



# Multi-Care Kidney Clinic Best Practices

Last Updated January 8 2019

# 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 patients, but for our loved ones as well. The experience is different for everyone. Some of us felt an eruption of emotion and had a torrent of concern and questions. Some of us were overwhelmed by the news and all the information that came with it. Stunned, we may have appeared uninterested, but we can assure you that wasn't the case.*

*Entering a multi-care kidney clinic (MCKC) for the first time is a significant life transition. It marks the beginning of a journey we likely didn't plan for. 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 healthcare 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 (CKD). Above all, we hope you recognize and appreciate that we are people, not just patients and estimated glomerular filtration rate (eGFR) readings. You are meeting us at a very low point in our lives. We're likely a long way from our "normal." Don't give up on us or on 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,  
A group of Ontario Renal Network Patient and Family Advisors*

# TABLE OF CONTENTS

---

<b>EXECUTIVE SUMMARY</b> .....	<b>4</b>
<b>1.0 ABOUT THIS DOCUMENT</b> .....	<b>6</b>
1.1 Purpose and Use .....	6
<b>2.0 BACKGROUND</b> .....	<b>7</b>
<b>3.0 CORE ELEMENTS</b> .....	<b>8</b>
3.1 Person-Centred Approach .....	8
3.2 Key Functions .....	8
3.3 Care Team Composition .....	9
<b>4.0 PATIENT FLOW ALGORITHM</b> .....	<b>10</b>
<b>5.0 REFERRAL, FREQUENCY OF VISITS AND ORIENTATION</b> .....	<b>11</b>
5.1 Target Population .....	11
5.2 Referral .....	11
5.3 Initial Visit and Orientation .....	12
5.4 Frequency of Visits .....	13
<b>6.0 GOALS OF CARE</b> .....	<b>15</b>
<b>7.0 PATIENT AND CAREGIVER EDUCATION</b> .....	<b>16</b>
7.1 Education on CKD Health .....	17
7.2 Education on Treatment Options and Decisions .....	18
<b>8.0 ACTIVE MANAGEMENT OF CKD</b> .....	<b>22</b>
<b>9.0 COORDINATION AND NAVIGATION OF CARE</b> .....	<b>24</b>
9.1 Dialysis .....	24
9.2 Pre-emptive Transplant .....	25
9.3 Comprehensive Conservative Renal Care .....	25
9.4 Transitions and Transfer of Accountability .....	26
9.5 Repatriation to Nephrologist .....	26
<b>10.0 CARE TEAM ROLES</b> .....	<b>28</b>
<b>11.0 INDICATORS</b> .....	<b>35</b>
<b>12.0 APPENDIX A: TASK GROUP MEMBERS</b> .....	<b>37</b>
<b>13.0 APPENDIX B: GLOSSARY</b> .....	<b>38</b>
<b>14.0 REFERENCES</b> .....	<b>40</b>

# EXECUTIVE SUMMARY

Below is a summary of the key best practices outlined in this document.

## Core Elements

### PERSON-CENTRED APPROACH

- MCKCs are specialized, multidisciplinary<sup>1</sup> clinics rooted in providing person-centered and culturally safe care.

### KEY FUNCTIONS

- Patients and caregivers<sup>2</sup> are empowered and supported to be partners in their care.
- Patients and caregivers participate in shared decision-making, including person-centred decision-making conversations.
- Patients receive education on CKD health and treatment options.
- Patients' CKD and its complications and cardiovascular risk are actively managed.
- Patients receive assistance in the coordination and navigation of their care.

### CARE TEAM COMPOSITION

- Should include, but not be limited to, the patient and caregiver, nurse, nephrologist, pharmacist, dietitian, and social worker.

## Referral, Frequency of Visits and Orientation

### TARGET POPULATION AND REFERRAL

- The target population is patients with advanced CKD with a two-year kidney failure risk equation (KFRE<sub>2</sub>) of at least 10%, or an eGFR of less than 15 ml/min/1.73m<sup>2</sup>. These patients are eligible for funded enrollment.

### INITIAL VISIT AND ORIENTATION

- The initial visit should include an orientation on MCKC goals, approaches, programs, services, team roles and logistics.

### FREQUENCY OF VISITS

- At a minimum, patients should be assessed twice a year.
- Nurse and nephrologist should be seen at each visit.
- Pharmacist, dietitian and social worker should be seen at least annually.

---

<sup>1</sup> We will use the term multidisciplinary to refer 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.

<sup>2</sup> For simplicity and readability, we will use the term caregiver 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.

## Goals of Care

- Patients should be engaged in goals of care conversations to identify and document their future substitute decision-maker and discuss their values, goals and preferences.
- Goals of care conversations should be completed within the first three MCKC visits or education visits, or within one year of MCKC registration (whichever comes first).

## Patient and Caregiver Education

- All education sessions and tools should be designed with consideration to the principles of adult learning, cultural safety, self-management skills and health literacy.
- Treatment education should be provided using a shared decision-making approach.
- For most patients, education on treatment options should be initiated between a KFRE<sub>2</sub> of 20% and 40%.

## Active Management

Active management of CKD includes:

- Employing strategies to reduce rate of kidney function decline or cardiovascular risk.
- Continuous management of:
  - Anemia and other CKD-related complications
  - Medications
  - Diet and nutrition
  - Symptoms, including psychosocial health and referrals to other services where needed
  - Facilitating patient and family understanding and confidence for managing care

## Coordination and Navigation of Care

- MCKC care team plays an active role in coordinating and navigating patients as they transition towards their treatment of choice.
- MCKC care team should have ongoing communication with all members of a patient's care team (e.g., primary care, community supports and other healthcare professionals/services).
- Transfer of accountability:
  - Peritoneal dialysis (PD) & home hemodialysis (HHD): first day of training
  - In-centre hemodialysis (HD): date of first dialysis
  - Pre-emptive transplant: date of transplant
  - Comprehensive conservative renal care (CCRC): may continue to be provided in MCKC

# 1.0 ABOUT THIS DOCUMENT

---

The Ontario Renal Network, the government's principal advisor on CKD, leads a province-wide effort to reduce the burden of CKD on Ontarians and the kidney care system through the effective management and funding of CKD services in Ontario. Working through 14 Integrated Renal Regional Program Councils and the Regional Renal Programs, the Ontario Renal Network's goal is to improve CKD management by preventing or delaying the need for dialysis, broadening appropriate care options for people with CKD, improving the quality of all stages of kidney care, and working with patients, caregivers, and healthcare providers to build a world-class system for delivering care to Ontarians living with CKD.

One strategy for the Ontario Renal Network is to ensure that patients with advanced stages of CKD who are at high risk of progressing towards end-stage renal disease (ESRD) have access to appropriate MCKC care. A survey conducted in 2017 of MCKCs across the province demonstrated significant variability in the composition and delivery of care in local MCKCs. Feedback from MCKC care teams and patients indicated a need for provincial best practices based on available evidence, expertise and experience.

This best practice document was developed by a multidisciplinary task group, including patients and various healthcare providers, convened by the Ontario Renal Network. The full membership list can be found in [Appendix A](#). In preparing this MCKC Best Practices document, the task group reviewed existing Ontario Renal Network documentation on multidisciplinary clinics, expert opinion, the British Columbia Renal Agency's [Best Practices: Kidney Care Clinics](#)(1) and performed a scoping review(2) to assess available evidence.

## 1.1 Purpose and Use

The purpose of this document is to clearly define best practices for high quality care for patients during the MCKC portion of their CKD journey.

