



SCIENTIFIC REGISTRY OF
TRANSPLANT RECIPIENTS
PEOPLE DRIVEN

2022 CONSENSUS CONFERENCE WORKBOOK



PEOPLE DRIVEN TRANSPLANT METRICS

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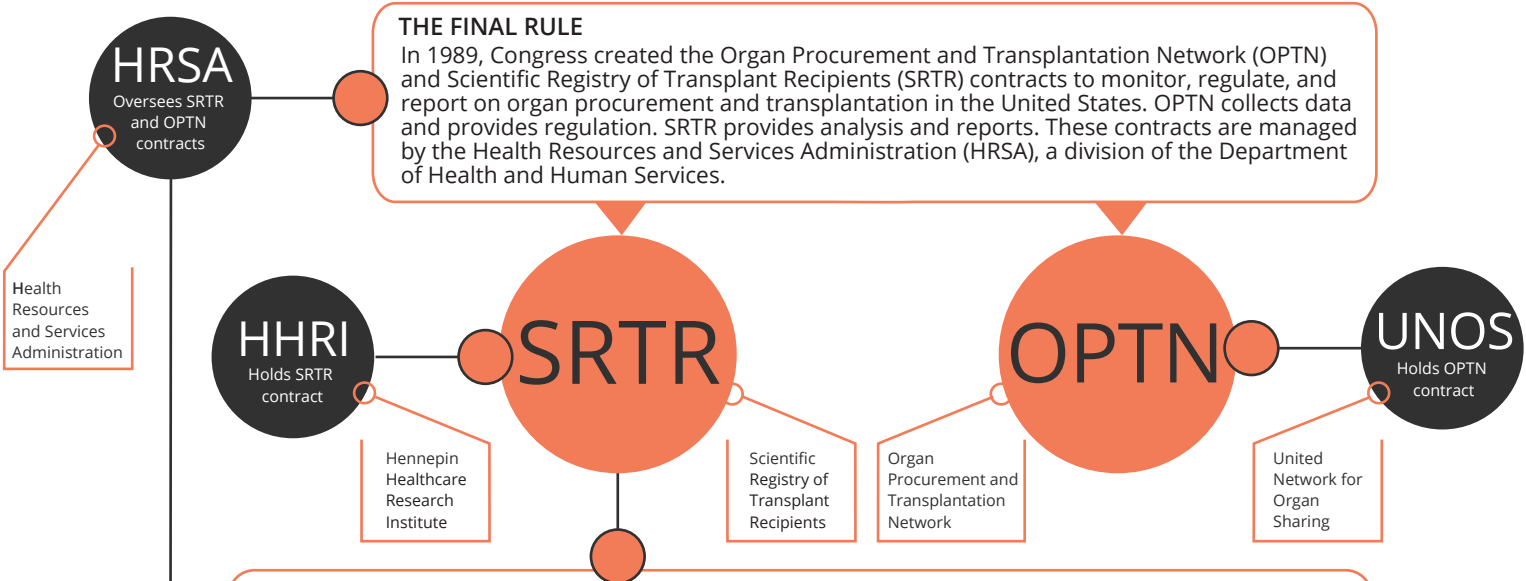
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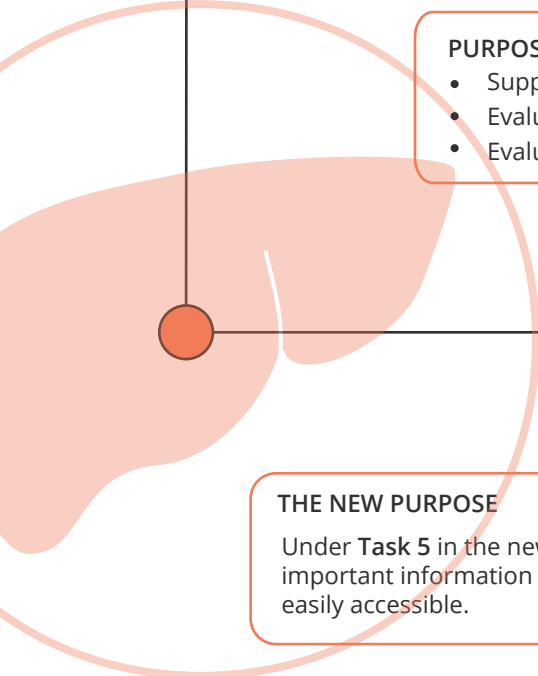
About SRTR



