End-Stage Renal Disease Network of the Ohio River Valley



2020 Annual Report



Hall of Champions along Indiana Central Canal, Indianapolis, IN

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ESRD DEMOGRAPHIC DATA

IPRO ESRD Network of the Ohio River Valley (Network 9) is one of four End Stage Renal Disease (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 9, IPRO manages the ESRD Network of New England (Network 1), ESRD Network of New York (Network 2), and ESRD Network of the South Atlantic (Network 6), 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 9 serves ESRD patients, dialysis providers, and transplant centers in the states of Kentucky, Indiana, and Ohio. The role of Network 9 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. Its goals, our methodology for attaining them, and our achievements are described throughout this report.

According to ESRD National Coordinating Center (NCC) 2000 end-of-year data; the ESRD population in the Network 9 region was 50,462, the fourth largest in the country.

The largest population of ESRD patients in our Network service area reside in Ohio, which has approximately three times the patient population of our smallest state, Kentucky. In 2020, six new Medicare-certified dialysis facilities opened in our Network service area, increasing the net number of facilities to 661. The Network 9 service area also includes 12 Veterans Affairs (VA) hospitals and 14 transplant centers. The Network 9 service area had the third largest number of ESRD facilities in the nation, with approximately 60 facilities less than the largest Network, but ranks fourth in patient census. As of December 31, 2020, the Network 9 service area included 50,462 patients; 33,672, of whom were prevalent dialysis patients.

An ongoing characteristic of the Network 9 service area has been its large number of facilities, which results in its region having a lower average patient census per facility than most other ESRD Networks. This provided the patients in the region with more options for selecting a facility, dialysis provider, treatment modality and schedule, and medical care. Conversely, the Network observes that the larger number of facilities can lead to staff shortages, leadership transition issues, and need for frequent retraining of staff due to continual turnover and recruitment for new facilities. These issues create challenges for Network 9 to establish continuity of care and to sustain practices for optimal outcomes.

The Advancing American Kidney Health Initiative signed into legislation in July 2019 focuses on increasing ESRD patients' access to transplant and home dialysis, based on the scientifically proven improvement in quality of life, mortality, and morbidity for ESRD patients using these modes of renal replacement therapy, as opposed to in-center hemodialysis. ESRD Networks are charged with increasing the number of ESRD patients offered and receiving these renal replacement modalities. Network 9 has seen a number of interesting shifts in data aligning with this initiative since 2016 but its most dramatic shift was noted this year. In 2020, for the second consecutive year, the Network observed a reduction in the number of patients dialyzing in-center going from 29,291 in 2019 to 28,107 in 2020. The growth in prevalent patient census has occurred exclusively within the treatment modalities of home and transplant. Network 9 has experienced an 8.8% increase in the number of patients dialyzing on a home therapy and a 14.2% increase in the number of patients who have received a kidney transplant from 2019. Currently, its overall percentage of patients dialyzing in-center represents 56% of our population, with a shift to 44% of prevalent patients dialyzing in the preferred modalities. The Network has continued efforts to promote increased use of these modalities as preferred choices in renal replacement therapy and to decrease the use of in-center hemodialysis (ICHD) as the primary option for care. In the past four years

Network 9 has been able to shift the census to 44% dialyzing within a preferred modality. Tables which include the overall demographic data for the Network 9 service area are found on the next four pages.

In 2020, the Network deployed interventions and strategies 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.























ESRD NETWORK GRIEVANCE AND ACCESS TO CARE DATA

In 2020, 70 grievances were reported to the Network by patients and/or patient representatives. This represents an approximate 22% decrease from the previous year. The most reported areas of concern were related to the patient treatment and quality of care (scheduling and transportation issues, physicians' orders, and policy and procedures); staff and interpersonal related conflicts (professionalism, clinical competency, staff/patient ratio, and communication); facility's physical environment (infestation, sanitary conditions, temperature control); and clinical quality of care (access site issues, infection control and patient safety). The Network investigated and monitored all grievances using a patient-centered approach.

Interventions and efforts to resolve the grievances included Network mediation, initiating and participating in interdisciplinary conference calls, an intensive review of patient medical records, education on appropriate communication techniques, promoting the improvement of the facility's professional culture, identifying resource materials and trainings for provider participation, seeking clinical input from the Network's quality improvement team, 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 executed. Four new resources were created including *Your Rights and Responsibilities as an ESRD Patient, We Can Help flyer, What the Network Cannot Do* handout, and the *Grievance Process Guide: A Guide for Patients and Families.*

The Network reported 32 involuntary discharges (IVDs) in 2020. This represents approximately a 37% decrease from the 49 patient discharges reported in 2019. Of these IVDs, 22 were initiated due to immediate severe threats. Physician discharges due to medical noncompliance and behavior constitute five of the discharges. The remaining were due to ongoing disruptive behavior and the dialysis facilities being unable to meet medical needs. Several of these cases resulted in the patient being denied admittance to an alternate outpatient facility (failure to place). Displaced patients have to rely on emergent dialysis therapy, as opposed to being placed in an outpatient dialysis facility. The Network responded to these cases by collaborating with hospital systems, dialysis providers, and patients in achieving placement at an outpatient facility for continuity of care.

Technical assistance and guidance continued as the Network helped facilities to address issues related to nonadherence, behavioral concerns, mental health issues, and potential access to care cases. In total, the Network provided technical assistance and consultation to address 131 facility concerns that included non-compliance with treatment, managing disruptive patients, and 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 facilities and patients to come to a better understanding of the current situation and develop a resolution. These conferences create 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 more engaged and active in their care as a strategy to improve patients' understanding and acceptance of their kidney disease and responsibilities as a kidney patient.

