

Chronic Kidney Disease in North Carolina

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In the middle of the last century, chronic diseases overtook communicable diseases as the leading causes of death in the United States.¹ Public health campaigns and the scientific community have responded and developed national strategies to prevent and cure diseases including cancer, diabetes, HIV/AIDS, and hypertension. While the morbidity and mortality resulting from these diseases warrant this attention, other equally serious chronic diseases unfortunately receive less attention. One of these conditions is chronic kidney disease (CKD). Death from kidney failure, the most severe form of CKD, is more common than many of the most prevalent forms of cancer. (See Figure 1.)

Chronic kidney disease encompasses various levels of kidney damage ranging from a relatively asymptomatic decline in kidney function to kidney failure. Chronic kidney disease, in all its stages, is estimated to affect 13% of the United States population.² In North Carolina alone, almost 1 million people have CKD not including those with kidney failure.³ Despite the large number of people living with CKD, there is an overall lack of knowledge about the disease even among people who have it. Nationally, only about 25% of Americans diagnosed with CKD reported awareness of weak or failing kidneys.⁴ Among the general population, there is even less awareness. Preliminary data from a University of North Carolina at Chapel Hill (UNC) Kidney Center study shows that many people are unfamiliar with the risk factors for CKD.⁵

The combination of high disease burden and low public awareness warranted an in-depth study of how North Carolina can best act to lower the CKD disease burden in the future.

In 2006 the North Carolina General Assembly asked the North Carolina Institute of Medicine to convene a task force to study chronic kidney disease (Session Law 2006-248). The task force was funded by the state of North Carolina through its annual appropriation to the North Carolina Institute of Medicine. Marcus Plescia, MD, MPH, chief of the Chronic

“Addressing this public health threat [chronic kidney disease] will take a concerted and coordinated effort by actors throughout the health care system intervening at multiple points...”

Disease and Injury Section of the Division of Public Health, and Leanne Skipper, chief executive officer of the National Kidney Foundation of North Carolina, served as coauthors of the task force. The task force consisted of 39 other members representing a wide range of health care professionals, insurers, policymakers, consumers, and other interested individuals. The task force was charged with developing a plan that would reduce the occurrence of chronic kidney disease, educate health

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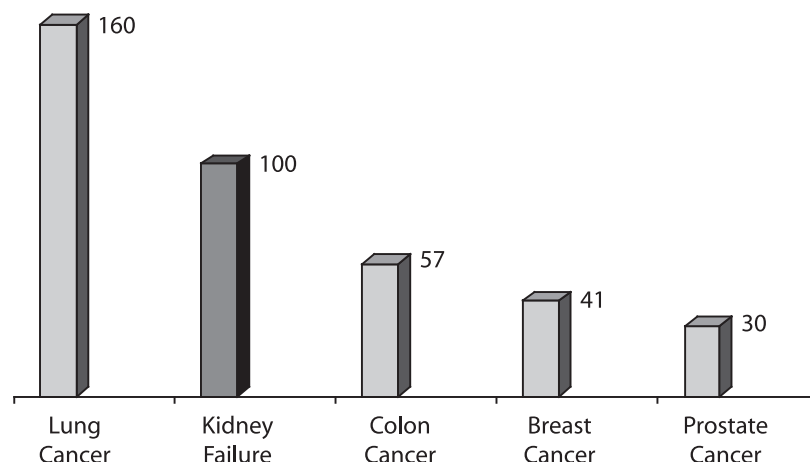
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Figure 1.
Deaths Due to Kidney Failure Compared to Cancer Deaths in the US, 2000 (in thousands)



Data taken from 2004 update to Gloeckler Ries GA, Reichman ME, Riedel Lewis D, Hankey BF, Edwards BK. Cancer survival and incidence from the Surveillance, Epidemiology, and End Results (SEER) Program. *The Oncologist*. 2003;8:541-552.

care professionals and the public, identify barriers to the adoption of best practices, and include recommendations to address these barriers. The task force met over a period of 18 months and made 15 recommendations which are discussed below. Because kidney function typically declines with age, the overwhelming majority of people with CKD are adults. Thus, the task force focused its analysis and recommendations on care for adults with CKD. The pediatric CKD population is unique in its needs and complications. Maria Ferris and colleagues outline concerns specific to children in their commentary focusing on pediatric chronic kidney disease.

