

Chronic Kidney Disease Management

1.0 Summary

Chronic kidney disease has been referred to as a “silent killer” because it often goes undetected or undiagnosed over several years and, in most cases, has no cure. 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).

There are numerous risk factors that increase the likelihood of developing chronic kidney disease, including diabetes, high blood pressure, age and family history. While chronic kidney disease is prevalent among the elderly population, it is also common among the middle-aged group. Of all people with end-stage renal disease in Ontario, the senior population (aged 65 or older) accounts for 47% and middle-aged adults (aged 45 to 64) account for about 39%. Although some risk factors such as age and family history are unavoidable, individuals can prevent or delay chronic kidney disease by having a healthy lifestyle that includes maintaining a balanced diet, living an active lifestyle, and avoiding tobacco consumption.

The Ontario Renal Network (Renal Network), established in 2009 as a division of Cancer Care

Ontario (CCO), is responsible for advising the Ministry of Health (Ministry) on chronic kidney disease management, determining funding to each of the 27 Regional Renal Programs in Ontario, and leading the organization of chronic kidney disease services (excluding transplants, which fall under the responsibility of the Ministry, Trillium Gift of Life Network [Trillium Network] and six adult kidney transplant centres). In 2018/19, the Renal Network’s expenditures on chronic kidney disease services was approximately \$662 million, and the Ministry provided approximately \$20 million to transplant centres for funding of about 700 kidney transplants.

Our audit found that the funding allocation for most chronic kidney disease services in Ontario has not been reviewed and adjusted for many years, and may not reflect the actual costs of providing specific services to patients. In addition, lack of integration and 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 the Ontario government has planned to integrate multiple provincial 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 following are some of our other significant findings.

Primary Care and Multi-Care Kidney Clinics

- **Patients are not always referred by primary care providers to nephrologists on a timely basis even though referral criteria have been met.** In 2017/18, over 40% (or about 8,700) of patients in Ontario who met the Renal Network's referral criteria did not have a visit with a nephrologist (a physician with a specialization in kidney care) even though these patients' lab test results indicated that they would benefit from a nephrology visit. The Renal Network has not followed up on these patients or with their primary care or health-care providers and the Regional Renal Programs do not receive enough information to identify and follow up on these patients. Late referrals to a nephrologist result in late referrals to a Multi-Care Kidney Clinic (Clinic), which is designed to help patients manage their chronic kidney disease and educate patients on the treatment options available.
- **Most patients do not receive the recommended amount of care from Multi-Care Kidney Clinics.** The Renal Network and Regional Renal Programs indicated that patients should receive at least 12 months of multidisciplinary care in the Clinics before starting dialysis in order to slow down the progression of the disease, delay dialysis starts and educate patients on the treatment options available. However, we found that almost 60% of patients did not receive at least 12 months of multidisciplinary care in the Clinics. 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 care in a Clinic prior to starting dialysis.

Dialysis

- **Capacity for in-centre dialysis in a hospital or clinic setting does not align with regional**

needs. Twenty-seven Regional Renal Programs have a total of 94 in-centre dialysis locations across Ontario with a capacity to serve about 10,200 patients. While the occupancy rate of all locations is about 80% on average, it ranges from 26% to 128% depending on location. About 35% of these locations have an occupancy rate of at least 90%, with some at or near full occupancy. Meanwhile, about 18% of these locations have an occupancy rate below 70%, meaning their dialysis stations are not being consistently used. We found that the mismatch between dialysis capacity and regional need can be the result of patients not always receiving dialysis at the locations closest to them. For example, a Regional Renal Program with an occupancy rate of approximately 90% at most of its locations has about 22% of its patients coming from outside of its catchment area.

- **Home dialysis usage rate has improved, but remains low and does not meet targets.** Compared with in-centre dialysis, home dialysis costs significantly less, improves patient quality of life, and allows for more treatment flexibility. While promoting and increasing the use of home dialysis has been part of the Renal Network's strategic direction since 2012, the home dialysis usage rate still has not met the Renal Network's target. We noted that the home dialysis usage rate varies significantly (16% to 41%) among the 27 Regional Renal Programs, and only six met the current target of 28%.
- **Initiatives to increase the rate of home dialysis usage have limited coverage and unclear cost effectiveness.** The Ministry and the Renal Network have implemented several initiatives aimed at increasing the use of home dialysis, but they have not evaluated their cost-effectiveness and potential for expansion. For example, the Ministry has been funding supports for patients on peritoneal dialysis in long-term-care homes since 2009, but only 4%

of long-term-care homes in Ontario provide these supports. Meanwhile, the Ministry has spent about \$10.5 million between 2017/18 and 2018/19 to transport approximately 450 patients each year from long-term-care homes to in-centre dialysis for treatment. However, it is not clear whether this initiative should be expanded to save the costs of transporting patients between long-term-care homes and dialysis facilities because neither the Ministry nor the Renal Network has collected information on the number of dialysis patients living in long-term-care homes. As another example, in 2015, the Renal Network introduced an initiative at eight Regional Renal Programs to provide patients with a personal support worker to assist with their home hemodialysis, but no fulsome evaluation has been done to determine whether it is cost-effective and should be expanded.

Kidney Transplants

- **Long wait times for deceased-donor kidney transplants have created a burden on patients and costs to the health-care system.** While kidney transplants are considered the best clinical treatment option for patients with end-stage renal disease, wait lists 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 transplant and the average wait time was approximately four years, resulting in some patients becoming too ill for a transplant or dying before receiving a transplant. Patients waiting for a kidney transplant 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.

- **Barriers to living-donor kidney transplants have not been fully addressed.** While a living-donor kidney transplant has a much shorter wait time (approximately one year), its growth has remained static since 2008 for several reasons, such as a lack of consistent information, education and public awareness on living-donor transplants, as well as the financial burden to living donors. While Ontario has a reimbursement program to compensate donors for eligible costs (such as travel, accommodation and lost income), the Ministry and Trillium Network have not updated the reimbursement rates since the program was introduced in 2008.

Funding

- **Funding for chronic kidney disease services does not align with the actual cost of providing services to patients.** The Renal Network has not reviewed its funding amounts for most chronic kidney disease services since implementing them between 2012/13 and 2014/15, even though they were meant to be a starting point given the limited evidence available at the time. We noted that the Renal Network does not collect actual expenditures incurred by the Regional Renal Programs to ensure that funding allocated to each of them aligned with costs of providing renal care. Through our review of expenditures of the five Regional Renal Programs we visited, we found possible surpluses of \$37 million over the last five years. As well, for Multi-Care Kidney Clinic (Clinic) patients, the Renal Network provides \$1,400 per year for each eligible patient registered with the Clinic, based on a patient making at least six visits to the Clinic in the year. However, the average number of visits by patients in 2018/19 was four, indicating that funding allocations may not align with the level of services being provided.

- **Base funding for kidney transplants is unchanged since 1988 and does not align with the actual cost.** The current funding rate per kidney transplant is approximately \$25,000, with a top-up amount of \$5,800 (introduced in 2004) for living-donor transplants to help offset additional costs (such as testing and retrieving a kidney from a living donor). Our review of information at the transplant centres we visited showed that the cost of a kidney transplant varies and that the current funding rate does not align with the actual cost incurred by the centres. For example, the average cost reported for a deceased-donor kidney transplant, including pre-transplant and pre-operative care provided by the transplant centre, was \$40,000, ranging from about \$32,000 at one centre to \$57,000 at another.
- **Further work is needed to identify potential savings related to peritoneal dialysis supplies.** The Renal Network has reviewed the cost of hemodialysis equipment and supplies and achieved a savings of approximately \$30 million through a provincial procurement initiative. While the Renal Network has not established a similar initiative for peritoneal dialysis supplies, it began reviewing the pricing of peritoneal dialysis supplies at the time of our audit to determine if additional savings are available. We reviewed a sample of invoices for peritoneal dialysis supplies across the Regional Renal Programs and found price differences ranging from 8% to 20%, indicating opportunities for cost savings.

Co-ordination of Renal Care

- **Variability in oversight, funding and reporting of dialysis has created challenges for planning and measuring renal care.** Apart from the 27 Regional Renal Programs funded and overseen by the Renal Network,

the Ministry also funds and oversees seven Independent Health Facilities (Facilities) that provide dialysis to patients. Unlike the Regional Renal Programs that also provide dialysis, these Facilities are not required to report the same data to the Renal Network. Because of this, the Renal Network does not have complete oversight of and information on dialysis across the province. This makes it difficult for the Renal Network to effectively plan and measure renal care in Ontario.

- **Inaccurate and incomplete transplant data have caused difficulty in measuring and reporting transplant activities.** The Renal Network has no oversight of kidney transplants, which fall under Trillium Network's responsibility. While Trillium Network and the Renal Network established a data-sharing agreement in September 2017 to capture patients' complete transplant journeys, concerns about the data's accuracy and completeness have made it difficult for the Renal Network to determine whether the Regional Renal Programs refer patients who are eligible for a transplant to a transplant centre on a timely basis. As well, while patients on dialysis may eventually receive a transplant and patients with failed transplants would go back on dialysis, there is limited co-ordination between the Renal Network and Trillium Network in terms of tracking the performance of transplant activities (such as post-transplant care) and patient outcomes.

Data Reporting and Performance Measures

- **Information on the performance of chronic kidney disease services is incomplete and not fully reported to the public.** The Renal Network has developed performance measures to assess and benchmark chronic kidney disease services provided by the Regional Renal Programs in Ontario. However, we noted that many Regional Renal

Programs do not report optional but useful information (such as primary nephrologist's name and home dialysis eligibility) to the Renal Network for planning and oversight responsibilities. For example, of the almost 8,600 patients that spent time in the Multi-Care Kidney Clinics and began dialysis between 2015/16 and 2018/19, more than 2,850 (33%) were missing data in the Renal Network's system that indicated their eligibility for home dialysis. The Renal Network acknowledged that the completeness of optional data varies. Meanwhile, we noted that the Renal Network has identified 39 performance measures over its last two strategic plans up to 2019, but it provides very limited public reporting as only the results of eight measures were made publicly available.

Overall Conclusion

Our audit concluded that the Ontario Renal Network, in conjunction with the Trillium Gift of Life Network and the Ministry of Health, does not have fully effective systems and procedures in place to ensure that chronic kidney disease services are provided in a timely, equitable and cost-efficient manner to meet Ontarians' needs and in accordance with applicable standards, guidelines and legislation. Specifically, patients who would benefit from visiting a nephrologist are not always being referred on a timely basis by their primary care provider, resulting in some patients going straight to dialysis without receiving enough multidisciplinary care to help delay or prepare for treatment.

In addition, the mismatch between dialysis capacity and patient needs results in some dialysis locations operating at maximum capacity and being unable to take more patients while other locations are not being fully utilized. We also found that funding amounts for multidisciplinary care, dialysis and kidney transplants do not align with the actual costs of providing these services.

Further, while a kidney transplant is the best clinical and cost-effective treatment for patients with end-stage renal disease, patients must wait about four years on average for a deceased-donor kidney transplant, resulting in some patients becoming too ill for a transplant or dying before a transplant can be done. While a living-donor kidney transplant has much shorter wait times, its growth has remained static because of various barriers. As well, there is a lack of integration and co-ordination between the Ministry, Renal Network and Trillium Network, because the Renal Network has no oversight over dialysis services provided by the Independent Health Facilities and kidney transplants co-ordinated by Trillium Network.

We also concluded that the Renal Network needs to do more to measure and report on the effectiveness of chronic kidney disease services and initiatives in meeting their intended objectives. While the Renal Network develops measures to evaluate the performance of goals set out in its public strategic plan, it does not release the results of all measures to the public on a regular basis.

This report contains 14 recommendations, consisting of 27 actions, to address our audit findings.

OVERALL RESPONSE FROM THE ONTARIO RENAL NETWORK

The Ontario Renal Network appreciates the Auditor General's comprehensive audit of chronic kidney disease management in Ontario. We welcome opportunities to work together with our partners, including the Ministry of Health, Trillium Gift of Life Network, patients and families, to improve these services in Ontario. In time, Ontario Health will take on the work of the Ontario Renal Network and Trillium Gift of Life Network. As a single agency, Ontario Health will have the opportunity to improve the oversight, integration and co-ordination of kidney care services in this province.

The Ontario Renal Network was launched in 2009 and—for the first time in this province’s history—began to systemically address the detection, diagnosis and treatment of chronic kidney disease. Transformational change takes time to realize, but in just 10 years there have been significant improvements in the way kidney care services are delivered and managed in Ontario. For example, there has been increased engagement with nephrologists, patients and families, as well as improved access to multi-disciplinary clinics for high-risk patients.

The Ontario Renal Network has enabled these improvements through strong partnerships, a robust performance management and accountability model, data infrastructure, and clinical expertise.

The recommendations within this report build upon the work that has been done to date by the Ontario Renal Network, the Ministry of Health, Trillium Gift of Life Network and many other partners. The report also identifies further opportunities to drive improvements in a number of areas, many of which echo the goals and objectives of the Ontario Renal Plan 2019–2023.

The Ontario Renal Network is committed to working with the Ministry of Health and our many partners, in particular renal patients and their families, to create a system that delivers person-centred, safe and effective kidney care services in an efficient, equitable and timely manner.

OVERALL RESPONSE FROM THE TRILLIUM GIFT OF LIFE NETWORK

Over the past five years, the Trillium Gift of Life Network has advanced the Ontario transplant system for chronic kidney disease patients with increasing rates of registration and increasing referrals for donation resulting in more patients in Ontario with healthy kidney transplants. We look forward to working with our partners to provide more options, more kidney transplants and

high-quality care for all renal patients and we are excited for the opportunity to collaborate with the Ministry and other stakeholders to increase and enhance living donation in Ontario.

Current and future initiatives at the Trillium Gift of Life Network, such as reviewing and comparing data, policies and best practices with other jurisdictions and reviewing and updating current funding models, will help to ensure that key services are appropriately resourced and reimbursed and that the best possible care is provided to chronic kidney disease patients.

The Trillium Gift of Life Network welcomes the recommendations from the Auditor General and knows that with the continued and ongoing support from the Ministry of Health and its stakeholders these recommendations can be achieved for a better quality and integrated health-care system.

OVERALL RESPONSE FROM THE MINISTRY OF HEALTH

The Ministry of Health (Ministry) agrees with the recommendations made by the Auditor General of Ontario directed to the Ministry and thanks her for conducting this timely audit. The Ministry is committed to the development and implementation of innovative initiatives and solutions that address the impact of chronic kidney disease on the lives of Ontarians. We welcome any insights and recommendations provided by the Auditor General.

In 2018/19, Ontario provided approximately \$662 million for renal services in Ontario. This funded the delivery of chronic kidney disease services, such as pre-dialysis services, dialysis (home and in-facility) and patient support. In addition, this funding developed and implemented various quality initiatives that provide specialized and person-centered care, and that promote early detection and prevention of progression of chronic kidney disease. In 2018/19, Ontario provided over \$14 million in new

funding for renal services, most of which was for volume funding for chronic kidney disease services. As Ontario continues to invest in renal services, the Ministry will aim to ensure there is continuous system improvement to renal services, including co-ordination of care, removal of barriers to treatment, appropriate capacity development, efficient funding, and measurement and evaluation.

The audit identifies areas of consideration that the Ministry is already taking measures to address and reinforces the Ministry's commitment to continuous improvement. The Ministry is confident that Cancer Care Ontario and the Trillium Gift of Life Network deliver high-quality care to Ontarians with chronic kidney disease, and that they will make full use of the audit's recommendations to further improve that care.

The Ministry will continue to work closely with Cancer Care Ontario and the Trillium Gift of Life Network (and, once the agencies have integrated, with Ontario Health) to ensure that Ontarians have access to equitable, integrated, cost-efficient renal services.

2.0 Background

2.1 Overview of Chronic Kidney Disease

2.1.1 Causes of Chronic Kidney Disease

Kidneys form an important filtering system for the body by removing extra water and waste from the blood, balancing salts and minerals in the blood, and creating hormones for producing red blood cells. Chronic kidney disease is the presence of kidney damage, or a decreased level of kidney function, for a period of three months or more.

Chronic kidney disease can be caused by many factors, but is often a result of diabetes and/or high blood pressure. **Figure 1** shows the major risk factors for chronic kidney disease. While some factors

(such as family history and age) are unavoidable, individuals can prevent or delay chronic kidney disease by making healthy lifestyle choices (such as maintaining a balanced diet, living an active lifestyle, and avoiding tobacco consumption).

2.1.2 Diagnostic Tests and Stages of Chronic Kidney Disease

The two primary measures of kidney function are the estimated glomerular filtration rate (GFR) and the albumin to creatinine ratio (ACR). The GFR is determined based on a blood test of creatinine (a waste product that is normally removed by kidneys), while the ACR is determined through a urine test of albumin (a protein that is found in blood but should not be present in urine). The GFR test is often included as part of routine blood work, but the ACR is less commonly tested and is often used for patients with diabetes.

There are five stages of chronic kidney disease, ranging from mild to severe, and each stage is represented by a range of GFR and ACR. **Figure 2** shows the percentage of kidney function by stage of chronic kidney disease.

When a patient is diagnosed with Stage 5 (or end-stage renal disease), the kidneys are approaching or at the point where they can no longer filter blood effectively, which can result in kidney failure and death if not treated.

While not all individuals with chronic kidney disease require medical intervention, those with more severe kidney disease require treatment to slow down the progression of kidney damage and stay alive. **Section 2.3** provides details on each treatment option.

