



PROGRAM
OVERVIEW



P R O G R A M
O V E R V I E W

EXECUTIVE SUMMARY

The Medicare End Stage Renal Disease (ESRD) Program, a national health insurance program for people with irreversible kidney failure, was established in 1972 with the passage of Section 299I of Public Law 92-603. In 1978, the U.S. Congress authorized the formation of ESRD Networks Organizations to further support the ESRD Program (Public Law 95-292) and currently eighteen (18) ESRD Networks support the federal government in assuring appropriate care for patients who receive treatment through dialysis facilities and kidney transplant centers certified by Medicare. The Networks' responsibilities include: quality monitoring and improvement of the care ESRD patients receive, the collecting of data to administer the national Medicare ESRD program, providing technical assistance to patients who have ESRD and providers, and addressing patient grievances.

All ESRD Networks are members of the Forum of ESRD Networks, a national organization which supports and advocates on behalf of ESRD Networks in promoting methods to improve the quality of care to patients with renal disease. The Forum aspires to provide leadership in the renal community through education, data management, dissemination of information, and quality improvement, and to promote collaboration within our profession. Each of the Networks' websites may be accessed from the Forum of ESRD Networks' website: www.esrdnetworks.org.

The 2003–2006 ESRD Network Statement of Work outlines five goals to provide direction to the national ESRD Network program. The first goal is broadly applied to the entire ESRD Program and supported by quality improvement (QI) projects within each ESRD Network and the remaining goals are specific to Network roles and responsibilities. Together these goals outline the basic Network functions allowing each Network to customize its activities to meet and exceed CMS' expectations.

GOAL ONE: IMPROVE THE QUALITY OF HEALTH CARE SERVICES AND QUALITY OF LIFE FOR ESRD BENEFICIARIES

ESRD Program – Network Accomplishments

- ~ Anemia – Percent of patients with mean hemoglobin \geq 11g/dL improved from 43% (1997) to 80% (2003 CPM data)
- ~ Adequacy of Dialysis – Percent of patients with single session, single pool Kt/V \geq 1.2 improved from 74% (1996) to 91% (2003 CPM data)
- ~ Vascular Access – Percent of prevalent patients dialyzing with an AV Fistula improved from 32.4% (2002) to 40.2% (2005 Fistula First dashboard)

Future Directions

- ~ Base all quality initiatives on the aims of the Institute for Medicine (Crossing the Quality Chasm, 2001): Safe, Effective, Patient-centered, Timely, Efficient, and Equitable care

Currently eighteen ESRD Networks support the federal government in assuring appropriate care for patients who receive treatment through dialysis facilities and kidney transplant centers certified by Medicare.

- ~ Form coalitions with the renal community, working together for the common goal of improved quality of care and quality of life for individuals with ESRD
- ~ Expand the scope of process improvement to areas such as patient safety, end of life, and quality of life initiatives aimed at such areas as achieving the maximum independence possible through transplantation, home therapies, and in-center self-directed care

GOAL TWO: IMPROVE DATA RELIABILITY, VALIDITY, AND REPORTING AMONG ESRD PROVIDERS/FACILITIES, NETWORKS, AND CMS (OR OTHER APPROPRIATE AGENCY)

ESRD Program – Network Accomplishments

- ~ Provided CMS with ESRD data management expertise for more than 30 years with a focus on accuracy, timeliness, and validity
- ~ Maintained systems to identify any/all ESRD patient's location, status, treatment facility, and modality of treatment for any point in time
- ~ Processed 101,792 Medical Evidence forms, 69,426 Death notifications, 4,829 Annual Facility Surveys, 221,881 patient events (changes in treatment type and location), 181,395 CPM forms, and 28,650 personnel and provider changes for a total of 609,973 forms in 2004

Future Directions

- ~ Participate in the development of an information technology infrastructure to serve the quality agenda
- ~ Maintain the accuracy, efficiency, and timeliness of the existing ESRD provider and patient registry
- ~ Drive the Core Data Set implementation through consolidated, unreplicated, electronic data submission

GOAL THREE: ESTABLISH AND IMPROVE PARTNERSHIPS, COALITIONS, AND COOPERATIVE ACTIVITIES. THESE ACTIVITIES MAY INCLUDE ESRD NETWORKS, QUALITY IMPROVEMENT ORGANIZATIONS (QIOs), STATE SURVEY AGENCIES, ESRD PROVIDERS/FACILITIES, MEDICARE ADVANTAGE ORGANIZATIONS, ESRD FACILITY OWNERS, NATIONAL AND/OR LOCAL RENAL RELATED PROFESSIONAL ORGANIZATIONS, AND PATIENT ORGANIZATIONS

ESRD Program – Network Accomplishments

- ~ Developed and facilitated special projects that address current issues in patient-centered care involving collaborative work with other ESRD-focused agencies and groups www.esrdnetworks.org/specialcontracts.htm
- ~ Used a collaborative model to develop, produce, and disseminate over 5,000 interactive toolkits addressing the reduction of patient-provider conflict www.esrdnetworks.org/dpc.htm
- ~ Partnered with state survey agencies (SSAs) and quality improvement organizations (QIOs) to assess and improve quality of care and to protect patients from harm Addressed patient crisis situations such as natural disasters in a timely and efficient manner to assist both patients and the facilities that serve them

Future Directions

- ~ Seek new partners to improve care throughout the CKD continuum
- ~ Expand disaster preparedness plans for emergency situations
- ~ Sustain the regional coalitions formed in each Network

GOAL FOUR: SUPPORT THE MARKETING, DEPLOYMENT, AND MAINTENANCE OF CMS APPROVED SOFTWARE (E.G. CROWN – CONSOLIDATED RENAL OPERATIONS IN A WEB-ENABLED NETWORK)

ESRD Program – Network Accomplishments

- ~ Exceeded the 2005 contract requirement to train 40% of the eligible dialysis facilities on VISION
- ~ Exceeded the 2005 contract requirement to have 20% of the eligible dialysis facilities consistently report through VISION

Future Directions

- ~ Serve in an integral role as CMS transitions from the current CROWN system to a Web-based application with content expertise, experience with users, and connection to end-users of the data
- ~ Continue to work with CMS to advance the electronic collection of ESRD data
- ~ Work with CMS to create a mechanism and process for developing a health information technology agenda to support quality and clinical performance

GOAL FIVE: EVALUATE AND RESOLVE PATIENT GRIEVANCES AS CATEGORIZED IN CROWN AND OTHER AUTOMATED DATA PROCESSING (ADP) SYSTEMS AS DIRECTED BY CMS

ESRD Program – Network Accomplishments

- ~ Received and responded to patient and facility concerns and inquiries, including: 43 formal grievances; 1,220 complaints; 1,594 beneficiary inquiries; 1,762 facility concerns; 3,588 facility inquiries; and 1,863 other inquiries (total of 10,070) in 2005
- ~ Provided unbiased review of patient grievances and facilitated resolution by using patient preferences and other suggestions based upon interdisciplinary input (Medical Review Board) in an active and timely manner
- ~ Developed pertinent resources as well as developed and conducted specific, applicable training and in-service programs for dialysis professionals as well as patients based upon concerns, complaints, and grievances received by the Network

Future Directions

- ~ Trend and address involuntary patient discharges as reported on Patient Activity Report
- ~ Coordinate with state survey agencies to ensure patient complaints and grievances are accurately monitored
- ~ Integrate with the Medicare Ombudsman Program

HISTORY OF ESRD NETWORKS

The Medicare End Stage Renal Disease (ESRD) Program, a national health insurance program for people with end stage renal disease, was established in 1972 with the passage of Section 299I of Public Law 92-603. The formation of ESRD Network Organizations was authorized in 1978 by Public Law 95-292 which amended Title XVIII of the Social Security Act by adding section 1881. Thirty-two ESRD Network areas were initially established. In 1986, the Omnibus Budget Reconciliation Act of 1986 (P.L. 99-509) amended section 1881c of the Social Security Act to establish at least 17 ESRD Network areas and revised Network Organizations responsibilities.

On July 1, 1988, CMS awarded contracts to 18 geographically designated Networks to administer various aspects of the ESRD program. In 1989 §1881(c) of the Act was amended by P.L. 100-239 to specify confidentiality and the extent of Network liability. Since 1990 CMS has awarded three-year contracts to the Networks.

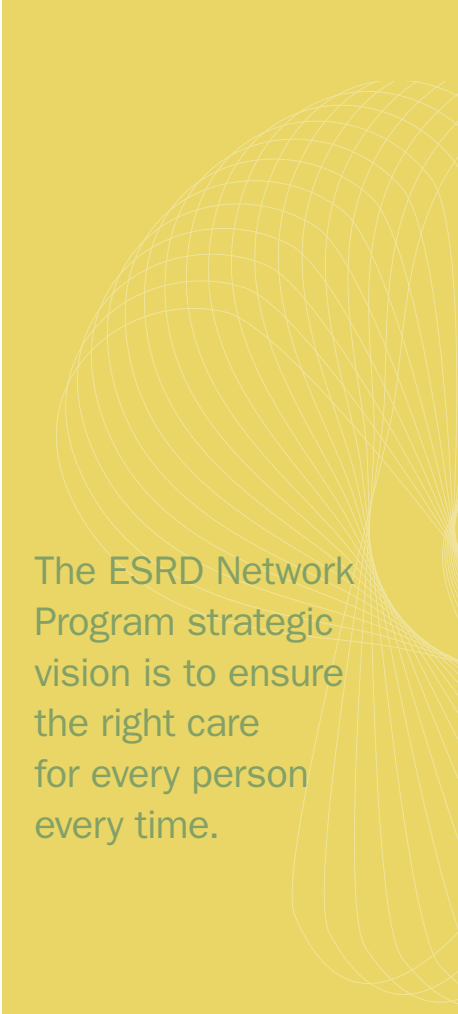
Today, the eighteen (18) ESRD Networks under contract to CMS serve as liaisons between the federal government and the providers of ESRD services. The Networks' responsibilities include: quality monitoring and improvement of the care of ESRD patients receive, the collection of data to administer the national Medicare ESRD program, and the provision of technical assistance to ESRD patients and providers.

All ESRD Networks are members of the Forum of ESRD Networks, a national organization which supports and advocates on behalf of ESRD Networks in promoting methods to improve the quality of care to patients with renal disease. The Forum aspires to provide leadership in the renal community through education, data management, dissemination of information, and quality improvement, and to promote collaboration within our profession. Each of the Networks' websites may be accessed from the Forum of ESRD Networks' website: www.esrdnetworks.org.

