Department of Health and Human Services

OFFICE OF INSPECTOR GENERAL

FOSTERING EQUITY IN PATIENT ACCESS TO TRANSPLANTATION:

Differences in Waiting Times for Kidneys

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MAY 1999
OEI-01-99-00211

OFFICE OF INSPECTOR GENERAL

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EXECUTIVE SUMMARY

For the past decade, the Office of Inspector General has maintained an active interest in this nation's organ allocation system. Our work has been guided by three underlying tenets that the Congress spelled out in the National Organ Transplant Act:

- An equitable system, with each person on a transplant waiting list having an equal opportunity to receive a transplant subject to established medical criteria;
- A national system adhering to uniform policies and standards; and
- A cooperative system based on the best interests of patients waiting for transplantation.

In 1991, we found that the access of patients to donated kidneys fell short of expectations in some important respects. For example, we found wide variation in waiting times among racial groups, transplant centers and geographic regions. We updated that report in 1998; we found that both racial and geographic disparities in waiting times still exist and, in some cases, seem to be growing. Today, more than 41,000 people are waiting for a kidney transplant, triple the number who were waiting to be transplanted in 1988.

This report is one in a series designed to shed light on the reasons for and implications of inequitable access to organ transplantation. This inquiry analyzes data on median waiting times for kidney transplants for two 3-year periods: January 1993 through December 1995 for median waiting times, and January 1994 through December 1996 for other data. These data are the most recent available from the Organ Procurement and Transplantation Network (OPTN).

Variation in waiting times for a kidney transplant. Our analysis shows considerable variation in median waiting time for kidney transplantation among the OPTN regions. For patients with Type O blood, the most common blood type, median waiting time ranged from 420 days to 1,538 days.

Likelihood of receiving a kidney transplant. Our review shows that patients in regions with a longer waiting time are less likely to receive a transplant. The percentage of patients with Type O blood who received a transplant ranged from 23 percent in the region with the longest median waiting time to 43 percent in the region with the shortest median waiting time.

Likelihood of death while awaiting a kidney transplant. Our review finds little variation in regional death rates, and a limited relationship with length of time on the waiting list. The use of dialysis may provide an explanation for this consistency across regions.

Our work on organ allocation and donation is continuing.

WAITING TIMES FOR KIDNEY TRANSPLANTATION

Background

In 1991, the Office of Inspector General documented the expectations that Congress and professional leaders had of organ allocation systems and then contrasted those expectations with actual practices.[1] We found that the access of patients to donated kidneys fell short of expectations in some important respects; for example, we found wide variation in waiting times among transplant centers and among different geographic regions of the country, as well as disparities between blacks and whites in waiting times for a kidney transplant. We also found that organ distribution remained heavily controlled by individual transplant centers. We found that among some transplant centers and professionals, a sense of local ownership toward organs impeded the development of a national system for distributing organs.

Our work in this area has led us to call for an organ allocation system that focuses on:

- equity among patients, not among transplant centers, and
- common medical criteria, not on the circumstances of a patient's residence or transplant center affiliation.

We reiterated these recommendations during testimony at the April 8, 1998, hearing of the House Subcommittee on Human Resources of the Committee on Government Reform and Oversight. We also updated differences based on race and geography for testimony before that subcommittee in June 1998. As of April 1999, more than 41,000 people are waiting for a kidney transplant, triple the number who were waiting to be transplanted in 1988.

This Inquiry

The purpose of this inquiry is to shed light on the implications of regional variation in median waiting time for kidney transplantation. Our analysis focuses at the Organ Procurement and Transplantation Network (OPTN) regional level.

We use aggregate data from the OPTN, published in January 1999.[2] These data cover two three-year periods: January 1993 through December 1995 for median waiting times, and January 1994 through December 1996 for data on rates of death and likelihood of transplantation.[3] The OPTN data are not risk-adjusted to account for the influence of a number of additional factors that may affect waiting time and access to transplantation. These factors could include individual patient medical status and characteristics; transplant center criteria for placing a patient on the waiting list; individual physician practices in referring and approving patients for transplant; the number, size, and maturity of transplant programs operating in a region; and the number of patients who are listed at more than one transplant center.

National Overview of Waiting List for Kidney Transplants

During the 3-year period January 1994 through December 1996, almost 74,000 people were registered on the waiting lists for a kidney transplant. About one-third of these people received a transplant, but 6 percent of the total died while on the transplant list.[4]

Table 1 shows the number of patients listed for kidney transplant in the 11 OPTN regions for all blood types. The regions comprise different geographical areas and population bases. Although regions serve a central role in the current organ allocation system, the number of patients listed, the number of transplant programs, and the number of organ procurement organizations vary among the regions.[5] Moreover, patients may be listed in a region in which they do not reside.

