

ESRD Networks: Past, Present, and Challenges for the Future

Jay B. Wish* and Klemens B. Meyer†

Summary

Established by Federal law in 1978, the ESRD Networks are regional nonprofit organizations that contract with the Centers for Medicare and Medicaid Services to provide quality oversight services to chronic dialysis facilities. The governing bodies and medical review boards of each network are populated by volunteer professionals and patients. The medical review boards drive the quality agenda for each network, addressing specific local barriers to improvement. The network contract deliverables are defined by the Centers for Medicare and Medicaid Services in a scope of work document (SOW) that is generally revised with each 3-year contracting cycle. The current SOW has not been revised since the implementation of the new Conditions for Coverage for dialysis facilities in 2008 or the implementation of a bundled payment system and quality incentive program for dialysis providers in 2011. The future success of the ESRD Network Program will depend upon adequate funding, data accessibility to drive rapid-cycle quality improvement efforts, and partnerships with other stakeholder groups to address the continuum of care of patients with CKD. The Forum of ESRD Networks has developed a strategic plan that aligns the priorities of the networks with the National Quality Strategy. The integration of these objectives into the next SOW will augment the relevance of the network program to the ESRD stakeholder community as the networks move from a task-oriented approach to a system-improvement approach to quality oversight.

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*Division of Nephrology, University Hospitals Case Medical Center, Cleveland, Ohio; and
†Tufts Medical Center, Boston, Massachusetts

Correspondence: Dr. Jay B. Wish, Division of Nephrology, University Hospitals Case Medical Center, 11100 Euclid Avenue, Cleveland, OH 44106. Email: jaywish@earthlink.net

History of the ESRD Networks

The Social Security Amendments of 1972 (Public Law 92603) extended Medicare coverage to individuals whose irreversible kidney failure, which it called ESRD, required dialysis or transplantation to sustain life. Public Law 95292 of 1978 established 32 ESRD Networks. Under this law, the Health Care Financing Administration (HCFA), which was renamed the Centers for Medicare and Medicaid Services (CMS) in 2001, contracted with regional organizations to assure Medicare beneficiaries access to dialysis and transplantation and to oversee the quality of their care. Subsequent legislation specified that HCFA fund the ESRD Network Program by withholding \$0.50 per patient per dialysis treatment from payments to dialysis facilities. The Omnibus Budget Reconciliation Act of 1986 allowed HCFA to consolidate the 32 networks to at least 17; Figure 1 shows the 18 ESRD Networks in existence since 1988.

Table 1 summarizes the ESRD Networks' statutory responsibilities, most of which are patient centered, intended to assure access to high-quality care, rehabilitative services, and grievance resolution. Dialysis facility Conditions for Coverage require participation in ESRD Network activities, including quality improvement projects, data collection, and response to patient complaints and grievances. The networks are ESRD quality improvement organizations; the quality assessment responsibility of assuring dialysis facility compliance with standards of the Conditions for Coverage is the responsibility of individual state health departments, which contract with Medicare to perform

survey and certification activities. ESRD Network contracts are held by contractor organizations with governing boards responsible for their business and contractual obligations. Networks are required by statute to establish medical review boards (MRBs) with responsibility for establishing the region-specific network quality agenda, based on their assessment of local dialysis facility needs and opportunities for improvement. The governing boards and MRBs comprise volunteer ESRD professionals and patients, are unpaid, and are subject to strict conflict of interest guidelines. Patient advisory committees increase patient engagement and enhance the patient-centeredness of the quality agenda. A 2004 survey of the networks estimated that the governing boards and MRBs of all networks collectively donated just under \$1 million in volunteer hours. This figure does not include the substantial contributions of volunteers on other standing and *ad hoc* committees. On average, each ESRD Network has 10 full time equivalent staff members, with expertise in administration, quality improvement, data analysis, and patient relations. This number has grown only slightly between 1988 and 2011, despite a 154% provider increase and a 202% patient increase during the same period.

