

Department of Health and Human Services

**OFFICE OF
INSPECTOR GENERAL**

**FOSTERING EQUITY IN PATIENT
ACCESS TO TRANSPLANTATION:**

Differences in Waiting Times for Livers



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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 for kidney and livers; we found that both racial and geographic disparities in waiting times still exist and, in some cases, seem to be growing. Today, more than 12,000 people are waiting for a liver transplant, triple the number who were waiting to be transplanted in 1994.

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 liver transplants for the 3-year period ending December 1996. These data are the most recent available from the Organ Procurement and Transplantation Network (OPTN).

Variation in waiting times for a liver transplant. Our analysis shows considerable variation in median waiting time for liver transplants among the OPTN regions. For patients with Type O blood, the most common blood type, median waiting time ranged from 123 days to 958 days.

Likelihood of receiving a liver transplant. Our review shows an inverse relationship between the median waiting time for liver transplants and the percentage of patients who actually receive a transplant: The longer the waiting time in an OPTN region, the lower the likelihood of a patient's actually receiving a transplant. The percentage of patients with Type O blood who received a transplant ranged from 30 percent in one region to 64 percent in another.

Likelihood of death while awaiting a liver transplant. Our review shows regional variation in rates of death, but only limited relationship with length of time on the waiting list. Rates of death for Type O patients waiting for a liver transplant ranged from 8 percent in two regions to 16 percent in one region. This implies that factors other than waiting time, such as patient characteristics and listing practices, may affect the rate of death among transplant candidates.

Our work on organ allocation and donation is continuing.

WAITING TIMES FOR LIVER 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 12,000 people are waiting for a liver transplant, triple the number who were waiting to be transplanted in 1994.

This Inquiry

The purpose of this inquiry is to shed light on the implications of regional variation in median waiting times for liver transplantation. Our analysis focuses at the Organ Procurement and Transplantation Network (OPTN) regional level.²

We use aggregate data from the OPTN, published in January 1999.³ These data cover the 3-year period January 1994 through December 1996. 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 Liver Transplants

During the 3-year period January 1994 through December 1996, almost 24,000 people were registered on the waiting lists for a liver transplant. Almost half of these people received a transplant, but 10 percent of the total died while on the transplant list.⁴

Table 1 shows the number of patients listed for liver 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 Liver 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	1,218
2	Delaware, Maryland, Pennsylvania, New Jersey, West Virginia, District of Columbia, Northern Virginia	4,036
3	Alabama, Arkansas, Florida, Georgia, Louisiana, Mississippi, Puerto Rico	1,997
4	Texas, Oklahoma	1,721
5	Arizona, California, Hawaii, Nevada, New Mexico, Utah	4,658
6	Alaska, Idaho, Montana, Oregon, Washington	735
7	Illinois, Minnesota, North Dakota, South Dakota, Wisconsin	2,701
8	Colorado, Iowa, Kansas, Missouri, Nebraska, Wyoming	1,711
9	New York	1,697
10	Indiana, Ohio, Michigan	1,829
11	Kentucky, North Carolina, South Carolina, Tennessee, Virginia (outside of Northern Virginia)	1,545

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

Waiting Times, Transplants Performed, and Death Rates

Here we present and describe data on median waiting time, patients who received a liver 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 84 percent of those waiting for a liver transplant.⁷ Where median waiting time is indicated, we refer to the

median waiting time for patients listed for a primary liver transplant.⁸

Patients with Type O Blood — Waiting Time for Transplant

Table 2 presents data for individuals with Type O blood, who comprise 47 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 time that patients spend on the waiting list. Although the national median waiting time is 374 days, it varies from 123 days in Region 3, comprising the Southeastern States, to 958 days in Region 1, New England.⁹

