

2019

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



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



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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 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 Health and Human Services (HHS) National Quality Strategy and CMS strategic priorities designed to improve the care of individuals with ESRD. This report provides an overview of ESRD and renal replacement therapies, details the activities carried out by the Networks in 2019, and provides information on kidney transplantation and ESRD-related grievances.

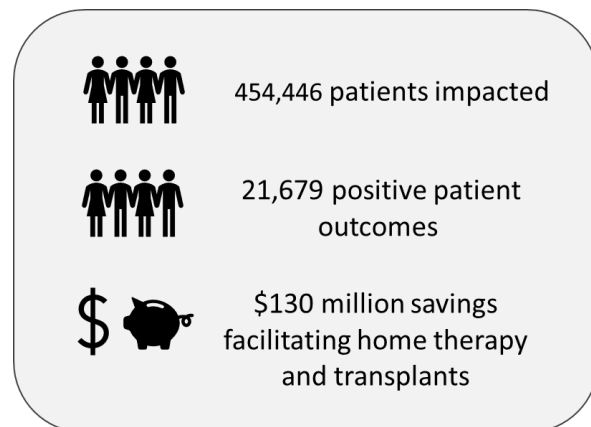
¹ Centers for Medicare & Medicaid Services (CMS). C.1 Purpose of the Statement of Work (SOW). In: CMS. *ESRD Network Statement of Work*. Baltimore, MD; October 30, 2017.

Impact of Network Quality Improvement Activities

The Networks serve all patients with 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 Quality Improvement Activities (QIAs), each Network collaborates with a specific subset of facilities in its service area to improve targeted outcomes and conducts data analysis to develop improvement strategies. The QIAs enrich the lives of kidney patients through a mix of clinical initiatives, quality of life improvements, and efforts to enhance continuity of care.

From January to September 2019, the ESRD Network Program Option Year 4 QIAs included 6,166 dialysis facilities, representing 79.5% of 7,752 CMS-certified dialysis facilities in the U.S. and its territories. During the period of intervention, Networks supported facilities and patients in improving patient care, directly or indirectly impacting 454,446 individuals who were patients at QIA facilities from January to September and experienced the effects of QIAs. Specifically, interventions were aimed at reducing the long-term use of catheters (90 or more days from initial dialysis); reducing rates of bloodstream infections (BSIs), which are a type of healthcare-associated infection (HAI); increasing the use of home dialysis; and increasing the number of patients on the transplant waitlist.

Figure 1. Overall patient impacts and estimated cost savings resulting from 2019 QIAs



Analysis of impacts on patients in facilities engaged in QIAs showed 21,679 positive patient outcomes in the 2019 QIA performance period. For QIAs facilitating the use of home therapy and transplants, for which cost savings estimates were available, improved outcomes represent an anticipated \$130 million in savings (Figure 1). The impact extends beyond those direct measurable outcomes. The changes in processes and policies that occurred and the increased education the QIA facilities received 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.

Reducing Long-Term Catheter Use

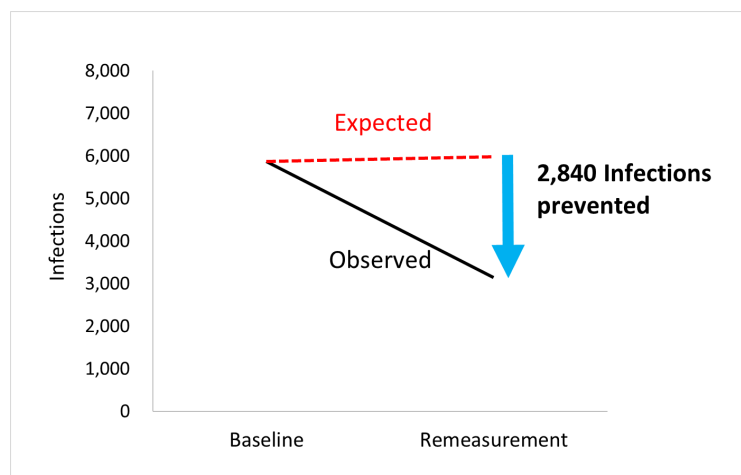
Compared with dialyzing with an arteriovenous fistula (AVF), dialysis performed with a long-term catheter (LTC) increases the risk of mortality and serious infections and may result in more frequent hospitalizations and access-related procedures and less adequacy in treatment.² Efforts to reduce catheter use offer significant positive impacts for patients. In 2019, 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 catheter (CVC) as their only access. During the first eight months of the performance period, facilities had 10,773 patients with a long-term catheter in use at some time during the eight months – the measure denominator. Among patients that were prevalent at the end of the remeasurement period, 3,445 were no longer using catheters.

3,445 patients were no longer using long-term catheters at the end of the performance period

Reducing Bloodstream Infections

Due to the regular and frequent access to patients' bloodstreams during dialysis, patients with ESRD are at increased risk for BSIs.³ Infections can jeopardize patients' quality and length of life. Attributable mortality for patients positive for a central line–associated BSI have ranged from

Figure 2. Reduction in expected bloodstream infections as a result of 2019 QIAs.



12.0% to 25.0%.⁴ Through the QIAs, awareness was increased, facility staff and patients were educated, and quality improvement interventions were implemented, directly impacting the quality of life for patients.

During the baseline period of January 1, 2018, to June 30, 2018, there were 5,874 BSIs in QIA facilities, corresponding to a rate of 1.1 infections per 100 patient-months. Applying this rate to the

² 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>.

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

⁴ 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.

prevalent patients in the remeasurement period of January 1, 2019, to June 30, 2019, yields 5,985 expected infections during this period. There were 3,145 observed infections during the remeasurement period—2,840 fewer than expected (Figure 2).

Increasing Home Dialysis Utilization

Home dialysis is defined as either peritoneal dialysis or home hemodialysis. In comparison with in-center hemodialysis, home dialysis has established benefits to patient length of life^{5,6}, and potential for reduced cost of treatment and overall costs to the health system.⁷

Insight Policy Research and Arbor Research Collaborative for Health estimated the cost difference between home peritoneal dialysis, the most common modality in the home setting, and in-center hemodialysis. The study was based on monthly Medicare expenditures and used a risk model to adjust for differences between patients receiving peritoneal dialysis and in-center hemodialysis. Home peritoneal dialysis was estimated to save \$950.18 per patient per month (\$11,402 per year) in 2019 dollars.⁸

10,223 patients transitioned to home dialysis with anticipated savings of \$97 million per year

As a result of education and outreach activities during the 2019 QIAs, 10,223 patients transitioned to home dialysis during the remeasurement period. Analysis of Consolidated Renal Operations in a Web-Enabled Network (CROWNWeb) data on home dialysis transitions from July 2018 to June 2019 indicates that patients who transitioned to home dialysis spent approximately 83% of days on dialysis in the home setting in the year following transition. Based on these data and the cost savings study, we estimate that home transitions observed among patients in the QIA facilities saved approximately \$97 million in the first year following transition.

⁵ 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.

⁶ 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.

⁷ 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. Executive Summary. Washington, DC: Department of Veterans Affairs (US); 2015 Apr. Available at: <https://www.ncbi.nlm.nih.gov/books/NBK344417/>.

⁸ Insight Policy Research and Arbor Research Collaborative for Health. Home Dialysis Return on Investment Analysis. Memorandum to CMS [internal document]. April 17, 2020.

Increasing Transplant Waitlisting

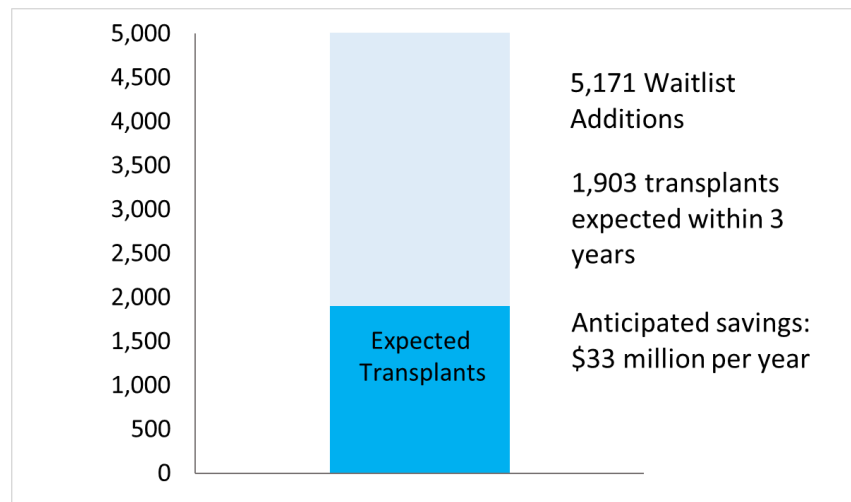
Patients receiving a kidney transplant have better outcomes than those remaining on dialysis, including higher five-year survival rates.^{9,10} The Networks' 2019 QIA interventions focused on moving patients to the transplant waitlist with the ultimate goal of achieving transplants for these patients.

The Department of Health and Human Services Office of the Actuary used a risk-adjusted analysis of Medicare expenditures to estimate the cost savings of transplants compared to dialysis.¹¹ The Office of the Actuary found that costs over a 5.5-year period for a patient who received a transplant

were \$93,000 less in 2017 dollars than for a patient on dialysis. Assuming a Consumer Price Index (CPI)¹² inflation factor of 1.04, this is \$96,720 or \$17,585 per year in 2019 dollars.