Table 1
Patients Listed for Kidney Transplant (all Blood Types) by OPTN Region
January 1994 - December 1996

OPTN Region	States in Region	Patients Listed for Transplant
1	Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, Vermont	3,602
2	Delaware, Maryland, Pennsylvania, New Jersey, West Virginia, District of Columbia, Northern Virginia	11,086
3	Alabama, Arkansas, Florida, Georgia, Louisiana, Mississippi, Puerto Rico	8,395
4	Texas, Oklahoma	4,890
5	Arizona, California, Hawaii, Nevada, New Mexico, Utah	13,236
6	Alaska, Idaho, Montana, Oregon, Washington	1,811
7	Illinois, Minnesota, North Dakota, South Dakota, Wisconsin	8,327
8	Colorado, Iowa, Kansas, Missouri, Nebraska, Wyoming	3,609
9	New York	6,090
10	Indiana, Ohio, Michigan	6,598
11	Kentucky, North Carolina, South Carolina, Tennessee, Virginia (outside of Northern Virginia)	6,284

Source: *1997 Report of the OPTN: Waiting List Activity and Donor Procurement, Kidney Volume*, January 1999.

Waiting Times, Transplants Performed, and Death Rates

Here we present and describe data on median waiting time, patients who received a kidney transplant, and patients who died while awaiting a transplant.[6] We focus our discussion on patients with Type O and Type A blood; patients with these two blood types comprise 81 percent of those waiting for a kidney transplant.[7] Where median waiting time is indicated, we refer to the median waiting time for patients listed for a primary kidney transplant.[8]

Patients with Type O Blood — Waiting Time for Transplant

Table 2 presents data for individuals with Type O blood, who comprise 49 percent of the total waiting list. Figures 1, 2, and 3 (pages 6-8) present map-based displays of these data. The data show striking differences among the OPTN regions with respect to the median time that patients spend on the waiting list. Although the national median waiting time is 915 days, it varies from as low as 420 days in Region 6, comprising the Northwestern States, to 1,538 days — more than 4 years — in Region 9, New York State.

Table 2
Median Waiting Time for Primary Transplant (January 1993 - December 1995)
Transplants Performed and Deaths (January 1994 - December 1996)
Kidney Patients with Type O Blood

OPTN Region	Patients Registered for Transplant	Median Waiting Time (days)	Percent Transplanted	Percent who Died
1	1,759	1,273	26 %	8 %
2	5,286	988	29	7
3	4,257	516	37	6
4	2,602	514	41	4
5	6,734	1,134	25	7
6	891	420	42	5
7	3,963	974	28	7
8	1,727	486	43	6
9	2,921	1,538	23	7
10	3,074	730	36	7
11	3,185	927	34	7
National Total	36,399	915	31 %	7 %

Source: *1997 Report of the OPTN: Waiting List Activity and Donor Procurement, Kidney Volume,* January 1999.

Percent Receiving a Transplant

Regions with the shortest median waiting times had the highest percentage of patients transplanted. For example, in Region 6, where median waiting time was 420 days, 42 percent of those on the list received a transplant, and in Region 8, where median waiting time was 486 days, 43 percent received a transplant. In contrast, only 23 percent of patients were transplanted in Region 9, which had the longest median waiting time of 1,538 days.

Deaths while Waiting for Transplant

As Table 2 shows, death rates are generally uniform from region to region. It is not surprising that death rates are relatively consistent across regions. Without transplantation, patients with

renal failure are sustained by dialysis which typically is provided on a continuing basis.

Patients with Type A Blood — Waiting Time for Transplant

Table 3 presents data for individuals with Type A blood, who comprise 32 percent of the total waiting list. Figures 4, 5, and 6 (pages 9-11) present map-based displays of these data. For all regions, waiting times for patients with Type A blood are noticeably shorter than for those with Type O blood. Waiting times range from a low of 202 days in Region 4 (Texas and Oklahoma) to a high of 1,159 days in Region 9 (New York State).

Table 3

Median Waiting Time for Primary Transplant (January 1993 - December 1995)
Transplants Performed and Deaths (January 1994 - December 1996)
Kidney Patients with Type A Blood

OPTN Region	Patients Registered for Transplant	Median Waiting Time (days)	Percent Transplanted	Percent who Died
1	1,229	797	32 %	6 %
2	3,552	591	39	7
3	2,476	235	49	5
4	1,511	202	57	4
5	4,102	595	36	6
6	615	211	57	4
7	2,841	588	35	7
8	1,367	358	48	6
9	1,933	1,159	28	6
10	2,332	584	40	7
11	1,928	367	48	6
National Totals	23,886	489	41 %	6 %

Source: *1997 Report of the OPTN: Waiting List Activity and Donor Procurement, Kidney Volume,* January 1999

Percent Receiving a Transplant

Regions 4 and 6, both with the shortest median waiting times of just over 200 days, also had the highest percentages of patients receiving transplants. In contrast, Region 9 had the longest median waiting time (1,159 days) and the lowest percentage of patients receiving transplants, 28 percent.

