



# **The National Kidney Foundation 2017 Patient Centered Outcomes Research Stakeholders' Orlando, Florida - April 22, 2017**

## **Summary Report**

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### *Executive Summary*

#### **CONFERENCE THEME AND OBJECTIVES**

The National Kidney Foundation (NKF) Patient-Centered Outcomes Research (PCOR) Stakeholders' Conference on April 22, 2017 in Orlando, FL was the first national effort to identify patient-led kidney disease national research priorities. This conference brought together individuals representing kidney patients of all stages, dialysis patients, kidney transplant recipients, living kidney donors and potential living donors, and kidney donor families as well as physicians, social workers, nurses, pharmacists, caregivers, stakeholders, and academics.

Over the course of a year leading up to the conference, patients and stakeholders were true partners throughout all phases of this project and were involved in event planning, shaping the agenda, and leading the conference activities. Patients, family members, researchers, and stakeholders shaped the agenda through their responses to a survey assessing their experiences and challenges in patient-centered research. A social media hashtag was created for the event- #PatientsDecide, and we obtained wifi access for the meeting room for attendees to easily use our online survey technology and promote the meeting through social media. The conference was co-chaired by Derek Forfang, a patient with kidney disease and member of the NKF Kidney Patient Advocacy Committee and Teri Browne, a kidney disease researcher and editor of the NKF's *Journal of Nephrology Social Work*. The event featured patient, caregiver, and researcher panel discussions and breakout group sessions.

Attendees learned about PCORI and its mission, gained insight into the experiences of patients, caregivers, and researchers about the importance of kidney disease PCOR. Attendees also identified patient-centered research priorities, challenges, and facilitators to acting on such priorities, as well as patient-identified best practice strategies for actively engaging patients in kidney disease research. The event was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington Engagement Award. The ideas and solutions developed during this conference will help NKF further define its role as an organization in facilitating patient involvement in chronic kidney disease (CKD) research. This conference project truly embodied how patients and researchers can work collaboratively to address questions most important to kidney patients.



## KEY FINDINGS

The following topics were identified by patients and researchers through the NKF 2017 Patient Centered Research Stakeholders' Conference. At least one of the following topics will be included in NKF's 2018 Research Grant Program.

- Understanding the biology of kidney disease
- Preventing and/or delaying kidney disease progression
- How to engage patients with kidney disease in research - including different communities/populations of patients
- Health literacy and communication barriers, patient education best practices (including - population/demographic-specific), cultural humility
- Patient self-management/patient activation - how do we best educate and partner with patients to understand and self-manage kidney disease
- Psychosocial issues - stigma, coping
- Kidney disease coordinated care

## DISSEMINATION PLANS

The conference proceedings will be submitted for publication in a peer reviewed journal and will be also be disseminated using the following fact sheets:

- *Kidney Disease Patients and Caregivers- Patient Centered Outcomes Research*
- *Researchers- Patient Centered Outcomes Research*

## *Pre-Conference Survey*

### AIMS AND OBJECTIVES

To plan the most effective panel questions and discussion topics, we surveyed patients living with kidney disease and their care partners, and CKD researchers, about their experiences with patient involvement in research to date. The objectives of these surveys were to find out:

- How common is patient involvement in research projects among our sample groups, and has this involvement consisted primarily of sharing clinical data?
- Have such experiences been positive or negative, and do feelings toward the experience tend to differ between patients and researchers?
- What research topics do patients and care partners prioritize?  
Results are ultimately intended to inform the conference structure and focus.

### METHODS

Two separate survey questionnaires were developed using the online software SurveyMonkey in summer 2016—one for patients living with kidney disease and their care partners, and one for kidney disease researchers. These surveys were 11 questions long and each included multiple choice, free-text, Likert-style, and ranking types. The evaluation for this conference, including this survey, was reviewed by the University of South Carolina Institutional Review Board. The patient survey was piloted by a selection of NKF's Kidney Advocacy Committee (KAC) members from September 8-13, 2016. The feedback from this pilot was used to validate the tool, resulting in format changes to two questions and further explanation of patient-centeredness added to the "About This Survey" preface.



