

2018

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



ESRD National Coordinating Center  
(ESRD NCC)  
[www.esrdncc.org](http://www.esrdncc.org)



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Additional information: For additional information about the ESRD Program or to review prior *Summary Annual Reports*, please visit [www.esrdncc.org](http://www.esrdncc.org) or contact the NCC at [NCCinfo@hsag.com](mailto:NCCinfo@hsag.com).

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## Table of Contents

Impact of Network Quality Improvement Activities (QIAs).....	4
Long-Term Catheter (LTC) Reduction.....	5
Bloodstream Infections Prevented.....	5
Home Dialysis Utilization.....	6
Transplant.....	8
Involuntary Discharges Averted.....	9
Summary.....	10
Introduction.....	10
Report Highlights.....	10
Dialysis Prevalence.....	10
Home Dialysis.....	11
Grievances.....	11
Patient Engagement.....	11
Emergency Management.....	11
ESRD Program Funding and Definition of Service Areas.....	11
The ESRD National Coordinating Center.....	12
Network Requirements.....	13
Network Staffing.....	13
Network Governance.....	13
Patient Profile.....	14
Patients and Facilities.....	14
Understanding Patient Characteristics.....	14
Prevalent Dialysis Patients.....	15
Improving Care for ESRD Patients by Increasing the Use of Permanent Accesses.....	15
Vascular Access.....	15
The Role of the Networks in Increasing Fistula Placement Rates and Decreasing Long-Term Catheter Use Rates.....	15
Patient Safety.....	17
Support for the National Healthcare Safety Network.....	17
Healthcare-Associated Infections Learning and Action Network.....	17
Quality Improvement Activities.....	18
Bloodstream Infections.....	18
Promote Appropriate Home Dialysis.....	19
Improve Transplant Coordination.....	19
Support for the ESRD Quality Incentive Program.....	20
Provider Education.....	21
Ensuring Data Quality.....	21
CROWNWeb.....	21
Veterans Health Administration and Transplant Facility Data.....	22
Disparities in ESRD Care.....	22
Population Health Focused Pilot QIAs.....	23
Improve Dialysis Care Coordination with a Focus on Reducing Hospital Utilization.....	23



Positively Impact the Quality of Life of the ESRD Patient with a Focus on Mental Health ...	24
Support Gainful Employment of ESRD Patients.....	24
Positively Impact the Quality of Life of ESRD Patients with a Focus on Pain Management..	25
Partnerships and Coalitions .....	25
Patient and Family Engagement.....	27
Education for Patients and Caregivers.....	27
Patient Experience of Care LAN .....	27
Network-Specific Patient Engagement Activities.....	27
National Patient and Family Engagement Learning and Action Network Activities.....	28
Grievances and Access to Care .....	28
Evaluation and Resolution of Grievances .....	28
Grievance Process and Data .....	29
Recommendations to CMS for Additional Facilities.....	30
Emergency Preparedness and Response.....	30
Special Projects .....	32
National Coordinating Center.....	32
Kidney Community Emergency Response Program.....	32
Data Tables .....	34
Table 1: ESRD Medicare-Certified Dialysis Facilities – Modality Offered .....	35
Table 2. Grievances and Non-Grievances by Case Type, Number, and Percent.....	36
Table 3. National ESRD Patient Data Overview.....	37

## Impact of Network Quality Improvement Activities (QIAs)

The Networks serve all patients with End-Stage Renal Disease (ESRD) and support all ESRD in-center and home dialysis providers, as well as kidney transplant providers, across the United States and its territories. Through the development and implementation of QIAs, each Network collaborates with a specific subset of facilities in its service area to improve targeted outcomes. These activities enrich the lives of kidney patients through a mix of clinical initiatives, quality of life improvements, and efforts to enhance continuity of care. Using quality improvement tools, the Networks conduct data analysis to develop improvement strategies. In 2018, the Networks implemented targeted facility-level interventions based on the results of root cause analyses (RCAs) and plan-do-study-act (PDSA) cycles.

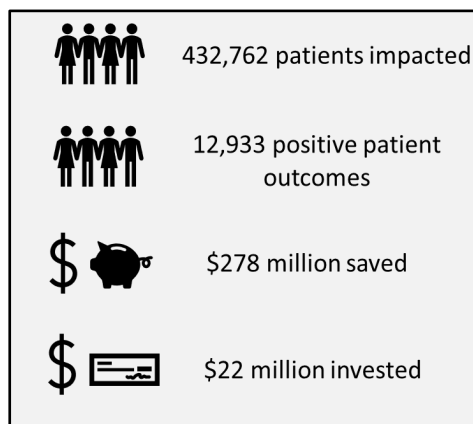


Figure 1. Overall patient impacts and estimated cost savings for the 2018 ESRD QIA program.

From January to September 2018, the ESRD Network Program Option Year (OY)2 QIAs included 5,580 dialysis facilities, representing 74.7% of all 7,473 dialysis facilities. During the period of intervention, Networks supported facilities and patients in improving patient care, directly or indirectly impacting 432,762 patients who were patients at QIA facilities from January to September and experienced the effects of quality improvement activities. Specifically, interventions were aimed at reducing the long-term use of catheters (greater than or equal to 90 days from initial dialysis), reducing bloodstream infections, increasing the use of home dialysis, increasing the number of patients on the transplant waitlist, and averting involuntary discharges. Analysis of impacts on patients in facilities engaged in QIAs showed 12,933 positive patient outcomes in the 2018 QIA performance period. In total, these improved outcomes represent an estimated \$228 million in savings with an additional \$50 million in future annual savings within three years for a total of \$278 million (Figure 1). These cost savings can be compared with an average annual budget of \$22 million for the Network program. The impact extends beyond those direct, measurable outcomes. The changes in processes and policies and increased education the QIA facilities receive touch all patients dialyzing in those centers. The following sections highlight the positive outcomes and avoided adverse events associated with each quality improvement area of focus.

## Long-Term Catheter (LTC) Reduction

Compared with dialyzing with an arteriovenous fistula, dialysis performed with an LTC increases the risk of mortality and serious infections and may result in more frequent hospitalizations and access-related procedures and less adequacy in treatment.<sup>1</sup> Efforts to reduce catheter use offer significant positive impacts for patients. In 2018, the Networks built upon their history of education and intervention regarding vascular access, focusing on reducing the number of patients dialyzing with a long-term central venous catheters (CVC) only access.

According to United States Renal Data System (USRDS) data, the cost of dialysis per year for an

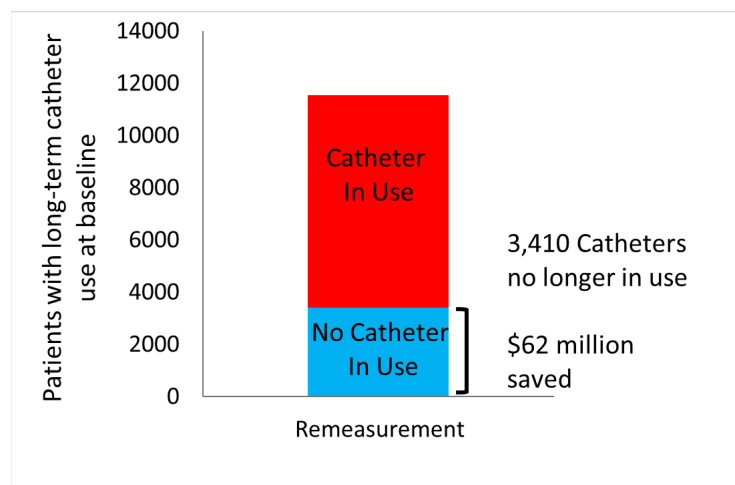


Figure 2. Transition of patients from catheter-only access to non-catheter modalities in the 2018 ESRD QIA program.

LTC patient is approximately \$90,000.<sup>2</sup> The cost for a patient dialyzing with a permanent access is approximately \$72,000 per year—a difference of \$18,000. At the beginning of the QIA period in 2018, QIA facilities had 11,535 patients with long-term catheter in use. By the end of the remeasurement period, 3,410 of these patients were dialyzing without a catheter. During OY 2 this reduction in the use of catheters represents approximately

\$62 million in cost savings (Figure 2).

## Bloodstream Infections Prevented

Due to the regular and frequent access to patients' bloodstreams while dialyzing, ESRD patients are at increased risk for hospital-acquired infections (HAIs), specifically bloodstream infections (BSIs).<sup>3</sup> Infections can jeopardize patients' quality and length of life. Attributable mortality for patients positive for a BSI is 12.0–25.0%.<sup>4</sup> The QIAs increased awareness and educated facility staff and patients, directly impacting the quality of life for patients.

