

2021

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 from January 2021-April 2022, which was the end of the Network Statement of Work. These activities included 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; August 25, 2021.

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 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 from January 2021-May 2021 due to the COVID-19 pandemic. However, the Networks continued to provide educational materials to patients and dialysis facility staff, maintain collaborative relationships, and offer data-driven technical assistance. Starting in June 2021, new ESRD Network contract quality improvement activities focused on Outcomes and Key Results (OKRs) across five different goals and ran through April 2022.

From June 2021 to April 2022, the ESRD Network Program QIAs included 7,956 dialysis facilities, representing 100% of dialysis facilities in the U.S. and its territories. During this period, Networks supported facilities and patients in improving patient care, directly or indirectly impacting 777,360 patients who experienced the effects of the QIA activities. Specifically, interventions were aimed at increasing the use of home dialysis; and increasing the number of patients on the transplant waitlist and number of patients receiving kidney transplant.

	777,360 patients impacted
	56,989 positive patient outcomes from home therapy and transplants
	\$747 million savings facilitating home therapy and transplants

Analysis of impacts on patients in facilities engaged in QIAs showed 56,989 positive patient outcomes from home therapy and transplants in the 2021 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

\$747million in savings. 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 associated with each quality improvement area of focus.

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^{2,3}, and potential for reduced cost of treatment and overall costs to the health system.⁴

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 \$1,032.68 per month (\$12,392 per year) in 2021 dollars.⁵

38,569 patients started home dialysis with anticipated savings of \$396 million per year

As a result of education, outreach, and technical assistance activities during the 2021 QIAs, 38,569 patients ----started 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 \$396 million in the first year following transition.

² 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.

³ 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.

⁴ 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/>.

⁵ Insight Policy Research and Arbor Research Collaborative for Health. Home Dialysis Return on Investment Analysis. Memorandum to CMS [internal document]. April 17, 2020.

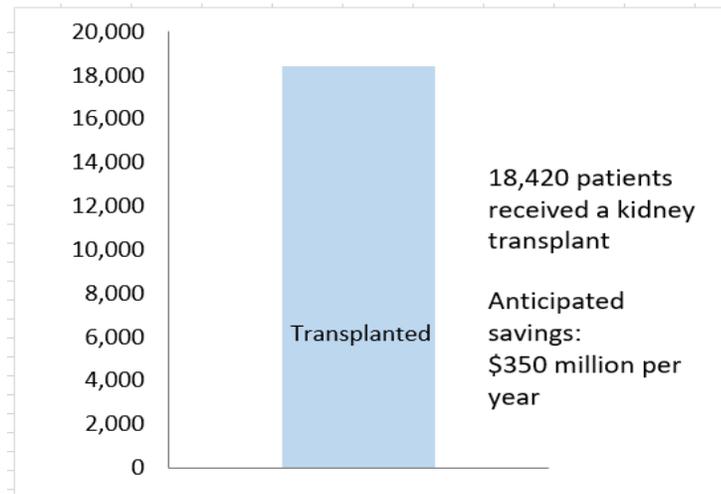
Increasing Patients Receiving a Kidney Transplant

Patients receiving a kidney transplant have better outcomes than those remaining on dialysis, including higher five-year survival rates.^{6,7} The Networks' 2021 QIA interventions focused on moving patients to the transplant waitlist with the ultimate goal of achieving transplants for these patients.

The 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.⁸

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)⁹ inflation factor of 1.13, this is \$104,768 or \$19,049 per year in 2021 dollars.

With the Networks' efforts, 18,420 patients received a kidney transplant during the remeasurement period. Based on these numbers and the 5.5-year time window analyzed by the Office of the Actuary, it was estimated that these transplanted patients saved approximately \$350 million per year.



Patients added to waitlists, expected transplants, and cost savings as a result of 2021 QIAs.

⁶ 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.

⁷ 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>.

⁸ DHHS. Office of the Actuary. Savings Estimate for Kidney Transplant Model. CMS Memorandum [internal document]. June 3, 2016.

⁹ U.S. Bureau of Labor Statistics. CPI Inflation Calculator. Available at: https://www.bls.gov/data/inflation_calculator.htm. Accessed October 11, 2022.



Summary

The ESRD Network Program is meaningfully impacting patient outcomes and reducing costs associated with care. Quality improvement activities to increase the use of home dialysis and increase the number of patients on the transplant waitlist and number of patients receiving a kidney transplant 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 56,000 positive patient impacts occurred, and these improved outcomes represent an anticipated \$747 million in savings. In addition to these projects, the Networks drove improvements related to vaccinations (e.g., influenza, COVID-19), hospital utilization (e.g., hospital readmissions, emergency department visits), data quality reporting (e.g., timeliness of 2728 forms), telemedicine, and dialysis care in the nursing home.

Report Highlights

Dialysis Prevalence

The Networks reported a 1.6 % 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 2021 as compared with the last day of the year in 2020. As also experienced 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.¹⁰ 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 (14,786). Network 14, which covers the state of Texas, had the largest number of patients (53,639).

