CCO Our future health built with care

Advancing Person-Centred Care in Ontario

A YEAR IN REVIEW 2016/17

Ontario
Cancer Care Ontario

Cover photo: Camille and Carl

contents

Michelle M: Remembrance with a purpose

Michelle M. has experienced every parent's worst nightmare: the loss of a child. Despite her grief, she sprang into action to improve the lives of other children with kidney disease and their families.

David was a kind, intelligent, gentle and very brave young man, who—despite living his entire 18 years with a serious illness—was filled with compassion, love and humour. "I know David would want to make sure that his ideals will continue," says Michelle.

To that end, Michelle and her husband established The David Gregory MacKinnon Memorial Foundation, dedicated to preserving their son's memory and supporting families affected by kidney disease. With money raised through events such as an annual golf tournament and a 10K race, the Foundation provides aid to help transport patients to and from dialysis, scholarships to enable higher education for students with kidney disease, and funds to acquire essential medical support and equipment. "I am very interested in doing whatever is possible to make sure patients and their families don't have to deal with added stress on top of having kidney disease," she says.

Michelle has also become a kidney care representative with Niagara Health Systems' quality control council and a member of the Ontario Renal Network's Patient and Family Advisor community. Both experiences have been "amazing," she says. "It is quite beautiful to be with like-minded people who are all working towards the same goal."

She is especially excited about her latest role as the lead of the newly launched Transplant Ambassador Program (TAP) with St. Joseph's Healthcare in Hamilton. As an ambassador, Michelle shares her personal story of living donation (four years after David died, she donated a kidney to an unrelated two-year-old boy). The goal of TAP is to improve the rate of living donations by sharing experiences and answering questions that potential donors and recipients might have. "A lot of people might be interested [in a living donation], but they may be afraid. They can ask me anything, even really personal questions," she explains. Already, Michelle has guided four people through the donation process.

To Michelle, TAP is a great example of person-centred care in action. "Doctors and nurses are experts in what they do, but patients and families are the experts in what it is like to live with kidney disease," she says. "We have a voice and it should be heard."

Photo: Bryn Gladding http://portfolio.bryngladdingphotography.com/

A Message from the President and CEO

As the Ontario government's principal advisor on cancer and chronic kidney disease (CKD) care as well as access to care for key health services, CCO partners with many stakeholders as we work to improve the performance of our health systems. Key among these partners are patients and their families. We recognize that people who have experienced a serious illness such as cancer or CKD have different perspectives of the health system than healthcare providers or administrators. It is critical that they have a voice in the design, delivery and evaluation of the care they receive.

Ever since CCO undertook the development of our first cancer system plan in 2005, our goal has been to improve the quality of care for current and future patients. Over the years, we have steadily strengthened our culture of person-centred care and increasingly engaged patients and families in our health system improvement initiatives. Their insights are driving change in many aspects of screening, treatment, survivorship and palliative care for both cancer and CKD.

CCO's commitment to person-centred care is embedded in our corporate strategy and aligns with the Ministry of Health and Long-Term Care's Patients First: Action Plan for Health Care, which focuses on the needs of patients and improving their healthcare experience. Patients are also at the heart of both our health system plans, the Ontario Cancer Plan IV and the Ontario Renal Plan II, both which benefitted in their development from partnership with patient advisors. The cancer plan includes a goal to optimize the quality of life and patient experience in the cancer system; the renal plan includes a goal to empower patients and families to be active in their own care.

This Year in Review highlights the progress we have made with our partners in implementing person-centred care initiatives stemming from these system plans.

A person-centred approach to the planning, delivery and evaluation of healthcare requires strong, sustainable partnerships among patients, family members, healthcare professionals and administrators. I want to thank our many partners – especially our terrific PFAs – for their contributions over the past year, which are helping us achieve our vision of working together to create the best health systems in the world.

Michael Sherar

Michael Sherar
President and CEO

setting the stage

Working Together to Advance Person-Centred Care (PCC)

> “The principles of person-centred care evolved from CCO’s Clinical Programs and Quality Initiatives portfolio, establishing the framework for how we plan, design and implement programs and tools to best support patients, their families and healthcare providers in Ontario’s cancer care system.”
>
> **Robin McLeod,** Vice-President, Clinical Programs and Quality Initiatives, Cancer Care Ontario

CCO is the Ontario government’s principal advisor on the cancer and kidney care systems, as well as on access to care for key health services. Our mission is to work together with our many partners to improve the performance of our health systems by driving quality, accountability, innovation and value. CCO is governed by the Cancer Act and is accountable to the Ministry of Health and Long-Term Care.

Encompassing Cancer Care Ontario and the Ontario Renal Network, CCO drives continuous improvement in disease prevention and screening, the delivery of care and the patient experience for chronic diseases. We provide tools, resources and evidence-based information to help our healthcare partners improve the delivery of care.

The people of Ontario are at the core of everything we do and every decision we make. Person-centred care (PCC) is a key driver of CCO’s work, including prevention and screening efforts tailored to meet the unique needs of Ontario’s population, and the development of system-level programs and guidelines that enable more person-centred treatment and care for patients, persons living with chronic disease, and their families.

This report highlights the planning, progress and achievements of CCO and our regional partners as we collaborate to advance PCC province-wide. Through patient and family engagement, as well as measuring and improving the patient experience, we are continually working to improve the healthcare system for all Ontarians.

Our Organizational Structure

CCO is the provincial agency responsible for continually improving cancer and kidney care systems through Cancer Care Ontario and the Ontario Renal Network.

Cancer Care Ontario is the government’s principal cancer advisor, providing the most up-to-date cancer knowledge and tools to prevent cancer and deliver high-quality care.

The Ontario Renal Network provides overall leadership, strategic direction and funding to effectively organize and manage the delivery of kidney care services in Ontario in a consistent and coordinated manner.

our advisors

Working Together: Engaging Patient, Family and Public Advisors

The involvement of Ontarians in the design, delivery and evaluation of the care they receive is a key objective throughout CCO. Our advisor community is made up of individuals from across the province who represent a range of backgrounds and experiences with the healthcare system—some as patients receiving treatment, others as caregivers to patients and some as members of the public. At CCO, advisors are embedded across all areas of the organization to ensure that the voice of Ontarians is always represented in decisions that shape the care they receive.

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Cancer Care Ontario's PFA community

Comprised of more than 100 patients, family members and caregivers from across Ontario's 14 Local Health Integration Networks (LHIN), Cancer Care Ontario's Patient and Family Advisors (PFAs) are involved with programs at all levels of the organization, including but not limited to Psychosocial Oncology, Systemic Treatment, Symptom Management, Radiation, Research, and Medical Imaging.

Cancer Care Ontario's PFAC

The Cancer Care Ontario Patient and Family Advisory Council (PFAC) is comprised of CCO PFA members who also serve as representatives from each of the 14 regions. Active since 2011, PFAC plays a key role in informing CCO's strategic priorities, developing the Ontario Cancer Plan and providing linkages to regional PFACs.

Key PFAC activities

Regional Linkages

The PFAC discusses ongoing regional work and opportunities for linkage with either CCO work, or work amongst individual PFACs.

Thought Leadership

A collaborative group of regional cancer centre PFAC co-chairs and administrators has been created to share work being done in all areas of the province to allow for shared learning.

Engagement

The model by which PFAs are engaged in program work at CCO has been re-evaluated to address gaps and highlight opportunities for improvement. As a result, with the help of the PFAC and members of the PFA community, a number of changes were implemented including more staff education and increased support for PFAs during and after the process. The PFAC will continue to advise on CCO engagement practices in order to improve the overall experience of PFAs engaged in program work and share best practices with other healthcare organizations.

Strategic Direction

The PFAC is involved in helping CCO make strategic decisions that are in line with the values and needs of patients, families and caregivers. PFAC co-chairs attend Clinical Council meetings to provide monthly updates on the PFAC's work and engagements in the organization. In addition, members of the PFAC and PFA community participate at corporate events, such as CCO Research Day, Spring Planning Day and the Cancer System Quality Index. PFAC plays a key role in developing and reviewing the Ontario Cancer Plan (OCP), and as such will be involved in the development of the OCP V.

Ontario Renal Network's PFA community

The Ontario Renal Network PFA community includes almost 30 people with lived experience with kidney disease. The PFA community ensures that the voice of those living with chronic kidney disease and the voice of their families are represented when shaping policies and initiatives that directly affect how kidney care is provided.

The Ontario Renal Network's PFAC

The purpose of the Patient and Family Advisory Council (PFAC) is to provide a forum for patients, family members and caregivers to advise on the design, planning, implementation and evaluation of Ontario Renal Network (ORN) initiatives outlined in the current Ontario Renal Plan (ORP). Introduced in October 2016, the PFAC advises on the development of initiatives to improve the patient and family experience of living with kidney disease in Ontario.

Key PFAC activities

Membership

The number of advisors in the Ontario Renal Network's PFA community has almost doubled, from 15 to 28. In December 2016, five new PFAs joined the PFAC, bringing the total number to 14.

Engagement

In 2016/17, 24 PFAs were engaged in 62 Ontario Renal Network initiatives.

PFA and PFAC Contributions

- PFAs continue to provide ongoing contributions to work related to palliative care, symptom management and on ORN Priority Panels.
- The PFAC contributed to several renal initiatives, including patient-borne costs, patient-reported experience measures, the renaming of Multi-Care Kidney Clinics (formerly referred to as pre-dialysis clinics), the development of five Patient and Family Experience videos and the Save My Vein Campaign.
- At the program level, 18 of 26 Regional Renal Programs in Ontario had renal-specific PFACs ranging in size from five to 20 members. Some programs also had treatment-specific councils for areas such as transplant, in-centre dialysis and home dialysis.

Leadership

The PFAC Chair and Vice-Chair have joined the Ontario Renal Network Executive Committee and the Provincial Leadership Table to ensure the voice of persons living with kidney disease is heard at the leadership level of the organization and to create a formal link between the PFAC and ORN leadership.

Strategic Direction

The PFAC broadened the scope of its terms of reference to encompass all three strategic goals of the Ontario Renal Plan (ORP II):

- empowering patients and families;
- integrating and coordinating care; and
- improving access to care.

> “By shining a light on quality in these areas, we can understand what is being done well and where there are opportunities for improvement. This work is vitally important. It helps ensure that, as users of these services, we will receive the same high-quality care wherever we access it in Ontario, whether at a small-town clinic or at a large, urban hospital.”

Judith John, Chair, Citizens’ Advisory Committee, Quality Management Partnership

> “CCO’s Prevention and Cancer Control portfolio is focused on planning, implementing, monitoring and evaluating the programs and initiatives aimed at improving cancer screening and detection. Our goals include increasing prevention efforts, reducing the number of Ontarians being diagnosed with cancer, and increasing screening rates in under- or never-screened areas to improve the overall health of Ontarians.”

Linda Rabeneck, Vice-President, Prevention and Cancer Control, Cancer Care Ontario

> “Being a public advisor has been an amazing opportunity for me to participate in positive change. CCO truly values our experiences and opinions, and what we can contribute to the patient and family experience.” **Susanne Ross,** High Risk Lung Cancer Public Advisor

Prevention and Cancer Control public advisors

High Risk Lung Cancer Screening Pilot for People at High Risk

In the summer of 2016, six public advisors (PAs) were recruited to participate in work for a Lung Cancer Screening Pilot designed for people at high risk of lung cancer. In August, they participated in an orientation session.

Five of the PAs participated in a day-long expert panel meeting held in October 2016.