The Network began tracking grievances and access to care cases directly related to COVID-19. Between the months of April and December 2020, there were 12 cases of grievance related to concerns surrounding COVID-19. Three access to care cases and one at-risk case were reported to the Network by two patients and two facilities. Eight facility concerns required guidance and consultation. Areas of concern included policy and procedure being followed (masks, disinfection), altered schedule and treatment times, and vascular access issues.

The Network continued to provide a variety of resources to educate facilities to enhance their skills in grievances and access to care management. In 2020, the Network hosted a new offering: a three-part webinar series for dialysis facilities covering the basics of assessing patient grievances, best practices in preventing patient

discharges and the role of the facility in the event of an involuntary discharge.

The Network worked one-on-one with all patients who contacted us with concerns or access to care issues, often serving as a mediator between the facility and patient. Facilities received one-on-one consultation to brainstorm potential interventions when working with the patients. Several resources developed by other organizations: *Managing Retaliation* from the ESRD National Coordinating Center (NCC) and the ESRD Forum's Patient Advisory Committee (*PAC*) *Grievance Toolkit* were shared to assist patients with communicating and managing concerns with their care. The Network has made these tools available on its website, creating a family of materials accessible by patients and providers at their convenience. In 2020, the Network's goal continued to be to prevent grievances and decrease the number of patient discharges through enhanced communication and problem solving between patients and the facility staff. Only through improving the experience of care and assisting facilities in managing disruptive patients can Network 9 seek to lower the number of potential and actual access to care issues. The Network has found that a key strategy to achieve this goal is to encourage the ESRD patient to become an active member of his or her care team, which is a constant focus of our Network activities.





ESRD NETWORK QUALITY IMPROVEMENT ACTIVITY DATA

In 2020, the Network conducted quality improvement activities (QIAs) focused on ensuring and improving the quality of care for the ESRD patients in the Network service area by working closely with ESRD patients, family members and caregivers, nephrologists, dialysis facilities, advocacy organizations, and other stakeholders. Areas of focus included:

	Increasing the number of patients initiated to a home modality
Increasing referrals and use of vocational rehabilitation services	Reducing healthcare associated infections
transplant wait list	Supporting facilities in the use of the National Healthcare Safety Network (NHSN) and health information exchange (HIE) systems

Empowering patients in 2020

The Network focused its quality improvement efforts on integrating the patient voice by encouraging use of patient facility representatives to promote a culture of patient centered care. The Network's Patient Advisory Committee (PAC) is composed of active dialysis patients, transplant recipients, care partners, and family members who volunteer within their facilities or throughout the community to promote communication among patients, staff and the Network and inform patients about the ESRD Network and its programs and resources. The Network's PAC is divided into a two-tier program to allow patients the opportunity to participate at whatever level of commitment they felt comfortable: Patient Facility Representatives (PFR) and Patient Subject Matter Experts (SME). The PFR's role was originally introduced by the Network in 2018 to build awareness of the need for patient representation within each facility participating in Network quality improvement activities. PFRs distribute project materials, serve as peer mentors, report QIA in facility quality assurance and performance improvement (QAPI) meetings and participate in lobby days or other promotional activities. Patient SMEs from the PAC advise the Network on resources and education, serve as board members and advisors, and participate on calls at the Network and national level.

In 2020, the Network recruited and engaged 276 patient volunteers from 206 facilities and added four additional Patient SMEs to provide the patient voice in all Network QIAs at the national level by serving as Network representatives to the Forum of ESRD Networks, the ESRD National Coordinating Center (NCC) and the Kidney Community Emergency Response (KCER) program. The Network worked to increase patient involvement in QAPI meetings, enhance patient involvement in their plans of care (POC) and increase patient participation/leadership in peer support groups. The Network began collecting data related to these metrics from all participating facilities in January 2020. Data collection ceased at the end of April 2020 due to the public health emergency. With the last reported data, the Network determined that 33.85% of the facilities in the Network Service Area (NSA) included patients in QAPI, 40% of all facilities reported having an active support group for patients, and 100% of all facilities hosted plan of care meetings between the patient and interdisciplinary team.

Long Term Catheter Quality Improvement Activity

The COVID-19 pandemic caused reductions in provider staffing and impacted all healthcare procedures including the placement of permanent vascular access. The Network worked toward the goals of this quality improvement activity, but was not able to achieve the outcomes due to the effect of the pandemic.

Background

Patients with Long Term Catheters (LTCs) are defined as those prevalent patients with a catheter in use for dialysis treatments for 90 days or longer. Network 9's data corroborates the CDC's 2013 findings indicating that 80% of ESRD incident patient population, i.e., patients who initiated hemodialysis within the past 90 days, began their treatment with a catheter. Research on the increased morbidity and mortality associated with the use of a long-term catheter is well known in the ESRD community. Network 9'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.

The work of the LTC reduction QIA is to drive improvement in access placement practices and reduce the utilization of LTC in the prevalent patient population. This improvement would be demonstrated by the increased number of ESRD patients initiating dialysis with a permanent access and a decreased rate of LTC use in the hemodialysis patient population. The Network has shown a consistent reduction in long-term catheter rates since (2016-2019) with a 3.2% reduction in LTC rates across the Network's service area (from16.43% to 13.2%).

The CMS prescribed goal for reduction in 2020 was a 1.25% reduction across the Network service area with the baseline of 13.20% (July 2019). In January 2020, the Network had achieved a reduction of 0.58% or 46% of the goal and was on track to achieve the 1.25% reduction. However, the public health emergency caused by the COVID-19 pandemic began to affect the LTC count in February with an overall incremental increase, culminating in an increase over baseline of 2.79% by December 2020. This correlates with national numbers that saw a 2% or greater increase. The barriers to goal achievement are detailed below.

