

Chapter One Introduction

he kidneys play an integral role in removing waste products and drugs from the body, balancing the body's fluids, regulating blood pressure, promoting strong bones, and controlling the production of red blood cells. Kidney damage can cause health problems like high blood pressure (hypertension) and cardiovascular disease, blood or protein in the urine, waste products in the blood, frequent urination, difficulty or pain with urination, and swelling or puffiness around the eyes, hands, and feet.¹

Chronic kidney disease (CKD) is a health condition that encompasses various levels of kidney damage ranging from a decline in function to kidney failure. It is estimated that over 13% of the US population has CKD, amounting to 26 million people. There are just under one million people with CKD in North Carolina not including those with kidney failure. The elderly and people with certain chronic diseases such as diabetes, high blood pressure, and cardiovascular disease are also more likely to develop CKD.

As described more fully in Chapter 2, the loss of kidney functioning can lead to a decline in other bodily functions. Kidney disease contributes to high blood pressure, high blood sugar, high lipid levels, anemia, and bone disease. In fact, people with kidney disease are more likely to die from cardiovascular disease than from kidney failure. However, many people with chronic kidney disease do progress to kidney failure, the most severe form of CKD. These patients need treatment including dialysis or transplantation to avoid the build up of toxins that can lead to death. People who receive treatment for their kidney failure are considered to have end-stage kidney disease (ESKD). According to the United States Renal Data System (USRDS), more than 1.8 million people suffer from ESKD worldwide including 387,000 people in the United States and 11,000 people in North Carolina. The number of people with ESKD per population in North Carolina ranked 10th highest for the number of people per population living with ESKD and 12th highest

a End-stage kidney disease (ESKD) and end-stage renal disease (ESRD) refer to the same condition. Throughout the report we use the term *end-stage kidney disease* as the term *kidney* is more widely understood by the public than *renal*. We use the term ESKD rather than ESRD except when referring specifically to a publication or report that uses the term *end-stage renal disease*.

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

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for new cases of ESKD among the state's population for the 50 states and the District of Columbia. The risk of developing ESKD is not uniform across the population and imposes considerable disparities across race and ethnicity. African Americans have 3.7 times the risk of developing kidney failure, as do Caucasians. Other racial and ethnic groups are also at greater risk; Native Americans have 1.9 times and Asians have 1.3 times the risk of developing kidney failure as Caucasians. ⁵

The USRDS shows that from the 1980s through 2004 the incidence and prevalence of ESKD have been increasing both nationally and statewide. Nationally, the number of ESKD cases has doubled since 1990, although the number of new cases has begun to level off in recent years. Nonetheless, as people live longer with this disease, the overall number of people (prevalence) with ESKD is expected to rise.

The costs of providing health care services to people with ESKD alone exceeded \$30 billion in 2006, and these costs are expected to grow. A relatively small number of patients account for these high health care expenditures. According to 2005 USRDS data, ESKD patients represent only 1.2% of the Medicare population but account for 6.4% of Medicare expenditures. Together, CKD and ESKD account for 19% of general Medicare expenditures. Moreover, CKD increases the costs of treating people with diabetes or congestive heart failure, further increasing costs to the health care system.

The growing prevalence of chronic kidney disease can be characterized as a public health threat. To qualify as a public health threat, the following four conditions must be met: (1) the condition must have a high burden of disease, (2) there must be unfair distribution of the problem, (3) there must be evidence that upstream prevention strategies could reduce the burden of the condition, and (4) prevention strategies must not yet be in place. CKD meets all four of these conditions. The impact of CKD, both in terms of health care consequences and economic costs, is enormous. However, there is reason for hope. We can do more as a state and as a society to prevent kidney disease from occurring and to delay the progression of kidney disease to kidney failure. This Task Force report provides a framework for addressing this public health threat.

Legislative Charge To The Task Force

The North Carolina General Assembly asked the North Carolina Institute of Medicine (NC IOM) to convene a Task Force to study Chronic Kidney Disease (Section 48 of Session Law 2006-248). Specifically, the NC IOM was asked to develop a plan to:

(1) Reduce the occurrence of chronic kidney disease by controlling the most common risk factors, diabetes and hypertension, through preventive efforts at the community level and disease management efforts in the primary care setting.

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(2) Educate the public and health care professionals about the advantages and methods of early screening, diagnosis, and treatment of chronic kidney disease and its complications based on Kidney Disease Outcomes Quality Initiative Clinical Practice Guidelines for chronic kidney disease or other medically recognized clinical practice guidelines.

- (3) Educate health care professionals about early renal replacement therapy education for patients (including in-center dialysis, home hemodialysis, peritoneal dialysis, vascular access options, and transplantation) prior to the onset of end-stage renal disease when kidney function is declining.
- (4) Make recommendations on the implementation of a cost-effective plan for prevention, early screening, diagnosis, and treatment of chronic kidney disease and its complications for the state's population.
- (5) Identify current barriers to adoption of best practices and potential policy options to address these barriers.

The Task Force was co-chaired by Marcus Plescia, MD, MPH, chief of the Chronic Disease and Injury Section, North Carolina Division of Public Health, and Leanne Skipper, chief executive officer of the National Kidney Foundation of North Carolina. The Task Force had 33 additional members including state policy makers, legislators, primary care physicians, nephrologists, clinical laboratory operators, nurses, dietitians, social workers, and persons with CKD. (See pages 9-11 for a complete list of Task Force members.)

Although the Task Force examined some issues as they relate to chronic kidney disease in children, the Task Force focused most of its work on care for adults with chronic kidney disease. Kidney damage is far more prevalent in adults than it is in children, and the likelihood of developing chronic kidney disease increases as a person ages beyond 65 years old. In addition, the evidence-based guidelines are not as well-developed for children.

The Task Force met 8 times over an 18-month period to study CKD and to develop a plan to address it. In addition, the Task Force held three subcommittee meetings to focus on care for people with

c According to the Southeastern Kidney Council, the data as of July 30, 2007 show that there were 12,691 people 18 years of age or older who were receiving dialysis in North Carolina and 8,152 people 18 years or older living in North Carolina with a functioning kidney transplant. In contrast, there are only 38 people under age 18 who were receiving dialysis in North Carolina and 135 who are living in North Carolina with a functioning kidney transplant.

d According to the American Society of Pediatric Nephrology, there is a lack of evidence-based outcomes in pediatric patients with chronic kidney disease. In the original KDOQI documents (discussed more fully in Chapter 2), pediatric guidelines were either not discussed or incorporated into the adult guidelines, and the clinical practice guidelines do not provide specific provisions for many areas of pediatrics. Children and adolescents have some strategies of care that are similar to adult strategies and others that are age-specific. One significant area of divergence is the expectation of long-term survival, making the emphasis on growth, development, and preparation for self-directed care of particular importance.

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CKD in primary care settings and on screening of CKD through use of an estimated glomerular filtration rate (eGFR). (See Chapter 4.) This report culminates the work of the Task Force. Chapter 2 includes an overview of chronic kidney disease and the evidence-based guidelines for identifying, screening, and treating people with kidney disease. Chapter 3 describes the economic consequences of kidney disease. Chapter 4 describes the current system of care for chronic kidney disease and includes recommendations about how to improve care for people with chronic kidney disease. Chapter 5 summarizes the findings and recommendations that address the legislative charge to the Task Force and includes a chart that includes all of the recommendations of the Task Force.

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