

**GIVING THE GIFT OF LIFE: INCREASING CANADA'S
ORGAN DONATION RATE**

by

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Abstract

Canada has one of lowest rates of organ donation among the industrialized nations. Through an analysis of the knowledge, attitudes, and perceptions of people living in Canada, this study examines effective ways to increase rates of organ donation in Canada, using a policy analysis approach to address the problem of low organ donation rates. A survey completed by 155 people over the age of 19 and living in Canada reveals potential gaps in people's understanding of the consent process in each jurisdiction and reveals factors that contribute to one's willingness to donate an organ. A study of policies legislated or endorsed in other jurisdictions contributes to the analysis by identifying potential policy strategies to consider in Canada. The study proposes a three-pronged national strategy to fill in the understanding gap and increase organ donor rates.

Keywords: Organ donation – Canada; Donor consent; Presumed consent; Donor rates; Spanish Model.

Executive Summary

Canada is falling behind other industrialized nations with respect to the number of available donors to meet the needs of those on transplant waiting lists; it has one of the lowest rates of donation among these nations. This study utilizes a policy analysis approach to explore options for increasing organ donation rates in Canada. It endorses a three-pronged strategy with short-, medium- and long-term goals which, when implemented in stages, will

- Improve Canada's wait list process;
- Increase the public's awareness about the organ donation and how to give consent; and
- Shift the current system toward adoption of a national framework with presumed consent combined with a strong hospital centric focus on working with potential donors (the "Spanish Model)."

The primary source of information is a web survey of 155 people over the age of 19 years, living in Canada. I drew the sample from members of the public using a "snowballing" technique. The survey addressed six key issues and concerns about organ donation: 1) general organ donation attitudes; 2) living donation; 3) attitudes toward presumed consent; 4) attitudes toward financial issues; 5) beliefs about organ and tissue donation; and 6) sources of information about organ and tissue donation. The aims of the survey were to design a profile of the typical Canadian donor or potential donor; explicitly test consent options not available in Canada; and determine the impact that sources and perceptions have on the knowledge and attitudes about organ donation of people in Canada. Analysis of the survey results netted seven conclusions:

- Those sampled for this survey express high rates of support for organ donation in general, but far fewer participated in consent activities than indicated by the level of support.
- Demographic and geographical considerations are important in understanding the typical profile of someone consenting to organ donation in Canada.
- Donor rates may be impeded by a lack of knowledge about the consent process in each province.
- There is a reluctance to discuss organ donation with family members. The role of family in the consent process appears poorly understood and may impede donations.
- Experience with living donation, as well as personal blood donations tend to increase the likelihood of consenting to be an organ donor after death.

- Those sampled indicated that they are open to the possibility of a public discourse that includes significant changes to the current regime (i.e. presumed consent, forms of compensation) in order to increase donation rates.
- Those surveyed present a sufficient understanding to counter misconceptions about organ donation.
- The more personal a source of information is, the more the information creates awareness of organ donation issues and influences decision making about organ donation.

A literature review supplemented the analysis by exploring alternative options to the status quo in Canada. I focus on four countries with some of the highest donor rates in the world: Spain, United States, the Netherlands and Norway. I assess four policy options to determine what impact they may have on increasing the organ donor rate in this country:

- The status quo option, which is made up of an informed consent model (opting in as a donor), across 13 separate, non-uniform jurisdictions, while Canadian Blood Services works on developing a national wait-list and donor registry.
- A strengthened education strategy that targets the public with an intensive campaign designed to improve knowledge about the consent process. This strategy must also be flexible and adaptable in order to target groups such as visible minorities and Aboriginals, whose donor rates are lower than the national rates.
- Explore compensation programs that provide assistance to live donors by compensating them for the indirect costs associated with the decision to donate an organ (i.e. lost wages, childcare, etc.) and may involve the offer of a modest contribution toward funeral expenses or a charitable organization.
- Adoption of the “Spanish Model”, which combines a policy of presumed consent with a strong hospital-centric focus for obtaining consent from potential donors or their families.

This study concludes that:

- Canada must move more quickly to adopt a registry similar to the one successfully operating in the United States;
- A comprehensive education strategy with public input forums is necessary to strengthen knowledge and dialogue about organ donation;
- Canada should take steps toward the adoption of the “Spanish Model” by making changes to its legal and administrative framework.

Dedication

To my parents, who didn't always understand my journey, but who did their best to support me through it. You raised me to understand the importance of giving the gift of life. All the work will pay off, though perhaps not in ways you ever expected, I promise.

To Rodney Chudyk, for giving up life as you knew it to follow me on this crazy journey. May your future be bright, no matter where it takes you. In Rod We....Trust.

To my brothers and sister. To Karyne; you always told me I could be more if I'd only believe in myself, and your encouragement got me through all my highs and lows. Thank you, big sister, for your encouragement. To Daryl; have hope.

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Glossary

F/P/T Federal/Provincial/Territorial

PMP Per Million Participants

CBS Canadian Blood Services

ONT Organización Nacional de Trasplantes

1: Introduction: Defining the Problem

In Margaret Lock's anthropological study of organ donation, Twice Dead: Organ Transplants and the Reinvention of Death, she presents the difficulties...intrinsic reciprocity has when the gift is not one of food or jewelry, but the "gift of life" itself. – Eric Michael Johnson

Canadians hope they never are in the position of being so ill that they need an organ transplant; but they hope that if they are in that position, an organ donor will be found, saving their lives. And why not be optimistic about the possibility of a match? Canada has a proven track record of success in the field of transplantation, and is the site of pioneering efforts for improving the medical and technical aspects of transplantation; and yet the media reports that Canada is falling behind other industrialized nations with respect to the number of available donors to meet the needs of those on transplant waiting lists. According to one example, the April 7, 2008 edition of the Edmonton Journal¹, Canada's organ donation rate is among the lowest in the world. The article lays out the plain numbers: for *deceased* donors, the Canadian donor rate was 13 people per million (pmp), compared to 20 per million in the United States, and a world-leading 31 per million in Spain for 2008.

Organ and tissue donation in Canada is a topic that contributes to a variety of public policy problems in the health and medical ethics fields; whatever progress made in improving and streamlining the process of transplantation through medical and technological achievements to decrease waitlist times is cancelled out by the low donor rate in Canada.

Knowing there are wider implications to a low donation rate, the problem is: how can Canada improve organ donation rates, given the challenges presented by the legal and

¹ *Canada's organ-donation rate among world's worst*, The Edmonton Journal, April 7, 2008

jurisdictional framework, professional acceptability, and public knowledge and perceptions? This study analyzes related literature, as well as the results of a survey I conducted to determine a set of recommendations designed to lead to an increase in organ donation rates.

This study aims at understanding the problem from the perspective of the Canadian general public. A study of the knowledge, attitudes and beliefs of Canadians when it comes to making the personal decision of becoming an organ donor is key to understanding what steps can be taken to increase Canada's donor rates, thus decreasing time spent on waitlists for those in need, and improving health outcomes.

2: Background: Why Donor Rates are Low

My study focuses on the supply side of the equation. The demand side (those in need of an organ donation) is a challenge to policy-makers because it deals with biological and medical issues that cannot necessarily be dealt with using policy instruments. The need for an organ transplant may be the result of a medical condition that is genetic in nature or preventable. It is true that some avoidable conditions can be the result of behaviours and lifestyle choices, however such policy issues would be topics other research projects. The supply side of the equation is where the constraint is located in improving donation rates.

Well over 4000 people across Canada are on a waiting list for an organ; nearly 7% die before a match can be found. Kidneys top the list of organs most needed for transplant – in British Columbia alone, 225 people are on the waiting list for a kidney; the next organ needed the most is the liver, with 29 people waiting (BC Transplant Society, 2009). The case for kidneys is particularly noteworthy because it is something of a ‘surplus’ organ; nearly everyone has two functioning kidneys, and generally can function quite safely with one. Table 2.1 provides a snapshot of what the situation looks like in four jurisdictions across Canada:

Table 2.1 A Snapshot of kidney waitlist rates in Canada, 2008-2009

Place	Year	Waitlist for kidney	Waitlist for kidney-pancreas combination	Source
British Columbia	2009	225		BC Transplant Society, 2009.
Ontario	2009	1192	45	Trillium Gift of Life Network, 2009.
Quebec	2008	866	27	Québec-Transplant, 2009.
New Brunswick	2008	56	1	MOTP, 2009.

The issue of successful transplantation is complicated by the fact that success depends on obtaining the best and closest blood and tissue match between donor and recipient in order to avoid rejection by the recipient's body. The low donor rate decreases the pool from which to draw the best match possible. The policy challenge facing decision makers in Canada is that there are too few kidney donors in Canada to meet the demand. For those individuals in need, a transplant becomes a matter of survival, and there are quality of life issues attached to being on a waitlist for a lengthy period of time; the health of the patient typically deteriorates the longer they wait.

Looking at the matter from a financial perspective, long waits typically cause household financial burdens. Klarenbach, Garg and Vlaicu (2006) argue that direct and indirect costs of being on a waitlist can be substantial. In addition to the direct costs incurred by some families (e.g. telephone charges, etc.), households with a member on a waitlist are also affected by the lost or impaired ability to work or engage in leisure activities, lost income and diminished household productivity (such as domestic maintenance and chores), as well as the emotional stress of dealing with the prognosis of their loved one.

There are also economic factors to consider when addressing the issue of organ transplants. The costs of transplantation are significantly lower than the costs of keeping a patient

on dialysis, or other necessary maintenance treatments, so this issue also affects the ability of the healthcare system to manage its resources better.

In this chapter, I provide a snapshot of Canada's position in the world and identify systemic barriers that have impeded progress.

2.1 Canada versus the World

In 2009, the Council of Europe presented its annual newsletter, 'International Figures on Organ Donation and Transplantation'; an assessment of the donation rates of countries in Europe, the Americas, Australia and New Zealand for 2008. Data is not available for Asia, Africa and Oceania. The report laid out the rates by country, categorized by type of donation (living, cadaveric) and type of organ or organ combination. The combination focused on in this analysis is *all combinations* (living and deceased) of kidney donation rates (number of organs per million population, pmp). The results spelled out the fact that Canada at 36.2 pmp² (a drop from 37.2 in 2007) falls far behind overall world leaders, Norway (58.1 pmp), and the United States (54.4 pmp)³:

² This figure differs from the figure provided by the media (Edmonton Journal) because the Council of Europe figure is the total of both living and cadaveric donations, whereas the media piece reflects only the cadaveric donations – likely to highlight how Canada is lagging significantly when it comes to that measure.

³ It should be noted that David Baxter of the Urban Futures Institute tried in 2001 to defend Canada's low donor rate as being the result of different methods of counting organ donors: he argued that countries such as Spain and the United States, world leaders in organ donor rates were inflating their numbers by counting "Potential" donors (those cases where a donor is identified, but a transplant may not have occurred), whereas Canada only reported "Actual" donors (those cases where at least one organ was donated). The problem with Baxter's argument is that it only counts actual instances of donation, and does not account for the *need* for a larger pool of donors to match the needs of recipients. The only way to determine if the pool can be capable of meeting the needs is to measure "potential" donors.

Table 2.2 Global kidney donation rates (Living and Deceased donors), 2008

Rank	Country	Donation Rate (pmp)
1	Norway	58.1
2	United States	54.4
3	Portugal	49.9
4	Spain	48.3
5	Netherlands	46.5
6	Belgium	45.7
7	Sweden	45.5
8	France	45.4
9	Estonia	43.8
10	Austria	43.3
11	United Kingdom	38.2
12	Switzerland	38
13	Uruguay	36.7
14	Australia	36.3
15	Canada	36.2

Source: Council of Europe (2009).

2.1.1 Canada versus the World - Policies

A key question to ask when trying to decipher the numbers is what policies are in place around the world that contribute to a donor rate higher than Canada. I explore the following factors:

- How active a government is in promoting or enforcing policies that increase donor rates;
- The public acceptability of policies;
- The default setting for a particular policy set to enhance organ donation.

2.2 Challenges to improvement of donation rates

General literature on the subject of organ donation rates identifies four key challenges to improving organ donor or transplantation rates:

1. Medical barriers: these are barriers involving issues about tissue and type matching, suitable candidates for donations, and the time constraint involved in taking organs from deceased donors.
2. Federal and Provincial Legal frameworks: federal regulations such as the *Safety of Human Cells, Tissues and Organs for Transplantation Regulations (2008)* enacted under the *Food and Drugs Act*, as well as the provincial and territorial laws are uniformly prohibitive in allowing the possibility of some potential policy options (i.e. compensation for donation). (See Klarenbach, Garg & Vlaicu, 2006)
3. Acceptability of policies among health care workers and transplant organizations: in November 2009, the British Columbia Transplant Society, a leading transplant support service in Canada, was cited as being against at least one major policy alternative that might increase donor rates. (See Oz, et. al., 2003; BCTS, 2009)
4. Public knowledge and perceptions: an informal survey of the ‘frequently asked questions’ portions of websites involving organ donation organizations reveals that one of the main challenges to increasing organ donation rates is the knowledge and perception about the issue among those living in Canada. These can take the form of religious, ethical, medical, social, and familial concerns that impede understanding of organ donation. (See Sanner, 1994)

Of these four challenges, only the first, potential medical barriers, cannot be considered through the policy lens, as these are issues relating to the finite physical implications of transplantation,

such as tissue type problems, or the donor's having medical conditions that would endanger the recipient should they receive an organ from that donor. I address the role of the legal framework, professional acceptability, and public knowledge and perceptions in explaining Canada's low donation rate.

2.2.1 Legal Framework

The legal framework in Canada is complex; 14 different jurisdictions have enacted regulations and laws to govern the legality and propriety of acts related to organ donation and transplantation. The federal regulations, managed by Health Canada, set out the standards for organ and tissue donation and transplantation; they reference the Canada General Standard, which dictates the regulations and places exclusions on the type of person who may donate, according to health concerns or conditions. These concerns or conditions are:

- Death from unknown causes
- Infection with a Prion disease or encephalitis
- Affliction with Dementia
- Infection with, *or a high risk of infection with*, HIV, viral hepatitis and rabies.

The final concern, involving those with a high risk of infection with HIV and viral hepatitis (primarily Hepatitis B and C) is expanded upon in an annex to the Standard, by listing the following exclusionary criteria:

- men who have had sex with men in the preceding five years;
- persons who have used intravenous, intramuscular or subcutaneous drugs in the preceding five years;
- persons with hemophilia who have received clotting factor concentrates;

- persons who have traded sex for money or drugs in the preceding five years;
- persons who have had sex in the past year with someone described in the above categories;
- persons who have been directly exposed in the preceding year to known or suspected HIV, HBV or HCV-infected blood;
- current inmates or individuals who have been incarcerated for 72 consecutive hours in the preceding year;
- persons who, within the preceding year, have undergone tattooing, ear or body piercing with shared instruments; and
- persons who have had close contact within the preceding year with another person having clinically active hepatitis.