The kidneys function to remove waste from the blood and produce hormones that help make red blood cells, regulate blood pressure, maintain calcium for bones, and regulate normal chemical balance in the body. Loss of kidney function can lead to a decline in other bodily functions. Kidney disease contributes to high blood pressure (hypertension), high blood sugar, high lipid levels, anemia, and bone disease—all of which can exacerbate other health problems. In fact, people with kidney disease are more likely to die from cardiovascular disease than from kidney failure. However, many people with chronic kidney disease progress to kidney failure, the most severe form of CKD. These patients need treatment including dialysis or transplantation to avoid the buildup of toxins that can lead to death.⁶

People who receive treatment for their kidney failure are considered to have end-stage kidney disease (ESKD).^{a,b} According to the United States Renal Data System, more than

1.8 million people suffer from ESKD worldwide including 387 000 people in the United States and 11 000 people in North Carolina. The number of people with ESKD per population in North Carolina has been consistently higher than the national average.

The risk of developing ESKD is not uniform across the population; racial and ethnic minorities are at higher risk than non-minorities. African Americans have 3.7 times the risk of developing kidney failure as do Whites. Native Americans have 1.9 times and Asian Americans have 1.3 times the risk of developing kidney failure as do Whites. Some people have clinical or other sociodemographic risks that increase their likelihood of developing CKD.⁷ For example, people with diabetes, high blood pressure, cardiovascular disease, autoimmune disease (eg, lupus), systemic infections, urinary tract infections, urinary stones, lower urinary tract obstruction,

cancer, family history of CKD, history of acute kidney failure, decreased kidney size, exposure to drugs toxic to the kidneys, or low birth weight are at increased risk of developing CKD.^{7,8} Similarly, older adults, people with low incomes or low educational achievement, or those with exposure to certain chemical and environmental conditions are in higher risk categories.⁷ Suma Vupputuri includes further details of the epidemiology of CKD in her commentary.

As useful as statistics and trends can be in describing the overall burden of the condition across the state, chronic kidney disease affects individuals. Understanding the multiple challenges people with CKD face is critical to understanding how to address CKD in North Carolina. Deidra Hall and Celeste Castillo Lee offer patient perspectives in their commentary.

The work of the task force was organized into a system of care for chronic kidney disease. (See Figure 2.) Ideally, the system begins with primary prevention of the conditions (eg, hypertension, diabetes) that can lead to kidney disease. This needs to be coupled with broad consumer education and outreach to help inform the general public about CKD and the risk factors that contribute to this problem. People at higher risk of kidney disease should be screened for the disease. Individuals who are identified as having CKD should be linked into a primary care medical home and have their kidney function regularly monitored. Primary care providers should help patients treat their disease and any comorbid conditions that could otherwise exacerbate their health problems. In addition, people with CKD should receive care management and disease management services to

a End-stage kidney disease (ESKD) and end-stage renal disease (ESRD) refer to the same condition.

b Kidney failure includes those patients who are not treated with dialysis or transplantation while the term ESKD does not.²³

help them control their disease. As their kidney disease progresses further, patients should be referred to nephrologists who work collaboratively with primary care providers and other health care professionals to develop treatment plans and manage patients' health problems. Nephrologists should also help educate patients about options for renal replacement therapy before they progress to end-stage renal failure.