<sup>1</sup> Rehman R, Schmidt RJ, Moss AH. Ethical and legal obligation to avoid long-term tunneled catheter access. *CJASN*. 2009; 4(2):456–460. doi: <https://doi.org/10.2215/CJN.03840808>.

<sup>2</sup> U.S. Renal Data System, 2010 USRDS Annual Data Report: Atlas of Kidney Disease and End Stage Renal Disease in the United States. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2010.

<sup>3</sup> Dialysis safety. Centers for Disease Control and Prevention website. Available at: <https://www.cdc.gov/dialysis/index.html>. 2018. Accessed on: October 24, 2018.

<sup>4</sup> Srinivasan A, Wise M, Bell M, et al. Vital Signs: Central Line–Associated Blood Stream Infections – United States, 2001, 2008, and 2009. *Morbidity and Mortality Weekly Report*. 2011; 60(08):243–248.

According to the National Healthcare Safety Network, the cost of treatment often including possible hospitalizations associated with catheter line-acquired BSIs ranges from \$3,700 to \$28,000 with a median cost of \$15,850 per patient per episode.<sup>5</sup> During the baseline period of January 1, 2017, to June 30, 2017, there were 5,937 BSIs in QIA facilities, corresponding to a rate of 1.29 infections per 100

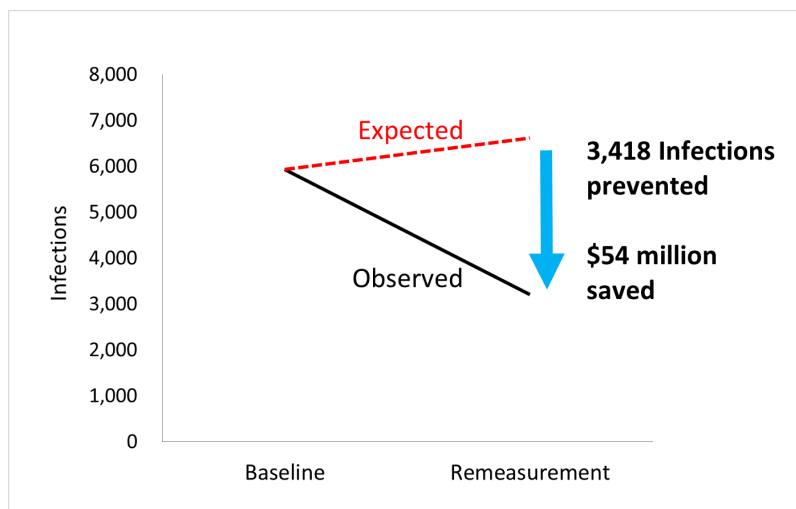


Figure 3. Reductions in expected bloodstream infections in the 2018 ESRD QIA program.

patient-months. Applying this rate to the prevalent patients in the remeasurement period of January 1, 2018, to June 30, 2018, yields 6,621 expected infections during this period. There were 3,203 observed infections during the remeasurement period—3,418 fewer than expected, representing cost savings of approximately \$54 million (Figure 3).

### Home Dialysis Utilization

Home dialysis is defined as either peritoneal dialysis (PD) or home hemodialysis (HHD). In comparison with in-center hemodialysis (ICHHD), home dialysis has established benefits to patient length of life<sup>6,7</sup> and potential for reduced cost of treatment and overall costs to the

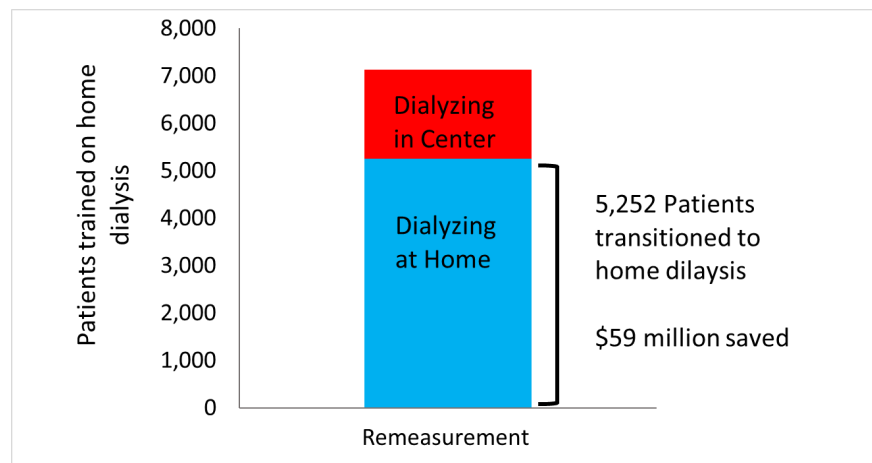
<sup>5</sup> Scott RD II. The direct medical costs of healthcare-associated infections in U.S. hospitals and the benefits of prevention (Publication No. CS200891-A). Atlanta, GA: Centers for Disease Control and Prevention. March 2009. Available at: [https://www.cdc.gov/hai/pdfs/hai/scott\\_costpaper.pdf](https://www.cdc.gov/hai/pdfs/hai/scott_costpaper.pdf). Accessed on: August 27, 2018.

<sup>6</sup> Walker RC, Howard K, Morton RL. Home hemodialysis: a comprehensive review of patient-centered and economic considerations. ClinicoEconomics and outcomes research: CEOR. 2017; 9:149–161. doi: 10.2147/CEOR.S69340.

<sup>7</sup> Mehrotra R, Chiu Y-W, Kalantar-Zadeh K, Bargman J, Vonesh E. Similar outcomes with hemodialysis and peritoneal dialysis in patients with end-stage renal disease. Arch Intern Med. 2011 Jan 24; 171(2):110–118. Published online 2010 Sep 27. doi: 10.1001/archinternmed.2010.352.

health system.<sup>8</sup> The home dialysis 2018 QIA focused interventions on training patients to dialyze at home.

Data from the USRDS indicate that annual cost of home dialysis is substantially less than in-center dialysis for qualified patients.<sup>9</sup> The annual cost of in-center therapy for all modalities is



approximately \$78,049 a year versus approximately \$66,751 for therapy at home—a difference of \$11,298 per year. As a result of education and outreach activities during the 2018 QIA program, 7,131 patients were trained to perform dialysis at home. At the end of the remeasurement

Figure 4. Transitions to Home Dialysis in the 2018 ESRD QIA program.

period, 5,252 of these patients had transitioned to home dialysis, representing cost savings of approximately \$59 million across QIA facilities (Figure 4).

<sup>8</sup> Ishani A, Slinin Y, Greer N, et al. Comparative effectiveness of home-based kidney dialysis versus in-center or other outpatient kidney dialysis locations—A systematic review [Internet]. Washington, DC: Department of Veterans Affairs (US); 2015 Apr. EXECUTIVE SUMMARY. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK344417/>.

<sup>9</sup> U.S. Renal Data System, USRDS 2012 Annual Data Report: Atlas of Kidney Disease in the United States. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2012. Available at: <https://www.usrds.org/atlas12.aspx>.



## Transplant

Patients receiving a kidney transplant have better outcomes than those remaining on dialysis, including improved five-year survival rates.<sup>10,11</sup> The ESRD Networks' 2018 QIA interventions focused on moving patients to the transplant waitlist with the ultimate goal of achieving transplants for these patients. Interventions took many forms.

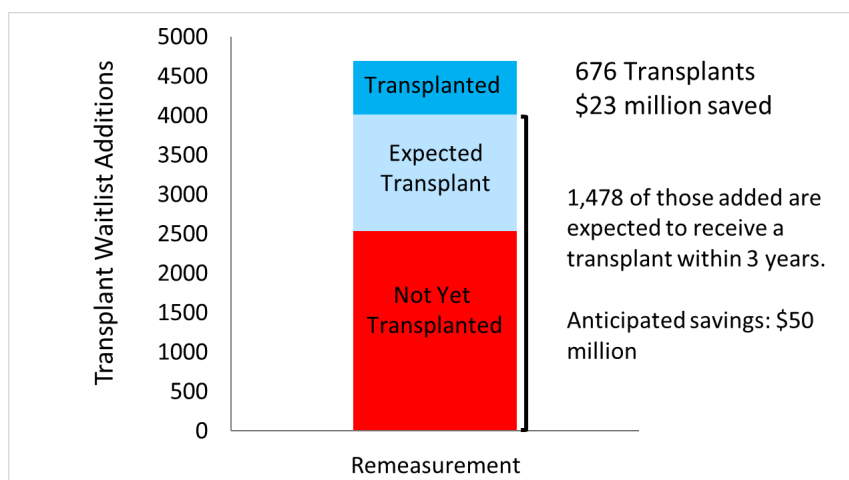


Figure 5. Patients added to the waitlist and transplanted in the 2018 ESRD QIA program.

