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Meeting Report

Stakeholders' perspectives on transplant metrics: the 2022 Scientific Registry of Transplant Recipients' consensus conference

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ABSTRACT

In July 2022, the Scientific Registry of Transplant Recipients (SRTR) hosted an innovative, multistakeholder consensus conference to identify information and metrics desired by

Abbreviations: CUSUM, cumulative sum; HRSA, Health Resources and Services Administration; NASEM, National Academies of Sciences, Engineering, and Medicine; OPO, organ procurement organization; OPTN, Organ Procurement and Transplantation Network; SRTR, Scientific Registry of Transplant Recipients.

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Scientific Registry of Transplant Recipients
metrics
consensus conference

stakeholders in the transplantation system, including patients, living donors, caregivers, deceased donor family members, transplant professionals, organ procurement organization professionals, payers, and regulators. Crucially, patients, caregivers, living donors, and deceased donor family members were included in all aspects of this conference, including serving on the planning committee, participating in preconference focus groups and learning sessions, speaking at the conference, moderating conference sessions and breakout groups, and shaping the conclusions. Patients constituted 24% of the meeting participants. In this report, we document the proceedings and enumerate 160 recommendations, 10 of which have been highly prioritized. SRTR will use the recommendations to develop new presentations of information and metrics requested by stakeholders to support informed decision-making.

1. Background

The Scientific Registry of Transplant Recipients (SRTR) was established by statute to support the ongoing evaluation of the scientific and clinical status of the US solid-organ transplantation system, and is overseen by the Health Resources and Services Administration (HRSA).[1-3] SRTR data have historically been used by a variety of stakeholders, including transplant professionals, organ procurement organization (OPO) professionals, payers, and transplant regulators (eg, the Membership and Professional Standards Committee and the Centers for Medicare & Medicaid Services). In 2012, SRTR hosted a consensus conference that was largely focused on transplant program performance evaluations.[4] SRTR implemented many important methodologic and reporting changes based on the conference recommendations,[5] including Bayesian statistical methods,[6] provision of cumulative sum (CUSUM) process control charts to transplant programs and OPOs,[7] and improved patient-facing information.[8,9] Although the 2012 consensus conference resulted in important innovations, it largely focused on the needs of professionals, whereas patients, caregivers, living donors, and deceased donor family members were not well represented.

In 2020, HRSA directed SRTR to "identify metrics to assess national transplantation system performance and support informed decision-making by critical audiences."[10] This mandate had 2 primary components: (1) to identify the information of interest to critical audiences and (2) to develop assessments and metrics that monitor information of interest to these critical audiences. To achieve this goal, SRTR was to "determine, in an open and transparent process, the final combination of metrics to be used to assess transplant center and organ procurement organization performance."[10] To this end, SRTR established a 5-year process (Fig. 1) and convened the *People Driven Transplant Metrics* consensus conference on July 18, 2022, to July 20, 2022. Herein, we detail the development of the conference, the recommendations that stemmed from the conference, initial prioritization of the recommendations, and how these recommendations fit within the broader context of continued improvement in our nation's organ donation and transplantation system.

2. Conference design and preparatory work

SRTR convened a Steering Committee to develop the conference. The committee comprised representatives from various stakeholder groups (Supplementary Table S1). The committee

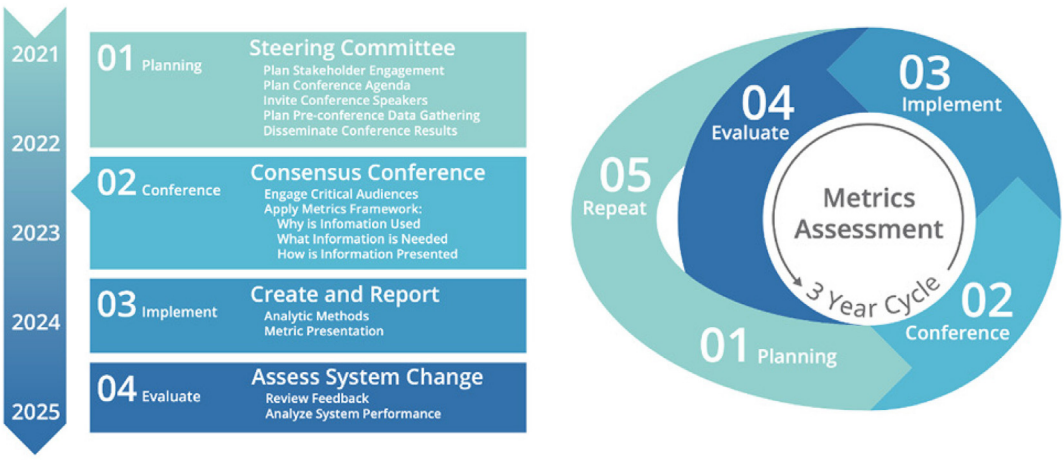

Figure 1. Five-year timeline of the Scientific Registry of Transplant Recipients' Task 5 Initiative (left panel) with a 3-year cycle envisioned to implement and study changes and re-evaluate them (right panel).

