

Geographic Variability in Access to Primary Kidney Transplantation in the United States, 1996–2005

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This article focuses on geographic variability in patient access to kidney transplantation in the United States. It examines geographic differences and trends in access rates to kidney transplantation, in the component rates of wait-listing, and of living and deceased donor transplantation. Using data from Centers for Medicare and Medicaid Services and the Organ Procurement and Transplantation Network/Scientific Registry of Transplant Recipients, we studied 700 000+ patients under 75, who began chronic dialysis treatment, received their first living donor kidney transplant, or were placed on the waiting list pre-emptively. Relative rates of wait-listing and transplantation by State were calculated using Cox regression models, adjusted for patient demographics. There were geographic differences in access to the kidney waiting list and to a kidney transplant. Adjusted wait-list rates ranged from 37% lower to 64% higher than the national average. The living donor rate ranged from 57% lower to 166% higher, while the deceased donor transplant rate ranged from 60% lower to 150% higher than the national average. In general, States with higher wait-listing rates tended to have lower transplantation rates and States with lower wait-listing rates had higher transplant rates. Six States demonstrated both high wait-listing and deceased donor transplantation rates while six others, plus D.C. and Puerto Rico, were below the national average for both parameters.

Key words: Access rates, deceased donor rates, living donor rates, OPTN, SRTR, wait-listing

Introduction

In the United States, access to the kidney transplant waiting list and to living donor transplantation, among pa-

tients with advanced renal disease, and access to deceased donor transplantation among wait-listed patients varies markedly by demographic characteristics, etiology of end-stage renal disease (ESRD), insurance and place of residence at wait-listing. Prior studies have shown that the recipients of renal transplants have better survival than comparable dialysis patients (1–4) and have a better quality of life (5–9) than do patients on dialysis. In addition, transplant recipients with longer dialysis exposures have a higher subsequent rate of graft failure and patient mortality than transplant recipients with shorter dialysis experiences (10–11). Although the final rule governing the operation of the Organ Procurement and Transplantation Network (OPTN), published in 1998, requires that patients with similar diagnoses and disease progression have similar access to transplantation (12), a large number of previous studies have documented the effect of various patient characteristics on rates of referral (13–19), wait-listing (17–23), living donor renal transplantation (23–28) and deceased donor renal transplantation (17–19,21,23,26–35), and have shown that certain patient demographic groups including minorities, females, older patients, diabetics and those with only Medicare or Medicaid insurance are relatively less likely to gain access to the waiting list and to receive a renal transplant (13–35). A few studies have examined geographic patterns in access to transplantation (36–38) and identified large variations in opportunity within the United States. This article examines geographic differences and trends in overall rates of access to kidney transplantation in the component rates of wait-listing, and of living and deceased donor transplantation that are not explained by adjustments for patient-specific demographic variables, insurance or disease state. It also explores interactions between these rates and the opportunity in the United States for kidney transplantation.

Study Methods

This article summarizes a special study employing data from the Centers for Medicare and Medicaid Services (CMS) and the Organ Procurement and Transplantation Network/Scientific Registry of Transplant Recipients (OPTN/SRTR). The CMS database includes information on all dialysis patients in the United States. The OPTN/SRTR database includes data on all wait-listed kidney transplant candidates and recipients in the United States and is described further in companion articles in this report (39). Both data sources were supplemented with vital status information from the Social Security Death Master File (40). Since transplants are rarely performed on patients older than 75 years, the following wait-listing and transplant data

discussions are limited to patients younger than 75 at time of entry into the study.

The study population consisted of 703 202 patients under the age of 75, who either began chronic dialysis treatment (N = 657 541), received a living donor kidney transplant without being placed on the OPTN kidney or kidney pancreas waiting list (N = 5902), or were placed on the OPTN kidney or kidney-pancreas waiting list for a first transplant prior to initiating chronic dialysis (pre-emptive wait-listing) (N = 39 849) between 1996 and 2005. For purposes of this study, States were defined as the fifty States plus Puerto Rico and the District of Columbia. Patients who had started dialysis, previously received a transplant, or were placed on the waiting list prior to 1996 were excluded from this study population. Patients living in a U.S. territory other than Puerto Rico or with an unknown State of residence were also excluded. Patients placed on the kidney waiting list prior to the start of dialysis were considered to have ESRD beginning on the date of wait-listing. Patients who were added to the waiting list on the same date that they underwent a living donor kidney transplant were not counted as having been placed on the waiting list.

This study examined by State and nationally: (1) wait-listing rates among ESRD patients, (2) living donor kidney transplant rates among ESRD patients, (3) deceased donor transplant rates among wait-listed patients and (4) overall (deceased and living donor) transplant rates among ESRD patients. Patients were followed from the onset of ESRD to the date of wait-listing, from the onset of ESRD to the date of transplantation, and from the date of wait-listing to transplantation. The study end-date was December 31, 2005. Follow-up for wait-listing rates and deceased donor transplant rates was censored at death, living donor transplant or end of study. Follow-up for living donor transplant rates was censored at death, deceased donor transplant or end of study. Follow-up for overall transplant rates was censored at death or end of study.

Multivariable analyses using Cox proportional hazards models, adjusted for patient demographics that are captured in the CMS and OPTN/SRTR databases, were used to calculate adjusted rates of wait-listing and transplantation for each State. Adjustments for waiting list rates, living donor transplant rates and overall transplant rates were patient age, race, ethnicity, gender, cause of ESRD, incidence year (dialysis, living donor transplant, wait-listing), comorbid conditions and insurance type. Adjustments for analyses of deceased donor transplant rates were patient age at wait-listing, race, ethnicity, gender, ESRD cause, wait-listing year, comorbid conditions at wait-listing, insurance type at wait-listing, blood type, panel reactive antibody (PRA) at wait-listing and candidate human leukocyte antigens (HLA). Results are displayed as the relative rates for each State compared to the overall or national average reference rate of 1.0. The national average is taken as the average rate over the States, the District of Columbia and Puerto Rico.

Changes in rates (wait-listing rate, living donor transplant rate and deceased donor transplant rate) over the 10-year period of the study were estimated by fitting a Cox model to the national data with year of entry included in the analysis as a covariate for each of the three rates of interest. This gave estimates of the overall average annual changes in the national rates of wait-listing, living donor transplantation and deceased donor transplantation. The average 5-year changes in rate were taken as the fifth power of the annual changes. Similarly, separate models were fitted to the data from each State to obtain State-specific average 5-year increases in the rates.

