A Review of the Economic Implications of Living Organ Donation:

Donor Perspectives and Policy Considerations

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EXECUTIVE SUMMARY

- **From the health care system perspective kidney transplantation, and especially live donor kidney transplantation, results in longer life, improved quality of life, and overall cost savings. While less is known regarding liver and lung transplantation, liver transplants are considered cost-effective, and increased living lung donation may improve the cost-effectiveness of this procedure.**

- **Living donors are exposed to financial risk through their altruistic act of donation. Costs include travel and accommodation, lost income, and childcare, and some believe it is just that donors who incur these costs be reimbursed by the government. While the existing literature likely underestimates the economic consequences, it appears that they are common and may represent a significant burden to some donors. Future studies which comprehensively measure all donor incurred costs are needed to better estimate true economic consequences. .**

- **Financial risk may be a disincentive or barrier to potential donors. However, there is no direct evidence indicating to what extent living donation rates would be altered by elimination of this risk.**

- **International organizational bodies have explicitly endorsed reimbursing financial consequences to living donors as acceptable, and differentiate this from for profit donation, which is deemed unacceptable. While many countries have adopted policies to this end, this is not yet universal.**

- **Currently Canada does not have a national unified strategy to reimburse living organ donors. Several federal, provincial, and charitable programs exist which may partially assist financial burdens of donors, although they highly variable and limited in scope.**

- **There are several policy and implementation options which could be used to develop unified strategies which reimburse living organ donors for incurred expenses.**

- **Twelve percent of donors are concerned about the effects of donation on their future insurability. There is some evidence to suggest insurability is negatively affected by living organ donation, and that this may be a potential barrier to becoming a donor.**

1. ECONOMICS OF LIVING ORGAN DONATION: A HEALTH CARE SYSTEM PERSPECTIVE

Living organ donation is firmly established as a viable and advantageous treatment for end-stage renal disease, providing increased life expectancy, improved quality of life, and net health care cost savings compared with dialysis (1), and as such it should be strongly encouraged provided that it occurs in a safe and ethical manner. One living kidney donation is estimated to result in a net increase of 2 to 3.5 quality adjusted life years for the recipient, and net health care savings of ~$100,000 CAN (2, 3).

Living liver and lung donation are emerging as options for the treatment of end-stage hepatic and pulmonary disease. While hepatic transplantation is not cost saving, it is considered to be cost-effective (4). Living liver donation is associated with increased work-up and surgical costs compared with deceased donation, although the positive impact on waiting list time and increased probability of a patient being transplanted with increased living donors has not been fully accounted for (5). Although substantial variability exists depending on the primary lung diagnosis (6), preliminary findings suggest that the cost-effectiveness of lung transplantation may not be as favorable (7), although increasing living lung donation may have a salutary effect on its cost-effectiveness(8).

In Canada, the growth of solid organ transplantation over the past decade has primarily been due to increases in living organ donation, for which rates have doubled within the past decade (9). In 2004, the rate of living donation was 14.7 per million, with 41% of all kidney transplants and 13% of all liver transplants being from living donors. Nevertheless, waiting lists continue to grow, and further strategies to increase organ donation from living donors continue to be explored (3, 10).

2. ECONOMIC IMPACT OF LIVING ORGAN DONATION: THE DONOR'S PERSPECTIVE

Despite the many benefits of living donor kidney transplantation, economic consequences can result for donors. Financial hardship or significant financial burden has been reported in 23% of living kidney donors (1, 2), and potential live donors often express concern about the financial implications of donation (3-5). While expenditures for medical evaluation, surgery, and hospital care are generally covered through public or private insurance, donors are often responsible for other costs associated with the donation process. Here we assemble and analyze existing quantitative data on the direct and indirect costs incurred by living kidney donors, in order to understand the strengths and limitations of existing literature. We considered the economic impact, monetary value, and timing of donors' direct and indirect costs.

Methods:

All possible direct and productivity (indirect) costs incurred were identified (3, 6-8), and then refined and expanded using detailed information provided through correspondence with 16 transplantation experts from 10 countries. The resulting cost framework is presented in Table 1. Direct costs consist of all resources consumed from the perspective of the donor (which may not involve a direct monetary transaction), and include: travel for tests, appointments and hospitalization; accommodation; long-distance telephone charges, and incidental medical costs such as fees for medications after discharge. Productivity costs consist of the economic consequences of lost or impaired ability to work or engage in leisure activities and include: lost income, and household costs related to dependent care and domestic chores.

Summary of results:

Description of cost for those who donated between 1964 and 2003 were identified. Most were from North America (n=18), with the remainder in the EU (n=12) and other countries. Analysis of donor costs was a primary aim in only 4 out of 35 identified studies. (All in results in US 2004 currency)

Table 1. The Direct and Indirect Costs Incurred by Living Donors

Type	Categories	Definition	Unit Costs
Direct	Travel	Return-trip travel costs because of tests, appointments, and hospitalization. Includes: (1) Flight, rail, ferry, bus and taxi fares; (2) Passport, visa, and travel insurance; (3) Vehicle rental plus mileage and parking fees; (4) Mileage and parking fees for a privately owned vehicle.	# Return-trips Distance per trip Travel modality
	Accommod-ation	Lodging and meal costs because of *out-of-town* appointments, hospitalization, and post-discharge recovery.	# Overnight stays Lodging type, # Meals
	Long-Distance Phone Calls	Costs for related long-distance phone calls placed. Examples: Calls to transplant center for decision-making regarding donation, calls to secure accommodation, and calls to family during hospitalization.	# Minutes Origin & destination of call
	Medical	Incidental medical costs not covered by public or private insurance. Example: Post-discharge medication fees.	Drug type, dose, and duration
Indirect	Lost Income	Missed earnings during absence from paid work because of tests, appointments, hospitalization, and post-discharge recovery. Includes: Income normally earned through self-employment.	# Hours
	Dependent Care	Hired caregiver costs because of tests, appointments, hospitalization, and post-discharge recovery. Includes: Child, elder, and spousal care.	# Hours
	Housework	Costs for domestic help hired because of tests, appointments, hospitalization and post-discharge recovery. Includes: Cleaning and laundry.	# Hours
	Other	Costs for miscellaneous services hired for help with daily activities because of tests, appointments, hospitalization, and post-discharge recovery. Examples: Personal care, shopping, errand running, food preparation, and pet care.	# Hours # Deliveries

