



Scientific Registry of Transplant Recipients: Collecting, analyzing, and reporting data on transplantation in the United States

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ABSTRACT

Founded in 1987, the Scientific Registry of Transplant Recipients (SRTR) operates under a contract from the US government administered by the Health Resources and Services Administration (HRSA). SRTR maintains a database of comprehensive information on all solid organ transplantation in the US. The registry supports the ongoing evaluation of the clinical status of solid organ transplantation, including kidney, heart, liver, lung, intestine, pancreas, and multi-organ transplants. Data in the registry are from multiple sources, but most are collected by the Organ Procurement and Transplantation Network (OPTN) from hospitals, organ procurement organizations, and immunology laboratories. The data include information on current and past organ donors, transplant candidates, transplant recipients, transplant outcomes, and outcomes of living donors. SRTR uses these data to create reports and analyses for HRSA, OPTN committees that make organ allocation policy, and the Centers for Medicare & Medicaid Services to carry out quality assurance surveillance activities; SRTR also creates standard analysis files for scientific investigators. In addition, SRTR and OPTN produce an Annual Data Report and provide information upon request for the general public. Thus, SRTR supports the transplant community with information services and statistical analyses to improve patient access to and outcomes of organ transplant.

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1. Historical background

The first successful kidney transplant in the US was performed in 1954. However, large numbers of transplants were not performed routinely until the late 1960s (Table 1). In 1969, the Southeastern Regional Organ Procurement Program (SEROPP) was formed to help transplant centers procure organs. One of the seven original organ procurement programs funded by the US government, SEROPP subsequently became the Southeastern Organ Procurement Foundation (SEOPF), the precursor to United Network for Organ Sharing (UNOS).

In 1984, the US Congress passed the National Organ Transplantation Act (NOTA) to address a critical organ donation shortage and improve the organ matching and placement process [1]. NOTA established the Organ Procurement and Transplantation Network (OPTN) to maintain a national registry for organ matching. In September 1986, the US Department of Health and Human Services

(HHS) awarded the initial OPTN contract to UNOS, a private, non-profit organization. In addition, NOTA stipulates, “The Secretary [of HHS] shall, by grant or contract, develop and maintain a scientific registry of the recipients of organ transplants. The registry shall include such information respecting patients and transplant procedures as the Secretary deems necessary to an ongoing evaluation of the scientific and clinical status of organ transplantation.”

The Health Resources and Services Administration (HRSA), an agency within HHS (Fig. 1), administers contracts for both OPTN and the Scientific Registry of Transplant Recipients (SRTR). From 1987 to 2000, HRSA contracted with UNOS to develop and operate SRTR. In September 2000, HRSA awarded the SRTR contract to the University Renal Research and Education Association, which became Arbor Research Collaborative for Health in July 2006. In September 2010, HRSA awarded the SRTR contract to the current contractor, the Minneapolis Medical Research Foundation (MMRF), whose Chronic Disease Research Group (CDRG) executes the contract.

The SRTR contract, NOTA, and the Transplantation Amendment Act of 1990 include requirements for the reporting of outcomes to the public. Under NOTA, SRTR and OPTN publish an Annual Data Report, which reports patient outcomes associated with organ procurement and transplantation at transplant centers across the US. The Transplantation

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Table 1
Historical Highlights of Organ Transplantation in the US.

| Year | Event |
|------|--|
| 1954 | First living donor kidney transplant |
| 1962 | First deceased donor kidney transplant |
| 1966 | First simultaneous kidney/pancreas transplant |
| 1967 | First liver transplant |
| 1968 | First heart transplant |
| 1969 | SEROPP formed in Richmond, Virginia |
| 1977 | First match run system under SEOPF, called UNOS |
| 1984 | National Organ Transplant Act P.L. 98-507 |
| 1986 | First federal OPTN contract awarded to UNOS |
| 1987 | SRTR founded and managed by UNOS |
| 1992 | First-ever comprehensive report on transplant survival rates for all active US transplant centers published by UNOS as OPTN contractor |
| 2000 | HHS Final Rule regulatory framework established |
| 2000 | SRTR contract awarded by HRSA to URREA (URREA became Arbor Research Collaborative for Health in 2006) |
| 2010 | SRTR contract awarded to MMRF |

HHS, US Department of Health and Human Services; HRSA, Health Resources and Services Administration; MMRF, Minneapolis Medical Research Foundation; SEOPF, The South-Eastern Organ Procurement Foundation; SEROPP, Southeastern Regional Organ Procurement Program; SRTR, Scientific Registry of Transplant Recipients; UNOS, United Network for Organ Sharing; OPTN, Organ Procurement and Transplantation Network; URREA, University Renal Research and Education Association.

