# Assessment of Patient Autonomy in ESRD Treatment Decision-Making Technical Expert Panel

## August 8, 2025

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## Assessment of Patient Autonomy in ESRD Treatment Decision-Making

The Centers for Medicare & Medicaid Services (CMS) has contracted with the University of Michigan Kidney Epidemiology and Cost Center (UM-KECC) to develop dialysis facility-level ESRD quality measures. The contract number is 75FCMC18D0041, task order number 75FCMC23F0001. As part of its measure development process, the University of Michigan Kidney Epidemiology and

Cost Center convenes groups of stakeholders who contribute direction and thoughtful input to the measure developer during measure development and maintenance.

UM-KECC has been tasked by CMS to explore development of dialysis facility quality measures that assess the occurrence and effectiveness of patient autonomy and treatment decision-making in patients with end-stage renal disease (ESRD) receiving care at US dialysis facilities.

## Technical Expert Panel (TEP) Objectives

The TEP had been tasked with using existing resources and their expert opinion to formulate recommendations to UM-KECC regarding the development of a draft measure that addresses potentially important quality gaps in patient autonomy in ESRD treatment decision-making. Recommended measures should be evidence based, scientifically acceptable (reliable and valid), feasible, and usable by CMS, patients, providers, and the public. Specifically, the TEP engaged in discussion to develop potential quality measures that could facilitate and measure meaningful discussions between patients and providers to help patients meaningfully participate in the determination of their own treatment plan. TEP input was sought regarding first-hand experiences with current ESRD medical decision-making, facility education programs, and existing tools for measuring patient decision-making. See Appendix 1 for the complete TEP Charter.

## Technical Expert Panel Composition

A public call for nominations opened on December 20th, 2024 and closed on January 20th, 2025. Nominations were sought from individuals with the following areas of expertise or experiential perspectives:

- Nephrologist providers (physicians, advanced practice providers), nephrology trained social workers, dieticians, and dialysis facility nursing staff
- Consumer/Patient/Family/Care Partner perspective, specifically patients with long-term dialysis
- Performance measurement experts
- Quality improvement experts
- Healthcare disparities experts
- Medical ethics experts
- Patient reported outcomes and instrument development experts

The following individuals were selected to serve on the TEP:

| Name and Credentials | Organizational Affiliation, City, State | Conflicts of Interest Disclosed |
|---|---|---|
| Alan Kliger, MD<br>***(TEP Co-chair)***<br>Nephrologist | Yale School of Medicine<br>Woodbridge, CT | None Reported |

| Name and Credentials | Organizational Affiliation, City, State | Conflicts of Interest Disclosed |
|---|---|---|
| Paul T. Conway, BA<br>***(TEP Co-chair)***<br>Chair, Policy and Global Affairs Patient Advocate | American Association of Kidney Patients (AAKP)<br>Tampa, FL | None Reported |
| Felicia Speed, PhD, LMSW<br>VP of Social Work Services | Fresenius Medical Care<br>Pelzer, SC | Employed by Fresenius Medical Care |
| Johnie Flotte, BSN, RN<br>VP of Clinical Services | US Renal Care<br>Franklin, TN | Employed by US Renal Care |
| Theodore Shaikewitz, MD<br>Nephrologist | Durham Nephrology Associates<br>Durham, NC | None Reported |
| Francesca Tentori, MD, MSCI<br>Physician Researcher, Industry Representative | DaVita Kidney Care<br>Portland, TN | Employed by DaVita Kidney Care |
| Craig Miller, PT, MPH<br>Regional Director of Therapy Home Care and Outpatient | Rivetus Rehabilitation<br>Macomb, MI | None Reported |
| Klemens Meyer, MD<br>Nephrologist | Tufts Medical Center and Dialysis Clinic, Inc<br>Boston, MA | Funds from Dialysis Clinic, Inc., which is used for salary support for DCI work. |
| Katie Cardone, PharmD, BCACP, FNKF, FASN, FCCP<br>Pharmacist | Albany College of Pharmacy and Health Services<br>Albany, NY | Sub-Investigator on Merck & Co. Clinical Trial; Consultant for GlaxoSmithKline; Spouse employed by Fresenius Kidney Care |
| Alvin Moss, MD, FACP, FAAHPM<br>Director, Center for Health Ethics and Law | West Virginia University Health Sciences Center<br>Morgantown, WV | Co-Investigator for grant from Fan Fox & Leslie R. Samuels Foundation; Co Investigator for grant from Gordon and Betty Moore Foundation |
| Vikram Aggarwal, MD, DNB, FASN<br>Nephrologist | Vantive (formerly Baxter)<br>Chicago, IL | Consultant for Vantive (formerly Baxter) |
| Samantha Gelfand, MD<br>Nephrologist | Dana-Farber Cancer Institute<br>Boston, MA | None Reported |
| Kristal Higgins<br>Patient | Olive Branch, MS | None Reported |

| Name and Credentials | Organizational Affiliation, City, State | Conflicts of Interest Disclosed |
|---|---|---|
| Jane DeMeis<br>Patient Advocate | Fairport, NY | None Reported |
| Stephanie Dixon<br>Patient Advocate | Kidney Patient Advisory Council (KPAC)<br>Rutherford, NJ | None Reported |
| ***Contractor Staff*** | | |
| Jonathan Segal, MD, MS | *Professor of Internal Medicine*, Division of Nephrology, University of Michigan, Kidney Epidemiology and Cost Center | None Reported |
| Joseph Messana, MD | *Professor of Internal Medicine*, Division of Nephrology, University of Michigan, Kidney Epidemiology and Cost Center | None Reported |
| Claudia Dahlerus, PhD | *Assistant Research Scientist,* Division of Nephrology;<br>University of Michigan, Kidney Epidemiology and Cost Center | None Reported |
| Marc Turenne, PhD | *Distinguished Research Scientist*<br>Arbor Research | None Reported |
| Jennifer Sardone, BA, PMP | *Senior Lead Project Manager,* University of Michigan, Kidney Epidemiology and Cost Center | None Reported |
| Shannon Lester-Pelham, BS | *Project Intermediate Manager,* University of Michigan, Kidney Epidemiology and Cost Center | None Reported |

## 1. Introduction

This report summarizes the discussions and recommendations that occurred during the Assessment of Patient Autonomy in ESRD Treatment Decision-Making TEP meetings convened on May 30th, and July 10th of 2025. Both meetings were public and held virtually via Zoom video-conference. The TEP provided advice and expert input on the development of potential patient autonomy and decision-making quality measures. The discussions were informed by technical expertise and experience of the TEP members, an annotated bibliography of relevant literature compiled by UM-KECC, and relevant survey instruments presented by UM-KECC.

## 2. Preliminary Activities

### 2.1 Information Gathering

Prior to the virtual TEP meeting, UM-KECC provided TEP members with Environmental Scan results that included an annotated bibliography (Appendix 2) of published literature related to patient autonomy in ESRD and patient choice in decision-making. The Annotated Bibliography included primary studies as well as meta-analyses and was organized into four categories:

- Background/Review of patient choice
- Incident Modality
- Other
- Survey Tools

UM-KECC also provided a list of related measures that are currently developed and in use (Appendix 2).

### 2.2 TEP Charter

The Assessment of Patient Autonomy in ESRD Treatment Decision-Making TEP Charter (Appendix 1) was distributed to the TEP members for review prior to the first meeting. At the first TEP meeting, UM-KECC reviewed key elements of the charter.

The role of the TEP was outlined and the following responsibilities were highlighted:

- Review evidence to determine the basis of support for the proposed measure
- Recommending draft measure specifications
- Assisting in completing the necessary documentation forms to support submission of the measures to CMS for review, and to the CBE for endorsement
- As needed, TEP members may be asked to provide input to UM-KECC as they prepare responses to CBE and public comments

There were no questions or concerns raised by TEP members about the TEP Charter and approval of the Charter was obtained.

## 3. Background for Patient Autonomy in ESRD and Decision-Making

The first TEP meeting included a brief summary of the limitations of quality measure development related to the inability to include patient choice adjustment in several quality measures submitted to the consensus endorsement entity over a period of several years while National Quality Forum (NQF) was the CBE. Some members of the Renal Standing Committee of the NQF argued that potential quality measures, particularly those involving major treatment decisions (e.g. modality choice, kidney transplant referral/listing) could not meet the Scientific Acceptability requirements set by the CMS Quality Measures Blueprint and operationalized by NQF without measuring patients' role in those treatment decisions.

As an example, assessment of a dialysis facility's rate of waitlisting for kidney transplantation or the facility's use of home dialysis modalities may not accurately reflect the quality of care by the facility if the patient makes a decision not to pursue transplantation or home dialysis. If a particular patient chooses NOT to pursue home dialysis or kidney transplantation, and the dialysis team attempted to coerce them into pursuing one of these modalities, the quality measure may demonstrate a higher success rate, but the effect on the patient could be negative and not reflective of their choice, resulting in a failure to accurately reflect quality of care from the patient perspective.

Several potential issues are highlighted by this discussion and example. First, most quality measures used in clinical medicine, and especially ESRD care, do not include assessment of patient choice, another concept termed shared decision-making, or more importantly, an assessment of adequacy of patient education about the various treatment options reflected in quality measure outcomes. Factors that may contribute to the failure of patient choice adjustment include lack of validated instruments for the assessment of patient choice for either global or specific treatment option decisions, and similarly, a relative paucity of validated instruments that address the quantity and quality of patient education regarding the available treatment options.

This TEP is an attempt to gather perspectives of both patients and providers regarding the role of patient choice in clinical decision-making, to begin to assess whether dialysis stakeholders believe that inclusion of patient choice measurement is an important component of most or all chronic dialysis quality measures, and to explore some specific options that could help inform development of potential patient choice instruments that might be applied to some or all dialysis facility quality measures in the future.

A high-level overview of Patient Autonomy in ESRD and Decision-Making was provided by TEP co-chairs, Dr. Alan Kliger and Mr. Paul T. Conway. The central question relates to how patient choice can be measured and how do we know if it has been included in subsequent medical decision-making. Quality measures need to reflect that patient choice should be at the center of decision-making based on the advice and information given by providers. Concern was raised that current measures could have the unintended consequences of pushing providers to meet a benchmark or outcome without engaging patients or considering patient choice. It was noted that there is no specified model of shared decision-making, but rather it is what patients perceive as their conversations with providers that they trust about choices that they can make to best facilitate their care. Examples of how patient choice has been included and excluded in medical decision-making were provided by the TEP Co-chairs which further detailed the importance of having patient autonomy be at the center of newly developed measures. The TEP Co-chairs further went on to describe Shared Decision-Making Models currently being used in medical care settings and asked the TEP for feedback about personal and professional experiences. This information was intended to be a framework for the TEP as they began their discussions surrounding patient autonomy and decision-making.

## 3.1 Discussion of Patient Autonomy in the Chronic Dialysis Setting

Several themes emerged from TEP members during the first meeting. Patients shared similar stories of difficulty after receiving an ESRD diagnosis and felt they had to learn more independently about treatment options after discussing them with dialysis providers. Several barriers to patients making informed choices were discussed. One patient noted that some dialysis providers do not adequately inform patients about modality options such as transplant or home dialysis, thus limiting choices. Another added that the overall quality of the education about modality options was inadequate and did not support decision making. Others noted that they wanted additional information to support decision making but had difficulty in obtaining access to education resources. In addition, complex medical terminology, if not simplified to a level that patients can readily understand, was raised as an additional barrier. Some patients indicated that they relied on family members to help with decision making due to cognitive difficulties related to advanced kidney disease before or just after starting dialysis.

There was general acknowledgement that there is a wide range of perceived patient autonomy based on demographics or cultural attitudes towards decision making. TEP members felt that substantive patient education is an important component of patient choice. However, many TEP members felt that the current approach to comprehensive patient education about treatment options often leaves patients feeling confused and overwhelmed. Several TEP members mentioned that it was helpful to have a trained Peer Mentor guide them through the process of understanding treatment options, but noted that not all patients have access to a patient advocate. A TEP member suggested that uniform educational materials would be helpful to standardize the process. However, potential difficulties related to a universal tool were also raised, specifically around potential difficulty accounting for differences between facilities, regions, and cultures.

Other examples were provided by healthcare provider TEP members of scenarios where patients request less information provided to them and would prefer for their provider to make the decisions for them. UM-KECC would need to consider the heterogeneity of patient choice preferences regarding patient involvement in clinical decision-making if a patient choice instrument is ultimately developed.

TEP members noted that informed patient choice is something that evolves over time in that an initial decision may impact subsequent decisions as information is processed or a patient's situation changes. A point was made that while the TEP is focused on patient choice for patients with ESRD as opposed to earlier stages of CKD. It was noted that there is a growing emphasis on moving care upstream to allow more opportunities for education, discussion, and patient choice. One TEP member offered the following comment regarding this dichotomy.

> "i.e. restricting ourselves to considering only decisions after the patient has been certified as having ESRD, limits our ability to think creatively about changes that will enhance both ESRD patient autonomy and health, and those of patients with earlier stages of kidney disease."