Home Dialysis

The number of eligible dialysis patients using home dialysis grew from 14.7% in 2020 to 15.3% in 2021 representing an additional 1,940 patients. 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 921 beneficiary grievances in 2021, which is a 22.9% decrease from the previous year. Of the 921 grievance cases processed, 451 (49.0%) were addressed using Immediate Advocacy, 323 (35.0%) were General Grievances, and 147 (16.0%) were based on a Clinical Area of Concern. The total number of non-grievance cases in 2021 was 4,046 (15.6% decrease from 2020). These included 2,906 Facility Concerns and 1,136 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, Patient 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.

¹⁰ Ziembra 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. Patient Concern: These non-grievances are initiated by a contact from the patient who wishes to discuss either a specific or general circumstance(s) about a 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, outreach, or resource documents for the patient.
3. 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 2021, the Networks recruited new and previous 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 2021, CMS continued its enhanced focus on emergency management practices and requirements for the Networks, especially related to the COVID-19 pandemic. The Networks' response to the pandemic included activities to drive patient and dialysis staff COVID vaccination rates nationwide and continued focus on 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 amplified its partnerships 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 enhanced outreach, training, and technical assistance activities to help ensure that the needs of patients with ESRD would be met in emergency situations. During 2021, the KCER Program responded to a total of 43 events (20 events more than in 2020) that resulted in changes in facility status, including closures and altered schedules, and the KCER team submitted over 70 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 2021, the Networks worked to improve healthcare for almost 517,000 dialysis patients and approximately 270,000 kidney transplant patients.

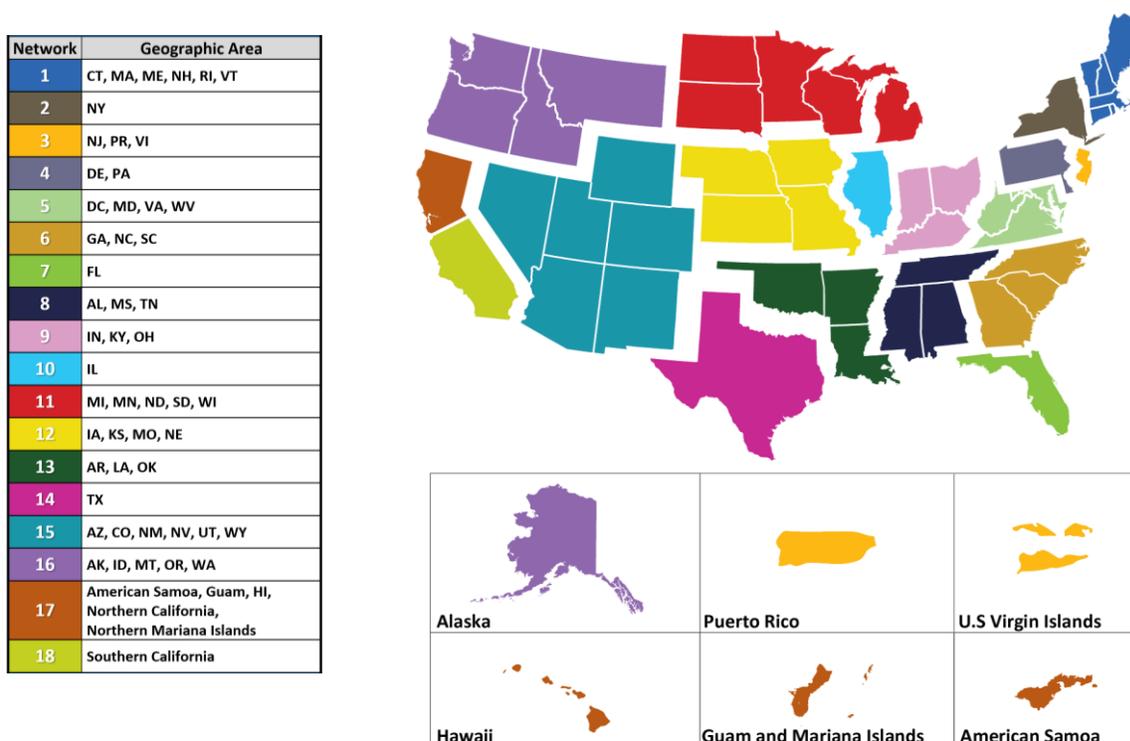


Figure 4. ESRD Network Service Areas



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. During the 2021 calendar year, the ESRD Networks completed a 5-year SOW (May 2021) and started a new 5-year SOW (June 2021 – April 2026).

For the new SOW starting June 2021, the CMS goals for the ESRD Network Program included:

- Improve Behavioral Health Outcomes
- Improve Patient Safety and Reduce Harm
- Improve Care in High Cost/Complex Chronic Conditions
- Reduce Hospital Readmissions
- Improve Nursing Home Care in Low-Performing Providers, and provide Targeted Quality Improvement Response

The Networks are charged with promoting positive change relative to the CMS goals, as well as quickly adapting to the evolving needs of ESRD patients and the renal community. The Networks are also tasked with addressing cross-cutting focus areas, including vulnerable populations and disparities, rural health, and patient and family engagement.

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 almost 8,000 dialysis facilities and 227 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 a group of Patient Subject Matter Experts (SMEs), sometimes called a 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.
- Patient SMEs ensure 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 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, 2021, there were 516,929 prevalent dialysis patients and 7,969 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 (812). Network 1, which covers the New England region states of Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont, had the fewest facilities (203).

