areas were less likely to register for deceased organ donation. For example, 14.8% of individuals living in the top quintile (5th quintile) most ethnically-concentrated areas were registered compared with 29.2% living in the middle quintile (adjusted PR 0.58; 95% CI 0.57–0.58; referent was middle quintile) (Table 5-2). We also found a weak association between 2 of the 4 measures of marginalization (instability and dependency) and donor registration (results not shown).

Among immigrants, economic immigrants (those selected based on skills), those who had a university education at landing, and those who spoke both English and French were more likely to register (Table 5-3). Separated, divorced, or widowed immigrants were less likely to register than married immigrants in unadjusted model but more likely in adjusted model. In general, immigrants living in Canada for longer period of years were more likely to be registered compared with those living in Canada for less than 4 years.

Table 5-3: Characteristics associated with donor registration among immigrants (n = 1 947 192)

		Prevalence ratio (95% CI)	
Characteristic	**No. registered (%)**	**Unadjusted**	**Adjusted***
World region of birth			
East Asia and Pacific	41 748 (8.4)	0.21 (0.21–0.21)	0.28 (0.27–0.28)
South Asia	53 066 (11.2)	0.28 (0.28–0.28)	0.37 (0.36–0.38)
Latin America and Caribbean	40 985 (15.2)	0.38 (0.38–0.39)	0.51 (0.50–0.52)
Eastern Europe and Central Asia	20 216 (9.4)	0.23 (0.23–0.24)	0.28 (0.27–0.28)
Middle East and North Africa	19 056 (10.5)	0.26 (0.26–0.27)	0.33 (0.32–0.33)
Western Europe	31 634 (20.6)	0.52 (0.51–0.52)	0.57 (0.56–0.58)
Sub-Saharan Africa	9 078 (7.9)	0.20 (0.19–0.20)	0.26 (0.26–0.27)
USA, Australia and New Zealand	15 207 (40.0)	1.00 [Reference]	1.00 [Reference]
Other	138 (17.8)	0.44 (0.38–0.52)	0.58 (0.50–0.67)
Age category, yr			
16–19	4 545 (6.0)	1.00 [Reference]	1.00 [Reference]
20–29	31 791 (11.0)	1.83 (1.78–1.89)	1.85 (1.80–1.91)
30–39	57 841 (13.8)	2.31 (2.24–2.37)	2.23 (2.16–2.30)
40–49	68 319 (13.8)	2.32 (2.25–2.39)	2.02 (1.95–2.08)
50–59	44 244 (11.9)	2.00 (1.94–2.06)	1.76 (1.70–1.82)
60–69	16 302 (9.9)	1.66 (1.61–1.72)	1.57 (1.52–1.63)
70–79	5 931 (6.9)	1.15 (1.11–1.20)	1.28 (1.23–1.33)
≥80	2 155 (4.6)	0.76 (0.73–0.80)	0.88 (0.84–0.93)
Sex			
Women	121 402 (12.0)	1.00 [Reference]	1.00 [Reference]
Men	109 726 (11.8)	0.98 (0.97–0.99)	0.93 (0.93–0.94)
Residence			
Urban	224 266 (11.7)	1.00 [Reference]	1.00 [Reference]
Rural†	6 862 (28.3)	2.43 (2.38–2.48)	1.24 (1.21–1.26)
Income quintile‡			
One (lowest)	43 634 (8.8)	0.73 (0.72–0.74)	0.96 (0.94–0.97)
Two	46 543 (10.9)	0.90 (0.89–0.91)	1.00 (0.99–1.01)
Three (middle)	49 520 (12.1)	1.00 [Reference]	1.00 [Reference]
Fourth	49 308 (13.4)	1.10 (1.09–1.12)	1.09 (1.08–1.11)
Fifth (highest)	42 123 (17.0)	1.41 (1.39–1.42)	1.02 (1.00–1.03)
Ethnic concentration§,¶			

One (lowest)	9 435 (23.4)	1.27 (1.25–1.30)	1.12 (1.10–1.15)
Two	15 272 (20.6)	1.12 (1.10–1.14)	1.06 (1.04–1.08)
Three (middle)	23 119 (18.4)	1.00 [Reference]	1.00 [Reference]
Fourth	43 565 (14.8)	0.81 (0.79–0.82)	0.88 (0.86–0.89)
Fifth (highest)	137 715 (9.9)	0.54 (0.53–0.54)	0.70 (0.69–0.71)
Material deprivation§,**			
One (lowest)	72 247 (14.4)	1.23 (1.21–1.24)	1.09 (1.08–1.10)
Two	52 477 (13.1)	1.11 (1.10–1.13)	1.04 (1.03–1.05)
Three (middle)	44 268 (11.9)	1.00 [Reference]	1.00 [Reference]
Fourth	33 461 (10.1)	0.86 (0.85–0.87)	0.92 (0.91–0.93)
Fifth (highest)	26 653 (8.4)	0.71 (0.70–0.73)	0.82 (0.80–0.83)
Educational qualification‡‡			
University degree or higher	71 901 (14.3)	1.00 [Reference]	1.00 [Reference]
Some university	11 142 (13.8)	0.97 (0.95–0.98)	0.96 (0.95–0.98)
Non-university qualifications (e.g., college diploma)	36 403 (13.1)	0.92 (0.91–0.93)	0.92 (0.91–0.93)
Secondary or less	95 818 (10.4)	0.73 (0.72–0.73)	0.78 (0.77–0.79)
No education	15 864 (9.6)	0.67 (0.66–0.68)	0.81 (0.80–0.83)
Time spent in Canada, yr			
≥20	56 371 (11.0)	1.23 (1.21–1.26)	1.31 (1.28–1.35)
15–19	53 046 (14.0)	1.57 (1.53–1.61)	1.76 (1.72–1.80)
10–14	60 633 (13.4)	1.50 (1.47–1.53)	1.66 (1.62–1.70)
4–9	53 695 (10.4)	1.16 (1.14–1.19)	1.21 (1.18–1.23)
< 4	7 383 (8.9)	1.00 [Reference]	1.00 [Reference]
Canadian language ability††			
English	160 835 (14.0)	1.00 [Reference]	1.00 [Reference]
French	1 305 (7.9)	0.56 (0.53–0.59)	0.66 (0.63–0.70)
Both	7 704 (15.7)	1.12 (1.10–1.14)	1.06 (1.04–1.08)
Neither	61 284 (8.4)	0.60 (0.59–0.60)	0.76 (0.75–0.77)
Marital status††			
Married	121 619 (11.7)	1.00 [Reference]	1.00 [Reference]
Separated, divorced, widowed	6 876 (9.2)	0.78 (0.77–0.80)	1.06 (1.04–1.09)
Single	102 633 (12.3)	1.04 (1.04–1.05)	1.11 (1.10–1.12)
Immigrant class††			
Economic	119 029 (13.2)	1.00 [Reference]	1.00 [Reference]
Family	74 731 (10.9)	0.82 (0.82–0.83)	0.86 (0.86–0.87)
Refugee	31 305 (10.0)	0.76 (0.75–0.77)	0.95 (0.94–0.96)

Other	6 063 (11.9)	0.90 (0.88–0.93)	0.96 (0.93–0.98)

Note: CI = confidence interval.

Total immigrants for this analysis was 1 947 192, of whom 231 128 were registered for organ and tissue donation; 454 immigrants, of whom 52 were registered, had missing data on immigration-related characteristics and were excluded from this cohort.

*Adjusted for world region of birth, sex, residence, age category, income quintile, material deprivation, ethnic concentration, educational qualification, time spent in Canada, Canadian language ability, marital status, immigrant class.

†Refers to areas with population less than 10 000.

‡Categorized into fifths of average neighbourhood income.

§Data missing for 15 102 individuals (< 1.0% missing), of whom 2022 were registered.

¶Measure of the proportion of recent immigrants and those who self-identify as visible minority.

**Measure of inability to afford consumption goods or services.

††Data missing for 454 people (<0.01%), of whom 52 were registered, who were then further excluded from analysis.

In Ontario, the top 5 countries of birth with the highest absolute number of unregistered immigrants were India (202 548; 13.7%; 95% CI 13.6–13.9), China (186 678; 6.4%; 95% CI 6.3–6.6), the Philippines (125 686; 8.5%; 95% CI 8.4–8.7), Pakistan (95 667; 5.8%; 95% CI 5.7–6.0), and Sri Lanka (72 304; 14.7%; 95% CI 14.5–15.0) (Table 5-4). In our 5 stratified models, we observed effect modification by country of birth for each examined characteristic, which suggests that each characteristic associates somewhat differently with donor registration across these 5 groups. Visually, the following characteristics were associated with a higher change of donor registration in each of the 5 groups: age categories 20 to 29 years, 30 to 39 years, 40–49 years (v. 16 to 19 yr), a greater time spent in Canada (v. < 4 yr). Not able to speak either language (v. English) and family type immigrant (v. economic immigrant) were associated with lower donor registration. Except for immigrants born in Pakistan, living in the highest ethnic concentration area was also associated with lower registration and higher educational qualifications were associated with higher registration rates.

Table 5-4: Characteristics associated with donor registration among the top 5 countries with the highest number of unregistered immigrants

Characteristic	**Adjusted prevalence ratio (95% CI)***				
Country	India	China	Philippines	Pakistan	Sri Lanka
Age category, yr					
16–19	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
20–29	1.57 (1.44–1.71)	1.64 (1.43–1.88)	1.74 (1.55–1.97)	2.1 (1.78–2.48)	1.87 (1.61–2.18)
30–39	1.69 (1.55–1.85)	1.41 (1.21–1.63)	1.85 (1.63–2.10)	2.1 (1.76–2.51)	2.09 (1.79–2.44)
40–49	1.85 (1.69–2.02)	1.28 (1.10–1.48)	1.44 (1.26–1.65)	2.18 (1.82–2.61)	1.75 (1.49–2.04)
50–59	1.71 (1.56–1.87)	1.17 (1.01–1.37)	1.10 (0.96–1.27)	2.37 (1.96–2.87)	1.44 (1.23–1.7)
60–69	1.40 (1.27–1.54)	1.08 (0.92–1.28)	0.83 (0.71–0.97)	2.56 (2.08–3.14)	1.26 (1.06–1.49)
70–79	1.19 (1.07–1.32)	0.85 (0.71–1.01)	0.54 (0.44–0.66)	2.37 (1.83–3.09)	1.3 (1.08–1.56)
≥80	0.94 (0.82–1.08)	0.58 (0.47–0.71)	0.38 (0.29–0.49)	2.3 (1.59–3.33)	0.94 (0.75–1.17)
Sex					
Men	1.01 (0.99–1.03)	1.03 (0.99–1.06)	0.81 (0.78–0.84)	1.09 (1.03–1.15)	1.04 (1.00–1.08)
Women	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Residence					
Urban	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Rural†	1.09 (0.96–1.23)	1.22 (0.98–1.52)	1.38 (1.16–1.65)	1.41 (1.02–1.93)	1.11 (0.83–1.48)
Income quintile‡					
First (lowest)	0.90 (0.87–0.94)	1.1 (1.04–1.18)	0.90 (0.85–0.97)	0.89 (0.80–0.98)	0.99 (0.93–1.06)
Second	0.95 (0.92–0.98)	1.01 (0.95–1.06)	0.96 (0.91–1.01)	1.04 (0.96–1.13)	0.96 (0.92–1.01)
Third (middle)	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Fourth	1.04 (1.01–1.07)	1.04 (0.99–1.1)	1.05 (0.99–1.11)	0.96 (0.89–1.04)	1.00 (0.95–1.06)
Fifth (highest)	1.14 (1.10–1.18)	1.06 (1.00–1.12)	0.98 (0.91–1.05)	1.18 (1.08–1.30)	1.15 (1.07–1.23)
Ethnic concentration					
First (lowest)	1.02 (0.92–1.12)	1.21 (1.04–1.41)	1.08 (0.93–1.24)	1.16 (0.91–1.49)	1.07 (0.87–1.32)