THE FINAL RULE
In 1989, Congress created the Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR) contracts to monitor, regulate, and report on organ procurement and transplantation in the United States. OPTN collects data and provides regulation. SRTR provides analysis and reports. These contracts are managed by the Health Resources and Services Administration (HRSA), a division of the Department of Health and Human Services.

MISSION
To provide advanced statistical and epidemiological analyses related to solid organ allocation and transplantation in support of the Department of Health and Human Services and its agents in their oversight of the national organ transplantation system.

- PURPOSE**
- Support OPTN Committees with advanced statistical analyses
 - Evaluate the performance of solid organ transplant programs
 - Evaluate the performance of organ procurement organizations



THE NEW PURPOSE
Under **Task 5** in the new SRTR contract with HRSA, SRTR was tasked to identify the most important information to critical audiences and to design a plan to make this information more easily accessible.

THE 2022 SRTR CONSENSUS CONFERENCE
SRTR is holding this consensus conference to bring together key stakeholders to further refine the topics of greatest importance, so SRTR can begin the next phase of the Task 5 Initiative: improving the tools and data available for patients, their caregivers, and living donors.

Acronyms & Abbreviations

ABO: blood type (ie, A, B, AB, or O)

ADR: Annual Data Report

AST: American Society of Transplantation

ASTS: American Society of Transplant Surgeons

BMI: body mass index

CMS: Centers for Medicare & Medicaid Services (part of the Department of Health and Human Services [HHS] that participates in both payment and quality monitoring of transplant programs)

CPRA: calculated panel reactive antibodies (a measure of how compatible a donor and recipient would be)

CUSUM: cumulative sum (a quality-control chart SRTR produces for programs to monitor their own outcomes)

DATA: Donation and Transplantation Analytics (an Interactive data query application on the SRTR website)

DBD: donation after brain death

DCD: donation after circulatory death

DSA: donation service area (the region an OPO serves)

eGFR: estimated glomerular filtration rate (an estimate of kidney function)

ESRD: end-stage renal disease

HCV: hepatitis C virus

HHRI: Hennepin Healthcare Research Institute (the organization that currently houses SRTR)

HHS: US Department of Health and Human Services (the government agency that oversees CMS and HRSA)

HLA: human leukocyte antigen

HRSA: Health Resources and Services Administration (the division of HHS that administers the SRTR and OPTN contracts)

KDPI: Kidney Donor Profile Index (a calculation based on KDRI that uses a range from 0-100)

KDRI: Kidney Donor Risk Index (a calculation of a deceased donor kidney quality)

LAS: Lung Allocation Score

LDC: Living Donor Collective (a pilot project to create a registry of living donors to collect long-term follow-up data)

MELD: Model for End-Stage Liver Disease (a measure of how sick a liver transplant candidate is)

MPSC: Membership and Professional Standards Committee (a committee at OPTN that monitors transplant program quality)

OPO: organ procurement organization (a group that works with hospitals and family members in an area to recover deceased donor organs)

OPTN: Organ Procurement and Transplantation Network (the "sister" contract to SRTR that oversees data collection from transplant programs and OPOs, makes transplant system policy, and monitors program performance)

OSR: OPO-specific report (a report with information about a single OPO)

PELD: pediatric end-stage liver disease

PSR: program-specific report

PTA: pancreas transplant alone

SLK: simultaneous liver-kidney (transplant)

SPK: simultaneous pancreas-kidney (transplant)

UNOS: United Network for Organ Sharing (the organization that currently holds the OPTN contract)

Definitions

5-Tier Evaluations: A 5-level system published on SRTR.org to classify transplant program performance from worse to better that is currently used with metrics of survival on the waiting list, transplant rate, and 1st-year graft survival.

