



Ontario Renal Network

Ontario Renal Plan II

2015-2019

together we will



Ontario
Cancer Care Ontario



Chronic kidney disease (CKD) is a serious, lifelong condition. People with CKD often require complex and intensive care from a multidisciplinary team of healthcare professionals. The Ontario Renal Network is the provincial resource for the kidney care system, providing overall leadership and direction to effectively organize and manage the delivery of CKD services in Ontario.

The Ontario Renal Plan II is the provincial road map to guide how we will all work together over the next four years to continue to improve the lives of those at risk for and living with CKD. This plan was developed in consultation with our partners and stakeholders—including the people who deliver kidney care across the province and, for the first time, the people who live with this condition. It builds on the foundation laid by our first strategic plan and addresses patient care across all stages of the kidney care journey, from early detection through dialysis, palliative care and transplant.

Working together, we will use this plan to increase opportunities to detect and slow the progression of CKD, and to improve the quality of life and kidney care services for current and future patients.

action



GOAL

Empower and support patients and family members to be active in their care

BY 2019 ...

Patients and families will be empowered to make shared decisions with their healthcare team across the kidney care journey.

Patient and family feedback will drive regional and provincial quality improvement.

Patients and families will be engaged in the planning and evaluation of kidney care services.

STRATEGIC OBJECTIVES

Engage and educate patients and families to make shared decisions with their multidisciplinary care team.

Support and enable patients and healthcare professionals in developing a self-management approach to CKD.

Use patient-reported outcomes to drive improvements in kidney care.

Collaborate with patients and families on the design, delivery and evaluation of kidney care services.

GOAL

Integrate patient care throughout the kidney care journey

BY 2019...

Hospitals and primary care providers will have the tools they need to reduce the incidence of avoidable harm, including acute kidney injury, in people with, or at risk of, CKD.

Primary care providers will have timely access to the tools and support they require to identify and manage care for people with early CKD.

STRATEGIC OBJECTIVES

Define care expectations, best practices and accountabilities to optimize the delivery of integrated and coordinated person-centred care.

Ensure partnerships with provider agencies are in place to facilitate seamless patient care transitions.

Support primary care providers in the early identification and management of people with CKD to reduce the risk of end-stage kidney disease.

Patients transitioning from primary care to nephrology will have timely access to appropriate pre-dialysis care.

Patients will receive person-centred and well-coordinated palliative care.

Patients will experience an easy-to-navigate pre- and post-transplant care journey.

Establish an integrated process for the early identification and management of people with CKD who would benefit from a palliative approach.

Enhance access to, and improve patients' experiences of, transplantation.

2015 - 2019

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GOAL

Improve patients' access to kidney care

BY 2019...

People living in rural and remote Ontario will have improved access to care solutions that allow them to remain in their communities.

Culturally and geographically appropriate kidney care will be available to First Nations, Inuit and Métis people.

Clinical, economic and cultural barriers to kidney care at home and in long-term care will be addressed.

A community-first approach to kidney care will be adopted in Ontario.

Patients will have timely access to vascular and peritoneal access services.

Models of care for the delivery of safe, high-quality, timely and accessible kidney care will be implemented, monitored and evaluated.

STRATEGIC OBJECTIVES

Identify barriers to accessing kidney care and develop person-centred solutions.

Establish a community-first approach to kidney care.

Ensure infrastructure and services are in place to enable home dialysis.



GOAL

Empower and support patients and family members to be active in their care

GOAL

Integrate patient care throughout the kidney care journey

INITIATIVES

Develop and implement standardized tools that enable shared decision-making, encourage self-management and jointly establish goals of care.

Partner with regional and provincial organizations to strengthen and broaden the use of peer-to-peer support.

Collect and report patient experience and outcome measures for targeted quality improvement.

Develop formal opportunities for patients and family members to be involved in kidney care system initiatives.

INITIATIVES

Explore and develop safety initiatives and tools to prevent avoidable harm, including acute kidney injury, in primary care and hospital settings.

Develop and implement tools to assist with the early identification and management of people with CKD in primary care.

Establish provincial standards and accountabilities with Regional Renal Programs to streamline the transition between primary care and nephrology, for people with CKD at risk of progression to end-stage kidney disease.

Define and implement a model of care that supports comprehensive delivery of palliative care for patients.

Adopt and adapt provincial frameworks and standards for palliative care of people with CKD.

Identify and optimize the care pathway for patients navigating the transplant process, including pre- and post-transplant, in collaboration with Trillium Gift of Life Network.

Ensure the necessary infrastructure is in place across the provincial network for kidney care programs to support pre- and post-transplant care in collaboration with Trillium Gift of Life Network.

2015 - 2019

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GOAL

Improve patients' access to kidney care

INITIATIVES

Adapt tools and approaches to improve access to kidney care for First Nations, Inuit and Métis, and rural and remote communities.

Develop and implement a flexible policy framework for a community-first approach to kidney care.

Enhance system capacity for optimal and timely vascular and peritoneal access.

Implement models for the delivery of safe, high-quality and accessible care to people with acute kidney injury, CKD and end-stage kidney disease; this includes people requiring specialized care such as those with complex glomerular disease and those with kidney disease during pregnancy.

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Together we will transform the way people receive kidney care in Ontario

Terminology

Chronic kidney disease (CKD) is defined as the presence of kidney damage, or a decreased level of kidney function, for at least three months. CKD can be divided into five stages, depending on severity. Stages 1 and 2 are quite mild, while Stages 3, 4 and 5 are progressively more serious. Stage 5 CKD includes end-stage kidney disease (or end-stage renal disease, ESRD). People with Stage 5 CKD are typically on or about to start renal replacement therapy (i.e., dialysis or transplant).

In this document, "CKD" refers to advanced kidney disease—i.e., Stages 3, 4 and 5.



leadership

“The strength of our partnerships—current and new—is more critical than ever before. Only through working together can we create a sustainable health system for Ontarians.”

Together we will create the best health systems in the world

I am pleased to present the Ontario Renal Plan II (ORP II), 2015-2019, a road map for how the Ontario Renal Network (ORN), the Regional Renal Programs, our many partners and the Ministry of Health and Long-Term Care will work together to continue to improve the lives of people at risk for and living with chronic kidney disease (CKD).

In the six years since ORN’s establishment, we have laid a solid foundation for a responsive kidney care system to meet the unique needs of the renal community. Our first ORP (2012-2015) addressed the detection, diagnosis and treatment of CKD in a systematic way for the first time in this province’s history. Under this first plan, we have already taken steps to improve the quality of care for current and future patients with CKD. With this second strategic plan, we are continuing to

strengthen the system to better serve the unique needs of people at risk of or diagnosed with CKD.

This plan reflects the clear purpose, collective wisdom and experience of our network of staff, healthcare professionals, regional and provincial partners, representatives from the Ministry of Health and Long-Term Care, and patients and their families. They all played a vital role in shaping ORP II. Their shared commitment and active participation will be crucial in realizing its successful implementation.