Deaths while Waiting for Transplant

As with patients with Type O blood awaiting kidney transplants, death rates are generally uniform

from region to region.

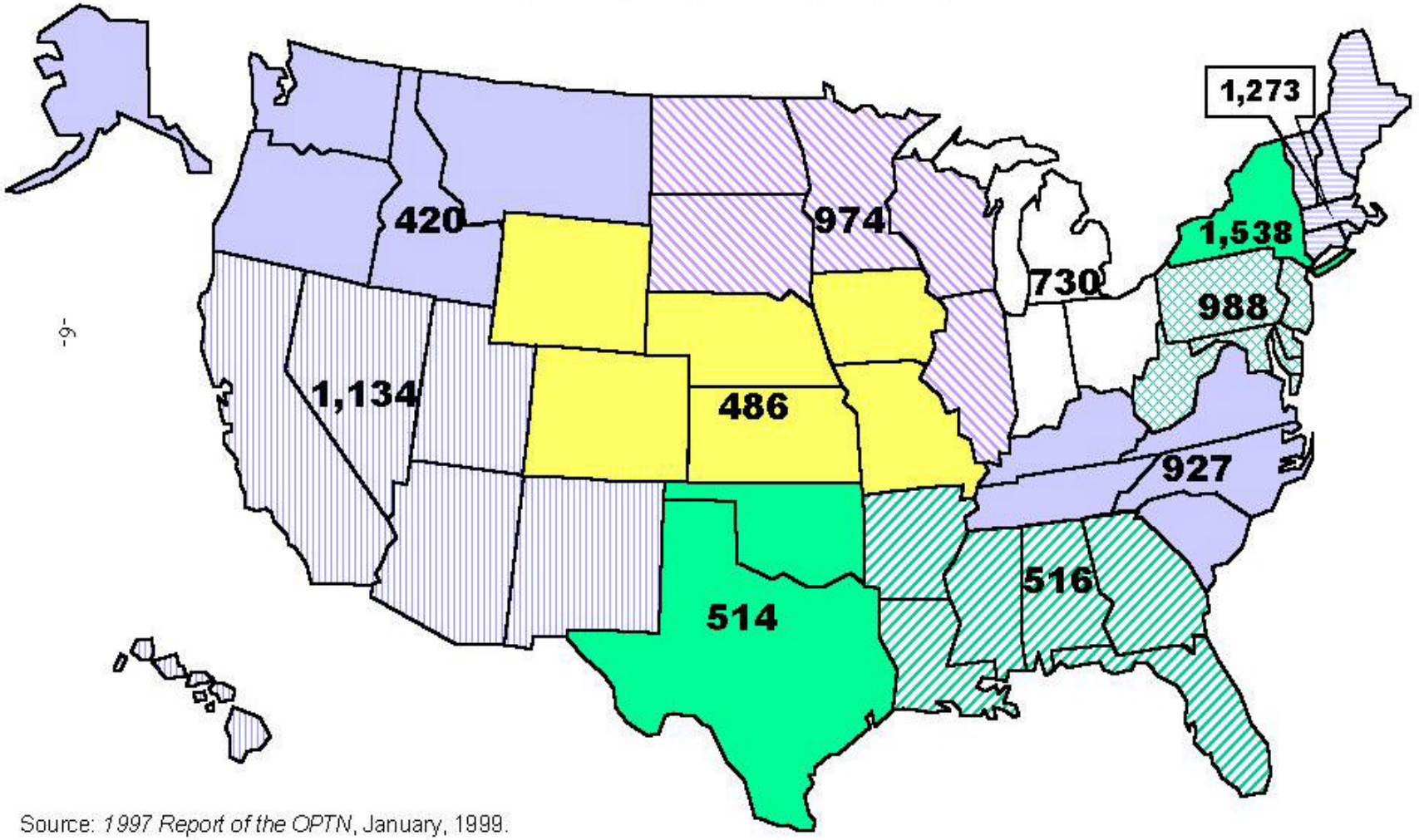
Conclusions

Our review found a relationship between the median waiting time for kidney transplants and the percentage of patients who actually receive a transplant. Not surprisingly, the longer the waiting time within an OPTN region, the lower the likelihood of a patient's actually receiving a transplant.

