



End-Stage Renal Disease
Network of New England

2020 Annual Report



Connecticut State Capital, Hartford, CT

June 2021
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Submitted to:
U.S. Department of Health and Human Services (HHS)
Centers for Medicare & Medicaid Services (CMS)
for Contract Number HHSM-500-2016-00019C

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ESRD DEMOGRAPHIC DATA

IPRO ESRD Network of New England (Network 1) is one of four ESRD Networks managed by IPRO, a non-profit organization that works with government agencies, providers, and consumers to implement innovative programs that improve healthcare. In addition to serving as Network 1, IPRO manages the ESRD Network of New York (Network 2), ESRD Network of the South Atlantic (Network 6), and ESRD Network of the Ohio River Valley (Network 9), collectively known as the IPRO ESRD Network Program. IPRO is fully committed to the goals and vision of the ESRD Network Program and supports the renal community in ensuring safe, effective, patient-centered care for the more than 130,000 renal patients in the four Network areas it manages.

Network 1 serves ESRD patients, dialysis providers, and transplant centers in the states of Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont. The role of Network 1 is to improve the quality of care for people who require dialysis and/or transplantation, for ESRD. The Network aligns its mission and activities with the National Quality Strategy's three broad aims and CMS' priorities for the ESRD Network Program. Our goals, our methodology for attaining them, and our achievements are described throughout this report.

New England's 14.9 million residents are distributed over approximately 72,000 square miles. Its six states differ widely in terms of geography, population density, and socio-economic factors, all of which influence the availability of services, treatment choices, and quality of care for ESRD patients. For example, Maine is the largest New England state but it has the lowest population density, which presents a challenge for ESRD patients who may have to travel long distances to reach the nearest dialysis facility.

Of the total population of New England in 2020, 77.36% resided in the three southernmost states (Connecticut, Massachusetts and Rhode Island), which also have the greatest number of metropolitan areas. The remaining 22.64% resided in the three northernmost states (Maine, New Hampshire and Vermont), which are primarily urban and rural and had the fewest dialysis facilities.

According to the U.S. Census Bureau estimates for 2020, New England's population was 83.81% white, 7.95% African American, 5.19% Asian, 0.56% American Indian and Alaska Native, and 2.49% other. The Latino population represented 11.38% of the population. With the exception of African American and white ESRD prevalent patients in 2020, at 21.79% and 73.78% respectively, data for the remaining U.S. Census Bureau populations closely aligned with the distribution of ESRD patients in New England.

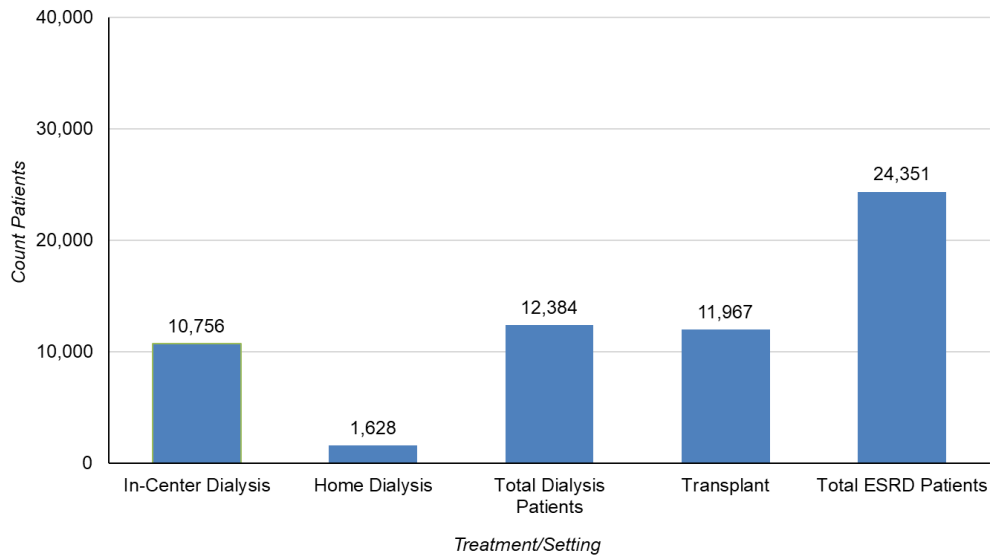
The ESRD population in the Network's service area was the second smallest in the country as of December 31, 2020, according to ESRD National Coordinating Center (NCC) end-of-year data. As of December 2020, 15,249 prevalent patients were reported as receiving dialysis treatment from facilities in the Network service area. This is a 0.26% increase from 15,210 patients dialyzing in 2019. There were 2,891 incident patients in 2020, which is a 30.29% decrease from the 4,147 patients that started treatment in 2019. These patients were served by 205 Medicare-certified dialysis facilities, which included four Veterans Affairs (VA) hospitals and 15 transplant centers. Despite the decrease in patient population during 2020, the number of operating Medicare-certified dialysis facilities in the New England region increased by 2.5%, from 200 in December 2019. One hundred forty-two (69.27%) dialysis facilities in the Network's service area provided evening services in 2020. Access to care after normal business hours can greatly improve quality of life for ESRD patients who are able to work full-time while receiving treatment.

In 2020, the Network worked in collaboration with its Network Council, Medical Review Board, Patient Advisory Committee, Grievance Committee, and Network activity-specific committees to develop quality

improvement projects aligned with the goals identified by CMS for the ESRD Network program. The Network worked closely with ESRD patients, patients' family members and care partners, nephrologists, dialysis facilities and other healthcare organizations, ESRD advocacy organizations, and other ESRD stakeholders to improve the care for ESRD patients throughout New England.

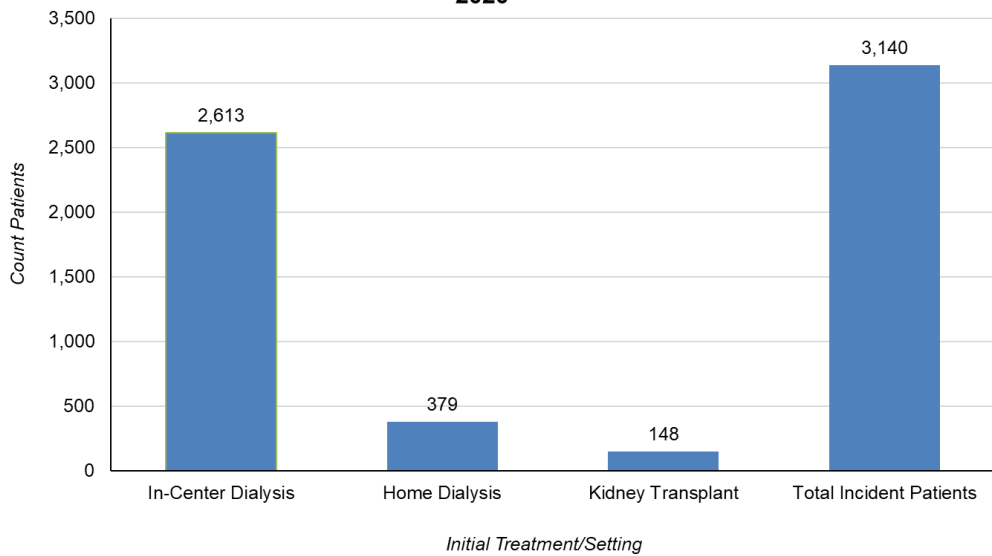
The Network deployed interventions that targeted patients, dialysis and transplant providers, and other stakeholders. These interventions, which focused on engaging patients, reducing disparities, and improving quality of care for ESRD patients are detailed in this report.

**Network 1: Count of Prevalent ESRD Patients by Treatment/Setting
2020**



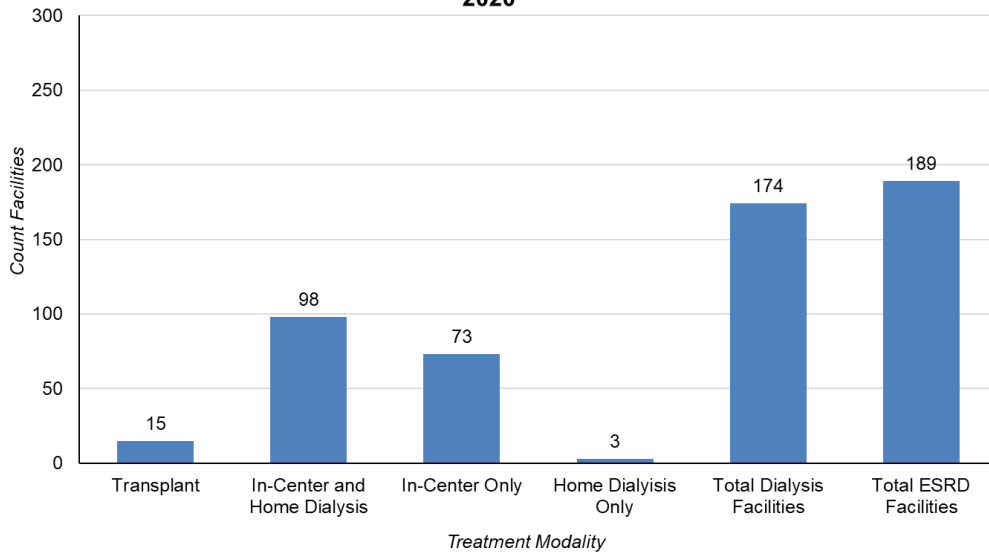
Total Dialysis Patients = In-Center Dialysis + Home Dialysis
 Total ESRD Patients = Transplant + Total Dialysis
 SNF dialysis patients are not shown due to small numbers.
 Source of data: [EQRS accessed May 13, 2021 \(Data is not final\)](#)

**Network 1: Count of Incident ESRD Patients by
Initial Treatment/Setting
2020**



Total Incident Patients = In-Center + Home + Kidney Transplant
 Source of data: [EQRS accessed May 13, 2021 \(Data is not final\)](#)