## 2.0 BACKGROUND

---

CKD, defined by a persisting eGFR of less than 60 ml/min/1.73m<sup>2</sup>, is estimated to affect at least 4% of people living in Ontario and increases with advancing age.(3) A small proportion of people with CKD are at high risk of progression to ESRD, are likely to develop further complications and would particularly benefit from multidisciplinary care.

Literature suggests that the use of multidisciplinary clinics in patients with CKD is associated with improved clinical outcomes. Such benefits may include:(4)

- Improved survival
- Delay in need for renal replacement therapy
- Greater utilization of home dialysis therapies
- Greater utilization of a fistula in those patients on HD
- Decrease in unplanned dialysis initiation

There is evidence of the benefits of multidisciplinary clinics for patients with various chronic diseases, including diabetes mellitus(5) and congestive heart failure.(6) As a result, Ontario and many other jurisdictions have advocated for the widespread employment of multidisciplinary clinics for patients with more advanced CKD.(1,7–9)

## 3.0 CORE ELEMENTS

---

### 3.1 Person-Centred Approach

Person-centred care is 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.(10,11) MCKCs are specialized, multidisciplinary clinics rooted in providing person-centred care. MCKCs consist of a team of diverse yet complementary healthcare professionals with specialized skills to support patients and their caregivers through shared and person-centred decision-making conversations.

Only patients truly understand how CKD impacts their day-to-day lives, thus they are the experts regarding what their current health priorities can or could be, and about their primary support systems. As such, patients and their caregivers should be encouraged and empowered to be active players in their healthcare. Evidence supports this approach in people with CKD to improve important clinical outcomes.(12)

Shared decision-making is a collaborative process that allows patients and their providers to make healthcare decisions together.(13) The shared decision-making approach considers the best scientific evidence available and a patient's values, goals, preferences, caregiver situation, culture and lifestyle. Having these conversations early and often helps to ensure patients and caregivers are supported appropriately throughout their care journey. These conversations include goals of care, treatment decisions and informed consent.

Ontario has the largest number of people with Indigenous ancestry in Canada.(14) It is also home to a large number of Canadians born outside of Canada. It is important for MCKC care to be culturally safe and acknowledge health beliefs and traditional medicines. Where possible, MCKCs should have interpreter services available for all patients.

### 3.2 Key Functions

MCKCs are important because they provide care to patients at a critical stage of advanced CKD. During this stage of their CKD, patients are progressing towards ESRD and need to make a number of crucial, stressful and often complex decisions about their future course of care. They are also at high risk of more severe complications requiring specialist multidisciplinary management. As a result, 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 following functions are intended to occur in MCKCs:

- Patients and caregivers are empowered and supported to be partners in their care.
- Patients and caregivers participate in shared decision-making, including person-centred decision-making conversations (namely goals of care, treatment decisions and informed consent).

- Patients receive education on CKD health and treatment options.
- Patients' CKD and its complications and cardiovascular risk are actively managed.
- Patients receive assistance in the coordination and navigation of their care.

### 3.3 Care Team Composition

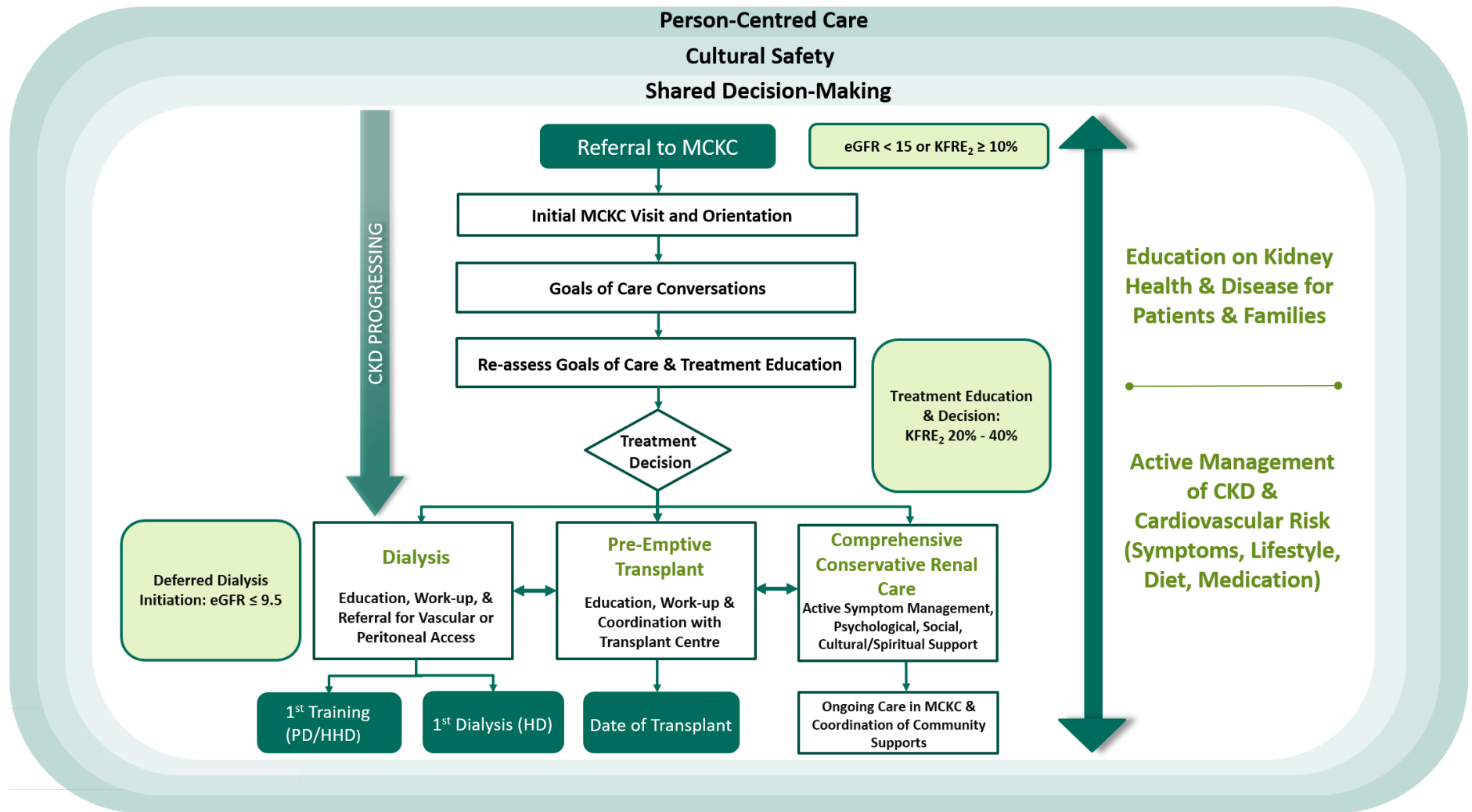
As previously mentioned, there is evidence to support multidisciplinary care for patients with various chronic diseases, including CKD. In particular, evidence exists for the involvement of pharmacists(15,16) and dietitians in multidisciplinary teams.(17–19)

The MCKC care team composition should include, but not necessarily be limited to, the following:

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

# 4.0 PATIENT FLOW ALGORITHM

The algorithm below outlines the major tasks, timelines and care involved in MCKCs from time of referral into MCKC through to transition to renal replacement therapy or CCRC. This document will provide further detail on each of the major tasks.



# 5.0 REFERRAL, FREQUENCY OF VISITS AND ORIENTATION

## 5.1 Target Population

The target population for MCKCs is patients with advanced CKD who are at high risk of progressing towards ESRD. The Ontario Renal Network recognizes that while the prevalence of CKD in the adult population is high, most patients will be at low risk of progression to ESRD. The risk of progression to ESRD can be calculated using the validated KFRE<sub>2</sub>(20)

## 5.2 Referral

Patients are referred to MCKCs by a nephrologist. Balancing the benefits of earlier multidisciplinary intervention versus the costs and potential harms of unnecessary interventions, it was determined that **patients with a KFRE<sub>2</sub> of at least 10%, or an eGFR of less than 15 ml/min/1.73m<sup>2</sup>, would be eligible for funded enrolment in these clinics.** All patients who meet either of these criteria should have the opportunity to be followed in these clinics.

