Building Research Capacity in the Dialysis Community

Jenny Flythe, MD, MPH
University of North Carolina School of Medicine
May 9, 2018
A Shared Goal

Commitment from diverse stakeholders

Engagement Dialogue

Action

Research

Clinical care

Better dialysis future
Overview

• Dialysis care and research in the United States

• Building research capacity in the dialysis community at the local level
  • Identifying barriers to and facilitators of dialysis research
  • Improving research capacity through knowledge, processes, and culture

• Workshop logistics and goals
Dialysis Care and Research in the U.S.
End-Stage Kidney Disease in the U.S.

- 661,648 prevalent (existing) patients in 2013
  - 64% on hemodialysis
  - 7% on peritoneal dialysis
  - 29% with functioning transplant

- 117,162 incident (new) patients in 2013
  - 88% treated with in-center hemodialysis as first treatment modality
  - 9% treated with peritoneal dialysis
  - 3% received a preemptive kidney transplant

Dialysis-Dependent ESKD

• Life-long dependence on dialysis unless transplanted

• Multiple competing medical conditions to manage

• Poor quality of life for many

• Death rates are improving, but are still too high
  • 21% in 1st year
  • 50% at 3 years

Dialysis Delivery in the U.S.

• **Dialysis organizations** have the features of large, highly structured businesses
  - Multiple administrative levels, regional divisions, and governance levels
  - Operate under business rules and conventions
  - Operate in a highly regulated environment which necessitates a level of uniformity and rigidity

• **Local dialysis clinics** are highly structured for efficiency to meet demands and safety of clinical care, but also have some degree of variability in practices
  - Small team of care providers
  - Local culture

*Slide (modified) courtesy of Laura Dember, TiME Trial.*
Federal Corporate organizations Local clinics ESRD Networks Local clinic stakeholders

Policy environment: Centers for Medicare and Medicaid Services

Patients Families and care partners Clinicians
Clinic personnel - clinic managers - nurses - care technicians - social workers - dieticians

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## Dialysis Delivery in the U.S.

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Dialysis Research

• Research Types
  • Large database (medical record, insurance claims) studies
  • Survey, focus group, and interview studies
  • Experimental research like clinical trials

• Clinical Trials
  • Few in number compared to other specialties
  • Usually small
  • Lack of participant diversity
  • Interventions found to be beneficial in smaller trials are often not tested in larger trials → not implemented in practice
Dialysis Research Challenges

• Corporate – local disconnect

• Many local stakeholders

• Competing clinical and life demands

• Historical lack of stakeholder engagement in research development and design \( \rightarrow \) lack of buy-in

• Limited research literacy among patients and clinic personnel

*Culture shift needed*
Building Research Capacity
PCORI Engagement Award

Building research capacity in the dialysis community at the local level

• Barriers to research
  • 1) Limited research literacy among patients, clinic personnel and clinicians
  • 2) Lack of a “research-ready” clinic culture to facilitate research

• Project premise
  • Build research capacity at the local dialysis clinic level by:
    1) imparting knowledge and
    2) generating research interest with the goal of
  • Facilitating more successful research conduct
Project Aims

• **Phase 1:**
  - Identify facilitators of and barriers to research in local dialysis clinics

• **Phase 2:**
  - Use knowledge learned in phase 1 to develop research educational materials

• **Phase 3:**
  - Convene a national stakeholder workshop to:
    - Identify and prioritize barriers to research implementation in the dialysis setting
    - Identify **solutions** for overcoming identified barriers
    - Develop a **collaborative** vision for improving research readiness in dialysis clinics
Celeste Castillo Lee
July 26, 1965 – February 9, 2017
## Project Team