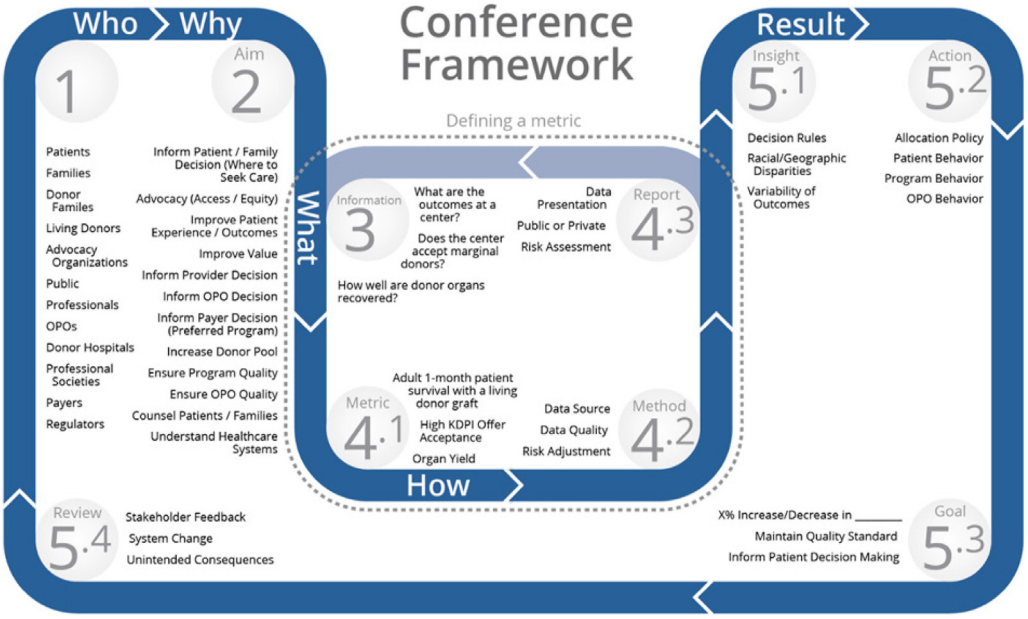

Figure 2. The conference framework. Attendees addressed the "who, why, what, and how" of transplant data and metrics (steps 1-4). Results (step 5) are addressed after the conference recommendations. KDPI, kidney donor profile index; OPO, organ procurement organization.

held 16 monthly meetings from March 2021 to June 2022. Conference scope was determined by the committee (Supplementary Table S2), and with scoping boundaries established, the committee identified a list of stakeholders in transplant data/metrics. Stakeholders fell into 5 broad categories: transplant patients/caregivers, living donors and deceased donor family members, transplant and OPO professionals, government agencies, and others (eg, payers, patient advocacy organizations, other allied organizations, industry, researchers, and press; Supplementary Table S3).

SRTR initiated a call for attendees for the consensus conference and opened public comment in November 2021. Importantly, the committee determined that it was critical to have a strong representation from patients at the meeting and encouraged SRTR to engage patients early in the process. The committee noted the importance of preparatory work to gather stakeholders to represent the patient voice ahead of the meeting through targeted focus groups. SRTR conducted 20 patient and family focus groups and patient interviews before the conference, the results of which will be published separately.

The committee then assisted SRTR in designing the conference. A framework was developed for guiding meeting participants through the "who, why, what, and how" of transplant data and metrics (Fig. 2). This framework, in turn, guided the development of the conference agenda (Supplementary Table S4). The committee agreed that the patient experience could help frame the discussion around which data would be most helpful at specific points in the complex process of organ donation and transplantation (Fig. 3, Supplementary Fig. S1). This system map was used throughout the conference to orient discussions regarding specific data that may help at each stop on the transplant journey.

3. Data capture

Before the conference, recommendations were captured through patient focus groups and public comments. During the conference, recommendations were captured during 3 breakout sessions comprising 35 breakout groups: 21 in-person and 14 virtual (Supplementary Table S5). Breakout groups were configured to be interdisciplinary, containing both patients and professionals. Data were gathered in various ways, including individual worksheets completed during breakout groups, breakout group summaries, moderator report-backs, and

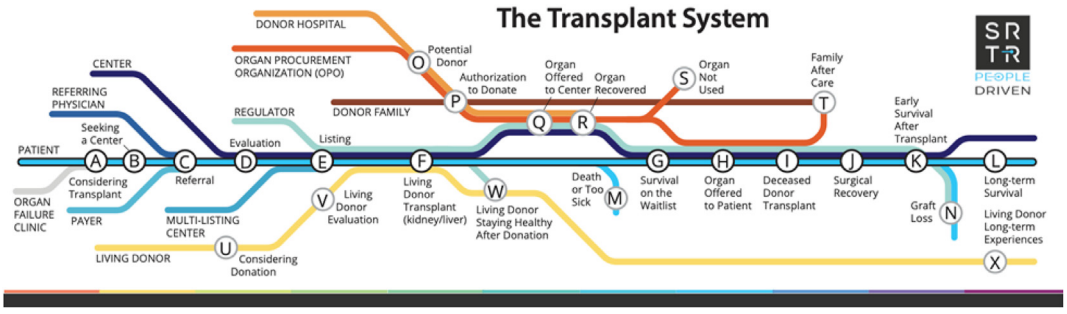

Figure 3. A map of the transplant system centered around the patient's journey.