However, death rates while awaiting a kidney transplant generally are consistent across regions, despite the variations in median waiting time. The availability and use of kidney dialysis may provide an explanation for this consistency. In the absence of transplantation, patients with renal failure must be sustained by dialysis on a continuing basis.7

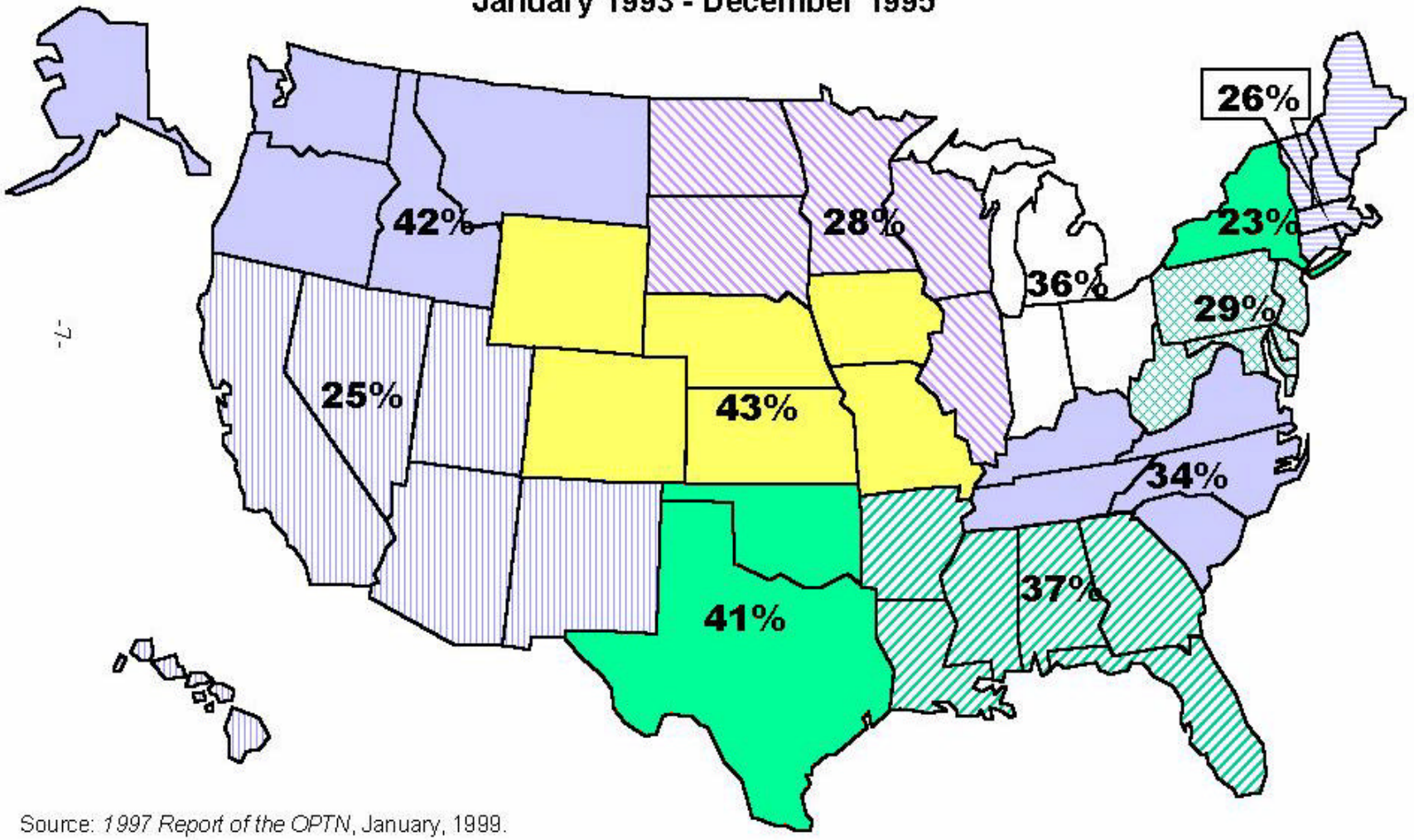
Our work on organ allocation and donation is continuing.

Figure 1
Median Waiting Time (days) for Primary Kidney Transplant (Type O Blood)
by OPTN Region
January 1993 - December 1995