Provincial health system plans such as ORP II are an integrating force in a complex healthcare system. They help drive continuous system improvement by setting clear goals, objectives and initiatives, and guide our work at all levels. They are endorsed by the government to help direct major initiatives

and funding decisions, and to ensure key gaps are addressed at the system level. At the same time, they promote health system sustainability by focusing efforts where they are most needed.

ORN is proud to be part of CCO in leading a transformation in healthcare, one that is driving quality, accountability, innovation and value throughout the system. By leveraging each other’s strengths and working towards our common goals, together we will create the best health systems in the world.



Michael Sherar
President & CEO of CCO



Person-centred care at the heart of our strategic plan

A conversation with Rebecca Harvey, Vice-President of the Ontario Renal Network; and Dr. Peter Blake, Provincial Medical Director of the Ontario Renal Network

Rebecca Harvey:

When the Ontario Renal Network (ORN) was established in 2009, we were presented with a monumental challenge: to lead a provincewide effort to diminish the negative impact of chronic kidney disease (CKD) in Ontario. In 2012, we launched an ambitious three-year strategy to better organize and manage the delivery of kidney care services in the province. Now, with this second Ontario Renal Plan (ORP II), which takes us to 2019, we take the next step in the evolution of our commitment to drive quality, accountability, innovation and value in Ontario's kidney care system.

Dr. Peter Blake:

We've done well in just a few short years, especially in terms of building infrastructure and forging partnerships to support system improvements in the organization and quality of kidney care. This work is vital, as the prevalence of CKD and its burden on the healthcare system are expected to continue to increase in coming years.

“Our regional partners are integral to the success of this plan. Dedicated people in our network across Ontario, while providing care at the local level, are part of a much bigger picture. Together, we will bring these initiatives to life to improve care for current and future patients.”

–Rebecca Harvey

“As patients move through their kidney care journey, they have to make important decisions that will affect their care and quality of life. We want to enable people to take a more active role in their care and fully participate with their care team in making those choices. This is what shared decision-making really means.” –Dr. Peter Blake

Rebecca Harvey:

The burden this disease puts on patients and families is tremendous as well. In the development of this plan, we engaged people with CKD in our strategic planning process for the first time, and they taught us so much about the unique realities of what it is like to live with kidney disease. Their perspective will help to transform the future of kidney care at the system level.

We also looked within our network—to our clinicians, Regional Renal Program staff and our regional and provincial partners—for guidance on how to achieve our triple aim of improving health, improving the patient experience and optimizing value. With this input, and building on the achievements and lessons of the first ORP, we identified and consolidated several themes that became the foundation for this plan’s three goals: empowering patients and families to be active in their care; integrating and coordinating care for patients; and improving access to kidney care.

Dr. Peter Blake:

Patients and their families are at the heart of all three goals. ORP II reframes the way we think about kidney care and the roles of everyone involved. Our focus

shifts beyond dialysis to kidney health; beyond medical treatments to quality of life; beyond making decisions for patients to empowering them to make choices with their care teams. This is true person-centred care, and its implementation will represent a significant shift in the way CKD and end-stage kidney disease are managed. Importantly, our goals require us to look at patient care across all stages of the kidney care journey.

Rebecca Harvey:

Our goals also require us to look at how we can support cohesive improvements at a system level. Together, everyone in the kidney care system—from patients to their healthcare teams to system administrators and partner organizations—will work in collaboration and partnership to implement initiatives that will have an impact on care.

We all have a lot to be proud of. Thanks to the collective efforts of our network of staff, healthcare professionals, patients and families, and regional partners, initiatives implemented under ORP I have already resulted in significant improvements for people with CKD. For example, we established the Body Access (BA) and Independent Dialysis (ID) quality improvement collaborative, a network of BA

and ID Coordinators committed to achieving improvements in vascular and peritoneal access, and in home dialysis, respectively. We also visited with CKD patients and staff in homes and hospitals across the province to better understand local barriers, share demonstrated successes and identify opportunities for local quality improvements. In addition, we implemented a capacity planning program to project future needs and manage the supply and demand for kidney care services across the province. We are particularly proud of our world-class Ontario Renal Reporting System (ORRS), which enables us to measure and report in real time on kidney care performance, patient outcomes and funding expenditure. Thanks to the accuracy and efficiency of ORRS, we were able to pioneer a CKD patient-based funding framework that puts ORN at the forefront of Health System Funding Reform in Ontario.

In the coming years, we will continue to see even greater results as we work together to build a system that meets the needs of people who currently have or are at risk of CKD.



My kidney life

“While the last 27 years on dialysis have not been easy, I have seen and done many things that I had dreamed of and many things that I never thought would be possible,” he says. “All along, the key has been a positive attitude and staying educated about and involved in my healthcare.”

In 1987, without any prior symptoms or warning, Mike M.'s kidneys failed as the result of a rare condition known as Focal Segmental Glomerular Sclerosis. Over the years, Mike has undergone hundreds of diagnostic tests, dozens of angioplasty procedures, eight fistula operations and two failed transplants. At the same time, he studied, established a successful career, travelled the world, played sports, married and became an advocate for the empowerment of people with chronic kidney disease (CKD).

Michael M.

Me with my nephrology nurses Joyce Hunter (left) and Mina Kashani (right), and Dr. Vern Campbell

In the beginning

“When my kidneys failed, overnight I went from being a healthy, athletic 18-year-old student to a dialysis patient stuck in a hospital. The sudden transformation was a truly strange and scary experience.”

My mother, Noreen, my father, Brendan, and me



My first transplant

“My nurses and I had a goodbye party on what was to be my last day of dialysis. I was devastated when the new kidney, donated by my father, failed less than 48 hours after the transplant.”

Meet my team

“When you spend four to five hours, three to five times every week, in a dialysis clinic, the nurses become your social network. Some of my first nurses at St. Michael's Hospital have been my friends for more than 20 years.”





← Me at the curling rink

Achieving independence

“Home dialysis was a really positive choice for me because of the flexibility it offered. Nocturnal home dialysis is even better because I am free to do what I want in the evening, like curl. I had a bit of a phobia about sleeping through the night with needles in my arm, but the training I received from the team at St. Mike’s gave me the skills and confidence I needed.”



Patient empowerment

“Mike is exemplary in wanting to take control of his own care. With proper assessment, education and support, many of our patients discover that they do not have to become institutionalized just because they need dialysis.”

Gemma O’Keefe (above left, with interventional radiologist Dr. Andrew Common), a medical imaging nurse at St. Michael’s Hospital, has been part of Mike’s care team for more than 25 years.



Ongoing challenges

“Vascular access is a dialysis patient’s lifeline. Mike has experienced multiple access failures, but he has never let fear dictate his treatment choices. He asks me to explain my recommendations and alternatives, he examines his options carefully, and we work together to create a plan that is right for him.”

Dr. Vern Campbell (above left), staff surgeon with the Division of Vascular Surgery at St. Michael’s Hospital, has performed several of Mike’s vascular surgeries since 2007.



