

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

Lesley A. Inker,¹ Anne Barr,² Alexander R. Chang,³ Silvia Ferrè,⁴ Derek Forfang,⁴ Femida Gwady-Sridhar,⁵ Kristi Mitchell,⁶ Michael Rocco,⁷ Kerry Willis⁴

¹Division of Nephrology, Tufts Medical Center, Boston, Massachusetts, USA, ²Brown and Toland, Oakland, California, USA, ³Kidney Health Research Institute, Geisinger Health, Danville, Pennsylvania, USA, ⁴National Kidney Foundation, New York, NY, USA, ⁵Pulse Inframe, London, Ontario, Canada, ⁶Avalere Health, Washington, DC, USA, ⁷Wake Forest School of Medicine, Winston-Salem, North Carolina, USA

INFO17

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. NKF launched the first national U.S. kidney disease patient registry, the “NKF Patient Network”, to accelerate kidney disease research, clinical care, drug development, and health policy decisions centered on patient perceptions and priorities, and to give patients the tools they need to stay educated and healthy.

Healthcare professionals are critical to the Network’s success—help introduce your patients to the NKF Patient Network!



Individualized education



Peer support



Involvement in research and innovation



Access to clinical trials

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. A feasibility study was conducted July-December of 2020 and the national U.S. launch was in February of 2021. The study is approved by the Tufts Health Sciences Institutional Review Board (IRB # STUDY00000053), which serves as the IRB of record for all U.S. sites.

Population: Patients with any stage of kidney disease, including dialysis and kidney transplant recipients, 18 years or older, English-speaking, and willing to provide informed consent. Geisinger is the first health system partner. We expect to recruit 2,000 U.S. patients by March 2022, and 10,000 to 50,000 U.S. patients overall.

Patient experience: 1) Register at [NKFPatientNetwork.org](https://www.nkfpatientnetwork.org); 2) Sign electronic informed consent; 3) Complete patient profile; 4) Complete follow-up surveys (EQ-5D-5L, KDQOL-36, others 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 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 will be available to the participants and partners via analytic portals, dashboards, and/or specialized reports. Researchers will be able to submit proposals for review and approval, with the analyses performed by the Data Coordination Center or Pulse Inframe.