OPTN Region	Patients Registered for Transplant	Median Waiting Time (days)	Percent Transplanted	Percent who Died
1	569	958	30 %	16 %
2	1,827	572	38	13
3	941	123	64	9
4	844	213	52	13
5	2,233	723	39	8
6	353	344	46	8
7	1,248	393	44	12
8	823	384	49	12
9	825	496	43	9
10	828	475	46	15
11	723	208	56	9
National Total	11,214	374	45 %	11 %

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

Percent Receiving a Transplant

Almost as striking is the relationship between median waiting time for a liver transplant, and the likelihood of a patient receiving a transplant. In three regions — Regions 3, 11, and 4 — more than 50 percent of patients on the waiting list during the 3 year period received a transplant. These patients were on the waiting lists in the regions with the shortest median waiting times. Conversely, in the three regions with the longest median waiting times — Regions 1, 2, and 5 — fewer than 40 percent of patients received a transplant.

Deaths while Waiting for Transplant

As Table 2 shows, the relationship between median waiting time and the rate of patient deaths for those with Type O blood is not as clear cut as the relationship between waiting time and the likelihood of receiving a transplant. The data show variation in the proportion of patients who died while on the waiting list, ranging from 8 percent in Regions 5 and 6, to 16 percent in Region 1 and 15 percent in Region 10. At one extreme, Region 1 exhibited both the highest death rate among patients waiting for transplant and the longest median waiting time. However, Region 5 showed the second longest waiting time, but it also had the lowest rate of patient deaths. And Region 4, with the third shortest waiting time, had the third highest death rate of 13 percent.

As we note above, these data are not risk-adjusted to reflect characteristics of individual patients, or the physicians and transplant centers involved in their care. The lack of relationship between waiting times and death rates may well reflect the importance of these other explanatory factors.

Patients with Type A Blood — Waiting Time for Transplant

Table 3 presents data for individuals with Type A blood, who comprise 37 percent of the total waiting list. Figures 4, 5, and 6 (pages 9-11) present map-based displays of these data. With one exception (Region 1), waiting times for patients with Type A blood were noticeably shorter than for those with Type O blood.

Table 3 Median Waiting Time for Primary Transplant, Transplants Performed, and Deaths Liver Patients with Type A Blood (January 1994 - December 1996)				
OPTN Region	Patients Registered for Transplant	Median Waiting Time (days)	Percent Transplanted	
1	457	953	36 %	13 %
2	1,518	359	44	11
3	758	91	67	9
4	640	202	60	9
5	1,679	299	50	7
6	301	214	56	6
7	993	146	54	9
8	646	159	63	7
9	603	245	49	10
10	706	311	58	10
11	589	96	67	8
National Total	8,890	210	54 %	9 %

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

Percent Receiving a Transplant

As with Type O patients, median waiting time for patients with Type A blood is closely associated with the likelihood of receiving a transplant. More than two-thirds of patients in Regions 3 and 11 received transplants; these are the regions with the shortest waiting times. At the other extreme, in Region 1, only 36 percent of patients received a transplant.

Deaths while Waiting for Transplant

An examination of data on those who died while on the waiting list shows only a limited relationship between length of time on the transplant list and patient death rates. At one end of the spectrum, Region 1 showed a death rate of 13 percent. However, that rate of death is only slightly higher than in other regions, even those with substantially shorter waiting times.

At the other extreme, shorter waiting times were not necessarily closely related with lower death rates. In Region 6, where 6 percent of patients died while on the waiting list, the median waiting time was 214 days. In those regions with the shortest waiting times — Region 3 (91 days) and Region 11 (96 days) — the death rates were 9 percent and 8 percent, respectively. As we note above, factors other than median waiting time may explain the regional variation in rates of death.

