End Stage Renal Disease Network Program

ZUMARY ANNUAL REPORT



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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Suggested citation:

Centers for Medicare & Medicaid Services. End Stage Renal Disease Network Organization Program 2013 Summary Annual Report. Baltimore, MD: CMS; 2015.

Additional information:

For additional information about the End Stage Renal Disease Network Organization Program or to review prior *Summary Annual Reports*, please visit www.esrdncc.org or contact the National Coordinating Center at ncc@ncc.esrd.net.

Please note that on January 1, 2015, the ESRD Network Coordinating Center changed its name to the ESRD National Coordinating Center.

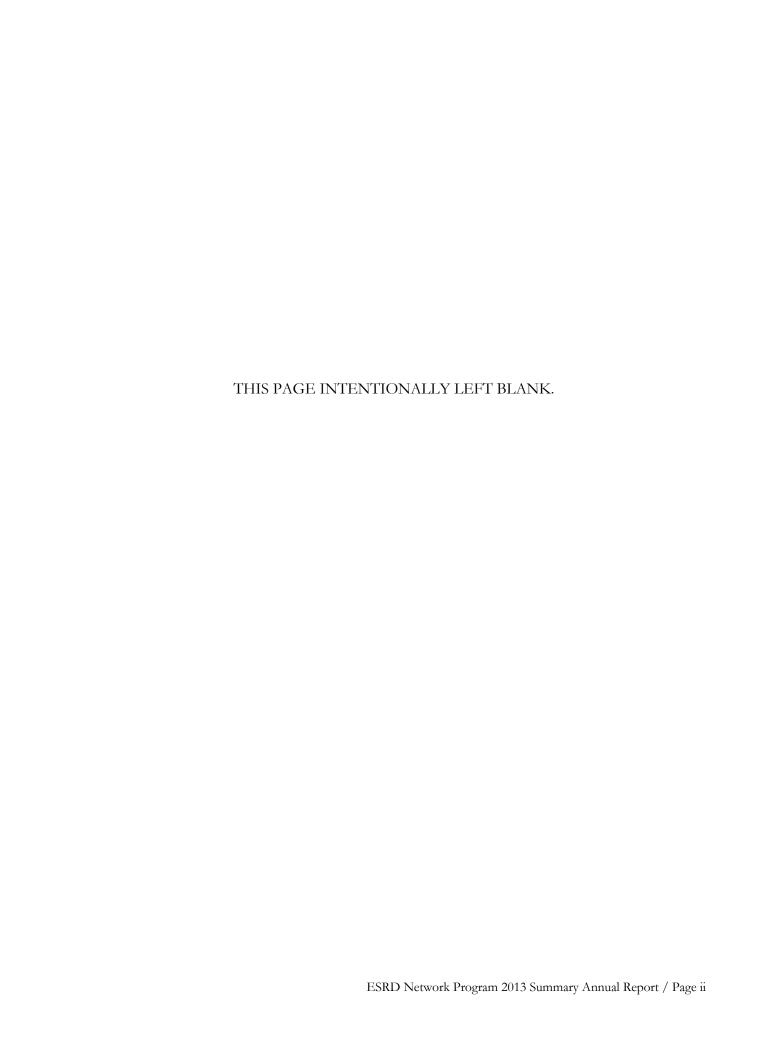


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Report Highlights

The End Stage Renal Disease Network Program (ESRD Network Program) is a national program funded by the Centers for Medicare & Medicaid Services (CMS) to improve the quality of care for individuals with irreversible kidney disease who require dialysis or transplantation to sustain life. The healthcare improvement activities of 18 ESRD Network contractors align with the Department of Health and Human Services' National Quality Strategy (NQS) and the CMS Quality Strategy. The ESRD Network Statement of Work (SOW) directs the activities of the 18 ESRD Network contractors that carry out the activities of the ESRD Network Program. Beginning in 2013, the SOW was revised to address the aims and priorities of the NQS, CMS' three AIMs for the ESRD Network Program, and other CMS priorities designed to improve the care of individuals with ESRD.

ESRD Incidence and Dialysis Prevalence

The rate of newly occurring cases of ESRD in the U.S. increased from 343 per million population in 2012 to 353 per million population in 2013 (Table 2). Of note, in 2013, there was considerable variation in ESRD incidence across the 18 ESRD Networks' geographic areas—from 234 patients per million population to 430 per million population.

The ESRD Networks reported a 3.7% increase in the prevalent dialysis population from December 31, 2012, to December 31, 2013 (Figure 3).

Home Dialysis

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). In addition, the ESRD Prospective Payment System's financial incentives for home dialysis training and treatment may make home hemodialysis an attractive alternative to standard in-center care. The use of home dialysis is continuing to increase, up 10% from 2012 to 2013 (Table 21). In the future, more dialysis patients are anticipated to use home hemodialysis as their preferred treatment modality and, as a result, are expected to achieve better clinical and psychosocial outcomes.^{1,2}

Fistula First Catheter Last

In 2013, the national rate for arteriovenous fistulas (AVFs) in use among in-center and home hemodialysis patients continued to improve, increasing from 61.1% of hemodialysis patients in 2012 to 62.2% in 2013.

¹ Finkelstein FO, Schiller B, Daoui R *et al.* At-home short daily hemodialysis improves the long-term health-related quality of life. *Kidney Int.* 2012;82(5):561-9.

² Rivara MB, Mehrotra R. The changing landscape of home dialysis in the United States. *Curr Opin Nephrol Hypertens*. 2014;23(6):586-91.

As of December 2013, 15 Networks exceeded the 60% threshold for AVFs in use among in-center and home hemodialysis patients. Additionally, 12 U.S. states (Arizona, Colorado, Idaho, New Hampshire, New Mexico, Oklahoma, Oregon, North Dakota, South Dakota, Utah, Vermont, and Washington) exceeded the 68% national goal according to Fistula First Catheter Last (FFCL) data. Five of these states (Colorado, Idaho, Utah, Vermont, and Washington) had AVF rates that were 70% or higher.

Grievances, Involuntary Discharges, and Sanctions in 2013

The 18 ESRD Networks processed 2,238 beneficiary grievances in 2013, with an average rate of 5.04 grievances per 1,000 dialysis patients. Only four of the 18 Networks reported a rate greater than 5.0 grievances per 1,000 patients. See Table 16 for Network-specific data. The 18 Networks processed 411 involuntary discharge (IVD) cases in 2013, seven more than in 2012. Of the 18 Networks, eight reported 20 or fewer IVDs, while the remaining ten Networks reported from 22 to 60 IVDs. See Table 16 for Network-specific data. In addition, the Networks engaged in strategic efforts to reduce the number of IVDs. In 2013, among the 690 patients at risk of IVD, 279 (40.4%) potential IVDs were averted. Although an ESRD Network worked closely with one facility over a two-year period to address and resolve performance concerns, a sanction was recommended for this facility by the ESRD Network in 2013.

Patient Engagement

In 2013, the ESRD Networks identified approximately 180 volunteer patient representatives to participate in the Networks' Patient Engagement Learning and Action Networks (LANs). These patient representatives ensured that the patient perspective was incorporated in all Network-developed patient educational resources. At the regional level, the input from patient subject matter experts and family members or caregivers was used by the LANs to help guide Network activities. In addition, LAN members help promote and provide peer-to-peer education within dialysis units.

Emergency Management

The 2013 ESRD Network SOW defined enhanced emergency management practices and requirements for the ESRD Networks. The emergency management contractor overseeing this initiative has developed relationships with CMS emergency management professionals, and has established and fostered new relationships with components of the U.S. Department of Health and Human Services, including the Office of the Assistant Secretary for Preparedness and Response. Establishing these relationships, and continuing to enhance existing ties to the emergency community, has provided these agencies with a new awareness of the needs of the ESRD population in emergency and disaster situations that disrupt the provision of healthcare services.

ESRD Network Program Overview



In 2013, the ESRD Network Program provided services and resources to more than 443,000 dialysis patients and 17,504 new kidney transplant recipients across the United States and its territories.

The End Stage Renal Disease Network Program (ESRD Network Program) is a national program funded by the Centers for Medicare & Medicaid Services (CMS) to improve the quality of care for individuals with irreversible kidney disease who require dialysis or transplantation to sustain life. To fund this essential program, CMS withholds \$0.50 from the Medicare composite rate payment for each dialysis treatment an ESRD patient receives. This rate has remained the same since 1989. In 2013, the Program was funded for approximately \$27.6 million via these withholdings. These funds supported ESRD Network Program activities such as patient and facility/provider education. In 2013, the ESRD Network Program worked to improve healthcare for 443,753 dialysis patients and 17,504 new kidney transplant recipients.

CMS contracts with the End Stage Renal Disease National Coordinating Center (ESRD NCC) to support the activities of the ESRD Networks and coordinate national initiatives. The ESRD NCC is charged with the preparation of this *ESRD Network Program Summary Annual Report*, which is distributed to the U.S. Secretary of Health and Human Services, the U.S. Congress, CMS, the ESRD Networks, and other stakeholders. The report compiles information from the Networks' Annual Reports as well as outcomes data from the ESRD NCC.

The ESRD NCC, in its support of the ESRD Network Program, also conducts national activities that include:

- Developing and distributing technical and educational materials to members of the ESRD community, including practitioners and new dialysis patients
- Collecting, analyzing, and reporting data for use by the Networks and CMS
- Providing support for the ESRD Networks, including support for the achievement of vascular access goals, reduction in rates of preventable hospitalizations, and reduction in rates of healthcare-acquired infections
- Centralizing coordination of emergency/disaster preparedness/response efforts
- Convening National Patient and Family Engagement and Clinical AIMs Learning and Action Networks (LANs).

E	FIGURE 1 SRD Network Areas
Netw ork	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



Network Requirements

The activities of the ESRD Network contractors are guided by the ESRD Network Statement of Work (SOW). Beginning in 2013, the SOW was revised to align with the U.S. Department of Health and Human Services' National Quality Strategy (NQS), CMS' three AIMs for the ESRD Network Program, and other CMS priorities designed to improve the care of individuals with ESRD.

CMS' three AIMs for the ESRD Network Program are:

- AIM 1: Better care for the individual through patient- 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 specific activities organized under each of these AIMs is influenced by a variety of individual, social, and organizational factors, including patient demographics, patients' social support networks, and aspects of the healthcare 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 are required to develop, implement, and assess interventions aimed at reducing disparities in ESRD patients' access to care and health outcomes.

The 2013 Summary Annual Report provides the first overview of ESRD Network activities that align with CMS' three AIMs for the ESRD Network Program.

Network Staffing

In 2013, the ESRD Networks reported a total of 193 full-time-equivalent staff members (FTEs). The FTE total for each Network is calculated based on the hours worked by both full-time and part-time employees.

Network staff members are charged with supporting ESRD patients and families through implementation of contract activities. Activities in 2013 focused on improving the quality of care provided to renal

In 2013, a total of 193 full-time equivalent staff members representing the 18 ESRD Networks supported 6,279 dialysis facilities and 226 transplant centers in improving the quality of care provided to renal patients across the country.

patients who receive care at 6,279 dialysis facilities (Table 1) and 226 transplant centers. Each Network had an average of 11 FTE (range = 7.20 to 21.50) staff members involved in contract activities that are focused on CMS' three AIMs for the ESRD Network Program and general requirements. Across all Networks, the largest FTE allocation was for activities that focused on issues that included patient engagement, vascular access, and healthcare-associated infections (AIM 1; mean across Networks = 3.79 FTEs); followed by AIM 3, which focused on reducing ESRD costs by improving care (mean = 2.58 FTEs); and AIM 2, which focused on improving health outcomes (mean = 1.22), and other services (mean = 0.91 FTEs). General requirements (mean = 2.26 FTEs) included responsibilities such as Network collaborations, emergency planning and response, reporting to CMS and other stakeholders, internal quality control, and performance improvement plans. Two of the 18 Networks in the ESRD Network Program implemented special projects (e.g., ESRD National Coordinating Center). These special projects are identified in the 'Other' category.