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 2021, 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.¹¹ 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 that identifies all patients who are alive and on dialysis as of December 31 of a given year. At the end of 2021, 516,929 patients were receiving dialysis in the U.S., according to the Networks’ Annual Reports—a decrease of 8,219 patients (1.6%) since December 31, 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.

¹¹ 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 7, 2022.

Quality Improvement Activities (QIAs)

During the 2021 calendar year, the ESRD Networks completed a 5-year contract cycle, plus an extension period, which focused on transplant waitlisting, home dialysis, and bloodstream infections. Due to the continuing COVID-19 pandemic, many quality improvement activities (QIAs) and other efforts were suspended through May 2021 to ensure the emphasis remained on direct patient care and mitigation of COVID-19 in the ESRD community.

Beginning in June 2021, the Networks began the new SOW with QIAs that addressed depression, home dialysis, transplantation, vaccination, hospitalization, and dialysis care in nursing homes. Quality improvement efforts utilized root cause analysis, rapid cycle improvement, evidenced-based practices, data-driven technical assistance, community coalitions, and advisory groups to advance change.

Transplant Waitlist QIA (January 2021 – May 2021)

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 limiting provider staffing and procedures, along with contract goal adjustments, the Networks worked toward the goals of this QIA but were not evaluated on results through May 2021. The Networks continued to provide educational materials to patients and dialysis facility staff and maintained communication relationships.

Transplant Waitlist & Transplanted QIA (June 2021 – April 2022)

In follow-up to the QI project regarding increasing the number of patients on the transplant waitlist, the Networks expanded efforts to also improve the number of patients receiving a kidney transplant. Networks planned, developed, and implemented QI concepts and strategies, including the mitigation of health equity issues and education targeted to patients about the choice of high Kidney Donor Profile Index (KDPI) or expanded donor criteria kidneys.

The Transplant QIA implemented from June 2021-April 2022 included two goals:

- Increase the number of patients added to a kidney transplant waiting list by 2%.
- Increase the number of patients receiving a kidney transplant by 2%.

The Networks and ESRD providers identified and executed best and promising practices that resulted in a national total of 24,511 patients added to the wait list and 18,424 patients receiving a kidney transplant. Examples included:

- Instituting a transplant center and dialysis facility check-in process to review active waitlist patients, obtain current health status, and address any barriers.



- Creating and disseminating patient-level waitlist status reports to dialysis facilities for review, accurate tracking, and action related to active and inactive waitlist status, as well as patient removals from the transplant waitlist.
- Utilizing a team-based approach to education, support, and provide encouragement to dialysis patients during the long process of waitlisting and keeping them ready for transplant and active on the waitlist.
- Adopting an electronic bi-directional referral system that streamlines communication between dialysis and transplant centers for coordination of care.
- 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 receiving a transplant sooner.
- Hosting physician-led webinars regarding high KDPI and increased risk kidneys.
- Collaborating with Organ Procurement Organizations to identify common goals and strategies for increasing kidney transplantation, such as high KDPI education programs.
- Conducting 1:1 technical assistance calls to poor-performing facilities to identify current workflow practices and challenges inhibiting success with patient transplant wait listing

Home Therapy QIA (January 2021 – May 2021)

In the U.S. in 2021, 79,071 (15.3%) of the total 516,929 dialysis patients utilized a home renal replacement therapy, which is an additional 1,940 patients 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 limiting provider staffing and procedures, along with contract goal adjustments, the Network worked toward the goals of this quality improvement activity but was not evaluated on results through May 2021. The Networks continued to provide educational materials to patients and dialysis facility staff and maintained communication relationships.

Home Therapy QIA (June 2021 – April 2022)

Because home dialysis modalities are proven to increase quality of life, many have also experienced better quality outcomes, the Networks continued to implement QI strategies to transitions in-center hemodialysis to home hemodialysis or peritoneal dialysis. This new SOW also included efforts to support patient education and choice of modality at treatment initiation. In collaboration with the renal community and other stakeholders, the Networks identified barriers and implemented solutions to increase utilization of home dialysis.

The Home Therapies QIA implemented from June 2021-April 2022 included two goals:

- Achieve a 10% increase in the number of incident patients that start dialysis using a home modality.



- Achieve a 2% increase in the number of prevalent patients that move to a home modality.

The Networks and ESRD providers identified and executed best and promising practices that resulted in a national total of 17,278 incident patients starting home dialysis and 22,967 prevalent patients moving to a home modality. Examples included:

- Utilizing alternative education methodologies to promote increased use of home dialysis, such as patient advocates, transitional care units, and short-term trials on home therapy machines to experience the difference in their treatment.
- Collaborating with physician home champions to grow home dialysis programs and operationalize the use of telemedicine for home clinic visits.
- Partnering with kidney education programs to education renal professionals about urgent start peritoneal dialysis and transitional care units.
- Teaming with Quality Improvement Network Quality Improvement Organizations (QIN-QIOs) to promote the provision of dialysis options in nursing homes.
- Launching a “Putting Patients First” initiative by encouraging home dialysis care plan goals and challenging providers to say “yes” to non-traditional home candidates.
- Using the ESRD NCC’s “Uncovering Myths About Home Dialysis: Myth vs. Reality” booklet to educate patients about home therapy.
- Recruiting and training patient navigators and peer mentors utilizing a customized guide to promote and educate home therapy to other dialysis patients.
- Building clinicians’ confidence in home therapy and improving home dialysis growth and program retention through partnership with Project ECHO’s case-based learning.