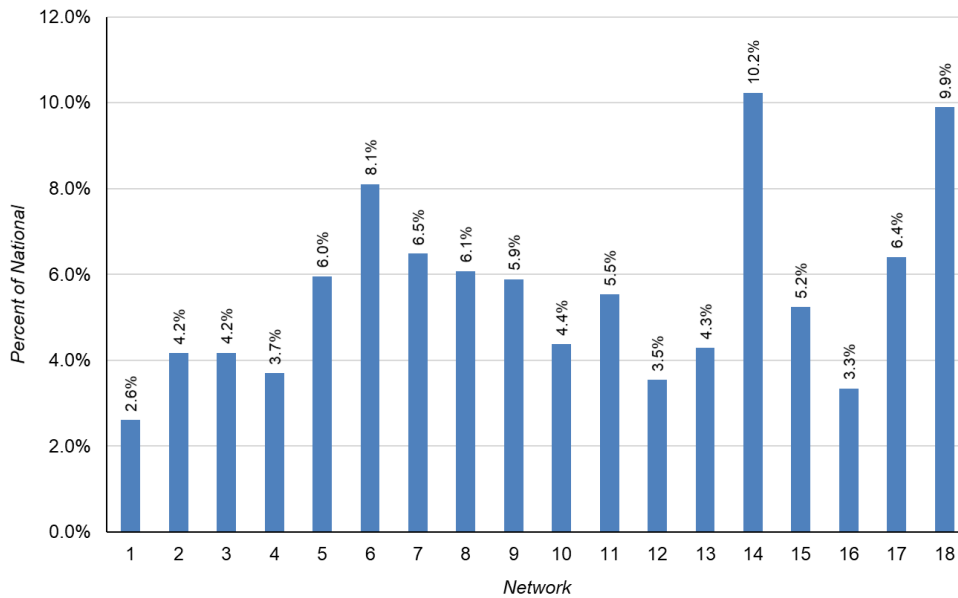
Network 1: Count of Medicare-Certified Facilities by Treatment/Setting 2020



Total Dialysis Facilities = In-Center and Home Dialysis + Home Dialysis Only + In-Center Only
 Total ESRD Facilities = Transplant + Total Dialysis Facilities

Source of data: EQRS accessed May 13, 2021 (Data is not final)

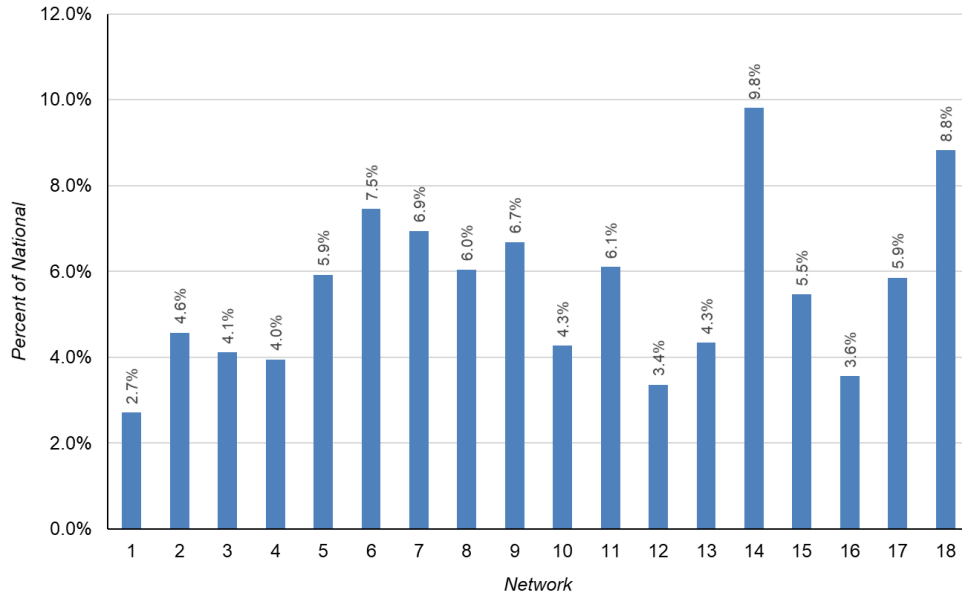
Percent of National Prevalent Dialysis Patients by ESRD Network 2020



National total dialysis patients: 473,780

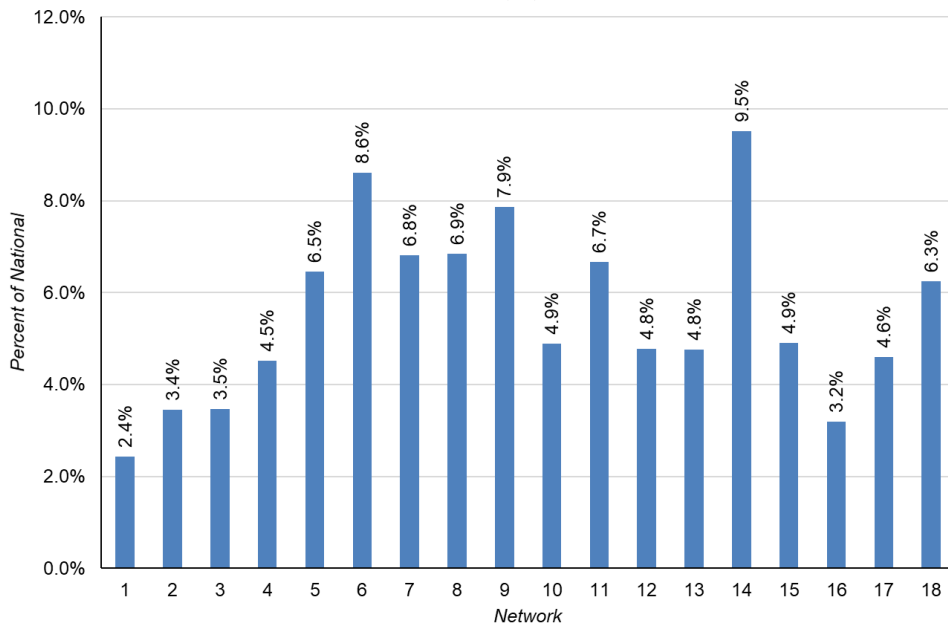
Source of data: EQRS accessed May 13, 2021 (Data is not final)

Percent of National Incident Dialysis Patients by ESRD Network 2020



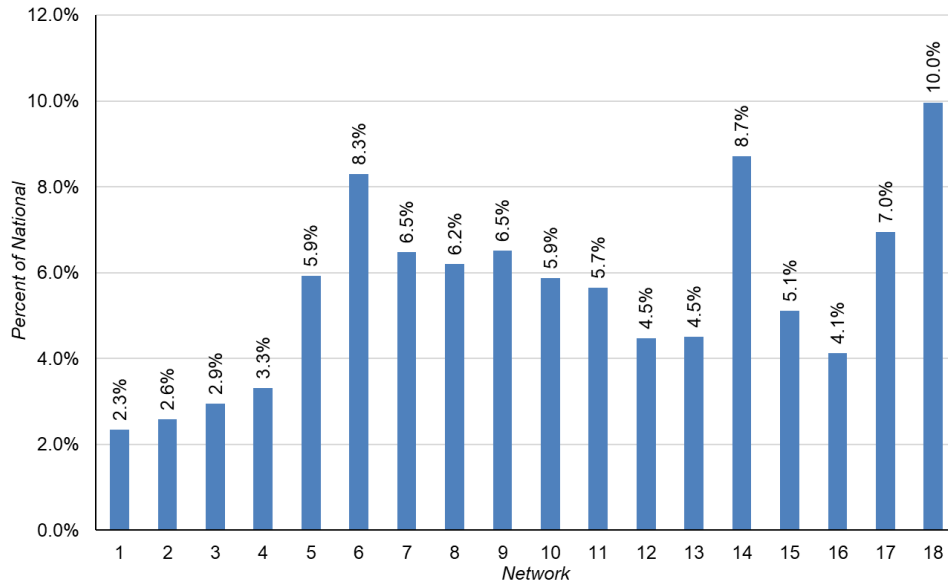
National total incident patients: 115,623
 Source of data: EQRS accessed May 13, 2021 (Data is not final)

Percent of Medicare-Certified Dialysis Facilities by ESRD Network 2020



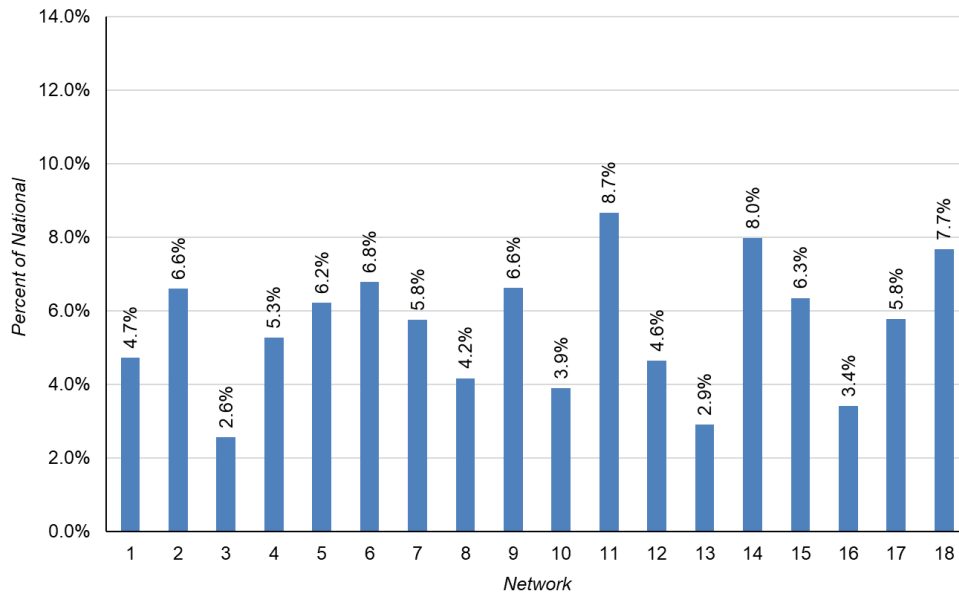
National total ESRD Medicare-certified dialysis facilities: 7,167
 Source of data: EQRS accessed May 13, 2021 (Data is not final)

Percent of National Home Hemodialysis and Peritoneal Dialysis Patients by ESRD Network 2020