Amendment Act of 1990 requires SRTR to report program-specific transplant survival rates for all solid organ transplants in the US. The first such report was published in 1992 and included 28,858 transplants performed between October 1, 1987, and December 31, 1989 [2]. In 1999, the program-specific reports (PSRs) were posted on the Internet for the first time. Currently, SRTR publishes PSRs on its Web site every 6 months, and these reports include statistics reported by the nation's organ procurement organizations (OPOs).

On March 16, 2000, HHS implemented a Final Rule establishing a regulatory framework for the structure and operations of OPTN and SRTR [3]. The Final Rule stipulates that SRTR provide statistics and analyses to the public regarding the performance of transplant programs at least twice per year. The Final Rule also stipulates that OPTN and SRTR respond to reasonable requests from the public for data needed for research. Finally, OPTN and SRTR carry out analyses requested by OPTN committees in support of efforts to improve organ allocation policies in the US (Table 2).

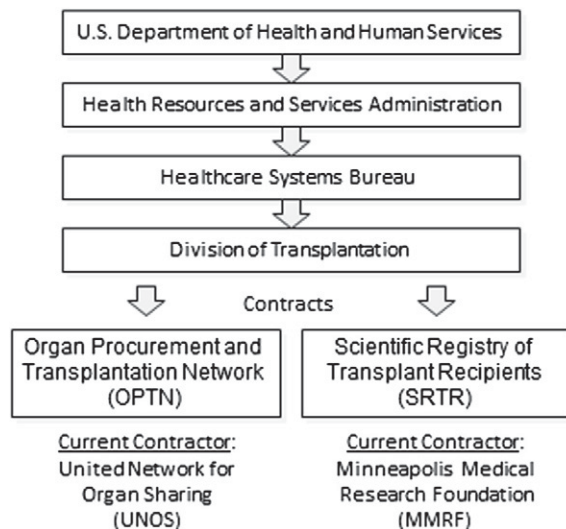


Fig. 1. Relationship between the US Department of Health and Human Services, its Divisions, and the two contractors. MMRF, Minneapolis Medical research Foundation; OPTN, Organ Procurement and Transplantation Network; SRTR, Scientific Registry of Transplant Recipients; UNOS, United Network of Organ Sharing.

Table 2
Contrasting Analytical Responsibilities of SRTR and OPTN.

| Parameter | SRTR | OPTN |
|-------------------|--|--|
| Purpose | Research and policy evaluation | Organ allocation policy development |
| Data and analyses | Inferential analyses and simulated allocation modeling | Data collection and descriptive statistics |

OPTN, Organ Procurement and Transplantation Network; SRTR, Scientific Registry of Transplant Recipients.

2. SRTR operational structure

The Division of Transplantation in the Healthcare Systems Bureau at HRSA provides oversight of the SRTR contract. The SRTR Project Director, Deputy Project Director, and Director of Operations oversee a team of SRTR Senior Staff. The 18 Senior Staff are transplant clinicians and experts in operations research, histocompatibility, health care economics, biostatistics, and epidemiology. The Senior Staff work closely with SRTR support staff to provide:

1. Data and analytical support.
2. Publications and other communications.
3. Information technology and data management.
4. Project management.

