2020

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 and details the activities carried out by the Networks in 2020, including the provision of resources, education, and data-driven technical assistance to patients with ESRD and their families, ESRD providers, and stakeholders related to the COVID-19 pandemic.

[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.

The goals and requirements of the QIAs were suspended in May 2020 due to the COVID-19 pandemic. However, the Networks continued to provide educational materials to patients and dialysis facility staff and maintained communication relationships.

From January to October 2020, the ESRD Network Program Option Year 4 QIAs included 7,734 dialysis facilities, representing 100% of 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 765,823 individuals who were patients at QIA facilities 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.

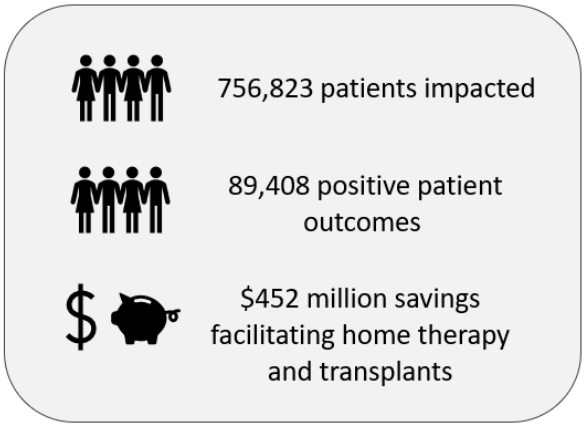

Figure 1. Overall patient impacts and estimated cost savings resulting from 2020 QIAs.

Analysis of impacts on patients in facilities engaged in QIAs showed 89,408 positive patient outcomes in the 2020 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 $452 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 2020, 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 nine months of the performance period, QIA facilities had accrued 120,765 patients with a long-term catheter in use at some time during the nine months. Among patients that were prevalent at the end of the remeasurement period, 32,475 were no longer using catheters.

> 32,475 patients were no longer using long-term catheters at 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 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.

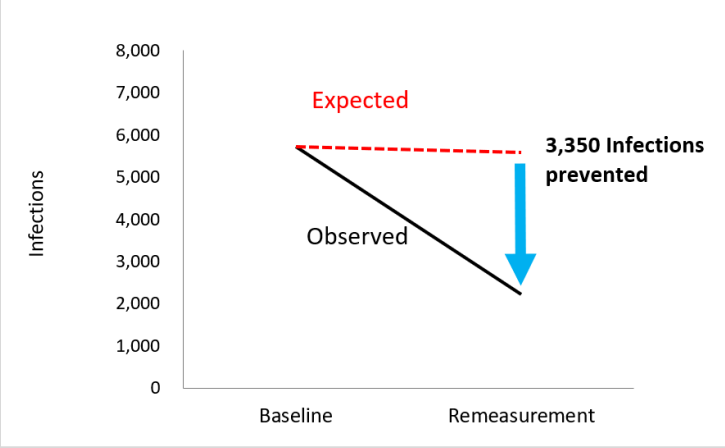

Figure 2. Reductions in expected bloodstream infections as a result of 2020 QIAs.

During the baseline period of January 1, 2019, to June 30, 2019, there were 5,724 BSIs in QIA facilities, corresponding to a rate of 1.02 infections per 100 patient-months. Applying this rate to the prevalent patients in the remeasurement period of January 1, 2020, to June 30, 2020, yields 5,579 expected infections during this

[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.

period. There were 2,229 observed infections during the remeasurement period—3,350 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]

35,337 patients transitioned to home dialysis with anticipated savings of $334 million per year

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 month ($11,402 per year) in 2019 dollars.[8]

As a result of education and outreach activities during the 2020 QIAs, 35,337 patients transitioned to home dialysis during the remeasurement period. Past analysis of CROWNWeb (Consolidated Renal Operations in a Web-Enabled Network) data on home dialysis transitions 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 $334 million in the first year following transition.

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[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' 2020 QIA interventions focused on moving patients to the transplant waitlist with the ultimate goal of achieving transplants for these patients.

The HHS 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.

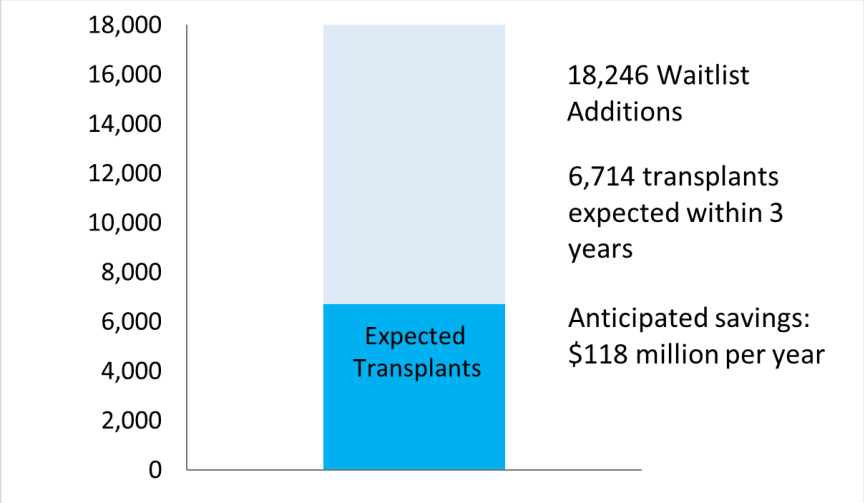

Figure 3. Patients added to waitlists, expected transplants, and cost savings as a result of 2020 QIAs.