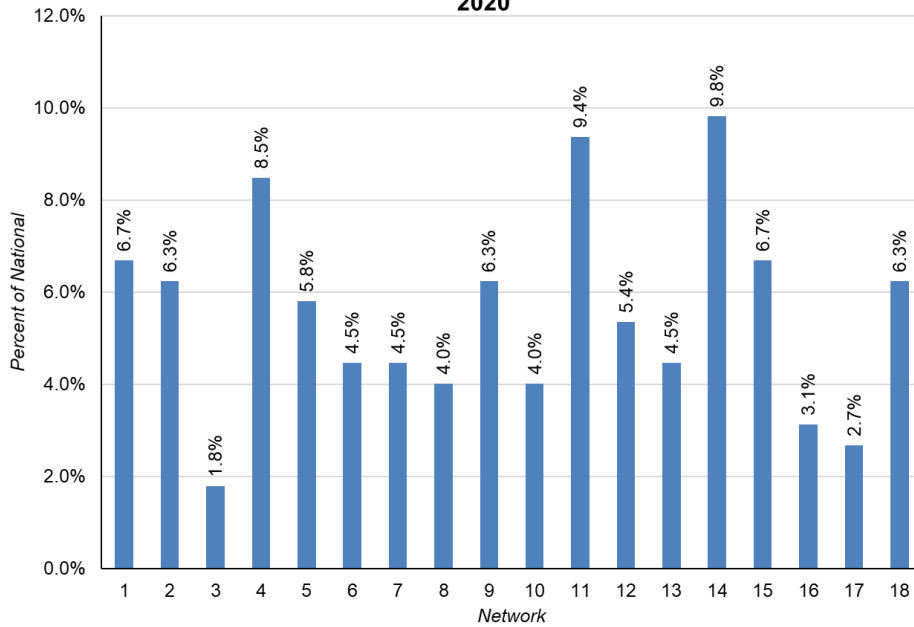
National total home hemodialysis and peritoneal dialysis patients: 69,318
 Source of data: EQRS accessed May 13, 2021 (Data is not final)

Percent of National Transplant Patients by ESRD Network 2020



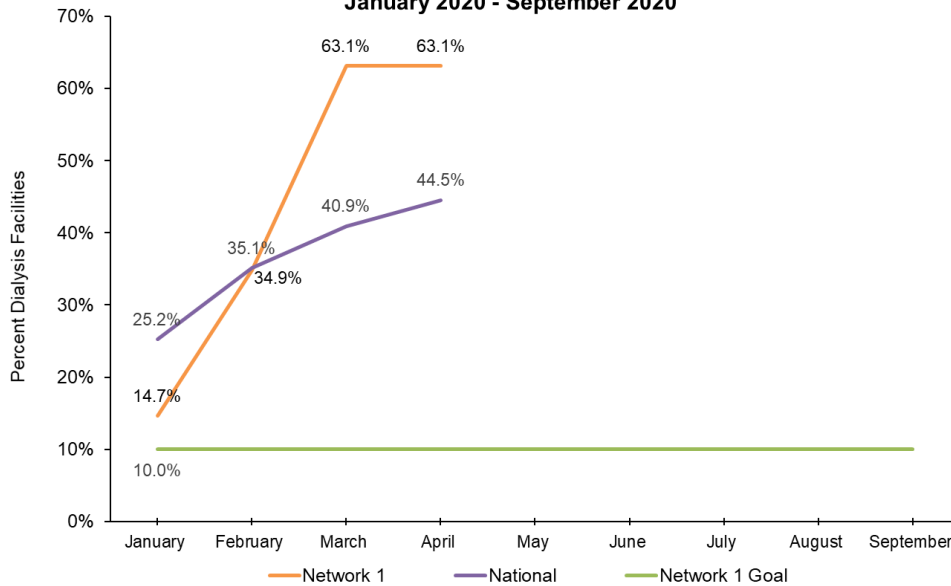
National total transplant patients: 253,527
 Source of data: EQRS accessed May 13, 2021 (Data is not final)

Percent of Medicare-Certified Kidney Transplant Facilities by ESRD Network 2020



National total ESRD Medicare-certified kidney transplant facilities: 224
 Source of data: EQRS accessed May 13, 2021 (Data is not final)

Network 1: Percent of Dialysis Facilities with a Health Information Exchange or Evidence-Based Highly Effective Information Transfer System January 2020 - September 2020



Source of data: ESRD NCC 2020 Dashboard accessed March 2021

ESRD NETWORK GRIEVANCE AND ACCESS TO CARE DATA

I PRO ESRD Network of New England responds to grievances filed by or on behalf of ESRD patients in Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island and Vermont with a goal to address and mitigate concerns.

According to CMS, a grievance is defined as “A written or oral communication from an ESRD patient, and/or an individual representing an ESRD patient, and/or another party, alleging that an ESRD service received from a Medicare-certified provider did not meet the grievant’s expectations with respect to safety, civility, patient rights, and/or clinical standards of care.” Case review activities fall into three categories: 1) Facility Concerns, 2) Grievances, which has three subcategories, and 3) Access to Care, which has two sub-categories.

A facility concern is 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. An “immediate advocacy” is a case of a simple, generally non-quality of care nature that can be completed in seven calendar days or less. A general grievance is a case of a more complex nature than an immediate advocacy, that does not involve clinical quality of care issues and that cannot be resolved within seven calendar days. A clinical quality of care (QoC) grievance involves situations in which the grievant alleges that an ESRD service received from a Medicare-certified provider did not meet professionally recognized standards of clinical care.

Access to Care and Involuntary Discharge (IVD) Cases

The Network works with individual facilities to identify and address difficulties in placing or maintaining patients in treatment. These “Access to Care” cases may come to the Network’s attention in the form of a grievance filed by or on behalf of the patient.

There are three types of Access to Care cases: involuntary transfers, involuntary discharges, and failures to place. Involuntary transfer occurs when a facility closes, either temporarily or permanently, requiring the patient to be transferred to another facility. Involuntary transfers may also occur when a patient is transferred to another facility due to having created safety concerns by exhibiting threatening or abusive behavior. An involuntary discharge is initiated by the treating dialysis facility without the patient’s agreement. Failure to place occurs when all local outpatient dialysis facilities have denied the patient acceptance for routine dialysis treatment.

In 2020 the Network addressed a total of 280 cases; one hundred eight (108) access to care cases, 15 patient grievance cases that were reported, 22 Immediate Advocacy cases, three Quality of Care cases and 135 cases involving facility concerns. For cases involving access to care and IVD, the Network promoted the option of the Second Chance program, which was successfully implemented with the respective state agency, and with regular and frequent updates provided to CMS.

In most of the reported cases the discharge was immediate due to a severe threat. The Network worked closely with each facility to ensure that staff provided the required care after discharge. The Network also encouraged facility staff members to continue supporting the patients even after discharge, by aiding in the referral to new facilities and by assisting in identifying new placements for the patients. All cases were based on actual physical harm or severe threat of physical harm. The Network responded to facility requests to discuss the disruptive behavior of patients and provided interventions to assist facilities with de-escalation techniques. The Network also provided educational resources about grievances and patient rights.

The Network guided facilities in reviewing practices in place to support patients and, when appropriate, recommended new approaches. Network recommendations focused on involving patients and their families in their care from the moment of admission. The Network advised facilities to pay particular attention to patients who isolate themselves and to those who do not have significant support in their lives, with a goal to find ways to provide these patients with additional support.

Technical assistance and guidance continued as the Network assisted facility staff in addressing issues related to non-adherence, behavioral concerns, mental health and potential loss of access to care. The Network provided technical assistance and consultation that addressed issues such as non-compliance with treatment and management of disruptive patients and those with other psychosocial concerns. Facilities were encouraged to look at all dimensions of patient care to determine the root cause for any patient's concerning behavior. Care conferences were often utilized as a tool for the facility and patient to come to consensus and resolution. These conferences created a safe environment for the patient to verbalize their concerns and request clarification on several aspects of their treatment, with a focus on encouraging patients to become engaged in their care as a strategy to improve patient understanding of their responsibilities as a kidney patient and ultimately to improve their health outcomes.

Network Assistance and Quality Improvement

For each of the cases described above, the Network advocated for patients, promoting the rights of patients to participate in their health care and to have a voice about services provided by the facility. The Network mediated cases regarding patients' concerns with the facility. Interventions were developed and implemented to provide facility staff with guidance on communication techniques that would better support their patients' care. In many cases the Network discussed with facility staff:

- The importance of establishing professional boundaries with patients;
- The value of patient centered care, reminding staff that understanding what matters to the patient is a critical first step in understanding how to best assist in his or her care;
- The importance of identifying patients' barriers that might limit their ability to comply with prescribed treatment plans (e.g. unaddressed mental health issues, lack of housing, immigration status, lack of health insurance). This assists staff in establishing goals that will be meaningful and helpful for each patient.

In addition, the Network provided patients and facilities with the following resources:

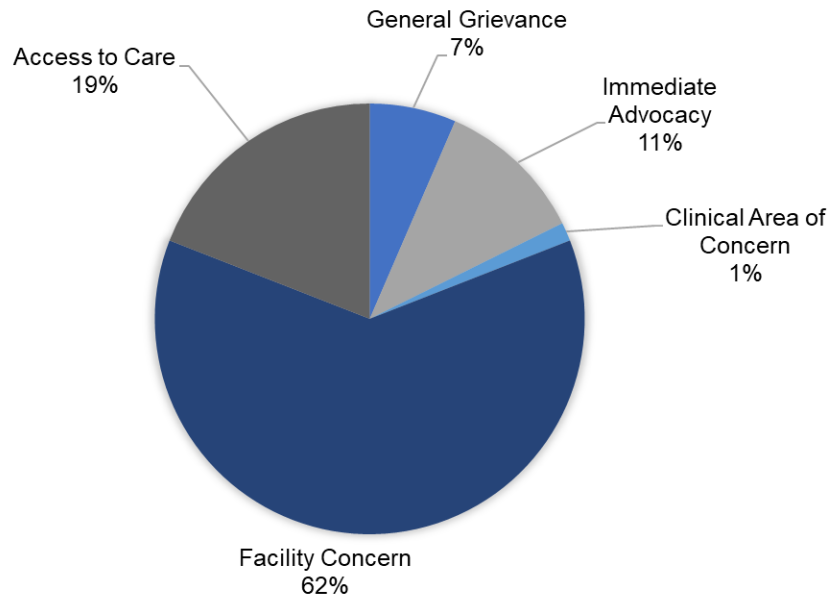
- The *Dialysis Patient Grievance Toolkit* created by the Kidney Patient Advisory Council (KPAC) of the Forum of ESRD Networks includes resources to support patients' understanding of how and when to escalate issues to a grievance;
- Grievance preparation worksheets and a poster create awareness of the resources available, with a focus on improving communication early in the grievance process;
- A poster and flyers (*What the Network Staff Can and Cannot Do*) that outline clearly defined parameters of the support that the Network could provide, as well a clear understanding of the types of support that the Network could not provide.
- A Network developed Peer Mentoring Bingo Game distributed to all dialysis facilities to encourage interaction between patients and peer to peer support for patients who experience challenges adjusting to the facility
- Telehealth toolkit for providers and patients to help educate the renal community of this option as a best practice to help prevent the spread of COVID-19
 - *Telehealth for ESRD Providers* Handout
 - *Benefits of Telehealth for ESRD Patients* Handout
 - *Telehealth Visit Checklist* for patients

The Network learned early on that transportation was a significant problem for COVID-19 patients; the transportation services in MA and CT were very fragmented and non-existent in certain areas (unable to cross county lines). Historically, the states that comprise the Network 1 service area have had a low incidence of natural disasters. The lack of natural disasters prevented emergency management services from being prepared to mitigate emergency response specifically related to transportation within the dialysis community. It wasn't until CMS put waivers in place that gave non-emergent ambulance services the needed mobility to transport COVID-19 patients, were they able to offer the training and supplies to care for these patients. While this measure helped for a time it led to ambulance services being stretched thin as COVID-19 cases increased. Network1 strived to get PT-1 transit and ride share programs back up and running to allow for more patients to get to their dialysis treatments. This included working with transport companies to get PPE for drivers and supplied them with cleaning and vehicle disinfection procedures. This information was disseminated to DPH, OEM, Boston DPH, and the transport companies: Veyo and Logisticare.