Barriers to achieving goals

Vascular access surgeries and procedures required to place permanent accesses and remove LTC were viewed by numerous providers as "non-essential" during the COVID-19 pandemic. Many vascular surgeons and interventional radiology departments were reassigned to assist other areas of the hospital burdened with the influx of COVID-19 patients. Initially the ability to access required COVID-19 for surgeries and procedures was a large barrier, especially in urban areas which offered only drive-through testing facilities.

In May 2020, as hospitals resumed performing surgeries and procedures related to access, many patients were found to be asymptomatic COVID-19 positive at the time of pre-operative testing. Additionally, the number of patients who lost kidney function due to a COVID-19 diagnosis created a larger than normal volume of acute renal patients initiating dialysis with catheters, and then deemed to be ESRD patients. This placed an added burden on an already backlogged system and further delayed the goal to proceed from LTC to permanent access within a 90-day period.

Interventions

Prior to the suspension of QIA projects the Network had begun implementation of a number of interventions to drive the reduction of LTCs in the NSA. These included:

• Establishing a vascular access champion in each facility to assist patients with scheduling appointments and procedures as a way to ensure movement through the process to permanent access

placement.

- Engaging a facility project lead and patient representative in each facility to assist in creating opportunities for education, communication, and implementation of interventions to reduce LTCs at the facility level
- Implementing a tool created in 2019 by the Network to share incident access information with facilities and physicians as a way to lower LTC- only incident admissions through benchmarking.
- Sharing of ESRD NCC *Fistula First Catheter Last (FFCL)* benchmark and communication data related to progress toward the Network's year end goal.

The Network helped clinics navigate surgical and procedural barriers during the public health emergency by releasing 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 for sharing of best practices as they are identified, but these efforts did not reverse the increase in LTC use during the pandemic.

Best practices spread to achieve goals

An environmental scan conducted by the Network in March 2020 through July 2020 revealed a number of best practices employed by facilities to mitigate challenges associated with LTC reduction and placement of permanent access. Identified best practices included: 1.) creation of alternative sites for catheter removal, e.g., hospital emergency rooms and physician offices; rather than waiting to schedule procedures in vascular access centers or surgery suites. 2.) nurse and vascular managers assisting patients with scheduling pre-procedure COVID-19 testing at area hospitals instead of relying on drive- through sites diminished the disparity that existed among urban patients with no personal transportation and accelerated vascular access procedures. The Network shared these best practices while continuing to spread the essential value of permanent vascular access placement throughout 2020.



Blood-Stream Infection Quality Improvement Activity

Dialysis patients are at higher risk than the general population for acquiring healthcare-associated infections (HAIs)—specifically, bloodstream infections (BSIs)—due to the regular and frequent use of catheters and other forms of access to their bloodstream while dialyzing. The physical and emotional toll of such infections on patients and their care partners/families is immeasurable, and the financial cost is staggering. The Direct Cost Report of Healthcare Associated Infection paper published on CDC.gov estimates that HAIs are responsible for more than \$28 billion in yearly national healthcare expenditures. The Network has demonstrated a decrease in the semi-annual pooled means (# of infections/100 patient months) within the reporting periods of January to June, annually since 2016 achieving a continual reduction in the infection rate within our NSA.

In 2020, Network 9 worked to reduce bloodstream infections with 120 target facilities that demonstrated the highest Standardized Infection Rate (SIR) from June to December of 2019. The SIR is a calculation of the number of expected infections for each facility based on past performance.

In 2020, Network 9 surpassed the 20% reduction with a semi- annual pooled means of 39.88% within 120 facilities from the baseline set by National Health and Safety Network (NHSN) data (January-June 2019). This affected a change from 420 infections/100 patient months to 161 infections/100 patient months.

The key strategies the Network has employed to reduce the spread of BSIs were based on strict adherence to the CDC core interventions and patient involvement in the infection prevention processes. The onset of the pandemic early in the quality improvement cycle in 2020 brought quick and undivided attention to use of the CDC core interventions and instantly pulled the patients into being part of the infection prevention team. The Network conducted over 700 COVID-19 technical assistance calls and collected best practices to prevent the spread of COVID-19. 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-19, but also simultaneously reduce the spread of bloodstream infections.

The Network also worked to create a community of practice to address infection prevention. Network 9 shared best practices to prevent the spread of infection in high risk situations, including transitions of care, by advocating for care partners to practice a call ahead culture and provided guidelines on how transport companies could disinfect and cohort patients to prevent infection.

Additional Quality Improvement Activities to Reduce Bloodstream Infection Rates

Lowering blood stream infection rates takes a coordinated approach that requires the direct actions of the facilities with high BSI rates as well as ongoing education of the ESRD provider community and good communication processes in transitions of care. In order to support those two processes CMS requested that ESRD Networks conduct two other activities within the BSI QIA as described below.

Documenting Facility Annual Completion of NHSN Dialysis Events Surveillance Training

The National Health Surveillance Network (NHSN) is the CDC infection reporting database. Appropriate data entry to capture infection related data is mandatory to effectively manage a reduction in BSIs. Not all facilities in the Network are required to participate in NHSN; those excluded are facilities that have been in operation less than six months, those providing only home-based dialysis, pediatric facilities, and Veterans Affairs dialysis centers. Each participating facility is required to complete Annual Dialysis Event Surveillance training to ensure accurate documentation and reporting of infection events. The Network's goal was to obtain documentation that verified a training completion rate of 90% of all eligible facilities. A total of 372 of the 566 eligible facilities, or 65.72% completed this training by April 2020, when the QIA activities were suspended and data was no longer provided.

Membership and Utilization of Health Information Exchange

To further improve the transition of care, an additional QIA was added to assure the usage and membership of Network 9's area facilities in a Health Information Exchange (HIE), an electronic secure system to relay reporting of blood culture results and utilization of antibiotics to treat infections between care partners. The Network surpassed the goal of 20% of the total facilities, with 413 of the 651 facilities or 63.44% participating in an HIE.