Trends in Wait-listing and Kidney Transplantation During the Past Decade

Table 1 shows the study population by entry criterion and by year of ESRD diagnosis. Between 1996 and 2005, the number of patients per year starting dialysis as their first form of ESRD therapy increased progressively from 56 855 to 70 604, and the yearly number of patients pre-emptively wait-listed more than doubled, from 2720 to 6381. The pattern for patients receiving a living donor kidney transplant prior to initiation of dialysis (pre-emptive living donor kidney transplant) was different, though. The number of patients receiving a pre-emptive living donor transplant without being wait-listed rose from 489 in 1996 to a peak of 678 in 2004, but that total dropped by 19% to 547 in 2005. The total percentage of incident ESRD patients who entered the study prior to initiation of dialysis on the basis of either pre-emptive wait-listing or pre-emptive living donor transplantation rose steadily over the past decade from 6.5% in 1996 to 8.9% in 2005. Furthermore, during that same interval, an additional 5699 patients, who were preemptively wait-listed, subsequently went on to receive a pre-emptive living donor kidney transplant (Table 2).

Table 2 shows that among the 703 202 patients, a total of 159 279 (23%) were placed on the waiting lists for a kidney or kidney-pancreas transplant by December 31, 2005. Of these wait-listed candidates, 25% (39 849) were wait-listed prior to initiating dialysis and 61% (96 429) received a living or deceased donor kidney transplant by December 31, 2005. Of those transplanted, 43% (44 033) received a living and 57% (58 298) a deceased donor transplant. Approximately 26% (11 601) of the living donor transplant recipients and 11% (6284) of the deceased donor recipients

Table 1: Study population by entry criterion and year, 1996–2005

Entry criterion	1996–2005	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Began dialysis	N	657 451	56 855	59 652	62 458	64 758	66 056	67 953	68 476	69 914	70 604
	%	93.50%	94.70%	94.70%	94.40%	94.30%	93.90%	93.90%	93.60%	92.90%	91.10%
Pre-emptively wait-listed	N	39 849	2720	2826	3251	3338	3650	3698	4030	4656	6381
	%	5.70%	4.50%	4.50%	4.90%	4.90%	5.20%	5.10%	5.50%	6.20%	8.20%
Received pre-emptive living donor transplant, never wait-listed	N	5902	489	482	483	587	621	688	674	653	547
	%	0.80%	0.80%	0.80%	0.70%	0.90%	0.90%	1.00%	0.90%	0.90%	0.70%
Total	N	703 202	60 064	62 960	66 192	68 683	70 327	72 339	73 180	75 223	77 532

Source: SRTR Analysis, May 2006.

Table 2: Outcomes of study population by entry criterion, 1996–2005

Entry criterion	N	Wait-listed	All transplants	Pre-emptive transplants		Not pre-emptive transplants	
				Living donor	Deceased donor	Living donor	Deceased donor
Began dialysis	657 451	119 430	73 172	–	–	28 708	44 464
Pre-emptively wait-listed	39 849	39 849	23 257	5699	6284	3724	7550
Received pre-emptive living donor transplant, never wait-listed	5902	–	5902	5902	–	–	–
Total	703 202	159 279	102 331	11 601	6284	32 432	52 014

Source: SRTR Analysis, May 2006.

were transplanted prior to starting dialysis; 13% (5902) received a living donor transplant without being wait-listed.

Table 3 shows the number and percentage of patients that were wait-listed and the percentage of patients that received a transplant during the study period by State of residence. The percentage of ESRD patients per State that were wait-listed ranged nearly threefold from 13% to 32%, while the percentage that were wait-listed pre-emptively varied more than 17-fold from 0.7% to 12%. Similar patterns were observed among kidney transplant recipients. The percentage by State of all ESRD patients receiving a kidney transplant ranged from 8% to 30% and the percentage of transplants among all ESRD patients that were pre-emptive ranged from 0.3% to 10%. The percentage of ESRD patients that received a living donor transplant ranged from 3% to 20%, while the percentage of ESRD patients that received a deceased donor transplant ranged from 4% to 14%. Overall, the ratio of living donor to deceased donor transplantation was 0.8. The State ratio ranged from 0.4 to 1.9, with 38 States having more deceased donor transplants than living donor transplants. Among wait-listed patients, the percentage of patients receiving a deceased donor transplant ranged from 21% to 67%. As expected, there were strong correlations between the percentage pre-emptively wait-listed and the overall percentage wait-listed ($r = 0.93$, $p < 0.0001$), between the percentage pre-emptively wait-listed and the overall percentage transplanted ($r = 0.63$, $p < 0.0001$) and between the percentage pre-emptively receiving a transplant and the overall percentage transplanted ($r = 0.93$, $p < 0.0001$). Additionally, there was a positive correlation between living donor and deceased donor transplant rates ($r = 0.66$, $p < 0.0001$).

Access to the Waiting List

The number of patients placed on the kidney waiting list has increased considerably over the past decade (35). However, after adjusting for patient age, race, ethnicity, gender, ESRD cause, year of starting dialysis, comorbid conditions and insurance type, there are large geographic differences in access to the kidney transplant waiting list (Figure 1). These rates ranged from 37% lower than the national average to 64% higher (RR = 0.63–1.64). The States in the lowest quartile had relative wait-listing rates that were less

than 0.81 (all statistically significant, $p < 0.05$), while the States in the highest quartile had relative rates above 1.23 (all statistically significant, $p < 0.05$).

Between 1996 and 2005, the average 5-year increase in the wait-listing rate was 10%. However, this increase was not uniform across the United States. It is notable that approximately one-third of the States demonstrated a minimal to large 5-year decline in the wait-listing rate (–0.4% to –33%). In contrast, about one-third of the States realized a 15% or greater 5-year increase in their wait-listing rate (Figure 2).

Access to a Living Donor Transplant

The number of living donor kidney transplants has increased over the past decade (35), but, as seen in Figure 3, the opportunity for living donor transplantation varies widely by State. The living donor transplant rate, after adjusting for patient age, race, ethnicity, gender, ESRD cause, starting year of dialysis, comorbid conditions and insurance type, ranged from 57% lower to 166% higher than the national average (RR = 0.43–2.66). The States in the lowest quartile had living donor transplant rates more than 28% lower than the national average (all statistically significant, $p < 0.05$), while the States in the highest quartile had relative rates above 129% of the national average (all statistically significant, $p < 0.05$).