Adjusted: (See “Risk adjusted”.)

Allocation: The process for distributing organs to candidates.

Cohort: A group of candidates, recipients, or donors from a specified time-frame (also called a reporting period or observation period).

Deceased donor organ nonutilization rate: The rate at which organs are not transplanted from a deceased donor (ie, the opposite of deceased donor organ yield).

Deceased donor organ yield: A metric describing how frequently organs are successfully transplanted from a deceased organ donor.

Discard rate: The rate at which organs are recovered for the purpose of transplant but then not transplanted (ie, discarded).

Donor conversion: A metric describing how often potential deceased organ donors become actual organ donors.

Graft survival: A measure of how likely a transplant recipient is to be alive with a functioning transplant at a certain time after the transplant procedure (note: a graft is a transplanted organ).

Inactive status: When a transplant program changes a candidate’s status to a condition where they will not receive organ offers.

Living donor: A living individual from whom at least one organ is recovered for transplant.

Methods: The descriptions and or definitions of how SRTR creates the metrics.

Metrics: Generally, statistics generated from SRTR data that describe how certain aspects of the nation’s transplantation system are performing.

Mortality: Patient death.

Multiorgan transplant: Any combination of two or more organs transplanted into the same recipient from the same donor.

Program-specific report (PSR): A report created by SRTR containing information about a single transplant program.

Offer acceptance rate: A metric describing how frequently transplant programs accept offers for deceased donor organs that they receive for their candidates.

Multilisting: One candidate being on the waiting list of different transplant programs at the same time.

OPO-specific report (OSR): A report containing metrics for a specific OPO.

Outcomes: Patient endpoints/events that SRTR tracks (survival, transplant success, donor outcomes, etc).

Definitions

Patient survival: A measure of how likely a transplant recipient is to be alive at a certain time after the transplant procedure, regardless of whether the transplanted organ continues to function.

Patient-time or patient-years: The amount of time (usually measured in days, months, or years) that a patient is at-risk for a given event. This is typically used to calculate rates such as pretransplant mortality rate, transplant rate, or post-transplant graft failure rate.

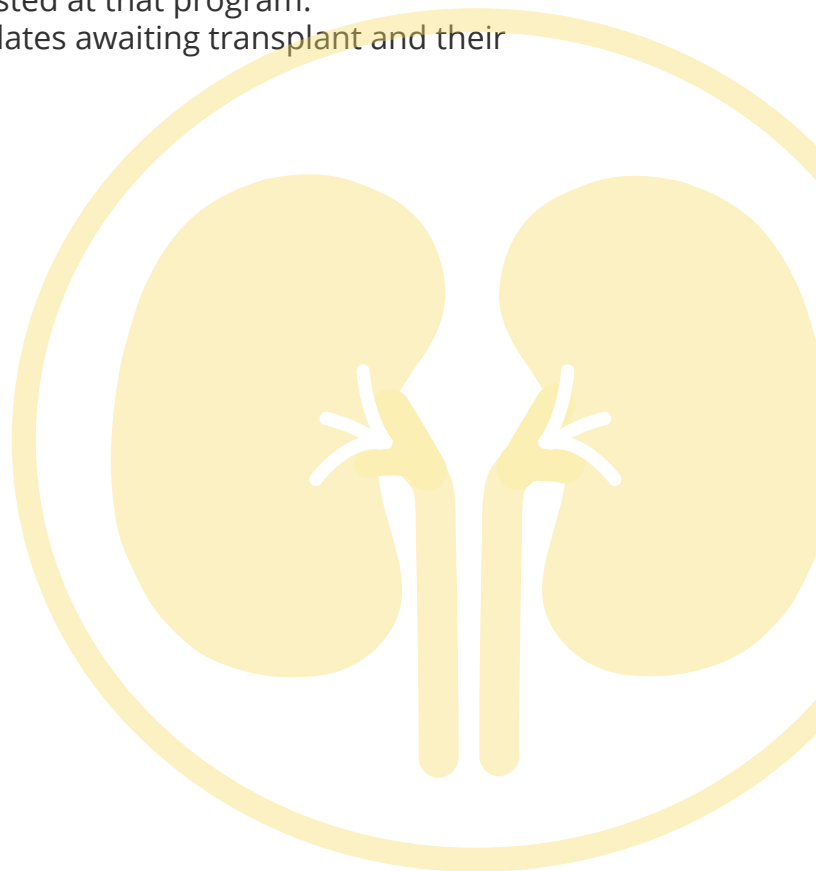
Pretransplant mortality rate: A metric describing how frequently patients die after they are added to a program's waiting list but before they undergo transplant.