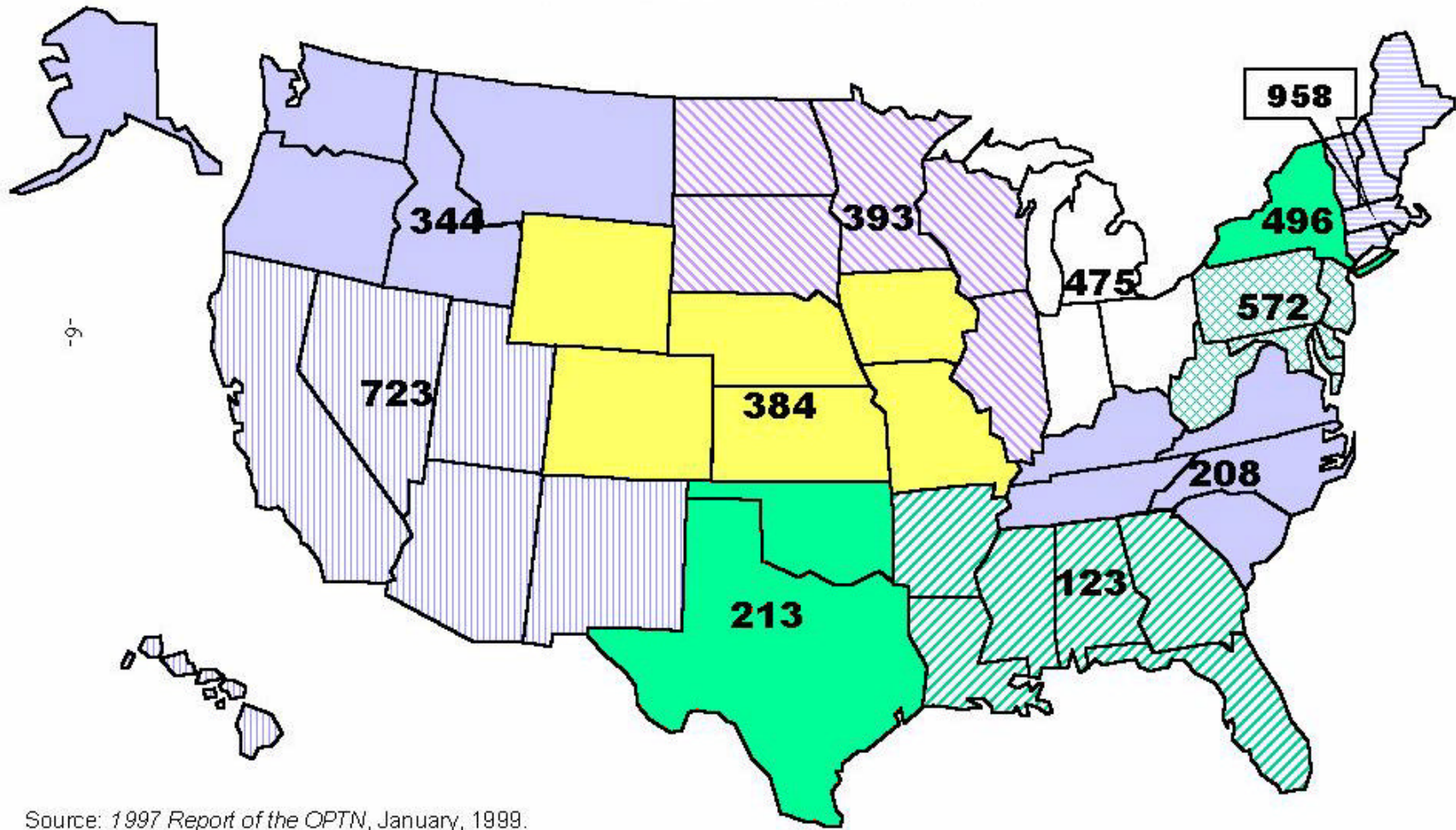
Conclusions

Differences among OPTN regions in median waiting times for liver transplants, likelihood of receiving a transplant, and death rates are considerable. Our analysis leads us to conclude that where liver transplant candidates live — or at least the region in which they are listed — will significantly impact their chances of receiving a liver transplant. We found a clear inverse relationship between the median waiting time for liver transplants and the percentage of patients who received a transplant. The longer the waiting time within an OPTN region, the lower the likelihood of a patient's actually receiving a transplant.