During the discussion, TEP members pointed out that understanding what is important to an individual patient, including their aspirations, is central to understanding how they will make decisions about their care.  This will obviously be different for each patient, and looking at the traditionally measured and valued "hard" outcomes, such as hospitalization or mortality, may miss the point of what matters most to patients and guides their choices.  The challenge then is how to translate the one-on-one interaction between a patient and clinician that considers patient choice in the decision making to the population health level with overarching quality measures.

There was additional discussion that few patients participate in dialysis plan of care conferences, where they at least theoretically have an opportunity to exercise choice, and that preferences are often communicated indirectly.  Members of the TEP emphasized that as committed as providers may be to shared decision making, current models of care do not encourage that process.

Ultimately, the TEP supported the concept that patient autonomy, informed patient choice, and patient preferences should always guide medical care. However, the group noted that there is significant variability in practical execution of, and achievement of this goal. One of the co-chairs described multiple advances in healthcare and bipartisan national health policy to support patient choice over the past decade, including: star rating quality reporting on healthcare facilities, FDA approval of medical devices, adoption of telemedicine, legislative actions by Congress, and the Executive Order on Advancing American Kidney Health.  It was noted that patient choice also comprises the patient's decision about how much information they want to hear, and about who the patient chooses to be the decision-maker, that is, the patient, a family member or a treating clinician.

The TEP discussed how best to measure patient choice in clinical practice.  This included the challenges of hearing directly from patients so as to avoid the inherent bias of provider attestation. A tool to assess patient choice would need to be relatively simple and easy to implement. Consideration needs to be given to when and how often it is done. In addition, that assessment may be different based on the quality measure for which it is being used. The theme of survey fatigue recurred the discussion a number of times. A TEP member suggested that the group try to decide whether the assessment of patient choice is going to come from the patient, or from the provider.

## 3.2 Summary of Discussion- TEP Meeting #1

1. Patient Choice/Autonomy is an important goal and is generally supported by TEP members.
2. Patient choice includes the option of the patient to defer care choices to others, both within and outside of healthcare team.
3. Some barriers to patient choice identified during discussion included cognitive impairment, particularly just prior to or just following initiation of dialysis (uremia, psychological stress related to number and complexity of changes occurring) and also lack of specific, substantive knowledge needed to make an informed choice.
4. At some points, not all patients are capable of making treatment-related choices. This raised the important question of whether a surrogate is always identified, available, and utilized.

## 3.3 Balancing Evidence Driven Care with Patient Autonomy and how to Measure Patient Choice

The starting point of discussion at the second TEP meeting was reiteration of the consensus that patient autonomy/choice is important and must be accounted for in patients' treatment decisions. UM-KECC and one of the TEP co-chairs summarized the key takeaways from the first meeting. TEP members also noted that other topics require further discussion, such as the timing of decision-making, who is the source of determining whether patient choice occurred, cases where the decision-maker is not the patient, the challenge posed when individual patients make a choice that is not consistent with best clinical practice, and tailoring decisions to patients' goals. The TEP co-chair felt it was important to re-state the above issues as the basis for further discussion on the following for the second meeting:

1. Do we support the primacy of patient autonomy? Do we agree that although best-evidence practice may suggest superior approaches for a population of individuals, each individual has the right to take that evidence into consideration and then exercise autonomy to decide what she/he chooses to do for him/herself?
2. ***How do we measure quality in a population where there is a best overall practice, yet each individual has the right and ability to make their own choice?*** What's best for the population may not be best for a particular individual.
3. If measuring best practice in a population allows for individual autonomy, ***then how do we measure it?*** How can we incorporate it into a measurement system in a way that is useful?

4. In light of these caveats, ***are there existing tools to help us move forward, and what are they?***

The TEP co-chair opened the discussion. TEP members generally agreed with the paradigm outlined in questions #1 and 2, insofar as there was strong agreement that patient autonomy and individual choice was of central ethical importance for clinical decision making.

One TEP member suggested measuring the number of patients that refuse a treatment option and then compare that against some threshold. It was suggested, for example, that the finding that a large proportion of a dialysis facility's patients decline transplant might be evidence that the facility is not educating patients well about transplant. The TEP co-chair noted that the patient decision should not be defined as a refusal, but rather a choice.

TEP members discussed the tension between best practice based on strong evidence versus what the patient chooses to do, and in some situations, not to do. Several comments described the importance of considering the individual's particular situation, including economic, social, and personal belief components, when deciding on the best treatment. Evidence based treatment, such as that based purely on guideline recommendations, may not be the best care for the individual. For example, a patient may choose not to pursue treatment that could be expected to improve physical health and prolong life, such as having a kidney transplant rather than continuing dialysis treatment. One TEP member said that decisions should be take account of a blend of objective and subjective considerations, including the patient's knowledge of themselves, but that many of our educational efforts may not be adequate to inform decisions. Some members favored standardized education, but others argued that standardization of education may not be the best way to help individuals figure out what is right for them, and emphasized the value of interaction of the patient with an individual clinician who has gotten to know the patient, and who can work with the patient to figure out what is best.

There was further discussion on what should be included in measurement of patient choice to make sure it is captures the extent to which choice is based on informed decision making. One TEP member made the point that the focus should be on goal-concordant care as opposed to best clinical practice, the latter focusing on outcomes such as patient longevity (living longer). The TEP member acknowledged this reflects a paradigm shift in how to think about delivering the best care, and that reports have shown many patients list independence as the most important thing to them, not longevity (a long life). Measuring goal concordant care at the individual level is possible but measuring it at the population level is very difficult, and there are no obvious instruments that can do that. The aim would be to figure out how to measure goal concordant care in kidney failure care. Another TEP member noted that the best treatment option is the one that the patient is most likely to stick with.

TEP members continued to discuss the concept of goals of care and how that relates to patient choice.  Two TEP members discussed the distinction that goals of care are not goals of treatment decisions, but rather the patient's personal goals – what the patient wants, not what the physician decides. The Co-chair asked them if they have tools in mind that get at incorporating goals of care in patient treatment decision making. One TEP member gave an example of short surveys they used to elicit goals of care that were used to support shared decision making about their treatment options. One TEP member referenced the patient life goals survey developed by UM-KECC which does get at this concept of goal concordant care. They noted that some implementation questions need to be sorted out, that such a goals survey does exist, but that it has not been implemented yet.

UM-KECC next presented an illustration of the potential sources of data for measuring patient choice. These are health care providers/health care team, physician, health care recipient, and their family and others. The tools used to collect data from these sources include electronic health records, paper forms including surveys, and other documents. Information about the content and effectiveness of those discussions in determining patient choice could be documented in the health record of the dialysis facility/organization, surveying the provider, the patient, or both, or by surveying family members and caregivers about the discussion and decision-making experience. For example, a document in the electronic health record documents a conversation or notes what the patient decided, or a brief survey that includes patient report of what they decided. All of these are sources of determining whether patient choice was part of informed decision making.

## 4. Current Instruments and Important Areas for New Instrument Development

The next area of discussion focused on a review of existing patient reported outcome instruments that are related to the concept of patient choice and autonomy. UM-KECC presented an overview of five existing survey tools that either measure shared decision-making, patient knowledge about treatment options, patient preference for level of involvement in decision-making, or some combination of these concepts (see Appendix 2 for individual tools and summary table).

UM-KECC presented an overview of the EDITH, KART, and discreet-choice SHPT which were developed specifically for use with people with kidney disease (advanced CKD and/or ESKD). The other two tools, SDM-9 and Control Preferences Scale, are "generic" and can be used with people with any condition/disease type; they have also been used in two studies on the advanced CKD population. SDM-9 and CPS are shorter compared to the kidney disease specific tools. EDITH, KART, and SHPT tools were developed with participation from patients (focus groups; interviews); the European Kidney Patients Federation also supported development of EDITH. UM-KECC highlighted specific items in each tool as potentially relevant to shared decision-making, or knowledge assessment of specific treatments (KART, SHPT), or measuring the level of involvement the patient wishes to be involved in decision-making (CPS), respectively.

The TEP co-chair asked UM-KECC if these tools are something that can be used as a starting point for measuring patient choice, for example, certain items in any of the surveys that could be used to build a patient choice measure, or using a combination of these tools to measure patient choice for a specific treatment decision and then use that to augment the clinical measure to which it applies. UM-KECC responded that some of the items are a potential starting point but that the major challenge will continue to be survey data collection from patients given there is no structure in place to collect these data and achieve sufficient response rates to support measure development and testing. Prior survey efforts faced major barriers in obtaining facility cooperation to support data collection.

The TEP co-chair then opened up the discussion to get feedback from the TEP members about these instruments as a potential starting point. Several TEP members raised the concern about burden as patients already fill out many surveys, and never get feedback or information on how their survey responses are used to improve their care. This continues to be a concern and patients feel like it is a waste of time to fill out surveys several times a year but not know how/if the results were used by the facility to address care delivery issues or patient quality of life. One TEP member related a perception by many dialysis patients that the surveys they complete may not result in meaningful change in the dialysis care environment, either because the results are ignored, or the survey may not be asking questions that are relevant from the patient perspective. This individual noted that “burden” needed to be considered in the context of meaningful questions with relevance to quality of care from the patient perspective. Additional survey requests that incorporate meaningful questions from the patient perspective and that result in actionable and important results for quality improvement and overall care improvement would more likely be supported by patients. There was general agreement that the potential burden of additional survey instruments should be minimized by keeping the survey brief as possible.

Several TEP members also raised the concern about facilities administering surveys because patients would feel pressure to give good marks, or may not even want to take the survey out of fear of retaliation. One TEP member raised the point that in addition to measuring if conversations about a patient’s choice are occurring, a new measure should also include what happens after the conversation. Timing of survey administration was raised as a potential issue as well. Several patients and some providers raised the issue that attempting to perform the survey at or near the initiation of dialysis would be difficult. Patients described “cloudiness” of mental processes attributed to uremia as well as the overwhelming psychosocial stresses and health implications of the transition to chronic dialysis. One TEP member suggested that a patient choice should be measured earlier in the disease process, when patients have CKD not yet requiring dialysis treatment. Another TEP member that suggested a different way to assess patient choice would be as part of the survey and oversight process. They suggested that surveyors could interview patients that are not on the kidney transplant waitlist to corroborate that they made an informed choice not to pursue a transplant. The TEP co-chair summarized the discussion and where it appeared there was TEP agreement.

1. First, patient autonomy in medical decision-making is important, but patients vary in their preferences with respect to autonomy. Some patients may choose to be the primary decision-maker for medical decisions, while others may defer to the clinical team, to family members, or choose a shared decision-making approach.
2. A number of existing survey tools related to different aspects of patient autonomy and goal-directed care could be used as a foundation for development of a specific PRO tool for use in the Medicare ESRD dialysis program.
3. There was general enthusiasm for the potential benefits of developing instrument(s) to assess the contribution of patient choice in dialysis facility quality outcomes. Potential unintended consequences include patient and provider burden, risks to patient confidentiality, and uninterpretable results if the number of responses from a facility is too small to allow interpretation of the results.
4. TEP members also generally felt that increased emphasis on assessment of patient choice in dialysis-related treatment decision-making could improve overall satisfaction with care for patients treated by chronic dialysis.

Next the TEP co-chair asked if UM-KECC had enough information to move forward with development of a patient choice measure. UM-KECC and the TEP co-chair discussed that there is no existing tool available that gets at all components of patient choice that the TEP felt were important. More work would be needed to determine whether it is possible to build on any of the existing tools to develop a patient choice measure. It was recognized that some definitional issues remain, and importantly, that data collection and low response rates remain a significant barrier without a structure in place to allow for regular data collection and encourage better response rates. Related to this is the consideration that any new measure development requires time to test a measure (once data are available) to make sure it satisfies the criteria of scientific acceptability.

## 5. Next Steps

Next steps include UM-KECC's plan to distribute the draft TEP Summary to all TEP members for review, with emphasis on accurate capture of TEP member discussion points and suggestions. After

TEP member review and completion of any required edits, the summary report will be provided to CMS.

## 6. Public Comments

No public comments were received at either of the two TEP meetings. Following the second TEP meeting, two TEP members offered the following comments after reviewing the draft TEP summary.

Comment #1

"This is a good representation of what was discussed. I was just at the second session, and on reading the transcript of session one, and am having trouble reconciling the generally agreed upon importance of patient autonomy, with the first session's recognition that patients can at times be poorly educated about the various choices.

If a patient makes a choice based on poor education from the dialysis providers, then the providers could reasonably be penalized for that choice.

The current system of penalties, for refusing transplant listing, or a "superior" type of dialysis access, would then not need to be revised.
Properly educated rational patients should always reach a particular conclusion that is a conclusion that some could reach.

I believe that the consensus opinion was that patient autonomy does exist and patients are entitled to customize their care in a way that might not seem optimal for an idealized patient, regardless of the education provided.

Complicated questionnaires and, by extension, complex assessment of the quality of education provided were not felt to be practical. The system of quality measures needs to be kept simple.

Assuming we still want some quality measures, then perhaps we could suggest using quality measures that are felt to be so obvious that a reasonable individual would be able to make these decisions based upon "common sense" rather than a well-executed education package. then we could allow a percentage of patients to opt out of meeting the quality measures."