Influenza QIA (June 2021 – April 2022)

The ESRD population is considered a high-risk group and can develop serious flu complications, which may result in hospitalizations and even death. To reduce risks from flu and related complications in dialysis patients, the Network provided technical assistance and education to increase influenza rates, as well as other vaccinations recommended by the Centers for Disease Control and Prevention (CDC). The primary goal of the QIA was to:

- Achieve a minimum of 85% of ESRD patients receiving an influenza vaccination.

The Networks and ESRD providers identified and executed best and promising practices that resulted in 78.8% of ESRD patients nationally being vaccinated for influenza. Examples included:

- Creating and launching vaccination campaigns, such as *Vaccination Olympic* and *Don’t Wait, Vaccinate* campaigns with websites, tools, and resources that encouraged facilities to commit to vaccination of patients and staff.
- Organizing structured “Vaccine Days” with leadership from medical directors and provision of education to bolster vaccination rates in facilities.



- Hosting an influenza poster contest with facilities designing bulletin boards that provide education about the importance of receiving the influenza vaccine.
- Facilitating monthly 1:1 coaching calls to clinics struggling to meet project goal to identify barriers, data inaccuracies, or reporting issues hindering progress.

COVID-19 Vaccinations Patients and Staff (June 2021-April 2022)

In addition to data-driven technical assistance and response to address the COVID-19 pandemic (e.g., cohorting recommendations), ESRD Networks provided technical assistance and education consistent with evolving CDC guidance surrounding all COVID-19 vaccine doses and booster vaccinations and encouraged vaccination for dialysis patients and staff. The QIA focused on the following goals:

- Achieve a COVID-19 patient vaccination rate of 80%.
- Achieve a COVID-19 patient booster vaccination rate of 80%.
- Achieve a COVID-19 staff vaccination rate of 100%.
- Achieve a COVID-19 staff booster vaccination rate of 100%.

Nationally, the Networks and ESRD providers identified and executed best and promising practices that achieved a COVID-19 patient vaccination rate of 73.9% and a patient booster vaccination rate of 54.4%. For COVID-19 staff vaccinations, a rate of 81.1% was achieved with a booster rate of 35.6% of ESRD patients being vaccinated for influenza. Examples included:

- Utilizing vaccine champions and patient and family representatives to advocate and support efforts to increase the vaccination rates, including discussions about increased risk of exposure to COVID and protecting family, friends, and colleagues through vaccination.
- Convening monthly state-specific COVID-19 calls to discuss local case trends, identify challenges in vaccination, and promote infection mitigation strategies to reduce risk of COVID-19 hospitalizations.
- Collaborating with State Departments of Health and Health Care Coalitions to develop educational resources.
- Disseminating other credible materials, such as the CDC's COVID-19 Vaccination Communication Toolkit and the 5-Diamond Patient Safety Program COVID-19 module.
- Promoting an instructional video to address stress related to the loss of ESRD patients and staff called "Grief Management for the Caregiver During the Pandemic."
- Developed a facility-focused infographic detailing "How Dialysis is Safely Offered to Patients with COVID-19."
- Holding vaccine clinic days and sharing "Why I Got the Vaccine " statements from patients and staff on a visual display to encourage the hesitant patients to obtain vaccinations.



Data Quality QIA (June 2021 – April 2022) – Admissions, CMS Form 2728, and CMS Form 2746

ESRD Networks collect, validate, and analyze data in support of CMS reports, contract goals, and maintenance of the ESRD patient registry. This includes, but is not limited to, patient admission records, CMS-2728 form, and CMS-2746 form. The Network's Data Quality QIA focused on improving the timeliness of submission in EQRS with goals including:

- Patient admissions data entered within five business days.
- CMS-2728 forms submitted within 45 business days.
- CMS-2746 forms submitted within 14 days of the date of death.

The Networks assisted ESRD providers with addressing timeliness and accuracy of reporting via technical assistance and educational resources. Networks achieved a national average for timeliness in 66.4% admissions, 73.2% 2728 forms, and 55.9% 2746 forms. The Networks identified best and promising practices that included:

- Assigning a primary individual at each facility to complete admissions, 2728 forms, and 2746 forms in addition to a back-up staff member to perform the tasks whenever the primary person is unavailable.
- Logging into EQRS on a weekly basis to review for any outstanding forms requiring submission.
- Creating and disseminating tools and resources to support timely submission by facilities, including an EQRS Monthly Checklist, FAQs for the CMS 2728, a caseload form to track patient activity, and a missing /overdue form report with a timeliness summary for the year.
- Creating a step-by-step instruction guide for running reports in EQRS to capture missing patient admissions.
- Developing a customer support portal to streamline the data quality audit process for non-LDO facilities.
- Providing data quality appointments that allowed facilities to schedule meetings for one-on-one technical assistance.

