Co-designing for the Triad: Design Considerations for Collaborative Decision-Making Technologies in Pediatric Chronic Care

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Abstract

In pediatric chronic care, the triadic relationship among patients, caregivers, and healthcare providers introduces unique challenges for youth in managing their conditions. Diverging values, roles, and asymmetrical situational awareness across decision-maker groups often hinder collaboration and affect health outcomes, highlighting the need to support collaborative decision-making. We conducted co-design workshops with 6 youth with chronic kidney disease, 6 caregivers, and 7 healthcare providers to explore how digital technologies can be designed to support collaborative decision-making. Findings identify barriers across all levels of situational awareness, ranging from individual cognitive and emotional constraints, misaligned mental models, to relational conflicts regarding care goals. We propose design implications that support continuous decision-making practice, align mental models, balance caregiver support and youth autonomy development, and surface potential care challenges. This work advances the design of collaborative decision-making technologies that promote shared understanding and empower families in pediatric chronic care.

CCS Concepts

• **Human-centered computing → User studies**; **HCI design and evaluation methods**.

Keywords

Collaborative decision-making, Situational awareness, Participatory design, Pediatric chronic care

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1 Introduction

Collaborative decision-making is essential in pediatric chronic care, where it is beneficial for youth patients, family caregivers, and healthcare providers (HCP) to work together to make informed treatment choices [30, 43]. However, achieving this collaboration

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is difficult because decision-makers often hold divergent goals, priorities, and needs, which can create tensions and misalignment [1, 2, 30]. With 40% of U.S. school-aged youth living with at least one chronic condition [5], addressing ineffective collaborative decision-making is a pressing challenge that directly impacts short- and long-term health consequences [45]. Researchers in human-computer interaction (HCI) have increasingly recognized the importance of designing patient-centered decision-support systems that reflect the complex realities of living with chronic illness [9, 10, 23, 24, 34]. However, existing technologies are not suitable to support collaborative decision-making in pediatric chronic care because most focus on dyadic relationships (e.g., adult patient–provider) [15, 21], overlooking the need to synchronize priorities, establish shared understanding, and align treatment goals across multiple groups.

We explore these challenges through the lens of youth diagnosed with chronic kidney disease (CKD), a life-threatening condition characterized by medical complexity and intensive treatment requirements [32]. We draw on Endsley's team situational awareness framework [13] to understand how decision-makers coordinate effectively when they maintain a shared understanding of goals, roles, and context. Situational awareness is defined as a three level framework: *"the perception of elements in the environment within a volume of time and space (Level 1), the comprehension of their meaning (Level 2), and the projection of their status in the near future (Level 3)"* [12]. In health contexts, breakdowns in situational awareness can result in miscommunication, undermine collective decision-making, and ultimately lead to poorer patient outcomes and experiences [27, 36]. Using the case of youth with CKD, we aim to demonstrate how situational awareness informs the understanding of triadic care relationships and expand the conceptual tools available for designing collaborative decision-making technologies. We explore the following research questions:

(1) RQ 1: What barriers do patients, caregivers, and HCPs identify across situational awareness levels that impact collaborative decision-making in pediatric CKD care?
(2) RQ 2: How can technologies be designed to support situational awareness needs among patients, caregivers, and HCPs to enable effective collaborative decision-making?

To address these questions, we conducted workshops with youth with CKD, caregivers, and pediatric HCPs to co-design speculative collaborative decision-making technologies. Together, we generated design concepts and iteratively refined features. This study contributes to HCI by (1) identifying barriers to collaborative decision-making in pediatric chronic care, and (2) proposing design guidelines for collaborative decision-making technologies that enhance unmet situational awareness needs across decision-makers.

