



National Institute of
Diabetes and Digestive
and Kidney Diseases

Kidney Interagency Coordinating Committee (KICC) Meeting

Improving Access to Transplantation

Natcher Conference Center, Building 45, Rooms E1/E2
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I. Welcome and Introductions

Andrew Narva, M.D., FACP

The goal of the committee is to encourage cooperation, communication, and collaboration across Federal agencies involved in kidney research and other kidney-related activities. This KICC meeting focused on improving access to transplantation. This topic was requested by the Centers for Medicare and Medicaid Services (CMS).

II. Improving Access to Transplantation

Shari M. Ling, M.D., CMS

Patients with end-stage renal disease (ESRD) are an important subset of the Medicare beneficiary population. They are both very costly and at risk of suffering adverse outcomes (e.g., mortality, hospital admission, readmissions). In addition, they are potentially vulnerable and may suffer harm that comes to them through no fault of their own but as a result of their healthcare. Currently, there are existing and emerging services and technologies that this population may not be receiving that may improve their outcomes. CMS, through its authorized programs and access to data, has the opportunity to enable spread of best practices and policies to improve outcomes for this important patient population.

CMS is focused on improving the quality of care, healthier populations, and smarter spending, and distributing information to enable more informed patient choice. CMS is moving toward building a learning health system, which means building policies on the best available evidence. As part of this, CMS uses the data to inform the public, patients and practitioners of evidence-supported treatment options.

Key staff at CMS that are involved in this effort, in addition to the speakers at the KICC meeting, are Joel Andress, who is leading CMS efforts on ESRD purchasing (not present) and Lauren Oviatt, a subject matter expert in the conditions for coverage in ESRD.

III. CMMI Transplant Payment Model

Emily Carrier, M.D., MS.c., CMS Innovations Center

The CMS Innovation Center, funded through the Affordable Care Act, tests innovative care models designed to improve quality and reduce costs, the end goal being higher value care. The Comprehensive ESRD Care (CEC) Model establishes a new Medicare model of payment to test whether financial risk arrangements with guaranteed discounts will reduce costs and improve outcomes. The model was launched in October 2015 and will run for 5 years (December 2020). Currently, there are 13 ESRD seamless care organizations (ESCOs), 12 of which are large dialysis organizations (LDOs). A second solicitation is now open with the goal of recruiting additional LDO and non-LDO ESCOs to start in January 2017.

The CEC is an accountable care model in which dialysis facilities, nephrologists, nephrology group practices, and other providers and suppliers form an ESCO to coordinate care and improve quality for ESRD beneficiaries. The goals are to improve care coordination, enhance communication between providers, and increase access to care. Under the model, at the end of

each year an assessment is conducted in terms of costs and quality of care, and providers may share in any savings or losses.

An emphasis in the ESCOs is the sharing of data, both across providers and to CMS, to ensure beneficiaries are receiving the most appropriate care. In addition, providers are encouraged to offer care in a way that increases access. Incentives are provided that focus on the time and place of care (e.g., extended business hours, transportation).

As part of the CEC model, CMS strives to balance promoting transplant with other goals and requirements. Currently, transplant-related expenditures are excluded from the model. Beneficiaries who receive a transplant are excluded from the model for 1 year. At the end of that year they are re-aligned to the model if they generate additional dialysis claims. Beneficiaries with a successful transplant are no longer included in the model.

CMS is exploring policy changes to the model that could increase incentives for transplantation. However, there are challenges that are beyond the control of providers, such as assigning an organ. Any changes must take these challenges into consideration so that providers are not rewarded or penalized for things that are beyond their control. CMS is also exploring the establishment of appropriate process metrics that take into consideration these challenges and how these measures can be benchmarked. Moving forward, it is critical to take into consideration any potential adverse unintended consequences, such as ensuring the most appropriate care when a beneficiary is not aligned to an ESCO.