Looking ahead

“Life on dialysis is always full of uncertainty, and I don’t know what tomorrow will bring. I persevere, I continue to move forward, and I deal with each challenge as it arises.”



← My wife, Heather, is my Number 1 supporter!

← My primary nephrologist, Dr. Phil McFarlane (far left) and my home dialysis nurse, Jumi Charles (far right), with Dad, Mom, Heather and me

Surrounded by support

“I never want to just ‘get by’ on dialysis. I want to live a full and active life. The team at St. Mike’s always works hard to find solutions that help me succeed personally and medically.”



caring

Impact of CKD in Ontario

Affecting every aspect of a person's life

Living with chronic kidney disease (CKD) can present considerable challenges for patients and their families. Depending on the stage of the disease and treatment modality, they may have to deal with significant physical discomfort, emotional stress, financial difficulties and major lifestyle changes.

Approximately 12,000 people in Ontario have CKD requiring pre-dialysis care. An additional 10,500 Ontarians with advanced CKD require dialysis.

The need for dialysis has been gradually rising for more than a decade, and is expected to continue climbing in the foreseeable future. This trend is largely driven by changing demographics and the increasing prevalence of risk factors associated with CKD, such as:

- **Aging:** CKD is more common in the later years of life. Ontario's population is not only growing, it is aging. Seniors aged 65 years and older now represent almost 15 per cent of this province's population; by 2036, they will constitute nearly one quarter of Ontario's projected 17.4 million people.¹
- **Diabetes:** A significant risk factor for CKD, diabetes is on the rise. In 2014, 9.8 per cent of Ontarians had diabetes, a figure projected to climb to more than 13 per cent by 2024.²
- **Hypertension:** The percentage of Canadian adults with high blood pressure, another important risk factor for the development and progression of CKD, rose from 2001 to 2013, and Ontario's rate of hypertension is higher than the national average.³

The prevalence of CKD is relatively high in Aboriginal populations. National data show that the incidence of end-stage kidney disease is more than three times higher in Aboriginal people than in their non-Aboriginal counterparts.⁴

Ontario Renal Reporting System

The work to improve the care and quality of life for people affected by CKD begins with understanding the scope of the disease's impact. Since 2010, the Ontario Renal Network, in cooperation with Regional Renal Programs in Ontario, has been collecting data on all CKD patients across this province. The resulting database, known as the Ontario Renal Reporting System (ORRS), provides information that guides our capacity planning, funding and future system improvements as well as performance management of the kidney care system.

Treatment options

CKD requires lifelong, intensive treatment. In the early stages of the disease, patients may begin working with a team of physicians, nurses, dietitians, social workers and pharmacists to slow the progression of kidney failure through lifestyle changes and medication. Early detection of CKD and prevention of progression are the ideal, yet we know CKD goes undetected in many Ontarians, as approximately a quarter of new dialysis patients were "crash starts" (i.e., started dialysis without prior care from a nephrologist) in 2014 (ORRS, 2014). This suggests a need for earlier CKD management by primary care physicians, and more timely and appropriate referrals to nephrology specialists.

When the kidneys fail, options include renal replacement therapies such as dialysis or transplant, or palliative care. Patients can receive hemodialysis

(in which the person's blood is filtered through a machine to remove waste products and toxins) in a hospital or community-based facility or at home. Peritoneal dialysis (in which fluid is infused into the peritoneal cavity and then drained out along with waste products and toxins) is normally performed at home.

Patients who are able to manage their dialysis treatment in their own homes frequently report better quality of life and a greater sense of independence than those who receive in-facility care. As of June 2014, almost one quarter of dialysis patients in Ontario managed their care at home (6% hemodialysis; 18% peritoneal dialysis), while more than three quarters received hemodialysis in a hospital or community-based facility.

Many CKD patients can benefit from dialysis support outside of hospital clinics—for example, through Community Care Access Centres (CCACs) or in

long-term care facilities. All Ontario CCACs now offer at least some peritoneal dialysis support in their regions, with approximately 575 patients receiving this service in 2013/14. However, fewer than five per cent of long-term care facilities in Ontario support the provision of dialysis within the long-term care home.

Kidney transplantation provides the best long-term outcome for patients with end-stage kidney disease in terms of both quality of life and reduced risk of dying from kidney disease. Despite these benefits, kidney transplantation rates in Ontario are relatively low, and many patients express frustration with the lack of communication and transparency about the wait list process.

In Ontario, Trillium Gift of Life Network maintains the transplant wait list, and plans, coordinates and supports organ and tissue donation and transplantation. As of 2013, 1,088 people were

deemed suitable for a transplant and placed on the wait list for a kidney (or combined kidney and pancreas). Between 2010 and 2012 in Ontario, the median time to receive a kidney from a deceased donor was 4.2 years, and 0.9 years from a living donor.⁵ While the total number of kidney transplants increased to 546 in 2013 from 404 in 2004, living donations, which result in better outcomes, have not kept pace with deceased donations. Over the most recent five-year period, the number of living donor transplants has fallen in Ontario.⁶

REFERENCES

All data retrieved June 2013 from Ontario Renal Reporting System, with these exceptions:

1. Ontario Ministry of Finance, 2011 Census
2. Canadian Diabetes Association, "My Diabetes Charter," 2014
3. Statistics Canada, "High Blood Pressure, 2013"
4. Canadian Institute for Health Information, "End-Stage Renal Disease Among Aboriginal Peoples in Canada: Treatment and Outcomes," February 2013.
5. Canadian Organ Replacement Register Report, 2014
6. Trillium Gift of Life, Public Reporting, November 2014





Cybelle L.

“Kidney disease has had a huge impact on my life financially, socially and emotionally. My employers were not at all supportive about all the time I had to take off because of my health, and I eventually had to stop working. Dialysis is so time-consuming and isolating, friends became distant. And when you are waiting for a transplant, it’s frustrating to wait and wait and wait, and not know where you are on the list.”

Cybelle L. received a kidney transplant in 2014 after eight years on the wait list. As her health improves, she is looking forward to travelling and going back to work.



About us

A network built for person-centred care

The Ontario Renal Network (ORN) is committed to facilitating a provincewide effort to diminish the burden of chronic kidney disease (CKD) on Ontarians and the healthcare system.

As the government's CKD advisor, ORN provides leadership and strategic direction to effectively organize and manage the delivery of kidney care services in Ontario in a consistent and coordinated manner. This includes preventing or delaying the need for dialysis, broadening appropriate patient-care options, improving the quality of all stages of kidney care, and building a world-class system for delivering care to Ontarians living with CKD.

As a network, ORN consists of a vast array of partners including healthcare professionals, Regional Renal Program staff, partner health agencies and organizations, patients and families, and many others. By working collaboratively, we can leverage the competencies and assets of all, to better achieve our common goal of creating a safe, sustainable, efficient and effective kidney care system for Ontario. For example, our provincial office works closely with Regional Directors and Medical Leads in planning, delivering and monitoring CKD care across the province. In total, 26 Regional Renal Programs provide dialysis and other kidney care services



Ontario Renal Network

within 105 facilities (including hospitals and community-based facilities). Community partners such as long-term care homes and independent health facilities also provide kidney care services.

