2005

SUMMARY REPORT

of the
End Stage Renal Disease (ESRD) Networks'
Annual Reports



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SUMMARY REPORT of the End Stage Renal Disease (ESRD) Networks' Annual Reports

2005

ESRD Networks are required by contract with the Centers for Medicare & Medicaid Services (CMS) to submit an Annual Report covering their activities during each calendar year. This Report summarizes those Annual Reports and is submitted to CMS as a contract deliverable by the Network Coordinating Center sub-contract to the Forum of ESRD Networks. This document covers the time period of January 1, 2005, through December 31, 2005.

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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 Network Organizations (authorization: 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 the 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 the Centers for Medicare & Medicaid Services (CMS) has awarded three-year or one-base year with two option-year contracts to the Networks.

Today, the 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 patient 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 ESRD Networks in promoting methods to improve the quality of care to patients with renal disease. Each of the Networks' websites may be accessed from the Forum of ESRD Networks' website: http://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

The Networks serve as liaisons between CMS and ESRD providers, and also between providers and the patients with ESRD under their care. CMS, providers, and patients all have a vested interest in achieving optimal treatment, and the Networks serve as a vital link in the quality chain. Network organizations accomplish their quality mission by:

- 1. Collecting and validating data
- 2. Distributing data feedback reports for facilities to use in improving care
- 3. Conducting quality improvement activities focused on specific areas of care
- 4. Providing professional educational materials and workshops for facility staff
- 5. Providing patient education materials and workshops to facilities and directly to patients
- 6. Offering technical assistance to dialysis and transplant facilities
- 7. Evaluating and resolving patient grievances

Networks are to 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) in the following areas:
 - o Anemia Management Percent of patients with mean hemoglobin ≥ 11 g/dL improved to 83% (2004)
 - o Adequacy of Dialysis Percent of patients with single session, single pool Kt/V ≥ 1.2 improved to 91% (2004)
 - Vascular Access (FistulaFirst) Percent of prevalent patients dialyzing with an AV fistula improved from 32.4% (2002) to 39 % (2005)
- The collection, monitoring, and improvement of clinical performance measures (CPMs). The data from 2004 (2005 CPM Report) documents the following:
 - o 87% of patients received adequate hemodialysis (defined as $URR \ge 65\%$), representing an increase of 44% since 1994
 - o 89% of blacks (53% increase since 1994) and 91% of whites (44% increase since 1994) received adequate hemodialysis
 - o In 2004, the proportion of patients with a three-month mean hemoglobin > 11, was 83%, compared to 59% in 1998.
 - o 6% of blacks and 5% of whites were severely anemic (hemoglobin <10%), representing decreases since 1994
- Conducting other quality improvement activities and information collection activities, as approved by CMS

GOAL TWO: Improve data reliability, validity, and reporting among ESRD providers/facilities, Networks, and CMS (or other appropriate agency)

The information tracked within Network databases is collected from the ESRD provider through the Medical Evidence Report Form (CMS 2728), the Death Notification Form (CMS 2746), patient event tracking forms, and facility rosters. The majority of this information is collected via paper form. Some data is submitted electronically by corporate offices that own dialysis centers and some is submitted electronically through VISION software. In 2005, Networks processed 115,371 Medical Evidence forms, 78,517 Death Notification forms, 4,946 Annual Facility Survey forms, 489,477 (double over last year) Patient events (changes in treatment type and location), 8,904 CPM forms, and 21,896 personnel and provider changes.

Each of the 18 Networks use the Standardized Information Management System (SIMS) to manage the data collected. This system allows for the entry, storage and reporting of information and connects to a central repository of the data which CMS can access. The central repository links directly to the Renal Management Information System (REMIS), which is then linked to Medicare's Enrollment Data Base (EDB). This system allows Networks to track patients through the continuum of care and keep accurate records of patients. Patient grievance calls and facility staff information are not stored on the repository and are only accessible to the Network that entered them.

GOAL THREE: Establish and improve partnerships, coalitions, and cooperative activities. Footer section 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

The ESRD Networks are actively involved with both quality-related and renal-related organizations to facilitate cooperation and joint ventures. Each Network creates unique partnerships with organizations to help provide better care for the ESRD patient population, including renal groups, professional organizations, dialysis corporations, and pharmaceutical companies.

The 2005 CMS/Forum of ESRD Networks' Annual Meeting "Strategic Partnership for Change" drew representatives from CMS, Networks (data, quality, patient services, executive staff, and Network Medical Review Board Chairs), as well as renal community members to discuss issues impacting the ESRD Networks. Other activities in 2005 included the interactive partnerships with renal community members such as National Kidney Foundation (NKF), American Association of Kidney Patients (AAKP), Rena Physicians Association (RPA), The Medical Education Institute, Inc. (MEI), and large dialysis organizations; the updating of the New Patient Orientation Packet materials for Year Six of the project; and the distribution of the final report of the Decreasing Dialysis Patient-Provider Conflict (DPC) project.

Support the marketing, deployment, and maintenance of CMS approved **GOAL FOUR:** Software (e.g. CROWN - Consolidated Renal Operations in a Web-Enabled Network)

CMS has sponsored development of several ESRD data systems with companion functions. In 2002, they consolidated these into the Consolidated Renal Operations in a Web Enabled Network (CROWN) system.

The purpose of the CROWN system is to enable the entry/import, validation, analysis, and reporting of ESRD data. The key components of the system, which are under the guidance of CMS, are SIMS (Standard Information Management System), VISION (Vital Information System to Improve Outcomes in Nephrology), REMIS (Renal Management Information System), and Quality Net Exchange. Other systems which are not under CMS but which link to the CROWN system include the USRDS (United States Renal Data System) and UNOS (United Network for Organ Sharing). The Kidney Epidemiology and Cost Center receives data from the CROWN system to produce the annual Unit-Specific Report and the clinical data for Dialysis Facility Compare (DFC). The facility demographic data comes directly from the CROWN system.

The data collected and managed through the CROWN system serves multiple functions and has many users. CMS is a primary user of the data. One important purpose is determining Medicare benefits eligibility for ESRD patients, from the initial certification of ESRD until the patient dies or is no longer eligible for benefits (e.g. when patient has been transplanted successfully for more than three years). The CROWN system provides a registry of all patients, including those who are not eligible or not applying for Medicare coverage. This data supports program analysis, policy development and epidemiological research by CMS, the Networks, researchers, and health planners.

GOAL FIVE: Evaluate and resolve patient grievances as categorized in CROWN and other Automated Data Processing (ADP) systems as directed by CMS

The Networks assume a proactive role in the prevention, facilitation, and resolution of complaints and grievances, including implementing educational programs that will assist facility staff in diffusing conflict and handling difficult situations. Networks also conduct trend analysis of reported situations to detect patterns of greater concern. Networks follow the CMS national policy in the ESRD Network Organizations Manual, for evaluating, resolving, and reporting patient grievances and facility concerns. Within 24 hours of receipt, Networks refer immediate and serious grievances to the appropriate CMS Regional Office and State Survey Agency. On request from CMS, Networks assist the State Survey Agency with the investigation of a complaint.

Each Network has a formal grievance resolution protocol, which is approved by CMS. A formal beneficiary grievance is a complaint alleging that ESRD services did not meet professional levels of care. 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 2005, Networks processed 43 formal beneficiary grievances in comparison to 45 in 2004 (Table 19). It is estimated that ESRD Networks process over 7,000 patient complaints annually. Less than 1% of patients file a formal grievance at the Network level.

SUMMARY REPORT of the END STAGE RENAL DISEASE (ESRD) NETWORKS' ANNUAL REPORTS

INTRODUCTION

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 Network Organizations (authorization: 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 the Network Organizations responsibilities.

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Today, the 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 patient 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 (The Forum), a national organization which supports ESRD Networks in promoting methods to improve the quality of care to patients with renal disease.

This Report, which summarizes the Annual Reports submitted by these 18 Network organizations for calendar year 2005, is prepared under NCC contract 500-02-NW18CH. Internet addresses are provided for additional information about the ESRD Networks and the ESRD program. All Network websites can be accessed through the home page of the Forum Office, www.esrdnetworks.org.

ESRD POPULATION & CHARACTERISTICS

Although the ESRD population is less than 1% of the entire U.S. population, it continues to increase at a rate of 1% 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. California (Networks 17 and 18) had the largest state population and had the largest population on dialysis. At the end of 2005 there were 333,064 patients being dialyzed and 106,367 were new (incident) ESRD patients. (Appendix A). The following table portrays the ESRD incident patient rates per million population by Network.

TABLE 1 ESRD INCIDENT PATIENT RATES PER MILLION POPULATION BY NETWORK **CALENDAR YEAR 2005**

NETWORK	INITIATED ESRD THERAPY	GENERAL POPULATION	INCIDENCE RATE PER MILLION POPULATION
1	3,867	14,239,724	272
2	7,033	19,254,630	365
3	4,732	12,738,584	371
4	5,261	13,273,140	396
5	6,465	15,535,230	416
6	8,749	22,010,901	397
7	6,637	17,789,864	373
8	5,697	13,441,855	424
9	8,409	21,909,420	384
10	4,617	12,763,371	362
11	7,536	22,202,470	339
12	4,097	13,270,118	309
13	4,372	10,850,666	403
14	8,355	22,859,968	365
15	4,734	17,926,539	264
16	2,955	12,957,242	228
17/18 *	12,851	37,718,613	341
TOTAL	106,367	300,742,335**	6,134

Source: Networks 1-18 Annual Reports, 2005

^{*}Networks 17 and 18 have been combined to incorporate the state of California. Hawaii and American territories are included.

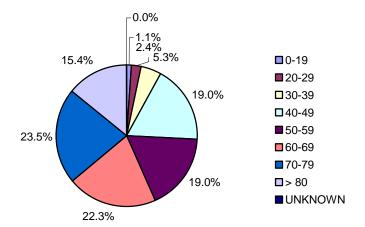
^{**} General Population numbers are taken from the July 2005 US Census Bureau estimates and includes all U.S. territories and Puerto Rico.

AGE

The age distribution for the ESRD incident population is described in Appendix B. In 2005 45.8% of incident ESRD patients were between the ages of 60 and 79 and the pediatric population remained relatively small with 1.1% of the ESRD incident population under 20 years old. These distributions have remained constant over the past five years and in 2005.

The age distribution of the dialysis prevalent population is described in Appendix C.

GRAPH 1 2005 ESRD Incident Patients by Age Calendar Year 2005



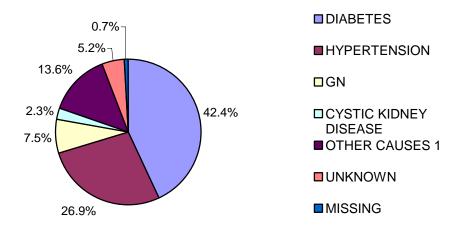
RACE

While the majority of dialysis patients are White, ESRD rates among Blacks and Native Americans are disproportionately high. While Black Americans comprise nearly 12.3% of the national population, they make up 27.3% of the total dialysis prevalent population. Network 6 has the largest population of Black patients and Network 15 is home to the largest number of Native American patients. Appendices D and E present tables comparing the incident and prevalent populations by race and Network.

DIAGNOSIS

A list of primary causes for ESRD can be found in Appendix F. The leading cause of renal failure in the United States is diabetes. Graph 2, below, portrays the breakdown of incident dialysis patients by primary diagnosis.

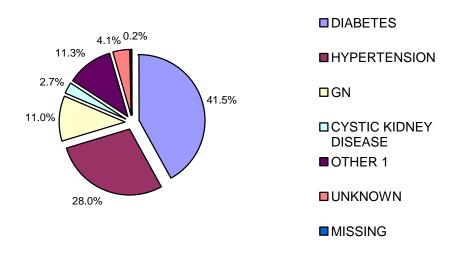
GRAPH 2
2005 ESRD Incident Dialysis patients by Primary Diagnosis
Calendar Year 2005



Appendices G and H describe dialysis patients by primary diagnosis and Network. Given the diverse patient populations seen within each geographic region it is surprising that there is little variation among the Network populations with respect to the diagnosis of their prevalent populations. All Networks reported diabetes as the primary cause of renal failure in 2005. Network 15, with 52.04%, had the highest percentage of prevalent patients with this primary diagnosis. Network 8 had the highest percentage of patients with hypertension, with 35.04%.

A primary diagnosis of diabetes represented 41.5% of the prevalent dialysis patient population in 2005. Hypertension followed with 28%, glomerulonephritis with 11%, and other causes accounted for 11.3% of the dialysis population. Cystic kidney disease accounted for 2.7% of the dialysis patient population. 4.1% of patients had an unknown primary cause. The percentage of patients with a primary diagnosis of diabetes remained relatively constant from 2004 to 2005.

GRAPH 3
Prevalent Dialysis Patients by Primary Diagnosis
December 2005



GENDER

In 2005, males represented over half of the ESRD incident (53.4%) and prevalent (52.4%) populations. All Networks reported a higher ratio of males to females on dialysis (Appendices I and J).

TREATMENT MODALITY

Today, ESRD patients have a variety of choices for outpatient renal replacement therapy that include 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. Appendices K and L display the number of dialysis patients in each Network by modality.

In-Center hemodialysis is the most predominate modality (Appendix M). The number of patients undergoing continuous cycling peritoneal dialysis (CCPD) in a self-care setting decreased 1% between 2004 and 2005, and the number of continuous ambulatory peritoneal dialysis (CAPD) patients decreased 4% between 2004 and 2005 (Appendix N).

Table 2 lists Medicare Approved ESRD Providers by Type of Service and Network. There were 248 transplant centers within the United States in 2005. Network 14 has the highest number of transplant facilities, with 24, followed by Network 11, with 21. Network 3 has the fewest transplant facilities, with 6. As expected based on patient populations, Network 6 has the largest number of dialysis providers (463) and Network 16 has the smallest number of providers (126).

TABLE 2 ESRD PROVIDERS BY TYPE OF SERVICE AND NETWORK AS OF DECEMBER 31, 2005

NETWORK	DIALYSIS	TRANSPLANT	HOSPITAL	INDEPENDENT	STATIONS
1	154	15	53	101	2,763
2	229	15	97	132	4,246
3	150	6	46	104	2,812
4	237	16	23	214	4,209
5	276	14	50	226	4,838
6	463	10	42	421	9,232
7	275	9	8	267	5,090
8	292	13	7	285	5,353
9	348	14	39	309	5,868
10	175	8	23	152	2,879
11	351	21	105	246	5,134
12	235	17	29	206	3,541
13	265	16	13	252	4,288
14	371	24	19	352	7,902
15	227	15	33	194	3,684
16	126	8	24	102	1,980
17	171	9	30	141	3,162
18	252	18	21	231	5,162
TOTAL	4,597	248	662	3,935	82,143

Source: CSC

Hospital and Independent counts are included in the Total Dialysis Count.

Note: Detail does not add to total because most transplant centers also provide dialysis services and are counted again as Dialysis Providers.

Appendix O lists the number of renal transplant recipients by donor source and Network. According to the annual facility surveys conducted by the Networks:

- 17,296 transplants were performed within the United States during 2005.
- Of these transplants, 10,826 were from deceased donors while 3,746 were from living related donors and 2,724 from living non-related donors.
- Deceased donors represent 62.6% of transplants performed.
- The percent of living related and living unrelated donor transplants have increased in recent years and in 2005 represented 37.4% of all transplants performed.

The transplant centers in Network 11 performed 1,802 transplants in 2005, the largest number of transplants among the Networks. Network 11 also had the largest number of transplants by living related

^{*} Puerto Rico and Virgin Islands are part of Network 3.

^{**} Hawaii, Guam, Saipan, and American Samoa are part of Network 17.

donor, 574, and the largest number of transplants by a living unrelated donor with 325. Network 3 had the fewest total number of transplants with 544 occurring.

A large number of patients are on waiting lists for kidney transplants. According to the United Network for Organ Sharing (UNOS), as of December 31, 2005, there were 68,980 potential kidney recipients on the Organ Procurement and Transplantation Network (OPTN) national patient waiting list (Source: United Network for Organ Sharing).

NETWORK DESCRIPTION

The ESRD Network program began in 1977 when the Department of Health and Human Services (formerly the Department of Health, Education and Welfare) published the final regulations establishing 32 Network Coordinating Councils to administer the newly funded program. With only 40,000 dialysis patients receiving care in 600 facilities, the Networks' responsibilities focused on program administration, health planning tasks, and medical review activities.

By December 31, 1987, the ESRD program encompassed 98,432 patients and 1,701 facilities administering renal replacement therapy. At this time, Congress consolidated the 32 Networks into 18, redistributing and increasing their geographical areas as well as their program responsibilities. Funding mechanisms changed when Congress mandated that \$ 0.50 from the composite rate payment from each dialysis treatment be withheld and allocated to fund the ESRD Network program. In 1988 CMS began formal contracting with the ESRD Networks to meet their legislative responsibilities. These contracts placed greater emphasis on quality improvement activities and standardized approaches to quality assessment and data analysis; health-planning functions were reduced.

In 2005, the ESRD program encompassed 333,055 patients and 4,843 ESRD providers. The Networks now operate on a three-year Statement of Work (SOW) cycle with one base year and two option years. The 2003 - 2006 SOW was implemented in July 2003. At the time of the contract renewal, CMS provided an updated ESRD Network Organization Manual that provided background and articulated responsibilities of the Networks as well as modifications to some requirements of the ESRD Network program. This manual provides additional direction for contract responsibilities.

As specified in the Statement of Work, each Network is responsible for conducting activities in the following areas:

- 1. Quality Improvement
- 2. Community Information and Resources
- 3. Administration
- 4. Information Management
- 5. Special Studies

CMS contracts require each Network, at a minimum, to have the following staff: an Executive Director/Project Director, a Quality Improvement Director/Quality Improvement Coordinator, an individual responsible for data related activities (i.e. Data Manager), sufficient support staff (including a registered nurse with nephrology experience), and a full time Patient Services Coordinator with a Masters in Social Work or equivalent qualifications. The role of the Executive Director is to manage and coordinate the activities of the Network. The Quality Improvement Director coordinates quality-related requirements and creates and implements quality improvement projects. The role of the Data Manager is the collection, accurate recording and secure, complete transmission of data between the facilities, the Network, and CMS. The Patient Services Coordinator is responsible for assisting patients and their families with questions and information requests, resolving patient and/or facility complaints and

grievances and conducting educational training on managing difficult patients and conflict resolution upon request.

These positions are supported by other positions, the deployment of which varies by Network. Though these positions vary from Network to Network, additional staff in the areas of quality improvement, data, and patient services are essential for the coordination of the many Network activities. Table 3 shows the Network staff by function and full-time equivalence (FTE).

TABLE 3 NETWORK STAFF BY FUNCTION AND FTE AS OF DECEMBER 31, 2005

NETWORK	DIALYSIS PREVALENT POPULATION	ESRD PROVIDER*	ADMINISTRATIVE	QUALITY IMPROVEMENT	DATA	PATIENT SERVICES	
1	11,109	168	2.10	3.36	3.36	1.68	10.50
2	22,769	244	2.50	2.00	4.00	1.00	9.50
3	13,875	155	1.50	3.50	2.50	1.00	8.50
4	14,639	245	3.00	3.00	4.00	1.00	11.00
5	19,883	290	4.00	3.00	3.00	1.00	11.00
6	31,544	473	1.30	4.90	4.40	3.40	14.00
7	19,254	286	2.00	2.50	3.00	1.50	9.00
8	18,686	305	2.40	3.10	3.90	1.00	10.40
9/10	38,143	546	4.00	4.00	6.50	4.00	18.50
11	20,793	372	1.00	4.50	5.30	1.20	12.00
12	12,456	252	3.00	2.00	3.00	1.00	9.00
13	12,923	280	1.70	4.00	2.80	2.50	11.00
14	29,371	401	2.50	3.50	3.50	2.00	11.50
15	15,042	242	3.00	2.50	2.50	1.00	9.00
16	8,874	134	1.70	1.50	2.85	1.15	7.20
17	17,353	180	2.00	2.60	3.00	1.20	8.80
18	26,341	269	2.70	2.70	3.70	1.70	10.80
TOTAL	333,055	4,842	40.40	52.66	61.31	27.33	181.70

Source: Networks 1-18 Annual Reports, 2005, with clarification from Network Executive Directors * Dialysis only

As seen in Table 3, Networks operate with a relatively small number of staff for the size of the ESRD patient population served. 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. The staffing pattern is similar across the Networks, with respect to the number of staff assigned to the various functional categories, however there are still regional variations.

The majority of the ESRD Networks are non-profit organizations with governing boards (Boards of Directors) that are responsible for their business and contractual obligations. They have Medical Review Boards with responsibility for quality improvement and oversight initiatives in their geographic region. Both Boards meet statutory requirements with respect to composition and adhere to strict conflict of interest guidelines. 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. Consumers are represented on these Boards and most Networks rely upon Patient Advisory Committees to increase patient involvement. 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 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 2005 Board 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 generous 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.

Each Network is required by contract to specify appropriate roles and functions for its committees. Each Network is required to have the following:

- **Network Council:** A body comprised of renal providers in the Network area that is representative of the geography and the types of providers/facilities in the entire Network area. The Council also includes at least one patient representative. The Network Council serves as a liaison between the provider membership and the Network.
- **Board of Directors (BOD):** A body comprised of representatives from the Network area, including at least one patient representative. The BOD (or Executive Committee) supervises the performance of the Network's administrative staff in meeting contract requirements and maintaining the financial viability of the Network.
- Medical Review Board (MRB): A body comprised of representatives of each of the professional disciplines (physician, registered nurse, social worker, and dietitian) and at least one patient representative that is engaged in treatment related to ESRD and qualified to evaluate the quality and appropriateness of care delivered to ESRD patients.
- **Any other committees** (or subcommittees) necessary to satisfy requirements of the SOW. These committees are designated by the Network and/or BOD and may include, but are not limited to, patient advisory, grievance, organ procurement, transplant, finance, and rehabilitation.

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.

CMS NATIONAL GOALS AND NETWORK ACTIVITIES

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.

GOAL ONE: Improve the quality of health care services and quality of life for ESRD

beneficiaries

GOAL TWO: Improve data reliability, validity, and reporting among ESRD

providers/facilities, Networks, and CMS (or other appropriate agency)

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

GOAL FOUR: Support the marketing, deployment, and maintenance of CMS approved

Software (e.g. CROWN - Consolidated Renal Operations in a Web-

Enabled Network)

GOAL FIVE: Evaluate and resolve patient grievances as categorized in CROWN and

other Automated Data Processing (ADP) systems as directed by CMS

These goals and how the Networks accomplished them are discussed in this Summary of Annual Reports which is a compilation based on the eighteen ESRD Networks' annual reports. Each ESRD Network's annual report includes:

- 1. Network's goals, and activities conducted to meet Network goals
- 2. Data on the comparative performance of facilities with respect to patients in self-care settings, transplantation, and vocational rehabilitation programs
- 3. Identification of facilities that have failed to cooperate with Network goals
- 4. Recommendations for additional or alternative ESRD services or facilities in the Network area

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

The Centers for Medicare & Medicaid Services (CMS) contract with the 18 ESRD Networks to design and administer quality improvement/assessment programs. The structure and composition of the Networks place them in a unique position to accomplish this purpose. The Networks are not-for-profit organizations, led by volunteer boards and committees comprised of nephrology patients and professionals. The Social Security Act and Regulation outlines the broad expectations for Networks and CMS following regulation specifies projects and tasks in the ESRD Network Statement of Work (SOW). The geographic distribution of the 18 Networks allows each to design projects most appropriate for the population served. The Networks can adapt projects for the different cultural and clinical needs of the area and take advantage of local resources to advance the project. Networks must determine which projects can have the broadest impact on improving quality of care. Networks share project ideas with one another so successful projects can be duplicated, and at times where warranted conduct projects nationally with each of the 18 Networks participating.

The Networks serve as liaisons between CMS and ESRD providers, and also between providers and the ESRD patients under their care. CMS, providers, and patients all have a vested interest in achieving optimal treatment, and the Networks serve as a vital link in the quality chain. Network organizations accomplish their quality mission by:

- 1. Collecting and validating data
- 2. Distributing data feedback reports for facilities to use in improving care
- 3. Conducting quality improvement activities focused on specific areas of care
- 4. Providing professional educational materials and workshops for facility staff
- 5. Providing patient educational materials and workshops to facilities and directly to patients
- 6. Offering technical assistance to dialysis and transplant facilities
- 7. Evaluating and resolving patient grievances

COLLECT AND VALIDATE DATA

ESRD Networks routinely collect, validate, and report patient-specific and facility-specific data for many uses. Data collected by the Networks provide CMS and other agencies with information for operational activities and policy decisions. Networks also supply data and/or support to the United States Renal Data System (USRDS) and to other CMS-approved research organizations. Data collected by the Networks are used to report on trends to the renal community and beyond. Examples of data collected by the Networks are listed in Table 4 below.

TABLE 4 DATA COLLECTED BY NETWORKS AS REQUIRED BY CONTRACT 2005

Standard CMS Forms	CMS - 2728: Medical Evidence CMS - 2746: Death Notification CMS - 2744: Annual Facility Survey	Demographics and clinical eligibility data for all new ESRD patients Date and cause of death Reconciliation of patient activity
Minimum Data Set (No Standard Forms)	Non-Clinical Patient Events Facility Characteristics and Staff	Allows Networks to place patient on any given day by treatment center and type of modality Size, ownership, staffing
Standard CMS Clinical Performance Measures	CMS - 820: In-Center Hemodialysis CPM Data Collection Form 2005 CMS - 821: Peritoneal Dialysis CPM Data Collection Form 2005	Clinical performance forms collected once per year on a sample of patients in each Network

ESRD Networks also use data in their individual quality improvement projects. Quality improvement data and identifiable data collected for Network quality improvement activities are protected from release to the public.

National ESRD Clinical Performance Measures (CPM) 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:

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

For each project year, CMS and/or its contractor selects a random sample of adult patients (≥ 18 years) who were alive and on dialysis as of December 31st of the previous year. Facility staff completes forms on selected patients and submits them to the Networks, which reviews the forms, clarifies questionable entries, inputs the data into the Network database using the Standard Information Management System (SIMS), and transmits the data to the CMS contractor. CMS and/or its contractor also selects a random five percent sample of forms from the hemodialysis and the peritoneal dialysis samples for the reliability study. Network staff re-abstract data for cases in the reliability sample (either on-site or via mailed medical record copies), enter the data, and transmit it to the CMS contractor.

This Project provides national (and Network-specific for the adult hemodialysis sample) rates based on the intermediate outcomes in the four areas of dialytic care. CMS uses these data to improve the quality of care being delivered to Medicare beneficiaries and to determine the effectiveness of the Network program's quality improvement efforts. Networks use the ESRD CPM Annual Report, in combination with other feedback reports, to select areas for quality improvement/assessment projects and activities. Since the sample is insufficient to provide facility-specific reporting, many Networks collect data on a broader sample in order to produce facility-specific rates on outcome measures. Methods used for this include:

- 100% of patients from 100% of facilities
- Sample of patients from 100% of facilities
- Aggregate facility data from 100% of facilities

The project cycles of ESRD CPM Project activities is clarified in the table below.

TABLE 5
ESRD CPM PROJECT CYCLES

Project Year	HD Data From	PD Data From	Data Collected	Report Issued
Year 1	Oct-Nov-Dec 93		Summer 1994	December 1994
Year 2	Oct-Nov-Dec 94	Nov 94 -Apr 95	Summer 1995	January 1996
Year 3	Oct-Nov-Dec 95	Nov 95 - Apr 96	Summer 1996	January 1997
Year 4	Oct-Nov-Dec 96	Nov 96 - Apr 97	Summer 1997	December 1997
Year 5	Oct-Nov-Dec 97	Nov 97 - Apr 98	Summer 1998	Spring 1999
Year 6	Oct-Nov-Dec 98	Oct 98 - Mar 99	Summer 1999	Spring 2000
Year 7	Oct-Nov-Dec 99	Oct 99 - Mar 00	Summer 2000	December 2000
Year 8	Oct-Nov-Dec 00	Oct 00 - Mar 01	Summer 2001	December 2001
Year 9	Oct-Nov-Dec 01	Oct 01 - Mar 02	Summer 2002	December 2002
Year 10	Oct-Nov-Dec 02	Oct 02 - Mar 03	Summer 2003	Spring 2004
Year 11	Oct-Nov-Dec 03	Oct 03 - Mar 04	Summer 2004	Summer 2005
Year 12	Oct-Nov-Dec 04	Oct 04 - Mar 05	Summer 2005	Summer 2006

Each year, a national random sample, stratified by Network, of adult in-center hemodialysis patients was drawn. The sample size of adult in-center hemodialysis patients was selected to allow estimation of a proportion with a 95% confidence interval (CI) around that estimate no larger than 10 percentage points (i.e. \pm 5%) for Network-specific estimates of the key hemodialysis CPMs and other indicators. Additionally a 30% over-sample was drawn to compensate for an anticipated non-response rate and to assure a large enough sample of the adult in-center hemodialysis patient population who were dialyzing at least six months prior to October 1, 2004, for the 2005 ESRD CPM Project. The final sample for 2004 analysis consisted of 8,479 adult in-center hemodialysis patients.

The peritoneal dialysis patient sample included a random selection of 5% of adult peritoneal dialysis patients in the nation. Additionally, a 10% over-sample was drawn to compensate for an anticipated non-response rate. The final sample for analysis consisted of 1,337 peritoneal dialysis patients for the 2005.

All pediatric (aged < 18 years) in-center hemodialysis patients in the U.S. (n=692) and peritoneal dialysis patients in the U.S. (n=761) were included in the 2005 ESRD CPM Project.

Selected findings from the 2005 ESRD Clinical Performance Measures Project are highlighted below. Important improvements in hemodialysis adequacy and anemia management have been realized since the onset of this project. It is important to note that although the project year is 2005, the data are from 2004

(Refer to Table 5 for clarification). When years are noted in the information below, it refers to the year the data are from, not the project year.

