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Posted Date: 4 March 2026

doi: 10.20944/preprints202603.0324.v1

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Article

Personalized Risk-Prediction Tool for Deceased Donor Kidney Offers: Stakeholder Perspectives from a Qualitative Study

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Abstract

Background: Rising kidney discard rates and uncertainty around accepting higher risk donor kidneys highlight the need for decision support tools that integrate donor and recipient factors and communicate risk in ways that are understandable and usable at the time of offer. Conventional indices (e.g., KDPI/KDRI) provide population level signals but do not deliver individualized, cognitively accessible information aligned with real time clinical workflows. **Objective:** To describe how key transplant stakeholders (patients, coordinators, and providers) interpret and evaluate a prototype Kidney Risk Calculator app that generates donor–recipient specific survival projections, and to identify the content, format and features, and functionality needed for clinically meaningful, patient-centered decision support. **Design:** Qualitative study using focus groups and individual interviews. **Setting:** University of New Mexico Hospital (UNMH) Kidney Transplant Center. **Participants:** Five patients (four transplant candidates and one patient advocate), three transplant coordinators, and five transplant providers (3 attending physicians and 2 advanced practice practitioners). **Methods:** Semi-structured sessions (45 to 60 minutes) with 13 stakeholders (patients, coordinators, and providers) included a live app demonstration and explored usability, interpretability, contextual information needs, perceived clinical utility, and anticipated barriers/facilitators. Data were collected via one coordinator focus group, one patient focus group, and five provider interviews; sessions were recorded, transcribed, de-identified, and analyzed using inductive reflexive thematic analysis. **Results:** Stakeholders affirmed the value of personalized projections as an adjunct to clinical judgment, particularly for higher risk offers. Participants prioritized: 1) **Content:** clear education on hepatitis C virus (HCV) positive donors and Public Health Service (PHS) risk criteria; plain explanations of Calculated Panel Reactive Antibody (CPRA); and framing that makes time on dialysis and tradeoffs salient; 2) **Format & Features:** plain language narratives, percentages rather than decimals, simple visuals, minimized acronyms, U.S. customary units, and a stepwise (“TurboTax-like”) input flow preferred by patients; and 3) **Functionality:** attention to cognitive load and workflow alignment, given phone-based time pressure and digital-access constraints. Stakeholders emphasized that the tool’s value hinges on clarity, context, and workflow fit—not predictive accuracy alone. **Limitations:** Single center, formative prototype study with a modest sample; findings are illustrative and may have limited transferability. Participants reacted to a demonstration rather than using the app during real time offer calls; convenience/email recruitment and Zoom only English sessions may introduce selection bias; team involvement in app development may contribute residual confirmation bias despite mitigation. **Conclusions:** Early stakeholder input suggests that a kidney offer decision support tool should integrate individualized predictions with plain language explanations, contextual information that addresses common misconceptions, workflow aligned functionality, and accessible outputs. Tools designed and implemented with these features may support acceptance of medically complex kidneys and may help reduce offer bypass and organ discard. These inferences reflect stakeholder perceptions in a formative qualitative study and warrant prospective evaluation.

Keywords: kidney transplantation; shared decision making; risk prediction; qualitative study; stakeholder perspective; user-centered

Introduction

Kidney transplantation (KT) is the preferred treatment for end-stage kidney disease (ESKD), offering superior survival, quality of life, and cost-effectiveness compared with dialysis [1–3]. Yet despite these well-established benefits, the supply of donor kidneys continues to fall short of demand. As a result, transplant programs increasingly consider kidneys from older donors or donors with comorbidities—organs previously labeled as “marginal” or higher risk [4]. Nevertheless, thousands of potentially transplantable kidneys are still discarded each year [5]. In the United States, deceased donor kidney discard rates have risen from approximately 20% prior to the COVID-19 pandemic to nearly 25% in 2022 [6], underscoring persistent uncertainty in real-time kidney-offer acceptance, particularly for higher-risk organs.