People with CKD and their families are at the centre of our network. They provided insight and advice on

the development of the Ontario Renal Plan II through a Patient Advisory Committee. Their ongoing contributions are invaluable, and we look forward to continued collaboration with patients and families in shaping the kidney care system at the regional and provincial levels.

The CCO umbrella

In 2009, Ontario's Ministry of Health and Long-Term Care transferred oversight and coordination of kidney care services to ORN under the umbrella of CCO. ORN has been able to leverage Cancer Care Ontario's successful model of quality improvement and change management practices. Today, ORN and Cancer Care Ontario are unified through CCO's common goal to create sustainable health systems for all Ontarians.

VISION

Working together to create the best health systems in the world.

MISSION

Together, we will improve the performance of our health systems by driving quality, accountability, innovation and value.

GUIDING PRINCIPLES

- The people of Ontario will be at the core of everything we do and every decision we make.
- We will be transparent in sharing performance-related information, and foster a culture of open communication with colleagues, partners and the public.
- We will ensure fairness across regions in the development of strong provincial health systems.
- We will make decisions and provide advice based on the best available evidence.
- We will consult widely, share openly and collaborate actively to achieve our goals.



A solid foundation

Groundwork for progress laid by our first strategic plan

Our first Ontario Renal Plan (ORP I, 2012-2015) outlined a set of strategic priorities to improve the quality of care and treatment for current and future patients with chronic kidney disease (CKD). These priorities focused on accountability to patients; early detection and prevention of progression; independent dialysis and vascular access; infrastructure; research and innovation; and alignment of funding to quality, patient-focused care.

Working together with our partners on these priorities, we have established a solid foundation on which to build future improvements. Transformational change takes time to realize, however. We have started to see modest improvements in priority areas of the first plan, and we are confident that we will continue to improve patient care through the initiatives and goals laid out in our second strategic plan. Here, we share some of our key accomplishments from the past three years. For additional details about these and other achievements, see www.renalnetwork.on.ca.

Accountability to patients

We introduced a person-centred care approach to our work and improved our capacity to engage people with CKD and their families in provincial initiatives. Patients, their families and caregivers were key partners in a variety of provincial Ontario Renal Network (ORN) activities, including strategic planning, the development of educational materials, and CKD research projects. In addition, we assessed how renal programs across Ontario currently engage patients and families in their care. As an essential first step in building a person-centred kidney care system, all Regional Renal Programs now have a comprehensive plan for how they will advance patient and family engagement within their programs based on the minimum expectations we set out for them.

Early detection and prevention of progression

New clinical tools and resources are promoting awareness of CKD among primary care providers, helping them to better detect and manage CKD so that kidney function is preserved and progression of the disease is delayed. A newly developed and tested primary care toolkit will enable patients to be referred more appropriately and with relevant information. A mentorship program was successfully piloted in 15 of 26 Regional Renal Programs; as it is expanded, it will further ensure that primary care providers have the support necessary to manage patients with CKD.

There has been a decline in sub-optimal dialysis starts—i.e., fewer patients who had been in 12 months or more of pre-dialysis care had to start dialysis as an

in-patient and/or with an unplanned temporary hemodialysis catheter. As of the first quarter of 2014/15, sub-optimal starts decreased more than 10 per cent compared to the first quarter of 2012/13.

Independent dialysis and vascular access

Each Regional Renal Program now has Independent Dialysis and Body Access Coordinators to coordinate patient education and assessment for home dialysis and appropriate body access. These coordinators participated in a provincewide quality improvement collaborative to facilitate and support local quality improvement initiatives aimed at improving the uptake of independent dialysis and appropriate body access. A successful pilot project to have personal support workers assist patients with home hemodialysis is an example of an innovative program-level initiative to support home therapies.

A new tool that tracks milestones in a patient's CKD journey is helping us to better understand barriers to improving the uptake of independent dialysis and appropriate body access. Similarly, wait time reporting identifies gaps in vascular access surgical and interventional radiology capacity and performance.

As of the second quarter of 2014/15, almost 80 per cent of patients were receiving their preferred dialysis modality in the location of their choice within three months of initiating dialysis. The percentage of people dialyzing at home increased by 1.5 per cent (Q2 2014/15 vs Q4 2011/12). While this growth may appear modest, it represents an additional 325 people dialyzing at home; home dialysis is typically

associated with better quality of life and independence in those who do it. In addition, prevalent hemodialysis catheter use has very modestly decreased to 56.0 per cent in 2013 (from 56.2% in 2012). While prevalent hemodialysis catheter use decreased only less than one per cent over the first year of the plan, more recent data indicate that fewer patients are starting dialysis with a catheter (incident catheter use decreased to 73% in the first quarter of 2014/15, compared to 79% in the first quarter of 2012/13), reducing the risk of hemodialysis catheter-related complications for patients.

Infrastructure

We have improved our ability to ensure that the necessary resources and infrastructure for kidney care are available. We developed a new tool to forecast patients' and hemodialysis station requirements across the province. Using this tool, we identify capacity shortages and make transparent, evidence-based decisions about short- and long-term capital and operating investments in kidney care to ensure patients have access to service when they need it. Between 2012 and 2015, more than 100 in-facility hemodialysis dialysis stations were added to the kidney care system.

The Ontario Renal Reporting System (ORRS) was established through the collaboration and efforts of the Regional Renal Programs. This system captures comparable data about all pre-dialysis, acute dialysis and chronic dialysis patients in the province, providing essential information to improve system quality, performance, planning and funding allocation.

Research and innovation

Several key initiatives focused on enhancing evidence-building research through collaboration with research institutions and leveraging ORN's funding and planning mandate to translate research into innovation in the field. For example, a collaboration was developed with the Institute for Clinical Evaluative Sciences and Toronto Health Economics and Technology Assessment; this will enhance analytic capacity and allow for better use of provincial data. In addition, the international Dialysis Outcomes and Practice Patterns Study expanded to 20 dialysis facilities, providing a more comprehensive view of hemodialysis facility performance.

Funding

As part of the provincial government's Health System Funding Reform initiative, the Chronic Kidney Disease Patient-Based Funding Framework was implemented in all hospital CKD programs beginning in 2012/13. This funding framework promotes patient-centred and evidence-based care, links funding to patients and best care practices, and ensures funding equity across service providers. In 2014/15, the framework expanded to incorporate funding for assisted peritoneal dialysis services provided by Community Care Access Centres and long-term care homes. This expansion supports the shift from hospital-based dialysis to home and community-based care so that patients can receive care at home or in the long-term care home where they live.

Celebrating regional success

Local initiatives brought our first strategic plan to life

For people with chronic kidney disease (CKD), the Ontario Renal Network is embodied by our 26 Regional Renal Programs. It is at the local level that dedicated front-line healthcare professionals and behind-the-scenes program administrators brought to life the improvements in care called for in the first Ontario Renal Plan. Here, we provide a snapshot of just some of these initiatives; for details about how the Regional Renal Programs are making a difference in the way people with CKD receive care, see www.renalnetwork.on.ca.