However, the relationship between median waiting time for a transplant and rates of death is not as direct, even though there is wide regional variation in rates of death. It may well be that other factors — for example, listing practices and criteria of transplant center and individual physicians; individual patients' medical characteristics; and the number, size, and maturity of transplant programs — exert a larger impact on death rates than do regional differences in waiting time.

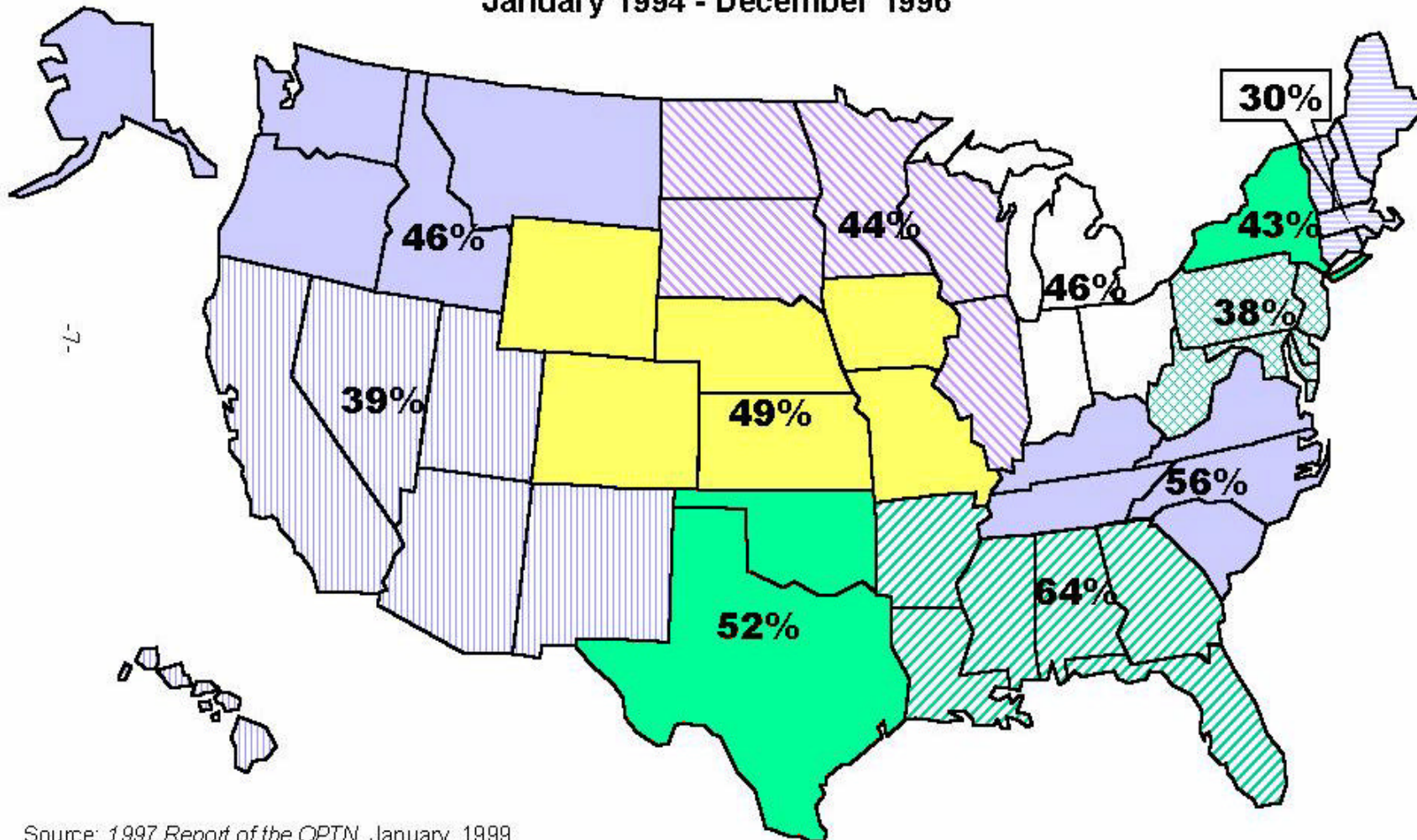
Our work on organ allocation and donation is continuing.

