

Supplemental Material

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SUPPLEMENTAL TABLES AND SUPPORTING MATERIAL

Workshop Description

Building Research Capacity in the Dialysis Community at the Local Level National Workshop

**May 9 – 10, 2018
Sheraton Imperial Hotel and Convention Center
4700 Emperor Blvd., Durham, NC 27703**

This workshop represented the culmination of a 2-year Patient-Centered Outcomes Research Institute (PCORI)-sponsored project, “Building Research Capacity in the Dialysis Community at the Local Level” (PCORI EA-3253). In developing and executing the workshop, we relied on the Patient-Centered Outcomes Research (PCOR) Engagement Principles to guide our stakeholder engagement approach (**Table S2**).⁸ A panel of 10 multidisciplinary stakeholders (patients, care partners, researchers, medical providers, corporate dialysis organization representatives, and dialysis clinic personnel) worked collaboratively with the project team to develop the workshop agenda (**Table S3**) and identify attendees (**Tables S1 and S4**).

To capture a range of professional and research experiences, we used purposive sampling to identify workshop attendees. To identify dialysis organization representatives, we contacted the Chief Medical Officers of the largest dialysis provider organizations and asked them to identify participants who fit specified stakeholder positions within their organizations. We relied on the local American Nephrology Nursing Association chapter to identify local nurses and patient care technicians from non-academic associated clinics; patient organizations (American Association of Kidney Patients, Home Dialyzors United, and Renal Support Network) to identify national patients; and local nephrologists to identify local patients. Among clinic-level stakeholders, we sought varying levels of research experience. We sought to include researchers with diverse experiences such as individuals with expertise in pragmatic trials, pilot feasibility studies, industry-sponsored trials, patient-centered outcomes, and patient communication. We also sought participation from medical providers in diverse practice settings including academics and private practice as well as those with experience in the Veterans Affairs healthcare system.

The workshop’s objectives were to: 1) engage diverse stakeholders in forward-thinking dialogue about the advancement of a research-ready dialysis culture; 2) identify concrete actions for increasing research capacity in the dialysis setting; and 3) build collaborative relationships toward advancing this work. The

workshop was held in May 2018 in Durham, North Carolina (NC) and included interactive sessions with activities to stimulate multi-stakeholder discussions and foster collaborative participation. The event began with introductory plenary presentations on the workshop's purpose and foundational research terms and concepts intended to bridge knowledge levels of the diverse participants, followed by panel discussions and guided, multi-stakeholder breakout sessions to generate further discussion on designated topics (research culture, research implementation barriers, and potential solutions to improve research readiness). We pre-assigned attendees to one of four multi-stakeholder discussion groups, which included the same participants in each session. Two trained moderators led each group using discussion guides. The workshop was audio-recorded, and field notes were taken.

Supplemental Table S1. Workshop participants.