Comment #2

"...raise the importance of respecting individual spiritual and cultural beliefs in the context of patient care choice, citing recent work examining this issue that appeared in the 2022 USRDS

Annual Report - https://usrds-adr.niddk.nih.gov/2022/end-stage-renal-disease/12-patient-experience-prognostic-expectations-values-around-life-prolongation-and-the-importance-of-religious-or-spiritual-beliefs]"

## 7. Appendices

1. TEP Charter
2. TEP Literature Review
3. TEP Slides

## Appendix 1- TEP Charter

# Technical Expert Panel (TEP) Charter

## Project Title: Assessment of Patient Autonomy for Clinical Outcomes used in Quality of Care Outcomes Reported for U.S. Chronic Dialysis Facilities and Providers

TEP Expected Time Commitment and Dates:

Participate in 2-3 virtual meetings, approximately 2-3 hours in duration. The meetings will take place between February 2025- March 2025.
All meetings will be held virtually, via a Zoom video conferencing platform.

## Project Overview:

The Centers for Medicare & Medicaid Services (CMS) contracted University of Michigan Kidney Epidemiology and Cost Center (UM-KECC) to collect stakeholder feedback for the assessment of patient autonomy in ESRD treatment decision making. The contract name is Kidney Disease Quality Measure Development, Maintenance, and Support. The contract number is 75FCMC18D0041 and the task order number is 75FCMC23F0001. As part of its measure development process, University of Michigan Kidney Epidemiology and Cost Center (UM-KECC) convenes groups of stakeholders who contribute direction and thoughtful input to the measure developer during measure development and maintenance.

In our society, there is a fundamental expectation that health care providers respect patient autonomy or choice in the process of shared decision-making. In practice, clinicians are trained that the informed consent process is one way in which we document our adherence to this critically important ethical principle. Addressing patient autonomy, patient choice, and informed consent during the measure development and maintenance process will be essential if new and pre-existing clinical outcome quality measures are to be truly patient centered and judged valid by the dialysis community.

What is somewhat less emphasized is the principle that informed consent and patient choice is very dependent on the quality and quantity of information provided about the risks, benefits, and alternatives available for treatment. Multiple barriers may affect shared decision making and informed consent, including inadequate education by the healthcare team, healthcare provider bias, limited understanding of medical concepts by the patient due to cognitive or educational limitations, and potential limitations of the provider-patient relationship. These can undermine the development of true informed consent for medical care as well as well-informed patient decisions about their care, and therefore, provide potential challenges to successful adherence to the principle of patient autonomy. In addition, financial or other incentives may sway healthcare providers to direct patients towards a particular type of treatment.  It is often very difficult to determine how many of these issues are present in any given treatment choice. When present, it is also difficult to determine if the issue influences the appropriate use of informed consent principles and practice regarding patient autonomy in treatment choices.

Identification of a method for assessing the contribution of patient choice in medical decisions is critical. In addition, quality improvement programs generally provide incentives for providers to deliver ESRD care in ways supported by evidence. These incentives may not be aligned with patient choice for those who choose an alternative treatment paradigm. Many clinicians and patients involved in the consensus endorsement process have voiced concerns that implementation of quality metrics failing to explicitly address patient choice may result in unacceptable consequences for members of the dialysis community.

## Project Objectives:

Develop a strategy for defining and measuring the contributions of "patient choice" to both the health outcomes and intermediate outcomes used to assess clinical quality in U.S. dialysis facilities. The project objective assumes that at least a partially operational shared decision model is currently present in the U.S dialysis system

## Technical Expert Panel (TEP) Objectives:

Develop recommendations for the most effective means of measuring the contributions of "patient choice" to both the health outcomes and intermediate outcomes used to assess clinical quality in U.S. dialysis facilities. A TEP of approximately *10-20* individuals will *1) Consider whether the shared decision model currently reflects the majority of treatment decisions made in U.S. chronic dialysis programs, 2) Review the types of and extent to which patient choices impacts clinical quality outcomes in a shared decision environment, and 3) Develop recommendations for the most effective means of measuring the contributions of "patient choice" to both the health outcomes and intermediate outcomes used to assess clinical quality in U.S. dialysis facilities.*

## TEP Requirements:

The TEP will be composed of individuals with differing areas of expertise and perspectives, including

- Patients 18 years or older who are receiving long-term dialysis in the United States/ US Territory;
- Dialysis care providers including nephrologists, nurses, social workers, and administrative staff;
- Individuals with consumer/patient/family perspective and consumer and patient advocates; specifically, patients with long-term dialysis;
- Individuals with perspectives on healthcare disparities in ESRD;
- Expertise in performance measurement and quality improvement;

- Expertise in patient reported outcomes and instrument development or implementation;
- Expertise in medical ethics

## Scope of Responsibilities:

UM-KECC is seeking balanced representation of members of the ESRD community, clinical, and ethical experts. This would include patients, patient-advocates, dialysis providers, and medical ethics experts gather feedback about patient autonomy in ESRD treatment and decision-making. It is UM-KECC's intent to facility a Technical Expert Panel (TEP) discussion through presentation of background information and a description of the quality measure. The TEP will be led by one or two Chairperson(s), whose responsibility is to lead the discussion and attempt to develop consensus opinions from TEP membership regarding the topics described in the TEP Objects section above. The TEP is intended to be advisory to UM-KECC.

The role of each TEP member is to provide advisory input to UM-KECC.

*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 moderator(s) will work with the TEP chairperson(s) to ensure the panel discussions focus on the review of the assessment of patient autonomy in ESRD treatment decision-making developed by the contractor. During discussions, UM-KECC moderator(s) may advise the TEP and chairperson(s) on the needs and requirements of the CMS contract and the timeline, may provide specific guidance and criteria that must be met with respect to CMS and the Consensus Based Entity (CBE) review of candidate measures.

*Role of TEP Chairperson(s):* Prior to the TEP meetings, one or two TEP members are designated as the chairperson(s) by the measure contractor. The TEP chairperson(s) are responsible, in partnership with the moderator(s), for directing the TEP to meet the expectations for TEP members, including provision of advice to the contractor.

*Duties and role of TEP members:* According to the CMS Measure Management System Blueprint, TEPs are advisory to UM-KECC, as the measure contractor. In this advisory role, the primary duty of the TEP is to discuss the impact of patient autonomy in ESRD treatment decision-making and quality measure outcomes, with particular emphasis on 1) importance of patient choice exclusions in assessment of clinical outcomes and 2) discussion and input regarding how to assess patient choice influence on dialysis facility outcomes. TEP members are expected to attend the virtual meetings in February and/or March 2025 and be available for any follow-up teleconferences and correspondence as needed in order to support the submission and review of the TEP Report to CMS. Some follow up activities may be needed after post-TEP work has occurred. TEP members will review the proposed charter prior to the planned teleconference along with any supporting documents. Any comments or concerns with the charter should be provided to the TEP chairperson(s) and UM-KECC prior to the planned teleconference. TEP members who choose to participate in the meetings are providing their implicit agreement to the TEP charter content in its final form as of the first TEP meeting. UM-KECC and the chairperson(s) will provide descriptions of the overall tasks of the TEP and the goals/objectives at the first TEP meeting. TEP members will also be provided with background information about the discussion topics and will be asked to contribute additional literature or other pertinent background for TEP consideration as appropriate.

During the TEP Meetings:

- TEP members will discuss the clinical relevance of this topic and how implementation of TEP recommendations might improve interpretation of clinical quality measures used in U.S. dialysis facility quality reporting programs.

Following the TEP meetings, UM-KECC will prepare a summary of recommendations in a TEP Report. The summary report will include TEP meeting discussions and recommendations. As necessary, UM-KECC will have additional contact with the TEP chairperson(s) and TEP members to ensure that the TEP deliberations and recommendations are accurately reflected in the TEP Report. As needed, TEP members may be asked to provide input to UM-KECC as they prepare responses to CMS and public comments.

## Guiding Principles:

Participation as a TEP member is voluntary and the measure developer records the participant's input in the meeting minutes, which the measure developer will summarize in a report that they may disclose to the public. If a participant has chosen to disclose private, personal data, then related material and communications are not covered by patient-provider confidentiality. Patient/caregiver participants may elect to keep their names confidential in public documents. TEP organizers will answer any questions about confidentiality.

All potential TEP members must disclose any significant financial interest or other relationships that may influence their perceptions or judgment. It is unethical to conceal (or fail to disclose) conflicts of interest. However, there is no intent for the disclosure requirement to prevent individuals with particular perspectives or strong points of view from serving on the TEP. The intent of full disclosure is to inform the measure developer, other TEP members, and CMS about the source of TEP members' perspectives and how that might affect discussions or recommendations.

The TEP may use both verbal consensus and formal voting by secret ballot for decision-making, depending on the context of the decision. For administrative and other decisions about the agenda, direction of discussion, and other minor operational decisions, informal verbal consensus directly by the TEP chairs will be utilized. In order to objectively record TEP recommendations, formal votes utilizing secret ballot may be employed.

## Estimated Number and Frequency of Meetings:

Attend 2-3 virtual meetings, approximately 2-3 hours in duration. The meetings will take place between February-March, 2025.

# Appendix 2- Literature Review

## Background/Review

Moss AH. **Revised dialysis clinical practice guideline promotes more informed decision-making.** *Clin J Am Soc Nephrol*. 2010;5(12):2380-2383. doi:10.2215/CJN.07170810

PMID: 21051749

Abstract: Over a decade ago, the Renal Physicians Association and the American Society of Nephrology published the clinical practice guideline, Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis, to assist nephrologists, patients, and families in making decisions to initiate and withdraw dialysis. Since then, researchers have extensively studied dialysis decision-making, and there is a substantial body of new evidence with regard to 1) the poor prognosis of some elderly stage 4 and 5 chronic kidney disease patients, many of whom are likely to die before initiation of dialysis or for whom dialysis may not provide a survival advantage over medical management without dialysis; 2) the prevalence of cognitive impairment in dialysis patients and the need to periodically assess them for decision-making capacity; 3) the under-recognition and undertreatment of pain and other symptoms in dialysis patients; 4) the underutilization of hospice in dialysis patients; and 5) the distinctly different treatment goals of ESRD patients based on their overall condition and personal preferences. The Renal Physicians Association developed this second edition of the guideline to provide clinicians, patients, and families with 1) the most current evidence about the benefits and burdens of dialysis for patients with diverse conditions; 2) recommendations for quality in decision-making about treatment of patients with acute kidney injury, chronic kidney disease, and ESRD; and 3) practical strategies to help clinicians implement the guideline recommendations.

Tamura MK, Tan JC, O'Hare AM. **Optimizing renal replacement therapy in older adults: a framework for making individualized decisions.** Kidney Int. 2012;82(3):261-269. doi:10.1038/ki.2011.384

PMID: 22089945

Abstract: It is often difficult to synthesize information about the risks and benefits of recommended management strategies in older patients with end-stage renal disease since they may have more comorbidity and lower life expectancy than patients described in clinical trials or practice guidelines. In this review, we outline a framework for individualizing end-stage renal disease management decisions in older patients. The framework considers three factors: life expectancy, the risks and benefits of competing treatment strategies, and patient preferences. We illustrate the use of this framework by applying it to three key end-stage renal disease decisions in older patients with varying life expectancy: choice of dialysis modality, choice of vascular access for hemodialysis, and referral for kidney transplantation. In several instances, this approach might provide support for treatment decisions that directly contradict available practice guidelines, illustrating circumstances when strict application of guidelines may be inappropriate for certain patients. By combining quantitative estimates of benefits and harms with qualitative assessments of patient preferences, clinicians may be better able to tailor treatment recommendations to individual older patients, thereby improving the overall quality of end-stage renal disease care.

Williams AW, Dwyer AC, Eddy AA, et al. **Critical and honest conversations: the evidence behind the "Choosing Wisely" campaign recommendations by the American Society of Nephrology.** Clin J Am Soc Nephrol. 2012;7(10):1664-1672. doi:10.2215/CJN.04970512

PMID: 22977214

Abstract: Estimates suggest that one third of United States health care spending results from overuse or misuse of tests, procedures, and therapies. The American Board of Internal Medicine Foundation, in partnership with Consumer Reports, initiated the "Choosing Wisely" campaign to identify areas in patient care and resource use most open to improvement. Nine subspecialty organizations joined the campaign; each organization identified five tests, procedures, or therapies that are overused, are misused, or could potentially lead to harm or unnecessary health care spending. Each of the American Society of Nephrology's (ASN's) 10 advisory groups submitted recommendations for inclusion. The ASN Quality and Patient Safety Task Force selected five recommendations based on relevance and importance to individuals with kidney disease. Recommendations selected were: (1) Do not perform routine cancer screening for dialysis patients with limited life expectancies without signs or symptoms; (2) do not administer erythropoiesis-stimulating agents to CKD patients with hemoglobin levels ≥10 g/dl without symptoms of anemia; (3) avoid nonsteroidal anti-inflammatory drugs in individuals with hypertension, heart failure, or CKD of all causes, including diabetes; (4) do not place peripherally inserted central catheters in stage 3-5 CKD patients without consulting nephrology; (5) do not initiate chronic dialysis without ensuring a shared decision-making process between patients, their families, and their physicians. These five recommendations and supporting evidence give providers information to facilitate prudent care decisions and empower patients to actively participate in critical, honest conversations about their care, potentially reducing unnecessary health care spending and preventing harm.