Figure 1
Median Waiting Time (days) for Primary Liver Transplant (Type O Blood)
by OPTN Region
January 1994 - December 1996



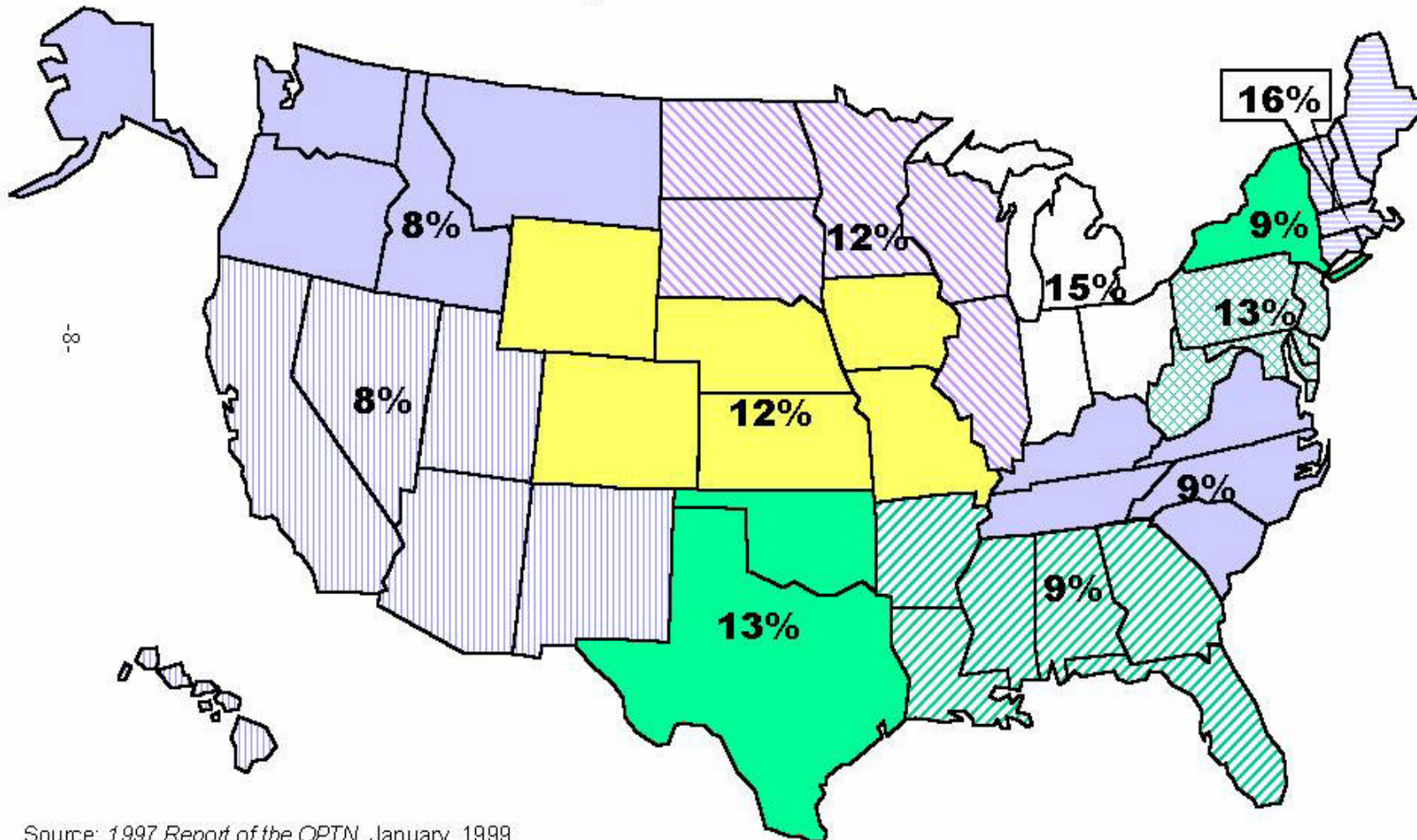
Source: 1997 Report of the OPTN, January, 1999.