However, section 40 of the regulations permits the use of organs and tissues from donors falling into the categories of risk in cases where it is judged as acceptable by the transplanting physician and with the informed consent of the recipient. According to Health Canada, “[t]his provision was included because of the often life-and-death circumstances that make transplantation essential, and the limited number of donors available.” (2009)

All provinces and territories have enacted or updated legislation that falls in line with the *Uniform Tissue Donation Act (1989)*. All jurisdictions prohibit direct compensation for organ donation, and do not have clear laws or guidelines laid out to address indirect compensation, a potential policy option that is discussed by medical ethicists, policy makers and academics in the literature. As an example, s. 10 of the British Columbia *Human Tissue Gift Act (1996)* states:

“A person must not buy, sell or otherwise deal in, directly or indirectly, for a valuable consideration, any tissue for a transplant, or any body or parts other than blood or a blood constituent, for therapeutic purposes, medical education or scientific research.”

There are provisions that may or may not be enshrined in provincial law, which allow donors to receive assistance for some expenses related to live donations (e.g., travel expenses, access to federal EI assistance for short term disability, etc.), however the provisions are not the same across all jurisdictions. As Klarenbach, Garg and Vlaicu (2006) point out,

“Currently Canada does not have a national unified strategy to reimburse living organ donors...Current federal initiatives include employment insurance and short-term disability as well as the tax credit for medical expenses. Provincial initiatives include coverage for medical services, limited travel coverage in some provinces (Newfoundland and Labrador, New Brunswick, Prince Edward Island and northern Ontario) and paid-leave programs (Saskatchewan). Assistance from nonprofit organizations such as the Kidney Foundation of Canada is potentially available. However, the requirements necessary to receive employment insurance and benefits delivered through tax credits may work to the disadvantage of people who work in alternative arrangements or have a lower income, and all existing programs are limited in scope and availability.”

2.2.2 Professional Acceptability

A successful strategy to increase organ donor rates requires support from the professionals who work directly with transplant issues. These professionals are divided into two groups in this study: the medical professionals involved directly with the care and transplantation process (doctors, nurses, specialists), and the donor and transplantation support organizations, which manage public education, registries, etc.

The professional medical staff involved in organ transplantation offer strong opinions on potential policy options. Oz (2003) conducted a survey in conjunction with the Foundation for the Advancement of Cardiac Therapies (FACT) of doctors who were members of the International Society for Heart and Lung Transplantation (ISHLT) to test support for policy

options designed to increase organ donor rates. While the members were overwhelmingly in favour of some options (e.g. presumed consent, indirect compensation), they also indicated they did not support other potential options (e.g. direct compensation, seeking further consent of next of kin in cases where an organ donor indicates consent). Perhaps the most surprising finding of the FACT survey was that members expressed support for increased education for the public, given their awareness of mass education campaigns that have failed to increase donor rates in other jurisdictions (United States, The Netherlands, Sweden).

Support for policy options is quite different from the perspective of transplantation support organizations. Two important organizations, the British Columbia Transplant Society and the Trillium Gift of Life Network in Ontario have moved toward creating donor registries, emphasizing the principles of public education/campaigning and informed consent (also known as “opting in”), while discouraging other potential options, such as direct compensation and presumed consent (BCTS *Transplant Times*, Winter 2003; Winter 2009).

This presents a potential rift between medical professionals and transplant support organizations on certain approaches that will make professional acceptability a difficult criterion to fulfil for potential policy options.

2.2.3 Public Knowledge and Perceptions

How the public understands the issues involved in organ donation and transplantation affects their willingness to donate. There are perceptions linked to organ donation that provide a challenge to increasing donation rates. Such common perceptions or motives, as Sanner (1994) terms them, are:

Table 2.3 Challenging perceptions (types)

Religious Beliefs/Problems with Death	Distrust of authorities, medical system or procedures	Wish to keep body intact	Concerns about difficult decisions/causing offence
<ul style="list-style-type: none"> • Fear of obstacle to rebirth • Anxiety about offending God/Nature • Problems with the concept of death • Apprehension about the funeral 	<ul style="list-style-type: none"> • Distrust of the doctors • Anxiety about biomedical and social development • Discomfort with donation of certain organs • Fear of giving useless organs • Uneasiness with exposure • Fear of destruction 	<ul style="list-style-type: none"> • Discomfort at offending the family. • Discomfort with changes of appearance. • Anxiety about not keeping the dead body intact • Uneasiness with cutting the dead body • Difficulty with cutting children 	<ul style="list-style-type: none"> • Fear of disrespect for the dead person • Dislike of having one's organ surviving in another body or having another's organ living in my own body

These reasons fall into four broad categories: motives involving religious beliefs and anxiety about death; distrust of or anxiety about authorities, the medical system or the procedures; a wish to keep the body (dead or alive) intact; and concerns about the decision being difficult or causing offence. A shift in public consciousness and understanding requires removal of these barriers to increasing organ donor rates.

2.3 Summary

A complex legal and regulatory framework encompassing 14 separate, non-uniform jurisdictions, difficulties with professional acceptability of certain policy options among key stakeholders such as doctors and organ procurement organizations, and psychological issues that shape public perceptions and knowledge all contribute to Canada's poor organ donor rates. These challenges must be thoroughly understood prior to analysis of policy tools to address the low donor rate.

3: Methodology: The Use of a Web Survey and Literature Review

This study employed two methodologies for collecting data to help diagnose the factors leading to Canada's low donation rates and to identify and assess potential policy options. The approaches are a web survey and a literature review.

3.1.1 Web Survey

The web survey consisted of 66 separate questions on a variety of topics designed to test the perceptions, knowledge and attitudes of the Canadian public about organ donation. The Gallup Group in the US did a similar survey for a federal government study that similarly tests the American public's perceptions, knowledge and attitudes about organ donation. Where the difference lies between the Gallop survey and mine is that a distinct goal of the US survey was to test the differences among different racial and ethnic groups; my survey did not study this issue in terms of responses from different races or ethnicities⁴.

I used Simon Fraser University's web survey tool to design and deliver the survey. In addition to key demographic questions, the survey contained five sections. The first three sections pertained to personal knowledge and attitudes in the following areas:

- Decision-making about organ donation
- Presumed Consent
- Compensation

⁴ The question of racial or ethnic differences about attitudes and behaviours is a crucial consideration, however I decided it was too large a topic in itself to be thoroughly addressed in this project. The implications of race and ethnicity are important to future trends, given that Canada is experiencing a significant growth in diversity presently.

The fourth section asked about personal experience with donation or organs and tissues. The final section tested participants' knowledge of issues involved with organ donation by asking them about their level of agreement to statements that are common perceptions linked to organ donation.

I recruited participants using a snowballing technique. I established initial contact with members of my social and professional networks, through email and the social networking site 'Facebook'. I asked contacts to forward the survey to people in their networks, with some suggested text to encourage participation. I hosted the web link for the survey on my personal weblog, hosted by 'Blogger.com', and weblogs of several friends posted my survey after receiving the initial contact.

The survey was conducted from November 17, 2009 to November 30, 2009, and received a total of 155 usable responses from all regions of Canada: the North; British Columbia; the Prairie provinces; Ontario; Quebec; and the Maritimes and Newfoundland and Labrador. I rejected two surveys because one came in after the deadline, and one was missing data.

3.1.2 Literature Review

Organ donation is an extensive topic, even when the literature involving the medical and technical aspects is set aside. My focus was on the social and ethical understanding of the issues involved.

Three purposes drove my literature survey: first, to define the scope of the policy issue and determine the policy problem; second, to gather data about background issues (particularly the ethics involved in decision-making), criteria and measures, and potential policy options; and third, to conduct a study of jurisdictions that adopted different policy options that could be applied to Canada. The cases selected – Spain, the United States, and Norway, consistently are

among the top five in organ donor rates in the world, and have been the focus of significant study in academic literature and policy briefings.

4: Survey Findings: Seven Key Areas of Focus

This section outlines and describes in detail the survey results. The topics covered include: general organ donation attitudes; organ donation behaviours; living donation; attitudes toward presumed consent; attitudes toward financial issues; beliefs about organ and tissue donation; and sources of information about organ and tissue donation.

The demographic characteristics of interest include gender; age; ethnicity; education; Health Care Professional (self-identified); marital status; and income.

It is crucial to note that by design, the survey is not a representative sample of the Canadian public. For instance, some provinces and territories are over-represented among respondents, while others are very under-represented (or not represented at all). This is due to the nature of the social networks used to spread word of this survey (i.e. the researcher has an extensive social network in British Columbia, the Northwest Territories and Ontario, areas with strong representation in the sample). Similarly, the social network would also be responsible for the heavier representation of younger participants, as well as those with higher levels of education.

The break down is as follows in Table 4.1:

Table 4.1 Sample Characteristics: Unweighted Results

Demographic Characteristic	Number	Percent
<i>Gender</i>		
Male	52	33.5
Female	103	66.5
<i>Age</i>		
20 – 39 years	132	85.2
40 – 59 years	16	10.3
60+ years	7	4.5
<i>Ethnicity</i>		
Non-visible minority/Aboriginal	131	84.5
Visible minority/Aboriginal	24	15.5
<i>Education</i>		
Less than high school graduate (0-11)	1	0.6
High school graduate/GED	3	1.9
Some post-secondary	15	10
Trade/Technical/Vocational training	7	5
College degree/diploma	21	13.5
University Undergraduate degree/diploma	71	45.8
Graduate degree	37	23.9
<i>Health Care Professional</i>		
Yes	13	8.4
No	142	91.6
<i>Marital Status</i>		
Single	75	48.4
Married	51	32.9
Common Law	24	15.5
Separated/Divorced	3	1.9
Widowed	2	1.3
Continued next page		

Demographic Characteristic	Number	Percent
<i>Income Level (before taxes)</i>		
Under \$12,000	13	8.4
\$12,000 to \$19,999	6	3.9
\$20,000 to \$29,999	14	9
\$30,000 to \$49,999	24	15.5
\$50,000 to \$74,999	38	24.5
\$75,000 to \$99,999	20	12.9
\$100,000 or more	40	25.8

It is important to note that the potential biases presented by this sampling are not all problematic for this study. British Columbia, Ontario and Quebec are the three most active provinces in the country in organ transplantation and waitlist activities, and the heavier sampling of British Columbia and Ontario may reflect that the issue of organ donation is an issue of interest to constituents of those jurisdictions in the sample. The absence of a larger French sampling from Quebec may be because I could not conduct the survey in French because of language constraints.

The oversampling of women for this survey is not entirely surprising; when the Gallup Group conducted their version of this poll in the US, women were also over-represented at a similar ratio of approximately 2 to 1.

Analysis of the results of the survey follows, and sampling issues or biases are discussed in contexts where unexpected results occur.

4.1 General Organ Donation Attitudes

The survey measures general attitudes toward organ donation via two questions: 1) In general, do you strongly support, support, oppose, or strongly oppose the donation of organs for transplants; and 2) How likely are you to have your organs donated after your death?

Overwhelmingly, the general response favours organ donation in general; responses were grouped into ‘support’ (responding strongly support or support) and ‘oppose’ (responding oppose or strongly oppose). Overall, 98.7% of respondents support the donation of organs for transplant, and only 1.3% were opposed to organ donation in general.

Most respondents indicated they were somewhat likely or very likely to donate their organs after they die; I group responses into ‘very likely’, ‘somewhat likely’ and ‘not likely’ (responding not very likely or not at all likely). Table 4.2 shows the demographic breakdown of likelihood to donate organs after death. The results of my survey reinforce findings in the study conducted in the United States in terms of describing the types of characteristics of the general public that make up those who support organ donation and those who oppose, including the following:

- Women are more likely to donate their organs after death than men;
- Members of minority race/ethnic groups are less likely to donate than Caucasians;
- People who are married or in common law relationships are more likely to donate;
- People living in lower income households are less likely to donate than those in middle- and high-income households.

However, the survey results also contained surprising findings that do not match previous studies involving the following demographics:

- Those who answered that they were not likely to donate after death all had higher levels of education
- There were no differences in the levels of responses between those who self-identified as health care professionals and those who did not.

Table 4.2 Likelihood of Organ Donation after death by demographic characteristic
Results in percentages

	N of Cases	Very Likely	Somewhat Likely	Not Likely
All	155	74.2	18.7	7.1
Male	52	65.4	23.1	11.5
Female	103	78.6	16.5	4.9
Non-Minority	131	77.1	18.3	4.6
Minority/Aboriginal	24	58.3	20.8	20.8
20 – 39 years	132	71.9	21.2	6.8
30 – 59 years	16	87.5	6.3	6.3
60+ years	7	85.7	-	14.3
High School or less	4	50	50	-
Vocational/Some College	22	90.9	9.1	-
College/University degree/diploma	129	72.1	19.4	8.5
Health Professional	13	76.9	15.4	7.7
Non H. Professional	142	73.9	19	7
Single	75	69.3	20	10.7
Married/Common	75	80	17.3	2.7
Sep/Div/Widow	5	60	20	20
Under \$29,999	33	63.6	24.2	12.1
\$30,000 - \$74,999	62	77.4	19.4	3.2
\$75,000+	60	76.7	15	8.3

Bøgh and Madsen (2005) conducted a study among health care professionals in Northern Denmark, and they found that the willingness among the general population of Denmark to donate organs after death was 74%; among doctors, the willingness among doctors was 70%, which is relatively similar to the general population rate; however, among nurses and auxiliary nurses, the rates were 45% and 47% respectively. The results of my survey differ from the Danish results largely because of the small sampling of health care professionals surveyed for my

study. However, my study suggests that the Danish study may not be representative of attitudes in other countries because willingness to donate by the public and health care professionals are similar in all three categories assessed.

The education results were also unexpected. Conesa, et. al. (2003) built a psychosocial profile in favour of organ donation, and among the characteristics of the profile is higher education; people with higher education are more likely to donate organs after death, and people with lower education are less willing or unwilling to donate after their death. The survey results for my study challenge the psychosocial profile of someone unwilling to donate; participants who said they were not very likely or not at all likely to donate their organs after death had an advanced education (college, undergraduate or graduate degree or diploma). The higher level of education may induce scepticism about organ donation in some individuals.

Among those who indicated that they are not very likely or not at all likely to have their organs donated after death, the reasons and number of responses are as follows:

Table 4.3 Reasons to reject donating organs after death

Reason	Number
NOT APPLICABLE (likely to donate)	134
Against my religious beliefs	4
Cannot donate for medical reasons	2
I do not want my body cut up or disfigured	3
I am afraid they will take organs before my death	1
I don't trust the medical system, I will not receive the best medical treatment if I am a donor	5
I feel I am too old to donate	0
Other	6

Among these reasons, the statement ‘Cannot donate for medical reasons’ stands alone as being a reason dictated by non-social forces; however it may be the case that a person *believes* they cannot be a donor for medical reasons, when in fact they may qualify as full or partial donors. All other reasons given are based on personal beliefs defined by social constructs, and are therefore not medical barriers to being an organ donor. I address these beliefs in section 4.7.

4.2 Organ Donation Behaviours

This section contains survey results covering the behaviour of respondents ‘signing up’ to be an organ donor as well as analysis of how families discuss organ donation decisions.

