End Stage Renal Disease
Network Organization Program

2012

Summary Annual Report

Centers for Medicare & Medicaid Services

This report was prepared by the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services.

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Report Highlights

The End Stage Renal Disease Network Organization Program (ESRD Network Program) is a national program funded by CMS to improve the quality of care for individuals with irreversible kidney disease who require dialysis or transplantation to sustain life. The health care improvement services provided by the ESRD Networks align with the National Quality Strategy and the CMS Quality Strategy.

The ESRD Network Statement of Work (SOW) provides direction to the ESRD Network Program to ensure that each Network meets contract requirements. From 2006 to 2012, the ESRD Network SOW focused on five tasks: Network Quality Improvement Program, Community Information and Resources, Administration, Information Management, and Special Projects.

This section summarizes ESRD Network task requirements, key findings, and outcomes from 2011–2012. It also includes recommendations to support the future direction for the ESRD Network Program.

ESRD Incidence and Dialysis Prevalence

*The rate of newly occurring cases of ESRD in the U.S. decreased slightly from 360 per million population in 2011 to 343 per million population in 2012 (Table 3), a difference of 23 per million population. These findings are not markedly different, thus, indicating a relatively stable population of patients. However, of note, there was considerable variation in ESRD incidence across ESRD Networks in 2012, from 226 patients per million population (***Network 16***) to 405 per million population (***Network 8***), a difference of 179 per million population. At the end of 2012, 427,743 patients were receiving dialysis in the United States (Table 1) according to the Networks' Annual Reports for 2012—a 2.9% increase from 2011 (Figure 8).*

Mortality Rates

Data released by the United States Renal Data System indicate that the unadjusted mortality rate for dialysis patients fell 9.8% from 2007 to 2011. Mortality adjusted for age, gender, race, and comorbidity fell 10.7% during the same time period.[1] *These data suggest*

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[1] United States Renal Data System. Chapter 5: Mortality. In: United States Renal Data System. *United States Renal Data System 2013 Annual Data Report: Atlas of End-stage Renal Disease in the United States.* Vol. II. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2013:264-70.

that the quality of care delivered to patients is better because the overall incidence of death is lower.

Fistula First Breakthrough Initiative (FFBI)

In 2012, the ESRD Networks achieved great success for increasing fistula use, which is a well-known treatment access portal to reduce the rate of infection in dialysis patients. Fifteen of the eighteen Networks (83%) reported success at increasing the use of arteriovenous fistulas (AVFs) among in-center and home hemodialysis patients as of December 31, 2012, relative to each Network's December 31, 2011 rate (Table 19). Of the Networks that saw an increase in reported fistula use, two exceeded the Network target of 66% of AVF use for all in-center and home dialysis patients. Interventions implemented by the ESRD Networks have contributed to this increase. From December 31, 2011 to December 31, 2012, the national rate of AVF placement among prevalent in-center and home hemodialysis patients increased 6.5%.

Home Dialysis

As a result of the ESRD Networks' persistent promotion of home hemodialysis, the rate of this treatment modality continues to increase. In fact, the rate of home dialysis went up 13% among dialysis patients from 2011 to 2012 (Table 13). The 2008 ESRD Conditions for Coverage mandate patient assessment, education, and training for home dialysis under the "Patient Plan of Care" Condition (Section 494.90). As a result, the financial incentives for home dialysis training and treatment, in the ESRD Prospective Payment System, may make home hemodialysis an attractive alternative to standard in-center care. In the future, more dialysis patients are expected to use home hemodialysis as their preferred treatment modality.

Grievances, Involuntary Discharges, and Sanctions in 2012

The 18 ESRD Networks processed 1,301 formal beneficiary grievances in 2012, with an average rate of 3.04 grievances per 1,000 dialysis patients. Of these 18 Networks, only three reported a rate greater than 5.0 grievances per 1,000 patients. See Table 21 for Network-specific data. The 18 Networks processed 404 involuntary discharge (IVD) cases in 2012, 38 (9%) fewer than in 2011. Of the 18 Networks, ten reported 20 or fewer IVDs, while the remaining eight Networks reported from 23 to 46 grievances. See Table 21 for Network-specific data. In 2012, no sanctions were recommended by the ESRD Networks.

Outreach, Education, and Technical Assistance

The ESRD Networks engaged in a variety of outreach, education, and technical assistance activities in 2012 including: (1) Network newsletters and websites, (2) annual reports and meetings, (3) outreach to and education for patients and families/caregivers, (4) outreach and professional education to renal professionals, and (5) support for vocational rehabilitation and employment.

Emergency Preparedness and Response to Superstorm Sandy

During and immediately in the aftermath of Superstorm Sandy, the Kidney Community Emergency Response held daily conference calls with representatives from CMS, the ESRD Networks, patient and professional organizations, and other stakeholders. These calls assisted in the communication, collaboration, and problem-solving processes associated with the effects of Superstorm Sandy.

Partnerships and Coalitions

The ESRD Networks engaged in a variety of collaborative activities in 2012. These collaborations involved communication and coordination with renal partners at the local, Network-area, regional, and/or national levels. The Networks' partners included organizations such as the National Kidney Foundation, the American Kidney Fund, the American Association of Kidney Patients, the National Association of Nephrology Technicians/Technologists, the National Renal Administrators Association, the Council of Nephrology Social Workers, the American Nephrology Nurses' Association, the Renal Physicians Association, the American Society of Nephrology, the National Hospice and Palliative Care Organization, the Association of Health Facility Survey Agencies, the Life Options Rehabilitation Advisory Council, the Medical Education Institute, the United Network for Organ Sharing, the United States Renal Data System Coordinating Center, the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health, independent dialysis corporations, and large corporate dialysis organizations. The Networks also actively collaborated with State Survey Agencies and Medicare Quality Improvement Organizations in their geographic areas.

In summary, the ESRD Network Program continues to bring value to Medicare beneficiaries by supporting the health of the ESRD population, improving overall health care quality, and lowering costs through their quality improvement efforts. This is evident by the Networks' success in increasing the use of fistulas, reducing infection rates, and increasing immunization rates. Also, the Networks provide critically needed technical assistance, education, and advocacy support to ESRD beneficiaries and their families as well as clinical providers and the broader dialysis community.

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ESRD Network Program Overview

The End Stage Renal Disease Network Organization Program (ESRD Network Program) is a national program funded by CMS to improve the quality of care for individuals with irreversible kidney disease who require dialysis or transplantation to sustain life.

> ***Medicare coverage was extended to most ESRD patients in the U.S. under the Social Security Act Amendments of 1972 (Public Law 92-603).***

Medicare coverage was extended to most ESRD patients in the U.S. under the Social Security Act Amendments of 1972 (Public Law 92-603). Individuals with irreversible kidney failure are eligible for Medicare if they need regular dialysis, or have had a kidney transplant, and if they meet certain work history requirements under Social Security, the railroad retirement system, or federal employment. Medicare eligibility is also extended to people with permanent kidney failure if they are the spouse or child of an individual who has met specific work history criteria.

Following passage of the 1972 Amendments, in response to the need for effective coordination of ESRD care, hospitals and other healthcare facilities were organized into Networks to enhance the delivery of services to people with ESRD. In 1978, Public Law 95-292 modified the Social Security Act to allow for the coordination of dialysis and transplant services by linking dialysis facilities, transplant centers, hospitals, patients, physicians, nurses, social workers, and dietitians into Network Coordinating Councils, one for each of 32 administrative areas. In 1988, CMS consolidated the 32 jurisdictions into 18 geographic areas and awarded contracts to 18 ESRD Network Organizations with responsibilities for: supporting use of the most appropriate treatment modalities to maximize quality of care and quality of life; encouraging treatment settings to support patients' vocational rehabilitation and employment; collecting, validating, and analyzing patient registry data; identifying providers that do not help achieve Network goals; and conducting onsite reviews as necessary. These ESRD Network Organizations, commonly known as ESRD Networks, serve the 50 states, the District of Columbia, and the U.S. territories of Puerto Rico, the Virgin Islands, American Samoa, Guam, and the Northern Mariana Islands (see map and Figure 1).

In 1989, Section 1881(c) of the Social Security Act was amended by PL 101-239 to provide the Networks both confidentiality in the medical review process and a limitation on liability. CMS has awarded the Networks fixed-price contracts on a three-year cycle since 1990.

CMS withholds $0.50 from the Medicare composite rate payment for each dialysis treatment an ESRD patient receives to fund this essential program. This rate has remained the same since 1978. In 2012, the Program was funded for approximately $28.0 million via these withholdings.

The ESRD Network Coordinating Center (NCC) supports the activities of the ESRD Networks as required by Section 1881(c) of the Social Security Act. The NCC provides centralized coordination and support for the operation of the ESRD Network Program. The NCC's primary responsibilities include collecting, maintaining, and disseminating ESRD information; coordinating national activities, including training initiatives; facilitating Special Projects as requested by CMS; and providing administrative support services.

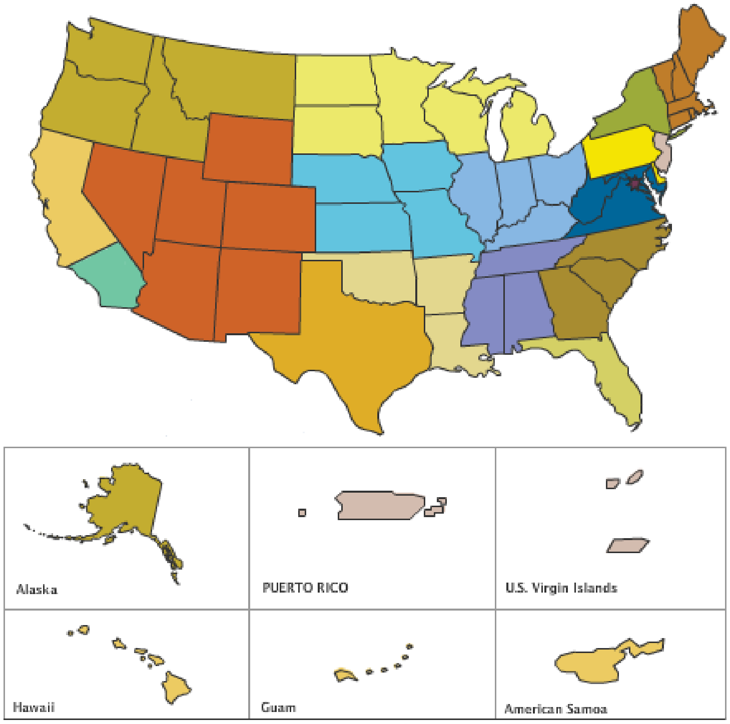


FIGURE 1
ESRD Network Areas

Network	Geographic Area
1	CT, MA, ME, NH, RI, VT
2	NY
3	NJ, PR, VI
4	DE, PA
5	DC, MD, VA, WV
6	GA, NC, SC
7	FL
8	AL, MS, TN
9	IN, KY, OH
10	IL
11	MI, MN, ND, SD, WI
12	IA, KS, MO, NE
13	AR, LA, OK
14	TX
15	AZ, CO, NM, NV, UT, WY
16	AK, ID, MT, OR, WA
17	American Samoa, Guam, HI, Northern CA, Northern Mariana Islands
18	Southern CA

The NCC is also charged with preparation of an *ESRD Network Program Summary Annual Report* each year for Congress, CMS, the ESRD Networks, and other stakeholders. The report compiles information from the Networks' Annual Reports as well as outcome data from the Network Coordinating Center.

Network Requirements

The ESRD Network Statement of Work (SOW) provides direction to the ESRD Network Program to ensure that each Network meets contract requirements. From 2006 to 2012, the ESRD Network SOW focused on five tasks: Network Quality Improvement Program; Community Information and Resources; Administration; Information Management; and Special Projects. The current *2012 Summary Annual Report* is the last document of its kind to provide a précis of ESRD Network activities guided by these five tasks.

Beginning in 2013, the SOW was revised to address the Department of Health and Human Services' National Quality Strategy (NQS), the CMS Three Aims, and other CMS priorities designed to improve the care of individuals with ESRD. The CMS Three Aims are:

- **Aim 1:** Better care for the individual through beneficiary- and family-centered care.
- **Aim 2:** Better health for the ESRD population.
- **Aim 3:** Reduce costs of ESRD care by improving care.

The achievement of each of these aims is influenced by a variety of individual, social, and organizational factors, including patient characteristics, patients' social support networks, and aspects of the health care delivery system. To address these multifactorial influences on ESRD care, each Network is responsible for focusing on disparities when conducting all of the activities outlined in the SOW. Specifically, Networks need to develop, implement, and assess interventions aimed at reducing disparities in ESRD patients' access to care and health outcomes.

From 2006 to 2012, the ESRD Network SOW focused on five tasks: Network Quality Improvement Program; Community Information and Resources; Administration; Information Management; and Special Projects.

In 2012 a total of 187 full-time equivalent staff members representing the 18 ESRD Networks supported 5,990 dialysis facilities and 236 transplant centers in improving the quality of care provided to renal patients across the country.

The *2013 Summary Annual Report* will provide the first overview of ESRD Network activities performed in accord with the CMS Three Aims.

Network Staffing

The structure and content of subsequent *Summary Annual Reports* will reflect the priorities outlined in the Three Aims and highlight Network activities to address disparities in ESRD care.

CMS requires each Network, at a minimum, to employ the following staff:

- **Executive Director/Project Director:** Responsible for the administration of all contract requirements and overall operation of the Network. The Director has professional relationships within the ESRD community and has expertise in administration of the CMS contract, management and supervision of staff, and fiscal oversight of the Network.
- **Quality Improvement Director/Quality Improvement Coordinator:** Coordinates quality-related initiatives and creates and implements the Network's quality improvement program.

- **Data Manager:** Oversees the collection, accurate recording, security, and transmission of data between providers, the Network, and CMS.

- **Patient Services Coordinator:** Responsible for assisting patients and their families by responding to questions and information requests, resolving patient or provider complaints and grievances, and on request, conducting training on conflict resolution and how to manage difficult patients. This position is full-time and performed by a person with a master's degree in social work or an equivalent qualification.

- **Community Outreach Coordinator:** Provides information and training to ESRD professionals, patients, family members, and other members of the renal community.

Additional staff in the areas of quality improvement, data management, and patient services are essential for the coordination of the many Network activities. Job titles vary from Network to Network.

In 2012, the ESRD Networks reported a total of 187 full-time equivalent staff members (FTEs) to implement core CMS contract activities for renal patients who receive care at 5,990 dialysis facilities (see Table 1) and 236 transplant centers. On average, there were approximately 10 FTE staff members involved in core contract activities per Network. Across all Networks, the largest FTE allocation was for data management (mean across Networks = 2.92 FTEs) followed by quality improvement (mean = 2.90 FTEs), administration (mean = 2.34), and patient services (mean = 2.25 FTEs).

Network Governance

Each Network must establish and maintain a Network Council (NC), which includes at least one patient representative and representatives from dialysis and transplantation providers located in the Network area. In addition, each Network must establish a Medical Review Board (MRB) made up of at least one patient representative and a mix of ESRD professionals— typically nephrologists, surgeons, physician assistants, nurses, social workers, dietitians— who are qualified to evaluate the quality and appropriateness of renal care. The MRB, which is advisory to the Network Council, serves as an expert panel on patient care issues. Both the NC and the MRB must meet statutory requirements with respect to composition and must adhere to strict conflict of interest guidelines to ensure objectivity.

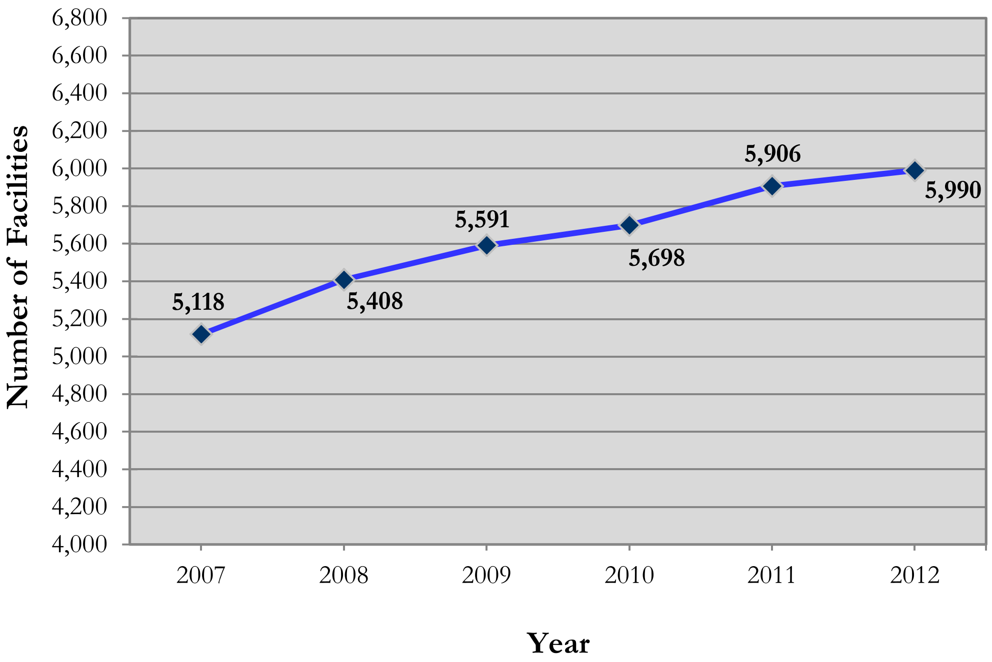
Each Network also relies on a Patient Advisory Committee or Patient Leadership Committee to provide a patient perspective that is incorporated into Network activities. Networks appoint additional standing or ad hoc committees as needed to perform their work. These committees may focus on issues such as patient grievances, vocational rehabilitation, or transplantation. The dialysis and transplant providers in each Network area are offered opportunities to appoint representatives to Network committees. Providers are required to participate in Network activities; see Section 1881(c)(2) of the Social Security Act.

Members of these bodies are volunteers who contribute many hours of service to the Networks. The collective contribution of these members is integral to the effective functioning of the Networks and the success of the ESRD Network Programs.

Patients and Facilities

Table 1 shows the number of prevalent dialysis patients, the number of dialysis facilities, and the distribution of FTEs by core contract activity for each Network in 2012. **Network 6** had the largest number of dialysis providers (608) in its geographic area, and **Networks 1 and 3** had the fewest facilities (174). As can be seen in Figure 2, the number of dialysis facilities in the U.S. has increased steadily from 2007 to 2012.

FIGURE 2
Number of Dialysis Facilities in the U.S.
as of December 31 of Each Year, 2007 2012



SOURCE OF DATA: Networks 1 18.

Data Management Systems

In 1978, the U.S. Department of Health and Human Services established the Program Management and Medical Information Systems (PMMIS) as a repository of Medicare ESRD beneficiary information. This system was accessed through the Renal Beneficiary and Utilization System (REBUS) interactive software. Concurrently the 32 ESRD Network Coordinating Councils (precursors to the ESRD Networks) developed local data systems to fulfill their program requirements, including forms entry, quality assurance, and oversight functions. These Network systems had similar components, and each provided a subset of the data in the PMMIS.

In 1988, the Health Care Financing Administration, now CMS, developed ESRD Data Entry and Editing Software (EDEES) to allow electronic completion and transmittal of CMS-required ESRD forms. The Network Coordinating Councils developed utilities to merge these data into their existing systems. In 1988, the 32 ESRD Network Coordinating Councils were consolidated by Congress into 18 ESRD Network Organizations, or ESRD Networks, and the individual Network data systems were expanded to meet increased responsibilities.

In 1995, CMS and the Networks recognized the need to standardize the collection, storage, and reporting of patient registry data. The 18 Networks and CMS formed workgroups to identify best practices in the existing local data systems and established requirements for the Standard Information Management System (SIMS). Networks voluntarily tested the system and converted their existing systems to SIMS in 2000, and EDEES was eliminated. Networks used SIMS for data collection, management, and reporting purposes from 2000 to May 2012.

CMS began development on the Vital Information System to Improve Outcomes in Nephrology (VISION) in 1999 to enable dialysis providers to enter and transmit their data electronically into SIMS. VISION was launched to all independent dialysis facilities in 2002 through the ESRD Networks, which recruited, trained, and supported local VISION users. This involved conducting workshops, preparing seed databases from SIMS, and providing phone support. After facilities submit data from VISION through the Quality Net Exchange secure data transport, Networks validate and import the data into SIMS.

In 2002, CMS replaced REBUS with the Renal Management Information System (REMIS) to provide easier access and increased functionality. Reliable linkages were built to the SIMS system, allowing data matching based on the unique patient identification number. This linkage formed the foundation for the Consolidated Renal Operations in a Web-Enabled Network (CROWNWeb) system to connect all ESRD registry components. Other data modules within CROWNWeb are Clinical Performance Measures (CPMs), the laboratory results database, and a Cognos-based reporting tool.

The five largest dialysis organizations began providing batched electronic data directly to CMS for inclusion into CROWNWeb in 2003. Other ESRD data resources that depend on CROWNWeb data include the United States Renal Data System (USRDS), the Social Security Administration's Master Beneficiary Record, the United Network for Organ Sharing (UNOS), and the annual facility data reports generated by the University of Michigan Kidney Epidemiology and Cost Center.

CROWNWeb
Consolidated Renal Operations in a Web Enabled Network

In 2012 a total of 93,343 Medical Evidence Reports and 58,801 Death Notification Forms were processed by the Networks and ESRD facilities, using SIMS and CROWNWeb data management systems.

CROWNWeb, released nationally in June 2012, is a Web-based data collection system that facilitates the collection and maintenance of patient and provider information. As mandated by CMS, and noted in Section 494.180(h) of the 2008 updated *Conditions for Coverage for End-Stage Renal Disease Facilities*, Medicare-certified dialysis facilities located within the United States are required to electronically submit administrative and clinical data through CROWNWeb. CROWNWeb is designed to facilitate the renal community's effort to receive and maintain complete and accurate data for dialysis patients. It is also meant to improve patient care efforts by providing timely access to clinical performance reports. Implementation of CROWNWeb transitioned the renal community from paper-based data collection efforts to an electronic platform.