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) that are no longer responding to GN treatments. 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. Note: GN care may be delivered in partnership with MCKC to meet patient care needs.
- Young adults with CKD transitioning to adult care. This group of patients faces unique challenges. In circumstances where these patients meet the above criteria, consideration should be given to providing their care in transitional clinics(18) in partnership with MCKCs. 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.

Intensive resources should be allocated where they are most needed. Below are considerations to determine whether patients require referral to MCKCs:

- Patients at lower risk of progression to ESRD can effectively receive high quality care in general nephrology clinics and/or the primary care setting to manage earlier stages of CKD

and minimize the risk of progression to ESRD and/or the development of cardiovascular complications.

- Anemia and metabolic complications of CKD become increasingly prevalent with more advanced CKD; in most circumstances these complications do not require intervention beyond what might be implemented and monitored during a general nephrology clinic visit (e.g., active vitamin D therapy for secondary hyperparathyroidism). More intensive interventions (e.g. nutritional counselling for hyperphosphatemia and erythropoiesis-stimulating agent therapy for anemia) are infrequently required until patients have more advanced CKD.(21–24)

## 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
<b>Last known laboratory dates</b>	<ul style="list-style-type: none"> <li>• eGFR</li> <li>• Serum creatinine</li> <li>• Urine albumin/creatinine ratio (ACR)</li> </ul>
<b>Last known value</b>	<ul style="list-style-type: none"> <li>• KFRE<sub>2</sub></li> </ul>
<b>Clinical information from the patient chart</b>	<ul style="list-style-type: none"> <li>• Consult letters/clinical summaries</li> <li>• Updated medication list</li> <li>• Relevant laboratory and diagnostic tests</li> </ul>
<b>Important information on patient needs and preferences</b>	<ul style="list-style-type: none"> <li>• Communication barriers/language preference</li> <li>• Patients’ geographical location and their ability to attend appointments (e.g., rural/remote with limited access to testing)</li> <li>• Family support</li> <li>• Access to transportation</li> <li>• Financial means to travel to appointments</li> <li>• Any requirement for an interpreter</li> </ul>

## 5.3 Initial Visit and Orientation

The initial MCKC visit should include an orientation for patients and their caregivers. 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 in a variety of ways, such as:

- A written handout or letter that is given to patients and their caregivers in combination with a group and/or individual information session.

- A group information session led by staff and peers; this could also include education on basic kidney health and disease.

The initial visit should also include an integrated assessment incorporating the perspectives of all MCKC care team members. The [Care Team Roles](#) section of this document outlines the roles and responsibilities of key members of the care team.

## 5.4 Frequency of Visits

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

Patients can also be managed remotely by phone or through another telehealth service to ensure access for remote patients or patients who are unable to attend in-person.

**At a minimum, patients should be assessed twice a year.** As patients progress towards ESRD, they may need to be followed as frequently as every month.

The minimum visit frequency for each care team member is outlined in the table below. The minimum stated is to ensure that patients have access to all disciplines and is not intended to restrict visits to a specific number. Recognizing that visits with multiple healthcare professionals at a single encounter can be tiring for patients, **clinics should typically strive to not have more than four team members** see the patient in a single visit unless there are exceptional circumstances. The average MCKC clinic visit length across the province is approximately 60 minutes.

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

Other factors in determining visit frequency include:

- Patient and caregiver needs and preferences
- Geographic distance to MCKC (although patients can also be managed remotely by phone or through a telemedicine service)
- Ability of patient to self-manage

Care should not be limited to clinic visits. Patients and caregivers should be supported between clinic visits and should be encouraged to contact the MCKC care team with any questions or concerns.

Further details about specific care team roles can be found in the [Care Team Roles](#) section of this document.

## 6.0 GOALS OF CARE

---

It is important to consider how treatment decisions align with patients' values, goals and preferences for their care. Goals of care and treatment decisions and informed consent are all part of the person-centred decision-making continuum.(25)

The MCKC care team should identify and document the patient's substitute decision-maker (either by accepting the automatic substitute decision-maker or assigning a power of attorney for personal care). Goals of care conversations 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 healthcare provider understand the patient's values, goals and preferences for their care.

These conversations should be ongoing and reassessed annually and with any changes in health status. Goals of care conversations should be documented in the patients' plan of treatment. This document, which should be shared with patients when requested, should 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.

**Goals of care conversations should be completed within the first three MCKC visits or education visits, or within one year of MCKC registration (whichever comes first).**

The desired outcome is for patients and healthcare providers to have a shared understanding of the patients' goals for their care. These goals are then used to support treatment decisions and informed consent.

### Resources

- [Person-Centred Decision-Making – Resource for Healthcare Providers](#)
- [Approaches to Goals of Care Conversations – Resource for Healthcare Providers](#)
- [Advance Care Planning, Goals of Care & Treatment Decisions and Informed Consent – Resource for Patients and Healthcare Providers](#)
- [Advanced Chronic Kidney Disease: Making Decisions About Your Care – Resource for Patients](#)
- [Instructional Shared Decision-Making skill-building video for healthcare providers](#)

# 7.0 PATIENT AND CAREGIVER EDUCATION

---

A core function of the MCKCs is for patients to receive education on CKD health and treatment options. All education sessions and tools in the MCKC should be designed with consideration to the principles of adult education and cultural safety, focus on the development of self-management skills and support health literacy.

An advanced CKD diagnosis impacts both patients and their caregivers. Caregivers can play a pivotal role in supporting patients with their CKD management; as such, they should be included, engaged and supported in CKD education alongside patients.

Education should be tailored to individual patients and their caregiver's prior knowledge and understanding of CKD, its treatment and their specific needs. Education is also best phased-in over time and paced as directed by the patients and their caregivers based on their stage of readiness to learn.(26) Team members should collaborate in the development and delivery of education plans to avoid overwhelming patients. Education may be covered in a variety of ways, including individual or group sessions, and discussed as part of MCKC care team appointment(s).

## **Adult Learning Principles**

The following principles of adult learning should be applied to the design and delivery of education programs for patients and caregivers(27,28):

- 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.

## **Shared Decision-Making**

There are multiple critical decisions that need to be made in MCKCs. These decisions may include:

- Goals of care
- Code status
- Dialysis, transplant or CCRC
- Which dialysis modality
- Which dialysis access
- When to start dialysis

MCKC patients often struggle with decision-making, and this can cause distress, anxiety, depression, denial and other forms of stress or conflict. To help alleviate this, MCKC care teams should approach treatment education using a shared decision-making approach. This collaborative process allows patients and caregivers and their providers to make informed healthcare decisions together.(13) Goals of care should be used to support treatment decisions to ensure alignment with patients' values, goals, and preferences.

Treatment options 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 an option that best suits their needs and those of their caregivers (see resource below). Additionally, MCKC care teams should refer patients to appropriate treatment modality teams for additional information and discussion to support with decision-making.

## **Peer Support**

Patients and family members impacted by CKD have consistently referenced the value in connecting with others who have a similar shared experience. Peer support is therefore 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.(29) 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.

