Attitudes Toward Strategies to Increase Organ Donation: Views of the General Public and Health Professionals

Lianne Barnieh,* Scott Klarenbach,† John S. Gill,§ Tim Caulfield,∥ and Braden Manns**†‡¶**

Summary
Background and objective The acceptability of financial incentives for organ donation is contentious. This study sought to determine (1) the acceptability of expense reimbursement or financial incentives by the general public, health professionals involved with organ donation and transplantation, and those with or affected by kidney disease; and (2) for the public, whether financial incentives would alter their willingness to consider donation.

Design, setting, participants, & measurements Web-based survey administered to members of the Canadian public, health professionals, and people with or affected by kidney disease asking questions regarding acceptability of strategies to increase living and deceased kidney donation and willingness to donate a kidney under various financial incentives.

Results Responses were collected from 2004 members of the Canadian public October 11–18, 2011; responses from health professionals (n=339) and people with or affected by kidney disease (n=268) were collected during a 4-week period commencing October 11, 2011. Acceptability of one or more financial incentives to increase deceased and living donation was noted in >70% and 40% of all groups, respectively. Support for monetary payment for living donors was 45%, 14%, and 27% for the public, health professionals, and people with or affected by kidney disease, respectively. Overall, reimbursement of funeral expenses for deceased donors and a tax break for living donors were the most acceptable.

Conclusion The general public views regulated donors were the most acceptable. Future research needs to examine the impact of financial incentives on rates of deceased and living donors.

Introduction
For patients with ESRD, kidney transplantation is the optimal treatment (1,2). Because of the increasing prevalence of ESRD (3), the need for transplantation continues to exceed the supply of transplantable kidneys (3,4). Donation rates from living and deceased donors have remained relatively unchanged over the last 10 years (3), despite strategies to increase the pool of transplantable organs by using expanded-criteria organs (5), unrelated living donation (6), ABO-incompatible transplants (7), and living donor paired exchange programs (8).

Each Canadian province has its own human tissue and gift act (9) that prohibits the buying or selling of organs, and the current system of organ donation relies on the public volunteering their organs. Because the volunteer system is not meeting the demand, many strategies to increase donation have been proposed, including the use of monetary-based strategies, the merits of which have been fiercely debated. These include such strategies as reimbursement of expenses or lost wages for living donors, or the use of financial incentives that result in net monetary gain as a means of motivating donation (10–14).

Previous surveys, with varying methods and populations, have been conducted to assess the feasibility and acceptability of financial incentives for increasing organ donation (15–30). Financial incentives have been implemented successfully to increase donation of sperm, oocytes, and blood (31); however, given legal and other concerns, the acceptability of financial incentives for organ donation to various stakeholders is contentious. The objective of this study was to determine the acceptability of the use of expense reimbursement or financial incentives by the Canadian general public, health professionals involved with organ donation and transplantation, and those affected by kidney disease. Further, we sought to determine whether financial incentives would change the willingness of the public to consider donating a kidney.

Materials and Methods
Study Design and Population
We designed a web-based survey and administered it to three distinct groups: the general public (potential kidney donors) aged 18–59 years living in one of the
Canadian provinces or territories, members of relevant health care professional associations, and people affected by kidney disease (Supplemental Material).

Ipsos (32) electronically invited members of the general public who were included on their panel to complete the questionnaire during a 1-week period from October 11 to 18, 2011; the survey was closed to enrollment once the target enrollment in each age (18–59 years) and geographic stratum was achieved. For each health professional group, the questionnaire was distributed to members via email hyperlink on October 11, 2011, and two reminders were sent 10 days apart. To elicit the views of people with or affected by kidney disease, we placed a hyperlink to the questionnaire on the Kidney Foundation of Canada website and Facebook page from October 12 to November 4, 2011, inviting people to respond. This study was approved by the Institutional Review Board at the University of Calgary.

Questionnaire Content
The questionnaire was administered online to participants in English or French, Canada’s two official languages (Supplemental Material). We used two versions of the questionnaire. An abbreviated 22-item version of the questionnaire was administered to all participants and assessed the acceptability of financial incentives to increase deceased and living donor organ donation. A longer, 29-item version of the questionnaire given only to members of the public included additional questions assessing how a variety of financial incentives might affect their willingness to donate.

Acceptability of Strategies to Increase Deceased Donation
Acceptability of strategies to increase deceased donation was determined by asking whether various types of financial incentives, in varying amounts (range, $0–$100,000), were acceptable. If participants did not find the strategies acceptable, they were given a choice of reasons to explain their rationale.

Acceptability of Strategies to Increase Living Donation
Acceptability of strategies to increase living donation was determined by asking whether various types of financial incentives, in varying amounts (range, $0–$150,000), were acceptable. If participants did not find the strategies acceptable, they were given a choice of reasons to justify.