The CROWNWeb system combines all existing SIMS systems into a Web-based information system shared by CMS, the Networks, and facility users, with role-based access. CMS worked with several contractors and the Networks to build the CROWNWeb system.

The CROWNWeb data system supports data collection for two primary CMS ESRD forms—the **End Stage Renal Disease Medical Evidence Report: Medicare Entitlement and/or Patient Registration** (CMS-2728) and the **ESRD Death Notification** (CMS-2746). Dialysis facilities, the primary users of CROWNWeb, use the system to add, modify, and delete information associated with these forms. CROWNWeb also requires facilities to enter clinical data on all dialysis patients and report administrative information on facility personnel and dialysis services.

Data Systems Used by ESRD Networks

All ESRD Networks rely on several data sources to fulfill their CMS contractual obligations for conducting quality improvement projects, providing technical assistance to ESRD providers and professionals, and responding to patient inquiries. These data systems are maintained and developed by CMS contractors. The following summaries briefly describe the scope and type of data available to ESRD Networks and CMS in each system.

SIMS

The SIMS software application was decommissioned in May 2012 with the implementation of CROWNWeb. Prior to CROWNWeb, SIMS was used by the ESRD Networks to populate an ESRD patient registry that contained information documenting treatment modality and ESRD provider services. The system was used for form entry and submission tracking, and included modules that created reports needed by the Networks. The forms that supported the registry included Forms CMS-2728, CMS-2746, and CMS-2744, and a monthly patient activity form. These forms provided data on patient demographics, patient events, and facility information, including dialysis modality history. The database utilities provided import and export capabilities as well as a way to create backup files and recover the database. SIMS provided data for quality management and reporting at the national and Network levels. SIMS also supported the data collection process for the Fistula First National Quality Improvement Initiative. As of 2006, CMS no longer supported SIMS software enhancements. Instead, CMS prioritized the development of web-based applications for provider transmission of registry data. In 2012, CMS achieved that goal with the national release of the web-based application CROWNWeb.

In 2012, using both SIMS and CROWNWeb data management systems, the Networks and ESRD facilities processed a total of 93,343 Medical Evidence Reports (CMS-2728 forms) and 58,801 Death Notification Forms (CMS-2746 forms) (Table 2).

With release of CROWNWeb in June of 2012, the SIMS database was decommissioned. Data entry efforts previously performed by the 18 ESRD Networks are now the responsibility of each dialysis facility. The notable decrease in Forms CMS-2728 and CMS-2746 processed between 2011 (data not shown) and 2012 could be the result of improved procedures to eliminate duplicate forms or potential under-reporting using the CROWNWeb data management platform.

Fistula First Breakthrough Initiative (FFBI) Dashboard

In 2003, the large dialysis organizations (LDOs) began submitting aggregate vascular access data electronically to CMS. Independent, hospital-based, and Veterans Health Administration dialysis clinics submit their aggregate vascular access data to the Networks. The data from both sources were compiled on a monthly basis by a CMS contractor. Each Network created standardized feedback reports for all providers participating in the FFBI and distributed them quarterly. CMS produced a monthly Fistula First Outcomes Dashboard, which depicted the Networks' progress in increasing arteriovenous fistula (AVF) placement rates as well as Network- and national-level data. With implementation of CROWNWeb in 2012, the Fistula First Outcomes Dashboard was last produced in May 2012.

Dialysis Facility Reports

Provider-specific data reports are generated annually based on data from Medicare dialysis hospitalization claims, Medical Evidence Reports (CMS-2728 forms), Death Notification Forms (CMS-2746 forms), Annual Facility Survey Reports (CMS-2744 forms), and other CMS and Social Security Administration data sources. The University of Michigan Kidney Epidemiology and Cost Center conducts statistical analyses of the information provided in these reports using funding from CMS. The reports facilitate comparisons of patient characteristics, treatment patterns, transplantation rates, hospitalization rates, and mortality rates to local and national averages.

United States Renal Data System

The United States Renal Data System (USRDS) is required by law to collect and analyze information about ESRD in the United States on an annual basis. USRDS collaborates with CMS, the United Network for Organ Sharing (UNOS), and the ESRD Networks by sharing datasets and actively working to improve the accuracy of ESRD patient information. The National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health, with input from CMS, directs the work of the USRDS Coordinating Center, which is operated by the Minneapolis Medical Research Foundation. The USRDS Coordinating Center produces an annual data report on ESRD in the United States, fulfills data requests, provides standard analysis files and specialized datasets to researchers, and presents the results of its research at national conferences and in peer-reviewed journals.

United Network for Organ Sharing (UNOS)

UNOS is a nonprofit scientific and educational organization that administers the nation's only Organ Procurement and Transplantation Network (OPTN). UNOS facilitates the organ matching and placement processes. UNOS also collects and manages data about every transplant event occurring in the United States and brings together medical professionals, transplant recipients, and donor families to develop organ transplantation policy.

Patient Characteristics

CMS defines end-stage renal disease (ESRD) as "permanent kidney failure treated with dialysis or a transplant." ESRD is the final stage on the spectrum of chronic kidney disease (CKD). The prevalence of CKD in the U.S. population is high, attributable in part to high rates of diabetes, hypertension, and obesity.[2] Not all CKD patients progress to ESRD, but the high CKD rate is one of the factors that contribute to the increasing prevalence of ESRD.[3] Rising trends have been observed over time for both incidence (number of new patients in a given time period) and prevalence (number of existing patients at a given time point) of ESRD.[1,4,5] It has been predicted that the number of ESRD patients in the U.S. will increase to more than 700,000 by 2015.[6]

The ESRD Network Program utilizes CROWNWeb to obtain data on patient age, gender, race/ethnicity, primary diagnosis, and treatment modality, among other characteristics, for both incident (new) and prevalent (currently treated) ESRD patients.

At the end of 2012, 427,743 patients were receiving dialysis in the United States (Table 1) according to the Networks' Annual Reports for 2012—a 2.9% increase from 2011.

The leading cause of kidney failure in new ESRD patients in 2012 was diabetes (43.2% of incident patients), followed by hypertension (27.6%).

The ESRD Network Program utilizes CROWNWeb to obtain data on patient age, gender, race/ethnicity, primary diagnosis, and treatment modality, among other characteristics, for both incident (new) and prevalent (currently treated) ESRD patients. These data are used by the Program to inform quality improvement activities, strengthen outreach efforts, document demographic trends, and assess disparities by age, gender, and race in the ESRD population.

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[2] United States Renal Data System. *United States Renal Data System 2013 Annual Data Report: Atlas of End-Stage Renal Disease in the United States*. Bethesda, MD: National Institute of Health, National Institute of Diabetes and Digestive and Kidney Diseases, National Institute of Health; 2013.

[3] Hsu CY, Vittinghoff E, Lin F, Shlipak MG. The incidence of end-stage renal disease is increasing faster than the prevalence of chronic renal insufficiency. *Ann Intern Med.* 2004;141(2):95-101.

[4] Hamer RA, El Nahas AM. The burden of chronic kidney disease. *BMJ.* 2006;332(7541):563-64.

[5] Coresh J, Selvin E, Stevens LA, Manzi J, Kusek JW, Eggers P, et al. Prevalence of chronic kidney disease in the United States. *JAMA.* 2007;298(17):2038-47.

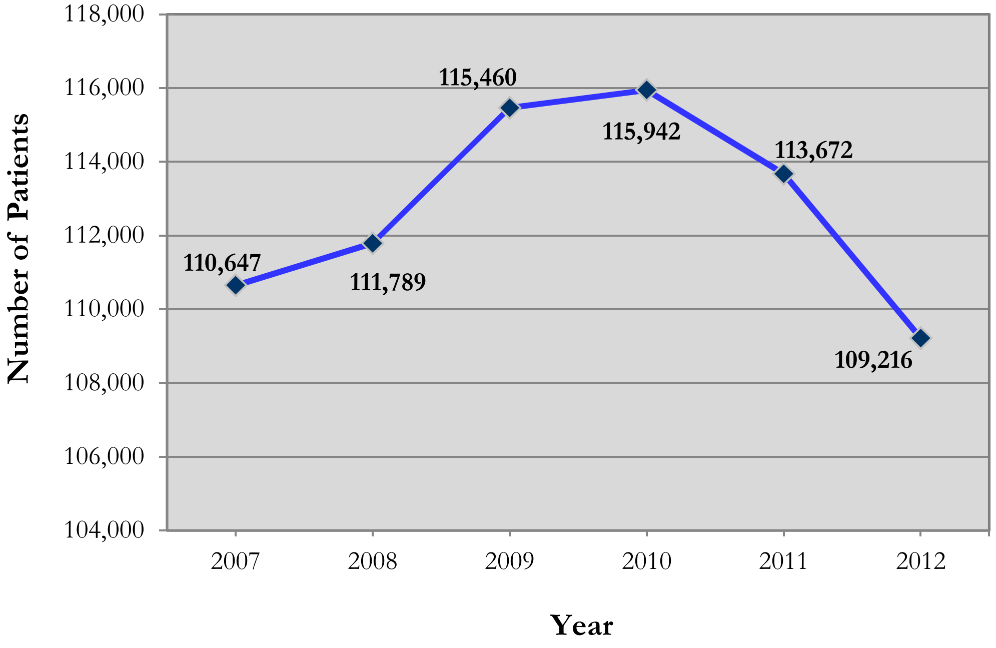
[6] Gilbertson DT, Liu J, Xue JL, Louis TA, Solid CA, Ebben JP, et al. Projecting the number of patients with end-stage renal disease in the United States to the year 2015. *J Am Soc Nephrol.* 2005;16(12):3736-41. Erratum in: *J Am Soc Nephrol.* 2006;17(2):591.

Incident ESRD Patients

Table 3 shows, for each Network and the ESRD Network Program as a whole, the number of new ESRD patients in 2012 as well as incident rates per million population for 2012. These incidence data are taken from the Networks' Annual Reports for 2012 and are based on CMS-2728 forms filed for new patients in 2012 and any supplementary information obtained by the Networks.

Form CMS-2728 is used to register ESRD patients with CMS. Dialysis facilities and transplant centers enter patient data from CMS-2728 forms for every newly diagnosed ESRD patient; patient data are entered into CROWNWeb. Under an agreement with CMS, the Veterans Health Administration also provides data on dialysis and transplant patients to be included in the CROWNWeb database. Some correctional systems and military facilities voluntarily report data on maintenance dialysis patients; these data are also included in the database.

FIGURE 3
Incident ESRD Patients by Calendar Year, 2007 2012



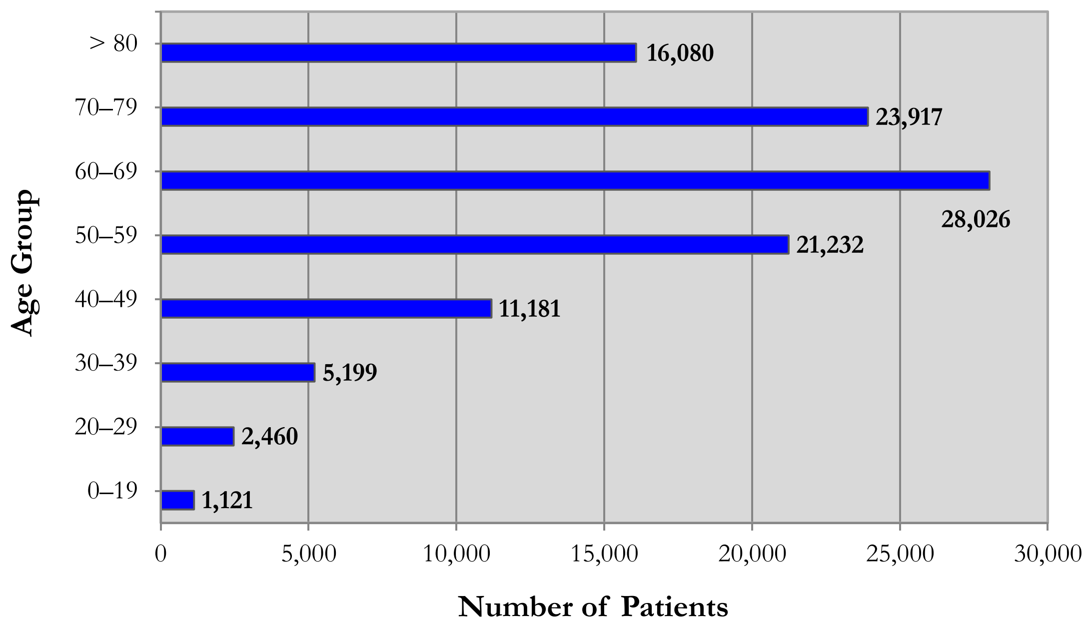
SOURCE OF DATA: Networks 1 18 Annual Reports, 2012.

Figure 3 shows ESRD Network Program incidence data for 2007 to 2012. Across the country, there were 109,216 new ESRD patients in 2012. The number of incident patients decreased by 3.92% from 2011 to 2012 (Figure 3), while overall ESRD incidence decreased from 360 per million population to 343 per million population (Table 3).

Age

The distribution of incident ESRD patients in 2012 by age category is shown in Table 4 for the 18 Network service areas and the nation as a whole. Approximately 4 out of 5 incident patients (81.7%) were 50 years of age or older; 62.3% were 60 years of age or older; and more than one-third (36.6%) were age 70 or older (Table 4 and Figure 4). The pediatric population was small; only 1% of the incident ESRD patients were younger than 20 years of age in 2012. The age distribution of incident ESRD patients has remained relatively stable since 2007.

FIGURE 4
Incident ESRD Patients by Age Group (in Years), Calendar Year 2012



SOURCE OF DATA: Networks 1 18 Annual Reports, 2012.

Gender

In 2012, males represented just over half of the incident ESRD population (57.3%; Table 5). All Networks reported a positive ratio of males to females for the incident population.

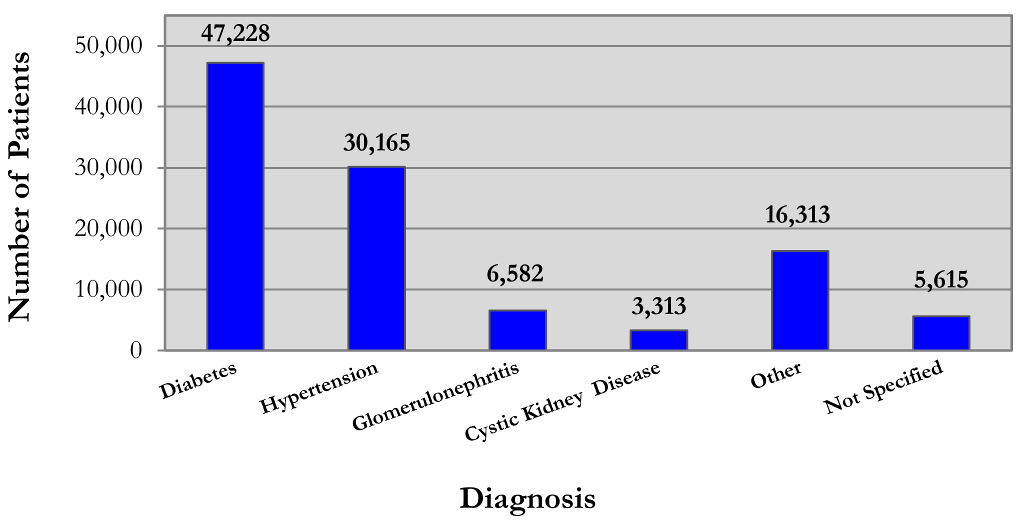
Race

Table 6 shows the distribution of incident ESRD patients by reported "race." Findings continue to demonstrate disparities by race— i.e., a disproportionately high percentage of new patients identified as "Black or African American" relative to the proportion of individuals identified as "Black" in the population as a whole.[7] Patients identified as “Black or African American” comprised 26.1% of the total incident dialysis population in 2012. It should be noted, however, that national and Network-specific race data should be interpreted with caution because of the inherent instability of such data. Form CMS-2728 also collects data on Hispanic “ethnicity,” but CMS does not currently require the Networks to report this information.

Primary Diagnosis

Data on primary diagnosis for incident patients comes from Form CMS-2728. The leading cause of kidney failure in new ESRD patients in 2012 was diabetes (43.2% of incident patients), followed by hypertension (27.6%); see Figures 5–7. Little variation existed across Networks with respect to the diagnosis leading to renal failure (Table 7).

FIGURE 5
Incident ESRD Patients by Primary Diagnosis, Calendar Year 2012



SOURCE OF DATA: Networks 1 18 Annual Reports, 2012.

NOTE: Other includes interstitial nephritis/pyelonephritis, secondary glomerulonephritis/vasculitis, neoplasms/tumors, and miscellaneous conditions.

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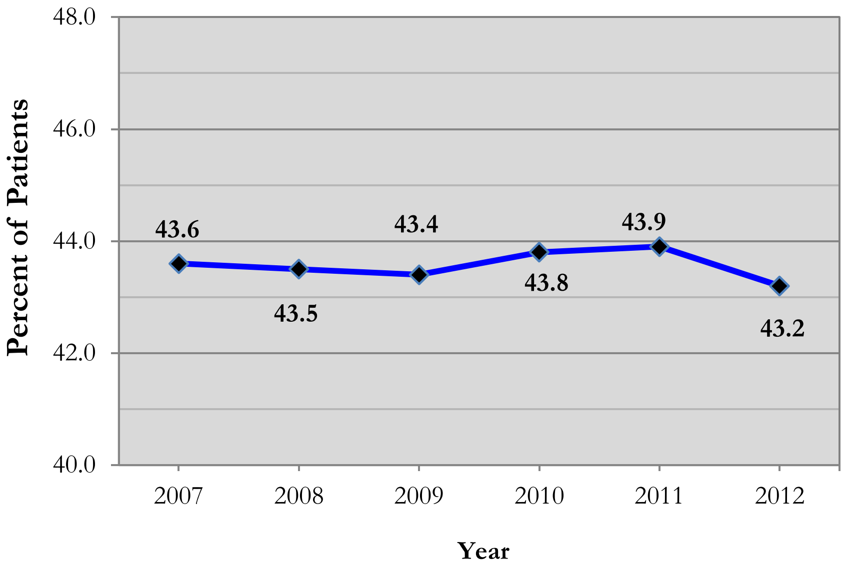
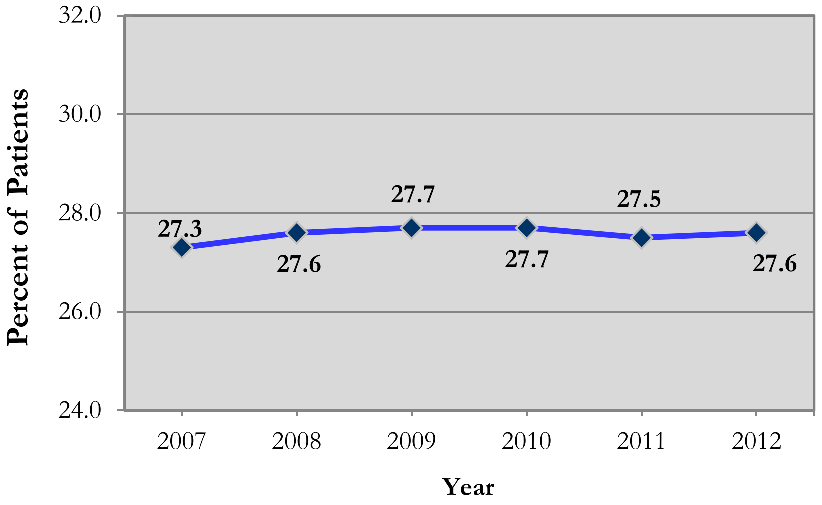
[7] U.S. Census Bureau. *Population Estimates, National Characteristics: Vintage 2012.* Available from: http://www.census.gov/popest/data/national/asrh/2012/index.html

FIGURE 6
Percent of Incident ESRD Patients with Primary Diagnosis of Diabetes, 2007 2012



SOURCE OF DATA: Networks 1 18 Annual Reports, 2012.

FIGURE 7
Percent of Incident ESRD Patients with Primary Diagnosis of Hypertension, 2007 2012



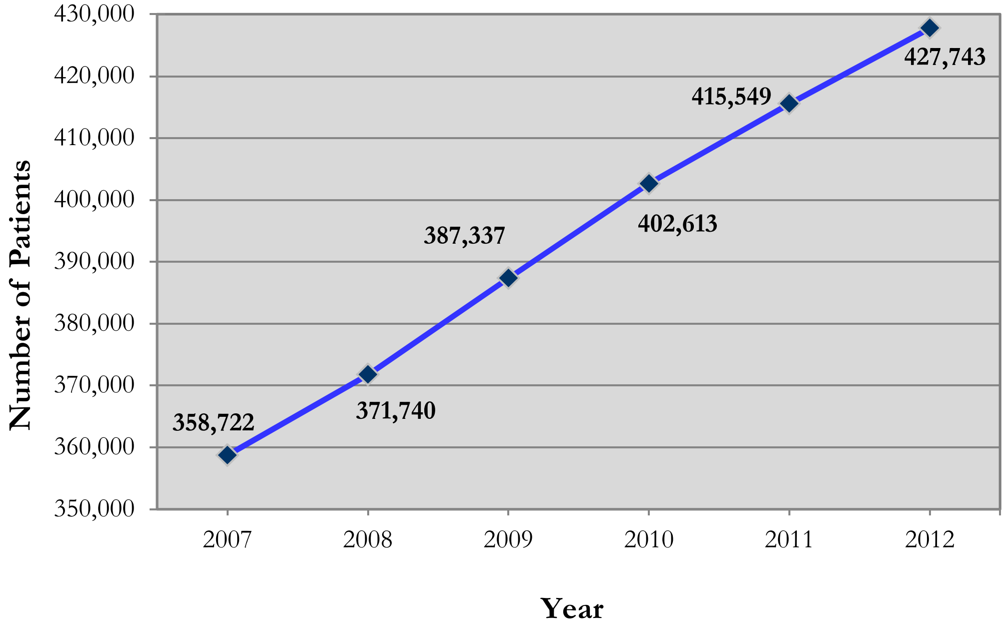
SOURCE OF DATA: Networks 1 18 Annual Reports, 2012.