Between September 2016 and March 2017, the PAs provided input and feedback on various processes and products for the public, including core messaging, the recruitment plan, the participant experience survey, scripts for navigator communications with the public, risk tools, wait times, and the content and concept design for the recruitment brochure and participant information sheet.

Quality Management Partnership

The Quality Management Partnership (the Partnership), which brings together CCO and the College of Physicians and Surgeons of Ontario, works in the public interest to ensure that all Ontarians have access to consistent, high-quality colonoscopy, mammography and pathology services. The Partnership continues to work with its Citizens' Advisory Committee to ensure that input from patients, service users and the public guides our work.

Key Activities

- Over the past year, the Citizens' Advisory Committee provided direction on the Partnership's public reporting strategy and co-developed focus areas for future public reporting efforts.
- Our advisors also participated in prioritizing quality improvement focus areas for colonoscopy facilities and composed an open letter for posting on the Partnership's website to explain why quality reporting is important.
- In the coming years, the Citizens' Advisory Committee will continue to play an important role in co-developing the content and design of publicly reported information.

Ontario Palliative Care Network

In 2016/17, the Ontario Palliative Care Network created a strategy to recruit Patient and Family Advisors to its Partnership Advisory Council (PAC). These advisors attend PAC meetings to provide their perspectives on how to best promote a person- and family-centred approach to palliative care. These insights are valuable in developing the Health Services Delivery Framework, which includes recommendations to the Executive Oversight about the future service delivery model for patients, focusing on the optimal use of clinical settings and healthcare personnel based on evidence and clinical guidance.

cco work

Initiatives in Advancing PCC

By developing a socio-demographic survey for its PFAs, CCO was able to compare the specific characteristics of its community of advisors to the province's diverse population and determine whether the voices of all communities were being heard at provincial tables.

Measuring experience: The patient and family advisory experience survey

At CCO, PFAs participate in a number of ongoing engagements at different levels of the organization. Previously, no formal mechanism was in place to assess and monitor their overall experience with the engagements they were involved in. This assessment and monitoring occurred only on an informal, case by case basis.

To formally assess the ongoing experience of PFAs, improve transparency and highlight potential gaps and opportunities for improvement, a PFA experience survey was developed by a working group comprised of program staff working in collaboration with PFA partners. The survey was first deployed in Q1 of 2016/17, and has been administered every quarter thereafter.

This initiative aimed to create a survey tool to be administered on a quarterly basis to PFAs actively participating in ongoing engagements. The survey has been completed 239 times to evaluate the PFA experience across 63 unique committees and working groups. PFAs were equal members of the working group that developed the survey, with questions designed to reflect the aspects they felt were important in order to successfully engage the public. The PFAC was also consulted as part of the development process once the survey was complete.

This initiative provided us with an opportunity to consult with PFAs and develop a mechanism to assess the level to which their expectations have been met.

Equity in engagement: the socio-demographic survey

At CCO, patient and family engagement is the cornerstone of person-centred care. In order to plan, deliver and evaluate programs and policies that are responsive to the individual needs of all Ontarians, it is crucial that CCO and its partners take into account the diversity of Ontario's population in its patient and family engagement strategy. In 2016/17, CCO sought to self-assess its performance against this objective.

By developing a socio-demographic survey for its PFAs, CCO was able to compare the specific characteristics of its community of advisors to the province's diverse population and determine whether the voices of all communities were being heard at provincial tables.

The results of the survey demonstrated that the engagement methods currently used by CCO are not reaching all Ontarians equitably. This evidence is an important step forward in advancing the equity objectives in the Ontario Cancer Plan IV (OCP IV) and Ontario Renal Plan II (ORP II), and will enable CCO and its partners to create targeted outreach strategies for communities that are presently under- or never-represented. In 2017/18, CCO will be prioritizing these under-represented and never-represented communities in our engagement efforts, working closely with existing organizations with whom these communities are already engaged, and developing and testing customized engagement initiatives. In doing so, CCO will once again take a leadership role in patient engagement, this time by becoming the first provincial organization to re-engineer its approach to reflect the diversity of its population.

> “As a patient advisor on the YSM project, it was my hope that this initiative would promote more involvement by patients in their own care and future treatment. To date, I am satisfied that the framework has been laid out to accomplish these goals and enhance person-centred care in a more structured format.” **Don Snair,** Patient and Family Advisor, Ontario Renal Network

Your Symptoms Matter: A CCO-wide focus

Your Symptoms Matter: Provincial Implementation and YSM-Prostate

At Regional Cancer Programs (RCPs) and partner sites in Ontario, the Edmonton Symptom Assessment Scale (ESAS) provides patients with a platform for discussion of symptom management with their healthcare team. ESAS has advanced PCC tremendously by starting conversations about symptoms and side effects from the patient’s perspective. Although this Patient-Reported Outcome Measure has enabled over 6.5 million screens for over 850,000 Ontarians to date, CCO and the RCPs wondered if a more person-centred approach to symptom screening might be possible.

ESAS is a general questionnaire that focuses on symptoms that are commonly associated with treatment for all cancers. The Expanded Prostate Cancer Index Composite (EPIC), on the other hand, is specifically designed to capture side effects and symptoms in men with early-stage prostate cancer. Between 2014 and 2016, CCO led a multi-site pilot project to determine how EPIC might be rolled out across the province. While the pilot confirmed that patients and healthcare providers were enthusiastic about a symptom management tool tailored to their specific symptoms, it also revealed the need to establish a uniform brand for symptom management tools that would better tie EPIC and ESAS together.

Through consultations with patients and healthcare providers, CCO launched the Your Symptoms Matter brand. Your Symptoms Matter – General (ESAS) is available in 94 hospitals across Ontario. By the summer of 2017, Your Symptoms Matter—Prostate Cancer (EPIC) was available in eight of 14 RCPs, with plans in place to expand province-wide.

Patients visiting cancer centres in Ontario can now select the symptom management tool that is most appropriate for them, based on their disease site and treatment plan. This is the first major milestone in implementing the new Symptom Management Strategic Framework at CCO, which will see a number of symptom management tools specific to disease site rolled out in the cancer care system over the next few years.

Addressing Symptom Burden: The Launch of Your Symptoms Matter for People Living with CKD

People living with CKD who require dialysis experience a high degree of symptom burden. As symptoms are not typically assessed or managed systematically in routine care, there may be gaps in care, particularly with chronic symptoms. There is also a lack of documentation of the symptom burden experienced by people living with CKD who require dialysis.

Your Symptoms Matter (YSM) is a pilot project that aims to improve patient-healthcare provider communication and the patient experience with dialysis care through routine symptom assessment. The project will also increase awareness of the CKD patient symptom burden and enable the Ontario Renal Network to identify and prioritize areas that require greater focus.

The goal of YSM is to improve symptom awareness for people living with CKD and their healthcare team by providing an organized approach to routine symptom screening, assessment and management. It also provides an opportunity for patients and caregivers to engage in meaningful conversations about their symptoms and actively participate in decisions about managing these symptoms.

CCO Cancer Care Ontario

What do I need to know about

Your Symptoms Matter?

- Your Symptoms Matter is the new name for the symptom screening kiosk & tools
- It is a set of questionnaires that lets you tell your health care team about your symptoms and how you are feeling
- Examples of Your Symptoms Matter questionnaires include:
  - Your Symptoms Matter – General Symptoms (previously Edmonton Symptom Assessment Scale - ESAS)
  - Your Symptoms Matter – Daily Activities (previously Patient Reported Functional Status - PRFS)

Why is it important?

Your answers are shared with your health care team and reviewed with you to help make decisions on how to manage your symptoms

Ask a staff member or volunteer to learn more

cancercare.on.ca/YourSymptomsMatter

Need this information in an accessible format?
1-855-460-2647, TTY (416) 217-1815, publicaffairs@cancercare.on.ca CPQ2064

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In 2014, CCO held a Patient and Family Advisory Council (PFAC) Summit, in order to strengthen advisory networks and collaboration among cancer PFAs in the province.

> “CKD patients often face high symptom burden. Improving symptom assessment and management may significantly improve communication between providers and patients, having a positive impact on the patient experience and quality of life.”

Dr. Michael Walsh, Provincial Medical Lead, Person-Centred Care

In April 2017, nine pilot sites began routinely assessing patients undergoing in-facility hemodialysis with the Edmonton Symptom Assessment System Revised—Renal (ESAS-r: Renal), a self-reported symptom questionnaire. Patients and healthcare providers were educated about the YSM project and the use of the screening tool prior to implementation, ensuring there was a common understanding of roles, responsibilities and expected outcomes.

YSM uses a co-design model that engages a provincial task group made up of patients, healthcare providers and administrators for project planning, development and implementation. In addition, PFAs were directly involved in the development and review of all patient-facing resources created for the pilot project, including a brochure, instruction sheet and poster. The ESAS-r: Renal questionnaire and instruction sheet were also translated into 14 languages for patients.

Strengthening Partnerships: Learning from the 2014 Person-Centred Care Summit

In 2014, CCO held a Patient and Family Advisory Council (PFAC) Summit, in order to strengthen advisory networks and collaboration among cancer PFAs in the province. Based on the Summit findings, it was determined that a formal committee of staff leaders should be established to oversee patient and family engagement in the Regional Cancer Programs and the advancement of Ontario’s PCC agenda.

The Provincial PCC Committee for cancer was thus created, with each region represented by one PCC Lead from their respective Regional Cancer Program. Following the successful completion of the first set of PCC priorities, the Committee determined that a system-level consultation was required in order to establish and confirm new priorities for PCC in both the cancer and kidney care systems. Between January and August of 2016, CCO planned a multidisciplinary summit with the main objective of critically discussing issues and opportunities for advancing PCC across both care systems.

The event was planned in collaboration with Patient and Family Advisors sitting on the formal planning committee, and the agenda developed and approved in partnership with the provincial and regional PFACs in the cancer and kidney care systems. Held in September 2016 at MaRS in Toronto, the PCC Summit brought together healthcare providers, planners and policy-makers with patients and their families for a one-day working session to establish the top system-level priorities for PCC in 2017 and 2018.

In total, 404 people attended the PCC Summit (both online and in person), with representatives from cancer and renal programs, system- and policy-level attendees and healthcare providers.

Throughout 2017, Cancer Care Ontario has been partnering with the Provincial PCC Committee to design and deploy a series of initiatives aligned with the two key priorities that emerged from the PCC Summit:

1. to enhance equity in the cancer and kidney care systems by increasing the voice of patients and families from under- and never-represented communities at provincial tables; and
2. to focus on implementing PCC in clinical care by improving patient-physician communication.

cancer care ontario

Initiatives in Advancing PCC

> “The information we collect will have a direct impact on not only the delivery of cancer care in Ontario, but also the processes involved within the cancer care system as a whole to continue to improve the lives of Ontarians.”

Dr. Simron Singh, Clinical Lead, Person-Centred Care

Assessing Person-Centred Care in regional cancer programs

The Person-Centred Care (PCC) Guideline provides recommendations for healthcare providers to implement PCC in the delivery of adult oncology services. However, it is unknown whether healthcare providers have incorporated these recommendations into their daily practice within the Regional Cancer Programs (RCPs).

Cancer Care Ontario developed a 44-question assessment tool, encompassing nine categories—organizational direction, leadership, symbolic action, access to information, communication, patient and family engagement, organizational capacity, training and education, and quality improvement—in order to understand and assess the organizational enablers and barriers to advancing PCC in Ontario RCPs.

CCO PFAs were engaged during the development of the PCC assessment tool. They provided feedback to help evaluate relevant organizational concepts to ensure the delivery of PCC in the RCPs.

