

ESRD Access to Kidney Transplantation TEP Summary Report

April 20 & 21, 2015

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ESRD Access to Kidney Transplantation Technical Expert Panel Summary

The Centers for Medicare & Medicaid Services (CMS) has contracted with The University of Michigan Kidney Epidemiology and Cost Center (UM-KECC) to maintain and develop quality measures for dialysis facilities, pertaining to their care of ESRD patients on chronic dialysis. As part of that ongoing project, UM-KECC was tasked with developing quality measures related to ESRD patients' access to kidney transplantation. Following the CMS Measures Blueprint process, a Technical Expert Panel (TEP) was convened to provide expert and stakeholder input to the development of the measures.

Technical Expert Panel Objectives

The objectives of the ESRD Access to Transplantation TEP were described in a charter that was reviewed and approved by the TEP members prior to the in-person meeting. The TEP was tasked with applying available evidence and their expert opinions to formulate recommendations to UM-KECC regarding the development of new measures, the reevaluation and maintenance of existing measures, and the identification of important quality gaps in access to transplantation. The TEP was to provide, where appropriate, specifications for draft quality measures such as recommendations for data collection requirements. These will be used to facilitate the collection of the elements necessary to develop and test new access to transplantation measures. Criteria for recommended measures include that they be evidence based, scientifically acceptable (reliable and valid), feasible without creating undue burden for dialysis facilities, and usable by CMS, providers, and the public.

Technical Expert Panel Meeting

The ESRD Access to Kidney Transplantation TEP met in Baltimore, Maryland on April 20 and 21, 2015.

The TEP was comprised of individuals with the following areas of expertise or experiential perspectives:

- The transplant process, from candidate evaluation through to transplantation, (transplant nephrologists, social workers, transplant coordinators, and/or nursing administration)
- Perspective of the dialysis facility regarding referral to transplant evaluation (nephrologists, nurses, and/or social workers)
- Transplant policy
- Consumer/patient/family perspectives and consumer and patient advocacy; specifically, patients with experience with transplant evaluation, time on the waitlist, transplantation, and/or failed transplants
- Research expertise with Medicare data and issues pertaining to access to kidney transplantation
- Perspectives on healthcare disparities in access to transplantation
- Expertise in performance measurement and quality improvement

The following individuals participated in this TEP:

Name and Credentials	Organizational Affiliation, City, State	Conflicts of Interest
Stephen Pastan, MD TEP Co-Chair	<p><i>Associate Professor of Medicine</i> Renal Division, Emory University School of Medicine, Atlanta, GA</p> <p><i>Medical Director of the Kidney and Pancreas Transplant Program</i> Emory Transplant Center, Emory University, Atlanta, GA</p> <p><i>Board of Directors Member ;</i> <i>Chair of the transplantation task subcommittee</i> National Kidney Foundation (NKF)</p>	<p>Old National Dialysis, College Park, Georgia. 15% owner in joint venture with Fresenius Medical Care</p> <p>Research Support from Bristol Meyers Squibb</p> <p>Data Safety Monitoring Committee for Retrophin, Inc.</p> <p>Consulting for Dompé Pharmaceuticals</p>
Amy Waterman, PhD TEP Co-Chair	<p><i>Associate Professor of Medicine, Division of Nephrology;</i> <i>Director of the Transplant Research and Education Center (TREC)</i> David Geffen School of Medicine, University of California, Los Angeles (UCLA), Los Angeles, CA</p>	<p>Dr. Waterman founded the non-profit Explore Transplant. She has since signed a royalty-free agreement and does not have any financial affiliation with the organization.</p> <p>In the past, Dr. Waterman had HRSA grants specific to dialysis center studies, but does not have any at this time.</p>
Todd Pesavento, MD	<p><i>Professor of Medicine,</i> Department of Medicine; <i>Medical Director of Kidney and Pancreas Transplantation,</i> Comprehensive Transplant Center, Ohio State University, Columbus, OH</p>	Grant/Research support from Bristol Meyers-Squibb
Sandra Amaral, MD, MHS	<p><i>Assistant Professor</i> Division of Nephrology, Department of Pediatrics; <i>Director of the Kidney Transplant Program</i> The Children's Hospital of Philadelphia, PA</p> <p><i>Senior Scholar</i> Center for Clinical Epidemiology and Biostatistics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA</p>	None
Ranjan Chanda, MD, MPH	<p><i>Medical Director</i> Centennial Kidney Transplant Center, Nashville, TN</p> <p><i>Partner</i> Nephrology Associates, Nashville, TN</p>	None
Mary Beth Callahan, ACSW, LCSW	<p><i>Senior Social Worker</i> Dallas Transplant Institute, Dallas, TX</p>	None

Name and Credentials	Organizational Affiliation, City, State	Conflicts of Interest
Duane Dunn, MSW	<i>National Director of Social Work Services</i> DaVita Healthcare Partners Inc., Columbia, SC	None
Linda Wright, DrNP, RN, CNN, CCTC	<i>Kidney and Pancreas Transplant Coordinator;</i> <i>Certified Nephrology Nurse</i> Thomas Jefferson University Hospital, Philadelphia, PA American Nephrology Nurses' Association	None
Robert Teaster, RN, MBA, CPTC, CPT	<i>Administrator for Transplant Services</i> University of Virginia Medical Center, Charlottesville, VA	None
Chris Elrod, CCHT	<i>Chief Technician/ Bio Med</i> Dialysis Clinic, Inc. (DCI)	None
Nancy Scott	<i>President</i> Dialysis Patient Citizens Education Center	None
Contractor Staff		
Vahakn Shahinian, MD, MS	Associate Professor of Internal Medicine	None
Joe Messana, MD	Collegiate Professor of Nephrology and Professor of Internal Medicine	None
Valarie Ashby, MA	Co-Managing Director/ Lead Manager of Research & Analysis	None
Doug Schaubel, PhD	Professor of Biostatistics	None
Lan Tong, MS	Senior Research Analyst	None
Casey Parrotte, BA	Research Analyst	None
Caitlin Hanna, BA	Research Analyst	None

1. Introduction

This report summarizes the discussions and recommendations of the ESRD Access to Kidney Transplantation TEP meeting convened on April 20 and 21, 2015 in Baltimore, Maryland, as well as the preparatory teleconference meetings held on March 26 and April 15, 2015. The purpose of these activities was consideration of the potential measurement of patient access to kidney transplantation. The sessions were informed by a review of relevant clinical guidelines and literature, as part of an environmental scan conducted by UM-KECC. Potential measure elements were evaluated using the criteria for clinical performance measures adopted by the National Quality Forum (NQF) and CMS. These criteria include each measure's importance, scientific acceptability, feasibility, and usability.

2. Background

For most patients with ESRD, transplantation is the treatment of choice. Numerous studies have indicated that the recipients of kidney transplants experience better survival and quality of life than comparable dialysis patients.¹ From a regulatory standpoint, the ESRD Conditions for Coverage mandate an annual comprehensive reassessment of each patient, at minimum, with documentation of the assessment and revision of the Plan of Care if indicated. Both the patient assessment and Plan of Care should include reevaluation of treatment modality and transplant status. Specifically, Section 494.80(a) (10) of the revised Conditions for Coverage for ESRD Facilities, effective October 14, 2008, sets forth requirements for evaluation of suitability for a transplantation referral, based on criteria developed by the prospective transplantation center and its surgeon(s). If the patient is not suitable for transplantation referral, the basis for non-referral must be documented in the patient's medical record."²

The Healthy People 2020 initiative includes national quality of care objectives for kidney disease. Objectives CKD-12 and CKD-13 establish goals to "increase the proportion of dialysis patients waitlisted and/or receiving a deceased donor kidney transplant within 1 year of ESRD start (among patients under 70 years of age)" and to "increase the proportion of patients with treated chronic kidney failure who receive a transplant".³ While efforts are made to reach the targets for these objectives, substantial variations in transplantation rates by dialysis facility and geographic region, as well as disparities by race and socio-economic status, raise serious concerns about current processes for provision of access to transplantation.⁴ These variations highlight the need for quality measures to facilitate improved and uniform access to transplantation for the ESRD population on dialysis.

3. Overview of Measure Areas to be Discussed

The ESRD Access to Kidney Transplantation TEP was asked to consider potential quality measures applicable to the entire spectrum of the transplantation process: discussion of treatment options with the patient,

¹ Wolfe RA, Ashby VB, Milford EL, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med.* 1999 Dec 2; 341(23):1725-30.

² [Medicare and Medicaid Programs; Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule.](#) *Federal Register* 73:73 (15 April 2008) p. 20479.

³ <http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicid=6>

⁴ Patzer RE et al. Dialysis facility and network factors associated with low kidney transplantation rates among United States dialysis facilities. *American Journal of Transplantation.* 14(7):1562-1572

referral for transplant evaluation, completion of transplant evaluation, waitlisting and/or identification of a living donor, maintenance of active status on the waitlist, and ultimately, transplantation.

TEP members were also asked to reflect on:

- The degree to which performance on a measure is under control of the dialysis facility
- The strength of the link between performance on a measure and outcomes that are valued by patients
- Issues of data element availability and collection
- The potential need for exclusion criteria and/or risk adjustment

The TEP was provided the option to develop measures based on data not currently collected or available, as a new process for testing of data elements is being developed by CMS (briefly described in section 4. *Measure Development Test Bed*). Additionally, TEP members were asked to provide input on relevant measures currently used as part of the provider feedback program Dialysis Facility Reports (DFR); these include facility waitlisting rate and the Standardized Transplantation Ratio (STR). Specifications for these DFR measures are summarized in the tables below.

Kidney Transplant Waitlisting Rate for Dialysis Patients

Measure Description	This measure evaluates the percentage of patients younger than age 70 treated at a given facility as of December 31, who were on the kidney or kidney-pancreas transplant waitlist each year.
Numerator	The number of facility patients who were on that facility's kidney or kidney-pancreas transplant waitlist as of December 31.
Denominator	All dialysis patients younger than age 70 treated in the facility as of December 31.
Exclusions	Patients aged 70 years and older

Standardized Transplantation Ratio (STR) for Dialysis Patients

Measure Description	The Standardized Transplantation Ratio (STR) is the ratio of the actual number of first transplants (living and deceased) to the expected number of first transplants for the facility, given the age composition of the facility's dialysis patients.
Numerator	The actual number of first transplants (living and deceased) for the facility
Denominator	Number of first transplants that would be expected among eligible dialysis patients at the facility during the time period, given the patient age at the facility. For all patients, each year, time at risk at a facility begins on the latest of the following occurrences: January 1, on day 91 of ESRD, or on the 60 th day of continuous treatment at that facility. Time at risk continues until the earliest of the following occurrences: transplant, date of death, end of the facility treatment period, or December 31. A patient may have been treated at one facility for multiple periods during the same year; in such a case, the number of patient years at risk included time at risk for all periods of treatment at that facility.
Exclusions	Patients aged 70 years and older

4. Measure Development Test Bed

As part of the End-stage Renal Disease (ESRD) Measure Development and Support Project, CMS has been developing a comprehensive system to conduct testing in support of new or previously developed quality measures, using a sample of dialysis facilities. The system will include alpha testing, which allows initial assessment of the feasibility, reliability, and validity of collecting data elements necessary for measure implementation. In beta testing, reliability and validity testing of complete measures will be performed to help establish scientific acceptability. The testing process is expected to extend over several years.

5. Preliminary Activities

5.1 Environmental Scan and Literature Review

Prior to the in-person TEP meeting, UM-KECC presented the group with a summary of published literature (Appendix B) and existing clinical practice guidelines (Appendix C) relating to access to kidney transplantation. The main findings from the literature review performed for the environmental scan included:

- Transplantation is the treatment of choice for most patients requiring renal replacement therapy
- The importance of discussing renal replacement modality options, and referring patients for renal transplant evaluation in a timely manner
- Potential benefits of preemptive kidney transplantation
- Guiding principles for determining candidacy for renal transplantation
- The importance of effective communication between providers and the transplant centers in identifying changes in the patient's condition that affect eligibility for transplantation
- Guiding principles for patient re-evaluation, and for helping the patient maintain an active status on the waiting list
- Potential barriers to transplantation, including patient education, timely referral, financial issues, transportation, post-procedural and medication costs, and the availability of organs and living donors

Based on the TEP's feedback on the literature review, an additional ten articles were added and referenced during the TEP deliberations. These supplementary citations are notated with an asterisk in the annotated bibliography.

Clinical Practice Guideline sources that were reviewed prior to the in-person TEP meeting included those of:

- The National Quality Forum (NQF)
- The National Quality Measures Clearinghouse (NQMC) and National Guideline Clearinghouse (via the Agency for Healthcare Research and Quality (AHRQ))
- The National Institute for Health and Care Excellence (NICE)
- The National Kidney Foundation Kidney Disease Outcomes Quality Initiative (KDOQI)
- Kidney Disease Improving Global Outcomes (KDIGO)
- European Best Practices (EBP)
- Caring for Australians with Renal Impairment (CARI)
- The American Society of Transplantation (AST)

Additional guideline recommendations cited in *Clinical Practice Guidelines on Wait-Listing for Kidney Transplantation: Consistent and Equitable?* by Pikli Batabyal et al. were later incorporated. These include contributions by various organizations, including the Canadian Society of Transplantation (CST), the UK Renal Association, the European Association of Urology (EAU), the Transplantation Society of Australia and New Zealand (TSANZ), and the Japanese Society of Nephrology.

5.2 TEP Charter

The Access to Kidney Transplantation TEP Charter (Appendix A) was distributed to the TEP members for review prior to the in-person meeting. It was revised, based on TEP member input, to clearly indicate a mandate of developing quality measures to assess the performance of dialysis facilities. Following this modification, the Charter was approved by all 11 TEP members.

5.3 Pre-TEP Teleconference Meetings

Two preparatory teleconferences preceded the in-person TEP meeting. The March 26, 2015 conference call focused on the introduction of TEP members, the role of the TEP, the process for accessing TEP tools and resources, and the requirement to achieve TEP approval of the Charter. In addition, TEP members and the contractor, UM-KECC, provided their respective Conflict of Interest disclosures. TEP members and UM-KECC staff were provided an additional opportunity to restate potential conflicts of interest during the in-person TEP meeting; these are noted in the table on pages 5-6 of this report. The discussion from the second pre-TEP conference call on April 16, 2015 focused on the announcement of the TEP Chair and Co-Chair, an initial discussion of the scope of access to transplantation and areas of interest, and establishing the agenda for the in-person TEP meeting.

6. In-person TEP Meeting

6.1 Introductory Summary Materials

The morning session began with three introductory presentations on access to kidney transplantation. These provided background information to inform discussions during the two day meeting. The presentations included a summary of the steps to transplantation, national and regional data on access to transplantation, and details about potential barriers and interventions to improve access to transplantation. The presenters were Rachel Patzer, PhD, MPH, of Emory University, Vahakn Shahinian, MD, MS, of UM-KECC, and Amy Waterman, PhD, of UCLA. Summaries of each presentation, in the order of delivery, are presented below.

6.1a. Measuring Steps in Access to Kidney Transplantation: Lessons Learned, Rachel Patzer, PhD, MPH

Dr. Patzer's presentation included an overview of the steps to transplantation, data on dialysis facility-level variability in transplantation, waitlisting, and referral, and the limitations of currently available measures. She also discussed lessons learned through her partnership with the Southeastern Kidney Transplant Coalition, specifically with respect to collecting transplant referral and evaluation data across dialysis facilities and transplant centers within ESRD Network 6. Dr. Patzer included a summary of the RaDIANT (Reducing Disparities in Access to Kidney Transplantation) Community Study, and its dialysis facility-level interventions aimed at improving transplant referral rates.

Steps to Transplantation

Each of the seven steps to transplantation captures something unique about the transplant process. These steps include pre-ESRD nephrology care, ESRD transplant education, referral, evaluation start, evaluation completion, waitlisting, and transplant surgery. While the dialysis facility can presumably impact all of the steps across the spectrum of transplantation, the greatest potential for facility influence exists for the steps that occur earlier in the process. Of the seven steps, only ESRD waitlisting and transplantation are well recorded in national surveillance data. Pre-ESRD nephrology care and transplant education are measured in some form, but the validity of these data may be questionable. Little aggregate information is available for the remaining steps (referral, evaluation start, and evaluation completion), as these elements are not currently measured in national surveillance data.

Standardized Transplantation Ratios (STRs)

Dialysis facility STRs vary greatly across the United States. ESRD Network 6 (Georgia, North Carolina, and South Carolina) reported some of the lowest STRs in the nation from 2008-2011, most of which were attributed to the ESRD population of Georgia. Of the 222 dialysis facilities located in Georgia, 84% had fewer transplants than expected. These low STRs served as Dr. Patzer's motivation to focus quality improvement interventions on Georgia facilities.

Potential limitations of the STR as an outcome measure were described, including the small number of events per facility, the amount of time it would take to show the impact of any changes made in dialysis facility practice (as results are aggregated over a four year period due to the low number of events), and the potentially limited impact of dialysis facility actions on completed transplants.

Variability in Transplant Referrals and Waitlisting Rates

There was modest (65.7%) agreement when comparing the transplant referrals reported by Georgia dialysis facilities with those of transplant centers. Some of the inconsistency may result from preemptive referrals for patients who had not been previously established in CROWNWeb. Transplant referral and waitlisting rates varied across Georgia dialysis facilities; overall, 28% of patients were referred to a Georgia transplant center within one year of dialysis start. Among those referred within one year, only 21.5% of patients were subsequently waitlisted for transplant within the following year. African Americans were more likely to be referred than Whites but less likely to be waitlisted, indicating differentiation in the factors affecting referral versus waitlisting.

Southeastern Kidney Transplant Coalition Quality Improvement Project

The RaDIANT study, performed in partnership with the Southeastern Kidney Transplant Coalition, was implemented across ESRD Network 6, beginning in Georgia. This initiative was comprised of various interventions aimed at improving Georgia's transplant referrals and decreasing disparities; interventions included feedback reports, Peer Mentor Programs, and educational tool-kits.

The most frequently reported barriers to kidney transplant identified in the RADIANT study included:

- Facility Level
 - Insufficient patient educational resources
 - Unclear transplant center requirements

- Patient Level
 - Insufficient social support for patients

- Patient transportation to transplant center
- Financial or insurance factors
- Lack of family support
- Patients not interested in kidney transplantation
- Patient fear
- Ineligibility due to health problems (dental, weight, etc.)
- Ineligibility due to non-compliance with dialysis treatment

Preliminary, crude data indicate that the interventions utilized in the initiative were associated with an increase in referral rates during the 9-month follow-up period (January—September 2014), particularly within the African American population. While the data do not provide sufficient information to determine which of the interventions had the greatest effect, Drs. Patzer and Pastan expressed interest in eliciting feedback from the facilities regarding the strategies with the strongest impact. Further analysis will be performed to examine the 12-month outcome data.

Transplant Referral as a Quality Measure

Dr. Patzer highlighted the potential limitations of a transplant referral rate measure, including a potential increase in referrals without education or patient discussion of transplantation, difficulty in capturing referrals made to out-of-state transplant centers, and difficulty validating referral data provided by the dialysis facility due to varying facility practices. Dr. Pastan emphasized the possibility of developing a standardized transplant referral ratio to address some of the limitations of a referral rate measure. The TEP agreed on the importance of measuring transplant referral, and later discussed the development of a referral measure in greater depth.

6.1b. Access to Kidney Transplantation, Vahakn Shahinian, MD, MS

Dr. Shahinian provided an overview of the benefits of kidney transplantation, the ESRD Networks Transplant Referral Project, and variations in waitlisting and transplantation:

Benefits of Kidney Transplantation

Dr. Shahinian briefly reviewed a seminal study providing evidence of the survival benefits of kidney transplantation over dialysis for patients with ESRD⁵. He noted that despite a modest increase in risk of death due to post-operative events, a net benefit to transplantation over remaining on dialysis accrues by approximately 9-months after transplant, and continues to increase thereafter. Almost all patient subgroups appear to have a survival benefit, with projected gains in life expectancy of over a decade in some cases. In addition, other studies have documented substantial quality of life benefits for patients with kidney transplants as compared to those continuing with dialysis.

ESRD Networks Transplant Referral Project

Dr. Shahinian next summarized UM-KECC's discussions with the seven ESRD Networks that participated in a project designed to improve kidney transplant referral rates and reduce disparities in referral. Each participating Network selected a disparity focus of age, race/ethnicity, or sex. Baseline referral data were collected in the latter half of 2012, and formed the basis to compare the results of interventions implemented throughout 2014. He noted that the networks did not employ a uniform definition of referral.

⁵ Wolfe RA, Ashby VB, Milford EL, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med.* 1999 Dec 2; 341(23):1725-30.

Various interventions were introduced by the Networks, including patient and staff education, transplant center presentations hosted at the local dialysis facilities, and Network feedback on referral data.

The ESRD Networks reported that dialysis facilities provided referrals via telephone, fax, or email. The majority of Networks highlighted communication barriers between the dialysis facilities and transplant centers, with frequent discrepancies between dialysis facilities and transplant centers as to whether or not referrals were considered to have occurred.

In addition, the method used to calculate referral rates created difficulty in assessing improvements. With this method, the numerator contained a cumulative number of referrals over time, but the denominator was fixed as the CROWNWeb-based dialysis facility census. Although definite conclusions could not be reached, most Networks had a sense that the number of referrals increased following the interventions.

Variations in Waitlisting and Transplantation

The concluding presentation topic was a brief overview of the kidney transplant waitlisting rate and STR as currently reported in the DFRs. These reports are made available to dialysis facilities on an annual basis, and provide data with which to compare a facility's performance on various outcome and clinical measures to performance averages of their state, network, and the nation.

In general, wide variations in waitlisting and transplantation occur across states. Differences in state waitlist and transplantation rankings suggest that the factors affecting these metrics are distinct. Dr. Shahinian presented data documenting wide national variations in age-adjusted standardized transplantation ratios across dialysis facilities. Special analyses conducted by UM-KECC (adjusted for age, comorbidities, and Organ Procurement Organization (OPO) donation rates) demonstrated persistently wide dialysis-facility variations in STRs, suggesting room for improvement even after accounting for the factors noted above that are beyond dialysis facility control.

6.1c. Transplant Education among Dialysis Staff: Needs and Current Practices, Amy Waterman, PhD

Dr. Waterman presented an overview of her research relating to kidney transplant education, including work describing the impact of patient knowledge and transplant education on subsequent completion of a transplant evaluation, patterns in using dialysis facility staff as transplant educators and their level of knowledge about transplantation, and the impact of transplant education practices on dialysis center waitlisting rates.

Assessing Transplant Knowledge in Dialysis Patients

In this study, eligible dialysis patients completed a telephone survey about their knowledge of transplantation, perceived pros and cons to transplant, readiness to pursue transplant, and potential socioeconomic barriers. Patients were classified into "began evaluation" or "no evaluation" groups based on their decision whether or not to pursue transplant. A large gap in patients' transplant knowledge was identified regardless of their progress with the evaluation process. These results indicate that the majority of dialysis patients making decisions about the pursuit of kidney transplantation are doing so without a basic awareness or understanding of the process.

Explore Transplant- a National Quality Improvement Initiative

The Explore Transplant initiative, led by Dr. Waterman, was a training program designed to equip dialysis providers to adequately educate their patients about kidney transplantation. The Explore Transplant team

surveyed 1,995 dialysis staff from 1,249 dialysis centers, across 30 states and 12 ESRD Networks, regarding their attitudes about transplant education, transplant knowledge levels, and transplant educational practices.

Transplant Educator Characteristics, Preparedness, and Knowledge

Many dialysis facilities did not have a designated transplant educator. There was a wide range of dialysis facility staff serving as transplant educators, the majority of whom were Social Workers or on care teams led by a Social Worker. Data on transplant educators' preparedness and knowledge indicated that a large percentage did not possess sufficient knowledge about transplantation or confidence in their abilities to educate a patient about transplantation. Participants identified a number of educator, system, and patient barriers that interfered with their ability to provide transplant education. Many facilities lacked the tangible resources (DVD player, print and/or video transplant education materials) necessary to provide effective education about kidney transplantation.

Dialysis Facility Transplant Education Practices

In general, the majority of transplant educators surveyed about their educational practices reported recommending to patients that they independently learn more about transplants, and that patients be evaluated for transplant. About half of the educators also referred patients to an external transplant educational program, or provided handouts or brochures about transplant. Less than half distributed transplant center phone numbers, and only one-quarter engaged in detailed discussions about the advantages and risks of living versus deceased donation. Facilities that implemented supplemental referral strategies, such as providing handouts or brochures about transplantation, distributing transplant center phone numbers, or showing transplant videos, had a greater numbers of their patients on the transplant wait-list. These results strongly suggest that there is an opportunity to improve access to kidney transplantation through educational practices.

Potential Metrics Related to Improved Transplant Education

Dr. Waterman offered the educators a number of potential metric options designed to improve transplant education, including:

- Formalizing a set of job responsibilities for a transplant educator or team, and assigning which staff member(s) are accountable
- Ensuring that transplant educators have adequate knowledge about transplant
- Ensuring that a transplant educator has key contacts at each local transplant center and has spoken with them at regular intervals
- Providing phone numbers of transplant centers and print and/or video-based education on transplant in addition to informing and providing oral referrals for evaluation
- Ensuring the presence of a DVD player, print and/or video transplant education resources for patients and potential living donors, as well as a translator who can provide transplant education for Spanish-speaking patients

6.2 Candidate Quality Measure Areas to Assess Patient Access to Kidney Transplantation

TEP members considered a number of potential measures across the spectrum of the transplantation process, evaluating each for the degree in which they may be under control of dialysis facilities, feasibility

of the required data-element collection, and impact on meaningful outcomes for patients. Measure areas ultimately chosen for discussion by the TEP and details of the discussion for each measure area are provided in the following sections:

- 6.3a. Patient Education on Kidney Transplantation (6.3a)
- 6.3b. Referral for Kidney Transplant Evaluation (6.3b)
- 6.3c. Waitlisting for Kidney Transplantation (6.3c)
- 6.3d. Tracking of Transplant Evaluation Process (6.3d)
- 6.3e. Transplantation Rate or Standardized Transplantation Ratio (6.3e)

6.3 Summary of TEP Discussion for the Proposed Measure Areas and Data Elements

For each measure area, the first section reflects discussion by the TEP surrounding the merits of the measure and how to operationalize it. This is followed by a summary of the TEP discussion of details of the measure specifications. Variations in the degree of detail provided in the summaries below for each measure area and section reflect the degree of discussion that occurred.

6.3a. Patient Education on Kidney Transplantation

The TEP members uniformly agreed on the importance of patient education regarding kidney transplantation. The group viewed education as a means to improve patient readiness and willingness to be evaluated for transplantation, waitlisting, and ultimately receipt of a living kidney donor transplant. They included the rationale that patient education plays a fundamental role in allaying patient concerns about the transplant process, including fear of surgery, complications, and financial costs. Dr. Waterman's research was also cited in support of a transplant education measure, as she demonstrated associations between patient transplant knowledge or dialysis facility transplant education practices and subsequent completion of transplant evaluation or waitlisting. It was noted that enriched educational efforts may not always lead to increased referral rates, as the number of patients making informed decisions not to pursue transplantation may theoretically increase as well.

The TEP also expressed the opinion that education about transplantation falls clearly under the responsibility of the dialysis facility. Furthermore, it was noted that from a regulatory perspective, the Conditions for Coverage for End-stage Renal Disease facilities state that patients have the right to be informed about all treatment modalities, including transplantation.

Additional discussion focused on how to operationalize a measure that would adequately capture the performance of high quality transplant education by dialysis facilities. As part of that discussion, the group reviewed potentially relevant data elements currently collected on the CMS 2728 Medical Evidence (ME) Form. One item determines if the patient has been informed of kidney transplant options (Yes/No); if No, the individual completing the form is asked to indicate why a kidney transplant is not currently a viable option for this patient (medically unfit, patient has not been assessed, patient declines information, psychologically unfit, unsuitable due to age, and other).

The TEP discussed potential reliability and validity issues surrounding the 2728 transplant education data elements. Problems include that binary answers do not robustly capture the extent of discussion that has occurred, and that research has shown poor agreement between responses on the form and a patient's

perceptions of discussions about transplantation. Furthermore, although the 2728 ME Form instructions state that the transplant education-related questions (26 and 27) should be completed by a physician at the dialysis facility, in practice this is often not the case. It is thus difficult to verify whether a discussion with a physician occurred at any time, or the extent of the discussion that occurred. The TEP also was concerned that the 45-day requirement associated with the 2728 ME Form completion may be too brief when considering transplant education, particularly for the patients that “crash” into dialysis and require additional time to stabilize in order to be able to participate in education. As such, the TEP felt that an education measure could not be constructed around the data elements on the 2728 ME Form.

The TEP members discussed various other suggestions for potential transplant education measures. One suggestion was to utilize an attestation checklist of transplant-specific educational domains (living donation, deceased donation, economics of transplantation, and post-transplant care requirements) to guide and document the patient discussion. Some concern was raised that such a checklist may have limited impact, and would not necessarily ensure that an adequate discussion had occurred. Several members of the TEP expressed interest in implementing a program for certifying dialysis facility staff serving as transplant educators, as a means of ensuring adequate knowledge and expertise for educating patients. However, the TEP believed that implementing such a program fell outside the domain of quality measure development, and would be potentially too prescriptive. The group additionally debated the practical utility of a measure that would require dialysis facilities to designate one individual responsible for providing transplant education within the facility; concerns were raised that such a measure was likely of low impact and setting “too low a bar”, leaving little room for improvement over time.

The TEP expressed substantial agreement that greater impact may be achieved through introducing a measure that incorporates the patient’s experience of the educational process. In its simplest form, this could document dialysis patients’ acknowledgement of receipt of educational materials on transplantation from the dialysis facility staff. An extension of this concept would include assessing patients’ knowledge about transplantation, or assessing the patient’s “engagement” or “readiness” to make a decision about transplantation. The group believed that these aspects may be assessable through some pre-existing instruments or surveys, although no specific tool was identified during the TEP discussion. Several TEP members raised cautionary notes about a measure based on patient experience. These included issues of burden on patients and potential language barriers for non-English speakers. In addition, it was noted that for patients without decision-making capacity, the assessment may need to be administered to a caregiver.

6.3a.1.Potential Measure Specifications

Numerator/Denominator

Numerator: As noted above, there was wide agreement that it was important to have an assessment of patient receipt of direct education and/or materials. The specific operationalization was not finalized during the discussion. Suggestions included 1) a simple acknowledgement by the patient of receipt of educational materials on transplantation and 2) a formal assessment through a survey instrument of either patient knowledge about transplant or evaluation of patient “readiness” to make a decision about transplantation.

Denominator: This measure was deemed to be applicable to all dialysis facility patients.

Timing and Frequency of Measurement

TEP members reflected on the utility of dividing the educational metric into two separate measures for incident and prevalent patients, and highlighted the importance of regular reeducation of established patients. The TEP subsequently recommended that transplant education occur within 90 days of dialysis initiation for incident patients, and reoccur annually for prevalent patients.

Exclusions/Risk Adjustment

The TEP generally felt that an education measure should be broadly applicable to all dialysis patients and therefore there was no need for exclusions or risk adjustments. In particular, the group highlighted the importance that patients identified as unsuitable for kidney transplantation understand why they are not candidates and, where appropriate, be made aware of the steps they can take towards achieving future eligibility.

Data Elements and Collection Method

The TEP discussed the possibility of utilizing the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH-CAHPS) survey as one possible avenue for assessing patient acknowledgement of educational materials. This could be accomplished by adding relevant questions to the survey such as “Were you given the transplant center phone numbers in your area?”, “Did you receive video or printed educational materials about kidney transplantation?”, or “Do you have questions about kidney transplantation that have not yet been addressed?”. Potential barriers to using the ICH-CAHPS survey for this purpose include its already substantial length, black-out dates that prohibit testing during various periods, and the limitation of the survey to a random sample of adult in-center hemodialysis patients.

For assessment of patient knowledge or readiness, it was determined that a separate survey instrument would be necessary, though the specific tool was not specified. One possibility for collecting survey results would be through CROWNWeb.

6.3b. Referral for Kidney Transplant Evaluation

The TEP members unanimously agreed that a measure assessing referral of dialysis patients for transplant evaluation was important, given that this is a necessary step in the process to receipt of transplantation. There was also unanimous agreement that referral for transplant evaluation was the responsibility of dialysis facilities, and under their control. In addition, both the preliminary evidence provided by Dr. Patzer from the RaDIANT Study and data from the transplant referral projects administered by several of the ESRD Networks document that referral rates can be improved by multi-faceted interventions at the dialysis facility level. Finally, from a regulatory perspective, the Conditions for Coverage for ESRD Facilities state that patients have the right to evaluation of suitability for referral to transplantation, based on transplant center criteria. The dialysis facility is obligated to have selection criteria for each transplant center on file, available at the patient’s request, and is required to document any reasons for non-referral in the patient’s record.⁶ Much of the TEP discussion relating to this area focused on details of measure specification, as described below.

⁶ ESRD Basic Technical Surveyor Training: Interpretive Guidance (V458). Interim Final Version 1.1, 2008 Oct 3: 195.

6.3b.1. Potential Measure Specifications

Numerator/Denominator

Numerator: The number of patients referred to at least one transplant center; it was deemed that patients with multiple referrals would count as one in the numerator, and those patients referred prior to dialysis start would be excluded. Patients who self-referred to a transplant center would be included in the numerator; it was considered the dialysis facility's responsibility to be aware of self-referrals.

Denominator: All dialysis facility patients, with exclusions for patients referred prior to dialysis start and meeting other exclusions as discussed below. Caution was advised to specify the denominator in such a way as to not disadvantage facilities with transient or recently transferred patients.

Timing and Frequency of Measurement

The TEP members agreed to divide the measure for incident versus prevalent patients. The rationale for this was that a measure for incident patients would potentially help incentivize early initiation of the process for transplant evaluation. A measure for prevalent patients would help provide an ongoing incentive for referral of patients who were not previously referred, or were not initially suitable for referral. However, there was substantial debate about the specified timing of the referral for incident patients. Some members believed that the measure should specify referral within 90 days of dialysis start, whereas others felt that some patients may require additional time to stabilize on dialysis prior to making a decision about being evaluated for transplant. Alternative proposals were either within 180 days of dialysis start or within one year of dialysis start. No consensus was achieved, with further discussion planned via email or teleconference.

Exclusions/Risk Adjustment

The group briefly discussed whether children should be excluded from measurement or assessed with a distinct pediatric measure. UM-KECC noted the reporting requirement that excludes facilities with fewer than 11 patients from measurement, and explained that a pediatric-specific measure would therefore be unlikely to capture the majority of pediatric patients, given the small pediatric population within facilities. The TEP agreed on the necessity of including pediatric assessment within the measure, and recommended retaining pediatric patients within the numerator and denominator specifications.

The TEP advocated for an exclusion of patients with either absolute contraindications to transplantation (based on criteria from the referred transplant center) or documentation that the patient does not wish a referral. However, it was noted that there may be challenges to adequately capturing those data elements.

Panel members agreed that distance to a transplant center should not be a determining factor for referral. Similarly, the majority of the TEP recommended against adjustment for socio-economic status, arguing that financial issues should not be used as a reason for non-referral. Several members remained concerned that facilities serving a greater percentage of impoverished patients will be at a disadvantage if a socioeconomic risk-adjustment strategy is not applied.

A participant suggested considering a standardized, transplant referral ratio measure, with adjustment for age, comorbidities, and other characteristics that reflect appropriate criteria for non-referral. The concern

was that without adjustment, facilities with older or sicker patient populations may be disadvantaged. This would be mitigated to some extent, however, if data on the presence of absolute contraindications to transplant could be adequately captured. It was decided that the issue of need for adjustment could be explored further through formal analysis once a mechanism for capturing referral data was established.

Data Elements and Data Collection Method

A majority of TEP members supported transplant referral metrics including specific information to validate the occurrence of a referral, such as the referral date and the name of the transplant center(s) to which the patient was referred. A concern was raised by one panel member about providing the name of the transplant center as a data element, as it may convey confidential information about the referring practices of dialysis facilities.

The discussion returned to the need to record the presence of absolute contraindications to transplantation, such as active malignancy, active infection, severe cardiovascular or pulmonary disease, or unstable psychosocial status, as well as patient refusal to be referred for transplant evaluation.

It is expected that data elements for the measure would ultimately be collected through CROWNWeb. A kidney transplant referral date element previously existed in CROWNWeb through 2012, though this was generally under-utilized and under-reported, perhaps due to the data field's location on the hospitalization page.

6.3c. Waitlisting for Kidney Transplantation

UM-KECC noted that a waitlisting measure has been reported as part of the DFRs for two decades, and that accurate capture of waitlist data is readily available via the Organ Procurement and Transplantation Network (OPTN). Although the TEP recognized waitlisting as an important outcome for dialysis patients, and a potential prelude to eventual transplantation, there was substantial debate about its merits as a quality measure for dialysis facilities.

Several TEP members expressed concern that as waitlisting is ultimately determined by transplant centers, it was questionable to hold dialysis facilities responsible for an outcome not under their direct control. There was further concern that in some regions, dialysis facilities may only have one transplant center to reasonably choose from, further limiting their ability to exert control over the waitlisting process. Other TEP members argued that dialysis facilities can significantly influence waitlisting by helping patients navigate the transplant process, from referral through completion of the transplant evaluation, ensuring that all necessary testing as part of the evaluation process is done in a timely manner, and contributing to their overall health and therefore suitability for transplantation. In addition, the importance of proper coordination of care and communication between dialysis facilities and transplant centers was highlighted as a means of achieving the outcome of waitlisting. Some TEP members therefore felt that a quality measure on waitlisting directed at the dialysis facility could incentivize and encourage facilities to improve communication with transplant centers and provide better support to patients throughout the process, thereby effecting a positive change. An alternative suggestion was to consider a measure evaluating the completion of a waitlisting decision (waitlisted vs not-waitlisted/ineligible vs requires further evaluation) as opposed to waitlisting itself. Several TEP members felt this would allay some concerns, as it would not hold dialysis facilities responsible for whether or not the patient was actually waitlisted, only that they proceeded to completion of the initial evaluation. It was noted, however, that currently data are only readily available on actual waitlisting, not the full details of the outcome of the initial transplant evaluation.