Adequacy of Dialysis: Adult In-Center Hemodialysis

- Mean URR has increased each year from 63% in 1993 to 72% in 2004.
- The proportion of patients with mean URRs ≥ 65 has also increased steadily from 43% in 1993 to 87% in 2004.
- 91% of prevalent patients had a mean delivered calculated, single session adequacy dose of _{sp}Kt/V ≥ 1.2 in 2004, representing a 23% increase from 74% in 1996 when _{sp}Kt/V was first profiled in the project.
- The mean $_{sp}$ Kt/V was 1.55.

Adequacy of Dialysis: Adult Peritoneal Dialysis

- Adequacy of dialysis was assessed during the study period (October 2004 March 2005) for an
 estimated 82% of patients. This is a dramatic increase from 66% in 1994-1995 when a peritoneal
 dialysis cohort was first added to the project, but a decrease of 4% from the 2004 ESRD CPM
 study.
- 73% of CAPD patients had both a mean weekly $Kt/V_{urea} \ge 2.0$ and creatinine clearance ≥ 60 L/wk/1.73m² or there was evidence that dialysis prescription was changed if the adequacy measurements were below these thresholds during the six-month study period. (PD Adequacy CPM III) This is an increase of 3% from the 2004 ESRD CPM study.
- 58% of cycler patients (no daytime dwell) had a mean $Kt/V_{urea} \ge 2.2$ and a mean weekly creatinine clearance of ≥ 66 L/wk/1.73m² or there was evidence that the prescription was changed according to NKF-K/DOQI recommendations during the study period. (PD Adequacy CPM III) This is a decrease of 4% from the 2004 ESRD CPM study.
- 59% of cycler patients (with daytime dwell) had a mean $Kt/V_{urea} \ge 2.1$ and a mean weekly creatinine clearance of ≥ 63 L/wk/1.73m² or there was evidence that the prescription was changed according to NKF-K/DOQI recommendations during the study period. (PD Adequacy CPM III) This is a decrease of 6% from the 2004 ESRD CPM study.

Nutrition: Serum Albumin – Adult In-Center Hemodialysis

- The percent of patients with mean serum albumin values ≥ 4.0 (BCG) or 3.7 (BCP) decreased from 39% in 2003 to 36% in 2004. These numbers compare to 27% in 1993. The 2004 figure represents a 3% decrease from 2003.
- The percent of patients with mean serum albumin values ≥ 3.5 (BCG) or 3.2 (BCP) in 2004 was 82%, compared to 78% in 1993.
- Mean serum albumin value in 2004 with bromcresol green (BCG) laboratory method was 3.8 gm/dL.
- Mean serum albumin value in 2004 with bromcresol purple (BCP) laboratory method was 3. 6 gm/dL.

Nutrition: Serum Albumin – Adult Peritoneal Dialysis

- The mean serum albumin value for the 2005 ESRD CPM study was 3.6 gm/dL (BCG) and 3.4 gm/dL (BCP).
- The percent of patients with mean serum albumin values ≥ 4.0 (BCG) or 3.7 (BCP) remained the same from the 2004 ESRD CPM study at 20%, an increase from 14% in the 1995 study.
- The percent of patients with mean serum albumin ≥ 3.5 (BCG) and 3.2 (BCP) was 62%, an increase from 52% in the 1995 study and a 1% decrease from the 2004 ESRD CPM study.

Anemia Management: Adult In-Center Hemodialysis

- In 2004, the proportion of patients with a three-month mean hemoglobin ≥ 11 was 83%, compared to 59% in 1998.
- The mean hemoglobin for all patients was 12.0 gm/dL in 2004.

Anemia Management: Adult Peritoneal Dialysis

- The mean hemoglobin for all patients in the 2005 ESRD CPM study was 12.0 gm/dL.
- 82% of patients had a six-month mean hemoglobin of ≥ 11 gm/dL, compared to 55% in the 1998 ESRD CPM study.

Vascular Access: Adult In-Center Hemodialysis

- 37% of incident patients were dialyzed via A-V fistula; this was a 2% increase from 2003.
- 39% of prevalent patients were dialyzed via A-V fistula; this was a 4% increase from 2003.
- 21% of prevalent patients were dialyzed via chronic catheter continuously for 90 days or longer; this was a 1% increase from 2003.
- 66% of prevalent patients with an A-V fistula or A-V graft were routinely monitored for the presence of stenosis.

Year 12 of the ESRD CPM Project also included 100% data collection in dialysis facilities operated by the Veterans Health Administration (VHA). Facility personnel abstracted required information from patient medical records and returned completed data forms to the Networks. Network staff clarified all questionable entries with facility staff, entered the data into a file, and transmitted the data to CMS for analysis. VHA facility-specific reports were returned to each Network for dissemination.

NOTE: Data for Year 12 of the ESRD Clinical Performance Measures Project were collected in the summer of 2005 and findings were distributed to all dialysis providers in summer 2006. The ESRD CPM report, entitled "2005 Annual Report - ESRD Clinical Performance Measures Project," contains details regarding the background and design of the project as well as pertinent findings. The 2005 Annual Report - ESRD Clinical Performance Measures Project will be published as a supplement to American Journal of Kidney Diseases (AJKD) in October 2006. A supplement to AJKD has been published every year since 2001 (1999 CPM data). Data are also available on the Centers for Medicare & Medicaid Services' (CMS) website (www.cms.hhs.gov/CPMProject).

Graphical representations of several measures of the ESRD CPM Project are provided below.

TABLE 6 PERCENT OF ADULT HEMODIALYSIS PATIENTS HGB \geq 11 g/dL (HCT \geq 30%) National Data over 12 Years of the ESRD CPM Project

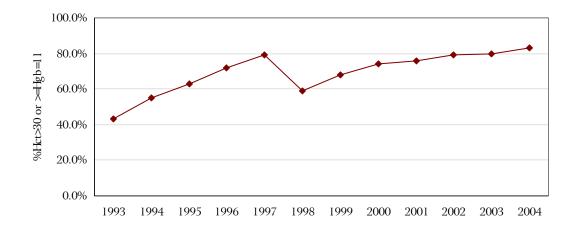
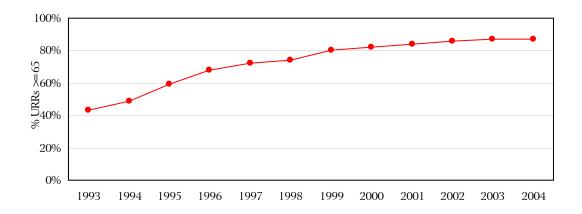


TABLE 7
PERCENT OF ADULT HEMODIALYSIS PATIENTS WITH URR ≥ 65%
National Data for 12 Years of the ESRD CPM Project



Information on the type of vascular access for the adult hemodialysis cohort was collected for the first time in Year 6 (data from 1998), and continues annually. Table 8 below provides a comparison of Network data to the recommended National Kidney Foundation's Dialysis Outcomes Quality Initiative (K-DOQI) Guidelines (40% of prevalent hemodialysis patients dialyzing by A-V fistula).

TABLE 8
PERCENT OF ADULT PREVALENT PATIENTS DIALYZING BY A-V FISTULA
All Networks - 7 Years of ESRD CPM Data Collection

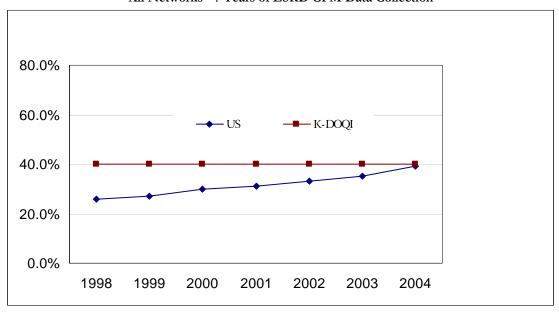


TABLE 9
PERCENT OF ADULT PATIENTS DIALYZING BY CATHETER ≥ 90 DAYS
All Networks - 7 Years of ESRD CPM Data Collection

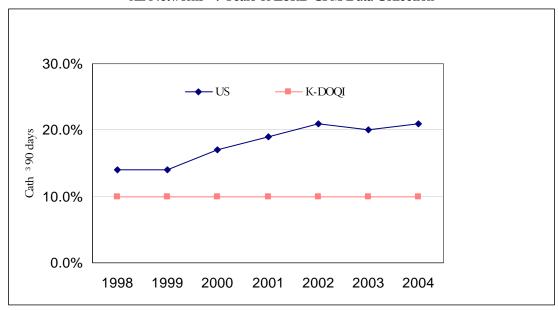


TABLE 10
PERCENT OF PREVALENT ADULT HEMODIALYSIS PATIENTS
WITH SERUM ALBUMIN

≥4.0/3.7 BCG/BCP and ≥3.5/3.2 g/dL BCG/BCP All Networks - 12 Years of the ESRD CPM Project

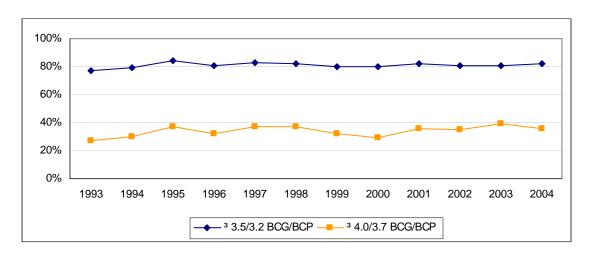
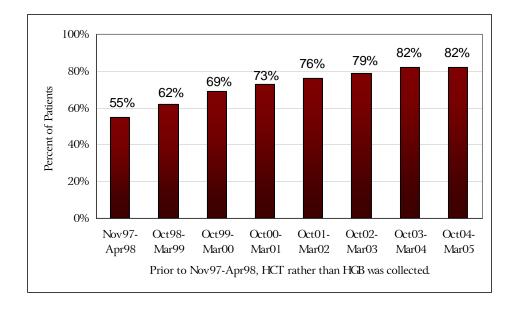
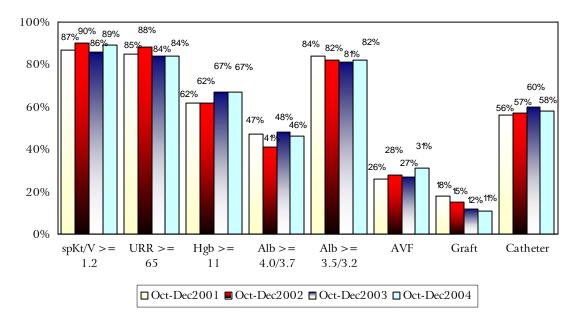


TABLE 11 PERCENT OF PERITONEAL DIALYSIS COHORT WITH AVERAGE HGB \geq 11 g/dL National Sample Compared Yearly



Beginning in Year 9 (data from 2001), 100% of pediatric (defined as age < 18) hemodialysis patients were included in data collection. Although there are no practice guidelines for pediatric dialysis patients, the graph below describes several parameters of care for this population.

TABLE 12 CLINICAL PARAMETERS FOR ALL (n=692) PEDIATRIC HEMODIALYSIS PATIENTS (Age < 18)



In Year 12, 100% of pediatric (defined as age < 18) peritoneal dialysis patients were included in the data collection. Although there are no practice guidelines for pediatric dialysis patients, the chart below describes several parameters of care for this population.

TABLE 13
CLINICAL PARAMETERS FOR ALL (n=761) PEDIATRIC
PERITONEAL DIALYSIS PATIENTS (Age < 18)

CLINICAL PARAMETERS	% MEETING TARGET
CAPD patients with weekly Kt/V $_{urea} \ge 2.0$	65%
Cycler patients with daytime dwell with weekly Kt/V $_{urea} \ge 2.1$	72%
Cycler patients without daytime dwell with weekly Kt/V $_{urea} \ge 2.2$	63%
$Hgb \ge 11.0 \text{ g/dL}$	69%
Albumin $\geq 4.0/3.7$ g/dL (BCG/BCP)	33%
Albumin $\geq 3.5/3.2$ g/dL (BCG/BCP)	69%

CONDUCT QUALITY IMPROVEMENT PROJECTS (QIPs) AND ACTIVITIES FOCUSED ON SPECIFIC AREAS OF CARE

CMS Quality Improvement Projects

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;
- The collection, monitoring, and improvement of clinical performance measures (CPMs); and
- Driving the FistulaFirst 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 supports statistical analysis, proposed intervention activities, and included an evaluation mechanism. For 2002, CMS requested all Networks conduct a QIP on Vascular Access while work continued on the 2001 QIP on Adequacy of Dialysis.

In 2001, all Networks were instructed by CMS to conduct a quality improvement project focused on vascular access management because of its importance in the overall clinical treatment of hemodialysis patients. Three projects were proposed for these studies:

- Increasing A-V Fistulas This project addressed one of three vascular access measures in the ESRD Clinical Performance Measures Project: Vascular Access CPM I, Maximizing Placement of Arterial Venous Fistulae. This measure follows Guideline 29 of the National Kidney Foundation's Dialysis Outcomes Quality Initiative (NKF-DOQI) 2000 Update.
- Vascular Access Monitoring This measure addressed Vascular Access CPM IV: Monitoring
 Arterial Venous Grafts for Stenosis and follows Guideline 10 of the K-DOQI as contained in the
 July 21, 2000, Medicare ESRD Network Organizations Manual: Monitoring Dialysis A-V Grafts
 for Stenosis.
- Reduction of Catheters in Hemodialysis This project intends to lower the Network catheter rate to the K-DOQI guideline of <10% per facility. The project addressed the assessment of patients who had catheters as the primary vascular access for more than 90 days, the employment of appropriate clinical processes to ensure appropriate and timely referral for an access (graft or fistula), and a concomitant reduction of catheters in hemodialysis (HD) patients.

In 2003, CMS and Networks initiated a new collaborative initiative on increasing the rate of Arterio-Venous (AV) fistula. This initiative – FistulaFirst, the National Vascular Access Quality Improvement Initiative (NAVII) - was designated in 2005 as a CMS Breakthrough Initiative.

CMS Quality Improvement Projects (QIP) - Performance Based

With the implementation of the 2003 - 2006 ESRD Network contracts, CMS mandated that the Networks should develop and implement quality improvement projects with dialysis providers in the area of vascular access as part of the National Vascular Access Improvement Initiative (NVAII) for at least the first two years of the SOW. Project design and other implementation considerations are developed in conjunction with dialysis providers and other stakeholders collaborating in the Institute for Healthcare Improvement (IHI) -facilitated national "FistulaFirst" project on vascular access.

The National Vascular Access Improvement Initiative – FistulaFirst, a new Network initiative in 2003, is 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 potentially preventable deaths each year.

In 2005, the FistulaFirst 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 FistulaFirst 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 initiation. After Network intervention the national average for prevalent patients was 41.0% in December 2005. The upcoming ESRD Network contract for 2006 - 2009 will support the five-year national goal of 66%.

TABLE 14

NATIONAL VASCULAR ACCESS IMPROVEMENT INITIATIVE - FISTULAFIRST

Project Goal: Fulfill the goals recommended by the NKF K-DOQI™ Guidelines: AVF rates of at least 40% for prevalent patients and 50% or greater for incident patients

NETWORK	GOAL	STATUS AS OF DECEMBER 2005
1	45%	47.1% as of December 2005
2	42%	47.4% as of December 2005 as reported by 80% of eligible facilities reporting
3	40%	40% as of December 2005
4	36%	40.5% as of December 2005 with 100% of eligible facilities reporting
5	31.6%	35.1% as of December 2005
6	33.2%	37.7% as of December 2005
7	40%	Network 7 continued the FistulaFirst Mini-Collaborative (47 facilities) and statewide spread techniques (267 facilities). This two-pronged strategy increased the overall AVF rate by 3.2% from the previous year, reaching 41.8% by December 2005. This exceeded the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative goal of 40%. As expected, the Mini-Collaborative was more successful than the statewide group, improving from 42.3% to 46.3%.
8	Increase the prevalent AV Fistula rate by 5%	35.7% as of December 2005, an increase of 9.4% above the CDC 2002 baseline
9	Increase AVF prevalence from 30.3% in 2002 to 34.3% in 2006	As of December 2005, Network 9 had a fistula prevalence of 38.1% The MRB directed a Vascular Access Advisory Panel and is charged with developing and implementing strategies to achieve FistulaFirst goals.

NETWORK	GOAL	STATUS AS OF DECEMBER 2005
10	• Increase AVF prevalence from 33.3% in 2002 to 37.3% in 2006	• As of December 2005, Network 10 had a fistula prevalence of 39.1%
	Vascular Access Advisory Panel	• The MRB directed a Vascular Access Advisory Panel and is charged with developing and implementing strategies to achieve FistulaFirst goals.
11	Increase the AVF rate to at least 35.3% by June 2006	37.8% as of December 2005, 6.2% increase from October 2003
12	35.1% AVF for prevalent patients by June 2006 & a 4% increase over the 2002 CDC baseline rate	40.5% as of November 2005
13	30.4%	36.9% as of December 2005
14	30.9%	39% as of December 2005, a 14% increase since the project began
15	42.5%	48.3% as of December 2005
16	3% point increase above the prevalent fistula rate at December 2002 (48.5%), due by March 2006	58.5% as of December 2005
17	4% net increase from the CDC baseline AVF prevalence rate of 34.9% established in December 2002	46.2% as of December 2005
18	4% point net increase of AVF over 35.7% CDC 2002 baseline	44.4% as of December 2005

Source: Networks 1-18 Annual Reports, 2005

Throughout 2005, the ESRD Networks continued work on additional CMS-approved QIPs. Table 15 lists these QIPs by area of care.

TABLE 15 ADDITIONAL CMS-APPROVED QIPs BY AREA OF CARE

GOAL	NETWORKS
VASCULAR ACCESS: REDUCTION OF CATHETERS	1, 3, 6, 8
VASCULAR ACCESS: STENOSIS MONITORING	1, 3, 8, 11, 14, 16
VASCULAR ACCESS: ARTERIO-VENOUS FISTULA	6, 9, 10, 16
ADEQUACY OF PERITONEAL DIALYSIS (PD)	1, 9, 10, 11, 14
ADEQUACY OF HEMODIALYSIS	1, 6, 7, 8, 13
ANEMIA MANAGEMENT	1, 3, 6, 8, 9, 10, 13, 14

Source: Networks 1-18 Annual Reports, 2005

Other 2003 - 2006 Contract Quality Improvement Projects - Non-Performance Based

In addition, each Network shall develop a written plan that assesses the relative and historical performance of each Clinical Performance Measure (CPM) indicator (below) and prioritizes/plans/designs improvement activities, as resources allow. The plan must be submitted to the Project Officer no later than 60 days after CPM data is delivered to the Networks in each contract year after the SOW begins. Any additional data collection outlined in the Network's plan (elements and/or frequency), that is not required in the SOW, must be approved by the Project Officer. These non-performance-based CPM QI projects should include quantitative targets, as with any quality improvement project. The timing of this plan (deliverable) is designed to allow assessment of the most current annual CPMs for each Network (available through annual CPM s report - preliminary results). Annually this plan shall be reviewed and updated as needed by the Network and submitted to the Project Officer for approval within 60 days after CPM data is delivered to the Networks.

Additional topics are limited to:

- Adequacy of Dialysis (In-Center Hemodialysis Patients) CPMs I-V
- Adequacy of Dialysis (Peritoneal Dialysis Patients) CPMs I-III
- Anemia Management CPMs I-III, and
- Other measures/indicators identified by CMS

Quality Improvement Activities

The Network may develop other improvement activities focused on ESRD care within its community. Networks are encouraged to form partnerships and collaborations with other entities (Quality Improvement Organizations (QIO), State Survey Agencies, Medicare and Choice Organizations, national and/or local renal-related organizations, providers, patients, other Networks, and CMS when appropriate). The Network shall have and maintain the capacity to respond to local needs upon request by facilities or when poor performance/problems are identified in conjunction with the responsibilities set forth in section C.3.B. These other Quality Improvement (QI) activities may differ from Network to Network depending upon local needs, variation in patient outcomes and practice patterns (processes of care). Other QI activities may be tailored to specific target areas, such as geographic area, provider group (dialysis and/or transplant), or specific clinical domains. Other OI activities may be developed in collaboration with CMS, the OIO, or the Network Medical Review Board (MRB). Any additional data collection being considered for these activities (elements and/or frequency) that is not required in the SOW must be approved by the Project Officer. The objectives of these QI activities are to assist in the development of local (i.e., facilities, clinics, etc.) capacity to conduct internal quality improvement activities, which may include measurement and improvement of local/internal processes and outcomes of care. Network MRBs also conduct quality assessment and improvement activities to address areas of concern and opportunities for improvement. These utilize individualized approaches and may be specific to the Network area. In 2005, Networks conducted numerous quality activities employing various approaches that included distributing data feedback reports, disseminating information using hardcopy or electronic transmission, patient counseling, benchmarking, and knowledge management. An overview of these activities is described in the table below, by area of care.

TABLE 16 SUMMARY OF OTHER NETWORK QUALITY ACTIVITIES CONDUCTED IN 2005

AREA OF CARE	NETWORKS
Glomerular Filtration Rate (GFR) Review	All Networks
Unit-Specific Reports	All Networks
Patient Safety	1, 2, 3, 4, 5, 12, 16
Patient Support	8, 12, 17
Modality Selection Study	12
Bacteremia and/or Infection Control	8, 12, 16
Vocational Rehabilitation/Employment	2, 3, 4, 5, 12, 14, 15, 17, 18
Immunizations	2, 4, 5, 6, 8, 11, 12, 17, 18
Transplantation	4, 5, 6, 8, 9/10, 11, 12, 16
Continuous Quality Improvement/Quality	8, 12, 14, 17, 18
Pediatric Dialysis	1, 2, 4, 5, 9/10, 12, 13, 14, 16
Early Referral/ Early Renal Insufficiency	8, 11, 12
Hepatitis B and/or Hepatitis C	12
Quality Measuring and Reporting, Physician Activity Reports, CPM and Profiling Reports	1, 2, 8, 11, 12, 13, 14, 16, 17, 18
Quality Awards	5, 7, 8, 12, 13, 14
Technician Training Program	5, 6, 12, 16, 17
Nutrition	8, 12
Challenging Patients	1, 2, 8, 9/10, 12, 14, 16, 17, 18
Standardized Mortality Rates	8, 12
Disaster Planning	1, 4, 7, 8, 12, 13, 17
Anemia Management	8, 11, 12, 13
Bone and Mineral Metabolism	3, 4, 8, 11, 12
In-Center Self-Care Dialysis	12
National Laboratory Project	1, 2, 3, 4, 5, 6, 7, 8, 9/10, 11, 12, 13, 14, 15, 18
Common Practices	4, 8
Home Dialysis	4, 8
Depression in the ESRD Patient	8
Ethical Issues	7, 8, 14
End of Life Issues	1, 4, 5, 8, 16
Monitoring Water Treatment Systems in Hemodialysis	8, 16
Renal Palliative Care	2, 8, 16
Developing CPMs on medications, transplant referral and bone disease	8, 9/10, 11
Involuntarily Discharged Patients	8, 11, 14, 18

Source: Networks 1-18 Annual Reports, 2005

Community Information and Resources

Each Network is to assist providers and patients in its area to improve the quality of care and the quality of life of ESRD patients by providing informational material and technical assistance on ESRD related issues. In carrying out the activities under the task, a Network shall perform the following functions:

- Encourage participation in vocational rehabilitation programs and develop criteria and standards relating to this effort (See Appendix P)
- Evaluate the procedures used by facilities and providers in the Network in assessing patients for placement in appropriate treatment modalities
- Implement a procedure for evaluating and resolving patient grievances
- Establish and/or maintain a national user-friendly toll-free number to facilitate communications with beneficiaries within its Network area
- Develop and/or maintain a website that follows CMS standards and guidelines
- Comply with laws that prohibit excluding or denying individuals with disabilities an opportunity to receive the same information and assistance provided to other patients without disabilities.

The Networks are committed to patient quality of life as indicated by patients maintaining active lifestyles. Each Network is required by federal legislation and contract requirements to encourage dialysis facility staff to assist patients in rehabilitation. On an annual basis, Networks make patients and providers aware of vocational rehabilitation programs that are available in their area. Facilities are surveyed by the Network to determine how many patients aged 18-54 years are working, in school, or referred to a vocational rehabilitation program. A comparative analysis by Network is provided in Appendix P.

PROVIDE PROFESSIONAL EDUCATIONAL MATERIALS AND WORKSHOPS FOR PROVIDERS/FACILITIES

The principles of quality improvement compel the healthcare team to identify opportunities for improvement and develop appropriate interventions. ESRD Networks are a vital resource to facilities, providing educational materials and workshops. Under contract to CMS, Networks are to provide, at a minimum, the following materials:

- 1. The Annual Report (either by hardcopy and/or referral to the Network's web site), which contains CMS and ESRD Network goals, the Network activities conducted to meet these goals, and the Network's plan for monitoring facility compliance with the goals
- 2. Regional and national patterns or profiles of care as provided in the Clinical Performance Measures Annual Report
- 3. Results of Network quality improvement projects
- 4. As directed, appropriate, and/or necessary (necessity would result from, for example, a substantive change to a grievance process that resulted in updated informational material on this process), the Network organization shall provide any updated information to providers/facilities in its Network area with a directive that each provider/facility make the information available to its patients or inform its patients how to contact the Network organization to obtain the information
- 5. Special mailings (up to two per year) as directed by CMS, including duplication of materials, as necessary
- 6. Annual printing and distribution of Dialysis Unit Specific Reports. Annually, within 30 days of receipt of the Dialysis Unit Specific Report (by hard copy or electronic) produced by the University of Michigan Kidney Epidemiology and Cost Center (or other CMS designee) for the dialysis facilities within the Network's area, the Network shall print and distribute two copies of the facility's Report to the individual facilities, to the attention of the Medical Director and the

- Unit Administrator. Each facility shall only receive a copy of its own report. Additionally, a copy of the report should be sent to national, corporate owners of a facility upon request of the provider
- 7. Annual notification of the updated Quality Measures for Dialysis Facility Compare. Annually, within 30 days of receipt of the Dialysis Unit Specific Report (by hard copy or electronic) produced by the University of Michigan Kidney Epidemiology and Cost Center (or other CMS designee) or other report that describes the three updated quality measures to be posted on Medicare's Dialysis Facility Compare (DFC) web site for the dialysis facilities within the Network's area, the Network shall notify the applicable dialysis facility of its updated DFC quality measures. The notification shall also include instructions as to how the dialysis facilities can provide comments to CMS regarding its updated measures. CMS, or its designee, shall provide the Network with instructions for preparing the notification to the dialysis facilities
- 8. Information on the importance of immunizations, as directed by CMS
- 9. Other materials (such as journal articles or pertinent research information) that providers/facilities can use in their quality improvement programs
- 10. Information on how to access and use Medicare's Dialysis Facility Compare (DFC) website and how to submit corrections to the Network on its facility characteristics that are displayed on DFC

The Networks develop materials as well as serve as clearinghouses for materials developed by others. A variety of communication formats and vehicles are used to disseminate these materials including hard copy, Network website postings, electronic mail, and broadcast fax.

In addition to the professional educational sessions offered to facility personnel and the educational materials distributed, several Networks published journal articles, displayed posters, and gave presentations at professional meetings during 2005. Highlights of new professional workshops and educational materials offered by Networks are highlighted in Appendix Q by Network.

PROVIDE EDUCATIONAL MATERIALS AND WORKSHOPS TO PATIENTS

ESRD Networks also develop and serve as a clearinghouse for patient education materials. Some materials are sent directly to patients, while others are distributed to facilities for use in patient education efforts. All Networks have toll-free numbers for patients and respond to numerous requests for patient assistance.

Many Networks utilize Patient Advisory Committees (PACs) and/or patient representatives at the facility level to gather patient concerns and distribute information. All Networks use a variety of media and dissemination methods to provide patients with information such as: meetings, teleconferences, direct mailings, booklets, posters, brochures, videos, training manuals, and website updates with items of interest to patients. Several Networks publish newsletters for patients (e.g., *Patient REMARCS, Renal Health News, The TransPacific Renal Newsletter, Lone Star Newsletter, Renal Roundup, Network News, Renal Outreach, Kidney Koncerns, Common Concerns, Nephron News and You*). Network personnel present information at conferences and participate in patient programs sponsored by other renal-related organizations (such as area transplant and dialysis support groups, civic organizations and church groups, NKF Patient Education Seminars, AAKP, community awareness seminars, and patient services symposiums).

Some of the new patient educational workshops and materials offered by Networks are highlighted in Appendix R by Network.

New Patient Orientation Packets

Beginning in the fourth quarter of 2000, new ESRD patients were sent a package of orientation materials. This was accomplished through a collaborative effort among the Networks, CMS, and the Forum Clearinghouse. New patients are identified upon entry into the Network data system (via the CMS 2728 Form). In the fifth year of the project, a total of 106,807 new patient orientation packets were distributed. The package of orientation materials has been revised and in Year Six (October 2005 – September 2006) of the project includes:

- A Medicare beneficiary letter from the administrator of CMS
- A letter from the Network Executive Director
- "Medicare Coverage of Kidney Dialysis and Kidney Transplant Services" (CMS booklet)
- "Preparing for Emergencies: A Guide for People on Dialysis" (CMS booklet)
- "You Can Live" (CMS booklet)
- "The Voice The Home The Hope" (NKF brochure)
- "AAKP Resources" (AAKP Brochure)
- "Dialysis Facility Compare" (CMS brochure)
- "Vascular Access is a hemodialysis patient's lifeline" (CMS brochure)

OFFER TECHNICAL ASSISTANCE TO DIALYSIS AND TRANSPLANT FACILITIES

Annually, a Network shall notify its providers, facilities, and patients, that it is available to provide technical assistance, guidance, and/or referrals to appropriate resources upon request. At a minimum, a Network shall:

- Identify available providers and/or facilities to patients seeking ESRD services (including transient patients) and
 - o refer those patients to the Medicare.gov Dialysis Facility Compare website
 - o educate dialysis facility professional staff regarding the use of the information on Dialysis Facility Compare in assisting patients to make choices about dialysis facilities, to participate in decision making regarding their treatment, and other applicable uses per guidance set forth in the ESRD Network Organizations Manual, and
 - o provide, upon request or inquiry, assistance in understanding the information provided on the Dialysis Facility Compare page of the Medicare.gov website per guidance set for the in the ESRD Network Organizations Manual
- Assist providers/facilities in developing community and patient education programs
- Promote patient education regarding kidney transplantation, and self-care home dialysis
- Encourage and assist providers/facilities to do timely patient assessments thus promoting appropriate referrals for kidney transplant
- Address impediments to referrals and/or transplantation, as appropriate and feasible
- Assist providers/facilities in accessing the functional status of patients
- Assist providers/facilities in defining or establishing rehabilitation goals for referring suitable candidates to vocational rehabilitation programs
- Assist providers/facilities (that are having difficulty in meeting Network goals) in developing appropriate plans for correction
- Assist providers/facilities in developing local disaster plans that include planning for emergencies such as floods, earthquakes, hurricanes, etc.

