United States Organ Transplantation

OPTN / SRTR

2012 ANNUAL DATA REPORT

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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 2012 Annual Data Report of the US Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients have been supplied by the United Network for Organ Sharing and the Minneapolis Medical Research Foundation 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 U.S. Government.

This report is available at srtr.transplant.hrsa.gov. Individual chapters, as well as the report as a whole, may be downloaded.

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notes

POPULATIONS REPORTED

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

Unless otherwise specified, data in each organ-specific chapter include both isolated transplants and multi-organ transplants of the given type. For example, patients on the kidney transplant waiting list include those listed for an isolated kidney, kidney-pancreas, or any other organ combination that includes kidney.

Wait-list populations are reported at the person level. If a patient is listed at more than one center, we concatenate those records from the time of earliest listing to the time of latest removal. Patients listed, removed (usually due to transplant), and subsequently re-listed are counted separately per concatenated listing.

AGE

Adult patients are defined as those aged 18 years or older for all organs except lung; lung allocation policy treats patients aged 12 years or older as adults. For wait-list figures, age is defined at the 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 waiting lists or transplants: simultaneous kidney-pancreas (SPK), pancreas after kidney (PAK), and pancreas-alone (PTA). Pancreata used for islet transplantation are excluded.

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. In the case of transplant recipients, data by LAS are presented using the LAS at the time of transplant.

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.)

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*
- *Medicare data*
- *maps of transplant centers*

preface

This Annual Data Report of the US Organ Procurement and Transplantation Network (OPTN) and the Scientific Registry of Transplant Recipients (SRTR) is the twenty-second annual report and is based on data pertaining to the period 1998-2012. The title OPTN/SRTR 2012 Annual Data Report reflects the fact that the report covers the most recent complete year of transplants, those performed in 2012.

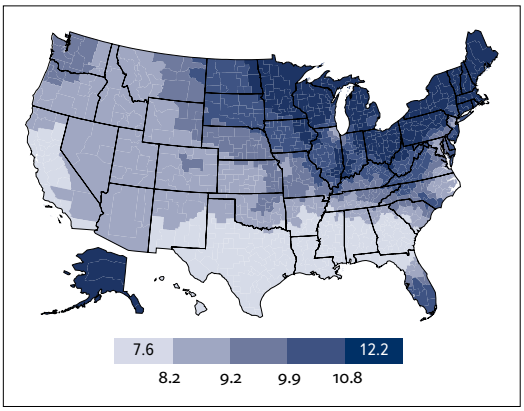
As the SRTR contractor, the Minneapolis Medical Research Foundation, through its Chronic Disease Research Group, determined which data to present, conducted the required analyses, created the figures and tables, drafted the text, and designed the document. As the OPTN contractor, the United Network for Organ Sharing reviewed the draft report, contributed to the content, and provided the glossary.

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. The organ-specific chapters include information on such topics as the waiting list, deceased donor organ donation, living donor organ donation, transplant, donor-recipient matching, outcomes, immunosuppression, and pediatric transplant. New this year is information on cost, including data on Medicare payments, in most organ chapters. When possible, similar data and formats are used for each chapter. However, this is not always possible because some data are not pertinent to all organs.

Graphical presentation of the data is emphasized: approximately 400 figures, tables, and maps are included in the various chapters. Graphics are downloadable as slides srtr.transplant.hrsa.gov. The data behind the graphics are downloadable from the same location in a spreadsheet format. Numerous data tables are also provided on the site.

Maps in this report present data divided into quintiles. Below is a sample map.



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 contain 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 2012. 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 2013.
Data were analyzed: May 2013.

DATA REQUESTS TO THE SRTR

Requests for data can be made to SRTR at http://www.srtr.org/ or to OPTN at http://optn.transplant.hrsa.gov.

WEBSITES

HTTP://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 prerelease 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)

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

FEDERAL PROGRAM INQUIRIES

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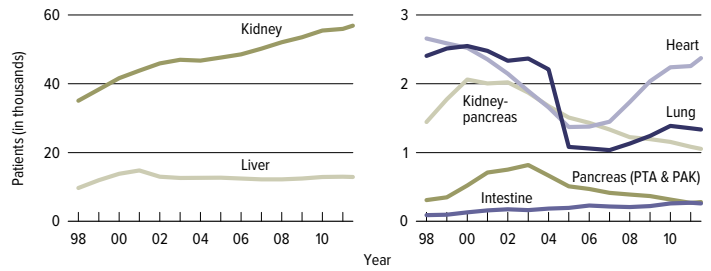
Rockville, MD 20857
301-443-7577

introduction

An imbalance continues between the supply of organs for transplant and the number of patients registered on deceased donor transplant waiting lists. Differences in supply and demand for different organs are highlighted below; also discussed are changes in wait-list activity, transplants performed, and discard of organs recovered for transplant.

TRENDS IN DECEASED DONOR TRANSPLANT WAITING LISTS

Separate waiting lists are maintained for each deceased donor organ allocated for transplant by the Organ Procurement and Transplantation Network. The numbers of new patients listed for transplant every year differ by organ type. In making comparisons, it is important to note that patients who need a kidney and, to a lesser extent, patients who need a liver may undergo living donor transplant and never appear on the deceased donor waiting list. Others who ultimately undergo living donor transplant may have been listed on the deceased donor waiting list.



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

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.

The kidney transplant waiting list is the largest solid organ waiting list by far (Figure 1a). On December 31, 2012, 57,903 active candidates were wait-listed for kidney transplant, 1021 for simultaneous pancreas-kidney (SPK) transplant, 290 for pancreas transplant alone (PTA) or pancreas after kidney (PAK) transplant, 12,774 for liver transplant, 251 for intestine transplant, 2493 for heart transplant, and 1315 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 increased 3.5% between December 31, 2011, and December 31, 2012, from 55,969 to 57,903 (Figure 1a). The numbers of prevalent candidates on the waiting list at the end of the year declined in 2012 compared with 2011 for liver (-1.8%), SPK (-5.9%), intestine (-7.7%), and lung (-2.9%) transplants, but increased for PTA/PAK (7.8%) and heart transplants (10.4%).