After extensive discussion, no consensus could be achieved regarding this measure, so an anonymous vote by the TEP membership was exercised. The group voted separately on the development of a detailed waitlisting measure and one that simply assessed whether a decision was completed. The TEP voted eight to three in favor of a waitlisting-rate measure, and nine to two in favor of a waitlisting decision measure. There was insufficient time to proceed with a discussion of detailed measure specifications. However, the TEP noted that a modified version of the current DFR waitlisting measure could be employed. The current DFR waitlisting measure only excludes patients aged 70 or older. TEP members believed that this age cut-off is too restrictive, and that additional risk adjustments and/or exclusions may be required. To assist with the development of measure specifications, UM-KECC will conduct analyses on currently available national waitlisting data to assess the need for additional risk adjustments and/or exclusions, and will follow-up in a teleconference presentation to the TEP.

6.3d. Tracking of Transplant Evaluation Process

The TEP expressed interest in developing a measure that would evaluate the process between referral and completion of the transplant evaluation, an area where patients often get “lost”. Evidence provided in Dr. Patzer’s presentation also clearly demonstrated that a substantial portion of referred patients do not complete, or even initiate, the actual evaluation. The TEP felt that although not entirely under control of the dialysis facility, this was another area where the dialysis facility could provide substantial support to patients. This may be in the form of ensuring adequate communication between the dialysis facility and the transplant center, and keeping patients informed of their progress in the evaluation process. However, despite substantial discussion and enthusiasm for this type of measure, a clear operationalization could not be developed. A final suggestion was to potentially operationalize this measure to represent the time between referral and waitlisting, once confirmatory data are available. Development of a relevant measure was deferred, but can be reconsidered in the future.

6.3e. Transplantation Rate or Standardized Transplantation Ratio

UM-KECC noted that STRs have been reported as part of the DFRs for two decades, and that accurate capture of transplantation data is readily available via the OPTN. The TEP unanimously agreed that measures of transplantation rates would not be appropriate quality measures for dialysis facilities. One major concern was that many factors completely outside the control of dialysis facilities influence transplantation rates, such as organ availability. Some consideration was given to whether any statistical adjustment strategies could allay the latter concern, but ultimately the TEP did not feel these issues could reasonably be overcome. An additional concern was the low event rate for a transplantation measure; the DFR measure requires four-year aggregate data. As a result, changes made by dialysis facilities to improve transplantation rates may not be evident for several years, further hampering the usability of this type of measure. The final recommendation of the TEP was against developing quality measures for dialysis facilities based on transplantation rates.

7. Post-TEP Public Comment Period

A public comment period was held at the conclusion of the in-person TEP meeting on April 21, 2015. No comments were received.

8. Summary and Conclusions

Overall, there was enthusiastic agreement about the goals of this TEP to improve access to kidney transplantation, as the benefits of transplantation for patients requiring renal replacement therapy are

clear. There was unanimous agreement about the importance of measures pertaining to kidney transplant education, and to referral for transplant evaluation. A majority of TEP members supported a waitlisting measure, though there was disagreement about the merits of such a measure as dialysis facilities do not have complete control over the waitlisting decision. While there was substantial interest in a measure that assessed the process between referral and completion of transplant evaluation, no consensus was reached regarding how to operationalize such a measure; its development was deferred. The group concluded that transplantation-rate measures were not appropriate quality measures for dialysis facilities, given concerns about lack of dialysis facility control over transplantation, and issues around usability of a measure with such low event rates.

8.1 Summary of Measure Areas and Follow-up Needs

Though discussed to various extents across the different potential measure areas, measure specifications were not finalized by the end of the in-person TEP meeting. It is anticipated that a subsequent teleconference will be held to further identify and refine measure specifications. Issues identified for follow-up are:

8.1a Patient Education on Kidney Transplantation

- Further discussion is needed to define the measure numerator, including a choice of simple patient acknowledgement of receipt of educational materials versus a survey instrument assessing transplant knowledge or readiness for decision-making about transplant
- Further investigation will be needed regarding potential survey instruments
- UM-KECC and CMS will investigate the potential for adding a question about receipt of educational materials on transplantation to the ICH-CAHPS survey
- Further refinement of measure specifications will be needed once clarifications on identified concerns are completed

8.1b Referral for Kidney Transplant Evaluation

- Further discussion is needed regarding choice of the most appropriate interval for assessment of referral following start of dialysis, 90 days, 180 days, or one year
- Further TEP discussion is needed on the necessity for an adjusted measure (i.e. referral ratio), although this may await availability of referral data collection to permit analyses
- Further discussion is required on the optimal way to capture data elements related to the absolute contraindications to transplantation, and to patient refusal to be referred for transplant evaluation
- A plan will be developed for data collection and testing of data elements related to referral (transplant center name, referral date, reasons for non-referral)
- Further refinement of measure specifications is needed once clarifications on the above points are complete

8.1c Waitlisting for Kidney Transplantation

- UM-KECC will conduct analyses on waitlisting rates to assess the potential need for exclusions and/or risk adjustment, which will be presented to the TEP for input
- A plan will be developed for data collection and testing of data elements related to a decision measure (i.e. capture of decision to waitlist vs. no waitlist/ineligible, vs. need for further evaluation)

- Further refinement of measure specifications will occur once clarifications on identified concerns are complete

8.1d Transplant Evaluation Tracking Measure

- This item was deferred; measures assessing the time between referral and waitlisting and/or decision on waitlisting will be considered in the future

8.1e Transplantation Rates or Standardized Transplantation Ratios

- No measures were recommended at this time

8.2 Summary of Data Collection Needs

Data availability and collection needs for each of the four recommended measure areas are summarized below.

Measure Area	Data Collection Needs
Patient Education on Kidney Transplantation	The development of a patient education measure will require identification and collection of new data elements. Once identified, the data elements will likely require evaluation in the measure development test bed process described earlier in this report. Data collection options potentially include elements added to the ICH-CAHPS survey, or alternatively through use of a yet to be established instrument implemented via CROWNWeb.
Referral for Kidney Transplant Evaluation	The development of a referral for kidney transplant evaluation measure will require collection of new data elements. The data elements will potentially need evaluation in the measure development test bed process described earlier in this report. Data collection will likely be implemented through CROWNWeb.
Waitlisting for Kidney Transplantation	A waitlisting rate or ratio measure can be implemented currently using readily available data via the OPTN. The development of a measure that captures the waitlisting decision will require collection of new data elements. These data elements will likely require evaluation in the measure development test bed process described earlier in this report.
Transplant Evaluation Tracking Measure	Future implementation of a transplant evaluation tracking measure will require collection of new data elements. Depending on the specifications, data elements may need to be evaluated in the measure development test bed process described earlier in this report.

9. References

1. Wolfe RA, Ashby VB, Milford EL, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med*. 1999 Dec 2; 341(23):1725-30.
2. [Medicare and Medicaid Programs; Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule.](#) "Federal Register 73:73 (15 April 2008) p. 20479.

3. <http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicId=6>
4. Patzer RE et al. Dialysis facility and network factors associated with low kidney transplantation rates among United States dialysis facilities. *American Journal of Transplantation* 14(7):1562-1572.
5. ESRD Basic Technical Surveyor Training: Interpretive Guidance (V458). Interim Final Version 1.1, 2008 Oct 3: 195.

10. Appendices

- A. Access to Kidney Transplantation TEP Charter
- B. Annotated Bibliography
- C. Clinical Practice Guidelines
- D. Slides presented at in-person TEP meeting

Technical Expert Panel Charter

Project Title:

End-Stage Renal Disease Access to Kidney Transplantation Technical Expert Panel

Dates:

April 20 – 21, 2015

Project Overview:

The Centers for Medicare & Medicaid Services (CMS) has contracted with The University of Michigan Kidney Epidemiology and Cost Center to develop a quality measure(s) for access to kidney transplantation. The contract name is the ESRD Quality Measure Development, Maintenance, and Support contract. The contract number is HHSM-500-2013-130171.

As part of its measure development process, CMS asks contractors to convene groups of stakeholders and experts who contribute direction and thoughtful input to the measure contractor during measure development and maintenance. For this project, TEP members will review available data on the three steps in the transplant process: referrals, waitlist, and receiving a transplant.

Background: The results of numerous studies have indicated that the recipients of renal transplants have better survival than comparable dialysis patients.¹ The ESRD Conditions for Coverage mandate a comprehensive reassessment of each patient annually (at minimum) with the revision of the Plan of Care. Both the patient assessment and Plan of Care should include reevaluation of treatment modality and transplant status. Specifically, Section 494.80(a)(10) of the revised Conditions for Coverage for ESRD Facilities, effective October 14, 2008, sets forth requirements for patient assessment with regard to transplantation referral: "Evaluation of suitability for a transplantation referral, based on criteria developed by the prospective transplantation center and its surgeon(s). If the patient is not suitable for transplantation referral, the basis for non-referral must be documented in the patient's medical record."² Additionally, objectives CKD-12 and CKD-13 of Healthy People 2020 have the goal to "increase the proportion of dialysis patients wait-listed and/or receiving a deceased donor kidney transplant within 1 year of ESRD start (among patients under 70 years of age)" and "increase the proportion of patients with treated chronic kidney failure who receive a transplant".³

¹ Wolfe RA, Ashby VB, Milford EL, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. *N Engl J Med.* 1999 Dec 2; 341(23):1725-30.

² [Medicare and Medicaid Programs; Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule.](#) *Federal Register* 73:73 (15 April 2008) p. 20479.

³ <http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicId=6>

Substantial variations by facility and geographic region, as well as disparities by race and socio-economic status in transplantation rates raise concerns about current processes for provision of access to transplantation.⁴

In 2004 and 2005, ESRD Network 9/10 conducted a Technical Expert Panel (TEP) to develop transplant referral clinical performance measures.⁵ The TEP proposed three clinical performance measures, Incident Patient Discussion, Prevalent Patient Discussion, and Referral to Transplant Center, and two descriptors, Interest and Contraindication. In its report, the TEP and Contractor stated that attention and measurement of the dialysis facility side of process, without equal attention and measurement of the transplant center side of the process was shortsighted. Ensuring all appropriate dialysis patients are referred to a transplant center is important, but equally critical is what happens between the time of referral and time of wait listing for deceased donor transplantation or live donor transplantation. Therefore, two additional transplant center-specific measures were also recommended (wait listing and live donor transplantation).

Project Objectives:

The University of Michigan Kidney Epidemiology and Cost Center, through its contract with the Centers for Medicare and Medicaid Services will convene a technical expert panel to make recommendations on access to kidney transplantation measures that would be appropriate for public reporting. These measures will be used to evaluate dialysis facilities.

TEP Objectives:

The TEP will use existing data and their expert opinion to formulate recommendations to UM-KECC regarding reevaluation and maintenance of existing measures and development of new measures that address important quality gaps. Recommended measures should be evidence based, scientifically acceptable (reliable and valid), feasible, and usable by CMS, providers, and the public.

Scope of Responsibilities:

The role of each TEP member is to provide advisory input to UM-KECC in the development of access to transplant measures for the US ESRD population.

Role of UM-KECC: As the CMS measure developer contractor, UM-KECC has a responsibility to support the development of quality measures for ESRD patients. The UM-KECC moderators will work with the TEP chair(s) to ensure the panel discussions focus on the development of draft measure specifications as recommended to the contractor. During discussions, UM-KECC

⁴ Patzer RE et al. Dialysis facility and network factors associated with low kidney transplantation rates among United States dialysis facilities. American Journal of Transplantation 14(7):1562-1572.

⁵ <http://www.therenalnetwork.org/qi/resources/TransTEPfinalrpt805.pdf>

moderators may advise the TEP and chair(s) on the needs and requirements of the CMS contract and the timeline, and may provide specific guidance and criteria that must be met with respect to CMS and NQF review of candidate measures.

Role of TEP chair(s): Prior to the in-person TEP meeting, one or two TEP members are designated as the chair(s) by the measure contractor and CMS. The TEP chair(s) are responsible, in partnership with the moderator, for directing the TEP to meet the expectations for TEP members, including provision of advice to the contractor regarding measure specifications.

Duties and Role of TEP members: According to the CMS Measure Management System Blueprint, TEPs are advisory to the measure contractor. In this advisory role, the primary duty of the TEP is to suggest candidate measures and related specifications, review any existing measures, and determine if there is sufficient evidence to support the proposed candidate measures. The level of supporting evidence is expected to vary by measure area.

TEP members are expected to participate in two to three pre-meeting teleconferences during February and March 2015, attend one in-person meeting in April of 2015 (dates are yet to be determined) in Baltimore, MD, and be available for additional follow-up teleconferences and correspondence as needed in order to support the submission and review of the candidate measures by NQF. Some follow up activities may occur after data collection and testing have occurred.

The TEP will review, edit (if necessary), and adopt a final charter at the first teleconference. A discussion of the overall tasks of the TEP and the goals/objectives of the ESRD quality measurement project will be described. TEP members will be provided with a summary of current clinical practice guidelines, literature, and review of other related quality measures prior to the in-person meeting. TEP members will be asked to submit additional studies to be included in the literature review. A review of the CMS and NQF measure development criteria will also be covered during the teleconference.

During the In-Person Meeting: The TEP will review evidence to determine the basis of support for proposed measure(s). The key deliverables of the TEP at the in-person meeting include:

- Recommending candidate measures if there is sufficient evidence to support the measures,
- Recommending draft measure specifications,
- Assisting in completing the necessary documentation forms to support submission of the measures to CMS for review, and to the NQF for endorsement
- As needed TEP members may be asked to provide input to UM-KECC as they prepare responses to public comments

At the end of the two day meeting the TEP chair(s) and TEP members will prepare a summary of recommendations. As necessary, the TEP chair(s) will have additional contact with UM-KECC moderators to work through any other issues. This will include votes for draft and final

measures. After the In-Person Meeting (approximately April – August, 2015): TEP members will review a summary report of the TEP meeting discussions, recommendations, draft measure specifications, and other necessary documentation forms required for submission to the NQF for endorsement.

Guiding Principles:

Potential TEP members must be aware that:

- Participation on the Technical Expert Panel is voluntary.
- Input will be recorded in the meeting minutes.
- Proceedings of the in-person meeting will be summarized in a report that is disclosed to the general public.
- Potential patient participants may keep their names confidential, if they wish to do so.
- If a TEP member has chosen to disclose private, personal data, that material and those communications are not covered by patient-provider confidentiality.
- All questions about confidentiality will be answered by the TEP organizers.
- All potential TEP members must disclose any current and past activities that may pose a potential conflict of interest for performing the tasks required of the TEP.
- All potential TEP members must commit to the expected time frame outlined for the TEP.
- All issues included in the TEP summary report will be voted on by the TEP members
- Counts of the votes and written opinions of the TEP members will be included, if requested.

Estimated Number and Frequency of Meetings:

- TEP members should expect to come together for one to three teleconference calls prior to the in-person meeting held April 20-21, 2015, in Baltimore, MD.
- The in-person meeting will be convened April 20-21, 2015.
- After the in-person meeting, additional conference calls may be needed.

Date Approved by TEP:

April 7, 2015

TEP Membership:

Name and Credentials	Organizational Affiliation, City, State
<p>Stephen Pastan, MD <i>TEP Co-Chair</i></p>	<p><i>Associate Professor of Medicine</i> Renal Division, Emory University School of Medicine, Atlanta, GA</p> <p><i>Medical Director of the Kidney and Pancreas Transplant Program</i> Emory Transplant Center, Emory University, Atlanta, GA</p> <p><i>Board of Directors Member ;</i> <i>Chair of the transplantation task subcommittee</i> National Kidney Foundation (NKF)</p>
<p>Amy Waterman, PhD <i>TEP Co-Chair</i></p>	<p><i>Associate Professor of Medicine, Division of Nephrology;</i> <i>Director of the Transplant Research and Education Center (TREC)</i> David Geffen School of Medicine, University of California, Los Angeles (UCLA), Los Angeles, CA</p>
<p>Todd Pesavento, MD</p>	<p><i>Professor of Medicine,</i> Department of Medicine; <i>Medical Director of Kidney and Pancreas Transplantation,</i> Comprehensive Transplant Center, Ohio State University, Columbus, OH</p>
<p>Sandra Amaral, MD, MHS</p>	<p><i>Assistant Professor</i> Division of Nephrology, Department of Pediatrics; <i>Co-Director of the Kidney Transplant Program</i> The Children's Hospital of Philadelphia, PA</p> <p><i>Senior Scholar</i> Center for Clinical Epidemiology and Biostatistics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA</p>
<p>Ranjan Chanda, MD, MPH</p>	<p><i>Medical Director</i> Centennial Kidney Transplant Center, Nashville, TN</p> <p><i>Partner</i> Nephrology Associates, Nashville, TN</p>
<p>Mary Beth Callahan, ACSW, LCSW</p>	<p><i>Senior Social Worker</i> Dallas Transplant Institute, Dallas, TX</p>
<p>Duane Dunn, MSW</p>	<p><i>National Director of Social Work Services</i> DaVita Healthcare Partners Inc., Columbia, SC</p>
<p>Linda Wright, DrNP, RN, CNN, CCTC</p>	<p><i>Kidney and Pancreas Transplant Coordinator; Certified Nephrology Nurse</i> Thomas Jefferson University Hospital, Philadelphia, PA</p>

Name and Credentials	Organizational Affiliation, City, State
	American Nephrology Nurses' Association
Robert Teaster, RN, MBA, CPTC, CPT	<i>Administrator for Transplant Services</i> University of Virginia Medical Center, Charlottesville, VA
Chris Elrod, CCHT	<i>Chief Technician/ Bio Med</i> Dialysis Clinic, Inc. (DCI)
Nancy Scott	<i>President</i> Dialysis Patient Citizens Education Center

End Stage Renal Disease (ESRD) Quality Measure Development, Maintenance, and Support

Access to Kidney Transplantation Technical Expert Panel Annotated Bibliography

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Overview

UM-KECC's Literature Review and Environmental Scan supporting access to kidney transplantation quality measure specification for chronic dialysis facilities began in January 2015. A series of searches were undertaken iteratively to identify pertinent PubMed content relating to the three steps in the transplant process: referrals, waitlist, and receiving a transplant. Search results were screened for general topic applicability prior to a focused review by two clinical investigators associated with the workgroup. Also included in the environmental are existing guidelines and measures relating to access to kidney transplantation for CKD and ESRD patients.

Literature Review Summary

A preliminary PubMed search in January 2015 limited to articles published in the English language since 2005 was conducted with the following search criteria: ("kidney transplantation"[All Fields] OR "kidney transplant"[All Fields] OR "renal transplant"[All Fields] OR "renal transplantation"[All Fields]) AND ("referral"[All Fields] OR "access"[All Fields] OR "disparities"[All Fields] OR "waitlist"[All Fields]) AND ("2005/01/09"[PDat] : "2015/01/06"[PDat] AND "humans"[MeSH Terms] AND English[lang]). A total of 937 articles were initially identified. The titles and a brief abstract review of the articles was performed to further limit them to those focusing more closely on access to transplantation and in particular, within the U.S. system. This resulted in 148 articles selected for further review.

In addition to the above, PubMed searches utilizing the search criteria outlined by the Healthy People 2020 (HP2020) CKD 12, 13.1 and 13.2 objectives were performed as described below:

The following search criteria from the HP 2020 CKD 12 objective to "Increase the proportion of dialysis patients waitlisted and/or receiving a deceased donor kidney transplant within 1 year of end-stage renal disease (ESRD) start (among patients under 70 years of age)" resulted in 69 articles:

(kidney transplantation[mh] AND kidney failure, chronic[mh]) AND (waiting lists[mh] OR tissue and organ procurement[mh] OR living donors[mh] OR quality of life[mh]) AND (united states[mh] OR (united[all fields] AND states[all fields]) OR united states[all fields]) AND english[la] AND "last 5 years"[dp] NOT aged[mh]

Upon further review, 15 of the 69 articles were selected as relevant to the scope of the TEP objectives.

An additional PubMed search using the following search criteria from the HP 2020 CKD 13.1 to "Increase the proportion of patients receiving a kidney transplant within 3 years of end-stage renal disease (ESRD)" and CKD 13.2 objective to "Increase the proportion of patients who receive a preemptive transplant at the start of ESRD", resulted in 114 articles:

("kidney transplantation"[MeSH Terms] AND "kidney failure, chronic"[MeSH Terms]) AND ("waiting lists"[MeSH Terms] OR "tissue and organ procurement"[MeSH Terms] OR "living donors"[MeSH Terms] OR "quality of life"[MeSH Terms]) AND ("united states"[MeSH Terms] OR (united[all fields] AND states[all fields]) OR ("united states"[MeSH Terms] OR ("united"[All Fields] AND "states"[All Fields]) OR "united states"[All Fields])) AND english[la] AND "2010/01/07"[dp] : "2015/01/05"[dp]

A preliminary review of the resulting articles resulted in a refined list of 36 articles deemed appropriate to the scope of the TEP.

The references identified through the above literature search processes were merged and duplicates were deleted, resulting in a master list of 155 articles. A more comprehensive review investigating the relevance of each article generated a condensed list of approximately 60 articles to be included in the annotated bibliography for the access to kidney transplantation technical expert panel.

**Citations that are preceded by an asterisk are indicative of recommendation by a member of the Access to Kidney Transplantation Technical Expert Panel and as such were incorporated in to the bibliography after UM-KECC's initial literature scan.*

Annotated Bibliography

Abecassis M, Bartlett ST, Collins AJ, et al. **Kidney transplantation as primary therapy for end-stage renal disease: a National Kidney Foundation/Kidney Disease Outcomes Quality Initiative (NKF/KDOQITM) conference.** *Clinical journal of the American Society of Nephrology : CJASN* 2008 3(2):471-80.

Notes: Proceedings of a transplantation disparities conference (NKF/KDOQITM).

Abstract: CONTEXT: Disparities in access to organ transplantation exist for racial minorities, women, and patients with lower socioeconomic status or inadequate insurance. Rural residents represent another group that may have impaired access to transplant services.

OBJECTIVE: To assess the association of rural residence with waiting list registration for heart, liver, and kidney transplant and rates of transplantation among wait-listed candidates.

DESIGN, SETTING, AND PATIENTS: Five-year US cohort of 174,630 patients who were wait-listed and who underwent heart, liver, or kidney transplantation between 1999 and 2004.

MAIN OUTCOME MEASURES: Rates of new waiting list registrations and transplants per million population for residents of 3 residential classifications (rural/small town population, <10,000; micropolitan, 10,000-50,000; and metropolitan >50,000 or suburb of major city).

RESULTS: Compared with urban residents, waiting list registration rates for rural/small town residents were significantly lower for heart (covariate-adjusted rate ratio [RR] = 0.91; 95% confidence interval [CI], 0.86-0.96; P<.002), liver (RR = 0.86; 95% CI, 0.83-0.89; P<.001), and kidney transplants (RR = 0.92; 95% CI, 0.90-0.95; P<.001). Compared with residents in urban areas, rural/small town residents had lower relative transplant rates for heart (RR = 0.88; 95% CI, 0.81-0.94; P = .004), liver (RR = 0.80; 95% CI, 0.77-0.84; P<.001), and kidney transplantation (covariate-adjusted RR = 0.90; 95% CI, 0.88-0.93; P<.001). These disparities were consistent across national organ allocation regions. Significantly longer waiting times among rural patients wait-listed for heart transplantation were observed but not for liver and kidney transplantation. There were no significant differences in posttransplantation outcomes between groups.

CONCLUSIONS: Patients living in rural areas had a lower rate of wait-listing and transplant of solid organs, but did not experience significantly different outcomes following transplant. Differences in rates of wait-listing and transplant may be due to variations in the burden of disease between different patient groups or barriers to evaluation and waiting list entry for rural residents with organ failure.

*Ahsanuddin S, Bento S, Swerdlow N, et al. **Candidate Comprehension of Key Concepts in Kidney Transplantation** *Annals of Transplantation* 2015 20():124-31.

Abstract: **BACKGROUND:** Although kidney transplant candidates receive education regarding transplantation and donation, little is known about the extent of their comprehension. We aimed to identify factors that affect patient comprehension of important concepts regarding kidney transplantation.

MATERIAL AND METHODS: We performed a cross-sectional survey of consecutive adult kidney transplant candidates seen at our center between July 2013 and October 2013 for initial evaluation (n=100) or for reevaluation (n=117). The main outcome measure was a Knowledge Assessment Questionnaire completed by patients. We assessed factors affecting patient understanding of key kidney transplant concepts as measured by mean knowledge score.

RESULTS: Mean knowledge scores of those at evaluation (72±21) and those at reevaluation (70±20; p=0.4769) were similar; therefore the entire cohort was analyzed as a single group. Compared to the high-scoring group, low-scorers (<75%; median value) were significantly more likely to be older, Hispanic, with lower education attainment, and have end-stage renal disease due to hypertension or diabetes rather than other etiologies. On multivariate analysis, independent risk factors for low-scores were increasing age (aOR 1.03 (95% CI 1.01-1.06) and educational level (less than high school; aOR 4.23, 95%CI 1.82-9.80; high school or GED aOR2.85, 95% CI 1.43-5.70 compared to some college or technical school). Of 139 candidates that consented to receive ECD and 152 consenting to CDCHR kidneys, 52% and 27%, respectively, answered the high-risk-specific question incorrectly.

CONCLUSIONS: Educational level and older age are independent risk factors for poor comprehension. Kidney candidate knowledge of organs with increased risks is suboptimal despite previous consent to receive such organs.

Amaral S, Patzer R. **Disparities, race/ethnicity and access to pediatric kidney transplantation.** *Current opinion in nephrology and hypertension* 2013 22(3):336-43.

Abstract: Kidney transplantation remains the optimal treatment for children with end-stage renal disease; yet, in the United States, profound differences in access to transplant persist, with black children experiencing significantly reduced access to transplant compared with white children. The reasons for these disparities remain poorly understood. Several recent studies provide new insights into the interplay of socioeconomic status, racial/ethnic disparities and access to pediatric kidney transplantation.

Amaral S, Patzer RE, Kutner N, McClellan W. **Racial disparities in access to pediatric kidney transplantation since share 35.** *Journal of the American Society of Nephrology : JASN* 2012 23(6):1069-77.

Abstract: Share 35 was enacted in 2005 to shorten transplant wait times and provide high-quality donors to children with ESRD. To investigate the possible effect of this policy on racial disparities in access to pediatric transplantation, we analyzed data from the US Renal Data System before and after Share 35. Among 4766 pediatric patients with incident ESRD, the probability of receiving a deceased-donor kidney transplant increased 46% after Share 35, with Hispanics experiencing the greatest improvements (increases of 81% for Hispanics, 45% for blacks, and 37% for whites). On average, patients received a deceased-donor kidney transplant earlier after Share 35, but this finding varied by race: 63 days earlier for whites, 90 days earlier for blacks, and 201 days earlier for Hispanics. Furthermore, a shift from living- to deceased-donor sources occurred with Share 35 for all races, with a 25% reduction in living donors for whites compared with 48% and 46% reductions for Hispanics and blacks, respectively. In summary, Share 35 seems to have attenuated racial disparities in the time to and probability of children receiving a deceased-donor kidney transplant. These changes coincided with changes in the rates of living-donor sources, which vary by race. Future studies should explore how these changes may impact racial differences in long-term graft outcomes.

Arbor Research Collaborative for Health, The Lewin Group, The National Opinion Research Center at the University of Chicago. **End-Stage Renal Disease (ESRD) Disease Management Demonstration Evaluation Report: Findings from 2006-2008, the First Three Years of a Five-Year Demonstration: Final Report 2010.**

Notes: Final Report

Abstract: This report describes the results of the Evaluation of the Medicare End-Stage Renal Disease (ESRD) Disease Management Demonstration. The Centers for Medicare & Medicaid Services (CMS) contracted with Medicare Advantage (MA) Plans that developed Disease Management programs. The Demonstration allowed patients with End-Stage Renal Disease to enroll in MA Plans. The programs in this Demonstration were operationalized by the three Disease Management Organizations (DMOs) (identified in this report as DMO A, B, and C) in order to deliver coordinated care interventions to ESRD beneficiaries enrolled in their plans.

Arce CM, Goldstein BA, Mitani AA, et al. **Differences in access to kidney transplantation between Hispanic and non-Hispanic whites by geographic location in the United States.** *Clinical journal of the American Society of Nephrology : CJASN* 2013 8(12):2149-57.

Abstract: Background and objectives Hispanic patients undergoing chronic dialysis are less likely to receive a kidney transplant compared with non-Hispanic whites. This study sought to elucidate disparities in the path to receipt of a deceased donor transplant between Hispanic and non-Hispanic whites.

Design, setting, participants, & measurements Using the US Rena IData System, 417,801 Caucasians who initiated dialysis between January 1, 1995 and December 31, 2007 with follow-up through 2008 were identified. This study investigated time from first dialysis to first kidney transplantation, time from first dialysis to waitlisting, and time from waitlisting to kidney transplantation. Multivariable Cox regression estimated cause-specific hazard ratios (HRCS) and sub-distribution (competing risk) hazard ratios (HRSD) for Hispanics versus non-Hispanic whites.

Results Hispanics experienced lower adjusted rates of deceased donor kidney transplantation than non-Hispanic whites (HRCS, 0.77; 95% confidence interval [95% CI], 0.75 to 0.80) measured from dialysis initiation. No meaningful differences were found in time from dialysis initiation to placement on the transplant waitlist. Once waitlisted, Hispanics had lower adjusted rates of deceased donor kidney transplantation (HRCS, 0.66; 95%CI, 0.64 to 0.68), and the association attenuated once accounting for competing risks (HRSD, 0.79; 95%CI, 0.77 to 0.81). Additionally controlling for blood type and organ procurement organization further reduced the disparity (HRSD, 0.99; 95% CI, 0.96 to 1.02).

Conclusions After accounting for geographic location and controlling for competing risks (e.g., Hispanic survival advantage), the disparity in access to deceased donor transplantation was markedly attenuated among Hispanics compared with non-Hispanic whites. To overcome the geographic disparities that Hispanics encounter in the path to transplantation, organ allocation policy revisions are needed to improve donor organ equity. *Clin J Am Soc Nephrol* 8: 2149–2157, 2013.

Ashby VB, Kalbfleisch JD, Wolfe RA, et al. **Geographic variability in access to primary kidney transplantation in the United States, 1996-2005.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2007 7(5 Pt 2):1412-23.

Notes: UM-KECC/Arbor analysis of CMS, OPTN and SRTR data to describe significant geographic variation in kidney transplant waitlisting and transplantation.

Abstract: This article focuses on geographic variability in patient access to kidney transplantation in the United States. It examines geographic differences and trends in access rates to kidney transplantation, in the component rates of wait-listing, and of living and deceased donor transplantation. Using data from Centers for Medicare and Medicaid Services and the Organ Procurement and Transplantation Network/Scientific Registry of Transplant Recipients, we studied 700,000+ patients under 75, who began chronic dialysis treatment, received their first living donor kidney transplant, or were placed on the waiting list pre-emptively. Relative rates of wait-listing and transplantation by State were calculated using Cox regression models, adjusted for patient demographics. There were geographic differences in access to the kidney waiting list and to a kidney transplant. Adjusted wait-list rates ranged from 37% lower to 64% higher than the national average. The living donor rate ranged from 57% lower to 166% higher, while the deceased donor transplant rate ranged from 60% lower to 150% higher than the national average. In general, States with higher

wait-listing rates tended to have lower transplantation rates and States with lower wait-listing rates had higher transplant rates. Six States demonstrated both high wait-listing and deceased donor transplantation rates while six others, plus D.C. and Puerto Rico, were below the national average for both parameters.

Axelrod DA, Dzebiasashvili N, Schnitzler MA, et al. **The interplay of socioeconomic status, distance to center, and interdonor service area travel on kidney transplant access and outcomes.** *Clinical journal of the American Society of Nephrology : CJASN* 2010 5(12):2276-88.

Abstract: BACKGROUND AND OBJECTIVES: Variation in kidney transplant access across the United States may motivate relocation of patients with ability to travel to better-supplied areas.

DESIGN, SETTING, PARTICIPANTS, & MEASUREMENTS: We examined national transplant registry and U.S. Census data for kidney transplant candidates listed in 1999 to 2009 with a reported residential zip code (n = 203,267). Cox's regression was used to assess associations of socioeconomic status (SES), distance from residence to transplant center, and relocation to a different donation service area (DSA) with transplant access and outcomes.

RESULTS: Patients in the highest SES quartile had increased access to transplant compared with those with lowest SES, driven strongly by 76% higher likelihood of living donor transplantation (adjusted hazard ratio [aHR] 1.76, 95% confidence interval [CI] 1.70 to 1.83). Waitlist death was reduced in high compared with low SES candidates (aHR 0.86, 95% CI 0.84 to 0.89). High SES patients also experienced lower mortality after living and deceased donor transplant. Patients living farther from the transplant center had reduced access to deceased donor transplant and increased risk of post-transplant death. Inter-DSA travel was associated with a dramatic increase in deceased donor transplant access (HR 1.94, 95% CI 1.88 to 2.00) and was predicted by high SES, white race, and longer deceased-donor allograft waiting time in initial DSA.

CONCLUSIONS: Ongoing disparities exist in kidney transplantation access and outcomes on the basis of geography and SES despite near-universal insurance coverage under Medicare. Inter-DSA travel improves access and is more common among high SES candidates.

Axelrod DA, Guidinger MK, Finlayson S, et al. **Rates of solid-organ wait-listing, transplantation, and survival among residents of rural and urban areas.** *JAMA* 2008 299(2):202-7.

Abstract: Context: Disparities in access to organ transplantation exist for racial minorities, women, and patients with lower socioeconomic status or inadequate insurance. Rural residents represent another group that may have impaired access to transplant services.

Objective: To assess the association of rural residence with waiting list registration for heart, liver, and kidney transplant and rates of transplantation among wait-listed candidates.

Design, Setting, and Patients: Five-year US cohort of 174 630 patients who were wait-listed and who underwent heart, liver, or kidney transplantation between 1999 and 2004.

Main Outcome Measures: Rates of new waiting list registrations and transplants per million population for residents of 3 residential classifications (rural/small town population, <10 000; micropolitan, 10 000-50 000; and metropolitan >50 000 or suburb of major city).

Results: Compared with urban residents, waiting list registration rates for rural/ small town residents were significantly lower for heart (covariate-adjusted rate ratio [RR]=0.91; 95% confidence interval [CI], 0.86-0.96; P=.002), liver (RR=0.86; 95% CI, 0.83-0.89; P=.001), and kidney transplants (RR=0.92; 95% CI, 0.90-0.95; P=.001). Compared with residents in urban areas, rural/small town residents had lower relative transplant rates for heart (RR=0.88; 95% CI, 0.81-0.94; P=.004), liver (RR=0.80; 95% CI, 0.77-0.84; P=.001), and kidney transplantation (covariate-adjusted RR=0.90; 95% CI, 0.88-0.93; P=.001). These disparities were consistent across national organ allocation regions. Significantly longer waiting times among rural patients wait-listed for heart transplantation were observed but not for liver and kidney transplantation. There were no significant differences in posttransplantation outcomes between groups.

Conclusions: Patients living in rural areas had a lower rate of wait-listing and transplant of solid organs, but did not experience significantly different outcomes following transplant. Differences in rates of wait-listing and transplant may be due to variations in the burden of disease between different patient groups or barriers to evaluation and waiting list entry for rural residents with organ failure.

Axelrod DA, Lentine KL, Xiao H, et al. **Accountability for end-stage organ care: implications of geographic variation in access to kidney transplantation.** *Surgery* 2014 155(5):734-42.

Abstract: BACKGROUND: The provision of effective surgical care for end-stage renal disease (ESRD) requires efficient evaluation and transplantation. Prior assessments of transplant access have focused primarily on waitlisted patients rather than the overall populations served by "accountable" providers of transplant services.

METHODS: Novel transplant referral regions (TRRs) were defined using United Network for Organ Sharing registry data for 301,092 kidney transplant listings to assign zip codes to "accountable" transplant programs. Subsequently, risk-adjusted observed to expected (O:E) rates of listing and transplant procedures were calculated for each TRR. Finally, the impact of variation in TRR listing and transplant rates on mortality was assessed for ESRD patients <60 years old diagnosed between 2000 and 2008.

RESULTS: In total, 113 TRRs were defined, 51% of which included >1 transplant center. The likelihood of being evaluated and listed for transplant varied significantly between TRRs (risk-adjusted O:E, 0.58-1.95). Variation was greater for the overall transplant rate (0.62-2.19), living donor transplantation (0.36-3.08), and donation after cardiac death transplant (0-15.4) than for standard criteria donors (0.64-2.86). Mortality was decreased for ESRD patients living in TRRs in the highest tertile of listings (hazard ratio, 0.89; P < .0001) and transplantation (0.90; P < .0001).

CONCLUSION: Residence in a TRR with care delivery systems that increase access to transplant services is associated with significant, risk-adjusted decreases in ESRD-related mortality. Transplant centers should continue to focus on improving access to care within the communities they serve.

Ayanian JZ, Cleary PD, Keogh JH, et al. **Physicians' beliefs about racial differences in referral for renal transplantation.** *Am J Kidney Dis.* 2004 43(2):350-7.

Abstract: **BACKGROUND:** Black patients with end-stage renal disease are much less likely than white patients to undergo renal transplantation, but previous research has shown that black patients are only slightly less likely to desire this procedure. A better understanding of physicians' views about racial differences in access to transplantation may help reduce disparities in care.

METHODS: We surveyed 278 nephrologists in 4 US regions about quality of life and survival for black and white patients undergoing renal transplantation and reasons for racial differences in access to transplantation. We also surveyed 606 of their patients about their care.

RESULTS: Physicians were less likely to believe transplantation improves survival for blacks than whites (69% versus 81%; $P = 0.001$), but similarly likely to believe it improves quality of life (84% versus 86%). Factors commonly cited by physicians as important reasons why blacks are less likely than whites to be evaluated for transplantation included patients' preferences (66%), availability of living donors (66%), failure to complete evaluations (53%), and comorbid illnesses (52%). Fewer physicians perceived patient-physician communication and trust (38%) or physician bias (12%) as important reasons. Black patients were less likely than white patients to report receiving some or a lot of information about transplantation (55% versus 74%; $P = 0.006$) when their physicians did not view patient-physician communication and trust as an important reason for racial differences in care.

CONCLUSION: Nephrologists' views about the benefits of renal transplantation and reasons for racial differences in access to this procedure may affect how they present this treatment option to black and white patients.

Balhara KS, Kucirka LM, Jaar BG, Segev DL. **Disparities in provision of transplant education by profit status of the dialysis center.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2012 12(11):3104-10.

