

# Canadian Organ Replacement Register Update

Welcome to the 2018 update for the Canadian Organ Replacement Register (CORR). This update includes information about the following: the availability of 2017 CORR data on end-stage organ failure; upcoming and released CORR products; an exploratory analysis of renal patient-reported outcome measures (PROMs) data; submitting 2019 transplant and donor data; the final update for the CORR Access to Kidney Transplantation Feasibility (WAVE) Study; and new research using CORR data.



## 2017 CORR data on end-stage organ failure available

2017 data on end-stage organ failure became available for use in September 2018. This data is being used for analytical and data quality purposes and for centre-specific feedback reporting by the CORR Program; it is also available for data requests. CORR data is intended for use by anyone interested in health system policy and/or clinical and service management related to end-stage organ failure in Canada. [Access the data on CIHI's website.](#)

## Newly released CORR products

In July 2018, the CORR Program released 2017 statistics in our *e-Statistics on Organ Transplants, Waiting Lists and Donors*. These data tables include annual information on transplants, donors and waiting lists, including the number of patients who died while waiting for a vital organ transplant. The data is based on summary statistics received from 9 organ procurement organizations (OPOs) across Canada.

## Upcoming CORR products

The CORR Program is working on the following analytical products for release this winter:

- Treatment of End-Stage Organ Failure in Canada, Canadian Organ Replacement Register, 2008 to 2017
- Canadian Organ Replacement Register Quick Stats (2017 data)

CIHI strives to ensure that the quality of the information in its data holdings is suited for the intended use. The CORR Program has been a leader in developing data quality documentation for users of its data. Data Quality Documentation for Users: Canadian Organ Replacement Register, 2008 to 2017 Data will also be available this winter.

CORR analytical and data quality products can be accessed on the [CORR page of CIHI's website.](#)

## Patient-reported outcome measures

PROMs are measurement tools completed by patients who provide information on their health status and quality of life. PROMs are an important complement to clinical measures in evaluating the effectiveness of care, providing the patient's perspective, and standardizing measurement of patients' quality of life. Working with the pan-Canadian PROMs Renal Care Working Group, CIHI undertook a demonstration project to explore whether a standardized tool to measure symptom burden in dialysis patients in British Columbia can be used as a PROM and whether it could be analyzed for secondary research and reporting purposes. Findings from this work are being presented at the 2018 Canadian Society of Nephrology Annual General Meeting and the 2018 American Society of Nephrology Kidney Week.

## Submitting 2019 transplant and donor data to CORR

The CORR Program at CIHI has been working in collaboration with Canadian Blood Services (CBS) to ensure minimal duplicate reporting to both organizations. For the 2019 data year, all transplant programs and OPOs will continue to submit all record-level organ donation and transplantation data to CORR. CBS will continue to collect data for the Kidney Paired Donation Registry, National Organ Waitlist and the Highly Sensitized Patient Registry.

## CORR access to Kidney Transplantation Feasibility (WAVE) Study update

In 2009, the CORR board of directors and Canadian Society of Transplantation Kidney Transplant Group identified a need to capture patient-level information on kidney transplant referrals and activations to the deceased donor waiting lists. The CORR board approached CIHI to manage the data collection activities, which spanned a 6-year period from June 1, 2010, to April 30, 2016. 16 of 18 Canadian transplant centres captured end-stage renal disease patient information and data at the time of referral and final disposition regarding activation to the wait list. CIHI closed this data set at the end of June 2016. Since then, the data has been analyzed and preliminary findings were presented by Dr. Joseph Kim at the 2018 Canadian Society of Nephrology Annual General Meeting in May. More complete analyses have been submitted for peer-reviewed publication.

## New research using CORR data

Data from CORR is used in many CIHI products, including annual reports, Analysis in Brief reports, Quick Stats, centre-specific comparative reports and more. CORR data is also frequently accessed by third-party data requestors for research purposes. Below is a list of journal articles and reports published in the last 2 years that used CORR data.

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- Hodge M, McArthur E, Garg AX, Tangri N, Clemens KK. [Hypoglycemia incidence in older adults by estimated GFR](#). *American Journal of Kidney Diseases*. 2017.
- Kalatharan V, Lemaire M, Lanktree MB. [Opportunities and challenges for genetic studies of end-stage renal disease in Canada](#). *Canadian Journal of Kidney Health and Disease*. 2018.
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- Lam NN, Kim SJ, Knoll GA, McArthur E, Lentine KL, Naylor KL, Li AH, Shariff SZ, Ribic CM, Garg AX. [The risk of cardiovascular disease is not increasing over time despite aging and higher comorbidity burden of kidney transplant recipients](#). *Transplantation*. 2017.
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