End-Stage Renal Disease Network of New York



2020 Annual Report



Bronx-Whitestone Bridge New York City, NY

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Table of Contents

ESRD DEMOGRAPHIC DATA	4
ESRD NETWORK GRIEVANCE AND ACCESS TO CARE DATA	12
ESRD NETWORK QUALITY IMPROVEMENT ACTIVITY DATA	16
Long Term Catheter Quality Improvement Activity	16
Blood-Stream Infection (BSI) Quality Improvement Activity	19
Transplant Waitlist Quality Improvement Activity	23
Home Therapy Quality Improvement Activity	26
Population Health Focus Pilot Project Quality Improvement Activity	28
ESRD NETWORK RECOMMENDATIONS	32
Facilities that Consistently Failed to Cooperate with Network Goals	32
Recommendations for Sanctions	32
Recommendations to CMS for Additional Services or Facilities	32
ESRD NETWORK SIGNIFICANT EMERGENCY PREPAREDNESS INTERVENTION	34
ACRONYM LIST APPENDIX	37



ESRD DEMOGRAPHIC DATA

IPRO ESRD Network of New York (Network 2) 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 2, IPRO manages the ESRD Network of New England (Network 1), 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 132,000 renal patients in the four Network areas it manages.

Network 2 serves ESRD patients, dialysis providers, and transplant centers in the state of New York. The role of Network 2 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. As the fourth most populous state in the country, New York had 20.2 million residents in 2020. New York is the fourth most populous state in the country, New York City having the highest population density of any major city in the United States, with over 27,000 people per square mile. An estimated 65% of the ESRD population resides in New York City (NYC), with over 90% of the state's population concentrated within the city and its surrounding counties on Long Island and in the Hudson Valley. The dramatic variance in population density between upstate and downstate New York impacts the availability of, and patient access to, healthcare services.

In the downstate region (Hudson Valley, New York City, and Long Island), healthcare services are plentiful and relatively easily accessible by public and private transportation. In upstate New York, where the population density is much lower, transportation options are limited and there are fewer treatment facilities. This means that ESRD patients in rural areas typically travel farther and longer to reach dialysis clinics, vascular surgeons, hospitals, and other healthcare providers and clinicians; factors that may affect treatment options, patient experience of and satisfaction with care, and quality of care. The ESRD prevalent patient population in New York State was the sixth largest in the country as of December 31, 2020, according to ESRD National Coordinating Center (NCC) end-of-year data.

The population of the five boroughs of NYC—Bronx, New York, Richmond, Kings, and Queens Counties—with 18.8 million in 2020, according to U.S. Census Bureau estimates. The state's population of over 20 million is rich in ethnic, racial, religious/spiritual, cultural, and lifestyle diversity. According to U.S. Census Bureau estimates for 2020, New York State's population was 69.6% White, 17.6% African-American, 9.1% Asian, 1.0% American Indian and Alaskan Native, and 0.1% Native Hawaiian; 2.7% of the population identified with two or more races. The Hispanic or Latino population of the state was approximately 19.3% in 2020, according to the same source. The Network's activities supported the near 30,000 renal patients reported as receiving dialysis treatment for ESRD in the Network service area as of December 2020. Almost 23,000 patients in the Network's service area received kidney transplantation in 2020. In New York State renal patients were served by 350 Medicare certified dialysis facilities, 14 transplant centers, and seven Veterans Affairs (VA) hospitals.

IPRO ESRD Network 2 actively promotes the value of home modalities and transplantation: Our efforts contributed to a savings of \$16M for the U.S. healthcare system in 2020 (Source: ESRD NCC dashboard October 2020) through the Network team's active promotion of the value of home modalities and transplantation. This outcome exceeded CMS' expectations for home initiations (reaching 124% of the QIA home initiations goal) during the height of the COVID pandemic. In addition, Network 2 ranked

fourth in the nation in the percent of patients on the UNOS transplant list. Our focus on home modalities and transplantation helped us lower costs while improving care.

In 2020, the Network continued its practice to identify and implement innovative ways to drive kidney care improvements: pairing cutting edge technology with high-level subject matter expertise has allowed us to create and sustain positive change across our Network service area. This was exemplified by the Network's work in co-founding Project ECHO DATE (Dialysis and Transplant ECHO), the first kidney transplant ECHO Hub in New York State. This effort touched 86% of the transplant centers and 25% of dialysis providers in the NSA and contributed to a 19.3% growth in the transplant waitlist in 2020. This improvement placed Network 2 at number four in the nation for percent of patients on the UNOS transplant list, with 1,293 transplants performed in the NSA in 2020. This is particularly noteworthy based on the fact that New York City was an epicenter of the COVID-19 pandemic in 2020.

IPRO ESRD Network 2 is a recognized leader in kidney care emergency response: Throughout the COVID pandemic, Network staff successfully educated the NYS ESRD community on the importance of following recommended practices to reduce infections and hospitalizations, resulting in a 0.47% COVID-19 infection rate in Network, as compared to 10.97% national infection rate as of December 2020. In light of these successful outcomes, Network 2 provided national COVID-19 spotlight presentations to CMS leadership, the Forum of ESRD Networks, KCER, and providers, on the promising practices and emergency response and recovery processes.

