PKD FOUNDATION
ADPKD REGISTRY

ADPKD Registry: A Patient-Centered Research Tool

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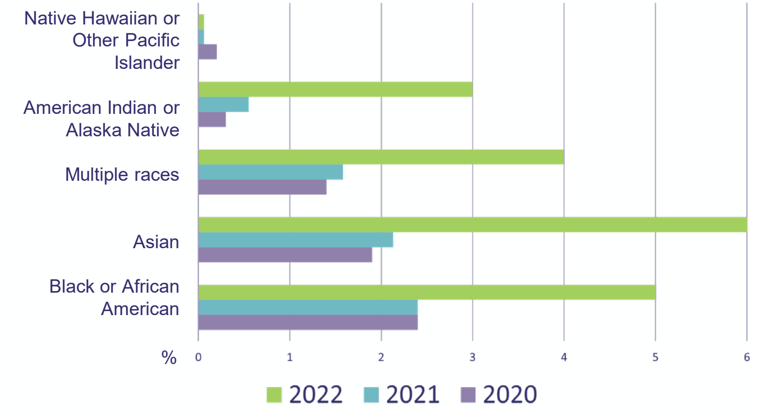
The ADPKD Registry has **3,005** enrolled participants as of October 19th, 2023. These participants are from **all 50 states** and the District of Columbia. The Registry is an opportunity to collective patient perspectives, recruit for clinical trials, and add depth to the knowledge of ADPKD progression through an IRB approved study.

Population Demographics*

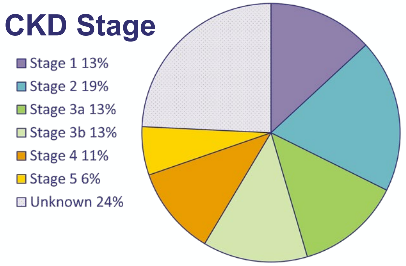
Non-White Participant Demographics Over Time



Caucasian › 93.8% › 89.4% › 85%

Identify as *Hispanic* or *Latino*
4% → 8%
2020 2022

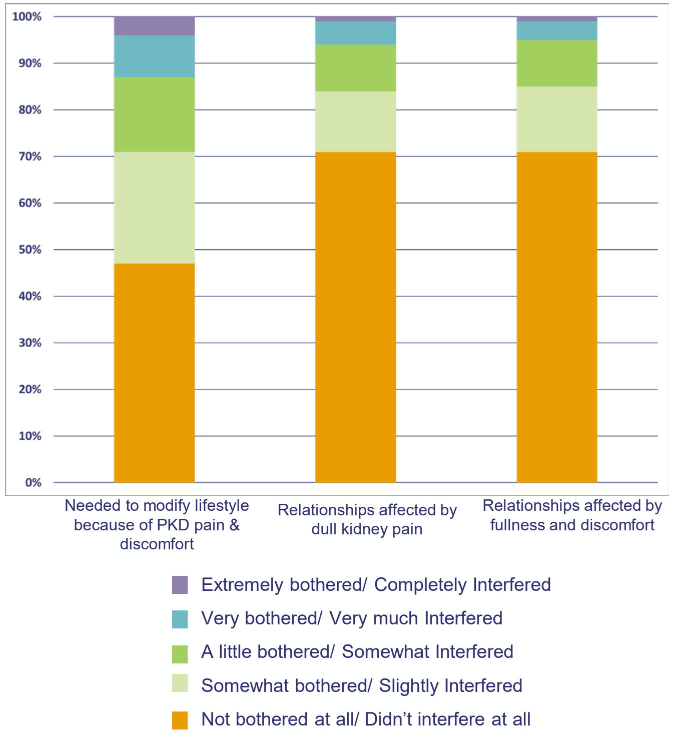
CKD Stage



Gender
Male 28%
Female 71.5%
Nonbinary, transgender, or other 0.5%

*Data from the 2020, 2021, and 2022 ADPKD Registry Annual Reports

Annual Impact Report 2022 Findings



ACTALERT
ACCELERATING CLINICAL TRIALS

Nearly 9,000 Recruitment Contacts for Likely-Eligible Patients!

★ 7 Clinical Trials
★ 11 Observational Studies

Electronic Health Records (EHR)

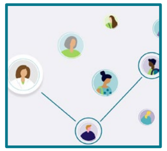
In August of 2023, the ADPKD Registry introduced patient-mediated EHR donation. This is made possible due to the 21st Century Cures Act[1].

Data from over 90 unique Medical Centers

150+ linked health records
*as of 10/23/23

Registry Data Sharing Portal

PKDF is excited to invite applications for access to Registry data!



