

2016

End Stage Renal Disease Network (ESRD) Organization Program Summary Annual Report



ESRD National Coordinating Center
(ESRD NCC)
www.esrdncc.org



This report was prepared Health Services Advisory Group, the 2016 ESRD NCC contractor.

Centers for Medicare & Medicaid Services (CMS) Contracting Officer Representative (COR):
Renee Dupee, JD

Suggested citation:

Centers for Medicare & Medicaid Services. End Stage Renal Disease Network Organization Program 2016 Summary Annual Report. Baltimore, MD: CMS; 2018.

Additional information:

For additional information about the ESRD Program or to review prior *Summary Annual Reports*, please visit www.esrdNCC.org or contact the NCC at NCCinfo@hsag.com or ncc@ncc.esrd.net.

This material was prepared by Health Services Advisory Group (HSAG), Inc., the ESRD NCC contractor, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy nor imply endorsement by the U.S. Government.
Pub #: FL-ESRD NCC-7N1T02-03192018-01

Publication Date: March 19, 2018



Table of Contents

Introduction	5
Report Highlights	5
ESRD Incidence and Dialysis Prevalence	5
Home Dialysis.....	5
Fistula First Catheter Last (FFCL).....	5
Grievances, Involuntary Discharges (IVDs), and Sanctions in 2016.....	6
Patient Engagement.....	6
Emergency Management.....	6
ESRD Program Funding and Definition of Service Areas	7
The ESRD NCC	7
Network Requirements.....	8
Network Staffing	8
Network Governance	9
Patient Profile	9
Patients and Facilities	9
Understanding Patient Characteristics	9
Incident ESRD Patients	10
Prevalent Dialysis Patients	11
Renal Transplant Patients	13
Vocational Rehabilitation and Employment	14
Improving Care for ESRD Patients by Increasing the Use of Permanent Accesses	15
Vascular Access	15
FFCL Workgroup Coalition	15
The Role of the Networks in Increasing AVF Placement Rates and Decreasing LTC Use Rates.....	16
Patient Safety: Network Support for the National Healthcare Safety Network (NHSN).....	17
Patient Safety: HAI LAN Events.....	18
Support for the ESRD QIP.....	19
Provider Education.....	20
Contributions to Professional Literature	20
Ensuring Data Quality	21
CROWNWeb.....	21
Veterans Health Administration and Transplant Facility Data	22
Disparities in ESRD Care.....	22
Population Health Innovation Pilot Projects (PHIPPs)	23
<i>Improve Dialysis Care Coordination with a Focus on Reducing Hospital Utilization</i>	<i>23</i>
<i>Improve Transplant Coordination</i>	<i>24</i>
<i>Promote Appropriate Home Dialysis in Qualified Patients</i>	<i>25</i>
<i>Support Improvement in Quality of Life.....</i>	<i>26</i>



Partnerships and Coalitions	26
Patient and Family Engagement	27
Education for ESRD Patients and Caregivers.....	27
Network-Specific Patient Engagement Activities.....	27
National Patient and Family Engagement Activities.....	28
Support for the ICH CAHPS Survey	30
Networks Address Involuntary Discharges (IVDs), Involuntary Transfers (IVTs), and Failures to Place (FTPs)	31
IVDs	31
Grievances and Access to Care	31
Evaluation and Resolution of Grievances	31
2016 Grievance Process and Data.....	32
Recommendations for Sanctions.....	32
Recommendations to CMS for Additional Facilities	33
Emergency Preparedness and Response	33
Special Projects	35
ESRD NCC	35
Data Tables.....	38
Table 1: Prevalent Dialysis Patients, Dialysis Facilities, and Transplant Centers in Network Area, 2016	39
Table 2: Incident ESRD Patients, 2016, and ESRD Incidence per Million Population, 2015 Compared with 2016	40
Table 3: Incident ESRD Patients by Age Group (in Years), Calendar Year 2016.....	41
Table 4: Incident ESRD Patients by Gender, Calendar Year 2016	42
Table 5: Incident ESRD Patients by Reported Race, Calendar Year 2016	43
Table 6: Incident ESRD Patients, Prevalent Dialysis Patients, and Transplant Recipients by Reported Race, 2016.....	44
Table 7: Incident ESRD Patients by Primary Cause of Renal Failure, Calendar Year 2016.....	45
Table 8: Prevalent Dialysis Patients by Age Group (in Years) as of December 31, 2016	47
Table 9: Prevalent Dialysis Patients by Gender as of December 31, 2016	48
Table 10: Prevalent Dialysis Patients by Reported Race as of December 31, 2016.....	49
Table 11: Prevalent Dialysis Patients by Primary Diagnosis as of December 31, 2016	50
Table 12: Renal Transplant Recipients by Age Group (in Years), Calendar Year 2016.....	52
Table 13: Renal Transplant Recipients by Gender, Calendar Year 2016.....	53
Table 14: Renal Transplant Recipients by Reported Race, Calendar Year 2016	54
Table 15: Transplant Events by Donor Type, Calendar Year 2016.....	55
Table 16: Number of Dialysis Patients Aged 18–54 Years, Number and Percent Employed, Number and Percent Receiving Vocational Rehabilitation Services, Number and Percent Attending School, and Number and Percent of Facilities Offering Dialysis after Regular Business Hours, as of December 31, 2016	56



Table 17: Number and Percent of In-Center and Home Dialysis Patients with an Arteriovenous Fistula (AVF) in Use, December 2015 Compared with December 2016	57
Table 18: Percentage of Dialysis Access Type by Network, as of December 31, 2016	58
Table 19: Number of In-Center Dialysis Patients as of December 31, 2015 and December 31, 2016 ...	59
Table 20: Number of Home Dialysis Patients by Modality as of December 31, 2015 and December 31, 2016	60
Table 21: Number of Patients Using In-Center and Home Dialysis as of December 31, 2015 and December 31, 2016.....	61
Table 22: Complaints, Grievances, Non-Grievance Access-to-Care Cases, and Involuntary Discharges, Calendar Year 2016.....	62



Introduction

The ESRD Network Program is a national program funded by CMS to improve the quality of care for individuals with irreversible kidney disease and who require dialysis or transplantation to sustain life. Eighteen ESRD Networks conduct the activities of the ESRD Network Program “in support of achieving national quality improvement goals and statutory requirements as set forth in Section 1881 of the Social Security Act and the Omnibus Budget Reconciliation Act of 1986.”¹ The healthcare improvement activities of the 18 ESRD Networks align with the HHS National Quality Strategy, the CMS Quality Strategy, and other CMS priorities designed to improve the care of individuals with ESRD. This report details the activities carried out by the Networks in 2016, as well as information on prevalence and incidence of ESRD, kidney transplantation, ESRD-related grievances, dialysis access types, dialysis types, data forms, and employment. The report highlights Network Program activities conducted in 2016 overall and then provides detailed descriptions of Network activities and data tables by Network.

Report Highlights

ESRD Incidence and Dialysis Prevalence

The rate of newly occurring cases of ESRD, i.e., incident ESRD patients, in the United States (U.S.) increased from 366 per million population in 2015 to 386 per million population in 2016, according to ESRD Network Program data. There was considerable variation in ESRD incidence across the 18 ESRD Networks’ geographic areas in 2016; from 254 patients per million population to 476 per million population. The ESRD Networks reported a 3.5% increase in the prevalent dialysis population, i.e., the total number of dialysis patients, between December 31, 2015 and December 31, 2016.

Home Dialysis

Following recent trends, the use of home hemodialysis (HD) increased by 3.9% from 2015 to 2016. It is expected that more dialysis patients will choose home dialysis as their modality in the future, as it has been linked to better clinical and psychosocial outcomes.

Fistula First Catheter Last (FFCL)

The national rate for arteriovenous fistulas (AVFs) in use among in-center and home HD patients declined slightly in 2016, to 61.8% from 62.3% in 2015. This likely reflects the shifting focus in the renal community to increase the rate of AVFs in use and decreasing the rate of long-term catheter (LTC) use. According to FFCL data as of December 2016, 11 of 18 Networks (61.1%) exceeded the 60.0% threshold for AVFs in use among in-center and home HD patients, and Network 15 exceeded the 68.0% national goal.

¹ Centers for Medicare & Medicaid Services. ESRD Network Statement of Work. C.1 Purpose of the SOW. February 25, 2016.



Grievances, Involuntary Discharges (IVDs), and Sanctions in 2016

The 18 ESRD Networks processed 1,872 beneficiary grievances in 2016, with an average rate of 3.8 grievances per 1,000 dialysis patients. Sixteen of the 18 Networks (88.9%) reported a rate lower than 5.0 grievances per 1,000 patients. Of the 1,872 grievance cases reported, 109 (5.8%) involved an access-to-care issue. The 18 Networks processed 47 grievances involving IVD cases, with 16 (88.9%) reporting five or fewer IVDs. Thirteen of the 18 Networks (72.2%) reported IVD rates that were lower than the mean rate of 0.09 per 1,000 patients. There were no Network recommendations for CMS to impose a sanction on any facility in 2016.

Patient Engagement

In 2016, the ESRD Networks recruited approximately 180 volunteer patient and family/caregiver representatives to provide input into Network activities and ensure that the patient perspective was incorporated in all Network-developed patient educational resources. Patient SMEs also helped to promote and provide peer-to-peer education within the dialysis units. Networks also recruited patients who wanted to serve at the national level as part of the ESRD NCC National Patient and Family Engagement Learning and Action Network (NPFE LAN). The NPFE LAN brings together healthcare professionals, patients, and other stakeholders to achieve rapid-cycle improvement; to create opportunities for in-depth learning and problem solving; and to harness their shared knowledge and skills in an effort to achieve specific Program-wide objectives.

Emergency Management

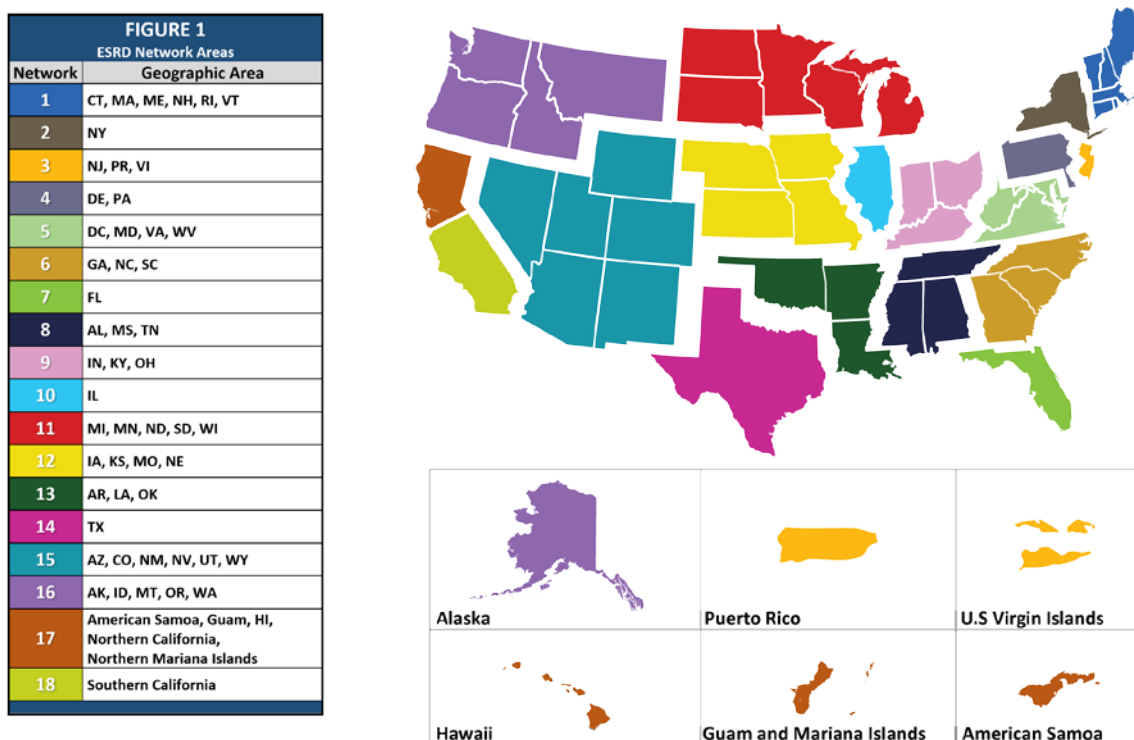
CMS enhanced its focus on emergency management practices and requirements for the ESRD Networks during 2016. On a national level, the Kidney Community Emergency Response Program (KCER) continued to expand relationships with CMS emergency management professionals and the Office of the Assistant Secretary for Preparedness and Response (ASPR) of HHS. On regional, state, and local levels, the ESRD Networks continued to engage in outreach, training, and technical assistance activities to help ensure that the needs of ESRD patients were met in emergency situations. In 2016, the Networks responded to over 80 incidents, including severe weather, tropical weather systems, gas leaks, chemical spills, earthquakes, and wildfires, that had the potential to impact ESRD patients and/or providers.

ESRD Program Funding and Definition of Service Areas

CMS funds the ESRD Network Program by withholding \$0.50 from the Medicare composite rate payment for each dialysis treatment received by an ESRD patient. This rate has remained the same since 1989. These withheld funds support ESRD Network Program activities, including patient and dialysis staff member education.

The 18 ESRD Networks serve the 50 states, the District of Columbia, and the U.S. territories of Puerto Rico, the Virgin Islands, American Samoa, Guam, and the Northern Mariana Islands (see Figure 1). In 2016, the ESRD Networks worked to improve healthcare for approximately 496,000 dialysis patients and almost 20,000 kidney transplant recipients. The number of patients receiving ESRD treatment as of December 31, 2016, was 3.5% higher than the comparable number for 2015.

Figure 1



The ESRD NCC

The ESRD NCC assists CMS in supporting ESRD Network activities and coordinates initiatives on a national scope that include:

- Convening NPFE and Clinical AIM LANs.
- Collecting, analyzing, and reporting data for use by the Networks and CMS.
- Providing support for the ESRD Networks. For example:
 - Achievement of vascular access goals.
 - Reduction in rates of preventable hospitalizations.



- Reduction in rates of healthcare-associated infections (HAIs).
- Developing and distributing technical and educational materials to members of the ESRD community, including practitioners and new dialysis patients.

The ESRD NCC also prepares the *ESRD Network Program Summary Annual Report* (this document), which is distributed to the U.S. Secretary of HHS, the U.S. Congress, CMS, the ESRD Networks, and other stakeholders. The report compiles information from the Networks' Annual Reports, as well as data from the ESRD NCC.

Network Requirements

The activities of the ESRD Network contractors are guided by the ESRD Network Statement of Work (SOW). In 2013, the SOW was revised to align with the HHS National Quality Strategy, CMS' three AIMs for the ESRD Network Program, and other CMS priorities designed to improve the care of individuals with ESRD.

In 2016, the CMS three AIMs for the ESRD Network Program were:

- 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 ESRD Networks are charged with promoting positive change relative to the three AIMs. The achievement of specific goals under each AIM is influenced by numerous factors, including patient characteristics, such as age and comorbid conditions; patients' social support networks; and aspects of the healthcare delivery system. To address these varied influences on ESRD care, each Network is charged with targeting disparities when conducting all of the activities outlined in the SOW; the Networks must develop, implement, and assess interventions aimed at reducing disparities in ESRD patients' access to care, quality of care, and health outcomes.