In October 2016, the PCC assessment tool was sent to the 14 regional PCC Leads, who are responsible for implementing provincial strategic objectives related to PCC at the regional level.

All 14 of the PCC Leads completed the PCC assessment for their respective RCP, for a response rate of 100%. Preliminary results identified three main recommendations for improvement:

1. provide additional PCC education and training for RCP physicians and staff;

2. develop and implement standardized tools to encourage and facilitate communication between healthcare providers and patients and their families; and

3. use patient experience data to drive quality improvement initiatives within the RCPs.

The results of this regional PCC assessment provide an understanding of the current state of PCC Guideline implementation in Ontario. The results will help to identify enablers and barriers and ensure that local and system-level planning and quality improvement in the cancer care system are rooted in activities that will help to advance a culture of PCC.

> “The services that fall under PSO are very important to a cancer patient during the diagnostic, treatment and survivorship phases. These services assist in coping with the side effects and the complications that we are often left with—our new normal. They are vital to us as we deal with our symptoms and our survival.” **Joanne M.,** PFA

The PSO committee: Integrating patient engagement

This initiative seeks to give Patient and Family Advisors (PFAs) an opportunity to share their input with the Psychosocial Oncology (PSO) Program about what is important to them regarding the access and quality of services provided through various models of PSO care. Patients may experience difficulty accessing such services, or are not aware of services and resources available to them.

PFAs have historically been engaged with the Psychosocial Oncology (PSO) program, but usually in larger forums that include clinicians and administrators. Forming a dedicated PSO PFA Committee allows PFAs to openly share their values and concerns among themselves, as well as directly with CCO staff. This initiative aimed to provide a more comfortable environment for PFAs to offer feedback and strengthen collaboration with the PSO program.

A cohesive and committed PSO PFA group is developing and becoming more comfortable in lending their voices when needed. The PFAs have reviewed, edited and provided testimonials for the PSO Cancer System Quality Index (CSQI) website page, as well as for our document highlighting PSO service delivery in the province.

Five PFAs sit on the PSO committee, and there is the possibility of adding more PFAs in the future to ensure the objectives of the PSO PFA Committee will continue to be advanced.

Your Voice Matters: Taking the tool province-wide

Understanding the patient experience is a key step in moving towards a person-centred healthcare system. In Ontario, patient experience has historically been captured through retrospective surveys that ask patients and their families to think back on their experience, or through individual surveys that vary from clinic to clinic.

In order to better understand the patient experience, CCO has launched an electronic tool that captures patient-reported experience measures through Your Voice Matters (YVM), a set of questions designed to measure patient experience as close to real time as possible.

YVM provides patients with the opportunity to confidentially share feedback on their most recent visit to the clinic. Aggregate data is made available to hospitals through access to a real-time dashboard, which allows administrators and health care teams across the RCPs to see experience data as a whole and plan relevant quality improvement initiatives. This feedback is also reviewed by CCO to identify areas for improvement that are most important to patients at a provincial level.

Between March 2016 and March 2017, 13 Regional Cancer Programs began offering YVM to patients, with approximately 18,000 survey responses received by March 31, 2017.

A significant benefit to the collection of YVM data is the ability to link patient experience data to other sets of data, such as patient reported outcome measures and demographic data.

YVM has been instrumental in understanding the needs, wants and preferences of patients in Ontario. Over the next year, we will do a deeper analysis of the incoming results and work to increase the use of YVM province-wide.

CCO Central Regional Cancer Program
in partnership with Cancer Care Ontario

Rhonel B., Patient Family Advisor and her niece.

Your Voice Matters

We Are Listening

Take 5 minutes to share feedback on your visit and help us improve care!

What do I need to know about Your Voice Matters?

- Your Voice Matters is a set of questions that gives you the chance to share feedback on every step of your visit
- Any adults being treated for cancer in Ontario are invited to complete it
- Caregivers can fill out Your Voice Matters on a patient's behalf
- Your responses will be confidential and won't impact the care you receive

Why is it important?

Your local care team and Cancer Care Ontario need to learn what these experiences are like from your perspective to understand how we can improve the experience for patients and caregivers across Ontario

Ask staff or a volunteer to learn more.

cancercare.on.ca/YourVoiceMatters

Contact:
Roseanne Pegler, Executive Lead
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> "Our Aboriginal Navigator has been incredible. They helped to educate the team, and provided cultural sensitivity training to 85% of our staff; this has gone a long way to ensuring that the cancer centre is a much more welcoming place for our Aboriginal patients and their families." **Lindsey Crawford**, Former Regional Vice-President, Simcoe Muskoka Regional Care Centre

Aboriginal Navigator Program

Navigating the cancer care system is a significant challenge for First Nation, Inuit and Métis (FNIM) patients and their families for the following reasons:

- intergenerational trauma (e.g., residential schools, colonialism, Indian Act, loss of culture);
- lack of understanding/awareness of cancer;
- no family physician;
- access to transportation a problem due to distance or expense;
- poor coordination of care;
- jurisdictional issues (non-insured health benefits);
- adverse social determinants of health;
- stereotypes and prejudice;
- communication barriers and lack of translation services;
- lack of trust in the medical system;
- health professionals not listening to or addressing needs; and
- fear.

Aboriginal Patient Navigators provide support for FNIM patients and their families at each step of the cancer care journey by:

- liaising and advocating for the needs of these patients, their families and other groups involved in their care;
- addressing their cultural and spiritual needs;
- improving access to cancer services for these patients and their families; and
- engaging with the 10 Navigator networks across the province.

Since it began in April 2013, the Aboriginal Navigator Program has provided support to a significant number of FNIM patients and their families at each stage of the cancer care journey, with the number of patients increasing each year.

Key initiatives at the regional level include:

- promoting respect for, understanding of and access to Indigenous spiritual care practices within RCPs (e.g., access to traditional knowledge keepers and/or ceremonies);
- supporting the development of the Mamawi Indigenous Healing Room (South East RCP);
- providing translation services to patients and families in Cree, Ojibway and Oji-Cree (North West RCP);
- expanding the FNIM voluntary self-identification process to include the use of a culturally relevant "Patient Status Icon." As a result, all patients who voluntarily self-identify are immediately recognizable to healthcare providers through electronic medical records, positioning them to provide culturally appropriate, trauma-informed care and address barriers to accessing services (North Simcoe Muskoka RCP); and
- participating in Psychosocial Therapy Peer Supervision to collaborate with psychosocial oncology colleagues with respect to FNIM patients and their families' psychosocial oncology needs (North East RCP).

The Aboriginal Navigator Program has helped advance PCC in the following ways:

- FNIM patients have access to a culturally-appropriate environment and support throughout their cancer care journey;
- patients' specific cultural and spiritual needs can now be met with the support of the program, and referrals made, based on patient needs; and
- CCO's Aboriginal Navigators are the first Aboriginal-specific navigators in the cancer care system worldwide.

As the Aboriginal Navigator Program is designed to support and respond to the specific needs of FNIM patients and their families, the program is entirely patient- and family-centred.

Aboriginal Relationship and Cultural Competency (ARCC) courses

In regional engagement work in collaboration with FNIM communities, the Aboriginal Cancer Control Unit (ACCU) hears stories of inequity in regards to the health care system. Research has shown that people who experience culturally safe health care are more likely to access care earlier, and are more likely to engage in shared decision making. The Aboriginal Relationship and Cultural Competency (ARCC) courses are a step towards resolving this by addressing a need to provide cultural competency training for health care providers.

ARCC courses have been launched alongside the Aboriginal Cancer Strategy III, and allow for health care providers to access cultural competency education at their own pace, outside of clinic hours. These courses are offered free of charge, and are refreshed regularly to incorporate current events for FNIM people. Since 2015, approximately 8,500 registrations have been made with a completion rate of 81%.

Success of the courses has been made evident by ongoing promotion by external organizations, such as the University of Ottawa and McMaster University, which have made the courses mandatory for first year family medicine residents and undergraduate medicine students respectively.

To learn more about ARCC, please visit **https://elearning.cancercare.on.ca/.**

Prevention and Screening: Cancer screening geomatics initiative

In 2017, Cancer Screening's Geomatics team developed an infographic-style report that leveraged health and market intelligence data to analyze the geographic, sociodemographic (e.g. age, education, language), and psychographic (e.g. health behaviour) characteristics of the eligible population living within five, 10 and 15 kilometres of each of the three lung cancer screening pilot sites: the Ottawa Hospital, Lakeridge Health (Oshawa) and Health Sciences North (Sudbury). The unique data methodology developed for this initiative allowed CCO to link local area smoking behaviour data to its health administrative data in order to understand where people who are at high risk for lung cancer are likely found and identifying their proximity to a screening pilot site.

This new information product is designed to support site-level decision-making related to tailored, person-centred recruitment and communication strategies that complement and enhance existing efforts, such as referrals by primary care physicians.

Shawn S.

Spoiler alert!

There's a happy ending

Even cancer, it seems, can have a positive impact for some people.

That's certainly not what Shawn S. thought when he was first diagnosed with follicular B-cell lymphoma (a type of blood cancer) 17 years ago at the age of 25. Life looked pretty bleak for several years as he struggled through treatments (including a total of 19 rounds of chemotherapy), two relapses and terrible lymphedema that caused him to retain more than 75 pounds of fluid. "It was incredibly painful," he remembers. "I had trouble breathing, eating, walking—I couldn't even wear shoes." After months of being unable to work or even reach the second floor of his house because he couldn't manage the stairs, Shawn was referred for a stem cell transplant. Fortunately, his brother was a match. After another difficult year that included the transplant, three months in isolation, and additional treatment for graft-versus-host disease, Shawn was finally cancer-free, at least in body if not in spirit.

"Once I was out of 'survivor mode,' reflection set in," he says. "I started to wonder, 'Why me? Why was I able to overcome the odds?" Recognizing that he needed support to guide him through his "new normal," Shawn sought help from a social worker and a therapist, while also doing a lot of meditation, positive visualization and self-help reading.

With a new view of his life and the world, Shawn started volunteering, offering peer support through the Canadian Cancer Society and Lymphoma Canada. "If I can share my story and offer hope to others, that will give some meaning for this whole experience," he says. He also volunteers as a Patient and Family Advisor with both the Waterloo Wellington Regional Cancer Program and Cancer Care Ontario's Stem Cell Transplant Steering Committee, where, he says, patients' unique perspectives will have an important impact on the way care is delivered.

The fulfillment Shawn discovered as a volunteer eventually led him to reexamine his career. Stuck in a high-stress job he didn't enjoy but hesitant to make a big change, Shawn says he received guidance from the universe when his company downsized. He grabbed the opportunity to become a certified health coach.

That wasn't the only change he made. After his transplant, he took the initiative to lose weight and become more active, starting with riding a stationary bike while he was still in isolation. "Now, I run, bike and play volleyball. I am more fit at 43 than I was at 22!" he says.

The universe had yet another curveball in store for Shawn. Despite being told that he was likely infertile due to all the chemotherapy he'd received, he and his wife had a daughter, Charlotte, four years ago. The flexible hours that he enjoys as a health coach allow him to be very involved with his daughter, and he especially enjoys taking her to preschool each day.

"The window of life can be short," he says, "and my experience reinforces that you have to make the most of it. In a way, I am grateful that my cancer experience led me to that knowledge."