Donor Incurred Costs by Category:

a) Travel and Accommodation - In countries with a large landmass to population ratio (such as Canada), 53% of donors were affected by transportation and parking costs(4). A study from multiple centers in the US found almost all donors experienced travel and accommodation costs. Transportation costs were claimed by 99% of donors in this study, while 88% declared costs for lodging. Demographic data revealed that 32% of donors in this US study had traveled from outside of state (9). 9% of living kidney donors at a UK transplant center incurred an average of $1,720 for travel and accommodation combined, while costs incurred by individual donors ranged from $76 to $12,579 (10). Costs incurred for travel and accommodation are common and are influenced by the geographical context.

b) Medical – Evaluation, surgery, and hospital care are generally covered by public or private insurance, but the scope and comprehensiveness may vary by region and nation. Personal medical costs were experienced in 8% of donors in a Canadian study (4), although the magnitude and source of costs were not described. Prescription and over-the-counter analgesics may be a major source of these costs (11, 12).

c) Lost Income – Return to part-time work is reported after an average of 22 days (13), however return to physically demanding work occurred after an average of 41 to 57 days (14). While infrequent, it has been reported that reported that physical limitations following surgery caused 3% of donors to either be fired or resign from previously held employment (15, 16). Lost income has been reported 14 to 30% of living kidney donors (4, 10, 17). The monetary value of donors' lost earnings was determined in only two studies. Average losses were $3,386 in a UK study (10) and $682 in a study from The Netherlands (18).

d) Home Productivity – While overall these are incompletely captured, dependent care costs are incurred by 9-44% of kidney donors (4, 9), and resumption of normal activities may take weeks to months to occur (care of others 13-22 days, housework 7-34 days, shopping 7-35 days, driving 11-42 days). While these may seem trivial, they represent real economic losses to an individual and their household, as evidenced by the report that 10% of family members of donors report lost wages (4).

e) Total Costs Incurred – Ten studies from seven countries found that an average 9 to 45% of living kidney donors incurred at least some costs as a result of donation (1, 2, 15-17, 19-23). Three studies, all from the US, measured their summed value. In the first, overall costs ranged from $0 to $28,906, with an average of $837 per donor (17). Average overall costs in the second was $107, however values ranged from $0 to $13,788 and 8% of donors assumed overall costs greater than $1,724 (1). The third study compared laparoscopic surgery to open nephrectomy costs. Donors' personal costs with the

open approach were an average of $3089 ± 2354 overall, and $907 ± 579 with the laparoscopic approach(24).

Quality of studies: The majority of studies were retrospective (30/35), with most employing mail-based surveys, telephone, and group interviews. Time frame for donor recall was reported in 5 studies, with 4/5 exceeding 12 months. This is important, as recalled costs recalled beyond a 1-year time frame are systematically underestimated (52). Response rate varied between 45-100%, although the majority had reported response rates of <80%, introducing another potential for bias. Further more, the framework for capturing donor economic consequences was poorly described, and no study comprehensively captured total costs. The year in which costs occurred were poorly described, which has implications for adjusting costs to net present value.

Summary of Systematic Review

Weaknesses of the current literature are likely to lead to systematic underestimates of the frequency of economic consequences to donors, as well as underestimated of their monetary value. However, it is evident that these economic consequences are common, and that some donors may experience severe financial consequences, especially those of lower socioeconomic status.

Other Data on Living Donor Costs

In 2004, the Canadian Council for Donation and Transplantation commissioned an environmental scan to assess major barriers to living organ transplantation. 74% of living donors reported out-of-pocket expenses associated with donation, and a majority reported lost income or wages (total reported financial losses added up to an average of $6,651). Only 41% of donors were partially reimbursed by government, insurance agencies, hospitals, transplant recipients, foundations, or relatives. Living donors felt that prescription drugs, loss of income, travel and parking costs (including an escort for out-of-town travel), post-surgery accommodation, and child care expenses for single parents, should be covered.

3. FINANCIAL RISKS: A BARRIER TO DONATION?

The perception of financial risk and how this influences the decision making process of a potential living donor is not clear. Biologically related and spousal donations comprise the majority of living donors, who may already be financially impacted by having a family member with a chronic medical illness. In these donors, altruism and the desire to improve the well being of the recipient may trump all other considerations, including donor medical and financial risk. Thus it is possible that donors, who may already be financially disadvantaged, may assume a large burden of financial risk through their altruistic act. In contrast, donation practices now include donors who may have a less close relationship with the recipient. In these potential donors, the possibility of financial risk may be an important consideration in the decision to donate.

While the impact of financial risk on decision-making has not been explored in detail, a single centre study of 133 potential donors to a family member reported that 24% did not donate due to the anticipated financial hardship (1). This same study indicated recipients with higher income levels were more likely to receive a living donor kidney, suggesting that household financial status may influence which recipients receive a living (vs. deceased) donor kidney. A similar pattern of higher aggregate income level for those receiving a living versus deceased donor kidney exists in Canada (unpublished data from the Canadian Organ Replacement Registry), and it is possible that these economic consequences may pose a larger burden to potential donors of lower income strata.

In the CCDT environmental scan, donors and health professionals reported that donor financial considerations – job loss, delay or difficulty in receiving employment insurance benefits, out-of-pocket expenses, availability and cost of insurance – were a barrier to donation. Transplant programs and physicians mentioned that potential live donors sometimes or usually express concern about financial implications of donation, and felt that living donors should not be responsible for these expenses. Also reported is that 92% of living donor respondents agreed that whether they received any reimbursement

had no bearing on their decision to donate; 85% of donor respondents mentioned they were able to cope with these financial losses, however, the study only included respondents who had donated. What is not clear is whether individuals have decided against donating an organ due to anticipated adverse financial consequences; no individuals belonging to such a group were included in the study.

The existence of financial barriers to potential live organ donors appears to runs contrary to the desire of increasing living organ donation rates in Canada, and is considered by some to be unjust. However it should be noted that it is unclear to what extent living organ donation rates would increase with institution of a reimbursement program, if at all.