Through the Networks' efforts, 5,171 patients from the QIA facilities were added to the transplant waitlist during the remeasurement period. An analysis of transplants from 2014 to 2017 showed that 36.8% of patients added to the transplant waitlist received a transplant within 3 years.¹³ Based on this rate, 1,903 of the 5,171 patients would be expected to get transplants within 3 years with savings of \$33 million per year, based on the 5.5 year time window analyzed by the Office of the Actuary (Figure 3).

Figure 3. Patients added to waitlists, expected transplants, and cost savings as a result of 2019 QIAs.



⁹ 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.

¹⁰ 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>.

¹¹ DHHS. Office of the Actuary. Savings Estimate for Kidney Transplant Model. CMS Memorandum [internal document]. June 3, 2016.

¹² U.S. Bureau of Labor Statistics. CPI Inflation Calculator. Available at: https://www.bls.gov/data/inflation_calculator.htm. Accessed August 29, 2020.

¹³ Hart A, Smith JM, Skeans MA, et al. 2017 Annual Data Report: Kidney. *American Journal of Transplantation*. 27 Feb 2019. Available at: <https://onlinelibrary.wiley.com/doi/full/10.1111/ajt.15274#ajt15274-fig-0022>.



Summary

QIAs to reduce LTC use, reduce BSIs, increase the use of home dialysis, and increase the number of patients on the transplant waitlist were conducted with more than 6,000 dialysis facilities involving more than 450,000 patients. Overall, analysis of the results of these QIAs suggests that more than 21,000 positive patient impacts occurred. For QIAs that facilitated the use of home therapy and transplants, for which cost savings estimates were available, improved outcomes represent an anticipated \$130 million in savings. The ESRD Network Program is meaningfully impacting patient outcomes and reducing costs associated with care.

Report Highlights

Dialysis Prevalence

The Networks reported a 2.4% increase in the prevalent dialysis population, i.e., the total number of dialysis patients receiving care from Medicare-certified facilities as of the last day of the year in 2018 as compared with the last day of the year in 2019. Considerable variation in ESRD prevalence was present across the 18 ESRD Networks' geographic areas as of December 31, 2019. 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 (15,120). Network 14, which covers the state of Texas, had the largest number of patients (54,406).

Home Dialysis

The number of eligible dialysis patients using home dialysis increased by 10.9% from 2018 to 2019. 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 compared to in-center hemodialysis. On July 10, 2019, a Presidential Executive Order, Advancing American Kidney Health, was signed, outlining a set of initiatives that included a focus on increased use of home dialysis. A new goal of 80% of incident ESRD patients on home dialysis or receiving a transplant by 2025 was introduced at that time.

Grievances and Non-Grievances

The 18 ESRD Networks processed 1,231 beneficiary grievances in 2019. Of the 1,231 grievance cases processed, 614 (49.9%) were addressed through the use of Immediate Advocacy, 398 (32.3%) were General Grievances, and 219 (17.8%) were based on a Clinical Area of Concern. The total number of non-grievance cases in 2019 was 4,007. These included 2,940 Facility Concerns and 1,067 Access to Care non-grievances. See Table 2 in the Data Tables section of this document for Network-specific data.

Networks enter grievances (Immediate Advocacy, General Grievance, and Clinical Quality of Care) and non-grievances (Facility Concern and Access to Care) into the Patient Contact Utility (PCU) database. Cases can change types during the review process. For example, a call may be categorized initially as an Immediate Advocacy grievance, but once other details are revealed, the case could move to General Grievance. Within the PCU, the user can document a revised case type.



Grievances

1. Immediate Advocacy: These are cases of a simple, generally non-quality of care nature that can be resolved in 7 calendar days or less. Examples are grievances involving staff issues, scheduling issues, and transportation issues for the patient if they can be resolved within 7 calendar days.
2. General Grievance: These are cases of a more complex nature that do not involve clinical quality of care issues and that cannot be resolved within 7 calendar days. Examples of General Grievances could be a bedbug infestation in the facility or televisions not working.
3. Clinical Quality of Care Grievance: These are circumstances in which the grievant alleges that an ESRD service received from a Medicare-certified provider did not meet professionally recognized standards of clinical care. Clinical Quality of Care cases may be either 1) a patient-specific Clinical Quality of Care case in which the care impacted a specific patient or 2) a general Clinical Quality of Care case in which two or more patients at a facility were impacted. Examples of Clinical Quality of Care grievances could be a patient's blood loss incident or multiple patients alleging problems with fluid removal and target weight adjustments.

Non-Grievances

1. Facility Concern: These non-grievances are initiated by a contact from a facility staff member who wishes to discuss either a specific or general circumstance(s) about a patient or the facility for which there is insufficient information to meet the criteria for a grievance or Access to Care case. Examples are hours of operation questions, transportation issues, facility employee inquiring about Network documentation on the involuntary discharge (IVD)/involuntary transfer (IVT) process, or a facility requesting technical assistance on a complex patient/staff incident.
2. Access to Care (IVD/IVT/Failure to Place): These are cases involving IVDs, IVTs, or failures to place the patient in an appropriate dialysis facility. The categories for these cases include Behaviors, Medical Needs, Non-payment Issues or Facility Refusal/Failure to Place. The patient could have multiple types of access to care events: He or she could be at risk for an IVD/IVT, then proceed to a confirmed IVD/IVT, and then move to a failure to place case in which the patient is having trouble finding a dialysis unit.



Patient Engagement

In 2019, the 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) and Caregiver SMEs helped to promote and provide peer-to-peer education within the dialysis units. Patient SMEs and Caregiver SMEs also served 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 ESRD Network Program-wide objectives.

Emergency Management

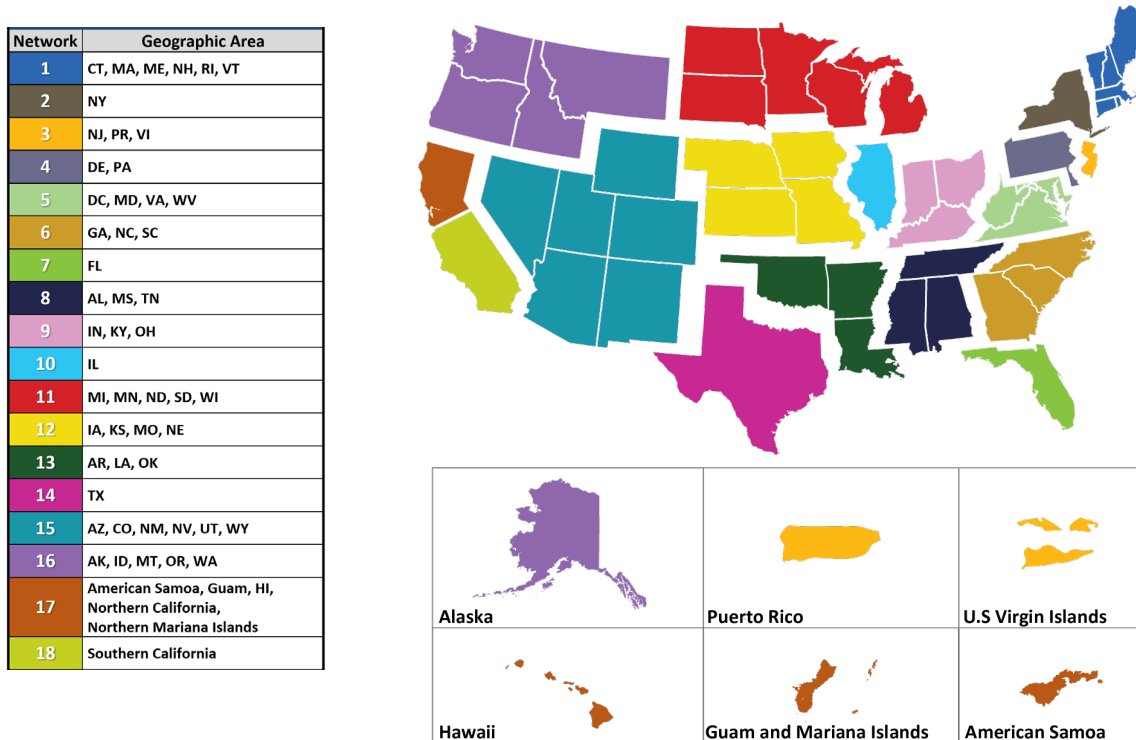
During 2019, CMS continued its enhanced focus on emergency management practices and requirements for the Networks. On a national level, the Kidney Community Emergency Response (KCER) Program strengthened relationships with CMS emergency management professionals, the HHS Office of the Assistant Secretary for Preparedness and Response (ASPR), and the U.S. Public Health Service. On regional, state, and local levels, the Networks continued to engage in outreach, training, and technical assistance activities to help ensure that the needs of ESRD patients would be met in emergency situations. During 2019, KCER responded to a total of 36 events that resulted in over 1,000 changes in facility status, including closures and altered schedules, and the KCER team submitted over 58 incident reports to CMS related to the events.

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 4). In 2019, the Networks worked to improve healthcare for approximately 530,000 dialysis patients and approximately 233,000 kidney transplant patients.