Prevalent Dialysis Patients

Information on prevalent patients is drawn from the CROWNWeb database that identifies all patients who are alive and on dialysis as of December 31 of the given year.

At the end of 2012, 427,743 patients were receiving dialysis in the United States (Table 1) according to the Networks' Annual Reports for 2012—a 2.9% increase from 2011 (Figure 8).

FIGURE 8
Number of Prevalent Dialysis Patients as of December 31 of Each Year, 2007 2012



SOURCE OF DATA: Networks 1 18 Annual Reports, 2012.

Age

Table 8 shows the age distribution of prevalent dialysis patients in 2012 for the 18 Network areas. The large majority (78.9%) of patients were 50 years of age or older, a little over half (57.4%) were 60 years of age or older, and almost one-third (31.3%) were age 70 or older (Table 8). Only 0.5% of prevalent dialysis patients were younger than 20 years of age in 2012. The age distribution of prevalent dialysis patients has remained relatively stable since 2007.

Gender

In 2012, males represented over half of the prevalent dialysis population (55.9%; Table 9). All Networks reported a positive ratio of males to females for the prevalent dialysis population.

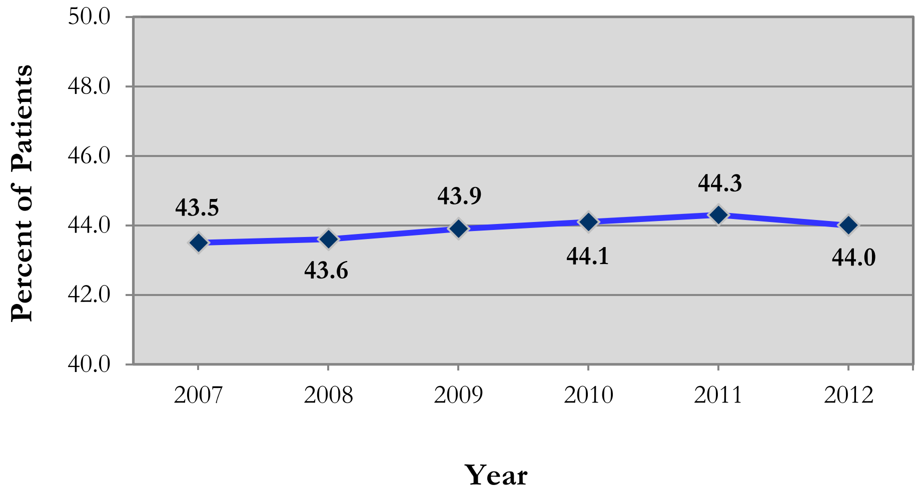
Race

Table 10 shows the distribution of prevalent dialysis patients by reported race. As noted above, Form CMS-2728 also collects data on Hispanic "ethnicity," but CMS does not currently require the Networks to report this information.

As was true for incident patients, the proportion of prevalent dialysis patients identified as "Black or African American" was disproportionately high in comparison to the representation of African Americans in the general population.[6] Patients identified as "Black or African American" made up 35.8% of the total prevalent dialysis population as of December 31, 2012. As noted above, data on patients' race should be interpreted with caution.

FIGURE 9

Percent of Prevalent Dialysis Patients with Primary Diagnosis of Diabetes, as of December 31 of Each Year, 2007 2012

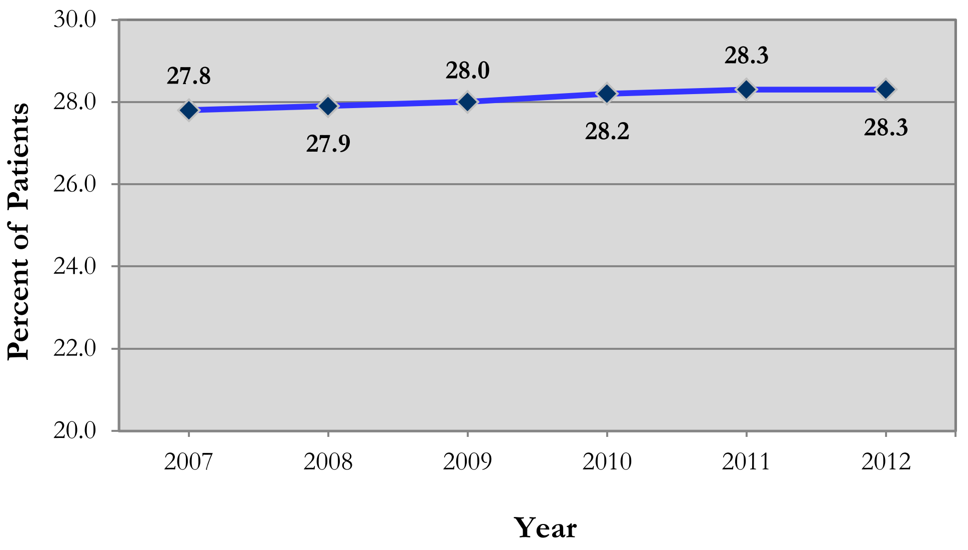


SOURCE OF DATA: Networks 1 18 Annual Reports, 2012.

Primary Diagnosis

Table 11 shows the distribution of prevalent dialysis patients by primary diagnosis for the 18 Network service areas in 2012. All Networks reported diabetes as the primary cause of renal failure in 2012 for prevalent patients as well as incident patients. Overall, 44% of prevalent dialysis patients had a primary diagnosis of diabetes while 28.3% had a primary diagnosis of hypertension. Figures 9 and 10 show comparative data on the primary diagnoses of diabetes and hypertension among prevalent dialysis patients over time.

FIGURE 10
Prevalent Dialysis Patients with Primary Diagnosis of Hypertension, as of December 31 of Each Year, 2007 2012



SOURCE OF DATA: Networks 1 18 Annual Reports, 2012.

Treatment Modality

ESRD patients require dialysis or transplantation to sustain life. Dialysis is the process of cleaning wastes from the blood using specialized equipment to take the place of the kidneys, organs that ordinarily perform this function. The two major forms of dialysis are hemodialysis and peritoneal dialysis. Kidney transplantation is a procedure in which the recipient receives a new kidney. The kidney can come from a family member, a nonrelated living donor, or a deceased donor.

In 2012, more than 89% of prevalent patients received in-center dialysis and 11% received home dialysis.

Of those patients receiving home dialysis, the predominant type of treatment was continuous cycling peritoneal dialysis (CCPD).

Patients can receive life-sustaining outpatient renal replacement therapy in a range of settings. "In-center" hemodialysis is performed at a hospital-based facility, a corporate or independently owned dialysis facility, or a transplantation center. (Some transplantation centers provide dialysis services in addition to transplant care.) Alternatively, hemodialysis can be performed in a community setting, such as the patient's home, with a back-up facility for emergencies and periodic clinical assessment. Peritoneal dialysis is typically performed at home or work, but one form of peritoneal dialysis, intermittent PD, is usually provided in a hospital.

In hemodialysis, blood travels through tubes to a filter, known as a dialyzer, which removes wastes and extra fluid. The cleaned blood then flows through another set of tubes back into the body. In peritoneal dialysis, a dialysis solution is drained from a plastic container into the abdomen. Fluids and wastes flow through the lining of the cavity and remain "trapped" in the dialysis solution. The solution is then drained from the abdomen, removing the extra fluids and wastes from the body.

There are two main types of peritoneal dialysis. The most common type is continuous ambulatory peritoneal dialysis (CAPD), which does not require a machine. The dialysis solution passes from a plastic container into the abdomen through a catheter. After several hours, the patient drains the solution into a disposable plastic container and refills the abdomen with fresh solution through the same catheter. The other form, continuous cycling peritoneal dialysis (CCPD), uses a machine that automatically fills and drains the dialysis solution from the abdomen. A typical CCPD schedule involves several exchanges during the night while the person sleeps and one daytime exchange that lasts the entire day.

Tables 12–14 show the distribution of prevalent patients by treatment modality. In-center dialysis was the predominant treatment modality in 2012 (382,029 of 427,743 prevalent patients, or 89.3%). Nearly 11% of prevalent patients (45,683 of 427,743) used home dialysis in 2012.

From 2011 to 2012, the number of home dialysis patients using hemodialysis increased 13%, the number using CCPD increased 22%, and the number of home dialysis patients on CAPD decreased 18% (see Table 13). Of note, the percentage of home patients using hemodialysis increased slightly from 15.5% in 2011 (6,395/41,369) to 15.8% in 2012 (7,203/45,683); the percentage using CCPD increased from 58.5% (24,181/41,369) to 64.8% (29,580/45,683); and the percentage using CAPD decreased from 26.0% (10,760/41,369) to 19.3% (8,829/45,683).

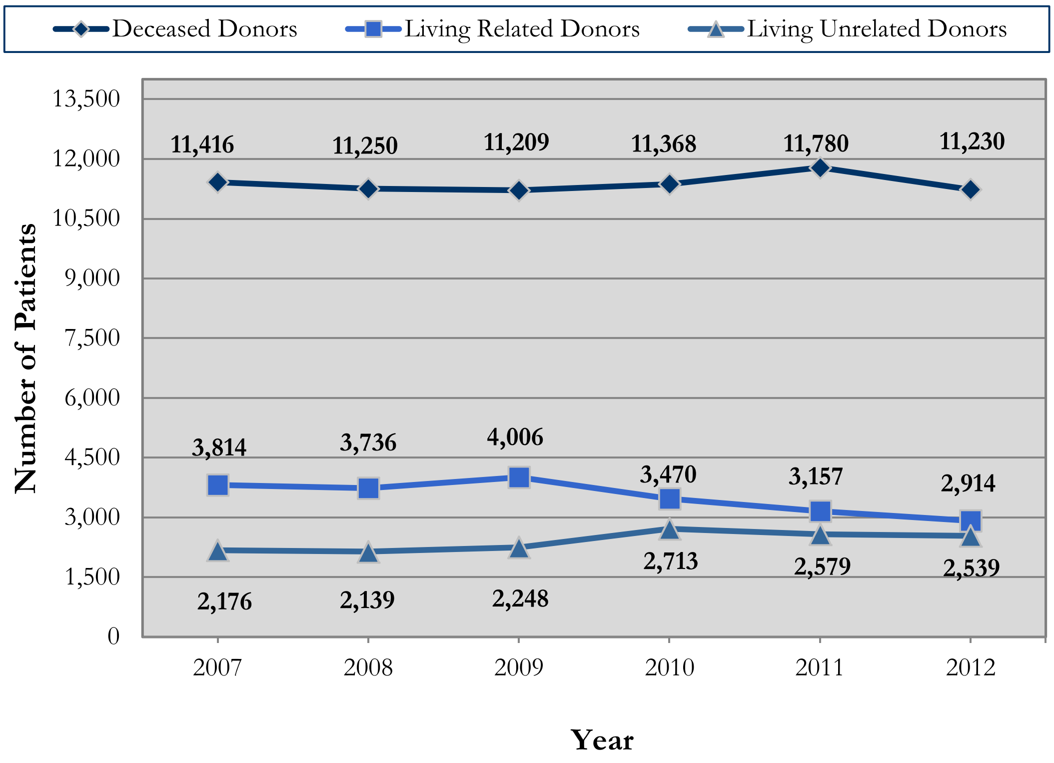
Transplant Patients

Nationwide, a total of 16,683 renal transplants were reported among Medicare ESRD beneficiaries in 2012 (Tables 15–18). Table 15 shows the age distribution of transplant patients for each Network area and the U.S. as a whole. More than two-thirds (68%) of transplant patients were in the 40–69 year age range, only 7.9% were age 70 or older, while 24% were 39 years old or younger. Data on the gender of transplant recipients are shown in Table 16. Overall, 61% of transplant recipients were male.

Table 17 shows the distribution of transplant recipients by race, as recorded on Form CMS-2728. The distribution was skewed relative to the racial distribution of the U.S. population as a whole: slightly less than one-quarter of transplant recipients fell into the “Black or African American” category. Of note, ESRD Network Program data suggest that “Black or African American” and “American Indian or Alaska Native” ESRD patients were less likely to receive transplants than ESRD patients from other racial/ethnic groups (data not shown).

Table 18 shows the distribution of renal transplant patients by donor type for 2012 and Figure 11 shows comparative data for 2007–2012.

FIGURE 11
Donor Transplants by Donor Type, 2007 2012



SOURCE OF DATA: Networks 1 18 Annual Reports, 2012.

Quality Improvement Program

Quality improvement activities are the centerpiece of the ESRD Networks' efforts to improve patient care and outcomes.

Quality improvement activities are the centerpiece of the ESRD Networks' efforts to improve patient care and outcomes. The Networks track regional and facility-specific clinical outcomes data; including data on vascular access, dialysis adequacy, and anemia management; to identify opportunities for improving care. Each Network annually develops a comprehensive Quality Improvement Work Plan (QIWP) under the direction of its Medical Review Board (MRB). QIWPs include activities focused on vascular access as well as Network-level Quality Improvement Projects and facility-level Quality Assessment and Improvement Projects.

As requested by a facility, a Network may assist in quality improvement initiatives at the facility level to help ensure that patients are receiving adequate services. All facility-specific quality improvement activities are developed in collaboration with CMS and the Network's MRB; these activities need to be approved by CMS prior to implementation.

In 2012, the Networks conducted quality improvement activities using various approaches, which included providing education and information to facility staff on clinical issues and performance benchmarking; distributing data feedback reports; and targeting facilities for focused quality improvement initiatives.

For example:

- **Network 1** initiated a project to increase influenza immunization rates among dialysis patients in the New England states. By increasing the number of educational offerings and materials distributed, as well as providing reminders about the importance of vaccinations, the Network improved the rate of influenza vaccinations from 75% of dialysis patients in 2009–2010, to 85% in 2012. This is more than 20 percentage points higher than the national vaccine rate for dialysis patients (64.3%) as reported by the USRDS in 2011.[8]

- **Network 3** reduced the rate of vascular access infections for dialysis patients in Puerto Rico through a quality improvement project that began in August 2011 and continued through

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[8] United States Renal Data System. *United States Renal Data System 2011 Annual Data Report: Atlas of End-Stage Renal Disease in the United States*. Bethesda, MD: National Institute of Health, National Institute of Diabetes and Digestive and Kidney Diseases, National Institute of Health; 2011.

the end of 2012. The project resulted in a 44% reduction in the vascular access–related infection rate during this timeframe. Additionally, antibiotic usage decreased by 33%. The Network provided education to dialysis unit staff, collected data, provided feedback via monthly conference calls, and worked with facilities to adopt the Centers for Disease Control and Prevention Core Interventions to prevent access–related infection.

- **Network 8** implemented a quality improvement program to increase influenza vaccination rates for targeted facilities. The Network's goal was that 50% of intervention facilities would reach or exceed a seasonal influenza vaccination rate of 70% of the facility's patients and staff. Data analysis confirmed that 34 of 39 facilities (87.2%) achieved the goal.

- **Network 13** implemented a project to identify and address region-specific barriers to AVF placement and in use in two large underperforming regions (Little Rock, AR and Shreveport, LA), that had AVF in use rates below 50%. In addition to performing a root cause analysis, the Network undertook region-specific interventions that led to improvements in the AVF in use rates in Little Rock, AR (53.1%) and Shreveport, LA (50%), as of December 2012.

- **Network 13** executed a project in nine targeted dialysis facilities that aimed to replace catheters with permanent vascular accesses (AVFs or AVGs) in patients for whom a permanent vascular access was clinically feasible. The project exceeded the goal of reducing catheter use within the target patient population by achieving a 31.5% reduction in catheter use from June to October 2012.

- **Network 15** embarked on a project to improve knowledge of quality improvement initiatives in 19 targeted facilities by providing clinicians with the training, tools, and resources to develop a Quality Assessment and Performance Improvement (QAPI) program. QAPI deficiencies were widely noted in Network 15's service area. The project's goals were to have 75% of target facilities implement at least one resource from the QAPI Toolkit following its distribution, and 50% of the target facilities complete the QAPI education modules within four months. Project findings showed that 76.5% of the facilities implemented at least one resource from the Toolkit and 82% completed the QAPI education modules either by attending the live or recorded presentations. These project outcomes exceeded the project goals.

- **Network 16** invited 60 Network-area facilities with AVF in use rates lower than the Network goal to attend an introductory WebEx presentation. Depending on their AVF-maturing, AVG, and LTC rates, facilities were invited to attend additional presentations on topics including assessing AVF maturity, creating AVF fistulas from forearm grafts, and/or reducing long-term catheters. Facilities were given blinded peer-comparison graphs, asked to complete a root cause analysis and an action plan for increasing their AVF in use rates, and provided with additional technical education materials and professional assistance. The Network monitored patients' maturing AVFs monthly. The goal of the project was to add 1.6 percentage points to the AVF in use rate at these facilities. Facilities that participated in the targeted intervention achieved an increase of 1.8 percentage points in their AVF in use rate, while all other Network-area facilities added 1.1 percentage points during the same timeframe.

- **Network 17** created the "Happy Feet" initiative to encourage and promote diabetic foot care for dialysis patients in the Pacific Islands. The project was presented to facilities in the Hawaiian Islands in the fall of 2012. Throughout the course of this project, the facilities reported an increase in the number of patient-performed foot checks (from 51% to 67%), an increase in the number of foot sores identified (from 0% to 25%), and a decrease in the number of amputations (from 21% to 17%).

Fistula First Breakthrough Initiative

From December 31, 2011 to December 31, 2012, the national rate of AVF placement among prevalent in-center and home hemodialysis patients increased by 0.7 percentage points, or 6.5% (Figures 12 and 13).

In 2003, in partnership with the ESRD Networks and other renal stakeholders, CMS initiated the Fistula First Initiative, a national quality improvement project to increase the use of arteriovenous fistulas (AVFs) among hemodialysis patients for whom an AVF is a viable option. When the initiative began in 2003, approximately one-third (34.2%) of all prevalent in-center and home hemodialysis patients in the United States were undergoing dialysis with an AVF, according to CMS data. In 2005, the Fistula First Breakthrough Initiative (FFBI) was established as CMS's first ESRD-related national "Breakthrough Initiative."

arteriovenous
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AVF — The first choice for hemodialysis

The goal established by CMS with the launch of the FFBI is to achieve an AVF use rate of at least 66% among all eligible hemodialysis patients in the U.S. In calendar year 2012, each ESRD Network was required to demonstrate a 20% decrease in its AVF quality deficit. The quality deficit is defined as the difference between the Network's AVF in use rate and the CMS goal of 66%. The Networks engage in a number of activities to encourage and support the use of AVFs.

Advantages of an AVF

Hemodialysis requires repeated vascular access to large blood vessels capable of effectively removing wastes from the blood. The three forms of vascular access are AVFs, arteriovenous (AV) grafts, and central venous catheters.

A patient's vasculature and other medical and physical conditions are used to determine access type. AVFs are considered the gold standard, although they are not appropriate for every hemodialysis patient. An AVF is a surgical connection between a vein and an artery, usually in the forearm. The AVF causes the vein to grow thicker, allowing the repeated needle insertions required for hemodialysis. AVFs offer less chance of infection or clotting and greater efficiency than other forms of vascular access. If properly maintained, AVFs can remain an effective means of hemodialysis access for many years.

An AV graft is created using a synthetic tube implanted under the skin to connect an artery and a vein. A graft is an acceptable alternative when AVF placement is not deemed possible or appropriate.

A central venous catheter, when used for vascular access in dialysis, is a flexible tubular instrument that is surgically inserted into a large vein near the heart. Catheters should be used only for temporary access while a permanent access is maturing, or as permanent access in patients who have exhausted other options. Catheters pose a higher risk of infection, clotting, and narrowing of vessels than AVFs and grafts and lead to a higher mortality rate in patients.[9]

Since 2010, the FFBI has been operating under an updated message—"Fistula first does not mean fistula only"—that promotes reducing the use of central venous catheters as well as increasing the use of AVFs.

FFBI Coordination

CMS contracts with a single Network to coordinate FFBI activities nationwide. **Network 2**, in its role as the ESRD Network National Coordinating Center (NCC), assumed full responsibility for the FFBI coordinating function in January 2011.

The NCC works closely with renal partners at the national level through the FFBI Coalition. The Coalition's membership represents a cross-section of the renal community, including ESRD Networks, large dialysis organizations, advocacy organizations, medical societies, the Institute for Healthcare Improvement, the United States Renal Data System Coordinating Center, the Centers for Disease Control and Prevention, and CMS, among others.

FFBI Workgroups

The FFBI Coalition has established several national workgroups composed of healthcare professionals dedicated to improving vascular access for hemodialysis patients through research, journal publications, and production of practical tools for use by renal patients, family members, and professionals. The five FFBI Workgroups are:

- The *Clinical Practice Workgroup*, whose members provide peer-to-peer education for renal professionals through attendance and networking at national conferences, WebEx sessions, and conference calls. In 2012, a subgroup focused on understanding why those who transition from peritoneal dialysis to hemodialysis initiate hemodialysis with a catheter. In doing so, the group was able to identify clinical education needs and potential barriers to

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[9] Reddan D, Klassen P, Frankenfield DL, Szczech L, Schwab S, Coladonato J, et al.; National ESRD CPM Work Group. National profile of practice patterns for hemodialysis vascular access in the United States." *J Am Soc Nephrol.* 2002;13(8):2117-24.

smooth transition. The subgroup also recommended the development of an additional clinical guideline to address access planning when care transitions occur.

- The *Community Education Workgroup,* which identifies or develops educational tools for renal professionals. In 2012, the Community Education Workgroup published a position paper, "Targeting Catheter Last in Fistula First," available on the Fistula First website at: http://www.fistulafirst.org/LinkClick.aspx?fileticket=GN8QYytKHFo%3d&tabid=39

- The *Data Workgroup*, which promotes accurate collection and maintenance of vascular access data. In 2012, the group completed a manuscript on renal recovery and submitted it for publication.