Results

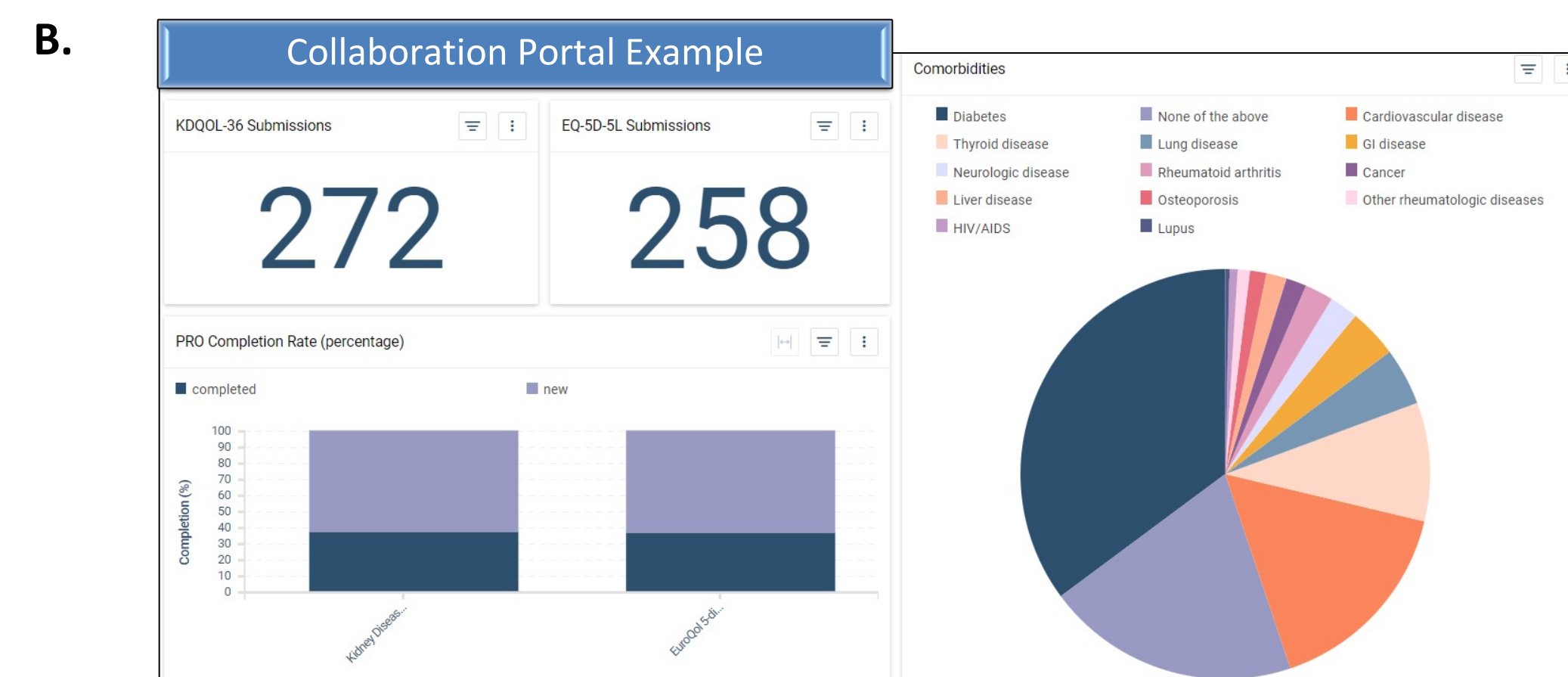
