Ontario Health
Ontario Renal Network

Multi-Care Kidney Clinic Best Practices

March 31, 2022

A Letter to Our Care Team

To Our Kidney Care Team,

Our lives changed the moment we learned our kidneys were failing. Not only for us as patients, but for our loved ones as well. The experience is different for everyone. Some of us felt an eruption of emotion or had a torrent of concern and questions. But we were all overwhelmed by the news and all the information that came with it. Stunned, we may have appeared uninterested, but we can assure you that was not the case.

Entering a multi-care kidney clinic (MCKC) for the first time or starting on dialysis emergently is a significant life transition. It marks the beginning of a journey we likely didn't plan for. That is why patient orientation and education are invaluable, as they can help us understand what is to come. They can also be incredibly overwhelming. Each new piece of information about our kidneys can unleash a mix of emotions: shock, denial, confusion, anxiety, guilt, depression, anger, isolation, or optimism. We face many important, stressful, and difficult decisions – most of which we could never make on our own. As our kidney care team, you play a pivotal role in guiding us through this transition, helping us understand complicated health information and illuminating the impact this disease may have on our lives. For this, we are eternally grateful.

Trust, respect, compassion, and transparency are at the foundation of the partnership between patients and health care providers. The knowledge you share with us – both the bad and the good – helps us better prepare for what's next. Of course, we will each react differently to the information you share and the approaches you take to support us, because we are all different. Our unique combination of values, preferences, culture, beliefs, and existing supports shape our thinking and decision-making about what is best for us and our families.

We hope that this letter provides MCKC care teams with a better understanding of how we may experience a wide range of emotions and the life-altering impact of chronic kidney disease. Above all, we hope you recognize and appreciate that we are people, not just patients and estimated glomerular filtration rate readings. You are meeting us at a very low point in our lives. We are likely a long way from our "normal", and we truly appreciate your skill, dedication and your compassion.

It is important that we are empowered to be partners in our care. The MCKCs, guided by this Best Practices document, provides an opportunity for us to work together to ensure that all patients and their loved ones feel safe to ask questions, share concerns and be involved in all our care decisions.

Sincerely,
Ontario Renal Network Patient and Family Advisors

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Person-Centred Approach

- Multi-Care Kidney Clinic (MCKC) is a specialized, multidisciplinary[1] clinic rooted in providing person-centred and culturally safe care for people with advanced chronic kidney disease (CKD).

MCKC Goals

Patients[2] and caregivers[3] will:

- Be empowered and supported to be partners in their care.
- Participate in shared decision-making on all aspects of care, including goals of care and treatment decisions.
- Receive active management of CKD symptoms and complications and reduce cardiovascular risk.
- Receive education on CKD health and modality options that both optimize patient outcomes and incorporate their culture and values.
- Receive assistance in the coordination and navigation of their care.

Care Team Composition

- Includes, but is not limited to, the patient and caregivers, nurse, nephrologist, pharmacist, dietitian, and social worker.

Referral, Frequency of Visits and Orientation

Target Population and Referral

- The target population is people with advanced CKD with a two-year kidney failure risk equation ($KFRE_2$) of 10% or greater or an estimated glomerular filtration rate (eGFR) of less than 15 ml/min/1.73m². These patients are eligible for funded enrollment.

Initial Visit and Orientation

- The initial visit and orientation should be conducted in-person, when possible and based on patient preference. Orientation should include MCKC goals, approaches, programs, services, team roles and logistics.

Frequency of Visits

- At a **minimum**, patients should have two MCKC visits in a year.
- Nurse and nephrologist should be seen at each visit.
- Pharmacist, dietitian, and social worker should be seen at **least** twice a year.

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[1] Multidisciplinary refers to both a team of health care workers who are members of different disciplines, as well as the process of interprofessional collaboration in which healthcare providers from different disciplines work together with patients and caregivers to enable optimal health outcomes.

[2] Patient(s) refer to people who have advanced chronic kidney disease and receive care in a MCKC.

[3] Caregiver refers to the people who provide patients with critical and often ongoing personal, social, psychological and physical support, assistance and care, without pay. Caregivers may include family, friends, neighbours and/or volunteers.

- MCKC care may be provided in a hybrid of in-person and virtual visits (e.g., videoconference or by phone). MCKC patients should be assessed in-person at **least** once a year, taking into consideration patient preference.

Goals of Care

- Patients should be engaged in goals of care discussions to identify, discuss, and document their values, preferences, and future substitute decision-maker.
- Goals of care discussions should be completed within the first three MCKC or education visits, or within one year of MCKC registration (whichever comes first).
- Goals of care discussions should be completed at in-person visits or virtual clinic visits where video conferencing is available.

Patient and Caregiver Education

- All education sessions and tools should be designed with consideration to the principles of adult learning, culturally safe care, self-management skills and health literacy.
- Whenever possible education should be provided in the patient's primary language.
- Modality education should be provided using a shared decision-making approach.
- For most patients, education on modality options should be initiated between a $KFRE_2$ of 20% and 40%.

Active Management

Active management of CKD includes:

- Employing strategies to reduce the rate of kidney failure and/or cardiovascular risk.
- Ongoing monitoring and treatment of anemia and other CKD-related complications.
- Ensuring safe medication prescribing.
- Counselling on diet and nutrition.
- Recognizing and treating symptoms, including mental health challenges and referrals to other services where needed.
- Supporting patient and caregiver understanding of CKD and care management.

Coordination and Navigation of Care

- The MCKC care team plays an active role in coordinating and navigating patients as they transition towards their preferred modality.
- The MCKC care team should have ongoing communication with all members of a patient's care team (e.g., primary care, community supports and other health care professionals/services).
- The MCKC care team transfers accountability for patient care to:
    - Peritoneal dialysis and home hemodialysis: first day of training
    - In-facility hemodialysis: date of first dialysis treatment
    - Transition Unit: day of first dialysis treatment
    - Pre-emptive transplant: date of transplant
    - Conservative renal care: may continue to be provided in MCKC or in CRC clinics.

1.0 About This Document

Ontario Renal Network (ORN), as part of Ontario Health, is responsible for funding, organizing, and managing the delivery of kidney care services in Ontario. ORN is responsible for funding, organizing, managing, and improving the delivery of high-quality care for people at all stages of chronic kidney disease (CKD) in a consistent and coordinated manner. A key priority of the ORN is to ensure access to high quality care in Multi-Care Kidney Clinics (MCKCs).

This Best Practice document was developed by a multidisciplinary group (Appendix A) using available evidence, expertise, and experience to describe the role and delivery of care in MCKCs across the province. (1,2) **The purpose of this document is to outline best practices with the aim to ensure high-quality care for all patients during the MCKC portion of their CKD journey.**

The first iteration of this document was released in 2019. In 2022, ORN released this document with the following changes:

Section	**Updates**
2.0 Core Elements	• Addition of Health Equity and Cultural Safety and First Nations, Inuit, Métis, Urban Indigenous (FNIMuI) Peoples
4.0 Referral, Frequency of Visits and Orientation	• Addition of MCKC patients should be assessed in-person at least once a year • Addition of virtual visits for MCKC patients • Update in minimum frequency of visits: Most MCKC patients will benefit from seeing a social worker, dietitian, and pharmacist at least twice annually
7.0 Education on CKD Health and Modality Options	• Updates to Transplant and Home Dialysis education • Addition of Transplant Ambassador Program (TAP)
9.0 Coordination and Navigation	• Updates to team tasks

Background

CKD, defined by a persistent eGFR of less than 60 ml/min/1.73m^2, is estimated to affect at least 4% of adults living in Ontario and increases with advancing age. (3) A small proportion of people living with CKD are at high risk of progressing to end-stage kidney disease (EKSD) and are likely to develop further complications and would benefit from multidisciplinary care.

As a result, Ontario and many other jurisdictions have advocated for the widespread employment of multidisciplinary clinics for patients with advanced CKD. (1,4-6) Literature suggests that the use of multidisciplinary clinics in patients with CKD is associated with greater patient preparedness and improved clinical outcomes. (7,8) Patient and system benefits may include improved survival, delayed need for renal replacement therapy, greater utilization of preferred vascular access and modality and decreases in unplanned dialysis initiation. (8-10). Further, there is evidence for the benefits of multidisciplinary clinics for patients with other chronic diseases, including diabetes mellitus (11) and congestive heart failure. (12)

2.0 Core Elements

2.1 Person-Centred Approach

MCKC is a specialized, multidisciplinary clinic rooted in providing person-centred care for people with advanced CKD. These clinics consist of a team of diverse yet complementary health care professionals with specialized skills to support, educate and collaborate in shared decision-making with patients and caregivers.

