

OPTN & SRTR ANNUAL DATA REPORT

U.S. Department of Health and Human Services Health Resouces and Services Administration December 2012







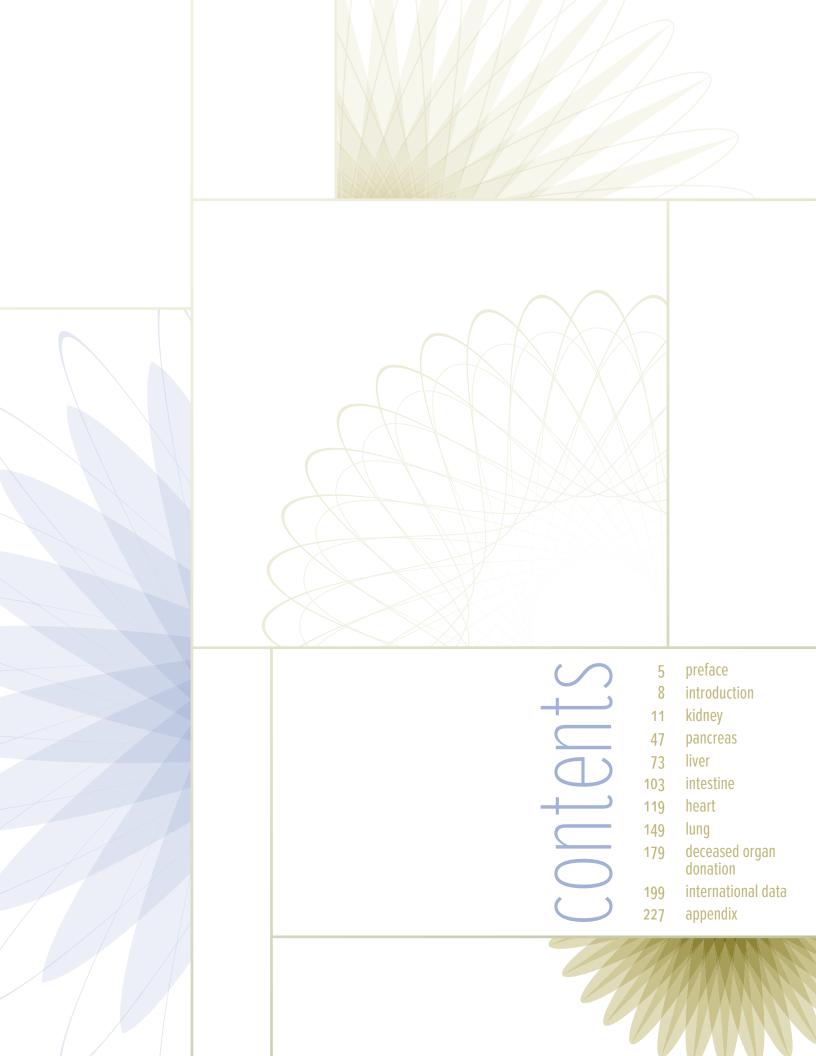


Figure titles specify adult and pediatric populations; if not listed, figure includes patients of all ages. (For lung data, patients aged 12 and older are grouped with adults.) And unless otherwise indicated, data in all figures are for solitary organ transplants.

Each chapter contains (when relevant to the specific organ) the following sections:

- wait list
- deceased donation
- live donation
- transplant
- donor-recipient matching
- outcomes
- immunosuppression
- pediatric transplant
- maps of transplant centers

POPULATIONS REPORTED

Figure titles indicate adult or pediatric populations; if not specified, data include all patients of all ages.

With the exception of the "total transplants" figure in each organ-specific chapter (i.e., KI 4.1), and of pancreas figures which specify SPK and PAK transplants, all figures in these chapters are limited to patients on the waiting list for a single-organ transplant (i.e, not heart-lung, not kidney-pancreas).

AGE

Adult patients are defined as those 18 and older for all organs except lung; lung allocation policy treats patients 12 and older as adults. For wait-list figures, age is defined at time of listing unless otherwise specified.