The utilization of telehealth has been valuable in sustaining access to care, while providing a safe way for patients to connect with their healthcare team. While this has been significant for the prevention of COVID-19 spread, the use of telehealth has also assisted patients in overcoming transportation challenges for initial or follow up appointments related to home modality and transplant evaluations. This was particularly true for patients in rural areas where there is a substantial distance barrier to access these services. It should be noted that patients are not always comfortable nor do they always have access to equipment to support telehealth. In 2020, the Network developed resources and educational training to support patients using technology platforms to support telehealth utilization.

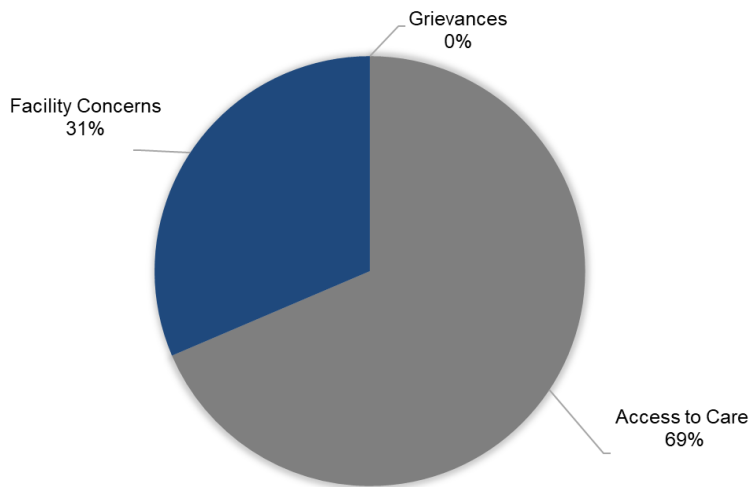
With the onset of the COVID pandemic, it has become evident that our ESRD community, especially those patients residing in skilled nursing homes, are the most vulnerable to illness and injury. Since not all nursing home ESRD patients are candidates for a transplant, expanding the awareness of home therapy options for this population helped to increase the sense of safety and comfort, and thereby reduce potential infections risks.

**Network 1: Percent of Grievances and Non-Grievances
by Case Type
December 2019 - December 2020**



Source of data: Patient Contact Utility (PCU) accessed April 2021

**Network 1: Percent of Mental Health Related
Grievances and Non-Grievances by Case Type
May 2020 - December 2020**



Grievances include Immediate Advocacy, General Grievance, and Clinical Quality of Care
Source of data: Patient Contact Utility (PCU) accessed April 2021

ESRD NETWORK QUALITY IMPROVEMENT ACTIVITY DATA

Long Term Catheter Quality Improvement Activity

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.

Project Overview

Infections are the second leading cause of death in patients with end-stage renal disease (ESRD). The majority of these infections stem from catheter-related bloodstream infections. Patients with long term catheters (LTC) are defined as patients with a catheter in use for dialysis treatments for 90 days or longer. As a result, the Network developed a QIA plan to decrease blood stream infections to assist dialysis facilities in the implementation of the CDC Core Interventions, improving communication between points of care, and reducing the rate of long-term catheters for dialysis access. In 2020 the Network planned to utilize the Achievable Benchmark of Care (ABC™) model to decrease the LTC rate in the Network service area by at least 0.25%. Network 1 baseline line data was 11.66% which was below the national average of 11.99%. The Network met the target goal from baseline during the months of January and February; however, the COVID-19 pandemic created challenges in scheduling surgical procedures to remove LTCs and replace them with permanent access types. As a result, the rate of in-use catheters continuously increased during the months of March through August. Network 1 noted LTC rates at 14.12% which were equivalent to national rates based on data available in September (July 2020).

Interventions

Network staff worked with target facilities to identify knowledge gaps, increase accurate reporting of central venous catheters (CVC), and improve communication with vascular surgeons throughout the region, communicate with regional operations directors, quality improvement personnel and other key stakeholders to increase participation and movement toward goal.

Based on the ABC model, target facilities had LTC rates greater than the 10% in the QIP threshold, as well as a patient census of 50 or more. CROWNWeb data reports were produced by the ESRD National Coordinating Center (NCC) for Long Term Catheter (LTC) reporting

Network interventions included:

- Distribution of educational materials and resources on infection prevention and hand washing from the Centers for Disease Control and Prevention (CDC)
- Inviting all providers in the NSA to participate in the ESRD NCC Learning and Action Network (LAN) calls on increasing permanent vascular access placement strategies were offered during the months of January and March of 2020.
- Distributed the Vascular Planning Guide for Professionals
- Requested that facilities display the Infection Prevention Catheter Countdown poster
- Monthly facility report cards were distributed to facilities so they could track progress in quality improvement projects
- Mailing of patient educational resources that included the *Vascular Access for Hemodialysis* Poster.
- Catheter countdown dry erase poster
- Network 1 developed the Monthly Activities Calendar and upcoming events included in all hard copy mailings and emailed to help facilities plan for upcoming QIA events
- “Ready, Set, Go” *The Steps to Catheter Freedom: Graft Healing & Readiness Check*
- “Ready, Set, Go” *The Steps to Catheter Freedom: Fistula Maturity Check*

- We're on the Right Track to Leave Healthcare-Associated Infections Behind
 - *It Only Takes a Minute to Save Your Patient's Lifeline*

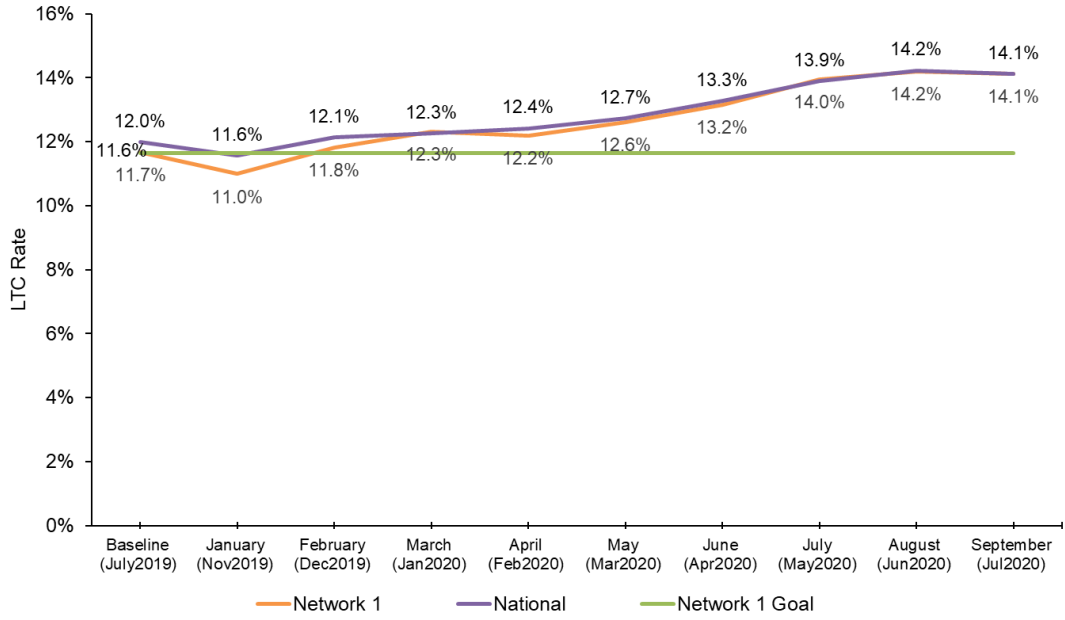
Barriers to achieving goals

Starting in March 2020, the Network noted that secondary to the pandemic, access interventions were being delayed, postponed and cancelled in an effort to reduce the spread of the COVID- 19 virus. The Centers for Medicare & Medicaid Services (CMS) released information in April that clarified what should be considered as essential procedures, noting that dialysis access interventions are essential. This directive described that all services related to access intervention should be continued. While CMS suspended the goal to reduce LTC rate in the Network service area by at least 0.25% the Network continued to provide educational materials to patients and dialysis facility staff in an effort to decrease LTCs.

Best practices spread to achieve goals

To address the hesitancy in the surgical community regarding the necessity of access interventions, Network 1 distributed the CMS notice on the essential nature of access intervention to all listed access surgeons, hospitals, nephrologists and dialysis centers with a clarifying letter created in partnership with the Network's Medical Board of Directors, which pushed the definition of the essential nature of access interventions. While this letter was intended to create awareness of the need in our community for access interventions, the Network still experienced a reduction in procedures. Network 1 continued to have a higher than anticipated LTC rate which was comparable to national levels and a direct consequence of the reduction of elective surgery secondary to limited access to PPE, surgical suite furloughs, and the reallocation of resources. Network 1 started to see an increase of access interventions in the August timeframe, however these were considered "backlogged" procedures.