Rate: A metric describing the number of events for a certain amount of time (eg, a death rate of 10 per 100 person-years means that if 100 patients were followed for 1 year, we would expect 10 deaths).

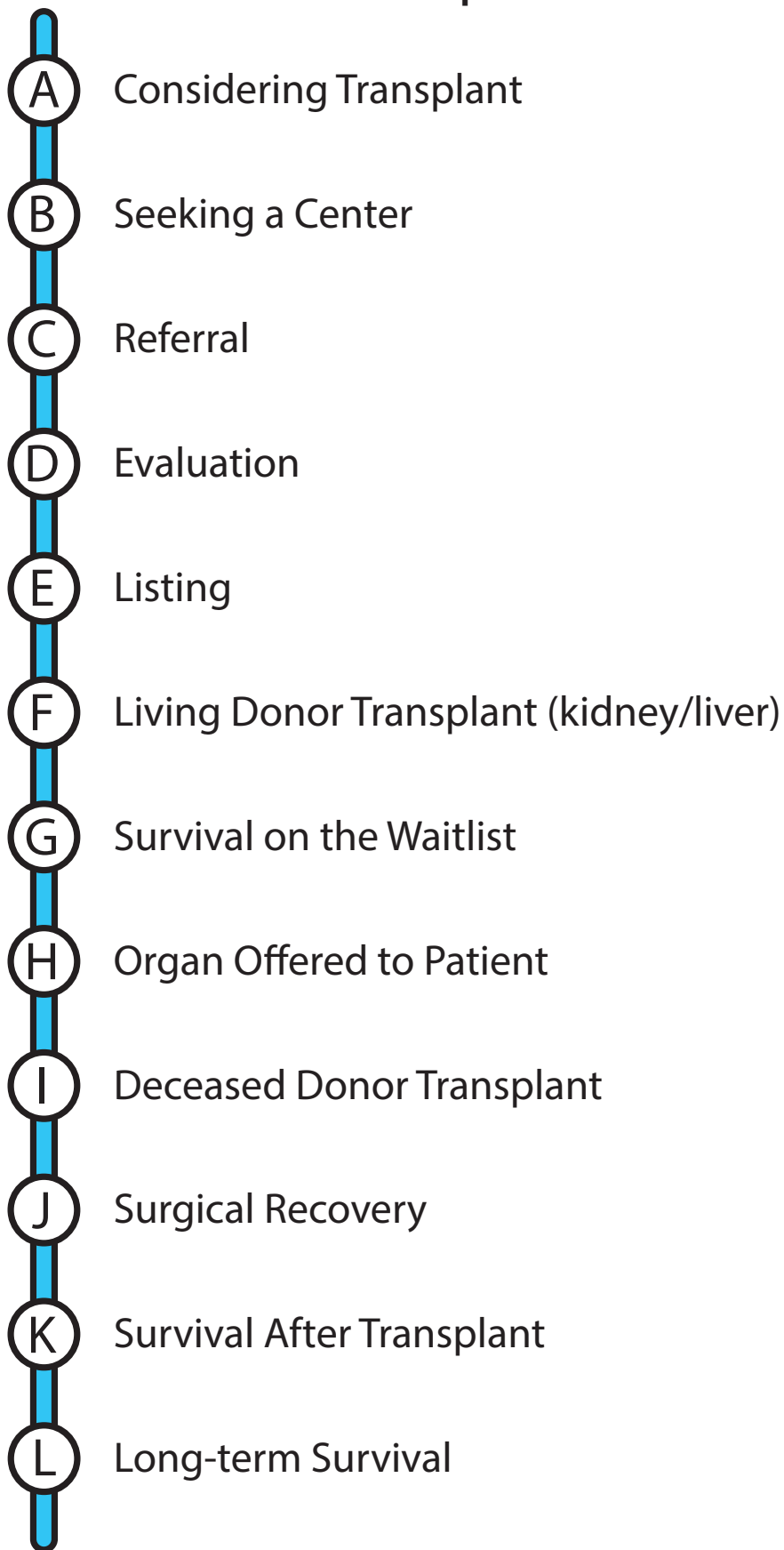
Risk adjusted: This statistical process is used to account for differences in patient characteristics at different locations when reporting outcomes. This process allows more meaningful comparisons because some locations may treat patients who are sicker or who have higher risks of complications than other locations. Risk adjustment accounts for the potential change in outcomes when treating sicker patients.