2 Related Work

2.1 Collaborative Decision-making in Pediatric Care

We define ***collaborative decision-making*** in pediatric care as *"the engagement of youth in healthcare decision-making processes while adapting to their evolving cognitive and emotional capacities"* [30]. Collaborative decision-making emphasizes inclusive and equal participation, involving youth patients in age-appropriate ways and respecting their experiences and perspectives [25]. Despite increased recognition of youth patients' roles, current interventions aimed at supporting collaborative decision-making have yielded inconsistent outcomes [2, 50]. Existing tools and programs often overemphasize parental perspectives [2] and provide limited insights into patient-caregiver-clinician dynamics [1, 50].

2.2 Decision-support Tools in Pediatric Care

In HCI, CSCW, and health informatics, there is growing recognition of the need to support patients and caregivers in making value-driven decisions throughout ongoing care [6, 18, 20, 35, 41, 52]. However, when viewed through the lens of team situational awareness, existing decision-support tools appear fragmented, addressing only isolated requirements—such as access to information [37], improved comprehension through communication [19, 41], or goal-setting [51]. Furthermore, many tools are designed for adult patients [11, 21, 38], or in-clinic use [3, 16, 17, 48, 49, 51]. These solutions overlook youth who are developing decision-making capacity beyond clinical visits [10]. Together, these gaps highlight the need for decision-making technologies that better support pediatric chronic care by fostering shared situational awareness among all stakeholders.

3 Methods

3.1 Participants.

We conducted a total of seven 2-hour co-design workshops via Zoom, each including a single decision-maker group, with the goal of having 2 to 4 participants per session and reducing power imbalances. This study received ethical approval from the University of Washington Institutional Review Board and Seattle Children's Hospital Ethics Committee. All participants were recruited through convenience sampling from a single large children's hospital in the United States either in person during clinic visits, or from the patient portal. Eligibility criteria included youth aged 12–25 years with pre-dialysis CKD stages 3–5, and their caregivers. HCPs were eligible if they have experience working in pediatric nephrology. Nineteen participants were recruited, including 6 youth (mean age 15.3 years, range: 13–17), 6 caregivers, and 7 HCPs (including physicians, a nurse, a physician assistant, a dietitian, and a social worker). Demographic characteristics of participants are summarized in Appendix 1.

3.2 Co-design Workshop Procedure.

Workshops began by introducing the concept of collaborative decision-making and the potential role of technology in improving decision-making processes. Participants reflected on past experiences navigating medical decisions, responding to prompts tailored to their roles. Participants then completed two design activities (described below), followed by a group discussion on how their feature suggestions align with values.

3.2.1 Vignette-based Role-Play for Values Elicitation. Participants were introduced to a visual storyboard (Appendix 2) portraying fictional characters navigating three phases of CKD treatment plans after a CKD diagnosis: an initial clinic visit, experiences outside of clinic, and a follow-up clinic visit. The goal of the storyboard was to prompt discussion around values, misaligned goals, and communication gaps by capturing the context- and time-dependent nature of patient values in relation to concrete events, similar to other uses of patient journey mapping [4] and scenario-based values elicitation [29]. The ecological validity of the vignette was vetted by two pediatric nephrologists and two patient advisory board members. Participants were asked to annotate the storyboard with pre-defined prompts, using digital sticky notes to identify key barriers of each character (patient, caregiver, HCP) for effective decision-making.

3.2.2 "Magical Tool" Ideation. Building on insights from the storyboard, participants were invited to design a "magical tool" that could alleviate pain points identified in the previous exercise and enhance collaborative decision-making. This speculative design exercise is inspired by Iacucci et al. [22], to encourage open-ended, creative ideation before translating concepts into concrete system features. Participants described their “magical tool" using text boxes or sketches on Google Slides. Reflective prompts were given, such as: *“How would this tool help you express your values or concerns?”*, and *“What kinds of information should the tool display?”*. Appendix 3 shows a magic tool example sketched by one of the participants.

3.3 Data Analysis.

Transcripts, storyboards, and magic tool prototypes were securely stored on a HIPAA-compliant shared drive. All data were anonymized using participant identifiers and decision-maker categories. A six-step mixed inductive–deductive thematic analysis [7] was used to examine textual and visual data collected during the study, including workshop transcripts and participant-generated artifacts. In the inductive phase, four researchers created affinity diagramming [28], organizing participant quotes excerpted from storyboards and the magic tool transcripts. Each researcher independently reviewed the quotes and then collaboratively grouped them under preliminary codes. In the deductive phase, two researchers mapped these themes onto the Situational Awareness framework [12] refining through multiple rounds of discussion with the larger research group.