Network Staffing

Network staff members provide support to ESRD patients and families, providers, and health professionals. Network contract activities support almost 7,000 dialysis facilities and more than 200 transplant centers across the U.S. and its territories (Table 1 in the Data Tables section of this document). CMS requires each Network to employ an Executive Director to oversee administration of all contract requirements and overall operation of the Network. The Executive Director is to have professional relationships within the ESRD community, as well as expertise in administration of the CMS contract, management and supervision of staff, and fiscal oversight of the Network.

Support staff, including a registered nurse with nephrology experience and other personnel with experience in program planning, implementation, data analysis, and evaluation, are utilized to conduct the activities and assume the responsibilities outlined in the Network contracts and other CMS directives. Job titles, specific responsibilities, and the number of support staff vary from Network to Network.

Network Governance

Each Network must establish and maintain a Network Council (NC), Board of Directors (BOD), Medical Review Board (MRB), and Patient Advisory Committee (PAC). Networks have the option of establishing additional committees as necessary. The responsibilities and composition of each mandatory board or committee are outlined below:

- The NC must include at least two patient representatives, as well as representatives from dialysis and transplantation providers located in the Network area. The NC meets at least annually to provide input on Network activities and serve as a liaison between the Network and providers.
- The BOD must include at least two patient representatives and sets overall policy and direction for the Network; it retains oversight responsibility. The BOD is also reviews and approves any recommendations from the MRB for sanctions to be imposed on ESRD facilities prior to submission of these recommendations to CMS.
- The MRB is made up of at least two patient representatives and a mix of ESRD professionals, typically nephrologists, surgeons, physician assistants, nurses, social workers, and dietitians, who are qualified to evaluate the quality and appropriateness of renal care. The MRB serves as an expert panel on patient quality of care issues.
- The PAC ensures that the patient perspective is incorporated into all Network activities and is instrumental in providing input into the development of informational and educational materials for patients and families/caregivers. The members must be representative of the diversity of the ESRD population in the Network service area.

The dialysis and transplant providers in each Network area are invited to appoint patient representatives to the Network boards and committees, and practitioners are encouraged to participate in Network-organized committees. Participants in these organizations offer their time on a volunteer basis and provide invaluable hours of service to the Networks. The contributions of these members as a whole is a critical part of the effective functioning of the Networks and the success of the ESRD Network Program.

Patient Profile

Patients and Facilities

Table 1 (in the Data Tables section of this document) provides an overview of the number of prevalent dialysis patients (496,201) and the number of dialysis facilities (6,965) covered by the ESRD Network Program as of December 31, 2016. Network 6, comprised of the states of Georgia, North Carolina, and South Carolina, served the largest number of dialysis facilities (707). Network 1, the New England region comprised of the states of Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont had the fewest facilities (194).

Understanding Patient Characteristics

CMS defines 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. adult population is high, with an estimate of more than 14% of adults affected.² This is attributable, in part, to high rates of diabetes and hypertension in the adult population. Information about 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 point in time), and new renal transplant patients in 2016 is highlighted in the following sections.

Incident ESRD Patients

According to ESRD Network Program data, there were 126,210 new ESRD patients in 2016. Table 2 (in the Data Tables section of this document) shows the number of new ESRD patients in 2016 for each Network service area and the ESRD Network Program as a whole, as well as incident rates per million population for 2015 and 2016. Incident patient counts are taken from the Networks' 2016 Annual Reports and are based on all CMS-2728 forms submitted in 2016 for new patients, as well as any supplementary information obtained by the Networks.

Table 3 (in the Data Tables section of this document) provides the distribution of incident ESRD patients in 2016 by age for the 18 Network service areas and for the nation as a whole. In 2016, approximately four of five incident patients (81.6%) were 50 years of age or older, and under 1 percent (0.9%) of the incident ESRD patients were younger than 20 years of age.

In 2016, the leading causes of kidney failure in new ESRD patients in the U.S. were diabetes (59,038, 46.8% of new patients) and hypertension (35,450, 28.1% of new patients).

In 2016, males represented more than half of the incident ESRD population (57.8%), as outlined in Table 4 (in the Data Tables section of this document). All Networks reported a positive ratio of males to females for the incident population.

Table 5 (in the Data Tables section of this document) illustrates 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 25.3% of the total incident dialysis population in 2016, compared to 12.6% of the general population.³

It should be noted, however, that national and Network-specific race data should be interpreted with caution because of the inherent instability of such data. Form CMS-2728 also collects data on Hispanic ethnicity, but CMS does not currently require the Networks to report this information. Table 6 (in the Data Tables section of this document) shows a comparison of

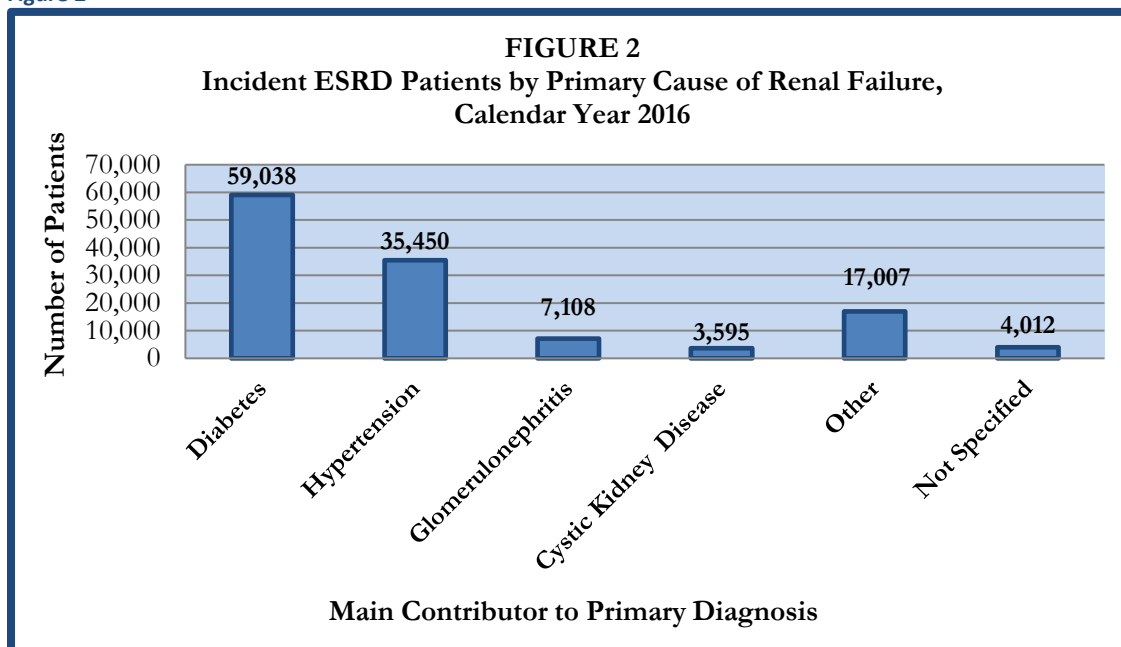
² United States Renal Data System. *2015 USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States*. Bethesda, MD: National Institute of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2015.

³ U.S. Census Bureau. *Population Estimates, National Characteristics: Vintage 2016*. Available at: <https://www.census.gov/programs-surveys/popest.html>

incident ESRD patients, prevalent dialysis patients, and transplant recipients by reported race for calendar year 2016.

In calendar year 2016, the leading causes of kidney failure in new ESRD patients in the U.S. were diabetes (59,038, 46.8% of new patients) and hypertension (35,450, 28.1% of new patients). See Figure 2 (below) and Table 7 (in the Data Tables section of this document).

Figure 2



Prevalent Dialysis Patients

Information on prevalent dialysis patients is drawn from the Consolidated Renal Operations in a Web-Enabled Network (CROWNWeb) database that identifies all patients who are alive and on dialysis as of December 31 of the given year. At the end of 2016, 496,201 patients were receiving dialysis in the U.S. (Table 1 [in the Data Tables section of this document]), according to the Networks’ Annual Reports—a 3.5% increase from 2015 (Figure 3).

Figure 3

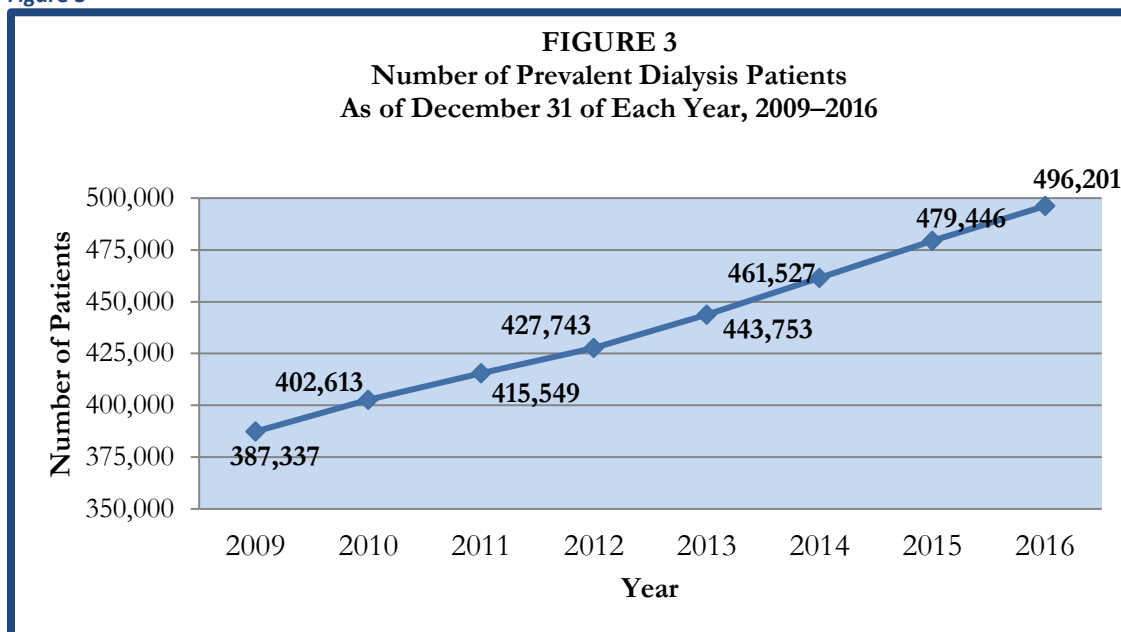


Table 8 (in the Data Tables section of this document) shows the age distribution of prevalent dialysis patients in 2016 for the 18 Network areas. The majority (80.3%) of patients were 50 years of age or older, and only 0.4% of prevalent dialysis patients were younger than 20 years of age in 2016.

In 2016, males represented more than half of the prevalent dialysis population (57.0%) as reported in Table 9 (in the Data Tables section of this document). All Networks reported a positive ratio of males to females for the prevalent dialysis population.

At the end of 2016, 496,201 patients were receiving dialysis in the U.S., according to the Networks' Annual Reports—a 3.5% increase from 2015.

Table 10 (in the Data Tables section of this document) 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 comprised 34.4% of the total prevalent dialysis population as of December 31, 2016, while residents identified as black or African American comprised 12.6% of the general population.⁴ As noted above, data on patients' race should be interpreted with caution. See Table 6 (in the Data Tables section of this

⁴ U.S. Census Bureau. *Population Estimates, National Characteristics: Vintage 2016*. Available at: <https://www.census.gov/programs-surveys/popest.html>

document) for a comparison of incident ESRD patients, prevalent dialysis patients, and transplant recipients by reported race for calendar year (CY) 2016.

Table 11 (in the Data Tables section of this document) shows the distribution of prevalent dialysis patients by primary cause of ESRD for the 18 Network service areas in 2016. All Networks reported diabetes as the most frequent cause of ESRD for prevalent patients, as well as incident patients. Overall, diabetes was listed as the primary cause of ESRD for 45.5% of prevalent dialysis patients, while hypertension was listed for 29.3%.

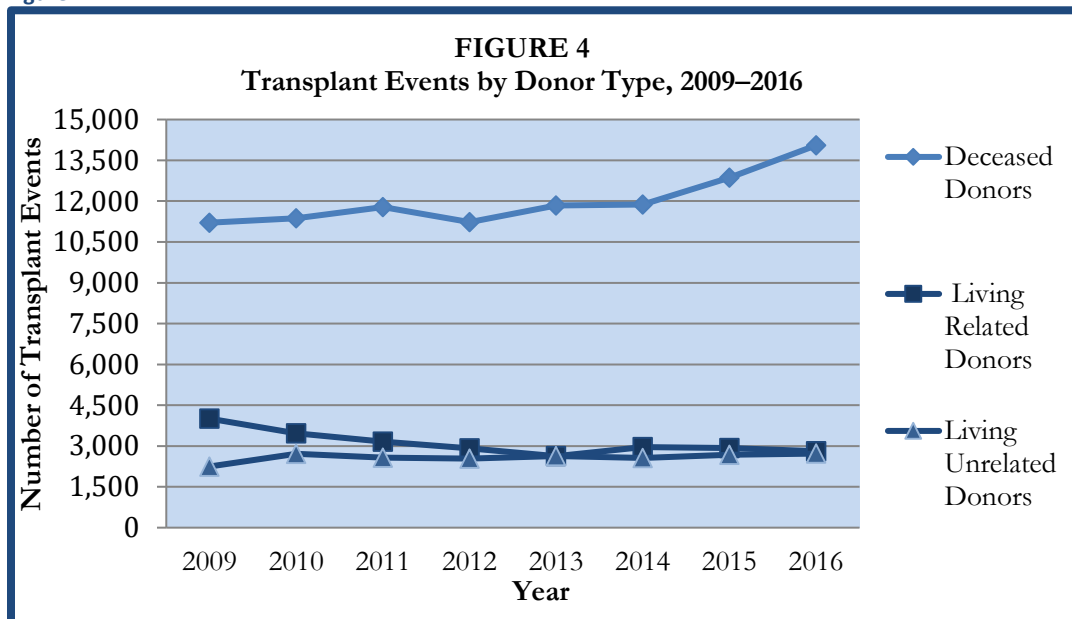
Renal Transplant Patients

In 2016, the ESRD Network Program reported a total of 19,533 renal transplants (Tables 12–15 [in the Data Tables section of this document]). Table 12 shows the age distribution of transplant patients for each Network. In 2016 slightly more than two-thirds (69.5%) of transplant recipients were in the age range of 40 to 69 years old; 6.4% were age 70 or older, while 24.1% were 39 years old or younger. Data on the gender of transplant recipients in 2016 are shown in Table 13. Overall, 60.1% of these transplant recipients were male.

Table 14 shows the distribution of transplant recipients in 2016 by race, as recorded on Form CMS-2728. In 2016, 65.4% of all renal transplant recipients were in the White category. Slightly more than one-quarter (25.5%) of the 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 2016.

Table 15 shows the distribution of transplant events by donor type for 2016, and Figure 4 highlights comparative data of transplant events by donor type for the years 2010–2016. Of the 19,581 transplant events in 2016, the majority of organs used in these transplants were from deceased donors (71.8%). Living related donors and living unrelated donors accounted for organs used in 14.3% and 13.9% of transplant events, respectively. Network 14 (Texas) had the highest number of transplants in calendar year 2016.

Figure 4



Vocational Rehabilitation and Employment

All ESRD Networks are required to inform patients and providers on an annual basis about vocational rehabilitation programs available in their service areas. Facilities are surveyed by the Networks to determine the demographics of patients 18 to 54 years old who are attending school, employed, or receiving vocational rehabilitation services (see Table 16 in the Data Tables section of this document).