Once I was out of ‘survivor mode,’ reflection set in,” he says. “I started to wonder, ‘Why me? Why was I able to overcome the odds?” Recognizing that he needed support to guide him through his “new normal,” Shawn sought help from a social worker and a therapist, while also doing a lot of meditation, positive visualization and self-help reading.

the ontario renal network

Capturing stories: The patient and family experience video series

Patients and their family members impacted by chronic kidney disease (CKD) find value in connecting directly with others who have been in their position. While healthcare providers can offer important information, patients and their family members want to hear about living with CKD from those who have actually "walked in their shoes." This first-hand experiential knowledge is perceived as highly credible and and cannot be matched by clinical information provided by a doctor or nurse.

In collaboration with the Ontario Renal Network Provincial Patient and Family Advisory Council (PFAC) and Patient and Family Advisors (PFA), the Ontario Renal Network developed a series of videos featuring patients and their family members sharing their perspectives on the experience of living with kidney disease. The videos feature patients and their family members talking about how kidney disease has affected their lives.

In total, five videos were produced in the series:

- Living with Kidney Disease
- Starting Dialysis
- Dialysis Treatments
- Patient to Patient Support
- Living with Kidney Disease: Family Member Perspective

The video series provides an opportunity for patients and their family members to hear about others' journeys with CKD, including information that healthcare providers aren't in a position to share.

The Patient and Family Experience Video Series is posted on the Ontario Renal Network website and CCO's YouTube channel. Since its introduction, each video has attracted hundreds of views.

ORN Palliative Care Report: Recommendations towards an approach for chronic kidney disease

End stage kidney disease requiring dialysis is a complex, life-limiting illness. Dialysis patients face unique challenges, including a high mortality rate, with a 43% five-year survival (Canadian Institute for Health Information, 2009), distressing symptoms, and low use of community palliative care services. An analysis of 5,507 Ontarians receiving dialysis from 2010 to 2012 found that only 9% had one or more community palliative care visits during the last month of their life (Institute for Clinical Evaluative Sciences, 2015).

Patients, families, and corporate leaders, multidisciplinary healthcare providers, and community partners from across the province worked together to develop the Ontario Renal Network Palliative Care Report. Six key recommendations were made to improve and advance high-quality palliative care in Ontario for people living with CKD by providing an integrated and continuous approach to care earlier and across care settings.

This report provides the Ontario Renal Network with a roadmap of how to ensure that by 2019 all patients will receive person-centred, well-coordinated palliative care. PFAs were involved in all steps of the development of the report and directly impacted the recommendations. An additional nine family representatives were interviewed to provide their accounts of their loved ones' palliative care experiences with CKD.

Work is currently underway across the province to implement the recommendations in order to improve patient care.

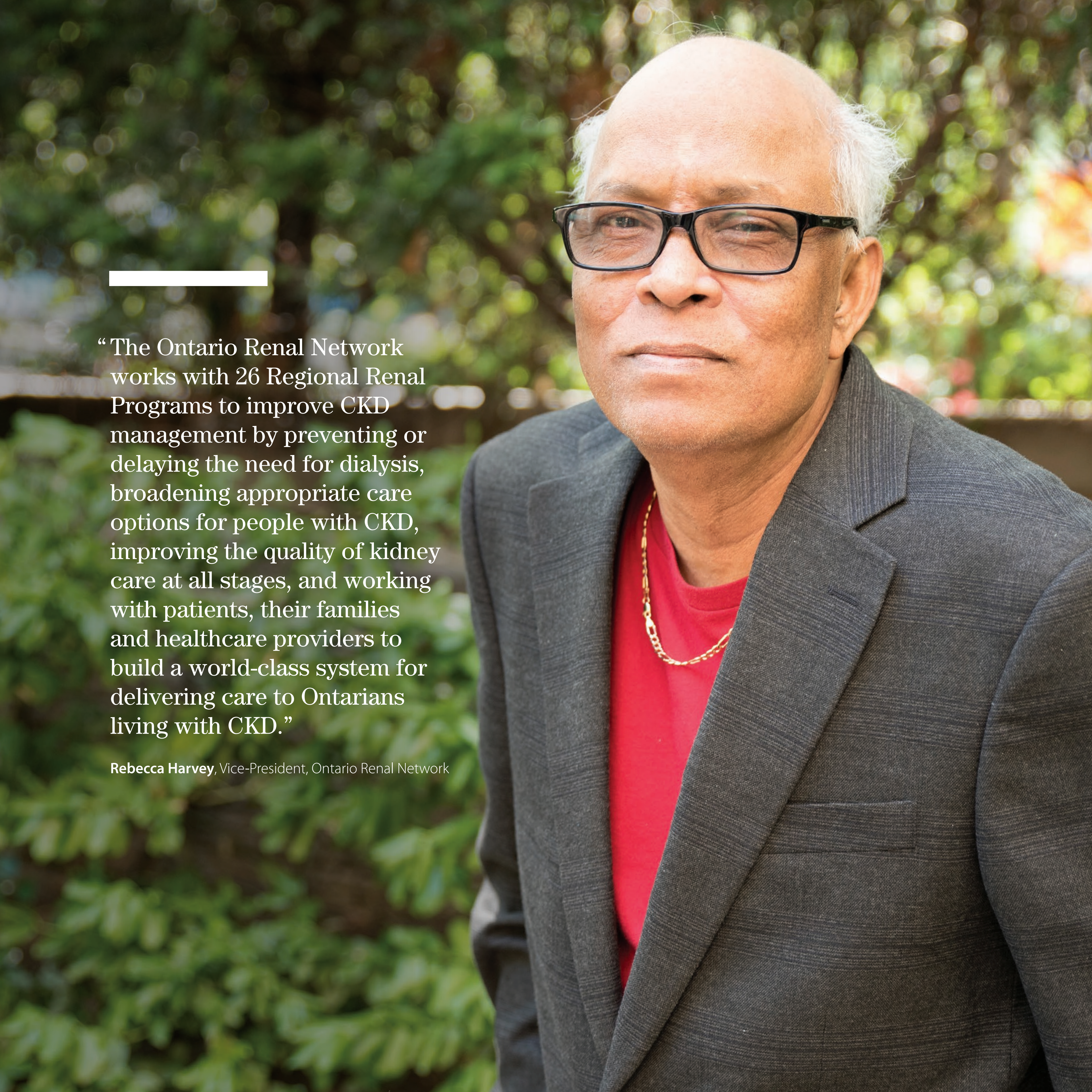
Patient-friendly language: Update to pre-dialysis clinic name

Pre-dialysis clinics are multidisciplinary care clinics that are located within a Regional Renal Program. These clinics support patients in slowing the progression of kidney failure and prepare patients and caregivers for renal replacement therapy. To align with ORP II, and to ensure patients have timely access to appropriate multidisciplinary care, the Ontario Renal Network assembled a task group to review patient eligibility criteria for pre-dialysis clinics using the latest evidence-based clinical best practices.

The task group recommended renaming pre-dialysis clinics to better reflect the population they serve and the fact that patients may pursue treatment options other than dialysis. In March 2016, the Ontario Renal Network PFAC recommended the name "multi-care kidney clinic," which was approved by the Ontario Renal Network Executive Committee in April 2016. The name change will better reflect the various types of patients who attend these clinics.

A communication and implementation plan to adopt the new name was endorsed by the Regional Renal Programs' Regional Directors in October 2016, to be phased in during 2017. Effective April 1, 2017, "multi-care kidney clinics" has replaced the previous name on all Ontario Renal Network materials, tools and products.

The new name is expected to provide a more consistent terminology for patients across Ontario and to better reflect the patients who attend the clinics. By December 31, 2017, all Regional Renal Programs are expected to have transitioned to the new name.



“The Ontario Renal Network works with 26 Regional Renal Programs to improve CKD management by preventing or delaying the need for dialysis, broadening appropriate care options for people with CKD, improving the quality of kidney care at all stages, and working with patients, their families and healthcare providers to build a world-class system for delivering care to Ontarians living with CKD.”

Rebecca Harvey, Vice-President, Ontario Renal Network

> "I started dialysis… it's given me quality of life back. Some days I can even pretend I'm not sick at all. Being on dialysis after a year, I was healthy enough to start trying to have kids. My doctor really instilled a lot of confidence in me in being able to have a baby."

Matti, Patient with kidney disease

Providing medication fact sheets to patients with glomerulonephritis

The Ontario Renal Network conducted 20 interviews with patients living with glomerulonephritis (GN) and their family members. GN refers to a group of rare renal diseases in which the kidney's filtering system (glomeruli) cause protein in the blood to leak into the urine. The interviews revealed that patients and families rarely had access to educational resources outside of their healthcare team, nor were they provided with GN-specific, patient-friendly information to review at home. Several patients were advised not to search for additional information online to avoid misinformation and undue anxiety. Patients who searched online for educational resources sometimes felt that it was either overwhelming or lacking in practical information, and felt it would have been helpful to be directed to credible sources. Overall, patients reported that they would have liked more information, including information about their medication and its side effects. Of the nephrologists surveyed, only 28% felt their renal program had adequate education, counselling and support for patients with GN and their family members.

To address these issues, the Ontario Renal Network leveraged medication fact sheets for patients with GN that were being developed by staff at GN specialty clinics. The hospitals shared the clinical content, which was modified and adopted by the Ontario Renal Network for provincial use.

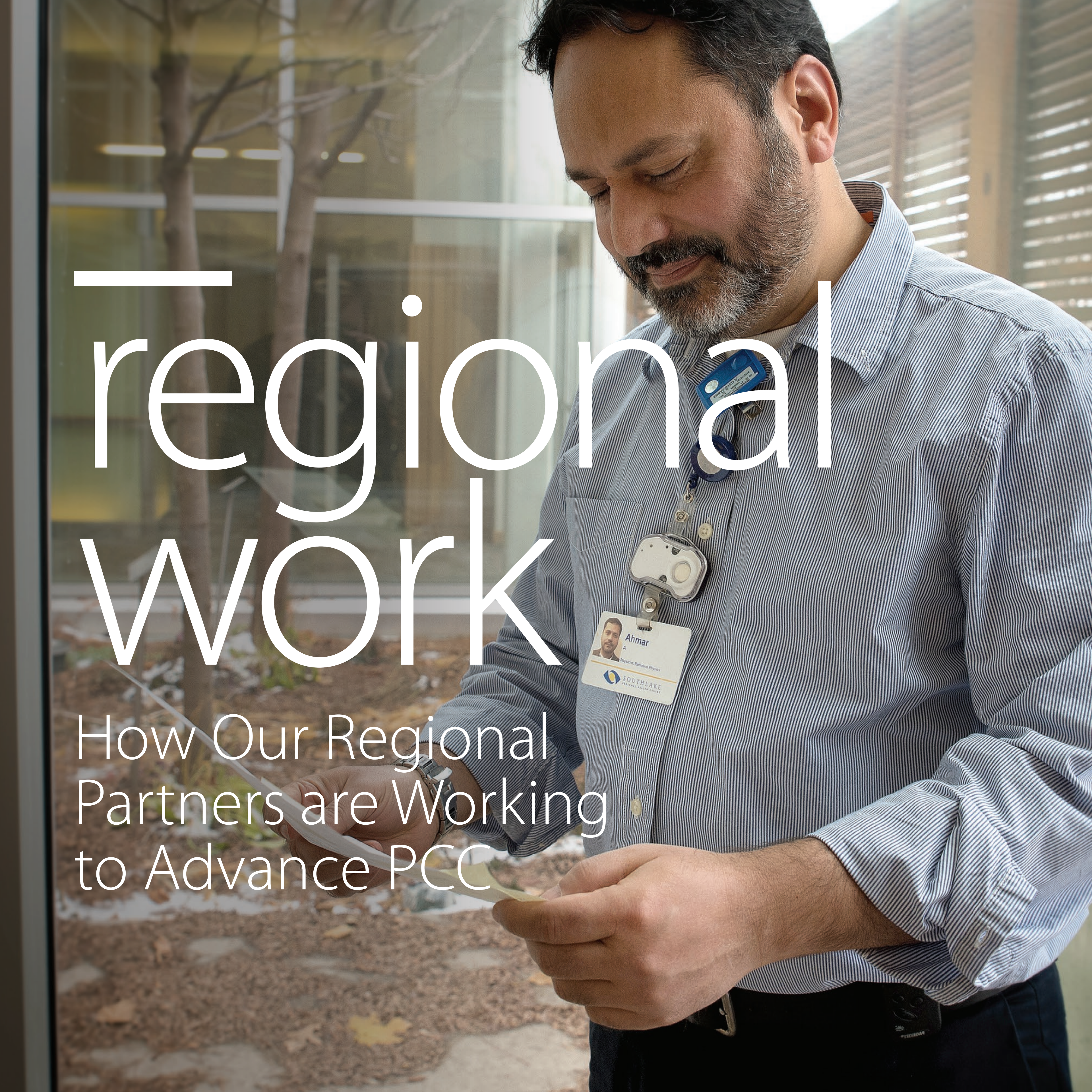
The medication fact sheets inform patients about their medications and related side effects, helping patients to better understand their treatment and perform self-management (i.e., monitoring side effects).

