

The State of Patient-Centered Outcomes Research in Chronic Kidney Disease: Perspectives from Patients, Care Partners, and Researchers

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Patient-centered outcomes research (PCOR) requires that patients and care partners be active partners throughout the entire research process. Although PCOR methodologies in health research have increased, PCOR on chronic kidney disease (CKD) remains relatively low. This project aimed to better understand the state of PCOR on CKD from the perspectives of patients, care partners, and researchers. Two National Kidney Foundation (NKF) surveys were completed by 847 CKD patients and care partners and 647 CKD researchers. Results indicate that a small minority (7%) of patient and care partner respondents were involved with kidney disease research, and less than a third (27%) of responding researchers indicated that they had involved patients and care partners in their research projects within the last five years. Despite relatively low numbers of PCOR projects on CKD, patients and care partner respondents are eager to participate in research and, likewise, CKD researchers are interested in doing PCOR. Implications include increasing PCOR on CKD and utilizing nephrology social workers to facilitate connections among CKD patients, care partners, and researchers.

INTRODUCTION

Patient-centered care in health settings, including kidney disease programs, is critically important. This approach to healthcare prioritizes patient needs, preferences, and feedback in care delivery (Epstein & Street, 2011; IOM Committee on Quality of Health Care in America, 2001). Aligned with the tenets of patient-centered care, patient-centered outcomes research (PCOR) has also increased and involves patients, care partners (a patient's family and friends involved in their care), and stakeholders partnering with researchers to perform research that is important for patients. PCOR is a research model that allows patients, care partners, and stakeholders to participate in all aspects of the research process, from research question design to disseminating results (Israel, Schulz, Parker, Becker, & Community-Campus Partnerships for Health, 2001). In the United States, the Patient-Centered Outcomes Research Institute® (PCORI®) was started in 2010 to fund research that includes patients, care partners, healthcare professionals, and stakeholders as partners (PCORI, 2017). Since their inception, evidence from PCORI-funded research projects suggests that the knowledge generated by PCOR is more meaningful to patients and communities, more attuned to patients' needs, more translational to "real-world" settings, and has a broader reach (Forsythe et al., 2019).

There have been many examples of CKD PCOR on topics such as mental health (Roumelioti et al., 2018), CKD treatment choices (Boulware et al., 2020; Green et al., 2018), medical homes (Chukwudozie et al., 2018; Hynes et al., 2019),

palliative care (Grubbs et al., 2014), patient-reported outcomes (Hanson et al., 2019; Jacobson et al., 2019; O'Lone et al., 2020), and care continuity (Lee, Cui, Tu, Chen, & Chang, 2018). However, despite this progress, PCOR on CKD remains relatively underutilized (Cukor et al., 2016). It is unclear to what extent patients with CKD and care partners are interested in and involved in the research process beyond these projects and, when they are involved in the research process, what the quality of their participation has been.

To address this literature gap and increase CKD PCOR, this study aimed to better understand how patients, care partners, and researchers experience patient-centeredness in CKD research and their CKD PCOR research priorities. The objectives of this study include understanding: how common patient and care partner involvement is in CKD research; to what degree patients and care partners are involved in the research process; the quality of experiences among patients, care partners, and researchers when including patients and care partners in research; and which research topics relevant to kidney disease are the most important among patients, care partners, and researchers. This paper also posits nephrology social workers as members of the inter-professional kidney healthcare team who can help facilitate connections among patients, care partners, and researchers interested in CKD PCOR. Social work's professional values of addressing social problems and the importance of human relationships uniquely positions nephrology social workers to help connect CKD researchers to patients and care partners experiencing CKD in their daily lives.

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STUDY DESIGN

Two online surveys were developed and deployed using SurveyMonkey (n.d.), one survey for patients with CKD and their care partners, and another survey for kidney disease researchers. A patient with CKD, a kidney disease researcher, and a kidney disease stakeholder organization (National Kidney Foundation (NKF)) created the surveys. The patient and care partner survey was reviewed and pilot tested by 52 patient, and care partner volunteers from NKF's Kidney Advocacy Committee (KAC). Feedback from the KAC members led to the rewording of two survey questions and a description of what is meant by "patient-centered" in the survey introduction (i.e., "Patient-centeredness refers to establishing a partnership among clinicians, patients, and their families, to ensure that healthcare decisions respect patients' preferences and that patients have the education and support they need to make decisions and participate in their own care."). These surveys were funded through a PCORI Eugene Washington Engagement Award (EAIN 3456-NKF). The University of South Carolina (Pro00058725) Institutional Review Board approved this study.