Hussain JA, Flemming K, Murtagh FE, Johnson MJ. **Patient and health care professional decision-making to commence and withdraw from renal dialysis: a systematic review of qualitative research.** *Clin J Am Soc Nephrol*. 2015;10(7):1201-1215. doi:10.2215/CJN.11091114

PMID: 25943310

Abstract: Background and objective: To ensure that decisions to start and stop dialysis in ESRD are shared, the factors that affect patients and health care professionals in making such decisions must be understood. This systematic review sought to explore how and why different factors mediate the choices about dialysis treatment.

Design, setting, participants, & measurements: MEDLINE, Embase, CINAHL, and PsychINFO were searched for qualitative studies of factors that affect patients' or health care professionals' decisions to commence or withdraw from dialysis. A thematic synthesis was conducted.

Results: Of 494 articles screened, 12 studies (conducted from 1985 to 2014) were included. These involved 206 patients (most receiving hemodialysis) and 64 health care professionals (age ranges: patients, 26-93 years; professionals, 26-61 years). For commencing dialysis, patients based their choice on "gut instinct," as well as deliberating over the effect of treatment on quality of life and survival. How individuals coped with decision-making was influential: Some tried to take control of the problem of progressive renal failure, whereas others focused on controlling their emotions. Health care professionals weighed biomedical factors and were led by an instinct to prolong life. Both patients and health care professionals described feeling powerless. With regard to dialysis withdrawal, only after prolonged periods on dialysis were the realities of life on dialysis fully appreciated and past choices questioned. By this stage, however, patients were physically dependent on treatment. As was seen with commencing dialysis, individuals coped with treatment withdrawal in a problem- or emotion-controlling way. Families struggled to differentiate between choosing versus allowing death. Health care teams avoided and queried discussions regarding dialysis withdrawal. Patients, however, missed the dialogue they experienced during pre-dialysis education.

Conclusions: Decision-making in ESRD is complex and dynamic and evolves over time and toward death. The factors at work are multifaceted and operate differently for patients and health professionals. More training and research on open communication and shared decision-making are needed.

Ladin K, Pandya R, Perrone RD, et al. **Characterizing Approaches to Dialysis Decision Making with Older Adults: A Qualitative Study of Nephrologists.** Clin J Am Soc Nephrol. 2018;13(8):1188-1196. doi:10.2215/CJN.01740218

PMID: 30049850

Abstract: Background and objectives: Despite guidelines recommending shared decision making, nephrologists vary significantly in their approaches to discussing conservative management for kidney replacement therapy with older patients. Many older patients do not perceive dialysis initiation as a choice or receive sufficient information about conservative management for reasons incompletely understood. We examined how nephrologists' perceptions of key outcomes and successful versus failed treatment discussions shape their approach and characterized different models of decision making, patient engagement, and conservative management discussion.

Design, setting, participants, & measurements: Our qualitative study used semi-structured interviews with a sample of purposively sampled nephrologists. Interviews were conducted from June 2016 to May 2017 and continued until thematic saturation. Data were analyzed using typological and thematic analyses.

Results: Among 35 nephrologists from 18 practices, 20% were women, 66% had at least 10 years of nephrology experience, and 80% were from academic medical centers. Four distinct approaches to decision making emerged: paternalist, informative (patient led), interpretive (navigator), and institutionalist. Five themes characterized differences between these approaches, including patient autonomy, engagement and deliberation (disclosing all options, presenting options neutrally, eliciting patient values, and offering explicit treatment recommendation), influence of institutional norms, importance of clinical outcomes (e.g., survival and dialysis initiation), and physician role (educating patients, making decisions, pursuing active therapies, and managing symptoms). Paternalists and institutionalists viewed initiation of dialysis as a measure of success, whereas interpretive and informative nephrologists focused on patient engagement, quality of life, and aligning patient values with treatment. In this sample, only one third of providers presented conservative management to patients, all of whom followed either informative or interpretive approaches. The interpretive model best achieved shared decision making.

Conclusions: Differences in nephrologists' perceptions of their role, patient autonomy, and successful versus unsuccessful encounters contribute to variation in decision making for patients with kidney disease.

Chan CT, Blankestijn PJ, Dember LM, et al. **Dialysis initiation, modality choice, access, and prescription: conclusions from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference.** Kidney Int. 2019;96(1):37-47. doi:10.1016/j.kint.2019.01.017

PMID: 30987837

Abstract: Globally, the number of patients undergoing maintenance dialysis is increasing, yet throughout the world there is significant variability in the practice of initiating dialysis. Factors such as availability of resources, reasons for starting dialysis, timing of dialysis initiation, patient education and preparedness, dialysis modality and access, as well as varied "country-specific" factors significantly affect patient experiences and outcomes. As the burden of end-stage kidney disease (ESKD) has increased globally, there has also been a growing recognition of the importance of patient involvement in determining the goals of care and decisions regarding treatment. In January 2018, KDIGO (Kidney Disease: Improving Global Outcomes) convened a Controversies Conference focused on dialysis initiation, including modality choice, access, and prescription. Here we present a summary of the conference discussions, including identified knowledge gaps, areas of controversy, and priorities for research. A major novel theme represented during the conference was the need to move away from a "one-size-fits-all" approach to dialysis and provide more individualized care that incorporates patient goals and preferences while still maintaining best practices for quality and safety. Identifying and including patient-centered goals that can be validated as quality indicators in the context of diverse health care systems to achieve equity of outcomes will require alignment of goals and incentives between patients, providers, regulators, and payers that will vary across health care jurisdictions.

Lok CE, Huber TS, Lee T, et al. **KDOQI Clinical Practice Guideline for Vascular Access: 2019 Update** [published correction appears in Am J Kidney Dis. 2021 Apr;77(4):551. doi: 10.1053/j.ajkd.2021.02.002.]. Am J Kidney Dis. 2020;75(4 Suppl 2):S1-S164. doi:10.1053/j.ajkd.2019.12.001

PMID: 32778223

Abstract: The National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (KDOQI) has provided evidence-based guidelines for hemodialysis vascular access since 1996. Since the last update in 2006, there has been a great accumulation of new evidence and sophistication in the guidelines process. The 2019 update to the KDOQI Clinical Practice Guideline for Vascular Access is a comprehensive document intended to assist multidisciplinary practitioners care for chronic kidney disease patients and their vascular access. New topics include the end-stage kidney disease "Life-Plan" and related concepts, guidance on vascular access choice, new targets for arteriovenous access (fistulas and grafts) and central venous catheters, management of specific complications, and renewed approaches to some older topics. Appraisal of the quality of the evidence was independently conducted by using a Grading of Recommendations Assessment, Development, and Evaluation (GRADE) approach, and interpretation and application followed the GRADE Evidence to Decision frameworks. As applicable, each guideline statement is accompanied by rationale/background information, a detailed justification, monitoring and evaluation guidance, implementation considerations, special discussions, and recommendations for future research.

## Incident Modality

Winkelmayer WC, Glynn RJ, Levin R, Owen W Jr, Avorn J. **Late referral and modality choice in end-stage renal disease.** Kidney Int. 2001;60(4):1547-1554. doi:10.1046/j.1523-1755.2001.00958.x

PMID: 11576371

Abstract: Background: We sought to determine whether late versus early referral to a nephrologist in patients with chronic kidney disease influences the initial choice of hemodialysis (HD) versus peritoneal dialysis (PD) or the likelihood of switching treatment modalities in the first six months of therapy.

Methods: Using New Jersey Medicare/Medicaid claims, all patients who started RRT between January 1991 and June 1996 and were diagnosed with renal disease more than one year prior to RRT were identified. In the resulting cohort of 3014 patients, 35% had their first nephrologist consultation < or =90 days prior to initiation of dialysis.

Results: After controlling for demographic characteristics, socioeconomic status and underlying renal disease, age, black race [Odds ratio (OR) = 0.56], race other than black or white (OR = 0.56), and socioeconomic status (OR = 0.68) influenced the choice of initial treatment modality, but timing of the referral did not. However, patients starting on PD who were referred late were 50% more likely to switch to HD than were patients who saw a nephrologist earlier [Hazard's ratio (HR) = 1.47]. In patients originally on HD, diabetic nephropathy (HR = 1.49) and black race (HR = 0.69) influenced the likelihood of switching to PD, but the timing of referral did not.

Conclusions: These results refute earlier findings that late referral may limit access to PD. We found that modality choice depends on factors such as age, race, or socioeconomic status, rather than on than timing of nephrologist referral. Late referral does not influence the likelihood to switch modality in patients starting on HD, but does so in patients starting on PD.

Wuerth DB, Finkelstein SH, Schwetz O, Carey H, Kliger AS, Finkelstein FO. **Patients' descriptions of specific factors leading to modality selection of chronic peritoneal dialysis or hemodialysis.** Perit Dial Int. 2002;22(2):184-190.

PMID: 11990402

Abstract: Objectives: There has been increasing interest in understanding how patients with chronic renal failure choose between chronic peritoneal dialysis (CPD) and hemodialysis (HD) for renal replacement therapy. The purpose of the present study was to examine the influences and specific factors that patients identify as significant in choosing a specific dialysis modality for treatment of their end-stage renal disease (ESRD).

Patients and design: 40 patients (20 CPD, 20 HD) who had started dialysis within the preceding 6 months were randomly selected to participate in the study. A structured interview was conducted with the patients, discussing and exploring what factors patients thought were important in helping them decide their treatment modality. The format of the interview was open-ended. Based on patients' comments, a taxonomy of the specific factors that influenced the patients' decisions was developed.

Setting: The study was conducted in a freestanding CPD unit and two freestanding HD units.

Results: All 20 CPD patients reported choosing their treatment modality; only 8 of the 20 HD patients reported having a choice of treatment modality. 18 of the 22 patients who participated in pre-dialysis educational programs opted for CPD. 83% of the patients reported that their physician was important in influencing their treatment choice; however, the CPD patients relied more on written material and the opinions of their spouse/significant other or other family members in making their decisions. Issues of autonomy and control were important for 95% of patients choosing CPD. Both CPD and HD patients cited a variety of treatment-specific factors. The three most frequently cited reasons for choosing CPD were (1) flexibility of schedule (19 patients), (2) convenience of performing CPD in their own home (19 patients), and (3) the option of doing dialysis at night while sleeping (8 patients). The 8 HD patients who selected their treatment modality cited the desirability of having a planned schedule (7 patients) and letting nurses or other take care of them (5 patients).

Conclusions: The present study explored factors perceived by patients as being important in determining their choice of renal replacement therapy. A taxonomy of patient influences and concerns has been developed to provide caregivers with a framework to structure their educational strategies and assist patients with progressive renal failure in making an informed choice of therapeutic modality for their ESRD treatment.

Mehrotra R, Marsh D, Vonesh E, Peters V, Nissenson A. **Patient education and access of ESRD patients to renal replacement therapies beyond in-center hemodialysis.** Kidney Int. 2005;68(1):378-390. doi:10.1111/j.1523-1755.2005.00453.x

PMID: 15954930

Abstract: Background: Nephrologists report that patients' choice should play an important role in the selection of renal replacement therapy (RRT) for end-stage renal disease (ESRD). In the United States, kidney transplant rates remain low and <10% of patients utilize home dialysis therapies. This study examined the effect of pre-ESRD processes on the selection of RRT among incident ESRD patients.

Methods: Using surveys, data were collected for all patients admitted to 229 dialysis units in ESRD Network 18 between April 1, 2002 and May 31, 2002. A total of 1365 patients began chronic dialysis and 1193 facility (87%) and 428 patient (31%) surveys were returned.

Results: Substantial proportions of patients were unaware of their kidney disease (36%) or were not seeing a nephrologist (36%) until <4 months before first dialysis. The presentation of treatment options was delayed (48% either after or < 1 month before the first dialysis). The majority of ESRD patients were not presented with chronic peritoneal dialysis, home hemodialysis, or renal transplantation as options (66%, 88%, and 74%, respectively). Using multivariate analyses, variables significantly associated with selection of chronic peritoneal dialysis as dialysis modality were the probability of chronic peritoneal dialysis being presented as a treatment option and the time spent on patient education.

Conclusion: An incomplete presentation of treatment options is an important reason for under-utilization of home dialysis therapies and probably delays access to transplantation. Improvements in and reimbursement for pre-ESRD education could provide an equal and timely access for all medically suitable patients to various RRTs.

Mendelssohn DC, Mujais SK, Soroka SD, et al. **A prospective evaluation of renal replacement therapy modality eligibility.** *Nephrol Dial Transplant*. 2009;24(2):555-561. doi:10.1093/ndt/gfn484

PMID: 18755848

Abstract: Background: Patient eligibility for renal replacement therapy (RRT) modalities is frequently debated, but little prospective data are available from large patient cohorts.

Methods: We prospectively evaluated medical and psychosocial eligibility for the three RRT modalities in patients with chronic kidney disease (CKD) stages III-V who were enrolled in an ongoing prospective cohort study conducted at seven North American nephrology practices.