1

ERIE ST. CLAIR

Windsor Regional Hospital is performing a research study that examines the use of medication to optimize dialysis access function.

2

SOUTH WEST

London Health Sciences Centre initiated an urgent-start peritoneal dialysis (PD) program to improve uptake of home dialysis.

3

WATERLOO WELLINGTON

Grand River Hospital introduced operational changes, aided by its relationship with Community Care Access Centres, to support patients on home dialysis.

4

HAMILTON NIAGARA HALDIMAND BRANT

St. Joseph's Healthcare Hamilton standardized education to increase the number of patients on home dialysis and reduce permanent central venous catheter use.

Niagara Health System implemented an online community trial project to improve patient involvement in shared decision-making.

5

CENTRAL WEST

William Osler Health System is using ultrasound-guided technology to assist nursing staff with cannulation and reduce patients' pain and anxiety.

6

MISSISSAUGA HALTON

Halton Healthcare Services, in collaboration with Trillium Health Partners, standardized peritoneal dialysis education to support patients on PD.

Trillium Health Partners implemented a community cannulation assistance training program to support patients on home hemodialysis.

7

TORONTO CENTRAL

St. Joseph's Health Centre launched a Peritoneal Dialysis Body Access Clinic that improves PD access.

St. Michael's Hospital started offering telemedicine clinic visits that support care close to home for patients.

Sunnybrook Health Sciences Centre implemented multiple initiatives led by the Interdisciplinary Vascular Access Best Practice Team to improve hemodialysis access, treatment and quality of life for patients.

University Health Network established three complementary programs that enhance the transition to home dialysis.

14



8

CENTRAL

Humber River Hospital developed a strategy to decrease prevalent central venous catheters in the hemodialysis unit.

Mackenzie Health opened a Patient Education Resource Centre at Oak Ridges that helps patients and families with the transition to home therapy and access creation.

9

CENTRAL EAST

Lakeridge Health added an Independent Dialysis Coordinator as well as corresponding tools and processes that support the uptake of home dialysis.

Peterborough Regional Health Centre launched a new transition unit that supports informed decisions and enhances the patient experience.

The Scarborough Hospital developed a Self-Management CKD Education Manual for all new patients in its program.

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SOUTH EAST

Kingston General Hospital added a Body Access Coordinator to bring clinical teams together to support best possible vascular access for patients.

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CHAMPLAIN

The Ottawa Hospital and Renfrew Victoria Hospital developed and implemented a patient decision aid to help patients make informed decisions about renal replacement therapy.

12

NORTH SIMCOE MUSKOKA

Orillia Soldiers' Memorial Hospital developed new processes and procedures to support modality education for all incident dialysis patients.

13

NORTH EAST

Health Sciences North organized an education road show to bring information about renal replacement options closer to home for patients and families.

North Bay Regional Health Centre used incremental PD and assigned a dedicated nurse to manage patient care to reduce sub-optimal starts.

Sault Area Hospital added a Renal Database Coordinator to support accurate data collection.

Timmins and District Hospital completed timely home visits for PD patients to provide patients and families with education and tools for success.

14

NORTH WEST

Thunder Bay Regional Health Sciences Centre recruited a vascular surgeon to improve their ability to offer patients care closer to home.



About this plan

Collaborating with our communities

In 2012, the Ontario Renal Network (ORN) introduced this province's first comprehensive strategy, the Ontario Renal Plan I (2012-2015), to guide the delivery of kidney care services in Ontario. With this second Ontario Renal Plan (ORP II), we build on the foundational achievements, experiences and lessons of the first plan. ORP II provides a road map for the collaborative journey we will take over the next four years as we continue to improve Ontario's kidney care system.

Meaningful consultation

We believe that this plan belongs to all Ontarians whose lives are affected by chronic kidney disease (CKD). As such, its development relied on extensive collaboration and meaningful consultations with key stakeholders, including healthcare professionals, renal program administrators, regional and provincial partners, and, for the first time, people with CKD and their families. In total, more than 260 participants provided invaluable insights about the challenges and opportunities that shaped the strategic goals of ORP II. In particular, they highlighted the importance of putting patients at the centre of care at every stage of their kidney care journey.

Out of these consultations, several key themes emerged—patient engagement, integration of care and access to care—that became the basis of the three goals identified in this plan. The underlying philosophy of these themes and goals is a fundamental shift away from traditional provider-driven care towards a new model centred on patients and their families. Under this model, patients and their families can, if they choose, participate in true shared decision-making about their care throughout their CKD journey.

At the same time, the three goals of ORP II highlight partnerships—between patients and their healthcare teams, among various healthcare professionals, among agencies, etc.—to ensure that we work together and are all accountable to deliver the best care possible.

ORP II also reflects the shared priorities of ORN, the Ministry of Health and Long-Term Care (MOHLTC) and the Regional Renal Programs, which bring the plan's objectives and initiatives to life at the local level. The plan aligns with MOHLTC's ongoing commitment to provide better access to care, higher-quality care and improved value from our healthcare investments.

Accountability

ORP II is a strategic document supported by a detailed operating plan, annual business plans and a robust evaluation plan that includes metrics against which we will measure our success. The "By 2019" statements included in this document hold us accountable to the plan's overall impact and highlight what we will achieve over the next four years. We are also

implementing an evidence-informed measurement framework to establish performance metrics aligned with ORP II's goals and objectives. These metrics are integral to the implementation of ORP II, and are vital in ensuring that we demonstrate measurable and sustained improvement in care for CKD patients.

The Ontario Renal Network is accountable to MOHLTC, our partners and the people of Ontario for the fulfillment of ORP II. Our progress is reported through several mechanisms, including our ORP progress reports, CCO annual reports and our ORN website, which all track Ontario's progress towards better outcomes in kidney care for patients and highlights opportunities for improvement.



Deb B.

"Having CKD is a difficult road for patients to travel. Having patients involved in the planning of kidney care services is like having someone on the journey with us. It is very empowering to know that someone is listening to our opinions and that together we are guiding others along the way."

Deb B. has had diabetes for more than 35 years. Although she knew her risk of CKD was high, she was still shocked when her kidneys failed in 2013. Nocturnal peritoneal dialysis gives her the freedom to continue working with seniors and young people, and to volunteer with such groups as the London Health Sciences Centre Patient and Family Advisory Committee.

Goal

Empower and support patients and family members to be active in their care

Chronic kidney disease (CKD) is a lifelong journey that is filled with many critical decisions. There is increasing evidence that there are significant physical and psychological benefits for patients when they actively participate in their care, so it is important for them to be empowered to make informed decisions along their journey. Examples of these decisions are whether and when to initiate dialysis, which modality of dialysis to choose and where to do it, which vascular access to use, whether to consider transplantation and choices regarding palliative care. The Ontario Renal Plan II (ORP II) aims to ensure that all patients who want to take an active role in their care have the support, confidence and opportunity to do so.