In order to respond to the technical needs of the renal community appropriately, Networks employ qualified personnel with expertise in dialysis and transplant nursing, renal social work, patient advocacy, healthcare quality, and data management. Technical assistance is provided using a variety of vehicles and venues, including (but not limited to) telephone consultation, on-site visits, meetings, distribution of materials, referral to individuals with additional expertise in the area queried, conference calls, and

educational workshops (described in a previous section). If multiple queries are received on one topic, an educational offering or other activity may be conducted to address the issue with a broader audience.

The functionality of SIMS and its expanded capability to enter "contacts" pertaining to issues other than patient concerns and grievances has enhanced the Networks' ability to track the nature of technical assistance provided, as well as the time required. An overview of issues referred to Networks for advice and assistance during 2005 is provided below. (This list is only an overview, and in no way represents all of the issues addressed by every Network during 2005.)

Abusive Patients Patient Transfer/Discharge Request for Forms

Physical Environment Requests for Technical Assistance Data Request

Dialysis Compare Website **Quality Improvement Project** Staff-related Disruptive Patients Reimbursement/Financial Transients

Information Request for Educational Treatment-related/Quality of Care

Non-Compliant Patients Materials

ESRD SPECIAL PROJECTS

In addition to national initiatives such as CPMs and FistulaFirst, 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 \$30,000

Award:

To understand the interpretation of important concepts such as withdrawal from dialysis, Purpose:

discontinuation of dialysis, and use of hospice care as reported in CMS death notification

Timeframe: July 2005–June 2006

Anticipated: provide definitions for withdrawal from and discontinuation of dialysis which Outcomes:

will allow the ESRD Networks to collect more consistent data and understand the barriers to

referral to hospice care.

Project Name: END-OF-LIFE CARE

Network: Mid-Atlantic Renal Coalition (Network 5) Partners: Academy for Educational Development

\$200,000 Award:

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; EOL Coalition continues to meet and provide EOL resources to the renal community.

Project Name: PEDIATRIC QUALITY OF LIFE

Network: Mid-Atlantic Renal Coalition (Network 5)

Partners: Networks 1, 2, 9/10, 12, 13, 14, 16 and Johns Hopkins University

\$30,000 Award:

To identify which aspects of quality of life (QOL) are impaired and to assess the prevalence Purpose

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: ICH-CAHPS SURVEY DEVELOPMENT AND QUALITY IMPROVEMENT PROJECT

Network: Intermountain ESRD Network (Network 15)

Partners: Networks 1, 5, 14; AHRO; 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.

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

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.

ESRD Network responsibilities for data processing, information management, and reporting are to:

- 1. Adhere to the policies and procedures outlined in the ESRD Network Infrastructure Operations and Support Manual, the Information Technology Administration Manual, and the QualityNet System Security Policies Handbook issued by CMS at all times during the contract, unless directed otherwise by CMS. These manuals delineate the roles and responsibilities for ESRD Network users, systems administrators, CMS personnel, and CMS supporting contractors.
- 2. Effectively manage the collection, validation, storage, and use of data, including data provided by CMS, for review, profiling, pattern analysis, and sharing appropriate data with the CMS Regional Office and the State Survey agency for use in their ESRD Medicare survey and certification activities
- 3. Ensure timely and accurate reporting by the providers/facilities
- 4. Train facilities in the proper procedures for completing and transmitting forms electronically and/or manually
- 5. Maintain an ESRD patient and facility database and ensure the confidentiality, integrity, and accuracy of the databases
- 6. Ensure the quality and accuracy of the CROWN database for inclusion in the ESRD Program Management and Medical Information System (PMMIS) and the United States Renal Data System (USRDS)
- 7. Ensure current patient events are reported to CMS timely for appropriate enrollment into and disenrollment from the Medicare program for ESRD benefits
- 8. On a quarterly basis, at a minimum, verify with dialysis facilities, patient event data maintained in CROWN
- 9. On an annual basis, profile facilities based on glomerular filtration rates to ensure the appropriateness of renal replacement therapy. The results of this activity shall be reported annually in the last quarter (April-June) of the Network quarterly report deliverable. The profile tables shall be made available to CMS upon request.

Networks are the primary managers of ESRD data and use the Consolidated Renal Operations in a Web Enabled Network (CROWN) 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, and identify patients and providers by numerous characteristics and outcomes. 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 FistulaFirst 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.

The information tracked within Network databases is collected from the ESRD provider through the Medical Evidence Report Form (CMS 2728), the Death Notification Form (CMS 2746), patient event tracking forms, and facility rosters. The majority of this information is collected via paper form. Corporate offices that own dialysis centers submit some data electronically and some is submitted electronically through VISION software. In 2005, Networks processed 115,371 Medical Evidence forms, 78,517 Death Notification forms, 4,946 Annual Facility Survey forms, 489,477 patient events (changes in treatment type and location), 8,904 CPM forms, and 21,896 personnel and provider changes. Table 17 shows the number of Medical Evidence forms and Death Notification forms transmitted to CMS in 2005.

TABLE 17
DATA FORMS PROCESSED
CALENDAR YEAR 2005

NETWORK	MEDICAL EVIDENCE (CMS 2728)	DEATH NOTIFICATION (CMS 2746)	TOTAL
1	4,221	3,077	7,298
2	7,262	5,173	12,435
3	4,887	3,670	8,557
4	5,729	4,061	9,790
5	6,816	4,729	11,545
6	11,956	9,363	21,319
7	7,252	5,419	12,671
8	5,898	3,962	9,860
9/10	13,779	7,608	21,387
11	7,977	5,349	13,326
12	4,286	2,914	7,200
13	4,575	3,474	8,049
14	9,462	5,835	15,297
15	4,851	3,013	7,864
16	3,068	2,088	5,156
17	5,178	3,461	8,639
18	8,174	5,397	13,571
Total	115,371	78,517	193,888

Source: Networks 1-18 Annual Reports, 2005

Each of the 18 Networks use the Standardized Information Management System (SIMS) to manage the data collected. This system allows for the entry, storage and reporting of information and connects to a central repository of the data which CMS can access. The central repository links directly to the Renal Beneficiary Utilization System (REBUS), which is then linked to Medicare's Enrollment Data Base (EDB). This system allows Networks to track patients through the continuum of care and keep accurate records of patients. Patient grievance calls and facility staff information are not stored on the repository and are only accessible to the Network that entered them. The five major components of SIMS are:

Patient Data

- 2728 Medical Evidence form enters patient in registry and serves as medical evidence for those patients applying for Medicare benefits
- 2746 Death Form filled out when a patient dies
- Patient Events modality shift, transfer in or out of a provider, transplant, discontinue, recover function, etc., that a patient has during their course of treatment
- 2744 Facility Survey reconciliation of the patient events that is performed once a year by all facilities

Provider and Personnel

• Facility files housing data on providers including address information, name, affiliation, certification dates, services offered, shift information, etc.

• Personnel files contain data on the majority of personnel at the facility level. Also tracks Network board members and other entities that need to be on mailing lists

Contacts

• Any complaint, inquiry, grievance, or concern coming in from any patient, provider, family member, or member of the renal community

Reports (all exportable for customization of the data presentation)

- Annual reports (incidence, prevalence, transplants, etc)
- Quarterly reports (form counts and some portions of the contacts reporting)
- Listing of providers, their staff, and services
- Miscellaneous reports

Utilities

- Data Cleanup utilities to verify and validate data
- CPM patient population files
- CMS output files including a termination candidate file, patient census files and current patient status file
- Administrative utilities (mailing label export, internal reports)

In calendar year 2005, there were 1,581,821 unique patients and 4,476,719 unique patient events in SIMS.

Additional information regarding the SIMS project and all deliverables is available to CMS and the Networks at http://simsproject.com.

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

The ESRD Networks are actively involved with both quality-related and renal-related organizations to facilitate cooperation and joint ventures. Each Network creates unique partnerships with organizations to help provide better care for the ESRD patient population, including renal groups, professional organizations, dialysis corporations, and pharmaceutical companies. Networks come together with local services and organizations 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, PhD. By the close of 2005, 17 of the ESRD Networks 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, FistulaFirst, Safe and Timely Immunization, Disaster Preparedness, Enhancing Patient Safety in the Dialysis Process (water processing), and Advance Health Care Directives.

The 2005 CMS/Forum of ESRD Networks' Annual Meeting "Strategic Partnership for Change" drew representatives from CMS, Networks (data, quality, patient services, executive staff, and Network Medical Review Board Chairs), as well as renal community members to discuss issues impacting the ESRD Networks. Other activities in 2005 included the completion and distribution of the final report of the Decreasing Dialysis Patient-Provider Conflict project, End of Life Care, use of technology, i.e. the VISION software, and renewed partnerships with renal community members such as NKF and AAKP.

The hurricane season of 2005 presented unique challenges to the community. In response, ESRD Networks partnered with local, state, and national entities to provide continuing care to patients with ESRD in the affected communities. CMS and Networks held daily calls that allowed 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.

Networks continue to develop relationships and partner with the Quality Improvement Organizations (QIOs) to improve the care received by individuals with renal disease.

Networks communicate with State Survey Agencies (SSAs) through the exchange of newsletters, Annual Reports, and other appropriate quality reports. This communication helps to facilitate the exchange of ideas on issues of quality improvement and patient grievances. Networks also work with their constituent State Survey Agencies in resolving patient grievances and assisting facilities in resolving performance issues.

Table 18 provides a summary of collaborative activities that Networks conducted in conjunction with their area QIOs, SSAs, and the renal community during 2005.

TABLE 18
NETWORK COLLABORATIVE ACTIVITIES IN 2005 BY NETWORK

NETWORK	ORGANIZATION	TOPIC OR PROJECT NAME	
	QIO COLLABORATION		
1	 FistulaFirst Presentation (RI) FistulaFirst Presentation (MA) 	 Joint presentation with RI QIO and the CT discharge planners in collaboration with Qualidigm to the Rhode Island hospital quality managers Collaborated with MassPro on a presentation in Massachusetts to hospital administrators and physicians to increase their knowledge and awareness 	
	 Vascular Management WebEx SIP/SCIP Collaborative	 of FistulaFirst goals Collaborated with MassPro to present to hospital nurses and discharge planners in Massachusetts Nephrologists and members of the Network NAVII Steering Committee presented on the FistulaFirst Initiative 	
7	"Are Your Patients At Risk For Kidney Disease?"	Describes benefits of early referral to a nephrologist and distributed to 425 primary care physicians in collaboration with the QIO Physician Office Team	
8	QSource—Tennessee Information and Quality Healthcare (IQH)— Mississippi Alabama Quality Assurance	 FistulaFirst FistulaFirst, SCIP, Hurricane Katrina Response FistulaFirst, distribution of CKD materials, CKD 	
	Foundation (AQAF)	continuing education offering, Hurricane Katrina Response	
11	All 5 QIO's in NW 11 regionStratis Health	Upper Midwest FistulaFirst CoalitionCommunity Outreach Committee	
12	QIO (IA, MO, KS, & NE)QIO (IA, MO, KS, & NE)	 FistulaFirst: Inclusion in medical school and residency programs Immunization: Promoting influenza and pneumonia vaccine in the ESRD population 	
13	Arkansas, Louisiana, Oklahoma QIO's	FistulaFirst/CKD	
14	• Texas Medical Foundation (TMF) QIO	Addressed concerns regarding lack of dialysis services at nursing homes; continued collaboration to obtain Medicare Part B claims data of vascular procedures by surgeons for utilization in NVAII QIP; recommendations for changes to DM Flow sheet for Primary Care Physicians	
	National Kidney Foundation (NKF)	Network AQMC served as Nursing Editor for NKF Family Focus Patient newsletter; Network QMC served on NQF Board of Directors; assisted NKF local offices with questions related to ESRD care and services	

15	Dialysis Access-Chronic Kidney Disease Coalition (DA-CKD)	Held in Denver, Colorado, the coalition meeting included QIO representatives from all six states in Network #15, Network #15 staff, a nephrologist, a surgeon a PCP and nurse educators from 2 of the corporate dialysis companies that have facilities in the Network. This coalition began examining the issue of pre-dialysis access placement and early identification of CKD patients. The meeting resulted in the formation of the Dialysis Access-Chronic Kidney Disease Coalition (DA-CKD). Two sub-committees, a patient advisory committee and a beneficiary advisory committee continue work in this area.
17	Toolkit	Collaborated with Lumetra to produce a toolkit on influenza and pneumococcal vaccination
18	Mountain Pacific QIO	Collaborative partner in Montana SWIM Project
	LARGE DIALYSIS ORGANIZ	ATION (LDO) COLLABORATION
All Networks	Fresenius Medical Care (FMC), DaVita, Renal Care Group (RCG), Gambro Healthcare	Participation in electronic data collection projects with LDOs, including the Lab Data Collection Project, Clinical Performance Measures (CPMs) and FistulaFirst. Ongoing status. Hurricane Katrina Response.
	STATE SURVEY AGENO	CY (SSA) COLLABORATION
4	State Survey Agency/CMS	Monthly conference calls to discuss common current and pending concerns
7	State Surveys Annual Meeting	Network staff also collaborated by presenting, "QI: Surveying ESRD Facilities for Quality Management" and "Emergency Preparedness: Lessons Learned, State/Network/CMS Collaboration" to state surveyors during their Annual Update Meeting in Tampa.
8	TennesseeMississippiAlabama	Facility survey/quality concernsHurricane Katrina responseHurricane response
11	 MN, ND, SD and WI State Survey Agencies All 5 SSA's in NW 11 region Three SSA 	 Upper Midwest FistulaFirst Coalition members Patient complaints and assistance on requests Processed quality of care referrals
12	State Survey Agencies (IA, MO, KS, & NE) and CMS project officer.	Quarterly conference calls (Ongoing and long standing meetings of several years to discuss issues of mutual interest.)
14	Texas Department of State Health Services (DSHS) State Agency DSHS – Kidney Health Program	 Emergency Operations Centers coordination and collaboration at city, county, state and national level; provided routine and emergency conference calls; Network MRB provided DSHS with guidance and recommendations regarding corrective actions when requested; Network participated in pre-survey conferences to share information about ESRD Network activities, review Network goals and objectives and offer assistance Network broadcast faxed and emailed information on Medicare Prescription card per request of Kidney Health; MRB recommended and partnered with Kidney Health to facilitate changes in eligibility for

14 Comtinue 1	T D LO ES	AVE placement prior to start of distance and in
14 Continued	Texas Renal Coalition	AVF placement prior to start of dialysis and issued clarification to surgeons
		Aimed at providing early prevention and education of
		chronic kidney failure with end goal of decreasing the
		increase in newly diagnosed ESRD patients; members met to share ideas on best approach to reach the
		community via media, print materials and educational
		events; Network provided statistical information to
		show impact and rate of growth of ESRD incidence
1.5	Natura da Mallina	over the last 10 years
15	Network Mailing	Each Department of Health in Network #15 received a mailing containing: Press Release for the FistulaFirst
		project, survey responsibilities related to vascular
		access, mailing for change concept #10, information
		regarding the Creating AV fistulae in All Eligible
		Hemodialysis patients, Data analysis information, Abstract from Poster FORUM, samples of AAKP
		Nutrition counters, DVDs containing the above
		presentation, a FistulaFirst calendar, DFC site poster
		and handout on how to search for a facility on dialysis
		facility compare and the Network "Have a Problem" poster.
	DENIAL COMMUN	VITY COLLABORATION
A 11 N T		
All Networks	CMS/Forum of ESRD Networks' Annual Meeting	Topics included: Forum Membership Meeting; Strategic Partnership for Change Training Session:
	Attitual Meeting	Sharpening Your Coalition Building Skills; National
		Disaster Planning Coalition; "Patient Participation in
		Care Decisions for Independence"; "Patient
		Independence: Evidence from the USRDS"; Payment for Performance; MMA 623 ESRD Bundled Payment
		Demonstration Project: In-Center Hemodialysis
		Consumer Assessment of Health Providers Survey;
		Quality Measurement Update; "Diversity/Disparity";
		"Developing and Supporting Collaborative Leadership"; Safe and Timely Immunization Coalition;
		Sustainability Case Sample: Connecticut Coalition for
		Organ & Tissue Donation; "Engage in Innovative
		Collaborative Problem Solving"
1	Donate Life Coalition	Collaborative activities for past 20 years with several
		agencies in CT to promote organ donor awareness. Annual poster high school contest was successful with
		over 225 posters received from students. Coalition
		members participated in Speaker Bureau. A "Thanks
		for Asking" project was conducted to thank all the CT
		Motor Vehicle Department employees for answering
	• CAHPS	 consumer questions about organ donation A special project with Networks # 5,14,15 to support a
	- (21110)	pilot project on patient experiences in dialysis units.
		Quality and educational efforts in two providers on staff communication with patients
	CT Dialysis Technician Bill	The Network coordinated the task force of ESRD
	-	representatives in developing recommendations for the
		expanded role of patient care technicians. These
		activities resulted in a new bill passed by the state legislature to allow trained technicians to administer
		regionature to anow trained tecrimerans to administer

1 Continued	Patient Safety	medications associated with starting and ending dialysis.
		 The development of the national hemodialysis survey involved this Network, RPA, KUFA, AAKP, ANNA, Forum of ESRD Networks and was supported by CMS.
2	Buffalo Collaborative	Meetings of several Network physicians, local surgeons, the Network Executive Director and Quality Improvement Director (QID). Discussed possible coalition of stakeholders in the Buffalo area to improve AVF rates.
4	"Partnering with SA and CMS in the Sanctions Process: The Experience of Three Networks"	 Poster presentation at the CMS/Forum Annual Meeting in collaboration with Network 11 & 13. The poster provided algorithms to describe the review process and agency collaboration from each Network's experience in quality review of problem facilities. The poster described the inconsistencies in the sanction and alternative sanction process that
	Advisory Council for the PA QIO	 occurred. Invited to join the Consumer Advisory Council, hosted by Quality Insights of Pennsylvania (QIO),
	A Renal Coalition: The PennDel Chronic Kidney Disease Partnership	 which advocates for the older population. The first meeting was held in Philadelphia on October 19, 2005. Individuals from local Quality Improvement Organizations, State Survey Agencies, Large Dialysis Organizations, and National Kidney Foundations participated in this coalition meeting. Two subgroups were formed with specific objectives. The "Education
	DOPPS Study	Group" will work on educational initiatives for the renal community. The "Champion Group" will work on the identification of champion performers in fistula rates and what practices can be utilized to increase positive outcomes of lower performers. • Collaboration with Amgen and NKF led to the presentation on "An Overview of the DOPPS Study and Updates on Vascular Access and Bone Mineral Metabolism" at the May 2005 NCC Professional
5	Evaluation of Quality of Life (QOL) in Pediatric Dialysis Patients	 Education Workshop. A CMS approved collaboration with Networks 1, 2, 5, 9/10, 12, 14, 16 and the Pediatric Division of Johns Hopkins Medical Institutions to study the impact of various treatments for ESRD on health outcomes
	Kidney End-of-Life Coalition	Evolved into a national collaborative effort with several LDOs, RPA, NHPCO, CMS, and other end-of- life experts to form the Kidney End-of-Life Coalition
	CAHPSDialysis Withdrawal	 Collaborated with Networks 1, 14, and 15 on this project A special study conducted with Networks 1 and 12
7	AHCA & EOC	The Network collaborated with AHCA and the State EOC throughout the year related to Hurricanes Katrina, Rita and other threats to the Florida dialysis community. Staff from the Network and AHCA remained in constant communication during hurricane season. Together, information and resources were provided to the Florida dialysis centers. The Network

T		,
7 Continued	Hurricane Wilma	 and AHCA worked to ensure that all patients received their necessary dialysis treatments. The Network collaborated with AHCA, the Florida DOH and the State EOC pre-Wilma and for two weeks post-Wilma, until all facilities were operable and patients were accounted for. Network staff also assisted with advocating for restoration of facility power, generators, fuel for generators, fuel for staff and other needs that arose.
8	 NKF, RPA, AAKP, ANNA, ASN, Nephron, HDCN, RenalWeb, FMCNA, DaVita, RCG, DCI, Gambro FMCNA, DaVita, DSI, ANNA (Memphis Blues Chapter), Methodist Healthcare, NKF of W. TN, QSource, Saint Francis Hospital, UT Center for Health Sciences, VA Medical Center— Memphis 	 ESRD Outpatient Medications Project FistulaFirst coalition partners
	 ESRD Network 7 ESRD Networks 7, 13 and 14 All Networks 	 Patient Advisory Council Meetings Educational materials shared during Hurricane Katrina were posted on our website and Network 7's disaster poster served as a model for the one produced inhouse by Network 8 and sent to our facilities. Patient grievance posters were shared with Network 8 as we developed our own poster.
9/10	 2005 Nephrology Conference Barriers to Outpatient Dialysis Placement DPC Toolbox 	 Held in Indianapolis on May 25th-26th, the Network plans the conference in coordination with the Network Coordinating Center and ANNA. Some presentation topics included End-Of-Life issues; "A Patient Centered Approach to Advance Care Planning"; Hospice and Bereavement; "Compassion Fatigue: The Cost of Chronic Caring & Strategies to Nourish the Caregiver"; Crisis Intervention Skills for Nursing; KDOQI & Nutrition Guidelines; and Sleep Disorders & the Renal Patient. Collaborated with other Networks regarding barrier information currently collected
11	Upper Midwest FistulaFirst Coalition DPC Toolkit	 Patient Services Director participated on the committee for the development of the DPC toolbox First meeting held in August 2005, including QIOs, State Survey Agencies, LDOs, and independent dialysis facilities Collaborated with Network 14 on the DPC toolbox portion of the DPC Project, with the Network 11 Patient Services Coordinator serving as Chairman of the DPC Toolbox Committee. WebEx trainings were conducted for area providers with LDO, CMS, and SSA participation.
12	National Kidney Foundation	• Kansas & Western Missouri: We support of the Shirley Melton Patient Awards Banquet and various fund raisers. The ED is a member of the Early Intervention planning committee. National: The PSC is the ESRD Network Liaison for the NKF Family Focus

12 Continued		Newsletter that is published quarterly.
12 Continued	Missouri Kidney Program	 Network representatives attend educational meetings as participants. The ED is on the Advisory Council and attends meetings as a non-voting member.
16	"Technical Considerations when Bringing Hemodialysis Facilities' Water Systems Back on Line after Hurricane Katrina"	With the Network QI Consultant as the lead in coordinating a multidisciplinary team of representatives from the CDC, CMS, AAMI, NANT and renal dialysis providers, this document was created and posted by the CDC on September 20, 2005, and also appeared in Nephrology News and Issues - October 2005
18	Kidney Community of Southern California Coalition	Created involving about twenty patient and provider organizations in the local renal community with Network 18 as the facilitator
	OTHER CO	LLABORATIONS
2	Site Visit Evaluation Survey Tool	 Collaborated with the Department of Health to develop a survey tool that would allow facilities to evaluate the site visit they just experienced. Plans are underway to distribute the tool to Medical Directors for review and comment in early 2006.
3	 Influenza Work Group New Jersey Transplant Designee Conferences 	 Joined the group with the State Department of Health for New Jersey, Epidemiology Division Network 3 was asked to remain on the planning board.
4	Regional Networks Meeting NKF	 Boston Regional Office hosted the first meeting of the regional Networks (1-5) to facilitate the exchange of information on quality improvement approaches and allow for partnership opportunities to develop. NKF Activities included: NKF of Western Pennsylvania, Pittsburgh: The NKF of Western Pennsylvania's Program Director was invited to the Network office to meet staff and discuss collaborations for the future. Plans were finalized for the PSC to present an overview to renal professionals in Western Pennsylvania about the Network organization and goals at an NKF-sponsored educational seminar. The Executive Director of the NKF of Western Pennsylvania serves on the Renal Coalition and its Education subgroup. The PSC participated as a speaker at the "Surviving in the Real World of Nephrology III" Conference held May 6, 2005 in Monroeville, Pennsylvania for renal professionals. The Council of Nephrology Social Workers (CNSW) of Western Pennsylvania sponsored the conference in conjunction with the NKF of Western Pennsylvania, the Council on Renal Nutrition (CRN)-Western Pennsylvania and the Three Rivers Chapter of the American Nephrology Nurses Association (ANNA). The PSC shared Network 4's visions and goals, an overview of the Fistula First data, and patient services statistics for patient and facility contacts. Other topics included the NKF-K/DOQI Guidelines for Renal Oesteodystrophy, Sorbent Hemodialysis, and the Thomas E. Starzl Transplant Institute staff discussed kidney

4 Continued

- transplant as a treatment option to the 80-member audience. The QI Coordinator also participated with distribution of Fistula First materials (lapel buttons and post-it notes) and answering questions. The PSC participated as the invited speaker at the Westmoreland County Kidney Alliance meeting sponsored by the NKF of Western Pennsylvania. The monthly meetings provide both educational and peer support opportunities for patients and families who are dealing with CKD. The PSC shared lunch with the eight participants and discussed the role and responsibilities of the Network in serving the patient and provider populations for the ESRD community. A Network 4 Patient Advisory Committee member is an active volunteer organizer for the NKF for the patient support groups in Western Pennsylvania.
- NKF of the Delaware Valley, Philadelphia: The PSC participated as a speaker at the NKF of Delaware Valley Patient Meeting in Bethlehem, Pennsylvania. The Network was also a financial sponsor supporting this patient-centered day of education presented by renal physicians, social workers, nurses and patients. The topics included vascular access, AAKP initiatives, overview of Network 4, and choices for treatment modality. Over 150 patients and guests enjoyed this annual event. The Network provided a financial contribution for the first joint Patient-Staff Workshop sponsored by the NKF of the Delaware Valley held in Philadelphia, Pennsylvania. Network 4 also provided an ad for the program book. Requested a report on patient characteristics in Pennsylvania, with emphasis on race and minority statistics. This information was compiled in Excel and sent via email.
- Kidney Foundation of Central Pennsylvania, Harrisburg: The PSC and IS Director represented the Network as both a contributing sponsor and vendor at the Update on End-Stage Renal Disease The Kidney Foundation of Central Pennsylvania, Penn State College of Medicine and the Susquehanna Valley Chapter of the American Nephrology Nurses Association (ANNA) jointly sponsored this professional educational program in Hershey, Pennsylvania on April 19, 2005. The event was designed to update participants on recent medical advances in the evaluation and treatment of patients with kidney failure. The Network 4 MRB Chairman, Paul Palevsky, M.D., was the keynote speaker. The Network displayed a Fistula First informational display board and provided educational handout material. Fistula First lapel buttons and post-it notes were also distributed to increase awareness and promote outreach. The Network was a partner and sponsor for the annual Patient and Family Workshop sponsored by the Kidney Foundation of Central Pennsylvania in

4 Continued		Harrisburg, Pennsylvania. The Kidney Foundation of Central Pennsylvania offers services to 28 counties in the mid-state region. The PSC provided educational materials promoting the Network at a vendor table. The PSC also had the opportunity to address the group of 100 attendees who represented a diverse modality base that included: home dialysis, in-center hemodialysis and transplantation. The PSC discussed the Network's commitment to patient advocacy and the mediation we offer between the facility personnel and the beneficiary.
		Marketing items that contained the Network 4 logo and toll-free telephone number were distributed to all participants.
5	Regional Networks Meeting	 Boston Regional Office hosted the first meeting of the regional Networks (1-5) to facilitate the exchange of information on quality improvement approaches and allow for partnership opportunities to develop.
	SSA & QIO Meetings	 Convened meetings to ensure that each organization was familiar with the FistulaFirst project and expectations of their roles
6	ANNA	Both the Director of Quality Improvement and the Assistant Director of Quality Improvement are active members
8	NKF of Mississippi, Alabama Kidney Foundation, University of South AL Regional Transplant Program, Nephrology Associates of Mobile, Middle Tennessee Chapter of AAKP, NKF of West Tennessee	Patient Advisory Council Meetings
	• AAKP	 Memphis "Finding Your Strength" Meeting. Educational materials given out during PAC meetings. PSC serves as President of the BOD.
	NKF of Mississippi	 NKF of Mississippi shared their office space with Network 8 personnel during Hurricane Katrina. Along with partnering on the Mississippi annual PAC meeting, Network 8 also partnered with NKF of MS on several KEEP screening, KIDney Kids Camp and several other activities.
	• ANNA	 Network 8 partnered with the Magnolia Chapter to produce a cannulation workshop in Jackson, MS. Also the PSC presented at the ANNA convention in Las Vegas.
	• MCIC	PSC is a member of the Mississippi Chronic Illness Coalition.
	• LORAC/MEI	 Network 8 utilized patient educational materials developed by MEI, Network 8 ED serves as the ESRD Network representative on the Life Options Rehabilitation Advisory Council (LORAC). MEI Director Dori Shatell was a presenter at the Network 8 annual meeting.
	• UNOS	PSC served as Region 3 representative to the UNOS Patient Affairs Committee.