Transplant rate: A metric of how quickly a transplant program is getting candidates to transplant once they are listed at that program.

Waiting list (or waitlist): A list of candidates awaiting transplant and their priority managed by OPTN/UNOS.

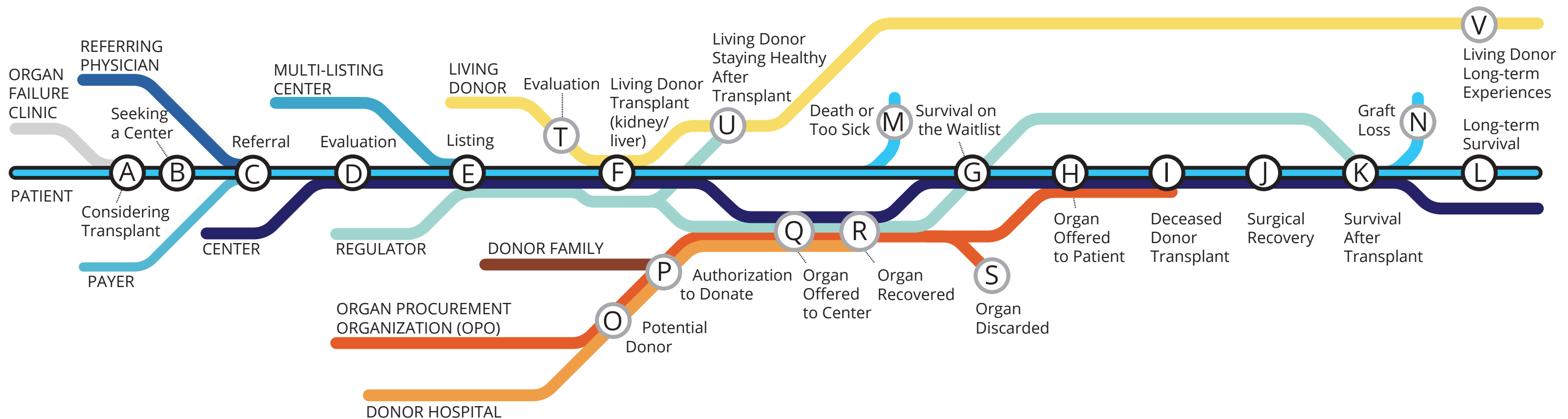


Transplant Patient Journey

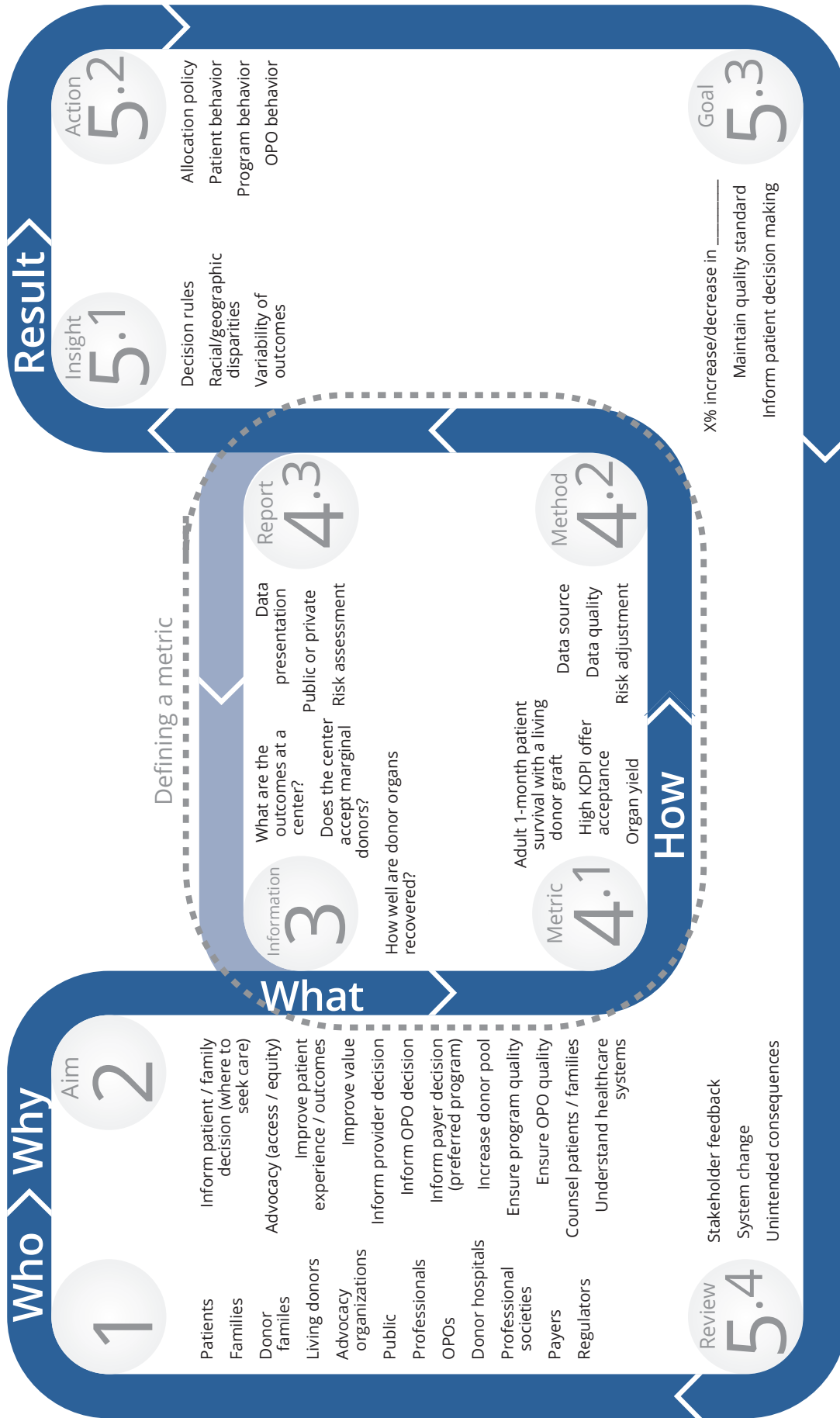


SEEK
EVALUATE
RECOVER

Transplant System



Metrics Framework Guide



Who: SRTR Stakeholders (Critical Audiences)

Patients, Families, and Donors

- Patients with late- or end-stage organ disease who are not yet listed for transplant
- Patients referred for transplant but not yet listed • Patients listed for transplant
- Transplant recipients • Potential living donors • Living donors • Deceased donor family members • Transplant candidate/recipient family members and caregivers

Patient Advocacy Organizations

- Transplant Recipients International Organization • National Kidney Foundation
- American Association of Kidney Patients • American Liver Foundation • Juvenile Diabetes Research Foundation • Transplant Families • Children's Organ Transplant Association
- Starzl Network • many other organizations...

Aligned Organizations and Paired Donation Programs

- UNOS • Donate Life America • Organ Donation and Transplantation Alliance • American Foundation for Donation and Transplantation • Association of Multicultural Affairs in Transplantation • National Kidney Registry • Alliance for Paired Donation
- many other organizations...