Barriers to Achieving Goals

The harsh reality of the high rates of mortality associated with the spread of infection during the Covid-19 pandemic was a unifying force in overcoming most barriers in the use of infection prevention practices. Shortages of supplies (e.g., masks and gloves) created intermittent issues which were typically resolved through communication and collaboration. One barrier the Network identified during the pandemic was the challenge many facilities had in documenting in NHSN. The ability to achieve a single user login for new users was delayed; staff who had access to many facilities were deployed to assist with patient care in facilities with increased COVID-19 burden; and facilities that had no authorized user of NHSN to document were commonly identified or reported barriers. The Network worked with 45 such facilities to gain access to NHSN during 2020. While the Network surpassed the prescribed goal for this activity the actual achievement may have been higher, as many facilities lacked the staffing capability and access to report in NHSN during the pandemic.

Best practices spread to achieve goals

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, hand sanitizer, and surface disinfection audits for facilities and patients/caregivers to use. The Network created a community of practice focused on infection prevention regularly releasing up to date information from the CDC and sharing best practices to prevent the spread of infection in high risk situations. Network 9 also provided one-on- one directed technical assistance to over 700 facilities in the NSA and assured that 100% of our facilities attested to understanding the CDC guidelines for infection prevention during the pandemic.









Transplant Waitlist Quality Improvement Activity

The Network worked toward the goals of this quality improvement activity, despite the reductions in provider staffing, the limitations on procedures due to the COVID-19 pandemic, and the changes in the goals of this quality improvement activity. However, the Network was not evaluated on the results of its activities.

Background

The Executive Order signed on July 10, 2019, titled Advancing American Kidney Health Initiative challenged the ESRD community to increase access to transplant through improved coordination between transplant centers and ESRD facilities as well as through increased access to organ offers and use of living donation. The goals of the order include doubling the number of kidneys available for transplant by 2025 and ensuring that 80% of all new dialysis patients are either placed on a home modality or receive a transplant, rather than receive in-center hemodialysis. The IPRO ESRD Network of the Ohio River Valley was already focused on creating a culture, in the community, that embraced the bold goals of the Executive Order to further our work. According to the 2017 United States Renal Data System (USRDS), kidney transplantation rates increased, while the number of patients being waitlisted for a kidney transplant continued to decline across the country. The 2008 CMS Conditions for Coverage for ESRD Facilities require dialysis providers to educate their patients about treatment modalities, including transplant. Despite this requirement, many facilities in the Network continue to operate with a lower than expected number of patients on a transplant waitlist. A patient's eligibility for transplant varies depending on the transplant center, the patient's health status, the physician's perception of the patient's eligibility for transplant, and the patient's financial status. The evaluation process for transplant is further hindered by numerous barriers and process changes that require improved communication among the dialysis facilities, transplant centers, and patients.

In 2020, the Network staff collaborated with the Medical Review Board (MRB), subject matter experts (SMEs), large and small dialysis organizations (LDOs, SDOs), Quality Innovation Network /Quality Improvement Organizations (QIN–QIOs), hospitals, Organ Procurement Organizations (OPO) transplant centers, patient family members / caregivers and other key stakeholders to establish a transplant coalition. The Ohio River Valley Transplant (ORVTx) Coalition was formed with a mission to improve patient wait listing and ultimately increase transplant rates in the region. As a community of practice we committed to work collaboratively on improving communication between transplant centers and ESRD facilities, share best practices broadly, and improve education on living donation and patient organ choice. The efforts of the ORVTx align with the quality improvement work of the Network, and education and resources developed by the coalition have been used to bolster the Network's efforts. Also by creating a community of practice focused on transplantation the Network has raised awareness and strengthened the commitment to increase access to transplant for our patients. The goal of this year's transplant quality improvement activity was to increase the aggregate number of waitlisted patients in the Network Service Area by 1.25% over the course of the QIA year (January through September 2020).

In terms of individuals affected, the Network's goal was to add 1,154 patients to the waitlist. Despite the challenges and barriers imposed by the pandemic, many of which are discussed below, the Network was able to add 1,265 patients to the waitlist during the QIA period, achieving 108 % of the goal. The Network transplant centers performed 1,475 transplants in 2020 and affected a > \$11.2 million cost savings in government funds. This cost savings was the second highest among all the ESRD Networks in

the nation. The ongoing QIA and ORVTx efforts have increased the number of patients in the Network's service area waitlisted from 30 patients/ month in 2019 to over 100 patients/ month in 2020.

Interventions

Prior to the pandemic the Network planned the following interventions for implementation during 2020 to improve processes to increase patient additions to the transplant wait list.

- Identifying and engaging a facility project lead and a patient facility representative in each targeted facility to assist in creating opportunities for education, communication, and implementation of interventions to increase transplant wait listing at the facility level.
- Building relationships with key transplant coordinators at facilities to assist in identifying opportunities for education, 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.
- Providing educational materials from various sources that speak to the transplant referral processes, barriers and benefits to transplantation, and living donation.
- Providing education and resources to patients, caregivers and facility staff to enhance the understanding of the Kidney Donor Profile Index (KDPI) and Estimated Post Transplant Survival Score (EPTS) to enhance acceptance of otherwise discarded organs.
- Increasing education and communication on the topic of living donation-both paired and unpaired donor sources.
- Recruiting and utilizing patient facility representatives to assist with transplant education and helping patients navigate the referral and workup process.
- Identifying geographic regions within the ESRD ETC regions to work intensive interventions and PDSA cycles using a Small Test of Change Model.
- Utilizing transplant waitlist referral reports to assist both dialysis facilities and transplant centers in validating United Network of Organ Sharing (UNOS) waitlist status and update records accordingly.
- Providing monthly goal and project participation scorecards to enhance facility understanding of progress to goal.
- Identifying where issues exist that create disparity in referral or wait listing and working toward changes in practices to reduce disparities.
- Sharing of best practices.