Figure 4. ESRD Network Service Areas





The ESRD National Coordinating Center

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

- Convening NPFE and Network QIA LANs.
- Collecting, analyzing, and reporting data for use by the Networks and CMS.
- Supporting the Networks in achieving CMS-defined goals in the following areas:
 - Vascular access.
 - Reduction in rates of preventable hospitalizations.
 - Reduction in rates of HAIs.
 - Increased use of home dialysis and kidney transplantation.
 - Increase in referrals of eligible patients to vocational rehabilitation.
 - Improved care coordination to decrease hospitalization rates.
- 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 ESRD NCC data.

Network Requirements

The activities of the 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 2019, 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 Networks are charged with promoting positive change relative to the CMS goals, as well as targeting disparities when conducting all 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 7,700 dialysis facilities and more than 220 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 responsible for maintaining professional relationships within the ESRD community, administration of the CMS contract, management and supervision of staff, and fiscal oversight of the Network.

Network staff with experience in program planning and implementation, data analysis, and evaluation conduct activities and assume responsibilities outlined in the Network contracts and other CMS directives. CMS also requires each 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 Network to 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 as follows:

- 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 including 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 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 play a critical role in the effective functioning of the Networks and the success of the ESRD Network Program.



Patient Profile

Patients and Facilities

As of December 31, 2019, there were 530,311 prevalent dialysis patients and 7,752 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 (790). Network 1, which covers the New England region states of Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, had the fewest facilities (208).

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). In 2019, the prevalence of CKD in the U.S. adult population was high, with an estimate of more than 15.0% of the adult population or 37 million adults affected.¹⁴ This is attributable, in part, to high rates of diabetes and hypertension in the adult population. Approximately 2.1% of the overall population with CKD is receiving dialysis or has had a transplanted kidney. 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.

Prevalent Dialysis Patients

Information on prevalent dialysis patients is drawn from the CROWNWeb database that identifies all patients who are alive and on dialysis as of December 31 of a given year. At the end of 2019, 530,311 patients were receiving dialysis in the U.S., according to the Networks’ Annual Reports—a 2.4% increase from December 31, 2018.

¹⁴ CDC. Chronic Kidney Disease Initiative. Chronic Kidney Disease in the United States, 2019. Available at: <https://www.cdc.gov/kidneydisease/publications-resources/2019-national-facts.html>. Accessed August 29, 2020.

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

Vascular Access

ESRD is the final stage on the spectrum of CKD. Individuals with ESRD need renal replacement therapy unless they obtain a kidney transplant.

Hemodialysis, one 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: AVF, arteriovenous graft (AVG), and 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 (stenosis) than AVFs and AVGs, leading to higher morbidity and mortality.¹⁵ As a result, a CVC 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 2019, the Networks developed targeted strategies to assist dialysis facilities in increasing AVF use rates and decreasing LTC use rates for incident patients (new to ESRD) and prevalent dialysis patients. Strategies were developed through the performance of root cause analyses (RCAs).

To achieve improvements in access use (more AVFs/AVGs and fewer LTCs), the Networks implemented a QIA to decrease LTC use rates by 2 percentage points. The 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 [from the 50% of facilities in

¹⁵ Vachharajani TJ. *Atlas of Dialysis Vascular Access*. 2010. Available at: <http://fistulafirst.esrdncc.org/wp-content/uploads/2015/12/Access-Atlas.pdf>

the Network's service area reporting the highest excess infection rates]). The Networks then provided individualized support to the identified facilities. The results of this 2019 QIA were reported in October 2019.

Examples of Network efforts are:

- **Network 9** initiated a number of interventions to achieve the project goal. These included engaging a lead contact and Patient Facility Representative in each facility, sharing educational resources from access management specialists, sharing best practices, developing and providing a template for RCA of LTC usage, educating providers on the use of CROWNWeb reports to promote accurate reporting of primary access, and providing ongoing data surveillance and communication on progress. The Network also created and distributed monthly Incident Access Reports to facilitate benchmarking within facilities and individual nephrologist practices related to access admissions, shared Fistula First-Catheter Last data quarterly on performance metrics, facilitated LAN meetings and activities, performed site visits with five facilities to provide assistance in developing sustainable interventions, and used individualized intervention models with groups of clinics in targeted regions. During the seven-month intervention period, the participating facilities achieved a 2.3 percentage-point reduction in the rate of LTC use.
- **Network 11** used a tiered interventional approach with cohort facilities based on their facility-level LTC rate. Tier 1 was given intensive technical assistance with monthly monitoring. For example, the Network conducted a webinar to address barriers, and three Network reviewers conducted a comprehensive review of facility BSI and LTC patient records. Tier 2 received modified off-site record review and focused technical assistance. The Network reviewed medical records for two patients in each Tier 2 facility, focusing on permanent vascular access placement and removal of the catheter. The Network then provided facility-specific recommendations and conducted follow-up. Tier 3 received virtual learning sessions and monthly facility-specific comparative reports. The Network shared resources (e.g., patient-developed brochure on choosing a vascular access) and strategies (e.g., Medical Director engagement in promoting surgical vascular accesses). The Network achieved a 2.8 percentage-point reduction in the LTC rate.
- **Network 12** utilized a monthly intervention strategy, where the Network shared a patient and staff resource, a patient engagement activity, and interim facility-specific data. Resources were created by the Network or sourced or adapted from other Networks and stakeholders, such as the Centers for Disease Control and Prevention (CDC). Resources included hands-on tools, e.g., a catheter monitoring tool and a catheter removal tracking tool. Interventions included ongoing CDC audits (e.g.,



catheter connection and disconnection) and Network collaborative learning webinars called Roundtable Calls held every other month. These calls focused on best practices, steps to overcoming barriers, and sharing of tools and processes. The Network PAC and staff developed Very Important Patient – Peer-to-Peer Sharing Calls, a series of patient-led calls to promote peer-to-peer support and education. Noted best practices were having a vascular access champion serve as a liaison between the patient, care team, and vascular access center and continued use of CDC’s Core Interventions to reduce dialysis BSIs.¹⁶ The Network realized a reduction of 2.5 percentage points in the rate of LTCs.

- **Network 14** provided assistance through one-on-one calls, site visits, data validation, electronic LTC monthly reports via SurveyMonkey®, and collaboration with large dialysis organizations’ (LDOs’) regional vascular access coordinators. Interventions encompassed RCA, rapid cycle improvement (RCI), updating and development of action/improvement plans with Medical Director sign-off during Quality Assessment & Performance Improvement (QAPI) monthly meetings, and attendance of Network staff at monthly regional/vascular access meetings. Other interventions included patient engagement (e.g., Facility Patient Representative), ESRD NCC HAI LAN calls, utilization of CDC Core Interventions and the *Medical Advisory Council (MAC) Catheter Reduction Toolkit* from the Forum of ESRD Networks, and completion of sustainability plans. Best practices included collection of self-reported data through the LTC Monthly Report via SurveyMonkey®, data validation between electronic medical records (EMRs) and CROWNWeb, and standardization of a sustainability plan to be approved by corporate/regional management. The LTC use rate was reduced by 3.4 percentage points.

¹⁶ Centers for Disease and Control and Prevention. Core Interventions. Available at: <https://www.cdc.gov/dialysis/prevention-tools/core-interventions.html>. Accessed September 24, 2020.

Patient Safety

Support for the National Healthcare Safety Network

The 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.¹⁷ NHSN data are critical to the improvement of care provided by dialysis facilities. The data also enable 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 2019, 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, as well as helping new users and facilities with completing enrollment in NHSN. The 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.

¹⁷ Centers for Disease Control and Prevention. Dialysis. Available at: <https://www.cdc.gov/dialysis/index.html>. Accessed August 2017.



Healthcare-Associated Infections Learning and Action Network

In 2019, the Networks continued to assist in the reduction of HAI rates 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 education for patients and family members about infection control, webinars for dialysis facility staff that featured presentations by public health and medical experts, and training on behavioral self-management policies and procedures (e.g., infection control protocols).

Quality Improvement Activities

Reducing the Rates of Bloodstream Infections

Dialysis patients are at higher risk than the general population for acquiring HAIs, specifically 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. The financial cost associated with HAIs is staggering.

All 18 ESRD Networks implemented a QIA to reduce BSIs. The goal of the BSI QIA was to demonstrate a 20% or greater relative reduction in the semi-annual pooled mean in a cohort of 20% of facilities with the highest excess infection rates in the Network service area at re-measurement compared with the previous year (January–June 2019 compared with January–June 2018).