- The *Health Policy Workgroup*, which translates FFBI clinical messages into national policy recommendations. In 2012, the group drafted a statement for submission to CMS that addressed factors contributing to case mixing specifically for vascular access. The Workgroup also identified factors contributing to health disparities as they relate to vascular access.

- The *Website Workgroup*, which is tasked with ensuring the consistency and accuracy of the content on the FFBI website (www.fistulafirst.org) and recommending changes and additions as needed. In 2012, the group reviewed literature to be posted on the website, with a specific focus on pediatric vascular access.

FFBI Website

The NCC supports the activities of the ESRD Networks in the area of vascular access by providing information and resources on the FFBI website (www.fistulafirst.org). FFBI Dashboard data are available on the site, along with monthly updates of Network-level data on incident and prevalent patients. The data included on the website represents data as of March 2012.

Welcome to the Fistula First website. Here you will find information and resources for vascular access management for patients and healthcare professionals.

Over the last decade, remarkable improvements in arteriovenous fistula (AVF) use in prevalent hemodialysis patients were achieved through the Fistula First Breakthrough Initiative (FFBI) in partnership with:

- the Centers for Medicare & Medicaid Services (CMS)
- the End Stage Renal Disease (ESRD) Networks
- Patients
- the renal community
- additional stakeholders

During its tenure the FFBI had as it central focus, increasing the percentage of AVF in use as the vascular access with the best outcomes showing an increase from 32% to >60%. Click here to review Fistula First data.

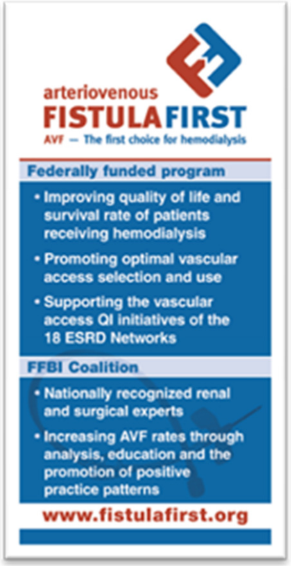
The FFBI had less impact on reducing catheter use. Accordingly, in May of 2013, the ESRD Network Coordinating Center (NCC) launched the Fistula First Catheter Last (FFCL) Workgroup Coalition project, building on the foundation of the Change Concepts and success of the FFBI, but with an emphasis on decreasing the use of tunneled dialysis catheters (TDC) as long-term vascular accesses. The FFCL Workgroup Coalition is comprised of patients, representatives from the CMS, ESRD Networks, the renal community, and other stakeholders.

Research shows that AVFs have the longest survival, result in fewer access related procedures, fewer hospitalizations due to infection and lower overall costs of care. The Kidney Disease Outcomes Quality Initiative (KDOQI) Vascular Access clinical practice guidelines provided the evidence base and expert opinion of the targets and framework of the FFBI. Quality improvement information was disseminated and implemented using the core clinical principles, the Fistula First Change Concepts.

Article: Targeting Catheters Last in Fistula First

Fistula First Outreach, Education, and Technical Assistance

The Networks use a variety of approaches in working with patients, facilities, and practitioners to increase AVF placement rates including:



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AVF — The first choice for hemodialysis

Federally funded program

- Improving quality of life and survival rate of patients receiving hemodialysis
- Promoting optimal vascular access selection and use
- Supporting the vascular access QI initiatives of the 18 ESRD Networks

FFBI Coalition

- Nationally recognized renal and surgical experts
- Increasing AVF rates through analysis, education and the promotion of positive practice patterns

www.fistulafirst.org

- Developing and disseminating posters, brochures, presentations, and other vascular access educational materials targeting patients, dialysis facility staff and clinicians, or both, and sharing this and other national Fistula First information, on the Network websites;

- Providing live or online training for dialysis facility staff, including nurses, patient care technicians, physicians, vascular surgeons, and nephrologists;

- Publishing articles on vascular access in the Network's patient and professional newsletters, developing Fistula First newsletters for distribution to dialysis facilities, and contributing articles to other renal organizations' newsletters;

- Providing national, state-level, facility-specific, and physician-specific data and other relevant information to dialysis facilities through quarterly Fistula First feedback reports;

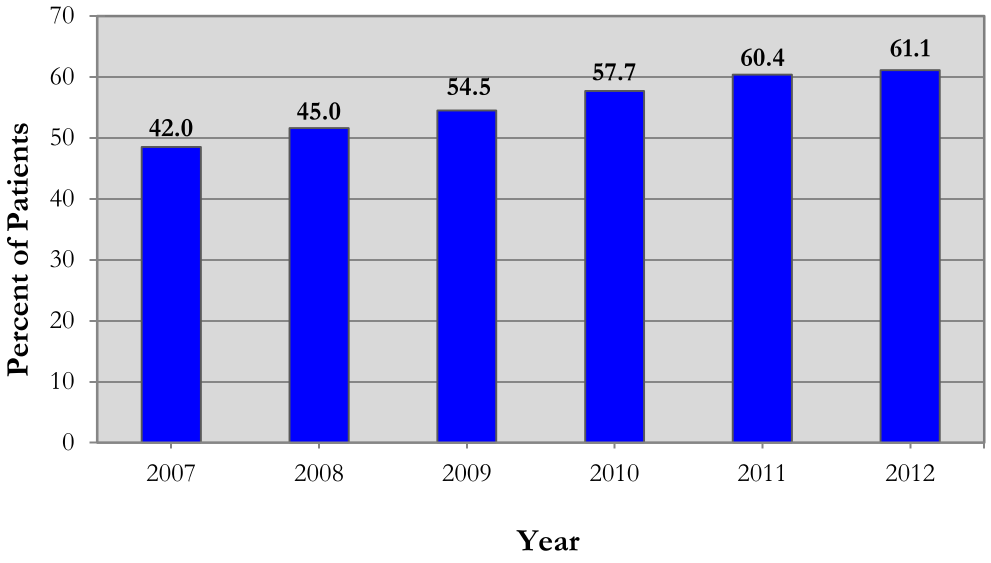
- Using awards and other forms of recognition to spotlight "Champions"—facilities and surgeons with high AFV rates—and facilities showing the most improvement within specified time frames;

- Encouraging facilities to designate one staff member as the point person for vascular access issues;

- Developing vascular access protocols; and

- Working closely with low-performing facilities as part of focused quality improvement projects.

FIGURE 12
Percent of In Center and Home Hemodialysis Patients with an Arteriovenous Fistula in Use, as of December 31 of Each Year, 2007 2012



SOURCE: Fistula First Outcomes Dashboard, Version 1.3.

NOTE: Starting in March 2010, the denominators used in calculating these percentages did not include a small number of patients with missing data on access type.

Fistula First Quality Improvement Projects

As part of the Network's Quality Improvement Work Plan, each Network

- identifies an opportunity for improvement related to vascular access,
- develops both outcome and process indicators,
- prepares a project design and methodology that support statistical analysis,
- proposes intervention activities, and
- identifies a mechanism and criteria for evaluation of interventions.

Some Networks were unable to obtain reliable data on the results of their vascular access quality improvement projects due to the switch from SIMS to the new CROWNWeb system in 2012. However, some Networks were able to quantify their successful quality improvement projects in 2012. These include:

- **Network 6** selected 235 facilities for intensive intervention to improve the Network-wide AVF in use rate by two percentage points. Project activities included monthly self-reported data collection, monthly root cause analysis, monthly updated action plans, required learning sessions and webinars, and outcomes reporting. The facilities increased the percentage of patients dialyzing with an AVF from 52.9% in March 2012 (baseline) to 54.8% in October 2012. Based on these findings, 235 more patients were dialyzed with an AVF from March 2012 to September 2012 in the intervention facilities.

- **Network 7** conducted a Fistula First Focus Group initiative working with 29 targeted dialysis facilities with an overall baseline AVF in use rate of 45.8% (measured in June 2011). By April 2012, the focus group facilities reached an overall rate of 51.6%. Fourteen of the 29 facilities continued in a six-month extension of the focus group, along with six new facilities in the Network, from July to December 2012. The extension group's aggregate baseline AVF in use rate was 47.8% in April 2012; by December 2012, the rate increased to 50.9%. Focus group activities conducted for these facilities during 2012 included monthly progress reports, onsite visits, conference calls, root cause analysis, and an interactive vascular access workshop.

- **In the Network 8** service area, the Memphis Area Fistula First Coalition, organized in 2005, held its final meeting on December 6, 2012. The coalition was chartered to increase the fistula rates in a metropolitan area with the lowest AVF in use rates and the highest incidence of ESRD in the Network. Facilities in the project successfully surpassed prevalent AVF in use goals by first reaching their 50% prevalence goal and then hitting the 60% mark, both ahead of their anticipated target time.

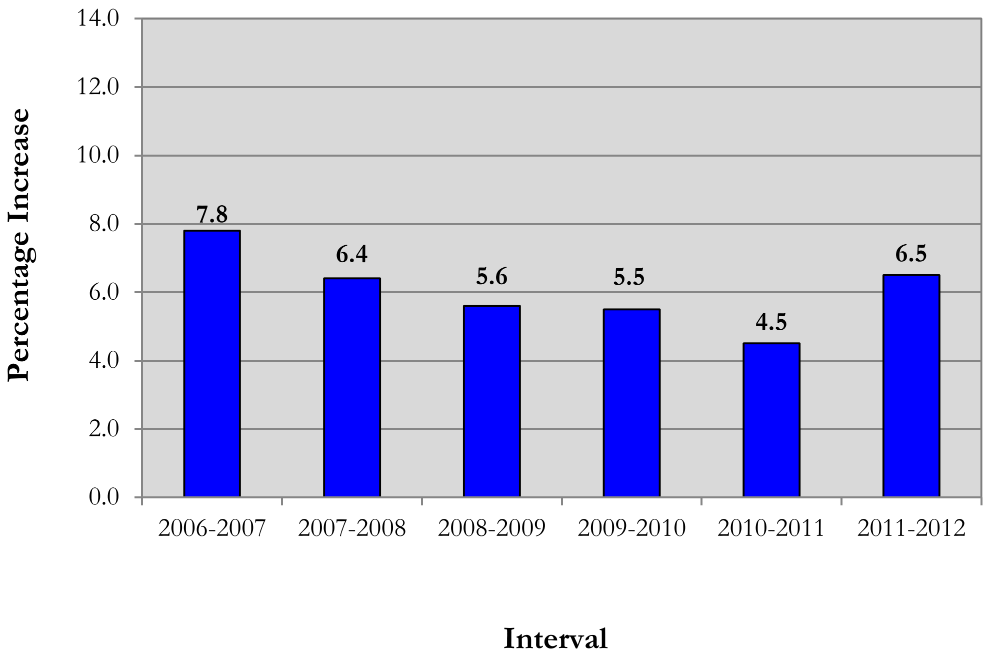
- **Network 17** staff members, with assistance from the Network's Fistula First Subcommittee and Larry Spergel, MD, FACS, provided one-on-one intervention with two facilities that were not showing improvement comparable to the rest of the Network. The two facilities increased their AVF in use rate from 38.4% and 42.9% to 49.4% and 49.3%, respectively, after a six-month intervention in 2012.

- **Network 18** piloted a mentoring program pairing "struggling facilities," which it defined as facilities with AVF in use rates of less than 50%, with mentoring facilities in their local area/county that had AVF in use rates above 63%. The mentoring facilities assisted project facilities in all aspects of vascular access care from admission to developing vascular access plans; QAPI; and sharing best practices, tools, and resources. The Network provided resources for both the project facilities and mentoring facilities, as necessary; facilitated bimonthly conference calls; monitored project facilities' progress; distributed feedback reports; and provided technical assistance. The ten facilities receiving mentorship in the project improved their aggregate AVF in use rates from 47.2% (May 2011) to 53.6% (April 2012).

2012 Fistula First Data

As shown in Table 19, 15 out of 18 Networks reported an increase in the rate of AVF use among in-center and home hemodialysis patients as of December 31, 2012, relative to each Network's December 2011 rate.

FIGURE 13
Annual Percentage Increase in Rate of Arteriovenous Fistula Use Among In Center and Home Hemodialysis Patients, 2006 2012



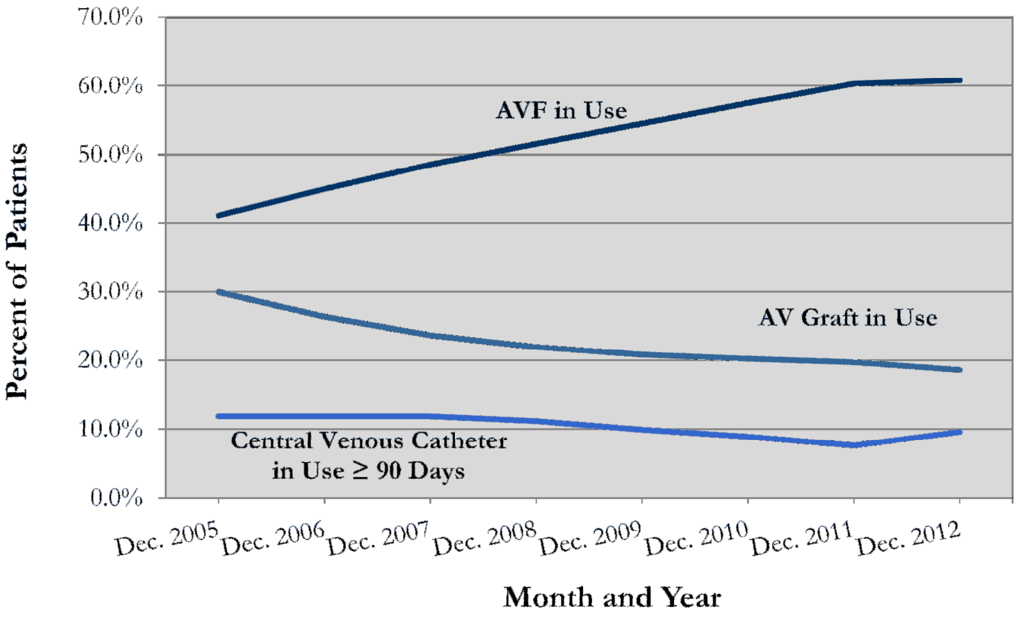
SOURCE: Fistula First Breakthrough Initiative Data.

NOTE: Starting in March 2010, the denominators used in calculating these percentages did not include a small number of patients with missing data on access type.

Data for all facilities participating in the Fistula First Initiative revealed that the national rate of AVF use among hemodialysis patients has continued to improve steadily (Figure 12), although the annual rate of increase has slowed in recent years (Figure 13). Interventions implemented by the ESRD Networks have contributed to the increase in AVF use. From December 31, 2011, to December 31, 2012, the national rate of AVF placement among prevalent in-center and home hemodialysis patients increased by 0.7 percentage points, or 6.5% (Figures 12 and 13).

Figure 14 shows trends for AVFs in use, AV grafts in use, and catheters in use for ≥ 90 days from December 2005 through December 2012.

FIGURE 14
Percent of In Center and Home Hemodialysis Patients with an Arteriovenous Fistula In Use, Arteriovenous Graft In Use, and Catheters In Use for ≥ 90 Days, December 2005–December 2012



SOURCE: Fistula First Breakthrough Initiative Data.

NOTE: Starting in March 2010, the denominators used in calculating these percentages did not include a small number of patients with missing data on access type.

Additional highlights of Fistula First data for 2012 include:

- The national rate for AVFs in use among in-center and home hemodialysis patients continued to climb, moving from a 60.3% rate in 2011 to 61.1% in 2012.

As of December 2012, 11 Networks exceeded the 60% barrier for AVFs in use among in-center and home hemodialysis patients. Of these 11 Networks, Networks 15 and 16 each exceeded 68%.

- As of April 2012, 13 U.S. states (Arizona, Colorado, Idaho, Kansas, North Dakota, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, South Dakota, Utah, and Washington) and one U.S. territory (American Samoa) exceeded the 66% national goal, according to FFBI data.

Outreach, Education, and Technical Assistance

The ESRD Networks provide a vital service to the renal community by making ESRD-related information and resources available to patients, facility staff, nephrologists, primary care practitioners, clinicians, and other members of the renal community.

Every Network has staff members who are content experts on aspects of ESRD care; these professionals share their knowledge and expertise through written materials, training opportunities, or on-site technical assistance.

The Networks develop their own patient- and provider-focused materials, make them available on their websites, and distribute them at patient and professional meetings and conferences. The Networks also provide access to resources from other sources such as the American Association of Kidney Patients (AAKP) and the National Kidney Foundation (NKF).

Every Network has staff members who are content experts on aspects of ESRD care; these professionals share their knowledge and expertise through written materials, training opportunities, or on-site technical assistance.

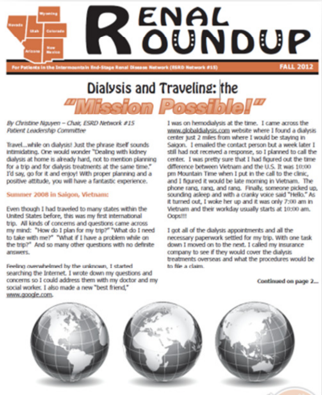
Network Newsletters

Each of the 18 ESRD Networks produces one or more newsletters. The focus of these newsletters varies by Network. Many Networks have both a patient newsletter and one or more newsletters for renal professionals. Some Networks produce and distribute Spanish-language patient newsletters.

The Networks' patient-focused newsletters present information designed to improve patients' understanding of their disease to enhance their quality of life. The publications include informative articles, dialysis-friendly recipes, ESRD-related puzzles, and lists of useful websites. Information about a Network's Patient Advisory Committee (PAC), Patient Leadership Committee, and complaint and grievance procedures may also be included.

NEWS FROM THE NETWORK

From the Executive Director's Desk



RENAL ROUNDUP

FALL 2012

Dialysis and Traveling: the "Mission Possible!"

REMARCS

March 2013

Network Websites

Each of the 18 ESRD Networks has a website that offers information of interest and importance to the renal community. Some Network sites offer information in languages other than English.

All Network websites offer content that includes the Network's contact information, details on the Network's grievance policy, information on emergency preparedness, Network-area data, and Network reports, such as its Annual Reports. Network websites offer (or link to) a wide range of additional materials and tools developed by the Network itself, other ESRD Networks, CMS, and other program sites, such as the Fistula First site.

To provide leadership and assistance to renal dialysis and transplant facilities in a manner that supports continuous improvement in patient care, outcomes, safety and satisfaction.

CMS monitors the Network websites regularly to ensure that the information is up-to-date and that the sites are in compliance with CMS accessibility and security requirements.

Network Annual Reports

Each Network prepares an Annual Report (available in hard copy and on the Network's website) that describes the ESRD Network Program, Network activities performed to meet CMS program goals, the Network's plan for monitoring provider compliance with these goals, data on Network-specific and national profiles and patterns of care, results of Network quality improvement projects, and other information, as directed by CMS.

Network Annual Meetings

The Networks offer educational sessions focusing on aspects of ESRD care at their Annual Meetings. The Networks also use these meetings to encourage quality improvement by recognizing facilities that have demonstrated outstanding performance or major improvement during the year. The meetings are open to patients, family members/caregivers, and renal professionals.

Outreach to Patients and Families/Caregivers

All new ESRD patients receive an orientation packet that contains information and resources to help them understand their condition and treatment (see **New ESRD Patient Orientation Packets** below).

In addition, the Networks proactively reach out to patients and their family members/caregivers by:

- Producing and distributing patient-focused newsletters,
- Providing dialysis facilities with resources such as flyers and posters to be posted in patient waiting areas,
- Holding patient and family conferences to encourage information sharing and mutual support, and
- Providing information to the public through radio and television appearances as well as public service announcements.

Members of the Networks' Patient Leadership Committees (PACs) play a role in Network outreach, as do the patient and facility representatives on the Network Councils. Members of these advisory bodies are able to provide information and resources to their respective facilities, identify information needs, and encourage participation in Network-sponsored events such as patient/family conferences.

New ESRD Patient Orientation Packets

Since 2003, all new ESRD patients have received informational packets containing orientation materials relative to their care. These **N**ew **E**SRD **P**atient **O**rientation **P**ackets (NEPOPs) are distributed nationally through a collaborative effort among the ESRD Network Coordinating Center (NCC), CMS, the 18 ESRD Networks, and the Network Information Technology Support (NWITS) contractor.

> ***The NEPOP serves as an introduction for new ESRD patients at a critical period in their lives. The packet contains important information for new patients on locating a facility, dialysis treatment options, vascular access, kidney transplantation, and preparing for emergency/disaster situations.***

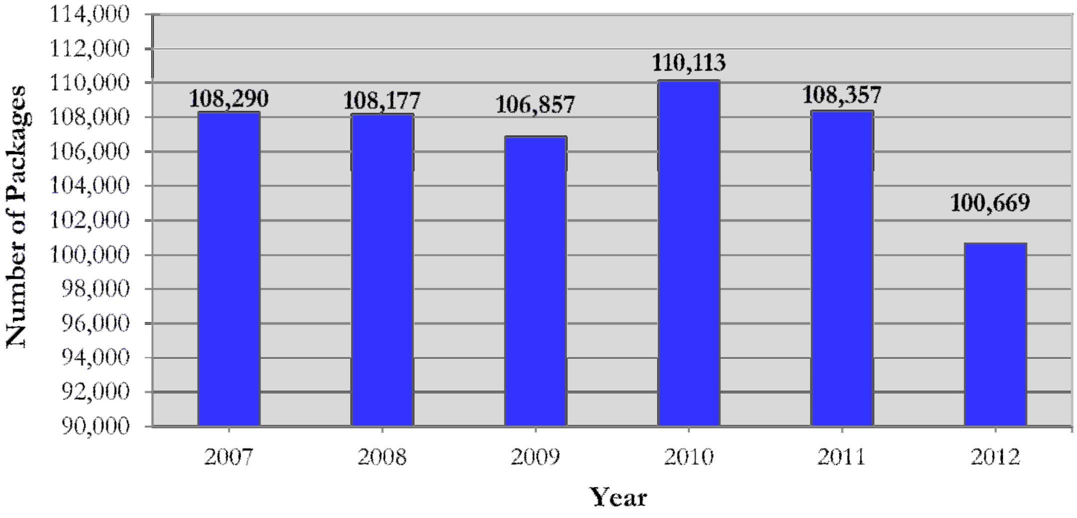
The NEPOP serves as an introduction for new ESRD patients at a critical period in their lives. The packet contains important information for new patients on locating a facility, dialysis treatment options, vascular access, kidney transplantation, and preparing for emergency/disaster situations.

