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## **National Kidney Disease Education Program**

### **STRATEGIC PLAN**

#### **SUMMARY OF THE PROBLEM**

Chronic kidney disease (CKD) is a growing epidemic in the United States. Presently, as many as 10.9 million individuals have substantially impaired kidney function. The two main causes of kidney disease, diabetes and hypertension, account for as much as 70% of all new cases of CKD. The epidemic is due in large part to the increase of type 2 diabetes in the country. Ethnic minority populations, particularly African Americans, Hispanics, and American Indians, bear a disproportionate burden of CKD. African Americans and American Indians are four times more likely and Hispanics are two times more likely to develop kidney failure than are whites.

Many people with CKD will progress to end-stage renal disease (ESRD), or kidney failure. The United States has seen an enormous increase in patients with ESRD. In 2000, almost 100,000 people entered ESRD, with the result that a total population of about 300,000 were sustained on dialysis and 80,000 with functioning transplants. These numbers have doubled since 1990 and are expected to nearly double again by 2010. Costs of ESRD are high, at almost \$18 billion in 1999, as well as \$2 billion to \$4 billion of lost income for patients. Although ESRD patients represented less than 1 percent of the Medicare population that year, their care required 6 percent of the Centers for Medicare and Medicaid Services' (CMS) health care expenditures. CMS is the federal agency that administers Medicare.

The good news is that CKD can be prevented in many populations at risk, and its progression can be slowed in those who already have the disease. Blood sugar control can prevent kidney injury in people with diabetes. Blood pressure control to levels somewhat lower than needed for ordinary hypertension can slow kidney damage in people with most types of kidney injury and high blood pressure. The angiotensin-converting enzyme (ACE) inhibitor class of blood pressure drugs is especially beneficial in diminishing kidney deterioration and is even useful in cases of early chronic kidney disease without hypertension. Low-protein diets also can lessen disease progression.

Despite these advances in treatment and prevention, evidence suggests that only a small fraction of people at serious risk or with established but early kidney disease is receiving proper screening or treatment. CKD is more likely to be found in patients visiting their primary care providers, the hospital, or the clinic. However, an NKF survey of primary care providers' knowledge of early intervention and prevention of CKD showed a tremendous variation in perception of patients at risk. Many doctors did not recognize that their patients were at risk for kidney failure. Moreover, a study by McClellan et al. showed that only about one-third of patients who were discharged from a hospital with hypertension or diabetes and kidney disease were on the correct medication to treat their kidney disease.

## **RATIONALE FOR THE PROGRAM**

The National Institute of Diabetes and Digestive and Kidney Diseases, encouraged and supported by the Council of American Kidney Societies (CAKS) and other interested public and private groups, initiated the National Kidney Disease Education Program (NKDEP) in the summer of 2000 to address the epidemic of kidney disease in the United States. The program will increase awareness about the seriousness of kidney disease, the importance of prevention, early diagnosis, and appropriate management of kidney disease, and the prevention and management of complications.

NIDDK held a series of meetings to review the current state of kidney disease in the United States, to assess the impact of the disease on the populations at greatest risk, and to obtain recommendations from experts on the design of an education program.

- July 2000 – Kidney Disease Education Task Force Meeting
- March 2001 – “Defining Audiences: Health Professionals and High Risk Groups”

In June 2001, NIDDK sponsored a 2-day strategic planning meeting to invite broad input from concerned people and groups on the goal, objectives, and design of an education program. This strategic plan synthesizes the input received from all planning meetings.

## **GOAL AND OBJECTIVES**

The overarching program goal is to decrease the incidence, prevalence, morbidity, mortality, and cost of chronic kidney disease in the United States.

The following program objectives support the NKDEP goal:

- For people at risk for CKD:
  - 1) Increase awareness of the seriousness of CKD, its risk factors, and strategies to prevent it.
- For health care providers:
  - 1) Improve understanding of CKD, its risk factors and its relationship to comorbid conditions.
  - 2) Increase identification of people at risk.
  - 3) Increase use of strategies to delay or prevent kidney failure in people with CKD.
  - 4) Adequately prepare patients for dialysis for those unable to delay kidney failure.
  - 5) Promote a multi-disciplinary, coordinated and integrated approach to care.
- For people with CKD and their family members:

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- 1) Promote positive self-care behaviors to delay or prevent kidney failure.
  - 2) Adequately prepare for dialysis among those unable to delay kidney failure.
- For policy makers, employers, and payers and purchasers of health care:
    - 1) Increase understanding about the value of early detection and treatment.
    - 2) Promote policies that improve quality and access to care.