Through the Networks' efforts, 18,246 patients 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, 6,714 of the 18,246 patients would be expected to get transplants within 3 years with savings of $118 million per year, based on the 5.5 year time window analyzed by the Office of the Actuary (Figure 3).

[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 7,000 dialysis facilities involving more than 750,000 patients. Overall, analysis of the results of these QIAs suggests that more than 89,000 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 $452 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 0.9% decrease 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 2019 as compared with the last day of the year in 2020. This decrease in prevalent dialysis patients may largely be related to COVID-19, as more than 10,316 excess deaths in patients with ESRD were identified during the early months of the pandemic.[14] Considerable variation in ESRD prevalence was present across the 18 ESRD Networks' geographic areas as of December 31, 2020. Network 1, which covers the New England region, including the states of Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, had the fewest patients (14,969). Network 14, which covers the state of Texas, had the largest number of patients (53,949).

Home Dialysis

The number of eligible dialysis patients using home dialysis increased by 8.0% from 2019 to 2020. 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.

Grievances and Non-Grievances

The 18 ESRD Networks processed 1,195 beneficiary grievances in 2020. Of the 1,195 grievance cases processed, 578 (48.4%) were addressed through the use of Immediate Advocacy, 348 (29.1%) were General Grievances, and 152 (12.7%) were based on a Clinical Area of Concern. The total number of non-grievance cases in 2020 was 4,795. These included 3,607 Facility Concerns and 1,188 Access to Care non-grievances. See Table 2 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.

[14] Ziemba R, Campbell KN, Yang TH, Schaeffer SE, Mayo KM, McGann P, Quinn S, Roach J, Huff ED. Excess Death Estimates in Patients with End-Stage Renal Disease - United States, February-August 2020. *MMWR Morb Mortal Wkly Rep*. 2021 Jun 4;70(22):825-829. doi: 10.15585/mmwr.mm7022e2.

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 2020, the Networks recruited approximately 183 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 National Coordinating Center (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 2020, CMS continued its enhanced focus on emergency management practices and requirements for the Networks. The ESRD community faced a unique call to action during 2020 as the COVID-19 pandemic became a worldwide crisis. The Networks' response to the pandemic included routine assessment of needs and distribution of current information and resources; collaboration with local, state, and federal public health agencies; and data-targeted technical assistance. 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 patients with ESRD would be met in emergency situations. During 2020, the KCER Program responded to a total of 23 events that resulted in changes in facility status, including closures and altered schedules, and the KCER team submitted over 150 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 2020, the Networks worked to improve healthcare for over 525,000 dialysis patients and approximately 253,000 kidney transplant patients.

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

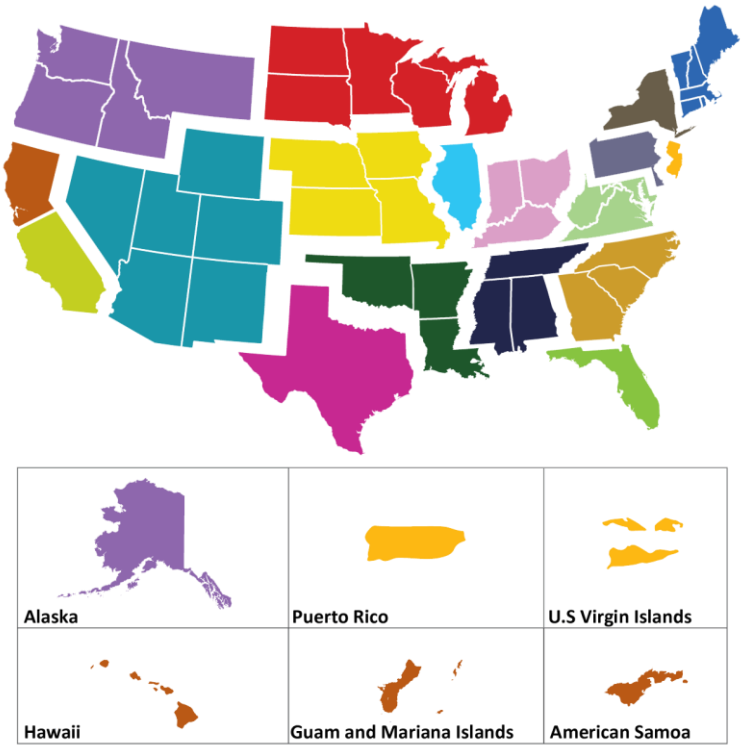

Figure 4. ESRD Network Service Areas

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 2020, the CMS goals for the ESRD Network Program were:

- **Goal 1:** Empowering patients to make decisions about their health care
- **Goal 2:** Increasing state flexibility
- **Goal 3:** Developing innovative approaches to improving quality, accessibility & affordability
- **Goal 4:** Improving the 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 patients with ESRD and their families, dialysis and transplant providers, and health professionals. Network contract activities support more than 7,850 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 social worker with a Master of Social Work degree 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 recommend 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, 2020, there were 525,148 prevalent dialysis patients and 7,864 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 (807). Network 1, which covers the New England region states of Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, had the fewest facilities (221).

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 2020, 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.[15] This is attributable, in part, to high rates of diabetes and hypertension in the adult population. Information about the number of prevalent dialysis patients (i.e., total dialysis patients at a given point in time) is highlighted in the following section.