Network Governance

Each Network is required to establish and maintain, at a minimum, a Network Council (NC), a Medical Review Board (MRB), a Board of Directors, and a Patient Advisory Committee (PAC) or Patient Leadership Committee. Statutory language requires that the NC include at least two patient representatives and representatives from dialysis and transplantation providers located in the Network area. MRB membership must include at least two patient representatives 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. Each Network's Board of Directors consists of ESRD stakeholders in the Network's geographic area, and must include at least two patient representatives.

Each Network also relies on a PAC or Patient Leadership Committee to provide a patient perspective that is incorporated into Network activities. These committees focus on issues that may include patient grievances, vocational rehabilitation, or transplantation. The dialysis and transplant providers in each Network area are offered opportunities to appoint representatives to Network committees, and providers are invited to participate in these Network-organized committees. 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 Program.

Patients and Facilities

Table 1 summarizes the number of prevalent dialysis patients (443,753), the number of dialysis facilities (6,279), and the Network distribution of FTEs by CMS' three AIMs for the ESRD Network Program in 2013. Georgia, North Carolina, and South Carolina combined had the largest number of dialysis facilities (632); whereas the six New England states, had the fewest facilities (181).

Understanding 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 and hypertension. The number of incident ESRD patients (i.e., new ESRD patients in a given time period), prevalent dialysis patients (i.e., total dialysis patients at a given time point), and renal transplant patients in 2013 are summarized in following sections.

Incident ESRD Patients

Table 2 shows, for each Network and the ESRD Network Program as a whole, the number of new ESRD patients in 2013 as well as incident rates per million population for 2012 and 2013. Incidence counts are taken from the Networks' Annual Reports for 2013 and are based on CMS-2728 forms filed for new patients in 2013 and any supplementary information obtained by the Networks. Given the transfer from the Standard Information Management System to the CROWNWeb data management platform in April 2012, all comparisons between 2012 and 2013 should be interpreted with caution due to the risk of underreporting of incidence data in 2012.

The distribution of incident ESRD patients in 2013 by age category is shown in Table 3 for the 18 Network service areas and the nation as a whole. In 2013, approximately four out of five incident patients (81.8%) were 50 years of age or older, and only 1% of the incident ESRD patients were younger than 20 years of age.

In 2013, males represented more than half of the incident ESRD population (57.6%; Table 4). All Networks reported a positive ratio of males to females for the incident population.

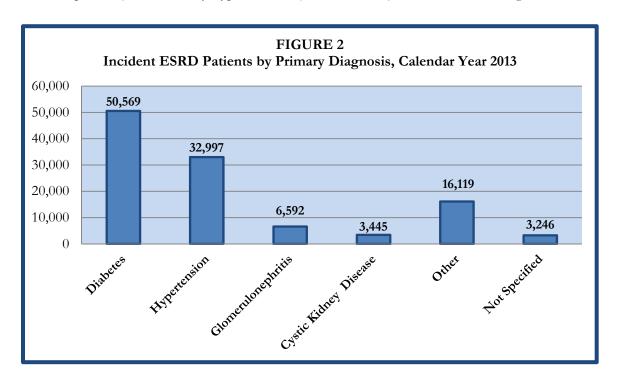
Table 5 shows the distribution of incident ESRD patients by reported "race." Findings continue to demonstrate disparities by race—i.e., a disproportionately high percentage of new patients identified as "Black or African American" relative to the proportion of individuals identified as "Black or African American" in the population as a whole. Patients identified as "Black or African American" comprised 25.8% of the total incident dialysis population in 2013. It should be noted, however, that

³ 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.

⁴ U.S. Census Bureau. *Population Estimates, National Characteristics: Vintage 2013.* Available from: http://www.census.gov/popest/data/national/asrh/2013/

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. See Table 6 for a comparison of incident ESRD patients, prevalent dialysis patients, and transplant recipients by reported race for calendar year 2013.

The leading cause of kidney failure in new ESRD patients in 2013 was diabetes (50,569, 44.8% of incident patients), followed by hypertension (32,997, 29.2%). See Table 7 and Figure 2.



Prevalent Dialysis Patients

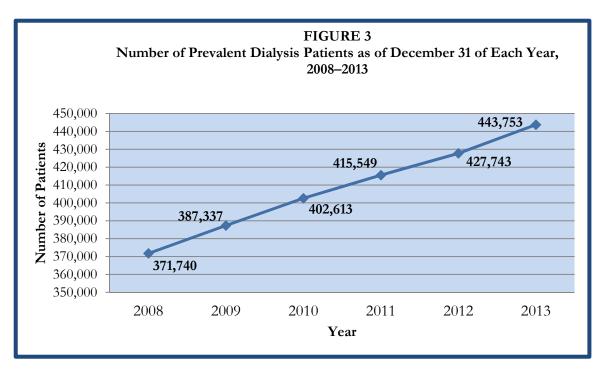
Information on prevalent dialysis patients is drawn from the CROWNWeb database that identifies all patients who are alive and on dialysis as of December 31 of the given year. At the end of 2013, 443,753 patients were receiving dialysis in the United States (Table 1) according to the Networks' Annual Reports for that year—a 3.7% increase from 2012 (Figure 3). Given the transfer from the Standard Information Management System to the CROWNWeb data management platform in April 2012, all comparisons between 2012 and 2013 should be interpreted with caution due to the risk of underreporting of prevalence data in 2012.

Table 8 shows the age distribution of prevalent dialysis patients in 2013 for the 18 Network areas. The large majority (79.3%) of patients were 50 years of age or older, and only 0.4% of prevalent dialysis patients were younger than 20 years of age in 2013.

In 2013, males represented more than half of the prevalent dialysis population (56.2%; Table 9). All Networks reported a positive ratio of males to females for the prevalent dialysis population. 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 Blacks or African Americans in the general population. Patients identified as "Black or African American" made up 35.5% of the total prevalent dialysis population as of December 31, 2013. As noted above, data on patients' race should be interpreted with caution. See Table 6 for a comparison of incident ESRD patients, prevalent dialysis patients, and transplant recipients by reported race for calendar year 2013.

Table 11 shows the distribution of prevalent dialysis patients by primary cause of ESRD for the 18 Network service areas in 2013. All Networks reported diabetes as the most frequent cause of ESRD in 2013 for prevalent patients as well as incident patients. Overall, diabetes was listed as the primary cause of ESRD for 44.2% of prevalent dialysis patients, while hypertension was listed for 28.7%.

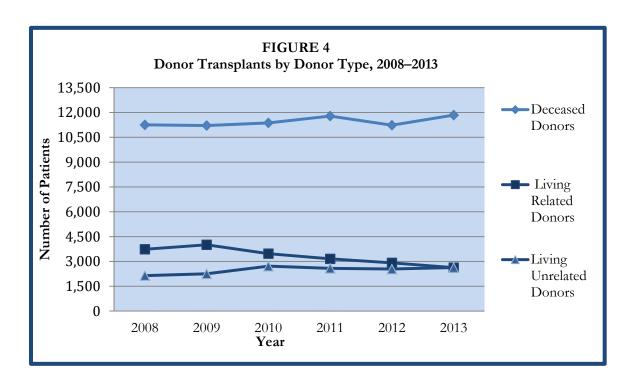


Renal Transplant Patients

In 2013, the ESRD Network Program reported a total of 17,504 renal transplants (Tables 12–15). Table 12 shows the age distribution of these transplant patients for each Network. More than two-thirds (69%) of transplant recipients in 2013 were in the 40–69 year age range; only 8% were age 70 or older, while 23% were 39 years old or younger. Data on the gender of transplant recipients in 2013 are shown in Table 13. Overall, 61% of these transplant recipients were male.

Table 14 shows the distribution of transplant recipients in 2013 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 fewer than one-quarter (23.9%) of these transplant recipients fell into the "Black or African American" category. See Table 6 for a comparison of incident ESRD patients, prevalent dialysis patients, and transplant recipients by reported race for calendar year 2013.

Table 15 shows the distribution of renal transplant recipients by donor type for 2013, and Figure 4 shows comparative data for 2008–2013.



Support for Vocational Rehabilitation and Employment

As outlined in the SOW, the Networks are required to inform patients and practitioners about vocational rehabilitation programs available in their service areas on an annual basis. Facilities are surveyed by the Networks to determine the demographics of patients aged 18–54 years who are attending school, employed, or receiving vocational rehabilitation services (see Table 23). 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
- Recognizing employers who hire ESRD patients.

AIM 1: Better Care for the Individual through Patient- and Family-Centered Care



More than 180 volunteer patient representatives participated in ESRD Network Program initiatives at the local Network level.

In addition, 54 volunteer patient representatives participated in national workgroups that supported and guided key initiatives.

Patient and Family Engagement Activities

LANs are initiatives that focus on achieving large-scale improvements associated with CMS' three AIMs for the ESRD Network Program using various change methodologies, implementation tools, or time-bounded projects. LANs create opportunities for in-depth learning and problem solving, and they provide an opportunity for stakeholders (e.g., patients, family members, healthcare providers) to harness their shared knowledge and skills in an effort to achieve specific objectives.

The ESRD Network SOW states that each Network is required to develop and facilitate a sustainable Patient Engagement LAN (PeLAN) that promotes patient and family engagement (i.e., active participation of patients and family members in healthcare decision making and planning). A PeLAN is patient-driven, with topics and activities selected by the Patient Subject Matter Experts (Patient SMEs) who serve on the LAN. These Patient SMEs are committed and informed patients who are representative of the demographic characteristics of the Network's geographic region. These SMEs provide an essential patient perspective that is used to guide Network improvement activities.

In 2013, each ESRD Network identified at least 10 volunteer patient representatives to participate in the Network's PeLAN. These patient representatives ensure that the patient perspective is incorporated in all Network-developed patient educational resources. At the regional level, the input from Patient SMEs and their family members or caregivers is used by the LAN to help guide Network activities. In addition, LAN members help promote and provide peer-to-peer education within dialysis facilities.

To facilitate CMS' commitment to patient engagement, the ESRD NCC embarked on a new national initiative to engage patients, family members, care partners, and ESRD Networks in developing an educational campaign with national impact. This initiative, known as the National Patient and Family Engagement Learning and Action Network (N-PFE LAN), officially launched nationally on July 30, 2013, with the involvement of ESRD Network PeLAN representatives and 54 volunteer patient representatives (three patients from each individual Network's PeLAN). The focus of the N-PFE LAN is to promote ESRD patients' engagement in their healthcare and ultimately

enhance their experience of care through the dissemination of ESRD-specific knowledge and resources to the patient community at large. At the national level, input from participating Patient SMEs is used in the development of national materials that are designed to improve patient care.

Meeting on a monthly basis, the N-PFE LAN supports patient discussions around resources and information the participating patient representatives identify as most important for newly diagnosed ESRD patients. In addition, these discussions identify information that is necessary for the patients' family members and other persons in the patients' lives who want to learn more about kidney disease management and how to improve the quality of life of a person with kidney disease. N-PFE LAN meetings are structured to promote collaboration among local Network PeLANs by sharing information and promoting best practices.

In August 2013, the N-PFE LAN identified three key action areas and formed workgroups to address these areas as part of a new national campaign:

- Workgroup 1: Education/Resources for New Patients
- Workgroup 2: Increasing Awareness and Education for All Patients
- Workgroup 3: Engaging and Partnering with Facilities.