Several factors contribute to this challenge: providers face uncertainty about how donor characteristics interact with individual patient profiles; acceptance thresholds vary widely across providers and centers; and few tools exist to support efficient, personalized decision-making when a kidney offer is received [7]. Standard approaches such as the Kidney Donor Risk Index (KDRI) and Kidney Donor Profile Index (KDPI) provide population-level risk assessments but have notable limitations for clinical decision-making [8–10]. These indices are donor-focused, offer modest discrimination for graft survival, and do not incorporate recipient factors or generate individualized survival estimates. Consequently, their use to support shared decision-making is limited, especially when accepting a high risk donor may benefit candidates with prolonged dialysis exposure or limited future opportunities for transplantation.

To address these gaps, we developed a prototype web-based Kidney Decision Aid app designed to integrate both donor and recipient characteristics and present personalized estimates of post-transplant risks and benefits [29,30]. The goal of this tool is to better inform providers and patients in their assessment of a donor kidney especially a higher risk one, and support more informed acceptance discussions. Given the complexity of transplant decision-making, quantitative performance metrics of the app alone cannot fully illuminate how providers and patients interpret personalized risk estimates, what contextual information they require, or how clinic workflow constraints shape tool usability.

Qualitative inquiry is therefore critical for understanding how stakeholders make sense of risk information, navigate uncertainty, and envision incorporating decision-support tools into real-world clinical processes [34–36]. Yet limited empirical evidence exists describing how transplant stakeholders understand and interpret individualized risk calculations or what features and formats are most desirable. Guided by International Patient Decision Aid Standards (IPDAS) and user-centered design principles [17–19], we conducted a qualitative study involving transplant candidates, transplant coordinators, and transplant providers. Our objective was to gather stakeholder perspectives on the app’s content, format & features, and functionality, as well as anticipated barriers and facilitators to adoption. Insights gained from the stakeholders will inform the refinement of next-generation kidney-offer decision-support tools that are patient-centered and ready for integration into high-stakes, time-sensitive clinical environments.

Methods

Study Design and Setting

We conducted a qualitative study at the University of New Mexico Hospital (UNMH) Kidney Transplant Center. This early-phase evaluation served as a formative component of user-centered tool development, aimed at gathering experiential feedback to guide iterative app refinement.

User-Centered Design Framework

The Kidney Risk Calculator app was developed using an iterative, user-centered design approach informed by IPDAS guidelines [17]. Early engagement of end users was prioritized to ensure relevance, clarity, and usability. Figure 1 illustrates the iterative design process, including prototype development, user engagement, and refinement cycles.

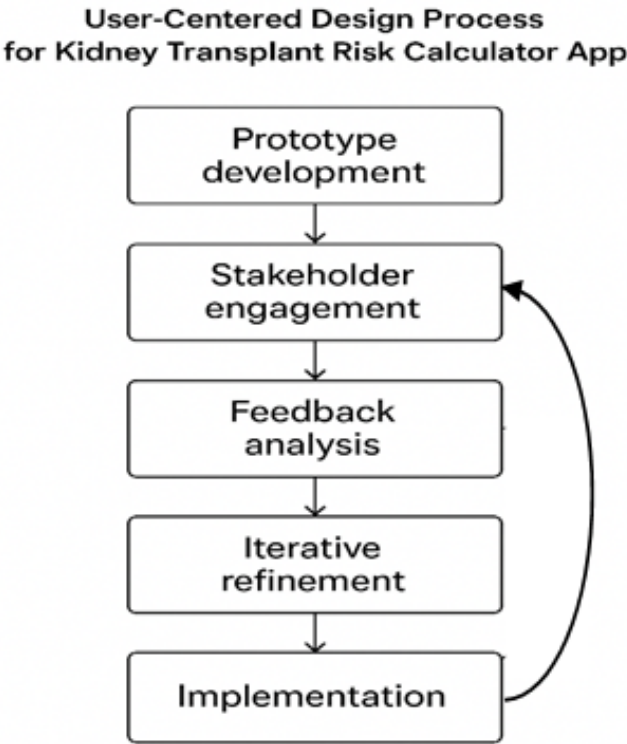


Figure 1. User-centered design process for the Kidney Risk Calculator App.

Participants and Recruitment

We recruited three stakeholder groups: transplant coordinators, transplant providers, and transplant candidates. Coordinators and providers were recruited by convenience sampling. Of eight coordinators invited, three participated in a focus group. All five invited providers completed individual interviews due to scheduling constraints. Patients were selected from a stratified random sample of the University of New Mexico Hospital (UNMH) transplant waitlist, stratified by sex, race/ethnicity, and dialysis status. Of 120 waitlisted patients, 30 were invited by email and five participated. Data collection comprised one coordinator focus group (n = 3), one patient focus group (n = 4 candidates and 1 patient advocate), and five provider interviews.

