

Chapter FourCoordinated System Of Care

eople in the United States with chronic kidney disease progress to kidney failure more frequently than in other countries, even though the prevalence of chronic kidney disease in the United States is similar to that in other countries. One of the reasons for the rapid deterioration in the health status of people with chronic kidney disease is the lack of a comprehensive system of care, especially for individuals at earlier stages of kidney disease. Curtin et al. describes the current fragmented system of care for people with chronic kidney disease in the United States:

Many believe, care delivered during CKD stages 1-4 is uncoordinated and suboptimal [citations omitted]. Kidney disease is often diagnosed relatively late in its course [citations omitted]. In many cases, interventions to delay progression may not be instituted in a timely fashion, albumin levels may be allowed to fall in the pre-ESRD period, and anemia and cardiovascular disease may be undertreated [citations omitted]. Additionally, patient education is not likely to be instituted during the pre-ESRD period, modality choice may be less than optimally 'informed' and access may not be placed in advance of dialysis [citations omitted]. Renal replacement therapy itself often occurs late and on an emergent basis [citations omitted].

Some of the problems with the delivered treatment might be attributed to the disjointed nature of the care. Patients with early stage CKD are usually treated by primary care physicians and referral to nephrologists frequently occurs late in the course of the disease [citations omitted]. Dialysis and transplant patients tend to be treated by different "teams," even within the same health care setting. Moreover, communication/coordination between these health care teams that might smooth the transitions through CKD and deliver continuous care does not occur with regularity [citations omitted]. ³

Studies suggest that our fragmented system of care leads to worse health outcomes for people with chronic kidney disease. Hallan et al. conducted a cross-country comparison to examine the prevalence of chronic kidney disease in the United States and Norway,

both countries with large data sets that could be used to identify people with CKD. The prevalence of early stages of CKD is similar in the two countries even after adjusted for age, race, and diabetes status. People in Norway, however, have a much lower risk of progressing to ESKD than do people in the United States. The researchers compared the care system offered in Norway to care in the United States and concluded that the difference in the prevalence of ESKD between the two countries is due to differences in management of patients with earlier stages of CKD. Norwegian patients were referred to nephrologists earlier in the course of their disease and had more visits prior to renal failure. As a result, patients were less likely to be anemic when starting dialysis and had better nutritional status than patients with kidney disease in the United States. Patients were more likely to receive transplantation services in Norway, reducing the need for dialysis. Because of this more coordinated system of care, the people with chronic kidney disease in Norway were able to maintain higher kidney function for longer periods of time than were people in the United States.

North Carolina needs a comprehensive system of care to ensure that people with chronic kidney disease are identified early and receive the services needed to help them manage their chronic health problem. ⁴ The system of care can be conceptualized as addressing five subpopulations defined by their risk for and stage of CKD. An effective system of care would ensure that the general population with normal kidney functioning has a basic understanding of kidney health and risk factors for kidney disease. Those with normal kidney function should be screened for CKD risk factors such as diabetes and hypertension. Better detection of CKD risk factors would help practitioners target the people at most risk for CKD. Individuals at higher risk for CKD (such as those with hypertension, diabetes, cardiovascular disease, or a family history of CKD) would be screened specifically for chronic kidney disease. Those with early stage kidney damage would have a treatment action plan, be treated for comorbid conditions (eg, hypertension or diabetes), and receive ongoing care to slow the progression of the disease. Numerous studies have demonstrated that treatment with specific agents such as inhibitors of the angiotensin converting enzyme (ACE-I) slow progression of CKD effectively. Unfortunately, one study of Medicare patients admitted to a hospital with diabetic- or hypertensive-related kidney disease showed that less than one-third of patients with CKD receive appropriate therapy. ⁵ Although proven strategies are available, they are simply not being utilized with sufficient frequency to slow progression in the population with CKD. Further, since CKD is an independent risk factor for accelerated cardiovascular disease, and most patients with CKD die of cardiovascular events before reaching end stage kidney disease, insufficient attention is being directed to treating cardiovascular disease in this subset of patients. As a person's kidney function declines further, he or she would be treated for complications (eg, anemia), educated about kidney replacement options, and begin early preparations for kidney replacement therapy. Finally, those who have kidney failure would receive appropriate kidney replacement therapy.

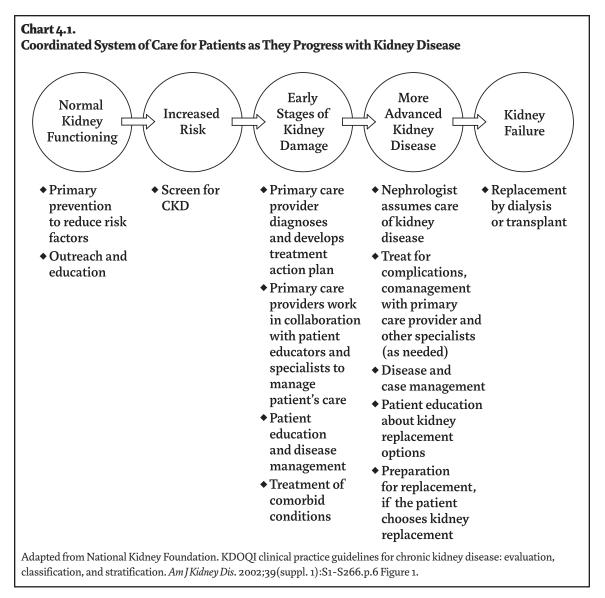


Chart 4.1 lays out a comprehensive system of care for people at risk of kidney disease or for people who have chronic kidney disease. A comprehensive system of care prior to kidney failure needs to have at least six elements:

- (1) *Primary prevention.* North Carolina can help reduce the occurrence of chronic kidney disease by controlling the most common risk factors that can lead to or exacerbate chronic kidney disease including diabetes and hypertension.
- (2) *Outreach and education*. The general public should be educated about chronic kidney disease, its risk factors, and the need to be screened for chronic kidney disease if they fall into a high-risk group. This is similar to health outreach and education efforts to encourage women to receive annual pap smears or mammograms or to encourage people over age 50 to obtain periodic colorectal cancer screening tests.

- (3) *Screen high-risk individuals*. Primary care providers should routinely screen people who are at risk for developing chronic kidney disease including people with diabetes, hypertension, cardiovascular disease, a family history of chronic kidney disease, or other evidence-based risk factors which have been demonstrated to contribute to the development of CKD.
- (4) *Primary care providers and collaborative care teams.* A person with chronic kidney disease should have a regular primary care provider who serves as the patient's medical home. The primary care provider should monitor the patient's kidney function, develop a care management plan using evidence-based clinical practice guidelines, treat the patient for comorbid conditions, and refer the patient to a nephrologist for consultation or ongoing care as the patient's kidney function declines and to other specialists for consultation or care to manage other comorbid conditions and complications.
- (5) Patient education, disease management, and care management services. The care from the primary care provider should be augmented, when necessary, with a trained case manager or disease management specialist.
- (6) Nephrologists. Nephrologists and other specialists should be available to provide consultative services to primary care providers to help the primary care provider manage patients with early stages of chronic kidney disease and the associated complications such as accelerated cardiovascular disease. Nephrologists, working collaboratively with the primary care provider and other specialists as needed, should be available to oversee the care of patients with more advanced stages of kidney disease or renal failure. Nephrologists should help provide early education regarding the different types of renal replacement therapies including kidney transplant, peritoneal dialysis, and hemodialysis, and ensure that vascular access is established prior to the need for kidney replacement therapy.

Although North Carolina has some of the necessary ingredients of a coordinated system of care, we lack many of the other essential elements needed to effectively reduce the occurrence of chronic kidney disease and to appropriately manage people with the disease. The NC IOM Task Force on Chronic Kidney Disease identified gaps in the existing health care system and made specific recommendations to address these problems. Each of the six elements outlined above is described in greater detail below.

Primary Prevention

Diabetes mellitus and hypertension are major causes of chronic kidney disease and kidney failure. Diabetes is an underlying cause of CKD in 42% of new patients diagnosed annually with CKD. Most of these patients (90%) have Type 2 diabetes mellitus, the prevalence of which is growing rapidly. In addition, people with uncontrolled hypertension (high blood pressure) have a greater risk of developing chronic kidney disease (as well as heart disease, stroke, and myocardial infarction). Not only do these chronic health conditions increase the risk of someone developing chronic kidney disease, they are also major contributors to kidney *failure*. Together, diabetes

mellitus and hypertension help contribute to approximately 60% of new cases of people with kidney failure. 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.

Reducing the number of people with chronic kidney disease or kidney failure will have a positive spillover effect on other health conditions. Decreased kidney function can lead to complications in all organ systems. This is particularly true for cardiovascular disease (CVD). Patients with CKD are 5 to 10 times more likely to die—primarily from cardiovascular causes—than to progress to kidney failure, and the rate of sudden death for this population is more than 3 times greater than that seen in individuals without CKD. Thus, controlling kidney disease in earlier stages may prevent comorbidities as well as prevent or slow the progression to kidney failure. Additional education is necessary to make physicians more aware of the independent influence of CKD on CVD and other vascular complications so that management of these comorbidities can be integrated into the patient's health plan in a coordinated manner.