Per the USRDS, the average annual cost of dialysis for patients using any modality is \$78,337. The cost of getting a transplant is \$97,935 for the transplant and \$11,975 in additional annual costs.<sup>12</sup> Since the direct cost of the transplant is incurred only in the first year, a 3-year amortized cost of living with a transplant can be calculated at approximately \$44,620. Therefore, for each patient who receives a transplant, the annual amortized cost savings are estimated at \$33,717. Through the Networks' efforts, 4,691 patients from the QIA facilities were added to the waitlist during the intervention period. By the end of the intervention period, 676 patients received a transplant, representing \$23 million in cost savings (Figure 5). In addition, an analysis of transplants between 2014 and 2017 showed that 36.8% of patients added to the transplant waitlist receive a transplant within 3 years.<sup>13</sup> Based on this rate, future transplants for patients added to the waitlist but still waiting as of the end of the QIA period would represent an additional \$50 million in estimated cost savings after three years.

<sup>10</sup> Tonelli M, Wiebe N, Knoll G, Bello A, Browne S, Jadhav D, Klarenbach S, Gill J. Systematic review: Kidney transplantation compared with dialysis in clinically relevant outcomes. *Am J Transplant*. 2011 Oct; 11(10):2093–109.

<sup>11</sup> U.S. Renal Data System, *USRDS 2018 Annual Data Report: Epidemiology of Kidney Disease in the United States*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2018. Available at: <https://www.usrds.org/atlas12.aspx>.

<sup>12</sup> U.S. Renal Data System, *USRDS 2012 Annual Data Report: Atlas of Kidney Disease in the United States*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2012. Available at: <https://www.usrds.org/atlas12.aspx>

<sup>13</sup> 2017 Annual Data Report: Kidney. Scientific Registry of Transplant Recipients. Available at: <https://onlinelibrary.wiley.com/doi/full/10.1111/ajt.15274#ajt15274-fig-0022>.

## Involuntary Discharges Averted

According to the ESRD Conditions for Coverage (CfCs) and the CMS definition of an involuntary discharge (IVD), an IVD from a facility may leave a dialysis patient without an outpatient facility to provide weekly dialysis. An ESRD patient who is unable to dialyze in an outpatient setting must be evaluated in a hospital emergency room for acute dialysis treatment at a substantial increase in cost and at a detriment to his or her life expectancy.<sup>14</sup> Treating ESRD only in the emergent setting places

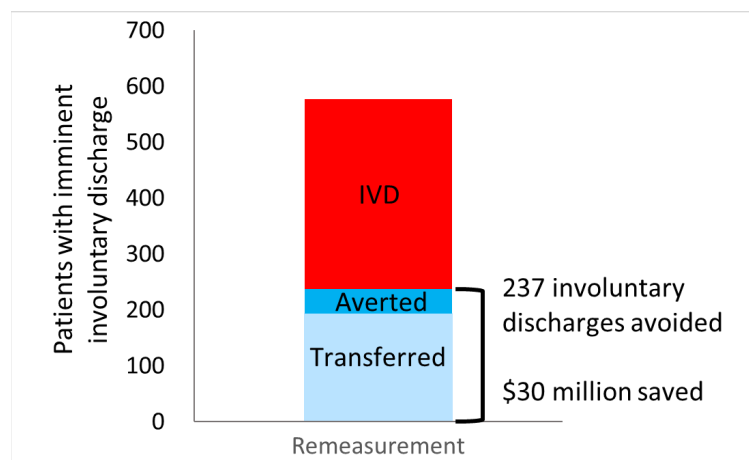


Figure 6. Involuntary discharges avoided in the 2018 ESRD QIA program.

medically complex patients at a disadvantage for proactive disease management. The Networks are often able to avert an IVD by educating both patients and staff on de-escalation techniques and the importance of patients' perceptions, by coaching patients through understanding of facility procedures, and through investigation and issue resolution.

The average estimated cost of outpatient dialysis per patient per year is approximately \$78,337. The estimated cost of emergency dialysis per patient provided by a hospital in 2017 was \$342,500 per year,<sup>15,16</sup> an increased cost over outpatient treatment per patient of \$253,800. Since not all IVDs are averted early in the year, we assumed that averted IVDs occur on average half-way through the year. Based on this assumption, the NCC calculated potential savings at \$126,900 per patient per year. In 2018, 577 patients served by QIA facilities had received a 30-day notice and were facing imminent involuntary discharge. The Networks averted 43 of these potential involuntary discharges and facilitated admissions to another outpatient facility for an additional 194, allowing for continuity of care for these patients. In total, 237 involuntary discharges were avoided, saving approximately \$30 million (Figure 6).

<sup>14</sup> Cervantes L, Tuot D, Raghavan R, et al. Association of emergency-only vs standard hemodialysis with mortality and health care use among undocumented immigrants with end-stage renal disease. *JAMA Intern Med.* 2018; 178(2):188–195.

<sup>15</sup> Sheikh-Hamad D, Paiuk E, Wright AJ, Kleinmann C, Khosla U, Shandera WX. Care for immigrants with end-stage renal disease in Houston: a comparison of two practices. (53) *Tex Med.* 2007; 103:54–58.

<sup>16</sup> Johnson TL, Rinehart DJ, Durfee J, Brewer D, Batal H, Blum J, Oronce CI, Melinkovich P, Gabow P: For many patients who use large amounts of health care services, the need is intense yet temporary. *Health Aff (Millwood).* 2015; 34:1312–1319.



## Summary

The impact analysis conducted for this report suggests both improved patient outcomes and costs avoided attributable to the QIA activities of the ESRD Networks. Based on this analysis, CMS achieved substantial cost savings relative to the costs expended for the ESRD Network Program. However, it is important to note that many impacts to patients' quality of life and additional cost savings resulting from the spread of these activities are not easily measured. For example, the ESRD program does not collect self-reported measures related to best practices stemming from QIAs; these include new strategies for patient and family engagement and adoption of new processes that are shared through collaboration with hospitals, Quality Innovation Networks-Quality Improvement Organizations (QIN-QIOs), large dialysis organizations (LDOs), and patient subject matter experts. Costs avoided are an estimate of the actual dollars saved based on USRDS 2010 data and are not adjusted for inflation. Overall, the analysis suggests that the ESRD Networks are meaningfully impacting patient outcomes and reducing costs associated with care through QIA activities with over 5,500 dialysis facilities. By focusing QIA activities on clinical initiatives, quality of life improvements, and enhancing continuity of care, over 432,000 patients were impacted in 2018.

## Introduction

The End Stage Renal Disease (ESRD) Network Program is a national program funded by the Centers for Medicare & Medicaid Services (CMS) to improve the quality of care for individuals with irreversible kidney disease 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."<sup>17</sup> The healthcare improvement activities of the 18 ESRD Networks align with the Health and Human Services (HHS) National Quality Strategy, the CMS Quality Strategy, and other CMS priorities designed to improve the care of individuals with ESRD. This report describes the prevalence of ESRD, details the activities carried out by the Networks in 2018, and provides information on kidney transplantation and ESRD-related grievances.

## Report Highlights

### Dialysis Prevalence

The ESRD Networks reported a 2.5% increase in the prevalent dialysis population, i.e., the total number of dialysis patients, from December 31, 2017, to December 31, 2018. There was considerable variation in ESRD prevalence across the 18 ESRD Networks' geographic areas as of

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<sup>17</sup> Centers for Medicare & Medicaid Services. *ESRD Network Statement of Work*. C.1 Purpose of the SOW. October 30, 2017. Washington, DC: Centers for Medicare & Medicaid Services; 2017.



December 31, 2018. Network 1, which covers the New England region, including the states of Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, had the fewest patients (14,856). Network 14, which covers the state of Texas, had the largest number of patients (52,197).

### Home Dialysis

The use of home dialysis increased by 6.6% from 2017 to 2018. 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.