Results: Ninety-eight percent of patients were considered medically eligible for haemodialysis (HD), 87% of patients were assessed as medically eligible for peritoneal dialysis (PD) and 54% of patients were judged medically eligible for transplant. Age was the leading cause of non-eligibility for both PD and transplant. Anatomical concerns (adhesions, hernias) were the second most frequent concern for PD eligibility followed by weight. Weight was also a concern for transplant eligibility. The proportion of patients medically eligible for RRT did not vary by CKD stage. There was, however, significant inter-centre variation in the proportion of patients medically eligible for PD and transplant. Ninety-five percent of patients were considered psychosocially eligible for HD, 83% of patients were assessed as psychosocially eligible for PD and 71% of patients were judged psychosocially eligible for transplant. The percentage of patients who were assessed as having neither medical nor psychosocial contraindications for RRT was 95% for HD, 78% for PD and 53% for transplant.

Conclusions: Most CKD patients are considered by their medical care providers to be suitable for PD. Enhanced patient education, promotion of home dialysis for suitable patients and empowerment of patient choice are expected to augment growth of home dialysis modalities.

Morton RL, Tong A, Howard K, Snelling P, Webster AC**. The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies.** BMJ. 2010;340:c112. Published 2010 Jan 19. doi:10.1136/bmj.c112

PMID: 20085970

Abstract: Objective: To synthesize the views of patients and carers in decision making regarding treatment for chronic kidney disease, and to determine which factors influence those decisions.

Design: Systematic review of qualitative studies of decision making and choice for dialysis, transplantation, or palliative care, and thematic synthesis of qualitative studies.

Data sources: Medline, PsycINFO, CINAHL, Embase, social work abstracts, and digital theses (database inception to week 3 October 2008) to identify literature using qualitative methods (focus groups, interviews, or case studies). Review methods Thematic synthesis involved line by line coding of the findings of the primary studies and development of descriptive and analytical themes.

Results: 18 studies that reported the experiences of 375 patients and 87 carers were included. 14 studies focused on preferences for dialysis modality, three on transplantation, and one on palliative management. Four major themes were identified as being central to treatment choices: confronting mortality (choosing life or death, being a burden, living in limbo), lack of choice (medical decision, lack of information, constraints on resources), gaining knowledge of options (peer influence, timing of information), and weighing alternatives (maintaining lifestyle, family influences, maintaining the status quo).

Conclusions: The experiences of other patients greatly influenced the decision making of patients and carers. The problematic timing of information about treatment options and synchronous creation of vascular access seemed to predetermine hemodialysis and inhibit choice of other treatments, including palliative care. A preference to maintain the status quo may explain why patients often remain on their initial therapy.

Winterbottom AE, Bekker HL, Conner M, Mooney AF. **Patient stories about their dialysis experience biases others' choices regardless of doctor's advice: an experimental study.** Nephrol Dial Transplant. 2012;27(1):325-331. doi:10.1093/ndt/gfr266

PMID: 21642512

Abstract: Background: Renal services provide resources to support patients in making informed choices about their dialysis modality. Many encourage new patients to talk with those already experiencing dialysis. It is unclear if these stories help or hinder patients' decisions, and few studies have been conducted into their effects. We present two studies comparing the impact of patient and doctor stories on hypothetical dialysis modality choices among an experimental population.

Methods: In total, 1694 participants viewed online information about haemodialysis and continuous cycling peritoneal dialysis and completed a questionnaire. In Study 1, using actors, treatment information was varied by presenter (Doctor, Patient), order of presenter

(Patient first, Doctor first) and mode of delivery (written, video). Information in Study 2 was varied (using actors) by presenter (Doctor, Patient), order of presenter (Patient first, Doctor first), inclusion of a decision table (no table, before story, after story) and sex of the 'patient' (male, female) and 'Doctor' (male, female). Information was controlled to ensure comparable content and comprehensibility.

Results: In both studies, participants were more likely to choose the dialysis modality presented by the patient rather than that presented by the doctor. There was no effect for mode of delivery (video versus written) or inclusion of a decision table.

Conclusions: As 'new' patients were making choices based on past patient experience of those already on dialysis, we recommend caution to services using patient stories about dialysis to support those new to the dialysis in delivering support to those who are new to the decision-making process for dialysis modality.

Song MK, Lin FC, Gilet CA, Arnold RM, Bridgman JC, Ward SE. **Patient perspectives on informed decision-making surrounding dialysis initiation.** Nephrol Dial Transplant. 2013;28(11):2815-2823. doi:10.1093/ndt/gft238

PMID: 23901048

Abstract: Background: Careful patient-clinician shared decision-making about dialysis initiation has been promoted, but few studies have addressed patient perspectives on the extent of information provided and how decisions to start dialysis are made.

Methods: Ninety-nine maintenance dialysis patients recruited from 15 outpatient dialysis centers in North Carolina completed semi-structured interviews on information provision and communication about the initiation of dialysis. These data were examined with content analysis. In addition, informed decision-making (IDM) scores were created by summing patient responses (yes/no) to 10 questions about the decision-making.

Results: The mean IDM score was 4.4 (of 10; SD = 2.0); 67% scored 5 or lower. Age at the time of decision-making (r = -0.27, P = 0.006), years of education (r = 0.24, P = 0.02) and presence of a warning about progressing to end-stage kidney disease (t = 2.9, P = 0.005) were significantly associated with IDM scores. Nearly 70% said that the risks and burdens of dialysis were not mentioned at all, and only one patient recalled that the doctor offered the option of not starting dialysis. While a majority (67%) said that they felt they had no choice about starting dialysis (because the alternative would be death) or about dialysis modality, only 21.2% said that they had felt rushed to make a decision.

About one-third of the patients perceived that the decision to start dialysis and modality was already made by the doctor.

Conclusions: A majority of patients felt unprepared and ill-informed about the initiation of dialysis. Improving the extent of IDM about dialysis may optimize patient preparation prior to starting treatment and their perceptions about the decision-making process.

Van Biesen W, van der Veer SN, Murphey M, Loblova O, Davies S. **Patients' perceptions of information and education for renal replacement therapy: an independent survey by the European Kidney Patients' Federation on information and support on renal replacement therapy.** PLoS One. 2014;9(7):e103914. Published 2014 Jul 31. doi:10.1371/journal.pone.0103914

PMID: 25079071

Abstract: Background: Selection of an appropriate renal replacement modality is of utmost importance for patients with end stage renal disease. Previous studies showed provision of information to and free modality choice by patients to be suboptimal. Therefore, the European Kidney Patients' Federation (CEAPIR) explored European patients' perceptions regarding information, education and involvement on the modality selection process.

Methods: CEAPIR developed a survey, which was disseminated by the national kidney patient organizations in Europe.

Results: In total, 3867 patients from 36 countries completed the survey. Respondents were either on in-centre haemodialysis (53%) or had a functioning graft (38%) at the time of survey. The majority (78%) evaluated the general information about kidney disease and treatment as helpful, but 39% did not recall being told about alternative treatment options than their current one. Respondents were more often satisfied with information provided on in-centre haemodialysis (90%) and transplantation (87%) than with information provided on peritoneal dialysis (79%) or home haemodialysis (61%), and were more satisfied with information from health care professionals vs other sources such as social media. Most (75%) felt they had been involved in treatment selection, 29% perceived they had no free choice. Involvement in modality selection was associated with enhanced satisfaction with treatment (OR 3.13; 95% CI 2.72-3.60). Many respondents (64%) could not remember receiving education on how to manage their kidney disease in daily life. Perceptions on information seem to differ between countries.

Conclusions: Kidney patients reported to be overall satisfied with the information they received on their disease and treatment, although information seemed mostly to have been focused on one modality. Patients involved in modality selection were more satisfied with their treatment. However, in the perception of the patients, the freedom to choose an alternative modality showed room for improvement.

Watanabe Y, Hirakata H, Okada K, et al. **Proposal for the shared decision-making process regarding initiation and continuation of maintenance hemodialysis.** Ther Apher Dial. 2015;19 Suppl 1:108-117. doi:10.1111/1744-9987.12295

PMID: 25817935

Abstract: Background and Objectives: Effective communication and shared decision making improve quality of care and patient outcomes but can be particularly challenging in pediatric chronic disease because children depend on their parents and clinicians to manage complex health care and developmental needs. We aimed to describe the perspectives of children with chronic kidney disease (CKD) and their parents with regard to communication and decision making.

Study Design: Qualitative study.

Setting and Participants: Children with CKD (n=34) and parents (n=62) from 6 centers across 6 cities in Australia, Canada, and the United States participated in 16 focus groups.

Analytical Approach: Transcripts were analyzed thematically.

Results: We identified 4 themes: (1) disempowered by knowledge imbalance (unprepared and ill-informed, suspicion of censorship, and inadequacy as technicians), (2) recognizing own expertise (intuition and instinct unique to parental bond, emerging wisdom and confidence, identifying opportunities for control and inclusion, and empowering participation in children), (3) striving to assert own priorities (negotiating broader life impacts, choosing to defer decisional burden, overprotected and overruled, and struggling to voice own preferences), and (4) managing child's involvement (respecting child's expertise, attributing "risky" behaviors to rebellion, and protecting children from illness burden).

Limitations: Only English-speaking participants were recruited, which may limit the transferability of the findings. We collected data from child and¬†parent perspectives; however, clinician perspectives may provide further understanding of the difficulties of communication and decision making in pediatrics.

Conclusions: Parents value partnership with clinicians and consider long-term and quality-of-life implications of their child's illness. Children with CKD want more involvement in treatment decision making but are limited by vulnerability, fear, and uncertainty. There is a need to support the child to better enable him or her to become a partner in decision making and prepare him or her for adulthood. Collaborative and informed decision making that addresses the priorities and concerns of both children and parents is needed.

Robinski M, Mau W, Wienke A, Girndt M. **The Choice of Renal Replacement Therapy (CORETH) project: dialysis patients' psychosocial characteristics and treatment satisfaction.** Nephrol Dial Transplant. 2017;32(2):315-324. doi:10.1093/ndt/gfv464

PMID: 28186578

Abstract: Background: Until today, research has underestimated the role of psychosocial conditions as contributing factors to dialysis modality choice. The novelty within the Choice of Renal Replacement Therapy (CORETH) project (German Clinical Trials Register #DRKS00006350) is its focus on the multivariate associations between these aspects and their consecutive significance regarding treatment satisfaction (TS) in peritoneal dialysis (PD) versus haemodialysis (HD) patients. In this article, we present the baseline results of a multicentre study, which is supported by a grant from the German Ministry for Education and Research.

Methods: Six to 24 months after initiation of dialysis, 780 patients from 55 dialysis centres all over Germany were surveyed. The questionnaire addressed psychosocial, physical, socio-demographic and shared decision-making (SDM) aspects. Furthermore, cognitive functioning was tested. After indexing the measures, two propensity score-matched groups (n = 482) were compared in a first step, after having chosen PD or HD. In a second step, a moderated multiple regression (n = 445) was conducted to initially investigate the multivariate impact of patient characteristics on TS.

Results: In comparison with HD patients, PD patients were more satisfied with their treatment (P < 0.001), had a more autonomy-seeking personality (P = 0.04), had better cognitive functioning (P = 0.001), indicated more satisfying SDM (P < 0.001) and had a larger living space (P < 0.001). All patients were more satisfied when they had a good psychological state and received SDM. Especially in HD patients, TS was higher when the patient had a less autonomous personality, lower cognitive functioning, more social support, a poorer physical state and poorer socio-demographic conditions (R2 = 0.26).

Conclusions: Psychosocial characteristics play a major role in TS in dialysis patients. Within a multivariate approach, these factors are even more important than physical or environment-related factors. In practice, focusing on SDM and screening patient characteristics at an early stage can foster patients' TS. Changes will be examined in a 1-year follow-up.

Brar RS, Whitlock RH, Komenda PVJ, et al. **Provider Perception of Frailty Is Associated with Dialysis Decision Making in Patients with Advanced CKD.** Clin J Am Soc Nephrol. 2021;16(4):552-559. doi:10.2215/CJN.12480720

PMID: 33771886

Abstract: Background and objectives: Frailty is common in patients with CKD. Little is known about the prevalence of frailty and its effect on prognosis and decisions surrounding dialysis modalities in patients with advanced CKD (eGFR<30 ml/min per 1.73 m2). Our objective was to determine the agreement between different frailty measures and physical function and their association with dialysis modality choice (home based versus in-center) and all-cause mortality in patients with advanced CKD.

Design, setting, participants, & measurements: Our study was a prospective, multicenter, cohort study. In 603 patients with advanced CKD, we collected demographics, comorbidities, and laboratory results in addition to objective (Fried frailty criteria) and subjective measures of frailty (physician and nurse impressions) and physical function (Short Physical Performance Battery). Logistic regression and Cox proportional hazards models were used to evaluate the association of frailty with dialysis modality choice and all-cause mortality, respectively.

Results: The prevalence of frailty varied with assessment tool used (Fried frailty criteria, 34%; Short Physical Performance Battery, 55%; physician impression, 44%; nurse impression, 36%). The agreement between all frailty and physical function measures was poor. We had 227 patients reach kidney failure and decide on a dialysis therapy, and 226 patients died during a mean follow-up of 1455 days. After adjusting for age, sex, and comorbid conditions, the Fried criteria and Short Physical Performance Battery were associated with a two-fold higher risk of all-cause mortality (hazard ratio, 1.96; 95% confidence interval, 1.47 to 2.61 and hazard ratio, 1.96; 95% confidence interval,1.42 to 2.76, respectively). Patients deemed as frail by physician and nurse frailty impressions were three to four times more likely to choose in-center dialysis (odds ratio, 3.41; 95% confidence interval, 1.56 to 7.44; odds ratio, 3.87; 95% confidence interval, 1.76 to 8.51, respectively).