8 Continued	Coalition on Donation	PSC serves as AAKP representative to the National Coalition on Donation and as the Network 8 representative on the newly formed Mississippi Coalition on Donation for which she is the Treasurer.
11	Sixteen (89%) of 18 Networks Computer Sciences Corporation and Biostatistics Consulting Laboratory	National Laboratory Project
1.2	CMS and CSC CMS and CSC CMS and CSC	National ESRD CPM Project A DEED A Significant Language Control of the Cont
13	Louisiana Dialysis Disaster Coalition (LA-DEEP)	LA-DEEP Activities initiated in June 2005 to address "Louisiana Hurricane Preparedness"
14	 AAKP ANNA Peritoneal Dialysis Special Interest Group PD Monograph for the Nephrology Nurse PD Travel Tool Box 	 Partnered with AAKP to provide an educational meeting for patients. Network AQMC served on the group Assisted in planning Co-authored with ANNA for PD staff and patients in
	ANNA –Texas Chapters	Network Executive Director presenteed on DPC project at Dallas area ANNA/NANT meeting. Network QIC is President-Elect for ANNA Dallas Chapter. Collaborated with Texas ANNA chapters to facilitate FistulaFirst Audio Conference in February 2006.
15	"Medicare Prescription Drug Coverage: The Basics"	Written by Network #15 staff in collaboration with the National Kidney Foundation Medicare Modernization Program Manager and a CMS Region VIII representative, the article was distributed to all Network #15 facilities in November 2005.
16	Washington State Department of Health	The Executive Director continued to participate in the Deaprtment's Facilities and Services Licensing Division committee re-evaluating the state's certificate of need program as it impacts upon ESRD services. Kidney Dialysis Methodology Committee meetings continued through 2005 with an anticipated completion of committee tasks in early 2006.
	Core Curriculum Advisory Board	The QI Coordinator and QI Consultant served on the Board and were contributing authors for the third edition of the Dialysis Technician Core Curriculum under the auspices of MEI, Inc. with an unrestricted educational grant from Amgen.
	ESRD Networks: On Course with Cannulation	• The QI Coordinator presented FistulaFirst educational programs in collaboration with several other ESRD Networks: On Course With Cannulation (Networks 5, 6, 8, 13, 17, 18); and Buttonhole Technique (Network 17).
	"Managing Catheter Dysfunction for Better Patient Outcomes: A Team Approach, Nephrology Nursing's Perspective"	ANNA invited the QI Coordinator to be a speaker for their collaborative program with Genentech throughout the western United States.
	ANNA and Council of Nephrology Social Workers (CNSW) Pediatric Quality of Life	 The QI Coordinator and Patient Services Coordinator worked with the local chapters to plan and participate in "The Renal Update," their joint spring conference. A collaborative research project developed by the Mid-

16 Continued		Atlantic Renal Coalition (Network 5), which surveyed pediatric patients to evaluate quality of life and health status to establish baseline information on this special population. Activities in 2005 included planning via conference calls and identifying the preliminary study sample patients. Primary activities of the project were
	Barriers to Outpatient Placement	 scheduled to commence in early 2006. A collaborative project developed by Network 9/10 defined as both a disparities project regarding admission/discharge processes and a barriers project related to complicated health or behavioral issues that affect the ability of facilities to provide adequate care.
	Montana State Renal Conference	PCS was a co-presenter on "Putting Palliative Care into ESRD Practice"
	AAKP and RSNCouncil of Nephrology Social	PSC collaborated with patient care groups. PSC presented "Caring for Caregivers" at AAKP Annual Convention
	Workers	Common membship of PSCs
18	Barriers to Outpatient Placement	A collaborative project developed by Network 9/10 defined as both a disparities project regarding admission/discharge processes and a barriers project related to complicated health or behavioral issues that affect the ability of facilities to provide adequate care.

Source: Networks 1-18 Annual Reports, 2005

Networks actively seek partnerships and conduct activities with renal-related organizations and quality associations, and have also have forged relationships with advocacy and research organizations. Several organizations with which Networks participated during 2005 are listed below.

Renal Community

- American Association of Kidney Patients
- American Nephrology Nurses' Association
- American Society of Nephrology
- Assoc. of Health Facility Survey Agencies
- Independent Dialysis Organizations
- Large Corporate Dialysis Organizations
- Life Options Rehabilitation Advisory Council, Medical Education Institute
- National Assoc. for Technicians/Technologists
- National Kidney Foundation
- National Renal Administrators Association
- NIH/NIDDK
- Renal Physicians Association
- United Network for Organ Sharing
- United States Renal Data System

Non-Renal Related

- American Society of Quality
- American Healthcare Quality Association
- Centers for Disease Control and Prevention
- Food and Drug Administration
- Institute for Healthcare Improvement
- National Association for Healthcare Quality
- National Quality Forum

Many of the ESRD Network personnel are actively involved on renal community boards and committees. The following are some of the organizations in the renal community with whom Networks serve on boards and committees: National Kidney Foundation (NKF), the American Association of Kidney Patients (AAKP), the American Nephrology Nurses' Association (ANNA), the Renal Physicians Association (RPA), and NIDDK's National Kidney Disease Education Program (NKDEP).

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

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

The key components of the current CMS CROWN system are SIMS (Standard Information Management System), VISION (Vital Information System to Improve Outcomes in Nephrology), REMIS (Renal Management Information System), and Quality Net Exchange. Other systems which are not under CMS are dependent on the CROWN system include the USRDS (United States Renal Data System), the Social Security Administration (Master Beneficiary Record), and UNOS (United Network for Organ Sharing). The Kidney Epidemiology and Cost Center (KECC) also receives data from the CROWN system and standard Medicare Claims data to produce the annual Unit-Specific Report and the clinical data for Dialysis Facility Compare (DFC). The facility demographic data comes directly from the CROWN system.

The data collected and managed through the CROWN system serves multiple functions and has many users. CMS is a primary user of the data. One important purpose is determining the eligibility of ESRD patients for Medicare benefits for ESRD patients, from the initial certification of ESRD until the patient dies or is no longer eligible for benefits (e.g. if a patient regains kidney function or when patient has been transplanted for more than three years). The CROWN system provides a registry of all patients, including those who are not eligible or not applying for Medicare coverage. This data supports program analysis, policy development and epidemiological research by CMS, the Networks, CMS-approved researchers, and health planners.

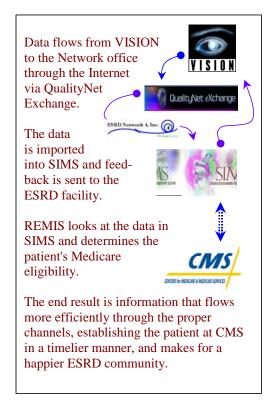
Another key function of the CROWN system is to provide quality oversight of the program. Currently, there are several, quality-oriented, public domain reports that are developed using CROWN:

- the Dialysis Facility Compare (DFC) website, which uses data from SIMS and REMIS to allow beneficiaries to compare ESRD facilities
- the FistulaFirst Dashboard that reports current fistula rates for ESRD facilities
- the Annual Clinical Performance Measures (CPM) Report
- the United States Renal Data System (USRDS) Annual Data Report

REMIS, SIMS, and VISION form the foundation for the CROWN system. SIMS is used by all of the eighteen Networks and is the repository for the entry, validation and maintenance and reporting of data submitted to the Networks by dialysis and transplant facilities. REMIS receives data from the Enrollment Database (EDB), CMS' repository for all patients enrolled in Medicare, Medicare Billing and SIMS. VISION is software developed by CMS to enable facilities to enter and submit their forms and clinical performance measures data electronically to the Network via Quality Net Exchange, a secure, HIPAA-compliant transport. CMS is also working with the large dialysis corporations to define elements and create files that will allow corporate data systems to provide data from their existing systems to CMS.

The next evolution for the CROWN system is to combine all the existing systems into a web-basd application shared by CMS, Networks, and facility users with role-based access.

The individual software package components can be thought of as a series of stages in which Medicare beneficiary information is processed as the following illustrates:



SIMS

The SIMS software is the backbone of Network data infrastructure. SIMS not only provides CMS with patient and facility data but is also used to record Contact information for analysis. The information entered in the Contact area of SIMS varies and may relate to a grievance, a data request, or a request for technical assistance. Due to confidentiality contact data is maintained at the Network level and only reported in the aggregate.

VISION

The VISION software is an equivalent of SIMS for use by dialysis and transplant facilities. VISION software records facility and patient information that can be submitted to the Network as an XML file. Using VISION, facilities can enter the non-reimbursable CMS forms: the CMS-2728 and CMS-2746. The Clinical Performance Measures (CPMs) were added to VISION this year. Long-range plans include converting VISION and SIMS to a role-based web application once CMS standards are released.

CMS is working with the larger national dialysis corporations (DaVita, Dialysis Care Incorporated, Fresenius Medical Care – North America, Gambro Healthcare, and Renal Care Group) to obtain quality data as files from their corporate systems. This includes DaVita, Dialysis Care Incorporated, Fresenius Medical Care - North America, Gambro Healthcare, and Renal Care Group. Networks are responsible for working with all of the other facilities not in large corporations to train them to use the software.

REMIS

REMIS is a web-based application and is used by the Network to verify patient information related to Medicare coverage. REMIS replaced REBUS in 2003.

QualityNet Exchange

QualityNet Exchange is a web-based application and is used by both the Network and the VISION facilities to transmit data in a secure manner. This application is accessed on a regular basis for the purpose of information exchange.

VISION Marketing

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. CMS established a June 30, 2005, goal for all Networks to train at least 40% of eligible facilities and for at least 20% of eligible facilities to be submitting data via VISION. 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.

In the early stages of this process, as the Networks began to market VISION, some challenges with the VISION implementation precluded rapid training and implementation. These challenges included:

- Facility staff turnover
- Quality of support from the QualityNet helpdesk
- Issuance of tokens by the QualityNet helpdesk
- Integrity of the transmitted data to the Network database
- Time and material utilized to support the VISION effort

Despite these challenges, Networks are optimistic that they will meet the prescribed goals before the CMS-established due date.

GOAL FIVE: EVALUATE AND RESOLVE PATIENT GRIEVANCES AS CATEGORIZED IN CROWN AND OTHER ADP SYSTEMS AS DIRECTED BY CMS

The Networks assume a proactive role in the prevention, facilitation, and resolution of complaints and grievances, including implementing educational programs that will assist facility staff in diffusing conflict and handling difficult situations. Networks also conduct trend analysis of reported situations to detect patterns of greater concern. Networks follow the CMS national policy in the ESRD Network Organizations Manual, for evaluating, resolving, and reporting patient grievances and facility concerns. Each Network has a formal grievance resolution protocol which is approved by CMS. Within 24 hours of receipt, Networks refer immediate and serious grievances to the appropriate CMS Regional Office and State Survey Agency. When requested by CMS, Networks assist the State Survey Agency with the investigation of a complaint. It is important to note that the State Survey Agencies have regulatory authority and responsibility for assuring facilities meet the conditions for coverage. Networks are concerned about the quality of care provided and improving the care ESRD patients receive as opportunities for improvement are identified.

The Network's ESRD Manual outlines several examples of the Network's role in resolving patient grievances. These include:

- **Expert Investigator:** This involves evaluating the quality of care provided to a patient where the investigation focus is the complaint. For example, if a patient complains about the procedures used by the dialysis nurse to initiate dialysis, the Network may investigate by reviewing the techniques used by the facility to initiate dialysis. At the conclusion of the investigation, findings are shared with the involved parties and when appropriate, recommendations may be made about the care provided.
- **Facilitator:** When communication between the patient and the provider/facility is difficult, the Network may be asked to facilitate communication and resolve the differences. For example, a patient may contact the Network to complain that the facility hours do not accommodate his/her work schedule. The Network may assist the patient by helping to discuss the situation with facility personnel or assist the patient in moving to another facility that can accommodate his/her needs.
- **Referral Agent:** Issues that are not specifically ESRD Network issues such as fire safety, handicap access to dialysis, civil rights, infectious disease, and criminal activity are more appropriately handled by either the State Survey Agency or other federal agencies. The Network may refer the beneficiary to the appropriate agency.
- **Coordinator:** Where both quality of care and survey and certification issues are involved (e.g., water quality or dialyzer reuse), the Network will coordinate the investigation with the appropriate State Survey Agency. The appropriate Regional Office is advised of the situation.
- **Educator:** When patients, families, or facility staff have questions regarding ESRD, the Network may provide the information. If the Network is not readily able to provide the education, the Network is able to refer the question to the appropriate source.

The Complaint/Grievance Procedure

The Network may receive a written, verbal, or electronic complaint or grievance from an ESRD patient, patient representative, family member, friend, facility employee, physician, State Agency, patient advocate, interested individual, or newspaper reporter concerning either dialysis or transplant facilities. The Network provides a toll-free number for patient use in the event of verbal inquiries, complaints, and

grievances. Complaints or grievances may also involve ESRD services provided in an acute care hospital, a nursing home, a home setting, or by a physician. The Network may also receive referrals of ESRD patient complaints or other ESRD concerns from Quality Improvement Organizations, State Agencies, Medicare 1-800 hotline numbers, and Medicare intermediaries. When verbal complaints and grievances are received, the person taking the complaint documents them in SIMS.

A <u>complaint</u> is a written, verbal, or electronic request for assistance initiated by, or on behalf of, an ESRD patient(s) regarding concern(s) about ESRD issues including, but not limited to care, treatment, or providers. A complaint is a request for assistance that requires Network staff to carry out information gathering/investigation and mediation and /or counseling and/or referral. Complaints require follow-up with the patient, provider, or other parties. Complaints include a wide range of beneficiary issues that are not formal grievances, but usually require more work by the Network staff than an inquiry for general; information, and may include referral to a State Agency or other Quality Improvement Organization.

A grievance is a request for a formal investigation of a complaint, or a serious complaint involving a facility, physician, or other provider. A grievance usually alleges ESRD services did not meet accepted standards of care, including services not provided. A grievance requires action by the Network, including investigation, a formal review of the information, an evaluation, with a determination of validity of the grievance and a summary report. A grievance may require the participation of the Medical Review Board, referral to the State Agency or other Quality Improvement Organization, or referral to the CMS Regional Office.

Complaints/grievances are encouraged to submit their complaint/grievance in writing, but it is not required. Once the information is received, Network staff will determine the most appropriate way to address the complaint or grievance. If a referral to an outside agency is required, Network staff will promptly make the referral. If the complaint/grievance is to be investigated by the Network, the Network will contact the facility or appropriate personnel for more information upon receiving the complainant's/grievant's verbal or written consent. This may include requesting documentation, interviewing facility staff, discussing issues with administration and corporate leadership, and possible on-site investigation or mediation. Network staff will work with the complainant/grievant and the facility or corporation to find an acceptable solution for all involved.

In the matter of a complaint, Network staff will document the resolution in writing to the complainant and the facility will be contacted by telephone or in writing regarding the resolution of the case. If the patient is not satisfied with the results of the investigation, the complainant/grievant is advised to contact the CMS Regional Office and /or the State Agency.

In the matter of a grievance, when necessary, the Network will make an appropriate referral to the CMS Regional Office. Otherwise, the Network will provide a report to the facility, physician and/or practitioners within 60 days of receiving the grievance, with an opportunity to submit additional information or comments relating to the grievance. The Network will afford the involved practitioner 15 calendar days (within the 30-day time period prior to sending the response letter to the complainant) to respond. The Network will advise the physician and/or the facility that a final report will be sent to the complainant. The Network will send a letter containing a grievance report and summary comments to all of the involved parties.

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. Where problems are identified the Network requires the facility to develop and carry out an improvement plan that will correct the problem(s). During 2005, Networks processed 43 formal beneficiary grievances. Table 19 displays the number of Formal Grievances processed in 2005.

TABLE 19 FORMAL GRIEVANCES PROCESSED CALENDAR YEAR 2005

NETWORK	NUMBER OF GRIEVANCES
1	0
2	1
3	1
4	0
5	8
6	0
7	2
8	0
9/10	3
11	0
12	12
13	3
14	5
15	1
16	0
17	0
18	7
TOTAL	43

Source: Networks 1-18 Annual Reports, 2005

Grievances come to the Network in many forms and from many sources including telephone calls and letters from patients, families, facilities, and concerned individuals or agencies. Though many of these complaints never reach the formal grievance stage, Networks dedicate large amounts of staff time responding to these complaints and assisting complainants. It is estimated that ESRD Networks process over 7,000 such patient complaints annually. Less than 1% of patients file a formal grievance at the Network level.

During 2005, Networks spent time discussing and focusing on "patient-provider conflict." Some of the Networks define the challenging patient as one who may act out in a violent manner or who is verbally abusive or threatening. However, facility staff can also create problems, and many do not have the crisis management skills needed to diffuse an escalating situation. Each Network has a social worker/patient services coordinator to conduct proactive work in this area. Many Networks continue to provide workshops and written material focusing on this issue and spend a great deal of staff time providing consultation to the clinics and assisting patients in an effort to prevent inappropriate discharges and to support a safe environment for patients and facility staff.

In January 2004, the Centers for Medicare & Medicaid Services (CMS) funded the Decreasing Dialysis Patient-Provider Conflict (DPC) project. The DPC Project was a coordinated, national effort by the ESRD community to understand, educate, and provide resources to the providers of dialysis services to better cope with the issue of conflict in dialysis facilities. The project goals were to help create safe dialysis facilities, provide training resources for handling conflict, improve patient-provider relations, improve

patient-provider satisfaction with the dialysis experience, and foster national collaboration on the development of a DPC Taxonomy & Glossary and in approaches to reduce conflict.

The National Task Force, comprised of 19 members, met three times during 2004 - 2005 in Baltimore, Maryland, to plan, review, and approve the work of the four subcommittees. Members also participated in and/or arranged for pilot testing in their facilities.

The DPC Project dissemination was completed in June 2005 with training for all ESRD Networks via WebEx sessions that were taped for future use. The DPC Poster was disseminated to all 4494 dialysis facilities in the US with a cover letter announcing the project. In this same time period DPC toolboxes were shipped to each ESRD Network in sufficient numbers to accommodate existing facilities with a small supply for new facilities. ESRD Networks conducted training and to disseminate facility-training toolboxes within their Network area during 2005 and 2006.

SANCTION RECOMMENDATIONS

Network responsibilities include the recommendation to CMS of alternative sanctions against facilities that are continually out of compliance with Network goals.

During 2005, no new sanctions were recommended to CMS; however, one 2004 sanction recommendation is ongoing (Network 11).

RECOMMENDATIONS FOR ADDITIONAL FACILITIES

Network responsibilities include making recommendations for additional facilities in the service area, as they become necessary to meet the needs of each particular Network area.

Several Networks made additional recommendations in their Annual Reports. These included:

- Assess the growing concern of coordination of care for dialysis patients in nursing homes (Network 2)
- CMS develop billing codes for short-term dialysis (non-chronic) patient population and consideration be given to future policy issues for these none-chronic patients with ESRD who require short-term outpatient dialysis treatments (Network 1, 6)
- Address the feasibility of "unique needs" dialysis units to reduce the number of patients experiencing an involuntary discharge from dialysis units (Network 1, 6, 13, 14, 18)
- Seek incentives to attract nurses to the ESRD program (Network 1)

FOR MORE INFORMATION

This Report summarizes highlights of the ESRD Networks' 2005 activities. For additional reference, Appendix S contains a list of acronyms and Appendix T a list of renal organization web addresses.

The following Internet addresses provide additional information about the ESRD Networks and the ESRD program. All Network websites (see table below) can be accessed through the home page of the Forum Office: http://www.esrdnetworks.org.

TABLE 20 NETWORK WEB ADDRESSES

Network	Web Address
1	http://www.networkofnewengland.org/
2	http://www.esrdny.org/
3	http://www.tarcweb.org/
4	http://www.esrdnetwork4.org/
5	http://www.esrdnet5.org/
6	http://www.esrdnetwork6.org/
7	http://www.fmqai.com/ersd/esrd.htm
8	http://www.esrdnetwork8.org/
9/10	http://www.therenalnetwork.org/
11	http://www.esrdnet11.org/
12	http://www.network12.org/
13	http://www.network13.org/
14	http://www.esrdnetwork.org/
15	http://www.esrdnet15.org/
16	http://www.nwrenalnetwork.org/
17	http://www.network17.org/
18	http://www.esrdnetwork18.org/
CSC/eSOURCE	http://www.esource.net/

NOTE: In 2006, Network 2 changed its website address to ckdny.ipro.org and Network 17 changed its website to www.esrdnet17.org

A copy of a specific Network Annual Report can be obtained from the individual Network office or by visiting the Network website linked through the Forum website. Network addresses and telephone numbers are listed on the inside front cover of this Report.

APPENDICES

APPENDIX A
2005 ESRD INCIDENT AND DIALYSIS PREVALENT PATIENTS BY NETWORK

NETWORK	ESRD INCIDENT PATIENTS	ESRD DIALYSIS PREVALENT PATIENTS
TIET WORLD	(CALENDAR YEAR 2005)	(AS OF DECEMBER 31, 2005)
1	3,867	11,109
2	7,033	22,769
3	4,732	13,875
4	5,261	14,639
5	6,465	19,883
6	8,749	31,544
7	6,637	19,254
8	5,697	18,686
9	8,409	24,076
10	4,617	14,067
11	7,536	20,793
12	4,097	12,465
13	4,372	12,923
14	8,355	29,371
15	4,734	15,042
16	2,955	8,874
17	5,040	17,353
18	7,811	26,341
TOTAL	106,367	333,064

Source: Networks 1-18 Annual Reports, 2005, Data Tables 1 and 2 $\,$

APPENDIX B 2005 ESRD INCIDENT PATIENTS BY AGE AND NETWORK CALENDAR YEAR 2005

NETWORK	0-19	20-29	30-39	40-49	50-59	60-69	70-79	≥ 80	UNKNOWN	TOTAL
1	47	64	147	384	572	829	1,011	813	0	3,867
2	77	157	333	729	1,282	1,515	1,645	1,295	0	7,033
3	40	106	216	428	841	1,066	1,162	873	0	4,732
4	40	96	218	513	894	1142	1352	1006	0	5,261
5	116	245	592	1,130	1,818	2,060	1,842	946	0	8,749
6	63	148	389	797	1,277	1,445	1,485	861	0	6,465
7	59	143	332	679	1127	1436	1641	1220	0	6637
8	58	152	377	729	1,195	1,303	1,248	635	0	5,697
9	86	157	395	799	1,637	1,871	2,115	1,349	0	8,409
10	62	117	251	501	847	1,028	1,074	736	1	4,617
11	100	161	367	793	1,343	1,616	1,846	1,310	0	7,536
12	54	87	202	411	711	884	1,014	734	0	4,097
13	48	130	260	478	848	1,026	991	591	0	4,372
14	105	261	473	1,013	1,877	1,963	1,728	935	0	8,355
15	89	142	268	524	945	1,077	1,085	604	0	4,734
16	32	81	135	299	560	614	747	487	0	2,955
17	62	132	256	612	911	1,132	1,165	770	0	5,040
18	112	214	388	838	1,488	1,710	1,823	1,238	0	7,811
TOTAL	1,203	2,593	5,599	11,657	20,173	23,717	24,974	16,403	1	106,367
% TOTAL	1.1%	2.4%	5.3%	19.0%	19.0%	22.3%	23.5%	15.4%	0.0%	100%

Source: Networks 1-18 Annual Reports, 2005, Data Table 1

APPENDIX C
2005 ESRD DIALYSIS PREVALENT PATIENTS BY AGE AND NETWORK
AS OF DECEMBER 31, 2005

NETWORK	0-19	20-29	30-39	40-49	50-59	60-69	70-79	<u>≥</u> 80	UNKNOWN	TOTAL
1	65	220	600	1,233	1,908	2,417	2,792	1,874	0	11,109
2	127	519	1,396	2,952	4,716	5,271	4,805	2,983	0	22,769
3	70	328	838	1,759	2,912	3,367	2,924	1,677	0	13,875
4	66	292	780	1,752	2,875	3,221	3,516	2,137	0	14,639
5	123	480	1,412	2,956	4,388	4,582	4,007	1,935	0	19,883
6	181	960	2,608	4,782	7,442	7,564	5,648	2,359	0	31,544
7	143	491	1,255	2,456	3,846	4,309	4,186	2,568	0	19,254
8	88	538	1,531	2,843	4,461	4,377	3,423	1,425	0	18,686
9	127	552	1,474	3,067	5,078	5,448	5,465	2,865	0	24,076
10	88	382	892	1,745	2,910	3,241	3,066	1,743	0	14,067
11	139	470	1,264	2,497	4,148	4,371	4,816	3,088	0	20,793
12	81	309	790	1,557	2,468	2,804	2,767	1,689	0	12,465
13	97	403	988	1,935	2,930	2,957	2,477	1,136	0	12,923
14	275	844	2,125	4,277	7,247	7,013	5,407	2,183	0	29,371
15	150	453	942	1,865	3,254	3,631	3,212	1,535	0	15,042
16	66	268	603	1,094	1,865	1,946	1,897	1,135	0	8,874
17	99	458	1,094	2,222	3,754	3,946	3,716	2,064	0	17,353
18	235	844	1,874	3,331	5,630	6,190	5,312	2,925	0	26,341
TOTAL	2,155	8,811	22,466	44,323	71,832	76,655	69,436	37,321	0	333,064
% TOTAL	0.6%	2.6%	6.7%	13.3%	21.6%	23.0%	20.8%	11.2%	0.00%	100.0%

Source: Networks 1-18 Annual Reports, 2005, Data Table 2

APPENDIX D 2005 ESRD INCIDENT PATIENTS BY RACE AND NETWORK CALENDAR YEAR 2005

NETWORK	BLACK	WHITE	ASIAN/ PACIFIC ISLANDER	NATIVE AMERICAN	OTHER 1	UNKNOWN ²	TOTAL
1	502	3,209	121	26	9	0	3,867
2	2,159	4,239	314	30	26	265	7,033
3	1,136	2,926	185	7	478	0	4,732
4	1,274	3,907	61	7	12	0	5,261
5	3,063	3,180	153	10	35	24	6,465
6	4,836	3,715	110	71	17	0	8,749
7	1,877	4,485	112	21	42	100	6,637
8	2,765	2,866	36	24	6	0	5,697
9	1843	6,427	38	9	33	59	8,409
10	1,386	2,871	117	6	28	209	4,617
11	1,701	5,504	120	177	34	0	7,536
12	856	3,167	41	27	6	0	4,097
13	1,717	2,434	39	162	20	0	4,372
14	2098	6054	141	46	16	0	8,355
15	404	3,745	171	409	5	0	4,734
16	181	2,485	188	97	4	0	2,955
17	669	2,956	1,344	39	32	0	5,040
18	1,093	5,810	858	31	19	0	7,811
TOTAL	29,058	69,980	4,149	1,199	822	657	106,367
% TOTAL	27.3%	65.8%	3.9%	1.1%	0.8%	0.6%	100%

Source: Networks 1-18 Annual Reports, 2005, Data Table 1. Patient numbers are derived from those patients receiving treatment.

¹ "Other" indicates patients for whom more than one race was selected; data taken from Network Annual Reports

² "Unknown" includes both "Missing" and "Unknown" data from Network Annual Reports

APPENDIX E
2005 ESRD DIALYSIS PREVALENT PATIENTS BY RACE AND NETWORK
AS OF DECEMBER 31, 2005

NETWORK	BLACK	WHITE	ASIAN/ PACIFIC ISLANDER	NATIVE AMERICAN OTHER 1		UNKNOWN ²	TOTAL
1	2,171	8,426	355	136	21	0	11,109
2	9,308	11,813	1,190	289	69	100	22,769
3	4,444	6,464	437	21	2,509	0	13,875
4	5,178	9,203	222	21	15	0	14,639
5	11,900	7,347	488	29	53	66	19,883
6	21,415	9,545	326	241	17	0	31,544
7	7,725	10,951	351	48	69	110	19,254
8	11,720	6,782	96	82	4	2	18,686
9	8,038	15,762	141	31	37	67	24,076
10	5,784	7,648	412	19	31	173	14,067
11	6,754	12,917	430	658	33	1	20,793
12	3,673	8,523	143	120	6	0	12,465
13	6,578	5,641	99	589	16	0	12,923
14	9,114	19,612	505	114	26	0	29,371
15	1,544	10,812	512	2,134	40	0	15,042
16	817	6,934	731	379	13	0	8,874
17	2,896	8,754	5,447	164	92	0	17,353
18	4,387	18,584	3,228	120	22	0	26,341
TOTAL	121,275	185,718	15,113	5,195	3,073	519	333,064
% TOTAL	36.4%	55.8%	4.5%	4.5%	0.9%	0.2%	100%

Source: Networks 1-18 Annual Reports, 2005, Data Table 2. Patient numbers are derived from those patients receiving treatment.