Name	Affiliation	Stakeholder Position(s)
Constance Anderson	Northwest Kidney Centers	Corporate dialysis
Yvonne Blake	University of North Carolina, Greensboro	Dialysis clinic (nurse)
Jason Burnette	Chapel Hill, NC	Patient
Vivian Burnette	Chapel Hill, NC	Care partner
Scott Burton	Pfafftown, NC	Patient
Theresa Campbell	Carolina Kidney Care, Fayetteville, NC	Medical provider (nurse practitioner)
Shalali Cassim	Frenova	Corporate dialysis (dialysis clinical research organization)
Kerri Cavanaugh	Vanderbilt University	Researcher, medical provider
Tara Chang	Stanford University	Researcher, medical provider
Colleen Chavis	Durham, NC	Patient
Maxine Chavis	Durham, NC	Care partner
Cynthia Christiano ^a	East Carolina University	Medical provider
Adrienne Clagett	Vanderbilt University	Researcher (research coordinator)
Shaun Collard	Satellite Healthcare	Corporate dialysis
Kelli Collins	National Kidney Foundation	Other
Lorien Dalrymple	Fresenius Medical Care	Corporate dialysis, researcher, medical provider
Laura Dember ^a	University of Pennsylvania	Researcher, medical provider
Duane Dunn	DaVita, Inc.	Dialysis clinic (social worker)
Jessica Farrell ^a	Fresenius Medical Care	Dialysis clinic (social worker)
Richard Fissel ^a	Newark, DE	Patient
Sonya Fleming	American Nephrology Nurses' Association	Dialysis clinic (nurse)
Jennifer Flythe ^a	University of North Carolina, Chapel Hill	Researcher, medical provider, organizer
Winnie Fontenelle	University of North Carolina, Chapel Hill	Dialysis clinic (nurse), transplant coordinator
Derek Forfang	San Pablo, CA	Patient
Nieltje Gedney	Kearneysville, WV	Patient
Barbara Gillespie ^a	Covance, Inc.	Researcher (clinical research organization), medical provider
Merle Green	Greensboro, NC	Care partner
Talia Gutman	University of Sydney	Researcher
Rainer Himmele	Fresenius Medical Care	Corporate dialysis
Beth Holloman	Raleigh, NC	Patient
Wael Hussein	Satellite Healthcare	Corporate dialysis, researcher, medical provider
Frankie Ingold	Fresenius Medical Care	Dialysis clinic (clinic manager)
Colleen Jabaut ^a	Fresenius Medical Care	Dialysis clinic (clinic manager)
Nirav Jasani	Will Bynum & Associates Nephrology and Hypertension Practice	Medical provider
Sahir Kalim	Massachusetts General Hospital	Researcher, medical provider
Jenny Kitsen ^a	Forum of ESRD Networks American Association of Kidney Patients	Other
Susan Kram	The Kidney Project University of California, San Francisco	Researcher (program manager)

Abhijit Kshirsagar	University of North Carolina, Chapel Hill	Researcher, medical provider
Jeff Kuhns	Punta Gorda, FL	Care partner
Lori Linke ^c	Kidney Research Institute	Researcher (research coordinator)
Yasmeen Long	Patient-Centered Outcomes Research Institute	Other
Dugan Maddux	Fresenius Medical Care	Corporate dialysis, researcher, medical provider
Dana Miskulin	Dialysis Clinic, Inc. Tufts University	Corporate dialysis, researcher, medical provider
Ann Mooney	American Renal Associates	Corporate dialysis
Kurt Mussina	Frenova	Corporate dialysis (dialysis clinical research organization)
Antoinette Ordish ^a	Fresenius Medical Care	Dialysis clinic (regional area manager)
Cynthia Palmiter	Fresenius Medical Care	Dialysis clinic (PCT)
Hannah Putnam	Fresenius Medical Care	Corporate dialysis
Dodie Robinson	IPRO ESRD Network	Other
Jeffrey Silberzweig	Rogosin Institute	Corporate dialysis, medical provider
Jennifer St. Clair Russell ^b	Duke University	Other
Maria Stasios	DaVita, Inc.	Dialysis clinic (dietitian)
Beverly Storck	Fresenius Medical Care	Dialysis clinic (nurse)
Terry Sullivan ^a	Fresenius Medical Care	Corporate dialysis
Tyvon Sumler	Fresenius Medical Care	Dialysis clinic (PCT)
Francesca Tentori	DaVita Clinical Research DaVita Clinic, Inc.	Corporate dialysis, researcher, medical provider
Allison Tong	University of Sydney	Researcher
Tushar Vachharajani	V.A. Health Care System, Salisbury, NC	Medical provider, researcher
Robin Wallace	Frenova	Corporate dialysis (dialysis clinical research organization)
Virginia Wang	Duke University	Researcher
Lucy Wessinger	University of North Carolina, Chapel Hill	Medical provider (nurse practitioner)
Melissa West	Kidney Health Initiative	Other
David White	Washington, D.C.	Patient
Sheila White	Fresenius Medical Care	Dialysis clinic (dietitian)
Caroline Wilkie ^a	Punta Gorda, FL	Patient
Kenneth Wilund	University of Illinois, Urbana-Champaign	Researcher
Rebecca Wingard	Fresenius Medical Care	Corporate dialysis
Myles Wolf	Duke University	Researcher, medical provider
Amy Young ^a	DaVita Clinical Research	Corporate dialysis (dialysis clinical research organization)
Andrew Amolegbe	American Institutes for Research	Facilitator
Magdalene Assimon	University of North Carolina, Chapel Hill	Notetaker
Adeline Dorough ^a	University of North Carolina, Chapel Hill	Notetaker
Karen Frazier	American Institutes for Research	Facilitator
Tandrea Hilliard	American Institutes for Research	Organizer
Katie Huffman	Chapel Hill, NC	Notetaker
Kourtney Ikeler	American Institutes for Research	Organizer
Denise Mitchell	American Institutes for Research	Facilitator