In 2013, the contractor overseeing the National Patient and Family Engagement Learning and Action Network began work on a comprehensive online patient resource library that will provide easy and free access to up-to-date information on kidney disease management and care.

In 2013, members of the N-PFE LAN underscored the primacy of patient engagement by: (1) increasing opportunities for patients to connect and share resources and experiences with other patients, i.e., patient-to-patient interactions and peer mentoring; and (2) creating a national online patient resource library that houses free and up-to-date information on kidney disease management and care. Subsequently, the N-PFE LAN developed a national campaign to launch an online discussion board, social media platforms, and a patient-centered website portal to serve the entire ESRD community.

The steadfast commitment of the PeLANs and the N-PFE LAN to implement initiatives that are patient-driven helps empower patients with kidney disease, create important opportunities for these patients to become involved in their care, and improve their health outcomes.

Patient Experience of Care

Evaluate and Resolve Grievances

In 2012, CMS amended the complaints and grievance policy to require all concerns about care that does not meet a Medicare beneficiary's expectations to be classified as grievances. A grievance can be filed with the Network—by an ESRD patient, an individual representing an ESRD patient, or another party—when there is a concern that an ESRD service did not meet recognized standards of safety or civility or professionally recognized clinical standards of care.

The Networks promoted the revised CMS policy for evaluating, resolving, and reporting patient grievances to the patient community. Each Network had a grievance resolution protocol approved by CMS, which included time frames for investigating and completing the investigation, with

shortened time frames for notifying patients of the outcome of the investigation. The new policy demonstrates a stronger spirit of collaboration with State Survey Agencies, which have the authority and responsibility to ensure that facilities meet the regulations outlined in the ESRD Conditions for Coverage (CfCs).

In 2013, as directed by CMS, the Networks assisted State Survey Agencies with the investigations of grievances. Patients or other parties with grievances were encouraged, but not required, to submit their grievances in writing. Additionally, any correspondence sent to patients, or to facilities for distribution to patients, included language on how to contact the Network to file a grievance. In 2013, patients, family members, friends, patient representatives or advocates, facility employees, physicians, State Survey Agencies, and other interested parties submitted grievances concerning dialysis facilities, transplantation centers, acute care hospitals, nursing homes, home care providers, or physicians to the Network. Grievances could be submitted by mail, telephone, or e-mail. Each Network provided a toll-free number for patients' inquiries and grievances. All grievances received by the Networks were entered into an online Patient Contact Utility.

Sections 494.70 and 494.180 of the 2008 revised CfCs provide the framework for summarizing 2013 data on grievances and involuntary discharges (IVDs) for the purposes of the present report.

Grievances in 2013

In 2013, as in previous years, patients had the option to implement the grievance process at the Network or facility level. The Network option allowed patients who had concerns about potential retaliation by facility staff the opportunity to have the Network investigate their claim to protect patients' confidentiality and alleviate their concerns.

The ESRD Network Program processed 2,238 beneficiary grievances in 2013, with an average rate of 5.04 grievances per 1,000 dialysis patients. Of the 18 Networks, 14 reported a rate less than 5.0 grievances per 1,000 patients. Details related to patient grievances are confidential. See Table 16 for Network-specific data.

Promote Use of ICH-CAHPS

The In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH-CAHPS) survey affords an opportunity for hemodialysis

In support of ESRD patients, the ESRD Network Program processed more than 2,200 formal beneficiary grievances in 2013, with an average rate of 5.04 grievances per 1,000 dialysis patients. Of the 18

Networks, 14 reported a rate less than 5.0 grievances per 1,000 patients.

patients to evaluate their healthcare experiences in domains such as practitioners' communication skills and ease of access to healthcare services. As part of the 2013 ESRD Quality Incentive Program (ESRD QIP), ESRD Networks promoted for the first time the use of the ICH-CAHPS survey in outpatient hemodialysis facilities and several Networks gathered preliminary surveillance data to assess facilities' planning and completion efforts. Overall, eight of the 18 Networks reported high ICH-CAHPS participation rates (range 97% to 100% over the eight Networks) in 2013.

Recommendations for Sanctions in 2013

In 2013, one sanction recommendation was submitted to CMS by an ESRD Network with more than 6,200 dialysis facilities. This sanction recommendation represents approximately 0.02% of all facilities.



In 2013, nine of the eighteen Networks did not report any instances of failure to place patients. The remaining nine Networks reported a total of 82 cases. This total is equivalent to 0.02% of the total dialysis population.

Patient-Appropriate Access to Dialysis Care

Networks Address Involuntary Discharges, Involuntary Transfers, and Failures to Place The following are CMS definitions of involuntary discharge (IVD), involuntary transfer (IVT), and failure to place.

Involuntary Discharge: A situation in which, consistent with 42 CFR §494.180(f), a patient is informed in writing that treatment at a dialysis facility will terminate in 30 days; or a situation in which the dialysis facility notifies the Network and State Survey Agency that it is following an abbreviated termination procedure for a patient who has made an immediate severe threat of physical harm.

Involuntary Transfer: A situation in which a patient who is registered to receive dialysis treatment at one dialysis facility is dissatisfied with being transferred to another dialysis facility when the transferring facility temporarily or permanently ceases to operate or exist, due to a merger, an emergency or disaster situation, or other circumstances. See 42 CFR §§494.70(b) and 494.180(f).

Failure to Place: A situation in which no outpatient dialysis facility can be identified to accept an ESRD patient for routine dialysis treatment. This may include situations in which a transient patient has been refused admission to a dialysis facility for a reason that violates the ESRD CfCs. An involuntary discharge may, but does not necessarily, lead to a failure to place.

Involuntary Discharges

IVDs present substantial challenges for the ESRD Network Program. In an effort to respond to these challenges, the ESRD community implemented a national, multi-year initiative to educate and provide resources to staff at dialysis facilities to help them effectively address conflicts between patients and care providers. Participants in this national initiative developed a Decreasing Dialysis Patient-Provider Conflict (DPC) taxonomy, manual, and toolkit. Information about the toolkit is available at http://esrdncc.org/decreasing-dialysis-patient-provider-conflict

Working on behalf of the ESRD Network Program, the Networks continue to educate dialysis facility staff about ways to identify potential conflicts and about the use of therapeutic communication techniques with patients and their families. There is an increased focus on reducing or averting IVDs by providing staff with materials and resources to help them work effectively with patients. In 2013, Networks used a variety of tactics to address and prevent conflicts between facility staff and patients, including developing print and electronic materials focused on education and prevention of IVDs; implementing 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 and to identify potential patterns of discrimination or unequal access to care; and providing training sessions for dialysis facility staff.

Involuntary Discharges in 2013

ESRD Network Program staff processed 411 IVD cases in 2013, seven more cases than were processed in 2012. Of the 18 Networks, eight reported 20 or fewer IVDs, while the remaining Networks reported from 22 to 60 IVDs. Of the 18 Networks, nine reported involuntary discharges below the mean rate of 0.93 per 1,000 patients. See Table 16 for Network-specific data. In addition, the Networks engaged in strategic efforts to reduce the number of IVDs. In 2013, of the 690 patients at risk, IVDs were averted for 279 patients (40.4%).

Involuntary Transfers in 2013

ESRD Network Program staff worked diligently in 2013 to address IVTs. The Networks' focused efforts to provide education and mediation before a patient situation rose to a level of possible transfer could explain how 13 of the 18 Networks did not report any IVTs in 2013. One Network reported an unusually high number of IVTs (101) because its dialysis patients were receiving care in facilities that were closed either temporarily or permanently after weather-related disasters (i.e., multiple tornados in the Network's geographic region) in May 2013. CMS continues to closely monitor IVTs that occur as a result of mergers and acquisitions in order to evaluate how these organizational changes affect patient care.

Failure to Place in 2013

Failure to place ESRD patients is an important concern for CMS and the ESRD Network Program. The ability to provide access to care to challenging or complex patients requires a concerted effort among the Networks, hospital discharge planners, the care team, and dialysis practitioners. In 2013, nine of 18 Networks did not report any instances of failure to place. The remaining nine Networks reported a total of 82 cases. This number is equivalent to 0.02% of the total population for 2013.

Vascular Access Management

Hemodialysis requires repeated vascular access to large blood vessels capable of effectively removing wastes from the blood. The three forms of vascular access are arteriovenous fistula (AVF), arteriovenous (AV) graft, and central venous catheter. 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 for adequate blood flow to support hemodialysis and 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, an AVF 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 in the neck with the tip resting in the heart. Catheters should be viewed as a "bridge" to an AVF or AVG while a permanent access is maturing or healing or as a permanent access in patients who have exhausted other options or whose clinical condition precludes the placement of an AVF or AVG. 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.⁵

In 2013, the Fistula First Catheter Last Workgroup Coalition (FFCL) was established to build on the success of the Fistula First Breakthrough Initiative but with a specific focus on hemodialysis catheter reduction as well as continuing to increase the number and percentage of AVFs in use. The FFCL is comprised of representatives from the ESRD Network Program, subject matter experts, access experts, dialysis providers, patients and other stakeholders. The four workgroups include: (1) FFCL Data Committee, (2) Access Monitoring, (3) Access Planning and Coordination, and (4) Access Infection Prevention. The ESRD Network Program has undertaken strategic efforts to reduce long-term catheter use (90 days or longer) in order to reduce the risk of mortality and improve the quality of life of hemodialysis patients.

CMS established bold goals for vascular access with the 2013 SOW. Specifically, the CMS goal was that at least 68% of ESRD patients would use AVFs for vascular access. In addition, CMS set a target maximum goal of 10% for the percentage of patients with tunneled hemodialysis catheters in place for 90 days or longer. The 2013 SOW called for Networks to increase their efforts to encourage and support the use of AVFs and decrease the use of catheters.



As of December 2013, 12 states (Arizona, Colorado, Idaho, New Hampshire, New Mexico, Oklahoma, Oregon, North Dakota, South Dakota, Utah, Vermont, and Washington) exceeded the 68% national goal of AVF in use. Five of these U.S. states (Colorado, Idaho, Utah, Vermont, and Washington) had AVF in use rates that were 70% or higher.

In March 2013, the FFCL Data Committee, made up of Network data managers and quality improvement directors working on behalf of the ESRD NCC, began work on the development of data files to show vascular access outcomes. In addition, the FFCL Data Committee identified areas in which to improve data accuracy and completeness and provided guidance on requirements for worksheets and reports needed by the Networks and the FFCL Workgroup Coalition. This led to

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⁵ 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.

the release of information to the ESRD Network community on a scheduled basis to show outcomes for the nation, ESRD Networks, states, and dialysis providers. In addition, this enabled the Networks to identify and work with the low performing clinics to address improvement in vascular access outcomes. The first release of data was in August 2013; however, it was provided only to the Network community in its first phase.

The data in Table 17 show that the national average AVF rate was 62.3% as of the end of 2013, which represents a 1.2 percentage point increase from 2012. Also, the national long-term catheter rate (i.e., catheters in place 90 or more days) was 9.22% (Table 18). As shown in Table 17, 17 out of 18 Networks reported an increase in the rate of AVF use among in-center and home hemodialysis patients as of December 31, 2013, relative to each Network's December 2012 rate.

As of December 2013, 15 Networks exceeded the 60% threshold for AVFs in use among in-center and home hemodialysis patients. In addition, 12 states (Arizona, Colorado, Idaho, New Hampshire, New Mexico, Oklahoma, Oregon, North Dakota, South Dakota, Utah, Vermont, and Washington) exceeded the 68% national goal, according to Fistula First Catheter Last (FFCL) data. Five of these states (Colorado, Idaho, Utah, Vermont, and Washington) had AVF rates that were 70% or higher.