4. EVALUATING INTERNATIONAL LEGISLATION

There is a global shortage of organs, with many countries seeking to remove barriers to living organ donation. Here we reviewed the legislation various countries have adopted which explicitly or implicitly allow for reimbursing living organ donors for incurred expenses

Methods

A comprehensive search of the literature was performed. We were only able to include countries for which information was available in English through one of the sources specified. However we benefited from the WHO legislation database with its officially-translated legislation, as well as from English-speaking contacts affiliated with the International Kidney Foundation.

Results

Low rates of organ procurement are a global issue. Most nations are investigating new approaches to increase organ donation and transplantation, and many have relaxed regulations, to allow living donors to be reimbursed for incurred expenses.

a) *Position of international entities and professional organizations on remuneration*: Major international organizations also moved towards acceptance of reimbursement and now clearly distinguish commercial trade in organs from remuneration of 'out of pocket' expenses. In a policy developed in 2002, the Council of Europe clearly defined both concepts. While it is unethical for any party participating in the procedure to financially benefit from the process (1), the Additional Protocol identified forms of payment not considered financial gain, such as compensation for loss of earnings and other fees (2). The World Medical Association, at the 52nd General Assembly in Edinburgh in October 2000, also made similar statements: "payment for organs and tissues for donation and transplantation should be prohibited" (3), but "…reasonable reimbursement of expenses such as those incurred in procurement, transport, processing, preservation, and implantation" should be allowed (4) .The American Medical Association's Council on Ethics and Judicial Affairs followed suit by amending Opinion E-2.15, in June 2004, to specifically address living donors: "It is not ethical to participate in a procedure to enable a living donor to receive payment, other than for the reimbursement of expenses necessarily incurred in connection with removal, for any of the donor's solid organs" (5).

b) *Countries with legislation allowing remuneration*: Many countries have started to address reimbursement of non-medical expenses for living donors, including: Belgium, the United Kingdom, France, Germany, Finland, Hong Kong, Japan, Luxemburg, the Netherlands, Poland, Spain, Sweden, Australia, and the United States (6). In each of these countries, national or sub-national legislation or policies allow organ donors to receive reimbursement for directly attributable costs, including expenses and lost wages (see Table 2). The United Kingdom allows reasonable reimbursement from NHS trusts to living donors for expenses such as travel, accommodation, and loss of earnings (7). In France, reimbursement of living donors (travel, accommodations, testing, and lost income) is mandated and carried out by individual transplant centers (8). In the United States, federal legislation provides federal employees with a 30-day paid leave for organ donation (9), and $5 million per year in grants for pilot programs to reimburse living donors. Pending legislation would add organ donation as eligible grounds for family/medical leave for private employers (10). States followed the federal model and implemented paid leave for their organ-donor employees (22), unpaid leave for all employees (Arkansas) or a

combination of paid and unpaid leave (Connecticut). In 2004-2005, almost 30 states introduced tax legislation to allow living donors to deduct up to $10,000 per year in related expenses; 7 states have already implemented the program (11). However, no existing state or federal program considers all costs incurred by donors.

Table 2. Selected Examples of Countries that Implicitly or Explicitly Allow Compensation

Country	Legislation
France*	- transplant centers are required to reimburse donor for travel and accommodation expenses - legislation also allows for health care establishment compensation to donors for 'lost remuneration', although this is not clearly defined
Belgium†	- the state is responsible for compensation for incurred living donor expenses
United Kingdom	-National Health Service Trusts and Primary Care Trusts are permitted, yet not required, to reimburse for costs associated with travel, accommodation, and loss of earnings up to an annual maximum allowable amount
Chile	- costs incurred by removal are to be covered by the costs of transplantation and charged against the recipient
Israel	- no law prohibits organ trafficking - state provides compensation for donors who travel abroad for transplantation
Iran	- organ trade is legal and regulated by the state
India	- organ trade is prohibited by law, but it allows for largely unregulated unrelated kidney donations, a loophole that allows donors to be paid directly for organs
Canada	- provincial and territorial healthcare plans protect donors from the medical costs of organ donation - although no national program is in place to reimburse donors for non-medical expenses, social programs, such as employment insurance, are available to offset some of the individual costs associated with donation
United States	- federal health insurance covers the medical costs of transplantation for the elderly and low-income earners - various states have adopted paid donor leave programs - the Organ Donation and Recovery Improvement Act (2004) provides some federal dollars for reimbursement of travel and subsistence expenses, however it is unclear if this program will be continued when the allocated funding expires.

* similar policies exist in Germany, Japan and Morocco
† similar policies exist in Spain, Finland and Singapore

c) *Countries with legislation opposing remuneration*: Other countries such as Hungary, Portugal, Slovakia and Turkey do not allow compensation for living donors, implicitly or explicitly (see Table 3). These countries emphasize the altruism of organ donation, with any form of payment as unethical.

Table 3. Selected Examples of Countries that Do Not Allow Compensation

Country	Legislation
Portugal*	- forbids compensation of any kind to donors - transplant centers are required by law to obtain insurance to cover the medical costs associated with the transplant
Argentina**	- no legislation exists to allow compensation for donors - medical costs, however, are covered by the state
Turkey***	- expressly forbids any compensation to donors

*similar policies exist in Slovakia **similar policies exist in South Africa ***similar policies exist in Hungary

Discussion

The analysis of international legislation shows considerable variations across countries. There is, however, a clear global policy trend towards differentiating between the unethical and unacceptable commercialization of organs and the just reimbursement of altruistic donors for incurred expenses. In the last several years, three major international health organizations have amended existing position statements to define financial reimbursement of living donors as ethically acceptable. Moreover, many countries have either adopted or are in the process of developing specific policies and legislation.

5. EVALUATING CURRENT CANADIAN INITIATIVES AND POLICIES WHICH REIMBURSE LIVING ORGAN DONORS FOR THEIR NON MEDICAL EXPENSES

We surveyed individuals within the field of transplantation from across the country to identify reimbursement initiatives in each province, to determine how these programs function, and to ascertain

provincial or institutional capacity to administer a comprehensive reimbursement program, should it be funded by the government.