Julia Narendra ^a	University of North Carolina, Chapel Hill	Organizer
Caroline Poulton	University of North Carolina, Chapel Hill	Notetaker
Matthew Tugman	University of North Carolina, Chapel Hill	Notetaker

^a Members of project research team or stakeholder panel.

^b Project education consultant.

^c Participation by telephone due to university travel restrictions.

Abbreviations: ESRD, end stage renal disease; V.A., Veterans Affairs; PCT, patient care technician.

Supplemental Table S2. Application of patient-centered outcomes research engagement principles to workshop development and execution.^a

Principle	Application
Reciprocal relationships	
Including patient and stakeholder partners as key personnel	<ul style="list-style-type: none"> • Project team included: researchers (2), patients (2), care partners (2) and clinic personnel (1) • Project stakeholder panel included: patient (1), clinic personnel (2), corporate dialysis organization representative (3), medical provider (2), researcher (1), and Forum of ESRD Networks representative (1)
Roles and decision-making are defined collaboratively	<ul style="list-style-type: none"> • Workshop objectives and content arrived at through iterative feedback from stakeholders
Partnerships	
Fair compensation and reasonable and thoughtful requests for time	<ul style="list-style-type: none"> • Project team patients and care partners were compensated for their time • Travel expenses were covered for patient and care partner workshop participants
Committed to diversity and cultural competence across all activities	<ul style="list-style-type: none"> • Workshop participants included diverse stakeholders
Co-learning	
Researchers help patients and other stakeholders to understand the research process	<ul style="list-style-type: none"> • Workshop introductory sessions included level-setting information and foundational research terms and concepts • Background materials, including a research term glossary, were provided to participants before the workshop
Team learning about patient-centeredness and stakeholder engagement	<ul style="list-style-type: none"> • Workshop participants were challenged to collaboratively identify ways to achieve a research-ready dialysis culture and breakdown barriers to research implementation
Patient-centeredness and stakeholder engagement incorporated into research process	<ul style="list-style-type: none"> • The overarching goal of the project and workshop was to identify ways to improve research capacity and, ultimately, patient outcomes. Patients were central to the mission throughout • The project (including funding application) was co-developed by a patient • Focus groups with diverse dialysis stakeholders provided the foundational content for the workshop focus • Diverse dialysis stakeholders, including patients, meaningfully contributed to the workshop development and implementation through service on a stakeholder panel • Diverse stakeholders participated in the workshop as panelists, speakers and moderators
Transparency-Honesty-Trust	
Inclusive decision-making	<ul style="list-style-type: none"> • Workshop discussion and identification of research capacity barriers and facilitators included diverse stakeholder participants to ensure inclusion of all perspectives • Project stakeholders contributed to workshop speaker and participant identification
Information is readily shared	<ul style="list-style-type: none"> • Conducted quarterly stakeholder panel conference calls and periodically emailed relevant workshop information • Workshop presentations and executive summary shared with participants following the workshop • Public website with summarized workshop findings
Commitment to open and honest communication	<ul style="list-style-type: none"> • Encouraged honest and transparent communication among all stakeholders during workshop development and execution • Workshop participants voluntarily completed anonymous workshop evaluation surveys and post-workshop commitment to action cards

^a Reference: Sheridan, S, Schrandt, S, Forsythe, L, Advisory Panel on Patient Engagement (2013 inaugural panel), Hilliard, TS, Paez, KA: The PCORI Engagement Rubric: Promising Practices for Partnering in Research. *Ann Fam Med*, 15: 165-170, 2017.

Abbreviations: ESRD, end-stage renal disease.

Supplemental Table S3. Workshop agenda.

