The KidneyCARE Study: A National Registry Linking Patient-Reported Outcomes with Electronic Health Record (EHR) Data to Advance Kidney Disease Research

KidneyCARE Study
Community Access to Research Equity™

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Introduction

The KidneyCARE™ (Community Access to Research Equity) Study is a national registry linking patient-reported outcomes with electronic health record (EHR) data. By combining the patient experience with real-world clinical data, the Registry drives research that can inform chronic kidney disease care and interventions.

Registry highlights:

- Tracks CKD progression and treatment effectiveness
- Assesses patient quality-of-life impacts
- Creates a trial-ready population for clinical study enrollment
- Collects patient insights through tailored one-time surveys on emerging topics of interest

Methods

Study Design and Population:

- Prospective, observational registry of adults (≥18 years) with any type or stage of kidney disease; includes English- or Spanish-speaking participants.
- Enrollment opened March 20, 2024; Participants self-enroll online via public outreach or through Geisinger Health System recruitment
- Approved by Tufts Health Sciences Institutional Review Board (IRB # STUDY00000053); registered on ClinicalTrials.gov (NCT05497518)

Data Collection:

- Core Survey captures demographics, medical/family history, lifestyle, and kidney disease characteristics
- Health-related quality of life is assessed using validated EQ-5D-5L and KDQOL-36 instruments
- EHR data were available for 173 Geisinger patients who signed the informed consent, including outpatient medication data for 171 patients over the 15-month period from March 4, 2024 to June 19, 2025.
- Surveys are collected at baseline and every 6 months
- Analyses shown here include patient-reported CKD stage, eGFR, and causes of kidney disease, with medication use derived from EHR data

Infrastructure and Data Analysis:

- Secure, HIPAA-compliant AWS platform for surveys, EHR integration, and real-time data management
- Survey and EHR data were cleaned, validated, and integrated for study analyses

Results

Table 1: Baseline Characteristics of Registry Participants with Core Survey Data

Period: March 20, 2024 – September 11, 2025; Patient-reported data.

Study Participants: Of 2,312 participants who signed an informed consent:

- 994 completed the Core Survey. Among these, 893 (90%) were from the general public and 101 (10%) were from Geisinger Health System.

Characteristic	Entire Cohort (N=994)	General Public (N=893)	Geisinger Patients (N=101)
Demographics			
Age, mean (range)	61.68 (20 – 97)	61.10 (20–97)	66.77 (30–86)
Women, N (%)	637 (64%)	578 (65%)	59 (58%)
Race, N (%)			
American Indian or Alaska Native	7 (1%)	7 (1%)	0 (0%)
Asian American	16 (2%)	16 (2%)	0 (0%)
Black or African American	90 (9%)	89 (10%)	1 (1%)
Native Hawaiian or Other Pacific Islander	3 (<1%)	3 (<1%)	0 (0%)
White	847 (85%)	749 (84%)	98 (97%)
Two or More Races	17 (2%)	16 (2%)	1 (1%)
Unknown	5 (1%)	5 (1%)	0 (0%)
Prefer Not to Answer	9 (1%)	8 (1%)	1 (1%)
Ethnicity, N (%)			
Hispanic or Latino	58 (6%)	55 (6%)	3 (3%)
Not Hispanic or Latino	893 (90%)	801 (90%)	92 (91%)
Unknown	26 (3%)	21 (2%)	5 (5%)
Prefer Not to Answer	17 (2%)	16 (2%)	1 (1%)
Clinical Characteristics, N (%)			
Currently on dialysis, N (%)	123 (12%)	121 (14%)	2 (2%)
Kidney transplant recipient, N (%)	148 (15%)	146 (16%)	2 (2%)
eGFR known, N (%)	745 (75%)	674 (75%)	71 (70%)
CKD Stage Unknown, N (%)	94 (9%)	84 (9%)	10 (10%)
CKD Stage Known, N (%)	900 (91%)	809 (91%)	91 (90%)
• Stage 1	40 (4%)	33 (4%)	7 (7%)
• Stage 2	52 (5%)	47 (5%)	5 (5%)
• Stage 3	445 (45%)	382 (43%)	63 (62%)
• Stage 4	185 (19%)	172 (19%)	13 (13%)
• Stage 5 or ESKD	178 (18%)	175 (20%)	3 (3%)

Table 2: Patient-Reported Causes of Kidney Disease in the KidneyCARE Registry (N=994)

Source: Patient-reported data. Patients could report more than one cause; percentages may exceed 100%.