Highlights of Network efforts conducted during 2019 include the following:

- **Network 3** enlisted stakeholders, including facility staff, corporate leaders, and Network SMEs for this QIA. Facilities were educated on and supported through the implementation of the CDC Core Interventions to reduce BSIs and appropriate use of the CDC Prevention Process Measure audit tools. Facilities conducted an assessment of prevention process measures using the audit tools and established plans to improve practices. Facilities were encouraged to attend CDC-led educational opportunities. The Network monitored data quality monthly and provided feedback. The Network also assisted in the development of improvement plans, conducted 83 site visits, and supported facilities with low rates of adherence to CDC recommendations and lack of active participation in the QIA. Best practices included engaging the team and improving adherence to infection prevention practices, involving patients in hand hygiene observations, using audit findings to reinforce policies and procedures, and incorporating SMEs for peer-to-peer discussions. A 44.7% reduction in the BSI rate was achieved with an estimated 109 BSIs prevented.
- **Network 6** launched a survey to identify best practices, challenges, and areas for improvement. The information guided interventions that included engaging regional leaders by establishing virtual meetings with low- and high-performing facilities to spread best practices and mitigate barriers, distributing the CDC Core Interventions to reduce BSIs poster and resources, providing staff education, encouraging facility attendance at ESRD NCC HAI LAN meetings, and launching the *Patient Education Initiative*. The Network also distributed monthly performance metric reports and worked with facility staff to ensure that yearly training on BSI reporting was completed and entered into NHSN. Best practices included achieving data transparency across the Network, facility staff, and the State Survey Agency (SA) via the BSI Progress Report/

Achievement Level Report and promoting an Infection Prevention Champion to conduct audits and provide real-time feedback to staff and patients. The Network achieved a 47.0% reduction in the BSI rate for the cohort with an estimated 237 BSIs prevented.

- **Network 8** staff reviewed BSI data monthly to assess trends. Facilities that reported increases in BSIs for three consecutive months were required to perform an RCA and develop an action plan. Facilities implemented interventions, including conducting monthly infection control audits; using the CDC Core Interventions to reduce BSIs protocols, checklists, and audit tools; and engaging patients. The Network collaborated with facilities to identify best practices and barriers and to develop and share improvement strategies. Best practices included implementing Scrub the Hub to prepare catheter hubs aseptically, implementing a Handwashing Pledge, obtaining hospital portal access to acquire information, using Tegaderm dressings to provide visibility of the catheter exit site, utilizing antimicrobial barrier caps, changing catheter dressings at each treatment, and using the *Days Since Last BSI* poster. The focus group (or cohort) achieved a 57.3% reduction in its BSI rate, while the non-focus group increased its BSI rate by 18%. An estimated 222 BSIs were prevented.
- **Network 15** identified its primary intervention as the use of the CDC BSI prevention audit tools and 9 CDC Core Interventions to reduce BSIs. Facilities provided patient education (e.g., on handwashing, signs/symptoms of infection); attended a webinar, developed with the Colorado Department of Health and Environment, on CDC approaches to preventing BSIs and accurate reporting in NHSN; and encouraged patients to sign a pledge as partners in infection prevention. Facility processes, prevention measures, and BSIs were tracked and analyzed. Monthly hand hygiene audits were conducted with patients completing the observations. The Network provided interventions monthly to facilities and promoted the use of a health information exchange (HIE). Best practices included engaging patients as auditors, reviewing CDC Core Interventions and Network-provided interventions during monthly QAPI meetings, and reviewing infection rates with facility medical directors. The focus group achieved a 72.2% reduction in the BSI rate, and an estimated 131 BSIs were prevented, exceeding the goal.
- **Network 16** shared data, such as high- and low-performer and aggregate results, with LDO leadership. All nine CDC Core Interventions to reduce BSIs were incorporated in monthly education with multiple CDC resources, including the Clean Hands Count campaign, Core Interventions documents, and social media graphics for hand hygiene. The Network collaborated with stakeholders to provide robust data validation and individualized education/support for implementing CDC audit tools. Both PAC and MRB members reiterated the need for education, so the Network expanded education of patients to include dialysis station disinfection audits in addition to hand hygiene. To



provide education in establishing an infection prevention program, the Network shared the Oregon Patient Safety Commission (OPSC) Infection Prevention Series webinars. The NCC BSI LAN widened the distribution of best practices; one impactful example was the early sepsis surveillance tool. Facilities' alignment with CDC recommendations led to significantly reduced infection rates. The cohort achieved a 63.2% reduction, which was an estimated 116 prevented BSIs, exceeding the Network goal.

Promoting Appropriate Home Dialysis

In the U.S. in 2019, 71,408 of the total 530,311 (13.5%) dialysis patients utilized 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. The goal for this project was to demonstrate a 2 percentage-point improvement in the natural trend of patients using a home modality in 30% of facilities in the Network service area. The natural trend was based on Network performance in the previous 5 years. A goal or target number of home dialysis initiations was calculated for each Network to achieve the 2 percentage-point improvement. Network efforts to increase the number of patients using home dialysis during 2019 included the following:

- **Network 4** centered improvement methods on the use of the Institute for Healthcare Improvement (IHI) Model and included the use of RCA, development of a facility-specific quality improvement plan, and use of plan-do-study-act (PDSA) cycles to test change. As facilities submitted monthly progress reports, they were expected to make changes to their proposed interventions if necessary until the completion of the project. The Network planned a multi-pronged approach that included comparative feedback reports, encouragement of process changes, and development of home dialysis educational materials. Best practices were identified: incorporating home dialysis education in the in-center dialysis routine for patients and staff members, utilizing Kidney Care Advocates (specialized educators) to provide home dialysis education for patients and staff, and mobilization of two Network patient advocates to lead education lobby days and mentor patients one-to-one. The 647 patients starting home dialysis exceeded the QIA goal of 596 home dialysis initiations.
- **Network 5** encouraged facilities to involve patients in the QIA and on the QAPI team. Patient SMEs assisted in the development of interventions and participated in the Network Council Meeting and the Outcomes Congress. The Network identified best practices, which were shared during webinars and at the Outcomes Congress and included Network encouragement of facilities' home and in-center departments collaborating. Home dialysis and hemodialysis departments developed stronger communications processes to create a seamless path for patients. Both MEI and NxStage were represented at the Network Council Meeting. At the meeting, a patient presented his experience with NxStage, and MEI provided tools (e.g., the online MATCH-



D decision tool) and live demonstrations. Patient SMEs served as peer mentors, assisting in lobby days and visiting in-center patients. The Network targeted newly admitted patients and promoted evidence-based decision tools. The Network goal was for 581 patients to transition to home modalities. This goal was exceeded with 661 patients initiating a home modality.

- **Network 10** trained facilities in conducting RCA and in PDSA methodologies to help them improve processes and carry out changes that could be sustainable. Each clinic submitted an individual PDSA plan. These were reviewed by Network staff. Technical assistance was offered throughout the project. The Network provided a Monthly Highlighted Resource with education and technical assistance for staff and resources to be shared with patients. The clinics were required to attend CMS-sponsored LAN Network webinars. Elements from each of these meetings were stressed during follow-up with the clinics, which were asked to implement at least one action item from each NCC LAN webinar. The Network focused on teaching staff how to use Motivational Interviewing to speak with patients about home modalities. Shared Decision Making and Relationship-Centered Care, along with goal planning sheets for patients and teach-back training, were also used. Network 10 exceeded the QIA goal of 445 with 460 patients initiating home dialysis.
- **Network 11** implemented interventions to enhance communication, including education and strategies to strengthen relationships between home and in-center facilities. The Network provided tools and education on the importance of patient voice and lifestyle values; convened calls with LDOs and independent dialysis facilities to discuss best practices, brainstorm barriers, and assess facility needs related to education; and produced and distributed PowerPoint presentations. Interventions also included establishing a process for communication between home and in-center dialysis facilities, working with Patient SMEs to produce videos, sharing best practices, and obtaining patient feedback on materials to shape strategies. The Network also collaborated with providers to present a webinar to share best practices to increase the number of patients starting home dialysis as a first modality choice. The Network exceeded its goal of 857 patients initiating home dialysis, with 868 patients starting or transitioning to a home dialysis modality.
- **Network 13** oriented facilities to the project, including providing education on the *7 Steps to Home Dialysis*.¹⁸ Among other interventions, facilities promoted communication among in-center dialysis facilities, home dialysis facilities, hospitals, nephrologists, and other providers to improve the rate of patients using a home dialysis modality. Best practices included encouraging nephrologists to conduct a “visit” with

¹⁸ ESRD National Coordinating Center. *7 Steps to Home Dialysis*. Available at: <https://www.esrdncc.org/en/qia/7-steps-to-home-dialysis/>. Accessed September 24, 2020.



patients interested in home dialysis to explain the procedure; providing education on home modalities to dispel myths; using the NCC Patient Affinity Group's¹⁹ *Uncovering Myths about Home: Myths vs. Reality* booklet; using the Forum of ESRD Networks' *Home Dialysis Toolkit*; using the NCC patient toolkit on treatment choices; providing patient-to-patient education; engaging families and patient support systems in education sessions; and arranging a tour of home programs to give patients an idea of what it would be like to do peritoneal dialysis. The cohort group increased the number of patients on home therapies to 426, exceeding the goal of 396 patients.

- **Network 15** identified barriers, provided education, and implemented interventions to assist practitioners in transitioning patients to a home modality. Patient SMEs provided the patient perspective for development of all QIA educational materials and interventions and gave input on the practicality and usefulness of interventions. Network interventions included initiating RCAs and providing technical assistance during tests of change using the PDSA cycle, training staff on how to approach patients about home modalities, educating staff and patients on the barriers and myths of home therapy, and helping facilities adopt LAN interventions, including encouraging communication between home dialysis and in-center programs. Examples of best practices are increased communication on home modality to improve participation by medical directors and nephrologists, monthly meetings with LDOs, and monthly trackers to follow patients with a review of the tracker at quality meetings. The goal was to move 387 patients to home dialysis. At the end of the QIA, 446 patients had transitioned to home dialysis.