¹ "Other" indicates patients for whom more than one race was selected; data from Network Annual Reports

² "Unknown" includes both "Missing" and "Unknown" data from Network Annual Reports

APPENDIX F

List of Primary Causes of End Stage Renal Disease

Diabetes

- Type II, adult-onset or unspecified diabetes
- Type I, juvenile type, ketosis prone diabetes

Glomerulonephritis

- Glomerulonephritis (GN)
- Focal glomerulonephritis, focal sclerosing GN
- Membranous nephropathy
- Membranoproliferative GN type 1, diffuse MPGN
- Dense deposit disease, MPGN type 2
- IgA nephropathy, Berger's disease (proven by immunofluorescence)
- IgM nephropathy (proven by immunofluorescence)
- Rapidly progressive GN
- Post infectious GN, SBE
- Other proliferative GN

Secondary GN/Vasculitis

- Lupus erythematosus, (SLE nephritis)
- Henoch-Schonlein syndrome
- Scleroderma
- Hemolytic uremic syndrome
- Polyarteritis
- Wegener's granulomatosis
- Nephropathy due to heroin abuse and related drugs
- Vasculitis and its derivatives
- Goodpasture's Syndrome
- Secondary GN, other

Interstitial Nephritis/Pyelonehpritis

- Analgesic abuse
- Radiation nephritis
- Lead nephropathy
- Nephropathy caused by other agents
- Gouty nephropathy
- Nephrolithiasis
- Acquired obstructive uropathy
- Chronic pyelonephritis, reflux nephropathy
- Chronic interstitial nephritis
- Acute interstitial nephritis
- Urolithiasis
- Other disorders of calcium metabolism

Hypertension/Large Vessel Disease

- Renal disease due to hypertension (no primary renal disease)
- Renal artery stenosis
- Renal artery occlusion
- Cholesterol emboli, renal emboli

Cystic/Hereditary/Congenital Diseases

- Polycystic kidneys, adult type, (dominant)
- Polycystic, infantile, (recessive)
- Medullary cystic disease, including nephronophthisis
- Tuberous sclerosis
- Hereditary nephritis, Alport's syndrome
- Cystinosis
- Primary oxalosis
- Fabry's disease
- Congenital nephrotic syndrome
- Drash syndrome, mesangial sclerosis
- Congenital obstruction of ureterpelvic junction
- Congenital obstruction of uretrovesical junction
- Renal hypoplasia, dysplasia, oligonephronia
- Prune belly syndrome
- Other (congenital malformation syndromes)

Neoplasms/Tumors

- Renal tumor (malignant, benign, or unspecified)
- Urinary tract tumor (malignant, benign, or unspecified)
- Lymphoma of kidneys
- Multiple myeloma
- Light chain nephropathy
- Amyloidosis
- Complication post bone marrow or other transplant

Miscellaneous Conditions

- Sickle cell disease/anemia
- Sickle cell trait and other sickle cell (HbS/Hb other)
- Post partum renal failure
- AIDS nephropathy
- Traumatic or surgical loss of kidneys
- Hepatorenal syndrome
- Tubular necrosis (no recovery)
- Other renal disorders
- Etiology uncertain

Source: CMS 2728 ESRD Medical Evidence Report Form (06/04) EF (03-2005)

APPENDIX G 2005 ESRD INCIDENT PATIENTS BY PRIMARY DIAGNOSIS AND NETWORK CALENDAR YEAR 2005

NETWORK	DIABETES	HYPERTENSION	GN	CYSTIC KIDNEY DISEASE	OTHER CAUSES ¹	UNKNOWN	MISSING	TOTAL
1	1,499	956	415	133	654	210	0	3,867
2	2,803	1,580	555	177	1,132	636	150	7,033
3	2,298	1,234	384	89	641	86	0	4,732
4	2,180	1,378	421	114	889	279	0	5,261
5	3,818	2,729	656	161	1,079	306	0	8,749
6	2,715	1,993	439	167	869	231	51	6,465
7	2,782	1,949	478	159	952	166	151	6,637
8	2,320	1,930	357	136	713	143	98	5,697
9	3,475	1,926	554	185	1,038	1145	86	8,409
10	1,726	1,285	280	78	518	501	229	4,617
11	3,106	2,015	635	215	1,281	284	0	7,536
12	1,746	1,162	333	119	613	124	0	4,097
13	1,928	1,419	259	83	554	129	0	4,372
14	4,410	2,157	471	160	942	215	0	8,355
15	2,370	927	465	134	659	179	0	4,734
16	1,248	607	273	112	523	192	0	2,955
17	2,420	1,173	429	120	659	238	1	5,040
18	3,766	2,188	535	128	775	419	0	7,811
TOTAL	45,111	28,608	7,939	2,470	14,491	5,483	766	106,367
% TOTAL	42.4%	26.9%	7.5%	2.3%	13.6%	5.2%	0.7%	100%

Source: Networks 1-18 Annual Reports, 2005, Data Table 1

¹ Other Causes includes: "Other" and "Other Urologic" data from Network Annual Reports

APPENDIX H
2005 ESRD DIALYSIS PREVALENT PATIENTS BY PRIMARY DIAGNOSIS AND NETWORK
AS OF DECEMBER 31, 2005

NETWORK	DIABETES	HYPERTENSION	GN	CYSTIC KIDNEY DISEASE	OTHER 1	UNKNOWN	MISSING	TOTAL
1	4,273	2,537	1,559	443	1,730	567	0	11,109
2	8,929	5,551	2,802	692	2,935	1,787	73	22,769
3	6,174	3,667	1,748	374	1,598	314	0	13,875
4	5,987	3,947	1,763	425	1,937	580	0	14,639
5	7,853	6,680	2,005	505	2,215	603	22	19,883
6	12,848	10,214	3,483	684	3,249	1,066	0	31,544
7	7,551	6,101	2,065	580	2,341	518	98	19,254
8	7,380	6,548	1,804	528	1,869	494	63	18,686
9	10,239	6,333	2,478	623	2,729	1,595	79	24,076
10	5,370	4,508	1,351	299	1,394	950	195	14,067
11	8,637	5,850	2,379	625	2,610	692	0	20,793
12	5,128	3,427	1,480	372	1,587	471	0	12,465
13	5,508	4,332	1,172	328	1,268	315	0	12,923
14	15,011	7,419	2,539	612	2,802	988	0	29,371
15	7,828	2,708	1,761	425	1,787	533	0	15,042
16	3,715	1,652	1,279	382	1,406	440	0	8,874
17	8,129	4,107	2,221	471	1,797	628	0	17,353
18	12,015	7,537	2,697	625	2,361	1,106	0	26,341
TOTAL	138,302	93,118	36,586	8,993	37,615	13,647	530	333,064
% TOTAL	41.5%	28.0%	11.0%	2.7%	11.3%	4.1%	0.2%	100%

¹ Other includes data listed as "Other" and "Other Urologic" on Network Annual Reports

APPENDIX I 2005 ESRD INCIDENT PATIENTS BY GENDER AND NETWORK CALENDAR YEAR 2005

NETWORK	MALE	FEMALE	UNKNOWN	TOTAL
1	2,210	1,657	0	3,867
2	4,002	3,031	0	7,033
3	2,714	2,018	0	4,732
4	2,931	2,330	0	5,261
5	3,503	2,962	0	6,465
6	4,649	4,100	0	8,749
7	3,873	2,749	15	6,637
8	3,053	2,644	0	5,697
9	4,541	3,868	0	8,409
10	2,574	2,043	0	4,617
11	4,168	3,368	0	7,536
12	2,269	1,828	0	4,097
13	2,345	2,027	0	4,372
14	4,427	3,928	0	8,355
15	2,777	1,957	0	4,734
16	1,697	1,258	0	2,955
17	2,812	2,228	0	5,040
18	4,446	3,365	0	7,811
TOTAL	56,781	47,361	15	106,367
% TOTAL	53.4%	44.5%	0.0%	100%

APPENDIX J
2005 ESRD DIALYSIS PREVALENT PATIENTS BY GENDER AND NETWORK
AS OF DECEMBER 31, 2005

NETWORK	MALE	FEMALE	UNKNOWN	TOTAL
1	6,247	4,862	0	11,109
2	12,802	9,967	0	22,769
3	7,979	5,896	0	13,875
4	8,098	6,541	0	14,639
5	10,813	9,070	0	19,883
6	16,288	15,256	0	31,544
7	9,700	8,986	0	18,686
8	11,021	8,216	17	19,254
9	13,048	11,028	0	24,076
10	7,760	6,306	1	14,067
11	11,317	9,476	0	20,793
12	6,764	5,701	0	12,465
13	6,694	6,229	0	12,923
14	15,231	14,140	0	29,371
15	8,354	6,688	0	15,042
16	4,933	3,941	0	8,874
17	9,334	8,019	0	17,353
18	14,522	11,819	0	26,341
TOTAL	174,658	152,141	18	333,064
% TOTAL	52.4%	45.7%	0.0%	100%

APPENDIX K
2005 ESRD IN-CENTER DIALYSIS PATIENTS BY MODALITY AND NETWORK
AS OF DECEMBER 31, 2005

NETWORK	HEMODIALYSIS	PERITONEAL DIALYSIS	TOTAL
1	9,885	0	9,885
2	21,410	0	21,410
3	12,955	0	12,955
4	13,581	0	13,581
5	17,988	3	17,991
6	28,761	2	28,763
7	17,636	8	17,651
8	16,840	0	16,840
9	21,637	5	21,642
10	12,501	5	12,506
11	18,971	4	18,975
12	11,017	1	11,018
13	11,807	0	11,807
14	27,122	0	27,122
15	13,684	0	13,684
16	7,653	7	7,660
17	15,475	0	15,475
18	24,235	4	24,241
TOTAL	281,384	34	303,197

Note: In-Center Peritoneal Dialysis includes patients in training for home modalities. Data for this table is limited to facilities submitting a Facility Survey Form (2744) and Network SIMS Database. Not all Veterans Affairs facilities submitted a form in 2005.

APPENDIX L
2005 ESRD HOME DIALYSIS PATIENTS BY MODALITY AND NETWORK
AS OF DECEMBER 31, 2005

NETWORK	HEMODIALYSIS	CAPD	CCPD	OTHER PD	TOTAL
1	54	414	747	0	1,215
2	103	473	721	2	1,299
3	29	228	655	0	912
4	57	294	639	0	990
5	115	649	1,052	1	1,817
6	102	1,058	1,612	4	2,776
7	116	463	905	0	1,484
8	75	745	1,039	1	1,860
9	165	1,082	1,131	1	2,379
10	295	479	714	0	1,488
11	121	945	768	0	1,834
12	96	571	704	1	1,372
13	19	360	737	0	1,116
14	139	626	1,460	1	2,226
15	44	470	849	0	1,363
16	146	397	665	5	1,213
17	57	671	1,141	0	1,869
18	54	812	1,234	0	2,100
TOTAL	1,733	10,737	16,773	16	29,313

APPENDIX M
2004 AND 2005 DIALYSIS MODALITY: IN-CENTER PATIENTS
AS OF DECEMBER 31, 2004, AND DECEMBER 31, 2005

NETWORK	I	HEMODIAI	LYSIS	PER	ITONE	AL DIALYSIS
	2004	2005	% Change	2004	2005	% Change
1	9,685	9,885	2%	0	0	0%
2	21,006	21,410	2%	0	0	0%
3	12,468	12,955	4%	1	0	-100%
4	13,279	13,581	2%	0	0	0%
5	17,718	17,988	2%	0	3	0%
6	27,477	28,761	5%	0	2	0%
7	4,393	4,605	5%	0	0	0%
8	16,222	16,840	4%	0	0	0%
9	20,582	21,637	5%	11	5	-55%
10	11,928	12,501	5%	7	5	-29%
11	17,975	18,971	6%	0	4	0%
12	10,543	11,017	4%	11	1	-91%
13	12,322	11,807	-4%	3	0	-100%
14	25,320	27,122	7%	0	0	0%
15	13,027	13,684	5%	0	0	0%
16	7,321	7,653	5%	5	7	40%
17	14,957	15,475	3%	2	0	-100%
18	23,561	24,235	3%	0	4	0%
TOTAL	279,784	290,127	4%	40	31	-23%

Note: In-Center Peritoneal Dialysis includes patients in training for home modalities. Data for this table is limited to facilities submitting a Facility Survey Form (2744) and Network SIMS Database. Not all Veterans Affairs facilities submitted a form in 2005.

APPENDIX N
2004 AND 2005 DIALYSIS MODALITY: SELF-CARE SETTING - HOME
AS OF DECEMBER 31, 2004, AND DECEMBER 31, 2005

NETWORK	HEMODIALYSIS		CAPD		CCPD		OTHER PD					
NEIWORK	2004	2005	% Change	2004	2005	% Change	2004	2005	% Change	2004	2005	% Change
1	48	54	13%	385	414	8%	761	747	-2%	0	0	0%
2	102	103	1%	517	473	-9%	740	721	-3%	1	2	100%
3	24	29	21%	237	228	-4%	726	655	-10%	0	0	0%
4	36	57	58%	286	294	3%	627	639	2%	0	0	0%
5	81	115	42%	563	649	15%	903	1,052	17%	2	1	-50%
6	94	102	9%	941	1,058	12%	1,582	1,612	2%	3	4	33%
7	129	116	-10%	424	463	9%	931	905	-3%	0	0	0%
8	73	75	3%	638	745	17%	1,134	1,039	-8%	0	1	0%
9	131	165	26%	1,067	1,082	1%	996	1,131	14%	1	1	0%
10	251	295	18%	486	479	-1%	659	714	8%	0	0	0%
11	57	121	112%	884	945	7%	825	768	-7%	0	0	0%
12	98	96	-2%	552	571	3%	703	704	0%	0	1	0%
13	13	19	46%	443	360	-19%	723	737	2%	0	0	0%
14	112	139	24%	618	626	1%	1,416	1,460	3%	0	1	0%
15	37	44	19%	424	470	11%	807	849	5%	0	0	0%
16	160	146	-9%	379	397	5%	598	665	11%	2	5	150%
17	46	57	24%	627	671	7%	1,070	1,141	7%	0	0	0%
18	37	54	46%	773	812	5%	1,267	1,234	-3%	0	0	0%
TOTAL	1,529	1,787	17%	10,244	10,737	5%	16,468	16,773	2%	9	16	78%

Source: Networks 1-18 Annual Reports, 2004 and 2005

APPENDIX O
2005 RENAL TRANSPLANT RECIPIENTS BY DONOR SOURCE AND NETWORK
CALENDAR YEAR 2005

NETWORK	DECEASED DONORS	LIVING RELATED	LIVING UNRELATED	TOTAL
1	440	180	152	772
2	722	331	178	1,231
3	324	139	81	544
4	806	130	178	1,114
5	653	236	264	1,153
6	720	188	107	1,015
7	767	147	69	983
8	441	213	123	777
9	727	182	335	1,244
10	463	193	152	808
11	903	574	325	1,802
12	461	143	115	719
13	413	99	33	545
14	846	232	109	1,187
15	495	222	140	857
16	337	117	106	560
17	562	177	108	847
18	746	243	149	1,138
TOTAL	10,826	3,746	2,724	17,296

Source: Networks 1-18 Annual Reports, 2005

APPENDIX P VOCATIONAL REHABILITATION DIALYSIS PATIENTS AGED 18-54 YEARS AS OF DECEMBER 31, 2005

NETWORK	NUMBER OF DIALYSIS FACILITIES ¹	NUMBER OF DIALYSIS PATIENTS AGED 18-54	NUMBER OF DIALYSIS PATIENTS RECEIVING SERVICES FROM VOC REHAB RELATED SERVICE PROVIDERS (PUBLIC OR PRIVATE)	NUMBER OF DIALYSIS PATIENTS EMPLOYED FULL-TIME OR PART- TIME	PATIENTS ATTENDING SCHOOL FULL- TIME OR PART- TIME	FACILITIES OFFERING DIALYSIS SHIFT AFTER 5 PM
1	156	2,922	93	746	92	53
2	248	7,045	182	1,588	199	83
3	155	4,211	127	1,121	157	54
4	245	4,105	46	669	67	57
5	294	6,848	252	1,678	183	76
6	467	11,808	399	1,789	246	27
7	297	5,889	166	1,163	167	34
8	296	7,031	100	1,013	125	5
9	382	7,396	103	998	139	71
10	194	4,324	95	758	78	33
11	363	6,157	147	1,226	166	65
12	259	3,770	76	973	103	22
13	253	4,524	37	685	104	15
14	386	10,617	221	1,958	315	48
15	231	4,754	140	1,400	235	52
16	128	2,794	73	805	77	60
17	171	5,464	271	1,083	194	50
18	264	8,721	326	1,642	293	76
TOTAL	4,789	108,380	2,854	21,295	2,940	881

¹ Source: CSC

All Other Data: Source: Networks 1- 18 Annual Reports, 2005

APPENDIX Q NEW PROFESSIONAL EDUCATION MATERIALS AND WORKSHOPS CONDUCTED IN 2005 BY CATEGORY BY NETWORK

NETWORK	NAME OF PROGRAM/MATERIAL	BRIEF DESCRIPTION, INCLUDING AUDIENCE
	·	CLINICAL
1	 "The Patient Speaks" – Patient Education Video Fistula First Educational Booth Letters to Vascular Surgeons and Nephrologists Letters of Concern to Medical Directors/Nursing Managers "Reasons for Central Venous Catheters" "Your Patient Has Kidney Disease, What Can You Do To Help? - WebEx created for the Masspro QIO directed at hospital staff with 1 hr CEU- entitled 	 Distributed to all Networks and dialysis providers in New England as well as to facilities across the country upon request Setup during several American College of Surgeon's meetings in Connecticut and Massachusetts Included national and local data on vascular access trends, maps of each state were included with stratification from 10 to 100% prevalent AVF rates for comparison to their practice Sent to clinics with prevalent AVF rate lower than 40%; requested perceived barrier to improvement be shared with MRB and that they provide written plan of improvement Poster Presentation for the ASN meeting in Philadelphia, PA All facets of CKD care discussed including the importance of vein preservation & the benefits of the AV fistula. Over 10 hospitals participated with excellent feedback by the audience.
	 Vascular Surgeons Educational DVD Fistula First Workshop in collaboration with the RI & CT QIO New England early adapters, both surgeons & nephrologists volunteered to present at several Masspro QIO, SIP/SCIP meetings Vascular Access Education power point Vascular Access Passports & Vein Preservation cards Vascular Surgeon's outcomes tracking tool Fistula First Initiative articles 	 Distributed at the American College of Surgeons meeting, to the New England Society of Vascular Surgeons as well as upon request Presentation was directed at the hospital quality managers & discharge planners to educate them on the benefits of the AV fistula, vein preservation and vein mapping needed in the CKD patient. Directed at hospital administrators and MDs explaining why the Fistula First Initiative was an important way to reduce hospitalizations, morbidity & mortality related to vascular access in ESRD patients. Shared with the LDO outcome educators to assist in improving staff's knowledge of all types of vascular access. Network-designed cards that were included in the RPA's tool kit for CKD care. Developed to assist in creating feedback reports to surgeons & CQI team. Tool is being pilot tested by several providers. Written for both patient & QIO newsletters as well as professional journals. Educational articles to helped spread awareness of the benefits of the AV fistula, vein preservation & early referral to the nephrologists.
2	 Vascular Access Coordinator Workshops Surgeon Education Program 	 Network staff presented two regional workshops. Content included the role of the coordinator engaging nephrologists and surgeons, facilitating permanent access placement and tracking and profiling vascular access improvement. Collaboration with Networks 3 and 4 to sponsor a surgeon education program. Dr. William Jennings and Dr. Lawrence Spergel were guest speakers. Content included ultrasound use for pre- and post-operative venous mapping, constructional transpositional AV fistulas, converting established grafts to AV

2 Continued		fistulas and defining the role of the intervention radiologists in
	Network webpage	dialysis access. • Fistula First information is maintained on the Network website. Change Package, quality improvement tools and other information for providers and patients are located on a page devoted to Fistula First.
	• Quarterly Fistula First Standard Reports	• Include Network and National comparative data for prevalent AVF use; Facility-specific vascular access use (all access types); AVF placement in incident patients. Reports are sent to medical directors, nurse managers and provided to Fistula First workshop participants as an additional educational tool. Distribution of reports was suspended in May 2005 due to a problem and recommenced March 2006.
	• Surgeon Vascular Access reports	• Data Reporting Workgroup of the Fistula First Breakthrough Initiative suggested that there was a substantial interest in the surgeon community to receive surgeon-specific vascular access reports. A standard report form was generated and it was requested that all Networks distribute the reports. 316 reports were distributed. Three surgeons called, upset with the data in their reports because they felt their patients were grossly underreported. Reports did not include Medicare Part A, private insurers or uninsured patients. Issues will be considered by CMS prior to future distribution. Questionnaire of surgeon practice was also distributed.
	Fistula First Dashboard	 Document available online at the www.esource.net. Table showing the prevalent rate AVF used by Network and the percent of eligible facilities reporting
	Buffalo Collaborative	 Meetings of several Network physicians, local surgeons, the Network Executive Director and Quality Improvement Director (QID). Discussed possible coalition of stakeholders in the Buffalo area to improve AVF rates.
	CPM Data Collection Project	• Facilities identified to have significant numbers of patients with Hgb less than 11% will receive educational materials such as appropriate scientific articles, tracking and profiling tools, and technical assistance. Network requests that facilities provide periodic information documenting their progress toward improving Anemia outcomes.
3	• 2004 Annual Meeting Videotapes	 Distributed to all facilities, administrators and medical directors for spread in NVAII project.
	NJ Department of Health	 Provided list to NJ Department of Health and Senior Services with a list of facilities with higher catheter rates.
	 Fistula First Initiative Medical Directors Meeting 	Held in Puerto Rico
	• FistulaGram	• Update of current NVAII activities, Listed "Top 20 NW 3 centers with current fistula rate above 40%. Sent to facilities, medical directors, surgeons, departments of health and quality improvement organizations in NJ, Puerto Rico and Virgin Islands.
	Partnered with NW 2 and NW 4 to give surgeon courseNVAII Video	 Specific surgical procedures and techniques to improve fistula creation Sent to surgeons from all NW 3 facilities, video of surgical
	Fistula First Breakthrough	presentations.Developed two task forces: patient community education and
	Medical Material from the	professional education.Faxed and emailed to all New Jersey facilities including copies
	Center of Disease Control and Prevention	of "Recommendations for Preventing Transmission of Infections Among Chronic Hemodialysis Patients."

3 Continued	 "Buttonhole" Technique Video Obtained, copied and will be distributed to facilities inquiring to the technique
	 Patient Education material to all Access Coordinators Caring for & Developing Your New Fistula: What You Should Know
4	 Health Care Quality Improvement Program (HCQIP) Fistula First Breakthrough Initiative Change Concepts Surgeon Training Workshop Organ Procurement/ Transplantation Committee (OP/TC) 2005 Dialysis Facility Reports received from the University of Michigan Epidemiology and Cost Center Communicates with beneficiaries and health care providers to promote informed health choices, protect beneficiaries from poor care and strengthen the health care delivery system. Mission that every patient will receive the most optimal form of vascular access Strategies for success to increase AVF placement and use. Network 4 collaborated with Networks 2 & 3; attended by 70 surgeons. Advisors to the Network; recommended strategies to increase referrals for transplantation Sent to each facility Medical Director and Administrator.
	 Information CD Sent to State Survey Agencies and Quality Improvement Organizations and to Patty Clark-Anderson of CMS Region III. 10 requests were received and were sent to recipients CMS authorized the individual Networks to conduct Network specific quality improvement projects using an approved data set for the 4th quarter 2004. Network 4 elected to collect 100% of the data elements from 100% of the patients. Data from the Large Dialysis Organizations (LDOs) were transmitted to CMS. Data from the non-LDO providers were requested to be submitted to the Network via hardcopy, or electronically if possible.
	 University of Michigan 2005 Dialysis Facility Report Distributed copies to facility Administrators and Medical Directors
5	 Fistula First Teaching Module Laboratory Data Collection Utility Available on Network website and downloaded 876 times in 2005 Data requests were sent to 96 independent dialysis providers. They were provided with information about use of the Utility and the paper tool and asked for facilities to select the data submission method that worked best for them
	 Fistula First Poster University of Michigan 2005 Dialysis Facility Report Staff Workshop and Cannulation Trainings Cannulation Session Network 5 Goals and Recommendations and Transplant Survival Summary Statistics Displayed at Virginia Association for Healthcare Quality annual conference Distributed copies to facility Administrators and Medical Directors Four workshop were given with a total of 125 attendees Mailed to each Network transplant center
	 Fistula First Presentations Nine presentations given to over 200 renal professionals; participants receive a workbook that includes Change Concepts, all the tools and resources developed in national project activities, K-DOQI guidelines and articles from literature. Surgical DVD set Fistula First Video/DVD from the Patient's Provided to Network facilities Provided to Network facilities

F.C: 1		
5 Continued	perspective	• Circuit and the latest the second of the latest the latest the latest the second of the latest the latest the latest the second of the latest the late
	Physician Sessions	 Six sessions were held with a total of 119 nephrologists and surgeons
	Physician Sessions	 Two sessions held with a third planned in 2006. Network received an educational grant from Amgen to support focused activities
	"Implementing Advance Directives: A Patient's Right" meeting in Washington, DC	 Representatives from LDO's, Renal Physicians Association, National Hospice and Palliative Care Organization, Centers for Medicaid and Medicare, attorneys and other considered experts in the field to discuss implanting end-of-life palliative care programs in all dialysis units
	• <u>www.kidneyeol.org</u>	Kidney End-of-Life Coalition website provides state-specific forms for download
	• In-Center Hemodialysis Consumer Assessment of Health Plans Survey	 Network 5 was one of 4 Networks chosen to pilot a version of this survey for use in dialysis facilities
	Quality Update Newsletter	 Six issues distributed in 2005; renamed to "Quality REMARCS"; distributed to administrators, head nurses and medical directors
	Patient Safety Poster"Back to School" session	 Distributed to all dialysis facilities for National Quality Week Educate dialysis staff in more rural areas of the Network; 4 sessions touched on vascular access, data submission, the Network, hospice and ESRD patients, patient safety and the effects of high protein diets for renal patients; 60 in attendance
	AV Fistulas for Hemodialysis Access: The Right Type, The Right Place, The Right Time	Total of 205 attending four presentations
	Buttonhole Cannulation Technique	• 50 in attendance
	Implementing Advance Directives: A Patient's Right	• 41 in attendance
	"Summer School" Tour	 Included presentation "Data Submissions Request How, When and Why;" Total of 101 attending three sessions
	• Fistula First: A Call to Action	• 23 in attendance
	Decreasing Patient Provider Conflict	Total of 46 attended three WebEx trainings
	Fistula First	• 43 in attendance
	Data Submission Training	Total of 169 attended two WebEx trainings
	Data Contact: General Information Packet	Distributed upon request
6	Educational Dinners	• 2 events were held, directed toward Nephrologists, Surgeons, Interventional Radiologists, Vascular Access Coordinators and other professionals. Speakers presented on the project, technique and methods to increase fistulas. John Ross, MD FACS spoke at February dinner. Lawrence M. Spergel, MD, FACS, Clinical Chair of the Fistula First project and Jack Work, MD spoke at October dinner. 73 participants attended these dinners.
	Network 6 Resource Directory	 Contains several items aimed for dialysis patients: nutrition for dialysis patients, rehabilitation including two aimed specifically at employment, 75 items aimed at renal transplantation and organ donation, items related to home hemodialysis and peritoneal dialysis
<u>l</u>	Cofo 0- Timeolar	75

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6 Continued	 Safe & Timely Immunizations Coalition (STIC) August meeting, Atlanta, GA New Facility Orientation Package Transplant Posters Five Cannulation Workshops 	 Identified existing factors supporting the goal of increasing immunizations and potential barriers to reaching that goal. Three workshop group directives were to focus on immunization education, data collection and ESRD-specific guidelines. Mailed to every new facility Administrator or other applicable staff member in the Network; Example of contents include: patient education videos, grievance process, disaster and emergency information, Network 6 Member Agreement and Mini-Directory. Mailed to facility social workers More than 300 nurses and patient care technicians attended workshop in Cary, NC, Columbia, SC, Charlotte, NC, Atlanta, GA and Savannah, GA. Lecture and hands-on training conducted by Lynda Ball, RN, BSN, CNN, Quality Improvement Director
7	 Fistula First Minicollaborative "Fistula First – Catheter Reduction Project" by Arif Asif, MD 	 Dialysis facilities could test and measure practice innovations. 47 facilities accepted the challenge. Presented at Network 7 Annual Forum, attended by 325 renal professionals
	"Collaborating for Improvement" by Kelly Mayo, MS	 Presented at Florida Renal Administrators Association Summer Meeting, 45 renal administrators attended.
	• "FMQAI: The Florida ESRD Network – 2005 Update" by Sharon Aiken, RN, CNN	St. Augustine Symposium; 50 renal professionals attended
	 "Outcome Congress" by Janet Holland, RN, CNN; Kay Bregel, RN, CNN, Bruce Kuolryk, MD; Suresh Lakshriminaryanaw, MD 	Learning Session III attended by 59 renal professionals.
	 "Fistula First Grand Rounds - Alternative Surgical Innovations" by Thomas Huber, MD and "Current Status of the Fistula First Initiative" by Kelly Mayo, MS 	Attended by 11 surgeons.
	• Fistula First Champion Presentations	By Thomas Huber, MD and Victor Bowers, MD
	 "Collaborating for AVF Improvement" by Kelly Mayo, MS, Cindy Woodward, RN, Susan McGovern, MS, ARNP 	 Quality Improvement Organization Project Kickoff. 136 Hospital QI staff attended
	 "Creating AV Fistulas in All Eligible Hemodialysis Patients" DVD 	Distributed to 150 surgeons via email request.
	AVF Surgical Placement Summary Report	• Distributed standard Summary Report and supplemental graph to 400 vascular surgeons, transplant surgeons and physician assistants.
	• "Are Your Patients At Risk for Kidney Disease?"	 Describes patient benefits for early referral to a nephrologist. Distributed to 425 primary care physicians.
	QIO Hospital Newsletter	 Distributed to 186 hospitals as part of the Surgical Care Improvement Project.
	• "A Practitioner's Resource Guide to Hemodialysis	 Distributed in new facility packets and to nephrologists and surgeons, as requested.

7 Continued	Arteriovenous Fistulas" & "A	
/ Continued	Practitioner's Resource	
	Guide to Physical Examination of Dialysis Vascular Access" both by Gerald Beathard, MD	Materials distributed describing change package and AVF placement rates for incident ESRD patients. 50 nephrologists attended.
	Fistula First Initiative - Florida Society of Nephrology exhibit	Available to all facilities within three months after project approval
	"Hemodialysis Adequacy Toolkit"	Distributed to nephrologists at staff at facilities included in the project.
	K/DOQI Guidelines and DOPPS articles	CD distributed to facilities. One continuing education unit was available for nurses completing training through Network 7's website.
	• "Strategies for Improving Adequacy" educational presentation	Distributed to facilities included in the project
	Quality Improvement plan format and sample plan	Posted on Network 7 website to assist facilities in submitting data.
	Hemodialysis Adequacy Monitoring Form	Introductory Fistula First information and its relationship to QIO Surgical Care Improvement Project distributed as resources to Florida hospitals.
	• Fistula First Tools and • Website	Distributed upon request.
	"Tools and Resources for Assessing Functional Status of ESRD Patients"	Network staff the meeting. Topics included: Medicaid prescription resources, Medicare Part D, NKF of Florida professional, patient and CKD programs
	CNSW Meetings at FMQAI	Collaborated with LifeLink Healthcare Institute; designed specifically for renal professionals
	• Free Medicare Part D • workshop	Presented at DaVita Sunsational Divisional Meeting
8	• 2005 Renal Update •	FistulaFirst exhibit to annual meeting of nephrology nurses, dietitians and social workers.
	Vascular access workshops	Workshops conducted by Debbie Brouwer (Jackson, MS) and Lynda Ball (Nashville, TN and Montgomery, AL) focusing on access assessment and cannulation theory and techniques.
	Alabama College of Surgeons Meeting	FistulaFirst exhibit by Network 8 and presentation made by Fistula First work group surgeon.
	• Fistula First Surgical Video • Set.	Distributed with meetings and by request
	Larry Spergel, MD—site visit; Nosratollah Nezakatgoo, MD	Network 8-hosted event during which Dr. Spergel visited two facilities, conducting rounds with nephrologists and providing separate presentation to facility staff on Fistula First goals and patient access evaluation/planning/care. In addition, Dr. Nezakatgoo made an additional presentation to physicians on surgical techniques for AVF creation.
	ANNA publication	Working in collaboration with one facility's vascular access coordinator, Fistula First success story was submitted for publication.
	Fistula First Special Edition newsletter	Newsletter collaboration between Network 8 staff and providers in Network 8 region published and distributed to each facility and medical director.
9/10	• Fall Pediatric Renal • Symposium	2-Day educational; Topics include: Cultural sensitivity, using child life resources, Fistula First for pediatrics, immunizations, HUS, BK, Virus and review of case histories. 50 pediatric center representatives participated.

