

Registration for deceased organ and tissue donation among Ontario immigrants: a population-based cross-sectional study

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Abstract

Background: Canada has low rates of deceased organ and tissue donation. Immigrants to Canada may differ in their registered support for deceased organ donation based on their country of origin.

Methods: We used linked administrative databases in Ontario (about 11 million residents aged ≥ 16 yr) to study the proportion of immigrants and long-term residents registered for deceased organ and tissue donation as of October 2013. We used modified Poisson regression to identify and quantify predictors of donor registration.

Results: Compared with long-term residents ($n = 9\,244\,570$), immigrants ($n = 1\,947\,646$) were much less likely to register for deceased organ and tissue donation (11.9% v. 26.5%). 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%). The largest numbers of unregistered immigrants were from India ($n = 202\,548$), China ($n = 186\,678$) and the Philippines ($n = 125\,686$). 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.

Interpretation: Immigrants in Ontario were less likely to register for deceased organ and tissue donation than long-term residents. There is a need to better understand reasons for lower registration rates among Canadian immigrants and to create culture-sensitive materials to build support for deceased organ and tissue donation.

I ncreasing 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 concerns may 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-Asian Canadians^{7,8} and lack of societal integration among

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Arab Americans.⁹ In addition, most 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 areas, we conducted a population-based study in Ontario to determine the registration status for deceased organ and tissue donation 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 numbers of unregistered people. Our secondary outcome was whether registered donors opted to exclude certain organs or tissues that they did not wish to donate.

Methods

Design and setting

We conducted a population-based cross-sectional study using linked health care databases in Ontario as of Oct. 22, 2013. These datasets were linked with the use of unique encoded identifiers and analyzed at the Institute for Clinical Evaluative Sciences. Ontario is Canada's most populous province (accounting for about 40% of the Canadian population),¹² with about 11 million residents aged 16 years (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 of citizens registered, at 65%, followed by New Brunswick (42%), Ontario (18%), Yukon Territory (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>).

Data sources

We ascertained sociodemographic and donor registration information from 2 main administrative databases: the Ontario Registered Persons Database and 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 every-

one who has registered for organ donation. We derived income using neighbourhood income quintiles (a measure of income adjusted to household size).¹³ Marginalization is the "process by which individuals and groups are prevented from fully participating in society."¹⁴ We used Matheson and colleagues'¹⁵ Canadian Marginalization Index to assign marginalization quintiles based on area of residence on 4 components of marginalization: residential instability (a measure of turnover in the population), ethnic concentration (a measure consisting of the proportions of recent immigrants and 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 Permanent Resident Database contains landing records for every permanent legal immigrant to Canada who arrived in 1985 or later. Data are captured at the time of immigration application.¹⁶ We used the Ontario portion of this database to ascertain immigration status and other migration-related variables. The database has been used previously to examine diabetes and cancer screening among immigrants.^{17,18} The migration-related variables included time since arrival in Canada, immigration visa class (economic, family, refugee or other), language ability (English, French, both or neither), marital status (married, single, separated, divorced or widowed) and education level at the time of immigration. "Economic" immigrants included those sponsored by the province, skilled workers, entrepreneurs and investors. "Family" immigrants were family members of economic immigrants and those who immigrated through family reunification. The "other" category included all other immigrant classes, such as live-in caregivers and those who immigrated on humanitarian grounds.

Study population

We included all permanent residents of Ontario as of October 2013 and classified them as immigrants or long-term residents based on their immigration status within the Permanent Resident Database. Long-term residents were those who did not have a record in the 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 included only people in Ontario.

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.¹⁹ 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.

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.²⁰ We used modified Poisson regression to estimate the prevalence ratio and 95% confidence intervals (CIs) of organ and tissue donor registration for immigrants relative to long-term residents.²¹ 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.²¹ We adjusted for variables chosen a priori (e.g., age, sex, income quintile) based on the findings of a previous study.²² We used the Wilson score method to calculate 95% CIs 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 owing to missing data). We conducted all analyses with SAS software, version 9.3. Finally, we examined the consistency of the associative relations 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.

Ethics approval

The study was approved by the institutional review board at Sunnybrook Health Sciences Centre, Toronto.