North Carolina already has many primary prevention programs aimed at reducing risk factors that lead to obesity, diabetes, and hypertension. For example, Eat Smart, Move More NC is a statewide social marketing campaign aimed at helping North Carolina citizens eat healthier and exercise more by changing social norms and practices in schools, worksites, communities, and healthcare settings. The NC Statewide Health Promotion Program provides funding to local health departments to focus on barriers to physical activity and good nutrition at the community level. The Office of Minority Health and Health Disparities provides grants to community-based organizations to address health disparities. In addition, Healthy Carolinians supports local coalitions that assess and address community health priorities, which may include primary prevention.

Unfortunately, these programs are predominantly federally funded and lack adequate resources to accomplish even a modest fraction of their ambitious agendas. Obesity rates continue to rise across North Carolina. The state was recently ranked 5th worse for childhood obesity rates, ¹² and the state's adult obesity rate is higher than the national average (CDC BRFSS). The prevalence of diabetes, a potent risk factor for kidney disease, has doubled over the last 10 years in North Carolina. In addition, the incidence of diabetes is 50% higher in our minority populations. ¹³ The dramatic increase in obesity in North Carolina also parallels a rapid increase in the prevalence of metabolic syndrome, an additional risk factor for CKD.

Recommendation 4.1

The Task Force supports ongoing efforts by the North Carolina Division of Public Health, the North Carolina Department of Public Instruction, and other state and local organizations to enhance community education about and reduce the risk factors for chronic kidney disease.

Recommendation 4.2

The North Carolina General Assembly should increase funding to the Division of Public Health to build statewide capacity for chronic disease prevention programs that reduce the risk factors that may lead to chronic kidney disease by funding implementation of the Eat Smart, Move More NC objectives and by increasing funding to local communities through the Statewide Health Promotion, Healthy Carolinians, and Health Disparities programs.

Outreach And Education

The National Kidney Foundation estimates that most of the nation's 20 million adults with CKD are unaware of it. ¹⁴ Chronic kidney disease is largely asymptomatic. In fact, most people do not experience health symptoms until their kidney functioning has deteriorated to a very low level. Thus, most people are unaware of the need to monitor their kidney health.

Certain groups are at increased risk of developing chronic kidney disease but often are unaware of these health risks. These groups include people diagnosed with diabetes or hypertension, people aged 65 or older, and people with a family history of kidney failure. In addition, certain racial and ethnic minorities face increased risks of developing CKD and progressing to kidney failure. For example, African Americans have a 3.8 times greater likelihood of having kidney failure than do whites. When compared to whites, American Indians have a 2 times higher risk of kidney failure, and Hispanics have a 1.5 times higher risk. ¹⁵ Many of these individuals, however, do not seek care for their kidney condition until they have extensive kidney damage and are experiencing kidney failure. Broad-based health education campaigns are needed to educate at-risk populations and the general public about kidney health, risk factors for kidney disease, and the need to monitor kidney functioning. These broad-based public health investments in communication programs aimed at increased awareness would be similar to the strategy adopted for other conditions such as high cholesterol and hypertension.

Many complementary outreach strategies are needed to educate the public about kidney health and chronic kidney disease. 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. ¹⁶ Further, disease management programs coupled with educational materials tailored to populations with low health literacy levels can be particularly effective. ¹⁷ In addition, health education provided by health care professionals has been shown to be effective in educating people who are already seeking care. For example, counseling by health care professionals on specific risk factors such as smoking cessation is effective. ^{18,19} However, different strategies are needed to broadly reach individuals who do not frequently use the health care system.

Many people rely on friends and family for their health information. ^{20,21} The use of lay health advisors has also been effective in communicating health information. ²² This is particularly true for underserved populations including the uninsured and other groups that have less access to or who are less likely to utilize health care services. People most at risk for chronic kidney disease are frequently those that clinicians find difficult to reach. Community-based cooperative outreach and education efforts have been shown to be successful in reaching underserved populations. ²³

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 the targeted population around diabetes or other health conditions.

- ◆ National Kidney Foundation Kidney Early Evaluation Program (KEEP). KEEP is a free kidney health screening program designed to raise awareness about kidney disease among high-risk individuals and provide free testing and educational information so that kidney disease and its complications can be prevented or delayed. KEEP targets adults with diabetes, high blood pressure, or a family history of chronic kidney disease, and provides follow-up referrals to providers when needed. The North Carolina affiliate of the National Kidney Foundation (NKF) will provide a screening anywhere in the state based on expressed interest from a local community group. However, the NKF KEEP program does not have a continuous outreach and screening program in any county in the state. Recently, the North Carolina NKF affiliate received a \$75,000 grant from the Office of Minority Health and Health Disparities, NC Department of Health and Human Services, to conduct focus groups, educational interventions, and screenings in 11 counties in eastern North Carolina including Beaufort, Cumberland, Durham, Edgecombe, Granville, Greene, Lee, Lenoir, Nash, Wake, and Wilson. The project began September 1, 2007 and will end on June 30, 2008.
- ◆ National Kidney Foundation North Carolina Chapter (NKFNC) "Know Your Score" Public Education Campaign. The "Know Your Score" public awareness campaign ran on radio stations throughout North Carolina from October through December, 2007. Paid advertising schedules were placed on leading news talk stations in Raleigh and Charlotte. This campaign encouraged listeners to speak with their doctors and "get the score" on their kidney health. Radio public service announcements featured celebrity spokespeople including North Carolina Commissioner of Labor Cherie Berry and Carolina Panther Brad Hoover. The NKFNC continues to work with regional and ethnic print publications such as *PRIDE* magazine and *La Noticia* to include stories about kidney health and the importance of monitoring estimated glomerular filtration rate (eGFR) on a regular basis.

◆ UNC Kidney Center Kidney Education Outreach Program (KEOP). KEOP has four components: (1) primary care provider surveys to assess their skills in managing and identifying early stages of CKD; (2) focus groups to assess high risk individuals' knowledge of the risk factors for CKD; (3) outreach activities aimed at educating at-risk populations and health care professionals about the importance of screening before clinical symptoms appear; and (4) free screenings to identify and provide interventions for people who are at higher risk of developing CKD. KEOP uses trained community-based leaders to assist in education and outreach efforts. In its first 18 months, KEOP screened 1,000 at-risk citizens, conducted 14 focus groups, and participated in 25 outreach activities across Anson, Bertie, Edgecombe, Martin, and Montgomery counties. KEOP will expand to an additional 12 counties including Bladen, Camden, Caswell, Chowan, Greene, Hyde, Moore, Northampton, Pamlico, Perquimans, Swain, and Washington. In addition, KEOP, in partnership with the Kate B. Reynolds Foundation, UNC Health Care, and citizen donors, has purchased a mobile outreach unit. Designed to provide stand-alone capability to host screenings, provide clinical follow-up, and promote citizen awareness about the risk factors for developing CKD, this mobile unit will facilitate KEOP's ability to provide screenings and outreach across all of North Carolina.

The UNC Kidney Center also initiated a public education campaign to promote understanding of kidney disease called "HEY DOC, HOW ARE MY KIDNEYS?™" This campaign includes billboards and television ads that use local citizens as spokespersons to promote awareness about the major risk factors for developing CKD and the importance of being screened before clinical symptoms appear. Advertising campaigns have occurred in Anson, Edgecombe, and Montgomery counties and are currently being initiated in Bertie County.

◆ Office of Minority Health and Health Disparities (OMHHD) Community Health Ambassador Program (CHAP). The CHAP program trains trusted leaders in the African American, American Indian, and Hispanic/Latino communities to serve as lay health advisors in their communities. OMHHD partners with the North Carolina Community College System, Community Care of North Carolina, the Old North State Medical Society, the University of North Carolina at Greensboro Nursing Program, and community-and faith-based organizations to help identify and train Community Health Ambassadors (CHAs). These volunteers help bridge the gap between community members, their health concerns, and health service providers. CHAs educate community members about how to prevent illnesses, recognize early warning signs, and access services. The goal of the program is help community members prevent chronic diseases and decrease morbidity and mortality.

Currently, CHAP focuses on diabetes and cancer education. However, there are plans to develop modules to address other health disparity issues including CKD, cardiovascular disease, and HIV/AIDS. CHAP began in the spring of 2006. CHAs must successfully complete 20 hours of classroom education and pass a competency examination. The program has trained more than 300 CHAs from the following counties: Buncombe, Mecklenburg, Guilford, Durham, Wake, Lee, Cumberland, Pitt, Martin, Bertie, Hertford, Gates, Greene, Lenoir, Nash, Robeson, and Wilson. There are plans to expand the program statewide as funding becomes available.

