

“You don’t know what you don’t know”: A qualitative study of informational needs of patients, family members, and living donors to inform transplant system metrics

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Tweet: Interviews and focus groups with transplant patients, family members, and living donors inform how new transplant system metrics and patient-facing data presentations can support shared decision-making

Funding information

US Department of Health and Human Services

Abstract

Introduction: Informational needs and potential use of transplant metrics, especially among patients, remain understudied and a critical component of the transplant community’s commitment to patient-centered care. We sought to understand the perspectives and needs of patients, family members/caregivers, living donors, and deceased donor family members.

Methods: We examined decision-making experiences and perspectives on the needs of these stakeholder groups for data about the national transplant system among 58 participants of 14 focus groups and 6 interviews.

Results: Three major themes emerged: 1) informational priorities and unmet needs (transplantation system processes, long-term outcomes data, prelisting data, patient-centered outcomes, and ability to compare centers and regions); 2) challenges obtaining relevant and trustworthy information (patient burden and effort, challenges with medical jargon, and difficulty finding trustworthy information); and 3) burden of facing the unknown (stress and anxiety leading to difficulty processing information, challenges facing the transplant journey when you “don’t know what you don’t know”).

Conclusion: Patient, family member, and living donor participation in shared decision-making has been limited by inadequate access to patient-centered information. New metrics and patient-facing data presentations should address these content gaps using best practices to improve understanding and support shared decision-making.

KEYWORDS

health services research, metrics, patient-centered

1 | INTRODUCTION

In 2020, the Health Resources and Services Administration (HRSA), part of the US Department of Health and Human Services that administers the Scientific Registry of Transplant Recipients (SRTR) contract, directed SRTR to identify metrics to assess national transplantation

system performance and support informed decision-making by critical audiences. Informational needs and potential use of transplant metrics, especially among patients, remain understudied and a critical component of the transplant community’s commitment to patient-centered care. This focus on the informational needs of patients, donors, and family members was also highlighted in the National Academies of

Sciences, Engineering, and Medicine's (NASEM's) 2022 report *Realizing the Promise of Equity in the Organ Transplantation System*, which calls for an increase in tools for shared decision-making and education of patients, as well as education for the public and increased transparency to maintain trust in the system.¹ This qualitative study examines the perspectives of patients, family, and donors who have relied on existing information about organ transplantation to make informed decisions, such as whether to seek transplant, where to get transplanted, and what kinds of questions should be considered in these decisions.

Previous research has shed light on transplant information needs and gaps that are related to living donation.²⁻⁵ Other qualitative studies have identified information patients and caregivers consider when selecting a transplant center,⁶⁻¹¹ as well as the decision support needs of kidney transplant candidates and their family members.^{12,13} These analyses have segregated participants by organ type and participant type (recipients, donors, deceased donor families), and most have not described experiences seeking care beyond clinical interactions with centers. Gaps remain in understanding the patient, donor, and family experience navigating the transplant system, and their associated needs regarding data required to maximize patient autonomy and shared decision-making. In addition, although reports and data about solid organ transplantation are publicly available for non-professionals on the SRTR website (Supplemental Material S1), the current technical content including national transplant data trends and adjusted program-specific reports do not make data easily accessible and are not consistent with best practices to improve equity in access to information.¹⁴ Therefore, use of these resources (e.g., SRTR) by patients, their family members/caregivers, living donors, and deceased donor family members, who represent the primary stakeholders of the US transplantation system, has been limited.^{11,15}

Lack of patient-centered discussions and key stakeholder engagement have contributed to disparities in transplant access and outcomes, lack of satisfaction and trust in the system, and a reduction in patient autonomy to make informed decisions about their care.¹⁶⁻²⁰ This qualitative study examined perspectives of patients, family members/caregivers, living donors, and deceased donor family members to better understand the informational needs and experiences navigating the US transplantation system of these critical audiences. These data may inform the development of informational resources by SRTR, transplant centers, and other organizations.

2 | MATERIALS AND METHODS

This study was conducted under a federal contract (HRSA contract 75R60220C00011 for SRTR) to evaluate, improve, or otherwise examine public benefit or service programs and is exempt from institutional review board oversight under the Public Benefit and Service Program (Exempt Category 5) provisions of 45 CFR 46.101(b)(5).