Current State of the ESRD Networks

Network Scope of Work

The scope of work (SOW) defines network contractual deliverables (Table 2). Since 1988, the SOW has

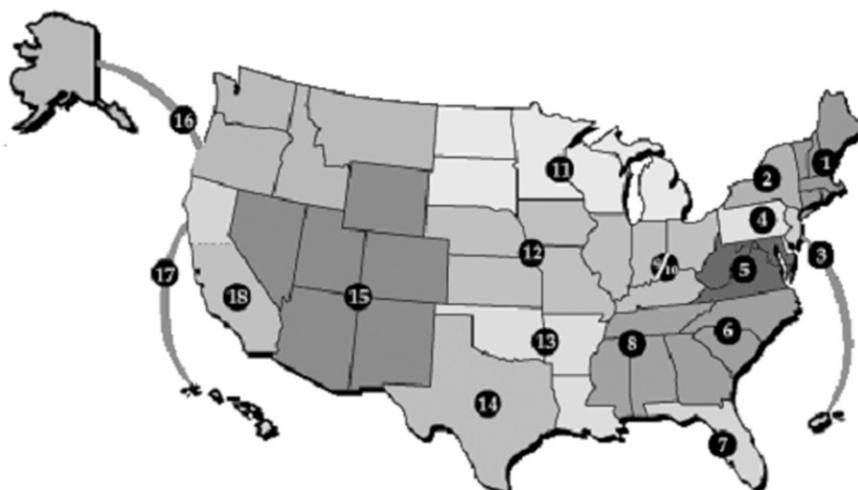


Figure 1. | ESRD Network geographic areas. Reprinted from Forum of ESRD Networks (<http://www.esrdnetworks.org>).

Table 1. ESRD Network statutory responsibilities

<p>Encourage use of those treatment settings most compatible with rehabilitation of the patient</p> <p>Encourage the participation of patients, providers of services, and ESRD facilities in vocational rehabilitation programs</p> <p>Develop criteria and standards relating to the quality and appropriateness of care</p> <p>Evaluate procedures used by facilities and providers to assess the appropriateness of patient treatment type</p> <p>Implement procedures for evaluating and resolving patient grievances</p> <p>Conduct on-site reviews of facilities and providers, as necessary, utilizing standards of care established by the ESRD Network</p> <p>Collect, validate, and analyze data for the preparation of reports and assure the maintenance of a national ESRD registry</p> <p>Identify facilities not meeting network goals, assist facilities in developing appropriate plans for correction, and report to CMS on facilities and providers that are not providing appropriate medical care</p> <p>Submit an annual report to CMS</p> <p>Establish a network council to include dialysis and transplant facilities in the network area and a medical review board to include physicians, nurses, social workers, and at least one patient</p>

CMS, Centers for Medicare and Medicaid Services.

been revised with each 3-year contracting cycle to reflect changes in dialysis practice, evidence, and regulations. Every year, its CMS project officer evaluates each network's performance in relation to the SOW and makes recommendations for improvement. On only four occasions since 1988 has an ESRD Network's performance been at a level that its contract with CMS was withdrawn and awarded to another organization. On two of these occasions, the network contract was awarded to a quality improvement organization (QIO) and on two occasions the network contract was awarded to another ESRD Network. As a result of these contract awards and voluntary realignments, currently five networks are affiliated with QIOs, five networks are administered by two ESRD Network organizations, and eight networks are independent.

Although the contract cycle has generally been 3 years, the current cycle has been prolonged. There has been no update in the SOW since the Conditions for Coverage for dialysis facilities were revised in 2008, for the first time in 32 years, or since a bundled payment system for dialysis was implemented in 2011. The current SOW has been in

effect with extensions since 2007; the most recent extension runs to the end of 2012.