Hospitalization – Inpatient Admissions, Emergency Department (ED) Visits, Readmissions, and COVID-19 Admissions (June 2021 – April 2022)

ESRD patients have multiple health conditions in addition to kidney disease that impact their care and overall well-being, including anemia, cardiovascular disease, and diabetes. Some health deficits may also be related to patient behavior (e.g., high fluid intake) or health-related social needs (e.g., transportation, healthy diet). The Network's Hospital Utilization QIA focused on reducing the following metrics by 2%:

- ESRD-related Inpatient Admissions
- ESRD-related 30-Day Unplanned Readmissions
- ESRD-related ED Visits

The Networks and ESRD providers identified and executed best and promising practices that resulted in a national relative decrease of 9.1% for hospital inpatient admissions, a national relative decrease of 9.0% for 30-day unplanned readmissions, and a national relative decrease of 5.1% for ED visits. Examples included:

- Distributing wallet cards to patients that include a dialysis plan of care, which improve communication between dialysis facilities and hospital staff.
- Integrating patients in hand hygiene and hand sanitizer audits at the facility level, which led to improved hand hygiene practices and lower infections rates and hospitalizations.
- Providing 1:1 coaching call to facilities with strategies regarding primary care providers, comorbidities (diabetes, high blood pressure, and obesity), missed treatments, and appropriate use of the emergency room.
- Identifying volunteer patient champions that share their stories with peers and promoting self-care, following plan of care and treatment orders, and receiving recommended immunizations.
- Identifying a designated hospitalizations manager at each facility.
- Convening monthly state specific COVID calls to discuss local case trends, identify challenges in vaccination, and promote infection mitigation strategies to reduce risk of COVID hospitalizations.
- Promoting the Forum of ESRD Networks' Transition of Care Toolkit to improve practices post-hospitalization and increase communication with inpatient units to reduce the risk of readmission.

Depression QIA (June 2021 – April 2022)

Research indicates that high rates of depression exist in the ESRD patient population with many individuals experiencing poor quality of life and higher levels of mortality. Due to contract goal adjustments, the Network worked toward the goals of this quality improvement activity but was not evaluated on results. As part of these efforts, the Networks identified best and promising practices that included the following:

- Using the *Facility Guide to Entering the Clinical Depression Assessment in EQRS* to assist facilities with appropriate reporting in EQRS.
- Sharing the interventions regarding depression with staff through monthly QAPI meetings, staff huddles, and as patient education.
- Integrated the use of educational resources for patients on depression screenings, discussing the difference between symptoms of depression and symptoms of chronic illness, and incorporating wellness screenings into patient education.
- Developing and distributing a patient self-management toolkit for patients who screen positive for depression but are resistant to a referral to a mental health provider.



- Disseminating a patient-centered document, *Finding the Words*, to help patients identify and share their feelings and symptoms regarding mental and behavioral health issues.
- Partnering with Long-Term Care Ombudsman Programs, Managed Care Organizations, and Area Agencies on Aging to address patient concerns related to managing behavioral health and cognitive decline.
- Partnering with behavioral health subject matter experts to create a series of videos, such as tips, tools, and resources to track, educate, and monitor depressed dialysis patients, PHQ-9 scoring, documentation and follow-up plans, and managing the emotional side effects of dialysis.

Nursing Home QIA (June 2021 – April 2022)

Nursing home residents that also require and receive dialysis in the nursing home setting are a vulnerable population, especially related to infection and anemia. This QIA focused on reducing long-term catheter infections and peritonitis events, as well as blood transfusions. Due to contract goal adjustments, the Network worked toward the goals of this quality improvement activity but was not evaluated on results. As part of these efforts, the Networks identified best and promising practices that included the following:

- Sharing goals and conducting regular care planning and QAPI meetings with nursing home staff and medical directors.
- Implementing educational mentoring activities with nursing homes and discussing how home therapies in long term care settings support patient care.
- Providing peritonitis education material, catheter care audit tools, and share upcoming webinars on the topics of anemia and access-related infections in dialysis patients.
- Collaborating with QIN-QIOs and serving as subject matter experts on calls to answer questions related to caring for dialysis patients in nursing homes.

Telemedicine QIA (June 2021 – April 2022)

In support of home dialysis goals, a QIA was also implemented to drive the use of telemedicine for rural patients utilizing home dialysis. The Networks and ESRD providers identified and executed best and promising practices that resulted in 4,685 rural patients using telemedicine to engage in home therapies. Examples included:

- Addressing barriers to using telemedicine with patients (e.g., no access to broadband, language barriers).
- Developing monthly facility performance scorecards that provided a list of eligible rural home patients that could benefit from a telehealth clinic visit.
- Offering easy-to-use platforms, creating reminder systems, and advocating for the use of telemedicine as equally beneficial as a face-to-face visit.



- Sharing success stories of local programs that had fully integrated the use of telemedicine as a method to complete clinic visits.
- Identifying free, HIPPA compliant telemedicine platforms (e.g., *Doximity and Doxy.me*) that are effective in maintaining a telemedicine program.
- Creating or identifying patient resources (e.g., CMS Telehealth Resources, *Telemedicine is Here to Stay: And Here's Why*), which contains links to technologies and describes the benefits of telehealth and how to use it.