### Grievances

The 18 ESRD Networks processed 1,377 beneficiary grievances in 2018. Of the 1,377 grievance cases processed, 785 (57.0%) were addressed through the use of Immediate Advocacy, and 249 (18.1%) were based on a Clinical Area of Concern. See Table 2 for Network-specific data.

### Patient Engagement

In 2018, the ESRD Networks recruited approximately 270 volunteer patient and family/caregiver representatives to provide input on Network activities and ensure that their perspectives were incorporated into all Network-developed patient educational resources. Patient Subject Matter Experts (SMEs) helped to promote and provide peer-to-peer education within the dialysis units. The 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, create opportunities for in-depth learning and problem solving, and harness participants' shared knowledge and skills to achieve specific Program-wide objectives.

### Emergency Management

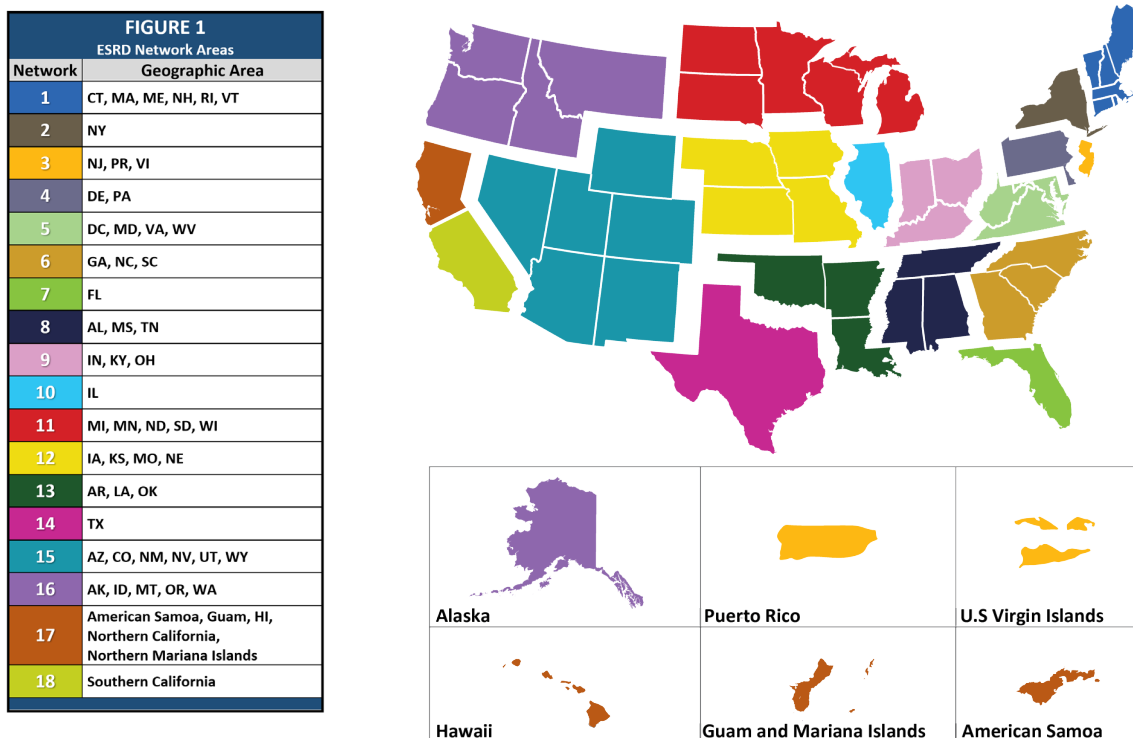
During 2018, CMS continued its enhanced focus on emergency management practices and requirements for the ESRD Networks. On a national level, the Kidney Community Emergency Response (KCER) Program strengthened relationships with CMS emergency management professionals, the Office of the Assistant Secretary for Preparedness and Response, and the U.S. Public Health Service. 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. During 2018, the ESRD Networks responded to a total of more than 30 events, resulting in over 1,000 changes in facility status, such as closures and altered schedules.

## 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 related to quality improvement and patient and family engagement.

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 2018, the ESRD Networks worked to improve healthcare for approximately 515,000 dialysis patients and approximately 220,000 kidney transplant patients.

Figure 7



### The ESRD National Coordinating Center

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

- Convening NPFE and Network Quality Improvement Activity (QIA) LANs.
- Collecting, analyzing, and reporting data for use by the Networks and CMS.
- Supporting the ESRD Networks in achieving CMS-defined goals in the following areas:
  - 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 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). The activities in the SOW align with the priorities of the HHS Secretary and CMS to improve the care of individuals with ESRD.

In 2018, the CMS goals for the ESRD Network Program were:

- Goal 1: Empower patients and doctors to make decisions about their health care
- Goal 2: Usher in a new era of state flexibility and local leadership
- Goal 3: Support innovative approaches to improve quality, accessibility, and affordability
- Goal 4: Improve the CMS customer experience

The ESRD Networks are charged with promoting positive change relative to the CMS goals, as well as targeting disparities when conducting all 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, dialysis and transplant providers, and health professionals. Network contract activities support more than 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.

Network staff with experience in program planning, implementation, data analysis, and evaluation conduct activities and assume responsibilities outlined in the Network contracts and other CMS directives. CMS also requires each ESRD Network to employ a registered nurse with nephrology experience and a Master of Social Work-level social worker with experience in case review. Job titles, specific responsibilities, and the number of support staff vary from ESRD Network to ESRD Network.

## Network Governance

Each of the 18 ESRD Networks must establish and maintain a Network Council (NC), Corporate Governing Body (CGB), 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 CGB must include at least one patient representative; it sets overall policy and direction for the Network and retains oversight responsibility. The CGB 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 who are qualified to evaluate the quality and appropriateness of renal care—typically nephrologists, surgeons, physician assistants, nurses, social workers, and dietitians. 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 the development of informational and educational materials for patients and families/caregivers. The members must represent various demographics, primary diagnoses, and treatment modalities to reflect the diversity of the ESRD population in the Network service area.

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

## Patient Profile

### Patients and Facilities

As of December 31, 2018, there were 517,767 prevalent dialysis patients and 7,442 dialysis facilities covered by the ESRD Network Program. Network 6, which covers the states of Georgia, North Carolina, and South Carolina, served the largest number of dialysis facilities (760). Network 1, which covers the New England region states of Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, had the fewest facilities (199).

### 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 14.8% of adults affected.<sup>18</sup> This is attributable, in part, to high rates of diabetes and hypertension in the adult population. Information about the number of prevalent dialysis patients (i.e., total dialysis patients at a given point in time) is highlighted in the following sections.

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<sup>18</sup> United States Renal Data System. *2016 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.

## 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 2018, 517,767 patients were receiving dialysis in the U.S., according to the Networks' Annual Reports—a 2.5% increase from December 31, 2017.

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

### Vascular Access

Hemodialysis, a form of renal replacement therapy, 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: arteriovenous fistula (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. 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.<sup>19</sup> 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. Some patients 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 for hemodialysis.

### The Role of the Networks in Increasing Fistula Placement Rates and Decreasing Long-Term Catheter Use Rates

In 2018, the ESRD Networks developed targeted strategies to assist dialysis facilities in increasing AVF use rates and decreasing long-term catheter (LTC) use rates in incident and prevalent dialysis patients. Strategies were developed through the performance of

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<sup>19</sup> Vachharajani TJ. *Atlas of Dialysis Vascular Access*. 2010. Available at: <http://fistulafirst.esrdncc.org/wp-content/uploads/2015/12/Access-Atlas.pdf>



environmental scans using root cause analysis (RCA), an approach used to identify the origins of a problem or error, and included:

- Educational webinars.
- Action plan development.
- Focus groups.
- Onsite visits by Network staff.
- Offsite review of records, policies, and procedures.

To achieve improvements in access use (more AVFs/AVGs and fewer LTCs), the ESRD Networks first identified dialysis facilities that had not reached CMS targets (i.e., facilities that still showed LTC use greater than 15.0% in the prevalent hemodialysis population). The ESRD Networks then provided individualized support to the identified facilities via QIAs.