To meet the program goal and objectives, the NKDEP will focus on the following broad components:

- Education: The program will educate patients, people at risk, and health professionals about the seriousness of CKD and strategies to treat and prevent its progression.
- Prevention: The program will focus on preventing kidney failure in people who have CKD and preventing kidney disease in people at risk.
- Early detection and treatment: The program will encourage screening and detecting people at high risk for kidney disease and better use of effective treatments for CKD.
- Patient activation: The program will empower patients to control their disease.

## **TARGET AUDIENCES**

Program strategies and activities will be designed for four broad audiences. The primary audiences that NKDEP will focus on are people at risk for CKD and health care providers. Secondary audiences include people with CKD and their family members, and policy makers, payers, and purchasers of health care.

Primary audiences:

- People at risk for CKD. Risk factors for CKD include:
  - diabetes
  - hypertension
  - family history
  - certain genetic disorders
  - heart disease
  - obesity
  - presence of proteinuria, abnormal serum creatinine, or other markers of disease
  - being a member of certain ethnic minority groups, specifically African Americans, American Indians, Hispanics and some Asian/Pacific Islanders

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- Health care providers, particularly primary care providers such as family physicians, internists, nurse practitioners and physician assistants, as well as health professional schools.

Secondary audiences:

- People with CKD and their family members. The program will address the needs of low-income patients and those with special challenges (such as illiteracy, vision- and hearing-impairment).
- Policy makers, employers and/or payers and purchasers of health care.

## **KEY MESSAGES**

Messages are the backbone of any NKDEP communication activity or product. The messages will be clear, action-oriented, and based on scientific evidence. While they will be consistent across all target audiences, they will also be specifically tailored for each target audience. Messages will be developed with adequate formative research and with guidance from the audience. They will be created in stages using a building-block approach, and will be integrated with those of other education programs. They will be communicated widely and repeatedly through multiple, targeted channels.

To address the fear and loathing towards the disease, the tone of the messages will be positive and hopeful, instilling confidence and empowering the target audience to act.

Messages for People at Risk for CKD:

- CKD is a serious, common, costly, preventable, and manageable public health problem and its incidence is on the rise.
- People at high risk of getting CKD should get tested because treatment at early stages slows disease progression.
- Know the risk factors for CKD. If you have risk factors, have your kidneys checked on a routine basis and modify your lifestyle to reduce your risk for CKD.

Messages for Health Care Providers:

- CKD is a serious, common, costly, preventable, and manageable public health problem and its incidence is on the rise.
- CKD is under-diagnosed and under-treated. Know the risk factors for CKD and detect and initiate treatment for people at high risk in both the ambulatory and in-patient care environments.

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- Effective treatment for CKD exists across the continuum of the disease. Adverse outcomes of CKD can be prevented or delayed.
- Recognize the association and the inter-related risk among kidney disease, diabetes, hypertension and renal-retinal complications. CKD is also a risk factor for cardiovascular disease - stroke, myocardial infarction, and heart failure. Know what measurements are necessary.
- Primary care providers can care for CKD patients and can make a difference.
- Partner with nephrologists to determine the triggers for nephrology referral.
- Support services for people with CKD are available.
- Patients and providers have a shared responsibility for managing CKD.

Messages for people with CKD and their family members:

- If you have kidney disease, you can delay or prevent its progression and the associated complications by managing it aggressively. Work with your health care provider to determine a treatment plan for managing your condition.
- You can live long and well with CKD.
- Support services for people with CKD are available.

Messages for policy makers, employers, and payers and purchasers of health care:

- Early detection and treatment are cost effective. Neglect of these problems can be very expensive.
- It is in your best interest to be aware of and to foster implementation of evidence-based guidelines for kidney disease.

## **PROGRAM STRATEGIES**

The program will employ a variety of strategies and activities to accomplish its program objectives. To enhance the program's effectiveness, NKDEP will develop partnerships with organizations concerned about kidney disease and the health status of their constituents (See Appendix A for list of potential partners). In cooperation with its partners, NKDEP will deliver consistent messages to its audiences and integrate NKDEP

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strategies and messages into existing systems of care, education programs, and community-based activities.

### **I. Review, support, and disseminate science-based kidney disease care guidelines.**

Health care providers, insurers, industry groups, and patients need information on guidelines that reflect quality kidney disease care. NKDEP will review, support, and disseminate guidelines that are scientifically based, include definable and measurable outcomes, represent a consensus of multiple provider groups, and include alternatives to allow for use in different practice settings.