Peer mentors can share life experiences relating to the challenges and successes of living with disease, self-care and coping strategies and navigating the healthcare 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
- Facilitated group peer support
- Online forums

## **Resources**

- [Kidney Foundation of Canada – Kidney Connect Peer Support Program](#)

## **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 high blood pressure
- Diet and nutrition for kidney health

- Living well with reduced kidney function, including benefits of exercise
- Hepatitis screening and appropriate timing and resources for vaccinations, including pneumococcal, influenza and varicella zoster vaccines
- Review and management of medications to maintain kidney health, including sick day management
- Laboratory tests, the meaning of test results and how to obtain copies of results
- Smoking cessation
- Person-centred decision-making conversations
- Palliative care and end-of-life care
- Psychosocial impact of CKD
- Mindfulness as complementary adjunct education

## **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 with CKD and their caregivers in acquiring and maintaining the skills needed to manage their life with a chronic disease. This includes:(30)

- Medical management of illness
- Adjustment of roles and relationships
- Management of the emotional and psychosocial impact of illness and of treatment
- Maintenance of a healthy lifestyle to optimize health across their CKD journey

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.(31)

### **Resources**

- [Book #1 of Living with Reduced Kidney Function by the Kidney Foundation](#)
- [Local Health Integrated Network \(LHIN\) self-management workshops](#)

## **7.2 Education on Treatment Options and Decisions**

As patients' risk of progression towards ESRD increases, the MCKC care team should dedicate time to provide focused education on treatment options to patients and their caregivers to allow them to make an informed decision about the management of ESRD. Patients and their caregivers should receive information about all treatment options, including transplant (where appropriate), PD, home and in-centre HD and/or CCRC. For those who are considering dialysis, where appropriate, a home therapy should be promoted (see [Home Dialysis Education](#)).

## **TIMING OF EDUCATION**

Considerations for the initiation of education on treatment options include ensuring sufficient time for patients to prepare for their treatment decision while also preventing undue stress for patients who are unlikely to progress towards ESRD and require renal replacement therapy within the next two years.

**For most patients, education on treatment options should be initiated between a KFRE<sub>2</sub> of 20% and 40%.**

Patients who are likely candidates for pre-emptive transplant should receive education on treatment options at the lower end of this KFRE<sub>2</sub> range. Earlier education ensures that the timing of referral to a transplant centre for assessment is consistent with the Ontario Renal Network's recommendation of KFRE<sub>2</sub> of approximately 25%.

The team should periodically revisit prior decisions regarding treatment options, particularly home therapies, to address new barriers that may have arisen.(32,33)

## **COMPONENTS OF EFFECTIVE TREATMENT OPTIONS EDUCATION**

Components of an effective treatment options education program include(26):

- A mix of one-on-one and group sessions
- Peer support and peer education
- A standardized curriculum that can be tailored to individual patient and caregiver needs
- Printed reference materials
- Experiential “hands on” learning that provide 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 function of kidneys, CKD and why renal replacement therapy is required
- Education covering all treatment options, including benefits, risks, barriers and supports available for each
- Criteria and processes used to assess eligibility for treatment options

## **TRANSPLANT EDUCATION**

Kidney transplantation as a treatment for patients with ESRD provides the best long-term outcomes, in terms of both quality of life and life expectancy.(34,35) Living kidney transplantation is often a more beneficial option for patients, allowing a patient to potentially avoid dialysis, provided they have a suitable donor.

While the benefits of transplant are well documented, kidney transplantation is not for everyone. Moreover, the decision to receive a transplant can be a difficult one, particularly for patients who have become aware of their diagnosis only recently.

The recommendations below can help MCKC care teams provide more impactful transplant education:

- Review the benefits of a kidney transplant (prolonged survival, improved quality of life, etc.).
- Encourage patients to learn about living donation, to share their stories with family and friends and to have discussions with potential donors.
- Create frontline “transplant champions” to promote transplant education and discussion.
- Incorporate transplant education into new and ongoing staff training.

If the preferred treatment modality is transplant, patients are asked to also select a secondary treatment option, as patients may require dialysis while waiting for their transplant or may experience complications related to their transplant.

## **HOME DIALYSIS EDUCATION**

Home dialysis, which includes PD and HHD, can be an appropriate treatment option for many patients. Where patients are suitable for home dialysis, it should be encouraged, as it provides a more flexible treatment schedule and greater independence to manage treatments which may lead to improved quality of life .(36,37) Education on the types of dialysis should begin well before a patient needs to start dialysis and should be ongoing.

As part of the education on treatment options, patients and caregivers should be informed about potential benefits and barriers (e.g. physical space needs, supply management) of home dialysis. Patients and caregivers should also be made aware of the various supports that may help patients with a home dialysis modality. For example, a utility grant is available in Ontario for HHD patients to offset electricity and water costs. Assistance is also available for patients who have challenges in doing PD independently. Providing information on these types of supports may further help patients to make an informed decision.

In order to promote home dialysis, it is essential that all team members are knowledgeable and comfortable with home dialysis and are providing consistent messaging to patients. 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.

## **COMPREHENSIVE CONSERVATIVE RENAL CARE EDUCATION**

Similar to dialysis and transplant, CCRC is recognized as a treatment option for advanced CKD. CCRC is planned, holistic, patient-centred care for patients with advanced CKD and their caregivers. It 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. CCRC 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.

Dialysis does not always provide a substantial survival advantage or improve quality of life. It should be emphasized that choosing CCRC is not a “no treatment” option and that patients will continue to receive high quality medical care. To assist patients and/or substitute decision-makers and their caregivers in choosing whether CCRC is the most appropriate treatment option, it is essential that all care team members are knowledgeable and provide consistent messaging to patients. Discussions around confirming patients’ illness understanding, discussing and documenting goals of care and ensuring informed consent are beneficial in supporting patients with making this treatment decision.

## **CODE STATUS**

Code status is an important treatment decision that must be made by patients or incapable patients’ substitute decision-maker. 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.(38)

## **Resources**

- [Book #2 of \*Living with Kidney Failure\*, The Kidney Foundation of Canada](#)
- [Nutrition Fact Sheets for Patients](#)
- [Shared Decision-Making Skill-Building Video for Healthcare Providers](#)
- [Renal Replacement Treatment Options Grid](#)
- [SHERPA-DM Patient Decision Aid](#)
- [PD Fact Sheets for Patients](#)
- [HHD Fact Sheets for Patients](#)
- [HHD Utility Grant](#)
- [Ontario’s Referral and Listing Criteria for Adult Kidney Transplantation](#)

## 8.0 ACTIVE MANAGEMENT OF CKD

---

Active management of CKD is a key function of the MCKC. This includes working closely with patients and caregivers to align care plans with stated goals, values and preferences and:

- Employing strategies proven to decrease the rate of decline of kidney function, including:
  - Initial and ongoing medical assessments of health condition;
  - Monitoring and follow-up of lab results, responding as necessary to abnormal results; and
  - Monitoring of fluid status, skin integrity and blood pressure.
- Employing strategies proven to reduce a patient's cardiovascular risk, including blood pressure control(39), use of renin-angiotensin system inhibition where indicated(40) and treatment with statins.(41)
- Managing anemia(42) and other CKD-related complications, including disorders of bone-mineral metabolism(43) and acidosis(44), as they arise.
- 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.(45) Medication reconciliation utilizes a Best Possible Medication History and verifies the medication using a secondary source such as, but not limited, to a community pharmacy or Ontario Drug Benefits Plan.
  - MCKC care teams are encouraged to review their hospital medication reconciliation policies to ensure it is completed at an appropriate frequency for all their patients.
  - Based on expert opinion, the best practice is for the pharmacist to perform the medication reconciliation.
- Monitoring diet and nutrition for patient health, including:
  - Assessment of nutritional status and ongoing dietary reviews to recommend appropriate therapeutic diet(s) that incorporates all concerns; and
  - Referrals to appropriate resources to assist in coping with diet concerns, such as meal programs.
- Empowering and supporting patients and caregivers to be partners in their care.
- Facilitating patients' and caregivers' understanding and confidence (self-efficacy) for managing their care and navigating the healthcare system, including:
  - Initial and ongoing social work assessments; and
  - Implementation of an appropriate psychosocial care/intervention plan that facilitates patient and family adaptation and well-being.
- Monitoring patients' mental health and identifying opportunities for referral to other services when required.