In 2016, 20.1% of dialysis patients aged 18–54 reported being employed either full- or part-time, 0.6% reported receiving vocational rehabilitation services, and 1.2% reported attending school either full- or part-time. Activities conducted by the Networks to encourage employment, vocational rehabilitation, and enrollment in school included:

- 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.

Improving Care for ESRD Patients by Increasing the Use of Permanent Accesses

Vascular Access

Hemodialysis requires repeated access to large blood vessels capable of effectively removing wastes, water, and excess electrolytes from the blood. There are three types of vascular access: AVF, arteriovenous graft (AVG), and central venous catheter (CVC). A patient's vasculature and other medical and physical conditions are considered in determining the access type most efficacious for each individual patient. AVFs are considered the gold standard, although not all patients can support the use of an AVF. An AVF is a surgical connection between a vein and an artery, usually in the forearm. The AVF causes the vein wall to thicken, allowing for adequate blood flow to support the repeated needle insertions. AVFs offer less chance of infection or clotting and greater access longevity than other forms of vascular access. If properly maintained, AVFs can remain an effective means of hemodialysis access for an extended period of time and is considered to be a permanent access. An AVG, another form of permanent access, is created using a synthetic tube implanted under the skin that connects an artery and a vein. An AVG is an acceptable alternative when AVF placement is not deemed possible.

A CVC, when used for vascular access in dialysis, is a flexible tubular instrument that is surgically inserted, often into a large vein in the neck, with the tip resting in the right atrium of the heart. Catheters pose a higher risk of infection, clotting, and narrowing of vessels than AVFs and AVGs, leading to increased morbidity and mortality in patients.⁵ As a result, CVCs should be viewed as a temporary "bridge" to an AVF or AVG if a patient needs dialysis before an AVF or AVG is created and/or ready for use. There are some patients who are unable to have an AVF or AVG created or have other clinical conditions that preclude AVF/AVG placement. In such cases, use of a CVC may be their only access option.

FFCL Workgroup Coalition

In 2013, the FFCL Workgroup Coalition was established to build on the success of the Fistula First Breakthrough Initiative, with the specific goals of reducing the use of HD LTCs and increasing the number and percentage of AVFs in use. The FFCL Workgroup Coalition comprises representatives from the ESRD Network Program, vascular access experts, dialysis providers, patient subject matter experts, and other stakeholders. The ESRD Network Program has implemented strategies to decrease LTC use (90 days or longer) in order to reduce vascular access-related morbidity and mortality and improve the quality of life for dialysis patients.

In 2016, the FFCL Workgroup Coalition focused on the research and development of tools and materials for surgeons and nephrologists that emphasized the placement of more AVFs or alternative accesses in lieu of LTCs. Additionally, the FFCL Workgroup began the process of

⁵ Vachharajani TJ. *Atlas of Dialysis Vascular Access*. 2010. Available at: <http://fistulafirst.esrdncc.org/wp-content/uploads/2015/12/Access-Atlas.pdf>

collecting data for a white paper on the need for insurance coverage for incident patients to cover permanent access surgery prior to initiating dialysis. New tools were posted to the FFCL website that addressed topics such as fatal vascular access hemorrhage. The Coalition also initiated development of a surgeon report card template for facilities and Networks to utilize.

The Role of the Networks in Increasing AVF Placement Rates and Decreasing LTC Use Rates

In 2016, the ESRD Networks developed targeted strategies to assist dialysis facilities in increasing AVF use rates and decreasing LTC use rates in incident and prevalent dialysis patients. Strategies were developed through the performance of environmental scans using root cause analysis (RCA), an approach used to identify the origins of a problem or error, and included:

- Educational webinars.
- Online surveys.
- Action plan development.
- Focus groups.
- Site visits by Network staff.

To achieve improvements in access use (more AVFs/AVGs and fewer LTCs), the Networks first identified dialysis facilities that had not reached CMS targets (i.e., facilities who still showed LTC use greater than or equal to 10% in the prevalent HD population). The Networks then provided individualized support via quality improvement activities (QIAs) to the identified facilities. Different Networks took different approaches:

- **Network 8** achieved success with their LTC QIA by holding monthly coaching calls with each focus facility. The coaching calls included a review of each patient in the facility who still had an LTC; the calls focused on identifying barriers to catheter removal. Based on the identified barriers, the Network recommended facility-specific interventions, including weekly physician review of maturing accesses and provision of early education for newly-admitted patients.
- **Network 9** hosted a series of educational webinars that blended patient experience, best practices, successful strategies, and clinical information; each successive topic reinforced and built on the information provided in the previous one. Supporting research articles were distributed at the end of each event that reinforced the information presented in the webinars. By project completion, the targeted facilities decreased LTC use rates by 2.13 percentage points, from 16.14% to 14.01%.
- **Network 13** conducted a QIA that included a patient engagement component aimed at increasing patient knowledge of vascular access types and their associated complications. The Network implemented the use of a *Patient Vascular Access Checklist* that was completed by patients with a catheter in use at the beginning of the QIA, and again at the end, following the provision of vascular access education. This innovative strategy increased patient understanding significantly. The rate of correct responses to the *Patient Vascular Access Checklist* prior to any vascular access education was 78.3%, and the rate of correct

responses after all educational materials were shared with patients was 87.3% ($p < 0.01$), a 9 percentage point improvement.

- **Network 17** conducted a QIA that focused on creating a foundation of sustainable facility processes for catheter reduction. The Network provided one-on-one technical assistance to facilities each month, first initiating an RCA plan using the Plan-Do-Study-Act (PDSA) cycle, then providing ongoing feedback to assist in developing individualized facility processes and resources. Monthly calls were held to discuss challenges and best demonstrated practices. Patient SMEs were invited to each call to share the patient perspective. Overall, the facilities reduced their aggregate LTC rate from 17.6% to 13.8%, representing a 3.8 percentage point decrease.

The data in Table 17 (in the Data Tables section of this document) show that the national average AVF rate in the prevalent HD population was 61.8% as of December 2016. This represents a 2.2 percentage point decrease from calendar year 2015. Table 18 (also in the Data Tables section of this document), indicates that the national LTC use rate was 10.2% as of December 2016. LTC use rates ranged from 9.0% to 12.9%, with eight out of 18 Networks (44.4%) reporting an LTC use rate of less than 10% of prevalent HD patients. As of December 2016, 11 of 18 Networks (61.1%) exceeded the 60.0% threshold for AVFs in use among in-center and home HD patients. Network 15 exceeded the 68.0% national goal, according to FFCL data.

As of December 2016, 11 of 18 ESRD Networks exceeded the 60% threshold for AVFs in use among in-center and home HD patients.

Patient Safety: Network Support for the National Healthcare Safety Network (NHSN)

The Centers for Disease Control and Prevention's (CDC's) NHSN is the nation's most widely used HAI tracking system. It provides facilities, states, regions, and the nation with the HAI data needed to identify areas for improvement, measure the progress of prevention efforts, and ultimately eliminate HAIs as a threat to patients' health.

Patients who undergo dialysis treatment are at a high risk for infection due to the frequent use of catheters or insertion of needles to access the bloodstream as part of the HD process.⁶ NHSN data is critical to the improvement of care provided by dialysis facilities. It also enables staff at all 18 ESRD Networks to easily identify high rates of HAIs in individual dialysis facilities. Once these facilities are identified, the Networks can work with facility staff to implement quality improvement efforts aimed at reducing incidence of HAIs. Additionally, NHSN's infection tracking system:

⁶ Centers for Disease Control and Prevention. Dialysis. Accessed August 2017. Available at: <https://www.cdc.gov/dialysis/index.html>

- Helps to identify both at-risk patients and which part of a facility might need improvement.
- Allows the CDC to see national trends and direct prevention efforts for the country.
- Permits facilities to categorize HD patients by type of vascular access used.
- Provides a variety of analysis options that can be used to better inform quality improvement decisions.

In 2016, a significant part of Network support for the NHSN included review of facilities' monthly reporting of intravenous (IV) antimicrobial starts, positive blood cultures, and evidence of local access site infections. Network support also included technical assistance to the facilities with data entry, so that these events were entered accurately and in a timely manner. The Networks were also charged with providing technical assistance and resources to ensure that a new ESRD Quality Incentive Program (ESRD QIP) reporting requirement for payment year (PY) 2018 (calendar year (CY) 2016) was understood and could be met by all dialysis facilities. The NHSN Healthcare Personnel (HCP) Influenza Vaccination Summary Surveillance requirement directed dialysis facilities to collect HCP influenza vaccination data, according to the HCP Influenza Vaccination Summary Protocol, beginning with the 2015–2016 influenza season, and to report a summary of those data to NHSN on or before May 15, 2016. This requirement applied to all outpatient dialysis facilities, whether they provided in-center HD, peritoneal dialysis (PD), or home HD services.

Patient Safety: HAI LAN Events

In 2016, the ESRD Networks continued to assist in the elimination of HAIs through national education for the ESRD community aimed at standardization of practice and widespread comprehension of relevant infection control concepts. This was accomplished through the work of the HAI LANs. The HAI LANs provided a variety of resources to assist dialysis facilities in reducing the occurrence of HAIs, including:

- Hands-on education for patients and family members about infection control.
- Webinars for dialysis facility staff that featured presentations by public health and medical experts.
- CDC audit tools and video courses.
- Behavioral self-management policies and procedures (e.g., infection control protocols).

By encouraging the LAN all-teach, all-learn concept, ESRD Networks were able to effect noticeable change in their stakeholder communities. For example:

- **Network 5** conducted a review of infection prevention techniques used by dialysis facilities in its service area that revealed gaps in implementation of the CDC's evidence-based practices. Based on this information, the Network conducted *Project Wipeout* with 73 facilities; the goal of the project was to reduce the rate of BSIs. *Project Wipeout* followed the Institute for Healthcare Improvement (IHI) Model for Improvement to assist facilities

with implementation of and adherence to recommended prevention practices. Overall, the facilities demonstrated a 44% reduction in BSIs ($p < 0.0001$) from baseline (January–June 2015) to re-measurement (January–June 2016)

- **Network 8** focused on vaccination improvement interventions. They targeted 25 facilities in March 2016. Vaccination data was reviewed with the facilities on a monthly basis, and patient and staff educational materials were provided during the course of the project. These materials addressed staff- and patient-related root causes, as policy- and process-related barriers were not a common occurrence in facilities owned by large dialysis organizations (LDOs). Barriers to vaccination were also identified via an extensive literature review. The Network exceeded the goal of a two percentage point increase for each vaccination type prior to the end of the project.
- **Network 14** initiated the *Infection Detection* QIA to reduce dialysis facility BSI rates within a group of 110 focus facilities that served 9,928 patients. As part of the QIA, facilities were required to select or develop a patient engagement activity that focused on BSIs and then engage and empower patients through the implementation of the activity. Out of the 110 facilities in the project, 94 facilities (85.5%) surpassed the goal of 5% or greater reduction in their pooled mean BSI rate at re-measurement compared to the baseline time period. Further analysis demonstrated a significant difference between the focus and non-focus facilities' change in BSI rates from baseline to re-measurement, with the focus facilities' BSI rates decreasing on average by 0.74, while the non-focus facilities increased on average by 0.15 ($p < 0.0001$).

Support for the ESRD QIP

The ESRD QIP was established under the provisions of the Medicare Improvements for Patients and Providers Act (MIPPA) of 2008. Administered by CMS, the ESRD QIP is designed to promote high-quality services in outpatient dialysis facilities. The ESRD QIP was CMS' first value-based purchasing (VBP) initiative, representing a shift from quantity-based payment to quality-based payment by the Medicare Program. A percentage of each dialysis facility's Medicare reimbursement is contingent on the facility's performance on:

- Kt/V dialysis adequacy in HD, PD, and pediatric dialysis patients.
- Maximizing placement of AVFs.
- Minimizing use of catheters.
- Decreasing the proportion of patients with hypercalcemia.
- Decreasing the rate of bloodstream infections.
- Lowering the rate of hospital readmissions.
- Reporting mineral metabolism and anemia values.
- Administering the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS) Survey.

The ESRD Network Program provides ongoing support to dialysis facilities by offering ESRD QIP education, technical support, and updates to help facilities understand and comply with ESRD



QIP requirements. The CROWNWeb system and the CDC's NHSN provide the necessary data to calculate facility performance.

During CY 2016, the ESRD Network Program used a multi-pronged approach to assist facilities in understanding and complying with ESRD QIP processes and requirements, including but not limited to site visits, webinars, and newsletters. The Networks also partnered with low-performing facilities to address areas of deficiency that resulted in payment reductions. CY 2016 also saw the Networks continuing to focus on educating patients and family members on accessing and understanding dialysis facility Performance Score Reports (PSRs) and Performance Score Certificates (PSCs) so that patients could make educated decisions about their care.

Provider Education

The Networks strive to ensure that dialysis facility and transplant center staff are up-to-date regarding developments in ESRD care by providing a robust program of educational activities and resources. In 2016, these activities and resources included:

- Hosting Network annual meetings.
- Providing on-site trainings and workshops to support QIAs and promote patient safety.
- Sponsoring continuing education seminars and symposia.
- Convening LANs to reduce HAIs.
- Developing and presenting webinars to educate dialysis facility staff on:
 - Increasing transplantation referrals.
 - Reducing LTC use.
 - Utilization of post-hospitalization checklists to reduce readmissions.
- Recognizing high-performing facilities in monthly newsletters.
- Spreading promising approaches and best practices.
- Maintaining frequent email communication with facilities.
- Posting information on Network websites.
- Producing and distributing provider-focused newsletters.
- Mailing and faxing information to providers on relevant clinical issues.
- Providing up-to-date information about product and medication recalls.

Contributions to Professional Literature

In 2016, authors associated with the ESRD Network Program published the following articles in peer-reviewed journals and other professional publications:

1. Arora, Swaty, Daniel Levitan, Narottam Regmi, Gurinder Sidhu, Raavi Gupta, Anthony D. Nicasri, Subodh J. Saggi, and Albert Braverman. "Cryoglobulinemia in a Patient with Chronic Lymphocytic Leukemia A Case Report and Review of Literature of Renal Involvement in CLL." *Blood Cells, Molecules, and Diseases*. 60 (2016): 7-11. Print

2. Ball LK, George C, Duval L, Hedrick, N. "Reducing Blood Stream Infection in Patients on Hemodialysis: Incorporating Patient Engagement into a Quality Improvement Activity." *Hemodialysis International*. 2016;20:S7-S11.
3. Culp S, Lupu D, Arenella C, Armistead N, Moss AH. Unmet supportive care needs in U.S. dialysis centers and lack of knowledge of available resources to address them. *Journal of Pain Symptom Management*. 2016 Apr;51(4):756-761.e2.
4. Davis, Kristina, K., Harris, Kathleen G., Mahishi, Brinda; Bartholomew, Edward G., and Kennard, Kevin. "Perceptions of Culture Safety in Hemodialysis Centers." *Nephrology Nursing Journal*. March-April 2016;43(2):119-126.
5. Hall, L., and Fain, M, "How social workers can help patients understand and address barriers with home options," *Nephrology News and Issues*, August 2016, Vol. 30, No. 9, 23-24.
6. Hall, L. "What is the Role of Social Workers in Patient Safety?" *RenalLink*, Fall 2016, Vol. 20.
7. Hall, L., Caruthers, R., and Gore, S. "Transportation requirements and dialysis care," *Nephrology News and Issues*, December 2016, Vol. 30, No. 13, 20-21; 26.
8. Maung, Stephanie, Ammar El Sara, Danielle Cohen, Cherylle Chapman, Subodh Saggi, and Daniel Cukor. "Sleep Disturbance and Depressive Affect in Patients Treated with Haemodialysis." *Journal of Renal Care* 43.1 (2016): 60-66. Print.
9. Smith, Evan. "An Innovative Approach in Addressing Dialysis Patient Placement Challenges." *Nephrology News & Issues*. Web. 6 April, 2016.
10. Velasquez-Peralta, D; Ramirez, A; & Beto, J. (2016) "Talking Control" as a method to improve patient satisfaction with staff communication in the dialysis setting. *Journal of Nephrology Social Work*, 40 (2), 16-24.
<https://www.kidney.org/professionals/CNSW/JNSWOnline>
11. Xu, Kathrine, Paul Rosenstiel, Neal Paragas, Christian Hinze, Xiaobo Gao, Tian Huai Shen, Max Werth, Catherine Forster, Rong Deng, Efrat Bruck, Roger W. Boles, Alexandra Tornato, Tejashree Gopal, Madison Jones, Justin Konig, Jacob Stauber, Vivette D'Agati, Hediye Erdjument-Bromage, Subodh Saggi, Gebhard Wagener, Kai M. Schmidt-Ott, Nicholas Tatonetti, Paul Tempst, Juan A. Oliver, Paolo Guarnieri, and Jonathan Barasch. "Unique Transcriptional Programs Identify Subtypes of AKI." *Journal of the American Society of Nephrology* (2016). Print.