Second	1.01 (0.94–1.09)	1.16 (1.03–1.32)	1.09 (0.98–1.22)	0.92 (0.76–1.12)	1.07 (0.93–1.24)
Third (middle)	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Fourth	0.91 (0.87–0.96)	0.96 (0.88–1.05)	0.87 (0.81–0.95)	1.07 (0.94–1.23)	0.89 (0.8–0.99)
Fifth (highest)	0.82 (0.78–0.86)	0.76 (0.70–0.82)	0.77 (0.72–0.83)	0.88 (0.77–0.99)	0.81 (0.74–0.89)
Material deprivation					
First (lowest)	1.06 (1.02–1.09)	0.99 (0.94–1.05)	1.11 (1.05–1.18)	0.97 (0.89–1.05)	1.13 (1.06–1.19)
Second	1.00 (0.97–1.03)	1.01 (0.96–1.07)	1.01 (0.95–1.07)	0.98 (0.91–1.06)	1.03 (0.98–1.08)
Third (middle)	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Fourth	0.89 (0.86–0.92)	0.89 (0.84–0.94)	0.93 (0.87–0.98)	0.77 (0.70–0.85)	0.94 (0.89–0.99)
Fifth (highest)	0.77 (0.74–0.81)	0.86 (0.80–0.93)	0.93 (0.86–0.99)	0.76 (0.68–0.86)	0.86 (0.80–0.92)
Educational qualification					
University degree or higher	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Some university	0.91 (0.86–0.96)	0.87 (0.8–0.93)	0.84 (0.79–0.91)	1.28 (1.11–1.48)	0.88 (0.79–0.98)
Non-university qualifications (e.g., college diploma)	0.81 (0.78–0.83)	0.55 (0.52–0.58)	0.82 (0.77–0.86)	0.90 (0.84–0.97)	0.70 (0.66–0.74)
Secondary or less	0.96 (0.93–0.99)	0.75 (0.71–0.79)	0.78 (0.74–0.82)	0.91 (0.84–1.00)	0.89 (0.83–0.95)
No education	0.71 (0.67–0.75)	0.58 (0.52–0.65)	0.76 (0.69–0.84)	0.92 (0.81–1.05)	0.72 (0.66–0.79)
Time spent in Canada, yr					
≥20	1.41 (1.32–1.51)	1.78 (1.54–2.06)	1.77 (1.61–1.95)	2.04 (1.63–2.55)	1.48 (1.32–1.67)
15–19	2.09 (1.96–2.23)	3.57 (3.14–4.06)	2.35 (2.15–2.57)	2.52 (2.05–3.09)	1.83 (1.64–2.06)
10–14	1.97 (1.85–2.09)	2.92 (2.58–3.31)	2.17 (1.99–2.37)	2.04 (1.67–2.50)	1.87 (1.67–2.10)
4–9	1.22 (1.15–1.30)	1.37 (1.21–1.55)	1.51 (1.39–1.65)	1.23 (1.01–1.51)	1.19 (1.06–1.33)
< 4	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Canadian language ability					
English	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
French	0.71 (0.69–0.73)	0.73 (0.70–0.75)	0.93 (0.88–0.98)	0.60 (0.56–0.65)	0.77 (0.74–0.81)
Both	1.16 (1.04–1.29)	0.93 (0.75–1.17)	1.60 (1.12–2.28)	1.18 (0.86–1.63)	1.02 (0.78–1.34)
Neither	0.71 (0.69–0.73)	0.73 (0.70–0.75)	0.93 (0.88–0.98)	0.60 (0.56–0.65)	0.77 (0.74–0.81)
Marital status					

Married	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Separated, divorced, widowed	1.09 (1.01–1.18)	1.23 (1.11–1.37)	1.08 (0.96–1.21)	1.10 (0.90–1.34)	0.98 (0.88–1.10)
Single	1.12 (1.09–1.15)	1.19 (1.14–1.25)	0.97 (0.93–1.01)	1.24 (1.16–1.33)	1.05 (1.01–1.10)
Immigrant class					
Economic	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Family	0.80 (0.78–0.82)	0.86 (0.82–0.91)	0.84 (0.81–0.88)	0.82 (0.76–0.88)	0.73 (0.69–0.77)
Refugee	0.96 (0.89–1.04)	0.73 (0.67–0.80)	1.33 (0.98–1.79)	1.39 (1.28–1.51)	0.83 (0.79–0.87)
Other	1.04 (0.93–1.17)	0.68 (0.60–0.76)	1.06 (0.90–1.25)	1.33 (1.10–1.62)	0.95 (0.86–1.05)

Note: CI = confidence interval.

*Adjusted for world region of birth, sex, residence, age category, income quintile, material deprivation, ethnic concentration, educational qualification, time spent in Canada, Canadian language ability, marital status, immigrant class.

†Refers to areas with population less than 10 000.

‡Categorized into fifths of average neighbourhood income.

5.3.4 Organ and tissue donor exclusion

During the donor registration process, when given the option to exclude certain organs and tissues from deceased organ donation, 53 473 (23.1%) immigrants and 409 389 (16.7%) long-term residents excluded at least one organ or tissue (Table 5-5). Registered South Asians donors (*n* = 15 267; 28.8%) were the most likely to exclude an organ and/or tissue. Across all groups, the most commonly excluded organ and/or tissue was skin and eyes (Table 5-6). Older individuals, men, and those living in rural areas were less likely to exclude an organ and/or tissue. Instability, dependency, and material deprivation showed no clear relationship with higher donor exclusion (results not shown).

Table 5-5:Characteristics associated with exclusion of at least one organ among registered Donors (n=2 684 296)

		Prevalence Ratio (95% confidence interval)	
Characteristic	**No. Excluded (%)**	**Unadjusted**	**Adjusted^a**
World Region of Birth			
Long-term Residents	409 389 (16.7%)	1.00 [Reference]	1.00 [Reference]
Immigrants	53 473 (23.1%)		
East Asia & Pacific	9 508 (22.8%)	1.36 (1.34 to 1.39)	1.22 (1.19 to 1.24)
South Asia	15 267 (28.8%)	1.72 (1.70 to 1.75)	1.56 (1.54 to 1.58)
Latin America & Caribbean	9 624 (23.5%)	1.41 (1.38 to 1.43)	1.25 (1.23 to 1.27)
Eastern Europe & Central Asia	4 541 (22.5%)	1.35 (1.31 to 1.38)	1.17 (1.14 to 1.20)
Middle East & North Africa	3 986 (20.9%)	1.25 (1.22 to 1.29)	1.11 (1.08 to 1.14)
Western Europe	6 324 (20.0%)	1.20 (1.17 to 1.22)	1.17 (1.15 to 1.20)
Sub-Saharan Africa	2 074 (22.8%)	1.37 (1.32 to 1.42)	1.25 (1.20 to 1.29)
United States, Australia and New Zealand	2 125 (14.0%)	0.84 (0.8 to 0.87)	0.83 (0.80 to 0.86)
Other	24 (17.4%)	1.04 (0.72 to 1.50)	1.26 (0.89 to 1.80)
Age Category			
16 – 19 years	26 762 (24.9%)	1.00 [Reference]	1.00 [Reference]
20 – 29 years	103 695 (25.5%)	1.02 (1.01 to 1.04)	1.00 (0.99 to 1.01)
30 – 39 years	117 454 (22.3%)	0.90 (0.89 to 0.91)	0.87 (0.86 to 0.88)
40 – 49 years	94 879 (17.1%)	0.69 (0.68 to 0.69)	0.67 (0.66 to 0.68)
50 – 59 years	64 225 (12.8%)	0.51 (0.51 to 0.52)	0.52 (0.51 to 0.52)
60 – 69 years	36 303 (10.4%)	0.42 (0.41 to 0.42)	0.43 (0.42 to 0.44)

70 – 79 years	14 464 (8.9%)	0.35 (0.35 to 0.36)	0.37 (0.36 to 0.37)
≥ 80 years	5 080 (7.4%)	0.30 (0.29 to 0.30)	0.31 (0.30 to 0.32)
Sex			
Female	291 269 (19.5%)	1.00 [Reference]	1.00 [Reference]
Male	171 593 (14.4%)	0.74 (0.74 to 0.75)	0.78 (0.77 to 0.78)
Residence			
Urban	406 153 (17.6%)	1.00 [Reference]	1.00 [Reference]
Rural[b]	56 709 (15.0%)	0.85 (0.85 to 0.86)	0.98 (0.97 to 0.99)
Neighbourhood Income Quintile[c]			
First (Lowest)	76 630 (17.8%)	1.02 (1.01 to 1.02)	0.97 (0.97 to 0.98)
Second	85 455 (17.4%)	0.99 (0.98 to 1.00)	0.98 (0.98 to 0.99)
Third (Middle)	94 165 (17.5%)	1.00 [Reference]	1.00 [Reference]
Fourth	101 813 (17.3%)	0.99 (0.98 to 0.99)	1.00 (0.99 to 1.00)
Fifth (Highest)	104 799 (16.5%)	0.94 (0.93 to 0.95)	0.99 (0.98 to 1.00)
Ethnic Concentration Quintile[d, e]			
First (Lowest)	61 387 (14.7%)	0.90 (0.89 to 0.91)	0.97 (0.96 to 0.98)
Second	81 340 (15.5%)	0.95 (0.94 to 0.96)	0.98 (0.97 to 0.98)
Third (Middle)	89 403 (16.3%)	1.00 [Reference]	1.00 [Reference]
Fourth	104 192 (17.9%)	1.10 (1.09 to 1.11)	1.04 (1.04 to 1.05)
Fifth (Highest)	120 150 (20.9%)	1.28 (1.27 to 1.29)	1.13 (1.12 to 1.14)

Total number of registered donors excluding at least one organ or tissue were 462 862 (17.2%)

[a] Adjusted for World Region of Birth, Sex, Residence, Age Category, Income, Ethnic Concentration

[b] Refers to areas with population less than 10 000.

[c] Categorized into fifths of average neighborhood income.

[d] Missing data on ethnic concentration on 36 501 individuals of which 6390 (17.6%) excluded an organ or tissue (1.3% missing)

[e] Measure of the proportion of recent immigrants and those who self-identify as visible minority.

Table 5-6: Organ and Tissue Exclusion

Number of Registrants that opted-out:										
Organ and/or Tissue:	**Long-term Residents**	**Western Europe**	**Eastern Europe and Central Asia**	**Middle East and North Africa**	**Sub-Saharan Africa**	**East Asia & Pacific**	**South Asia**	**United States, Australia and New Zealand**	**Latin America & Caribbean**	**Other[a]**
Kidney	24129 (1.0%)	287 (0.9%)	354 (1.8%)	446 (2.3%)	205 (2.3%)	1 272 (3.0%)	3654 (6.9%)	94 (0.6%)	921 (2.2%)	≤5 (3.5%)
Heart	39326 (1.6%)	535 (1.7%)	574 (2.8%)	662 (3.5%)	338 (3.7%)	2 131 (5.1%)	4203 (7.9%)	176 (1.2%)	1 353 (3.3%)	≤5 (3.5%)
Eyes	255784 (10.4%)	4887 (15.4%)	3 554 (17.6%)	2544 (13.3%)	1345 (14.8%)	4 993 (12.0%)	5 544 (10.4%)	1 397 (9.2%)	6 380 (15.6%)	15 (10.6%)
Bone	121168 (4.9%)	1 677 (5.3%)	1 404 (6.9%)	1750 (9.2%)	863 (9.5%)	4 326 (10.4%)	8 488 (16.0%)	634 (4.2%)	3 850 (9.4%)	8 (5.7%)
Liver	25560 (1.0%)	290 (0.9%)	360 (1.8%)	471 (2.5%)	225 (2.5%)	1 333 (3.2%)	4 194 (7.9%)	108 (0.7%)	971 (2.4%)	≤5 (3.5%)
Lung	39210 (1.6%)	412 (1.3%)	429 (2.1%)	637 (3.3%)	277 (3.1%)	1 476 (3.5%)	4 612 (8.7%)	150 (1%)	1 043 (2.5%)	≤5 (3.5%)
Skin	228722 (9.3%)	3350 (10.6%)	2 626 (13%)	2521 (13.2%)	1253 (13.8%)	5 579 (13.4%)	10 456 (19.7%)	1 234 (8.1%)	5 973 (14.6%)	11 (7.8%)
Pancreas	54937 (2.2%)	667 (2.1%)	594 (2.9%)	774 (4.1%)	357 (3.9%)	1 897 (4.5%)	5 920 (11.2%)	204 (1.3%)	1 393 (3.4%)	≤5 (3.5%)
Any of the Above	409 389 (16.7%)	6324 (20%)	4541 (22.5%)	3 986 (20.9%)	2 074 (22.8%)	9 508 (22.8%)	15 267 (28.8%)	2 125 (14%)	9 624 (23.5%)	24 (17.4%)

[a] Cell sizes less than 5 are suppressed for privacy reasons.

5.4 Interpretation

In this cross-sectional study, we documented that Canadian immigrants had lower organ and tissue registration rates compared with long-term residents. Immigrants born in the USA, Australia and New Zealand had the highest registration rates even higher than long-term residents. In addition, among immigrants, age 30–39 years, higher education, English language fluency, economic-status immigrant, married/single, and living in less ethnically-concentrated areas were characteristics associated with higher donor registration. These findings highlight the marked differences in donor registration rates across immigrant groups, and inform the development and execution of targeted, culturally-sensitive public campaigns to raise awareness about organ and tissue donation.