2.1. Data and analytic support

The data and analytic support function is SRTR's largest operational component. SRTR provides research support to HRSA and OPTN. OPTN operates 20 committees charged with policy development and enforcement regarding solid organ transplantation in the US. When the committees need research support to inform policy development, SRTR provides that support, often working closely with the OPTN contractor. To fulfill this role, SRTR employs biostatisticians, epidemiologists, research and policy liaisons, and clinicians. SRTR assigns a team consisting of a research and policy liaison, a biostatistician/epidemiologist, and a clinician to support each of the major OPTN committees. SRTR also supports the broader research community by providing analysis files and responding to requests for data and data analyses, and develops and maintains a suite of simulated allocation modeling (SAM) software. The SAMs are used internally to model potential effects of changes to organ allocation policy, and are made available to external researchers.

2.2. Publications and other communications

The SRTR publications group consists of medical editors and production editors. SRTR publishes the Annual Data Report and scientific articles in peer-reviewed journals, and presents data and analyses at major scientific meetings.

2.3. Information technology and data management

SRTR receives monthly data updates from the OPTN contractor. These updates include current information on all wait-list candidates, transplant recipients, deceased donors, and living donors. The SRTR information technology (IT)/data management team processes these data monthly and generates standard analysis files (SAFs) for use by SRTR biostatisticians and epidemiologists. In addition, the IT/data management team constructs ad hoc analysis files in support of SRTR research and responds to numerous simple data requests from external researchers.

SRTR currently maintains two public Web sites (<http://srtr.transplant.hrsa.gov> and www.srtr.org) along with a private or "secure" Web site, all managed by the IT/data management team.

The .gov public Web site hosts SRTR Annual Data Reports. It complies with requirements of Section 508 of the Rehabilitation Act to assure that people with disabilities can access Web content. The second public Web site hosts all PSRs and OPO-specific reports (OSRs). In addition, the .org public Web site provides supporting documentation, such as analytical methods, maps of transplant program locations, detailed flowcharts describing the organ allocation system for each organ, and links to publications and presentations. The secure Web site is available to all transplant programs and OPOs in the US; it posts preview versions of the PSRs and OSRs for programs to review prior to public release.

Finally, the IT/data management team manages software and application development in support of SRTR activities. For example, SRTR developed the donor yield calculator to help OPOs compare their actual rates of organs recovered for transplant (donor yield) to rates that would be expected based on the models maintained by SRTR.

2.4. Project management

The SRTR project management team maintains all contracts and subcontracts, produces mandated progress reports, manages invoicing, and monitors budgets. In addition, the project management team assists with budget development for SRTR special projects requested by HRSA.

3. Principal SRTR tasks

The SRTR mission is to “support the transplant community with statistical analyses to improve patient outcomes.” To fulfill this mission, SRTR is required to:

1. Maintain a Steering Committee. This committee consists of SRTR leadership, HRSA leadership, and OPTN leadership. It provides oversight of SRTR activities, prioritizes tasks, and addresses issues relevant to the operation of the OPTN and SRTR contracts.
2. Maintain an SRTR Technical Advisory Committee (STAC). This committee is made up of nine members and ex-officio members. It provides scientific oversight of SRTR activities and methodologies, and oversees two subcommittees. The STAC-SAM subcommittee provides expertise regarding operations research in support of the development of SAM software. The STAC-PSR subcommittee advises SRTR on the development and application of advanced statistical methodologies for assessing transplant program performance.
3. Provide research and analytic support to OPTN committees. SRTR currently supports 20 OPTN committees and several subcommittees.
4. Provide research and analytic support to HRSA. SRTR provides research support to HRSA leadership when special analyses are required to support HRSA initiatives or inquiries.
5. Analyze OPO and transplant program performance. The PSRs and OSRs are released to the public every 6 months.
6. Publish and present results from research activities. SRTR regularly publishes scientific articles in peer-reviewed journals and presents study results at scientific meetings.
7. Develop and enhance SAM software. This ongoing activity enhances SRTR's ability to model the potential impact of changes to national allocation policies.
8. Make data available to the transplant community and the public.
9. Develop and publish an Annual Data Report. This report is an annual summary of statistics pertinent to organ transplantation in the US.
10. Produce a biennial report to Congress. This report, mandated by Congress, describes all federal activities related to organ transplantation.
11. Conduct special studies. Occasionally, HRSA identifies topics requiring special study. For example, SRTR is currently engaged

in a special study to assess optimal systems for allocating deceased donor livers, with the goal of reducing disparities in access to deceased donor livers based on where the candidate is listed.