THE ESRD PATIENT POPULATION

Although the ESRD population is less than 1% of the entire U.S. population, it continues to increase at a rate of 3% per year and includes people of all races, age groups, and socioeconomic standings. Because the Networks cover all 50 states plus the District of Columbia, Puerto Rico, American Samoa, the Commonwealth of the Northern Mariana Islands, Guam, and the U.S. Virgin Islands, much variation is seen in both the overall population and the ESRD population. At the end of 2004 there were 321,539 patients being dialyzed of which 104,056 were new (incident) ESRD patients in that year.

ESRD patients have a variety of choices for outpatient renal replacement therapy that include transplantation and dialyzing at home, in a hospital-based facility, or at an independent facility. Some transplant centers, in addition to providing kidney transplants, offer dialysis services. In-center hemodialysis is the most dominate modality. The leading cause of renal failure in the United States is diabetes.



The ESRD Network Program strategic vision is to ensure the right care for every person every time.

Each year, the Networks compile and profile data, including but not limited to age, race, and gender on the ESRD population. Of all groups, the pediatric population (under 20 years old) is consistently the smallest, with approximately 1.1% of the ESRD incident population. Over the past five years, almost half (46.6%) of the incident patients were between the ages of 60 and 79. The majority of dialysis patients are white and ESRD rates among blacks and Native Americans are disproportionately high when compared to the general population. Black Americans comprise only 12% of the national population, yet make up 36.4% of the total dialysis prevalent population. In 2004, males represented over half the ESRD incident (57.2%) and prevalent (51.9%) populations.

NETWORK GOVERNANCE AND STRUCTURE

Regulations (now found in 42 CFR 405, Subpart U) require ESRD treatment facilities to be organized into geographic areas called Network organizations in order to promote a system of effective coordination. These ESRD Networks originally assured coordinated patient referral, as well as access to resources to permit the concentration of equipment and specifically trained personnel in centers where they would be used efficiently to treat a large number of patients.

The majority of the ESRD Networks are non-profit organizations with a governing board, basic administrative staff, and infrastructure to support their operations and meet their statutory requirements and other work activities as set forth in the ESRD Statement of Work (SOW). A Network Organization must establish and maintain a Network Council of representatives from renal dialysis and transplant facilities or providers located in its geographic area that includes at least one patient representative.

The Network must be governed by a Board of Directors (BOD) composed of representatives from the Network area including at least one patient representative. The BOD supervises and is responsible for:

- ~ Performance of the Networks' administrative staff in meeting contract deliverables and requirements as well as responding to CMS' requests
- ~ Financial operation of the Network including the Internal Quality Control program
- ~ Review and approval of the Network Annual Report
- ~ Review and approval of request for contract modifications involving additional funding
- ~ Review and approval of MRB recommendations to sanction ESRD facilities

Each Network must also establish a Medical Review Board (MRB) that includes physicians, nurses, and social workers who are engaged in treatment relating to ESRD and qualified to evaluate the quality and appropriateness of care, and at least one patient representative. The MRB serves as an advisory panel to the Network on the care and appropriate placement of ESRD patients on dialysis and has responsibility for quality improvement and oversight initiatives in the Network area. Both Boards meet statutory requirements with respect to composition and adhere to strict conflict of interest guidelines. Most Networks rely upon Patient Advisory Committees to obtain the patient perspective.

Networks appoint other standing or ad hoc committees as needed to perform their work. The dialysis and transplant providers in each Network are offered opportunities to appoint representation to the Network. Providers are required by regulation to participate in Network activities and rarely has a lack of active cooperation been an issue in the Network community.

Board members are all volunteers who contribute an enormous number of hours to the Network program. It is estimated that for the year 2004 Boards of Directors/Trustees and Medical Review Boards alone donated the equivalent of 5,000 hours. This figure would significantly increase if other committee volunteers were included. This unprecedented volunteerism is frequently overlooked as an important contributor to the program's success and has allowed the Networks to function effectively with limited government resources.

Network key staff consists of an Executive Director, Quality Improvement Director, Data Manager, and Patient Services Coordinator. These positions are supported by other positions, the deployment of which varies by Network. On average each Network has 10 staff members. The average number of staff per Network has grown only slightly since 1988 despite a 154% provider increase and a 202% patient increase in the same time period.

CMS awards to Networks contracts that provide service for a fixed price that is not subject to any adjustment. Traditionally contracts are for one year with two additional option years. In order to exercise the option, the Network must receive a satisfactory annual evaluation from the Project Officer and demonstrate ability to meet contract requirements and deliverables.

RESPONSIBILITIES OF ESRD NETWORK ORGANIZATIONS

- ~ Encouraging the use of those treatment settings most compatible with the successful rehabilitation of the patient
- ~ Encouraging the participation of patients, providers of services, and ESRD facilities in vocational rehabilitation programs
- ~ Developing criteria and standards relating to the quality and appropriateness of patient care
- ~ Evaluating procedures used by facilities and providers to assess the appropriateness of patient treatment type
- ~ Implementing procedures for evaluating and resolving patient grievances
- ~ Conducting on-site reviews of facilities and providers, as necessary, utilizing standards of care established by the Network
- ~ Collecting, validating and analyzing data for the preparation of reports and assuring the maintenance of a national ESRD registry
- ~ Identifying facilities consistently not meeting Network goals, assisting facilities in developing appropriate plans for correction, and reporting to the Secretary (CMS) on facilities and providers that are not providing appropriate medical care
- ~ Submitting an annual report to include:
 - Network's goals, and activities conducted to meet goals
 - Data on the comparative performance of facilities with respect to patients in self-care settings, transplantation, and vocational rehabilitation programs
 - Identification of facilities that have consistently failed to cooperate with Network goals
 - Recommendations for additional or alternative ESRD services or facilities in the Network area
- ~ Establishing a Network Council to include dialysis and transplant facilities in the Network area and a MRB to include physicians, nurses, social workers and at least one patient

The ESRD Network Program strategic vision is to ensure the right care for every person every time. Overarching ESRD Program goals include:

- ~ Improve the quality and safety of health care services provided in dialysis and transplant facilities for patients with ESRD
- ~ Improve the quality of life for individuals with ESRD through the end of life
- ~ Establish and improve strategic partnerships and renal coalitions at the national and regional level to ensure optimum quality of care along the continuum of CKD/ESRD
- ~ Improve the collection, reliability, timeliness, and use of data to measure processes of care, outcomes and support the ESRD program

The Networks support the Health Care Quality Improvement Program (HCQIP) mission of patient-centered, effective, safe, efficient, equitable and timely care by assisting ESRD providers and facilities to assess and improve the care provided to individuals with ESRD.

2003 – 2006 CMS NETWORK GOALS

The ESRD Network Statement of Work outlines five goals to provide direction to the national ESRD Network program. These goals outline the basic Network functions allowing each Network to customize its activities to meet and exceed CMS' expectations.

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Future Directions

- ~ Base all quality initiatives on the aims of the Institute for Medicine (Crossing the Quality Chasm, 2001): Safe, Effective, Patient-centered, Timely, Efficient, and Equitable
- ~ Form coalitions with the renal community, working together for the common goal of improved quality of care and quality of life for individuals with ESRD.
- ~ Expand the scope of process improvement to areas such as patient safety, end of life, and quality of life initiatives aimed at such areas as achieving the maximum independence possible through transplantation, home therapies, and in-center self-directed care
- ~ Deploy transplant referral measures developed in 2005
- ~ Deploy mineral metabolism (bone disease) measures developed in 2005
- ~ Expand measure set for clinical performance indicators

Networks assist ESRD providers in assessing and improving the care provided to Medicare ESRD beneficiaries. Networks accomplish this by:

- ~ Establishing a Network quality improvement program which includes quality improvement projects (QIPs) with a national and local scope
- ~ Collecting, monitoring, and improving clinical performance measures (CPMs)
- ~ Driving the Fistula First Breakthrough Initiative
- ~ Identifying local quality initiatives by Network Medical Review Boards

Historically, the Networks conducted at least two Quality Improvement Projects (QIPs) during the three-year contract period. These projects addressed areas of care for which clinical performance measures and indicators have been developed. Each Network defined the opportunity for improvement, employed both outcome and process indicators, prepared a project design and methodology that supported statistical analysis, proposed intervention activities, and included an evaluation mechanism. For 2002, CMS requested all Networks conduct a QIP on Vascular Access Management while work continued on the 2001 QIP on Adequacy of Dialysis. In 2003, CMS and Networks initiated a new collaborative initiative on increasing the rate of AV fistulas. This initiative—Fistula First, a national vascular access quality initiative—was designated in 2005 as a CMS Breakthrough Initiative.

“One of the things that makes the Networks effective is the active and enthusiastic participation by provider representatives of all disciplines on the Medical Review Boards to develop a quality improvement agenda that addresses unique regional issues. This success of this approach is reflected by the continuous improvement in patient outcomes that has become a hallmark of the ESRD program.”

Jay Wish, MD, Chair
Network 9/10 and
ESRD CPM QI Committee

The Institute of Medicine's reports on healthcare quality have helped the Network program frame their quality agendas. Remaining mindful of the six aims for improvement (safe, effective, patient centered, timely, efficient, and equitable care) the Networks have participated in national initiatives as well as conducted projects unique to their area.