During 1996–2005, there was an average 5-year increase in the living donor transplant rate of 12%. Approximately one-third of the States had an average 5-year decline in the living donor transplant rate, while during this time period nearly one-third had more than a 20% increase in the 5-year rate (Figure 4).

Access to a Deceased Donor Transplant

There are also large and meaningful geographic differences in deceased donor kidney transplantation rates for wait-listed patients, ranging from 60% lower to 150% higher than the national average (RR = 0.40–2.50), after adjusting for patient age, race, ethnicity, gender, ESRD cause, wait-list year, comorbid conditions, insurance type, blood type, PRA and HLA antigens (Figure 5). The States in the lowest quartile had deceased donor transplant rates below 75% of the national average (all statistically significant,

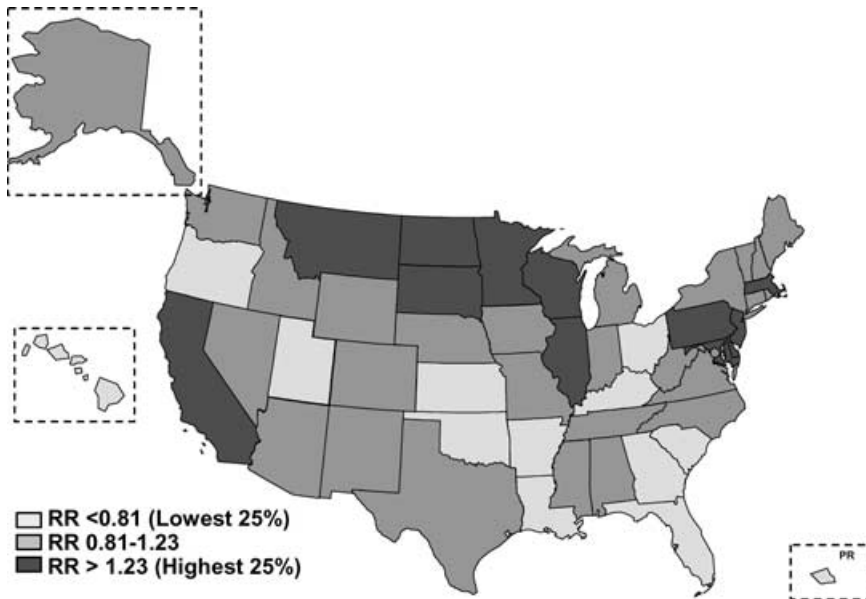
Table 3: Percent of patients placed on the waiting list and receiving a transplant by State, 1996–2005

State	N	Wait-listed (%)	Pre-emptive WL (%)	All transplants (%)	Pre-emptive transplants (%)	Living donor transplants (%)	Deceased donor transplants (%)	Deceased donor transplants among wait-listed (%)
All	703 202	22.6	5.7	14.6	2.5	6.3	8.3	36.6
AK	737	24.6	4.9	23.2	4.3	13.7	9.5	38.7
AL	13 790	21.9	4.9	11.4	2.1	5.6	5.8	26.5
AR	6679	14.4	2.5	13.1	1.9	5.6	7.5	52.2
AZ	12 107	20.5	4.3	13.8	2.0	7.1	6.6	32.4
CA	81 907	32.4	9.1	13.8	2.2	5.8	8.0	24.7
CO	6394	31.2	9.4	19.5	3.3	8.9	10.6	33.9
CT	6935	19.6	4.6	14.1	3.2	8.1	6.0	30.4
DC	3569	18.1	4.4	7.9	1.3	4.0	3.9	21.3
DE	2179	27.3	8.6	16.6	3.3	7.5	9.1	33.3
FL	38 935	17.4	3.6	13.2	2.1	3.9	9.3	53.7
GA	24 114	15.2	3.2	10.4	1.6	3.6	6.8	44.6
HI	3853	23.6	5.2	10.5	1.5	4.3	6.3	26.5
IA	4906	24.6	7.2	24.5	6.2	12.0	12.5	51.0
ID	1852	22.7	5.7	23.5	4.2	11.8	11.7	51.5
IL	33 006	25.6	7.7	16.3	3.3	6.9	9.4	36.9
IN	13 694	19.1	4.5	15.2	2.7	5.5	9.7	51.0
KS	4957	16.6	4.1	15.6	2.8	5.9	9.7	58.8
KY	9542	15.5	3.2	13.9	2.5	4.8	9.1	58.9
LA	16 286	15.4	2.8	9.7	1.3	3.2	6.5	42.2
MA	11 366	27.8	6.1	19.5	3.7	10.5	9.0	32.4
MD	16 890	27.3	8.1	16.2	3.1	8.0	8.2	30.2
ME	2068	23.0	5.0	20.5	4.3	9.9	10.6	46.0
MI	25 717	24.1	7.0	15.5	3.0	8.2	7.3	30.4
MN	7894	30.7	12.0	30.3	9.8	19.9	10.4	33.9
MO	13 392	19.1	4.4	13.9	2.1	5.2	8.7	45.5
MS	9758	16.8	2.1	8.8	1.1	3.2	5.6	33.5
MT	1343	28.1	7.1	24.7	4.2	12.6	12.1	43.2
NC	23 377	17.8	3.9	10.6	1.7	4.7	5.9	33.0
ND	1082	27.9	10.1	29.8	9.8	18.4	11.4	40.7
NE	3237	21.1	5.4	18.4	3.5	8.4	10.0	47.4
NH	1760	24.4	5.0	22.5	4.4	12.2	10.3	42.1
NJ	22 632	26.9	8.8	14.9	3.0	7.2	7.8	28.9
NM	4482	18.3	4.1	12.0	1.9	5.3	6.6	36.4
NV	4319	26.2	6.6	15.4	2.3	6.3	9.1	34.7
NY	48 380	23.0	5.5	13.4	2.3	6.5	6.8	29.7
OH	29 755	17.9	4.1	15.1	2.7	7.0	8.2	45.7
OK	8396	17.1	3.1	12.2	1.4	3.7	8.5	49.5
OR	5469	17.6	2.9	21.6	3.6	10.6	11.0	62.8
PA	31 168	28.1	8.9	17.8	3.1	5.9	11.9	42.4
PR	9468	12.6	0.7	7.9	0.3	3.3	4.6	36.2
RI	1982	24.0	5.8	21.6	3.4	12.1	9.5	39.7
SC	13 284	16.2	3.3	10.9	1.8	3.3	7.6	46.5
SD	1595	29.3	8.8	23.3	5.2	10.5	12.8	43.6
TN	14 858	18.3	3.0	13.3	1.9	5.3	8.0	43.5
TX	55 691	19.6	2.8	12.6	1.4	4.3	8.3	42.4
UT	2756	19.7	5.4	30.4	7.0	17.2	13.2	66.9
VA	19 192	24.0	6.0	14.4	2.5	7.5	7.0	29.0
VT	908	26.0	8.5	19.7	4.5	9.0	10.7	41.1
WA	9506	24.8	6.5	20.6	3.3	8.7	11.9	48.0
WI	10 416	31.1	10.8	24.7	6.9	11.0	13.7	43.9
WV	4956	18.9	3.7	14.7	2.3	5.5	9.2	48.6
WY	663	26.7	6.3	21.7	4.7	10.6	11.2	41.8