- **Network 6** led a QIA that included a group of 56 facilities that received more intensive interventions based on LTC performance rates for the period January to June of 2017. The Network conducted an RCA with the facilities to find common barriers to catheter reduction. Identified barriers included lack of patient education, appointment delays, and patient refusal. The results of the RCA guided QIA interventions and education topics for the projects. One intervention was to establish a peer mentorship program to facilitate patients sharing information with other patients about the benefits of permanent access placement. Mentors received a toolkit that included educational resources such as a poster outlining the pros and cons of the different types of vascular access, a *Questions and Concerns about Permanent Accesses* booklet, and the *Lifeline for a Lifetime—Planning for Your Vascular Access* guide. The baseline for the 56 facilities was 19.4%, with a goal of reducing the baseline by 2 percentage points, or to 17.4%. At project remeasurement, the facilities reduced their aggregate LTC rate to 15.9%, which was a decrease of 3.5 percentage points. This exceeded the QIA goal.
- **Network 13** conducted a QIA that included a patient engagement component aimed at increasing patient knowledge of vascular access types and associated complications. Barriers to reducing LTC use were identified based on facility RCA results. Barriers included patient refusal of permanent access placement and a high number of new catheter-only admits. One best practice identified by QIA facilities was to provide patient education using a series of catheter complications puzzles focused on low adequacy, infections, stenosis, and hospitalization. Another best practice was to assess patient knowledge using the Patient Vascular Access Checklist. The baseline LTC rate for this activity was 20.6%. The goal was to reduce the rate of LTC use by 2 percentage points from baseline. By July 2018, the group reduced the aggregate LTC rate to 17.5%, a 3.1 percentage point reduction that exceeded goal.
- **Network 14** led a QIA that included a targeted group of 54 facilities with high LTC rates. The Network reviewed known barriers to LTC reduction with the MRB and the Network 14 PAC. Together, these stakeholders provided input and feedback for intervention resources. Interventions implemented as part of the QIA included developing or updating an action/improvement plan, signed by the facility's medical director, and reviewing the plan during monthly Quality Assessment and Performance Improvement (QAPI) meetings. At the



conclusion of the QIA, the 54 targeted facilities achieved a 3.1 percentage point reduction in the LTC rate, moving from a baseline of 20.0% to 16.9%. This represents a total decrease of 119 LTCs.

## Patient Safety

### Support for the National Healthcare Safety Network

The Centers for Disease Control and Prevention's (CDC's) National Healthcare Safety Network (NHSN) is the most widely used HAI tracking system in the nation. 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 an elevated risk for infection due to the frequent use of catheters or insertion of needles to access the bloodstream as part of the hemodialysis process.<sup>20</sup> 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:

- 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 hemodialysis patients by type of vascular access used.
- Provides a variety of analysis options that can be used to better inform quality improvement decisions.

In 2018, a significant part of ESRD 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. ESRD Network support also included technical assistance to the facilities with data entry, so that these events were entered accurately and in a timely manner, as well as helping new users and facilities with completing enrollment in NHSN. The ESRD Networks were also charged with providing technical assistance and resources to ensure that ESRD Quality Incentive Program (ESRD QIP) reporting requirements were understood and could be met by all dialysis facilities.

### Healthcare-Associated Infections Learning and Action Network

In 2018, the ESRD Networks continued to assist in reduction 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

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<sup>20</sup> Centers for Disease Control and Prevention. Dialysis. Accessed August 2017. Available at: <https://www.cdc.gov/dialysis/index.html>.

LANs. The HAI LANs provided a variety of resources to assist dialysis facilities in reducing the occurrence of HAIs, including education for patients and family members about infection control, webinars for dialysis facility staff that featured presentations by public health and medical experts, and behavioral self-management policies and procedures (e.g., infection control protocols).

## Quality Improvement Activities

### Bloodstream Infections

Dialysis patients are at higher risk than the general population for acquiring HAIs, specifically bloodstream infections (BSIs), due to the regular and frequent use of catheters and other forms of access to their bloodstream while dialyzing. The physical and emotional cost of these infections for patients and their families is immeasurable. In addition, the financial cost associated with HAIs is staggering. The goal of the BSI QIA was to increase awareness and reporting of BSIs in at least 20.0% of facilities in each ESRD Network's service area, while decreasing rates of NHSN-defined Dialysis Events. Examples of ESRD Network efforts conducted during 2018 included:

- **Network 3** used an assessment and response approach toward improvement of current facility processes and to identify and address areas of opportunity for catheter reduction. The QIA included multiple stakeholders, including facility staff, corporate leadership, patient SMEs. Throughout the QIA the facilities were educated and supported through the implementation of the CDC Core Interventions and appropriate use of the CDC Prevention Process Measure audit tools. The facilities also used the CDC Making Dialysis Safer Coalition tool, *Conversation Starter to Prevent Infections in Hemodialysis*. The tool was translated to Spanish for the patients in Puerto Rico. The Network distributed pledge cards on which patients indicated topics they planned to use to guide their conversations with staff and committed to encourage others to start a conversation about infection control. At project conclusion, the Network met the CMS goal. To support CDC efforts to capture BSIs that occur in dialysis patients, 27.0% of dialysis facilities in this project gained access to a hospital electronic medical record (EMR) or to a regional or national health information exchange (HIE).
- **Network 10** used an environmental scan to determine barriers to reducing bloodstream infections in a cohort of 59 facilities. Each month, facilities were provided resources for staff and patient education, including materials developed by dialysis patients. Central to the QIA was the use of CDC Core Intervention Audits tools, including hand hygiene audits that facilities were required to conduct monthly. Another intervention was to establish an infection control manager, or team, to quickly determine the root cause(s) of patient infections and perform the appropriate steps to accurately document the event into NHSN. The Network's interventions succeeded in decreasing the pooled mean BSI rate for the 59 facilities from 1.07 at baseline to 0.60 at remeasurement. This exceeded the QIA goal to decrease to 0.9.

- **Network 18** focused its QIA on reducing catheter infections, promoting antibiotic stewardship, and increasing sepsis awareness. A key intervention was involving patients in the implementation of CDC audit tools. Additionally, facilities were required to complete a minimum number of hand hygiene audits every month; the Network monitored results of both patient and staff audits monthly in NHSN. Facilities conducted initial RCAs to identify individual barriers and reported progress on a monthly basis. Additionally, Network 18 provided CDC resources to support comprehensive staff education. The Network 18 QIA included 80 participating facilities with an aggregate baseline BSI rate of 0.98. The facilities successfully reduced the pooled mean BSI rate to 0.49, exceeding the CMS goal.

### Promote Appropriate Home Dialysis

In the U.S., only 8.0% of patients utilize a home renal replacement therapy. The purpose of this QIA was to promote referral to home dialysis modalities, identify and mitigate barriers to timely referral, and determine steps patients and providers can take to improve referral patterns. ESRD Network efforts to increase the number of patients using home dialysis during 2018 included the following:

- **Network 15** identified 99 dialysis facilities with low home therapy referrals for inclusion in the QIA, impacting approximately 7,326 hemodialysis patients. Final measurement for the QIA was 5.4%, an increase of 4.6 percentage points. Network 15's large Hispanic population required bilingual patient advocates and/or phone translation. The Network was proactive in addressing diversity by providing materials in Spanish, as well as sharing information about disparities in hemodialysis and how to overcome language and cultural barriers with dialysis staff. Best practices identified included: Increasing communication about home modality to create interest, posting home modality tools and resources on the Network website, and using monthly trackers to follow patients from interest to access to training.
- **Network 16** evaluated root causes of why patients treat in-center more often than in a home modality. Root causes identified included: in-center staff lack proper home modality knowledge, in-center staff hold incorrect beliefs regarding home dialysis modalities, and dialysis modality education for patients is not effective. One patient resource for home dialysis, "*Myth and Fact Sheets*," which was developed by patients and in-center staff, was selected by the NPFE-LAN as a resource to update for use as a national tool. An example of a project intervention was to use home dialysis patients to provide patient-to-patient education through events such as a lobby day. Final project results included a 5.4 percentage point increase, representing 274 patients using a home modality.

### Improve Transplant Coordination

The benefits of transplantation extend to ESRD patients regardless of age, gender, or ethnicity. The intent of this QIA was to promote early referral to transplant and assist patients and providers in improving referral patterns by addressing patient barriers. Examples of ESRD Network efforts conducted during 2018 included the following:

- **Network 1** utilized a "7 Step" methodology to monitor patient progression through the transplant evaluation process. These steps were designed to track the patients through

their journey from their initial interest in transplant to placement on the waitlist. Target facilities identified the following strategies as best practices: identifying a dedicated transplant coordinator in each dialysis facility, obtaining contact information for patient transplant coordinators, fostering regular communications between the dialysis facility and the transplant center, and having transplant centers host a lobby day at the dialysis facility. The Network achieved 6.37 percentage point improvement, reaching 18.9%.

