

Design of a User-Centered Electronic Health Tool for Glomerular Disease Management

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Keywords

Disease management · Nephrotic syndrome ·
Glomerulonephritis · Mobile applications · Electronic health

Abstract

Introduction: Patients with primary glomerular disease (GN) have unique management needs. We describe the design of a user-centered, patient-facing electronic health (eHealth) tool to support GN management. **Methods:** We surveyed patients and GN expert nephrologists on disease management tasks, educational needs, and barriers and facilitators of eHealth tool use. Results were summarized and presented to patients, nephrologists, engineers, and a behavioral and implementation science expert in stakeholder meetings to jointly design an eHealth tool. Key themes from the meetings are described using rapid qualitative analysis. **Results:** Sixty-six patients with minimal change disease, focal segmental glomerulosclerosis, IgA nephropathy, and membranous

nephropathy responded to the survey, as well as 25 nephrologists from the NIH-funded Cure Glomerulonephropathy study network. Overall, patients performed fewer management tasks and acknowledged fewer informational needs than recommended by nephrologists. Patients were more knowledgeable about eHealth tools than nephrologists. Nine patient stakeholders reflected on the survey findings and noted a lack of awareness of key recommended management tasks and receiving little guidance from nephrologists on using eHealth. Key themes and concepts from the stakeholder meetings about eHealth tool development included the need for customizable design, trustworthy sources, seamless integration with other apps and clinical workflow, and reliable data tracking. The final design of our eHealth tool, the UrApp System, has 5 core features: “Profile” generates personalized data tracking, educational information, facilitation with provider discussions and inputting other preferences; “Data Tracking” displays patient health data with the ability to communicate important trends to

patients and nephrologists; “Resources” provides trusted education information in a personalized manner; “Calendar” displays key events and generate reminders; and “Journal” facilitates information documentation using written or audio notes. **Conclusion:** Our theory- and evidenced-based, stakeholder-engaged design process created designs for an eHealth tool to support the unique needs of patients with GN, optimized for effectiveness and implementation.

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Introduction

Primary glomerular disease (GN) is a major cause of chronic kidney disease (CKD) and kidney failure in the USA, conferring significant morbidity, mortality, and healthcare cost [1]. In addition to progression to kidney failure, GN complications include infections, thromboembolism, acute kidney injury, and cardiovascular disease. Relapses and progression of symptoms are frequent and unpredictable. Treatment typically involves months to years of corticosteroids and other immunosuppressive agents that produce significant side effects [2, 3]. Thus, optimal GN management necessitates vigilant home monitoring and self-management that can disrupt daily life [4]. Patients with GN have lower health-related quality of life and higher prevalence of depression compared to healthy controls due to disease factors such as edema, frequency of disease relapses, use of immunosuppressive agents, and disease duration [4–10]. Yet, there is limited research on effective patient support strategies.

Electronic health (eHealth) tools, such as mobile applications (apps), leverage the widespread utilization of mobile devices. An estimated 97% of Americans own some type of cellphone, 85% of which are smartphones [11], representing an opportunity to support equitable, low-cost access to home-based chronic disease management for conditions such as diabetes mellitus, cardiovascular disease, and CKD. Studies evaluating eHealth tools have reported high rates of patient acceptance and positive impacts on adherence and monitoring behaviors, as well as disease outcomes [12–14]. We previously found that a text-messaging program for GN disease monitoring was well-accepted by caregivers of pediatric patients and adolescent patients and was able to reliably and accurately capture disease activity and symptoms [15]. Our multi-disciplinary team of clinicians and research engineers further created a mobile app for children with GN and their caregivers (UrApp®) to support home urine protein

testing and tracking, communication with providers, and provide patient education, reminders, and alerts for disease relapses. Users during beta-testing all perceived the app to be helpful and indicated they would use the app for disease management [16]. Our experiences suggested that eHealth tools may be effective in supporting patients with GN.

Compared to children, adult patients with GN are more likely to experience a slower response to treatment or refractory disease with higher risk of progression to kidney failure [17, 18]. Edema is also more common, a symptom that is strongly linked to poor health-related quality of life and may require prescription of diuretics or inpatient treatment [9]. Thus, management needs differ between adult and pediatric patients. Furthermore, adult patients with GN present across a wide age spectrum [19], which may affect preference and familiarity with eHealth tools [20–22]. Finally, adults with GN have specific management needs when compared to adults with CKD in general, which is most often due to diabetes or hypertension. In response to this, we expanded the UrApp® app functionality to the UrApp System suite of eHealth solutions to specifically support the unique needs of adult patients with GN. Our goal is to ensure the resulting tool is evidence-based, practical, user-friendly and impactful. In this paper, we describe our design process and the features of the UrApp System.

Methods

Overview of Study Design

The functional requirements for the UrApp System, a user-centered, patient-facing eHealth tool to support GN management, were identified and refined through a two-phased approach; needs assessment and stakeholder engagement (Fig. 1). The needs assessment took place between November 2022 and January 2023, followed by stakeholder engagement through May 2023.

Investigative Team

The UrApp System investigative team includes nephrologists with research focus on GN and experience building eHealth tools for GN management and decision support (A.L.O., L.H.M., and C.W.), human factors engineers and usability experts (A.P., R.M., A.M., and M.D.), a behavioral and implementation science expert with experience building eHealth tools for chronic disease management (C.E.), and adult nephrologists with clinical focus on GN (A.L.O., L.H.M., J.C., and A.A.O.).