At the program and system levels, there are clear benefits to involving patients and families in

designing healthcare improvements that will have a direct impact on their care. Some Regional Renal Programs are engaging with CKD patients and families through advisory councils, recognizing them as valued partners in quality improvement. Provincially, the Ontario Renal Network (ORN) actively engaged patients and families in the development of ORP II. Moving forward, we will continue to work with these key people in shaping and evaluating kidney care system initiatives.

Over the next four years, initiatives will focus on ensuring that patients, families and healthcare professionals have the tools, resources and supports needed to enable shared decision-making, self-management and self-reporting of their experiences.

Strategic objectives

Engage and educate patients and families to make shared decisions with their multidisciplinary care team.

Support and enable patients and healthcare professionals in developing a self-management approach to CKD.

Use patient-reported outcomes to drive improvements in kidney care.

Collaborate with patients and families on the design, delivery and evaluation of kidney care services.

Initiatives

Develop and implement standardized tools that enable shared decision-making, encourage self-management and jointly establish goals of care.

Partner with regional and provincial organizations to strengthen and broaden the use of peer-to-peer support.

Collect and report patient experience and outcome measures for targeted quality improvement.

Develop formal opportunities for patients and family members to be involved in kidney care system initiatives.



Randy R.

"I have polycystic kidney disease (PKD), just like my father had. I want to be proactive with my health, and I do everything I can to maintain the kidney function I have. I am so grateful for the comprehensive education I've received at the pre-dialysis clinic. I know I can't control the disease, but I can stack the deck in my favour."

Randy R. says that even with his health challenges, "life is beautiful." He retired in 2012 following a 36-year career as a federal public servant and moved to the country with his wife, where he volunteers as a palliative care attendant at a local hospital, is an active member of his church, and enjoys his "toys," including his 1969 Chevy Impala.

By 2019...

Patients and families will be empowered to make shared decisions with their healthcare team across the kidney care journey.

Patient and family feedback will drive regional and provincial quality improvement.

Patients and families will be engaged in the planning and evaluation of kidney care services.

Goal

Integrate patient care throughout the kidney care journey

What is palliative care?

Under ORP II, we will work to advance Ontario's *Declaration of Partnership and Commitment to Action* regarding palliative care, and integrate palliative care into CKD programs across Ontario.

Palliative care is a holistic person-centred approach to caring for patients facing a life-limiting illness. The aim is to prevent and ease suffering, while promoting quality of life from the time of diagnosis, through management of the illness, right up until the end of life.

Palliative care should be a standard part of care that is integrated throughout the kidney care journey. Discussions should begin early and be ongoing. It should be available across all care settings, be provided by an inter-professional team of healthcare professionals, and include family, informal caregivers and the community.

As patients progress through their kidney care journey, they will see various healthcare professionals in multiple care settings. They often have to attend multiple appointments, are asked to repeat information and may be uncertain about whom to turn to for help. Healthcare professionals in different settings, in turn, may not fully understand each other's roles and how to coordinate with other members of the care team to address patients' needs. Through better integration, each patient will experience well-organized care from a multidisciplinary team, with easy-to-navigate

transitions at every stage of their kidney care journey. This person-centric model of care requires excellent communication and supportive partnerships between patients and their care providers.

As we implement ORP II, we will focus on three areas that our stakeholders (including patients and families) identified as offering the greatest potential impact for improved integration of care: early detection and prevention of progression of kidney disease; palliative care; and transplant.

Strategic objectives

Define care expectations, best practices and accountabilities to optimize the delivery of integrated and coordinated person-centred care.

Ensure partnerships with provider agencies are in place to facilitate seamless patient care transitions.

Support primary care providers in the early identification and management of people with CKD to reduce the risk of end-stage kidney disease.

Establish an integrated process for the early identification and management of people with CKD who would benefit from a palliative approach.

Enhance access to, and improve patients' experiences of, transplantation.

Initiatives

Explore and develop safety initiatives and tools to prevent avoidable harm, including acute kidney injury, in primary care and hospital settings.

Develop and implement tools to assist with the early identification and management of people with CKD in primary care.

Establish provincial standards and accountabilities with Regional Renal Programs to streamline the transition between primary care and nephrology, for people with CKD at risk of progression to end-stage kidney disease.



integrate

Jody B.

“The healthcare system is set up so that you have to see your family physician for all your non-kidney-related health issues. But a lot of primary care doctors are uncomfortable having anything to do with CKD patients—even prescribing an antibiotic—so they send you back to the nephrologist for care. We need to ensure that primary care doctors have the knowledge and experience to support CKD patients; otherwise patients become hot potatoes that no one takes responsibility for.”

Jody B. was diagnosed with hemolytic uremic syndrome when he was just six years old. When he is not working as a business analyst or receiving hemodialysis at a self-care dialysis centre (what he calls his “second job”), he is drumming, golfing, kayaking, fishing or antique hunting.

Define and implement a model of care that supports comprehensive delivery of palliative care for patients.

Adopt and adapt provincial frameworks and standards for palliative care of people with CKD.

Identify and optimize the care pathway for patients navigating the transplant process, including pre- and post-transplant, in collaboration with Trillium Gift of Life Network.

Ensure the necessary infrastructure is in place across the provincial network for kidney care programs to support pre- and post-transplant care in collaboration with Trillium Gift of Life Network.

By 2019...

Hospitals and primary care providers will have the tools they need to reduce the incidence of avoidable harm, including acute kidney injury, in people with, or at risk of, CKD.

Primary care providers will have timely access to the tools and support they require to identify and manage care for people with early CKD.

Patients transitioning from primary care to nephrology will have timely access to appropriate pre-dialysis care.

Patients will receive person-centred and well-coordinated palliative care.

Patients will experience an easy-to-navigate pre- and post-transplant care journey.

Goal

Improve patients' access to kidney care

Not everyone in Ontario is able to receive their choice of kidney care, in their desired location. Barriers to accessing care may include geographic isolation, financial limitations, lack of awareness of treatment options, comorbidities, socio-demographic factors, wait times for vascular and peritoneal access surgery, or limited care support in the community. First Nations, Inuit and Métis populations may face these and other unique challenges to accessing care. Many of these barriers can be reduced when care is offered and supported in the patient's home (including long-term care facilities) or community.

In 2013, ORN launched a tracker tool that helps identify and quantify specific barriers to home dialysis within each region and across Ontario. With accurate data, we will be able to develop tailored approaches to enable home dialysis as a viable choice for more patients.

ORN also expanded the CKD Patient-Based Funding Framework to include dialysis support to patients in their place of residence (home or long-term care home). We now have management agreements with all Community Care Access Centres (CCACs) across the province and 27 long-term care homes, which are providing patients with the option to dialyze in their residence. At the same time, the participating CCACs and long-term care homes are submitting data to ORN that will help inform the development of a revised funding model for assisted home dialysis.

Over the course of this Ontario Renal Plan, we will continue to identify and reduce barriers to care. With a person-centred, community-first approach, more patients across the province will be able to access their choice of kidney care services as close to home as possible.

