

## Perspectives on Research Participation and Facilitation Among Dialysis Patients, Clinic Personnel, and Medical Providers: A Focus Group Study



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**Background:** Most prospective studies involving individuals receiving maintenance dialysis have been small, and many have had poor clinical translatability. Research relevance can be enhanced through stakeholder engagement. However, little is known about dialysis clinic stakeholders' perceptions of research participation and facilitation. The objective of this study was to characterize the perspectives of dialysis clinic stakeholders (patients, clinic personnel, and medical providers) on: (1) research participation by patients and (2) research facilitation by clinic personnel and medical providers. We also sought to elucidate stakeholder preferences for research communication.

**Study Design:** Qualitative study.

**Setting & Participants:** 7 focus groups (59 participants: 8 clinic managers, 14 nurses/patient care technicians, 8 social workers/dietitians, 11 nephrologists/advanced practice providers, and 18 patients/care partners) from 7 North Carolina dialysis clinics.

**Methodology:** Clinics and participants were purposively sampled. Focus groups were recorded and transcribed.

**Analytical Approach:** Thematic analysis.

**Results:** We identified 11 themes that captured barriers to and facilitators of research participation by patients and research facilitation by clinic personnel and medical providers. We collapsed these themes into 4 categories to create an organizational framework for considering stakeholder (narrow research understanding, competing personal priorities, and low patient literacy and education levels), relationship (trust, buy-in, and altruistic motivations), research design (convenience, follow-up, and patient incentives), and dialysis clinic (professional demands, teamwork, and communication) aspects that may affect stakeholder interest in participating in or facilitating research. These themes appear to shape the degree of research readiness of a dialysis clinic environment. Participants preferred short research communications delivered in multiple formats.

**Limitations:** Potential selection bias and inclusion of English-speaking participants only.

**Conclusions:** Our findings revealed patient interest in participating in research and clinical personnel and medical provider interest in facilitating research. Overall, our results suggest that dialysis clinic research readiness may be enhanced through increased stakeholder research knowledge and alignment of clinical and research activities.

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The quality and quantity of published research in kidney disease generally lags behind that of other disciplines.<sup>1,2</sup> Clinical trials among individuals receiving maintenance dialysis often have low patient recruitment, incomplete protocol adherence, and poor clinical practice translatability.<sup>2,3</sup> These challenges, among others, have contributed to a paucity of high-quality data to inform clinical guidelines and few proven interventions to ameliorate the unacceptably poor outcomes experienced by individuals receiving dialysis.

In recent years, there have been efforts to broaden stakeholder engagement in dialysis research to inform study outcomes and enhance clinical trial relevance and reliability. The Standardized Outcomes in Nephrology-Hemodialysis (SONG-HD) initiative has generated a patient-, care partner-, and professional-prioritized list of consensus hemodialysis outcomes.<sup>4</sup> This initiative represents progress in dialysis stakeholder engagement, but additional work in aspects of research beyond outcome selection is needed. For example, little is known about

dialysis stakeholders' perceptions of research participation and facilitation.

Acknowledgment of key stakeholder competing priorities and workplace challenges are central to establishing successful research partnerships.<sup>5</sup> Research facilitation barriers may arise if clinic environments are not considered when developing study protocols. In the US dialysis delivery system, research oversight is typically centralized at the dialysis provider corporate level. However, research activities take place at local clinics that have their own stakeholders, including clinic managers, nurses, patient care technicians (PCTs), social workers, dietitians, patients, care partners, and medical providers (nephrologists and advanced practice providers). Better understanding of these diverse stakeholders' research-related perceptions may facilitate improved research participation and facilitation, ultimately enhancing research quality. To begin to address this knowledge gap, we undertook exploratory focus groups to characterize perspectives of dialysis clinic stakeholders (patients, clinic personnel, and medical

providers) regarding: (1) patient participation in research and (2) clinic personnel and medical provider facilitation of research in dialysis clinics. We also sought to elucidate stakeholder preferences for research-related communication materials.

## Methods

### Overview

We followed the Consolidated Criteria for Reporting Qualitative Health Research (COREQ; [Table S1](#)).<sup>6</sup> The study was approved by the University of North Carolina at Chapel Hill Institutional Review Board (16-2479). All participants provided written informed consent.