Building Research Capacity in the Dialysis Community at the Local Level Sheraton Imperial Hotel & Convention Center and IQVIA, Durham, NC		
Wednesday, May 9, 2018 (Session 1 at Sheraton Hotel. Dinner & showcase at IQVIA)		
3:00-4:00	Registration	
	Session 1: Setting the stage	
4:00-5:05	Welcome and introduction	Jennifer Flythe Antoinette Ordish Caroline Wilkie
5:05-5:20	Leveling the field: Introduction to research concepts	Barbara Gillespie
5:20-5:30	Questions	
5:30-6:00	Break / Walk or shuttle to IQVIA	
	Dinner with Research Showcase Panel	
6:00-6:45	Drinks and hors d'oeuvres	
6:45-8:15	Dinner and panel	
	-TiME Trial	Laura Dember
	-The Kidney Project	Susan Kram, Richard Fissel
	-Blood Pressure in Dialysis Trial	Dana Miskulin
	-SONG Initiative	Allison Tong, Caroline Wilkie
	-KINDRED Study	Sahir Kalim
8:30	Adjourn	
Thursday, May 10, 2018 (All sessions at Sheraton Hotel)		
7:30-8:00	Breakfast	
	Session 2: The 3 R's: Research rules, regulations and red tape	
8:00-8:15	Institutional Review Boards, contracting and legal issues	Laura Dember
8:15-8:30	Engaging patients in research: from design to dissemination	Derek Forfang
8:30-8:50	Dialysis clinic personnel engagement in research and improving research readiness of dialysis clinics	Hannah Putnam, Terry Sullivan
8:50-9:00	Questions	
9:15-10:30	Break-out session #1: Promotion of research readiness in dialysis clinics	
10:30-10:40	Break	
	Session 3: Research implementation and facilitation in dialysis clinics (PANEL)	
10:40-11:00	Group reporting from break-out session #1	
11:00-11:40	A dialysis provider organization's perspective	Amy Young
	A local dialysis clinic's perspective	Antoinette Ordish
	A patient's perspective	Richard Fissel
	A research coordinator's perspective	Adrienne Clagett, Lori Linke
11:40-12:00	Questions	
12:00-12:45	Lunch	
12:45-2:00	Break-out session #2: Research implementation barriers and facilitators	
2:00-2:15	Break	
	Session 4: Communication, communication, communication (PANEL)	
2:15-2:45	Group reporting from break-out session #2	
2:45-3:15	A dialysis provider's perspective	Shaun Collard
	A nurse manager's perspective	Colleen Jabaut
	A researcher's perspective	Kerri Cavanaugh
	A patient's perspective	David White
3:15-3:30	Group discussion and Questions	
3:30-3:45	Wrap-up and next steps	Jennifer Flythe

Supplemental Table S4. Workshop composition (N=69 participants).^a

Characteristic	n (%)
<i>Stakeholder position</i>	
Patients	9 (13.0)
In-center hemodialysis	2
Home hemodialysis	2
Peritoneal dialysis	1
Transplant	4
Care partners	4 (5.8)
Clinic Personnel	14 (20.3)
Regional area manager	1
Clinic manager	3
Nurse	4
Patient care technician	2
Social worker	2
Dietitian	2
Medical Providers	13 (18.8)
Non-research physician	2
Advanced practice provider	2
Physician-investigator	9
Researchers	8 (11.6)
Non-physician investigator	4
Research coordinator	3
Clinical research organization	1
Corporate dialysis organization representative	16 (23.2)
Medical office	6
Operations	5
Dialysis clinical research organization	5
Community organizations	2 (2.9)
Government	3 (4.4)
Funding agency	1
Forum of ESRD Networks	2
<i>Place of residence of participants</i>	
Australia	2
United States	
California	5
Connecticut	1
Delaware	1
Florida	2
Illinois	1
Maryland	3
Massachusetts	7
Minnesota	2
New York	4
North Carolina	31
Oregon	1
Pennsylvania	1
South Carolina	1
Tennessee	4
Washington	2
West Virginia	1
<i>Dialysis organizations^b</i>	7

^a Data presented as n(%) for main stakeholder position categories.

^b Fresenius Kidney Care North America, DaVita, Inc., Dialysis Clinic, Inc., American Renal Associates, Satellite Healthcare, Northwest Kidney Centers, and Rogosin Institute.