Email research@pkdcure.org with details of your research question. Data Dictionaries and Quarterly Data Profiles are available to help determine if our data is appropriate for your project.

Refer Patients Today!

pkdcure.org/registry

ADPKD Registry

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1. https://www.fda.gov/regulatory-information/selected-amendments-fdc-act/21st-century-cures-act

Gender

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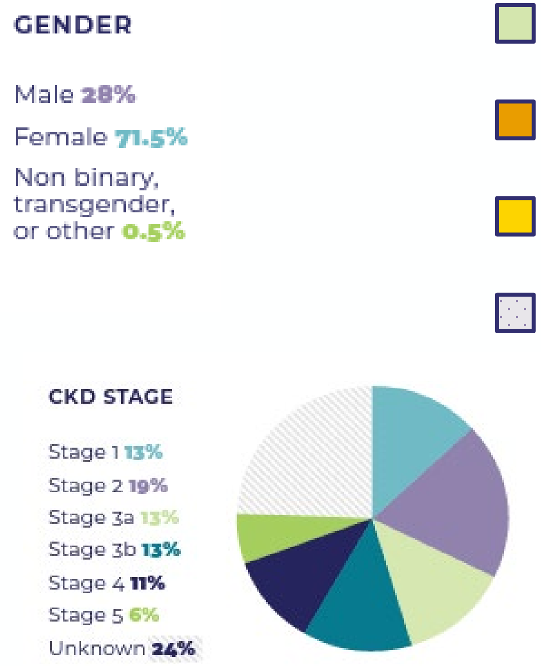
Female 71.5%
Nonbinary, transgender, or other 0.5%



