



Achieving Person-Centered Metrics: A Qualitative Study of Informational Needs of Patients, Caregivers, and Living Donors About the US Solid Organ Transplant System

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Introduction

- In 2022, the Scientific Registry of Transplant Recipients (SRTR) convened the *People Driven Transplant Metrics* consensus conference to identify metrics to assess transplant system performance and information to support decision-making.
- SRTR organized focus groups in advance of the conference to examine decision-making experiences and perspectives on metrics from patients, donors, and caregivers.

Methods

- Interviews and focus groups examined:
 - experiences searching for and using information
 - relevance and acceptability of that information when navigating the transplant system
 - feedback on alignment of existing SRTR reports with patient and caregiver needs
- Participants were purposively recruited to reflect all solid organ groups.
- Study sessions were stratified by stakeholder group (eg, candidate, recipient, donor, family / caregiver).
- Transcripts were analyzed using a combination of deductive and inductive approaches to thematic analysis.

Results

Table 1: Participant Characteristics

Characteristic	Value
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)
Participant type, n	
Kidney recipient	7
Black kidney recipient	3
Kidney candidate	4
Liver recipient	5
Heart recipient	2
Lung recipient	5
Pancreas recipient	2
Living donor	11
Family /caregiver of patient	6
Pediatric recipient family member	6
Deceased donor family member	7

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Theme 1: Informational priorities and unmet needs

- “Two things: number one, figuring out wait time, estimated wait time...Then, the second thing was trying to determine outcomes.” (Family member)
- “I remember one of the things that I was obsessed with when I was researching was, I wanted to now who had a donor death” (Living donor)
- “If I were investigating where to go for a transplant, I think that would be very valuable to a patient and the family. To be able to compare.” (Kidney candidate)
- “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)

Theme 2: Challenge obtaining relevant and trustworthy information

- “I definitely think if we had known about this [SRTR] 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)
- “So, I physically was calling centers myself and asking. It was very labor-intensive, very difficult.” (Patient family member)
- “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)
- “So 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. So what’s factual and what’s not is, I think, a challenge” (Donor family)

Theme 3: Burden of facing the unknown

- “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 family member)
- “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)
- “I think some of the stuff for potential donors though, is like you don’t know what to ask.” (Living donor)

Conclusions

- Inadequate access to patient-centered information limits opportunities for patients and related stakeholders to participate in shared-decision making.
- Ongoing engagement with multiple stakeholder groups in the development of novel metrics and patient-facing information will ensure alignment with values and needs.
- Participants’ recommendations align with the final recommendations from the consensus conference.¹
- Conference recommendations included 160 areas of focus and SRTR will create new metrics, explore novel data collection, and modify existing website and reports.

Citations

1. Snyder JJ, Schaffhausen CR, Hart A, Axelrod DA, Dils D, Formica RN Jr, Gaber AO, Hunt HF, Jones J, Mohan S, Patzer RE, Pinney SP, Ratner LE, Slaker D, Stewart D, Stewart ZA, Van Slyck S, Kasiske BL, Hirose R, Israni AK. Stakeholders’ perspectives on transplant metrics: The 2022 Scientific Registry of Transplant Recipients’ consensus conference. *Am J Transplant.* 2023. <https://doi.org/10.1016/j.ajt.2023.03.012>

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