## Resources

- [Medication Reconciliation by Canadian Patient Safety Institute](#)

## Symptom Management

Patients often experience symptoms related to their CKD that can be very distressing and overwhelming for them and their caregivers. Symptoms experienced by patients should be reviewed and addressed on a regular basis. Standardized tools, such as ESAS-r: Renal(46), can be used to assess symptoms. These include, but are not limited to:

- Pain
- Tiredness
- Drowsiness
- Problems sleeping
- Nausea
- Lack of appetite
- Shortness of breath
- Depression
- Anxiety
- Itching
- Restless legs

## Resources

- [ESAS-r: Renal Tool](#)

## 9.0 COORDINATION AND NAVIGATION OF CARE

---

Once a treatment option is decided on, 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 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 healthcare professionals/services).

First Nations, Inuit, Métis and Urban Indigenous patients may require assistance in coordinating supports provided by federal, provincial and community entities (e.g., [Non-Insured Health Benefits](#), [Métis Nation of Ontario](#)).

### 9.1 Dialysis

For patients who are beginning dialysis (whether in-centre or at home), the MCKC care team:

- Coordinates and collaborates with the respective dialysis team as early as possible to confirm the suitability of the preferred dialysis option for the individual patient; this includes assessment, additional testing, specialty consultations, etc.
  - The MCKC care team should work with patients to identify a different treatment option if their first option is not suitable.
- Actively monitors, treats and provides physical care and psychosocial support up to the point of hand-off to the receiving dialysis team.
- Advises the dialysis team of significant changes in patient health status.
- Works with the dialysis team to prepare patients for pre-dialysis tests, consults and procedures.
- Works with the vascular access clinic or the clinic responsible for arranging peritoneal catheters 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, nephrologist and dialysis team.
  - Where appropriate, a deferred dialysis approach should be taken. See section on [MCKC Indicators](#) for more information.
- Coordinates with external supports that are important to the patients' transition (e.g., primary care, home care).

## 9.2 Transplant

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

- Coordinates with the transplant centre to confirm suitability for pre-emptive transplantation for patients.
  - The MCKC care team should work with patients to identify a different treatment option if a pre-emptive transplant is not suitable.
- Refers patients for transplant if:
  - The patient is expected to require dialysis within the next year
  - The patient has one or more potential living kidney donors\* *and* meet any of these criteria:
    - Have an eGFR less than 15 mL/min/1.73m<sup>2</sup>
    - Have a KFRE<sub>2</sub> greater than or equal to 25%
    - Is expected to need dialysis in the next 2 years
- Works with the transplant centre and/or general practitioner to prepare patients for transplant tests, consults and procedures.
- Actively monitors, treats and provides physical care and psychosocial support up to the point of hand-off to the transplant centre.
- Advises the transplant centre of significant changes in patient health status.
- Coordinates with external supports that are important to the patient's transition (e.g., primary care, home care).

\* Potential donors are encouraged 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?](#)

## 9.3 Comprehensive Conservative Renal Care

For patients who opt to receive CCRC<sup>3</sup>, the MCKC care team:

- Confirms the suitability of the CCRC treatment modality for patients.
- Continues to provide care if patients choose to stay within the MCKC.
- Ensures smooth transition to a receiving provider (e.g., primary care provider, nephrologist, palliative care specialist) 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.
- Coordinates with community supports (e.g., hospice) when needed.

---

<sup>3</sup> Note, the Ontario Renal Network is currently undertaking work to define the clinical pathway for renal CCRC patients and will be releasing additional resources in the future.

- Coordinates with external supports that are important to the patients' transition (e.g., primary care, home care).

## 9.4 Transitions and Transfer of Accountability

MCKC care teams should work collaboratively with the receiving team (e.g., the dialysis team, the transplant centre, etc.) to ensure seamless transitions for patients to and from the MCKC.

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:

- If patients are transitioning to PD, ongoing care is assumed by the PD team at time of first training.
- If patients are transitioning to HHD, ongoing care is assumed by the HHD team at time of first training.
- If patients are transitioning to in-centre HD, ongoing care is assumed on the day of first dialysis treatment.
- If patients are receiving a pre-emptive transplant, ongoing care is assumed by the transplant team on the date of transplant.
- If a patient has been referred for transplant assessment but the patient has initiated dialysis therapy prior to transplantation occurring, the relevant dialysis team should assume responsibility for working with the transplant team to determine transplant eligibility.

## 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 KFR<sub>E2</sub> that is consistently below 10%;
- Have opted out of receiving MCKC care; or
- Do not wish to have dialysis or transplant, have opted out of receiving CCRC in MCKC and have a care plan, and the nephrologist/primary care provider 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 required at a later date, the patient may be re-referred to MCKC by the nephrologist.

# 10.0 CARE TEAM ROLES

---

## Shared Team Functions

The following functions are responsibilities shared by all members of the MCKC care team, regardless of their discipline.

### *Assessment and Care Planning*

- Creates and fosters environments that support patient safety and is considerate of the patients' and caregivers' experience.
- Recognizes the patient as a person, not a disease.
- Respects diverse views, culture, spiritual traditions, gender identity, gender expression, sexual orientation and abilities of patients and their families.
- Acknowledges First Nations, Inuit and Métis and Urban Indigenous patients in their desire to incorporate traditional healing practices into their care plan.
- Assesses patient health literacy to determine the degree to which they have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.
- Ensures patients are continually engaged partners in their care by regularly confirming patients' health priorities, seeking feedback regarding their experiences managing CKD and collaborating with them to develop and revise care plans and goals of care.
- Collaborates with patients and caregivers in developing self-management plans, goal setting and treatment planning, including providing support and follow-up between MCKC visits.
- Manages symptoms of CKD.

### *Education*

- Be knowledgeable and comfortable educating patients and caregivers on CKD health and all treatment 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.

### *Transitions*

- Prioritizes intake of new referrals, with consideration to the referring nephrologist's input.
- Communicates patient-specific information, including patient and caregiver values, goals, and preferences to the appropriate treatment modality team when patients transition to PD, home or in-centre HD, transplant or CCRC.
- 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.
- Refers patients and communicates and coordinates care with other healthcare professionals/services as needed (e.g., primary care, diabetes education centre, heart health, home care, palliative care specialist).

- Acts as a resource to other healthcare professionals in the area of CKD and related treatments/supports.

## Specific Care Team Functions

The following functions are specific responsibilities expected by each member of the MCKC care team.

### Patient

- Empowered patients 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 healthcare decisions and treatments.

### Nurse

#### *Assessment and Care Planning*

- Assesses health condition, symptoms, diagnosis and medications.
- Monitors fluid status, skin integrity and vital signs (blood pressure and heart rate).
- Monitors and follows up on lab results (e.g., anemia and declining eGFR).
- Monitors status of fistula or graft, if in place.
- Assesses changes in psychological state.
- Assesses significant change in health status, such as recent discharge from hospital.
- Completes appropriate nursing care planning as indicated.
- Actively participates in person-centred decision-making conversations within their scope of practice (shared role with social worker and nephrologist).
- 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 treatment options (transplant, dialysis, CCRC) to support person-centred decision-making and to ensure selected treatment is aligned with patients' goals of care (shared role with social worker).
  - Medication information: anemia management, nephrotoxic medications to avoid, symptom management and sick day management (shared role with pharmacist).