### Participant Selection and Setting

Seven dialysis clinic stakeholder-specific focus groups were conducted from November 2016 through February 2017: patients/care partners (n = 2 groups), nurses/PCTs (n = 2 groups), clinic managers (n = 1 group), social workers/dietitians (n = 1 group), and medical providers (n = 1 group). Participants were recruited from a convenience sample of 7 North Carolina dialysis clinics ([Table 1](#)). We strove for clinic diversity and selected clinics based on

location (urban vs rural), modality offerings (in-center hemodialysis, peritoneal dialysis, and home hemodialysis), size, and academic affiliation status. Participant recruitment methods included dialysis clinic fliers, announcements at clinic personnel meetings, e-mail, and in-person dialysis clinic interactions. Iterative purposive sampling was used to capture a range of participant characteristics (age, education, dialysis modality, and prior research experience). The target focus group size was 8 participants, with an acceptable size of 6 to 12 participants. We recruited up to 12 participants per group to allow for nonattendance.

Dialysis patients and care partners were eligible to participate if they had been receiving dialysis for 3 or more months or were care partners of patients receiving dialysis for 3 or more months. Individuals with cognitive impairment were excluded. Outpatient dialysis nurses, PCTs, social workers, dietitians, and medical providers (physicians and advanced practice providers) were eligible to participate if they had 1 or more years of dialysis experience. All participants were 18 years or older and English speaking. Participants were reimbursed for time and transportation.

Given the exploratory nature of the study and intent to capture diverse perspectives, we did not evaluate thematic saturation by stakeholder type. Due to low representation of home therapies nurses, patients, and care partners in the initial focus groups, we conducted additional nurse/PCT and patient/care partner groups with oversampling of the under-represented groups. The additional groups did not uncover new themes.

### Data Collection

We drafted a focus group moderator guide based on literature review and research team discussions. The guide was finalized after input from 10 multidisciplinary stakeholders (academic and community nephrologists, dialysis clinic personnel, corporate dialysis executives, clinical research organization employees, patients, and care partners). Moderator guide topics included research knowledge and perceptions, research barriers, ideas for increasing interest in research participation and facilitation, and research education and communication preferences ([Table S2](#)).

Focus groups were led by an experienced moderator (J.H.N.) who had no prior contact with participants. The focus groups were semistructured, and the moderator asked questions to encourage discussion among participants. Groups lasted 90 to 120 minutes and took place in dialysis clinic conference rooms. Focus groups were audiorecorded and professionally transcribed. A research assistant took notes on group dynamics and participant nonverbal body language. Participant characteristics were self-reported.

### Data Analysis

Transcribed interviews were entered into ATLAS.ti qualitative data analysis software. Thematic analysis and principles

**Table 1.** Participating Dialysis Clinic and Surrounding Area Characteristics

Characteristic	Description <sup>a</sup>
Dialysis clinic (n = 7)	
No. of hemodialysis stations	22 [13-41]; (10-43)
No. of hemodialysis patients	78 [49-120]; (32-157)
No. of peritoneal dialysis patients	34 [25-57]; (25-57) <sup>b</sup>
No. of home hemodialysis patients	5 [3-26]; (3-26) <sup>b</sup>
For-profit status <sup>c</sup>	7 (100%)
University-affiliated	6 (86%)
Nurse to patient ratio	10:1-14:1
PCT to patient ratio	4:1
Certification date	September 1976-June 2014
Clinic municipality (n = 6)	
Population	15,487 [7,887-29,094]; (3,743-731,424)
Black, %	20.0 [19.1-27.6]; (10.1-35.0)
Hispanic, %	13.5 [8.9-25.6]; (6.0-49.8)
Below poverty level, %	12.2 [8.7-17.0]; (8.5-20.4)
Clinic county (n = 5)	
County population, per square mile	336.2 [227.0-356.5]; (93.1-1,755.5)

Note: Unless otherwise indicated, values for categorical variables are given as number (percentage) and values for continuous variables, as median [interquartile range]; (range).

Abbreviations: PCT, patient care technician; LDO, large dialysis organization.

<sup>a</sup>Data taken from the Centers for Medicare & Medicaid Services Dialysis Facility Compare<sup>21</sup> and US Census Bureau, 2011-2015 American Community Survey 5-year estimates.<sup>22</sup>

<sup>b</sup>Based on 3 clinics.

<sup>c</sup>Six clinics are university and LDO joint ventures and 1 clinic is LDO owned and operated.

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