

Designing a Dashboard to Streamline Pediatric Heart Transplant Decision Making

A Technical Report submitted to the Department of Engineering Systems and Environment

Presented to the Faculty of the School of Engineering and Applied Science
University of Virginia • Charlottesville, Virginia

In Partial Fulfillment of the Requirements for the Degree
Bachelor of Science, School of Engineering

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Spring, 2023

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Designing a Dashboard to Streamline Pediatric Heart Transplant Decision Making

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Abstract—Only 56% of eligible pediatric cardiac donor hearts are ultimately being accepted even though there are long waitlists for transplants and high waitlist mortality. A major contributing factor to low acceptance rates is due to the highly variable decision-making process of cardiologists who must determine the suitability of a potential transplant in an extremely short period of time. The current system, DonorNet, does not present information ideal for decision making under these conditions which has resulted in suboptimal decisions and cardiologists not being confident in their decisions. The goal of this project aims to adopt a user-centered systems design approach to develop a new DonorNet dashboard to better support the decision-making process for pediatric cardiologists. The design of an improved DonorNet dashboard was based on: (1) a literature review to understand the factors that influence practitioners in their decision-making process and identifying post hoc factors that are predictors of transplant success and (2) interviews by the research team with eight pediatric heart transplant practitioners to understand how end-users make decisions with DonorNet and identify common pain points. Based on this, we designed a dashboard using Figma based on our research findings that addressed identified pain points such as difficulty finding relevant data. We measured success with user satisfaction surveys before and after the redesign that included questions regarding how easy it was to find information and confidence in their decision. The expected results of the project will include a semi-functional dashboard that incorporates real data from databases containing information on patient and donor heart characteristics. Success of the interface will be evaluated through surveys assessing user satisfaction, time to arrive at a decision, and self-rated stress levels.

I. INTRODUCTION

Optimally utilizing the limited organ supply in the practice of pediatric heart transplants has remained a pressing issue, as only about 56% of eligible donor hearts offered for transplants in the United States are ultimately being used [1]. When a pediatric heart becomes available, cardiologists have limited time to decide whether they want to accept or reject the donor organ for a patient—an hour if it is for the first candidate on the organ transplant waitlist and thirty minutes for all other potential transplant recipients [2]. Pediatric cardiologists may encounter an overload of data to guide their decision-making, sometimes even in the middle of

the night. The data that the cardiologists must consider often is presented ineffectively, e.g., they are provided with a deluge of text and numbers that would be much more effectively presented using a graph. These suboptimal decision-making conditions have resulted in a significant variation in donor acceptance practices between and within pediatric heart transplant programs. To date, there is no consensus on what makes a donor “acceptable” versus “unacceptable” [3]. Research has also shown that a more comprehensive and standard approach to assessing the suitability of a potential donor can be beneficial in decreasing the organ discard rate and waiting list times in pediatric heart transplantation without affecting post-transplant outcomes [4].

The goal of this project is the first attempt to develop a dashboard to support cardiologists using DonorNet, the software program that presents information about a potential donor heart. The end goal is to move towards a more streamlined and standardized decision-making process. The dashboard will be used to present donor data currently provided to cardiologists in a more effective, organized manner that reduces the time needed to understand the information. To gain insights into the design of the dashboard, we reviewed actual patient data that cardiologists need to consider. We also conducted interviews with pediatric cardiologists across the United States and Canada. We then designed and prototyped a new dashboard system that includes feedback from the cardiologists to streamline how the donor data is presented. When conducting the design of the interface, an iterative process was used in which the team collected feedback from cardiologists on the current design and made updates iteratively.