The final patient/family survey email was sent to 28,808 patients and care partners in NKF's database. This email list contains individuals identifying themselves as a patient (CKD, dialysis, transplant), family member or caregiver of a patient, or living donor. The researcher survey was distributed to the 41,593 individuals subscribed to NKF's professional and clinical list serves. Links to both surveys were distributed between September 15 and 20, and were closed on October 14, 2016. Additionally, both survey links were advertised on NKF's social media channels. Free text answers to each question were compiled within a single document and reviewed for common themes, phrases and sentiments.

*Limitations:* This patient sample was not intended to be representative of all patients with CKD due to exclusion of those without internet access, and known selection bias toward those already seeking connection with support organizations and patient advocacy resources (subscribed to NKF email list serves). However, we hypothesize that due to their proactivity in seeking such support and resources, this group is also more likely to have sought out or seen opportunities for involvement in CKD research than all kidney patients on average. Therefore, they may have been better able to provide insight on such experiences.

## RESULTS

### Patient/Family Survey - Major points

860 responses submitted

Many respondents (>20%) identified as care partners

Most respondents selected that they had not been involved with CKD research. Therefore, the majority of the survey questions pertaining to research involvement were answered by a much smaller subset.

Of those who had participated in research, a majority (72%) had done so by consenting to their clinical data being used.

Most respondents believe patients should be involved throughout the research process and that it is crucial to involve diverse types of patients and groups of patients (stages, ages, disease characteristics, etc.)

However, they noted barriers to patient/ care partner participation:

- Illness (inability to travel or leave home)
- Lack of motivation - why should I get involved?
- It is too late to benefit me/ advanced disease
- I do not feel invited to participate or engage in my own care, why engage with research?
- Incentives – financial or otherwise, were encouraged
- Other barriers (social, financial)
- Lack of understanding of the research process and what it means to be involved (other than as a 'subject')
- Lack of awareness of what research is being carried out and how to get involved
- For those who have participated in studies, lack of follow-up communication from research teams - (why participate again if you're not sure it helped?)



Respondents indicated they would welcome more research-related information from dialysis centers and care providers, including opportunities to get involved, and results of recent CKD studies.

They indicated the importance of kidney patient forums or patient newsletters for reading about published research and research opportunities.

Quite a few respondents suggested a need for an interactive, centralized forum where patients could access easy-to-understand research results and opportunities

**Patient and caregiver priorities for research topics included: ‘Understanding the biology of kidney disease’, ‘Preventing kidney disease’ and ‘Keeping kidney disease from getting worse’ as most or very important** (while ‘Support for care partners’ and ‘Healthcare delivery’ were often ranked least important.)

### **Researcher Survey - Major Points**

647 responses submitted

Majority of respondents (73.18%) had not been involved with a study that directly engaged patients

When they did it was often through consent of use for clinical data, or as subjects who participated in interviews or focus groups (same results as from patient survey).

Most common recruitment method was selection of patients who were known to the researchers or clinicians running the study 39.72%. (This also reflects patient answers, indicating they lack information on how to get involved).

Many researchers 46.82% did not promote results to lay audiences (also reflects patient survey responses on not sure where to access research information)

Also reflected patient feelings that they should be involved throughout the process and that patients would feel more vested in the research if they felt like more than just "sick subjects" and more like research partners.