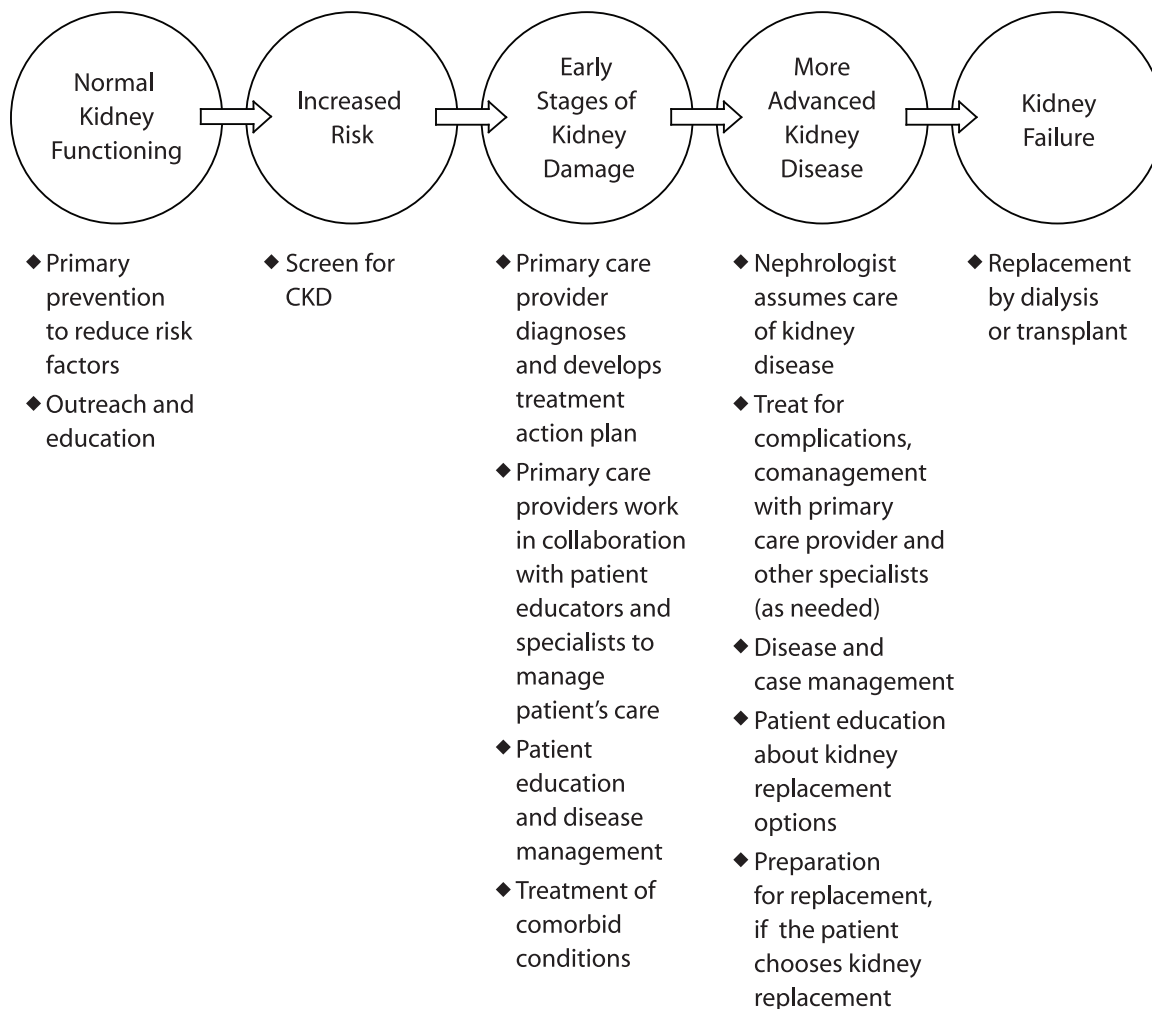
Primary Prevention, Outreach, and Education