Ensuring Data Quality

CROWNWeb

The ESRD Network Program uses the CROWNWeb data management system to obtain and track data on patient age, gender, ethnicity, race, primary diagnosis, and treatment modality, among other characteristics, for incident and prevalent ESRD patients. These data are used by Network staff to inform quality improvement activities, strengthen outreach efforts, document demographic trends, and assess disparities in ESRD care.

The CROWNWeb system supports data collection for two primary CMS ESRD forms, the ESRD Medical Evidence Report: Medicare Entitlement and/or Patient Registration (CMS-2728) and the ESRD Death Notification (CMS-2746). Dialysis facilities and ESRD Networks, the primary



users of CROWNWeb, employ the system to add, modify, and delete information associated with these forms. CROWNWeb is also used by facility staff to enter clinical data on all dialysis patients and report administrative information on facility personnel and dialysis services.

In 2016, the Networks continued their ongoing collaborations with the ESRD NCC on two national data committees, the ESRD Data Committee and the FFCL Data Committee. The work done by these committees advanced the refinement and evolution of the library of data reports provided to Networks from the ESRD NCC utilizing CROWNWeb data. Network representatives on these committees:

- Informed the ESRD NCC on the ever-changing Network data reporting needs, priorities, and perspectives.
- Offered guidance on the requirements for specific reports.
- Tested data report updates prior to release to the entire community.
- Collaborated with the ESRD NCC to make important data available to the facilities (e.g., updates to FFCL and gap reports, which identify patients in CROWNWeb not currently admitted to a specific facility) to support Network quality improvement activities and to assist in enhancing the accuracy and completeness of data reported in CROWNWeb.

The ESRD NCC utilized feedback from these committees to produce updated reports quarterly throughout the contract year.

Veterans Health Administration and Transplant Facility Data

In 2016, Veterans Health Administration facilities and transplant facilities were not required to use CROWNWeb for data submission. To assist these organizations with timely processing of required CMS forms, the ESRD Networks accepted paper copies (instead of digital copies in CROWNWeb) of the CMS-2728, CMS-2746, and Annual Facility Survey (CMS-2744) forms and dialysis patient tracking forms. The Networks then manually entered the data on these forms into CROWNWeb for the facilities.

Disparities in ESRD Care

In 2016, each of the 18 ESRD Networks developed a Population Health Innovation Pilot Project (PHIPP) to promote better health in the ESRD population. Each Network selected a project based on one of the following CMS-approved priorities:

- Improve Dialysis Care Coordination with a Focus on Reducing Hospital Utilization
- Improve Transplant Coordination
- Promote Appropriate Home Dialysis in Qualified Patients
- Support Improvement in Quality of Life

As part of the project, each Network conducted a disparity assessment to determine the target population for the project. The following categories were considered in identifying the target disparity: 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 following six attributes were incorporated into each Network's project:

- 1. Rapid Cycle Improvement in Quality Improvement Activities and Outputs**
On a routine basis, each Network evaluated and assessed the success of the project's interventions in order to make appropriate adjustments based on available information and feedback from project participants.
- 2. Customer Focus and Value of the QIAs to Patients, Participants, and CMS**
Each project incorporated a focus on the needs of customers. Input from patients, family members/care partners, and other stakeholders helped to inform the strategies and guide the quality improvement initiative.
- 3. Ability to Prepare the Field to Sustain the Improvement**
In the early development stage of the project, each Network established a sustainability plan that outlined how the project would continue after the Network was no longer actively involved.
- 4. Value Placed on Innovation**
Each project incorporated innovative approaches based on recommendations and ideas from identified participants; new tools and/or interventions were developed when needed in an effort to benefit all participants.
- 5. Commitment to Boundarilessness**
Information about each Network's project was communicated to and supported by stakeholder groups and organizations.
- 6. Unconditional Teamwork**
To further demonstrate each Network's commitment to boundarilessness, best practices and lessons learned through the project were disseminated to stakeholders, including other Networks.

Population Health Innovation Pilot Projects (PHIPPs)

Improve Dialysis Care Coordination with a Focus on Reducing Hospital Utilization

In 2016, Networks coordinated stakeholders, including state hospital associations, Quality Innovation Networks-Quality Improvement Organizations (QIN-QIOs), and ESRD professionals to reduce hospital utilization for ESRD patients. Following are a few examples of Network projects on this topic:

- **Network 15** successfully conducted a project with six dialysis facilities in Maricopa County, Arizona, using *Questions About You*, an innovative interview-structured intervention that fostered patient and family engagement at the facility level. The intervention was used with patients who had been discharged from the hospital. A significant aspect of the intervention was that staff *sat down* with the recently discharged patient to guide discussion about key elements of transitions of care, including understanding of the reason(s) for the hospitalization, his or her feelings regarding being out of the hospital, and an understanding of follow-up needs, such as appointments and medication changes. The results were to be compared with the actual hospital records in order to close identified gaps in knowledge

and clarify any patient misunderstandings.

- **Network 18** conducted a project with the goal of reducing hospital utilization among ESRD patients by 2% and to improve access to electronic medical records (EMRs) for dialysis providers at admitting hospitals. The effort resulted in new community collaborations with area hospital systems and regional quality organizations that encourage EMR exchanges between the hospital and the dialysis facility upon the hospitalization discharge of a dialysis patient. The Network worked with San Diego Health Connect to identify information in the Health Information Exchange that could assist with improving dialysis patients' quality of care.

Improve Transplant Coordination

For the purposes of this project, a “transplant referral” was defined as any first-time referral for a patient (i.e., the patient had not already been referred or placed on a transplant waitlist), and for which either a dialysis facility or transplant center provided an indication that the patient had been referred. Examples of Network efforts conducted during 2016 to increase transplant referral rates included:

- **Network 1** developed a Transplant Resource Toolkit, which included reference materials and decision tools developed by United Network for Organ Sharing (UNOS), as well as handouts with discussion points for patients about transplantation. The Network provided technical assistance and helped facilities to identify best practices in overcoming barriers to referrals, establish new procedures, and improve upon processes already in place for patient referrals. The Network's Advisory Committee members worked to develop, review, and adapt resources for both facilities and patients throughout the course of the project. Community member input contributed to the effectiveness of information shared with the community, and helped to ensure that the needs of patients and providers were represented throughout this initiative.
- **Network 2** implemented innovative interventions to increase the rate of referrals to transplantation for qualified patients, including:
 - Establishing and supporting “education stations” at facilities.
 - Training patient Transplant Navigators to serve as mentors in helping patients initiate conversations about transplantation.
 - Establishing a Transplant Advisory Committee as a mechanism to solicit ongoing input from key community stakeholders.

Overall, the Network demonstrated a 1.8% reduction in the disparity between African-American patients and White patients, and a 7.7% increase in transplant referral rates, meeting both goals of the project.

- **Network 9** conducted site visits to selected facilities and conducted RCAs of their transplant status lists, which helped to identify potential transplant candidates who had previously been missed. Analysis of the RCAs identified a need for a document that contained concise and consolidated transplant center selection criteria, disparity-based educational tools, and ongoing processes to evaluate the patient referral list. Goals for this project included increasing transplant referrals by 5%, reducing noted population disparities in referrals by 1%, and achieving a 75% or better referral rate for all eligible patients in project facilities.

The Network met or exceeded every goal of the project, increasing overall transplant referrals by 20%, decreasing the disparity between males and females in referrals by 13%, and achieving a greater than 75% eligible patient referral rate in all project facilities.

Promote Appropriate Home Dialysis in Qualified Patients

During 2016, the ESRD Networks worked with facilities to improve home dialysis referrals for qualified patients. The following are examples of Network projects on this topic:

- **Network 3** conducted educational site visits and conference calls and developed a Home Therapies Resource Toolkit, with a goal of increasing referrals to home dialysis [state the goal--by what percent?]. The toolkit included reference materials, resource articles, and helpful decision-making tools developed by the Medical Education Institute (MEI), as well as handouts with discussion points for patients about therapy options. The Network increased referrals for home dialysis to 75.7% by the end of the project. The Network also decreased the racial disparity in referrals between white and African American patients by 13.2 percentage points, exceeding the CMS goal of 1%.
- **Network 4** implemented a multi-pronged approach to improve home modality referrals that included comparative feedback reports, analysis of home therapy referral processes, and the development of educational materials geared toward the female dialysis patient. The Network also convened an internal Home Therapy Workgroup (HTW) that included Network MRB representatives and two patients from the dialysis community. The HTW assisted in the development, implementation, and evaluation of the project, including reviewing focus facility progress and incorporating new interventions based on results of PDSA cycles. At the conclusion of the project, focus facilities had improved from 8.4% to 28.5% of their patients having been referred for home therapy. The disparity baseline of a 5.1 percentage point difference between males and females decreased to 1.5 percentage points, a 3.6 percentage point reduction, exceeding the one percentage point reduction CMS goal.
- **Network 10** utilized a Patient Liaison, who was a transplant recipient and former in-center HD patient, to serve as the direct patient interface for patients in the project facilities through site visitations. The Patient Liaison also began production of a podcast series, one installment of which focused on the journey to home dialysis. The format was designed to be easily accessed by smartphone or tablet, making it ideal for patient viewing while on treatment. By the end of the project period, the goal of an 8.8% home HD referral rate had been surpassed, with an achievement of 10.4%, or 68 patients referred for home dialysis evaluation.
- **Network 11** selected 24 dialysis facilities, serving about 1,900 in-center dialysis patients, to participate in a project to increase the percent of patients referred to home dialysis. As part of the project, the Network conducted patient interviews to identify barriers influencing equity by race. As part of the interviews, patients explained why they chose and why they did not choose home dialysis. Patients who overcame challenges to dialyze at home shared their success stories, and the wife of a patient dialyzing at home shared her experience as a home dialysis partner. These interventions resulted in a 17.6% increase in referrals to home dialysis, exceeding the project goal.



Support Improvement in Quality of Life

The topic area focusing on supporting improvement in quality of life for ESRD patients was not selected by any of the 18 Networks for the 2016 PHIPP.

Partnerships and Coalitions

In 2016, the ESRD Networks engaged in a variety of collaborative activities that included communication and coordination with renal partners at the local, state, Network, regional, and/or national levels. The Networks partnered with organizations such as the:

- National Kidney Foundation (NKF).
- American Kidney Fund (AKF).
- American Association of Kidney Patients (AAKP).
- National Association of Nephrology Technicians/Technologists (NANT).
- National Renal Administrators Association (NRAA).
- Council of Nephrology Social Workers.
- American Nephrology Nurses' Association (ANNA).
- Association of Professionals in Infection Control and Epidemiology (APIC).
- Renal Physicians Association (RPA).
- American Society of Nephrology (ASN).
- National Hospice and Palliative Care Organization (NHPCO).
- Dental Lifeline Network's Donated Dental Services (DDS) program.
- Forum of ESRD Networks.
- Association of Health Facility Survey Agencies (AHFSA).
- Life Options Rehabilitation Advisory Council (LORAC).
- Medical Education Institute (MEI).
- United Network for Organ Sharing (UNOS).
- United States Renal Data System Coordinating Center (USRDS).
- National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health (NIH).

Of equal importance to the collaborative activities of the Networks were their partnerships with patients, family members/ caregivers, independent dialysis corporations, and LDOs.

The Networks also actively collaborated with hospital associations, health departments, emergency medical services, transplant organizations, patient and professional organizations, Offices of Emergency Management, State Survey Agencies (SAs), and Medicare QIN-QIOs in their geographic areas. Some examples of Network collaborative projects include the following:

- **Network 5** continued to expand their *5-Diamond Patient Safety Program* (www.5diamondpatientsafety.org), originally launched in 2008. The Program includes 17 online modules, each serving as a complete educational course with objectives, required activities, optional activities, tools and resources, and measures. Upon completion of at

least five modules, as well as a program review questionnaire, participating facilities earn the *5-Diamond Patient Safety Facility* designation. The *5-Diamond Program* is available to all facilities nationwide. In 2016, more than 3,100 dialysis centers participated, representing a more than 125% increase over 2015. Fresenius Medical Care, an LDO, partnered with the Network in 2016 to launch a corporate-wide initiative to get all facilities working toward and earning their 5-Diamond status.

- **Network 14** participated in the Texas ESRD Emergency Coalition (TEEC), a statewide disaster coalition in the in its service area that was formed in 2005 after hurricanes Katrina and Rita. The mission of TEEC is to coordinate planning, preparedness, response, and recovery for emergency events affecting the Texas ESRD community. TEEC remained active and ready to provide disaster assistance to patients and providers in 2016. The Steering Committee is composed of representatives from the Network, all of the LDO facilities and other facilities operating in Texas, and the State Survey Agency. TEEC activities in 2016 included a presentation at the regional Houston Hurricane Conference, community education meetings, and a disaster drill to activate the TEEC Command Center housed at the Dallas County Health and Human Services Dallas Medical Operation Command Center with all steering committee representatives and the Dallas County Preparedness Coordinator participating.

Patient and Family Engagement

Education for ESRD Patients and Caregivers

In 2016, the ESRD Networks partnered with dialysis facilities to strengthen patient and family engagement and to help patients and their care partners to better understand patients' rights and responsibilities. An important aspect of this was helping them feel comfortable with the grievance process. The Networks distributed printed materials and published newsletters targeting both patients and providers, as well as using social media outlets, such as YouTube, Facebook, and Twitter, to share tools, resources, and best practices. Additional Network outreach included site visits, LANs, and QIA meetings. All of these approaches shared the goal of providing educational resources to ESRD patients, family members, and care partners.

Network-Specific Patient Engagement Activities

In 2016, the ESRD Networks implemented a wide range of notable patient and family engagement QIAs. For example:

- **Network 3** continued its work with *EnGAGE*, a voluntary program designed to empower a facility's entire healthcare team and assist with their patient, family, and staff engagement initiatives. *EnGAGE* shifted its focus in 2016, to an action-based agenda by providing selected facilities with guidance and tools to develop their own Patient/Family Member Representative Guide. Each *EnGAGE* facility was tasked with identifying two patient/family member representatives to participate with the interdisciplinary team in their Quality Assessment Performance Improvement (QAPI) meetings and focus on the development of their guide. Not only did the selected patients and family member representatives act as a liaison between the Network and the facility's patients, but with direction from the

interdisciplinary team, they offered assistance to build and sustain patient-centered care initiatives in a meaningful way.

