#### OPINION



### Toward continuous improvement of Scientific Registry of **Transplant Recipients performance reporting: Advances** following 2012 consensus conference and future consensus building for 2022 consensus conference

Aiav K. Israni<sup>1,2,3</sup> Ryutaro Hirose<sup>2,4</sup> Dorry L. Segev<sup>2,5</sup> Allyson Hart<sup>1,2</sup> Cory R. Schaffhausen<sup>1,2</sup> David A. Axelrod<sup>2,6</sup> Bertram L. Kasiske<sup>1,2</sup> Jon J. Snyder<sup>1,2,3</sup> (1)

#### Correspondence

Ajay K. Israni, Nephrology Division, Department of Medicine, Hennepin Healthcare, 701 Park Avenue, Minneapolis, MN 55415-1829, USA.

Email: isran001@umn.edu

### **Abstract**

The Scientific Registry of Transplant Recipients (SRTR) held a consensus conference in 2012 that examined methods used by SRTR for constructing performance metrics and made recommendations on how to improve program-specific reports. That consensus conference provided 25 recommendations categorized as follows: statistical methods, risk adjustment, and outcomes and data. During the subsequent decade, SRTR has implemented most of these recommendations; these are described in this article along with plans for another consensus conference in 2022. With the present article, SRTR aims to create transparency in the field of transplant metrics and guide discussion in the planning of the next consensus conference in 2022. The new conference will revisit the previous topics and have a broader focus to improve the metrics and information that SRTR provides. Readers can provide feedback on topics to be discussed at the next consensus conference as early as possible, by emailing srtr@srtr.org with the subject line "Task 5 Public Comment."

#### **KEYWORDS**

Organ Procurement and Transplantation Network (OPTN), program-specific reports (PSRs), risk adjustment, Scientific Registry of Transplant Recipients (SRTR), statistical methods, transplant outcomes and data

#### 1 | INTRODUCTION

The Scientific Registry of Transplant Recipients (SRTR) is charged with providing public information on transplant program performance, as per the Final Rule. To meet this mandate, SRTR provides program-specific reports (PSRs) and organ procurement organization (OPO)-specific reports (OSRs), as well as data on public and private websites for additional quality improvement and decision support.

SRTR and the Organ Procurement and Transplantation Network (OPTN) cosponsored a consensus conference, "Consensus Conference on Transplant Program Quality and Surveillance," held February 13-15, 2012.<sup>2</sup> In the 10 years since then, SRTR has implemented numerous changes in response to the generated recommendations, which we describe herein. The time is right to take stock of the past and begin strategizing continued improvements. The Health Resources and Services Administration has directed SRTR to convene another consensus conference

© 2022 John Wiley & Sons A/S. Published by John Wiley & Sons Ltd.

<sup>&</sup>lt;sup>1</sup>Department of Medicine, Hennepin Healthcare, University of Minnesota, Minneapolis, Minnesota, USA

<sup>&</sup>lt;sup>2</sup>Scientific Registry of Transplant Recipients, Hennepin Healthcare Research Institute, Minneapolis, Minnesota, USA

<sup>&</sup>lt;sup>3</sup>Department of Epidemiology and Community Health, University of Minnesota, Minneapolis, Minnesota, USA

<sup>&</sup>lt;sup>4</sup>Department of Surgery, University of California San Francisco, San Francisco, California, USA

<sup>&</sup>lt;sup>5</sup>Department of Surgery, Johns Hopkins University, Baltimore, Maryland, USA

<sup>&</sup>lt;sup>6</sup>Department of Surgery, University of Iowa, Iowa City, Iowa, USA

The new conference, planned for July 18–20, 2022, will revisit the previous topics and have a broader focus to improve the metrics and information that SRTR provides. The 2012 consensus conference had recommendations categorized as follows: statistical methods, risk adjustment, and outcomes and data. A few recommendations and SRTR's changes in response are discussed in this report, and others are covered in the Supporting Information. With the present article, SRTR aims to create transparency in the field of transplant metrics and guide discussion in the planning of the next consensus conference in 2022.

# 2 RECOMMENDATIONS AND RESULTING STATISTICAL METHODS CHANGES

# 2.1 | PSRs should be better suited to the needs of all users, particularly patients

This recommendation led to converting the tabular, text-based reports for transplant programs and OPOs into reports with graphics and maps. An Agency for Healthcare Research and Quality (AHRQ) R01 grant (HS 24527) funded interviews and focus groups with transplant candidates, transplant recipients, and their family members and patient surveys to better understand their needs and their understanding of these PSRs, testing various websites improvements.<sup>3–9</sup> In 2016, SRTR launched 5-tier summary metrics to improve patient understanding of key metrics. These changes were based on AHRQ best practice guidelines. <sup>10–12</sup> Extensive testing with patients and the general public was conducted on many features of the key metrics. <sup>4,8,9</sup> The future consensus conference may include further discussion about creating separate sections of the public website for patients and clinicians.