Through the work of the ORVTx Coalition the Network spread best practices and launched two innovative resources for use within the community. Best practice sessions educated the community on the use of Telehealth to complete the pre-evaluation transplant work up, how to create a living donor champion program, the effects of the pandemic on living donation, and an advanced recovery surgical program for donors. The innovative tools focused on improving patient centered choices. One tool known as "Wait Less" was created to educate patients about their options to decrease wait for a transplant through methods like multiple listing, living donation and consideration of a high KDPI kidney. The other resource "Transplant Center Compare" provides unique characteristics of each transplant center which could assist patients and caregivers in finding the transplant center that would be the best match. Self-reported data was collected from each transplant center related to patient to complete a transplant workup, and whether any community outreach was provided by the transplant center to facilitate work up completion closer to the patient's home. The Network mined data from the *Scientific Report of Transplant Recipients(SRTR)* to provide performance information for each transplant center in metrics that would make a difference to patients (e.g. average time from waitlist to transplant, number of transplants performed each year and the

organ procurement organization the transplant center used for the purpose of streamlining multiple wait listing). The absolute and relative criteria for transplant candidates and those for living donors were included as well. By sharing this information in a "one-stop" format the Network and the ORVTx community are working to help drive patient advocacy and understanding in making choices leading to transplant.

In January 2020, the Network also conducted a small test of change model to increase communication between 30 large dialysis organization facilities and one transplant center. The 30 facilities were further divided into groups of 10, with the specific transplant center coordinator responsible for that geographic area. The facilities participated in a root cause analysis and determination of barriers to wait listing. Each facility and the transplant center were identified. Though the first meetings between these groups were completed the follow up to the effort was not completed due to QIA suspension. Facility level data review of these thirty facilities revealed at project end a 30% increase in wait list additions for a total of 14 additional patients waitlisted over the previous year.

Barriers to achieving goals

The barriers Network 9 were aware of at the start of our work in 2020 continue to be a factor, but they are slowly improving, these include:

- Lack of consistency in wait listing guidelines;
- Lack of communication on the transplant workup process between transplant centers and dialysis facilities;
 - Varying levels of patient assistance throughout the transplant workup process;
 - o Lack of a required support person for each transplant candidate;
- 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.

The public health emergency added an additional layer of barriers as transplant surgeons were transitioned to support COVID-19 hospital functions and multiple transplant centers furloughed or redirected staff as there was no capacity in the hospital systems to support pre-transplant procedures and consultations. Living donor transplants were put on hold because they were considered non-essential surgeries that could be deferred until a later date and because of concerns about exposing donors and recipients to the virus. Many patients were hesitant to visit the hospitals for appointments to complete work up due to perceived risk despite multiple safeguards.

Best practices spread to achieve goals

The ongoing collaboration to build a community of practice within the ORVTx Coalition focused on improving access to transplant was identified by the Network as a sustainable best practice that the Network has worked to promote and build upon. This collaboration in combination with the Network's focus on quality improvement, has led to the Network's success in achieving our transplant goals during the pandemic. It supported the identification of some of the most promising best practices of 2020 (e.g., the use of telemedicine to expedite the transplant intake process, which included a chart view and health assessment by the transplant nephrologist, financial office review and social work psycho-social assessment via virtual technology). This creative solution along with other resources (e.g. Transplant *Center Compare* and *Wait Less*,) were developed to mitigate the barriers created by the pandemic, and were shared across the Network transplant coalition and the nation at the virtual 2021 CMS Quality Conference.



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.

Background

IPRO End Stage Renal Disease (ESRD) Network of the Ohio River Valley supports the national focus to promote appropriate home dialysis. The objective of this quality improvement activity (QIA) is to increase the number of patients receiving home dialysis therapy and improve processes and communication between dialysis facilities and home modality clinics to effect a change in the number of ESRD patients receiving a home modality by 2025. The Executive Order signed on July 10, 2019, titled Advancing American Kidney Health, challenges ESRD professionals to promote home modalities, either peritoneal (PD) or home hemodialysis (HHD), as the preferred treatment option until the patient receives a transplant. The Network created a "Home First" culture as early as 2016, in which every patient considers home as the primary option. To support and sustain this effort, the Network spread best practices learned over the course of the contract (2016-2020) at every point of contact with patients, caregivers and healthcare providers.

Learned best practices include:

- Dedicated and flexible home training staff.
- Home champions in place, especially in those facilities that are partnered with physician group champions.
- Early education of patients preferably prior to the start of dialysis.
- Patient champions who educate and support home therapies.
- Transitional care units that educate on treatment modalities early in a patient's transition to in- center hemodialysis.
- And, most importantly the philosophy of "Never Say No," and allow every patient to attempt home therapies despite perceived obstacles.

The goal of this project was to demonstrate a 2.5 percentage point improvement in the number of patients added to a home modality in the NSA. The Network sought to demonstrate a growth of 2,701 patients initiating a home modality. Despite the barriers discussed below, the Network added 3,131 patients to home modalities during the QIA period, achieving 114.64% of the goal. The Network gain of 3,131 patients affected a >\$18.2 million cost savings for CMS resulted in Network 9 having the third highest number of patients on a home modality of all ESRD Networks, with 15.64% of our population dialyzing at home.

Interventions

Below is a list of some of the interventions the Network identified pre-pandemic to align processes to increase the number of patients using home modalities. The Network continued to support these activities as the pandemic progressed.

- Identify a home modality champion within the staff and the patients of each facility for education and process change.
- Collaborate with successful home dialysis facilities in the Network to pilot best practices. Work with physician champions to collaborate with other facility MDs to promote home dialysis.