Throughout 2020, the Network's patient and family engagement efforts were grounded in providing our patients and families timely and relevant services to address their needs. To minimize pandemic—related social isolation and mitigate mental health (MH) issues during the COVID pandemic the Network initiated bi-weekly virtual patient support groups and patient-designed educational MH webinar sessions, sharing both offerings to patients across the NSA. The bi-weekly virtual patient support groups provided peer-to-peer mentoring and one-on-one interactions. We hosted two virtual game nights using Network 2-developed Bingo- and Jeopardy-inspired educational programs to encourage direct patient interactions during a time of social distancing. These and our other patient activities facilitated a change in the mindset of our providers, who now see the benefits of active and engaged patients and how this leads to improved health outcomes.

The Network's Patient Advisory Committee (PAC) grew to include 127 active members in 2020, with patients serving as PSMEs on the national level. Network staff created easier ways for patients to engage with the Network, using innovative tools that included broadcast calling/texting, allowing for quick check-ins with staff to ensure patients always felt connected. Through the Network's PAC program, patients received education and participated in facility QIAs, bringing the patient voice to the QAPI team. The Network adopted IHI's Small Test-of-Change model, which support our efforts to work successfully with providers and patient groups within unique-needs localities, through small tests of change, with a goal to improve healthcare outcomes in these areas.

In 2020, the Network worked in collaboration with its Medical Review Board, Patient Advisory Committee, Grievance Committee, Education 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 works closely with ESRD patients, family members, facilities, patient advocacy organizations, and other ESRD stakeholders to improve the quality of care provided to ESRD patients in New York. The Network deployed focused interventions that targeted patients, dialysis staff, transplant programs, and renal community stakeholders. These interventions focused on engaging patients, reducing disparities, and improving quality of life for ESRD patients are detailed in this report.























ESRD NETWORK GRIEVANCE AND ACCESS TO CARE DATA

Grievances

The Network responds to grievances filed by or on behalf of ESRD patients throughout New York State. This often involves working with individual facilities to identify and address difficulties in placing or maintaining patients in treatment. In 2020, the Network addressed 64 reported patient grievance cases involving Immediate Advocacy (58), Quality of Care Grievance (1), and General Grievance (5). A review of the grievance cases from this time period reveals the most common reasons for grievances are environment (30 cases), staff-related concerns (22 cases), and treatment-related concerns regarding the delivery of care (12 cases). With each of these cases, the Network advocated for the patient, promoting the patient's right to participate in his or her healthcare and to have a voice in the services provided by the facility. Network 2 averted 68 involuntary discharge (IVD) cases in 2020, the most in the past five years, resulting in the avoidance of 300+ IVDs over the contract period. Many of these situations involved patients with mental health issues and/or depression.

To calm patients' fears about possible infection, the Network encouraged facilities to be transparent about COVID-19 protocols put into place; to provide education to their patients; and to open a dialogue about the changes they were making to keep both staff and patients safe. The Network mediated cases regarding patients' concerns. In many cases, the Network discussed with facility staff:

- The importance of educating patients on changes in care due to COVID-19.
- The need for staff to reduce burnout and compassion fatigue by implementing self-care strategies. This can improve patient care and assist staff with maintaining professional boundaries.
- The inclusion of care partners to support a patient's care plan
- Acknowledgement of the effect of patients' stress on their mental health needs, and the provision of resources, referrals for patients with mental health needs.

In addition, the Network provided the following resources to facilities:

- 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 information to create patient awareness of the resources available, a focus on improving communications early in the grievance process, and information on how to file a grievance with the Network and New York State Department of Health.
- Mental health resources and webinars created by the Network and behavioral health organizations to provide education and support to patients and staff.

Interventions and efforts to resolve the grievances included Network-sponsored mediation, initiating and participating in interdisciplinary conference calls, an intensive review of patient medical records, education on appropriate communication techniques, introduction of strategies to promote the improvement of the facility's professional culture, identifying resource materials and trainings for provider participation, and collaborating with the Network's Medical Review Board when appropriate.

With each grievance case patients were educated on their rights and responsibilities, the Network's role in resolving the grievance, and how the grievance process is implemented. Four new resources were created including *Your Rights and Responsibilities as an ESRD Patient*, the *We Can Help* flyer, *What the Network Cannot Do* handout, and the *Grievance Process Guide: A Guide for Patients and Families*.

Access to Care

Access to care cases include those involving involuntary discharges, involuntary transfers, and failures to place. An involuntary discharge is initiated by the treating dialysis facility without the patient's agreement. An involuntary transfer occurs when the facility temporarily or permanently closes (i.e. due to a merger, an emergency, a disaster situation, or other circumstance) and the patient is dissatisfied with the transfer to another facility. A failure to place occurs when no outpatient dialysis facility can be located that will accept an ESRD patient for routine dialysis treatment.

Access to Care: Involuntary Discharges

In 2020, the Network received 23 cases of involuntary discharges. In most of the cases, the discharge was immediate due to a severe threat (15) followed by ongoing disruptive behavior (eight). The Network also encouraged facility staff members to continue supporting the patient even after discharge, by aiding in the referral to a new facility and by assisting hospitals that were working to identify a new placement for the patient.