Both the researcher and patient surveys consisted of 11 questions. Survey items included seven to eight multiple-choice, two ranking questions, and two open-ended questions. Participants were also allowed to select "Other (Please explain.," and were provided with dialogue boxes to provide additional information on the multiple-choice and ranking questions. Some questions prompted respondents to explain their responses further. The final questions in each survey were open-ended, asking, "In your opinion, what can be done to make research about CKD more patient-centered?" and "Is there anything else you want to suggest or share about patient-centered CKD research?"

In 2016, the surveys were distributed nonrandomly using a convenience sampling approach. The patient and care partner survey link was emailed to 41,593 patients and care partners in the NKF database. This database includes those who identified as a patient (including those with CKD, on dialysis, or who have received a kidney transplant), as a care partner (a family member or friend involved in a CKD patient's care), or as a living kidney donor. The researcher survey link was distributed to 28,808 kidney care professionals who subscribed to NKF's professional and clinical email Listservs. Both surveys were also advertised on NKF's social media outlets to encourage followers who met inclusion criteria to complete the surveys.

To examine the frequency of patients', care partners', and researchers' involvement in PCOR, percentages, means, and standard deviations were calculated for each survey item in SPSS (version 26; IBM, 2019). Qualitative data from the CKD patient and care partner and CKD researcher surveys

were compiled and analyzed in MAXQDA Plus 2018 (version 18.2.0; VERBI Software, 2019). Data were coded using an inductive thematic analysis approach (Braun & Clarke, 2006). The first author completed the initial coding of provisional codes, with additional open coding of emergent themes and subthemes. All authors reviewed these codes and themes, and the final coding was completed based on group consensus.

RESULTS

PATIENT AND CARE PARTNER SURVEY

Demographics/Interest in Research

Eight-hundred and forty-seven respondents completed the full patient and care partner survey. Full results from the patient and care partner survey multiple-choice questions are presented in **Table 1**. About 80% of respondents to the patient and care partner survey were patients living with kidney disease (79.46%, $n = 673$). Only 20 of the 847 respondents (2.36%) indicated that they were not interested in research. The majority of respondents indicated that they read about kidney disease research when they "happen to see it" (54.18%, $n = 460$) or that they actively seek out research to read (49.35%, $n = 419$). Respondents stated that they usually read about studies in kidney patient forums or newsletters (60.22%, $n = 501$).

Involvement in Research

Most patients and care partners (87.31%, $n = 743$) stated that they had never been involved in a research study. Among those who were involved with research and answered further questions (45%, $n = 103$), most were involved passively as research subjects, with 71.84% ($n = 74$) having clinical data collected and 38.83% ($n = 40$) participating in interviews or focus groups. A minority of patient and care partners who participated in previous research projects had an active role in the research process, with 20.39% ($n = 21$) providing feedback on research implementation materials, 14.56% ($n = 15$) informing research questions, and 10.68% ($n = 11$) helping disseminate research findings. Even fewer patients and care partners participated in the development or selection of research methods (8.74%, $n = 9$), recruiting or selecting participants (6.8%, $n = 7$), or reviewing and commenting on research findings (4.85%, $n = 5$). Nearly 50% of 101 respondents who had been involved in research projects felt that their input on a research study had a meaningful impact on the research being carried out (49.5%, $n = 50$).

A majority (86%) of 728 respondents also identified ways in which patients and care partners could best ensure that research on kidney diseases is relevant to their needs. They indicated this could be done by having patients and care partners help share information about the research results (63.05%, $n = 459$), give input into the research topic and question selection (53.98%, $n = 393$), actively participate in

the research project design, and implementation (50.69%, $n = 369$), and review research results (41.48%, $n = 302$).