Discussion

- Dr. Narva asked how the model impacts referral to transplant centers for evaluation and how the centers are compensated for these evaluations. Dr. Carrier stated that the intention of the model is not to discourage transplantation. The CEC is based on a fee-for-service model and those enrolled receive all the benefits of a Medicare beneficiary. Patients can seek the services of any transplant center. Under Medicare, the nephrologist, the patient, and the transplant center work together to conduct evaluations. These services do not generate a claim as would typically be done under a fee-for-service model. Instead, the transplant center generates a cost report that is evaluated separately by Medicare. Unfortunately, not all nephrologists are aware of this process so CMS is working with providers to make sure they are not being penalized when working for the best interest of the beneficiary.
- Dr. Narva asked whether the process measures will reflect the sequential process of transplant evaluation (e.g., patient informed of transplantation, patient evaluated for transplantation, etc.). Dr. Carrier answered that all the steps on the road to transplant could become process measures. CMS would like to limit the number of measures in order to limit the reporting burden for providers and to not dilute the impact of the measures.
- Dr. Zieman asked about the strategy to follow patients over time to track outcomes (e.g., successful transplantation, rejection, etc.) and the actual costs associated with the care. Dr. Carrier answered that CMS is exploring cost patterns and cost trends. She added that

tracking patients over time is difficult since some patients change nephrologist and those that have successful transplants leave the model.

- Dr. Archdeacon stated that outcomes are better for patients if they go directly to transplant and are not on dialysis. This model focuses on patients who are on dialysis, but the transplant evaluation should be taking place earlier. Dr. Carrier answered that the Innovation Center has multiple accountable care organization (ACO) models. These models cover the entire Medicare beneficiary lifespan (e.g., CKD to ESRD). There is room in these models to do care innovations such as early transplantation. With the ESRD model, CMS is looking specifically at the role of the dialysis facility in the transplantation process.
- Ms. Oviatt added that Medicare will not cover transplantation until a beneficiary reaches Stage 5. In the Medicare world there is a wall between the early stages of CKD and ESRD. There is a separate ESRD benefit.
- Dr. Archdeacon added that while he understands the limitations, these policies have an impact on patient outcomes. Dr. Ling responded that these are statutory policies and any changes must come from Congress. Dr. Donohue commented that the impact of such policies should be documented. Providers should not just continue to try to work around them. Ms. Oviatt added that through the affinity groups, CMS has a process for making recommendations for statutory changes. Dr. Ling added that data from other Federal agencies can help to inform the development of models and/or modifications.
- Dr. Oliver stated that with the model it is important to take into consideration case mix (i.e., some populations may have more patients that are suitable for transplant). Providers should not be penalized for lower referral rates. The process should be based on incentives. Dr. Carrier responded that benchmarking can address this. CMS needs to determine whether their risk adjusters are able to appropriately determine what steps toward transplant should be measured.
- Dr. Abbott asked what is the time horizon for costs. Dr. Carrier stated that it is a calendar year. Dr. Abbott commented that historically, costs have been calculated for United States Renal Data System (USRDS) for CKD or pre-ESRD. This is very confusing as there are no standards. This does not capture costs that are incurred pre-dialysis. Dr. Carrier stated that for a beneficiary who is already in the model the cost of care is calculated every year. For new beneficiaries, costs are considered from the first 72x claim on.
- Dr. Narva commented that patients—many under the age of 65—can be referred to transplant before dialysis. The transplant centers are reimbursed for the cost of evaluation. This care does not show up in the model. Dr. Ling stated that data can provide more insight into that care that is being provided in various populations, including those outside Medicare. To scale the models, they must reach thresholds for both cost and quality. While many studies look at therapeutics and diagnostics, cost of services is also an important consideration.
- Dr. Narva commented that in his work with Indian Health Service (IHS) he sees the cultural and geographic barriers facing this population. Cost is not always the barrier. A single evaluation measure could not capture these barriers. There should be a measure focused on the point of listing. Dr. Ling stated that due to the complexity in the system there will likely be multiple metrics.

IV. ESRD Affinity Group: Transplantation Subgroup

Tamyra Garcia, MS, CMS

The ESRD Affinity Group began meeting in February 2016 and is designed to bring together people from across the department to address the quality of renal care and gaps in renal care.

The work of the Affinity Group is informed by previous efforts, such as the Institutes of Medicine (IOM) report released in 2006, *Organ Donation: Opportunities for Action*. The report makes the following recommendations:

- Sustain continuous quality improvement initiatives;
- Increase research on innovative system changes;
- Strengthen and integrate organ donation and quality end-of-life care practices; and
- Enhance training for health care professionals.

Building on these IOM recommendations, the Affinity Group is exploring how to expand the population of potential donors. In particular, it is exploring:

- Implementation of initiatives to increase rates of donation after circulatory determination of death;
- Encourage and fund DCD demonstration projects;
- Maintain opportunities for organ donation;
- Increase research on organ quality and enhance organ viability;
- Promote and facilitate individual and family decisions to donate (e.g., increase public understanding; increase opportunities to record decisions to donate; enhance donor registries);
- Develop incentives for deceased donations (but not financial incentives of preferential treatment); and
- Ethical considerations (e.g., follow up and care for living donors).