Improving Transplant Coordination

The benefits of transplantation extend to ESRD patients regardless of age, gender, or ethnicity. Increased use of transplantation is a focus of the Advancing American Kidney Health Initiative.

The intent of this QIA was to promote early referral to transplant centers and assist patients and providers in improving referral patterns by addressing patient barriers. The goal of this project was to increase the number of dialysis patients on the transplant waitlist. Networks were to demonstrate a 2 percentage-point improvement in the natural trend of the Network of patients on the transplant waitlist in 30% of facilities in the Network service area. The natural trend was based on Network performance in the previous 5 years. A goal or target number of transplant waitlist additions was calculated for each Network to achieve the 2 percentage-point improvement.

¹⁹ Affinity Groups are smaller topic-specific groups within the LAN designed to promote conversation and build on the group's individual and collective strengths to adapt or develop patient-focused resources for sharing in the LAN and beyond.



The Networks identified multiple barriers to achieving the QIA goal, including patient-related factors (e.g., refusal or lack of interest in kidney transplantation, multiple major co-morbidities such as obesity, ineligibility due to cognitive impairment or advanced age, and lack of social support), facility-related issues (e.g., staff time constraints), and others (e.g., areas without a transplant center, extended travel distance, and undocumented patients with no SSN or Medicare coverage). Although none of the Networks met the goal, 5,171 patients were added to the transplant waitlist (74.2% of the goal of 6,970) January through September 2019.

Examples of Network efforts conducted during 2019 included the following:

- **Network 1** tailored interventions to ensure that all interested and suitable patients were given the opportunity for transplantation as a treatment option and to improve communication between dialysis facilities and transplant centers. Strategies to achieve these goals included supporting each facility in conducting an RCA to identify barriers, providing education on the “Six Step” process to track patients from interest in transplant to placement on the waitlist, addressing communication barriers between dialysis facilities and transplant centers, and identifying patient navigators to help guide transplant candidates through the evaluation process. Facility-identified best practices included identifying a dedicated transplant coordinator, fostering regular communications between the dialysis facility and the transplant center, having the transplant center host a lobby day, conducting frequent and ongoing patient education, and referring every patient interested in transplant to a transplant center for evaluation. The Network assisted facilities in getting 132 patients added to the United Network of Organ Sharing (UNOS) kidney transplant waitlist.
- **Network 2** partnered with the New York Center for Kidney Transplantation (NYKidney), a transplant-focused stakeholder dedicated to enhancing the quality of kidney transplant services. The partnership focused on addressing communication breakdowns between dialysis facilities and transplant centers. In a multi-agency collaboration with a NYKidney-assembled Transplant Consortium and a Network-developed adaptation of a dialysis-focused Project ECHO™ through bi-weekly Dialysis and Transplant ECHO virtual learning series and subsequent monthly ECHO University, staff from NYKidney, the Network, Lawyers for Public Interest Law, and transplant centers worked together to find ways to educate dialysis facility staff, address disparities, and assist patients who otherwise were unable to be considered for transplant. QIA interventions included engaging patients through educational events and partnering with additional transplant facilities beyond the Network service area to bring a fresh perspective and encourage multi-listing. Best practices included facilities developing relationships with transplant centers, identifying Patient Champions, developing a process for facilities to order printed educational materials from the Network to establish dedicated Transplant “Education Stations” within facilities, and monitoring patient transplant status and step



navigation monthly. The Network attained an increase of 231 patients on the transplant waitlist.

- **Network 5** worked with facilities to promote early referral to the transplant waitlist and assist patients and providers in improving referral patterns by addressing barriers. Staff were surveyed pre- and post-QIA on patient engagement knowledge and practices and reviewed an educational module on patient engagement. Facilities were encouraged to involve patients in the QIA and on the QAPI team. Ten percent of patients were surveyed monthly to ascertain awareness and impact of the QIA. Patient SMEs assisted in the development of the QIA interventions and participated at the Network Council Meeting and the Outcomes Congress. Best practices included engaging patients who encouraged one another to self-refer and served as mentors. The Network Council Meeting featured a transplant panel, including professionals and a transplant recipient. The Network collaborated with transplant centers to develop a question-and-answer document for facility teams. The 5-Diamond Patient Safety Transplant module was revised and promoted to facilities. Facilities added 422 patients to the transplant waitlist.
- **Network 7** implemented interventions that included creating a resource that the facilities could use to ask patients why they were not interested in pursuing a transplant. Based on results reported to the Network and feedback from Network Patient SMEs, a transplant referral guide and *Let's Get Started Checklist* were created. The Network also encouraged facilities to build a workable, structured communication process with transplant centers to track patients and exchange information to expedite the referral and evaluation process. Best practices included building better communication processes for exchanging information between dialysis facilities and transplant centers; referring patients to more than one transplant center if they met the criteria; using a tracking tool to follow patients; educating patients and staff on transplantation, the waitlist process, and referral criteria; supporting patients throughout the process; and using the *Let's Get Started Checklist* to help prepare patients for the work-up process. At the end of the QIA, 361 patients were added to the transplant waitlist.

Population Health Focused Pilot Quality Improvement Activities

In 2019, each of the 18 ESRD Networks developed a Population Health Focused Pilot QIA (PHFPQ) 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.
- 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.

The objective of the PHFPQ was to facilitate achievement of CMS national quality improvement goals. Throughout the PHFPQ, the Networks provided leadership and guidance for quality improvement efforts in collaboration with the CMS SME and COR.

Excluding the PHFPQ related to hospitalization, 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. 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.

Improving Dialysis Care Coordination with a Focus on Reducing Hospital Utilization

The intent of this QIA was to identify the drivers of ineffective care transitions that can lead to poor health outcomes, resulting in increased utilization of acute care services. The goal was to improve the coordination of care for ESRD patients and their families between care settings. The Network aimed to achieve (1) a 2 percentage-point decrease in the average rate of overall hospitalizations and (2) a 10% decrease in ESRD-related hospitalizations among dialysis patients in selected QIA facilities from the baseline period (October 2017–June 2018) to remeasurement (February–October 2019). The Network that selected this topic identified challenges that impacted the results: patient-related factors (e.g., lack of follow-up with appointments, lack of family support, and socioeconomic issues such as unstable housing), dialysis facility-related factors (e.g., lack of designated staff to follow up on hospitalizations), and organizational factors (e.g., no specific protocol for data sharing for hospitalized patients between settings). Although the Network did not meet its goals during the project period, after an initial increase in rates, the ESRD-related hospitalization rate decreased 2.4 percentage points from April to October 2019, with overall hospital admissions decreasing 2.3 percentage points during the same time period.

- **Network 14** guided facilities in performing an RCA via SurveyMonkey® to identify the top causes leading to hospitalizations. Interventions included implementation of the Forum of ESRD Networks' *Transitions of Care Toolkit*, Quality Improvement best practices toolkit on transitions of care, and a monthly data collection tracking tool. All QIA focus facilities were required to have staff attend the NCC LAN meetings and provided feedback on at least one intervention used from the LAN. The Network partnered with TMF to establish a Texas Renal Coalition to address hospitalizations and readmissions. The coalition enabled the Network to brainstorm with representatives impacted by ESRD hospital admissions and find solutions to common barriers. Other best practices included distributing interventions based on top diagnosis codes for admissions each month and engaging PAC SMEs to develop resources.

Supporting Gainful Employment of ESRD Patients

In 2019, the Networks assisted patients with seeking gainful employment and/or returning to work. Each Network participating in the PHFPQ was required to identify a minimum of five Employment Networks (ENs) and/or State Vocational Rehabilitation (VR) agencies servicing the patient population. ENs and VRs “coordinate and provide appropriate services to help eligible



beneficiaries find and maintain employment.”²⁰ The goal was to demonstrate at least a 10 percentage-point increase in referrals of eligible patients in the QIA facilities to ENs and/or VR agencies and at least a 5 percentage-point increase in the percentage of referred eligible patients receiving EN and/or VR services in the QIA facilities from February through September 2019.