Our findings are consistent with another study where the immigrant population were more reluctant to register.(24) Similar to López and associates' study of Spain immigrants' attitudes toward to donate, our study on actual donor registration rates found that among the immigrant population as a whole, women, people with higher education and higher income were more likely to register for organ donation.(24) López and associates found that immigrants from East Europe and North African are more reluctant to donate their own organs compared with other immigrant groups, whereas in our study, we found that immigrants born in the Sub-Saharan Africa and East Asia and Pacific Region were the least likely groups to be registered.(24) These results are also similar to our previous study where we used a surname algorithm to identify Chinese and South Asian individuals.(25) Many immigrant groups were much less likely to register for organ donation compared with long-term residents, but these differences decreased by up to 10% in some cases after adjusting for residential ethnic concentration. Further, living in a rural community, higher neighbourhood income quintile and lower material deprivation was no longer strongly positively associated with donor registration after adjustment of ethnic concentration among all Ontario residents. In another study examining how community-level factors affects organ donor registration rates, Ladin and associates found that groups with higher levels of racial homogeneity, native-born residents and other social capital variables had higher rates of organ donor registration. They suggest that minority populations may have higher rates of altruistic behaviour (i.e., organ donor registration) if they feel less isolated and better integrated with their community.(26)

Our study has a number of strengths. To our knowledge, this is the first study examining organ and tissue donor registration rates, rather than expressed support or a positive attitude toward donation among immigrants and characteristics associated with registration. A systematic review reported that many quantitative studies on this topic lacked methodological rigor and did not account for important variables such as age and socio-economic status when comparing ethnic groups.(4) Further, most studies focused on specific ethnic or cultural collectives such as Hispanics, African Americans, Asians and Arabs, rather than the entire immigrant population of a national state. However, our study does have important limitations. First, we had no information on the reasons why many immigrants did not register, which is important for the design of educational programs. The low organ and donor registration rates in specific immigrant groups may be influenced by many factors including knowledge, attitude, and awareness of organ donation that were not measured in our study. It may also be possible that the low registration rates may be due to unawareness of the registry(7,8) or fear of placing their name in a large database(27) rather than negative attitude toward organ donation. Second, the

Immigration, Refugees and Citizenship Canada’s Permanent Resident Database data set only contains data recorded at time of immigration. More than 50% of our cohort arrived in Canada more than 10 years ago and certain variables such as education, language ability, and marital status may have changed over the years. For example, Okrainec and associates found that self-reported language barriers in the Citizen and Immigration Canada Database which records status at time of immigration is a poor indicator of persistent language barrier when compared with the 2007–2008 Canadian Community Health Survey.(17) Despite the limitations in our data, strong differences in registration rates among immigrants and long-term residents persisted even after controlling for many socio-demographic factors.

In conclusion, this study documents that Ontarian immigrants register less often for deceased organ donation compared with long-term residents. There is an opportunity to better understand the causes for lower donor registration among the different immigrant groups. However, to fill the Ontario donor registry, it is also important to better understand the low rate of donor registration in long-term residents given that they represent a large absolute number of non-registered individuals. More research on other community factors associated with higher donor registration such as volunteerism and civic participation is needed. More research is needed to develop and evaluate culturally-tailored interventions that can build support for deceased organ and tissue donation.

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CHAPTER 6: Familial consent for deceased organ donation amongst immigrants and long-term residents in Ontario, Canada: A population-based retrospective cohort study

[a] A version of this chapter to be summited: Alvin Ho-ting Li, Ahmed A. Al-Jaishi, Matthew Weir, Ngan N. Lam, Janet Maclean, Sonny Dhanani, S. Joseph Kim , Greg Knoll, Amit X. Garg

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6.1 Background

The ongoing shortage of organs for transplantation demands strategies that maximize the availability of this scarce resource. Several countries are working to increase the proportion of families who consent to deceased organ donation at the time of their relative's death, which ranges between 40-70% across jurisdictions.(1–3) Consent rates are undoubtedly a significant factor for increasing transplantation across all ethnicities. Ethnic minorities have been shown to have lower rates of organ donation registration and families of critically ill ethnic minorities may be less likely to consent on their relative's behalf.(2,4) Therefore, this population may represent an important source of under-utilized organs that could be better accessed through culturally sensitive education programs.

Canada has the highest proportion of foreign-born individuals among the eight leading industrial and developed countries in the world, with the majority of immigrants living in its most populated province, Ontario.(5) The province also houses some of the most comprehensive, large, administrative health care databases in the country, which facilitates population-level health research. Using these resources, we compared the familial consent rates of immigrants to long-term residents in general, and by region of origin. We also identified patients who were already registered donors to see if registration modified the likelihood of obtaining final consent from families.

6.2 Methods

6.2.1 Study Design and Setting

We conducted a population-based retrospective cohort study in the province of Ontario, Canada (population: 13 million) using large administrative healthcare databases held at the Institute for Clinical Evaluative Sciences (ICES). These datasets were linked using unique encoded identifiers. In Ontario, residents have universal healthcare coverage. To be an organ donor, the decedent must have suffered a non-recoverable injury and be mechanically ventilated at the time the provincial organ procurement organization is notified.(6) Each decedent's eligibility to donate is evaluated on an individual basis. At the time of imminent death or family's interest in organ donation, a donor coordinator experienced in talking to families about donation will access the decedent's donor registration information. If the decedent is registered, the coordinator will provide this information to the donor's family members at an appropriate time. In Ontario, the next-of-kin makes the final decision on proceeding with organ and tissue donation regardless if the decedent, prior to death, had registered their desire for organ and tissue donation or not. We did not include decedents who were only referred for tissue-only donation. We conducted this study according to a pre-specified protocol that was approved by the research ethics boards at Sunnybrook Health Sciences Centre (Toronto, Canada). We used the RECORD statement to guide the reporting of this study (Appendix E).

6.2.2 Data Sources

We ascertained demographic information, potential confounders and outcome information of potential donors from linked administrative databases. A.A had access to the database population used to create the study population.

First, we obtained data of those who were referred for deceased organ and tissue donation from the Trillium Gift of Life Network. Patients who meet any of the following are referred for potential organ donor consideration: 1) Glasgow Coma Scale score of 3; 2) injured brain or non-recoverable injury or illness; 3) family initiated discussion of organ donation with the healthcare team or withdrawal of life sustaining therapy and/or 4) planned discussion of therapy limited, de-escalation of treatment or withdrawal of life-sustaining therapy. All patients referred for organ donation are then evaluated for medical suitability. This dataset also contains information on whether the family was approached for donation and if consent from their family was obtained. These data are recorded on a real-time basis by a call center. We refer to these patients as potential donors.

Second, we obtained demographics from the Ontario Registered Persons Database. This database has demographic and vital status information on all residents who have ever been issued a health card. We estimated the individual’s income using neighborhood income quintiles.

Third, we used Matheson’s Canadian Marginalization Index to assign marginalization quintiles. This index describes four components of marginalization: residential instability, ethnic concentration, dependency, and material deprivation.

Fourth, we used the Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD) to obtain information on hospitalizations to ascertain the patient’s cause of death and to determine if the admitting hospital of the potential donor had an academic affiliation. We classified cause of death using the International Classification of Disease Revision 10 codes into Traumatic Brain Injury (S06, S07, S08, S09), Subarachnoid and Intracranial Hemorrhage (I60, I61, I62), Other Damage to the Brain (I63, I64), Acute Myocardial Infarction, Cardiac Arrest (I21, I22, I23, I46), and All Other Causes of Death.

Finally, we used the Immigration, Refugees and Citizenship Canada’s (IRCC) Permanent Resident Database to ascertain immigration status. This database contains landing records for every permanent legal immigrant who landed in Canada since 1985 onwards. All information is captured at the time of immigration application. We generally grouped each immigrant’s country of birth by their world region of origin, according to the World Bank system [(a) South Asia (b) East Asia and Pacific (c) Latin America and Caribbean (d) USA, Australia, New Zealand, and Western Europe (e) Middle East, North Africa, and Sub-Saharan Africa and (f) Eastern Europe and Central Asia].(7) Because of small sample sizes, we combined Western Europe with USA, Australia and New Zealand in one group, as well as Sub-Saharan Africa, Middle East and North Africa in another group. This grouping because we hypothesized that differences in familial consent are primarily due to cultural awareness and attitudes.

6.2.3 Study Population, Outcomes, and Statistical Analysis

We included all permanent residents of Ontario who were approached for deceased organ and tissue donation with a record of hospitalization from November 1, 2008 to March 31, 2013. For our comparison of immigrants and long-term residents, we classified immigrants as having a record within the IRCC’s Permanent Resident Database. Everyone else without a record in the

IRCC database was classified as long-term residents (including immigrants who landed in Canada prior to 1985).

The outcome of interest was obtaining consent from the families of potential donors. We assessed differences in baseline characteristics between immigrants and long-term residents using the chi-square test for categorical variables and the Mann-Whitney U test for continuous variables. We used a Modified-Poisson regression model with a robust error estimator to compare familial consent rates among immigrants and long-term residents. We used complete case analysis as the amount of missing data was low (about 2%). We also evaluated the association between immigrant status and familial consent in four subgroups: age, sex, hospital type, and cause of death. We determined *p* values for interaction by including the interaction terms in the regression models. We hypothesized that these four characteristics affect long-term residents and immigrants similarly. We adjusted for 11 potential confounders: world region of birth, age, sex, residence (urban vs, rural), neighborhood income quintile, material deprivation, ethnic concentration, dependency, residential instability, cause of death, and academic hospital affiliation. We conducted analyses using SAS software version 9.4 (SAS Institute Inc., Cary, NC) and a two-sided p-value <0.05 was considered to be statistically significant.

6.3 Results

From November 1, 2008 to March 31, 2013, there were 2926 potential donors approached to obtain familial consent (Figure 6-1). Of the 2926 potential donors, 291 were immigrants and 2635 were long-term residents. The median age of immigrants was 54 (interquartile range [IQR]: 42, 65) and median age of long-term residents was 57 (IQR: 44, 68). The baseline characteristics for the potential donors whose families were approached for consent by immigration status are presented in Table 6-1. The groups differed on most baseline characteristics; immigrants were more likely to be younger, live in areas with lower income, and demonstrate higher levels of marginalization. Of the 2926 potential donors, no immigrants and 53 long-term residents (2%) had missing data on the marginalization quintiles. Thus, 2873 potential donors were used to determine the rate of familial consent among immigrants and long-term residents.

Figure 6-1: Flowchart of Study Selection

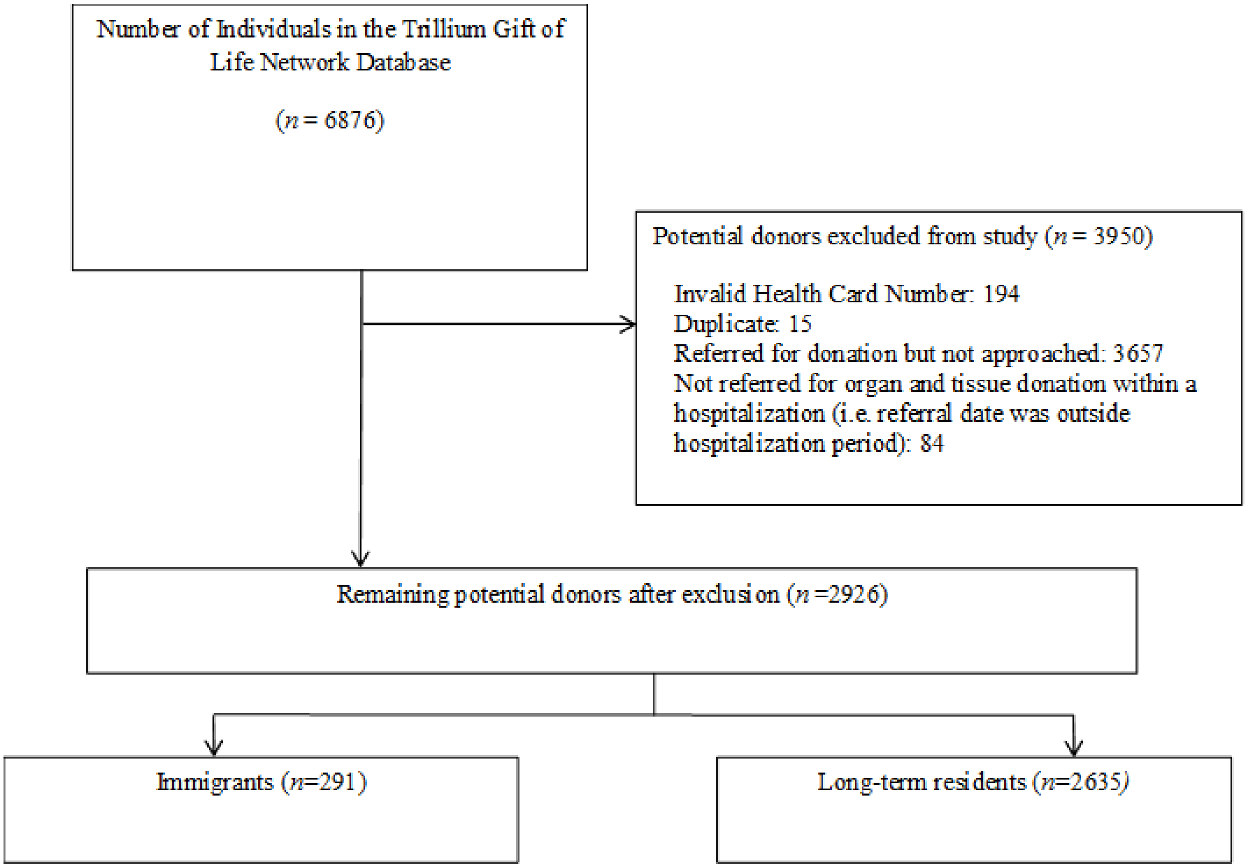

Table 6-1: Baseline Characteristics of Deceased Immigrants and Long-term Residents whose Families were Approached for Organ and Tissue Donation