Fistula First

The only contract deliverable in the current ESRD Network SOW for which contractors are financially penalized for failure to reach a goal is the proportion of hemodialysis treatments delivered by native vein arteriovenous fistula (AVF). CMS establishes, funds, and sets deliverables for the Fistula First Breakthrough Initiative (FFBI). FFBI aims to maximize AVF use placement in all suitable patients, minimize dialysis catheter use, and avoid vascular access complications. On the basis of current AVF prevalence, CMS sets an annual goal of AVF prevalence increase for each ESRD Network. Networks with the lowest prevalence have the greatest incremental goal. Although some ESRD Networks have failed along the way to achieve their incremental goal AVF goal for a particular year by less than a percentage point, the aggregate increase in AVF prevalence in the United States since FFBI began has averaged 4% per year, from 33% in 2003 to 60% at the end of 2011. Although it was widely

Table 2. Summary of current ESRD Network scope of work

Task 1. Network quality improvement program	Quality improvement projects that are national, local, and facility/provider specific
Task 2. Community information and resources	Provision of educational information and technical assistance to patients, dialysis providers/facilities, and transplant facilities; coalition building activities; responsibilities in a disaster; and resolution of difficult situations, complaints, and grievances
Task 3. Administration	Network administrative activities, including staffing and reporting, specifically mandated by statute or regulation and as directed by CMS
Task 4. Information management	System development and information management responsibilities applicable to all network activities
Task 5. Special projects	Network-specific projects as directed or approved by CMS

CMS, Centers for Medicare and Medicaid Services.

believed that the longer maturation time and higher primary failure rate of AVFs, compared with synthetic grafts, would increase the use of dialysis catheters, the prevalent dialysis catheter rate has decreased from 27% to 20% (Figure 2). The ESRD Networks have organized vascular access educational and quality improvement programs for patients, dialysis facilities, nephrologists, surgeons, interventional radiologists, and other stakeholders. The success of FFBI is an example of how a well funded coalition with clear goals, an evidence basis, an excellent data collection and reporting infrastructure, and accountability at multiple levels can dramatically improve patient outcomes.

Challenges for the Future

Funding

The \$0.50 per dialysis treatment withheld to fund the ESRD Network Program has not been increased, despite an increase in the number of dialysis facilities from 2148 in 1988 to 5430 in 2008 and yearly increases in the consumer price index that affect the cost of doing business. According to the Bureau of Labor Statistics, the goods and services that would cost \$0.50 in 1988 would cost \$0.95 in 2011. Although the 204% increase in the dialysis patient population since 1988 would appear to have doubled the networks' budget, not all of the funds collected from the \$0.50 per dialysis treatment are awarded to the networks. CMS uses a significant portion of these funds to support special projects such as the development of Consolidated Renal Operations in a Web-Enabled Network (CROWN-Web), the ESRD data collection platform scheduled to be implemented nationally in 2012. Furthermore, CMS funding per patient varies substantially across networks. In 1988, CMS funded networks in proportion to the number of patients they served, but this approach underfunded smaller networks, with fewer patients over which to spread fixed administrative costs. In 1990, CMS increased funding to smaller networks. Over the past 2 decades, however, larger networks' patient populations have grown faster than smaller networks' and it is now the larger networks that are relatively underfunded. Network funding ranges from \$0.23 to \$0.58 per dialysis treatment (Figure 3A) and the ratio of dialysis and transplant facilities ratio to network staff ranges from 15 to 50 (Figure 3B). In both cases, it is the networks with the most patients and

facilities that have the least funding per dialysis treatment and the highest ratio of facilities to network staff. It will be essential for these funding issues to be resolved if the ESRD Networks are to function effectively in the future.