Results

We identified 1 947 646 immigrants and 9 244 570 long-term residents (Appendix 1, available at www.cmajopen.ca/content/4/4/E551/suppl/DC1). Compared to long-term residents, immigrants were more likely to be younger (mean age 44.1 v. 47.3 yr), from lower socioeconomic neighbourhoods and from areas with a higher ethnic concentration; they were less likely to be from rural areas (Table 1). Half of all immigrants were from the East Asia and Pacific region (25.6%) or South Asia (24.3%).

Registration for organ and tissue donation

A total of 231 180 immigrants (11.9%, 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 2).

When we assessed the proportion of immigrants registered for deceased organ donation according to world region of origin, the region with the highest proportion of registered donors was United States, Australia and New Zealand (40.0%, 95% CI 39.5–40.5), followed by Western Europe (20.6%, 95% CI 20.4–20.9) and Latin America and 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 (8.4%, 95% CI 8.3–8.5) and sub-Saharan Africa (7.9%, 95% CI 7.7–8.0) were registered.

Characteristics associated with registration

For the overall group of immigrants and long-term residents combined, those aged 30–39 years had the highest donor registration rate (29.2%; adjusted prevalence ratio 1.96, 95% CI 1.94–1.99; referent 16–19 yr) (Table 2). In adjusted analyses, we observed no association between income and registration rates. There was a gradient with ethnic concentration and material deprivation: people living in areas with a higher ethnic concentration were less likely to register for organ donation. For example, 14.8% of people living in the area with the highest ethnic concentration were registered, compared to 29.2% of those living in the middle quintile (adjusted prevalence ratio 0.58, 95% CI 0.57–0.58) (Table 2). We also found a weak association between 2 of the 4 measures of marginalization (residential instability and dependency) and donor registration (results not shown).

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 (Table 3). Separated, divorced or widowed immigrants were less likely to register than married immigrants in the unadjusted model but were more likely to register in the adjusted model. In general, immigrants who had been living in Canada for longer periods were more likely to be registered than those living in Canada for less than 4 years.

The 5 countries of birth with the highest absolute numbers of unregistered immigrants were India (202 548 unregistered [13.7% registered, 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 4). In our 5 stratified models, we observed effect modification by country of birth for each examined characteristic, which suggests that each characteristic associated somewhat differently with donor registration across these 5 groups. The following characteristics were associated with a higher chance of donor registration in each of the 5 groups: age categories 20–29 years, 30–39 years and 40–49 years (v. 16–19 yr), longer time since arrival in Canada (v. < 4 yr), English and English/French language ability (v. not able to speak either language) and economic immigrant (v. family immigrant). Except for immigrants born in Pakistan, living in the area with the highest ethnic concentration was also associated with lower registration, and higher educational qualifications were associated with higher registration rates.

Exclusion of organs and tissues

During the donor registration process, when given the option to exclude certain organs and tissues from deceased organ donation, 53 473 immigrants (23.1%) and 409 389 long-term residents (16.7%) excluded at least 1 organ or tissue (Appendix 2, available at www.cmajopen.ca/content/4/4/E551/suppl/DC1). South Asian donors were the most likely to exclude an organ or tissue or both (15 267 people [28.8%]). Across all groups, the most commonly

Table 1 (part 1 of 2): Baseline characteristics of Ontario immigrants and long-term residents

Characteristic	No. (%) of people*		Standardized difference, %†
	Immigrants (n = 1 947 646)	Long-term residents (n = 9 244 570)	
Age, yr, mean ± standard deviation	44.1 ± 15.5	47.3 ± 19.2	17
Age category, yr			
16–19	76 073 (3.9)	599 264 (6.6)	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
Female sex	933 639 (47.9)	4 841 077 (52.4)	9
Rural residence‡	24 848 (1.3)	1 243 904 (13.4)	48
Neighbourhood 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	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
Residential instability quintile			
First (lowest)	604 813 (31.0)	2 350 648 (25.4)	13
Second	350 284 (18.0)	1 969 402 (21.3)	8
Third	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 quintile			
First (lowest)	40 269 (2.1)	1 280 350 (13.8)	45
Second	73 994 (3.8)	1 620 959 (17.5)	46
Third	125 735 (6.4)	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 quintile			
First (lowest)	663 665 (34.1)	1 977 392 (21.4)	29
Second	529 973 (27.2)	2 034 206 (22.0)	12
Third	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 quintile			
First (lowest)	502 397 (25.8)	2 461 225 (26.6)	2
Second	402 011 (20.6)	2 135 074 (23.1)	6
Third	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

