Background

Kidney growth and gradual function decline impacts health related quality of life (HRQoL) in people with autosomal dominant polycystic kidney disease (ADPKD). To encourage the utilization of patient-reported outcomes in both clinical practice and trial design, the PKD Foundation designed an ADPKD Registry of patient-reported data in the USA.

The ADPKD Registry is a national, online collection of U.S. patient-reported data related to ADPKD, launched in September of 2019. The purpose of the Registry is to simultaneously facilitate research discoveries while supporting patient-centered outcomes research to learn more about the patient journey and discover unmet needs.

The significance and relevance of the Registry design, implementation, and management are maintained through the activities of Advisory Committees and Working Groups consisting of clinician scientists, researchers and patient stakeholders. The Registry is hosted on a secure, online platform; participants are registered and consented through the online system.

Methods, IS and PDS

The Registry collects data on individual disease characteristics, demographics, and diagnosis. Participants also periodically report their latest kidney function lab values and complete validated HRQoL standardized instruments (the ADPKD-Pain and Discomfort Scale (PDS) and the ADPKD-Impact Scale (IS)) (Table 1). Patient-reported pain is then tracked longitudinally with eGFR-estimated chronic kidney disease (CKD) stage and other characteristics.

Conclusions

• In launching the Registry, the PKDF aimed to empower patients to share their disease experience including the impact of PKD on their HRQoL, and to increase the opportunities to participate in research.

• Analysis of the initial cohort reveals that patients from all CKD stages are willing and eager to contribute to the body of knowledge in ADPKD.

• These data will contribute to the increased understanding of pain experience in ADPKD, including characterization of the patients more likely to report it.

References
