Chronic Kidney Disease and Care Coordination: Working Together to Improve Outcomes

Developed in partnership with: National Kidney Foundation®

Key Takeaways

• Chronic kidney disease (CKD) affects 26 million adults in the United States⁴, and another 73 million (1 in 3 American adults⁵) are at risk of developing the disease.

• Early signs are hard to detect and easily missed, and nine out of ten people with CKD – over 22 million Americans⁶ – remain undiagnosed, increasing the possibility of kidney failure, heart attack, stroke, or premature death.

• Even individuals at the highest risk, such as those with diabetes and hypertension, do not always get the proper screenings.

• Because most kidney disease patients have multiple complex health conditions, and see multiple providers and specialists, care coordination presents a particular challenge.

• Access to effective care coordination services – and healthcare plans that offer these services – can make the difference between kidney disease progression and kidney disease control.
Background

Kidneys play an essential role in helping people live healthy lives. They filter waste and toxins from the blood, release a hormone that regulates blood pressure, keep minerals in balance, and perform other important tasks. However, sometimes disease affects the kidneys and stops them from performing their duties. This is known as chronic kidney disease (CKD), a prevalent, but often undetected disorder that has far-reaching public health and economic implications.

CKD is the 9th leading cause of death in the United States. Approximately 73 million people are at risk for developing kidney disease and about one in nine, or 26 million, already have it. The two main risk factors are diabetes and high blood pressure, responsible for up to two-thirds of cases. African Americans, Hispanics, Pacific Islanders, American Indians, and seniors are also at increased risk. African Americans develop kidney disease at a rate of 3 to 1 compared to whites, and Hispanics at a rate of 2 to 1.

Yet, surprisingly, most adults with CKD don’t know they have the disease because symptoms rarely appear in early stages, and nine out of ten of those living with the disease remain undiagnosed in primary care. Early identification – starting with a simple, low-cost urine and blood test in the primary care provider’s (PCP) office – and appropriate referral to a nephrologist can offset more invasive and costly treatments in the later stages of the disease, and increase the likelihood of slowing or stopping progression. This is why it is so important that Medicare, together with the nephrology community, do its part to educate primary care providers about how and when to screen, what interventions they can initiate in a primary care setting, and when and where to send patients in need of more specialized care.

However, because most CKD patients have multiple chronic health conditions, even if early detection is achieved, lack of care coordination across providers and specialists can create conflict and confusion, leading to additional costs and health challenges.

Medicare makes a substantial investment in the care of people with kidney disease. Total Medicare fee-for-service expenditures for all stages of kidney disease were nearly $100 billion in 2013, not including prescription medications. To make the most of this investment, and stem the rising tide of suffering and cost associated with CKD, it is essential that at-risk patients be screened, diagnosed, and treated as early as possible, and that care teams work together to improve patient outcomes.

The Medicare Advantage Care Coordination Task Force (MACC) recently met with a number of individuals with expertise in this field – including patients, providers, and community health leaders – to learn more about what resources are available to patients and what opportunities exist to improve care coordination in the near- and long-term. Here are their perspectives.

Care for Us Project

The MACC Task Force is Proud to sponsor the Care for Us Project, which provides chronic care resources to Medicare beneficiaries, their family members, providers and the broader policy community on an ongoing basis. In recognition of National Kidney Month, the Task Force published a suite of resources in partnership with Task Force member National Kidney Foundation focused on chronic kidney disease and care coordination. Moving forward, the Care for Us Project will produce resources on cardiovascular disease, mental health, Alzheimer’s, and asthma & allergic diseases.
What Patients Can Do to Improve Care Coordination

Based on the feedback from our experts, the MACC Task Force has identified seven steps that people with or at risk of kidney disease can take to improve their care.

1. **Know your risk factors**: Major risk factors for chronic kidney disease (CKD) include diabetes, high blood pressure, heart disease, family history of kidney failure, and being age 60 or older. African Americans, Hispanics, Pacific Islanders, and American Indians are also at increased risk. Since most people with CKD do not have symptoms in the early stages, it is important that patients understand their level of risk and talk to their doctors about early detection. “The goal is to catch the disease before it progresses to stage IV or stage V,” says Dr. Jeffrey Berns, president of the National Kidney Foundation. “The earlier kidney disease is caught, the less invasive the treatments will be, and the easier it will be to manage the disease and keep it from getting worse.”