A semistructured focus group guide was first adapted from previous kidney transplant candidate and recipient qualitative studies,^{11,12} and guided by the expanded Ottawa Decision Support Framework²² with input from a multidisciplinary steering committee for SRTR's met-

rics initiative. Finally, the guide was piloted with patients, donors, and family members in the 10-member SRTR Patient and Family Affairs Subcommittee before data collection/recruitment.²³ (Table S1). The discussion guide began with general questions about seeking and using information during the transplantation or donation process. Participants were then shown the SRTR website and types of data that exist, and perceptions were sought about existing public SRTR reports. Discussions reflected lived experiences, evolution of perspectives, and consideration of examples and counterexamples.

2.1 | Stakeholder group and participant selection

We sought perspectives from all nonprofessional stakeholders in the US transplantation system to understand the spectrum of recognized and unrecognized needs among transplant candidates, recipients, recipient family members, living donors, and deceased donor family members. Participants included adults (18 years and older) from all solid organ groups. Non-English-speaking participants were excluded. No compensation was provided. Focus groups were stratified by organ type or stakeholder type (e.g., deceased donor family members in one focus group).

Participants were recruited from across the US using multiple phases to ensure that purposive sampling criteria were met. Sampling criteria, identified through literature review, included organ type, stakeholder type (e.g., family members, donors, patients), gender, US region, and self-identified race (given disproportionate burden of organ failure and persistent disparities among non-White patients²⁴⁻²⁸). A notification about the study was disseminated through social media as well as advocacy and transplant organizations, and interested participants contacted the research team. Additional details about how participants were identified and purposefully sampled are provided in Supplemental Material S2. Participants provided verbal consent. Recruitment continued until 1) participants from all identified stakeholder groups were represented, and 2) saturation in the themes across the groups emerged. Researchers had no prior relationship with participants. Interviewers disclosed their relationship with SRTR and the goal of the study to understand the informational needs of patients, donors, and families about the US transplantation system. Researchers' demographic information is provided in Table S2.

2.2 | Data collection

The interviews and focus groups were conducted via virtual video (Zoom) November 2021 through February 2022; only the interviewers and participants attended. Interviews and focus groups were moderated by A.H. and C.R.S., researchers trained in qualitative research methods. One researcher conducted the interview while the other took field notes. If a focus group was scheduled but only a single participant attended, or additional attendees joined late, the focus group was instead conducted as one or more individual interviews. Moderators explained confidentiality and emphasized that no identifiable

information would be shared. Member checks were performed by restating and summarizing comments; transcripts were not sent to participants for editing. Sessions were audio-recorded and professionally transcribed verbatim.

2.3 | Analysis

A preliminary codebook was developed deductively, following the questioning structure of the interview guide and allowing for emergent codes.^{29,30} Three analysts (J.P., K.G., W.T.M.) initially coded three transcripts independently, then discussed and refined the coding, and added new codes. The codebook was revised through weekly deliberative meetings. The initial transcripts were recoded, and an additional three transcripts were independently coded by each analyst using NVivo (QSR International Ltd, 2020). Intercoder reliability was calculated with specialized coding software (NVivo) and assessed based on the Kappa measures of each code of $>.9$. Following consensus among the research team (all authors), the codebook was finalized, and all transcripts (the initial six plus all others) were coded with the final codebook. The analysis included a combination of inductive and deductive coding of emergent concepts, themes and subthemes, using both open and focused codes. Transcripts were open coded and axial coded through an inductive, thematic analysis.^{29,31} All authors iteratively developed themes until consensus was reached.

3 | RESULTS

3.1 | Participants

Overall, 58 patients, family members/caregivers, living donors, or deceased donor family members participated in 14 focus groups and six interviews lasting 60–120 min. Groups ranged from two to six participants. Characteristics of participants are provided in Table 1. In total, 28 patients, 12 patient family members, 11 living donors, and 7 deceased donor family members participated. Some participants had prior experience with transplant organizations and advocacy. Prior knowledge of the existence of SRTR was also mixed, with some having visited the SRTR website and others never having heard of SRTR. One family member group comprised pediatric recipient family members only.

Participants reported seeking information from a wide range of sources (Table 2), and most participants reported searching for information on the internet. The main source of information varied by stakeholder group. For example, deceased donor family members received most of their information from OPOs. Social workers as a source of information were reported primarily by Black kidney transplant recipients. While uncommon overall, the SRTR or OPTN websites were cited as sources of information chiefly by living donors. Transplant centers and providers were cited as sources of information most by candidates and recipients.