The Affinity Group is focusing on the following issues:

- Limited availability of kidneys despite increase in deceased donors;
- Opportunities for policy alignment;
- New technologies;
- Care coordination;
- Persistent disparities (e.g., referrals, wait lists, transplants, graft survival).

Kidney Transplantation: Statistics, 2013

- 17,600 kidney transplants performed
- 87,000 candidates were on the wait list at the end of the year
- 16 percent of kidneys recovered from deceased donors were discarded
- 117,162 incident ESRD patients (2.6 percent received a preemptive kidney transplant)
- 661,648 prevalent ESRD patients (29.2 percent with a functioning kidney transplant)
- Deceased donations have increased to 8,000 donations with at least one kidney
- Living donations have declined since 2004

-USRDS

Across all these areas it is important to facilitate communication and break down silos. Including the patient voice is also critical.

Policy Opportunities. The Affinity Group is exploring the statutory limitations that prevent CMS from extending immunosuppressive therapy past 3 years given the impact in terms of cost, patient years, and quality of life. Quality improvement and measurement are also being explored, such as aligning measurement and program incentives for dialysis facilities and transplant centers. Transplantation and CKD policy should be aligned with ESRD.

Technological Opportunities. New technologies have the potential to alleviate some of the fundamental problems related to kidney transplantation (e.g., supply vs. demand). These technologies include wearable kidneys, implantable artificial kidneys, and new kidney growth. As these technologies become available it is important to consider coverage determinations, payment policy, quality incentives, and standards of practice.

Disparities. At every stage in the evaluation process disparities exist. These disparities are associated with race/ethnicity, gender, and geographic region. Potential causes for these disparities including providers viewing patients as reluctant to receive transplants, nephrologists not seeing the transplant as improving quality of life, and patients not wanting transplants. For example, black patients have lower odds of being wait listed or receiving a transplant than white patients. Women and black dialysis patients are less likely to receive a kidney transplant. Hispanic and Native American patients are also less likely to receive a transplant than whites, despite similar referral rates.

Discussion

Increasing the Donor Pool

- Dr. Archdeacon stated that in addressing the discard rate it is important to look at the factors related to discard. The discard rate will never reach zero. There will always be some marginal organs. There are also regional variations. Dr. Ling stated that what is needed is to identify the best information to guide decisions related to ensuring that living donors remain healthy. Ms. Oviatt added that HRSA celebrates every living donation but recognizes that there are gaps in knowledge related to the long-term consequences for donors so live donors have not been pursued as actively.
- Dr. Archdeacon stated that there is a ceiling on the number of deceased donors and the living donor rate has been decreasing. To meet demand it is necessary to increase the number of living donors. What can be done to encourage these donors (e.g., better after care)? Dr. Ling stated that there is need to better understand how to protect living donors and keep them healthy. While there are still quality issues, there is currently more availability with deceased donors. Getting at the “right” discard rate is difficult because

Key Discussion Questions

- How successful have efforts been to increase the kidney donor pool, and how can we improve on them?
- What issues will Federal and private stakeholders need to consider as we begin to integrate new technologies to treat ESRD?
- Given the breadth of disparities present in the transplant process, what disparities matter most for patient health outcomes?

there are issues related to both the recipient and the donor. To get to the “right” factors that will inform these decisions must be identified. Ms. Oviatt added that the Affinity Group is looking at data from other countries, such as Japan.