Person-Centred Care and Shared Decision-Making

Person-centred care is an approach that views people using health services as equal partners in planning, developing, and monitoring their care to make sure it meets their needs. (13,14) Only patients truly understand how CKD impacts their day-to-day lives, thus they are the experts regarding their current health priorities and their primary support systems. Caregivers can play a pivotal role in supporting patients with their care, and both patients and their caregivers should be encouraged and empowered to be active players in their health care.

Shared decision-making is a collaborative process that allows patients and their providers to make health care decisions together. (15) The shared decision-making approach considers the best scientific evidence available in conjunction with a patient's values, goals, preferences, caregiver situation, culture, and lifestyle. Having shared decision-making discussions early and often help to ensure patients and caregivers are supported appropriately throughout their care journey.

Health Equity

Health equity is a state where "…all people (individuals, groups and communities) have a fair chance to reach their full health potential and are not disadvantaged by social, economic and environmental conditions." (16) Applying a health equity perspective to patient care is part of a person-centred care approach. Health equity recognizes that patients may require different strategies and resources based on their individual circumstances and how they are impacted by social determinants of health such as income, geography, race, and ethnicity. For example, compared to non-Indigenous people, Indigenous peoples in Canada have higher incidence and prevalence rates of ESKD and are more likely to live in remote and lower income areas. (17) Furthermore, being of minority ethnicity (especially Black) and living in a low socioeconomic status area is associated with faster CKD progression. (18) It is critical that the impact of anti-Indigenous and anti-Black racism be recognized and addressed within the healthcare system. (19)

Each MCKC patient is unique in terms of their lived experience and CKD journey. MCKC care teams should consider how individual circumstances and inequitable conditions may impact the ability of MCKC patients to:

- Attend MCKC appointments.
- Feel safe and empowered and actively participate in discussions about their care. Receive information and education related to their care.
- Self-manage their CKD and follow through with their plan of care.
- Spend adequate time in MCKC to receive multidisciplinary care and prepare for next steps.
- Initiate and remain on their preferred modality.

Cultural Safety and First Nations, Inuit, Métis, Urban Indigenous (FNIMuI) Peoples

Ontario has the largest number of people with Indigenous ancestry in Canada, of which 85.5% live off-reserve in urban and rural areas. (20) Due to impacts of colonialism and racism, FNIMuI peoples experience health inequities and worse health outcomes compared to other Canadians. (21) These poor health outcomes are created by social inequities, organizational practices, policy-driven poverty, and racism. (22) Equally important, the strengths and resilience of First Nation, Inuit, and Métis people are often invisible due to incorrect assumptions and racist stereotypes. (22)

There is growing recognition of the importance of cultural safety at the care provider and organizational level in eliminating FNIMuI health inequities. Cultural safety is an outcome based on respectful engagement and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving healthcare and is associated with improved health outcomes and patient satisfaction. (23, 24) Culturally safe care is not focused on understanding “Indigenous culture” but is care provided by health care professionals who have adopted “a humble, self-reflective clinical practice that positions them as respectful and curious partners when providing care, rather than as a figure of higher knowledge and authority.” (25)

All patients should feel respected and safe while interacting with the MCKC care team. All care plans should integrate cultural expression, traditions, and practices, and support them to draw strength from their identity, culture, and community. MCKC care teams need to recognize social and historical contexts of FNIMuI health and reduce health care inequities. All members of MCKC care teams should recognize that their own world views and health beliefs impact the care they deliver and pursue opportunities to examine how their own culture, biases, attitudes, assumptions, stereotypes, and prejudices impact their clinical interactions with FNIMuI Indigenous patients.

Resources

- Person-Centred Decision-Making - Resource for Healthcare Providers (ORN)
- Indigenous Cultural Safety Training (Indigenous Primary Health Care Council)
- Indigenous Relationship and Cultural Awareness Courses (Cancer Care Ontario)
- Indigenous Allyship Toolkit: A guide to honouring culture, authentic collaboration and addressing discrimination (Indigenous Health Network, HNHB LHIN)
- The Unforgotten Toolkit: An educational guide to learn about, reflect on and dismantle anti-indigenous racism in health care (Canadian Medical Association and Government of Northwest Territories)

2.2 MCKC Goals

Patients in MCKC need to make many crucial, stressful, and often complex decisions about their future course of care. They are also at high risk of clinically important complications that would benefit from specialized multidisciplinary management. Understandably, patients are often anxious or distressed, and need support.

MCKC care teams work collaboratively with patients and their caregivers to provide evidence-based, high quality multidisciplinary CKD care. The goals in MCKCs are patients and caregivers will:
- Be empowered and supported to be partners in their care.
- Participate in shared decision-making on all aspects of care, including goals of care and treatment decisions.
- Receive active management of symptoms and complications of kidney disease and reduce cardiovascular risk.
- Receive education on CKD health and modality options that both optimize patient outcomes and incorporate their culture and values.
- Receive assistance in the coordination and navigation of their care.

2.3 Care Team Composition

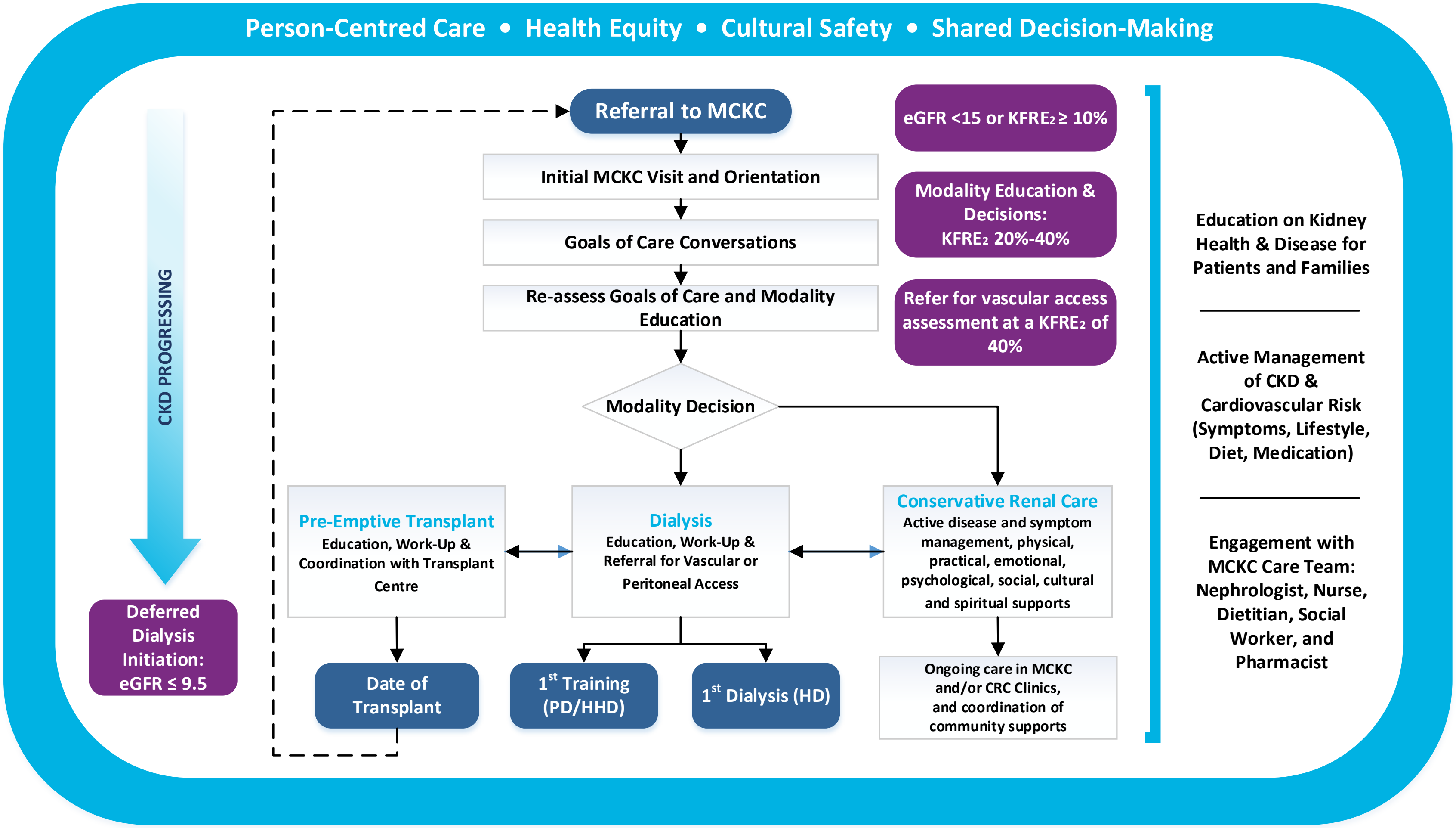
Evidence supports the provision of multidisciplinary care for patients with various chronic diseases, including CKD. (26-31) The MCKC care team composition should include, but not necessarily be limited to, the following:

- Patient and caregiver
- Nurse
- Nephrologist
- Pharmacist
- Dietitian
- Social worker

In addition, interpreter services and peer support services (e.g., Transplant Ambassador Program, Indigenous Elder/Knowledge Keepers, Spiritual/Faith Supports, etc.) should be readily available for all patients.