Supplementary Questions for General Public
The general public was asked supplementary questions to determine whether their willingness to donate would vary if they were offered financial incentives. Specifically, for deceased donation, the likelihood of joining an organ donor registry for monetary payment was assessed, whereas for living donors, their willingness to consider donating a kidney, while alive, for monetary payment was examined.

Statistical Analyses
Univariate relationships between the financial incentive acceptability (yes or no) and the three subgroups were described using descriptive statistics (number [percentage]), and a chi-squared test was used to test for differences in proportions between the public and health professionals. Because one concern regarding financial incentives is that people with lower income might be more likely to respond to financial incentives, stratified analyses were done according to household income. All analyses were done using Stata/IC 11.0 (Stata Corp, College Station, TX).

Results
Response Rate and Participant Characteristics
Within 1 week of data collection, 2004 invited members of the Canadian public completed the questionnaire. Compared with the latest Canadian census data, respondent demographic characteristics were similar to those of the general population and were geographically representative. During the 1-month period that the survey was available to the health professional groups, 339 total responses were collected. Assuming that all people on the mail-out list were alive members with a valid email address, the response rate for the health professionals was 19%. A total of 268 responses were collected through the Kidney Foundation of Canada for the group of people affected by kidney disease. Characteristics of the study population by group are presented in Table 1, including willingness to donate after death or while alive without any financial incentive. Of note, the majority of respondents stated they were willing to donate their organs after death, indicating strong support of organ donation.

Overall Attitudes regarding Financial Incentives to Increase Deceased Donation
Around 71% of the general public, 66% of people affected by kidney disease, and 62% of health professionals supported one or more types of financial incentives to increase deceased donation. In general, all groups were most supportive of reimbursing funeral expenses (>45%), followed by providing a tax break or credit to the donors family. A monetary payment to the donor’s estate garnered the least amount of support (Figure 1). The majority of respondents suggested a tax break or credit value between $0 and $10,000.

Approximately 16% of the general public, 32% of health professionals, and 23% of people affected by kidney disease found that none of the proposed strategies for deceased donation were acceptable. The most commonly cited reason was that a kidney should be donated from the goodness of one’s heart. Nearly 10% of the total sample of the public stated that giving a kidney should not involve any exchange of money as a rationale, although the rate of respondents choosing this answer was higher in the health professional group and people affected by kidney disease (24% and 18%, respectively).

Overall Attitudes regarding Financial Incentives to Increase Living Donation
Support for acceptability of removing financial disincentives (i.e., reimbursing expenses) to living donation was strong across the three groups (Figure 2). Few respondents among the three subgroups found any of these strategies unacceptable (5.7% of the public, 2.7% of health professionals, and 1.1% of people affected by kidney disease). Overall, approximately 40% of all three groups found a government tax break or credit to a person once the kidney...
has been removed to be acceptable (Figure 3). Only 15% of health professionals found a monetary payment acceptable, compared with 45% of the general public \( (P<0.001) \). For those who supported incentive monetary payment or a tax break, a payment between $10,000 and $50,000 was found acceptable to the majority \( (50\%) \) of all groups; approximately 20% of respondents in each subgroup found a payment of $50,000–$100,000 acceptable.

Nearly 45% of health professionals felt that a financial incentive in the form of a tax break or monetary incentive was not acceptable, compared with only 10% of the general public \( (P<0.001) \). Among the 14% of the public who felt that financial incentives were not acceptable for living donors, the most frequently cited reason among the public was that giving a kidney should come from the goodness of one’s heart \( (55\%) \). Among the 44% of health professionals and 34% of people affected by kidney disease who stated that financial incentives were not acceptable, the most frequently cited reason was that giving a kidney should not involve an exchange of money \( (28\% \text{ and } 22\%, \text{ respectively}) \).

