

RESULTS HIGHLIGHTS

ORGAN DONATION AND TRANSPLANTATION IN CANADA

System Progress Report 2006–2015



This document summarizes the key findings of the Organ Donation and Transplantation in Canada: System Progress Report 2006–2015. These findings draw on data from the Canadian Transplant Registry, the Canadian Organ Replacement Register, and the various transplant programs and provincial organ donation organizations (ODOs) across the country.



Canadian Blood Services
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The organ donation and transplantation system in Canada

Provincial and territorial governments are responsible for health care in Canada. As such, they manage their own programs and laboratories to provide organ donation and transplantation services in their jurisdictions. Canadian Blood Services, collaboratively with provincial programs, provides national programs and services to advance the practice of organ and tissue donation and transplantation. Professional societies provide support and focused education for health-care professionals. A variety of organizations and institutions provide direction through legislation, regulation and accreditation, and contribute to research efforts to improve the system.

Canada's organ donation and transplantation system: Progress

Since 2006, Canada has seen incremental progress in its organ donation and transplantation system. While these findings are encouraging, organ donation and transplantation is not improving quickly enough to help the thousands of Canadians waiting for lifesaving or life-improving transplants. More can and must be done to support the adoption of these proven leading practices in Canada and internationally to continue advancing donation and transplantation performance.

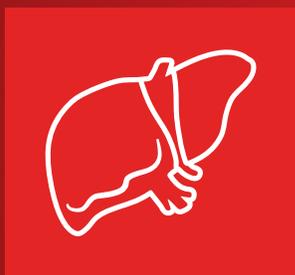
The Canadian Transplant Registry

A significant achievement of the past 10 years is the development of interprovincial patient programs. Canadian Blood Services is responsible for operating the Canadian Transplant Registry (CTR), a web-based resource that provides critical real-time data and information through various programs for organ listing and sharing. These programs include the Kidney Paired Donation program (a living donation program); the National Organ Waitlist; and organ-sharing programs for high-priority patients, including the Highly Sensitized Patient program, which focuses on kidney patients. These programs have improved access to transplants for many patients and increased the effectiveness and efficiency of national organ-sharing programs for living donors and critically ill patients.

While the early development of the CTR programs and services was focused on the development of new listing and allocation practices, the service is now in place to support and advance national sharing for all organ groups. Through the CTR, the technology now exists to ensure all patients in Canada are listed, evaluated and reported in a similar manner.

The following highlights from the *Organ Donation and Transplantation in Canada: System Progress Report 2006–2015* provide the most current available national data on deceased and living donation and transplantation performance.

DONATION RATE



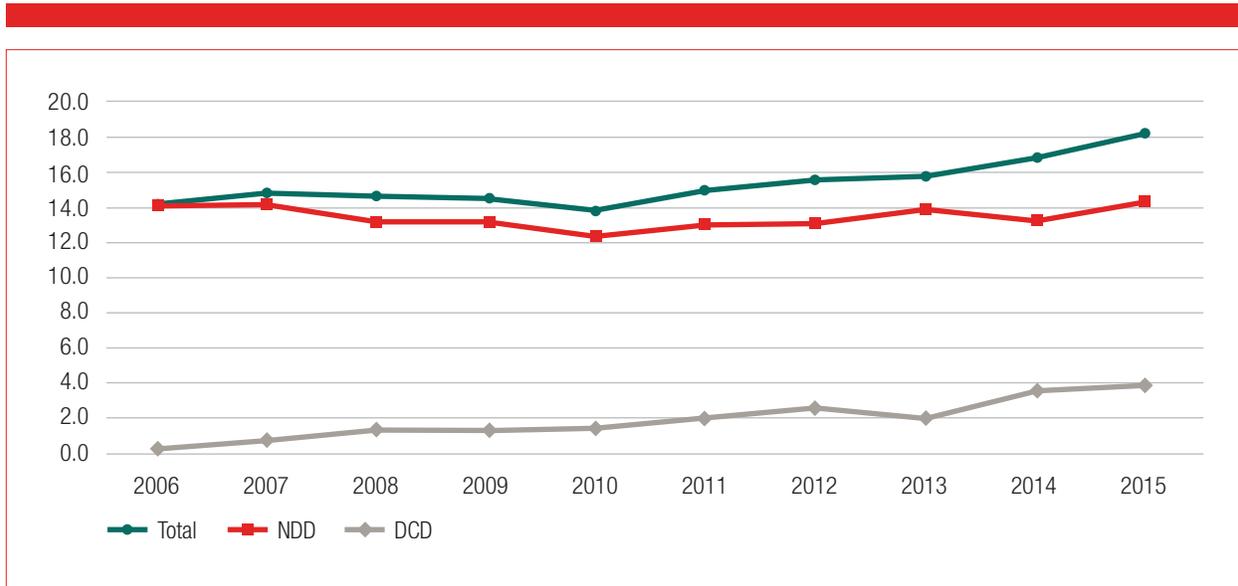
Organs are donated by deceased donors — through donation after neurological determination of death (NDD) and donation after circulatory death (DCD) — and by living donors. The national deceased donation rate has risen from 14.1 to 18.2 donors per million population. **This is the highest national deceased donor rate reported in over a decade.**