- Recruit and encourage patient representatives to share their journey to home modality and how it improved their clinical outcomes and quality of life.
- Monitor home referral data to determine if there are any disparities or access to care issues in referring or initiating home therapy.
- Plan interventions to manage any disparities discovered through analysis of the data.
- Provide and promote a professional educational offering to educate facility staff on home modality options, identify the benefits and resources needed to increase patient understanding.
- Engage hospitals, home modality facilities, and nephrologists along with other healthcare providers to educate patients about home modalities pre-ESRD or early after ESRD diagnosis.
- Routinely share best practices identified during regional and national learning and action network meetings.
- Collaborate with early referral programs and transitional care programs to develop a model to assist in the promotion of home education and the transition of patients to a home modality early in their ESRD journey.

Barriers to achieving goals

The public health emergency caused by the COVID-19 pandemic created a shortage of home modality training nurses, who were frequently reassigned to assist in in-center hemodialysis facilities. These facilities were challenged with an increased burden of COVID-19 positive patients and decreased staffing due to the spread of COVID-19 among direct care staff. Their concerns regarding viral spread during the required pre-training and post-training home visits limited and delayed new patient starts. Additionally, many patients were hesitant to leave their homes for the additional facility appointments needed to conduct training.

Regardless of these challenges, the pandemic also drove Network facilities to continue to grow patient census, open transitional care units and increase the reach of home modalities due to the improved safety from infection exposure afforded in home dialysis.

Best practices spread to achieve goals

The ability to use telemedicine to expedite the home patient intake process, patient interviews and psycho-social assessment minimized the direct contact time between patient and staff as they began a home modality. Once the patient was initiated and stabilized on a home modality, facilities utilized telemedicine applications to provide technical assistance to patients, review protocols and procedures and most importantly to conduct required monthly facility visits.

The best practice of utilizing telemedicine was spread to both the patients and staff utilizing multimedia, educational pamphlets for patients on the use of virtual technology to complete not only home visits but physician visits. The Network provided patient facility representatives and SMEs educational resources to share with their peers the successes and benefits of using telemedicine. In addition, the Network launched a "Healthy at Home" campaign to promote the benefits of dialyzing at home during the public health emergency and beyond. The materials developed for this campaign included brief informational flyers and tri-folds on each modality, home hemodialysis and peritoneal dialysis, designed to stimulate patient interest in the modalities. Intended to be used early in the modality decision making process, these materials included the use of mobile applications for both the patients and staff. These were distributed throughout the Network, via direct mailings to patients, presentation of materials at PAC meetings and to the professionals through email and *Provider Insider* releases with the goal of encouraging patients and healthcare providers to advocate for a home modality as their first treatment choice if transplant is not an option.



Population Health Focus Pilot Project Quality Improvement Activity

Background

Due to the COVID-19 pandemic limiting provider staffing and procedures, along with contract goal adjustments, the Network worked toward providing education on vocational rehabilitation (VR) but was not evaluated on results.

Within the dialysis community, the Network recognizes several patients are not able to sustain employment due to psychosocial barriers aside from dialysis. However, dialysis facilities are strongly encouraged to continue efforts to identify eligible patients with a desire and potential for employment. Research has shown patients who remain engaged in their life activities and maintain some type of employment minimize debilitation, depression, and detachment from society.

The QIA - *Support Gainful Employment of ESRD Patients* is designed to ultimately increase overall referrals to employment networks and vocational rehabilitation (VR) services and increase the number of patients utilizing these services, while reducing an identified disparity in the referral process.

Additionally, facilities were responsible for screening all eligible patients, striving for a goal of 95%. The Network's first step was to identify barriers associated with low VR referrals. Participating facilities were given the necessary tools to complete a root cause analysis (RCA). The Vocational Rehabilitation RCA Algorithm created by the Network and the Five Whys Analysis, followed with a plan do study act (PDSA) to test processes were put in place to overcome those barriers. The Vocational Rehabilitation Screening Tool was used to initiate this project with facility staff who screen their patients to determine if they are eligible for VR services. Through the RCA and PDSA model, facilities identified the barriers keeping patients from pursuing vocational rehabilitation.

Project goals included demonstration of a 50% increase in the number of eligible patients referred from baseline as well as at least a one percent increase in the denominator population receiving VR services. A minimum of at least ten patients who were referred had to be between the ages of 55 and 64, an age limit higher than the population of the rest of the QIA. Additionally, 95% of patients needed to be appropriately screened for VR services. Due to the COVID-19 pandemic this project was suspended, measurable goals were removed, and the Network was responsible only for providing education to the facilities. Non-measurable goals included assisting facilities with creating a VR referral process which could be incorporated into any patient's plan of care and become a best practice, and guidance on appropriate documentation of a patient's VR status in the CROWNWeb system.

Interventions

Below is a list of some of the interventions the Network identified for use prior to the pandemic and continued to support as the pandemic progressed to support this initiative.

- Complete RCA to identify the top three barriers to lack of patients identified as eligible and referred for VR Assist facilities.
- Support facilities with implementing interventions to overcome barriers using a Plan-Do-Study- Act (PDSA) cycle
- Identify and disseminate key contacts for federal/state/county representation of VR/EN services to facilities and patients; Identify agencies to work with facilities on educating patients about work incentives;
- Release and have facilities implement a VR Screening Tool to assist facilities with identifying patients eligible for VR. Use rapid cycle improvement to address emergent barriers or issues throughout the project period.
- Develop resources for use by patients in VR outlier groups (i.e. ages 55-64)

- Work with facilities to incorporate processes and resources for VR in a sustainable manner in their practice. Use kick-off webinars to educate facility leadership on project, roles, responsibilities, and reporting
- Include CROWNWeb representatives as co-leads on the projects, and use data check-in tools to track patient referral and usage of VR throughout the year
- Develop a patient support social media page to engage VR participants and patients with resources, education and discussion about projects and activities
- Provide outreach to establish connection and partnership between facilities and employment Networks or other affinity/community groups
- Offer free online Work Incentives Seminar Event (WISE) webinars to learn more about the Ticket to Work program and share information with patients

Barriers to achieving goals

Potential barriers to meeting Network 9's goals were identified early on and included facilities having a lack of knowledge about available VR services for patients, patients' fear of losing their established financial benefits, and no established process for referring eligible patients for VR services. Additionally, due to the COVID-19 pandemic, several VR agencies temporarily discontinued providing services to eligible individuals.