The Network provided education to hospital discharge planners to help them support patients who were involuntarily discharged. This included information on possible solutions to finding placement, dialysis facility resources, and information of the *30-day Second Chance Trial Program*. The Network guided facilities in reviewing practices they currently follow 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.

Access to Care: At Risk for Involuntary Discharges

In 2020, the Network averted 52 involuntary discharges through monthly check-ins with the facility. These check-ins promoted best practices, including:

- Provider education about the rights of patients and the role of the facility.
- Inclusion of family members in all meetings with the patient.
- Clear communication to the patient related to the facility's concerns and risk of involuntary discharge.
- Formation of a treatment plan to support the patient's identified barriers. (e.g. unmet mental health needs, lack of housing, immigration, lack of health insurance).
- Education of patients on the concept of boundaries, to assist in reducing conflict.
- Information about the availability of mobile crisis resources: interdisciplinary psychiatric teams that support patients in the community with high-risk mental health needs, along with encouraging facility staff to partner with other organizations that could assist in supporting patients with mental healthcare needs.

Ongoing disruptive and abusive behavior (35 cases) was the most common reason for a patient to become at risk for involuntary discharge, followed by immediate severe threat (eight cases), Facility unable to meet the medical needs of the patient (six cases), and nonpayment (three cases). An analysis of 2020 cases indicated that of the total 140 cases reviewed by the Network (Grievance and Access to Care) 102 occurred in the state's downstate area (NYC and Long Island), while the remaining 38 cases occurred in the upstate regions. The areas with the most cases were Brooklyn (43 cases), the Bronx (15 cases) and Manhattan (13 cases).

Network Assistance and Quality Improvement

In 2020, cases that were directly related to COVID-19 were tracked by the Network. There were 52 cases related to the pandemic with 39 general cases, 10 cases involving mask refusal, two cases involving refusal to follow rules, and one "other category" case.







ESRD NETWORK QUALITY IMPROVEMENT ACTIVITY DATA

Long Term Catheter Quality Improvement Activity

Despite reduced provider staffing and limited procedures due to the COVID-19 pandemic, along with contract goal adjustments, the Network worked toward the goals of this quality improvement activity, but was not evaluated on results.

In 2020, the Network assisted clinics in navigating surgical and procedural barriers that arose due to the pandemic. The Network distributed CMS guidance related to the essential nature of these surgeries to promote the well-being of ESRD patients and to provide the most effective dialysis treatments. We continued to advocate for a reduction in incident LTC-only admissions and shared best practices as discovered, but these efforts did not reverse the increase in LTC use during the pandemic.

Project Overview

Patients with long term catheters (LTC) are defined as patients with a catheter in use for dialysis treatments for 90 days or longer. The Network's efforts to lower LTC rates have primarily focused on improving processes within the ESRD facility. While these efforts are important, a paradigm shift is necessary to decrease the number of patients who present to an ESRD facility with a LTC by focusing on placement of permanent access at the start of dialysis.

The work of the LTC reduction QIA focused on driving improvement in access placement practices and reducing the utilization of LTC in the prevalent patient population. This improvement is demonstrated by the increased number of ESRD patients initiating dialysis with a permanent access and a decreased rate of LTC use in the prevalent hemodialysis patient population. The Network was able to meet the target goal from baseline during the months of January and February 2020; however due to the challenges imposed by the COVID-19 pandemic on scheduling access surgical procedures to remove LTCs and replacing them with permanent access types, the rate of catheter-use steadily increased during the months of March-August. As of data reports from September (July 2020 data), the Network achieved stable LTC rates with a 15.3% rate.

Interventions

The Network worked with QIA facilities across its service area by creating intervention tier levels based on facility performance at baseline. A subset of 56 facilities comprised a focused intervention cohort. The Network provided technical assistance to the facilities as follows:

All facilities in the NSA received interventions to support provider and patient education. These included:

- Mailing of patient educational resources that included the *Vascular Access for Hemodialysis* poster.
- Establishing a vascular access champion at the facility level, to assist patients with scheduling appointments and procedures to assure movement through the process to permanent access placement.
- Resources and support were provided to encourage facilities to participate in Network sponsored contests for the best Education Station, Bulletin Board or Lobby Day as a way to promote patient education. In addition, Patient Facility Representatives were involved in the activity. Participating facilities sent a picture of their patient education setting to the Network, and Patient Subject Matter Experts (PSMEs) selected the top performers for recognition on the Network's website.
- Inviting all providers in the NSA to participate in the ESRD NCC Learning and Action Network (LAN) calls on vascular access that were offered during the months of January and March of 2020.

• Sharing of data provided by the ESRD NCC Fistula First Catheter Last (FFCL) benchmarks and communication regarding [progress to year end goal.