Researchers reported similar barriers to patient engagement with research (see patient list above)

Additional barriers to researchers’ ability to engage patients included:

- Lack of correspondence and cooperation from dialysis centers
- Lack of funding for patient engagement within projects
- Lack of knowledge of how to best engage with patients and communicate regarding the research throughout the process.
- Institution or funding-specific regulations regarding communication of findings

Researcher respondents were able to correctly estimate which topics would be the highest priorities of patients and care partners. They ranked “Preventing the onset of CKD and disease progression” as most important, and “Support for care partners” and “Healthcare delivery” as least important

As with patients, researchers advocated for more involvement of care providers and dialysis clinicians in providing patients with information on research and related opportunities

### Survey Conclusions

This survey suggests that the barriers to CKD patient involvement in research are identifiable, similar (among respondents), and widely realized by patients as well as CKD researchers. Because of this, we focused conference discussions on:

- Identifying the barriers that we can most feasibly and effectively remove, and
- Developing ideas and solutions for addressing these barriers.

In addition, we asked attendees to identify research priorities that were not listed on our survey.

### *NKF - PCOR Conference Report*

#### ATTENDEES

Ninety-nine people registered for the conference, 56 people attended the conference and 40 people (71%) completed a program evaluation. The attendees included: 22 patients with kidney disease, 5 family members of people with kidney disease, 8 kidney disease stakeholders (i.e. American Society of Nephrology, American Kidney Fund, National Kidney Foundation), 11 physicians, 4 social workers, 2 nurses, 2 dietitians, 1 pharmacist, and 1 public health professional. 62% of the attendees were people with kidney disease, their family members or kidney disease stakeholders.



Attendees represented 17 states (AL, CA, CO, DE, FL, IL, MD, MI, MN, NC, NJ, NY, OH, PA, TN, VA, WA) and Canada- the majority of attendees came from the eastern United States (where - the conference was held).



## AGENDA AND FORMAT

To accommodate possible flights home that day, the conference started at 8am and ended at 2pm. The committee worked with the hotel to make sure that the food provided at the conference accommodated a renal diet for people with kidney disease (i.e. low phosphorus, potassium and sodium). To make sure that stakeholders, patients and family members were the majority of attendees, we limited the number of professional registrations to 25.

The committee created a conference agenda that would allow for maximum discussion and feedback from attendees:

8:00am - 8:05am	<b>Welcome</b> – <i>Kathryn Pucci, Senior Vice President, Education and Programs</i>
8:05am - 8:10am	<b>Housekeeping</b> – <i>Teri Browne, PhD, MSW, NSW-C (Conference Co-Chair)</i>
8:10am - 8:15am	<b>Introduction to Kidney Disease/PCORI</b> – <i>Derek Forfang (Conference Co-Chair)</i>
8:15am - 8:45am	<b>Patient PCOR Experience Panel</b> - Valerie Bailey, Kevin Fowler, Katina Lang-Lindsey, Roberta Wager, Caroline Wilkie
8:45am - 9:15am	<b>Patient-Centered Outcomes Researchers Panel</b> - Jamie Green, MD, Rachel Patzer, PhD, Wendy St. Peter, PharmD, Mark Unruh, MD
9:15am - 9:30am	<b>Audience Questions</b>
9:30am - 9:40am	<b>Break</b>
9:40am - 11:55am	<b>Breakout Session:</b> Kidney Disease PCOR Priorities Identification & Discussion of Ideas/Solutions to Address Barriers to Patient/Caregiver Engagement in Research
11:55am - 12:40pm	<b>Lunch</b>
12:40pm - 1:55pm	<b>Group Panel Discussion:</b> Identifying the Highest Priority PCOR Issues and Ideas/Solutions to Address Barriers to Patient/Caregiver Engagement in Research
1:55pm - 2:00pm	<b>Evaluation and Next Steps</b> – <i>Kathryn Pucci</i>
2:00pm	<b>Adjournment</b>

Panelists were chosen based on their experience with PCOR, geographic diversity and kidney disease treatment modality experience (i.e. patients who have been on dialysis and have received transplants). The committee had three calls with panelists to review their role in the event. During the panel presentations, speakers shared their own experiences with PCOR.





