

## Sampling frame for questionnaire

Group, as defined in questionnaire	Identified through	Made up of	Mission statement	How many members at time of questionnaire	Sampling
Health professionals	Canadian Society of Transplantation (CST)	Health professionals in transplant	Organization of professionals dedicated to leading, advancing, and advocating for patient care, research, and education in donation and transplantation in Canada.	720	Questionnaire distributed electronically over a one month period. Two reminders, sent 10 days apart, were sent as well.
	Canadian Society of Nephrology (CSN)	Health professionals in nephrology	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.	350	
	Canadian Association of Nephrology Nurses & Technologists (CANNT)	Nurses and technologists in nephrology	To provide leadership and promote the best nephrology care and practice through education, research, and communication.	400	
	Canadian Critical Care Society (CCCS)	Health professionals in critical care	To promote and enhance critical care medicine in Canada.	300	
People affected by kidney disease	Kidney Foundation of Canada	People with or affected by kidney disease – individuals living with kidney disease, donors, recipients, and family members or friends or the above	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.	Not available	Questionnaire link placed on Kidney Foundation of Canada website and Facebook page for a period of one month.

## 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

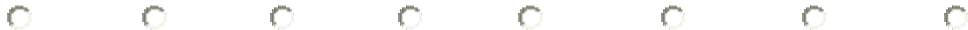


**[ASK D4 IF MONETARY GIFT SELECTED IN D2]**

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*

Other reason (please specify)

*Please select all that apply*

None of these strategies are acceptable [SINGLE PUNCH]

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

Please select all that apply

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

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**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