Phase 1: Patient and Nephrologist Surveys Survey Instrument

The investigative team created two surveys, 1 for adult patients with GN and one for nephrologists, to assess patient and provider perspectives on GN management needs, potential barriers, and facilitators of using eHealth tools. Survey items were created to

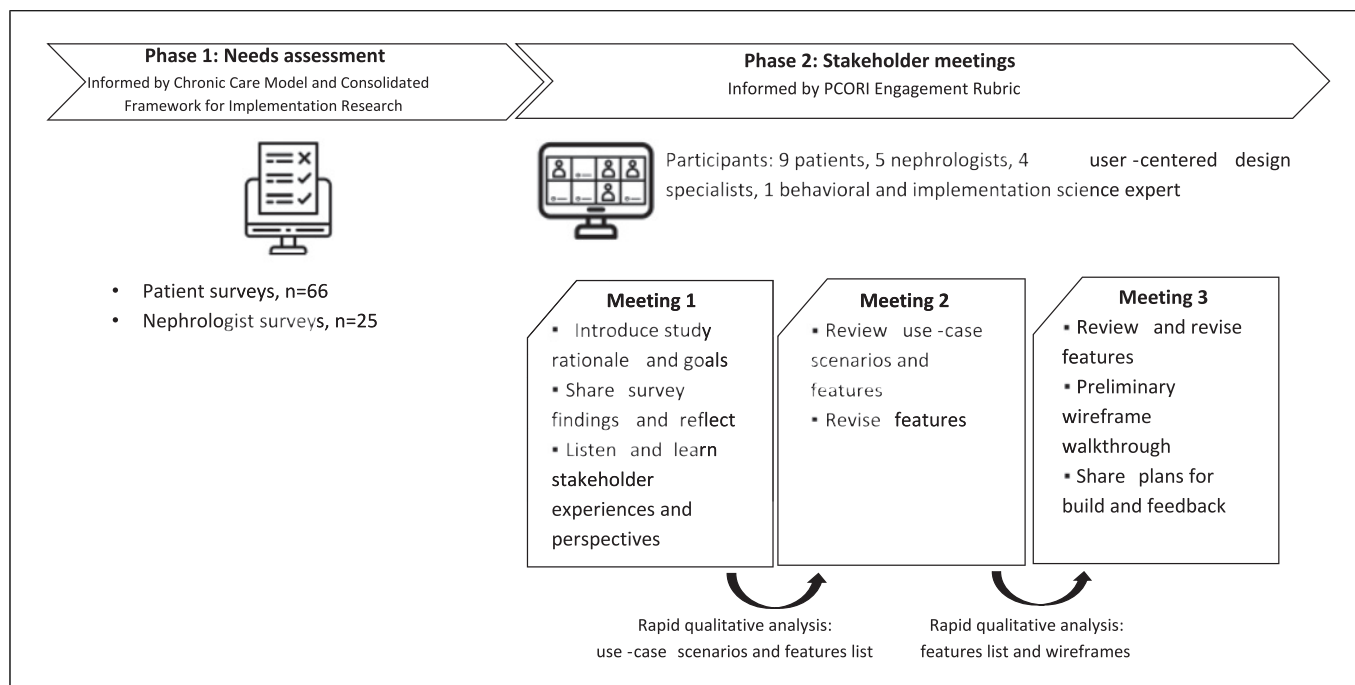


Fig. 1. Expert- and guidelines-informed, stakeholder-engaged participatory design of the UrApp System to support patients with GN self-management.

systematically address key domains of effective chronic disease management as identified by the Chronic Care Model: self-management support, delivery system design, decision support, and clinical information systems [23]. Multiple choice responses regarding disease management tasks and educational needs were derived from the KDIGO 2021 Clinical Practice Guideline for the Management of Glomerular Diseases to cover expert, consensus-based recommendations for effective GN care [24]. The surveys also systematically assessed potential implementation influences affecting the success of real-world adoption of eHealth tools by creating items to address informed by the Consolidated Framework for Implementation Research (CFIR) framework [25]. Specifically, we assessed access to internet and electronic devices (i.e., computer, cell phones, smartphones), familiarity and preferences for various devices, use and preference for eHealth tools, and other barriers and facilitators of eHealth adoption. For providers, we also surveyed time and personnel resource availability for GN management.

The survey design was led by A.L.O. and C.W., then the rest of the team reviewed and revised based on comments and feedback for face validity. The theory-informed, expert guidelines-based surveys are included in online supplementary Files 1 and 2 (for all online suppl. material, see <https://doi.org/10.1159/000539169>).

Survey Participants and Procedures

This multisite collaboration included two participant groups; adult patients diagnosed with GN and nephrologists specializing in GN. Patient participants were recruited from the University of Michigan (UMich) Glomerular Disease and General Nephrology Clinics in Ann Arbor, Michigan and the Emory Nephrology

Clinic in Atlanta Georgia. These two sites allowed for an enriched patient population for race and ethnicity and rural-urbanicity. Adult patients ≥ 18 years with primary GN (biopsy diagnoses of minimal change disease, focal segmental glomerulosclerosis, membranous nephropathy, or IgA nephropathy/vasculitis) not secondary to another systemic condition such as lupus erythematosus were eligible. Participants were required to be able to understand the survey in English. Sample size target was 60 patient participants, with at least 20 participants in each of three age groups (18–35, 36–64, and ≥ 65 years) and at least 20 participants each with disease duration < 12 months and ≥ 12 months. Potential participants were identified and recruited in person at the clinics and via telephone. Participants provided either written or electronic consent and conducted the survey on paper or their personal devices. Twenty-dollar gift cards were provided upon survey completion.

