The ADPKD Registry

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**Participants at Enrollment**

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<table>
<thead>
<tr>
<th>Pre-ESRD</th>
<th>On dialysis</th>
<th>Post-kidney transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age</td>
<td>46</td>
<td>66</td>
</tr>
<tr>
<td>Median eGFR</td>
<td>48 mL/min/1.73 m²</td>
<td>8 mL/min/1.73 m²</td>
</tr>
</tbody>
</table>

Table 1. Participant cohort eGFR status (N = 1352)

- **Pre-ESRD**: 74.7%
- **On dialysis**: 3.5%
- **Post-kidney transplant**: 19.8%

Participants are recruited and engaged through PKDF social media and other communications. A personalized Dashboard is provided on the Registry Portal to show participants select aggregated data. A quarterly newsletter is released, highlighting what the Registry is learning and what is coming next.

**Features of Enrollees**

Participants have a median age of 52 years, and are 72% female, 94% Caucasian, 4% self-identifying as Hispanic/Latino and 2.4% as African American. 12% had a genetic test for PKD, with a vast majority (94%) reporting diagnosis by imaging (69% by ultrasound, 22% by CT and 13% by MRI).

Below are representative examples of the data we’ve collected.

**ADPKD Pain and Discomort Scale**

This validated patient-reported survey assesses the impact of PKD on quality of life.

**Vascular Outcomes COVID-19 Impact**

Health Care Access

- Modules are released either three month, six month, or annual time points starting at enrollment. New patient-reported modules are designed and implemented utilizing Advisory Committee-directed working groups and patient beta testing panels.

**Participants in August 2020.**

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- Future goals of the project include increasing the diversity of registry participants, creating a process for data access requests, continuing outcomes of modules development, and expansion to clinical data sets.

- The Registry began utilizing the self-reporting process for data collection to create cohorts of potentially eligible study participants in August 2020. Thus far, 59% of participants are between the ages of 18-55 with a eGFR above 30 mL/min/1.73 m², which are eligible criteria for most ADPKD clinical trials. Researchers and industry partners are encouraged to contact the Registry team to aid in recruitment for clinical trials and other outcomes research.

**Conclusions**

- The ADPKD Registry is a valuable resource in which to engage with ADPKD patients, and to collect patient-reported outcomes and perspectives.
- Future goals of the project include increasing the diversity of registry participants, creating a process for data access requests, continuing outcomes of modules development, and expansion to clinical data sets.
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**Methods**

- Participants are asked to fill out a series of longitudinal modules about their ADPKD.
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