pcornet® The National Patient-Centered Clinical Research Network

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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

Solution: Real-world data from everyday healthcare encounters with more than 47 million people annually across the U.S.

Challenge: High participant nonadherence

Solution: Proven, low-burden models for pragmatic research

Challenge: Irrelevant study outcomes

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 **23 pediatric healthcare systems** participating in PCORnet
- Included 1,290 youth (ages 8–21) receiving kidney stone surgery
- Co-designed with patients, caregivers, surgeons, and health systems
- Published a design paper with a pragmatic research framework for pediatric nephrology

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.

Ready to begin your next kidney research project? Contact the PCORnet® Front Door to get started.

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

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