Vaccinations -- Pneumococcal 13 & 23 and Staff Influenza QIA (June 2021 – April 2022)

This SOW also focused on other CDC-recommended vaccinations, including those to address pneumococcal pneumonia (i.e., PCV13, PPSV23) and influenza vaccinations for facility staff. Due to contract goal adjustments, the Network worked toward the goals of this quality improvement activity but was not evaluated on results. As part of these efforts, the Networks identified best and promising practices that included the following:

- Asking patients post-hospitalization or post-primary care physician visit if they had obtained a “pneumonia shot” to identify updates in vaccination status.
- Informing patients upon admission that the pneumococcal vaccine is essential to maintain their health and providing it during the first few days of dialysis treatment.
- Providing dialysis staff with education on the benefits of vaccinations and resources educate both patients and staff with credible information (e.g., CDC’s Pneumococcal Vaccination: Summary of Who and When to Vaccinate).
- Encouraging cross-reporting between hospitals, PCPs, nursing homes, and dialysis providers to identify all vaccinations and prevent multi-dosing.



Ensuring Data Quality

End Stage Renal Disease Quality Reporting System (EQRS)

The ESRD Network Program used the EQRS 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 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 three primary CMS ESRD forms, the ESRD Medical Evidence Report: Medicare Entitlement and/or Patient Registration (CMS-2728), the ESRD Death Notification (CMS-2746) and the End Stage Renal Disease Medical Information System ESRD Facility Survey (CMS-2744). 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 2021, 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. The COVID Dashboard developed with recommendations from the Networks shows Patient and Staff Vaccination Rates.

Network representatives:

- Inform the ESRD NCC on updates to Network data reporting needs, priorities, and perspectives.
- Offer guidance on the requirements for specific reports and dashboard releases.
- Test data report updates prior to release to the entire community.
- Collaborate 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 representatives 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 2021, Veterans Health Administration facilities and transplant facilities were not required to use 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 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 EQRS for the facilities.



Patient and Family Engagement

Education for Patients and Caregivers

In 2021, Networks continued to support 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 continually partner 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 2021-2022 NPFE-LAN organized into Affinity Groups to address the mandatory Network OKRs areas, including:

- Increase the number of patients accurately screened and treated for depression.
- Increase the number of ESRD patients starting dialysis using a home modality and decrease the catheter infection rate in dialysis patients receiving home dialysis at nursing homes.
- Decrease the number of COVID-19 hospitalizations in ESRD patients and increase the number of dialysis patients receiving an influenza vaccination.
- Increase the number of patients added to a kidney transplant waiting list and increase the number of patients receiving a kidney transplant.



- Support the reduction of all-cause hospitalizations, readmissions, and emergency department visits.

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. The groups created the following resources related to the Network OKR areas:

- Feelings Flashcard
- Self-help Flashcard
- Home Dialysis Poster - Professional
- Home Dialysis Poster - Patient
- Why I Received the COVID-19 Vaccine – video
- Transplant Times with a Transplant Recipient – podcast
- 10 Steps to Avoid Hospitalization
- Hospital Discharge Checklist
- Medical Appointment Tracker

Through the Affinity Group model and continuous collaboration, the NPFE-LAN members created patient-friendly educational tools to support the ESRD NCC and TAQIL goals. NPFE-LAN members reviewed and provided feedback for the Dialysis Facility-Focused Transplant Change Package. Members alone with members from the ESRD Networks also created a patient friendly resource called, “You May Be Eligible for a Kidney Transplant.”

NPFE-LAN SMEs also partners with CMS to host its first Health Equity Listening and Learning Session. The event featured a panel of patient leaders sharing their experiences with racial and sex bias in healthcare, access to care, and communication. The panelists identified what they viewed as long-standing systemic health and social inequities that contribute to health disparities. They also highlighted opportunities for actionable solutions.

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 March 2021.

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.¹² 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 January 2021 – April 2022, 920 patients were at risk for an Access-to-Care event with the Networks successfully averting approximately two-thirds of those cases. Over 500 patients received a 30-day notice and were facing imminent IVD. The Networks averted 52 of these potential IVDs and facilitated admissions to another outpatient facility for an additional 176, 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 was filed with

¹² 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.



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 2021, 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 921 beneficiary grievances in 2021. Of the 921 grievance cases processed, 451 (49.0%) were addressed using Immediate Advocacy, and 147 (16.0%) were based on a Clinical Area of Concern. See Table 2 for Network-specific data. In 2021, 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 2021, 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

- National nephrology education for all renal disciplines and promotion of a national program to recruit nephrologists, nurses, social workers, registered dietitians, and technicians to support increased chronic kidney disease (CKD) efforts, maintain ESRD care, and advance QI initiatives in CKD and ESRD.
- Enhanced surveillance of nursing home - home dialysis providers through better CMS Certification Number delineation to capture location of services and increased offering of this service line.
- Growth of home support staffing to offer training and increase the number of patients receiving treatment in their homes, including modifications to regulations regarding nursing oversight and training.
- Transportation, dental, and social support network services to overcome barriers in transplantation.
- Access to concurrent hospice and dialysis services -- currently patients must discontinue treatment or have hospice assume the cost of treatment if dialysis is continued.
- Unique needs chronic facilities to serve dialysis patients with complex clinical conditions (e.g., ventilator-dependent, morbidly obese, antibiotic-resistant infections) or histories of aggression, mental illness, substance abuse, or involuntary discharge, which facilities for the general dialysis population are unable to provide.