NATIONAL ESRD CLINICAL PERFORMANCE MEASURES (CPM) PROJECT— HIGHLIGHTS FROM THE NATIONAL 2004 ESRD PROJECT

The Balanced Budget Act of 1997 required CMS to develop a method for measuring and reporting the quality of renal dialysis services provided to persons covered by Medicare. Sixteen (16) clinical performance measures, based on Kidney Disease Outcomes Quality Initiative (K/DOQI) Practice Guidelines, were developed. This project, formerly known as the National ESRD Core Indicators Project, involves the collection and reporting of data and provides the foundation for many of the Network quality improvement activities. It provides important feedback and advice to CMS on outcome measures at both the national and Network levels. The four areas of care identified by CMS for the focus of this project are listed below:

- ~ Adequacy of dialysis measured by URR and Kt/V (hemodialysis) and weekly Kt/V_{urea} and creatinine clearance (peritoneal dialysis)
- ~ Nutritional status measured by albumin
- ~ Anemia management measured by hemoglobin, serum ferritin, and transferrin saturation
- ~ Vascular access (hemodialysis only)

Networks, individually and collectively, examined their opportunities for improvement and implemented programs to specifically improve these rates and health outcomes to thousands of Medicare beneficiaries. Networks engaged their Medical Review Boards and distributed evidence-based materials, studied the quality literature to learn effective strategies for improvement, conducted training sessions for themselves and dialysis providers on designing and implementing internal quality improvement programs, and collected data for trending and benchmarking. Throughout this process, continuous and steadfast improvement has been realized since the onset of this project in 1994. The CPM data from 2003 (2004 CPM Report) documents the following:

- ~ 87% of patients received adequate hemodialysis (defined as URR \geq 65%), representing an increase of 44% since 1994
- ~ 90% of blacks (54% increase since 1994) and 91% of whites (44% increase since 1994) received adequate hemodialysis
- ~ 80% of patients had a mean hemoglobin \geq 11, representing a significant increase since 1994
- ~ 6% of blacks and 6% of whites were severely anemic (hemoglobin < 10%), representing decreases since 1994

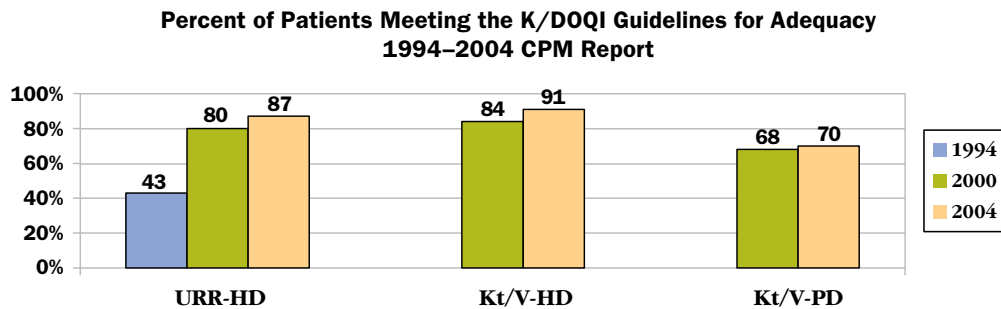
Over the years, the CPM project has been expanded to include new indicators (such as peritoneal dialysis indicators) and changed to reflect more appropriate measures (such as measuring adequacy by Kt/V rather than URR and measuring anemia by hemoglobin rather than hematocrit). In 2002 data collection on 100% of the pediatric population and the Veterans Administration dialysis population was initiated. Data on these populations are returned to each provider allowing for comparison to their individual practices.

PROGRAM SUCCESSES

The following graphs highlight a few of the clinical indicators measured since the inception of the Core Indicators/CPM Project:

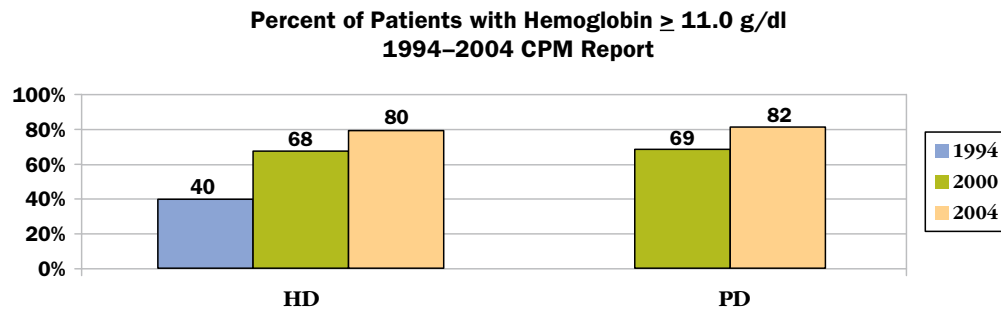
ADEQUACY OF DIALYSIS

Beneficiaries with ESRD are unable to clear toxins normally filtered by the kidneys from their blood. To prevent symptoms and medical complications, it is essential that adequate dialysis be provided to remove these toxins. The K/DOQI Guidelines define adequate dialysis as an URR of 65% or greater and/or a Kt/V of ≥ 1.2 for hemodialysis patients (HD) and ≥ 2.0 for peritoneal dialysis (PD) patients.



ANEMIA MANAGEMENT

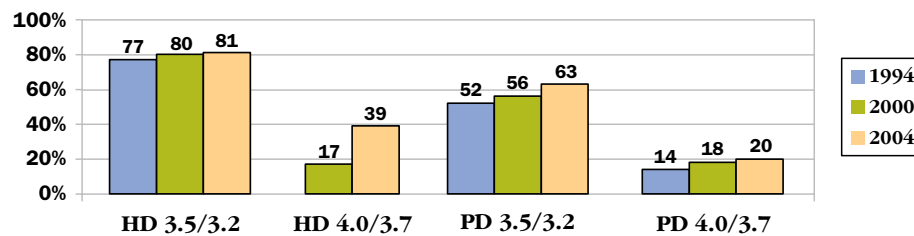
In most cases, the body's chemicals, which stimulate the production of red blood cells, are decreased or lost at the onset of renal failure. ESRD patients have difficulty maintaining an adequate number of red blood cells and consequently become anemic as measured by hematocrit/hemoglobin. Anemia affects both quality of life and health of the ESRD patient as evidenced by increased exhaustion due to decreased oxygen, which is carried through the body by hemoglobin in red blood cells. There are treatments available to help raise the hemoglobin and keep it at a level which will help increase energy and stamina. The K/DOQI Guidelines recommend target hemoglobin of 11.0-12.0 g/dl.



NUTRITIONAL STATUS

Albumin (a type of protein) is the marker used to measure nutritional status. Although there is some debate in the nephrology community regarding the utility/validity of this marker in people with ESRD, this indicator continues to be the one recommended by the K/DOQI Guidelines. Beneficiaries with renal failure generally begin dialysis with poor nutritional status for many reasons. Malnourishment begins during the early stages of CKD due to nausea, decreased feeling of wellness and other manifestations of the disease process. There are two methods for Albumin measurement (BCG and BCP); both methods are collected in the CPM process. ESRD patients on peritoneal dialysis may have more difficulty holding onto albumin due to the mechanics of the treatment process (albumin is washed away with each dialysis exchange).

**Percent of Patients with an Albumin \geq 3.5/3.2 and 4.0/3.7 g/dl (BCG/BCP)
1994–2004 CPM Report**



BREAKTHROUGH INITIATIVE: FISTULA FIRST

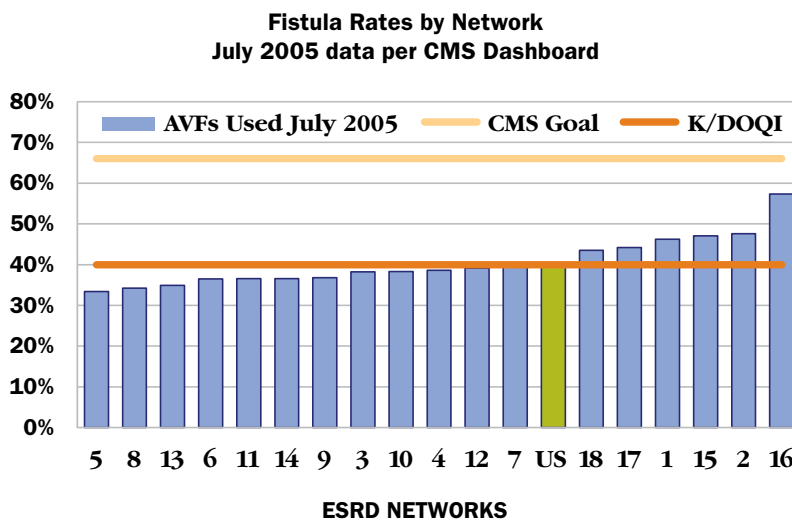
The National Vascular Access Improvement Initiative—Fistula First, a new Network initiative in 2003, was aimed at increasing the use of arteriovenous fistulas (AVFs) for hemodialysis access. Patients who receive dialysis with an access other than a fistula have a 20 to 70 percent greater chance of death in the first year after their placement. Currently, only a third of patients are dialyzed with a fistula, compared with 60 to 90 percent in other countries. This difference in practice patterns is one of the primary reasons why the unadjusted mortality rate for ESRD patients is much higher in the U.S. (about 21 percent) than in Europe (about 16 percent) and is associated with over 5,000 unnecessary deaths each year.

“This Breakthrough Initiative reflects a clear, immediate opportunity to substantially improve the health of Americans who need kidney dialysis or transplantation. It illustrates how CMS can collaborate with health professionals, patients, and other partners to have significant impact on the quality of medical treatment.”

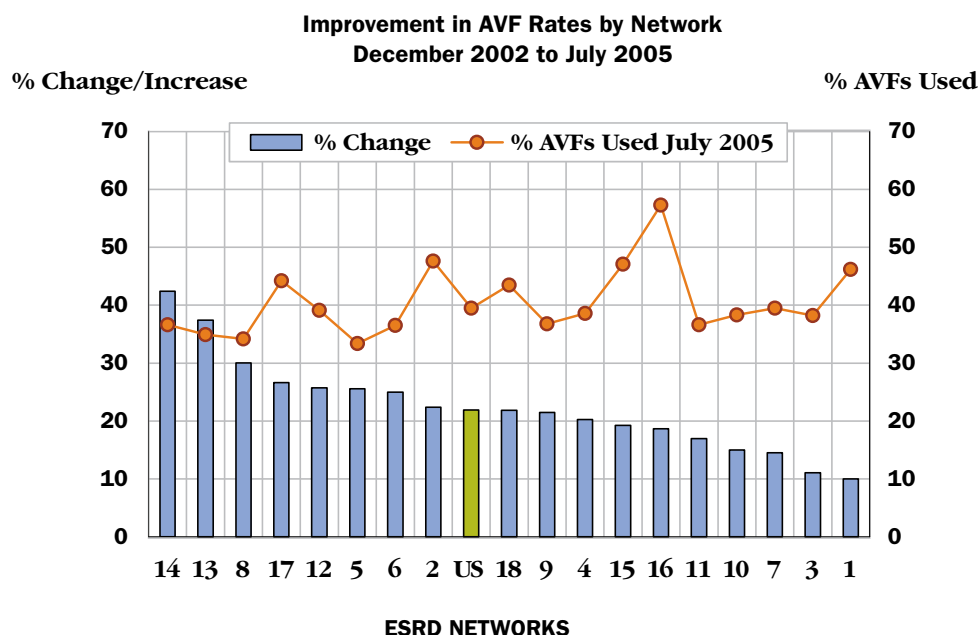
Mark B. McClellan, MD, PhD
CMS Administrator

In 2005, the Fistula First project was designated as the first CMS Breakthrough Initiative—and has a five-year national goal of 66% fistula use in all prevalent patients. The Fistula First project established an initial target to fulfill the goals recommended by K/DOQI: AVF rates of 50% or greater for incident patients, and at least 40% for prevalent patients undergoing hemodialysis. This constitutes a significant increase over national averages, which were 29% for incident patients and 31% for prevalent patients at the project's start. After Network intervention the national average for prevalent patients is 40.9% in October 2005. The upcoming ESRD Network contract for 2006–2009 will support the five-year national goal of 66%.