- **Network 1** launched a VR campaign to distribute a list of ENs, information about adult career/education services and the Social Security Administration’s (SSA’s) Ticket to Work Program, and Network-developed resources addressing disparity in the VR setting to help facilities promote services to all segments of the patient population. The Network provided education on the Vocational Rehabilitation Tracking Tool, which tracks the number of patients referred to VR and utilizing services. Tracking tools were submitted to the Network monthly. The Network also collaborated with EN/VR agencies. Best practices included ongoing assessment of barriers, increased education of patients, inclusion of VR during care plan meetings, education of staff about documenting VR referrals in CROWNWeb, and follow-up with patients to monitor employment and/or VR interest/involvement. The referral rate surpassed the goal by 55.0 percentage points. The rate of referred patients receiving services exceeded the goal by 11.0 percentage points.
- **Network 2** provided community educational resources and materials, including EN materials, VR resources, Veterans Administration resources, and SSA Ticket to Work Program information. The Network collaborated with the ENs, which resulted in webinars, remote access to ENs for patients in the Network’s service area, and easier access for facility staff to create relationships with EN contacts. Best practices included 1:1 coaching calls with facilities to help them identify patients referred for or receiving services but not documented in CROWNWeb; collaborative calls to bridge communication between providers, create a network of support, and share best practices; and establishment by provider staff of a peer network, resulting in a documentation tool for initial contact with an EN/VR agency and the integration of a Network-developed ESRD SMART Goals worksheet into the workflow at a number of VR agencies. Both goals were exceeded with a 36.3 percentage-point improvement in the VR/EN referral rate and an 8.0 percentage-point improvement in the VR/EN utilization rate.
- **Network 4** incorporated the six attributes outlined by CMS into the interventions. Examples of best practices include: *Innovation in Action* – Distributed facility performance on VR metrics monthly and a toolkit with local, state, and Ticket to Work

²⁰ Social Security Administration. Ticket to Work Program overview [cited 2017 Jul 6]. Available at: <https://www.ssa.gov/work/overview.html>. Cited by: Centers for Medicare & Medicaid Services (CMS). *ESRD Network Statement of Work*. Baltimore, MD; October 4, 2018.



resources. *Rapid Cycle Improvement in Action* – Distributed internal “stoplight” dashboards to track performance and provided technical assistance through visits and 1:1 calls. *Boundarilessness and Teamwork in Action* – Partnered with VR/EN offices to facilitate training and education. *PFE in Action* – Encouraged the inclusion of Patient Representatives to serve as peer mentors and provide input in the development of interventions. *Customer Focus in Action* – Distributed CROWNWeb Job Aide to guide how to document VR status. *Sustainability* – Developed and distributed a sustainability action plan to guide integration, sustainability, and scale/spread. Both goals were achieved with a 42.7 percentage-point increase in VR/EN referrals and a 5.3 percentage-point improvement in VR/EN utilization.

- **Network 12** shared interventions and resources for patients and staff monthly, e.g., the Network collaborated with transplant centers and other Networks to develop a resource that explains additional benefits afforded to individuals with Medicare who seek VR services and receive additional years of immunosuppressant medications following transplantation. The Network also generated a monthly report that displayed facility-specific goals and QIA outcomes, shared a feedback report with patient statuses in CROWNWeb, and created a quick-start guide to update the VR status field in CROWNWeb. Network Patient Representatives helped create bulletin boards, shared stories, and assisted in Lobby Days. The Network partnered with ENs to provide education to facilities on the Ticket to Work Program and help patients with employment using Social Security work incentives. Both goals were exceeded with an increase of referrals of patients to VR of 27.3 percentage points and an increase in the percentage of patients receiving services from a VR agency of 11.5 percentage points.
- **Network 17** provided technical assistance to ensure all patients were screened for interest, identified more than one CROWNWeb user in each facility, and created and disseminated a CROWNWeb documentation tool. The Network shared patient testimonials to increase engagement, disseminated patient educational resources on VR/EN services and how to access them, and partnered with VR and EN providers. Technical assistance also included providing staff education and a VR QIA QAPI form to assist facilities with discussing patient VR/EN status during monthly meetings and obtaining feedback from patients and family members to identify barriers. The Network collected monthly data from the facilities on completed screenings and referrals, the number of patients receiving services, and the documentation of patient status in CROWNWeb. Facilities also reported feedback on the usefulness of QIA and LAN interventions monthly. Goals were exceeded: referrals increased 47.0 percentage points; the percentage of patients receiving services increased 13.3 percentage points.
- **Network 18** and its PAC VR Advisors developed resources to aid facilities with individualized care planning strategies. These included supporting patients’ goals by



offering work-friendly treatment, identifying barriers to VR and intervening (e.g., NW 18 *Social Work Interventions to Address Patient Reported Barriers to VR*), providing education (e.g., NW 18 *Top 10 Reasons for VR* poster, NW 18 *Patient Success Stories*, NW 18 *Patient Guide to Working with VR/EN Offices*), teaching patients about Social Security work incentives, referring patients to VR and tracking VR referral outcomes, reviewing VR outcomes in QAPI meetings and adjusting interventions, educating staff (e.g., NW 18 *VR Best Practices Checklist*), and reaching out to VR Offices. In addition to providing project facilities with monthly report cards, the Network hosted monthly meetings with LDO leadership to review VR outcomes. Referrals increased by 33.7 percentage points, and the percentage of patients receiving services increased by 10.1 percentage points, exceeding QIA goals.

Support for the ESRD Quality Incentive Program

The ESRD Quality Incentive Program (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.²¹ A percentage of each dialysis facility's Medicare reimbursement is contingent on the facility's performance on the following metrics²²:

- Percentage of patient responses to the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS) Survey
- Reducing unplanned hospital readmissions as evidenced by the Standardized Readmission Ratio
- Risk-adjusted Standardized Hospitalization Ratio of observed to expected hospitalizations
- Percentage of patients for whom one of six conditions are successfully reported in the Clinical Depression Screening and Follow-Up
- Kt/V dialysis adequacy in hemodialysis and peritoneal dialysis patients
- Increasing the Vascular Access Standardized Fistula Rate
- Decreasing continuous catheter use for three months or longer
- Reducing the Observed Standardized Transfusion Ratio
- Minimizing hypercalcemia or missing values
- Percentage of patient-months of ultrafiltration rate reported
- Number of months facility completes NHSN reporting (NHSN BSI Clinical, Dialysis Event)

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.

In 2019, 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 focused on educating patients and family members on accessing and understanding dialysis facility Performance

²¹ Details of the ESRD QIP can be found at: <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/ESRDQIP>.

²² CMS. End-Stage Renal Disease Quality Incentive Program (ESRD QIP) Payment Year (PY) 2021 Measure Technical Specifications. Last revised October 26, 2018. Available at: <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/ESRDQIP/Downloads/PY-2021-Final-Technical-Specifications-ESRD.pdf>. Accessed August 29, 2020.



Score Reports (PSRs) and Performance Score Certificates (PSCs) to help patients make educated decisions about their care.

Provider Staff 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 2019, these activities included:

- Hosting Network Annual Meetings
- Developing and/or distributing educational materials and resources
- Conducting 1:1 virtual coaching calls and on-site visits to provide:
 - Education on critical elements of QIAs, such as RCAs, intervention plans, performance monitoring, and sustainability
 - Staff training on various other topics (e.g., IVDs, change concepts) and resources (e.g., toolkits and audit tools)
- Encouraging participation in the LANs to reduce HAIs
- Developing and presenting webinars to educate dialysis facility staff, e.g., on increasing transplantation referrals, reducing LTC use, and BSIs
- Sharing 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 interventions, 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 2019, the Networks continued their ongoing collaboration with the ESRD NCC on the ESRD Dashboard Committee. The work of the committee advanced the refinement and evolution of the data reports and the NCC ESRD Dashboard. The dashboard, presented in an interactive, customizable, and secure format, provides monthly results of each QIA comparable between Networks, by cohort, and against a national trend. An executive summary, estimated cost savings for home dialysis and transplant, visibility into demographic variables by measure, and an LDO section altogether allow Networks timely information to support QIA work.

Network representatives on these committees:

- Informed the ESRD NCC on updates to Network data reporting needs, priorities, and perspectives
- Offered guidance on the requirements for specific reports and dashboard releases
- Tested data report updates prior to release to the entire community
- Collaborated with the ESRD NCC to make important data available to 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 and dashboards throughout the contract year. Additional enhancements and refinements were made to assist the Networks with their QIAs and based on ad hoc requests from CMS.



Veterans Health Administration and Transplant Facility Data

In 2019, 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 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.

Partnerships and Coalitions

In 2019, the 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 LDOs, the Networks partnered with organizations such as:

- American Association of Kidney Patients (AAKP)
- American Kidney Fund (AKF)
- American Nephrology Nurses Association (ANNA)
- American Society of Nephrology (ASN)
- Association for Professionals in Infection Control and Epidemiology (APIC)
- Council of Nephrology Social Workers (CNSW)
- Forum of ESRD Networks
- Home Dialyzors United (HDU)
- Medical Education Institute (MEI)
- National Association of Nephrology Technicians/Technologists (NANT)
- National Hospice and Palliative Care Organization (NHPCO)
- National Institutes of Health (NIH) National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
- National Kidney Foundation (NKF)
- National Renal Administrators Association (NRRRA)
- Renal Physicians Association (RPA)
- United States Renal Data System (USRDS)
- United Network of Organ Sharing (UNOS)

Of equal importance are the Network collaborations with hospital associations, health departments, emergency medical services, transplant providers, other patient and professional organizations, Offices of Emergency Management, SAs, and Medicare Quality Innovation Network-Quality Improvement Organizations (QIN-QIOs) in their geographic areas.

Examples of Network collaborations include the following:

- **Network 3** built and strengthened partnerships with federal, state, and county partners, including the HHS ASPR and the New Jersey Office of Homeland Security and Preparedness. As a result of these partnerships, as well as those with DaVita, DCI, Fresenius, Physicians Dialysis, and independent providers, the Network hosted a Dialysis Active Shooter Conference on October 24, 2019. Attendees numbered 217 from facilities across New Jersey. Presenters included the New Jersey Office of Emergency



Management and the Department of Human Services, Disaster & Terrorism Branch – Division of Mental Health & Addiction Services.

- **Network 6** collaborated with multiple entities related to emergency preparedness. Examples include: (1) working with the Georgia Department of Public Health Dialysis Workgroup and the South Carolina Healthcare Coalition to create and launch a critical asset survey to identify facility and patient needs, key information, and facility assets and (2) attending the North Carolina Healthcare Partnership and Engagement Forum on emergency management response to strategize ways to strengthen healthcare preparedness, support continuity of operations, enhance situational awareness, improve incident management, and augment medical surge.