TABLE 1 Participant characteristics and focus group composition.

Characteristic	N = 58 ^a
Age, mean (SD)	54.7 (11.2)
Sex, n (%)	
Female	28 (48.2)
Male	20 (34.5)
No answer	10 (17.2)
Race and ethnicity, n (%)	
Asian	3 (5.2)
Black	7 (12.1)
Indian American	1 (1.7)
Native American	1 (1.7)
White	35 (60.3)
No answer	11 (19.0)
Distance to center, n (%)	
Less than 1 h	9 (15.5)
1–4 h	22 (37.9)
More than 4 h	12 (20.7)
No answer or not applicable	15 (25.9)
OPTN region	
1	0
2	16 (27.6)
3	2 (3.4)
4	1 (1.7)
5	6 (10.3)
6	0
7	5 (8.6)
8	2 (3.4)
9	4 (6.9)
10	6 (10.3)
11	1 (1.7)
No answer	15 (25.9)
Participant type	
Kidney recipients	10
Kidney candidates	4
Liver recipients	5
Heart recipients	2
Lung recipients	5
Pancreas recipients	2
Living donors	11
Family members/caregivers of patients	6
Pediatric recipient family members	6
Deceased donor family members	7

^aDemographic data for some participants are incomplete, therefore numbers may not sum to 100%.

TABLE 2 Current sources of information for patients, donors, and family members.

Professional organizations

- Transplant providers and social workers
- Organ procurement organizations
- Insurance companies
- Organ Procurement and Transplantation Network (OPTN)/United Network for Organ Sharing (UNOS)
- Scientific Registry of Transplant Recipient websites

Internet sources

- Google
- YouTube
- Social media

Other sources

- Other patients, donors, and family members
- Peer support groups

3.2 | Thematic analysis

Three major themes and related subthemes emerged: informational priorities and unmet needs, challenges obtaining relevant and trustworthy information, and the burden of facing the unknown. Themes are summarized in Table 3. A synthesis of patient and family informational needs and current gaps, and the organization or entity positioned to address these needs, is provided in Table 4.

3.3 | Theme 1: Informational priorities and unmet needs

3.3.1 | Information priorities about the US transplant system

Although stakeholders' informational priorities varied greatly by stakeholder group, some commonalities emerged. Participants most commonly reported seeking information and metrics regarding "outcomes" or "success rates" after transplant. Waiting times and center locations were also commonly sought.

"Two things: number one, figuring out wait time, estimated wait time... Then, the second thing was trying to determine outcomes." (Patient family member)

Most reported wanting more long-term outcomes, rather than only 1-year patient and graft survival. Pediatric family members were particularly interested in longer-term (>10-year) outcomes. Several groups expressed interest in regional variation of transplant rates and organ availability.

Other priorities differed between stakeholder groups. Recipients and candidates wanted more information about the waitlist evaluation criteria and process, as well as the organ allocation process and metrics that illustrate a center's willingness to take risks in terms of both candidates and donor organs. Living donors reported interest in information

about insurance coverage and cost, whether a center participated in paired exchanges or the National Kidney Registry, and information about postdonation patient-centered outcomes beyond mortality (e.g., symptoms, other health effects). Kidney recipients reported interest in access to information about organ offers being declined by centers on behalf of patients, as well as outcomes broken down by race and ethnicity.

Deceased donor family members reported informational needs relating to helping families cope with the donation process and ensuring that the gift of deceased donor organs was maximized. Donor family members expressed interest in information about how OPOs and donor hospitals honor the donors (e.g., moments of silence, honor walks). Like recipients and candidates, deceased donor family members were also interested in how organs are allocated and how transplant centers differ in their acceptance rates as well as the rates of recovered organ nonuse. Donor families were also interested in information that can be used for advocacy work to improve donation and access to transplant.

3.3.2 | Comparing transplant centers and regions

Most candidates, recipients, family members, and living donors reported wanting metrics that allow them to compare transplant centers to each other in selecting a site for care. Others expressed a need to be able to compare regions to each other, or center outcomes to national averages. Comparing centers based on time to listing, waitlisting criteria, and posttransplant outcomes were especially important.

