THE KIDNEY MOBILE HEALTH REGISTRY PILOT STUDY

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BACKGROUND

- Mobile Health (mHealth) technologies offer investigators novel approaches to research and data collection, while reducing traditional barriers to study participation.
- Potential benefits to research use of mHealth include representative sample acquisition of rare disease participants, access to external electronic health record (EHR) data, and real-time disease metric tracking.
- To date, mHealth initiatives in the kidney health space have been limited.

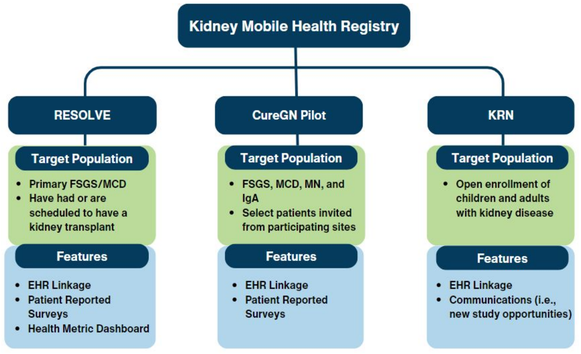
OBJECTIVES

- Assess the feasibility and potential value of mHealth use in targeted kidney disease study populations including integration into existing traditional clinical studies through a pilot of the Kidney Mobile Health Registry.

METHODS

- Three ongoing, diverse observational cohort studies were selected as pilot sub-studies for the Kidney Mobile Health Registry, as shown in Figure 1.
- The registry was built in collaboration with developers from CareEvolution (*Ann Arbor, MI*) and is offered via the MyDataHelps (MDH) application, available on iOS, Android, or web browser.
- Target enrollment is uncapped and includes children and adults with kidney diseases of interest.
- Participants may enroll remotely or in-person, and are consented directly within the app.

Figure 1. Kidney Mobile Health Registry Structure



RESULTS

- Studies were moved to production in a phased approached, with all project pilots launched by March 2024 (Figure 2).
- The CureGN Pilot launched at two sites (University of Michigan and Columbia University) and showed the most robust recruitment of the pilots (Table 1).
- CureGN Pilot data was extracted from the MDH platform in July 2024. However, usable data was not available for analysis until September 2024, following data transformation to Observational Medical Outcomes Partnership (OMOP) common data model.
- EHR data available via the MDH Extraction included: lab data, vital measures, medications, notes, and diagnoses.
- EHR export laboratory values were validated against existing CureGN lab data for the study's 2 most important endpoints: urine protein to creatinine ratio (UPCR) and creatinine. Comparison showed 96% accuracy (Table 4).

Figure 2. MDH Build and Production Launch Timeline

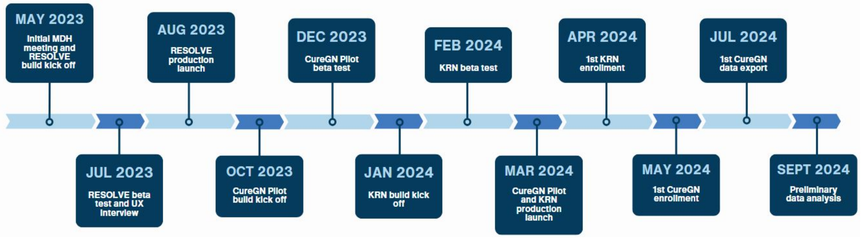


Table 1. Study Enrollment to Date (N = 13)

Study	Enrollments (N)
RESOLVE	0
KRN	2
CureGN Pilot	11

Table 2. CureGN Participant Demographics (N = 11)

Demographics	N (%)
Gender, Male	7 (63%)
Operating System/Platform, IOS	9 (82%)
Decade of Birth, 1940s	2 (18%)
Decade of Birth, 1950s	1 (9%)
Decade of Birth, 1960s	3 (27%)
Decade of Birth, 1970s	5 (45%)
Participating Site, Columbia	8 (73%)

RESULTS

Table 3. CureGN Pilot – mHealth Favorability (N = 11)

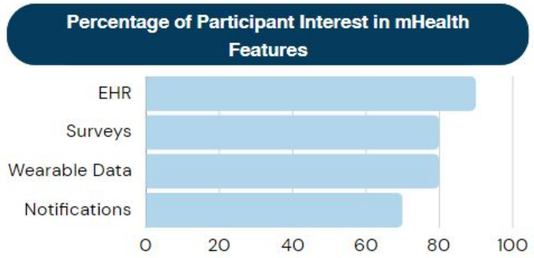
Favorability Category	Agree (%)
Utility	60%
Ease	40%
Support	50%
Comfort	60%

Table 4. CureGN Initial EHR Data Extract Agreement (N = 11)

	UPCR	Creatinine
New Values via MDH EHR Extract	162	137
Vales in Both CureGN SAF and MDH Extract	100%	95%*

** 4/78 have a difference of < 0.12

Figure 3. CureGN Pilot Future Interest in MDH Features (N = 11)



CONCLUSIONS

- Our pilot data suggests mHealth has the potential to offer significant value to kidney health research, where there is a significant need for innovation.
- Our results suggest significant opportunity to: 1) prolong follow up times for important kidney outcomes remotely, regardless of clinical site IT infrastructure, and 2) reduce clinical coordinator burden.
- Further exploration of recruitment, retention, and engagement strategies specific to the glomerular disease and larger kidney disease populations are needed.

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patients who contributed their data to the registry and enabled this work. Learn more at www.KidneyResearchNetwork.org.