RACE/ETHNICITY

Multi-racial patients are defined as other/unknown. When a given race group is not shown, it is included with other/unknown.

ECD KIDNEYS

Data on willingness to accept an ECD kidney are available from 2003.

PANCREAS DATA

Pancreas data encompass the three types of pancreas wait lists or transplants: simultaneous kidney-pancreas (SPK), pancreas after kidney (PAK), and pancreas-alone (PTA).

LUNG ALLOCATION SCORE

The lung allocation score (LAS) became available in 2005. Data by LAS are presented using the most recent LAS before December 31 of each year.

preface

This Annual Data Report of the US Organ Procurement and Transplantation Network (OPTN) and the Scientific Registry of Transplant Recipients (SRTR) is the 21st annual report and is based largely on data pertaining to the period 1998-2011. The previous report, OPTN/SRTR 2010 Annual Data Report, was based on data from the period 1998-2009. Thus, the current report contains two additional years of data, for 2010 and 2011, and therefore includes more recent data than the previous report. In addition, the title OPTN/SRTR 2011 Annual Data Report reflects the fact that the report covers the most recent complete year of transplants, those performed in 2011.

This publication was developed for the US Department of Health and Human Services, Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation, by the SRTR contractor, the Minneapolis Medical Research Foundation (MMRF), and the OPTN contractor, the United Network for Organ Sharing (UNOS), under contracts HHSH250201000018C and 234-2005-37011C, respectively.

As the SRTR contractor, MMRF, through its Chronic Disease Research Group (CDRG), determined which data to present, conducted the required analyses, created the figures and tables, drafted the text, and designed the document. As the OPTN contractor, UNOS reviewed the draft report, contributed to the content, and provided the glossary. This report is available at http://www.srtr.org/. Individual chapters, as well as the report as a whole, may be downloaded.

OVERVIEW AND HIGHLIGHTS

This Annual Data Report includes chapters on kidney, pancreas, liver, intestine, heart, and lung transplantation, a chapter on deceased donor organ donation, and an appendix. Also, new this year is a chapter on international transplant rate comparisons. The organ-specific chapters include sections describing the waiting list, deceased donor organ donation, living donor organ donation, transplant, donor-recipient matching, outcomes, immunosuppression, and pediatric transplant. When possible, similar data and formats are used for each chapter and section. However, this is not always possible because some data are not pertinent to all organs.

Graphical presentation of the data is emphasized: approximately 500 figures, tables, and maps are included in the various chapters. Graphics are downloadable from the SRTR website as slides. The data behind the graphics are downloadable from the SRTR website in a spreadsheet format. Numerous data tables are also provided on the site.

Maps in this report present data divided into quintiles. A sample map is provided on the next page.

In this example, approximately one-fifth of all data points have a value of 10.8 or above. Ranges include the number at the lower end of the range, and exclude that at the upper end (e.g., the second range here is 8.2 to < 9.2). To facilitate comparisons of maps for different periods, we commonly apply a single legend to each map in a series. In this case, the data in each individual map are not evenly distributed, and a map for a single year may not con-

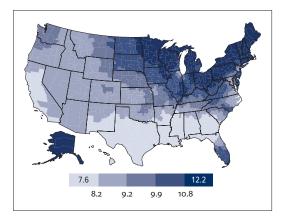
tain all listed ranges. Numbers in the first and last boxes indicate the mean values of data points in the highest and lowest quintiles, not the minimum and maximum of observed data.

Maps by donation service area (DSA) use DSA boundaries in effect at the end of 2011. Some DSAs include non-contiguous areas. If a DSA has no transplant program for a given organ, the DSA is not shaded on the map.

On the SRTR website, the Excel page for each map includes additional data. The map-specific mean is calculated using only the population included in the map; this does not usually match other data in the Annual Data Report, and should be quoted with caution. The overall mean includes all patients for whom data are available, whether or not their residency, transplant center, or DSA is known. We also include the number of patients excluded in the map-specific mean, and the total number of patients used in the calculation.

MILESTONE DATES IN THE PRODUCTION OF THIS REPORT

Data were cut: April 2012. Data were analyzed: May 2012.