Panelists: front row (L-R) Forfang, Patzer, St, Peter, Wager, Wilkie, Bailey  
back row (L-R) Fowler, Lang-Lindsey, Pucci, Browne, Green, Unruh

Conference attendees received a packet of information that included: event description and agenda, panelist biographies, small group discussion guide, summary of pre-conference survey findings and a program evaluation. Attendees were assigned seats at nine round tables- the conference committee created these seat assignments to make sure that all tables included a mix of patients, family members, stakeholders, professionals and researchers. Each of the nine panelists sat at different tables and helped facilitate small group discussion. Every table had patients at them to make sure that patients were represented in each small group at each table. At each table were copies of the full survey results from our pre-conference surveys, and a large flip-chart and markers to take notes. The event was recorded and transcribed.





### ***Social Media Engagement***

To include patients and family members who were unable to attend the event in person, we had a dedicated NKF staff person posting live updates about the event on the NKF Facebook and twitter pages. We also posted Facebook live survey questions to engage people who could not attend. In addition, conference attendees posted updates about the event on their own social media accounts and we also posted summary information about the event on NKF social media after the conference.



**Rachel Patzer, PhD** @RachelPatzerPhD · Apr 22

Such an honor to spend the day with kidney patient advocate and my patient partner in research! [@nkf](#) [#SCM17](#) [#PatientsDecide](#)



1 4 14





**Kevin J. Fowler** @grateful080504 · Apr 22

I am hoping that today is the dawn of a new era of #patientcentered research in #kidneydisease #patientsdecide @NephJC #patientsincluded



1 8 23

**National Kidney Fdn** @nkf · Apr 22

We're live tweeting this am from @PCORI Stakeholders' Conference to understand how patients can influence #CKD research. #patientsdecide



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National Kidney Fdn Retweeted



**Derek Forfang** @ForfangDerek · Apr 22

Replying to @nkf @iCare\_USC and 3 others

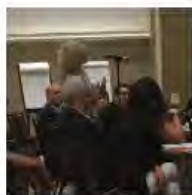
This is just the beginning, turning discussions into actions! Changing the landscape, #PatientsDecide

1 3 4



**Jesse Morales** @beaucorps · Apr 25

Communicating a patient perspective at the @NKF #PCOR conference #patientsdecide



**Tonya Saffer, MPH** @tonyasaffer

Fabulous audience participation and insights from patients @NKF PCOR conference #patientsdecide

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National Kidney Fdn Retweeted



**HSR\_Research@EmoryTx** @Transplant\_HSR · Apr 22

Fantastic discussion with patients and researchers on how to ensure patients' priorities are reflected in research. #SCM17 #PatientsDecide



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**IPE\_UofSC** @iCare\_USC · Apr 22

Small groups are working hard at @nkf @PCORI kidney disease #PCOR conference #PatientsDecide – at Dolphin Convention Center



Kevin J. Fowler, PREPARE NOW, Derek Forfang and 4 others

🗨️ 4 ❤️ 7 |||





National Kidney Fdn Retweeted



**Kevin J. Fowler** @gratefull080504 · Apr 22

Thank @PCORI + @nkf for the opportunity to have #patientvoice heard in #kidneydisease Well done @ForfangDerek +Teri Brown! Cc @tonyasaffer



**National Kidney Fdn** @nkf

Amazing meeting & incredible conversation about patient engagement in research. Thank you panel & participants #patientsdecide

3 retweets 4 likes



**National Kidney Foundation**

April 25 · 🌐

For the first time ever, we hosted patients, their care partners AND researchers in one room to talk about how patients can meaningfully influence and contribute to kidney disease research. The NKF Patient Centered Outcomes Research Stakeholders' Conference is the first step in identifying patient-centered research priorities and challenges. #PatientsDecide

Read more: <http://bit.ly/29AD2yh>



Like Comment Share

139

Top Comments



**National Kidney Fdn**  @nkf · May 16

NKF's Hosts Patient-Driven Research Stakeholders' Conference at 2017 Spring Clinical Meeting Where [#PatientsDecide](#)



**NKF's Hosts Patient-Driven Research Stakeholders...**

On April 22, 2017 in Orlando Florida, the National Kidney Foundation (NKF) hosted the first effort to identify patient-led kidney disease national research priorities by brin...