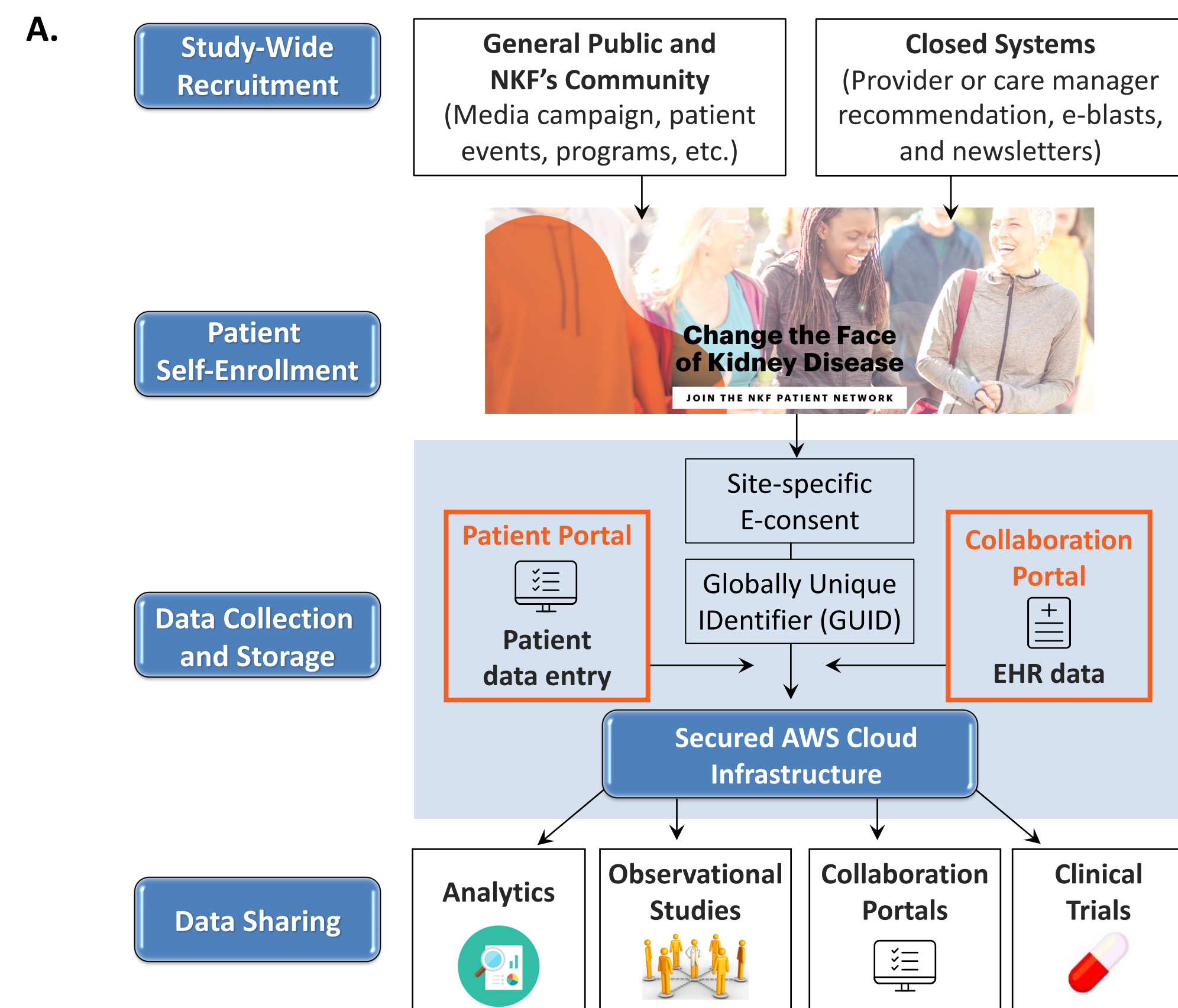
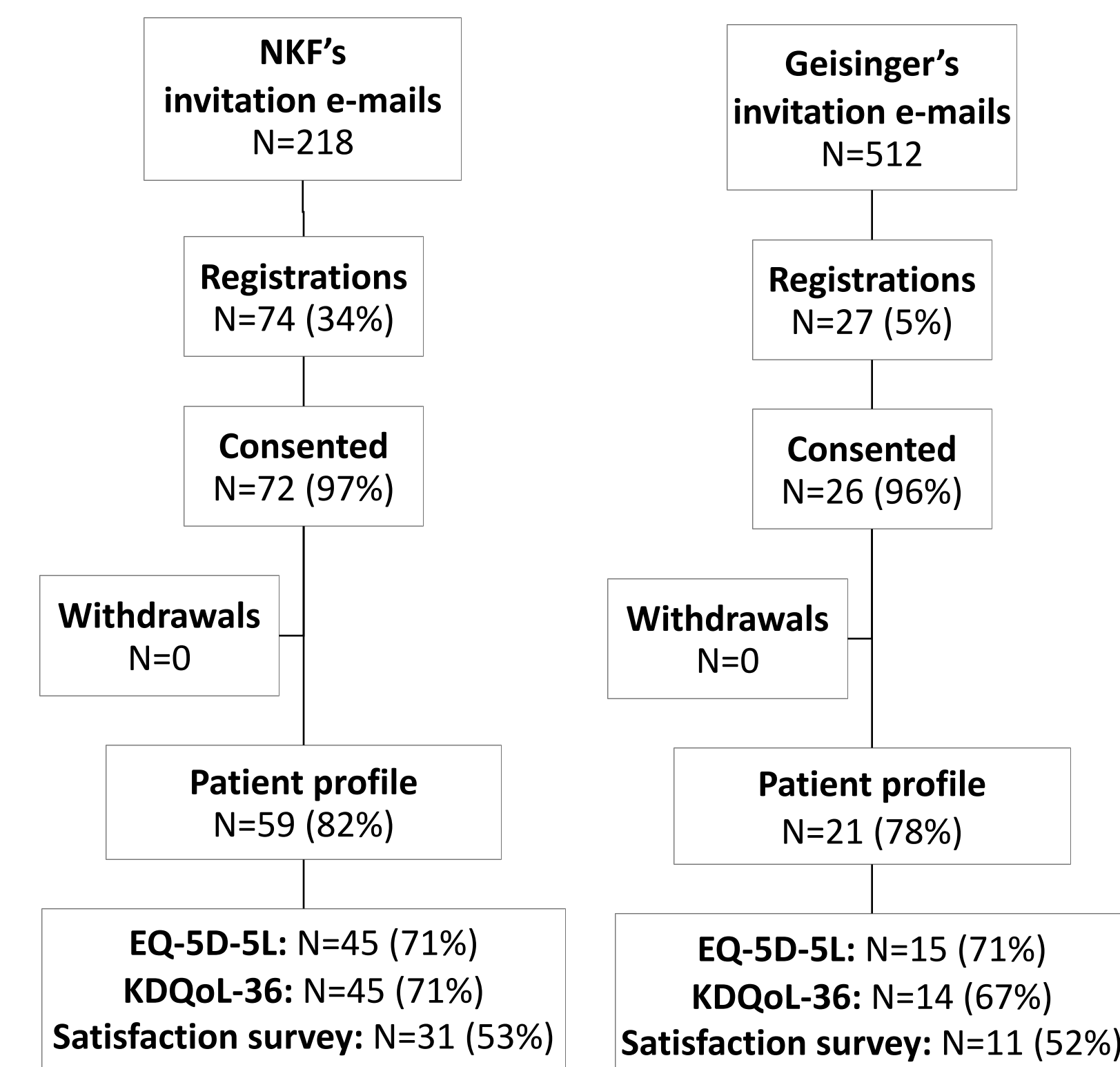