II. LITERATURE REVIEW

The current DonorNet interface has been the primary method for pediatric cardiologists across the country to assess donor hearts and come to a decision on whether to accept or reject a donor heart for transplantation. When a new donor organ becomes available, cardiologists must log into this interface and use the information provided to determine if the organ is suitable for use on the patient within their hospital. While the interface succeeds in displaying all relevant information, several problems exist with the current design that may lead cardiologists to have a difficult time analyzing the data and coming to an informed decision on the assessment process. Based on initial

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interviews conducted with a pediatric transplant specialist, one issue is that the information is presented in small font, includes little to no color, and information is spread out between large areas of blank space [5]. This lack of user-friendly design may cause cardiologists to miss important information during their assessment and lead them to spend an unnecessary amount of time parsing through data that is not helpful to their decision-making.

For example, variables such as vital signs are presented in a table-style format to show values over time without the use of graphs, which creates difficulty in analyzing trends and atypical behavior. Similarly, echocardiograms, which typically show pictures of the donor heart and provide a description of how the organ is functioning, are crucial in the decision-making process; however, these images can be difficult to locate and have long loading times. Lastly, it was noted that the current dashboard offers no way to customize the data that is presented and does not give users the ability to reorganize the variables based on their own preferences. This is problematic given that different transplant programs vary in the variables that they consider important for predicting transplant success.

There has been success in presenting data in different ways for other organ transplants. The creation of risk indices has assisted doctors in quickly assessing large amounts of data and making more confident, objective, and systematic decisions for different organ transplants. While there are currently no widely accepted risk indices for hearts and lungs, there are established risk indices used in kidney, liver, and pancreas transplantations [6]. For example, The Kidney Donor Risk Index (KDRI) includes ten donor and four transplant characteristics that have been found to be significantly and independently associated with graft failure or recipient death [7]. According to the Organ Procurement & Transplantation Network, the Kidney Donor Profile Index (KDPI), which is a remapping of the KDRI onto a cumulative percentage scale, has been provided with all kidney donor offers since 2012 [2].

Despite the benefits that combining several variables into a single index score, there are limitations to using risk indices in organ transplantation decision-making. Studies have shown that the KDRI has strong predictive power in the extreme quartiles, but low predictive otherwise [6]. Furthermore, a study conducted in 2016 designed to compare the organ discard rate before and after the implementation of the KDPI found that the overall discard rate did not change with the KDPI, and the discard rate for high-risk grafts increased suggesting a harmful “labeling effect” for these types of donors [8]. A risk index may not be appropriate considering both data scientists and doctors cannot confidently agree on risk predicting factors. A survey created about the practices and attitudes about the Liver Donor Risk Index

(LDRI) found that 73% of respondents believed that the LDRI does not adequately describe a liver's relative risk of graft failure, and 88% of respondents thought there were factors included in the LDRI that made its value misleading [9].

While risk indices have shown some success in accelerating, objectifying, and standardizing transplant decision-making, they may not be the most appropriate in the pediatric heart transplant field. The highly variable decision-making practices of cardiologists — both within and between programs — suggest that a single index may be too restrictive. Furthermore, the risk indices that currently exist for pediatric heart transplants have only moderate predictability power. Unless cardiologists converge on identifying a set of variables that are significant or the predictive power of an existing risk indices increases, they are likely to continue to trust their own expertise. Here we propose a dashboard that offers the best of both worlds—expediting the decision-making process through standardization but allowing for flexibility in the variables that are emphasized on practitioner-to-practitioner basis.

III. METHODS

A. Literature Review

First, we performed a literature review on pediatric heart transplant decision-making to better understand the problem space. Fifteen research articles were identified to be relevant to this line of work and the topics included: behavioral economics in donor evaluation, donor and transplant variable significance in predicting transplant outcomes, and the variability in decision-making practices both between and within transplant programs. The literature review helped us understand the current donor evaluation practices from a systems perspective. Moreover, it also allowed us to identify common misconceptions and suboptimal decision-making practices that we should consider in our design.

B. Interviews with End-Users

Second, we also interviewed eight different pediatric cardiologists, including four from the University of Virginia Children's Heart Center and four from various other programs in North America. During these forty-five-minute interviews, we asked about pain points with the current DonorNet system, the variables considered when evaluating a donor, and what information took the most time to evaluate. Interviewees were also given the opportunity to provide a live demonstration of their decision-making process using the current DonorNet interface.