3.0 Patient Flow Algorithm

The algorithm below outlines major tasks and care involved in MCKCs from time of referral into MCKC through to modality decision (includes dialysis, transplant, conservative renal care). This document will provide further details on each of the major tasks.



Person-Centred Care • Health Equity • Cultural Safety • Shared Decision-Making

CKD PROGRESSING

Deferred Dialysis Initiation: eGFR ≤ 9.5

Referral to MCKC

Initial MCKC Visit and Orientation

Goals of Care Conversations

Re-assess Goals of Care and Modality Education

Modality Decision

Pre-Emptive Transplant
Education, Work-Up & Coordination with Transplant Centre

Dialysis
Education, Work-Up & Referral for Vascular or Peritoneal Access

Conservative Renal Care
Active disease and symptom management, physical, practical, emotional, psychological, social, cultural and spiritual supports

Date of Transplant

1st Training (PD/HHD)

1st Dialysis (HD)

Ongoing care in MCKC and/or CRC Clinics, and coordination of community supports

eGFR <15 or $\text{KFRE}_2 \geq 10\%$

Modality Education & Decisions: KFRE_2 20%-40%

Refer for vascular access assessment at a KFRE_2 of 40%

Education on Kidney Health & Disease for Patients and Families

Active Management of CKD & Cardiovascular Risk (Symptoms, Lifestyle, Diet, Medication)

Engagement with MCKC Care Team: Nephrologist, Nurse, Dietitian, Social Worker, and Pharmacist

4.0 Referral, Frequency of Visits and Orientation

4.1 Target Population and Referral

The target population for MCKCs is people with advanced CKD who are at high risk of progressing towards ESKD. To balance the benefits of earlier multidisciplinary intervention with the costs and potential harms of unnecessary interventions, **patients with a KFRE$_2$ of 10% or greater or an eGFR of less than 15 ml/min/1.73m^2 are eligible for funded enrolment in MCKCs**[4]. All individuals who meet either of these criteria should have the opportunity to be followed in MCKC. Patients are referred to MCKCs by a nephrologist.

The risk of progressing to ESKD can be calculated using the validated KFRE$_2$. (32) The KFRE$_2$ has been shown to accurately predict the 2-year risk of developing ESKD and has been externally validated in numerous patient cohorts. (32,33) In other jurisdictions where the KFRE$_2$ is used, patients and health care providers have indicated that utilization of the KFRE$_2$ as a risk-based approach rather than an eGFR value in isolation, has improved the focus of the multidisciplinary CKD clinics by targeting patients at highest risk. (34) Further, survey results found no difference in patient care experience or healthcare provider job satisfaction with the transition from an eGFR-based to risk-based approach to multidisciplinary CKD clinic enrolment eligibility. (34)

The following unique populations have special circumstances and should be considered for referral if they meet the MCKC eligibility requirements:

- Patients living with a kidney transplant.
- Patients living with glomerulonephritis (GN) whose disease is no longer responding to treatment. Patients living with GN require specialized, multidisciplinary GN care to prevent or delay progression of disease in accordance with the appropriate GN Acuity Level. If patients with GN are no longer responding to GN treatments, referral to MCKC should be considered.[5]
- Young adults with CKD transitioning to adult care. This group of patients faces unique challenges and consideration should be given to providing their care in transitional clinics in partnership with MCKCs (29). Where transitional clinics do not exist, MCKCs should strive to incorporate the principles and philosophy of a transitional clinic into the care of these unique patients.

Patients with CKD that do not meet MCKC eligibility requirements can receive care and support in multiple settings. General nephrology clinic visit funding, as outlined in the Quality-Based Procedure CKD Funding Guide, is also available and provides for multi-disciplinary care team services (e.g., nurse, social worker, dietitian) as required in collaboration with the nephrologist. This helps ensure that intensive MCKC resources are allocated where they are most needed according to patients' risk of progression to ESKD. For example:

- Patients with earlier stages of CKD can receive high quality care in general nephrology clinics and/or primary care settings. Care provided in these settings can support the management of

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[4] As of 2021/22 fiscal year, the eGFR calculation no longer includes the race adjustment to reduce health inequities to access CKD services and minimize the risk of unintended consequences.

[5] GN care may be delivered in partnership with MCKC to meet patient care needs.

earlier stages of CKD and minimize the risk of progression to ESKD and/or the development of cardiovascular complications.

- Patients with anemia and/or metabolic complications of CKD can generally be cared for and monitored in general nephrology clinics (e.g., receive active vitamin D therapy for secondary hyperparathyroidism). Intensive interventions (e.g., nutritional counselling for hyperphosphatemia and erythropoiesis-stimulating agent therapy for anemia) are infrequently required until patients have more advanced CKD. (35-38)

Referral Package

If patient information is not centrally shared between referring nephrologists and the MCKC, the following information should be provided as part of the referral to the MCKC:

Category	Elements
Last known laboratory values	• eGFR • Serum creatinine • Urine albumin/creatinine ratio (ACR)
Last known value	• $KFRE_2$
Clinical information from the patient chart	• Consult letters/ clinical summaries • Updated medication list • Other relevant laboratory and diagnostic tests
Important information on patient needs and preferences	• Patients' geographical location and their ability to attend appointments (e.g., rural/remote with limited access to testing) • Patients' preference for visit type (e.g., in-person, telephone or videoconference, group or individual) • Disability-related accommodation(s) • Communication barriers/language preference • Requirement for an interpreter • Family and/or caregiver support • Access to transportation • Access to basic resources (e.g., food, clothing, shelter) • Financial means to travel to appointments

4.2 Initial Visit and Orientation

The initial MCKC visit should include an orientation for patients and their caregivers. When possible, the orientation should include information on MCKC goals, philosophy, programs, services, team roles and logistics (e.g., clinic hours, appointment times). The purpose of the orientation is to familiarize patients and their caregivers with the MCKC care team and clarify what they can expect throughout their MCKC care journey.

Orientation information may be provided to patients and their caregivers in various formats, such as:

- Physical and electronic handouts/letters.
- Group and/or individual information sessions.

- Individual or group information sessions led by staff and/or peers; this could also include education on basic kidney health and disease.

The initial visit and orientation should be conducted in-person, when possible and based on patient preference. During the initial visit, patient and caregivers should meet with all members of the MCKC care team. The initial visit should also include an integrated assessment incorporating the perspectives of all MCKC care team members, the patient and their caregivers. The Care Team Roles section of this document outlines the roles and responsibilities of key members of the care team. The patient's ability to attend appointments and preference for visit type (e.g., in-person, videoconference and/or phone) should be discussed during the initial visit.

4.3 Frequency of Visits and Visit Types

Frequency of Visits

The frequency of MCKC visits should be based on the severity and stability of the individual patient's CKD status. Patients should be followed as often as needed to manage their health care needs, build rapport, receive ongoing education, and participate in goals of care discussions and shared decision-making on treatment decisions.

At a minimum, patients should have two MCKC visits per year though most patients will need to be seen more often. MCKC patients should be assessed in-person at least once a year, taking into consideration patient preference. As patients progress towards ESKD, frequency of visits should increase, and they may need to be followed as frequently as every month.

Most MCKC patients will benefit from seeing care team members at the frequency outlined in the table below:

Care Team Member	Minimum Visit Frequency
Nurse and Nephrologist	**Each visit**
Dietitian	**At least twice annually** And as needed or upon patient request; it is anticipated that as CKD progresses, more frequent assessments will be required.
Pharmacist	**At least twice annually** And as needed or upon patient request, after an intervening hospital admission or transitions in care.
Social Worker	**At least twice annually** And as needed or upon patient request; it is anticipated that as CKD progresses or other significant stressors arise, more frequent assessments will be required.

The minimum visit frequency stated is to ensure that patients have access to all disciplines and is not intended to restrict visits to a specific number. Excluding the initial clinic visit, clinics should typically strive to not have more than four team members see the patient in a single visit unless there are exceptional circumstances, as visits with multiple health care professionals at a single encounter can be tiring for patients.

Other factors determining visit frequency include:

- Patient and caregiver needs and preferences
- Ability of patient to self-manage

Visit Types

MCKC patients may have access to both in-person and virtual visits. Virtual visits include videoconferencing or by phone to ensure access for remote patients or patients who are unable to attend in-person visits. Care should not be limited to clinic visits. Patients and caregivers should be supported between clinic visits and encouraged to contact the MCKC care team with any questions or concerns.