Figure 1. NKF Patient Network implementation. A. NKF Patient Network workflow. Closed systems may include health systems, academic medical centers, payers, testing laboratories, contract research organizations (CROs), biotech, federal agencies, or rare kidney disease groups. B. Partners can receive access to a collaboration portal showing real-time data.

A. Feasibility Study (July-December 2020)



B. National Launch in the U.S. (Data as of October 2021)

Consented participants: N=1,095 from 47 U.S. states and 1 health system; Data source: Patient-reported

Age 60-80+ (%)	58	Ethnicity (%)	
Female sex (%)	58	Hispanic or Latino	4
CKD Stage (%)		Not Hispanic or Latino	90
Stage 1	3	Unknown	3
Stage 2	2	Prefer not to answer	3
Stage 3	45	Race (%)	
Stage 4	12	Asian	3.0
Stage 5 or ESKD	25	Black or African American	7.0
Don't know	13	Native Hawaiian or Other Pacific Islander	0.1
PROMs completion (N)		White	87.0
EQ-5D-5L	258	American Indian or Alaska Native	0.9
KDQOL-36	272	Prefer not to answer	2.0

Figure 2. NKF Patient Network data. A. Feasibility study data. B. U.S. national launch data.

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 ensure representation of target populations including people with early stages of kidney disease, and promote diversity and inclusion among the participants. We will also focus on long-term retention and engagement strategies.

Next Milestones

- The Network is expanding to other closed systems in the U.S. and internationally
- The NKF Patient Network – Alport Syndrome is launching by the end of 2021
- The registry will be available in Spanish in 2022

Acknowledgments

The authors thank the NKF Patient Network partners (in alphabetical order): Alport Syndrome Foundation, Geisinger, LabCorp, Pulse Inframe, University of Manitoba. The authors would also like to thank all the members of the governance committees.

Funding

Foundational support for the NKF Patient Network was provided through a collaboration with Bayer AG. AstraZeneca and Novartis are platinum sponsors; Boehringer Ingelheim is gold sponsor.

To learn more, visit us at: [NKFPatientNetwork.org](https://www.nkfpatientnetwork.org) or contact: NKFPatientNetwork@kidney.org

National Kidney Foundation

PATIENT NETWORK