C. Prototyping Process

Once we gathered these insights, we then began our design process by determining potential functional requirements through a How-Might-We (HMW)

brainstorming exercise. To develop HMW questions, we took our insights, translated them into needs, then framed each as a “How might we...” question. An example of one we considered is, “How might we allow users to better digest and analyze the information, especially data, over time?” Each question was posed on a whiteboard and members of our team used sticky notes to suggest ideas on what design features could be used to address the users’ needs.

After we exhausted the list of insights and decided on the most feasible or effective design ideas, we then moved onto the wireframing phase on paper and using Figma, an online design tool. On Figma, we created the dashboard prototype, first starting with a basic black and white wireframe. Multiple alternatives were considered in the initial wireframing stage.

D. Soliciting End-User Feedback

To maximize the likelihood of the dashboard’s success, we solicited user feedback. Cardiologists were given a wireframe depiction of the prospective interface and asked to review the organization of information. Our goal was to allow them to follow a hierarchical structure they routinely use, while encouraging them to adopt some of the dashboard’s new features. The feedback collected provided considerations for improvements on future iterations.

As the new dashboard was presented, a member of our team leading the interview walked the cardiologist through each tab and allowed for discussion. The objective was to both inform the cardiologist on how the interface functions and to assess whether the new dashboard could improve decision-making.

IV. RESULTS

A. Literature Review and Initial Interviews

From the interviews, we were able to compare various pediatric cardiologist perspectives of the current DonorNet interface. A commonly noted pain point between users was that they must scroll and parse through lots of information before reaching the patient data that is most relevant to their decision-making. The hierarchy of variable importance differed slightly between pediatric cardiologists, but there were many commonalities identified through the interviews. These included echocardiograms, human leukocyte antigens (HLA) crossmatch results, ischemic time, age, height, and blood type. Variables that were typically not considered include if CPR was administered, cause of death, and lab work, which currently dominates much of DonorNet displays.

We then aggregated the key insights from our research and the responses we collected during our interview process to create a comprehensive list of findings. To visualize any discrepancies we found, we created the following Venn diagram where Primary

Research is the information collected from interviews and Secondary Research includes what we found in our literature review. We were then able to compare what factors our interviewees found significant in the donor decision making process with what has been found in research.

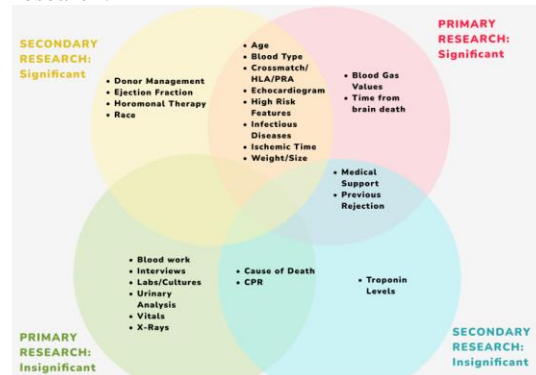


Figure 1: Venn Diagram of variables that were significant and insignificant based on interviews (primary research) and literature review (secondary research).

When asked about changes they would like to see with DonorNet, interviewees would like to see current data with access to data over time rather than prioritizing past data. Given the interface is not specific to heart transplants, many cited that they would like to see a display more heart centric. This would include a timeline of events for the donor (e.g., transportation time to the hospital and vitals collected alongside the echocardiogram). Additionally, since the information is currently dispersed throughout the system, it was noted that it can be confusing to differentiate between when lab was taken and when patient vital signs occurred. From this initial data gathering stage, we developed a set of initial wireframes.