2.2 Importance of Chronic Kidney Disease Management

2.2.1 Prevalence of Chronic Kidney Disease in Ontario

Chronic kidney disease is much more widespread than people realize and could be a “silent killer”

Figure 1: Major Risk Factors for Chronic Kidney Disease

Prepared by the Office of the Auditor General of Ontario

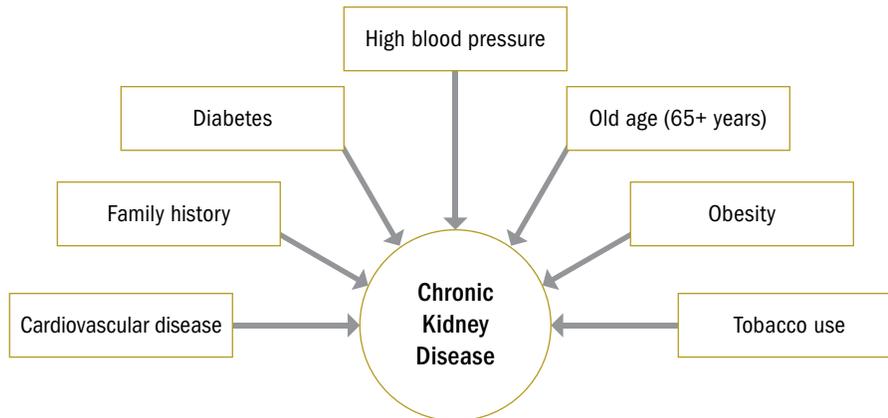
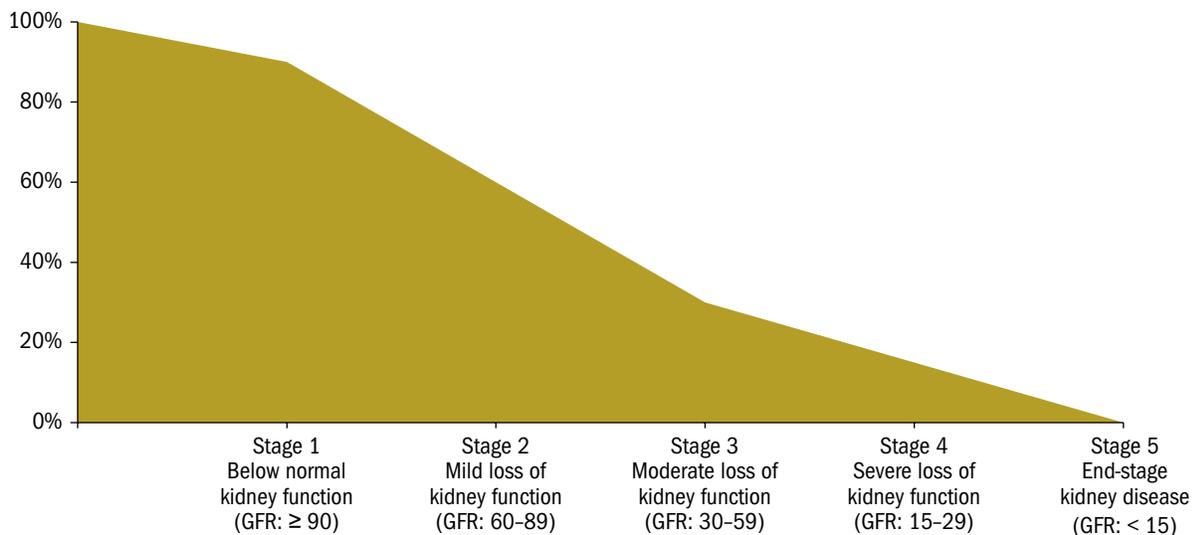


Figure 2: Percentage of Kidney Function by Stage of Chronic Kidney Disease

Prepared by the Office of the Auditor General of Ontario



Note: Estimated glomerular filtration rate (GFR) measures the level of kidney function and determines the stage of kidney disease. GFR is calculated using a blood test of creatinine (a waste product that is normally removed by the kidneys), and albumin is calculated using urine to measure the excretion of protein in the urine.

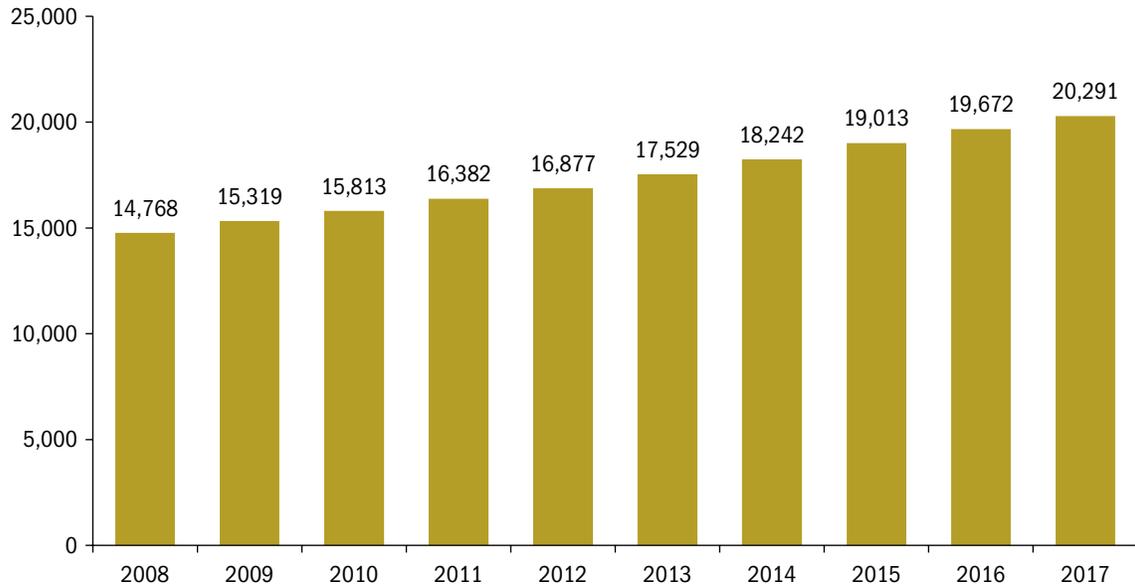
because it often starts slowly and goes undetected or undiagnosed over several years. Although symptoms of chronic kidney disease are silent in the early stages and a person could lose more than 50% of kidney function before symptoms appear, individuals can prevent or delay the need for treatment by making healthy lifestyle choices such as maintaining a balanced diet and getting regular exercise. As well, in most cases there is no cure for chronic kidney disease, which means treatment is focused

on controlling symptoms, reducing complications, and slowing down progression of the disease.

Statistics from various sources (such as the Canadian Institute of Health Information and Kidney Foundation of Canada) showed that the number of patients with chronic kidney disease and kidney failure is on the rise in Canada and Ontario, leading to a greater need for dialysis treatment and higher demand for kidney transplants. As shown in **Figure 3**, the number of people with end-stage renal

Figure 3: Number of People with End-Stage Kidney Disease in Ontario, 2008–2017

Source of data: Canadian Institute for Health Information



disease (Stage 5) in Ontario has grown over 37% between 2008 and 2017 (from about 14,800 people to about 20,300 people).

The increasing prevalence of chronic kidney disease can be attributed in part to an aging population and higher rates of high blood pressure and diabetes. Our analysis of data on Ontarians who started dialysis in 2018/19 found that about 88% had high blood pressure and about 57% had diabetes.

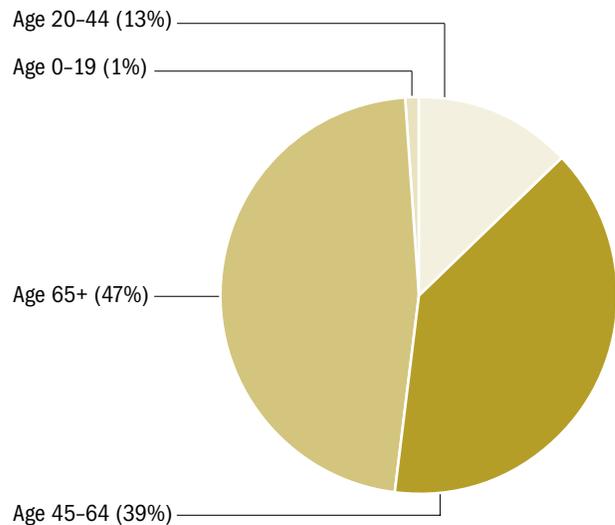
While old age is a risk factor, chronic kidney disease also affects those in middle adulthood. As shown in **Figure 4**, of all people with end-stage renal disease in Ontario in 2017, the senior population (aged 65 or older) accounted for 47% and adults in middle age (aged 45 to 64) accounted for about 39%. According to the Kidney Foundation of Canada, about 46% of new patients with kidney failure across Canada are under the age of 65.

2.2.2 Impacts of Chronic Kidney Disease on Patients and the Health-Care System

Chronic kidney disease and its treatments not only take a great physical, psychological and financial toll on patients, they also create a significant burden

Figure 4: Breakdown of Patients with End-Stage Kidney Disease by Age Group in Ontario, 2017

Source of data: Canadian Institute for Health Information



and cost to the health-care system. Patients with kidney failure often must undergo dialysis (which is the most common treatment for Stage 5 or end-stage renal disease) multiple times per day or week, depending on the type of dialysis (see **Section 2.3**).

Transportation to and from dialysis can also be a significant and costly challenge for patients. A 2018 survey administered by the Kidney Foundation of Canada and the Canadian Association of Nephrology Social Workers found that out-of-pocket costs associated with dialysis can range from \$1,400 to \$2,500 per year and can amount to 12.5% of some patients' income.

Dialysis is also costly to the health-care system. For example:

- According to a 2017 study published in the *Canadian Journal of Kidney Health and Disease*, dialysis costs the health-care system nearly \$100,000 per patient per year and the total cost to the Canadian health-care system for patients on dialysis is nearly \$2.5 billion annually.
- According to another study in 2018 conducted by researchers from various hospitals and universities based on data in Ontario, the mean direct health-care cost for a dialysis patient in a hospital or clinic setting in the first year is about \$140,000, which is more than 30 times the average Ontario per capita public health expenditure (\$4,362), and is substantially higher than for adults with cancer (\$26,000), heart failure (\$28,000) or late-stage liver disease (\$11,000).

2.3 Patient Journey and Treatment Options for Chronic Kidney Disease

2.3.1 Journey of Patient with Chronic Kidney Disease

The journey of a patient with chronic kidney disease typically begins with a primary care provider (such as a family physician). Primary care providers are responsible for managing the day-to-day health of their patients and are often involved in providing care during the early stages of a patient's chronic kidney disease. If a primary care provider notes that a patient is showing signs of high-risk chronic kidney disease according to the Kidneywise Clinical

Toolkit (see **Section 4.1.1**), they are encouraged to refer the patient to a nephrologist (a physician specializing in kidney care), who is responsible for diagnosing the patient based on a blood and/or urine test, determining the patient's stage of chronic kidney disease (see **Section 2.1.2**), and providing the patient with recommendations to slow progression of their kidney disease. If a patient shows a high risk of progression toward end-stage renal disease, a nephrologist will refer the patient to a Multi-Care Kidney Clinic, which provides active management for a patient's chronic kidney disease as well as education on the different end-stage renal disease treatment options (see **Section 2.3.2**). **Appendix 1** provides an illustration of the ideal journey of a patient with chronic kidney disease.

2.3.2 Treatment Options for Chronic Kidney Disease

As discussed in **Section 2.1.2**, there are five stages of chronic kidney disease. When a patient is diagnosed with early chronic kidney disease, he or she can typically be managed by a primary care provider with common treatment options, including prescription medication (which can vary from patient to patient depending on a patient's symptoms and/or other illnesses) and lifestyle changes (such as healthy eating and regular exercise). If a patient with high-risk chronic kidney disease has been seen by a nephrologist and is assessed as progressing toward end-stage renal disease, the nephrologist refers the patient to a Multi-Care Kidney Clinic (see **Section 4.1**), which provides multidisciplinary care to help patients manage the disease.

As shown in **Figure 5**, if a patient is diagnosed with end-stage (Stage 5) chronic kidney disease, three treatment options are available: (1) dialysis; (2) transplant; and (3) conservative care. **Figure 6** provides a summary of each of these treatment options.

Figure 5: Treatment Options by Stage of Chronic Kidney Disease

Prepared by the Office of the Auditor General of Ontario

Treatment Options	
Early Stages ¹	<ul style="list-style-type: none"> • Prescription medication²
Progressing Stages	<ul style="list-style-type: none"> • Lifestyle changes (e.g., healthy eating, regular exercise) • Referral to a Multi-Care Kidney Clinic³
End Stage ⁴	<ul style="list-style-type: none"> • Dialysis • Transplant • Conservative Care⁵

1. Generally, patients with early stage chronic kidney disease do not require significant treatment for their disease.
2. There is no medicine specifically for chronic kidney disease, but medication can help stop or slow down its progression by targeting an underlying health condition, or it can prevent consequences or complications that can occur as a result of the disease. Examples include medications that control high blood pressure and diabetes, reduce cholesterol and treat anemia. The medication options will be influenced by other medical conditions of the patients.
3. A Multi-Care Kidney Clinic consists of a team of multidisciplinary health professionals within a regional renal program that provides care for a patient including active management of chronic kidney disease and education on end-stage renal disease treatment options (see Section 4.1.2).
4. See Figure 6 for details on each treatment option for patients with end-stage kidney disease.
5. Conservative care is like palliative care, which aims to delay progression of the disease and reduce any pain and suffering a patient is experiencing until death.

Figure 6: Treatment Options for a Patient with End-Stage Renal Disease or Kidney Failure

Prepared by the Office of the Auditor General of Ontario

Treatment Options	Type of Treatment	Description
1. Dialysis	Hemodialysis	<ul style="list-style-type: none"> • This involves extracting a patient's blood and passing it through a machine that replicates kidney function and then delivering the filtered blood back into the patient. • This can be done in-centre (in a hospital or clinic setting) or at home with appropriate training and resources. • This is usually done three to four times a week, for approximately four hours per treatment, but it can also be done overnight and/or daily.
	Peritoneal Dialysis	<ul style="list-style-type: none"> • This involves inserting a liquid into the lining of a patient's abdomen, which acts as a filter to absorb toxins, and draining the waste-filled liquid out. • This is primarily done at home and is commonly used by those who prefer home dialysis because it does not require the large equipment necessary for hemodialysis. • This must be done daily, approximately three to five times a day for about 30 minutes each (if done manually) or once overnight (if using a machine).
2. Transplant	Living-Donor Kidney Transplant	<ul style="list-style-type: none"> • This involves removing a kidney from a living donor (who is often a biological family member such as a parent, sibling or child but can also be a distant relative, spouse, friend or even stranger) and transplanting it into a patient.
	Deceased-Donor Kidney Transplant	<ul style="list-style-type: none"> • This involves removing a kidney from a deceased donor (who has consented to be an organ donor directly or indirectly through family) and transplanting it into a patient.
3. Conservative Care		<ul style="list-style-type: none"> • This includes palliative care and treatment to delay progression of the disease and reduce any pain and suffering a patient is experiencing until death. • This treatment option is generally selected by patients who are severely ill and prefer not to go through frequent dialysis treatments and who are not medically eligible for a transplant.

2.4 Management and Delivery of Chronic Kidney Disease Services

2.4.1 Roles and Responsibilities of Key Parties Involved

Figure 7 outlines the key parties involved in the management and delivery of chronic kidney disease services in Ontario and their working relationships. The major parties include the Ministry of Health (Ministry), Ontario Renal Network (Renal Network), Trillium Gift of Life Network (Trillium Network), hospitals (27 Regional Renal Programs and six adult kidney transplant centres) and independent health facilities. **Appendix 2** provides a summary of each party's roles and responsibilities.

The Renal Network was created as a division of Cancer Care Ontario (CCO) in 2009 to use CCO's experience with clinical engagement and quality improvement through its oversight of cancer services. It is responsible for advising the Ministry on chronic kidney disease management, determining funding for each of the 27 Regional Renal Programs in Ontario, and organizing chronic kidney disease services (excluding transplants, which fall under

the responsibility of the Ministry, Trillium Network and six adult kidney transplant centres).

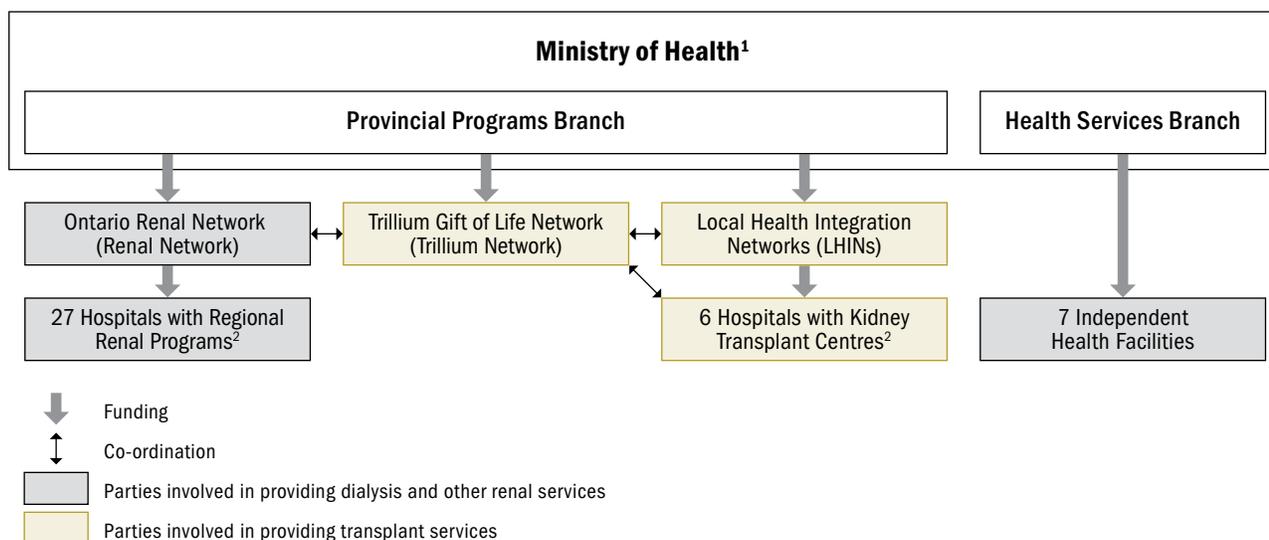
2.4.2 Funding for Chronic Kidney Disease Services

The Ministry provides funding to the Renal Network, which manages and allocates the funding to the 27 Regional Renal Programs that deliver chronic kidney disease services. Over the last five fiscal years (2014/15–2018/19), the Renal Network's expenditures on chronic kidney disease services (excluding transplants) grew by about 8% (from about \$612 million to \$662 million), as shown in **Figure 8**.

In 2018/19, almost 93% (or about \$617 million) of the Renal Network's funding was for direct services (such as Multi-Care Kidney Clinics and dialysis) delivered by the 27 Regional Renal Programs to patients with chronic kidney disease, with the remaining 7% primarily for capital and administration (such as dialysis equipment and initiatives related to quality improvement, staffing and information technology). **Appendix 3** shows the

Figure 7: Key Parties Involved in the Management and Delivery of Chronic Kidney Disease Care in Ontario

Prepared by the Office of the Auditor General of Ontario

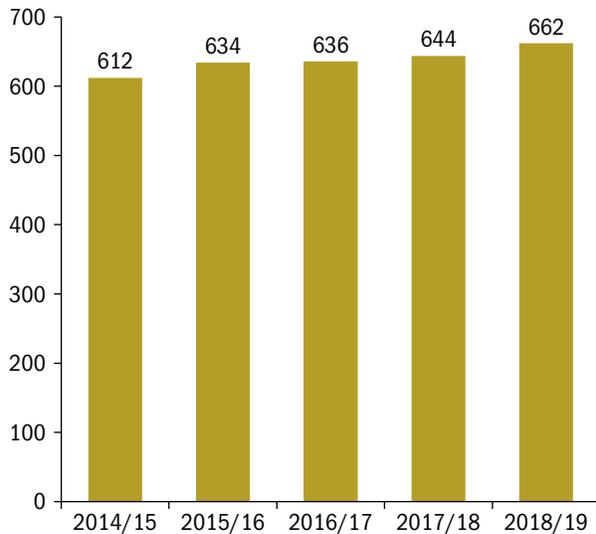


1. Other parties involved are the Ministry of Long-Term Care and the Health Capital Branch within the Ministry of Health.

2. In total, the 27 hospitals with Regional Renal Programs have a combined 94 dialysis locations across the province, including 42 satellite hospitals. Each Regional Renal Program has a Multi-Care Kidney Clinic. Six of these 27 hospitals are also kidney transplant centres. There are seven kidney transplant centres in Ontario. Our audit focused on six adult kidney transplant centres.

Figure 8: Ontario Renal Network's Expenditure on Chronic Kidney Disease Services, 2014/15–2018/19 (\$ million)

Source of data: Ontario Renal Network



Quality-Based Procedure funding for direct services (see **Section 4.1.1**) and the average number of dialysis patients for each Regional Renal Program in 2018/19.