- Dr. Archdeacon stated is that there is great variation across patients. For some, kidney disease is their only issue. Others have multiple chronic conditions such as diabetes and hypertension. Outcomes depend on the health status of the patients. These variables have an impact on the discard rate. Dr. Dupee stated that they are considering these variables and that there are interventions that can be implemented to address the discard rate.
- Dr. Abbott stated that in Japan, the leading cause of ESRD has been diabetes (about 50 percent as opposed to 40 percent of patients in the United States). Population factors like this can impact comparability.
- Dr. Narva stated that NIDDK funded the Minority Organ Tissue Transplant Program. One of the main themes identified was lack of trust in the system. Since minority communities have high rates of ESRD this has serious implications for organ donation since potential donors may not believe that the organ will be fairly distributed. This issue is hard to address and takes a long-term commitment, both via education and by addressing disparities in care.
- Dr. Zieman stated that social media can be a useful tool to educate people about donation. Ms. Garcia stated that social media is an important way that patients can connect. For example, home dialysis patients have established a network. People involved in such a network find it very empowering and consider it a “safe space.” Providers and researchers must be careful and respectful when they try to engage (e.g., patients, through their networks, create their own, separate networks to engage patients). Dr. Zieman added that this is not a mindset familiar with providers (i.e., letting patients have their own space). She also stated that social media will be important in reaching healthy donors.
- Dr. Walsh stated that the discard rate is a moving target given the huge variability across the country in demand and wait times. Given demand in some areas, more marginal organs are accepted. It is necessary to acknowledge that there are some organs that are not pursued. Practice changes and increases in demand may result in an increase in the discard rate.
- Dr. Bohan stated that she is a member of her local organ procurement organizations (OPO). These organizations are extensive users of social media. For example, Donate America has a campaign that encourages people to become donors when they get their drivers license and most states do not allow family members to reverse this decision. When families are approached to donate the organs of a loved one, the conversion rate is about 70 percent. These are often catastrophic situations. However, ways to increase the effectiveness of the approach need to be explored. The taboos of incentivizing donations need to be addressed. Starting with deceased donors to explore the use of incentives might be the best approach. Discard rates are impacted by the local population—some have a greater burden of disease, especially in urban areas. Expanding sharing from local to regional to national could expand availability. There have been changes in the ways kidneys are classified. Currently, the Kidney Donor Profile Index (KDPI) is being used, however, understanding about the meaning of this measure is lacking. It is important to note that programs are risk averse. This makes them reluctant to use marginal organs.
- Dr. Walsh stated that this is a very complex process and the performance metrics are important. HRSA is working on a pilot project that will look at a new way of promoting

quality. It will look at real-time data to assess an organ and reduce the fear of accepting a marginal organ. It focuses on building up the pool of organs as well as educating physicians about KDPI.

- Dr. Walsh stated that organ discharges are based on histology of the biopsy; it is not clear what these patterns mean. NIH is looking at this.
- Dr. Walsh stated that research has shown that covering immunosuppressive medications for more than 3 years medications is cost effective. In 2011, five (5) percent of patients starting dialysis did so as a result of a failed renal graft. Improving these outcomes could reduce demand for transplant. Ms. Oviatt stated that the decision to cover immunosuppressive therapy for 3 years was made several decades ago, with the expectation that people undergoing a transplant would fully recover their health and be covered by their employer. This assumption no longer holds true.
- Dr. Ling stated that this requires partnerships and a consideration of the roles and responsibilities of each part of the health care delivery system.

Integrating New Technologies

- Dr. Archdeacon stated that FDA is partnering with the American Society for Nephrology on the issue of bioartificial kidneys. These new technologies are very challenging. Are there other Federal agencies (e.g., NIH, CMS) that should be involved in this process?

Disparities

- Dr. Narva stated that in some populations (e.g., VA, DOD) disparities are not apparent. In others, such as American Indians being served by IHS, there are variations in terms of who they will accept for transplantation based on various measures such as BMI. As CMS moves forward, it should require data to support the development of evidence-based measures. Best practices should be implemented across Federal agencies.

IV. Status of CMS/HRSA Interagency Initiative to Increase Kidney Transplantation

Renée Dupee, J.D., CMS

CMS and HRSA are engaged in a collaboration to increase kidney donation for transplantation. The focus is to reduce kidney discard rate from 19 percent to 15 percent and increase donation after circulatory death (DCD) so that 30 percent of deceased donors are DCD. While the goal is improved outcomes, this initiative could also realize significant cost savings. The project is responsive to the White House request that Federal agencies explore ways to increase kidney transplantation. If successful, the model could be implemented across the Center for Clinical Standards and Quality (CCSQ) ESRD Quality Improvement Network.

5-year Cost Savings per Kidney Transplant

The ESRD population is one (1) percent of the Medicare population but accounts for seven (7) percent of costs.

- Annual cost per patient for dialysis: \$82,338
- Medicare annual cost for dialysis: \$30.9 billion
- Annual cost per patient in year of transplant: \$118,669
- Annual cost per patient in 2-3 years post transplant: \$22,161
- Annual cost per patient in 4-5 years post transplant: \$9,972
- Average savings per kidney transplanted over 5 years: \$228,754

Project Hypothesis

Spreading proven best practices through, goal-directed, rapid systematic quality improvement methods will lead to higher quality, better health outcomes, more cost efficient care for 3,200+ persons living with ESRD, and substantial cost-savings to the nation and to the Medicare program.