CKD Research Priorities

Research priority ranking by patients and care partners is summarized in **Table 2**. Respondents were asked to rank nine CKD research topics from “most important” (1) to “least important” (9). The CKD research topic most important to patients and care partners was preventing kidney disease ($M = 3.14$, $SD = 2.55$). This is followed by keeping kidney disease from getting worse ($M = 3.25$, $SD = 1.96$), quality of life ($M = 3.58$, $SD = 1.85$), treatment options, ($M = 4.78$, $SD = 2.07$), kidney disease biology ($M = 4.76$, $SD = 2.95$), costs ($M = 5.57$, $SD = 2.38$), mental health ($M = 5.79$, $SD = 2.09$), healthcare delivery ($M = 6.08$, $SD = 2.5$) and care partner support ($M = 6.54$, $SD = 2.08$).

Open-ended Responses

Open-ended responses to the patient and care partner survey indicate that most respondents used the internet as their primary source for finding kidney disease research, including websites and social media. Respondents who had participated in research were asked to explain their answers to question six (Q6), “Did you feel your input had a meaningful impact on the research being carried out?” For those who felt that their research participation was meaningful or somewhat meaningful (71.28%, $n = 72$), three broad, explanatory themes emerged from patients and care partners: they had a clear understanding of their contribution to the research; they saw essential changes in their kidney care being implemented as a result of the research; or they felt that their perspectives as kidney disease patients and care partners were being highly respected and valued by the researchers.

For the respondents who did not feel that their research participation was meaningful or were not sure if it was (28.71%, $n = 29$), the most common open-ended response to explain their answer was that they never received any updates or communication from the research team following their involvement in the study and that the study results were never shared with them. For example, one respondent stated, “You are asked to participate, but then you never hear from the study group.” Another participant wrote, “Zero feedback. The questions asked were only ones I could answer favorably as if [it was] set up for good results for them—not constructive. No questions centered around my concerns.” One patient summarized this concern by stating plainly, “I was a guinea pig!”

Question seven on the patient and care partner survey asked, “How do you think patients and care partners can best ensure that research about kidney disease is relevant to their needs?” Among those respondents choosing the “Other (Please explain.)” response option for this question (5.08%, $n = 37$), the most frequently mentioned theme was

communication. Many respondents felt that the best way to ensure that research about kidney disease is relevant to patient and care partner needs is to create a bidirectional communication loop where patients and care partners can both learn about what is happening in the realm of CKD research while also providing feedback to researchers from their unique perspectives as CKD patients. For example, one respondent stated, “I believe patients living with the disease can best explain what it’s like to live with the disease.” Many respondents mentioned that they wished to offer feedback on the goals of a study and how study results will be disseminated. “Involvement of people LIVING WITH CKD is key to any relevant research. Too many projects are designed and managed by people who are not directly impacted by kidney disease,” one respondent wrote. Another said, “Please involve us in the ongoing studies and then remember to share the relevant findings.”

Examining the answers to the open-ended question, “What can be done to make research about kidney disease more patient-centered?” there were three themes that emerged from patients and care partners’ responses ($n = 510$): better engagement of patients and care partners in the research process; more awareness of research project opportunities; and better communication from researchers. Respondents wanted to be engaged and included in the overall research process, with one respondent stating, “Involve patients in the research design—they are in the front line, so they should play a more active role,” and another commenting, “[P]atients and caregivers are not just statistics and should be consulted in order to make research projects more applicable.”

Patients and care partners also greatly desired to learn more about ways to get involved in CKD research: “Make more information available to the patients. It is very difficult to locate information about different research projects that are being/or that will be conducted,” one patient respondent wrote. Another patient responded with, “Talk to the patients!! Don’t expect them to come to you.” Similarly, one care partner said, “My son has been on different trials, but we’ve never heard anything about them. It would be good that when he went for appointments he was told how he has helped these trials.”

Many respondents felt that dissemination of research findings to the CKD community should occur regularly and that the public should have a greater awareness of CKD. Other subthemes included a need for more information regarding alternatives to dialysis, such as kidney transplantation, artificial kidney technology, and stem cells. Patients and care partners also mentioned that they think research on chronic kidney disease should use more diverse patient populations such as pediatric patients and people with genetic kidney diseases.

RESEARCHER SURVEY

Demographics

Six-hundred and forty-seven responses were submitted to the researcher survey. Full results from the researcher survey multiple-choice questions are presented in **Table 3**. The majority of research respondents came from the disciplines of nursing (24.18%, $n = 155$), social work (22.46%, $n = 144$), dietetics (20.75%, $n = 133$), and clinical medicine (14.82%, $n = 95$).