- Recommended timing of hepatitis, influenza, varicella zoster virus and pneumococcal vaccinations.
- Maintenance of kidney health through self-management of other medical conditions (diabetes, high blood pressure, etc.), exercise, smoking cessation and reduced sodium intake.
- Ensures all resources are in place (e.g., translation) to ensure patients and caregivers have the opportunity to understand information that is presented.

### *Transitions*

- Reviews treatment choice and readiness for transition regularly.
- Assists with coordination and referral for:
  - If PD, referral to PD team and or clinic responsible for arranging peritoneal catheters.
  - If HD, referral to vascular access clinic and HHD team (if home) or HD unit (if in-centre).
  - If pre-emptive transplant, referral to transplant centre and selection of back-up dialysis option.
  - If CCRC, ongoing assessment and monitoring, education about symptom control and management. Supports initiation of referrals to home care and/or palliative care as appropriate.

## **Nephrologist**

### *Assessment and Care Planning*

- Performs initial medical assessment and reassessments at each visit, including review of intercurrent medical events, including hospitalizations.
- Engages in person-centred decision-making conversations.
- Initiates and documents goals of care conversations 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.
- 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.

### *Transitions*

- Completes referrals for access to support services (e.g., LHIN, medications, specialists, etc.).

## **Pharmacist**

### *Assessment and Care Planning*

- Completes initial medication reconciliation at first MCKC visit and aims to have a comprehensive review of medications completed at each visit.
- Reviews patients' allergies and intolerance to medications (may be done by either a pharmacist or pharmacy technician).
- 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).
- Reviews medications for renal dosage adjustments and drug interactions and aids in interpretation of drug levels, where appropriate.
- 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.).

### *Patient/Caregiver Education*

- Instructs on medication use, side effects and adherence.
- Informs about nephrotoxic medications to avoid and what to do when sick.
- Educates on use of over-the-counter medications, including herbal products (shared role with dietitian).

### *Transitions*

- Liaises with community pharmacies, if needed, to ensure continuity of care (e.g., timing of medications in compliance packages, ensuring timely delivery of prescription) (pharmacist or pharmacy technician).

## **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.
- Addresses signs and symptoms related to oral intake and nutritional status; reviews protein, potassium, phosphorus, sodium, lipids and other pertinent nutrients.
- Conducts ongoing dietary reviews and provides recommendations and self-management support on:
  - 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)
- Recommends appropriate therapeutic diet(s) and establishes a diet plan that incorporates all nutrition concerns, including the management of diabetes, cardiovascular disease and special diets.
- Liaises, as appropriate, with a home and community care dietitian and/or an assisted living or long-term care dietitian.
- Refers patients and caregivers to appropriate resources to assist in coping with diet-related concerns (e.g., meal programs or community supports).
- 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 and counsels patients on food choices and meal ideas. Individualizes education and counselling regarding CKD, diabetes, heart disease, weight loss, etc.
- Educates on label reading, menu planning 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 renal 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*

- Educates team on how to ensure patients are emotionally and mentally ready for CKD education, making care decisions and transitions in care.
- Conducts initial and ongoing social work assessments: gathers and analyzes biopsychosocial and ethno-cultural data on patients and their primary support systems. Assesses community and other large system factors impacting patients' health and treatment.
- 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.
- Provides resource counselling for patients and caregivers on services and benefits (e.g., finances, medical insurance, medication coverage, transportation programs and other benefits to overcome barriers and address current/future needs).
- Liaises and establishes linkages with the Department of Indigenous Services Canada's First Nations and Inuit Health Branch to address the unique needs of these patient populations.
- Actively participates in person-centred decision-making conversations (e.g., confirming and documenting patient's choice of substitute decision-maker or discussing the appointment of a power of attorney for personal care) (shared role with nurse and nephrologist).
- Advocates for patients and caregivers, helping them navigate systems which may be overwhelming and confusing.
- Mediates conflict between patients, their primary support and the healthcare team.
- Facilitates caregiver meetings/care conferences and documents social work aspects of care plans.
- 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.
- Refers patients to mental health and community health programs, social agencies and government ministries if further assessment or services are required.
- 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.
- Triggers for additional review include:
  - Existing diagnosis of a mental health condition that would impact patients' ability to participate in education and or clinic visits.
  - Significant changes in patients' mood or engagement in care (e.g., missed appointments, not participating in clinic appointments or education).
  - Significant changes in patients' living situation (e.g., changes in social determinants of health).
  - The team feels the patient and/or caregiver is not coping with the diagnosis and the required CKD self-management activities.

### *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 needs
  - Substitute decision-makers and/or power of attorney for personal care
- All treatment options (transplant, dialysis, CCRC) to support person-centred decision-making conversations and to ensure selected treatment is aligned with their goals of care (shared role with nursing).

### *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 appropriate supports to help enable smooth transition to chosen treatment 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 following key indicators are monitored by the Ontario Renal Network to support continuous quality improvement in MCKCs. Note, this list will continually be updated as quality initiatives evolve and new indicators may be added in the future (e.g. pre-emptive transplantation, CCRC).

## **Referral to MCKC**

This indicator is a prevalence measure to understand the proportion of patients who are followed by a nephrologist and who meet the MCKC funding criteria are actually being referred into MCKCs.

This indicator provides a guide as to whether patients with progressive advanced CKD who are followed by a nephrologist are getting access to MCKC care at the right time in their journey.

## **Time Spent in MCKC Prior to Dialysis Initiation**

This indicator is an incident measure to understand the proportion of chronic dialysis patients who have had at least 12 months of funded MCKC follow up care.

An analysis of Ontario data indicates that at least 12 months of MCKC follow up care is associated with improved patient outcomes, such as more home dialysis starts and fewer catheter starts, compared to less than 3 months of MCKC follow up care. This suggests that at least 1 year of MCKC follow up care gives patients a reasonable amount of multidisciplinary care and education to prepare for their next steps.

## **Deferred Dialysis**

This indicator is an incident measure to understand the proportion of patients who initiate chronic dialysis with a deferred elective start.

Research evidence indicates that planned earlier dialysis does not improve patient outcomes, including quality of life.<sup>(47)</sup> Nephrologists and clinic staff are therefore encouraged to use a deferred strategy as opposed to a strategy of starting early when caring for patients with ESRD. The current target for the province is set at 75%, measured by the percentage of incident chronic dialysis patients starting dialysis with an eGFR  $\leq 9.5$  mL/min/1.73m<sup>2</sup>. It is recognized that for some individual patients, an earlier dialysis start may be appropriate.

## **Home Dialysis**

Both incident and prevalent home dialysis rates are reported. The incident home dialysis indicator is a measure to understand the proportion of patients who initiated chronic dialysis on a home dialysis modality. The prevalent home dialysis indicator is a measure to understand the proportion of prevalent chronic dialysis patients on a home dialysis modality.

Home modalities have been shown to enable positive clinical outcomes, quality of life, and independence for patients who choose dialysis as their treatment option. It can be suggested that spending more time in MCKCs provides patients a reasonable amount of time for treatment education, decision-making and training that can result in more home dialysis starts.

### **Goals of Care**

This indicator is an incident measure that measures the proportion of patients in MCKC with whom goals of care have been documented by their MCKC care team.

### **Patient Reported Experience Measures**

Patient experience is the sum of all interactions that patients have with the health care system. Patient reported experience measures will be monitored to evaluate patient experience in MCKCs, which includes their experience with education, information sharing and shared decision-making. Patient reported experience measures help inform what is working and opportunities to improve the way care is delivered to patients and caregivers.