Table 1. Characteristics of participants and baseline willingness to donate

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Public (n=2004)</th>
<th>Health Professionals (n=339)</th>
<th>People Affected by Kidney Disease (n=268)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–39 yr</td>
<td>949 (47)</td>
<td>88 (26)</td>
<td>115 (43)</td>
</tr>
<tr>
<td>40–59 yr</td>
<td>1055 (53)</td>
<td>227 (67)</td>
<td>122 (46)</td>
</tr>
<tr>
<td>≥60 yr</td>
<td>NA</td>
<td>34 (10)</td>
<td>31 (12)</td>
</tr>
<tr>
<td>Men</td>
<td>984 (49)</td>
<td>136 (40)</td>
<td>62 (23)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>622 (31)</td>
<td>0</td>
<td>37 (14)</td>
</tr>
<tr>
<td>Some college or university</td>
<td>351 (18)</td>
<td>3 (1)</td>
<td>37 (14)</td>
</tr>
<tr>
<td>Technical school or college</td>
<td>540 (27)</td>
<td>55 (16)</td>
<td>69 (26)</td>
</tr>
<tr>
<td>University degree</td>
<td>475 (24)</td>
<td>278 (82)</td>
<td>116 (43)</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working full-time or part-time</td>
<td>1354 (68)</td>
<td>330 (97)</td>
<td>167 (72)</td>
</tr>
<tr>
<td>Student, homemaker or retired</td>
<td>448 (22)</td>
<td>3 (1)</td>
<td>76 (28)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>119 (6)</td>
<td>2 (1)</td>
<td>7 (3)</td>
</tr>
<tr>
<td>Other</td>
<td>59 (3)</td>
<td>3 (1)</td>
<td>14 (5)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or living with someone</td>
<td>1381 (69)</td>
<td>277 (82)</td>
<td>186 (69)</td>
</tr>
<tr>
<td>Separated, divorced, or widowed</td>
<td>135 (7)</td>
<td>23 (7)</td>
<td>30 (11)</td>
</tr>
<tr>
<td>Single or never married</td>
<td>462 (23)</td>
<td>36 (11)</td>
<td>49 (18)</td>
</tr>
<tr>
<td>Ethnicity(^a)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>1710 (85)</td>
<td>286 (84)</td>
<td>248 (93)</td>
</tr>
<tr>
<td>First Nations</td>
<td>40 (2)</td>
<td>1 (0.3)</td>
<td>8 (3)</td>
</tr>
<tr>
<td>Asian/Indian</td>
<td>147 (7)</td>
<td>34 (10)</td>
<td>5 (2)</td>
</tr>
<tr>
<td>Other</td>
<td>86 (4)</td>
<td>13 (4)</td>
<td>6 (2)</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$30,000</td>
<td>234 (12)</td>
<td>1 (0.3)</td>
<td>31 (12)</td>
</tr>
<tr>
<td>$30,000–$59,999</td>
<td>493 (25)</td>
<td>6 (2)</td>
<td>47 (18)</td>
</tr>
<tr>
<td>$60,000–$89,999</td>
<td>389 (19)</td>
<td>42 (12)</td>
<td>51 (19)</td>
</tr>
<tr>
<td>≥$90,000</td>
<td>563 (28)</td>
<td>244 (72)</td>
<td>101 (38)</td>
</tr>
<tr>
<td>No response</td>
<td>325 (16)</td>
<td>44 (13)</td>
<td>36 (14)</td>
</tr>
<tr>
<td>Willing to donate after death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1414 (71)</td>
<td>308 (91)</td>
<td>249 (93)</td>
</tr>
<tr>
<td>No</td>
<td>148 (7)</td>
<td>9 (3)</td>
<td>6 (2)</td>
</tr>
<tr>
<td>Not sure</td>
<td>442 (22)</td>
<td>22 (6)</td>
<td>13 (5)</td>
</tr>
<tr>
<td>Willing to donate while alive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>663 (33)</td>
<td>237 (70)</td>
<td>107 (40)</td>
</tr>
<tr>
<td>No</td>
<td>405 (20)</td>
<td>27 (8)</td>
<td>23 (9)</td>
</tr>
<tr>
<td>I would like to but am not healthy</td>
<td>184 (9)</td>
<td>19 (6)</td>
<td>87 (32)</td>
</tr>
<tr>
<td>Yes, I have already donated</td>
<td>2 (0.1)</td>
<td>0</td>
<td>18 (8)</td>
</tr>
<tr>
<td>Unsure</td>
<td>750 (37)</td>
<td>56 (17)</td>
<td>33 (12)</td>
</tr>
</tbody>
</table>

Values are expressed as number (percentage) of respondents. NA, not applicable.

\(^a\)May not add up to 100% because respondents were able to identify with more than one ethnicity.
Current Participation and Future Willingness to Join a Deceased-Donor Registry

Among the 1032 public respondents who reside in British Columbia and Ontario (the only two provinces in Canada with a deceased-donor registry), 56.7% said they were not aware of a registry for donors; 17.3% of respondents said that they had already registered their wishes. Almost 70% of those who had not already registered or were unaware of a registry stated that they would register with a new national government registry, without payment. Of the remainder (the 30% who said they wouldn’t register above), 89% would still not register, regardless of payment.