FISTULA FIRST RATES FOR PREVALENT PATIENTS BY ESRD NETWORK



IMPROVEMENT IN AVF RATES BY NETWORK



“Even before the national Fistula First Breakthrough Initiative, the Medical Review Board directed a fistula project in a large metropolitan area. We have seen improvements in practice patterns, professional collaborations, data collection, access monitoring and patient participation; fistula rates have risen considerably and continue to improve.”

Cynthia Kristensen, MD, Chair
Network 15 Medical Review Board
Denver Nephrologists PC

ESRD SPECIAL PROJECTS

In addition to national initiatives such as CPMs and Fistula First, Networks conduct other projects and oversight activities within their own regions as part of their CMS contract. The projects are directed by their Medical Review Boards and are designed to address local opportunities for improvement. These are well detailed in the Networks' Annual Reports to CMS. In addition, CMS has funded a number of special projects which benefit the entire renal community.

PROJECT NAME: PATIENT SAFETY IN THE ESRD PROGRAM

- Network:** Network of New England (Network 1)
- Partners:** N/A
- Award:** \$113,000 (Phase III)
- Purpose:**
- ~ To develop and distribute a resource tool kit with reference materials and PowerPoint presentations (Phase I)
 - ~ To provide leadership training for CMS and Networks on the principles of no-blame safety culture and the methods to evaluate failed systems design (Phase II)
 - ~ To partner with RPA, AAKP, and the Forum of ESRD Networks to develop and conduct professional and patient surveys about perceptions and experiences for medical error (Phase III)
 - ~ To conduct pilot project with a limited number of providers within Network 1 region using a selected core set of safety measures approved by CMS (Phase III)
- Timeframe:** 2001–2005
- Outcomes:**
- ~ Training provided in March 2001 for all Networks
 - ~ Tool kit distributed to all Networks and then distributed to providers
 - ~ Networks conducted local training sessions on safety principles and management foundations needed for a safety culture
 - ~ Pilot conducted and report on lessons learned submitted to CMS

PROJECT NAME: ANALYSIS OF WITHDRAWAL FROM DIALYSIS, DISCONTINUATION OF DIALYSIS, AND REFERRAL TO HOSPICE CARE IN DIALYSIS PATIENTS

- Network:** Network of New England (Network 1)
- Partners:** Networks 5 & 12
- Award:** \$30,000
- Purpose:** To understand the interpretation of important concepts such as withdrawal from dialysis, discontinuation of dialysis, and use of hospice care as reported in CMS death notification form
- Timeframe:** July 2005–June 2006
- Outcomes:** Anticipated: provide definitions for withdrawal from and discontinuation of dialysis which will allow the ESRD Networks to collect more consistent data and understand the barriers to referral to hospice care.

“The Dialysis Patient Provider Conflict Project (DPC) is an extensive development and implementation plan for managing conflict and patient grievances in dialysis centers. The project is a living, breathing example of CMS-sponsored, Forum managed, and ESRD Network-directed improvement in patient centered care.”

Richard S. Goldman, MD
Vice-President, Forum Board of Directors, and Forum Representative, Network 15

PROJECT NAME: SPECIAL VOCATIONAL REHABILITATION PILOT PROJECT

Network: Network of New York (Network 2)
Partners: N/A
Award: \$100,350
Purpose: To provide information and assistance to dialysis and transplant patients, social workers, and Vocational Rehabilitation (VR) Counselors
Timeframe: July 2000–June 2003
Outcomes: During the first three years of the project, the Network VR Specialist trained the VR Counselors and gave individualized information and assistance to 487 patients and 187 social workers and sent 678 information packets tailored to their specific needs. An additional 1,019 patients and professionals received VR information at 139 group presentations. These activities received national recognition when the American Association of Kidney Patients (AAKP) presented its Dominick Gentile, M.D. Memorial Award to the Network for its leadership in “efforts to promote vocational rehabilitation for people with kidney disease.”

PROJECT NAME: DIALYSIS CARE: COMMUNICATION FOR QUALITY

Network: Mid-Atlantic Renal Coalition (Network 5)
Partners: Academy for Educational Development
Award: \$466,911
Purpose: ~ To conduct formative research with literature review, interviews with corporate entities and onsite visits to dialysis units to determine their training needs and to better understand how training occurs in the dialysis unit
~ To better engage patients in understanding quality indicators such as those available on the Dialysis Facility Compare website
Timeframe: July 2001–June 2005
Outcomes: ~ Development of five training modules providing step-by-step instructions for short in-service trainings (about 45 minutes in length), with exercises and handouts intended to be “off the shelf—ready to go” on the following topics: Professionalism in Dialysis Care; Patient-Centered Care; When Patients Have Concerns; Fistula First; Caring Through the End: Final Stage of Chronic Kidney Disease
~ Modules distributed to Networks and posted to MARC website. Between July 2004 and July 2005 approximately 7,500 copies of the modules were downloaded

PROJECT NAME: END-OF-LIFE CARE

Network: Mid-Atlantic Renal Coalition (Network 5)
Partners: Academy for Educational Development
Award: \$200,000
Purpose: To educate the renal community about the need for more extensive attention to end-of-life concerns in the dialysis unit
Timeframe: July 2004–June 2006
Outcomes: ~ Conference conducted in December 2004 with approximately 200 participants
~ CD-ROM entitled *Core Curriculum in Nephrology—Palliative Care* produced and distributed to all dialysis units in the country
~ Conference proceedings posted to the HDCN website for CMEs/CEUs
~ Development of a brochure entitled: *Advance Care Planning: For the Dialysis Patient and their Family*. 200,000 copies of this brochure will be made available to dialysis facilities

PROJECT NAME: PEDIATRIC QUALITY OF LIFE

- Network:** Mid-Atlantic Renal Coalition (Network 5)
- Partners:** Networks 1, 2, 4, 9/10, 12, 13, 14, 16 and Johns Hopkins University
- Award:** \$30,000
- Purpose:** ~ To identify which aspects of quality of life (QOL) are impaired and to assess the prevalence of serious QOL impairment in pediatric dialysis patients
~ To assess the relationship between QOL and measurements of dialysis adequacy in pediatric dialysis patients
~ To assess the impact of dialysis type (HD vs PD) on quality of life
~ To quantify the relationship between intermediate outcomes (i.e. level of hemoglobin and albumin) and QOL in pediatric dialysis patients
~ To assess the impact of access type on QOL (physical functioning, school functioning, and psychosocial functioning)
- Timeframe:** July 2005–June 2006
- Outcomes:** This study is currently undergoing IRB review and will be implemented in early 2006.

PROJECT NAME: SAFE & TIMELY IMMUNIZATIONS COALITION (STIC)

- Network:** Southeastern Kidney Council, Inc. (Network 6)
- Partners:** CMS, Network 15, Network 11, CDC, North Carolina QIO, South Carolina QIO, North Carolina State Survey Agency, South Carolina State Survey Agency, Gambro Healthcare, RCG, Fresenius Medical Care, ANNA, DCI, NANT, AAKP, GAKP (Georgia Association of Kidney Patients), Oklahoma QIO, Health Systems Management (independent facility)
- Award:** Year One–\$134,967
- Purpose:** To create a coalition to increase the rate of Hepatitis B, Influenza, and Pneumococcal immunizations in ESRD patients and facility staff, therefore decreasing morbidity and mortality associated with these diseases. Additionally, the project would be used as a way to test the data elements that are necessary to track immunization rates in the country, and any barriers that exist to reporting data.
- Timeframe:** Year One–July 1, 2005–June 30, 2006, with possible second year extension
- Outcomes:** Expect an increase in the rate of Hepatitis B, Influenza, and Pneumococcal immunizations in ESRD patients and facility staff in Network 6, 11, and 15. Develop of a toolbox that will be shared with all ESRD Networks containing educational resources, tracking tools, and identified best practices for increasing immunizations among ESRD patients and staff.

PROJECT NAME: DISASTER PREPAREDNESS AND RESPONSE PROJECT

- Network:** Florida ESRD Network (Network 7)
- Partners:** N/A
- Award:** \$170,000
- Purpose:** To enhance access to care and decrease disruption of dialysis services due to disasters through development of relationships and cooperative activities with key partners; establishment of systems for education/communication; and maintenance of these partnerships throughout the year for optimal readiness. The initial meeting of this new Coalition is planned for January 19, 2006.

Timeframe: July 2005–June 2006

Outcomes: To create a national coalition that has processes in place to expeditiously support local response to disasters through such measures as coordinated and efficient use of national resources, information exchange, and problem resolution.

PROJECT NAME: ESRD OUTPATIENT MEDICATIONS PROJECT

Network: Network 8, Inc.

Partners: University of Mississippi Department of Pharmacy Administration

Award: \$278,070

Purpose: To establish a baseline for medication use by ESRD dually-enrolled patients and to identify drug-related issues specific to the population with ESRD to assist in the implementation of Part D of the Medicare Modernization Act

Timeframe: July 2004–June 2005

Outcomes: The final report, submitted June 2005, establishes a drug categorization scheme tailored to this special population, and identifies medications that should always be available as well as those that should always be avoided. These findings can be used to promote improved and safer formularies for ESRD patients, help identify coverage issues in the MMA that may need to be addressed, and guide prescription drug plans (PDPs) in any marketing of non-covered MMA drugs to the population with ESRD.

PROJECT NAME: TRANSPLANT REFERRAL MEASURES

Network: The Renal Network, Inc. (Network 9/10)

Partners: N/A

Award: \$350,000

Purpose: To develop measures which will track the steps for a renal patient to complete the process of kidney transplant

Timeframe: July 2004–June 2006

Outcomes: Draft measures were developed and are discussed in a report to CMS June 2005. Once tested, these measures will be added to the Clinical Performance Measures (CPM).

PROJECT NAME: BARRIERS TO OUTPATIENT PLACEMENT

Network: The Renal Network, Inc. (Network 9/10)

Partners: Networks 1, 2, 11, 14, 15, 16, and 18

Award: \$50,000

Purpose: To identify and explore the extensiveness of the barriers to receiving dialysis treatment in an outpatient facility, the impact this has on the quality of patient care, and recommend resolutions.

Timeframe: July 2005–June 2006

Outcomes: A Technical Expert Panel will be convened to provide guidance for the project and identify specific barriers to receiving outpatient dialysis care.