Conclusions: We found that the agreement between objective and subjective measures of frailty and physical function was poor. Objective measures of frailty and physical function were associated with mortality, and subjective measures of frailty were associated with dialysis modality choice.

Van Dulmen S, Peereboom E, Schulze L, et al. **The use of implicit persuasion in decision-making about treatment for end-stage kidney disease.** Perit Dial Int. 2022;42(4):377-386. doi:10.1177/08968608211027019

PMID: 34212786

Abstract: Background: There are various options for managing end-stage kidney disease. Each option impacts the lives of patients differently. When weighing the pros and cons of the different options, patients' values, needs and preferences should, therefore, be taken into account. However, despite the best intentions, nephrologists may, more or less deliberately, convey a treatment preference and thereby steer the decision-making process. Being aware of such implicit persuasion could help to further optimise shared decision-making (SDM). This study explores verbal acts of implicit persuasion during outpatient consultations scheduled to make a final treatment decision. These consultations mark the end of a multi-consultation, educational process and summarize treatment aspects discussed previously.

Methods: Observations of video-recorded outpatient consultations in nephrology (n = 20) were used to capture different forms of implicit persuasion. To this purpose, a coding scheme was developed.

Results: In nearly every consultation nephrologists used some form of implicit persuasion. Frequently observed behaviours included selectively presenting treatment options, benefits and harms, and giving the impression that undergoing or foregoing treatment is unusual. The extent to which nephrologists used these behaviours differed.

Conclusion: The use of implicit persuasion while discussing different kidney replacement modalities appears diverse and quite common. Nephrologists should be made aware of these behaviours as implicit persuasion might prevent patients to become knowledgeable in each treatment option, thereby affecting SDM and causing decisional regret. The developed coding scheme for observing implicit persuasion elicits useful and clinically relevant examples which could be used when providing feedback to nephrologists.

Frazier R, Levine S, Porteny T, et al. **Shared Decision Making Among Older Adults With Advanced CKD.** Am J Kidney Dis. 2022;80(5):599-609. doi:10.1053/j.ajkd.2022.02.017

PMID: 35351579

Abstract: Rationale & objective: Older adults with advanced chronic kidney disease (CKD) face difficult decisions about dialysis initiation. Although shared decision making (SDM) can help align patient preferences and values with treatment options, the extent to which older patients with CKD experience SDM remains unknown.

Study design: A cross-sectional analysis of patient surveys examining decisional readiness, treatment options education, care partner support, and SDM.

Setting & participants: Adults aged 70 years or older from Boston, Chicago, San Diego, or Portland (Maine) with non-dialysis advanced CKD.

Predictors: Decisional readiness factors, treatment options education, and care partner support.

Outcomes: Primary: SDM measured by the 9-item Shared Decision Making Questionnaire (SDM-Q-9) instrument, with higher scores reflecting greater SDM. Exploratory: Factors associated with SDM.

Analytical approach: We used multivariable linear regression models to examine the associations between SDM and predictors, controlling for demographic and health factors.

Results: Among 350 participants, mean age was 78 ± 6 years, 58% were male, 13% identified as Black, and 48% had diabetes. Mean SDM-Q-9 score was 52 ± 28. SDM item agreement ranged from 41% of participants agreeing that "my doctor and I selected a treatment option together" to 73% agreeing that "my doctor told me that there are different options for treating my medical condition." In multivariable analysis adjusted for demographic characteristics, lower estimated glomerular filtration rate, and diabetes, being "well informed" and "very well informed" about kidney treatment options, having higher decisional certainty, and attendance at a kidney treatment options class were independently associated with higher SDM-Q-9 scores.

Limitations: The cross-sectional study design limits the ability to make temporal associations between SDM and the predictors.

Conclusions: Many older patients with CKD do not experience SDM when making dialysis decisions, emphasizing the need for greater access to and delivery of education for individuals with advanced CKD.

Gonzales KM, Koch-Weser S, Kennefick K, et al. **Decision-Making Engagement Preferences among Older Adults with CKD.** J Am Soc Nephrol. 2024;35(6):772-781. doi:10.1681/ASN.0000000000000341

PMID: 38517479

Abstract: Background: Older adults with kidney failure face preference-sensitive decisions regarding dialysis initiation. Despite recommendations, few older patients with kidney failure experience shared decision making. Clinician uncertainty about the degree to which older patients prefer to engage in decision making remains a key barrier.

Methods: This study follows a mixed-methods explanatory, longitudinal, sequential design at four diverse US centers with patients (English-fluent, aged ≥70 years, CKD stages 4–5, non-dialysis) from 2018 to 2020. Patient preferences for engagement in decision making were assessed using the Control Preferences Scale, reflecting the degree to which patients want to be involved in their decision making: active (the patient prefers to make the final decision), collaborative (the patient wants to share decision making with the clinician), or passive (the patient wants the clinician to make the final decision) roles.

Semi-structured interviews about engagement and decision making were conducted in two waves (2019, 2020) with purposively sampled patients and clinicians. Descriptive statistics and ANOVA were used for quantitative analyses; thematic and narrative analyses were used for qualitative data.

Results: Among 363 patient participants, mean age was 78±6 years, 42% were female, and 21% had a high school education or less. Control Preferences Scale responses reflected that patients preferred to engage actively (48%) or collaboratively (43%) versus passively (8%). Preferred roles remained stable at 3-month follow-up. Seventy-six participants completed interviews (45 patients, 31 clinicians). Four themes emerged: control preference roles reflect levels of decisional engagement; clinicians control information flow, especially about prognosis; adapting a clinical approach to patient preferred roles; and clinicians' responsiveness to patient preferred roles supports patients' satisfaction with shared decision making.

Conclusions: Most older adults with advanced CKD preferred a collaborative or active role in decision making. Appropriately matched information flow with patient preferences was critical for satisfaction with shared decision making.

## Other

Orsino A, Cameron JI, Seidl M, Mendelssohn D, Stewart DE. **Medical decision-making and information needs in end-stage renal disease patients.** Gen Hosp Psychiatry. 2003;25(5):324-331. doi:10.1016/s0163-8343(03)00069-0

PMID: 12972223

Abstract: Health information and decision-making are increasingly important to patients with diverse illnesses. The aim of this study was to examine health information needs and decision-making in individuals with end-stage renal disease (ESRD) and to examine the influence of age and gender. A self-report survey was administered to 197 consecutive ESRD patients receiving renal replacement therapy. Their mean age was 52.8 years; 58.2% were male, 64.3% were on hemodialysis, and 35.7% on peritoneal dialysis. Actual participation levels in decision-making were not necessarily in agreement with the preferred degree of participation. Eighty percent of patients wanted the health care team (HCT) to make their treatment decisions for them, but only 40% of those who preferred autonomous and 30% of those who preferred shared decision making with their HCT reported that this was their actual experience. Consequently, many more patients perceived that their decision-making was made by their HCT than preferred this. No significant gender differences were observed; however, older participants preferred and experienced their HCT make their treatment decisions (P<.05). All patients wanted high levels of information with some differences by gender and age. HCT should strive to ascertain and meet the information needs and treatment decision-making roles preferred by individual patients.

Murray MA, Bissonnette J, Kryworuchko J, Gifford W, Calverley S. **Whose choice is it? Shared decision making in nephrology care.** Semin Dial. 2013;26(2):169-174. doi:10.1111/sdi.12056

PMID: 23432352

Abstract: Patients living with end-stage renal disease (ESRD) are faced with numerous decisions across the trajectory of their illness. Shared decision making (SDM) offers a patient-centered approach to engage patients in decision making in meaningful ways. Using an SDM approach, patients and providers collaborate to make healthcare decisions by taking into account the best available empirical evidence, in conjunction with the patient's values, preferences, and individual circumstances. In this article, we outline the principles of SDM; highlight the broad range and context of decisions faced by patients living with ESRD; review decision-support interventions; and consider opportunities and challenges for implementing SDM into usual ESRD practice. A summary of current knowledge and areas for research and further investigation concludes the paper. Because nephrology team members spend a lot of time interacting with patients during treatments and follow-up care, they are well positioned to engage in SDM. Healthcare systems need innovation in communication to ensure the ethical application of important technological improvements in renal treatments, and to ensure that patient decision-support processes are available. SDM is a promising innovation to support the recalibration of care for patients living with end-stage renal disease.

Gander J, Browne T, Plantinga L, et al. **Dialysis Facility Transplant Philosophy and Access to Kidney Transplantation in the Southeast.** Am J Nephrol. 2015;41(6):504-511. doi:10.1159/000438463

PMID: 26278585

Abstract: Background: Little is known about the impact of dialysis facility treatment philosophy on access to transplant. The aim of our study was to determine the relationship between the dialysis facility transplant philosophy and facility-level access to kidney transplant waitlisting.

Methods: A 25-item questionnaire administered to Southeastern dialysis facilities (n = 509) in 2012 captured the facility transplant philosophy (categorized as 'transplant is our first choice', 'transplant is a great option for some', and 'transplant is a good option, if the patient is interested'). Facility-level waitlisting and facility characteristics were obtained from the 2008-2011 Dialysis Facility Report. Multivariable logistic regression was used to examine the association between the dialysis facility transplant philosophy and facility waitlisting performance (dichotomized using the national median), where low performance was defined as fewer than 21.7% of dialysis patients waitlisted within a facility.

Results: Fewer than 25% (n = 124) of dialysis facilities reported 'transplant is our first option'. A total of 131 (31.4%) dialysis facilities in the Southeast were high-performing facilities with respect to waitlisting. Adjusted analysis showed that facilities who reported 'transplant is our first option' were twice (OR 2.0; 95% CI 1.0-3.9) as likely to have high waitlisting performance compared to facilities who reported that 'transplant is a good option, if the patient is interested'.

Conclusions: Facilities with staff who had a more positive transplant philosophy were more likely to have better facility waitlisting performance. Future prospective studies are needed to further investigate if improving the kidney transplant philosophy in dialysis facilities improves access to transplantation.

Taylor DM, Bradley JA, Bradley C, et al. **Limited health literacy in advanced kidney disease.** Kidney Int. 2016;90(3):685-695. doi:10.1016/j.kint.2016.05.033

PMID: 27521115

Abstract: Limited health literacy may reduce the ability of patients with advanced kidney disease to understand their disease and treatment and take part in shared decision making. In dialysis and transplant patients, limited health literacy has been associated with low socioeconomic status, comorbidity, and mortality. Here, we investigated the prevalence and associations of limited health literacy using data from the United Kingdom-wide Access to Transplantation and Transplant Outcome Measures (ATTOM) program. Incident dialysis, incident transplant, and transplant wait-listed patients ages 18 to 75 were recruited from 2011 to 2013 and data were collected from patient questionnaires and case notes. A score >2 in the Single-Item Literacy Screener was used to define limited health literacy. Univariate and multivariate analyses were performed to identify patient factors associated with limited health literacy. We studied 6842 patients, 2621 were incident dialysis, 1959 were wait-listed, and 2262 were incident transplant. Limited health literacy prevalence was 20%, 15%, and 12% in each group, respectively. Limited health literacy was independently associated with low socioeconomic status, poor English fluency, and comorbidity. However, transplant wait-listing, preemptive transplantation, and live-donor transplantation were associated with increasing health literacy.

Balamuthusamy S, Miller LE, Clynes D, Kahle E, Knight RA, Conway PT**. American Association of Kidney Patients survey of patient preferences for hemodialysis vascular access.** J Vasc Access. 2020;21(2):230-236. doi:10.1177/1129729819870962

PMID: 31464539

Abstract: Objectives: To determine the vascular access modalities used for hemodialysis, the reasons for choosing them, and determinants of satisfaction with vascular access among patients with end-stage renal disease.

Methods: The American Association of Kidney Patients Center for Patient Research and Education used the American Association of Kidney Patients patient engagement database to identify eligible adult hemodialysis patients. Participants completed an online survey consisting of 34 demographic, medical history, and hemodialysis history questions to determine which vascular access modalities were preferred and the reasons for these preferences.

Results: Among 150 respondents (mean age 54 years, 53% females), hemodialysis was most frequently initiated with central venous catheter (64%) while the most common currently used vascular access was arteriovenous fistula (66%). Most (86%) patients previously received an arteriovenous fistula, among whom 77% currently used the arteriovenous fistula for vascular access. Older patients and males were more likely to initiate hemodialysis with an arteriovenous fistula. The factors most frequently reported as important in influencing the selection of vascular access modality included infection risk (87%), physician recommendation (84%), vascular access durability (78%), risk of complications involving surgery (76%), and impact on daily activities (73%); these factors were influenced by patient age, sex, and race. Satisfaction with current vascular access was 90% with arteriovenous fistula, 79% with arteriovenous graft, and 67% with central venous catheter.

Conclusion: Most end-stage renal disease patients continue to initiate hemodialysis with central venous catheter despite being associated with the lowest satisfaction rates. While arteriovenous fistula was associated with the highest satisfaction rate, there are significant barriers to adoption that vary based on patient demographics and perception of procedure invasiveness.