The Network worked with 56 intervention cohort facilities that received all above interventions, and also were asked to work with the additional interventions:

- Facilities were asked to identify a *Patient Facility Representative*, a patient leader who would support patient to patient education on placement of a permanent access.
- The assignment of a staff member to take on the Vascular Access Navigator Role was key in supporting the project lead and fostering an interdisciplinary approach to reducing LTC rates. These staff members were asked to take the *Coaching Fundamentals* and *Coaching to Support Kidney Care Choices Vascular Access Planning Module* modules; then were established as leaders to assist patients with appointment scheduling and tracking of procedures to assure movement through the process from catheter to permanent access.
- Facilities were asked to use the provided LTC Toolkit, a collection of professional and patient education resources that included the *Vascular Access Planning for Professionals*, *Lifeline for a lifetime Vascular Access Planning for Patients*, *Questions or Concerns about a Permanent Access*? and the *Vascular Access at Time of Initiation*.
- Facilities were encouraged to implement a "huddle board" which included patients' status on permanent access placement/maturing and removal of LTC to continuously discuss with the interdisciplinary team. Facilities were provided with supporting material such as the NCC *Change Concept Review Vascular Access during QAPI, and* the Network developed a LTC *Rapid Cycle Improvement Worksheet.*
- The Network created and provided a CROWNWeb Job Aid How to Run a Vascular Access and Vascular Access Cleanup to assure that facility efforts were adequately captured in the program.

Barriers to Achieving Goals

- The COVID-19 pandemic created significant challenges in the scheduling of vascular access surgery, causing an increase in the LTC rates. In addition, for many individuals, COVID-19 resulted in newly diagnosed kidney failure, which further increased the demand for such services.
- Additional barriers include patients being discharged from the hospital with no vascular access plan, patient refusal of permanent access placement, inaccessibility to vascular access providers in some regions.

Best Practices Spread to Achieve Goals

- While completing an environmental scan March-July the Network uncovered best practices used by facilities to mitigate challenges associated with LTC reduction and placement of permanent access. One best practice identified was the creation of alternative sites for catheter removal such as in hospital emergency rooms and physician offices rather than waiting to schedule this procedure in vascular access centers or surgery suites.
- 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.
- To mitigate challenges in vascular access placement resulting from the COVID-19 pandemic facilities focused their efforts on scheduling surgery appointments and supporting new CDC guidelines and required logistics such as a negative COVID-19 tests results, socially distanced transportation, and telehealth communication with nursing home facilities as needed due to the COVID-19 pandemic.



Blood-Stream Infection (BSI) 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. In 2020, the Network collaborated with individual facilities on improving infection prevention practices for COVID-19. These efforts resulted in a significant decrease (0.15) in the BSI rate in the NSA. The BSI rate reported for the period March through June 2019 was 0.41%, while the BSI rate reported for March through June 2020 was 0.26%. The key strategies the Network employed to lower the spread of BSIs in our community focused on strict adherence to the CDC core interventions and patient involvement in infection processes.

Project Overview

In 2020, the Network supported the CMS national initiative to reduce the rate of bloodstream infection (BSI) by 50% over the next five years. Hemodialysis patients are at higher risk than the general population for acquiring healthcare associated infections (HAIs) and specifically bloodstream infections (BSIs), due to the regular and frequent use of catheters and other forms of access to their bloodstream while dialyzing. The 2020 BSI QIA was designed to increase facility implementation of the nine CDC Core Interventions. The Network identified 95 targeted facilities reporting the highest BSI rates (those facilities with reported BSI rates in the top 50% within the Network's service area) based on the National Health Safety Network (NHSN) semi-annual pooled mean at baseline (Quarters 1 and 2, 2019). The Network worked intensively with the top 20% cohort of 62 facilities with the highest rates of infection in the Network's service area; ranging from -2.90 to 7.88 per 100 patient months.

The Network also worked with facilities in the 50% cohort to support their efforts to join a Health Information Exchange (HIE) or another evidence-based, effective information transfer system to bridge communication gaps that often exist between the dialysis facility and hospital or physician's office.

Goals and Outcomes

The goals of the BSI QIA were to increase awareness and reporting of BSIs as well as achieve a 20% relative reduction in the pooled mean BSI rate in 20% of facilities in the Network's service area (a 20% reduction in the semi-annual pooled mean BSI rate from baseline). Data for this activity came from the Centers for Disease Control and Prevention (CDC) National Healthcare Safety Network system. Baseline for this project was the semi-annual quarterly pooled mean BSI rate from January to June 2019, with the re-measure period being the semi-annual quarterly pooled mean BSI rate for January to June 2020.

Interventions

The Network's interventions succeeded in achieving a significant decrease in the pooled mean BSI rate from 1.12% at baseline to 0.55%, at re-measurement, exceeding the targeted goal of 0.89% and achieving an overall 36.85% relative reduction. Of the facilities in the 50% cohort, the Network's support resulted in 58.92% joining an HIE, exceeding the 20% enrollment goal; 83.3% using all nine CDC Core Interventions; and 91.9% of target facilities completing NHSN Dialysis Event Surveillance Training, exceeding the 90% completion goal.

To help identify best practices, challenges, barriers and areas for improvement, the Network implemented a Knowledge and Practice Assessment as part of the root cause analysis tool for identified facilities. Information from the RCA guided the selection of interventions and educational webinar topics for this project, which included:

- Distribution of the CDC-created poster: *Core Interventions for Dialysis BSI Prevention*; to support facilities in the use of the CDC Core interventions as part of a targeted approach to prevent BSIs.
- Root cause analysis (RCA) was conducted for every identified BSI during the project period, with findings discussed during QAPI meetings.