- ◆ **Division of Public Health Diabetes Today Program.** Diabetes Today focuses on the strengths of communities and their ability to work creatively to deal with problems associated with diabetes. Local health departments serve as lead agencies and collaborate with surrounding health departments to increase the spread of community-based programs focused on reducing the burden of diabetes through awareness, education, and prevention strategies. Currently there are 4 lead Diabetes Today programs in local health departments in Hertford, Robeson, Surry, and Wake counties. Through the collaborative efforts of each of these departments within its region, Diabetes Today initiatives are implemented in 29 counties in North Carolina. ^a
- ◆ **Division of Public Health WISEWOMAN Program.** The North Carolina WISEWOMAN (Well-Integrated Screening and Evaluation for Women Across the Nation) program provides expanded cardiovascular disease screening, intervention, counseling, and referral services to women age 40 and older who are at or below 250% of the Federal Poverty Guidelines (FPG), uninsured or underinsured, and eligible for the Breast and Cervical Cancer Control Program (BCCCP). Special emphasis is placed on the population of women 50-64 years of age, especially minorities. WISEWOMAN is administered locally through 39 North Carolina county or district health departments and community health centers. ^b

a The counties currently covered by the initiative are Ashe, Alleghany, Surry, Stokes, Watauga, Wilkes, Yadkin, Forsyth, Guilford, Davie, Davidson, Chatham, Durham, Granville, Vance, Franklin, Nash, Wilson, Wake, Johnston, Harnett, Lee, Scotland, Hoke, Robeson, Bladen, Columbus, Halifax, Northampton, Hertford, Martin, Washington, and Tyrrell.

b The counties currently covered by the initiative are Ashe, Alleghany, Watauga, Buncombe, Cabarrus, Caldwell, Cleveland, Columbus, Cumberland, Forsyth, Duplin, Graham, Granville, Vance, Guilford, Halifax, Haywood, Hyde, Jackson, Johnston, Lincoln, Martin, Mecklenburg, Moore, New Hanover, Northampton, Pamlico, Pasquotank, Perquimans, Chowan, Person, Richmond, Robeson, Surry, Swain, Union, Vance, Wayne, Yadkin, and Yancey. In November 2007 Ashe, Catawba, and Robeson will be added.

◆ Division of Public Health Heart Disease and Stroke Prevention (NC HDSP) Program. The NC HDSP Program is a state-based cardiovascular health program that focuses on systems-level change to create communities, work places, schools, and health care systems that are supportive of cardiovascular health promotion and cardiovascular disease prevention. The NC HDSP Program works with 4 lead counties (Henderson, Cabarrus, Hertford, and Pitt) to facilitate and coordinate the work among key health promotion and disease prevention partners and to serve as a resource for technical assistance for policy and environmental change interventions to prevent heart disease and stroke.

These 7 programs help reach the public with information about kidney disease or with information on other health conditions such as diabetes that can lead to kidney disease. However, more is needed to reach target populations throughout the state. In order to reach more of the at-risk population, the NC IOM Chronic Kidney Disease Task Force recommends:

Recommendation 4.3 (PRIORITY RECOMMENDATION)

- (a) The North Carolina General Assembly should appropriate \$500,000 in recurring funding to the Division of Public Health and the Office of Minority Health and Health Disparities to expand diabetes prevention and control funding. Funding should be limited to programs that are built on evidence-based or promising practices that educate at-risk populations about chronic kidney disease and the importance of early screening. Funding priority should be given to programs that:
 - (1) Increase outreach in existing counties and expand outreach to counties that are not being adequately served by existing programs.
 - (2) Include a plan for ongoing evaluation of effectiveness.
 - (3) Target populations at increased risk for developing chronic kidney disease and incorporate local partners such as faith-based health ministries, beauty salons/barber shops, civic and senior citizen groups, public health departments, and primary care practitioners.
- (b) Programs must be evaluated in a timely fashion to demonstrate effectiveness in order to receive continued funding.
- (c) In order to ensure that the most effective elements of programs are emulated appropriately, the Division of Public Health and the Office of Minority Health and Health Disparities should work with existing grantees and others to foster inter-program collaboration. Collaborative activities should include, but not be limited to, sharing of appropriately privacy-protected evaluative data to allow improvement in a program's current (or potential) design.

Collaboration should ensure that the program messages are coordinated to minimize confusion among the targeted populations.

Recommendation 4.4

Public and private insurers should examine patient-level eligibility and claims data to identify people who are at risk of or diagnosed with chronic kidney disease. Insurers should explore mechanisms to increase awareness of chronic kidney disease among consumers at risk, such as targeted messaging that encourages consumers to be screened for kidney function.

Screening High-Risk Individuals

As noted previously, the National Kidney Foundation estimates that most people with chronic kidney disease are unaware of having it. Chronic kidney disease is not often recognized or treated by primary care physicians. In fact, although being diabetic and older than age 65 are two of the primary risk factors for having chronic kidney disease, one study found that primary care practices screen fewer than 20% of Medicare patients with diabetes for kidney disease. ²⁴

More effort is needed to screen people who are high risk for developing chronic kidney disease. The KDOQI evidence-based guidelines suggest primary care providers should routinely screen people with diabetes, hypertension, or a family history of kidney disease, and should monitor kidney functioning over time.^{c,6}

More recent research shows that cardiovascular disease is also a risk factor which contributes to CKD, and thus patients with CVD should also be screened for chronic kidney disease. The National Kidney Foundation's KDOQI evidence-based guidelines recommend that providers obtain a "spot" urine sample to measure the microalbumin to creatinine ratio and a blood test to obtain the serum creatinine. The urine microalbumin to creatinine ratio checks for abnormal levels of protein in the urine (microalbuminuria) which is a marker of kidney damage. Serum creatinine can be used to measure the estimated glomerular filtration rate (eGFR), which measures how well the kidney is eliminating waste from the blood. These helpful tests are widely available, easily obtained, and relatively inexpensive.

People with health insurance generally will have coverage for screening if their provider orders it, but there is no statewide screening program for people who are uninsured. The National Kidney Foundation's KEEP program and the UNC Kidney Center's KEOP program provide screenings to individuals who have been identified as high risk in 26 counties throughout the state. However, uninsured individuals in other areas of the state may not have access to regular screenings.

a The CDC will be providing funds to 4 states for targeted screening. Pilots will start next year.

b Serum creatinine can be used to measure the estimated glomerular filtration rate using the Modification Diet in Renal Disease (MDRD) prediction formula.

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To compound this problem, uninsured individuals who have been diagnosed with CKD may not have a source of coverage 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 on a sliding fee scale to the uninsured. 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. The North Carolina General Assembly created the Community Health Center Grants program to help increase access to preventive and primary care services for low-income uninsured. Last year (2007), the General Assembly appropriated \$2 million on a recurring basis and \$5 million in nonrecurring funds to the Office of Rural Health and Community Care to create or expand safety net organizations. However, these funds are not sufficient to ensure sufficient primary care safety net capacity throughout the state.

In addition to the Community Health Center grants program, the North Carolina General Assembly funds special programs (eg, Purchase of Medical Care program) to help pay for services for uninsured individuals with certain chronic illnesses or health problems. Generally, these programs operate through the Division of Public Health (DPH). For example, DPH operates a program (State Kidney Program) which provides funding to help pay for limited services for people with end stage kidney disease. However, funding is limited to people with ESKD and is not available to manage the care of uninsured individuals with less advanced stages of CKD. In contrast, the state does have some funding to help pay for screening and limited treatment services for people with cancer, epilepsy and neurological diseases, HIV/AIDS, sickle cell syndrome, sexually transmitted diseases, tuberculosis, and vision problems.

To address this issue, the Task Force recommends:

e 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 scale 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—are not set up to provide ongoing comprehensive primary care services to individuals to help them manage their chronic conditions.

f Sec. 10.6(a) of Session Law 2007-323. Funding is available on a competitive basis to federally qualified health centers, state-designated rural health centers, free clinics, public health departments, school-based health centers and other nonprofit organizations that provide primary and preventive services to low-income uninsured patients.

g NCGS §130A-220.

h NCGS §130A-205, 130A-206 (Cancer Control Program); NCGS §130A-223 (Epilepsy and Neurological Disease Program); NCGS §130A-5(3) (AIDS Drug Assistance Program); NCGS §130A-124 (Hemophilia program); NCGS §130A-135, 130A-144 (Sexually Transmitted Disease Control); NCGS §130A-129 (Sickle Cell program); NCGS §130A-144 (Tuberculosis Control), NCGS §111-8, 143B-157 (Medical Eye Care Program).

Recommendation 4.5 (PRIORITY RECOMMENDATION)

- (a) The North Carolina General Assembly should provide \$550,000 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 including people with diabetes, hypertension, cardiovascular disease, family history of chronic kidney disease, or other evidence-based risk factors which have been demonstrated to contribute to the development of chronic kidney disease.
- (b) The North Carolina General Assembly should appropriate an additional \$2,400,000 to the Community Health Center grants program to expand care to uninsured individuals with chronic kidney disease. Priorities should be given to:
 - (1) Areas of the state that do not have sufficient safety net capacity.
 - (2) Programs that provide primary care, disease management, and care management to patients with chronic kidney disease.
 - (3) Organizations that provide comprehensive services, including pharmaceuticals, to the uninsured with incomes <200% FPG.
- (c) The North Carolina General Assembly should appropriate an additional \$15 million to the Community Health Center grants program to expand care to the uninsured with other chronic illnesses that can lead to chronic kidney disease. Priorities should be given to:

i This cost estimate assumes that the Division of Public Health will screen 5% of the uninsured population with hypertension. The Division of Public Health estimated there are approximately 328,000 uninsured adults with hypertension. The current combined cost for a urine microalbumin and serum creatinine laboratory report is approximately \$38. Multiplying these figures indicates a total cost of close to \$11.5 million. The Division estimates they may be able to screen approximately 5% of these individuals for a cost of \$550,000.