The number of new (active and inactive) candidates added to the deceased donor kidney waiting list increased 2.9% between 2011 and 2012 (Figure 1b). The annual numbers of candidates added to the waiting lists also increased for SPK (6.6%) and

heart (5.6%) transplants, but declined for PTA/PAK (-12.2%), lung (-4.5%), and liver (-2.3%) transplants.

In summary, the most notable wait-list trends over the past decade have been the continuing gradual increases in the numbers of candidates waiting for a kidney on the deceased donor waiting list. In contrast, the number of candidates waiting for pancreas transplants has steadily declined. The most rapidly growing waiting list has been for heart transplants.

TRENDS IN ORGAN TRANSPLANTS

For 3 years in a row, the total number of kidney transplants performed in the US has declined. Between 2011 and 2012, the number declined by 1.7%, from 18,367 to 18,048 (Figure 2). This decline in transplants is probably not due to a declining demand for kidneys, since many more candidates were active on the waiting list than underwent transplant. On December 31, 2012, for example, 57,903 candidates were active on the deceased donor kidney waiting list, approximately 3-fold more than underwent transplant in 2012. The situation is not improving, since in 2012 many more patients were added to the deceased donor kidney transplant waiting list (20,093 active, 31,157 active plus inactive) than underwent transplant.

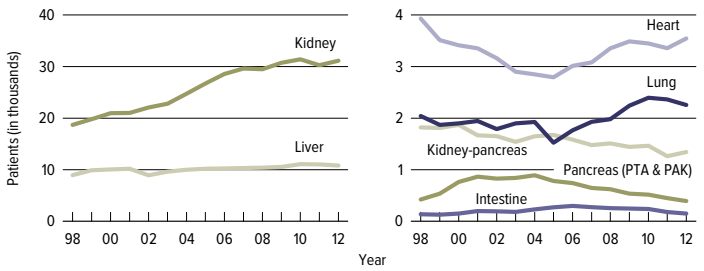
The number of pancreas transplants has declined markedly and progressively. Between 2011 and 2012, the total number of pancreas transplants (pancreas alone or combined with a kidney) performed in the US declined by 3.6%, from 1082 to 1043. Since the peak of 1484 pancreas transplants performed in 2004, numbers have declined annually. Reasons for this decline are unclear, but it parallels a decline in the number of patients listed, rather than in the number of donors.

The number of liver transplants performed declined by 6.2%, from a peak of 7228 in 2006 to 6781 in 2012. This represents a decline of about 1% per year. The number of lung transplants decreased by 3.9%, from 1868 in 2011 to 1795 in 2012, the first time since 2002 that this number has declined. The number of heart transplants increased 2.0% between 2011 and 2012.

In summary, the numbers of abdominal organ transplants have been flat or have declined over the past 5 years, while the numbers of heart and lung transplants have increased.

DISCARDS

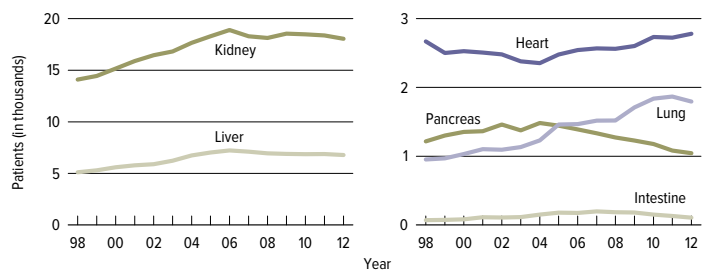
A general shortage of most deceased donor organs for transplant continues. A frequently asked question is how often organs removed for transplant



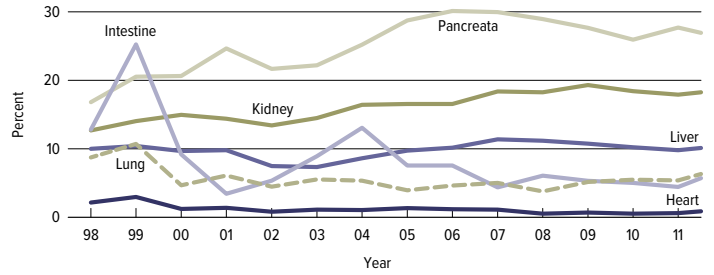
INT 1b Patients added to the waiting list during the year (active & inactive at listing)

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.

are subsequently discarded. The answer varies for different organs, and discards occur for 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.



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. Kidney: Kidneys are counted individually. The reference population for the KDPI conversion is all deceased donor kidneys recovered for transplant in the US in 2012. Lung: Lungs recovered as a block are counted as one organ. Lungs recovered separately are counted as two organs.

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 recovered for transplant is the biopsy result. This result may be somewhat biased, since biopsies are more likely to be obtained when the donor kidney is suspected of being 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

The number of kidney transplants has declined 3 years in a row, despite growth in the number of new patients added to the deceased donor kidney waiting list, both active and total (active plus inactive). The reasons for this worrisome trend are unknown, and they represent an ongoing source of controversy. This is particularly true given the relatively high rate at which kidneys removed for the purpose of transplant are discarded. Even more dramatic has been the decline in pancreas transplants, which has occurred despite an adequate source of deceased donor pancreata. This could reflect better alternative treatments for diabetes or other factors leading to less demand. The most rapid change in solid organ transplantation has been in heart and lung transplants.