4. The SRTR database

4.1. Overview

SRTR receives data collected by other organizations, manages and analyzes these data, and supplies data, summary reports, and analyses to the transplant community (Fig. 2). Data in the SRTR database are largely from OPTN (from transplant centers, OPOs, and histocompatibility laboratories), and also from the Centers for Medicare & Medicaid Services (CMS) and the Social Security Administration Death Master File (SSADMF). SRTR processes all of the data it receives and provides information upon request to HRSA, CMS, private insurance providers, OPTN committees, external investigators, and the public. The publicly released data include SAFs, PSRs, OSRs, Annual Data Reports, articles in the scientific literature, and presentations at scientific meetings. The HHS Final Rule requires that SRTR make all data available to the public while honoring patient privacy and applicable statutes. The Final Rule also requires SRTR to respond to requests from the public for data needed for bona fide research or analytical purposes, data needed to assess the performance of HRSA contractors and transplant programs, and data needed for other purposes.

4.2. Data sources

SRTR's primary source of data is OPTN (Fig. 2). OPTN collects data from transplant centers, OPOs, and histocompatibility laboratories. UNOS first developed the OPTN data collection system in 1986 under contract to HHS. This system has undergone numerous changes; it is currently an Internet-based system called UNet™ [4], which enables organ transplant programs to:

- Register candidates for transplant.
- Match donated organs to waiting candidates.
- Submit data on donors, candidates, and recipients before and after transplant.

The UNet™ database system includes data from every transplant and organ donation that has occurred in the US since October 1,

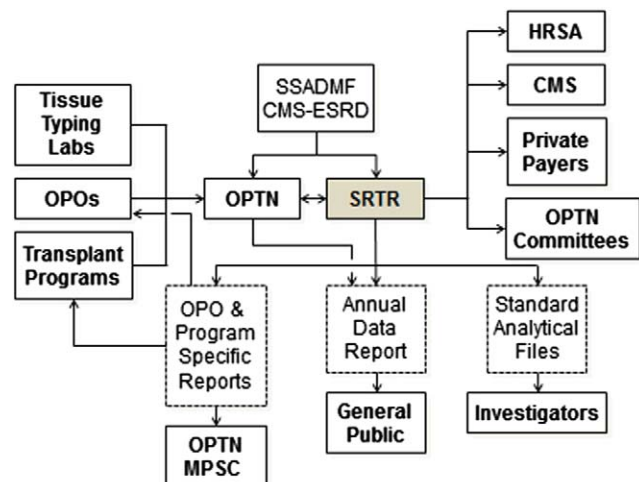


Fig. 2. Sources and uses of SRTR data. CMS, Centers for Medicare & Medicaid Services; ESRD, end-stage renal disease; HRSA, Health Resources and Services Administration; MPSC, Membership and Professional Standards Committee; OPO, organ procurement organization; OPTN, Organ Procurement and Transplantation Network; SSADMF, Social Security Administration Death Master File; SRTR, Scientific Registry of Transplant Recipients.

1987. Once a month, SRTR receives a snapshot of the OPTN database, which provides current and complete data including all new and existing information as well as any historical revisions. SRTR electronically evaluates and compiles these and other data into the SRTR database.

SRTR and OPTN also receive monthly updates from the SSADMF. SRTR uses an internally developed person-matching algorithm against the SSADMF to determine when transplant candidates, living donors, and transplant recipients have died. These death dates are extremely important, since OPTN does not require transplant centers to follow transplant candidates who have been removed from the waiting list, or living donors for more than 2 years after donation. Centers may voluntarily submit death dates after these defined follow-up intervals, but they are not required to do so.

SRTR also accesses CMS data for kidney transplant candidates and recipients collected by its Consolidated Renal Operations in a Web-Enabled Network (CROWN). CROWN is a CMS Web-based data-compilation system that allows dialysis facilities to comply with mandatory Medicare data submission policies. CROWN data include:

- Patient admission and discharge history.
- Form CMS-2728, End-Stage Renal Disease (ESRD) Medical Evidence Report: Medicare Entitlement and/or Patient Registration.
- Form CMS-2746, Death Notification.
- Form CMS-2744, ESRD Facility Survey.
- Patient Attributes and Related Treatment (monthly Patient Activity Reports).
- Hemodialysis, peritoneal dialysis, and vascular access information.

