



Fact Sheet for Kidney Disease Patients and Caregivers- Patient Centered Outcomes Research

Did you know that you could play an important role to improve kidney disease patient care? A big way that you can do this if you are a person with kidney disease, or a family member or loved one of someone with kidney disease, is to be part of a research project.

There is research happening all over the country about many different questions important to kidney disease-like: How can we slow down kidney disease? What is the best treatment for people with kidney disease? or How can we help more people get kidney transplants?

More and more, researchers are including patients on their teams to help them with all parts of the research process. This is called “patient centered outcomes research.” As a patient or family member, you can be part of these teams in many ways!

- You can help set up research questions that are important to answer
- You can help plan a research project that will answer these questions
- You can help think of ways to get patients to be part of a research project
- You can help make materials used in research studies
- You can help collect information (data) and help review that information
- You can help look at what the research study data means
- You can help share information about research study results

Ask your medical team if they are doing any research and if you can be part of it. Also, join kidney disease groups like the National Kidney Foundation. to learn more about national research studies. You can find a clinical trial at <https://www.kidney.org/atoz/content/how-can-i-find-clinical-trial>
By getting involved in research you can help improve kidney disease care for all patients!

The Patient-Centered Outcomes Research Institute also has lots of information for you about how you can get involved in research <https://www.pcori.org/>