Patient-Centeredness under Bundling

The 2011 expansion of the dialysis treatment bundle has prompted concerns that dialysis patients may lose access to care, that both technical and interpersonal care may deteriorate, and that the quality incentive program (QIP) may make this worse by penalizing poor performance on quality indicators substantially influenced by patient behavior over which the dialysis facility has limited influence. For example, in 2014, the QIP will include catheter and fistula rates: facilities may choose not to accept patients who make an informed choice to use a dialysis catheter and decline permanent vascular access placement. Future QIP indicators under consideration include fluid weight management, hospital admissions, emergency department visits, and serum phosphorus level, all of which are significantly influenced by patient behavior. One manifestation of adverse patient selection might be an increase in involuntary patient discharges, which facilities must report to their ESRD Network. Fortunately, in 2011, the first year of bundled payment, the total number of involuntary discharges nationally was actually less than in 2010, as was the number of patient grievances related to withholding of services by dialysis facilities. It remains to be seen whether this trend will continue as more QIP indicators are added. On the other hand, at least some networks received more telephone calls from hospital discharge planners unable to place patients in outpatient dialysis facilities. The networks are currently working to assess the scope of this problem and to develop collaborative programs to expedite incident ESRD patient placement.

Leveraging Partnerships

The success of FFBI, which has been a collaborative effort involving CMS, networks, dialysis providers, professional organizations, and other stakeholder groups, provides a model for future collaborations both on a regional and national level. QIP indicators for 2014 include vascular access (AVF and catheter rates), reporting of infections, and reporting of patient experience of care. It will be difficult for networks and facilities to affect the prevalent AVF and

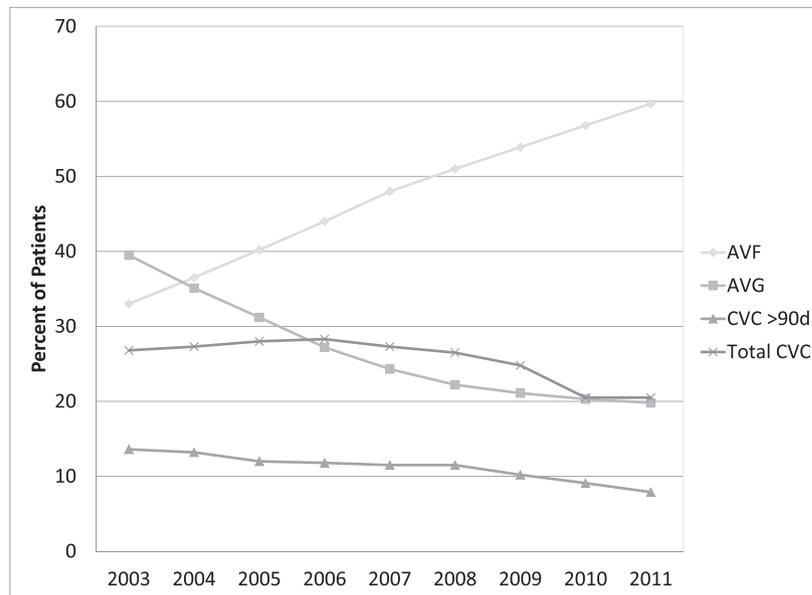


Figure 2. | Prevalent vascular access rates in the United States, 2003–2011. Data points represent September from each year. The figures on the y axis represent percentage in use. AVF, arteriovenous fistula; AVG, arteriovenous graft; CVC, central venous catheter. Data adapted from Fistula First (<http://www.fistulafirst.org/AboutFistulaFirst/FFBIDData.aspx>).

catheter rate when the incident catheter rate remains around 70% nationally. In order for this rate to decrease, more attention must be given to care of patients with late stage 3 and stage 4 CKD to promote timely permanent vascular access placement. This will require collaboration with stakeholders who are involved in the care of such patients, including nephrology organizations, hospital systems, QIOs, and referring physician groups. Improved prevention and treatment of dialysis-associated infections will not only depend on decreasing the prevalent catheter rate, but will also benefit from increased collaboration with infection control authorities such as the Centers for Disease Control and Prevention, infectious disease and epidemiology societies, and industry. The appropriate focus on patient-centeredness, which should not be confined to the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH-CAHPS) survey of patient experience, will benefit from collaboration with patient organizations, social scientists, logistical experts, and psychologists.