Involvement of Patients and Care Partners in Research

Over 70% of the researcher respondents (73.18%, $n = 472$) stated that they had not worked on a research project involving patients or care partners within the past five years. Among the minority ($n = 173$) who said they had, 85.31% ($n = 122$) stated that they had merely collected patient clinical data to use as part of their studies, and 46.15% ($n = 66$) responded that patients and care partners had participated in interviews or focus groups. Even fewer researchers who had done PCOR within the past five years had worked with patients and care-partners to create research questions/topics (18.88%, $n = 27$), select research methods (4.9%, $n = 7$), create study materials (18.88%, $n = 27$), reviewed and commented on findings (6.99%, $n = 10$) or disseminate findings (4.9%, $n = 7$). When patient and care partners provided feedback on a research project (Q4), respondents stated that it most often occurred individually between researcher and patients or care partners (66.19%, $n = 92$).

Researchers (Q5, $n = 141$) most frequently stated that they recruited participants for PCOR projects among patients and care partners who were already known to them (39.72%, $n = 56$). A majority of researcher respondents who had done PCOR (68.57%, $n = 96$) felt that patient or care partner input had a meaningful impact on the research being carried out, whereas 11.43% ($n = 16$) did not and 20% ($n = 28$) were not sure. When asked (Q7) whether they or their institution promote research findings to patients or lay audiences, about half of all respondents ($n = 425$) said they or their institution do not do so (46.82%, $n = 199$). Additionally, when responding to the question (Q8) of how patients and ics can most effectively engage with CKD research, researchers ($n = 429$) responded most frequently that patients and care partners could provide their input into research topic and question selection (37.30%, $n = 160$). However, the second most frequent response to this question was, “I am not sure” (21.68%, $n = 93$).

CKD Research Priorities

When asked to rank topics most important in kidney disease research, researchers most frequently selected quality of life issues ($M = 2.53$, $SD = 1.57$), followed by preventing the onset of CKD and disease progression ($M = 2.82$, $SD = 2.26$). **Table 4** includes the average score and standard deviation for each research topic.

Open-ended Responses

Researchers who responded to the open-ended questions on the survey ($n = 284$) were asked to share their opinion about what can be done to make CKD research more patient-centered. The most salient themes that emerged from this question included: the need to compensate patients and care partners for their participation; better information for patients and care partners about the research process and research opportunities; and more funding for CKD PCOR. A final theme was the need for broader dissemination of research findings; as one respondent said, “Translate the research findings into more broad [sic], patient-centered things that they can understand and use in their everyday life.” Researchers also commented on the need behind CKD PCOR in general, as one respondent stated:

“We need to make sure that patients and family members are driving the questions we seek to answer. Often the questions that we as researchers think are most important are of little interest to patients or caregivers. While clinical research is very important, we must always ask ourselves the question, ‘How does this benefit our patients?’”

DISCUSSION

These survey findings are the first to broadly examine the state of CKD PCOR utilization from the perspective of patients, care partners, and researchers. Survey results were used as part of the first national CKD PCOR conference hosted and led by the National Kidney Foundation (NKF) (2016) and were the impetus for the first NKF PCOR research award (NKF, 2018).

Overall, these results suggest that there is much work to be done to improve CKD PCOR. Most patient and care partner respondents were not involved in CKD research, despite almost all of the patients and care partners being interested in research participation. When they were involved, it was mostly as passive participants (i.e., providing clinical data or answering survey or focus group questions), which is not in accordance with the tenets of PCOR (PCORI, n.d.). The patients’ and care partners’ answers align with the researcher responses, the majority of whom also indicated that they had not been involved in a research project that involved patients and care partners within the past five years and mainly work with patients and care partners passively when conducting research. The CKD community needs more PCOR and more examples of robust patient and care partner participation on PCOR teams (Demian, Lam, Mac-Way, Sapir-Pichhadze, & Fernandez, 2017).

The majority of patients, care partners, and researchers agree that research results are seldom disseminated in “patient-friendly” ways. Researchers are encouraged to create non-

academic summaries of their research and share them with patients and care partners, especially on the internet. Also, researchers should create lay research summaries and provide them to any patient or care partner who provided data or samples to inform them how their information was used to advance science (Huang, Lipman, & Mullins, 2017).