The Ministry also provides funding to the Trillium Network and hospitals for kidney transplants. In 2018/19, the Ministry provided approximately \$20 million in funding for about 700 kidney transplants.

3.0 Audit Objective and Scope

Our audit objective was to assess whether the Ontario Renal Network (Renal Network) within Cancer Care Ontario (CCO), in association with the Ministry of Health (Ministry), the Trillium Gift of Life Network (Trillium Network) and Regional Renal Programs, has effective systems and procedures in place to:

- ensure that chronic kidney disease services are provided in a timely, equitable and cost-efficient manner to meet Ontarians' needs

and in accordance with applicable standards, guidelines and legislation; and

- measure and report periodically on the results and effectiveness of chronic kidney disease services and initiatives in meeting their intended objectives.

In planning for our work, we identified the audit criteria (see **Appendix 4**) we would use to address our audit objective. These criteria were established based on a review of applicable legislation, policies and procedures, internal and external studies, and best practices. Senior management at the Renal Network, Ministry and Trillium Network reviewed and agreed with the suitability of our objectives and associated criteria.

We conducted our audit between December 2018 and June 2019. We obtained written representation from the Renal Network, the Ministry and Trillium Network management that, effective October 30, 2019, it had provided us with all the information they were aware of that could significantly affect the findings or the conclusion of this report.

We conducted our audit work at the Renal Network within CCO where we:

- interviewed senior management and staff responsible for managing and overseeing the delivery of chronic kidney disease services in Ontario;
- reviewed applicable policy and procedure manuals, reports and briefing notes related to chronic kidney disease services in Ontario;
- collected and analyzed data to identify trends, gaps and outcomes of chronic kidney disease services in Ontario; and
- reviewed strategic plans and targets and related performance of all 27 Regional Renal Programs in delivering chronic kidney disease services in Ontario.

We conducted site visits at five of the 27 Regional Renal Programs located in different Local Health Integration Networks (LHINs), three of which are also kidney transplant centres (see **Appendix 3**). We selected the following five sites based on geography

(to obtain representation across Ontario), demand for chronic kidney disease services (to reflect the number of people served in the region), and types of services provided (to cover both dialysis and transplants).

1. **Kingston Health Sciences Centre (South East LHIN):** Large catchment geography and a transplant centre.
2. **London Health Sciences Centre (South West LHIN):** Research and academic affiliation and a transplant centre.
3. **Scarborough Health Network (Central East LHIN):** Highest funding from Renal Network and largest number of dialysis patients.
4. **Thunder Bay Regional Health Sciences Centre (North West LHIN):** Largest catchment geography and patient population that includes First Nations, Inuit and Metis.
5. **University Health Network (Toronto Central LHIN):** Highest home dialysis rate and number of kidney transplants over the last five years.

Our audit work at each of the five Regional Renal Programs included the following:

- interviewing management and front-line staff, including physicians involved with the program;
- reviewing program policies, procedures and other relevant documentation to understand their services and operations;
- reviewing measures and indicators being used to evaluate program performance; and
- reviewing patient files for details on the services provided by the Regional Renal Programs, patient journey, and patient experience with various treatment options including dialysis and kidney transplants (such as how often patients visited Regional Renal Programs for services and why patients selected specific treatment options).

We also conducted a survey of all 27 Regional Renal Programs to get a better understanding of the renal care system in Ontario. We received responses from 21 Regional Renal Programs, representing a 78% response rate.

As well, we conducted audit work at Trillium Network, including collecting and reviewing transplant policies and data. We contacted and obtained documentation from the Ministry related to kidney transplants and independent health facilities that provide dialysis.

In addition, we met with and obtained feedback from stakeholders, including the Kidney Foundation of Canada as well as members of provincial and regional patient and family advisory groups.

Further, we reviewed relevant research and studies in Ontario and other jurisdictions. We contacted other jurisdictions and compared their eligibility criteria, funding and delivery methods for renal services, and performance measures with those of Ontario.

We engaged an independent advisor with expertise in the field of chronic kidney disease services to assist us on this audit.

At the time of our audit, Bill 74, *The People's Health Care Act, 2019*, received royal assent on April 18, 2019. It will come into force on a date to be proclaimed by the Lieutenant Governor. The legislation is designed to integrate multiple provincial agencies, including the LHINs, CCO and Trillium Network, into a single agency called Ontario Health. It has implications for our recommendations presented herein. All recommendations to the Renal Network within CCO and Trillium Network in this report have been addressed directly to Ontario Health and/or to the Ministry of Health.

4.0 Detailed Audit Observations

4.1 Patients Do Not Always Receive Sufficient and Consistent Specialty and Multidisciplinary Care on a Timely Basis

As discussed in **Section 2.3** and **Appendix 1**, the typical journey of a patient with chronic kidney

disease begins with a primary care provider, who refers a patient with signs of chronic kidney disease to a nephrologist. If the nephrologist determines that the patient is at high risk of progressing to end-stage renal disease, the patient will be referred to a Multi-Care Kidney Clinic (Clinic) within a Regional Renal Program for follow-up and monitoring. However, we found that patients do not receive sufficient and consistent services on a timely basis because of late referrals and that not all Clinics provide equitable access to multidisciplinary care.

4.1.1 Patients Are Not Always Referred to Nephrologists on a Timely Basis Despite Meeting Referral Criteria

Most patients diagnosed with early-stage chronic kidney disease can be managed by a primary care provider (such as a family physician or a nurse practitioner) who monitors and treats their health conditions and risk factors (such as diabetes and high blood pressure) to ideally slow down or delay the disease's progression. In 2015, the Ontario Renal Network (Renal Network) developed, as part of its Kidneywise Clinical Toolkit, criteria to help primary care providers identify patients who are at high risk of progressing to advanced stages of chronic kidney disease and should be referred to a nephrologist. However, we found that such referrals are not always done on a timely basis.

The Ontario Laboratories Information System (OLIS) is an information repository that gives authorized health-care providers access to lab test data from hospitals, community labs and public health labs. The Renal Network uses data from the OLIS and other sources to measure the percentage of patients who visited a nephrologist within 12 months of meeting the referral criteria outlined in the Kidneywise Clinical Toolkit.

Our review of the Renal Network's most recent (2017/18) results on this measure noted that over 40% of patients (or about 8,700) had not been referred to a nephrologist even though they met the referral criteria. We also noted that about

2,200 patients who initially met referral criteria in 2015/16 and continued to meet criteria in subsequent years were never referred to a nephrologist.

However, the Renal Network has not followed up on these cases, and it does not provide the Regional Renal Programs with adequate and complete lab data that would enable them to identify and follow up on these patients. Instead, the Regional Renal Programs only receive high-level regional information on the percentage of people who have met the criteria and have already been referred. As a result, the Regional Renal Programs must wait until patients are referred to them or until patients arrive at the Regional Renal Program needing to start dialysis urgently without having received sufficient care in a Multi-Care Kidney Clinic, as discussed further in **Section 4.1.3**.

Our review of statistics from the Kidney Foundation of Canada also noted that:

- 1 in 4 patients starting dialysis had never seen a nephrologist; and
- nearly 25% of patients in Canada had late referrals, which means they started dialysis only 90 days after first seeing a nephrologist.

According to a 2012 study of Kaiser Permanente Hawaii (a region of Kaiser Permanente, which is one of the United States' leading health-care providers), a care model with an integrated electronic health record helps reduce late referrals by enabling nephrologists and primary care providers to collaborate and share information on chronic kidney disease patients. While this study focused on the population and care model in Hawaii, we noted that something similar could be implemented in Ontario by proactively providing nephrologists and/or Regional Renal Programs with details of patients who meet the referral criteria according to the Kidneywise Clinical Toolkit so that they can reach out to these patients or their primary care providers.

As discussed in **Section 4.1.2**, the Multi-Care Kidney Clinics (Clinics) are staffed and connected with nephrologists. Therefore, referring patients to nephrologists in a timely manner is important to

ensure that patients have timely access to the multi-disciplinary care at the Clinics, which help patients manage their chronic kidney disease and educate them on the treatment options available.

RECOMMENDATION 1

To help patients receive timely referrals to a nephrologist and slow down the progression of their chronic kidney disease, we recommend that the Ontario Renal Network:

- work with the Ministry of Health to share lab data from the Ontario Laboratory Information System with the Regional Renal Programs to help them identify and follow up on patients who are eligible for referral to a nephrologist; and
- work with the Regional Renal Programs to investigate cases where patients are not being referred to see nephrologists on a timely basis to ensure these patients are referred for assessment.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees that timely referral to nephrology is important to slow and delay the progression of chronic kidney disease.

Currently, the Ontario Renal Network reports to the Regional Renal Programs the early chronic kidney disease referral rate to nephrology on an annual basis. In order to better understand the trends and opportunities for improved referrals, the Ontario Renal Network is conducting an in-depth analysis of the available information. The analysis explores regional variation and identifies potential barriers and reasons for no or late referrals, including demographic variances and primary care patient enrolment models. The results of this analysis will be shared with the Regional Renal Programs to ensure that local initiatives are focused on these patients and their physicians.

In collaboration with the Ministry of Health and other partners, the Ontario Renal Network will explore mechanisms to use the Ontario Laboratories Information System database to identify eligible patients so that Regional Renal Programs and primary care physicians can ensure timely and appropriate referrals. This exploration would include privacy considerations related to personal health information for direct communication with patients and primary care providers.

The Ontario Renal Network will continue to work with the Regional Renal Programs to increase awareness among primary care providers of the KidneyWise Clinical Toolkit, which includes guidelines on how to identify patients at high risk of chronic kidney disease, diagnose and manage patients with chronic kidney disease in a primary care setting and refer patients at high risk of progression to nephrology.

MINISTRY RESPONSE

The Ministry recognizes the potential for Ontario Laboratories Information System data to inform important clinical care pathways to improve outcomes for renal patients. The Ministry is prepared to work with the Ontario Renal Network (and/or Ontario Health) to explore the potential for Ontario Laboratories Information System data sharing and how that might be achieved.

4.1.2 Patients Do Not Receive Equitable and Consistent Services from Multi-Care Kidney Clinics across the Province

In 2013/14, the Renal Network introduced a Multi-Care Kidney Clinic (Clinic) within each Regional Renal Program in Ontario. Each Clinic (previously known as a predialysis clinic) is staffed by a multidisciplinary team (which includes nephrologists, nurses, dietitians, social workers and pharmacists). While the Renal Network requires each Clinic to have a multidisciplinary team and provides best practices for team composition, we found that it does not track

nor specify the staffing level or staff-to-patient ratio for each discipline to ensure that Clinics provide consistent services across the province.

A Clinic focuses on helping patients manage their chronic kidney disease, educating patients on end-stage treatment options and preparing patients for transition to the treatment option selected. As of 2018/19, over 16,000 patients received care at the Clinics across the province. Most of these patients had advanced chronic kidney disease and are at high risk of kidney failure. Our review of various studies noted that multidisciplinary care is associated with improved clinical outcomes such as fewer urgent dialysis starts and improved survival when on dialysis.

In January 2019, the Renal Network released a document that outlines best practices for the Clinics. One of the best practices is related to the composition and responsibilities of the multidisciplinary team. Specifically, apart from the patient and caregiver, the team should include at a minimum a nephrologist, nurse, pharmacist, dietitian and social worker. **Figure 9** summarizes the roles and responsibilities of staff in the multidisciplinary team.

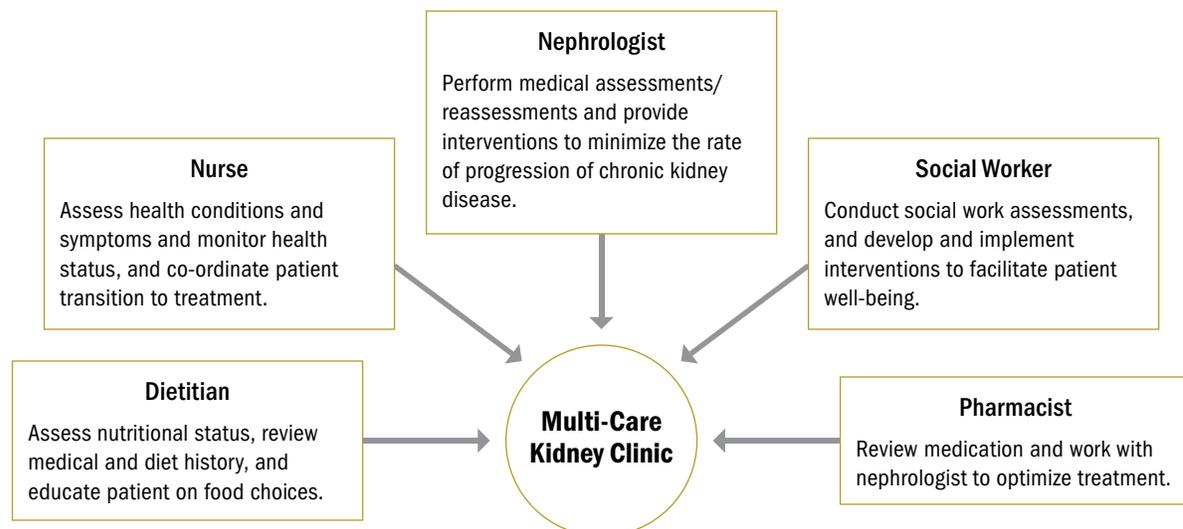
Despite the Renal Network's best practices, through our survey we found that staffing levels

vary from one Clinic to another. For example, one Regional Renal Program with approximately 500 Clinic patients had access to two full-time pharmacists, while another with a similar patient volume only had access to one part-time pharmacist. Our survey also found that approximately 50% of Regional Renal Programs that responded indicated having gaps in their Clinic as a result of either not having a specific discipline of staff (for example, a pharmacist) or not having enough access to a specific discipline. Therefore, patients' access to care at the Clinics varies depending on which Regional Renal Program they are connected to, creating an inequity in the availability of services across the province.

Unlike Ontario, we noted that the best practice guide in British Columbia specifies and provides examples of staffing levels for each discipline based on the size of the clinic and the estimated hours of service that will be provided by each clinic. For example, it provides an estimate on the number of hours per year a social worker provides services for new cases and discharged cases based on patient volumes and the size of the clinic. This estimate is then converted into the number of full-time equivalents for social workers required.

Figure 9: Roles and Responsibilities of Staff in the Multidisciplinary Team of the Multi-Care Kidney Clinics in the 27 Hospitals with Regional Renal Programs

Prepared by the Office of the Auditor General of Ontario



RECOMMENDATION 2

To help patients with advanced stages of chronic kidney disease obtain access to equitable and consistent services across the province, we recommend that the Ontario Renal Network:

- collect information on the composition and staffing level of the multidisciplinary team at each Multi-Care Kidney Clinic from the Regional Renal Programs on an annual basis to identify teams that do not meet best practices and make changes accordingly; and
- review the composition and practices of each multidisciplinary team to identify whether to implement minimum patient-to-staff ratios.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees that access to equitable and consistent services within Multi-Care Kidney Clinics is a key service for patients with high-risk chronic kidney disease. In 2019, the Ontario Renal Network released a best practices document that establishes the quality and type of care to be delivered in Multi-Care Kidney Clinics.

The Ontario Renal Network will continue to monitor access and quality indicators related to Multi-Care Kidney Clinics. The Ontario Renal Network will regularly conduct on-site quality-focused assessments of Regional Renal Programs and also continue to request annual reporting from all Regional Renal Programs to ensure compliance with the Multi-Care Kidney Clinic best practices, including collecting information on access and composition of multidisciplinary teams.

4.1.3 Most Patients Do Not Receive the Recommended Amount of Care from Multi-Care Kidney Clinics Based on Best Practice

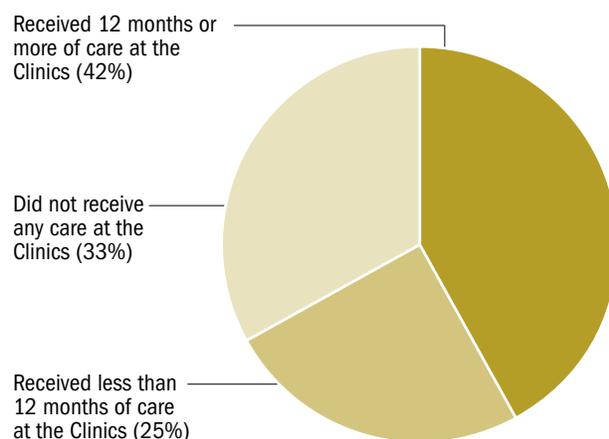
While the Renal Network has identified a best practice for the length of time spent in a Clinic prior to starting dialysis, we found that most patients had not received this recommended amount of multidisciplinary care.

Through expert consultation, the Renal Network has identified that at least 12 months of multidisciplinary care is associated with improved patient outcomes when compared to less than three months. Our survey of Regional Renal Programs also found that approximately 90% of them agreed that patients should ideally be in a Clinic for at least 12 months in order to receive adequate care from the multidisciplinary team and enough information to understand and make a decision on the treatment options available.

The Renal Network measures the percentage of patients who had at least 12 months of multidisciplinary care at the Clinics prior to starting dialysis. Our review of data on about 3,350 patients who started dialysis in 2018/19 found that more than half of these patients had not received the recommended amount of multidisciplinary care in the Clinics (see **Figure 10**). Specifically:

Figure 10: Length of Time Spent by Patients in the Multi-Care Kidney Clinics (Clinics) Prior to Starting Dialysis, 2018/19

Source of data: Ontario Renal Network



- about 25% of patients received an insufficient amount (less than 12 months) of care in the Clinics prior to starting dialysis; and
- about 33% of patients did not receive any care in the Clinics at all prior to starting dialysis.

People receiving less than 12 months or no multidisciplinary care in a Clinic in accordance with best practice means that they likely did not receive sufficient care to help manage their chronic kidney disease prior to requiring dialysis or did not receive enough information or time to learn about the treatment options available.

While neither the Renal Network nor Regional Renal Programs have tracked why patients received insufficient or no multidisciplinary care before starting dialysis, they cited several potential reasons, including:

- lack of access to a primary care provider, who helps monitor a patient's health conditions and risks for chronic kidney disease;
- late referral by a primary care provider to a nephrologist;
- late referral by a nephrologist to a Clinic;
- a significant change in a patient's health condition that triggered a kidney-related disease; and
- patient's preference and choice.

Regarding access to primary care, our review of data from the Renal Network noted that about 34% of patients were not registered with a primary care provider. This means patients may not have received an adequate level of chronic disease management and preventive care, which is usually provided by a primary care provider, and could contribute to late referrals to the Clinic.

Our review of patient files confirmed instances where patients were not referred to a Clinic on a timely basis. We also noted cases where patients had visited a hospital in prior years for conditions related to chronic kidney disease (such as diabetes) and were referred back to their regular health-care provider, only to return to hospital when their condition worsened to the point where they needed urgent dialysis and spent little to no time in a Clinic

beforehand. If these patients had been referred to a Clinic earlier and had spent more time at a Clinic, their need for starting dialysis could potentially have been deferred or avoided altogether.

Additionally, we found that most patients (61%) that started home dialysis (which costs less than in-centre dialysis) in 2018/19 received at least 12 months of multidisciplinary care at the Clinics. This suggests that patients who are referred to and receive at least 12 months of care from a Clinic are more likely to choose home dialysis as their treatment option, which helps save costs and time for patients, and lowers the cost to Ontario's health-care system (see **Section 4.2.3**).