"... if you go to this hospital, it could be anywhere from 2 to 4 years. Where if you went to a hospital, the next hospital, you probably could do less, get listed within 6 months... Yes absolutely that would matter." (Liver recipient)

3.3.3 | Unmet informational needs about the US transplant system

Much of the information cited by patients, family members, and living donors is not currently available. For example, data on patients who are referred for transplant but not yet listed was of interest, including the time from evaluation to listing. Many expressed a need for more patient-centered outcomes data beyond survival or graft failure, such as the potential symptoms experienced after living donation and quality of life (e.g., whether help is needed for activities of daily living, ability to work full time).

"I can't imagine I'm the first person in the history of kidney donations to have a numb left leg after surgery. And yet, [doctors] haven't heard of it. And this is probably because that data is not collected... no one knows about it." (Living donor)

TABLE 3 Illustrative quotations.

Themes and subthemes	Quotations (stakeholder type)
Theme 1: Informational priorities and unmet needs	
Information sought	<p>"Distance. And success rates... How long the transplant lasted and how long the patient lasted." (Kidney candidate interview)</p> <p>"How many transplants do you do a year?"; "What are the survival rates of your patients?"; "How long do people wait for a transplant here?"; you know, "What's the average length of time after transplant before patients are discharged from the hospital?." (Lung recipient)</p> <p>"Initially, when I looked, I was looking at numbers. 'What were your success rates?' "How many transplants have failed?' Just statistical information about the particular center that I was, you know, that they provided as far as what their success rates are." (Pancreas recipient)</p> <p>"I know that several times over the past few years they have changed the allocation process, and I know they've done it for different organs. I've tried to look at it. It gets a little above my head really fast" (Heart recipient)</p> <p>"About average time on the wait list. And certainly want to know more about what the process is, if I can get anybody to tell me on second calls or third calls down the list." (Kidney candidate)</p> <p>"Outcomes for the type of surgery that it would have been, and I could see okay, here are the risks. Here are the risks specifically for this center." (Living donor)</p> <p>"... what is the out-of-pocket cost for a kidney donor... Do they cover parking, like yeah, these kinds of things can add up to somebody who is trying to donate, I would imagine, follow up appointments, that kind of thing, or if there were complications?" (Living donor)</p> <p>"The honor walk that [another participant] was talking about, incredibly impactful to me and my family. It wasn't shared on social media. I had none of that information prior to this whole process." (Donor family member)</p> <p>"How about volunteer experiences, events, ways to get involved? I mean those things are really important. Again, because I think I sought them out. I wished it came to me a little bit more. And you don't have to be a donor family or a donor friend to get involved." (Donor family member)</p>
Comparing transplant centers and regions	<p>"I like the idea of making or considering having two centers side-by-side to compare." (Kidney recipient)</p> <p>"I did compare to a couple others just to see how they compared to other donor programs. There wasn't really anything that compared program to program that I was able to find. But when you looked at anecdotal information online from people who had had experiences at those others, whether it was Chicago or it was New York or it was on the West Coast, that was really the only information that you had." (Living donor)</p> <p>"... that would be very valuable to a patient and the family. To be able to compare." (Kidney candidate)</p> <p>"But I found it helpful to be able to compare centers... I found that that information was helpful." (Living donor)</p>
Unmet informational needs	<p>"... if you are looking or you're thinking about underserved communities, community where they're affected by certain social determinants of health or maybe even health illiteracy in access, mental health support is really—it's critical. I think it's important to prioritize your mental health going through that. But is there access to resources? Do transplant centers have the resource for people to talk to, to vent to, to get support through these things? I would just want to know like how are you supporting—health equity? How are you prioritizing mental health?" (Kidney recipient)</p> <p>"This is a beef I have with SRTR data, and this is driven by the industry is that it focuses on the 1-year mark. As parents, and we're all through parents here, we really focus on the next 17-18 years or beyond." (Patient family member)</p> <p>"What kind of support do you have for transplant recipients post-transplant? Even pre-transplant while you're on the waiting list.' [...] I would probably ask for pre-transplant support group, maybe even a post -or a transplant support group, as well. Mental health is so important" (kidney recipient)</p> <p>"I just wonder are any of the statistics that they're looking for post-transplant I guess side effects, things like that? Long-term? Short-term? Is there any of that information that's going to be included? I think that would be something." (Pancreas recipient)</p> <p>"I feel like the surgery is just a small part of the whole equation. You know, I mean, how do we deal with the insurance because I'm telling you, you know, they go back and forth all the time. like with mine, the insurance kept denying because they kept saying I'm not my mom's dependent anymore. Like I know I am not a dependent, but you know, she's getting my liver. really knowing what facilities and how do they handle that with all of that other stuff because honestly, the health part of it, the surgery and the aftercare, that was the smaller piece of it" (Living donor)</p> <p>"You know, again, the support groups and knowing what I know now and having done it once already, I would definitely go directly to SRTR and ask for specific outcomes data broken down in as granular a fashion as possible; possibly even breaking it down by race and ethnicity, of course, mortality. I don't know if failed transplants is something that can be tracked or return to dialysis." (Kidney recipient)</p>