Network 1: Long-Term Catheter Rates January 2020 - September 2020



X-axis: Reporting Month (Data Month)
 QIA: Quality Improvement Activity
 Source of data: ESRD NCC 2020 Dashboard accessed March 2021

Blood-Stream Infection Quality Improvement Activity

Project Overview

The IPRO ESRD Network of New England supported the national initiative to reduce the rate of bloodstream infection (BSI) by 20% during this project period with an overarching goal of a 50% reduction of the 2016 BSI rate by 2023. To achieve this initiative, the Network planned to work with 20% of the facilities in the Network service area with the highest reported access infections. To align with the Centers for Medicare & Medicaid Services (CMS) End Stage Renal Disease (ESRD) Option Year 4 (OY4) Statement of Work (SOW) Making Care Safer by Reducing Harm Caused in the Delivery of Care Quality Improvement Activity (QIA) initiatives, IPRO ESRD Network of New England staff planned to work with the entire Network service area to accomplish both a reduction in bloodstream infections (BSI) and long-term catheters (LTC), while ensure that 90% of eligible facilities complete the 2020 annual National Healthcare Safety Network (NHSN) training. The Network continued to demonstrate a decrease of 0.09 percentage points (24.32%) in the BSI rate due to the dedicated efforts of Network staff and individual facilities related to infection prevention practices for COVID-19. The BSI rate observed from March through June 2019 was 0.37%, while the BSI rate observed from March through June 2020 was 0.28%

Interventions

The Network invited all Network services area facilities, departments of public health, long term care facilities and hospitals to attend bi-monthly Blood Stream Infection (BSI) Learning Action Network (LAN) activities hosted by the ESRD National Coordinating Center (NCC). The Network planned to collaborate with and engage patients, healthcare providers, and dialysis facility staff in the promotion and implementation of best practices shared during the event.

In addition to participation in LANs, Network staff provided tools and education to support facilities in conducting a root cause analysis (RCA) identifying the source of each BSI. Network staff also supported facilities in conducting Plan-Do-Study-Act (PDSA) cycles for all implemented interventions. Throughout the project, Network staff fostered a positive learning and sharing environment for dialysis patients and staff in target facilities. Patients were educated and empowered to participate in intervention activities at the facility and Network level.

Network interventions included:

- Reduce LTCs and increase sepsis awareness and early intervention
- Assure ESRD facility completion of NHSN education
- Identify and sharing of BSI reduction best practices with the following:
 - Visit the Dialysis Safety section on the CDC website
 - Conduct an Infection Control Assessment to identify gaps in Dialysis Prevention Process Measures (PPM) Protocol
 - *Test Your Hand Hygiene Knowledge Interactive Tutorial*
 - Monitor Days Since Last Bloodstream Infection (BSI)
 - Complete the Annual National Healthcare Safety Network (NHSN) Dialysis Event Surveillance Training
- The creation of patient-centered care protocols and engagement opportunities, by facilitating communication opportunities between healthcare settings and providers to share Positive Blood Cultures (PBC) and increasing the utilization of an approved HIE to share PBC
- Network 1 developed the Monthly Activities Calendar and upcoming events included in all hard copy mailings and emailed to help facilities plan for upcoming QIA events

Barriers to achieving goals

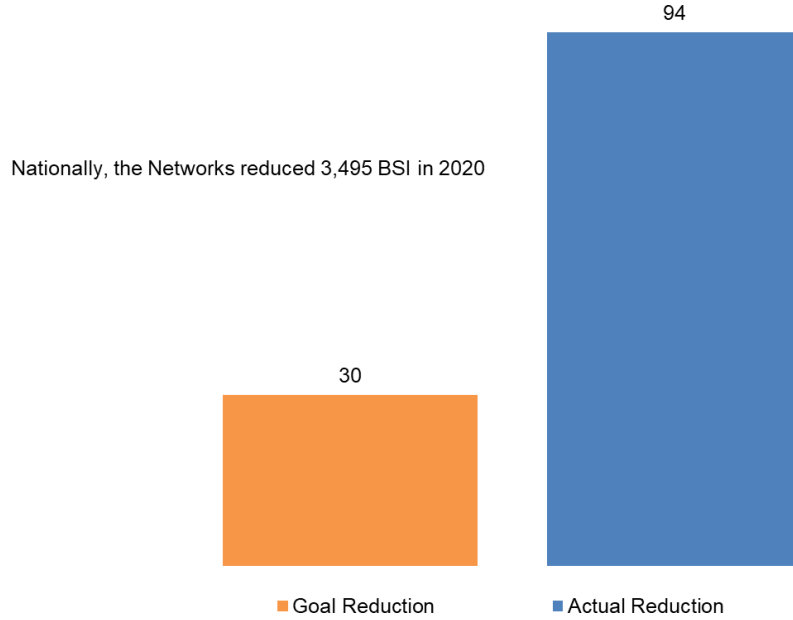
Infections are the second leading cause of death in patients with end-stage renal disease (ESRD). The majority of these infections stem from catheter-related bloodstream infections. Starting in March 2020 moving into April and May it was noted that secondary to the pandemic, access interventions were being severely delayed, postponed and cancelled in an effort to reduce the spread of the COVID19 virus. Centers for Medicare & Medicaid Services (CMS) released information in April that clarified what procedures were considered as essential, stating that access intervention was indeed essential and all services should be continued. While CMS suspended the goal to reduce LTC rate in the Network service area by at least 0.25% the Network continued to provide educational materials to the patients and dialysis facility staff in an effort to decrease LTCs.

Best practices spread to achieve goals

While NHSN training was suspended by CMS, the Network identified an opportunity to promote the use of the essential theory of CDC Core interventions with the CORE Knowledge to Prevent Transmission of COVID as outlined by the Centers for Disease Control and Prevention that included a survey that assessed facilities on CORE interventions Knowledge. Network 1 had a 96% response rate of acknowledgement and use of CORE interventions. The CORE Interventions focused on:

- Screening/Triage Procedures to Minimize Exposure Adherence to Standard and Transmission Based Precautions
- Hand Hygiene
- Personal Protective Equipment
- Patient Placement
- Appropriate Surface Disinfection
- Management of Visitor Access and Movement Within the Facility
- Reporting COVID 19+ to Local and State Health Authorities
- How to appropriately discontinue transmission based precautions
- Use of telemedicine in caring for home dialysis patients

Network 1: Reduction in Bloodstream Infections (BSI) in QIA Facilities

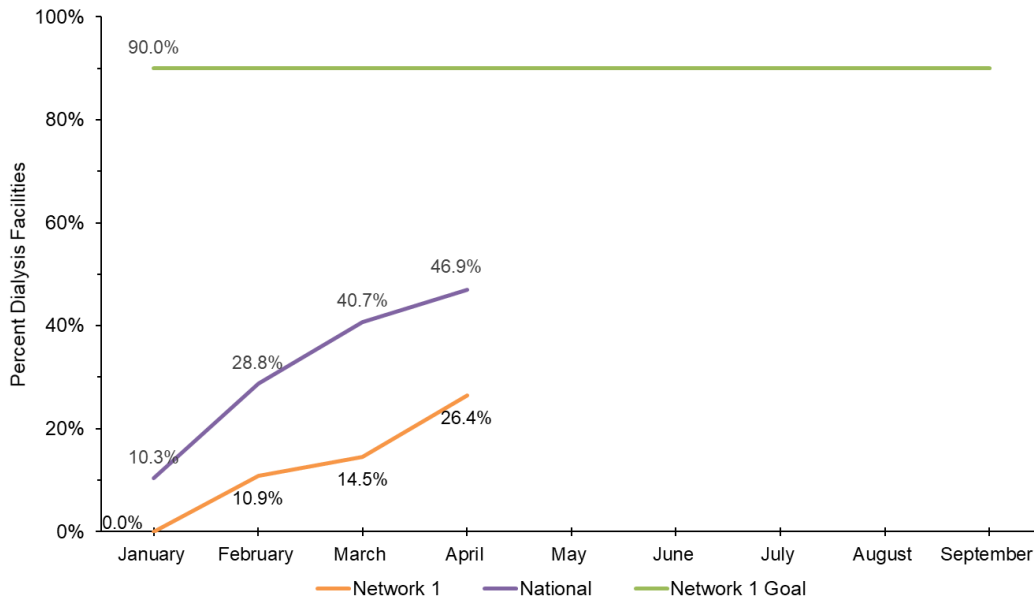


The Network goal was to decrease the rate of BSI by 20% or greater relative reduction in the pooled semi-annual mean in facilities participating in the QIA

QIA: Quality Improvement Activity

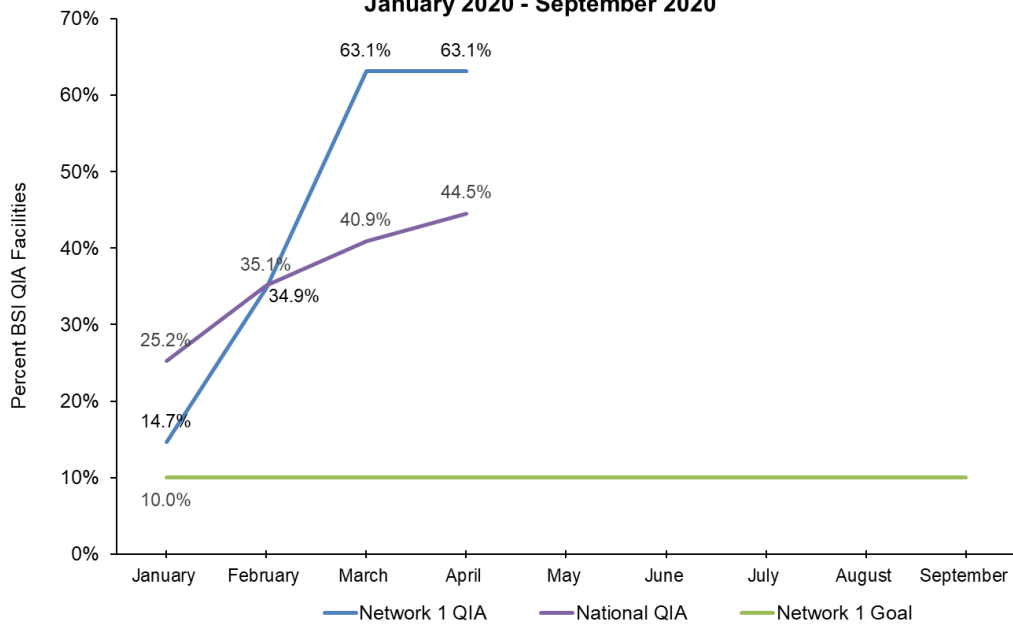
Source of data: National Healthcare Safety Network (NHSN) January 2020 - June 2020 compared to January 2019 - June 2019

**Network 1: Percent of Dialysis Facilities with At Least One Person Who Has Completed the NHSN Dialysis Event Surveillance Training
January 2020 - September 2020**



Source of data: ESRD NCC 2020 Dashboard accessed March 2021

**Network 1: Percent of BSI QIA Facilities with a Health Information Exchange or Evidence-Based Highly Effective Information Transfer System
January 2020 - September 2020**



QIA: Quality Improvement Activity

BSI: Bloodstream Infection

Source of data: ESRD NCC 2020 Dashboard accessed March 2021

Transplant Waitlist Quality Improvement Activity

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.