Characteristic	Immigrants (n=291)	Long-term Residents (n=2635)	*p*-value
Age			*<0.01*
<18 years	8 (2.7%)	153 (5.8%)	
18 to <45 years	75 (25.8%)	518 (19.7%)	
45 to <65 years	134 (46.0%)	1093 (41.5%)	
≥65 years	74 (25.4%)	871 (33.1%)	
Women	120 (41.2%)	1060 (40.2%)	0.7391
Rural Residence[a]	≤5*	367 (14%)	*<0.01*
Income Quintile[b]			*<0.01*
First (Lowest)	90 (30.9%)	584 (22.2%)	
Second	69 (23.7%)	543 (20.6%)	
Third (Middle)	67 (23.0%)	535 (20.3%)	
Fourth	38 (13.1%)	525 (19.9%)	
Fifth (Highest)	27 (9.3%)	448 (17.0%)	
Residential Instability[c]			*<0.01*
First (Lowest)	92 (31.6%)	565 (21.4%)	
Second	42 (14.4%)	540 (20.5%)	
Third (Middle)	48 (16.5%)	400 (15.2%)	
Fourth	72 (24.7%)	499 (18.9%)	
Fifth (Highest)	57 (19.6%)	578 (21.9%)	
Missing	0	53 (2.0%)	
Ethnic Concentration[d]			*<0.01*
First (Lowest)	≤5*	410 (15.6%)	
Second	≤10*	444 (16.9%)	
Third (Middle)	23 (7.9%)	509 (19.3%)	
Fourth	31 (10.7%)	570 (21.6%)	
Fifth (Highest)	225 (77.3%)	649 (24.7%)	
Missing	0	53 (2.0%)	
Dependency[e]			*<0.01*
First (Lowest)	89 (30.6%)	457 (17.3%)	
Second	76 (26.1%)	576 (21.9%)	
Third (Middle)	70 (24.1%)	532 (20.2%)	
Fourth	37 (12.7%)	484 (18.4%)	
Fifth (Highest)	19 (6.5%)	533 (20.2%)	
Missing	0	53 (2.0%)	
Material Deprivation[f]			0.422
First (Lowest)	51 (17.5%)	554 (21.0%)	
Second	60 (20.6%)	574 (21.8%)	

Third (Middle)	65 (22.3%)	529 (20.1%)	
Fourth	58 (19.9%)	488 (18.5%)	
Fifth (Highest)	57 (19.6%)	437 (16.6%)	
Missing	0	53 (2.0%)	
Hospital Type Where Death Occurred			*<0.01*
Academic Hospital	126 (43.3%)	1584 (60.1%)	
Community Hospital	165 (56.7%)	1051 (39.9%)	
Cause of Death			*<0.01*
Traumatic Brain Injury	54 (18.6%)	449 (17.0%)	
Subarachnoid and Intracranial Hemorrhage	92 (31.6%)	618 (23.5%)	
Other Damage to the Brain	25 (8.6%)	148 (5.6%)	
Acute Myocardial Infarction, Cardiac Arrest	17 (5.8%)	263 (10.0%)	
All Other Causes of Death	103 (35.4%)	1157 (43.9%)	
Region of Birth			
South Asia	82 (28.2%)	-	-
East Asia and Pacific	76 (26.1%)	-	-
Latin America and Caribbean	46 (15.8%)	-	-
USA, Australia, New Zealand, and Western Europe	34 (11.7%)	-	-
Middle East, North Africa, and Sub-Saharan Africa	32 (11.0%)	-	-
Eastern Europe and Central Asia	21 (7.2%)	-	-

[a] Refers to areas with population less than 10,000.

[b] Categorized into fifths of average neighborhood income.

[c] Measure of the turnover in the population.

[d] Measure of the proportion of recent immigrants and those who self-identify as visible minority.

[e] Measures the size of the “dependent” population [i.e. seniors and children] in relation to the “working age” population who provide social and economic support).

[f] Measure of inability to afford consumption goods or services.

“-“ Represents data that is not available among long-term residents.

* To comply with privacy regulations for minimizing the chance of identification of a study participant, numbers of participants are suppressed in the case of 5 or fewer participants, (reported as ≤5 and ≤10).

6.3.1 Outcomes

6.3.1.1 All Potential Donors

Of 2873 potential donors, 1912 families provided consent (66.5%). Families of immigrants were less likely to provide consent compared to families of long-term residents (46.4% [135/291]) vs. 68.8% [1777/2582]; adjusted rate ratio (RR) 0.72; 95% confidence interval (CI) 0.63 to 0.81) (Table 6-2). When examined by the region of origin, families of immigrants from different regions were less likely to consent to organ and tissue donation compared to long-term residents: South Asia (RR 0.71; 95% CI 0.55 to 0.91), East Asia and Pacific (RR 0.68; 95% CI: 0.53 to 0.88) and Middle East, North Africa, and Sub-Saharan Africa (RR 0.58; 95% CI 0.37 to 0.91).

Table 6-2: Rate of Familial Consent among Immigrants and Long-term Residents (n = 2873)

		Rate Ratio (95% confidence interval)	
Characteristic	**Number Consented (%)**	**Unadjusted**	**Adjusted[a]**
World Region of Birth			
Long-term residents	1777 (68.8%)	1.00 [Reference]	1.00 [Reference]
Immigrants (as a whole)[b]	135 (46.4%)	0.67 (0.59 to 0.76)	0.72 (0.63 to 0.81)*
South Asia	36 (43.9%)	0.64 (0.50 to 0.82)	0.71 (0.55 to 0.91)*
East Asia and Pacific	33 (43.4%)	0.63 (0.49 to 0.81)	0.68 (0.53 to 0.88)*
Latin America and Caribbean	25 (54.3%)	0.79 (0.61 to 1.03)	0.82 (0.63 to 1.08)
USA, Australia, New Zealand, and Western Europe	19 (55.9%)	0.81 (0.60 to 1.10)	0.80 (0.59 to 1.07)
Middle East, North Africa, and Sub-Saharan Africa	12 (37.5%)	0.54 (0.35 to 0.85)	0.58 (0.37 to 0.91)*
Eastern Europe and Central Asia	10 (47.6%)	0.69 (0.44 to 1.08)	0.67 (0.43 to 1.05)

Total immigrants and long-term residents that consented was 1912 (66.5%). We used complete-case analysis on 2873 patients because 53 had missing data (2.0% missing).

[a] Adjusted for World Region of Birth, Sex, Residence, Age Category, Neighborhood Income Quintile, Residential Instability, Material Deprivation, Dependency, Ethnic Concentration, Cause of Death, Academic Hospital Affiliation.

[b] Two separate analyses were conducted. One analysis adjusted for immigrant group as a whole and the second analysis compare immigrants grouped by world region of birth to long-term residents.

* denotes groups were less likely than long-term residents to provide familial consent

6.3.1.2 Registered Potential Donors

Among the 2926 potential donors, 606 (20.7%) had previously registered for deceased organ and tissue donation. Among these potential donors, we found no statistically significant difference in consent rates among registered immigrants and long-term residents. Of these registered potential donors, 83.8% (31/37; 95% CI: 68.9% to 92.7%) of immigrant families provided consent compared to 89.3% (508/569; 95% CI: 86.5% to 91.6%) of registered long-term residents.

6.3.1.3 Subgroup analyses

Age, sex, and cause of death did not modify the relative association between immigrant status and familial consent (Table 6-3). The relative rate of familial consent in immigrants (vs. long-term residents) was lower in community hospitals compared to academic hospitals (p-value for interaction = 0.045).

Table 6-3: Familial consent associated with immigrant status examined in subgroups defined by age, sex, type of hospital and cause of death.

	Immigrants		**Long-term Residents**		
Subgroup	**Number Consented (%)**	**Adjusted Rate Ratio**	**Number Consented (%)**	**Adjusted Rate Ratio**	**p-value for interaction**
Age					
<44	46 (55%)	1.00 [Reference]	483 (77%)	1.00 [Reference]	***0.89***
45-65	63 (47%)	1.00 (0.76 to 1.31)	803 (73%)	0.93 (0.88 to 0.99)	
65+	26 (35%)	0.75 (0.51 to 1.09)	491 (57%)	0.74 (0.68 to 0.79)	
Sex					
Men	77 (45%)	0.85 (0.66 to 1.09)	1066 (69%)	1.01 (0.96 to 1.07)	***0.24***
Women	58 (48%)	1.00 [Reference]	711 (68%)	1.00 [Reference]	
Hospital Type Where Death Occurred					
Academic Hospital	70 (56%)	1.00 [Reference]	1083 (70%)	1.00 [Reference]	***0.045***
Community Hospital	65 (39%)	0.76 (0.57 to 1.00)	694 (67%)	1.02 (0.97 to 1.08)	
Cause of Death					
Traumatic Brain Injury	31 (57%)	1.00 [Reference]	332 (75%)	1.00 [Reference]	***0.75***
Subarachnoid and Intracranial Hemorrhage	41 (45%)	0.91 (0.65 to 1.27)	168 (72%)	1.02 (0.94 to 1.10)	
Other Damage to the Brain	10 (40%)	0.82 (0.49 to 1.37)	104 (71%)	0.98 (0.87 to 1.11)	
Acute Myocardial Infarction, Cardiac Arrest	7 (41%)	0.90 (0.46 to 1.72)	442 (65%)	0.89 (0.80 to 0.99)	
All Other Causes of Death	46 (45%)	1.02 (0.72 to 1.44)	731 (65%)	0.88 (0.82 to 0.94)	
All analyses adjusted for World Region of Birth, Sex, Residence, Age Category, Neighborhood Income Quintile, Residential Instability, Material Deprivation, Dependency, Ethnic Concentration, Cause of Death, Academic Hospital Affiliation.					

6.4 Discussion

We found that families of immigrants in Ontario, Canada were less likely to consent to deceased organ donation compared to long-term residents. However, among those who were registered for organ and tissue donation, we found no difference in the likelihood of consent.

The two largest ethnic groups in Ontario, Canada are South Asians and Chinese. Similar to our previous findings that families of South Asian and Chinese individuals were less likely to provide consent,(8) we found that families of immigrants born from the East Asia and Pacific region and South Asia were also less likely to consent to deceased organ and tissue donation even after adjustment for multiple characteristics. We also found that families of immigrants born from the Middle East, North Africa, and Sub-Saharan Africa region were less likely to consent. This finding is not surprising given lower levels of support for organ donation documented within these groups.(9)

The similarity in donation rates that we observed among immigrants and long-term residents who had previously registered for organ donation supports the value of donor registries. Although our findings may have resulted from selection bias, it is also possible that the documented wishes of potential donors helped families concur with their choice to donate. In contrast, a British report found that 25% of Black and Asian families refuse to consent to organ donation even if their loved one was on the donor register compared to 10% for the rest of the population.(10) Researchers have suggested that in situations where an individual has registered for deceased organ donation, the emphasis should be on providing families with the registration information in addition to educative and support services rather than solely focusing on obtaining familial consent.(11) In Ontario, this has been our practice since 2009. Future research that examines differences in the reasoning behind familial refusal among immigrants compared to long-term residents may be useful to support efforts to provide educative and support services.

Our study has some limitations. First, our study was designed to measure differences in donation consent rates, and although our databases provided highly accurate information on that, we could not determine the reasons for failing to obtain familial consent for deceased organ donation. This information would be important for the design of strategies to increase consent rates and will be the subject of future work. Second, although our findings seem to support the value of organ donation registries, our analysis was limited by our small sample of immigrants and registered potential donors. Estimates from small sample sizes are imprecise and these results should be interpreted with caution. Furthermore, while it is tempting to assume that the potential donor's registration status helped encourage family members to provide consent, our findings may have been the result of high levels of support for organ donation throughout the families of registered potential donors. Third we only had access to the potential donors' information and not the family member who was approached for consent. It may have been possible that there are important distinguishing characteristics of families that provide (vs. do not provide) consent. Fourth, many of the characteristics we examined were non-modifiable and this limits the number of interventions that could arise from our findings. Simpkin *et al.* found that modifiable characteristics such as the skills of the requestor and the timing of the conversation may have a significant impact on consent rates.(12)

Overall, our findings show that a significant number of potentially life-saving organs are going unused among all potential donors, but particularly among those of ethnic minorities. This provides an important starting point for improving the availability of organ from these subpopulations. Further research will be targeted at defining specific factors responsible for this disparity and strategies for overcoming them, including the role for expanding organ donor registration.