j Combining information from a variety of data sources including the Behavioral Risk Factor Surveillance Survey (BRFSS) and the National Health and Nutrition Examination Survey (NHANES), the NC IOM estimates there are approximately 40,000 uninsured North Carolinians with stage 3 or higher CKD. Furthermore, the same analysis estimates that approximately 16,000 of the uninsured with CKD indicate they have no usual source of care; they would need to be linked with a primary care medical home. The Bureau of Primary Health Care suggests that community health centers use a standard budget of approximately \$150 per year per patient to provide primary care services to the uninsured (New Access Points (NAP) Grant Competition Announcement Number HRSA08-077. Health Resources and Services Administration. US Department of Health and Human Services. http://www.hrsa.gov/grants/. Accessed November 1, 2007). Using \$150 as a per person estimate, primary care services for these 16,000 uninsured are estimated at \$2,400,000. This cost estimate is conservative since providing services to the uninsured with chronic illnesses will be more expensive than providing services to the uninsured without chronic illnesses. Further, this includes only the estimated cost of providing primary care services to people with CKD and does not include other uninsured individuals with diabetes, hypertension, cardiovascular disease, or other chronic illnesses who do not also have CKD. Providing a primary care home to other people with chronic illnesses would require additional funds. For more details on estimation see Appendix.

k BRFSS data suggest there are approximately 250,000 uninsured North Carolinians with diabetes, hypertension, or cardiovascular disease who do not have CKD; 100,000 of this number have no usual source of care. The Bureau of Primary Health Care estimates that community health centers should budget approximately \$150 per year per patient to provide primary care services to the uninsured (New Access Points (NAP) Grant Competition Announcement Number HRSA08-077. Health Resources and Services Administration. US Department of Health and Human Services. http://www.hrsa.gov/grants/. Accessed November 1, 2007). Using \$150 as a per person estimate, primary care services for these 100,000 uninsured are estimated at \$15,000,000. This cost estimate is conservative since providing services to the uninsured with chronic illnesses will be more expensive than providing services to the uninsured without chronic illnesses.

- (1) Areas of the state that do not have sufficient safety net capacity.
- (2) Programs that provide primary care, disease management, and care management to patients with high-cost chronic illnesses including, but not limited to, diabetes, hypertension, cardiovascular disease, and other evidence-based risk factors which have been demonstrated to contribute to the development of chronic kidney.
- (3) Organizations that provide comprehensive services, including pharmaceuticals, to the uninsured with incomes <200% FPG.
- (d) The North Carolina General Assembly should provide \$5 million to the Division of Public Health Purchase of Medical Care (POMC) program to help pay for nephrologist consults for uninsured patients with incomes <200% FPG. Funding should be used to:
 - (1) Pay for nephrology consultations that follow the Renal Physicians Association consultation standards for patients with chronic kidney disease with <30 eGFR or other patients with higher eGFR if a clinical action plan cannot be prepared or the appropriate evaluation performed.
 - (2) Support a coordinated system of care between the primary care provider and nephrologist.

Primary Care And Collaborative Care Teams

People obtain most of their outpatient health care services through primary care providers. Primary care providers (PCPs), including physicians, nurse practitioners, or physician assistants, are trained to provide comprehensive care that meets most of a patient's health care needs. PCPs provide preventive, primary, and acute medical services and help coordinate the care that people with complex or chronic illnesses receive from specialists. Optimal primary care is comprehensive, accessible to the patient, coordinated, and continuous. Primary care providers are generally more widely disbursed than are specialists; thus people have more ready access to primary care providers than to most specialists. Approximately 60% of office visits in 2005, including 55% of the office visits for people with chronic illnesses, were to primary care providers.

While primary care providers 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 with new clinical guidelines for different health conditions. There are more than 1800 evidence-based clinical guidelines to treat patients with different health

l The NC IOM estimates there are approximately 40,000 uninsured individuals with CKD who are in stages 3-5 and who are not receiving dialysis. For purposes of this estimate, we assumed that all of the uninsured would need access to a nephrology consult once a year even if they otherwise had access to primary care providers for the ongoing management of their health problem. Medicaid pays between \$49.50-\$202.50 to nephrologists for consultations depending on the CPT code. For purposes of this estimate, we assumed that each patient would receive 1 consult per year with an average cost of \$125.

conditions.³² These guidelines change over time, and new ones are developed as health professionals gather new evidence about what treatments work best for different conditions. Research suggests that it would take more than 7 hours a day for primary care providers to provide all the recommended evidence-based preventive services to a typical daily panel of patients and another 10 hours a day to provide recommended services to patients with chronic illnesses.³³⁻³⁵ Practice redesign and other supports are needed to help primary care providers provide optimal care. (See Rec. 4.8 and 4.9 below.)

Ideally, primary care providers should screen people at high risk and identify patients with chronic kidney disease. However, national screening programs suggest that chronic kidney disease is often not detected even when patients have access to primary care. PCPs may be unaware of all the risk factors for CKD. Further, many primary care providers are unaware of existing clinical guidelines for care of people with CKD. The people with CKD.

The Task Force recognized the need to provide further education to primary care providers about chronic kidney disease, risk factors which can make people more likely to develop chronic kidney disease, the impact of CKD on overall health care spending, death and comorbidities, and evidence-based treatment of people with chronic kidney disease. Studies have shown that primary care providers who are aware of the KDOQI guidelines were more likely to have knowledge of all of the risk factors ³⁶ and more likely to follow the recommendations. ³⁷ Therefore, the Task Force recommends:

Recommendation 4.6

The North Carolina Area Health Education Centers program, the National Kidney Foundation (NC Chapter), the UNC Kidney Center, North Carolina Renal Care, the North Carolina Medical Society, the North Carolina Academy of Family Physicians, the North Carolina Chapter of the American College of Physicians, the Old North State Medical Society, the North Carolina Academy of Physician Assistants, the North Carolina Nurses Association Council of Nurse Practitioners, the North Carolina Association of Pharmacists, and Community Care of North Carolina should collaborate to provide targeted chronic kidney disease educational programs for primary care providers. The education should include information about the importance of early screening for at-risk populations, the use of the eGFR to identify people with chronic kidney disease, stages of the disease, diagnosing the etiology of the disease, and evidence-based treatment guidelines for people with the disease. Education should be provided in a variety of settings including, but not limited to, health professional training schools, residency programs, continuing medical or nursing education programs, practice consultants, and quality improvement initiatives.

Once identified, most people with chronic kidney disease continue to be treated by primary care providers. ³⁸ Primary care providers are appropriate sources of care for people in the early stages of the disease and can help manage patients' kidney disease along with other comorbidities. PCPs who identify patients with CKD should determine the type of kidney disease, comorbid conditions, and severity of the disease using the KDOQI stages of chronic kidney disease. ¹⁰ (See Chart 2.1 in Chapter 2.) Physicians can use the stages of CKD to help explain the disease process to their patients and to develop care plans. PCPs should also assess potential complications such as development of cardiovascular disease and risk of kidney failure.

The evidence-based clinical guidelines for chronic kidney disease will vary somewhat depending on the etiology of the disease. In general, patients should be prescribed ACE inhibitors or angiotensin receptor blockers (ARBs) to control blood pressure, aspirin to lower the risk of cardiovascular disease, and cholesterol-lowering therapy when their LDL is elevated. ³⁹ Patients need to control their hypertension (to achieve a blood pressure of <130/80 mm Hg) and manage their lipids in order to slow progression of CKD to more advanced stages. ⁴⁰ Successful hypertension control and lipid management could slow the progression toward kidney failure and limit the damage caused by cardiovascular diseases. Patients should also be encouraged to implement lifestyle changes to support their treatment regimen including smoking cessation and a light-to-moderate exercise program three to five times a week.

Primary care providers should monitor the progress of the disease and treat complications of decreased kidney failure. PCPs should work in a collaborative care team involving patient educators, disease management or case management staff, and appropriate specialists as needed to manage comorbid conditions. Primary care providers may need to consult with nephrologists or other specialists to develop care plans for patients with CKD and any incident comorbidities. The National Kidney Disease Education Program and Renal Physicians Association have developed a model template nephrology consult letter to provide information about a patient's level of kidney disease and treatment recommendations. The second consult is a patient's level of kidney disease and treatment recommendations.

As the kidney function declines further (to <30 eGFR), patients should be referred to nephrologists for clinical management of kidney disease. Even after referral, the primary care provider will still play an important role in serving as the patient's medical home and helping to manage the patient's comorbid conditions.

Nephrologists and other trained kidney educators should help patients prepare for kidney failure and replacement of kidney function by dialysis or transplantation. ¹⁰ Patients need better modality education of different renal replacement options in advance of when their kidney failure reaches

 $m\ See\ http://nkdep.nih.gov/professionals/consult/consult.pdf.$

stage 5. (See Recommendation 4.15 below.) Unfortunately, many patients with chronic kidney disease do not see nephrologists until advanced stages of their disease. More than one-fifth (22%) of all patients do not see a nephrologist until they are almost ready to begin dialysis (less than four months prior to initiating dialysis). African Americans are much more likely to be evaluated late in the progression of their disease with 42.4% receiving their first consult from nephrologists within four months of beginning dialysis compared to 27.7% of whites. Patients who receive these late evaluations are more likely to die than those who receive earlier evaluations even after controlling for comorbid conditions, type of dialysis, demographic characteristics, and socioeconomic factors. Because of the lack of nephrologists in certain communities, it may not be possible for nephrologists to assume the care of all the patients in later stages of the disease. In these instances, the primary care provider and nephrologist should develop models of shared clinical care to provide treatment and care management to the patients.