PROJECT NAME: DELIVERY OF DIALYSIS TREATMENT WITHIN THE SKILLED NURSING FACILITY

Network: The Renal Network, Inc. (Network 9/10)
Partners: Network 1
Award: \$40,000
Purpose: To develop recommendations for providing dialysis in the Skilled Nursing Facility (SNF)
Timeframe: July 2005–June 2006
Outcomes: The report will include recommendations in the following areas: Certification for SNF dialysis as an ESRD provider; Program Structure & Responsibilities; Medical Oversight; Staffing & Multi-disciplinary Care Planning; Coordination of Care between the ESRD Provider and the SNF; Equipment, Maintenance & Treatment Area; Treatment Supplies; Water Quality; Back-Up Treatment Facility (outpatient & acute); Reimbursement; Determining Patient Eligibility; Data Collection; and Oversight

PROJECT NAME: BONE DISEASE CLINICAL PERFORMANCE MEASURES (CPM) PROJECT

Network: Renal Network of the Upper Midwest, Inc. (Network 11)
Partners: N/A
Award: \$350,000
Purpose: To expand the ESRD CPMs by developing a new set of CPMs for bone disease and mineral metabolism.
Timeframe: July 2005–June 2006
Outcomes: The following CPMs were recommended to CMS
CPM #1 Measurement of serum phosphorus concentration
CPM #2 Evaluation of serum phosphorus concentration
CPM #3 Measurement of serum calcium concentration
CPM #4 Evaluation of serum calcium concentration
CPM #5 Measurement of parathyroid hormone concentration
CPM #6 Evaluation of parathyroid hormone concentration

PROJECT NAME: DECREASING DIALYSIS PATIENT-PROVIDER CONFLICT PROJECT (DPC)

Network: ESRD Network of Texas (Network 14)
Partners: Forum of ESRD Networks, Network 12
Award: \$260,000
Purpose: To decrease conflict in the dialysis setting
Timeframe: January 2004–June 2006
Outcomes: Working with a Task Force of renal stakeholders and content experts, workgroups developed tools and resources for staff training, quality improvement, and a taxonomy and glossary. After testing and revisions, the DPC program was rolled out to the ESRD Networks in 2005 for regional training and dissemination of resources to all 4,500 dialysis providers.

PROJECT NAME: WORKING WITH THE NON-CONFORMING PATIENT

Network: TransPacific Renal Network (Network 17)
Partners: N/A
Award: \$144,929
Purpose: To disseminate and implement the practical, easy to understand behavioral definitions applicable to dialysis, to develop teaching tools for dialysis professionals, to improve customer service skills, and to encourage Network facilities to develop, publicize and implement a facility safety program that includes a well thought out zero tolerance policy
Timeframe: July 2002–June 2004
Outcomes: A taxonomy of behavioral definitions, some training materials, and recommendations to CMS were developed. Project was withdrawn before completion.

PROJECT NAME: ICH-CAHPS SURVEY DEVELOPMENT AND QUALITY IMPROVEMENT PROJECT

Network: Intermountain ESRD Network (Network 15)
Partners: Networks 1, 5, 14; AHRQ; Harvard School of Public Health; AIR; and RAND
Award: \$280,440
Purpose: To support a quality improvement project with a small number of facilities included in the ICH-CAHPS pilot test, along with their respective ESRD Networks. The immediate objective of the project is for each facility, with the help of their Network, to design and implement a quality improvement project over a period of approximately six months, with the input of the CAHPS grantees
Timeframe: July 2005–June 2006
Outcomes: A training session was conducted in August 2005 with the facilities, Networks and Grantees and 7 facilities are currently working on projects.

PROJECT NAME: STRATEGIC PARTNERSHIP FOR CHANGE: A TRAINING AND CONSULTATION PROJECT

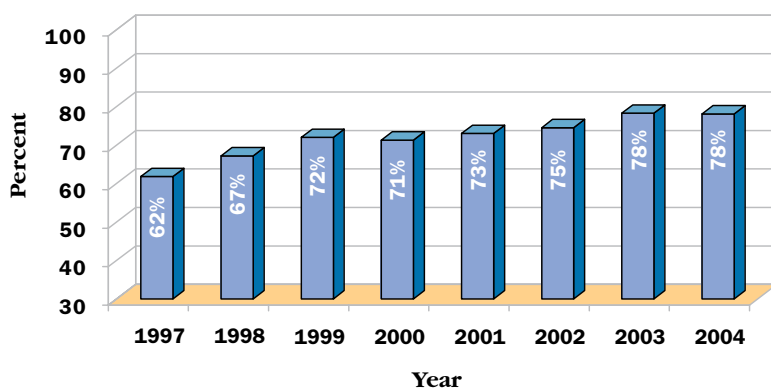
Network: Network Coordinating Council (Network 18)
Partners: All ESRD Networks
Award: \$350,000/year
Purpose: To support full utilization of local/regional resources and improved patient knowledge and outcomes by providing strategic partnership and coalition building expertise to the ESRD Networks and their renal community partners
Timeframe: January 2004–June 2006
Outcomes: The project was initiated in March 2005 with a training session conducted during the 2005 CMS/Forum of ESRD Networks' Annual Meeting. The Networks at regional coalition building sessions, which are facilitated by Tom Wolff, PhD have continued work begun at this session.

ESRD REGIONAL QUALITY IMPROVEMENT INITIATIVES

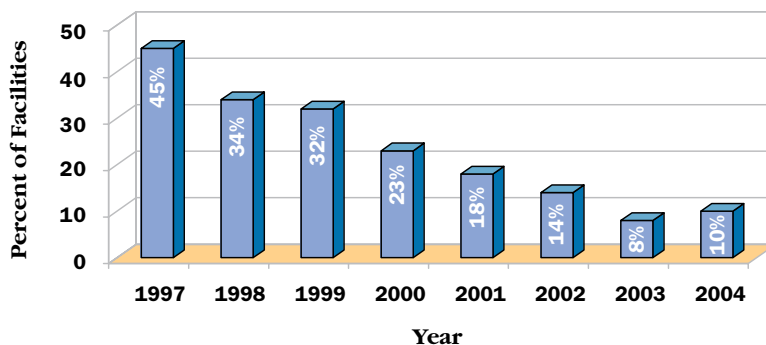
IMPROVING INFLUENZA IMMUNIZATION IN NETWORK 6

Network 6 has conducted a quality improvement project since 1997 to increase influenza immunization in ESRD patients. At the start of each influenza season, the Network sends each dialysis facility a packet of educational materials for patients and staff and a tracking tool to record patient immunizations. At the end of the season, the Network collects this information and sends each facility a comparative outcomes report. Facilities with high immunization rates are recognized at the Network annual meeting and the Medical Review Board contacts facilities with low immunization rates to help them improve. Through this QI project, the Network has successfully raised the mean facility immunization rate from 62% to 78% and reduced the percentage of facilities with less than 60% of their patients immunized from 45% to 10%. Network 6 and two other Networks have formed a coalition with community leaders and the CDC to expand this project to include hepatitis and pneumococcal immunizations and to extend it to all Networks.

**ESRD Network #6
Mean Vaccination Rate 1997–2004**



**ESRD Network #6
Percent of Facilities with 60% or Less Patients Vaccinated**

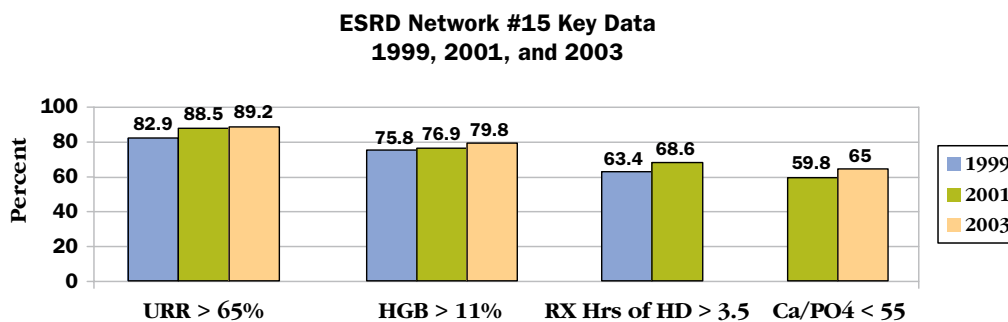


“Serving on the Network MRB has been a valuable professional experience, but also has provided me with an opportunity to give back to a program that has done so much to improve the quality of care for our dialysis patients.”

Jack Moore, MD, Chair
Network 5 Medical Review Board
Washington Hospital Center

“KEY DATA” PROJECT IN NETWORK 15

Network 15 conducted the annual “Key Data” project from 1999 through 2003. Facility-specific aggregate data were collected for the first calendar quarter of each year for a set of clinical indicators. These data were returned to each participating facility in the form of a feedback report which included not only the facility information, but comparison data for the state in which the facility was located, the Network and where available the US data, from the CPM results from the previous quarter. Over the course of this five-year period, the Network saw a continuous increase in the percent of patients achieving the goals for these indicators. The CPM project allows data comparison only at the Network level. Since Network 15 is a multi-state Network, the Key Data project allowed the Network to target opportunities for improvement and assist specific providers as needed.



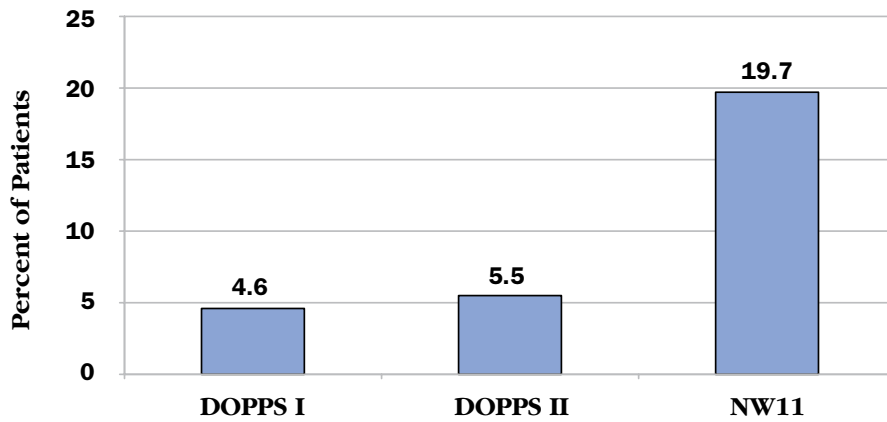
ADEQUACY OF DIALYSIS TO PERITONEAL PATIENTS IN NETWORK 5

Network 5 conducted a quality improvement project to improve the adequacy of dialysis provided to peritoneal patients in Network 5. Overall Network 5 results showed statistically significant improvement in measuring PD adequacy (84% baseline to 92% re-measurement), with a corresponding 51% reduction in failure rate (RFR). Improvement in reaching desired levels of adequacy was also statistically significant (55% baseline to 64% re-measurement), and a 21% RFR. Analysis by intervention group showed that mandatory intervention facilities improved more than the voluntary facilities in measuring adequacy and in reaching desired levels, and these differences were statistically significant. Further, facilities attending the workshop and developing an improvement plan improved more than facilities receiving only one intervention. All statistical significance was at the 0.05 level.

