


# The Impact of Engaging Transplant Recipients in Health Care Policy Deliberations

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## Introduction

In September 2020, the Health Services and Resources Administration (HRSA) established the Scientific Registry of Transplant Recipients (SRTR) Task 5 Initiative to develop performance metrics for the national transplant system by engaging critical audiences.<sup>1</sup> In July 2022, the SRTR under a contract from HRSA, hosted a consensus conference in suburban Minneapolis, Minnesota, to discuss the information and metrics governing the solid organ transplant community.

The event convened individual transplant patients, transplant physicians, transplant professionals, organ procurement organizations, patient advocacy organizations, transplant societies, and federal agencies to identify meaningful transplant system measures. It is critical for high-level deliberations that will impact complex care processes to include lived experiences of system users.<sup>2,3</sup> Without patient involvement, it is more likely that the resulting system measures will not encourage the values, operational enhancements, and aspirations patients have for transplant outcomes.

## Relevancy to Treatment

Historically, the patient voice has been minimally included in transplant quality and performance improvement discussions. Although patients have increasingly been included as representatives in scientific discourse, it is often members of advisory boards and tacit committees. This tactic often leads to patient desires being sidelined when the functional deliberations take place. Both HRSA and SRTR staff recognized the value of more substantial patient inclusion in what have traditionally been professional spaces. As system measures influence outcomes and outcomes influence operations, including the views of all stakeholders at the foundation of the Task 5 Initiative was important to realizing a patient-driven transplant system.

## Improving Transplant Outcomes

Participants proclaimed that SRTR staff successfully bridged the gap between transplant donor/recipient stakeholders and the professionals tasked with cultivating an efficient and equitable transplant system. The ability of the conference to achieve its

stated goals not for patients, but with patients, suggests that some critical actions may be pulled from the event for other professional organizations to implement. Recipient, donor, and family member attendees have coalesced the standout processes from the event into a recommendation of best practices that future health care conferences should strive to adopt.

*Planning and preparing with patients.* The SRTR conference leadership took a progressive approach to conference planning. They included a transplant recipient and a living donor on the conference planning team from its inception. In addition, the Patient and Family Affairs Subcommittee of the SRTR Review Committee advised on both the content of the meeting and the approach to support attendees outside the transplant professions.

Patients, donors, and family members who registered for the conference were invited to a preconference webinar hosted by SRTR staff to give them background information, introduce common jargon and definitions, provide information about the transplant system, and encourage patients to speak up at the conference. This preparatory webinar provided patients with an opportunity before the conference to ask questions. It also allowed conference planners to set goals for the conference

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higher based on what they learned from patients. Materials developed for the preparatory webinar included definitions for common scientific, medical, and research terms.

The prework dedicated to this stakeholder group by SRTR staff ensured that we knew what to expect. Patients previewed some of the topics and gathered thoughts in advance to gain an entry-level understanding of some prevailing industry politics influencing the conference topic. It also helped participants understand what the metrics meant to the transplant industry and how important they were to patient care and decision-making. We realized that intentionally lessening some of the knowledge asymmetry, which dulls impactful patient participation, was imperative to full engagement.

The conference planning committee also created roles for patient participation and leadership at the conference. Those in the patient role were included in every aspect of the event as speakers, plenary session moderators, breakout session moderators, and panelists. The stories and thoughts that we shared served as the proverbial glue to connect the priorities of physicians, payers, and regulators. The conference planners ensured that our questions and comments were addressed with the same importance as those of the professionals in attendance. Every session included an opportunity for patient attendees to respond, offer pushback, and suggest ideas that illuminated specific areas of future investment. There was no division made between patient input and medical professional input during the meeting or in the analysis of qualitative data that followed.

The authors acknowledge that every patient with an opinion is not going to be a gifted speaker or a literary savant. Yet the planning helped us interject our stories, experiences, and opinions to help shape the conference findings. Deceased donor family member stories at this conference sparked a national movement to cease the use of the term discard in reference to deceased donor organs that are recovered but not transplanted. This is illustrative of the fact that attendees in the patient role were invited to speak up—and when we did, we were heard.

*Patient engagement as a measure of success.* In planning for conference attendance, a goal of 25% patient and family attendance, and attention to cultural diversity of that subset of attendees, was prioritized and met. Technical planning with the patient in mind continued through the budget that supported travel and lodging fees for patients to attend and the breakout session planning that ensured our perspectives were present in each discussion. It was clear that the patient voice was established as a measure of success, where organizers would not consider conference deliverables valid without being cocreated, enhanced, and corroborated by the patient, donor, and family stakeholders in attendance.

Incorporating patients into medical conferences as anything more than attendees is not without risk. Engaged, educated patients who question or even challenge the professionals' points of view or advocate based on an experiential perspective can sometimes be ridiculed or reprimanded by professionals. The conference leaders from SRTR set the tone from its leadership down, holding preparation calls with presenters to inform

them of the added patient attendee element and asking professionals to be mindful of avoiding acronyms and medical jargon when speaking. The welcome messages solicited engagement from those in the patient role and agreement from the professional attendees to create an environment where donors and families felt comfortable participating. In addition, the HRSA administrator welcomed attendees with a specific charge: "...we must hear from everyone... if you need clarification or additional background from the moderators, please make your voices heard. All questions are welcome." Patients were treated as peers for 3 days, and the conference deliverables benefitted from their engagement.

*Treating patients as investors in the system.* The preconference planning and conference approach of treating patients as partners resulted in a technical conference where the patients' lived experiences were treated with dignity and respect. Having patients and families dispersed among all the breakout sessions—not just those focusing on patient issues—ensured that their feedback influenced critical conversations and kept the patient-centered approach as a guiding principle. Participating as peers we felt no embarrassment when asking questions. Throughout the conference when patients spoke, they were affirmed with frequent questions and discussion in follow-up to their contributions. We did not sense or witness any feeling of inferiority.

Evolving medical conferences from a patient-as-customer model to a patient-as-investor framework is just as much cultural as procedural. The SRTR staff accomplished this principle in its intentional respect for patient contributions and, importantly, through the visuals shared. The enduring image from the presentations was the transplant system map, which presented the transplant ecosystem through a subway map model with the patient at its core.<sup>1</sup> Medical professionals in attendance remained prideful of their very important roles in transplant but could visualize just how central the patient experience was to every metric being deliberated. This diagram was a significant contributor to the success of the event by creating a common language for the myriad constituencies to align on.

### *Future Implications*

Having activated patient stakeholders at the table provided an opportunity to humanize the data in a way that clarified its need, regardless of data collection burden and industry norms, during deliberations at the consensus conference. The eventual system of person-centered metrics will be refined by patient insights, such as the need for more long-term outcomes data, additional patient-centered outcomes data beyond mortality and graft loss, and data that facilitate shared decision-making between patients and providers in preparation for an organ offer.

Based on the success of the conference, our group of patient, donor, and family members poses these key recommendations: (1) Identify, prepare, and assign defined roles to a cohort of patients that are representative of the patient populations. (2) Establish the patient voice as a measure of success, which

requires that direct experiences be shared with each topic or agenda item. (3) Develop questions, discussion topics, and a culture that treat patients as investors in the system rather than as transactional customers.

The HRSA-sponsored SRTR Consensus Conference demonstrated that the patient voice can uncover factors that perpetuate underperformance and disparity in outcomes. Establishing the patient voice as a measure of success at a medical conference demands that patients graduated from the role of passive recipients of medical care to equal and crucial peers in improving medical research and health care systems.


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