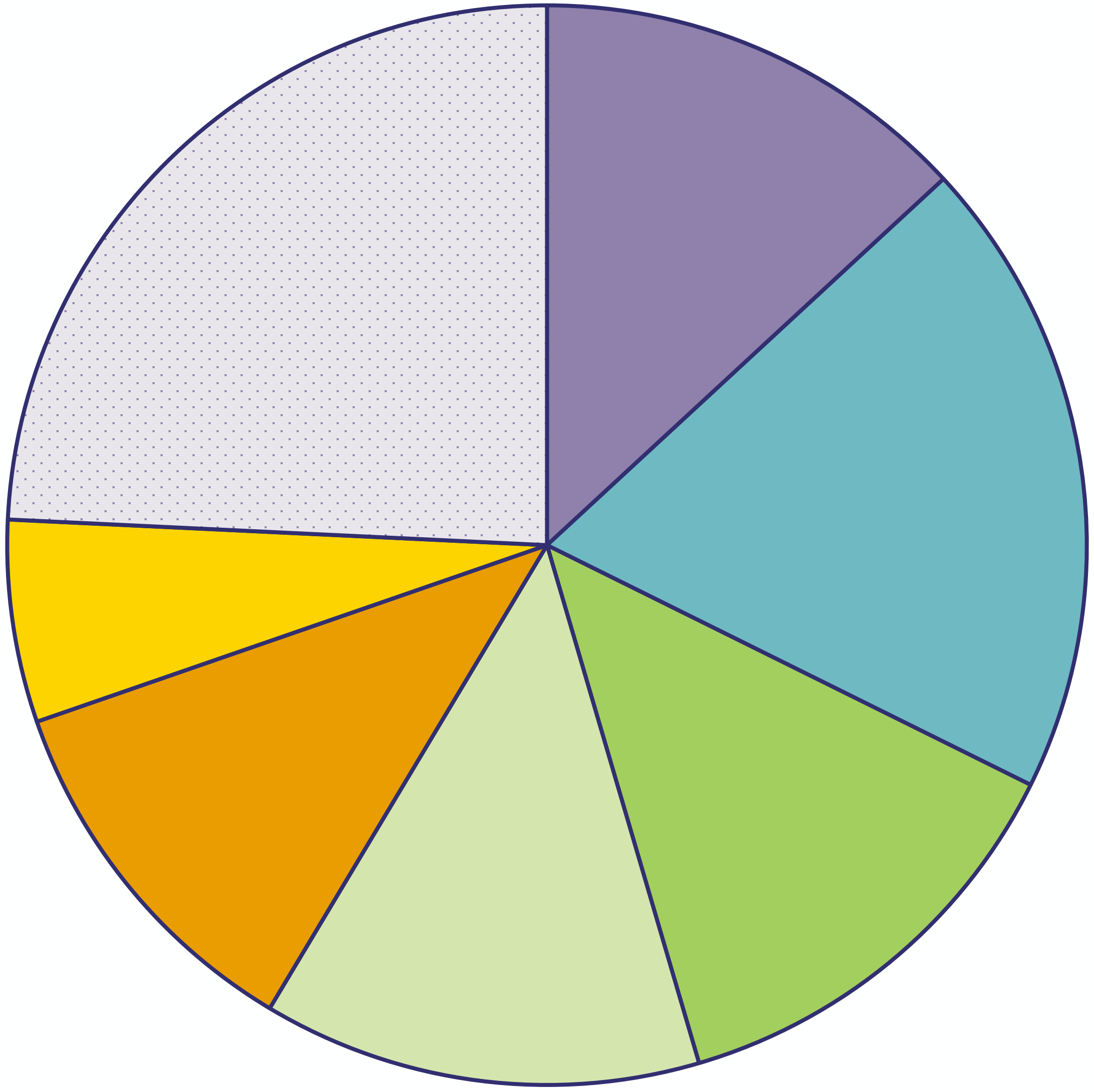
GENDER

Male 28%
Female 71.5%
Non binary, transgender, or other 0.5%

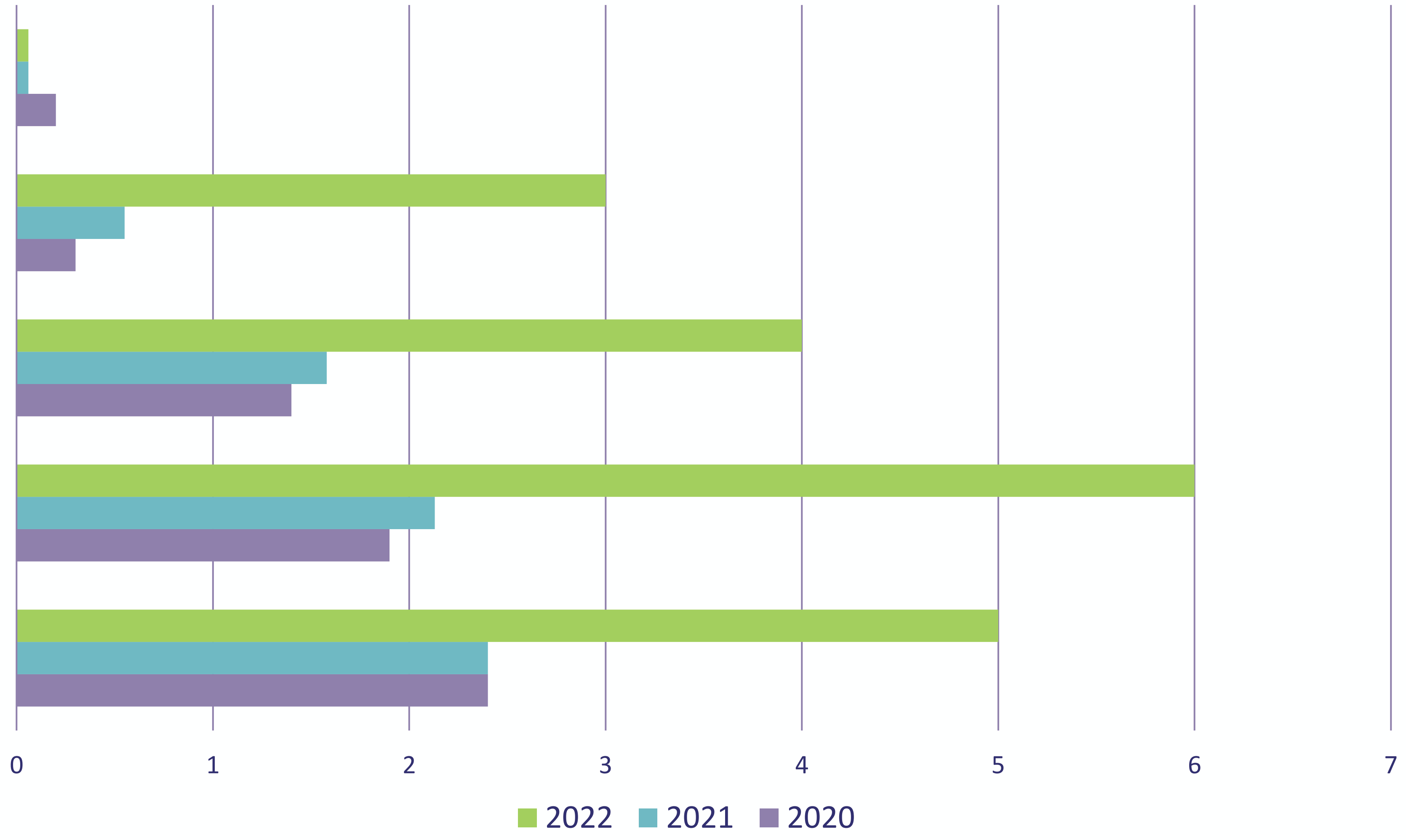
CKD STAGE

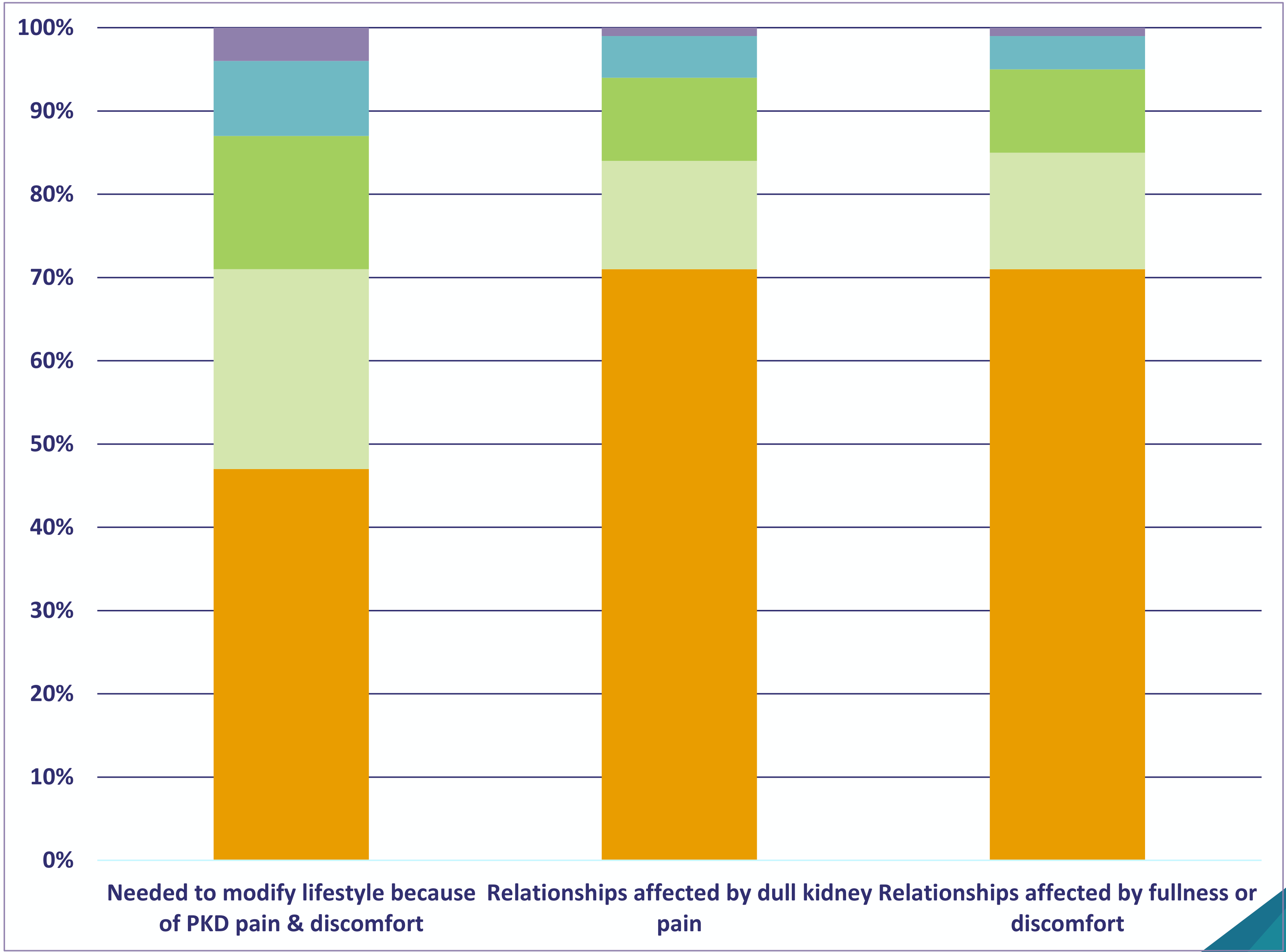
Stage 1 13%
Stage 2 19%
Stage 3a 13%
Stage 3b 13%
Stage 4 11%
Stage 5 6%
Unknown 24%

- 🟪 Stage 1 13%
- 🟦 Stage 2 19%
- 🟩 Stage 3a 13%
- 🟩 Stage 3b 13%
- 🟧 Stage 4 11%
- 🟨 Stage 5 6%
- ▨ Unknown 24%



Race and Ethnicity in the ADPKD Registry




100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Needed to modify lifestyle because of PKD pain & discomfort
Relationships affected by dull kidney pain
Relationships affected by fullness or discomfort