- Increased number of facilities with nocturnal dialysis shifts and a home hemodialysis program.
- More outpatient chair availability in regions or states where there are delays in hospital discharges due to the need for outpatient dialysis
- Transplant evaluations and follow-up appointments closer to a patient's home, especially in state without transplant facilities.
- Workgroup representing all aspects of the community (especially rural/urban, racial/ethnic, age and gender), including development a change package for health equity and rural health care

The policy recommendations and additional services represent important approaches to improving the scope and quality of care for patients with ESRD. However, the costs associated with implementing many 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 address patient 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 2021, the Networks responded to a variety of emergencies with the potential to impact patients with ESRD and providers, including the continued data-driven response to 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:

- Collaborating with stakeholders to facilitate communication; obtaining and distributing resources to patients and facilities (e.g., guidelines, waivers); discussing emerging issues (e.g., staffing crisis), 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.
- Working to prevent access to care issues related to lack of transportation in collaboration with facility social worker and administrators, state OEMs and transportation companies.
- 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, and email on interventions and strategies to improve safety, infection control, and patient and staff vaccination rates; engaging patients; screening for and managing COVID-19; reporting COVID infections; communicating with nursing homes; implement telehealth; implementing CDC prevention guidance; solving COVID-19 challenges, e.g., transportation, supply, and staffing issues; and other relevant COVID-19 areas of concern.

Other Emergencies

In addition to COVID-19, the Networks offered comprehensive support to patients and providers during other emergencies, including:

- Tropical Depression TD06W
- Tropical Storm Claudette
- Hurricanes Elsa, Fred, and Ida
- Winter Storm Uri
- Multiple no-name winter storms and snow events
- China Grade, Bonny Doone Complex, Panther Ridge, Freedom Fires, Telegraph, Mescal, Lava, Salt, Dixie, River, Cache, Bennett, and Washington wildfires
- Heavy rains, flash flooding, and strong winds
- Tornadoes
- Heatwaves and extreme temperatures
- Planned Public Safety Power Shutoffs and power outages
- Water system and water main breaks



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. Examples of these activities include:



- Collected, developed, and disseminated a weekly national technical assistance infographic that demonstrates the data-driven technical assistance being provided across the 8 OKRs throughout the 18 ESRD Networks.
- Utilized social media to inform patients and providers about educational resources on the ESRD NCC website.
- Conducted monthly ESRD Network OKR Community of Practice (CoP) calls to uncover intervention development and dissemination, and best practice sharing across the 18 ESRD Network Service areas.
- Facilitated 27 quarterly Expert Team calls reaching over 1,000 dialysis professionals focused on improving access to home dialysis and transplant, improving depression screening, increasing vaccination utilization, reducing COVID-19 hospitalizations, improving access to dialysis care in nursing homes, and improving health equity for people with kidney disease.
- Convened 30 bimonthly patient subject matter expert calls focused on creating patient education materials to improve access to home dialysis and transplant, increase depression screenings, decrease hospitalizations and readmissions, and improve vaccination rates including COVID-19.
- Redesigned the ESRD NCC website to simplify navigating to available tools and resources for providers and patients resulting in increased breadth of website pageviews.
- Developed a monthly email listserv for informing over 7,500 dialysis providers about the New ESRD Patient Orientation Packet available online for distribution to all new ESRD patients each month.

In 2021, 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 monthly dashboard for the ESRD community that enabled the provision of data-driven technical assistance by the ESRD Networks.
- Conducted COVID-19 vaccination and hospitalization Expert Team meetings with high performing dialysis center staff to identify data-driven case studies that support increasing COVID-19 vaccinations and reducing COVID-19 hospitalizations.



- Interfaced with patient subject matter experts to discover patient barriers to the COVID-19 vaccination and boosters.
- Prepared and disseminated resources via social media that supported the benefits of the COVID-19 vaccination and booster shots.



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 2021. KCER 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 2021 activities are highlighted in this section.



The National KCER Patient and Family Engagement (N-KPFE) LAN was convened. It included 25 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 Quality Improvement Activity (QIA) with two resources called [KCER Communications Plan—Dialysis](#) and [KCER Communications Plan—Transplant](#). The two wallet-sized resources were designed to assist dialysis and kidney transplant patients with having vital information on hand in the event of 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. The Basecamp platform allowed the KCER team to pose questions and discussion topics to the N-KPFE-LAN members on issues impacting the ESRD community to help ensure that the patient voice was incorporated into all KCER activities. 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 posting resources on a facility bulletin board, and sharing printed resources at the facility.

KCER was initially activated on March 2, 2020, when response activities related to COVID-19 began. The team remained partially activated through the contract Base Period in response to the COVID-19 pandemic. Throughout that time, KCER coordinated national-level preparedness and response activities, including leading monthly 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 January 1, 2021—December 31, 2021, the KCER team coordinated 13 monthly 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, KCER submitted a total of 53 incident reports to CMS related to COVID-19. Additionally, KCER, in coordination with the 18 ESRD Networks and ESRD NCC, provided weekly COVID-19 Emergency Situational



Status Reports (ESSRs) to CMS, CMS EPRO, and HHS ASPR, which included a nationally compiled report of all outpatient dialysis COVID-19 case data from the National Healthcare Safety Network (NHSN) Outpatient Dialysis COVID-19 Module.