Once an ESRD Medical Evidence Report Form (Form CMS-2728) is entered for a new patient into CROWNWeb, a NEPOP is mailed to the patient's residence. In 2012, the NCC distributed more than 100,669 NEPOPs (see Figure 15).

The NEPOP mailing included the following resources:

- A Medicare beneficiary letter from the CMS Administrator
- A letter from the Executive Director of the appropriate ESRD Network
- "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: Your Guide for Living with Kidney Failure" (CMS booklet)
- "Dialysis Facility Compare Tool at www.medicare.gov: Your Guide to Medicare-Certified Dialysis Facilities" (CMS brochure)
- "Hemodialysis Vascular Access " (Fistula First Breakthrough Initiative flyer)
- "Join Us: We Can Help" (National Kidney Foundation brochure)

FIGURE 15
Number of NEPOP Packages Mailed by Year, 2007–2012



SOURCE OF DATA: ESRD Network Coordinating Center New ESRD Mailing Organizer (NEMO) Tracking Reports.

The NCC receives undeliverable NEPOP envelopes from the U.S. Postal Service monthly. The NCC provides a secure electronic listing of returned envelopes to each Network on a monthly basis, and the Networks are required to research and investigate each return, updating the NCC records to ensure that the NEPOP is delivered to the intended recipient.

To streamline NEPOP tracking and reporting, the NCC uses an electronic database system known as the **N**ew **E**SRD **M**ailing **O**rganizer (NEMO). Since 2008, the NCC and the ESRD Networks have used the NEMO system to organize, track, and report on monthly NEPOP data. Since its inception, the NEMO system has reduced data collection and entry errors, improving data accuracy.

Education for Patients and Families/Caregivers

Each Network distributes brochures, booklets, and other educational materials to patients, including materials developed by the Network, other Networks, and other local and national renal organizations. These materials address topics such as treatment options, community resources, patients' rights, complaint and grievance procedures, emergency and disaster preparedness, and Medicare coverage policies. The Networks also provide education to ESRD patients through workshops and conferences. Some Networks hold at least one patient and family conference per year, frequently in conjunction with partners such as the AAKP or NKF. In addition, all Networks recruit patient representatives who provide peer support and education on issues of concern to patients.

Examples of educational activities for patients and families/caregivers conducted by the Networks in 2012:

- **Network 1** addressed the patient education gap in the area of healthcare-acquired infections by producing a short video, *Dialysis Patients Speak: Preventing Infections*. The video shows real patients in a dialysis unit interacting with real dialysis staff to demonstrate patient responsibilities for infection control: access area washing and protection, hand washing, and the use of gloves and masks. The video emphasizes the importance of patients asking questions and being vigilant about infection control measures. Funding for this video was provided by Office of the Regional Health Administrator, Region I, U.S. Department of Health and Human Services. This video is used in dialysis units across the country and can be found on YouTube.

- **Network 6** sent approximately 42,000 calendars to 605 facilities with the goals of having facility staff use the calendars in their monthly educational initiatives and disseminating them to every patient. The Network conducted a survey in the Summer of 2012 to evaluate the effectiveness and usefulness of the calendar. Five hundred and ninety three (593) surveys were returned, and more than 75% of the 2012 respondents reported that topics covered in the calendar were useful.

- **Network 8's** Patient Advisory Council (PAC) recognized the need to identify a patient representative for each dialysis facility in the Network service area who could serve as a resource for patients and Network 8 staff. In order to recruit patient representatives, the PAC developed a "Patient Representative Booklet" to explain the role of the ESRD Network and clearly define the role and responsibilities of the patient representative. One hundred percent of the PAC members described the booklet as an adequate depiction of the role of the Network 8 patient representative and felt the booklet would assist with increasing patient involvement at the facility level.

- CMS contracted with **Network 9** (The Renal Network, Inc.) on a special project to establish an ESRD Beneficiary Focused Learning Network (BFLN). All 18 ESRD Networks participated in this special project and a Technical Expert Panel (TEP) was convened to facilitate a collaborative process. The main outcomes of the special project consisted of developing a mechanism to identify indicators that signal potential issues related to CMS reimbursement policies and increasing beneficiaries' knowledge.

- **Network 12's** PAC participated in patient meetings in St. Louis, Missouri (during April) and Omaha, Nebraska (during June) as part of a series of meetings that began in late 2011. The planning committee developed the theme "Our Lives, Our Choices: Knowledge is Power." Over 150 patients and family members attended the meetings to learn about and share patient perspectives regarding treatment modality options and how to make the most of their in-center dialysis experience. Patients and dialysis professionals presented in the meetings.

- **Network 14** organized the *Speak Up!* Campaign to encourage patients to take an active role in their care and safety. The Network adapted an educational resource for patients from The Joint Commission, modifying it for the dialysis environment. This informational flyer was tested for effectiveness by the Network's PAC, and then made available on the Network's website.

- **Network 15** launched the renal TIP Line, a toll-free phone line that offers written and recorded messages by patients and renal professionals about various aspects of kidney disease and treatment. Topics include "ESRD Network #15—Who We Are and What We Do for Patients"; "Treatment Options; Taking Charge of your Health"; "Coping with the Renal Diet for People on Hemodialysis"; "What to Do If You Have a Problem with Your Care"; "Patient-Centered Care"; "Coping"; "Missing Treatments"; "Tips on Adhering to a Medication Regimen for the Dialysis and Kidney Transplant Patient"; and "Travel and Dialysis." In 2012, 359 calls were received from across the Network's six states, other areas of the country, and Canada.

Outreach to Renal Professionals

The Networks keep dialysis facilities and transplant centers up-to-date on developments in ESRD care by:

- Posting useful information on Network websites,
- Producing and distributing provider-focused newsletters,
- Mailing or faxing information to providers on relevant clinical issues, and
- Providing information about product and medication recalls, including voluntary recalls and recalls imposed by the Food and Drug Administration.

Professional Education

Providing education for dialysis facility staff and other renal professionals is a major focus for the Networks. Typical activities include:

- Regularly scheduled conference calls with dialysis facility staff;
- WebEx presentations on relevant topics;
- Online courses that can be used by facilities for training new staff and for in-service training;
- Onsite training sessions for facility staff;
- Discipline-specific education programs for professionals including nurses, dietitians, nephrologists, primary care practitioners, and surgeons; and
- Cross-discipline education programs on aspects of ESRD care.

The Networks devote considerable resources to educating members of the renal community through presentations at state and local professional conferences and provider meetings sponsored by other organizations. In addition, Network subject matter experts are routinely asked to present at national conferences.

The following are examples of the many provider- and practitioner-focused outreach activities conducted by the Networks in 2012:

- As of December 2012, 13 of the 18 ESRD Networks were participating in the **5 Diamond Patient Safety Program** (www.5diamondpatientsafety.org), launched by **Networks 1 and 5** in 2008. The program, which has been endorsed by the Renal Physicians Association and the American Nephrology Nurses' Association, offers a series of patient safety modules that can be used for in-service training. A dialysis facility that completes a module and submits documentation of implementation and outcomes is recognized with one "Diamond." A dialysis facility that completes five modules is recognized publicly and awarded a plaque.

- In March 2012, **Network 3** formed the Puerto Rico Healthcare-Associated Infections (HAI) Learning and Action Network (LAN) in collaboration with more than a dozen partners, with the goal of decreasing vascular access infection rates. Accomplishments in 2012 included physician meetings on infection control in the dialysis setting and multidrug resistant organisms; an all-day infection control education program for over 125 dialysis nurses; and a Spanish version of the WAVE campaign that was developed by the USDHHS' Office of Healthcare Quality and the Partnership for Patients. The *VELA* campaign, as it was called in Spanish, was a contest for dialysis facilities to compete for the best facility project to decrease HAIs.

- **Network 12** worked closely with the State of Kansas Healthcare Acquired Infections Program Director, Mr. Joseph Scaletta, MPH, RN, CIC, of the Kansas Department of Health, to offer a series of webinars to train facilities on the CDC's National Healthcare Safety Network (NHSN). The webinars included information about the enrollment process, joining the Network group, and the reporting process. By the end of December 2012, 94.9% of facilities in the Network's service area enrolled in NHSN which far exceeded the goal of 80%.

- **Network 16** partnered with the Oregon Patient Safety Commission for a Northwest Bloodstream Infection (BSI) Collaborative. Thirty-three facilities from Washington and Oregon used CDC tools for reducing bloodstream infections in dialysis facilities during the collaborative. Findings showed improved patient safety culture, strong self-assessment of improved patient care process, increased hand hygiene compliance, improved vascular access technique, and reduced access-related bloodstream infections.

Contributions to Professional Literature

Staff members from several Networks published articles in peer-reviewed journals in 2012, as shown in Figure 16.

FIGURE 16
Articles Published by Network Authors in Peer Reviewed Journals, 2012

NETWORK 5	Schell J, Bova-Collis R, Deziel S, Moss A. The patient wants to stop dialysis: the latest evidence on how to respond. Nephrol News Issues. 2012;26(4):22–8. Available at: http://www.nephrology-digital.com/201204/201204#&pageSet=0 Lilly M, Lynch J, Wish, J, Huff, E, Chen S, Armistead N, McClellan W. Prevalence of arteriovenous fistulas in incident hemodialysis patients: correlations with patient factors that may be associated with maturation failure. Am J Kidney Dis. 2012;59(4):541–9. McClellan AC, Luthi JC, Lynch JR, Kulkarni R, Guasch A, Huff ED, Gilbertson D, McClellan WM, DeBaun MR. High one year mortality in adults with sickle cell disease and end-stage renal disease. Br J Haematol. 2012;159(3):360–7.
NETWORKS 15 AND 17	Rodgers, DJ, Hossli S, Messana T. Today's dialysis environment: an overview. Module One-Core Curriculum for the Dialysis Technician. 2012;October:1–14.
NETWORK 16	Hall L. Social networking and boundaries: where to draw the line? Renal Business Today. 2012;7(4):18–19.Available at: http://www.renalbusiness.com/articles/2012/06/social-networking-and-boundaries-where-to-draw-the-line.aspx#content Hall L, Spaeth N. Nancy Spaeth's Story: a little history and a lot of hope. J Nephrol Social Work. 2012;36:43–47. Available at: http://www.kidney.org/professionals/CNSW/JNSWonline/index.cfm Hall L. Social Media: An examination of renal professional practices and guiding principles. J Nephrol Social Work. 2012;36:31–36. Available at: http://www.kidney.org/professionals/CNSW/JNSWonline/index.cfm Ball L, Buss J. Improving the fistula rate: the Northwest Renal Network experience. Nephrol News Issues. 2012;26(2):22–30. Available at: http://www.nephrology-digital.com/201202#&pageSet=12
NETWORK 18	Boyte E. Coping with end stage renal disease. AAKP Renalife. 2012;28(4):8–9.

FIGURE 16
Articles Published by Network Authors in Peer Reviewed Journals, 2012

	Boyte E. A patient centered approach to addressing non-adherence to treatment. Renal Business Today. 2012;Aug:19–24. Available at: http://www.renalbusiness.com/digital-issues/2012/07/patient-comfort.aspx Boyte E. You & Your End-Stage Renal Disease Network. AAKP Renalife. 2012;30(3):8–10. Available at: https://www.aakp.org/education/resourcelibrary/dialysis-resources/item/you-and-your-esrdnetwork.html

The Networks serve as a resource to dialysis facilities, providing technical assistance as needed or requested. Technical assistance is offered to providers as part of many Network quality improvement projects. In addition to responding to telephone and e-mail requests, Network staff members make onsite visits, as needed, to support facilities in providing the most appropriate care to dialysis patients.

Examples of technical assistance activities conducted in 2012 include:

- Providing support and technical assistance to all CROWNWeb users with the launch of the new system in 2012

- Guiding facilities wishing to support national infection control and reporting through the CDC's National Healthcare Safety Network (NHSN) enrollment and data entry processes

- Working with dialysis providers to improve their Performance Score Reports. These reports are used to provide dialysis facilities, patients, state surveyors, and clinicians with valuable information on patient characteristics, treatment patterns, hospitalization, mortality, and transplantation patterns in their facilities.

Support for Vocational Rehabilitation and Employment

As outlined in each Network contract, the Networks are required to annually supply information to inform patients and providers about vocational rehabilitation programs available in their area. Facilities are surveyed by the Networks to determine the demographics of patients aged 18–54 years who are in school or employed through a vocational rehabilitation program (see Table 20 and Figure 17).

Vocational rehabilitation, employment, and school participation data in the *2012 Summary Annual Report (SAR)* reflect a systematic error that is a result of the transfer from SIMS to CROWNWeb data management platforms. Specifically, the manner in which CROWNWeb extracted these data in 2012 produced aggregate summaries that under-report the actual number of dialysis patients aged

18-54 who received vocational rehabilitation services, were employed, or attended school. This reporting issue may reoccur in the 2013 and 2014 *SARs* because there is a defect in CROWNWeb that has not been corrected so that vocational rehabilitation, employment, and school participation data can be accurately summarized from Form CMS-2744 (see Table 20 and Figure 17).

Activities conducted by the Networks to encourage employment and vocational rehabilitation include:

- Developing and/or distributing brochures and other written materials (e.g., the Life Options publication, *Employment: A Kidney Patient's Guide to Working & Paying for Treatment*);

- Posting contact information for vocational rehabilitation programs on the Network's website and/or mailing this contact information to dialysis facilities;

- Advocating for patients who are threatened with job loss;

- Referring patients and employers or potential employers to advocacy and disability rights organizations; and

- Recognizing employers who hire ESRD patients.

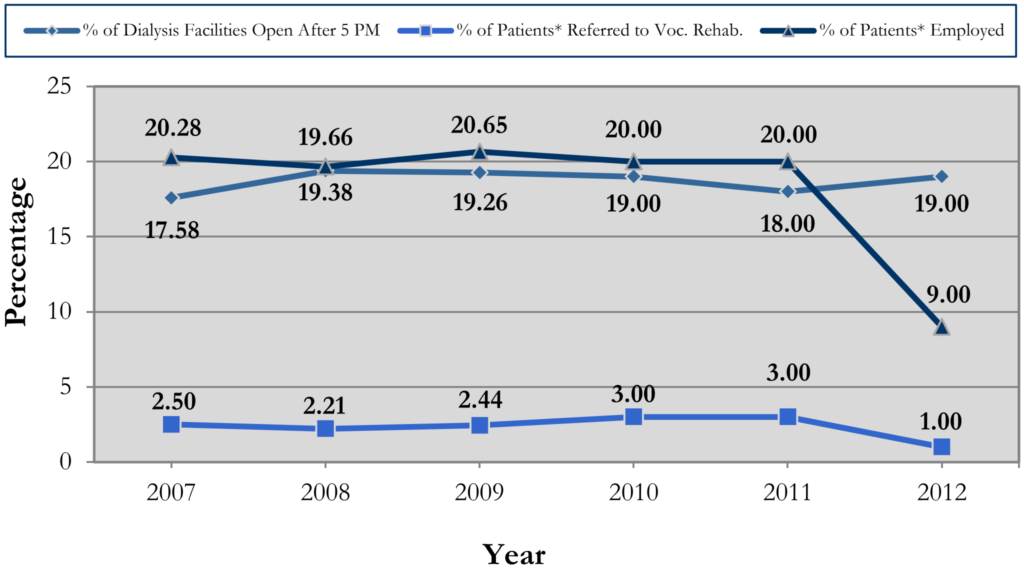
Examples of 2012 Network activities to promote vocational rehabilitation:

- **Network 7** distributed the 2012 Vocational Rehabilitation Toolkit, which was developed in collaboration with its Vocational Rehabilitation Advisory Committee, to all dialysis facility social workers and transplant centers in the Network region. The toolkit provided data, resources such as a best practices checklist and a tracking tool, and educational materials to assist the renal social worker in identifying and referring appropriate patients for vocational rehabilitation services. Informational materials for patients in both English and Spanish were also available.

- **Network 15** created a new area on its website to allow patients easy access to educational resources related to vocational rehabilitation. This area was regularly updated in 2012 to ensure that the most current resources were available. Network 15 also informed all facility social workers via e-mail of the availability of its 2012 Vocational Rehabilitation Resources packet.

FIGURE 17

Percent of Dialysis Facilities Open after 5 PM, Percent of Patients Referred to Vocational Rehabilitation, and Percent of Patients Employed, by Year, 2007 2012



SOURCE OF DATA: Networks 1 18.

*Patients aged 18 54 years.

Support for Emergency Planning and Preparedness

Within their individual service areas, the Networks engage in outreach, training, and technical assistance activities to help ensure that the needs of ESRD patients are met in emergency/disaster situations.

The following examples are representative of emergency/disaster preparedness and response activities conducted in 2012:

- **Network 1** staff, while working without power, heat or running water, continued to provide emergency response to the dialysis facilities affected by Superstorm Sandy throughout New England. Severe weather advisory emails were sent to Network-area providers, alerting them about the storm, evacuation information by state, hurricane preparedness information for dialysis patients, dialysis provider "To Do" lists, and patient hotline numbers. Direct contact was made with dialysis providers located along the shoreline—the facilities at greatest risk—

to determine operational status as a result of the storm and assess resources needed. After much coordination and resource planning, there were minimal interruptions for New England dialysis providers. In addition, the Network staff assisted facilities in New York by tracking dialysis patients displaced to New England as a result of this catastrophe.

- **Network 2's** ESRD Disaster Preparedness Coalition (EDPC) was very active throughout 2012, producing a series of "Tip Sheets" for dialysis providers to distribute to patients. In the days leading up to potential emergency disruptions, the Network sent out status reports and EDPC "Tip Sheets" to assist ESRD facilities in preparing their patients for emergency situations. The "Tip Sheets" include "Signs and Symptoms of Distress and When to Call 911," "Emergency Diet Guidelines," "Extreme Summer Heat: Tips for Dialysis Patients," and "Snowstorm Health: Tips for People on Dialysis." In 2012, "Tip Sheets" were distributed to more than 1,400 patients, providers and other stakeholders; some of these materials were utilized by local Offices of Emergency Management in Suffolk County and New York City during Superstorm Sandy to inform their helpline staff and volunteer first responders of the specific needs of dialysis patients.

- **Network 3** staff collaborated with the New Jersey Department of Health, CMS, KCER, the state Office of Emergency Management, and other stakeholders to ensure all dialysis patients received dialysis during Superstorm Sandy. The storm resulted in only one facility closure due to significant flooding; all 98 patients were placed in nearby facilities.

- **Networks 8 and 12** staff and providers participated in the Great Central U.S. Shakeout from February 7–8 in 2012. The exercise was a drill designed to prepare providers for earthquake readiness and test how facilities would respond to a severe earthquake.

- **Network 16** participated in the Evergreen Quake exercise in June, 2012. This exercise tested how hospitals and other providers would respond to a massive earthquake in the Puget Sound area. Based on hypothetical scenario, facilities were called by the Network and asked to indicate how they would react to a particular situation, for example, complete power outage, no water service, or bridge closures. Each facility communicated how it "handled the situation" on paper and faxed back their solution to the Network within a specified timeframe.

Special Projects

Special Project: ESRD Network Coordinating Center

Since 2003, the ESRD Network Coordinating Center (NCC) has served CMS and the 18 Networks by providing centralized coordination and support for the operation of the ESRD Network Organization Program. The NCC contract has been held by **Network 2** since 2007.

The NCC's responsibilities include:

- Providing support to the ESRD Networks and CMS through coordinating and hosting conference calls, providing meeting services, and tracking and compiling Network reports including Quarterly and Annual Reports
- Providing educational resources to the ESRD community via the NCC website
- Planning and coordinating ESRD-related sessions at the annual CMS-sponsored QualityNet Conference
- Mailing the New ESRD Patient Orientation Packet (NEPOP) to every new dialysis patient and tracking the delivery of these packets (see the **Outreach, Education, and Technical Assistance** section of this report for more details)
- Preparing reports under CMS guidelines, including this *Summary Annual Report* , which condenses patient and provider data and the activities of the 18 ESRD Networks into one document that gives an overview of the state of ESRD care in the United States
- Annually updating and distributing the *Directory of ESRD Network Organizations*.

The Fistula First Breakthrough Initiative (FFBI) was transitioned to the NCC in 2011. The FFBI has continued to be successful in pursuing its goals and objectives since its inception in 2003. The weighted national AVF in use rate rose from 60.4% in June 2011 to 61.1% in March 2012—an increase of 0.7 percentage points as illustrated in Table 19. This increase resulted, in part, from the FFBI Coalition's commitment to improve patient care and outcomes by increasing hemodialysis patients' knowledge of available treatment options and the health benefits of an AVF.

The NCC's charge is to support the FFBI Coalition, assist all 18 Networks with building upon their vascular access improvement initiatives, and maintain the Fistula First website (fistulafirst.org). The NCC's FFBI Clinical Lead has served as the national vascular access expert in representing the FFBI. In association with FFBI clinical and surgical consultants, the NCC's Clinical Lead provides communication to the Networks and renal community regarding FFBI.

Although there was steady and positive progress since the FFBI began, there is still work to be done. As of March 2012, the weighted national AVF in use rate was 61.1%, with the national goal of 66% still to be realized.