4.2.1 Granting Permission to Donate Organs (Self)

- This section specifically addresses the knowledge and attitudes of those surveyed about the procedures for granting permission to donate their own organs after death. Three questions were asked: Have you granted permission for organ and tissue donation on your driver’s licence/health care card, on a signed donor card, or by joining an organ donor registry;
- Do you believe that marking Organ Donor on your license or health care card registers you to be an organ donor;
- Would you be willing to grant permission for organ and tissue donation on your driver’s licence/health care card, on a signed donor card, or by joining an organ donor registry?

In total, 89% (n=138) people said they personally would be willing to grant permission for organ donation after death using any of the three permission-granting methods tested. Sixty percent (n=93) of those surveyed believed that marking organ donation on a driver’s license or healthcare card registered them to be an organ donor.

Figure 4.1 Granting Permission for Organ and Tissue Donation

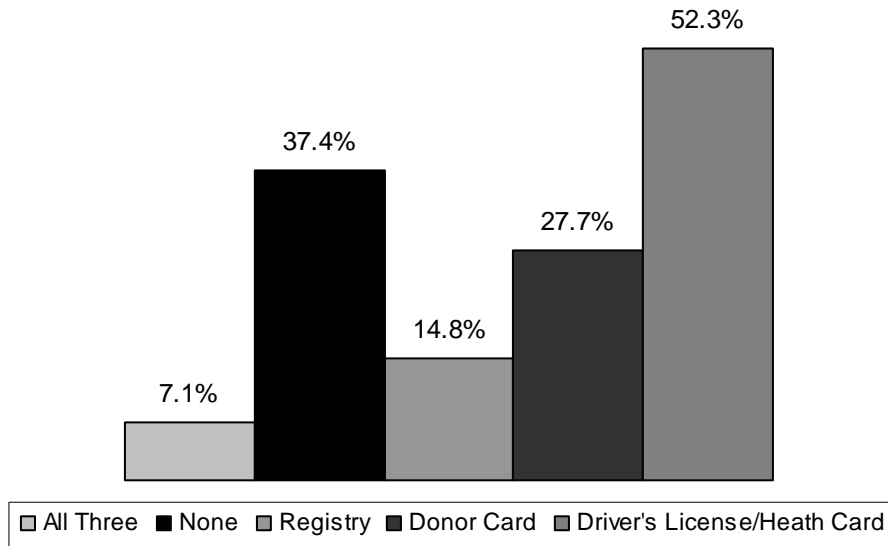


Figure 4.1 shows the breakdown of types of permission given by respondents to donate organs after their death. To test the knowledge of respondents on how to grant permission in their province or territory, the question was set up so they could check all that apply from the options (Driver's license/Health care card, Donor Card, joining a registry). While 37.4% of respondents indicated that they have not granted permission in any of the three ways, 25.2% of respondents indicated that they granted permission in two or three ways; the test for respondents is to see if they understand the rules governing permission in their jurisdiction. These jurisdictions vary in the method used for granting permission (see table 4.4).

Table 4.4 *Methods for Granting Permission after death by Province/Territory*

Province	Method
British Columbia	Join the organ donor registry
Alberta	Sign the back of provincial Health Care Card
Saskatchewan	Get an orange “organ and tissue donor” sticker placed on Saskatchewan Health Services Card
Manitoba	Sign the back of driver's license
Ontario	Join the provincial organ donor registry (Trillium)
Quebec	Have a sticker placed on Health Insurance card
New Brunswick	Register with Medicare
Nova Scotia	Sign the back of provincial Health Care Card
Prince Edward Island	Get a red heart put on driver's license and a sticker for PEI Health Card
Newfoundland and Labrador	Sign the back of driver's license
Yukon Territory	Join the organ donor registry
Northwest Territories	Sign the back of provincial Health Care Card
Nunavut Territory	Sign the back of provincial Health Care Card

Of the 13 jurisdictions in Canada, people in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia, and Northwest Territories provided responses to the survey. Respondents from all those jurisdictions except Manitoba indicated that they had granted permission in some manner, but responses indicated that knowledge about the correct way to grant permission in the eight jurisdictions represented is partially or completely inaccurate. See Table 4.5 for details:

Table 4.5 Permission Granted by Method by Jurisdiction

**Indicates the correct manner for granting permission in each jurisdiction*

Province	# Respondents	# DL/HC	# Donor Card	# Registry
BC	71	31	17	*16
AB	19	*10	3	1
SK	6	*4	2	1
ON	33	20	12	*3
QC	1	*1	-	-
NB	7	*6	2	*-
NS	7	*7	3	-
NWT	10	*2	4	2

Respondents may confuse terminology, indicating that difficulties exist in understanding and interpreting the name or meaning of methods. For instance, in New Brunswick, the information provided by the government is that people are to *register* with Medicare to become organ donors, and this information is contained on their renewed *health care card*. This is different from the act of signing a health care card such as in Alberta, Nova Scotia, NWT or Nunavut, because there is no registration process in those jurisdictions. There can also be mixed signals and information available, as is the case in Ontario. There, individuals are told they must add their name to a registry monitored by the Ministry of Health and Long Term Care, but on the Trillium Gift of Life Network website (the body administering the registry) the information given is that all a person needs to do is sign a donor card.

The kind of confusion noted above indicates that people do not clearly understand the process for granting permission to take organs after death among a significant portion of those surveyed, particularly in British Columbia and Ontario. This has important implications for policy options favouring public education as a means for increasing organ donation rates.

4.2.2 Donating Family Members' Organs and Discussion Donation with Family

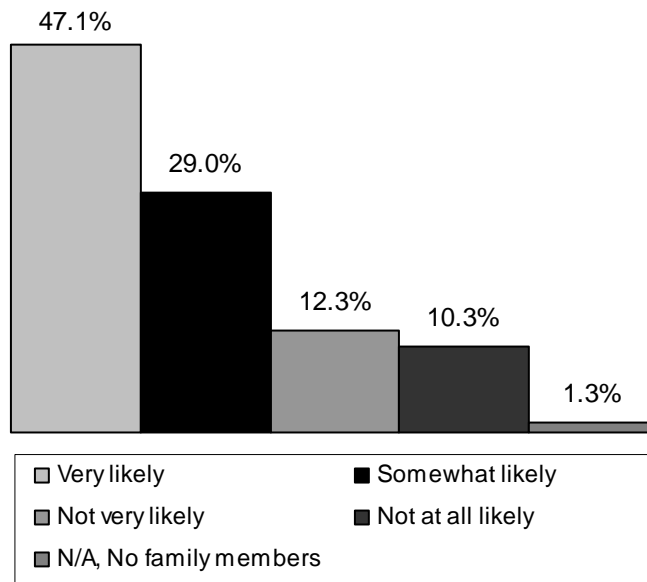
This section deals with involvement of family members in the process of organ donation. The aspect of family in the process of organ donation is crucial because in all jurisdictions in Canada, family permission is required in order to take organs from a deceased person, regardless of whether or not they indicated that they granted permission. It is important to understand the relationship between organ donation and family discussions about consent because it is often the case that the family members of a deceased person may not know his or her wishes, so they are reluctant to consent to donation.

Seven questions ascertained knowledge of family involvement in a decision about organ donation (Appendix A, Questions 12-18). These questions dealt specifically with willingness to discuss organ donation wishes with family members, and making decisions about organ donation based on whether or not discussions had occurred.

4.2.2.1 Making the decision for another family member

The question posed to respondents was how they likely they would be to make the decision about organ donation in the event of the death of a family member. Figure 4.2 shows the breakdown of responses when the respondent did not know the wishes of a family member:

Figure 4.2 Likelihood of donating family member's organs without knowing their wishes.



Nearly half of those surveyed (47%) would be very likely to donate their family member's organs if they did not know their wishes, and a further 29% answered that they would be somewhat likely to do so. Less than a quarter of those surveyed would be not very likely or not at all likely to donate the organs of a family member if they do not know the wishes of the deceased.

The situation is far more certain if the deceased family member had requested donation of his or her organs: 95.5% (n=148) would be very likely to follow through on the wishes of the deceased, and a further 3.2% (n=5) would be somewhat likely to do so. Only 1.3% (n=2) responded that they would be not at all likely to follow through on the wishes of the deceased.

4.2.2.2 Discussing decisions with family members

Participants were surveyed about whether they have engaged in discussions about organ donation with family members, or at least if they were willing to engage in the discussion. A supplementary question asked those who indicated an unwillingness to discuss donation with family members what those reasons might be.

In terms of expressing willingness, nearly three-quarters of respondents indicated they were very willing to discuss their organ donation wishes with family members (74.2%, n=115), and a further 21.9% (n=34) were somewhat willing to discuss their wishes. Only 3.9% of respondents (n=6) indicated they were not very willing or not at all willing to discuss their wishes with family members. Responses to the question of why are you unwilling to discuss family members' wishes indicate that people hadn't given it much thought or had no particular reason. Very few listed concerns that one might expect such as "we won't discuss death" or "it's personal". Table 4.6 provides the responses of all participants to the question "Why are you unwilling to discuss wishes with family members."

Table 4.6 Reasons respondents are unwilling to discuss wishes with family members

Reason	Number
NOT APPLICABLE (expressed willingness to discuss)	132
Haven't given it much thought	12
No, no reason in particular	4
We don't discuss death, makes me/them nervous	3
Family would not understand	0
Family believes people should be buried whole	0
They are too young	0
They are not in good health	1
It's personal, none of their business	1
It is my decision	0
I'm afraid talking about my death will increase the chance that I will die	1
Other	1
N/A, no family members	0

Further study is necessary to determine the level of knowledge about or awareness of the legal role the family plays in the decision to donate organs after death. In all jurisdictions in Canada,

family members must give consent to organ donation, regardless of the wishes of the deceased, and a critical hypothesis that needs to be tested is whether or not knowing the law would induce Canadians to discuss their wishes with their family members.

Almost 66% (n=102) of those surveyed responded that they had discussed their wish to be an organ donor after their death with family members. Almost a quarter (24.5%, n=38) indicated they had not discussed their wish to donate after death with family members, while 9.7% (n=15) indicated the question was not applicable, as they did not wish to donate their organs after death.

Of the almost 24% of those who indicated they did NOT want to be organ donors after their death (n=46), eleven of them had made their wishes not to donate known to family members and 35 said they had not discussed their wishes with family members. When it came to knowing the wishes of their family members, about half the respondents (n = 78) said yes, the rest (n = 77) said no.

4.3 Living Donation

This section is concerned with the issue of living donation; the donation of an organ or tissues by a donor who is still living. The survey asked nine questions (Appendix A: Questions 7-9, 30-35) in order to gather information about experience with living donation, as well as to ascertain the circumstances under which a person would consider living donation.

4.3.1 Living Donation and Relationships

Table 4.7 shows the responses of participants asked about their willingness to be a live donor according to whether the recipient had a certain relationship to them: a close friend, a family member, or someone they did not know.

Table 4.7 Willingness to be a live donor depending on relationship to recipient

(%)	Close Friend	Family Member	Stranger
Very likely	25.8	74.8	1.9
Somewhat likely	45.2	16.8	16.1
Not very likely	15.5	3.2	45.8
Not at all likely	3.9	1.9	25.8
I don't know	9.0	3.2	9.7
Already donated	0.6	-	0.6

A clear hierarchy is established; based on the results of the survey responses, those surveyed are nearly three times more likely to be a living donor if the recipient is a family member than if they are a friend. Only 1.9% (n=3) responded that they would be very likely to be a living donor if the recipient was someone they did not know. However, two respondents indicated that they have already been living donors. Their recipients were a close friend and a stranger, and not a family member.

4.3.2 Experience with Living Donations

This section details the results of inquiries about participants' actual experiences with live organ and tissue donation, as well as their experience with blood donation. The reason blood donation was included was because of the hypothesis that those who have donated blood may be more likely to consent to organ and tissue donation, whether living or after death.

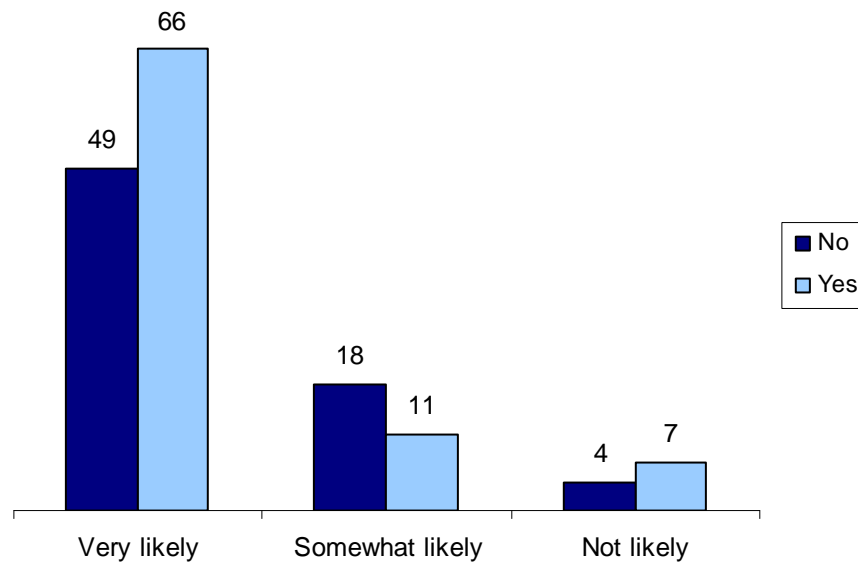
4.3.2.1 Blood Donations and Likelihood of Organ Donation after Death

Table 4.8 Have you ever donated blood

Blood Donation	Number (n)	Percent (%)
Yes	84	54.2
No	71	45.8

More than half of the respondents indicated that they had donated blood in their lifetime, though when asked further, only 16.1% (n=25) indicated that they had done so one or more times in the past year. In order to determine if blood donation has any relationship to organ donation, the results of the questions “Have you ever donated blood?” (Q 30, Appendix A) and “How likely are you to have your organs donated after your death?” (Q 10, Appendix A) were compared. As figure 4.3 demonstrates, more people who indicated that they had donated blood in their life also indicated that they were ‘very likely’ to have their organs donated after death. Interestingly, more people with *no* experience giving blood indicated they are somewhat likely to donate their organs than those with experience giving blood. Clearly, a lack of experience with blood donation does not stop those surveyed from considering the possibility of cadaveric organ donation, which is equally as important as finding that experience with blood donation has a positive relationship to the choice to be a donor after death.

Figure 4.3 Number of cases where blood donation relates to likelihood of organ donation



Furthermore, of those not likely to donate an organ, more were blood donors (7 versus 4 respondents). This unexpected finding is worth noting because it proposes the question “Why did some people stop at blood donation?” This may be an area for future study.

4.3.2.2 Actual Experiences with Organ Donation

The questionnaire asked respondents if they or family members had any experience with the actual organ donation process as a donor or a recipient. This data was then cross tabulated with the likelihood of donating organs after death to see if there was a positive relationship.

Out of the sample of 155 responses, two people indicated that they had been organ or tissue donors, and another two people indicated that they had received organs or tissues through a transplant.