Table 1
Recommendations specific to points in the transplant process

	Recommendations (*prioritized by breakout groups)	Ease of implementation	Discussion topic	SRTR Review Committee near-term priority
A: Considering transplant				
A.1	*Provide personalized predicted waiting times	2	PFD	Yes
A.2	*Provide survival benefit of transplant vs alternative therapies	2, 3	PFD	Yes
A.3	*Provide measures of posttransplant quality of life	3	PFD	
A.4	*Provide information on any absolute contraindications to transplant (eg, high BMI)	2	PFD	
A.5	Provide information that instills hope (eg, best-case scenarios)	1	PFD	
A.6	Provide education on what information patients *should* be considering ("I don't know what I don't know")	1	PFD	
A.7	Provide information on potential impacts on childbearing	3	PFD	
A.8	Provide information on costs of posttransplant medications	3	PAY	
A.9	Provide information on costs not covered by insurance	3	PAY	
B: Seeking a center				
B.1	*Provide data on which centers are most likely to refer, to evaluate, to list, and to perform transplant for a patient like me or my loved one	2, 3	PFD, PRO	Yes
B.2	*Provide data on whether one center may accept me, whereas another may decline to list me	3	PFD, PRO	
B.3	*Provide data on which centers specialize in certain diagnoses/ conditions	3	PFD	
B.4	*Provide information on absolute contraindications at a particular center (eg, BMI cut-offs)	3	PFD, PRO	
B.5	Provide information on which centers have certain opportunities to find living donors (eg, access to paired exchange programs)	2, 3	PFD	
B.6	Provide data to guide referring providers to the best center for their patient	3	PFD, PRO	
B.7	Provide information on whether there are financial reserve criteria to be listed	3	PAY	
B.8	Provide program-to-program comparative data	1	PFD	
B.9	Provide a personalized prediction of whether a patient will undergo transplant if listed at a particular center	1	PFD	
B.10	Provide information on novel surgical techniques used at the center	3	PFD	
B.11	Provide information on immunosuppressive regimens used at the center and why they may be different for different patients or different from what other centers would prescribe	1, 3	PFD	
B.12	Provide information on insurance coverage accepted at the center, coverage of travel, etc.	3	PFD	

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Table 1 (*continued*)

Recommendations (*prioritized by breakout groups)		Ease of implementation	Discussion topic	SRTR Review Committee near-term priority
C: Referral				
C.1	Provide current contact information of the program	2	PFD	
C.2	Provide information on the probability of listing after referral	3	PFD, PRO, PAY	
C.3	Create a "kidney transplant equity index" (ie, data on equity comparing characteristics of population vs listed), including social determinants of health data	2	PRO, PAY	
C.4	Provide information on where referrals come from	3	PFD	
C.5	Provide predicted life expectancy at the time of referral	3	PFD, PRO	
D: Evaluation				
D.1	Provide information to help patients comprehend medication protocols, potential side effects, and potential complications	3	PFD	
E: Listing				
E.1	*Provide information on the potential for and benefits of listing at multiple centers	1	PFD, PRO	Yes
E.2	*Provide information on potential coverage mechanisms for medically complex patients with increased costs. These may affect center risk aversion and access to transplant	3	PAY	
E.3	*Provide data on how many patients were referred and then listed or not listed	3	PFD, PRO, PAY, REG	
E.4	*Provide rates of referrals vs expected rates of referrals	3	PFD, PRO, PAY	
E.5	*Provide rates of listing	3	PFD, PRO, PAY	
E.6	*Provide data on timing of referral, listing, and transplant process (eg, time from end-organ failure to referral, time from referral to evaluation, and time from evaluation to [active] listing). Data presented with stratification/adjustment for underserved communities	1, 3	PFD, PRO, PAY	Yes
E.7	*Provide data on the impact of patient-specific factors on the likelihood of listing (eg, medical, economic, linguistic, psychiatric, and psychosocial factors)	3	PFD, PRO	
E.8	*Provide data on outcomes after listing	1	PFD, PRO, PAY	
E.9	Provide information to help patients "do better" while on list	3	PRO	
E.10	Provide information back to referring providers on the status of their referrals	3	PRO	
E.11	Provide data on granular reasons why patients are denied listing	3	PFD, PRO	
E.12	Provide resources to guide patients and centers as they navigate through their journey and interact with payers throughout that journey, including evaluations and multilisting. Information that conveys the patient's perspective, advocates for patients, and conveys the payer's perspective	2	PAY, PFD, PRO	

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Table 1 (*continued*)

	Recommendations (*prioritized by breakout groups)	Ease of implementation	Discussion topic	SRTR Review Committee near-term priority
E.13	Provide transparent information to patients on whether patients are listed or not, with updates to patients throughout the process	3	PFD	
E.14	Provide transparency to patients as to whether a patient is active or inactive	2	PFD	
E.15	Provide rates of preemptive listing before starting dialysis	1	PRO, REG, PAY	
E.16	Provide predicted life expectancy at the time of listing	2	PFD, PRO	
E.17	Provide information on time and support offered to help people find living donors	3	PFD	
F: Living donor transplant (kidney/liver)				
	See recommendations in sections I, J, K, and L that can be specific to living donor recipients			
G: Survival on the waiting list				
G.1	*Provide waitlist management tools to help programs manage and understand their waiting list, including data that counter potential risk aversion to list complex patients	2	PFD, PRO	
G.2	Provide predicted life expectancy at any point on the waiting list	2	PFD, PRO	
H: Time of organ offer to patient				
H.1	*Provide predicted survival benefit to accept or decline an offer	2	PFD, PRO	
H.2	*Provide data about the risks/benefits of willingness to accept medically complex donor types	2	PFD, PRO	Yes
H.3	*Provide the estimated time to the next offer in case of declining current offer	2	PFD, PRO	
H.4	*Provide the estimated time to a "better" offer in case of declining current offer	2	PFD, PRO	
H.5	*Provide tools that facilitate shared decision-making between patients and providers in preparation for and at the time of organ offer	2	PFD, PRO	Yes
H.6	*Provide a public-facing tool to predict donor-specific organ use	2	OPO	
I: Deceased donor transplant				
I.1	*Provide transplant rates; considerations include organ-specific, breakout living donor and overall transplant rates, include breakdowns by medical urgency status, apply a consistent start time (eg, dialysis start)	1, 2	PRO	Yes
I.2	*Provide utilization rates of medically complex donor organs	1	PRO, REG	
J: Surgical recovery				
J.1	*Provide data on the length of stay	1	PFD	
J.2	Provide data on time away from work after transplant or total time away from work due to organ failure	3	PFD	
J.3	Provide rehospitalization rates	3	PFD	