[nkfadvocacy.wordpress.com](http://nkfadvocacy.wordpress.com)







### **Conference Discussion Summaries**

Most of the event was dedicated to small and large group discussions to maximize the attendees' participation in gathering knowledge. Small groups were tasked to identify:

- Top 3 kidney disease research priorities (that were not identified on our pre-conference survey)
- Top 3 barriers to doing kidney disease PCOR
- Top 3 solutions to these barriers

Each group self-identified a note taker and reporter. Groups were given two hours and 15 minutes to discuss these points and report their conclusions to the larger group. Almost all the nine groups listed more than 3 priorities, barriers and solutions.

Each group used the same discussion guide for these small group conversations. The program co-chairs circulated through the room and groups, helping as needed.

#### **The National Kidney Foundation Patient Centered Outcomes Research Stakeholders' Conference- Group Discussion Guide**

- **9:40-9:50:** introduce yourselves, everyone reviews the list of priorities from patient survey/ranking + list of biggest barriers from the survey (in your folder). Pick someone from your group who will write things down for your group on your flip chart, and someone who will report out to the larger group
- **9:50-10:55:** each small group talks about (use the flip chart to write this down):
  - Top Kidney Disease Research Priorities (what priorities did we overlook from the survey? List top 3 we should add)
  - Barriers & solutions to Patient Centered Outcomes research (list 3 of each)
- **10:55-11:55:** each group reports out their top 3 research priorities, 3 barriers to doing Patient Centered Outcomes research, and 3 ways to fix those barriers

#### **REMEMBER:**

- Remember why we are here! To try to involve more patients and their family members/care partners in kidney disease research
- Please make sure that everyone in your group is participating in your small group discussion
- No idea is a bad idea!
- Get creative! Think outside of the box



### **CONFERENCE DISCUSSION SUMMARY- KIDNEY DISEASE RESEARCH PRIORITIES**

Attendees identified eight kidney disease PCOR priorities to add to the top priorities identified by the pre-conference survey (priorities in bold were identified by more than one group):

- 1. How to engage patients with kidney disease in research- including different communities/populations of patients**
- 2. Health literacy and communication barriers, patient education best practices (including population/demographic-specific), cultural humility**
- 3. Patient self-management/patient activation- how do we best educate and partner with patients to understand and self-manage kidney disease**
- 4. Psychosocial issues- stigma, coping**
- 5. Kidney disease coordinated care**
6. Kidney transplant disparities
7. Mental health/Quality of Life
8. Impact of multiple comorbidities for people with kidney disease

### **CONFERENCE DISCUSSION SUMMARY- KIDNEY DISEASE PCOR BARRIERS**

Attendees identified eleven barriers to kidney disease PCOR (barriers in bold were identified by more than one group):

- 1. Mistrust of medical research- especially in underserved communities and with vulnerable populations**
- 2. Research is not accessible to patients- distance to meetings, timing of meetings (during business hours), lack of time to participate in research, lack of technology/internet access**
- 3. Patients are overwhelmed- have bigger problems/concerns to deal with than to be involved in research, e.g. financial issues, health issues, mental health issues, family issues**
- 4. Patients don't know how to get involved in research opportunities**
- 5. Patients don't understand research process- research literacy**
6. Research does not focus on patient priorities
7. Organizational barriers- difficult to work with dialysis units to get patients involved in research, fragmentation across different organizations
8. Patients don't get any information about completed research/research findings
9. Researchers do not know how to work with patients as research partners
10. Researchers do not know to best disseminate research findings to patients and their families
11. Limited funding to do research on patient education