Diabetes mellitus and hypertension are major causes of chronic kidney disease and kidney failure. Diabetes is an underlying cause in 42% of new patients diagnosed annually with CKD.⁹ Almost 90% of these patients have type 2 diabetes mellitus, the prevalence of which is growing rapidly. From 2001 to 2006 the percentage of North Carolina adults who

reported being told by a physician they had diabetes rose by over one-third from 6.7% to 9.1%.¹⁰ People with uncontrolled high blood pressure also have a greater risk of developing chronic kidney disease.¹¹ Not only do these chronic health conditions increase the risk of someone developing CKD, they are also major contributors to kidney failure. Together, diabetes mellitus and hypertension contribute to approximately 60% of new cases of people with kidney failure.¹² North Carolina can help prevent chronic kidney disease by reducing risk factors that lead to diabetes or hypertension such as obesity, poor nutrition, and lack of exercise. The task force recommended that **existing primary prevention efforts aimed at reducing the risk factors which contribute to diabetes and hypertension be further supported and expanded.**

In addition to primary prevention of diabetes and hypertension, many complementary outreach strategies are

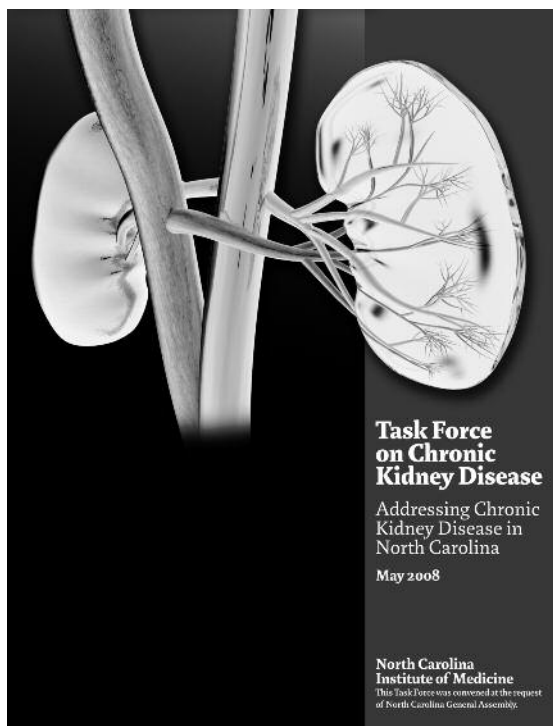
Figure 2.
Coordinated System of Care for Patients as They Progress with Kidney Disease



Adapted from: National Kidney Foundation. K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *Am J Kidney Dis.* 2002;39(2)(suppl 1):S1-S266.

needed to educate the public about kidney health and CKD. Broad-based health education efforts can be effective in reducing the primary risk factors that ultimately lead to chronic kidney disease, especially when these approaches are combined with policy and environmental change interventions.¹³ There are already several community-based health education efforts that could be expanded to reach more people or different at-risk populations. Some of these initiatives are designed to increase awareness of kidney health and related risk factors for CKD; others work with targeted populations around diabetes or other health conditions. Barbara Pullen-Smith and Marcus Plescia provide an overview of programs housed within the North Carolina Division of Public Health in their commentary. Two particular programs that show promise are outlined further: Leanne Skipper focuses on National Kidney Foundation programs while Donna Harward focuses on the UNC Kidney Education Outreach Program.

Existing programs help educate the public on chronic kidney disease and other health conditions that can lead to CKD, but there is a need for greater outreach to target at-risk populations throughout the state. The task force recommended that **the North Carolina General Assembly appropriate \$500,000 to the Office of Minority Health and Health Disparities to expand existing diabetes education programs that educate at-risk populations about CKD and the importance of early screening.** These programs should be developed in collaboration with community partners such as faith-based health ministries, civic organizations, and senior citizen groups and should be evaluated to determine their effectiveness. The task force also recommended that **public and private insurers should examine patient-level data to determine those at risk for or diagnosed with CKD and explore mechanisms to increase awareness of CKD among those at risk.**



Screening High-Risk Individuals

The Kidney Disease Outcomes Quality Initiative (KDOQI) of the National Kidney Foundation (see below) suggests primary care practitioners should routinely screen people with CKD risk factors (eg, diabetes, hypertension, family history of kidney disease) for kidney function and should monitor kidney function over time.⁷ More recent research shows that cardiovascular disease (CVD) is also a risk factor which contributes to CKD, and therefore patients with CVD should also be screened for chronic kidney disease.^{14,15} There are a variety of screening tests that are widely available, easily obtained, and relatively inexpensive.