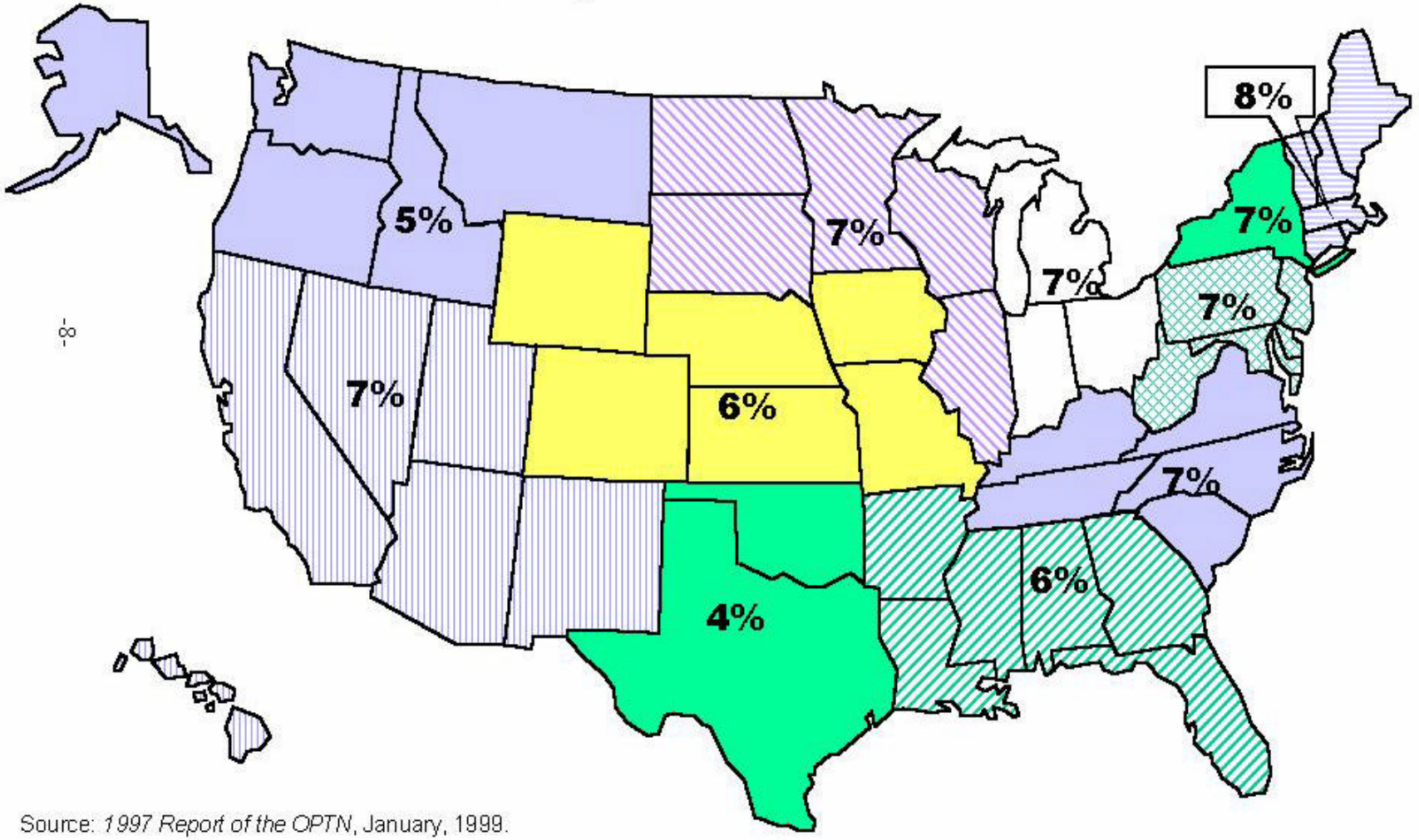
Source: *1997 Report of the OPTN*, January, 1999.

Figure 2
Percent of Patients on Waiting List for Kidney Transplant Who Received Transplant (Type O Blood)
by OPTN Region
January 1993 - December 1995



