



Fact Sheet for Researchers Patient Centered Outcomes Research

There is an increasing emphasis on patient centered outcomes research (PCOR) in kidney disease. Encouragingly, **people living with kidney disease and their loved ones are very interested in partnering with investigators to be part of research teams**, even though very few have done so before. The National Kidney Foundation conducted a national survey on PCOR and held the first kidney disease PCOR conference in 2017 that provided helpful information for researchers.

What research topics matter most to patients and family members?

You should work with patient and family partners to identify the research questions that matter most to them. Nationally, patients & family members who responded to our survey were most interested in research about:

- 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
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What can I do as a researcher to most effectively engage patients and family members as research partners?

- Have broad research teams and research champions
- Partner with community stakeholders on research and have them help with patient recruitment on research teams
- Have large groups of patients involved on research teams
- Conduct research meetings on weekends, evenings
- “Treat patients like people” (not research subjects)
- Have diverse and inclusive research teams
- Translate research findings in patient-friendly formats and language
- Build trust with patients about research
- Provide patients with fair compensation to be research team members
- Include patients and family members on research ethics boards