Monetary Gain to Living Donors as a Means of Increasing Living Kidney Donation among the General Public

Among the general public who stated previously they would not consider donating while alive (405 of 2004), >50% (n=219) would consider donating to a relative for $10,000, and >60% (n=251) would consider donating to a relative for $100,000 (Table 2). This was more prominent among those who were previously unsure about living donation (750 of 2004): Almost 80% would donate to a relative, for $10,000 (n=591) or $100,000 (n=588). The greatest increase in willingness to consider donating to an acquaintance or someone on the waiting list was noted among those previously unsure, who would consider...
Some people were not responsive to monetary gain. Of those who previously wouldn’t consider donating, 31% would still not donate for a monetary gain of $100,000, stating that giving a kidney should be from the goodness of one’s heart (n=48).

Among those who were willing to donate without payment, a slight decrease was observed when payment was offered: Of those who were willing to donate without payment (n=663), 7% stated they would not consider donating for $10,000 and 2% would not consider donating for $100,000.

Subgroup Analyses for Members of the Public

When acceptability of the strategies for both deceased and living donors were examined by baseline income (<$60,000 and >$60,000), we noted differences in the preferred type of financial incentive. Forty-nine percent of those with lower income found a monetary payment to living donors acceptable compared with 44% of those with higher income (P=0.03). Conversely, 45% of those with higher income found a tax break for living donation acceptable compared with 34% of those with lower income (P<0.001). The likelihood of donating for payment also varied by income; among those who were unsure or were not willing to donate at baseline, 67% of those with a household income <$60,000 were willing to consider donating to a relative for a payment of $10,000 compared with 74% of those with a household income >$60,000 (P=0.01). The same trend was noted for a payment of $100,000, with 70% of those with a household income <$60,000 being willing to consider donating to a relative compared with 78% of those with a household income >$60,000 (P=0.01).

Discussion

Our study shows that the public, health professionals, and people affected by kidney disease view some regulated financial incentives for both living and deceased donors to be acceptable. Further, our survey suggests that the public may be more willing to donate while alive for monetary gain, potentially increasing the pool of potential kidney donors.
donors, if the public’s stated views translate into a behavior change.

Although there was strong support for deceased donation, along with the reimbursement of funeral expenses and tax breaks as financial incentives for deceased donation, the public was generally unaware of and appeared unmotivated by deceased-donor registries as an incentive to increase deceased donation. Being aware of donation and finding alternative means to increase awareness (and thereby the potential pool of deceased donors) are imperative because current campaigns and registries do not appear to be having the desired effect—living and deceased donation rates have been stagnant in Canada over the last few years (3). All groups supported the reimbursement of expense and lost wages for living donors, which is consistent with current policy in most provinces, and there was consistent support among the three groups in acceptability of a tax break to a person after the kidney has been removed. There were differences, however, in acceptability of monetary payment for living donors by group, but not the value for financial incentives. The majority of public respondents felt that a value >$10,000 was acceptable; however, the health professionals generally felt that monetary payment as a strategy to increase donation was not acceptable, regardless of the amount. As such, it appears that it is not necessarily the magnitude of the financial incentive but the type of financial incentive that varies in acceptability.

When examining whether the use of monetary payment would change the willingness of the public to donate, we found the percentage of those previously unwilling to consider donation who would donate for monetary gain was higher than the percentage of those who would no longer consider donating for monetary gain, resulting in a net effect of more potential donors when presented with monetary gain. The resistance to consider living donation or the loss of potential donors, despite a monetary payment, could reflect people who would not donate under any circumstances or are put off by the offer of money to donate. Barriers to living donation have been examined previously, and financial disincentives are but one barrier noted. Increasing the pool of potential living kidney donors may require use of several incentives, including financial ones, to maximize the pool of potential donors. Further, careful evaluation on the impact of all potential donors would need to be considered during a pilot of such a program.

Our results echo the findings of previous surveys, including a few done in the United States, which have noted that financial incentives could increase the proportion of nondonors who would be willing to donate, while living or deceased, when an incentive is offered (15,16,18,21,22,24,29). Similar to our study, these studies have noted that the majority of the public views many of the financial incentives as acceptable, whereas health professionals working in the field of transplantation and nephrology are much less supportive. Surveyed health professionals in transplantation have suggested previously that providing incentives to the family or potential donor may increase the number of potential donors (20,27) and found similar support for financial incentives similar to those studied here (28). The lack of acceptability of certain financial incentives, notably monetary payment, by health professionals may stem from their comfort level in discussing donation with families once financial incentives are offered (33) or their perceived “moral inappropriateness” of offering cash (20). Further, it is interesting to note that whereas a tax credit is akin to monetary payment in terms of value in this survey, there were notable differences in preferences for the two forms of financial incentives across the different groups.