- **Network 6** implemented the *ACT Now* campaign (A= Ask questions; C=Communicate effectively; T=Take action) to decrease the number of patient grievances filed at a targeted group of facilities. The *ACT Now* campaign encouraged dialysis facility staff to ask about all aspects of each patient’s care through “check-in” sessions. A pocket card was distributed to the facilities, giving staff an easy reference for proactive communications strategies that could be used to start discussions to “check in” with their patients. The Network provided education on how to conduct the check-in sessions and asked that each staff member integrate communications of this nature into their care process. Best practices for working through common issues were also shared with staff. Recognizing that some concerns raised by patients might be beyond a staff member’s ability to correct, the Network also provided patients with information to help them take steps to resolve some common issues themselves. One example of this strategy was the *Why Do I Feel So Cold During Dialysis?* poster, which provided tips for patients on how to be more comfortable during their treatment.
- **Network 12** continued the “Share How You Care” initiative, a reporting mechanism for facilities to share efforts made in patient engagement. As part of this initiative, facilities provided detailed descriptions of their educational efforts and ways in which they engaged with patients; for example, many had their Network patient representatives help with the development of bulletin boards and participate in Lobby Days. Pictures of these activities were also shared with the Network. The Network then highlighted these facility-level activities in the monthly electronic newsletter, “Heartland Happenings.” Facilities in the QIA that had an interesting or unique activity were asked to present on monthly project calls. In total, over 60% of “Share How You Care-”eligible facilities reported an activity to the Network. The picture and project ideas were compiled in a workbook for future use and sharing.
- **Network 16** ensured that the perspectives of patients, family members, and other caregivers were incorporated into QIAs by including 16 culturally diverse patients representing all ESRD modalities from all five states in the Network’s region, in the Network PAC. These PAC members participated in all 2016 Network projects, in Network Board and MRB in-person meetings, and in the development of all Network patient educational activities and materials. The majority of the Network’s LAN members were active in the renal community as national presenters and authors, board members, and patient advocates through, for example, the AAKP, the Portland Kidney Group, the Alaska Kidney Patient Association, the National Kidney Foundation, regional provider foundation boards, Dialysis Patient Citizens, local and national peer mentoring initiatives, training for new ESRD staff and nephrology fellows from a patient perspective, the Kidney Care Transitions national initiative, and the Forum of ESRD Networks.

National Patient and Family Engagement Activities

The NPFE LAN includes patient and care partner representatives drawn from the 18 ESRD Networks, as well as representative Network staff members, delegates from CMS, and participants from the ESRD NCC. The ESRD NCC works with NPFE LAN members to ensure that



all project goals and objectives are driven by patients' viewpoints and experiences. In collaboration with the ESRD Networks, the ESRD NCC supports the NPFE LAN in its leadership efforts that focus, in part, on giving a voice to ESRD patients and facilitating dialogue between patients and CMS leadership.

The NPFE LAN's vision is that all ESRD patients and care partners will be actively involved in the continuum of kidney care, resulting in patients living longer, healthier lives. Its mission is to serve as a national leader and partner in enhancing the quality of life and care for patients with kidney disease through active engagement and the provision of education to empower patients in the renal community to make better health choices. The NPFE LAN provides strategic leadership in determining goals that will help all ESRD patients manage their health and well-being. It supports these goals by assisting in the development of educational materials focused on raising awareness, increasing knowledge, and improving the health behaviors of ESRD patients. The NPFE LAN also helps guide the dissemination of educational resources using social media and an easily accessible website portal.

The 2016 NPFE LAN continued the work of the 2015 NPFE LAN by stepping-up efforts to enhance patient and family engagement, including:

- Educating and coaching patients and family members on ways they can become more active as partners in their healthcare teams.
- Encouraging patient-to-patient support through mentorship and coaching programs.

Additionally, in response to requests from NPFE LAN members, affinity groups focused on specific outcome areas were formed that focused on:

- HAIs
- Improving the grievance process
- ICH CAHPS
- Mental health

Organizing into these focus areas allowed the workgroups to target specific clinical goals and act collaboratively to achieve shared objectives. The groups discussed their interests and identified how they could work to enhance or create new educational materials to inspire and engage others to become actively involved in improving kidney care outcomes. Through the new workgroup model and continuous collaboration, the NPFE LAN created patient-friendly educational tools. The group focused on mental health, a patient-selected topic, initiated work on a QIA to encourage ESRD patients to live productive lives. Members of the group recorded selfie videos in which they talked about how they were thriving in life, not just surviving, despite having a chronic illness. These extraordinary efforts demonstrate the strong leadership NPFE LAN members provided to their renal communities at the local and national level. Additionally, many NPFE LAN members contributed to national conferences during the year, including the CMS Quality Conference held in December 2016.

Support for the ICH CAHPS Survey

In 1995, the Agency for Healthcare Research and Quality (AHRQ), in conjunction with CMS, developed a CAHPS survey to collect data about the healthcare patients receive in a variety of settings, including hospital and home health. In 2004, CMS partnered with AHRQ to develop a more focused version of the CAHPS Survey for ESRD patients who receive in-center hemodialysis from Medicare-certified dialysis facilities. AHRQ and CMS developed and tested the ICH CAHPS Survey in 2005. The survey's measures were endorsed by the National Quality Forum (NQF) in 2007. Beginning in calendar year 2014, the ICH CAHPS Survey was conducted by CMS-approved survey vendors.

In an effort to assist qualified dialysis facilities in utilizing the ICH CAHPS Survey to successfully fulfill the ESRD QIP measurement requirements related to patient experience of care, the Networks disseminated information and training resources about the survey, including the current final CMS ESRD QIP Rule and AHRQ guidelines posted at www.ahrq.gov/cahps. The Networks provided CMS with surveillance data reflecting the number of facilities that were utilizing the ICH CAHPS Survey on a monthly basis.

In 2016, the Networks conducted QIAs to improve scores for one Network-selected ICH CAHPS survey question. For example:

- **Network 7** developed the Learn About Blood Test Results (or L.A.B.) intervention to improve scores for the question, "In the last three months, how often did your dialysis center staff explain your blood test results in a way that was easy to understand?" The intervention included the use of laminated educational cards, in both English and Spanish, to educate patients about their blood test results. The cards were given to patients to keep and refer to on an ongoing basis. The baseline for the QIA was 74.7% of patients answering "Usually" or "Always" to the selected question. The goal was that 75.9% (5% relative improvement) of patients would answer "Usually" or "Always" To the same question. The Network exceeded this goal, achieving 95.7% of survey respondents answering "Usually" or "Always." One best practice identified during the QIA was to keep a laminated set of the educational cards in each treatment area so that the information was readily available to patients when they had time to read it.
- **Network 18** focused on the question, "In the past 12 months did either your kidney doctors or dialysis center staff talk to you about peritoneal dialysis?" At baseline, of the 20 facilities selected for participation, only 30.5% of patients surveyed responded "yes" to this question. At the completion of this project, the project facilities achieved considerable improvement in the number of patient's responding "yes," obtaining 90.4% positive (yes) responses, representing a nearly a 60 percentage point improvement. The Network utilized existing materials on PD education to support the project, including tools and resources from MEI, NCC, and the Forum of ESRD Networks. Additionally, the Network's PAC developed Modality Referral Tracking Sheets, Home Unit Referral Appointment Cards, Best Practice Checklists, and Myth & Fact Sheets.

Networks Address Involuntary Discharges (IVDs), Involuntary Transfers (IVTs), and Failures to Place (FTPs)

The following are CMS definitions of IVD, IVT, and FTP:

- **IVD:** *A situation in which, consistent with the Conditions for Coverage for End-Stage Renal Disease Facilities (ESRD CfCs), a patient is informed in writing that treatment at a dialysis facility will terminate in 30 days or the dialysis facility notifies the Network and State Survey Agency (SA) that it is following an abbreviated termination procedure for a patient who has made an immediate severe threat of physical harm.*
- **IVT:** *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.*
- **FTP:** *A situation in which no outpatient dialysis facility can be located that will 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.*

IVDs

IVDs continue to present substantial challenges for the ESRD Network Program. In 2016, Program activities focused on reducing or averting IVDs by providing staff with materials and resources to help them work effectively with patients, including how to identify potential conflicts and about the use of therapeutic communication techniques to use with patients and their families. The Networks provided education and assistance through print and electronic materials; identification of potential patterns of discrimination or unequal access to care; and training sessions for dialysis facility staff.

Grievances and Access to Care

Evaluation and Resolution of Grievances

In 2012, CMS amended the ESRD complaints and grievance policy to require that all concerns related to care that does not meet a Medicare beneficiary's expectations be classified as grievances and that the Networks' procedures for evaluating and resolving grievances be patient-centered. 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 the grievant's expectation, recognized standards of safety or civility, or professionally-recognized clinical standards of care.

As of 2016, the ESRD Networks were also responsible for resolving all patient-appropriate access to care cases, both at the grievance and non-grievance level. Patient-appropriate access to care is determined by the nephrologist working with the patient to identify a clinically appropriate treatment modality that takes into consideration patient choice. Access-to-care



cases included cases in which ESRD patients were at risk for an IVD or IVT, and cases in which a patient was scheduled for, or had already experienced an IVD or IVT.

Each ESRD Network established a system for promoting awareness of all options for filing grievances, including the option of filing grievances anonymously. The ESRD Networks worked to ensure that patients were able to file grievances without fear of reprisal. When a grievance is filed with the Network, the Network reminds the provider and/or practitioner(s) of their responsibility to support the grievant throughout the grievance process and that no reprisal may be imposed as a result of the grievance. The Networks have also advised the patient community about the revised CMS policy for evaluating, resolving, and reporting patient grievances. Each Network's grievance resolution protocol had to be approved by CMS, including the time frames for investigating and completing an investigation, as well as for notifying patients of investigation outcomes. All correspondence sent to patients and/or facilities for distribution to patients, included language on how to contact the Network to file a grievance.

2016 Grievance Process and Data

In 2016, as in previous years, patients had the option to initiate the grievance process at either the Network or facility level. The Network option allowed patients who had concerns about potential retaliation by facility staff the opportunity to protect their confidentiality. Patient family members, friends, representatives and/or advocates, facility employees, physicians, SAs, and other interested parties also submitted grievances concerning dialysis facilities and transplantation centers to the Networks. Grievances regarding care provided at acute care hospitals, in nursing homes, at home by home care providers, or by physicians were also received by the Network. When a grievant had concerns outside the scope of the ESRD Network, the Network assisted the grievant in forwarding his or her concern to the appropriate regulatory entity, such as one of two CMS Beneficiary- and Family-Centered Care Quality Improvement Organizations. Grievances could be submitted by mail, telephone, or email. As required by CMS, each Network provided a toll-free number for patients' inquiries and grievances. All grievances received by the Networks were entered into the Patient Contact Utility (PCU) database.

The 18 ESRD Networks processed 1,872 beneficiary grievances in 2016, representing 3.8 grievances per 1,000 dialysis patients. Sixteen of the 18 Networks (88.9%) reported a rate lower than 5.0 grievances per 1,000 patients. Of the 1,872 grievance cases processed, 109 (5.8%) involved an access-to-care issue and 47 involved IVD, with 16 Networks (88.9%) reporting five or fewer IVD cases. Thirteen of the 18 Networks (72.2%) reported IVD rates lower than the mean rate of 0.09 per 1,000 patients. See Table 22 for Network-specific data.

Recommendations for Sanctions

In 2016, no sanction recommendations were submitted to CMS by an ESRD Network.

Recommendations to CMS for Additional Facilities

Although CMS received no formal recommendations for additional facilities in 2016, the 18 ESRD Networks did provide policy recommendations that included:

- Waiving the three-month Medicare waiting period for new patients to have an AVF placed prior to beginning dialysis or at the start of dialysis.
- Mandating pre-ESRD educational programs throughout the country.
- Studying ESRD Medicare medication payment policies to identify ways to reduce costs by improving care.
- Providing innovative ESRD treatment options for involuntarily discharged patients and special needs patients.
- Coordinating comprehensive care for ESRD patients due to patients' comorbid conditions for which dialysis facilities and their staff members are not trained, equipped, or reimbursed.
- Adopting a special needs composite rate to help ESRD facilities that accept care for special needs patients.
- Allowing inpatient dialysis units to accept special needs ESRD patients (e.g., a patient on a ventilator) and reimbursement comparable to the composite rate.
- Establishing special needs dialysis facilities that can accommodate/treat patients who:
 - Have special physical requirements, such as patients who are ventilator-dependent or morbidly obese, or who have antibiotic-resistant infections or other needs that require services that are unavailable in a typical dialysis facility.
 - Require a short-term course of dialysis as an outpatient, usually less than three months, as kidney function is recovered.
 - Have been involuntarily discharged from other dialysis programs, many of whom have exhibited socially unacceptable or erratic behavior and may represent a risk to other patients and staff.

The aforementioned policy recommendations and special facility requests represent important ways to improve the scope and quality of care for patients with ESRD. However, the costs associated with implementing these recommendations present a recognized and significant barrier. The ESRD Networks strongly encourage consideration of short- and long-term strategies that will support ESRD facilities in the provision of services to a complex patient population that presents with many psychosocial and healthcare needs.

Emergency Preparedness and Response

For ESRD patients, missed dialysis treatments can have serious adverse health effects. This makes the ESRD patient population especially vulnerable during emergencies and disasters. Networks partner with state and city health departments, offices of emergency management, and regional/national coalitions to ensure the safety and continuity of care for ESRD patients

during emergencies. Network responsibilities related to emergency preparedness and response include:

- Development of a Comprehensive Emergency Management Plan (CEMP)
- Provision of information to educate facilities and patients on the actions to take during emergency and disaster situations
- Reporting of open and closed facilities, alterations in dialysis facility schedules, and unaccounted for patients during actual incidents.

For more information about Network disaster preparedness activities, see the Kidney Community Emergency Response (KCER) overview in this report.

Within their individual service areas, the Networks engaged in outreach, training, and technical assistance activities to help ensure that the needs of ESRD patients were met in emergency situations. During 2016, Networks responded to more than 80 incidents with the potential to impact ESRD patients and/or providers. The incidents included severe weather, tropical weather systems, gas leaks, chemical spills, earthquakes, and wildfires. Following are representative examples of emergency preparedness and response activities conducted:

- **Network 1** sent water and sewer alerts to facilities in Winchester, Massachusetts, and other facilities within a 10-mile radius in May. Facilities were notified that the Town of Winchester had ended the temporary supply of water from the Massachusetts Water Resource Authority and returned to the Town of Winchester's water supply. Facilities were notified of changes in appearance of the water during the transition back to Winchester water and informed that the water was safe for use. Patient dialysis treatments were not affected.
- **Network 3** activated members of the Puerto Rico Emergency Preparedness and Response Activities Renal (PREPARAR) Coalition in September to assess the level of impact from a fire at a power plant that left an estimated 1.5 million people without electricity. The fire and power outage affected towns throughout the island and impacted all 45 dialysis facilities, although all dialysis facilities remained operational using generators. The Network hosted calls twice a day during the incident with members of the PREPARAR Coalition, KCER, CMS, the Puerto Rico Department of Health, and other stakeholders and continued to monitor the incident until all dialysis facilities reported being operational.
- **Network 6** addressed multiple complex emergency situations during 2016 that resulted in multi-state facility closures, patient evacuations, and involvement of federal, state and local agencies. For example, flooding events in May impacted 338 dialysis facilities that served 24,442 patients. Hurricane Hermine impacted 442 dialysis facilities serving 31,803 patients in September. In October, Hurricane Matthew and its aftermath flooding impacted 227 dialysis facilities serving 14,882 patients. By partnering with stakeholders, including state departments of public health and offices of emergency management, the Network was able to effectively support ESRD facilities and patients. The Network, along with the Healthcare Preparedness Coordinator at the South Carolina Department of Health and Environmental Control and a patient family member, participated as part of a panel discussion on the impact of Hurricane Matthew at the 2016 CMS Quality Conference in Baltimore.