6.5 References

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CHAPTER 7: Discussion

7.1 Integrated Discussion: Main Findings

This thesis presents three studies comparing registration and familial consent to deceased organ and tissue donation between different important ethnic groups in a large, population-based cohort in Ontario, Canada. This thesis provides information that may help inform policies and strategies to further increase support for organ and tissue donation and help prevent deaths on the waiting list. The main findings of this thesis are:

1) Chinese (9%) and South Asian (13%) individuals were less likely to register for deceased organ donation than the general public (25%). Families of Chinese and South Asian individuals were also less likely to consent for deceased organ donation than the general public. Factors associated with donor registration included women (vs. men), younger age (vs. older age), higher income (vs. lower income) and living in a rural (vs. urban) location. Factors associated with lower familial consent include being older (55+ years old compared to 18-34 years old) and those who died from other causes of death compared to traumatic brain injury.
2) Immigrants as a group were much less likely to register for deceased organ donation compared to long-term residents (26.5% vs. 11.9%). Immigrants from the United States, Australia and New Zealand had the highest registration rate (40.0%) whereas immigrants with the lowest registration rates were from Eastern Europe and Central Asia (9.4%), East Asia and Pacific (8.4%) and sub-Saharan Africa (7.9%). Characteristics among the immigrant population associated with a higher likelihood of registration included living in a rural population (population <10 000), a residence in Ontario with a lower ethnic concentration, less material deprivation, higher education, fluency in English and more years residing in Canada.
3) Families of immigrants were less likely to consent for deceased organ donation compared to long-term residents. When examined by world region of birth, families of immigrants from East Asia and Pacific Region, Middle East North Africa and Sub-Saharan Africa and South Asia were less likely to consent compared to long-term residents. There was no statistical difference in consent rates among registered immigrants and long-term residents.

7.2 Integrated Discussion: Research Implications

Our findings are similar to other studies comparing ethnic differences in intention to donate and consent to deceased organ donation. For example, the Canadian study from Edmonton found that East-Asian descent and Indo-Asian descent were approximately half as likely to be willing to donate their organs as compared to Caucasians.(1) We also found that a quadratic relationship with age, with middle aged being the most likely which mirrors results from other studies.(2) Other characteristics found to be associated with higher donor registration in other studies was also found in this study (e.g. higher education and living in areas with less marginalization).(2)

A borderline interaction for familial consent to deceased organ donation was identified between immigrant status and hospital type (academic affiliation). It may be possible that transplant professionals receive more culturally sensitive training in academic hospitals compared to community hospitals. However, this finding was limited by small sample sizes.

Overall, the main objective of this thesis was to identity groups that have lower rates of donor registration or familial consent to deceased organ donation. These findings can now be targeted to develop donation campaigns and strategies. The main research implication of this thesis is that compared to the general public, ethnic minorities register and their families consent less for deceased organ donation in Ontario, Canada. The shortage of available organs for transplantation poses a major problem. The lifetime probability of receiving an organ for a 60 year old Canadian patient is predicted to be only 60%.(3) Creating culturally-sensitive strategies targeted at groups identified in this thesis may be an important strategy to further increase organ donation in Canada.

7.3 Strengths

There are several major strengths unique to this thesis.

First, as mentioned in Chapter 1, there are important limitations of previous survey studies assessing ethnic differences in support for deceased organ donation. Important limitations such as social desirability bias and low response rate are all addressed by the current population-based study using administrative data.

Second, this thesis used rich data provided by Trillium Gift of Life Network on all patients who were referred for deceased organ donation from 2008 to 2013. The major limitation among existing literature on consent rates on organ donation is that most studies only collect data on who ultimately became a donor. Important information on the ethnicity of those who did not become donors were not collected.

Third, this thesis used organ donor registration data provide by the Ministry of Health and Long-term Care. This donor registration provides actual registration status whereas previous studies relied on self-reported registration status.

Fourth, this thesis used an integrated knowledge translation approach. The research questions described in this thesis have been identified by Trillium Gift of Life Network (TGLN) as important knowledge gaps. I met regularly with knowledge users to involve them as important partners in these studies. Knowledge users were included in each stage of the research project from refinement of the research questions to dissemination of the findings. For example, Chapter 4 received media attention in the Toronto Star. TGLN launched a campaign in partnership with the Council of Agencies Serving South Asians. They highlighted the study's main finding that South Asians registered and consented less compared to the general public. In addition, they partnered with community leaders to promote discussion and address myths surrounding organ donation.(4)

7.4 Limitations

There are several limitations that have been discussed in detail in the previous chapters. However, the main limitations will be summarized in this section.

First, there are important limitations of the administrative databases used for these population-based studies. We used a surname algorithm and the immigration database to ascertain ethnicity. The surname algorithm is affected by interethnic marriages or "mixed couples" if one partner adopts their spouse's surname.(5) According to the 2006 Census, approximately 4% of the 7.5 million couples in Canada were mixed unions.(6) However, Chinese and South Asian individuals (the two ethnic groups that we ascertained by surnames) had among the lowest proportions married or partnered outside their groups.(6) Also, surname algorithms would only work if the ethnic group has a distinctive surname nomenclature, which does not exist for some ethnic groups such as the Black population.(5) We only used Chinese and South Asian surnames, although surname algorithms also exist for other Asian populations such as Filipino, Japanese, Korean and Vietnamese.(7) For the immigrant database, we relied on country and world region of birth to group individuals. Therefore, individuals born in countries with mixed ethnicities would represent a wide range of cultural differences in organ donation. Nonetheless, we found that Chapters 4 to 6 had similar results, showing similar low proportions in consent rates and registration rates particularly among Chinese and South Asian groups. Although self-reported ethnicity has been reported to be the "gold standard" (5), it is not without limitations. For example, in a comparison of self-identified ethnicity between the First National Health and Nutrition Examination Survey and the Epidemiologic Follow-up Survey, only 58% of all participants reported the same ethnicity on both surveys.(8) Self-reported ethnicity may also be affected by social and political environment, and the phrasing of the questions.(9) Some self-reported ethnicity data is recorded in Canada's census such as the Canadian Community Health Survey but this data is significantly smaller compared to the administrative databases used (approximately 35,000 Ontarian respondents with 83% linkage success rate).(10)

Second, another important limitation is that we had no information on the reasons why certain ethnic or immigrant groups did not register for organ donation. There may be other factors that can affect an individual's choice to register as a donor that are not captured by our databases. For example, knowledge about organ donation, exposure to transplant recipients and donors, and experiences of family discussions of organ and tissue donation are important predictors of one's willingness to becoming an organ donor.(11) This information is important for the designs of interventions to target these reasons. Nonetheless, the population-based aspect of this work helps *identify* groups to target. Future research should seek to identify modifiable barriers to not registering or providing familial consent in these groups (discussed further in opportunities for future research).

Third, another limitation is that we lacked information demographic information on the family members providing consent. There may be certain demographics of family members that are highly associated with providing familial consent. Rodrigue et al. found that white next-of-kin members were more likely to consent compared to non-whites.(12) However, they do note that next-of-kin sex and age were not significantly associated with donation decision.(12)

Fourth, another important limitation is the low number of immigrants or ethnic minorities approached for obtaining consent for organ donation. The small number of immigrants may have limited our statistical power. For example, in Chapter 6, we did not have adequate power to detect statistical difference in certain world regions. Thus, we were also unable to make meaningful analyses stratified by country of birth.

Fifth, health administrative data contain information collected from government and healthcare providers for managing patients.(13,14) These databases were not designed for research purposes and prone to data entry errors.(15) No studies reported on the validity of the hospitalization codes for causes of death in Chapter 6. However, the outcome measures for study one and two (organ and tissue donor registration status and consent rates) are clearly defined measures provided by the Ministry of Health and Long-term Care and Trillium Gift of Life.

Sixth, the results of these studies may not be fully generalizable outside of Ontario, Canada. Compared to other provinces, Ontario is the most ethnically diverse and has the largest immigrant population. Nonetheless, the findings from this thesis will hopefully guide the promotion of organ donation activities in Canada’s diverse, growing ethnic population.

7.5 Future research

This thesis addressed many of the limitations faced in the previous literature on deceased organ donation and ethnic minorities. However, there are many important areas for further study.

7.5.1 Recommendations for Future Studies assessing Ethnic Differences in Organ and Tissue Donation

Future studies should explore the reasoning behind not registering for organ donation or consenting to organ donation on behalf of their loved ones in these ethnic groups. Large surveys incorporating additional demographic characteristics such as religion and trust in the medical community may also be useful. Qualitative studies can be used to help reveal in-depth information on the reasons certain ethnic groups are less likely to register. Most of the recent qualitative studies are conducted in USA and UK and it is unclear whether their results can generalize to Canada.(16) Most previous studies identified themes but none have mapped them into domains that can be targeted for behavior change.(16) The Theoretical Domains Framework summarizes 128 constructs from 33 psychology behaviour change theories into parsimonious framework of 12 domains of barriers and facilitators to behaviour change.(17) This framework can be used to identify barriers and enablers to organ donor registration or familial consent which can then be used for evidence-based intervention development.

Although we do not know the reasons why these ethnic groups have not registered for organ donation, there are several potential strategies that may improve organ and tissue donor registration rates. For immigrants, one option may be to provide information about organ and tissue donation/donor registration, along with other health related information, in orientation packages so that immigrants receive information to better prepare them to consider registration when they apply for a health card, which may be the first opportunity that they encounter to register. Since English language fluency was associated with higher registration rates, it may be important to have information about organ donation in an appropriate language at time of immigration. Indeed, many studies have reported that one barrier for ethnic minorities is the lack of information about organ donation and the Canadian donor registration process.(18–20) Immigrants from countries with high donation rates may simply need a prompt or immediate opportunity to register in their native language. Others may require information that can help address misconceptions about organ donation, their religion’s stance on organ donation and the need for organs. Given that not all individuals may be ready to register, interventions should consider the intermediary steps through which individuals go through before donor registration and identify their stage of readiness.(20)

7.5.2 Recommendations for Intervention Design

One of the goals of this thesis was to identify important groups that could be targeted to increase support for organ and tissue donation. Interventions could then be tailored to these groups. However, there is a current lack of well-designed and powered studies of interventions to increase organ and tissue donor registration. For example, Andrew Li et al. reviewed 63 studies with over 170,000 participants to describe and evaluate the effectiveness of community-based interventions to increase individuals' willingness to be a deceased organ donation.(21) They concluded from their review that community partnerships and active learning community-based interventions may be effective in increasing commitment but not intentions to donate. The main implication is that community-based programs are most suitable for targeting individuals already interested in donating by getting them to make a formal commitment but less consistently effective in changing people's attitudes toward donation.(21) In another systematic review that focused on increasing organ donor registration and knowledge among ethnic minorities, Deedat et al. reported that a strong interpersonal component and offering an immediate opportunity to register as important characteristics of the intervention.(22) However, they also note that there were many weaknesses involved with the studies such as use of measures of knowledge that have not been validated and heterogeneity of the study population. More importantly, many studies lacked theory and reporting of important contextual information relating to the intervention. These findings are similar to a systematic review I conducted to describe the effectiveness of school-based educational programs on knowledge, attitudes, intent to register and whether these programs prompted family discussions for deceased organ donation among adolescents.(23)

In order to advance the development of interventions to increase support for deceased organ donation, interventions need to be grounded in theory and described in detail. The lack of reporting important contextual information has also been indicated in other areas such as smoking-related and obesity-related health interventions.(24) The UK Medical Research Council has developed a framework to create and evaluate complex interventions, which recognizes the need to establish and report clearly the theoretical basis of interventions.(25) To improve the reporting of interventions, an international group of experts and stakeholders developed the Template for Intervention Description and Replication (TIDier) checklist and guide.(26) This checklist will allow researchers to conduct more accurate meta-analyses of interventions and replication.

Another potential area to improve the beneficial effect of these interventions is use an intervention content classification system to identify behavior change techniques within the intervention. For example, in a review of diabetes intervention, Presseau et al. applied the Behavior Change Techniques Taxonomy to trials of implementation interventions for diabetes care.(27) They clearly characterized the detail of the implementation interventions to identify specific, active ingredients. The Behavior Change Techniques Taxonomy includes 93 behavior change theories grouped within 16 categories described and defined in-detailed.(28) Applying behavior change lens and drawing upon applied research from social and health psychology to develop interventions to increase donor registration may effectively change individuals' behaviors to register or support organ and tissue donation. For example, Andrew Li et al.'s review grouped a number of studies as "education".(21) However, "education" could be further broken down by content, mode of delivery and provider. Therefore, a further breakdown of the active ingredients in donor registration intervention may be useful to account for the heterogeneity in systematic reviews of organ donation.