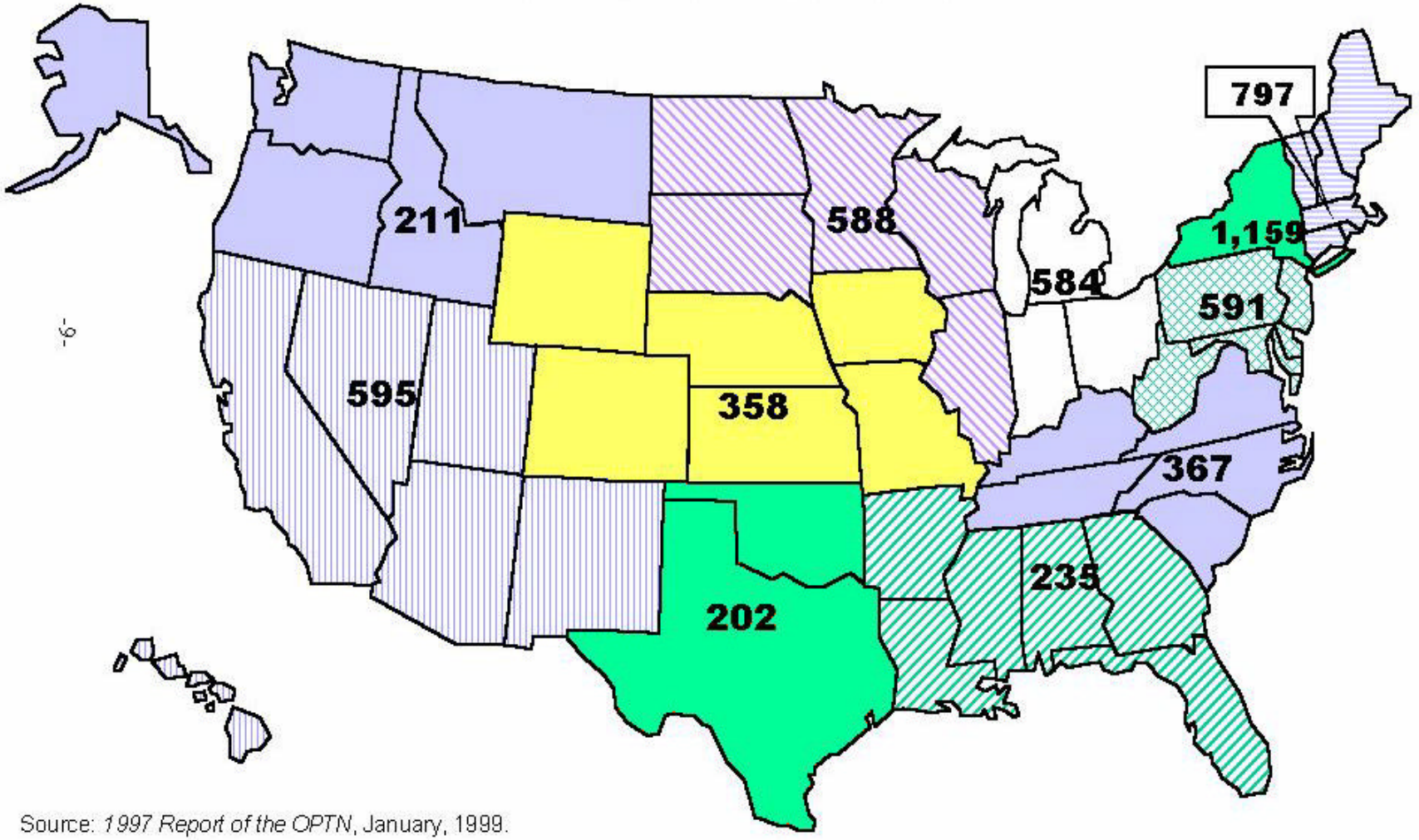
Source: *1997 Report of the OPTN*, January, 1999.

Figure 3
Percent of Patients on Waiting List for Kidney Transplant Who Died While Awaiting Transplant (Type O Blood) by OPTN Region
January 1993 - December 1995



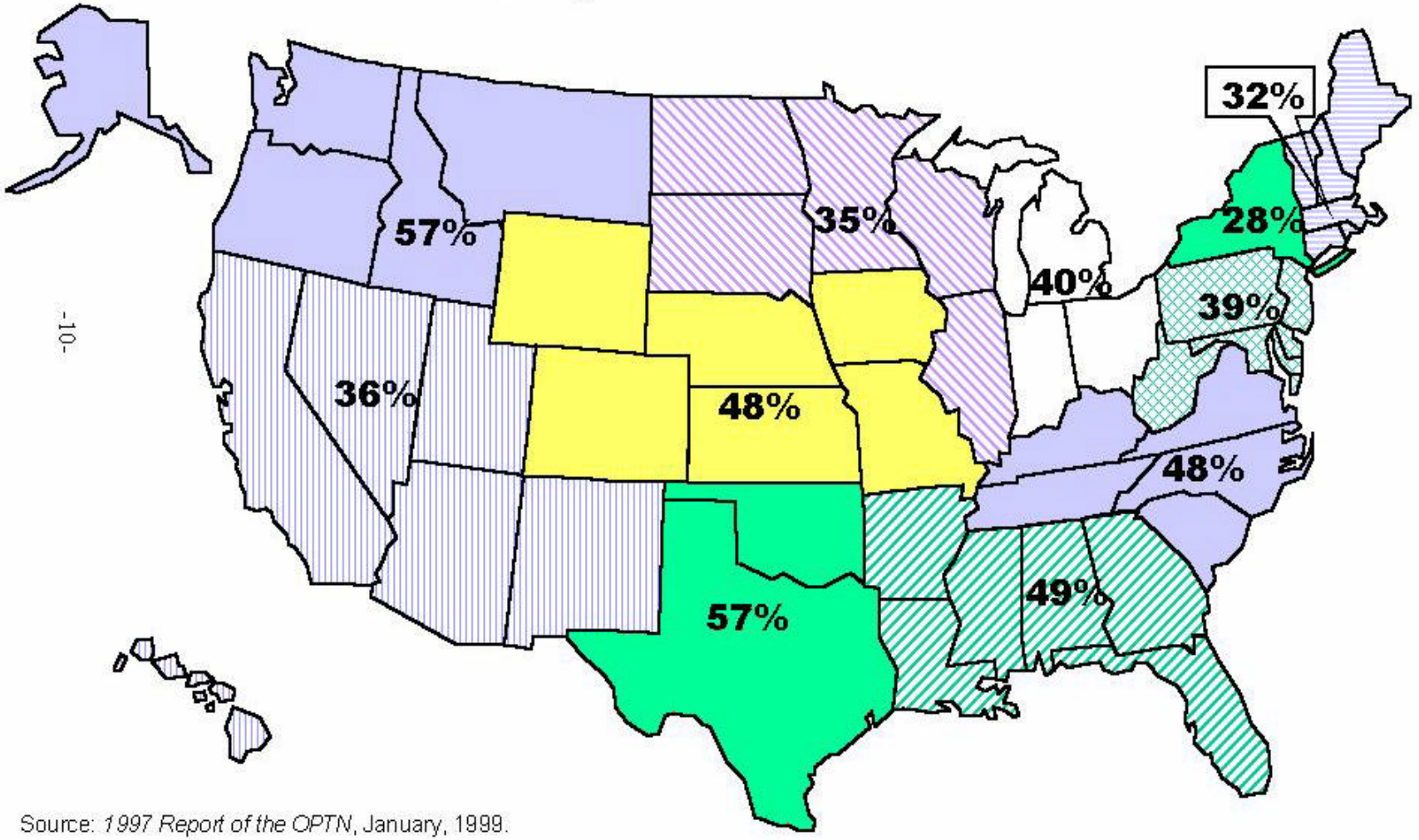
Source: *1997 Report of the OPTN*, January, 1999.