While much is known about effective treatment which could delay the deterioration of kidney function, this evidence-based care is not often provided. To encourage more widespread adoption of evidence-based care for people with chronic kidney disease, the Task Force recommends:

Recommendation 4.7 (PRIORITY RECOMMENDATION)

- (a) Primary care providers should routinely screen their patients who are at high risk for chronic kidney disease including patients with diabetes mellitus, hypertension, cardiovascular disease, family history of chronic kidney disease, or other evidence-based risk factors which have been demonstrated to contribute to the development of the disease. Screening should include albumin measurement from a spot urine sample and serum creatinine to obtain the estimated GFR.
- (b) Patients who have been identified with chronic kidney disease should be staged using the National Kidney Foundation 5 stages of disease categories.
- (c) Health care providers who have patients who have been diagnosed with chronic kidney disease should follow the KDOQI or other evidence-based guidelines to manage and slow the progression of the disease. These guidelines include, but are not limited to:
 - (1) Treating patients to achieve a target blood pressure of <130/80.
 - (2) Prescribing an ACE inhibitor or ARB as specific therapy to slow the progression of kidney disease as well as control blood pressure.
 - (3) Using combination hypertensive therapy which should include a diuretic.
 - (4) Evaluating patients with eGFR<60 mL/min/1.73m2 for anemia.
 - (5) Treating to ensure strict glucose control in diabetes.
 - (6) Detecting and managing other cardiovascular risk factors, particularly cholesterol and tobacco use.

n The KDOQI guidelines state that albumin should be measured in a spot urine sample using either albumin-specific dipstick or albumin-to-creatinine ratio.

- (7) Monitoring the rate of eGFR decline in patients with chronic kidney disease at least yearly and more often for patients with rapid decline or specific risk factors.
- (8) Referring patients to registered dietitians for nutrition therapy when appropriate.
- (d) Primary care providers should refer patients with eGFR <30 to nephrologists for ongoing care. Other patients, with higher eGFR, should also be referred to a nephrologist for consultation or comanagement if a clinical action plan cannot be prepared or the appropriate evaluation performed or if a patient is experiencing rapid decline in kidney function. There should be sustained coordination between the primary care provider, disease management or care management staff, the nephrologist, and other specialists.

Primary care practitioners need to actively monitor the rate of decline of kidney function in their patients. The risk of progression to kidney failure can vary markedly across patients, based on the stage of the disease, comorbidities, racial and ethnic and other sociodemographic factors. ⁴³ While many practitioners are aware of certain requirements within the diabetes and hypertension guidelines, many are unaware of the chronic kidney disease guidelines. ³⁸ Both the American Diabetes Association's evidence-based guidelines for treatment of patients with diabetes ⁴⁴ and the Joint National Committee on Prevention, Detection and Treatment of High Blood Pressure report (JNC 7) on evidence-based guidelines for treatment of patients with hypertension recommend that practitioners obtain a serum creatinine to calculate the estimated GFR. The serum creatinine alone is simply too imprecise, too dependent on a number of variables, and has too wide a range of "normal" values to be clinically useful in patients with mild to moderate chronic kidney disease. As noted earlier, the KDOQI guidelines also recommend screening high-risk individuals including those with diabetes, hypertension, or a family history of kidney disease. ⁶ Despite these guidelines, it appears that few providers are specifically requesting an eGFR routinely when a serum creatinine is ordered as part of a basic or complete metabolic profile even among high-risk individuals.

The Task Force considered a variety of alternative mechanisms to facilitate primary care providers in obtaining eGFR results. Theoretically, PCPs could calculate the results themselves using various prediction equations including the Modification of Diet in Renal Disease (MDRD) equation. The MDRD equation is based on the following 4 factors: the serum creatinine level, age, gender, and race (with a correction factor for African Americans). For most individuals, the eGFR is a far

There are two commonly used measurements to estimate GFR: Cockroft-Gault and MDRD. The MDRD estimation is superior to the Cockroft-Gault calculation in adults.

more accurate measure than other tests of kidney function and is more revealing of kidney disease. PRealistically, however, primary care providers have little time to do everything else that is required of them. Therefore, it is unlikely that primary care providers will routinely calculate the eGFR on all at-risk patients.

One promising method to increase physician awareness of chronic kidney disease and identification of patients with CKD is to automatically calculate and report the eGFR on all adult clinical laboratory creatinine determinations. Automatic reporting, coupled with an educational program, has been shown to lead to increased CKD recognition by primary care providers. ^{9,46}

Some states have implemented statutory language to require eGFR calculation on all creatinine determinations. ⁴⁷ The College of American Pathologists and the National Kidney Foundation issued a joint statement and the American Medical Association adopted a resolution opposing statutorily mandating automatic reporting of eGFR for all creatinine measurements because of their concerns regarding legislative mandates of clinical practice. ^{48,49} While not opposing the use of eGFR, these groups opposed legislatively mandating how medicine is practiced; as clinical practice evolves and improves over time, legislation does not always keep pace with these changes. Because of the national controversy, the NC IOM Task Force on Chronic Kidney Disease convened a separate workgroup to explore automatic eGFR reporting.

After considering different options, the workgroup and the full Task Force recommended that clinical laboratories in North Carolina be encouraged to report eGFR values on all creatinine determinations voluntarily rather than requiring a legislative mandate. Because of the importance of identifying people with chronic kidney disease, the full Task Force strongly supported that laboratories automatically calculate eGFR whenever the provider orders a creatinine measurement. If North Carolina laboratories do not voluntarily begin computing the eGFR on all creatinine determinations, then the Task Force recommended that the General Assembly mandate this practice. Simultaneously, the Task Force members recommended that primary care providers receive education about CKD and the use of the eGFR as a measure of kidney function. (See Recommendation 4.6.)

p While the eGFR is the best measurement of kidney function for most people, it may not be appropriate for everyone, particularly those who have abnormal production of basal creatinine (ie, the morbidly obese or severely malnourished, amputees, paraplegics, or those with other muscle wasting diseases), are on unusual diets (ie, taking creatinine supplements), or are under age 18. However, the eGFR may be useful as a reference among some of these populations to measure changes over time.

q Although there are no data on the cost of implementing these changes into the laboratory reporting software, most people familiar with these information systems indicate that the cost of adding an eGFR would be relatively low (J. Keene, personal communication, February 26, 2008).

Given concerns about the precision of current estimating equations (such as the MDRD formula) for eGFR values above 60 mL/min/1.73 m 2 , 50 the Task Force recommends that laboratories should report the calculated eGFR levels that exceed 60 mL/min/1.73 m 2 as ">60" rather than denoting the calculated value. Laboratories that already report calculated values greater than 60 should educate providers about the lack of precision for values greater than 60.

Recommendation 4.8 (PRIORITY RECOMMENDATION)

The estimated glomerular filtration rate (eGFR) values should be computed and reported on all creatinine determinations by clinical laboratories in North Carolina.

- (a) Hospital and commercial clinical laboratories should incorporate a calculated eGFR on all patient laboratory data that includes measurement of the serum creatinine. Carolina Renal Care, the College of American Pathologists, and the National Kidney Foundation North Carolina Chapter should work collaboratively to educate clinical laboratories of the importance of reporting the eGFR when a provider orders a serum creatinine or when the creatinine is part of a metabolic panel.
- (b) Payers and insurers should require that all serum creatinine determinations for their members and dependents automatically include the eGFR.
- (c) The Division of Public Health along with Carolina Renal Care should monitor the clinical laboratories to determine if reporting of GFR has become standard practice throughout the state when a serum creatinine is ordered. If the preceding recommendations are insufficient to make eGFR reporting standard practice throughout the state within one year for all laboratories, the General Assembly should amend the General Statutes to require all creatinine laboratory reports to include eGFR values.

In addition to automatically reporting eGFR when a provider orders a creatinine, certain practice redesigns (eg, disease registries) can assist primary care providers in identifying patients with specific chronic illnesses and trigger periodic screening and evidence-based treatment guidelines. Some providers have electronic health records (EHRs) with the capacity to identify patients with chronic illnesses and which include clinical decision support prompts. However, EHRs do not universally have this capacity. Further, one study found that in 2005 less than one-quarter of practices had electronic health records. ⁵¹

The Task Force recognized the need for practice redesign to support care of patients with chronic kidney disease. Thus, the Task Force recommends:

Recommendation 4.9

Businesses and organizations that develop electronic health records should provide the capacity for chronic disease registries and clinical decision support prompts that incorporate chronic kidney disease screening and treatment measures for at-risk groups.

Patient Education, Disease Management, And Case Management Services

People with chronic kidney disease should be involved in their own self-management at all stages of the disease. ¹⁰ A survey of research studies suggests individuals who have been trained in effective self-management techniques generally have better health outcomes than those who have not. ⁵² People need to be taught the information and skills necessary to manage their own health. In addition, some individuals may need additional assistance maneuvering through the health care system to ensure that their chronic health care needs can be met.

In general, all patients who have health problems should be educated about the course of their disease, treatment options, and management of their health condition. 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, and recommended treatment, medications, and diet. The goal is to give patients the skills to better manage their own health.

Primary care providers and nephrologists can assist in the patient education process. However, individuals often need more intensive health education than can be provided in a physician's office. Patient education, disease management, and case management services can augment the information and services provided by physicians.

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. Disease management activities are designed to provide individuals with these conditions with the information and support necessary to assist them in monitoring their own care and adhering to recommended treatment guidelines. Disease management is typically offered through insurance coverage. Nationally, approximately one-fourth of all firms that offered health insurance in 2006 included at least one disease management program. ^{7,53} Disease management activities can be delivered in person through community networks of care or can be provided through mail or telephone contact. As described below, both types of disease management activities are operational in North Carolina.