People with health insurance generally are covered for screening, but there is no statewide screening program for people who are uninsured. To compound this problem, uninsured individuals who have been diagnosed with CKD may not be able to pay for the care and treatment needed to slow the progression of the disease. There are safety net programs in certain communities that provide ongoing primary care services to the uninsured on a sliding fee scale.^{c,16} However, these organizations do not serve all areas of the state, and not all safety net organizations have the capacity to provide comprehensive and ongoing primary care services to people with chronic illnesses.

With these gaps in mind, the task force recommended that **the North Carolina General Assembly should provide \$500,000 in recurring funding to the Division of Public Health to help pay for the screenings of uninsured patients who are at high risk for developing kidney disease, \$2.4 million to expand safety net organizations to provide primary care to uninsured individuals with CKD,^d \$15 million to expand care to the uninsured with other chronic illnesses that can lead to CKD, and \$5 million to the North Carolina Division of Public Health Purchase of Medical**

c Certain health care organizations have a legal responsibility or mission to provide ambulatory health care services to the uninsured for free or on a sliding fee basis. These include community and migrant health centers (federally qualified health centers), state-funded rural health clinics, free clinics, local health departments, hospital emergency departments or outpatient clinics, and other nonprofit community organizations. However, certain organizations—including many free clinics, health departments, and hospital emergency rooms—do not have the capacity or resources to provide ongoing comprehensive primary care services to individuals to help them manage their chronic conditions.

d The North Carolina General Assembly already appropriates some funding to expand and strengthen the health care safety net for uninsured patients. In FY 2008 the General Assembly appropriated \$2 million in recurring funds and \$5 million in nonrecurring funds to the Office of Rural Health and Community Care in the North Carolina Department of Health and Human Services to expand the health care safety net. This initiative is called the Community Health Center grants program. The task force recommended that this program be expanded further to meet the primary care needs of people with CKD who do not otherwise have a medical home (\$2.4 million) and for uninsured with other chronic health problems that could lead to CKD (\$15 million).

Care program to help pay for nephrologist consults for uninsured patients with incomes <200% of federal poverty guidelines.

Primary Care and Collaborative Care Teams

Most people receive outpatient health care services through primary care practitioners (PCPs) who provide preventive, primary, and acute medical services and help coordinate the care that people with complex or chronic illnesses receive from specialists. While they are the principal source of outpatient medical care for most patients, PCPs face significant challenges providing all the recommended care to their patients. The practice of medicine is constantly evolving as clinical guidelines are added, deleted, or refined, making it difficult for primary care practitioners to remain current with all existing guidelines relevant to their patients.

The National Kidney Foundation, using an expert consensus process, has identified evidence-based strategies for screening, staging, and treating patients with CKD. These guidelines, called the Kidney Disease Outcomes Quality Initiative (KDOQI), recommend—as do evidence-based guidelines for treatment of patients with diabetes and hypertension—that primary care practitioners screen people at high risk and identify patients with chronic kidney disease.⁶ However research suggests that chronic kidney disease is often not detected even when patients have access to primary care.¹⁷ Some PCPs are unaware of all the risk factors or the current evidence-based guidelines for CKD.^{18,19} To address this information gap among some practitioners, the task force recommended that **health professions organizations across the state collaborate to provide targeted CKD education for primary care practitioners.**

The task force spent considerable time discussing ways to reduce the barriers PCPs face in identifying people with CKD. The most specific test of kidney function tests for creatinine, a waste product in the blood. Creatinine is normally removed by the kidneys, but people with declined kidney function have increased creatinine levels. Primary care practitioners often order blood serum creatinine tests as a part of a routine screening. An estimated glomerular filtration rate (eGFR), used to measure kidney function, can be calculated by analyzing a person's blood for serum creatinine using certain patient characteristics (eg, age, race, gender). However, laboratories do not always report the eGFR when reporting lab results for routine blood serum creatinine screenings unless it is specifically ordered by the physician.²⁰ The task force therefore recommended that **estimated GFR values should be computed and reported on all creatinine determinations by clinical laboratories in North Carolina**, which should assist PCPs in identifying people with CKD. Thomas DuBose discusses this issue more fully in his commentary.