Donation by deceased donors

Canada's organ donation rate by deceased donors — the deceased donation rate — has increased by 29 per cent since 2006, from 14.1 to 18.2 donors per million population in 2015. The number of deceased donors has increased by 42 per cent, from 460 in 2006 to 651 in 2015.

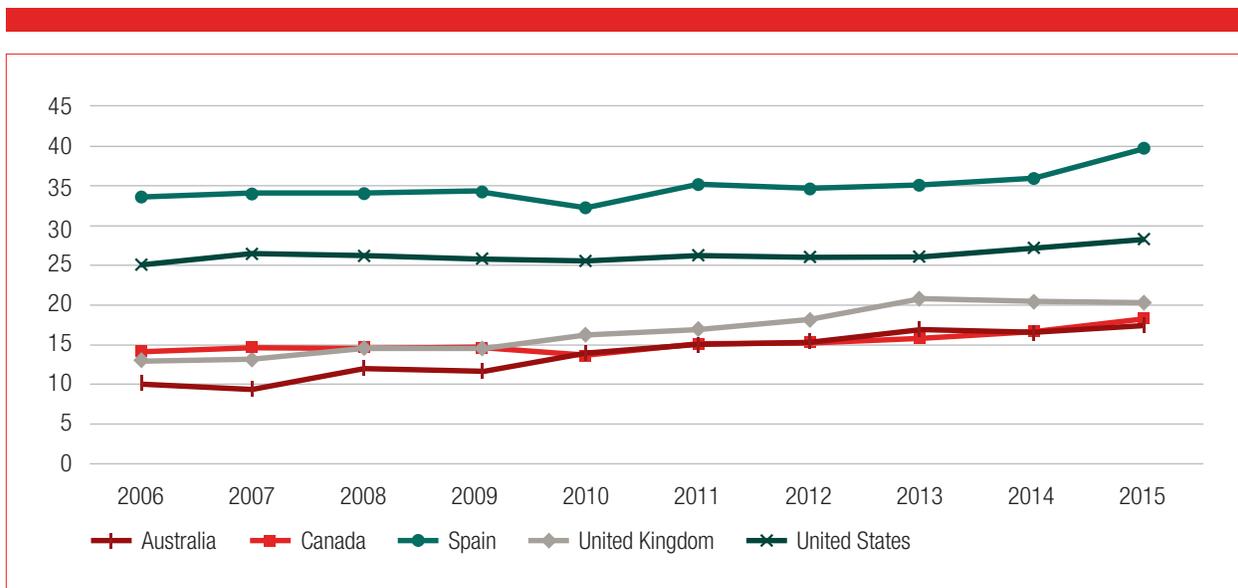
DCD accounts for the largest increase in the number of deceased donors over time. There were 138 DCD donors in Canada in 2015. Donations by DCD donors make up 21 per cent of the total donations made by deceased donors. **DCD has the greatest potential for future increases in donations.**

Deceased donors in Canada, 2006–2015 (DPMP)



Despite these increases, the system is underperforming. The national deceased donation rate is still well below the proposed target of 22 donors per million population* and well below those of leading countries internationally.

International deceased donation rates, 2006–2015 (DPMP**)



* This target was proposed in *Call to Action*, a strategic plan to improve organ and tissue donation and transplantation performance for Canadians. This document can be found at blood.ca.

** Although the DPMP measure has been criticized as not being an accurate indication of donation performance, it is still widely used for comparative purposes. For this metric, most countries report actual donors, a figure that only requires an organ to be removed or an incision made in the operating room for the purposes of transplantation. Canada, however, reports utilized donors, a metric that requires at least one organ to have been transplanted into a patient. Annual reports on organ donation and transplantation activity issued by the National Health Service in the United Kingdom (2012–2015) estimate differences of between four to eight per cent when comparing actual donors and utilized donors.