Figure 2
Percent of Patients on Waiting List for Liver Transplant Who Received
Transplant (Type O Blood)
by OPTN Region
January 1994 - December 1996



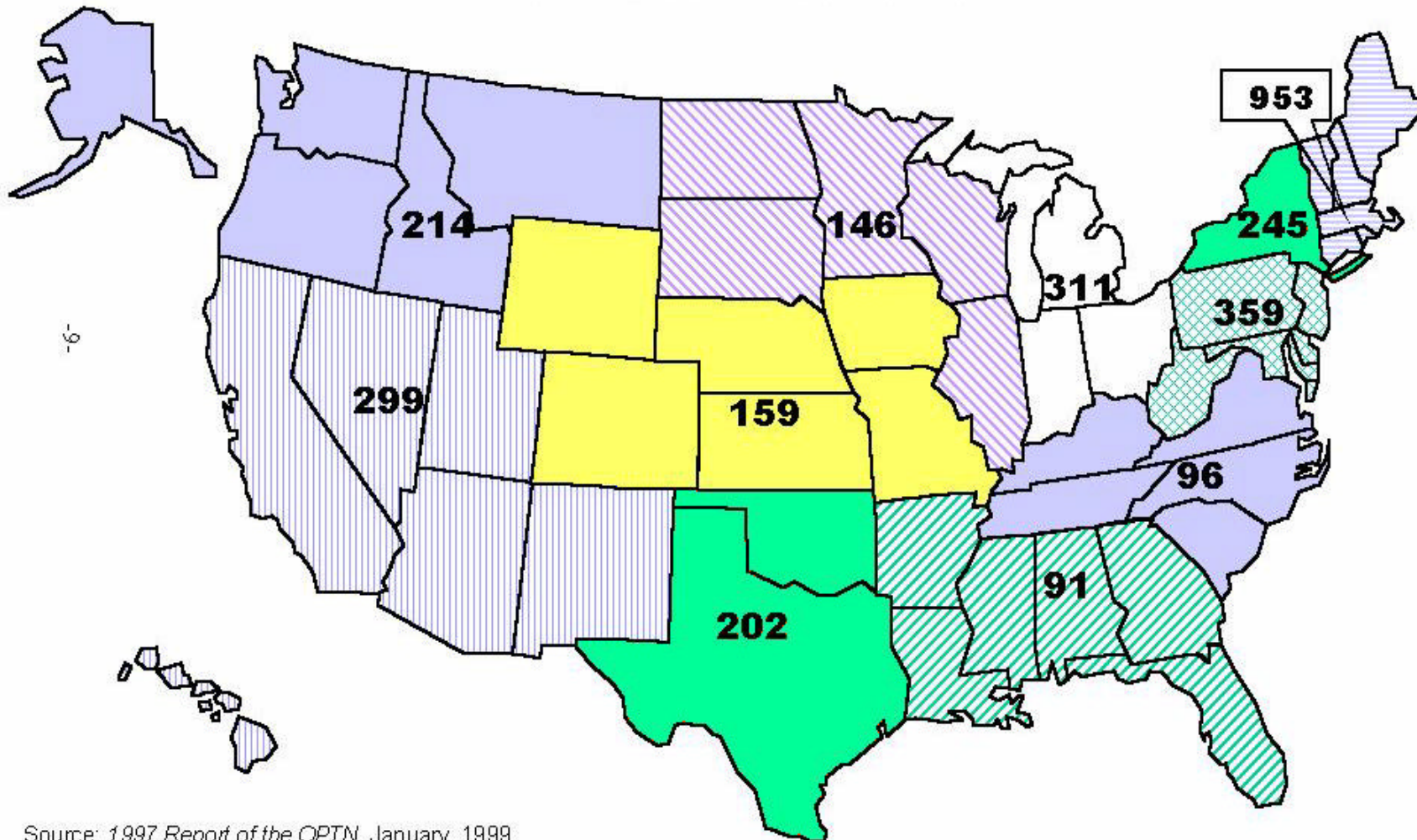
Source: 1997 Report of the OPTN, January, 1999.