Notes: Survey of 906 practicing nephrologists attitudes regarding transplant education. Provides some insight about nephrologist opinions about the optimal time required to discuss transplantation with patients and how frequently they did so. Also differences

Abstract: Kidney transplant education is associated with higher transplantation rates; however national policies regarding optimal timing and content of transplant education are lacking. We aimed to characterize nephrologists' attitudes regarding kidney transplant education, and to compare practices between nephrologists at for-profit and nonprofit centers. We surveyed 906 nephrologist practicing in the United States. Most respondents (81%) felt the ideal time to spend on

transplant education was >20 min, but only 43% reported actually doing so. Spending >20 min was associated with covering more topics, having one-on-one and repeated conversations, involving families in discussions and initiating discussions at CKD-stage 4. Providers at for-profit centers were significantly less likely to spend >20 min (RR = 0.89, 95%CI: 0.80-0.99) or involve families (RR = 0.57, 95%CI: 0.38-0.87); they reported that fewer of their patients received transplant counseling (RR = 0.58, 95%CI: 0.37-0.96), initiated transplant discussions (RR = 0.58, 95%CI: 0.38-0.88), or were eligible for transplantation (RR = 0.45, 95%CI: 0.30-0.68). Of nephrologists who spent ≤20 min, those at for-profit centers more often cited lack of reimbursement as a reason (30.0% vs. 18.9%, $p = 0.02$). Disparities in quality of education at for-profit centers might partially explain previously documented disparities in access to transplantation for patients at these centers. National policies detailing the optimal timing and content of transplant education are needed to improve equity.

Batabyal P, Chapman JR, Wong G, et al. **Clinical practice guidelines on wait-listing for kidney transplantation: consistent and equitable?** *Transplantation* 2012 94(7):703-13.

Notes: Review of available waitlist guidelines (international). May be useful as general background reference.

Abstract: BACKGROUND: Apparent variability in wait-listing criteria globally has raised concern about inequitable access to kidney transplantation. This study aimed to compare the quality, the scope, and the consistency of international guidelines on wait-listing for kidney transplantation.

METHODS: Electronic databases and guideline registries were searched to December 2011. The Appraisal of Guidelines for Research and Evaluation II instrument and textual synthesis was used to assess and compare recommendations.

RESULTS: Fifteen guidelines published from 2001 to 2011 were included. Methodological rigor and scope were variable. We identified 4 major criteria across guidelines: recipient age and life expectancy, medical criteria, social and lifestyle circumstances, and psychosocial considerations. Whereas some recommendations were consistent, there were differences in age cutoffs, estimated life expectancy (2-5 years), and glomerular filtration rate at listing (15-20 mL/min/1.73 m). Cardiovascular contraindications were broadly defined. Recommended cancer-free periods also varied substantially, and whereas uncontrolled infections were universally contraindicated, human immunodeficiency virus thresholds and adherence to highly active antiretroviral therapy were inconsistent. Most guidelines recommended psychological screening but were not augmented with specific clinical assessment tools.

CONCLUSIONS: Wait-listing recommendations in current guidelines are based on life expectancy, comorbidities, lifestyle, and psychosocial factors. Some recommendations are different across guidelines or broadly defined. There is a case for developing comprehensive, methodologically robust, and regularly updated guidelines on wait-listing for kidney transplantation.

Boulware LE, Hill-Briggs F, Kraus, ES, et al. **Protocol of a randomized controlled trial of culturally sensitive interventions to improve African Americans' and non-African Americans' early, shared, and**

informed consideration of live kidney transplantation: the Talking About Live Kidney Donation (TALK
BMC nephrology 2011 12():34.

Notes: Protocol description of TALK Study (design and test culturally sensitive interventions to improve consideration of living donor kidney transplantation)

Abstract: BACKGROUND: Live kidney transplantation (LKT) is underutilized, particularly among ethnic/racial minorities. The effectiveness of culturally sensitive educational and behavioral interventions to encourage patients' early, shared (with family and health care providers) and informed consideration of LKT and ameliorate disparities in consideration of LKT is unknown.

METHODS/DESIGN: We report the protocol of the Talking About Live Kidney Donation (TALK) Study, a two-phase study utilizing qualitative and quantitative research methods to design and test culturally sensitive interventions to improve patients' shared and informed consideration of LKT. Study Phase 1 involved the evidence-based development of culturally sensitive written and audiovisual educational materials as well as a social worker intervention to encourage patients' engagement in shared and informed consideration of LKT. In Study Phase 2, we are currently conducting a randomized controlled trial in which participants with progressing chronic kidney disease receive: 1) usual care by their nephrologists, 2) usual care plus the educational materials, or 3) usual care plus the educational materials and the social worker intervention. The primary outcome of the randomized controlled trial will include patients' self-reported rates of consideration of LKT (including family discussions of LKT, patient-physician discussions of LKT, and identification of an LKT donor). We will also assess differences in rates of consideration of LKT among African Americans and non-African Americans.

DISCUSSION: The TALK Study rigorously developed and is currently testing the effectiveness of culturally sensitive interventions to improve patients' and families' consideration of LKT. Results from TALK will provide needed evidence on ways to enhance consideration of this optimal treatment for patients with end stage renal disease.

Boulware LE, Meoni LA, Fink, NE, et al. **Preferences, knowledge, communication and patient-physician discussion of living kidney transplantation in African American families.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons 2005 5(6):1503-12.*

Notes: small (n=182), non-randomized interview survey and analysis of kidney transplant attitudes and perspectives of African-American dialysis patients and their families. Rates of family-physician and patient-physician discussion of transplantation are low, b

Abstract: It is unknown whether patient-physician discussion about live kidney transplantation (LT) among African Americans (AA) is affected by preferences, knowledge and family discussions regarding LT. We recruited 182 AA dialysis patients and their families and assessed the relation of preferences, knowledge and family discussions regarding LT to the occurrence of patient-physician discussion using multivariable logistic regression. Most patients (76%) desired a transplant, and

most patients (93%), spouses (91%) and children (88%) had knowledge of LT. Nearly half of the families discussed transplantation. Only 68% of patients and less than half of their spouses (41%) and children (31%) had discussed transplantation with physicians. Patient-physician discussion was more common among patients: whose spouses acknowledged their interest in transplantation (adjusted odds ratio (AOR) (95% CI):3.5 (1.61-7.8)); who discussed transplantation with spouses (AOR(95% CI):5.25 (2.22-12.41)); whose spouses agreed that they discussed transplantation with patients (AOR (95%CI):5.20 (1.76-15.37)) and whose children discussed transplantation with patients' physicians (AOR (95%CI):7.4 (1.3-40.0)). Universal patient-physician discussion of LT does not occur despite patient preferences. Rates of family-physician discussions are low, and rates of family discussions vary. Early family-physician discussion of LT, use of allied health professionals to promote family discussion of LT and the institution of culturally appropriate programs to enhance discussion of LT in AA families could improve rates of discussion and enhance patients' access to LT.

Clark CR, Hicks LS, Keough JH, et al. **Promoting access to renal transplantation: the role of social support networks in completing pre-transplant evaluations.** *Journal of general internal medicine* 2008 23(8):1187-93.

Notes: Evaluation of instrumental support networks as a factor associated with completion of kidney pre-transplant evaluation in 4 US ESRD Networks in 1996-97. n=742 Higher level of instrumental support associated with higher rate of successful completion of e

Abstract: BACKGROUND: Completing pre-transplant evaluations may be a greater barrier to renal transplantation for blacks with end-stage renal disease (ESRD) than for whites.

OBJECTIVE: To determine whether social support networks facilitate completing the pre-transplant evaluation and reduce racial disparities in this aspect of care.

DESIGN, SETTING, AND PARTICIPANTS: We surveyed 742 black and white ESRD patients in four regional networks 9 months after they initiated dialysis in 1996 and 1997. Patients reported instrumental support networks (number of friends or family to help with daily activities), emotional support networks (number of friends or family available for counsel on personal problems) and dialysis center support (support from dialysis center staff and patients). The completion of pre-transplant evaluations, including preoperative risk stratification and testing, was determined by medical record reviews.

OUTCOME MEASUREMENT: Complete renal pre-transplant evaluations.

RESULTS: Compared to patients with low levels of instrumental support, those with high levels were more likely to have complete evaluations (25% versus 46%, respectively, $p < .001$). In adjusted analyses, high levels of instrumental support were associated with higher rates of complete evaluations among black women ($p < .05$), white women ($p < .05$), and white men ($p < .05$), but not black men. Among black men, but not other groups, private insurance was a significant predictor of complete evaluations.

CONCLUSIONS: Instrumental support networks may facilitate completing renal pre-transplant evaluations. Clinical interventions that supplement instrumental support should be evaluated to improve access to renal transplantation. Access to supplemental insurance may also promote complete evaluations for black patients.

Davis AE, Mehrotra S, McElroy LM, et al. **The extent and predictors of waiting time geographic disparity in kidney transplantation in the United States.** *Transplantation* 2014 97(10):1049-57.

Abstract: **BACKGROUND:** Waiting time to deceased donor kidney transplant varies greatly across the United States. This variation violates the final rule, a federal mandate, which demands geographic equity in organ allocation for transplantation.

METHODS: Retrospective analysis of the United States Renal Data System and United Network for Organ Sharing database from 2000 to 2009. Median waiting time was calculated for each of the 58 donor service areas (DSA) in the United States. Multivariate regression was performed to identify DSA predictors for long waiting times to kidney transplantation.

RESULTS: The median waiting time varied between the 58 DSAs from 0.61 to 4.57 years, ranging from 0.59 to 5.17 years for standard criteria donor kidneys and 0.41 to 4.69 years for expanded criteria donor kidneys. The disparity in waiting time between the DSAs grew from 3.26 years (range, 0.41-3.67) in 2000 to 4.72 years (range, 0.50-5.22) in 2009. In DSAs with longer waiting times, there were significantly more patients suffering from end-stage renal disease and more patients listed for kidney transplant, lower kidney procurement rates, and higher transplant center competition. Patients were more likely black, sensitized, with lower educational attainment and less likely to waitlist outside of their DSA of residence. Donor organs used in DSAs with long waiting times were more likely hepatitis C positive and had a higher kidney donor profile index. Graft and patient survival at 5 years was worse for deceased donor kidney transplant, but rates for living donor kidney transplant were higher.

CONCLUSION: Our analysis demonstrates significant and worsening geographic disparity in waiting time for kidney transplant across the DSAs. Increase in living donor kidney transplant and use of marginal organs has not mitigated the disparity. Changes to the kidney allocation system might be required to resolve this extensive geographic disparity in kidney allocation.

DePasquale N, Hill-Briggs F, Darrell L, et al. **Feasibility and acceptability of the TALK social worker intervention to improve live kidney transplantation.** *Health & social work* 2012 37(4):234-49.

Notes: Article includes a lot of detail about the TALK (SW intervention to increase interest in transplantation). Primary TALK study results need to be searched for in Pubmed.

Abstract: Live kidney transplantation (LKT) is underused by patients with end-stage renal disease. Easily implementable and effective interventions to improve patients' early consideration of LKT are needed. The Talking About Live Kidney Donation (TALK) social worker intervention (SWI) improved consideration and pursuit of LKT among patients with progressive chronic kidney disease in a recent

randomized controlled trial: Patients and their families were invited to meet twice with a social worker to discuss their self-identified barriers to seeking LKT and to identify solutions to barriers. The authors audio recorded and transcribed all social worker visits to assess implementation of the TALK SWI and its acceptability to patients and families. The study social worker adhered to the TALK SWI protocol more than 90 percent of the time. Patients and families discussed medical (for example, long-term risks of transplant), psychological (for example, patients' denial of the severity of their disease), and economic (for example, impact of donation on family finances) concerns regarding LKT. Most patients and families felt that the intervention was helpful. Consistently high adherence to the TALK SWI protocol and acceptability of the intervention among patients and families suggest that the TALK SWI can be feasibly implemented in clinical practice.

Epstein AM, Ayanian JZ, Keogh JH, et al. **Racial disparities in access to renal transplantation--clinically appropriate or due to underuse or overuse?** *N Engl J Med.* 2000 343(21):1537-44.

Abstract: BACKGROUND: Despite abundant evidence of racial disparities in the use of surgical procedures, it is uncertain whether these disparities reflect racial differences in clinical appropriateness or overuse or underuse of inappropriate care.

METHODS: We performed a literature review and used an expert panel to develop criteria for determining the appropriateness of renal transplantation for patients with end-stage renal disease. Using data from five states and the District of Columbia on patients who had started to undergo dialysis in 1996 or 1997, we selected a random sample of 1518 patients (age range, 18 to 54 years), stratified according to race and sex. We classified the appropriateness of patients as data on candidates for transplantation and analyzed rates of referral to a transplantation center for evaluation, placement on a waiting list, and receipt of a transplant according to race.

RESULTS: Black patients were less likely than white patients to be rated as appropriate candidates for transplantation according to appropriateness criteria based on expert opinion (71 blacks [9.0 percent] vs. 152 whites [20.9 percent]) and were more likely to have had incomplete evaluations (368 [46.5 percent] vs. 282 [38.8 percent], $P < 0.001$ for the overall chi-square). Among patients considered to be appropriate candidates for transplantation, blacks were less likely than whites to be referred for evaluation, according to the chart review (90.1 percent vs. 98.0 percent, $P = 0.008$), to be placed on a waiting list (71.0 percent vs. 86.7 percent, $P = 0.007$), or to undergo transplantation (16.9 percent vs. 52.0 percent, $P < 0.001$). Among patients classified as inappropriate candidates, whites were more likely than blacks to be referred for evaluation (57.8 percent vs. 38.4 percent), to be placed on a waiting list (30.9 percent vs. 17.4 percent), and to undergo transplantation (10.3 percent vs. 2.2 percent, $P < 0.001$ for all three comparisons).

CONCLUSIONS: Racial disparities in rates of renal transplantation stem from differences in clinical characteristics that affect appropriateness as well as from underuse of transplantation among blacks and overuse among whites. Reducing racial disparities will require efforts

Fissel RB, Srinivas T, Fatica R, et al. **Preemptive renal transplant candidate survival, access to care, and renal function at listing.** *Nephrology, dialysis, transplantation : official publication of the European Dialysis and Transplant Association - European Renal Association* 2012 27(8):3321-9.

Notes: SRTR data (n=57677) evaluating likelihood of preemptive kidney transplantation, candidate survival and renal function at listing and the association of sociodemographic factors with those dependent variables. More education, white race, presence of diabe

Abstract: BACKGROUND: Preemptive transplantation is associated with better survival and transplant outcomes than transplantation after dialysis has been started. The purpose of this study is to examine associations between candidate characteristics, likelihood of preemptive transplant, candidate survival and renal function (RF) at the time of listing.

METHODS: We looked at 57 677 solitary renal transplant candidates from the Scientific Registry of Transplant Recipients database listed prior to dialysis from 2000 to 2009. Using multivariable models, we measured associations between candidate characteristics, likelihood of preemptive transplantation, candidate survival and RF at listing.

RESULTS: Candidates with higher RF at listing were more likely to be male, Caucasian, diabetic, be a prior transplant recipient and have more education. Higher RF at listing was strongly associated with greater likelihood of receipt of preemptive transplant [adjusted odds ratio = 1.45, 95% confidence interval (CI) 1.38-1.51] and conferred a significant survival advantage [adjusted hazards ratio = 0.84, 95% CI 0.79-0.89, per 5 mL/min/1.73 m(2)].

CONCLUSIONS: Patient characteristics associated with higher RF at listing suggest differences in access to care. Given that higher RF at the time of listing was also significantly associated with greater likelihood of preemptive transplantation and better survival prior to transplantation, our results suggest that listing at higher levels of RF may improve transplant candidate outcomes.

Gill J, Dong J, Rose C, et al. **The effect of race and income on living kidney donation in the United States.** *Journal of the American Society of Nephrology : JASN* 2013 24(11):1872-9.

Abstract: Studies of racial disparities in access to living donor kidney transplantation focus mainly on patient factors, whereas donor factors remain largely unexamined. Here, data from the US Census Bureau were combined with data on all African-American and white living kidney donors in the United States who were registered in the United Network for Organ Sharing (UNOS) between 1998 and 2010 (N=57,896) to examine the associations between living kidney donation (LKD) and donor median household income and race. The relative incidence of LKD was determined in zip code quintiles ranked by median household income after adjustment for age, sex, ESRD rate, and geography. The incidence of LKD was greater in higher-income quintiles in both African-American and white populations. Notably, the total incidence of LKD was higher in the African-American population than in the white population (incidence rate ratio [IRR], 1.20; 95% confidence interval [95% CI], 1.17 to 1.24)), but ratios varied by income. The incidence of LKD was lower in the African-American population than in the white population in the lowest income quintile (IRR, 0.84; 95% CI,

0.78 to 0.90), but higher in the African-American population in the three highest income quintiles, with IRRs of 1.31 (95% CI, 1.22 to 1.41) in Q3, 1.50 (95% CI, 1.39 to 1.62) in Q4, and 1.87 (95% CI, 1.73 to 2.02) in Q5. Thus, these data suggest that racial disparities in access to living donor transplantation are likely due to socioeconomic factors rather than cultural differences in the acceptance of LKD.

Goldfarb-Rumyantzev AS, Sandhu GS, Baird B, et al. **Effect of education on racial disparities in access to kidney transplantation.** *Clinical transplantation* 2012 26(1):74-81.

Notes: Study using USRDS data evaluating sociodemographic factors associated with access to kidney transplantation. Main observation of interest was that the racial differences in transplant access were eliminated after adjustment for education in blacks with c

Abstract: Higher education level might result in reduced disparities in access to renal transplantation. We analyzed two outcomes: (i) being placed on the waiting list or transplanted without listing and (ii) transplantation in patients who were placed on the waiting list. We identified 3224 adult patients with end-stage renal disease (ESRD) in United States Renal Data System with education information available (mean age of ESRD onset of 57.1 ± 16.2 yr old, 54.3% men, 64.2% white, and 50.4% diabetics). Compared to whites, fewer African Americans graduated from college (10% vs. 16.7%) and a higher percentage never graduated from the high school (38.6% vs. 30.8%). African American race was associated with reduced access to transplantation (hazard ratio [HR] 0.70, $p < 0.001$ for wait-listing/transplantation without listing; HR 0.58, $p < 0.001$ for transplantation after listing). African American patients were less likely to be wait-listed/transplanted in the three less-educated groups: HR 0.67 ($p = 0.005$) for those never completed high school, HR 0.76 ($p = 0.02$) for high school graduates, and HR 0.65 ($p = 0.003$) for those with partial college education. However, the difference lost statistical significance in those who completed college education (HR 0.75, $p = 0.1$). In conclusion, in comparing white and African American candidates, racial disparities in access to kidney transplantation do exist. However, they might be alleviated in highly educated individuals.

Gore JL, Danovitch GM, Litwin MS, Pham PTT, Singer JS. **Disparities in the utilization of live donor renal transplantation.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2009 9(5):1124-33.

Notes: US national observational study using UNOS data of patients undergoing primary kidney transplantation in 2004-2006. Dependent variable was relative rate of LRD (vs. deceased donor) transplant and the analyses demonstrate that sociodemographic variables a

Abstract: Despite universal payer coverage with Medicare, sociodemographic disparities confound the care of patients with renal failure. We sought to determine whether adults who realize access to kidney transplantation suffer inequities in the utilization of live donor renal transplantation (LDRT). We identified adults undergoing primary renal transplantation in 2004-2006 from the United Network for Organ Sharing (UNOS). We modeled receipt of live versus deceased donor renal transplant on multilevel multivariate models that examined recipient, center and UNOS region-specific covariates. Among 41 090 adult recipients identified, 39% underwent LDRT. On multivariate

analysis, older recipients (OR 0.62, 95% CI 0.56-0.68 for 50-59 year-olds vs. 18-39 year-old recipients), those of African American ethnicity (OR 0.54, 95% CI 0.50-0.59 vs. whites) and of lower socioeconomic status (OR 0.72, 95% CI 0.67-0.79 for high school-educated vs. college-educated recipients; OR 0.78, 95% CI 0.71-0.87 for lowest vs. highest income quartile) had lower odds of LDRT. These characteristics accounted for 14.2% of the variation in LDRT, more than recipient clinical variables, transplant center characteristics and UNOS region level variation. We identified significant racial and socioeconomic disparities in the utilization of LDRT. Educational initiatives and dissemination of processes that enable increased utilization of LDRT may address these disparities.

Grams ME, Chen BP, Coresh, J, Segev DL. **Preemptive deceased donor kidney transplantation: considerations of equity and utility.** *Clinical journal of the American Society of Nephrology : CJASN* 2013 8(4):575-82.

Notes: SRTR based study of sociodemographic factors associated with pre-emptive kidney transplantation, renal transplantation in first year of dialysis. Study also reports on similarity of outcomes (kidney allograft survival) comparing pre-emptive and first year

Abstract: BACKGROUND AND OBJECTIVES: There exists gross disparity in national deceased donor kidney transplant availability and practice: waiting times exceed 6 years in some regions, but some patients receive kidneys before they require dialysis. This study aimed to quantify and characterize preemptive deceased donor kidney transplant recipients and compare their outcomes with patients transplanted shortly after dialysis initiation.

DESIGN, SETTING, PARTICIPANTS, & MEASUREMENTS: Using the Scientific Registry of Transplant Recipients database, first-time adult deceased donor kidney transplant recipients between 1995 and 2011 were classified as preemptive, early (on dialysis ≤ 1 year), or late recipients. Random effects logistic regression and multivariate Cox proportional hazards regression were used to identify characteristics of preemptive deceased donor kidney transplant and evaluate survival in preemptive and early recipients, respectively.

RESULTS: Preemptive recipients were 9.0% of the total recipient population. Patients with private insurance (adjusted odds ratio=3.15, 95% confidence interval=3.01-3.29, $P < 0.001$), previous (nonkidney) transplant (adjusted odds ratio=1.94, 95% confidence interval=1.67-2.26, $P < 0.001$), and zero-antigen mismatch (adjusted odds ratio=1.45, 95% confidence interval=1.37-1.54, $P < 0.001$; Caucasians only) were more likely to receive preemptive deceased donor kidney transplant, even after accounting for center-level clustering. African Americans were less likely to receive preemptive deceased donor kidney transplant (adjusted odds ratio=0.44, 95% confidence interval=0.41-0.47, $P < 0.001$). Overall, patients transplanted preemptively had similar survival compared with patients transplanted within 1 year after initiating dialysis (adjusted hazard ratio=1.06, 95% confidence interval=0.99-1.12, $P = 0.07$).

CONCLUSIONS: Preemptive deceased donor kidney transplant occurs most often among Caucasians with private insurance, and survival is fairly similar to survival of recipients on dialysis for < 1 year.

Grams ME, Kucirka LM, Hanrahan CF, et al. **Candidacy for kidney transplantation of older adults.** *Journal of the American Geriatrics Society* 2012 60(1):1-7.

Notes: Retrospective analysis of national registry data to develop model predictive of transplant outcome in older patients and subsequently define a population of older patients who were not offered access to transplantation. Results may be relevant in discuss

Abstract: OBJECTIVES: To develop a prediction model for kidney transplantation (KT) outcomes specific to older adults with end-stage renal disease (ESRD) and to use this model to estimate the number of excellent older KT candidates who lack access to KT.

DESIGN: Secondary analysis of data collected by the United Network for Organ Sharing and U.S. Renal Disease System.

SETTING: Retrospective analysis of national registry data.

PARTICIPANTS: Model development: Medicare-primary older recipients (aged ≥ 65) of a first KT between 1999 and 2006 (N = 6,988). Model application: incident Medicare-primary older adults with ESRD between 1999 and 2006 without an absolute or relative contraindication to transplantation (N = 128,850).

MEASUREMENTS: Comorbid conditions were extracted from U.S. Renal Disease System Form 2728 data and Medicare claims.

RESULTS: The prediction model used 19 variables to estimate post-KT outcome and showed good calibration (Hosmer-Lemeshow P = .44) and better prediction than previous population-average models (P < .001). Application of the model to the population with incident ESRD identified 11,756 excellent older transplant candidates (defined as >87% predicted 3-year post-KT survival, corresponding to the top 20% of transplanted older adults used in model development), of whom 76.3% (n = 8,966) lacked access. It was estimated that 11% of these candidates would have identified a suitable live donor had they been referred for KT.

CONCLUSION: A risk-prediction model specific to older adults can identify excellent KT candidates. Appropriate referral could result in significantly greater rates of KT in older adults.

Grams ME, Massie AB, Schol JD, et al. **Trends in the inactive kidney transplant waitlist and implications for candidate survival.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2013 13(4):1012-8.

Notes: Observational study describes national trends in waitlisted patients and status (inactive vs. active). In addition, the timing and durability of status changes and association between inactive status and likelihood of eventual transplantation is reported

Abstract: In November 2003, OPTN policy was amended to allow kidney transplant candidates to accrue waiting time while registered as status 7, or inactive. We evaluated trends in inactive listings

and the association of inactive status with transplantation and survival, studying 262,824 adult first-time KT candidates listed between 2000 and 2011. The proportion of waitlist candidates initially listed as inactive increased from 2.3% prepolicy change to 31.4% in 2011. Candidates initially listed as inactive were older, more often female, African American, and with higher body mass index. Postpolicy change, conversion from initially inactive to active status generally occurred early if at all: at 1 year after listing, 52.7% of initially inactive candidates had been activated; at 3 years, only 66.3% had been activated. Inactive status was associated with a substantially higher waitlist mortality (aHR 2.21, 95%CI:2.15-2.28, $p<0.001$) and lower rates of eventual transplantation (aRR 0.68, 95%CI:0.67-0.70, $p<0.001$). In summary, waitlist practice has changed significantly since November 2003, with a sharp increase in the number of inactive candidates. Using the full waitlist to estimate organ shortage or as a comparison group in transplant outcome studies is less appropriate in the current era.

*Green JA, Cavanaugh KL. **Understanding the Influence of Educational Attainment on Kidney Health and Opportunities for Improved Care** *Adv Chronic Kidney Dis* 2015 22(1):24-30.

Abstract: Educational attainment is an important but often overlooked contributor to health outcomes in patients with kidney disease. Those with lower levels of education have an increased risk of ESRD, complications of peritoneal dialysis, worse transplant outcomes, and mortality. Mediators of these associations are poorly understood but involve a complex interplay between health knowledge, behaviors, and socioeconomic and psychosocial factors. Interventions targeting these aspects of care have the potential to reduce disparities related to educational attainment; however, few programs have been described that specifically address this issue. Future research efforts should not only systematically assess level of educational attainment but also report the differential impact of interventions across educational strata. In addition, routine measurement of health literacy may be useful to identify high-risk patients independent of years of schooling. A better understanding of the influence of educational attainment on kidney health provides an opportunity to improve the care and outcomes of vulnerable patients with kidney disease.

Hall EC, James NT, Garonzik Wang JM, et al. **Center-level factors and racial disparities in living donor kidney transplantation.** *American journal of kidney diseases : the official journal of the National Kidney Foundation* 2012 59(6):849-57.

Notes: US national observational study at the transplant center level, evaluating racial disparities. They remain present at all facilities, but magnitude of effect varies across facilities.

Abstract: BACKGROUND: On average, African Americans attain living donor kidney transplantation (LDKT) at decreased rates compared with their non-African American counterparts. However, center-level variations in this disparity or the role of center-level factors is unknown.

STUDY DESIGN: Observational cohort study.

SETTING & PARTICIPANTS: 247,707 adults registered for first-time kidney transplants from 1995-2007 as reported by the Scientific Registry of Transplant Recipients.

PREDICTORS: Patient-level factors (age, sex, body mass index, insurance status, education, blood type, and panel-reactive antibody level) were adjusted for in all models. The association of center-level characteristics (number of candidates, transplant volume, LDKT volume, median time to transplant, percentage of African American candidates, percentage of prelisted candidates, and percentage of LDKT) and degree of racial disparity in LDKT was quantified.

OUTCOMES: Hierarchical multivariate logistic regression models were used to derive center-specific estimates of LDKT attainment in African American versus non-African American candidates.

RESULTS: Racial parity was not seen at any of the 275 transplant centers in the United States. At centers with the least racial disparity, African Americans had 35% lower odds of receiving LDKT; at centers with the most disparity, African Americans had 76% lower odds. Higher percentages of African American candidates (interaction term, 0.86; $P = 0.03$) and prelisted candidates (interaction term, 0.80; $P = 0.001$) at a given center were associated with increased racial disparity at that center. Higher rates of LDKT (interaction term, 1.25; $P < 0.001$) were associated with less racial disparity.

LIMITATIONS: Some patient-level factors are not captured, including a given patient's pool of potential donors. Geographic disparities in deceased donor availability might affect LDKT rates. Center-level policies and practices are not captured.

CONCLUSIONS: Racial disparity in attainment of LDKT exists at every transplant center in the country. Centers with higher rates of LDKT attainment for all races had less disparity; these high-performing centers might provide insights into policies that might help address this disparity.

Hall YN, Choi AI, Xu P, et al. **Racial ethnic differences in rates and determinants of deceased donor kidney transplantation.** *Journal of the American Society of Nephrology* : JASN 2011 22(4):743-51.

Abstract: Contemporary studies have not comprehensively compared waiting times and determinants of deceased donor kidney transplantation across all major racial ethnic groups in the United States. Here, we compared relative rates and determinants of waitlisting and deceased donor kidney transplantation among 503,090 nonelderly adults of different racial ethnic groups who initiated hemodialysis between 1995 and 2006 with follow-up through 2008. Annual rates of deceased donor transplantation from the time of dialysis initiation were lowest in American Indians/Alaska Natives (2.4%) and blacks (2.8%), intermediate in Pacific Islanders (3.1%) and Hispanics (3.2%), and highest in whites (5.9%) and Asians (6.4%). Lower rates of deceased donor transplantation among most racial ethnic minority groups appeared primarily to reflect differences in time from waitlisting to transplantation, but this was not the result of higher rates of waitlist inactivity or removal from the waitlist. The fraction of the reduced transplant rates attributable to measured factors (e.g., demographic, clinical, socioeconomic, linguistic, and geographic factors) varied from 14% in blacks to 43% in American Indians/Alaska Natives compared with whites. In conclusion, adjusted rates of deceased donor kidney transplantation remain significantly lower among racial ethnic minorities compared with whites; generally, differences in time to waitlisting were not as pronounced as differences in time between waitlisting and transplantation.

Determinants of delays in time to transplantation differed substantially by racial ethnic group. Area-based efforts targeted to address racial- and ethnic-specific delays in transplantation may help to reduce overall disparities in deceased donor kidney transplantation in the United States.

Hall YN, O'Hare AM, Young BA, et al. **Neighborhood poverty and kidney transplantation among US Asians and Pacific Islanders with end-stage renal disease.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2008 8(11):2402-9.

Notes: Study of 22,152 incident dialysis patients in California, Hawaii and US Pacific Islands examining relationship between race, neighborhood poverty and kidney transplant rates.

Abstract: The degree to which low transplant rates among Asians and Pacific Islanders in the United States are confounded by poverty and reduced access to care is unknown. We examined the relationship between neighborhood poverty and kidney transplant rates among 22 152 patients initiating dialysis during 1995-2003 within 1800 ZIP codes in California, Hawaii and the US-Pacific Islands. Asians and whites on dialysis were distributed across the spectrum of poverty, while Pacific Islanders were clustered in the poorest areas. Overall, worsening neighborhood poverty was associated with lower relative rates of transplant (adjusted HR [95% CI] for areas with > or =20% vs. <5% residents living in poverty, 0.41 [0.32-0.53], $p < 0.001$). At every level of poverty, Asians and Pacific Islanders experienced lower transplant rates compared with whites. The degree of disparity increased with worsening neighborhood poverty (adjusted HR [95% CI] for Asians-Pacific Islanders vs. whites, 0.64 [0.51-0.80], $p < 0.001$ for areas with <5% and 0.30 [0.21-0.44], $p < 0.001$ for areas with > or =20% residents living in poverty; race-poverty level interaction, $p = 0.039$). High levels of neighborhood poverty are associated with lower transplant rates among Asians and Pacific Islanders compared with whites. Our findings call for studies to identify cultural and local barriers to transplant among Asians and Pacific Islanders, particularly those residing in resource-poor neighborhoods.

Huang E, Shye M, Elashoff D, et al. **Incidence of conversion to active waitlist status among temporarily inactive obese renal transplant candidates.** *Transplantation* 2014 98(2):177-86.

Abstract: BACKGROUND: Candidates may be active or temporarily inactive (status 7) on the kidney transplant waiting list. One reason candidates may be inactive is for a "weight currently inappropriate for transplantation." We hypothesized that many of these candidates would not achieve active status.

METHODS: Using OPTN/UNOS data from 2006 to 2012, we used competing risks methods to determine the cumulative incidence of conversion to active status (activation), death, and delisting before conversion among 1679 obese adult kidney candidates designated as status 7 because of a weight inappropriate for transplantation. Fine and Gray competing risks regression was performed to characterize factors associated with conversion to active status in the overall study population and of transplantation among a subgroup of activated candidates.

RESULTS: At 6 years, the cumulative incidence of activation was 49%, of death before conversion was 15%, and of delisting was 21%. Higher body mass index (BMI) was strongly associated with a decreased subhazard of activation (BMI ≥ 45 versus 30-34.9, sHR: 0.22; 95% CI, 0.16-0.33). Female sex, diabetic end-stage renal disease, history of a previous transplant, panel reactive antibodies less than 80%, dialysis dependence at listing, and UNOS region 5 were negatively associated with activation. Among activated candidates, the cumulative incidence of transplantation at 6 years after initial waitlisting was 61%.

CONCLUSION: Our findings indicate that half of obese status 7 candidates with a weight inappropriate for transplantation will not achieve active waitlist status. BMI at listing had a strong association with conversion to active status; comorbid factors and regional variation also impact activation.

Huml AM, Sullivan CM, Pencak JA, Ashwini R. **Accuracy of dialysis medical records in determining patients' interest in and suitability for transplantation.** *Clinical transplantation* 2013 27(4):541-5.

Notes: Observational study of medical record documentation vs. patient interview of perspectives/preferences re. kidney transplantation in patients from 23 Ohio dialysis facilities. Significant disagreement regarding transplant opinion was present.

Abstract: **BACKGROUND:** We sought to determine the accuracy of dialysis medical records in identifying patients' interest in and suitability for transplantation.

STUDY DESIGN: Cluster randomized controlled trial.

SETTING AND PARTICIPANTS: A total of 167 patients recruited from 23 hemodialysis facilities.

INTERVENTION: Navigators met with intervention patients to provide transplant information and assistance. Control patients continued to receive usual care.

OUTCOMES: Agreement at study initiation between medical records and (i) patient self-reported interest in transplantation and (ii) study assessments of medical suitability for transplant referral.

MEASUREMENTS: Medical record assessments, self-reports, and study assessments of patient's interest in and suitability for transplantation.

RESULTS: There was disagreement between medical records and patient self-reported interest in transplantation for 66 (40%) of the 167 study patients. In most of these cases, patients reported being more interested in transplantation than their medical records indicated. The study team determined that all 92 intervention patients were medically suitable for transplant referral. However, for 38 (41%) intervention patients, medical records indicated that they were not suitable. About two-thirds of these patients successfully moved forward in the transplant process.

CONCLUSION: Dialysis medical records are frequently inaccurate in determining patient's interest in and suitability for transplantation.

Isranai AK, Salkowski N, Gustafson S, et al. **New national allocation policy for deceased donor kidneys in the United States and possible effect on patient outcomes.** *Journal of the American Society of Nephrology* : JASN 2014 25(8):1842-8.

Abstract: In 2013, the Organ Procurement and Transplantation Network in the United States approved a new national deceased donor kidney allocation policy that introduces the kidney donor profile index (KDPI), which gives scores of 0%-100% based on 10 donor factors. Kidneys with lower KDPI scores are associated with better post-transplant survival. Important features of the new policy include first allocating kidneys from donors with a KDPI \leq 20% to candidates in the top 20th percentile of estimated post-transplant survival, adding waiting time from dialysis initiation, conferring priority points for a calculated panel-reactive antibody (CPRA) $>$ 19%, broader sharing of kidneys for candidates with a CPRA \geq 99%, broader sharing of kidneys from donors with a KDPI $>$ 85%, eliminating the payback system, and allocating blood type A2 and A2B kidneys to blood type B candidates. We simulated the distribution of kidneys under the new policy compared with the current allocation policy. The simulation showed increases in projected median allograft years of life with the new policy (9.07 years) compared with the current policy (8.82 years). With the new policy, candidates with a CPRA $>$ 20%, with blood type B, and aged 18-49 years were more likely to undergo transplant, but transplants declined in candidates aged 50-64 years (4.1% decline) and \geq 65 years (2.7% decline). These simulations demonstrate that the new deceased donor kidney allocation policy may improve overall post-transplant survival and access for highly sensitized candidates, with minimal effects on access to transplant by race/ethnicity and declines in kidney allocation for candidates aged \geq 50 years.

Johansen KL, Zhang R, Huang Y, et al. **Association of race and insurance type with delayed assessment for kidney transplantation among patients initiating dialysis in the United States.** *Clinical journal of the American Society of Nephrology* : CJASN 2012 7(9):1490-7.

Notes: USRDS data describing disparities present at initiation of chronic dialysis in access to kidney transplantation based on sociodemographic factors. Documents general disparities in access to transplantation, but not the role of dialysis facilities in those

Abstract: BACKGROUND AND OBJECTIVES: The extent to which racial and socioeconomic disparities in access to kidney transplantation are related to not being assessed for transplant suitability before or shortly after the time of initiation of dialysis is not known. The aims of this study were to determine whether there were disparities based on race, ethnicity, or type of insurance in delayed assessment for transplantation and whether delayed assessment was associated with lower likelihood of waitlisting and kidney transplantation.

DESIGN, SETTING, PARTICIPANTS, & MEASUREMENTS: This retrospective cohort study used data from the US Renal Data System and included 426,489 adult patients beginning dialysis in the United States between January 1, 2005 and September 30, 2009 without prior kidney transplant.

RESULTS: Overall, 12.5% of patients had reportedly not been assessed for transplantation. Patients without private insurance were more likely to be reported as not assessed (multivariable adjusted

odds ratio=1.33, 95% confidence interval=1.28-1.40 for Medicaid), with a pronounced racial disparity but no ethnic disparity among patients aged 18 to <35 years (odds ratio=1.27, 95% confidence interval=1.13-1.43; $P<0.001$ for interaction with age). Not being assessed for transplant around the time of dialysis initiation was associated with lower likelihood of waitlisting in multivariable analysis (hazard ratio=0.59, 95% confidence interval=0.57-0.62 in the first year) and transplantation (hazard ratio=0.46, 95% confidence interval=0.41-0.51 in the first year), especially within the first 2 years.