Data Collection

Between December 2022 and May 2023, we conducted all focus groups and interviews via secure, password-protected Zoom sessions. Each session began with a live demonstration of the prototype app [29] and lasted approximately 45–60 minutes. Using a semi-structured guide, we explored stakeholder perceptions of: 1) app content (clarity, missing information, relevance); 2) format & features (visual display, navigation, usability); 3) functionality (perceived utility, workflow fit); and 4) anticipated barriers and facilitators. All sessions were recorded, professionally transcribed, and de-identified for analysis. The interview guide is provided in Supplementary Table S1.

Data Analysis

We conducted an exploratory, formative qualitative evaluation to inform iterative app refinement; consistent with early-stage, user-centered design, we did **not** seek thematic saturation, which is not required at this phase [27,28]. Two analysts (a qualitative methodologist and a senior specialist) independently reviewed transcripts, kept reflexive memos, documented interpretive decisions, met for peer debriefs, and jointly developed the codebook. The primary analyst coded all transcripts in NVivo (QSR International, 2020); the secondary analyst double-coded a subset to enrich interpretation. Inter-rater reliability was not used, aligning with reflexive thematic analysis [44,45]. We ran matrix queries to visualize the distribution of coded references across stakeholder groups and topics. We present a descriptive heatmap and a cleaned matrix table (Supplementary Figure S2 and Supplementary Table S2) to support quotation selection and cross-group coverage checks. This study was approved by the University of New Mexico Human Research Protection Office (HRPO 23-071).

Participant Demographics

A total of 13 stakeholders participated: 5 patients (4 transplant candidates and 1 patient advocate), 3 transplant coordinators, and 5 transplant providers (3 attending physicians and 2 advanced practice practitioners). All participants were affiliated with, or received care through, the University of New Mexico Transplant Program, representing roles across the transplant decision-making continuum. Patients reflected varied lived experiences, including current dialysis, awaiting transplantation, and caregiving roles. Coordinators and providers included personnel involved in organ offer evaluation, patient counseling, and transplant decision-making processes. Detailed demographic data were collected for patients: sex (2 female, 3 male) and race/ethnicity (Black, Native American, and White). Coordinators (all female) and providers (3 female, 2 male) participated in their professional roles; race/ethnicity data were not collected for these groups. Collectively, the sample captured perspectives shaped by distinct responsibilities in transplant care, differing levels of clinical expertise, and personal experience with kidney disease. Participant characteristics are summarized in Table 1.

Table 1. Participant Characteristics.

Characteristic	Category	Patients (n=5)	Coordinators (n=3)	Providers (n=5)
Sex	Female	2	3	3
	Male	3	0	2
Race/Ethnicity	Black	1		
	Native American	1		
	White	2		
	Unknown	1		

Values are reported as number of participants. Race/ethnicity was collected for patient participants only; coordinators and providers participated as part of their professional roles.

Results

Analysis yielded a set of inductively developed codes, which were organized into three domains—**content**, **format and features**, and **functionality**—with some codes recurring across domains (e.g., HCV education, workflow fit). We present brief anchors followed by quotations to reflect convergence and divergence across stakeholder groups.

1) Content: What users want to see in the app—education on HCV/CPRA and survival trade-offs; avoid overload; add missing context (wait time, COVID-19).

Patients emphasized risk information—especially HCV, antibodies (PRA/CPRA), and kidney survival—as central to decision-making, while also cautioning against information overload. Several participants wanted more educational content on HCV risks and benefits so they could revisit

information after clinic visits: "...it would be helpful to have additional information about Hep-C risks and benefits within the app so patients can review the information beyond medical appointment conversations." At the same time, they asked the team to avoid "loading one tab" with dense material, preferring concise, plain-language modules: "...be careful overwhelming people with information... try to throw everything on one page... make it... draw people to the app." Willingness to accept kidneys varied, but some patients prioritized access over granular donor details. When asked whether output information would be sufficient to decide within an hour, one participant responded, "I'll take whatever they give me," to which another replied, "Heck yeah," highlighting that for some, availability and timing outweighed specific donor characteristics that underlie kidney quality. A patient advocate similarly noted readiness to accept "any kidney," though remaining "super skeptical" about HCV, reflecting nuance in risk tolerance.