DATA REQUESTS TO THE SRTR

Simple data requests can be fulfilled with existing data, do not require additional programming or analyses, can generally be fulfilled quickly (i.e., in less than 4 hours), and do not require a data use agreement (DUA) or payment. Requests for a standard analysis file (SAF) or a simulated allocation model (SAM) require a DUA and payment. SRTR offers a student discount for researchers who qualify.

Data requests requiring linkages with other public or private data sources can often be accommodated. To protect the privacy of individuals in the transplant registry, SRTR will perform linkages and analyses that require use of personal identifiers; SRTR will release the resulting data as summary data or as individual data with encrypted identifiers. In exceptional circumstances, identifiers may be released to other government agencies or to investigators for linkage, but only after authorization by the SRTR Technical Advisory Committee and the SRTR Project Officer at HRSA. Data requests for additional SRTR programming will be considered depending on available resources and reviewed on a case-by-case basis by SRTR and the SRTR Project Officer at HRSA. Requesters must sign a DUA. An hourly rate will be assessed for time spent on the request; cost to fulfill the request is based solely on the programming time required. Data sets require payment in addition to payment for programming time.

WEBSITES

www.srtr.org is a public website containing transplant program-specific reports, organ procurement organization (OPO)-specific reports, summary tables, archives of past reports, timelines for future reports, risk-adjustment models, methods, basic references for researchers who use SRTR data files, a link to the Annual Data Report and its supporting documentation and data tables, answers to frequently asked questions, and other information.

HTTPS://**SECURESRTR.TRANSPLANT.HRSA.GOV** is a secure website that provides access to the pre-

release program- and OPO-specific reports, survival spreadsheets, and other useful information. All individual authorized users from transplant programs and OPOs have their own unique logins for the secure site.

HTTP://UNOS.ORG is a public website containing information on donation and transplantation, data collection instruments, data reports, education materials for patients and transplant professionals, policy development, and other information. This website also links to the OPTN website.

HTTP://OPTN.TRANSPLANT.HRSA.GOV is a public website containing news, information, and resources about transplantation and donation, including transplant data reports; policy development; and related boards and committees. It also contains allocation calculators, a calendar of events, answers to frequently asked questions, and other information.

CONTACT INFORMATION

PATIENT INQUIRIES

888-894-6361 (toll free)

RESEARCH INQUIRIES

OPTN/UNOS requests: 804-782-4876 (phone); 804-782-4994 (fax) SRTR data requests: 877-970-SRTR (toll free); 612-347-5878 (fax)

MEDIA INQUIRIES

301-443-3376 (HRSA / Office of Communications) 804-782-4730 (OPTN) 612-337-8960 (SRTR)

FEDERAL PROGRAM INQUIRIES

HHS/HRSA/HSB/DOT 5600 Fishers Lane Parklawn Bldg, Rm 12C-06 Rockville, MD 20857 301-443-7577

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SUGGESTED CITATIONS

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Or, provide the URL for the webpage cited and the access date: Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR). OPTN/SRTR 2011 Annual Data Report. Department of Health and Human Services, Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation; 2012. Available at [insert URL here]. Accessed [insert date here].

Abbreviated citation: OPTN/SRTR 2011 Annual Data Report. HHS/HRSA/HSB/DOT.

PUBLICATIONS BASED ON DATA IN THIS REPORT OR SUPPLIED ON REQUEST MUST INCLUDE A CITATION AND THE FOLLOWING STATEMENT

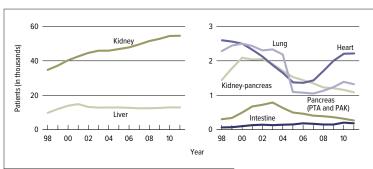
The data and analyses reported in the 2011 Annual Data Report of the Organ Procurement and Transplantation Network and the US Scientific Registry of Transplant Recipients have been supplied by the Minneapolis Medical Research Foundation and UNOS under contract with HHS/HRSA. The authors alone are responsible for reporting and interpreting these data; the views expressed herein are those of the authors and not necessarily those of the US Government.

introduction

As in previous years, a recurring theme in this year's Annual Data Report is the imbalance between the supply of organs and the number of patients who could benefit from transplant. Differences in supply and demand for different organs are highlighted below; also discussed are changes in waiting list activity, transplants performed, and organs recovered for transplant but discarded.