9/10 Continued	• Transplant Educational Packet	Developed for Transplant Awareness Month, sent to Nurse Managers and available on the Network website
Jonandea	Vascular Access CD/DVD	 Developed through the University of Oklahoma and provided to all surgeons in the Network area. Surgeon-specific claims
		data was provided to all surgeons along with a surgeon survey.
	Fistula First Newsletter	 Introduced in December 2005; copies provided to all dialysis facilities
	 Fistula First Educational Campaign 	 Sending resources and material via direct mail, quarterly, to nurse managers
11	Fistula First Taskforce	 Build awareness of Fistula First project by communicating and sharing resources with facilities' personnel, medical directors, surgeons and patients.
	• Video "Your Access to Success"	 Patients talking to patients on the importance of having a fistula; video premiered at Network 11 annual meeting and was then distributed to all Network 11 facilities.
	• Fistula First Workshops	 Resources shared, quality improvement plans written incorporating concepts from the national change packet. Best practice facilities shared their strategies for AFV improvement during bi-monthly conference calls. Audience included: facility nurses, medical directors and vascular access coordinators.
	Fistula Awareness Week	 Network 11 facilities received materials to promote the event; materials included tools to reach patients e.g. Your Access to Success video and accompanying poster and brochures. Included were tools to aid staff education.
	Fistula First Newsletter	 Includes information on upcoming Fistula First events, current data trends, best practices, tools and resources, and national and Network 11 goals; sent to all Network 11 dialysis facilities. Lowest Quartile AVF-rated facilities were asked to complete
	Facility Action Plan	 Lowest Quartile AVF-rated facilities were asked to complete and implement an action plan involving facility, nephrologist and vascular access surgeon collaboration. Network 11 staff followed-up with these facilities to assess the effectiveness of the implemented change concepts. 10% overall improvement was achieved. Initiative has been expanded to include all Network 11 hemodialysis facilities.
	 Fresenius Medical Care (FMC) and DaVita partnerships 	 FMC and DaVita regional representatives worked with NW 11 regarding partnership opportunities to increase AVF rates. Regional comparative facility reports were prepared to use in their quality improvement processes and regional cannulation workshops have been planned for 2006.
	 Fistula First Best Practices sessions held at NW 11 Annual Meeting 	 First session highlighted three NW 11 facilities with best practices that led to significant improvement in their AVF rates. Second session highlighted the best practices of nephrologist/nephrology nurse practitioner team that lead to significant improvement in their patients' AVF incidence rates.
	Vascular Access Claims Data	2004 Vascular access claims data was distributed to NW 11 surgeons; data included ratio of AVF places as compared to arteriovenous grafts (AVG), as well as state and network comparison. Data was accompanied by two-page questionnaire. Results reviewed by NW 11 Fistula First Task Force.
	Upper Midwest Fistula First Coalition	Three workgroups were formed to focus on further improvement in AVF: Chronic Kidney Disease (CKD) Early Referral; CKD Management; ESRD.

12	Kidney Transplantation, Overvie	ew of current trends. Audience included dialysis facility
	(Daniel Murillo, MD, FACS) manage • Pathogenesis of Renal • Overvio	ers, nurses, dietitians, social workers, and physicians. ew of osteodystrophy. Audience included dialysis facility ers, nurses, dietitians, social workers, and physicians.
	Management of Secondary Audience	drug therapy for secondary hyperparathyroidism. ce included dialysis facility managers, nurses, dietitians, vorkers, and physicians.
		lrug therapy for renal osteodystrophy. Audience included facility managers, nurses, dietitians, social workers, and ans.
13	the Fig	ch applicable QI tools based on 11 change concepts in stula First Initiative. Distributed at all Network ops and upon request.
	Reports months	h FF data analysis, change concepts. Distributed every 6 to surgeons, interventionalists, nephrologists, dialysis rse managers, facility administrators, LDO chief medicales.
		aVG ratios provided from claims data. Analysis focused eons performing vascular access for hemodialysis.
	"Creating AV Fistulae in All upon re	n / interventionalist training course (CME provided equest). Distributed upon request throughout NW to as, nephrologists, radiologists.
	Cannulation Training and can Sessions City, O	g to assist dialysis nurses/technicians in AVF evaluations nullations. Sessions held in Shreveport, LA, Oklahoma K, and Little Rock, AR
	13 Mentoring Workshop Worksh Hyperto	topics presented at the ESRD Network 13 Mentoring nop. Areas include: Anemia, Adequacy, DOPPS, ensive management, Fluid Management, Stages of CKD, ransplantation. Attendance at the workshop was 159 ants.
14	Contain utilization tools, N K/DO cannula procedu	o nephrologists, nurses, surgeons and administrators; as project information, facility specific vascular access on data, statewide AVF ranking, facility self-assessment NVAII change package and recommended strategies, QI VA Guidelines, Fiscal Intermediary information, and clamping procedures, Secondary AVF are and a vide demonstrating vascular access physical and cannulation.
		ed aggregate and surgeon specific Medicare Part B r access placement data
	Fistula First regional educational programs Nine programs nurses, clinical	rograms attended by over 350 physicians, surgeons and focused on Fistula First Project, change strategies, practice presentations given by surgeons, radiologists, logists and nurses.
	Fistula First presentation	hted strategies and FF data was displayed at regional conferences. Accompanied by distribution of
	facilities project	ast fax, email or US Postal Service used to notify ESRD s and personnel of important patient-care concerns, updates, data collection activities, educational programs ilability of Network resources.

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15	 Dialysis Access-Chronic Kidney Disease Coalition (DA-CKD) "Creating AV Fistulas in Most (All?) Hemodialysis Patients" Network 15 Update "Fistula First Access Options" "On Course with Cannulation" workshop "Forms Compliance Workshop" Fistula First Project 	Arizona Presented to local DaVita Facility Administrators monthly meetings throughout 2005 Quarterly, Network summarizes fistula data and reports back to facilities using monthly SIMS-generated reports; Network Summary Reports are distributed to all Facility Administrators and Medical Directors as well as surgeons in AZ, CO, NM, NE, UT, WY.
	"Medicare Prescription Drug Coverage: The Basics"	Written by Network 15 in collaboration with the National Kidney Foundation Medicare Modernization Program Manager and a CMS Region VIII representative; distributed to all Network facilities
16	DaVita Trainings	2 Trainings; Quality Improvement Coordinator (QI Coordinator) presented on "Quality Measures and Provider-Patient Interactions for Renal Dietitians"; QI Coordinator and QI Consultant covered infection control for patients, safety precautions in dialyze reprocessing, understanding and monitoring water, documentation, policies and procedures, importance of periodic CQI review, ANNA standards of practice and appropriate follow-up for adverse incidents
	Buttonhole Technique ANNA monograph article	
	Buttonhole information and reference sheet	Created and submitted to NCC and CMS for Fistula First booth at the ANNA symposium and displayed at QualNet Fistula First booth
	• "Preparing the Vascular Access for Cannulation" article	Emailed to facilities
	 Surgical video, surgeon data and surgeon survey Surgical Video 	Mailed to 153 Network surgeonsMailed to 21 interventional radiologists and 13 additional
	AVF Outcomes for Network, states and facility-specific	surgeons Mailed to all facility Medical Directors along with a CD/DVD on "Creating AV Fistulae"
	 update Network, states and facility-specific trend data and AVF outcomes 	• Mailed to all facility representatives and nurse managers
	Transplant Alphabet Soup: Helping the Patients Understand It All	Powerpoint presentation developed by the QI Coordinator to enable staff to provide current and correct information to patients about the modality choice of transplantation; presented during Renal Care Group Meeting
	"Determining Maturity of New Fistulas"	Powerpoint presentation developed by the QI Coordinator to improve patient care staff skills as to when to cannulate a new fistula

16 Continued

- Vascular Access
 Troubleshooting
- "Staff Can You See It, Patients Won't You Let Them, The Importance of Washing Your Access Arm" and "Preparing Vascular Access for Cannulation"
- "On Course with Cannulation" booklets
- Annual Dimensions in Dialysis Conference
- AAKP Annual Convention
- Clover Park Technical College Presentations
- CNSW Oregon Chapter Meeting and Northwest Chapter Meeting
- "Improving Your AV Fistula Cannulation Skills"
- "Dealing with Patient Preferences for Specific Staff Members for Cannulation"
- Seattle Veterans Administration Hospital
- Idaho NANT Chapter Conference
- ANNA Cascades Chapter Meeting
- Fistula First Trainings
- St. Patrick's Dialysis Center
- "The Cost of ESRD"
- ANNA Siskiyou and Cascades Chapters
- ANNA San Joaquin Meeting
- ANNA Greater Puget Sound Annual Meeting
- "On Course with Cannulation"

- Powerpoint presentation developed by the QI Coordinator to look at issues related to all forms of vascular access
- Provider and Patient articles promoting patient safety written by the QI Coordinator
- Provided to attendees at Boise, ID NANT meeting
- PSC participated in panel presentation regarding Ethics in the dialysis setting, including end of life issues and challenging situations
- PSC presented on Caring for Caregivers, moderated a panel of family members on the same topic, and hosted a lunch with the expert roundtable on caregiver issues
- PSC presented on "Putting Professionalism into Practice" for PCT training classes
- PSC presented on train-the-trainer session on the DPC program toolkit
- Published in ANNA Nephrology Nursing Journal, written by OI coordinator
- Published in ANNA Nephrology Nursing Journal, written by QI coordinator
- QI Consultant presented "Monitoring Your Dialysis Water Treatment System" and a full educational program for technicians.
- QI Consultant presented on "Monitoring Your Dialysis Water Treatment System" and information on nocturnal dialysis
- QI Consultant presented on "Providing Safe Water Treatment"
- QI Coordinator conducted 40 trainings for facility staff at regional locations within the Network; topics covered included national Fistula First Initiative, improving cannulation technique and using the buttonhole technique for cannulation of AVFs.
- QI Coordinator conducted buttonhole technique training with staff of St. Patrick's in order to initiate a buttonhole program
- QI Coordinator presented to senior Seattle Central Community College nursing students.
- QI Coordinator presented "Getting to Know the Network", "Neckties, Doorknobs and Catheters: What do They Have in Common", "A Buttonhole Program for Dialysis Facilities"; QI Consultant presented "Understanding and Monitoring Your Dialysis Water Treatment System"
- QI Coordinator presented "On Course with Cannulation", "Buttonhole Technique" and "Managing Dysfunctional Catheters"
- QI Coordinator presented "The Buttonhole Technique"; QI Consultant presented "Monitoring Your Water Treatment System"; PSC was moderator for a breakout session "Renal Resources"
- QI Coordinator presented at ANNA Chumash Annual Meeting, to dialysis facilities in the greater Indianapolis area and

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16 Continued		during Networks 5, 6, 8, 13 and 17's Cannulation Training Programs. Videotaped for the CMS Fistula First national cannulation video.
	• "Managing Catheter Dysfunction"	QI Coordinator presented at ANNA Pacific Island Chapter Meeting and ANNA Salt Lake City Chapter Meeting in collaboration with ANNA local chapter and ANNA national office.
	• "Hemodialysis Catheter Management, Are We That Different?"	QI Coordinator presented at Canadian Association of Nephrology Nurses and Technicians (CANNT)
	"Buttonhole Technique"	QI Coordinator presented at Renal Care Group Meeting, Mt. Sinai Dialysis Center and during Network 17 Cannulation Training Programs.
	• "Neckties, Doorknobs and Catheters: What do They Have in Common?"	QI Coordinator presented at Renal Care Group meeting, Samaritan Dialysis Services annual meeting
	• "AVF: Construction, Development and Cannulation"	QI Coordinator presented at the NKF annual conference
	Northwest Kidney Centers Patient Expo Day	QI Coordinator presented buttonhole/self-cannulation talk. PSC and QI Coordinator provided patient education materials from their booth at the expo.
	Annual Dialysis Conference	QI Coordinator presented two programs: "AV Access Cannulation" and "Strategies to Comply with CMS" Fistula First Project.
	Kaiser Permanente Annual Meeting	QI Coordinator spoke on cannulation techniques
	• Montana State Renal • Conference	QI Coordinator, PSC and QI Consultant were key presenters. Topics included: "Setting Up a Buttonhole Program - With Hands on Practice", "Hemodialysis Water Safety Issues" and "Putting Palliative Care into ESRD Practice"
	• Strategic Partnerships for Change Coalition Meeting	Safe Water in Montana (SWIM); purpose of building relationships between dialysis facilities and municipal water suppliers to improve patient safety with effective communication to prevent patient complications related to changes in the water supply
	AVF Surgical CD/DVD	Sent to all Medical Directors
	"Improving AVF Cannulation Skills" article	Submitted to ANNA Journal and published December 2005
	• "Clinical Consult" article •	Submitted to ANNA Journal and published September 2005
17	Fistula First Change Package	Fistula First Change Toolkit was mailed to all Network 17 facility Nurse Managers, Medical Directors, Nephrologists and Vascular Surgeons. It was also distributed at local and professional meetings where Network Staff held a Fistula First information booth.
	• Fistula First Workgroup Committee (subgroup of MRB – comprised of Nephrologists, RN's, a vascular surgeon and the Network 17 staff)	Frontline staff training to ensure maintenance of new AVF access through proper cannulation techniques.
	• Focus on facilities with less than 30% AVF rates at the end of Quarter 1.	MRB mailed Medical Directors and Nurse Managers at these facilities were mailed letters and copies of their vascular access data reports. They were asked to submit a Quality Improvement Plan (QIP) in regards to vascular access. After 30-days, if there was no response, a follow-up letter and educational materials along with sample QIP tools were sent along with a reminder

17	Continued	

• Facility Visits to those reporting less than 30% AVF

- Fistula First data reports
- Nephrologist and Surgeon Involvement
- "Creating an AV Fistula in All Eligible Hemodialysis Patient" CD/DVD
- Fistula First Information
 Poster Session and Staffed
 Booths at professional
 meetings
- New Fistula First Website CMS Press release
- Four special newsletters
- Cooperation with the Department of Health personnel in Hawaii
- Four "On Course with Cannulation" workshops (3.5 hours in length) held in collaboration with Network 16
- Creative Cannulation Workshops (4 hours in length)

- that participating in Network activities was required. Many of returned QIPs referred to changes that were already underway to achieve higher-level AVF rates.
- Quality Improvement staff traveled to Central Valley region at the end of the first quarter to meet with Medical Directors and Nurse Managers regarding low AVF rates. Additional copies of vascular data access reports and educational materials and sample QI tools were given during these visits. Early referral and surgeon referral plans were discussed. Follow-up visit was made at the end of the fourth quarter to setup preliminary dates for cannulation in early 2006. Problems with delayed access intervention and an established fistula were discussed. Clinic Manager and Medical Director were presented with additional Fistula First materials and copies of the surgeon training CD/DVDs.
- Network staff prepared reports for Chairman on the Fistula First Initiative for a presentation given to Network facilities in the Central Valley of California.
- Information bulletins regarding newly revised G0365 Vessel Mapping Code was mailed to all Nephrologists and Vascular surgeons in the Network 3.
- CD/DVD made available through CMS National Vascular Access Improvement Initiative and were developed by Dr. William Jennings, MD and Dr. Lawrence Spergel, MD. Request forms for complimentary CD/DVDs were sent to all Medical Directors, Nephrologists and Vascular Access Surgeons. 100 CD/DVDs were mailed in 2005.
- Poster Sessions and Staffed Booths held at the following professional conferences: NKF – Northern California Kidney Early Evaluation Program (KEEP); NKF – Northern California Annual Meeting; TransPacific Renal Network Annual Meeting; Creative Cannulation Workshop Booth
- Faxed and included CMS press release regarding new Fistula First website in Network Newsletter
- Newsletters to update facilities on new changes; special newsletter developed and distributed during Network Annual Meeting; special newsletter developed regarding facilities visited in Hawaii and Pacific Islands during cannulation workshops.
- Network staff distributed vascular access data reports including Hawaii AVF prevalence and incidence rates by provider. AVF prevalence rate by region and Hawaii aggregate vascular access prevalence and incidence data by month and dashboard results to the Chief of the Department were also distributed
- Taught by Network 16's QI Coordinator. Held in California and Hawaii. Workshops were open to all RNs, patient care technicians and LVNs. Objectives:
 - Identify symptoms of Steal Syndrome
 - Demonstrate the Allen Test
 - Introduce the Buttonhole Technique
 - Identify patient advantages for using Buttonhole Technique
 - Demonstrate technique for identifying venous stenosis in a hemodialysis patient
- Taught by QID. Held in Honolulu, Hawaii. To increase knowledge and proficiency in cannulation, fistula care and maintenance of new AV fistula. QID presented "Master Cannulator" program. Physician Clinical Advisor to the Fistula First Initiative and an MRB member presented information

17 Continued		regarding Buttonhole Technique in conjunction with the
17 Continued	 Clinical Advisor to NVAII held surgical grand rounds Vascular Access Tool Core standard indicating AVF, AVG, catheter, Network and National access rates Cooperation with LDO and Non-LDO quality managers Cooperation with Vascular Surgeons 	regarding Buttonhole Technique in conjunction with the cannulation workshops. Surgical grand rounds at the local hospital in Honolulu, Hawaii. Information packets regarding Fistula First Initiative were distributed to all 25-physician attendees. Mailed to all Non-LDO facilities Mailed to all Fistula First eligible facilities at the end of each Quarter. Network reports were also sent to all Nurse Managers and Medical Directors along with requests that they share their data reports with staff members and Nephrologists. Provide regional vascular access reports with graphs as comparison for their corporation and distributed additional Fistula First Initiative information. Vascular Surgeons were mailed vascular access Medicare Part B Claims data reports and questionnaires, made available by CMS. Cover memo included defining results of data, questionnaire, instructions for use, surgeon-specific reports were sent to participating surgeons. Fistula First educational materials and a flyer announcing availability of the surgeon CD/DVD were also mailed. Results from questionnaire will be used to target quality improvement activities for surgeons and nephrologists in the Network.
18	 Dialysis Facility Compare reports from CMS Clinical Performance Measures Project 	 Distributed to all Network 18 facilities 787 patients were randomly selected by CMS (615 hemodialysis and 172 PD) for a study. A 100% sample of pediatric in-center hemodialysis and a 100% sample of VHA dialysis facility patients were also included. Network 18 had a total of 1,007 CPM forms.
	 New Facility Packet PAC Facts Quality Improvement assistance Influenza Campaign 	 Includes poster that describes Network's basic functions and how patients can access resources and "How to Address Your Concern" Poster and fact sheet for patient and facility staff education Provided at the request of a State Agency District Office; Included consultation with physician and technical representatives from the Network 18 MRB Sent out information handouts, Vaccine Information Statements and sample tracking forms
		CQI
3	CQI Meetings	Quarterly meetings
	TARC assisted QI	Supported several facilities in QI activities including Fistula First
9/10	Midwest CKD Coalition	Ohio KePRo, Illinois Foundation for Quality Healthcare and Health Care Excel worked under CMS contract to improve quality within the hospital, physician office and outpatient center settings.
	Phosphorous Management Education Quality Improvement Project Prince Project Prince Project	Utilize a rigorous education program for dialysis facility staff and patients; Promote the use of guidelines for the management of phosphorous and to encourage communication of compliance enhancing strategies to patients through an education program for dialysis facility staff
	 Dialysis Facility-Specific Kidney Transplant Referral Measures Project Special Study of Dialysis Treatment Delivered in the 	 Technical Expert Panel (TEP) made recommendations on the development of clinical performance measure to track outcomes in referral to transplant at the dialysis facility level. CMS funded a special project to examine current practices and make recommendations on a model for this form of treatment

9/10	Nursing Home Setting	
Continued	Barriers to Admission - Special Study	CMS funded a special project to examine current practices and make recommendations on a model to alleviate these difficulties for patients seeking to change dialysis units.
12	Six-Sigma: An Organizational Tool for Performance Improvement in Healthcare (Beth Lanham, RN – Six Sigma Black Belt)	Six-Sigma and CQI educational session and panel discussion Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians.
	Have Physicians Given Up Their Role In Quality? (Gene Fibuch, MD)	 A Malcolm Baldrige Award Winner speaks about the role physicians must play in continuing quality improvement. Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians.
	CQI Tools: Run Charts	 Available for download on the Network 12 website. (HD & PD adequacy, anemia management, vascular access, nutrition, hospitalization, and infection: VRE & MRSA)
14	Quality Assurance/ Improvement Manual	Provided to all facilities that opened in 2005
	Network Core Indicator Run Charts	Includes Texas and national comparison and, if applicable, the K/DOQI recommended guideline
	 Quality Management Consultations Criteria and Standards for Recommended Practices 	 Provided telephone and onsite consultation for facilities requesting assistance developing quality management programs Provided to each new dialysis facility. Guides the ESRD community in providing appropriate and quality care. These are recommended practice standards.
	Support and Use of National Practice Guidelines	All comparative data reports provided to facilities.
17	Quality Improvement Manual	 Quality Improvement staff, with the approval of the MRB, began construction of an ESRD Provider Quality Improvement Manual for NW 17 to assist facilities in the area of quality performance, provide quality services and care for ESRD beneficiaries. Information in the manual was taken from CMS regulations and condensed into a workable format. The manual was finished and completed but due to contract issues was held and presented to new contractor with name change, logo, etc.
	Facility Quality Measures Demonstration Project	• Included Quality Improvement, Patient Services and Data measures. Sources included the Michigan Kidney Epidemiology & Cost Center (KECC) report for 2000, USRDS, Network measurements including Fistula First, data compliance and patient grievances. Project showed that few Network facilities failed to meet with overall standard. Several failed to meet quality standard and the MRB instructed staff to request performance improvement plans from those failing to meet standard for URR and/or Hematocrit as well as Fistula First. Those failing to meet CMS data compliance were asked to submit process improvement plans. Network staff conducted facility visits. During the visit, written information on improving adequacy, Dialysis Facility Compare website, Preparing for Emergencies, the importance of vaccination (the facility toolkit on Flu and Pneumococcal Vaccination Program), and the Fistula First Initiative was distributed. USRDS Dialysis Facility Compare 2005 Report and current fistula rates were reviewed with individual copies given to the facility. Facility feedback form was given to managers to complete and mail to the Network.

18	Internal CQI Project	Encouraged facilities to choose patient falls, vascular access-
	• Internal CQ1110ject	related incidents and other important/recurring safety-related topics for an internal CQI project
	Involuntary Discharges	• Tracked by the Network
	Facility Accuracy &	Tracked by the Network
	Compliance: non-VISION Facility Forms Receipt and Follow-up	
	New and Existing Employee Orientation	• Incorporates all CMS, SCRDC, Departmental, and office building policy/procedure, compliance and informational items.
		Γ-RELATED ISSUES
1	Summer Issue of Network	Produced and distributed to New England renal professionals
	Notes Holiday Issue of Network	Produced and distributed to New England providers in
	Notes	December 2005
2	 "Completing the Continuum of Quality Patient Care: Renal Palliative Care" Cooperation with ANNA 	 Workshop for professionals provided information on palliative care as an option for ESRD patients. Videotape of speakers and copies of Powerpoint presentations were available as a web-based tutorial to increase awareness of options for end of life care decisions and help staff with patient death aftermath. Committee developed full-day conference that includes 1-hour
		presentation by QIC "What to do with the Challenging Patient."
	Patient Safety Awareness	• Winter 2005 issue of PAC Notes on the importance of patient awareness concerning patient safety. Discussions included the importance of knowing you lab values and being involved in your healthcare, not being afraid to ask questions, and reporting anything of concern to the nurse manager, social worker or a PAC representative for assistance. Manhattan/Staten Island chairs conducted their representatives meeting in which patient safety discussions included annual emergency take-off procedure.
	Council of Nephrology Social Workers	 54 social workers attended a 90-minute presentation given by the Network Patient Service Coordinator and Quality Improvement Director on the importance of the Conditions for Participation, following Network goals, information on the Network committees with special emphasis on the PAC and CMS goals of patient-centered care.
3	Consumer Health and Safety Information	• Included Flu, Fistula First, Medicare Part D and Quality Improvement.
	Network Grievance Procedure	• Distributed to all Medicare-certified facilities within NJ, PR and VI.
4	"Patient-Centered End-of- Life Care for Chronic Kidney Disease Patients"	One of two educational programs presented for the Network Coordinating Council. 125 professionals attended.
7	AAKP and NKF Collaborations	Promoted programs within the state
	Dominick Gentile, MD Memorial Award	Network received award at 2005 AAKP Annual Convention for outstanding work on behalf of patients
8	ANNA Annual Conference	PSC presented to the group on the "Importance of Self-Esteem in ESRD Patients."
9/10	Medicare Part D and ESRD workshop	• 100 renal professionals including social workers and nurses attended the meeting. CMS provided technical support with three speakers to discuss the new Medicare benefit.

9/10	Alternative Solutions	Brochure offering alternative methods to deal with difficult
Continued	Thermative Solutions	situations distributed to nurse managers and social workers and posted on website
	 DaVita Trainings 	 Social worker trainings on writing behavioral contracts
	Social Worker Meeting	 Provided training sessions on professional boundaries and creative problem-solving for dealing with difficult patients
12	Chronic Illness & The Dialysis patient: An African- American Perspective (Denedria Banks, MSW, ACSW)	 Recognizing the value of cultural differences. Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians.
	 Barriers to Employment Following Renal Transplantation: The Patient Perspective (Lisa Raiz, PhD) 	• Information about kidney transplantation from a patient perspective. Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians.
	 Heritage and Health: Kidney Disease in American Indians (Andrew Narva, MD, FACP) 	 Recognizing the value of cultural differences. Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians.
	• Sex, Drugs, and Hypertension (Jean Holley, MD)	 Addressing sexuality in ESRD patients. Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians.
	 Sexual Functioning Following Renal Transplantation. (Lisa Raiz, PhD) 	 Addressing sexuality in ESRD patients. Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians.
	 Gonadal Dysfunction in Chronic Renal Failure Population: A Review From the Endocrine Perspective (Victoria Lim, MD) 	 Reviewing the endocrine system. Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians.
14	AAKP Chapter Meetings	• Director of Patient Services supported and participated in chapter meetings around the state.
	• Social Work Ethics Workshops	DPS led three workshops focused specifically on the dialysis setting
17	Coalition - Strategic Partnership for Change facilitated by Dr. Tom Wolff which focused on "Improving Advance Health Care Planning: Creating an Environment of Acceptance, Support and Implementation in the ESRD Population"	• Dialysis, Transplant, Emergency Medical Services, Health Maintenance Organizations, Consumers, Patient Advocacy Groups, Nephrology, Medical Ethics, Social Work Organizations, Quality Improvement Organizations and State Federal Agencies came together for an initial training by Dr. Tom Wolff; Coalition organized itself into three groups: Education/Public Awareness; Best Practices; Policy. Each group was co-chaired by Network staff and a coalition member to develop action strategies including leadership, staff assistance, goals, tasks and resources needed and follow-up. Each group has had at least one conference call since the initial meeting.
18	 Health Insurance California Department of Aging Un-documented Immigrants 	 Makes referrals and works together on behalf of ESRD patients experiencing health insurance related issues Provided information and guidance on treatment availability/options to healthcare providers
	COMMUNICAT	ION/CRISIS MANAGEMENT
2	• "Help! Non-violent Crisis Intervention in the Dialysis Unit"	 1-day regional workshops for facility staff. Network Patient Services Coordinator (PSC) demonstrated methods for defusing disruptive and threatening situations. Participants practiced techniques for de-escalating verbal threats,

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2 Continued	 Crisis Prevention in a Healthcare Setting New York City Office of Emergency Cooperation (OEM) Cooperation with National Coalition for Disaster Preparedness Dealing with a Challenging Patient 	 maintaining personal safety and gaining adherence from challenging individuals. Attendees included nurses, social workers, a technician and a nurse practitioner. Continuing Education Contact hours are provided by the National Kidney Foundation (NKF) for this event. Also, DPC Toolkit contents were reviewed and discussed. 1-day workshop on crisis prevention. Session reviews crisis development model, non-verbal behaviors, para-verbal communication, precipitating factors, rational detachment, verbal tips & techniques. Participants discuss the importance of maintaining unit policies universally. DPC Toolkit, its purpose and necessity for its use were discussed. Total, 131 dialysis staff members attended 12 sessions. Network PSC initiated contact with NYC OEM to communicate special needs of dialysis patients for city planning in response to Asian Bird Flu Pandemic. Discussed emergency response with NYC agencies. PCS communicated with Network 7 that Network 2 would participate in the national effort for disaster preparedness. 1-hour presentation attended by 138 nurses. Included recommended techniques for dealing with challenging patients, including behavior modification, interdisciplinary meetings and
	Decreasing Patient-Provider Conflict (DPC)	 including behavior modification, interdisciplinary meetings and behavior agreements. Need to document each episode and to include the Network in the process for discharging those patients whose behavior is out of control was reviewed. Network resources include the DPC Toolkit, In-services, Policy Statement on Patient Referral, Transfer or Discharge, and website. Distributed to Nurse Managers; assists unit administration in their staff training. Review of tool kit and the importance for its use was reviewed at Network providers, nurses and social
		workers trainings.
3	TARC Consumer Rights & Responsibilities and Consumer Grievance Procedure posted on TARC Website	Posted in Spanish and English
4	 Emergency/Disaster Preparedness and Response Programs Business Continuity Contingency Plan Facilitating Encouragement, Pittsburgh Pennsylvania Decreasing Patient-Provider Conflict Orientation WebEx Conference Call Data Issues Related to Hurricane-Affected Patients 	 Focused on Power, Water, Facility Operations, Staffing, Communications, Patient Education, Transportation, Medical Records, Public Education and Inter-Agency Collaboration. Include maintenance of emergency telephone system and other business continuity and recovery requirements. Network has the capacity to track available services, assist patients seeking treatment, provide phone and fax services, track and publish OPEN/CLOSED facilities, assist and if directed by CMS, provide patient family information. PSC's attended educational seminar on Theories, Principles and the Practice of Encouragement. PSC and Interim Executive Director/QI Director, Office Manager, Data Director, QI Coordinator and Information Systems Director attended. Network received poster, interactive software and several pamphlets to review. Network distributed CMS-provided procedures to dialysis units. Included procedures to follow in processing evacuees
	DPC Presentation and	whom are being transferred to surrounding units.Team members from 65 facilities in the Network participated
	DPC Presentation and	• reall members from 00 facilities in the Network participated