Leadership and Relevance in the ESRD Community

Dialysis care has changed dramatically since the ESRD Networks were created in 1978 and the networks have evolved to keep pace with those changes. They have also provided important leadership. For example, in 1984, a committee of the National Forum of ESRD Networks, the advocacy organization that represents the common interests of the regional networks, issued a report recommending standard definitions for data collected on HCFA Form 2728 laying the groundwork for all subsequent epidemiology in the field (1,2). The forum, with HCFA funding, developed the ESRD Core Indicators, which evolved to the Clinical Performance Measures project (3). The concept of the National Vascular Access Improvement Initiative, which became Fistula First, originated with the forum.

A project in one ESRD Network documented the variability in facility practices with respect to timing of posthemodialysis BUN sampling and led to standardization of this practice, a necessary underpinning for the use of the urea reduction ratio as a measure of hemodialysis quality (4). Work in another network led to development of the Decreasing Patient-Provider Conflict toolkit, an important resource for developing professionalism in dialysis facilities (5,6). In conjunction with the Renal Physicians Association in 2011, the forum, responding to concerns of ESRD Networks, issued a position paper regarding the solicitation of ESRD patients (7). In 2011 and 2012, the forum issued a series of reports regarding implementation issues associated with the CROWNWeb project (8). In 2009, the forum had assembled comments very critical of a CMS draft ESRD Network Redesign document (9). Most recently under the leadership of Dr. Louis Diamond, the Forum of ESRD Networks has offered a strategic plan, National Priorities for Kidney Patients for 2012–2021 (10), which aligns network program priorities with those of the CMS “Triple Aim” of better care, healthy people and communities, and affordable care.

The Affordable Care Act of 2010 required that the Secretary of Health and Human Services (HHS) define a National Quality Strategy. The first National Quality Strategy, released in March 2011, was developed by HHS in collaboration with the National Priorities Partnership (NPP), which had been convened in 2008 by the National Quality Forum. The NPP represents a public-private collaboration among 51 major organizations that aims to balance the interests of consumers, purchasers, health plans, clinicians, providers, communities, states, and suppliers. It provides consultative support to HHS, identifying national goals that map to the priorities of the National Quality Strategy, providing input on measures for tracking national progress toward the goals, and offering

