

Engaging patients in research: from design to dissemination

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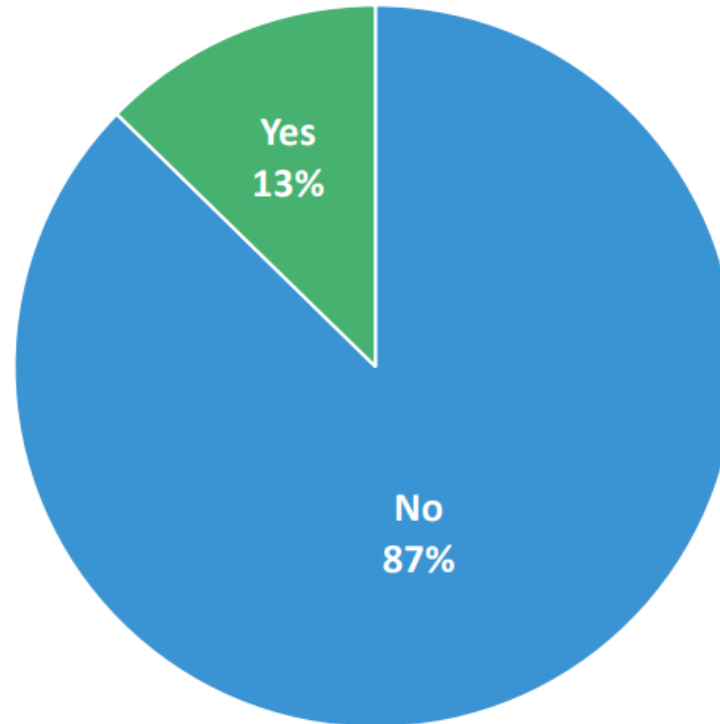
Outline

- Patient-centered kidney disease research: findings from a PCORI-sponsored NKF project
- Patient engagement in research
 - Design
 - Conduct
 - Dissemination
- My own experiences with research

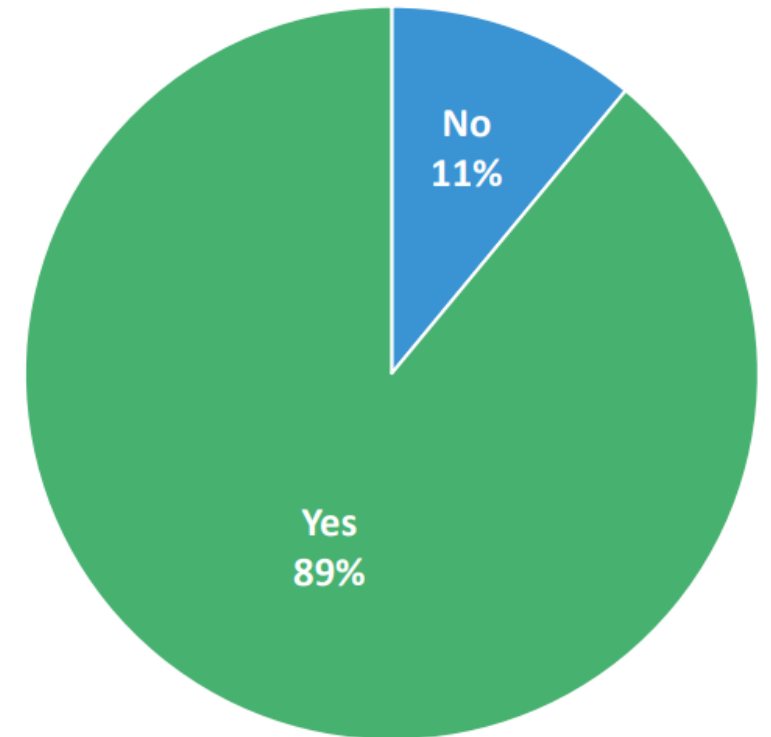


NKF: Patient experience with research

- Administered an 11 question survey on research experience to:
 - 673 patients
 - 147 care partners
 - 647 researchers