The project builds on the work of HRSA’s Organ Donation Breakthrough Collaborative. The Collaborative focused on disseminating best practices to increase organ donation rates. The community of practice involved in the Collaborative (e.g., hospitals, transplantation centers) was very effective in implementing the best practices and were successful in achieving and maintaining increased donation rates.

The project is using the Institute for Healthcare Improvement (IHI) breakthrough collaborative model, which includes large learning sessions for participants. The Project ECHO model is also being utilized with an emphasis on peer-to-peer learning and focused webinars led by experts. The community of practice includes transplant centers, transplant surgeons, OPOs, and large donor hospitals. Specific interventions include:

- Inventory expert mentors, coaches, and counselors in OPO and team community;
- Identify best practices for DCD donation, utilization of moderate to high-risk kidneys, and DCD kidneys;
- Develop and continuously refine improvement guides; and
- Establish and support national technical assistance infrastructure using small, peer-to-peer intensive learning networks.

DCD donation and transplantation, while growing, is still very limited. It varies across the 58 donation service areas (DSAs) and transplant centers. There are evidence-proven practices related to DCD. For example, DCD can be increase by:

- Enlisting active support of administrative and clinical leaders in large volume donor hospitals to make DCD a priority;
- Developing OPO-controlled surgical recovery model to minimize/eliminate dependence on busy transplant clinicians; and
- Establishing robust OPO-controlled pulsatile preservation programs to minimize delayed graft function and increase receptivity to using these kidneys.

In DSAs, the discard rate varies from around six (6) percent to over 30 percent, with the average being 15 percent. In terms of reducing kidney discards. Proven practices include: establish protocols that anticipate and overcome kidney placement obstacles (proactive, preemptive approach); build effective relationships with high volume, risk tolerant kidney transplant programs and establish protocols for expedited placement; and maintain intensive real-time focus on kidneys at risk of discard, before it’s too late, including escalation protocols to ensure “all hands on deck” approach to placement.

If the goals of the project—reduce kidney discard rate from 19 percent to 15 percent and increase DCD so that 30 percent of deceased donors are DCD—are achieved, the following results are projected:

- 3,236 more kidney transplants over the 4 years of the project;
- 1,626 kidney transplants in Year 4 of the project; and
- \$300 million in savings over the 5.5 year period following these transplants.

Beyond the project, expansion could have a significant impact. These include:

- Quality improvement work to increase kidney transplantation by ESRD networks and quality improvement organizations (QIOs);
- IOM estimates uncontrolled DCD potential at 22,000 donors per year; and
- Potential cost saving to the nation would exceed \$5 billion per year—money that could be used to cover other needs such as immunosuppressive therapy past 3 years.

Discussion

- Dr. Archdeacon asked how the goal of a discard rate of 15 percent was identified. Ms. Dupee stated that the focus was rapid cycle improvement. While the highest performers have much better rates, the intent was to bring everyone up to the national average of 15 percent. Dr. Archdeacon stated that given the variables, OPOs should not be labeled as high and low performers. With a set goal (i.e., 15 percent) OPOs will work to meet this number and might avoid trying strategies that could be effective (i.e., taking risks). Ms. Dupee stated that in projects of this nature CMS sets stretch goals. The best practices were identified by high performing OPOs. The analysis focused on setting goals that reflected the implementation of these best practices.
- Dr. Narva stated that one of the greatest opportunities to improve donation is to improve the process of making requests to families. Are there best practices in this area and have they been disseminated to OPOs? Ms. Dupee stated that the Organ Donation Breakthrough Collaborative identified best practices in terms of who should make the request and how it should be done. For example, during the Collaborative most participants reported that they had appropriate requestors (e.g., an African-American approaching an African-American potential donor family) but these requestors were not always effective.
- Dr Walsh stated that conversion was a main focus of the Collaborative. The goal for the conversion rate was 75 percent (before the Collaborative there were OPOs with conversion rates of about 50 percent). Now, the national average is 74 percent. There are lessons learned about the best person to approach families. Some OPOs are going a step further and looking at the effectiveness of individual requestors with different types of potential donor families (e.g., cultural background). This is the type of real-time monitoring of performance that can improve outcomes.