Methods

Using open-ended questions we surveyed key Canadian informants in transplant centres, provincial governments, professional associations, non-governmental organizations and charities active in the field of transplantation (1, 2), prioritized based on their direct experience in working with living organ donors on issues of reimbursement. Once the information was synthesized, respondents were contacted again and asked to validate a written summary of findings for their province.

Results

Survey respondents: There was a general consensus among our respondents that reimbursing living organ donors for their non-medical expenses is desirable; moreover, they agreed with the fairness principle that donors should not be penalized for giving up an organ, financially or otherwise. Only a few expressed concerns that awarding money to living donors could lead to the commercial trade of organs. Most respondents believed their province or institution could administer a reimbursement program, provided there was funding for hiring additional personnel.

Federal governmental policies: Although a comprehensive program is lacking, several federal policies may offer partial financial support to living donors: federal income tax credits, the Employment Insurance (EI) program for those donors who become unemployed, and long-term disability insurance. The Medical Expense Tax Credit allows living donors to claim some medical expenses on their federal tax return including travel, meals, and accommodations. Expenses are calculated using receipts or a provincial flat rate. Those traveling under 40 kilometres can only claim travel costs, while for distances over 80 kilometres, the cost of meals, accommodations, and companion (if recommended by a doctor) can be added. For 2004, a donor could claim only expenses in excess of 3% of his net income or $1,813, whichever was less. This is a non-refundable tax credit (i.e., reduces the individual's federal income tax). Lower income donors are at a disadvantage since their tax liability is lower.

Donors employed prior to donation may receive financial assistance under Canada's Employment Insurance (EI) program. Eligibility requires previous contributions to the program and 600 hours of work in the 52 weeks before taking time off. The EI program has a 'sickness benefits' component for those who cannot work due to health reasons and 'regular' benefits for people who lose their jobs through no fault of their own. An EI recipient can obtain benefits (sickness and regular) for a maximum of 50 weeks. Sickness benefits are not available before the surgery, but can be received after transplant for a maximum of 15 weeks which not always cover the entire recovery (3, 4). After this period, donors can switch to regular EI benefits for 35 more weeks if they are able to work but unable to find employment. During these 50 weeks, the maximum benefit is the lesser of 55% of average income or $413/week. Thus a person with an insured income of $35,000 in the previous year would receive about $370/week; one with an insured income of $45,000 or more would receive the maximum benefit of $413/week. However, due to alternative work arrangements (part-time, no EI contributions) more than a half of Canadians who become unemployed are ineligible for the EI program (5). If unable to work after sickness benefits, a donor can use private short-term disability insurance, if available. However, only 42% of all Canadian employers provide their employees with health-related benefits, such as disability insurance (6). The Canada Pension Plan (CPP) disability benefit is available to donors whose disability prevents them from working for more than a year and who contributed to the plan. To be eligible, the physical or mental impairment must be 'severe and prolonged.'

Provincial policies: Provincial health plans cover medical costs associated with living donation, yet financial support for non-medical expenses such as travel, accommodations, lost income, or dependent care is less available and inconsistent across the country. To date, no province has implemented a formal, comprehensive program to cover all these costs. Nonetheless, living donors have access to initiatives such as medical travel assistance programs or limited reimbursement programs through charities or transplant centers (See Table 4). Most non-governmental initiatives are ad hoc and limited in scope; they generally lack formal annual budgets and clearly formulated guidelines to establish need.

TABLE 4. Provincial Reimbursement Initiatives

Province	Plans for Implementing a Comprehensive Reimbursement Initiative	Travel Program	Hospital Initiatives	Provincial Charities	Institutional or Provincial Capacity to Administer a Reimbursement Program
Alberta	In 2003, a governmental working group recommended compensating living donors for costs directly related to donation; no policy or program implemented to date.	Not reported.	Social workers connect donors with aid or discount programs. The transplant community works to increase financial support.	Limited financial support through Kidney Foundation and various other charities (such as Kinsmen Foundation, Rotary Club)	Yes. Clear federal guidelines and flexibility are preferred, to allow for regional differences in costs.
British Columbia	Proposal recently prepared that would provide donors on average with $3,170 for travel, lost income, and living expenses. This is the only comprehensive provincial initiative to provide guidelines for financing and methods of reimbursement.	The Travel Assistance Program offers travel discounts to donors and escorts on: ferries, airlines and coach lines.	The British Columbia Transplant Society assesses the financial situation of each donor and assists in applying for funding to help cover non-medical expenses.	The Kidney Foundation owns 3 'kidney suites' in which donors, recipients, and families can stay around the time of donation and recovery. It so provides limited grants and no-interest loans to donors in need.	Yes. In BC, organ donation registry and transplantation are centralized, allowing increased efficiency and better use of infrastructure.
Manitoba	Not reported.	Manitoba Health may reimburse costs of economy air, train, or bus fare for out-of-province care (and escort) if approved by doctors.	Not reported.	Limited patient grants from Kidney Foundation – maximum of $200 per patient per year.	Maybe. Some respondents questioned the province's institutional capacity to administer a comprehensive reimbursement program.
New Brunswick	Not reported.	Program with dedicated infrastructure and budget that funds travel, accommodations, and meals.	Limited funds from local hospitals for needy donors; social workers assist with other applications.	Kidney Foundation makes efforts to assist donors in financial need	Yes, as a government-run program is already in place.
Newfoundland and Labrador	Not reported.	The most comprehensive travel program: airfare, hotels, meals, and taxi; arranges travel beforehand or reimbursement afterwards. 50% reimbursement for escorts.	Not reported.	Not reported.	Yes, as there is a complex travel program already in place managed by the provincial government.
Nova Scotia	A steering committee works on organ donation planning; financial issues of living donors not yet a priority.	Not reported.	Not reported.	Limited support from Kidney Foundation.	Yes, at provincial level.
Ontario	Not reported.	Northern Health Travel Grants are available for residents of Northern Ontario who must travel long distances within Ontario or to Manitoba to receive medically needed specialty services.	Assistance is not available on a regular basis. (In special cases, reimbursement is provided with money from hospital global budgets or community funds.)	Kidney Foundation is very active with small grants or interest-free loans –amounts vary by case and by branch from $300 to over $1,000 per donor. The Lions Club also offers help.	Maybe. There are existing good networks among providers, charities, and government; transplant centers would not be able to administer any program without additional personnel and infrastructure. The provincial government has the capacity to administer the program,
Prince Edward Island	Not reported.	Transportation to specialty care is reimbursed, but escorts, hotels, and other expenses are not. Hostel program with good rates for donors.	Social workers help donors apply for funding from various sources.	Financial assistance to donors who really need it in small amounts from Kidney Foundation and other charities.	Respondents had doubts about institutional capacity to administer such a program – government is restructuring and lacks resources.
Quebec	The 2004-07 Organ and Tissue donation action plan of the Ministry of Health identified this as a priority. Doctors have submitted the problem of non-medical expenses to the ministry.	Not reported	Social workers make efforts to find money to reimburse donors, including testing-related expenses. Also, they help donors apply for external funding from charities.	The Kidney Foundation may provide limited support to donors in financial need and would gladly integrate a reimbursement program as part of the help provided to kidney patients.	Quebec has good networking in the transplant field. The provincial government might be able to administer a program better than transplant centers, as the latter lack personnel and resources. Respondents are not welcoming the idea of grants to hospitals.
Saskatchewan	Not reported	Not reported	Social workers help donors identify and apply for external funds	Limited interest-free loans or reimbursement through Kinsmen Foundation or local service clubs.	Difficult to administer a comprehensive reimbursement program without additional human resources.