Proponents of incentives point to the long-standing and successful practices of payment for blood, blood products, sperm, and oocytes (34,35). One theory states that incentives alone may not motivate donations but may tip the balance by lowering perceived societal costs (perceived barriers to donation) (35), acting as a prompt for those who are inclined to donate but have not taken action (36). In oocyte donation, donors cite both altruism and financial compensation as reasons to donate (34), and assuming that incentives obliterate all altruistic motives is undoubtedly too simple a picture for human behavior (37). Altruism can be defined as “the doctrine that each of us has a special obligation to benefit others” (38) and supports the current organ donation system of volunteers, or exhortation, where potential donors are urged to donate. Given the plateau of donation rates, further increases in the supply of kidneys in the current system are unlikely. Financial incentives may be one strategy to appeal to those who don’t respond to exhortation such as they proceed with organ donation.

Opponents of incentives argue that a system with financial incentives will replace all intrinsic motivation with material motivation (35), challenges ethical constructs of the commodification of the human body (39), and is potentially exploitive (37,40). Although it is not possible to determine through a survey whether incentives will exploit the poor, the results herein are consistent with those of other studies (19) and indicate that persons in lower-income households are less willing to consider donating for $10,000 or $100,000 compared with those in higher-income households. A system of financial incentives where the government is the payer (as outlined in our survey) might not discriminate against the poor given that it is available to everyone equally, on both the supply and the demand side, unlike a market in which only those with more disposable money can afford a kidney. It is speculative to predict exactly how potential donors will react to financial incentives and whether incentives will bring forward a new pool of potential donors, or conversely, whether any potential backlash would limit the current pool of donors stepping forward. Although not all potential donors may respond to monetary payment, we believe that on the basis of these results, the public finds financial incentives acceptable enough to proceed with a pilot trial. This pilot trial, in addition to determining the extent to which monetary payment brings forth potential donors, needs to formally assess the reaction of the public to such a program more broadly.

Our study has limitations. Because the survey was distributed electronically, it was limited to those with access to a computer and the Internet, although the anonymous nature of responding may avoid any social desirability bias (41). The electronic nature of the survey might not
bias the results of health professionals, but it may limit the generalizability of the responses from the public and those affected by kidney disease. However, our sample of the public reflected the Canadian general population as identified through census data, including education and employment status. It is possible that because of the lower response rate of the health professionals, our sample may not be entirely representative of the broader group of health professionals. We recognize that the results reflected in this study do not measure actual changes in behavior: that hypothetical willingness to donate may not translate later to real decisions, and donations may not increase with financial incentives. This may be truer in the case of payment to living donors because it involves a risk to the individual, and it is not known how surveys can predict behavior change where risk is involved. Further work needs to be done to clarify the unacceptability of financial incentives among health professionals, as they are a key stakeholder in the organ donation process. Engaging them in the process should financial incentives be incorporated into the organ donation system is critical. In the interim, these results can inform health professionals that financial incentives do not appear to deter the public in their willingness to donate, which may alleviate some of their discomfort.

Much of the focus in discussions of financial incentives for organ donation has been directed to ethical implications and speculation of impact on current practices. Our intent in this study was to examine the acceptability of the various financial incentives from the perspective of the public, health professionals, and people affected by kidney disease. Our findings demonstrate that the acceptability of financial incentives to increase the number of deceased and living donors differs for the public, health professionals, and people affected by kidney disease, with the majority of the public seeing financial incentives as largely acceptable. Future research in this area should focus on the determination of the impact, effectiveness, and cost-effectiveness of financial incentives on donation rates.

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Disclosures
None.

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# Sampling frame for questionnaire

<table>
<thead>
<tr>
<th>Group, as defined in questionnaire</th>
<th>Identified through</th>
<th>Made up of</th>
<th>Mission statement</th>
<th>How many members at time of questionnaire</th>
<th>Sampling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health professionals</td>
<td><strong>Canadian Society of Transplantation (CST)</strong></td>
<td>Health professionals in transplant</td>
<td>Organization of professionals dedicated to leading, advancing, and advocating for patient care, research, and education in donation and transplantation in Canada.</td>
<td>720</td>
<td>Questionnaire distributed electronically over a one month period. Two reminders, sent 10 days apart, were sent as well.</td>
</tr>
<tr>
<td></td>
<td><strong>Canadian Society of Nephrology (CSN)</strong></td>
<td>Health professionals in nephrology</td>
<td>A society of physicians and scientists specializing in the care of people with kidney disease, and in research related to the kidney and kidney disease.</td>
<td>350</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Canadian Association of Nephrology Nurses &amp; Technologists (CANNT)</strong></td>
<td>Nurses and technologists in nephrology</td>
<td>To provide leadership and promote the best nephrology care and practice through education, research, and communication.</td>
<td>400</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Canadian Critical Care Society (CCCS)</strong></td>
<td>Health professionals in critical care</td>
<td>To promote and enhance critical care medicine in Canada.</td>
<td>300</td>
<td></td>
</tr>
<tr>
<td>People affected by kidney disease</td>
<td><strong>Kidney Foundation of Canada</strong></td>
<td>People with or affected by kidney disease – individuals living with kidney disease, donors, recipients, and family members or friends or the above</td>
<td>The Kidney Foundation of Canada is people working together for a common cause. We are volunteers, individuals living with kidney disease, donors, and staff — from all walks of life, all across Canada.</td>
<td>Not available</td>
<td>Questionnaire link placed on Kidney Foundation of Canada website and Facebook page for a period of one month.</td>
</tr>
</tbody>
</table>
Full version of questionnaire