- **Network 13** experienced multiple weather events that required Network notices and/or other interventions, as well as recurring events that required ongoing intervention and/or monitoring, including extensive flash and river flooding in Louisiana that occurred in January, May, and August 2016, as well as earthquake activity in Oklahoma starting in January 2016 and continuing throughout the year. To respond to these incidents, the Network leveraged its strong relationships with community stakeholders, such as state agencies and the QIN-QIOs for Arkansas, Louisiana, and Oklahoma. The Network also distributed state-specific disaster preparedness materials to each state's Emergency Operations Center (EOC). EOC materials included a listing of satellite coordinates for all dialysis and transplant facilities in the Network service area and data on patient demographics to assist local authorities in their resource allocation efforts.

Special Projects

ESRD NCC

CMS contracted with HSAG: The ESRD Network of Florida (Network 7) to act as the ESRD NCC. The ESRD NCC serves as a coordinator for the 18 ESRD Networks and liaison between the Networks and CMS. Tasks under the NCC contract are varied and include data analytics and delivery, patient outreach, coordination of QIAs with ESRD Networks and facilities, and production of ESRD events at the annual CMS Quality Conference held by CMS. In 2016, the ESRD NCC accomplished the following:



- **The ESRD Data Committee** partnered with data managers and other staff from all 18 ESRD Networks to create reports based on data from CROWNWeb and other sources, to create functional requirements for requested reports and to perform User Acceptance Testing (UAT) on report output.
 - **Network Interviews** were conducted on a quarterly basis, one-on-one, to ensure that the needs of the ESRD Networks were met. These meetings were conducted via telephone. Although the interviews were structured according to a five-question template to ensure that feedback could be measured, there was ample opportunity for Networks to provide feedback on any areas that were of particular importance to them. The NCC utilized these quarterly sessions to gauge the status of the NCC and the Networks to enhance services provided as feasible.
- New ESRD Patient Orientation Packet (NEPOP)** distribution transition from printed, hard copy to electronic distribution with opt-in print requests. Utilizing the feedback from the 2015 NEPOP Workgroups, the ESRD NCC designed a new trifold brochure and tear-away prepaid postcard for mailing to all new ESRD patients. Patients could indicate which materials they wished to receive on the prepaid return card, or they could access the materials in digital formats online. Digital access through the website was tracked utilizing a patient-specific reference number printed on each postcard. On Pilot Workgroup calls, ESRD Networks and patients voiced their approval of the new format and offered constructive suggestions to help the ESRD NCC refine and improve the postcard-based

approach. In September 2016, the pilot program was expanded to all 18 ESRD Networks, formally replacing the previous print-only approach.

KCER Program

Supporting dialysis facilities and patients in preparing for an emergency or disaster continued to be a priority for the ESRD Network Program in 2016.

HSAG: The Florida ESRD Network (Network 7) was funded by CMS to serve as the national emergency management contractor. Under the KCER contract, HSAG provided support to the ESRD Networks to strengthen their disaster preparedness and response capacities. KCER's 2016 activities included:



- Collaborating with the renal community in response to weather-related events, including tropical storms, flooding, and wildfires, and in monitoring other situations with the potential to impact the ESRD population, such as a nursing strike or power outage. The KCER contractor also fostered relationships with HHS ASPR in an effort to connect dialysis information and preparedness with existing federal protocols, so that all entities would benefit from information sharing and mutual understanding of an emergency or disaster situation.
- Participating in national-level emergency preparedness exercises with federal partners in an effort to integrate the dialysis population into the overall national emergency strategy. KCER participated in the exercises by providing ESRD tracking information, including a list of facilities and patient counts, the operational status of facilities, and any facility needs or services. KCER also provided multiple status updates over the course of the exercises at the request of CMS. KCER utilized the exercise as an opportunity to test processes and information in the KCER Emergency Standard Operating Procedure (SOP) and updates were made to the SOP following each exercise based upon lessons learned.
- Planning and implementing the third annual Emergency Preparedness Exercise to address a simulated emergency, which for 2016 was an operations-based functional exercise that included actual reactions to the exercise scenario. The scenario was based on a 7.7 magnitude earthquake along the New Madrid Seismic Zone that caused major damage and destruction throughout the Central United States. Prior to implementation of the simulated 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. All 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.
- Convening the National KCER PFE LAN (N-KPFE-LAN) to ensure that the patient voice was incorporated into all KCER activities, and to encourage incorporation of the patient perspective within the emergency and disaster community. The N-KPFE-LAN included 34 patients, family members, and caregivers drawn from across the kidney community. The



N-KPFE-LAN Kickoff Meeting took place in June, with subsequent meetings held every other month. During meetings, patients were asked to share their firsthand experiences with disaster preparedness and response. The members also reviewed pre-existing preparedness campaigns and materials and provided feedback to assist in building a framework for a patient-driven QIA.



Data Tables

The following data tables are included and begin on the next page:

Table 1:	Prevalent Dialysis Patients, Dialysis Facilities, and Transplant Centers in Network Area – 2016	Table 14:	Renal Transplant Recipients by Reported Race, Calendar Year 2016
Table 2:	Incident ESRD Patients, 2016, and ESRD Incidence per Million Population, 2015 Compared with 2016	Table 15:	Transplant Events by Donor Type, Calendar Year 2016
Table 3:	Incident ESRD Patients by Age Group (in Years), Calendar Year 2016	Table 16:	Number of Dialysis Patients Aged 18–54 Years, Number and Percent Employed, Number and Percent Receiving Vocational Rehabilitation Services, Number and Percent Attending School, and Number and Percent of Facilities Offering Dialysis after Regular Business Hours, as of December 31, 2016
Table 4:	Incident ESRD Patients by Gender, Calendar Year 2016	Table 17:	Number and Percent of In-Center and Home Dialysis Patients with an Arteriovenous Fistula (AVF) in Use, December 2015 Compared with December 2016
Table 5:	Incident ESRD Patients by Reported Race, Calendar Year 2016	Table 18:	Percentage of Dialysis Access Type by Network, as of December 31, 2016
Table 6:	Incident ESRD Patients, Prevalent Dialysis Patients, and Transplant Recipients by Reported Race, 2016	Table 19:	Number of In-Center Dialysis Patients as of December 31, 2015 and December 31, 2016
Table 7:	Incident ESRD Patients by Primary Cause of Renal Failure, Calendar Year 2016	Table 20:	Number of Home Dialysis Patients by Modality as of December 31, 2015 and December 31, 2016
Table 8:	Prevalent Dialysis Patients by Age Group (in Years) as of December 31, 2016	Table 21:	Number of Patients Using In-Center and Home Dialysis as of December 31, 2015 and December 31, 2016
Table 9:	Prevalent Dialysis Patients by Gender as of December 31, 2016	Table 22:	Complaints, Grievances, Non-Grievance Access-to-Care Cases, and Involuntary Discharges, Calendar Year 2016
Table 10:	Prevalent Dialysis Patients by Reported Race as of December 31, 2016		
Table 11:	Prevalent Dialysis Patients by Primary Diagnosis as of December 31, 2016		
Table 12:	Renal Transplant Recipients by Age Group (in Years), Calendar Year 2016		
Table 13:	Renal Transplant Recipients by Gender, Calendar Year 2016		

Table 1: Prevalent Dialysis Patients, Dialysis Facilities, and Transplant Centers in Network Area, 2016

Network	Number of Dialysis Patients as of December 31, 2016	Number of Dialysis Facilities in Network Area as of December 31, 2016	Number of Transplant Centers in Network Area as of December 31, 2016
1	14,415	194	15
2	29,572	286	13
3	20,145	222	6
4	19,939	324	19
5	27,424	420	13
6	47,837	707	10
7	30,504	448	9
8	27,854	445	12
9	33,415	599	14
10	20,226	308	9
11	27,744	509	21
12	16,483	318	14
13	19,947	326	10
14	48,614	616	23
15	24,335	361	15
16	14,426	214	8
17	27,658	282	6
18	45,663	386	15
TOTAL	496,201	6,965	232
Mean	27,567	387	13

SOURCE: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 2: Incident ESRD Patients, 2016, and ESRD Incidence per Million Population, 2015 Compared with 2016

Network	Number of Incident Patients, Calendar Year 2016*	Population of Network Area 2016	Incidence per Million Population 2015	Incidence per Million Population 2016
1	4,085	14,735,525	271	277
2	7,743	19,745,289	390	392
3	5,211	12,458,727	409	418
4	5,341	13,736,292	372	389
5	6,917	16,940,527	398	408
6	10,858	25,418,278	412	427
7	8,405	20,612,439	398	408
8	6,904	14,503,220	455	476
9	9,343	22,684,400	409	412
10	5,324	12,801,539	412	416
11	7,678	22,850,366	322	336
12	4,761	14,042,098	327	339
13	5,073	11,593,475	432	438
14	11,752	27,862,596	423	422
15	6,168	21,129,407	280	292
16	3,772	14,849,019	242	254
17	6,574	16,520,112	376	398
18	10,301	24,428,865	418	422
TOTAL	126,210	326,912,174	377	386

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

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016. Population data for 50 U.S. states,

District of Columbia, and Puerto Rico: U.S. Census Bureau, retrieved from: <https://www.census.gov/data/tables/2016/demo/popest/state-total.html> in August 2017.

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/resources/the-world-factbook/> in August 2017.

County-level population data for California: U.S. Census Bureau 2016 data, retrieved from: <https://www.census.gov/data/tables/2016/demo/popest/counties-total.html> in August 2017.

Table 3: Incident ESRD Patients by Age Group (in Years), Calendar Year 2016

Network	0–19	20–29	30–39	40–49	50–59	60–69	70–79	≥80	Total Number of Incident ESRD Patients, Calendar Year 2016
1	50	80	186	336	739	1,123	974	597	4,085
2	63	195	345	744	1,383	2,047	1,742	1,224	7,743
3	17	81	200	467	968	1,343	1,312	823	5,211
4	51	103	199	473	986	1,472	1,280	777	5,341
5	56	143	375	663	1,378	2,001	1,513	788	6,917
6	101	262	635	1,273	2,263	3,051	2,353	920	10,858
7	71	157	381	696	1,430	2,176	2,090	1,404	8,405
8	54	150	377	819	1,382	2,021	1,476	625	6,904
9	70	170	429	859	1,631	2,602	2,324	1,258	9,343
10	36	128	241	508	909	1,448	1,276	778	5,324
11	73	194	396	765	1,419	2,115	1,780	936	7,678
12	64	120	252	424	894	1,322	1,074	611	4,761
13	36	131	307	634	1,010	1,396	1,061	498	5,073
14	124	284	663	1,421	2,593	3,305	2,332	1,030	11,752
15	86	142	334	681	1,259	1,681	1,336	649	6,168
16	37	107	196	387	740	1,034	876	395	3,772
17	66	151	353	690	1,282	1,828	1,392	812	6,574
18	66	258	484	1,086	2,032	2,688	2,215	1,472	10,301
TOTAL	1,121	2,856	6,353	12,926	24,298	34,653	28,406	15,597	126,210
% of Total	0.9%	2.3%	5.0%	10.2%	19.3%	27.5%	22.5%	12.4%	100%

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 4: Incident ESRD Patients by Gender, Calendar Year 2016

Network	Male	Female	Total Number of Incident Patients, Calendar Year 2016
1	2,471	1,614	4,085
2	4,556	3,187	7,743
3	3,106	2,105	5,211
4	3,163	2,178	5,341
5	3,920	2,997	6,917
6	6,028	4,830	10,858
7	5,007	3,398	8,405
8	3,850	3,054	6,904
9	5,343	4,000	9,343
10	2,994	2,330	5,324
11	4,450	3,228	7,678
12	2,762	1,999	4,761
13	2,796	2,277	5,073
14	6,630	5,122	11,752
15	3,654	2,514	6,168
16	2,236	1,536	3,772
17	3,898	2,676	6,574
18	6,098	4,203	10,301
TOTAL	72,962	53,248	126,210
% of Total	57.8%	42.2%	100%

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

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 5: Incident ESRD Patients by Reported Race, Calendar Year 2016

Network	Black or African American	White	Asian	Native Hawaiian or Other Pacific Islander	American Indian or Alaska Native	Multiracial	Not Specified	Total Number of Incident ESRD Patients, Calendar Year 2016
1	574	3,359	101	10	3	8	30	4,085
2	2,224	4,794	544	95	14	61	11	7,743
3	1,064	3,932	164	33	1	11	6	5,211
4	1,206	3,990	91	20	1	4	29	5,341
5	2,917	3,682	212	43	4	18	41	6,917
6	5,361	5,198	130	39	57	15	58	10,858
7	2,297	5,852	129	61	10	24	32	8,405
8	3,100	3,686	45	23	38	7	5	6,904
9	1,987	7,198	89	31	5	9	24	9,343
10	1,526	3,564	198	12	3	8	13	5,324
11	1,760	5,487	175	18	195	14	29	7,678
12	950	3,651	74	21	32	11	22	4,761
13	1,843	2,948	64	24	153	18	23	5,073
14	2,553	8,818	256	65	17	18	25	11,752
15	484	4,902	216	89	405	33	39	6,168
16	240	3,033	230	125	120	22	2	3,772
17	685	3,643	1,413	672	38	62	61	6,574
18	1,120	7,661	1,176	251	28	44	21	10,301
TOTAL	31,891	85,398	5,307	1,632	1,124	387	471	126,210
% of Total	25.3%	67.7%	4.2%	1.3%	0.9%	0.3%	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: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 6: Incident ESRD Patients, Prevalent Dialysis Patients, and Transplant Recipients by Reported Race, 2016

Patient Category	Black or African American		White		Asian		Native Hawaiian or Other Pacific Islander		American Indian or Alaska Native		Multiracial		Not Specified		Total	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Incident ESRD Patients, Calendar Year 2016	31,891	25.3%	85,398	67.7%	5,307	4.2%	1,632	1.3%	1,124	0.9%	387	0.3%	471	0.4%	126,210	100%
Prevalent Dialysis Patients as of December 31, 2016	170,656	34.4%	289,526	58.3%	21,665	4.4%	7,203	1.5%	5,657	1.1%	1,281	0.3%	213	0.0%	496,201	100%
Transplant Recipients, Calendar Year 2016	4,992	25.5%	12,793	65.4%	1,033	5.3%	181	0.9%	121	0.6%	69	0.4%	364	1.9%	19,553	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.