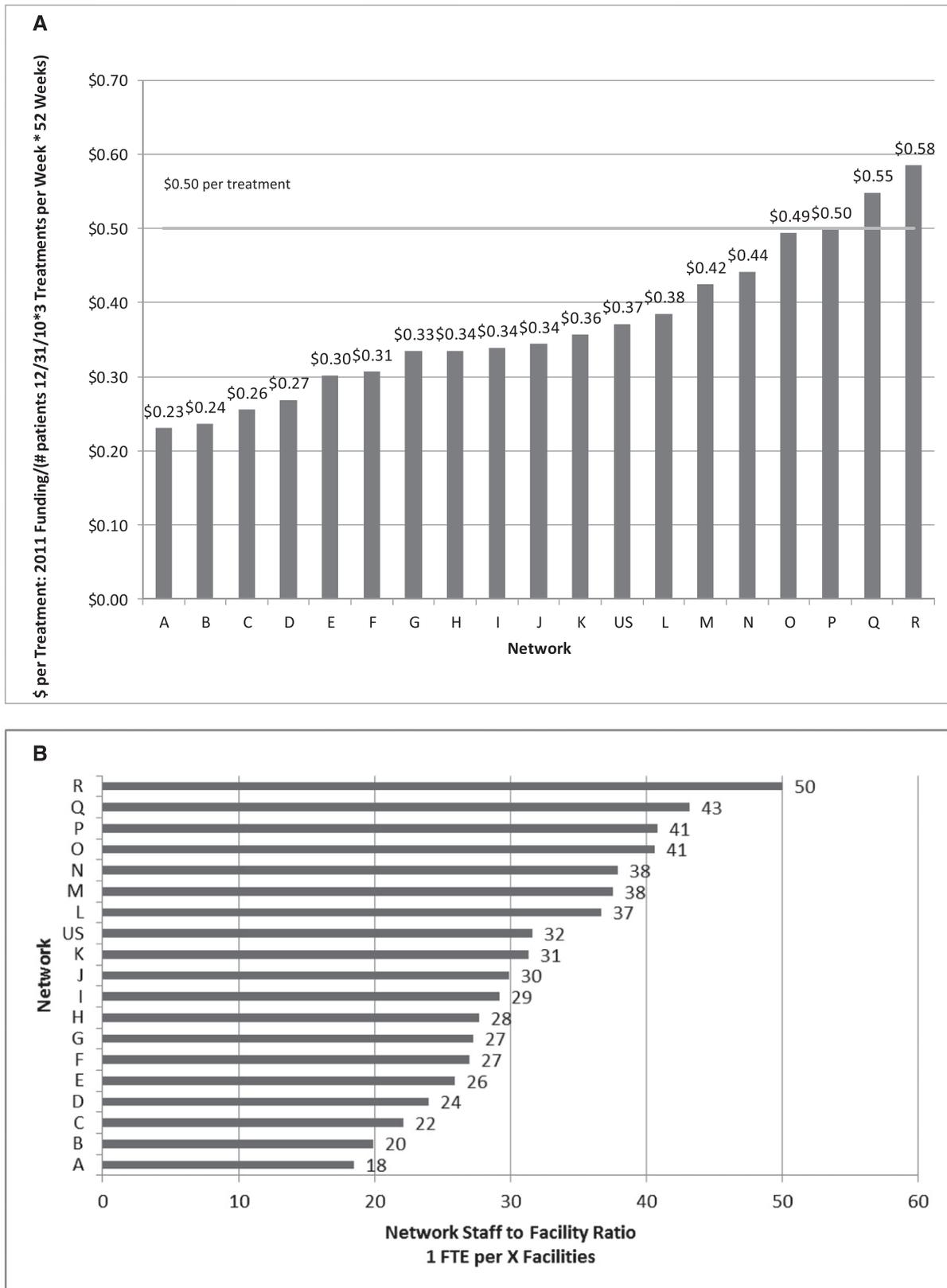


Figure 3. | Per dialysis treatment funding and facility/network staff ratio by ESRD Network. (A) Per dialysis treatment funding by ESRD Network. Data represent the December 31, 2010, dialysis population and calendar year 2011 network funding (ESRD Network Program, unpublished data). (B) Facility/network staff ratio by ESRD Network. Data represent facilities as of December 31, 2010 and full time equivalent staff funded in the 2011–2012 network contract (ESRD Network Program, unpublished data).