Strategic objectives

Identify barriers to accessing kidney care and develop person-centred solutions.

Establish a community-first approach to kidney care.

Ensure infrastructure and services are in place to enable home dialysis.

Initiatives

Adapt tools and approaches to improve access to kidney care for First Nations, Inuit and Métis, and rural and remote communities.

Develop and implement a flexible policy framework for a community-first approach to kidney care.

Enhance system capacity for optimal and timely vascular and peritoneal access.

Implement models for the delivery of safe, high-quality and accessible care to people with acute kidney injury, CKD and end-stage kidney disease; this includes people requiring specialized care such as those with complex glomerular disease and those with kidney disease during pregnancy.



Becky S.

“I liked the social aspect and nursing support that came with having dialysis in the hospital, but I knew there had to be a better way for me. When my nurse talked to me about my lifestyle and what was important to me, she suggested home hemodialysis. I like taking control of my life again, and I love that I can have three days in a row off dialysis.”

Becky S’ kidneys failed in 2010 as a result of polycystic kidney disease. In addition to travelling with her husband and two adult sons—including a four-day trip to Oregon and sailing around Lake Ontario—she gardens, knits baby blankets for charity, and writes about her CKD experiences.

access

By 2019...

People living in rural and remote Ontario will have improved access to care solutions that allow them to remain in their communities.

Culturally and geographically appropriate kidney care will be available to First Nations, Inuit and Métis people.

Clinical, economic and cultural barriers to kidney care at home and in long-term care will be addressed.

A community-first approach to kidney care will be adopted in Ontario.

Patients will have timely access to vascular and peritoneal access services.

Models of care for the delivery of safe, high-quality, timely and accessible kidney care will be implemented, monitored and evaluated.



Enablers of success

Creating an environment for change

If the Ontario Renal Plan II (ORP II) is the road map guiding the way we develop and deliver kidney care services over the next four years, enablers are the vehicles that will help get us to our destination. Enablers are the capabilities, conditions, concepts and people that we rely on to successfully implement the initiatives that will help make Ontario's kidney care system the best in the world.

Planning

We will conduct provincial planning for the kidney care system to ensure the availability of timely, high-quality, high-value services that offer the greatest benefit to patients and the system at every stage of the care journey. To achieve this, we will continue to collaborate with key stakeholders and base our planning on data and evidence. We will expand our planning expertise and strengthen our planning tools by building and applying effective planning models.

For example, we will continue to refine and strengthen the Provincial Dialysis Capacity Assessment Model, which enables us to ensure that the Ontario kidney care system has the infrastructure required to meet the province's growing demands for kidney care.

Information management and information technology (IM/IT)

We will implement systems, processes and tools to capture, organize and retrieve reliable, high-quality data; we will analyze data and provide sophisticated interpretation of analytic results. This work will support continuous quality improvement across the care journey, inform clinical decision-making and drive the adoption of person-centred care. Using innovative approaches, we will identify new data requirements and sources, facilitate data acquisition, and conduct data analysis and complex modelling. This work will align with CCO's IM/IT Strategic Plan, which will be implemented concurrently with ORP II.

We will continue to build on the success of the Ontario Renal Reporting System (ORRS), a world-class database of all pre-dialysis, acute dialysis and chronic dialysis patients in Ontario. ORRS enables us to drive improvements in the quality, performance, planning and value for money of the kidney care system, in alignment with the goals of ORP II.

Partnerships and engagement

We will continue to foster strong partnerships with our many provincial and regional stakeholders, while building new connections. In particular, we will increase our engagement with patients and families by creating formal opportunities for partnership to deliver on this strategy. We will build new partnerships with organizations that provide care in the

community, and strengthen our collaboration with key provincial agencies to enhance patient engagement and kidney transplant care. We will seek opportunities to combine our competencies and assets with those of our partners, in order to achieve common goals and priorities.

Provincial Medical Leaders work across Ontario to direct provincial groups focused on the strategic goals and objectives, and program and physician leaders work collaboratively to champion the implementation of ORP II's strategic initiatives. These leaders are integral members of the Ontario Renal Network, and we will continue to engage with them and support their on-the-ground work to achieve positive change for patients in the kidney care system.

Evidence and knowledge generation

We will conduct and enable research, surveillance and evidence-based reviews to better understand and close critical knowledge gaps. We will translate knowledge and evidence into planning, policy and program design to shape action across the kidney care journey.

Value assessment

We will improve the use of resources by advancing our ability to assess the impact of initiatives on patient outcomes and patient experience against the required investment.

Quality and performance improvement

We will continue to enhance our accountability model (which includes funding levers, clinical leadership, standards and guidelines), which enables patients to receive care in the most appropriate setting for the best outcomes and the best value for the system.

The CKD Patient-Based Funding Framework allocates funding based on the types and volumes of patients treated, allowing funding to follow the patient. As a leader in the area of patient-based funding, we will continue to refine and adapt the Funding Framework to encourage and support the initiatives of this plan. We will also develop and implement accountability models that will drive the adoption of person-centred care, support integrated care across multiple settings beyond hospitals, and better embed value assessment into our work.

Knowledge transfer and exchange

We will work collaboratively with all our partners to enable the appropriate use of our quality and performance improvement approaches, and to enable action on policy, planning and program design. We will deliver the right knowledge to the right people at the right time by using multiple formats and mediums to communicate in ways that are creative, timely, audience-specific and dynamic.



innovating

Looking ahead

Stories from the field

Over the next four years, Regional Renal Programs across Ontario will work together to improve the lives of people with chronic kidney disease (CKD) by implementing the initiatives of the Ontario Renal Plan II (ORP II). And several programs are already ahead of the curve. The examples here show how initiatives that are aligned with ORP II's three goals can be implemented at the regional and local levels to improve patient care.

Sharing the lived experience

LHSC's website focuses on patient support

A quick Internet search for information about CKD or dialysis will turn up a wealth of resources, but virtually all of this information is presented by clinicians. The Renal Patient Website of the London Health Sciences Centre (LHSC.on.ca/renal) is markedly different, with engaging and informative content presented by patients, for patients.

To ensure the website content met patients' actual (not just perceived) needs, LHSC's website committee, led by program social worker Susan Scott and nurse case manager Sandra Bartlett, consulted a focus group of 12 patients from all areas of the CKD program (pre-dialysis, hemodialysis and peritoneal dialysis). "Patients told us loud and clear that the



Some of the team behind LHSC's Renal Patient Website: (left to right) South West Regional Director Janice McCallum, nurse case manager Sandra Bartlett and manager Don Bester.

most valuable information our website could offer would be presented by other patients about their journey living with CKD," says Don Bester, Manager of LHSC's Renal Program. "The most profound message we heard was how isolated many dialysis patients feel," he adds.

While peer support can help patients feel less alone, not everyone wants to or can share with other patients in person or on the phone. The solution: videotaped messages of patients talking about their experiences. The easy-to-navigate website is organized so that visitors can watch short clips on

topics such as adjusting to kidney disease or supporting a loved one, or longer videos in which patients detail their kidney care journeys. The videos and the website's written content—all of which was carefully vetted by LHSC's clinical experts—also offer patients and their families the opportunity to learn about CKD at their own pace.