(Continues)

TABLE 3 (Continued)

Themes and subthemes	Quotations (stakeholder type)
	<p>“do they use steroids or not; what is their protocol for immunosuppression? Do the kids who are young do they consider having a G-tube put in so they can get water overnight if they are still sleeping 12 hours? Things like that I would make a decision based on that now [...] It is not enough to know what their procedures are, and their protocols but it also needs to know what that means in laymen’s terms because I would not have had a clue.” (Pediatric recipient family member)</p> <p>“I’ve wondered what kind of inquiries are made to make sure, to ensure that the organ that someone is about to receive is going to be reasonably cared for? If, like, if someone has had a questionable lifestyle, do you want to give them a liver if they’re not committed to, maybe not drinking anymore?” (Donor family member)</p> <p>“I also think it’s important for people to know that your organ procurement center is not always at your hospital. Sometimes it’s offsite. Which I didn’t know about until we went through our experience and left at 3 a.m. in the morning to go from the hospital to the organ procurement center.” (Donor family member)</p>
Theme 2: Challenges ascertaining relevant and trustworthy information	<p>“But data wise, I would say, there wasn’t much available to me. I look now just out of curiosity about like who’s the longest living recipient and like are there certain diseases that have better outcomes. And I look at a lot of published articles, but it’s very disorganized. I keep thinking, ‘I wish there was one place I could go and I could put in “pulmonary hypertension,” see how many patients are living, you know, x amount of time.” (Lung recipient)</p> <p>“As I mentioned, we were given a stack of papers to sort through. I looked at the papers and then figured out, well, maybe I should actually look at the OPTN website. I preferred to go through that” (Patient family member)</p> <p>“And that was like you felt like you were digging underneath and you had to kind of like Google and see what happened. Like somebody who had a death at their hospital, oh then that must be a bad place, you know or something like that. But how do you get that? Is that information that you share? Certainly nobody’s volunteering it.” (Living donor)</p> <p>“I do find there isn’t enough information shared willingly that I certainly have to ask a million questions and do research of my own. And that’s been a constant.” (Kidney candidate)</p> <p>“the medical community, despite kind of the scientific overview, tends to speak in vague terms. It was difficult to get specific data that would back up those terms. A couple of examples. ‘You’re a good match.’ I don’t know what that means as we were trying to make a decision to do a direct donation or a paired donation. Good match didn’t help us.” (Living donor)</p> <p>“And the only thing I had saw about kidney transplants was based on what I saw on TV. And, you know, TV and movies, someone is told today they need to get a kidney. Tomorrow they have a kidney.” (Kidney candidate)</p> <p>“I think your question about where we got this information, is it readily available? It is but where to get accurate information is a struggle in every capacity on the Internet these days...what’s factual and what’s not is, I think, a challenge” (Donor family member)</p>
Theme 3: Burden of facing the unknown	<p>“For the patient who’s on the waiting list ... we’re stressed. We don’t want to think. Our mind is already in a million places. That was really the situation that I was in when I had that big stack of papers. I couldn’t decide what was relevant, and I think it was only because I’m data oriented that even I set myself back from the emotional side and think of it in that manner, but another where you can do that.” (Patient family member)</p> <p>“Transplant clinics aren’t always forthcoming with information. I mean, we shouldn’t have to ask for everything. But you have to know what to ask. Like I didn’t know and I guess a lot of other people looking for transplant, they don’t know. And even if you do know what to ask, you don’t know where to look, you know” (Kidney recipient)</p> <p>“Without knowing some type of connection, you’re lost without having someone else who’s in a similar situation who can help you. I think that’s a key thing to know. How does somebody even know to go to SRTR, let alone what the data means?” (Patient family member)</p> <p>“More often than not, you’re gonna see people in clinic who are afraid to ask questions or don’t think they’re educated enough to ask the question.” (Heart recipient)</p> <p>“...to answer your question though, it is a little bit of you don’t know what you don’t know.” (Living donor)</p>

Abbreviations: OPTN, Organ Procurement and Transplantation Network; SRTR, Scientific Registry of Transplant Recipients.