The only provincial-level initiatives that are appropriately funded and managed are travel reimbursement programs in Newfoundland and Labrador, New Brunswick, PEI and Northern Ontario; these usually cover accommodations, meals, and travel. These travel programs are not targeted to organ donors per se; rather, they provide support for general out-of-area specialty care. Donors need prior physician approval for out-of-province or out-of-area treatment and can obtain financial assistance as upfront help or reimbursement. Medical expenses outside the donor's province are paid directly to the health provider. Saskatchewan is the only province that implemented a paid leave program for public employees. In Ontario, the Trillium Gift of Life proposed extending the Family Medical Leave Act (unpaid leave, job protection) to organ donors. British Columbia is the first to actually propose a comprehensive program for donor reimbursement that would cover all major categories of non-medical expenses, proportionally to donor's income and subject to a maximum (7). There are different planning committees working to improve financial support for living donors in Alberta, Quebec, and Nova Scotia.

Charitable and non-profit organizations: In cases of financial hardship, social workers from transplant centres and not-for-profit organizations try to help, in many cases by applying for funding on the donor's behalf. The Kidney Foundation of Canada (KFOC) is generally the first organization contacted. Although KFOC relies entirely on donations, it is often able to offer at least minimal support through interest-free loans or patient grants. The extent and availability of assistance varies across provinces. For example, in Saskatchewan, KFOC has funded one living donor to date with $250. The Ontario branch has given out a total of $3-4,000 over the past two years. One of the Alberta branches did not provide any money in 2004, while the Manitoba branch capped patient grants at $200 per year. Occasionally, groups such as the Lions Club, Rotary or Kinsmen foundations also provide donations to particular patients. Hope Air is a national charity that helps Canadians with financial need fly to necessary medical treatment and uses a point-system method to assess need. This system accounts for number of dependents, income relative to the poverty line, and community size. Recognizing their altruistic act, Hope Air is less strict with living donors. While available to all Canadian patients who need the service, respondents from Alberta and Nova Scotia particularly mentioned Hope Air as a way in which donors from those provinces can receive assistance with travel.

Discussion

Currently Canada does not have a unified strategy to reimburse living donors for incurred non-medical expenses. Our survey identified limited initiatives through which federal and provincial governments and charities provide partial reimbursement (more detailed survey findings are available upon request). Previous studies have confirmed that only 41% of living donors receive any type of reimbursement.[11] Most initiatives identified at federal and provincial level are not targeted to living organ donors and do not provide reimbursement for all categories of expenses. Notably missing is the reimbursement for lost income and lost productivity. Moreover, both governmental and non-governmental initiatives vary significantly across provinces in terms of structure and available resources. Although more comprehensive initiatives have been proposed in several provinces, a national strategy for reimbursement of living donors may facilitate uniformity of benefits across the country, increase accessibility, and address provincial governments' budgetary concerns.