Word has spread about the success of the website, and several other Regional Renal Programs across the province have reached out to LHSC for tips on developing their own patient websites.

“The biggest piece of advice I can offer is to not underestimate the amount of time and work required,” says Bester, adding that the website development took a full year and a huge commitment from both staff and management. That commitment reflects “a culture change here at LHSC and across healthcare,” he says. “We’re shifting from doing things to and for patients to doing things with patients.”

Palliative care: starting the conversation

Halton, Trillium and Kingston bring palliative care to the forefront

Talking about palliative care is often difficult for care providers, but evidence shows that early identification of patients who may benefit from palliative care is associated with a higher quality of life and improved overall well-being. At least three CKD programs in Ontario are collaborating with regional partners to develop initiatives in alignment with Ontario’s recently established *Declaration of Partnership and Commitment to Action* to improve the way palliative care services are integrated throughout their patients’ care journeys.

Halton Healthcare Services (HHS) and Trillium Health Partners (THP), in collaboration with the Ontario Renal Network (ORN), are developing an integrated renal palliative care strategy that will ensure CKD patients have access to consistent best practice renal palliative care services regardless of where the service is provided. The strategy will improve the referral processes to palliative care for patients with end-stage kidney disease, expand palliative care education for CKD healthcare professionals, and strengthen partnerships with hospices and other community palliative care supports.



HHS and THP are opening a dialogue about palliative care: (left to right) Yolanda Richardson, Professional Practice Clinician, Palliative Care; Dr. Daniel Sapir, Physician Lead, Renal Program; Heather Chrystie, Nurse Practitioner, Renal Program; Bill Campbell, Director, Renal Program, and Regional Director, ORN.

Similarly, Kingston General Hospital (KGH) has developed a three-year implementation strategy that will ensure all patients with a life-threatening illness and their families and caregivers have access to high-quality palliative care services. For CKD patients and their families, that will require honest, transparent conversations about all aspects of care, including palliative, with staff who have the skills to support them in their choices as they transition through their care journey.

Perhaps one of the greatest benefits offered by the creation of a focused strategy on renal palliative care is that it encourages staff to discuss palliative care issues and to recognize that offering these services is just as much a part of treating CKD as dialysis or transplant. “If we are going to relieve suffering and improve the quality of our patients’ living and dying, then we need to start counselling about palliative care issues very early in the disease pathway,” says Richard Jewitt, Program Operational Director of Medicine with KGH and Regional Director with ORN.



Many people at KGH provided advice on the hospital's new palliative care strategy. Pictured here (left to right): Wilma Cohrs, Program Manager, Renal Services; Brenda Carter, Vice-President Cancer Services and Diagnostic Imaging; Julia Niblett, Director, Regional Cancer Program; Tyler Hands, Program Manager, Inpatient Cancer and Stem Cell Services; Richard Jewitt, Program Operational Director, Medicine, and Regional Director, ORN.

Keeping care close to home

Thunder Bay offers creative options for remote patients

Northern Ontario has some of the most beautiful landscapes in the country. But this same geography can make accessing healthcare services a challenge for many residents, particularly those living in remote First Nations communities. "Our team had to

develop some creative solutions to help patients in our region access kidney care services," says Debbie Gallant, Independent Dialysis Coordinator with the Peritoneal Dialysis (PD) Unit of the Thunder Bay Regional Health Sciences Centre.

Home dialysis is the best option for many CKD patients who live too far away to feasibly access in-facility dialysis services (some people live in communities that are only accessible by air or over

800 kilometres of rough roads). Successful home dialysis for patients living in the remote reaches of the North requires a lot of care planning, especially when there are unique considerations for First Nations communities. For example, Gallant works with Aboriginal band leaders to ensure that patients have housing with adequate heat and water to perform dialysis. The team also works with community liaisons and social workers to help break down cultural barriers and build trusting relationships. To overcome language challenges, the team has developed picture-based order forms for their PD supplies.

The team, which includes four nephrologists, also provides training, support and telemedicine assistance to community-based primary care nurses and physicians so that they can better assist patients in these remote areas. In another creative outreach initiative, Sue Buob-Corbett, a registered nurse with the PD unit, records television and radio segments about kidney health, which are translated into Oji-Cree and broadcast throughout the region.

Thanks to these initiatives and the coordinated efforts of family, friends, care providers in the community and the team in Thunder Bay, many patients in the region are able to successfully continue with PD and stay in their own homes. "The key is good communications with everyone involved," says Buob-Corbett. "It is an honour to know that our team is part of that circle of care."



A call to action

Together we will transform
the way people receive
kidney care in Ontario

The Ontario Renal Plan II (ORP II) is not a shiny brochure to gather dust on a shelf. It is a living strategic document that will guide the work of delivering kidney care in Ontario. It is a road map that we will reference routinely and repeatedly as we continue to make strides in improving patient care at every stage of the kidney care journey.

This plan clearly defines our goals for the next four years: to empower and support patients and family members to be active in their care; to integrate patient care throughout the kidney care journey; and to improve patients' access to kidney care. Successfully fulfilling these goals will require the ongoing active involvement and the collaborative efforts of every person involved in the kidney care system in Ontario. From bedside to boardroom, from local kidney care units and Regional Renal Programs to our provincial offices and the Ministry of Health and Long-Term Care, we must all work together to bring the initiatives of this plan to life.

Teamwork has been critical throughout the development of ORP II. We wish to express our appreciation to everyone who shared their experiences, expertise and insights to help create this plan, including:

- ORP II Patient Advisory Committee;
- Ontario Renal Network (ORN) provincial and regional leadership;
- Regional Renal Steering Committees, including clinicians, administrators, community partners and patients;
- ORN Executive Committee;
- Ontario Renal Council;
- CCO Executive Team; Strategic Planning, Performance and Risk Management Committee; and CCO Board;
- Partner agencies and associations;
- Ministry of Health and Long-Term Care; and
- ORP II planning teams, and ORN and CCO staff.

Most especially, we would like to acknowledge all Ontarians living with kidney disease, their families and caregivers, and to thank those who lent their voices and faces to this document. You are at the centre of everything we do at ORN. With this plan, we reaffirm our commitment to designing a kidney care system that continually improves to address your needs.



Marci O.

“If you haven’t lived with CKD, you have no idea what it is really like to face this disease. That’s why it is so important to include patients and their families in planning kidney care services. This Ontario Renal Plan, which our Patient Advisory Committee helped shape, will improve the lives of future patients.”

Marci O. has a trip to Estonia on the top of her To Do list as soon as she receives a kidney transplant to replace a recently failed kidney from a 1990 transplant. On leave from her job as a pharmacy assistant, she accepts her health challenges as “the hand I’ve been dealt. I just focus on staying informed, staying positive and living my life as normally as possible.”



Ontario Renal Network

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