

A National Registry For People With All Stages and Types Of Kidney Disease: The National Kidney Foundation (NKF) Patient Network

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Introduction

People with kidney disease may be unaware of the significance of their disease or what can be done to preserve kidney function and avoid its complications. The National Kidney Foundation (NKF) Patient Network is the first national U.S. kidney disease patient registry that enables research, clinical care, and health policy decisions to be centered on patient perceptions, priorities, and activities, while giving patients the tools they need to stay educated and healthy.



Up-to-date education



Peer support



Involvement in research studies



Access to clinical trials

The NKF has recently launched a registry expansion, the NKF Patient Network – Alport Syndrome, in partnership with the Alport Syndrome Foundation (ASF), to help advance treatments for Alport syndrome.

Methods

Study Design: Longitudinal observational cohort study that collects both patient-entered data as well as clinical and laboratory data from electronic healthcare records (EHR). Patient recruitment follows two strategies: general public and through closed systems. The study is approved by the Tufts Health Sciences Institutional Review Board (IRB # STUDY0000053; NCT05497518), which serves as the IRB of record for all U.S. sites.

Population: People with any stage of kidney disease, including dialysis and kidney transplant recipients, 18 years or older (Alport syndrome patients can be of any age), English-speaking, and willing to provide informed consent. Geisinger is the first health system partner. We expect to recruit 3,000 U.S. patients by December 2023.

Patient experience: 1) Register at NKFPatientNetwork.org or kidney.org/NKFAlport (for Alport syndrome patients); 2) Sign electronic informed consent and assent (the latter only for minors 7-17 years old with a diagnosis of Alport syndrome); 3) Complete the patient profile surveys; 4) Complete follow-up surveys (EQ-5D-5L and KDQOL-36 [not collected for Alport syndrome patients], other surveys when available); 5) At any time, access education, online communities, and learn about research. EHR data is extracted from the sites upon receipt of consent. Both patient-entered and EHR data are collected at baseline and at least every six months.

Infrastructure: Pulse Inframe (Pulse) healthie™ through Amazon Web Services (AWS) cloud-based platform that meets existing GDPR, HIPAA and other international standards for security of personal and health information. Data management using the Observational Medical Outcomes Partnership Common Data Model (OMOP CDM).

Analytics: Aggregate data are available to partners via analytic portals, dashboards, and/or specialized reports. Researchers will be able to submit proposals for approval, with the analyses performed by the Data Coordination Center or Pulse.