Patient Safety: Healthcare-Associated Infections (HAIs)

Support National Healthcare Safety Network (NHSN), Establish Healthcare-Associated Infection Learning and Action Network (HAI LAN), and Reduce Rates of Dialysis Events In 2012, the Secretary of Health and Human Services launched the *Partnership for Patients* campaign. The aim of this campaign is to reduce the prevalence of adverse healthcare-associated conditions. All ESRD Networks are charged with establishing strategies in accordance with the requirement to reduce the occurrence of adverse healthcare-associated conditions among dialysis patients, as specified in the Networks' 2013 SOW.

HAIs are associated with high rates of morbidity and mortality in the general patient population, and billions of dollars in healthcare expenditures each year. ESRD patients are particularly vulnerable to HAIs, given that their treatment regimen requires an access point so that wastes can be removed from their blood over the course of several hours. This is an especially critical issue for patients who use a central venous catheter as their dialysis access.

CDC has established a national health surveillance system called the National Healthcare Safety Network (NHSN). This surveillance system provides a platform for tracking and reporting of bloodstream infections so that Networks can easily identify facilities that have high rates of this type of dialysis event and implement quality improvement efforts to reduce their occurrence.

In 2013, ESRD Networks assisted dialysis facilities by supporting NHSN enrollment through HAI Learning and Action Networks (LANs), establishing monthly reporting of dialysis events, and assisting facilities with data entry so that dialysis events were entered accurately and in a timely manner. One Network, for example, has shown a noteworthy outcome related to reducing vascular access-related infection rates in a specific geographic locale over a multi-year period. Specifically, ongoing collaborations among Network staff, HAI LAN members, dialysis staff, and patients resulted in a decrease from 8.0 episodes of vascular access-related infections per 100 patient months for dialysis patients in 2010 to 3.1 episodes per 100 patient months in 2013. The 2010 rate was

nearly three times the national rate of 2.85 for that year. Given the ESRD patient population of the geographic locale being examined (estimated dialysis patient population N=5,000), vascular access-related infections decreased from 401 patients per month in 2010 to 156 per month in 2013. This translates into 245 fewer vascular access-related infections per month or 2,940 fewer infections per year in 2013 compared with 2010.

AIM 2: Better Health for the ESRD Population



Seven of the eighteen Networks selected the Health Innovation Pilot
Project focused on Improving Transplant Coordination to enhance the quality of life of ESRD patients.

Network Innovation Pilot Projects

CMS required each Network to develop a Population Health Innovation Pilot Project to promote better health in the ESRD population. Networks were required to select their projects from the following CMS-approved priorities: Increase Hepatitis B and Pneumococcal Pneumonia Vaccination Rates; Improve Dialysis Care Coordination with a Focus on Reducing Hospital Utilization; Improve Transplant Coordination; Promote Appropriate Home Dialysis in Qualified Patients; and Support Improvement in Quality of Life. In carrying out this work, each Network was tasked with applying the following attributes to its identified Innovation Pilot Project:

- 1) Customer Focus and Value of the Quality Improvement Activities to Patients, Participants, and CMS: Each Network is required to meet its customers' needs by soliciting feedback from patients and other stakeholders and using this feedback to inform its quality improvement initiatives.
- 2) Ability to Prepare the Field to Sustain the Improvement: At the onset of project development, each Network is tasked with establishing a sustainability plan that outlines how the project will continue after the Network is no longer actively involved.
- 3) Value Placed on Innovation: Each Network is required to apply innovative approaches based on recommendations and ideas gained from working with identified participants and to develop new tools or interventions that benefit all participants.
- 4) Commitment to Boundarilessness: Upon implementation of the project, the Network must demonstrate its ability to identify and involve outside groups and organizations to support the project.
- 5) Unconditional Teamwork: In its commitment to boundarilessness, the Network is required to demonstrate the project's reach and how it disseminates best practices to stakeholders, including other Networks.
- 6) Rapid Cycle Improvement in Quality Improvement Activities and Outputs: On a routine basis, each Network is required to evaluate and assess the value of the identified interventions and make appropriate adjustments based on available information and feedback from project participants.

Population Health Innovation Pilot Projects

Increase Hepatitis B and Pneumococcal Pneumonia Vaccination

In 2013, five of the 18 ESRD Networks selected a focus on Increased Hepatitis B and Pneumococcal Pneumonia Vaccination Rates for their Population Health Innovation Pilot Projects.

CMS requires that each Network conduct a disparity assessment to determine its project topic based on the following comparisons: race (African American versus White or race other than White versus White); ethnicity (Hispanic versus Non-Hispanic); facility location (rural versus urban); gender (female versus male); and age (65 years and older versus younger than 65 years). The goal of this work is to increase hepatitis B and pneumococcal vaccination rates among eligible dialysis patients by 5 percentage points. The Networks started development of this work in 2013, with planned implementation and analysis in 2014.

Improve Dialysis Care Coordination with a Focus on Reducing Hospital Utilization

One Network identified eight target facilities, using the disparity of urban compared with rural, to examine whether dialysis care coordination reduces hospitalization rates. The Network reviewed 30-day hospital readmission rates for participating facilities and provided monthly updates to CMS as required. This project is an ongoing initiative, and findings will continue to be monitored and reported to promote quality improvement in the area of hospital readmissions.

Improve Transplant Coordination

In 2013, seven of the 18 Networks focused their efforts on increasing transplant referral rates in their patient populations. In support of this effort, the seven Networks collaborated on a brochure to include patient stories representing both donor and recipient perspectives. Through the duration of this project, the Networks will continue to promote this booklet as a resource for eligible patients and will identify additional campaigns to promote transplant awareness.

Promote Access to Home Dialysis to Qualified Patients

In 2013, five of the 18 ESRD Networks selected Promotion of Home Dialysis for qualified ESRD patients as the focus of their Population Health Innovation Pilot Projects. These Networks identified qualified patients within their respective service areas and outlined strategies to expand awareness of home dialysis treatment modalities. Although the project was placed on hold until January 2014, formative efforts were undertaken by the Networks in 2013.

Tables 19–21 show the distribution of prevalent patients by treatment modality as of December 31, 2013. In-center dialysis was the predominant treatment modality in 2013 (392,400 of 443,753 prevalent patients, or 88.4%). Slight more than 11% of prevalent patients (50,179 of 443,753) used home dialysis in 2013. From 2012 to 2013, the number of home dialysis patients using hemodialysis increased 8%, the number using CCPD increased 14%, and the number of home dialysis patients on CAPD decreased 3% (see Table 20).

Support Improvement in Quality of Life

In 2013, no Networks selected this focus for their Population Health Innovation Pilot Project.

AIM 3: Reduce Costs of ESRD Care by Improving Care



The 18 Networks utilized various data sources and benchmarks to advance quality improvement efforts and cost savings for the ESRD population.

Support the ESRD Quality Incentive Program for Performance Improvement

The ESRD Quality Incentive Program (ESRD QIP) was established under the provisions of the Medicare Improvements for Patients and Providers Act (MIPPA) of 2008. This Act required CMS to develop specific measures and scoring terms to implement a payment reduction scale relative to dialysis facility performance. The ESRD QIP was CMS' first value-based purchasing (VBP) initiative that represented a shift from payment based solely on number of patients treated to one that factors in quality of treatment. A percentage of the facility's dialysis payment is contingent on the facility's performance on a specific set of measures.

The ESRD Network Program provides ongoing support to dialysis facilities by overviewing ESRD QIP requirements and offering individualized guidance to assess performance improvement on QIP-specific measures. CROWNWeb and the Centers for Disease Control and Prevention's National Healthcare Safety Network provide the necessary data to calculate facility performance.

Provide Technical Assistance to Facilities for Data Submission to CROWNWeb, NHSN, or other CMS-Designated Data Systems

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. The following summaries briefly describe the scope and type of data available to ESRD Networks and CMS in each system.

National Healthcare Safety Network

The National Healthcare Safety Network (NHSN), which was created by CDC, is a tracking system that collects and analyzes healthcare-associated infection (HAI) data from more than 13,000 medical facilities across the United States. These facilities include acute care hospitals, psychiatric hospitals, rehabilitation hospitals, outpatient dialysis centers, ambulatory surgery centers, and nursing homes. NHSN can produce facility-level and aggregate data that can be used to reduced HAIs and improve health outcomes through targeted primary and secondary prevention efforts. The ESRD Network helps facilities enroll in the NHSN and provides ongoing support so that dialysis events such as blood-stream infections can be documented and interventions can be executed to reduce the occurrence of these events in the ESRD population.

CROWNWeb

The ESRD Network Program uses CROWNWeb to obtain data on patient age, gender, ethnicity,

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

The CROWNWeb 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) form and the ESRD Death Notification (CMS-2746). See Table 22 for a Network-level summary of Medical Evidence Report and Death Notification forms processed in 2013. 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.

In 2013, the Business Requirements for ESRD Systems (BRES) contractor overseeing CROWNWeb activities reported a 75% increase in reporting capabilities. To learn more about BRES, please refer to the Special Projects section in this report.

In 2013, a total of 136,027
Medical Evidence Reports and 92,283 Death
Notification Forms were processed by ESRD
facilities using the CROWNWeb data
management system.

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 with 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. 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

The United Network for Organ Sharing (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.

Emergency Management



Emergency Management Practices and Achievements in 2013

- Implemented National Comprehensive Emergency Management Plan
- Executed First Annual Tabletop Exercise
- Developed Hazard Vulnerability Analysis

The 2013 ESRD Network Program SOW specified an enhanced role in supporting dialysis facilities and patients in preparing for an emergency incident or event. The Kidney Community Emergency Response (KCER Program) Program, coordinated by a single Network funded by CMS to serve as an emergency management contractor, provided support to the ESRD Networks to strengthen their disaster response capacity.

In 2013, the KCER Program's efforts included:

- Providing training, in compliance with federal emergency guidance and standards, for all ESRD Networks. This training provided an overview of emergency management principles, policies, and templates. The ESRD Networks were instructed on the standardization of Comprehensive Emergency Management Plans (CEMPs), Hazard Vulnerability Analyses (HVAs) and the National Incident Management System (NIMS), along with the importance of common language and use of the Incident Command System (ICS) to effectively prepare for and respond to an emergency or disaster. The development of standardized plans helped the ESRD Networks to be uniform in their emergency planning and better able to support one another in times of crisis.
- Developing documents and templates to assist the ESRD Networks in the completion of their CEMPs, HVAs, ICS planning, After-Action Reports, and Improvement Plans.
 Fourteen of the 18 ESRD Networks completed their CEMPs, ICS, and HVAs according to national protocols in 2013.
- Conducting the first annual Emergency Preparedness Exercise to address a mock emergency. This exercise, based on a power outage scenario, was developed to test the newly implemented CEMPs. Prior to implementing the mock exercise, the ESRD Networks were trained in the U.S. Department of Homeland Security Exercise and Evaluation Program protocol. The 18 ESRD Networks formed a team in conjunction with the KCER contractor to plan the national exercise and design a realistic scenario that considered the various levels of ESRD community and agency involvement in an emergency situation. Seventeen of the 18 ESRD Networks participated in the National Network Exercise to test their emergency management plans and procedures, identify gaps that required further development to improve overall preparedness, and pinpoint areas of success. The participants in this exercise benefitted from strong ESRD Network collaborations and information sharing.
- Building stakeholder relationships to strengthen interactions and obtain accurate information
 in an emergency or disaster in order to achieve optimal response and recovery. The KCER
 contractor fostered relationships with the office of the Assistant Secretary for Preparedness
 and Response to connect dialysis information and preparedness with existing federal
 protocols so that all entities would benefit from information sharing and mutual
 understandings of an emergency or disaster situation.