BONE DISEASE AND MINERAL METABOLISM IMPROVING CARE IN NETWORK 11

Bone disease and associated mineral metabolism abnormalities contribute to increased morbidity and mortality among dialysis patients. For over a decade, Network 11 has implemented several renal bone disease related quality improvement initiatives. In the last five years, clinically significant improvements have occurred in percentages of patients meeting recommended target goals in indicators including phosphorus, calcium, calcium-phosphorus product, and parathyroid hormone (PTH). Network 11 results in 2003 compare favorably to results reported by the Dialysis Outcomes Practice Patterns Study (DOPPS) I and II (1996-1999 and 2002 respectively). An article summarizing Network 11's work in improving bone disease management has been submitted for publication to the *American Journal of Kidney Diseases*.

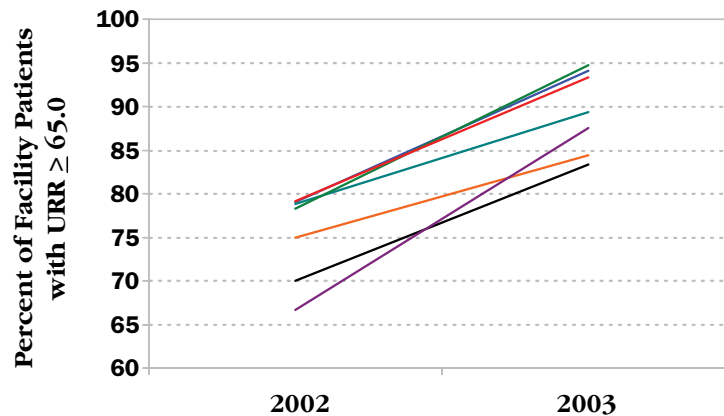
Percent of Patients Meeting 4 Targets
 (Phosphorus \leq 5.5 mg/dL, Calcium \leq 10.2 mg/dL,
 PTH 2–4 Times ULN, CaX P Product $<$ 55)



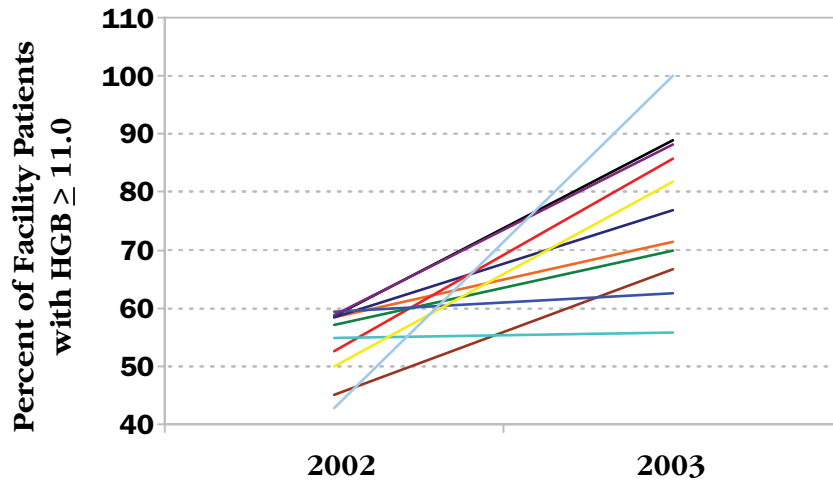
QUALITY OF CARE IN NETWORK 14

Utilizing comparative data, the Medical Review Board identified facilities as quality of care concern regarding Adequacy of Hemodialysis, Management of Anemia and Referral for Transplantation. Facilities received focused improvement efforts through quality improvement activities and monitoring by the Network and Medical Review Board. Below are results of targeted interventions in facilities over a one-year period.

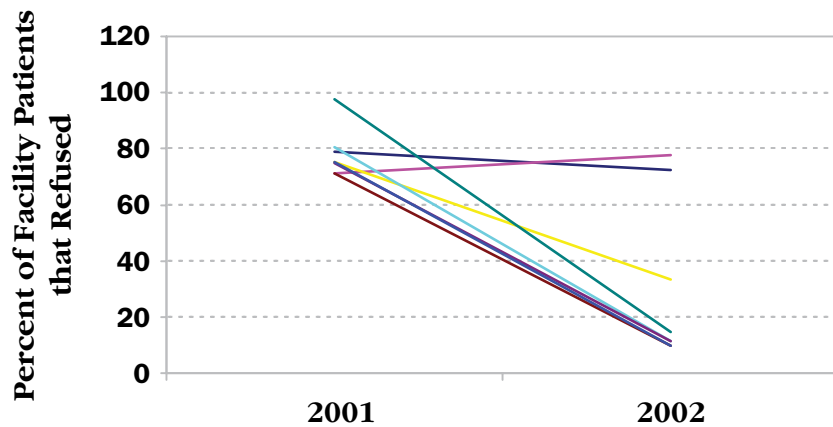
ESRD Network #14
Urea Reduction Ratio Changes in
MRB Facilities of Concern
N = 9



**ESRD Network #14
Hemoglobin Changes in
MRB Facilities of Concern
N = 11**



**ESRD Network #14
Percent Refusing Transplant 2001 Focus Facility
(Facility Average > 70% – 2001
N = 8
Mean Unstable 2001 = 78.3%
Mean Unstable 2002 = 30.2%**



Facilities received focused improvement efforts through quality improvement activities and monitoring by the Network and Medical Review Board.

GOAL TWO: IMPROVE DATA RELIABILITY, VALIDITY, AND REPORTING AMONG ESRD PROVIDERS/FACILITIES, NETWORKS, AND CMS (OR OTHER APPROPRIATE AGENCY)

ESRD Program – Network Accomplishments

- ~ Provided CMS with ESRD data management expertise for over 30 years with a focus on accuracy, timeliness, and validity
- ~ Maintained systems to identify any/all ESRD patient's location, status, treatment facility, and modality of treatment for any point in time
- ~ Processed 101,792 Medical Evidence forms, 69,426 Death notifications, 4,829 Annual Facility Surveys, 221,881 Patient events (changes in treatment type and location), 181,395 CPM forms, and 28,650 personnel and provider changes for a total of 609,973 forms in 2004
- ~ Maintained a real-time registry of over 400,000 ESRD patients in over 4,500 ESRD providers and sustained an accuracy rate of 90% or better for all forms
- ~ Collected, validated, and entered Clinical Performance Measure data that has supported quality improvement activities resulting in improved care for Medicare beneficiaries

Future Directions

- ~ Participate in the development of an information technology infrastructure to serve the quality agenda
- ~ Maintain the accuracy, efficiency, and timeliness of the existing ESRD provider and patient registry
- ~ Drive the Core Data Set implementation through consolidated, unreplicated, electronic data submission

Information management, including accurate data collection and reporting is an essential function of the Networks and serves two primary functions:

1. Establish a disease-specific surveillance system to provide descriptive demographics for national and regional ESRD populations and ensure a system for measuring facility accuracy and timeliness in data submission
2. Support quality improvement initiatives, CMS policy decisions, and research activities

Networks are the primary managers of ESRD data and use the CROWN (Consolidated Renal Operations in a Web Enabled Network) system to enter, validate, store, and report all information. This system is described in detail under Goal Four. The CROWN system provides a registry of all patients, including those who are not eligible or not applying for Medicare coverage and allows Networks to follow all ESRD patients from the point of incidence, through changes in modality and treatment centers to the point of discontinuation of treatment and/or death.

Data from the CROWN system forms the backbone for Network activities, allowing Networks to profile patterns of care, identify areas for improvement

The ESRD Networks pride themselves on the accuracy of data they maintain on ESRD patients. Through their efforts, CMS is able to maintain a very rich disease specific database.

Andy Hanks, MBBS
CROWN Program Manager, CSC

and identify patients and providers by numerous characteristics and outcomes. As noted elsewhere in this report, Network staff and MRBs use this information internally to conduct healthcare oversight and also supply this information to the providers for comparative feedback of their performance to others in the Network area. Several quality-oriented public domain reports have been developed using CROWN data, including the Dialysis Facility Compare (DFC) website, which uses CROWN data to allow beneficiaries to compare ESRD facilities; the Fistula First dashboard that reports current fistula rates for ESRD facilities; the Annual Clinical Performance Measures (CPM) Report, the annual Unit-Specific Reports and the United States Renal Data System (USRDS) Annual Data Report.

Networks perform rigorous data validations to ensure the data is accurate and useful. Since patients are followed through the continuum of their ESRD care, Networks must ensure that the sequence of events and demographic data is logical and complete. The CROWN system provides edit checks at the point of entry and Networks also run frequent utilities to identify and correct data anomalies. Data from the various CROWN components is also reconciled for consistency and providers receive reports at least quarterly showing the data reported so they can be sure all of the data submitted was properly recorded. Networks and providers conduct an intensive annual reconciliation of all demographic and patient tracking data, which is used for population trending.

The ESRD surveillance system is unparalleled in the community for its completeness and accuracy. The Networks play a key role in its success through commitment to and meticulous scrutiny of the data.

