

PCORnet[®] Resources are Powering Nephrology Research for Children and Adults

PCORnet[®] is intended to improve the nation's capacity to efficiently conduct patient-centered health research, particularly comparative clinical effectiveness research (CER), by providing a large, highly representative network of health data, research expertise, and patient insights. PCORnet has been developed with funding from the Patient-Centered Outcomes Research Institute[®] (PCORI[®]).

THE PCORnet[®] INFRASTRUCTURE SOLVES KEY CHALLENGES IN NEPHROLOGY RESEARCH

 Challenge: Underpowered trials	 Challenge: High participant nonadherence	 Challenge: Irrelevant study outcomes
 Solution: Real-world data from everyday healthcare encounters with more than 50 million people annually across the U.S.	 Solution: Proven, low-burden models for pragmatic research	 Solution: Patient input integrated across the study lifecycle

CASE STUDIES: NEPHROLOGY RESEARCH POWERED BY PCORnet[®]

Evaluating Comparative Effectiveness of Empagliflozin in Type 2 Diabetes Population With and Without Chronic Kidney Disease ([Empa DKD](#))

Design: Retrospective
Observational

Funder: Boehringer Ingelheim

Principal Investigator:
Neha Pagidipati,
Duke Clinical Research Institute



Study questions:

- Why aren't patients with type 2 diabetes receiving guideline-recommended screening for diabetic kidney disease (DKD)?
- Which medications are safest and most effective for patients with type 2 diabetes, with or without chronic kidney disease (CKD)?

Methods:

- Used PCORnet to partner with **20 large healthcare systems**
- Included 62,197 adults with type 2 diabetes with or without kidney disease

Results:

- Published results in [JAMA Network Open](#) revealing CKD screening gaps and potential improvement strategies
- Published results in the [Journal of the American College of Cardiology](#) and [The American Journal of Cardiology](#) comparing medication effectiveness for kidney and heart outcomes in patients with type 2 diabetes

"PCORnet resources offer the only networked datasets out there that could support this research."

Neha Pagidipati, Principal Investigator of the Empa DKD and IRIS-CKD studies

Pediatric KIDney Stone (**PKIDS**) Care Improvement Network

Design: Prospective Observational

Funder: Patient-Centered Outcomes Research Institute® (PCORI®)

Principal Investigator: Gregory Tasian, The Children's Hospital of Philadelphia

Study question:

What are the differences in stone clearance and the lived experiences of youth following ureteroscopy, shock wave lithotripsy, and percutaneous nephrolithotomy for the removal of kidney and ureteral stones?

Methods:

- Collaborated with **20 pediatric healthcare sites** participating in PCORnet
- Included 1,290 youth (ages 8–21) receiving kidney stone surgery
- Co-designed with patients, caregivers, surgeons, and health systems
- Published trial findings as two studies in *JAMA Network Open*
 - [Ureteroscopy vs Shockwave Lithotripsy Results](#)
 - [Percutaneous Nephrolithotomy vs Ureteroscopy Results](#)

Preserving Kidney Function in Children with Chronic Kidney Disease (**PRESERVE**)

Design: Retrospective Observational

Funder: Patient-Centered Outcomes Research Institute® (PCORI®)

Principal Investigator: Christopher Forrest, The Children's Hospital of Philadelphia

Study questions:

- Which monitoring strategies and blood pressure medications best preserve kidney function in pediatric patients with CKD?
- What are the lived experiences of families and patients managing pediatric CKD?

Methods:

- Partnered with **15 healthcare institutions** participating in PCORnet that provide pediatric clinical care services
- Included 20,100 children (ages 1–17) with CKD seen between Jan. 2009-Dec. 2021
- Engaged parent partners to assess lived experiences managing blood pressure
- Expanded the PCORnet® Common Data Model for pediatric and rare kidney disease research

ONGOING NEPHROLOGY STUDIES POWERED BY PCORnet®

- Choosing Immune Suppression in Renal Transplantation by Efficacy and Morbidity (CISTEM2) [Learn more](#)
- USDHub: Community Resource for Urinary Stone Disease Research [Learn more](#)
- Implementation pRogram to Improve Screening and management for CKD in Diabetes (IRIS-CKD) [Learn more](#)
- PREvention of Cardiovascular and DiabEtic kidNey disease in Type 2 Diabetes (PRECIDENTD) [Learn more](#)

POWER YOUR NEPHROLOGY RESEARCH WITH PCORnet®

PCORnet resources are available to researchers, patient groups, industry, and agencies from all funding sources and affiliations. PCORI also offers [funding](#) for broad pragmatic studies using PCORnet.

Are you ready to find out how PCORnet can support your next research effort? Contact the [PCORnet® Front Door](#) to start the conversation.



PCORnet is a national resource, funded by PCORI, that enables insights from high-quality health data, patient partnership, and research expertise to deliver fast, trustworthy answers that advance health outcomes. The network supports both observational and interventional research.