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r Nationally, among firms offering health benefits that include a disease management program, 95% offer disease management for diabetes, 87% for asthma, 88% for hypertension, and 88% for high cholesterol.

Case management activities can be offered in conjunction with, or separate from, disease management efforts. Case management is often targeted to individuals with multiple chronic diseases and/or costly health problems, those patients most at risk of hospitalizations or other costly care. The Case managers help patients obtain care for unmet needs, coordinate the care they receive, and may assist patients in addressing other non-health related needs that prevent individuals from properly managing their health condition. Case management of patients undergoing dialysis has been shown to lead to mortality reductions and other positive outcomes. Case management is generally more customized to the individual needs of the patient. Case managers who can help the patient manage multiple conditions may be more effective than multiple disease managers each trained in the management of one disease affecting the patient.

North Carolina insurers offer both disease management and case management activities for selected individuals. Typically, these initiatives do not specifically target people with chronic kidney disease, although they may target individuals with comorbid conditions such as diabetes or hypertension which could lead to or exacerbate chronic kidney disease. For example:

◆ *Medicaid.* The North Carolina Division of Medical Assistance and the North Carolina Office of Rural Health and Community Care developed a comprehensive disease management and quality improvement initiative focused on care of Medicaid recipients with certain chronic illnesses. Community Care of North Carolina (CCNC) provides disease and case management services to certain Medicaid recipients with chronic or complex health conditions. CCNC is built around provider-led community networks that include, at a minimum, primary care physicians, specialists, hospitals, departments of social services, and health departments. There are currently 14 networks that cover the state. In September 2007 there were approximately 890 000 Medicaid recipients enrolled in CCNC.56 Medicaid pays participating providers \$2.50 per member per month (PMPM) to serve as the patient's medical home and an additional \$3.00 PMPM for the network to hire nurses or social work case managers to help patients manage their health conditions.

CCNC uses nationally recognized evidence-based guidelines to help patients with chronic conditions manage their health. CCNC currently operates a statewide disease management and quality improvement initiative for people with diabetes and is in the process of developing similar statewide initiatives to help people with hypertension or cardiovascular disease manage their health problems. CCNC disseminates evidence-based clinical guidelines for the care of patients with these conditions to the primary care practices and then collects performance measure data to determine how well practices are doing in providing evidence-based standards of care. CCNC does not currently have a specific disease management or quality improvement initiative targeting people with chronic kidney disease. However, people with diabetes, hypertension, and cardiovascular disease

are at greater risk of developing chronic kidney disease. Thus, CCNC could augment their current quality improvement initiatives to develop strategies to identify, monitor, and manage the care of people with chronic kidney disease. Further, CCNC should consider adding performance measures to ensure that people who are at risk of developing CKD or who have been diagnosed with CKD are receiving evidence-based standards of care.

◆ Blue Cross and Blue Shield of North Carolina (BCBSNC). BCBSNC offers disease and lifestyle management programs and quality improvement initiatives that focus on certain health conditions that are risk factors for chronic kidney disease. In addition, BCBSNC offers case management services to people with risk factors for ESKD. The Member Health Partnership Program is a lifestyle management program that provides targeted information and services to help patients manage their health needs. The program focuses on several health conditions that either contribute to CKD or exacerbate the condition including diabetes, weight, high blood pressure, high cholesterol, heart failure, and tobacco use. Members receive educational materials targeted to their specific condition. They can also receive one-on-one assistance through a nurse or case manager (for high-risk patients). Members who are enrolled in this lifestyle promotion program are eligible to receive up to 6 nutritional counseling sessions per year.

In addition to the disease and lifestyle management programs, BCBSNC also contracts with Health Dialog to help ensure members receive appropriate care based on nationally recognized evidence-based standards of care. BCBSNC has quality improvement initiatives for people with diabetes, coronary heart disease, and congestive heart failure, each of which would also benefit people with CKD. BCBSNC's quality improvement initiative ensures that:

- ◆ Patients with diabetes or coronary artery disease (CAD) receive lipid profile tests and cholesterol lowering medications.
- ◆ Patients with diabetes, congestive heart failure, or CAD receive ACE/ARB therapy.
- ◆ Patients with diabetes are tested for microalbuminuria and hemoglobin A1C (HbA1C).

BCBSNC also provides case management services for their members with risk factors for ESKD. Case managers collaborate with other clinical staff, medical directors, providers, vendors, family, and hospital/facility staff to provide individual health coaching, coordination of care, and decision support to the members. Case managers work directly with the BCBSNC member and his or her physician to develop a care plan for the treatment of ESKD as needed. The goal is to ensure that the member receives medically appropriate care in the right setting in order to increase the member's quality of health care and achieve improved health outcomes.

◆ North Carolina State Health Plan (SHP). The State Health Plan has 2 programs that help identify and educate patients with kidney disease. Health Dialog is the SHP's chronic disease management vendor. Health Dialog offers disease management services targeting members with diabetes and coronary artery disease (among other conditions). Health coaches provide members with patient education materials and support to help them manage their health problems. For example, members with diabetes are sent patient education materials related to chronic kidney disease. SHP members with coronary artery disease receive information about hypertension control. In addition, Health Dialog includes a quality improvement initiative targeted at providers. Twice a year, primary providers are given information about clinical gaps related to microalbuminuria testing for members with diabetes as part of the Health Smart Registry. Health Dialog does not currently have performance measures related to collection of creatinine or eGFR to measure kidney disease.

In addition to the disease management services offered through Health Dialog, the State Health Plan offers more intensive case management services to patients with more advanced stages of CKD. The SHP contracts with Renaissance Health Care to provide patient education, disease management, and case management services to patients with an eGFR less than or equal to 45 (stage 3 of KDOQI guidelines). Renaissance Health Care helps identify clinical gaps in the care provided to patients with CKD. Renaissance works with the members and treating providers to improve blood pressure control as well as blood glucose control for people with diabetes. In addition, each identified SHP member is offered more intensive case management and education to help members prepare to transition into renal replacement therapy. As a part of the needs assessment, members are screened for depression and are referred to treatment as needed.

Renaissance Health Care identifies members with more advanced stages of CKD through claims data. Because the claims data do not identify all patients with CKD, the SHP has worked with the UNC Kidney Center to develop alternative methods of identifying patients with CKD. The Kidney Center has identified SHP members with eGFR of 45 or less and referred those patients to Renaissance Health Care for case management services. Within the first 3 months of the program (3rd quarter 2007), there were over 30 referrals with the majority screened and engaged with a case manager. The SHP is evaluating this model to determine whether it could be duplicated with other kidney clinics throughout the state.

s Renaissance targets individuals with an eGFR of 45 or less because it is at this time people need to start thinking of transitions to renal replacement therapy and need more intensive case management and education.

Of the members who have been in Renaissance Health Care case management for at least 180 days:

- ♦ 80% of members have completed educational modules on dialysis modalities.
- 90% of members have an appropriate hemoglobin level.
- ♦ 80% of members have a fistula placed to allow vascular access before the inception of dialysis, without the use of a central venous catheter.
- ♦ 50% of members transition to dialysis on an outpatient basis in contrast to requiring emergency inpatient hospitalization to begin dialysis.

In addition, inpatient admission rates for SHP members with ESKD have declined by more than 35% since the inception of intensive case management and the implementation of the patient education program with Renaissance Health Care.

Naturally, it will be important that these and other disease management programs are consistent with their messages to minimize confusion among the public. If programs offer differing messages as patients move between multiple insurers and case managers, the patient may become confused about his or her best course of action. Coordination across multiple insurers will be important.

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 providers screen high-risk individuals for chronic kidney disease. Further, there are few quality initiatives focused on the care that patients with identified CKD are receiving. Nationally, fewer than one-third of people with diabetes or hypertension identified with chronic kidney disease are receiving an ACE inhibitor. The Task Force recognized the need to focus additional attention on chronic kidney disease prevention, screening, and management. Thus, the Task Force recommends:

Recommendation 4.10

- (a) Public and private insurers, payers, and other organizations that offer disease management or quality improvement initiatives targeted at people with diabetes, hypertension, or cardiovascular disease should give greater emphasis to chronic kidney disease prevention, screening, and management.
 - (1) Payers, insurers, and other organizations should remind patients and providers to obtain regular screenings for chronic kidney disease including urine microalbumin and estimated GFR from serum creatinine.
 - (2) Payers, insurers, and other organizations should adopt evidence-based clinical practice recommendations for screening and management of chronic kidney disease (including those referenced in Recommendation 4.7) and should develop and include performance measures relevant to chronic kidney disease detection and treatment in quality improvement and quality assurance programs.

(b) Public and private payers and insurers should provide targeted disease management or case management services and medical nutrition therapy to all patients with chronic kidney disease once patients have progressed to stage 4. Patients should be provided information about different types of renal replacement therapy.