In 2014, the OSRs were also changed into reports with graphics and maps following extensive development and review with members of the SRTR Technical Advisory Committee (subsequently this committee underwent name changes to the SRTR Visiting Committee [2015-2020] and the SRTR Review Committee [2020-present]).

To continue advancing the presentation of these reports, SRTR launched new interactive web-based reports in 2020 with improved navigation of the content, improved graphical design, interactive components, and mobile-friendly technology. When a user searches for a transplant program within a defined geographical region, the search results are now presented as a patient-friendly list highlighting two pretransplant (survival on the waiting list, and transplant rate or "getting a deceased-donor transplant faster") and one posttransplant metric (1-year organ survival). The more detailed PDF report and the new data visualization of the complete PSR are then available for advanced site users.

Although content and design improvements have been made during the past 10 years, further recommendations to improve SRTR metrics, the methodology used, and the design and presentation will be heard at the 2022 conference, so that all public reports meet the needs of varied stakeholders and patients can use SRTR data to make informed decisions.

# 2.2 | Provide transplant centers, the MPSC, and CMS with tools such as the cumulative sum (CUSUM) technique and tools to allow subgroup analysis to facilitate quality assessment and performance improvement

SRTR developed CUSUM charts for posttransplant outcomes of allograft and patient survival and has released them to all transplant programs monthly on the SRTR secure site since 2014. Subsequently, SRTR added CUSUMs for organ offer acceptance in 2017–2018; the CUSUM for organ donor yield for OPOs was released in 2019 (Figure 1).

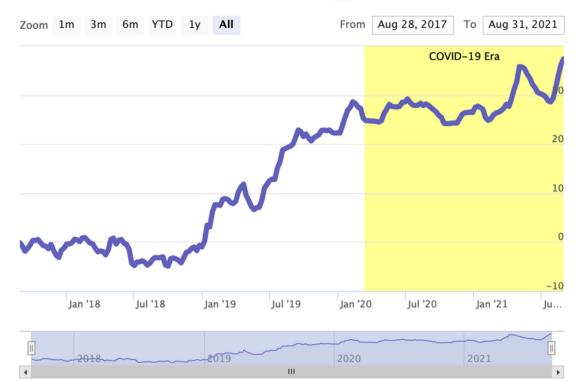
SRTR also held a webinar to educate the transplant community on using the Excel spreadsheets<sup>14</sup> for performing subgroup analysis (Figure 2). Further recommendations on making such tools, and webinars describing them, more user-friendly will be heard at the 2022 conference.

### 3 | RECOMMENDATIONS AND RESULTING CHANGES IN RISK ADJUSTMENT

### 3.1 | Identify centers that manage high-risk patients and donors well

SRTR has added metrics of offer acceptance, including offers from higher-risk donors. The acceptance of harder-to-place organs, as defined on an organ-specific basis, is shown in every PSR. For example, each kidney program has offer-acceptance metrics for all offers: low kidney donor risk index (KDRI) score, medium KDRI score, high KDRI score, and hard-to-place kidneys that have already been declined by more than 100 previous candidates.

SRTR does not specifically report outcomes metrics stratified by recipient and donor risks. The PDF and interactive reports contain information about transplants among candidates with high body mass index and older age for each transplant program. SRTR can provide more information on a center's willingness to perform transplants with higher-risk candidates or higher-risk donors. Whether patients need to know which programs perform transplants with higher-risk candidates or higher-risk donors can be explored at the 2022 conference. There have been efforts using SRTR data to develop decision aids to inform patients of programs that perform transplants for patients with such high-risk factors (www.transplantcentersearch.org). 4,8,9 Monitoring outcomes in groups stratified by recipient or donor risk would be difficult because of small numbers of such patients at most centers and the potential for statistical errors. Whether stratified results might be made available on the private, confidential website of transplant programs if deemed beneficial may be discussed at the 2022 conference.



Reliability: CUSUMs capture most but not all donors recovered after 2021-08-01. Yellow Shading = COVID-19 Era.

**FIGURE 1** Example of an organ procurement organization cumulative sum (CUSUM). CUSUM shown is for deceased donor kidney yield from August 28, 2017, to August 31, 2021. Yellow area highlights COVID-19 era.