When researchers sought to include patients and care partners in a study, the most common recruitment method was by selecting patients and care partners known to the researchers or clinicians, according to the patient and care partner survey results. Researchers can go beyond their institutions to involve patients and care partners more broadly in CKD PCOR (Browne et al., 2020). Both respondent groups in our study also generally agreed on the top research priorities for CKD: primary prevention, treatment options, and quality of life. CKD researchers who engage in PCOR should align their research priorities with the research priorities of patients and care partners.

Many patients and care partners indicated that they believe dialysis units, transplant centers, and CKD clinics are excellent places to learn about CKD research and opportunities to become involved. Because nephrology social workers often serve as resource brokers for CKD patients in dialysis and kidney transplant clinics and work to address the psychosocial aspects of living with CKD, this finding presents a unique opportunity for the profession to potentially bridge the gap between research and the patients and care partners who are interested in consuming and participating in research.

Social workers can collaborate with their interdisciplinary colleagues or other social workers to lead research projects that involve patients and care partners in the research. Social workers are urged to also actively participate in and lead PCOR projects. The social work code of ethics recommends that social workers participate in research and has an entire "Evaluation and Research" section (Section 5.02) (NASW, 2017). There are numerous psychosocial barriers to CKD care, and social workers have expertise in these areas (Browne et al., 2019). They can contribute their research expertise by connecting with others in their organizations who are conducting research or by seeking out partnerships with faculty at local schools of social work or public health. Social workers employed by academic medical centers can also connect with researchers in those institutions to see how they can contribute to CKD PCOR. Those who work in large dialysis companies can seek out collaborative opportunities with their organization's research departments. Additionally, PCORI has funding for smaller PCOR projects and research-related events and activities that may be a good "first step" for social workers looking for support for CKD PCOR projects. PCORI also has a free research fundamentals training (<https://www.pcori.org/engagement/research-fundamentals>) that social workers can complete.

Many patients and care partners in our study stated that having a centralized information and communication hub about CKD research and ways to get involved would be beneficial. Currently, NKF is working on a PCORI-funded project to improve the knowledge of PCOR among researchers, patients, and other stakeholders; building an infrastructure that will provide education about PCOR, connect patients, family members, and researchers for collaboration; and creating a centralized location for patient-friendly research summary results (PCORI, 2020). Nephrology social workers should be aware of the development of these resources and use them to help connect interested CKD patients and care partners to researchers when the communication hub is launched.

Encouragingly, most of the respondents from both the patient and care partner survey and the researcher surveys believed patients and care partners should be involved throughout the research process, from question generation to disseminating results. Both groups also commonly stated that they thought PCOR requires a more diverse pool of CKD patients to be involved.

Study Limitations

There are some limitations to this study. Although our sample sizes for both patients and care partners ($n = 847$) and kidney disease researchers ($n = 647$) were large, our lack of demographic data and convenience sampling methodology limited our ability to say whether these samples were representative. These results were likely biased toward patients, care partners, and researchers who subscribe to, read, and respond to NKF listservs and communications and are, naturally, more interested in research and the research process. However, these patients and care partners who were engaged with stakeholder organizations like NKF may also be an excellent representation of patients and care partners more likely to be engaged in research.

CONCLUSIONS

Overall, these results suggest that patients with CKD, care partners, and CKD researchers have valuable ideas about patient-centeredness in CKD research and that both groups share many of the same beliefs about PCOR. Both groups indicated that patient-centeredness is essential for the field of CKD research. Patients with CKD and care partners in the sample group expressed significant interest in research and a willingness to engage in the research process. Likewise, CKD researchers expressed a willingness to engage in patient-centered research methodology. These findings should be encouraging to the field of CKD PCOR. Future patient-centered research on CKD may highlight programs that successfully navigate the challenges of PCOR within the CKD community, inform other researchers about the value of PCOR, and include best practices for actively engaging patients and care partners in the research process. Specifically, we believe

that nephrology social workers can utilize their patient engagement and patient empowerment skills to help achieve these goals for CKD PCOR. Future research may also seek to better understand the barriers that kidney care providers experience when incorporating PCOR into kidney healthcare services delivery.