4 Results

4.1 Perception: Gathering Information about Illness, Treatment, and Options

4.1.1 Barriers for Perception. HCPs described that some pediatric patients seemed detached and uninterested during visits, impacting discussions about their care. However, caregivers and patients clarified that this behavior often stems from ***emotional barriers***. Patient 5 drew on their own experience to suggest that the storyboard character's lack of engagement likely reflects the fear and anxiety of a new diagnosis: *“Assuming [the patient] just got diagnosed with [CKD], he's probably concerned with fear, anxiety and nervousness.”*. In addition, ***limited time*** and ***cognitive constraints*** were frequently identified as barriers to receiving relevant information during clinic visits. Both patients and caregivers emphasized the overwhelming nature of the first appointment, where large volumes of new information are presented in a short period of time. Many described struggling to retain new information while simultaneously trying to formulate questions under time pressure. As Caregiver 1 explained, *“it's really hard when in the doctor's office to remember all of the things [and] to share the concerns that we had. Because oftentimes the doctor is trying to give us information that we need or ask me specific questions [about] information that they need from us.”*

4.1.2 Envisioning Support for Perception. Some HCPs suggested tools to support in-clinic communication, such as artificial intelligence (AI) note-taking software that ***capture key information from clinical conversations***, freeing families to focus on communication rather than transcription. However, many patients and caregivers envisioned support beyond the clinic, such as immersive tools like Virtual Reality (VR) and gaming environments that allow them to practice conversations and rehearse clinical scenarios to ***prepare for clinical interactions***. Caregiver 2 suggested role-playing simulations: *“A role play or like a simulation [patients] could play, act, talk and work with the doctor, so they would be prepared.”*. In addition, patients and caregivers alike envisioned tools that ***support anxiety management and encourage self-expression***. For example, Caregiver 3 proposed an anonymous messaging feature: *“Patients could ask questions anonymously so they don't feel the pressure ... because sometimes [patients] think their questions are dumb.”*.

4.2 Comprehension: Integrating and Interpreting Information

4.2.1 Barriers for Comprehension. Patients and caregivers were expected to absorb extensive treatment, medication, exercise and dietary information within a single visit, resulting in an ***information overload*** that compromises their ability to process critical information. As Patient 2 shared,*“There is a lot of things to process, like all the new meds you might take, the new schedules and everything ... appointments can be very tiring and overwhelming”*. Compounding this challenge, patients and caregivers often struggled with ***limited mental models*** about CKD and its implications, which made it difficult to interpret lifestyle options and trade-offs. Here, we define *mental models* as the background knowledge and contextual understanding that shape how individuals interpret information and make sense of medical guidance, which can vary critically across individuals [14]. Dietary changes were a particularly frequent source of concern. While HCPs provide extensive recommendations, these guidelines often clash with families' existing mental models of how their children eat and live, creating barriers to adherence. As Caregiver 6 mentioned: *“Is there going to be like, taking away 90% of the stuff [the patient] likes to eat or none of the stuff they like to eat? ... [I'm] thinking of what to ask for types of food [the patient] needs to eat and types they needs to stay away from.”*.

4.2.2 Envisioning Support for Comprehension. Participants across groups envisioned tools that ***translate complex medical information into accessible, visually rich formats*** tailored to non-experts. HCP 2 reimagined patient education materials using visual media: *“Maybe turning some of the patient education materials into short videos, animated or in the style of social media or TikTok, where it's approachable for teenagers.”*. Furthermore, consensus across groups highlighted a need for tools that ***scaffold lifestyle change alternatives and provide personalized feedback*** to help families integrate treatment recommendations into daily life. Caregiver 2 proposed a *"Diet and Lifestyle Recommendation Options Navigator"*: *"You could put different foods up there and [users] could choose the good foods and recognize bad foods. And so the more good foods they chose, the more points they would get."*.