Tables 4.9 and 4.10 show how likely respondents are to donate an organ after death given the experiences of family members with organ donation. In both tables, it is notable that 17 respondents knew a family member who had been an organ donor, as well as 17 respondents who knew a family member who had received organs through transplant:

Table 4.9 Relationship between likelihood of organ donation and a family member being an organ donor

	No (donor)	Yes (donor)	I don't know
Very likely	71	14	30
Somewhat likely	16	3	10
Not very likely	4	-	1
Not at all likely	5	-	1

Table 4.10 Relationship between likelihood of organ donation and a family member receiving an organ

	No (recipient)	Yes (recipient)	I don't know
Very likely	78	14	23
Somewhat likely	22	3	4
Not very likely	5	-	-
Not at all likely	5	-	1

In both cases, 82.4% (n=14) of respondents indicated they were very likely to have their organs donated after death, and the remaining 17.6% (n=3) indicated they were somewhat likely to have their organs donated after death. No respondents indicated that they were not very likely or not at all likely to do so. This result confirms the hypothesis that a positive relationship exists between knowing a family member who has donated or received organs or tissues, and an increased likelihood of deciding to donate organs after death.

Overall, a positive relationship appears to exist between the likelihood that a person intends to donate organs after death and their experience with organ, tissue and blood donations.

4.4 Attitudes toward Presumed Consent

This section deals with the concept of presumed consent as a policy option adopted or considered by jurisdictions around the world. Presumed consent is a policy whereby the default

option is set to ‘everyone is included, unless they specifically opt out’ by signing a document indicating that they do not wish to donate their organs. Four questions ascertain the knowledge, feelings and perceptions about presumed consent:

- Would you strongly support, support, oppose, or strongly oppose using this presumed consent approach in Canada?
- Is there a particular reason why you oppose presumed consent?
- Do you think a system of presumed consent would increase or decrease the number of available organs for transplant?
- If a system of presumed consent were adopted in Canada, would you sign up as a non-donor?

Table 4.11 Support for Presumed Consent policy adoption in Canada

Support or Oppose	Value (%)
Strongly support	38.7
Support	27.1
Oppose	21.3
Strongly oppose	12.9

As table 4.11 shows, support for presumed consent is mixed. Overall, 65.8% of those surveyed support or strongly support the adoption of presumed consent in Canada, while 34.2% oppose or strongly oppose it. The questionnaire provided an opportunity for those expressing opposition to select up to five reasons for their opposition (table 4.12).

Table 4.12 *Reasons for opposition to presumed consent in Canada*

Values = number of cases

Reason	Value (n)
NOT APPLICABLE – I am not opposed	98
Haven't given it much thought	6
No reason in particular	2
Feel presumed consent is unethical	45
Privacy Issues	17
You feel it is a violation of your rights	35
Distrust of government	8
Religious preferences or beliefs	17
Other	10

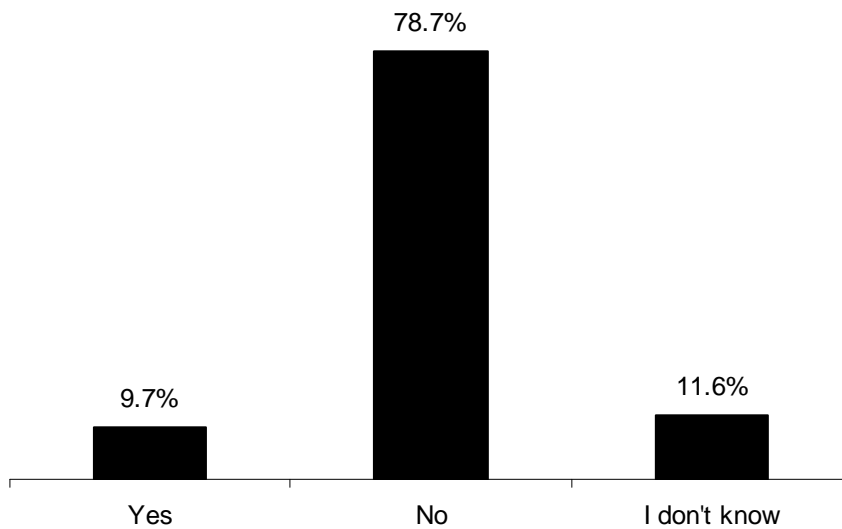
Only eight responses reflected indifference (“Haven’t given it much thought” and “No reason in particular”). A further 42 responses fall under a category of ‘personal’ boundaries (“Privacy issues”, “Distrust of Government” and “Religious preferences or beliefs”). The bulk of the remaining responses (n=80) to fall under the category of ‘societally-constructed’ boundaries (“Feel presumed consent is unethical” and “You feel it is a violation of your rights”), which can be complex to interpret because it requires understanding how an individual processes ethics and rights, which are concepts that are defined by society at large.

Despite the concerns about why people might oppose presumed consent in Canada, the overall perception of the concept is positive, and there is reason to believe that it could be a successful strategy in terms of increasing donor rates if adopted nationally. When asked if they believe that presumed consent would increase or decrease the number of available organs for transplant, 93% (n=144) of respondents answered that they believed it would increase the number of available organs for transplant. Ten respondents (6.5%) felt that presumed consent would have no impact on the availability rates, and 0.6% (n=1) believed presumed consent would lead to a decrease. This indicates that the knowledge about presumed consent is sufficiently strong in

Canada, which is beneficial in the discussion about policy options to address the shortage of donors.

Finally, participants were asked if they would opt out as donors if presumed consent were adopted in Canada.

Figure 4.4 *Opting out of presumed consent*



The results of my survey indicated that nearly 80% of participants would remain with the default option, meaning they would not likely opt out as organ donors if Canada adopted presumed consent. This result supports the hypothesis of Thaler and Sunstein (2008) that people tend to remain with the default option (instead of actively opting in or out).

4.5 Attitudes toward Financial Issues

This section discusses questions about financial issues and compensation for organ donation. In recent years, the concept of providing compensation (either direct or indirect) to a living donor or a deceased donor's estate has been discussed as a policy option designed to increase the number of organ donors. Direct compensation, which is the payment of cash to

donors, is illegal in Canada and most jurisdictions around the world, so the questions asked in this survey are about indirect compensation. Four questions address the perception of financial compensation, including one open-ended question inviting personal responses:

- Would indirect compensation make you more likely or less likely to donate your organs, or would it have no effect?
- Would indirect compensation make you more likely or less likely to donate the organs of a Family Member, or would it have no effect?
- Is there a particular reason a payment would make you more or less likely to donate your organs or a family member’s organs? What reason? (open-ended)
- The medical and surgical expenses of individuals who donate an organ while living are currently paid for by provincial/territorial health care plans. Some people believe that these living donors should also receive other compensation for any expenses related to their donation, such as travel, childcare, or lost wages. Please state whether you strongly agree, somewhat agree, somewhat disagree, or strongly disagree.

Table 4.13 shows the results of whether indirect compensation would be more or less likely to lead to donations of the respondent’s own organs or those of deceased family members:

Table 4.13 The effect indirect compensation has on organ donation (self and family members)
Values in percent

	Self	A Family Member
More likely to donate	20.0	13.5
Would have no effect	69.0	78.1
Less likely to donate	1.3	2.6
I don’t know	9.7	5.8

More respondents indicated that indirect compensation for their own donation (20%, n=31) would make them more likely to donate than it would make them more likely to donate the organs of a family member (13.5%, n=21). Despite this, the overall finding is that indirect compensation would have no effect on the decision of a significant majority of respondents to donate their own organs (69% , n=107) or those of family members (78.1%, n=121).

Of those respondents who responded to the open-ended question about whether indirect compensation would have any effect on their decision to donate their own or a family member's organs, many responded that indirect compensation is not applicable to their decision. However, other respondents lined up on both sides, arguing that it would make them more or less likely to donate. For instance, respondents in favour of compensation argued:

“Incentives work, especially when faced with funeral/estate costs. The classic carrot and stick - if you're struggling with a decision and there is a tangible known benefit, it contributes to the decision making.”

“Personally I believe it would assist to alleviate concerns about leaving survivors in financial difficulty if they had to pay costs of travel, funeral and related costs.”

“I'd donate my own or a family members organs 100% of the time if it was up to me and they had not specifically requested not to do so (and even then I'd probably do it). Any compensation would just go towards burial costs or their children, or a charity. That being said, I can see why it might be an incentive for someone in more financial need.”

“Compensation for lost wages in order to maintain a standard of living.”

Meanwhile, those who against compensation argued:

“This is a moral and ethical matter and not a financial matter”

“I think payment of organs would have a cascading negative effect from nefarious individuals who would see it as a money grab. Donation is a GIFT and I think payment would sully the gesture.”

“Compensation for organ donation makes me uncomfortable”

“I don't believe that anyone should be financially compensated for organ donation, even indirectly. This may lead to members not respecting the wishes of the deceased to not donate. It should absolutely be up to the donor.”

Many respondents were careful to make a distinction between donating their own organs versus their family member's organs, but another distinction became apparent: living donation versus deceased donation. Some argued in favour of compensation in the form of lost wages and productivity, which leads to the next question about whether respondents agree or disagree with the concept of indirect compensation in the form of travel, childcare, lost wages, etc.

Table 4.14 Indirect Compensation to living donors in the form of travel or childcare costs, or lost wages, etc.

Statement	Value (%)
Strongly agree	52.9
Agree	43.2
Disagree	2.6
Strongly disagree	1.3

There is overwhelming agreement among respondents that some form of indirect compensation should be available to living donors (96.1%, n=149). A hypothesis to explain this high rate of support for this concept may be that respondents recognize that there are challenges beyond medical costs that need to be considered when making the decision to make a live organ donation.

Overall, response to the concept of indirect compensation among participants is mixed. Some people are not comfortable with compensation when considering their family members, but are okay with compensation for living donations, while others express outright disagreement with the whole concept of any form of compensation.

4.6 Beliefs about Organ and Tissue Donation

This section deals with a series of statements put to participants to test their knowledge, perceptions and feelings about the overarching issue of organ and tissue donation. The idea here is to take that test the strength of beliefs (whether based on fact or misinformation), as well as to test willingness to grant permission or to make a donation. These tests are key to understanding the impact that public education is having on awareness about organ donation.

Twenty-four belief statements were included in the survey, and the questionnaire asked respondents to state whether they strongly agree, agree, disagree, or strong disagree with each statement (Appendix A: Questions 36 – 60). These belief statements included questions about equity of distribution, safety and viability of transplanted organs, implications of deceased donations on those living, and other issues that may affect a personal decision regarding organ donation.

I then compared these statements against the results from two previous questions in the survey: “How likely are you to have your organs donated after your death?” (Q 10, Appendix A) and “Would you be willing to grant permission for organ and tissue donation on your driver’s license or health care card, on a donor card, or by joining an organ donor registry?” (Q 21, Appendix A). The comparison enabled the search for correlations indicating the strength and direction of the relationship between each belief statement at the permission and willingness variables.

The 2005 National Survey of Organ and Tissue Donation Attitudes and Behaviors explains the meaning behind correlations in relation to this survey:

“[The strength can range from 0 (no relationship) to 1 (a perfect relationship)]. A larger correlation means that the more people “strongly agree” with the belief statement, the more likely they are to grant permission to donate or be willing to donate. Direction of the relationship is indicated by the negative sign in front of the number. Negative correlations imply that as agreement with the statement increases the likelihood of donation decreases. A positive correlation...indicates that as the agreement with the statement increases, the likelihood of donation also increases.” (The Gallup Group, 2005).

Appendix B indicates that there are few significant relationships between the decision to grant permission and the level of agreement with the statements; there are also significant correlations between the willingness to donate and the level of agreement with the statements. This indicates that public perceptions may not be as challenging a barrier as prior literature would indicate.

4.7 Sources of Information about Organ and Tissue Donation

This section deals with the sources of information about organ and tissue donation to which people are typically exposed. The key is to understand which sources of information they trust, which will indicate which sources are best to target for public education and awareness campaigns. Participants were first asked if they had heard, read, or seen and information at all about organ and tissue donation or transplantation. 70.3% (n=109) of respondents indicated they had come into contact with information at some point in the past year, and 29.7% (n=46) indicated they had not.

Sources of information examined included: family member, friend, medical professional, clergy or religious organization, attorney, personal experience or involvement with organ and tissue donation, billboard or poster, general news media coverage, work or school, Department of Motor Vehicles, public service advertisement on TV, public service advertisement on the radio, movie or TV show, community activity, internet or a web site, Health Canada or a Government Department/Agency, organ and tissue donation organization, local news (TV, radio, newspaper), and other.

Participants selected all sources of information about organ donation and transplantation that applied from the past year. They were then asked to select the top three sources that would likely influence how they act about organ donation and transplantation. Table 4.15 shows the results of both questions:

Table 4.15 *Important Sources of Information about Organ and Tissue Donation*

Values in number of cases

Sources	Important Source	Most Influential
Family member	57*	101*
Friend	54*	57*
Medical professional	4	53*
Clergy or religious organization	0	4
Attorney	0	2
Personal experience or involvement	10	50*
Billboard or poster	26	2
General news media coverage	55*	10
Work or school	21	11
Department of Motor Vehicles	16	2
Public Service Announcement on TV	27	11
Public Service Announcement on radio	5	2
Movie or TV show	53*	12
Community Activity	3	3
Internet or website	29	6
Health Canada or Gov't Dept/Agency	14	19
Organ and Tissue donation organization	26	30*
Local news (TV, radio, newspaper)	35*	18
Other	10	7

The top five in both categories are noted (*).

Family and friends are the most important and influential sources of information, according to those surveyed. After that, the highest ranked sources of information all come from media and entertainment sources; however media and entertainment sources prove to be far less influential in the decision making process. Medical professionals, organizations dedicated to organ and tissue donations, as well as personal experience prove to be the most influential sources for respondents in making their decisions about organ donation. Yet it is possible to hypothesize that the media and entertainment sources maintain indirect influence over the decisions of

individuals because friends and family are both the top ranked as well as the most influential sources, and they likely receive information from similar sources as the top five ranked sources.

4.8 Overall Analysis

Based on the results of the survey, some conclusions useful in shaping policy options and recommendations are evident:

- Those sampled for this survey express high rates of support for organ donation in general, but participation in consent activities is not consistent with the support.
- Demographic and geographical considerations are important in understanding the typical profile of someone consenting to organ donation in Canada.
- Knowledge about consent processes across jurisdictions, as well as a varying level of willingness to address the issue personally and with family members impede growth in the donor rate. The role of family in the consent process appears poorly understood.
- Experience with living donation, as well as personal blood donations tend to increase the likelihood of consenting to be an organ donor after death.
- Those sampled indicated that they are open to the possibility of a public discourse that includes significant changes to the current regime (i.e. presumed consent, forms of compensation) in order to increase donation rates.
- Those surveyed present a sufficient understanding to counter misconceptions about organ donation.
- The more personal a source of information is, the more influential it is in knowledge formation and decision making about organ donation.

5: Case Findings: What More Successful Countries are Doing

This section briefly reviews strategies adopted in four countries where donor rates are higher than donor rates in Canada. This analysis introduces possible new approaches to consider for adoption in Canada. The cases are:

(1) Spain, which implemented an approach found commonly approach in Europe called Presumed Consent;

(2) the United States, which adopted a national strategy for operating a real-time national waiting list to increase the likelihood of matches;

(3) the Netherlands, which implemented a National Live Kidney Donor Exchange program that required a complex computer system to make matches between donors and recipients; and

(4) Norway, which relies heavily on living donor renal transplants, with more than a third of donors having a family relationship to the recipient.