Through the person-matching process against this CMS data source, SRTR obtains information on ESRD death date, first dialysis date, cause of death, and primary cause of kidney disease.

The final SRTR database consists of hundreds of tables and many components, including the national transplant waiting lists, the donor–recipient matching process, and data on donors and recipients.

4.3. Data processing

The SRTR monthly update process starts with the arrival of the OPTN data snapshot. SRTR first evaluates, cleans, and reorganizes the OPTN data, then combines these data with data from other sources. Through the person-matching process, SRTR identifies and combines any duplicate patient or donor entries that relate to the same person. Then, three processes are performed to generate usable data:

- SAF generation. Data files are created in the Statistical Analysis System (SAS®; SAS Institute, Inc., Cary, North Carolina, US) format used by researchers and biostatisticians.
- Data dictionary generation. Documentation is created for the SAFs.
- Data quality validation. Numerous tests are performed to identify potential errors in the data. A report is generated and sent to OPTN so these issues can be addressed and resolved, enhancing the overall quality of the data in future releases.

4.4. Standard analysis file structure

The SAFs include files in SAS format organized by candidate, donor, transplant, and transplant follow-up information (Table 3). Candidate files include status history and status justification; donor files include donor disposition and living donor follow-up information; transplant files include summarized candidate, donor, and follow-up information and transplant immunosuppression, recipient histocompatibility, and cross-match information; and transplant follow-up files include follow-up immunosuppression, malignancy, and malignancy treatment information. All files can be linked to each other at the person level and are accompanied by an electronic data dictionary.

Table 3
Data Elements Included in the Public SAF.

| Files | Data |
|--|--|
| All organs | |
| Deceased donor information | All deceased donor information |
| Donor disposition | Organ dispositions of each organ for each recovered deceased donor |
| Living donor information | All living donor information |
| Living donor follow-up information | Information on living donors who are followed at 6 months and 1 year posttransplant |
| Immunosuppression medications given during follow-up | Data on immunosuppression medications given to a transplant recipient during the follow-up period |
| Immunosuppression medications given at transplant | Data on immunosuppression medications given to a transplant recipient at the time of transplant |
| Malignancies diagnosed | Data on any malignancies diagnosed during the follow-up period |
| Recipient histocompatibility | One record for the recipient histocompatibility lab results for each transplant performed |
| Recipient histocompatibility cross-match | Cross-match results |
| Treatment data | Treatment data for each de nova solid tumor reported |
| Candidate information | Includes candidates registered on the OPTN waiting list and candidates who received a living donor organ, even if they were never wait-listed; gives candidate information during the waiting time |
| Transplant follow-up information | For each transplant, a record at 1 year posttransplant and annually until retransplant, death, or loss to follow-up; information from the TRF form, including patient characteristics at the time of follow-up and posttransplant (1 year) or last follow-up (all others) |
| Transplant table | One record per transplant; TRR form information, including patient characteristics at the time of transplant and transplant characteristics; donor characteristics, donor–recipient interactions (e.g., calculated HLA mismatch scores, blood compatibilities, and organ sharing, based on the relationship between the OPO and the transplant center. |
| Status history table | At least one record for each wait-list registration; characteristics that may change during the wait |
| Specific organs | |
| Kidney/pancreas PRA history | History of kidney, kidney-pancreas, and pancreas wait-list records based on changes in PRA and copra |
| Liver MELD exception | MELD exception information |
| MELD exception tumors | Original and current MELD exception HCC tumors |
| Liver status justification | Liver status justification for 1, 2A, and 2B |
| Thoracic status justification | Status justification for 1A and 1B |

HCC, hepatocellular carcinoma; MELD, model for end-stage liver disease; OPO, organ procurement organization; OPTN, organ procurement and Transplantation Network; PRA, panel-reactive antibody; TRF, transplant recipient follow-up; TRR, transplant recipient registration.