Special Projects



In 2013, the Business Requirements for ESRD Systems contractor was instrumental in increasing the clinical data reporting capabilities of CROWNWeb by 75%. This increase greatly facilitated real-time data sharing with CMS.

Business Requirements for ESRD Systems

CMS assigned the Business Requirements for ESRD Systems (BRES) contractor to oversee the deployment of CROWNWeb beginning in 2012.

In 2013, the BRES contractor noted the following achievements:

- Developed user guides and documentation to support implementation and continued use of CROWNWeb
- Released a new, user-friendly website that provides access to not only information about CROWNWeb and its road to implementation but also on the legacy systems used by the ESRD Network Program prior to 2012
- Developed newsletters and resources designed to aid in CROWNWeb usage
- Created a user feedback website, the CROWNWeb Portal, which gives registered users an opportunity to review questions and answers previously submitted by users
- Developed and maintained a kidney data dictionary
- Developed a log capturing all change requests in support of enhancements for CROWNWeb
- Increased CROWNWeb clinical data reporting capabilities by 75% by reducing the time needed to access, analyze, and report data to dialysis facilities.

Additionally, the BRES contractor overseeing the Network Contact Utility (NCU) also began development of a Patient Contact Utility (PCU) in early 2013. The PCU was released in July 2013 to support Network tracking of patient grievances and monitor any potential consequences that may occur as a result of the patients contact with the Network. The PCU has provided the Networks with the ability to track and trend data on grievances, IVDs, IVTs, and patients at risk for IVD and has given them a valuable tool to generate a variety of reports that can be shared with CMS and other renal stakeholders. The BRES contractor overseeing these efforts provided training to Network-level personnel on this platform in June 2013. The contractor continues to support the ESRD Network Program with enhancements based on feedback received from users of the PCU.



The New ESRD Patient Orientation Packet serves as an introduction for new ESRD patients at a critical period in their lives.

In 2013, more than 112,000 packets were distributed to ESRD patients across the nation.

ESRD National Coordinating Center

The ESRD National Coordinating Center (ESRD NCC) supports and coordinates national activities for the ESRD Network Program. The ESRD NCC's role includes:

- Developing technical and educational materials and distributing them to members of the ESRD community, including providers and new dialysis patients
- Collecting, analyzing, and reporting data for use by the Networks and CMS
- Providing support for the ESRD Networks' focus on achieving vascular access goals, reducing preventable hospitalizations, and reducing healthcare-associated infections
- Supporting the centralized coordination of emergency preparedness and response efforts
- Convening National Patient and Family Engagement Learning and Action Network.

In 2013, ESRD NCC achievements included:

- Mailing more than 112,000 New ESRD Patient Orientation Packets to ESRD patients across
 the country through a collaborative effort with CMS and the 18 ESRD Networks
- Creating patient videos focused on safety in the dialysis facility and patient and family engagement
- Working closely with the Fistula First Catheter Last Data Committee to improve accuracy and completeness of worksheets and reports needed by the Networks
- Establishing the Fistula First Catheter Last Workgroup Coalition to build on the success of the Fistula First Breakthrough Initiative, with a specific focus on reducing hemodialysis catheter reduction and increasing AVFs in use
- Creating the National Patient and Family Engagement Learning and Action Network, which
 includes 54 volunteer patient representatives who focused on patients' engagement in their
 healthcare and ultimately enhancing their experience of care
- Supporting AIM 2 Innovation Pilot Projects, the ESRD NCC provided data extracts from CROWNWeb to help facilitate project selection. By providing the same data from CROWNWeb to all Networks, consistent trending of data across projects was supported.

Contributions to Professional Literature

In 2013, authors associated with the ESRD Network Program published the following scholarly articles:

- 1. Allon M, Harbert G, Bova-Collis R, Roberts SV, Moss AH. The demented patient who declines to be dialyzed and the unhappy armed police office son: what should be done? *Clin I Am Soc Nephrol.* 2014;9(4):808-8. doi: 10.2215/CJN.08400813 (Epub 2013 Nov 14)
- 2. Mohan S, Huff E, Wish J, Lilly M, Chen S-C, McClellan WM. Recovery of renal functioning among ESRD patietns in the US Medicare program. *PLoS ONE*. 2013;3(12);e83447. doi: 10.1371/journal.pone.0083447
- 3. Moss AH, Armistead NC. Improving end-of-life care for ESRD patients: an initiative for professionals. *Nephrol News Issues*. 2013;27(10):30-2.
- 4. Patzer RE, Pastan SO. Measuring the disparity gap: quality improvement to eliminate health disparities in kidney transplantation. *Am J Transplant*. 2013;13(2):247-8. doi: 10.1111/ajt.12060

TABLE 1

Prevalent Dialysis Patients, Dialysis Facilities, and Full-Time Equivalent (FTE)

Network Staff Assigned to AIM Activities, by Function, 2013

2 27,408 259 2.80 3.00 0.70 2.00 13.00 2 3 18,317 192 1.00 4.40 0.40 2.20 0.00 8 4 18,392 305 2.03 3.13 0.43 1.55 0.08 7 5 24,949 343 3.20 3.70 1.05 1.70 0.15 9 6 42,245 632 4.40 5.35 1.45 3.80 0.00 1 7 26,431 384 2.00 2.30 1.10 1.80 2.30 9 8 25,008 404 2.70 3.75 0.75 3.30 0.00 1 9 30,323 559 1.54 4.99 1.84 2.59 0.24 1 10 18,134 273 0.64 3.02 0.83 2.67 0.24 7 11 25,447 454 2.30 5.80 0.40	Network	Number of Dialysis Patients as of December 31, 2013	Number of Dialysis Facilities in Network Area as of December 31, 2013	General Requirements FTEs	AIM 1 FTEs	AIM 2 FTEs	AIM 3 FTEs	Other	Total FTEs
3 18,317 192 1.00 4.40 0.40 2.20 0.00 8 4 18,392 305 2.03 3.13 0.43 1.55 0.08 7 5 24,949 343 3.20 3.70 1.05 1.70 0.15 9 6 42,245 632 4.40 5.35 1.45 3.80 0.00 1 7 26,431 384 2.00 2.30 1.10 1.80 2.30 9 8 25,008 404 2.70 3.75 0.75 3.30 0.00 1 9 30,323 559 1.54 4.99 1.84 2.59 0.24 1 10 18,134 273 0.64 3.02 0.83 2.67 0.24 7 11 25,447 454 2.30 5.80 0.40 4.50 0.00 1 12 15,017 302 1.65 2.90 2.80	1	13,297	181	1.60	3.20	1.00	2.20	0.00	8.00
4 18,392 305 2.03 3.13 0.43 1.55 0.08 7 5 24,949 343 3.20 3.70 1.05 1.70 0.15 9 6 42,245 632 4.40 5.35 1.45 3.80 0.00 1 7 26,431 384 2.00 2.30 1.10 1.80 2.30 9 8 25,008 404 2.70 3.75 0.75 3.30 0.00 1 9 30,323 559 1.54 4.99 1.84 2.59 0.24 1 10 18,134 273 0.64 3.02 0.83 2.67 0.24 7 11 25,447 454 2.30 5.80 0.40 4.50 0.00 1 12 15,017 302 1.65 2.90 2.80 1.60 0.25 9 13 17,499 300 1.70 4.40 0.3	2	27,408	259	2.80	3.00	0.70	2.00	13.00	21.50
5 24,949 343 3.20 3.70 1.05 1.70 0.15 9 6 42,245 632 4.40 5.35 1.45 3.80 0.00 1 7 26,431 384 2.00 2.30 1.10 1.80 2.30 9 8 25,008 404 2.70 3.75 0.75 3.30 0.00 1 9 30,323 559 1.54 4.99 1.84 2.59 0.24 1 10 18,134 273 0.64 3.02 0.83 2.67 0.24 7 11 25,447 454 2.30 5.80 0.40 4.50 0.00 1 12 15,017 302 1.65 2.90 2.80 1.60 0.25 9 13 17,499 300 1.70 4.40 0.38 2.05 0.00 8 14 42,609 568 2.85 6.09 1.	3	18,317	192	1.00	4.40	0.40	2.20	0.00	8.00
6 42,245 632 4.40 5.35 1.45 3.80 0.00 1 7 26,431 384 2.00 2.30 1.10 1.80 2.30 9 8 25,008 404 2.70 3.75 0.75 3.30 0.00 1 9 30,323 559 1.54 4.99 1.84 2.59 0.24 1 10 18,134 273 0.64 3.02 0.83 2.67 0.24 7 11 25,447 454 2.30 5.80 0.40 4.50 0.00 1 12 15,017 302 1.65 2.90 2.80 1.60 0.25 9 13 17,499 300 1.70 4.40 0.38 2.05 0.00 8 14 42,609 568 2.85 6.09 1.00 3.06 0.00 1 15 21,064 327 3.60 4.00 2	4	18,392	305	2.03	3.13	0.43	1.55	0.08	7.20
7 26,431 384 2.00 2.30 1.10 1.80 2.30 9 8 25,008 404 2.70 3.75 0.75 3.30 0.00 1 9 30,323 559 1.54 4.99 1.84 2.59 0.24 1 10 18,134 273 0.64 3.02 0.83 2.67 0.24 7 11 25,447 454 2.30 5.80 0.40 4.50 0.00 1 12 15,017 302 1.65 2.90 2.80 1.60 0.25 9 13 17,499 300 1.70 4.40 0.38 2.05 0.00 8 14 42,609 568 2.85 6.09 1.00 3.06 0.00 1 15 21,064 327 3.60 4.00 2.80 3.00 0.00 1 16 12,842 183 2.10 1.40	5	24,949	343	3.20	3.70	1.05	1.70	0.15	9.80
8 25,008 404 2.70 3.75 0.75 3.30 0.00 1 9 30,323 559 1.54 4.99 1.84 2.59 0.24 1 10 18,134 273 0.64 3.02 0.83 2.67 0.24 7 11 25,447 454 2.30 5.80 0.40 4.50 0.00 1 12 15,017 302 1.65 2.90 2.80 1.60 0.25 9 13 17,499 300 1.70 4.40 0.38 2.05 0.00 8 14 42,609 568 2.85 6.09 1.00 3.06 0.00 1 15 21,064 327 3.60 4.00 2.80 3.00 0.00 1 16 12,842 183 2.10 1.40 1.35 3.15 0.00 8 17 24,568 259 3.60 3.20 <th< th=""><th>6</th><th>42,245</th><th>632</th><th colspan="2">632 4.40 5.35 1.45</th><th>3.80</th><th>0.00</th><th>15.00</th></th<>	6	42,245	632	632 4.40 5.35 1.45		3.80	0.00	15.00	
9 30,323 559 1.54 4.99 1.84 2.59 0.24 1 10 18,134 273 0.64 3.02 0.83 2.67 0.24 7 11 25,447 454 2.30 5.80 0.40 4.50 0.00 1 12 15,017 302 1.65 2.90 2.80 1.60 0.25 9 13 17,499 300 1.70 4.40 0.38 2.05 0.00 8 14 42,609 568 2.85 6.09 1.00 3.06 0.00 1 15 21,064 327 3.60 4.00 2.80 3.00 0.00 1 16 12,842 183 2.10 1.40 1.35 3.15 0.00 8 17 24,568 259 3.60 3.20 2.10 2.50 0.00 1	7	26,431	384	2.00	2.30	1.10	1.80	2.30	9.50
10 18,134 273 0.64 3.02 0.83 2.67 0.24 7 11 25,447 454 2.30 5.80 0.40 4.50 0.00 1 12 15,017 302 1.65 2.90 2.80 1.60 0.25 9 13 17,499 300 1.70 4.40 0.38 2.05 0.00 8 14 42,609 568 2.85 6.09 1.00 3.06 0.00 1 15 21,064 327 3.60 4.00 2.80 3.00 0.00 1 16 12,842 183 2.10 1.40 1.35 3.15 0.00 8 17 24,568 259 3.60 3.20 2.10 2.50 0.00 1	8	25,008	404	2.70	3.75	0.75	3.30	0.00	10.50
11 25,447 454 2.30 5.80 0.40 4.50 0.00 1 12 15,017 302 1.65 2.90 2.80 1.60 0.25 9 13 17,499 300 1.70 4.40 0.38 2.05 0.00 8 14 42,609 568 2.85 6.09 1.00 3.06 0.00 1 15 21,064 327 3.60 4.00 2.80 3.00 0.00 1 16 12,842 183 2.10 1.40 1.35 3.15 0.00 8 17 24,568 259 3.60 3.20 2.10 2.50 0.00 1	9	30,323	559	1.54	4.99	1.84	2.59	0.24	11.20
12 15,017 302 1.65 2.90 2.80 1.60 0.25 9 13 17,499 300 1.70 4.40 0.38 2.05 0.00 8 14 42,609 568 2.85 6.09 1.00 3.06 0.00 1 15 21,064 327 3.60 4.00 2.80 3.00 0.00 1 16 12,842 183 2.10 1.40 1.35 3.15 0.00 8 17 24,568 259 3.60 3.20 2.10 2.50 0.00 1	10	18,134	273	0.64	3.02	0.83	2.67	0.24	7.40
13 17,499 300 1.70 4.40 0.38 2.05 0.00 8 14 42,609 568 2.85 6.09 1.00 3.06 0.00 1 15 21,064 327 3.60 4.00 2.80 3.00 0.00 1 16 12,842 183 2.10 1.40 1.35 3.15 0.00 8 17 24,568 259 3.60 3.20 2.10 2.50 0.00 1	11	25,447	454	2.30	5.80	0.40	4.50	0.00	13.00
14 42,609 568 2.85 6.09 1.00 3.06 0.00 1 15 21,064 327 3.60 4.00 2.80 3.00 0.00 1 16 12,842 183 2.10 1.40 1.35 3.15 0.00 8 17 24,568 259 3.60 3.20 2.10 2.50 0.00 1	12	15,017	302	1.65	2.90	2.80	1.60	0.25	9.20
15 21,064 327 3.60 4.00 2.80 3.00 0.00 1 16 12,842 183 2.10 1.40 1.35 3.15 0.00 8 17 24,568 259 3.60 3.20 2.10 2.50 0.00 1	13	17,499	300	1.70	4.40	0.38	2.05	0.00	8.53
16 12,842 183 2.10 1.40 1.35 3.15 0.00 8 17 24,568 259 3.60 3.20 2.10 2.50 0.00 1	14	42,609	568	2.85	6.09	1.00	3.06	0.00	13.00
17 24,568 259 3.60 3.20 2.10 2.50 0.00 1	15	21,064	327	3.60	4.00	2.80	3.00	0.00	13.40
7	16	12,842	183	2.10	1.40	1.35	3.15	0.00	8.00
18 40,203 354 0.90 3.60 1.50 2.70 0.10 8	17	24,568	259	3.60	3.20	2.10	2.50	0.00	11.40
	18	40,203 354 0		0.90	3.60	1.50	2.70	0.10	8.80
TOTAL 443,753 6,279 40.61 68.23 21.88 46.37 16.36 19	TOTAL	443,753	6,279	40.61	68.23	21.88	46.37	16.36	193.43
Mean 24,653 349 2.26 3.79 1.22 2.58 0.91 1	Mean	24,653	349	2.26	3.79	1.22	2.58	0.91	10.75