DECEASED DONOR TRANSPLANT WAITING LISTS

Separate waiting lists are maintained for each deceased donor organ that is allocated for transplant by the Organ Procurement and Transplantation Network (OPTN). The numbers of new patients listed for transplant every year differ by organ type. In making comparisons, it is important to remember that patients who need a kidney and,



INT 1a Patients on the waiting list on December 31 of the year (active listings only)

All except PA: Patients waiting for a transplant on 12/31 of the given year. Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive. PA only: Patients waiting for a transplant on 12/31 of the given year. Patients concurrently listed at multiple centers or on more than one list (pancreas-alone, kidney-pancreas) are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.

to a lesser extent, patients who need a liver may undergo living donor transplant and never appear on the deceased donor waiting list. However, some patients who ultimately undergo living donor transplant may have been listed on the deceased donor waiting list.

The kidney transplant waiting list is the largest by far (Figure 1a). On December 31, 2011, 54,599 active candidates were wait-listed for kidney transplant, 1,086 for simultaneous pancreas-kidney (SPK) transplant, 267 for pancreas transplant alone (PTA) or pancreas after kidney (PAK) transplant, 12,905 for liver transplant, 183 for intestine transplant, 2,208 for heart transplant, and 1,323 for lung transplant. Of note, in 2005, a new allocation system based on the Lung Allocation Score (LAS) was implemented in an attempt to allow sicker patients to undergo lung transplants more quickly. With implementation of this new system, many patients who would not undergo transplant were removed from the lung transplant waiting list, resulting in an abrupt decline in the number of candidates listed (Figure 1a). In addition, some patients are listed for multiple organs and appear on more than one waiting list.

The number of active (prevalent) candidates on the kidney transplant waiting list was virtually unchanged between December 31, 2010, and December 31, 2011; it increased by only 0.2%, from 54,505 to 54,599 (Figure 1a). Previously, the number of active candidates on the kidney transplant waiting list had increased every year, averaging a 2.7% per year increase over the past 5 years. The numbers of prevalent candidates on the waiting list at the end of the year declined in 2011 compared

with 2010 for SPK (-6.2%), PTA (-15.5%), and lung (-4.8%) transplants, but were unchanged for heart (0.0%) and liver (-0.2%) transplants.

The number of new (active and inactive) candidates added to the deceased donor kidney waiting list declined 3.4% between 2010 and 2011 (Figure 1b). The annual numbers of candidates added to the waiting lists also declined for SPK (-14.7%), PTA (-12.8%), heart (-1.9%), and, to lesser extents, lung (-0.9%) and liver (-0.7%).

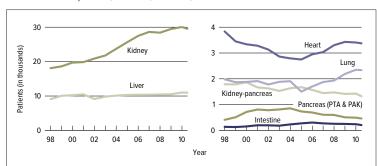
One can speculate that the small reduction in the demand for deceased donor kidney transplant may reflect the slowing rate of new end-stage kidney failure. Less clear is why the demand for pancreas transplant decreased so dramatically in the past few years. The new pancreas allocation system, in which pancreas allocation is virtually independent of kidney allocation, has been approved by the OPTN Board of Directors but has not yet been implemented. In the new allocation system, organ procurement organizations will no longer be able to give preference to candidates for simultaneous pancreas-kidney transplant or candidates for solitary pancreas transplant (pancreas after kidney or pancreas transplant alone). Instead, these two types of pancreas candidates will be given equal priority within locality, HLA mismatch status, calculated panel reactive antibody (CPRA) status, and waiting time.

ORGAN TRANSPLANTS

Between 2010 and 2011, the total number of kidney transplants performed in the US declined slightly (by 0.7%), from 17,726 to 17,604 (Figure 2). In fact,

since 2007, when 17,496 transplants were performed, the number of kidney transplants performed annually has changed little. This is not due to a declining demand for kidneys, since many more candidates were active on the waiting list than underwent transplant. On December 31, 2011, for example, 54,599 candidates were wait-listed for kidney transplant, roughly 3-fold more than underwent transplant in 2011.