Following the KDOQI guidelines, the task force also recommended that **primary care practitioners routinely screen their patients who are at high risk for chronic kidney disease, stage patients who have been identified with CKD according to the KDOQI disease categories, follow the KDOQI or other evidence-based guidelines to manage and slow the progression of CKD, and refer patients with severely declining function to nephrologists for ongoing care.** PCPs can use the stages of CKD to help explain the disease process to their patients, develop care plans, and assess the risk of potential complications such as development of cardiovascular disease or kidney failure. As kidney function declines further, patients should be referred to nephrologists for clinical management of kidney disease. Even after referral, the PCP will still play an important role in serving as the patient's medical home and helping to manage the patient's comorbid conditions. Cynda Ann Johnson discusses the role of primary care practitioners in her commentary.

The use of disease registries can also assist primary care practitioners in identifying patients with specific chronic illnesses and can trigger the application of evidence-based screening and treatment guidelines. Some practitioners have electronic health records (EHRs) with the capacity to identify patients with chronic illnesses or to provide clinical decision support prompts. However, this capacity is not universal in EHRs. The task force recommended that **electronic health records provide the capacity for chronic disease registries and clinical decision support prompts that incorporate CKD screening and treatment measures for at-risk groups.**

Patient Education, Disease Management, and Case Management Services

In general all patients who have health problems should be educated about the course of their disease, treatment options, and management of their health conditions. Patients with chronic kidney disease need education about the role of the kidneys in maintaining their overall health, the progression of the disease, risk factors that can exacerbate CKD, recommended treatment, medication, and diet. Providing patients with the skills to better manage their own health will help improve outcomes. Primary care practitioners and nephrologists can assist in the patient education process. However, individuals often need more intensive health education than can typically be provided in a physician's office.

Patient education, disease management, and case management services can augment the information and services provided by health care practitioners. Disease management activities are generally targeted to individuals with specific health conditions or diseases such as diabetes, asthma, congestive heart failure, coronary artery disease, or hypertension. The activities are

e Both the American Diabetes Association's evidence-based guidelines for treatment of patients with diabetes²⁴ and the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure report (JNC 7) on evidence-based guidelines for treatment of patients with hypertension⁹ recommend that practitioners obtain a serum creatinine to calculate the estimated GFR.

designed to provide individuals with the information and support necessary to assist them in monitoring their own care and adhering to recommended treatment guidelines. Case management activities can be offered in conjunction with, or separate from, disease management efforts. North Carolina insurers offer both disease management and case management activities for selected individuals.

Although many insurers and payers offer disease management and quality improvement efforts targeting people with diabetes, hypertension, or cardiovascular disease, these initiatives do not always measure how well practitioners screen high-risk individuals for chronic kidney disease. Thus, the task force recommended that **disease management and quality improvement initiatives aimed at diabetes, hypertension, or cardiovascular disease give greater emphasis to CKD prevention, screening, and management.** These services should be available to all patients with CKD once they reach stage 4. Anne Rogers discusses how the North Carolina State Health Plan has moved to strengthen CKD education and disease management in her commentary. Similarly, Annette DuBard and Jennifer Cockerham discuss how Community Care of North Carolina (CCNC), the state's Medicaid disease management program, can be changed to strengthen CKD education and management in their commentary. In addition to the existing disease and care management programs that reach Medicaid-only populations, CCNC is developing plans to extend the program to Medicare and dually-eligible beneficiaries. Because the likelihood of having CKD increases as people age, the task force recommended **the creation of a CKD specific disease management and quality improvement initiative if CCNC is expanded to include the Medicare population.**