7.5.3 Promising Setting to Test Intervention for Deceased Organ Donation

In Ontario and elsewhere, most individuals register for organ donation where they obtain or renew their driver's license or health card.(29) However, these centres are often fraught with frustration, which can lead to not registering.(30) One comment from a focus group in the U.S stated "*...Anything associated with the DMV automatically has a negative connotation*".(30) In addition, licensing staff generally have not been trained to provide health information or to answer personal questions regarding organ donation.(31)

An alternative setting is the family physician office which is a promising yet underutilized alternative place to register for organ donation for several reasons. First, many individuals report that their family physician is a trusted source of information for organ and tissue donation.(32) This is important given that many ethnic individuals reported medical mistrust as barriers to donor registration. Second, patients already have their health card number readily available, which is necessary to register for organ donation. Third, patients are ready to think about health issues while waiting to see their doctor. Finally, family physicians believe that discussing organ donation with their patients is within their scope of practice.(33)

7.6 Conclusion

In conclusion, this study documents that ethnic minorities and immigrants from Ontario register less often and their families consent to deceased organ donation compared to the general public and long-term residents. There is an opportunity to better understand the causes for lower donor registration amongst the different immigrant groups. More research is needed to develop and evaluate culturally-tailored interventions that can build support for deceased organ and tissue donation.

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Appendices

Appendix A: Summary of Variables used in Chapters 4,5,6

CATEGORY	VARIABLE	WORKING DEFINITION	MEASUREMENT
Exposure	Immigrant based on country of birth	Categorical; 8 major world regions will be considered: East Asia & Pacific, Eastern Europe & Central Asia, Latin America &Carribean, Middle East & North Africa, Sub-Saharan Africa, Western Europe, South Asia, and USA & New Zealand & Australia.	See Country Classification Table. From Citizenship and Immigration Canada database
Primary Outcomes	Donor Registration Status	Binary; Yes or No	From Registered Persons Database
	Family Consented	Binary; Yes or No	From Trillium Gift of Life Database
Secondary Outcome	Organ Exclusion	Binary; Yes or No	From Registered Persons Database
Potential Confounders	Age	Categorical	From Registered Persons Database
	Sex	Binary	From Registered Persons Database
	Residency	Binary; Rural or Urban	Derived from Postal Code information from Registered Persons Database
	Income Quintile	Categorical	Derived from Postal Code information from Registered Persons Database

	Time since arrival in Canada	Categorical	From Citizenship and Immigration Canada database
	Pre-migration level of education	Categorical	From Citizenship and Immigration Canada database
	Marital status at landing	Categorical	From Citizenship and Immigration Canada database
	English speaking ability at landing	Categorical	From Citizenship and Immigration Canada database
	Ethnic Concentration	Categorical	From Ontario Marginalization Database
	Dependency	Categorical	From Ontario Marginalization Database
	Residential Instability	Categorical	From Ontario Marginalization Database
	Material Deprivation	Categorical	From Ontario Marginalization Database
	Type of Hospital	Binary; Academic or General	From CIHI-DAD
	Cause of Death	Categorical	See Cause of Death codes table. From CIHI-DAD

Causes of Death	**Codes**

Traumatic Brain Injury	S06-S09
Subarachnoid Hemorrahage events	I60
Intracerebral Hemorrhage	I61 and I62
Other (anoxic brain damage, cerebral edema, cerebral infarction, cerebral thrombosis and asphyxiation)	I136, I138, I630-635, I639 and I640
Combination of above	Combination of above
Other	None of the above

Appendix B: Classification of Countries based on World Region

East Asia & Pacific	Eastern Europe & Central Asia	Latin America & Caribbean	Middle East & North Africa	Sub-Saharan Africa	Western Europe
Asia NES	Albania	Anguilla	Algeria	Angola	Andorra
Brunei	Armenia	Antigua and Barbuda	Bahrain	Benin, Peoples Republic of	Austria
Cambodia	Azerbaijan	Argentina	Bhutan	Botswana, Republic of	Azores
China, People's Republic o	Belarus	Aruba	Egypt	Burkino-Faso	Belgium
Cook Islands	Bosnia-Hercegovina	Bahama Islands, The	Iran	Burundi	Denmark
Fiji	Bulgaria	Barbados	Iraq	Cameroon, Federal Republic	Finland
French Polynesia	Croatia	Belize	Israel	Cape Verde Islands	France
Guam	Cyprus	Bermuda	Jordan	Central Africa Republic	Germany, Democratic Republ
Hong Kong	Czech Republic	Bolivia	Kuwait	Chad, Republic of	Germany, Federal Republic
Indonesia, Republic of	Estonia	Brazil	Lebanon	Comoros	Gibraltar
Japan	French Guiana	Cayman Islands	Libya	Congo, Democratic Republic	Greece
Korea, People's Democratic	Georgia	Chile	Morocco	Congo, People's Republic o	Greenland

Korea, Republic of	Kazakhstan	Colombia	Oman	Eritrea	Hungary
Macao	Latvia	Costa Rica	Qatar	Ethiopia	Iceland
Macau Sar	Lithuania	Cuba	Saudi Arabia	Gabon Republic	Ireland, Republic of
Malaysia	Montenegro, Republic of	Dominica	Tunisia	Gambia	Italy
Laos	Poland	Dominican Republic	United Arab Emirates	Guinea, Equatorial	Liechtenstein
Mongolia, People's Republi	Moldova	Ecuador	Western Sahara	Guinea, Republic of	Luxembourg
Myanmar (Burma)	Romania	El Salvador	Yemen, People's Democratic	Guinea-Bissau	Madeira
Nauru	Russia	Grenada	Yemen, Republic of	Ghana	Malta
Papau New Guinea	Serbia and Montenegro	Guadeloupe	Syria	Kenya	Monaco
Philippines	Serbia, Republic of	Guatemala	Palestinian Authority	Lesotho	Netherlands, The
New Caledonia	Slovak Republic	Guyana	**South Asia**	Liberia	Norway
Samoa, American	Slovenia	Haiti	Afghanistan	Madagascar	Spain
Samoa, Western	Tadjikistan	Honduras	Bangladesh	Malawi	Sweden
Singapore	Turkey	Jamaica	India	Mali, Republic of	Switzerland
Soloman Islands	Turkmenistan	Martinique	Maldives, Republic of	Mauritania	United Kingdom and Colonie
Taiwan	Ukraine	Mexico	Nepal	Mauritius	Portugal
Thailand	Uzbekistan	Montserrat	Pakistan	Mozambique	San Marino

Tibet	FYR Macedonia	Netherlands Antilles, The	Sri Lanka	Namibia	Czechoslovakia
Tonga	Republic of Kosovo	Nicaragua	Sikkim (Asia)	Niger, Republic of the	Union of Soviet Socialist
Vanuatu	Kyrgyzstan	Panama Canal Zone	**USA, Australia & New Zealand**		
				Nigeria	Yugoslavia
Vietnam, Socialist Republic		Panama, Republic of	Australia	Reunion	Canary Islands
		Paraguay	New Zealand	Rwanda	
		Peru	United States of America	Sao Tome E Principe	
		Puerto Rico	**Other**		
				Senegal	
		St. Kitts-Nevis	Africa NES	Seychelles	
		St. Lucia	Canada	Sierra Leone	
		St. Vincent and the Grenad	Commonwealth of the Northe	Somalia, Democratic Republ	
		Surinam	Country not stated	South Africa, Republic of	
		Trinidad & Tobago, Republi	Europe NES	Sudan, Democratic Republic	
		Turks and Caicos Islands	Pitcairn Island	Swaziland	
		Uruguay	St. Helena	Tanzania, United Republic	
		Venezuela		Togo, Republic of	

		Virgin Islands, British		Uganda	
		Virgin Islands, U.S.		Zambia	
		Nevis		Zimbabwe	
				Djibouti, Republic of	
				Ivory Coast, Republic of	

Appendix C: Checklist of recommendations for reporting of observational studies using the STROBE guidelines (Chapter 4)

	Item No	Recommendation	Reported
Title and abstract	1	(a) Indicate the study’s design with a commonly used term in the title or the abstract	Abstract
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Abstract
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Introduction
Objectives	3	State specific objectives, including any pre-specified hypotheses	Introduction
Methods			
Study design	4	Present key elements of study design early in the paper	Methods
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Methods
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	Methods
		(b) For matched studies, give matching criteria and number of exposed and unexposed	Not Applicable
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Methods
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Methods
Bias	9	Describe any efforts to address potential sources of bias	Discussion
Study size	10	Explain how the study size was arrived at	Methods, based on availability of the data
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Methods
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Methods
		(b) Describe any methods used to examine subgroups and interactions	Not applicable
		(c) Explain how missing data were addressed	Not Applicable
		(d) If applicable, explain how loss to follow-up was addressed	Not Applicable
		(e) Describe any sensitivity analyses	Not Applicable
Results			

Participants	13	(a) Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Methods, Results, Figure 4-1, 4-2
		(b) Give reasons for non-participation at each stage	Methods, Figure 4-1, 4-2
		(c) Consider use of a flow diagram	Figure 4-1, 4-2
Descriptive data	14	(a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders	Table 4-1, Table 4-3
		(b) Indicate number of participants with missing data for each variable of interest	Essentially Complete
		(c) Summarise follow-up time (e.g. average and total amount)	Not applicable
Outcome data	15	Report numbers of outcome events or summary measures over time	Results, Table 4-2,4-4
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g. 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Results, Table 4-2, 4-4
		(b) Report category boundaries when continuous variables were categorized	Table 4-2, 4-4
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Not applicable
Other analyses	17	Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses	Not applicable
Discussion			
Key results	18	Summarise key results with reference to study objectives	Discussion
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Discussion
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Discussion
Generalisability	21	Discuss the generalisability (external validity) of the study results	Discussion
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Cover page

Appendix D: Checklist of recommendations for reporting of observational studies using the STROBE guidelines (Chapter 5)

	Item No	Recommendation	Reported
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	Abstract
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	Abstract
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	Introduction
Objectives	3	State specific objectives, including any pre-specified hypotheses	Introduction
Methods			
Study design	4	Present key elements of study design early in the paper	Methods
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Methods
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	Methods
		(b) For matched studies, give matching criteria and number of exposed and unexposed	Not Applicable
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Methods
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	Methods
Bias	9	Describe any efforts to address potential sources of bias	Discussion
Study size	10	Explain how the study size was arrived at	Methods, based on availability of the data
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Methods
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	Methods
		(b) Describe any methods used to examine subgroups and interactions	Methods
		(c) Explain how missing data were addressed	Not Applicable
		(d) If applicable, explain how loss to follow-up was addressed	Not Applicable

		(e) Describe any sensitivity analyses	Not Applicable
Results			
Participants	13	(a) Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	Methods, Results, Figure S1
		(b) Give reasons for non-participation at each stage	Methods, Results, Figure 5-1
		(c) Consider use of a flow diagram	Figure 5-1
Descriptive data	14	(a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders	Table 5-1
		(b) Indicate number of participants with missing data for each variable of interest	Essentially Complete
		(c) Summarise follow-up time (e.g. average and total amount)	Not applicable
Outcome data	15	Report numbers of outcome events or summary measures over time	Results, Table 5-2, 5-3, 5-4
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g. 95% confidence interval). Make clear which confounders were adjusted for and why they were included	Results, Table 5-2, 5-3, 5-4, 5-5
		(b) Report category boundaries when continuous variables were categorized	Table 5-2, 5-3, 5-4
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Not applicable
Other analyses	17	Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses	Table 5-3, 5-4.5-6
Discussion			
Key results	18	Summarise key results with reference to study objectives	Discussion
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	Discussion
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	Discussion
Generalisability	21	Discuss the generalisability (external validity) of the study results	Discussion
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	Cover page