Considerations for conducting in-person MCKC visits include:

- Initial MCKC visit
- Rapid decline in kidney function
- Need for physical examination (e.g., fluid status, dialysis access exam or follow-up)
- Modality education visits
- Nearing the transition to modality of choice (e.g., kidney transplantation or dialysis)

For virtual visits, encourage patients where possible to monitor their blood pressure, heart rate and weight to support assessments.

Resources

- Kidney Failure Risk Equation (KFRE) Information (ORN)
- Kidney Failure Risk Equation Calculator
- Virtual Visits with Your Kidney Care Team During COVID-19 – Patient Resource (ORN)

5.0 Goals of Care

It is important to consider how treatment decisions align with patients' values, world views, health and wellness beliefs, goals, and preferences for their care. The desired outcome is for patients and health care providers to have a shared understanding of the patients' goals for their care. **Goals of care discussions should be completed within the first three MCKC visits or education visits, or within one year of MCKC registration (whichever comes first).**

Substitute Decision-Maker and Goals of Care

The MCKC care team should identify and document the patient's substitute decision-maker (either by accepting the patient's automatic substitute decision-maker or the patient assigning a power of attorney for personal care). Goals of care discussions should occur between a care team member and a capable patient (or the incapable patient's substitute decision-maker) in a private setting and should focus on:

- Ensuring the patient understands the serious, progressive, and sometimes incurable nature of their illness; and
- Helping the health care provider to understand the patient's values, goals, and preferences for their care.

Goals of care discussions should be completed at in-person visits or virtual clinic visits where video conferencing is available. If this is not possible, health care providers may assess if the goals of care discussion can be completed by telephone on a case-by-case basis. All goals of care discussions should use essential communication skills:

- Ask open-ended/clarifying questions
- Offer reflections and validation
- Use silence to allow time for processing of information and emotions
- Be prepared for emotions

A patient's goals and values may change over time as new information or changes in health status arise. It is important for goals of care discussions to be ongoing and updated (or assessed) annually and upon any health status change. Goals of care discussions should be documented in the patients' treatment plan, shared with patients when requested, and include a summary of all treatment decisions that are developed with patients in conjunction with the multidisciplinary team. Patients should be encouraged to share their goals of care with their substitute decision-maker and family or friends to prepare them for possible future decision-making. MCKC care teams should ensure processes include individuals such as Spiritual and Faith Supports, Indigenous Elders and Knowledge Keepers to support discussions.

Health Care Code Status

Code status is an important treatment decision that must be made by patients or incapable patients' substitute decision-makers. It is important for the MCKC care team to discuss the risks and benefits of resuscitation with patients and caregivers. Patients or substitute decision-makers can change code status at any time.

Informed Consent

During the process of making treatment decisions, informed consent requires providing patients with information about the nature of treatment, expected benefits, risks, side effects, alternative courses of action and likely consequences of not receiving treatment. (39)

Resources

- Multi-Care Kidney Clinic Goals of Care Discussion Guide – Resources for Health Care Providers (ORN)
- Approaches to Goals of Care Discussions - Resource for Healthcare Providers (ORN)
- Advance Care Planning, Goals of Care & Treatment Decisions and Informed Consent FAQ – Resource for Patients and Health care Providers (ORN)

6.0 Patient and Caregiver Education Principles

A core function of the MCKC is for patients to receive education on CKD health and modality options that both optimize patient outcomes and incorporate the patient's goals of care, culture, and values. The timing of education on CKD health should be initiated early and continue during a patient's renal journey, while modality education will occur as risk of progression towards ESKD increases.

MCKC care teams should:

- Provide education using a shared decision-making and person-centred approach.
- Support, acknowledge and explore patient and caregivers' fears, concerns, barriers and needs.
- Provide patients and caregivers adequate time to make decisions.
- Provide education in the patient's primary language whenever possible.

All education sessions and tools should be designed with consideration of adult learning principles, cultural safety, health literacy and self-management skills. Education should be in plain language, avoid medical jargon, and tailored to individual patients and their caregiver's knowledge and understanding of CKD. Education materials should be referred to during visits and provided to patients to review after visits. Education is best phased over time and paced as directed by patients and their caregivers based on their stage of readiness to learn. (40)

Treatment option grids and decision aid tools may be used to support patients (or a substitute decision-maker, if applicable) with making an informed decision to proceed with a modality option that best suits their needs and those of their caregivers (see resource below). Additionally, MCKC care teams should refer patients to appropriate modality teams for additional information and discussion to support with decision-making.

6.1 Self-Management Education for Patients and their Caregivers

Given the persistent nature of CKD, education programs should be focused on chronic disease management and self-management interventions. Self-management education interventions should focus on supporting patients and caregivers in acquiring and maintaining skills needed to manage their life with a chronic disease. This includes: (41)

- Medical management of illness
- Adjustment of roles and relationships
- Management of symptoms, including mental health challenges as a result of illness and/or treatment
- Psychosocial impact of illness and of treatment
- Maintenance of a healthy lifestyle to optimize health across their CKD journey
- Integration of traditional healing and wellness practices

Patients who are supported to develop self-management behaviours may feel more empowered and better able to make informed decisions, cope with treatment and treatment-related side effects and navigate the health system. As a result, they may be more satisfied with their care and therefore have a better care experience. It is important that MCKC care teams recognize that patient self-efficacy is a key component of successful self-management. Education should be grounded in an approach that supports hope, optimism and feasibility of accomplishing change that supports CKD management. (42)

6.2 Peer Support

Patients and caregivers impacted by CKD have consistently referenced the value in connecting with others who have a similar shared experience. Peer support is recommended as part of the education process. Peer support can be described as a unique type of social support provided by those who share characteristics with the person being supported and is intentionally fostered within formal interventions (43). Peer mentors can share life experiences relating to the challenges and successes of living with disease, self-care and coping strategies, and navigating the health care system. Peers may have the potential to influence health outcomes of other patients by addressing feelings of isolation, promoting a positive outlook, and encouraging healthy behaviour.

Peer support can be facilitated in a variety of ways, including:

- One-to-one peer matching (e.g., Transplant Ambassador Program)
- Facilitated group peer support
- Online forums
- Indigenous Elder/Knowledge Keepers
- Spiritual/Faith Supports

Given the important and influential role peer mentors can play, supports and structures for ongoing monitoring, supervision and training for peer supporters is strongly recommended.

6.3 Components of Effective Modality Education

To promote effective modality education, it is essential that all team members are knowledgeable and comfortable with all modalities and are providing consistent messaging to patients. Components of an effective modality education program include (40):

- A mix of one-on-one and group sessions
- Peer support and education (e.g., Transplant Ambassador Program)
- A standardized curriculum that can be tailored to individual patient and caregiver needs
- Printed or electronic reference materials
- Experiential “hands on” learning that provides opportunities for patients and their caregivers to gain knowledge through “doing” (e.g., showing and using different dialysis machines, touring dialysis unit, allowing patients to touch and practice using different types of dialysis access)

Suggested content to include:

- Refresher on the functions of kidneys, CKD health and why renal replacement therapy is required
- Education covering all modality options, including benefits, risks, barriers and supports available for each
- Criteria and processes used to assess eligibility for modality options

It is particularly important that patients selecting a modality option understand that they will always have the opportunity to revisit modality options with the MCKC care team. Given the amount of information provided in MCKCs, it is critical for MCKC care teams to explore a patient’s perceived understanding of the education being provided. (44) Patients may benefit from a variety of education delivery methods, including in-person and virtual sessions, individual or group sessions, and discussed as part of MCKC care team appointment(s). Initial training or re-training for patients should be completed in-person to ensure patient understanding and assess challenges.

Resources

- Book One: Living with Reduced Kidney Function (The Kidney Foundation of Canada)
- Book Two: Living with Kidney Failure (The Kidney Foundation of Canada)
- Stand Up to Diabetes, Ontario Diabetes Strategy – Self-Management Programs (Ministry of Health and Long-Term Care)
- Living well with Chronic Kidney Disease (CKD) (Can-Solve CKD Network)
- Renal Replacement Treatment Options Grid (SHERPA-DM)
- Patient Decision Aid (SHERPA-DM)
- Kidney Peer Support Program (The Kidney Foundation of Canada)

7.0 Education on CKD Health and Modality Options

7.1 Education on CKD Health

Suggested elements to cover in general CKD health education include:

- How kidneys function
- Risk factors, common causes and understanding of CKD
- Management of other medical conditions, such as diabetes and hypertension
- Diet and nutrition for overall health
- Living well with reduced kidney function, including benefits of exercise
- Hepatitis screening and appropriate timing and resources for vaccinations, based on Ontario's Publicly Funded Immunization Schedule
- Review and management of medications, including sick day management
- Laboratory tests, the meaning of test results and how to obtain copies of results
- Smoking cessation
- Palliative care and end-of-life care
- Psychosocial impact of CKD