5. SRTR data uses

5.1. Health Resources and Services Administration

Ultimately, HHS is responsible for administering deceased donor organ allocation in the US (Fig. 1). SRTR provides data and data analyses to HRSA as necessary and as defined in its contract with MMRF/CDRG. In addition to data reporting outlined in the contract and described below, Congress has mandated that HHS report every 2 years on the involvement of HHS in organ transplantation. SRTR provides much of the data and helps HHS produce this Biennial Report to Congress. The Secretary of HHS convenes an Advisory Committee

on Organ Transplantation (ACOT) that occasionally may request data and analyses from OPTN or SRTR. HHS also participates with the transplant community in task forces designed to improve the supply of organs for transplant and transplant outcomes; SRTR may provide data or analyses to assist these endeavors.

5.2. Centers for Medicare & Medicaid Services

CMS pays for many organ transplants in the US and maintains its own quality assurance process for transplant programs [5]. Much of the data used in the CMS surveillance of transplant programs are supplied by SRTR to CMS through its contractor, the University of Michigan Kidney Epidemiology and Cost Center (UM-KECC). Data include the PSRs and OSRs, and other data as requested. To date, CMS has chosen to use criteria for identifying transplant programs needing scrutiny and audit similar to the criteria used by the OPTN's Membership and Professional Standards Committee (MPSC).

5.3. Private payers

Private payers use the PSRs and other information to select transplant programs to provide services for their insured patients. Payers often request additional information on transplant program outcomes that is not provided in the PSRs. Transplant programs may voluntarily request that UNOS release information to insurance providers under a uniform request for information (RFI) program developed for transplant programs in conjunction with UNOS. SRTR provides some of the RFI data to UNOS for this purpose.

5.4. Organ Procurement and Transplantation Network Committees

OPTN committees often request information that requires data analyses. OPTN provides descriptive statistics, and SRTR provides inferential analyses of data. Typically, SRTR carries out analyses regarding the potential effects of newly proposed allocation policies at the request of organ-specific OPTN committees. To support these analyses, SRTR maintains and updates the SAMs. There are currently three SAMs, the kidney-pancreas simulation allocation model (KPSAM), the liver simulation allocation model (LSAM), and the thoracic simulation allocation model (TSAM).

The SAMs use actual data previously collected for transplant donors, candidates, and recipients, but change organ allocation rules to simulate reallocation of organs using committee-requested “what if?” scenarios. The SAM programs have the flexibility to specify new candidate and donor characteristics along with new organ allocation policies. The resulting output can provide information about allograft survival, relisting rate, number of transplants performed, and wait-list mortality under a proposed allocation policy. Comparisons can be made with simulations using current allocation policy.

5.5. Researchers

One of SRTR's primary missions is to provide data to individuals or groups performing research. Researchers and clinicians can request data by completing a data use agreement (DUA) specific to each project. Each DUA includes a research plan and a security plan. All DUAs are approved by SRTR prior to the release of data. The STAC advises SRTR regarding data release practices, and reviews all requests for data linkages and patient-identified data. These policies and procedures help protect patient privacy.

SRTR fulfills four types of data requests:

1. Simple data requests. These are requests for existing data and do not require additional programming or analyses; they can generally be fulfilled in less than 4 h and do not require a DUA or formal approval.

2. Data requests for standard analysis files or simulated allocation models. These requests can be fulfilled with a SAF and/or a SAM; they require a DUA.
3. Data requests requiring linkages. Data requests that require a linkage to an external data source or use of personal identifiers to link with other public or private data sources can usually be accommodated. All such requests must be authorized by the STAC and the HRSA SRTR Project Officer. Once the request is approved, performing or arranging a linkage with SRTR data may take a few weeks to several months.
4. Data request for additional SRTR programming. Data requests requiring additional SRTR analyses are considered depending on resources available, and are reviewed on a case-by-case basis by SRTR and the HRSA SRTR Project Officer.