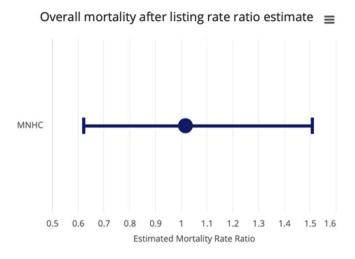
	A	B	-1 D-4-	D	E	F G	Н	n\ =		K	. м	N N	0	
	Overall Transplant Rate				Decease	Deceased Donor (DD) Transplant Rate				Ov	Overall Waitlist Mortality Rate			
2	All candidates					All candidates					All candidates			
3	Number of Candidates 1000			Nur	Number of Candidates				N	Number of Candidates				
4	Obse	Observed Transplants (O) 221			Observ	Observed DD Transplants (O)		159			Observed Deaths (O)		62	
5	Exp	Expected Transplants (E) 223.22		223.22		Expec	Expected DD Transplants (E)		155.71			Expected Deaths (E)		59.32
6	Overa	Overall Transplant Rate Ratio 0.99			DD T	DD Transplant Rate Ratio		1.02		Overall	Overall Waitlist Mortality Rate Ratio		1.04	
7														
8														
9	Candidate age: <40					Candidate age: <40						Candidate age: <40		
10	Number of Candidates 198			Nur	Number of Candidates				N	Number of Candidates		198		
11	Observed Transplants (O)		53		Obsen	Observed DD Transplants (O)		32			Observed Deaths (O)		1	
12	Expected Transplants (E) 52.46		52.46		Expec	Expected DD Transplants (E)		33.79			Expected Deaths (E)		5.21	
13	Overa	Overall Transplant Rate Ratio 1.01			DD T	DD Transplant Rate Ratio		0.95		Overall	Overall Waitlist Mortality Rate Ratio		0.42	
4														
5														
16	Candidate age: 40-<60						Candidate age: 40-<60					Candidate age: 40-<60		
17	Number of Candidates 502				Number of Candidates			502		N	Number of Candidates			
18	Observed Transplants (O) 105			Observed DD Transplants (O)			77			Observed Deaths (O)		31		
19	Exp	Expected Transplants (E) 110.09		110.09		Exped	Expected DD Transplants (E)		76.14			Expected Deaths (E)		27.79
20	Overa	Overall Transplant Rate Ratio 0.95			DD Transplant Rate Ratio			1.01		Overall	Overall Waitlist Mortality Rate Ratio		1.11	

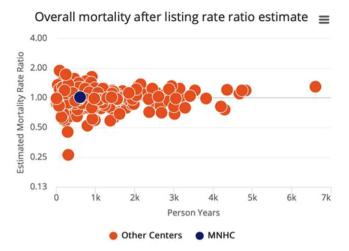
**FIGURE 2** Pretransplant worksheets for waitlist mortality. These worksheets allow for subpopulations to be examined to assess overperformance or underperformance in subsets of transplant candidates. Subsets shown focus on candidate age.

# 3.2 | Provide more data on waiting list risk and outcomes

The SRTR PSRs now publicly display pretransplant metrics in several ways. New interactive data visualizations were introduced in 2015 and enhanced in 2020. The PSRs display mortality on the waiting list and transplant rate, in addition to posttransplant outcomes, in the ini-

tial program search results on the SRTR website. In 2020, another metric was developed showing overall mortality after listing, which is calculated in an intent-to-treat manner. This display acknowledges that patient mortality after listing describes the relative experience of patients after listing. It also acknowledges that this metric depends on many factors, some being outside of the transplant program's control.





**FIGURE 3** Overall survival after listing. Figure on right shows mortality after listing for 1 center, Hennepin Healthcare System, compared with other kidney transplant centers. MNHC, Hennepin Healthcare System.

Whether there should be a patient-friendly PSR showing mortality after listing that combines pretransplant and posttransplant metrics, or other such metrics that are important to patients and family members, can be explored at the 2022 conference.

# 4 | RECOMMENDATIONS AND RESULTING CHANGES IN OUTCOMES

### 4.1 | Enhance reporting of access to transplant and pretransplant outcomes

SRTR has enhanced reporting of pretransplant metrics, such as mortality on the waiting list, transplant rate, and overall survival following listing (Figure 3). However, SRTR does not currently have access to data on all patients evaluated for listing at a transplant program because these are not collected by OPTN.

The Final Rule requires OPTN to provide information on patients who were inappropriately left off the waiting list.<sup>15</sup> Whether OPTN should collect information from all programs about all patients who were evaluated for the purpose of listing can be determined at the 2022 conference.