Professionals and Programs/Hospitals

- Transplant physicians and surgeons • Transplant administrators • Transplant coordinators, social workers, pharmacists, patient advocates, etc • Nurses • Transplant quality and performance (QAPI) professionals • Histocompatibility professionals • Organ procurement organization professionals • Transplant Programs • End-stage renal disease networks
- Referring physicians • Donor hospitals

Professional Societies

- American Society of Transplantation • American Society of Transplant Surgeons
- Association of Organ Procurement Organizations • American Society for Histocompatibility and Immunogenetics • NATCO: The Organization for Transplant Professionals
- The Transplantation Society • American Nurses Association • Society for Transplant Social Workers • Organ-specific societies (eg, American Society of Nephrology, American Association for the Study of Liver Diseases, International Society for Heart and Lung Transplantation, Society of Thoracic Surgeons, many other organizations...)

Regulators and Government

- US Department of Health and Human Services (Health Resources and Services Administration; Centers for Medicare & Medicaid Services [CMS] - Center for Clinical Standards and Quality; National Institutes of Health; Food and Drug Administration; Centers for Disease Control and Prevention) • Veterans' Health Administration • Members of Congress • Judicial branch • State government and legislators • Organ Procurement and Transplantation Network (OPTN) and OPTN Committees (Membership and Professional Standards Committee, Ethics Committee, other committees)

Payers

- Government (CMS Center for Medicare & Medicaid Innovation; Medicare; Medicaid; Veterans' Health Administration) • Private Payers

Industry

- Device manufacturers (eg, ex vivo perfusion manufacturers) • Pharmaceutical companies
- Biotechnology companies

Other / General Public

- Press / media • Researchers • Global transplant community (other national registries, World Health Organization, etc) • Other stakeholders and groups

Why: Stakeholder Needs

Stakeholders	Why Stakeholders Need Information
<p>Patients, Families, and Donors</p> <p>Patients Advocacy Organizations</p>	<p>Inform patient / family decision (where to seek care)</p> <p>Advocacy (access / equity)</p> <p>Improve patient experience / outcomes</p> <p>Improve value</p> <p>Increase donor pool</p> <p>Counsel patients / families</p> <p>Understand healthcare systems</p>
<p>Aligned Organizations and Paired Donation Programs</p>	<p>Advocacy (access / equity)</p> <p>Improve patient experience / outcomes</p> <p>Improve value</p> <p>Increase donor pool</p> <p>Counsel patients / families</p> <p>Understand healthcare systems</p>
<p>Professionals and Programs/Hospitals</p>	<p>Advocacy (access / equity)</p> <p>Improve patient experience / outcomes</p> <p>Improve value</p> <p>Inform provider decision</p> <p>Inform OPO decision</p> <p>Increase donor pool</p> <p>Ensure program quality</p> <p>Ensure OPO quality</p> <p>Counsel patients / families</p>
<p>Professional Societies</p>	<p>Advocacy (access / equity)</p> <p>Inform provider decision</p> <p>Inform OPO decision</p>
<p>Regulators and Government</p>	<p>Ensure program quality</p> <p>Ensure OPO quality</p> <p>Change policy</p>
<p>Payers</p>	<p>Inform payer decision (preferred program)</p> <p>Counsel patients / families</p> <p>Advocacy (access / equity)</p>
<p>Industry</p>	<p>Improve value</p> <p>Increase donor pool</p> <p>Understand healthcare systems</p>
<p>Other/General Public</p>	<p>Advocacy (access / equity)</p> <p>Understand healthcare systems</p>



What: Information of Interest (Examples for Patients and Families)

Describing information of interest is a primary focus of Day 2 breakout sessions

Information not currently available at SRTR*:

- A** Considering Transplant
 - How long do transplants last?
 - How long will I have to wait for a transplant?
- B** Seeking a Center
 - What centers are in my area for the organ or multiorgan that I need?
 - How many transplants are performed?
- C** Referral
 - What centers transplant for patients like me?
 - What centers have good outcomes?
 - What centers may have shorter waits?
- D** Evaluation
 - How many patients are on the waiting list?
- E** Listing
 - What regions would increase my chances of transplant if I multilist at another center?
- F** Living Donor Transplant (kidney/liver)
 - How many living donor transplants are performed at a center?
 - How do outcomes compare for living donor and deceased donor transplants?
- G** Survival on the Waitlist
 - What are the outcomes of patients on the waiting list?
- H** Organ Offered to Patient
 - Does the center have options to expand my donor pool?
 - Has my center received an organ offer for me and turned it down?
- I** Deceased Donor Transplant
 - Are my outcomes expected to be better or worse if I accept this donor organ?
- J** Surgical Recovery
 - What antirejection medications are used at a center?
- K** Survival After Transplant
 - What are outcomes at a center right after surgery?
- L** Long-term Survival
 - What are outcomes at a center after recovering from surgery?

What will a transplant cost?

What centers are covered by my insurance?

Has the center received flags for outcomes?

What patient support services are provided?

Are patients treated how they want to be treated?

What is the ratio of patients for each transplant nurse coordinator?

Are there devoted hospital beds for candidates or recipients?

What patients get a referral for transplant?

Which referred patients are listed?

What room or area is available for rehospitalized transplant recipients?

Is there an emergency facility available?

What are the requirements for posttransplant follow-up?

Is posttransplant care team-based? Is there night and weekend coverage?

What centers are doing clinical trials?

What are long-term outcomes at a center?

What are the criteria for living donors?

What are long-term outcomes for living donors?

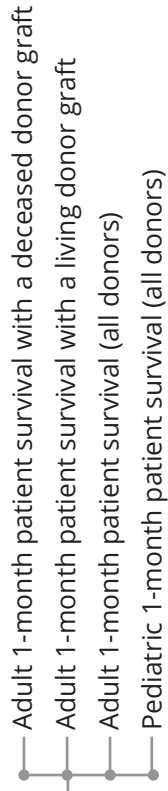
**information may be available outside of SRTR, for example, directly from transplant centers or insurance providers.*

How: Metrics, Methods, and Reporting

Describing potential metrics is a primary focus of Day 3 breakout sessions

Information of interest is a general statement or question that may be useful for a stakeholder to navigate the transplant journey.

What are outcomes at a center right after surgery?



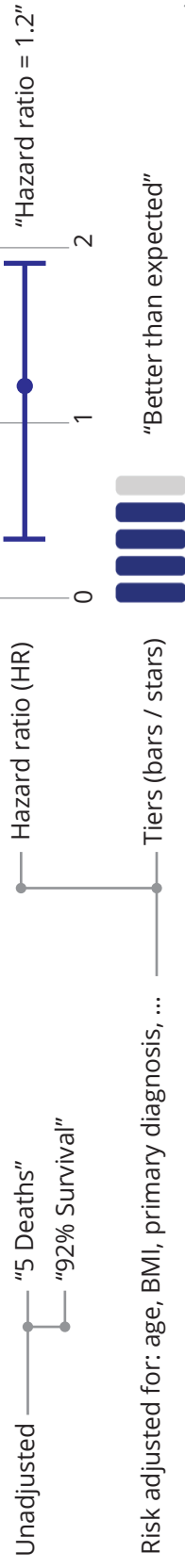
A metric is a precisely defined measurement that is calculated from existing data. More than one metric could relate to the general information of interest.

Methods and reports for a metric will be continuing work after the conference

A metric can be created with different methods. Common methods include “risk adjusted” or “unadjusted.” Adjusted metrics can account for differences in patient characteristics at different locations when reporting outcomes. This process allows more meaningful comparisons, because some locations may treat patients who are sicker or who have higher risks of complications than other locations. Risk adjustment accounts for the potential change in outcomes when treating sicker patients. The methods to risk adjust need to describe exactly what characteristics are adjusted for and by how much.



A metric can be displayed with different report styles, and reports can have different audiences and levels of public access.



Meeting Room Maps

SRTR Rooms

Second Floor

 Sky Bridge- Registration and Reception

 The Lakes Ballrooms A/B- Main Plenary Sessions

 The Lakes Ballrooms C/D- Break-outs

 Cedar- Break-outs

Third Floor

 Nokomis- Break-outs

Second Floor



Third Floor