RECOMMENDATION 3

To provide enough multidisciplinary care to patients with advanced stages of chronic kidney disease, we recommend that the Ontario Renal Network work with the Regional Renal Programs to fully investigate the reasons for late referrals to the Multi-Care Kidney Clinics and implement practices to allow for timely referral.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees with this recommendation and will continue to work with Regional Renal Programs to investigate the reasons for late referral to Multi-Care Kidney Clinics and implement initiatives as appropriate.

The Ontario Renal Network reviews Regional Renal Program performance on a quarterly basis; indicators include the proportion of Multi-Care Kidney Clinic referrals and time spent in Multi-Care Kidney Clinic prior to dialysis. The Ontario Renal Network will set provincial targets for both and will continue to monitor Regional Renal Program performance against these targets.

The Ontario Renal Network has developed criteria to provide guidance to nephrologists on timing of referral. Ultimately, however,

nephrologists, who may or may not be affiliated with a Regional Renal Program, use clinical judgment to determine if or when it is appropriate for a patient to be referred to a Multi-Care Kidney Clinic, considering patient preference and patient prognosis.

4.1.4 New Eligibility Criteria for Multi-Care Kidney Clinics Getting Mixed Feedback

One of the main goals for the Renal Network is to ensure that the right patients receive the right care in the right place at the right time. In order to identify the right patients, in 2016 the Renal Network revised the eligibility criteria for admission into the Clinics to ensure that only patients with a high risk of kidney failure are admitted. However, we noted that the Regional Renal Programs expressed mixed opinions on the new criteria and some raised concerns that warrant further review by the Renal Network.

In 2016, the Renal Network revised the eligibility criteria for admission to the Clinic because the original criteria (established in 2013) had resulted in many patients with a lower risk of kidney failure being referred to the Clinics unnecessarily. Subsequent to the criteria changes, the number of patients admitted to the Clinics fell about 39% between 2015/16 and 2018/19, which resulted in cost savings of about \$8 million per year for the Renal Network to use for other initiatives.

In 2016/17 and 2017/18, the Renal Network evaluated the impact of revised eligibility criteria and found no negative impact on patient outcomes. However, the Renal Network received mixed feedback from a survey it conducted during the first year of implementation. For example:

- Staff at the Clinics indicated that patient feedback about the change of criteria varied (positive, negative or neutral).
- Administrators, nephrologists and health-care providers wanted more information about the evidence and rationale for changing the criteria.

We also noted that 73% of Regional Renal Programs that responded to our survey indicated they provided Clinic care to patients using other sources of funding even though these patients did not meet the new eligibility criteria. The survey result aligns with what we found during our site visits.

RECOMMENDATION 4

To help the Multi-Care Kidney Clinics (Clinics) admit the right patients who would benefit from multidisciplinary care at the right time, we recommend that the Ontario Renal Network:

- collect further information and feedback regarding the revised eligibility criteria for Clinics from health-care providers at the Regional Renal Programs as well as experts in the field of renal care; and
- update the revised eligibility criteria if needed, based on information and feedback.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees it is important for patients who would benefit from multidisciplinary care to access Multi-Care Kidney Clinics at the right time.

The Ontario Renal Network completed an evaluation of the new funding eligibility criteria. Responses from Multi-Care Kidney Clinic staff indicated: patients had a neutral or positive response to the change; most administrators and health-care providers believed the primary driver of the criteria change was to focus care on the right patients; and, critically, the change in criteria resulted in no negative outcomes for patients.

The Ontario Renal Network will continue to review relevant clinical literature and will update the Multi-Care Kidney Clinic Best Practices document, including the Multi-Care Kidney Clinic eligibility criteria, to reflect the latest evidence as needed. The Ontario Renal Network will continue to evaluate any changes that are implemented.

4.2 Dialysis Services Do Not Fully Meet People’s Needs or Provincial Target

Dialysis, which is the most common treatment for people with end-stage renal disease, can be done in a hospital or clinic setting (referred to as in-centre dialysis) or at home. We identified areas for improvements for both in-centre dialysis and home dialysis. For example, in the case of in-centre dialysis, capacity does not align with regional needs, and inconsistent oversight and funding has caused hardship for some patients. Meanwhile, the usage rate of home dialysis (which has added benefits for patients who are medically suitable) does not meet the province’s overall target and varies significantly across the province, and more needs to be done to increase it.

As discussed in **Section 2.3** and **Figure 6**, there are two types of dialysis:

1. **Hemodialysis** (using a machine to filter waste and fluid from the blood) can be delivered in a hospital or clinic setting (also referred to as in-centre) or at home.
2. **Peritoneal dialysis** (using the lining of the abdomen to clean the blood) is primarily delivered at home.

Patients can choose the type of dialysis they want depending on, for example, the severity and stability of their medical conditions and the available space in their homes. **Figure 11** provides a breakdown of about 11,800 dialysis patients in Ontario by type of dialysis in 2018/19. Specifically, 79% of patients are on hemodialysis and the remaining 21% are on peritoneal dialysis. Regarding dialysis location, 74% of patients received dialysis in a hospital or clinic setting while 26% received dialysis at home (hemodialysis or peritoneal dialysis).

4.2.1 Capacity for In-Centre Dialysis Does Not Align with Regional Needs

The 27 Regional Renal Programs have a total of 94 in-centre dialysis locations across Ontario. These locations have almost 1,800 dialysis stations, with an estimated capacity to serve approximately 10,200 patients in Ontario if each location is running three dialysis shifts per day. However, we found that many locations are operating at or near full capacity while other locations have excess capacity.

Our review of data on these locations found that the occupancy of in-centre dialysis stations varies across the province and does not align with regional needs. Specifically, at the end of 2018/19:

- The occupancy rate was about 80% on average, but varied significantly from one dialysis facility to another, ranging from 26% to 128%. According to the Renal Network, it is possible that in situations where demand for dialysis increases at a faster rate than the physical capacity available, the Regional Renal Programs may need to create additional dialysis stations within their existing space, leading to a less-than-ideal environment for receiving dialysis treatment.
- 33 dialysis locations (or 35% of all locations) had an occupancy rate of at least 90%. For example, one Regional Renal Program in the Greater Toronto Area had an occupancy rate of approximately 90% at most of its locations and noted difficulties in keeping up with demand.
- 16 dialysis locations (or 18% of all locations) had an occupancy rate lower than 70%, meaning that they had dialysis stations that were not being used consistently.

A contributing factor to this capacity issue is that patients do not always receive in-centre dialysis at the location that is closest to them. For example, a patient living in Mississauga may choose to receive in-centre dialysis in Toronto. When a patient does not receive dialysis at the facility closest to them, it can result in a mismatch between dialysis capacity and regional demand.

Our review of data and documents from the Renal Network and Regional Renal Programs noted that approximately 49% of patients were not receiving in-centre dialysis at the location closest to them. This primarily happens in larger urban locations where patients have more options as to where to receive treatment. For example:

- At one Regional Renal Program in Toronto, 83% of its dialysis patients lived closer to another Regional Renal Program.
- At another Regional Renal Program (with an approximately 90% occupancy rate at most of its locations in the Greater Toronto Area), almost 22% of its dialysis patients came from outside of its catchment area and 81% of dialysis patients did not receive treatment at the facility closest to them. An external review of this Regional Renal Program in 2017 also raised concerns about patients coming from outside of the region for care. For instance, a patient lived in the Durham Region, but commuted to the Greater Toronto Area for dialysis.

While the Renal Network and Regional Renal Programs have not collected information on why patients received dialysis from sites other than the ones closest to them, they informed us that this is usually due to a patient's preference based on factors such as proximity to employment, family members and other health-care providers; referral by a patient's primary care provider or nephrologist; and availability of transportation for patients.

RECOMMENDATION 5

To better align the capacity for in-centre dialysis with regional needs, we recommend that the Ontario Renal Network conduct a province-wide capacity analysis and realign the supply of in-centre dialysis spots to alleviate high-demand situations in some Regional Renal Programs and reduce the amount of under-used capacity at others.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees with this recommendation. Recognizing that patient choice is a critical factor in where people receive dialysis, the Ontario Renal Network will continue its efforts to optimize system capacity to support the efficient use of resources.

Since 2011, the Ontario Renal Network has conducted biannual provincial in-centre Dialysis Capacity Assessments, which forecast the capacity required to meet patients' needs over the next 10 years. The 2019 assessment is being finalized and will be used to work with the Regional Renal Programs to develop a multi-year provincial Dialysis Capital Investment Strategy that reflects regional and local needs. This strategy will be used to inform the prioritization, location, size and timing of investments required to create additional capacity where necessary, and to optimize the utilization of existing resources. This strategy will be updated regularly, based on changes in demand over time.

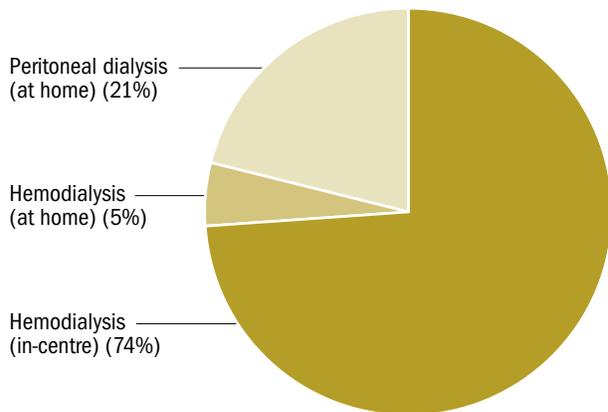
As part of this work, the Ontario Renal Network will work with Regional Renal Programs to conduct collaborative capacity planning across regions and to monitor patient referral patterns to ensure alignment with future planned capacity, making adjustments to these plans where necessary.

4.2.2 Home Dialysis Usage Rate of Most Regional Renal Programs Has Not Met Target and Varies Significantly across the Province

Home dialysis is when patients with end-stage kidney disease undergo dialysis in their homes, either on their own or with help from care providers or family members. Compared with dialysis in a hospital or clinic setting, evidence indicates that the possible benefits of dialysis at home include better quality of life and greater independence

Figure 11: Breakdown of Dialysis Patients by Type of Dialysis, 2018/19

Source of data: Ontario Renal Network



Note: Hemodialysis can be delivered in a hospital setting (also referred to as in-centre) and at home, while peritoneal dialysis is primarily delivered at home.

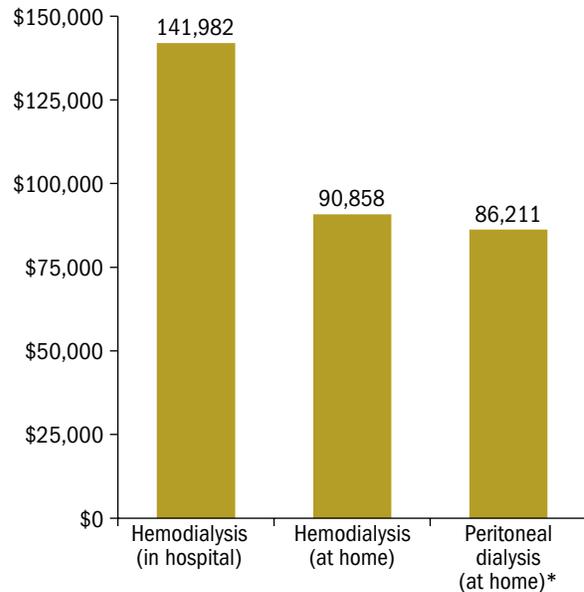
for patients, and lower costs for the health-care system. Despite these benefits, Ontario's home dialysis usage rate of 26% does not meet the Renal Network's target (which is currently 28%) and rates across the province vary significantly.

While both types of dialysis (hemodialysis and peritoneal dialysis) can be done at home, **Figure 11** shows that most patients (about 74%) still receive their dialysis treatments in a hospital or clinic setting (also known as in-centre), which is the most expensive form of dialysis. The direct health-care cost for in-centre hemodialysis is almost \$142,000 per year per patient, about 1.6 times higher than home hemodialysis and peritoneal dialysis (see **Figure 12**). Based on the Renal Network's Quality-Based Procedure funding allocation method (see **Section 4.4.1**) and the number of dialysis patients in 2018/19, a 1% increase in home dialysis usage in Ontario could result in savings of approximately \$1.8 million per year.

Increasing the percentage of patients receiving home dialysis has been one of the Renal Network's main priorities since 2012. Although close overall, the home dialysis usage rate in Ontario still has not met the Renal Network's current target of 28% (measuring the percentage of patients on

Figure 12: Average Total Direct Health-Care Costs by Type of Dialysis

Prepared by the Office of the Auditor General of Ontario



Note: Cost data is provided by the Ontario Renal Network based on a research study published in 2019.

* Peritoneal dialysis is primarily done at home.

home dialysis out of all patients on dialysis). Our analysis of home dialysis usage rates in 2018/19 at each of the 27 Regional Renal Programs found that (see **Figure 13**):

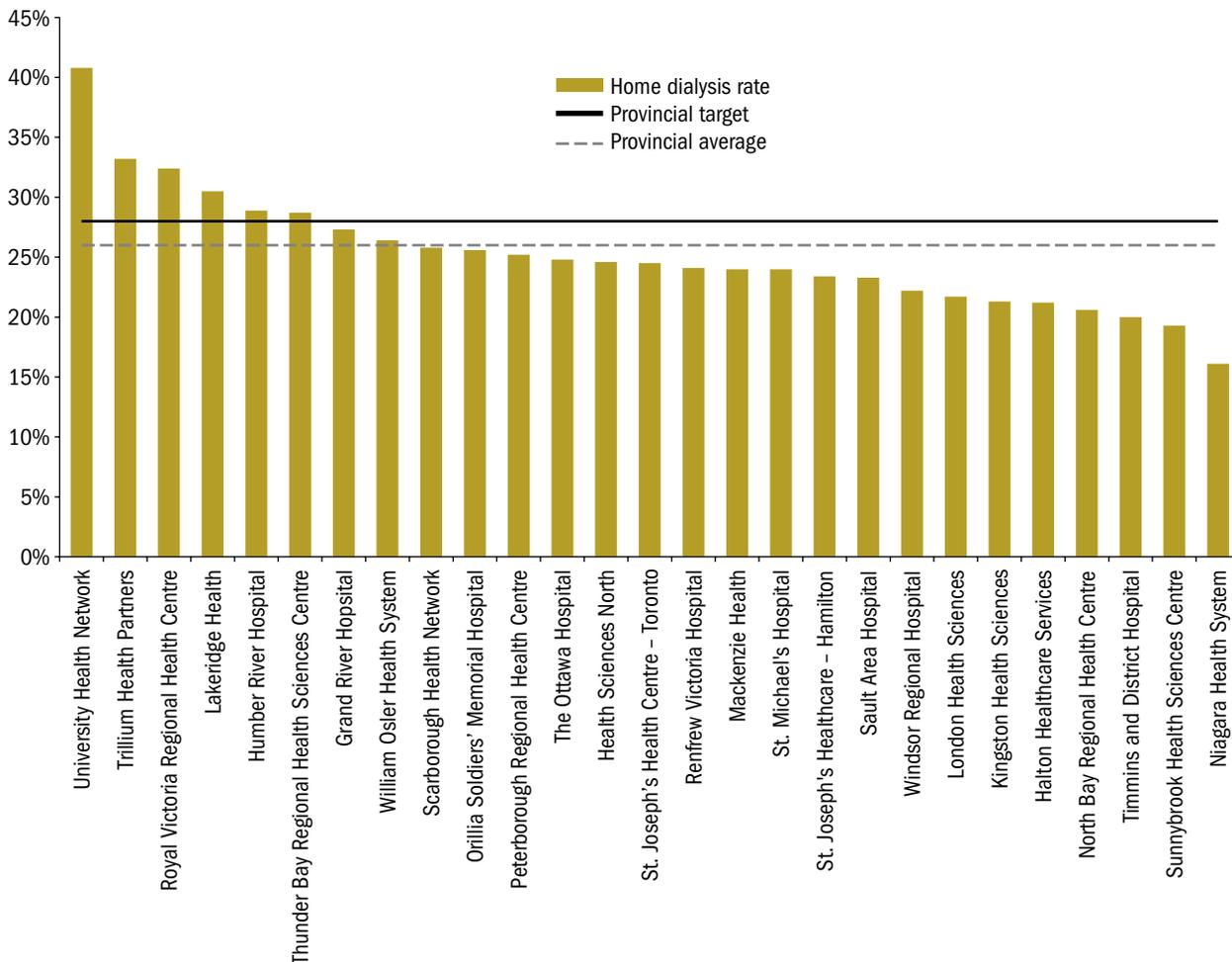
- the rate across the province is 26% on average, but it varies significantly, ranging from approximately 16% at one Regional Renal Program to about 41% at another; and
- only six (or 22%) of the 27 Regional Renal Programs met the current home dialysis target of 28%.

Through discussion with the Regional Renal Programs as well as our review of patient files and documents submitted by the Regional Renal Programs to the Renal Network, we noted that increasing and maintaining home dialysis usage rates has been challenging for many reasons, mainly related to patients' choices or medical conditions and staffing or resource issues (see **Figure 14**).

Additionally, our review of the most recent data available for home dialysis usage rates in

Figure 13: Home Dialysis Rate by Regional Renal Program, 2018/19

Source of data: Ontario Renal Network

**Figure 14: Why Increasing Home Dialysis Usage Rates Can Be Challenging**

Prepared by the Office of the Auditor General of Ontario

Patients' choice or medical condition

- Patients may have clinical factors (such as comorbidities, frailty and obesity) that make them unsuitable for home dialysis.
- Patients often prefer to receive care in a hospital or clinic setting even if they are suitable for home dialysis because they feel uncomfortable doing their own treatment.
- Patients are less likely to choose home dialysis if they live near a facility that provides in-centre dialysis.
- Patients may be too ill to be able to dialyze on their own and do not have the necessary supports (such as family members) to assist them at home.
- Patients do not always attend their scheduled home dialysis education and information sessions.
- Patients going straight into the system without enough previous multidisciplinary care require immediate dialysis, which must be done in a hospital or clinic setting.

Staffing or resource issues

- Some Regional Renal Programs and/or nephrologists promote home dialysis more than others, and this can influence patient choice.
- Regional and community-based agencies, such as Local Health Integration Networks and long-term-care homes, do not have enough resources to support patients who require assistance with home dialysis.
- Not all Regional Renal Programs have the same staffing and capacity resources to dedicate to home dialysis.

Canada and other countries noted that the rate in Ontario has remained steady (around 25% to 26% in recent years), but is lower than some provinces and other countries:

- According to the most recent (2017) data from the Canadian Institute for Health Information, Ontario's home dialysis usage rate was about 25%, the same as the rate in Canada but lower than the rates in Alberta (29%) and British Columbia (30%), as shown in **Figure 15**.
- According to the 2018 United States Renal Data System Annual Data Report, home dialysis rates vary worldwide, ranging from less than 5% in some countries (such as Japan) to over 40% and 70% in New Zealand and Hong Kong, respectively. The rate in Canada is about 25%, which is higher than 12% in the United States and is about the same as Ontario's current average rate of 26%. The rates are high in some jurisdictions for various reasons, including a longstanding culture and history of promoting home dialysis as well as a reim-

bursement system that reimburses patients for home dialysis, but requires patients to pay out of pocket for in-centre dialysis.