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<th>Investigative Team</th>
<th>Stakeholder Panel</th>
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<tr>
<td>Jenny Flythe- UNC <em>physician-research</em></td>
<td>Cindy Christiano- ECU <em>physician</em></td>
</tr>
<tr>
<td>Laura Dember- Penn <em>physician-research</em></td>
<td>Jessica Farrell- FMC/RRI <em>social worker</em></td>
</tr>
<tr>
<td>Daniel Lee- Michigan <em>family member</em></td>
<td>Richard Fissel- DE <em>patient</em></td>
</tr>
<tr>
<td>Jon Oberlander- UNC <em>family member</em></td>
<td>Barbara Gillespie- Covance <em>physician-research</em></td>
</tr>
<tr>
<td>Antoinette Ordish- FMC <em>area manager</em></td>
<td>Jay Ginsberg- CT <em>private practice physician</em></td>
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<tr>
<td>Caroline Wilkie- FL <em>patient</em></td>
<td>Colleen Jabaut- FMC/RRI <em>clinic manager</em></td>
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<td></td>
<td>Jenny Kitsen (prior ESRD network director)</td>
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<tr>
<td>Celeste Lee <em>(In memoriam, patient)</em></td>
<td>Brigitte Schiller- Satellite <em>dialysis prov. CMO</em></td>
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<td>Terry Sullivan- FMC/RRI <em>dialysis prov. Ops</em></td>
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<tr>
<td>Jennifer St. Clair Russell- Duke <em>edu</em></td>
<td>Amy Young- DaVita <em>dialysis CRO GM</em></td>
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Workshop Team

American Institute for Research (AIR)

Tandrea Hilliard, PhD
Karen Frazier, PhD
Kourtney Ikeler, BA
Andrew Amolegbe, MPH
Denise Mitchell, BA

Julia Narendra
Adeline Dorough

Matthew Tugman
Magdalene Assimon
Caroline Poulton
Katie Huffman
Phase 1: Focus Groups- Objectives

1) To learn what diverse dialysis clinic stakeholders thought about:
   a) patient participation in research, and
   b) clinic personnel and medical provider facilitation of research

2) To learn about stakeholder preferences for research-related communication
Phase 1: Focus Groups- Results

- 7 stakeholder-specific focus groups (Nov 2016- Feb 2017)
  - Patient/care partner, nurse/PCT, clinic manager, SW/dietitian, medical provider

- 59 participants from 7 NC dialysis clinics
  - 5 academic (UNC-FMC): Carrboro, Pittsboro, Siler City, Mebane, Sanford
  - 2 community (FMC): Charlotte
  - In-center and home therapies

- Methods
  - Semi-structured moderator guide
  - Thematic analysis
# Thematic Analysis

<table>
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<tr>
<th>Organizing Category</th>
<th>Themes</th>
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<tr>
<td><strong>Individual Stakeholder</strong></td>
<td>• Narrow research understanding by patients and clinic personnel</td>
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<tr>
<td></td>
<td>• Competing personal priorities among patients</td>
</tr>
<tr>
<td></td>
<td>• Low literacy and education levels of patients and inadequate research expertise of clinic personnel</td>
</tr>
<tr>
<td><strong>Relationship</strong></td>
<td>• Necessity of trust between clinic personnel and patients and between the research team and clinic stakeholders</td>
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<tr>
<td></td>
<td>• Research buy-in by all stakeholders</td>
</tr>
<tr>
<td></td>
<td>• Altruistic motivations of all stakeholders</td>
</tr>
<tr>
<td><strong>Research Design and Operations</strong></td>
<td>• Research convenience for all stakeholders</td>
</tr>
<tr>
<td></td>
<td>• Timely follow-up for all stakeholders</td>
</tr>
<tr>
<td></td>
<td>• Incentives as participation motivators for patients</td>
</tr>
<tr>
<td><strong>Dialysis Clinic</strong></td>
<td>• Competing professional demands among clinic personnel and medical providers</td>
</tr>
<tr>
<td></td>
<td>• Importance of teamwork and communication for all stakeholders</td>
</tr>
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*Flythe et al. AJKD 2017.*
It’s not about the money. It’s about knowing that we did something to benefit patients in the long run. (clinic manager)

You’re racing against time and you’re racing between different units. (provider)

Our jobs and day are long enough as it is. (patient care technician)

She transferred her trust to you, so I never had to worry about anything you said… The trust in the nurse is transferred to you [research asst] and so I don’t have to worry about that non-trust building up because they transferred their power. (patient)

I think that’s where the improvement needs to come in, is communicating back to us what they actually did with the data. Did it go into an article? Did it make a change somewhere? What happened? (clinic manager)
Aspects influencing research readiness

- **Individual**
  - **Barriers**
    - narrow understanding
    - competing priorities
    - low education/literacy
  - **Facilitators**
    - research education
    - level-specific education