Before finalizing the medication fact sheets, the Ontario Renal Network held a focus group to gather feedback from patients on the drafts of the documents. Their input helped to ensure that the language was patient-friendly, and that the format was clear and easy to read. On an ongoing basis, Regional Renal Programs have been encouraged to continue to share the fact sheets with their patients.

Pregnancy and glomerulonephritis: educating through patient experience videos

The Ontario Renal Network conducted 20 interviews with patients living with GN and their family members. Patients with GN are complex not only because of their disease type, but also as a result of their psychosocial needs. Commonly, patients are shocked and upset by their diagnosis. Due to the relative rarity of GN, patients often feel isolated in their diagnosis and management. Patients with this kidney disease, which impacts a younger patient population, are often diagnosed just as they are starting to plan a family. This can be a great source of anxiety and stress for female patients as they are at higher risk for adverse maternal events and loss of kidney function. The interviews revealed that women living with GN did not relate well to concerns and issues faced by other pregnant women.

A nephrologist survey validated that there was a lack of adequate counselling, education and support for patients with GN. To address this, the Ontario Renal Network created two GN patient experience videos, each with a focus on pregnancy, to assure women living with GN that a safe and healthy pregnancy is possible. The GN patient experience videos share real-life experiences of people with GN with other patients and their family members. The videos were presented at the Ontario Renal Network Provincial Leadership Table in June 2017 in the hopes of promoting GN and pregnancy as an important renal topic.



regional work

How Our Regional Partners are Working to Advance PCC

Regional Cancer Programs

Standardizing telemedicine visits to ensure access

All cancer patients should have the same access to services and quality initiatives, regardless of the location of their care. Regional Cancer Care Northwest encompasses a vast geographic area, which includes a Regional Cancer Centre (RCC) in Thunder Bay and 13 satellite locations in hospitals across the Northwest Local Health Integration Network (LHIN). A current-state assessment of the telemedicine service within the Regional Cancer Program revealed that patients connecting with cancer specialists through telemedicine were not provided with the same, consistent opportunity to access support and services as those patients who visited the RCC in person. Services such as Smoking Cessation, New Patient Orientation and patient-reported outcomes through Your Symptoms Matter are all shown to improve patient experience, equip patients with tools for self-management and, where possible, help them maintain independence. A working group, including members of the Patient and Family Cancer Partnership, developed a pathway to standardize telemedicine visits across sites and cancer care providers. The pathway aimed to ensure that all patients were offered equal opportunity for support and important services.

Using a standardized telemedicine assessment tool piloted at Riverside Health Care in Fort Frances, patients living more than 350 km away from Thunder Bay can access the same support and services offered within the cancer centre.

This initiative is now being rolled out in the rest of the region and aligns with many of the recommendations outlined in the Person-Centred Care (PCC) Guidelines. The standardized assessment tool is simple to use and will ensure that the same information is gathered during each telemedicine visit. This will enable the care team to provide each patient with information, education and support tailored to their individual needs.

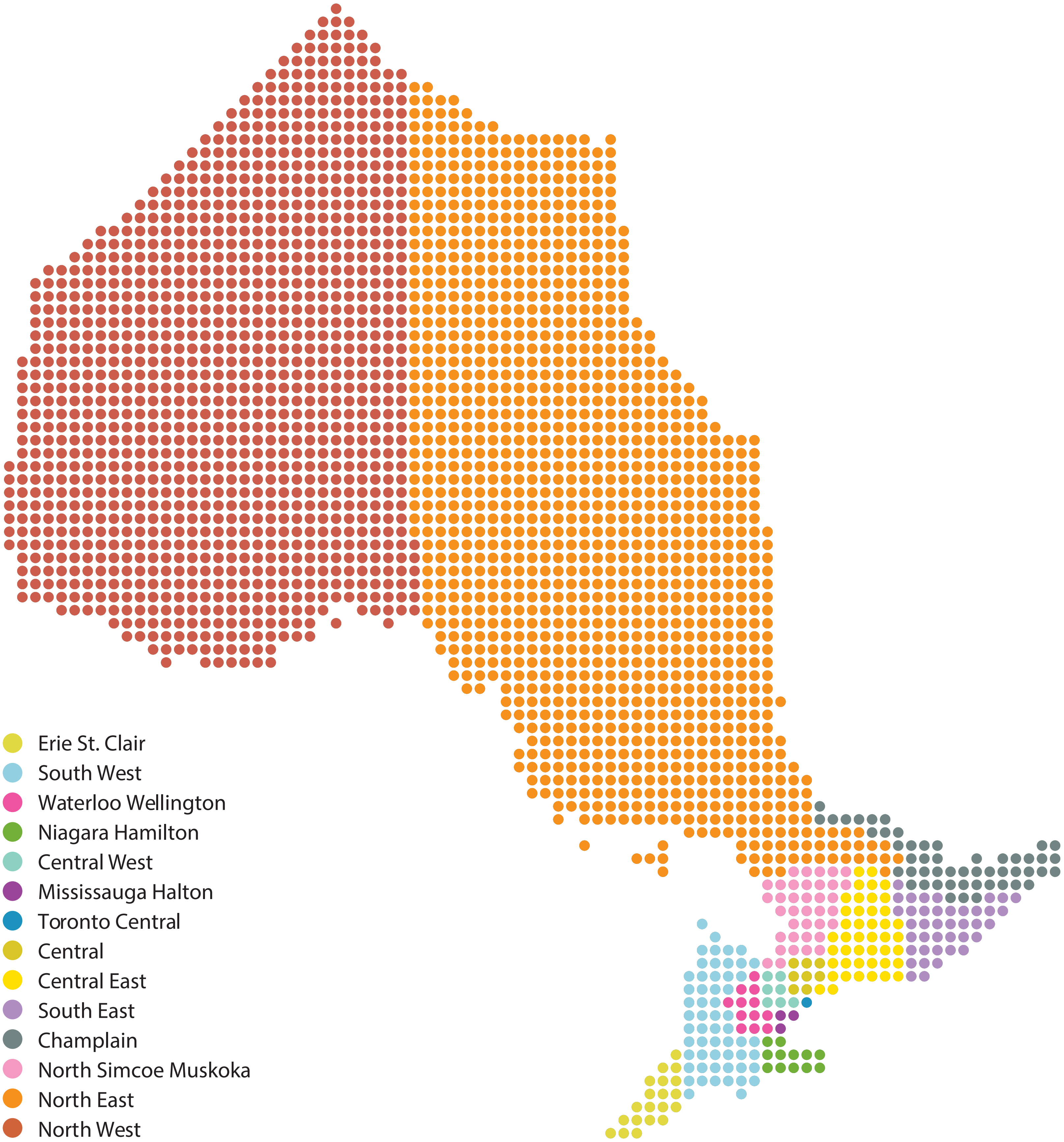
This initiative would not have been possible without the partnership of the telemedicine programs in each community, ensuring improved access to services closer to home. Patients and their family members who were involved in the pilot were asked to evaluate the visit using the standardized assessment tool. This real-time feedback allowed the working group to make adjustments to the tool and to the resources provided to patients, based on the patient experience.

Partnering for patients: After-hours telephone support for symptom management

The Stronach Regional Cancer Program launched a new initiative in 2016/17 that was guided by the Ministry of Health and Long-Term Care's Patients First agenda, the goals of equity and integrated care within Cancer Care Ontario's Ontario Cancer Plan IV (OCP IV), and the Central Regional Cancer Program's vision to develop sustainable partnerships to maximize resources for the betterment of patients.

Patients identified an urgent need for after-hours support with symptom management, to assist them in self-managing their cancer diagnosis and the side effects of their treatment. An opportunity arose for the Central Regional Cancer Program to partner with Bayshore HealthCare Limited (specifically, its CAREpathTM division), whose mandate is to ensure that clients receive the advice, information and support they need to navigate the healthcare system.

As a result, in July 2016, the Central Regional Cancer Program and Bayshore HealthCare Limited developed a mutually-beneficial solution to provide enhanced after-hours telephone cancer symptom management advice to patients receiving systemic therapy.


Erie St. Clair
South West
Waterloo Wellington
Niagara Hamilton
Central West
Mississauga Halton
Toronto Central
Central
Central East
South East
Champlain
North Simcoe Muskoka
North East
North West

> “The feedback from patients has been very positive and reinforces that we’re on the right track. It’s rewarding when patients leave here saying that they feel as if a weight has been lifted from their shoulders and that some of their fears and concerns are alleviated by attending the clinic.” **Janet Giroux,** Nurse Practitioner

The initiative aimed to improve patient access to side effect management, improve patient satisfaction with timely response to concerns and reduce unplanned patient emergency room (ER) visits and unplanned hospital admissions.

Today, specialized oncology nurses provide after-hours telephone advice and support to patients when they call a 1-800 number. Patients are provided with information about the service as well as a general personal health information sheet that outlines their type of cancer, their treatment regimen, and any other information that would be helpful for the nurse in managing the patient’s symptoms by phone.

Patient feedback confirmed the need for this particular program, as access to after-hours support from a healthcare provider prevents unnecessary ER visits. Patients also participated in the development of the letter and health information sheet that they now receive as part of this service. Through this initiative, patients are triaged by a specialized oncology nurse in a timely manner—typically within 15 minutes of their call, which relieves anxiety over symptoms for many patients, and, in turn, reduces trips to the ER. During the pilot, only 7% of the 460 patients who used the service were referred to the ER, with 80% of those patients requiring medical intervention. Patients noted that the after-hours nurses provided helpful advice and guidance, and 50% said that they would have visited the ER without access to this program.

The pilot has recently been expanded to include other Regional Cancer Programs across the province to further define its feasibility, usability and sustainability.

Connecting patients to programs: Simcoe muskoka cancer screening hotline

The Simcoe Muskoka Cancer Screening Hotline connects residents of North Simcoe Muskoka (NSM) to cancer screening, particularly under- and never-screened populations. Past campaigns consistently identified a need to improve access to screening, especially for Pap tests. The hotline addresses this need by working with provincial programs and community partners to offer screening services throughout NSM.

This sustainable, person-centred call-in service provides tailored advice to help individuals navigate the various screening programs. Residents of NSM are encouraged to call the hotline, where they are assessed for eligibility for the provincial breast, cervical and colorectal screening programs. They receive health education specific to their needs and are directed to the services provided closest to their home.