4.2.3 Home Dialysis Training Does Not Always Meet Patients' Needs

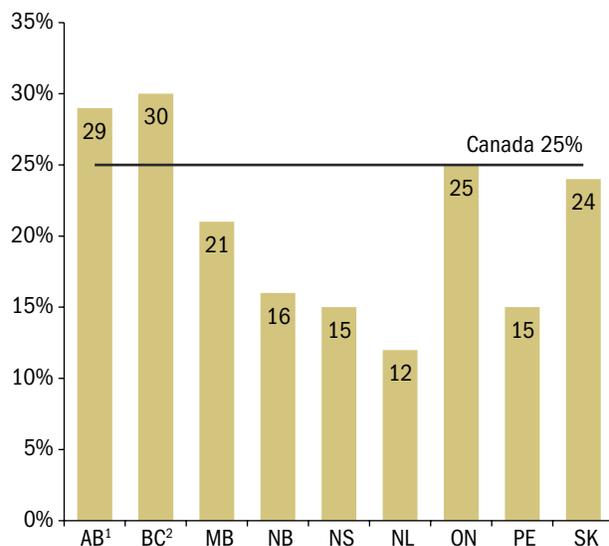
Providing patients with enough training on home dialysis can help prevent patients from returning to in-centre dialysis after starting home dialysis. The Renal Network funds Regional Renal Programs to provide 21 days of training to patients choosing home hemodialysis and five days of training to patients choosing home peritoneal dialysis. The Renal Network also funds retraining for patients as required. Some Regional Renal Programs informed us that while five days of training for peritoneal dialysis is usually sufficient, 21 days of training for home hemodialysis is often not enough to ensure that a patient is adequately trained. This means that patients may have to go back to in-centre dialysis.

We found that home dialysis attrition to in-centre dialysis (patients who tried home dialysis, but returned to in-centre dialysis within 12 months of beginning home dialysis) varies across the province. Our review of home attrition to in-centre dialysis noted that while the average attrition rate was approximately 13% province-wide in 2018, the rate varied significantly between the Regional Renal Programs, ranging from 0% to over 20% for peritoneal dialysis and approximately 0% to 45% for home hemodialysis.

Some Regional Renal Programs informed us that they have provided training for longer than the length of training funded by the Renal Network. For example, a Regional Renal Program that has one of the highest home dialysis rates in Ontario indicated that in 2018/19, the average length of training required for its home hemodialysis patients was 46 days, over two times longer than the 21-day training funded by the Renal Network. After the 21-day training term was up, the Regional Renal Program would continue providing training while classifying the patients as in-centre dialysis patients

Figure 15: Home Dialysis Usage Rates Across Canada, 2017

Source of data: Canadian Institute for Health Information



Note: This figure excludes data from Quebec because of under-reporting.

1. Data from Alberta includes Northwest Territories and Nunavut.
2. Data from British Columbia includes Yukon Territory.

to recoup some of the costs of training. Our survey of Regional Renal Programs also found that the average number of training days for home hemodialysis was 31 days.

4.2.4 Initiatives to Increase Home Dialysis Have Limited Coverage, Unclear Effectiveness and Mixed Outcomes

Promoting the appropriate use of home dialysis is a major strategic direction in Ontario that is supported by a number of initiatives collectively known as the “Home First” Strategy. With limited home and community supports, however, patients are more likely to choose in-centre dialysis even if they are eligible for or prefer home dialysis. For example, our analysis of Renal Network data noted that of the approximately 3,350 patients beginning dialysis in 2018/19, more than 1,300 were assessed as eligible for home dialysis but only 780 (or about 60%) of these patients intended to go on home dialysis.

While the Renal Network has introduced initiatives to help patients who prefer to receive home dialysis but are unable to manage treatment by themselves, they have had mixed results. Through discussion with patient representatives and our survey of Regional Renal Programs, we found that the following initiatives, for example, have generally been received positively.

- In 2018/19, the Renal Network provided approximately \$9.2 million to the 14 Local Health Integration Networks (LHINs) for arranging community nurses or personal support workers to visit and help patients perform peritoneal dialysis at their homes. We noted that additional work on this initiative is needed, as our survey found that 64% of Regional Renal Programs noted that there are not enough LHIN and community resources available to help patients with home dialysis, and 73% of Regional Renal Programs indicated that the quality and consistency of care provided is not always adequate.
- In 2017, the Renal Network introduced a grant to help offset patients’ utility costs (electricity and water) when conducting hemodialysis independently at home. The amount of the grant varies by patient as it is calculated based on, for example, municipal water and electricity rates, as well as treatment frequency and duration. In 2018/19, a total of about \$295,000 was paid to approximately 650 patients on home hemodialysis. However, we found that other initiatives have limited coverage, unclear effectiveness and mixed outcomes. For example:
 - In 2009, the Ministry began funding supports for patients on peritoneal dialysis in long-term-care homes so that patients would not have to travel to in-centre dialysis sites for treatment. Since then, the Ministry has spent about \$5.7 million on funding these supports. However, neither the Ministry nor the Renal Network has collected information on the number of dialysis patients living in long-term-care homes. Without this information, it is not clear whether the Ministry’s funding is sufficient to meet the dialysis needs in long-term-care homes or how much can be saved on transporting patients between long-term-care homes and dialysis facilities. In 2018/19, the Ministry’s funding for supporting patients on peritoneal dialysis in long-term-care homes was approximately \$324,000, but only 27 (or 4%) of 630 long-term-care-homes offered these supports to 38 patients on peritoneal dialysis. The Ministry also spent a total of about \$10.5 million between 2017/18 and 2018/19 to transport approximately 450 patients each year from long-term-care homes to in-centre dialysis facilities for treatment.
 - In 2015, the Renal Network began funding a personal support worker for home hemodialysis patients at eight of the 27 Regional Renal Programs to assist with their dialysis treatments. This initiative targeted patients who would not have been able to

do home hemodialysis without this support. Since 2015, the Renal Network has spent approximately \$5.4 million to provide home hemodialysis and support to approximately 74 patients through this initiative. A recent review of this initiative found that by 2018, 29 patients were receiving this support and more than half of the personal support workers (39 out of 75 workers) either resigned for personal reasons (such as unstable hours or stress from work) or were asked to leave for various reasons (such as not meeting clinical requirements). Although the Renal Network estimated this initiative would be more costly than in-centre dialysis during the first year given upfront training costs for personal support workers, it expected savings in subsequent years as more patients chose to go on home dialysis. However, we found that no costing analysis or fulsome evaluation on this initiative have been completed. Without this information, it is unclear whether this initiative is cost-effective and should be expanded to other Regional Renal Programs.

RECOMMENDATION 6

To further increase the rate of home dialysis in Ontario and meet the target, we recommend that the Ontario Renal Network work with the Ministry of Health to:

- assess and address the challenges (such as staffing and resources issues) of increasing the home dialysis usage rate and take corrective action;
- collect information on home dialysis training from the Regional Renal Programs to determine the appropriate funding for training and adjust the current funding allocation if needed; and
- conduct a province-wide and cross-jurisdictional analysis to identify best practices for increasing home dialysis usage rates and implement those practices across the province.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees that home dialysis is a priority and will continue to work with the Ministry of Health and Regional Renal Programs on this area.

The Ontario Renal Network has made significant efforts to increase and sustain the home dialysis rate. The rate has increased from 22.2% to 25.8% since 2012, with the number of home dialysis patients increasing from 2,260 to 3,060. Since 2014, kidney transplantation has also increased by about 40%. Since patient demographics and medical characteristics of transplant and home dialysis candidates tend to be similar, the increase in kidney transplantation has influenced the ability to further improve home dialysis rates.

As challenges to home dialysis vary based on unique program factors, the Ontario Renal Network has worked with individual Regional Renal Programs to identify areas of opportunity. Additionally, applicable practices have been identified from comparable jurisdictions, including British Columbia and Australia. Despite continuing efforts to address challenges to home dialysis, patient choice remains a critical factor.

The Ontario Renal Network will continue to focus on inadequate assistance for peritoneal dialysis patients and catheter complications associated with peritoneal dialysis, two common barriers. A home dialysis mentorship model will further support sharing best practices among Regional Renal Programs. It is recognized that training is a key enabler for patients to successfully conduct home dialysis. The Ontario Renal Network will collect and analyze data on home dialysis training from Regional Renal Programs to determine whether adjustments to the funding model for home dialysis training and retraining are needed.

MINISTRY RESPONSE

The Ministry supports this recommendation and agrees that it is important to understand and address the challenges inherent in increasing the usage rate of home dialysis, and to take corrective action where possible. The Ministry will work with the Ontario Renal Network to provide chronic kidney disease patients with access to the right type of treatment.

The Ministry will also collaborate with the Ontario Renal Network to ensure that training for home dialysis is appropriately funded in the light of the information that the Ontario Renal Network gathers from the Regional Renal Programs. The Ministry will work with the Ontario Renal Network to determine how best to implement best practices from the cross-jurisdictional analysis.

4.3 Despite Benefits of Kidney Transplants, Wait Times Remain Long

Despite the benefits of kidney transplants (such as better quality of life and improved survival rates for patients and lower costs for the health-care system), the increasing number of people in need of a new kidney and the shortage of organ donors means that some patients will still never receive a transplant. Since barriers to kidney transplants have not been fully addressed, wait times for kidney transplants remain long, creating hardship on patients and higher costs for the health-care system.

As discussed in **Section 2.3**, there are two types of kidney transplants: (1) deceased-donor transplant; and (2) living-donor transplant. Kidney transplants make up the majority of organ transplants in Ontario. In 2018/19, approximately 700 (or 57%) of 1,221 organ transplants in Ontario involved a kidney. **Appendix 5** provides the patient journey for a kidney transplant.

A kidney transplant is the best clinical treatment for patients who have end-stage renal disease and

are eligible to receive a transplant. There are additional benefits to a living-donor kidney transplant compared to a deceased-donor transplant, including longer patient and organ survival rates and shorter wait times to receive a kidney (see **Section 4.3.2**). As well, multiple studies we reviewed found that when compared to dialysis, a kidney transplant is more cost-effective in the long run and is associated with better patient outcomes and lower costs to the health-care system. For example, these studies noted that kidney transplants result in:

- **Better quality of life:** Patients have renewed freedom and productivity.
- **Improved survival:** A 2018 study by the Canadian Institutes for Health Information found that up to 74% of Canadians with a kidney transplant still have a functioning kidney after 10 years, but only 16% of Canadians on dialysis survive past 10 years.
- **Lower health-care system costs:** A 2018 study published by the National Institute of Health in the U.S. noted that over a five-year period, every 100 kidney transplants save the Canadian health-care system about \$20 million in averted hospital-based dialysis costs.

4.3.1 Long Wait Times for Kidney Transplants Create Hardship on Patients and Costs to Health-Care System

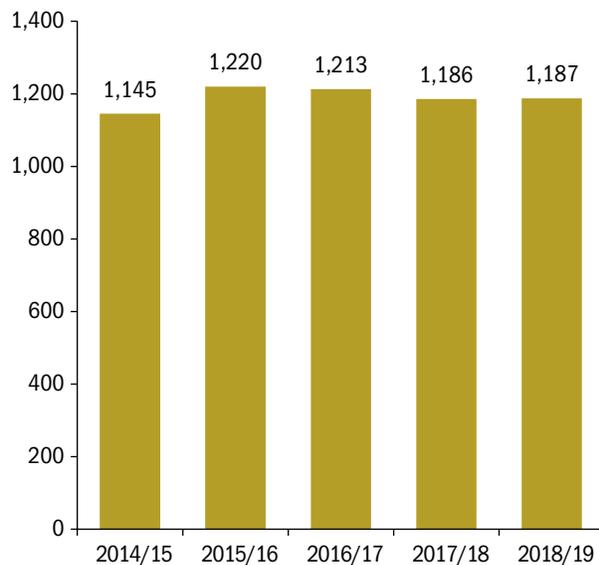
Patients are often on dialysis while waiting for a kidney transplant, and wait times for kidney transplants in Ontario have remained long. Besides the ongoing costs of dialysis, patients must also undergo an assessment every year in order to stay on the wait list, which creates further burdens for patients and additional costs for the health-care system. We noted that the current pre-transplant assessment process could be resulting in unnecessary costs in many cases.

Of all Ontarians on the wait list for an organ donation, more than 70% on average were waiting for a kidney. Over the last five fiscal years (2014/15–2018/19), the number of people waiting

for a kidney transplant remained high, on average about 1,200 in each fiscal year (see **Figure 16**). During the same period, the number of people being added to the wait list for a kidney transplant each year increased by 26% (from about 600 to over 750) (see **Figure 17**).

Figure 16: Number of People on Wait List for Kidney Transplant in Ontario, 2014/15–2018/19

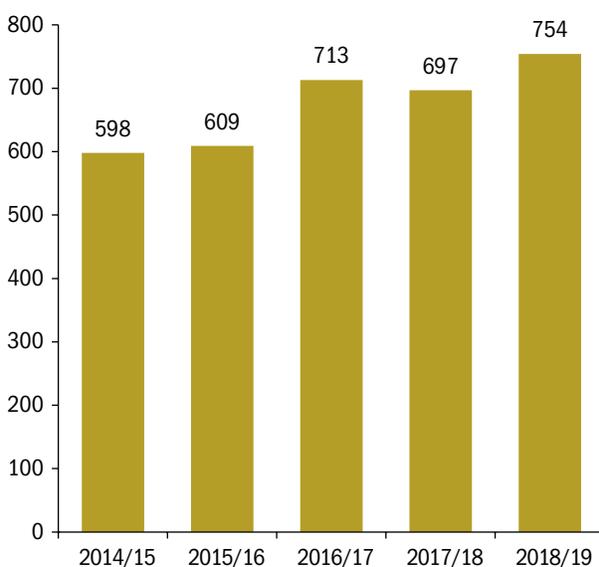
Source of data: Trillium Gift of Life Network



Note: Data is point-in-time or snapshot based on the number of people waiting as of April 1 of the fiscal year.

Figure 17: Number of People Added to Wait List for Kidney Transplant in Ontario, 2014/15–2018/19

Source of data: Trillium Gift of Life Network



Most patients who choose the option of a deceased-donor transplant receive dialysis while they wait. According to the Kidney Foundation of Canada, the median wait time for a deceased-donor transplant in Canada is approximately four years, with the longest wait time in Manitoba (six years) and the shortest in Nova Scotia (three years). The average wait time for a deceased-donor kidney transplant in Ontario is about four years.

As a result of the long waits, we noted that a number of people were taken off the wait list and were unable to receive kidney transplants because they were either no longer medically eligible or they passed away. Specifically:

- Over the last five fiscal years (2014/15–2018/19), almost 300 people were removed from the wait list either because they were too ill and no longer medically suitable for a kidney transplant or because they died while waiting for a transplant, which could have been for reasons other than chronic kidney disease, such as other health complications.
- In 2018/19, over 50 people were taken off the wait list because they were too ill or had died. The average wait time for these patients was about three and a half years, almost 30% of them had been waiting for longer than four years, and the longest wait time was almost 13 years. Some patients may face a longer-than-average wait if they require a medically unique kidney or if they have medical complications that take a long time to resolve.

As well, patients waiting for a kidney transplant must undergo continuous work-ups (including blood work, ongoing testing and evaluation) to reconfirm their eligibility and stay on the deceased-donor transplant wait list. However, some of the Regional Renal Programs informed us that this work-up not only creates a burden on patients, but also results in significant costs to the health-care system. Our review of costing submissions by the six adult kidney transplant centres in Ontario noted that the average cost of this work-up for a deceased-donor kidney transplant is approximately \$8,000 per patient per

year. Based on the average wait time of approximately four years for a deceased-donor kidney, the health-care system could save up to \$24,000 per patient by delaying the annual work-up until a patient is a year away from receiving a deceased-donor kidney.

A 2019 study conducted by the European Renal Association—European Dialysis and Transplant Association also identified considerable agreement among experts that the work-up for a kidney transplant for low-risk patients should only include a limited number of tests. Yet, the existing work-up process for a kidney transplant in Ontario aims to cover all patients and circumstances, even though complicating factors (such as age and presence of other health conditions) can vary significantly between kidney transplant candidates.

One of the transplant centres in Ontario informed us that it will pilot a new initiative to defer transplant work-ups until a patient is closer to receiving a suitable kidney. It will use transplant and organ donation data to predict how long it would take for a suitable kidney to become available and use that information to determine when the work-up for each patient is needed. This could eliminate years of unnecessary work-ups and assessments and reduce the burden on patients and the health-care system.

RECOMMENDATION 7

To provide eligible patients with timely access to kidney transplants in Ontario and appropriate pre-transplant care, we recommend that the Trillium Gift of Life Network, in collaboration with the Ministry of Health and the Ontario Renal Network:

- study transplant policies and initiatives in other jurisdictions to identify best practices that would help increase organ donations and shorten wait times in Ontario; and
- work with kidney transplant centres and Regional Renal Programs to review the transplant eligibility and annual

pre-transplant assessment or work-up process in order to identify efficiencies and cost savings.

TRILLIUM GIFT OF LIFE NETWORK RESPONSE

The Trillium Gift of Life Network supports this recommendation and will continue to work with the Ministry and Ontario Renal Network to improve timely and efficient access to kidney transplants and provide appropriate pre-transplant care for all Ontarians.

The Trillium Gift of Life Network will continue to collaborate with the Ontario Renal Network to further advance the Access to Kidney Transplantation strategy, which is aimed at enhancing access to, and improve patients' experience of, kidney transplantation with a focus on increasing living kidney donation. The Trillium Gift of Life Network will also continue to collaborate with the Ministry and other partners to review policies and initiatives in other jurisdictions to increase kidney transplants from organ donors, which may help to shorten wait times for kidney transplantation.

The Trillium Gift of Life Network will also continue to work with the Ontario Renal Network, transplant programs and other stakeholders to review transplant eligibility and annual assessment requirements while on the kidney wait list. These criteria are reviewed every two years and, in collaboration with the Ontario Renal Network, result in materials produced for patients and referring centres. In addition, the Trillium Gift of Life Network will continue with renewing the organ wait list and allocation IT system that will allow for integration with referring programs to track the patient's journey from referral to post transplant.

This will also enhance the ability to measure and evaluate the process to identify efficiencies and new improvement opportunities such as deferring transplant work-ups until a patient is

closer to transplant and supporting pre-transplant evaluation closer to patients' homes.

MINISTRY RESPONSE

The Ministry is supportive of the Trillium Gift of Life Network's ongoing work to increase organ donations in Ontario. The Ministry agrees with the recommendation to review transplant eligibility and the annual pre-transplant assessment and work up process in order to identify efficiencies. The Ministry anticipates that the Kidney Transplant Working Group, which is responsible for establishing Ontario's referral and listing criteria for kidney transplantations, would participate in this review.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees with this recommendation and will continue to work with Regional Renal Programs to optimize pre-transplant care for patients with chronic kidney disease.

The Ontario Renal Network is partnered with Trillium Gift of Life Network to implement a provincial Access to Kidney Transplant and Living Donation Strategy based on practices in place in other jurisdictions. As part of this strategy, Regional Renal Programs have introduced several initiatives to promote and improve the rate of kidney transplantation, including quality improvement, education for health-care providers, patients and potential living donors, and the development of peer support networks focused on kidney transplantation. In 2021, this strategy will be expanded to all 27 Regional Renal Programs.