Nephrologist participants were recruited from the National Institutes of Health funded Cure Glomerulonephropathy (CureGN) study network of 71 centers (65 US sites, 4 Canadian sites, 2 European sites). Recruitment e-mails were sent by CureGN research consortium administrators and contained a link to an anonymous electronic survey. These nephrologists were purposively recruited based on their expertise in GN management.

Survey Analysis

Descriptive statistics summarize patient participant demographics, clinical characteristics, and available electronic tools, as well as clinical practice characteristics among the nephrologist participants. Survey responses were displayed graphically by

percentages of respondents who selected a particular response, comparing patients versus nephrologists. Once completed, the investigative team met to interpret survey results to design preliminary app features that would address the needs identified.

Phase 2: Stakeholder Meetings

Meeting Participants

Patient survey participants from Emory who indicated willingness to participate in stakeholder meetings during initial consent were invited to the meetings, targeting ten participants with at least two participants from the three age strata (18–35, 36–64, and ≥65 years) and at least three with disease duration <12 months and three with disease duration ≥12 months. Invitations were extended via telephone. Fifty-dollar gift cards were provided to patients after attending each stakeholder meeting. The investigative team also participated in the meetings.

Meeting Format and Analysis

To minimize risk to participants during the COVID-19 pandemic, participants met in three 1.5 h video conferences between February 2023 and May 2023 (Fig. 1). Each stakeholder meeting was recorded and two participants took field notes (AM and CW) to describe discussion details and perceptions of the strength of the statements – i.e., level of agreement among participants and intensity of convictions (based on verbal and nonverbal cues). Meeting format followed a user-centered approach that stressed reciprocal relationships, partnership, co-learning, and transparency-honesty-trust between researchers and stakeholders according to the Patient-Centered Outcomes Research Institute (PCORI) Engagement Rubric [26]. Following each meeting, the recordings and field notes were reviewed by the investigative team to map contents of the meetings to deductive constructs based on the Chronic Care Model and CFIR frameworks to systematically capture management needs and potential influences on adoption and use of the final eHealth tool. We chose this rapid qualitative analysis method which eliminates transcription and manual coding as compared to traditional qualitative analysis approaches in order to allow timely creation of use-case scenarios, features list, and wireframes for stakeholder review and feedback during subsequent stakeholder meetings [27]. The rapid qualitative analysis approach shortens the analysis time between stakeholder meetings in order to effectively use the stakeholder meeting data and minimize risk of participants forgetting what was discussed in prior meetings.

Meeting one focused on introducing participants to the overall study goals and sharing survey findings to gather unique patient and provider perspectives on the interpretation of the data. The investigative team consolidated the feedback and challenges identified to create narratives of salient disease management needs for various users (i.e., use-case scenarios). The investigative team drew from survey data and the use-case scenarios to develop preliminary eHealth tool features and adoption requirements.

Meeting two involved reviewing the use-case scenarios with proposed features to assess alignment with user needs and adoption requirements. The investigative team revised and expanded the requirements and functionality list based on the feedback and stakeholder discussions. These functional requirements were used to create low-fidelity wireframes (i.e., a graphic representation of functionality, flow, and logic) of the UrApp System.

Meeting three involved reviewing the revised functionality and conducting cognitive walk-through of the wireframes to assess alignment to needs, quality, and potential use issues. Following the stakeholder meetings, finalized UrApp System wireframes were created.

Results

Phase 1: Patient and Nephrologist Surveys

Survey Respondents

Sixty-six patients and 25 nephrologists responded to the phase 1 surveys (Fig. 2). A total of 17 patient surveys were received for the 18–35 age group (85% of target enrollment), 16 surveys were received for the ≥65 age groups (80% of target enrollment), and 13 responses for those with disease duration <12 months (43% of target enrollment). Survey patient participants' demographics, disease characteristics, and access to technology are found in Table 1. The majority of nephrologists surveyed were in nephrology practice for 5 years or longer (23/25; 92%) and 10/25 (40%) spend >60% of their time on clinical practice.

Patient and Provider Perspectives on GN Management

Figure 3 displays survey results comparing patient versus provider responses. Among patient respondents, 86% “agreed” or “strongly agreed” with the statement: “I am confident that I can do everything to manage my kidney condition,” and 36% “agreed” or “strongly agreed” with the need for new tools to help management their kidney condition. In contrast, only 52% of providers “agreed” or “strongly agreed” with having enough time to monitor GN patients and 48% “agreed” or “strongly agreed” with the need for new tools to help with GN patient management. In general, activities recommended by most nephrologists are not always performed by all GN patients (Fig. 3a). Fewer patients report the need to have certain information regarding GN versus what nephrologist recommend (Fig. 3b). Overall, patients selected fewer reminders and fewer tracking features desired in an eventual eHealth tool for GN management support (Fig. 3c).