Providers viewed the app's incorporation of recipient factors as "new and different," filling a gap beyond KDPI-only assessments. As one provider put it, "...we're not looking at everything else that you guys are putting into the app... I think that's nice. It's different," underscoring the value of integrating donor and recipient variables in a single estimate. Another noted, "we have... the probability considering both the donor and the recipient which we lack currently because we go by KDPIs and donors."

Stakeholders identified additional variables/content to add or refine. Providers suggested coronary artery disease (replacing "angina"), diabetes management (A1c), dialysis compliance, smoking/substance use, kidney size, recent hospitalizations, cold ischemia time defaults (local/out-of-state/maximum), last (not average) donor creatinine, and CPRA to better reflect clinical practice and patient risk. Some argued for removing HCV from the risk calculation given contemporary outcomes: "...Hep C is probably not... should probably not be included in the calculation... those kidneys actually do really well."

Coordinators requested content to contextualize "increased risk donors" (the public health risk model) to reduce refusals driven by misconceptions. They described patients often conflating "high risk" with acquiring infections, despite negative testing, and recommended embedding content that clarifies how such designations are assigned and what they imply: "...they automatically associate it with, 'Oh, I'm going to get HIV...'... just providing that education."

Participants also surfaced missing or uncertain content areas. A patient highlighted that the app did not capture "time" and personal decline on dialysis—"I'm running out of time... I'm going downhill pretty quick"—suggesting the need to make waiting-time salience explicit. Coordinators raised COVID-19 as an external factor not yet modeled, asking: "So how much would it change if we accepted a COVID positive donor for this patient? ... I don't know how that would affect probabilities ... because that's not something we're doing." They also questioned whether the "number of kidney offers" could be meaningfully included, noting that coordinators often lack access to this information.

2) Format & Features: How users want information displayed—plain-language narratives; percentages; simple visuals; stepwise inputs; U.S. units.

Patients strongly preferred plain-language narratives and percentages over numeric decimals or dense charts. One participant suggested, "Make it a narrative form like 'This person will have a 25% survival rate after three years...' so that... you're not just looking at numbers..." and another added, "...put it in percentages... I think better in percentages than I do in digital." Providers echoed this, recommending percentage displays so patients more readily grasp probabilities: "...if you guys do percentages, they might understand it a little better." Patients described the current interface as "a calculator... a scientific tool" and urged the team to make it more visually appealing, with progressive, page-by-page inputs ("like TurboTax") to explain each field in plain terms. They also asked to spell out acronyms rather than rely on a glossary, to reduce tab-hopping and cognitive load. Units and accessibility mattered for patient usability. A request to support U.S. customary units captured a common barrier: "I don't know how many centimeters I am or how many kilograms I am. Can you make it American standard measurements?"

Providers generally found the interface straightforward but advised several refinements to the views. A provider praised it as "very clear, very easy to understand... not a lot of words and... very direct,"

while recommending mobile availability (app Store/Google Play) and web access for sharing during clinical communication. Some suggested emphasizing allograft survival or, for select patients, framing outcomes as probability of remaining on dialysis to reduce anxiety relative to “risk of death” charts.

Coordinators described the current format as straightforward with data entry and output: *“I think it’s easy to follow. It’s easy to be able to put in the information and then come up with the probability.”* They valued the tabular/graphical display of numbers as concrete evidence to support conversations: *“Having something concrete, I think really helps... for not only us as providers and people that are offering the kidneys, but on both sides, providers and recipients.”*

3) Functionality: Perceived utility and workflow fit—supportive of clinical judgment; helpful for education; constrained at offer time (phone, confidentiality).