Project Overview

Network 1 acts as a support and champion for patients regardless of age, gender, or ethnicity as well as those with common comorbid conditions, including diabetes and hypertension by supporting and advancing of the Executive Order on Advancing American Kidney Health (AAKH) goal for 2025 to have 80% of new ESRD patients either receiving dialysis at home or receiving a transplant. The Network's goal was to increase the number of patients on the United Network for Organ Sharing (UNOS) waitlist in the Network service area by at least 1.25%.

Using the Achievable Benchmark of Care (ABC™) model, the Network encouraged facilities to conduct Plan-Do-Study-Act (PDSA) for all implemented interventions, including those promoted by the ESRD NCC Transplant LAN. The Network applied human centered design (HCD) practices in the development of patient-centered activities, Quality Assessment Performance Improvement (QAPI), support groups, and patient plans of care.

The Network facilitated participation and collaboration across all healthcare entities to create a culture of support and knowledge about transplantation. Patient Ambassadors (PA), Patient Advisory Committee (PAC) members, and Patient Subject Matter Experts (PSMEs) were recruited to collaborate with the Network on the development of educational content and resource material. Additionally, patient feedback was requested to determine the effectiveness of implemented interventions. The Network team worked to achieve and surpassed that goal by achieving 23.37% of patients on the transplant waitlist which is above the national average of 15.23%.

Interventions

Network interventions included:

- Mailing of patient educational resources that included *Kidney Transplant Referral Guide* and the *Transplant Referral is an Option Regardless of your Age* poster.
- The Network invited all providers in the NSA to the ESRD NCC Learning and Action Network (LAN) Calls that were offered for transplant during the months of January and March of 2020.
- Facilities were encouraged to participate in the Education Station, Bulletin Board or Lobby Day Contest for patient education by including their Patient Facility Representative in the activity.
- Network staff continued to work on improving the transplant referral rate by improving communication between transplant centers and dialysis facility staff and providing resources to help patients move through the five steps to become listed on the transplant waitlist
- Network 1 developed the Monthly Activities Calendar and upcoming events included in all hard copy mailings and emailed to help facilities plan for upcoming QIA events

Even with the suspension of the goals of transplant in 2020 due to the pandemic, the Network continued to provide educational materials to patients and dialysis facility staff in an ongoing effort to increase the number of patients on the transplant waitlist. This included multiple webinars on the benefits of transplant with a focus on concerns surrounding the pandemic as well as new telehealth options to help patients keep the momentum towards being waitlisted.

- “Your Kidney Care During COVID-19: Transplant”- June
- “Optimizing Telehealth for Transplant” webinar.” -November
- “Webinar on Living Donation: Giving the Gift of Life” -December

The following resources to help patients and dialysis facilities to continue support of transplant as an option:

- The National Forum of ESRD Networks has released the “*ESRD Patient Transplant Toolkit: Is a Kidney Transplant Right for Me?*”
- “*Telehealth for Patients and Providers*”
- “*11 Things You Can Do to Get Ready for a Kidney Transplant During COVID-19*”
- “*Waitless - Shorten your wait for Kidney Transplant*” (patients and providers)
- “*A Kidney Transplant for Any Age*”

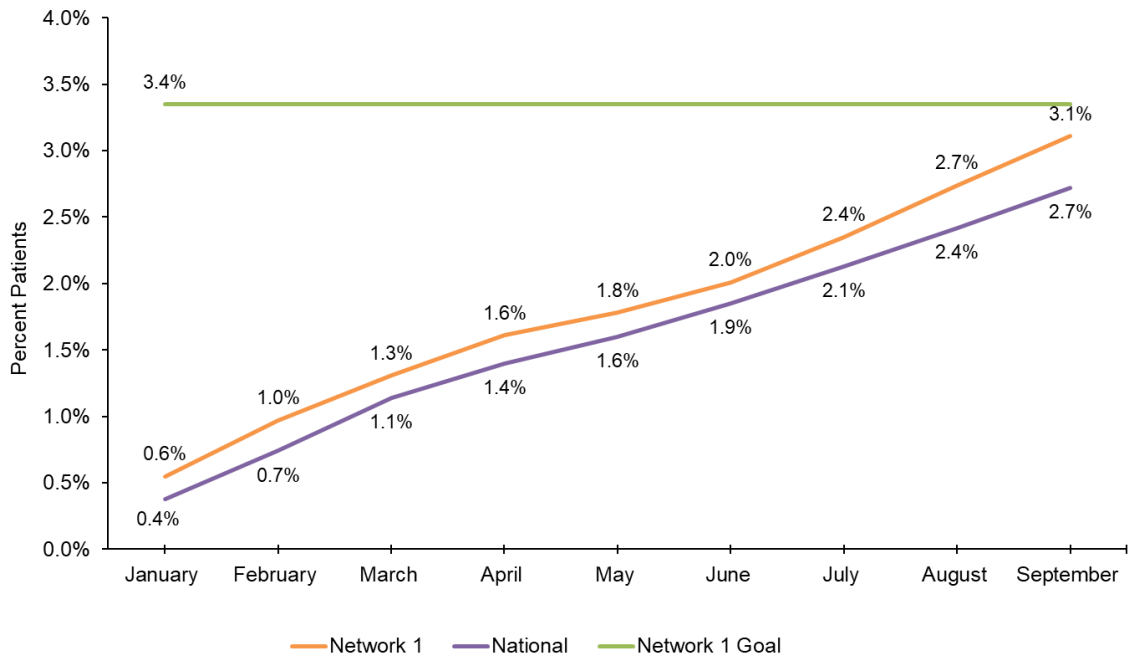
Barriers to achieving goals

While the pandemic halted broader national discussions on transplant with the NCC LANs, the Network was able to focus on supporting improved connections among our region’s transplant centers and dialysis facilities. The common barrier identified was the lack of a standardized communication process between stakeholders. This gap in communication is largely due to the high rate of staff turnover rate in dialysis centers and the different processes that each transplant center has for referral. The Network recognized this as a missed opportunity and sought to help streamline this process during 2021. It was also noted that Tacrolimus shortages were reported to the NSA transplant centers during the pandemic. Transplant center providers were able to provide alternative medications to prevent loss of transplanted kidneys, the Network created a website page with these medication resources

Best practices spread to achieve goals

Despite CMS’ suspension of the QIA goals, Network 1 added 636 patients to the transplant waitlist in 2020, exceeding our goal by 4.85% and saving the Medicare Program \$4.8M. This success was due in part to the rapid adoption by transplant centers of telehealth to continue educating and assessing patients toward the goal of kidney wait listing and transplantation during the pandemic. To support this the Network worked in collaboration with transplant centers, to offer a best practice webinar on the use of telehealth for transplant, which included the patient perspective. Early communication with transplant centers on changes of referral practice during the pandemic with the utilization of telehealth as well as continued education to all dialysis providers on these changing practices helped to keep interest and momentum towards our goals.

Network 1: Percent of Patients Added to the Transplant Waitlist January 2020 - September 2020



QIA: Quality Improvement Activity
Source of data: ESRD NCC 2019 Dashboard accessed March 2021

Home Therapy Quality Improvement Activity

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.

Project Overview

Network 1 supports and serves as a champion for patients regardless of age, gender, or ethnicity as well as those with common comorbid conditions, including diabetes and hypertension. This support is exemplified by our work to advance the Executive Order on Advancing American Kidney Health (AAKH), which seeks to have 80% of new ESRD patients either receiving dialysis at home or receiving a transplant by 2025. The Network goal was to increase home therapy utilization in the Network service area by at least 2.5%.

Using the Achievable Benchmark of Care (ABC™) model, the Network encouraged facilities to conduct Plan-Do-Study-Act (PDSA) for all implemented interventions, including those promoted by the ESRD NCC Transplant LAN. The Network applied human centered design (HCD) practices in the development of patient-centered activities, Quality Assessment Performance Improvement (QAPI), support groups, and patient plans of care.

To support the national focus to provide ESRD patients with more treatment options such as Home Hemodialysis (HHD) and Peritoneal Dialysis (PD), the Network focused on the implementation of patient and provider education through interventions and the promotion of best practices to increase home dialysis utilization rates throughout the NSA. Initially, Network staff worked to meet this goal by sharing recommended practices presented on the ESRD National Coordinating Center (NCC) Home Therapies National Learning and Action Networks (LAN) and Affinity groups, with a goal to improve communication between in-center and home dialysis clinics, performing root cause analysis, monitoring home therapies utilization rates, and providing technical assistance to facilities.

