

# Resource Summary Report

Generated by [Kravitz](#) on Sep 10, 2026

## Polycystic Kidney Disease Outcomes Consortium

RRID:SCR\_003674

Type: Tool

### Proper Citation

Polycystic Kidney Disease Outcomes Consortium (RRID:SCR\_003674)

### Resource Information

**URL:** <http://c-path.org/programs/pkd/>

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**Description:** Consortium to develop evidence supporting the use of imaging Total Kidney Volume (TKV) as a prognostic biomarker that predicts the progression of Autosomal Dominant Polycystic Kidney Disease (ADPKD) to select patients likely to respond to therapy into clinical trials. It aims to replace the currently used measurement of glomerular filtration rate (GFR). Scientists will use the data collected to develop a disease progression model that will evaluate the relationship between TKV and the known complications of ADPKD, including rate of loss of kidney function, hypertension, gross hematuria, kidney stones, urinary tract infections, development of end-stage renal disease, and mortality. These analyses will be used to support the regulatory qualification of TKV as an accepted measure for assessing the progression of ADPKD in clinical trials in which new therapies are tested. PKDOC has the following goals: # Develop standard clinical data elements and definitions that are specific to ADPKD # Create a database of aggregated data from existing multiple, longitudinal, and well-characterized research registries maintained over decades by the leading institutions in ADPKD clinical investigation # Advance and harmonize the missions of regulatory agencies by creating tools that help with the evaluation of new pharmaceutical compounds # Develop a quantitative disease progression model to examine the linkage between TKV and disease outcomes

**Abbreviations:** PKDOC

**Synonyms:** PKD Outcomes Consortium, PKD Consortium, Polycystic Kidney Disease (PKD) Outcomes Consortium

**Resource Type:** consortium, data or information resource, organization portal, portal

**Keywords:** consortium, drug, imaging, total kidney volume, biomarker, rate, disease progression, imaging biomarker, drug development, kidney volume, kidney, clinical, common data element, therapeutic, clinical trial, standard specification, database

**Funding:** PKD Foundation ;  
Philanthropic donations ;  
U.S. Food and Drug Administration

**Resource Name:** Polycystic Kidney Disease Outcomes Consortium

**Resource ID:** SCR\_003674

**Alternate IDs:** nlx\_157909

**Record Creation Time:** 20220129T080220+0000

**Record Last Update:** 20260905T132506+0000

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## Ratings and Alerts

No rating or validation information has been found for Polycystic Kidney Disease Outcomes Consortium.

No alerts have been found for Polycystic Kidney Disease Outcomes Consortium.

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## Data and Source Information

**Source:** [SciCrunch Registry](#)

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## Usage and Citation Metrics

We have not found any literature mentions for this resource.