Across stakeholders, the app was seen as a decision support that augments—rather than replaces—clinical judgment. Providers emphasized its role as a supplemental tool: *“It’s not going to change your clinical judgment, but it’s going to guide you towards making a better decision,”* and *“...another tool in that toolbox to provide care to the patient.”* Coordinators anticipated that data-driven outputs could reassure both providers and patients, potentially increasing acceptance of offers that might otherwise be bypassed. One coordinator summarized, *“...it may actually push providers to accept kidney offers even more...,”* especially when *“providers are looking for that extra confirmation.”*

The app also functioned as an educational scaffold for patients—but real-time offer decisions pose constraints. Patients and caregivers described the app as a way to digest “word vomit” from short clinic visits, creating time and space to process risks/benefits: *“...with your little app... I understand these numbers... you literally have 10 minutes with your doctor... this actually gives you time to digest everything...”* However, providers noted that when offers occur, patients are called and must decide quickly, often without access to the app at the point of decision, especially if they live far from the center: *“...we’re calling them... they could live 5 hours from the transplant center... We don’t want them to come in if they’re going to decline the kidney.”*

Donor confidentiality limits what patients can see or use at the moment. Providers explained that detailed donor information cannot be disclosed; patients may be told if a donor is DCD or high-risk/HCV, but not age, sex, or medical history, restricting patients’ ability to replicate provider inputs in real time: *“...I don’t even know why or how a patient will actually use this [during an offer].”*

4) Anticipated barriers and facilitators to using the App—Barriers: confidentiality, digital access, numeracy, unpredictable events; Facilitators: ease, willingness to recommend, confidence with higher-risk offers.

Anticipated barriers included external/clinical uncertainties, digital access, and health literacy challenges. Coordinators emphasized that certain clinical events are inherently unpredictable and cannot be fully captured by any prediction model: *“There’s always going to be those outside factors that you can’t anticipate, such as primary graft nonfunction... nothing is perfect.”* They cautioned that the app is “a good tool to help make a decision, but it may not be the decision maker.” Providers highlighted technology barriers (limited internet access, difficulty using Zoom) and conceptual complexity among some patients (e.g., explaining CPRA).

Facilitators included perceived ease of use, willingness to recommend the tool to others, and strong interest in trying the app in practice. Coordinators characterized the tool as easy to follow and reported they would recommend it to colleagues; one expressed being *“excited to try it and see how it works in real time.”* Providers described potential for greater confidence in accepting higher-risk donors—*“...more inclined to take a donor that I probably wouldn’t have using just KDPI”*—and for strengthening patient communication, particularly around the advantages of HCV-positive donors in the direct-acting antiviral (DAA) era.

In summary, across groups, stakeholders prioritized clear, percentage-based outputs for patients but differed in comfort with HCV-positive offers and feasibility at the time of offer. Priorities were: (1) clearer, more digestible risk explanations without overwhelming patients; (2) clear, visual, stepwise outputs; (3) a supportive—not determinative—role within confidentiality-constrained,

phone-based workflows; and (4) implementation planning that tackles confidentiality/time pressure, digital skills/connectivity, and CPRA complexity while harnessing ease-of-use, reassurance from numbers, willingness to recommend, and support for higher-risk acceptance discussions.

Discussion

This study identifies design considerations for a kidney-offer decision-support tool. The Discussion focuses on what these findings mean for the tool's clinical content, its design and deployment in ways that enhance understanding and interpretation of estimated benefit and risk, and how it can be integrated into real-world offer workflows that face time pressure and confidentiality limits.

Content scope and clinical relevance. Contemporary evidence shows that transplanting kidneys from HCV-RNA-positive donors into HCV-negative recipients—when paired with timely direct-acting antiviral therapy—yields excellent outcomes (~98% 1-year allograft survival) [49–51]. These outcomes challenge the legacy “HCV penalty” embedded in indices such as KDRI/KDPI and reinforce the need for updated, recipient-directed education that reframes HCV-positive offers as evidence-supported options. Likewise, clarifying Public Health Service (PHS) criteria aligns with post-2020 practice (universal donor nucleic acid testing (NAT) and universal post-transplant monitoring) intended to reduce refusals based on misperception [52,53]. Accordingly, content should reflect current outcomes and risk-communication best practices.

Health literacy, numeracy, and digital access. Limited health literacy and numeracy are common among transplant candidates and recipients and are associated with worse outcomes and adherence challenges [54]. Rural and underserved populations also face persistent telehealth and digital-access gaps—such as lower video-visit use and portal activation—which underscores that a patient-directed app cannot assume uniform internet access or digital skills [55]. Modern digital-health equity frameworks emphasize designing tools that account for patient abilities, community infrastructure, and system-level constraints across the digital-health lifecycle [56]. The app's plain-language summaries, percentage-based outputs, and printable views align with these principles; however, sustained attention to usability for patients with limited connectivity or numeracy will be essential for equitable implementation. In our setting, where large rural catchment areas contribute to pronounced variation in digital access, these equity-oriented design choices are especially salient.