The SRTR SAF provides data elements from the SRTR database, including heart, lung, kidney, pancreas, liver, and intestine transplants and combinations thereof. The SAF includes encrypted patient identifiers, encrypted transplant center codes, and encrypted OPO codes. Currently, the SAF does not include geographic data or text fields. Some data elements that are not part of the standard files, such as OPTN region, may be included upon request. The SAF is released quarterly (March, June, September, and December of each year) and is available only in SAS formatted files.

SRTR provides the SAMs to the public for use in research. The three types of SAMs available allow for analysis of changes to organ allocation policies. The SAMs have limitations and require programming skills to use.

5.5. OPTN Membership and Professional Standards Committee

Like CMS, the OPTN MPSC quality assurance process monitors outcomes of transplant programs and OPOs. The MPSC applies performance criteria to data reported in the PSRs and OSRs to determine transplant programs and OPOs that may need further scrutiny. SRTR produces PSRs and OSRs every 6 months and publishes them on its Web site. SRTR provides other data to the MPSC as requested.

5.6. General public

SRTR publishes PSRs and OSRs on its Web site every 6 months. In addition, in conjunction with OPTN, SRTR publishes an Annual Data Report providing the latest transplant statistics. These reports provide the information needed to answer most inquiries. However, SRTR also responds to more specific requests for information, as described above.

6. Reports

6.1. Program-specific reports

The PSRs contain information on wait-list candidates, deceased donors, living donors, transplant recipients, and outcomes for all OPTN-approved transplant programs in the US. These include heart, intestine, kidney, liver, lung, and pancreas programs. In addition, PSRs are produced for two types of multi-organ transplant programs, heart–lung and kidney–pancreas, since OPTN separately certifies these types of programs. If an institution maintains multiple transplant programs, e.g., a kidney program and a liver program, separate reports are produced for each organ type. This results in a large number of PSRs (Table 4).

The PSRs follow the same basic structure, with slight modifications for each organ type. For example, the liver and kidney reports contain data on living donors but the other PSRs do not, because living donor transplants are not performed or are uncommon. The structure of the

Table 4
Numbers of PSRs Produced by SRTR, July 2012.

| Program Type | Number of Programs, July 2012 PSR |
|-----------------|-----------------------------------|
| Heart | 146 |
| Kidney | 264 |
| Intestine | 35 |
| Liver | 137 |
| Lung | 70 |
| Pancreas | 143 |
| Heart-lung | 41 |
| Kidney-pancreas | 148 |
| Total PSRs | 984 |

PSR, program-specific report; SRTR, Scientific Registry of Transplant Recipients.

PSRs follows the transplant process from registration on the waiting list, through transplant, through death:

6.2. Section A: Program Summary

- Wait-list activity (total candidates, active candidates, and new candidates).
- Census of transplant recipients the program is following.
- Observed and expected transplant rates.
- Observed and expected mortality rates following registration on the waiting list.
- First-year, adult and pediatric, observed and expected patient and graft survival.

6.3. Section B: Wait-List Information

- Wait-list activity, with comparisons to the OPTN region and to the nation as a whole.
- Demographic characteristics of wait-list candidates.
- Medical characteristics of wait-list candidates.
- Transplant rates for all wait-list candidates, adult and pediatric.
- Mortality rates following registration on the waiting list, adult and pediatric.
- Wait-list candidate status 6, 12, and 18 months after listing.
- Percent of candidates who undergo deceased donor transplants by demographic and medical characteristics.
- Estimates of time to transplant for candidates in each program, donation service area (DSA), OPTN region, and the nation as a whole.

6.4. Section C: Transplant Information

- Transplant recipient demographic characteristics, including age, sex, and race.
- Transplant recipient medical characteristics.
- Characteristics of deceased donors compared with the OPTN region and the nation.
- Characteristics of living donors compared with the OPTN region and the nation.
- Graft and patient survival compared with the nation. For each outcome, an expected adjusted survival is provided. Each program is then determined to be performing as expected, better than expected, or worse than expected based on a statistical comparison of its observed and expected graft failure and death counts. These statistics are provided for the most recent 30-month cohort of transplant recipients in the program. The statistical models that determine the expected event counts for each transplant program are publicly available on the SRTR Web site.