Patient and Provider Perspectives on eHealth

Patients and nephrologists also differed in their experiences with eHealth. Only 20% of nephrologists “agreed” with the statement, “I am knowledgeable about eHealth resources that may be helpful for patients with glomerular diseases,” versus 45% of patients who “agreed” or “strongly agreed” with the statement. Just 52% of providers currently recommend eHealth tools to

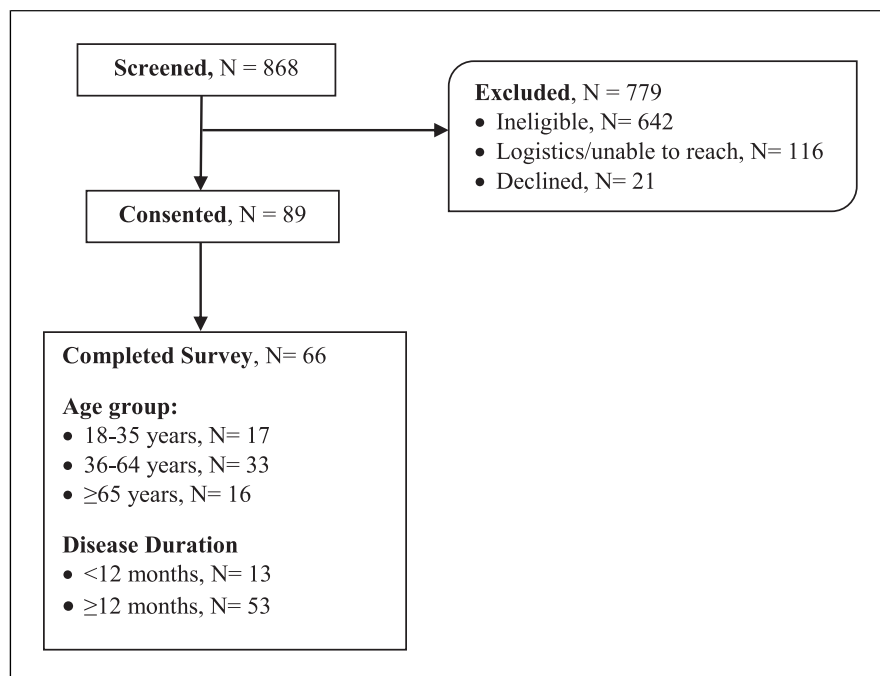


Fig. 2. Flowchart of patient participants in needs assessment survey.

their patients “frequently” (4%) or “sometimes” (48%), versus 56% of patients “frequently” (32%) or “sometimes” (24%) use eHealth tools for GN management. The most commonly used eHealth tools for patients include websites (39%), smartwatches (27%), mobile apps (21%), and social media (15%). Both patients and nephrologists have a favorable view of eHealth for GN management. 76% of nephrologists and 69% of patients “agreed” or “strongly agreed” that eHealth tools may be effective in GN management. 68% of nephrologists and 72% of patients “agreed” or “strongly agreed” that they are likely to use eHealth tools developed to support GN management.

Expressed concerns over the use and adoption of eHealth tools differed between the two groups (Fig. 4). Leading concerns for nephrologists include lack of technologic support patients (68%), lack of time (56%), concerns over the accuracy and quality of information contained in eHealth tools (56%), and concerns over compatibility with workflow (48%). For patients, fewer reported concerns over eHealth tools, and leading concerns were relevance of the tool to GN management (61%) and accuracy and quality of information (48%).

Phase 2: Stakeholder Meetings

Stakeholders

Nine patient participants attended the stakeholder meetings. By age breakdown, two were 18–25 years old, five were 36–64 years-old, and two were 65 years or older.

Three had focal segmental glomerulosclerosis, three membranous nephropathies, and three IgA nephropathies. One of the participants had disease duration <12 months, while the eight others had disease duration 12 months or longer.

Rapid Qualitative Analysis

Several key insights were derived from analysis of the stakeholder meetings (Table 2) and informed the functional requirements, use-case scenarios, and wireframes of the UrApp System. First and foremost, patients are aware of the uniqueness of their disease, and therefore require customizable and flexible design architecture for an eHealth tool to be useful. Next, patients frequently alter disease management with their doctors, so informing themselves with trustworthy educational resources regularly is crucial. Lastly, patients are tasked to track many components when it comes to their disease management, including diet, laboratory results, and appointments. To balance these many factors and reduce management burden, patients desire an eHealth tool that seamlessly communicates with their healthcare provider and patient portal while tracking management strategies at home. Nephrologist stakeholders noted that seamless tracking of important measures such as proteinuria should carefully include units, as urine protein-to-creatinine and albumin-to-creatinine ratios may be reported differently across laboratories. Both patients and nephrologists envisioned

Table 1. Characteristics of patient participants in needs assessment survey

Characteristic (total N = 66)	
Age, mean (SD)	50.7 (16.8)
Female sex, N (%)	31 (47)
Race, N (%)	
Asian	2 (3)
Black or African American	13 (20)
White	51 (77)
Other/unknown	0 (0)
Hispanic ethnicity, N (%)	1 (2)
Education attainment, N (%)	
Grade school	0 (0)
High school/diploma equivalent	12 (18)
2-year associate's degree or certificate	9 (14)
4-year college degree	29 (44)
Graduate level diploma	16 (24)
Prefer not to say	0 (0)
GN type, N (%)	
Minimal change disease	8 (12)
FSGS	18 (27)
IgA nephropathy	16 (24)
Membranous nephropathy	24 (36)
CKD stage, N (%)	
1 (eGFR \geq 90 mL/min/1.73 m ²)	14 (21)
2 (eGFR 60–89 mL/min/1.73 m ²)	27 (41)
3 (eGFR 30–59 mL/min/1.73 m ²)	18 (27)
4 (eGFR 15–29 mL/min/1.73 m ²)	7 (11)
5 (eGFR <15 mL/min/1.73 m ²)	0 (0)
Disease duration, N (%)	
<6 months	5 (8)
6–12 months	7 (11)
1–2 years	4 (6)
>2 years	50 (76)
Number of medications, mean (SD)	7.9 (5.3)
Currently on immunosuppression, N (%)	23 (35)
Comorbidities, N (%)	
Hypertension	38 (58)
Diabetes	11 (17)
Cardiovascular disease	11 (17)
Reliable internet at home, N (%)	65 (98)
Available eHealth tools, N (%)	
Desktop computer	27 (41)
Laptop computer	52 (79)
Tablet	36 (55)
Phone with call and text functions only	13 (20)
Smartphones	64 (97)
Smartwatches	27 (41)

FSGS, focal segmental glomerulosclerosis; CKD, chronic kidney disease; EGFR, estimated glomerular filtration rate.

the tool as predominantly patient-facing, with some ability to send messages or alerts to the eHealth record that the nephrologist would receive. Overall, patients and nephrologists agree that having a trustworthy tool would be useful for GN management.