B. Follow Up Interviews

Among the most prominent comments echoed across the three user feedback interviews conducted was the need to include when the patient was admitted to the hospital, when/how they were declared cerebral dead, and a narrative summarizing the incident that placed the patient in a critical medical state. Quotes extracted from the interviews illustrate these points:

One cardiologist noted: “I think you might want to add when the patient was admitted to the hospital and when they were declared dead. For example, if I get an offer just one day after the death versus four days and the heart still looks bad, then this tells a different story, so I really do look at the offer date and date of pronouncement of death. There’s definitely a narrative that the OPOs like to give – like cause of death. This could be helpful to have on the front page [Donor Summary tab].” Another cardiologist noted: “The

confirmation of brain death and the documentation of how it's done. You may want that to be easy to review. You get a good sense of what time 0 really is. How it was done is important.”

The narrative aims to provide context to the donor's death and potential external factors that are contributing to the current heart status and its ability to be a suitable match for a candidate recipient. This context influences how variables are analyzed; therefore, it is crucial that this information is presented at the beginning of the decision-making process. To adequately interpret an echocardiogram, it is necessary to understand the context in which it was taken; an important contextual piece is the time since cerebral death. The comments from the users were considered in our final version of the dashboard (Figure 2). While these comments represented some of the main pain points with the donor summary tab, other changes were made per the recommendations of interviewed cardiologists that included minimizing the mental calculations that needed to be made.

C. Design and Prototyping

We initially considered a customizable dashboard to summarize the patient's information so that a practitioner could see all the information on a single page. However, there were concerns that this may lead users to miss other data, so we ultimately decided to also include all variables. This combination was the best of both worlds, as it consolidated the most used information on the main page, with other pertinent data organized on different cards.

Once the general layout was decided, we created a mockup of our design using a recommended style guide with respect to typeface, paragraph spacing, icons, colors, organization, and various components. Principles of human interface design were incorporated throughout this process, including an emphasis on correct contrast, salient features, and ease of navigation.

The outcome of the Figma design process was a full mockup of the new DonorNet interface with three navigation tabs: (1) Donor Summary, (2) Donor Information, and (3) Candidates.

Donor Summary tab. This included comparisons of the donor to candidate characteristics, HLA antigens, offer information, and a timeline of vitals, medications, and other variables (Figure 2). The comparison chart allows users to easily compare characteristics between the donor heart and the patient who is considered for transplantation. Users can use a drop-down feature to select the patient that they would like to compare, and the system will automatically calculate the comparison ratios for characteristics such as age, height, and weight, allowing for an easy analysis to be made.

The HLA section is used to indicate whether a positive crossmatch exists between the patient and

candidate and shows which Class 1 and Class 2 antigens have a positive crossmatch. Showing this information was deemed to be a critical aspect for several cardiologists in their decision-making process, and thus it was included in the donor summary tab to provide users immediate access to these results. The offer information section displays basic details about the donor heart that is being assessed, including details such as the donor hospital, distance to procurement, estimated time travel, and the time of cerebral death of the donor patient. A narrative section is also included, which shows the information on the donor patient before cerebral death occurred. Lastly, the timeline section is included to provide cardiologists with a detailed outline of the various medications, imaging, and other labs that the donor patient has incurred since admittance to the hospital. The timeline can be manually zoomed in or out to allow users to view specific portions of information if desired. Users can view this information with respect to when the echocardiogram was taken, which was emphasized as being useful by several cardiologists.

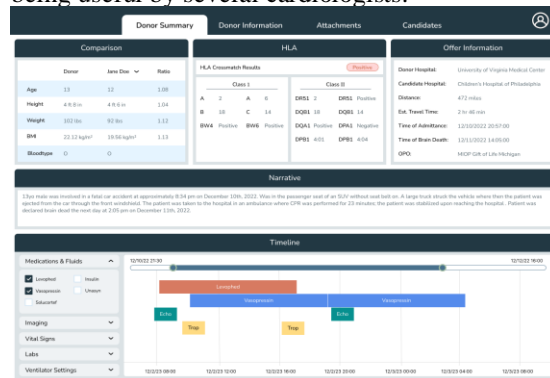


Figure 2: The Donor Summary tab provides high-level information about the donor heart. Clockwise starting from top left, “Comparison” compares the donor heart offer with a candidate recipient, “HLA” shows the crossmatch results, “Offer Information,” “Narrative,” and “Timeline” of events.