2. **Ask your primary care practitioner about your kidney function**: Primary care practitioners (PCP), the healthcare providers most Americans go to in non-emergency situations, can play an important role in finding and treating kidney disease before painful and expensive interventions are needed. However, because there are usually no symptoms in the early stages, it is not unusual for CKD to be missed in routine screenings. That is why it is so critical for anyone at risk for the disease to ask their PCP about their kidney function – whether or not symptoms have appeared. Dr. Michael Choi, clinical director of nephrology at Johns Hopkins, suggests that patients ask specifically about two things: 1) the level of protein in their urine, and 2) their glomerular filtration rate (GFR), which is calculated by using serum creatinine from a blood test. “Most doctors don’t default to kidney disease on their checklist,” says Jeremy Waterbury, a kidney transplant recipient and member of the NKF Kidney Action Committee. “If my primary care provider had known what to look for, it could have delayed dialysis and even put off my transplant.”

3. **Identify a care coordinator** – Because many kidney patients live with more than one disease, it is very common for them to see multiple providers at the same time (such as a primary care physician, endocrinologist, nephrologist, cardiologist). However, the level of interaction across care teams varies widely. A lack of communication between providers can create confusion and conflict in the care plan, which is particularly risky when a patient is left to navigate these issues on their own. Jessica Davis of the National Transitions of Care Coalition (NTOCC) suggests that patients identify a care coordinator from within their medical team – someone separate and apart from themselves or their caregiver – who can help ensure that everyone involved is sharing information and working as a team.

4. **Keep a list of your medications and dietary needs** – Medication errors are one of the biggest reasons patients go back to the doctor or hospital, but the systems used to track whether medications are being taken correctly, or whether certain medications are safe to take together, vary from provider to provider. To avoid dangerous outcomes, patients should create an up-to-date list of their medications and share it with any doctor or specialist involved in their care. That list should have the names of all prescription and over-the-counter medications they take, including frequency and dose; any reactions, positive or negative; the name of the prescribing physician; the names and doses of all vitamins and/or herbal supplements; and any dietary recommendations they have been given by members of their care team.
5. **Keep a list of your care providers**: Patients should also keep an up-to-date list of all of the doctors and healthcare providers they see, with contact information. This list should include any personal caregivers as well, such as family members or loved ones involved in making care decisions. These caregivers are often the only individuals who have been involved in the patient's care throughout every transition.

6. **Seek out support services**: As patient Jeremy Waterbury points out, “This is a life altering disease, and if you don’t have someone you can talk to, or somewhere you can go to get information, you won’t have any idea about what’s coming next.” The National Kidney Foundation offers a variety of resources to patients, including a series of educational guides, a patient information helpline, access to peer support networks and mentors, and numerous patient navigation tools. Throughout the year, NKF offers free screenings across the country to those most at risk for kidney disease – anyone with diabetes, high blood pressure or a family history of kidney failure. Locations and information can be found at [www.kidney.org](http://www.kidney.org).

7. **Check to see what care coordination tools your health plan offers**: Patients should educate themselves about their health plan and the services available to them through that plan. Medicare Advantage (MA) plans, for example, offer access to advanced monitoring, nutrition, medication, and home infusion services, however, they are not available to all kidney patients. A sub-type of MA plans called Chronic Condition Special Needs Plans, or C-SNPS, are experimenting with enrolling those in the later stages of the disease, including patients with kidney failure.
Systems-Level Changes Needed to Support Better Care

While there are a number of things that patients can do on their own, these efforts must be supported by system-wide changes that foster earlier detection, strengthen disease management, and enable greater coordination across providers. Only by changing certain policy and cultural norms will the full health and economic potential of coordinated care be realized. Based on the feedback from our experts, the MACC Task Force offers the following recommendations:

1. **Educate primary care providers on how and when to screen**: Earlier detection of those at risk for kidney disease allows the introduction of low-cost medical management strategies and patient education needed to slow the progression of the disease, and, by extension, the rate of entry into Medicare’s expensive End Stage Renal Disease (ESRD) program. However, early signs are hard to detect and easily missed, and primary care practitioners do not always have the knowledge and resources necessary to catch the disease in its formative stages. Given the limited number of kidney disease specialists in the U.S. – there is only 1 nephrologist for every 2,800 patients with moderate CKD – the role of PCPs as critical partners in finding and treating kidney disease cannot be overstated. By making small, but targeted investments in primary care education – from simple decision support tools to care and referral guidelines – Medicare could realize outsized improvements on outcomes and cost.

2. **Increase awareness about reimbursement for chronic care management**: Traditional barriers to early diagnosis and treatment in the primary care setting, such as lack of time and reimbursement, are being offset by new tools such as the Centers for Medicare & Medicaid Services (CMS) chronic care management code, which pays clinicians an average of $43.12 per month to spend at least 20 minutes in non-face-to-face consults with patients that have two or more chronic conditions. While still in its formative stages, it represents an important cultural shift, which is poised to change kidney disease management for the better. However, a recent survey found that insufficient reimbursement for the time required, lack of awareness about the opportunity, and compliance concerns have limited the number of providers who are taking advantage of the new code. By building awareness and increasing adoption, a tool like like could become a powerful weapon against CKD.

3. **Apply core quality measures to CKD-specific payment models**: Congress should direct the Secretary of Health and Human Services to design a demonstration project that creates a bundled payment to primary care practitioners tied to quality metrics that incentivize the early detection of at-risk individuals and improved management of existing kidney disease patients; develops a capitated payment to nephrologists tied to quality metrics for the management of stage 4 kidney disease; and establishes core quality measures designed to improve care and support CKD-specific payment models.

4. **Modify the Medicare Advantage risk adjustment program**: MA plans are well equipped to provide the care patients need most – comprehensive high quality, affordable coverage with innovative and targeted services. Services critical to the care management of advanced stage kidney disease – such as access to specialized centers with advanced treatment and monitoring, nutrition guidance, medication reviews, home infusion, access to durable medical equipment and nurse help hotlines – are often not available for those not enrolled in MA plans. And for many people with kidney failure, MA is not even an option. It is critical for CMS to fix the MA risk adjustment program to better encourage plans to invest in earlier CKD management and coordination. This will save the Medicare program a substantial amount of money, while also saving lives.
Conclusions

- Care coordination is essential for the management of chronic kidney disease (CKD), however, most patients do not have a formal care coordinator and end up taking on the role themselves.

- By identifying and treating kidney disease further upstream, hospitalization and expensive medical interventions can be prevented, cutting costs and saving lives.

- Primary care physicians are often a patient’s best bet for finding out whether or not they have CKD, and they should be equipped with the knowledge, resources, and reimbursement structures necessary to catch and treat the disease in its earliest stages.

- Realizing the full health and economic potential of coordinated care will require not only the involvement of patients and providers, but also the commitment of policymakers to implement system-wide changes that enable it.
Chronic Kidney Disease Care Coordination Resources

There are many resources that contribute to better care coordination for people in Medicare with CKD. Below are some suggested resources from our MACC Task Force members:

1. **NKF Peers** - A national, telephone-based peer support program from the National Kidney Foundation (NKF) that helps people adjust to living with chronic kidney disease, kidney failure, or a kidney transplant, and offers support to those considering living kidney donation or who have been living kidney donors. To learn more: Call 855-653-7337 (855-NKF-PEER) or email nkfpeers@kidney.org

2. **NKF Cares** – The National Kidney Foundation’s Patient Information Help Line, NKF Cares, offers support for people affected by kidney disease, organ donation or transplantation. It’s designed just for patients, family members and caregivers. Call toll-free at 1.855.NKF.CARES (1.855.653.2273) or email nkfcares@kidney.org

3. **CKDintercept** — Launched by the National Kidney Foundation, this initiative employs a diverse, ever-broadening strategy of activities involving primary care practitioners (PCPs), managed care, laboratories, educational institutions, government agencies, and the patients themselves. A component of the program, called “CKDinform,” provides continuing medical education targeted for PCPs on detecting and treating CKD. Learn more at https://www.kidney.org/CKDintercept