UrApp Systems Features

Using the meeting findings, the UrApp Systems features were generated to address user needs and preferences, with focus on key themes of personalized, informative, seamless, and trustworthy. The UrApp System includes five core features: Profile, Data Tracking, Resources, Calendar, and Journal (Fig. 5). The “Profile” feature allows users to enter and update their clinical information whenever appropriate, such as GN histologic subtype and CKD stage. The information will be used to generate recommendations for data tracking, features educational information, and questions to ask during clinic visits. Additional user preferences on clinic contacts, link to other apps or patient portals, as well as reminders can be customized under the “Profile” feature.

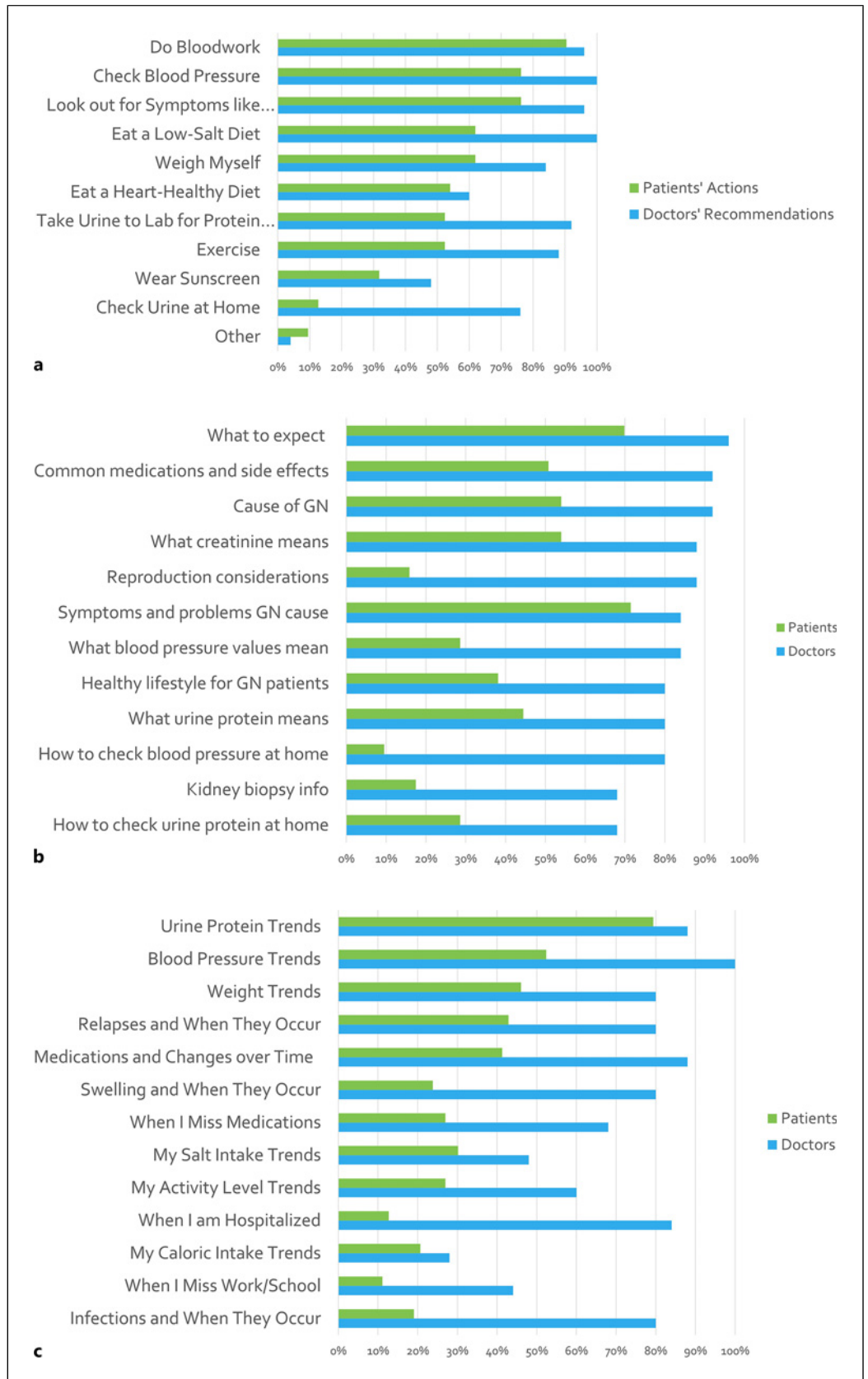
The “Data Tracking” feature displays health data such as urine protein to creatinine ratio, serum creatinine, and blood pressures visually. It contains a GN nephrologist-curated list of variables which users can customize. The graphs can be overlaid to help patients and nephrologists understand the relationship between selected variables, such as medication changes and urine protein trends. Users can customize importing data from other apps or electronic medical records and to set alerts for out-of-range values.