Prevalent Dialysis Patients

Information on prevalent dialysis patients is drawn from the ESRD Quality Reporting System (EQRS) database, previously called CROWNWeb, that identifies all patients who are alive and on dialysis as of December 31 of a given year. At the end of 2020, 525,148 patients were receiving dialysis in the U.S., according to the Networks' Annual Reports—a 0.9% decrease from December 31, 2019. This decrease in prevalent dialysis patients may largely be related to COVID-19, as more than 10,316 excess deaths in patients with ESRD were identified during the early months of the pandemic.

[15] CDC. Chronic Kidney Disease Initiative. Chronic Kidney Disease in the United States, 2021. Available at: https://www.cdc.gov/kidneydisease/publications-resources/ckd-national-facts.html. Accessed October 25, 2021.

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

Vascular Access

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. The three types of vascular access are AVF, arteriovenous graft (AVG), and central venous catheter (CVC). A patient's vasculature and other medical and physical conditions are considered in determining the access type most efficacious for each individual patient. AVFs are considered the gold standard, although not all patients can support the use of an AVF. An AVF is a surgical connection between a vein and an artery, usually in the forearm. An AVG, another form of permanent access, is created using a synthetic tube implanted under the skin that connects an artery and a vein. An AVG is an acceptable alternative when AVF placement is not deemed possible.

A CVC, when used for vascular access in dialysis, is a flexible tubular instrument that is surgically inserted, often into a large vein in the neck, with the tip resting in the right atrium of the heart. Catheters pose a higher risk of infection, clotting, and narrowing of vessels (stenosis) than AVFs and AVGs, leading to higher morbidity and mortality.[16] 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 Decreasing Long-Term Catheter Use Rates

In 2020, the Networks developed targeted strategies to assist dialysis facilities in 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 with dialysis facilities that had not reached CMS targets and provided Network-wide and targeted individualized support to the identified facilities via QIAs. Due to the COVID-19 pandemic, the Network QIA goal was suspended in May 2020. The Networks continued to provide educational materials to patients and dialysis facility staff.

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

The Networks identified best and promising practices that included:

- Setting up the patient's surgical consult prior to hospital discharge or on the day of first dialysis treatment.
- Referring patients for vein mapping and vascular access evaluation prior to hospital discharge or within 2 weeks of admission.
- Reviewing all patients dialyzing via catheter during monthly Quality Assessment and Performance Improvement (QAPI) meetings to discuss progress and next steps.
- Creating alternative sites for catheter removal, including hospital emergency departments and physician offices, rather than waiting to schedule the procedure in vascular access centers or surgery suites.
- Using physician extenders (e.g., nurse practitioners), CKD coordinators, and vascular access managers to implement vascular access plans, including removal of catheters.
- Educating surgeons, hospitals, nephrologists, and dialysis centers on the essential nature of access intervention to address surgical hesitancy during the COVID-19 pandemic.
- Conducting meetings with local surgeon offices to address delays caused by the COVID-19 pandemic.

Patient Safety

Support for the National Healthcare Safety Network

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

Patients who undergo dialysis treatment are at an elevated risk for infection due to the frequent use of catheters or insertion of needles to access the bloodstream as part of the hemodialysis process.[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 the 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 2020, 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. Due to the COVID-19 pandemic, these Network requirements were suspended in May 2020.

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

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 costs 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. Due to the COVID-19 pandemic, the Network QIA requirements were suspended in May 2020.

The Networks identified best and promising practices that included the following:

- Creating a back-to-basics campaign to reinforce hand hygiene and surface disinfection during the pandemic.
- Creating a community of practice focused on infection prevention, including the most current CDC information and best practices to prevent the spread of infection in high-risk situations.
- Creating an Infection Prevention Station that focused on the CDC "Days Since Last Infection" poster, "Conversation Starter to Prevent Infections in Dialysis Patients," and the nine Core Interventions to guide discussions with patients and staff.
- Implementing and adapting the Forum of ESRD Networks' Nursing Home Communication Form to assist with the transfer of information between dialysis and nursing home facilities and ensure COVID status was communicated appropriately.
- Implementing the 5-Diamond Patient Safety module, which focused on patient engagement at the patient-, facility-, and governance-levels.
- Obtaining timely and direct patient feedback on staff performance of hand hygiene using verbal discussion and audits.
- Utilizing the ESRD NCC's Patient and Family Engagement Learning and Action Network (NPFE LAN) resources, such as the Clean Hands Count badge and other tools created by patients for patients.

Promoting Appropriate Home Dialysis

In the U.S. in 2020, 77,131 (14.7%) of the total 525,148 dialysis patients utilized a home renal replacement therapy, which is a 1.2% increase over the previous year. 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. Due to the COVID-19 pandemic, the Network QIA goal was suspended in May 2020. The Networks continued to provide educational materials to patients and dialysis facility staff and maintained communication relationships.

The Networks identified best and promising practices that included the following:

- Utilizing the medical director as the leader of home transitions.
- Launching a "Healthy at Home" campaign to promote the benefits of dialyzing at home during the public health emergency and beyond.
- Providing patient-level reports to assist in the review of incident and prevalent patients to identify and address modifiable factors that are preventing patients from pursuing a home modality.
- Using the MATCH-D tool to help identify and assess patients for home dialysis candidacy.
- Educating all in-center staff on home dialysis options.
- Using the Forum of ESRD Networks' Home Dialysis Toolkit.
- Incorporating patient perspectives into actionable strategies, including short videos and printed materials that focus on the patient experience.