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Table 1 (*continued*)

Recommendations (*prioritized by breakout groups)		Ease of implementation	Discussion topic	SRTR Review Committee near-term priority
J.4	Provide near-term survival metrics	1	PFD, PRO, REG	
J.5	Provide near-term rejection/graft failure metrics	2	PFD, PRO, REG	
J.6	Provide peritransplant complications rates	2, 3	PFD, PRO	
K: Early survival after transplant				
K.1	*Provide predicted outcomes for a particular patient at that center if the patient undergoes transplant with a particular donor	2	PFD, PRO, REG, PAY	
K.2	*Provide metrics of tailored outcomes relevant to specific organ types beyond just graft failure and death	2, 3	PFD, PRO, REG, PAY	
K.3	Provide outcomes by specific medical, psychosocial, and psychiatric conditions	3	PFD, PRO, REG, PAY	
L: Long-term survival after transplant				
L.1	*Provide posttransplant graft/patient survival metrics, adult vs pediatric, longer-term outcomes (eg, 10 y) – more important by patient characteristics than by center	1	PFD, PRO, PAY	Yes
L.2	*Provide long-term outcomes for multiorgan recipients	2	PFD, PRO, PAY	
L.3	*Provide data that could support increased payer coverage to support long-term graft survival	3	PAY	
L.4	Provide information on medication coverage and costs of patients	3	PAY	
L.5	Provide data on medication compliance, rates of noncompliance, graft loss due to noncompliance, or inability to pay	2, 3	PAY	
L.6	Provide data on how often medication regimens are changed	2, 3	PAY	
M: Removal from list due to death or too sick to transplant				
M.1	Provide data on removal due to death or too sick to transplant with detailed causes	2	PFD	
N: Graft loss				
N.1	Provide data on reasons for graft failure or patient death, with variation by center	2	PFD, PRO	
O: Potential deceased donor				
O.1	*Provide timing data for potential deceased donor families (eg, time from brain death declaration to recovery, total process time, and milestones)	2	PRO, OPO	
O.2	*Provide metrics at the donor hospital level (eg, effectiveness of referral process)	3	PFD, OPO	
O.3	Provide data on factors associated with successful donation of specific organs (eg, age and clinical factors)	2, 3	PFD	
O.4	Provide data to increase transparency about the allocation process (eg, how longevity matching affects placement)	2	PFD	

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Table 1 (*continued*)

Recommendations (*prioritized by breakout groups)		Ease of implementation	Discussion topic	SRTR Review Committee near-term priority
O.5	Provide a public-facing predictive analytics tool to predict the longevity of donated organs	2	OPO	
O.6	Provide metrics on potential donor conversion with stratification by adult/pediatric donors and donor hospital/donor care unit	2, 3	PAY, PRO	
P: Authorization to donate				
P.1	*Provide customer experience feedback for potential donor families	3	PFD	
P.2	Provide data on the timing of family conversations relative to referral; stratify by DBD/DCD pathway	3	PRO, OPO	
Q: Organ offered to a center				
Q.1	*Provide data on acceptance and decline patterns by program, stratified by organ quality, organ type, and candidate characteristics; specific information tailored for pediatric candidates	1, 2	PFD	Yes
Q.2	*Provide granular timing data for the organ offer process; eg, when centers are made primary on an offer, how long it takes for center to respond, and timing around late declines	3	OPO	
Q.3	*Provide rates for late declines	3	PRO, REG	
Q.4	Provide data to increase transparency for patients as to why an organ offer was declined; this could be tailored to patient preferences as some may want more detail and others less	2, 3	PFD, PRO	
Q.5	Provide prediction of patient and graft longevity if accepted for this specific patient	2	PFD	
Q.6	Provide data on the use of expedited placement and where it is being used effectively	2	PAY	
R: Organ recovered				
R.1	Provide data on organ biopsy practices	1, 3	PRO	
R.2	Provide data on the efficiency of offer process and ways to reduce cold time (eg, whether offers are made pre/post crossclamp)	2	PAY	
S: Organ not transplanted				
S.1	*Provide organ nonuse rates stratified by organ and abdominal/thoracic	2	PFD, OPO, REG	
T: Deceased donor family aftercare				
T.1	*Provide information on why organs that were donated were not used	2, 3	PFD	
T.2	Provide information on donor family aftercare practices by OPOs	3	PFD	
U: Considering living donation				
U.1	*Provide information on life restrictions after donation	3	PFD	
U.2	*Provide information on expected donation outcomes and a typical recovery process	1, 3	PFD	

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Table 1 (*continued*)