The “Resource” feature will generate “snippets” of information as relevant to the patient’s clinical information entered under “Profile.” The short snippets allow user to browse educational topics quickly, minimizing time spent. All curated information is searchable and will be clearly labeled with sources. Different media types such as articles, videos, links to other web apps will be available to meet user preferences. Information can be bookmarked and saved under “Journal”.

The “Calendar” feature will display user entered appointments and key events. Based on user preference, it can be integrated with other calendar apps or patient portals to seamlessly integrate information and minimize user burden. Reminders can also be selected from events listed under “Calendar.”

The “Journal” feature is designed to support patient-provider communication, patient participation in decision making and self-management. Users can save and create written or audio notes, audio-recordings, photos,

Fig. 3. Surveys responses on GN self-management needs comparing patient versus provider response. Bars indicate the proportion of respondents who selected each response. **a** Self management tasks recommended by nephrologists versus tasks performed by patients. **b** Information believed to be important to have for effective GN management. **c** Tracking information believed to be important to have.



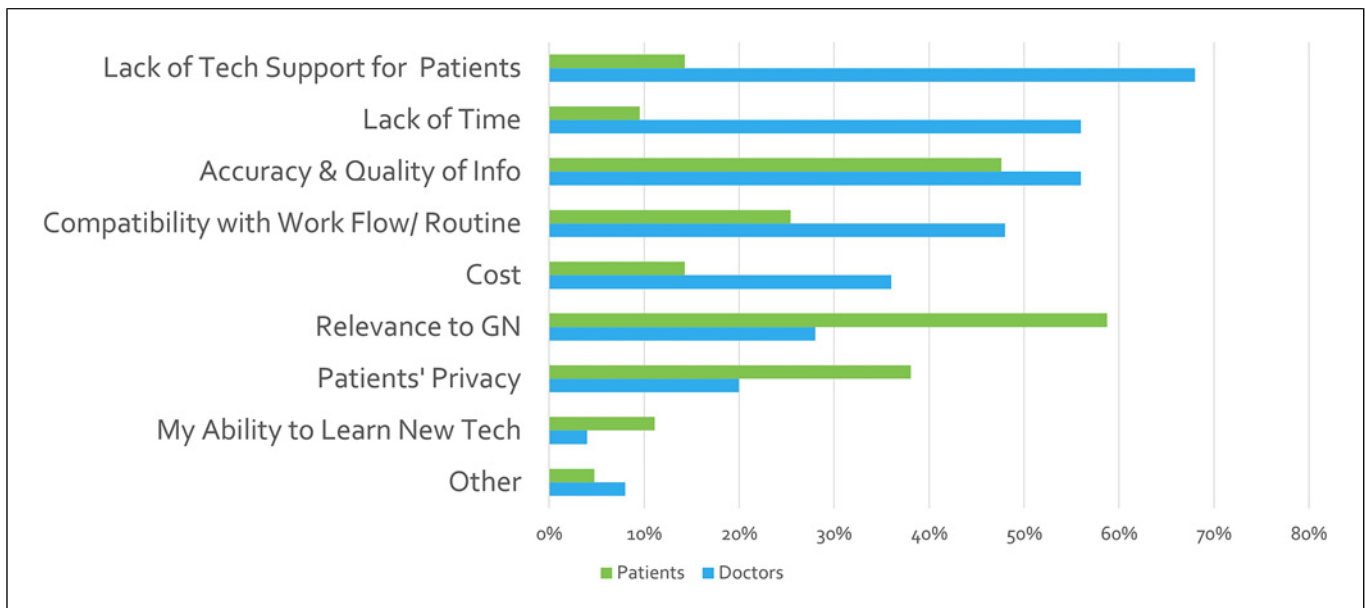


Fig. 4. Concerns with the use of eHealth tools for GN management (blue, proportion of nephrologists that endorse a specific concern; green, proportion of patients).

documents, and web links. For an upcoming clinic appointment, it can offer suggested questions for doctors based on “Data Tracking” and “Profile” information. For example, the tool may recommend the patient ask about blood pressure medications if their blood pressure readings have been out of range. Patients may record the discussions with providers during clinic to help them remember the discussion. Users can also access bookmarked “Resource” information.

Additional design consideration of the UrApp System include readability on a mobile device as mobile devices are much more commonly owned (smartphone or tablet), secondarily for a desktop computer or laptop. Text sizes are customizable. Color schemes are chosen to function for those with color vision deficiency. The tool needs to be built with interoperability considerations to integrate with other apps or patient portals. By the third meeting, all stakeholders approved the wireframes and features and decided jointly that another meeting was not needed.

Discussion

We describe our process to design a theory-driven, evidence-based, practical eHealth tool for self-management of GN that meets both patient and nephrologist needs and expectations. Both survey and

stakeholder meeting participants indicated openness to incorporating a new tool for self-management. The results of this iterative user-centered design approach included wireframes for an eHealth tool that would meet the needs of the stakeholders, namely that it is customizable, informative, and able to seamlessly integrate with other systems. This tool was perceived to be a reliable addition to the current paradigm of GN self-management.