V. ESRD Network Program: Kidney Transplantation

Renée Dupee, J.D., CMS

The ESRD networks have always considered themselves to be quality improvement organizations with a renal focus. During the last contracting cycle, the majority of ESRD networks were under the umbrella of the quality improvement organization. This is significant

because the quality improvement organizations are tasked with working in the area of CKD. This creates the opportunity to do work across the entire continuum of kidney disease.

As part of their statement of work, networks are required to conduct innovation pilot projects. The networks select the focus of the project—not all focus on transplantation. Examples of these activities include:

- Development of transplant resource toolkits with materials targeted to both patient and provider education;
- Assisting dialysis facilities to establish dedicated education stations in units to facilitate patient education activities;
- Partnering with transplant centers, State agencies, and transplant organizations such as United Network for Organ Sharing, Donate Life, and the National Kidney Foundation for integration and dissemination of transplant toolkits;
- Training peer mentors to provide information on transplantation at chair side; and
- Establishing transplant learning and action networks (LANs) to increase patient literacy and encourage an overall increase in transplant referrals.

Last year, four networks participated in projects to increase transplant referrals. Over a 6-month period, the four networks referred 1,822 patients to a transplant center. Individual networks achieved the following outcomes.

- Network 4 achieved an 11.7 percent increase over baseline and reduced gender disparity by 4.6 percent.
- Network 5 achieved a 30.8 percent increase over baseline and reduced race disparity by 16.1 percent.
- Network 6 achieved a 24.9 percent increase over baseline and reduced race disparity by 1.4 percent.
- Network 17 achieved a 10.6 percent increase over baseline and reduced age disparity by three (3) percent.

It is important to note that CMS set a goal of a five (5) percent increase over baseline.

Currently, six networks are working on population health-focused projects to improve transplant coordination.

Discussion

- Dr. Narva asked whether the patients that were referred by the dialysis units were actually listed. Ms. Dupee stated the interventions focused specifically on referral. Sustaining the intervention (and the gains) beyond the pilot is also important.
- Mr. Black asked if increasing organ transplant for older patients on Medicare could reduce the number of organs available for younger patients. Ms. Dupee stated that the number of people who want a transplant exceeds the number of available organs. The goal is to increase the pool of organs and the number of transplants that occur. The wait list must be reduced. Hopefully innovations will help make this treatment available to

those who want it. Dr. Ling added that the Medicare population is complex, with many beneficiaries having multiple chronic conditions. CMS wants to create the opportunity for appropriate candidates to receive a transplant.

VI. Transplantation Education

Amy Waterman, Ph.D., UCLA

The goal of the Transplant Research and Education Center (TREC) is to understand the critical, modifiable patient, provider, and system barriers affecting deceased and living donor kidney transplant rates and outcomes and design interventions to overcome or improve them. Better education improves wait listing and living donor kidney transplant rates (LDKT). Having better quality education about transplant is associated with a 36-49 percent increase in transplant wait listing rates and 22-35 percent increase in LDKT rates. Patients who start transplantation evaluation with greater readiness to pursue LDKT are 4.3 times more likely to have a LDKT. Starting the evaluation with greater knowledge results in patients being 1.2 times more likely to have a LDKT.

There are significant disparities in LDKT rates, which can be related to both knowledge and preparedness. In a study of 462 patients at UCLA (214 whites, 135 blacks, and 113 hispanics), whites showed higher knowledge related to transplant and were significantly more likely to have read about or watched a video on transplant, shared information with people in their life, talked to people they trust about getting a transplant, and have a list of people who might be a living donor. Socioeconomic factors also play a role. Blacks and Hispanics are more likely than whites to report being unable to live less than 2 months without their current income, lack of access to a vehicle, feeling unsafe in their neighborhood or home, and lacking social support. Even if black and hispanic patients are informed and prepared, these factors can limit their access to a LDKT. Of these patients, whites were significantly more likely to receive an LDKT. Over a period of 600 days only one black patient received a transplant. While whites were 3.4 times more likely to receive a LDKT, when education/preparedness was taken into consideration this disparity was greatly reduced.

Factors that Play a Role in Likelihood of an LDKT

- More knowledgeable
- More ready
- Shared education

General Education. The findings discussed above support recommendations from the American Society of Transplantation (AST) Consensus Conference on Living Donation (June 2014). Participants discussed why living donation had decreased and what could be done prior to patients reaching a transplant center and as well as once the evaluation has begun. Recommendations include:

- Education should be repeated at multiple points through the progression of the disease;
- Produce simple, well-validated, engaging education tools;
- Build patients' and potential living donors' knowledge, readiness, and action taking small steps toward LDKT over time; and
- Disseminate education widely using technology and many points of patient and donor contact.