Donation by deceased donors varies among provinces

The systems of those countries with the highest deceased donation rates share some common features:

- Mandatory referral to ensure donation opportunities are not missed.
- The presence of in-hospital donation specialists who are accountable for performance and quality.
- Optimized deceased donation programs (NDD and DCD).
- Highly developed and consistently implemented leading practices.

These features have been applied to differing degrees across the country.

Factors contributing to higher donation rates

	B.C.	ALTA.	SASK.	MAN.	ONT.	QUE.	N.B.	N.S.	N.L.
Mandatory referral	●	■	■	●	●	●	●	▲	■
Donation physicians	●	▲	■	●	●	▲	■	▲	■
NDD leading practices	●	●	●	●	●	●	●	●	●
DCD programs	●	▲	▲	▲	●	●	■	●	■
% DCD donors, 2015	25	13	10	0	31	11	0	15	0
Leading practices in donor management	●	●	●	●	●	●	●	●	●
Deceased donors, 2015 (DPMP)	20.1*	12.2**	8.8	13.1	19.5	20.8	10.6	21.2***	15.2
Number of donors, 2015	95	52	10	17	269	172	8	20	8
2011–2015 % change in DPMP	76	33	-17	89	22	26	14	-20	-20

* The population of Yukon is included in the calculation of this rate.

** The populations of Nunavut and the Northwest Territories are included in the calculation of this rate.

*** Donors from Prince Edward Island are included in the calculation of these rates.

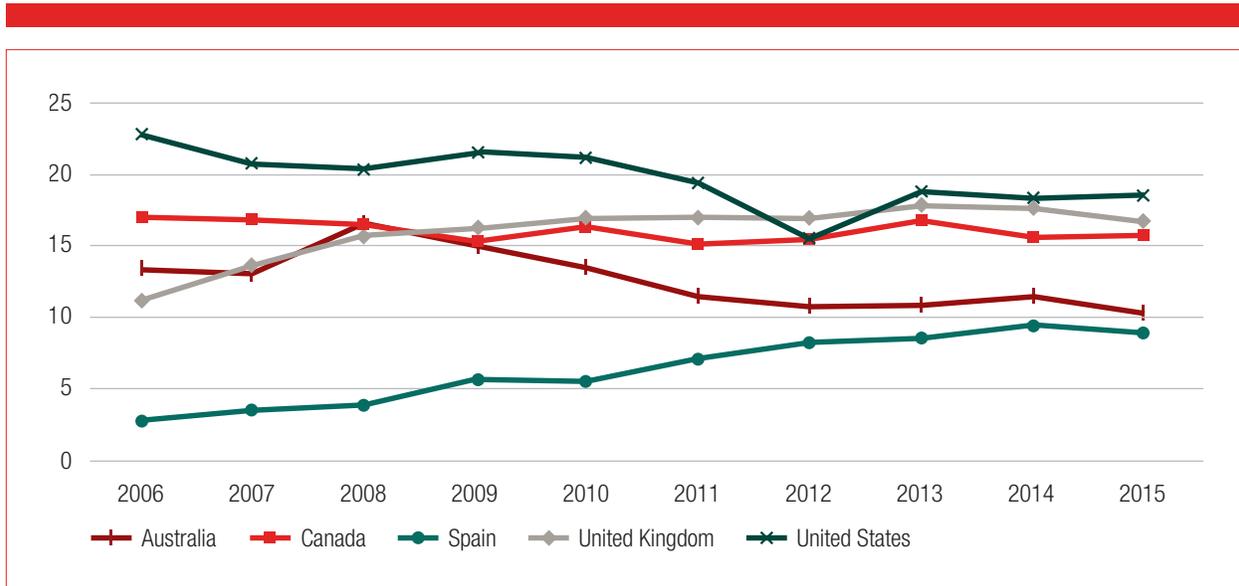
- Implementation complete or near completion
- ▲ Implementation in progress
- Implementation not started

Donation by living donors

In 2015, Canada's organ donation rate by living donors — the living donation rate — was 15.7 donors per million population. This rate, which includes mostly kidney donors, but also liver and lung donors, has gone down by eight per cent over the last 10 years. However, Canada's rate compares well internationally, and outcomes for kidney transplant recipients and their living donors are among the best in the world. Collaborative focus on improving living donation is ongoing and important.