As one of the patient respondents commented, “[I]nvolvement of people living with CKD is key to any relevant research. Too many projects are designed and managed by people who are not directly impacted by kidney disease.” More CKD PCOR is needed to address the disconnect between the patient, care partner, and researchers. Nephrology social workers can play a critical role in facilitating these connections through their professional skills in addressing problems of human relationships. They can help bring about the next era of CKD research that is more patient-centered, outcomes-oriented, and empowering to CKD patients, care partners, and researchers.

Support: This project was funded by a Patient Centered Outcomes Institute (PCORI) Eugene Washington Engagement Award (EAIN 3456-NKF).

Acknowledgements: The authors thank all the patients, care partners, and researchers who participated in this project. The first author thanks the Health Services Research Methods course instructor and peers for providing feedback on the original manuscript.

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Table 1. Patient and Care Partner Survey Multiple-Choice Answers (n = 847)

Question	Response Options	Answers % (n)
Q1: Are you a:	Patient living with kidney disease	79.46% (673)
	Care partner for a patient living with kidney disease	20.54% (174)
Q2: Are you interested in research being carried out on the prevention and treatment of kidney disease? (Please check all that apply.) (n = 849)	Yes, I read about it when I happen to see it.	54.18% (460)
	Yes, I seek it out to read.	49.35% (419)
	I am not sure. I do not know enough about it.	9.54% (81)
	Yes, I have been involved in the research process.	7.18% (61)
	No, it does not interest me.	2.36% (20)
Q3: If you read about research on kidney disease, where do you find it? (Please check all that apply) (n = 832)	I read studies that are referenced in kidney patient forums or patient newsletters.	60.22% (501)
	I read studies that are published in national or regional newspapers (print or online).	48.20% (401)
	I read studies that are published in medical journals (print or online).	36.90% (307)
	I read studies that a healthcare provider recommends to me.	31.25% (260)
	Other (Please explain.)	15.02% (125)
Q4: Have you ever been directly involved with a research study related to kidney disease? (n = 851)	Yes	12.69% (108)
	No	87.31% (743)
Q5: How would you describe your involvement with kidney disease research? (Please check all that apply.) (Answered by n = 103 (95%) of those who responded "yes" on Q4.)	My clinical data was collected and used as part of a study.	71.84% (74)
	I was interviewed or participated in a focus group.	38.83% (40)
	I commented on documents for use in the study. (For example: proposals, questionnaires, participant handouts.)	20.39% (21)
	I helped to inform the research topics or questions being developed.	14.56% (15)
	I helped share the results of the research study.	10.68% (11)
	I helped select or develop the methods used.	8.74% (9)
	I helped recruit or select participants.	6.8% (7)
	I formally reviewed and commented on the findings or interim findings.	4.85% (5)
	Other (Please explain.)	13.59% (14)
Q6: Did you feel your input had a meaningful impact on the research being carried out? (Answered by n = 101 (94%) of those who responded "yes" on Q4.)	Yes, definitely	49.50% (50)
	Somewhat	21.78% (22)
	No	4.95% (5)
	I am not sure.	23.76% (24)
Q7: How do you think patients and care partners can best ensure that research about kidney disease is relevant to their needs? (Please check all that apply.) (86% of respondents who answered "yes" to Q4; n = 728.)	Helping share information about the research results with other patients, family members, and the medical and research community	63.05% (459)
	Giving input into topic and question selection	53.98% (393)
	Actively participating in the research project design and implementation	50.69% (369)
	Reviewing research results	41.48% (302)
	I am not sure.	14.01% (102)
	Other (Please explain.)	5.08% (37)

Table 2. Patient and Care Partner Survey Results on Importance of Kidney Disease Research Topics

In your opinion, which topics are most important in kidney disease research? Please rank the following topics in order of most important to least important, with 1 being “most important” and 9 being “least important.” (n = 717)	Mean (SD)
Preventing kidney disease	3.14 (2.55)
Keeping kidney disease from getting worse	3.25 (1.96)
Quality of life (For example: controlling symptoms, personalizing treatment to lifestyle preferences.)	3.58 (1.85)
Helping patients get the treatment options they prefer (For example: home hemodialysis, transplant.)	4.78 (2.07)
Understanding the biology of kidney disease	4.76 (2.95)
Patient costs	5.57 (2.38)
Mental health	5.79 (2.09)
Healthcare delivery (For example: clinician training, dialysis center management.)	6.08 (2.50)
Support for care partners	6.54 (2.08)