- **Network 9** initiated the QIA by evaluating transplant waitlist data for the Network service area. The evaluation indicated that of the 33,270 patients in the Network service area, only 3,959 (11.9%) of the patient population were on a transplant waitlist. The Network identified 185 facilities for inclusion in the project with a total combined census of 9,250 patients. The Network structured interventions to ensure that providers understood the United Network for Organ Sharing (UNOS) allocation system criteria, as well as techniques for speaking with patients about transplant as an option. The Network also deployed patient-facing interventions and tools, such as using Patient Ambassadors to educate patients on transplant wait listing or working with SMEs to create a patient education toolkit. The participating facilities achieved a 4.5 percentage point increase in waitlisted patients, which represented 130 patients added to a waitlist.

## Support for the ESRD Quality Incentive Program

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 hemodialysis, peritoneal dialysis (PD), and pediatric dialysis patients.
- Maximizing placement of AVFs.
- Minimizing use of catheters.
- Decreasing the proportion of patients with hypercalcemia.
- Decreasing the rate of BSIs.
- 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 2018, 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 ESRD Networks also focused 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 ESRD 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 2018, 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.
  - Utilizing post-hospitalization checklists to reduce readmissions.
  - Improving communication with patients to reduce grievances and increase patient satisfaction.
- 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.

## 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. Network staff uses these data points 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 2018, the ESRD Networks continued their ongoing collaboration with the ESRD NCC on the ESRD Data Committee. The work done by the committee 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 and gap reports, which identify patients in CROWNWeb not currently admitted to a specific facility) to support Network QIAs 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 2018, 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 ESRD Networks then manually entered the data on these forms into CROWNWeb for the facilities.

## **Disparities in ESRD Care**

In 2018, each of the 18 ESRD Networks developed a Population Health Focused Pilot QIA (PHFPQ) to promote better health in the ESRD population. Each ESRD Network selected a project based on one of the following CMS-approved priorities:

- Improve dialysis care coordination with a focus on reducing hospital utilization.
- Positively impact the quality of life of the ESRD patient with a focus on mental health.
- Support gainful employment of ESRD patients.
- Positively impact the quality of life of the ESRD patient with a focus on pain management.

Each ESRD 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 ESRD Network's project:

- 1. Commitment to Boundarilessness and Unconditional Teamwork**  
Information about each Network's project was communicated to and supported by stakeholder groups and organizations. To further demonstrate each Network's commitment to boundarilessness, best practices and lessons learned through the project were disseminated to stakeholders, including other Networks.
- 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. 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 to benefit all participants.
- 4. Patient and Family Engagement**  
Patient SMEs, family members, and caregivers participated in the planning, development, and selection of interventions and tools to support QIA goals. When conducting facility site visits, each Network incorporated discussion and evaluation of patient and family engagement interventions.
- 5. Rapid Cycle Improvement in QIAs and Outputs**  
On a routine basis, each Network evaluated and assessed the success of the project's interventions to make appropriate adjustments based on available information and feedback from project participants.
- 6. 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.

## Population Health Focused Pilot QIAs

### *Improve Dialysis Care Coordination with a Focus on Reducing Hospital Utilization*

The one ESRD Network that selected this PHFPQ topic coordinated with stakeholders to reduce hospital utilization for ESRD patients. The Network engaged ESRD professionals, state hospital associations, and a Quality Innovation Network-Quality Improvement Organization (QIN-QIO) to decrease ESRD hospital admissions. A secondary goal of this activity was to reduce disparities in hospitalization rates between populations within the ESRD Network's service area.

- **Network 18** initiated the project by assisting facilities with gaining access to EMRs, HIEs, and Emergency Department Information Exchanges to support patient care coordination. The facilities completed an RCA, which included a review of discharge data for diagnosis; reason for admission; living situation; whether the hospitalization was planned or unplanned; and population group. The facilities used the medical records to guide RCA results and identify appropriate interventions tailored to the targeted patient population. The outcome of the QIA was a 4.3 percentage point reduction over nine months, or a prevention of 160 hospitalizations. The reduction is estimated to result in Medicare savings of \$2.5 million.



### *Positively Impact the Quality of Life of the ESRD Patient with a Focus on Mental Health*

The intent of this PFPHQ was to improve the screening and treatment of depression for ESRD patients. The ESRD Networks provided dialysis facilities with technical assistance to develop a process to ensure the completion, documentation, and appropriate follow-up of an annual depression screening for 100.0% of qualifying patients. If a diagnosis of clinical depression was made, facilities were required to provide treatment options tailored to the specific needs of the patient and the resources available to the dialysis facility.

- **Network 11** conducted a pilot that included 50 dialysis facilities serving 3,300 patients. Patient SMEs made significant contributions to this project including: producing a Facebook Live event on depression, participating as faculty on webinars, and serving as primary authors of a national Depression Toolkit. The Network convened monthly Patient SME calls to obtain input on educational materials designed for patients and dialysis staff. By QIA completion, Network 11 achieved a 15.6% decrease in percent of patients with no documentation of depression screening in CROWNWeb, improved follow up documentation for patients with a positive screening for depression, addressed barriers such as language, and shared strategies for Asian patients experiencing depression.

### *Support Gainful Employment of ESRD Patients*

In 2018, ESRD Networks assisted dialysis patients with seeking gainful employment and/or returning to work. Each ESRD Network participating in the PFPHQ was required to identify a minimum of five Employment Networks or State Vocational Rehabilitation (VR) agencies servicing the recruited patient population. The goal was to demonstrate an increase in referrals to identified ENs and/or VR agencies.

- **Network 4** conducted facility-specific kick off webinars to explain the project background and improvement goals. Facilities received a project toolkit that contained improvement concepts from the Institute for Healthcare Improvement (IHI) Model for Improvement, along with quality improvement tools such as Plan-Do-Study-Act cycle templates, root cause analysis templates, and systems process mapping tools. Participating facilities were provided with patient-level reports for targeted VR/EN education. At the conclusion of the project, the overall VR/EN referral rate for the participating facilities improved from a baseline of 4.4% to 32.8%, an increase of 28.5 percentage points. The overall VR/EN utilization rate for the participating facilities improved from a baseline of 1.2% to 5.9% of patients receiving services, an increase of 4.68 percentage points. Both measures exceeded the identified CMS goals.
- **Network 8** required project facilities to conduct an RCA prior to implementation of monthly interventions. The most commonly identified patient barriers were fear of losing Medicare and/or disability benefits, a belief that the process takes too much time, and lack of personal motivation and willingness to participate in VR. Monthly, data for patient VR referrals and patients receiving VR services were reviewed to monitor improvement. Target facilities then received monthly coaching calls to discuss barriers, interventions, and potential VR candidates. Conducting a root cause analysis was the first step to learn more about patient-level reporting processes in order to develop actionable, sustainable

improvement plans for each participating facility. Throughout the duration of the project, the Network collaborated with facilities to identify best practices and barriers. At the conclusion of the project, best practices were shared with all facilities. The Network exceeded project goals with an overall improvement of 12.7 percentage points for referrals and 4.2 percentage points for patients receiving services by September 30, 2018.

### *Positively Impact the Quality of Life of the ESRD Patient with a Focus on Pain Management*

For this pilot QIA, ESRD Networks provided technical assistance to dialysis facilities with developing a process to ensure the completion, documentation and appropriate follow-up of the twice annual pain assessment of qualifying patients. If the pain assessment was documented as positive, treatment options were required to be created based on the specific needs of the patient and the resources available to the dialysis facility.

- **Network 7** conducted a QIA that focused on improving pain management in 10% of the dialysis facilities in the Network service area. RCA conducted on 44 facilities identified causes for poor performance on the completion of pain assessments, including a lack of facility leadership knowledge, lack of facility processes to track pain assessments, lack of streamlined process for reporting of pain assessments in CROWNWeb, and CROWNWeb batching errors. The baseline rate for “no pain assessment and no reason given” for the 44 facilities was 68.5% based on CROWNWeb data. By QIA completion, the pain assessment rate for “no pain assessment and no reason given,” decreased to 0.2%, representing a reduction of 68.3 percentage points. By the QIA’s closure, the Network reduced the disparity from 6.1% to 0.1%, representing a 6.0% reduction.
- **Network 17** led a QIA with 28 facilities, with a baseline rate for “no pain assessment and no reason given” of 54.8%. The QIA interventions included using a tracking and monitoring tool, collecting monthly feedback regarding pain assessments, educating patients on non-medication strategies for pain management, referring patients to a primary care provider (PCP) or specialist for pain management, documenting appointments related to pain management, and educating staff about conducting pain assessments. By QIA completion, the rate for “no pain assessment and no reason given,” decreased to 0.1%, representing a reduction of 54.7%. The Network was also able to decrease the number of patients with a positive pain assessment and no follow-up plan from 0.7% to 0.0% by the end of the QIA.