6. DEVELOPING POLICY OPTIONS TO REIMBURSE CANADIAN LIVING ORGAN DONORS FOR INCURRED OUT-OF-POCKET EXPENSES

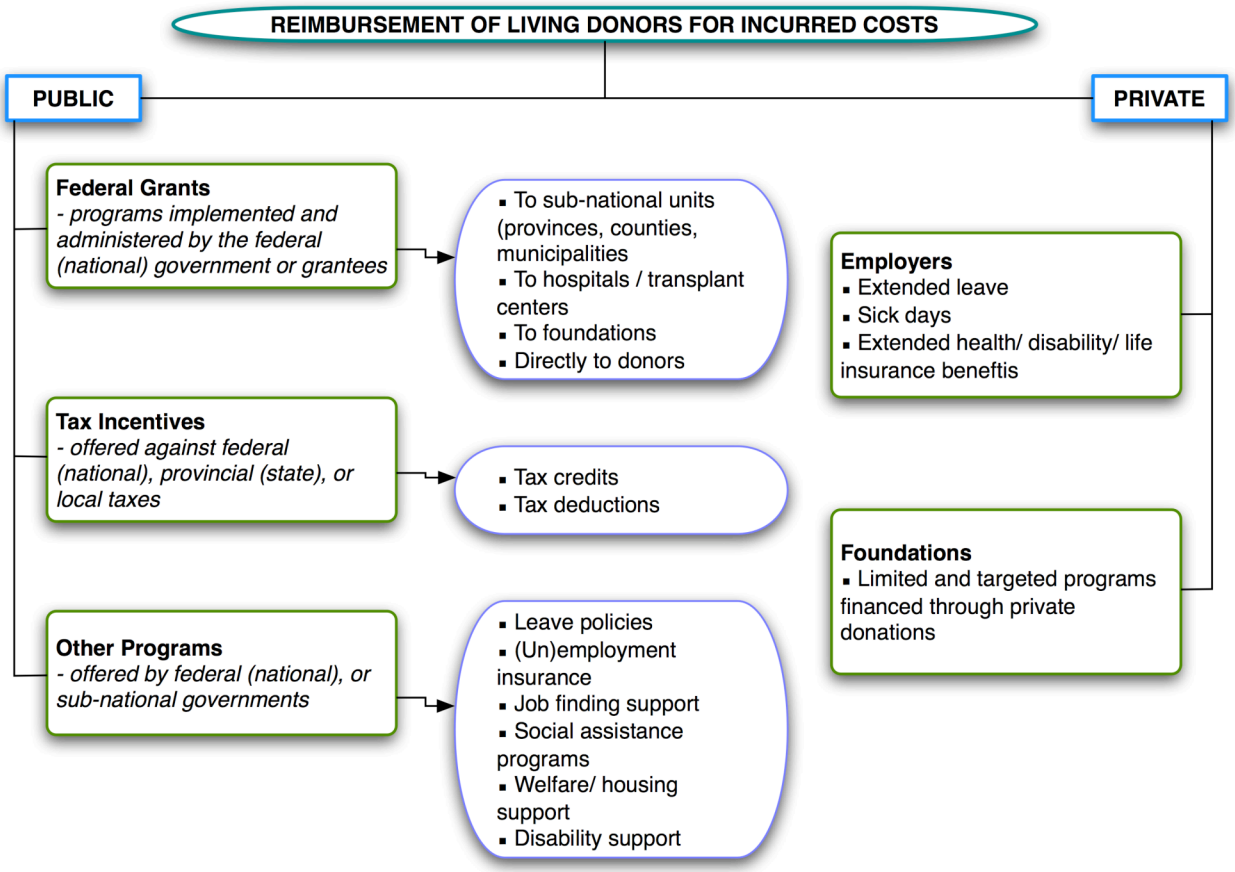
Proponents of a Canada-wide donor reimbursement will need to develop a strategy that is feasible, effective, sustainable, and provides donors in various provinces with comparable benefits. There are a number of policy options the federal government can employ to reimburse non-medical expenses incurred by living organ donors in Canada.

Factors which influence the creation of health policy:
In general, policy designs should take into account:

a. Economic issues – availability and source of funds. Confronted with increasing health care expenditures due to population aging and expensive new technologies, a living donor reimbursement program should aim to be both just and cost-effective
b. Social issues– the equitable distribution of costs and benefits across regions and groups is a key factor in increasing stakeholder support for the program;
c. Political issues– disputes between different levels of government, parties and leaders, political risks associated with increased taxation or redistribution of funds, proximity of elections and the pressure of interest groups on either side have a significant influence not only on the selection of viable policy options, but also on how soon proposals advance through the political system to become policy.
d. Regulatory/technical issues– existing infrastructure, material and human resources to implement the system require consideration. It is easier to use existing structures—such as the tax system or health transfers from the federal to state or provincial governments—than to build an entirely new system to implement the reimbursement program.

Available policy options for remunerating living donors vary form public to private reimbursement mechanisms, and from comprehensive alternatives that would cover all non-medical expenses to smaller, targeted programs that address only a limited range of expenses (Figure 1).

Figure 1. Instruments that could be used to build a reimbursement program.



Grants may be provided by the federal (national) government to various sub-national units or organizations (such as provinces, states, counties, or municipalities, hospitals and transplant centers), or non-government organizations - foundations. Grantees would be responsible for distributing the funds and determine eligibility criteria for reimbursement. The national government's role would be to

distribute funds equitably and provide evaluation and oversight. These various types of grants are not mutually exclusive—grants to provinces/states could coexist with smaller amounts given to foundations or transplant centers. Grants given directly to hospitals, research and transplant centers would provide donors with easy access. However, different reimbursement packages could lead to competition for donors among medical institutions and a general lack of uniformity. In addition, hospitals are often understaffed; a reimbursement program may require human resources for a claims office, and generally force medical institutions to administer social programs, which are outside of their main scope of activity.

Tax incentives may come as credits or deductions on federal or provincial (state, local) taxes, and could be efficient in reimbursing many categories of living donors and easier to implement, since they would use an already established system. This policy tool introduces delays in reimbursement and potential disadvantages for the poor, since tax incentives usually favor middle or upper socio-economic groups.

A paid leave program, would cover wages lost by the donor during the surgery and recovery period, and would not be counted against the annual sick days limit. While amenable to public employees, this type of reimbursement would be difficult to implement in the private sector, where governments would have to change private business practices. Tax incentives to corporations providing extended donor leave benefits, as well as combined public/private programs may be less controversial.

Employment insurance (EI) programs would help unemployed donors and those who become unemployed after donation. However, most EI programs have strict eligibility guidelines, require extensive paperwork, a work history and/or previous contributions to the program, and would reimburse the donor only for a portion of lost salary. Those unemployed or self-employed before the transplant would not, in general, benefit from these programs to the same extent as those with salaried positions.

Health policy options for Canada: A Commentary

After studying the various reimbursement initiatives across the country, we believe that any viable program would need to be comprehensive, preferably with national guidelines and/or funding, and centered on the idea that the donor should neither make any profit from donating, nor suffer any financial loss. The program should cover, if possible and in reasonable amounts, major categories of expenses such as lost income, travel and accommodations for donation and follow-up visits, dependent care and unpaid work, testing and outpatient medications (1). Some fear that such a program would represent a slippery slope towards the commercialization of organs. We consider this extremely unlikely, if the process is strictly regulated.

To be successfully implemented, a policy solution must be not only technically feasible, but also politically acceptable and fiscally sound (2). First, the transplant community has to agree on the problem definition and the main course of action; disagreement over technical feasibility among experts would make policy-makers perceive change as controversial and politically risky.

Formulation of a complex policy will be a long-term process involving a steady financial commitment, public education, development of institutions and infrastructure, and continuous program evaluation and knowledge exchange. The process will also require strong policy leadership at both the federal and provincial levels, and sufficient flexibility to motivate provincial governments to participate and overcome jurisdictional barriers. A major obstacle in gaining policy-makers' support remains the cost of a comprehensive program. In the survey of the Canadian transplantation community, most respondents believed their provinces have the institutional capacity to administer a reimbursement program; the involvement of transplant centers—although desired—is presently limited by infrastructure and human resources. Thus, a reimbursement program would have to include funding for creation of networks at the provincial level and hire additional personnel, rather than just add responsibilities to the existing workforce.