Donor Information tab. This tab provides a scrollable design that lists all relevant variables and information related to assessing a donor. The variables presented include donor information, infectious diseases, CDC risk factors, ventilator settings, imaging, medications and fluids, vital signs, and HLA. Each variable is presented using a variable card, which the user can reorganize using a sidebar on the left of the screen. Each variable card also has an option to pin or hide the information within it. If a card is pinned by the user, it will automatically be moved to the top of the scrollable screen. If a card is hidden, it will be moved to the bottom of the screen and be minimized.

For each card, information pertaining to that variable is displayed. Several of the cards, such as “Vitals,” have

the option to view the current values and the past values history (Figure 3). With historical values, users can view the content with a graph or table. The information presented in all variable cards was based on the current DonorNet interface and customized based on feedback gathered during the design process.

Candidate tab. Here users may add, edit, or review existing transplant candidates. This information feeds into the donor-recipient comparison on the Donor Summary tab. When adding a transplant candidate, information including the height, weight, BMI, age, blood type, and HLA can be manually inputted. This feature was added to allow users to easily compare characteristics between the donor and their patient—reducing the amount of information that must be retrieved from memory.

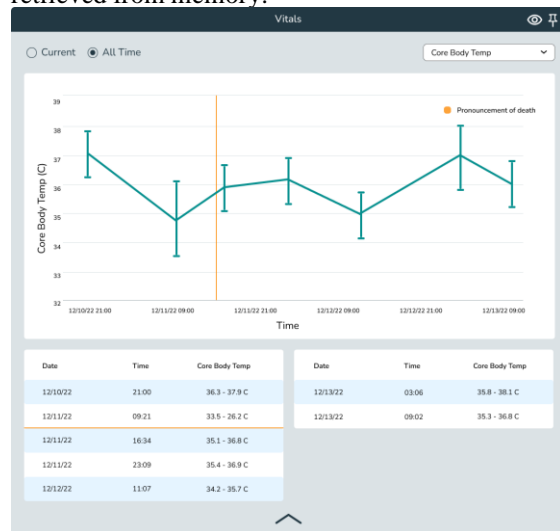


Figure 3: An example variable card, “Vitals,” displays vitals graphically and with a table with the corresponding raw data.

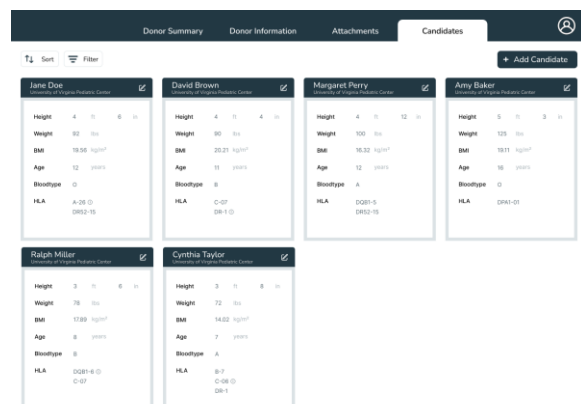


Figure 4: The Candidate tab allows users to add, edit, or review transplant candidates on one page.

V. DISCUSSION

To build an intuitive and effective user interface prototype, we found it necessary to take on a user-focused design approach. The user-centered design (UCD) process is essential towards gaining an explicit understanding of the users, their tasks, and the contexts they complete them in. Without this understanding, the interface built would have likely been futile in aiding practitioners with the organ offer decision process.

A. Interviews

We needed our dashboard design to reflect the highly variable decision-making practices of our users. Throughout the interviews, we discovered there exists high variability in decision making practices both within and between transplant programs. For example, some cardiologists immediately look at the echocardiogram imaging when they open an offer whereas others look at it towards the end of an assessment. This observation led us to incorporate important elements of *flexibility* and *customizability* in our final design. To accomplish this, we allow users to rearrange variables, pin and hide variables, and preset their variable ordering.