7.2 Education on Modality Options and Decisions

As patients' risk of progression towards ESKD increases, the MCKC care team should dedicate time to provide focused education on modality options to patients and their caregivers to allow them to make an informed decision about the management of ESKD. Patients and their caregivers should receive information about all modality options, including:

- Transplantation (living and deceased donation)
- Dialysis including in-facility hemodialysis (HD), peritoneal dialysis (PD) and home hemodialysis (HHD)
  - For those who are considering dialysis, where appropriate, a home therapy should be promoted (see Home Dialysis Education).
- Conservative renal care (CRC)

Timing of Modality Education

Considerations for the initiation of education on modality options include ensuring sufficient time for patients to prepare for their modality decision while also preventing undue stress for patients who are unlikely to progress towards ESKD and require renal replacement therapy within the next two years. **For most patients, education on modality options should be initiated between a $KFRE_2$ of 20% and 40%.**

Timely modality education for patients who may progress more rapidly than anticipated by their $KFRE_2$ should have a decision made at least one year prior to the anticipated need for modality treatment. MCKC care teams should periodically revisit prior modality decisions, particularly home dialysis, to address new enablers or barriers that may have arisen. (45,46)

For patients who are likely candidates for pre-emptive transplant, patients should receive modality education at the lower end of this $KFRE_2$ range. Earlier education ensures that the timing of referral to a transplant centre for assessment is consistent with the Trillium Gift of Life Network's recommendation of $KFRE_2$ of approximately 25%.

For patients who select hemodialysis and an arteriovenous fistula as their preferred modality and vascular access, MCKC care teams should refer for vascular access assessment at a $KFRE_2$ of 40%. (8)

7.3 Transplant Education

Kidney transplantation for patients with ESKD provides the best long-term outcomes, in terms of both quality of life and life expectancy. (47,48) Living kidney transplantation is often a more beneficial option for patients, allowing a patient to potentially avoid dialysis, provided they have a suitable donor. Timely education about kidney transplant and living donation can ensure patients and caregivers have the information they need to pursue pre-emptive kidney transplantation and to support timely work-up, as well as work-up for any potential living donor. Patients will benefit from multiple conversations with their care team and transplant ambassadors over time (see Transplant Ambassador Program for additional information).

The MCKC care team should follow Ontario's Referral and Listing Criteria for Adult Kidney Transplantation, to identify those who would benefit from kidney transplantation and, where appropriate, communicate to patients why a kidney transplant may not be suitable for them.

Suggested content to include:

- Review the benefits of kidney transplantation (e.g., prolonged survival, improved quality of life).
- Review the benefits of living kidney donor transplant over deceased donor transplant (e.g., shorter wait time to transplant, improved patient and graft survival).
- Encourage patients to learn about living donation, to share their stories with family and friends and to have discussions with potential donors.
- Provide patients with resources and supports to help find a living kidney donor.
- Encourage patients to talk to transplant ambassadors, individuals with lived experiences donating a kidney or receiving a kidney transplant.
- Patients and their caregivers should be made aware of:
- Educational resources about kidney transplantation and living donation.
- Available financial supports for living kidney donors, such as the Government of Ontario's Program for Reimbursing Expenses of Living Organ Donors (PRELOD). PRELOD reimburses eligible out-of-pocket expenses for costs incurred by potential and actual living donors for travel, parking, meals, accommodation, and loss of income.

If the preferred modality is transplant, patients are asked to also select a secondary modality option, as patients may require dialysis prior to the transplant taking place or may experience complications related to their transplant.

Transplant Ambassador Program

The Transplant Ambassador Program is a provincial patient-led grassroots support program that aims to support patients and their caregivers in learning more about kidney transplantation and living donation. Transplant ambassadors are individuals with lived experiences donating a kidney or receiving a kidney transplant. They can play an important role in helping patients and their caregivers pursue transplantation as a modality option. Patients and potential donors can connect with transplant ambassadors either in-person in clinics or remotely by phone or video conferencing. The ambassadors are trained to share their lived experience, and not to give medical advice.

MCKC care teams can connect patients and potential donors with transplant ambassadors by contacting their Regional Renal Program's TAP lead(s). Peer mentorship can increase referrals for kidney transplantation and support patients while they are progressing through transplant evaluation and wait-listing. (49) Peer mentorship can also reduce racial disparities in access to transplantation. (50)

7.4 Home Dialysis Education

When pre-emptive kidney transplantation is not an option, home dialysis (PD, HHD) should be encouraged as it allows for flexibility and greater independence, which may lead to improved quality of life (51,52) and is more cost-effective for the healthcare system. (53) It is recommended that all patients be assessed for home dialysis. It is also beneficial for MCKC care team members to be in regular contact with the home dialysis unit, to discuss patients who have selected or are considering a home dialysis modality. This can help to facilitate a smooth transition once patients need to start dialysis.

Suggested content to include:

- Review the potential benefits and barriers of home dialysis (e.g., physical space needs, supply management).
- Patients and their caregivers should be made aware of:
- Education resources on how PD and HHD work, and guide patients on how to safely conduct dialysis at home.
- Available financial supports, such as the Home Dialysis Utility Grant, is available for HHD patients to offset electricity and water costs.
- Assistance for dialysis at home may be available for patients who have challenges in doing PD and HHD independently. The type of assistance may vary by Regional Renal Program.

The MCKC care team should review ORN's Home Dialysis Assessment Document, created to support team members in overcoming barriers to starting patients on home dialysis.

The ORN is committed to supporting the unique needs of Indigenous peoples and ensuring remoteness is not a barrier to home dialysis options. Additional funding may be available to cover expenses that typically would not be incurred with supporting a home dialysis patient (e.g., freight charges for supply delivery).

7.5 Conservative Renal Care Education

Similar to dialysis and transplant, CRC is recognized as a modality option for advanced CKD. CRC is planned, holistic, patient-centred care for patients with advanced CKD and their caregivers. Dialysis does not always provide a substantial survival advantage or improve quality of life. It should be emphasized that choosing CRC is not a "no treatment" option and that patients will continue to receive high quality medical care. Discussions around confirming patients' illness understanding, discussing, and documenting goals of care and ensuring informed consent are essential in supporting patients with making this modality decision.

Health care providers should ensure that CRC education is provided. Refer to ORN's Approaches to CRC Conversations, a resource for providers, for tips on discussing CRC with people with advanced CKD, their families and caregiver(s). The ORN's Key Elements of CRC document includes detailed information about CRC education for patients and caregivers. In general, the following concepts for CRC modality education should be covered:

- Expectations for the CRC treatment option, including what treatments may be included and their benefits and side effects.
- Description of the care team and how often the person choosing CRC can expect to meet each team member.
- Definition and introduction of the concept of crisis (e.g., occurrence of acute and worsening of symptoms, urgent needs for personal care services, sudden change in functional status).
- Definition of the palliative approach to care and identify and respond to the person's holistic needs
- It is particularly important that those considering CRC understand that they will always have the choice to change their decision or initiate dialysis if required.

Resources

For Transplant:

- Ontario's Referral and Listing Criteria for Adult Kidney Transplantation (Trillium Gift of Life Network)
- Transplantation Resources for Patients and Donors (ORN)
- Transplantation Tools for Health Care Professionals (ORN)
- Factors Impacting Wait Times for a Deceased Donor Kidney Transplant (Trillium Gift of Life Network)
- Transplant Ambassador Program (TAP)

For Home Dialysis:

- PD Fact Sheets for Patients (ORN)
- HHD Fact Sheets for Patients (ORN)
- Home Hemodialysis Utility Grant (ORN)
- ORN Home Dialysis Eligibility Assessment

For Conservative Renal Care:

- Key Elements of Conservative Renal Care (ORN)
- Approaches to Conservative Renal Care Conversations – Resource for Healthcare Providers (Ontario Health)
- Conservative Renal Care – What Can I Expect? – Resource for Patients (Ontario Health)

8.0 Active Management of CKD

Active management of CKD is a key function of the MCKC. This includes:

- Providing general CKD care, including:
  - Initial and ongoing medical assessments.
  - Monitoring and follow-up of lab results, responding as necessary to abnormal results.
  - Monitoring of fluid status, identification of wounds[6], and vital signs.
    - For virtual visits: patient's monitoring of blood pressure, heart rate and weight to support assessments.
    - For in-person visits: monitoring of vital signs and weight should be completed at each visit.
- Employing therapies proven to reduce the rate of decline of kidney function and/or reduce a patient's cardiovascular risk, including blood pressure control (54), use of renin-angiotensin-aldosterone system inhibition (55-57), SGLT2 inhibitors (58-61), and GLP-1 receptor antagonists (61) where appropriate[7], and treatment with statins. (62)
- Managing anemia (63) and other CKD-related complications, including disorders of bone-mineral metabolism (64) and acidosis (65), as they arise.
- Modification of risk factors, including smoking cessation and exercise.
- Actively managing medications to maintain patient health.
  - Medication reconciliation has been recognized as an essential strategy to reduce medication errors that result in patient harm. (66,67) Medication reconciliation utilizes a Best Possible Medication History and verifies the medication using a secondary source such as a community pharmacy or Ontario Drug Benefits Plan.
  - MCKC care teams are encouraged to review medications at each clinic visit and provide education, reinforcing sick day advice where appropriate.
  - Based on expert opinion, the best practice is for the pharmacist to perform the medication reconciliation.
  - Be open to and where possible facilitate the integration of Indigenous traditional medicines.
- Monitoring diet and nutrition for kidney health, including:
  - Assessment of nutritional status and ongoing dietary reviews to recommend appropriate therapeutic diet(s) that integrates management of concurrent health conditions as well as food preferences and religious/spiritual dietary practices.
  - Referrals to appropriate resources to assist in coping with diet concerns and improving access to food such as meal programs and social assistance.
- Empowering and supporting patients and caregivers to be partners in their care.
- Facilitating patients' and caregivers' understanding and confidence for managing their care and navigating the health care system (self-management).
- Monitoring patients' mental health and identifying opportunities for referral to other services when required.