TABLE 2

Incident ESRD Patients, 2013, and ESRD Incidence per Million Population, 2012 Compared with 2013

Network	Number of Incident Patients, Calendar Year 2013*	Population of Network Area 2013	Incidence per Million Population 2012	Incidence per Million Population 2013
1	3,551	14,618,806	237	243
2	7,014	19,651,127	352	357
3	4,959	12,619,162	384	393
4	5,176	13,699,550	346	378
5	6,240	16,689,972	383	374
6	9,392	24,615,066	380	382
7	7,224	19,552,860	363	369
8	6,156	14,320,907	405	430
9	8,762	22,537,005	389	389
10	5,065	12,882,135	379	393
11	7,001	22,626,985	303	309
12	4,201	13,897,060	290	302
13	4,513	11,435,411	380	395
14	10,188	26,448,193	357	385
15	5,286	20,253,944	250	261
16	3,337	14,263,904	226	234
17	5,588	16,063,243	356	348
18	9,315	23,939,599	377	389
TOTAL	112,968	320,114,929	343	353

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

SOURCES: Patient data: Networks 1–18 Annual Reports, 2013. 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/2013/

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-2013/

County-level population data for California: U.S. Census Bureau, retrieved from: http://www.census.gov/popest/data/counties/totals/2013/index.html

TABLE 3

Incident ESRD Patients by Age Group (in Years), Calendar Year 2013

Network	0–19	20–29	30–39	40–49	50–59	60–69	70–79	≥80	Total Number of Incident ESRD Patients, Calendar Year 2013
1	38	70	147	288	635	891	861	621	3,551
2	64	177	331	669	1,267	1,719	1,598	1,189	7,014
3	21	86	194	476	911	1,236	1,213	822	4,959
4	42	90	191	417	907	1,277	1,323	929	5,176
5	58	125	294	640	1,219	1,638	1,445	821	6,240
6	89	236	543	1,125	1,954	2,624	1,939	882	9,392
7	78	177	288	640	1,283	1,729	1,784	1,245	7,224
8	46	131	352	674	1,299	1,740	1,332	582	6,156
9	81	171	364	762	1,607	2,311	2,118	1,348	8,762
10	41	120	230	483	949	1,229	1,169	844	5,065
11	89	155	302	653	1,263	1,807	1,604	1,128	7,001
12	52	85	175	394	783	1,092	1,000	620	4,201
13	41	122	242	528	945	1,157	969	509	4,513
14	100	230	576	1,240	2,259	2,797	1,986	1,000	10,188
15	68	116	279	614	1,035	1,326	1,230	618	5,286
16	39	83	197	299	678	853	764	424	3,337
17	58	157	265	613	1,075	1,437	1,231	752	5,588
18	88	251	426	919	1,867	2,304	1,972	1,488	9,315
TOTAL	1,093	2,582	5,396	11,434	21,936	29,167	25,538	15,822	112,968
% of Total	1.0%	2.3%	4.8%	10.1%	19.4%	25.8%	22.6%	14.0%	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, 2013.

TABLE 4

Incident ESRD Patients by Gender, Calendar Year 2013

Network	Male	Female	Total Number of Incident Patients, Calendar Year 2013
1	2,171	1,380	3,551
2	4,200	2,814	7,014
3	2,964	1,995	4,959
4	3,031	2,145	5,176
5	3,572	2,668	6,240
6	5,184	4,208	9,392
7	4,281	2,943	7,224
8	3,434	2,722	6,156
9	5,072	3,690	8,762
10	2,837	2,228	5,065
11	4,067	2,934	7,001
12	2,399	1,802	4,201
13	2,497	2,016	4,513
14	5,749	4,439	10,188
15	3,076	2,210	5,286
16	1,968	1,369	3,337
17	3,209	2,379	5,588
18	5,355	3,960	9,315
TOTAL	65,066	47,902	112,968
% of Total	57.6%	42.4%	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, 2013.

TABLE 5

Incident ESRD Patients by Reported Race, Calendar Year 2013

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 2013
1	489	2,941	111	2	8	0	3,551
2	2,059	4,424	473	17	31	10	7,014
3	1,176	3,586	183	2	6	6	4,959
4	1,214	3,880	72	0	6	4	5,176
5	2,700	3,294	217	2	7	20	6,240
6	4,860	4,281	129	42 5		75	9,392
7	2,072	4,932	159	11	11	39	7,224
8	2,806	3,261	50	13	4	22	6,156
9	1,758	6,884	69	0	3	48	8,762
10	1,405	3,405	137	2	15	101	5,065
11	1,482	5,134	187	177	12	9	7,001
12	861	3,234	58	17	2	29	4,201
13	1,779	2,529	55	130	11	9	4,513
14	2,269	7,631	250	21	4	13	10,188
15	349	4,342	198	385	6	6	5,286
16	206	2,782	238	101	5	5	3,337
17	641	3,144	1,714	26	20	43	5,588
18	1,068	7,027	1,185	16	7	12	9,315
TOTAL	29,194	76,711	5,485	964	163	451	112,968
% of Total	25.8%	67.9%	4.9%	0.9%	0.1%	0.4%	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, 2013.

TABLE 6

Incident ESRD Patients, Prevalent Dialysis Patients, and Transplant Recipients by Reported Race, 2013

Patient Category	Black or Amei		WI	nite	Asian and Native Hawaiian or Other Pacific Islander		American Indian or Alaska Multiraci Native		aiian or Other Indian or Alaska		Multiracial		Not Specified		Not Specified		Total	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%				
Incident ESRD Patients, Calendar Year 2013	29,194	25.8%	76,711	67.9%	5,485	4.9%	964	0.9%	163	0.1%	451	0.4%	112,968	100%				
Prevalent Dialysis Patients as of December 31, 2013	157,325	35.5%	256,568	57.8%	23,618	5.3%	5,217	1.2%	706	0.2%	319	0.1%	443,753	100%				
Transplant Recipients, Calendar Year 2013	4,191	23.9%	11,816	67.5%	1,029	5.9%	110	0.6%	45	0.3%	313	1.8%	17,504	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, 2013.