Figure 4
Median Waiting Time (days) for Primary Kidney Transplant (Type A Blood)
by OPTN Region
January 1993 - December 1995



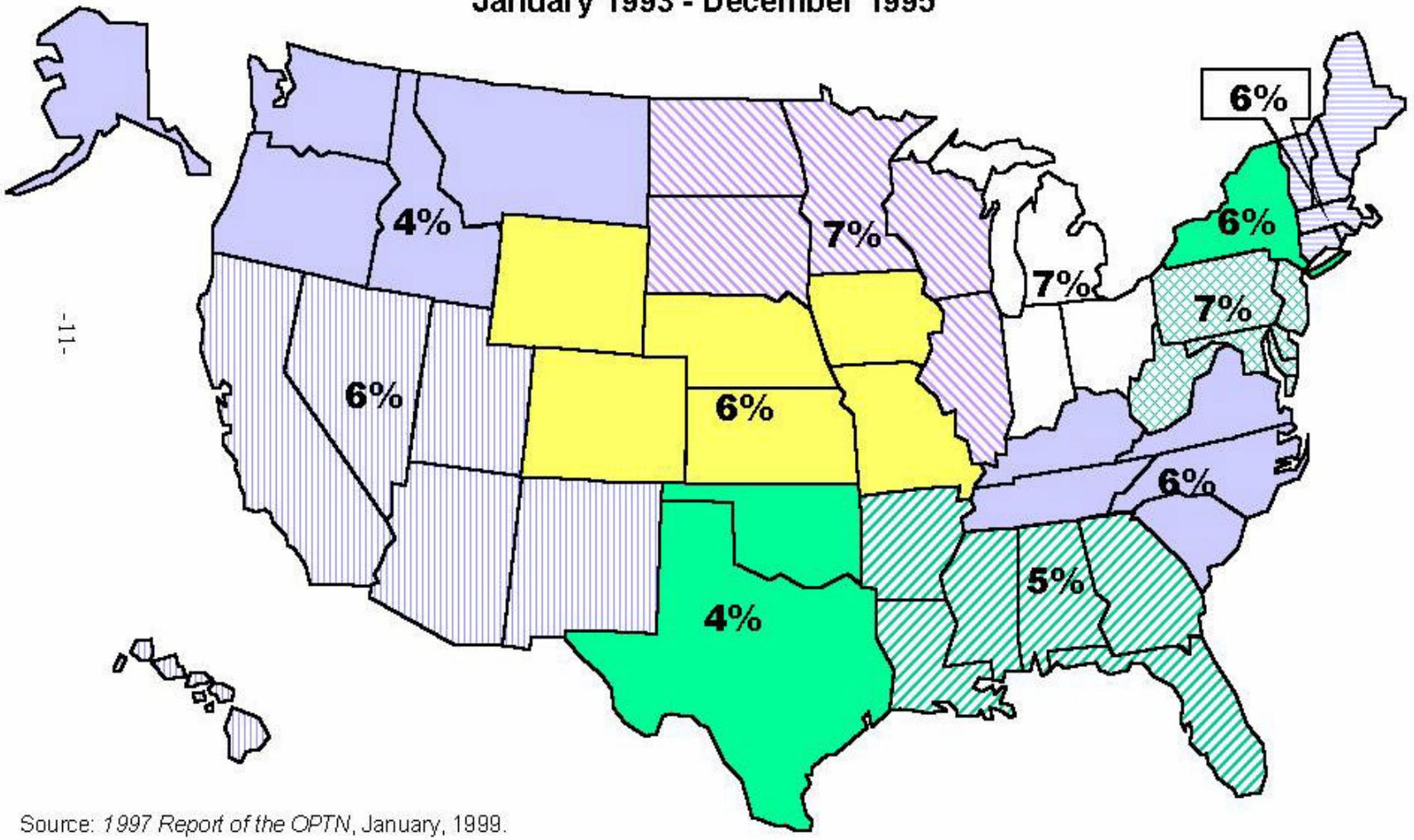
Source: *1997 Report of the OPTN*, January, 1999.