CONCLUSIONS: Racial and insurance-related disparities in transplant assessment potentially delay transplantation, particularly among younger patients.

Joshi S, Gaynor JJ, Bayers S, et al. **Disparities among Blacks, Hispanics, and Whites in time from starting dialysis to kidney transplant waitlisting.** *Transplantation* 2013 95(2):309-18.

Notes: single center retrospective observational study of sociodemographic factors associated with time to waitlisting after starting chronic dialysis.

Abstract: **BACKGROUND:** Although a longer time on dialysis before kidney transplant waitlisting has been shown for Blacks versus non-Blacks, relatively few studies have compared this outcome between Hispanics and Whites.

METHODS: A multivariable analysis of 1910 (684 Black, 452 Hispanic, and 774 White) consecutive patients waitlisted at our center for a primary kidney transplant between 2005 and mid-2010 was performed for time from starting dialysis to waitlisting (months), the percentage who were preemptively waitlisted (waitlisted before starting dialysis), and time from starting dialysis to waitlisting after excluding the preemptively waitlisted patients.

RESULTS: The variables associated with significantly longer median times from starting dialysis to waitlisting and less preemptive waitlisting included Medicare insurance for patients ages <65 years (by far, the most significant variable in each analysis), Black race, higher percentage of households in the patient's zip code living in poverty, being a non-U.S. citizen (for preemptive waitlisting), Medicaid insurance, waitlisted for kidney-alone (vs. kidney-pancreas) transplant, and higher body mass index (longer median times for the latter three variables). Although the effect of Black race was mostly explained by significant associations with lower socioeconomic status (Medicare insurance for patients ages <65 years and greater poverty in the patient's zip code), an unexplained component still remained. The univariable differences showing poorer outcomes for Hispanics versus Whites were smaller and completely explained in multivariable analysis by significant associations with lower socioeconomic status and non-U.S. citizenship.

CONCLUSION: Black and Hispanic patients had significantly longer times from starting dialysis to waitlisting, in large part related to their lower socioeconomic status and less preemptive waitlisting. A greater focus on earlier nephrology care may help to erase much of these disparities.

Kasiske BL, Snyder JJ, Skeans MA, et al. **The geography of kidney transplantation in the United States.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2008 8(3):647-57.

Abstract: The distance kidney transplant patients live from the centers where they undergo transplantation could affect long-term care and outcomes, but little is known about this distance and its associations. We used data from the United States Renal Data System to examine distance between home and transplant center for 92 224 adults undergoing kidney transplantation in 1995-2003. The 5th, 25th, 50th, 75th and 95th percentiles for distances were 2.4, 8.4, 23.0, 67.3 and 213.7 miles, respectively. Compared to whites (median distance 28.5 miles), African Americans (11.5 miles) and Asians (13.5 miles) lived closer to their centers, while Native Americans lived farther away (90.1 miles). Hispanics lived closer (14.7 miles) than non-Hispanics (24.3 miles). Even after adjusting for center density, we found substantial regional variability, with median distance of 15.1 miles for patients living in the Northeast and 40.6 miles for those in the Southeast. Distance was also associated with center size, median zip code income, listing on more than one deceased-donor waiting list and other factors, but greater distance (adjusted for these other factors) was not associated with worse patient or graft survival. The substantial variability in geographical access to kidney transplantation could have important implications for long-term care.

Kazley AS, Simpson KN, Chavin KD, Baliga P. **Barriers facing patients referred for kidney transplant cause loss to follow-up.** *Kidney international* 2012 82(9):1018-23.

Abstract: End-stage renal disease affects many Americans; however, transplant is the best treatment option increasing life years and offering a higher quality of life than possible with dialysis. Ironically, many who are eligible for transplant do not follow through on the complex workup protocols required to be placed on the transplant waiting list. Here we surveyed vascular access clinic patients at an academic medical center referred for transplant, who did not follow up on the needed workup to be added to the national transplant waiting list. The most frequent responses of 83 patients for not pursuing transplantation were that the patients did not think they would pass the medical tests, they were scared of getting a transplant, and they could not afford the medicine or the transplantation. These impediments may result from unclear provider communication, misinformation received from peers or other sources, misperceptions related to transplant surgery, or limited health literacy/health decision-making capacity. Thus, patients with end-stage renal disease lost to follow-up after referral for kidney transplant faced both real and perceived barriers pursuing transplantation.

Keith D, Ashby VB, Port F, Leichtman AB. **Insurance type and minority status associated with large disparities in prelisting dialysis among candidates for kidney transplantation.** *Clinical journal of the American Society of Nephrology : CJASN* 2008 3(2):463-70.

Notes: Arbor/KECC evaluation of insurance type and minority status on likelihood of deceased donor listing.

Abstract: Disparities in time to placement on the waiting list on the basis of socioeconomic factors decrease access to deceased-donor renal transplantation for some groups of patients with end-stage renal disease. This study was undertaken to determine candidate factors that influence duration of dialysis before placement on the waiting list among candidates for deceased-donor renal transplantation in the United States from January 2001 to December 2004 and the impact of Medicare eligibility rules on access.

Kucirka LM, Grams ME, Balhara KS, et al. **Disparities in provision of transplant information affect access to kidney transplantation.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2012 12(2):351-7.

Notes: US national observational study of incident ESRD patients using 2728 Form reported data re. whether or not patient was informed of transplant options at time of start of dialysis.

Abstract: Recently Centers for Medicare and Medicaid Services (CMS) began asking providers on Form-2728 whether they informed patients about transplantation, and if not, to select a reason. The goals of this study were to describe national transplant education practices and analyze associations between practices and access to transplantation (ATT), based on United States Renal Data System (USRDS) data from 2005 to 2007. Multinomial logistic regression was used to examine factors associated with not being informed about transplantation, and modified Poisson regression to examine associations between not being informed and ATT (all models adjusted for demographics/comorbidities). Of 236,079 incident end-stage renal disease (ESRD) patients, 30.1% were not informed at time of 2728 filing, for reasons reported by providers as follows: 42.1% unassessed, 30.4% medically unfit, 16.9% unsuitable due to age, 3.1% psychologically unfit and 1.5% declined counsel. Older, obese, uninsured, Medicaid-insured and patients at for-profit centers were more likely to be unassessed. Women were more likely to be reported as unsuitable due to age, medically unfit and declined, and African Americans as psychologically unfit. Uninformed patients had a 53% lower rate of ATT, a disparity persisting in the subgroup of uninformed patients who were unassessed. Disparities in ATT may be partially explained by disparities in provision of transplant information; dialysis centers should ensure this critical intervention is offered equitably.

Kurella-Tamura M, Goldstein BA, Hall YN, et al. **State medicaid coverage, ESRD incidence, and access to care.** *Journal of the American Society of Nephrology : JASN* 2014 25(6):1321-9.

Abstract: The proportion of low-income nonelderly adults covered by Medicaid varies widely by state. We sought to determine whether broader state Medicaid coverage, defined as the proportion of each state's low-income nonelderly adult population covered by Medicaid, associates with lower state-level incidence of ESRD and greater access to care. The main outcomes were incidence of ESRD and five indicators of access to care. We identified 408,535 adults aged 20-64 years, who developed ESRD between January 1, 2001, and December 31, 2008. Medicaid coverage among low-income nonelderly adults ranged from 12.2% to 66.0% (median 32.5%). For each additional 10% of the low-income nonelderly population covered by Medicaid, there was a 1.8% (95% confidence interval, 1.0% to 2.6%) decrease in ESRD incidence. Among nonelderly adults with ESRD, gaps in access to

care between those with private insurance and those with Medicaid were narrower in states with broader coverage. For a 50-year-old white woman, the access gap to the kidney transplant waiting list between Medicaid and private insurance decreased by 7.7 percentage points in high (>45%) versus low (<25%) Medicaid coverage states. Similarly, the access gap to transplantation decreased by 4.0 percentage points and the access gap to peritoneal dialysis decreased by 3.8 percentage points in high Medicaid coverage states. In conclusion, states with broader Medicaid coverage had a lower incidence of ESRD and smaller insurance-related access gaps.

Kutner NG, Zhang R, Huang Y, Johansen KL. **Impact of race on predialysis discussions and kidney transplant preemptive wait-listing.** *American journal of nephrology* 2012 35(4):305-11.

Notes: Comprehensive Dialysis Study evaluating association between early transplant discussion with incident ESRD patients on eventual listing and transplantation.

Abstract: BACKGROUND/AIMS: US registry data have consistently shown that blacks are less likely than whites to be wait-listed before beginning dialysis.

METHODS: The Comprehensive Dialysis Study (CDS) was a special study conducted by the US Renal Data System (USRDS) in which a national cohort of patients who began maintenance dialysis therapy in 2005-2007 were asked whether kidney transplantation (KT) had been discussed with them before they started dialysis. Using responses from black and white CDS participants and information from the USRDS, we investigated preemptive wait-listing as a function of patient-reported predialysis KT discussion.

RESULTS: Among those reporting early KT discussion, 31.0% of patients preemptively wait-listed were black, compared to 27.5% of those not preemptively wait-listed. Two thirds of preemptively wait-listed patients had received nephrology care more than 12 months before starting dialysis and reported that KT was discussed with them 12 months or more before dialysis. Early KT discussion and higher serum albumin and hemoglobin levels remained significant predictors of preemptive wait-listing in an adjusted logistic regression analysis. Among those preemptively wait-listed, 33% of blacks and 60% of whites had received a transplant by September 30, 2009 (study end date).

CONCLUSION: Early KT discussion appeared to reduce barriers to black patients' waiting list placement before the start of dialysis, which in turn may facilitate earlier access to a deceased donor organ transplant.

Ladin K, Rodrigue, JR, Hanto DW. **Framing disparities along the continuum of care from chronic kidney disease to transplantation: barriers and interventions.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2009 9(4):19344460.

Notes: Disparities review and contextual framework as general background information.

Abstract: Research in renal transplantation continues to document scores of disparities affecting vulnerable populations at various stages along the transplantation process. Given that both

biological and environmental determinants contribute significantly to variation, identifying factors underlying an unfairly biased distribution of the disease burden is crucial. Confounded definitions and gaps in understanding causal pathways impede effectiveness of interventions aimed at alleviating disparities. This article offers an operational definition of disparities in the context of a framework aimed at facilitating interventional research. Utilizing an original framework describing the entire continuum of the transplant process from diagnosis of chronic kidney disease through successful transplant, this article explores the case of racial disparities, illustrating key factors predicting and perpetuating disparities. Though gaps in current research leave us unable to identify which stages of the transplant pathway adversely affect most people, by identifying key risk factors across the continuum of care, this article highlights areas suited for targeted interventions and presents recommendations for improvement and future research.

*LaPointe Rudow D, Hays R, Baliga P, et al. **Consensus Conference on Best Practices in Live Kidney Donation: Recommendations to Optimize Education, Access, and Care (Meeting Report)**. *American Journal of Transplantation* 2015 15():914-22.

Abstract: Live donor kidney transplantation is the best treatment option for most patients with late-stage chronic kidney disease; however, the rate of living kidney donation has declined in the United States. A consensus conference was held June 5-6, 2014 to identify best practices and knowledge gaps pertaining to live donor kidney transplantation and living kidney donation. Transplant professionals, patients, and other key stakeholders discussed processes for educating transplant candidates and potential living donors about living kidney donation; efficiencies in the living donor evaluation process; disparities in living donation; and financial and systemic barriers to living donation. We summarize the consensus recommendations for best practices in these educational and clinical domains, future research priorities, and possible public policy initiatives to remove barriers to living kidney donation.

Leffell MS, Kim D, Vega RM, et al. **Red blood cell transfusions and the risk of allosensitization in patients awaiting primary kidney transplantation**. *Transplantation* 2014 97(5):525-33.

Notes: Patients with serial HLA antibody testing data matched with transfusion data from USRDS. Matched cohort of 89 patients with transfusion and 251 controls analyzed. Second analysis of 69 patients in "crossover study. Study demonstrates semi-quantitative d

Abstract: BACKGROUND: Most studies of HLA sensitization after red blood cell transfusion in transplant candidates were done before widespread use of leuko reduced blood and based on relatively insensitive, nonspecific antibody assays. We evaluated the effect of transfusion on the breadth and magnitude of HLA antibody formation using current, sensitive, HLA-specific immunoassays.

METHODS: Serial HLA antibody data were merged with transfusion data from the US Renal Data System for 1324 patients on the kidney transplant wait list (2004-2010). Two study groups were identified: a matched cohort consisting of 89 patients who received transfusion and 251 patients who did not receive transfusion and a crossover cohort consisting of 69 patients. Changes in

antibody levels and calculated panel-reactive antibody (CPRA) were compared using χ and Sign tests, respectively. Logistic regression was used to estimate the relative risk of antibody responses.

RESULTS: Among the matched cohort, 20% of those who received transfusion compared to 3% of those who did not receive transfusion exhibited an antibody response ($P=0.001$), whereas in the crossover cohort, 19% exhibited a response in those who received transfusion compared to 1% of those who did not receive transfusion ($P=0.0001$). Moreover, 26.3% of those who received transfusion had increased CPRA compared to 5.8% of those who did not receive transfusion. These effects were greater in women and blacks compared to men and whites, respectively. Importantly, patients who received transfusion were at an increased risk of a potentially crossmatch positive response (odds ratio=9.6, 95% confidence interval=3.0-30.7).

CONCLUSIONS: Sensitization from transfusion can occur in up to 20% of transplant candidates, resulting in higher antibody levels and CPRA values that adversely impact access to transplantation. These results support transfusion avoidance whenever possible.

Lenihan CR, Hurley MP, Tan JC. **Comorbidities and kidney transplant evaluation in the elderly.** *American journal of nephrology* 2013 38(3):204-11.

Notes: single transplant center evaluation of referred patients stratified by age. Useful for descriptive characteristics of older vs. younger recipient evals. Limited by single center nature of study.

Abstract: **BACKGROUND/AIMS:** The elderly are the fastest growing subpopulation with end-stage renal disease. The goal of our study was to define characteristics of elderly patients who were considered ineligible for transplantation compared to those who were listed.

METHODS: 984 patients were referred for evaluation during a 2-year period. Records of patients ≥ 65 years of age ($n = 123$) were reviewed. Patients who were listed versus not listed were characterized. Factors associated with waitlisting were determined using standard statistical tools.

RESULTS: Half of elderly transplant candidates were accepted for listing compared to 75.4% of those aged < 65 years. In multivariable logistic regression, older age (OR 1.29 per year ≥ 65 , 95% CI 1.14-1.45), coronary artery disease (OR 8.57, 95% CI 2.41-30.53), and poor mobility (OR 13.97, 95% CI 4.76-41.00) were independently associated with denial of listing. The receiver operating characteristic curve showed good discrimination for denial of listing (area under the receiver operating characteristic curve of 0.88).

CONCLUSION: Elderly candidates carry a heavy burden of comorbidities and over half of those evaluated are deemed unsuitable for waitlisting. Better delineation of characteristics associated with suitability for transplant candidacy in the elderly is warranted to facilitate appropriate referrals by physicians and management of expectations in potential candidates.

Lentine KL, Segev DL. **Health outcomes among non-Caucasian living kidney donors: knowns and unknowns.** *Transplant international : official journal of the European Society for Organ Transplantation* 2013 26(9):853-64.

Notes: Review of recent studies of donor outcomes. Could concern over donor outcomes contribute to racial/ethnic disparities observed widely?

Abstract: The growth in living kidney donation has been accompanied by greater racial diversity. Most information on post-donation health comes from single-center studies of dominantly Caucasian cohorts. Recent linkage of U.S. donor registration data with death records demonstrated higher mortality risks among African American donors, but importantly, no differences in death compared with demographically matched, healthy controls. Within the donor population, some recent studies have also identified higher likelihoods of post-donation hypertension, diabetes mellitus and kidney failure in African American and Hispanic donors. Thus, based on concerns for higher risks of long-term end-organ damage, it may be reasonable to consider race within the living donor selection process, such as use of more stringent exclusion criteria among non-Caucasian living donors with baseline elevated blood pressure. Recently identified associations of coding variants in the apolipoprotein L1 (APOL1) gene with nondiabetic renal failure in African Americans raise promise of APOL1 genotyping as a novel tool for risk stratifying African American potential donors, but more data are needed to understand implications for post-donation outcomes. To tailor counseling and informed consent, focused attention to long-term medical outcomes among non-Caucasian living donors is needed, and should include assembly of healthy non-donor controls for assessment of attributable risks of donation.

*Lipstein SH, Dunagan WC. **The Risks of Not Adjusting Performance Measures for Patient Sociodemographic Factors** *Ann Intern Med* 2014 161(8):594-6.

Abstract: The National Quality Forum (NQF) recently convened an expert panel to make recommendations on a much-debated topic: whether to risk-adjust health care outcomes for sociodemographic factors present at the initiation of medical care and treatment. The Panel completed its work in early July 2014, making the following recommendation: “When there is a conceptual relationship (i.e., logical rationale or theory) between sociodemographic factors and outcomes or processes of care and empirical evidence (e.g., statistical analysis) that sociodemographic factors affect an outcome or process of care reflected in a performance measure: those sociodemographic factors should be included in risk adjustment of the performance score (using accepted guidelines for selecting risk factors) unless there are conceptual reasons or empirical evidence indicating that adjustment is unnecessary or inappropriate; and the performance measure specifications must also include specifications for stratification of a clinically adjusted version of the measure based on the sociodemographic factors used in risk adjustment” (1). *(Text truncated)*

Mathur AK, Ashby VB, Sands RL, Wolfe RA. **Geographic variation in end-stage renal disease incidence and access to deceased donor kidney transplantation.** *American journal of transplantation : official*

journal of the American Society of Transplantation and the American Society of Transplant Surgeons 2010 10(4 Pt 2):1069-80.

Notes: KECC/Arbor analysis of geographic variation in ESRD prevalence by donation service areas (DSA) and access to transplantation.

Abstract: The effect of demand for kidney transplantation, measured by end-stage renal disease (ESRD) incidence, on access to transplantation is unknown. Using data from the U.S. Census Bureau, Centers for Medicare & Medicaid Services (CMS) and the Organ Procurement and Transplantation Network/Scientific Registry of Transplant Recipients (OPTN/SRTR) from 2000 to 2008, we performed donation service area (DSA) and patient-level regression analyses to assess the effect of ESRD incidence on access to the kidney waiting list and deceased donor kidney transplantation. In DSAs, ESRD incidence increased with greater density of high ESRD incidence racial groups (African Americans and Native Americans). Wait-list and transplant rates were relatively lower in high ESRD incidence DSAs, but wait-list rates were not drastically affected by ESRD incidence at the patient level. Compared to low ESRD areas, high ESRD areas were associated with lower adjusted transplant rates among all ESRD patients (RR 0.68, 95% CI 0.66-0.70). Patients living in medium and high ESRD areas had lower transplant rates from the waiting list compared to those in low ESRD areas (medium: RR 0.68, 95% CI 0.66-0.69; high: RR 0.63, 95% CI 0.61-0.65). Geographic variation in access to kidney transplant is in part mediated by local ESRD incidence, which has implications for allocation policy development.

Myaskovsky L, Almario Doebler D, Posluszny DM, et al. **Perceived discrimination predicts longer time to be accepted for kidney transplant.** *Transplantation* 2012 93(4):423-9.

Notes: Small survey study evaluating non-medical factors associated with time to waitlisting in new transplant recipient evaluations focusing on racial differences.

Abstract: BACKGROUND: Although end-stage kidney disease in African Americans (AAs) is four times greater than in whites, AAs are less than one half as likely to undergo kidney transplantation (KT). This racial disparity has been found even after controlling for clinical factors such as comorbid conditions, dialysis vintage and type, and availability of potential living donors. Therefore, studying nonmedical factors is critical to understanding disparities in KT.

METHODS: We conducted a longitudinal cohort study with 127 AA and white patients with end-stage kidney disease undergoing evaluation for KT (December 2006 to July 2007) to determine whether, after controlling for medical factors, differences in time to acceptance for transplant is explained by patients' cultural factors (e.g., perceived racism and discrimination, medical mistrust, religious objections to living donor KT), psychosocial characteristics (e.g., social support, anxiety, depression), or transplant knowledge. Participants completed two telephone interviews (shortly after initiation of transplant evaluation and after being accepted or found ineligible for transplant).

RESULTS: Results indicated that AA patients reported higher levels of the cultural factors than did whites. We found no differences in comorbidity or availability of potential living donors. AAs took

significantly longer to get accepted for transplant than did whites (hazard ratio=1.49, P=0.005). After adjustment for demographic, psychosocial, and cultural factors, the association of race with longer time for listing was no longer significant.

CONCLUSIONS: We suggest that interventions to address racial disparities in KT incorporate key nonmedical risk factors in patients.

Nguyen S, Martz K, Stablein D, Neu A. **Wait list status of pediatric dialysis patients in North America.** *Pediatric transplantation* 2011 15(4):376-83.

Notes: limited value, but does include basic descriptives for pediatric waitlisting. Informative for scope of the issue in this age group.

Abstract: Kidney transplantation is the treatment of choice for the majority of pediatric patients with end-stage kidney disease. Previous studies demonstrating racial or gender disparities in access to the deceased donor transplant list could not evaluate the impact of medical concerns or patient preference on waitlist status. We undertook a retrospective cohort study using the NAPRTCS registry to begin to determine barriers to wait list registration for kidney transplantation among pediatric dialysis patients. Clinical and demographic factors were compared in listed vs. non-listed patients. Reasons cited for not listing patients were examined by clinical and demographic factors. At dialysis initiation, 88.7% of pediatric dialysis patients were not on the renal transplant wait list. Twelve months after dialysis initiation, 67.1% of pediatric dialysis patients were not on the wait list. The groups least likely to be on the wait list were infants (adjusted OR 0.23, 95% CI 0.16, 0.32) and girls (adjusted OR 0.78, 95% CI 0.67, 0.90) after adjusting for multiple confounders. The reason most often cited for not listing was medical reason for young infants and that the transplant workup was pending for girls. Further study is needed to identify barriers to wait list registration.

O'Hare AM, Johansen KL, Rodriguez RA. **Dialysis and kidney transplantation among patients living in rural areas of the United States.** *Kidney international* 2006 69(2):343-9.

Notes: investigation of dialysis facility characteristics (geographic, racial composition) and modality distribution, including transplantation.

Abstract: Although one-fifth of the United States population is rural, little is known about the characteristics and outcomes of rural dialysis patients. We measured the association of rural residence with patient characteristics, survival, and time to transplant among 552,279 patients who initiated dialysis between January 1, 1995 and December 31, 2002 and survived more than 90 days. We also examined the characteristics of 4363 Medicare-certified dialysis facilities by degree of rurality. Compared with urban patients, rural dialysis patients were older, less racially diverse with a higher prevalence of most co-morbid conditions. Hemodialysis was the dominant modality in both urban and rural areas, although the use of peritoneal dialysis was more frequent in rural areas. Survival and time to transplant differed by racial-ethnic group. Most notably, despite slightly better survival associated with rural vs urban residence among black populations, black populations living in rural areas were less likely to be transplanted than their urban counterparts (and than any other

group examined). Compared with urban facilities, rural facilities are smaller, less likely to be for profit or owned by a large chain. Nonetheless, rural facilities perform at least as well as urban facilities based on standard performance measures. Despite more frequent use of peritoneal dialysis among rural patients, rural facilities were markedly less likely to offer peritoneal dialysis or home hemodialysis training than urban facilities. Rural black patients (most of whom live in the south) should be targeted in policies to reduce racial disparities in access to transplant. Further studies are needed to determine whether rural dialysis patients have adequate access to home-based therapies.

Patibandla BK, Narra A, DeSilva R, et al. **Access to renal transplantation in the diabetic population-effect of comorbidities and body mass index.** *Clinical transplantation* 2012 26(3):E307-15.

Notes: USRDS data based analysis exploring mediators of the observed differences in waitlisting and actual transplantation for diabetics. Analyses suggest that the effect is mediated by obesity and comorbidities.

Abstract: BACKGROUND: In this study, we hypothesized that higher level of comorbidity and greater body mass index (BMI) may mediate the association between diabetes and access to transplantation.

METHODS: We used data from the United States Renal Data System (01/01/2000-24/09/2007; n = 619,151). We analyzed two outcomes using Cox model: (i) time to being placed on the waiting list or transplantation without being listed and (ii) time to transplantation after being listed. Two primary Cox models were developed based on different levels of adjustment.

RESULTS: In Cox models adjusted for a priori defined potential confounders, history of diabetes was associated with reduced transplant access (compared with non-diabetic population) - both for wait-listing/transplant without being listed (hazard ratio, HR = 0.80, p < 0.001) and for transplant after being listed (HR = 0.72, p < 0.001). In Cox models adjusted for BMI and comorbidity index along with the potential confounders, history of diabetes was associated with shorter time to wait-listing or transplantation without being listed (HR = 1.07, p < 0.001), and there was no significant difference in time to transplantation after being listed (HR = 1.01, p = 0.42).

CONCLUSION: We demonstrated that higher level of comorbidity and greater BMI mediate the association between diabetes and reduced access to transplantation.

Patzer RE, Amaral S, Lein M, et al. **Racial disparities in pediatric access to kidney transplantation: does socioeconomic status play a role?** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2012 12(2):369-78.

Notes: USRDS pediatric data documenting disparities in access to transplantation by race and ethnicity.

Abstract: Racial disparities persist in access to renal transplantation in the United States, but the degree to which patient and neighborhood socioeconomic status (SES) impacts racial disparities in

deceased donor renal transplantation access has not been examined in the pediatric and adolescent end-stage renal disease (ESRD) population. We examined the interplay of race and SES in a population-based cohort of all incident pediatric ESRD patients <21 years from the United States Renal Data System from 2000 to 2008, followed through September 2009. Of 8452 patients included, 30.8% were black, 27.6% white-Hispanic, 44.3% female and 28.0% lived in poor neighborhoods. A total of 63.4% of the study population was placed on the waiting list and 32.5% received a deceased donor transplant. Racial disparities persisted in transplant even after adjustment for SES, where minorities were less likely to receive a transplant compared to whites, and this disparity was more pronounced among patients 18-20 years. Disparities in access to the waiting list were mitigated in Hispanic patients with private health insurance. Our study suggests that racial disparities in transplant access worsen as pediatric patients transition into young adulthood, and that SES does not explain all of the racial differences in access to kidney transplantation.

Patzer RE, Amaral S, Wasse H, et al. **Neighborhood poverty and racial disparities in kidney transplant waitlisting.** *Journal of the American Society of Nephrology* : JASN 2009 20(6):1333-40.

Notes: Observational study of incident ESRD patients from Network 6 (SE US) n=35,346. Dependent variable was placement on kidney transplant waiting list. Multiple covariates included. Interesting finding of apparent interaction between poverty and race.

Abstract: Racial disparities persist in the United States renal transplantation process. Previous studies suggest that the distance between a patient's residence and the transplant facility may associate with disparities in transplant waitlisting. We examined this possibility in a cohort study using data for incident, adult ESRD patients (1998 to 2002) from the ESRD Network 6, which includes Georgia, North Carolina, and South Carolina. We linked data with the United Network for Organ Sharing (UNOS) transplant registry through 2005 and with the 2000 U.S. Census geographic data. Of the 35,346 subjects included in the analysis, 12% were waitlisted, 57% were black, 50% were men, 20% were impoverished, 45% had diabetes as the primary etiology of ESRD, and 73% had two or more comorbidities. The median distance from patient residence to the nearest transplant center was 48 mi. After controlling for multiple covariates, distance from patient residence to transplant center did not predict placement on the transplant waitlist. In contrast, race, neighborhood poverty, gender, age, diabetes, hypertension, body mass index, albumin, and the use of erythropoietin at dialysis initiation was associated with waitlisting. As neighborhood poverty increased, the likelihood of waitlisting decreased for blacks compared with whites in each poverty category; in the poorest neighborhoods, blacks were 57% less likely to be waitlisted than whites. This study suggests that improving the allocation of kidneys may require a focus on poor communities.

Patzer RE, Perryman JP, Pastan S, et al. **Impact of a patient education program on disparities in kidney transplant evaluation.** *Clinical journal of the American Society of Nephrology* : CJASN 2012 7(4):648-55.

Notes: Single center retrospective historical controlled study of the impact of implementation of specific educational program for renal transplant evaluation. n=1126 Fraction of patients completing the evaluation process in 1 year doubled. Methodologic limita

Abstract: BACKGROUND AND OBJECTIVES: In 2007, the Emory Transplant Center (ETC) kidney transplant program implemented a required educational session for ESRD patients referred for renal transplant evaluation to increase patient awareness and decrease loss to follow-up. The purpose of this study was to evaluate the association of the ETC education program on completion of the transplant evaluation process.

DESIGN, SETTING, PARTICIPANTS, & MEASUREMENTS: Incident, adult ESRD patients referred from 2005 to 2008 were included. Patient data were abstracted from medical records and linked with data from the United States Renal Data System. Evaluation completion was compared by pre- and posteducational intervention groups in binomial regression models accounting for temporal confounding.

RESULTS: A total of 1126 adult ESRD patients were examined in two transplant evaluation eras (75% pre- and 25% postintervention). One-year evaluation completion was higher in the post- versus preintervention group (80.4% versus 44.7%, $P<0.0001$). In adjusted analyses controlling for time trends, the adjusted probability of evaluation completion at 1 year was higher among the intervention versus nonintervention group (risk ratio=1.38, 95% confidence interval=1.12-1.71). The effect of the intervention was stronger among black patients and those patients living in poor neighborhoods (likelihood ratio test for interaction, $P<0.05$).

CONCLUSIONS: Standardizing transplant education may help reduce some of the racial and socioeconomic disparities observed in kidney transplantation.

Patzer RE, Perryman JP, Schragger JD, et al. **The role of race and poverty on steps to kidney transplantation in the Southeastern United States.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2012 12(2):358-68.

Notes: Detailed study of the racial differences present at multiple steps in the journey from referral to kidney transplantation. Limitation is single-center experience (Emory). Can these results be generalized?

Abstract: Racial disparities in access to renal transplantation exist, but the effects of race and socioeconomic status (SES) on early steps of renal transplantation have not been well explored. Adult patients referred for renal transplant evaluation at a single transplant center in the Southeastern United States from 2005 to 2007, followed through May 2010, were examined. Demographic and clinical data were obtained from patient's medical records and then linked with United States Renal Data System and American Community Survey Census data. Cox models examined the effect of race on referral, evaluation, waitlisting and organ receipt. Of 2291 patients, 64.9% were black, the mean age was 49.4 years and 33.6% lived in poor neighborhoods. Racial

disparities were observed in access to referral, transplant evaluation, waitlisting and organ receipt. SES explained almost one-third of the lower rate of transplant among black versus white patients, but even after adjustment for demographic, clinical and SES factors, blacks had a 59% lower rate of transplant than whites (hazard ratio = 0.41; 95% confidence interval: 0.28-0.58). Results suggest that improving access to healthcare may reduce some, but not all, of the racial disparities in access to kidney transplantation.

Purnell TS, Hall YN, Boulware LE. **Understanding and overcoming barriers to living kidney donation among racial and ethnic minorities in the United States.** *Advances in chronic kidney disease* 2012 19(4):244-51.

Notes: May be a source for additional references and conceptual framework may be useful.

Abstract: In the United States, racial-ethnic minorities experience disproportionately high rates of ESRD, but they are substantially less likely to receive living donor kidney transplants (LDKT) compared with their majority counterparts. Minorities may encounter barriers to LDKT at several steps along the path to receiving it, including consideration, pursuit, completion of LDKT, and the post-LDKT experience. These barriers operate at different levels related to potential recipients and donors, health care providers, health system structures, and communities. In this review, we present a conceptual framework describing various barriers that minorities face along the path to receiving LDKT. We also highlight promising recent and current initiatives to address these barriers, as well as gaps in initiatives, which may guide future interventions to reduce racial-ethnic disparities in LDKT.

Purnell TS, Xu P, Leca N, Hall YN. **Racial differences in determinants of live donor kidney transplantation in the United States.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2013 13(6):1557-65.

Notes: Evaluation of factors associated with LDKT in US incident patients between 2005-08, focusing on sociodemographic factors and predialysis care. General background information about factors other than facility-specific factors contributing to racial/ethnic

Abstract: Few studies have compared determinants of live donor kidney transplantation (LDKT) across all major US racial-ethnic groups. We compared determinants of racial-ethnic differences in LDKT among 208 736 patients who initiated treatment for end-stage kidney disease during 2005-2008. We performed proportional hazards and bootstrap analyses to estimate differences in LDKT attributable to sociodemographic and clinical factors. Mean LDKT rates were lowest among blacks (1.19 per 100 person-years [95% CI: 1.12-1.26]), American Indians/Alaska Natives-AI/ANs (1.40 [1.06-1.84]) and Pacific Islanders (1.10 [0.78-1.84]), intermediate among Hispanics (2.53 [2.39-2.67]) and Asians (3.89 [3.51-4.32]), and highest among whites (6.46 [6.31-6.61]). Compared with whites, the largest proportion of the disparity among blacks (20%) and AI/ANs (29%) was attributed to measures of predialysis care, while the largest proportion among Hispanics (14%) was attributed to health insurance coverage. Contextual poverty accounted for 16%, 4%, 18%, and 6% of the disparity

among blacks, Hispanics, AI/ANs and Pacific Islanders but none of the disparity among Asians. In the United States, significant disparities in rates of LDKT persist, but determinants of these disparities vary by race-ethnicity. Efforts to expand preESKD insurance coverage, to improve access to high-quality predialysis care and to overcome socioeconomic barriers are important targets for addressing disparities in LDKT.

*Reams BN, Birkmeyer JO, Dimick JB, Ghaferi AA. **Socioeconomic Disparities in Mortality After Cancer Surgery: Failure to Rescue** *JAMA Surg* 2014 149(5):475-81.

Abstract: IMPORTANCE: Disparities in operative mortality due to socioeconomic status (SES) have been consistently demonstrated, but the mechanisms underlying this disparity are not well understood.

OBJECTIVE: To determine whether variations in failure to rescue (FTR) contribute to socioeconomic disparities in mortality after major cancer surgery.

DESIGN, SETTING, AND PARTICIPANTS: We performed a retrospective cohort study using the Medicare Provider Analysis and Review File and the Medicare Denominator File. A summary measure of SES was created for each zip code using 2000 US Census data linked to residence. Multivariable logistic regression was used to examine the influence of SES on rates of FTR, and fixed-effects hierarchical regression was used to evaluate the extent to which disparities could be attributed to differences among hospitals. A total of 596,222 patients undergoing esophagectomy, pancreatectomy, partial or total gastrectomy, colectomy, lung resection, and cystectomy for cancer from 2003 through 2007 were studied.

MAIN OUTCOMES AND MEASURES: Operative mortality, postoperative complications, and FTR (case fatality after ≥ 1 major complication).

RESULTS: Patients in the lowest quintile of SES had mildly increased rates of complications (25.6% in the lowest quintile vs 23.8% in the highest quintile, $P = .003$), a larger increase in mortality (10.2% vs 7.7%, $P = .0009$), and the greatest increase in rates of FTR (26.7% vs 23.2%, $P = .007$). Analysis of hospitals revealed a higher FTR rate for all patients (regardless of SES) at centers treating the largest proportion of patients with low SES. The adjusted odds ratios (95% CIs) of FTR according to SES ranged from 1.04 (0.95-1.14) for gastrectomy to 1.45 (1.21-1.73) for pancreatectomy. Additional adjustment for hospital effect nearly eliminated the disparity observed in FTR across levels of SES.

CONCLUSIONS AND RELEVANCE: Patients in the lowest quintile of SES have significantly increased rates of FTR. This finding appears to be in part a function of the hospital where patients with low SES are treated. Future efforts to improve socioeconomic disparities should concentrate on hospital processes and characteristics that contribute to successful rescue.

Reese P, Shea JA, Berns JS, et al. **Recruitment of live donors by candidates for kidney transplantation.** *Clinical journal of the American Society of Nephrology : CJASN* 2008 3(4):1152-9.

Notes: A cross-sectional study of renal transplant candidates was performed at initial transplant evaluation (n=91). Describes patient characteristics and specific concerns associated with likelihood of a potential recipient initiating a conversation with a pot

Abstract: BACKGROUND: Little is known about efforts that renal transplant candidates make to recruit live donors. It was hypothesized that preference for live donor kidney transplantation and greater knowledge about live donor transplantation are associated with candidates' initiating conversations about donation with potential donors.

DESIGN, SETTING, PARTICIPANTS, & MEASUREMENTS: A cross-sectional study of renal transplant candidates was performed at initial transplant evaluation. Candidates completed a questionnaire that specified whether they had initiated conversations about donation with any potential donors. The questionnaire also measured preference for live donor transplantation, knowledge about transplantation, concern about donor harm, willingness to ask for help in coping with kidney disease, and social support.

RESULTS: Ninety-six candidates participated. Forty-nine (51%) reported initiating a conversation with at least one potential donor. In multivariable logistic regression, domains associated with initiating a conversation included: preference for live donor transplantation, willingness to ask for help, and female gender. Older age was associated with a lower odds of initiating a conversation. Knowledge, concern about donor harm, social support, and ethnicity were not associated with initiating a conversation with a donor.

CONCLUSIONS: Attempts at donor recruitment by kidney transplant candidates are common. These findings suggest that interventions that influence preferences about transplantation and willingness to ask others for help are logical targets to enhance access to live donor transplantation.

Reese PP, Hwang H, Potluri V, et al. **Geographic determinants of access to pediatric deceased donor kidney transplantation.** *Journal of the American Society of Nephrology* : JASN 2014 25(4):827-35.

Abstract: Children receive priority in the allocation of deceased donor kidneys for transplantation in the United States, but because allocation begins locally, geographic differences in population and organ supply may enable variation in pediatric access to transplantation. We assembled a cohort of 3764 individual listings for pediatric kidney transplantation in 2005-2010. For each donor service area, we assigned a category of short (<180 days), medium (181-270 days), or long (>270 days) median waiting time and calculated the ratio of pediatric-quality kidneys to pediatric candidates and the percentage of these kidneys locally diverted to adults. We used multivariable Cox regression analyses to examine the association between donor service area characteristics and time to deceased donor kidney transplantation. The Kaplan-Meier estimate of median waiting time to transplantation was 284 days (95% confidence interval, 263 to 300 days) and varied from 14 to 1313 days across donor service areas. Overall, 29% of pediatric-quality kidneys were locally diverted to adults. Compared with areas with short waiting times, areas with long waiting times had a lower ratio of pediatric-quality kidneys to candidates (3.1 versus 5.9; P<0.001) and more diversions to adults (31% versus 27%; P<0.001). In multivariable regression, a lower kidney to candidate ratio

remained associated with longer waiting time (hazard ratio, 0.56 for areas with <2:1 versus reference areas with ≥5:1 kidneys/candidates; P<0.01). Large geographic variation in waiting time for pediatric deceased donor kidney transplantation exists and is highly associated with local supply and demand factors. Future organ allocation policy should address this geographic inequity.