The Ontario Renal Network will continue to work with Trillium Gift of Life Network, Transplant Centres and Regional Renal Programs to identify how to improve the transplant work-up process, recognizing that there are opportunities to make the process more efficient for the

benefit of both patients and the health-care system. The Ontario Renal Network is currently collecting information from Regional Renal Programs on their local models for supporting transplant work-up, and understanding their local barriers and challenges. This information will be used to identify and promote more timely and efficient work-up processes within Regional Renal Programs.

4.3.2 Various Barriers to Kidney Transplants Remain

As discussed in **Section 4.3.1**, wait lists and wait times for a kidney transplant have remained long, but the number of people in need of a kidney transplant continues to rise. This is due to various barriers that limit the growth of kidney transplants, including living-donor transplants (including costs to potential donors and a lack of consistent information, education and public awareness).

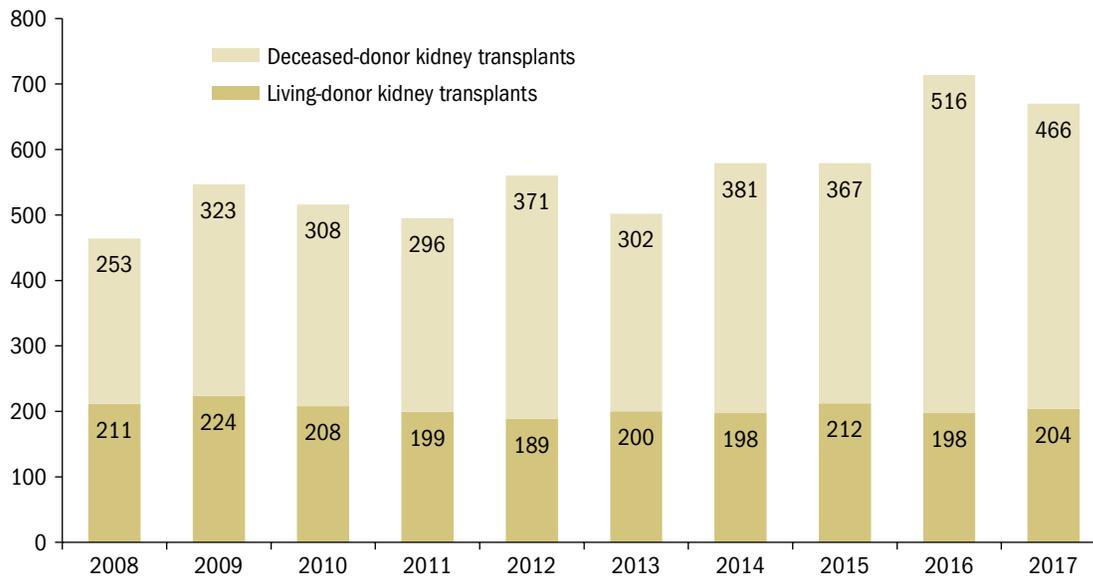
Growth of Living-Donor Transplants in Ontario Remains Static

While the number of deceased-donor transplants per year has increased in Ontario, it is not enough to keep up with the pace of growing needs. The alternative is a living-donor transplant, and while anyone can be assessed to become a living donor, it is often a family member who donates a kidney to a patient. A living-donor transplant has a much shorter wait time and a higher transplant success rate. For example, the wait time for a living-donor transplant is about one year (once a living-donor candidate is identified), while the wait time for a deceased-donor transplant is on average four years but could be longer depending on the unique needs of the patient (such as blood type). The five-year survival rate for adults with transplanted kidneys is 92% from living donors and 82% from deceased donors.

Over the last 10 years, the number of living-donor transplants has remained static even though a living-donor transplant presents an opportunity

Figure 18: Number of Living-Donor and Deceased-Donor Kidney Transplants in Ontario, 2008–2017

Source of data: Canadian Institute for Health Information



to improve a patient's survival and quality of life. **Figure 18** shows that the overall number of kidney transplants has been increasing in Ontario, but this growth was due to an increase in deceased-donor transplants while living-donor transplants have remained almost unchanged since 2008. Specifically, living-donor transplants accounted for about 45% of all kidney transplants in 2008, but dropped to 30% in 2017. This is much lower than the world average, as a 2018 study published by the American Society of Nephrology noted that approximately 40% of the kidneys for transplant worldwide come from living donors.

In comparison with other provinces, as shown in **Figure 19**, while the rate per million population for a deceased-donor kidney transplant in Ontario (30.9) was higher than other provinces, except British Columbia (41.4), the rate for a living-donor kidney transplant in Ontario (13.5) was lower than Alberta (13.7), British Columbia (17.5) and Manitoba (20.9).

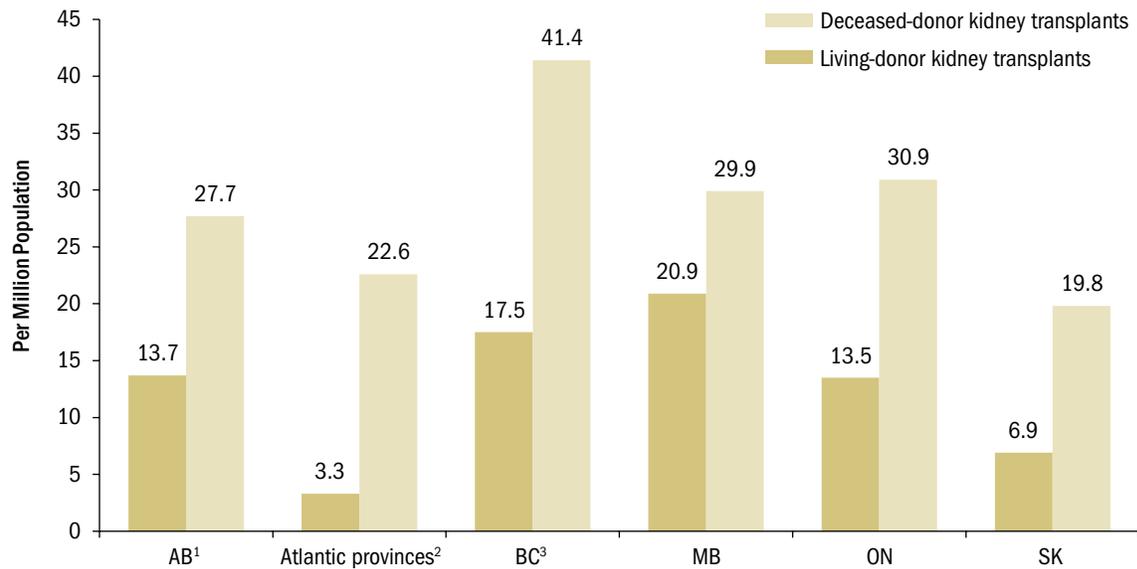
Various Barriers Hinder the Increase of Kidney Transplants, Especially Living-Donor Transplants

One of the barriers to a living-donor transplant is the costs that potential donors may incur during the kidney donation process. While Ontario has a program called Program for Reimbursing Expenses of Living Organ Donors (PRELOD) to reimburse living organ donors for eligible expenses, the reimbursement rate has not been changed since April 2008 when PRELOD was first introduced.

The purpose of PRELOD is to reduce the financial burden of living-organ donors by reimbursing actual out-of-pocket expenses and lost income associated with living-organ donation. Trillium Gift of Life Network (Trillium Network) administers PRELOD on behalf of the Ministry. PRELOD reimburses travel, parking, accommodation, meals and loss of income up to a maximum of \$5,500. Over the last five fiscal years (2013/14–2017/18), a total of \$930,000 was paid to over 920 applicants through PRELOD. However, we noted that despite completing a review of PRELOD in 2009 and 2012 that showed donors were still experiencing financial hardship, the reimbursement rate of \$5,500 has remained unchanged.

Figure 19: Living-Donor and Deceased-Donor Kidney Transplants by Province in Canada, 2017

Source of data: Canadian Institute for Health Information



Note: This figure excludes data from Quebec because of under-reporting.

1. Data from Alberta includes Northwest Territories and Nunavut.

2. Data from the Atlantic Provinces (including New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island) was combined because of small numbers.

3. Data from British Columbia includes Yukon Territory.

Several recent studies noted financial costs incurred by donors as one of the barriers for a living-donor kidney transplant. For example, two studies in 2018 and 2019 (published by the National Institutes of Health in the United States) identified gaps between costs incurred by living-kidney donors and costs reimbursed through living-donor reimbursement programs. Another study of living-kidney donors and recipients in Ontario in 2017 (published in the *Canadian Journal of Kidney Health and Disease*) also identified financial costs incurred by donors as one of the barriers to living-kidney donations. It noted that nearly all kidney donors (96%) incur out-of-pocket costs as a result of donor evaluation and surgery (including expenses related to travel, accommodation, lost wages, medications and child care) and that the current system still has limitations and cannot yet support the total financial costs incurred by most donor candidates. It went on to identify other barriers, which we also noted as part of our audit, including:

- **Lack of consistent information and education:** Patients and their families find that it is difficult to obtain direct access to clear, timely and consistent information because multiple parties (including the Regional Renal Programs, Renal Network and Trillium Network) provide transplant-related education with an unco-ordinated approach.
- **Lack of integration between Regional Renal Programs and transplant centres:** There are communication gaps during patient transitions between the Regional Renal Programs and transplant centres, and during long-term follow-ups for donors. For example, after Regional Renal Programs perform an initial work-up and a patient is seen by a transplant centre, there are often gaps in information and communication.
- **Lack of public awareness:** There is uncertainty within various religious and cultural groups regarding the ability to donate and,

among the general public, there are gaps in knowledge and understanding about the need for and benefits of living-donor donation. These barriers can cause confusion, delay and even dismissal of the donation process altogether.

We also found that financial burden is not only a barrier to living-kidney donation, but also an obstacle for patients who are eligible for a kidney transplant. In particular, costs can be a financial barrier for any patient who must pay for travel and accommodation to be close to the transplant centre for their work-up, surgery and recovery period, which can also result in lost income for patients who are currently working. Patient-borne cost is especially pronounced for patients from rural and remote regions such as Northern Ontario (where there is no transplant centre) given the greater travel distances involved. One of the Regional Renal Programs in Northern Ontario (Health Sciences North) estimated that more than 50% of its patients that are eligible for a kidney transplant do not pursue it because of the travel and accommodation costs. Our review of patient files also identified a case where a patient in Thunder Bay was eligible for a kidney transplant in 2018, but did not have the financial resources to cover the travel and accommodation costs (as there is no transplant centre near Thunder Bay). This patient has continued to undergo dialysis since October 2017. Over 80% of Regional Renal Programs that responded to our survey indicated that additional financial support for patients and donors could increase the number of patients willing to pursue transplants, which are much more cost-effective than dialysis.

RECOMMENDATION 8

To improve patient access to living-donor transplants in Ontario, we recommend that the Trillium Gift of Life Network, in collaboration with the Ministry of Health and the Ontario Renal Network:

- conduct a review of the Program for Reimbursing Expenses of Living Organ Donors to determine if the reimbursement rate is reasonable and if any adjustment is needed; and
- study living-donor transplant policies and initiatives in other jurisdictions to identify best practices that would help increase the rate of living-donor transplants in Ontario.

TRILLIUM GIFT OF LIFE NETWORK RESPONSE

The Trillium Gift of Life Network supports this recommendation and commits to continue to work with its partners to improve patient access to living-donor transplants in Ontario with the appropriate Ministry support and directives.

The Trillium Gift of Life Network is currently undertaking a review to assess gaps and limitations of the Program for Reimbursing Expenses of Living Organ Donors. The details of the review along with recommendations to support changes to the policy will be shared with the Ministry.

The Trillium Gift of Life Network will continue to collaborate with the Ontario Renal Network to further advance the Access to Kidney Transplantation strategy. The Trillium Gift of Life Network will also work with the Ministry to determine a value-added role to support living donation in Ontario and review living-donor transplant practices in other jurisdictions to identify best practices to be implemented in Ontario.

MINISTRY RESPONSE

The Ministry is in agreement with the recommendation to review the Program for Reimbursing Expenses of Living Organ Donors. The Ministry is supportive of the Trillium Gift of Life Network's continued collaboration with the Ontario Renal Network to increase living kidney donations in Ontario. Additionally, the Ministry and the Trillium Gift of Life Network are participating in Health Canada's Organ Donation and

Transplantation Collaborative (ODTC), which has the goal to develop concrete and actionable options to improve organ donation and transplantation performance that meet Canadians' needs and improve patient outcomes. The Ministry is part of an ODTC working group dedicated to increasing living donation.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees with this recommendation. Consultations with Regional Renal Programs, patients and family members consistently highlight patient-borne costs as a barrier to kidney transplantation.

Many of the initiatives that have been introduced in Ontario as part of the Access to Kidney Transplant and Living Donation Strategy were based on studies completed in other jurisdictions. The Ontario Renal Network will continue to investigate and monitor how other jurisdictions have successfully implemented policy or program changes to improve the rate of living-donor kidney transplantation. The Access to Kidney Transplant and Living Donation Strategy has focused on improving access to living kidney donation through education, quality improvement, peer support and data. A suite of resources to support and promote living-donor kidney transplant will be available to all Regional Renal Programs by 2021, after which a comprehensive evaluation will be completed to inform future interventions.

4.4 Funding Needs to Be Reviewed to Match Actual Costs and Identify Potential Savings

Funding amounts for most chronic kidney disease services (including Multi-Care Kidney Clinics, dialysis and kidney transplants) may not reflect the actual costs of providing services to patients. As well, the pricing of peritoneal dialysis supplies has not been reviewed to identify potential savings.

4.4.1 Funding for Chronic Kidney Disease Services Does Not Align with Actual Cost of Providing Services to Patients

Beginning in 2012/13 and phased in over a three-year period, the Renal Network's funding for most chronic kidney disease services (including Multi-Care Kidney Clinics and dialysis treatments) was standardized across the province using the Quality-Based Procedure (QBP) method, which bases funding on the needs of the population, number of patients seen, types of services delivered and quality of care. Under the QBP method, the Renal Network bundles the cost of most services based on several factors (such as the types and volumes of patients treated at Regional Renal Programs) to arrive at a fixed amount of funding per service. However, we found that the current funding may not reflect the current actual cost of providing services as the QBP funding has not been changed since it was implemented.

In 2017, the Renal Network engaged an external consultant to study the QBP funding. The study noted that the initial volumes used to calculate the fixed amounts of funding per service was meant to be a starting point given the limited evidence available at the time. While the Renal Network planned to adjust the service volumes when additional evidence became available, it has not yet done so, but began reviewing the QBP in 2019.

Funding Allocated for Chronic Kidney Disease Services Exceeds Expenditures Reported by Hospitals

Our review of the Regional Renal Programs' budget submissions and their annual reporting to the Renal Network found that their budget submissions were based on the QBP funding model, but their report back to the Renal Network did not include the actual expenditures they incurred to provide services. Therefore, the Renal Network does not know if the allocated funding to Regional Renal Programs reflects the cost of providing renal services.

In order to gather the actual expenditures incurred by the Regional Renal Programs, we reviewed expenditure information over the last five years (2013/14–2017/18) at the five Regional Renal Programs we visited. These expenditures are neither reported to nor reviewed by the Renal Network. We found that funding received by the Regional Renal Programs from the Renal Network was higher than the expenditures incurred, resulting in a possible surplus of about \$37 million. This indicates that the current funding allocation, which is primarily based on the QBP method, may not reflect the actual costs incurred by the Regional Renal Programs to provide services to patients.

Funding for Chronic Kidney Disease Services Does Not Align with Actual Amount of Services Provided

For each patient that meets the eligibility criteria for and is registered with a Multi-Care Kidney Clinic (Clinic) for a full fiscal year, a Regional Renal Program receives about \$1,400. When this amount was determined using the QBP method, it was based on a patient making six visits on average per year to the Clinic. In 2018/19, the total funding for the Clinics was about \$13 million.

In order for a Clinic to qualify for funding, each of its patients has to meet specific medical criteria; make at least two visits a year to the Clinic (one visit during the first half of the fiscal year and another visit during the rest of the fiscal year); and has to be seen by at least three health professionals at each visit (which may include a nephrologist, nurse, dietitian, pharmacist or social worker). Although not tracked, we noted that Clinics sometimes provide care between visits through phone calls.

Based on a data analysis of all patients who met the criteria above in 2018/19, we noted that patients on average made four visits per year, which does not align with the number of visits (six per year) that was used when setting the funding amount.

Apart from funding for the Clinics, we also noted that in 2016/17, Cancer Care Ontario (CCO) conducted an analysis of the funding for in-centre

hemodialysis (the most common and costly form of dialysis) and found possible surpluses when comparing the number of dialysis sessions funded through the Renal Network's QBP method to the number of dialysis sessions reported by hospitals through other data sources. We requested CCO to re-perform this analysis using 2017/18 data and noted similar results. Specifically, the financial impact of presumed missed sessions was at least \$7.4 million (which could be higher given differences in the data sources used for the analysis). CCO had to use various data sources to calculate the number of missed sessions and the financial impact because the Renal Network does not collect data on the number of dialysis sessions attended by patients.

RECOMMENDATION 9

To better reflect the volume and costs of services actually provided to patients in the funding amounts that are set based on the Quality-Based Procedure (QBP) method, we recommend that the Ontario Renal Network:

- conduct a review of the QBP funding per service to determine if the amount is reasonable and adjust if needed based on costing information from the Regional Renal Programs and best practices; and
- collect renal expenditures from Regional Renal Programs on an annual basis and use the information to inform changes in future funding allocation.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees with the need to review the Chronic Kidney Disease Quality-Based Procedure (QBP) funding model and has begun work to refresh this model. Detailed costing information from Regional Renal Programs and current best practices will be used to review funding rates as well as the type and volume of services provided, and adjustments will be made where necessary. The

QBP refresh will be conducted so that future changes to costs or to best practices can be readily incorporated into the funding model.

The Ontario Renal Network also agrees with the recommendation to collect information on renal expenditures from Regional Renal Programs on an annual basis. The QBP funding model is complex and includes patient-care services provided within the dialysis unit as well as those provided by other hospital departments. The Ontario Renal Network will work with Regional Renal Programs to develop a reporting methodology to capture all appropriate expenses as accurately as possible.

4.4.2 Base Funding for Each Kidney Transplant Unchanged Since 1988

Each of the six adult kidney transplant centres in Ontario receives a fixed amount of funding from the Ministry for each kidney transplant performed. The current funding rate per kidney transplant is approximately \$25,000 and this rate has not been updated since it was implemented in 1988. The only change made since then was in 2004 when a top-up amount of \$5,800 was introduced to help offset additional costs when performing a living-donor transplant (such as the costs of testing and retrieving a kidney from a living donor).

In 2018, Trillium Gift of Life Network (Trillium Network) began assessing the cost information from the kidney transplant centres to determine if the funding amount is still reasonable. While this funding review was still under way at the end of our audit, our review of preliminary costing information from the six adult kidney transplant centres in Ontario noted that the cost of a kidney transplant varies from one transplant centre to another and the current funding rate for a kidney transplant does not reflect the actual costs incurred by the centres. For example:

- For each deceased-donor transplant, the actual costs reported by the transplant centres ranged from about \$32,000 at one centre

to \$57,000 at another. On average, the cost was approximately \$40,000, compared to the current funding rate of about \$25,000.