- NKDEP will promote and disseminate existing guidelines such as the JNC VI, the Veterans Administration, and K/DOQI. NKDEP will develop new guidelines only if needed and where consensus does not exist. Topics to achieve consensus on include:
  - Methods for clinical assessment
  - Description of stages in progression of kidney disease
  - Stratification of risk for progression of CKD and development of CVD
  - Targets for blood pressure control and a suggested treatment path
- NKDEP will identify and disseminate simple, easy-to-use tools for clinicians on preventing the development, progression and complications of kidney disease. These tools may include web-based resources such as consultation sheets for use in the clinical setting, and educational components in health professional training programs, licensing boards, medical schools, and board reviews for those requiring recertification. NKDEP will identify clinician learning and sharing opportunities through regional symposia, peer-to-peer interactions at the local level, and through pharmaceutical representatives. NKDEP will also identify effective communication channels such as electronic updates, AMA Alerts and government direct mail.
- NKDEP will translate guidelines into performance measures to track implementation of guidelines and to assess the effect of the education program.

### **II. Develop, implement and disseminate kidney disease awareness and education activities, materials and resources.**

NKDEP and its partners will build national support for kidney disease through awareness and education campaigns and other efforts. NKDEP will identify existing materials, resources and programs and promote them through a variety of channels. In areas where there are gaps, NKDEP will work with partners to develop materials that meet the needs of the target audiences, with emphasis on making the materials culturally sensitive and appropriate, user-friendly and easy to reproduce.

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- NKDEP will educate the different target audiences on the seriousness of CKD, and the importance of early detection, treatment and prevention of complications.
- NKDEP will utilize various strategies and communication channels to successfully reach the target audience. NKDEP will coordinate with its partners to promote existing programs and activities and to develop programs where gaps exist. NKDEP will explore communication channels such as print and broadcast venues, speakers' bureau, family learning centers, dialysis centers, and the Internet.
- NKDEP will promote and disseminate information for people at risk about kidney disease risk factors, symptoms and disease prevention. An example is the development of a renal risk scorecard with a checklist of risk factors.
- NKDEP will develop and promote educational materials and tools for people with CKD that address the medical, social, and educational needs of patients throughout the spectrum of the disease, especially in the area of early disease management.

**III. Promote policies and activities to improve quality and access to care.** NKDEP will strive to focus attention on the economic and clinical benefits of providing quality kidney disease care. Program efforts will be directed toward maximizing access to and the quality of care by encouraging use of guidelines for screening, prevention and treatment of kidney disease.

- NKDEP will develop and disseminate white papers to policy makers and health care payers and purchasers citing the scientific evidence supporting the prevention, detection and treatment of kidney disease.
- NKDEP will encourage laboratories to calculate and flag high creatinine levels, and routinely report GFRs based on prediction equations.
- NKDEP will work with appropriate partners to encourage changes in coding, billing and reimbursement for tests and treatment for people with CKD, and in coverage payment policies for patient education providers (nurses, dietitians, social workers).
- NKDEP will coordinate with appropriate partners to promote health systems changes that reduce medical errors. Examples include increased use of electronic medical record popup messages, flowsheets for primary care providers, computerized order entry, assigned barcodes for patients, and standing orders for routine and recurrent services.

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- NKDEP will develop performance measures for quality improvement, and will work with CMS to integrate kidney disease activities into its existing diabetes and hypertension activities, such as including kidney disease indicators for DQIP. NKDEP will identify ways to improve quality of care such as the use of comparative practice profiles, report cards for doctors and hospitals, and provision of feedback through interpersonal channels (i.e., academic detailing).

**IV. Define new aspects of the NIH research agenda.** NKDEP and its partners will help to determine new aspects of NIH's research agenda in the area of kidney disease such as finding better disease and risk markers, devising better therapies, and determining the influence of early detection on health outcomes.

## EVALUATION

NKDEP will evaluate its activities to assess its effectiveness in meeting the program's goals and objectives and to plan and revise future activities. NKDEP will build on existing evaluation models and measurement tools. The program will conduct process and outcome evaluations of NKDEP activities using quantitative and qualitative measures.

Evaluation strategies will be incorporated from the beginning of the program, with initial efforts focusing on the collection of baseline data. Where there are challenges to adequately collecting and monitoring data, NKDEP will work with the appropriate partners to develop a comprehensive system for data collection and monitoring to better track the incidence and prevalence of CKD and changes in detection and treatment of the disease.