The most common barriers for women calling the hotline include not having a healthcare provider and not being comfortable seeing a male healthcare provider for a Pap test. The hotline reduces these barriers by coordinating with local healthcare providers to provide the Pap tests, leveraging its provider network to connect women with someone who fits their individual needs. Callers also receive information about Health Care Connect and can be connected with healthcare providers who are currently accepting new patients.

As part of ongoing quality improvement, the hotline also collects information about real and perceived barriers to cancer screening in order to inform future initiatives and better facilitate screening for people living in the region. The Simcoe Muskoka Regional Cancer Program’s (SMRCP) Patient and Family Advisory Council (PFAC) was consulted on the design of the hotline and provides regular feedback on the service.

Today, all staff are encouraged to use the phrase "Do you have any questions about the next steps in your care?" during every interaction with patients and their families.

The hotline serves as the "call to action" during public campaigns and initiatives. The hotline has enhanced the reach of the SMRCP by providing a unique way to assess uptake services and evaluate the effectiveness of large campaigns. By connecting callers with the necessary screening services, the hotline provides direct and personalized public education and helps to increase cancer screening rates across the region.

Support for prostate cancer patients: The cancer centre sexual health clinic

Cancer treatment can help improve the quality and longevity of a patient's life, but sometimes the treatment can have negative impacts on other areas of life. One area that is often overlooked is the impact treatment can have on a patient's sexual health.

At the Cancer Centre of Southeastern Ontario, the Oncology Sexual Health Clinic makes it easier for cancer patients to discuss their sexual health. Patients and their partners receive education, tools and counselling to help them throughout their care journey. When patients undergo cancer treatment, some of the changes they may experience include low sexual desire, physical changes, body image concerns, changes in relationships and overall wellbeing.

The aim of the clinic is to observe these changes and develop a plan with the patient to respond to them. It is a confidential, non-judgmental service, available to patients who are currently in treatment or have already completed treatment but still need support.

The clinic launched as a pilot in January 2016 supported by an Advisory Council of multi-disciplinary team members and is modelled after clinics in other regions. It is a Nurse and Social Worker led clinic, whose staff have an interest and knowledge base in sexual health. The clinic staff are required to complete courses focused on sexual health and cancer. As a team, clinic staff assess and manage patients based on their needs. Along with helping patients, the clinic also educates and supports Cancer Centre staff to approach the topic of sexual health with patients.

Tailored to each patient: The next steps in your care campaign

A New Patient Experience Task Force was created at the Windsor Regional Cancer Centre in late 2016, with representation from front-line staff—clerks, medical radiation technologists, nurses and physicians—along with patients. The first initiative was a communication plan focused on patient engagement.

The Next Steps in Your Care campaign was designed and launched to ensure that patients and their families know exactly what to expect when it comes to their care. The campaign engages patients and staff through simple graphical tools, including buttons, posters and floor decals.

Today, all staff are encouraged to use the phrase "Do you have any questions about the next steps in your care?" during every interaction with patients and their families. They are expected to answer questions where possible and to link or refer patients, where needed.

The Patient Experience Task Force officially launched the campaign through various communications and "lunch and learns" for clinical staff on May 9, 2017. Two PFAC members participated on the Patient Experience Task Force and contributed to this initiative during its development and for the launch.

Symptom management for patients with head and neck cancer: A person centred approach

The team at the Ottawa Hospital Cancer Centre (OHCC) identified the need to improve symptom management for all cancer patients, and is working towards a number of interventions including a telephone support line, a resource centre, and an online educational resource known as Patient Learning Links. One of the more complex groups of patients from a symptom management perspective are those with head and neck cancer, due largely to the intensive nature of treatment. Compared to other patients, head and neck patients are 25% less likely to report receiving instructions on how to manage treatment side effects. In addition, many of these patients report moderate to severe pain, including severe lack of appetite.

Patients and families receive a tremendous amount of verbal information from members of the health care team, however, the lack of written resources limits patient understanding, retention, and compliance.

With a goal to empower patients around the management of symptoms, the OHCC team took on an initiative to develop patient education materials specific to the head and neck cancer population.

As part of this initiative, members of the health care team were provided with training and education specific to head and neck cancer, and evidence based tools to help manage symptoms. Patients were engaged in the development and evaluation of all education materials including an information guide, patient passport, and orientation class. The "Head and Neck Cancer: Information Guide and Personal Record" resource was developed and reviewed by the OHCC Patient and Family Advisory Council (PFAC), and has gone on to be disseminated in OHCC clinics.

A mandatory education class has also been developed for head and neck cancer patients, which incorporates content from two previous classes (Chemotherapy Teach, and Radiation Therapy Teach) to meet the needs of this unique population. The class involves an interprofessional approach with nurses, dieticians, physiotherapists and medical radiation therapists present.

The work from this initiative has now been implemented as part of a standard of practice for the head and neck patient population.

J. Wesley Graham Patient and Family Resource Centre

The renovation of the J. Wesley Graham Patient and Family Resource Centre is a person centred care initiative that has been launched in the Waterloo Wellington region. At the Grand River Regional Cancer Centre (GRCC), the resource centre was an underutilized space with outdated materials. As identified by the GRCC Patient and Family Advisory Committee (PFAC), the room itself did not promote a sense of community and knowledge sharing, and was in need of revitalization.

As a result of this interest, the existing resource space has been renovated to create a bright and inviting atmosphere. Through innovation, the GRCC team has partnered with the Kitchener Public Library (KPL) to provide current, informative resources to patients and their families with a dedicated cancer centre library card. The renovated resource centre serves as a satellite health library within the cancer centre, focusing on the informational needs of patients with a new cancer diagnosis. The resource centre has been opened 5 days a week from 830am until 430pm and is staffed largely by volunteers. In addition to the excellent written resources that have been made available, the GRCC team has offered an "ask an oncology expert" day, a computer literacy program, and onsite KPL staff member support.

The GRCC partnership with KPL has allowed for the inclusion of updated, relevant education materials for patients and their families. The renovated resource centre has served as an additional patient counselling space to accommodate focused patient teaching. Disease site pathfinders, modelled after those created by the Juravinski Cancer Centre, have been created for patients and families to help direct them towards evidence based, relevant, and current information within the resource centre.

A formal launch party for the renovated resource centre is to be held in the fall of 2017, and will be showcased as a partnership between the GRCC, the Grand River Hospital Foundation, the Graham family, the KPL, and the GRCC PFAC.

Hamilton Niagara Haldimand Brant (HNHB) mobile screening coach: Partnership with six nations and new credit territories

The Mobile Coach is a 45-foot bus operated by the Hamilton Niagara Haldimand Brant (HNHB) Regional Cancer Program (RCP) since July 2013 that offers a cancer risk and screening eligibility assessment with a Registered Nurse, a series of screening tests for eligible men and women, and screening for tobacco use including support referral for clients interested in making changes in their use of tobacco.

The staff team works with clients and their primary care providers to ensure all clients with a screen-detected abnormality are linked to an organized assessment program and receive a definitive diagnosis. If clients do not have a regular provider, staff will link them with a local provider who has agreed to take on unattached Coach clients.

The priority population for the Coach is clients who are 'under' or never screened and face barriers to accessing existing screening services in the region. A geospatial analysis of screening participation rates, socio-demographic characteristics and existing services identified Six Nations and New Credit Territories as two areas that could benefit from mobile cancer screening services.

In 2016/17, the HNHB RCP and Six Nations and New Credit communities continued to build on their longstanding partnership to bring the Coach to provide on-territory screening services on seven occasions at six different on-territory locations for the third year in a row. This was done in collaboration with the Reclaiming Well-being: Cancer Free Lives Committee, which is a grass roots community group of on-territory health service providers dedicated to improving cancer screening rates in their communities.

The HNHB RCP team uses a participatory approach to engage local community groups, build trust and seek input from local partners to ensure that services are provided in a way that meets the needs of each individual community that the Coach visits. This approach is consistent with the Public Health Agency of Canada's "Ways Tried and True" framework for Aboriginal health promotion and chronic disease prevention. In partnership with the community, the Coach uses a three-pronged strategy to engage with under- or never-screened clients by:

- Raising awareness about the Coach and its services through distribution of a variety of promotional items, media and social media outlets;
- Engaging and educating communities about Coach services and the importance of screening through community events, as well as one-on-one and group education sessions; and
- Partnering with local health care providers to encourage their never or under-screened patients to visit the coach.

In an effort to provide high quality standardized care to patients receiving outpatient palliative care services, a framework was developed to enhance the home visiting program. The new framework supports the transition of patients with a score of 40% or less on the Palliative Performance Scale to the home visiting program.

Prior to launching the Coach in Six Nations and New Credit, several meetings were held with the Reclaiming Well-being: Cancer Free Lives Committee to identify, and respond to, community cancer screening service needs that would need to be considered when bringing the Coach on-territory communities. The Committee identified key locations where the Coach could park so that it would be visible, accessible, and approachable to the community. Volunteers from the Committee came to each Coach location to promote the service and to help establish trust and build a supportive environment for local residents.

To date, coach visits have been advertised in local newspapers (Two Row Times and Turtle Island News) and radio stations. To continue promotional efforts, large pull-up banners were created featuring local champions that could be displayed in key places on territory.

In 2016/17, 44 women had an OBSP mammogram, 17 women had a pap test and 30 FOBT kits were distributed to women and men visiting the Coach at an on-territory location.

For more about the Mobile Coach please visit:
http://hnhbscreenforlife.ca/screenforlifecoach/

Capturing the voice of the patient to improve patient experience

At the Durham Regional Cancer Centre (DRCC), the team is committed to involving patients in the design, delivery and evaluation of the care they receive. Patient engagement is an integral component of person-centred care, and an improved patient experience is a primary outcome of both person-centred care and patient engagement.

The goal of the Rapid Response Oncology Clinic (RROC) project was to implement a care pathway that would optimize the experience of patients receiving a paracentesis. This project was initiated in response to feedback from patients who identified varying care pathways from one visit to the next. One pathway required the patient to visit the Diagnostic Imaging department before having a paracentesis, while the other did not. To support a better understanding of the patient experience, face to face interviews were completed with patients in real time during their appointment for this procedure. This feedback helped to identify where the care pathway could be improved and standardized to support a consistent patient experience.

In an effort to provide high quality standardized care to patients receiving outpatient palliative care services, a framework was developed to enhance the home visiting program. The new framework supports the transition of patients with a score of 40% or less on the Palliative Performance Scale to the home visiting program. In collaboration with both internal and external partners, continuity of care is supported by a 'most responsible physician' (MRP). The development of a process allowing physicians to prescribe medications off site with direct communication to the pharmacy using an auto fax feature of our electronic health record facilitates timely access to medications for patients after hours and on weekends and supports a safer medication experience. Key accomplishments of this initiative include a significant increase in the number of patients receiving care at home with fewer

> **Cancer Care Ontario data shows that between 40- 50% of breast cancer patients on active treatment present in the ED. Toronto Central South data (2013) showed 41% of breast cancer patients treated with adjuvant chemotherapy had unplanned emergency visits.**

unnecessary visits to the emergency department or an urgent care clinic and supported in their wish to die at home. Intentional engagement through a telephone interview with patients and their family members/partners-in-care identified positive improvements in the patient experience.

The DRCC Systemic Therapy Program implemented registered nurse (RN) pre-treatment assessments for patients receiving certain chemotherapy regimens. The goal for this initiative was to create a better patient experience with fewer appointments and shorter wait times. Overall this has been a very successful initiative with extremely positive feedback obtained through a real time patient experience survey.