- Distribution to facilities of bi-monthly performance metric reports. These Network- developed data feedback reports allowed facilities to monitor outcomes, trends and, if necessary, to identify barriers that impeded progress toward the project end-goal.
- The Network worked with those responsible for infection prevention/control monitoring at each targeted facility to ensure that the required yearly training on BSI reporting was completed and entered in NHSN.
- The Network launched a "Back to Basics" campaign to reinforce the importance of hand hygiene and surface disinfection during the pandemic. This campaign featured hand washing and hand sanitizer and surface disinfection audits for facilities and patients/caregivers.

Best Practices Spread to Achieve Goals

To support achievement of BSI reduction goals, the Network promoted use of patient success stories and CDC Core intervention resources, which included an educational poster and accompanying resources focused on nine components to prevent infections in a dialysis setting. The Network's in-depth technical assistance focusing on infection prevention and patient activation during the pandemic helped to not only prevent the spread of COVID but also, simultaneously, reduce the spread of BSIs. Using education and increased compliance with CDC infection prevention strategies, the Network consistently exceeded CMS' goal, successfully decreasing BSIs on average by >34% from previous contract periods.

- Network interventions promoted implementation of the CDC recommended audit tools, involved patient subject matter experts in directing the interventions, and included provision of data trending reports for each facility's performance and one-to-one coaching for low performing facilities.
- Data transparency across the Network, dialysis facility staff and State Surveyor Agency was achieved through monthly distribution of the BSI Progress Report/Achievement Level Report to facilities, indicating the progress toward BSI reduction goals as well as facility participation in interventions.
- The Network created a community of practice focused on infection prevention through which the most current CDC information was regularly released and best practices to prevent the spread of infection in high risk situations was shared.

Barriers to Achieving Goals

• One barrier the Network identified during the pandemic was the challenge many facilities had in documenting in NHSN. Contributing factors included delay in the ability to achieve a single user login for new users, staff at certain facilities being deployed to assist with patient care in facilities with increased COVID burden, and for some facilities, lack of an authorized user of NHSN to document.





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. In the midst of a global pandemic, the Network saw continued growth in transplant referrals and new additions to the UNOS waitlist. The halting of non- essential surgeries, patient surge, and staff shortages at the 14 transplant hospitals in NY State placed severe limitations on the number of transplants able to be performed in spring and early summer 2020. During the COVID-19 pandemic, Network 2-area transplant centers performed 1,293 transplants, achieving a 19.30% growth in patients added to the UNOS wait list due to the ability for Transplant Centers to complete backlogged administrative processing of placing patients on the wait list due to shifting focuses in the healthcare system during the pandemic.

Project Overview

Transplant facilities used much of the shutdown time to conduct administrative work, and were able to add patients to the waitlist, and ramp up telehealth activities for outreach and education. Network transplant QIA activities were adapted to support these practice changes, and Network staff worked to promote best practices and utilization of telehealth, virtual education sessions and social distancing to adapt to pandemic infection prevention practices. Despite the suspension of QIA goals due to COVID-19, the Network was able to achieve a 3.0 percentage point improvement in the natural trend of UNOS listings which was 0.05 percentage points above the national average.

Improvement was achieved through patient and staff education, and action-oriented interventions adapted for use during the COVID-19 pandemic that facilitated practice changes and process improvements, including promoting facility partnerships with transplant stakeholders to broaden their resources for transplant education at the facility level. These engagement efforts to improve communication and coordination between dialysis facilities and transplant center programs, led to the availability of additional resources and options to help patients and their family members better understand and begin the transplant process.

Interventions

Network staff launched resources and interventions as part of quality improvement activities to increase the number of dialysis patients pursuing transplant as a treatment option, by supporting and tracking their progress through the transplant workup process toward a living donor transplant or through steps they were taking to be listed with UNOS for a deceased donor transplant. Network staff continued a close partnership with the New York Center for Kidney Transplantation (NYKidney), a transplant focused stakeholder group dedicated to enhancing the quality of kidney transplant services. As co-founders of a Transplant ECHO Hub, Network 2 facilitated monthly ECHO DATE sessions with a provider group that included 86% transplant centers and 25% of dialysis providers in the Network's service area. The partnership focused on innovative, multi-agency collaboration with NYKidney-hosted Project ECHO monthly e-University, staff from NYKidney, the Network team, dialysis facility staff, and transplant centers which all worked together to find ways to assist patients to navigate the transplant process during COVID.

During the nine-month QIA performance period, Network staff worked with other Networks, the ESRD NCC and stakeholders to provide participating facilities with educational webinars to support sharing of best practice models, educational articles, resources, and recommendations for interventions. The goal of this project was to streamline the transplant referral and wait listing process by:

• Bridging the communication, information and resource gaps between dialysis facility providers and transplant center care settings; and

• Overcoming known variables in the transplant coordination process (e.g., patient health status, patient eligibility, varying referral options by transplant facility, transplant center program criteria, and availability of donors).