Improving Transplant Coordination

The benefits of transplantation extend to ESRD patients regardless of age, gender, or ethnicity. The intent of this QIA was to promote early referral to transplant 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. Due to the COVID-19 pandemic, the Network QIA goal was suspended in May 2020. The Networks continued to provide educational materials to patients and dialysis facility staff and maintained communication relationships.

The Networks identified best and promising practices that included the following:

- Discussing with patients reasons for not wanting a transplant and revisiting the option later, as patients may experience life changes that may make them more likely to choose a transplant.
- Educating patients on the Kidney Donor Profile Index (KDPI), how the KDPI is used to rate how long deceased donor kidneys are expected to last after transplant, and the benefits of possibly receiving a transplant sooner.
- Collaborating with transplant centers to offer a webinar on the use of telehealth to expedite the transplant intake process; holding bi-monthly meetings to identify barriers and needs as well as discuss the status of program operations during the pandemic; and providing transplant center staff with monthly or quarterly status updates on patients who have been referred to their center.
- Using a tracking tool to follow patients through the transplant waitlist process.

- Hosting a quarterly transplant advisory group that includes dialysis social workers, nurses, transplant surgeons, transplant coordinators, and Patient SMEs to identify challenges and best practices and recommend process changes.
- Collaborating with Organ Procurement Organizations to identify common goals and strategies for increasing kidney transplantation.
- Conducting 1:1 technical assistance calls to poor-performing facilities to identify current workflow practices and challenges inhibiting success with patient transplant wait listing.

Population Health Focused Pilot Quality Improvement Activities

In 2020, 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.
- Support gainful employment of ESRD patients.
- Positively impact the transition of dialysis care with a focus on peer mentoring.

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 the Contracting Officer's Representative (COR).

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 and increased utilization of acute care services. The goal was to improve the coordination of care for ESRD patients and their families between care settings. Due to the COVID-19 pandemic, Network QIA requirements were suspended in May 2020.

The Networks identified best and promising practices that included the following:

- Partnering with Quality Innovation Network-Quality Improvement Organizations (QIN-QIOs) and establishing a Renal Coalition to address hospitalizations and re-admissions in the ESRD community. The coalition enabled the Network to brainstorm with representatives impacted by hospital admissions and find solutions to common barriers.
- Engaging the MRB and PAC SMEs in the development of tools, resources, and interventions to manage fluid overload, which was one of the top reasons leading to unplanned hospitalizations.

Supporting Gainful Employment of Patients with ESRD

In 2020, 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 and/or State Vocational Rehabilitation agencies servicing the patient population. Employment Networks and Vocational Rehabilitation agencies "coordinate and

provide appropriate services to help eligible beneficiaries find and maintain employment."[18] Due to the COVID-19 pandemic, Network QIA requirements were suspended in May 2020.

The Networks identified best and promising practices that included the following:

- Providing education and resources to facilities, so they could create a process for screening, referring, and following up with patients on vocational rehabilitation.
- Providing facilities with a patient questionnaire to determine patient readiness for and interest in vocational rehabilitation services.
- Involving patients in the QIA and on the QAPI team.
- Using patient educational resources to dispel myths about losing health or financial benefits if a patient accesses Vocational Rehabilitation agency or Employment Network services or returns to work or school.
- Creating a vocational rehabilitation bulletin board in place of hosting a vocational rehabilitation Lobby Day due to COVID-19 precautions.
- Providing facilities with links to websites that specialize in work-from-home opportunities.
- Sharing patient inspirational stories within the facility, on the Ticket to Work website, and with peer mentoring opportunities.

Positively Impact the Transition of Dialysis Care with a Focus on Peer Mentoring

The Networks implemented systematic processes to ensure the initial and continued training and pairing of ESRD patient mentors with CKD or ESRD patient mentees. Peer programs may improve goal setting and decision-making and increase self-management. Peer mentoring efforts focused on patients first diagnosed with CKD or ESRD, decision-making about treatment therapy (i.e. modality, access type), and/or transplant. Due to the COVID-19 pandemic, Network QIA requirements were suspended in May 2020.

Best practices identified include the following:

- Using virtual engagement platforms and adapting virtual applications, especially those involving face-to-face interfaces (Facebook Messenger, Instagram, and Zoom).
- On LAN calls, exchanging peer mentoring strategies between the Network and facilities to increase the facilities' understanding of peer mentoring.
- Collaborating with dialysis organizations' leadership to select facility mentors and incorporating the organization's own materials to contribute to the success of peer mentor recruitment and training, mentor-mentee interactions, and a higher performance in adding patients to the transplant waitlist.

[18] 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.

Support for the ESRD Quality Incentive Program

The ESRD QIP was established under the provisions of the Medicare Improvements for Patients and Providers Act (MIPPA) of 2008. Administered by CMS, the ESRD QIP is designed to promote high-quality services in outpatient dialysis facilities. The ESRD QIP was CMS' first value-based purchasing (VBP) initiative, representing a shift from quantity-based payment to quality-based payment by the Medicare Program.[19] A percentage of each dialysis facility's Medicare reimbursement is contingent on the facility's performance.

The ESRD Network Program provided support to dialysis facilities by offering ESRD QIP education, technical support, and updates to help facilities understand and comply with ESRD QIP requirements. The EQRS and the CDC's NHSN provide the necessary data to calculate facility performance.

In response to the COVID-19 pandemic, CMS granted an exception under the ESRD QIP for reporting requirements for the deadlines for submission of data from clinical months January through June 2020 and encounters prior to the COVID-19 public health emergency declaration that fall during March, April, and May 2020.