Rhee CM, Lertdumrongluk P, Streja E, et al. **Impact of age, race and ethnicity on dialysis patient survival and kidney transplantation disparities.** *American journal of nephrology* 2014 39(3):183-94.

Abstract: BACKGROUND: Prior studies show that African-American and Hispanic dialysis patients have lower mortality risk than whites. Recent age-stratified analyses suggest this survival advantage may be limited to younger age groups, but did not concurrently compare Hispanic, African-American, and white patients, nor account for differences in nutritional and inflammatory status as potential confounders. Minorities experience inequities in kidney transplantation access, but it is unknown whether these racial/ethnic disparities differ across age groups.

METHODS: The associations between race/ethnicity with all-cause mortality and kidney transplantation were separately examined among 130,909 adult dialysis patients from a large national dialysis organization (entry period 2001-2006, follow-up through 2009) within 7 age categories using Cox proportional hazard models adjusted for case-mix and malnutrition and inflammatory surrogates.

RESULTS: African-Americans had similar mortality versus whites in younger age groups (18-40 years), but decreased mortality in older age groups (>40 years). In contrast, Hispanics had lower mortality versus whites across all ages. In sensitivity analyses using competing risk regression to account for differential kidney transplantation rates across racial/ethnic groups, the African-American survival advantage was limited to >60-years age categories. African-Americans and Hispanics were less likely to undergo kidney transplantation from all donor types versus whites across all ages, and these disparities were even more pronounced for living donor kidney transplantation (LDKT).

CONCLUSIONS: Hispanic dialysis patients have greater survival versus whites across all ages; in African-Americans, this survival advantage is limited to patients >40 years of age. Minorities are less likely to undergo kidney transplantation, particularly LDKT, across all ages.

Rodrigue JR, Pavlakis M, Egbuna O, et al. **The "House Calls" trial: a randomized controlled trial to reduce racial disparities in live donor kidney transplantation: rationale and design.** *Contemporary clinical trials* 2012 33(4):811-8.

Abstract: Despite a substantially lower rate of live donor kidney transplantation among Black Americans compared to White Americans, there are few systematic efforts to reduce this racial disparity. This paper describes the rationale and design of a randomized controlled trial evaluating the comparative effectiveness of three different educational interventions for increasing live donor kidney transplantation in Black Americans. This trial is a single-site, urn-randomized controlled trial with a planned enrollment of 180 Black Americans awaiting kidney transplantation. Patients are

randomized to receive transplant education in one of three education conditions: through group education at their homes (e.g., House Calls), or through group (Group-Based) or individual education (Individual Counseling) in the transplant center. The primary outcome of the trial is the occurrence of a live donor kidney transplant, with secondary outcomes including living donor inquiries and evaluations as well as changes in patient live donor kidney transplantation readiness, willingness, knowledge, and concerns. Sex, age, dialysis status, and quality of life are evaluated as moderating factors. Findings from this clinical trial have the potential to inform strategies for reducing racial disparities in live donor kidney transplantation. Similar trials have been developed recently to broaden the evaluation of House Calls as an innovative disparity-reducing intervention in kidney transplantation.

Salter ML, McAdams-Demarco MA, Law A, et al. **Age and sex disparities in discussions about kidney transplantation in adults undergoing dialysis.** *Journal of the American Geriatrics Society* 2014 62(5):843-9.

Abstract: OBJECTIVES: To explore whether disparities in age and sex in access to kidney transplantation (KT) originate at the time of prereferral discussions about KT.

DESIGN: Cross-sectional survey.

SETTING: Outpatient dialysis centers in Maryland (n = 26).

PARTICIPANTS: Individuals who had recently initiated hemodialysis treatment (N = 416).

MEASUREMENTS: Participants reported whether medical professionals (nephrologist, primary medical doctor, dialysis staff) and social group members (significant other, family member, friend) discussed KT with them and, when applicable, rated the tone of discussions. Relative risks were estimated using modified Poisson regression.

RESULTS: Participants aged 65 and older were much less likely than those who were younger to have had discussions with medical professionals (44.5% vs 74.8%, $P < .001$) or social group members (47.3% vs 63.1%, $P = .005$). Irrespective of sex and independent of race, health-related factors, and dialysis-related characteristics, older adults were more likely not to have had discussions with medical professionals (relative risk (RR) = 1.13, 95% confidence interval (CI) = 1.03-1.24, for each 5-year increase in age through 65; RR = 1.28, 95% CI = 1.14-1.42, for each 5-year increase in age beyond 65). Irrespective of age, women were more likely (RR = 1.45, 95% CI = 1.12-1.89) not to have had discussions with medical professionals. For each 5-year increase in age, men (RR = 1.04, 95% CI = 0.99-1.10) and women (RR = 1.17, 95% CI = 1.10-1.24) were more likely not to have discussions with social group members. Of those who had discussions with medical professionals or social group members, older participants described these discussions as less encouraging (all $P < .01$).

CONCLUSION: Older adults and women undergoing hemodialysis are less likely than younger adults and men to have discussions about KT as a treatment option, supporting a need for better clinical guidelines and education for these individuals, their social network, and their providers.

Salter ML, Orandi B, McAdams-DeMarco MA, et al. **Patient- and provider-reported information about transplantation and subsequent waitlisting.** *J Am Soc Nephrol* 2014 25(12):2871-7.

Abstract: Because informed consent requires discussion of alternative treatments, proper consent for dialysis should incorporate discussion about other renal replacement options including kidney transplantation (KT). Accordingly, dialysis providers are required to indicate KT provision of information (KTPI) on CMS Form-2728; however, provider-reported KTPI does not necessarily imply adequate provision of information. Furthermore, the effect of KTPI on pursuit of KT remains unclear. We compared provider-reported KTPI (Form-2728) with patient-reported KTPI (in-person survey of whether a nephrologist or dialysis staff had discussed KT) in a prospective ancillary study of 388 hemodialysis initiates. KTPI was reported by both patient and provider for 56.2% of participants, by provider only for 27.8%, by patient only for 8.3%, and by neither for 7.7%. Among participants with provider-reported KTPI, older age was associated with lack of patient-reported KTPI. Linkage with the Scientific Registry for Transplant Recipients showed that 20.9% of participants were subsequently listed for KT. Patient-reported KTPI was independently associated with a 2.95-fold (95% confidence interval [95% CI], 1.54 to 5.66; P=0.001) higher likelihood of KT listing, whereas provider-reported KTPI was not associated with listing (hazard ratio, 1.18; 95% CI, 0.60 to 2.32; P=0.62). Our findings suggest that patient perception of KTPI is more important for KT listing than provider-reported KTPI. Patient-reported and provider-reported KTPI should be collected for quality assessment in dialysis centers because factors associated with discordance between these metrics might inform interventions to improve this process.

Sandhu GS, Khattak M, Pavlakis M, et al. **Recipient's unemployment restricts access to renal transplantation.** *Clinical transplantation* 2013 27(4):598-606.

Abstract: Equitable distribution of a scarce resource such as kidneys for transplantation can be a challenging task for transplant centers. In this study, we evaluated the association between recipient's employment status and access to renal transplantation in patients with end-stage renal disease (ESRD). We used data from the United States Renal Data System (USRDS). The primary variable of interest was employment status at ESRD onset. Two outcomes were analyzed in Cox model: (i) being placed on the waiting list for renal transplantation or being transplanted (whichever occurred first); and (ii) first transplant in patients who were placed on the waiting list. We analyzed 429 409 patients (age of ESRD onset 64.2 ± 15.2 yr, 55.0% males, 65.1% White). Compared with patients who were unemployed, patients working full time were more likely to be placed on the waiting list/transplanted (HR 2.24, $p < 0.001$) and to receive a transplant once on the waiting list (HR 1.65, $p < 0.001$). Results indicate that recipient's employment status is strongly associated with access to renal transplantation, with unemployed and partially employed patients at a disadvantage. Adding insurance status to the model reduces the effect size, but the association still remains significant, indicating additional contribution from other factors.

Saunders MR, Cagney KA, Ross LF, Alexander GC. **Neighborhood poverty, racial composition and renal transplant waitlist.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2010 10(8):1912-7.

Notes: US national incident ESRD patient observational study from 2000-2006 (n= 283,088) evaluating association between time to waitlist and sociodemographic characteristics (including race, neighborhood poverty) adjusting for other demographic and comorbid cond

Abstract: To date, no study has characterized the association between neighborhood poverty, racial composition and deceased donor kidney waitlist. Using the United States Renal Data System data linked to 2000 U.S. Census Data, we examined Whites (n = 152 788) and Blacks (n = 130 300) initiating dialysis between January 2000 and December 2006. Subjects' neighborhoods were divided into nine strata based on the percent of Black residents and percent poverty. Cox proportional hazards were used to determine the association between time to waitlist and neighborhood characteristics after adjusting for demographics and comorbid conditions. Individuals from poorer neighborhoods had a consistently lower likelihood of being waitlisted. This association was synergistic with neighborhood racial composition for Blacks, but not for Whites. Blacks in poor, predominantly Black neighborhoods (adjusted hazard ratio [HR] 0.57, 95% confidence intervals [CI] 0.53-0.62) were less likely to appear on transplant waitlist than those in wealthy, predominantly Black neighborhoods (HR 0.80, CI 0.67-0.96) and poor, predominantly White neighborhoods (HR 0.79, CI 0.70-0.89). All were all less likely to be waitlisted than their Black counterparts in wealthy, predominantly White or mixed neighborhoods ($p < 0.05$). Interventions targeted at individuals in poor and minority neighborhoods may represent an opportunity to improve equitable access to the deceased donor kidney waitlist.

Schaeffner ES, Mehta J, Winkelmayr WC. **Educational level as a determinant of access to and outcomes after kidney transplantation in the United States.** *American journal of kidney diseases : the official journal of the National Kidney Foundation* 2008 51(5):811-8.

Notes: USRDS special study associating education level and association with access to and results of kidney transplantation.

Abstract: BACKGROUND: Disparities in access to kidney transplantation exist, yet few studies investigated educational level as a determinant of access to and outcomes after kidney transplantation.

STUDY DESIGN: Prospective cohort study.

SETTINGS & PARTICIPANTS: Nationally representative sample of incident US dialysis patients, in which 3,245 patients reported their educational level.

PREDICTOR: Educational level, categorized as some high school, high school graduate, some college, and college graduate.

OUTCOMES & MEASUREMENTS: Access to kidney transplantation was defined as time from first dialysis treatment to: (1) the day of being wait-listed and (2) first kidney transplantation. Outcomes after kidney transplantation were: (3) all-cause mortality and graft failure ([4] all-cause and [5] death

censored). Using Cox regression, we studied the relationship between predialysis educational level and access to and outcomes after kidney transplantation.

RESULTS: During follow-up, 692 patients were wait-listed and 670 underwent kidney transplantation. Of those, 164 died and 241 lost their allograft (121 from nondeath causes). After multivariate adjustment, college graduates experienced 3 times greater rates of wait-listing (hazard ratio, 2.81; 95% confidence interval, 2.21 to 3.58) or kidney transplantation (hazard ratio, 3.06; 95% confidence interval, 2.38 to 3.92) compared with patients without a high school degree (P for trend across educational level for both outcomes < 0.001). Although mortality was not associated with educational level, increased rates of death-censored allograft loss were observed with less education (P for trend = 0.03).

LIMITATIONS: Not a randomized study.

CONCLUSION: The latter finding is novel and important and requires confirmation. Its possible mechanisms (eg, adherence to immunosuppressants) warrant additional study.

Schold JD, Gregg JA, Harman JS, et al. **Barriers to evaluation and wait listing for kidney transplantation.** *Clinical journal of the American Society of Nephrology : CJASN* 2011 6(7):1760-7.

Notes: single center experience limits value of information.

Abstract: BACKGROUND AND OBJECTIVES: Many factors have been shown to be associated with ESRD patient placement on the waiting list and receipt of kidney transplantation. Our study aim was to evaluate factors and assess the interplay of patient characteristics associated with progression to transplantation in a large cohort of referred patients from a single institution.

DESIGN, SETTING, PARTICIPANTS, & MEASUREMENTS: We examined 3029 consecutive adult patients referred for transplantation from 2003 to 2008. Uni- and multivariable logistic models were used to assess factors associated with progress to transplantation including receipt of evaluations, waiting list placement, and receipt of a transplant.

RESULTS: A total of 56%, 27%, and 17% of referred patients were evaluated, were placed on the waiting list, and received a transplant over the study period, respectively. Older age, lower median income, and noncommercial insurance were associated with decreased likelihood to ascend steps to receive a transplant. There was no difference in the proportion of evaluations between African Americans (57%) and Caucasians (56%). Age-adjusted differences in waiting list placement by race were attenuated with further adjustment for income and insurance. There was no difference in the likelihood of waiting list placement between African Americans and Caucasians with commercial insurance.

CONCLUSIONS: Race/ethnicity, age, insurance status, and income are predominant factors associated with patient progress to transplantation. Disparities by race/ethnicity may be largely explained by insurance status and income, potentially suggesting that variable insurance coverage

exacerbates disparities in access to transplantation in the ESRD population, despite Medicare entitlement.

Schold JD, Heaphy ELG, Buccini LD, et al. **Prominent impact of community risk factors on kidney transplant candidate processes and outcomes.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2013 13(9):2374-83.

Abstract: Numerous factors impact patients' health beyond traditional clinical characteristics. We evaluated the association of risk factors in kidney transplant patients' communities with outcomes prior to transplantation. The primary exposure variable was a community risk score (range 0-40) derived from multiple databases and defined by factors including prevalence of comorbidities, access and quality of healthcare, self-reported physical and mental health and socioeconomic status for each U.S. county. We merged data with the Scientific Registry of Transplant Recipients (SRTR) and utilized risk-adjusted models to evaluate effects of community risk for adult candidates listed 2004-2010 (n = 209 198). Patients in highest risk communities were associated with increased mortality (adjusted hazard ratio [AHR] = 1.22, 1.16-1.28), decreased likelihood of living donor transplantation (adjusted odds ratio [AOR] = 0.90, 0.85-0.94), increased waitlist removal for health deterioration (AHR = 1.36, 1.22-1.51), decreased likelihood of preemptive listing (AOR = 0.85, 0.81-0.88), increased likelihood of inactive listing (AOR = 1.49, 1.43-1.55) and increased likelihood of listing for expanded criteria donor kidneys (AHR = 1.19, 1.15-1.24). Associations persisted with adjustment for rural-urban location; furthermore the independent effects of rural-urban location were largely eliminated with adjustment for community risk. Average community risk varied widely by region and transplant center (median = 21, range 5-37). Community risks are powerful factors associated with processes of care and outcomes for transplant candidates and may be important considerations for developing effective interventions and measuring quality of care of transplant centers.

Schold JD, Srinivas TR, Kayler LK, Meier-Kriesche HU. **The overlapping risk profile between dialysis patients listed and not listed for renal transplantation.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2008 8(1):58-68.

Notes: US national study comparing the association (and discordance) between expected survival of incident dialysis patients and transplant listing. The study implies that listing decisions may not reflect viability of candidates in all cases.

Abstract: The survival advantage of kidney transplantation extends to many high-risk ESRD patients; however, numerous factors ultimately determine which patients are evaluated and listed for the procedure. Broad goals of patient evaluation comprise identifying patients who will benefit from transplantation and excluding patients who might be placed at risk. There is limited data detailing whether current access limitations and screening strategies have achieved the goal of listing the most appropriate patients. The study estimated the life expectancy of adult patients in the United

States prior to transplantation with ESRD onset from 1995 to 2003. Factors associated with transplant listing were examined based on patient prognosis after ESRD. Approximately one-third of patients listed for transplantation within 1 year of ESRD had ≤ 5 -year life expectancy on dialysis. In contrast, one-third of patients not listed had > 5 -year life expectancy. The number of patients not listed with 'good' prognosis was significantly higher than those listed with 'poor' prognosis (134 382 vs. 16 807, respectively). Age, race, gender, insurance coverage and body mass index (BMI) were associated with likelihood for listing with 'poor' prognosis and not listing with 'good' prognosis. Over the past decade, many ESRD patients viable for transplantation have not listed for transplantation while higher-risk patients have listed rapidly.

Segen DL, Kucirka LM, Oberai P, et al. **Age and comorbidities are effect modifiers of gender disparities in renal transplantation.** *Journal of the American Society of Nephrology* : JASN 2009 20(3):621-8.

Notes: US national observational study evaluating access to transplantation and survival benefit of transplantation as dependent variables as effected by covariates including age, sex.

Abstract: Women have less access to kidney transplantation than men, but the contributions of age and comorbidity to this disparity are largely unknown. We conducted a national cohort study of 563,197 patients with first-onset ESRD between 2000 and 2005. We used multivariate generalized linear models to evaluate both access to transplantation (ATT), defined as either registration for the deceased-donor waiting list or receiving a live-donor transplant, and survival benefit from transplantation, defined as the relative rate of survival after transplantation compared with the rate of survival on dialysis. We compared relative risks (RRs) between women and men, stratified by age categories and the presence of common comorbidities. Overall, women had 11% less ATT than men. When the model was stratified by age, 18- to 45-yr-old women had equivalent ATT to men (RR 1.01), but with increasing age, ATT for women declined dramatically, reaching a RR of 0.41 for those who were older than 75 yr, despite equivalent survival benefits from transplantation between men and women in all age subgroups. Furthermore, ATT for women with comorbidities was lower than that for men with the same comorbidities, again despite similar survival benefits from transplantation. This study suggests that there is no disparity in ATT for women in general but rather a marked disparity in ATT for older women and women with comorbidities. These disparities exist despite similar survival benefits from transplantation for men and women regardless of age or comorbidities.

Segev DL, Simpkins CW, Thompson RE, Let al. **Obesity impacts access to kidney transplantation.** *Journal of the American Society of Nephrology* : JASN 2008 19(2):349-55.

Notes: USRDS data used to evaluate impact of obesity categories on likelihood of receiving a transplant, and separately likelihood of being bypassed when organ became available. Value of these results are unclear as appropriateness of the decisions made, in ter

Abstract: Current billing practices and mandates to report surgical outcomes are disincentives to surgical treatment of obese patients, who are at increased risk for longer hospital stays and higher complication rates. The objective of this study was to quantify the independent association between

body mass index (BMI) and waiting time for kidney transplantation to identify potential provider bias against surgical treatment of the obese. A secondary data analysis was performed of a prospective cohort of 132,353 patients who were registered for kidney transplantation in the United States between 1995 and 2006. Among all patients awaiting kidney transplantation, the likelihood of receiving a transplant decreased with increasing degree of obesity, categorized by ranges of BMI (adjusted hazard ratios 0.96 for overweight, 0.93 for obese, 0.72 for severely obese, and 0.56 for morbidly obese, compared with a reference group of patients with normal BMI). Similarly, the likelihood of being bypassed when an organ became available increased in a graded manner with category of obesity (adjusted incidence rate ratio 1.02 for overweight, 1.05 for obese, 1.11 for severely obese, and 1.22 for morbidly obese). Although matching an available organ with an appropriate recipient requires clinical judgment, which could not be fully captured in this study, the observed differences are dramatic and warrant further studies to understand this effect better and to design a system that is less susceptible to unintended bias.

Shellmer D, Brosig C, Wray J. **The start of the transplant journey: referral for pediatric solid organ transplantation.** *Pediatric transplantation* 2014 18(2):125-33.

Abstract: The focus of the majority of the psychosocial transplant literature is on post-transplant outcomes, but the transplant journey starts much earlier than this, at the point when transplantation is first considered and a referral for transplant evaluation is made. In this review, we cover information regarding the meaning of the referral process for solid organ transplantation. We discuss various factors of the referral for transplantation including the impact of referral on the pediatric patient and the family, potential expectations and misconceptions held by pediatric patients and parents, the role of health literacy, decision-making factors, and the informational needs of pediatric patients and parents. We elucidate steps that providers can take to enhance transplant referral and provide suggestions for much needed research within this area.

Smart NA, Dieberg G, Ladhani M, Titus T. **Early referral to specialist nephrology services for preventing the progression to end-stage kidney disease (Review)** *The Cochrane Library: Cochrane Database Syst Rev.* 2014 (6).

Abstract: BACKGROUND: Early referral of patients with chronic kidney disease (CKD) is believed to help with interventions to address risk factors to slow down the rate of progression of kidney failure to end-stage kidney disease (ESKD) and the need for dialysis, hospitalisation and mortality.

OBJECTIVES: We sought to evaluate the benefits (reduced hospitalisation and mortality; increased quality of life) and harms (increased hospitalisations and mortality, decreased quality of life) of early versus late referral to specialist nephrology services in CKD patients who are progressing to ESKD and RRT. In this review, referral is defined as the time period between first nephrology evaluation and initiation of dialysis; early referral is more than one to six months, whereas late referral is less than one to six months prior to starting dialysis. All-cause mortality and hospitalisation and quality of life were measured by the visual analogue scale and SF-36. SF-36 and KDQoL are validated measurement instruments for kidney diseases.

SEARCH METHODS: We searched the Cochrane Central Register of Controlled Trials (CENTRAL) (The Cochrane Library, 2012; Issue 1) which contains the Cochrane Renal Group's Specialised Register; MEDLINE (1966 to February 2012), EMBASE (1980 to February 2012). Search terms were approved by the Trial Search Co-ordinator.

SELECTION CRITERIA: Randomised controlled trials (RCTs), quasi-RCTs, prospective and retrospective longitudinal cohort studies were eligible for inclusion.

DATA COLLECTION AND ANALYSIS: Two authors independently assessed study quality and extracted data. Events relating to adverse effects were collected from the studies.

MAIN RESULTS: No RCTs or quasi-RCTs were identified. There were 40 longitudinal cohort studies providing data on 63,887 participants; 43,209 (68%) who were referred early and 20,678 (32%) referred late. Comparative mortality was higher in patients referred to specialist services late versus those referred early. Risk ratios (RR) for mortality reductions in patients referred early were evident at three months (RR 0.61, 95% CI 0.55 to 0.67; $I^2 = 84\%$) and remained at five years (RR 0.66, 95% CI 0.60 to 0.71; $I^2 = 87\%$). Initial hospitalisation was 9.12 days shorter with early referral (95% CI -10.92 to -7.32 days; $I^2 = 82\%$) compared to late referral. Pooled analysis showed patients referred early were more likely than late referrals to initiate RRT with peritoneal dialysis (RR 1.74, 95% CI 1.64 to 1.84; $I^2 = 92\%$). Patients referred early were less likely to receive temporary vascular access (RR 0.47, 95% CI 0.45 to 0.50; $I^2 = 97\%$) than those referred late. Patients referred early were more likely to receive permanent vascular access (RR 3.22, 95% CI 2.92 to 3.55; $I^2 = 97\%$). Systolic blood pressure (BP) was significantly lower in early versus late referrals (MD -3.09 mm Hg, 95% CI -5.23 to -0.95; $I^2 = 85\%$); diastolic BP was significantly lower in early versus late referrals (MD -1.64 mm Hg, 95% CI -2.77 to -0.51; $I^2 = 82\%$). EPO use was significantly higher in those referred early (RR 2.92, 95% CI 2.42 to 3.52; $I^2 = 0\%$). eGFR was higher in early referrals (MD 0.42 mL/min/1.73 m², 95% CI 0.28 to 0.56; $I^2 = 95\%$). Diabetes prevalence was similar in patients referred early and late (RR 1.05, 95% CI 0.96 to 1.15; $I^2 = 87\%$) as was ischaemic heart disease (RR 1.05, 95% CI 0.97 to 1.13; $I^2 = 74\%$), peripheral vascular disease (RR 0.99, 95% CI 0.84 to 1.17; $I^2 = 90\%$), and congestive heart failure (RR 1.00, 95% CI 0.86 to 1.15; $I^2 = 92\%$). Inability to walk was less prevalent in early referrals (RR 0.66, 95% CI 0.51 to 0.86). Prevalence of chronic obstructive pulmonary disease was similar in those referred early and late (RR 0.89, 95% CI 0.70 to 1.14; $I^2 = 94\%$) as was cerebrovascular disease (RR 0.90, 95% CI 0.74 to 1.11; $I^2 = 83\%$). The quality of the included studies was assessed as being low to moderate based on the Newcastle-Ottawa Scale. Slight differences in the definition of early versus late referral infer some risk of bias. Generally, heterogeneity in most of the analyses was high.

AUTHORS' CONCLUSIONS: Our analysis showed reduced mortality and mortality and hospitalisation, better uptake of peritoneal dialysis and earlier placement of arteriovenous fistulae for patients with chronic kidney disease who were referred early to a nephrologist. Differences in mortality and hospitalisation data between the two groups were not explained by differences in prevalence of comorbid disease or serum phosphate. However, early referral was associated with better preparation and placement of dialysis access.

Sullivan C, Leon JB, Sayre SS, et al. **Impact of navigators on completion of steps in the kidney transplant process: a randomized, controlled trial.** *Clinical journal of the American Society of Nephrology : CJASN* 2012 7(10):1639-45.

Notes: cluster randomized, controlled unblinded intervention at 23 Ohio dialysis facilities evaluating the effect of "transplant navigators" on progression through the steps of transplant evaluation. n=167 The intervention was associated with successful complet

Abstract: BACKGROUND AND OBJECTIVES: Many patients with ESRD, particularly minorities and women, face barriers in completing the steps required to obtain a transplant. These eight sequential steps are as follows: medical suitability, interest in transplant, referral to a transplant center, first visit to center, transplant workup, successful candidate, waiting list or identify living donor, and receive transplant. This study sought to determine the effect of navigators on completion of steps.

DESIGN, SETTING, PARTICIPANTS, & MEASUREMENTS: Cluster randomized, controlled trial at 23 Ohio hemodialysis facilities. One hundred sixty-seven patients were recruited between January 2009 and August 2009 and were followed for up to 24 months or until study end in February 2011. Trained kidney transplant recipients met monthly with intervention participants (n=92), determined their step in the transplant process, and provided tailored information and assistance in completing the step. Control participants (n=75) continued to receive usual care. The primary outcome was the number of transplant process steps completed.

RESULTS: Starting step did not significantly differ between the two groups. By the end of the trial, intervention participants completed more than twice as many steps as control participants (3.5 versus 1.6 steps; difference, 1.9 steps; 95% confidence interval, 1.3-2.5 steps). The effect of the intervention on step completion was similar across race and sex subgroups.

CONCLUSIONS: Use of trained transplant recipients as navigators resulted in increased completion of transplant process steps.

Szeifert L, Bragg-Gresham JL, Thumma J, et al. **Psychosocial variables are associated with being wait-listed, but not with receiving a kidney transplant in the Dialysis Outcomes and Practice Patterns Study (DOPPS).** *Nephrology, dialysis, transplantation : official publication of the European Dialysis and Transplant Association - European Renal Association* 2012 27(5):2107-13.

Notes: DOPPS study associating indicators of depression with lower likelihood of being waitlisted (but not lower rates of transplantation for those who get listed). Uncertain if this study can be of value, but it raises the question of depression as a potential

Abstract: BACKGROUND: Psychosocial factors are associated with clinical outcomes in patients with end-stage renal disease. It is not known if self-reported depression and quality of life influence the likelihood of being wait-listed and receiving a transplant.

METHODS: Prevalent cross section of 18- to 65-year-old hemodialysis (HD) patients in the USA (N = 2033) and seven European countries (N = 4350) from the Dialysis Outcomes and Practice Patterns

Study phase II and III was analyzed. Wait-listed patients (N = 1838) were followed until kidney transplantation. Self-reported depressive symptoms were assessed by the Center for Epidemiologic Studies-Depression scale, 10-item version (CES-D) and health-related quality of life (HR-QoL) by the Kidney Disease Quality of Life Short Form 12 scale Physical Component Score (PCS).

RESULTS: At study entry, 27% (USA) to 53% (UK) of patients were wait-listed in participating countries. Variables associated with lower odds of being on the waiting list included worse HR-QoL, more severe depressive symptoms, older age, fewer years of education, lower serum albumin, lower hemoglobin, shorter time on dialysis and presence of multiple comorbid conditions. Among wait-listed patients, significantly lower transplantation rates were seen for females, blacks, patients having prior transplantation and multiple comorbid conditions but not PCS or CES-D.

CONCLUSIONS: Fewer depressive symptoms and better HR-QoL are associated with being on the waiting list in prevalent HD patients but not with receiving a kidney transplant among wait-listed dialysis patients. Regular assessment of subjective well-being may help identify patients with reduced access to wait-listing and kidney transplantation.

The Renal Network, Inc. ESRD Network 9/10, Arbor Research, UM-KECC. **ESRD Special Study: Developing Dialysis Facility-Specific Kidney Transplant Referral Clinical Performance Measures: Final Project Report 2005.**

Notes: TEP Summary Report

Abstract: The Centers for Medicare & Medicaid Services (CMS) contracted with End Stage Renal Disease (ESRD) Network 9 for a special study between July 1, 2004 and June 30, 2005 to develop kidney transplant referral measures at the dialysis facility level. These measures will track steps in the transplant referral process and may be used for quality improvement and public reporting. CMS chose to develop quality measures in this area because of the Department of Health and Human Services interest in increasing organ donation and transplantation and because not all ESRD patients are offered the opportunity for transplantation, despite being the treatment modality of choice.

*Timmerman L, Ismail SY, Luchtenburg AE, et al. **Exploring Knowledge About Dialysis, Transplantation, and Living Donation Among Patients and Their Living Kidney Donors** *Int J Behav Med* 2015 [Epub ahead of print].

Abstract: **BACKGROUND:** In order to make a well-considered decision and give informed consent about renal replacement therapy, potential living kidney donors and recipients should have sufficient understanding of the options and risks.

PURPOSE: We aimed to explore knowledge about Dialysis & Transplantation (DT) and Living Donation (LD) among prospective living kidney donors and recipients.

METHODS: Eighty-five donors and 81 recipients completed the Rotterdam Renal Replacement Knowledge-Test (R3K-T) 1 day before surgery. The questionnaire was available in various languages.

RESULTS: Recipients knew significantly more about DT than donors ($p < 0.001$); donors knew more about LD than recipients ($p < 0.001$). A minority of donors (15 %) and recipients (17 %) had a score that was comparable to the knowledge level of the naïve general population. Recipients and donors knew less about DT and LD if their native language was not Dutch. In addition, recipients knew less about DT if they were undergoing pre-emptive transplantation.

CONCLUSIONS: We conclude that recipients and donors retain different information. The decision to undergo living donation appears to be not always based on full knowledge of the risks. We recommend that professionals assess knowledge of prospective donors and recipients during the education process using the R3K-T, and extra attention is required for non-native speakers.

Tonelli M, Klarenbach S, Rose C, et al. **Access to kidney transplantation among remote- and rural-dwelling patients with kidney failure in the United States.** *JAMA* 2009 301(16):1681-90.

Abstract: CONTEXT: US residents with end-stage renal disease (ESRD) may live far away from the closest transplant center, which could compromise their access to kidney transplantation.

OBJECTIVE: To assess access to kidney transplantation as a function of distance from the closest transplant center or as a function of rural rather than urban residence.

DESIGN, SETTING, AND PARTICIPANTS: Observational study of 699,751 adult patients with kidney failure who had initiated renal replacement in the United States between 1995 and 2007 and were thus placed on a prospective mandatory registry list.

MAIN OUTCOME MEASURES: Time to placement on the kidney transplant waiting list and time to kidney transplantation, both measured at the start of renal replacement.

RESULTS: During a median follow-up of 2.0 years (range, 0.0-12.5 years), 122,785 (17.5%) patients received a kidney transplant. Median distance to the closest transplant center was 15 miles. Participants were classified into distance categories by miles from a transplant center with 0 to 15 miles serving as the referent category. Compared with the referent category, the adjusted hazard ratios of deceased or living donor transplantation within each category follows: 16 to 50 miles, 1.03 (95% CI, 1.02-1.05); 51 to 100 miles, 1.11 (95% CI, 1.09-1.12); 101 to 136 miles, 1.14 (95% CI, 1.11-1.17); 137 to 231 miles, 1.16 (95% CI, 1.13-1.20); 232 to 310 miles, 1.20 (95% CI, 1.12-1.28); and more than 310 miles, 1.16 (95% CI, 1.09-1.23). When residence location was classified using rural-urban commuter areas, 79.6% of patients lived in urban; 10.3%, micropolitan; and 10.0%, rural areas. Compared with those living in metropolitan areas, the adjusted hazard ratios of deceased or living donor transplantation among patients residing in micropolitan communities was 1.13 (95% CI, 1.11-1.15) and 1.15 (95% CI, 1.13-1.18) for rural areas. Results were similar for both deceased donor and living donor transplantation and were consistent in multiple sensitivity analyses.

CONCLUSION: Remote or rural residence was not associated with increased time to kidney transplantation among people treated for ESRD in the United States.

Unruh M, Dew MA. **Asking dialysis patients about what they were told: a new strategy for improving access to kidney transplantation?** *J Am Soc Nephrol* 2014 25(12):2683-5.

Abstract: Comment on “Patient- and provider-reported information about transplantation and subsequent waitlisting.”

Waterman AD, Peipert JD, Hyland SS, et al. **Modifiable patient characteristics and racial disparities in evaluation completion and living donor transplant.** *Clinical journal of the American Society of Nephrology : CJASN* 2013 8(6):995-1002.

Notes: Is there an issue with reverse causation?

Abstract: BACKGROUND AND OBJECTIVES: To reduce racial disparities in transplant, modifiable patient characteristics associated with completion of transplant evaluation and receipt of living donor kidney transplant must be identified.

DESIGN, SETTING, PARTICIPANTS, & MEASUREMENTS: From 2004 to 2007, 695 black and white patients were surveyed about 15 less-modifiable and 10 more-modifiable characteristics at evaluation onset; whether they had completed evaluation within 1 year and received living donor kidney transplants by 2010 was determined. Logistic regression and competing risks time-to-event analysis were conducted to determine the variables that predicted evaluation completion and living donor kidney transplant receipt.

RESULTS: Not adjusting for covariates, blacks were less likely than whites to complete evaluation (26.2% versus 51.8%, $P < 0.001$) and receive living donor kidney transplants (8.7% versus 21.9%, $P < 0.001$). More-modifiable variables associated with completing evaluation included more willing to be on the waiting list (odds ratio=3.4, 95% confidence interval=2.1, 5.7), more willing to pursue living donor kidney transplant (odds ratio=2.7, 95% confidence interval=1.8, 4.0), having access to more transplant education resources (odds ratio=2.2, 95% confidence interval=1.5, 3.2), and having greater transplant knowledge (odds ratio=1.8, 95% confidence interval=1.2, 2.7). Patients who started evaluation more willing to pursue living donor kidney transplant (hazard ratio=4.3, 95% confidence interval=2.7, 6.8) and having greater transplant knowledge (hazard ratio=1.2, 95% confidence interval=1.1, 1.3) were more likely to receive living donor kidney transplants.

CONCLUSIONS: Because patients who began transplant evaluation with greater transplant knowledge and motivation were ultimately more successful at receiving transplants years later, behavioral and educational interventions may be very successful strategies to reduce or overcome racial disparities in transplant.

*Waterman AD, Robbins ML, Paiva AL, et al. **Measuring kidney patient's motivation to pursue living donor kidney transplant: Development of Stage of Change, Decisional Balance and Self-Efficacy Measures** *Journal of Health Psychology* 2015 20(2):210-221.

Abstract: While educational interventions to increase patient motivation to pursue living donor kidney transplant have shown success in increasing living donor kidney transplant rates, there are

no validated, theoretically consistent measures of Stage of Change, a measure of readiness to pursue living donor kidney transplant; Decisional Balance, a weighted assessment of living donor kidney transplant's advantages/disadvantages; and Self-Efficacy, a measure of belief that patients can pursue living donor kidney transplant in difficult circumstances. This study developed and validated measures of these three constructs. In two independent samples of kidney patients (N 1 = 279 and N 2 = 204), results showed good psychometric properties and support for their use in the assessment of living donor kidney transplant interventions.

*Waterman AD, Robbins ML, Paiva AL, Hyland SS. **Kidney Patient's Intention to Receive a Deceased Donor Transplant: Development of Stage of Change, Decisional Balance and Self-efficacy Measures** *Journal of Health Psychology* 2010 15(3):436-45.

Abstract: In order to sustain life, patients whose kidneys fail must receive dialysis or obtain a transplant. This study reports on the development and validation of measures of Stage of Change, Decisional Balance and Self-efficacy based on the Transtheoretical Model (TTM) to assess patients' readiness to receive a deceased donor transplant. We surveyed 293 transplant-eligible kidney patients about their deceased donation readiness. Exploratory and confirmatory analyses for all measures demonstrated factor structures similar to previous application of the TTM to other health behaviors, excellent model fit and good internal and external validity. These brief, reliable instruments with good psychometric properties can guide the development of improved, individually-tailored transplant education for patients.

Weng FL, Brown DR, Peipert JD, et al. **Protocol of a cluster randomized trial of an educational intervention to increase knowledge of living donor kidney transplant among potential transplant candidates.** *BMC nephrology* 2013 14():14:256.

Notes: Protocol description for ELITE cluster-randomized interventional trial of educational intervention during initial transplant evaluation.

Abstract: BACKGROUND: The best treatment option for end-stage renal disease is usually a transplant, preferably a live donor kidney transplant (LDKT). The most effective ways to educate kidney transplant candidates about the risks, benefits, and process of LDKT remain unknown.

METHODS/DESIGN: We report the protocol of the Enhancing Living Donor Kidney Transplant Education (ELITE) Study, a cluster randomized trial of an educational intervention to be implemented during initial transplant evaluation at a large, suburban U.S. transplant center. Five hundred potential transplant candidates are cluster randomized (by date of visit) to receive either: (1) standard-of-care ("usual") transplant education, or (2) intensive education that is based upon the Explore Transplant series of educational materials. Intensive transplant education includes viewing an educational video about LDKT, receiving print education, and meeting with a transplant educator. The primary outcome consists of knowledge of the benefits, risks, and process of LDKT, assessed one week after the transplant evaluation. As a secondary outcome, knowledge and understanding of LDKT are assessed 3 months after the evaluation. Additional secondary outcomes, assessed one week and 3 months after the evaluation, include readiness, self-efficacy, and decisional balance

regarding transplant and LDKT, with differences assessed by race. Although the unit of randomization is the date of the transplant evaluation visit, the unit of analysis will be the individual potential transplant candidate.