The Kidney Paired Donation program has facilitated 391 kidney transplants from living donors from 2009 to 2015 — transplants that may otherwise have not occurred. Canada's liver donation rates by living donors have also increased.

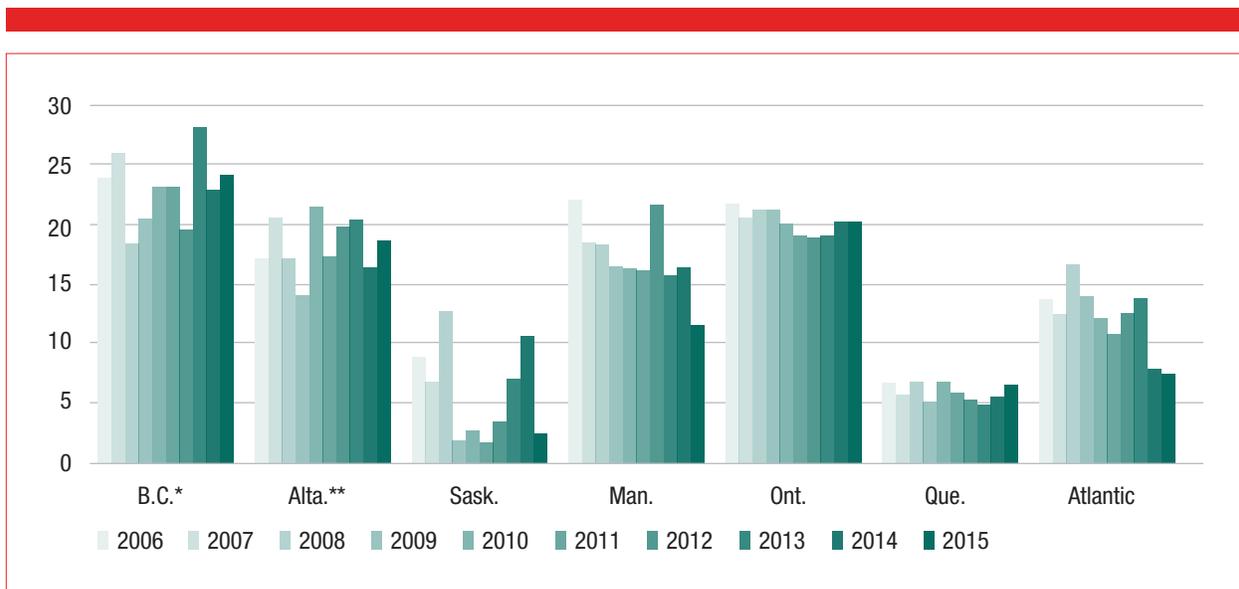
International living donation rates, 2006–2015 (DPMP)



Donation by living donors varies significantly among provinces

While the national living donation rate decreased, the living donation rates and patient wait times for a transplant from a living donor vary significantly among provinces. The best-performing provinces stress the importance of donations by living donors, and have efficient programs and professional education systems that teach hospital staff and patients about the benefits of these donations. They also provide access to timely pre-transplant testing for both donors and patients, and to operating rooms reserved for transplant surgeries.

Number of living kidney, liver and lung donors per million population by province, 2006–2015



* The population of Yukon is included in the calculation of this rate.

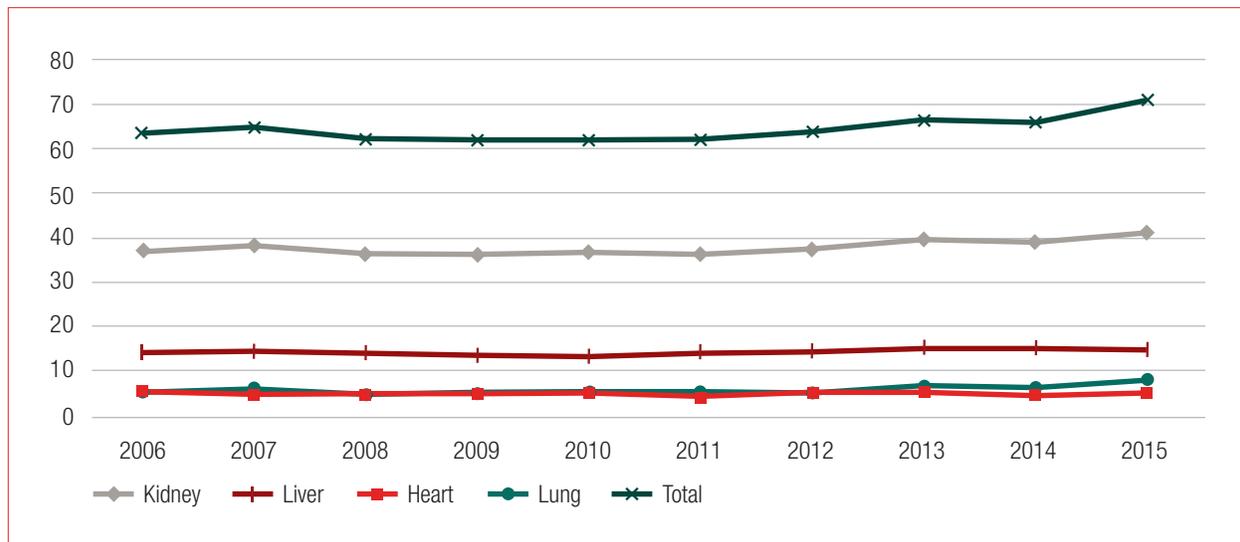
** The populations of Nunavut and the Northwest Territories are included in the calculation of this rate.