TABLE 7

Incident ESRD Patients by Primary Diagnosis, Calendar Year 2013

Network	Diabetes	Hypertension	Glomerulonephritis	Cystic/ Hereditary/Congenital Diseases	Interstitial Nephritis/ Pyelonephritis	Neoplasms/Tumors	Secondary GN/Vasculitis	Miscellaneous Conditions	Not Specified	Total Number of Incident ESRD Patients, Calendar Year 2013
1	1,488	780	353	188	142	114	83	351	52	3,551
2	3,029	1,823	494	229	196	178	157	718	190	7,014
3	2,473	1,422	308	119	149	81	92	296	19	4,959
4	2,234	1,497	334	156	159	146	80	467	103	5,176
5	2,407	2,207	325	166	110	130	105	457	333	6,240
6	3,822	3,328	497	244	159	176	202	608	356	9,392
7	2,957	2,543	359	216	125	171	150	498	205	7,224
8	2,612	2,202	300	147	147	136	120	395	97	6,156
9	3,885	2,290	490	277	257	195	146	949	273	8,762
10	2,030	1,824	211	107	80	74	81	328	330	5,065
11	2,800	1,843	498	325	271	196	178	835	55	7,001
12	1,778	1,125	275	131	115	114	81	378	204	4,201
13	1,934	1,504	243	128	88	67	80	280	189	4,513
14	5,554	2,776	419	266	193	149	165	484	182	10,188
15	2,539	1,324	370	198	163	113	133	374	72	5,286
16	1,491	645	289	174	150	121	101	343	23	3,337
17	2,845	1,233	349	165	150	66	96	402	282	5,588
18	4,691	2,631	478	209	168	143	121	593	281	9,315
TOTAL	50,569	32,997	6,592	3,445	2,822	2,370	2,171	8,756	3,246	112,968
% of Total	44.8%	29.2%	5.8%	3.0%	2.5%	2.1%	1.9%	7.8%	2.9%	100%

TABLE 8

Prevalent Dialysis Patients by Age Group (in Years) as of December 31, 2013

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, 2013
1	46	264	611	1,335	2,521	3,321	3,041	2,158	13,297
2	90	619	1,403	3,120	5,692	6,811	5,737	3,936	27,408
3	47	352	887	2,017	3,724	4,886	4,004	2,400	18,317
4	63	351	881	2,007	3,675	4,814	3,923	2,678	18,392
5	78	561	1,440	3,092	5,502	6,541	5,092	2,643	24,949
6	154	999	2,796	5,990	9,686	11,537	7,794	3,289	42,245
7	147	565	1,401	3,079	5,449	6,609	5,599	3,582	26,431
8	85	566	1,688	3,570	5,689	6,726	4,669	2,015	25,008
9	131	612	1,653	3,544	6,233	8,006	6,403	3,741	30,323
10	61	503	1,011	2,094	3,746	4,575	3,786	2,358	18,134
11	108	611	1,369	2,891	5,090	6,451	5,335	3,592	25,447
12	93	321	755	1,719	3,078	3,946	3,232	1,873	15,017
13	109	454	1,214	2,403	4,014	4,716	3,145	1,444	17,499
14	274	977	2,571	5,557	10,192	12,188	7,531	3,319	42,609
15	123	563	1,180	2,653	4,456	5,604	4,335	2,150	21,064
16	65	375	860	1,427	2,691	3,427	2,593	1,404	12,842
17	87	611	1,359	2,804	5,211	6,545	4,901	3,050	24,568
18	198	1,208	2,329	4,838	8,681	10,353	7,807	4,789	40,203
TOTAL	1,959	10,512	25,408	54,140	95,330	117,056	88,927	50,421	443,753
% of Total	0.4%	2.4%	5.7%	12.2%	21.5%	26.4%	20.0%	11.4%	100%

TABLE 9

Prevalent Dialysis Patients by Gender as of December 31, 2013

Network	Male	Female	Total Number of Dialysis Patients as of December 31, 2013
1	7,746	5,551	13,297
2	15,739	11,669	27,408
3	10,837	7,480	18,317
4	10,627	7,765	18,392
5	13,987	10,962	24,949
6	23,015	19,230	42,245
7	15,211	11,220	26,431
8	13,506	11,502	25,008
9	16,948	13,375	30,323
10	10,116	8,018	18,134
11	14,366	11,081	25,447
12	8,483	6,534	15,017
13	9,414	8,085	17,499
14	23,281	19,328	42,609
15	12,001	9,063	21,064
16	7,292	5,550	12,842
17	13,614	10,954	24,568
18	23,119	17,084	40,203
TOTAL	249,302	194,451	443,753
% of Total	56.2%	43.8%	100%

SOURCES: Patient data: Networks 1–18 Annual Reports, 2013.

TABLE 10

Prevalent Dialysis Patients by Reported Race as of December 31, 2013

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, 2013
1	2,772	10,021	448	25	27	4	13,297
2	10,630	14,680	1,814	101	142	41	27,408
3	5,692	11,836	612	6	161	10	18,317
4	6,416	11,661	290	8	13	4	18,392
5	14,458	9,642	784	14	15	36	24,949
6	28,054	13,443	524	185	12	27	42,245
7	10,729	15,063	543	40	36	20	26,431
8	15,265	9,451	197	85	5	5	25,008
9	10,001	19,995	264	18	27	18	30,323
10	7,081	10,408	585	4	36	20	18,134
11	8,064	15,866	737	743	26	11	25,447
12	4,468	10,195	236	89	9	20	15,017
13	9,172	7,441	225	643	18	0	17,499
14	12,105	29,442	942	82	17	21	42,609
15	2,099	15,523	904	2,510	22	6	21,064
16	1,095	10,142	1,172	415	13	5	12,842
17	3,534	12,639	8,141	145	81	28	24,568
18	5,690	29,120	5,200	104	46	43	40,203
TOTAL	157,325	256,568	23,618	5,217	706	319	443,753
% of Total	35.5%	57.8%	5.3%	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, 2013.

TABLE 11

Prevalent Dialysis Patients by Primary Diagnosis as of December 31, 2013

Network	Diabetes	Hypertension	Glomerulonephritis	Cystic/ Hereditary/Congenital Diseases	Interstitial Nephritis/ Pyelonephritis	Neoplasms/Tumors	Secondary GN/Vasculitis	Miscellaneous Conditions	Not Specified	Total Number of Dialysis Patients as of December 31, 2013
1	5,419	2,889	1,552	701	615	614	375	1,074	58	13,297
2	11,348	7,044	2,556	978	861	888	657	2,764	312	27,408
3	8,678	5,031	1,572	588	544	545	378	938	43	18,317
4	7,551	5,057	1,641	707	594	844	380	1,399	219	18,392
5	9,390	8,534	1,923	662	517	697	498	2,147	581	24,949
6	16,808	15,104	3,409	1,210	785	968	996	2,432	533	42,245
7	10,760	8,945	2,009	967	604	786	615	1,459	286	26,431
8	10,227	9,123	1,863	756	564	605	543	1,207	120	25,008
9	13,229	7,830	2,540	1,099	915	1,125	595	2,668	322	30,323
10	7,070	6,394	1,296	516	386	479	381	1,150	462	18,134
11	10,604	6,852	2,524	1,062	938	698	696	1,913	160	25,447
12	6,386	4,149	1,352	590	521	478	346	888	307	15,017
13	7,345	5,988	1,175	597	368	556	390	719	361	17,499
14	22,726	11,166	2,681	1,246	812	1,042	877	1,729	330	42,609
15	10,838	4,516	1,909	793	686	611	542	1,094	75	21,064
16	5,626	2,302	1,590	695	573	635	373	1,018	30	12,842
17	12,448	5,620	2,272	760	649	555	500	1,324	440	24,568
18	19,791	10,863	2,900	1,190	724	880	758	2,128	969	40,203
TOTAL	196,244	127,407	36,764	15,117	11,656	13,006	9,900	28,051	5,608	443,753
% of Total	44.2%	28.7%	8.3%	3.4%	2.6%	2.9%	2.2%	6.3%	1.3%	100%

TABLE 12

Renal Transplant Recipients by Age Group (in Years), Calendar Year 2013

Network	0–19	20–29	30–39	40–49	50–59	60–69	70–79	≥80	Total Number of Transplant Recipients, Calendar Year 2013
1	31	49	71	135	193	175	60	2	716
2	43	78	145	177	298	289	91	2	1,123
3	10	22	57	100	138	128	38	1	494
4	43	51	107	194	271	290	98	5	1,059
5	45	49	108	212	277	287	99	8	1,085
6	67	57	117	256	275	298	88	2	1,160
7	45	77	112	184	217	230	87	7	959
8	40	55	105	173	218	195	31	0	817
9	69	73	156	227	313	267	87	5	1,197
10	32	51	81	148	206	154	45	3	720
11	76	93	170	287	372	383	114	5	1,500
12	38	62	95	143	223	226	62	4	853
13	28	28	68	99	152	115	22	1	513
14	81	100	182	267	388	273	74	1	1,366
15	53	64	152	197	285	268	117	4	1,140
16	33	26	70	100	139	169	68	2	607
17	45	71	120	200	232	295	77	5	1,045
18	66	80	142	187	331	278	65	1	1,150
TOTAL	845	1,086	2,058	3,286	4,528	4,320	1,323	58	17,504
% of Total	4.8%	6.2%	11.8%	18.8%	25.9%	24.7%	7.6%	0.3%	100%

TABLE 13

Renal Transplant Recipients by Gender, Calendar Year 2013

Network	Male	Female	Total Number of Transplant Recipients, Calendar Year 2013
1	470	246	716
2	711	412	1,123
3	322	172	494
4	648	411	1,059
5	664	421	1,085
6	670	490	1,160
7	555	404	959
8	468	349	817
9	726	471	1,197
10	442	278	720
11	933	567	1,500
12	531	322	853
13	313	200	513
14	834	532	1,366
15	696	444	1,140
16	400	207	607
17	664	381	1,045
18	692	458	1,150
TOTAL	10,739	6,765	17,504
% of Total	61.4%	38.6%	100%

TABLE 14

Renal Transplant Recipients by Reported Race, Calendar Year 2013

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 2013
1	118	574	19	2	3	0	716
2	321	698	95	1	6	2	1,123
3	129	336	23	1	2	3	494
4	284	733	37	0	2	3	1,059
5	480	540	62	0	1	2	1,085
6	537	517	26	6	3	71	1,160
7	276	622	33	0	5	23	959
8	352	432	8	1	1	23	817
9	249	893	16	0	1	38	1,197
10	186	414	18	0	2	100	720
11	284	1,123	52	27	1	13	1,500
12	156	660	24	1	4	8	853
13	162	312	24	8	1	6	513
14	276	1,039	48	1	0	2	1,366
15	75	953	60	52	0	0	1,140
16	53	482	66	3	3	0	607
17	126	616	272	3	10	18	1,045
18	127	872	146	4	0	1	1,150
TOTAL	4,191	11,816	1,029	110	45	313	17,504
% of Total	23.9%	67.5%	5.9%	0.6%	0.3%	1.8%	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).

TABLE 15

Renal Transplant Recipients by Donor Type, Calendar Year 2013

Network	Deceased Donors	Living Related Donors	Living Unrelated Donors	Total Number of Renal Transplant Recipients, Calendar Year 2013
1	426	142	148	716
2	660	249	214	1,123
3	317	76	101	494
4	730	165	164	1,059
5	724	112	249	1,085
6	874	219	67	1,160
7	699	179	81	959
8	583	120	114	817
9	734	293	170	1,197
10	431	214	75	720
11	889	283	328	1,500
12	693	86	74	853
13	382	74	57	513
14	902	217	247	1,366
15	816	166	158	1,140
16	434	79	94	607
17	746	175	124	1,045
18	799	189	162	1,150
TOTAL	11,839	3,038	2,627	17,504

TABLE 16

Complaints, Grievances, and Involuntary Discharges, Calendar Year 2013

1		Rate of Number of Grievances per N Grievances 1,000 Prevalent Patients		Discharges	Discharges per 1,000 Prevalent Patients
	13,297	16	1.20	4	0.30
2	27,408	90	3.28	22	0.80
3	18,317	79	4.31	8	0.44
4	18,392	435	23.65	26	1.41
5	24,949	102	4.09	28	1.12
6	42,245	308	7.29	60	1.42
7	26,431	70	2.65	28	1.06
8	25,008	64	2.56	24	0.96
9	30,323	66	2.18	42	1.39
10	18,134	45	2.48	12	0.66
11	25,447	524	20.59	21	0.83
12	15,017	25	1.66	10	0.67
13	17,499	105	6.00	28	1.60
14	42,609	134	3.14	48	1.13
15	21,064	41	1.95	13	0.62
16	12,842	47	3.66	15	1.17
17	24,568	5	0.20	12	0.49
18	40,203	82	2.04	10	0.25
TOTAL	443,753	2,238		411	
Mean			5.04		0.93

SOURCE: Networks 1–18, 2013.