4 Continued	WebEx calls	in the DPC-Train-the-Trainer format
6	DPC Toolkit and Poster	Decreasing Patient-Provider Conflict project designed to assist dialysis providers to better manage conflict in the dialysis facility. Sent to all facilities.
7	 "Disasters Happen: Best Practices for Preparing Your Patients" Presentation "ESRD Disaster Response Planning" Presentation "Collaborating for Improvement" Presentation "ESRD Disaster Response Planning" Presentation National Disaster Coalition ESRD Disaster Triage Tools and Posters "Successful Disaster Planning Through Strategic Partnerships" "Patient Disaster To Do List" shared with Network 8 NKFF Public Policy Committee and the Florida Renal Coalition (FRC) "The Florida ESRD Network Roles 7 Responsibilities/Working with Challenging Patients" 	 Southeastern Kidney Council's Annual Meeting 2005 CMS/Forum of ESRD Networks Annual Meeting 2005 Florida Renal Administrators Association Summer Meeting Network 3 Annual Meeting Will assist in reducing disruption that occurs when the country is affected by any type of emergency or disaster Distributed to EOC at the state level; shared with Florida Hospital Association; shared with Centers for Disease Control upon request; shared with all Executive Directors and Patient Services Coordinators (PSC) Staff participated in the poster session at the CMS/Forum Annual Meeting Network 8 incorporated this tool into their educational planning. Informed them that new legislation was necessary to increase utility disaster priority levels. FRC advised that this issue will be added to its legislative agenda. Presented to DaVita Regional Social Workers
	 Hurricanes and health Care Conference exhibit Florida ESRD Emergency Contact Information Statewide Dialysis Disaster 	 Disaster materials were presented Updated and distributed list to all Florida stakeholders 28 participants attended from various organizations
	Preparedness and Planning Coalition Patient and Provider newsletters and articles "Ethics and Boundaries in the ESRD Setting"	 Grievance process information Network 7 Annual General Session
9/10	 DPC Toolkit and Poster DPC Trainings A Leadership Perspective to Growth Through Problem- Solving 	 Decreasing Patient-Provider Conflict project designed to assist dialysis providers to better manage conflict in the dialysis facility; sent to all facilities Regional meetings and WebEx trainings Calendar with resources for handling conflicts sent as a calendar and also as a resource without calendar dates
12	 Grievance Booklet, Forms, and FAQs Network 12 Guideline on Threats and Harassment 	 Sent to facilities and patients upon request Sent to facilities and patients upon request

12 Continue		
12 Continued	 Behavior Contract Examples Cultural Diversity: A Resource for Dialysis (Ramiro Valdez, MSW, PhD) 	 Sent to facilities upon request Communication resources for dialysis personnel. Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians.
	• "We're Here For You" Network Poster (Grievance Information)	Sent to facilities upon request
	Decreasing Patient Provider Conflict (DPC)	Two sets of pilot groups were trained in 2005 (Kansas City, MO) prior to rolling out the training to the four-state area in 2006.
13	 Fall 2005 ESRD Network 13 Mentoring Workshop. Disaster Preparedness 	 Communication/Crisis Management topics presented at Network 13 Mentoring Workshop. Attendance 253 participants Louisiana Hurricane Preparedness. Materials were developed and distributed to assist secondary to Hurricanes Katrina, Rita.
14	• 2005 Texas Gulf Coast Disaster Coalition	Initial Meeting included six participants from LDO and non-LDO facilities, Texas Department of State Health Services, National Kidney Foundation, Texas Medical Foundation Health Quality Institute, Dallas Nephrology Association, CMS and the Regional Hospital Planning Group Disaster Unified Command.
	Decreasing Patient-Provider Conflict	CMS special study under NW 14 Contract. Provided education to ESRD facility staff about strategies for decreasing patient-provider conflicts. Trainings via WebEx sessions, taped for future use. DPC poster disseminated to all 4494 dialysis facilities in the US. DPC Toolboxes were sent to each ESRD Network to accommodate existing facilities with surplus for new facilities.
	• Intensive Intervention with Non-Compliant Patient Booklet – Guidance and Resources for Dialysis Facility Personnel	Provided to all facilities contacting the Network for assistance with non-compliant patients
	• On-site workshops at clinics request	• 22 clinics received training in working with difficult patients, professionalism and working with noncompliance.
	Disaster Preparedness and Information	Community contribution made by Network 14 in response to hurricane disasters of 2005. Received 8328 incoming disaster- related calls; participated in National Disaster calls; hosted Hurricane Conference Calls for Texas Nephrology Community to discuss needs of dialysis community following Hurricane Rita.
	• Intervention with Problem Situations	DPS visited 17 clinics at request of the medical director, area administrator or clinic manager DPS
	Mediation MeetingsSite Visits Investigating Patient Complaints	 DPS assisted three clinics with mediation 17 clinics received visits from DPS as part of an investigation resulting from patient complaints
15	"Protocol for the Evaluation of Patient Complaints and Grievances"	Guide Network 15's action taken on patient complaints and grievances; sent to all facilities in 2005
	• "Dealing with Difficult Patient Situations in the Dialysis Unit"	Presentation made to Colorado CNSW, DaVita Facility Administrators, two groups of Arizona Facility Administrators, nurses and social workers and Nevada Facility Administrators, nurses and social workers
	DPC Toolkit and WebEx Training	Sent to all facilities in October 2005; notified of pre-recorded training regarding implementation of DPC program
16	Decreasing Patient-Provider Conflict Toolkit and 6	Toolkit developed in a national project supporting facility staff training to improve communication and conflict resolution

16 Continued	Introductory Training Sessions	skills. It was sent to every dialysis provider in the Network. Network PSC conducted six DPC Toolkit trainings.
	DPC Toolkit and Decreasing Patient-Provider Conflict	 PSC presented at CNSW - Northwest Chapter meeting, DaVita Regional Managers meeting and the Second Annual Mid- Columbia Nephrology Conference. Also presented at the Renal Care Group regional meeting, there, a second meeting was held in which more practical use instruction was given to the Social Work team.
	"Technical Considerations with Bringing Hemodialysis Facilities' Water Systems Back on Line after Hurricane Katrina" document	 QI Consultant lead coordinating team of representatives from CDC, CMS, AAMI, NANT and renal dialysis facilities which prepared the document. It was posted by the CDC and appeared in Nephrology News - October 2005.
	DPC Train the Trainer classes	 Presented at Mid-Columbia Nephrology Conference, Renal Care Group regional social workers meeting and DaVita regional managers meeting
17	Decreasing Dialysis Facility Patient-Provider Conflict	DPC Toolkit was sent to regional LDO offices for distribution and directly to the independent dialysis facilities. PSC staff attended a two-hour web-ex training regarding the use of the toolkit. PSCs provided staff training in procedures for handling conflict, improving communication and professionalism. PSCs offered one-hour web-ex training attended by 100 participants in 45 clinics and a review of the material at a regional CNSW meeting. Further trainings are planned for 2006.
18	 Grievance Procedure/Grievance Form Grievance Poster Pandemic Flu 	 Available in English and Spanish and distributed to all facilities Helps patients and providers understand the grievance process Exchanged information with State Agency, provider community and Lumetra. Information was posted to Network 18 website. QI Director participated in a community service question and answer session about Pandemic Flu on a local ethnic cable television station.
	GE	NERAL/OTHER
1	Network Directory "Keep Choice Alive: A Continuum" Network 1 2005 Annual Meeting	 Directory was updated and expanded to include information on the Fistula First project as well as to supply local vascular data to renal physicians Over 600 attendees including nurses, social workers, renal dieticians, dialysis technicians, nephrologists and state surveyors were represented at the meeting. The program covered topics regarding choosing modalities of treatment, Fistula First and vocational rehab to end of life issues for the CKD & ESRD patient populations. There were 18 poster displays on various topics related to improving patient care.
2	 Spring Network Council Meeting/Provider Session Cooperation with NYS DOH on a Site Visit Evaluation Survey Tool 	 Medical Directors, unit Administrators, and other facility professional staff were invited to attend. Guest speakers from NYS DOH and CMS Region II gave presentations on state survey procedures, opening and closing of dialysis units and issues of governance. Network Vocational Rehabilitation Specialist presented six employer recognition awards for their support in assisting ESRD patients in their workplace. Draft of survey tool that would allow facilities to evaluate the site visit they just recently experienced was developed and approved. In early 2006, tools will be distributed to Medical Directors for review and comment. State Surveyors will leave tools at facilities following site visits. Completed surveys will be

2 Continued		returned to the Network to provide the State Survey Agency
	State Survey Agency Cooperation – Clinical Scope of Practical Issues	with aggregate summary data. Representatives from the Department of Health, State Education Department, ESRD Network, New York State Nurse's Association, Union 1199, DaVita and Fresenius attended coalition meeting. Reviewed Renal Dialysis Center Staffing Task Comparison Data, an in-depth list of dialysis tasks and staff members who could perform each task after proper training. List provided by New York State Department of Health Bureau of Hospital and Primary Care Services in conjunction with the New York State Department of Education Office of the Professions, State Board for Nursing.
	Professional newsletter, Network Notes	
	• Guideline: Vaccine Administration – Influenza, Pneumonia, and Hepatitis B	recommendations, was developed by the Medical Review Board and distributed to all dialysis facilities.
	Bulletin Board Kit: Patient Safety	• These are multiple, colorful, laminated, 8.5" x 11" sheets that facilities can use as instant bulletin board patient education displays.
3	Updates to facilities	• Includes: ESRD Program goals and Network activities to achieve goals; Network annual report; state and regional vocational rehabilitation programs available in Network area; consumer grievance procedure
	New facilities receive "New Facility" binders	
	Reference/resource collection of materials	 Provided by network to facilities, contains important aspects of ESRD program and CMS/network requirements and quality improvement resources.
	• VISION	H . 10 TF . T1 10 TF . 144 D D. C. TF
4	New Facility Packet	• Sent to facilities that completed a Network Membership Agreement for the first time.
	Medicare-Approved Drug Cards "Call? Enroll! Save!"	• Sent to administrators of dialysis and transplant facilities
	Medicare Replacement Drug Demonstration	• Link for brochure describing demonstration for beneficiaries to read was provided
	Network Newsletter	• Communication with dialysis community including patients/families and facility staff.
	Network Website	
	Lean-In Service	
	"An Overview of the Dialysis Outcomes and Practice Patterns Study (DOPPS) and Updates on Vascular Access and Bone Mineral Metabolism" The body of the Dialysis Outcomes And Practice Patterns Study (DOPPS) And Updates on Vascular Access And	 One of two educational programs presented for the Network Coordinating Council. 95 professionals attended.
	Technical Support	 Network provided diverse technical and educational support to the dialysis facilities in Pennsylvania and Delaware.

4 Continued	Poster Collaboration	Collaborated with Networks 11 and 13, presented one poster at
	"Partnering with SA and CMS in the Sanctions Process: The Experience of Three Networks"	the 2005 Annual CMS/Forum Meeting
	National Core Data Set – Data Standardization Workgroup	• Information Systems Director participated in a three-day workshop at the CSC offices to discuss and review all data elements to be included in the National ESRD Core Data Set
	• Reporting Tool JAD • Workshop	• Interim Executive Director/QI Director served as a member of the JAD Workshop. Group met and reviewed reports produced by COGNOS software.
	Improving QualityNet Exchange Conference Calls	 Director of Information Systems participated in a series of calls designed to improve the flow and communication of QualityNet Exchange information.
	Renal Administrators Association (RAA) Support	 Provides mailing labels for Network 4 renal administrators of dialysis and transplant centers to send correspondence related to RAA, its activities and new membership applications.
	Council of Nephrology Social Workers (CNSW)	 Provides mailing labels to CNSW-East to send materials related to CNSW
	National Kidney Foundation Support	• Network provided various requested information such as dialysis unit contact information, and a report on patient characteristics in Pennsylvania with emphasis on race and minority statistics. Network also provided financial support for Patient-Staff workshop.
	Lean Training Conference Call	 Participated on conference call that provided instructional preparation for Lean Training Workshop that all Networks were required to attend.
	CMS Information Systems Visit	 Data Entry Specialists provided CMS staff with an analysis of CMS-2728 and CMS-2746 forms.
		Three VISION Training Sessions led by NetworkContinued to provide technical support
5		• 92 in attendance
	777.1 77.1 77.14 6 17.1	• 18 in attendance
6	30	 Quarterly newsletter mailed to all Network 6 facilities, other Networks, State Agencies and other interested parties. Also posted on network website 234 Nurses, Social Workers, Dietitians, Physicians, vendors and
	Annual Meeting "Mission Possible: Quality Care for ESRD Patients"	staff attended. Ms. Joyner presented "Unleashing the Data Chains: How to Submit Accurate Data Forms, Surveys and Reports." Quality Data Awards presented following presentation "Mission Possible: Taking it to the Next Level."
7	Phone Assistance	 Provided to facilities as needed
	FMAQAI.com website	 Provides goals of the program, a significant amount of education and resource materials, many of which are available in English and Spanish
	Network 7 Annual Awards	• Educational sessions were held and awards were presented to renal professionals and facilities in the following categories: Fistula First Champions, Data Achievement, Community Services, Outcomes Excellence and Volunteer of the Year.
	Planning of 2 nd Annual Renal Professionals Forum	 Collaborated with NKF, CNSW and Florida Council on Renal Nutrition (FCRN). 200 Florida renal dietitians and social workers attended.
	Florida Renal Administrators Association presentation	 Network was invited to present on current projects and dealing with difficult patients.

7 Continued	 Planning of 3rd Annual Renal Professionals Forum Collaboration with NKFF Public Policy Committee and the Florida Renal Coalition (FRC) 	 Collaborated with NKF, CNSW and Florida Council on Renal Nutrition (FCRN). Network will be presenting at this event. Disaster preparedness at the statewide level and regarding Florida Medicaid Changes
8	2005 Annual Meeting "Partnering to Improve Quality Across the Continuum of Care"	• Pre-meeting events included a morning DPC session conducted by Mark Meier, MSW, LICSW and an afternoon session by Abbott, conducted by Julie Franklin, RN. An additional dinner symposium by Watson was conducted by Martha Colfer, BSN, RN. Meeting sessions included presentations on Fistula First, palliative care, DOPPS data, current transplantation trends, treatment of depression in ESRD patients, ethics in ESRD, advance care planning, K/DOQI bone guidelines, new ESRD conditions for coverage, patient self-management, prevention of burnout and OSHA violations in dialysis.
	 2005 Quality Counts! Calendar Network News—Three editions were distributed in 	 Monthly topics such as bone disease, renal replacement modalities, nutrition, infection control, water treatment, anemia management, dialysis adequacy, disaster planning, vaccination, patient-provider conflict and vascular access. Newsletters containing clinical articles as well as general information articles distributed to each facility and medical
9/10	Nephrology Conference	 Two educational programs offered for administrators, physicians, nurses, social workers, dietitians and technicians. A Board of Nephrology Examiners, Inc., Nursing and Technology (BONENT) certification exam was held for nurses and technicians one day prior to the conference.
	Network Connections Newsletter	 Quarterly newsletter distributed to state surveyors and Quality Improvement Organization personnel; topics include data regarding complaints and grievances, news about Network activities, special projects and timely topics; Three issues were distributed in 2005 and available through the Network website.
	"Exploring the Survey Process for the ESRD Facility"	• Presented by Network Executive Director and Quality Improvement Director for the Kentucky Cabinet for Public Health
	Renal Outreach Newsletter	• 10,000 copies distributed in each mailing; directed toward ESRD patient community but ESRD professionals and members of the renal community receive the newsletter as well; three issues produced in 2005; contains information on new therapies, rehabilitation, medications, nutrition, exercise and general topics of interest as well as Network news and Patient Leadership Committee activities
	Progress Notes Newsletter	• 5,000 copies distributed in each mailing; written for renal community professionals; two issues produced in 2005
	Midwest Nephrology Fellows Research Day	• Supported through an unrestricted educational grant from Amgen. Featured presentations from 18 Nephrology fellows representing 10 academic centers throughout the Midwest
12	• Fistula First: Leading the Cause (Surendra Shenoy, MD, PhD)	• Why even seemingly unsuitable candidates may be able to have AVF. Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians.
	 Fistula First: The Nurses & Interventional Radiologist Perspectives (Diana Layes, RN & Lynne Dryer, ARNP) 	• An overview of how the team works together. Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians.
	• Fistula First: AV Fistulas in	• A discussion of AVF using the Proximal Radial Artery.

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14	Promoting Medically Suitable Modalities	 Annually, each facility is provided with specific transplant activity reports in comparisons to state averages with education resources.
	Transplant-related education materials	 Distributed at network meetings and upon request; designed for both professionals and patients.
	Home Peritoneal and Hemodialysis utilization	Provided CMS New Patient Book "You Can Live" to new patients
	List of home hemodialysis training facilities	Network maintains list and offers it on their website
	Lone Star Bulletin – professional newsletter	• Published twice in 2005.
	Network Website	Outreach to patients and professionals
	Network resource list of	Maintains library of videos, pamphlets and articles in both
	clearinghouse materials	English and Spanish for both patients and professionals
	Educational Presentations and In-Services	 Nine presentations at Network, regional, local facilities and national meetings of renal professional organizations designed to assist patients and professionals in learning more about ESRD, modality selection and methods of improving
		outcomes.
	American Nephrology Nurses Association – Texas Chapters	 Distributed Dallas ANNA/NANT Chapter meeting flyer; developed and distributed statewide ANNA meeting flyer.
	Texas Department of State Health Services – Kidney Health Program	Broadcast faxed and emailed information on the Medicare Prescription card information numerous times.
15	Intermountain Messenger newsletter	 Professional and administrative newsletter distributed to all Network facilities, Network Council members, Network Committees, state health departments, NKF chapters and other interested parties; Autumn issue included a Fistula First project update and Tips for Improving AVF Use Rates plus a short update on vascular access coding. Distributed twice in 2005
	VISION Training"Road Show"	 For an independent dialysis unit in Denver, CO Features Network overview, QI, Patient Services and Data presentations
16	Network Website	Posted: "Staff Can You See It, Patients Won't You Let Them?" article, "On Course with Cannulation" PowerPoint presentation, Buttonhole Technique information and reference sheets, "Importance of Washing Your Access Arm" article, Trend data and an update on AVF outcomes, "Preparing the Vascular Access for Cannulation" article
	VISION Training	• 12 data coordinators attended from 18 facilities
	• Summer 2005 Consumer News patient newsletter	Distributed to patients
17	Influenza and Pneumococcal Vaccination Program	 Posters, tips for a successful immunization campaign, Center for Disease Control (CDC) fact sheets, vaccination record keeping forms, English and Spanish versions of questions about pneumonia vaccination, sample guidelines for flu and pneumonia administration, and Medicare billing tips. Network announced its ability to provide technical assistance as needed.
	Cooperation with State Survey Agencies (SSA)	• Network 17 maintained relations with California and Hawaii SSA's through exchange of information and quarterly meetings. The meetings, ROSAN, provide a forum for Networks and state surveyors to identify problems and arrive at solutions. Network encourages its facilities to work with state surveyors pro-actively. State surveyors routinely contact Network staff before a survey to obtain input on any issues of concern and to keep the Network informed if and when a

17 Continued		facility might be approaching immediate jeopardy (IJ) status so the Network has the opportunity to offer assistance to the
	Network Annual Meeting conducted in conjunction with November 2005 meeting of the California Dialysis Council	facility. • Topics included disaster preparedness, lessons from Katrina and new initiatives from CMS for the ESRD program. Presentation given by the Sacramento dialysis facility that was destroyed by fire while patients were being treated. Served as a
	Collaboration with Mountain House Water District	 clear example of disaster preparedness, which saved the lives of both patients and staff. Notifications sent to dialysis facilities in Alameda, Contra Costa and San Joaquin counties that they would be affected by upcoming chlorine/chloramine water conversion. There were 38 facilities affected and were all given the opportunity to
	VISION Interest and Readiness Surveys	respond to Mountain House. Conversion took place in November 2005 without incidence. • Network 17 sent surveys to all its independent dialysis facilities. These facilities were defined as not belonging to a Large Dialysis Organization (LDO). Marketing, in addition to the Interest and Readiness Survey, included brochures sent with
	VISION Training	 Non-LDO new facility mailings, at training sessions, with facility data mailing and phone calls to facilities. Training for four facilities took place in August 2005. Presentation of the software was made for the management and IT staff of two hospital-based units considering use.
18	Kidney Community Council of Southern California Coalition (KCSC)	• Formed by 20 patient provider and Renal Community organizations with a focus on Patient-Centered Issues. Will form a website www.kidney411.org that will offer educational materials and learning opportunities for kidney patients and professionals in Southern California
	Transplant IssuesEducational Material Library	 Provided assistance and information to Donate Life accessing provider and patient groups that supported the new online organ registration system implemented in California in 2005 Available to both patients, family member and facilities as
	,	appropriate
	VISION TrainingSite Visits	 26 facilities received training Purpose of Data/QI Training, VISION implementation, patient complaint/grievance follow-up, special studies/medical records reviews, new facility orientation, Fistula First project follow-up or community outreach
	Los Angeles County Sheriff's Office	Technical assistance provided regarding provision of dialysis to
	Office Corporate Partners - Fresenius, DaVita and Gambro	 Routinely receive Network publication on Fistula First and other important issues
	California Dialysis Council (CDC)	• Executive Director regularly attends meetings to present updates on CMS/Network activities
	California Department of Health Services Licensure & Certification (DHS L&C)	 Included on the Network mailing list to ensure receipt all official communications such as Fistula First newsletters and the Annual Report.
	Facility referral to DHS L&C	• Referred for guidance/information concerning plant & equipment, infection control, health & safety, staff certification/training/experience requirements and other regulatory issues
	DHS L&C Communication	DHS L&C regularly contact Network before or during facility surveys to ascertain compliance and other information that may merit examination during surveys
<u> </u>	• DHS Division of	Utilizes Networks 17 & 18 to convey information to dialysis

18 Continued	Russian-Armenian Television Station Council of Nephrology Social Workers Renal Support Network, local American Nephrology Nurses Association Chapter, American Kidney Fund, local American Association of Kidney Patients chapters and local Licensed Clinical Social Workers chapters Medicare Part D Corporate Dialysis Provider Meetings	facilities regarding infection control issues of immediate and statewide importance Distributed to all facilities and other interested parties Relationship developed by the QI Director allows her to give interviews on topics such as influenza and hepatitis Patient Service Coordinator attends local meetings to provide updates on Network activities Presented at local and regional meetings covering various quality improvement and patient-related topics PSC worked closely with local CNSW chapters to disseminate information to patients and other healthcare providers PSC invited to speak on a variety of topics including conflict resolution and professional boundaries
•	Network Website	• List of patient educational materials from other renal organizations that are available in Spanish continues to be updated and disseminated to all facilities
	PSYCHOSO	CIAL/REHABILITATION
	 Sensitivity Training for Dialysis Staff - "Mental Health in Dialysis - A Chronic Treatment" Patient Advisory Committee (PAC) Activities 	 On-site, interactive sessions include group self-exploration and discussion that promote better understanding of how one's life changes as a dialysis patient, and ways in which professional boundaries can assist in approving quality of patient care and staff-patient relationships. Review of Patient Functioning Chart demonstrates how symptomatic behaviors develop from mental states due to common dialysis patient experiences. 15 sessions where all levels of staff attended, including maintenance and clerical workers. Continuing Education Credits provided by the National Kidney Foundation. Vocational Rehabilitation Specialist (VRS) presents current information and handouts on back-to-work incentives and tips and techniques in working with the state vocational rehabilitation program, Vocational and Educational Services for Individuals with Disabilities (VESID), and answers questions. PAC activities include: efforts to enhance awareness of Patient Safety among consumers; PAC chairperson regional meeting of PAC representatives; Queens PAC chairperson responded to request from two facilities to provide
	• Vocational Rehabilitation (VR) Specialist Activities	 information on ESRD Network and PAC organization to patients; Several PAC chairpersons visited units without PAC representation to encourage and educate social workers of the benefits of having a PAC and assisted in patient recruitment at some units; Quarterly conference calls and an Annual Meeting were held; Two chairs were sponsored by the Network to attend patient educational conferences. One chair attended the American Association of Kidney Patients (AAKP) conference and the other attended the Renal Support Network (RSN) conference. Over 200 patients received individual vocational counseling on work-related issues from the VR specialist. 74 social workers were given information to help patients deal with vocational concerns. 183 packets were mailed to individuals requesting information. During seventeen site visits and group

2 Continued	Patient Depression Packet	presentations, 292 professional staff and patients were educated and made aware of services provided by VR specialist and encouraged to assess the vocational potential of their patients. Four training programs on the special needs of ESRD patients to District Offices of VESID, New York State's VR agency for people with disabilities. Training was provided to 142 professional staff members. • Depression assessment materials were distributed to all social workers. Patient improvement was shown after social worker intervention.
4	 Rehabilitation Committee Employer Recognition Program 	 Address multiple components that contribute to an individual's ability to retain or regain employment "Giving People a Chance" recognized Chronic Kidney Disease patients' employers
9/10	 PLC Rehabilitation Committee "Guidelines for Assessment and Referral to Vocational Rehabilitation" 	 Developed a list of articles for patient newsletter to encourage independence, work, volunteering, modality choice Developed by PLC
12	 The Value of Outcome-Driven Nephrology Social Work (Stephanie Johnstone, LCSW) Bulletin Board Kit: Renal Rehabilitation 	 Using outcomes to guide interventions. Audience included dialysis facility managers, nurses, dietitians, social workers, and physicians. These are multiple, colorful, laminated, 8.5" x 11" sheets that facilities can use as instant bulletin board patient education displays.
14	 Vocational Rehabilitation Workshops and Continuing Education Sessions Facility specific charts displaying VR activity compared to statewide averages Ticket to Work National Alliance Community Outreach Forum meeting 	 Nurses and socials workers are instructed to assume patients will continue working and mention disability or employment stoppage only when medically indicated Distributed to network facilities to promote rehabilitation Encouraged participation and distributed information
15	Vocational Rehabilitation Resource Packet	Mailed to all facilities
17	Information Bulletin regarding functional status assessment and assisting patients with rehabilitation goals	Sent to all facility workers. Useful web links from Medical Education Institute were provided as well as tools for measuring quality of life, Dialysis Facility Compare, Employment Development Department and a directory of center for independent living.
18	 Vocational Rehabilitation Mailing Vocational Rehabilitation Referral 	 Materials provided to all Network 18 facilities Supports referral and application process

Source: Networks 1-18 Annual Reports, 2005

APPENDIX R NEW PATIENT EDUCATION WORKSHOPS AND MATERIALS DISTRIBUTED IN 2005 BY CATEGORY BY NETWORK

NETWORK	NAME OF PROGRAM/MATERIALS	BRIEF DESCRIPTION
		ACCESS
1	 Fistula First Breakthrough Initiative Network Webpage 	 NW 1 PSC was an active member of the FFBI Subcommittee that developed the nationally comprehensive listing of all relevant AVF patient education materials. The committee also undertook a gap analysis to determine what areas within the topic are lacking; the work is ongoing at this writing. During 2005, NW 1 enhanced its website through the addition of AVF patient educational information and AVF links for patients conducting research and self-education.
2	 Fistula First Breakthrough Initiative Network webpage 	 CMS launched the Breakthrough Initiative; Brings together stakeholders from the CMS, ESRD Network, surgical, medical, nursing, dialysis provider and patient communities to provide education and support for the placement of AV fistulas in eligible patients Fistula First information is maintained on the Network website.
	• Spring 2005 PAC Notes patient newsletter	 Change Package, quality improvement tools and other information for providers and patients are located on a page devoted to Fistula First. Contained an article addressing vascular access. Articled described three access types (fistula, graft and catheter), discussed the possible complications associated with each access type and encouraged patients to discuss vascular access choices with their nephrologist or surgeon.
6	 "Choosing Your Vascular Access" "Dialysis Patients Speak: A Conversation About the Importance of AV Fisulas" 	 Brochure developed to educate dialysis patients on the risk associated with catheters, mailed to Vascular Access Coordinators, Nursing Supervisors and Vascular Surgeons and posted to Network website. Educational video developed by ESRD Network of New England educates dialysis patients on the importance of AV fistulas, mailed to Vascular Access Coordinators
7	Fistula educational materials	Cooperation with PSC group to develop series of materials
8	Partnered with AAKP for a "Finding Your Strength" workshop in Memphis.	QID presented to the group of CKD patients on the Importance of Fistulas. The PSC co-hosted the meeting. See additional summaries under Patient Meetings and newsletters.
9/10	Ease the Ouch	Fistula educational brochure
11	Video "Your Access to Success"Fistula Awareness Week	 Patients talking to patients on the importance of having a fistula; video premiered at Network 11 annual meeting and was then distributed to all Network 11 facilities. Network 11 facilities received materials to promote the event; materials included tools to reach patients e.g. Your Access to Success video and accompanying poster and brochures. Included were tools to aid staff education.
12	 Putting U in Fist-u-la Navigating the Vascular SEAS A Self-Assessment of Vascular Access 	 A patient newsletter describing arteriovenous fistula issues. A unique and comprehensive booklet for patients regarding self-vascular access examination and care.