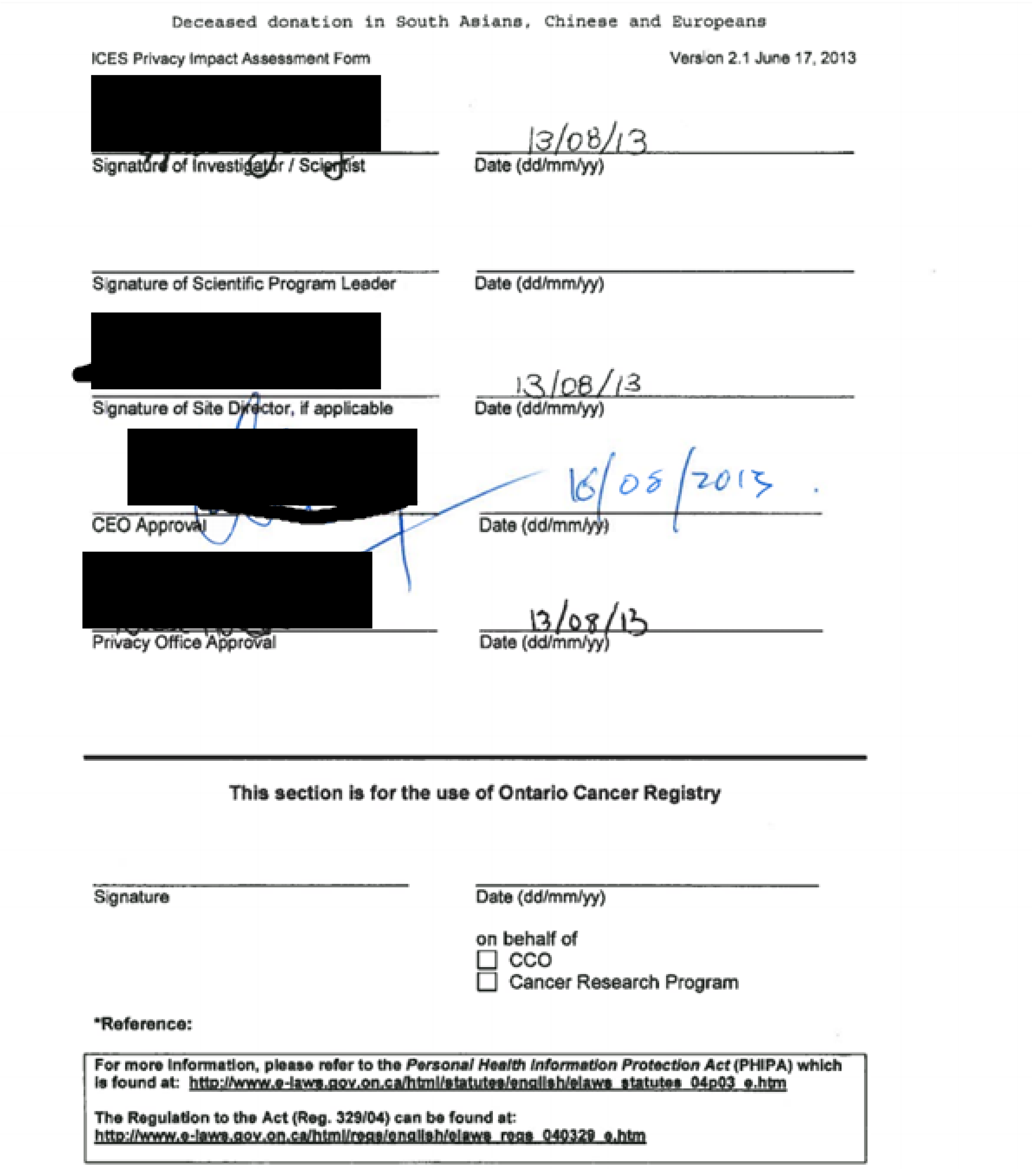
Appendix E: Checklist of recommendations for reporting of observational studies using the REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement (Chapter 6)

	Item No	STROBE items	RECORD items	Reported
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract. (b) Provide in the abstract an informative and balanced summary of what was done and what was found.	(1.1) The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. (1.2) If applicable, the geographic region and time frame within which the study took place should be reported in the title or abstract. (1.3) If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	Title and abstract
Introduction				
Background/ rationale	2	Explain the scientific background and rationale for the investigation being reported.		Introduction
Objectives	3	State specific objectives, including any prespecified hypotheses.		Introduction
Methods				
Study design	4	Present key elements of study design early in the paper.		Study Design and Setting
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection.		Study Design and Setting
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up. (b) For matched studies, give matching criteria and number of exposed and unexposed.	(6.1) The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided. (6.2) Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided. (6.3) If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.	Study Population

Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.	(7.1) A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	Data Sources
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group.		Data Sources
Bias	9	Describe any efforts to address potential sources of bias.		N/A
Study size	10	Explain how the study size was arrived at.		Figure 6-1
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why.		Data sources
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding. (b) Describe any methods used to examine subgroups and interactions. (c) Explain how missing data were addressed. (d) If applicable, explain how loss to follow-up was addressed. (e) Describe any sensitivity analyses.		Statistical Analysis
Data access and cleaning methods		N/A	(12.1) Authors should describe the extent to which the investigators had access to the database population used to create the study population. (12.2) Authors should provide information on the data cleaning methods used in the study.	Data Sources
Linkage		N/A	(12.3) State whether the study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	Methods
Results				
Participants	13	(a) Report numbers of individuals at each stage of study--e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analyzed. (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram.	(13.1) Describe in detail the selection of the persons included in the study (i.e., study population selection), including filtering based on data quality, data availability, and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	Results, Figure 6-1

Descriptive data	14	(a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders. (b) Indicate number of participants with missing data for each variable of interest. (c) Summarize follow-up time (e.g. average and total amount).		Table 6-1
Outcome data	15	Report numbers of outcome events or summary measures over time.		Results, Table 6-2
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g. 95% confidence interval). Make clear which confounders were adjusted for and why they were included. (b) Report category boundaries when continuous variables were categorized. (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period.		Results
Other analyses	17	Report other analyses done (e.g. analyses of subgroups and interactions, and sensitivity analyses).		N/A
Key results	18	Summarize key results with reference to study objectives.		Results
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	(19.1) Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	Discussion
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.		Discussion
Generalizability	21	Discuss the generalizability (external validity) of the study results.		Discussion
Other information				
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based.		Acknowledgement
Accessibility of protocol, raw data, and programming code		N/A	(22.1) Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	N/A

Appendix F: ICES Approval Chapter 4



Deceased donation in South Asians, Chinese and Europeans

ICES Privacy Impact Assessment Form

Version 2.1 June 17, 2013

[redacted]

13/08/13

Signature of Investigator / Scientist

Date (dd/mm/yy)

Signature of Scientific Program Leader

Date (dd/mm/yy)

[redacted]

13/08/13

Signature of Site Director, if applicable

Date (dd/mm/yy)

[redacted]

16/08/2013 .

CEO Approval

Date (dd/mm/yy)

[redacted]

13/08/13

Privacy Office Approval

Date (dd/mm/yy)

This section is for the use of Ontario Cancer Registry

Signature

Date (dd/mm/yy)

on behalf of

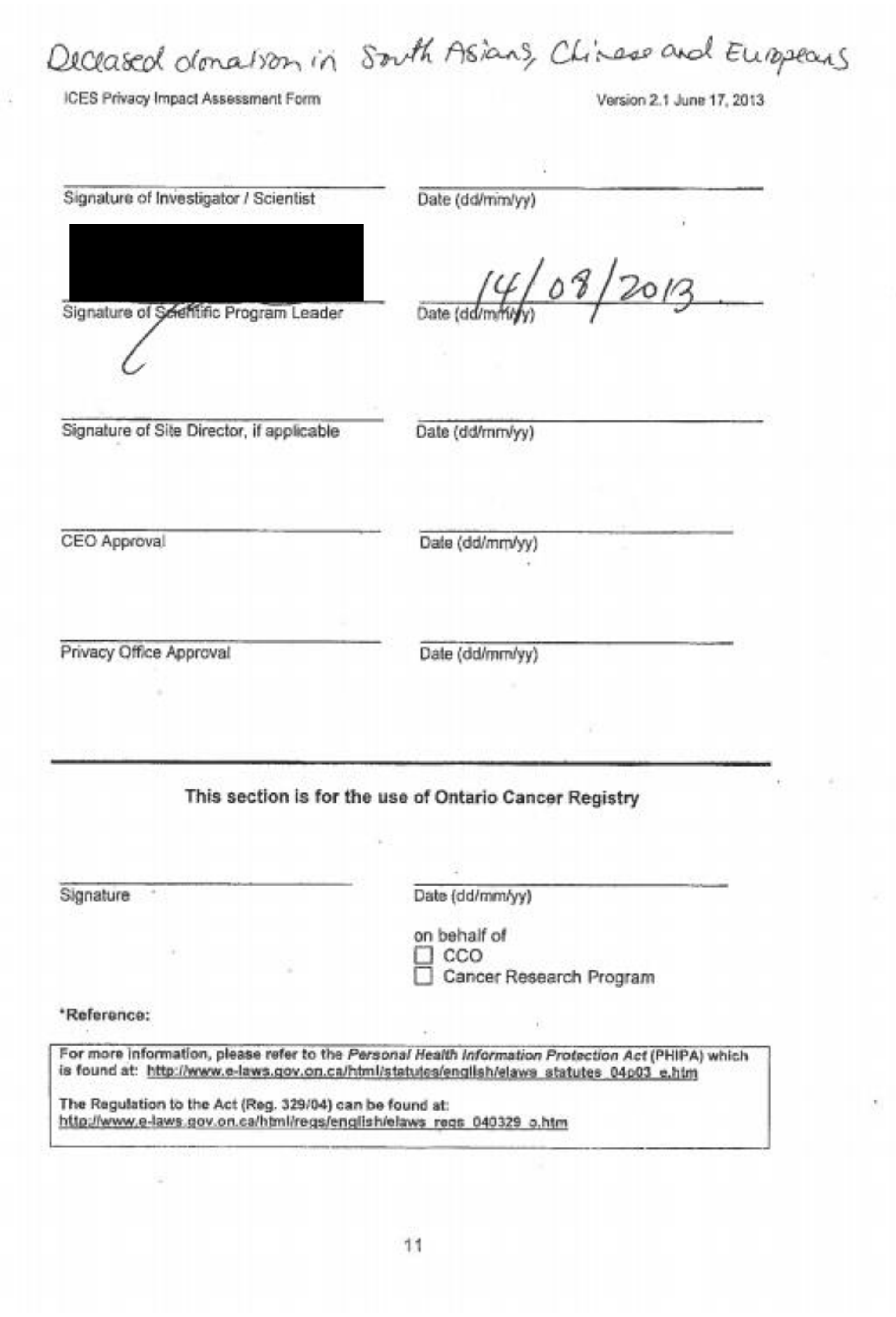
☐ CCO

☐ Cancer Research Program

***Reference:**

For more information, please refer to the *Personal Health Information Protection Act* (PHIPA) which is found at: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_04p03_e.htm

The Regulation to the Act (Reg. 329/04) can be found at: http://www.e-laws.gov.on.ca/html/regs/english/elaws_regs_040329_e.htm



Deceased donation in South Asians, Chinese and Europeans

Signature of Investigator / Scientist

Date (dd/mm/yy)

[redacted]

Signature of Scientific Program Leader

Date (dd/mm/yy) 14/08/2013

Signature of Site Director, if applicable

Date (dd/mm/yy)

CEO Approval

Date (dd/mm/yy)

Privacy Office Approval

Date (dd/mm/yy)

This section is for the use of Ontario Cancer Registry

Signature

Date (dd/mm/yy)

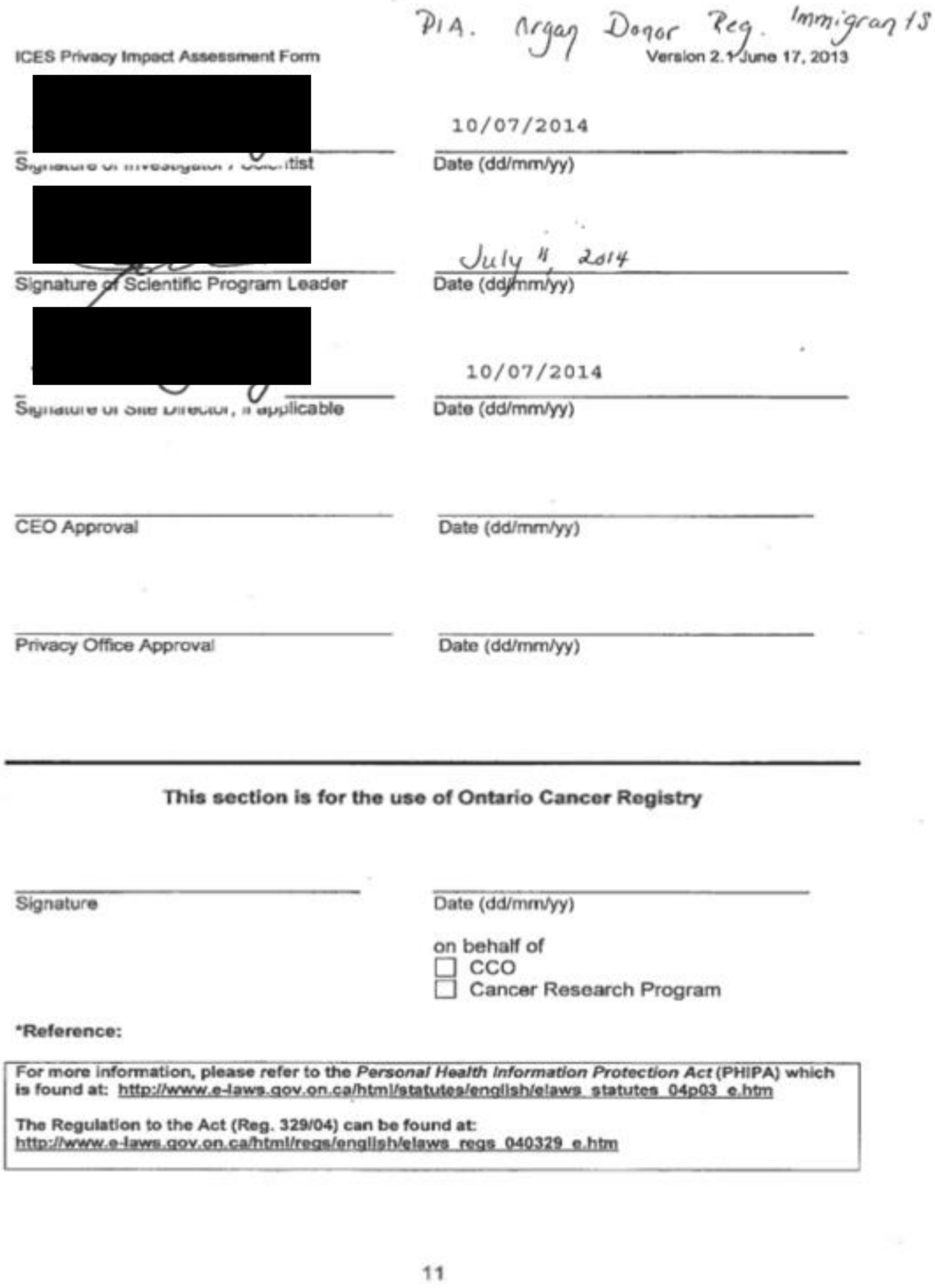
on behalf of
☐ CCO
☐ Cancer Research Program