Special Project: Kidney Community Emergency Response Coalition

Under contract with CMS, **Network 7** continued to provide administrative support to the Kidney Community Emergency Response (KCER) Coalition in 2012. Among other responsibilities, Network 7 supported a national website (www.kcercoalition.com), maintained a toll-free number, and served as a central coordination point during emergency/disaster situations to ensure that backups were in place for dialysis patients.

See the **Partnerships and Coalitions** section of this report for more details on the activities of the KCER Coalition in 2012.

Special Project: Renal Requirements, Communications, and Training (R-RCT)

During 2012, **Network 7** continued work on the Renal Requirements, Communication, and Training (R-RCT) special project. This project supports the development of CROWNWeb, the primary source of ESRD data collection from Medicare-certified dialysis facilities and ESRD Networks. After several phases of pilot testing with various ESRD Networks and dialysis facilities, CROWNWeb was launched nationally with over 5,600 dialysis facilities utilizing the system. Now in full release, CROWNWeb allows CMS, ESRD Networks, and dialysis providers to enter and view ESRD patient data through a secured web portal.

Data submitted via CROWNWeb will aid the ESRD community in assessing patient progress, measuring provider success, and gauging the overall success of the ESRD initiative through measures reporting and data availability. R-RCT provided information on CROWNWeb to the ESRD community through e-mail distribution lists, the project website (www.projectcrownweb.org), and the CROWNWeb and CROWNWeb Responsiveness and Feedback Tree (CRAFT) newsletters. These newsletters, which were distributed monthly, included updates on the latest CROWNWeb news, links to web resources, details on the next scheduled CRAFT call, training information, and recognition of Networks participating in CROWNWeb workgroups.

As part of the R-RCT Special Study, Network 7 developed and maintains the Business Requirements and Kidney Data Dictionary. These vital community reference documents provide valuable information about the background and design of CROWNWeb, in addition to insight into future development of the system.

As part of the R-RCT special study, Network 7 was tasked with increasing the outward visibility of CROWNWeb from a requirements and development perspective. In addition to holding monthly stand-alone national User Group calls (with attendance frequently exceeding 500 users), the R-RCT team also participated in CRAFT calls and Community Town Halls sponsored by the CROWNWeb Outreach, Communication, and Training (OCT) team. The Network made live presentations and provided relevant content for publications and newsletters in order to increase visibility.

Special Project: Network Information Technology Support (NWITS)

In 2012, **Network 2** continued to serve as the contractor for the Network Information Technology Support (NWITS) Special Project. The NWITS contractor:

- Supported three newly created ESRD data systems and processes:
    - The CROWNWeb User Interface, which allows dialysis facilities to manually enter patient information;
    - Batch processing of CROWNWeb data; and
    - The QualityNet Identity Provisioning (QIPS)/QualityNet Identity Management System (QIMS) user authentication applications, which control user access to the CROWNWeb system. Users must first register and be authenticated by these systems before they can access patient data stored in the CROWNWeb system.
- Supported three legacy data systems:
    - The Standard Information Management System (SIMS);
    - The Vital Information System to Improve Outcomes in Nephrology (VISION) facility reporting software; and
    - The Vascular Access Utility.
- Produced Fistula First Outcomes Dashboard data
- Responded to ad hoc data requests as approved by CMS

In 2012, the NWITS Special Project continued to support the resolution of complex issues in ESRD legacy data systems and provide support for the Fistula First Special Project. The NWITS contract expired on December 31, 2012.

Partnerships and Coalitions

The ESRD Networks engaged in a variety of collaborative activities in 2012. These collaborations involved communication and coordination with renal partners at the local, Network-area, regional, and/or national levels.

The Networks' partners included organizations such as the National Kidney Foundation (NKF), the American Kidney Fund (AKF), the American Association of Kidney Patients (AAKP), the National Association of Nephrology Technicians/Technologists, the National Renal Administrators Association (NRAA), the Council of Nephrology Social Workers (CNSW), the American Nephrology Nurses' Association (ANNA), the Renal Physicians Association (RPA), the American Society of Nephrology, the National Hospice and Palliative Care Organization (NHPCO), the Association of Health Facility Survey Agencies, the Life Options Rehabilitation Advisory Council, the Medical Education Institute, the United Network for Organ Sharing, the United States Renal Data System Coordinating Center, the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health, in addition to independent dialysis corporations, and large corporate dialysis organizations (LDOs).

The Networks also actively collaborated with State Survey Agencies and Medicare Quality Improvement Organizations (QIOs) in their geographic areas.

Local and Regional Partnerships and Coalitions

Each Network sponsors a renal coalition that includes professionals from a range of disciplines representing renal providers, state and local health departments, professional organizations, advocacy organizations, and other healthcare–related groups and agencies. The Networks also develop and/or participate in a variety of focused partnerships and coalitions in their geographic jurisdictions.

Examples of local and regional Network partnership and coalition activities conducted in 2012 include:

- **Network 1** worked closely with Donate Life Connecticut, a statewide coalition of volunteer agencies and individuals interested in increasing education about organ and tissue donation. The partnership activities were designed to raise awareness and encourage donor registration. These activities included a high school poster contest, fundraising events, participation in the activities surrounding the 2012 Hartford ING Marathon, and supporting *20 Million in 2012,* the national Donate Life America campaign.

- **Network 1** also partnered with large dialysis organizations (LDOs) to promote fistula placement and use, and to support catheter reduction programs. This partnership included identifying clinics with low AVF in use rates and/or high catheter rates and sharing quality improvement tracking tools and educational material. Representatives from the Network and LDO leadership made several site visits to promote this partnership.

- **Network 2** partnered with Explore Transplant, a non-profit corporation that disseminates transplant education nationally. Together they held a one-day educational event in October 2012 in New York City. This event was attended by 136 dialysis staff members representing over 100 dialysis facilities in the New York City metro area.

- In March 2012, **Network 3** formed the Puerto Rico HAI Learning and Action Network (LAN) and worked with more than a dozen local partners to assist in decreasing vascular access infection rates. The LAN convened educational sessions on infection prevention for patients and families, physicians, and nurses.

- **Network 5** collaborated with two LDOs and one small dialysis organization (SDO) to hold an educational session for nephrologists and vascular surgeons focused on surgical techniques for AVF creation, interventions for AVF salvation, and the benefits of emergent peritoneal dialysis.

- **Network 6** and the Georgia and North Carolina ANNA chapters presented "Nephrology Knowledge Exchange 2012" to more than 250 nurses, patient care technicians, dietitians, and social workers in order to provide updates and education on dialysis care.

- **Network 7** partnered with Explore Transplant, a non-profit corporation that disseminates transplant education nationally, to host a three-day training session for 101 attendees.

- **Network 7** was a principal player in the activities of the Florida Kidney Disaster Coalition (FKDC) and in launching the Coalition's Piecing Together Preparedness program. This online program was developed with input from independent, large, and small dialysis providers, as well as emergency preparedness officials from throughout the state. FKDC received permission from the Mid-Atlantic Renal Coalition (**Network 5**) and The ESRD Network of New England (**Network 1**) to utilize the format of their *5 Diamond Patient Safety Program*. It then created six modules, including the tools and resources necessary to implement the activities it outlines. By the end of 2012, 25 Florida dialysis facilities had enrolled in the program, four had completed at least one module, and one facility had completed all six of the modules. All materials needed to complete the program are accessible via the FKDC website (www.fkdc.org).

- **Network 9** collaborated with Indiana University to implement two Patient Empowerment Workshops in 2012. Representatives from the Network's Patient Leadership Committee assisted in planning the workshops, and two committee members delivered presentations. One of the sessions held during the workshops was directed specifically toward physicians and their staff. This meeting encouraged participants to engage their patients in discussions about treatment options.

- **Network 10** worked in partnership with Explore Transplant and the Gift of Life Organ Procurement Organization to offer transplant education workshops to Illinois facilities in November, 2012.

- **Network 11** completed several projects with the Upper Midwest Fistula First and Chronic Kidney Disease Coalition, including vessel preservation posters and the QAPI algorithm and checklist. Members of this coalition include consumers, dialysis facility providers, state Departments of Health, and National Kidney Foundation affiliates.

- **Network 15** began work with the Arizona Department of Health on an HAI collaborative project that addressed infection control in dialysis care during the fall of 2012. Working together, the groups planned a state-wide ESRD HAI meeting to be held in spring 2013 to encourage best practices in infection control and strategic partnerships among stakeholders.

- In collaboration with Medical Education Institute/Life Options, **Network 15** assisted in the development of two patient education "mini movies" on fluid management and dialysis adequacy. These video presentations are part of a new series of three-minute multimedia tools designed to help start a conversation between patients and the care team about key health topics. The videos are available in English and Spanish.

- **Network 16** partnered with the Oregon Patient Safety Commission to form a Northwest Bloodstream Infection (BSI) Collaborative. Thirty-three dialysis facilities from Washington and Oregon participated in this collaborative. Data showed an improved patient safety culture, stronger self-assessment of improved patient care processes, increased hand hygiene compliance, improved vascular access technique, and reduced access-related bloodstream infections in participating facilities.

- **Network 17** collaborated with the Hawaii Department of Health Immunization Branch Chief to educate patients and staff about cultural barriers to vaccination. Findings from the project indicated that patient vaccination rates increased from 55.3% in 2011 to 91.3% in 2012. Staff influenza vaccination rates increased from 77.5% in 2011 to 90% in 2012.

Collaborations with State Survey Agencies (SSAs)

An important component of each Network's collaborative work is a relationship with the State Survey Agency(ies) in the Network area. Ongoing communication with these agencies helps ensure facilities' compliance with the ESRD Conditions for Coverage and Network goals. Coordination with State Survey Agency personnel ensures that consistent messages are provided to facilities and that performance issues are readily identified. The Networks also serve as a resource for any ESRD-related questions or concerns and work with State Survey Agencies on patient complaints and grievances.

The Networks engaged in various activities with State Survey Agencies in 2012, including:

- Establishing communications channels such as regularly scheduled conference calls with State Survey Agency staff and CMS Regional Office personnel, or ad hoc calls when needed;
- Convening face-to-face meetings with State Survey Agency staff to discuss roles, responsibilities, issues such as complaints and grievances, and cited deficiencies; and developing evacuation and sheltering plans for dialysis patients;
- Providing ESRD-related information, including information on the Fistula First Breakthrough Initiative, updates on FDA safety alerts and manufacturers' recalls, and technical assistance to agency staff;
- Referring patient complaints and grievances to the State Survey Agency, as appropriate;
- Providing facility-specific information to state surveyors prior to scheduled surveys, and collaborating to improve care in facilities with identified survey deficiencies;
- Developing tools for communication of facility-specific information. For example, **Network 15** developed a state surveyor reporting tool which is completed and sent to the state agency when the Network is alerted to an impending survey. The Network worked with its six state agencies to develop and test the form.

Collaboration with Quality Improvement Organizations (QIOs)

CMS funds a national network of 53 QIOs that work to improve the quality of health care for Medicare beneficiaries. The QIOs support quality improvement in the 50 U.S. states, Washington, DC, Puerto Rico, and the Virgin Islands, along with three other U.S. territories (American Samoa, Guam, and the Northern Mariana Islands). The Networks and QIOs work together to resolve ESRD patient complaints. They also typically share resources related to emergency and disaster preparedness.

Other collaborations between the Networks and QIOs in 2012 included:

- **Network 6** met via conference call with Georgia's QIO in January 2012 to discuss a strategy to assist a community in the state that has low AVF in use rates and high AVG rates. The Network participated in the QIO Hospital Engagement Network while the QIO participated on Transplant Coalition conference calls and meetings, and provided educational sessions for Network facilities.
- **Network 8** partnered with the Tennessee Kidney Foundation and Qsource, the QIO for Tennessee, to design a cannulation workshop that could simultaneously be presented live and via videoconference across the state. The workshop, titled "Assessment, Management, and Cannulation of the Dialysis Vascular Access," was developed and implemented to enhance the clinical skills of direct care staff in dialysis facilities.

Network 8 staff members continued participation in the Memphis Area Care Transitions Community, a coalition aimed at decreasing the re-hospitalization rate among all patients in the Memphis area.

- **Network 11** joined the Collaborative Healthcare Associated Infection Network (CHAIN) with StratisHealth, the Minnesota QIO, and the Minnesota Health Association.

- **Network 12** was invited to join the Kansas City Quality Improvement Consortium (KCQIC) in 2012 so it could bring the perspective of the dialysis community to the group. KCQIC includes both the Kansas QIO (KFMC) and the Missouri QIO (Primaris). The current focus of the group is to reduce avoidable hospital readmissions of all patients.

- **Network 18** partnered with Health Services Advisory Group (HSAG), the California QIO, to reduce rates of avoidable 30-day hospital readmissions. Through this collaboration, the Network and QIO achieved approximately 50% reduction in the rate of hospital readmissions among targeted dialysis facility patients.

Kidney Community Emergency Response Coalition (KCER)

The Kidney Community Emergency Response Coalition (KCER) was formed at a National Disaster Summit convened by **Network 7** in January 2006. Coalition members represent the ESRD Networks, patient and professional organizations, physicians and other healthcare practitioners, independent dialysis and transplant facilities, large dialysis organizations, hospitals, suppliers, state emergency management agencies, State Survey Agencies, CMS, and other federal agencies including the Centers for Disease Control and Prevention and the Food and Drug Administration. KCER's mission is to collaboratively develop and implement a coordinated preparedness and response framework for the kidney community for emergencies and disasters.

ESRD patients are uniquely vulnerable in emergency or disaster situations. Each of the ESRD Networks is required to have an Emergency and Disaster Response Plan in place. Coordination and support are provided at the national level by KCER. As part of their emergency and disaster planning efforts, the Networks collaborate with local, state, and federal agencies and emergency response organizations to educate them on the special needs of ESRD patients and ensure a coordinated response to their needs. In an actual emergency or disaster situation, the Networks work closely with individual dialysis facilities to make sure that patients' needs are met. The

Networks work hard to ensure that ESRD patients are located and that they receive life-sustaining services in alternative facilities when they are unable to reach their usual facilities or their usual facilities are closed.

Network 7 provided administrative support to KCER and coordinated its activities at the national level. KCER is made up of eight Response Teams that are tasked with holding one conference call every other month or as needed and resources allow.

The eight teams and their areas of responsibility are as follows:

- *Patient Assistance:* educate patients on preparedness, resources, and financial assistance.
- *Communication:* facilitate communication within the renal community during emergencies via a toll-free helpline, a listserv, and conference calls.
- *Facility and Patient Tracking:* track displaced patients and report on facility open/closed status.
- *Federal Response:* educate federal agencies and state partners, and direct federal resources during a disaster response.
- *Facility Operations:* assist facilities with preparedness and response.
- *Coordination of Staff and Volunteers:* maintain a database of emergency/disaster volunteers and provide education to volunteers.
- *Physician Team:* coordinate nephrology expertise for the management of dialysis and transplant patients during a large-scale crisis and identify tools needed to assist physicians whose practices have been disrupted by a disaster.
- *Pandemic Preparedness:* collaborate with federal and state agencies to ensure continuation of dialysis and transplant services in the event of a major pandemic.

KCER Website

KCER maintains a website (www.kcercoalition.com) that provides information, resources, and emergency-related tools for renal providers and individuals with kidney disease. The website is hosted at a separate location to ensure that it is always operational. In addition, the website offers a translation widget that translates the site's content into a number of languages.

FLOOD SAFETY: No matter what time of year it is, there is always a risk for flooding. There are many states being impacted by floods. Be sure to listen to your local news and weather for safety information specific to your area. For more information, visit the following sites:

- http://www.weather.gov/ahps/
- http://emergency.cdc.gov/disasters/floods/
- http://www.fema.gov/hazard/flood/index.shtm

WELCOME TO THE KCER COALITION

An emergency or disaster is an event that can result in significant harm to lives and/or property, as well as disruption in daily activities. For the people receiving kidney dialysis or living with a kidney transplant, planning for emergencies and disasters can be the difference between life and death. Dialysis and kidney transplant patients must take special preparedness measures to ensure their own health and safety during and after disasters.

The **Kidney Community Emergency Response (KCER) Coalition** provides technical assistance to ESRD Networks, Medicare organizations, and other groups to ensure timely and efficient emergency preparedness, response, and recovery for the kidney community.

KCER strives to provide resources to save lives, improve outcomes, empower patients and families, educate healthcare workers, build partnerships with stakeholders, promote awareness in the community, and support the ESRD Network Program.

KCER Outreach, Education, and Technical Assistance

The Kidney Community Emergency Response (KCER) Coalition coordinates emergency and disaster planning and response for the renal community at the national level. KCER held multiple educational webinars and meetings in 2012.

The KCER annual in-person meeting, "In the Eye of the Storm," took place on December 12, 2012 in Baltimore, Maryland, in conjunction with the CMS QualityNet Conference. Over 50 attendees interacted with an expert panel of personnel from ESRD **Networks 2, 3, 13, and 18** that participated in the Hurricane Isaac and Superstorm Sandy response efforts. Information was shared regarding successes, challenges, and lessons learned to assist attendees in improving their emergency preparedness and response plans. Attendees also participated in roundtable activities and left the meeting with actionable items to address future response efforts.

As part of KCER's public awareness and outreach activities, two national WebEx meetings were held to address key concerns identified by coalition members and share tools and resources available through KCER.

On December 6, 2012, KCER held its annual Community Partner Meeting, "Dialysis and Disasters," via WebEx. The meeting facilitated the development of community partnerships through education and information sharing between all stakeholders in attendance. The meeting agenda included presentations by KCER staff, the HHS Office of the Assistant Secretary for Preparedness and Response (ASPR), KCER Response Teams and KCER Task Force leadership. Additionally, the Coordination of Staff and Volunteers Response Team conducted a WebEx event called "Emergency Preparedness and Response for the Dialysis and Transplant Community: What You Need to Know" on December 18, 2012.

Response to Superstorm Sandy

During and in the immediate aftermath of Superstorm Sandy, KCER held daily conference calls with representatives from CMS, the Networks, patient and professional organizations, and other stakeholders. These calls assisted in the communication, collaboration, and problem solving processes associated with the effects of Superstorm Sandy.

Beneficiary Protection and Advocacy

Grievances and Involuntary Discharges

In 2012, CMS amended the complaints and grievance procedure so that all instances of care that do not meet a Medicare beneficiary's expectation are classified as a grievance. A grievance can be filed with the Network by an ESRD patient, and/or an individual representing an ESRD patient, and/or another party alleging that a Medicare-covered ESRD service did not meet recognized standards of safety or civility, and/or professionally recognized clinical standards of care.

The ESRD Networks were charged with informing patients about the procedures used to file a grievance and with taking steps to resolve patient grievances. The authority for these actions is found in Section 1881(c)(2)(D) of the Social Security Act, and in CMS regulations found at 42 CFR §405.2112(g). The Omnibus Budget Reconciliation Act of 1989 amended the Social Security Act to provide for confidentiality in the medical review process (see §1160 of the Social Security Act) and established a limitation on the Network's liability (see §1157 of the Social Security Act)." In addition, Section 6219(b) of the Omnibus Budget Reconciliation Act of 1989 amended Section 1881(c) of the Social Security Act to apply §1160 ("Prohibition against Disclosure of Information") and §1157 ("Limitation on Liability") of the Act to the ESRD Networks. The Networks also played a role in monitoring and resolving involuntary patient discharges (IVDs).

In 2012, CMS amended the complaints and grievance procedure so that all instances of care that do not meet a Medicare beneficiary's expectation are classified as a grievance.

The 18 Networks processed 1,301 formal beneficiary grievances in 2012, with an average rate of 3.04 grievances per 1,000 dialysis patients. Of the 18 Networks, only three reported a rate greater than 5.0 grievances per 1,000 patients.

The Networks prioritized responding to patients who have concerns about quality of care, or about access to ESRD services or rehabilitation. CMS encouraged the Networks to work with the facilities and all relevant parties to resolve grievances. As appropriate, the Networks provided educational information to assist dialysis facility staff in addressing current and future grievances. The Networks were required to collect data on all grievances to detect regional, local, or facility-specific patterns of concern.

The Networks followed CMS policy set forth in the *Medicare ESRD Network Organizations Manual* for evaluating, resolving, and reporting patient grievances. Each Network had a formal grievance resolution protocol approved by CMS, which typically included time frames for referring grievances to CMS and/or the State Survey Agency. State Survey Agencies had the authority and responsibility to ensure that facilities met the regulations outlined in the ESRD Conditions for Coverage (CfCs). As requested by CMS, the Networks assisted State Survey Agencies with the investigations of grievances.

In accordance with applicable statutes, regulations, and CMS policies, the Networks maintained confidentiality of the identity of the patient or other grievant, the involved practitioner, the Network's deliberations, and certain correspondence and documentation related to the Network's investigation and resolution.

Patients with grievances were encouraged, but not required, to submit them in writing. Patients, family members, friends, patient representatives or advocates, facility employees, physicians, State Survey Agencies, and other interested parties were able to submit grievances concerning a dialysis facilities, transplantation centers, acute care hospitals, nursing homes, home care providers, or physicians to the Network by mail, telephone, or e-mail during 2012. Each Network provided a toll-free number for patients' inquiries and grievances. All grievances received by the Networks were entered into Patient Contact Utility.

Sections 494.70 and 494.180 of the 2008 revised CfCs provide the framework for summarizing 2012 data on grievances and IVDs for the purposes of the present report.

Grievance Process

Once a grievance was received, the Network determined the appropriate next steps. The Network acted as a facilitator/coordinator, directly investigated the concern, or referred the concern to a more appropriate agency or organization. If a referral to an outside agency or organization was required, the Network made the referral. When the Network investigated a grievance, Network staff requested documentation, interviewed facility staff, discussed issues with the administration and/or corporate leadership, and conducted on-site investigations to resolve the grievance. The Network worked with the grievant and the facility and/or practitioner to find an acceptable solution for all involved. The Network documented the resolution in writing to the grievant, and contacted the facility and/or practitioner in writing regarding the resolution of the case. If the grievant was not satisfied with the results of the investigation, s/he was advised to contact the appropriate CMS Regional Office and/or State Survey Agency. Beginning in July 2012, if grievants were not satisfied with the outcome of the investigation, they had the option to ask for a re-review of the case by the Network.