Figure 3
Percent of Patients on Waiting List for Liver Transplant
Who Died While Awaiting Transplant (Type O Blood)
by OPTN Region
January 1994 - December 1996



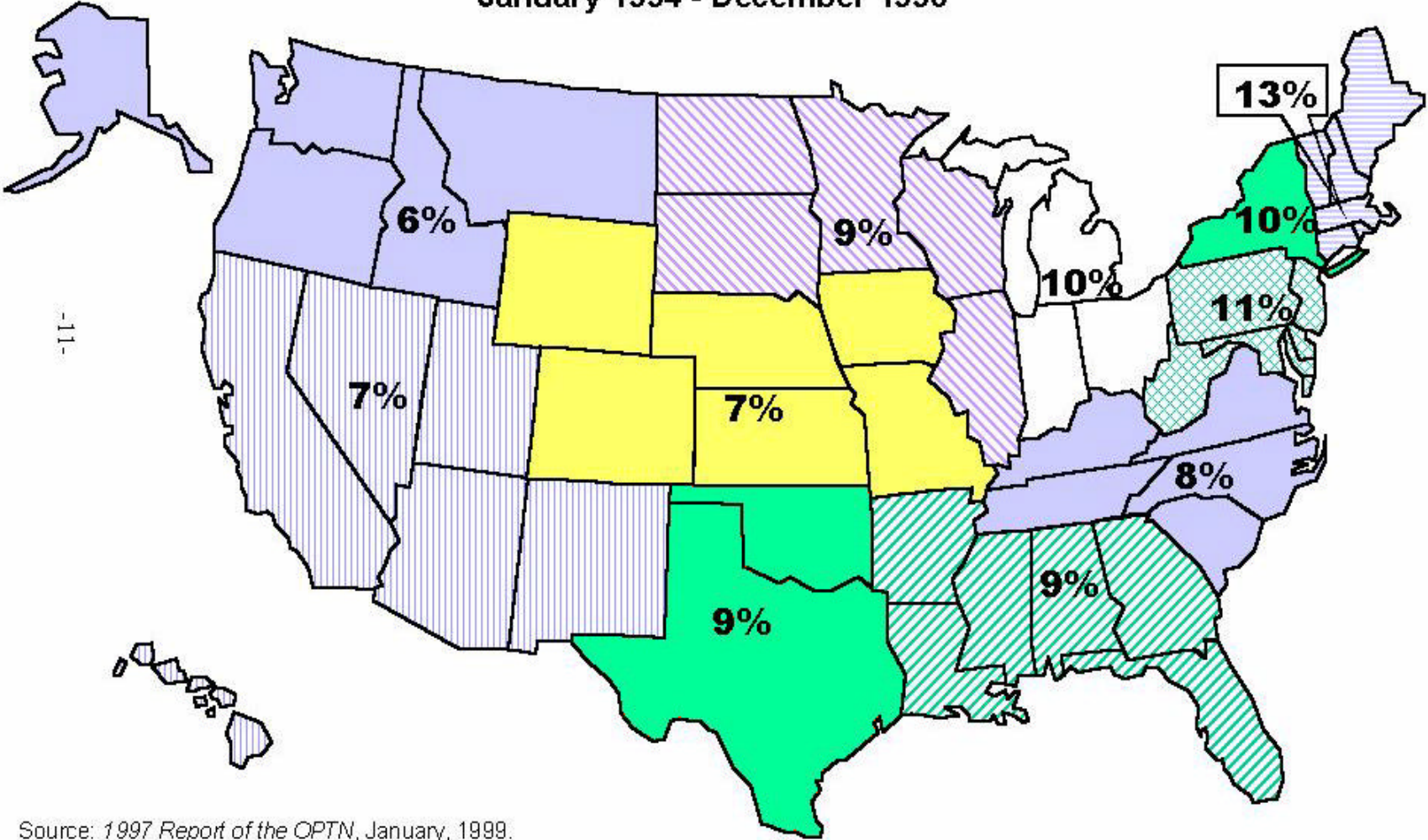
Source: 1997 Report of the OPTN, January, 1999.