Interventions

The Network planned to carry out the goals and priorities of CMS by empowering patients to make decisions about their healthcare, increasing state flexibility, developing innovative approaches to improving quality, accessibility and affordability, and improving the customer experience. The Network and improve kidney health and help patients move through the seven steps leading to home dialysis utilization by:

- Promoting referral to home dialysis modalities and identifying barriers to timely referrals
- Mailing of patient educational resources that included the *Home Dialysis Treatment Options* Poster.
- The Network invited all providers in the NSA to the ESRD NCC Learning and Action Network (LAN) Calls that were offered for Home Dialysis during the months of January and March of 2020.
- Promoted the 7 Step Process Leading to Home Dialysis with staff and patients
- Monitoring progression through 7 steps
- Utilize *Let's Talk: Home Dialysis* conversation cards (LAN Intervention)
- Increasing communication between participating dialysis facilities, hospitals, and home dialysis programs
- Assisting facilities in the implementation of interventions to support patients through the process of training to dialyze at home
- Partnering with stakeholders to offer physician education
- Network 1 developed the Monthly Activities Calendar and upcoming events included in all hard copy mailings and emailed to help facilities plan for upcoming QIA events

- CMS Adult Elective Surgery and Procedure Recommendations
- How to Support Home Dialysis Patients During a Pandemic
- Know Your Options Crossword Puzzle: Peritoneal Dialysis
- *Let's Start Healthy at Home*" campaign including the following resources
 - *Healthy at Home Guide*
 - *Do Your Patients Know About Home Treatment Options?*
 - *Do you know your home treatment options? (Home Dialysis)*
 - *Do you know all of your treatment options? (Home Hemodialysis)*
 - *Do you know all of your treatment options? (Peritoneal Dialysis)*
- Supported telehealth in home therapies including resources and webinar presentation on benefits
- Hosted webinar with NxStage HHD programming on the benefits of hemodialysis in the nursing home

Barriers to achieving goals

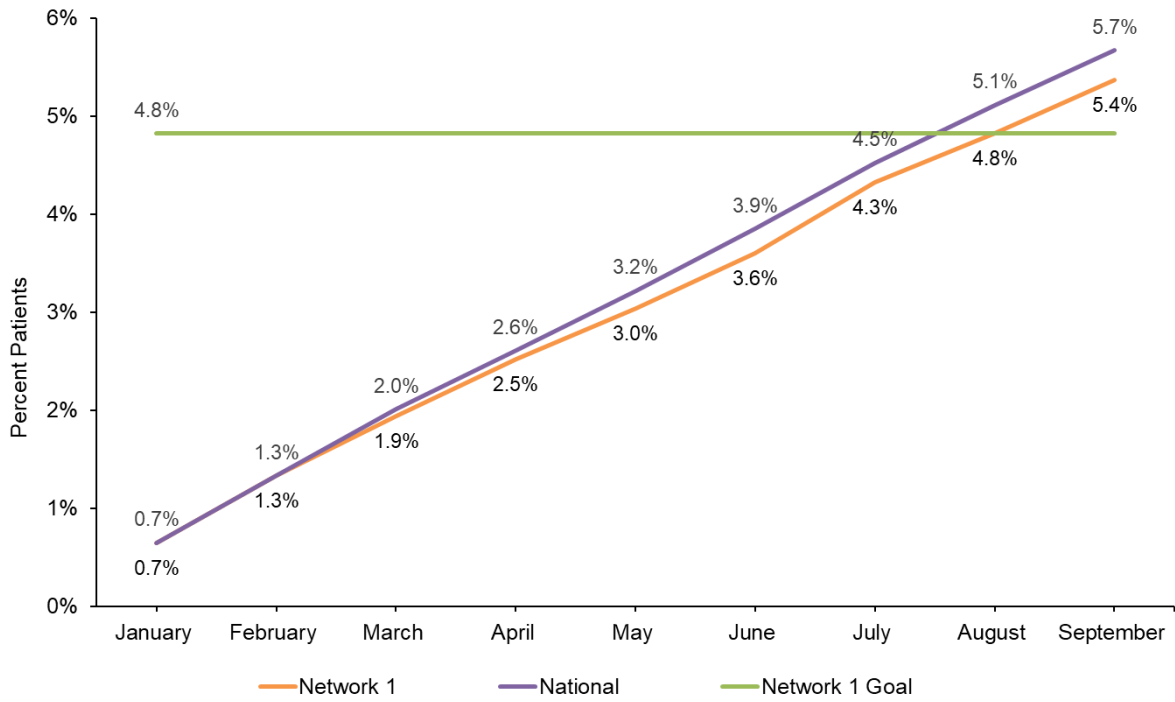
In addition to reduction of the broader national discussions on home therapies with the NCC LANs, the Network identified the reduction of appropriate surgical access interventions for patients willing to transition to a home therapy as another barrier. Without the appropriate access, moving to a home therapy was more difficult for patients. This realization made the CMS clarification of essential surgeries even more pressing, so the Network continued to promote awareness of such surgeries to our target population.

Best practices spread to achieve goals

The Network was able to take a regional focus on educating our community on home therapies and spreading of best practices learned during the pandemic. The Network quickly came to realize that many patients who had, in the past, refused home therapies were now considering this treatment as an alternative to being exposed to COVID.

The Network's efforts resulted in an additional 1,008 patients moving to home modalities in 2020, exceeding our goal by 21.55%, and saving the Medicare program \$6M.

Network 1: Percent of Patients Starting Home Dialysis January 2020 - September 2020



QIA: Quality Improvement Activity
Source of data: ESRD NCC 2020 Dashboard accessed March 2021

Population Health Focus Pilot Project Quality Improvement Activity

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.

Project Overview

Studies have correlated an improved quality of life for chronically ill patients with the implementation of peer mentoring programs. Peer mentoring provides patients with the ability to build relationships with other end-stage renal disease (ESRD) peers based on shared experiences, characteristics and in some cases treatment type. The ESRD Network of New England utilized an electronic assessment to formally identify all facilities with active peer mentors, patient representatives and advocates. The Network further sought to identify if these individuals were trained through the IPRO ESRD E-University Peer Mentoring Program. The Network identified 21 facilities that met qualifications for participation. The E-University Peer Mentoring Training Modules focus on defining peer mentoring, the roles of a peer mentor, and how to be an effective peer mentor. It provided educational content on the most effective ways to discuss treatment options with the mentee through the utilization of the strengths, understanding perspective and empathic listening skills. The peer mentoring activities were conducted through a monthly themed calendar. During the months of January 2020 through March 2020 the Network identified six peer mentors from the participating facilities. During the early weeks of March identified peer mentors started to engage in the E-University Peer Mentoring Program.

However, the onset of the COVID-19 pandemic halted many of the peer mentoring activities. Facility social workers were reassigned to different tasks, and peer mentorship was not a critical task at the facility level. As a result of facility restrictions, the Network focused on transitioning the peer mentoring program to a strictly virtual interface. The Network continued recruitment strategies and conducted peer mentoring webinars focusing on how to utilize online virtual platforms to continue to engage mentor-mentee interactions. The virtual platform included social media applications like Facebook, Instagram; and telecommunication applications (Zoom, WebEx, Go-to-Meeting).

Interventions

- Educational resources focusing on empathic listening. The main concept of these resources was to educate mentors on how to engage in active listening and make the mentee feel heard and understood, while being empathic to the mentee's plight as an ESRD patient.
- Peer Mentoring LAN Call: In March 2020, the Network created and facilitated a webinar to which all facilities in the NSA were invited. The webinar was created in collaboration with stakeholder organizations including American Association of Kidney Patients, TransplantFirst and the Renal Support Network. Each organization had an opportunity to share its experiences and engagement with Peer Mentoring and its positive impact on its clients and members. Moreover, the webinar explicitly provided facilities with different strategies to improve peer mentor engagement.
- Alternative Approaches to Peer Mentoring: The COVID-19 pandemic restricted in-center interaction among patients at all dialysis facilities within the New England area. Additionally, the strict lockdown protocols limited in-person interactions outside of the dialysis facility. As a result, the Network created resources that explained different types of virtual interfaces, how to use them and the tools necessary to efficiently utilize them. NCC resources were also shared with the ESRD community.
- Virtual Bingo Game: The virtual bingo game was offered to peer mentors as another engagement strategy. The Bingo game included an assortment of bingo cards, an interactive PowerPoint, a glossary and instructions. The PowerPoint made the game possible for virtual engagement as well as in-person engagement.

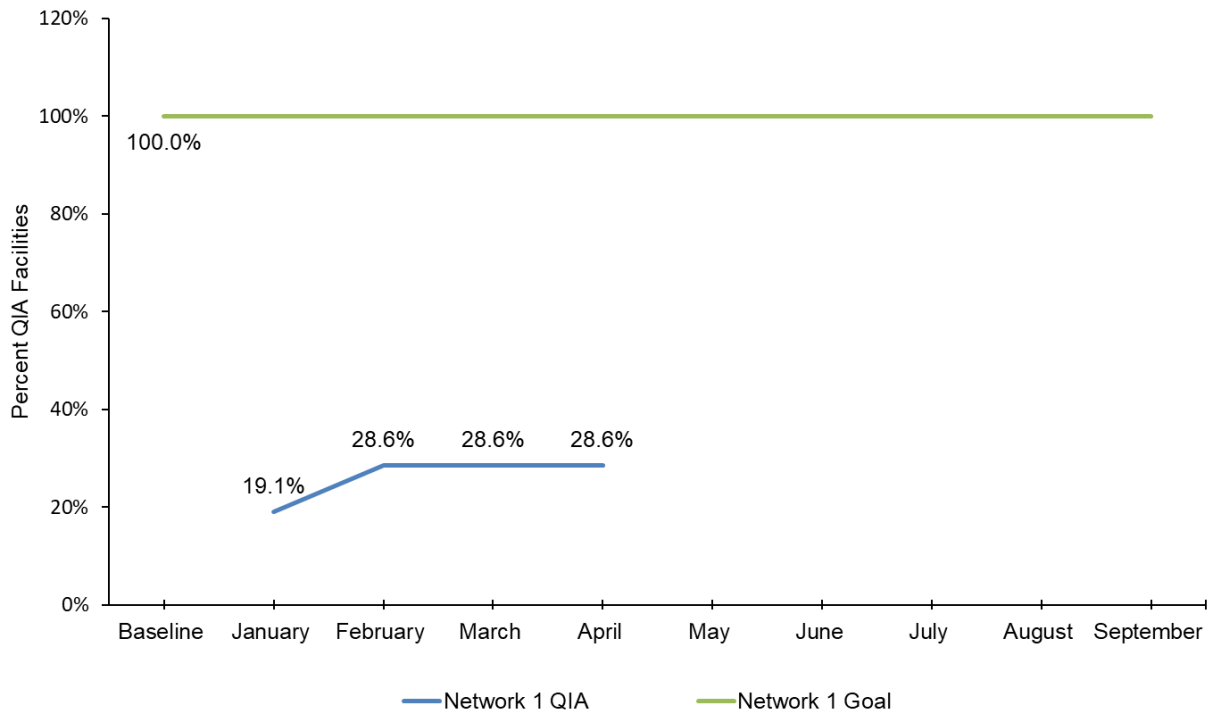
Barriers to achieving goals

- The COVID-19 pandemic created a significant barrier to the success of the peer mentoring implementation. As the pandemic spread to all states, facilities struggled with strict regulations, the transferring of patients (due to the increased incidence of the COVID-19 virus), and patient and staff death.
- Patients were not computer savvy and some did not have access to computers. In addition, community centers (local community centers, libraries were no longer accessible to the public. These issues all contributed to patients' inability to complete the peer mentoring training.
- Limited virtual engagement and increased isolation among patients. Patients began to feel that the program was not feasible due to their new circumstances, causing participation to falter.