Patient and Family Engagement

Education for Patients and Caregivers

In 2019, the 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 patients and their care partners feel comfortable with the grievance process. The Networks distributed printed materials and published newsletters targeting both patients and facility staff. The Networks also used 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 approaches shared the goal of providing educational resources to ESRD patients, family members, and care partners.

Patient Experience of Care Learning and Action Network

In 2019, the 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 2019, LAN activities focused on:

- Utilizing the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) survey to improve the patient experience of care
- Structuring an anonymous grievance process and identifying ways to reduce patient's fear of retaliation
- Engaging Patient Representatives to connect with their peers to provide support.

The 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 2019, the Networks recruited patients to integrate the patient voice into Network and facility activities and implemented a wide range of notable patient and family engagement interventions as part of the QIAs. For example:

- **Network 9** engaged 237 active Patient Facility Representatives that included 50 Patient SMEs. Their tasks included assisting the facility with distributing project materials, serving as peer mentors for other patients, participating in facility QAPI meetings to report QIA progress, and participating in lobby days. The Network also recruited 273 patients from 193 facilities to serve on the PAC and six new Patient SMEs who provide the patient voice in all Network QIAs at the national level by serving as Network representatives to the Forum of ESRD Networks, the ESRD NCC, and the KCER Program.



- **Network 10** educated patients on rights and responsibilities; initiated or participated in discussions about substance use/withdrawal, mental health evaluation and follow-up, or other modalities; and identified providers for patients and caregivers. The Network also offered mediation; referred patients, families, or caregivers to the ESRD website and resources; assisted patients and representatives with self-advocacy by encouraging participation in care planning; discussed depression and coping skills; coached patients on communication techniques; and identified agencies for possible referrals when appropriate.

National Patient and Family Engagement Learning and Action Network Activities

The NPFE-LAN includes patient and care partner representatives drawn from the 18 ESRD Network service areas, as well as representative Network and CMS staff members, 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 Networks, the ESRD NCC supports the NPFE-LAN in giving a voice to ESRD patients and facilitating dialogue between patients and CMS leadership.

The 2019 NPFE-LAN organized into Affinity Groups to address the mandatory Network QIA areas, including:

- Reducing BSI rates
- Increasing the number of patients dialyzing at home
- Increasing the number of patients pursuing transplantation.

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 the 2019 Network QIAs. For example, the Home Dialysis Affinity Group created a deck of conversation-starting cards, titled *Let's Talk: Home Dialysis*. The Transplant Affinity Group developed the visually engaging *Partnering Along the Road to Transplant* flyer. These resources encourage bidirectional communication between patients and professionals, engaging all parties in shared decision-making.

In addition to the QIA-focused Affinity Groups, the NPFE-LAN formed an Affinity Group based on a patient-selected topic. In 2019, the topic was Emotional Well-Being for Patients and Caregivers. The group developed resources toward achievement of personal goals and support for caregivers and patients. The booklet and handout produced were *Goal Setting: Getting Back to Me* and *Tips for Kidney Caregivers*, which was made available in English and Spanish.



These 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 2020.

Grievances and Access to Care

Involuntary Discharges Averted

According to the ESRD Conditions for Coverage (CfCs) and the CMS definition of an IVD, an IVD from a facility may leave a dialysis patient without an outpatient facility to provide regular 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 the patient's life expectancy.²³ Treating ESRD only in the emergent setting places 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.

In 2019, 237 patients received a 30-day notice and were facing imminent IVD. The Networks averted 25 of these potential IVDs and facilitated admissions to another outpatient facility for an additional 212, allowing for continuity of care for these patients. In total, 237 IVDs were avoided.

The Networks are responsible for resolving all patient-appropriate Access to Care cases. 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 or did not currently have access to an outpatient dialysis facility.

Examples of Network activities include the following:

- **Network 8** developed the Second Chance Program—90-day Trial Basis to address access to care issues and decrease the use of dialysis in the emergency department. Facilities collaborated with the Network to admit difficult-to-place patients and receive ongoing support from the Network for 90 days. Network interventions included monthly contact with the patient and facility, notification to the SA, and collaboration to develop an Expectations of Treatment Agreement. If there were no behavioral issues, the patient was admitted as a permanent patient at the end of the 90 days. The Network shared the program with CMS and other Networks to aid in the development of similar programs.
- **Network 18** used a multitude of interventions related to IVDs. These included advocating for patient-centered care, connecting facilities to resources that can assist

²³ 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.



staff in the management of difficult behaviors, providing education and individualized case consultation, conducting community outreach, referring to the *Decreasing Patient Provider Conflict Toolkit*, establishing relationships with local mental health organizations to provide staff with tools, and relying on the PAC to ensure that the patient perspective and the patient voice were at the forefront of all improvement efforts. In 2019, the Network had an 85% success rate in keeping patients in their dialysis units when conflicts arose.

Evaluation and Resolution of Grievances

The CMS ESRD grievance policy requires that all concerns related to care that does not meet a dialysis patient's expectations, recognized standards of safety or civility, or professionally-recognized clinical standards of care 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. It is the Network's responsibility to take all necessary steps to evaluate and resolve these grievances.

Each Network established a system for promoting awareness of all options for filing grievances, including the option of filing grievances anonymously. The 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 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 to facilities for distribution to patients included language on how to contact the Network to file a grievance.

Grievance Process and Data

In 2019, 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.

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 Networks. 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 (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 1,231 beneficiary grievances in 2019. Of the 1,231 grievance cases processed, 614 (49.9%) were addressed through the use of Immediate Advocacy, and 219 (17.8%) were based on a Clinical Area of Concern. See Table 2 in the Data Tables section of this document for Network-specific data.

In 2019, no sanction recommendations were submitted to CMS by a Network.



Recommendations to CMS for Additional Facilities

Although CMS received no formal recommendations for additional facilities in 2019, the 18 ESRD Networks did provide policy recommendations that include:

- Establishing “unique needs” dialysis facilities that would allow for higher staff-to-patient ratios and/or employ clinicians with specialized training to enable intensive, individualized services. Special needs dialysis facilities could accommodate/treat patients who have:
 - Complex, clinical challenges or histories of aggression, being disruptive, mental illness, or substance abuse, which may result in many patients being involuntarily discharged from chronic care facilities and without access to another chronic care facility.
 - Physical conditions (e.g., ventilator-dependency, morbid obesity, antibiotic-resistant infections) that require services that typical facilities for the general dialysis population are unable to provide.

The aforementioned policy recommendations and special facility requests represent important approaches to improving 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 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 and 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 Networks engaged in outreach, training, and technical assistance activities to help ensure that the needs of ESRD patients were met in emergency situations. During 2019, Networks responded to a variety of incidents with the potential to impact ESRD patients and providers, including winter storms and blizzards, a spring snowstorm, hurricanes, tropical storms, typhoons, tornadoes, earthquakes, water main breaks, wildfires, planned public safety power shutoffs (PSPS), and the Great Flood of 2019. The following are representative examples of emergency preparedness and response activities conducted:

- **Network 7** conducted activities before, during, and after Hurricane Dorian. Emergency preparedness activities included distributing weather alerts, patient education materials, and links to resources; participating in calls with the Florida Division of Emergency Management and KCER; and monitoring facilities' planned closing schedules. Response activities included assessing and tracking operational status and identifying access to care issues; addressing patient and stakeholder calls related to facility operational status, including patients who evacuated and needed placement; collaborating with stakeholders to resolve access to care issues; participating in daily status calls with essential ESRD and emergency preparedness stakeholders; and monitoring 261 facilities until all facilities were open and operational.
- **Network 13** intervened during two significant weather-related events. In May, severe weather brought flooding throughout Oklahoma with flash flooding threatening levees along the Arkansas River protecting Tulsa. The Network interacted with Tulsa-area emergency operations personnel to monitor facility operations with the potential for impact, including transportation for patients and staff. Facilities monitored water supply

and quality, provided patient education, and rescheduled treatments. No dialysis unit operations were affected long-term. In July, Tropical Storm Barry impacted Louisiana with 142 facilities within the projected storm track. The Network facilitated activities with the Louisiana emergency operations center for the six-day duration of the event.

- **Network 16** provided support during February winter storms throughout the Network's region that resulted in heavy snow, dangerous driving conditions, and interruptions in power. The Network office lost power on February 10. Network phones were transferred to a staff member, and all staff worked remotely. Sixty-two percent of facilities reported transportation barriers, e.g., hazardous driving conditions, transportation providers not operating, and patients unable to get out of their driveways. Two Washington facilities reported altered dialysis schedules and provision of three-hour emergency dialysis. Network assistance included working with the SA, CMS Survey & Certification, and Washington Certificate of Need Program to facilitate a request from a facility for expanded stations.
- **Network 17** worked with the KCER Program and other stakeholders to ensure patients had access to dialysis before and after emergencies. The Network issued weather alerts to facilities, collected information on planned closures, and tracked the open and closed status of facilities and the location of patients. For example, the Network began facility support to the Guam and Northern Mariana Islands facilities related to Tropical Storm Hagibis on October 6, which grew to super typhoon status on October 7. Island-wide power outages were reported on Saipan, and a boil water notice was issued. Facilities on Guam and Saipan were closed for one day until they could run on generator power. By October 10, all patients were accounted for, and the facilities were using municipal power and water.