CANADA'S TRANSPLANT RATE



Canada's transplant rate — which includes organs from both deceased and living donors — increased from 63.7 to 71.4 transplants per million population. The actual number of transplants increased by 23 per cent from 2,074 to 2,559. **Despite these modest increases in transplant numbers, Canada still has a shortage of organs. More than 4,600 patients are waiting for transplants.**

Transplants per million population in Canada by organ type, 2006–2015



Access to transplants

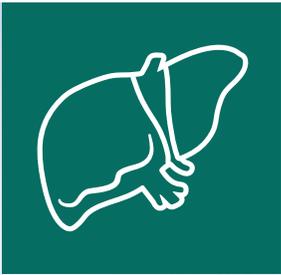
Patients today have significantly better access to transplants. This is especially true for patients who have highly sensitized immune systems because of a past organ transplant, a blood transfusion or a pregnancy, and for whom the wait to find the right match was much longer. The variation in access to transplants remains high with potential consequences for patients.

Transplantation benefits: Good for patients, good for governments

We know transplantation is the best therapy for patients with end-stage kidney disease, and the only treatment for patients suffering from end-stage liver, heart and lung disease. Compared to dialysis, a kidney transplant can more than double a patient's life expectancy.

Transplantation is also the most cost-effective treatment for patients with end-stage kidney disease. **Starting in the second year after transplant, the health-care system avoids between \$33,000 and \$84,000 per transplant patient per year of dialysis.**

Investment in national improvement initiatives, such as the Kidney Paired Donation program, pays off — both in successful transplants and in infrastructure that serves other purposes. Investments to date in the Kidney Paired Donation program alone will have covered the full cost of building and operating the Canadian Transplant Registry by 2018, the program's tenth year of operation.



Reg Parker

Born with common variable immune deficiency (CVID), Reg has needed gamma globulin (made from plasma) to boost his immunity since he was 14 — first monthly, then every two weeks.

When he was in his early 30s, sarcoidosis (an inflammatory disease that affects multiple organs in the body) did major damage to his lungs, while years of medication also took a toll, scarring his liver. In 2014, Reg underwent a double lung and liver transplant.

“The best way to thank donors and pay my respect to them is to live my life to its fullest. That’s what I try to do. I don’t know how many lives I have left, but I know I’m one of the lucky ones.”





Sherry Provis and Peter Carruthers

In 2007, Sherry's father, Peter, was diagnosed with chronic kidney disease. Peter began dialysis and, with no matches for a transplant within his own family, joined a wait-list for a transplant.

While Peter prepared for a transplant, his family considered the newly launched Kidney Paired Donation program, which registers incompatible donor/recipient pairs into a database to be matched with other incompatible pairs to create a chance for the two recipients to receive kidneys from each other's living donor. Sherry, Peter's daughter, registered with Peter as a pair.

In October 2010, Sherry flew to Halifax to donate her kidney to one recipient and Peter received his kidney from another donor in Toronto.

"I did it without hesitation because it was my dad. What's amazing is that I helped two people at the same time."