Another key observation we made during the interviews was that cardiologists want to always have all information available accessible even if they do not always consider it. To accomplish this, we incorporated different data views in order to declutter the display without eliminating any information. For example, most groups of variables have expanded and unexpanded views. The default view is the unexpanded view where only critical information is shown, and the users can easily toggle to the expanded view where all information about that variable is shown. This improves the overall organization, but still allows the user to easily access all the data if needed.

B. End-User Testing

End-user testing took place on a set of cardiologists distributed throughout the United States and Canada that yielded important feedback on our wireframe prototype. We arrived at a tab organization system consisting of 3 main tabs: (1) Donor Summary, (2) Donor Information, and (3) Candidate Information. The Donor Summary tab provides an overview of the donor offer and includes a direct comparison of key information between the donor and recipient, as well as illustrating a complete timeline of recorded information regarding the donor heart. The Donor Information tab was similar to the current DonorNet system, following a scrollable design; however, we included new features such as the ability to pin or hide the information. This functionality is key to reducing redundant information while also providing customizations for users. The ability to control variables that are hidden or pinned can be set within the settings tab, which provides other

customization options as well. In the candidate information tab, users may add, edit, or review existing transplant candidates to easily access necessary information during the decision-making process. This was integrated into the donor summary tab to allow users to select and directly compare candidate recipients.

The focus of end-user testing was on the Donor Summary tab, as its functionality and effectiveness were key to the success of the interface. Comments frequently stated across the interviews regarded information missing from the Donor Summary tab that included: when the patient was admitted to the hospital, when/how they were declared cerebral dead, and a narrative summarizing the incident that placed the patient in a critical medical state. The inclusion of this data onto the donor summary tab merges multiple streams of information, allowing users to develop a cohesive mental model.

C. Limitations

Time provided the biggest limitation as it constrained our ability to thoroughly review information and properly iterate on our design. Takeaways from our interview phase were aggregated by major themes and this largely informed the design. However, our design choices ideally could have been corroborated with end-user testing to collect quantitative data (e.g., task completion time). This could have identified discrepancies between the qualitative data collected as part of this study and actual performance data.

A subset of cardiologists from the United States and Canada also largely influenced the design. This could have resulted in bias to exist within the design based on this limited sample size; however, we do span more than one country in the proposed design. Moreover, the cardiologists who participated in end-user testing reviewed a non-functional wireframe prototype that illustrated a general layout of variables but did not include a fully functional display. Moving forward, an additional round of user testing would be conducted using a fully functional mockup dashboard. This would offer the ability to collect quantitative data that could inform the next iteration of the dashboard design.

D. User-Focused Design

Focusing our design process on the users rather than just the findings from our background research allowed us to produce a design best suited to the user's needs. Throughout the iterative design process, we sought to understand our users. The interview questions were framed to get a broad perspective on the current system and understand where challenges exist. The interviews also provide insights into the contexts under which the interface is used and how factors, such as time constraints, impact decision making. Ultimately, we

organized our findings from background research and commonalities noted across our interviews to explicitly define user tasks, goals, and pain and gain points. Our ideation process consisted of a series of wireframes detailing various screen layouts based on the current interface and new potential features derived from our interview insights. Once we had settled on aspects of the wireframes that we felt achieved the goals of the users, we began prototyping.

With our follow-up interviews, we were able to begin the validation and testing process by walking the users through our final design dashboard. While there is still testing to be done to assess the effectiveness of our new interface, we were able to get useful feedback from this first iteration.

Overall, the user perspectives were critical to building the infrastructure and selecting the content for a useful and inclusive design.

ACKNOWLEDGMENT

We would like to thank Sara Riggs for her guidance on this project. We would also like to thank Michael McCulloch, Michael Porter, and the pediatric cardiologists interviewed for their insight that guided our design process.

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