Best practices spread to achieve goals

Despite the Covid-19 pandemic, the Network continued to provide education and resources to facilities. The purpose was for facilities to create an intentional process for screening, referring, and following up with patients when it came to the VR process. These resources are a sustainable family of materials that can continue to be used and integrated into everyday assessment. Informational webinars including Ticket to Work's free monthly Work Incentives Seminar Event (WISE) webinar was shared with the Network community.







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. We had no facilities who failed to cooperate with the goals.

Recommendations for Sanctions

In 2020, the Network did not refer any facilities to their respective state surveyor for sanctions.

Recommendations to CMS for Additional Services or Facilities

The Network referred one facility to its respective state surveyor in 2020 due to failure to follow its policy and procedure in accordance with the involuntary discharge process. The facility was investigated by the Ohio Department of Health and the complaint was found to be unsubstantiated.

Additionally, the Network reported one facility to the state surveying agency due to its inability to follow proper cohorting of COVID-19 patients and to provide personal protective equipment to its staff and patients to prevent viral spread. The facility was investigated by the Indiana Department of Health, was found to be compliant, and the complaint was unsubstantiated.

The Network worked with multiple facilities when COVID-19 isolation facilities were too great a distance for patients to travel to from their home. The Network worked with managers to accommodate patients in the home facilities by expanding hours and days of operation to avoid access to care issues.



ESRD NETWORK COVID-19 EMERGENCY PREPAREDNESS INTERVENTION

As a member of the Northeast Ohio Emergency Coalition, the Network first became aware of the novel Coronavirus in late January with the release of a situation status report, and subsequently confirmed the spread of the pandemic with the release of a flyer from the Assistant Secretary for Preparedness and Response (ASPR) within the department of Health and Human Services. The ASPR flyer alerted the community about symptom identification for the virus and regions of concern and spread; The flyer also encouraged people to take the influenza vaccination to minimize spread of influenza, in light of the new virus on the horizon. These communications also linked the Network to portals within the state and nationally to maintain situational awareness of the impending pandemic.

As the pandemic took hold in Network 9's service area in early March, to gain a better understanding of the challenges and needs of our community, the Network implemented a process to call any facility with newly diagnosed COVID-19 cases and began reaching out to these facilities. The quality improvement staff of Network 9 made 15-30 calls daily to facilities reporting more than one newly diagnosed case the previous day. Network 9 completed516 calls (environmental scan) in the initial four months of the pandemic. This environmental scan provided a method to perform facility needs assessment to detect trends and determine the need for technical assistance in the form of education or guideline clarification. These calls also allowed the Network to assess receipt of *Network Emergency Messaging Channel Communications* and verify data validity of COVID-19 case reporting by the large and independent dialysis organizations. The Network continued these technical assistance calls per CMS directive (July 2020-ongoing). Network staff called clinics in COVID-19 hot spots and those identified as outliers, making an additional 200+ calls to discuss COVID-19 barriers, share best practices and work through vaccination challenges with the Kidney Community Emergency Response (KCER) Team.

Within two weeks after initiating these calls, the Network identified a trend in which facilities and other care partners struggled to share thorough patient information that could be used to prevent exposure to the Covid-19 infection. It was identified that a "call ahead culture" was needed to provide accurate guidance and prevent exposure during care transitions especially for those patients who were coming from a nursing home facility. The Network created a webinar to provide this guidance to key care partners. Network 9 worked with LDO and SDO leadership, nursing home professional organizations, and State Survey Agencies (SSA) to create a comprehensive invitation list for attendance to the program. Using this list, we disseminated a toolkit of information that featured CDC COVID-19 guidance and Network supplemental materials.

This webinar was presented live to dialysis facilities, nursing home leadership and transportation providers. The program was posted to YouTube, and the link was shared with all dialysis providers, transplant centers, nursing homes and transportations companies; and posted to the Network website for further review and spread of these critical concepts. To ensure this CDC guidance was understood and being utilized, the Network distributed a *COVID-19: Core Knowledge to Prevent Transmission Assessment Redcap* survey including all educational links with an attestation to verify understanding.

The assessment verified that 96% of respondents had reviewed and acknowledged understanding of the CDC frontline toolkit.

- The Network realized the importance of accurate and streamlined communications to disseminate key guidance into our community. It released information using a branded format known as the Emergency Messaging Channel for visual recognition, and we distributed it on the same day and time each week.
- The Network compiled and provided:
 - 47 resources on screening and management of COVID-19

- 80 resources on significant guidance for COVID-19
- 30 telehealth resources

This branded electronic newsletter was divided into sections based on content enclosed and featured direct hyperlinks to vetted resources as well as credible sources for educational webinars. As new information and resources were added, the additions were flagged as new to pinpoint focus. All Emergency Messaging Channel communications were posted to the Networks COVID-19 Provider Website page to ensure ongoing availability of the issue beyond the distribution date. Fourteen issues were produced and distributed between March 9 and June 15, 2020 including over 200 resources to our Network contact list which comprises over 2,400 members of interdisciplinary ESRD and transplant teams. The Network monitored for receipt of information using our email bounce back rate data. This data was measured after each release with a goal to assure at least one representative from each facility received the Network communications. Based on bounce back analysis, the Network had less than a 2% bounce back from staff categorized as facility managers in our system, which was well below the industry standard and assured that at least one member of the dialysis facility team received the information.