Source: SRTR Analysis, May 2006.

$p < 0.05$), while the States in the highest quartile had relative rates above 129% of the national average (all statistically significant, $p < 0.05$).

Although the number of deceased donor transplants has increased by 8% over the past decade, the number of patients on the waiting list has doubled (35). As a



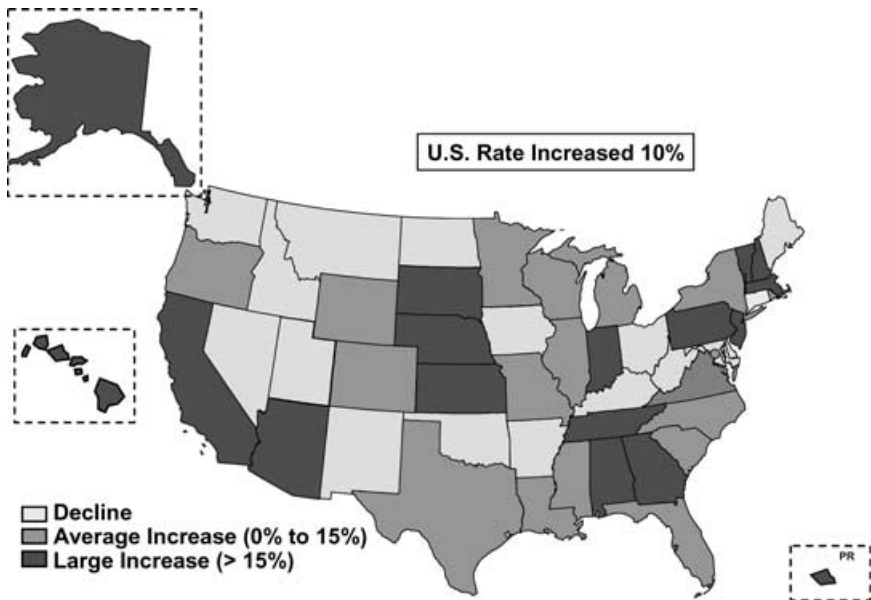
*Adjusted for age, race, ethnicity, sex, ESRD cause, incidence year, comorbid conditions, and insurance type at incidence; Censored at death, living donor transplant, or end of study; Compared to National average of 1.00; 159,279 of 703,202 were placed on the waiting list
Source: SRTR Analysis, May 2006.

Figure 1: Relative rate* of wait-listing among ESRD patients by state, 1996–2005.

consequence of these two dynamics, there has been a 12% average 5-year decrease in the US deceased donor transplant rate among wait-listed patients from 1996 to 2005. Only 18 states had an increase in the average 5-year deceased donor transplant rate, while 19 states had more than a 25% average 5-year decrease in this rate (Figure 6).

The majority of states (N = 31) are served by a single Organ Procurement Organization (OPO). Twelve states do not have an OPO headquartered within their state and share an OPO with another state, while nine states have two or more OPOs. Table 4 shows that compared to states with

one OPO, wait-list rates are higher both in states that have no OPOs headquartered in the state and in states with two or more OPOs (RR = 1.22 and 1.12, respectively, both $p < 0.0001$). Table 4 also shows that compared to states with one OPO, states that share an OPO have a 58% higher rate of living donor kidney transplantation (RR = 1.58, $p < 0.0001$), and a 14% higher adjusted rate of deceased donor kidney transplantation (RR = 1.14, $p < 0.0001$). In contrast, states that have two or more OPOs have an 18% lower living donor adjusted transplant rate (RR = 0.82, $p < 0.0001$), and an 8% lower adjusted deceased donor kidney transplant rate (RR = 0.92, $p < 0.0001$). Similarly, Table 5 shows that states that had more transplant programs had

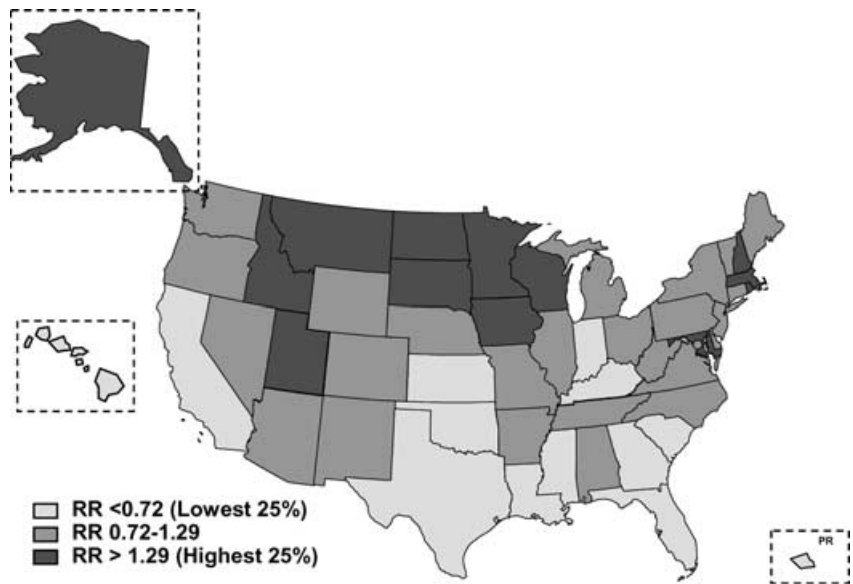


Source: SRTR Analysis, May 2006.

Figure 2: Average 5-year change in wait-listing rate during 1996–2005 by state.