	Recommendations (*prioritized by breakout groups)	Ease of implementation	Discussion topic	SRTR Review Committee near-term priority
U.3	Provide data on how long living donor evaluation process takes	3	PFD	
U.4	Provide data on time from donor evaluation to acceptance decisions and variation across programs	3	PFD	
U.5	Provide information on the costs of becoming a living donor (eg, billing, coverage, who pays, time off work, and assistance opportunities)	3	PFD	
U.6	Provide information on KPD and directed/nondirected donations	3	PFD	
U.7	Provide data on long-term outcomes of living donation (promoting center participation in Living Donor Collective) and center-level donor outcomes to better inform the consent process	2	PFD	
U.8	Provide living donor acceptance rate ratios	3	PFD, PRO	
U.9	Provide data on living donor transplants as a percentage of registered recipients	1	PRO, PAY	
U.10	Provide data on differences between centers for living donor acceptance criteria and a center's prior experience with donors with my characteristics	3	PFD, PAY	
U.11	Provide data on surgical procedures used, including minimally invasive, laparoscopic, and robotic-assisted	1	PFD	
U.12	Provide rates of conversion from laparoscopic to open procedures	1	PFD	
U.13	Provide rates for aborted procedures	2	PFD	
U.14	Provide rates of readmission to hospital	3	PFD	
U.15	Provide information on pain management protocols, including the use of opioids	3	PFD	
U.16	Provide rates of wound complications and cosmesis	3	PFD	
U.17	Provide rates of symptoms such as bloating and numbness	3	PFD	
V: Living donor evaluation				
V.1	*Provide information on whether programs can fast-track evaluation process for participation in KPD programs	3	PFD	
W: Living donor recovery				
W.1	*Provide data on the time it takes to ''return to normal''	3	PFD	
W.2	*Provide data on near-term complication rates	1	PFD	
X: Long-term living donor experience				
X.1	*Provide long-term living donor outcomes (eg, personalized risk of organ failure and overall survival)	3	PFD, PRO, PAY	
X.2	Provide data on living donor's quality of life	3	PFD	
X.3	Provide living donor's patient-reported outcomes	3	PFD	

Headings describe the ease of implementation (1 = readily implementable; 2 = data are available but need development; and 3 = requires novel data collection and development) and the discussion group topic from which the recommendation was made. Recommendations subsequently prioritized by the SRTR Review Committee are indicated as near-term priorities.

BMI, body mass index; DBD, donation after brain death; DCD, donation after circulatory death; KPD, kidney paired donation; PAY, payers; PFD, patients, families, and living donors; PRO, transplant professionals; OPO, organ procurement organizations; Q&A, plenary open discussion; REG, regulators.

Table 2
General recommendations not specific to a point in the transplant process

Recommendations (*prioritized by breakout groups)		Ease of implementation	Discussion topic
1: General education and process			
1.1	*Provide education throughout the patient's journey, including resources for patient's decision-making, resources for providers to counsel patients, resources to use for shared decision-making, and information to allow patients to be active participants in the process and educate patients on what they can influence	3	PFD
1.2	Help users/patients effectively interpret data (eg, magnitude of outcome differences). Use plain language/appropriate literacy. Limit/explain acronyms. Use videos, stories, and narratives. Help users access information in multiple languages. Mobile-friendly. Patient-friendly	2, 3	PFD
1.3	Create a guide to navigating through all information provided by SRTR	2	PFD, REG
1.4	Provide information on COVID-19 (eg, vaccine efficacy and treatment)	3	PFD
1.5	For pediatric patients, provide information on transition to adult care and transitions back to normal childhood, school, impact on families, etc.	3	PFD, PAY
1.6	Increase discoverability of the SRTR website for patients through search engine optimization	1	PFD
1.7	Be a trusted source of information for patients alongside other patient resources (eg, Facebook groups). Create links and coordinate content across other trusted sources (eg, OPTN, UNOS, and TransplantLiving.org websites)	2	PFD
2: Center-level data and intercenter variation			
2.1	*Provide quality-of-life assessments, including mental health, depression, anxiety, and functional status	3	PFD, PRO, REG, PAY
2.2	*Provide complication rates, including cancers, compared with alternative therapies (eg, dialysis)	2, 3	PFD, PRO, REG, PAY
2.3	*Enable comparisons of "like" centers (eg, urbanicity)	2	PAY
2.4	Provide patient-reported outcomes, use of validated instruments; stratify by social determinants of health; and include financial burden	3	PFD, PRO, PAY
2.5	Provide metrics within sociodemographic strata (eg, race, ethnicity, age, disability, English as a secondary language, social support, and distance from transplant program)	2, 3	PFD, REG
3: OPO and donor hospital data and variation			
3.1	*Remove concepts of "imminent" and "eligible" potential donor data collection and metrics	1	OPO
3.2	*Develop a new donor potential definition and metric, leverage existing OPO data captured within OPO electronic medical records, present metrics at OPO and donor hospital levels, and include risk adjustment	3	OPO
4: Payer data and variation			
4.1	Standardize the process of expert opinion or expert panels that are used by payers to inform coverage decisions or coverage of difficult cases	3	PAY

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Table 2 (*continued*)