A novel eHealth tool for adults with GN is necessary because they have a high risk of morbidity, both related to their underlying disease and the medications often required to control disease activity. This results in unique self-management needs for optimal care, recently detailed by KDIGO [24]. Both our survey and stakeholder findings confirmed that nephrologists have more extensive expectations of patient self-management tasks than patients are completing regularly. The majority of survey participants indicated they were confident they could do all the tasks needed to manage their GN. However, when this was explored qualitatively with the stakeholder patient participants, some were surprised and dismayed to find that they were not aware of key management tasks recommended by nephrologists and GN guidelines. It is possible this is due to responder bias, wherein patients who were less confident or knowledgeable were more likely to participate in this research study. However, an alternative explanation is

Table 2. Stakeholder meetings findings for the creation of the UrApp system features and wireframes mapped to Chronic Care Model and the Consolidated Framework for Implementation Research constructs

Model domains	Deductive constructs	Meeting findings
Chronic Care Model		
Self-management support	<ul style="list-style-type: none"> Educational needs Lifestyle/behavior modifications Goals of care 	<ul style="list-style-type: none"> Patients searched for information frequently online particularly early on in the diagnosis and when there is disease worsening Information is confusing, frightening, and not always applicable Doctors did not help patients with information finding, sometimes dissuaded patients from searching online There is a strong desire to have trustworthy information, on topics that are relevant to each individual patient Patients differ in the amount of information needed, the topics, and sometimes do not know what information is needed Patients were not aware of all the recommended care activities and expressed frustration Patients often do not understand certain laboratory values, medical jargon, or acronyms Patients expressed feeling isolated. <i>"This is the first time I've talked to others who have the same disease"</i>
Delivery system design	<ul style="list-style-type: none"> Clinic, provider interactions Communications in-between clinic encounters 	<ul style="list-style-type: none"> Patients expressed the importance of finding a nephrologist that is trustworthy, knowledgeable, and communicative, and builds longitudinal relationships Some patients reported a preference for eHealth portals as a way to communicate with their doctors, while others prefer calling Doctors are receptive to emails and calls from patients, but are concerned about who will monitor patient messages when they are away and not available Patients want a better way to remember what to ask providers and to recall information discussed during their visit
Decision support	<ul style="list-style-type: none"> Advice and information sources Clinic, provider interactions 	<ul style="list-style-type: none"> Patients express concern with the amount of misinformation on the internet Sources of reliable information differ, including friends, social media sources, and websites Patients desired guidance that is tailored to their needs and relevant to them
Clinical information system	<ul style="list-style-type: none"> Reminder frequency and method Data tracking Data sharing 	<ul style="list-style-type: none"> Patients differed in desire for reminders, and generally preferred fewer reminders Patients preferred centralized and customizable notifications (for clinic visits, for labs, for medications) Patients want to track laboratory values and disease trends to inform their care, which requires customizability and a flexible design architecture Providers are concerned about data interoperability and interpretation (e.g., urine protein is expressed in different units) Patients want seamless bi-directional data exchange with their clinician
Consolidated Framework for Implementation Research		
Intervention characteristics	<ul style="list-style-type: none"> Modality preference Tool source Relative advantage Adaptability Complexity Design and presentation 	<ul style="list-style-type: none"> Most patients preferred a mobile device: smartphone or tablet, to bring around with them, particularly to the doctor's office Some patients express when at home, it would still be helpful to use a laptop for longer battery life and larger screens Patients expressed the importance that the tool is created by reliable sources with verified information Patients expressed the need for a centralized tool, which they do not feel is available currently

Table 2 (continued)

Model domains	Deductive constructs	Meeting findings
		<ul style="list-style-type: none"> • Patients expressed the need for the tool to be customizable to their specific needs • Some users currently use the eHealth portal and would like different mobile health apps to be integrated with the eHealth portal, others prefer keeping them separate to make things less complex • Some patients would like the option to copy and import information or tips obtained from other sites or sources • Patients and doctors desire options for free text to enter and keep track of events that are important to each individual patient
Inner setting	<ul style="list-style-type: none"> • Available resources for eHealth • Constraints for eHealth adoption 	<ul style="list-style-type: none"> • Patients feel comfortable using eHealth technology • Patients expressed desire to have both Android and iOS options

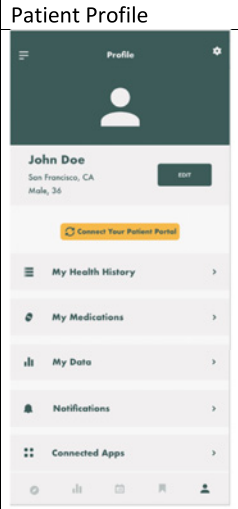

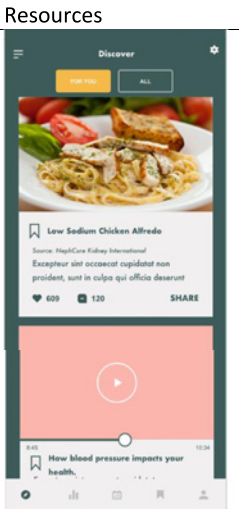
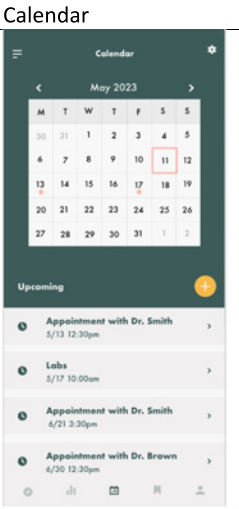
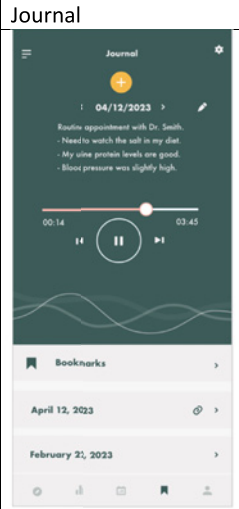
Patient Profile	Data Tracking	Resources	Calendar	Journal
				