You are being invited to participate in a research study that is gathering information about possible strategies to increase kidney donation, from both living and deceased donors. Your responses in this study will be used anonymously to help us understand which strategies merit further examination, in order to increase living and deceased kidney donation for people with kidney failure.

Participating in this study means completing a one-time survey that should take you less than 10 minutes. Participation in this study is voluntary. There are no risks, nor benefits, to you for participating in this study. Please be assured that all information you provide will be kept strictly confidential. When completing this survey, it is important that you give us YOUR opinion. Not that of another person, or what you think we might want to read.

Your decision to now click on the “next” button below, and to complete the survey will be interpreted as an indication of your agreement to participate. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the survey at any time by simply closing your browser window.

If you have further questions concerning matters related to this research, please contact:

Dr. Braden Manns or Dr. Lianne Barnieh
(403) 955-2595

*If you have any questions concerning your rights as a possible participant in this research, please contact the Ethics Research Officer of the University of Calgary, at (403) 220-3782.*

*The University of Calgary Conjoint Health Research Ethics Board has approved this research study.*

Instructions for the survey
It is important to realize that there are no RIGHT or WRONG answers. We are only asking YOUR personal opinion. Your responses will be looked at anonymously once all surveys have been completed.
Kidney Transplantation

People with complete kidney failure can be treated with dialysis or kidney transplantation. As there are not enough kidneys from donors, most people with kidney failure are treated with dialysis, where toxins are removed from patients by cleaning their blood. The need for kidneys for transplantation is increasing, and currently, most patients who are eligible for a transplant wait over 5 years for a kidney. Compared with staying on dialysis, kidney transplantation provides patients a better quality of life and improves their chances of survival, and also is less costly to the health care system. Dialysis, the only alternative for patients with complete kidney failure, costs the health system up to $80,000 per year, while transplant has an initial cost of just over $100,000 and maintenance costs of around $15,000 per year.

There are two types of kidney transplants: those received from a person who has died (deceased) and those received from a person who is alive (living). In a deceased kidney transplant, patients on the transplant wait list receive a kidney from an unrelated person who has died, often from an accident of some type. In a living kidney transplant, healthy individuals can undergo an operation to remove one of their kidneys to transplant into another person with kidney failure.
Strategies to increase organs for transplantation after death

Deceased donors are people who donate their organs after death, usually resulting from a serious accident or brain injury, after all other life saving measures have failed. Currently, in Canada, people are encouraged to discuss their wishes for organ donation with their loved ones, especially those responsible for making decisions on their behalf after death. However, many people who could be organ donors do not make their wishes known to their next of kin, and do not end up donating their organs after death. This could be due to many reasons, including lack of awareness, lack of motivation, or conflict with beliefs.

After a person has died, the family has the final say over whether or not the organs are used for transplantation. Several strategies have been suggested to increase kidneys from deceased donors. These strategies include covering the cost of funeral expenses, or providing money to a donor’s estate, among others.

We wish to determine which, if any or all, of the strategies you would find acceptable.
D1. Would you donate your organs after death?

Please select one response only

Yes
No
Not sure

D1B. Have you made your wishes known to your next of kin about your decision to/not to donate your organs after death?

Please select one response only

Yes
No

D2. The following types of strategies to increase deceased donor kidneys have been proposed. Which do you find acceptable?

Please select all that apply

- Reimbursement of funeral expenses (paid directly to the funeral home) by government or non-profit organization
- Government tax break or credit to the donor’s estate
- Monetary payment (cash) provided by the government to the donor’s estate
- Not sure [SINGLE PUNCH]
- I do not think any of these strategies are acceptable [SINGLE PUNCH]

[IF NOT SURE SELECTED IN D2, SKIP TO D5]

[ASK D2B IF I DO NOT THINK ANY OF THESE STRATEGIES ARE ACCEPTABLE SELECTED IN D2]

D2B. Why don’t you think any of these strategies are acceptable?