*Adjusted for age, race, ethnicity, sex, ESRD cause, incidence year, comorbid conditions, and insurance type at incidence; Censored at death, or end of study; Compared to National average of 1.00; 11,601 of 703,202 received a living donor transplant
 Source: SRTR Analysis, May 2006.

Figure 3: Living donor transplantation rate* among ESRD patients, 1996–2005.



higher wait-list rates and lower deceased donor transplant rates. Compared to states that have between four and eight transplant programs, states that have more than nine programs have higher wait-list rates (RR = 1.07 for 9–15 programs and 1.30 for 15+ programs, both $p < 0.0001$) and lower deceased donor transplant rates (RR = 0.78 for 9–15 programs and 0.76 for 15+ programs, both $p < 0.0001$). States with less than three programs have a 7% lower rate of wait-listing (RR = 0.93, $p < 0.0001$). There was not a consistent pattern between the number of transplant programs and the living donor transplant rate.

Most patients (86.3%) are wait-listed for their initial, primary listing in the same state as their state of residence (Table 6). However, the population of kidney transplant

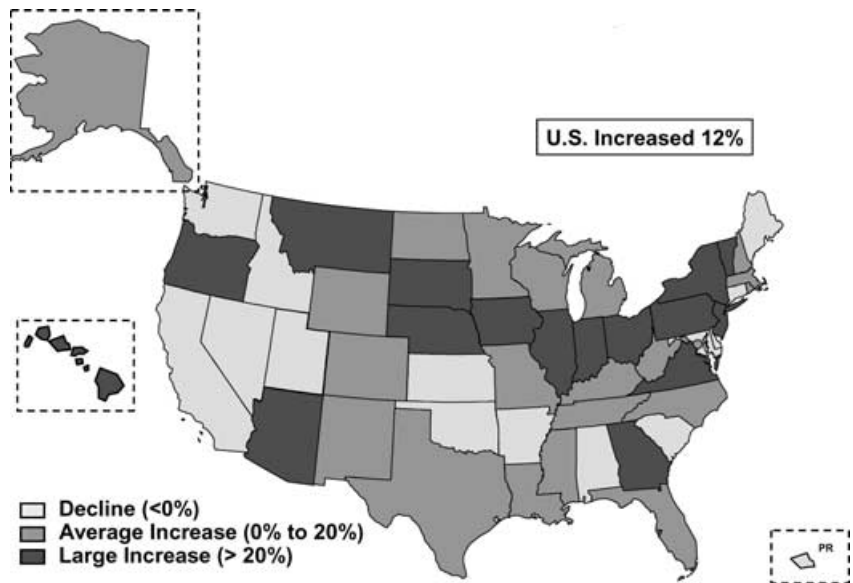
recipients that were wait-listed for their initial, primary listing in a state other than their state of residence had a higher deceased donor transplant rate than those who were wait-listed within their state of residence for their initial, primary listing (RR = 1.04, $p < 0.001$).

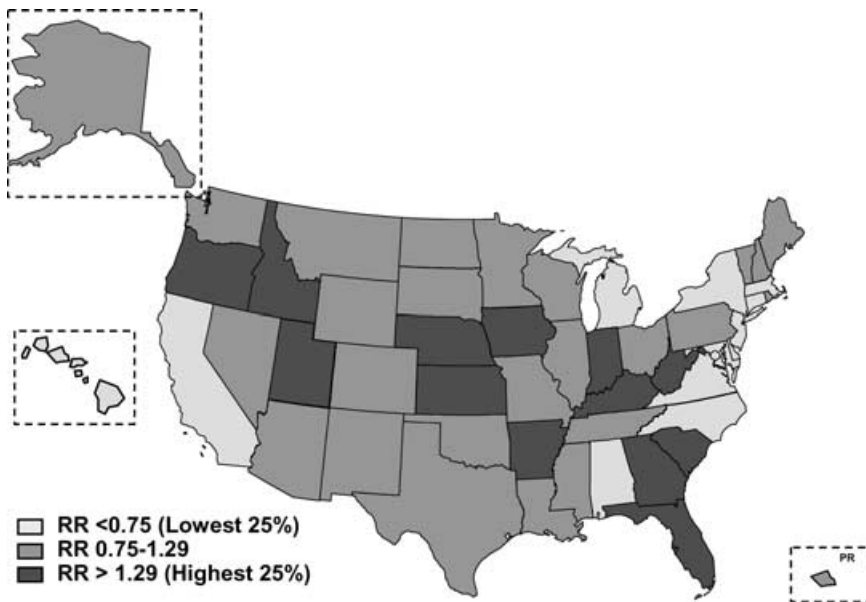
Examining the Relationship Between Wait-listing Rates and Deceased Donor Transplantation Rates

Figures 7 and 8 show the states grouped into four categories based on the adjusted relative wait-listing rates and deceased donor transplantation rates, conditional upon wait-listing. The reference relative rate (RR = 1.0) was set

Source: SRTR Analysis, May 2006.

Figure 4: Average 5-year change in living donor transplant rates during 1996–2005.



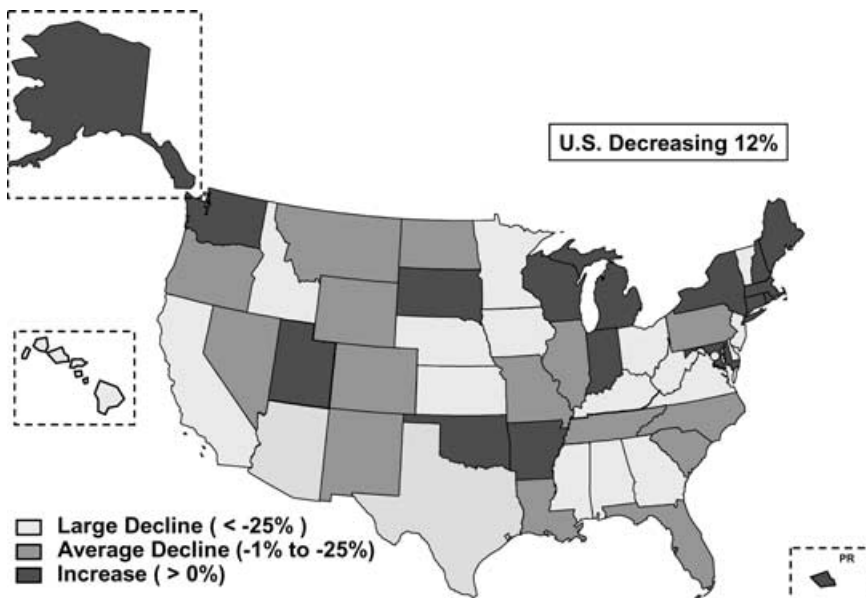


*Adjusted for age, race, ethnicity, sex, ESRD cause, wait- list year, comorbid conditions, insurance type, blood type, PRA, and HLA; Censored at death, living donor transplant or end of study; Compared to National average of 1.00; 58, 298 of 159, 279 received a deceased donor transplant. Source: SRTR Analysis, May 2006.