Following the June 2020 release of the Emergency Messaging Channel, the Network transitioned to communicating via a monthly newsletter called the *Provider Insider*. This format allowed us to share not only pertinent COVID-19 guidance as needed, but also re-established a focus on the quality improvement activities.

The Network created a COVID-19 resource page for facilities with a direct link on Network 9's home page. The resource page was also accessible through a link embedded in our COVID-19 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-19 websites and resources were branded with a professional or patient COVID-19 emblem to streamline focus. The Network monitored traffic to our COVID-19 resource pages through Google Analytics, which demonstrated that our COVID-19 Alerts and Resource page and COVID-19 provider resource page both had over 400 unique views being the third and fourth highest accessed pages on our website during the pandemic. It also monitored the website activity for our patient portal of COVID-19 resources. These resources were accessible directly from our landing page. Our patient resource page had 344 unique views and was ranked as our sixth most popular page.

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 these contacts to share these resources with patients and family members in the care setting. Approximately 6,032 texts/calls were sent out between March 3, 2020 and August 31, 2020, promoting LAN, NCC and Affiliate webinars, new resources and available podcasts.

On analysis of Network 9's mass texting and call broadcasting platform, we were able to measure that 94% of all calls and texts reached patient participants. Approximately 40 e-mails between March 3, 2020 and August 31, 2020 were sent out to the PAC/PSME Groups promoting webinars, COVID-19 related resources (telehealth, mental health, support groups, home modalities, webinar and call recordings). There were no bounce-back notifications received by the Network for e-mails sent to patients.

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-19 prevention and how to stay healthy during the pandemic. Out of the 100 Facebook users 100% viewed all the units on COVID-19 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 researched and developed to release to the community to help with this area of concern. The Network initiated and maintained a 24/7 COVID-19 Hotline number for facilities and patients to express concerns and grievances related to the Public Health Emergency. Concerns identified through this hotline and mitigated by the Network program include:

- PPE shortages and concerns
- Patient questions and concerns with COVID-19 protocols
- Transportation concerns
- Access to care concerns by patients and facilities
- Guidance with COVID-19 protocols

ESRD Network Significant Emergency Preparedness Interventions

The Network created the following interventions/resources to mitigate the significant challenges we identified during the COVID19 technical assistance calls.

Support safe and seamless dialysis therapy - 5 Urgent Reminders for Dialysis Patients During COVID-19: A Network 9's developed resource, this was created in response to patient feedback expressing confusion about stay-at-home orders to help patients feel safe and encourage them to continue their dialysis treatments as scheduled during the pandemic. This resource was adopted by the ESRD NCC for national release to the ESRD patient community.

Increase use of telehealth - To ensure patients and facilities utilized **telehealth** to provide a safe and effective alternative to in- person healthcare appointments and monitoring, the Network disseminated 30 telehealth resources, sponsored a professional telehealth webinar featuring Dr. Michael Kraus and created a telehealth toolkit directed at home modality patients and professionals. Each toolkit included an educational fact sheet, checklist, a resource guide and a recorded webinar. The provider materials were released in August 2020 with an email release to all Network facilities and follow up release in the *Provider Insider* the Network's monthly newsletter. The complementary patient materials were released in September 2020 with these materials introduced on Network PAC and SME calls. Following the release of the Network generated Telehealth Toolkit to providers the Network completed a follow up COVID-19 screening assessment. It was identified that 100% of the Network's 285 home programs were utilizing telehealth with home patients.

<u>Assure transport to and from dialysis</u> - Transportation was identified as an area of concern during the pandemic, and the Network started to receive notification from facilities about disruptions in transport services for patients. Through outreach and data gathering the Network determined that a number of resources were needed to ensure stop-gap measures were in place to transport patients to appointments. To meet this need, the Network created four significant guidance resources.

- 1. An *Emergency Transportation FAQ* for all three states which summarized the management of dialysis transportation in each state (which is unique and based on different management protocols administered through the state departments of transportation, state departments of Medicaid, and county emergency management agencies).
- 2. A searchable Microsoft database that housed *Emergency Transportation Data* for each state in the service area which provided contact information on public transit options, and county emergency management agencies. The database was updated regularly with new information received regarding the state of transportation in a particular county. This information could range from specific points of contact for transportation companies, to EMA contacts, to community network contacts for alternative transportation options.
- 3. A *Safety Tips Sheet for Patient Travel* for patients who are utilizing public or shared rides/transportation to and from dialysis. Guidance on sanitization, social distancing, and hand washing procedures were highlighted. This resource was adopted by the ESRD NCC.
- 4. A *Transportation Best Practices* fact sheet was developed targeting transportation providers and state and emergency contacts to educate about the urgent need for transportation and the unique medical profile and risk associated with dialysis and kidney disease. It contains best practices for transporting patients, and identifying and/or developing community transportation networks to provide transport to appointments for patients when no other options are available.

<u>Support Mental Health -</u> The Network identified mental health challenges and increased grief due to the vast changes in day to day life as a result of the COVID-19 pandemic creating isolation, loss and grief. The Network produced a webinar called "Grief- Loss- Change and Other Tales from the Quarantine" by Julia Ellfriut, LISW-S, a hospice and bereavement counselor for over 37 years. The webinar focused on

providing strategies to assist caregivers in coping in our ever changing world. This live webinar was attended by 343 persons and was shared in the Network service area via email and Emergency Messaging. Post webinar surveying showed 100% positive feedback for this event. The Network posted all provider and patient resources on a <u>mental health portal accessed from</u> the COVID-19 specific resources page, through which we shared 22 resources and /or strategies.

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.