<ul style="list-style-type: none"> • Clinical information entered here are used to personalize experience including evidence-based educational content • Users can input clinic contacts for seamless connection to providers • Users can opt for linking to other apps or portals and reminders 	<ul style="list-style-type: none"> • Recommended data for monitoring based on <i>Profile</i> • Additional search for curated list of variables for visual display • Clearly labelled data units • Ability to overlay tracked variables • Ability to import and export data • Customized alerts for out-of-range values 	<ul style="list-style-type: none"> • Featured information snippets prioritized by <i>Profile</i> • Searchable library of curated information from reliable sources • Various media types including articles, recipes, videos, links to other patient networks • Can bookmark and save resources in <i>Journal</i> 	<ul style="list-style-type: none"> • Display appointments, labs, key events • Can integrate with other calendar apps or portals • Reminders can be selected from events under this feature 	<ul style="list-style-type: none"> • Save and create notes, audio-recordings, photos, documents, and web links • Help patients participate in care with suggested questions for doctors at clinical appointments based on <i>Data Tracking</i> and <i>Profile</i> • Access to bookmarked references

Fig. 5. UrApp System core features.

that higher self-confidence among survey respondents could be due to the “unknown unknowns” in GN self-management. Indeed, only half of nephrologists sur-

veyed indicated that they had sufficient time for GN monitoring and stakeholders elaborated that time for education is limited.

Most of the surveyed patients are already using eHealth tools, about a third of the patients reported using eHealth tools frequently, while only 4% of the nephrologists “frequently” recommend them to patients. Our stakeholders expanded on this, describing how they use different tools for different tasks related to their GN management. For example, GN-specific information could be found through reputable websites, whereas general apps may help them plan meals or exercise, and patient portals monitored their clinical data. However, patient stakeholders report little guidance from nephrologists and uncertainty about the reliability of the internet sources. The utility and frequency with which they use different tools changed with disease duration and activity, with more resources sought early in the disease course or with complications, relapses, or new diagnoses. Customization of these needs within one single tool was a key theme elicited from the stakeholder meetings. A prior study of adults with CKD and a multidisciplinary interprofessional team of CKD care providers similarly found that customizable components of education and monitoring are important in mobile app development [28]. Our tool design focuses on customizable components of education and monitoring specific to GN to address this salient finding and optimize effectiveness and adoption of the tool. All information sources will be clearly labeled to ensure transparency and trustworthiness of the information.

A strength of our study was eliciting the needs of both patients and nephrologists to reach a planned tool that both groups agreed would be high quality and useful for supporting patients. Most prior eHealth tools for CKD management were not designed by patients with CKD or their nephrologists, and thus few were rated highly by either group [29]. Our study is limited by the use of a small and convenience sample of patients and nephrologists. Because surveys and stakeholder meetings were conducted in English, Hispanic patients were also under-represented in our study. We did purposively recruit patients to meet disease duration and age strata due to a priori hypotheses that their needs may differ across these variables; however, those diagnosed with GN within the prior year were underrepresented, as were participants 18–35 and ≥ 65 years. While all stratified recruitment targets were not met, the surveys included in this analysis do represent diverse levels of educational attainment as well as GN disease type and kidney function. Additionally, given that the functional characteristics and wireframes of the UrApp

System were perceived to be useful by patients with more experience managing GN, those with less experience may find them even more beneficial.

In this study, we purposefully surveyed CureGN nephrologists to obtain expert opinions on GN management needs to inform the build of a quality tool for disease management. However, this group of providers mostly works in large academic settings and has research and practice focus on GN. Their views may not represent the majority of practicing nephrologists. It is conceivable that community-based nephrologists would have even less time or resources to make evidence-based management recommendations and effectively monitor GN patients. Thus, an expert-guided, evidence-based eHealth tool that automatically generates personalized educational information and data tracking may have increased utility for community-based nephrologists and cut down on the time and resource demands of nephrology practices. On the other hand, facilitating communication between patients and providers, such as enabling patient-generated questions and alerts to providers, may add to physician workload and need to be weighed with other time-saving features and potential benefits. Additional formative research with patients of different ethnicities and socioeconomic backgrounds and nephrologists outside of the CureGN network could be conducted to inform refinements to the UrApp System.

In conclusion, patients with GN have complex self-management needs with no previously identified single tool for supporting this care at home to optimize outcomes. Through a user-centered design approach, we were able to develop wireframes for a future eHealth tool for adult patients with GN that meets their specific needs. Further study is needed to determine the impact of the tool on patient-reported and clinical outcomes.

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Statement of Ethics

The study was approved by the University of Michigan (HUM00211071) and the Emory University Institution Review Boards (STUDY00003728). Written or electronic informed consent was obtained from all survey and stakeholder participants.

Conflict of Interest Statement

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Concept and design: A.L.O. and C.W. Acquisition, analysis, or interpretation of data: A.L.O., A.P., R.M., A.M., M.D., L.H.M., J.C., A.A.O., G.A., M.A., Y.P., J.P.T., C.E., and C.W. Statistical analysis: A.L.O., J.P.T., and C.W. Supervision: C.E. and C.W. Each author contributed important intellectual content during manuscript drafting or revision and agrees to be personally accountable for the individual's own contributions and to ensure that questions pertaining to the accuracy or integrity of any portion of the work, even one in which the author was not directly involved, are appropriately investigated and resolved, including with documentation in the literature if appropriate.

Data Availability Statement

The data that support the findings of this study are not publicly available due to risk of participant identification and risk of compromising the privacy of research participants. Further inquiries can be directed to the corresponding author and are available upon reasonable request.

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