Table 3. ESRD Networks' strategic plan for 2012–2021

1. Engage patients and families (CKD and early ESRD focused)	<ul style="list-style-type: none"> a. Deploy shared decision making tools in <ul style="list-style-type: none"> i. Prevention of ESRD (slowing progression) ii. Modality choice iii. Mental health issues iv. Health literacy v. Rehabilitation b. Deploy patient experience of care tools and use results to improve patient satisfaction
2. Improve safety and reduce harm	<ul style="list-style-type: none"> a. Healthcare-associated infection management <ul style="list-style-type: none"> i. Vaccinations ii. Catheter prevention/reduction iii. Water quality iv. Environmental v. Hand hygiene vi. Bloodstream infections b. Provide beneficiary protection services <ul style="list-style-type: none"> i. Patient complaints and grievances ii. Report unintended consequences iii. Disaster planning and coordination iv. Create error and adverse event reporting program v. Patient safety tools vi. Ensure outcomes consistent with community-based guidelines
3. Ensure receipt of well coordinated care	<ul style="list-style-type: none"> a. Care transition processes <ul style="list-style-type: none"> i. CKD to ESRD ii. Handoffs between service providers iii. Transplantation iv. Timely AVF creation b. Reduce high-cost/high-frequency hospitalizations <ul style="list-style-type: none"> i. Admissions and readmissions ii. Emergency department visits iii. Catheter reduction
4. Palliative and end-of-life care	<ul style="list-style-type: none"> a. Adoption and implementation of “shared decision making” tools and strategies from the Renal Physicians Association <ul style="list-style-type: none"> i. Hospice utilization ii. Pain management iii. Adoption of physician orders for life-sustaining treatment iv. Promote advanced directives v. Promote palliative care—medical management without dialysis vi. Improvements to fellowship training on end-of-life care vii. Development of kidney end-of-life strategic plan
5. Equitable access and affordable care	<ul style="list-style-type: none"> a. Identify and reduce disparities b. Improve access to transplantation <ul style="list-style-type: none"> i. Financial viability for medication payment ii. Medicare coverage limits
6. Overuse and waste	<ul style="list-style-type: none"> a. Promote efforts to reduce futile care b. Promote efforts to reduce overuse of medications
7. Improve population health	<ul style="list-style-type: none"> a. Timely referral for CKD and ESRD treatment b. Promote patient self-management
8. Infrastructure support	<ul style="list-style-type: none"> a. Measurement system <ul style="list-style-type: none"> i. Continue creation of a robust measurement system and create a measure gap analysis ii. Harmonize measures focused on dialysis facilities, transplant centers and physicians iii. Create measurement reporting and coordination activities for new structures of healthcare delivery (such as accountable care organizations) b. Public reporting <ul style="list-style-type: none"> i. Continue to populate Dialysis Facility Compare and Physician Compare with and expanded measurement set ii. Promote CMS authorization for networks to publicly report network-level data c. Health information technology <ul style="list-style-type: none"> i. Evaluate the current state of CROWNWeb and the roll-out plan ii. Create a health information technology infrastructure roadmap

Table 3. (Continued)	
	<ul style="list-style-type: none"> d. Professional development on health information technology for healthcare delivery team members and network staff e. Conduct research <ul style="list-style-type: none"> i. Claims data ii. Analytic support iii. Develop programs and perform quality improvement activities iv. Explore application of comparative effectiveness research to ESRD
<p>AVF, arteriovenous fistula; CMS, Centers for Medicare and Medicaid Services; CROWNWeb, Consolidated Renal Operations in a Web-Enabled Network.</p>	

guidance on high-leverage strategic opportunities to accelerate improvement. The initial goals identified were as follows: engagement of each person and family as partners in care; promoting effective communication and coordination of care; promoting the most effective prevention and treatment practices for the leading causes of mortality, starting with cardiovascular disease; working with communities to promote wide use of best practices to enable healthy living; making quality care more affordable for individuals, families, employers, and governments by developing and spreading new health care delivery models; and making care safer by reducing harm caused in its delivery.

In April 2011, HHS launched the Partnership for Patients, a public-private collaboration to support the Triple Aim, with two specific goals: first, to keep patients from getting injured or sicker, reducing the 2010 rate of preventable hospital-acquired conditions by 40% by the end of 2013; second, to help patients heal without complication, reducing preventable complications during a transition from one care setting to another. By the end of 2013, hospital readmissions would be reduced by 20% compared with 2010. The partnership is open to hospitals, clinicians and other care providers; consumer, community, and patient organizations; employers; unions; health plans; states; and other organizations. Participants in the partnership, including the Federal Government, “pledge to join in a shared effort to save thousands of lives, stop millions of injuries, and take important steps toward a more dependable and affordable health care system,” (11) and its website offers prospective partners the opportunity to sign pledges specific to their various roles. In the summer and early fall of 2011, all networks joined the partnership, pledging “to raise public awareness and educate patients, families, and consumers about the importance of making care safer and better coordinated; to develop and provide information, tools, resources, and technical assistance to help patients, families, and consumers effectively engage with their providers in these activities; and to encourage providers to work in partnership with patients, families, and consumers to implement practices that foster more patient-centered care that improves safety, communication, and care coordination.”