5.1 Spain

Prior to the introduction of a combined strategy of presumed consent and the hospital-centric model in Spain in 1989, the number of organ donors was at 14.3 per million population (pmp); after implementation, the organ donor rate jumped to 25 per million population in 1994 (Kaushik, 2009). By 1998, Spain's donor rate surpassed 30 per million (Bosch, 1999), more than doubling the rate of 14.3 pmp just 10 years earlier.

Miranda, Vilardell and Grinyó (2003, 1190) provide a snapshot of the Spanish organizational system in 2002: 41.8 million inhabitants living in 17 autonomous regions, with 17

Health Services comprising all facilities and public services devoted to health. This means that 99.5% of the population has access to public health care, and the national health budget comprises 6.4% of GDP. Health counsellors from each region, together with the State Minister for Health, comprise the Interregional Council for the National Health System, which operates a Transplant Working Group in charge of coordination, design and implementation of national transplant policies.

Presumed consent is a system where the state presumes people grant consent unless an individual takes steps to declare that they do *not* wish to be a donor during his or her lifetime. Crowe and Cohen (2006) argue that there are two main kinds of presumed consent laws: “strong” laws that rely solely on the individual citizen to declare him or herself as a non-donor; and “weak” laws allowing the family members of a decedent to opt out if they desire to do so. Spain operates a model where procurement staff approaches the family to see if they would prefer not to allow donation to proceed. Presumed consent was actually legislated in Spain in 1979. However, it was the move in 1989 toward the hospital-centric model with the compensated staff position to manage the consent-seeking process and administration that spurred the impressive growth in the following decade. (Thomas and Klapdor, 2008)

Luskin and Delmonico (2003, 1186-87) note that even using the so-called weak model, Spain reports a national consent rate of 80%; this contrasts with the United States, where the opt-in approach yields a national consent rate approximating 50%. They explain the difference in two ways: first, Spanish hospitals “own” the donation process by having a staff physician who assumes primary responsibility for donation, whereas many North American hospitals lack such a position, or else the position is filled in a voluntary capacity. This provides a modest financial incentive for hospitals to ensure that the staff physician is achieving results. Second, the nature of the Spanish health system, where all providers are funded by the government (more similar to Canada than the US), allows for a modest contribution toward funeral expenses for some donors.

While Spain's approach increases the rates of potential organ donors, it has its critics, specifically with regard to the presumed consent aspect. At the heart of the argument made by critics are concerns that are libertarian in nature; Kaushik notes: "It has been argued that presumed consent disregards autonomy, privacy and the right to choose how one's body will be used after one's death. Contrary to this it is argued that presumed consent respects the principle of individual choice by giving objectors to organ donation an opportunity to empower their anti-donation preference and thus does not infringe the right to choose" (2009, p.150). These concerns are mirrored in the initial response by the Spanish public to the new changes to the organ donation process. Ammann notes that in 1993, shortly after the adoption of the new system, up to 60% of Spanish citizens believed that the presumed consent law was an abuse of authority. In order to address this concern, the Organización Nacional de Trasplantes (ONT), the national body created to manage organ transplantation issues, began discouraging healthcare providers from mentioning the presumption of consent and absolutely respecting a family's refusal even if their deceased relative had not registered a non-consent, believing the mention of presumed consent would cause grief or feelings of coercion. The adoption this approach of "weak" presumed consent lowered the family refusal rate from 27.6% of all interviews for donation in 1992 to 21.3% in 1998 (Miranda et al., 1999).

The Spanish approach to presumed consent has contributed to the dramatic rise in donor rates because it still maintains a respect for individual and family consent, which negates the libertarian critiques attributed to the policy.

5.2 United States

The United States bases its organ donation regime on the similar principle of informed consent that operates in Canada. This consent system requires a person or the family of a deceased person to opt-in as an organ donor. What sets the two countries apart is the fact that the United States operates a very sophisticated real-time national waiting list, maintained by the

United Network for Organ Sharing (UNOS), which links all professionals involved in organ donations, and provides donor-matching information (Library of Parliament, 2009).

The national waiting list facilitates transplants across the country because the potential for matching is much higher than in system looking for matches in a smaller regional area. Canada currently does not operate a national registry; matches with deceased persons occur mostly within the province where a donor and recipient live.

The organizational system in place in the US is complex. Crowe and Cohen (2006) explain that there are four main kinds of rules governing the organ transplantation process: state laws, federal laws, federal regulations, and United Network for Organ Sharing (UNOS) policies:

“The *state laws* primarily cover issues pertaining to the donation process, such as the criteria for declaring death, the consent requirements for being a donor, the scope of public education programs, and the composition of donor registries. With a few notable exceptions, these laws do not differ significantly from state to state.

The *federal laws* primarily outline the processes of organ procurement, allocation, and transplantation by establishing the Organ Procurement and Transplantation Network (OPTN) and guidelines for organ procurement organizations (OPO). OPTN is the national organization that coordinates, implements, and monitors the organ transplantation system as a whole; OPOs are local or regional organizations responsible for retrieving organs and notifying potential recipients. The federal law also sets boundaries on the transfer of organs from one person to another by prohibiting the buying and selling of organs.

The *federal regulations* expand on the federal laws by describing how the OPTN, OPOs, and transplant hospitals should function. More specifically, they explain the internal structure of the organizations and the nature of their principal operations.

UNOS rules further define the functions of the OPTN, and describe the policies OPOs and transplant hospitals must follow in order to be members of the OPTN. Collectively, these laws, regulations, and rules affect every group and every individual involved or potentially involved in the donation, procurement, allocation, and transplantation of organs.”

Under the complex structure that supports the OPTN/UNOS, the country is divided into 10 regions to minimize morbidity of the organs and tissues while in transit. If there is one critique about this system, it is that regions account for varying levels of success in achieving consent and obtaining organs for transplant, meaning that a person’s chances of receiving a match depends on what region they are in (Nathan, 2003). This of course reveals structural inequities because some regions have access to more resources, fewer geographical concerns, or a population that is more inclined to consider donation. Increases in organ procurement from deceased donors ranged from a 7% increase in the Great Lakes region to a 30% increase in the Northern Midwest region between 1992 and 2001, indicating that more donors are available in the Northern Midwest region than are available in the Great Lakes region.

Canada should bear in mind the critique of the US system, as it would potentially face a similar problem in attempting the National Registry approach. Given its large landmass, geographical conditions, and population patterns, Canada would have to adapt the US model to address such concerns. This may include letters or memoranda of understanding between regional health authorities across provinces, which would allow recipients to access donors in their region, regardless of provincial borders.

For example, the geographical issues make it more difficult to organ donors or recipients to access fast care in Vancouver, the major centre for the province of BC. However, residents of communities close to the Alberta Border could fall under a letter or memorandum of understanding that allows them to be matched with donors or recipients in Calgary, which is

much closer to their location. This would work in many cases to overcome the structural inequalities that plague the US system, which emphasizes a state-regional-national hierarchy.

5.3 The Netherlands

In an effort to try to lower the waitlist times for kidneys, the Netherlands has recently implemented a National Living Donor Kidney Exchange program. Otherwise known as a crossover kidney transplant, this program “makes it possible for patients that cannot receive a kidney from their intended donor, due to ABO blood type incompatibility or to a positive serological cross match, to exchange donors in order to receive a kidney” (de Klerk et. al., 2005, p. 2302).

In 2005, 60 donor-recipient pairs were enrolled in a pilot where testing for type and tissue revealed 26 matches; 24 transplants were successfully conducted among the matched donors and recipients, which had positive implications the kidney waitlist (shorter wait times, freeing up spots/reprioritizing patients without matches). This pilot developed an independent system, operated by an independent organization (in this case, the Dutch Transplantation Foundation) in order to ensure that the matching was done based on ethically-sound and logical reasoning (i.e. best match possible, waitlist time, etc.), thus removing the element of “bartering”.

It is the creation and operation of an independent system that uses algorithms to determine matches that is important for my study. The Canadian health care system values equity as a pillar of the overall system, and concerns about equity of the demand side dictate that the distribution of organs among those on the waitlist be fair, with those most urgently or mortally in need receiving organs first, without consideration for age, wealth, race, religion or pre-illness lifestyle choices. The adoption of this system in the Netherlands has circumvented potential issues arising from doctors being the ones to make the decision about who should receive an organ, decisions that may be biased based on the knowledge a physician has about non-medical

characteristics of the potential recipient (i.e. favouring one potential recipient over another because of the different lifestyle choices and resources available to each person).

Canada announced in February 2009 the creation of a Live Kidney Donor Exchange program, managed by Canadian Blood Services, however, the program is too new to have accurate data available on the details about it. If Canada wants to ensure that the pillar of equity is maintained by the health care system, the Canadian Blood Services should give serious consideration to the adoption of a non-biased computer selection program, not only in its kidney exchange program, but also in the creation and administration of the forthcoming National Donor Registry and Waitlist.

5.4 Norway

Norway leads the world in kidney donor rates at 55 pmp. This is largely due to the country's decision to focus on a strategy of living donor renal transplants, a program heavily focused on recruiting donors from within the family of the recipient. This strategy has been dominant since 1969, when transplantation became a standard treatment option. While Norway still operates a cadaveric donation program, the emphasis is on the living donor program.

Norway is a country of 4.5 million inhabitants; it has one transplant centre for the whole country, located in Oslo. From 1969 to 2002, 4581 kidneys were transplanted in Oslo, with 1792 (39%) coming from living donors. According to Jakobsen, Holdaas and Leivestad, this results in more than 200 kidneys yearly or 45 to 46 transplants per million (2003: p. 1177). The foundation of this program is that the transplant centre prefers to find a donor kidney as quickly as possible, preferably to avoid the use of dialysis therapies, which can take a toll on the body of patients.

Fauchald (2002:951) notes that the process for recruiting donors is a detailed one and deals with issues such as approaching family members, evaluation, written consent, and the biological process of determining a match.

The nephrologist is the primary actor in raising the question of living donation. In many cases the question is raised spontaneously by the family, but often too late to accomplish the goal of pre-emptive transplantation. If the family does not turn up spontaneously, they are actively approached for information.

The nephrologist will discuss the possibility of live donation with the patient, and will advise the patient not to raise the question with the family. It is then up to the recipient to accept or refuse the idea; if acceptance is given, the nephrologist approaches the family, and if a volunteer comes forward, the potential donor gets information about the consequences of living donation, preferably in a one-on-one conversation, with written information and ample time for further decision. Assuming consent to donate is granted, the next phase is evaluation. Tissue typing is performed in motivated and blood group-compatible potential donors.

The evaluation stage of the process is prolonged if an unrelated friend is identified as a potential donor. It requires a spontaneous wish to donate, and Fauchald argues that it should only be performed when a living related donation is not an option. The process in this case now includes the involvement of an independent counsellor to identify unsuitable donors with a lack of motivation or obvious psychiatric or medical contraindications. The written informed consent process also requires the statement of a long-lasting relationship, the donor's spontaneous and altruistic wish to donate, and information about potential donor risk. The consent can be withdrawn at any time (Fauchald, 2002).

A key component of Norway's policy is the fact that it also engaged in a program that allowed for the long-term study of the physical recovery of donors, as well as the psychological impacts of the donor process. It is not discussed in the literature, but I hypothesize that the concentration of the organ donation and transplantation process in one centre allows for strong information gathering. This component has provided a wealth of information and a sense of openness that can bolster the value of organ donation among the Norwegian public, thus making

it easier to recruit donors. The Norwegian model's emphasis on living donation and its strong research component is worth further study in Canada; the model may be something to consider because of its success. In fact, Andrews states, "Norway is almost alone in seeing a reduction in the numbers of patients on its waiting list for transplants." (2002: 531)

Of course the model would have to be adapted to the Canadian context; a larger landmass and population are considerations rule out the possibility of a single centre. However, the research component is something that can be implemented in identified transplantation centres, which may yield a more open and articulated discussion on living donation in Canada.

5.5 Summary

Spain, the United States, and Norway all ranked in the top five for global kidney donor rates, whereas Canada does not even rank in the top 10 countries. Examples set by these countries, along with data from the survey conducted for this study indicate that there is significant room for improvement to Canada's organ donation rates.

6: Policy Options: What can Canada do?

Based on the two previous sections of survey and literature analysis, I consider five policy options to improve organ donation rates in Canada: the status quo option; Education Plus strategy; Formal Indirect Compensation; ‘Spanish Model’ Plus; and the promotion of Donor Exchange Program.

6.1 Status Quo

Until recently, Canada’s strategy centred on the plans and policies of the 13 individual provincial and territorial jurisdictions, which did not coordinate with each other for dealing with deceased or living donations. No coherent policy was in place nationally to provide consent or join a registry; the only universal policy in place then and now is that consent from family members is still required in cases of deceased donors, regardless of whether the donor expressed wishes or intentions to be a donor or not.

Administration and costs for organ procurement and transplantation are the responsibility of each of the jurisdictions. Programming administration and costs for social marketing is the responsibility of each jurisdiction, and procurement organizations that may or may not be tied to provincial/territorial governments typically undertake these tasks. Non-profit assistance and advocacy agencies such as the National Kidney Foundation and smaller regional groups also engage in social marketing.

After nearly a decade of consultations, reports and planning, in August 2008, Canadian Blood Services (CBS) took over a mandate from the Canadian Council for Donation and Transplantation (CCDT) to create and maintain a national registry of donors (Library of Parliament, 2009). The CBS will receive \$35 Million over 5 years to implement a national

registry program. Currently, this national registry has not been implemented, as it is still in the stage of assessment, trying to determine what type of registry to deploy. Without this potential tool for improving efficiency in matching donors and recipients, the status quo has to rely on the rules and programs in place in each jurisdiction, as well as the social marketing campaigns conducted by support organizations in those jurisdictions in order to increase potential donorship.

One program that the Canadian Blood Services has been able to roll out is a Live Kidney Donor Exchange registry, similar to the approach taken in the Netherlands in 2004. However, implementation of this program only occurred in February 2009, and to date there has been no data available to judge whether this has increased donor rates or had any significant impact on waitlists for kidneys.

6.2 Education Plus Strategy

This policy option goes further than the status quo and calls for each jurisdiction to design and implement comprehensive education campaigns to better inform the public about how exactly to become an organ donor and to engage Canadians in a discourse about the best course of action for increasing potential donor rates, both living and deceased.

At present, the social marketing of informed consent is a passive approach, only encouraging potential users to access materials and ‘consider’ the idea of becoming an organ donor. This strategy involves a media blitz through the traditional mediums of print, television and radio. Incorporation of new mobile and internet-based mediums such as blogging and social networking websites like Facebook and Twitter, as well as the addition of support and advice from certain professionals or organizations linked to legal, medical and ethical matters would improve the existing system.

Canadian Blood Services is the national lead on current projects involving organ donation, and each province and territory has a designated procurement organization, which will

make efforts to work with specific experts in organ donation matters to tailor campaigns for professional adoption. My survey results indicated that, outside of friends and family members, most people considered medical professionals to be the most important and best known sources of information about organ donation. Knowing this, a campaign can be tailored, with the assistance of the Canadian Medical Association, to bring General Practitioners and Family Medicine Doctors on board with promoting organ donation with the patients they see in their office.