Resources

- Medication Safety and Medications that Must be Considered for Dose Adjustment or Avoidance (ORN)

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[6] For patients with diabetes, examination of feet is recommended.

[7] Management of diabetes care may require coordination and referral with a Diabetes Specialist.

8.1 Symptom Management

Patients with CKD can have frequent and severe symptoms that can be distressing and overwhelming for them and their caregivers. Patients may develop symptoms directly related to their CKD, comorbidities and/or the occurrence of new health problems. Symptoms are frequently not reported by patients because there is uncertainty whether the symptoms are related to their kidney disease or because there are other medical issues being addressed that overshadow broader discussions of health concerns. As a result, symptoms may be under-treated despite research consistently showing that uncontrolled symptoms are amongst the biggest health concerns that patients with CKD have (68). Monitoring patients for symptoms may lead to improved symptom control and quality of life for patients, improve patient-provider communication, and inform conversations around health priorities and goals of care. Symptoms common in CKD include, but are not limited to:

- Anxiety
- Depression
- Fatigue
- Sleeping problems (e.g., insomnia)
- Pruritus
- Diminished appetite
- Nausea
- Pain
- Restless legs
- Shortness of breath

It is important for MCKC care teams to understand that symptoms can impact a patient’s engagement with their care and may require a multidisciplinary approach to manage. Standardized tools and resources, such as Edmonton Symptom Assessment System Revised Renal Questionnaire (ESAS-r: Renal) (69) and EQ-5D-5L, can be used to help screen patients for common symptoms (see resources below). Once symptoms are identified, ruling out alternative, clinically important etiologies are important. Symptoms may be treated with non-pharmacologic and/or pharmacologic measures. Response to treatment may change as the safety of treatments are reviewed in conjunction with the patient’s kidney function.

Discussions with patients and their caregivers about their expectations and the goals of management can be important. Further, it is important to recognize that symptoms may change in intensity and nature over time and reassessment is required periodically.

Resources

- Symptom Management Tools - Resources for Health Care Providers (ORN)
- Managing your Symptoms – Resources for Patients (ORN)
- Edmonton Symptom Assessment System Revised – Renal Questionnaire (ESAS-r: Renal Tool) (ORN)
- EQ-5D-5L Tool (EuroQol Research Foundation)
- Living well with Chronic Kidney Disease (CKD) (Can-SOLVE CKD Network)

9.0 Coordination and Navigation of Care

Once a modality option is chosen, the MCKC care team plays an active role in coordinating and navigating patients along the selected pathway. This includes coordinating care provided within the MCKC as well as accessing and establishing linkages for patients and their caregivers with other care providers and/or resources. The MCKC care team should also play an active role in communicating with all members of a patient's care team (e.g., primary care, community supports and other health care professionals/services).

First Nations, Inuit, Métis, and Urban Indigenous people often receive care from multiple service providers, including federal, provincial and community entities, and may require assistance in coordinating supports and addressing cross-jurisdictional gaps. To improve health care experience and ensure Indigenous patients receive care that is culturally appropriate, the MCKC care team should establish mutually trusting and respectful relationships with patients and their support system. Where possible and with permission from the patient, collaborating with Indigenous supports available within the hospital, within the patients' community and/or from Indigenous organizations. This may include, Indigenous Navigators, Elder/Knowledge Keepers, Traditional Healers, Non-Insured Health Benefits (NIHB), Aboriginal Health Access Centres, Indigenous Primary Care Teams, Indigenous Friendship Centres, Métis Nation of Ontario, and/or Tungasuvvingat Inuit.

For all modality options, the MCKC care team:

- Coordinates and collaborates with the respective modality team as early as possible to confirm the preferred modality option for the individual patient and completes required assessment, testing, specialty consultations and procedures.
- Actively monitors, treats, and provides physical care and psychosocial support up to the point of transfer of care to the receiving modality team.
- Advises the modality team of significant changes in patient health status.
- Coordinates with external supports that are important to the patients' transition (e.g., primary care, home care).

9.1 Transplant Coordination

In addition to the tasks noted above, for patients who will be receiving a transplant, the MCKC care team:

- Refers patients for transplant assessment if:
    - The patient is expected to require dialysis within the next year
    - The patient has potential living kidney donors* *and* meet any of these criteria:
        - Have an eGFR less than 15 mL/min/1.73m^2
        - Have a KFRE$_2$ greater than or equal to 25%
        - Is expected to need dialysis in the next 2 years
- Liaises with the Regional Renal Program's pre-transplant coordinator to ensure patients receive education about the pre-transplant process, including the required tests, expected travel, and expected process duration.
- Collaborates with the Regional Renal Program's pre-transplant coordinator to ensure completion of the transplant referral package in an efficient and person-centred manner.
- Encourages patients to talk to transplant ambassadors throughout their transplant journey, including during the pre-transplant referral/work-up process.
- Communicates to the patient about their status or progress during the pre-transplant process. This may include liaising with the transplant centre and/or pre-transplant coordinator.
- Helps identify potential living kidney donors.
- Works with the living donor program and/or the Regional Renal Program's pre-transplant coordinator to determine whether there is a potential living donor candidate for patients to pursue pre-emptive transplant.
- Encourages potential donors to contact a transplant centre for evaluation once the recipient is referred.

For more information on referral eligibility, see Would Your Patient Benefit from a Kidney Transplant Referral?

9.2 Dialysis Coordination

In addition to the tasks noted above, for patients who are beginning dialysis (whether in-facility or at home), the MCKC care team:

- Collaborates with the home dialysis team to proactively identify patients that may be appropriate for home dialysis, identify potential barriers to starting home dialysis, and jointly develop strategies to overcome barriers.
- Works with the dialysis team to prepare patients for pre-dialysis tests, consults and procedures.
- Works with Body Access Coordinators, the vascular access clinic and/or the clinic responsible for arranging peritoneal catheters and arteriovenous fistulas to ensure timely access creation.
- Prepares and shares a current patient summary with the dialysis team.
- Determines the appropriate dialysis start date jointly with the patient and caregivers, nephrologist, and dialysis team.
    - Where appropriate, a deferred dialysis approach should be taken. See section on Indicators for more information.

9.3 Conservative Renal Care Coordination

CRC is delivered primarily in the MCKC setting by the multidisciplinary team and includes ongoing intervention or active treatment to minimize complications of CKD, symptom management, psychosocial and spiritual support, and shared decision-making. CRC should involve the coordination of home and community supports (e.g., hospice), primary care and engagement with palliative care specialists if needs become more complex. Some Regional Renal Programs may have a designated CRC clinic, in which MCKC care teams are to support referral and transition of care.

For patients who will be receiving CRC, the MCKC care team:

- Supports the person's right to make this decision.
- Continues to provide care if patients choose to stay within the MCKC, in alignment with the Key Elements of CRC.
- Ensures smooth transition to a receiving provider (e.g., primary care provider, nephrologist, palliative care specialist, CRC clinic) if patients prefer to receive care outside of the MCKC.
- Ensures the patients' values, goals and preferences are respected.
- Focuses on the patients' psychosocial support and symptom management.

9.4 Transitions and Transfer of Accountability

Incoming transitions:

- If patients are transitioning from a nephrologist office, ongoing care is assumed by the MCKC on the day of the first MCKC clinic visit.

Outgoing transitions:

- Regional Renal Programs should develop and implement transfer protocols/policies to appropriate care settings and teams.
- MCKC care teams should work collaboratively with the receiving team (e.g., the dialysis team, the transplant centre, CRC clinic team) to ensure seamless transitions for patients to and from the MCKC.