Interventions and facility self-assessment tools were found to help increase transplant referrals, wait listing, and ultimately patient opportunity to achieve transplantation, resulting in an overall growth of 88.95% in the Network service area. The most common and successful facility-level interventions included: Encouraging patients to focus on telemedicine as part of their transplant workup journey; engaging patients (both pre- and post-transplant) through virtual educational events and as mentors in a socially distant environment (phone, social media and web based communicating); the Network recruited facility staff to train as transplant navigators and utilize Project ECHO for case-based learning and consultations with transplant centers; creating excitement in the facility through creation of engaging displays that promoted the different treatment options available to patients; and engaging with family members to discuss living donation.

Best Practices Spread to Achieve Goals

- By providing tools to monitor and assist patients as they took the steps to transplant, facility staff and patients were better equipped to make informed choices and streamline the transplant work up process. Having dialysis facilities develop working relationships with a transplant center was vital to ensuring involvement of transplant facility staff in providing patient education at the dialysis facility level.
- Building relationships with key transplant coordinators at facilities helped to assist in identifying opportunities for education and data sharing and to enhance methods to track referrals for beneficiaries
- Supporting regular follow up with the transplant coordinator and educators on patient progression through the process helped patients navigate the journey and supported facility staff in helping patients remain on track through evaluation completion.
- Providing educational materials from various sources that speak to transplant referral processes, barriers and benefits to transplantation, and living donation
- Providing education and resources to the patients, caregivers and facility staff enhanced understanding of the Kidney Donor Profile Index (KDPI) and Estimated Post Transplant Survival Score (EPTS) to increase acceptance of otherwise discarded organs.

Barriers to Achieving Goals

- Lack of consistency in wait listing guidelines;
- Lack of communication between transplant centers and dialysis facilities on the transplant workup process;
- Difficulty scheduling transplant workup appointments around other medical and dialysis appointments; and
- Lack of education and promotion of transplant prior to the initiation of dialysis.



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. A diagnosis of ESRD requires life-sustaining kidney replacement therapy. Patients with ESRD have several treatment options, including in-center hemodialysis, home hemodialysis, peritoneal dialysis or transplantation. Home dialysis (hemodialysis or peritoneal dialysis) offers several benefits for the patient, including improved outcomes, enhanced quality of life, flexible treatment schedules, reduced costs associated with travel to the dialysis unit, and a feeling of being in control. Combine these benefits with infection prevention precautions due to a global pandemic, and you can see how despite being an epicenter for COVID-19 in the early part of 2020, New York State was able to grow home therapies utilization by 124%.

Project Overview

As with all QIAs, the Network launched the Home Therapies QIA with an initial activity – a facility level root cause analysis conducted to establish facility level awareness of unique barriers to home therapies utilization. Within months after QIA launch, the state was in "pause" during which time only essential services were in operation. The logistics of travel to and from dialysis treatments three times a week created a breeding ground for transmission of COVID-19, and by June, home therapy providers in NYC were reporting up to a 200% increase in patient interest in home therapies.

Network staff quickly pivoted QIA interventions to stress the importance of social distancing and imperative need to refer and train patients on home modalities in a safe socially distanced environment. Despite the suspension of QIA goals due to COVID-19, the Network was able to exceed the goal of a 3.2 percentage point improvement in the natural trend of patients starting home dialysis.

Interventions

- Through the nine month QIA performance period, the Network implemented the following interventions:
- Monitoring of home referral data to determine if there were any disparities or access to care issues in referring or initiating home therapy. Interventions were planned to manage any disparities discovered through analysis of the data.
- Promotion and education about the value of using telehealth: The ability to use telemedicine to expedite the home patient intake process, patient interviews and psycho-social assessment minimized the increased contact time between patient and staff as they began a home modality.
- Provision and promotion of a professional educational offering to increase facility staff understanding of home modality options; identifying the benefits and resources needed to increase patient understanding
- Launched of "Healthy at Home' campaign to promote the benefits of dialyzing at home during the public health emergency and beyond. Campaign materials included brief informational flyers and tri folds on each modality--home hemodialysis and peritoneal dialysis-- designed to stimulate patient interest in the modalities.
- Collaboration with the State Survey Agency to provide guidance for staff assisted home therapies in nursing homes
- Collaboration with patient Subject Matter Experts (SMEs), the ESRD NCC Home Dialysis Learning and Action Network (LAN), stakeholders, the State Survey Agency, LDO management, independent providers and local and national patient groups;



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. 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 individuals dealing with end stage renal disease (ESRD) (their peers) based on shared experiences, characteristics and, in some cases, treatment type.

Project Overview

The ESRD Network of New York used an electronic assessment to formally identify all facilities with active peer mentors, patient representatives and advocates. The Network further sought to determine if these individuals were trained through the IPRO ESRD e-University Peer Mentoring Program. The Network identified 35 facilities that qualified to participate in the QIA. The IPRO E-University Peer Mentoring training modules offered educational content on the definition of peer mentoring; the roles of a peer mentor, and how to be an effective peer mentor; and the most effective ways to discuss treatment options with the mentee through the strengths perspective and empathic listening skills.

