Summary

Treatment of End-Stage Organ Failure in Canada, 2004 to 2013 reports on data from the Canadian Organ Replacement Register (CORR) at the Canadian Institute for Health Information (CIHI). The report examines dialysis, organ transplantation and donation characteristics, trends and patient outcomes in Canada during the decade 2004 to 2013.

In 2013, there were 41,931 Canadians living with end-stage kidney disease (ESKD); 57.5% were receiving some form of dialysis. The remaining 42.5% had a functioning kidney transplant.

- Of the 24,114 patients on dialysis, more than three-quarters were receiving institutional hemodialysis, the most expensive treatment option.
- There were 5,333 newly diagnosed ESKD patients reported in 2013.
- More than half (53%) of the newly diagnosed ESKD patients were 65 and older.
- Nearly 36% of the newly diagnosed patients had diabetes as the main cause of their kidney failure.
- For the latest available data of unadjusted five-year patient survival, 44.8% of patients on dialysis treatments survived at least five years.
- The average age of patients receiving a deceased donor kidney transplant was 55, and nearly 42% of patients were 60 and older.

For the latest available data of unadjusted five-year graft survival, 89.2% and 82.6% of kidneys transplanted into adults from living and deceased donors, respectively, survived at least five years.

In 2013, a total of 2,367 transplant procedures were performed, an increase of 6% over 2012. The number of transplants performed has increased annually over the last five years, up from 2,076 in 2008. The 2,367 transplant procedures performed in 2013 resulted in 2,432 solid organs being transplanted, as highlighted below:

- Kidneys: 1,419
- Livers: 509
- Lungs: 247
- Hearts: 192
- Pancreases: 65

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i. In 2011, 2012 and 2013, there was known under-reporting of incident dialysis cases in several provinces. Counts of organ donors and transplants from Quebec have been supplemented with additional data from Transplant Québec. For additional information, see Section 1.2.

ii. The kidney transplant total includes 44 simultaneous kidney–pancreas transplants, and is also supplemented with 58 kidney transplants and 5 simultaneous kidney–pancreas transplants from under-reporting in Quebec.

iii. The pancreas transplant total is supplemented with five kidney–pancreas transplants and one pancreas-only transplant from under-reporting in Quebec.
In 2013, there were 553 deceased organ donors in Canada, 12 more than the 541 reported in 2012. In addition, there were 588 living organ donors.

- While a living donor provides a single organ for transplant, a deceased organ donor can provide up to eight organs.
- The number of deceased organ transplants also increased between 2012 and 2013, with 130 more organs being transplanted.
- In 2013, a total of 43.5% of living organ donors were not related to the transplant recipient. Spouses accounted for 13.3% of living donors, while the remaining 30.2% had no relationship to the organ recipient. This latter group has grown from 14% in 2004, possibly reflecting the increased frequency of living donor paired exchange kidney transplants.
Highlights

Treatment of End-Stage Organ Failure in Canada, 2004 to 2013 draws on data from the Canadian Institute for Health Information (CIHI) Canadian Organ Replacement Register (CORR), primarily for the years 2004 through 2013 (the most current year available). The report examines dialysis and transplantation characteristics, trends and patient outcomes in Canada during that period.

The information presented is relevant to a wide array of stakeholders. Individuals interested in health system policy, as well as clinical and service management related to end-stage organ failure, will find the report useful, as will individuals and groups generally interested in end-stage organ failure in Canada.

2013 Overview

- In 2013, 5,333 patients started renal replacement therapy (RRT).
- The 1,141 organ donors (living and deceased) resulted in 2,367 solid organ transplant procedures.
- There were 15.7 deceased organ donors per million population, an increase of 22% since 2004. The living donor rate was 16.7 donors per million population.
- Altogether, 4,433 patients were waiting for a solid organ transplant at the end of the year.
- A total of 246\(^v\) Canadians died waiting for an organ transplant.

Diabetes and ESKD

- Diabetes continued to be the most frequently reported primary cause of ESKD, accounting for 36% of incident patients in Canada.
- The self-reported prevalence of diabetes increased by 60% between 2003 and 2013 from 1.2 million to 2.0 million.\(^1\) The prevalence of ESKD increased by 42% during the same time frame.
- The increase in self-reported prevalence of diabetes between 2003 and 2013 was most striking for patients age 45 to 64 and age 65 and older, at 62% and 74%, respectively.\(^1\) During the same time frame, ESKD increased for patients in these age groups, at 46% and 66%, respectively.
- The percentage of incidence for adult dialysis patients with a primary diagnosis of diabetes increased between 2004 and 2013 by 19% and 15% for patients receiving hemodialysis and peritoneal dialysis, respectively.
- Between 2004 and 2013, the prevalence rate per million population of patients with diabetes as a primary diagnosis increased by 36%.