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

Data-Driven Technical Assistance

Utilizing data provided by the ESRD NCC, reported by facilities, and available from other sources, the Networks collaborate with ESRD facilities to provide data-driven technical assistance in support of improved care and quality of life for kidney patients. In 2020, that included hands-on technical assistance related to the pandemic, including:

- Root cause analysis and tailored strategies.
- Training on COVID reporting, screening/testing protocols, and use of CDC audits.
- Coaching guidance on cohorting, CDC guidelines, staff burnout, and telehealth.
- Recommendations and referrals to local resources, including transportation, personal protective equipment suppliers, and other community partners.

Key issues identified during technical assistance included:

- Nursing home outbreaks with ineffective communication between the dialysis facility and nursing homes.
- Failure to utilize infection control audit tools and understand requirements.
- Increased community transmission, including poor social distancing by younger patients and multi-generational/large households.
- Lack of patient understanding about COVID transmission and infection control practices.
- Patients being tired of restrictions and not forthcoming with answers to screening questions.
- Limited patient education in languages other than English and Spanish.
- Additional problems, e.g. staff burnout/availability, lack of telemedicine use, and mental health issues.

Networks also identified and spread best practices, including:

- Telehealth for virtual nephrologist visits.
- Special procedures for nursing home patients, including cohorting at the dialysis unit, use of a communication form, and screening calls before transport to dialysis.
- Regular infection control audits and increased surface disinfection.
- Both verbal and written patient education as well as teaching via text messaging.
- Specific staff assigned to screen and assess everyone before entering the building, including transporters.
- Pre-screening of all patients via a call-ahead culture and on-site screening in the car.
- Encouragement of patients to be honest with screening questions with assurance of no stigma with a positive result.
- State- and territory-specific meetings of dialysis providers and community partners.
- Enhanced screening questions on COVID tests and activities since last dialysis treatment.
- Regular corporate leadership meetings about COVID+ cases.

Ensuring Data Quality

End Stage Renal Disease Quality Reporting System

The ESRD Network Program used the CROWNWeb data management system (converted to EQRS in November 2020) to obtain and track data on patient age, gender, ethnicity, race, primary diagnosis, and treatment modality, among other characteristics, for incident and prevalent patients with ESRD. Network staff use these data to inform quality improvement interventions, strengthen outreach efforts, document demographic trends, and assess disparities in ESRD care.

EQRS 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 EQRS, employ the system to add, modify, and delete information associated with these forms. EQRS 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 2020, the Networks continued their ongoing collaboration with the ESRD NCC to refine and evolve data reports and the NCC ESRD Dashboard. The dashboard, presented in an interactive, customizable, and secure format, provided monthly results of each QIA comparable between Networks, by cohort, and against a national trend. An executive summary within the dashboard also provided an estimated cost savings for home dialysis and transplant. A new COVID Dashboard was also developed with recommendations from the Networks that allowed for rapid identification of COVID hot spots and use of data for targeted technical assistance to ESRD providers.

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 EQRS not currently admitted to a specific facility) to support Network QIAs and to assist in enhancing the accuracy and completeness of data reported in EQRS.

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 2020, Veterans Health Administration facilities and transplant facilities were not required to use CROWNWeb/EQRS 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/EQRS) 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/EQRS for the facilities.

Partnerships and Coalitions

In 2020, 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 large dialysis organizations (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)
- Dialysis Patient Citizens (DPC)
- 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 (NRRA)
- Renal Physicians Association (RPA)
- The Renal Support Network (RSN)
- 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, State Survey Agencies (SAs), and Medicare QIN-QIOs in their geographic areas.

Patient and Family Engagement

Education for Patients and Caregivers

In 2020, Networks supported dialysis facilities throughout the COVID-19 pandemic by sharing resources and patient educational materials and by providing technical assistance on how to engage patients, e.g., disseminating best practices on how to engage patients in plan of care meetings, QAPI meetings, and support groups. The Networks also used a variety of approaches to engage patients, including encouraging patients to participate in the ESRD NCC's COVID-19 webinar series, asking patients to submit questions on COVID-19, interacting through helplines, partnering with PACs and Patient SMEs on COVID-19 materials, and providing numerous patient resources on a patient portal and websites and through social media.

The Networks also 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, and educational webinars, to share tools, resources, and best practices. All approaches shared the goal of providing educational resources to patients with ESRD and their family members and care partners.

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, 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 2020 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.

In addition to the QIA-focused Affinity Groups, the NPFE-LAN formed an Affinity Group based on patient-selected topics. In 2020, the topics were Questions to Get You Started and Questions to Help with Your Treatment Choices. The resources were designed to help patients and caregivers develop questions to ask their healthcare team about their treatment options. The resources are available in English and Spanish.

The COVID-19 pandemic shifted the priority of the NPFE-LAN and each of the Affinity Groups. The Affinity Groups pivoted to develop resources to educate fellow patients on preventing the spread of COVID-19. Through the Affinity Group model and continuous collaboration, the NPFE-LAN created patient-friendly educational tools to support the 2020 Network QIAs and in response to the COVID-19 pandemic. Examples include the following:

- The BSI Affinity Group created a podcast, "Staying Healthy Inside and Outside the Dialysis Clinic."
- The Home Dialysis Affinity Group created two resources, "My Home Dialysis Checklist" and "Choosing Home Dialysis with Your Care Team."
- The Transplant Affinity Group developed a series of resources about the kidney transplant process:
    - What Is a Kidney Transplant?
    - What Is a Kidney Transplant Center?
    - Meet the Members of the Kidney Transplant Team
    - Types of Kidney Donors
    - The Kidney Transplant Surgery
    - Post Kidney Transplant Diet
    - How Much Does a Kidney Transplant Cost?
- COVID-19 for Safe Grocery Shopping
- Staying Safe in a Multigeneration Household
- Telemedicine Patient Toolkit

The Patient SMEs also worked with the ESRD Networks to address content related to reducing hospitalizations, care planning, QAPI meetings and traveling as a dialysis patient. Resources for these topics were developed in hard copy form supported by an electronic tool.