Workflow realities: time pressure and confidentiality. Real-time kidney-offer decisions occur under compressed timelines, often by phone, and with strict limits on what donor information can be disclosed [57]. These constraints complicate patient-provider shared decision-making: clinicians may understand the donor–recipient match in detail, but patients receive only a small subset of information. A probabilistic calculator helps address this gap by producing a non-identifying summary that conveys clinical meaning without revealing protected donor details. This allows clinicians to review numeric or narrative outputs with patients even when the underlying variables cannot be shown. The app therefore functions as an interpretive layer that situates donor–recipient characteristics within a patient's broader clinical trajectory (e.g., expected allograft function, remaining dialysis time), supporting informed decision-making while maintaining confidentiality.

Implications for design and implementation. Our findings suggest several directions for tool refinement. First, educational content should explicitly address contemporary HCV outcomes [49], PHS risk criteria [50], and dialysis-vs-transplant trade-offs in plain language, supplemented with natural-frequency or percentage formats. Second, output views should prioritize accessible narratives, percentage-based absolute risk, and optional icon arrays or bar charts for patients who benefit from visual aids [59,60]. Third, contextual assumptions—such as CIT ranges or last-versus-average creatinine conventions—should be transparent and adjustable, enabling clinicians to test plausible offer scenarios rapidly. Fourth, the variable set may require refinement (e.g., replacing angina with coronary artery disease, dialysis adherence proxies, or kidney size/weight matching) and re-examining the weighting or exclusion of donor HCV status in light of current

DAA-era outcomes. Finally, implementation should adopt an equity-first approach, ensuring offline or low-bandwidth usability, U.S. customary units, and clinician training in risk framing to mitigate digital or numeracy-related barriers [56].

Limitations

This early-phase, single-center formative evaluation reflects preliminary stakeholder perspectives from a modest sample and was designed to inform iterative refinement rather than to produce an exhaustive thematic account. As such, transferability to other settings may be limited. Participants interacted with a prototype demonstration rather than using the app during actual offer calls; stated preferences may diverge from behavior under time pressure and stress. Convenience and email-based recruitment may introduce selection bias (digital access, interest). Although reflexive memos and peer debriefs were used, involvement of team members in app development introduces potential residual confirmation bias despite mitigation. Because all sessions were conducted via Zoom in English, views of individuals with limited internet access or different language preferences may be under-represented. Finally, findings from one transplant center with specific workflow and population characteristics may not generalize to other settings; future work should examine use during simulated or actual offer encounters across diverse sites.

Conclusion

Stakeholders viewed the Kidney Risk Calculator app as a promising tool to support recipients and clinicians in navigating complex kidney-offer decisions. By converting donor–recipient data into plain-language summaries, the app addresses cognitive load, acknowledges confidentiality limits, and provides patients with contextualized risk information that is easier to understand and anchor to their own circumstances. Participants emphasized that the tool must remain a decision aid—not a decision maker—and that it must align with real-world workflows, including phone-based offers, limited patient-visible donor information, and variability in digital and health literacy. Moving forward, refinement should include updated modeling (e.g., HCV weighting, KDPI calibration), accessible views, and deployment strategies that accommodate differences in internet access, numeracy, and language. Prospective evaluation should assess the effect of app usage on patient comprehension, clinical communication, and the acceptance of medically complex kidneys. When designed and implemented with these considerations, decision-support tools such as this may positively influence acceptance of medically complex kidneys and may reduce offer bypass and organ discard.

Supplementary Materials: The following supporting information can be downloaded at the website of this paper posted on Preprints.org.

Data Availability: De-identified data may be shared upon request via data use agreement. The current version of the prototype web-based Kidney Risk Calculator app is available at <https://kcalculator.shinyapps.io/kidneycalc/>

Acknowledgments: This study was financially supported by Dialysis Clinic, Inc. (Grant C-4130). This project is supported by an award from the National Center for Advancing Translational Sciences, National Institutes of Health under the grant number UL1TR001449.

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