For outgoing transitions, patients typically transition to:

Outgoing transition	**Care Transitions and Accountability**
PD	PD team at or near the time of first training
HHD	HHD team at or near the time of first training
In-facility HD	In-facility HD team on the day of first dialysis treatment
Transition Unit	Transition team on the day of first dialysis treatment
CRC care at a designated clinic	CRC Team
Pre-emptive transplant	Transplant team on the date of transplant

Note: For patients who have initiated dialysis therapy while waiting for transplantation, the dialysis team should assume the responsibility to work with the transplant team to monitor the status of the referral.

9.5 Repatriation to Nephrologist

A minority of MCKC patients may no longer require MCKC support and may be appropriate to discharge back to their nephrologist. These include patients who:

- Have a $KFRE_2$ that is consistently below 10%.
- Have opted out of receiving MCKC care.
- Do not wish to have dialysis or transplantation, have opted out of receiving CRC in MCKC and have a care plan, and the nephrologist/primary care provider/palliative care specialist and the patient are comfortable in the arrangements for ongoing care.

Considerations prior to discharge from clinic should include:

- Availability of a physician to receive/manage the patient after discharge
- A plan for ongoing care, clearly communicated to the patient, caregiver, and primary care provider
- Availability of community supports, communicated to patients and their caregivers (e.g., peer support)

Note: If MCKC support is required later, the patient may be re-referred to MCKC by their nephrologist.

10.0 Care Team Roles

Shared Team Functions

Assessment and Care Planning

- Recognizes the patient as a person and not a disease and fosters environments that support patient safety and is considerate of the patients' and caregivers' experience.
- Assesses patient health literacy, preferred language for speaking and reading, patient's ability to attend appointments, preference for visit type (e.g., in-person, videoconference and/or phone) and access to technologies.
- Respects diverse views, culture, spiritual traditions, gender identity, gender expression, sexual orientation and abilities of patients and their caregivers; Acknowledges First Nations, Inuit and Métis and Urban Indigenous patients in their desire to incorporate Indigenous worldview and traditional healing practices into their care plan.
- Seeks and supports patient's access to social, financial, emotional and self-determination support programs.
- Ensures patients and caregivers are continually engaged partners in their care by regularly confirming patients' health priorities, seeking feedback regarding their experiences managing CKD.
- Actively participates in decision-making conversations within their scope of practice.
- Following a clinic visit, coordinates follow up with care team members to discuss care planning and provides supports to patients and caregivers between MCKC visits.
- Fulfills legislated mandates related to adult guardianship, mental health, child protection, privacy and freedom of information and other relevant legislation as needed while managing complex patient situations.
- Manages symptoms of CKD.

Education

- Be knowledgeable and comfortable educating patients and caregivers on CKD health and modality options, ensuring messaging is consistent across the care team.
- Educates peers, students, and other learners about CKD.
- Participates in program planning and quality improvement activities.
- Completes self-assessment and seeks out opportunities to enhance knowledge and skills (e.g., Cultural Safety training).

Transitions

- Prioritizes intake of new referrals for timely MCKC access, with consideration to the referring nephrologist's input.
- Communicates patient-specific information, including patient and caregiver values, goals, and preferences to the appropriate modality team when transitioning patient to PD, HHD, in-centre HD, transplant, or CRC.
- Advocates on behalf of patients and caregivers, when required, to ensure access to appropriate services in alignment with their goals of care.
- Participates in case management (if applicable).
- Refers, communicates, and coordinates care for patients with other health care. professionals/services as needed (e.g., primary care, diabetes education centre, heart health, home care, palliative care specialist, Aboriginal Health Access Centres).

Patient and Caregivers

- Empower patients and caregivers to feel confident and in control of their lives and the management of their CKD. They should be willing to share the responsibility to manage their CKD in partnership with their care team. As a MCKC care team member, patients can expect to:
    - Feel safe, including when asking questions and expressing concerns.
    - Receive individualized care from a skilled and compassionate MCKC care team.
    - Give or refuse consent for any procedure or treatment.
    - Participate in all health care decisions and treatments.
    - Integrate cultural expression such as special traditions or practices into care.

Nephrologist

Assessment and Care Planning

- Performs initial medical assessment and reassessments at each visit, including review of intercurrent medical events, symptoms, and significant changes in health status (e.g., hospitalization).
- Participates in shared decision-making conversations.
- Initiates and documents goals of care discussions in the patients' plan of treatment, annually and with health status change.
- Supports patients in shared decision-making, including selecting an appropriate treatment option.
- Discusses with patients their physical limits (e.g., ability to exercise).
- Employs interventions to minimize rate of progression of CKD.
- Employs interventions to reduce patients' cardiovascular risk.
- Determines frequency of lab monitoring and clinic visits.
- Follows up on abnormal laboratory results and intervenes as necessary (shared role with nurse).
- Documents in chart (dictated and/or written) all communications with primary care provider and other specialists involved in the patients' care.
- Provides primary-level palliative care including symptom management.

Patient/Caregiver Education

- Reinforces education efforts by multidisciplinary team.
- Supports modality education (deceased and living donor kidney transplantation, dialysis, CRC) and ensures selected treatment is aligned with patients' goals of care (shared role with nurse).

Transitions

- Completes referrals for access to support services (e.g., Home and Community Care, medications, specialists, etc.).

Nurse

Assessment and Care Planning

- Assesses health condition, symptoms, diagnosis, and significant changes in health status (e.g., recent discharge from hospital).
- Assesses and supports patient and/or caregivers understanding of health condition.
- Monitors fluid status, identification of wounds, vital signs (blood pressure and heart rate), and vascular access (if in place).
- Monitors and follows up on lab results (e.g., anemia and declining eGFR).
- If a pharmacist not available (best practice is that these functions be done by a pharmacist), updates the patient's medication list at each MCKC visit based on the Best Possible Medication History.
- Documents nursing assessment and patient interaction in patient chart.
- Completes appropriate nursing care planning as indicated.
- Reviews patient chart after each clinic visit to ensure all orders have been processed completely and accurately.

Patient/Caregiver Education

- Educates on:
  - Nursing specific aspects of CKD and its implications: normal kidney function, blood tests, causes, symptoms and complications of CKD and indications for kidney transplant/dialysis.
  - All modality options (deceased and living donor kidney transplantation, dialysis, CRC) to support decision-making and to ensure selected treatment is aligned with patients' goals of care (shared role with nephrologist).
  - Medication information: anemia management, nephrotoxic medications to avoid, symptom management and sick day management (shared role with pharmacist).
  - Recommend getting vaccinated or immunized to protect against preventable disease based on Ontario's Publicly Funded Immunization Schedule (shared role with pharmacist).
  - Self-management of medical conditions (diabetes, high blood pressure, etc.), symptom management, exercise, smoking cessation and if dietitian is not available, dietary modifications (e.g., sodium, phosphate, potassium intake).
- Ensures all resources are in place (e.g., translation service) to ensure patients and caregivers understand that information that is presented.

Transitions

- Reviews preferred modality and readiness for transition regularly (see section Coordination and Navigation of Care for more information).
- Assists with coordination of referral for selected modality.

Pharmacist

Assessment and Care Planning

- Completes initial Best Possible Medication History and medication reconciliation at first MCKC visit and aims to have a comprehensive review of medications completed at each visit.
- Completes required pre-clinic information gathering from several reliable resources (e.g., Connecting Ontario, community pharmacy, patient chart) for Best Possible Medication History and medication reconciliation.
- Reviews patients’ allergies and intolerance to medications (may be done by either a pharmacist or pharmacy technician), medications for renal dosage adjustments and drug interactions and aids in interpretation of drug levels, where appropriate.
- Facilitates medication coverage (e.g., erythropoietin stimulating agents) with Ontario Drug Benefit/Trillium Drug program and private insurance plans, as required (pharmacist or pharmacy technician; shared role with social worker).
- Works with nephrologist to optimize treatment (e.g., blood pressure, pain management, glycemia, lipids, acidosis, gout, anemia, bone mineral metabolism, potassium, antibiotic selection, etc.).
- Detects and resolves actual and potential drug therapy problems and documents these in the patient record.
- Follows up with patients and caregivers as required (e.g., regarding tolerability of medications, blood pressure monitoring, etc.).
- Comprehensive medication review is documented in patient’s chart.

Patient/Caregiver Education

- Educates on:
  - Engaging with one pharmacy.
  - Notifying MCKC Care Team staff of any new prescriptions from non-MCKC providers.
  - Instructions of medication use, side effects and adherence.
  - Nephrotoxic medications to avoid and what to do when sick.
  - Use of over-the-counter medications, including herbal products (shared role with dietitian).

Transitions

- Liaises with community pharmacist to ensure patient’s medications are appropriately dosed and continuity of care (e.g., timing of medications in compliance packages, ensuring timely delivery of prescription) (pharmacist or pharmacy technician).
- Assists with transition of medication history for selected modality.