The formal grievance process required the Network to conduct a complete review and evaluation of all available information. This may have required the involvement of a Network Grievance Committee and/or the Medical Review Board (MRB). The Network provided a report to the facility and/or practitioner within 60 calendar days of receiving the grievance; the 60-day periods included a 15 calendar day timeframe in which to receive additional information or comments from the facility and/or practitioner. The Network informed the facility and/or practitioner that a final report would be sent to the grievant. The Network was required to send a letter of acknowledgement at the beginning of the grievance process and a grievance report (findings and recommendations) at the conclusion of the process to all involved parties. When the Network identified a problem at a facility, the Network required the facility to develop and carry out an improvement plan to correct the problem(s).

Grievances in 2012

The 18 Networks processed 1,301 formal beneficiary grievances in 2012, with an average rate of 3.04 grievances per 1,000 dialysis patients. Of the 18 Networks, only three reported a rate greater than 5.0 grievances per 1,000 patients. See Table 21 for Network-specific data.

IVD Process

Involuntary patient discharges present substantial challenges for the Networks. In an effort to respond to these challenges, the ESRD community initiated a national, multi-year effort to educate and provide resources to dialysis facilities to help them effectively cope with conflicts between patients and care providers. This national initiative, which began in 2001, served as the foundation for the larger-scale Decreasing Dialysis Patient-Provider Conflict (DPC) Project. The project is credited with the development of a DPC taxonomy, manual, and toolkit that were originally distributed to the ESRD community in 2005. A revised version of the DPC toolkit was redistributed in 2009.

The 18 Networks processed 404 IVD cases in 2012, 38 (9%) fewer than in 2011.

The 2008 ESRD CfCs provide explicit guidelines regarding IVD policies and procedures. It is incumbent upon the facility's Medical Director to ensure that no patient is involuntarily discharged unless specific criteria are met, as outlined in the 2008 ESRD CfCs. These guidelines stipulate that patients must be informed of their facility's IVD policies and receive written notice 30 days in advance if a facility deems such a discharge necessary. (If a patient poses an immediate threat to the health and safety of others, the facility can shorten the discharge procedure.) In the case of a patient who exhibits disruptive or abusive behavior, the facility must document in the medical record all assessments and reassessments of the patient and the problem behavior, as well as attempts made to resolve the problem behavior; notify the patient and ESRD Network of the planned discharge 30 days in advance (unless the individual poses an immediate health or safety threat); obtain a signed physician order from the facility's Medical Director and the patient's attending physician; document all attempts to place the patient in another facility; and notify the State Survey Agency of the IVD.

IVDs in 2012

The 18 Networks processed 404 IVD cases in 2012, 38 (9%) fewer than in 2011. Of the 18 Networks, ten reported 20 or fewer IVDs, while the remaining eight Networks reported from 23 to 46 grievances. See Table 21 for Network-specific data.

In 2012, the Networks continued to educate dialysis facility staff about IVDs, providing them with materials and resources to help them work effectively with patients who were at risk of IVD and avoid pending discharges to the greatest extent possible. Many Networks distributed the Decreasing Dialysis Patient-Provider Conflict (DPC) toolkit or Network-developed print and electronic materials. In addition, many Networks implemented tracking tools to assess IVD cases (e.g., demographic profiles of at-risk and discharged patients, primary reasons for discharge) to inform future educational and intervention activities.

Several examples of IVD-focused activities conducted by the Networks in 2012 include:

- **Network 2** implemented a project that identified and monitored dialysis facilities with more than one IVD. The goal of this project, which began in 2011, was to decrease the percentage of facilities with more than one IVD and lower the risk of IVDs in facilities that had a history of IVDs. The Network's Patient Services Coordinator educated facility staff on the benefits of using the DPC toolkit and worked with facilities to ensure that their IVD policies were consistent with CfC guidelines. The Network also offered three DPC toolkit webinars and developed an environmental scan to help identify factors that may lead to an IVD. Findings indicated a decrease in the percentage of facilities with multiple IVDs from July 2011 (21%) to June 2012 (13.6%).

- **Network 7** executed an intensive, two-phase project to avert IVDs among patients who were at risk. The project had two components: the primary intervention consisted of providing facilities with IVD resources and information by fax blast, offering an in-person educational session at an annual meeting, distributing newsletters, and delivering a webinar; the secondary intervention entailed conducting focus groups with facilities that reported a patient at risk for IVD. During the first phase of this project, which ended in June 2012, the Network received notice of 34 patients at risk for IVD. Of the reported patients, 11 (32%) cases were averted, 21 (62%) resulted in discharge from the facility, one patient died, and one patient transferred to another facility. In the second phase of this project, from July to December of 2012, 10 (38%) of the 26 total at-risk cases reported to the Network were averted, 15 (58%) resulted in an IVD, and in one case, the patient transferred to another facility.

- **Network 11** encouraged facility staff to call the Network to discuss patient concern issues before they escalate to the point of IVD, and to use the DPC toolkit to assist in managing conflict. In 2012, of the 205 calls received from facilities for issues that could potentially lead to an IVD, only 23 (11%) patients were eventually discharged. This suggests that close communications between dialysis facilities and the Network staff can greatly reduce the number of IVDs.

Recommendations for Sanctions

Section §1881(c)(3) of the Social Security Act requires the Networks to recommend sanctions to CMS for dialysis facilities and transplantation centers that fail to consistently cooperate with Network goals and improvement plans. Prior to recommending sanctions, the Network follows a series of protocols laid out in CMS's policies and procedures. These protocols include providing technical assistance and making on-site visits to help low performers improve their quality of patient care.

In 2012, no sanctions were recommended by the ESRD Networks.

Recommendations for Additional Facilities

The Networks have recommended that CMS address specific identified needs, such as the treatment of dialysis patients with behavioral problems who have been involuntarily discharged from dialysis facilities. Several Networks included recommendations to CMS in their 2012 Annual Reports. For example:

- Noting that the "increasing number of challenging or disruptive patients requires unique staff communication and interpersonal skills," **Network 1** suggested that CMS develop a pilot project to test the feasibility of "unique needs" dialysis facilities "with additional provider reimbursement, to allow for higher staff-to-patient ratios, [which] would reduce the number of patients experiencing involuntary discharges."

- **Network 6** also emphasized the need for CMS to address the treatment needs of patients who have been involuntarily discharged due to noncompliance or behavioral concerns. These patients may have comorbid psychiatric illnesses that require care in addition to their dialysis treatment. Network 6 also reported that some "patients [are] discharged by their physician when no other physician with privileges at the facility will accept them." The Network pointed out that these IVDs require that patients be treated in local Emergency Departments.

- **Network 14** reaffirmed its recommendation that CMS support the establishment of special needs dialysis facilities in major metropolitan areas to serve displaced patients who require chronic dialysis but do not have a consistent provider.

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TABLE 1

Prevalent Dialysis Patients, Dialysis Facilities, and Full-Time Equivalent (FTE) Network Staff Assigned to Core Contract Activities, by Function, 2012

Network	Number of Dialysis Patients as of December 31, 2012	Number of Dialysis Facilities in Network Area as of December 31, 2012	Administrative FTEs	Quality Improvement FTEs	Data FTEs	Patient Services FTEs	Non-Core Contract	Total FTEs
1	12,996	174	1.95	2.45	3.35	2.15	1.00	10.90
2	26,543	249	2.00	1.75	3.00	2.75	3.00	12.50
3	17,709	174	0.75	2.68	2.25	1.38	0.00	7.05
4	17,847	294	4.05	2.00	2.50	1.50	0.00	10.05
5	24,193	325	4.25	4.50	2.00	1.00	0.00	11.75
6	40,731	608	2.25	4.75	2.30	4.70	0.00	14.00
7	25,377	369	1.98	2.80	2.45	2.75	10.52	20.50
8	24,176	400	2.00	3.40	3.00	2.00	0.00	10.40
9	29,558	536	1.93	2.20	2.70	2.10	0.95	9.88
10	17,584	251	2.03	1.80	2.90	1.15	0.75	8.63
11	24,821	454	1.05	3.20	3.80	2.35	0.60	11.00
12	14,627	291	2.00	2.75	2.00	2.00	0.00	8.75
13	17,026	287	3.25	5.50	4.50	4.50	1.50	19.25
14	40,445	504	2.25	4.25	4.50	2.50	0.50	14.00
15	20,244	315	2.80	3.00	3.60	2.40	0.00	11.80
16	12,281	175	1.75	1.25	2.75	1.25	0.00	7.00
17	23,662	243	2.80	2.00	3.00	2.00	0.00	9.80
18	37,923	341	3.00	2.00	2.00	2.00	0.00	9.00
TOTAL	**427,743**	**5,990**	**42.08**	**52.28**	**52.60**	**40.48**	**18.82**	**206.25**
Mean	**23,764**	**333**	**2.34**	**2.90**	**2.92**	**2.25**	**1.05**	**11.46**

SOURCE: Networks 1–18, 2012.

TABLE 2

Data Forms Processed in Calendar Year 2012

Network	Medical Evidence Report (Form CMS-2728)	Death Notification (Form CMS-2746)	Total
1	3,728	2,429	6,157
2	7,016	4,413	11,429
3	2,726	1,888	4,614
4	2,642	1,892	4,534
5	2,652	1,645	4,297
6	9,160	5,564	14,724
7	7,780	5,373	13,153
8	3,372	2,174	5,546
9	8,953	5,706	14,659
10	5,095	2,736	7,831
11	7,341	5,186	12,527
12	3,178	1,968	5,146
13	1,848	1,322	3,170
14	9,544	5,894	15,438
15	5,418	3,152	8,570
16	3,167	1,822	4,989
17	5,308	3,056	8,364
18	4,415	2,581	6,996
TOTAL	**93,343**	**58,801**	**152,144**

NOTE: The notable decrease in Forms CMS-2728 and CMS-2746 processed between 2011 (data not shown) and 2012 could be the result of improved procedures to eliminate duplicate forms or potential under-reporting using the CROWNWeb data management platform.

SOURCE: Networks 1–18 Annual Reports, 2012.

TABLE 3

Incident ESRD Patients, 2012, and ESRD Incidence per Million Population, 2012 Compared with 2011

Network	Number of Incident Patients, Calendar Year 2012*	Population of Network Area 2012	Incidence per Million Population 2011	Incidence per Million Population 2012
1	3,449	14,562,704	253	237
2	6,880	19,570,261	356	352
3	4,848	12,636,949	401	384
4	4,736	13,680,628	387	346
5	6,345	16,588,166	406	383
6	9,281	24,395,741	387	380
7	7,008	19,317,568	387	363
8	5,779	14,263,192	431	405
9	8,737	22,461,974	401	389
10	4,874	12,875,255	382	379
11	6,819	22,521,879	321	303
12	4,006	13,837,604	313	290
13	4,318	11,365,844	405	380
14	9,315	26,059,203	376	357
15	5,006	20,017,005	273	250
16	3,188	14,128,683	237	226
17	5,672	15,922,943	351	356
18	8,955	23,777,056	396	377
TOTAL	**109,216**	**317,982,655**	**360**	**343**

*Drawn from data recorded on Form CMS-2728 supplemented by additional information obtained by the Networks.

SOURCES: Patient data: Networks 1–18 Annual Reports, 2012. Population data for 50 U.S. states, District of Columbia, and Puerto Rico: U.S. Census Bureau, retrieved from: http://www.census.gov/popest/data/state/totals/2012/index.html

Population data for American Samoa, Guam, the Northern Mariana Islands, and the Virgin Islands: Central Intelligence Agency World Factbook, retrieved from: https://www.cia.gov/library/publications/download/download-2012/index.html

County-level population data for California: U.S. Census Bureau, retrieved from: http://www.census.gov/popest/data/counties/totals/2012/index.html

TABLE 4

Incident ESRD Patients by Age Group (in Years), Calendar Year 2012

Network	0–19	20–29	30–39	40–49	50–59	60–69	70–79	≥80	Missing	Total Number of Incident ESRD Patients, Calendar Year 2012
1	42	79	130	307	644	819	807	621	0	3,449
2	71	150	307	633	1,263	1,681	1,513	1,262	0	6,880
3	31	86	194	460	897	1,262	1,106	812	0	4,848
4	31	71	159	416	828	1,208	1,124	899	0	4,736
5	57	134	332	650	1,295	1,612	1,405	860	0	6,345
6	113	251	481	1,092	1,889	2,527	1,949	979	0	9,281
7	47	134	299	629	1,204	1,709	1,663	1,323	0	7,008
8	42	124	322	675	1,220	1,536	1,239	621	0	5,779
9	78	165	379	821	1,631	2,216	2,119	1,328	0	8,737
10	48	116	222	501	877	1,247	1,038	825	0	4,874
11	77	156	331	674	1,177	1,766	1,526	1,112	0	6,819
12	40	95	180	351	771	1,005	937	627	0	4,006
13	48	82	253	467	906	1,141	900	521	0	4,318
14	117	228	503	1,080	2,102	2,529	1,815	941	0	9,315
15	68	142	262	572	975	1,307	1,088	592	0	5,006
16	32	82	167	320	629	863	690	405	0	3,188
17	80	119	270	586	1,167	1,461	1,142	847	0	5,672
18	99	246	408	947	1,757	2,137	1,856	1,505	0	8,955
TOTAL	**1,121**	**2,460**	**5,199**	**11,181**	**21,232**	**28,026**	**23,917**	**16,080**	**0**	**109,216**
% of Total	**1.0%**	**2.3%**	**4.8%**	**10.2%**	**19.4%**	**25.7%**	**21.9%**	**14.7%**	**0.0%**	**100%**

NOTE: Reporting based on data recorded on Form CMS-2728 supplemented by additional information obtained by the Networks.

SOURCE: Networks 1–18 Annual Reports, 2012.

TABLE 5

Incident ESRD Patients by Gender, Calendar Year 2012

Network	Male	Female	Total Number of Incident Patients, Calendar Year 2012
1	2,055	1,394	3,449
2	4,037	2,843	6,880
3	2,850	1,998	4,848
4	2,760	1,976	4,736
5	3,664	2,681	6,345
6	5,148	4,133	9,281
7	4,107	2,901	7,008
8	3,135	2,644	5,779
9	4,874	3,863	8,737
10	2,746	2,128	4,874
11	3,941	2,878	6,819
12	2,290	1,716	4,006
13	2,350	1,968	4,318
14	5,123	4,192	9,315
15	3,022	1,984	5,006
16	1,869	1,319	3,188
17	3,249	2,423	5,672
18	5,313	3,642	8,955
TOTAL	**62,533**	**46,683**	**109,216**
% of Total	**57.3%**	**42.7%**	**100%**

NOTE: Reporting based on data recorded on Form CMS-2728 supplemented by additional information obtained by the Networks.

SOURCES: Patient data: Networks 1–18 Annual Reports, 2012.

TABLE 6

Incident ESRD Patients by Reported Race, Calendar Year 2012

Network	Black or African American	White	Asian and Native Hawaiian or Other Pacific Islander	American Indian or Alaska Native	Multiracial	Not Specified	Total Number of Incident ESRD Patients, Calendar Year 2012
1	478	2,859	96	5	7	4	3,449
2	1,937	4,436	406	13	40	48	6,880
3	1,122	3,565	133	3	10	15	4,848
4	1,074	3,584	70	1	3	4	4,736
5	2,784	3,266	198	4	3	90	6,345
6	4,881	4,117	126	55	5	97	9,281
7	2,075	4,776	130	6	7	14	7,008
8	2,689	3,009	47	15	2	17	5,779
9	1,795	6,804	72	3	6	57	8,737
10	1,355	3,252	147	4	4	112	4,874
11	1,505	4,943	166	167	15	23	6,819
12	818	3,062	58	23	10	35	4,006
13	1,646	2,444	44	154	7	23	4,318
14	2,152	6,903	220	18	6	16	9,315
15	366	4,003	208	412	10	7	5,006
16	182	2,665	241	95	4	1	3,188
17	636	3,239	1,639	21	48	89	5,672
18	1,024	6,612	1,127	29	27	136	8,955
TOTAL	**28,519**	**73,539**	**5,128**	**1,028**	**214**	**788**	**109,216**
% of Total	**26.1%**	**67.3%**	**4.7%**	**0.9%**	**0.2%**	**0.7%**	**100%**

NOTE: Reporting based on data recorded on Form CMS 2728 supplemented by additional information obtained by the Networks. The form also provides data on ethnicity, defined as Hispanic or Latino” or not Hispanic or Latino” (data not shown).

SOURCES: Patient data: Networks 1–18 Annual Reports, 2012.

TABLE 7

Incident ESRD Patients by Primary Diagnosis, Calendar Year 2012

Network	Diabetes	Hypertension	Glomerulonephritis	Cystic Kidney Disease	Interstitial Nephritis/ Pyelonephritis	Neoplasms/Tumors	Secondary GN/Vasculitis	Miscellaneous Conditions	Not Specified	Total Number of Incident ESRD Patients, Calendar Year 2012
1	1,349	787	318	179	156	111	82	392	75	3,449
2	2,896	1,693	469	227	196	174	131	818	276	6,880
3	2,420	1,365	290	140	133	88	79	294	39	4,848
4	1,916	1,264	297	173	157	133	92	540	164	4,736
5	2,307	1,857	332	173	106	113	102	456	899	6,345
6	3,642	3,099	531	238	191	155	194	586	645	9,281
7	2,833	2,533	351	196	190	149	132	548	76	7,008
8	2,509	2,008	289	136	103	106	106	381	141	5,779
9	3,789	2,100	503	253	264	233	162	1,123	310	8,737
10	1,860	1,721	241	113	112	68	77	317	365	4,874
11	2,712	1,691	528	299	269	197	162	756	205	6,819
12	1,631	1,081	285	145	141	117	70	333	203	4,006
13	1,761	1,291	204	119	85	81	70	254	453	4,318
14	5,025	2,312	445	244	194	187	156	541	211	9,315
15	2,418	1,206	373	182	159	128	119	343	78	5,006
16	1,411	599	327	157	127	113	81	330	43	3,188
17	2,665	1,250	382	153	141	115	96	418	452	5,672
18	4,084	2,308	417	186	139	122	145	574	980	8,955
TOTAL	**47,228**	**30,165**	**6,582**	**3,313**	**2,863**	**2,390**	**2,056**	**9,004**	**5,615**	**109,216**
% of Total	**43.2%**	**27.6%**	**6.0%**	**3.0%**	**2.6%**	**2.2%**	**1.9%**	**8.2%**	**5.1%**	**100%**

NOTE: Reporting based on data recorded on Form CMS 2728 supplemented by additional information obtained by the Networks.

SOURCE: Networks 1–18 Annual Reports, 2012.

TABLE 8

Prevalent Dialysis Patients by Age Group (in Years) as of December 31, 2012

Network	**0–19**	**20–29**	**30–39**	**40–49**	**50–59**	**60–69**	**70–79**	**≥80**	**Total Number of Dialysis Patients as of December 31, 2012**
1	44	256	568	1,372	2,392	3,195	2,947	2,222	12,996
2	83	587	1,348	3,088	5,510	6,530	5,509	3,888	26,543
3	55	345	880	1,953	3,600	4,781	3,793	2,302	17,709
4	67	358	864	1,970	3,639	4,588	3,730	2,631	17,847
5	88	521	1,422	3,086	5,286	6,253	4,931	2,606	24,193
6	159	1,010	2,672	5,815	9,346	11,063	7,410	3,256	40,731
7	131	539	1,397	3,006	5,243	6,295	5,300	3,466	25,377
8	87	564	1,672	3,448	5,608	6,374	4,458	1,965	24,176
9	135	621	1,621	3,520	6,160	7,615	6,200	3,686	29,558
10	93	463	987	2,030	3,556	4,472	3,647	2,336	17,584
11	109	609	1,344	2,896	4,826	6,302	5,165	3,570	24,821
12	89	351	747	1,624	3,070	3,785	3,054	1,907	14,627
13	107	424	1,229	2,336	3,940	4,519	3,050	1,421	17,026
14	267	920	2,478	5,358	9,907	11,352	7,071	3,092	40,445
15	125	566	1,194	2,477	4,293	5,357	4,136	2,096	20,244
16	69	344	833	1,384	2,475	3,334	2,452	1,390	12,281
17	88	591	1,353	2,757	5,053	6,206	4,627	2,987	23,662
18	205	1,145	2,213	4,686	8,208	9,605	7,317	4,544	37,923
TOTAL	**2,001**	**10,214**	**24,822**	**52,806**	**92,112**	**111,626**	**84,797**	**49,365**	**427,743**
% of Total	**0.5%**	**2.4%**	**5.8%**	**12.3%**	**21.5%**	**26.1%**	**19.8%**	**11.5%**	**100%**

NOTE: Reporting based on data recorded on Form CMS-2728 supplemented by additional information obtained by the Networks.

SOURCE: Networks 1–18 Annual Reports, 2012.

TABLE 9

Prevalent Dialysis Patients by Gender as of December 31, 2012

Network	Male	Female	Total Number of Dialysis Patients as of December 31, 2012
1	7,486	5,510	12,996
2	15,143	11,400	26,543
3	10,422	7,287	17,709
4	10,193	7,654	17,847
5	13,555	10,638	24,193
6	22,039	18,692	40,731
7	14,504	10,873	25,377
8	12,877	11,299	24,176
9	16,358	13,200	29,558
10	9,834	7,750	17,584
11	13,971	10,850	24,821
12	8,224	6,403	14,627
13	9,115	7,911	17,026
14	21,891	18,554	40,445
15	11,629	8,615	20,244
16	6,987	5,294	12,281
17	13,113	10,549	23,662
18	21,827	16,096	37,923
TOTAL	**239,168**	**188,575**	**427,743**
% of Total	**55.9%**	**44.1%**	**100%**

NOTE: Reporting based on data recorded on Form CMS-2728 supplemented by additional information obtained by the Networks.

SOURCES: Patient data: Networks 1–18 Annual Reports, 2012.