Figure 5: Deceased donor transplantation rate* among kidney waiting list patients by state, 1996–2005.

at the national average. The four categories were (1) both wait-listing and deceased donor transplant rates were below the national average (Quadrant I), (2) waitlisting rates were below and deceased donor transplant rates above the national average (Quadrant II), (3) wait-listing rates were above and deceased donor transplant rates below the national average (Quadrant IV) and (4) both wait-listing and deceased donor transplant rates were above the national average (Quadrant III). Only six states (Iowa, Maine, Pennsylvania, Rhode Island, South Dakota and Wisconsin) had both wait-listing and deceased donor transplant rates that were above the national average, while six states

(Arizona, Connecticut, Hawaii, Mississippi, North Carolina and New Mexico) and the District of Columbia and Puerto Rico had both wait-listing and deceased donor transplant rates that were below the national average. There was a negative correlation ($r = -0.65, p < 0.0001$) between wait-listing rates and deceased donor transplant rates after placement on the waiting list (Figure 8). In general, states with higher wait-listing rates tended to have lower transplantation rates and states with lower wait-listing rates showed trends for higher transplant rates. A separate study of wait-listing and deceased donor transplant rates in the decades' two 5-year periods (1996–2000 and 2001–2005)



Source: SRTR Analysis, May 2006.

Figure 6: Average 5-year change in deceased donor transplant rate, 1996–2005.

Table 4: Relative rate of waiting list and deceased and living donor transplantation by state OPO density, 1996–2005

OPOs residing in the State	States	Patients	Waiting list RR ¹	p-Value	Living donor transplant RR ¹	p-Value	Deceased donor transplant RR ²	p-Value
None ³	12	21 125	1.22	< 0.0001	1.58	< 0.0001	1.14	<0.0001
1 OPO	31	347 590	1.00	Ref	1.00	Ref	1.00	Ref
2–4 OPOs ⁴	9	334 487	1.12	< 0.0001	0.82	< 0.0001	0.92	< 0.0001

¹Adjusted for patient age, race, ethnicity, gender, ESRD cause, year of starting dialysis and insurance type.

²Adjusted for patient age, race, ethnicity, gender, ESRD cause, waitlisting year, insurance type, blood type, PRA and HLA antigens.

³Shares OPO with another State (AK, DE, ID, ME, MT, ND, NH, RI, SD, VT, WV, WY).

⁴CA, FL, NC, NY, OH, PA, TN, TX, WI.

Source: SRTR Special Analysis, May 2006.

demonstrated similar correlations ($r = -0.691$, $p < 0.0001$ and $r = -0.688$, $p < 0.0001$, respectively).

Overall Access to a Transplant

Figure 9 illustrates that the overall kidney transplant (deceased and living combined) rate among all ESRD patients, after adjusting for patient age, race, ethnicity, gender, ESRD cause, year of starting dialysis, comorbid conditions and insurance type, ranged from 52% lower to 107% higher than the national average (RR = 0.48–2.07). The states in the lowest quartile had relative transplant rates below 0.85 (all statistically significant, $p < 0.05$), while the states in the highest quartile had relative rates above 1.19 (all statistically significant, $p < 0.05$).

Figure 10 shows the distribution of adjusted (as described for each above) relative rates by access metric. These box plots summarize the state-to-state variability in access rates. When compared to the national average and despite adjustments for patient demographics, there are substantial state-to-state differences between the 5th and the 95th percentiles in all four measures: access to the waiting list, from 35% less to 50% greater, access to living donor kidney transplantation, from 39% less to 71% greater, access to deceased donor kidney transplantation, from 48% less to 99% greater and in overall access to kidney transplantation from 31% less to 64% higher.

The question could be raised as to whether averages should be adjusted for variables such as race, ethnicity and insurance that are recognized barriers to access. Figure 11 shows the relative rates by access measure without these adjustments. Without adjustment there was little difference in the observed ranges of variability, and there was little change in the rankings among the states for each access measure (data not shown).

Summary

These results reveal, after adjustment for insurance status and for important patient demographic and clinical variables, both medically and statistically significant geographic differences in access to the kidney transplant waiting list, and to living donor and deceased donor kidney transplantation. During the study period, there was a modest upward trend in pre-emptive wait-listing practices, but more than 90% of the study population became eligible for analysis as a consequence of initiation on dialysis. Twenty-three percent of the 703 202 evaluable patients under age 75 in this study were wait-listed and an additional 5902 underwent a pre-emptive living donor transplant without being added to the deceased donor kidney transplant waiting list. One quarter of those added to the kidney transplant waiting list were wait-listed prior to initiating dialysis. Almost 15% of the total study population ultimately

Table 5: Relative rate of waiting list and deceased and living donor transplantation by state transplant program density, 1996–2005

Transplant programs residing in the State	States	Patients	Waiting list RR ¹	p-Value	Living donor transplant RR ¹	p-Value	Deceased donor transplant RR ²	p-Value
0–3 programs	28	150 238	0.93	< 0.0001	1.04	0.002	1.01	0.36
4–8 programs ³	17	268 980	1.00	Ref	1.00	Ref	1.00	Ref
9–15 programs ⁴	4	115 218	1.07	< 0.0001	1.18	< 0.0001	0.78	<0.0001
15+ programs ⁵	3	168 766	1.30	< 0.0001	0.82	< 0.0001	0.76	<0.0001

¹Adjusted for patient age, race, ethnicity, gender, ESRD cause, year of starting dialysis and insurance type.

²Adjusted for patient age, race, ethnicity, gender, ESRD cause, waitlisting year, insurance type, blood type, PRA and HLA antigens.

³ AZ, CO, GA, IA, WI, DC, MN, WA, NC, LA, NJ, OK, VA, IL, MO, FL, TN.

⁴MA, MI, OH, NY.

⁵PA, CA, TX.