Dietitian

Assessment and Care Planning

- Assesses nutritional status, including an initial and ongoing review and analysis of medical and diet history, lab values and anthropometric measurements.
- Conducts ongoing dietary reviews and provides recommendations and self-management support on:
  - Oral intake and nutritional status; reviews protein, potassium, phosphorus, sodium, lipids, and other pertinent nutrients.
  - Vitamins and minerals; recommendations based on intake, availability of food/nutrition where patient resides, nutritional status, lab values and stage of CKD.
  - Oral nutrition supplements.
  - Potentially harmful herbal products (shared role with pharmacist).
  - Integration of food preferences and religious/spiritual dietary practices.
- Recommends appropriate therapeutic diet(s) and establishes a diet plan that incorporates all nutrition requirements, including the management of CKD, diabetes, cardiovascular disease, and other concurrent illnesses.
- Liaises and refers patients and caregivers to appropriate resources to assist with diet related. questions and concerns (e.g., meal programs or community supports; home and community care dietitian, assisted living or long-term care dietitian and/or diabetes educator).
- Responds to patients or caregivers' potential or expressed food insecurity. As appropriate and necessary, completes the Special Diet Application for the Ontario Disability Support Program or completes a letter to Veterans Affairs.
- Responds to patients' and caregivers' emotional/lifestyle adjustment issues about therapeutic renal diet/CKD status (shared role with social worker).
- Triggers for additional review include:
  - Unintentional weight loss, anorexia, nausea and/or vomiting, malnutrition.
  - Obesity with a goal of weight loss, especially in preparation for transplant.
  - Lab results concerning potassium, phosphorus, or glucose level.

Patient/Caregiver Education

- Educates on:
  - Food choices and meal ideas. Individualizes education and counselling regarding CKD, diabetes, heart disease, weight loss, etc.
  - On the impact of progressive CKD on the management of diabetes and specifically on the prevention, treatment, and management of hypoglycemia (where appropriate).
  - Label reading, menu planning, sources of potassium (where appropriate) and phosphate additives.
- Reinforces appropriate use of medications, including phosphate binders and iron supplements.
- Develops or provides appropriate renal-specific nutrition resources based on a variety of factors which may include nutrition care plan, patient goals, stage of CKD, ethnicity, culture, language, health/food literacy, living situation and access to support and resources.

Transitions

- Provides information and answers questions about changes in diet depending on treatment choice.
- Ensures continuity of nutritional care if patient care is transferred to another service area.

Social Worker

Assessment and Care Planning

- Develops and implements appropriate psychosocial care/intervention plan that facilitates patient and caregiver adaptation and well-being. Some psycho-emotional factors to be considered include cognitive decline, anxiety, depression, anger, caregiver burden, traumatic stress, crisis, grief and loss, abuse/neglect, and safety concerns.
- Provides assessment/referral for social determinants of health related to self-management of CKD- functional status, income, food and housing situations, and mental health services.
- Provides resource counselling for patients and caregivers on services and benefits (e.g., finances, medical/coverage, transportation programs and other benefits to overcome barriers and address current/future needs).
- Liaises and establishes linkages with Indigenous health service providers and organizations such as e.g., Non-Insured Health Benefits, Aboriginal Health Access Centres, Indigenous Friendship Centres.
- Mediates conflict between patients, their primary support, and the health care team.
- Facilitates caregiver meetings/care conferences and documents social work aspects of care plans.
- Helps patients develop relationships within the renal community (particularly the Kidney Foundation) for the purposes of self-advocacy and to help them access beneficial programs.

Patient/Caregiver Education

- Provides individual, caregiver, or group education on:
  - Hospital processes, the impact of illness/disability on relationships and life transitions when health conditions require a modified lifestyle.
  - Internal and external resources/services to help address their specific psychosocial barriers and needs, including peer support services.
  - Substitute decision-makers and/or power of attorney for personal care.

Transitions

- Provides information and answers questions about specific resources available to patients transitioning to another service area.
- Enhances and supports the capacity of First Nations, Inuit, Métis, and Urban Indigenous patients to access culturally relevant supports to help enable smooth transition to chosen modality choice.
- Regularly reviews patients' social and psycho-emotional readiness for transitions and provides clinical counselling for patients and their support system on transitions along the CKD journey.

11.0 Indicators

The ORN publicly reports on key indicators reflective of high quality MCKC care to support continuous quality improvement. Data and methodology details for advanced CKD performance indicators are available on the ORN website.

Key Performance Indicators

- **Referral to MCKC:** An incident measure to understand the proportion who are followed by a nephrologist and who had an MCKC visit within one year of meeting eligibility criteria.
- **Time Spent in MCKC Before Starting Dialysis**: An incident measure to understand the proportion of chronic dialysis patients who are known to nephrology for at least 12 months prior to chronic dialysis start, who had at least 12 months (and at least 2 visits) of funded MCKC follow-up care.
- **Delaying the Start of Dialysis:** An incident measure to understand the proportion of patients known to nephrology for at least 3 months prior to chronic dialysis start, who initiate chronic dialysis with a deferred start (defined as an eGFR ≤ 9.5 mL/min/1.73m^2).

Additionally, the ORN produces data and tools for internal MCKC care teams (e.g., Regional Renal Program MCKC Insights Report, Scorecards) to support performance management and enable local quality improvement. In particular, the MCKC Insights Report provides additional analyses (e.g., laboratory values reflective of kidney function at the time a patient meets MCKC eligibility, home dialysis starts for patients who spent adequate time in MCKC, proportion of MCKC patients with documented goals of care discussions) to support Regional Renal Programs improve the quality of care and patient experiences in MCKCs.

12.0 Appendix A: Task Group Members

The ORN wishes to acknowledge the significant contributions of members who shared their experiences, expertise, and insights to support the development of this document.

MCKC Priority Panel (2022)

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13.0 Appendix B: Glossary

Adult Learning Principles
Adult learning principles should be applied to the design and delivery of education programs for patients and caregivers. (70,71) These principles include adults need to know why they need to learn something; adults need to be involved in the planning and evaluation of their instruction; experience (including mistakes) provides the basis for learning activities; adults are most interested in learning subjects that have immediate relevance to their life; adults approach learning as problem-solving.

Caregivers
For simplicity and readability, the Best Practices uses the term caregivers to refer to the people who provide patients with critical and often ongoing personal, social, psychological, and physical support, assistance, and care, without pay. Caregivers may include family, friends, neighbours and/or volunteers.

Conservative Renal Care
CRC is a holistic, person-centred, and active treatment option for people with ESRK), which focuses on prioritizing quality of life, providing support and advice, addressing symptoms, and maintaining kidney function. CRC does not include renal replacement therapy (dialysis and transplant).

Culturally Safe Care
Culturally safe care is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care. (23)

Equity
Unlike the notion of equality, equity is not about sameness of treatment. It denotes fairness and justice in process and in results. Equitable outcomes often require differential treatment and resource redistribution to achieve a level playing field among all individuals and communities. This requires recognizing and addressing barriers to opportunities for all to thrive in our society. (16)

Goals of Care Discussion
Discussions between a provider and a patient (or if the person is incapable, the substitute decision maker) that aim to ensure a patient understands the nature and trajectory of their illness and help the health care provider to understand the patients' values, goals, and preferences they have for their care. It is important that these discussions are ongoing and occur throughout the illness trajectory.

Health Equity
A state where "…all people (individuals, groups and communities) have a fair chance to reach their full health potential and are not disadvantaged by social, economic and environmental conditions." (16)

Kidney Failure Risk Equation ($KFRE_2$)
A validated equation that uses the patient's age, sex (male or female), eGFR and urine ACR to provide the 2-year probability of kidney failure for a patient with an estimated glomerular filtration rate (eGFR) of less than 60 ml/min/$1.73m^2$.

Medication Reconciliation
Medication reconciliation, as defined by the Canadian Patient Safety Institute and Accreditation Canada, is a structured process in which health care professionals' partner with patients and caregivers that results in a comprehensive review and evaluation of all medications.

Multidisciplinary
Multidisciplinary refers to both a team of health care workers who are members of different disciplines, as well as the process of interprofessional collaboration in which health care providers from different disciplines work together with patients and caregivers to enable optimal health outcomes.

Patient and Caregiver Engagement
The cornerstone of a person-centred care approach. It focuses on building strong, sustainable partnerships between patients, family members, health professionals and community groups to plan, deliver and evaluate health services.

Person-Centred Care
An approach to care that views people using health services as equal partners in planning, developing, and monitoring care to make sure it meets their needs.

Shared Decision-Making
A collaborative process that allows patients and their providers to make health care decisions together. The shared decision-making approach considers the best scientific evidence available and a patient's values, goals, preferences, caregiver situation, culture, and lifestyle.

World view
Worldviews are sets of beliefs and assumptions that express how cultures interpret and explain their experiences and is the foundation of a person's belief system. (72, 73)

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