Please select all that apply

- I feel that the donor’s family should not benefit from deceased donation
- I feel that giving a kidney should not involve any exchange of money
- I feel that giving a kidney should be done from the goodness of your heart
- Other reason (please specify) [JUMP TO SECTION B]
[ASK D3 IF GOVERNMENT TAX BREAK OR CREDIT TO THE DONOR’S ESTATE SELECTED IN D2]

D3. What do you think is a reasonable amount for a government tax break to the donor’s estate as a strategy to increase deceased donor kidneys?

*Please select the response that corresponds to the range*

- $0
- $2,000
- $4,000
- $6,000
- $8,000
- $10,000
- $20,000
- $50,000
- $100,000

[ASK D4 IF MONETARY GIFT SELECTED IN D2]

D4. What do you think is a reasonable amount for a monetary payment provided by the government to the donor’s estate as a strategy to increase deceased donor kidneys?

*Please select the response that corresponds to the range*

- $0
- $2,000
- $4,000
- $6,000
- $8,000
- $10,000
- $20,000
- $50,000
- $100,000

D5. Some provinces have organ donor registries where people can sign up, indicating that they would be willing to donate their organs in the case of unexpected death (please note that indicating your wishes on your driver’s license is NOT part of an organ registry). If such a registry is in your area, have you registered your wishes with any government organization about donating your organs?

*Please select one response only*

- Yes
- No
- Not aware of registry

[IF YES AT D5, SKIP TO LIVING DONATION INFORMATION SCREEN. IF NO OR NOT AWARE CONTINUE WITH D6.]

D6. If a national government registry were created, would you register your wishes now about donating your organs after death, knowing that this decision could NOT be reversed by your family member or friends?
Please select one response only

Yes
No

[IF YES AT D6, SKIP TO LIVING DONATION INFORMATION SCREEN. IF NO, CONTINUE WITH D7.]

D7. Imagine that this same government registry would pay you a small amount (<$100) to register your wishes now about donating your organs after death, knowing that this decision could NOT be reversed by your family member or friends. Would you register your wishes about donating your organs?

Please select one response only

Yes
No

[CONTINUE WITH D7B IF NO AT D7, ELSE SKIP TO D8]

D7B. Why wouldn't you register your decision about deceased donation, ?

Please select all that apply

It is not acceptable for a government organization to pay people to register
It is a private matter between myself and my family members or friends
I’m not sure what decision I would want to register
I would like the option that my decision could be changed by my family member or friends
Other reason (please specify)

[SKIP TO LIVING DONATION INFORMATION SCREEN]

[ASK D8 ONLY IF YES AT D7]

D8. What do you think is a reasonable amount of money provided by the government for registering your decision to donate?

Please select one response only

Up to $10
Up to $20
Up to $50
Up to $100
Other (please specify)
Strategies to increase kidneys for transplantation from living persons

People are born with two kidneys, and people can live normal, healthy lives with only one kidney. In living kidney donation, healthy individuals can choose to donate one of their kidneys to someone with kidney failure. They can donate their kidney to family members, friends, acquaintances, or someone they don’t know. All living donors go through a careful screening process to ensure that they are healthy enough to go through surgery and live with one kidney. There is, as with all operations, a small risk associated with the surgery itself, though donors usually leave the hospital within one week of the surgery. After about two to three months, donors get back to their normal lives.

Several strategies have been suggested to remove financial barriers or disincentives that can arise from donating a kidney. These strategies can vary from reimbursing costs that living donors experience during the donation process, to reimbursing for lost income. Of course, these strategies would only be considered for people who have considered or support donating a kidney while they are alive.

Monetary incentives (payment) are another strategy to influence the number of kidneys available for transplantation.

We wish to determine which, if any or all, of these strategies you would find acceptable.
L1. Would you ever consider donating one of your kidneys while alive (becoming a living kidney donor)?

Please select one response only

Yes
No
I would like to donate but am not healthy
Yes, I have already donated
Unsure

[CONTINUE WITH L2 IF YES AT L1, ELSE SKIP TO L3]

L2. Would you consider donating one of your kidneys to...?

Please select all that apply

A Relative
A Friend
An Acquaintance
Someone you don't know on the waiting list
Other (Please specify)

L3. Living donors, throughout the evaluation process and surgery, incur costs that include travel, accommodation and time off work. The following are strategies to reimburse these costs to living donors. Which strategy/strategies would you find acceptable?