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 7: Incident ESRD Patients by Primary Cause of Renal Failure, Calendar Year 2016

Network	Diabetes	Hypertension/ Large Vessel Disease	Glomerulonephritis	Cystic/ Hereditary/ Congenital Diseases	Interstitial Nephritis/ Pyelonephritis	Neoplasms/ Tumors	Other*
1	1,796	875	361	214	138	95	0
2	3,331	1,904	512	219	175	165	0
3	2,496	1,667	275	113	117	94	0
4	2,450	1,395	341	172	131	102	0
5	2,862	2,293	330	187	97	111	0
6	4,756	3,736	570	245	122	175	0
7	3,447	3,039	357	214	138	142	0
8	3,033	2,487	318	145	74	124	0
9	4,463	2,351	529	300	217	183	0
10	2,312	1,854	240	132	90	89	0
11	3,348	1,816	606	316	237	160	0
12	2,173	1,207	321	162	114	83	0
13	2,400	1,686	198	118	80	91	0
14	6,282	3,028	489	295	166	123	0
15	3,083	1,311	404	190	148	111	0
16	1,823	649	387	140	138	120	0
17	3,538	1,502	381	172	117	77	0
18	5,445	2,650	489	261	151	120	0
TOTAL	59,038	35,450	7,108	3,595	2,450	2,165	0
% of Total	46.8%	28.1%	5.6%	2.8%	1.9%	1.7%	0.0%

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

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 7 (Cont'd): Incident ESRD Patients by Primary Cause of Renal Failure, Calendar Year 2016

Network	Secondary GN/ Vasculitis	Acute Kidney Failure	Genitourinary System	Disorders of Mineral Metabolism	Transplant Complications	Miscellaneous Conditions	Not Specified	Total Number of Incident ESRD Patients, Calendar Year 2016
1	97	98	16	5	26	289	75	4,085
2	153	349	41	7	40	463	384	7,743
3	77	107	9	1	10	228	17	5,211
4	76	139	17	1	37	356	124	5,341
5	91	156	13	3	22	346	406	6,917
6	211	202	27	7	24	500	283	10,858
7	138	159	17	3	24	400	327	8,405
8	122	126	15	5	28	236	191	6,904
9	136	306	24	5	43	534	252	9,343
10	85	98	12	1	19	260	132	5,324
11	145	297	23	2	39	544	145	7,678
12	92	129	12	0	28	292	148	4,761
13	78	106	7	2	15	228	64	5,073
14	189	214	17	2	37	375	535	11,752
15	140	132	31	9	21	274	314	6,168
16	80	98	19	0	11	263	44	3,772
17	98	135	22	9	16	245	262	6,574
18	140	289	23	6	37	381	309	10,301
TOTAL	2,148	3,140	345	68	477	6,214	4,012	126,210
% of Total	1.7%	2.5%	0.3%	0.1%	0.4%	4.9%	3.2%	100.0%

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

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 8: Prevalent Dialysis Patients by Age Group (in Years) as of December 31, 2016

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, 2016
1	40	262	635	1,386	2,767	3,810	3,320	2,195	14,415
2	78	568	1,544	3,086	6,068	7,841	6,293	4,094	29,572
3	33	308	911	2,002	3,973	5,396	4,747	2,775	20,145
4	74	371	921	2,045	4,030	5,519	4,371	2,608	19,939
5	63	505	1,571	3,264	5,834	7,467	5,769	2,951	27,424
6	143	1,011	2,974	6,480	10,690	13,514	9,104	3,921	47,837
7	121	539	1,579	3,270	6,070	8,093	6,623	4,209	30,504
8	88	575	1,722	3,785	6,229	7,864	5,296	2,295	27,854
9	129	624	1,666	3,754	6,797	9,334	7,157	3,954	33,415
10	68	485	1,159	2,332	3,935	5,433	4,317	2,497	20,226
11	103	621	1,579	3,022	5,531	7,511	5,881	3,496	27,744
12	93	363	818	1,746	3,400	4,573	3,477	2,013	16,483
13	93	451	1,349	2,683	4,400	5,597	3,740	1,634	19,947
14	279	1,019	2,778	6,242	11,174	14,215	9,065	3,842	48,614
15	137	588	1,373	2,919	5,221	6,664	4,992	2,441	24,335
16	62	399	881	1,649	2,923	3,991	2,993	1,528	14,426
17	94	579	1,532	2,935	5,724	7,682	5,671	3,441	27,658
18	171	1,163	2,610	5,168	9,791	12,292	9,010	5,458	45,663
TOTAL	1,869	10,431	27,602	57,768	104,557	136,796	101,826	55,352	496,201
% of Total	0.4%	2.1%	5.6%	11.6%	21.1%	27.6%	20.5%	11.2%	100%

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

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 9: Prevalent Dialysis Patients by Gender as of December 31, 2016

Network	Male	Female	Total Number of Dialysis Patients as of December 31, 2016
1	8,435	5,980	14,415
2	17,271	12,301	29,572
3	12,107	8,038	20,145
4	11,710	8,229	19,939
5	15,403	12,021	27,424
6	26,295	21,542	47,837
7	17,737	12,767	30,504
8	15,104	12,750	27,854
9	19,092	14,323	33,415
10	11,605	8,621	20,226
11	15,828	11,916	27,744
12	9,363	7,120	16,483
13	10,947	9,000	19,947
14	27,096	21,518	48,614
15	14,145	10,190	24,335
16	8,339	6,087	14,426
17	15,763	11,895	27,658
18	26,713	18,950	45,663
TOTAL	282,953	213,248	496,201
% of Total	57.0%	43.0%	100%

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

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 10: Prevalent Dialysis Patients by Reported Race as of December 31, 2016

Network	Black or African American	White	Asian	Native Hawaiian or Other Pacific Islander	American Indian or Alaska Native	Multi-racial	Not Specified	Total Number of Dialysis Patients as of December 31, 2016
1	3,053	10,766	469	62	25	31	9	14,415
2	11,154	15,824	2,059	244	80	192	19	29,572
3	5,902	13,305	635	135	7	157	4	20,145
4	6,855	12,647	324	73	14	23	3	19,939
5	15,561	10,801	806	180	20	39	17	27,424
6	30,835	15,980	555	168	213	59	27	47,837
7	11,855	17,820	486	207	48	70	18	30,504
8	16,654	10,824	168	62	118	24	4	27,854
9	10,918	22,072	260	94	16	46	9	33,415
10	7,641	11,789	686	66	6	34	4	20,226
11	8,811	17,066	850	81	875	52	9	27,744
12	4,829	11,221	216	77	114	22	4	16,483
13	10,056	8,848	211	91	684	55	2	19,947
14	13,198	34,042	1,004	226	75	49	20	48,614
15	2,529	17,749	814	463	2,666	84	30	24,335
16	1,232	11,203	989	525	425	49	3	14,426
17	3,658	14,161	6,218	3,301	143	164	13	27,658
18	5,915	33,408	4,915	1,148	128	131	18	45,663
TOTAL	170,656	289,526	21,665	7,203	5,657	1,281	213	496,201
% of Total	34.4%	58.3%	4.4%	1.5%	1.1%	0.3%	0.0%	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: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 11: Prevalent Dialysis Patients by Primary Diagnosis as of December 31, 2016

Network	Diabetes	Hypertension/Large Vessel Disease	Glomerulonephritis	Cystic/ Hereditary/Congenital Diseases	Interstitial Nephritis/ Pyelonephritis
1	6,144	3,129	1,625	772	592
2	12,420	7,888	2,691	1,052	789
3	9,608	5,889	1,664	623	524
4	8,497	5,467	1,696	746	586
5	10,703	9,693	1,978	771	519
6	19,307	17,547	3,623	1,325	795
7	12,505	10,594	2,074	1,080	629
8	11,693	10,457	1,883	822	496
9	15,032	8,846	2,752	1,254	937
10	8,379	7,089	1,399	624	422
11	11,846	7,337	2,632	1,193	993
12	7,272	4,613	1,424	649	513
13	8,726	7,009	1,228	653	366
14	26,144	13,112	2,794	1,336	765
15	12,595	5,261	2,054	863	712
16	6,569	2,531	1,806	743	609
17	14,728	6,308	2,304	813	653
18	23,773	12,385	3,091	1,343	730
TOTAL	225,941	145,155	38,718	16,662	11,630
% of Total	45.5%	29.3%	7.8%	3.4%	2.3%

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

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

TABLE 11 (Cont'd): Prevalent Dialysis Patients by Primary Diagnosis as of December 31, 2016

Network	Neoplasms/ Tumors	Other*	Secondary GN/Vasculitis	Miscellaneous Conditions	Not Specified	Total Number of Dialysis Patients as of December 31, 2016
1	583	120	398	989	63	14,415
2	859	320	704	2,527	322	29,572
3	498	105	360	840	34	20,145
4	807	166	430	1,312	232	19,939
5	648	161	538	1,791	622	27,424
6	1,084	190	1,097	2,412	457	47,837
7	846	147	692	1,474	463	30,504
8	589	128	578	1,066	142	27,854
9	1,094	302	662	2,251	285	33,415
10	563	92	414	1,048	196	20,226
11	761	271	755	1,768	188	27,744
12	502	134	362	885	129	16,483
13	583	100	390	809	83	19,947
14	1,091	197	950	1,636	589	48,614
15	671	153	620	1,160	246	24,335
16	571	102	411	1,054	30	14,426
17	572	155	537	1,292	296	27,658
18	876	247	880	1,920	418	45,663
TOTAL	13,198	3,090	10,778	26,234	4,795	496,201
% of Total	2.7%	0.6%	2.2%	5.3%	1.0%	100%

*“Other” includes all other Primary Diagnosis Codes from Field 15 of the CMS-2728 Form not specified in individual columns. Please refer to Page 3 of the CMS-2728 Form (<https://www.cms.gov/Medicare/CMS-Forms/CMS-Forms/Downloads/CMS2728.pdf>) for a list of additional codes.

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

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 12: Renal Transplant Recipients by Age Group (in Years), Calendar Year 2016

Network	0–19	20–29	30–39	40–49	50–59	60–69	70–79	≥80	Total Number of Transplant Recipients, Calendar Year 2016
1	46	47	95	152	223	229	68	2	862
2	49	95	152	275	400	389	92	4	1,456
3	17	41	80	112	145	126	30	0	551
4	51	62	122	180	290	328	93	1	1,127
5	45	63	154	257	329	319	93	2	1,262
6	56	76	185	298	332	299	64	2	1,312
7	43	62	142	203	231	247	72	1	1,001
8	33	58	109	226	204	202	33	0	865
9	44	91	162	251	291	276	58	0	1,173
10	22	58	91	148	169	152	38	0	678
11	67	110	225	360	449	388	135	3	1,737
12	48	75	118	173	199	220	57	2	892
13	27	43	97	107	142	142	24	1	583
14	92	145	234	362	459	407	72	3	1,774
15	55	87	162	232	303	310	107	3	1,259
16	30	53	72	132	137	151	45	2	622
17	60	103	158	222	262	272	60	0	1,137
18	59	100	149	244	290	336	83	1	1,262
TOTAL	844	1,369	2,507	3,934	4,855	4,793	1,224	27	19,553
% of Total	4.3%	7.0%	12.8%	20.1%	24.8%	24.5%	6.3%	0.1%	100%

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

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 13: Renal Transplant Recipients by Gender, Calendar Year 2016

Network	Male	Female	Total Number of Transplant Recipients, Calendar Year 2016
1	547	315	862
2	889	567	1,456
3	361	190	551
4	697	430	1,127
5	720	542	1,262
6	794	518	1,312
7	610	391	1,001
8	504	361	865
9	707	466	1,173
10	429	249	678
11	1,073	664	1,737
12	558	334	892
13	337	246	583
14	1,037	737	1,774
15	731	528	1,259
16	393	229	622
17	637	500	1,137
18	723	539	1,262
TOTAL	11,747	7,806	19,553
% of Total	60.1%	39.9%	100%

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

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 14: Renal Transplant Recipients by Reported Race, Calendar Year 2016

Network	Black or African American	White	Asian	Native Hawaiian or Other Pacific Islander	American Indian or Alaska Native	Multiracial	Not Specified	Total Number of Transplant Recipients, Calendar Year 2016
1	144	640	34	6	1	7	30	862
2	450	873	106	5	1	15	6	1,456
3	140	373	26	4	0	1	7	551
4	366	694	32	5	0	2	28	1,127
5	568	600	62	15	0	1	16	1,262
6	648	586	28	5	1	1	43	1,312
7	331	606	28	10	2	2	22	1,001
8	458	394	12	0	1	0	0	865
9	254	873	20	6	2	0	18	1,173
10	206	372	29	2	0	1	68	678
11	285	1,307	90	4	20	7	24	1,737
12	171	662	28	3	4	3	21	892
13	205	324	14	1	14	4	21	583
14	368	1,318	59	14	3	5	7	1,774
15	102	1,015	51	13	61	4	13	1,259
16	46	481	70	16	6	3	0	622
17	122	684	228	50	4	9	40	1,137
18	128	991	116	22	1	4	0	1,262
TOTAL	4,992	12,793	1,033	181	121	69	364	19,553
% of Total	25.5%	65.4%	5.3%	0.9%	0.6%	0.4%	1.9%	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: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 15: Transplant Events by Donor Type, Calendar Year 2016

Network	Deceased Donors	Living Related Donors	Living Unrelated Donors	Total Number of Renal Transplants, Calendar Year 2016
1	561	150	152	863
2	962	248	247	1,457
3	357	88	108	553
4	850	133	147	1,130
5	897	265	101	1,263
6	1,002	221	91	1,314
7	826	109	67	1,002
8	695	68	103	866
9	784	171	219	1,174
10	436	132	111	679
11	1,066	272	400	1,738
12	695	127	76	898
13	461	80	42	583
14	1,252	246	277	1,775
15	968	146	147	1,261
16	452	67	104	623
17	866	116	157	1,139
18	922	168	173	1,263
TOTAL	14,052	2,807	2,722	19,581

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 16: Number of Dialysis Patients Aged 18–54 Years, Number and Percent Employed, Number and Percent Receiving Vocational Rehabilitation Services, Number and Percent Attending School, and Number and Percent of Facilities Offering Dialysis after Regular Business Hours, as of December 31, 2016

Network	Number of Dialysis Patients Aged 18–54 Years as of December 31, 2016	Number Employed*	Percent Employed*	Number Receiving Vocational Rehabilitation Services	Percent Receiving Vocational Rehabilitation Services	Number Attending School*	Percent Attending School*	Number of Dialysis Facilities After Regular Hours (5 PM)	Percent of Dialysis Facilities After Regular Hours (5 PM)
1	3,468	807	23%	25	1%	37	1%	59	30%
2	7,864	1,679	21%	44	1%	97	1%	113	40%
3	4,986	992	20%	19	0%	47	1%	70	32%
4	5,068	968	19%	17	0%	31	1%	50	15%
5	7,936	1,767	22%	16	0%	47	1%	74	18%
6	15,354	2,466	16%	73	0%	166	1%	36	5%
7	8,072	1,707	21%	62	1%	176	2%	65	15%
8	8,917	1,341	15%	15	0%	53	1%	25	6%
9	9,001	1,884	21%	46	1%	60	1%	89	15%
10	5,722	1,197	21%	7	0%	40	1%	35	11%
11	7,698	1,792	23%	99	1%	173	2%	280	55%
12	4,444	1,006	23%	10	0%	33	1%	33	10%
13	6,406	1,208	19%	134	2%	120	2%	26	8%
14	15,044	3,131	21%	137	1%	233	2%	68	11%
15	7,276	1,609	22%	16	0%	46	1%	91	25%
16	4,237	1,097	26%	57	1%	104	2%	111	52%
17	7,536	1,606	21%	14	0%	63	1%	68	24%
18	13,278	2,413	18%	61	0%	142	1%	386	100%
TOTAL	142,307	28,670	—	852	—	1,668	—	1679	—
% of Total	—	—	20%	—	1%	—	1%	—	24%

*Full- or part-time. NOTE: Items in this table are reported on the CMS-2744 Form in CROWNWeb. Due to the manner in which CROWNWeb calculates employment, vocational rehabilitation, and school on the CMS-2744 Form, the numbers reported in this table may vary slightly from actual totals.