# 12.0 APPENDIX A: TASK GROUP MEMBERS

---

The Ontario Renal Network wishes to acknowledge the significant contributions of the MCKC Best Practices Task Group who shared their experiences, expertise and insights to support the development of this document.

**Chair:**

**Dr. Scott Brimble**

Nephrologist, Provincial Medical Lead, Ontario Renal Network

**Co-Chairs:**

**Dr. Peter Blake**

Nephrologist, Provincial Medical Director, Ontario Renal Network

**Monisha Patel**

Group Manager, Ontario Renal Network

**Members:**

**Dr. David Collister**

Nephrologist, St. Joseph's Healthcare Hamilton

**Brooke Cowell**

Acting Director, Renal Program, Joseph's Healthcare Hamilton

**Lori Elliott**

Senior Analyst, Ontario Renal Network

**Esti Heale**

Group Manager, Ontario Renal Network

**Dr. Vincent Ki**

Nephrologist, Trillium Health Partners

**Nick Maclean-Bowman**

Senior Analyst, Ontario Renal Network

**Janice McCallum**

Regional Director, London Health Sciences Centre

**Dr. Peter Wagner**

Nephrologist, Provincial Medical Lead, Ontario Renal Network

**June Martin**

Registered Dietitian, Certified Diabetes Educator, Grand River Hospital

**Dr. Amber Molnar**

Nephrologist, St. Joseph's Healthcare Hamilton

**Carmen Morris**

Social Worker, St. Michael's Hospital

**Jenny Ng**

Pharmacist, Sunnybrook Health Sciences Centre

**Yanchini Rajmohan**

Analyst, Ontario Renal Network

**Randy Russell**

Patient Advisor

**Ann Thomas**

Senior Specialist, Ontario Renal Network

**Jim Thompson**

Patient Advisor

**Charles-Anne Wardlaw**

Registered Nurse, Sault Area Hospital

**Stephanie Winn**

Regional Director, Health Sciences North

# 13.0 APPENDIX B: GLOSSARY

---

## **Comprehensive Conservative Renal Care**

CCRC is active and holistic patient-centred care for patients with CKD that includes care meant to slow down kidney disease and lower the risk of complications, active symptom management, as well as emotional, social and family support; does not include dialysis.

## **Cultural Safety**

Culturally safe care is the end point of the cultural competency continuum. Culturally safe health care shows respect for culture and identity; it incorporates needs and rights and is free of discrimination. For the renal system to provide culturally safe care, clinicians must become culturally humble by reflecting on how their culture impacts the care they provide and the renal system must examine processes/policies that create or promote racism, discrimination or prejudice.

## **Caregivers**

For simplicity and readability, we will use 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.

## **Goals of Care**

Discussions between a provider and a patient that focus on ensuring patients understand the nature of their illness, and help the healthcare provider to understand the patients' values, goals and preferences they have for their care.

## **Kidney Failure Risk Equation**

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 CKD stages 3 to 5.

## **Medication Reconciliation**

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

## **Multidisciplinary**

We will use the term multidisciplinary to refer 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.

## **Patient and Family 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.

## **Person-Centred Decision-Making**

Comprised of goals of care, treatment decisions and informed consent; ensures treatment decisions align with the patient's values, goals, and preferences with respect to their health care.

## **Shared Decision-Making**

A collaborative process that allows patients and their providers to make healthcare 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.

## 14.0 REFERENCES

---

1. Kidney Care Advisory Committee. Best Practices: Kidney care clinics [Internet]. BC Provincial Renal Agency; 2014. Available from: [http://www.bcrenalagency.ca/resource-gallery/Documents/Best%20Practices-%20Kidney%20Care%20Clinic\\_0.pdf](http://www.bcrenalagency.ca/resource-gallery/Documents/Best%20Practices-%20Kidney%20Care%20Clinic_0.pdf).
2. Collister D, Pyne L, Cunningham J, Donald M, Molnar A, Beaulieu M, et al. Multidisciplinary Chronic Kidney Disease Clinic Practices: A Scoping Review, *submitted*.
3. Hayward JS, McArthur E, Nash DM, Sontrop JM, Russell SJ, Khan S, et al. Kidney Disease Among Registered Metis Citizens of Ontario: A Population-Based Cohort Study. *Can J Kidney Health Dis*. 2017;4:2054358117703071.
4. Strand H, Parker D. Effects of multidisciplinary models of care for adult pre-dialysis patients with chronic kidney disease: a systematic review. *Int J Evid Based Healthc*. 2012 Mar;10(1):53–9.
5. Community-based care for the management of type 2 diabetes: an evidence-based analysis. *Ont Health Technol Assess Ser*. 2009;9(23):1–40.
6. McAlister FA, Stewart S, Ferrua S, McMurray JJJV. Multidisciplinary strategies for the management of heart failure patients at high risk for admission: a systematic review of randomized trials. *J Am Coll Cardiol*. 2004 Aug 18;44(4):810–9.
7. Okada H. Essentials from clinical practice guidelines for CKD stage G3b-5 2017. *Clin Exp Nephrol*. 2018 Apr;22(2):245–8.
8. Davison SN, Levin A, Moss AH, Jha V, Brown EA, Brennan F, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney Int*. 2015 Sep;88(3):447–59.
9. Kidney Disease: Improving Global, Outcomes (KDIGO) CKD Work Group. KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. *Kidney IntSuppl*. 2013;3(1):1–150.
10. Person-Centered Care: A Definition and Essential Elements. *J Am Geriatr Soc*. 2016 Jan;64(1):15–8.
11. Montague T, Gogovor A, Aylen J, Ashley L, Ahmed S, Martin L, et al. Patient-Centred Care in Canada: Key Components and the Path Forward. *Healthc Q Tor Ont*. 2017;20(1):50–6.
12. Valentijn PP, Pereira FA, Ruospo M, Palmer SC, Hegbrant J, Sterner CW, et al. Person-Centered Integrated Care for Chronic Kidney Disease: A Systematic Review and Meta-Analysis of Randomized Controlled Trials. *Clin J Am Soc Nephrol CJASN*. 2018 Mar 7;13(3):375–86.