Results

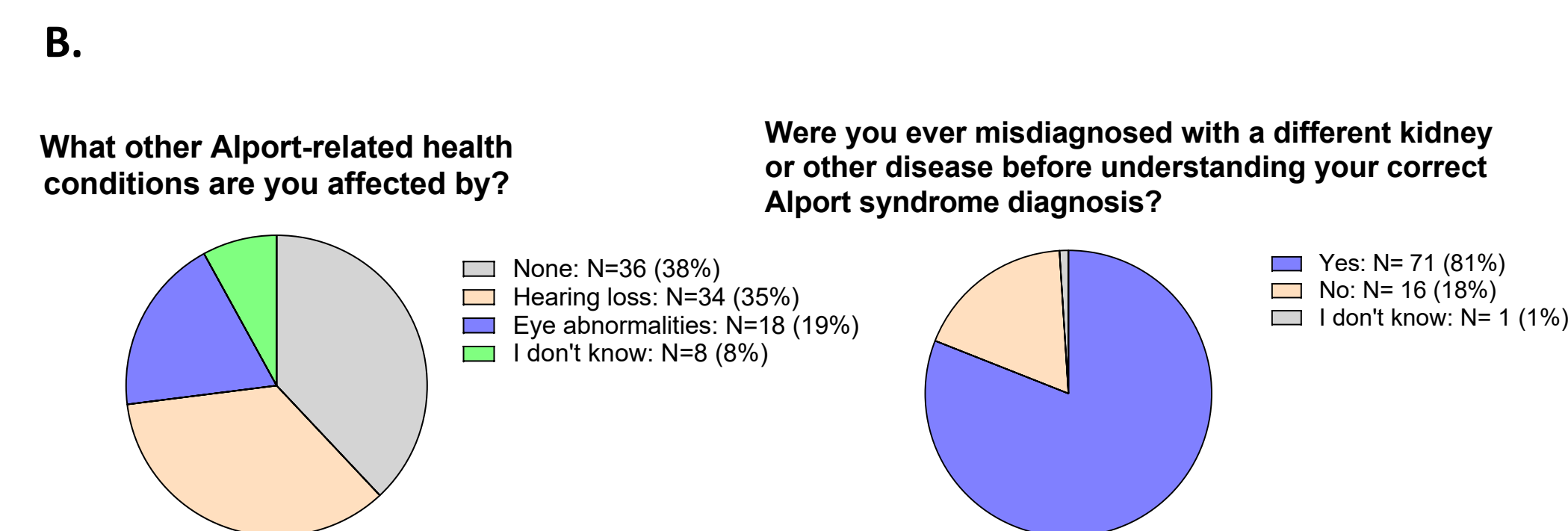
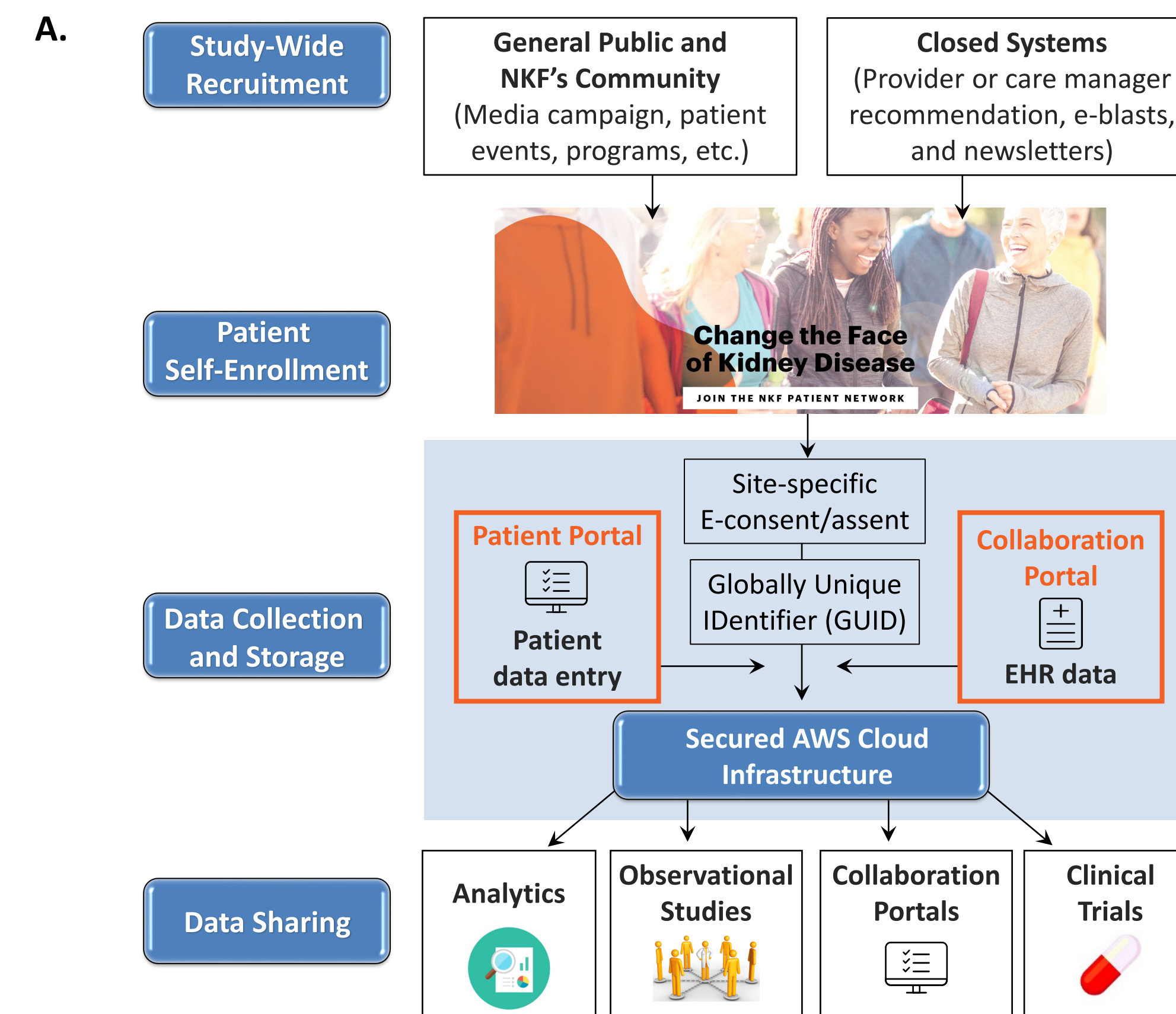