TABLE 4 Content gaps identified by patients, patient families, living donors, and deceased donor families.

Content gap	Who should provide this information	Expressed need from stakeholders
Mental health services, support groups, housing available, assistance with social determinants as barriers to transplant	Transplant center	Patients and families need to be able to identify what resources are available at a center
Acceptance criteria	Transplant center	Patients and families need to be able to access waitlist and living donor acceptance criteria to avoid futile waitlist and living donor evaluations
Out-of-pocket costs for transplant workup, procedure, posttransplant medications	Insurance company	Patients, family members, and living donors need access and transparency in out-of-pocket costs
Comparing center waitlist and posttransplant outcomes, long-term data on transplant outcomes	SRTR	Patients and family members need increased awareness of the availability of these data, patient-centered data presentation, and help navigating to information they may not realize is important
Data about patients referred but not waitlisted, time to waitlisting	New data collection	Patients and family members want data on transplant access, to improve decision-making about transplantation and transplant center choice
Patient-centered outcomes including quality of life, symptoms	New data collection	Patients, family members, and donors need better information about what to expect to help with informed decision-making and coping
OPO practices to support families and honor deceased donors	OPO	Deceased donor family members want to be able to share and advocate for best practices in deceased donor family care

Abbreviations: OPO, organ procurement organization; SRTR, Scientific Registry of Transplant Recipients.

Participants wanted granular center-level information, such as center participation in living donor exchanges, variation in surgical techniques, or long-term steroid use. Many were also interested in psychosocial support data, such as the availability of support groups or patient and family networks, mental health services, or assistance with psychosocial barriers to health.

"You know, if you are ... thinking about underserved communities, community where they're affected by certain social determinants of health or maybe even health illiteracy in access, mental health support is really—it's critical."
(Kidney recipient)

3.4 | Theme 2: Challenges ascertaining relevant and trustworthy information about the US transplant system

The examples of information sought by participants was often not available in a central location. Family members reported expending great effort and energy to obtain information, including calling or visiting multiple transplant centers.

"So, I physically was calling centers myself and asking. It was very labor-intensive, very difficult." (Patient family member)

In addition, when information was provided, it often contained medical jargon and few visual aids, so was not helpful for many participants.

"... it made such sense once they explained it in layman's terms because you can read everything that you want to read, but you may not understand the technical terms and verbiage. There were times I was back and forth with the glossary...." (Liver recipient)

"That was really the situation that I was in when I had that big stack of papers. I couldn't decide what was relevant..."
(Patient family member)

All stakeholder groups expressed difficulty in finding reliable information about the US transplant system, and consequently, reported reliance on social media such as transplant Facebook pages, expressing concerns about the reliability of that information.

"So, we're starting from a massive information deficit. And we're not medical experts and you know, so we go consult Dr. Google and see what we can learn." (Living donor)

"...where to get accurate information is a struggle in every capacity on the internet these days. So what's factual and what's not is, I think, a challenge." (Deceased donor family member)

Most participants were either unfamiliar with or had minimal exposure to data available through SRTR. When asked to reflect on what information they would have wanted to know about the system when making decisions, knowing what they know now, responses were very similar to previous responses. However, on viewing the range of data

currently available through SRTR (e.g., waitlist survival), participants overwhelmingly viewed this as a critical resource of information that patients may not have known was important. Participants reported that this information could serve as a trustworthy alternative to social media, such as to provide information about variation between centers, help manage expectations for wait times and patient outcomes, build confidence in decision-making, and facilitate shared decision-making with providers (e.g., serve as an evidence-based discussion guide).

"I definitely think if we had known about this website during the process, even if I couldn't make heads or tails of the information, my brother and my mother might have been able to navigate through and just see what I was going through or decisions that would have to be made..." (Liver recipient)

"... if, [the] nephrologists came and said, 'You need a transplant' and this [SRTR website] is what I did, I now have a start... This helps a whole lot for someone that knows absolutely nothing. I absolutely love this." (Kidney candidate)

Participants also noted the importance of information to generate hope for candidates and families learning about transplantation, and to support patient advocacy work to increase awareness of transplantation and organ donation.