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Table 17: Number and Percent of In-Center and Home Dialysis Patients with an Arteriovenous Fistula (AVF) in Use, December 2015 Compared with December 2016

Network	2015		2016	
	Number	Percent	Number	Percent
1	8,136	66.1%	8,495	65.4%
2	17,729	66.4%	18,510	65.9%
3	10,934	61.0%	11,081	58.9%
4	10,790	63.5%	11,179	60.7%
5	14,117	60.5%	14,653	58.7%
6	24,199	60.9%	25,425	59.5%
7	15,270	60.5%	16,174	59.0%
8	14,456	61.2%	14,999	60.3%
9	16,601	59.7%	17,255	57.9%
10	10,325	60.9%	10,650	58.8%
11	14,763	63.0%	15,090	60.0%
12	8,348	63.2%	8,763	61.5%
13	10,194	61.7%	10,732	60.6%
14	25,484	61.6%	26,984	60.9%
15	14,013	69.5%	14,763	68.5%
16	8,123	70.2%	8,444	67.9%
17	14,875	66.2%	15,870	65.2%
18	25,605	66.7%	27,186	66.5%
Weighted Mean	---	63.2%	---	61.8%
TOTAL	263,962	---	276,253	---

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 2016 were obtained from the Fistula First Dashboard, as of December 2016.

Table 18: Percentage of Dialysis Access Type by Network, as of December 31, 2016

Network	AVF	AVG	Catheter ≥90 Days	Catheter Less Than 90 Days	AVF with AVG	AVF with Catheter	AVG with Catheter	Port	Other/ Unknown
1	65.41%	14.66%	10.15%	6.49%	0.08%	0.22%	0.22%	0.02%	0.00%
2	65.94%	13.09%	11.38%	6.25%	0.05%	0.20%	0.20%	0.01%	0.02%
3	58.95%	17.57%	12.88%	7.04%	0.08%	0.26%	0.26%	0.01%	0.01%
4	60.73%	16.79%	10.50%	6.72%	0.07%	0.31%	0.31%	0.01%	0.00%
5	58.72%	18.09%	10.95%	6.82%	0.09%	0.31%	0.31%	0.02%	0.00%
6	59.53%	21.21%	9.03%	6.32%	0.10%	0.37%	0.37%	0.03%	0.01%
7	59.00%	18.23%	10.84%	7.46%	0.09%	0.32%	0.32%	0.04%	0.02%
8	60.35%	20.44%	9.29%	6.46%	0.08%	0.40%	0.40%	0.02%	0.00%
9	57.92%	18.62%	10.81%	7.08%	0.17%	0.43%	0.43%	0.01%	0.00%
10	58.84%	17.86%	11.57%	6.84%	0.08%	0.40%	0.40%	0.02%	0.01%
11	59.99%	16.62%	10.90%	6.79%	0.10%	0.26%	0.26%	0.02%	0.02%
12	61.45%	17.10%	9.27%	7.68%	0.13%	0.28%	0.28%	0.04%	0.01%
13	60.55%	17.98%	10.62%	6.94%	0.11%	0.42%	0.42%	0.01%	0.01%
14	60.86%	18.58%	9.54%	6.55%	0.10%	0.34%	0.34%	0.02%	0.01%
15	68.47%	12.73%	9.07%	6.37%	0.04%	0.18%	0.18%	0.01%	0.01%
16	67.89%	13.46%	9.10%	6.74%	0.08%	0.29%	0.29%	0.02%	0.02%
17	65.25%	16.30%	9.08%	5.90%	0.06%	0.21%	0.21%	0.01%	0.00%
18	66.47%	14.37%	9.85%	5.87%	0.03%	0.17%	0.17%	0.02%	0.01%
National Total	61.88%	17.17%	10.19%	6.61%	0.09%	0.30%	0.02%	0.01%	0.00%

SOURCE: Data for 2016 were obtained from the Fistula First Dashboard, as of December 2016.

Table 19: Number of In-Center Dialysis Patients as of December 31, 2015 and December 31, 2016

Network	Number of In-Center Dialysis Patients* as of December 31, 2015	Number of In-Center Dialysis Patients* as of December 31, 2016	% Change
1	12,386	12761	3%
2	27,264	27667	1%
3	18,204	18672	3%
4	17,334	17712	2%
5	23,679	24350	3%
6	40,019	41793	4%
7	25,637	26753	4%
8	23,662	24380	3%
9	28,535	29160	2%
10	16,762	17313	3%
11	24,038	24553	2%
12	13,175	13825	5%
13	16,709	17410	4%
14	41,875	43801	5%
15	20,439	21253	4%
16	11,532	12129	5%
17	23,030	24018	4%
18	38,849	40506	4%
TOTAL	423,129	438,056	4%

*Includes patients in training for home modalities.

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016.

Due to changes in data sources, slight differences may exist between the 2016 counts reported above and those provided for the 2015 Summary Annual Report.

Table 20: Number of Home Dialysis Patients by Modality as of December 31, 2015 and December 31, 2016

Network	Hemodialysis			Continuous Ambulatory Peritoneal Dialysis			Continuous Cycling Peritoneal Dialysis			Other Peritoneal Dialysis*		Total	
	2015	2016	% Change	2015	2016	% Change	2015	2016	% Change	2015	2016	2015	2016
1	231	234	1%	251	266	6%	1,078	1149	7%	1	0	1,561	1,649
2	370	405	9%	478	449	-6%	1,015	1086	7%	0	0	1,863	1,940
3	130	127	-2%	209	181	-13%	1,134	1210	7%	0	0	1,473	1,518
4	306	346	13%	319	307	-4%	1,495	1595	7%	2	3	2,122	2,251
5	530	612	15%	632	550	-13%	1,844	2010	9%	7	16	3,013	3,188
6	908	920	1%	859	824	-4%	4,105	4319	5%	1	0	5,873	6,063
7	610	667	9%	451	434	-4%	2,537	2672	5%	1	6	3,599	3,779
8	446	475	7%	437	425	-3%	2,474	2590	5%	2	0	3,359	3,490
9	631	634	0%	847	784	-7%	2,652	2872	8%	3	4	4,133	4,294
10	824	790	-4%	309	262	-15%	1,718	1911	11%	2	0	2,853	2,963
11	517	602	16%	809	760	-6%	1,720	1853	8%	0	0	3,046	3,215
12	453	438	-3%	389	381	-2%	1,754	1857	6%	5	2	2,601	2,678
13	272	316	16%	396	356	-10%	1,712	1849	8%	0	1	2,380	2,522
14	605	539	-11%	684	702	3%	3,423	3576	4%	6	5	4,718	4,822
15	303	311	3%	456	444	-3%	2,151	2351	9%	0	0	2,910	3,106
16	333	309	-7%	318	348	9%	1,606	1653	3%	1	0	2,258	2,310
17	304	307	1%	681	652	-4%	2,529	2579	2%	1	0	3,515	3,538
18	407	402	-1%	957	885	-8%	3,638	3887	7%	1	0	5,003	5,174
TOTAL	8,180	8,434	3%	9,482	9,010	-5%	38,585	41,019	6%	33	37	56,280	58,500

*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.

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016. Due to changes in data sources, slight differences may exist between the 2016 counts reported above and those found in the 2015 Summary Annual Report.

Table 21: Number of Patients Using In-Center and Home Dialysis as of December 31, 2015 and December 31, 2016

Network	In-Center Dialysis			Home Dialysis			Total		
	2015	2016	% Change	2015	2016	% Change	2015	2016	Total
1	12,386	12,761	3%	1,561	1,649	6%	13,947	14,410	3%
2	27,264	27,667	1%	1,863	1,940	4%	29,127	29,607	2%
3	18,204	18,672	3%	1,473	1,518	3%	19,677	20,190	3%
4	17,334	17,712	2%	2,122	2,251	6%	19,456	19,963	3%
5	23,679	24,350	3%	3,013	3,188	6%	26,692	27,538	3%
6	40,019	41,793	4%	5,873	6,063	3%	45,892	47,856	4%
7	25,637	26,753	4%	3,599	3,779	5%	29,236	30,532	4%
8	23,662	24,380	3%	3,359	3,490	4%	27,021	27,870	3%
9	28,535	29,160	2%	4,133	4,294	4%	32,668	33,454	2%
10	16,762	17,313	3%	2,853	2,963	4%	19,615	20,276	3%
11	24,038	24,553	2%	3,046	3,215	6%	27,084	27,768	3%
12	13,175	13,825	5%	2,601	2,678	3%	15,776	16,503	5%
13	16,709	17,410	4%	2,380	2,522	6%	19,089	19,932	4%
14	41,875	43,801	5%	4,718	4,822	2%	46,593	48,623	4%
15	20,439	21,253	4%	2,910	3,106	7%	23,349	24,359	4%
16	11,532	12,129	5%	2,258	2,310	2%	13,790	14,439	5%
17	23,030	24,018	4%	3,515	3,538	1%	26,545	27,556	4%
18	38,849	40,506	4%	5,003	5,174	3%	43,852	45,680	4%
TOTAL	423,129	438,056	4%	56,280	58,500	4%	479,409	496,556	4%

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 = 496,556) differs from the total prevalence reported in Tables 1, 8, 9, and 10 (N = 496,201).

SOURCES: ESRD NCC Data Tables provided to Networks 1–18 for Annual Reports, 2016. Due to changes in data sources, slight differences may exist between the 2016 counts reported above and those published in the 2015 Summary Annual Report.

Table 22: Complaints, Grievances, Non-Grievance Access-to-Care Cases, and Involuntary Discharges, Calendar Year 2016

Network	Number of Dialysis Patients as of December 31, 2016	Number of Grievance Cases Opened by the Network	Rate of Grievance Cases per 1,000 Prevalent Patients	Total Number of Grievance Cases Involving Access to Care	Rate of Grievance Cases Involving Access to Care per 1,000 Prevalent Patients	Number of Grievance Cases Involving Involuntary Transfer	Rate of Grievance Cases Involving Involuntary Transfer per 1,000 Prevalent Patients
1	14,415	6	0.42	0	0.00	0	0.00
2	29,572	73	2.47	2	0.07	0	0.00
3	20,145	60	2.98	2	0.10	0	0.00
4	19,939	243	12.19	7	0.35	1	0.05
5	27,424	69	2.52	2	0.07	0	0.00
6	47,837	260	5.44	32	0.67	2	0.04
7	30,504	98	3.21	0	0.00	0	0.00
8	27,854	104	3.73	21	0.75	0	0.00
9	33,415	116	3.47	0	0.00	0	0.00
10	20,226	47	2.32	6	0.30	0	0.00
11	27,744	71	2.56	0	0.00	0	0.00
12	16,483	39	2.37	0	0.00	0	0.00
13	19,947	84	4.21	0	0.00	0	0.00
14	48,614	133	2.74	22	0.45	0	0.00
15	24,335	116	4.77	8	0.33	0	0.00
16	14,426	72	4.99	0	0.00	0	0.00
17	27,658	89	3.22	4	0.14	3	0.11
18	45,663	192	4.20	3	0.07	0	0.00
TOTAL	496,201	1,872	---	109	---	6	---
Mean	---	---	3.77	---	0.22	---	0.01

NOTE: The data in this table reflect only IVD, IVT, and FTP cases.
SOURCE: Networks 1–18, 2016 Annual Report.

Table 22 (Cont'd): Complaints, Grievances, Non-Grievance Access-to-Care Cases, and Involuntary Discharges, Calendar Year 2016

Network	Number of Grievance Cases Involving Involuntary Discharge	Rate of Grievance Cases Involving Involuntary Discharges per 1,000 Prevalent Patients	Number of Grievance Cases Involving Failure to Place	Rate of Grievance Cases Involving Failure to Place per 1,000 Prevalent Patients	Total Number of Non-Grievance Cases Involving IVT, IVD, and FTP	Rate of Non-Grievance Cases Involving IVT, IVD, and FTP per 1,000 Prevalent Patients
1	0	0.00	0	0.00	5	0.35
2	1	0.03	1	0.03	43	1.45
3	2	0.10	0	0.00	30	1.49
4	3	0.15	3	0.15	51	2.56
5	1	0.04	1	0.04	82	2.99
6	26	0.54	4	0.08	50	1.05
7	0	0.00	0	0.00	85	2.79
8	0	0.00	21	0.75	53	1.90
9	0	0.00	0	0.00	51	1.53
10	0	0.00	6	0.30	33	1.63
11	0	0.00	0	0.00	27	0.97
12	0	0.00	0	0.00	19	1.15
13	0	0.00	0	0.00	51	2.56
14	8	0.16	14	0.29	93	1.91
15	3	0.12	5	0.21	34	1.40
16	0	0.00	0	0.00	42	2.91
17	1	0.04	0	0.00	22	0.80
18	2	0.04	1	0.02	32	0.70
TOTAL	47	---	56	---	803	---
Mean	---	0.09	---	0.11	---	1.62
NOTE: The data in this table reflect only IVD, IVT, and FTP cases. SOURCE: Networks 1–18, 2016 Annual Report.						

Table 22 (Cont'd): Complaints, Grievances, Non-Grievance Access-to-Care Cases, and Involuntary Discharges, Calendar Year 2016

Network	Number of Non-Grievance Access-to-Care Cases Involving Involuntary Transfer	Rate of Non-Grievance Access-to-Care Cases Involving Involuntary Transfer per 1,000 Prevalent Patients	Number of Non-Grievance Access-to-Care Cases Involving Involuntary Discharge	Rate of Non-Grievance Access-to-Care Cases Involving Involuntary Discharge per 1,000 Prevalent Patients	Number of Non-Grievance Access-to-Care Cases Involving Failure to Place	Rate of Non-Grievance Access-to-Care Cases Involving Failure to Place per 1,000 Prevalent Patients	Total Number of Grievance and Non-Grievance Cases Involving Access to Care
1	1	0.07	4	0.28	0	0.00	5
2	2	0.07	32	1.08	9	0.30	45
3	2	0.10	27	1.34	1	0.05	32
4	0	0.00	41	2.06	10	0.50	58
5	3	0.11	40	1.46	39	1.42	84
6	0	0.00	45	0.94	5	0.10	82
7	0	0.00	61	2.00	24	0.79	85
8	7	0.25	28	1.01	18	0.65	74
9	6	0.18	28	0.84	17	0.51	51
10	0	0.00	21	1.04	12	0.59	39
11	1	0.04	22	0.79	4	0.14	27
12	0	0.00	9	0.55	10	0.61	19
13	19	0.95	28	1.40	4	0.20	51
14	0	0.00	79	1.63	14	0.29	115
15	2	0.08	17	0.70	15	0.62	42
16	1	0.07	22	1.53	19	1.32	42
17	3	0.11	6	0.22	13	0.47	26
18	0	0.00	28	0.61	4	0.09	35
TOTAL	47	---	538	---	218	---	912
Mean	---	0.09	---	1.08	---	0.44	---
NOTE: The data in this table reflect only IVD, IVT, and FTP cases. SOURCE: Networks 1–18, 2016 Annual Report.							