Recommendations (*prioritized by breakout groups)		Ease of implementation	Discussion topic
4.2	Increase transparency in centers-of-excellence determination	3	PAY
4.3	Create exceptions in coverage decisions for special circumstances (eg, pediatric or rural candidate access)	3	PAY
4.4	Patient-reported outcomes/satisfaction by payers, including employee satisfaction, and enrollee satisfaction with their payers	3	PAY
5: Regulatory oversight			
5.1	*Prioritize minimization of false positives when flagging programs and consider outcome thresholds	2	REG
5.2	*Expand regulations that promote improved data integrity	2	REG
5.3	*Promote the regulatory position as a dual fiduciary to patients and society	2	REG
5.4	*Provide data on staffing within programs/OPOs, and consider data on succession planning	3	REG
5.5	*Create ‘‘carve-outs’’ or other protections for innovations (eg, trial participation or other factors that are not captured for risk adjustment)	3	PRO, REG
5.6	*Keep SRTR risk adjustment models current with updates in the field, new technologies, etc.	1, 2	PRO
5.7	Review use of 1-y outcomes as a regulatory target	2	PRO, PAY
5.8	Align interest across regulatory bodies where possible	2	REG
5.9	Define ‘‘safety’’ as a regulatory target (eg, safety of transplant recipient and transplant candidate), balancing outcomes with access and societal benefit of organ donation	2	REG
5.10	Standardize a process for the introduction of new regulatory metrics. Metrics should be generally accepted prior to use by regulatory bodies	2	REG
6: System performance			
6.1	*Define system goals and behavior we want to incentivize. Design metrics that demonstrate transplant benefit and value, improve patient care, improve patient access, improve equity, increase preemptive kidney transplants, increase organ use and reduce organ nonuse, and increase living donor transplants	3	PRO
6.2	*Process map and value stream the organ donation process. Create an OPO-specific system map analogy for the organ donation process. Create metrics specific to these points in the system to support continued improvement	3	OPO
6.3	How busy/stressed is the national transplant system? Can SRTR provide data on the number of donor cases active at any one time or within a given 24-h period?	2	OPO
6.4	Create a dashboard of system performance that could be reviewed (eg, at OPTN regional meetings)	2	REG
7: Information technology and data capture			
7.1	Support development of APIs to common EHRs to minimize the data collection burden on transplant programs	3	PFD, PRO, OPO, PAY
7.2	Exploit existing OPO EMRs to capture more granular data on the donation process	3	OPO

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Table 2 (*continued*)

Recommendations (*prioritized by breakout groups)		Ease of implementation	Discussion topic
7.3	Support APIs from donor hospitals for automated referrals to OPOs of in-hospital, ventilated deaths/potential donors	3	OPO
7.4	Promote standardized capture of *ICD-10*–coded diagnostic and procedure codes	3	OPO
7.5	Build candidate-/donor-specific predictions directly into DonorNet to be made available at the time of organ offer	3	PRO
7.6	Create efficiencies in the organ offer/allocation process by tailoring offers by likelihood program would accept organs; attempt to decrease the number of offers to increase system efficiency while not limiting patient access	2	PRO
7.7	Collect long-term data on patient and living donor outcomes as a moral and ethical obligation	3	PFD
7.8	Publicly funded living donor data collection	3	PFD
7.9	Pilot regional-scale data links from new sources (eg, insurance companies)	3	Q&A
8: Miscellaneous recommendations			
8.1	Eliminate the use of the term "discard" when describing nonuse of donated organs	1	PFD, Q&A
8.2	Create a program like the National Living Donor Assistance Center for transplant candidates and recipients	3	Q&A
8.3	Incentivize innovation in organ donation and transplantation	3	REG
8.4	Improve or eliminate the use of KDPI; develop a race-free implementation; and eliminate percentile standardization	2	PRO, PAY
8.5	Create a better definition and capture of delayed graft function after a kidney transplant, supporting recent National Kidney Foundation work. Consider eGFR and sustained need for dialysis	3	PRO, PAY
8.6	Capture burden of end-organ failure with stratification by social determinants of health	3	PFD, PRO, PAY

Headings describe the ease of implementation (1 = readily implementable; 2 = data are available but need development; and 3 = requires novel data collection and development) and the discussion group topic from which the recommendation was made.
API, application programming interface; eGFR, estimated glomerular filtration rate; EHR, electronic health record; EMR, electronic medical record; KDPI, kidney donor profile index; OPO, organ procurement organizations; OPTN, Organ Procurement and Transplantation Network; PAY, payers; PFD, patients, families, and living donors; PRO, transplant professionals; Q&A, plenary open discussion; REG, regulators; SRTR, Scientific Registry of Transplant Recipients; UNOS, United Network for Organ Sharing.

summaries of virtual breakout discussions. Each breakout group also had the opportunity to prioritize the recommendations. After the conference, all sources of data were synthesized by the Steering Committee to identify a final list of recommendations and themes.

4. Conference results and subsequent prioritization

In total, 258 attendees participated in the conference: 140 in-person attendees and 118 virtual attendees. Attendees identified as transplant professionals (76%), as patients or families (17%), and as both (7%; eg, a transplant patient working at a transplant program or OPO). Altogether, 24% of the attendees identified as patients or family members (Supplementary Table S6).

Table 1 presents a synthesis of recommendations (A.1 to X.3) using points on the transplant system map (Fig. 3) as a guide to when the information may be the most useful. Table 2 presents more generalized recommendations (1.1 to 8.6) that are not specific to any given point on the system map. Note that common themes may appear at different points within the system if the recommendation was made with regard to more than one point in the process. Conference participants made 160 recommendations, several of which received prioritized rankings within the breakout groups or emerged from several different breakout group types (Tables 1 and 2).