The peer mentoring activities were conducted based on a monthly themed calendar. During the months December 2019 through March 2020, the Network identified 42 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. In early spring 2020, when New York State became the epicenter of the pandemic all interactions within dialysis centers, with the exception of dialysis treatments, were prohibited.

As a result of facility restrictions the Network focused on transitioning the peer mentoring program to a strictly virtual interface. The Network continued with recruitment strategies and conducting peer mentoring webinars focusing on how to utilize online virtual platforms, as a way to continue to engage mentor-mentee interactions. The virtual platform that was used included social media applications (Facebook, Instagram, and WhatsApp) and telecommunication applications (Zoom, WebEx, Go-to-Meeting). We successfully trained 192 peer mentors on communication skills development and best practices for improved health outcomes related to transplantation, home therapies, and vascular access management.

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 for all facilities in the NSA. This effort involved the collaboration of 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, as well as its positive impact on their clients and members. The webinar also 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 New York State. Additionally, the strict lockdown protocols within NYS limited in-person interactions outside of the dialysis facility. As a result, the Network created a resource that explained different types of virtual interfaces, how to use them and the tools necessary to efficiently utilize them.
- Virtual Jeopardy Game: The Network created a dialysis education based Jeopardy game with a COVID-19 focus. The game was intended to be conducted as an ice breaker and an assessment

for the mentor to determine a mentee's level of knowledge about ESRD and its associated treatments.

• 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, and interactive PowerPoint presentation, 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 implementation of peer mentoring. New York State based facilities struggled with strict regulations, the transferring of patients (due to the increased incidence of the COVID-19 virus), and patient and staff death.
- 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

- Virtual engagement and the adaption of different virtual applications especially those involving face-to-face interfaces (Facebook Messenger, Instagram, WhatsApp and Zoom). Many of our peer mentors have maintained long standing relationships with their mentees through these applications.
- The exchange of peer mentoring strategies between the Network and the facilities during LAN calls increased the facilities' understanding of peer mentoring as evidenced by the post-webinar assessment.
- Collaboration with other Networks in the IPRO ESRD Network Program provided Network 2 with a larger perspective on how to effectively implement a peer mentoring program, as well as a clearer understanding of barriers that impact the ESRD community nationally, allowing us to specifically address these perceived barriers.
- Collaboration 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.





ESRD NETWORK RECOMMENDATIONS

Facilities that Consistently Failed to Cooperate with Network Goals

The Network did not identify any facilities in its service area that failed to cooperate with Network goals in 2020.

Recommendations for Sanctions

No recommendations were made to CMS for additional services or facilities in the Network service area during 2020.

Recommendations to CMS for Additional Services or Facilities

In 2020, the Network made the following recommendations to CMS for additional services to support the ESRD Network program.

- Improving communication and streamlining the referral process between dialysis centers and transplant centers
- Improving access to COVID-19 vaccinations by prioritizing ESRD patients within NYS regulatory systems for vaccine distribution phases, in addition to collaborating with hospitals and LTC facilities to provide vaccinations to ESRD patients
- Promoting the importance of telehealth for mental health services for patients and staff, including 1:1 counseling, support groups, and psychiatric appointments.



ESRD NETWORK SIGNIFICANT EMERGENCY PREPAREDNESS INTERVENTION

COVID-19 Pandemic Epicenter: New York State

As part of the Network's responsibility to respond to emergency events, staff began monitoring the COVID-19 virus in mid-January 2020looking for potential impacts and strategizing support needs for the ESRD community. This work was coordinated with CMS, KCER, the State Department of Health, New York City Office of Emergency Management (NYCEM) and regional healthcare coalitions. In February 2020, the Network activated a virtual Network Operation Center (NOC) to begin preparing for a pandemic situation. This included planning with NYCEM and the State Department of Health to discuss potential impacts and needs of the ESRD community. The first community alert was sent on February 19, 2020, and a Network COVID-19 Resources webpage was created early February. By March, when the first New York State dialysis patient tested positive, the Network was fully activated and engaged in partnerships with emergency stakeholders to monitor and address the needs of the ESRD community. Although the pandemic peaked in April/May (NYC/Downstate), the second wave, which began in September/October 2020 brought outbreaks to upstate and western New York State. Within the first three months of the COVID-19 pandemic, when NY was the epicenter, Network 2 provided direct 1:1 telephonic support and personalized TA to >85% of NYS dialysis providers.

Formation of a COVID-19 Task Force

In early March 2020, the Network identified a group of clinicians and a patient from hospitals and dialysis facilities throughout the state to create a NW COVID-19 Task Force. Task force members met first daily, weekly, then bi-weekly to discuss clinical guidelines, barriers and potential issues within the dialysis community. The group proved invaluable in identifying resources and guidance for the community, and shared insight and experience with other states across the nation as the pandemic spread. To date the Task Force is still in place providing guidance to Network staff.

Communication with Network Service Area and Stakeholders

As part of our early response to the pandemic, the Network established an internal process for review and approval of communications and dissemination of information to the community. At the beginning of the pandemic, the Network released the information as it became available, and continued that practice throughout the process of (State stay at home orders), slowly re-opening based on state-defined metrics.