In terms of the main policy tool to be used, we put forward that a grant program to the provinces with strict federal criteria and oversight and based on the number of estimated living-donor transplants should be considered first. Other alternatives are tax-only instruments and expanding social programs.

Policy Options and Evaluation Criteria

Based on the policy goals defined and using a federal grant program to the provinces as the main policy instrument, we identified three major policy alternatives to building a national reimbursement program for living donors. The first option would be similar to what some provinces currently employ – a program providing travel reimbursement only, if the surgery takes place outside the donor's immediate area of residence. The second option would add lost income, while the third one, the most comprehensive, will provide effective reimbursement for all major categories of non-medical expenses a living donor can incur (see Table 5).

Table 5. Categories of expenses covered by each policy option

Cost Category	Option 1 (travel only)	Option 2 (limited)	Option 3 (comprehensive)
Travel	X	X	X
Lodging and meals	X	X	X
Long-Distance Phone Calls			X
Lost Income		X	X
Dependent Care			X
Housework			X

To evaluate these three policy options, we used Bardach's Criteria-Alternatives Matrix (CAM) as methodology (3), with the following six criteria identified as key for the evaluation of alternatives: 1) Comprehensiveness; 2) Cost; 3) Ease of implementation (technical feasibility); 4) Likelihood of successful adoption – by federal government (depends on public opinion, other policy priorities); 5) Likelihood of successful adoption – by provincial governments (depends on program structure and flexibility), and 6) Fairness to the donor. The Criteria-Alternative matrix, provided in Table 6, can be a useful decision-making tool experts can use to analyze policy options and reach consensus, if a decision is made that a national living donor reimbursement program is needed.

Table 6. Criteria-Alternatives Matrix

CRITERION / POLICY OPTION	Option 1 (travel only)	Option 2 (limited)	Option 3 (comprehensive)
Comprehensiveness	Low	Intermediate	High
Cost	Low	Intermediate	High
Ease of implementation (technical feasibility)	high	intermediate	low
Likelihood of successful adoption (federal)	High	Intermediate	Low
Likelihood of successful adoption (provincial)	High	Intermediate	Low
Fairness to the donor	Low	Intermediate	High

Estimating Cost

A major obstacle in gaining stakeholder support remains the cost of a comprehensive reimbursement program. In order to appreciate the impact of this policy change and assess if funding could be a potential barrier, we estimated the average cost of each of the three policy options analyzed using dollar values published in the existing literature and rounded up to take into account increases in cost of living, transportation costs and income, as follows:

- the average cost of Option 1, travel and accommodations reimbursement only, was estimated at $1,800 per donor (by adjusting up the cost of provincial programs that currently provide travel reimbursement)
- the average cost of Option 2, limited reimbursement using the BCTS model, was estimated at $3,500 per donor (by using the BCTS calculations) (4)

- the average cost of Option 3, comprehensive reimbursement, was estimated at $7,000, based on the self-reported financial losses of living donors from the CCDT environmental scan and other reviewed literature (5)

The number of living donors by province over the next 5 years was estimated by adding a 10% increase to the 2004 numbers. This increase should cover the natural increase without a reimbursement program (which was 10% over the 1994-2004 decade) and any effect introduced by a new reimbursement program. The estimated cost by program option is provided in Table 7.

Table 7. Estimated Cost by Program Option

PROVINCE	Estimated Number of Living Donors	COST		
		Option 1: $1,800/donor	Option 2: $3,500/donor	Option 3: $7,000/donor
Alberta	79 + 8 = **87**	$156,600	$304,500	$609,000
Atlantic Canada (NB, NL, NS, PE)	26 + 3 = **29**	$52,200	$101,500	$203,000
British Columbia	79 + 8 = **87**	$156,600	$304,500	$609,000
Manitoba	14 + 2 = **16**	$28,800	$56,000	$112,000
Ontario	212 + 22 =**234**	$421,200	$819,000	$1,638,000
Quebec	44 + 5 = **49**	$88,200	$171,500	$343,000
Saskatchewan	14 + 2 = **16**	$28,800	$56,000	$112,000
Total	**468 + 50 = 518**	**$932,400**	**$1,813,000**	**$3,626,000**
Total (+10% administrative cost)	-	$1,025,640	$1,994,300	$3,988,600
Total (+20% administrative cost)	-	$1,118,880	$2,175,600	$4,351,200

The average total amount needed for living donor reimbursement would vary from $932,400/year to $3,626,000/year, depending on the program option chosen. This estimate does not include the initial investment in infrastructure and the administrative costs of running the program. While the initial investment would vary significantly by province (and depend on existing networks and reimbursement initiatives, willingness of provincial governments to use some of the existing resources, labor market, etc), under the worst case-scenario administrative costs should not exceed 10 to 20%. By adding these very liberal estimates of administrative costs, the total program cost would vary between $1,025,640 and $4,351,200. For reference, the cost for providing dialysis therapy in Canada (2000) is estimated at $9.4 billion (6, 7). As each kidney donation is expected to save the healthcare system approximately $100,000 (8) and provide 2 additional quality adjusted life years, even a 10% increase in kidney donation from removal of economic disincentives may result in neutral or net negative costs from a societal perspective.

If the program is federal, a 5% reserve fund should be made available to the federal agency overseeing the program, to be redistributed to provinces that experience unexpected increases in costs or number of donors, as needed. This would drive the cost up to almost $5 million per year for the most expensive reimbursement option. Thus, a comprehensive reimbursement program would add up to no more than $25 million for the first five years of the program, a low figure for a national program. The other two program options would cost significantly less. Costs were overestimated by allowing for a higher increase than the likely trend in the number of donors and for very high administrative costs. Moreover, additional savings will come to provincial governments in the form of reduction in health expenses (e.g., dialysis treatment) if the implementation of the reimbursement program leads to an increase in the number of live organ donors.