A similar campaign can be developed in conjunction with lawyers who deal with family and estate law, as well as financial planners and planned giving advisors, who would similarly be able to speak to clients about facts and information about donation. However, this strategy also requires the caveat that the campaign must be sensitive to concerns about pressure and the ‘slippery slope’ involved in managing estate affairs. The drafting of wills, living will, and personal medical directives can be negatively impacted by clients feeling pressured by their lawyers or financial advisors, or friends and family members who may not want to deal with the hassles associated with keeping someone alive. Therefore, this strategy requires a very delicate balance of information and sensitivity to the circumstances of clients wishing to discuss organ donation.

This option increases the level of social marketing by developing targeted materials and strategies designed with multiple aims:

- to reach demographic communities that prove more resistant to consenting to organ and tissue donation, such as Aboriginals, Visible Minorities, young people and males;
- to improve knowledge of the consent procedures; to provide more outreach opportunities for interaction with communities; and
- to encourage family discussions so that individual wishes are respected.

Customization of materials will help target particular groups by including information in relevant languages and tones to address the characteristics of each specific community in areas where the population comprises a significant portion of the overall population. For this reason, it is important for procurement organizations and the Canadian Blood Services to identify partnerships with local and regional cultural/ethnic organizations, and find champions among those communities to advocate for organ donation from within.

It is also important to identify partnerships with religious organizations, particularly those associated with or ministering to groups that are reluctant to donate their organs. These organizations can assist in tackling the perceptions that organ donation goes against the tenets of a particular faith. Currently, the opinion of the major religions in Canada is that organ donation, when done with altruistic intentions, does not violate the tenets, and it is encouraged, but this advice is only given on an ad-hoc basis to followers who engage in the discussion with their religious leader first. The Education Plus strategy I propose involves procurement organizations and Canadian Blood Services seeking public endorsement of organ donation, as well as working with regional and local representatives of the religions on a campaign that engages followers in open dialogue with their local religious leaders, as well as encouraging the dialogue with family members.

6.3 Indirect Compensation strategy

This option takes the step of formally implementing a strategy in Canada where the government offers an indirect form of compensation to living donors or to the family or estate of deceased donors in order to encourage higher rates of donation. This option requires a two-pronged approach to ensure that both living and deceased donors receive an appropriate form of indirect compensation.

Indirect compensation refers to the provision of some form of compensation for consenting to live or cadaveric donations that is *not* a direct payment for the organ itself. For living donors, financial hardships created by lost income opportunities, auxiliary expenses such as telephone and travel expenses for an accompanying caregiver, or a decrease in household maintenance are serious enough impediments to agreeing to be a live organ donor. At present, some jurisdictions provide some form of indirect compensation, such as the federal employment income assistance scheme. However, these schemes are not universal, nor are the benefits equitable.

For deceased donors, considerations have been given to providing some assistance for funeral considerations, or for a one time gift to be given to a charitable organization of the individual's or family's choice as incentives for making the decision to consent to donation from a deceased relative.

Indirect compensation involving monetary compensation has not formally been adopted as a national strategy in any jurisdiction in the world⁵, so this option requires a proposal for how this system could be implemented in Canada. I propose that it can be tied to, and delivered through, other federal programs currently in place, with varying degrees of administrative complexity.

In the case of deceased donors, survivors can make a claim for a funeral benefit or alternatively a charitable donation benefit through the Canada Pension Plan as they simultaneously make a claim for the death benefit. This program can be an opt-in program, allowing CPP contributors to designate an extra amount from each pay period; if the deceased contributor cannot be a donor, the option may be given to convert the donation benefit to a

⁵ Singapore adopted a form of Indirect Compensation in 2009 whereby consenting to live or cadaveric organ donation moves a person up on the list if he or she ever finds himself or herself on the wait list for an organ. No monetary compensation is involved.

regular death benefit contribution. Alternatively, the survivor can opt to donate that amount to the charitable donation of their choice on behalf of the estate of the deceased.

For living donors, Klarenbach, Garg and Vlaicu propose a national reimbursement program with federal funding and coordination but provincial implementation. They estimate costs incurred by a living donor to be at the midpoint of \$1045 to \$5225, and allowing for growth in rates of donation, the anticipated annual national costs for such a reimbursement program for living donors of kidneys is \$560,000–\$2.8 million. In contrast, the cost in 2000 of providing dialysis therapy in Canada was an estimated \$9.4 billion. Each kidney donation may save the health care system about \$100,000 and provide additional quality-adjusted life-years. Assuming a 25% overhead for administering a national reimbursement program, even a 10% increase in kidney donations caused by the removal of economic disincentives may result in neutral or net negative costs from a societal perspective. (Klarenbach, Garg & Vlaicu, 2006)

6.4 ‘Spanish Model’ Plus

This policy option directs the jurisdictions of Canada to change the legal framework to a system where consent to become a donor after death is presumed unless an individual formally takes steps to withdraw his or her consent. In effect, it resets the default from opting into a program to donate organs after death (informed consent) to opting out of a program that implies consent is given unless stated otherwise⁶. The option takes the current Spanish Model, including a hospital-centric approach, and adapts it to the Canadian context, but goes a step further than just adopting the Spanish Model, because it requires an extensive education campaign to provide knowledge about the concept of Presumed Consent.

⁶ Presently, countries that have adopted Presumed Consent include: Austria, Spain, Portugal, Italy, Belgium, Bulgaria, France, Luxembourg, Norway, Denmark, Finland, Sweden, Switzerland, Latvia, Czech Republic, Slovak Republic, Hungary, Slovenia, Poland, Greece, and Singapore. Eight of these countries listed rank higher than Canada in 2009 for PMP donation rates.

As with other jurisdictions in the world that have adopted presumed consent, there is no requirement to change the legal framework interfering with family consent. It should be noted that of all of the options, this one is the most legally complex because of the presumed consent aspect, due to concerns about freedom of choice as laid out in Sections 2 (a) and 2(b), or Section 7 of the Canadian Charter of Human Rights and Freedoms. However, Dolling notes that presumed consent is capable of withstanding a charter challenge because it does not overrule the right to decide, it instead changes the default from ‘opt in’ to ‘opt out’. “However, as presumed consent legislation would allow for opting out, there is no obvious reason that it would run afoul of *Charter* rights, as “an opting-out system that reasonably reduced the risk of an unintended donation would be likely to satisfy the requirements of due process” (2009: p. 75).

The nature of the present system, with each province or territory managing its own consent processes need not be a barrier. With the agreement of all jurisdictions, the Federal government can introduce legislation, and any operational or administrative details can be the responsibility of Health Canada. However, it is not enough to simply legislate presumed consent and expect to see an increase in donor rates; similar to the Spanish model, it is also crucial to set up a national board consisting of federal and provincial/territorial partners with a mandate to work with designated transplant centres in Canada to make the process more hospital-centric. The success of this approach is dependent on the compensated staff professional component to address the issue of consent with the families of the deceased.

This option would also require an extensive education campaign to inform the public about the rights and responsibilities of the public to opt out, as well as to inform the public of the issues involved with deceased organ donation. A key component of the education strategy must be not only to see more people opt to remain as donors, but also to educate families about organ donation in order to see a decrease in refusal rates. Refusal rates could counter any gains made by simply switching to presumed consent, so this part of the donation discourse must be

addressed in the overall education component. Religious organizations must also be apart of the education component, in order to address concerns of morality and ethics raised by followers.

Provincial/territorial or the federal government could orchestrate the campaign depending on the level of government intending to adopt the option. It will involve print and digital media, information sessions, and forums open to the public to address issues and concerns. A media campaign with radio, newspaper and television exposure is also an essential component so that the public is aware of changes to come. I propose that the federal government take responsibility for creating an environment where all jurisdictions can move toward uniform adoption of presumed consent, as well as paying for the education campaign, and identifying partnerships among medical professionals and procurement organizations to ensure that the most accurate information is reaching the public in the most effective manner.

6.5 Excluded Policy Alternatives

Among the options excluded for consideration in this study are direct compensation; xenotransplantation; a grouping called ‘Non Heart-Beating Donors’ (NHBDs); and the expansion of eligible donors ruled out due to medical and physical reasons as noted by Health Canada earlier.

Direct compensation, where someone is paid a cash sum for agreeing to donating organs, is illegal in nearly every place in the world⁷; the only exception is Iran, where live donors are given a cash sum for their organ donation. It is seen as morally dangerous and a slippery slope for equity due largely to the current state of the black market. This market thrives in lesser developed countries, such as The Philippines and Turkey, where poor people are paid in cash sums for organs by rich people from developed countries. Direct compensation also raises

⁷ It should be noted that the question of legality does not stop a black market or ‘Transplant Tourism’ from occurring, which is why governments must at least take this option into consideration when addressing donor rates.

concerns about individuals choosing or being forced to donate for unscrupulous reasons. There is a large literature available in the legal, sociological, anthropological⁸, and medical fields discussing the exploitation of poverty and human slavery that is driving forced donations.

Xenotransplantation refers to the transfer of living cells, organs and tissues taken from non-human animal species into humans. It is currently not recognized as a medical practice because of the stringent rules and regulations regarding transplantation in industrialized countries; indeed, Health Canada has yet to approve any human trials of xenotransplantation. This controversial option also raises issues of morals, ethics and compatibility; people have a concerns that tissues, organs and living cells from other animals will lead to cross-germination of diseases that currently are endogenous to animals, but do not affect humans. There is further concern that the tissues of other animals are not compatible with human bodies due to different aging processes. It should be noted however that trials involving xenotransplantation have been approved in other jurisdictions in the world (for example the United States and the United Kingdom), and the changing technologies and biomedical processes may make this option one that requires further study in the future when it interacts with policy.

With regard to NHBDs, Knoll and Mahoney have argued that 3 main issues have delayed the use of organs from NHBDs in Canada: education, ethics and availability of resources. NHB donations are similar to those that occur in situations where brain death has been determined (and brain dead organ donors are the main source of deceased organ donations in Canada); in the case of NHBDs, when cardiac death has been determined, it is still possible, if acted on quickly enough, to remove other organs and tissues for transplant before degradation sets in, making the organ a less successful candidate for transplant. However, as Knoll and Mahoney point out, Canada's medical professionals have little experience with the issue, and in fact, they identify only six other countries in the world where protocols have been set up to deal with NHBDs. For

⁸ See studies by Nancy Scheper-Hughes

these reasons, it is determined that Canada must first lay the foundation in building up confidence and knowledge among professionals before this option can be considered for recommendation.

Finally, the option of expanding donors to include those previously excluded due to medical and physical concerns or issues must be addressed. It has already been noted that under certain circumstances, it is possible to be a donor so long as the recipient and medical staff involved have complete knowledge of the potential risks; however in order to remove certain restrictions listed by Health Canada (such as the 5 year male sex with male criterion, for example) and increase potential donorship, Canada would have to embark on an extensive campaign to change the way society thinks about donation and risks in a way that encourages current and former members of such risk groups to engage in full disclosure. This strategy would require a long term discourse so that understanding can be improved before this option becomes a legitimate one for recommendation.

7: Policy Analysis: Using Criteria to Determine the Best Approach

This section is devoted to analyzing the policy options against a defined set of criteria.

7.1 Criteria

I assess each of the four policy options using five key considerations to identify a strategy that will increase Canadian organ donor rates. The criteria employed in this study are not exhaustive, however they have been identified by studying the literature to determine the most important when dealing with the complex and sensitive nature of the problem.

Table 7.1 Criteria Definitions

Criterion	Definition
Effectiveness	The degree (% increase) to which the policy affects the rate of organ donation among people living in Canada in a timely manner
Legal Feasibility	The ability of the F/P/T legislative frameworks to adapt and accommodate the new policy
Stakeholder Acceptability	The degree of acceptability of the policy to each of the three main stakeholders involved in organ procurement: <ul style="list-style-type: none"> • The Public • Medical Professionals • Procurement Organizations
Cost (operating)	The costs to operate the option (CAD\$)
Implementation complexity	The level of administration/operational changes needed to implement the option

Table 7.2 refers to the thresholds used to create the ranking system for all criteria in determining the most effective policy option(s).

Table 7.2 Criteria Definitions and Measures

Criteria	Measure	Source	Scale
Effectiveness**	High (100%+ increase in rate) Medium (25% - 99% increase) Low (0 – 24% increase)	Survey; case studies	2 = High 1 = Medium 0 = Low
Legal Feasibility	Yes (Laws permit option fully) Partial (Laws vague/allow part of option) No (Laws do not permit option currently)	Canadian legal codes	2 = Yes 1 = Partial 0 = No
Stakeholder Acceptability*	Yes (more than 60%) Partial (30% to 60%) No (less than 30%)	Survey; literature	2 = Yes 1 = Partial 0 = No
Cost – Operating	Low (less than \$3 Million) Medium (\$3 Million to \$6 Million) High (\$6 Million +)	Literature	3 = Low 2 = Medium 1 = High
Implementation Complexity	High (Requires new framework) Medium (some admin/ops change required) Low (little or no change required)	Literature; Case studies	1 = High 2 = Medium 3 = Low

** indicates double weighting; * indicates multiple scores

7.1.1 Effectiveness

I double weight this criterion because it is the most important measure. The goal of any policy is to improve outcomes, so I judge a policy's success by how effective it is in increasing donor rates in Canada. The ranking of this criterion depends on whether the option exists in Canada or another jurisdiction, and whether it has demonstrated success in increasing organ donation rates significantly (100%+ increase), modestly (25% - 99%), or has failed to show a noticeable increase (0-24%). Sources used to judge this criterion include, but are not limited to: Chang et. al (2003); CORR (2002); and the Council of Europe (2009). No jurisdiction has tested the indirect compensation option by itself until late 2009 in Singapore, and no data is available to indicate its effectiveness in increasing donation rates. However, indirect compensation has been introduced in some jurisdictions as a component of other successful strategies (in Spain, British Columbia), and professional organizations such as the International Society for Heart and Lung

Transplantation (ISHLT), and the American Medical Association (AMA) (see Josefson, 2002: 1541) have come out in favour of studying its use. The measure for effectiveness for this option comes from question 26 of my survey.

7.1.2 Legal Feasibility

Available data from F/P/T legal frameworks in Canada form the basis of this criterion. As all jurisdictions operate under similar laws and regulations, there is no need to differentiate among the jurisdictions in terms of scores. The ranking of this criterion depends on the flexibility of the legal framework to permit any changes proposed. The legal framework could entirely allow an option (Yes), allows for partial adoption of an option (Partial), or does not legally permit the proposed option and requires changes to do so (No). The sources reviewed to judge this criterion are: Canada, *Uniform Human Tissue Donation Act*, 1980. Alberta, *Human Tissue and Organ Donation Act*, 2006. British Columbia, *Human Tissue Gift Act*, 1996. Manitoba, *Human Tissue Gift Act*, 1987. New Brunswick, *Human Tissue Gift Act*, 2004. Newfoundland, *Human Tissue Act*, 1990. Nova Scotia, *Human Tissue Gift Act*, 1989. Ontario, *Trillium Gift of Life Network Act*, 2000. Prince Edward Island, *Human Tissue Donation Act*, 1992. Saskatchewan, *Human Tissue Gift Act*, 1978. Quebec, *Civil Law of 1993 Articles 42, 43, 44*. Northwest Territories and Nunavut Territory, *Human Tissue Act*, 1988. Yukon Territory, *Human Tissue Gift Act*, 2002.