Figure 1. NKF Patient Network is live. A. NKF Patient Network workflow. Closed systems may include health systems, academic medical centers, rare kidney disease groups (e.g., ASF), payers, testing laboratories, contract research organizations (CROs), biotech, or federal agencies. B. Partners, such as ASF, can suggest data dictionary expansions to collect disease-specific information and can receive access to a collaboration portal showing real-time aggregate data.

A. NKF Patient Network in the U.S. (Data as of October 2022)

Consented participants: N=1,758 including Alport syndrome (N=150) and Geisinger (N=276) patients
Data source: Patient-reported (non-missing data)

	N	%		N	%
Age 60-80+	968	56	Ethnicity	991	100
Female sex	589	59	▪ Hispanic or Latino	40	4
CKD Stage	534	100	▪ Not Hispanic or Latino	884	89
▪ Stage 1	32	6	▪ Unknown	30	3
▪ Stage 2	31	6	▪ Prefer not to answer	37	4
▪ Stage 3	205	38	Race	991	100.0
▪ Stage 4	68	13	▪ Asian	33	3.3
▪ Stage 5 or ESKD	105	20	▪ Black or African American	63	6.4
▪ Don't know	93	17	▪ Native Hawaiian or Other Pacific Islander	2	0.2
PROMs completion			▪ White	867	87.5
▪ EQ-5D-5L	407	-	▪ American Indian or Alaska Native	7	0.7
▪ KDQOL-36	419	-	▪ Prefer not to answer	16	1.6
			▪ Unknown	3	0.3

B. NKF Patient Network – Alport Syndrome in the U.S. (Data as of October 2022)

Consented participants: Adults=128, Minors=22; Data source: Patient-reported (non-missing data)

	N	%		N	%
Female sex	72	67	Ethnicity	108	100
Genetic type of Alport syndrome	72	100	▪ Hispanic or Latino	3	2
▪ X-linked	51	71	▪ Not Hispanic or Latino	101	94
▪ Autosomal dominant	15	21	▪ Prefer not to answer	4	4
▪ Autosomal recessive	4	5	Race	108	100
▪ I am not sure	2	3	▪ Asian	2	2
CKD Stage	86	100.0	▪ Black or African American	1	1
▪ Stage 1	20	23.3	▪ White	103	95
▪ Stage 2	13	15.1	▪ Prefer not to answer	2	2
▪ Stage 3	13	15.1			
▪ Stage 4	8	9.3			
▪ Stage 5 or ESKD	12	13.9			
▪ Don't know	20	23.3			

Figure 2. NKF Patient Network data. Baseline characteristics of the NKF Patient Network (A) and NKF Patient Network – Alport Syndrome (B) participants in the U.S.

Next Milestones

- The Network is expanding to other closed systems in the U.S.
- The Network is recruiting at the first Canadian clinic (Dr. T Bhanu Prasad's Clinic, Regina, Saskatchewan) and is expanding to other Canadian sites.
- The registry will be available in Spanish by the end of 2022

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To learn more, contact us at:
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Or visit:



Conclusions

The Network will accelerate kidney disease research focused on patient outcomes and priorities and will facilitate the planning and implementation of clinical trials that will ultimately help develop new treatments for kidney disease. We are currently strategizing on methods to facilitate the recruitment of vulnerable populations, those with low digital readiness, and those who were not previously aware of having kidney disease. To do so, the Network will partner with additional health systems, community clinics, and patient advocacy groups in the U.S. and globally to increase recruit from previously unengaged populations.