6.5. Organ procurement organization-specific reports

There are currently 58 OPOs in the US (Fig. 3). Each OPO serves a DSA defined by a grouping of counties. The OPO services each donor hospital in its DSA to manage the donation process and facilitate placement of the donated organs. The OSRs contain information on deceased donation in each of the 58 DSAs, including information on eligible deaths at donor hospitals in the DSA, conversion rates of eligible deaths to actual organ donors, characteristics of deceased donors procured by the OPO, and organ utilization statistics per deceased donor.

The OSRs include information on:

- Organs recovered and transplanted per donor in the DSA.
- Number and location of organs transplanted in the US.
- Donation rates for all donors and for donors meeting eligibility criteria.
- Observed and expected organ-specific yields.
- Donor characteristics including ethnicity/race, age, sex, blood type, cause of death, and donation after circulatory death or donation after brain death status.
- Percent of candidates who undergo transplant by 30 days, 1, 2, and 3 years.
- Recipient characteristics by organ type.

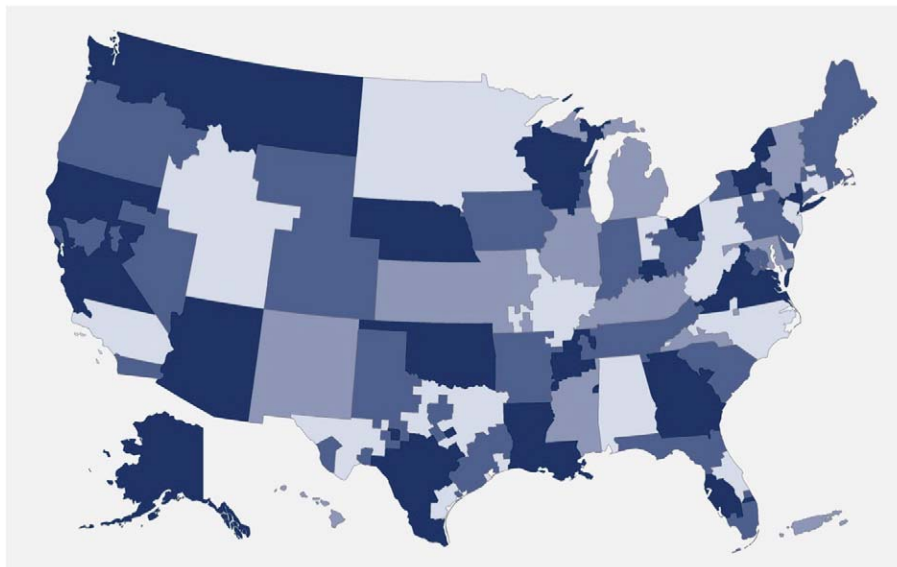


Fig. 3. The 58 donation service areas in the US identified by organ procurement organization.

Annual data report

Each year, with OPTN support and HRSA review and approval, SRTR produces a report that provides data on organ donation and transplantation in the US, showing recent activity and trends over time. The report includes chapters on kidney, pancreas, liver, intestine, heart, and lung transplantation, with sections describing the waiting list, deceased donor organ donation, living donor organ donation, transplant, donor-recipient matching, outcomes, immunosuppression, and pediatric transplant. The report also includes chapters on deceased donor organ donation and international transplant rate comparisons and an appendix. The 2011 report contains approximately 500 figures and tables. The full report is published on the Internet at <http://srtr.transplant.hrsa.gov>. Online viewing options include e-reading, printer-friendly PDFs, and PowerPoint slides. A print version of the report appears in the *American Journal of Transplantation* [6].

Conclusion

SRTR is a registry that contains current and past information on the full continuum of transplant activity in the US. Data in the registry come largely from OPTN, and from CMS and the SSADMF. SRTR employs an extensive system involving several technologies to combine, reorganize, and clean data to create the SRTR database. Data in the database are then evaluated, reorganized, and eventually extracted into more useful forms, such as the SAFs. Researchers and clinicians request the SAFs and other data elements for research at their institutions.

SRTR provides data for research; analyses for US government agencies, including HRSA and CMS; and information for transplant

centers, OPOs, OPTN committees, and the general public. SRTR thereby supports the development of policy and research to shape the future of solid organ transplantation in the US.

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