The University of North Carolina at Chapel Hill, in conjunction with the North Carolina Community College System, has developed a proposal for a certification program for kidney care managers to ensure the availability of care managers appropriately trained in the management of people with chronic kidney disease. The task force recommended that **North Carolina foundations provide funding to the University of North Carolina at Chapel Hill to pilot test and evaluate the effectiveness of the Kidney Care Prevention Program, and that public and private payers and insurers provide reimbursement for CKD trained educators if determined to be effective and cost-efficient.** Donna Harward and Ronald J. Falk discusses the program more fully in their commentary. The task force also recommended that **disease management or case managers who manage patients with diabetes, hypertension, or cardiovascular disease should be cross-trained in disease management for people with chronic kidney disease, and the North Carolina General Assembly should support the infrastructure needed to expand the Division of Public Health Diabetes Education Recognition Program with a special focus on CKD screening and management.**

Initiatives aimed at improving the quality of health care rely on evidence-based performance measures such as those recognized by the National Quality Forum, National Committee for Quality Assurance, or other disease-specific organizations. However,

quality measures do not exist for all evidence-based guidelines. North Carolina health care professionals are more likely to adopt new performance measures if they have been nationally recognized. Thus, the task force recommended that **national health professions organizations that focus on kidney disease should work with national quality and standard setting organizations to devise quality performance measures that assess the degree to which practitioners screen and manage patients with or at risk of developing chronic kidney disease in accordance with nationally recognized guidelines.**

Nephrologists

Nephrologists play a critical role in the effective management of patients with kidney disease, but there are too few nephrologists to assume the care of everyone with CKD. In North Carolina there are 215 nephrologists or about 3.4 nephrologists per 10 000 people with CKD stages 2-5.²¹ In contrast there are approximately 9 primary care practitioners for every 10 000 people in North Carolina.²² Because of the low relative number of nephrologists, most of their work is limited to people who have more advanced forms of kidney disease. Paul Bolin discusses the coordination of care between nephrologists and primary care practitioners in his commentary. The task force recognized the critical importance of creating a collaborative team of primary care providers, nephrologists, and other health care professionals to manage the care of people with CKD throughout the course of their disease. Therefore the task force recommended that **nephrologists should actively build collaborative relationships with primary care practitioners. In addition, professional associations of nephrologists should actively encourage and educate their peers on the importance of developing these collaborative relationships and should distribute tools to assist in consulting with PCPs.**

Nephrologists should assume more active management of patients as their disease begins to approach kidney failure (stage 4 of the KDOQI guidelines). One of the issues nephrologists should discuss with CKD patients is the choice of kidney replacement therapy (including the option of no therapy if that is the patient's preference). Kidney replacement therapy includes peritoneal and home dialysis, in-center dialysis, and transplantation. Linda Upchurch focuses on the various modalities of dialysis in her commentary. In addition, nephrologists or other care managers should help educate patients about the need for early vascular access prior to starting dialysis; this can prevent possible medical complications that may arise in the event of emergency medical treatment for kidney failure. The task force recommended that **nephrologists help educate patients about different renal replacement options and early vascular access well in advance of kidney failure.**

Although it has relatively low awareness among the general public, chronic kidney disease imposes a high burden of disease on nearly a million North Carolinians. As discussed above, a number of recommendations emanated from the North Carolina Institute of Medicine Task Force on Chronic Kidney Disease, and the commentaries included in this issue

complement and extend these recommendations. Addressing this public health threat will take a concerted and coordinated effort by actors throughout the health care system intervening at multiple points to decrease the number of people developing CKD, slow the progression of the disease, and improve the care provided to those with CKD. Like many of our most pressing challenges in health policy, no one solution will be able to effectively manage this threat. But by leveraging the efforts of many organizations, we can lessen the impact of chronic kidney disease on nearly one million fellow North Carolinians facing this condition every day. **NCMJ**

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