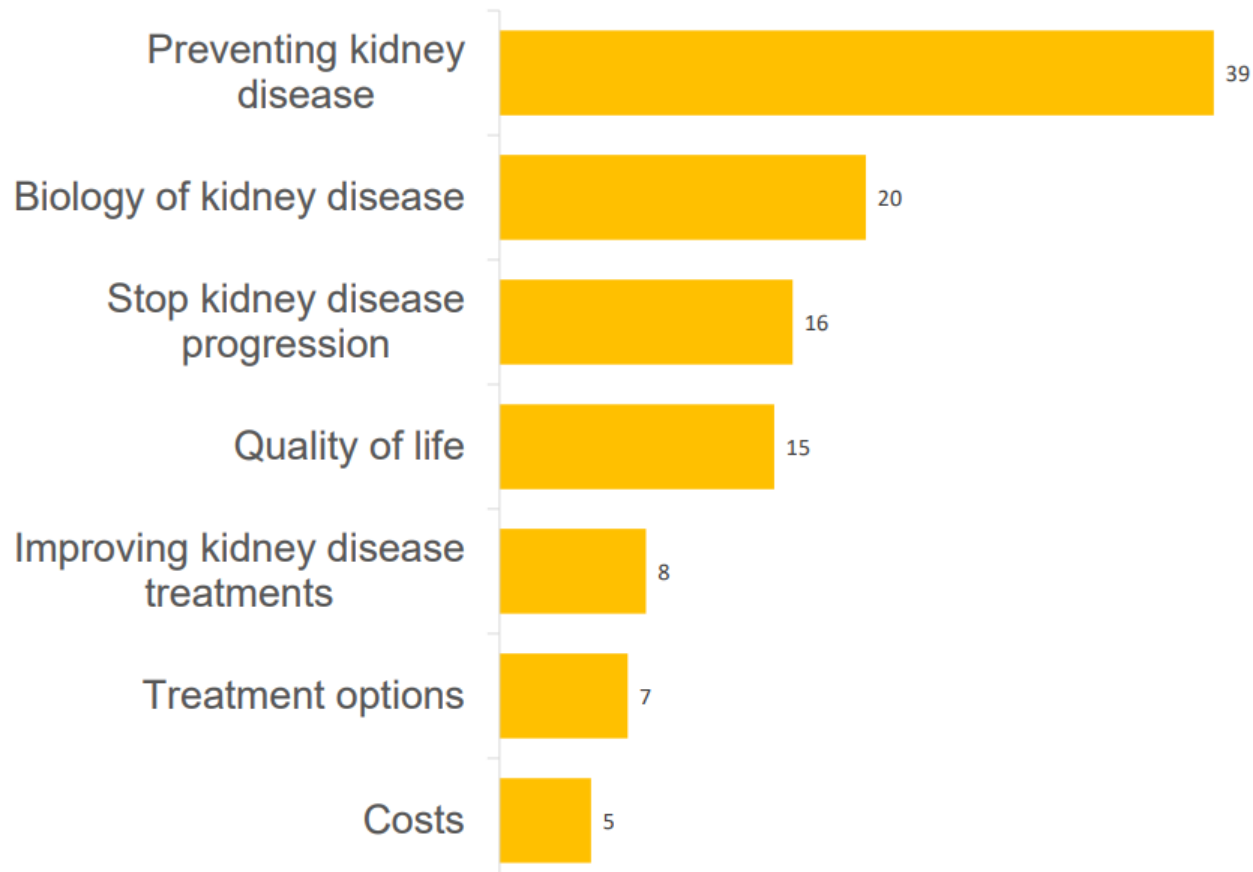
**Patients and care partners
who have been involved in
kidney-related research**