The recommendations are further divided into 3 major categories: those that can be acted on immediately, those for which data are available but need to be developed with multidisciplinary input, and those for which data are not yet available. For example, many of the information needs of patients and family members include data that may already exist but are difficult to find on the SRTR website. The development of a website that better meets

the needs of all stakeholders, including patients, living donors, and family members, can be prioritized. Conference recommendations also included several potential metrics that are feasible using existing data, including long-term outcomes based on patient characteristics, or offer acceptance metrics that are patient-friendly, but will require discussion and input from the SRTR Review Committee (SRC) and other stakeholders to determine the analytical approach, content, and presentation. Some recommendations include novel metrics focused on aspects of the system that are not yet captured in the current Organ Procurement and Transplantation Network (OPTN)/SRTR data; therefore, new metrics may be contingent on collecting new data or identifying external data sources. For example, a major theme of the conference was the call for data on the experience of patients "upstream" from listing, such as referral rates, evaluation rates, and listing rates. In addition, the conference attendees called for patient-reported outcomes metrics, quality of life, and satisfaction with transplant providers and payers; rates of preemptive listing for kidney patients; rates of use/nonuse of organs; rates of late turn-downs; longer-term survival posttransplant; improved metrics of donor potential and potential donor conversion; rates of live donor complications; rates of posttransplant complications; length of stay; out-of-hospital days; metrics of program staffing levels; metrics of system stress/capacity; and metrics of the burden of end-organ failure. Attendees also noted opportunities to re-evaluate and potentially reduce/eliminate the use of some metrics, including the ongoing use of 1-year posttransplant outcomes, eligible death donation rates, and deceased donor organ yield.

To further prioritize the recommendations, the SRC reviewed the recommendations at its meeting on November 29, 2022, and chose to initiate a survey of the members of the SRC, members of the Patient and Family Affairs Subcommittee of the SRC, and representatives from HRSA's Division of Transplantation. The survey was administered anonymously using Qualtrics and focused on 26 recommendations that were prioritized by conference attendees and deemed to be in categories 1 or 2 for ease of implementation (Tables 1 and 2). Results of the survey were reviewed at the February 3, 2023, meeting of the SRC, and a final list of 10 recommendations were chosen as the initial focus of SRTR (Supplementary Fig. S2). These recommendations are indicated as prioritized by the SRC in Table 1.

A few themes emerged from these recommendations. First, the expressed desire for more "personalized" information to educate patients throughout their transplant journey. Top priorities include provision of predicted waiting times (A.1), data on the typical process flow from referral through transplant (B.1, E.6), data on which centers may list and transplant "patients like me" (B.1), transplant rates (I.1), and data on longer-term outcomes (L.1). Second, recommendations to facilitate shared decision-making between patients and their providers, including the decision around organ offer acceptance (H.5), the decision to explore listing at more than one transplant program (E.1), and the decision to be willing to accept offers from medically complex donors (H.2). Third, recommendations that describe inequities in access to care (E.6), variation in offer acceptance patterns by program (Q.1), and data comparing survival with and without a transplant (A.2).

In addition, many general recommendations were made to make the data more accessible and understandable to the patients for whom our system exists to serve (1.1, 1.2, 1.3, 1.6, 1.7). To that end, SRTR is engaging in a full website redesign in partnership with our Human-Centered Design and Patient and Family Affairs Subcommittees of our SRC. This work is ongoing and will support the eventual presentation of new data and tools in a manner that better supports patients, caregivers, and professionals.

The aforementioned recommendations represent areas where SRTR will initially focus our improvement activities during 2023 to 2025; however, some recommendations were also highly prioritized even though data may not currently be available within the SRTR/OPTN data system. For example, both recommendations B.1 and E.6 recommend reporting on referral, evaluation, and listing practices. SRTR will begin to explore novel ways to capture data during the prelisting phase to better inform patients during this part of their transplant journey. Patient-reported outcomes were also highly prioritized at the meeting (A.3, X.2, X.3, 2.1, 2.4, 4.4), and SRTR will work to explore ways to systematically capture these data.

5. Discussion and next steps

The conference represents an important and unique step in the continued evolution of the types of data SRTR can or should present to the many interested stakeholders. Transplantation is a complex field, and the patient journey can be complicated. A successful transplant requires the involvement of many interested parties, and SRTR made great efforts to engage with and be inclusive of these parties, particularly patients. The mix of both professionals and patients was a unique opportunity to hear about the needs and desires of many stakeholders. Importantly, there were many areas of shared goals and aligned concerns among the patients, professionals, regulators, and payers. Major themes that emerged across stakeholder groups included the need for more "upstream" data on the denominator of patients with advanced organ failure prior to listing and the need to both value transparency and limit risk aversion, creating metrics that drive the behavior and outcomes we want to see. Recommendations also stressed the importance of online patient-specific risk prediction tools and patient-centered search functionality, so patients and referring providers can identify programs that may list and perform transplants for patients like them.

In addition to the discussion of novel metrics, there was a strong call for simply more "data" or "information" to be made available. The recommendations for information served many purposes, including making informed decisions as a patient, family member, or caregiver; advocating for others; and advocating for system change. Conference recommendations stressed the importance of both having information available and providing a human-centered process to find the information and interpret it. In response to the limitation of "you don't know what you don't know," patients requested guidance to understand the

transplant journey and what information is relevant, especially for patients new to the transplantation system. Living donors and deceased donor family members also expressed a need to better understand and navigate through the system. SRTR has already begun to focus on the production of useful decision aids and tools to support quality improvement.[11-13] In addition, work is ongoing to support the development of more patient-friendly and patient-specific search tools to aid patients as they navigate through the transplantation system.[14,15] These calls for more information for use by patients navigating through this process were recently supported by the OPTN Ethics Committee's Transparency in Program Selection Workgroup.[16]

Recommendations will be considered within the context of metrics HRSA continues to require be reported publicly (Table 3). For example, while reporting on short-term patient and graft survival is required, SRTR can evaluate conference recommendations to report longer-term survival and guide patients to other information that some stakeholders may not yet realize to be relevant and predictive of overall survival, such as access to the waiting list or the probability of receiving an organ within a certain period.