## **CONFERENCE DISCUSSION SUMMARY- SOLUTIONS TO KIDNEY DISEASE PCOR BARRIERS**

Attendees identified twelve solutions to barriers to kidney disease PCOR (solutions in bold were identified by more than one group):

- 1. Have broad research teams and research champions- Put primary care physicians, receptionists, patient care technicians and nurses on research teams, and train them about research and research projects since they work with patients the most, and can help engage patients in research; create patient research champions- create culture of research support**
- 2. Partner with community stakeholders (churches, community organizations) on research and have them help with patient recruitment on research teams- teams need to be diverse and reflect the community- partnerships need to be long term- offer research opportunities where patients are (including rural areas) - build relationships with communities**
3. Have large groups of patients involved on research teams (to accommodate those who may need to take a break from the project)
4. Conduct research meetings on weekends, evenings
5. Each research project needs to individualize PCOR approach- no one-size-fits-all
6. "Treat patients like people" (not research subjects)
7. Need a research information portal for patients and family members that gives information about research study opportunities- can include patient educational materials about research- use marketing skills, social media and IT to make the best website- Canadian example of something similar- <http://www.centrecmi.ca/>
8. Patient engagement workshops
9. Have diverse and inclusive research teams
10. Need for more "mid-level" information about ongoing and completed research - in-between lay and clinical descriptions
11. Build trust with patients about research- educate patients about the impact they can have on research, establish two-way relationship, include patients in research planning, need persistent engagement with patients about research i.e. don't just ask once
12. Provide patients with fair compensation to be research team members  
Include patients and family members on research ethics boards



## **Conference Evaluations**

### **CONFERENCE EVALUATIONS- PRE-SURVEY**

To immediately promote and encourage the interactive spirit of the conference, the committee decided to use ARS technology to complete the pre-survey questions. Using their cell phones, attendees answered questions about their initial thoughts related to kidney disease PCOR. The results of these questions were shared live-time in the event. As many as 31 attendees (55%) participated in answering these questions, however the total responses per question varied.

**Knowledge level/understanding of patient centered kidney research.** The majority of the 21 attendees who answered this question (38% of all attendees) indicated that they had good ( $n=7$ , 33% of respondents to this question), very good ( $n=4$ , 19%) or excellent ( $n=4$ , 19%) understanding of kidney disease PCOR, with fewer respondents noting they had fair ( $n=4$ , 19%) or poor ( $n=2$ , 10%) understanding.

**If you are a patient or family member/care partner, do you want to be involved in a kidney disease research study?** Of the nine respondents to this question, 89% indicated that they want to be involved in a research study.

**If you are a patient or family member/care partner, have you been involved in a kidney disease research study?** Of the ten respondents to this question, 70% indicated that they have not been involved in a research study.

**If you are a researcher or professional, have you ACTIVELY involved patients in a kidney disease research study?** Of the twenty respondents to this question, 65% indicated that they have actively involved patients in research studies.

To engage patients and family members who were unable to travel to this meeting, we also conducted a Facebook survey at the beginning of the event (and shared this on Twitter), asking our community two questions (respondents could choose more than one answer:





**How would you describe your involvement with kidney disease research?** Of the 87 people who answered this question, the majority (54%) indicated that they have never participated in a kidney disease research study. Of those who had been involved in a research study, 39% had clinical data collected, 14% were interviewed/part of a focus group, 9% commented on documents for use in a study, 8% informed research topics, 8% helped share research results, 6% selected or developed research methods and 5% helped recruit research participants.

**How do you think patients and care partners can best ensure that research about kidney disease is relevant to their needs?** Of the 85 people who answered this question, almost half of the respondents answered, “actively participating in the research project design and implementation” (49%), “helping share information about research results” (46%) or “giving input into topic and question selection” (45%). 31% of respondents answered “reviewing research results” and 11% were “not sure.”