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 department for acute dialysis treatment at a substantial increase in cost and at a detriment to the patient's life expectancy.[20] 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 2020, 663 patients were at risk for an Access-to-Care event with the Networks successfully averting approximately two-thirds of those cases. Over 400 patients received a 30-day notice and were facing imminent IVD. The Networks averted 27 of these potential IVDs and facilitated admissions to another outpatient facility for an additional 106, allowing for continuity of care for these patients.

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 patients with ESRD 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.

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 a patient with ESRD, an individual representing a 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

[20] 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.

was filed with the Network, the Network reminded 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 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 2020, 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 1,195 beneficiary grievances in 2020. Of the 1,195 grievance cases processed, 578 (48.4%) were addressed through the use of Immediate Advocacy, and 152 (12.7%) were based on a Clinical Area of Concern. See Table 2 for Network-specific data. In May 2020, the Networks also began tracking cases that included patient mental health concerns in response to growing reports of mental health distress caused by the COVID-19 pandemic. In 2020, 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 2020, the 18 ESRD Networks provided policy recommendations and recommendations for additional services:

Policy Recommendations:

- Provide additional clarification of CMS' policy of the physician's responsibility to the dialysis facility's adherence to the Conditions for Coverage related to acceptable reasons for IVD as well as ethical considerations with respect to patient autonomy.
- Consider covering telehealth visits for home dialysis and kidney transplantation beyond the COVID-19 pandemic.
- Improve access to COVID-19 vaccinations by prioritizing patients with ESRD for vaccine distribution phases in addition to collaborating with hospitals and long-term care facilities to provide vaccinations to patients with ESRD.
- Promote the importance of telehealth for mental health services for patients and staff, including 1:1 counseling, support groups, and psychiatric appointments.
- Make home dialysis at skilled nursing facilities more accessible to providers.

Additional Services

- Access to concurrent hospice and dialysis, since patients currently must stop dialysis or have the hospice assume the cost of treatment if patients choose to continue dialysis.
- Chronic facilities for challenging or disruptive patients, many of whom have been involuntarily discharged from chronic facilities and are without access to another chronic facility.
- Unique needs facilities to serve dialysis patients with complex clinical conditions (e.g., ventilator-dependent, morbidly obese, antibiotic-resistant infections) or histories of aggression, mental illness, or substance abuse, which require services that typical chronic facilities for the general dialysis population are unable to provide.
- Increased number of facilities with nocturnal dialysis shifts, a home hemodialysis program, and ability to take higher acuity level patients (e.g., stable long-term tracheotomy patients).

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 patients with ESRD, missed dialysis treatments can have serious adverse health effects. This makes this 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 patients with ESRD 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 patients during actual incidents.

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

COVID-19

in 2020, the Networks responded to a variety of emergencies with the potential to impact patients with ESRD and providers. This included the COVID-19 pandemic. Highlights of Network-provided support, guidance, education, and technical assistance to providers and patients related to COVID-19 include the following:

- Conducting assessments of needs and facilities' understanding of critical CDC, CMS, and Network guidance.
- Collaborating with stakeholders to facilitate communication; obtaining and distributing resources to patients and facilities; discussing emerging issues, the potential impact on dialysis care, and response activities; identifying needs of patients and providers; assisting with the procurement of personal protective equipment; and creating synergies to assist patients and providers with COVID-19 challenges. Stakeholders included CMS, CDC, the ESRD NCC, KCER, state health departments, LDOs, patient advocacy groups, SAs, the Forum of ESRD Networks, ASPR Technical Resources, Assistance Center, and Information Exchange (TRACIE), AAKP, DPC, RSN, NKF, QIN-QIOs, and others.
- Distributing credible information and resources to patients through dialysis facilities, PAC SMEs, Facility Patient Representatives (FPRs), social media, webinars, text messaging, recorded call messages, conference calls, newsletters, and postings on the Networks' websites. Topics included mental health, use and benefits of telehealth, living safely in multigenerational homes, celebrating holidays safely, finding credible information, transportation safety, and strategies to assist caregivers in coping.

- Developing tools (e.g., COVID-19 Screening Fatigue tool; Frontline Staff Toolkit), resources (e.g., Mental Health Guide), and educational materials (e.g., FAQs).
- Sharing information, educational materials, tools, and resources with facilities through webinars, mass communications, e.g., text messaging, electronic newsletters with hyperlinks, emails, blogs, websites, social media, learning management system for on-demand learning, and helplines.
- Providing technical assistance to facilities via webinars, one-to-one calls, 24-hour helplines, and email on interventions and strategies to improve safety and infection control; engaging patients; screening for and managing COVID-19; reporting COVID infections; communicating with nursing homes; implement telehealth; developing vaccination processes; implementing CDC prevention guidance; solving COVID-19 challenges, e.g., transportation, supply, and staffing issues; and other relevant COVID-19 areas of concern.
- Working to prevent access to care issues.