- **Research design/operations**
  - **Barriers**
    - hectic environment
    - professional demands
    - poor study f/u
    - hesitancy
  - **Facilitators**
    - efficiency
    - ↓ burden
    - interval, specified f/u
    - incentives

- **Dialysis clinic**
  - **Barriers**
    - heavy clinical workload
    - disconnected duties
    - research unaware
  - **Facilitators**
    - operations support
    - teamwork
    - communication

- **Relationships**
  - **Barriers**
    - mistrust
    - potential ulterior motives
    - doubt
    - ambivalence
  - **Facilitators**
    - trusted messenger
    - trusting relationship
    - buy-in
    - potential study benefit

- **Stakeholder research interest**
  - Clinical and research activities

Flythe et al. AJKD 2017.
Phase 2: Educational Materials

• Build on key concepts identified in focus groups
  • Need for improved patient and clinic personnel research understanding
  • Need for patient and clinic personnel research buy-in and enthusiasm

• Stakeholder suggestions
  • Multiple formats (video + written + on-line)
  • Color and video animation for visual appeal
  • Real people telling real stories
  • Realistic and dialysis-specific
  • Up-beat tone

"There needs to be a sense of encouragement in there for the patient." (social worker)

"We read a lot of black and white and we read all the time, so I'd rather see a video." (nurse)
Phase 2: Video Development

• Format: animated + live people

• Audience: patients, care partners, clinic personnel

• Content (14+ script iterations):
  • What is research?
  • What are examples of dialysis research?
  • What types of research are there?
  • How are research participants protected?
  • What should you expect from researchers?
  • Why might you want to participate in research?
Phase 2: Video Creative Team

Terence Oliver, Animator
UNC School of Media and Journalism

Robb Kehoe, Videographer
UNC School of Medicine

Darrel Greene, Audio Producer
Jesty Beatz Productions, Los Angeles, CA

Megan Hollingshead, Voice Talent, Los Angeles, CA

Nate Auler and Jason Burnette, Nurse and Patient
Carrboro, NC
Video
KEEP OUT

THIS IS AN ACTIVE SET. PLEASE DO NOT ENTER OR DISTURB. THANKS! - IMS
Phase 2: Video Uses and Dissemination

• go.unc.edu/DialysisResearchVideo

• Website statistics
  • Unique page views: 1,413
  • YouTube video views: 942

• How can your organization use the video?
Phase 2: Written Materials Development

• Goal
  • Supplement video
  • Responsive to stakeholder requests for follow-up written materials that can be viewed outside of the dialysis clinic
  • Engage dialysis clinic personnel

• Content
  1) Research education booklet
  2) Glossary of research terms
  3) Research education lunch and learn session toolkit
Please Provide Feedback on the Materials

Adeline Dorough
**Coming Soon:** Research Readiness Toolkit

1. **WATCH** → video
2. **REVIEW** → materials
3. **TALK** → discussion questions
4. **RECORD** → research preferences

**Discussion Guide**

**Video**

**Written Materials**

**Lunch & Learn Module**
Phase 3: National Workshop

The workshop is the first of its kind to focus on the research capacity of dialysis clinics. Participants will collaboratively identify facilitators of and barriers to research performance in local dialysis clinics and develop a collective vision for improving research capacity.

May 9-10, 2018
Sheraton Imperial Hotel and Convention Center, Durham, NC
Stakeholder Comments

• Caroline Wilkie
  • Home hemodialysis patient
  • Punta Gorda, FL

• Antoinette Ordish, RN, MSN, MHA
  • Director of Operations, Pacific River Bend, Fresenius Medical Care, NA
  • Battle Ground, WA
Workshop Logistics and Goals
Workshop Purpose

• Engage diverse stakeholders in forward thinking dialogue

• Identify and prioritize barriers to research implementation in the dialysis setting

• Identify **concrete action steps** toward breaking down prioritized barriers and creating ‘research-ready’ clinic cultures

• Build **collaborative** relationships toward advancing this work
Expectations

- Maintain confidentiality.
- Equal participation. Everyone was brought here for a reason.
- Challenge ideas, not people.
- Share airtime.
- Understand and learn from each other.
- Please avoid multi-tasking and reserve checking email, laptops for breaks and lunch.
A Shared Goal

Commitment from diverse stakeholders

Engagement Dialogue

Action

Research

Clinical care

Better dialysis future
Thank You and WELCOME!