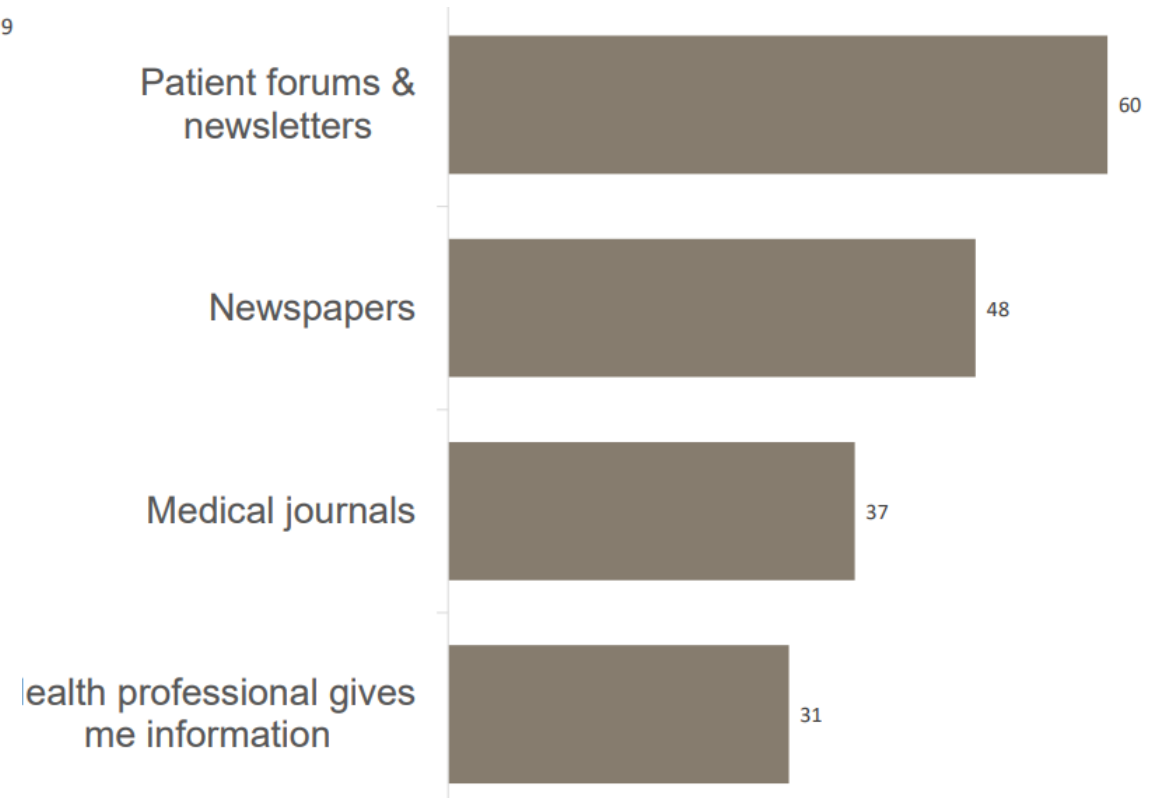
**Patients and care partners
who are interested in
kidney-related research**

NKF: Patient experience with research

Patients and care partners research priorities



Where do patients learn about kidney-related research?



Key Steps in the Dialysis Research Process

Design

- Identify problem(s)
- Formulate research question(s) and hypotheses
- Design strategy
 - cohort study, clinical trial, interview/focus group(s)
- Develop proposal outlining the protocol (plan)
 - recruitment, data collection, analysis, and dissemination plans
 - consider obtaining dialysis organization and patient input
- Secure research funding
- Obtain Institutional Review Board (IRB)
- Obtain dialysis organization approval to conduct study in clinic(s) including legal contracting

Conduct

- Train clinic staff on protocol
- Recruit study participants
- Collect study data
 - Medical record information, blood samples, interviews
- Analyze study data and interpret findings
- During conduct, consider need for re-trainings of clinic staff and/or updates to participants and facilitators

Disseminate

- Share key findings with important stakeholders (e.g., patients, clinicians, administrators, policymakers)
 - Manuscripts published in journals
 - Presentations, conferences, and meetings
 - Tools and resources
 - Websites, social media
- Provide follow-up to participants and facilitators
- Identify areas for future research and potential collaborators, funders

Patient engagement in research design

- Is topic meaningful? Review potential impact based on your patient experience
- Help researchers select research questions that are most important to patients.
- Recommend other patients with knowledge, expertise, and insight to on-board.
- Assist by reviewing research grant/funding proposal.

Patient engagement in research conduct

- Recruit other patients for the study.
- Assist in communication with transparency for all involved.
- Assist in data review and interpretation.

Patient engagement in research dissemination

- Follow-up with research participants is essential.
- Patients want to help other patients. Use patients and patient advocacy groups to spread the word about research findings.
- Use social media to share the findings.
- Discuss possible next steps based on findings.

My own experiences with research

- Experience as a research participant
 - Gives purpose to help others
- Experience as a patient research collaborator
 - Becomes personal knowing you're helping others

Dialysis research is a TEAM effort

To increase the relevance and success of dialysis research, we must involve **patients** in all research stages.