Because of the nature of the education that needs to be provided, it is important to provide it over time. Patients do not make these important decisions after one session. This education “pipeline” needs to take place along a continuum:

- General transplant information to public and potential living donors (provided outside of transplant and dialysis centers);
- Nephrologists’ offices (CKD 3 & 4);
- Dialysis centers;
- Transplant evaluation;
- Wait list; and
- Post-transplant (adherence).

To realize such a pipeline requires resources. At the recent White House Organ Donation Summit a national online transplant education repository was proposed—housed on a neutral national website. This would serve as a clearinghouse of educational resources about transplant and living donation for patients, living donors, and the interested public. Making such resources available would help to ensure informed transplant and living donation decision-making. Improved access to information may also help to decrease disparities in racial/ethnic populations. Potential partners in this process include transplant education leaders, Kaiser Permanente, dialysis chains, and national organizations. There is also a role for Federal agencies.

Role of Education Providers. It is also important to look at how education is being provided to patients and potential donors. CMS mandates that education be provided to patients. A study of over 1,351 dialysis facilities shows that for the most part, teams of individuals are conducting education in dialysis centers. Most teams are led by a social worker. Other providers of education include nurses, physicians, nurse managers, dialysis technicians, and dieticians. This study shows the variety of educators within facilities. It raises the question of whether there should be specific mandates related to who does the education, their qualifications and training, and the content. For example, only 55 percent of educators thought they were sufficiently knowledgeable to answer patients’ questions about transplant. Less than half reported that they thought the education materials provided in the facility were “excellent,” and only 35 percent reported that there was a formal education program. Only 40 percent reported having detailed discussions about transplant advantages and risk.

Another study of 170 dialysis centers, using data abstracted from CMS Form-2728 and wait list records showed that 77 percent of patients were informed of their transplant options. The centers were divided into three groups—ones providing fewer than three education interventions, those providing 4-5 educational interventions, and those providing more than six. The two groups with more interventions had higher wait list rates.

A study of 1,695 educators in dialysis centers—focused on the “best educator” per center—looked at barriers to conducting transplant education. These included: staff with low transplant knowledge (55%), competing priorities (49%), staff has insufficient time to educate (36%), poor communication with treatment center (29%), facility has no DVD player (28%), and administration does not support transplant education (12%). These findings were then linked to outcomes (e.g., wait listed patients). The most important take away from this study is that there is

a direct relationship between the culture of the organization— that is how supportive it is of education, and patient outcomes.

Characteristics of Patients on Wait Lists. A study of 555 dialysis patients explored patients' knowledge, perceived pros and cons to transplant, readiness to pursue transplant, and potential socioeconomic barriers. Patients who had higher rates in terms of the perceived benefits of transplant (pros)—the value of a transplant—were more likely to move forward in the process. Those that did not move forward were scared of the process (cons). They worry about having to take medicine after the transplant, not being able to pay for these drugs, and complication or pain from the surgery. There were also factors related to the donor, such as feeling guilty about having someone donate a kidney or not wanting to involve other people in their health problems. While there was not a significant difference in knowledge between the two groups, those that moved forward with the process were significantly more motivated and less afraid than those who did not.

Example of Educational Program: Explore Transplant. Dr. Waterman has developed *Explore Transplant*, a train-the-trainer quality improvement initiative that prepares dialysis providers to educate their patients about transplant. Since 2009, over 4,000 dialysis providers in 115 centers have been trained. Patients that received the training were much more likely to read information, talk to friends/family about transplantation, share materials, share that they are looking for a living donor, and make a list of potential donors. Of these patients, 38 percent went on to contact a transplant center (compared to 24 percent of the control group). Providers who reported using *Explore Transplant* with at least five patients were 32 percent more likely to have a LDKT in their center in the following 2 years. *Explore Transplant* is being implemented in Canada. It is also being modified for patients with CKD stage 3-5 and as a home-based curriculum.

Skills Building. Work still needs to be done to help patients increase their readiness to act. One model that has shown success is house calls—a health educator goes to the patient's home to provide education and work with the patient to remove barriers. In the evaluation of this model, those receiving the intervention were more likely to receive a LDKT (52 percent vs. 30 percent).

Conclusions.