Cause of CKD	N (%)
Metabolic and Vascular Causes	
Diabetes	195 (20%)
High Blood Pressure (Hypertension)	260 (26%)
Renal Artery Stenosis	6 (1%)
Structural and Urologic Causes	
Nephrolithiasis	12 (1%)
Obstruction of Urinary Tract	24 (2%)
Reflux Nephropathy	17 (2%)
Glomerular and Immune-Mediated	
Anti-GBM Disease/Goodpasture Syndrome	1 (<1%)
Atypical HUS (aHUS)	4 (<1%)
C3G Glomerulopathy (C3G)	10 (1%)
Focal Segmental Glomerulosclerosis (FSGS)	31 (3%)
Glomerulonephritis (unspecified)	35 (4%)
Henoch-Schönlein Purpura (HSP)	0 (0%)
IgA Nephropathy (IgAN)	64 (6%)
Immune Complex (IC-MPGN)	3 (<1%)
Lupus Nephritis (LN)	14 (1%)
Membranous Nephropathy (MN)	2 (<1%)
Vasculitis	17 (2%)
Hereditary Causes	
Alport Syndrome	22 (2%)
Cystinosis	2 (<1%)
Fabry Disease	0 (0%)
Polycystic Kidney Disease (PKD)	101 (10%)
Secondary Causes	
Acute Kidney Injury (AKI)	51 (5%)
Kidney Cancer	36 (4%)
Lithium	17 (2%)
Other / Unknown / Prefer Not to Answer	
Other	188 (19%)
Unknown	415 (42%)
Prefer Not to Answer	21 (2%)

NOTE: 42% of patients report an unknown cause of kidney disease

Table 3: Real-World Use of Cardiorenoprotective Medications Among Geisinger Patients (N=173)

Source: Geisinger outpatient medication data (3/04/2024-6/19/2025)

Patients counted only once per medication; percentages may reflect therapy switches over the 15-month period.

Medication Class	% of Patients Prescribed (n/173)
(1) Angiotensin-Converting Enzyme (ACE) Inhibitors	
Lisinopril (Prinivil, Zestril)	24% (42/173)
Enalapril (Vasotec)	0% (0/173)
Ramipril (Altace)	1% (1/173)
Benazepril (Lotensin)	1% (1/173)
(2) Angiotensin II Receptor Blockers (ARBs)	
Losartan (Cozaar)	26% (45/173)
Olmesartan (Benicar)	5% (8/173)
Valsartan (Diovan)	2% (3/173)
Telmisartan (Micardis)	5% (8/173)
Irbesartan (Avapro)	1% (2/173)
Candesartan (Atacand)	1% (2/173)
(3) Sodium-Glucose Cotransporter 2 (SGLT2) Inhibitors	
Empagliflozin (Jardiance)	20% (35/173)
Dapagliflozin (Farxiga)	3% (6/173)
Canagliflozin (Invokana)	0% (0/173)
Ertugliflozin (Steglatro)	0% (0/173)
(4) Glucagon-Like Peptide-1 (GLP-1) Receptor Agonists	
Semaglutide (Ozempic, Rybelsus)	10% (17/173)
Dulaglutide (Trulicity)	5% (8/173)
Liraglutide (Victoza, Saxenda)	1% (1/173)
Exenatide (Byetta and Bydureon)	0% (0/173)
(5) Steroidal Mineralocorticoid Receptor Antagonists (sMRAs)	
Spironolactone (Aldactone)	5% (8/173)
Eplerenone (Inspra)	0% (0/173)
(6) Vasopressin V2 Receptor Antagonists	
Tolvaptan (Jynarque)	1% (2/173)
(7) Other Classes of Medications	
• **Non-Steroidal Mineralocorticoid Receptor Antagonists** (Finerenone)	0% (0/173)
• **Endothelin Receptor Antagonists** (Sparsentan, Atrasentan)	0% (0/173)
• **Targeted-Release Corticosteroids** (Budesonide)	0% (0/173)
• **Complement Pathway Inhibitors** (Iptacopan)	0% (0/173)

Conclusions

The KidneyCARE Registry integrates patient-reported outcomes with EHR data, offering a unique, patient-centered perspective on kidney disease. Geisinger participants typically enroll at earlier disease stages, enabling capture of early disease features. Hypertension and diabetes are the most commonly reported causes of CKD, and real-world EHR data reveal broad use of cardiorenoprotective medications.

Future Directions

- Increase racial and ethnic diversity in the Registry
- Expand rare disease enrollment

References

1. Inker LAI, Ferrè S, Baliker M et al. *Am J Kidney Dis*, 2023 [PMID: 36191726]

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For more information, please visit:
KidneyCAREStudy.org

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Disclosures

RHM is an employee of Novartis. AS is an employee of Bayer. JM is a previous employee of Bayer. All other authors report no relevant conflicts of interest.