

# Technical Expert Panel (TEP)

## Membership List

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

### **Project Overview:**

The Centers for Medicare & Medicaid Services (CMS) has contracted with the 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 number is 775FCMC18D0041, 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.

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 member of the dialysis community.

## Technical Expert Panel (TEP) Membership

We have selected these individuals and they have agreed to serve as the TEP for this project:

<b>Name, Credentials, Professional Role*</b>	<b>Organizational Affiliation, City, State*</b>	<b>Consumer/ Patient/ Family/ Caregiver Perspective*</b>	<b><i>Nephrologist, Nephrology Trained Social Worker, Dialysis Facility Trained, Nursing Staff</i></b>	<b>Performance Measurement</b>	<b>Quality Improvement Expert</b>	<b>Conflict of Interest Disclosure*</b>
<b>Felicia Speed</b> PhD, LMSW VP of Social Work Services	Fresenius Medical Care Pelzer, SC		X			None Reported
<b>Johnie Flotte</b> BSN, RN VP of Clinical Service	US Renal Care Franklin, TN		X	X	X	None Reported
<b>Paul Conway</b> BA Chair, Policy and Global Affairs Patient Advocate	American Association of Kidney Patients Tampa, FL	X		X	X	None Reported
<b>Theodore Shaikewitz</b> MD Nephrologist	Durham Nephrology Associates Durham, NC		X	X	X	None Reported
<b>Francesca Tentori</b> MD, MSCI Physician Researcher Industry Representative	DaVita Kidney Care Portland, TN		X	X	X	Employed by DaVita Kidney Care
<b>Craig Miller</b> PT, MPH Regional Director of Therapy Home Care and Outpatient	Rivetis Rehabilitation Macomb, MI	X				None Reported
<b>Katie Cardone</b> PharmD, BCACP, FNKF, FASN, FCCP	Albany College of Pharmacy and Health Sciences		X	X	X	Sub-Investigator on Merck & Co Clinical Trial; Consultant for GlaxoSmithKline; Spouse employed by Fresenius Kidney Care

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<b>Klemens Myer</b> Nephrologist M.D. Physician and Researcher on Decision Making and Patient Reported Outcomes	Tufts Medical Center and Dialysis Clinic, Inc Boston, MA		X	X	X	Funds from Dialysis Clinic, Inc., which is used for salary support for DCI work.
<b>Alvin Moss</b> MD, FACP, FAAHPM Director, Center for Health Ethics and Law	West Virginia University Health Sciences Center Morgantown, WV		X	X	X	Co-Investigator for grant from Fan Fox & Leslie R. Samuels Foundation & Co-Investigator for grant from Gordon and Betty Moore Foundation
<b>Vikram Aggarwal</b> MD, DNB, FASN	Vantive (Formerly Baxter) Chicago, IL		X	X	X	Consultant for Vantive (formerly Baxter)
<b>Samantha Gelfand</b> MD	Dana-Farber Cancer Institute Boston, MA		X	X	X	None Reported
<b>Kristal Higgins</b>	Olive Branch, MS	X	X			None Reported
<b>Jane DeMeis</b> Patient Advocate	Fairport, NY	X				None Reported
<b>Stephanie Dixon</b>	Kidney Patient Advisory Council (KPAC) Rutherford, NJ	X				None Reported
<b>Alan Kliger</b> MD	Yale School of Medicine Woodbridge, CT		X	X	X	None Reported