4.3 Projection: Linking Treatment Plans to Impact

4.3.1 Barriers for Projection. Patients and caregivers faced challenges in ***anticipating how treatment would affect routines and social lives***. Patient 5 reflected on how understanding the long-term implications earlier would have influenced their behavior: *"I would probably take the information more seriously ... [if I understood] listening and doing those activities that are recommended to me by my doctor would help me live longer and live a much more healthier life."*. For some families, caregiver presence during clinic visits became a barrier to open communication, which indirectly hindered the HCP's ability to comprehend patients' struggles and project actionable plans. These dynamics sometimes lead to ***patient–caregiver conflicts***, which surfaces as a notable barrier when patients' concerns and caregivers' priorities do not fully align. Some patients value having private conversations with the medical team to express their perspectives more freely, as Patient 4 expressed: *"I would probably ask for a more one-on-one experience, so that I don't feel like someone else is watching. I'm about to turn [into] an adult, I have all this stuff going on, and I don't know what this is about. ... as patients get older, they'll probably have more of a louder voice and care more about what they want."*. Only a few caregivers acknowledged this tension between providing parental support and respecting patient autonomy. Caregiver 5 acknowledged the importance of creating space for patients' voices, but noted that this transition often takes time: *"I need to probably sit back and not talk as much and let [my child] speak up for themselves, because I've always spoken for them. So all of a sudden, it's [hard to realize] they can actually speak for themselves [as a teenager]."*.

4.3.2 Envisioning Support for Projection. Participants across groups integrated ***goal-setting and projections of potential challenges*** features in their magic tools. HCP 6 suggested a game-like environment where users could explore and prepare for upcoming treatment challenges: *"A game that [users] could put their goals in to manage med management, salt counting, etc."*. In addition, collaborative decision-making technologies should be designed for patients, caregivers, and, in some cases, HCPs to support collaboration and reduce power imbalances in decision-making. Caregivers envisioned tools that ***facilitate shared ownership of care via collaborative features*** to make patient preferences visible and actionable. Caregiver 6 suggested a feedback loop for sharing preferences: *"Apps could have a star [review system], like 5 stars, 'It was good.' And then that information could go to the parent, so then [they] know this is [a recipe] I should cook again."*.

5 DISCUSSION

5.1 Design Considerations

Grounded in these insights, we propose a set of design principles for future collaborative decision-making technologies in healthcare settings.

Support decision-making practice outside-of-clinic. Patients and caregivers struggled to access and absorb relevant information during clinic visits because of limited time, cognitive overload, and emotional barriers. Practice-based tools could allow them to prepare prior to appointments by rehearsing "if-then" treatment-related decisions for scenarios they may not have previously considered. Many technologies are designed primarily for in-clinic use [3, 37, 48], offering limited support for the broader experience of navigating decisions across home, school, social contexts and clinic visits. Prior work on augmented reality, virtual agents, and gaming systems shows potential in supporting mental barriers [31], address health knowledge gaps [44], and develop self-management skills [8].

Aligning mental models through accessible visualizations. Patients and caregivers can enter clinical encounters with misaligned mental models of CKD, hindering their ability to interpret treatment recommendations, anticipate trade-offs, and integrate clinical guidance into daily life. These challenges align with prior findings on mismatched interpretations arising from differing mental models [13, 36]. Workshop participants across decision-maker groups suggested dashboards that visualize clinical metrics in accessible formats, tools that summarize and contextualize risks, and patient education materials redesigned as animations or social media–style content to better engage adolescents. These ideations align with prior systems that translate complex information into accessible formats, such as animated educational systems for youth [44] and approaches that convert academic papers into design cards [42].