7.1.3 Stakeholder Acceptability

Stakeholder Acceptability will combine the scoring for each of the three key stakeholders – the public, medical professionals, and procurement organizations. Each group can have a maximum of 3 points for a total of 9 points, and these scores are based on data taken from the following sources: the survey conducted for this study; Oz, et. al., 2003; BC Transplant Society, Winter 2003, Winter 2009. Survey results and literature results for public and professional

stakeholders must meet certain thresholds: 60% or higher indicates high support; 30-60% indicates partial support; and below 30% indicates little or no support.

7.1.4 Cost – Operating

The cost criterion measures the cost of operating the proposed option. This criterion is a crucial consideration for policy makers who have to bear in mind the responsibility of optimizing both results and use of public funds. However, finding measures of this criterion proved difficult. Most literature about organ donation focuses on the cost savings of transplantation versus renal treatment therapies (i.e. dialysis), and very few sources offer any insight into the cost of operating or administering a policy. This is perhaps the most significant fault of literature involving organ donation. After surveying the few sources available, I ascertained that all of the policy options have operating costs below \$10 Million per year. The thresholds for this measure are: Less than \$3 million is low; \$3 million to \$6 million is medium cost; and over \$6 million is high cost. All dollar amounts shown were for inflation to show the nominal price in 2010 dollars. In the case of presumed consent, it was also necessary to calculate the exchange rate from Euros to Canadian Dollars. The data is sourced from: Klarenbach, Garg & Vlaicu (2006); Canadian Blood Services (2009); Health Canada (1999); and Matesanz (2001).

7.1.5 Implementation Complexity

This criterion is unique in that it relies not on the literature and survey results, but rather on judging the degree of complexity involved in adopting an option by comparing it to the present system in Canada. There is already a significant level of administration and operation supporting organ donation in Canada, so this criterion interprets the ability of the existing non-monetary resources to adapt to proposed changes. An option requiring significant or systemic overhaul or even a new framework rates as high in implementation complexity; medium complexity means

that some change will be required, though not extensive in nature; and a low complexity rating means that little or no changes are required to adopt the policy.

7.2 Analysis of Policy Options

Table 7.3 Evaluation Matrix

Criteria	Policy Options			
	Status Quo	Education Plus Strategy	Indirect Compensation	'Spanish Model' Plus
Effectiveness (x2)	Canada 3% increase (0)	US 62% increase (2)	Survey 20% increase* (1)	Spain 139% increase (4)
Legal Feasibility	Yes (2)	Yes (2)	Partial (1)	No (0)
Stakeholder Acceptability				
• Public	No (0)	Partial (1)	No (0)	Yes (2)
• Professional	Partial (1)	No (0)	Yes (2)	Yes (2)
• Support Organization	Yes (2)	Yes (2)	Partial (1)	No (0)
Cost – Operation	\$7 Million/year (1)	\$4.78 Million (2)	\$3 Million/year (2)	\$8.3 Million/year (1)
Implementation Complexity	Medium to High (2)	Low (3)	Medium (2)	High (1)
Total (out of 16)	8	12	9	10

*Based on percentage of survey respondents who indicated that indirect compensation would make them more likely to donate. Not based on actual case studies

7.2.1 Evaluation Matrix Findings

The ranking of the results is close: the education plus strategy and the presumed consent option both score similarly, though the education strategy comes out as best ranked overall. The highlights of each option are discussed below.

7.2.1.1 Status Quo

The status quo option scored the lowest for effectiveness, as the current system has proven ineffective in increasing organ donation rates. In fact, according to the Council of Europe Newsletters of 2009, Canada has slipped from 14th overall in 2008 to 15th overall among the countries in the report, not just because other countries are doing better, but because Canada slipped from 37.2 pmp to 36.2 pmp. The impact of a National Donor Registry currently in development may raise the prospects for the status quo option in terms of effectiveness. The status quo also did poorly among the public and medical professionals. Support among the public is strong in general, but that is not translating into increasing rates. Support among medical professionals is also low because, as the Oz survey indicates, medical professionals want to see more and drastic action taken to increase organ donor rates. In terms of implementation complexity, the Canadian Blood Services is currently in the process of developing a National Registry, and it has the administrative ability to carry out strategies currently under consideration.

7.2.1.2 Education Plus Strategy

This option scores well in implementation complexity and legal feasibility because the structures already exist to support a wider campaign. It is also a relatively low cost alternative for reaching across the country. In terms of support, it received the highest ranking from support organizations, as they favour education over other more drastic options. However, as the survey and literature indicate, similar large scale campaigns have failed to see significant increases in

donor rates in Sweden, the Netherlands, and the U.S, thus hurting effectiveness. The option also did poorly among medical professionals, scoring only 18% support in the ISHLT poll. Again this reflects the desire of medical professionals for stronger actions.

7.2.1.3 Indirect Compensation

This option received a low ranking. This was due to poor performance in effectiveness, public support and the mixed reaction from support organizations. The survey indicated that the option would not lead to increased rates, and procurement organizations are weary of the slippery slope between paying to support organ donation, and outright payment for an organ. In terms of effectiveness, there is no study indicating that this option by itself has any impact in donation rates. The option did moderately well in terms of cost, being a low cost option, and legal feasibility; it is interesting to note that there is nothing in any legislation about providing indirect compensation such as travel costs and lost wages. Medical professionals also strongly support this option, at least in terms of study and pilot programming.

7.2.1.4 ‘Spanish Model’ Plus

This option did the best in terms of effectiveness, because it makes every eligible person a donor unless they expressed otherwise. It received mixed scores for acceptability: among those surveyed, there was two-thirds support for presumed consent, and most respondents indicated they would not likely opt out if Presumed Consent was introduced in Canada. It has also proven a successful strategy in countries that have adopted in. Yet it has been noted that support for this option is low with certain support organizations. It did poorly in terms of legal feasibility and implementation complexity because the structures do not exist to support the option, and it is the costliest option due to the education component and because it requires a large input of cash and resources at the hospital level, increasing the costs of health care in most jurisdictions.

8: Policy Recommendations: Next Steps for Canada

The analysis of data for this study lends itself to the development of an overarching strategy in order to increase organ donation in Canada. The evaluation of the policies highlighted that components of the Status Quo, the Education Plus strategy, and the ‘Spanish Model’ Plus option all offered significant benefits, which can be implemented in steps so that the Canadian public has time to adapt to a new policy framework.

8.1 National Donor Registry

The centrepiece of these recommendations is the timely development of the National Donor Registry, which is currently the task of Canadian Blood Services. This is a key element of an overall strategy, and as such, it must be done right. A first step is for decision-makers to consider seriously to the development of a real-time information system similar to UNOS, as operated in the United States. The importance of using a similar real-time system is twofold. First, it will provide accurate and efficient data that will improve the likelihood of a match between donor and recipient. Second, the Living Donor Exchange Program currently in place in Canada can use the real-time data.

8.2 Comprehensive National Education Strategy

Concurrent to the development of the National Donor Registry, it is necessary for a national strategy to educate the public about issues involving organ donation, particularly emphasizing current consent standards in each province or territory. This would also be an opportunity for governments to encourage dialogue on understanding the legal and medical issues involved with consent and family matters. A priority is to focus the strategy on ensuring a better

understanding about organ donations, so that Canadians can make informed decisions and be a part of future discussions on organ donation policy. It is crucial that the education component also address the issue of presumed consent versus informed consent. At present, parliamentary documents have examined the idea, however, I found no evidence in the literature, nor any polling results (other than my own non-specific survey results) that would indicate whether presumed consent received approval or opposition among the Canadian public.

There is an opportunity to deploy a curriculum-based education component into schools, as has been done in London, ON, where organ donation is part of the health curriculum as part of a pilot program, known as *One Life...Many Gifts*, which has been in operation in some London high schools since 2001. There is no doubt that a positive outcome of this strategy is that students become more socially-aware of organ donation in general, and could potentially bring their knowledge home to family members, where there is the possibility of engaging in discussion about the topic. This would be highly beneficial for the public discourse, as well as private decision-making regarding organ donation.

However, this potential strategy comes with a caveat: a program dedicated to teaching youth about organ donation *must* be prepared with a great deal of care for the age of the students, the proper context (e.g. the proper class to teach the subject in; the predominant cultural or ethnic backgrounds of the school or district), cultural, religious and ethnic considerations, and consideration for parental objections to their child being exposed to sensitive issues related to organ donation. The program needs to be designed to meet the specific dynamics of the school, and should be sensitive to avoid ‘shaming’ or ‘guilting’ among groups with historically lower organ and tissue donation rates.

8.3 Adoption of the “Spanish Model”

The hospital-centric approach employing a professional staff member to address organ donation with families of ill patients and the deceased can help improve donation rates, as it has in Spain. In order to ensure uniformity, I recommend the creation of a body similar to the Spanish Ministry of Health Working Group on Organ Donation, comprised of representatives from the federal and provincial/territorial governments. The group’s initial mandate should include setting the parameters for the hospitals in approaching families about both live and cadaveric organ donation.

8.4 Overall Strategy Considerations

It is important to note that a strong communications plan accompany any strategy adopted by Canada in improving donor rates. The communication plan should be inclusive of all groups, well balanced in approaching the facts and misconceptions about organ donation, and discuss the value in changing the Canadian system by adopting elements taken from more successful countries.

Organ donation is not a topic that people in Canada address in their everyday lives. Therefore, the delivery of information must be handled carefully to ensure that discussion about this topic is more commonplace and sensitive; the goal is to increase the knowledge of the public so individuals make informed decisions about organ donation. Campaigners must show due caution that the campaigns they design are not distorted by misinformation or problems with transmitting the message to certain groups. I have already noted the importance of avoiding the ‘shame’ or ‘guilt’ factor in messages to groups with historically lower donation rates.

Another concern is the adoption of a “nudge” approach, as championed by Thaler and Sunstein (2008). Nudging is a non-coercive strategy adopted by policy-makers that make simple procedural or substantive changes to policies to “nudge” the public to make better choices.

Changing the default is an example of a nudge; the choice is still available to consumers, however the default is now set to opting out in the case of organ donation, instead of opting in. The use of this strategy must be carefully planned and implemented in order to avoid being seen as manipulation of the public. In this respect, the communications piece needs to be very clear and open: a choice to opt-out still belongs to the public.

8.5 Summary

With the exception of the adoption of components of the “Spanish Model”, these recommendations build on current policies in place. Implementation of the education strategy is quick and does not require a huge infusion of cash. The funds already spent on public education will require bolstering, but set the stage for potential changes, such as the national registry and the adoption of the “Spanish Model” components.

The national registry is already in the planning and development stages by the Canadian Blood Services, making it a medium term project, I recommend implementation of a real-time system similar to the UNOS system in the United States. UNOS has proven a very successful tool in increasing rates of organ donation in that country.

By far, the most ambitious of the recommendations is the adoption of components of the “Spanish Model”. This recommendation will require a concerted effort to establish a national working group among both levels of government, as well as a costly implementation strategy that requires hospitals to create or formalize a professional position, and work with government to develop guidelines for procuring consent. This model also must consider the locations and types of facilities where this framework will be implemented, given the realities of Canada’s remote communities and access to varying levels of community health care. The ‘Spanish Model’ is a long term recommendation for seeing increases in organ donation rates.

9: Conclusion: Looking to the Future

Using the policy analysis framework, I have determined that increasing the donor rate in Canada requires multiple strategies implemented over a staggered timeline. First, an extensive national education campaign addressing key components such as culture, refusal rates, and public dialogue about new strategies for increasing donor rates must be rolled out. Second, heavy consideration must be given to adopting a UNOS-style, real-time national donor registry that can be adapted to the Canadian context. Finally, Canada should move toward the adoption of the ‘Spanish Model’, which includes a presumed consent approach, a national working group on donation and transplantation, and a hospital-centric approach that better addresses the concerns of families or individuals facing the decision to donate organs.

I have also concluded that Canada has a real opportunity to survey global practices and use successful components of other countries to formulate a comprehensive strategy that would both increase the supply of organs for transplantation, and would make Canada a world leader in organ donation rates.

I have also identified areas for further research; these issues could only be mentioned here because they were either outside of the scope of this study, or their scope was large enough to warrant an entire study devoted to those issues. These issues include:

- A detailed analysis of the racial, cultural or ethnic differences in rates of donation among people living in Canada. There is little data available to understand why some and not other groups are more open to the idea of organ donation.
- Further study on the relationship between the choice to be a blood donor and the choice to be an organ donor. It is important to determine whether blood donors

can be targeted as a strong cohort to draw organ donors from, as well as determine if blood donors can be a valuable educational resources for spreading the word about organ and tissue donation.

- A more in-depth analysis into the reasons why individuals or family members refuse to become donors. By knowing more about the reasons, researchers, professionals and policy-makers can do more to address concerns that keep donor rates from increasing.
- A study to determine if a 'hierarchy of organ donation' exists among potential living donors. It may be the case that people are choosing not to become donors because they hold beliefs about lifestyle choices made by recipients or are concerned that organs that can be replaced so easily can be abused again and again.
- An analysis about developing linkages between health promotion and organ donation outcomes. The literature available deals with each consideration exclusively, however it may be important to understand the decision to live a healthier lifestyle has on decreasing demand for organ transplants.
- A better understanding about the sources of information and the dialogue that does take place in families may provide support for existing educational tools and resources, or provide new tools and resources for professionals and organizations engaged in the procurement of organs for donation.

Finally, a future area of concern and study involves the pursuit and implications of organ transplant tourism. Globalization has given rise to markets in countries where relatively wealthy Canadians can skip the waitlist and purchase organs from living donors in poor or less developed nations. This issue has implications for the Canadian health system, as it will be Canadian

doctors these ‘tourists’ seek if there are post-operative complications, or if problems arise requiring another organ transplant (a failed transplant moves an individual up the waitlist in terms of priority).

Overall, my study has indicated that there is little doubt that problems exist because of the current state of affairs concerning organ donation in Canada, and that mitigating the fallout can be handled with carefully-measured steps to improve donation rates.

Appendices

Appendix A: Survey Questionnaire

Q1. What is the first letter of your postal code?

- 1 British Columbia (V)
- 2 Alberta (T)
- 3 Saskatchewan (S)
- 4 Manitoba (R)
- 5 Ontario (P, N, L, M, K)
- 6 Quebec (J, G, H)
- 7 New Brunswick (E)
- 8 Nova Scotia (B)
- 9 Prince Edward Island (C)
- 10 Newfoundland and Labrador (A)
- 11 Yukon Territory (Y)
- 12 Northwest Territories/Nunavut (X)

Q2. ETHNICITY: Are you ABORIGINAL and/or a member of a VISIBLE MINORITY? Visible minorities in Canada are defined as “persons, other than Aboriginal people, who are non-Caucasian in race or non-white in colour.”