**CONFERENCE EVALUATIONS - POST-SURVEY**

42 attendees (75%) returned a post-conference evaluation paper survey, and all 42 answered all the survey questions. When applicable, SPSS version 24 was used to calculate significant differences in answers.

**Knowledge level/understanding of patient centered kidney research.** The majority of the attendees who completed the survey indicated that they had good ( $n=8$ , 19% of respondents to this question), very good ( $n=21$ , 50%) or excellent ( $n=5$ , 12%) understanding of kidney disease PCOR, with fewer respondents noting they had fair ( $n=6$ , 14%) or poor ( $n=2$ , 5%) understanding. Because of the poor response rate of the same pre-survey question, we cannot assess the statistical difference between the pre- and post-event knowledge of kidney disease PCOR, however **knowledge/understanding about patient centered kidney research improved after this event.**

*“I've been trying to form a patient/family advisory council at my organization & have faced resistance. This event has re-energized me to form this committee and engage*

**What is your overall assessment of this event?** Encouragingly, **all respondents assessed the event positively**, with 17% rating the event as “good,” 33% rating it as “very good” and 50% rating it as excellent. No one rated the event as “poor” or “fair.” There was no significant difference between the patient/family and professionals’ assessment of the event. **All respondents also rated the quality of the speaker panelists as good (5%), very good (38%) or excellent (55%).**



**How would you rate the quality of your small group discussion?** Encouragingly, **almost every respondent was satisfied with their small groups**, with 2% rating their group as “good,” 36% rating it as “very good” and 57% rating it as excellent. One respondent (2%) rated his/her small group as “fair.”

**All respondents rated the conference meeting room as good (10%), very good (33%) or excellent (55%). All but one respondent (98%) indicated that they would recommend this conference to their peers.**

Of the 36 respondents who answered the open-ended question **“What parts of today's event were most helpful to you?”** Twenty-three (64%) replied that the discussion format of the event was the most helpful. One respondent replied “the part of this event I enjoyed and was most helpful was listening to the panel, small group, each table & person.” Eight respondents (all professionals) commented that having the opportunity to hear from patients was the most helpful part of the event.

*“By attending this event I will be able to speak to other patients, peers and friends about patient-centered research to help them understand better.”*

Patient attendee

*“I thought I did a decent job at engaging patients but I realize I have much to learn.”*

Researcher attendee, reflecting on “hearing from patients, especially patients involved with research development & who are co-investigators” at this event.

Fifteen respondents answered the question “What parts of today's event were least helpful to you?” Three of these attendees mentioned that the panelists' introduction or talks were too long. The other 12 answers varied, and included answers like “some discussion on barriers and solutions are already known,” there was “not a clear distinction between patients as research subjects and patients as partners in research,” “some of it was preaching to the choir,” “too little discussion of what research really is” and “open discussion went a bit off track.” One patient replied that some information on the pre-conference survey report was too technical.

*“I will work harder to become more involved in research.”*

Patient attendee

*“Patients are more motivated to learn & participate than I realized.”*

Researcher attendee





## **Appendices**

- Press Release
- *Facebook Video Announcement*
- *Conference Agenda*
- *List of Attendees*
- *Conference Evaluation Tools*
- *Post-Conference – Patient Advocacy Blog Post*
- *Fact Sheet- Kidney Disease Patients and Caregivers- Patient Centered Outcomes Research*
- *Fact Sheet- Researchers- Patient Centered Outcomes Research*

Press Release: <https://www.kidney.org/content/patients-lead-national-research-priorities-kidney-disease>

Patient Advocacy Blog post: <https://nkfadvocacy.wordpress.com/2017/05/15/nkfs-hosts-patient-driven-research-stakeholders-conference-at-2017-spring-clinical-meeting-a-conference-where-patientsdecide/>

Video hosted on NKF's Facebook page:

<https://www.facebook.com/nationalkidneyfoundation/videos/10154341324949106/>