The recommendations coming from this conference must also be contextualized within the broader evolution of our nation's transplantation system. In 2022, the National Academies of Sciences, Engineering, and Medicine (NASEM) published a report titled "Realizing the promise of equity in the organ transplantation system," which contains numerous recommendations for improving our nation's transplantation system.[17] Several commonalities are evident (Table 4). Notably, the conference recommendations dovetail well with the NASEM report recommendations to develop prelisting metrics, extend posttransplant metrics beyond 1 year, develop tools for shared decision-making and patient education, educate the public and patients about the benefits of and alternatives to transplant, increase transparency and shared decision-making around organ offers, and create a dashboard of metrics to evaluate the national transplantation system. The NASEM report specifically calls on SRTR to "create a publicly available dashboard of standardized metrics to provide a complete human-centered picture of the patient experience—from patient referral for transplant evaluation, time on the waiting list, to posttransplant quality of life—managed by the Scientific Registry of Transplant Recipients (SRTR) or a similar

Table 3
Data and metrics required to be included in the Scientific Registry of Transplant Recipients' public reports

Metric domain	Metrics/data required[a]
Pretransplant waitlist data	The number of candidates on the waiting list as of the beginning of the reporting period, the number of candidates added, the number of candidates removed from the list, and reasons for removal stratified and reported by demographic and clinical information (eg, sex, age, race and ethnicity, and blood type).
Pretransplant waitlist outcomes	Probabilities of receiving a transplant (eg, percent who had transplant within a given time frame) and dying or being removed from the waiting list while awaiting a transplant, as well as other outcome measures (eg, overall survival after listing, morbidity, functional impairment, and quality of life of transplant candidates).
Posttransplant outcomes	The number of recipients receiving transplants by organ type stratified by demographic and clinical information. Short- and long-term risk-adjusted information for graft and patient survival after transplant. Outcomes of multiorgan transplants and other outcome measures (eg, morbidity, functional impairment, and quality of life for transplant recipients).
Acceptance and utilization of organs	Acceptance and utilization rate of organs from donors of various characteristics (eg, kidneys from donor age >65 y and donation after circulatory death donors).
Living donor outcomes	The number of living donors by organ type stratified by demographic and clinical information (eg, age, sex, race and ethnicity, and comorbidities) and outcomes related to donation (eg, death, rehospitalization, reoperation, and other complications as data are available).
Organ donation, recovery, and nonuse	Risk-adjusted numbers of potential deceased donor, actual deceased donor, organs recovered for transplant, and organ nonuse, by organ type, stratified by appropriate demographic and clinical information (eg, race and ethnicity, age, and blood type).
System performance	Measurements of process variables reflecting patient and family engagement with the transplant system, assessment of patient and family education and support resources, and assessment of transplant center internal processes were used to determine information of most use and value to specific patients and their caregivers.

[a] HRSA contract #75R60220C00011.

Table 4
Commonalities between conference recommendations and NASEM recommendations

Applicable NASEM recommendation[17] with a summary	Conference recommendation(s)[a]
#1. Develop national performance goals to drive metrics of system performance	6.1
#3. Expand federal oversight earlier in the process to at least the time of end-stage organ failure and extending beyond 1-y posttransplant	B.1, B.2, C.2, C.3, E.3, E.4, E.5, E.6, E.11, L.1, L.2, 5.3, 7.7
#3. Increase tools for shared decision-making and education of patients	H.5, 1.1
#3. Increase reporting of data by social determinants of health	C.3, E.7, K.3, 2.1, 2.4, 2.5, 8.6
#3. Communicate with potential transplant recipients regarding their status in the transplant process	E.13, E.14, Q.4
#3. Educate the public about the risks, benefits, and alternatives to organ transplant	A.2, A.3, A.5, A.6, A.7, A.8, A.9, 1.1
#7. Update the prediction model for KDRI/KDPI and eliminate the use of race in the equation	8.4
#10. Increase transparency in the organ offer accept/decline decision and promote patient engagement and shared decision-making	H.1, H.2, H.3, H.4, H.5, Q.4, Q.5
#12. Create a dashboard of metrics to evaluate the performance of the nation's transplant system[b]	6.4

KDPI, kidney donor profile index; KDRI, kidney donor risk index; NASEM, National Academies of Sciences, Engineering, and Medicine.

[a] See Tables 1 and 2.

[b] NASEM specifically calls on SRTR to create such a dashboard: "Create a publicly available dashboard of standardized metrics to provide a complete human-centered picture of the patient experience—from patient referral for transplant evaluation, time on the waiting list, to posttransplant quality of life—managed by the Scientific Registry of Transplant Recipients (SRTR) or a similar entity."[17]

entity."[17] In addition, SRTR's design-thinking, iterative approach aligns with the NASEM report's recommendation that SRTR review any metrics to ensure that goals are being achieved and unintended consequences are mitigated.[17]

In summary, the *People Driven Transplant Metrics* consensus conference brought together 258 representatives of key stakeholder groups with interest in our nation's organ donation and transplantation system, including patients, family members, living donors, deceased donor family members, and the federal government. Conference recommendations included 160 recommended areas of focus, of which 10 were elevated to top priority by the SRC. SRTR will begin the work to create new metrics, explore novel data collection to support new metrics, and modify the existing websites and reports. SRTR will engage the community again in 2025 to assess progress.

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Disclosure

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Data availability

The data presented were captured at the 2022 Scientific Registry of Transplant Recipients consensus conference *People Driven Transplant Metrics*, held July 18, 2022, through July 20, 2022, in Bloomington, Minnesota. Conference proceedings are publicly available at www.srtr.org/about-srtr/the-task-5-initiative/.

Appendix A. Supplementary data

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