In early 2011, the forum undertook a formal prioritization process, using its members’ collective knowledge of the current state of dialysis care to identify opportunities to advance the Triple Aim in this domain. The first area of focus is patient and family engagement, with one focus on CKD stages 4 and 5 and the transition to ESRD. The forum proposes that there is a role for networks to deploy shared

decision making tools that can be used first to slow progression of kidney disease, by raising patient awareness of the importance of their kidney disease and of the potential of BP control and angiotensin antagonist treatment to slow its progression. For those patients whose disease does progress, shared decision making regarding treatment modality becomes relevant: considering the options for transplantation, peritoneal dialysis, home hemodialysis, in-center hemodialysis, and medical management. These activities would represent a substantial expansion of networks’ role, one that would require legislation and allocation of additional resources. Despite these barriers, the networks are the organizations best positioned to achieve improvement in the quality of care in advanced CKD, because they are responsible for overseeing the consequences of this care. Other areas of focus with respect to patient and family engagement include health literacy, mental health, rehabilitation, and patient experience of care. Health literacy is obviously relevant to all aspects of patient and family engagement, and can be very limited in segments of the ESRD population. Inadequately treated mental illness was identified by networks on the basis of their work as patient advocates as an important source of poor adherence, and of patient-provider conflict, another area in which the networks have already made important contributions. It is also clearly relevant to the affordability of care. Vocational rehabilitation was one of the ESRD Program’s original purposes, not only to save lives, but to get patients back to work. Measuring experience of care is central to engaging patients and families, and there is an obvious task for the networks in helping dialysis facilities to interpret and use the results of the ICH-CAHPS. ESRD Network 14 has led the way with a pilot study (12).

A second area of focus chosen by the forum was to reduce harm by making care safer. Again, the networks have been active in this area for more than a decade. For example, the ESRD Network of New England (Network 1) and the Mid-Atlantic Renal Coalition (Network 5) founded the 5 Diamond Patient Safety Program (13), which offers graded certificates of recognition, from one to five diamonds, to facilities in which all staff successfully complete a series of educational modules. Currently, all networks are playing a major role in implementing the National Health Safety Network to collect data on infections in dialysis facilities, and to help facilities to respond to the findings by implementing the Centers for Disease Control and Prevention’s recommendations to reduce catheter-associated bacteremia.

Another important network patient safety activity is the development of a series of quality improvement toolkits by members of the forum's Medical Advisory Committee, comprising representatives of the MRBs of all networks (14). These toolkits cover a variety of topics, including medication reconciliation, vaccination in the dialysis facility, diabetes management, hemodialysis catheter reduction, the process of quality improvement and performance improvement, and most recently, the role of the dialysis facility medical director. Table 3 lists all of the areas of focus of the ESRD Networks' strategic plan for 2012–2021.

Over the past 34 years, the ESRD Networks have played a crucial role in coordinating kidney failure care in the United States. The networks have moved from an initial task of assuring access to care to a quality improvement role. The networks, historically predominantly nonprofit organizations, have been supported over the years by a vigorous community of volunteer professionals, including social workers, dietitians, technicians, nurses, and physicians, whose expertise, enthusiasm, and creativity contribute substantially to the quality of the ESRD program. The regional nature of the network program assures that projects address local barriers to quality improvement and increases buy-in by stakeholders. The increased complexity of the networks' responsibilities has fostered alignment with QIOs, consolidation of network contractors, and partnership with other stakeholder organizations to increase resources, knowledge, and cost-effectiveness. It can be hoped that to augment the leadership and relevance of networks to the ESRD community, the next SOW will evolve from the traditional task-oriented approach to one that places the networks in more of a system-improvement mode, addressing the needs of ESRD patients and providers in adapting to the inevitable changes in healthcare delivery that will occur over the next decade.

Disclosures

J.B.W. was president of the Forum of ESRD Networks from 1998 to 2001. K.B.M. is currently president of the Forum of ESRD Networks.

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