Source: SRTR Special Analysis, May 2006.

Table 6: Relative rate of deceased donor transplantation by state residence and waiting list center similarity, 1996–2005

State of residence and waiting list the same?	No.		Deceased donor transplant RR ¹	
	No. Patients	% Patients	1.00	p-Value
Yes	137 386	86.3	1.00	Ref
No	21 893	13.8	1.04	< 0.0001

¹Adjusted for patient age, race, ethnicity, gender, ESRD cause, wait-listing year, insurance type, blood type, PRA and HLA antigens

Source: SRTR Analysis, May 2006.

received a living donor (6%) or deceased donor (8%) kidney transplant.

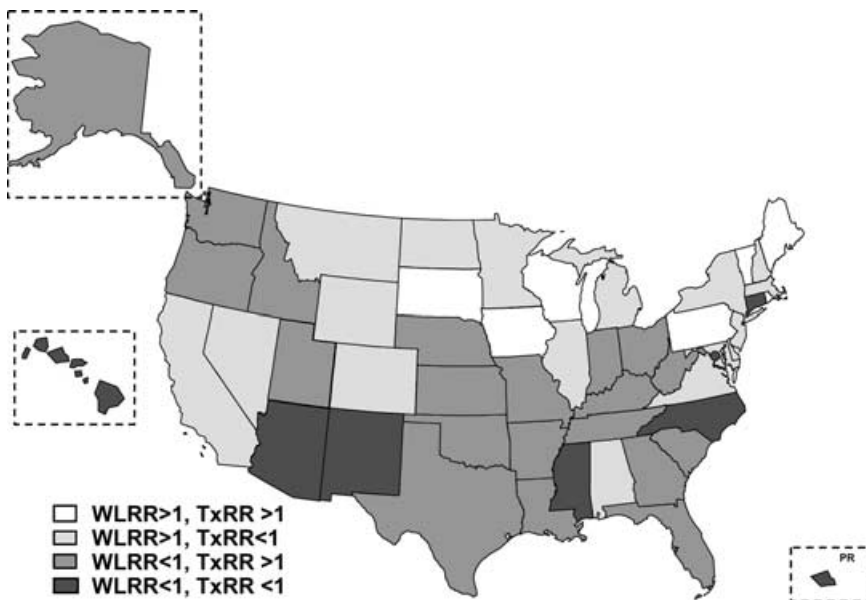
Access to kidney transplantation varied markedly by state for unadjusted observed rates of overall wait-listing, pre-emptive wait-listing, overall transplantation, pre-emptive transplantation and living donor and deceased donor transplantation. With adjustment for patient case mix and for insurance, there remained statistically significant differences in access by state to the kidney transplant waiting list, and to either a living or deceased donor kidney transplant.

In general and even with adjustments, states with higher wait-listing rates had lower transplantation rates and states with lower wait-listing rates had higher transplant rates ($r = -0.65, p < 0.0001$). Six states demonstrated both wait-listing rates and deceased donor transplant rates above and six states (plus the District of Columbia and Puerto Rico) had both wait-listing rates and deceased donor transplant rates below the national average.

This study does not imply that those states with higher than average wait-listing or transplantation rates are optimally meeting the needs of their ESRD population, but only that they perform in these regards at rates that exceeded the national average. These data do highlight that 20 of the 26 states with higher than average transplantation rates have lower than average wait-list rates for their ESRD populations. Conversely, the benefits of wait-listing are diminished in 18 of the 24 states with higher wait-listing rates by the concomitant existence of lower than average rates for transplantation once wait-listed.

Although this investigation demonstrates the existence of state-to-state disparities within the United States in access to kidney transplantation, it does not identify underlying causes. It may be that much of these differences reflect variables, not captured in existing databases, that might reflect regional differences in practice patterns among primary care physicians, nephrologists and transplant programs or differing levels of development of health-care infrastructure in portions of the country. These disparities may also reflect different attitudes toward illness, in general, or toward renal failure, in particular, among patient populations that are specific to individual states. A careful investigation of those states that demonstrate high rates of wait-listing, coupled with high rates of living and deceased donor transplantation, may prove valuable in planning interventions aimed at fostering access to transplantation for the ESRD population.

Potential interventions could be undertaken to improve both wait-listing and transplantation metrics. To succeed, such strategies will need to be wide-ranging and include monitoring of appropriately adjusted referral and wait-

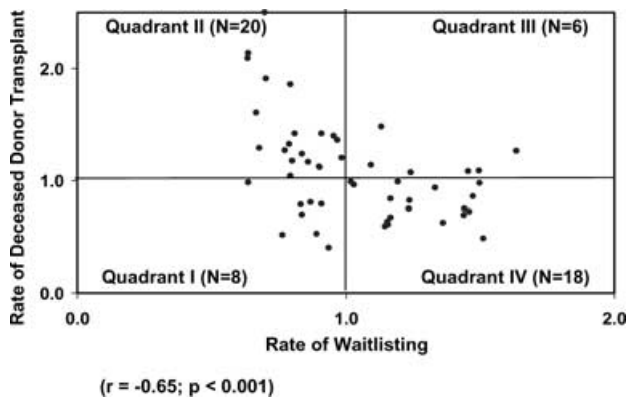


*Adjusted for age, race, ethnicity, sex, ESRD cause, incidence year, comorbid conditions, and insurance type at incidence;

**Adjusted for age, race, ethnicity, sex, ESRD cause, wait-list year, comorbid conditions, insurance type, blood type, PRA, HLA, and employment; Censored at death, living donor transplant or end of study; Compared to National average of 1.00.

Source: SRTR Analysis, May 2006.

Figure 7: Wait-listing rate* among ESRD patients and deceased donor transplantation rate among waiting list patients by state, 1996–2005.**



Source: SRTR Analysis, May 2006.

Figure 8: Correlation of wait-listing rate among ESRD patients and deceased donor transplantation rates among waiting list patients by state, 1996–2005.

listing rates among dialysis units, referral of eligible deaths among donor hospitals, OPO performance in converting referred eligible donors to actual donors, transplant center acceptance rates for allocated organs and donor service area discard rates. These disparities warrant the coordination of efforts and interventions by the dialysis community, organ procurement and transplant professional communities, government and patient advocacy groups.