Enabling shared ownership of care. Youth patients expressed a desire to gradually assume more responsibility for their care, but many struggled to exercise agency, leading caregivers to fill the gap. This dynamic is further complicated by the caregivers' own difficulty in relinquishing decision-making authority. Mismatched expectations about when and how caregivers should participate versus when patients should have greater voice often created friction in collaborative decision-making, reflecting prior work [1, 20]. At the same time, it is important to account for patients' developmental stages when designing technologies to support evolving patient–caregiver dynamics [46]. Insights from workshops suggest that multi–decision-maker interaction features can help align priorities and support role negotiation, echoing prior approaches such as interactive storyboards [19] and AI chatbots [41] that facilitate communication and shared understanding in pediatric care.

Supporting anticipation of potential challenges. Patients and families need support in anticipating how treatment decisions affect daily routines and social lives, where misaligned goals with HCPs often emerge. Participants across decision-maker groups envisioned technologies that emphasize goal-setting and context-aware feedback to foster shared understanding among patients, caregivers, and HCPs. Prior work supports this approach: goal-setting tools have been shown to improve alignment and collaborative planning for pediatrics [51], while goal-directed features can help patients prepare for and engage more effectively in clinical interactions [39].

5.2 Future Directions

We plan to integrate our design considerations into a refined prototype and conduct a next round of iteration involving a larger-scale, multi-site user study for evaluation. While our current work focused on CKD as a representative chronic condition, the alignment of our preliminary results with prior work [8, 20] suggests broader transferability. We invite the HCI community to further explore how these findings might be generalized to other complex healthcare contexts, such as mental health [40, 47] or long-term care [26, 33]—where caregivers are also heavily involved in triadic decision-making—to further validate and extend the impact of our collaborative decision-making framework.

6 CONCLUSION

Our findings emphasize the value of designing collaborative decision-making technologies grounded in situational awareness theory and tailored to the unique dynamics of pediatric chronic care. Supporting collaborative decision-making requires more than simply providing information or helping patients interpret data. Technologies should equip users to prepare for clinical interactions, align mental models of clinical information, balance caregiver support with youth autonomy, and facilitate goal alignment and anticipation of challenges in care. By surfacing these insights, this work provides a preliminary design framework for collaborative decision-making technologies that promote shared understanding and empower families within the complex ecosystem of pediatric chronic care.

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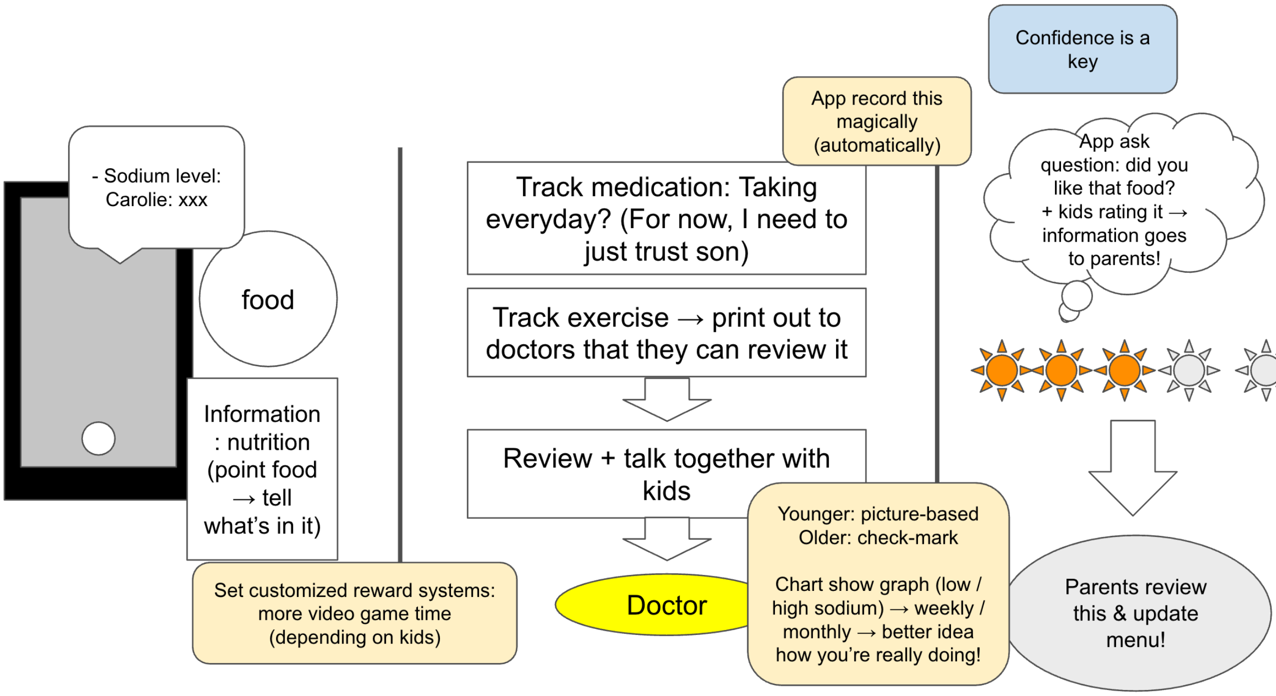
A Participant demographics