# 4.2 | Improve monitoring and reporting of short-term living donor outcomes

In response to this recommendation, SRTR now presents data on short-term living donor follow-up per OPTN policy 18.5.A, although timely laboratory findings at 24 months posttransplant are available for only approximately half of the living kidney donors nationally. SRTR has also launched the Living Donor Collective (LDC; www. livingdonorcollective.org), which is enrolling living donor candidates at the time of evaluation. These candidates, regardless of their eventual donor status, will be followed up to support various studies of

long-term outcomes. National trends are reported in the OPTN/SRTR Annual Data Report, and LDC has reported its early findings. <sup>16</sup> Which data collected by LDC are of interest at the program level can be discussed at the 2022 conference.

### 5 | RECOMMENDATIONS AND RESULTING CHANGES IN DATA

### 5.1 | Examine whether data sources such as DonorNet and Medicare claims can be used

SRTR explored data collected within the UNET system that were outside of the standard TEIDI data collection (e.g., SRTR has incorporated various data elements from the status update form on the Waitlist application into pretransplant and posttransplant risk-adjustment models). Unfortunately, Medicare claims do not capture many of the transplant recipients.

### 5.2 | Offer better education and data collection tools to assist programs in maintaining OPTN data

SRTR now offers many educational videos and webinars on our YouTube channel, all of which are on the public website. SRTR provides monthly data, along with the CUSUMs, to allow programs to assess the quality of data used in the CUSUMs.

### 6 | CONCLUSION

In conclusion, SRTR has acted on all recommendations from the 2012 consensus conference and implemented most of them. Please provide feedback on topics to be discussed at the next consensus conference (Table 1) as early as possible, by emailing srtr@srtr.org with the subject line "Task 5 Public Comment."





**TABLE 1** List of topics to be discussed at the 2022 consensus conference focused on the who, why, what, and how of transplant metrics

Topic	Subtopic
Stakeholder Overview of Who & Why of Metrics	
	Patient & family member perspective
	Payer & referring provider perspective
	Transplant provider perspective
	Transplant regulator perspective
History and Current State of Transplantation	
	Review of SRTR 2012 Consensus Conference
	Private & public metrics
	National Academy of Sciences, Engineering and Medicine Report recommendations
What of Metrics	
	What do patients, living donors, and their families want?
	What do professionals want to know?
How of Metrics	
	What metrics do programs suggest?
	What metrics do patients suggest?
	What metrics do payers suggest?
	What metrics do regulators suggest?

Some of the subtopics will be discussed in breakout groups.

### **ACKNOWLEDGEMENTS**

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, Healthcare 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 or display publicly, by or 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. A.K.I. is partially supported by AHRQ R01 grant HS 24527.

The authors acknowledge participation in the Transplant Peer Review Network and complied with the journal's author guidelines and policies.

#### **CONFLICTS OF INTEREST**

Dr. Israni has received research funds awarded to Hennepin Health-care Research Institute from Gilead for investigator-initiated research related to hepatitis C; is supported by grants and contracts awarded to Hennepin Healthcare from the Health Resources and Services Administration, National Institute of Allergy and Immunology, the National Institute of Diabetes and Digestive and Kidney Diseases, and the Agency of Healthcare Research and Quality; has served on an advisory board for CSL Behring; and receives consulting fees from Medical Review Institute of America. Dr. Axelrod reports consulting for CareDx and Talaris. Drs. Hirose, Segev, Hart, Schaffhausen, Kasiske, and Snyder have no conflicts of interest to report. No involvement of a commercial organization in manuscript preparation or funding.

#### **AUTHOR CONTRIBUTIONS**

Ajay K. Israni: concept/design, drafting manuscript, critical revision, approval, funding secured.

Ryutaro Hirose: drafting manuscript, critical revision, approval Dorry L. Segev: drafting manuscript, critical revision, approval Allyson Hart: drafting manuscript, critical revision, approval Cory R. Schaffhausen: drafting manuscript, critical revision, approval

David A. Axelrod: drafting manuscript, critical revision, approval Bertram L. Kasiske: drafting manuscript, critical revision, approval, funding secured

Jon J. Snyder: concept/design, drafting manuscript, critical revision, approval, funding secured

### DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

#### ORCID

Ajay K. Israni https://orcid.org/0000-0002-7607-0430

Dorry L. Segev https://orcid.org/0000-0002-1924-4801

Allyson Hart https://orcid.org/0000-0003-3517-0141

Cory R. Schaffhausen https://orcid.org/0000-0003-1705-1560

David A. Axelrod https://orcid.org/0000-0001-5684-0613

Bertram L. Kasiske https://orcid.org/0000-0003-4809-6956

Jon J. Snyder https://orcid.org/0000-0001-7974-8940

### **REFERENCES**

- Electronic Code of Federal Regulations. Part 121—Organ Procurement and Transplantation Network. Record maintenance and reporting requirements. https://www.ecfr.gov/cgi-bin/text-idx?node=pt42. 1.121&rgn=div5#se42.1.121\_110 Published 1998. Accessed December 22, 2021.
- Kasiske BL, McBride MA, Cornell DL, et al. Report of a consensus conference on transplant program quality and surveillance. Am J Transplant. 2012; 12(8): 1988–1996.
- 3. Schaffhausen CR, Bruin MJ, Chesley D, et al. What patients and members of their support networks ask about transplant program data. *Clin Transplant*. 2017; 31(12). 10.1111/ctr.13125
- Schaffhausen CR, Bruin MJ, Chu S, et al. Tool to aid patients in selecting a liver transplant center. *Liver Transpl.* 2020; 26(3): 337–348. https://doi.org/10.1002/lt.25715

- Schaffhausen CR, Bruin MJ, Chu S, et al. Comparing pretransplant and posttransplant outcomes when choosing a transplant center: focus groups and a randomized survey. *Transplantation*. 2020; 104(1): 201–210. https://doi.org/10.1097/TP.000000000002809
- Schaffhausen CR, Bruin MJ, Chu S, et al. The importance of transplant program measures: surveys of three national patient advocacy groups. Clin Transplant. 2018; 32(12): e13426. https://doi.org/10.1111/ctr. 13426
- Schaffhausen CR, Bruin MJ, McKinney WT, et al. How patients choose kidney transplant centers: a qualitative study of patient experiences. Clin Transplant. 2019; 33(5): e13523. https://doi.org/10.1111/ ctr.13523
- McKinney WT, Schaffhausen CR, Bruin MJ, et al. Development of a patient-specific search of transplant program outcomes and characteristics: feedback from kidney transplant patients. *Transplant Direct*. 2020;6(8):e585. https://doi.org/10.1097/txd.0000000000001036
- McKinney WT, Schaffhausen CR, Schladt D, et al. Designing a patientspecific search of transplant program performance and outcomes: feedback from heart transplant candidates and recipients. Clin Transplant. 2021; 35(2): e14183. https://doi.org/10.1111/ctr.14183. Epub 2020 Dec 19.
- Hibbard J, Sofaer S. Best practices in public reporting no. 1: how to effectively present health care performance data to consumers. Agency for Healthcare Research and Quality; 2010: 10-0082-0081-EF.
- Sofaer S, Hibbard J. Best practices in public reporting no. 2: Maximizing consumer understanding of public comparative quality reports: Effective use of exploratory information. Agency for Healthcare Research and Quality; 2010: 10-0082-0081-EF.
- Sofaer S, Hibbard J. Best practices in public reporting no. 3: How to maximize public awareness and use of comparative quality reports through effective promotion and dissemination strategies. Agency for Healthcare Research and Quality; 2010: 10-0082-0081-EF.
- Snyder JJ, Salkowski N, Zaun D, et al. New quality monitoring tools provided by the Scientific Registry of Transplant Recipients: cUSUM.

- Am J Transplant. 2014; 14(3): 515-523. https://doi.org/10.1111/ajt. 12628
- Scientific Registry of Transplant Recipients. SRTR Tools 101: Helpful Tools for Transplant Programs. https://www.srtr.org/news-media/webinars-and-educational-videos/webinar-items/webinars/. Accessed February 15, 2021.
- 15. Electronic Code of Federal Regulations. Part 121—Organ Procurement and Transplantation Network. https://www.ecfr.gov/cgibin/text-idx?node=pt42.1.121&rgn=div5#se42.1.121\_110. Accessed February 16. 2021.
- Kasiske BL, Ahn S, Conboy M, et al. on behalf of the Living Donor Collective participants. Outcomes of living kidney donor candidate evaluations in the Living Donor Collective Pilot Registry. *Transplant Direct.* 2021; 7(5): pe689. https://doi.org/10.1097/TXD. 0000000000001143. eCollection 2021 May.

#### 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: Israni AK, Hirose R, Segev DL, et al. Toward continuous improvement of Scientific Registry of Transplant Recipients performance reporting: Advances following 2012 consensus conference and future consensus building for 2022 consensus conference. Clin Transplant. 2022;e14716. https://doi.org/10.1111/ctr.14716