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\(^{iv}\) In 2011, 2012 and 2013, there was known under-reporting of incident ESKD cases in several provinces. Counts of organ donors and transplants from Quebec have been supplemented with additional data from Transplant Québec. For additional information, see Section 1.2.

\(^{v}\) Total includes 38 patient deaths in Quebec, as reported in Transplant Québec’s Statistiques officielles 2013.
Among prevalent patients in 2013 with a primary diagnosis of diabetes, 62% were being treated with hemodialysis and 26% had transplants.

Between 2004 and 2013, the percentage of adult kidney transplant recipients with a primary diagnosis of diabetes who received a kidney from a deceased donor increased by 61%. Over the same time period, the percentage of these transplant recipients who received a kidney from a living donor increased by 13%.

**Kidney**

- At the end of 2013, 41,931 Canadians were living with ESKD. Since 2004, this number has grown 35% from 30,953.
- Of these patients, 24,114 were on dialysis and 17,817 were living with a functioning kidney transplant.
- In total, 5,333 patients started RRT in 2013, with 77% receiving hemodialysis as their initial treatment.
- For the latest available data of unadjusted five-year patient survival, 42.7% of patients on hemodialysis treatments survived at least five years, approximately 12% fewer patients than the 54.5% of patients on peritoneal dialysis.
- There were 1,419 kidneys transplanted, including simultaneous kidney–pancreas (SKP) transplants, an increase of 32% over the 1,074 in 2004.
- On December 31, there were 3,382 patients waiting for a kidney or SKP transplant.
- A total of 88 patients died while waiting for a kidney transplant in 2013.
- For the latest available data of unadjusted five-year graft survival, 89.2% of kidneys transplanted into adults from living donors survived at least five years, approximately 7% more than the 82.6% of kidneys from deceased donors.

**Liver**

- There were 5,833 Canadians living with a liver transplant.
- In 2013, 509 liver transplants were performed, 22% more than the 417 performed in 2004.
- On December 31, there were 498 patients waiting for a liver transplant.
- A total of 86 patients died while waiting for a liver transplant in 2013.
- Hepatitis C was the cause of liver failure for 21% of liver transplant patients between 2004 and 2013.
- For the latest available data of unadjusted five-year patient survival, 83.9% of patients who received a first liver transplant from a deceased donor survived at least five years.

**Heart**

- There were 2,611 Canadians living with a transplanted heart.
- A total of 192 heart-only transplants were performed.
- On December 31, there were 167 Canadians waiting for a heart transplant.
- A total of 20 Canadians died while on the heart transplant waiting list in 2013.
• Between 2004 and 2013, 21% of heart transplants resulted from narrowing of the coronary arteries (ischemic cardiomyopathy).
• For the latest available data of unadjusted five-year patient survival, 89.9% of patients who received a first heart transplant survived at least five years.

**Lung**
• There were 1,524 Canadians living with a lung transplant.
• In 2013, 247 lung transplants were performed, 86% of which were double lung transplants. Since 2004, the number of lung transplants has grown 86%.
• On December 31, there were 314 Canadians waiting to receive a lung transplant.
• A total of 52 Canadians died while waiting for a lung transplant.
• Between 2004 and 2013, 28% of lung transplants resulted from lung tissue scarring with no known cause (idiopathic pulmonary fibrosis). Emphysema and chronic obstructive pulmonary disease (COPD) were the causes of an additional 25% of lung transplants.
• For the latest available data of unadjusted five-year patient survival, 65.9% of patients who received a first lung transplant from a deceased donor survived at least five years.

**Pancreas**
• There were 59 pancreatic transplants performed in 2013. Of these, 44 were simultaneous kidney–pancreas transplants.
• A total of 177 Canadians were waiting for a pancreas transplant.
• For the latest available data of unadjusted five-year graft survival, 86.7% of simultaneous kidney–pancreas transplants survived at least five years.

**Small Intestine**
• Small intestine transplantation is an emerging and evolving field with the potential to improve the outcomes of children and adults with intestinal failure in Canada. Between 1994 and 2013, there were 56 such procedures performed in Canada, with more than half (57%) of the recipients younger than age 18.

End-stage organ failure presents complex issues and challenges for Canadian patients, clinicians and the health care system. Treatment options continue to evolve, and organ-donation practices and processes are continuously examined to optimize outcomes. It is only through the ongoing and systematic collection of data that sound information can be produced to assist with decision-making. It is the intent of this report to provide information that may help to improve the health of Canadians with end-stage organ failure.

In addition to this annual summary report, more information and data tables are available online at [www.cihi.ca/corr](http://www.cihi.ca/corr), in the form of special reports (Analysis in Brief reports) and reports from the organ procurement organizations entitled e-Statistics on Organ Transplants, Waiting Lists and Donors.

If you have questions about this report or would like further information, please write to CORR at corr@cihi.ca.