Using more than one mode of patient engagement allows us to have a more comprehensive picture of the patient experience allowing us to continue to identify opportunities for improvement in the care we provide.

Avoidable emergency visits for breast cancer patients: A quality improvement project

A Quality Improvement Program (QIP) was launched at Princess Margaret Cancer Centre (PMCC) to investigate why breast cancer patients on active treatment present to the Emergency department (ED). The purpose of this QIP was to support the development of strategies to support patients and improve patient experience.

Cancer Care Ontario data shows that between 40- 50% of breast cancer patients on active treatment present in the ED. Toronto Central South data (2013) showed 41% of breast cancer patients treated with adjuvant chemotherapy had unplanned emergency visits. ESAS chart audits from 2015/16 showed over 60% of breast patients reported having a mild, moderate or severe anxiety and over 50% of breast patients reported having mid, moderate or severe depression.

127 patient charts with breast cancer receiving neoadjuvant chemotherapy at PMCC from Jan. 27, 2015 to August 26, 2016 were reviewed retrospectively as part of the QIP. It was found that 49 of these patients visited the ED 55 times while on chemotherapy. To further analyze the data, ED visits were classified by two clinicians as avoidable (with the right instruction, prophylaxis and intervention, the visit may have been avoided), not avoidable (it is probably not reasonable to think this visit could have been avoided), or uncertain.

22 visits were classified as avoidable (40%), 25 visits as not avoidable (45%) and 8 visits as uncertain (15%). When the PMCC team investigated the reasons for avoidable ED visits, nausea and vomiting, fever, chest heaviness or discomfort, and pain were all found. In a review of patient reported symptom data, through the Edmonton Symptom Assessment Scale (ESAS), it was found that patients indicated two or more symptoms as severe before presenting in the ED. For the PMCC team, this data demonstrated an opportunity to improve patient education, patient experience and health outcomes.

Based on the data, two person-centred interventions were recommended for implementation: the development of regimen specific patient education materials and proactive telephone calls.

In regards to regimen specific patient education materials, work is underway to develop resources for patients that will better reflect the information required to avoid ED visits and better support patients. These resources will be tailored to include clear contact information, regiment specific symptom management information, and self-management strategies.

A second recommendation to implement a proactive telephone call approach has been proposed. In this recommendation, calls by specialized breast oncology nurses in the PMCC breast clinic before and after starting specific treatments will be made. These calls will work to assess symptoms, and offer symptom management strategies.

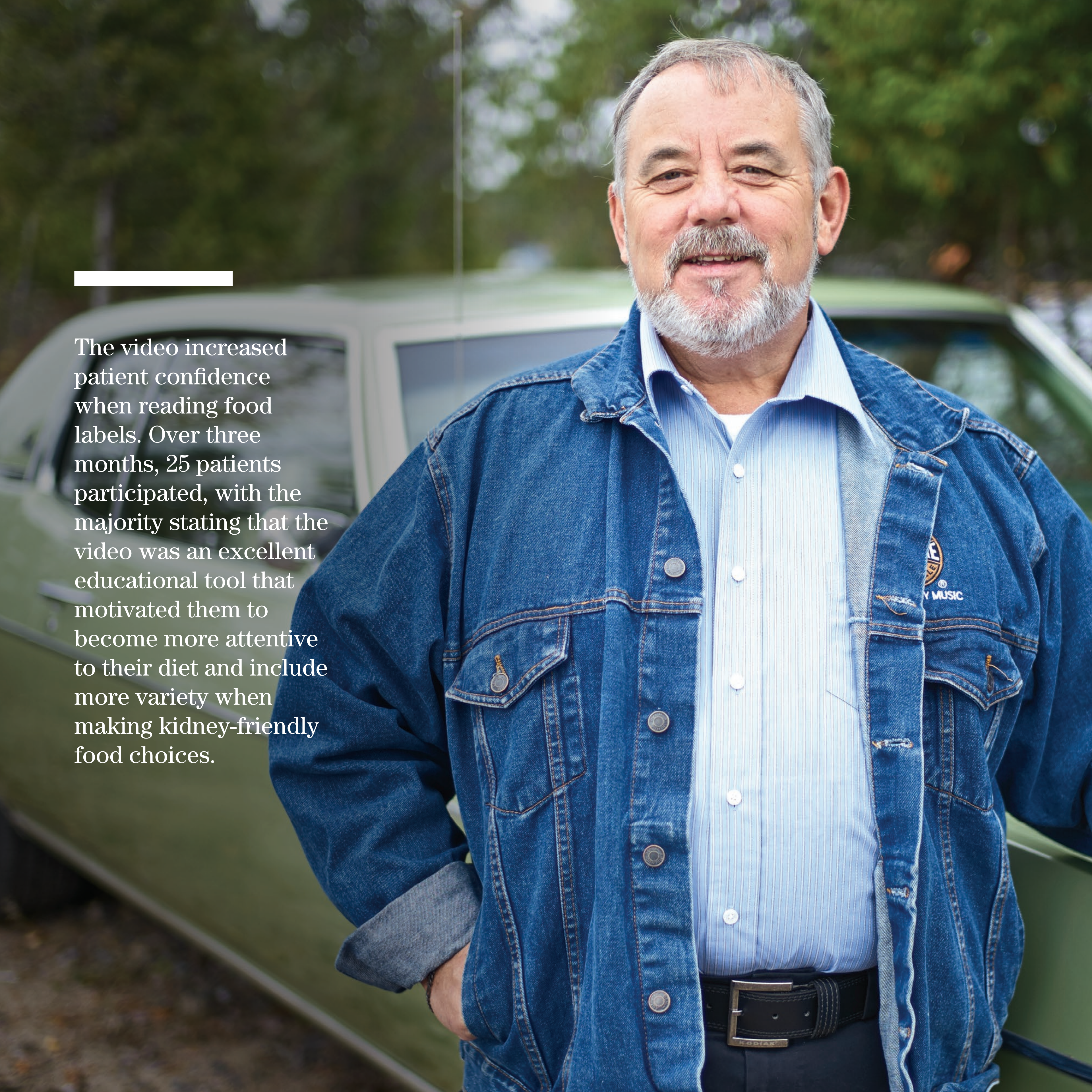
Live voice answer

Live Voice Answer is an initiative at the Odette Cancer Centre (OCC) that aims to support patients and families during key transition points in care and to provide health advice and information. This initiative exemplifies the person centred care approach at the Sunnybrook Health Sciences Centre by seeking and embedding the patient and family voice.

Live Voice Answer is a program whereby OCC staff connect with patients through introductions, ask what is most important to that person, and act on what matters most. Prior to the implementation of Live Voice Answer, patients would call into a voice mail for their respective oncology site team nurses. Patient and families often described the voicemail line as a "black hole" that was often "confusing, frustrating, and disjointed" because they were never sure when the call from the nurse would be returned. When patient satisfaction was assessed through a survey, satisfaction scores rated 3.6 out of 5 for the original voicemail system.

With the implementation of Live Voice Answer, cancer patients and their families or caregivers can call into a specific nursing site line and reach a live voice to deal with their appointment and/or health-related concern in real time. Patients are screened by a clerical support person to address any appointment related concerns, and then directed to a specialized oncology Registered Nurse to have their health related concerns addressed and resolved immediately. Patients are asked key assessment questions along with "what is your greatest concern today?" in an effort to best meet their needs and reduce distress.

This initiative has been piloted with several cancer patient populations with excellent patient satisfaction results. When patient satisfaction was assessed after the implementation of Live Voice Answer, patients and families rated their satisfaction as a 4.9 out of 5, and have commented that they are delighted with the initiative. Live Voice Answer will be rolled out to all cancer disease site groups in the summer of 2017.



The video increased patient confidence when reading food labels. Over three months, 25 patients participated, with the majority stating that the video was an excellent educational tool that motivated them to become more attentive to their diet and include more variety when making kidney-friendly food choices.

Regional Renal Programs

Promoting collaborative goal-setting: Brief action planning

Chronic kidney disease (CKD) patients often cope with complex health issues. Self-management support can help these patients by improving their motivation, encouraging shared decision-making, enabling self-efficacy and supporting healthy behaviours.

Developed by the Centre for Collaboration, Motivation and Innovation (CCMI), Brief Action Planning (BAP) is an innovative self-management support technique grounded in the principles and practice of motivational interviewing. BAP is a structured, easy-to-use tool for patients. This year, BAP was applied for the first time at Mackenzie Health to nephrology, specifically to home dialysis.

BAP was piloted with Mackenzie Health home dialysis patients to determine the impact of collaborative goal-setting on self-management behaviours, self-efficacy and clinical outcomes. The initiative aimed to enhance self-management support and help patients build skills and confidence.

Eighteen patient participants created 32 action plans, with 72% at least partially-to-fully completed. The patients' motivation to set goals increased when they related to a symptom, functional status or quality-of-life indicator. Common themes also emerged from within the action plans.

Increasing confidence in reading food labels: A self-management media approach

Patients on hemodialysis manage multiple renal diet modifications and are often challenged by reading food labels. There is also limited research evaluating the impact of tools such as educational videos on patients' confidence in reading food labels.

Patients at Mackenzie Health requiring hemodialysis were invited to watch a 30-minute educational video entitled "Grocery Shopping for your Kidney Diet," created by the British Columbia Renal Agency dietitians. Patients completed a short questionnaire rating their confidence in reading food labels for specific food categories and for managing health. Participants received either a grocery store certificate or a Canadian Association of Nephrology Dietitians kidney-friendly cookbook.

The objective was to determine how an educational video would affect patients' confidence in making renal-friendly food choices.

The video increased patient confidence when reading food labels. Over three months, 25 patients participated, with the majority stating that the video was an excellent educational tool that motivated them to become more attentive to their diet and include more variety when making kidney-friendly food choices.

Conservative care kidney clinic: A palliative approach

At the Kingston Health Sciences Centre, interviews were conducted in the multi-care kidney clinic (MCKC) with patients who were considering conservative care. The interviews uncovered several limitations of the current model. Many patients had questions about how dialysis would affect their quality of life and what they could expect if they chose not to pursue dialysis. They wanted to discuss the goals of their care, and some wanted to know about their prognosis and life expectancy. Following the patient interviews, their concerns were brought to the Nephrology Division and the PFAC to discuss how best to address them.

Kingston Health Sciences Centre (KHSC) launched an innovative clinic for patients requiring more support in exploring conservative care as their choice for management of end-stage renal disease (ESRD). The Conservative Care Kidney Clinic (CCKC) runs weekly and receives consults from the MCKC for patients who have either chosen conservative care, or would like further information about this option.

The clinic facilitates goals-of-care conversations so patients can inform their SDM and family members about their wishes and how they want to live.

At the CCKC, staff meet with the patient, their substitute decision-maker (SDM), and any other family or friends they wish to bring. The discussion focuses on the patient's current quality of life, upcoming goals and milestones, their views on death and any spiritual aspects of their life. The clinic facilitates goals-of-care conversations so patients can inform their SDM and family members about their wishes and how they want to live. Specific treatment options are also discussed, such as dialysis. Finally, if the patient wishes to discuss their prognosis, they are provided with information regarding survival, based on their medical history and available clinical studies.

If the patient chooses to pursue conservative care, palliative care services are arranged to be introduced once their mobility becomes limited or their symptom burden increases. The patient is then transitioned to the family physician for referral to community palliative care, if the physician does not provide palliative services.

The CCKC has four main objectives:

1. to provide education to patients regarding conservative care as a choice for management of ESRD;
2. to assess patient understanding of kidney disease and other illnesses;
3. to discuss goals of care, including patient values and fears, quality of life and end-of-life plans; and
4. to incorporate goals of care (patient values) into the treatment plan.