13. Elwyn G, Dehlendorf C, Epstein RM, Marrin K, White J, Frosch DL. Shared decision making and motivational interviewing: achieving patient-centered care across the spectrum of health care problems. *Ann Fam Med*. 2014 Jun;12(3):270–5.
14. Statistics Canada. Aboriginal peoples in Canada: Key results from the 2016 Census [Internet]. 2017. Available from: <https://www150.statcan.gc.ca/n1/en/daily-quotidien/171025/dq171025a-eng.pdf?st=2scZQKag>
15. Stemer G, Lemmens-Gruber R. Clinical pharmacy activities in chronic kidney disease and end-stage renal disease patients: a systematic literature review. *BMC Nephrol*. 2011 Jul 22;12:35.
16. Lalonde L, Quintana-Barcelona P, Lord A, Bell R, Clement V, Daigneault A-M, et al. Community Pharmacist Training-and-Communication Network and Drug-Related Problems in Patients With CKD: A Multicenter, Cluster-Randomized, Controlled Trial. *Am J Kidney Dis Off J Natl Kidney Found*. 2017 Sep;70(3):386–96.
17. Bhopal RS, Douglas A, Wallia S, Forbes JF, Lean MEJ, Gill JMR, et al. Effect of a lifestyle intervention on weight change in south Asian individuals in the UK at high risk of type 2 diabetes: a family-cluster randomised controlled trial. *Lancet Diabetes Endocrinol*. 2014 Mar;2(3):218–27.
18. Huang M-C, Hsu C-C, Wang H-S, Shin S-J. Prospective randomized controlled trial to evaluate effectiveness of registered dietitian-led diabetes management on glycemic and diet control in a primary care setting in Taiwan. *Diabetes Care*. 2010 Feb;33(2):233–9.
19. Karavetian M, de Vries N, Rizk R, Elzein H. Dietary educational interventions for management of hyperphosphatemia in hemodialysis patients: a systematic review and meta-analysis. *Nutr Rev*. 2014 Jul;72(7):471–82.
20. Tangri N, Stevens LA, Griffith J, Tighiouart H, Djurdjev O, Naimark D, et al. A predictive model for progression of chronic kidney disease to kidney failure. *JAMA*. 2011 Apr 20;305(15):1553–9.
21. Clase CM, Kiberd BA, Garg AX. Relationship between glomerular filtration rate and the prevalence of metabolic abnormalities: results from the Third National Health and Nutrition Examination Survey (NHANES III). *Nephron Clin Pract*. 2007;105(4):c178-184.
22. Barbour SJ, Er L, Djurdjev O, Karim MA, Levin A. The prevalence of hematologic and metabolic abnormalities during chronic kidney disease stages in different ethnic groups. *Kidney Int*. 2008 Jul;74(1):108–14.
23. Bowling CB, Inker LA. Metabolic complications in elderly adults with CKD. *Am J Kidney Dis Off J Natl Kidney Found*. 2012 Dec;60(6):893–5.
24. Skali H, Lin J, Pfeffer MA, Chen C-Y, Cooper ME, McMurray JJV, et al. Hemoglobin stability in patients with anemia, CKD, and type 2 diabetes: an analysis of the TREAT (Trial to Reduce Cardiovascular Events With Aranesp Therapy) placebo arm. *Am J Kidney Dis Off J Natl Kidney Found*. 2013 Feb;61(2):238–46.

25. Incardona N, Myers J. Advance Care Planning Conversation Guide: Clinician Primer [Internet]. 2016. Available from: <https://www.speakupontario.ca/wp-content/uploads/2018/07/ACP-Conversation-Guide-Clinician-Primer.pdf>
26. Lopez-Vargas PA, Tong A, Howell M, Craig JC. Educational Interventions for Patients With CKD: A Systematic Review. *Am J Kidney Dis Off J Natl Kidney Found*. 2016 Sep;68(3):353–70.
27. Knowles M. *The Adult Learner: A Neglected Species*. 4th ed. Gulf Pub Co; 1990. 294 p.
28. Knowles M. *Self-directed Learning*. Cambridge; 1983. 144 p.
29. Embuldeniya G, Veinot P, Bell E, Bell M, Nyhof-Young J, Sale JEM, et al. The experience and impact of chronic disease peer support interventions: a qualitative synthesis. *Patient Educ Couns*. 2013 Jul;92(1):3–12.
30. Howell D, Harth T, Brown J, Bennett C, Boyko S. *Self-Management Education for Patients with Cancer: Evidence Summary*. Ontario: Cancer Care Ontario; 2016 p. 83.
31. Bandura A. Self-efficacy. In: *Encyclopedia of human behavior*. New York: Academic Press; 1994. p. 71–81.
32. Hanko J, Romann A, Taylor P, Copland M, Beaulieu M. Optimizing AVF creation prior to dialysis start: the role of predialysis renal replacement therapy choices. *Nephrol Dial Transplant Off Publ Eur Dial Transpl Assoc - Eur Ren Assoc*. 2012 Nov;27(11):4205–10.
33. Keating PT, Walsh M, Ribic CM, Brimble KS. The impact of patient preference on dialysis modality and hemodialysis vascular access. *BMC Nephrol*. 2014 Feb 22;15:38.
34. Laupacis A, Keown P, Pus N, Krueger H, Ferguson B, Wong C, et al. A study of the quality of life and cost-utility of renal transplantation. *Kidney Int*. 1996 Jul;50(1):235–42.
35. Wolfe RA, Ashby VB, Milford EL, Ojo AO, Ettenger RE, Agodoa LY, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med*. 1999 Dec 2;341(23):1725–30.
36. Wong CKH, Chen JY, Fung SKS, Lo WK, Lui SL, Chan DTM, et al. Health-related Quality of Life and Health Utility of Chinese Patients Undergoing Nocturnal Home Haemodialysis in comparison to Other Modes of Dialysis. *Nephrol Carlton Vic*. 2018 Jun 21;
37. Kutner NG, Zhang R, Barnhart H, Collins AJ. Health status and quality of life reported by incident patients after 1 year on haemodialysis or peritoneal dialysis. *Nephrol Dial Transplant Off Publ Eur Dial Transpl Assoc - Eur Ren Assoc*. 2005 Oct;20(10):2159–67.
38. Health Care Consent Act [Internet]. S.O. 1996, c. 2, Sched. A 1996. Available from: <https://www.ontario.ca/laws/statute/96h02#BK9>
39. Malhotra R, Nguyen HA, Benavente O, Mete M, Howard BV, Mant J, et al. Association Between More Intensive vs Less Intensive Blood Pressure Lowering and Risk of Mortality

in Chronic Kidney Disease Stages 3 to 5: A Systematic Review and Meta-analysis. *JAMA Intern Med.* 2017 Oct 1;177(10):1498–505.

40. Palmer SC, Mavridis D, Navarese E, Craig JC, Tonelli M, Salanti G, et al. Comparative efficacy and safety of blood pressure-lowering agents in adults with diabetes and kidney disease: a network meta-analysis. *Lancet Lond Engl.* 2015 May 23;385(9982):2047–56.
41. Tonelli M, Wanner C. Lipid management in chronic kidney disease: synopsis of the Kidney Disease: Improving Global Outcomes 2013 clinical practice guideline. *Ann Intern Med.* 2014 Feb 4;160(3):182.
42. Moist LM, Troyanov S, White CT, Wazny LD, Wilson J-A, McFarlane P, et al. Canadian Society of Nephrology commentary on the 2012 KDIGO Clinical Practice Guideline for Anemia in CKD. *Am J Kidney Dis Off J Natl Kidney Found.* 2013 Nov;62(5):860–73.
43. Ketteler M, Block GA, Evenepoel P, Fukagawa M, Herzog CA, McCann L, et al. Diagnosis, Evaluation, Prevention, and Treatment of Chronic Kidney Disease-Mineral and Bone Disorder: Synopsis of the Kidney Disease: Improving Global Outcomes 2017 Clinical Practice Guideline Update. *Ann Intern Med.* 2018 Mar 20;168(6):422–30.
44. Ikizler TA, Cano NJ, Franch H, Fouque D, Himmelfarb J, Kalantar-Zadeh K, et al. Prevention and treatment of protein energy wasting in chronic kidney disease patients: a consensus statement by the International Society of Renal Nutrition and Metabolism. *Kidney Int.* 2013 Dec;84(6):1096–107.
45. Mekonnen AB, McLachlan AJ, Brien J-AE. Effectiveness of pharmacist-led medication reconciliation programmes on clinical outcomes at hospital transitions: a systematic review and meta-analysis. *BMJ Open.* 2016 Feb 23;6(2):e010003.
46. Edmonton Symptom Assessment System Revised – Renal Questionnaire [Internet]. Ontario Renal Network; 2018 [cited 2108 Sep 19]. Available from: <https://www.ontariorenalnetwork.ca/en/kidney-care-resources/clinical-tools/symptom-management>
47. Cooper BA, Branley P, Bulfone L, Collins JF, Craig JC, Fraenkel MB, et al. A randomized, controlled trial of early versus late initiation of dialysis. *N Engl J Med.* 2010 Aug 12;363(7):609–19.