Evaluation measures could include:

- Public awareness of prevalence and seriousness of CKD and its risk factors.
- Percent of at-risk individuals who are aware of their risk status
- Percent of at-risk individuals who are screened
- Percent of patients who are prepared for dialysis
- Patient knowledge of their "kidney number"
- Percent of individuals having urinalysis (garnered from HEDIS guidelines and HMO databases)
- Changes in lifestyle behaviors of patients such as decreased smoking, weight loss, increased physical activity
- Earlier referrals (derived from 2728 forms)
- Changes in modality selections (peritoneal dialysis or home hemodialysis)
- Reduction in incidence of ESRD or fewer patients with high creatinine

Survey Instruments and Data Sets



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- NHANES (National Health and Nutrition Examination Survey) - intermediate
- BRFSS (Behavioral Risk Factor Surveillance System)
- HEDIS
- HMO databases
- HQIP (Health Care Quality Improvement Program)
- 2728 forms
- PRO system claims data - process measure to assess people are having their kidneys checked
- USRDS (United States Renal Data System) - outcome/impact
- Medicare Disease Surveillance System
- Pharmacy-based information
- KEEP (Kidney Early Evaluation Program)

## **CHALLENGES**

Developing NKDEP is a major step toward closing the gap between current and desired kidney disease care and practices. The program faces numerous challenges; however, these challenges present enormous opportunities for the program and its partners.

- Discrimination of people who have CKD is a potential problem in worksite or other types of screening. Labeling individuals at the earliest stages of impaired renal function can be problematic.
- CKD is asymptomatic through much of its course and screening tests are often not applied or incorrectly interpreted.
- It is not clear who will and who will not progress from CKD to ESRD. This lack of understanding may pose challenges as we develop messages and target the messages to segments of the population.
- A lack of consensus guidelines makes it difficult to provide a clear, concise message.
- Screening of people at risk of CKD and their subsequent treatment may be perceived to increase health care costs. It is critical to learn more about the prevalence of this perception and its potential impact on the program's messages.
- A large proportion of the at-risk population has limited or no access to care, particularly health insurance. This is a huge barrier that must be surmounted.

## **NEXT STEPS**

### **1. Establish the NKDEP Steering Committee.**

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The new NKDEP Steering Committee is currently being appointed and its first meeting was held in September 2001.

**2. Finalize the strategic plan.**

The Steering Committee will review the NKDEP Strategic Plan and prioritize the audiences, messages, and activities, and identify new ones if necessary. An implementation plan will be developed that outlines the specific steps to implement the activities, required resources, and evaluation activities.

**3. Collect information.**

NKDEP is compiling a compendium of existing materials, programs and resources to determine where gaps exist and to identify potential partners and model programs to coordinate with. NKDEP is also exploring existing data sources to gather evaluation measures and to establish baseline data.

**4. Establish NKDEP work groups.**

NKDEP will form ad hoc work groups to help plan, develop, implement and evaluate the priority activities that are determined by the Steering Committee. The work groups will consist of Steering Committee members and others who have the necessary expertise, experience and organizational linkages to address the group's tasks. Work groups are being considered in the areas of guideline consensus, evaluation, and education for patients and at-risk populations.

## **APPENDIX A. Potential NKDEP Partners**

- Kidney organizations
- Federal agencies such as the CDC, VA, IHS, CMS, HRSA
- Health professional organizations, including pediatrics, geriatrics, emergency room physicians, school nurses, occupational health specialists, pharmacists, and those that serve minority groups
- Industry
- Employers, unions, health and life insurance companies
- Disease management organizations (DMOs)
- Culturally diverse patient advocacy groups
- Aging organizations and other non-health partners, such as the American Association of Retired Persons (AARP), the National Caucus and Center on Black Aged (NCBA), and college fraternities/sororities
- Celebrities
- Opinion leaders in high-risk communities
- The Leapfrog Group (a group that helps align health interests with employer interests) and other business coalitions
- National and State public policymakers, and legislative aids and assistants
- State health departments (surveillance)
- Organization of human resource professionals
- Clergy and religious organizations
- Health professional schools, training programs (including the AAMC) and licensing boards
- Subspecialty organizations
- Dialysis centers, particularly in reaching families of patients with kidney disease
- Association of Community Health Centers
- Federal Employees Health Benefits Program
- Diabetes Quality Improvement Project
- National Forum for Quality Measurement and Reporting
- Peer Review Organizations
- ESRD Network
- Health Insurance Association of America
- American Student Medical Association