In terms of intended outcomes, the clinic will help patients make informed decisions when choosing conservative care, and create a treatment plan that aligns with the patient's values. Outcomes will be evaluated based on the clinic's ability to facilitate decision-making (i.e., the number of patients who are undecided about treatment modality choice who decide after visiting the clinic), as well as the total number of patients who choose conservative care.

Overall, the clinic has been well received, with very positive feedback from patients and their families, and the hope is to expand this type of clinic to other centres in the future.

Patients felt more involved in the decision-making process for choosing treatment plans and better understood their current medical status. Families became more aware of patient wishes in the event of having to make decisions as an SDM. In terms of impact on the healthcare system, the CCKC will save costs associated with hemodialysis for patients who would prefer not to pursue dialysis. Patients' costs associated with transport, parking, etc., will also be reduced.

Living your life to the fullest: Providing ongoing education for patients

The Living Your Life to the Fullest program has been developed at the Peterborough Regional Health Centre, based on an identified need to provide ongoing education to renal and dialysis patients outside the traditional clinic and treatment centre. When choosing treatment options, patients and family members often expressed the desire to speak to others who have shared similar experiences.

At the Multi-Care Kidney Clinic (MCKC), it is difficult to provide peer support on a day-to-day basis. The program created an education and engagement opportunity for interested patients, families and caregivers to come together a few times a year to learn about a variety of topics.

Over the past few years, the program has hosted two group educational events per year on a variety of topics with a range of speakers.

The Spring Education Event focuses on self-management techniques, including home dialysis options, coping with CKD and renal replacement therapy (RRT). As well, a transplant education event is hosted in the fall. Group cooking classes have also been provided, with a focus on learning about and choosing healthy renal meal options.

The initiative provides a way to share information from peers and professional staff with patients in the program living with CKD and on RRT. The goal is to increase awareness of home therapies, transplant and arteriovenous fistula (AVF) use, and to connect patients and their families with resources.

Attendees are asked to provide feedback by completing an evaluation form, and to include suggestions for topics they would like to learn about at future events. The goal is to have at least 20 registered patients in attendance at each event. Past event attendance has ranged from 10 to more than 40 people.

At these events, renal patient advocates have shared their stories relating to coping with CKD, enabling information sharing and peer support. Patients and their families have been given the opportunity to share their experiences and feel empowered.

The program's Patient and Family Engagement Committee (PFEC) members are involved and have attended the events in the past to speak about their committee and recruit new members. The event is included in the Peterborough Regional Health Centre renal newsletter and invitations are sent to patients in the MCKC and home programs. Information posters were also developed to raise awareness of upcoming events.

Developing a consent form to disclose patient health status

Many patients who dialyze in facility centres have developed long-standing friendships with fellow patients on dialysis, creating a close-knit community. If someone does not appear for dialysis, other patients often inquire after the health and wellbeing of their friend and fellow patient. Providers previously have not been allowed to share the reason behind another patient's absence (such as death, serious illness resulting in hospitalization, receipt of a kidney transplant or transferred to another program) with concerned fellow patients. Concerns about maintaining confidentiality in accordance with the Personal Health Information Protection Act (PHIPA) standards made it challenging to share this information.

In collaboration with St. Joseph's Health Centre PFAC members, staff at the St. Joseph's Health Centre – Toronto (SJHC), in consultation with the hospital's Information Access and Privacy Coordinator, have developed a "Consent to Disclose Confidential Information Between Renal Patients" form to address those concerns.

Once implemented, the form will allow staff to comfortably disclose information about the status of a patient who is no longer in the hemodialysis unit, knowing they have their consent. It will enable patients to inquire and learn about the status of fellow patients.

The consent would be located directly on the patient's chart for the renal team to refer to in the event that patients inquire about the status of a fellow patient who is no longer undergoing dialysis in the unit. The consent form has been finalized and formatted, and is currently awaiting a formal policy from SJHC before being implemented with patients.

PFAC members were the first to request a formal way for staff to communicate to patients the status of fellow patients. PFAC members took an active role in developing the form and provided feedback as the form was created. The patient care manager (PCM) attended the PFAC meetings to clarify patient goals for the form.

> “Amazing class. I learned a lot and feel I can challenge myself to use ingredients like celery root. I appreciate that these classes are offered and the value of the information will definitely enhance my road to better health.”
>
> **Participant,** Cooking For Your Kidneys Class

Cooking for your kidneys

The renal therapeutic diet is complex and requires ongoing education of nutrition principles for optimal health. To provide this education in a novel way, an interactive cooking demonstration was developed by the Patient and Family Education team at the University Health Network (UHN), in collaboration with renal dietitians and a chef from the health, wellness and survivorship centre at UHN (ELLICSR). This demonstration was developed to provide information on renal nutrition topics, and is offered to patients in the UHN Nephrology Program as well as their family and caregivers.

The interactive cooking class was developed to empower patients by enhancing both the education of renal nutrition principles, as well as strengthening cooking skills through a fun and engaging teaching method. It also provided tips, tools and resources for patients to take home for ongoing learning. This initiative was originally piloted in 2013, and due to its overwhelming success has allowed the renal dietitians to offer bi-annual cooking classes on a variety of patient-driven topics of interest. These classes are supported by the UHN Nephrology and ELLICSR programs. Sessions to date have been well-attended and feedback is positive. Participant evaluations have shown that all attendees “strongly agreed” they would recommend the class to others and 92% “strongly agreed” the class was helpful and would like to attend a class in the future.

The interactive nature of the cooking class has enabled rich discussions; not only between dietitians and participants, but amongst participants themselves. Participants come from various stages of kidney disease and dialysis modalities; they share their stories and knowledge, resulting in a supportive and engaging environment for all involved.

New home dialysis patient council

At the University Health Network, patients on home dialysis have expressed a desire to provide feedback on their care and have requested more education in issues such as the transplant process, tax preparation information, diet, and advance care planning. To address this feedback, UHN has initiated a new home dialysis patient council focused on education, support, and feedback on services.

The new council is meant to empower patients through increased education on topics which impact the ability of patients to manage their care as well as to engage patients and families in their care in a more meaningful way. The council also provides members with a sense of belonging with others who experience similar challenges.

The council meets every three months and has had good participation in education sessions on tax preparation, the transplant process, and Advance Care Planning. To plan for future sessions, members have provided a list of topics of interest, and have provided feedback on sessions held to date.

Thus far, this initiative has empowered patients through education and advocacy, and has provided them with the opportunity to be more engaged in their own health.

> “I believe this initiative assists patients in obtaining the education needed to better manage their own care as well as to provide them with a voice and an opportunity to shape some of the services they receive. It is an opportunity to build a sense of community and of a shared purpose.” **Patient Advisory Council Member**

Indigenous Navigator at the Thunder Bay Regional Health Sciences Centre

It is estimated that one in 10 Canadians have kidney disease, and Canadian research suggests this is much higher in Indigenous populations. The Northwest Regional Renal Program (NWRRP) recognized that within the population served, approximately 40 percent of renal patients are Indigenous. A portion of Indigenous patients reside in Thunder Bay, Fort Frances, Sioux Lookout and Kenora, however a greater number live in communities all across Northern Ontario. Over time, it has become clear that language and cultural barriers present challenges in providing appropriate, patient and family-centred care to Indigenous populations.

When planning for self-care and relocation to an urban centre for hemodialysis, these patients face issues such as isolation from their family and community. Many Indigenous patients have never lived outside their community and have difficulty navigating the systems and processes for accessing housing, finances, food and transportation.

The renal services team at the NWRRP identified that an Indigenous Navigator role could bridge the cultural and language barriers between the multidisciplinary team, patients and their families. After much investigation, the first Indigenous Navigator was hired to the multidisciplinary team.

The role of the Indigenous Navigator was initially developed to help the NWRRP team understand the northern communities where our Indigenous patients lived, as well as the cultural aspects of living with kidney disease. The greatest operational need was for translation between the patients, families and the healthcare team. This often includes team discussions about the important factors around health for the individual, their family and the community’s perspective on decision-making. The Indigenous Navigator also works to assist the team in making self-management plans in partnership with patients, and supporting patients in decisions for renal replacement therapies. The role quickly grew to be a significant resource for all multidisciplinary team members, patients and family members in the NWRRP.

From the perspective of patients, it is imperative for them to have a person to connect with who can support and explain things, as well as someone who understands their culture, values, and spiritual beliefs. The Indigenous Navigator assists individuals with learning new tasks they may not be familiar with, such as using bank machines, using community resource, and learning a new geographic area, including how to use various forms of transportation. The Navigator assists individuals who may have a language barrier to communicate throughout the city, at various appointments, as they transition to Thunder Bay. The Indigenous Navigator provides support for patients during clinics, throughout other medical appointments and education sessions, helping to explain the purpose of the tests and arranging transportation. In addition to this, the Indigenous Navigator helps individuals make healthcare decisions that align with their beliefs and values.

Overall, the Indigenous Navigator provides an opportunity for open discussion regarding indigenous culture, beliefs and values.

This role is unique and makes it possible to provide person and family-centred care to the Indigenous population. The role has no limits to the assistance and support it can provide to Indigenous patients as well as to the renal care team.

Finding a new multi-care kidney clinic space inside OSMH

At the Orillia Soldiers' Memorial Hospital (OSMH), the Regional Renal Patient and Family Advisory Council (RRPFAC) raised concerns to senior management about the Multi-Care Kidney Clinic (MCKC) space. The MCKC clinic area lacked privacy and confidentiality for patients when registering; some rooms lacked windows and lighting was poor. The space consisted of six small rooms, where patients were seen by each discipline (doctor, nurse, dietitian, pharmacist and social worker) separately. In addition, some rooms were not wheelchair accessible. For patients and family members starting their kidney journey, the existing space was not a welcoming environment.

Hearing the voice of the RRPFAC and working with the committee, OSMH undertook the development of a new MCKC space. With input from the RRPFAC, the new initiative served as an opportunity to improve the flow of clinic. The goal was to develop a space that would allow for privacy, include larger rooms to accommodate patients, and support a welcoming environment. As a result of these efforts, the new MCKC opened in the spring of 2017.

The new MCKC includes a registration area (which allows for the confidentiality of patients to be maintained), a separate waiting room with large windows, comfortable seating, cable television, and a gender neutral washroom. Beyond these comfort measures, changes have been implemented to improve the flow of the clinic, with patients and family members seeing a nurse and pharmacist in one room, a physician in a second, and a social worker, nurse, and dietitian in the third. These flow changes have not only decreased wait times for patients and families between healthcare providers, but has also allowed for more discussion and focus on the patient's goals of care.

Get Involved

Share your experience

CCO’s Patient and Family Advisor communities have lived experience with either cancer or kidney disease. Our advisors come from across Ontario and have experienced the health system as patients, family members and/or caregivers. In their role, they provide direct input into the design, delivery and evaluation of policies, programs and initiatives that impact patient care. By sharing their unique perspectives and experiences, advisors help us improve the lives of people living with cancer and kidney disease.

If you are interested in learning more about the program or becoming a CCO PFA, please contact us at the email addresses below:

Cancer Care Ontario: patientfamilyadvisors@cancercare.on.ca
Ontario Renal Network: pfa@renalnetwork.on.ca

CCO may collect your personal information for the purposes of responding to your inquiry and administering the Engagement Program. This information will not be shared with third parties and will not be used for any other purpose. If you have any questions about your information and how it is managed, please contact us at one of the email addresses above.

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