***Reference:**

For more information, please refer to the *Personal Health Information Protection Act* (PHIPA) which is found at: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_04p03_e.htm

The Regulation to the Act (Reg. 329/04) can be found at: http://www.e-laws.gov.on.ca/html/regs/english/elaws_regs_040329_e.htm

Appendix G: ICES Approval Chapter 5



PIA. Organ Donor Reg. Immigrants

ICES Privacy Impact Assessment Form

Version 2.1 June 17, 2013

[redacted]

10/07/2014

Signature of Investigator / Scientist — Date (dd/mm/yy)

[redacted]

July 11, 2014

Signature of Scientific Program Leader — Date (dd/mm/yy)

[redacted]

10/07/2014

Signature of Site Director, if applicable — Date (dd/mm/yy)

CEO Approval — Date (dd/mm/yy)

Privacy Office Approval — Date (dd/mm/yy)

This section is for the use of Ontario Cancer Registry

Signature — Date (dd/mm/yy)

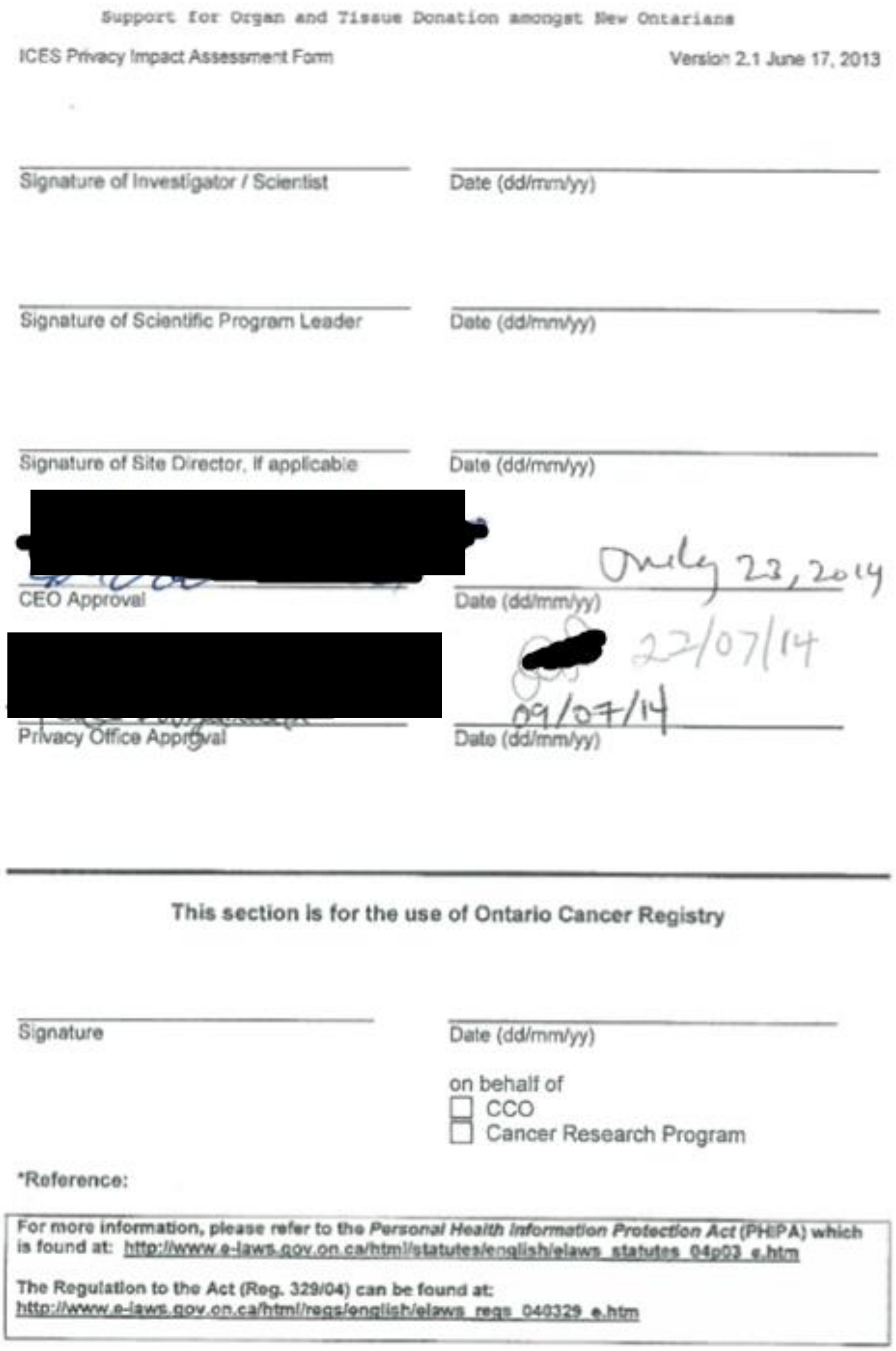
on behalf of
☐ CCO
☐ Cancer Research Program

***Reference:**

For more information, please refer to the *Personal Health Information Protection Act* (PHIPA) which is found at: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_04p03_e.htm

The Regulation to the Act (Reg. 329/04) can be found at: http://www.e-laws.gov.on.ca/html/regs/english/elaws_regs_040329_e.htm

11



Support for Organ and Tissue Donation amongst New Ontarians

ICES Privacy Impact Assessment Form Version 2.1 June 17, 2013

Signature of Investigator / Scientist Date (dd/mm/yy)

Signature of Scientific Program Leader Date (dd/mm/yy)

Signature of Site Director, if applicable Date (dd/mm/yy)

[redacted]

CEO Approval Date (dd/mm/yy) July 23, 2014

[redacted]

[redacted] 22/07/14

09/07/14

Privacy Office Approval Date (dd/mm/yy)

This section is for the use of Ontario Cancer Registry

Signature Date (dd/mm/yy)

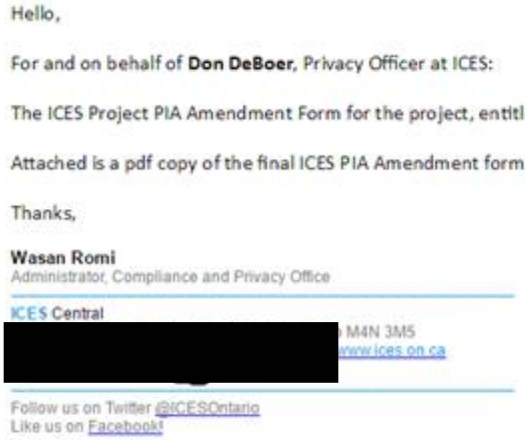
on behalf of
☐ CCO
☐ Cancer Research Program

***Reference:**

For more information, please refer to the *Personal Health Information Protection Act* (PHIPA) which is found at: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_04p03_e.htm

The Regulation to the Act (Reg. 329/04) can be found at: http://www.e-laws.gov.on.ca/html/regs/english/elaws_regs_040329_e.htm

Appendix H: ICES Approval Chapter 6



Hello,

For and on behalf of **Don DeBoer**, Privacy Officer at ICES:

The ICES Project PIA Amendment Form for the project, entitled: "**Familial Consent Rates among Ontario Immigrants**" has now been approved.

Attached is a pdf copy of the final ICES PIA Amendment form, for your files.

Thanks,

Wasan Romi
Administrator, Compliance and Privacy Office

ICES Central
[redacted] M4N 3M5
www.ices.on.ca

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Like us on Facebook!

Curriculum Vitae

Name	Alvin Li
Post-secondary Education and Degrees	Western University London, Ontario, Canada 2007-2011 BSc
	Western University London, Ontario, Canada 2011-2016 Ph.D.
Honours and Awards	CIHR Doctoral Scholarship, 2014-2016
	CIHR Michael Smith Foreign Exchange Study Supplement (Stanford University), 2015
	Transplantation Society Young Investigator Award, 2015
	ASPHER Young Researchers Forum, 2014
	Kidney Foundation of Canada Allied Health Doctoral Award, 2013-2014
	Heart and Stroke Foundation, 2012-2013
	Schulich Graduate Scholarship, 2011-2016
	Ontario Graduate Scholarship, 2012 (Declined), 2013 (Declined)
	Canadian National Transplant Research Program Training Program, 2013-present
Related Work Experience	*Graduate Research Assistant* London Health Sciences Centre Kidney Clinical Research Unit 2011-2016

Graduate Teaching Assistant
Western University
Department of Biology
January-April 2014

Graduate Teaching Assistant
Western University
Department of Epidemiology & Biostatistics
September-December 2013

Publications

Li AH, Lam NN, Dhanani S, Weir M, Prakash V, Kim J, et al. Registration for deceased organ and tissue donation among Ontario immigrants: a population-based cross-sectional study. cmajo. 2016 Oct 11;4(4):E551–61.

Li AH-T, Lam NN, Naylor KL, Garg AX, Knoll GA, Kim SJ. Early Hospital Readmissions After Transplantation: Burden, Causes, and Consequences. Transplantation. 2016 Apr;100(4):713–

Lam NN, Kim SJ, Knoll GA, McArthur E, Lentine KL, Naylor KL, **Li, AHT** et al. The Risk of Cardiovascular Disease Is Not Increasing Over Time Despite Aging and Higher Comorbidity Burden of Kidney Transplant Recipients. Transplantation. 2016 Mar 16

Chavalarias D, Wallach JD, **Li AHT**, Ioannidis JPA. Evolution of Reporting P Values in the Biomedical Literature, 1990-2015. JAMA. 2016 Mar 15;315(11):1141–8.

Li AH-T, McArthur E, Maclean J, Isenor C, Prakash V, Kim SJ, et al. Deceased Organ Donation Registration and Familial Consent among Chinese and South Asians in Ontario, Canada. PLoS ONE. 2015;10(7):e0124321.

Li AH-T, Thomas SM, Farag A, Duffett M, Garg AX, Naylor KL. Quality of survey reporting in nephrology journals: a methodologic review. Clin J Am Soc Nephrol. 2014 Dec 5;9(12):2089–94.

Li AH-T, Dixon S, Prakash V, Kim SJ, Knoll GA, Lam NN, et al. Physician registration for deceased organ donation. JAMA. 2014 Jul 16;312(3):291–3.

Marras C, Hincapié CA, Kristman VL, Cancelliere C, Soklaridis S, **Li A,** et al. Systematic review of the risk of Parkinson's disease after mild traumatic brain injury: results of the International Collaboration on Mild Traumatic Brain Injury Prognosis. Arch Phys Med Rehabil. 2014 Mar;95(3 Suppl):S238-244.

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Li AH-T, Rosenblum AM, Nevis IF, Garg AX. Adolescent classroom education on knowledge and attitudes about deceased organ donation: a systematic review. Pediatr Transplant. 2013 Mar;17(2):119–28.

Li AH, Kim SJ, Rangrej J, Scales DC, Shariff S, Redelmeier DA, et al. Validity of physician billing claims to identify deceased organ donors in large healthcare databases. PLoS ONE. 2013;8(8):e70825.

Rosenblum AM, **Li AH-**T, Roels L, Stewart B, Prakash V, Beitel J, et al. Worldwide variability in deceased organ donation registries. Transpl Int. 2012 Aug;25(8):801–11.