TABLE 10

Prevalent Dialysis Patients by Reported Race as of December 31, 2012

Network	Black or African American	White	Asian and Native Hawaiian or Other Pacific Islander	American Indian or Alaska Native	Multiracial	Not Specified	Total Number of Dialysis Patients as of December 31, 2012
1	2,711	9,822	402	30	31	0	12,996
2	10,317	14,202	1,645	112	173	94	26,543
3	5,504	11,427	550	7	221	0	17,709
4	6,233	11,306	278	9	20	1	17,847
5	14,186	9,216	710	19	16	46	24,193
6	27,304	12,686	499	201	19	22	40,731
7	10,370	14,469	451	40	38	9	25,377
8	14,873	9,040	162	93	3	5	24,176
9	9,747	19,506	240	20	36	9	29,558
10	7,009	9,940	576	12	23	24	17,584
11	7,972	15,444	671	696	28	10	24,821
12	4,323	9,943	225	91	16	29	14,627
13	8,879	7,260	214	645	17	11	17,026
14	11,679	27,812	844	80	23	7	40,445
15	2,077	14,802	865	2,468	32	0	20,244
16	1,060	9,667	1,123	405	25	1	12,281
17	3,524	12,211	7,585	144	196	2	23,662
18	5,496	27,395	4,807	104	57	64	37,923
TOTAL	**153,264**	**246,148**	**21,847**	**5,176**	**974**	**334**	**427,743**
% of Total	**35.8%**	**57.5%**	**5.1%**	**1.2%**	**0.2%**	**0.1%**	**100%**

NOTE: Reporting based on data recorded on Form CMS 2728 supplemented by additional information obtained by the Networks. The form also provides data on ethnicity, defined as “Hispanic or Latino” or “not Hispanic or Latino” (data not shown).

SOURCES: Patient data: Networks 1–18 Annual Reports, 2012.

TABLE 11

Prevalent Dialysis Patients by Primary Diagnosis as of December 31, 2012

Network	Diabetes	Hypertension	Glomerulonephritis	Cystic Kidney Disease	Interstitial Nephritis/ Pyelonephritis	Neoplasms/Tumors	Secondary GN/Vasculitis	Miscellaneous Conditions	Not Specified	Total Number of Dialysis Patients as of December 31, 2012
1	5,218	2,848	1,512	671	650	558	369	1,111	59	12,996
2	10,850	6,727	2,505	964	843	807	632	2,789	426	26,543
3	8,678	5,031	1,572	581	544	545	354	969	43	18,317
4	7,237	4,776	1,612	732	614	765	384	1,472	255	17,847
5	9,100	7,983	1,883	639	528	638	478	2,282	662	24,193
6	16,281	14,370	3,376	1,153	804	871	942	2,410	524	40,731
7	10,347	8,507	2,045	937	630	714	597	1,454	146	25,377
8	9,842	8,790	1,823	768	547	558	532	1,174	142	24,176
9	12,768	7,528	2,605	1,076	893	1,026	602	2,762	298	29,558
10	6,854	6,100	1,287	529	408	438	380	1,190	398	17,584
11	10,417	6,638	2,517	1,041	952	545	657	1,852	202	24,821
12	6,228	4,037	1,362	612	539	407	348	828	266	14,627
13	7,218	5,703	1,174	585	372	495	366	769	344	17,026
14	21,486	10,489	2,675	1,197	807	958	856	1,732	245	40,445
15	10,505	4,144	1,880	774	696	597	528	1,045	75	20,244
16	5,353	2,190	1,559	675	554	568	347	983	52	12,281
17	11,839	5,449	2,318	745	609	510	497	1,351	344	23,662
18	18,478	10,215	2,823	1,161	719	768	741	2,139	879	37,923
TOTAL	**188,699**	**121,525**	**36,528**	**14,840**	**11,709**	**11,768**	**9,610**	**28,312**	**5,360**	**428,720**
% of Total	**44.0%**	**28.3%**	**8.5%**	**3.5%**	**2.7%**	**2.7%**	**2.2%**	**6.6%**	**1.3%**	**100%**

NOTE: Due to differences in data abstraction protocols using CROWNWeb and the dynamic nature of the patient population, the total prevalence reported in this table (N = 428,720) differs from the total prevalence reported in Tables 1, 8, 9, and 10 (N =427,743).

NOTE: Reporting based on data recorded on Form CMS 2728 supplemented by additional information obtained by the Networks.

SOURCE: Networks 1–18 Annual Reports, 2012.

TABLE 12

Number of In-Center Dialysis Patients as of December 31, 2011, and December 31, 2012

Network	Number of In-Center Dialysis Patients* as of December 31, 2011	Number of In-Center Dialysis Patients* as of December 31, 2012	% Change
1	11,435	11,629	2%
2	24,717	25,007	1%
3	16,216	16,659	3%
4	16,006	16,101	1%
5	21,240	21,767	2%
6	34,997	36,058	3%
7	21,875	22,550	3%
8	21,088	21,504	2%
9	25,397	25,941	2%
10	14,775	15,333	4%
11	22,415	22,298	-1%
12	12,251	12,423	1%
13	14,915	15,033	1%
14	35,468	36,447	3%
15	17,760	17,979	1%
16	10,031	10,410	4%
17	20,120	20,733	3%
18	32,850	34,157	4%
TOTAL	**373,556**	**382,029**	**2%**

*Includes patients in training for home modalities.

SOURCE: Networks 1–18 Annual Reports, 2012. Due to changes in data sources, slight differences may exist between the 2011 counts reported above and those published in the *2011 Summary Annual Report.*

TABLE 13

Number of Home Dialysis Patients by Modality as of December 31, 2011, and December 31, 2012

	Hemodialysis			Continuous Ambulatory Peritoneal Dialysis			Continuous Cycling Peritoneal Dialysis			Other Peritoneal Dialysis*		Total	
Network	**2011**	**2012**	**% Change**	**2011**	**2012**	**% Change**	**2011**	**2012**	**% Change**	**2011**	**2012**	**2011**	**2012**
1	155	164	6%	307	263	-14%	799	921	15%	1	13	1,262	1,361
2	284	302	6%	480	426	-11%	829	939	13%	0	7	1,593	1,674
3	100	100	0%	170	175	3%	828	877	6%	0	0	1,098	1,152
4	286	279	-2%	251	222	-12%	994	1,220	23%	3	1	1,534	1,722
5	332	412	24%	752	589	-22%	1,029	1,340	30%	3	15	2,116	2,356
6	637	683	7%	1,345	856	-36%	2,364	3,154	33%	6	9	4,352	4,702
7	397	459	16%	576	429	-26%	1,532	1,902	24%	0	3	2,505	2,793
8	326	348	7%	560	530	-5%	1,566	1,839	17%	4	6	2,456	2,723
9	469	748	59%	1,039	909	-13%	1,521	1,994	31%	1	3	3,030	3,654
10	793	914	15%	370	272	-26%	913	1,146	26%	2	0	2,078	2,332
11	419	452	8%	829	780	-6%	967	1,277	32%	0	0	2,215	2,509
12	359	426	19%	636	396	-38%	925	1,349	46%	4	1	1,924	2,172
13	145	154	6%	379	306	-19%	1,210	1,413	17%	0	6	1,734	1,879
14	466	502	8%	721	576	-20%	2,359	2,731	16%	1	4	3,547	3,813
15	262	230	-12%	485	407	-16%	1,318	1,593	21%	0	0	2,065	2,230
16	305	343	12%	322	348	8%	1,111	1,187	7%	6	0	1,744	1,878
17	317	307	-3%	553	570	3%	1,760	1,950	11%	0	2	2,630	2,829
18	343	380	11%	985	775	-21%	2,156	2,748	27%	2	1	3,486	3,904
TOTAL	**6,395**	**7,203**	**13%**	**10,760**	**8,829**	**-18%**	**24,181**	**29,580**	**22%**	**33**	**71**	**41,369**	**45,683**

*Includes Intermittent Peritoneal Dialysis, which is similar to Continuous Cycling Peritoneal Dialysis but is usually performed in a hospital.

NOTE: Home dialysis includes dialysis received in another residential setting such as a nursing home.

SOURCE: Networks 1–18 Annual Reports, 2012. Due to changes in data sources, slight differences may exist between the 2011 counts reported above and those published in the *2011 Summary Annual Report* .

TABLE 14

Number of Patients Using In-Center and Home Dialysis as of December 31, 2011, and December 31, 2012

	In-Center Dialysis			Home Dialysis			Total		
Network	**2011**	**2012**	**% Change**	**2011**	**2012**	**% Change**	**2011**	**2012**	**Total**
1	11,435	11,629	2%	1,262	1,361	8%	12,697	12,990	2%
2	24,717	25,007	1%	1,593	1,674	5%	26,310	26,681	1%
3	16,216	16,659	3%	1,098	1,152	5%	17,314	17,811	3%
4	16,006	16,101	1%	1,534	1,722	12%	17,540	17,823	2%
5	21,240	21,767	2%	2,116	2,356	11%	23,356	24,123	3%
6	34,997	36,058	3%	4,352	4,702	8%	39,349	40,760	4%
7	21,875	22,550	3%	2,505	2,793	11%	24,380	25,343	4%
8	21,088	21,504	2%	2,456	2,723	11%	23,544	24,227	3%
9	25,397	25,941	2%	3,030	3,654	21%	28,427	29,595	4%
10	14,775	15,333	4%	2,078	2,332	12%	16,853	17,665	5%
11	22,415	22,298	-1%	2,215	2,509	13%	24,630	24,807	1%
12	12,251	12,423	1%	1,924	2,172	13%	14,175	14,595	3%
13	14,915	15,033	1%	1,734	1,879	8%	16,649	16,912	2%
14	35,468	36,447	3%	3,547	3,813	7%	39,015	40,260	3%
15	17,760	17,979	1%	2,065	2,230	8%	19,825	20,209	2%
16	10,031	10,410	4%	1,744	1,878	8%	11,775	12,288	4%
17	20,120	20,733	3%	2,630	2,829	8%	22,750	23,562	4%
18	32,850	34,157	4%	3,486	3,904	12%	36,336	38,061	5%
TOTAL	**373,556**	**382,029**	**2%**	**41,369**	**45,683**	**10%**	**414,925**	**427,712**	**3%**

NOTES: Home dialysis includes dialysis received in another residential setting such as a nursing home.
Due to differences in data abstraction protocols and the dynamic nature of the patient population, the total prevalence reported in this table (*N* = 427,712) differs from the total prevalence reported in Tables 1, 8, 9, and 10 (*N* = 427,743).

SOURCE: Networks 1–18 Annual Reports, 2012. Due to changes in data sources, slight differences may exist between the 2011 counts reported above and those published in the *2011 Summary Annual Report* .

TABLE 15

Renal Transplant Recipients by Age Group (in Years), Calendar Year 2012

Network	0–19	20–29	30–39	40–49	50–59	60–69	70–79	≥80	Total Number of Transplant Recipients, Calendar Year 2012
1	36	43	79	123	192	183	52	2	710
2	58	68	127	227	282	302	113	4	1,181
3	12	38	62	118	133	102	34	2	501
4	21	30	49	92	113	127	43	7	482
5	43	61	118	245	301	272	96	8	1,144
6	63	68	172	252	291	283	91	5	1,225
7	38	65	105	192	213	247	92	8	960
8	36	49	101	166	210	163	29	1	755
9	64	91	134	221	317	301	87	6	1,221
10	33	47	95	135	157	175	48	1	691
11	74	109	182	262	360	359	121	1	1,468
12	35	54	110	141	197	186	70	3	796
13	25	41	71	120	143	124	25	1	550
14	85	107	172	280	335	263	54	0	1,296
15	46	64	135	187	221	227	87	3	970
16	33	40	75	105	145	133	56	3	590
17	70	62	116	170	243	261	89	2	1,013
18	70	77	156	225	297	229	71	5	1,130
TOTAL	**842**	**1,114**	**2,059**	**3,261**	**4,150**	**3,937**	**1,258**	**62**	**16,683**
% of Total	**5.0%**	**6.7%**	**12.3%**	**19.5%**	**24.9%**	**23.6%**	**7.5%**	**0.4%**	**100%**

NOTE: Reporting based on data recorded on Form CMS-2728 supplemented by additional information obtained by the Networks.

SOURCE: Networks 1–18 Annual Reports, 2012.

TABLE 16

Renal Transplant Recipients by Gender, Calendar Year 2012

Network	Male	Female	Total Number of Transplant Recipients, Calendar Year 2012
1	454	256	710
2	711	470	1,181
3	331	170	501
4	308	174	482
5	682	462	1,144
6	690	535	1,225
7	587	373	960
8	476	279	755
9	740	481	1,221
10	443	248	691
11	934	534	1,468
12	509	287	796
13	308	242	550
14	758	538	1,296
15	567	403	970
16	369	221	590
17	615	398	1,013
18	692	438	1,130
TOTAL	**10,174**	**6,509**	**16,683**
% of Total	**61.0%**	**39.0%**	**100%**

NOTE: Reporting based on data recorded on Form CMS-2728 supplemented by additional information obtained by the Networks.

SOURCE: Networks 1–18 Annual Reports, 2012.

TABLE 17

Renal Transplant Recipients by Reported Race, Calendar Year 2012

Network	Black or African American	White	Asian and Native Hawaiian or Other Pacific Islander	American Indian or Alaska Native	Multiracial	Not Specified	Total Number of Transplant Recipients, Calendar Year 2012
1	105	579	20	0	2	4	710
2	315	749	77	5	21	14	1,181
3	138	327	24	0	10	2	501
4	94	371	15	0	1	1	482
5	503	571	62	0	3	5	1,144
6	567	564	32	9	4	49	1,225
7	248	666	29	2	1	14	960
8	357	380	8	1	1	8	755
9	250	886	22	1	8	54	1,221
10	189	378	25	0	1	98	691
11	283	1,093	58	20	5	9	1,468
12	158	598	18	5	4	13	796
13	184	336	12	16	1	1	550
14	260	971	49	5	5	6	1,296
15	67	800	48	50	1	4	970
16	48	455	75	7	5	0	590
17	92	618	234	5	6	58	1,013
18	136	843	128	1	8	14	1,130
TOTAL	**3,994**	**11,185**	**936**	**127**	**87**	**354**	**16,683**
% of Total	**23.9%**	**67.0%**	**5.6%**	**0.8%**	**0.5%**	**2.1%**	**100%**

NOTE: Reporting based on data recorded on Form CMS-2728 supplemented by additional information obtained by the Networks. The form also provides data on ethnicity, defined as “Hispanic or Latino” or “not Hispanic or Latino” (data not shown).

SOURCE: Networks 1–18 Annual Reports, 2012.

TABLE 18

Renal Transplant Recipients by Donor Type, Calendar Year 2012

Network	Deceased Donors	Living Related Donors	Living Unrelated Donors	Total Number of Renal Transplant Recipients, Calendar Year 2012
1	401	178	131	710
2	751	197	233	1,181
3	308	116	77	501
4	324	100	58	482
5	769	144	231	1,144
6	934	170	121	1,225
7	730	159	71	960
8	549	122	84	755
9	787	212	222	1,221
10	381	177	133	691
11	853	305	310	1,468
12	616	132	48	796
13	425	72	53	550
14	837	241	218	1,296
15	639	159	172	970
16	412	78	100	590
17	735	133	145	1,013
18	779	219	132	1,130
TOTAL	**11,230**	**2,914**	**2,539**	**16,683**

SOURCE: Networks 1–18 Annual Reports, 2012.

TABLE 19

Number and Percent of In-Center and Home Dialysis Patients with an Arteriovenous Fistula (AVF) in Use, December 2012 Compared with December 2011

Network	2011		2012	
	Number	Percent	Number	Percent
1	7,238	63.5%	7,099	64.3%
2	15,556	62.8%	14,776	63.0%
3	9,559	59.1%	8,669	58.3%
4	9,674	60.0%	9,108	60.0%
5	11,954	57.9%	11,695	58.1%
6	19,910	55.7%	19,913	56.8%
7	13,300	59.7%	12,764	59.4%
8	12,172	57.2%	11,899	57.6%
9	14,772	56.9%	14,159	58.4%
10	9,158	59.4%	8,531	60.7%
11	13,118	58.1%	13,141	60.6%
12	7,571	60.3%	7,052	61.0%
13	8,848	59.4%	8,523	59.6%
14	21,584	60.3%	21,226	60.4%
15	11,970	67.1%	11,600	68.3%
16	7,000	68.3%	6,927	68.4%
17	12,777	62.8%	12,220	63.3%
18	21,016	63.9%	20,806	64.5%
Weighted Mean	—	**60.4%**	—	**61.1%**
TOTAL	**227,177**	—	**220,108**	—

NOTES: Home dialysis includes dialysis received in another residential setting such as a nursing home. Starting in March 2010, a small number of patients with missing data on access type were excluded from the denominators used in calculating these percentages.

SOURCE: Fistula First Vascular Access Reporting Tables.

TABLE 20

Number of Dialysis Patients Aged 18–54 Years, Number and Percent Employed,* Number and Percent Receiving Vocational Rehabilitation Services, Number and Percent Attending School,* Number of Dialysis Facilities, and Number of Facilities Offering Dialysis after Regular Business Hours, as of December 31, 2012

Network	Number of Dialysis Patients Aged 18–54 Years as of December 31, 2012	Number Employed*	Percent Employed*	Number Receiving Vocational Rehabilitation Services	Percent Receiving Vocational Rehabilitation Services	Number Attending School*	Percent Attending School*	Number of Dialysis Facilities	Number of Facilities Offering Dialysis after 5:00 PM	Percent of Facilities Offering Dialysis after 5:00 PM
1	3,284	319	10%	22	1%	17	1%	174	62	36%
2	7,595	599	8%	37	0%	35	0%	249	101	41%
3	4,858	293	6%	12	0%	9	0%	174	61	35%
4	4,688	322	7%	29	1%	29	1%	294	53	18%
5	7,338	605	8%	8	0%	24	0%	325	76	23%
6	2,646	123	5%	7	0%	19	1%	608	30	5%
7	7,244	535	7%	47	1%	72	1%	369	58	16%
8	3,138	181	6%	4	0%	13	0%	400	23	6%
9	4,668	852	18%	31	1%	27	1%	536	97	18%
10	5,076	340	7%	13	0%	18	0%	251	39	16%
11	6,947	1,015	15%	104	1%	150	2%	454	83	18%
12	4,067	317	8%	18	0%	25	1%	291	30	10%
13	1,451	66	5%	2	0%	5	0%	287	32	11%
14	12,996	1,317	10%	127	1%	160	1%	504	54	11%
15	6,185	1,022	17%	4	0%	21	0%	315	79	25%
16	1,892	340	18%	24	1%	40	2%	175	82	47%
17	7,008	496	7%	12	0%	24	0%	243	72	30%
18	11,775	602	5%	22	0%	38	0%	341	80	23%
TOTAL	**102,856**	**9,344**	**9%**	**523**	**1%**	**726**	**1%**	**5,990**	**1,112**	**19%**

NOTE: Vocational rehabilitation, employment, and school participation data in the 2012 SAR reflect a systematic error that is a result of the transfer from SIMS to CROWNWeb data management platforms. Specifically, the manner in which CROWNWeb extracted these data in 2012 produced aggregate summaries that under-report the actual number of dialysis patients aged 18-54 who received vocational rehabilitation services, were employed, or attended school. This reporting issue may reoccur in the 2013 and 2014 SARs because there is defect in CROWNWeb that has not been corrected so that vocational rehabilitation, employment, and school participation data can be accurately summarized from Form CMS-2744 (see Table 20 and Figure 17).

*Full- or part-time.

SOURCE: Networks 1–18 Annual Reports, 2012.

TABLE 21

Complaints, Grievances, and Involuntary Discharges, Calendar Year 2012

Network	Number of Prevalent Dialysis Patients as of December 31, 2011	Number of Complaints	Rate of Complaints per 1,000 Prevalent Patients	Number of Grievances	Number of Involuntary Discharges
1	12,996	17	1.31	3	13
2	26,125	144	5.51	1	25
3	17,709	90	5.08	3	9
4	17,847	41	2.30	0	26
5	24,193	82	3.39	3	16
6	40,731	228	5.60	0	46
7	25,377	110	4.33	2	34
8	24,176	73	3.02	0	32
9	29,558	66	2.23	0	31
10	17,854	39	2.18	0	16
11	24,821	60	2.42	1	23
12	14,627	19	1.30	4	19
13	17,026	84	4.93	0	20
14	40,445	127	3.14	5	42
15	20,244	58	2.87	0	13
16	12,281	34	2.77	4	16
17	23,662	41	1.73	0	13
18	37,923	63	1.66	8	10
TOTAL	**427,595**	**1,376**	—	**34**	**404**
Mean	—	—	**3.22**	—	—

SOURCE: Networks 1–18, 2012.

TABLE 22

Incident ESRD Patients, Prevalent Dialysis Patients, and Transplant Recipients by Reported Race, 2012

Patient Category	Black or African American		White		Asian and Native Hawaiian or Other Pacific Islander		American Indian or Alaska Native		Multiracial		Not Specified		Total	
	n	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**	***n***	**%**
Incident ESRD Patients, Calendar Year 2012	28,519	26.1%	73,539	67.3%	5,128	4.7%	1,028	0.9%	214	0.2%	788	0.7%	109,216	100%
Prevalent Dialysis Patients as of December 31, 2012	153,264	35.8%	246,148	57.5%	21,847	5.1%	5,176	1.2%	974	0.2%	334	0.1%	427,743	100%
Transplant Recipients, Calendar Year 2012	3,994	23.9%	11,185	67.0%	936	5.6%	127	0.8%	87	0.5%	354	2.1%	16,683	100%

NOTE: Reporting based on data recorded on Form CMS 2728 supplemented by additional information obtained by the Networks.
The form also provides data on ethnicity, defined as “Hispanic or Latino” or “not Hispanic or Latino” (data not shown).
Race data are reported here to highlight disproportionate burdens of disease for certain population groups.

SOURCE: Networks 1–18 Annual Reports, 2012.

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