## Partnerships and Coalitions

In 2018, 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. In addition to conducting collaborative activities with patients, family members/caregivers, independent dialysis corporations, and large dialysis organizations (LDOs), the ESRD 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.
- National Renal Administrators Association.
- Council of Nephrology Social Workers.
- American Nephrology Nurses' Association.
- Association of Professionals in Infection Control and Epidemiology.
- Renal Physicians Association.
- American Society of Nephrology.
- National Hospice and Palliative Care Organization.
- Forum of ESRD Networks.
- Medical Education Institute.
- UNOS.
- United States Renal Data System (USRDS).
- National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health.

Of equal importance are the ESRD Network collaborations with hospital associations, health departments, emergency medical services, transplant providers, patient and professional organizations, Offices of Emergency Management, State Survey Agencies (SAs), and Medicare QIN-QIOs in their geographic areas. Some examples of ESRD Network collaborative projects included the following:

- **Network 6** maintained a robust partnership with key transplant stakeholders through an established Southeastern Kidney Transplant Coalition (SeKTC) representing each of the 11 transplant centers in the Network region. The SeKTC is composed of patients, dialysis providers, and other community stakeholders. SeKTC members guided the interventions and webinar topics. Members of the Coalition participated in different interventions, served as webinar speakers, and participated in the development of educational materials and the creation and testing of an electronic communication tool between transplant center and dialysis units.
- **Network 12** worked with 36 dialysis facilities to promote quality of life, mental health, and depression awareness, partnering with many community leaders, patients, and other stakeholders. As an innovative approach and to increase reach, Network 12 was able to collaborate on a webinar with the Forum of ESRD Networks, the National Kidney Foundation, and the American Association of Kidney Patients to present the new *Dialysis Patient Depression Toolkit*. The Network participated in a workgroup with ESRD Networks 10, 11, 13, and 14 to collaborate on project interventions and resources, as well as share successes and barriers faced.

## Patient and Family Engagement

### Education for Patients and Caregivers

In 2018, 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 ESRD 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 ESRD Network outreach included site visits, LANs, and QIA meetings. All approaches shared the goal of providing educational resources to ESRD patients, family members, and care partners.

### Patient Experience of Care LAN

In 2018, the ESRD Networks selected facilities with grievance or access to care issues to participate in the Patient Experience of Care LAN. LAN content embraced principles of patient-centered care and highlighted successful strategies used by facilities that excelled at empowering patients and resolving issues before escalation. During 2018, LAN activities focused on:

- Facility awareness and utilization of the Forum of ESRD Networks Kidney Patient Advisory Council (K-PAC) Grievance Toolkit.
- The difference between patient-centered and relationship-centered care.
- Managing dialysis patients' psychological challenges.

The ESRD Networks shared LAN interventions with all facilities in the Network service area to improve facility culture and reduce grievances and access to care issues.

### Network-Specific Patient Engagement Activities

In 2018, the ESRD Networks implemented a wide range of notable patient and family engagement interventions as part of the QIAs. For example:

- **Network 3** identified one intervention that was particularly successful, an Innovation Challenge. This intervention was implemented in collaboration with Networks 4, 5, and 8. Facility staff members were asked to submit their most innovative intervention. The most innovative idea was selected and shared with all participating facilities. The second step in this intervention was a multi-Network challenge. The goal of this intervention was the sharing of best practices. Each Network selected its top three submissions for review and voting by all participating facilities in the four Network service areas. A grand prize was awarded to the winning facility, which used the gift card to purchase an iPad for patient use.
- **Network 5** offered training and support for increasing partnerships between patients and staff to build trust, rapport, and effective communication, as well as increase patient involvement in their care and self-management. Articles in newsletters provided tips and resources for decreasing patient-provider conflict, communication, professionalism, and patient-centered care including the Decreasing Dialysis Patient-Provider Conflict (DPC) toolkit and 5-Diamond Patient Safety Program.



## National Patient and Family Engagement Learning and Action Network 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 giving a voice to ESRD patients and facilitating dialogue between patients and CMS leadership.

The 2018 NPFE-LAN organized into Affinity Groups to address the mandatory Network QIA areas, including:

- Reducing BSIs.
- Increasing the number of patients dialyzing at home.
- Increasing the number of patients on a transplant waitlist.

Organizing into these focus areas allowed the Affinity Groups 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 Affinity Group model and continuous collaboration, the NPFE-LAN created patient-friendly educational tools to support 2019 Network QIAs. For example, the Home Dialysis Affinity Group created a handout titled *Uncovering Myths about Home Dialysis: Myths vs. Reality*, and the Transplant Affinity Group enhanced two previously developed resources, *Why Transplant is a Good Idea for Me* and *Road to Transplant*.

In addition to the QIA-focused Affinity Groups, the NPFE-LAN formed an Affinity Group based on a patient-selected topic. For 2018, the topic was mental health and helping patients cope with feelings of grief, loss, and abandonment. The group developed resources for patients to use when there is a death of a friend at their dialysis facility, including a condolence card and a memorial poster. This group also created celebratory posters for patients leaving the in-center setting for a home modality or transplant.

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 February 2018.

## Grievances and Access to Care

### Evaluation and Resolution of Grievances

The CMS ESRD complaints and grievance policy requires that all concerns related to care that do not meet a dialysis patient'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. It is the Network’s responsibility to take all necessary steps to evaluate and resolve these grievances.

The ESRD Networks are 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 Involuntary Discharge (IVD) or Involuntary Transfer (IVT), and cases in which a patient was scheduled for, or had already experienced an IVD or IVT, or did not currently have access to an outpatient dialysis facility.

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 because 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 followed grievance resolution protocols as directed 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.

### **Grievance Process and Data**

In 2018, 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 QIOs. 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 PCU database.

The 18 ESRD Networks processed 1,377 beneficiary grievances in 2018. Of the 1,377 grievance cases processed, 785 (57.0%) were addressed through the use of Immediate Advocacy, and 249 (18.1%) were based on a Clinical Area of Concern. See Table 2 for Network-specific data. Recommendations for Sanctions. In 2018, 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 2018, the 18 ESRD Networks did provide policy recommendations that included:

- 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.
  - 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.
  - Reside in extended care facilities that have dialysis on-site.
- Increasing the numbers of facilities that provide nocturnal dialysis in some geographic areas.
- 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 for CKD patients throughout the country.
- Studying ESRD Medicare medication payment policies to identify ways to reduce costs by improving care.
- 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.

The aforementioned policy recommendations and special facility requests represent important approaches 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. 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.
- Provision of information to educate facilities and patients on the actions to take during emergency situations.
- Reporting of open and closed facilities, alterations in dialysis facility schedules, and unaccounted for patients during actual incidents.

For more information about ESRD Network emergency preparedness activities, see the KCER Program overview in this report.

Within their individual service areas, the ESRD Networks engaged in outreach, training, and technical assistance activities to help ensure that the needs of ESRD patients were met in emergency situations. During 2018, the ESRD Networks responded to a variety of incidents with the potential to impact ESRD patients and providers, including wildfires, tornadoes, winter storms, earthquakes, structure fires, and power outages. Following are representative examples of emergency preparedness and response activities conducted:

- **Network 6** collaborated with the Lowcountry Healthcare Coalition to conduct response activities for Hurricane Florence, which produced catastrophic and deadly flash and river flooding. The coalition, which represented 11 counties in the southern coastal area of South Carolina, included representatives from county-level emergency management and department of health agencies, three LDOs, the Medical University of South Carolina, and 39 dialysis facilities. During Hurricane Florence, the coalition met daily to discuss operational challenges, and collaborated to resolve patients' access to care issues, including transportation and patient surge.
- **Network 7** conducted preparedness and response activities for Hurricane Michael, which made landfall in the Florida Panhandle area. The storm caused widespread damage and flooding across 10 counties, with extensive power outages across the region in the days immediately following landfall. Hurricane Michael also caused damage to critical infrastructures and disruptions in systems and services within the impacted areas, including power, water, roads, transportation, communication, and 911 systems. Forty-one facilities in the Network service area reported changes to their operational status due to the storm, impacting over 2,615 dialysis patients. Multiple facilities required use of a water tanker and/or generator to re-open after the storm; one facility remained closed long-term.