This study documents the degree of geographic disparity that currently exists within the United States in access to the kidney transplant waiting list and to living donor and deceased donor kidney transplantation. These disparities

are not explained by differences in insurance, or by adjustments for important patient demographic variables including age, race, gender and cause of ESRD. Posttransplant patient and graft survival outcomes have been shown to be negatively correlated with duration of dialysis exposure (10). Thus, it may be reasonable to extrapolate that these disparities contribute to morbidity and mortality among affected ESRD patients. In addition, and importantly, the final rule charges the transplant community with assuring comparable opportunities for transplantation for patients with similar diagnoses and disease progression. It is evident from these data that this obligation is not being adequately fulfilled.

Acknowledgments

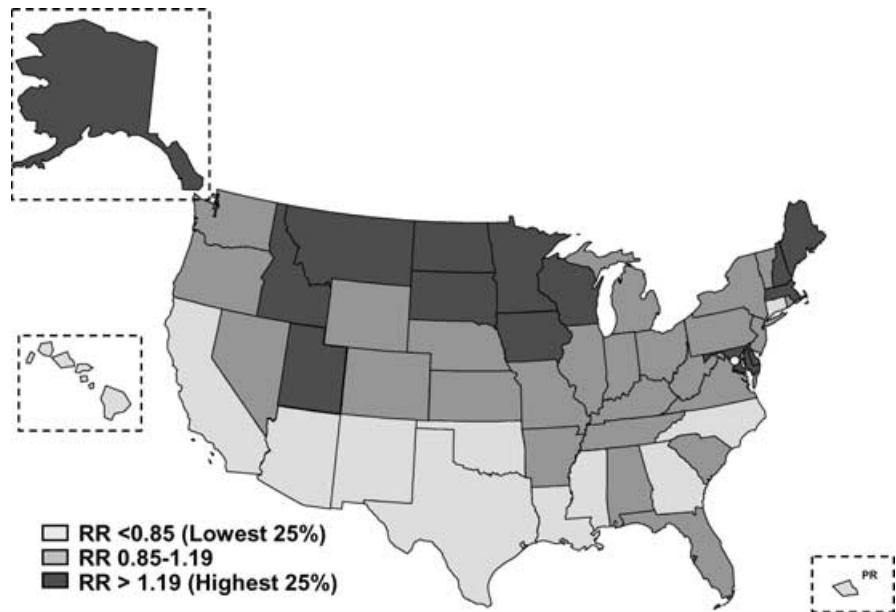
The Scientific Registry of Transplant Recipients is funded by contract number 234-2005-37009C from the Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services. The views expressed herein are those of the authors and not necessarily those of the U.S. Government. This is a U.S. Government-sponsored work. There are no restrictions on its use.

This study was approved by HRSA’s SRTR project officer. HRSA has determined that this study satisfies the criteria for the IRB exemption described in the ‘Public Benefit and Service Program’ provisions of 45 CFR 46.101(b)(5) and HRSA Circular 03.

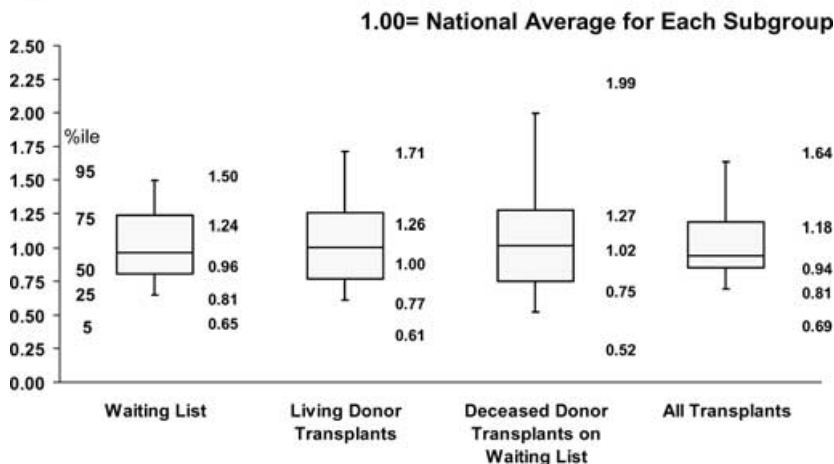
Note on sources: The articles in this report are based on the reference tables in the 2006 OPTN/SRTR Annual Report, which are not included in this publication. Many relevant data appear in the figures and tables included here; other tables from the Annual Report that serve as the basis for this article can be found at: <http://www.ustransplant.org>.

*Adjusted for age, race, ethnicity, sex, ESRD cause, incidence year, comorbid conditions, and insurance type at incidence; Censored at death or end of study; Compared to National average of 1.00; 102,331 of 703,202 received a living or deceased donor transplant. Source: SRTR Analysis, May 2006.

Figure 9: Relative rate* of receiving a kidney transplant among ESRD patients by state, 1996–2005.



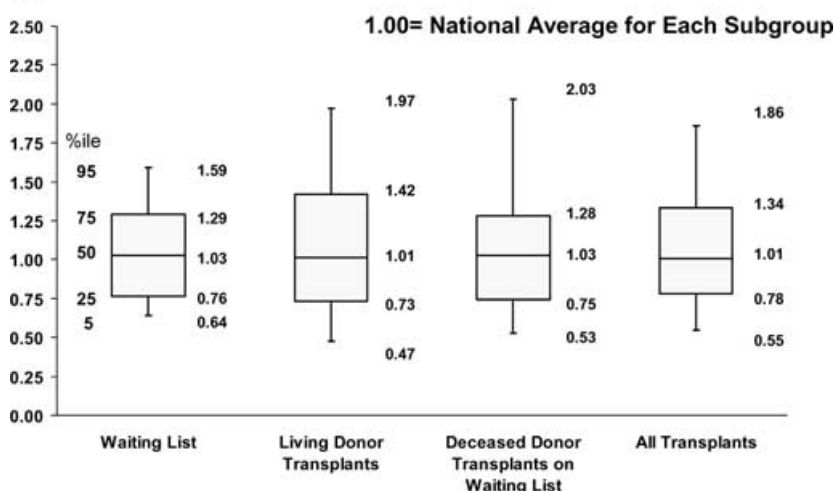
RR



Source: SRTR Analysis, May 2006.

Figure 10: Percentiles of adjusted relative access rates compared to the national average by access measure, 1996-2005.

RR



*No adjustment for race, ethnicity or insurance status

Source: SRTR Analysis, May 2006.

Figure 11: Percentiles of adjusted relative access rates* compared to the national average without adjusting for race, ethnicity or insurance status, 1996-2005.

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