The Network created a COVID resource page for facilities with a direct link on our website home page as well as links from staff members email signature banner. This page was updated regularly to keep up with current information that was being released from credible sources across the nation and created a repository of information for facility staff to access on demand. A similar page was created for patients with up-to-date patient focused COVID-19 guidance and resources. All COVID websites and resources were branded with a professional or patient COVID emblem to clarify audience focus. The Network communicated with the patient population by utilizing a multi-pronged approach which relied on dissemination of resources through one-on-one calls, direct email, mass text messaging platforms, and social media platforms (Facebook). Patients were encouraged to contact the Network with questions about stay-at-home orders, COVID-19 safety, and changes to facility treatment protocols. The Network also utilized facility staff as a means to share information with patients copying key contacts on the releases of patient aimed information and guidance encouraging to share resources with patients/family members.

Patient Communication

To communicate with patients, the Network used email, social media, text messaging, recorded call messages, and conference calls. The Network has a well-established group of Patient Facility Representatives (100+ members) that are part of the overall Patient Advisory Committee. These patients

serve as a conduit between the Network, dialysis providers and patients who receive treatment at the facility they represent. To assess effectiveness of patient communications, the Network created learning units on Facebook that contained important information which the Network had disseminated through the patient community regarding COVID prevention and how to stay healthy during the pandemic. Out of the 100 Facebook users 100% viewed all the units on COVID and 68% completed all segments of the learning units demonstrating that they had effectively received and reviewed Network communications. The effectiveness of the information released during the pandemic to assist with mental health needs for both patients and providers is still an area of concern for the Network based on feedback from social workers and patient advocates. Additional resources to help with depression, anxiety, and provider burnout are being developed and researched to release to the community to help with this area of concern.

The Network created weekly patient educational newsletters focused on COVID-19 related information, support services, and symptom tracking. Moreover, the newsletters have a mental health component, which focuses on different proven mental health techniques that are effective in helping individuals cope with trauma and continuous stressors. Network 2's active bi-weekly virtual patient support group and patient-designed educational webinar series mitigates the impact of MH issues during the COVID-19 pandemic. During the initial months of the COVID-19 pandemic, we implemented a virtual support group using WebEx, twice a week, in response to PAC members expressing feelings of depression and anxiety. This group became an integral part of the patients' well-being and fostered support for one another, helping to ease depression and anxiety.

Patient Support and Technical Assistance

The Network established a 24/7 Hotline Support for facilities and patients. Calls that were received through that dedicated line or any other Network line were tracked and trended to quantify the issues, resolutions or technical assistance provided. As part of the greater ESRD and healthcare community, Network staff participated in a number of stakeholder-led webinars and conference calls, Facebook group live chats, and events to provide resources, highlight guidelines and answer questions about COVID-19 in the ESRD community. Weekly data driven technical assistance was provided to all facilities that were identified in either a "Hot Zone" or "Outlier," assessment, and needs were reviewed with facility staff.

Patient Transportation Issues

The Network worked to address the >100 transportation concerns related to driver refusal and driver shortages by collaborating, promoting and trending and tracking a State DOH safety net resource. The NY State DOH subcontracted with MAS Transportation to provide transportation for patients under investigation for COVID-19 and for those who were COVID-19 positive and were unable to get to dialysis. This safety net resulted in patients being treated at a dialysis center during the course of their positive status, thus keeping them out of hospital systems that were already overburdened.

Promoting Telemedicine and Telehealth to Assist in Social Distancing

The Network created a 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. The resources listed below comprised the initial Network Telehealth Toolkit, and were released to providers on June 18, 2020.

Lessons Learned

The Network has learned that existing partnerships with local and state level agencies and stakeholders proved to be extremely valuable in speeding up collaborative efforts in dealing with COVID-19 and to resolve issues as they arose within the community. These partnerships were strengthened in our combined response to the healthcare community as a whole, and have cemented the ESRD Network as a subject matter expert with many stakeholders and as a primary access to all of the 345+ dialysis facilities in the NSA. In addition to clinical guidance, infection control and transportation issues, there was a need for emotional and mental health support resources to assist the ESRD community in coping with

communicable disease outbreaks. The continuity of transportation during an emergent event is critical to the infrastructure of patient care, especially for those on dialysis, and in a pandemic situation, dialysis patients (unless using home modalities) cannot fully self-isolate, as they need to travel to dialysis three times a week, and that in itself poses many challenges to contain the spread of a communicable disease.

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 The Kidney Community Emergency Preparedness Coalition (KCER), state and city health departments, offices of emergency management, and emergency preparedness coalitions to ensure safety and continuity of care for ESRD patients throughout New York State.

In addition to supporting the activities to mitigate the spread of COVID-19, and advocating for the ESRD community to have access to scarce resources (Testing, PPE and vaccines) Network staff offered comprehensive support to patients and linked healthcare practitioners to appropriate resources to mitigate and recover from 36 regional and facility level emergencies which included Snow events, Water issues, and power loss. In 2020, the Network successfully managed 26 emergency events that required intervention, response, and/or tracking. These events accounted for a total of nine calendar days of facility closures and 22 schedule alterations.

ACRONYM LIST APPENDIX

This appendix contains an <u>acronym list</u> 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.