Other Emergencies

In addition to COVID-19, the Networks offered comprehensive support to patients and providers during other emergencies, including Tropical Storm Laura; Hurricanes Douglas, Hanna, Isaias, Marco, Sally, and Zeta; Tropical Storms Beta and Eta; Winter Storm Jayden; snow events; water main breaks; power loss; a heatwave; wildfires; tornadoes; flash flooding; earthquakes; windstorms; riots; and planned public safety power shutoffs.

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 2020, in response to the pandemic, the ESRD NCC also:

- Provided analytic support to track and trend confirmed and suspected cases of COVID-19, including an interactive COVID-19 dashboard for the ESRD community that enabled the provision of data-driven technical assistance by the ESRD Networks.
- Collected, developed, and disseminated both patient and provider resources to support the ESRD community's response to COVID on topics such as telehealth and telemedicine, mental health, social distancing, and infection control.
- Revised and deployed the Patient Mobile Tool to rapidly communicate information about COVID-19 (e.g., tips to stay safe, webinars) to patients and dialysis facility staff.
- Partnered with NPFE-LAN SMEs to develop patient and family resources. Examples include the handouts "The Doctor Will See You Now: Telemedicine Makes It Easy" and "COVID-19: A Positive or Under Investigation." Several resources were also translated into Spanish.
- Conducted a series of patient and provider COVID-19 webinar events that were offered both live and on-demand and covered important topics, such as burnout and compassion fatigue, avoiding COVID complacency, changing treatment options during COVID, and vaccination. Meetings featured presentations from national experts, best practice facilities, and patients with ESRD and showcased NCC materials, such as "Staying Safe in Multigenerational Households."
- Posted content daily across the ESRD NCC Facebook and Twitter social media feeds to promote ESRD Network Program activities and CMS initiatives. Topics included COVID-19, infection control, home dialysis, transplantation, emergency preparedness, and mental health. The NCC reached more than 140,000 users across all social media with more than 5,000 shares by December 31, 2020.

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 2020. 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 2020 activities are highlighted in this section.

The National KCER Patient and Family Engagement (N-KPFE) LAN was convened. It included 29 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. The N-KPFE-LAN members worked together to create a patient-centered resource called "Are You Prepared? Get Your Go-bag Ready Now!" The resource was created to assist dialysis and kidney transplant patients with creating an emergency go-bag that includes key life-saving items needed during an emergency or disaster. Additionally, between scheduled meetings, the N-KPFE-LAN utilized the online platform Basecamp to encourage SMEs to remain engaged in sharing ideas and resources. Utilizing Basecamp, N-KPFE-LAN members also shared stories on how they educated patients, providers, and caregivers on preparing for an emergency or disaster, including hosting a lobby day at their facilities, posting resources on a facility bulletin board, and sharing printed resources at the facilities during National Preparedness Month.

KCER was activated on March 2, 2020, when response activities related to COVID-19 began. The team remained continually activated through the remainder of 2020 in response to the COVID-19 pandemic. Throughout that time, the KCER Program coordinated national-level preparedness and response activities, including leading emergency status calls, reporting on COVID-19 patient and staff data, and collaborating with CMS, Networks, dialysis organizations, and other stakeholders to identify and address issues related COVID-19.

- From March 2 to December 31, 2020, the KCER team coordinated over 50 national COVID-19 KCER Status calls with the ESRD Community. The calls were used as a platform for providers to discuss gaps and unmet needs with KCER, the ESRD Networks, CMS, CDC, and HHS ASPR. In addition to facilitating the calls, the KCER team tracked action items and provided detailed meeting minutes following each call. During this same time period, the KCER Program submitted a total of 100 incident reports to CMS related to COVID-19.
- The KCER Program began collecting data to monitor the impact of COVID-19 on the outpatient dialysis population on March 10, 2020, and reporting was required daily until June 5, 2020. In order to address the burden of daily reporting by the Networks and providers, reporting was moved to once weekly beginning the week of June 8, 2020. The

18 ESRD Networks and seven of the larger dialysis providers utilized a KCER COVID-19 Emergency Situational Status Report (ESSR) template, which is an Excel spreadsheet, to report all COVID-19 data to KCER. Additionally, the KCER team assisted the CDC with the development of a new NHSN Outpatient Dialysis COVID-19 Module, which, beginning in mid-November 2020, replaced the data reporting the KCER Program began collecting in March 2020.

- In coordination with Healthcare Ready, the KCER Program partnered with ESRD Networks, dialysis providers, and other stakeholders to complete an in-process after-action review of the ESRD community's response to COVID-19. The final report was distributed to the ESRD community and posted to the KCER website on November 4, 2020. The purpose of the project was to drive system-wide improvements for the KCER and the ESRD Network Programs and increase ESRD community resilience against pandemics and other disasters. The project also aimed to collect best practices and opportunities for improvement that could be spread across the ESRD community to help prepare for a second wave of the virus.

During 2020, the KCER Program responded to two additional major events during the COVID-19 pandemic. KCER was activated from August 27 to September 2, 2020, in response to Hurricane Laura and again from September 16 to September 21, 2020, in response to Hurricane Sally. During this time, the KCER Program coordinated national-level preparedness and response activities, including leading daily emergency status calls, reporting on facility operational status and needs, and collaborating with CMS, ESRD Networks, dialysis organizations, and other stakeholders to identify and address patient access to care issues.