## Special Projects

### National Coordinating Center

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 2018, the ESRD NCC:



- Partnered with NPFE-LAN SMEs to develop patient and family resources for use in ESRD Network QIAs. Examples included the *Uncovering Myths about Home Dialysis: Myths vs. Reality* brochure, the *Why Transplant is a Good Idea* booklet, and celebratory posters that facilities can display to congratulate patients leaving the in-center setting for a home modality or transplant.
- Conducted bi-monthly LAN meetings to support achievement of ESRD Network QIA goals for BSI, home dialysis, and transplant. Meetings featured presentations from best practice facilities and showcased NPFE-LAN materials relevant to each LAN topic. LAN meetings averaged more than 1,000 attendees per call.
- Provided data reports to support response activities that were initiated during 2017, when three overlapping category 5 hurricanes, Harvey, Irma, and Maria, caused significant impact on facility operations within five Network service areas. The reports included facility and patient tracking data and were used to monitor the status and treatment location for dialysis patients who were evacuated from the U.S. Virgin Islands and Puerto Rico following Hurricanes Irma and Maria. Each report was tailored to the specific region and impacted counties within the respective Network service areas.
- Posted content daily across the ESRD NCC Facebook and Twitter social media feeds to promote ESRD Network Program activities and CMS initiatives. Topics included home dialysis, transplantation, kidney disease articles, emergency preparedness, and mental health. As of December 31, 2018, the NCC Facebook feed had over 600 followers and the NCC Twitter feed received over 400 “likes.”

### Kidney Community Emergency Response Program

Supporting dialysis facilities and patients in preparing for emergencies continued to be a priority for the ESRD Network Program in 2018. 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 emergency preparedness and response capacities. KCER’s 2018 activities included:



- Convening the National KCER Patient and Family Engagement (N-KPFE) LAN, which included 31 patient, family member, and caregiver SMEs from across the ESRD community. During LAN meetings, members discussed the unique needs of kidney patients during emergencies, and the aspects of emergency preparedness they felt were most important. Members also

shared examples of how KCER educational materials were being used to support preparedness at the individual and facility levels, as well as in the local community.

- Building and sustaining positive relationships among partners to ensure continuity of care and services for ESRD patients during an emergency. For example, KCER reached out to Healthcare Ready for help addressing medication needs and supply chain distribution issues following Hurricanes Florence and Michael. Healthcare Ready and KCER worked in collaboration to urgently connect patients with resources to facilitate rescues from flood and post-hurricane conditions and to assist with emergency transportation needs for dialysis treatment.
- Activating in response to Hurricane Florence and Hurricane Michael. During this time, KCER coordinated national-level preparedness and response activities, including leading daily emergency status calls, reporting on facility operational status and needs, and collaborating with CMS, Networks, dialysis organizations, and other stakeholders to identify and address patient access to care issues. In total, more than 650 dialysis facilities and 46,000 dialysis patients were impacted by the two storms.



## Data Tables

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

- Table 1: ESRD Medicare-Certified Dialysis Facilities – Modality Type – Calendar Year 2018
- Table 2: Grievances and Non-Grievances by Case Type, Number, and Percent - Calendar Year 2018
- Table 3: National ESRD Patient Data Overview

**Table 1: ESRD Medicare-Certified Dialysis Facilities – Modality Offered – Calendar Year 2018**

Network	Transplant	In-Center Hemodialysis and Home Dialysis	In-Center Hemodialysis (Only)	Home Dialysis (Only)	Total Dialysis Facilities (Home, In-Center, Both)	Total Facilities (including Transplant)
1	15	114	83	2	199	214
2	13	130	165	10	305	318
3	4	145	94	2	241	245
4	20	222	125	2	349	369
5	12	191	224	30	445	457
6	10	398	344	18	760	770
7	11	236	222	28	486	497
8	10	191	270	7	468	478
9	14	262	333	44	639	653
10	9	110	162	57	329	338
11	21	174	306	32	512	533
12	13	144	184	16	344	357
13	10	137	198	9	344	354
14	24	318	385	13	716	740
15	15	148	202	13	363	378
16	7	137	82	3	222	229
17	6	83	180	41	304	310
18	15	168	209	39	416	431
<b>NATIONAL</b>	229	3,308	3,768	366	7,442	7,671

**Table 2. Grievances and Non-Grievances by Case Type, Number, and Percent - Calendar Year 2018**

Network	Total All Case Types	Total Grievance Cases	Percent of National Grievance Cases	Total Non-Grievance Cases	Percent of National Non-Grievance Cases
1	37	24	1.74%	13	0.29%
2	114	43	3.12%	71	1.57%
3	137	50	3.63%	87	1.93%
4	139	34	2.47%	105	2.33%
5	397	86	6.25%	311	6.89%
6	411	135	9.80%	276	6.12%
7	348	126	9.15%	222	4.92%
8	258	48	3.49%	210	4.65%
9	405	67	4.87%	338	7.49%
10	396	69	5.01%	327	7.25%
11	521	114	8.28%	407	9.02%
12	192	43	3.12%	149	3.30%
13	216	46	3.34%	170	3.77%
14	478	103	7.48%	375	8.31%
15	189	67	4.87%	122	2.70%
16	176	59	4.28%	117	2.59%
17	810	80	5.81%	730	16.18%
18	666	183	13.29%	483	10.70%
<b>NATIONAL</b>	<b>5,890</b>	<b>1,377</b>	<b>--</b>	<b>4,513</b>	<b>--</b>



**Table 3. National ESRD Patient Data Overview**

Network	Dialysis Facilities	Percent of Dialysis Facilities Nationally	Transplant Facilities	Percent of Transplant Facilities Nationally	Dialysis Patients	Percent of Dialysis Patients Nationally	In-Center Patients	Home Patients	Percent of Home Patients Nationally	Transplant Patients	Percent of Transplant Patients Nationally	Total Patients Dialysis and Transplant
1	199	2.67%	15	6.55%	14,856	2.87%	13,085	1,771	2.75%	11,281	5.09%	26,137
2	305	4.10%	13	5.68%	30,337	5.86%	28,170	2,167	3.36%	13,025	5.88%	43,362
3	241	3.24%	4	1.75%	20,774	4.01%	19,173	1,601	2.49%	5,491	2.48%	26,265
4	349	4.69%	20	8.73%	20,574	3.97%	18,261	2,294	3.56%	12,444	5.62%	33,018
5	445	5.98%	12	5.24%	28,038	5.42%	24,548	3,490	5.42%	12,983	5.86%	41,021
6	760	10.21%	10	4.37%	50,370	9.73%	43,792	6,567	10.19%	15,338	6.92%	65,708
7	486	6.53%	11	4.80%	31,948	6.17%	27,927	4,021	6.24%	12,663	5.72%	44,611
8	468	6.29%	10	4.37%	28,829	5.57%	25,025	3,778	5.86%	9,230	4.17%	38,059
9	639	8.59%	14	6.11%	33,890	6.55%	29,291	4,599	7.14%	14,323	6.47%	48,213
10	329	4.42%	9	3.93%	20,773	4.01%	17,213	3,560	5.53%	9,553	4.31%	30,326
11	512	6.88%	21	9.17%	28,628	5.53%	25,048	3,580	5.56%	18,861	8.51%	47,489
12	344	4.62%	13	5.68%	16,927	3.27%	14,089	2,838	4.41%	10,248	4.63%	27,175
13	344	4.62%	10	4.37%	20,808	4.02%	17,903	2,905	4.51%	5,893	2.66%	26,701
14	716	9.62%	24	10.48%	52,197	10.08%	46,599	5,557	8.63%	17,069	7.71%	69,266
15	363	4.88%	15	6.55%	26,056	5.03%	22,669	3,387	5.26%	14,601	6.59%	40,657
16	222	2.98%	7	3.06%	15,513	3.00%	13,219	2,294	3.56%	7,985	3.60%	23,498
17	304	4.08%	6	2.62%	29,404	5.68%	25,432	3,972	6.17%	12,951	5.85%	42,355
18	416	5.59%	15	6.55%	47,845	9.24%	41,808	6,037	9.37%	17,572	7.93%	65,417
<b>NATIONAL</b>	7,442	--	229	--	517,767	--	453,252	64,418	--	221,511	--	739,278