Number and Percent of In-Center and Home Dialysis Patients with an Arteriovenous Fistula (AVF) in Use,
December 2012 Compared with December 2013

TABLE 17

	20	012	20	013
Network	Number	Percent	Number	Percent
1	7,099	64.3%	7,356	65.3%
2	14,776	63.0%	15,489	64.0%
3	8,669	58.3%	9,724	60.2%
4	9,108	60.0%	9,560	61.5%
5	11,695	58.1%	12,508	60.6%
6	19,913	56.8%	21,328	59.4%
7	12,764	59.4%	13,410	60.4%
8	11,899	57.6%	12,448	59.4%
9	14,159	58.4%	14,735	59.6%
10	8,531	60.7%	8,287	60.5%
11	13,141	60.6%	13,748	62.4%
12	7,052	61.0%	7,370	61.2%
13	8,523	59.6%	8,610	60.5%
14	21,226	60.4%	22,528	61.8%
15	11,600	68.3%	11,950	69.2%
16	6,927	68.4%	7,330	69.3%
17	12,220	63.3%	12,528	64.8%
18	20,806	64.5%	22,372	65.7%
Weighted Mean		61.1%		62.3%
TOTAL	220,108		231,281	

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: Data for 2013 were obtained from the Fistula First Dashboard, as of September 2014.

TABLE 18
Percentage of Dialysis Access Type by Network, as of December 31, 2013

Network	AVF	AVG	Catheter ≥90 Days	Catheter Less Than 90 Days	AVF with AVG	AVF with Catheter	AVG with Catheter	Port	Other/ Unknown
1	65.3	15.0	9.3	6.3	0.2	3.2	0.8	0.01	0.00
2	64.0	15.0	11.9	6.6	0.1	2.1	0.4	0.00	0.01
3	60.2	17.4	11.3	5.9	0.2	4.3	0.8	0.01	0.02
4	61.5	16.8	9.5	6.4	0.7	4.0	1.1	0.01	0.07
5	60.6	19.6	10.2	6.2	0.1	2.7	0.6	0.01	0.01
6	59.4	24.1	7.3	5.6	0.3	2.7	0.6	0.01	0.02
7	60.4	18.7	9.5	7.0	0.3	3.3	0.8	0.02	0.02
8	59.4	21.8	7.1	6.1	0.5	3.9	1.1	0.01	0.10
9	59.6	19.2	9.3	6.9	0.2	4.0	0.9	0.01	0.04
10	60.5	17.4	10.1	7.8	0.1	3.3	0.7	0.01	0.01
11	62.4	17.1	10.4	6.6	0.2	2.7	0.5	0.01	0.02
12	61.2	17.4	9.5	7.7	0.5	2.8	0.8	0.00	0.07
13	60.5	18.3	9.3	7.1	0.3	3.8	0.7	0.01	0.05
14	61.8	20.9	7.4	6.2	0.3	2.7	0.7	0.01	0.06
15	69.2	13.2	7.8	5.6	0.3	3.4	0.6	0.01	0.01
16	69.3	12.7	8.1	5.9	0.3	3.2	0.4	0.00	0.09
17	64.8	16.8	10.8	6.2	0.1	1.1	0.2	0.02	0.00
18	65.7	16.2	9.7	6.3	0.1	1.7	0.3	0.01	0.07
National	62.3	18.3	9.2	6.4	0.2	2.9	0.6	0.01	0.04

SOURCE: Fistula First Catheter Last Dashboard.

TABLE 19
Number of In-Center Dialysis Patients as of December 31, 2012, and December 31, 2013

Network	Number of In-Center Dialysis Patients* as of December 31, 2012	Number of In-Center Dialysis Patients* as of December 31, 2013	% Change
1	11,629	11,761	1%
2	25,007	25,594	2%
3	16,659	17,113	3%
4	16,101	16,409	2%
5	21,767	22,232	2%
6	36,058	37,028	3%
7	22,550	23,282	3%
8	21,504	22,028	2%
9	25,941	26,228	1%
10	15,333	15,539	1%
11	22,298	22,652	2%
12	12,423	12,590	1%
13	15,033	15,446	3%
14	36,447	38,153	5%
15	17,979	18,482	3%
16	10,410	10,817	4%
17	20,733	21,309	3%
18	34,157	35,737	5%
TOTAL	382,029	392,400	3%

*Includes patients in training for home modalities.

SOURCE: Networks 1–18 Annual Reports, 2013. Due to changes in data sources, slight differences may exist between the 2013 counts reported above and those published in the 2012 Summary Annual Report.

TABLE 20

Number of Home Dialysis Patients by Modality as of December 31, 2012, and December 31, 2013

	Hemodialysis			Continuous Ambulatory Peritoneal Dialysis		Continuous Cycling Peritoneal Dialysis			Other Peritoneal Dialysis*		Total		
Network	2012	2013	% Change	2012	2013	% Change	2012	2013	% Change	2012	2013	2012	2013
1	164	216	32%	263	263	0%	921	1,047	14%	13	1	1,361	1,527
2	302	336	11%	426	395	-7%	939	1,035	10%	7	1	1,674	1,767
3	100	99	-1%	175	192	10%	877	911	4%	0	0	1,152	1,202
4	279	295	6%	222	258	16%	1,220	1,387	14%	1	2	1,722	1,942
5	412	481	17%	589	607	3%	1,340	1,543	15%	15	21	2,356	2,652
6	683	780	14%	856	808	-6%	3,154	3,562	13%	9	2	4,702	5,152
7	459	539	17%	429	401	-7%	1,902	2,157	13%	3	3	2,793	3,100
8	348	342	-2%	530	467	-12%	1,839	2,142	16%	6	1	2,723	2,952
9	748	809	8%	909	838	-8%	1,994	2,312	16%	3	7	3,654	3,966
10	914	964	5%	272	269	-1%	1,146	1,324	16%	0	0	2,332	2,557
11	452	484	7%	780	721	-8%	1,277	1,530	20%	0	0	2,509	2,735
12	426	443	4%	396	355	-10%	1,349	1,563	16%	1	2	2,172	2,363
13	154	165	7%	306	303	-1%	1,413	1,514	7%	6	7	1,879	1,989
14	502	552	10%	576	607	5%	2,731	3,017	10%	4	3	3,813	4,179
15	230	249	8%	407	406	0%	1,593	1,898	19%	0	1	2,230	2,554
16	343	343	0%	348	339	-3%	1,187	1,350	14%	0	0	1,878	2,032
17	307	287	-7%	570	625	10%	1,950	2,179	12%	2	1	2,829	3,092
18	380	427	12%	775	754	-3%	2,748	3,237	18%	1	0	3,904	4,418
TOTAL	7,203	7,811	8%	8,829	8,608	-3%	29,580	33,708	14%	71	52	45,683	50,179

^{*}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, 2013. Due to changes in data sources, slight differences may exist between the 2013 counts reported above and those published in the 2012 Summary Annual Report.

TABLE 21

Number of Patients Using In-Center and Home Dialysis as of December 31, 2012, and December 31, 2013

	In	-Center Dialy	sis]	Home Dialysis	s	Total			
Network	2012	2013	% Change	2012	2013	% Change	2012	2013	Total	
1	11,629	11,761	1%	1,361	1,527	12%	12,990	13,288	2%	
2	25,007	25,594	2%	1,674	1,767	6%	26,681	27,361	3%	
3	16,659	17,113	3%	1,152	1,202	4%	17,811	18,315	3%	
4	16,101	16,409	2%	1,722	1,942	13%	17,823	18,351	3%	
5	21,767	22,232	2%	2,356	2,652	13%	24,123	24,884	3%	
6	36,058	37,028	3%	4,702	5,152	10%	40,760	42,180	3%	
7	22,550	23,282	3%	2,793	3,100	11%	25,343	26,382	4%	
8	21,504	22,028	2%	2,723	2,952	8%	24,227	24,980	3%	
9	25,941	26,228	1%	3,654	3,966	9%	29,595	30,194	2%	
10	15,333	15,539	1%	2,332	2,557	10%	17,665	18,096	2%	
11	22,298	22,652	2%	2,509	2,735	9%	24,807	25,387	2%	
12	12,423	12,590	1%	2,172	2,363	9%	14,595	14,953	2%	
13	15,033	15,446	3%	1,879	1,989	6%	16,912	17,435	3%	
14	36,447	38,153	5%	3,813	4,179	10%	40,260	42,332	5%	
15	17,979	18,482	3%	2,230	2,554	15%	20,209	21,036	4%	
16	10,410	10,817	4%	1,878	2,032	8%	12,288	12,849	5%	
17	20,733	21,309	3%	2,829	3,092	9%	23,562	24,401	4%	
18	34,157	35,737	5%	3,904	4,418	13%	38,061	40,155	6%	
TOTAL	382,029	392,400	3%	45,683	50,179	10%	427,712	442,579	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 = 442,579) differs from the total prevalence reported in Tables 1, 8, 9, and 10 (N = 443,753).

SOURCE: Networks 1–18 Annual Reports, 2013. Due to changes in data sources, slight differences may exist between the 2013 counts reported above and those published in the 2012 Summary Annual Report.

TABLE 22

Data Forms Processed in Calendar Year 2013

Network	Medical Evidence Report (Form CMS-2728)	Death Notification (Form CMS-2746)	Total
1	3,551	2,536	6,087
2	8,113	5,441	13,554
3	5,808	4,140	9,948
4	6,032	4,233	10,265
5	6,626	4,566	11,192
6	20,413	13,551	33,964
7	7,658	5,322	12,980
8	7,121	4,996	12,117
9	10,041	7,141	17,182
10	5,186	3,544	8,730
11	8,192	6,105	14,297
12	4,802	3,231	8,033
13	5,195	4,085	9,280
14	11,174	7,229	18,403
15	5,963	3,615	9,578
16	3,886	2,481	6,367
17	6,133	3,667	9,800
18	10,133	6,400	16,533
TOTAL	136,027	92,283	228,310

NOTE: The notable decrease in Forms CMS-2728 and CMS-2746 processed between 2012 (data not shown) and 2013 could be the result of improved procedures to eliminate duplicate forms or potential under-reporting using the CROWNWeb data management platform.

TABLE 23

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, 2013

Network	Number of Dialysis Patients Aged 18–54 Years as of December 31, 2013	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	3,328	502	15%	32	1%	24	1%	181	72	40%
2	7,724	1,200	16%	65	1%	74	1%	259	106	41%
3	4,963	600	12%	29	1%	31	1%	192	58	30%
4	4,810	512	11%	33	1%	31	1%	305	53	17%
5	532	37	7%	1	0%	1	0%	343	75	22%
6	14,148	1,252	9%	90	1%	133	1%	632	30	5%
7	7,459	1,066	14%	110	1%	145	2%	384	59	15%
8	3,200	320	10%	10	0%	27	1%	404	26	6%
9	8,608	1,615	19%	51	1%	52	1%	559	96	17%
10	5,242	596	11%	14	0%	29	1%	273	39	14%
11	7,086	1,283	18%	192	3%	204	3%	454	83	18%
12	4,158	559	13%	25	1%	28	1%	302	29	10%
13	5,829	475	8%	15	0%	28	0%	300	26	9%
14	13,535	2,000	15%	211	2%	222	2%	568	55	10%
15	5,291	1,182	22%	11	0%	46	1%	327	79	24%
16	3,871	903	23%	104	3%	135	3%	183	84	46%
17	7,096	817	12%	1	0%	32	0%	259	71	27%
18	12,256	1,140	9%	69	1%	86	1%	354	81	23%
TOTAL	119,136	16,059	13%	1,063	1%	1,328	1%	6,279	1,122	18%

NOTE: The manner in which CROWNWeb extracted these data in 2013 may have 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 occurred in the 2012 SAR, and may reoccur in the 2014 SAR because there is an anomaly in CROWNWeb that has not been corrected so that vocational rehabilitation, employment, and school participation data can be accurately summarized from Form CMS-2744.

*Full- or part-time.