Disease management and quality initiatives such as those provided through Community Care of North Carolina, BCBSNC, or the North Carolina State Health Plan rely on nationally recognized evidence-based performance measures to evaluate quality of care. These include measures that may be recognized by the National Quality Forum or the National Committee for Quality Assurance or by disease-specific organizations such as the National Kidney Foundation or the American Diabetes Association (ADA). North Carolina health care professionals are more likely to adopt new performance measures if they have been nationally recognized. While KDOQI has developed evidence-based standards of care for people with chronic kidney disease, performance measures to assess whether these standards are being applied have not been incorporated into care of people with diabetes, hypertension, or cardiovascular disease. Thus, for example, the ADA and the Joint National Committee on Prevention, Detection and Treatment of High Blood Pressure recommend that providers obtain a serum creatinine in order to calculate the eGFR. (See Appendix C for a comparison of the KDOQI, ADA, and INC guidelines.) These guidelines also recommend the use of ACE inhibitors or ARBs to control blood pressure. However, while quality measures assessing providers' performance in appropriately prescribing ACE inhibitors or ARBs are commonly used in the United States, there is no quality measure assessing whether providers collect eGFR on CKD patients, although the British Medical Association has developed a quality measure for eGFR calculation for patients with diabetes. Thus, to assure that providers routinely collect eGFR to identify people with chronic kidney disease, the Task Force recommends:

Recommendation 4.11

The National Kidney Foundation, the American Society of Nephrology, the American Society of Pediatric Nephrology, and the American Dietetic Association 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.

The Task Force also recommends that Medicaid develop a specific disease management and quality improvement initiative for people with chronic kidney disease. North Carolina is currently seeking a Section 646 Medicare demonstration waiver to improve the care delivered to North Carolina Medicare beneficiaries. North Carolina Community Care Networks, Inc., the statewide parent organization of the local CCNC networks, applied for a waiver to manage the care of Medicare recipients using the CCNC disease management and quality improvement model.

Initially, the program would focus on dual eligibles (ie, individuals who receive both Medicare and Medicaid) but the initiative would soon be expanded to include Medicare beneficiaries not eligible for Medicaid. These individuals are generally 65 years or older, although the dual eligibles also include some younger individuals with disabilities. Because kidney functioning normally declines with age, approximately 17% of people age 60 years or older have mild to severe kidney disease. This means that the population that would be served by the waiver will have a high risk of CKD.

Medicare is the primary insurer after kidney transplantation or at onset of dialysis.^t More than one-third of people with kidney failure are over 65, and many also have insurance coverage under Medicaid. Kidney failure is a major cost to the Medicare program, accounting for approximately 6.4% of all Medicare payments in 2005 for only 1.2% of the Medicare population.⁵⁹

More than 80% of Medicaid-eligible older adults (age 50 or older) have been diagnosed with hypertension. The Task Force recommends that CCNC create a separate CKD disease management initiative for the dually eligible since this is the group that is most likely to have chronic kidney disease. Focusing on the care of people with chronic kidney disease should be cost-effective for the dual eligibles given that kidney functioning naturally declines as people age, and better management of people with chronic kidney disease can help reduce the incidence of ESKD (and thereby reduce Medicare and Medicaid costs).

To improve the care provided to Medicare recipients with or at risk of developing chronic kidney disease, the Task Force recommends:

Recommendation 4.12

Community Care of North Carolina (CCNC) should create a disease management initiative for chronic kidney disease as part of its §646 Medicare waiver, if approved, which will focus on older adults age 65 or older or people with disabilities who are also receiving Medicare. CCNC should incorporate evidence-based treatment of people with chronic kidney disease into the initiative and identify clinical performance measures to assess the quality of care provided to patients with the disease.

In order for patient educators, case managers, or disease management professionals to appropriately provide services for people with chronic kidney disease, they must first be educated about the

t There is a 30-month waiting period for individuals with employer-sponsored group health insurance during which Medicare is the secondary payer.

disease and the evidence-based guidelines for care of the disease. Individuals can receive certification in diabetes disease management. However, there is no similar certification or recognized training program for people working with chronic kidney disease patients.

The University of North Carolina at Chapel Hill, in collaboration with the North Carolina Community College System, has developed a proposal to create a kidney disease certification program, the Kidney Care Prevention Program (KCPP). The KCPP would be offered throughout the 58 North Carolina community college campuses. The community colleges would offer a kidney education curriculum similar to the diabetes education curriculum so that people can be certified as having the skills necessary to monitor the risk profiles of patients with chronic kidney disease (including clinical, behavioral, and demographic factors) and certified to provide patients with self-management education and skills. The intent is to train local kidney disease educators who can be cross-trained in the management of other comorbid diseases as well as trained to provide patient education and disease management to at-risk individuals in their communities. Funding would be used to support curriculum development, to provide salaries for community college faculty, and to secure an external evaluation of the effectiveness of KCPP.

The goal is to test the cost-effectiveness of providing CKD education and case management early in the progression of the disease to determine if it can help prevent the more costly progression to kidney failure (requiring dialysis or transplant). Insurers and payers should reimburse appropriately trained CKD educators if the pilot is shown to be effective in helping to improve patient self-management and slow the progression of the disease to more advanced stages of kidney disease. This is similar to the reimbursement provided to diabetes educators. Insurers and payers should require that CKD educators meet certain competency requirements, either through certification or another mechanism to demonstrate appropriate knowledge of CKD self-management education and skills.

To further this initiative, the Task Force recommends:

Recommendation 4.13

(a) North Carolina foundations and/or national foundations should provide funding to the University of North Carolina at Chapel Hill to pilot test and evaluate the effectiveness of the Kidney Care Prevention Program (KCPP), a chronic kidney disease certification program being developed in conjunction with the North Carolina Community College System. People who are trained for disease management of

u Diabetes education certification is through the National Certification Board for Diabetes Educators (NCBDE). There is no national certification for asthma education, but the National Respiratory Training Center conducts training that is accredited by multiple organizations including but not limited to the American Academy of Nurse Practitioners.

See http://www.nrtc-usa.org/trainingcourses.html.

- chronic kidney disease should also be cross-trained for diabetes, hypertension, and cardiovascular disease.
- (b) Public and private payers and insurers should provide funding for chronic kidney disease trained educators if determined to be effective and cost efficient in slowing the progression of the disease or improving health.

The Task Force also recommends that disease management professionals or case managers who manage patients with diabetes, hypertension, or cardiovascular disease be cross-trained in the management of people with chronic kidney disease. People with multiple health problems generally benefit by having one disease management expert who can help them manage all their health problems rather than multiple individuals who help them with different diseases. One key element in effective disease management is the coordination among the multiple caregivers (eg, case/disease managers, primary care providers, specialist providers). Many researchers have thus advocated a "generalist" case management approach. Indeed, researchers note that single-disease management would not be effective for the care of patients with comorbid health conditions. Managers should be required to consider all of a patient's comorbidities and diseases. Turther, it may not be cost-effective to have multiple case managers/disease educators in all communities. Many communities, particularly rural communities, cannot support separately trained individuals. North Carolina needs care coordinators/educators with multi-disease training. However, once a person with CKD reaches stage 4, he or she needs a care manager with specialized training in the care of people with kidney disease.

The Division of Public Health has applied to the American Diabetes Association to become an umbrella organization that is recognized to provide diabetes self-management education including education about kidney disease. Medicare, Medicaid, and many private insurers limit reimbursement for diabetes self-management education to entities that have been recognized by either the American Diabetes Association or Indian Health Services. Once DPH receives ADA recognition, it can include additional local health departments under the DPH umbrella, enabling the local health departments to receive reimbursement for diabetes self-management education. Although this reimbursement is limited to people with diabetes, it is a source of funding to support CKD education as diabetes educators must include information about kidney disease as a potential complication of diabetes. The goal is to get more diabetes educators who can focus on kidney disease in clinical settings. The division is piloting this initiative for the 2007-2008 fiscal year in five local

v The term *cost efficient* here means "leads to a generally accepted reasonable cost per unit of improvement in health." This is a lower standard of effectiveness than *cost-saving* (meaning the program leads to overall cost decreases). For more discussion see Chapter 3.

w In order to obtain ADA recognition, the division must meet certain staffing requirements including having a registered nurse (RN) and a registered dietitian (RD). As an umbrella program, DPH will be responsible for other health departments or programs that come under its umbrella to assure that program criteria are met. Local health departments would qualify for reimbursement for the diabetes self-management education provided by an RN, RD, pharmacist, or certified diabetes educator.

health departments in Brunswick, Clay, Robeson, Rockingham, and Wake counties. Additional funding would allow the project to expand to additional health departments across the state more rapidly, thus providing increased access to diabetes self-management education.

Recommendation 4.14 (PRIORITY RECOMMENDATION)

- (a) Disease managers or case managers who manage patients with diabetes, hypertension, or cardiovascular disease should be cross-trained in the management of people with chronic kidney disease.
- (b) Existing programs that provide disease management education and/or certification for diabetes, hypertension, or cardiovascular disease management should ensure that the curriculum includes information about prevention, screening, treatment, and self-management skills for people with chronic kidney disease.
- (c) The North Carolina General Assembly should provide funding to the Department of Health and Human Services to support the infrastructure needed to expand the Division of Public Health Diabetes Education Recognition Program with a special focus on chronic kidney disease screening and management. The General Assembly should appropriate \$150,000 in FY 2008-2009, \$300,000 in FY 2009-2010, and \$450,000 in FY 2010-2011 and thereafter to support this program.

In addition to disease management services, many patients with kidney disease need nutrition therapy. For example, many patients with CKD need to monitor their protein intake. Medicare and many private providers will pay for medical nutrition therapy services for people with an eGFR of 13-50 ml/min/1.73m² or with diabetes. In order to be covered, medical nutrition therapy must be prescribed by a physician and provided by a registered dietitian or another qualified nutrition professional. Nephrologists and other primary care providers managing patients with more advanced stages of CKD should refer patients for medical nutrition therapy when appropriate. (See Recommendation 4.15 below.)