The number of pancreas transplants has declined markedly and progressively. Between 2010 and 2011, the total number of pancreas transplants (pancreas alone or combined with a kidney) performed in the US declined by 7.6%, from 1,137 to 1,051. Since the



INT 1b Patients added to the waiting list during the year (active & inactive at listing)

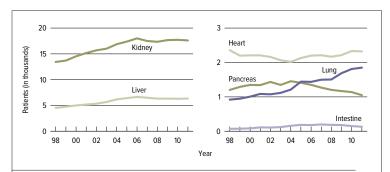
All except PA: Patients waiting for a transplant. A "new patient" is one who first joins the list during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a "new patient." Patients concurrently listed at multiple centers are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive. PA only: Patients waiting for a transplant. A "new patient" is one who first joins one of the three lists during the given year, without having listed in a previous year. However, if a patient has previously been on the list, has been removed for a transplant, and has relisted since that transplant, the patient is considered a "new patient." Patients concurrently listed at multiple centers or on more than one list are counted only once. Those with concurrent listings and active at any program are considered active; those inactive at all programs at which they are listed are considered inactive.

peak of 1,454 pancreas transplants performed in 2004, numbers have declined annually. Reasons for this decline are unclear, but it is not due to fewer donors.

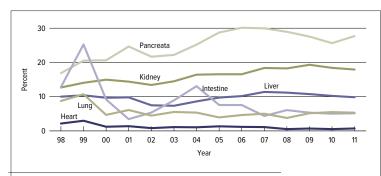
The number of liver transplants declined by 4.7%, from a peak of 6,651 in 2006 to 6,341 in 2011. This represents a decline of about 1% per year. The number of lung transplants increased slightly, by 2.1%, from 1,811 in 2011 to 1,849 in 2010. This continues an annual increase in lung transplants over the past decade of about 7% per year. The number of heart transplants changed little (a decline of 0.4%) between 2010 and 2011.

DISCARDS

A general shortage of deceased donor organs for transplant continues. A frequently asked question



INT 2 Transplants performed during the year (adult & pediatric combined)
Kidney: Patients receiving a kidney-alone or simultaneous kidney-pancreas transplant. Lung:
Patients receiving a lung-alone or simultaneous heart-lung transplant. Other organs: Patients receiving a transplant. Retransplants are counted.



INT 3 Discard rates among organs recovered for transplant

Percent of organs discarded out of all organs recovered for transplant. Lungs and kidneys are counted individually.

is how often organs removed for transplant are subsequently discarded. The answer varies for different organs and different reasons (Figure 3). The discard rate is highest (25% to 30%) for pancreata. This is undoubtedly because the shortage of pancreata is not as critical as for other organs. Hence, patients and their physicians can wait for a high-quality pancreas. Since 2005, the annual percentage of discarded pancreata has changed little.

The least often discarded organ is the heart, followed by lung and liver. This is because these organs are seldom removed from a deceased donor unless a recipient has already been found. The discard rate for lungs is approximately 5%, and the rate for hearts is less than 1%. The liver discard rate is approximately 10%, and has changed little since 2005.

The discard rate for kidneys is about 18%, and has changed little in the past several years. The most common reason given for discarding a kidney that has been recovered for transplant is the biopsy result. This result may be a somewhat biased, since biopsies are more likely to be obtained when the donor kidney for some reason is suspected to be suboptimal. An argument can be made that biopsies, which have been shown to be poor predictors of graft outcomes, should be used less often.

SUMMARY

Overall, growth in the demand for some organs, such as kidneys, has lessened slightly, as reflected by slowing growth in the deceased donor kidney transplant waiting list. Nevertheless, there are far more candidates on the waiting list than there are available organs. Efforts to increase the supply of donors should continue. However, many organs that are recovered for transplant are not used. Thus, some relief of the organ shortage may be possible by focusing efforts on minimizing the number of discarded organs recovered for transplant.