- Build an educational pipeline offering repeated education over time for patients in CKD 3-5.
- Establish ways to educate more potential living donors through public channels.
- Reduce variation in transplant educational practices and pro-transplant cultures in US dialysis centers.
- Create a pro-transplant culture.

Recommendations.

- Create a pro-transplant culture within dialysis centers that increases wait list rates.
 - Formalize job responsibilities for a transplant educator or team and assign accountabilities.

- Ensure that transplant educators have adequate knowledge about transplant, time to educate, and patient education resources.
- Provide other types of assistance (e.g., peer mentors).
- Expand education beyond verbal referrals for transplant evaluation.
 - Provide phone numbers of transplant centers.
 - Provide print and/or video-based education about transplant.
 - Make time for more detailed discussions to ensure informed consent.
 - Ensure patient comprehension of key risk/benefit information.
- Racial/Ethnic minority patients who present to transplant centers are less knowledgeable and prepared, or are not presenting at all.
 - Need interventions to increase their preparedness before and once at center.
 - Culturally tailored interventions are key.

Discussion

- Dr. Ling stated that she is pleased that Dr. Waterman is working with the ESRD networks. The data related to who is providing the education is important. It is important to look at different settings and expanding who is doing the education.
- Ms. Oviatt stated that the work related to barriers to education on the provider side is important.
- Dr. Oliver asked if CMS should play a role in documenting education. However, it should be done in a way to get people to expand their efforts, not just check off boxes and do the bare minimum. Dr. Waterman stated that University of Michigan is working to develop education metrics for CMS. In these discussions, transplantation education was identified as an important area for improvement—beyond the currently mandated verbal discussion of transplantation. There could also be a role for auditing. This could motivate people to improve their programs.
- Dr. Narva stated that the need for transplant education is just part of the picture. Many people on dialysis are not aware that home dialysis is available. Much of the education in dialysis units is done by social workers and dietitians. Mandating what must be covered during educational sessions can be gamed. Another way to approach it might be through limiting the number of patients to be served by each social work or dietitian FTE. People in dialysis units are highly motivated, but they just don't have the time to do the work. Dr. Waterman stated that the culture needs to be pro-transplant. What are the elements that contribute to this culture (e.g., prepared educators, time to educate)?
- Dr. Archdeacon stated that addressing the socioeconomic barriers faced by patients is critical. Everyone wants the best outcomes for themselves or their loved one. Dr. Waterman stated that there should be a living donor learning program for people who are thinking about donating. With the barriers to education in dialysis centers, these efforts might be more effective outside of centers.
- Dr. Waterman stated that she submitted a Pioneer Grant to solve the living donor kidney transplant shortage. It was not funded. She encouraged participants to contact her if they wanted to learn more about the proposed program.

- Dr. Abbott stated that despite efforts there will still be disparities. There are some sub groups of patients that are at increased risk and there are unresolved implications for living donors. Dr. Waterman stated that work is being done to standardize risk information.

VII. Closing Discussion

- Dr. Ling stated that there are many opportunities to move forward. The roles for each Federal agency, as well as non-Federal partners, need to be defined.
- Dr. Evered stated that in addition to the CMS Affinity Group on transplantation there are also sub groups on utilization of home modalities, improving patient safety in the first 120 of dialysis, and payment and incentives.
- Dr. Archdeacon asked if the discussion of home modalities include discussion of the home as the origination site. There are some reimbursement issues related to origination sites and consultations via phone or skype. Ms. Oviatt stated that this is being considered. There is a requirement that the physician see the patient once a month. Whether this can be done by phone is under discussion.
- Ms. Garcia stated that the group is exploring home modalities for patients that want it and are good candidates. The education piece of this needs to be considered since many people are not aware of this option. There have also been questions about changing their mind about home treatment. It is necessary to create a care plan reflective of the patient's needs and wishes. There are also considerations related to payment and how it might influence the patient's choice.
- Dr. Narva stated that Medicare will reimburse for telemedicine if certain criteria are met. Dr. Ling added that there is a vehicle to suggest new services over time.
- Dr. Archdeacon stated that there is a Kidney Health Initiative Organization with a work group addressing telemedicine. This may present an opportunity for cross pollination.

VIII. Adjournment

Dr. Narva thanked members for their participation. He also thanked CMS for using KICC as a venue to address raise issues related to their work.

Dr. Narva announced that the Urology Interagency Coordinating Committee (UICC) is currently working to identify staff in Federal agencies who would be appropriate members of this committee. Recommendations from KICC members would be appreciated.