DISCUSSION: The ELITE Study will help to determine how education in a transplant center can best be designed to help Black and non-Black patients learn about the option of LDKT.

Weng FL, Joffe MM, Feldman HI, Mange KC. **Rates of completion of the medical evaluation for renal transplantation.** *American journal of kidney diseases : the official journal of the National Kidney Foundation* 2005 46(4):734-45.

Notes: Prospective cohort study (single center, n= 175) of patients beginning kidney transplant evaluation, identifying factors associated with likelihood of completing the evaluation process. 57% of patients completed the evaluation process. Blacks were less likely to complete evaluation. Dialysis vs. predialysis status did not predict likelihood of completing evaluation requirements. Does this small study imply that dialysis facilities (associated with UPenn at least) don't have much impact on the evaluation process?

Abstract: Background: Failure to complete the medical evaluation for renal transplantation may impede access to transplantation and preclude the possibility of preemptive transplantation. We sought to (1) characterize completion rates of the transplantation medical evaluation and (2) determine factors associated with completion of the evaluation. We hypothesized that patients not on dialysis therapy complete the evaluation process more quickly than patients receiving dialysis.

Methods: Between September 2002 and September 2003, a total of 175 patients who were evaluated for renal transplantation at the Hospital of the University of Pennsylvania were enrolled in a prospective cohort study. Patients completed a self-administered questionnaire. The progress of patients' medical evaluations, including completion of requested tests and evaluations, was extracted from the electronic medical record.

Results: During follow-up, 100 patients (57.1%) completed the evaluation, including tests and evaluations requested by the transplant team, whereas 49 patients (28.0%) had tests still pending. The remaining patients died (2.3%), lost interest in transplantation (1.1%), or were immediately (7.4%) or later (4.0%) declared medically ineligible for transplantation. In the multivariable Cox proportional hazards model, black race (adjusted hazard ratio, 0.63; 95% confidence interval, 0.40 to 1.00; P 0.05) was associated with time to completion of the transplantation evaluation, but receiving maintenance dialysis at the time of the initial transplantation evaluation was not (adjusted hazard ratio, 0.92; 95% confidence interval, 0.60 to 1.42; P 0.72).

Conclusion: Completion of the medical evaluation for transplantation is slower in blacks than nonblacks. We were unable to detect a significant difference between dialysis and nondialysis patients in rates of completion of the evaluation. *Am J Kidney Dis* 46:734-745.

Winkelmayer WC, Mehta J, Chandraker A, Owen WF, Avorn J. **Predialysis nephrologist care and access to kidney transplantation in the United States.** *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2007 7(4):872-9.

Notes: observational analysis of n=2253 patients with detailed information about predialysis care from national study of incident dialysis care. Dependent variables were transplant waitlisting and transplantation. Predialysis care associated with increased lik

Abstract: Predialysis nephrologist care is associated with morbidity and mortality in incident dialysis patients, but the relationship with access to kidney transplantation (KT) is unclear. From a national study of incident US dialysis patients, we identified 2253 patients with detailed information about predialysis care, sociodemographic characteristics and comorbidities. We used multivariate Cox proportional hazards models to study associations between predialysis nephrology care and two outcomes: time from first dialysis to the first day on the KT wait-list, and time to first KT. Two-thirds of patients first encountered a nephrologist >3 months prior to dialysis and one-third <or=3 months prior to dialysis (early vs. late nephrologist care; ENC vs. LNC). Overall, 515 patients were added to the KT wait-list and 406 underwent KT during follow-up (2.3 years). In multivariate analyses, ENC was associated with a 41% (95%CI: 15-72%) greater rate of being wait-listed compared to LNC and a 54% (95%CI: 22-96%) greater rate of KT. Similar associations existed with number of predialysis nephrology visits. Earlier and more frequent predialysis nephrologist care were associated with greater access to the KT wait-list as well as a higher rate of KT, indicating that LNC may augment existing inequalities that impair access to KT.

Yabu JM, Anderson MW, Kim D, et al. **Sensitization from transfusion in patients awaiting primary kidney transplant.** *Nephrology, dialysis, transplantation : official publication of the European Dialysis and Transplant Association - European Renal Association* 2013 28(11):2908-18.

Notes: Limited by overall small numbers (n=230), but interesting description of effects of blood transfusion on HLA antibody sensitization. Insofar as anemia management is an accepted dialysis facility role and transfusion requirement may reflect anemia managem

Abstract: BACKGROUND: Sensitization to human leukocyte antigen (HLA) from red blood cell (RBC) transfusion is poorly quantified and is based on outdated, insensitive methods. The objective was to evaluate the effect of transfusion on the breadth, magnitude and specificity of HLA antibody formation using sensitive and specific methods.

METHODS: Transfusion, demographic and clinical data from the US Renal Data System were obtained for patients on dialysis awaiting primary kidney transplant who had ≥ 2 HLA antibody measurements using the Luminex single-antigen bead assay. One cohort included patients with a transfusion (n = 50) between two antibody measurements matched with up to four nontransfused patients (n = 155) by age, sex, race and vintage (time on dialysis). A second crossover cohort (n = 25) included patients with multiple antibody measurements before and after transfusion. We studied

changes in HLA antibody mean fluorescence intensity (MFI) and calculated panel reactive antibody (cPRA).

RESULTS: In the matched cohort, 10 of 50 (20%) transfused versus 6 of 155 (4%) nontransfused patients had a ≥ 10 HLA antibodies increase of >3000 MFI ($P = 0.0006$); 6 of 50 (12%) transfused patients had a ≥ 30 antibodies increase ($P = 0.0007$). In the crossover cohort, the number of HLA antibodies increasing >1000 and >3000 MFI was higher in the transfused versus the control period, $P = 0.03$ and $P = 0.008$, respectively. Using a ≥ 3000 MFI threshold, cPRA significantly increased in both matched ($P = 0.01$) and crossover ($P = 0.002$) transfused patients.

CONCLUSIONS: Among prospective primary kidney transplant recipients, RBC transfusion results in clinically significant increases in HLA antibody strength and breadth, which adversely affect the opportunity for future transplant.

Zhang Y, Thamer M, Kshirsagar O, et al. **Dialysis chains and placement on the waiting list for a cadaveric kidney transplant.** *Transplantation* 2014 98(5):543-51.

Abstract: **BACKGROUND:** The proliferation of multi-unit for-profit dialysis chains in the ESRD industry has raised concerns for patient quality of care including access to renal transplantation therapy (RTT). The effect of dialysis facility chain status on RTT is unknown.

METHODS: Data from the United States Renal Data System were used to identify 4,465 dialysis facilities and 56,714 dialysis patients who started hemodialysis in 2006. Patients were followed from initiation of hemodialysis in 2006 to placement on the renal transplant waiting list or to December 31, 2009. The role of dialysis facility chain status (affiliation, size, and ownership) on placement on the renal transplant waiting list was evaluated by multi-level mixed-effect regression models that account for clustering within facilities.

RESULTS: Patients from for-profit chain facilities, compared to nonprofit chain facilities, were 13% (95% CI 0.77-0.98) less likely to be waitlisted. In contrast, among nonchains, facility ownership did not influence likelihood of being waitlisted. There was also a marginally significant difference in waiting list placement by chain size: large chains compared with mid or small chains were 8% (95% CI 0.84-1.00) less likely to place patients on the waiting list. After adjustment for patient and facility characteristics, dialysis facility chain affiliation (chain-affiliated or not) was not found to be independently associated with the likelihood of placement on the transplant waitlist.

CONCLUSION: Dialysis chain affiliation expands previously observed ownership-related differences in placement on the waiting list. For-profit ownership of dialysis chain facilities appears to be a significant impediment to access to renal transplants.

End Stage Renal Disease (ESRD) Quality Measure Development, Maintenance, and Support

Access to Transplantation Technical Expert Panel Draft Clinical Practice Guidelines

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Environmental Scan Summary

In order to identify existing guidelines and quality measures that may be relevant and applicable to access to transplantation in the ESRD community, UM-KECC performed a preliminary scan of the leading quality measure databases, inventories, and measure development programs.

Key search terms included “kidney transplant”, “kidney replacement”, “renal transplant”, “renal replacement” and “chronic kidney disease”. The terms “referral” and “access” were then added to the aforementioned phrases to capture any additional recommendations.

Resources utilized in January 2015 included the National Quality Forum (NQF), the National Quality Measures Clearinghouse (NQMC) and National Guideline Clearinghouse—via the Agency for Healthcare Research and Quality (AHRQ), the National Institute for Health and Care Excellence (NICE), the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (KDOQI), Kidney Disease Improving Global Outcomes (KDIGO), European Best Practices (EBP), Caring for Australians with Renal Impairment (CARI), and the American Society of Transplantation (AST). Additional guideline recommendations cited in *Clinical Practice Guidelines on Wait-Listing for Kidney Transplantation: Consistent and Equitable?* by Pikli Batabyal et al. were later included from various organizations, including the Canadian Society of Transplantation (CST), the UK Renal Association, the European Association of Urology (EAU), the Transplantation Society of Australia and New Zealand (TSANZ), and the Japanese Society of Nephrology.

The identified guideline recommendations and measures generally fall into three categories relevant to the TEP objectives: 1) those highlighting transplantation as the treatment of choice for most patients requiring renal replacement therapy 2) those emphasizing the importance of discussing renal replacement modality options and potentially referring patients for renal transplant evaluation in a timely manner and 3) those outlining guiding principles for determining candidacy for renal transplantation. From the standpoint of the TEP, the latter may be useful for assessing the potential need for exclusion/inclusion criteria or adjustments in the assessment of access to transplantation, and the first two provide affirmation of the basic importance of developing a measure of access to transplantation.

Clinical Practice Guidelines

KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease

Group: Kidney Disease Improving Global Outcomes (KDIGO)

Target population: Adults and children identified with chronic kidney disease (CKD) who are not on renal replacement therapy (RRT) (i.e., not on dialysis or have not received a kidney transplant)

Link: <http://www.guideline.gov/content.aspx?id=46510&search=kidney+replacement>;
http://www.kdigo.org/clinical_practice_guidelines/pdf/CKD/KDIGO_2012_CKD_GL.pdf

Date: 2012

Strength/Level of Evidence

Grade	Quality of Evidence	Meaning
A	High	The Work Group is confident that the true effect lies close to that of the estimate of the effect.
B	Moderate	The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
C	Low	The true effect may be substantially different from the estimate of the effect.
D	Very Low	The estimate of effect is very uncertain, and often will be far from the truth.

Grade*	Implications		
	Patients	Clinicians	Policy
Level 1: 'The Work Group recommends'	Most people in your situation would want the recommended course of action and only a small proportion would not.	Most patients should receive the recommended course of action.	The recommendation can be evaluated as a candidate for developing a policy or a performance measure.
Level 2: 'The Work Group suggests'	The majority of people in your situation would want the recommended course of action, but many would not.	Different choices will be appropriate for different patients. Each patient needs help to arrive at a management decision consistent with her or his values and preferences.	The recommendation is likely to require debate and involvement of stakeholders before policy can be determined.

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

Referral to Specialists and Models of Care

Referral to Specialist Services

- The Work Group recommends referral to specialist kidney care services for people with CKD in the following circumstances (**1B**):
 - AKI or abrupt sustained fall in GFR
 - GFR <30 ml/min/1.73 m² (GFR categories G4–G5)*
 - A consistent finding of significant albuminuria (ACR ≥300 mg/g [≥30 mg/mmol] or AER ≥300 mg/24 hours, approximately equivalent to PCR ≥500 mg/g [≥50 mg/mmol] or PER ≥500 mg/24 hours)
 - Progression of CKD (see above for definition)

- Urinary red cell casts, red blood cells (RBCs) >20 per high power field sustained and not readily explained
 - CKD and hypertension refractory to treatment with 4 or more antihypertensive agents
 - Persistent abnormalities of serum potassium
 - Recurrent or extensive nephrolithiasis
 - Hereditary kidney disease
- The Work Group recommends timely referral for planning renal replacement therapy (RRT) in people with progressive CKD in whom the risk of kidney failure within 1 year is 10% to 20% or higher†, as determined by validated risk prediction tools. **(1B)**

Care of the Patient with Progressive CKD

- The Work Group suggests that people with progressive CKD should be managed in a multidisciplinary care setting. **(2B)**
- The multidisciplinary team should include or have access to dietary counseling, education and counseling about different RRT modalities, transplant options, vascular access surgery, and ethical, psychological, and social care. **(Not Graded)**

Timing the Initiation of RRT

- Living donor preemptive renal transplantation in adults should be considered when the GFR is <20 ml/min/1.73 m², and there is evidence of progressive and irreversible CKD over the preceding 6–12 months. **(Not Graded)**

Potential Benefits

- Identification of people at earlier time points in the trajectory of chronic kidney disease (CKD), with appropriate management and earlier referral of those who would benefit from specialist kidney services, should lead to both economic and clinical benefits.
- If CKD is detected early, the associated complications and the progression to kidney failure can be delayed or even prevented through appropriate interventions.

KDOQI Clinical Practice Guidelines for Chronic Kidney Disease: Evaluation, Classification, and Stratification

Group: Kidney Disease Outcomes Quality Initiative (KDOQI)

Target population: patients with chronic kidney disease and those at increased risk of chronic kidney disease, except where noted

Link: http://www2.kidney.org/professionals/KDOQI/guidelines_ckd/p1_exec.htm;

Date: 2000

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

Guideline 2: Evaluation and Treatment

The evaluation and treatment of patients with chronic kidney disease requires understanding of separate but related concepts of diagnosis, comorbid conditions, severity of disease, complications of disease, and risks for loss of kidney function and cardiovascular disease.

Patients with chronic kidney disease should be evaluated to determine:

- Diagnosis (type of kidney disease);
- Comorbid conditions;
- Severity, assessed by level of kidney function;
- Complications, related to level of kidney function;
- Risk for loss of kidney function;
- Risk for cardiovascular disease.

Treatment of chronic kidney disease should include:

- Specific therapy, based on diagnosis;
- Evaluation and management of comorbid conditions;
- Slowing the loss of kidney function;
- Prevention and treatment of cardiovascular disease;
- Prevention and treatment of complications of decreased kidney function;
- Preparation for kidney failure and kidney replacement therapy;
- Replacement of kidney function by dialysis and transplantation, if signs and symptoms of uremia are present.

A clinical action plan should be developed for each patient, based on the stage of disease as defined by the KDOQI CKD classification (see table below).

Patients with chronic kidney disease should be referred to a specialist for consultation and co-management if the clinical action plan cannot be prepared, the prescribed evaluation of the patient cannot be carried out, or the recommended treatment cannot be carried out. In general, patients with GFR <30 mL/min/ 1.73 m² should be referred to a nephrologist.

RPA Guideline recommendations and their rationales for the treatment of adult patients

Group: Renal Physicians Association (RPA)

Target population: Adult patients with acute kidney injury, stage 4 or 5 chronic kidney disease, or end-stage renal disease

Link: <http://www.guideline.gov/content.aspx?id=24176>

Date: January 2000 (revised October 2010)

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

Informing Patients

Recommendation No 2: Fully Inform AKI, Stage 4 and 5 CKD, and ESRD Patients about Their Diagnosis, Prognosis, and All Treatment Options

In the setting of critical illness many patients with CKD will require urgent dialysis and the vast majority of patients with AKI will have multiple medical problems, in addition to kidney failure. The concept of shared decision making necessitates a multidisciplinary approach including nephrologists, intensivists, and others as appropriate and decisions about acute renal replacement therapy should be made in the context of other life-sustaining treatments. For example, a decision to withhold dialysis in a patient agreeing to and receiving multiple other forms of life sustaining therapy could represent discordant treatment in the same way that offering dialysis to a patient who has decided to forgo other forms of life-sustaining therapy might be inappropriate. Intensive care physicians need to be included in shared decision making for kidney patients in the intensive care unit (ICU).

For ESRD patients, these options in shared decision-making include: 1) available dialysis modalities and kidney transplantation if applicable; 2) not starting dialysis and continuing medical management; 3) a time limited trial of dialysis, and 4) stopping dialysis and receiving end-of-life care. Choices among options should be made by patients or, if patients lack decision-making capacity, their designated legal agents. Their decisions should be informed and voluntary. The renal care team, in conjunction with the primary care physician, should insure that the patient or legal agent understands the benefits and burdens of dialysis and the consequences of not starting or stopping dialysis. Research studies have identified a population of chronic kidney disease patients for whom the prognosis is particularly poor. This population has been found to include patients with two or more of the following characteristics: 1) elderly (defined by research studies identifying poor outcomes in patients who are age 75 years and older); 2) patients with high comorbidity scores (e.g., modified Charlson Comorbidity Index score of 8 or greater); 3) marked functional impairment (e.g., Karnofsky Performance Status Scale score of less than 40); and 4) severe chronic malnutrition (e.g., serum albumin level less than 2.5 g/dL using the bromocresol green method). Patients in this population should be informed that dialysis may not confer a survival advantage or improve functional status over medical management without dialysis and that dialysis entails significant burdens that may detract from their quality of life.

Recommendation No. 10: Use a Systematic Approach to Communicate about Diagnosis, Prognosis, Treatment Options, and Goals of Care

Good communication improves patients' adjustment to illness, increases adherence to treatment, and results in higher patient and family satisfaction with care. Patients appreciate sensitive delivery of information about their prognosis and the ability to balance reality while maintaining hope. In communicating with patients, the critical task for clinicians is to integrate complicated biomedical facts and conditions with emotional, social, and spiritual realities that are equally complex but not well described in the language of medicine. This information must be communicated in a way that patients, legal agents, and families can understand and use to reach informed decisions about dialysis and transplantation options. Patients' decisions should be based on an accurate understanding of their condition and the pros and cons of treatment options. To facilitate effective communication, reliance upon a multidisciplinary approach including nephrologists, intensivists, and others as appropriate is warranted. Decisions about acute renal replacement therapy in AKI should be made in the context of other life-sustaining treatments. Intensive care physicians should be included in shared decision-making for kidney patients in the ICU to facilitate discussions on global disease or injury prognosis. Fellowship programs should incorporate training to help nephrologists develop effective, empathetic communication skills, which are essential in caring for this patient population.

RPA Guideline recommendations and their rationales for the treatment of neonates, infants, children, and adolescents

Group: Renal Physicians Association (RPA)

Target population: Infant, neonatal, children, and adolescent patients with acute kidney injury (AKI), chronic kidney disease (CKD), and end-stage renal disease (ESRD)

Link:

<http://www.guideline.gov/content.aspx?id=24177&search=chronic+kidney+disease+and+kidney+and+transplant>

Date: October 2010

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

Informing Patients and Parents

Recommendation No. 2: Fully Inform Patients with AKI, Stage 4 or Stage 5 CKD, or ESRD and Their Parents about the Diagnosis, Prognosis, and All Appropriate Treatment Options. Inform Children and Adolescents in a Developmentally Appropriate Manner, and if Feasible, Seek Their Assent about Treatment Decisions

Treatment options include: 1) initiating or continuing dialysis; 2) transplantation for ESRD; 3) not starting dialysis and continuing optimal medical management; and 4) stopping dialysis and continuing to receive palliative treatment. The nephrologist and the medical team should make every effort to inform parents about the potential benefits and burdens of dialysis initiation or dialysis withdrawal before providing or

withdrawing treatment. In the rare circumstances when this is not possible, parents should be informed as soon as possible about the rationale for emergent initiation and the efforts that were made to contact the parents before changing the medical plan.

As a component of informed permission/informed assent, and in keeping with the on-going process of both shared decision making and advance care planning, the treating nephrologist may determine that dialysis is no longer providing net benefit (i.e., the risks or burdens outweigh the benefits, the underlying condition is progressive and dialysis is only prolonging the dying process without improving the quality of life during the dying process). In this case, the nephrologist and the medical team should approach the family and discuss the undue burden of dialysis given the patient's medical condition and recommend stopping dialysis and intensifying palliative treatment. This will typically occur in the intensive care setting and intensivists should coordinate the shared decision-making in the context of other aspects of supportive care. Children and adolescents should be given the opportunity to communicate their feelings and perceptions regarding the benefits and burdens of dialysis to the extent they desire to do so and their developmental abilities and health status permits. When seeking informed permission/informed assent for discontinuing dialysis, the medical team should explicitly describe comfort measures and other components of palliative treatment that will be offered.

Facilitating Advance Care Planning

Recommendation No. 5: Institute Family-centered Advance Care Planning for Children and Adolescents with AKI, CKD, and ESRD. The Plan Should Establish Treatment Goals Based on a Child's Medical Condition and Prognosis

Family-centered advance care planning is recommended for infants with poorly functioning or nonfunctioning kidneys due to genetic conditions and those with a non-reversible urological or kidney abnormality. In the event that the health care team has information that the viability of a fetus with suspected multisystem organ involvement is questionable, family-centered advance care planning should occur before the birth of the baby. This will allow the health care team to be able to act decisively in light of the neonate's health status and prognosis at the time of delivery.

Advance care planning should be an ongoing process in which treatment goals are determined and revised based on observed benefits and burdens of dialysis and the values of the pediatric patient and the family. The renal care team should designate a person to be primarily responsible for ensuring that advance care planning is offered to each patient. Patients with decision-making capacity should be *strongly* encouraged to talk to their parents to ensure that they know the patient's wishes and agree to make decisions according to these wishes. Ongoing discussions that include reestablishing goals of care based on the child's response to medical treatment and optimal quality of life is the mechanism by which advance care planning occurs. Discussions should include the pros and cons of dialysis as well as potential morbidity associated with dialysis. Kidney transplantation should also be discussed if appropriate.

Children and adolescents should be allowed to participate in advance care planning commensurate with their preference and developmental status. Parent or pediatric patient questions regarding discontinuation of dialysis if the patient's medical condition becomes irreversible and non-responsive to currently available treatments should be addressed frankly. Such questions can be used as a springboard for obtaining information about parent and child wishes regarding end-of-life care. Assurance should be

given that the pediatric patient's comfort is paramount in the event that dialysis is discontinued. In addition, such questions should be used as an opportunity to explicitly describe comfort measures and other components of palliative care.

RPA Clinical Practice Guideline 3: Appropriate Patient Preparation for Renal Replacement Therapy

Group: Renal Physicians Association (RPA)

Target population:

Link: www.renalmd.org/WorkArea/DownloadAsset.aspx?id=974

Date: October 2002

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

Timing Guidelines:

Early Counseling about Modality of RRT

- If a patient has GFR 30 ml/min per 1.73 m², modality of RRT should be discussed with him/her. (Grade B).

GFR as a Guide to RRT Timing

- No recommendation can be made for initiating RRT based solely on a specific level of GFR. (Grade B).

Early Referral for Transplant Evaluation

- If a patient has GFR 30 ml/min per 1.73 m² and is willing to have a renal transplant, then s/he should receive a transplant evaluation (Grade B), unless s/he has an unacceptable level of surgical risk or does not satisfy the United Network for Organ Sharing (UNOS) Ethics Committee criteria for transplant candidacy.

AST Clinical Practice Guidelines for the Evaluation of Renal Transplant Candidates

Group: American Society of Transplantation (AST) (Kasiske BL, Cangro CB, et al.)

Target population: Adult or pediatric CKD or ESRD patients

Link: <http://onlinelibrary.wiley.com/doi/10.1034/j.1600-6143.2001.0010s2001.x/pdf>

Date: 2001

Strength/Level of Evidence

Accordingly, recommendations are graded A, B, C,D, or E when:

- A. There is good evidence to support the recommendation that the condition be considered in the evaluation process.
- B. There is fair evidence to support the recommendation that the condition be considered in the evaluation process.
- C. There is poor evidence regarding the inclusion of the condition in the evaluation process, but recommendations may be made on other grounds.
- D. There is fair evidence to support the recommendation that the condition be excluded from consideration in the evaluation process.
- E. There is good evidence to support the recommendation that the condition be excluded from consideration in the evaluation process.

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

The timing of renal transplantation

Rationale:

Ideally, renal transplantation should be delayed long enough to maximize the use of the patient's own kidneys. On the other hand, preemptive transplantation can sometimes allow patients, especially children, to avoid the morbidity and expense of acquiring a dialysis access and initiating dialysis treatments. Preemptive transplantation requires advanced planning and careful attention to the rate of renal disease progression. Early referral to a transplant center is mandatory.

Recommendations:

(C) Candidates should be referred to a transplant center as soon as it appears probable that renal replacement therapy will be needed within the next 6–12 months.

(C) Some candidates who are not yet on dialysis should be considered for preemptive transplantation.

(C) The medical status of patients on the cadaveric transplantation waiting list should be reviewed at least every 2 years. Patients who are diabetic, older than 65, or have a medical condition that could change relatively quickly should be reviewed at least annually.

(C) Candidates should be informed that placement on the cadaveric waiting list does not guarantee transplantation, since changes in their medical status may delay or preclude transplantation.

Donor Source:

Rationale:

Outcomes after renal transplantation are strongly influenced by the choice of the donor. Excellent data are available to advise renal transplant candidates concerning the relative likelihood of successful transplantation from living related, living unrelated (emotionally related) and cadaveric donors.

Recommendations:

(C) Renal transplant candidates should be informed of the risks and benefits (to the donor and/or recipient) and of the risks of using a particular donor, and should be allowed to refuse that donor based on medical grounds.

Cancer:

Most patients treated for cancer benefit from a waiting period prior to renal transplantation. For most patients previously treated for cancer, it appears prudent to recommend a minimum waiting period of 2 years. In the case of some cancers at increased risk for recurrence, a longer waiting interval, e.g. 5 years, should be considered. Some patients with cancers incidentally discovered at the time of evaluation may not require a waiting period prior to renal transplantation.

Rationale:

It is generally accepted that immunosuppression increases the morbidity and mortality of cancer. Effective screening and treatment of cancer prior to transplantation could reduce the risk of posttransplant malignancy. It is prudent to allow sufficient time between the treatment of malignancy and transplantation to exclude patients who will otherwise develop recurrence.

Recommendations:

(A) Patients should be screened for cancer at the time of evaluation and while on the waiting list, following recommendations for the general population.

(B) An appropriate disease-free interval before transplantation should be used to reduce the risk of recurrence (see tables that follow for specific types of cancer).

Infection: Whenever possible, all treatable infections should be eradicated prior to transplantation.

Human immunodeficiency virus (HIV):**Rationale:**

There are reasons to believe that outcomes may be either better or worse with renal transplantation and immunosuppression in patients who are HIV antibody positive.

Recommendations:

(A) All renal transplant candidates should be tested for HIVS.

(C) There are insufficient data on which to base a recommendation for or against renal transplantation in patients

Other infection recommendations include:

- Tuberculosis (TB)
- Cytomegalovirus (CMV)
- Dental infections and gingival hyperplasia

- Influenza A and B
- Pneumococcal (*Streptococcus pneumoniae*) infections
- Childhood infections/immunizations
- Possible screening

Other topics covered include:

- Recurrent Disease
- Gastrointestinal
- Pulmonary
- Cardiovascular disease
- Psychosocial
- Genitourinary
- Endocrine
- Coagulopathies
- Age
- Medications
- Histocompatibility

Steinman-Clinical Practice Committee (AST) Guidelines for the Referral and Management of Patients Eligible for Solid Organ Transplantation

Group: American Society of Transplantation (AST) (Steinman TI, Becker BN, Frost AE, et al.)

Target population:

Link: <http://dl2af5jf3e.search.serialssolutions.com/?sid=Entrez:PubMed&id=pmid:11397947>

Date: 2001

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

Guideline 1: patient access to referral and consultation at a transplant center.

A. Primary care and/or referring physicians should consider it appropriate to include transplant center referral in their care of patients with organ insufficiency who are ultimately amenable to transplantation.

1. Advantages

a. Kidney transplant candidates may potentially benefit from the possibility of preemptive transplantation.

Guideline 2: indications for referral to or the involvement of a transplant specialist in the care of a patient with organ insufficiency.

A. The patient is a potential organ transplant recipient.

B. Progression towards organ failure has been established.

C. The patient has stated that he or she is willing and interested in transplantation as a possible medical treatment for his or her condition.

D. Discussion about the possibility of living donation can be initiated. Evaluation of the living donor can be processed once the recipient is eligible for transplantation.

Guideline 3. While patients are on the waiting list for transplantation, their primary physician dealing with the organ dysfunction should be advised about necessary follow-up referral at appropriate intervals to the transplant center. Re-evaluation of the patient and advice to the referring physician as to tests required to maintain the patient on the active waiting list are important.

Guideline 4: information management. Primary care providers and the transplant center need to communicate regularly about any changes in the condition of the patient that affect eligibility for transplantation and also maximize quality care for the patient with a complex problem frequently encumbered by co-morbid conditions.

Evaluation of Adult Kidney Transplant Candidates

Group: Suphamai Bunnapradist, MD, and Gabriel M. Danovitch, MD

Target population: Adults with CKD

Link: <http://www.ajkd.org/article/S0272-6386%2807%2901147-X/pdf>

Date: 2007

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

Kidney transplantation is the treatment of choice for suitable patients with end-stage kidney disease and must be discussed with patients with advanced chronic kidney disease (CKD) preparing for renal

replacement therapy. Referral to a transplant program should be performed early to assess candidacy for a preemptive transplantation. One of the main goals of the visit to the transplant center is to educate patients about living and deceased donor transplant options. Potential transplant candidates and their family members should be encouraged to attend formal educational sessions and obtain further information through available literature, including center specific outcomes. Potential transplant recipients also should be familiar with deceased donor organ allocation policy (Table 1).

Evaluation of kidney transplant candidates includes an initial assessment for transplantation suitability. This includes medical, surgical, immunologic, and psychosocial evaluations. The patient's individual risks and benefits of transplantation are discussed so that he or she can make an informed decision about whether to proceed with transplantation. After candidates are placed on the deceased donor list, a periodic reevaluation is necessary to address new issues that may impact on transplant suitability.

WHEN TO REFER

- I. Kidney transplantation should be discussed with all patients with irreversible advanced CKD
- II. Patients with CKD without known contraindications for transplantation should be referred to a transplant program when they approach CKD stage 4 or a glomerular filtration rate (GFR) less than 30 mL/min/1.73 m² (≤ 0.5 mL/s/1.73 m²)
- III. Early referral will improve the chances of a patient receiving a preemptive transplant, especially those with a potential living donor; referral to a kidney transplant program does not imply immediate transplantation

TRANSPLANTATION WORKUP

Table 2. Contraindications for Kidney Transplantation

Severe uncorrectable systemic conditions with short expected life expectancy

Reversible renal failure

Recent or untreatable malignancy

Uncontrolled psychiatric disorders and active substance abuse

Ongoing noncompliance

Chronic or ongoing active infection

Primary oxalosis (evaluate for combined liver-kidney transplantation)

Limited irreversible rehabilitative potential

OPTN Educational Guidance on Patient Referral to Kidney Transplantation

Group: Organ Procurement and Transplant Network (OPTN) Minority Affairs Committee

Target population: All patients with advanced CKD

Link: http://optn.transplant.hrsa.gov/ContentDocuments/Guidance_Kidney_Transplant_Referral.pdf

Date: 2014

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

Purpose

This educational guidance is intended to raise awareness among referring physicians about current trends in the field of kidney transplantation and provide education on identifying patients who are appropriate to be referred for transplant evaluation. The goal of this document is to promote early referral to transplant, explain the barriers to timely referral, and describe the steps patients and providers can take to improve referral patterns.

Kidney Function

All patients with advanced CKD should be considered for transplant evaluation. The medical literature clearly demonstrates that kidney transplant is a superior form of kidney replacement therapy compared to dialysis. As such, referral to transplant should be the default care plan for CKD patients. There are no strict criteria for referral, but most patients with stage 4-5 CKD are appropriate for referral. In select cases, referral at higher levels of kidney function may be appropriate, particularly for patients requiring partial or total nephrectomy or those with rapidly progressive CKD. Early referral provides time for identification and evaluation of potential living kidney donors as well as improved patient education regarding transplant options.

Glomerular Filtration Rate (GFR)

Glomerular filtration rate (GFR) is the measure of kidney function and ranges from 0 to 140 mL/minute with measures ≥ 90 mL/minute considered normal. As GFR may vary from person to person, physician judgment is necessary to appropriately determine the rate of ESRD progression. Since individual patient management will also vary by physician, the GFR measurement should be kept broad with conversations between patients about their CKD status encouraged to be continuous. For example, in patients with a GFR of 30-59 mL/minute (Stage 3 CKD), the referring physician could begin to initiate a conversation about transplantation and prepare the patient for referral if the GFR approaches 30 mL/minute. Referral to transplant evaluation would preferably occur for patients with a GFR of less than 30 mL/minute. Patients progressing toward ESRD at a slower rate may appropriately be referred at a GFR of approximately 25-29 mL/minute but may need to occur at a GFR of 30 mL/minute or above if a patient is rapidly progressing toward ESRD. Physicians are encouraged to refer all medically appropriate patients to transplant once a GFR of less than 30 mL/minute is reached in order to provide sufficient time to consider and become educated about transplantation, complete a transplant evaluation, and possibly locate a potential living donor.

The goal for referral should be that all potential candidates are referred for transplant at a GFR above 20 to avoid the development of comorbidities associated with dialysis and to allow the patient the maximum waiting time available.

Table 1: Five Stages of Chronic Kidney Disease: GFR Ranges for Referral to Transplant Evaluation

CKD Stage	CKD Description	GFR	Action
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1	Kidney Damage with Normal GFR	≤90	Diagnose and Treat Kidney Disease ☐ Slow Progression of Kidney Disease ☐ CVD Risk Reduction
2	Kidney Damage with Mild GFR	60-89	Estimate Progression of Kidney Disease
3	Moderate GFR	30-59	Evaluate and Treat Complications ☐ Initiate discussion about transplantation with all medically appropriate patients, including living donation (GFR 30-35)
4	Severe GFR	15-29	Initiate discussion about transplantation with all medically appropriate patients, including living donation ☐ Recommend transplant education ☐ Refer patients for transplant evaluation.
5	Kidney Failure	<15 or patient on dialysis	Initiate renal replacement therapy ☐ Refer patient for transplant evaluation.

Interest in Transplant

Conventional wisdom has been that patients should express some level of interest in transplantation prior to referral. However, prior to transplant evaluation, many patients have no basis on which to have an opinion about transplant. Expecting interest prior to information may not be a fair basis to decide on referral for evaluation, considering that for every other standard of care therapy patient interest is not a requisite criterion. For example, a patient referred for a heart catheterization is not expected to have knowledge of catheterization risk and benefits and alternatives. Rather, it is expected that the patient will be educated once he sees the cardiologist. Similarly, in transplant, interest necessarily follows information about the survival and quality of life benefits of transplant compared to dialysis. Interest in transplantation should be appropriately gauged after transplant education has been provided and should not be part of the decision to refer for kidney transplant evaluation.

Comorbid Conditions

Kidney transplant candidates often have comorbid conditions in addition to ESRD. Advances in pre- and post-transplant care have made transplantation an option for patients with significant comorbid conditions including coronary artery disease, peripheral vascular disease, chronic obstructive pulmonary disease, and chronic liver disease. Assessment of the impact of concomitant illness on perioperative and post-transplant morbidity and mortality is often the primary focus of the transplant evaluation, and the process often requires input from consulting services. Exclusion criteria based upon medical conditions vary significantly between programs. These criteria are often quite broad and listing decisions are often based on close review of each specific patient's conditions. While such patients with severe comorbid illness may not qualify for a kidney transplant alone, they may be candidates for combined transplants such as heart-kidney or liver-kidney. Ideally, most patients should be allowed the opportunity to be evaluated for a transplant. The existence of comorbid conditions should not preclude referral for transplant evaluation.

Age

There is no consensus on an exclusion criterion based solely on age. In fact, nearly 20% of all transplant recipients in the U.S. are 65 years old or older. Data show a survival benefit for transplantation even for recipients of advanced age. Transplant outcomes with carefully selected octogenarians have been excellent. Most transplant centers evaluate older candidates and base listing decisions on medical criteria rather than age. Again, patients should be referred to their local transplant center for a full evaluation and determination of their medical qualification for kidney transplant.

Transplant Evaluation

During a typical transplant evaluation, the patient will meet with a transplant nephrologist, transplant surgeon, transplant coordinator, social worker, psychologist and potentially also a financial coordinator, pharmacist, and dietician. Testing typically includes cardiac testing (EKG, Echo, stress test, and may include cardiac catheterization, if deemed necessary), chest X-rays, blood tests, routine health screenings (PAP/mammogram for women; colonoscopy for patients over age 50), and a dental examination. Additional testing may be needed based on the patient's medical history.

Timely referral of patients for transplant evaluation allows the patient an opportunity to learn more about the processes of transplantation including the evaluation, waitlisting, and post-transplant protocols. The patients may be overwhelmed at first with the volume of information presented, which is why it is essential for patients to be seen early to be able to receive the necessary information and understand their options.

Most transplant centers provide patients with easy-to-read brochures explaining the process of evaluation and waitlisting. This allows the patient the opportunity to learn about the kidney transplant surgery and to find out what to expect after transplant at a more leisurely pace. Transplant centers are also making a concerted effort to ensure that the referring providers are kept abreast of their patient's progress through the evaluation process.

Barriers to Transplantation

Although transplantation is considered to be the optimal therapy for ESRD, many factors pose as barriers to transplantation for patients who could receive benefit.²³ The most significant barriers identified in the literature are identified and discussed below:

1. Timing of referral
2. Medical insurance
3. Financial issues and transportation
4. Availability of living kidney donors
5. Patient education and understanding of ESRD/transplantation
6. Provider understanding of the waitlisting and transplantation process
7. Other barriers

Timing of Referral

The ideal approach to the problem of CKD and ESRD is prevention through education and lifestyle changes. However, patients with progressive CKD should be proactively directed towards kidney transplantation. Multiple studies have shown that, compared to dialysis, kidney transplantation offers superior quality of life and improvement in patient survival.^{2,3} In this light, the default pathway for

patients with advanced CKD should be transplantation. However, in current practice, physicians see that transplant options are not presented to patients in a timely manner.

Transplant Education

Clinicians are encouraged to work with local transplant centers to advocate for providing transplant education to patients. There is currently a precedent for provision of transplant education which may be reimbursed through the federal government. Providers are incentivized to provide transplant education to patients with chronic kidney disease, which is billed separately through specific coding/billing mechanisms.