- 1 Yes
- 2 No

Q3. ORGAN AND TISSUE DONATION means the donation of organs, such as hearts or kidneys from a person who has died, or the donation of organs, such as kidneys or parts of a liver or lung, from a person who is alive, and the donation of tissues, such as skin, bone, or corneas from a person who has died. Transplantation is the surgical transfer of an organ or tissue from one person to another.

In the past year, have you heard, read, or seen any information at all about organ and tissue donation or transplantation?

- 1 Yes
- 2 No

Q4. In the past year, which of the following has been an important source of information for you about organ and tissue donation and transplantation? PLEASE CHECK ALL THAT APPLY.

- A. A discussion with a family member
- B. A discussion with a friend
- C. Information provided by a medical professional
- D. Information provided by a member of the clergy or your religious organization
- E. Information provided by an attorney
- F. Personal experience or involvement with organ and tissue donation

- G. A billboard or a poster in a clinic or public place
- H. General news media coverage
- I. Your work or school
- J. The Department of Motor Vehicles
- K. A public service advertisement on TV
- L. A public service advertisement on the radio
- M. A movie and/or TV show
- N. A community activity, such as a health fair
- O. The Internet or a Web site
- P. Health Canada or a Government Department/Agency
- Q. An organ and tissue donation organization
- R. Local news (TV, radio, newspaper)
- S. Other source(s)

Q5. Which sources of information WOULD BE MOST LIKELY to influence how you think or act about organ and tissue donation and transplantation? **(Allow up to three responses)**

- 01 Family member
- 02 Friend
- 03 Medical professional
- 04 Clergy or religious organization
- 05 Attorney
- 06 Personal experience or involvement with organ and tissue donation
- 07 Billboard or poster
- 08 General news media coverage
- 09 Work or school
- 10 Department of Motor Vehicles
- 11 Public service advertisement on TV
- 12 Public service advertisement on the radio
- 13 Movie or TV show
- 14 Community activity
- 15 Internet or a Web site
- 16 Health Canada or a Government Department/Agency
- 17 Organ and tissue donation organization
- 18 Local news (TV, radio, newspaper)
- 19 Other
- 20 (DK)

Q6. In general, do you strongly support, support, oppose, or strongly oppose the donation of organs for transplants?

- 4 Strongly support
- 3 Support
- 2 Oppose
- 1 Strongly oppose

Q7. Some organs such as kidneys or parts of lungs or livers can be donated while you are alive. How likely are you to donate an organ while you are living to A CLOSE FRIEND?

- 4 Very likely
- 3 Somewhat likely
- 2 Not very likely
- 1 Not at all likely
- 5 (Have donated)
- 6 I do not know

Q8. Some organs such as kidneys or parts of lungs or livers can be donated while you are alive. How likely are you to donate an organ while you are living to A FAMILY MEMBER?

- 4 Very likely
- 3 Somewhat likely
- 2 Not very likely
- 1 Not at all likely
- 5 (Have donated)
- 6 I do not know

Q9. Some organs such as kidneys or parts of lungs or livers can be donated while you are alive. How likely are you to donate an organ while you are living to SOMEONE YOU DON'T KNOW?

- 4 Very likely
- 3 Somewhat likely
- 2 Not very likely
- 1 Not at all likely
- 5 (Have donated)
- 6 I do not know

Q10. How likely are you to have your organs donated after your death?

- 4 Very likely
- 3 Somewhat likely
- 2 Not very likely
- 1 Not at all likely

Q11. If you ARE NOT VERY LIKELY OR NOT AT ALL LIKELY to have your organs donated after your death, is there a particular reason you are not likely to have your organs donated upon your death?

- 08 Not Applicable
- 01 Against religion

- 02 Can't donate for medical reasons
- 03 Don't want body cut up or disfigured
- 04 Afraid they will take organs before death
- 05 Don't trust the medical system, feel you will not receive the best medical treatment if you are a donor
- 06 Feel you are too old to donate
- 07 Other

Q12. Have you discussed with a member of your family your wish NOT to donate your organs after your death?

- 4 Not Applicable
- 1 Yes
- 2 No
- 3 (Not applicable/No family members)

Q13. IF YOU WISH TO BE an organ donor, have you discussed your wish with a member of your family?

- 4 Not Applicable
- 1 Yes
- 2 No
- 3 (Not applicable/No family members)

Q14. How willing are you to discuss your wishes about organ and tissue donation with your family?

- 4 Very willing
- 3 Somewhat willing
- 2 Not very willing
- 1 Not at all willing

Q15. Is there a particular reason why you are UNWILLING to discuss donation with your family? What is the reason?

- 01 Other
- 02 Haven't given it much thought
- 03 No, No reason in particular
- 04 Not applicable
- 05 Don't discuss death, it makes me/them nervous
- 06 Family would not understand
- 07 Family believes people should be buried whole
- 08 They are too young
- 09 Not in good health
- 10 Personal/none of their business
- 11 It is my decision

12 Afraid that talking about my death, will increase the chance that I will die

Q16. Has any member of your family told you about his or her wish to donate or not to donate his or her organs or tissues after death?

- 1 Yes
- 2 No

Q17. IF YOU DIDN'T KNOW your family member's wishes, how likely would you be to donate his or her organs and tissues upon his or her death, if it were up to you?

- 4 Very likely
- 3 Somewhat likely
- 2 Not very likely
- 1 Not at all likely
- 5 (Not applicable/No Family Members)

Q18. If a family member HAD REQUESTED that his or her organs and tissues be donated upon death, how likely would you be TO DONATE his or her organs and tissues if it were up to you?

- 4 Very likely
- 3 Somewhat likely
- 2 Not very likely
- 1 Not at all likely
- 5 Not applicable/No Family Members

Q19. Have you granted permission for organ and tissue donation? (check any/all that apply, or leave empty if none apply)

- A. On your driver's license or health care card
- B. On a signed donor card
- C. By joining an organ donor registry

Q20. Do you believe that marking organ donor on your license or health care card REGISTERS you to be an organ donor?

- 1 Yes
- 2 No

Q21. Would you be willing to grant permission for organ and tissue donation on your driver's license or health care card, on a donor card, or by joining an organ donor registry?

- 1 Yes
- 2 No

Q22. Some countries presume that people wish to donate their organs at death. This is called “presumed consent”. Their organs may be used for transplanting unless they have signed a document indicating that they don't wish to donate their organs. Would you strongly support, support, oppose, or strongly oppose using this presumed consent approach in Canada?

- 4 Strongly support
- 3 Support
- 2 Oppose
- 1 Strongly oppose

Q23. Is there a particular reason why you OPPOSE presumed consent? Please select up to 5 that apply.

- 09 Not Applicable
- 01 Other
- 02 Haven't given it much thought
- 03 No reason in particular
- 04 Feel presumed consent is unethical
- 05 Privacy Issues
- 06 You feel it is a violation of your rights
- 07 Distrust of the government
- 08 Religious preferences or beliefs

Q24. Do you think a system of presumed consent would increase or decrease the number of available organs for transplants?

- 3 Increase
- 2 (Stay the same/neither)
- 1 Decrease

Q25. If a system of presumed consent were adopted in Canada, would you sign up as a non-donor?

- 1 Yes
- 2 No
- 3 I don't know

Q26. Would indirect compensation make you more likely or less likely to donate YOUR organs, or would it have no effect?

- 3 More likely to donate
- 2 Would have no effect
- 1 Less likely to donate
- 4 I don't know

Q27. Would indirect compensation make you more likely or less likely to donate the organs of A FAMILY MEMBER, or would it have no effect?

- 3 More likely to donate
- 2 Would have no effect
- 1 Less likely to donate
- 4 I don't know

Q28. Is there a particular reason a payment would make you MORE or LESS LIKELY to donate your organs or a family member's organs? What reason? (Open ended and code responses by similarity)

Q29. The medical and surgical expenses of individuals who donate an organ while living are currently fully paid by provincial/territorial health care plans. Some people believe that these living donors should also receive other compensation for any expenses related to their donation, SUCH AS TRAVEL, CHILDCARE, OR LOST WAGES. Please state whether you strongly agree, somewhat agree, somewhat disagree, or strongly disagree.

- 4 Strongly agree
- 3 Somewhat agree
- 2 Somewhat disagree
- 1 Strongly disagree

Q30. Have you ever donated blood?

- 1 Yes
- 2 No

Q31. How many times in the past year have you donated blood?

- 9 Not Applicable
- 0 Zero or none
- 1 Once
- 2 Twice
- 3 Three times
- 4 Four times
- 5 Five times
- 6 Six times
- 7 Seven or more times
- 8 (DK)

Q32. Have you ever BEEN an organ or tissue DONOR?

- 1 Yes
- 2 No

Q33. Have you ever RECEIVED a DONATED organ or tissue?

- 1 Yes
- 2 No

Q34. Has any member of your family ever BEEN an organ or tissue DONOR, either while living or after death?

- 1 Yes
- 2 No
- 3 I don't know

Q35. Has any member of you family ever RECEIVED a DONATED organ or tissue?

- 1 Yes
- 2 No
- 3 I don't know

Q36 - 60. Below are several statements. For each one, please state whether you strongly agree, somewhat agree, somewhat disagree, or strongly disagree.

- 4 Strongly agree
- 3 Somewhat agree
- 2 Somewhat disagree
- 1 Strongly disagree

36 All people who need an organ transplant receive a transplant

37 Discrimination prevents minority patients from receiving the organ transplants they need

38 You are worried that a loved one's body would be disfigured if his or her organs were donated

39 It is possible for a brain-dead person to recover from his or her injuries

40 Organ and tissue donation helps families cope with their grief

41 Every year, hundreds of people in Canada die due to a lack of donated organs for transplantation

42 Organ and tissue donation can often transmit diseases, such as HIV, hepatitis, or West Nile virus

43 A person's wish to donate his or her organs should be honored under all circumstances

44 There should be a registry of people who wish to be organ donors that can be accessed at the time of a persons death to make sure his or her wishes are known

45 If you indicate you intend to be a donor, doctors will be less likely to try to save your life

46 Transplants often go to undeserving people

47 You wouldn't want to donate an organ yourself

- 48 It is important for a person's body to have all of its parts when it is buried
- 49 It is important for people to tell their families whether or not they would want their organs to be donated upon death
- 50 Most members of your family support the idea of organ and tissue donation
- 51 Most people who receive transplants gain additional years of healthy life
- 52 Organ donation allows something positive to come out of a person's death
- 53 A deceased person's next of kin should be able to override the deceased person's wish to donate his or her organs
- 54 Given equal need, a poor person has as good a chance as a rich person of getting an organ transplant
- 55 Doctors will do everything they can to save a person's life before organ donation is even considered
- 56 Organ transplantation is an experimental medical procedure
- 57 Organ and tissue donation is against your religion
- 58 People your age are too old to DONATE organs
- 59 It is impossible to have a regular funeral service following organ and tissue donation
- 60 People your age are too old to RECEIVE transplants

DEMOGRAPHICS

61. What gender do you identify as?

- 1 Male
- 2 Female
- 3 Other

62. What is the highest level of education you have completed? Choose one:

- 1 Less than high school graduate (0-11)
- 2 High school graduate/General equivalency diploma
- 3 Some post-secondary
- 4 Trade/Technical/Vocational training
- 5 College degree/diploma
- 6 Undergraduate degree/diploma
- 7 Graduate degree

63. What is your month and year of birth? (Open answer) **(code actual age according to codes below)**

- 1 Under 19
- 2 19 – 30 Years
- 3 31 – 45 Years
- 4 46 – 60 Years
- 5 61 – 75 Years
- 6 76+ Years

64. Do you work in the healthcare profession?

- 1 Yes
- 2 No

65. What is your marital status?

- 1 Single
- 2 Married
- 3 Common Law
- 4 Separated/Divorced
- 5 Widowed

66. What is your total annual household income before taxes?

- 1 Under \$12,000
- 2 \$12,000 to \$19,999
- 3 \$20,000 to \$29,999
- 4 \$30,000 to \$49,999
- 5 \$50,000 to \$74,999
- 6 \$75,000 to \$99,999
- 7 \$100,000 or more

Appendix B: Correlation table: beliefs about donation, granting permission, and willingness to donate

Beliefs about Donation and Correlations with Donation and Willingness to Donate.

Question	Percentage Responding				Correlation With	
	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Granted Permission	Willing to Donate
All people who need an organ transplant receive a transplant	5.2	12.3	20.0	62.6	0.157	0.022
Discrimination prevents minority patients from receiving the organ transplants they need	4.5	14.8	42.6	38.1	-0.164	0.063
You are worried that a loved one's body would be disfigured if his or her organs were donated	3.2	14.2	21.9	60.6	0.263	-0.302
It is possible for a brain-dead person to recover from his or her injuries	4.5	21.3	25.2	49.0	0.139	-0.026
Organ and tissue donation helps families cope with their grief	18.7	66.5	11.0	3.9	-0.154	0.198
Every year, hundreds of people in Canada die due to a lack of donated organs for transplantation	61.9	36.1	1.3	0.6	-0.078	0.174
Organ and tissue donation can often transmit diseases, such as HIV, hepatitis, or West Nile virus	5.8	25.2	41.3	27.7	0.225	-0.336
A person's wish to donate his or her organs should be honored under all circumstances	65.8	26.5	5.2	2.6	0.016	0.008
There should be a registry of people who wish to be organ donors that can be accessed at the time of a persons death to make sure his or her wishes are known	66.5	30.3	1.9	1.3	-0.262	0.214
If you indicate you intend to be a donor, doctors will be less likely to try to save your life	3.2	10.3	18.7	67.7	0.350	-0.287
Transplants often go to undeserving people	1.9	10.3	37.4	50.3	0.254	-0.305
You wouldn't want to donate an organ yourself	5.8	7.1	26.5	60.6	0.582	-0.662

Question	Percentage Responding				Correlation With	
	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Granted Permission	Willing to Donate
It is important for a person's body to have all of its parts when it is buried	1.9	5.2	14.8	78.1	0.462	-0.422
It is important for people to tell their families whether or not they would want their organs to be donated upon death	79.4	16.8	1.3	2.6	-0.114	0.210
Most members of your family support the idea of organ and tissue donation	46.5	36.1	13.5	3.9	-0.379	0.377
Most people who receive transplants gain additional years of healthy life	58.1	38.1	3.2	0.6	-0.038	0.053
Organ donation allows something positive to come out of a person's death	75.5	22.6	0.6	1.3	-0.164	0.250
A deceased person's next of kin should be able to override the deceased person's wish to donate his or her organs	1.9	7.1	23.9	67.1	0.103	-0.125
Given equal need, a poor person has as good a chance as a rich person of getting an organ transplant	25.8	32.3	32.9	9.0	0.050	-0.022
Doctors will do everything they can to save a person's life before organ donation is even considered	68.4	24.5	5.8	1.3	-0.445	0.326
Organ transplantation is an experimental medical procedure	0.0	7.1	39.4	53.5	0.129	-0.092
Organ and tissue donation is against your religion	1.9	4.5	9.0	84.5	0.197	-0.347
People your age are too old to DONATE organs	1.3	2.6	3.9	92.3	0.118	-0.373
It is impossible to have a regular funeral service following organ and tissue donation	5.2	2.6	11.6	80.6	0.068	-0.193
People your age are too old to RECEIVE transplants	0.6	2.6	3.2	93.5	0.205	-0.396

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