GOAL THREE: ESTABLISH AND IMPROVE PARTNERSHIPS, COALITIONS, AND COOPERATIVE ACTIVITIES. THESE ACTIVITIES MAY INCLUDE ESRD NETWORKS, QUALITY IMPROVEMENT ORGANIZATIONS (QIOs), STATE SURVEY AGENCIES, ESRD PROVIDERS/FACILITIES, MEDICARE ADVANTAGE ORGANIZATIONS, ESRD FACILITY OWNERS, NATIONAL AND/OR LOCAL RENAL RELATED PROFESSIONAL ORGANIZATIONS, AND PATIENT ORGANIZATIONS

ESRD Program – Network Accomplishments

- ~ Developed and facilitated special projects that address current issues in patient-centered care involving collaborative work with other ESRD-focused agencies and groups www.esrdnetworks.org/specialcontracts.htm
- ~ Used a collaborative model to develop, product, and disseminate over 5000 interactive toolkits addressing the reduction of patient-provider conflict www.esrdnetworks.org/dpc.htm
- ~ Partnered with state survey agencies (SSAs) and quality improvement organizations (QIOs) to assess and improve quality of care and to protect patients from harm
- ~ Addressed patient crisis situations such as natural disasters in a timely and efficient manner to assist both patients and the facilities that serve them
- ~ Established regional/local coalitions in each of the Networks www.esrdnetworks.org/spc.htm

Future Directions

- ~ Seek new partners to improve care throughout the CKD continuum
- ~ Expand disaster preparedness plans for emergency situations
- ~ Sustain the regional coalitions formed in each Network

Networks are actively involved with local services and organizations that come together to facilitate and support joint ventures that improve care or services for local renal patients. The partnering organizations may include renal groups, State Survey Agencies (SSAs), Quality Improvement Organizations (QIOs), pharmaceutical companies, and others. In 2005 the Networks also initiated a coalition building initiative facilitated by Tom Wolff, Ph.D. By the close of 2005, 17 of the ESRD Networks will have sponsored a regional coalition meeting to address a topic of importance in the Network area. Topics have included: Coalition for Organ & Tissue Donation, End of Life, Fistula First, Safe and Timely Immunization, Disaster Preparedness, Enhancing Patient Safety in the Dialysis Process (water processing), and Advance Health Care Directives.

VOCATIONAL REHABILITATION SERVICES

The Networks work with dialysis providers and others in the community to promote rehabilitation of all ESRD patients. The greatest emphasis is placed on vocational rehabilitation for patients age 18 to 54. At the end of 2003 there were 106,065 patients in this age group and 24% of them were working (full or part time) or attending school (full or part time). During the calendar year over 4,100 patients received services from vocational rehabilitation related providers (either public or private).

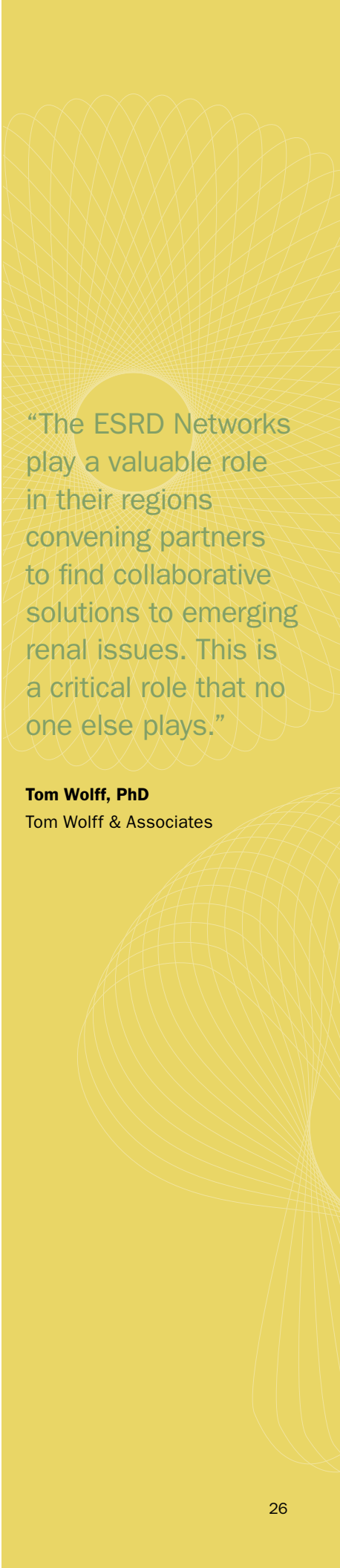
Networks encourage patient empowerment and independence and when possible the use of home dialysis and transplantation as the most suitable treatment modalities compatible with successful vocational rehabilitation. Networks share resources with the dialysis providers to promote these treatment options. They also encourage the dialysis providers to have treatment shifts starting after 5:00 pm to accommodate the working patient. The Networks also are a resource for vocational rehabilitation educational materials and referrals.

Networks assist and support the dialysis provider community in a number of ways. They recognize units with high vocational rehabilitation rates, conduct in-service training programs for social workers and others, work directly with rehabilitation agencies in their area, provide resources and links on their websites, and partner with Life Options, a non-profit research-based education and outreach organization devoted to helping people live long and live well with kidney disease.

HIGHLIGHT

ESRD NETWORKS' INTEGRAL ROLE IN NATURAL DISASTER PREPAREDNESS AND RECOVERY—HURRICANE SEASON 2005

Network leadership, teamwork in the renal community and commitment to care contributed to and ensured that kidney disease patients had access to life-sustaining dialysis treatments during times of distress and natural disaster along the East Coast of Florida and throughout the US Gulf Coast.



“The ESRD Networks play a valuable role in their regions convening partners to find collaborative solutions to emerging renal issues. This is a critical role that no one else plays.”

Tom Wolff, PhD

Tom Wolff & Associates

STORMS AND MORE STORMS- 4 HURRICANES WITHIN 45 DAYS IN FLORIDA IN 2004

Four hurricanes—Charley, Frances, Ivan and Jeanne—affected Florida in 2004, making it the only state since 1886 to sustain the impact of four hurricanes in one season. All four of these hurricanes made landfall in the state within 45 days of each other and resulted in large proportions of the dialysis community being unable to function normally. The severity of the 2004 Florida Hurricane Season and the effect it had on the Florida renal community was unexpected and unprecedented. Approximately 8,800 patients were displaced during this season and 165 facility closures occurred. At year end 2004 two facilities remained closed. Network 7 and the renal community came together to assure that dialysis patients received the care that they required.

HURRICANE KATRINA

On August 25, 2005, Hurricane Katrina crossed the southern tip of the Florida peninsula. Ten facilities were affected by power outages. Katrina caused minimum damage to Florida as a category 1 storm, but on August 29, 2005, a much stronger and dangerous Hurricane Katrina made landfall in Louisiana, Mississippi, and Alabama. Thousands of ESRD patients resided in and received dialysis (5849) and renal transplant care in the affected area. Also involved were 94 dialysis facilities- 9 in Alabama; 31 in Mississippi and 54 in Louisiana- that were closed at some point during the aftermath of the storm. As of November 2005, four facilities in Mississippi, 23 facilities in Louisiana, and one facility in Alabama remain closed and of those, two units in Mississippi tentatively have elected not to reopen due to extensive damage. The affected area covered three states that are served by two ESRD Networks. A third ESRD Network was heavily impacted by the tide of evacuees when over (600) ESRD patients evacuated (to Texas) immediately before and after the hurricane. Many arrived in the southeastern area of Texas called the “Golden Triangle” as well as east Texas and Houston.

HURRICANE RITA

Less than one month later, on September 24, 2005, before many of the Louisiana evacuees could return home, Hurricane Rita made landfall in the Sabine Pass of Texas affecting southeastern Texas and western Louisiana. Over 900 patients (including Katrina evacuees) in the “Golden Triangle” area and Galveston Island of Texas evacuated to East Texas, Houston, Dallas and other cities and states. Hundreds of the more than 5,000 dialysis patients in Houston also evacuated due to the threat of flooding. The largest influx was in the communities of East Texas. Patients from southwestern Louisiana, many of whom were Katrina evacuees, were forced to evacuate again. At the peak of displacement, 20 dialysis facilities were closed in south Texas although many quickly reopened. As of November 2005 one facility in Beaumont remains closed though all are expected to reopen.

HURRICANE WILMA

On October 24, 2005, Hurricane Wilma struck the west coast of Florida, making landfall around Naples and exiting the state near Fort Lauderdale. Wilma’s powerful winds knocked out power and water in the most populated areas of Florida. Almost 40% of Florida’s dialysis facilities (102) were rendered powerless, which affected the dialysis treatment of more than 7,300 ESRD patients. Some facilities were without utilities for as long as two weeks; however,

through the use of generators and by combining patients and staff at nearby units, the renal community was able to provide services to its patient population. Only one unit in Key West remains closed due to damage from Wilma. This facility has relocated temporarily to a hospital based in Marathon. There were no patient deaths reported due to inability to receive dialysis during and after this storm.

ESRD NETWORK RESPONSE

The activities and services of the Network(s) in response to these disasters revolved around tasks outlined in the CMS Statement of Work under which ESRD Networks are contracted.

Networks coordinated placement for transient dialysis including multiple relocations as evacuation routes and shelters changed; provided assistance with obtaining shelter in collaboration with other agencies, locating missing dialysis patients for providers and families, arranging or coordinating transportation and passing communications from displaced providers.

CMS and Networks held daily calls that allowed the renal providers, local and state officials, and FEMA to exchange information, identify problems, and develop solutions for impediments to the provision of ESRD services that ranged from transportation to housing for patients and staff, to assisting facilities find power and safe water. In addition, Medicare providers were given technical assistance in communicating with facilities receiving evacuees and providing patient demographic information from SIMS, CDC recommendations and guidelines, CMS communications, liaison with state and federal agencies, assistance with curfew and road block issues, coordinating transfer of supplies and identifying and prioritizing facilities in affected areas for FEMA services.

Disaster preparedness was done through the provision of fax broadcasts, conference calls and individual consultations that provided disaster information such as emergency diet, information on transient placement, contents of Emergency Packets and Public Service Announcements.

Direct interventions were made in organizing triage sites within evacuation shelters, recruiting volunteer professionals, supporting establishment of triage area, meeting with local and state officials to encourage special dialysis shelters and emphasizing the need for triage of dialysis patients.

Communications involved Emergency Operations Centers to coordinate and collaborate at city, county, state and national levels. Additionally Networks worked with State Agency in advising on special needs facilities, recommending needed services, and communicating issues of concern. Routine and emergency conference calls were facilitated to communicate vital information and emerging situations, establish support systems within the renal community and to establish new partnerships to meet diverse needs.

Information Management was conducted through the immediate establishment of a patient tracking system on the location of evacuees that involved the participation of the large dialysis organizations to receive and transmit events via the Quality Net Exchange system, the collection of event information from independent and regional provider groups and data entry of thousands of patient events nationally. Additional tracking involved identifying and following closed dialysis and transplant providers as well as coordinating reopening of facilities and repatriation of patients.