The education can be provided by physicians and non-physician providers (nurse practitioners, clinical nurse specialists, and physician assistants) and hospital-based dialysis providers in rural areas only. Outpatient dialysis facilities may not provide this service.

Perhaps the most significant barrier to preemptive kidney transplantation is timely referral for transplant evaluation. Currently, the majority of patients referred for kidney transplant evaluations are already on dialysis. Part of the consequence of these late referrals is that only 14.4% of adult kidney transplants performed in 2011 were preemptive.²⁵ Late referral is not a sensible approach to maximize patient outcomes when one has a good understanding of the kidney transplant allocation system. Currently, an evaluated and medically and psychosocially approved patient can be placed on the waiting list and accrue waiting time at the time the estimated glomerular filtration rate (eGFR) or equivalent measure is less than or equal to 20 mL/minute.²⁶ As such, providers should strive to have a patient evaluated and approved so that as soon as the eGFR is 20 mL/minute the patient can be activated on the waiting list. The importance of early referral is two-fold. Given that patients typically initiate dialysis at a GFR of 10-15 mL/minute, early referral allows the patient to accumulate some and ideally all of their waiting time prior to initiation of dialysis.²⁶ Second, early referral allows the patient more time to look for potential living donor candidates, enhancing the chances that they will obtain a preemptive live donor transplant. Providers should also consider that many patients presenting for kidney transplant evaluation have multiple medical comorbidities and, as a result, may require multiple tests and procedures prior to being deemed medically acceptable for transplantation. This work-up can take months to complete, so early referral allows the patient to accrue the maximum amount of waiting time possible.

Canadian Society of Transplantation consensus guidelines on eligibility for kidney transplantation

Group: Canadian Society of Transplantation (CST)

Target population: Canadian patients with ESRD

Link: <http://www.cmaj.ca/content/173/10/S1.full.pdf>

Date: 2005

Strength/Level of Evidence

Grade A — There is good evidence to support

Grade B — There is fair evidence to support

Grade C — The existing evidence is conflicting, but other factors may influence decision-making

Grade D — There is fair evidence to recommend against

Grade E — There is good evidence to recommend against

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

1. All patients with end-stage renal disease should be considered for kidney transplantation provided no absolute contraindications exist (Grade A).
2. Eligibility for kidney transplantation should be determined on medical and surgical grounds. Criteria for eligibility should be transparent and made available to patients and the public. Eligibility should not be based on social status, gender, race or personal or public appeal (Grade C).
3. A patient declined for transplantation should routinely be offered a second opinion from an alternative physician or surgeon or a committee able to assess the relative risks and benefits of kidney transplantation (Grade C).

Timing of referral

1. Potential transplant recipients should be referred for evaluation by a transplant program once renal replacement therapy is expected to be required within the next 12 months (Grade C).
2. Patients already requiring dialysis support should be referred for transplant evaluation as soon as their medical condition stabilizes (Grade C).

Renal function

1. Preemptive kidney transplantation is the preferred form of renal replacement therapy and should be encouraged where feasible (Grade A).
2. Preemptive kidney transplantation should not proceed unless the measured or calculated glomerular filtration rate is < 20 mL/minute and there is evidence of progressive and irreversible deterioration in renal function over the previous 6–12 months. Exceptions may be made for patients receiving combined organ transplants where a kidney transplant is combined with a non-renal organ. However, the appropriate policy on this issue is not clear at this time (Grade C).

Other evaluation considerations discussed in the guidelines for transplantation include:

- Age and functional capacity
- Obesity
- Cause of end-stage renal disease
- Systemic diseases
- Infections
- Malignancy

- Pulmonary disease
- Cardiac disease
- Cerebral vascular disease
- Peripheral vascular disease
- Gastrointestinal disease
- Liver disease
- Genitourinary disease
- Hematologic disorders
- Hyperparathyroidism
- Psychosocial considerations

Early identification and management of chronic kidney disease in adults in primary and secondary care

Group: National Clinical Guideline Centre/ National Institute for Health and Clinical Excellence (NICE)

Target population: Adults aged 18 and over who have or are at risk of developing chronic kidney disease (CKD), with specific consideration given to the needs of subgroups:

- Older people (75 years and older)
- Black and minority ethnic people where these differ from the needs of the general population
- People at high risk of developing CKD (for example, people with: diabetes, hypertension, cardiovascular disease, or people recovering from acute kidney injury)

Link: <http://www.guideline.gov/content.aspx?id=48405&search=kidney+transplantation+guidelines>

Date: 2008 Sep (revised 2014 Jul)

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

Information and Education

Offer people with CKD education and information tailored to the severity and cause of CKD, the associated complications and the risk of progression. **[2008]**

When developing information or education programmes, involve people with CKD in their development from the outset. The following topics are suggested.

- What is CKD and how does it affect people?
- What questions should people ask about their kidneys?
- What treatments are available for CKD, what are their advantages and disadvantages and what complications or side effects may occur as a result of treatment/medication?
- What can people do to manage and influence their own condition?
- In what ways could CKD and its treatment affect people's daily life, social activities, work opportunities and financial situation, including benefits and allowances available?
- How can people cope with and adjust to CKD and what sources of psychological support are available?

- When appropriate, offer information about renal replacement therapy (such as the frequency and length of time of dialysis treatment sessions or exchanges and preemptive transplantation) and the preparation required (such as having a fistula or peritoneal catheter).
- Conservative management and when it may be considered. **[2008]**

Offer people with CKD high-quality information or education programmes as appropriate to the severity of their condition to allow time for them to fully understand and make informed choices about their treatment. **[2008]**

Healthcare professionals providing information and education programmes should ensure they have specialist knowledge about CKD and the necessary skills to facilitate learning. **[2008]**

Healthcare professionals working with people with CKD should take account of the psychological aspects of coping with the condition and offer access to appropriate support – for example, support groups, counselling or a specialist nurse. **[2008]**

Referral Criteria

Take into account the individual's wishes and comorbidities when considering referral. **[2008]**

People with CKD in the following groups should normally be referred for specialist assessment:

- GFR less than 30 ml/min/1.73 m² (GFR category G4 or G5), with or without diabetes
- ACR 70 mg/mmol or more, unless known to be caused by diabetes and already appropriately treated
- ACR 30 mg/mmol or more (ACR category A3), together with haematuria
- Sustained decrease in GFR of 25% or more, and a change in GFR category or sustained decrease in GFR of 15 ml/min/1.73 m² or more within 12 months
- Hypertension that remains poorly controlled despite the use of at least 4 antihypertensive drugs at therapeutic doses (see also the NGC summary of the NICE guideline [Hypertension. Clinical management of primary hypertension in adults](#) [NICE clinical guideline 127])
- Known or suspected rare or genetic causes of CKD
- Suspected renal artery stenosis. **[2008, amended 2014]**

UK Renal Association Clinical Practice Guidelines for the Assessment of the Potential Kidney Transplant Recipient

Group: UK Renal Association

Target population: Patient with chronic kidney disease stage 5

Link: <http://www.european-renal-best-practice.org/content/guidelines-topic-transplantation>;
<http://www.renal.org/guidelines/modules/assessment-of-the-potential-kidney-transplant-recipient#sthash.U06sP0rP.dpbs>

Date: 2010 (final version 2011)

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

Guideline 1. Access to renal transplantation (Tx) (Guidelines Tx 1.1 – 1.9)

Guideline 1.1

We recommend that kidney transplantation should be the renal replacement therapy of choice for the patient with chronic kidney disease stage 5 who is considered fit for major surgery and for chronic immunosuppression. All patients predicted to have an increased life expectancy post-transplantation should be assessed for transplantation. Placement on the transplant waiting list will be limited by individual co-morbidity and prognosis.

Guideline 1.2

We recommend that living donor transplantation should be considered the treatment of choice for all patients suitable for renal transplantation when there is an appropriate donor.

Guideline 1.3

We recommend that patients with progressive deterioration in renal function suitable for transplantation should be placed on the national transplant list within six months of their anticipated dialysis start date. Pre-emptive transplantation should be the treatment of choice for all suitable patients whenever a living donor is available.

Guideline 1.4

We recommend that there must be demonstrable equity of access to deceased donor kidney transplantation irrespective of gender, ethnicity or district of residence.

Guideline 1.5

We recommend that age is not a contra-indication to transplantation but age related co-morbidity is an important limiting factor.

Guideline 1.6

We recommend that all transplant units should have written criteria for acceptance on to the waiting list. The benefits and potential risks associated with transplantation should be fully explained both verbally and in writing. Potential transplant recipients should be informed of all donor options including living related and unrelated donation and the NHSBT/BTS guidelines for consent for solid organ donation should be followed.

Guideline 1.7

We recommend that all CKD 5 patients and CKD 4 patients with progressive disease should have their suitability for transplantation assessed annually and that appropriate patients should be referred to a transplant centre. When transplantation is considered inappropriate the reason(s) should be documented. All patients on the transplant list should be assessed annually to determine whether transplantation remains appropriate. Patients should be placed on, or removed from the waiting list only after discussion and agreement with the nephrologist, transplant surgeon and the patients themselves according to local practice.

Guideline 1.8

We recommend that the care of the renal transplant recipient is best undertaken by a multi-disciplinary team.

Guideline 1.9

We recommend that simultaneous kidney-pancreas transplantation or living donor renal transplantation is the treatment of choice for patients with Type 1 diabetes mellitus who are suitable for renal transplantation.

**Guideline 2. Evaluation, selection and preparation of the potential transplant recipient (Tx)
(Guidelines Tx 2.1 – 2.9)****Guideline 2.1 – Tx : Pre-transplant assessment**

We recommend that the object of pre-transplant assessment is: a) to ensure transplantation is technically possible; b) to ensure the recipient's chances of survival are not compromised by transplantation; c) to ensure that graft survival is not limited by premature death (maximum benefit obtained from a limited resource); d) to ensure pre-existing conditions are not exacerbated by transplantation; e) to identify measures to be taken to minimise peri- and post-operative complications; f) to inform patients of the likely risks and benefits of transplantation.

Guideline 2.2 – Tx : Pre-transplant cardiac assessment

We suggest that there is no compelling evidence that pre-transplantation screening tests for coronary artery disease in asymptomatic patients with established renal failure is effective in preventing future cardiac events or reducing mortality after transplantation.

Until better evidence emerges, screening tests may be best used to identify high-risk patients for exclusion from the transplant waiting list.

Guideline 2.3 – Tx : Preparation of the renal transplant recipient

We suggest that the use of pre-operative beta-blockers may be considered in patients at high cardiovascular risk undergoing renal transplantation but should be introduced at least 1 month before transplantation. Beta-blockers should not be discontinued abruptly peri-operatively. Low dose aspirin and clopidogrel therapy are not contraindications to transplantation.

Guideline 2.4 – Tx : Preparation of the renal transplant recipient

We recommend that patients should be strongly encouraged to stop smoking before and after transplantation. Formal smoking cessation programs should be offered and accessed in primary care.

Guideline 2.5 – Tx : Preparation of the renal transplant recipient

We suggest that obese patients (BMI >30 kg/m²) present technical difficulties and are at increased risk of peri-operative complications. They should be screened rigorously for cardiovascular disease and each case considered individually. Although obesity is not an absolute contra-indication to transplantation, individuals with a BMI >40 kg/m² are less likely to benefit.

Guideline 2.6 – Tx : Preparation of the renal transplant recipient

We recommend that all potential transplant recipients should be tested for prior exposure to viral infections including: cytomegalovirus (CMV), Epstein-Barr virus (EBV), varicella zoster virus (VZV), hepatitis B and C and human immunodeficiency virus (HIV). Immunization should be offered to all

hepatitis B (if not already immunized) and VZ virus antibody negative patients before transplantation. Patients otherwise suitable for renal transplantation with evidence of chronic hepatitis B and/or C or HIV infection should be managed according to British Transplantation Society and European Best Practice Guidelines prior to transplantation.

Guideline 2.7 – Tx : Evaluation and selection of the renal transplant recipient

We recommend that renal transplantation should only be considered in potential recipients with previous malignancy (excluding non-melanoma skin cancer) if there is no evidence of persistent cancer. It is recommended that the waiting time between successful tumor treatment/remission and transplantation be at least 2 years. For certain malignancies the waiting time may need to be extended to more than 5 years. The Israel Penn International Transplant Tumor Registry should be consulted for tumor specific advice (www.ipittr.uc.edu/Home.cfm).

Guideline 2.8 – Tx : Evaluation and selection of the renal transplant recipient

We recommend that patients who are at risk of developing recurrence of original renal disease should be managed according to the European Best Practice Guidelines (EBPG).

Guideline 2.9 – Tx : Screening investigations in the renal transplant recipient

We suggest that there is no evidence that asymptomatic potential transplant recipients require screening for diverticular disease, peptic ulceration or gall bladder stones.

Summary of audit measures in assessment for renal transplantation

- The proportion of patients with and without diabetes mellitus < 65 years old with CKD stage 5 listed for transplantation.
- The proportion of transplant patients who receive a living donor transplant.
- The time to placement on the UK Transplant national transplant list in relation to start date of dialysis.
- The proportion of living donor transplant recipients transplanted before starting dialysis.
- A comparison between renal units of the proportion of dialysis patients placed on the national transplant list corrected for differences in identified unit and patient specific variables including co-morbidity.
- The proportion of CKD stage 5 patients with a transplant status recorded.
- The proportion of CKD stage 5 dialysis patients with Type 1 diabetes mellitus listed for simultaneous kidney-pancreas transplantation.
- The proportion of patients who smoke (or have given up within the last year)
 - a. whilst listed for transplantation
 - b. one year after renal transplantation.
- The number of patients with BMI >40 kg/m² who are on the transplant waiting list and the reason for their inclusion.
- The proportion of patients on the transplant waiting list whose viral status is known for CMV, EBV, VZV, hepatitis B and C and HIV.
- The proportion of VZV and HBc antibody negative patients on the transplant .

EAU Guidelines on Renal Transplantation

Group: European Association of Urology (EAU)

Target population: European patients with CKD or ESRD

Link: <http://www.uroweb.org/gls/pdf/Renal%20Transplantation%202010.pdf>

Date: 2005 (updated 2009)

Strength/Level of Evidence

Grade:	Nature of Recommendations
A	Based on clinical studies of good quality and consistency addressing the specific recommendations and including at least one randomised trial
B	Based on well-conducted clinical studies, but without randomised clinical trials
C	Made despite the absence of directly applicable clinical studies of good quality

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

- Active infection, which may exacerbate after transplantation causing life-threatening infection, is a contraindication to transplantation (B)
- Carry out screening for viral and bacterial diseases in all transplant candidates; Screen all patients for HBV, HCV, HIV and CMV and TB (history and chest X-ray) (B)
- Routine screening examination of all patients in all subspecialties is not necessary (B)
- In severe co-morbidity or non-compliance, a thorough and individual assessment should be performed (C)
- Pre-transplant work-up should focus on the presence of cardiac disease (B)
- In patients with a high risk of cardiac disease, an extensive work-up is strongly recommended to firmly rule out coronary artery disease (B)
- Perform any revascularisation before transplantation (B)
- During pre-transplant work-up, special attention should be paid to iliacal, peripheral and cerebrovascular disease. Appropriate diagnostic and therapeutic measures are recommended (C)
- Patients with diabetes mellitus should be transplanted. They require an extensive pre-transplant work-up (B)

- Obesity itself is not a contraindication for transplantation. However, a thorough pre-transplant evaluation and attempt to reduce weight are recommended (C)
- A careful examination of coagulopathies in patients at risk in order to prevent early post-transplant thrombotic events is recommended (C)
- Pre-transplant work-up for patients with retransplantation or previous non-renal transplantation should focus on the immunological risk, including a thorough analysis for the presence of anti-HLA antibodies

European Best Practice Guidelines for Renal Transplantation (Part 1)

Group: ERBP (European Renal Best Practice)

Target population: All patients with end-stage renal disease (ESRD) with exception of absolute contraindications

Link: <http://www.european-renal-best-practice.org/content/ebpg-european-best-practice-guidelines-documents>; http://ndt.oxfordjournals.org/content/15/suppl_7

Date: December 2, 2000

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

I.1 Epidemiological data concerning end-stage renal failure (ESRF) and its treatment in Europe Guideline

- In estimating the number of patients in need of renal transplantation, one should integrate the basic epidemiological data concerning end-stage renal failure (ESRF), and in particular the currently linear increase of the point prevalence by ~7.5% each year.

I.2 General evaluation guidelines

- All patients with end-stage renal disease (ESRD) should be considered for renal transplantation unless they have absolute contra-indications, because renal transplantation offers a better life expectancy and quality of life than dialysis.
- Long duration of dialysis, previous incidence of recurrent infections, cancer, cardiovascular disease of gastrointestinal complications should not be considered as absolute contra-indications to renal transplantation, despite these conditions increasing the risk of post-transplant morbidity and mortality.
- Psychological evaluation of transplant candidates may be useful in assessing compliance with future immunosuppressive treatment. Poor compliance significantly worsens the outcome of renal allografts.

I.3 Information for the transplant recipient guidelines

- Comprehensive information on renal transplantation should be given to all potential candidates with ESRF, including mortality, morbidity, results compared with dialysis, and also data concerning the different sources of kidneys, including marginal organs.
- The specific transplant evaluation should only be performed after this information is delivered and clear acceptance is given by the patient. Inclusion on the waiting list is the final step of the procedure and requires formal information consent (often legal) from the prospective recipient.
- All critical aspects concerning kidney donor selection for transplantation, including the use of marginal organs, need clear informed consent from the prospective candidate, both in advance, whenever possible, and at the time of an offer.

I.4 Contra-indications for transplant guideline

- There are a few absolute contra-indications to renal transplantation. These include uncontrolled cancer, HIV positivity, active systemic infections and/or any condition with a life expectancy < 2 years.

I.5 Risk factors / relative contra-indications

I.5.1 Work-up for cancer and waiting time for pre-existing cancer guidelines

- Candidates for renal transplantation, particularly those older than 50 years of age, should be screened for the presence of pre-existing cancer.
- Inpatients with previous cancer, renal transplantation should only be considered if there is no evidence of persistent cancer. It is recommended that the waiting time between tumor treatment and transplantation be based on the type of cancer.
- After renal transplant, general preventive measures of surveillance for occurrence of *de novo* cancer are recommended.

I.5.2 Infection risk. Hepatitis C virus (HCV) infection in kidney transplant recipients and kidney donors guidelines

- All transplant candidates should be tested for anti-HCV antibodies. Anti-HCV positive patients with negative HCV viraemia are at very low risk of liver disease after renal transplantation. The presence of HCV_RNA in serum may be searched for in all prospective recipients with liver disease, even in cases where anti-HCV antibodies are not detectable.
- All HCV-positive patients should be considered for renal transplantation, as this procedure is not associated with increased mortality compared with dialysis, at least not during the first post-transplant decade.
- HCV-infected transplant candidates with elevated transaminase levels should undergo a liver biopsy. It is desirable, but not essential, to perform a liver biopsy in HCV-infected patients who display consistently normal liver enzymes, because HCV liver disease is often undetected.
- Transplant candidates with existing cirrhosis should not be considered for isolated renal transplantation, but should be considered for combined kidney and liver graft.
- Patients with chronic active hepatitis (CAH) might be offered a treatment with interferon (IFN- α) prior to transplantation. They may be maintained on the active transplant waiting list during the period of IFN- α administration, the drug being stopped if transplantation occurs before the end

of planned therapy. Patients without improvement after IFN- α therapy may still be put on the waiting list for transplantation, but only after careful consideration and information.

- Kidneys from HCV-infected living or cadaveric donors may be offered to HCV RNA-positive recipients with their consent and when permitted by the national law. Obtaining the donor and recipient HCV genotypes is desirable for further careful evaluation of the results.

KHA-CARI Guideline: Recipient Assessment for Transplantation

Group: Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI)

Target population: All kidney transplant candidates

Link:

http://www.cari.org.au/Transplantation/transplantation%20recipient%20assessment/transplant_recipient_assessment.html;

http://www.cari.org.au/Transplantation/transplantation%20recipient%20assessment/Summaries/Campbell_2013_455.pdf

Date: 2013

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

1. Cardiovascular disease guideline recommendations

- We recommend that all candidates for kidney transplant are screened for cardiovascular risk factors.
- We suggest that kidney transplant candidates with a low clinical risk of cardiovascular disease do not require stress testing for coronary artery disease.
- We suggest that kidney transplant candidates with a moderate or high clinical risk of cardiovascular disease undergo cardiac stress testing prior to transplantation.
- We recommend that coronary angiography be considered for kidney transplant candidates with abnormalities on screening procedures.
- We suggest that the benefit of revascularization prior to transplantation be reviewed on an individual basis.

2. Diabetes mellitus guideline recommendations

- We recommend that diabetes should not on its own preclude a patient from being considered for kidney transplantation.
- We recommend that potential renal transplant candidates with diabetes are screened for cardiovascular disease in accordance with the 'Cardiovascular Disease' sub-topic guidelines.
- We suggest that renal transplant candidates with diabetes be considered for pre-emptive transplantation due to better patient and graft survival compared with transplantation after the commencement of dialysis.

- We suggest that, following screening for cardiovascular disease, Type 1 diabetic transplant candidates should be considered for referral for simultaneous pancreas and kidney transplantation (SPK) or live donor renal transplantation.

3. Human immunodeficiency virus, hepatitis b virus, hepatitis c virus guideline recommendations

- **Human Immunodeficiency Virus (HIV)**
We recommend that HIV infection should not preclude a patient from being assessed for kidney transplantation.
- **Hepatitis B Virus (HBV)**
We recommend that HBV infection should not preclude a patient from being assessed for kidney transplantation.
- **Hepatitis C Virus (HCV)**
We recommend that HCV infection should not preclude a patient from being assessed for kidney transplantation.

4. Malignancy guideline recommendations

- We recommend that screening for malignancy prior to transplantation be conducted in accordance with usual age and sex appropriate cancer screening policies for the general population.
- We recommend that patients with the following malignancy not be transplanted:
 - i. Uncontrolled or untreated malignancies
 - ii. Multiple myeloma
 - iii. Advanced breast cancer (stage III)
 - iv. Colorectal cancer (stage D)
- We suggest minimum waiting periods from successful treatment of malignancy to transplantation.
- We suggest advising patients with a prior malignancy that they are at increased risk of de novo malignancy post-transplantation compared with those with no prior history of malignancy undergoing transplantation.

5. Obesity guideline recommendations

- We recommend that obesity should not on its own preclude a patient from being considered for kidney transplantation.
- As a pre transplant BMI (Body Mass Index) >40 kg/m² may not be associated with a survival advantage compared to remaining on dialysis, we suggest that the suitability for transplant be carefully assessed on an individual basis.
- As patient and graft survival of obese transplant recipients may be mediated by comorbid factors, particularly cardiovascular, we recommend that obese transplant candidates are

screened for cardiovascular disease (refer to 'Cardiovascular Disease' sub-topic guidelines for recommendations).

6. Pediatric recipient guideline recommendations

- In relation to age at the time of transplantation, we recommend that:
 - There be no lower age limit set for transplantation.
 - In infants under 1 year of age, transplantation should be performed in highly specialized units with extensive experience in pediatric transplantation.
 - In infants under 1 year of age, adult live donors should be used in preference to cadaveric donors.
- In all patients but particularly in adolescents we recommend that:
 - Risk factors for non-adherence are identified prior to transplantation.
 - Specific strategies are implemented to actively manage factors and behaviors that contribute to non-adherence.
- We recommend that children with urological abnormalities be carefully assessed prior to transplantation and that abnormalities in bladder emptying are corrected before transplantation.
- We suggest that asymptomatic vesicoureteric reflux does not require correction prior to transplantation.
- We suggest that children with Wilms tumor wait at least 2 years following completion of chemotherapy before undergoing transplantation.
- We suggest that post-transplant anticoagulation be considered for children with thrombophilic disorders.
- We recommend that mental retardation should not preclude an individual from consideration for transplantation.

TSANZ Consensus statement on eligibility criteria and allocation protocols

Group: The Transplantation Society of Australia and New Zealand (TSANZ)

Target population:

Link: http://www.tsanz.com.au/downloads/concensusstatementv1.38jan2014_000.pdf

Date: 2014

Major Recommendations

3.1 Inclusion criteria

Inclusion criteria for kidney transplantation are: end-stage kidney failure requiring dialysis; anticipated low perioperative mortality; and a reasonable postoperative life expectancy, defined as an 80% likelihood of surviving for at least 5 years after transplantation.

3.2 Exclusion criteria

Exclusion criteria for kidney transplantation are as follows.

An anticipated likelihood of less than 80% chance of surviving a minimum of 5 years following transplantation — comorbidities that might have a significant impact on the life expectancy of a kidney transplant recipient include cardiac disease, vascular disease, diabetes mellitus and malignancies.

Cardiovascular disease — Substantial, uncorrectable cardiovascular disease would be an absolute exclusion. Lesser levels of disease would potentially contribute to a lower anticipated 5-year survival, and hence would be a relative consideration.

Diabetes mellitus — Uncomplicated diabetes mellitus is not a contra-indication to transplantation. The presence of diabetes should lead to detailed assessment of potential vascular complications that would potentially contribute to a lower anticipated 5-year survival, and hence would be a relative consideration.

Infection — Uncontrolled infection is a contraindication to transplantation.

Malignancy — Active malignancies other than non-melanoma skin cancers remain an absolute contraindication to kidney transplantation, however patients with ‘cured’ malignancy as evidenced by prolonged disease-free survival may be suitable for transplantation. A decision on whether or not to refer patients with a history of malignancy for kidney transplant assessment needs to be individualised and generally should only be made in consultation with the oncologist caring for the patient.

Inability to comply with complex medical therapy — The ability to correctly follow a treatment plan, particularly with respect to anti-rejection medications is an important predictor of a successful outcome after renal transplantation, and as such is a requirement for renal transplant listing. Every effort should be made to assist patients and their carers to optimise their adherence to therapy.

Other medical conditions — Patients with renal failure can have any number of comorbid medical conditions that can affect the chances of a successful outcome. Others include cardiac failure, chronic airways disease, cirrhosis of the liver, peripheral vascular disease and cerebrovascular disease. The impact of these conditions needs to be considered on a case-by-case basis.

Age — Although advanced age in the absence of significant medical comorbidity is not necessarily a contraindication for kidney transplantation, fewer than 5% of the end-stage kidney failure patients in Australia aged over 65 are currently listed for renal transplantation due to the presence of comorbidities.⁷

Similar survival outcomes should be expected for recipients receiving combined transplants, where a kidney is transplanted with another organ (liver, pancreas, heart, and lung).

Patients who are being considered for a second or subsequent kidney transplant should be assessed according to the same requirements as candidates for their first kidney transplant.

3.3 Assessment and acceptance principles

Referrals for renal transplantation (from renal/dialysis units) should be assessed initially at the level of the transplanting hospital. This review and a decision regarding acceptance for listing should involve a transplant physician and surgeon.

The transplant unit should have a system to allow borderline candidates to be assessed by a broader group of transplant specialists.

Each state should have a second-tier review committee (the structure of which may vary between states) to review cases where requested.

Reassessment of patients on the waiting list should occur at least annually by the transplant unit. Usually this would be in person. Transplant units will have a process to formally ensure ongoing suitability.

Only the Director of a transplant unit (or their delegate) has the authority to have patients added to the active renal transplant waiting list.

Japanese Society of Nephrology Evidence-based practice guideline for the treatment of CKD

Group: Japanese Society of Nephrology

Target population: Japanese patients with CKD

Link: <http://www.jsn.or.jp/en/guideline/pdf/guideline2009.pdf>

Date: 2009

Major Recommendations

The following text is an abridged version of the guideline recommendations; please refer to the full report for additional information.

1. Kidney transplantation as a treatment option for end stage kidney disease (Grade A, Level 4)

Since kidney transplantation generally confers a survival benefit, this treatment option for end-stage kidney disease should be explained to all patients with CKD stage 4 and 5, and also to their family [1].

2. Significance of pre-emptive kidney transplantation (Grade B, Level 4)

Living donor kidney transplantation can be performed prior to the initiation of dialysis, which is called “preemptive kidney transplantation (PET)”. PET is reported to be superior in terms of patient and graft survival compared to kidney transplantation after the initiation of dialysis [2, 3].

3. Importance of management of CKD in kidney transplant recipients and donors (Grade A, Level 4)

A number of kidney transplant recipients and donors have developed into CKD stage 3 to 5 after kidney transplantation and donor nephrectomy, respectively. Thus, long-term and periodical follow-up and management of CKD in both recipients and donors are important [4].

Access to Kidney Transplantation

Technical Expert Panel
April 20 and 21, 2015

Agenda: April 20, 2015

- 9:00 – 9:30 Introductions and Conflicts of Interest
- 9:30 – 10:30 Data Presentations
- *10:30 – 10:45* *BREAK*
- 10:45 – 12:00 Data Presentations, continued
- *12:00 – 1:00* *LUNCH*
- 1:00 – 5:00 Identification of Quality Measures

Agenda: April 21, 2015

- 9:00 – 12:00 Draft measure specifications
- 12:00 – 1:00 *LUNCH*
- 1:00 – 2:20 Final Measure Recommendations
- 2:20 – 2:30 Wrap-up
- 2:30 – 3:00 Public Comment Period

Disclosures of potential conflicts of interest – TEP members

Name	Title & Organization	Potential Conflicts of Interest
Stephen Pastan, MD TEP Co-Chair	Associate Professor of Medicine Renal Division, Emory University School of Medicine, Atlanta, GA	Old National Dialysis, College Park, Georgia. 15% owner in joint venture with Fresenius Medical Care
	Medical Director of the Kidney and Pancreas Transplant Program, Emory Transplant Center, Emory University, Atlanta, GA	Research Support from Bristol Meyers Squibb
	Board of Directors Member; Chair of the transplantation task subcommittee, National Kidney Foundation (NKF)	Data Safety Monitoring Committee for Retrophin, Inc.
Amy Waterman, PhD TEP Co-Chair	Associate Professor of Medicine, Division of Nephrology; Director of the Transplant Research and Education Center (TREC)	Consulting for Dompé Pharmaceuticals
	David Geffen School of Medicine, University of California, Los Angeles (UCLA), Los Angeles, CA	Dr. Waterman founded the non-profit Explore Transplant. She has since signed a royalty-free agreement and does not have any financial affiliation with the organization. In the past, Dr. Waterman had HRSA grants specific to dialysis center studies, but does not have any at this time.

Disclosures of potential conflicts of interest – TEP members (Continued)

Name	Title & Organization	Potential Conflicts of Interest
Todd Pesavento, MD	Professor of Medicine, Department of Medicine; Medical Director of Kidney and Pancreas Transplantation, Comprehensive Transplant Center, Ohio State University, Columbus, OH	Grant/Research support from Bristol Meyers-Squibb
Sandra Amaral, MD, MHS	Assistant Professor Division of Nephrology, Department of Pediatrics; Co-Director of the Kidney Transplant Program The Children's Hospital of Philadelphia, PA Senior Scholar Center for Clinical Epidemiology and Biostatistics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA	None
Ranjan Chanda, MD, MPH	Medical Director Centennial Kidney Transplant Center, Nashville, TN Partner Nephrology Associates, Nashville, TN	None

Disclosures of potential conflicts of interest – TEP members (Continued)

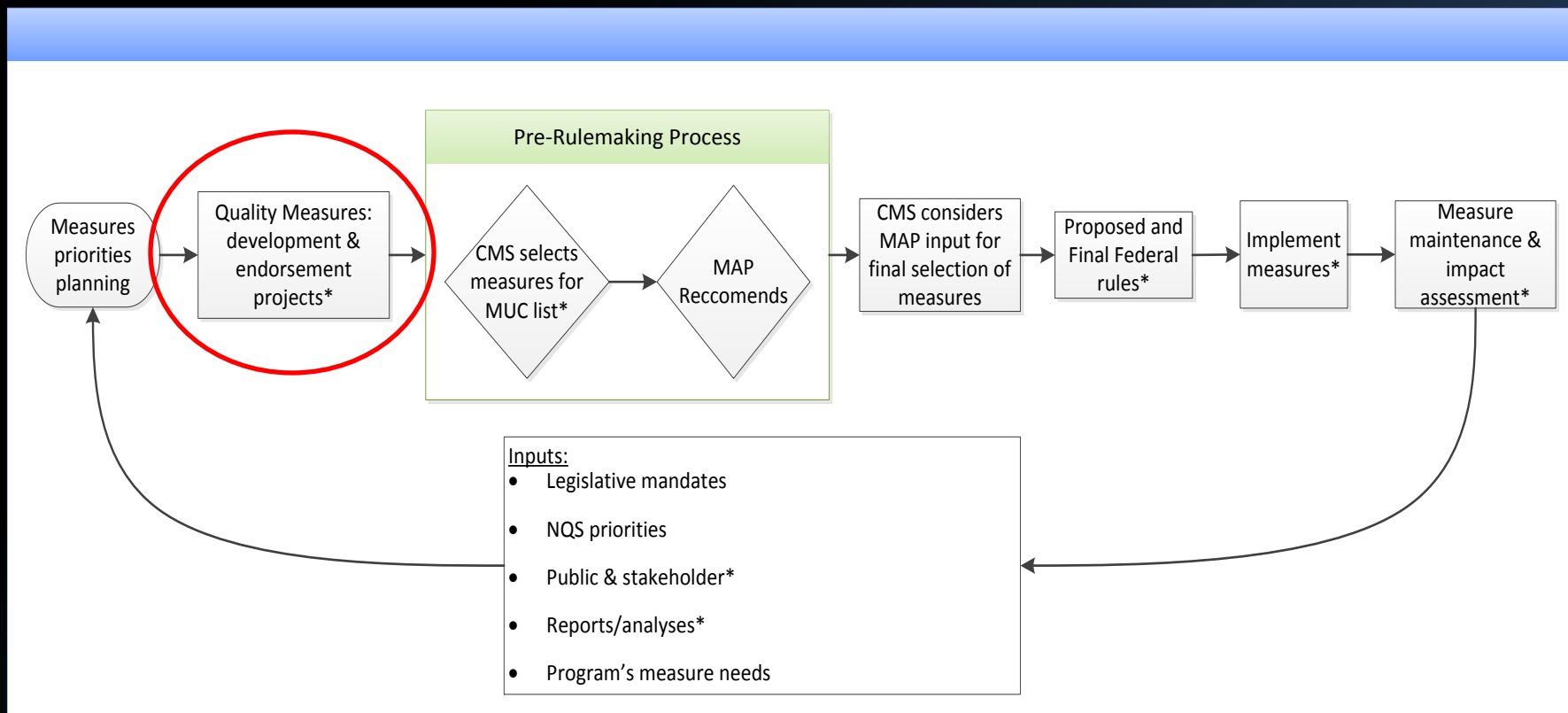
Name	Title & Organization	Potential Conflicts of Interest
Mary Beth Callahan, ACSW, LCSW	Senior Social Worker Dallas Transplant Institute, Dallas, TX	None
Duane Dunn, MSW	National Director of Social Work Services DaVita Healthcare Partners Inc., Columbia, SC	None
Linda Wright, DrNP, RN, CNN, CCTC	Kidney and Pancreas Transplant Coordinator; Certified Nephrology Nurse Thomas Jefferson University Hospital, Philadelphia, PA	None
Robert Teaster, RN, MBA, CPTC, CPT	Administrator for Transplant Services University of Virginia Medical Center, Charlottesville, VA	None
Chris Elrod, CCHT	Chief Technician/ Bio Med Dialysis Clinic, Inc. (DCI)	None
Nancy Scott	President Dialysis Patient Citizens Education Center	None

Disclosures of potential conflicts of interest – UM-KECC

Name	Title & Organization	Potential Conflicts of Interest
Vahakn Shahinian, MD, MS	Associate Professor of Internal Medicine UM-KECC	None stated
Joe Messana, MD	Collegiate Professor of Nephrology and Professor of Internal Medicine UM-KECC	None stated
Valarie Ashby, MA	Co-Managing Director/ Lead Manager of Research & Analysis UM-KECC	None stated
Doug Schaubel, PhD	Professor of Biostatistics UM-KECC	None stated
Lan Tong, MS	Senior Research Analyst UM-KECC	None stated
Casey Parrotte, BA	Research Analyst UM-KECC	None stated
Caitlin Hanna, BA	Research Analyst UM-KECC	None stated

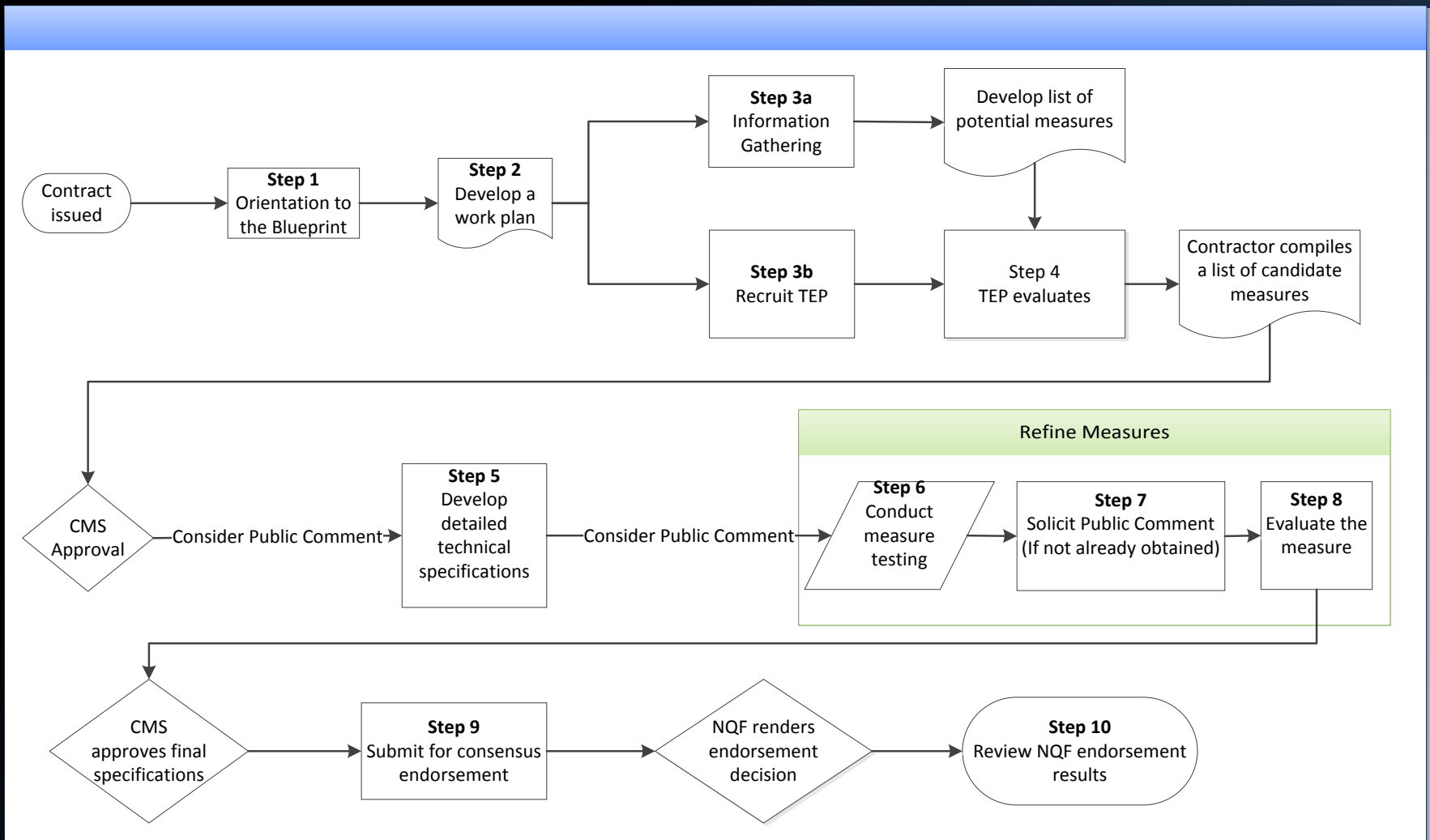


Quality Measure Development and Maintenance



Blueprint for the CMS Measures Management System
Version 10.0 September 2013

Flow of Measure Development Processes



A Blueprint for the CMS Measures Management System
Version 10.0 September 2013

Measure Evaluation Criteria

- Evidence, Performance Gap, and Priority (Impact)- Importance to Measure and Report
- Reliability and Validity- Scientific Acceptability
- Feasibility
- Usability
- Comparison to Related or Competing Measures (Harmonization)

