# **Volume 1, Chapter 3.03—Chronic Kidney Disease Management** 2019 Value-for-Money Audit

### Why We Did This Audit

- In 2018/19, the Ontario Renal Network (Renal Network) provided approximately \$662 million in funding for chronic kidney disease services, and the Ministry of Health (Ministry) provided about \$20 million to transplant centres for funding of about 700 kidney transplants.
- Our Office has never audited the Renal Network, which is a division of Cancer Care Ontario (CCO) and responsible for advising the Ministry on chronic kidney disease management.

## **Why It Matters**

- The prevalence of chronic kidney disease is on the rise in Ontario, leading to a higher need for dialysis treatment and a greater demand for kidney transplants. Over the last decade, the number of Ontarians with end-stage renal (kidney) disease has grown over 37%, from about 14,800 people to about 20,300 people.
- Chronic kidney disease has been referred to as a "silent killer" because it often goes undetected or undiagnosed over several years and it has no cure in most cases.

#### What We Found

- Patients are not always referred by primary-care providers to nephrologists (physicians specializing in kidney care) on a timely basis. In 2017/18, over 40%, or about 8,700, of patients who met the Renal Network's referral criteria did not have a visit with a nephrologist even though their lab test results indicated that they would benefit from a nephrology visit.
- The Renal Network indicated that before starting dialysis, patients should receive at least 12 months of multidisciplinary care in the Multi-Care Kidney Clinics, which help patients manage chronic kidney disease and educate patients on the treatment options available. However, of the approximately 3,350 patients who started dialysis in 2018/19, about 25% received less than 12 months of care in a Clinic while 33% did not receive any Clinic care prior to starting dialysis.
- Compared with in-centre dialysis, home dialysis costs significantly less, improves patient quality of life and allows for more treatment flexibility. Promoting and increasing the use of home dialysis has been part of the Renal Network's strategic direction since 2012, but the home dialysis usage rate varies significantly—16% to 41%—among the 27 Regional Renal Programs and only six met the Renal Network's current target of 28%.
- While transplants are considered the best treatment option, wait list and wait times for deceased-donor kidney transplants remain long.
   In each of the last five years, approximately 1,200 patients on average were waiting for a deceased-donor kidney and the average wait time was approximately four years. Patients waiting for a transplant typically have to undergo dialysis as well as continuous testing and evaluation to stay on the wait list, creating mental and physical burdens on patients and resulting in significant costs to the health-care system.
- The Renal Network has not reviewed its funding for most chronic kidney disease services since implementing them between 2012/13 and 2014/15. The Renal Network does not collect actual expenditures incurred by the Regional Renal Programs to ensure that funding allocations align with costs of providing renal care. Our review of expenditures of the Regional Renal Programs we visited found possible surpluses of \$37 million over the last five years.
- Apart from the 27 Regional Renal Programs funded and overseen by the Renal Network, the Ministry also separately funds and oversees
  seven Independent Health Facilities for dialysis and provides funding directly to six adult kidney transplant centres that report data to
  the Trillium Gift of Life Network (Trillium Network). As a result, the Renal Network does not have complete information on dialysis or
  transplants, making it difficult to effectively plan and measure renal care in Ontario.
- While the Renal Network has identified 39 performance measures over its last two strategic plans up to 2019 to assess and benchmark chronic kidney disease services provided by the Regional Renal Programs, it provides very limited public reporting; only the results of eight measures were made publicly available.

#### **Conclusions**

- The Renal Network, in conjunction with the Ministry and Trillium Network, does not have fully effective systems and procedures in place to provide chronic kidney disease services in a timely, equitable and cost-efficient manner to meet Ontarians' needs and in accordance with applicable standards, guidelines and legislation. Patients who would benefit from visiting a nephrologist are not always being referred on a timely basis. Long wait times for a deceased-donor kidney transplant result in some patients becoming too ill for a transplant or dying before a transplant can be done. Funding allocation for most chronic kidney disease services in Ontario has not been reviewed and adjusted for many years, and does not reflect the actual costs of providing renal care to patients.
- Lack of co-ordination between the Ministry, Renal Network and Trillium Network has contributed to a fragmented renal care system that creates difficulties in planning, monitoring and evaluating the services provided. As Ontario has planned to integrate multiple agencies, including the Renal Network within CCO and Trillium Network, into a single agency called Ontario Health, it is important that going forward, renal services are better co-ordinated to meet the needs of Ontarians.
- The Renal Network needs to do more to measure and report on the effectiveness of chronic kidney disease services, as information on the performance of chronic disease services is incomplete and not fully reported to the public.

Read the audit report at www.auditor.on.ca