Best practices spread to achieve goals

- Use of virtual engagement platforms and the adaption of different virtual applications especially those involving face-to-face interfaces (Facebook Messenger, Instagram, and Zoom). Many of our identified peer mentors had maintained long standing relationships with other patients through the utilization of these applications.
- LAN Call- The exchange of peer mentoring strategies between the Network and the facilities increase the facilities understanding of peer mentoring as demonstrated by the post-webinar assessments.
- Collaboration with other IPRO ESRD Networks provided Network 1 with a larger perspective on how to effectively implement a peer mentoring program, gave a clearer understanding of barriers that impact the ESRD community nationally, allowing us to target strategies to address these perceived barriers.
- Collaborating with stakeholder organizations provided the Network with the opportunity to understand the strategies these organizations used that were successful in their large scale program. It also allowed us to align our goals and programs.

Network 1: Percent of QIA Facilities with a Patient Mentor January 2020 - September 2020



QIA: Quality Improvement Activity
Source of data: ESRD NCC 2020 Dashboard accessed March 2021

ESRD NETWORK RECOMMENDATIONS

Facilities that Consistently Failed to Cooperate with Network Goals

The Network has garnered facility support throughout our community to support Network initiatives and goals throughout 2020 even with modifications due to the pandemic. The Network did not identify any facilities in its service area that failed to cooperate with Network goals in 2020.

Recommendations for Sanctions

The Network did not recommend any facilities for sanctions in 2020.

Recommendations to CMS for Additional Services or Facilities

The Network has identified increased concern in involuntary discharges led by physicians terminating patient relationships for non-adherence concerns, which is against the CMS Conditions for Coverage. Through investigation and case review, the root cause is a limited assessment on barriers and challenges identified by the patient in following medical orders. The Network has observed that when a patient reports feeling “better” with less dialysis or reports kidney function, the patient is seldom offered a reassessment or to being in a sample prior to a termination letter or even notice to the Network. The Network recommends additional clarification of CMS policy in the physician's responsibility to the dialysis facility adherence to the Conditions for Coverage acceptable reasons for IVD as well as ethical considerations in respect to patient autonomy.

Another lesson that the Network learned during the COVID-19 pandemic was the increased access to care that patients had with the use of telehealth for home dialysis therapies and kidney transplant evaluation. CMS waivers to cover care offered through telehealth, positively impacted provider capabilities of making care accessible to ESRD patients seeking these modalities. The Network recommends CMS to consider covering telehealth visits as it regards home dialysis and kidney transplantation beyond the COVID-19 pandemic.

ESRD NETWORK COVID-19 EMERGENCY PREPAREDNESS INTERVENTION

As part of the Network responsibility to respond to emergency events, the Network began monitoring the COVID-19 virus in mid-January 2020. The Network first became aware of the novel Coronavirus after meeting with partners from the state health departments, and the release of a situation status report indicating that our region was being placed on a watch. Subsequently, the Network received an ASPER flyer that identified virus symptoms and regions of concern and spread, and encouraged infection control practices to minimize spread. The Network began monitoring the COVID-19 virus for potential impact, and strategized support needs for the ESRD community by coordinating activities with the Centers for Medicare & Medicaid Services (CMS), Kidney Community Emergency Response (KCER) coalition, and the six New England state departments of public health.

The Network relied on collaborations with, and information sharing from, the ESRD National Coordinating Center (NCC), Centers for Disease Control and Prevention (CDC), CMS, KCER, state health departments, large dialysis organizations (LDOs), patient-advocacy groups, renal listservs, and other stakeholders, to stay abreast of changing guidance. The Network uses a number of processes to communicate information and/or guidance to facilities and patients. These methods were based on strategies that had previously been found to be effective in that population based on the controls we had in place. Critical information (guidelines, waivers, tools, resources, requests to assess local/regional impact, and strategies to address barriers to access to care) was disseminated to dialysis facility staff and/or patients via electronic newsletters, email, fax, website postings, webinars, blogs, and social media. The Network created and continues to maintain COVID-19 designated pages for both patients and professionals on our website, where new resources are easily identified by “New!” to alert the ESRD community of timely content. The Network created a COVID-19 banner that directed facility providers, patients, and stakeholders to updates on our website. This banner continues to appear in all Network emails and communications.

To ensure that our community had the tools, information and supplies needed to appropriately confront the pandemic, the Network logged and tracked all calls and communications from facilities, DPH, OEM, during the early months of COVID to assess reductions in staff, PPE and infection prevention measures and to promote CDC guidance. The Network actively worked to prevent access to care issues related to lack of transportation, secondary to COVID-19 and non COVID-19 problems. By conducting environmental scans via focused communications with facility social worker/facility administrators, contacts at the state OEM and other transportation companies, we were able to understand and appropriately address transportation concerns.

The Network implemented a number of controls to ensure timely receipt of information and guidance sent to dialysis facilities. Between March and December 2020, one-on-one calls were conducted to provide technical assistance to 242 facilities. These calls enabled the Network to garner direct feedback from providers about receipt and utilization of information, and aided us in ascertaining the need for additional resources or if further guidance was needed.

In addition to one-on-one technical assistance the Network developed a provider emergency management contact group to send mass communications to target audiences. For dialysis facilities, state and local Office of Emergency Management (OEM), healthcare coalitions, Medical Review Board (MRB) members, and other key leaders in the Network’s Emergency Task Force, the Network distributed COVID-19 guidance and resources utilizing a branded Emergency Messaging Channel. This newsletter was disseminated twice a week and included relevant information as it became available, with a request to

spread this information to peers and patients. When targeting patients, the Network utilized a multi-pronged approach for communication through one-on-one calls, email, text messaging, and social media (Facebook). Patients were encouraged to contact the Network with questions about stay-at-home orders, COVID-19 safety, and changes to facility treatment protocols.

During the pandemic the Network measured the effectiveness of the communication system by assessing facility and patient understanding of the core principles in prevention of disease transmission and infection control practices. On June 2, 2020 the Network released a Core Knowledge Assessment tool to all 203 dialysis facilities in the region. These facilities were asked to complete and return the assessment to the Network to help us determine their understanding of critical CDC, CMS, and Network guidance in the management of COVID 19. The Network received 96% of the 203 assessments surveys sent. The assessment verified that 100% of respondents had reviewed the CDC frontline toolkit, Network generated supporting information, and CMS guidance that had been provided through the Network communication strategy that was initiated in mid-March of 2020.

In the fall, Network priorities shifted slightly to encompass COVID-19 vaccination capability and education. In speaking with our community we recognized the need to address vaccination hesitancy in both patients and staff, which led to the development of the IPRO ESRD Network webinar “Fact over Fiction.”

In addition to supporting dialysis facilities in coping with the pandemic the Network continued to promote home and transplant modalities as optional to be considered in light of the pandemic, recognizing a renewed interest by patients in these modalities. The utilization of telehealth was valuable in sustaining access to care while providing a safe way for patients to connect with their healthcare team. While this has been significant for the prevention of infection, telehealth has also been valuable in assisting to overcome transportation challenges for initial or follow up appointments related to home modality growth and transplant evaluations, particularly for patients in rural areas where there is a substantial distance barrier to access to these services. It should be noted that patients are not always comfortable or do not have access to equipment needed to support telehealth. In 2020, the Network began working on resources and educational training to support patients in using technology platforms to support expanded use of telehealth.

ESRD NETWORK SIGNIFICANT EMERGENCY PREPAREDNESS INTERVENTION

For individuals who have been diagnosed with ESRD, missed dialysis treatments can have serious adverse health effects. This makes the ESRD patient population especially vulnerable during emergencies and disasters. The Network relies on longstanding partnerships with state health departments, offices of emergency management, and large dialysis organization emergency management teams to ensure safety and continuity of care for ESRD patients in New England.

As the pandemic took hold and became more prevalent in the New England service area in early March 2020, the Network provided technical assistance to facilities facing challenges with individuals who were diagnosed with COVID-19. For all emergencies reported in 2020 that were related to the COVID-19 pandemic, Network staff offered comprehensive support to ESRD patients and linked dialysis providers with appropriate emergency response resources, including the Kidney Community Emergency Response (KCER) program, state offices of emergency management, and other stakeholders. The Network worked with facility staff to ensure that all patients received treatment and were connected to cohort facilities. Recognizing the importance of accurate and streamlined communications to disseminate key guidance to patient and dialysis facility staff across our New England community, the Network complied and provided all communications related to COVID-19 guidance and updates to facilities through an Emergency Messaging Channel. These communications included, but were not limited to, resources on screening and management of COVID-19, resources on significant guidance for COVID-19 and telehealth resources developed by the Network as well as the ESRD NCC.

The Network promoted NCC Quickinars that occurred on a weekly basis. The Network continued to participate in weekly KCER updates calls as well as weekly calls with CMS and all Networks. KCER as well as CMS were closely monitoring the progression of COVID-19 and provided assistance to the ESRD community. Twice a week, the Network sent emergency notifications to all facilities for distribution to patients, highlighting emergency events. In July 2020, dialysis facilities were invited to participate in the Kidney Community Response Program, in partnership with the Tampa Bay Health & Medical Coalition, to cover the basics of preparing a disaster-related After Action Report (AAR). The objective was to understand the key components of an AAR that would meet the requirements of the CMS Emergency Preparedness Rule. Patients and dialysis social workers were invited to a webinar, “Maintaining Emotional Balance in an Unbalancing Time.”

The Network initiated and maintained a 24/7 COVID Hotline number for facilities and patients to express concerns and grievances related to the public health emergency. Concerns identified through this hotline and migrated by the Network program included:

- PPE shortage and concerns
- Patient questions and concerns with COVID protocols
- Transportation concerns
- Access to care concerns by patients and facilities
- Guidance with COVID protocols

During COVID-19 technical assistance calls that began in March 2020 and ran through the end of the year, the Network identified a number of interventions as having been successful in mitigating the challenges facing providers and patients in the New England region.

The Network recognized the impact of mental health challenges and increased grief resulting from of the COVID pandemic isolations, restriction and loss as issues to be addressed. The Network hosted a

webinar, "Grief-Loss-Change and Other Tales from the Quarantine," by Julia Ellfruit, LISW, a hospice and bereavement counselor to provide strategies to assist caregivers in coping during the pandemic.

ACRONYM LIST APPENDIX

This appendix contains an [acronym list](#) created by the KPAC (Kidney Patient Advisory Council) of the National Forum of ESRD Networks. We are grateful to the KPAC for creating this list of acronyms to assist patients and stakeholders in the readability of this annual report. We appreciate the collaboration of the National Forum of ESRD Networks especially the KPAC.