Table 1 (part 2 of 2): Baseline characteristics of Ontario immigrants and long-term residents

Characteristic	No. (%) of people*		Standardized difference, %†
	Immigrants (n = 1 947 646)	Long-term residents (n = 9 244 570)	
World region of birth			
East Asia and Pacific	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)	–	–
United States, Australia and New Zealand	38 014 (2.0)	–	–
Other	777 (< 0.1)	–	–
Education			
University degree or higher	502 234 (25.8)	–	–
Some university	80 655 (4.1)	–	–
Nonuniversity qualifications (e.g., college diploma)	277 160 (14.2)	–	–
Secondary or less	923 002 (47.4)	–	–
None	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 (4.2)	–	–
Language ability			
English	1 149 609 (59.0)	–	–
French	16 612 (0.8)	–	–
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)	–	–

*Except for age (mean ± standard deviation).

†Compared to long-term residents. Standardized differences greater than 10% represent a meaningful difference between the 2 groups.

‡Areas with a population less than 10 000.

Table 2: Characteristics associated with donor registration among immigrants and long-term residents combined

Characteristic	No. (%) registered	Prevalence ratio (95% confidence interval)	
		Unadjusted	Adjusted*
World region of birth			
Long-term residents (<i>n</i> = 9 244 570)	2 453 116 (26.5)	1.00 [Reference]	1.00 [Reference]
Immigrants (<i>n</i> = 1 947 646)	231 180 (11.9)		
East Asia and Pacific	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	9080 (7.9)	0.30 (0.29–0.30)	0.35 (0.33–0.36)
United States, 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			
Female	1 495 776 (25.9)	1.00 [Reference]	1.00 [Reference]
Male	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)
Neighbourhood 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	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 quintile†			
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	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 quintile†			
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	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)
*Adjusted for world region of birth, sex, residence, age category, neighbourhood income quintile, material deprivation quintile and ethnic concentration quintile. Adjusted analysis based on a random sample of 20% (<i>n</i> = 2 238 443).			
†Data missing for 145 466 people (1.3%), of whom 36 051 were registered for donor and tissue donation.			

excluded organ or tissue were skin and eyes (Appendix 3, available at www.cmajopen.ca/content/4/4/E551/suppl/DC1). Older people, men and those living in rural areas were less likely to exclude an organ or tissue. Residential instability, dependency and material deprivation showed no clear relation with higher rates of organ or tissue exclusion (results not shown).

Interpretation

In this cross-sectional study, we documented that immigrants in Ontario had lower rates of registration for organ and tissue donation than did long-term residents of the province. Immigrants born in the United States, Australia and New Zealand

Table 3 (part 1 of 2): Characteristics associated with donor registration among immigrants			
Characteristic	No. (%) registered*	Prevalence ratio (95% confidence interval)	
		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)
United States, 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			
Female	121 402 (12.0)	1.00 [Reference]	1.00 [Reference]
Male	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)
Neighbourhood income quintile			
First (lowest)	43 634 (8.8)	0.73 (0.72–0.74)	0.96 (0.94–0.97)
Second	46 543 (10.9)	0.90 (0.89–0.91)	1.00 (0.99–1.01)
Third	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 quintile‡			
First (lowest)	9 435 (23.4)	1.27 (1.25–1.30)	1.12 (1.10–1.15)
Second	15 272 (20.6)	1.12 (1.10–1.14)	1.06 (1.04–1.08)
Third	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)

Table 3 (part 2 of 2): Characteristics associated with donor registration among immigrants

Characteristic	No. (%) registered*	Prevalence ratio (95% confidence interval)	
		Unadjusted	Adjusted†
Material deprivation quintile‡			
First (lowest)	72 247 (14.4)	1.23 (1.21–1.24)	1.09 (1.08–1.10)
Second	52 477 (13.1)	1.11 (1.10–1.13)	1.04 (1.03–1.05)
Third	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)
Education§			
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)
Nonuniversity 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)
None	15 864 (9.6)	0.67 (0.66–0.68)	0.81 (0.80–0.83)
Time since arrival 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]
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)
*Total number of 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, neighbourhood income quintile, material deprivation quintile, ethnic concentration quintile, education, time since arrival in Canada, language ability, marital status and immigrant class.			
‡Data missing for 15 102 people (< 1.0%), of whom 2022 were registered.			
§Data missing for 454 people (< 0.01%), of whom 52 were registered, who were then further excluded from analysis.			

region had the highest registration rates, even higher than those for long-term residents. In addition, among immigrants, age 30–39 years, higher education, ability to speak English or both English and French, economic immigrant status, married or single status, and living in an area with a lower ethnic concentration were associated with higher registration rates. These findings highlight the marked differences in donor registration rates across immigrant groups and inform the development and

implementation of targeted, culture-sensitive public campaigns to raise awareness about organ and tissue donation.