To ensure program costs do not exceed the estimates, several methods to contain costs could be used, such as: 1) limiting the length of the recovery period for which the donor is reimbursed to the minimum recommended by a physician; 2) using average wages/income for the donor's area of residence rather than real wages/income, while allowing for exceptional circumstances; 3) using the government's (federal or provincial) bargaining power to obtain discounts for travel (particularly airfare) and accommodations, and 4) capping the total reimbursement amount per donor.

Full implementation of a national living donor reimbursement program will be a long-term process that would involve: consultations with the provinces; public education; passage of federal legislation; passage of provincial legislation in the provinces that want to add supplemental benefits to those provided by the federal program; steady financial commitment and clear financing scheme; development or upgrade of federal and provincial institutions and infrastructure to ensure adequate human resources and communication networks and allow for continuous data exchange; and continuous program evaluation and knowledge exchange to make sure that the program remains fair and within legal parameters (i.e., does not move towards commercialization).

One of the key issues will be how to reconcile a national reimbursement program with other (federal and provincial) existing programs and initiatives. At the federal level, the Medical Expense Tax Credit can be left as is; receipts used for reimbursement through the living organ donor reimbursement program cannot be used for the tax credit and vice versa. Similarly, there are no changes needed to the Employment Insurance program; the amount of money received through the EI program (sickness or regular benefits related to the donation) should be deducted from the amount that donors can receive from the reimbursement program. If the donor has short-term, private disability insurance, the amount of money received for the post-transplant recovery should be deducted from the amount that donors can receive from the reimbursement program.

At the provincial level, one of the first steps will be to decide if the provincial government wants to enhance the federal program through provincial funding. For instance, a province might choose (and be encouraged) to open up its prescription drug plan to living donors who would not otherwise qualify and do not receive extended health benefits from other sources. Also, a province could use a higher reimbursement to average cost-of-living ratio than the one established through national guidelines, by supplementing federal money with provincial funds.

There are other difficult policy questions that should be resolved through negotiation among provinces and with the federal government. For example, how is the reimbursement done for donors who reside in a different province than the recipient? What about foreign living donors (whose number is likely to increase in a multicultural society such as Canada's)? One alternative would be for the funding to come from the provincial program where the recipient resides, since that province will presumably be the one to obtain the benefits of having that patient come off dialysis therapy. This alternative would also address the problem of foreign living donors.

Future work

More information is needed to fully assess the costs and benefits of a program for reimbursement of living donors for non-medical expenses. On the short-term, that could be achieved through increased support for research initiatives in the field and/or funding and implementation of reimbursement pilot programs in provinces or territories.

7. DISABILITY & LIFE INSURABILITY OF LIVING ORGAN DONORS

There are many known short- and long-term risks associated with living organ donation and many authors are advocating that donors should be protected by health, life and disability insurance (1,2). At a minimum, experts recommend that the issue of future insurability be discussed with potential living organ donors as part of the informed consent process (3,4).

Nevertheless, relatively little direct data exist on the effect of living organ donation on one's ability to obtain life and disability insurance. Most of the available literature addressed this issue indirectly, either by surveying the attitude of the insurance companies, or by examining donors to determine if insurability impacted donors' psychosocial well-being.

From 1972 to 2002, four studies surveyed major life insurance companies in the United States (5-8), and consistently, almost all companies (97 to 100%) responded that they would offer life insurance to

living kidney donors. Only a small proportion (1.9 to 6%) would consider raising the premium. However, the response rates have dropped over the years, leading an author to suspect whether the insurance companies were "becoming more uncomfortable with this issue" (8). A similar survey included 14 major life insurance companies in the United Kingdom (9), and found all 14 willing to offer life insurance to living kidney donors without increased premiums. Moreover, 13 of 14 companies would honour their policies if existing customers died during living kidney donation without informing the companies of their intention to donate beforehand.

However, there are concerns that insurance companies' responses to surveys may not reflect their actual business practices, and donor insurability is, in fact, detrimentally affected by living organ donation. For instance, a young healthy male donor was apparently rejected by three different companies when he applied for life insurance (7). In a follow-up study of 274 living kidney donors, 9% of the respondents reported that being a living kidney donor had a negative impact on their ability to obtain health, life, and disability insurance (10). Another study found that 3% of living kidney donors encountered difficulty obtaining life insurance (11). Similarly, an even larger survey of 918 donors from 9 different transplant centres in the United States found 4.2% of respondents had difficulty obtaining or maintaining life insurance, and 2.3% disability insurance (12). An official from the California State Department of Health Services also concluded that the risk to future insurability for disability "is not known but may be considerable"(3).

What is well known is that insurability (or uncertainty thereof) is a source of stress for some living kidney donors. Four different studies done in the United States, Canada, and Japan were surprisingly consistent in their findings (11,13-15). Almost one in eight donors (12% when the results from the four studies were averaged) reported having concerns about future insurability. More importantly, another large study of 918 living kidney donors found those whose insurance premiums increased following donation were less likely to reaffirm their decision to donate. In other words, insurability not only has a negative impact on the donors' well-being, it may even prevent some individuals from becoming living organ donors.

Some insurance coverage is available for living organ donors. In the United States, the American International Group (AIG) underwrote an insurance product specifically designed for living kidney donors. It covers accidental death related to donation nephrectomy, and medical expenses as well as disability income related to complications of donation (16). Analogous to disability insurance, protection against income loss surrounding organ donation is available to federal employees in the United States in the form of the Federal Family Leave, which allows for 30 days of paid leave after living kidney donation (17). These existing models may be used to guide policy in Canada.

Although very little literature exists for non-kidney living organ donors, the most direct evidence of living organ donation affecting insurability came from a study surrounding living right hepatic lobe donation. By submitting two fictitious profiles differing only by the history of uncomplicated right lobe donation to 10 large life insurance companies, the authors found one company refusing to insure the living liver donor, while three companies would charge the donor a slightly higher premium ($189/yr vs. $202/yr) (18).

In conclusion, the results of several studies seem to suggest living organ donation has a negative impact on obtaining and maintaining affordable life and disability insurance. However, the current level of evidence is not strong enough to be considered definitive. Even less is known about how insurability may be affected by previously unknown health concerns which are uncovered during the donor work-up process. More studies are needed to address donor concerns and to determine the magnitude to which insurability is a barrier to donation.

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