Nephrologists

Nephrologists play a critical role in the effective management of patients with kidney disease, although there are too few nephrologists to assume the care of everyone with chronic kidney disease. In North Carolina, there are 215 nephrologists ⁶⁸ or about 3.4 nephrologists per 10,000 people with CKD stages 2-5. In contrast, there are approximately 9 primary care providers for every 10 000 people in North Carolina. ⁶⁹ Because of the relative dearth of nephrologists, most of

x The main difference between 4.3(a) and 4.14(c) is that the former is geared toward expansion of existing programs that educate and screen at-risk populations through community education and partnerships, and the latter expands a new program that specifically targets persons diagnosed with diabetes through a formal diabetes education program with a component that focuses on CKD as a complication of diabetes.

y Information about Medicare coverage of medical nutrition therapy is available at http://www.cms.hhs.gov/MedicalNutritionTherapy/.

their work is concentrated with people who have more advanced forms of kidney disease. Although the supply of nephrologists in North Carolina increased 105% between 1984 and 2005, the ratio of nephrologists per patient with ESKD declined by 40% because of the 240% increase in the prevalence of people with ESKD during that time period. The Health Professions Data System (HPDS) at the Cecil G. Sheps Center for Health Services Research also shows that nephrologists are concentrated around academic medical centers, leaving 44 counties where there are no nephrologists practicing regularly. Because of this maldistribution and the overall shortage of nephrologists, primary care providers will continue to play a key role in the management of patients with chronic kidney disease. However, nephrologists should assist primary care providers in the care of patients with CKD by providing easy referrals and consultation.

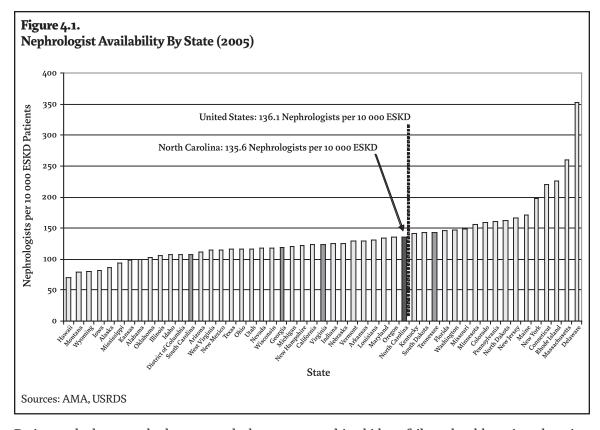
The relative supply of nephrologists in North Carolina is nearly identical to the nation as a whole. Using 2005 data from the American Medical Association, there were 218 North Carolina physicians indicating nephrology as their primary specialty. The US Renal Data System reports 16,071 North Carolina residents with ESKD in 2005, which amounts to approximately 135.6 nephrologists per 10,000 ESKD patients. National data from this same time period puts the supply across the country at 136.1, so North Carolina has essentially the same ratio as the rest of the country. Our 4 border states are also highlighted in Figure 4.1. Although Tennessee has more nephrologists per ESKD patient, North Carolina has more nephrologists than South Carolina, Virginia, and Georgia.

The KDOQI guidelines recommend that patients with <30 GFR be referred to nephrologists for clinical management. However, many patients do not receive their first evaluation with a nephrologist until they are almost ready to begin dialysis, and their health care outcomes suffer as a result of the late evaluations. ⁴¹ One study found that mortality during the first year of dialysis was about 20% overall, but those seeing a nephrologist more than one month prior to the initiation of dialysis had a 35% lower mortality rate in the first 120 days of dialysis. ⁷⁰ Further, the Task Force heard from some primary care providers that it is sometimes difficult to obtain a nephrology consultation, especially in rural areas. Even when a patient obtains a nephrology consultation, the information that the primary care provider receives back from the nephrologist is not always helpful to the ongoing management of the patient with chronic kidney disease. The Renal Physicians Association and the National Kidney Disease Education Program developed a model consultation letter that helps nephrologists communicate information to primary care providers. ^{bb} However, nephrologists do not always use this letter or provide all the recommended information to primary care providers.

z United States Renal Data System. USRDS 2006 Annual Data Report: Atlas of End-Stage Renal Disease in the United States. National Institutes of Health. National Institute of Diabetes and Digestive and Kidney Diseases:Bethesda, MD; 2006.

aa Note this differs slightly from the 215 reported by the HPDS. When using interstate comparisons, AMA data are used; HPDS data are used for North Carolina analyses.

bb The consultation letter can be accessed online at http://www.renalmd.org/consult/index.cfm.



Patients who have reached stage 4 and who are approaching kidney failure should receive education about kidney replacement options including in-center hemodialysis (dialysis provided in a licensed dialysis center), home hemodialysis (dialysis using equipment in the person's home), peritoneal dialysis (dialysis in the patient's home using the patient's abdominal cavity), or preemptive transplantation. Patients should also be informed of the option not to have kidney replacement therapy and the consequences of this choice. This patient education should assist patients in making informed choices about the type of renal replacement therapy, or lack thereof, which reflects their needs and preferences. Studies have shown that the clinical outcomes are similar among different dialysis modalities, but satisfaction is higher and costs are lower with peritoneal dialysis than with in-center hemodialysis or kidney transplants. ^{71,72}

Typically, kidney replacement therapies other than in-center hemodialysis are not offered to most ESKD patients when considering renal replacement options.⁷³ The duration of time spent in discussing treatment options and discussion of peritoneal dialysis as one of the options for renal replacement therapy increases the likelihood of patients selecting home kidney replacement therapy.⁷² Further, the lack of education about kidney transplant options earlier in the disease process effectively excludes the possibility of preemptive transplantations, which has been shown to have better health outcomes than waiting until the patient has total kidney failure.⁷³ Because of the

overall lack of patient education, more than 90% of dialysis patients receive in-center hemodialysis. In North Carolina, the percentage of patients who have chosen in-center hemodialysis has increased slightly over the last 5 years, from 89.7% (2001) to 91.5% (2006).⁷⁴

In addition, patients with earlier stages of chronic kidney disease need to be educated about the importance of protecting their veins to support vascular access in the event that their kidneys fail, and they need dialysis. CKD and ESKD patients will need reliable intravenous access for their treatment, especially if the patient later needs dialysis. Patients who have their blood drawn frequently or have central venous catheters or peripherally inserted central catheters (PICC) can experience damage to veins and prevent the placement of fistulas or other venous equipment needed for later treatment. CC

Further, for optimal care patients should have a fistula placed prior to the initiation of dialysis. A fistula is an operation which makes it easier to allow blood to flow from the patient's veins to the dialysis machine. dialysis show that patients who have a fistula placed prior to initiating dialysis have fewer complications and lower hospital rates for infection in the first 12 months of therapy. Conversely, the lack of permanent access to the veins (typically a fistula) prior to initiation of dialysis leads to higher hospitalizations, higher costs, and higher mortality. Patients who are receiving ongoing care from nephrologists prior to kidney failure are much more likely to have had a fistula placed prior to ESKD initiation.

Recommendation 4.15 (PRIORITY RECOMMENDATION)

- (a) Nephrologists should actively build collaborative relationships with primary care providers in their referral base and provide consultations when requested to help in developing care management plans. Nephrologists should also help educate primary care providers and other health care professionals on current recommendations regarding detection and management of people with chronic kidney disease and the accompanying vascular complications including cardiovascular disease.
- (b) Academic health centers, Area Health Education Centers, and Carolina Renal Care should widely disseminate the Renal Physicians Association toolkit to all nephrologists across the state to promote better understanding of chronic disease management and to incorporate this knowledge into management of patients with

cc There is a nationwide effort to increase the preservation of vascular access through the NKF KDOQI Clinical Practice Guidelines for Vascular Access, the Centers for Medicare and Medicaid Services, and regional ESRD networks.

dd A fistula involves a small operation to join an artery and vein which allows arterial blood to flow directly into the vein. The purpose is to make it easier to place a needle into the vein to allow blood to flow to the dialysis machine. Optimally it should be created using the patient's own veins and arteries (arterial venous fistula); however, when that is not possible, it can be established using a graft of synthetic material. NKF KDOQI Guidelines 2000. Guidelines for Vascular Access.

- chronic kidney disease. Specifically, nephrologists should be referred to the model consultation template and other tools for communicating effectively with primary care providers.
- (c) The American Society of Nephrology should provide educational programs to nephrologists pertaining to chronic kidney disease management, the need for early collaborative relations with primary care providers, and information that should be included in any nephrology consultation letter for a primary care provider.
- (d) Nephrologists and/or primary care providers who are managing the care of patients with later stages of chronic kidney disease should refer patients for medical nutrition therapy, when appropriate.
- (e) Nephrologists, in conjunction with disease management or patient educators, primary care providers, and private dialysis centers should provide patients with early education prior to the onset of kidney failure including:
 - (1) All options of kidney therapy including transplantation, home dialysis (including hemodialysis and peritoneal dialysis), in-center hemodialysis and supportive therapy only.
 - (2) The need to protect veins prior to the need for dialysis.
- (f) Nephrologists should work with patients in stage 4 to ensure they are offered transplantation or timely placement of peritoneal or vascular access to prevent possible medical complications from emergency treatment for kidney failure and to reduce the utilization of temporary catheters for access to circulation for renal replacement unless there is no other option.

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Chapter Four

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