Our findings are consistent with those of López and colleagues,²³ who investigated the attitudes of immigrants in Spain toward deceased organ donation. Like those authors, we found that, among the immigrant population as a whole, women, people with higher education and those with a higher income were more likely to register for organ donation. However, López and

colleagues²³ found that immigrants from East Europe and North Africa were more reluctant to donate their organs compared to other immigrant groups, whereas in our study, immigrants born in sub-Saharan Africa and the East Asia and Pacific region were the least likely groups to be registered for organ donation.

Our results are also similar to those of a previous study, in which we used a surname algorithm to identify people of Chinese and South Asian origin in Ontario.²⁴

In the current study, 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 we adjusted for residential ethnic concentra-

tion. Furthermore, living in a rural community, higher neighbourhood income quintile and lower material deprivation quintile were no longer strongly positively associated with donor registration after adjustment for ethnic concentration among all Ontario residents. In another study examining how community-level factors affect rates of registration for organ donation, Ladin and colleagues²⁵ found that groups with higher levels of racial homogeneity, native-born residents and other social capital variables had higher registration rates. They suggested 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.

Table 4 (part 1 of 2): Characteristics associated with donor registration among immigrants from the 5 countries with the highest numbers of unregistered immigrants

Characteristic	Adjusted prevalence ratio (95% confidence interval)*				
	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					
Female	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]	1.00 [Reference]
Male	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)
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)
Neighbourhood 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	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 quintile					
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	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 quintile					
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	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)

Table 4 (part 2 of 2): Characteristics associated with donor registration among immigrants from the 5 countries with the highest numbers of unregistered immigrants

Characteristic	Adjusted prevalence ratio (95% confidence interval)*				
	India	China	Philippines	Pakistan	Sri Lanka
Education					
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)
Nonuniversity 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)
None	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 since arrival 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]
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)

*Adjusted for world region of birth, sex, residence, age category, neighbourhood income quintile, material deprivation quintile, ethnic concentration quintile, education, time since arrival in Canada, language ability, marital status and immigrant class.

Strengths and limitations

Our study has several strengths. First, we examined actual rates of registration for organ and tissue donation rather than attitudes toward donation among immigrants as well as characteristics associated with registration. In addition, we accounted for important variables such as age and socioeconomic status when comparing ethnic groups.⁴ Furthermore, most previous studies focused on specific ethnic or cultural collectives such as Hispanics, African Americans, Asians and Arabs, whereas our study focused on the entire immigrant population of a large jurisdiction.

However, our study has important limitations. First, we had no information on the reasons why many immigrants did not register for organ donation, which is important for the design of educational programs. Low 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. The low registration rates may also have been due to unawareness of the registry^{7,8} or fear of placing one's name in a large database²⁶ rather than a negative attitude toward organ donation. Second, Immigration, Refugees and Citizenship Canada's Permanent Resident Database contains only data recorded at the 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 colleagues¹⁶ found that self-reported language barriers in the Permanent Resident Database are a poor indicator of persistent language barrier compared with the Canadian Community Health Survey. Despite the limitations in our data, strong differences in registration rates between immigrants and long-term residents persisted even after we controlled for many sociodemographic factors.

Conclusion

This study documents that fewer Ontario immigrants than long-term residents of the province registered for deceased organ and tissue donation. There is a need to better understand the causes of lower registration rates among various immigrant groups. However, to fill the Ontario donor registry, it is also important to better understand the reasons for the low rate of donor registration among long-term residents, given that they account for a large absolute number of unregistered residents. More research on other community-level factors associated with higher donor registration rates, such as volunteerism and civic participation, is needed. More research is also needed to develop and evaluate culture-tailored interventions that can build support for deceased organ and tissue donation.

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