During 2021, the KCER Program responded to two additional major events during the COVID-19 pandemic. KCER was activated from February 13 to February 22, 2021, in response to Winter Storm Uri and again from August 27 to September 17, 2021, in response to Hurricane Ida. 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 Winter Storm Uri and Hurricane Ida, 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 Winter Storm Uri and Hurricane Ida. The information was updated daily during the response to Winter Storm Uri and Hurricane Ida, utilizing the dialysis facility operational status information tracked by the KCER Program.



List of Data Tables

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- Table 2: Grievances and Non-Grievances by Case Type, Number, and Percent – Calendar Year 2021
- Table 3: National ESRD Patient Data Overview 2021

Table 1. Medicare-Certified Dialysis Facilities – Modality Offered – Calendar Year 2021

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	79	4	203	218
2	14	142	204	15	361	375
3	4	142	107	8	257	261
4	20	175	174	19	368	388
5	13	193	240	32	465	478
6	10	322	437	53	812	822
7	11	264	243	33	540	551
8	10	142	317	37	496	506
9	14	275	337	48	660	674
10	9	108	184	59	351	360
11	21	188	310	38	536	557
12	12	146	180	21	347	359
13	9	145	197	15	357	366
14	24	315	422	46	783	807
15	15	166	208	17	391	406
16	7	138	96	9	243	250
17	6	95	195	48	338	344
18	13	185	230	46	461	474
NATIONAL	227	3,261	4,160	548	7,969	8,196

Table 2. Grievances and Non-Grievances by Case Type, Number, and Percent – Calendar Year 2021

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	Percent of National Non-Grievance Cases
1	17	20	*	165	30	*	239	44	4.78%	195	4.82%
2	33	26	*	163	64	*	288	61	6.62%	227	5.61%
3	*	20	*	39	33	*	94	22	2.39%	72	1.78%
4	17	13	*	32	39	*	111	40	4.34%	71	1.75%
5	34	23	14	167	129	*	367	71	7.71%	296	7.32%
6	53	35	*	235	133	*	458	90	9.77%	368	9.10%
7	16	56	13	299	84	*	468	85	9.23%	383	9.47%
8	13	30	*	62	33	*	141	46	4.99%	95	2.35%
9	26	21	*	181	65	*	296	50	5.43%	246	6.08%
10	18	*	*	92	102	*	225	31	3.37%	194	4.79%
11	*	37	*	333	99	*	483	51	5.54%	432	10.68%
12	19	*	*	104	78	*	218	36	3.91%	182	4.50%
13	*	14	*	30	30	*	84	24	2.61%	60	1.48%
14	24	32	12	107	53	*	229	68	7.38%	161	3.98%
15	*	13	*	44	25	*	90	21	2.28%	69	1.71%
16	*	*	18	75	38	*	142	29	3.15%	113	2.79%
17	22	27	*	391	47	*	493	55	5.97%	438	10.83%
18	15	62	20	387	54	*	541	97	10.53%	444	10.97%
National	323	451	147	2,906	1,136	*	4,967	921	--	4,046	--

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

** New case type added since June 2021.

Table 3. National ESRD Patient Data Overview 2021

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	203	2.55%	15	4.64%	14,786	2.86%	12,630	2,156	2.73%	12,514	4.64%	27,300
2	361	4.53%	14	6.76%	29,036	5.62%	26,322	2,714	3.43%	18,222	6.76%	47,258
3	257	3.22%	4	2.37%	20,709	4.01%	18,551	2,158	2.73%	6,398	2.37%	27,107
4	368	4.62%	20	4.92%	19,806	3.83%	16,806	3,000	3.79%	13,244	4.92%	33,050
5	465	5.84%	13	6.29%	27,691	5.36%	23,393	4,298	5.44%	16,937	6.29%	44,628
6	812	10.19%	10	6.94%	50,158	9.70%	42,454	7,704	9.74%	18,704	6.94%	68,862
7	540	6.78%	11	5.82%	33,048	6.39%	27,918	5,130	6.49%	15,676	5.82%	48,724
8	496	6.22%	10	4.27%	28,082	5.43%	23,645	4,437	5.61%	11,493	4.27%	39,575
9	660	8.28%	14	6.68%	32,698	6.33%	26,995	5,703	7.21%	18,002	6.68%	50,700
10	351	4.40%	9	3.99%	20,291	3.93%	16,183	4,108	5.20%	10,752	3.99%	31,043
11	536	6.73%	21	8.31%	28,763	5.56%	24,329	4,434	5.61%	22,382	8.31%	51,145
12	347	4.35%	12	4.61%	16,561	3.20%	13,414	3,147	3.98%	12,424	4.61%	28,985
13	357	4.48%	9	2.91%	20,397	3.95%	17,123	3,274	4.14%	7,831	2.91%	28,228
14	783	9.83%	24	8.20%	53,639	10.38%	46,186	7,453	9.43%	22,099	8.20%	75,738
15	391	4.91%	15	6.46%	26,827	5.19%	22,654	4,173	5.28%	17,413	6.46%	44,240
16	243	3.05%	7	3.41%	15,829	3.06%	12,880	2,949	3.73%	9,180	3.41%	25,009
17	338	4.24%	6	5.73%	30,577	5.92%	25,572	5,005	6.33%	15,447	5.73%	46,024
18	461	5.78%	13	7.69%	48,031	9.29%	40,803	7,228	9.14%	20,706	7.69%	68,737
NATIONAL	7,969	--	227	--	516,929	--	437,858	79,071	--	269,424	--	786,353