- For each living-donor transplant, the actual costs reported by the transplant centres ranged from about \$26,000 at one centre to \$52,000 at another. On average, the cost was approximately \$35,000, compared with the current funding rate of approximately \$30,800 (\$25,000 plus the \$5,800 top-up).

The transplant centres we visited raised additional concerns. For example, the time and resources involved in managing patients waiting for transplants are significant given the ongoing testing and evaluation required (see **Section 4.3.1**). The current funding rate of \$25,000 only covers the cost of the transplant procedure during the surgical phase. Therefore, if the patient dies while waiting for a transplant, the transplant centres do not receive any funding for providing pre-transplant care to the patient and maintaining the patient on the wait list. As well, some transplant centres indicated that the top-up of \$5,800 for each living-donor transplant is not enough to cover the additional costs of evaluating donors, as multiple donors typically have to be evaluated for suitability in each kidney transplant case.

The Renal Network and the Regional Renal Programs we visited raised similar concerns. Regional Renal Programs are responsible for educating patients and their families on kidney transplants and, in some cases, are also involved in assisting transplant centres with pre-transplant testing and evaluation. However, there is currently no direct funding provided for this work.

RECOMMENDATION 10

To better reflect the actual costs incurred by the transplant centres for kidney transplants, we recommend that the Trillium Gift of Life Network, in collaboration with the Ministry of Health:

- continue to collect and review cost information from the transplant centres; and
- conduct a review of the current funding rates for both deceased-donor and living-donor transplants to confirm what adjustments are needed.

TRILLIUM GIFT OF LIFE NETWORK RESPONSE

The Trillium Gift of Life Network supports this recommendation and commits to review the costs of kidney transplant in Ontario and explore opportunities to continue and expand on this work with the appropriate Ministry support and directives. The Trillium Gift of Life Network will also review the living-donor transplant funding rate as part of the overall funding evaluation for transplantation.

The Trillium Gift of Life Network will continue to work with the Ministry, Ontario Renal Network and other provincial agencies and partners to finalize the costing and funding model, which includes pre-transplant, transplant and post-transplant related activities that are performed at transplant centres and Regional Renal Programs. Determining the costs across the patient continuum will help to identify the types of funding adjustments that are needed to develop innovative care models that will aim to enhance patient-centred care.

MINISTRY RESPONSE

The Ministry continues to support the efforts of the Trillium Gift of Life Network and the transplant program stakeholders in their work to evaluate the current transplant funding model. The current model includes incremental volume-based funding, which may be augmented by the hospital global budgets and activity-based funding.

4.4.3 Pricing of Peritoneal Dialysis Supplies Has Not Been Reviewed to Identify Potential Savings

While the Renal Network has a procurement initiative in place to reduce the costs of hemodialysis equipment and supplies, it has not reviewed the pricing of peritoneal dialysis supplies to identify potential savings.

Prior to 2016, each Regional Renal Program was responsible for its own procurement of hemodialysis equipment and supplies. The Renal Network's policy did specify the maximum funding rate for each item, but the actual costs varied across Regional Renal Programs, as some of them were able to secure better pricing than others. In December 2017, the Renal Network secured fixed-price agreements with major vendors of hemodialysis equipment and supplies, reducing the maximum funding rates outlined in the Renal Network's policy. For example, the maximum funding rate for one specific hemodialysis machine went down from \$30,000 to \$17,000, resulting in savings of up to \$13,000 per machine. This was the first-ever provincial procurement for hemodialysis machines and supplies.

Overall, the Renal Network estimated that this procurement initiative would result in cost savings of approximately \$30 million over the terms of the agreements based on the number of hemodialysis machines and supplies that will need to be purchased. In order to verify whether the Regional Renal Programs have benefited from this initiative, we reviewed a sample of invoices and found that this initiative has resulted in savings. For example, one Regional Renal Program's cost per hemodialysis machine went from just over \$26,000 to about \$17,000, resulting in savings of \$9,000.

While cost savings have been achieved through fixed-price agreements for hemodialysis equipment and supplies, the Renal Network has not yet established similar agreements for peritoneal dialysis supplies, although at the time of our audit, it began work on an initiative that is expected to

result in additional cost savings. Our review of a sample of invoices for peritoneal dialysis supplies found a wide range of prices paid by Regional Renal Programs, indicating opportunities for cost savings. For example:

- The price for a peritoneal dialysis cyclor drainage set ranged from \$207.40 to \$248.19 per unit, representing an almost 20% difference.
- The price for a peritoneal dialysis solution bag ranged from \$56.74 to \$68.10 per bag, representing about a 20% difference.
- The price for a peritoneal dialysis cyclor ranged from \$740.40 to \$802.93 per unit, representing about an 8% difference.

The Renal Network informed us that it has conducted a preliminary analysis based on a limited sample of pricing data for peritoneal dialysis supplies. It was in the process of obtaining a larger sample of data from the Regional Renal Programs in order to confirm whether similar fixed-price agreements for peritoneal dialysis supplies would provide additional savings. Without setting standard provincial pricing through these agreements, there is a risk that vendors may increase their prices of peritoneal dialysis supplies for individual Regional Renal Programs.

RECOMMENDATION 11

To help identify and achieve potential savings from the procurement of peritoneal dialysis equipment and supplies, we recommend that the Ontario Renal Network:

- collect cost information on peritoneal dialysis equipment and supplies from the Regional Renal Programs; and
- analyze whether a provincial procurement initiative (similar to the fixed-price agreements for hemodialysis equipment and supplies) would provide additional savings.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees with this recommendation and appreciates the Auditor General's acknowledgment of the savings realized from the implementation of the Ontario Renal Network's provincial procurement strategy for hemodialysis-related equipment, supplies and services.

As the next phase of work in this domain, the Ontario Renal Network has identified the supplies and service offerings related to peritoneal dialysis as an opportunity to achieve additional savings and improve services for patients, and has begun planning for a provincial procurement. As one of the early steps of this initiative, the Ontario Renal Network is developing an approach to obtaining detailed information on the costs of peritoneal dialysis equipment and supplies from Regional Renal Programs. This information will be used to analyze variances in current pricing and to estimate the potential savings from a provincial procurement. Any savings realized may allow for reinvestment in the renal system for the benefit of patients.

4.5 Lack of Co-ordination Creates Challenges for Planning and Managing Renal Care

While the Renal Network is responsible for managing the delivery of chronic kidney disease care in Ontario, it has no oversight on dialysis services provided by the Independent Health Facilities (which are overseen by the Ministry) and kidney transplants (which fall under the responsibility of the Ministry and Trillium Gift of Life Network). Lack of co-ordination and integration between the Ministry, Renal Network and Trillium Network results in a fragmented renal care system in Ontario.

4.5.1 Ontario Renal Network Does Not Have Complete Oversight of and Information on Dialysis across the Province

In addition to the 27 Regional Renal Programs funded and overseen by the Renal Network, the Ministry also funds and oversees seven Independent Health Facilities (Facilities) that provide dialysis to patients. In 2018/19, the Facilities provided dialysis to approximately 250 patients. However, we noted that variability in oversight, funding and reporting of dialysis services by the Regional Renal Programs and the Facilities has created challenges for the Renal Network to adequately plan and measure renal care across the province. Since the Facilities are under the oversight of the Ministry, the Renal Network neither collects complete information from these Facilities nor measures the performance of them in the delivery of dialysis.

The Renal Network indicates that its “Ontario Renal Reporting System (ORRS) identifies all people receiving care for chronic kidney disease in Ontario. All kidney care service providers in Ontario submit data to [it] through this reporting system. The data they provide supports [its] reporting, planning and system management activities.” However, we noted that the Facilities are not required to submit data in ORRS, although they do submit optional data on the services they provide.

We identified the following gaps in information-sharing and co-ordination between the Ministry and Renal Network with respect to the dialysis services provided by the Facilities:

- While the Facilities are required to report certain information directly to the Ministry, they are not required to report data to the Renal Network similar to what is being reported by Regional Renal Programs that provide dialysis.
- The Ministry does not proactively and regularly share information related to the Facilities with the Renal Network.
- The information collected by the Ministry is very limited, at a high level, and does not contain the patient-level details that the

Renal Network collects from the Regional Renal Programs.

- While both Facilities and Regional Renal Programs provide dialysis to patients, the performance measures used by the Ministry to evaluate the performance of the Facilities are different from the measures used by the Renal Network to evaluate the Regional Renal Programs. For example, the Renal Network cannot assess the results of patient-reported experience measures at the Facilities as it does for Regional Renal Programs because the Ministry does not collect this information.

Since the Facilities are not subject to the same reporting requirements and performance measures as the Regional Renal Programs, the Renal Network cannot assess whether the dialysis services provided by the Facilities are effective, efficient and consistent with the Regional Renal Programs and whether the operations of the Facilities align with the goals outlined in the Renal Network’s strategic plans.

RECOMMENDATION 12

To provide patients with equal access to quality dialysis services across the province, we recommend that the Ontario Renal Network (Renal Network) work with the Ministry of Health (Ministry) to:

- conduct a review of the oversight and funding of dialysis services provided at the Independent Health Facilities (Facilities) to identify opportunities to improve the co-ordination between the Facilities and the Regional Renal Programs and evaluate the benefits of transferring the Ministry’s responsibility for the Facilities to the Renal Network; and
- begin collecting information from the Facilities that is consistent with the information collected from Regional Renal Programs so that the data on all dialysis patients is complete for planning and performance measurement purposes.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees with this recommendation and the importance of providing patients with equal access to quality dialysis services across the province.

The Ontario Renal Network will work with the Ministry of Health to identify opportunities for improved co-ordination between the Regional Renal Programs and Independent Health Facilities that provide dialysis services. This will include an investigation of the benefits and legislative considerations of transferring the responsibility for funding, quality improvement, as well as performance measurement and management, of these Independent Health Facilities from the Ministry of Health to the Ontario Renal Network.

Currently, Independent Health Facilities that provide dialysis services are not required to report data to the Ontario Renal Network; however, most do submit certain data elements to the Ontario Renal Reporting System on a voluntary basis. The Ontario Renal Network will work with the Ministry of Health to evaluate options for collecting data from these Independent Health Facilities that is further aligned with the information collected from Regional Renal Programs, where this is appropriate and applicable, based on the services provided to patients.

MINISTRY RESPONSE

The Ministry supports this recommendation and will work with the Ontario Renal Network to explore opportunities to improve co-ordination between the Independent Health Facilities and the Regional Renal Programs and explore the benefits of transferring the Ministry's responsibility for the Independent Health Facilities to the Ontario Renal Network/Cancer Care Ontario.

As part of new agreements recently executed, the Independent Health Facilities are required

to collect data on key performance indicators. The Ontario Renal Network was consulted in the development of these indicators and further alignment will be considered through the initiatives noted above.

4.5.2 Ontario Renal Network Does Not Obtain Accurate and Complete Transplant Data and Has Limited Co-ordination with Trillium Network

Apart from the dialysis services provided by the Facilities (see **Section 4.5.1**), the Renal Network also does not have oversight of kidney transplants, which fall under the responsibility of the Ministry and Trillium Gift of Life Network (Trillium Network). A kidney transplant is the best treatment option for people with advanced chronic kidney disease (see **Section 4.3**).

Effective September 6, 2017, Trillium Network and the Renal Network established a data-sharing agreement to exchange renal and transplant data between their systems. This link was meant to provide both parties with a view of each patient's complete transplant journey from the time the patient begins receiving renal care within a Regional Renal Program to the time the patient receives a kidney transplant at one of Ontario's six adult kidney transplant centres.

However, inaccurate and incomplete data transfers from Trillium Network to the Renal Network, as well as limited co-ordination between the Renal Network and Trillium Network on tracking the performance of kidney transplant activities and patient outcomes, have made it difficult for either party to measure and report on the effectiveness of kidney transplants and activities.

Inaccurate and Incomplete Transplant Data Have Caused Difficulty and Challenge in Measuring and Reporting Transplant Activities

Trillium collects data from transplant centres and then shares this data with the Renal Network. However, some files have had data-quality issues that

had not been fully resolved at the time of our audit. Specifically:

- Two data files that contained data on transplant recipient referrals and consultations as well as potential living-donor candidates were not accurately and consistently reported by transplant centres and/or not adequately validated by transplant centres and the Trillium Network before sharing with the Renal Network. Therefore, the Renal Network has faced challenges in generating any performance measurement indicators based on these data sets.
- Inability to link data from Trillium Network's system to the Renal Network's system has made it difficult for the Renal Network to determine whether a patient has been referred for a kidney transplant and whether a potential living donor has come forward.
- The Renal Network also indicated that the data-quality issues have made it challenging to determine whether the Regional Renal Programs refer eligible patients to a transplant centre on a timely basis.

We noted that the Renal Network presented proposals to Trillium Network in May 2019 on how to improve data quality. These proposals included several short- and medium-term solutions for Trillium Network and the Renal Network to work together to resolve data issues, but no formal process has been identified and confirmed by both the Renal Network and Trillium Network at the end of our audit fieldwork. Trillium Network informed us that it is working with a vendor to create a new system that will allow data to be collected and shared more quickly and accurately.

Effectiveness of Kidney Transplants Is Unknown Because of Limited Co-ordination between the Renal Network and Trillium Network

Although patients on dialysis may eventually receive a kidney transplant and patients with failed kidney transplants would need to go back on dialysis, there is limited co-ordination between

the Renal Network and Trillium Network in terms of tracking the performance of kidney transplant activities and patient outcomes.

While the Renal Network can identify when patients are referred to or receive a kidney transplant, it has no information on whether the transplant is successful. Patients who have a kidney transplant will only show up in the Renal Network's system if their transplants begin failing and the patients end up in a Multi-Care Kidney Clinic or start dialysis again.

Staff from the transplant centres we visited indicated that there is a gap in clearly defining the responsibility for post-transplant care, which could be done either by the transplant centres or Regional Renal Programs, or a combination of both. Our review of data collected by the Renal Network and Trillium Network noted that while Trillium Network tracks post-transplant care activity such as follow-up visits and lab test results, this data is not shared with the Renal Network for the purpose of monitoring patients who may need additional renal care if their transplant fails. Without sharing this data and the related patient outcomes, neither the Renal Network nor Trillium Network can fully report on the effectiveness of kidney transplants.

RECOMMENDATION 13

To collect accurate and complete transplant data for performance measurement and reporting purposes, we recommend that the Trillium Gift of Life Network, in collaboration with the Ontario Renal Network:

- continue to work with kidney transplant centres and Regional Renal Programs to identify and address the data issues, understand the underlying data flow, and explore potential options to support the data-validation process; and
- continue to develop and improve performance measures related to post-transplant activities (such as transplant failure rate and frequency of follow-up visits).

TRILLIUM GIFT OF LIFE NETWORK RESPONSE

The Trillium Gift of Life Network supports this recommendation and commits to continue to work with the Ontario Renal Network, Regional Renal Programs and kidney transplant centres to enhance data quality for performance measurement and reporting purposes.

The Trillium Gift of Life Network will continue to work with the Ontario Renal Network, Regional Renal Programs and Kidney Transplant Centres to improve and enhance data quality and to leverage the new IT system to reduce data entry redundancy, support data validation and accuracy and to share and exchange relevant patient data.

The Trillium Gift of Life Network is currently working with transplant programs to further define, enhance and develop transplant performance indicators. The Trillium Gift of Life Network will leverage this work and collaborate with the Ontario Renal Network and Regional Renal Programs to further develop and improve post-transplant kidney performance measures, and to support system monitoring, reporting and quality improvement.

ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees with this recommendation and will continue to work with Trillium Gift of Life Network to improve data quality for kidney transplantation.

Consultations are under way with Regional Renal Programs and Transplant Centres to investigate the barriers to submitting timely and accurate transplant data. These consultations will be used to inform the implementation of short- and long-term solutions to improve data quality, which will improve the Ontario Renal Network's ability to monitor and evaluate the impact of interventions to improve access to kidney transplantation.

The Ontario Renal Network, in partnership with Trillium Gift of Life Network, will consult with Transplant Centres, Regional Renal Programs, patients and living donors to gather a more complete understanding of where post-transplant care can most appropriately be provided, taking into consideration clinical best practice, funding, patient preferences and Regional Renal Program and Transplant Centre capacity. The Ontario Renal Network will explore models of care for post-transplant patients and, with stakeholder consensus, define and implement performance indicators to monitor and evaluate post-transplant care activities. The Ontario Renal Network will work with partners to develop and report key process and outcome measures to monitor the effectiveness of the full kidney care system, including transplant, which is the optimal treatment option for chronic kidney disease patients.

4.6 Information on the Performance of Chronic Kidney Disease Services Is Incomplete and Not Fully Reported to the Public

The Renal Network does not have complete data on renal care from the Regional Renal Programs, because the Regional Renal Programs have faced a significant burden related to data collection and reporting. The Renal Network also does not publicly report the results of most of the performance indicators for measuring chronic kidney disease services.

4.6.1 Regional Renal Programs Do Not Report Optional but Useful Information to Ontario Renal Network

Although the Renal Network's Ontario Renal Reporting System (ORRS) allows the Regional Renal Programs to submit additional information on patients (such as primary nephrologist's name and home dialysis eligibility), the submission of this

information is voluntary. Even though this information is helpful for the Renal Network to plan and oversee chronic kidney disease services, we found that many Regional Renal Programs do not typically report such optional information. For example, of the almost 8,600 patients that spent time in the Multi-Care Kidney Clinics and began dialysis between 2015/16 and 2018/19, more than 2,850 (33%) were missing data in ORRS that indicated their eligibility for home dialysis.

The Renal Network determines what information must be reported by Regional Renal Programs in ORRS and what information can be optionally reported, and it has acknowledged that the completeness of the optional data varies. Its preliminary review identified significant missing data in certain areas (such as a patient's eligibility for home dialysis or education on treatment options available), but more complete data in other areas (such as the presence of more than one health condition in a patient).

Through our discussion with Regional Renal Programs, some of them agreed that such optional information would be helpful to the Renal Network for its planning and oversight responsibilities. However, all Regional Renal Programs we visited raised concerns about the increasing data burden and lack of resources provided by the Renal Network to collect and report data. Our survey also found that 95% of Regional Renal Programs noted that their data required a significant amount of customization to report into ORRS.

4.6.2 Public Reporting on the Performance of Chronic Kidney Disease Services Is Limited

The Renal Network developed performance measures for each of its past strategic plans—Ontario Renal Plan 1 (2012–15) and Ontario Renal Plan 2 (2015–19)—to assess and benchmark the performance of Regional Renal Programs, identify opportunities for growth and improvement, and ensure that dialysis services are provided effectively, efficiently and consistently across Ontario.

However, the Renal Network provides very limited public reporting on the results of these performance measures.

Our review of all performance measures (39 in total) established by the Renal Network over the last two strategic plans covering 2012 to 2019 found that the Renal Network only publicly released the results of eight of these measures, including the proportion of dialysis patients receiving home dialysis (see **Appendix 6**). However, we noted that the results of other important measures that specifically involve educating patients and assisting patients in decision-making were not made public. For example, results for the following measures were not publicly released:

- the proportion of patients/families who are informed about treatment options including dialysis modality (in-centre or at home), transplant and conservative care;
- the proportion of patients within the Multi-Care Kidney Clinics referred for a kidney transplant within a year of meeting eligible laboratory referral criteria; and
- the proportion of patients who had the opportunity to participate in the development of their plan of care.