Please select all that apply

Reimbursement of all expenses related to the donation (travel, accommodation, parking)
Reimbursement of some of the expenses related to the donation (travel, accommodation, parking)
Reimbursement of all lost wages, regardless of income (about two to three months of work)
Reimbursement of some of the lost wages
Not sure [SINGLE PUNCH]
None of these strategies are acceptable [SINGLE PUNCH]

[CONTINUE WITH L3B IF NONE OF THESE STRATEGIES SELECTED IN L3, ELSE SKIP TO L4]

L3B. Why don’t you support any of these strategies for living donation?

Please select all that apply
I feel that donation should not involve any exchange of money
I feel that donation should be done from the goodness of your heart
Other reason (please specify)

L4. The following refer to strategies which provide money to people in exchange for a kidney that will be used for transplantation. This is different from reimbursing donor expenses in the previous question since additional money is provided beyond expenses. Which strategies would you find acceptable?

Please select all that apply

Government tax break or credit to the person after the kidney has been removed.
Money provided directly to the person after the kidney has been removed (provided by government directly, or through a non-profit organization)
Not sure [SINGLE PUNCH]
None of these strategies are acceptable [SINGLE PUNCH]

[CONTINUE WITH L4B IF NONE OF THESE STRATEGIES SELECTED IN L4. SKIP TO L5 IF GOVERNMENT TAX BREAK OR MONEY PROVIDED DIRECTLY SELECTED IN L4. SKIP TO L6 IF NOT SURE IN L4.]

L4B. Why don’t you support any of these strategies for payment in exchange for a kidney?

Please select all that apply

I feel that people should not benefit from giving a kidney.
I feel that giving a kidney should not involve any exchange of money
I feel that giving a kidney should be done from the goodness of your heart
Other reason (please specify)

[SKIP TO L6]

L5. What do you think is a reasonable maximum value for the previous strategy/strategies?

Please select the response that corresponds to the range

$0 ----$10,000----$20,000----$30,000----$40,000----$50,000----$75,000----$100,000----$150,000

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
L6. Imagine that a new government program was put in place and, in an effort to save lives and costs, offered you $10,000 in exchange for one of your kidneys. In this situation, would you now consider giving one of your kidneys to...?

Please select all that apply

A Relative
A Friend
An Acquaintance
Someone you don't know on the waiting list
I would not give [SINGLE PUNCH]

L7. Imagine that this same government program decided that the amount should be higher and that you would receive $100,000 in exchange for one of your kidneys. In this situation, would you give one of your kidneys to...?

Please select all that apply

A Relative
A Friend
An Acquaintance
Someone you don't know on the waiting list
I would consider giving if the amount was greater (Please specify amount: $ ) [SINGLE PUNCH]
I would not give [SINGLE PUNCH]

[ASK L8 IF I WOULD NOT DONATE AT L7, ELSE SKIP TO DEMOGRAPHICS]

L8. Why wouldn't you give your kidney?

Please select all that apply

I feel that donors and/or their families should not benefit from living donation
I feel that donation should not involve any exchange of money
I feel that donation should be done from the goodness of your heart
Other reason (Please specify)
[Demographics]

S1. I am...
Male
Female

S2. I am aged...
18-30
31-39
40-49
50-59
60 and over

S3. I am a ...

*Please select the one you most closely identify with*

Patient with kidney disease, on dialysis
Patient with kidney disease, not on dialysis
Recipient of a deceased donor kidney
Recipient of a living donor kidney
Kidney donor
Family member or friend of someone with kidney disease
Family member or friend of someone with a kidney transplant
Family member or friend of someone who gave a kidney
None of the above

DM1. What is the highest level of education you have attained?

*Please select one response only*

Grade school or some high school
High school diploma
Post-secondary technical school
Some college or university
College degree or diploma
University undergraduate degree
University graduate degree
Prefer not to answer
DM2. Which of the following best describes your employment status?

*Please select one response only*

- Working full time (35 hours a week or more)
- Working part time (less than 35 hours a week)
- Student
- Homemaker
- Retired
- Unemployed
- Other
- Prefer not to answer

DM3. What is your current marital status?

*Please select one response only*

- Married or living together with someone
- Widowed
- Separated or divorced
- Single/never married
- Prefer not to answer

DM4. Are you...?

*Please select all that apply*

- Caucasian
- First Nations
- Asian/Indian
- Other
- Prefer not to answer

DM5. What was the total income for all members from all sources in your household before taxes and deductions in 2010 (in Canadian dollars)?

*Please select one response only*

- Less than $29,999
$30,000 – $59,999
$60,000 – $89,999
$90,000 – $119,999
$120,000 or more
Unable to assess/prefer not to answer
DM6. Which of the following provinces do you live in?
Newfoundland and Labrador
Prince Edward Island
Nova Scotia
New Brunswick
Quebec
Ontario
Manitoba
Saskatchewan
Alberta
British Columbia
Yukon Territory
Northwest Territories
Nunavut