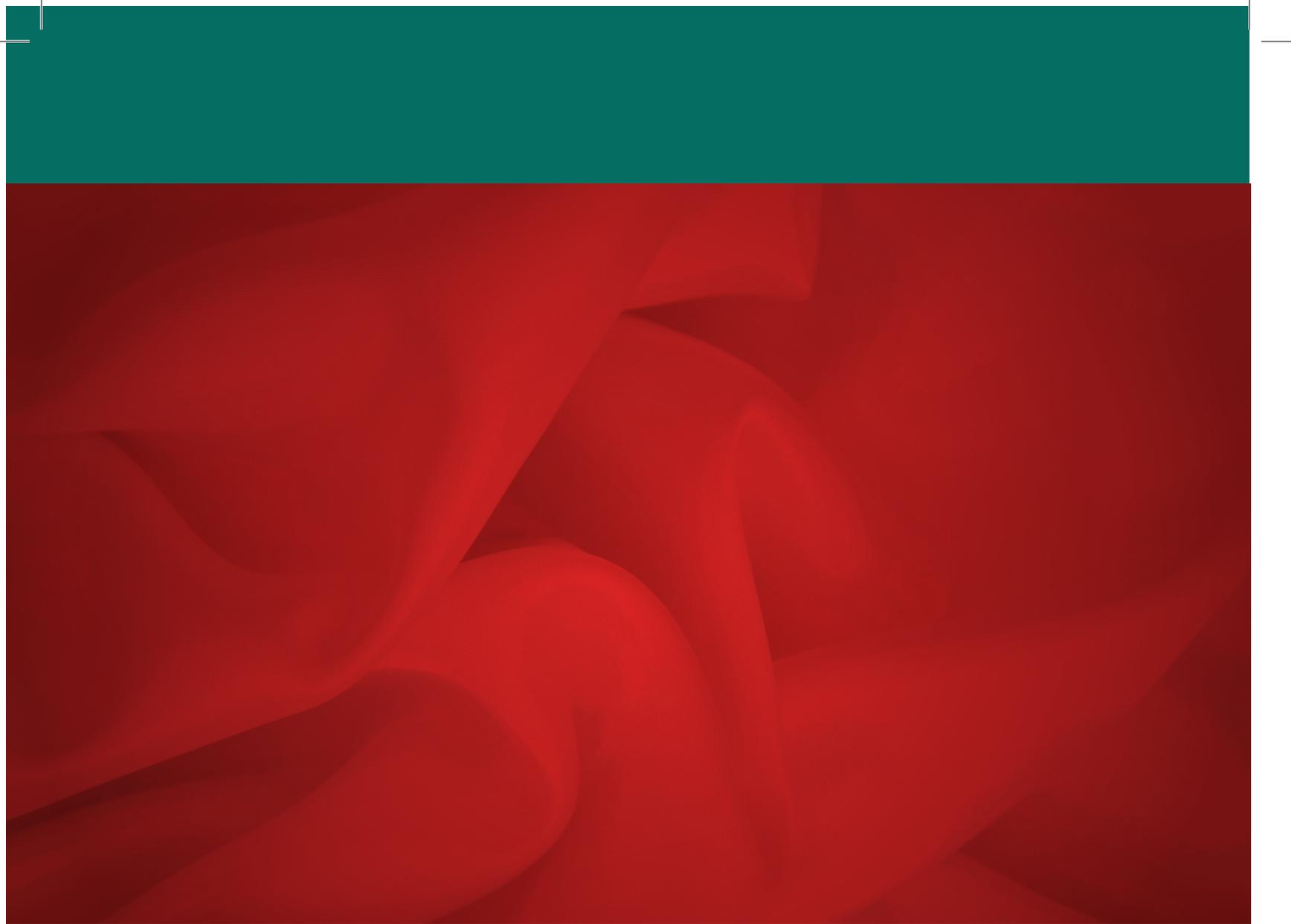


MOVING FORWARD, TOGETHER

Given the proven health benefits for patients and the economic benefits for governments, there are many reasons to move forward in a focused and collaborative way to advance transplantation where possible. We have seen consistent improvements in programs across Canada using strategies that have been proven successful here and around the world. Programs can build on the foundational elements of successful donation and transplantation programs to ensure Canadian patients have access to the transplants they need, now and in the future.

Canadians have their say

- **71%** of respondents trust that the organ and tissue donation system in Canada is administered in the best interest of the public.
- **51%** of respondents indicate they have made the decision to donate their organs and tissues at the time of their death.
- **72%** of those who have made the decision to donate their organs and tissues have discussed their decision with the person who would act on their behalf in the event of a medical emergency.
- **Over 90%** of Canadians approve of organ donation but **only 51%** have made the decision to donate their organs at the time of their death.



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