Figure 4
Median Waiting Time (days) for Primary Liver Transplant (Type A Blood)
by OPTN Region
January 1994 - December 1996



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

Figure 6
Percent of Patients on Waiting List for Liver Transplant
Who Died While Awaiting Transplant (Type A Blood)
by OPTN Region
January 1994 - December 1996



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. This type of analysis could also be performed at the level of the individual organ procurement organizations (OPO); however, 13 of the OPOs do not have a liver transplant program within their service area. In addition, according to the OPTN, median waiting times cannot be calculated at the OPO level for 6 OPOs for registrants with Type O blood (and 3 OPOs for those with Type A blood) in areas that have liver transplant programs.
3. *1997 Report of the Organ Procurement and Transplantation Network: Waiting List Activity and Donor Procurement, Liver 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.
4. 23,848 people were listed on the waiting lists for liver transplants. 2,367 of these people (10 percent) were listed at the start of this period, and 21,481 were added to the list during this period — 19,269 were added for their first (or primary) transplant, and 2,238 for retransplantation, *i.e.*, they already had received a transplant.

Of the 23,848 people on the list, almost half (11,730) received a transplant. More than 10 percent (2,426) died while on the waiting list, and another 12 percent — 2,859 — 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 OPOs and transplant centers by OPTN region:

OPTN Region	Number of OPOs (1996)	Number of Transplant Centers
1	2	6
2	5	14
3	12	12
4	4	12
5	10	18
6	2	4
7	4	11
8	5	11
9	5	6
10	6	10
11	10	13

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, 1994 and December 31, 1996.

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 the OPTN, this figure is about 2 percent of all patients awaiting a liver. For this reason, the 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 12 percent of the waiting list, and those with Type AB blood comprise 4 percent of the waiting list. For these blood types, the distribution of waiting times, percent of patients receiving a transplant types, and deaths while awaiting a transplant is similar to that for patients with Type O and Type A blood.

8. Between January 1, 1994, and December 31, 1996, 21,507 registrants were added to transplant lists; 19,269 (90 percent) were added for a primary transplant and 2,238 (10 percent) were added for a repeat transplant.

9. Wide variation also exists within, as well as among, the OPTN regions. At the level of the organ procurement organizations, the shortest median waiting time is 46 days; the longest median waiting time that the OPTN was able to calculate was 721 days. In Region 2, which has 5 OPOs, median waiting time for patients with Type O blood ranged from 56 to 721 days, and in Region 8, also with 5 OPOs, median waiting times ranged from 51 to 596 days. Within other regions, the median waiting times were more narrowly distributed; in Region 11, with 10 OPOs, median waiting times ranged from 136 to 274 days, and in Region 3, comprising 12 OPOs, median waiting times ranged from 90 to 233 days.