Woo K, Pieters H. **The patient experience of hemodialysis vascular access decision-making.** J Vasc Access. 2021;22(6):911-919. doi:10.1177/1129729820968400

PMID: 33118395

Abstract: Background: To describe vascular access (VA)-related decision-making from the patient perspective, in patients who have already chosen hemodialysis as their renal replacement modality, and identify areas where physicians can improve this experience.

Methods: In-person, semi-structured interviews with 15 patients with end-stage kidney disease were systematically analyzed by two independent researchers using thematic analysis. Interviews were conducted until systematic analysis revealed no new themes.

Results: Patients had mean age 57 (range 22-85), with seven males and diverse racial/ethnic/marital status. All (15/15) patients viewed VA as "intertwined and interrelated" with dialysis, prioritized the dialysis, described the VA merely as the "hookup" to life-preserving dialysis and gave it minimal consideration. Three themes were identified: consolidation of dialysis and VA, reliance on supportive advisors and communication with physicians. Although 14/15 patients described processes common to medical decision-making, including information seeking, learning from the experiences of others, and weighing risks and benefits, they did not apply these processes specifically to VA. While all participants took ownership of the VA decision, they lacked clear understanding about the different types of VA and their consequences. Most patients (14/15) depended on family and friends for reinforcement, motivation and advice. Patients all described physician characteristics they associated with trustworthiness, the most common being listening and explaining, demonstrating empathy and making an effort to meet the patient's individual needs. Perceived arrogance, unavailability and lack of expertise represented untrustworthiness. The majority (14/15) accepted VA recommendations from physicians they found trustworthy and authoritative.

Conclusions: The study participants were minimally engaged in VA decision-making. Educational aids and shared decision-making tools are needed to empower patients to make better-informed, self-efficacious VA decisions.

Elliott MJ, Ravani P, Quinn RR, et al. **Patient and Clinician Perspectives on Shared Decision Making in Vascular Access Selection: A Qualitative Study.** Am J Kidney Dis. 2023;81(1):48-58.e1. doi:10.1053/j.ajkd.2022.05.016

PMID: 35870570

Abstract: Rationale & objective: Collaborative approaches to vascular access selection are being increasingly encouraged to elicit patients' preferences and priorities where no unequivocally superior choice exists. We explored how patients, their caregivers, and clinicians integrate principles of shared decision making when engaging in vascular access discussions.

Study design: Qualitative description.

Setting & participants: Semi-structured interviews with a purposive sample of patients, their caregivers, and clinicians from outpatient hemodialysis programs in Alberta, Canada.

Analytical approach: We used a thematic analysis approach to inductively code transcripts and generate themes to capture key concepts related to vascular access shared decision making across participant roles.

Results: 42 individuals (19 patients, 2 caregivers, 21 clinicians) participated in this study. Participants identified how access-related decisions follow a series of major decisions about kidney replacement therapy and care goals that influence vascular access preferences and choice. Vascular access shared decision making was strengthened through integration of vascular access selection with dialysis-related decisions and timely, tailored, and balanced exchange of information between patients and their care team. Participants described how opportunities to revisit the vascular access decision before and after dialysis initiation helped prepare patients for their access and encouraged ongoing alignment between patients' care priorities and treatment plans. Where shared decision making was undermined, hemodialysis via a catheter ensued as the most readily available vascular access option.

Limitations: Our study was limited to patients and clinicians from hemodialysis care settings and included few caregiver participants.

Conclusions: Findings suggest that earlier, or upstream, decisions about kidney replacement therapies influence how and when vascular access decisions are made. Repeated vascular access discussions that are integrated with other higher-level decisions are needed to promote vascular access shared decision making and preparedness.

## Survey Tools

Winterbottom A, Bekker HL, Conner M, Mooney A. **Choosing dialysis modality: decision making in a chronic illness context.** Health Expect. 2014;17(5):710-723. doi:10.1111/j.1369-7625.2012.00798.x

PMID: 22748072

Abstract: Background: Patients with chronic kidney disease (CKD) are encouraged to make an informed decision about dialysis. Survival rates for dialysis are equivalent yet there is wide variation in peritoneal dialysis uptake in the adult UK population. It is unclear how much is attributable to variations in patients' preferences. Kidney function usually declines over months and years; few studies have addressed how a chronic illness context affects choice. This study describes patients' decision making about dialysis and understands how the experience of CKD is associated with treatment choice.

Method: Survey employing interview methods explored 20 patients' views and experiences of making their dialysis choice. Data were analysed using thematic framework analysis to provide descriptive accounts of how patients experienced their illness and made treatment decisions.

Results: Patients talked about challenges of living with CKD. Patients were provided with lots of information about treatment options in different formats. Patients did not distinguish between different types of dialysis and/or have an in-depth knowledge about options. Patients did not talk about dialysis options as a choice but rather as a treatment they were going to have.

Conclusion: Most patients perceived their choice as between 'dialysis' and 'no dialysis'. They did not perceive themselves to be making an active choice. Possibly, patients feel they do not need to engage with the decision until symptomatic. Despite lots of patient information, there were more opportunities to encounter positive information about haemodialysis. A more proactive approach is required to enable patients to engage fully with the dialysis treatment options.

Robinski M, Mau W, Wienke A, Girndt M. **Shared decision-making in chronic kidney disease: A retrospection of recently initiated dialysis patients in Germany.** Patient Educ Couns. 2016;99(4):562-570. doi:10.1016/j.pec.2015.10.014

PMID: 26527307

Abstract: Objective: To compare differences in shared decision-making (SDM) and treatment satisfaction (TS) between haemodialysis (HD) and peritoneal dialysis (PD) patients.

Methods: 6-24 months after initiation of dialysis, we surveyed 780 patients from throughout Germany (CORETH-project) regarding SDM, the reason for modality choice and TS. Data were compared between two age-, comorbidity-, education-, and employment status-matched groups (n=482).

Results: PD patients rated all aspects of SDM more positively than did HD patients (total score: MPD=84.6, SD=24.1 vs. MHD=61.9, SD=37.3; p≤0.0001). The highest difference occurred for the item "announcement of a necessary decision" (delta=1.3 points on a 6-point Likert-scale). PD patients indicated their desire for independence as a motivator for choosing PD (65%), whereas HD patients were subject to medical decisions (23%) or wanted to rely on medical support (20%). We found positive correlations between SDM and TS (0.16≤r≤0.48; p≤0.0001).

Conclusion: Our findings increase awareness of a participatory nephrological counseling-culture and imply that SDM can pave the way for quality of life and treatment success for dialysis patients.

Practice implications: Practitioners can facilitate SDM by screening patient preferences at an early stage, being aware of biases in consultation, using easy terminology and encouraging passive patients to participate in the choice.

Durand MA, Bekker HL, Casula A, et al. **Can we routinely measure patient involvement in treatment decision-making in chronic kidney care? A service evaluation in 27 renal units in the UK.** Clin Kidney J. 2016;9(2):252-259. doi:10.1093/ckj/sfw003

PMID: 26985377

Abstract: Background: Shared decision making is considered an important aspect of chronic disease management. We explored the feasibility of routinely measuring kidney patients' involvement in making decisions about renal replacement therapy (RRT) in National Health Service settings.

Methods: We disseminated a 17-item paper questionnaire on involvement in decision-making among adult patients with established kidney failure who made a decision about RRT in the previous 90 days (Phase 1) and patients who had been receiving RRT for 90-180 days (Phase 2). Recruitment rates were calculated as the ratio between the number of included and expected eligible patients (I : E ratio). We assessed our sample's representativeness by comparing demographics between participants and incident patients in the UK Renal Registry.

Results: Three hundred and five (Phase 1) and 187 (Phase 2) patients were included. For Phase 1, the I : E ratio was 0.44 (range, 0.08-2.80) compared with 0.27 (range, 0.04-1.05) in Phase 2. Study participants were more likely to be white compared with incident RRT patients (88 versus 77%; P < 0.0001). We found no difference in age, gender or social deprivation. In Phases 1 and 2, the majority reported a collaborative decision-making style (73 and 69%), and had no decisional conflict (85 and 76%); the median score for shared decision-making experience was 12.5 (Phase 1) and 10 (Phase 2) out of 20.

Conclusion: Our study shows the importance of assessing the feasibility of data collection in a chronic disease context prior to implementation in routine practice. Routine measurement of patient involvement in established kidney disease treatment decisions is feasible, but there are challenges in selecting the measure needed to capture experience of involvement, reducing variation in response rate by service and identifying when to capture experience in a service managing people's chronic disease over time.

McPherson L, Basu M, Gander J, et al. **Decisional conflict between treatment options among end-stage renal disease patients evaluated for kidney transplantation.** Clin Transplant. 2017;31(7):10.1111/ctr.12991. doi:10.1111/ctr.12991

PMID: 28457025

Abstract: Although kidney transplantation provides a significant benefit over dialysis, many patients with end-stage renal disease (ESRD) are conflicted about their decision to undergo kidney transplant. We aimed to identify the prevalence and characteristics associated with decisional conflict between treatment options in ESRD patients presenting for transplant evaluation. Among a cross-sectional sample of patients with ESRD (n=464) surveyed in 2014 and 2015, we assessed decisional conflict through a validated 10-item questionnaire. Decisional conflict was dichotomized into no decisional conflict (score=0) and any decisional conflict (score>0). We investigated potential characteristics of patients with decisional conflict using bivariate and multivariable logistic regression. The overall mean age was 50.6 years, with 62% male patients and 48% African American patients. Nearly half (48.5%) of patients had decisional conflict regarding treatment options. Characteristics significantly associated with decisional conflict in multivariable analysis included male sex, lower educational attainment, and less transplant knowledge. Understanding characteristics associated with decisional conflict in patients with ESRD could help identify patients who may benefit from targeted interventions to help patients make informed, value-based, and supported decisions when deciding how to best treat their kidney disease.

Peipert JD, Hays RD, Kawakita S, Beaumont JL, Waterman AD. **Measurement Characteristics of the Knowledge Assessment of Renal Transplantation.** Transplantation. 2019;103(3):565-572. doi:10.1097/TP.0000000000002349

PMID: 29965952

Abstract: Background: Kidney transplant is the best treatment for most end-stage renal disease (ESRD) patients, but proportionally few ESRD patients receive kidney transplant. To make an informed choice about whether to pursue kidney transplant, patients must be knowledgeable of its risks and benefits. To reliably and validly measure ESRD patients' kidney transplant knowledge, rigorously tested measures are required. This article describes the development and psychometric testing of the Knowledge Assessment of Renal Transplantation (KART).

Methods: We administered 17 transplant knowledge items to a sample of 1294 ESRD patients. Item characteristics and scale scores were estimated using an Item Response Theory graded response model. Construct validity was tested by examining differences in scale scores between patients who had spent less than 1 and 1 hour or longer receiving various types of transplant education.

Results: Item Response Theory modeling suggested that 15 items should be retained for the KART. This scale had a marginal reliability of 0.75 and evidenced acceptable reliability (>0.70) across most of its range. Construct validity was supported by the KART's ability to distinguish patients who had spent less than 1 and 1 hour or longer receiving different types of kidney transplant education, including talking to doctors/medical staff (effect size [ES], 0.61; P < 0.001), reading brochures (ES, 0.45; P < 0.001), browsing the internet (ES, 0.56; P < 0.001), and watching videos (ES, 0.56; P < 0.001).

Conclusions: The final 15-item KART can be used to determine the kidney transplant knowledge levels of ESRD patients and plan appropriate interventions to ensure informed transplant decision making occurs.

Zee J, Zhao J, Subramanian L, et al. **Perceptions about the dialysis modality decision process among peritoneal dialysis and in-center hemodialysis patients.** BMC Nephrol. 2018;19(1):298. Published 2018 Oct 29. doi:10.1186/s12882-018-1096-x

PMID: 30373558

Abstract: Background: Patients reaching end-stage renal disease must make a difficult decision regarding renal replacement therapy (RRT) options. Because the choice between dialysis modalities should include patient preferences, it is critical that patients are engaged in the dialysis modality decision. As part of the Empowering Patients on Choices for RRT (EPOCH-RRT) study, we assessed dialysis patients' perceptions of their dialysis modality decision-making process and the impact of their chosen modality on their lives.

Methods: A 39-question survey was developed in collaboration with a multi-stakeholder advisory panel to assess perceptions of patients on either peritoneal dialysis (PD) or in-center hemodialysis (HD). The survey was disseminated to participants in the large US cohorts of the Dialysis Outcomes and Practice Patterns Study (DOPPS) and the Peritoneal DOPPS (PDOPPS). Survey responses were compared between PD and in-center HD patients using descriptive statistics, adjusted logistic generalized estimating equation models, and linear mixed regression models.

Results: Six hundred fourteen PD and 1346 in-center HD participants responded. Compared with in-center HD participants, PD participants more frequently reported that they were engaged in the decision-making process, were provided enough information, understood differences between dialysis modalities, and felt satisfied with their modality choice. PD participants also reported more frequently than in-center HD participants that partners or spouses (79% vs. 70%), physician assistants (80% vs. 66%), and nursing staff (78% vs. 60%) had at least some involvement in the dialysis modality decision. Over 35% of PD and in-center HD participants did not know another dialysis patient at the time of their modality decision and over 60% did not know the disadvantages of their modality type. Participants using either dialysis modality perceived a moderate to high impact of dialysis on their lives.