Table 3. Researcher Survey Multiple-Choice Answers (n = 647)

Question	Response Options	Answers % (n)
Q1: Please select your field or primary interests: (n = 641)	Nursing	24.18% (155)
	Social work	22.46% (144)
	Dietetics	20.75% (133)
	Clinical medicine	14.82% (95)
	Healthcare delivery or policy	5.3% (34)
	Basic science	1.40% (9)
	Psychology	0.78% (5)
	Other (Please explain.)	10.30% (66)
Q2: Have you worked on a research project involving CKD patients or care partners in the past 5 years? (n = 645)	Yes	26.82% (173)
	No	73.18% (472)
Q3: How were patients or care partners involved with the project? (Check all that apply.) (Answered by n = 143 (83%) of those who responded “yes” on Q2.)	Their clinical data was collected and used as part of a study.	85.31% (122)
	They participated in interviews or focus groups.	46.15% (66)
	They helped to inform the research topics or questions being developed.	18.88% (27)
	They commented on documents for use in the study. (For example: proposals, questionnaires, participant handouts.)	18.88% (27)
	They helped to recruit or select other participants.	13.29% (19)
	They formally reviewed and commented on the findings or interim findings.	6.99% (10)
	They helped select or develop the methods used.	4.90% (7)
	They helped disseminate/translate the research findings.	4.90% (7)
Q4: What was the process for patients/care partners to provide input into your project(s)? (Answered by n = 139 (80%) of those who responded “yes” on Q2.)	Patients or care partners provided individual input.	66.19% (92)
	Patients or care partners provided input through a panel or group.	19.42% (27)
	Other (Please explain.)	14.39% (20)

continues

Question	Response Options	Answers % (n)
Q5: How were the patient or care partner participants recruited? (Answered by n = 141 (82%) of those who responded "yes" on Q2.)	Patients were known to the researchers or clinicians involved with the study.	39.72% (56)
	Patients were purposefully selected based on particular characteristics.	23.40% (33)
	Patients were chosen as part of an existing dataset.	19.15% (27)
	Patients responded to an advertisement or invitation.	9.22% (13)
	Other (Please explain.)	8.51% (12)
Q6: Did you feel that patient or care partner input had a meaningful impact on the research being carried out? (Answered by n = 140 (81%) of those who responded "yes" on Q2.)	Yes	68.57% (96)
	No	11.43% (16)
	I am not sure.	20.00% (28)
Q7: Do you (or does your institution) promote your research to patients or lay audiences? (Check more than one, if applicable.) (n = 425)	Yes, through healthcare provider or clinic materials.	31.53% (134)
	Yes, through non-profit or patient advocacy organization publications (print or online).	4.24% (18)
	Yes, through national or regional newspapers (print or online).	3.53% (15)
	Yes, through CKD patient online forums or message boards.	3.06% (13)
	No	46.82% (199)
	Yes, other (Please explain.)	10.82% (46)
Q8: How do you think patients and care partners can most effectively engage with CKD research? (Please choose the one you feel would matter most.) (n = 429)	Giving input into topic and question selection	37.30% (160)
	By helping disseminate/translate research findings	12.12% (52)
	Participating in the research design	8.16% (35)
	Reading and responding to published research	6.76% (29)
	Reviewing interim and final results	1.86% (8)
	I am not sure.	21.68% (93)
	Other (Please explain.)	12.12% (52)

In your opinion, which topics are most important in kidney disease research? Please rank the following topics in order of most important to least important, with 1 being "most important" and 8 being "least important."	Mean (SD)
Quality of life (For example: controlling symptoms, personalizing treatment to lifestyle preferences.)	2.53 (1.57)
Preventing the onset of CKD and disease progression	2.82 (2.26)
Helping patients get the treatment options they prefer (For example: home hemodialysis, transplant.)	4.06 (1.73)
Patient costs	4.25 (2.55)
Mental health	5.12 (1.81)
Basic science/understanding the biology of CKD	5.54 (2.45)
Healthcare delivery (For example, clinician training, dialysis center management.)	5.53 (2.15)
Support for care partners	5.49 (1.70)