"... I had a lot of pushback from everybody, like my family, my friends... I wish I had more information to give to those people, ... to say, like... I am going to live. It's going to be fine." (Living donor)

"And you're going to give a lot of people a lot of hope and a lot of information because a lot of people are nervous about this process because they just don't know. They don't know what the outcomes are." (Lung recipient)

3.5 | Theme 3: Burden of facing the unknown

All groups expressed feeling stress, fear, and anxiety associated with end-stage organ disease or the loss of a loved one who has donated their organs. They described how feelings of uncertainty about the US transplant system led to more fear and anxiety. Many described their stressed state exacerbating the challenges of navigating complex information and adding to the emotional burden. Participants explained that patient-facing metrics and information need to be curated and presented in ways that maximize comprehension, and should be more readily accessible to reduce emotional burdens.

"For the patient who's on the waiting list ... we're stressed. We don't want to think. Our mind is already in a million places." (Patient family member)

In addition, participants noted that even if information is available, patients and families often do not know what information they should be seeking to make decisions about their treatment. All stakeholder groups overwhelmingly expressed a need to guide patients and families to the questions that they should be asking, because they "don't know what they don't know." After viewing and gaining awareness of the available public data on the SRTR website, participants emphasized the need to lead patients to relevant information that they may not yet realize is important.

"But you have to know what to ask. Like, I didn't know... And even if you do know what to ask, you don't know where to look, you know?" (Kidney recipient)

"I made a comment earlier that one thing we talk about a lot ... is that you do not know what you do not know. A lot of times that leads to a lot of fear and anxiety." (Pediatric recipient family member)

4 | DISCUSSION

This study of diverse stakeholders in the transplant community across the US reveals critical informational gaps identified by patients, donors, and families, key stakeholders who have historically been under-engaged in transplantation health services research. Patients, donors, and families often relied on nonscientific sources of information, and few had the information they needed to make decisions about their care. These barriers in access to information are surmountable, but require an understanding of the specific needs of stakeholders. This study helps elucidate what information these stakeholders need to engage in shared decision-making in their transplant journey.

Access to information constitutes the foundation of shared decision-making, as highlighted in the 2022 OPTN Ethics Committee paper on transparency in program selection,³² the NASEM report on realizing equity in transplantation,¹ and HRSA initiatives to improve the system to promote transparency and meet the needs of patients and families.³³ Candidates, recipients, patient family members, living donors, and deceased donor family members represent a heterogeneous group of critical stakeholders, with needs that vary across groups—and even within groups, depending on the stage of the individual's transplant journey. However, common themes emerged, including a desire for access to accurate information that is tailored to a nonmedical audience, the ability to compare centers, data about transplant evaluations, and help navigating the information and coping with decision-making burdens.

This study highlights opportunities for the SRTR and other organizations, including transplant centers, to better support patients and family members as they navigate the transplantation system. Patients and families communicated the need to develop both metrics and reliable information tailored to a nonprofessional audience. Consistent with other studies on patient education,^{34,35} this study revealed gaps in both the comprehensibility and content of currently

available information about the transplant system. Although SRTR is one source, clinicians, health educators, and others can also adapt data presentations to better serve patient and family stakeholders by taking a human-centered design approach including ongoing stakeholder engagement,³⁶ minimizing jargon, reducing statistical displays,³⁷ and improving navigation with interactive features to help guide users from different stakeholder groups to view data relevant to their needs. Decision support tools³⁸ can also help guide patients' use of information and metrics, including those provided by SRTR. Content should also inform patients and families about the factors affecting patient-centered outcomes that they may not be aware of, such as access to transplant or variation in waitlist criteria. These approaches will facilitate the goal of addressing the needs identified in this analysis, such as exploring ways to convey how analyses account for differences in complexity of patients served by a center or what centers are more willing to list and transplant patients like them. This approach is also critical to improving equitable outcomes, given the intersection between health literacy and equitable outcomes.³⁹⁻⁴¹ Finally, analyses and data presentations can also be used to highlight ongoing inequity in solid organ transplantation, thus informing the community where progress must be made.⁴²

Participants also highlighted the use of data by patients and family members beyond making personal decisions about transplantation. Although the need for metrics to help choose a transplant center and compare centers is important to many, patients and family members identified additional needs for information, including helping to manage expectations, educating other friends and family members, participating in advocacy to support other patients and promote change, and providing comfort to deceased donor family members.

While much of the data sought by our most critical stakeholders are currently available, these data highlight important gaps. Most important, patients and family members first need to be aware of the existence of transplant system data to maximize the potential benefits of creating patient- and family-centered metrics and information. In addition, critical data elements, such as patient-centered outcomes and data on patients before waitlisting, are not currently collected.