4. **Advanced CKD Patient Management Toolkit** – The Renal Physicians Association developed the Advanced CKD Patient Management Toolkit through a rigorous scientific process to assist practitioners with implementing the recommendations included in RPA’s third evidence-based clinical practice guideline, *Appropriate Patient Preparation for Renal Therapy (RRT)*. The toolkit is organized in four main areas – assess, tailor, implement and evaluate - includes 16 categories and sets of tools for healthcare providers and kidney patients. https://www.renalmd.org/RPA-Advanced-CKD-Patient-Management-Toolkit/

5. **Taking Care of MY Health Care Guide** – Created by the National Transitions of Care Coalition (NTOCC), this guide helps patients and their caregivers understand how to take an active role in the management of their disease. The guide offers tips to keep track of important health information and a medicine list to keep track of which medicines to take and when. Available through www.ntocc.org

6. **A Practical Approach to Detection and Management of Chronic Kidney Disease for the Primary Care Clinician** – These guidelines, published in the American Journal of Medicine in February of 2016, outline simple steps that PCPs can follow to improve the process of screening, treating, managing and referring their chronic kidney disease patients.

*Issue Brief Sources:*


ii www.cdc.gov/bloodpressure

iii www.kidney.org/sites/default/files/02-96-7007_CKDI_SellSheet_ProgramSummary%20(1).pdf


v www.cdc.gov/diabetes/pdfs/programs/CKDBrief.pdf


vii www.usrds.org/2014/view/

About the Experts

• Jeffrey Berns, MD, FNKF – Dr. Berns serves as President of the National Kidney Foundation (NKF), and Chair of the American Board of Internal Medicine (ABIM)’s Nephrology Board. He is a Professor of Medicine and Pediatrics at the University of Pennsylvania School of Medicine, Associate Chief and Fellowship Training Program Director of the University of Pennsylvania's Renal-Electrolyte and Hypertension Division, and Associate Dean for Graduate Medical Education.

• Michael James Choi, MD – Dr. Choi serves as President-elect of the National Kidney Foundation (NKF). He is an Associate Professor of Medicine at the Johns Hopkins University School of Medicine where also serves as Clinical Director of Nephrology. Dr. Choi co-chaired the NKF Education Committee, and co-authored “A Practical Approach to Detection and Management of Chronic Kidney Disease for the Primary Care Clinician,” in The American Journal of Medicine.

• Jessica Davis – Jessica is the policy director for the National Transitions of Care Coalition (NTOCC). NTOCC is a group of concerned organizations and individuals who have joined together to address problems associated with transitions of care: the movement of patients from one practice setting to another.

• Elizabeth Lee – Elizabeth Lee is a Principal at Venn Strategies in Washington, D.C., and manages the Alliance for Home Dialysis. The Alliance promotes activities and policies that will facilitate treatment choice in dialysis care while identifying and addressing systematic barriers that limit access to the benefit so home dialysis for patients and their families. Prior to her current post, Lee served as Senior Policy Advisor to the Administrator of the Health Resources and Services Administration (HRSA).

• Jeremy Waterbury – Jeremy, 34, is an ESRD patient who underwent emergency transplant surgery in the spring of 2012 after being diagnosed with an IgA neuropathy, despite having no previous symptoms. He is a member of the NKF’s Kidney Advocacy Committee, through which he works to raise awareness of CKD and advance the initiatives and policies that will benefit patients most.

About the Campaign

The Coalition for Medicare Choices (CMC), an AHIP-founded effort, has launched a unique venture called the Medicare Advantage Care Coordination (MACC) Task Force. Through its “Care Coordination Saves Lives” campaign, the MACC Task Force aims to identify and raise awareness of best-in-class care coordination practices and policies that have the potential to improve the health and well-being of Medicare beneficiaries.

About the National Kidney Foundation

The National Kidney Foundation is the leading organization in the U.S. dedicated to the awareness, prevention and treatment of kidney disease. For more information, visit www.kidney.org.