Measure Considerations

- “Attributability”
 - The degree to which performance on the measure is under control of the facility
- Impact/Importance
 - The strength of the link between performance on the measure and outcomes that matter to patients
- Data Issues (collection/analytics)
 - Is data readily available/easy to collect?
 - Are there sufficient number of “events” to meaningfully distinguish performance across facilities

Measure Considerations (Continued)

- Risk Adjustments
 - Accounting for factors that may influence measure and vary across facilities
 - Ideally applied to factors outside the facilities' control
- Exclusion Criteria
 - Removing patients from consideration in the measure
 - Should be clearly justifiable clinically

Steps to Transplant

Discussion of Options



Referral for Transplant Evaluation



Completion of Transplant Evaluation



Waitlisting and/or Identification of Living Donor



Maintenance of Active Status on Waitlist



Transplantation

Candidate Measures

Measure Name	Brief Description	Numerator Statement	Denominator Statement	Public Domain Yes/No	Care Setting
Incident Patient Discussion	This measure indicates percentage of facility incident patients informed of the option of kidney transplantation within 90 days of starting dialysis at the current facility.	Yes response	All incident patients of dialysis facility (i.e. < 90 days at current facility)	No	Dialysis Facility
Prevalent Patient Discussion	This measure indicates percentage of facility prevalent patients informed of the option of kidney transplantation within the last 12 months.	Yes response	<p>Potential Denominators:</p> <p>Denominator 1: All prevalent patients of dialysis facility (i.e. > 90 days at current facility).</p> <p>Denominator 2: All prevalent patients of dialysis facility (i.e. > 90 days at current facility) minus patients with permanent contraindications to kidney transplantation.</p>	No	Dialysis Facility

Candidate Measures (Continued)

Measure Name	Brief Description	Numerator Statement	Denominator Statement	Public Domain Yes/No	Care Setting
Referral to Transplant Center	This measure tracks percent of facility patients referred to a transplant center.	Yes response	<p>Potential Denominators:</p> <p>Denominator 1: All patients</p> <p>Denominator 2: Exclude patients with contraindications</p> <p>Denominator 3: Exclude uninterested/undecided patients</p> <p>Denominator 4: Exclude patients with contraindications, uninterested/undecided patients</p>	No	Dialysis Facility
Waitlisting Rate	This measure evaluates the percentage of patients under age 70 that were treated at a facility on December 31 who were added to the kidney or kidney-pancreas transplant waitlist that year.	The number of patients who were on the kidney or kidney-pancreas transplant waitlist as of December 31	All dialysis patients under age 70 that were being treated on December 31 of each year in the facility	Yes, DFR	Dialysis Facility

Candidate Measures (Continued)

Measure Name	Brief Description	Numerator Statement	Denominator Statement	Public Domain Yes/No	Care Setting
Transplantation Rate	This measure evaluates the percentage of patients under age 70 that were treated at the facility and received a transplant.	The number of dialysis patients under the age of 70 in each facility who received a transplant	All dialysis patients under age 70	Yes, DFR	Dialysis Facility
Standardized Transplantation Ratio (STR)	The Standardized Transplantation Ratio (STR) is the ratio of the actual number of first transplants (living and deceased) to the expected number of first transplants for the facility, given the age composition of the facility's patients.	The actual number of first transplants (living and deceased)	The expected number of first transplants for the facility	Yes, DFR	Dialysis Facility

UM-KECC Presentation

- Brief word on benefits of kidney transplantation
- ESRD Networks Transplant Referral Project
- State and Facility Variations in Waitlisting and Transplantation

Benefits of Kidney Transplantation

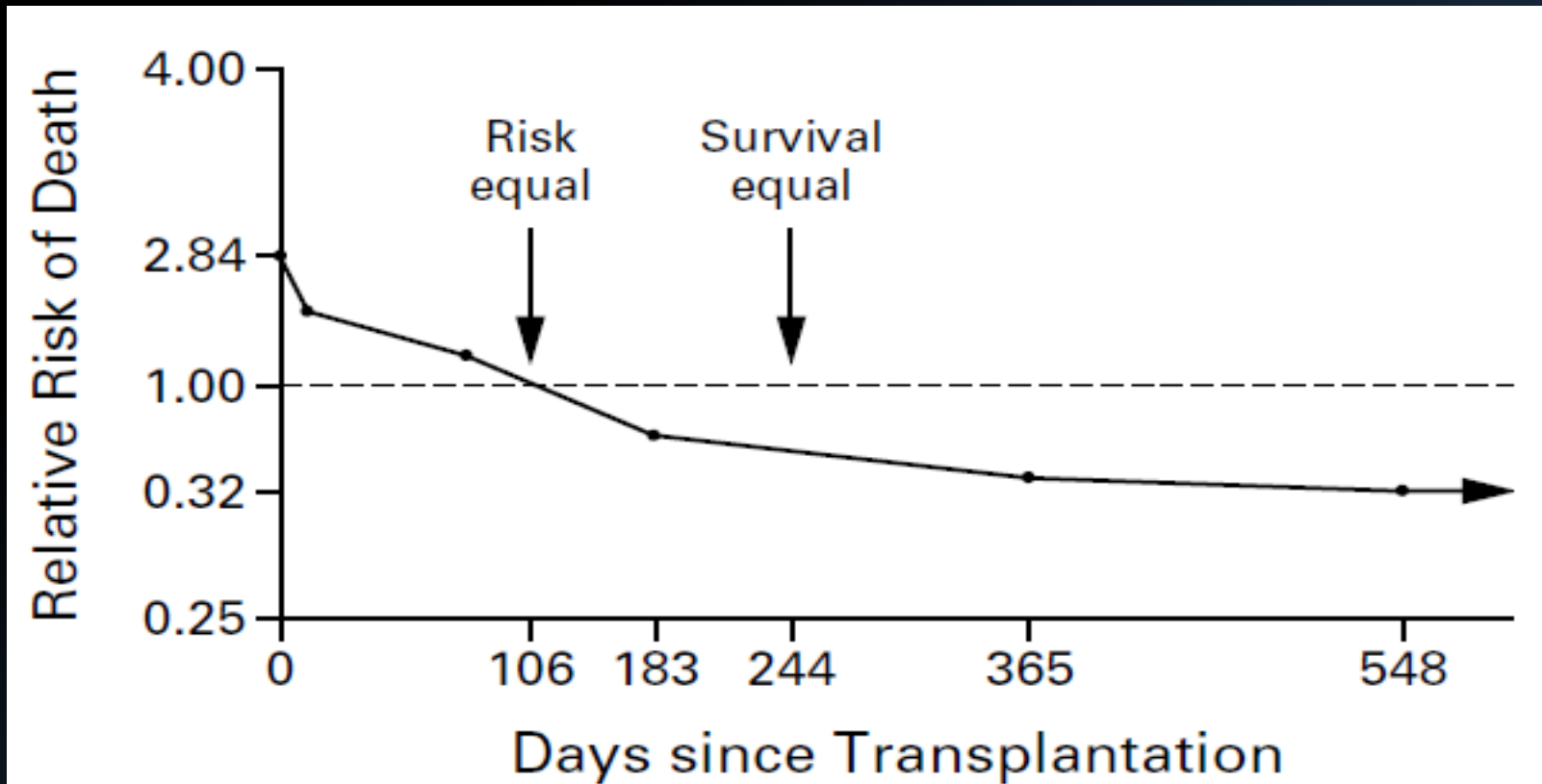


Figure 2. Adjusted Relative Risk of Death among 23,275 Recipients of a First Cadaveric Transplant.

Benefits of Kidney Transplantation

GROUP	RELATIVE RISK 18 MO AFTER TRANSPLANTATION (95% CI)†	P VALUE	TIME AT WHICH RISK OF DEATH EQUALS THAT IN REFERENCE GROUP	TIME AT WHICH LIKELIHOOD OF SURVIVAL EQUALS THAT IN REFERENCE GROUP	PROJECTED YEARS OF LIFE (IN REFERENCE GROUP) WITHOUT TRANSPLANTATION†‡	PROJECTED YEARS OF LIFE WITH TRANSPLANTATION‡
			days after transplantation			
All recipients of first cadaveric transplants	0.32 (0.30–0.35)	<0.001	106	244	10	20
Age						
0–19 yr	0.33 (0.12–0.87)	0.03	3	5	26	39
20–39 yr	0.24 (0.20–0.29)	<0.001	11	57	14	31
40–59 yr	0.33 (0.29–0.37)	<0.001	95	251	11	22
60–74 yr	0.39 (0.33–0.47)	<0.001	148	369	6	10
Sex						
Male	0.34 (0.30–0.38)	<0.001	110	255	10	19
Female	0.30 (0.26–0.34)	<0.001	94	220	11	23
Race						
Native American	0.50 (0.27–0.96)	0.04	123	304	9	14
Asian	0.43 (0.25–0.75)	0.003	161	673	15	23
Black	0.52 (0.44–0.62)	<0.001	109	305	13	19
White	0.28 (0.25–0.30)	<0.001	100	220	9	19
Cause of end-stage renal disease						
Diabetes	0.27 (0.24–0.30)	<0.001	57	146	8	19
Glomerulonephritis	0.39 (0.31–0.48)	<0.001	130	360	11	18
Other	0.38 (0.33–0.43)	<0.001	137	353	12	20
Age and diabetes status						
20–39 yr, no diabetes	0.38 (0.28–0.50)	<0.001	14	220	20	31
20–39 yr, diabetes	0.18 (0.14–0.23)	<0.001	10	35	8	25
40–59 yr, no diabetes	0.38 (0.33–0.43)	<0.001	126	356	12	19
40–59 yr, diabetes	0.27 (0.23–0.32)	<0.001	66	181	8	22
60–74 yr, no diabetes	0.37 (0.30–0.46)	<0.001	159	442	7	12
60–74 yr, diabetes	0.46 (0.34–0.61)	<0.001	89	247	5	8

ESRD Networks Transplant Referral Project

- Involved ESRD Networks 1,2,4,6, 8, 15 and 17
- Aimed at increasing transplant referral rates in selected dialysis facilities and reducing disparities in referral (age, sex, race/ethnicity)
- Baseline data in last half of 2012, interventions in 2014
- UM-KECC met with representatives from all the Networks to discuss lessons learned during performance of the project

Defining and Collecting Data on Referral

- Definition of referral was not uniform
- Issues with specification of referral rate (numerator/denominator)
- Discrepancies between dialysis facility vs transplant center reporting referral
- Networks used a variety of processes for collecting referral data (previous CROWNWEB entry was problematic)

Interventions to Increase Referral

- Patient education (Peer mentoring, “Transplant Stories”)
- Dialysis Staff education
- Transplant center presentations at dialysis facilities
- Network feedback of referral data to dialysis facilities
- Issues around eligibility of patients for transplant

Potential Transplantation Measures (all currently included in Dialysis Facility Reports)

- Waitlisting for transplantation
- Transplantation rate
- Standardized Transplantation Ratio

Waitlisting

- Numerator: patients on waitlist as of 12/31 of the year
- Denominator: all eligible patients within dialysis facility
- Exclusion: patients 70 years or older
- Reported annually

Transplantation Rate

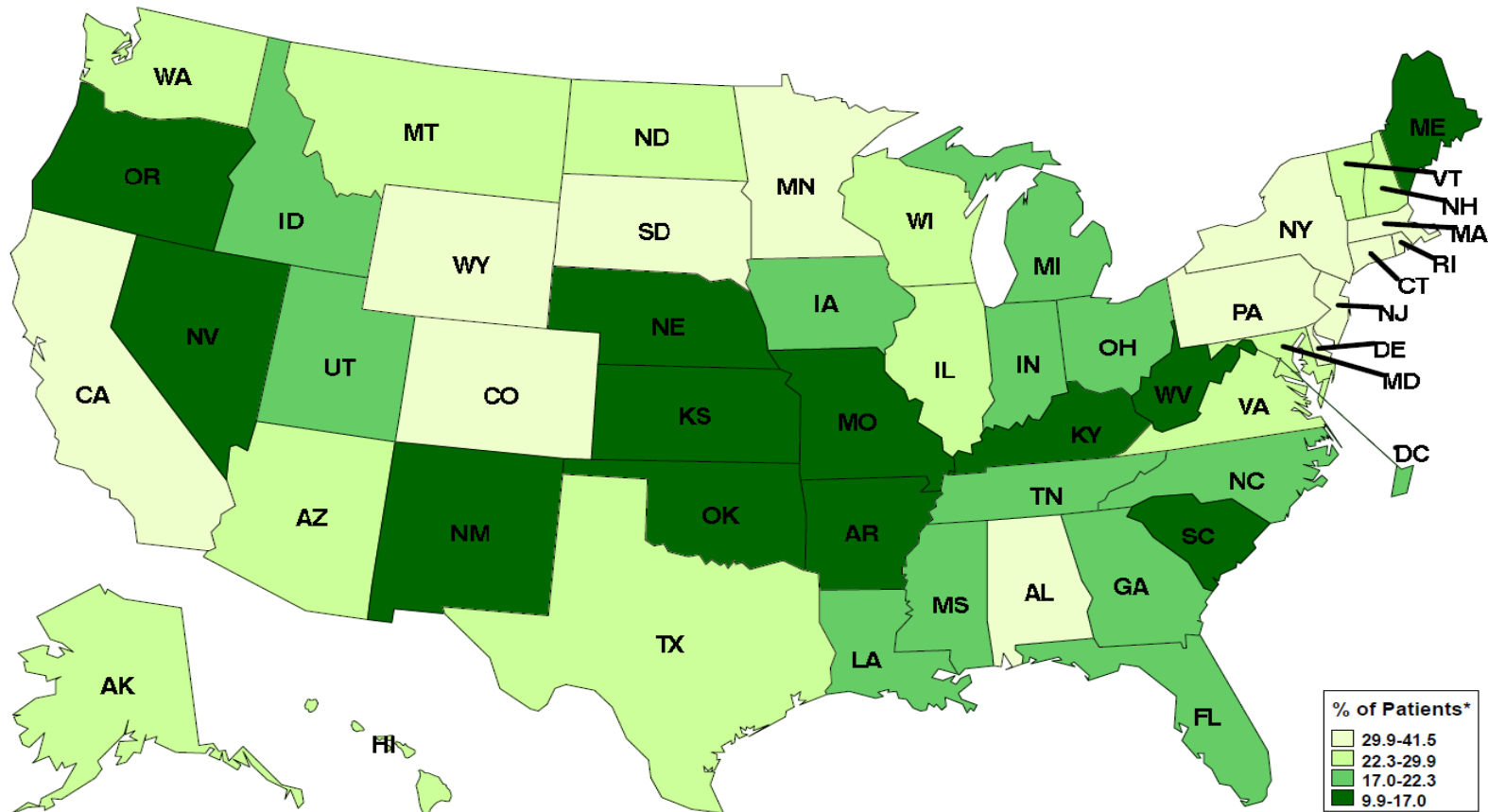
- Numerator: patients transplanted (deceased or living donor) that year
- Denominator: all eligible patients within dialysis facility
- Exclusion: patients 70 years or older
- Reported per 4 years

Standardized Transplantation Ratio

- Ratio of observed to expected number of transplants, accounting for age composition
- > 1.0 Better than nation, < 1.0 Lower than nation; statistics used to account for chance
- Exclusion: patients 70 years or older; facilities with less than 3 expected transplants
- Reported per 4 years
- Risk adjustment: Age

State Level Variation in Waitlisting

Percent of Patients on the Kidney Transplant Waiting List*
by State (2013)

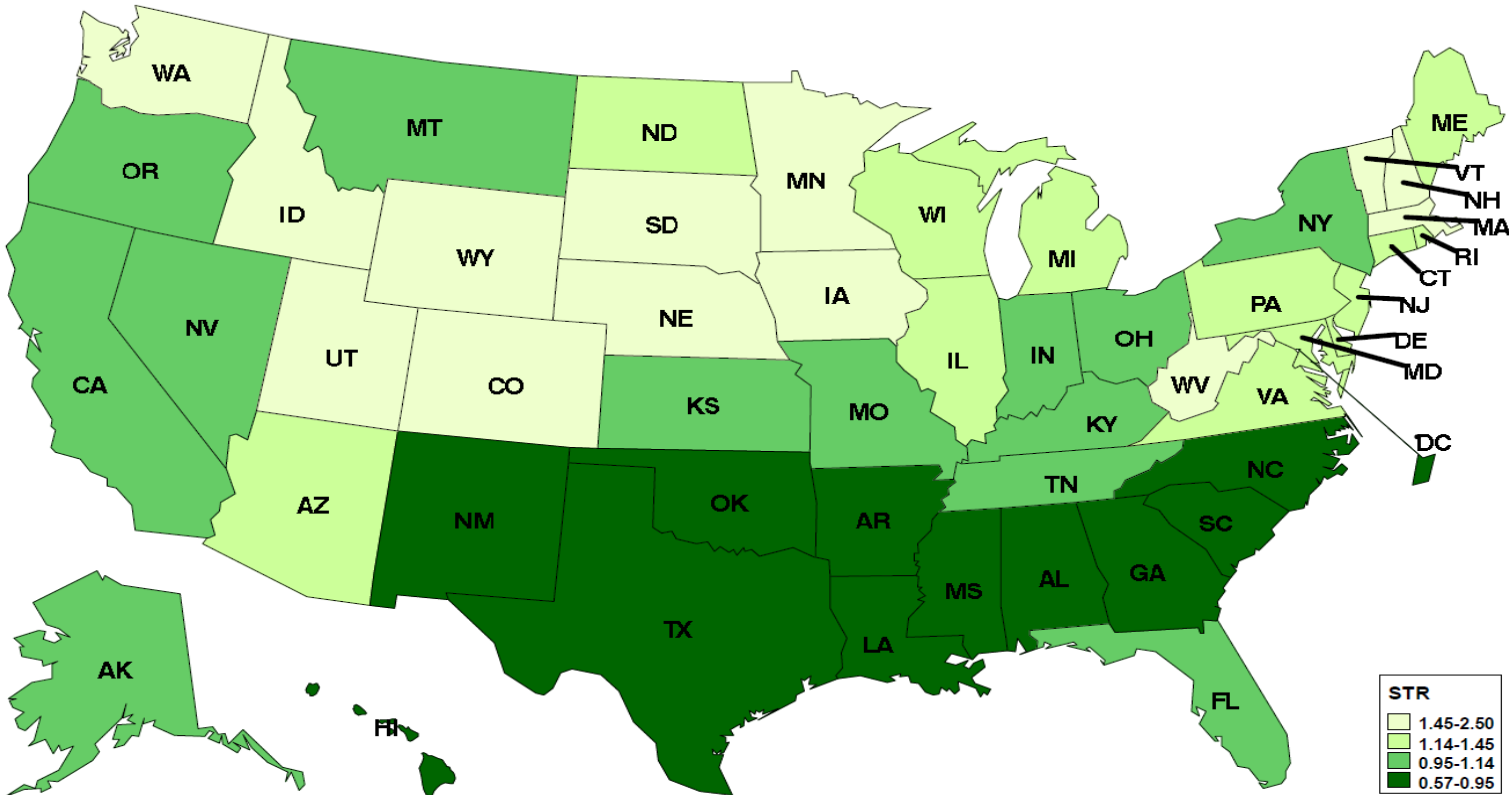


*Lighter shades indicate more patients on the waitlist.

State specific values are reported in the Table of Key Statistics along with p-values indicating the level of statistical significance of the value compared to the 2013 national average of 24.5%.

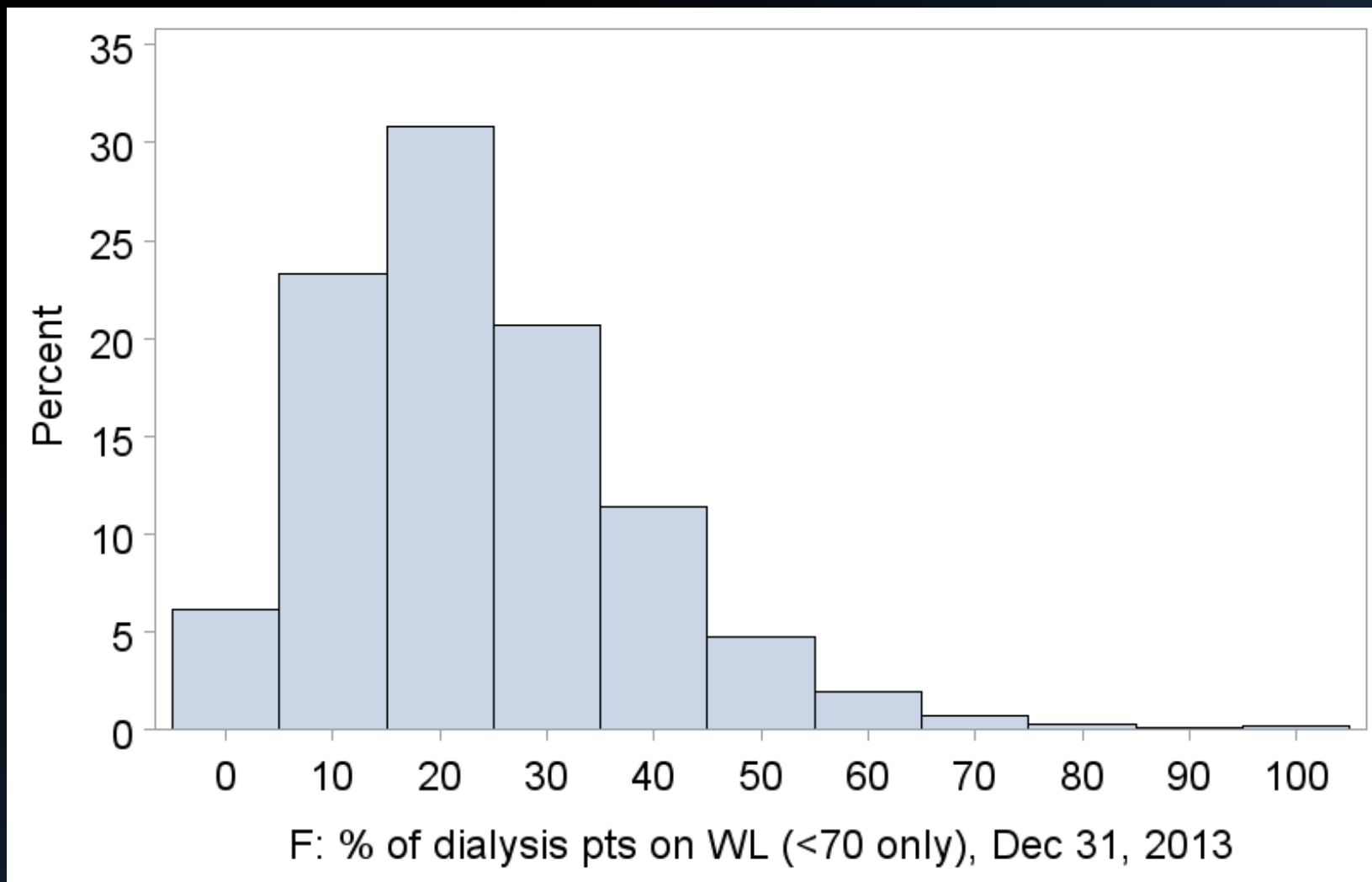
State Level Variation in STR

Standardized Transplantation Ratio (STR)*
by State (2013)

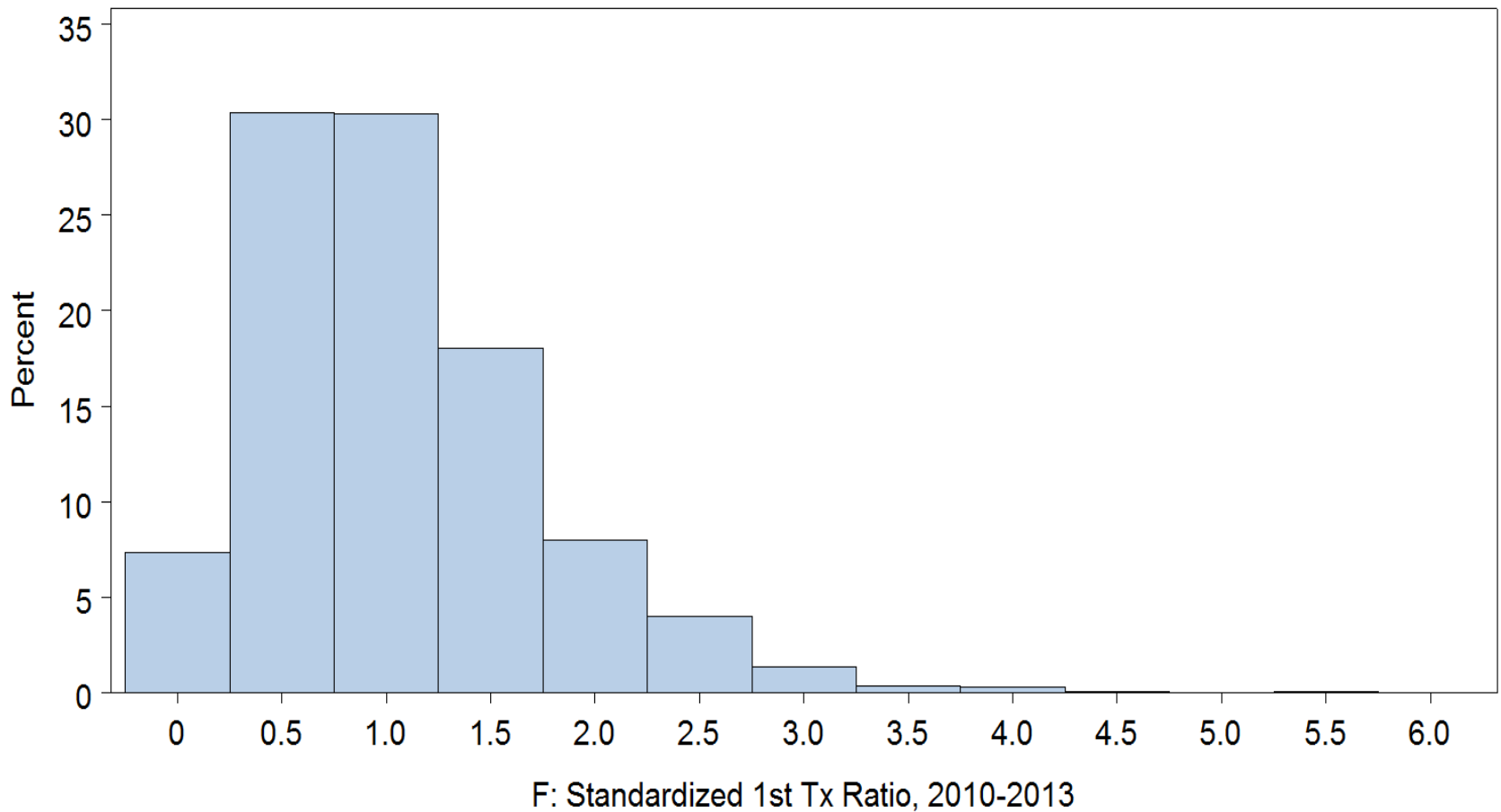


*Higher STRs (lighter shades) indicate better transplantation rates.
State specific values are reported in the Table of Key Statistics along with p-values indicating the level of statistical significance of the value compared to 0.95 or 1.05. The 2013 US value = 0.99.

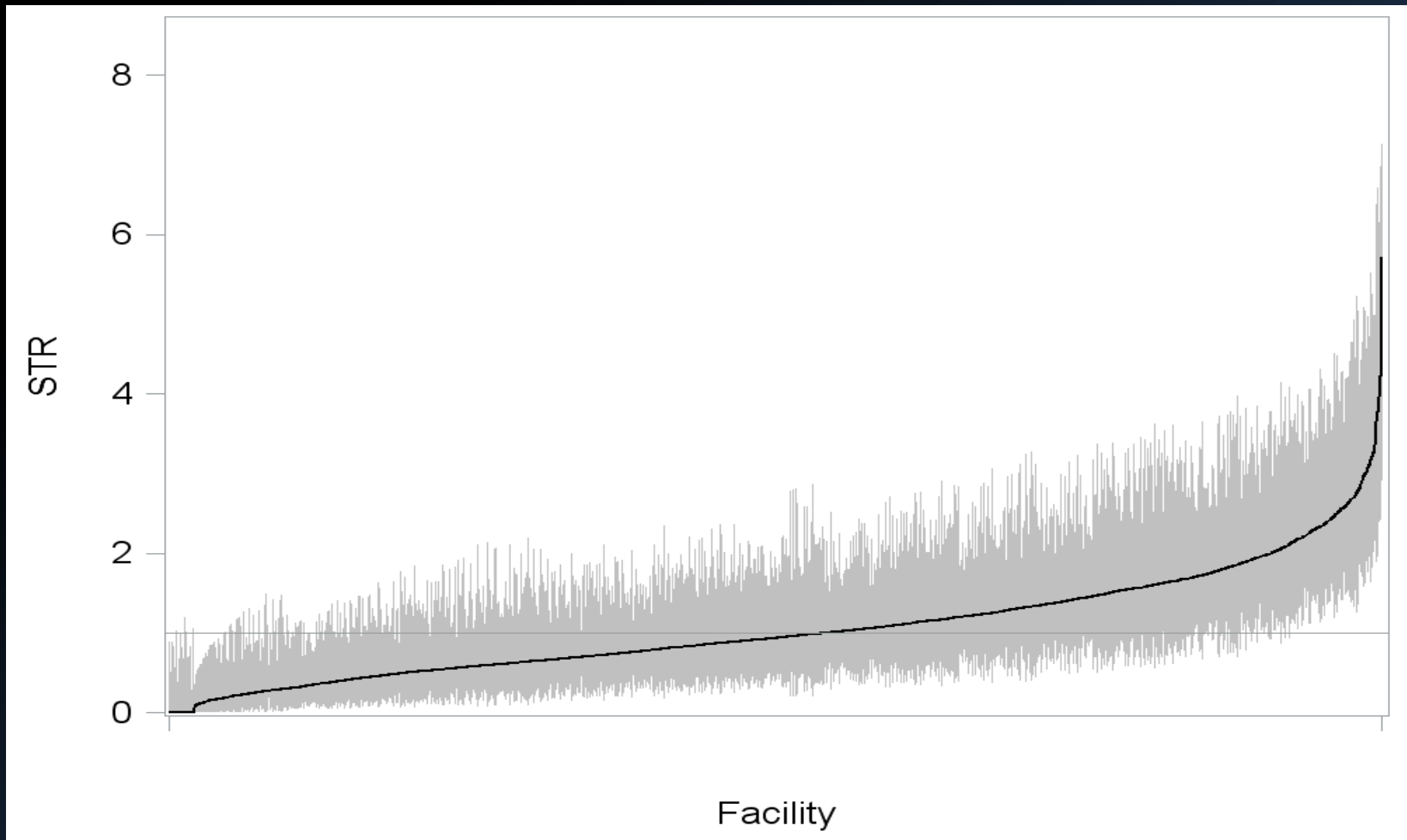
Facility Level Variation in Waitlisting Rates (n=6,130)



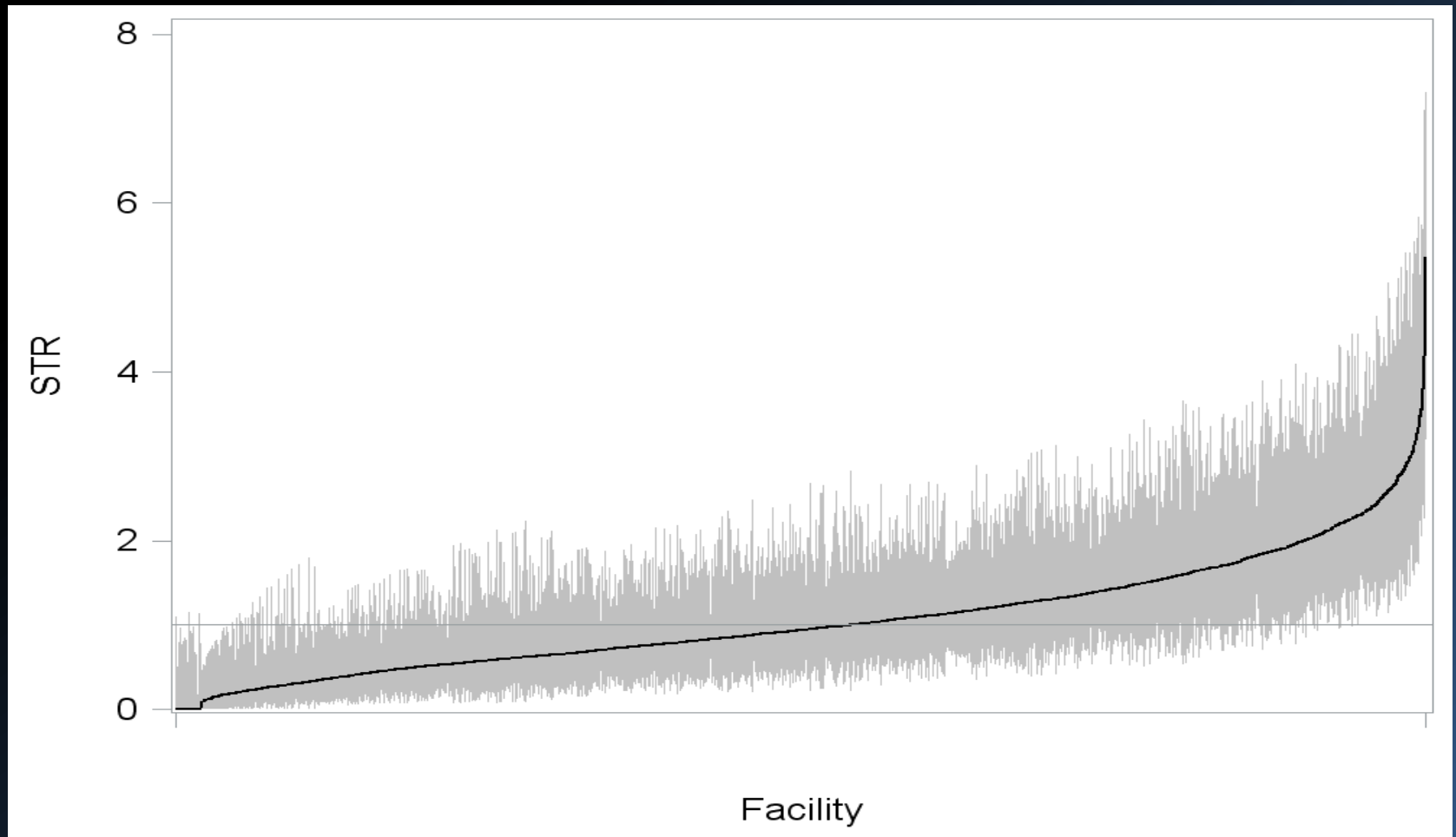
Facility Variation in Standardized Transplantation Ratio (Adjusted for Age, N=4,494)



Facility Variation in Standardized Transplantation Ratio (Adjusted for Age, N=4,494)



Facility Variation in Standardized Transplantation Ratio (Adjusted for Age, Comorbidities, OPO Donation Rate N=4,142)



Facility Variation in Standardized Transplantation Ratio (Adjusted for Age, N=4,494)

STR Category	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Facility txp rate significantly higher than national average txp rate	524	11.66	524	11.66
Facility txp rate not significantly different from national average txp rate	3508	78.06	4032	89.72
Facility txp rate significantly lower than national average txp rate	462	10.28	4494	100.00

Facility Variation in Standardized Transplantation Ratio (Adjusted for Age, Comorbidities, OPO Donation Rate N=4,142)

STR Category	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Facility txp rate significantly higher than national average txp rate	503	12.14	503	12.14
Facility txp rate not significantly different from national average txp rate	3211	77.52	3714	89.67
Facility txp rate significantly lower than national average txp rate	428	10.33	4142	100.00

Summary

- “Downstream” measures MAY have greater impact
- Under less direct control of dialysis facility
- Issues with small number of events for transplantation measures
- Risk adjustment may allow for some accounting of factors outside of dialysis facility control

Conditions for Coverage

Condition	Detail
Information about all treatment modalities	Documentation in patient record of provision of unbiased education about transplantation
Evaluation of suitability for referral to transplantation based on criteria of transplant center	Dialysis facility should have selection criteria for each center on file Reasons for non-referral must be documented
Plan of care documentation for transplantation status a) Plan for transplantation b) Patient's decision if declines c) Reason's for patient's ineligibility	Interdisciplinary team should be aware of patient self-referral to transplant center
Transplantation Referral tracking 1) Track results of referral 2) Monitor status of patients on waitlist 3) Communicate status with transplant center annually or change	Intended to enhance communication and ensure patients do not get "lost" during the process