- During the response and recovery efforts for Hurricanes Laura and Sally, the KCER Program worked directly with many new and existing stakeholders to improve the overall outcome for the ESRD patient population. The KCER Program also provided daily reports outlining the current status of the incident response and the operational status and needs of dialysis providers.
- The KCER Program collaborated with an existing partner, Healthcare Ready, to post dialysis facility status information on the RxOpen online platform during the response to Hurricanes Laura and Sally. The information was updated daily during the response to Hurricanes Laura and Sally, utilizing the dialysis facility operational status information tracked by the KCER Program.
- The KCER Program participated in daily emergency calls with the ASPR Critical Infrastructure Protection (CIP) Healthcare Sector Coordinating Council (HSCC) during the response to Hurricanes Laura and Sally. Attendance at these calls served to elevate the profile of the KCER Program and brought the current status and unmet needs of the ESRD community to the group.

List of Data Tables

Table 1. Medicare-Certified Dialysis Facilities – Modality Offered – Calendar Year 2020

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	120	82	4	206	221
2	14	137	196	17	350	364
3	4	138	111	9	258	262
4	19	169	181	18	368	387
5	13	198	237	31	466	479
6	10	321	433	53	807	817
7	10	254	235	30	519	529
8	9	135	321	39	495	504
9	14	270	344	47	661	675
10	9	107	185	58	350	359
11	21	179	305	35	519	540
12	12	144	181	18	343	355
13	9	137	200	10	347	356
14	22	305	412	43	760	782
15	15	155	215	15	385	400
16	7	140	86	9	235	242
17	6	94	192	47	333	339
18	14	178	239	45	462	476
NATIONAL	**223**	3,181	4,155	528	7,864	8,087

Table 2. Grievances and Non-Grievances by Case Type, Number, and Percent – Calendar Year 2020

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	14	24	*	133	41	215	41	3.43%	174	3.63%
2	*	25	*	54	42	131	35	2.93%	96	2.00%
3	*	22	*	58	43	125	24	2.01%	101	2.11%
4	*	*	19	30	24	84	30	2.51%	54	1.13%
5	52	33	16	173	151	425	101	8.45%	324	6.76%
6	108	57	*	315	155	641	171	14.31%	470	9.80%
7	*	91	17	263	109	491	119	9.96%	372	7.76%
8	*	45	*	112	51	222	59	4.94%	163	3.40%
9	45	19	*	135	73	277	69	5.77%	208	4.34%
10	28	12	*	176	70	294	48	4.02%	246	5.13%
11	*	79	11	381	64	537	92	7.70%	445	9.28%
12	17	15	17	155	78	282	49	4.10%	233	4.86%
13	*	*	*	39	36	95	20	1.67%	75	1.56%
14	39	20	16	378	69	522	75	6.28%	447	9.32%
15	*	39	*	65	34	153	54	4.52%	99	2.06%
16	11	15	13	121	34	194	39	3.26%	155	3.23%
17	*	52	12	613	55	742	74	6.19%	668	13.93%
18	34	30	31	406	59	560	95	7.95%	465	9.70%
National	**348**	**578**	**152**	**3607**	**1188**	**5990**	**1195**		**4795**	

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

Table 3. National ESRD Patient Data Overview 2020

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	206	2.6%	15	6.7%	14,969	2.9%	12,853	2,116	2.7%	11,970	4.7%	26,939
2	350	4.5%	14	6.3%	29,765	5.7%	27,129	2,636	3.4%	16,733	6.6%	46,498
3	258	3.3%	4	1.8%	2,0731	3.9%	18,656	2,075	2.7%	6,514	2.6%	27,245
4	368	4.7%	19	8.5%	20,285	3.9%	17,415	2,870	3.7%	13,340	5.3%	33,625
5	466	5.9%	13	5.8%	28,351	5.4%	24,209	4,142	5.4%	15,763	6.2%	44,114
6	807	10.3%	10	4.5%	51,415	9.8%	43,734	7,681	10.0%	17,214	6.8%	68,629
7	519	6.6%	10	4.5%	32,880	6.3%	28,060	4,820	6.2%	14,602	5.8%	47,482
8	495	6.3%	9	4.0%	28,887	5.5%	24,547	4,340	5.6%	10,567	4.2%	39,454
9	661	8.4%	14	6.3%	33,672	6.4%	28,107	5,565	7.2%	16,790	6.6%	50,462
10	350	4.5%	9	4.0%	20,701	3.9%	16,624	4,077	5.3%	9,878	3.9%	30,579
11	519	6.6%	21	9.4%	29,126	5.5%	24,745	4,381	5.7%	21,942	8.7%	51,068
12	343	4.4%	12	5.4%	16,789	3.2%	13,690	3,099	4.0%	11,735	4.6%	28,524
13	347	4.4%	9	4.0%	20,925	4.0%	17,633	3,292	4.3%	7,345	2.9%	28,270
14	760	9.7%	22	9.9%	53,949	10.3%	46,825	7,124	9.2%	20,237	8.0%	74,186
15	385	4.9%	15	6.7%	27,159	5.2%	23,148	4,011	5.2%	16,096	6.3%	43,255
16	235	3.0%	7	3.1%	16,163	3.1%	13,269	2,894	3.8%	8,654	3.4%	24,817
17	333	4.2%	6	2.7%	30,772	5.9%	25,919	4,853	6.3%	14,640	5.8%	45,412
18	462	5.9%	14	6.3%	48,609	9.3%	41,454	7,155	9.3%	19,467	7.7%	68,076
NATIONAL	7,864	--	223	--	525,148	--	448,017	77,131	--	253,487	--	778,635