GOAL FOUR: SUPPORT THE MARKETING, DEPLOYMENT, AND MAINTENANCE OF CMS APPROVED SOFTWARE (E.G. CROWN – CONSOLIDATED RENAL OPERATIONS IN A WEB-ENABLED NETWORK)

ESRD Program – Network Accomplishments

- ~ Exceeded the 2005 contract requirement to train 40% of the eligible dialysis facilities on VISION
- ~ Exceeded the 2005 contract requirement to have 20% of the eligible dialysis facilities consistently report through VISION

Future Directions

- ~ Serve in an integral role as CMS transitions from the current CROWN system to a web-based application with content expertise, experience with users, and connection to end-users of the data
- ~ Continue to work with CMS to advance the electronic collection of ESRD data
- ~ Work with CMS to create a mechanism and process for developing a health information technology agenda to support quality and clinical performance
- ~ Assist facilities to comply with requirement to submit data in electronic format as anticipated in new Conditions for Coverage for ESRD Services

CMS has sponsored development of several ESRD data systems with companion functions. In 2002, they integrated these into the Consolidated Operations in a Web-enabled Network (CROWN) system which provides for the entry/import, validation, analysis and reporting of ESRD data.

This system has evolved through the life of ESRD Medicare program. The Secretary of the Department of Health, Education and Welfare established the Program Management and Medical Information Systems (PMMIS) in 1978 as a repository for ESRD information. This was accessed through an interactive tool, Renal Beneficiary and Utilization System (REBUS). Concurrently the thirty-two Networks developed local data systems to fulfill the program requirements, including forms entry and quality assurance and oversight. Each of these systems had similar components and provided a subset of the data to the PMMIS.

The Network systems continued to expand and evolve and in 1988 were merged or replaced when the Networks were consolidated. In 1988, HCFA (now CMS) developed the ESRD Data Entry and Editing Software (EDEES) to enter and transmit CMS-required forms and Networks built bridges between this and their existing systems.

In late 1990, both CMS and the Network recognized the need to standardize the collection and storage of ESRD data. The eighteen Networks and CMS formed workgroups to identify best practices in the existing systems and establish requirements for SIMS, the Standardized Information Management System. Networks voluntarily tested the system and converted their existing systems to SIMS in 2000 and EDEES was eliminated. Networks continue to use SIMS today to manage the ESRD registry.

CMS began development on the Vital Information Systems to Improve Outcomes in Nephrology (VISION) in 1999 to enable dialysis providers to enter and transmit their data electronically. The five largest dialysis organizations provide some electronic data directly to CMS for inclusion in CROWN. VISION is available to all other facilities and uses the Quality Net Exchange for secure data transport. The information is transmitted to the Network for validation and import into SIMS.

In 2002, CMS replaced the PMMIS/REBUS with the Renal Information Management System (REMIS) to provide easier access and increased functionality. Reliable linkages were built to the SIMS system, matching data based on the unique patient identification number. Also in 2002, CMS formed the CROWN system to connect all of these components, along with the Fistula First database, the lab results database and a Cognos-based reporting tool. Other systems which are not under the CMS direction but which depend on CROWN data include the United States Renal Data System (USRDS), the Social Security Administration (Master Beneficiary Record), the United Network for Organ Sharing (UNOS), and the Kidney Epidemiology and Cost Center (KECC).

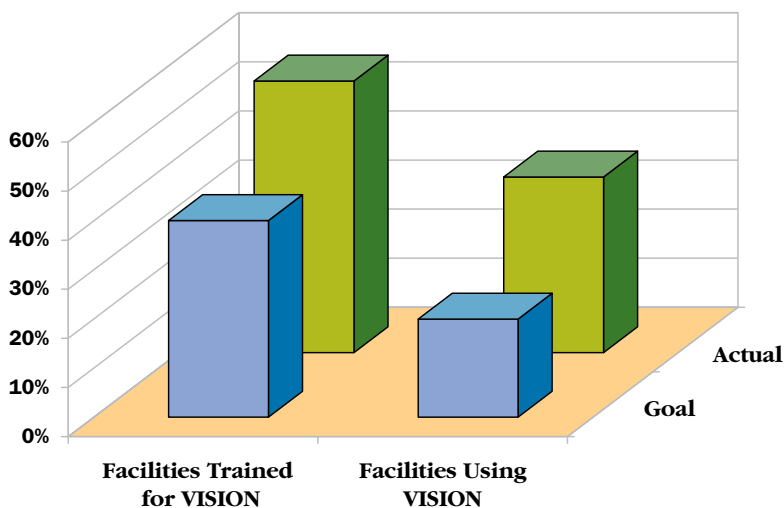
Networks are responsible for recruiting, training, and supporting the local VISION users. This involves conducting workshops, preparing seed databases from SIMS, and providing phone support. At the end of 2005, Networks had trained 665 of 1232 eligible dialysis facilities (54%) and 422 of those (34%) had begun to use the software and transmit forms. The goals established by CMS are 40% and 20% respectively.

The next evolution for the CROWN system is to combine all the existing systems into a web-based application shared by CMS, Networks and facility users with role-based access. The Networks look forward to participating in the design, testing, and implementation of this system.

CSC is extremely proud and excited to work with the ESRD Networks on the next phase of these ESRD Systems.

Andy Hanks, MBBS
CROWN Program Manager, CSC

2004–05 Network VISION Goals



GOAL FIVE: EVALUATE AND RESOLVE PATIENT GRIEVANCES AS CATEGORIZED IN CROWN AND OTHER AUTOMATED DATA PROCESSING (ADP) SYSTEMS AS DIRECTED BY CMS

ESRD Program – Network Accomplishments

- ~ Received and responded to patient and facility concerns and inquiries, including: 43 formal grievances; 1,220 complaints; 1,594 beneficiary inquiries; 1,762 facility concerns; 3,588 facility inquiries; and 1,863 other inquiries (total of 10,070) in 2005
- ~ Provided unbiased review of patient grievances and facilitated resolution by using patient preferences and other suggestions based upon interdisciplinary input (Medical Review Board) in an active and timely manner
- ~ Developed pertinent resources as well as developed and conducted specific, applicable training and in-service programs for dialysis professionals as well as patients based upon concerns, complaints, and grievances received by the Network
- ~ Provided immediate support and conflict resolution techniques to patients and staff who are experiencing challenging situations in the dialysis unit
- ~ Provided and taught conflict resolution skills through national roll-out of the Decreasing Dialysis Patient Provider Conflict resource kit to every dialysis provider in the country, with focused training for reinforcement

Future Directions

- ~ Trend and address involuntary patient discharges as reported on Patient Activity Report
- ~ Coordinate with state survey agencies to ensure patient complaints and grievances are accurately monitored
- ~ Integrate with the Medicare Ombudsman Program
- ~ Identify and address barriers to outpatient dialysis placement
- ~ Develop and conduct educational training on working with difficult patients

Networks are responsible for evaluating and resolving patient grievances. Each Network has a formal grievance resolution protocol which is approved by CMS. A beneficiary grievance is a request for a formal investigation of a complaint, or a serious complaint involving a facility, physician, or other provider. The formal grievance process requires the Network to conduct a complete review of the information and an evaluation of the grievance, which may require the involvement of a Grievance Committee and/or the Medical Review Board. During 2004, Networks processed 45 formal beneficiary grievances in comparison to 40 in 2003. It is estimated that ESRD Networks process over 7,000 patient concerns/complaints annually. Less than 1% of patients filed a formal grievance at the Network level, indicating that the Networks effectively respond to complaints before they become formal grievances.

PATIENT OUTREACH

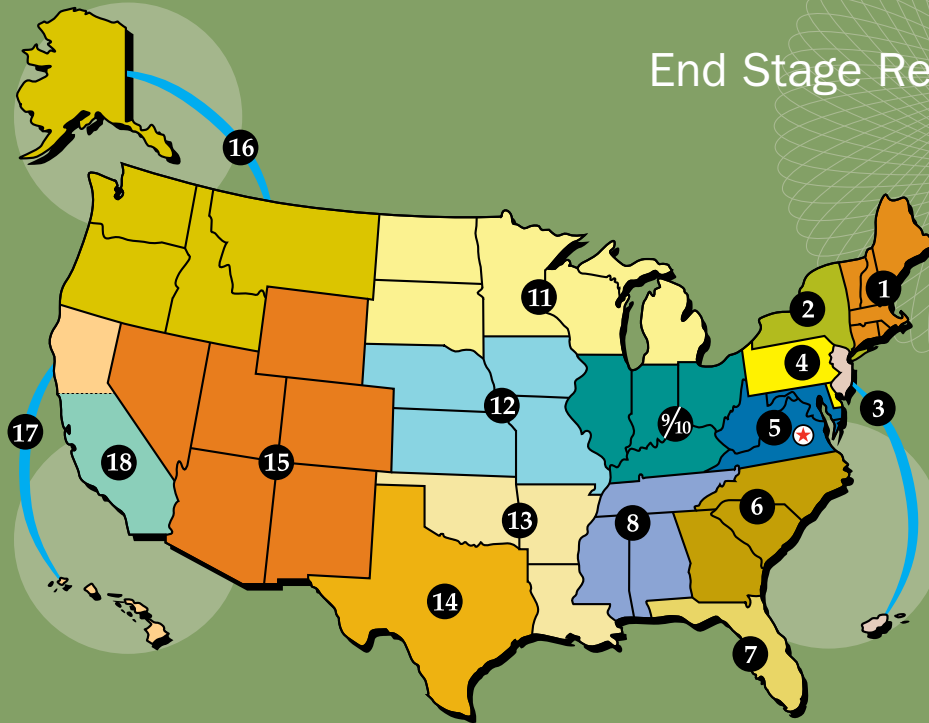
As health oversight agencies, ESRD Networks work to assure that ESRD patients receive safe, effective, timely, and equitable care. Special patient-centered projects include the following:

- ~ New ESRD Patient Orientation Packets – All ESRD Networks through the Forum Office work together to send patient educational materials to newly diagnosed ESRD patients. In Year 5 of the project (10/1/04–9/30/05) 97,287 packets were sent to new patients.
- ~ Decreasing Dialysis Patient-Provider Conflict – ESRD Networks, dialysis providers, renal organizations, and CMS collaborated to launch a multi-faceted project to address and better manage conflict in dialysis facilities.
- ~ Involuntary patient discharge project – Twelve Networks participated in a project to collect data on the number of patients involuntarily discharged from a dialysis facility and the reasons for discharge.
- ~ Patient Advisory Committees – Networks have Patient Advisory Committees to address consumer issues on a regional level. Work products include patient newsletters, rehabilitation projects, and patient education materials.
- ~ Fistula First Focus – Many Networks have developed materials to explain the advantages of an arteriovenous fistula to patients. These educational materials include videos, posters, and brochures.

FOR MORE INFORMATION:

You can learn more about the ESRD Networks by visiting www.esrdnetworks.org.

End Stage Renal Disease Networks



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