Table 1: Participant demographics from the Co-Design Workshops.

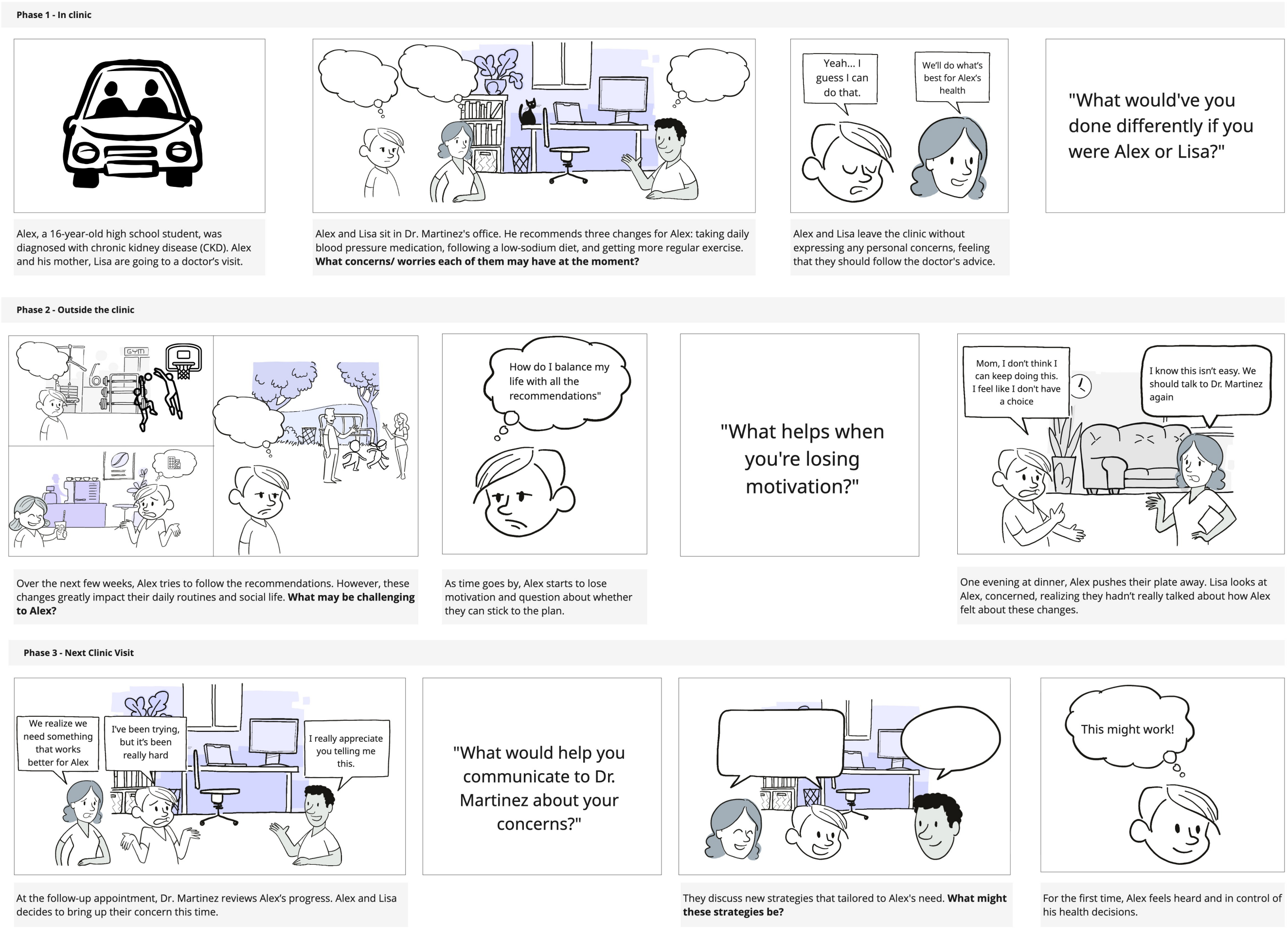
ID	Age	Sex	Role	YE in PN (Total Clinical YE)
C1	14	F	Caregiver	4
C2	17	F	Caregiver	10
C3	17	M	Caregiver	7
C4	14	F	Caregiver	1
C5	14	F	Caregiver	14
C6	16	F	Caregiver	16
P1	13	F	Patient	7
P2	14	F	Patient	10
P3	17	F	Patient	14
P4	16	M	Patient	16
P5	17	M	Patient	12
P6	15	M	Patient	15
H1	–	M	HCP (Dietitian)	6 (10)
H2	–	F	HCP (Social Worker)	5 (15)
H3	–	F	HCP (Physician Assistant)	8 (10)
H4	–	F	HCP (MD - Fellow)	1 (4)
H5	–	M	HCP (MD)	16 (16)
H6	–	F	HCP (MD)	3 (6)
H7	–	F	HCP (Nurse)	24 (24)