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 Networks and facilities, and production of ESRD-related events at the annual CMS Quality Conference. In 2019, the ESRD NCC:



- Partnered with NPFE-LAN SMEs to develop patient and family resources for use in Network QIAs. Examples include the workbook *Goal Setting: Getting Back to Me* and the handout *Tips for Kidney Caregivers* from the Emotional Well-Being for Patients and Caregivers Affinity Group; the *Let's Talk: Home Dialysis* conversation cards; and the *Partnering Along the Road to Transplant* flyer. Several of these resources were translated into Spanish. The NCC also facilitated its first Caregiver, Transplant, and Home Dialysis Peer Connection Calls and podcasts on home hemodialysis and kidney transplant. The Peer Connection Calls were designed to facilitate knowledge sharing and peer-to-peer learning. Patients discussed topics related to dialysis with a panel of professionals to provide guidance, if needed.
- Conducted bi-monthly LAN meetings to support achievement of each of the Network QIA goals for BSI, home dialysis, and transplantation. 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 initiated during Hurricane Dorian in August 2019 and the California wildfires in October 2019. At KCER's request, only GeoHealth data, which is facility-specific information, not patient-specific, was supplied. None of the Networks impacted by Dorian or the California power outages/wildfires requested patient-level data for tracking. Each report was tailored to the specific region affected by the disaster or event 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, emergency preparedness, and mental health. The NCC reached more than 150,000 users across all social media with more than 7,000 shares by December 31, 2019.

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 2019. Network 7 was funded by CMS to serve as the national emergency management contractor. Under the KCER contract, HSAG provided support to the Networks to strengthen their emergency preparedness and response capacities. KCER's 2019 activities included:



- Convening the National KCER Patient and Family Engagement (N-KPFE) LAN, which included 33 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. SMEs created a brochure, *The Kidney Community Emergency Response Program*. It provides education on the work of KCER. The tri-fold document lists KCER's goal, function, and contact information, so the renal community can learn more about KCER. It can be used by the KCER Program and dialysis facility staff to educate patients on how KCER supports their emergency preparedness efforts. Members 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.
- Participating in National Preparedness Month during the week of September 23–27, 2019. During the KCER Emergency Preparedness Week, the SMEs promoted KCER emergency preparedness resources on social media, hosted facility lobby days, handed out resources to patients while they were on dialysis, and posted emergency preparedness resources on facility bulletin boards. The SMEs reported sharing the KCER *Emergency Preparedness* poster with more than 630 patients and dialysis facility staff members.
- Activating for two major events, Hurricane Dorian and the California wildfires and PSPS. KCER was activated from August 27 to September 9, 2019, in response to Hurricane Dorian, and again from October 9 to October 31, 2019, for the California wildfires and PSPS. 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.
 - During the response and recovery efforts for Hurricane Dorian and the California wildfires, KCER worked directly with many new and existing stakeholders to improve the overall outcome for the ESRD patient population. KCER also provided daily reports outlining the current status of the incident response and the operational status and needs of dialysis providers.



- KCER participated in daily emergency calls with the ASPR Critical Infrastructure Protection (CIP) Healthcare Sector Coordinating Council (HSCC) during the response to Hurricane Dorian. Attendance at these calls served to elevate the profile of KCER and brought the current status and unmet needs of the ESRD community to the group.
- Improving ESRD community stakeholder relationships by continually striving to enhance collaboration opportunities among these groups. Building and sustaining positive relationships among partners is imperative to ensure continuity of care and services for ESRD patients during emergencies or disasters.
- Collaborating with an existing partner, Healthcare Ready, to address medication needs as well as supply chain distribution issues. Healthcare Ready also assisted with patient rescues and transportation resources for dialysis patients and facility staff.



List of Data Tables

- Table 1: Medicare-Certified Dialysis Facilities – Modality Type – Calendar Year 2019
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- Table 3: National ESRD Patient Data Overview 2019

Table 1. Medicare-Certified Dialysis Facilities – Modality Offered – Calendar Year 2019

Network	Transplant Centers	In-Center Hemodialysis and Home Dialysis	In-Center Hemodialysis Only	Home Dialysis Only	Total Dialysis Facilities (Home, In-Center, Both)	Total Facilities (including Transplant Centers)
1	15	122	82	4	208	223
2	13	133	184	10	327	340
3	4	136	107	9	252	256
4	20	174	176	16	366	386
5	12	194	235	32	461	473
6	10	316	425	49	790	800
7	11	239	235	28	502	513
8	10	132	319	35	486	496
9	14	266	343	47	656	670
10	9	102	186	63	351	360
11	21	176	312	33	521	542
12	13	147	187	14	348	361
13	10	136	206	10	352	362
14	22	297	424	40	761	783
15	15	152	211	15	378	393
16	7	137	88	7	232	239
17	6	88	189	45	322	328
18	15	175	223	41	439	454
NATIONAL	227	3122	4132	498	7752	7979

Table 2. Grievances and Non-Grievances by Case Type, Number, and Percent – Calendar Year 2019

Network	General Grievance	Immediate Advocacy	Clinical Area of Concern	Facility Concern	Access to Care	Total All Case Types	Total Grievance Cases	Percent of National Grievance Cases	Total Non-Grievance Cases	Percent of National Non-Grievance Cases
1	*	11	*	32	22	71	17	1.38%	54	1.35%
2	*	29	*	*	92	132	38	3.09%	94	2.35%
3	*	28	*	50	26	107	31	2.52%	76	1.90%
4	*	*	*	32	23	77	22	1.79%	55	1.37%
5	54	*	18	144	101	327	82	6.66%	245	6.11%
6	78	23	*	189	134	429	106	8.61%	323	8.06%
7	*	88	12	138	115	363	110	8.94%	253	6.31%
8	33	42	12	109	42	238	87	7.07%	151	3.77%
9	50	38	*	131	44	263	88	7.15%	175	4.37%
10	27	15	16	112	41	211	58	4.71%	153	3.82%
11	*	113	13	324	50	508	134	10.89%	374	9.33%
12	*	11	20	81	71	191	39	3.17%	152	3.79%
13	*	*	*	81	40	143	22	1.79%	121	3.02%
14	34	27	24	469	64	618	85	6.90%	533	13.30%
15	19	23	*	60	44	156	52	4.22%	104	2.60%
16	*	27	14	33	30	112	49	3.98%	63	1.57%
17	*	45	*	558	56	669	55	4.47%	614	15.32%
18	36	65	55	395	72	623	156	12.67%	467	11.65%
NATIONAL	398	614	219	2,940	1,067	5,238	1,231	--	4,007	--

* Indicates that there were fewer than 11 cases; therefore, the numbers were suppressed.



Table 3. National ESRD Patient Data Overview 2019

Network	Dialysis Facilities	Percent of Medicare-Certified 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 Dialysis and Transplant Patients
1	208	2.68%	15	6.61%	15,120	2.85%	13,221	1,899	2.66%	11,556	4.95%	26,676
2	327	4.22%	13	5.73%	30,622	5.77%	28,272	2,350	3.29%	13,957	5.97%	44,579
3	252	3.25%	4	1.76%	21,240	4.01%	19,456	1,784	2.50%	5,620	2.41%	26,860
4	366	4.72%	20	8.81%	20,661	3.90%	17,984	2,677	3.75%	12,862	5.50%	33,523
5	461	5.95%	12	5.29%	28,657	5.40%	24,712	3,945	5.52%	13,862	5.93%	42,519
6	790	10.19%	10	4.41%	51,455	9.70%	44,313	7,142	10.00%	16,204	6.94%	67,659
7	502	6.48%	11	4.85%	33,133	6.25%	28,746	4,387	6.14%	13,444	5.75%	46,577
8	486	6.27%	10	4.41%	29,404	5.54%	25,271	4,133	5.79%	9,638	4.12%	39,042
9	656	8.46%	14	6.17%	34,235	6.46%	29,124	5,111	7.16%	15,021	6.43%	49,256
10	351	4.53%	9	3.96%	21,131	3.98%	17,188	3,943	5.52%	9,904	4.24%	31,035
11	521	6.72%	21	9.25%	29,148	5.50%	25,281	3,867	5.42%	21,612	9.25%	50,760
12	348	4.49%	13	5.73%	17,326	3.27%	14,296	3,030	4.24%	10,705	4.58%	28,031
13	352	4.54%	10	4.41%	21,344	4.02%	18,220	3,124	4.37%	6,365	2.72%	27,709
14	761	9.82%	22	9.69%	54,406	10.26%	47,905	6,501	9.10%	17,590	7.53%	71,996
15	378	4.88%	15	6.61%	27,076	5.11%	23,318	3,758	5.26%	15,310	6.55%	42,386
16	232	2.99%	7	3.08%	15,903	3.00%	13,235	2,668	3.74%	8,273	3.54%	24,176
17	322	4.15%	6	2.64%	30,266	5.71%	25,919	4,347	6.09%	13,345	5.71%	43,611
18	439	5.66%	15	6.61%	49,184	9.27%	42,442	6,742	9.44%	18,382	7.87%	67,566
NATIONAL	7,752	--	227	--	530,311	--	458,903	71,408	--	233,650	--	763,961