13	• Kidney Koncerns-Patient Newsletter. Access Issues included:	• 58,000 (average quarterly distribution 14,500)
	Fistula First	
15	"Fistula First Your Access Options"	Presented by Network Executive Director during AAKP convention
16	 Fistula First project Three-Part Patient Education Materials Patient Education Resource Packet "Staff Can You See It, Patients Won't You Let Them, The Importance of Washing Your Access Arm" and "Preparing Vascular Access for 	 Co-authored the first section, "Have More Control Over Your Dialysis and Health" and assisted in editing the other two sections Mailed to all Network facilities; Included video "Vascular Access for Hemodialysis", tips sheet "Protect Your Access - It's Your Lifeline," instructional handout "A Patient Guide to Monitoring Machine Alarms," reprint of the article "Focus on Fistulas: A Patient's Perspective" and the brochure "Using the Buttonhole Technique for Your AV Fistula" Provider and Patient articles promoting patient safety written by the QI Coordinator
	Cannulation"	DEQUACY OF DIALYSIS
10		-
12	Looking At Adequacy	A patient focused newsletter frequently downloaded from the Network website in 2005.
	O	THER CLINICAL ISSUES
1	 General Season Reminder Facility-Specific Reminder 	 In the 2005 Fall Issue of Network Notes, the New England renal professional newsletter, a general flu shot reminder was published in article format. This type of communication, while directed toward professionals is intended to reach both targets – patients and staff. A facility-specific mailing was went to all New England ESRD providers containing "Get the Flu Shot, Not the Flu" educational
5	Kidney End-of-Life Coalition	materials. CD distributed to each Network dialysis unit in the country
12	A Shot of Information (Immunization)	A patient focused newsletter frequently downloaded from the Network website in 2005.
13	Self Care	Discussed self-care options. Reviewed activities of self-care that patients can engage in in-center, inclusive of self-cannulation.
	COMMU	NICATION & PSYCHOSOCIAL
8	Alabama Adult Kidney Camp	PSC presented to the group on the "Importance of Self-Esteem."
12	 New Patient Orientation Packet Network 12 Guideline on Threats and Harassment 	 Including information on the grievance procedure, technical assistance, and influenza hepatitis B, and pneumonia immunization. Sent to facilities and patients upon request
		DIET & NUTRITION
12	Evaluating AlternativesFood For Thought	 A patient focused newsletter emphasizing the Dialysis Facility Compare (DFC) website. And the disaster preparedness 3-day Diet. A patient focused newsletter frequently downloaded from the Network website in 2005.
	When Your Thirst Is At Its Worst	A patient focused newsletter frequently downloaded from the Network website in 2005.

	DISASTER/EMERGENCY PREPAREDNESS		
1	Disaster Preparedness for Dialysis Patients	NW 1 produces and distributes its own educational booklet that provides guidance to dialysis patients in emergency circumstances. The booklets are sent upon request for providers to give to patients and directly to patients by request.	
4	"Emergency Preparedness Resource for Patients"	Revised and distributed to over 14,000 patients. Network 14 will continue to revise and distribute as necessary	
5	Preparing for Emergencies: Patient Guide	Distributed upon request	
7	 Disaster Poster Patient Disaster "To Do" List Patient Vital Information Cards Tips for ESRD Disaster Planning Emergency Contact Information After the Hurricane – Some Steps to Healthy Coping "Be Prepared: Dealing with Emergencies" and "Changing Docs: Shuffling the Deck" Presentations Florida Kidney Disaster Coalition CMS, American Nephrology Nurses Association and National Renal Administrators Association Collaboration 	 Mailed to all facilities to be displayed in waiting rooms. Mailed to providers for distribution to patients. Wallet-sized emergency information card template mailed to all facilities Distributed and posted to FMQAI website Distributed and posted to FMQAI website Distributed and posted to FMQAI website 2005 American Association of Kidney Patients Annual Convention Goals: Statewide communication tool, develop and implement mock disaster drills, develop guidelines for disaster response, identify key materials for providers and stakeholders Goal to develop materials and tools to solicit and track volunteers willing to assist in disaster-stricken areas and help facilities receive evacuees 	
8	Pensacola Beach Patient & Family Conference Network 8 Disaster Poster	Staff collaborated and planned with Network 8 Modeled on the Network 7 disaster poster, this in-house	
0	Network o Disaster Poster	publication was sent to all Network 8 facilities during Hurricane Season.	
12	 Evaluating Alternatives Emergency Preparedness for Dialysis Facilities a Guide for People on Dialysis 	 A patient focused newsletter emphasizing the Dialysis Facility Compare (DFC) website. And the disaster preparedness 3-day Diet. Booklet sent to patients upon request 	
13	 Network services and involvement with patients during hurricane Katrina and Rita Services provided to patients in a disaster 	 Discussed role and activities of Network staff in assisting patients during the immediate crisis of the hurricanes and during the recovery period. Discussed the role and activities the Network can provide to patients in a disaster. Discussed collaborative activities with other agencies in meeting patient's needs in a disaster. 	
14	Emergency Preparedness	29-page resource guide available to patients in both English and Spanish. Facilities directed to website to access resources during hurricane season. Links to find facility, meal plan information, emergency kits, emergency diabetes care, links to emergency management by county, id cards and placards, mental health, emotional and physical needs, education on post-traumatic stress and water boiling advisory.	

17	Emergency Preparedness 2-sided Tips card	Advising patients how to prepare for an emergency, what to do if they could not get to their usual dialysis clinics. Enough cards were printed and distributed so that each patient could have a card and surplus was provided to distribute to new patients. Facility Social Workers were asked to incorporate the card into their quality improvement and education program. Results obtained from a random voluntary sampling of patients who had taken emergency preparations were very positive.
		GENERAL
2	 Patient Safety Awareness Patient Newsletter 	 Included the importance of knowing your lab values and being involved in your healthcare, not being afraid to ask questions, and reporting anything of concern to the nurse manager, social worker or a PAC representative for assistance. Contains National Kidney Foundation (NKF) Office of Scientific and Public Policy legislative news. PAC News section contains Patient Advisor Committee activities. Poet's Corner: A Place for Prose and Munchies Madness are sections where patients can contribute content and recipes. In Munchies Madness, NKF and National Institute of Health information can be found.
3	 TARC Consumer Website Education Materials distributed to dialysis facilities and patients Articles sent to dialysis facilities 	 Contains patient safety and quality improvement information on issues such as medications, immunizations/vaccinations, injury, accident prevention, safety and wellness. Included: Complaints and Grievances, Dialysis Access, Dialysis Treatment, Health Care, and Medicare information. Includes: "Staying Warm in Winter can be a Matter of Life and Death for Older People"; "Spectrum of Bone Disorder in CKD 2005"; "Caring for and Developing your Fistula: What you Should Know"; "Dialysis Patients Speak" DVD
4	 Patient Workshop Presentations Patient Safety BINGO Patient Bulletin Board Medicare-approved drug cards "Call? Enroll! Save!" Medicare Replacement Drug Demonstration Network Newsletter Network Website 	 Invitation flyers were distributed to dialysis units that announced semi-annual patient workshops Received 139 game boards from patients at 39 facilities. Game board was included in Winter 2005 Patient Newsletter. Participants received illuminated keychain-whistles and one participant was randomly selected for a \$25 Walmart Gift Card. Sent to every facility to be posted in the waiting room as a way to communicate information to patients. Sent to administrators to distribute to patients Link for brochure describing demonstration for beneficiaries to read was provided Communication with dialysis community including patients/families and facility staff. Communication with dialysis community including patients/families and faculty staff.
5	Patient Safety presentationsPatient REMARCS	 Conducted at workshops held in Roanoke, VA, Newport News, VA, Columbia, MD and Charleston, WV Articles included: "Longest Fistula Winners"; "Have More Control over Your Dialysis and Health"; "The Fistula First Project"; "Medicare Part D: Prescription Coverage for You?"; "Home Dialysis Central"
6	Renal Health NewsSoutheastern Kidney Council	 Semi-annual newsletter includes articles on treatment options, understanding lab values, information on Network activities and other areas of interest. Also posted on Network website Designed to introduce patients to the Network; Mailed up on

6 Continued	Brochure	request and distributed at patient workshops
	 "Living with Kidney Failure, A Patient Manual" Georgia Patient Workshop South Carolina Patient Workshop North Carolina Patient Workshop Network 4 Website 	 Comprehensive review of the treatment of ESRD, developed by the Network Consumer Committee for patient education, available in large and small print, distributed to facilities whom are asked to share it with their patients; Patients can request a free copy from the Network. Also posted on Network website Patients, family members, vendors and staff attended May meeting 115 patients, staff, vendors and family members attended the October meeting. 77 patients, staff, vendors and family members attended the December meeting. "Key Information About Kidney Transplant" and Preparing for A Kidney Transplant: Frequently Asked Questions" were placed on the Network 4 website and mailed to the dialysis unites for distribution to their patients
7	 FMAQI.com website Invitations to NKF of Florida's People Like Us Live program 	 Provides goals of the program, a significant amount of education and resource materials, many of which are available in English and Spanish Mailed to South Florida ESRD patients
	 NKFF and AAKP Chapters exhibits 	Exhibits at Patient & Family conferences
8	 Mississippi Patient Advisory Council Meeting Birmingham Patient Advisory Council Meeting 	 Joint meeting with NKF of Mississippi. Presentations included Medicare Part D, Fistula First, Polypharmacy, Bone Disease, Sexual Issues and Patient Helping other Patients. The highlight was an exercise session featuring an "Afrocentrik" dance troupe showing patients how to do "Afto-aerobics". Joint meeting with the Alabama Kidney Foundation. Presentations included Living Well with Kidney Disease, Taming Thirst, Transplant Medications, Healthy Eating During the Holidays, What to Expect regarding Transplantation Outcomes, ESRD modalities, What's New in Transplantation, Vascular Access and Controversies in Transplantation and Donation.
	Tennessee Patient Advisory Council Meeting	• Joint meeting with the NKF of West Tennessee and the Middle Tennessee Chapter of AAKP. Presentations included Transplant Issues, Bone disease, Why Fistulas are Best, Diet and Health, Exercise, Medicare Part D and Patients Giving Back to other Patients.
	Mobile Patient Meeting	• Joint meeting with the Alabama Kidney Foundation, USA Regional Transplant Program, Nephrology Associates of Mobile and Network 7. Presentation included Healthy Eating Basics, New Findings in Chronic Dialysis, Transplant Controversies, Vascular Access, Post-transplant Complications, Medicare Prescription Drug Plans and Medicare Part D. Additional, the PSC for Network 7 gave a presentation of Dealing with Stress and Other Mental Issues following disasters such as Hurricane Katrina.
	• Patient Newsletter, "Kidney Patient Update", Winter 2004 – was sent to facilities in January, 2005	 Topics included winners of the "Longest Lasting Fistula Contest", the continuing features, "The 20 Year Club" and "The Doctor Is In", along with articles on the Benefits of Getting Adequate Dialysis, The Right to be Evaluated for a Transplant, Tips to Avoid the Flu, along with AAKP News and other updates.
	• Spring 2005 edition of "Kidney Patient Update" was sent to facilities in May, 2005	• It included the continuing features, "The Doctor Is In" and "The 20 year Club" along with articles on the grievance procedure (our new grievance poster), DFC, vascular access, the unveiling of the new Network 8 website, vocational rehabilitation, KIDney Kids Camp, and how the U.S. Dialysis System works.

8 Continued	• Fall 2005 edition of "Kidney Patient Update" was sent to facilities in October, 2005	• Newsletter has a new look, but continues to have the regular features, "The Doctor Is In" and "The 20 Year Club". Additional articles included Information on the Flu Vaccine, Stories from Hurricane Katrina, a Patient Disaster "To Do" List, Medicare Part D, Frequently asked questions about fistulas, the Alabama Adult Kidney Camp, and an article on Patient Responsibilities which go along with patient rights.
9/10	Renal Outreach Newsletter	• 10,000 copies distributed in each mailing; directed toward ESRD patient community but ESRD professionals and members of the renal community receive the newsletter as well; three issues produced in 2005; contains information on new therapies, rehabilitation, medications, nutrition, exercise and general topics of interest as well as Network news and Patient Leadership Committee activities
	Family Multi-media CDArticles for patient newsletter	 Cooperation with IUPUI and PLC to develop multimedia program for families Topics include issues related to having a family member with
12	• Blood is Thicker Than	 kidney disease and articles on going back to work, volunteering, etc A patient focused newsletter frequently downloaded from the
	Dialysate Taking the Monster Out of	network website in 2005. • A patient focused newsletter frequently downloaded from the
	the MachinePatient Education Certificates	network website in 2005. • Sent to patients for completion of the educational portion of
	• "Who Is The Network"	patient newsletters.Sent to facilities and patients upon request
	materialsPatient Safety Toolkits	Sent to facilities and nationts upon recurrent
	Bulletin Board Kit: Patient Safety	 Sent to facilities and patients upon request These are multiple, colorful, laminated, 8.5" x 11" sheets that facilities can use as instant bulletin board patient education displays.
	 Newsletter, Topics Include: Maintaining Your Lifeline Looking at Adequacy A Shot of Information (Immunization) Food for Thought When Your Thirst is At its Worst Taking the Monster Out of the Machine Blood is Thicker than Dialysate Transplant Booklet 	A patient focused newsletter frequently downloaded from the Network website in 2005.
	 Taking Care of Self New Patient Orientation Packet Evaluating Alternatives 	 Information on the grievance procedure, technical assistance, and influenza hepatitis B, and pneumonia immunization. A patient focused newsletter emphasizing the Dialysis Facility Compare (DFC) website. And the disaster preparedness 3-day Diet.
13	Medicare Part D	SSA and SHIP discussed the new Medicare Part D program and the process in signing up. Reviewed the plan options and how
	Sign-up for extra help	 they can impact a patient. SSA and SHIP discussed the extra help program of Medicare Part D and provided the opportunity for patients to sign-up.
	• Kidney Koncerns - Patient Newsletter that included the	• 58,000 (average quarterly distribution 14,500)

13 Continued	following topics: Access Issues, Clinical Information, Communication and Psychosocial, Diet and Nutrition, Grievance and patient Concerns, Treatment Options/Transplant Information, Vocational Rehabilitation Services, Disaster/ Emergency Preparedness and General Information. • Self Care	Discussed self-care options. Reviewed activities of self-care that
	Modality Options	 patients can engage in in-center, inclusive of self-cannulation. Discussed not starting dialysis, withdrawal from dialysis. Home, self-care and in-center.
	Home Dialysis	 Advances made in home-dialysis with emphasis on mobility of new home hemodialysis machines.
14	 Patient Poster, encourages patients to request information on Modalities and Facility Specific Kidney Transplantation charts and resources 	Available in both Spanish and English
	Lone Star Patient Newsletter	 Available in both Spanish and English. Mailed in bulk to each Texas ESRD facility and posted on network website.
	Patient Workshops	 Director of Patient Services (DPS) made 39 visits to dialysis clinics, pediatric dialysis clinics and transplant centers. Topics include: How to file a complaint at your clinic; how the Network can be a resource, filing a complaint at the Network and psychosocial adjustment to ESRD.
	Educational Seminars	 Patients are invited to Question and Answer session; average of 25 to 30 attendees per session.
	 Network Website Network resource list of clearinghouse materials 	 Outreach to patients and professionals Maintains library of videos, pamphlets and articles in both English and Spanish for both patients and professionals
	Educational Presentations and In-Services	 Nine presentations at Network, regional, local facilities and national meetings of renal professional organizations designed to assist patients and professionals in learning more about ESRD, modality selection and methods of improving outcomes.
	• Publications	• DPS had two articles published: "A Sticky Situation: A Patient's Rights Regarding Cannulation" and "Dialysis in Mexico: Neither Fiesta nor Siesta"
	Patient Education Meetings	• Presented 42 patient meetings, 39 of these meetings were in local waiting rooms of dialysis clinics and three were scheduled patient events such as local meetings of the National Kidney Foundation.
15	Renal Roundup	 Patient newsletter published periodically as an information-sharing resource for patients. December 2005 issue focused on the importance of AV Fistulas with articles from the patient perspective as well as from a professional viewpoint.
	 "ESRD Networks - What do They Do for Me?" "Don't Sin Protect Your	 Presented by Network QID at AAKP Convention Presented by Network QIC at AAKP Convention
	Skin?" Network New Patient Packet	Mailed to each new patient; includes: Network brochure "Dialysis
	THE THE TRACE	Keeps People with Kidney Failure Alive Are you Getting Adequate Hemodialysis?"; Network Patient Grievance Protocol

15 Continued		"Statement of Patient Rights and Responsibilities"; copy of Renal Roundup, patient newsletter; National Kidney Foundation brochure "Working with Kidney Disease"
16	 Network Website Summer 2005 Consumer 	 Posted: article "Staff Can You See It, Patients Won't You Let Them?", Spanish and Russian language versions "Using the Buttonhole Technique for Your AV Fistula", Buttonhole Technique information and reference sheets, "Importance of Washing Your Access Arm" article Focused on transplantation, including articles written by a
	News newsletter	transplant recipient and his living related donor. Newsletter was mailed to all facilities for distribution to patients.
17	Self-Care Modalities Promotion	Information of self-care modalities is available on Network 17 website and in the Community Information Resource Mailing
18	PAC FactsNew Facility Packet	 Poster and fact sheet for patient and facility staff education Includes poster that describes Network's basic functions and how patients can access resources and "How to Address Your Concern"
	 Patient Guidance Educational Materials Library	 Provided patient guidance and/or referrals on clinical issues Available to both patients, family member and facilities as appropriate
	• Russian-Armenian Television Station	Relationship developed by the QI Director allows her to give interviews on topics such as influenza and hepatitis
	 Renal Support Network, local American Nephrology Nurses Association Chapter, American Kidney Fund, local American Association of Kidney Patients chapters and local Licensed Clinical Social Workers chapters 	Presented at local and regional meetings covering various quality improvement and patient-related topics
	• Renal Support Network partnership	Presented a series of three patient education meetings focused on renal diet, immunizations/infection control and vascular access management
	Medicare Part D	PSC worked closely with local CNSW chapters to disseminate information to patients and other healthcare providers
	Network Website	 List of patient educational materials from other renal organizations that are available in Spanish continues to be updated and disseminated to all facilities
	GRIEVAN	NCES & PATIENT CONCERNS
1	Laminated Network Notification Cards for Patients	NW 1 provides laminated Network Notification cards to all New England Dialysis clinics, with instructions to display the cards in the patient waiting area. These placards provide contact information to patients who need assistance with a complaint.
3	 Consumer Rights & Responsibilities flyer TARC Website "I am a Dialysis Patient What Can I Do if I Have a Complaint?" 	 Available in both English and Spanish, distributed to all Network facilities. Provides a Question/Answer section for consumers Brochure developed and distributed; information on network grievance procedure available via patient bulletin boards, handouts and orientation packets.
4	"Patient's Rights and Responsibilities and Grievance Procedures"	Brochure provided to dialysis facilities to display on their bulletin board
5	• Grievance Policy Brochure/Form	Distributed upon request
	Grievance Poster	Distributed upon request

6	"What Can I Do When I Have a Complaint?" brochure	Guides a patient in the process of what to do when they have a complaint, lists State Survey Agencies contact information, available in both English and Spanish, provided to facility Social Workers and also posted to the Network website
7	Patient and Provider newsletters and articles Grievance Posters	 Grievance Process information Updated to reflect FMQAI website address; distributed to all Florida renal facilities, available in both English and Spanish
8	Network 8 Grievance Poster	Poster giving a brief overview and contact information for filing a grievance or complaint was distributed to all Network 8 facilities.
12	 Evaluating Alternatives Grievance Booklet, Forms, and FAQs 	 A patient focused newsletter emphasizing the Dialysis Facility Compare (DFC) website. And the disaster preparedness 3-day Diet. Sent to facilities and patients upon request
13	 Network role and responsibility in resolving patient complaints and grievances. Kidney Koncerns-Patient Newsletter. Grievance and Patient Concerns Issues include: Network 13 Grievance process 	 Discussed the Network complaint and grievance process. Discussed the role and responsibility of the Network grievance committee in investigating patient complaints and grievances. Discussed the referral options to other agencies to address issues not under the Networks purview. 58,000 (average quarterly distribution 14,500)
15	"Have a Problem?" Poster	Available in English and Spanish and distributed to all facilities; provides suggested steps for problem resolution within a facility and external resources specific to each Network 15 state
16	Grievance information Complaints	 Patients were sent information including Network's grievance procedures, a summary of the grievance review process, Patient Rights and Responsibilities Statements, federal standards and regulations, and other information as applicable to their concerns Addresses complaints using active listening and mediation skills to prevent escalation to formal grievances
17	Patient Grievance Process	Patient Service Coordinator (PSC) offered the process to beneficiaries when they called the Network with a complaint but none chose the option.
18	 Grievance Poster Grievance Procedure and Grievance Form Complaints 	 Helps patients and providers understand the grievance process Available in English and Spanish and distributed to all facilities Addresses complaints using active listening and mediation skills to prevent escalation to formal grievances
	TREATM	ENT OPTIONS/TRANSPLANT
1	Transplant Awareness Poster	The locally developed and produced poster was created in 2004 and redistributed to all New England dialysis facilities in 2005 for the purpose of public posting in the patient waiting area.
6	"Kidney Transplant Basics: A Patient's Resource Guide"	Educates patients about the treatments option of transplantation. Outlines basic facts, advantages and disadvantages, how to get on the transplant list and answers to some frequently asked questions about Medicare. Mailed to facility Social Workers and Medical Directors and posted on Network website.
	Transplant Posters	Mailed to facility Social Workers to be posted

12	Transplant Booklet	A patient focused booklet frequently downloaded from the network website in 2005.
13	Modality Options Home Dialysis Kidney Koncerns-Patient Newsletter. Treatment Options/Transplant Issues include: Transplant- "Are you informed?"	 Discussed the treatment modality options that patients have inclusive of choosing to not start dialysis and withdrawal from dialysis. Modalities inclusive of home, self-care and in-center. Discussed advances made in the area of home dialysis with an emphasis in mobility of new home hemodialysis machines. 58,000 (average quarterly distribution 14,500)
16	Transplant issue of patient newsletter "Consumer News"	Distributed to patients
	VOCATIONAL REHABILITA	ATION/EMPLOYMENT/FINANCES/EXERCISE
1	 Freddie & Freda Fistula Consumer Assessment of Healthcare Patients (CAHPS) 	 Created in first quarter of 2005 as part of the national effort to increase the number of native AV Fistulae for ESRD patients. Assisted in the project by testing the proposed survey tool during its final revisions
2	Patient Advisory Committee (PAC) Activities Vocational Rehabilitation (VR) Specialist Activities	 Vocational Rehabilitation Specialist (VRS) presents current information and handouts on back-to-work incentives and tips and techniques in working with the state vocational rehabilitation program, Vocational and Educational Services for Individuals with Disabilities (VESID), and answers questions. PAC activities include: efforts to enhance awareness of Patient Safety among consumers; PAC chairperson regional meeting of PAC representatives; Queens PAC chairperson responded to request from two facilities to provide information on ESRD Network and PAC organization to patients; Several PAC chairpersons visited units without PAC representation to encourage and educate social workers of the benefits of having a PAC and assisted in patient recruitment at some units; Quarterly conference calls and an Annual Meeting were held; Two chairs were sponsored by the Network to attend patient educational conferences. One chair attended the American Association of Kidney Patients (AAKP) conference and the other attended the Renal Support Network (RSN) conference. Over 200 patients received individual vocational counseling on work-related issues from the VR specialist. 74 social workers were given information to help patients deal with vocational concerns. 183 packets were mailed to individuals requesting information. During seventeen site visits and group presentations, 292 professional staff and patients were educated and made aware of services provided by VR specialist and encouraged to assess the vocational potential of their patients. Four training programs on the special needs of ESRD patients to District Offices of VESID, New York State's VR agency for people with disabilities. Training was provided to 142 professional staff members.
4	Rehabilitation Brochure "Rehabilitation: Getting Back to Work!"	Created by members of the Rehabilitation Committee. Supports rehabilitation and offers referral numbers. Mailed invitations to all Florida Parkandle facilities for distribution.
7	Mental Health Presentation at Network 8 Annual Patient Meeting	Mailed invitations to all Florida Panhandle facilities for distribution to patients

12	Bulletin Board Kit: Renal Rehabilitation Taking Care of Self	 These are multiple, colorful, laminated, 8.5" x 11" sheets that facilities can use as instant bulletin board patient education displays. A patient focused newsletter frequently downloaded from the network website in 2005.
13	Vocational Rehabilitation Programs Social Security Work Incentive Program	 Oklahoma Vocational Rehabilitation Counselor reviewed the programs available to patients. Counselor discussed the requirement to qualify for the services and the barriers to services for the dialysis patient. Social Security Representative discussed and reviewed the program opened to dialysis patients who have disability. Representative discussed requirements for qualification and how to access the programs.
15	Rehabilitation/Vocational Rehabilitation Packet	Information mailed directly to each new patient in the Network. Packet includes National Kidney Foundation brochure "Working with Kidney Disease"
17	 State Rehabilitation Office Website links for rehabilitation information "A Message about Rehabilitation for Dialysis Patients" Bulletin 	 PSC site visit made to acquire current information in regards to how patients can access their services Links on Network website for California Rehabilitation Offices and for Life Options Rehabilitation Advisory Council. Educational Bulletin mailed to each facility social worker. Promoted goal setting and personal improvement activities to help them achieve progress toward employment and a better quality of life. Resources provided were a link to the Life Options website and an inspirational book by an ESRD patient.
18	Vocational Rehabilitation Resources	Materials provided to all Network 18 facilities for distribution

Source: Networks 1-18 Annual Reports, 2005

APPENDIX S LIST OF ACRONYMS

ACRONYM	ORGANIZATION	ACRONYM	ORGANIZATION
AAKP	American Association for Kidney Patients	NKF	National Kidney Foundation
AHRQ	Agency for Healthcare Research and Quality	NRAA	National Renal Administrators Association
AKF	American Kidney Fund	OCSQ	Office of Clinical Standards and Quality
ANNA	American Nephrology Nurses Association	ODIE	Online Data Input and Edit
BOD	Board of Directors	OGC	Office of General Counsel
BUN	Blood Urea Nitrogen	OPO	Organ Procurement Organization
CAPD	Continuous Ambulatory Peritoneal Dialysis	OPTN	Organ Procurement and Transplanation Network
CCPD	Continuous Cycling Peritoneal Dialysis	OSCAR	Online Survey Certification and Reporting
CMS	Centers for Medicare & Medicaid Services	PD	Peritoneal Dialysis
CO	Central Office (CMS)	PID	Project Idea Document
CPM	Clinical Performance Measures	PIP	Performance Improvement Plan
CQI	Continuous Quality Improvement	PO	Project Officer
DHHS	Department of Health and Human Services	QA	Quality Assurance
DMMS	Dialysis Mortality and Morbidity Study	QI	Quality Improvement
DOQI	Dialysis Outcomes Quality Initiative	QIO	Quality Improvement Organization
DVA	Department of Veterans Affairs	QIP	Quality Improvement Project
EDEES	ESRD Data Entry and Editing System	REBUS	Renal Beneficiary and Utilization System
ELAB	Electronic Transfer of Laboratory Data	REMIS	Renal Management Information System
EPO	Erythropoietin	RO	Regional Office (CMS)
ESRD	End Stage Renal Disease	RPA	Renal Physicians Association
HCQIP	Health Care Quality Improvement Program	SA/SSA	State Agency/State Survey Agency
HCT	Hematocrit	SIMS	Standard Information Management System
HD	Hemodialysis	SOW	Statement of Work
HIC	Health Insurance Claim	SSA	Social Security Administration
LEA	Lower Extremity Amputation	SSN	Social Security Number
MRB	Medical Review Board	UNOS	United Network for Organ Sharing
NCC	Network Coordinating Council	URR	Urea Reduction Ratio
NIDDK	National Institute of Diabetes & Digestive & Kidney Diseases	USRDS	United States Renal Data System
NIH	National Institutes of Health	VISION	Vital Information System to Improve Outcomes in Nephrology

APPENDIX T RENAL ORGANIZATION WEB ADDRESSES

ORGANIZATION	WEB ADDRESS
American Association of Kidney Patients (AAKP)	www.aakp.org
American Health Quality Association (AHQA)	www.ahqa.org
American Kidney Fund	www.akfinc.org
American Nephrology Nurses' Association (ANNA)	www.annanurse.org
American Society for Artificial Internal Organs	www.asaio.com
American Society of Nephrology	www.asn-online.org
American Society of Pediatric Nephrology	www.aspneph.com
Centers for Disease Control and Prevention (CDC)	www.cdc.gov
Centers for Medicare and Medicaid Services (CMS)	cms.hhs.gov
Dialysis and Transplantation	www.eneph.com
Dialysis Facility Compare	www.medicare.gov
Emergency Care Research Institute (ECRI)	www.ecri.org
Food and Drug Administration	www.fda.gov
Hypertension, Dialysis and Clinical Nephrology (HDCN)	www.hdcn.com
iKidney.com	www.ikidney.com
International Society of Nephrology	www.isn-online.org
International Society for Peritoneal Dialysis	www.ispd.org
Kidney Disease Outcomes Quality Initiative (K/DOQI)	www.kidney.org/professionals/KDOQI
Kidney & Urology Foundation of America	www.kidneyurology.org
Kidney School	www.kidneyschool.org
Life Options Rehabilitation Program (LORAC)	www.lifeoptions.org
National Association for Healthcare Quality (NAHQ)	www.nahq.org
National Association of Nephrology Technicians/Technologists (NANT)	www.dialysistech.org
National Institutes of Health	www.nih.gov
National Kidney Foundation (NKF)	www.kidney.org
National Renal Administrators Association (NRAA)	www.nraa.org
National Transplant Assistance Fund (NTAF)	www.transplantfund.org
Nephron Information Center	www.nephron.com
National Institute of Diabetes and Digestive and Kidney Disease	www.niddk.nih.gov
Occupational Safety and Health Administration	www.osha.gov
PKD Foundation	www.pkdcure.org
Renal Physicians Association	www.renalmd.org
RENALNET	www.renalnet.org
Renal Support Network	www.renalnetwork.org
RenalWEB	www.renalweb.com
TransWeb	www.transweb.org
United Network for Organ Sharing (UNOS)	www.unos.org
United States National Library of Medicine (NLM)	www.nlm.nih.gov
United States Renal Data System (USRDS)	www.usrds.org

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