Figure 5
Percent of Patients on Waiting List for Kidney Transplant
Who Received Transplant (Type A Blood)
by OPTN Region
January 1993 - December 1995



Source: *1997 Report of the OPTN*, January, 1999.

Figure 6
Percent of Patients on Waiting List for Kidney Transplant
Who Died While Awaiting Transplant (Type A Blood)
by OPTN Region
January 1993 - December 1995



Source: *1997 Report of the OPTN*, January, 1999.

Endnotes

1. HHS Office of Inspector General (OIG), *The Distribution of Organs for Transplantation: Expectations and Practices*. (OEI-01-89-00550), March 1991.

2. *1997 Report of the Organ Procurement and Transplantation Network: Waiting List Activity and Donor Procurement, Kidney Volume*, January 1999. These data, although somewhat dated, are the latest publicly available from the OPTN. They are the type of data that are accessible to the members of the public who want to assess waiting times and likelihood of a transplant among various OPTN regions and, indeed, at transplant centers within those regions.

3. "Due to the typically longer waiting times for patients awaiting kidney transplantation, the median waiting time and the percent of patients transplanted analyses were based on patient registrations during 1993-95. If a more recent time period were used, medians would not be calculable for many categories." *1997 Report of the Organ Procurement and Transplantation Network: Waiting List Activity and Donor Procurement, Kidney Volume*, January 1999, p. 6.

4. 73,928 registrants were listed on the waiting lists for kidney transplants. 21,851 of these (30 percent) were listed at the start of this period, and 52,077 were added during this period.

Of the 73,928 registrants, 34 percent (25,320) received a transplant. Six percent (4,758) died while on the waiting list, and 17 percent (12,594) were removed from the list for other reasons. These include refusing a transplant, being transferred to another center, being medically unsuitable, either improving so a transplant was not needed or deteriorating so that the patient was too sick to transplant, being transplanted at another center, receiving a living donor transplant, or some other reason.

5. The following table provides data on number of organ procurement organizations (OPOs) and kidney transplant centers by OPTN region:

OPTN Region	Number of OPOs (1996)	
1	2	16
2	5	33
3	12	26
4	4	26
5	10	38
6	2	7
7	4	22
8	5	25
9	5	15
10	6	24
11	10	25

6. The median waiting time is the number of days by which 50 percent of the cohort received a transplant. The cohort in this analysis includes all patients who were added to the waiting list between January 1, 1993 and December 31, 1995.

As used in the OPTN report, median waiting time is based on the number of days between the patient being listed and one of three outcomes: (a) receipt of a transplant; (b) removal from the transplant list, including death of the patient; or (c) September 17, 1997, the cutoff date for the OPTN data analysis.

In addition, the OPTN data include patients who are listed at more than one center; according to OPTN, this figure is about 5 percent of all patients. For this reason, OPTN uses the term registrants, rather than patients. A registrant is counted as having received a transplant only at the center (or within the region) at which the transplant was performed.

7. We use blood type in our analysis because the OPTN report aggregates data for all statistics presented in this report by blood type only. Patients with Type B blood comprise 15 percent of the waiting list, and those with Type AB blood comprise 3 percent of the waiting list. For these blood types, the distribution of waiting times, percent of patients receiving a transplant, and deaths while awaiting a transplant is similar to that for patients with Type O and Type A blood.

8. Between January 1, 1993, and December 31, 1995, 49,909 registrants were added to kidney transplant lists; 42,190 (85 percent) were added for a primary transplant and 7,719 (15 percent) were added for a repeat transplant.