The perspective of patients and family members is a critical input into tool development to support clinical decisions and work with transplant professionals to map out the development of metrics to drive ongoing quality improvement of the US transplantation system. Future data collection and quality metrics could promote patient-centered care by including patient-centered outcomes, or encourage increased access to transplant by developing patient-friendly prelisting metrics. Critically, long-term data of any kind, including patient-centered outcomes, are not collected on living donors, and efforts to collect these data to inform those considering living donation should be prioritized.⁴³⁻⁴⁵ These data can also inform transplant centers regarding what information to provide on their own websites, such as the availability of patient and family support groups, participation in living donor exchanges, and important listing criteria to avoid futile transplant evaluations.

This study has several strengths that add to our understanding of the needs of patients, their families, living donors, and deceased donor

families. This is a uniquely large national sample of patients and family members, representing experiences from diverse organs, regions, and stages along the transplant journey. Purposeful sampling ensured that data included historically underrepresented communities in transplantation, specifically Black participants. Participants also included a mix of participants with and without prior knowledge of the transplantation system and SRTR. Finally, the analytic approach included multiple analysts who differed from the researchers who conducted the focus groups and interviews, which allowed for the introduction of coding perspectives from multiple researchers with differing experience with the transplant system and differing roles in data collection.⁴⁶ However, several limitations should be noted. While a broad spectrum of perspectives from diverse participants provides insight into the large range of stakeholder experiences, perspectives expressed within some of these subgroups should be interpreted with caution, because the study was not designed to identify meaningful differences between these subgroups. For example, purposeful sampling was used to ensure participation by Black patients in order to be representative and inclusive, not to identify differences between the experiences of different racial groups. We did not get perspectives from non-English-speaking patients and family members and did not achieve adequate representation of Latina/o/x or American Indian/Alaskan Native patients and family members. Future work should intentionally recruit members of these communities, as well as assessing how information is received and understood by users from a range of educational background. Recruitment was conducted primarily through patient, donor, and family education and advocacy groups, so those who are not yet engaging with or aware of these organizations may have unique perspectives. Most participants were recipients rather than candidates, and recall bias may affect what patients and family members report experiencing when they were first interacting with the transplantation system, especially given that many of the information gaps concern the pre-transplant process. Finally, as with all clinical research, the patients and family members who willingly participate in research may differ from those who do not.

5 | CONCLUSION

In conclusion, patients, family members, and living donors have informational needs that can be better supported by clinicians, educators, and the SRTR. Ongoing engagement with our most important stakeholder groups while developing and improving patient-centered information will be critical to achieving the potential benefits of SRTR data.

AUTHOR CONTRIBUTIONS

Concept/design: Allyson Hart, Cory R. Schaffhausen, Jon J. Snyder; Data collection: Allyson Hart, Cory R. Schaffhausen, Jon J. Snyder; Data analysis/interpretation: Allyson Hart, Cory R. Schaffhausen, Warren T. McKinney, Kristina Gonzales, Julia Perugini, Keren Ladin; Drafting article: Allyson Hart, Cory R. Schaffhausen, Warren T. McKinney, Kristina Gonzales, Julia Perugini, Keren Ladin; Critical revision of

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ACKNOWLEDGMENTS

This work was conducted under the auspices of the Hennepin Healthcare Research Institute (HHRI), contractor for the Scientific Registry of Transplant Recipients (SRTR), as a deliverable under contract no. 75R60220C00011 (US Department of Health and Human Services, Health Resources and Services Administration, Health Systems Bureau, Division of Transplantation). The US Government (and others acting on its behalf) retains a paid-up, nonexclusive, irrevocable, worldwide license for all works produced under the SRTR contract, and to reproduce them, prepare derivative works, distribute copies to the public, and perform publicly and display publicly, by or on behalf of the Government. The data reported here have been supplied by HHRI as the contractor for SRTR. The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy of or interpretation by SRTR or the US Government. The authors thank SRTR colleague Anna Gillette for manuscript editing.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Deidentified data are available on reasonable request to the authors.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Hart A, Schaffhausen CR, McKinney WT, et al. "You don't know what you don't know": A qualitative study of informational needs of patients, family members, and living donors to inform transplant system metrics. *Clin Transplant*. 2024;38:e15240. <https://doi.org/10.1111/ctr.15240>