RECOMMENDATION 14

To better oversee and report on chronic kidney disease services across Ontario, we recommend that the Ontario Renal Network:

- conduct a comprehensive review of all data fields and determine what data must be reported by the Regional Renal Programs to effectively plan and measure the delivery of renal care; and
- publish the results of all performance measures related to the goals outlined in its strategic plans regularly (such as quarterly or annually).

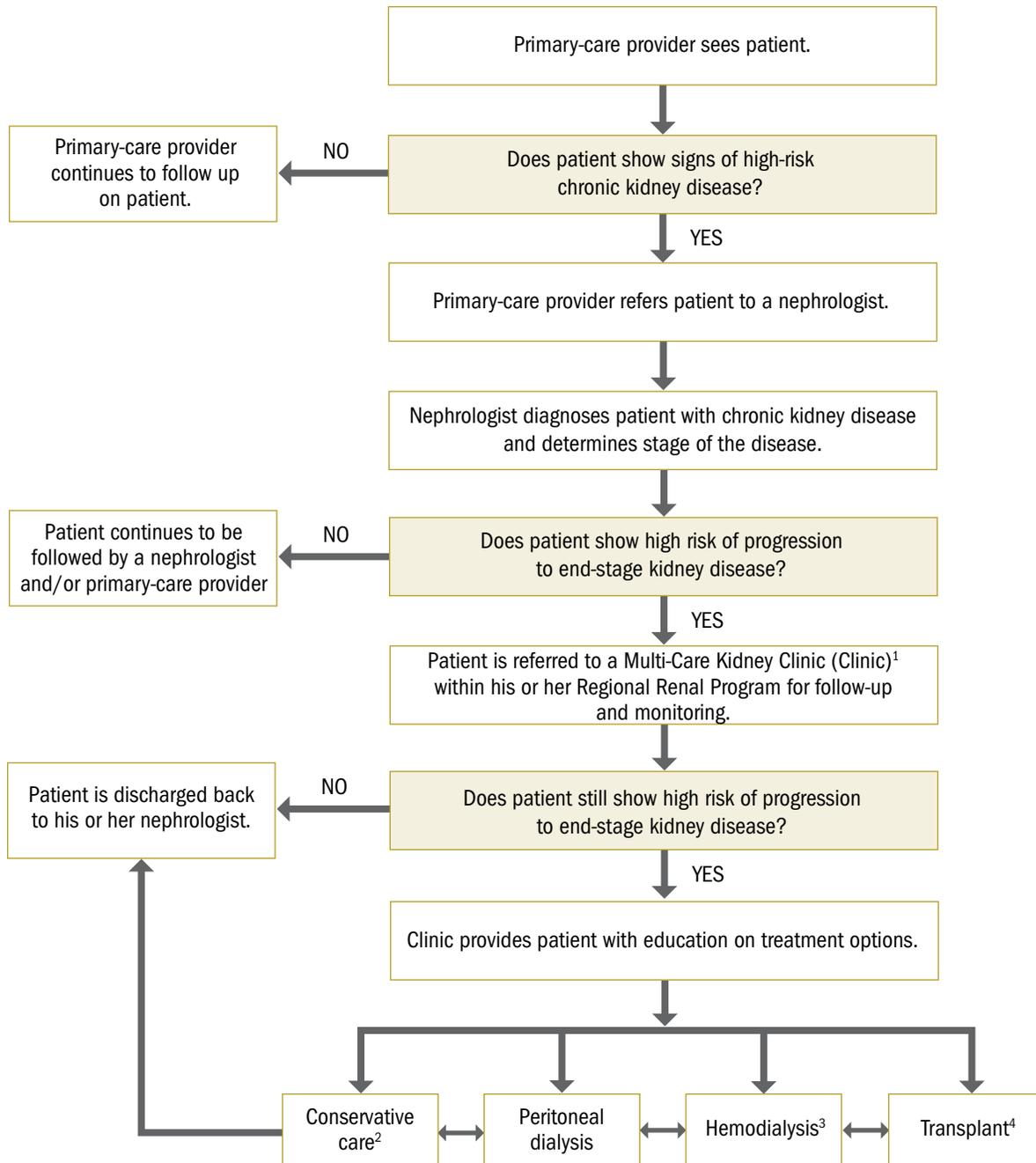
ONTARIO RENAL NETWORK RESPONSE

The Ontario Renal Network agrees with this recommendation. The Ontario Renal Network recognizes that all data collected from the Regional Renal Programs should have a clear purpose and use, and has completed work to map all data elements in the Ontario Renal Reporting System to their current uses for reporting and disclosure. Building upon this work, the Ontario Renal Network will work with the Regional Renal Programs to conduct a review of all data elements to determine where items should be removed or modified to optimize data collection for the planning, funding and improvement of renal care, and to reduce the overall burden of reporting for the Regional Renal Programs.

The Ontario Renal Network will review its suite of performance measures and develop a plan to expand its public reporting. This will include a comprehensive set of measures that reflect the priorities outlined in the Ontario Renal Plan as well as the impact of the Ontario Renal Network's initiatives on the provincial renal system in order to deliver meaningful improvements in care for people affected by chronic kidney disease.

Appendix 1: Journey of a Patient with Chronic Kidney Disease

Prepared by the Office of the Auditor General of Ontario



1. At a Multi-Care Kidney Clinic, a team of multidisciplinary health professionals provide care to help patients manage their chronic kidney disease.

2. Similarly to palliative care, conservative care aims to reduce the pain and suffering a patient experiences in the time before they die.

3. Hemodialysis is provided either in a medical facility or at home.

4. See **Appendix 5** for the journey of a patient undergoing a kidney transplant.

Appendix 2: Roles and Responsibilities of Key Parties Involved in the Delivery of Chronic Kidney Disease Care in Ontario

Prepared by the Office of the Auditor General of Ontario

Key Party	Role/Responsibility
Ministry of Health (Ministry)	Responsible for overseeing all services relating to chronic kidney disease in Ontario. This includes providing strategic direction and funding to the Ontario Renal Network and Trillium Gift of Life Network, as well as determining funding approaches. The Ministry, through the Local Health Integration Networks (LHINs), also funds transplant centres that perform kidney transplants and directly funds seven independent health facilities that provide dialysis services.
Ontario Renal Network (Renal Network)	Responsible for advising the provincial government on chronic kidney disease management. The Renal Network was created in 2009 as a division of Cancer Care Ontario (CCO). The Renal Network also leads the organization of chronic kidney disease services (excluding transplants, which fall under the responsibility of the Ministry and the Trillium Gift of Life Network). This includes determining how much funding to provide to each of the 27 Regional Renal Programs in the province.
27 Regional Renal Programs	Responsible for delivering services (including dialysis, nephrology clinics and a multi-care kidney clinic) in their regions, either directly or in collaboration with satellite sites (which may include other hospitals and health organizations). Each Regional Renal Program is run by a hospital or hospital network. Appendix 3 lists the 27 Regional Renal Programs, which are funded by, and report directly to, the Renal Network. Each of the 14 LHINs has at least one Regional Renal Program.
6 Transplant Centres	Responsible for performing adult kidney transplants. Each transplant centre is located in a hospital with a Regional Renal Program. Six of the 27 hospitals with a Regional Renal Program are also transplant centres, and patients are referred to one of these centres when they opt for a transplant.
Trillium Gift of Life Network (Trillium Network)	Responsible for policy on, and co-ordination of, the donation of organs and tissue (including kidneys), as well as some transplantation activities (such as wait-list management). Trillium Network is a government agency that began operations in 2002. Trillium Network's role includes promoting consent for organ and tissue donation, and co-ordinating kidney donations with Ontario's six transplant centres. Trillium Network also works with Canadian Blood Services to co-ordinate national organ donations. This includes sharing organs with other Canadian jurisdictions.
7 Independent Health Facilities (Facilities)	Responsible under the Independent Health Facilities Act for providing dialysis and other health services. Each Facility is independently owned and run, mainly by physicians. Ontario's seven Facilities are funded by, and report directly to, the Ministry.

Appendix 3: The Regional Renal Programs in Ontario

Prepared by the Office of the Auditor General of Ontario

Provider	LHIN	Associated Transplant Centre?	Funding 2018/19 (\$ million) ¹	Average # of Dialysis Patients 2018/19
1. Grand River Hospital	Waterloo Wellington		28.1	540
2. Halton Healthcare Services	Mississauga Halton		16.6	322
3. Health Sciences North	North East		15.5	290
4. Humber River Hospital	Central		31.1	580
5. Kingston Health Sciences Centre ²	South East	✓	25.7	527
6. Lakeridge Health	Central East		20.9	428
7. London Health Sciences Centre—University Hospital ²	South West	✓	43.8	805
8. Mackenzie Health	Central		30.0	542
9. Niagara Health System	Hamilton Niagara Haldimand Brant		25.0	478
10. North Bay Regional Health Centre	North East		3.3	65
11. Orillia Soldiers' Memorial Hospital	North Simcoe Muskoka		13.1	255
12. Peterborough Regional Health Centre	Central East		15.3	310
13. Renfrew Victoria Hospital ³	Champlain		—	89
14. Royal Victoria Regional Health Centre	North Simcoe Muskoka		9.0	178
15. Sault Area Hospital	North East		5.9	116
16. Scarborough Health Network—Scarborough and Rouge Hospital ²	Central East		47.2	934
17. St. Joseph's Health Centre Toronto	Toronto Central		13.2	252
18. St. Joseph's Healthcare Hamilton	Hamilton Niagara Haldimand Brant	✓	36.1	603
19. St. Michael's Hospital	Toronto Central	✓	27.4	500
20. Sunnybrook Health Sciences Centre	Toronto Central		20.0	357
21. The Ottawa Hospital	Champlain	✓	42.4	882
22. Thunder Bay Regional Health Sciences Centre ²	North West		18.2	353
23. Timmins and District Hospital	North East		1.9	36
24. Trillium Health Partners	Mississauga Halton		35.7	704
25. University Health Network—Toronto General Hospital ²	Toronto Central	✓	39.6	625
26. William Osler Health System	Central West		34.1	663
27. Windsor Regional Hospital	Erie St. Clair		18.0	351
Total			617.1	11,785

1. Funding is based on Quality-Based Procedures (QBP) method and covers the majority of direct services, including dialysis and Multi-Care Kidney Clinics.

2. One of the five Regional Renal Programs we visited as part of our audit.

3. Renfrew Victoria Hospital, due to its small size, does not receive QBP funding; instead, its chronic kidney disease services are funded through its global hospital funding.

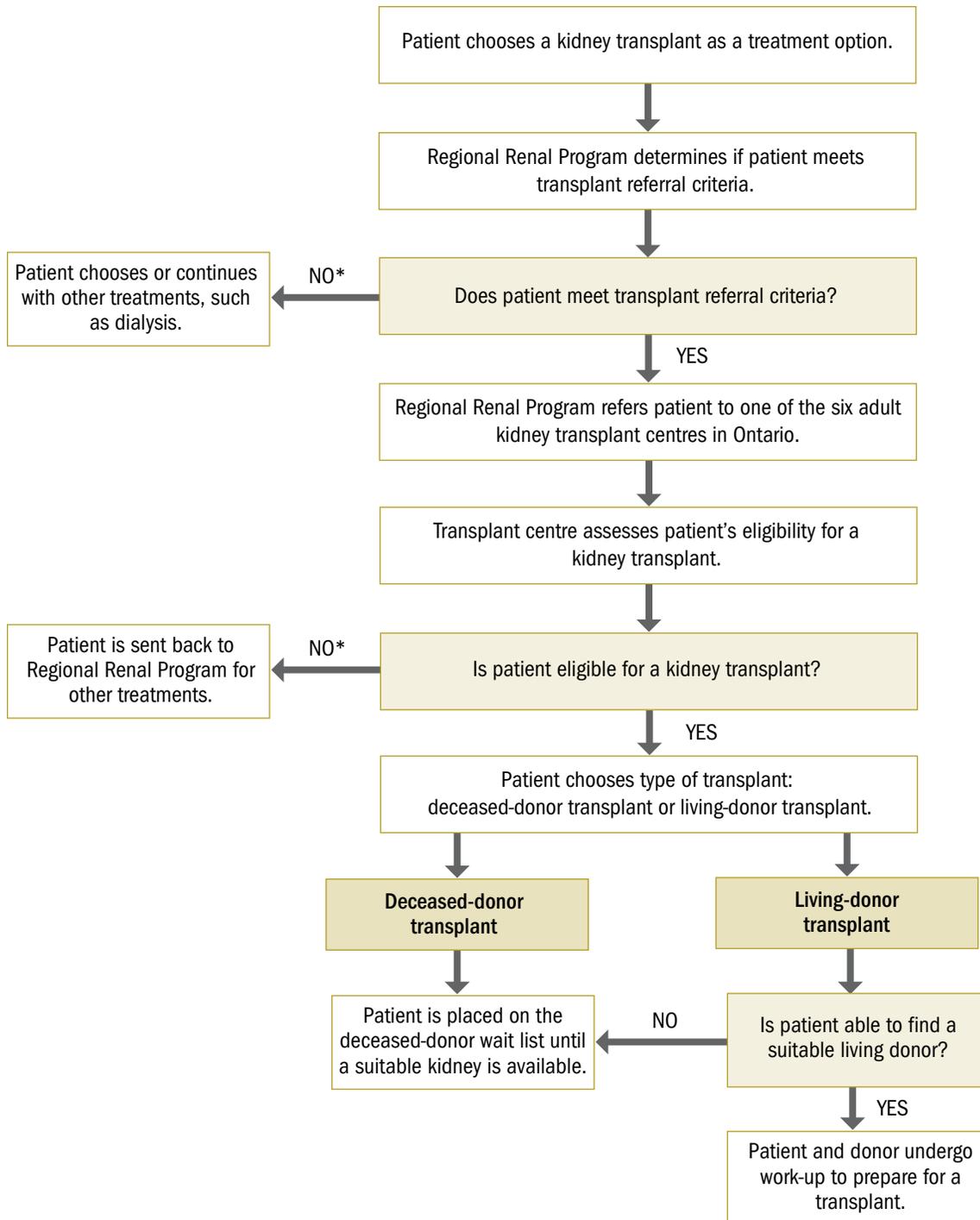
Appendix 4: Audit Criteria

Prepared by the Office of the Auditor General of Ontario

1. Effective procedures and co-ordination among service providers are in place to ensure patients have timely and equitable access to safe and evidence-based chronic kidney disease services that meet their needs regardless of where they live.
2. Effective procedures and controls are in place to ensure patients are assessed on a timely and consistent basis in accordance with eligibility and prioritization criteria.
3. Roles and responsibilities of all parties involved in the delivery of chronic kidney disease services are clearly defined, and accountability requirements are established, to ensure effective service delivery, co-ordination and oversight.
4. Funding and resources are allocated in a timely and equitable manner to service providers based on patient needs, used for the purposes intended, and administered with due regard for economy and efficiency.
5. Sufficient, accurate and timely financial and operational data across all chronic kidney disease services is regularly collected and assessed to help guide management decision-making.
6. Appropriate performance measures and targets are established and continuously monitored against actual results to ensure that intended outcomes are achieved, and corrective actions are taken on a timely basis when issues are identified.

Appendix 5: Journey of a Patient Choosing a Kidney Transplant

Prepared by the Office of the Auditor General of Ontario



* A patient may be reassessed in the future and become eligible for a transplant referral and/or a kidney transplant.

Appendix 6: List of Performance Measures Not Publicly Reported

Prepared by the Office of the Auditor General of Ontario

Performance Measure	Publicly Reported?
Ontario Renal Plan 1 (2012–2015)	
1. Proportion of complex predialysis patients having a comprehensive care plan (education)	
2. Proportion of complex predialysis patients having a comprehensive care plan (patient decision)	
3. Proportion of Stage 5 chronic kidney disease patients that received education on home dialysis	
4. Proportion of Stage 5 chronic kidney disease patients that received education on access type	
5. Proportion of patients receiving care in their modality and location of choice (initiation)	
6. Proportion of patients receiving care in their modality and location of choice (3 months following initiation)	
7. Proportion of patients receiving care in their modality and location of choice (6 months following initiation)	
8. Minimum educational resources/materials made available to patients and families	
9. Proportion of chronic kidney disease programs that have a patient engagement plan in place	
10. Percent decrease in patients that initiated dialysis as a sub-optimal start	
11. Percent decrease in patients that initiated dialysis as crash start	
12. Proportion of predialysis patients receiving multidisciplinary care	
13. Proportion of chronic kidney disease programs that have a mentorship program with primary care providers	
14. Proportion of predialysis patients assessed for access type prior to starting dialysis	
15. Percent decrease in prevalent patients with catheter	✓
16. Establish a target for improvement in access wait times	
17. Proportion of patients that started on independent dialysis within 6 months of initiation	✓
18. Proportion of dialysis patients assessed for independent dialysis prior to starting dialysis	
19. Proportion of facility-based dialysis patients who travel less than 30 minutes	✓
20. Proportion of facility-based dialysis patients who travel more than 60 minutes	✓
21. Capacity planning analysis	
22. Expand Dialysis Outcomes and Practice Patterns Study (DOPPS) ¹ to include a sample of patients and facilities from at least 50% of chronic kidney disease programs	
23. Implement a report from two field evaluations on emerging drugs and technology	
24. Establish a patient-based funding framework in Ontario with associated accountability	
25. Extend patient-based funding beyond the hospital sector, including Community Care Access Centres (CCACs) ² and long-term care	
Ontario Renal Plan 2 (2015–2019)	
26. Proportion of programs that have structures or standardized tools in place (e.g., patient passport and/or patient portal) to regularly document a plan of care (including modality choice, access choice, goals of care)	
27. Proportion of patients/families who are informed about treatment options including dialysis modality, conservative care, access and transplant	
28. Proportion of patients who had the opportunity to participate in the development of their plan of care	
29. Proportion of incident chronic dialysis patients with at least 12 months of Multi-Care Kidney Clinics follow-up prior to dialysis start	
30. Proportion of chronic kidney disease patients who had a nephrology visit and met at least one KidneyWise Clinical Toolkit referral criterion	

Performance Measure	Publicly Reported?
31. Proportion of dialysis patients referred for a kidney transplant within the first year of starting chronic dialysis	
32. Proportion of patients within the Multi-Care Kidney Clinics referred for kidney transplant within one year of an eligible laboratory value for referral	
33. Proportion of incident chronic dialysis patients with whom a Goals of Care Conversation has been documented	
34. Proportion of patients receiving access creation surgery within recommended time frame – Priority 2 Cases	✓
35. Proportion of patients receiving access creation surgery within recommended time frame – Priority 3 Cases	✓
36. Proportion of patients receiving access creation surgery within recommended time frame – Priority 4 Cases	
37. Proportion of prevalent chronic dialysis patients on a home dialysis modality	✓
38. Proportion of incident chronic dialysis patients with deferred elective dialysis start	✓
39. Proportion of Multi-Care Kidney Care-eligible patients referred from general nephrology to Multi-Care Kidney Clinics	

1. The Dialysis Outcomes and Practice Patterns Study (DOPPS) is a prospective, observational study of hemodialysis practices based on the collection of data for a random sample of patients from dialysis facilities in a representative and random sample of units in 20 countries.
2. The term Community Care Access Centre (CCAC) is no longer in use. In May 2017, the Ontario government transferred the responsibility for home-care services from CCAC to the Local Health Integration Networks.