Conclusions: PD participants were more engaged in the modality decision process compared to in-center HD participants. For both modalities, there is room for improvement in patient education and other support for patients choosing a dialysis modality.

Dubin R, Rubinsky A. **A Digital Modality Decision Program for Patients With Advanced Chronic Kidney Disease.** JMIR Form Res. 2019;3(1):e12528. Published 2019 Feb 6. doi:10.2196/12528

PMID: 30724735

Abstract: Background: Patient education regarding end-stage renal disease (ESRD) has the potential to reduce adverse outcomes and increase the use of in-home renal replacement therapies.

Objective: This study aimed to investigate whether an online, easily scalable education program can improve patient knowledge and facilitate decision making regarding renal replacement therapy options.

Methods: We developed a 4-week online, digital educational program that included written information, short videos, and social networking features. Topics included kidney transplant, conservative management, peritoneal dialysis, in-home hemodialysis, and in-center hemodialysis. We recruited patients with advanced chronic kidney disease (stage IV and V) to enroll in the online program, and we evaluated the feasibility and potential impact of the digital program by conducting pre- and postintervention surveys in areas of knowledge, self-efficacy, and choice of ESRD care.

Results: Of the 98 individuals found to be eligible for the study, 28 enrolled and signed the consent form and 25 completed the study. The average age of participants was 65 (SD 15) years, and the average estimated glomerular filtration rate was 21 (SD 6) ml/min/1.73 m2. Before the intervention, 32% of patients (8/25) were unable to make an ESRD treatment choice; after the intervention, all 25 participants made a choice. The proportion of persons who selected kidney transplant as the first choice increased from 48% (12/25) at intake to 84% (21/25) after program completion (P=.01). Among modality options, peritoneal dialysis increased as the first choice for 4/25 (16%) patients at intake to 13/25 (52%) after program completion (P=.004). We also observed significant increases in knowledge score (from 65 [SD 56] to 83 [SD 14]; P<.001) and self-efficacy score (from 3.7 [SD 0.7] to 4.3 [SD 0.5]; P<.001).

Conclusions: Implementation of a digital ESRD education program is feasible and may facilitate patients' decisions about renal replacement therapies. Larger studies are necessary to understand whether the program affects clinical outcomes.

Finderup J, Lomborg K, Jensen JD, Stacey D. **Choice of dialysis modality: patients' experiences and quality of decision after shared decision-making.** BMC Nephrol. 2020;21(1):330. Published 2020 Aug 5. doi:10.1186/s12882-020-01956-w

PMID: 32758177

Abstract: Background: Patients with kidney failure experience a complex decision on dialysis modality performed either at home or in hospital. The options have different levels of impact on their physical and psychological condition and social life. The purpose of this study was to evaluate the implementation of an intervention designed to achieve shared decision-making for dialysis choice. Specific objectives were: 1) to measure decision quality as indicated by patients' knowledge, readiness and achieved preferences; and 2) to determine if patients experienced shared decision-making.

Method: A mixed methods descriptive study was conducted using both questionnaires and semi-structured interviews. Eligible participants were adults with kidney failure considering dialysis modality. The intervention, based on the Three-Talk model, consisted of a patient decision aid and decision coaching meetings provided by trained dialysis coordinators. The intervention was delivered to 349 patients as part of their clinical pathway of care. After the intervention, 148 participants completed the Shared Decision-Making Questionnaire and the Decision Quality Measurement, and 29 participants were interviewed. Concordance between knowledge, decision and preference was calculated to measure decision quality. Interview transcripts were analysed qualitatively.

Results: The participants obtained a mean score for shared decision-making of 86 out of 100. There was no significant difference between those choosing home- or hospital-based treatment (97 versus 83; p = 0.627). The participants obtained a knowledge score of 82% and a readiness score of 86%. Those choosing home-based treatment had higher knowledge score than those choosing hospital-based treatment (84% versus 75%; p = 0.006) but no significant difference on the readiness score (87% versus 84%; p = 0.908). Considering the chosen option and the knowledge score, 83% of the participants achieved a high-quality decision. No significant difference was found for decision quality between those choosing home- or hospital-based treatment (83% versus 83%; p = 0.935). Interview data informed the interpretation of these results.

Conclusions: Although there was no control group, over 80% of participants exposed to the intervention and responded to the surveys experienced shared decision-making and reached a high-quality decision. Both participants who chose home- and hospital-based treatment experienced the intervention as shared decision-making and made a high-quality decision. Qualitative findings supported the quantitative results.

de Jong RW, Stel VS, Rahmel A, et al. **Patient-reported factors influencing the choice of their kidney replacement treatment modality.** Nephrol Dial Transplant. 2022;37(3):477-488. doi:10.1093/ndt/gfab059

PMID: 33677544

Abstract: Background: Access to various kidney replacement therapy (KRT) modalities for patients with end-stage kidney disease differs substantially within Europe.

Methods: European adults on KRT filled out an online or paper-based survey about factors influencing and experiences with modality choice (e.g. information provision, decision-making and reasons for choice) between November 2017 and January 2019. We compared countries with low, middle and high gross domestic product (GDP).

Results: In total, 7820 patients [mean age 59 years, 56% male, 63% on centre haemodialysis (CHD)] from 38 countries participated. Twenty-five percent had received no information on the different modalities, and only 23% received information >12 months before KRT initiation. Patients were not informed about home haemodialysis (HHD) (42%) and comprehensive conservative management (33%). Besides nephrologists, nurses more frequently provided information in high-GDP countries, whereas physicians other than nephrologists did so in low-GDP countries. Patients from low-GDP countries reported later information provision, less information about other modalities than CHD and lower satisfaction with information. The majority of modality decisions were made involving both patient and nephrologist. Patients reported subjective (e.g. quality of life and fears) and objective reasons (e.g. costs and availability of treatments) for modality choice. Patients had good experiences with all modalities, but experiences were better for HHD and kidney transplantation and in middle- and high-GDP countries.

Conclusion: Our results suggest European differences in patient-reported factors influencing KRT modality choice, possibly caused by disparities in availability of KRT modalities, different healthcare systems and varying patient preferences. Availability of home dialysis and kidney transplantation should be optimized.

DePasquale N, Green JA, Ephraim PL, et al. **Decisional Conflict About Kidney Failure Treatment Modalities Among Adults With Advanced CKD.** Kidney Med. 2022;4(9):100521. Published 2022 Aug 4. doi:10.1016/j.xkme.2022.100521

PMID: 36090772

Abstract: Rationale & objective: Choosing from multiple kidney failure treatment modalities can create decisional conflict, but little is known about this experience before decision implementation. We explored decisional conflict about treatment for kidney failure and its associated patient characteristics in the context of advanced chronic kidney disease (CKD).

Study design: Cross-sectional study.

Setting & participants: Adults (N = 427) who had advanced CKD, received nephrology care in Pennsylvania-based clinics, and had no history of dialysis or transplantation.

Predictors: Participants' sociodemographic, physical health, nephrology care/knowledge, and psychosocial characteristics.

Outcomes: Participants' results on the Sure of myself; Understand information; Risk-benefit ratio; Encouragement (SURE) screening test for decisional conflict (no decisional conflict vs decisional conflict).

Analytical approach: We used multivariable logistic regression to quantify associations between aforementioned participant characteristics and decisional conflict. We repeated analyses among a subgroup of participants at highest risk of kidney failure within 2 years.

Results: Most (76%) participants reported treatment-related decisional conflict. Participant characteristics associated with lower odds of decisional conflict included complete satisfaction with patient-kidney team treatment discussions (OR, 0.16; 95% CI, 0.03-0.88; P = 0.04), attendance of treatment education classes (OR, 0.38; 95% CI, 0.16-0.90; P = 0.03), and greater treatment-related decision self-efficacy (OR, 0.97; 95% CI, 0.94-0.99; P < 0.01). Sensitivity analyses showed a similarly high prevalence of decisional conflict (73%) and again demonstrated associations of class attendance (OR, 0.26; 95% CI, 0.07-0.96; P = 0.04) and decision self-efficacy (OR, 0.95; 95% CI, 0.91-0.99; P = 0.03) with decisional conflict.

Limitations: Single-health system study.

Conclusions: Decisional conflict was highly prevalent regardless of CKD progression risk. Findings suggest efforts to reduce decisional conflict should focus on minimizing the mismatch between clinical practice guidelines and patient-reported engagement in treatment preparation, facilitating patient-kidney team treatment discussions, and developing treatment education programs and decision support interventions that incorporate decision self-efficacy-enhancing strategies.

Koch-Weser S, Kennefick K, Tighiouart H, et al. **Development and Validation of the Rating of CKD Knowledge Among Older Adults (Know-CKD) With Kidney Failure.** Am J Kidney Dis. 2024;83(5):569-577. doi:10.1053/j.ajkd.2023.09.024

PMID: 38070590

Abstract: Rationale & objective: Few older adults with kidney failure engage in shared decision making (SDM) for kidney replacement therapy. The lack of instruments to assess SDM-relevant knowledge domains may contribute to this. We assessed the reliability and validity of a new instrument, the Rating of CKD Knowledge Older Adults (Know-CKD).

Study design: Multistage process, including a stakeholder-engaged development phase, pilot testing, and validation of a knowledge instrument using a cross-sectional survey of older adults with CKD.

Setting & participants: 363 patients aged 70+years with non-dialysis advanced chronic kidney disease (CKD) (estimated glomerular filtration rate [eGFR]<30mL/min/1.73m2) in Boston, Chicago, Portland, ME, and San Diego from June 2018 and January 2020.

Exposure: Educational level, higher literacy (Single Item Literacy Screener [SILS]) and numeracy (Subjective Numeracy Scale [SNS]), having participated in clinic-sponsored dialysis education, and self-reported "feeling informed" about options for treatment.

Outcome: Validity and reliability of the Know-CKD instrument.

Analytical approach: Reliability was assessed with the Kuder-Richardson-20 coefficient. Construct validity was demonstrated by testing a priori hypotheses using t test, analysis of variance (ANOVA) tests, and linear regression analyses.

Results: The mean (± SD) participant age was 77.6±5.9 years, and mean eGFR was 22.7±7.2mL/min/1.73m2; 281 participants (78%) self-reported as White. The 12-item Know-CKD assessment had good reliability (Kuder-Richardson-20 reliability coefficient=0.75), and a mean score of 58.2% ± 22.3 SD. The subscales did not attain acceptable reliability. The proportion answering correctly on each item ranged from 20.1% to 91.7%. In examining construct validity, the hypothesized associations held; Know-CKD significantly associated with higher education (β=6.98 [95% CI, 1.34-12.61], P=0.02), health literacy (β = -12.67 [95% CI, -19.49 to-5.86], P≤0.001), numeracy per 10% higher (β=1.85 [95% CI, 1.02-2.69], P≤0.001), and attendance at dialysis class (β=18.28 [95% CI, 13.30-23.27], P≤0.001). These associations were also observed for the subscales except for prognosis (not associated with literacy or numeracy).

Limitations: Know-CKD is only available in English and has been used only in research settings.

Conclusions: For older adults facing dialysis initiation decisions, Know-CKD is a valid, reliable, and easy to administer measure of knowledge. Further research should examine the relationship of kidney disease knowledge and SDM, patient satisfaction, and clinical outcomes.

Shukla AM, Visconti B, Pearce K, et al. **Development and Validation of KRT Knowledge Instrument.** Clin J Am Soc Nephrol. 2024;19(7):877-886. doi:10.2215/CJN.0000000000000472

PMID: 38748976

Abstract: Background: Awareness of KRTs is associated with greater home dialysis use. However, validated instruments evaluating patient knowledge and awareness of various KRTs are currently lacking and are critical for informed decision making.

Methods: We developed a 24-item KRT knowledge instrument (Know-KRT) encompassing three domains of General, Technical, and Correlative information critical for informed dialysis decision making. We conducted a cross-sectional study among Veterans with advanced CKD to determine its reliability, dimensionality, and validity.

Results: The Know-KRT instrument dimensionality was acceptable with a root mean squared error of approximation of 0.095 for the conceptual three-domain model fit

($\chi2=824.6$, $P < 0.001$). Corrected Item-Total Correlation indices were excellent ($>0.4$) for all individual items. Internal consistency was excellent for the full instrument, Cronbach's alpha, $\alpha=0.95$, with $\alpha=0.86$, 0.91, and 0.79 for the General, Technical, and Correlative domains, respectively. The Know-KRT score correlated strongly with the CKD knowledge score ($r=0.68$, $P < 0.001$). KRT awareness was low, with an ease index of 0.181 for the full instrument. The General, Technical, and Correlative domain scores demonstrated strong correlations with the Know-KRT total score ($r=0.68$, 0.61, and 0.48, respectively, $P < 0.001$) and CKD instrument score ($r=0.95$, 0.93, and 0.77, respectively, $P < 0.001$). KRT and CKD awareness correlated negatively with age and positively with health literacy, employment status, hypertension, and quality of nephrology care.

Conclusions: We report a newly developed Know-KRT instrument with three domains having acceptable internal consistency, reliability, and validity. We show that patients with advanced CKD have low awareness of KRTs, even for items related to basic descriptions of modalities, highlighting the need for targeted patient education efforts