C = caregivers; **P** = patients; **H** = healthcare providers;
Age = for caregivers, the age of their youth patient (i.e., their child); for patients, the patient's own age;
YE in PN = for caregivers/patients, years since CKD diagnosis; for HCPs, years of experience in pediatric nephrology;
Total Clinical YE = total years of clinical experience (clinicians only); "–" indicates not applicable.

B Study Materials



Appendix 3: Example sketch of a proposed magical tool from the co-design workshop. The tool is a mobile app with features to support gathering and contextualizing dietary information, and future planning.



Phase 1 - In clinic

Alex, a 16-year-old high school student, was diagnosed with chronic kidney disease (CKD). Alex and his mother, Lisa are going to a doctor's visit.

Alex and Lisa sit in Dr. Martinez's office. He recommends three changes for Alex: taking daily blood pressure medication, following a low-sodium diet, and getting more regular exercise. **What concerns/ worries each of them may have at the moment?**

Alex and Lisa leave the clinic without expressing any personal concerns, feeling that they should follow the doctor's advice.

"What would've you done differently if you were Alex or Lisa?"

Phase 2 - Outside the clinic

Over the next few weeks, Alex tries to follow the recommendations. However, these changes greatly impact their daily routines and social life. **What may be challenging to Alex?**

As time goes by, Alex starts to lose motivation and question about whether they can stick to the plan.

"What helps when you're losing motivation?"

One evening at dinner, Alex pushes their plate away. Lisa looks at Alex, concerned, realizing they hadn't really talked about how Alex felt about these changes.

Phase 3 - Next Clinic Visit

At the follow-up appointment, Dr. Martinez reviews Alex's progress. Alex and Lisa decides to bring up their concern this time.

"What would help you communicate to Dr. Martinez about your concerns?"

They discuss new strategies that tailored to Alex's need. **What might these strategies be?**

For the first time, Alex feels heard and in control of his health decisions.

Appendix 2: Vignette storyboard used for role-playing and values elicitation during co-design sessions.