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## User Guide

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This report contains a wide range of useful information about the heart transplant program at Boston Children's Hospital (MACH). The report has three main sections:

- A. Program Summary
- B. Waiting List Information
- C. Transplant Information

The Program Summary is a one-page summary highlighting characteristics of the program, including the number of candidates on the waiting list, the number of transplants performed at the program, the number of patients being cared for by the program, and patient outcomes, including outcomes while on the waiting list (the transplant rate and the death rate while on the waiting list) and outcomes after transplant (patient and graft survival probabilities). If the program performed transplants in both adults and children, survival probabilities for adults and children (pediatrics) are provided separately. For each of the outcomes measures presented, a comparison is provided showing what would be expected at this program if it were performing as similar programs around the country perform when treating similar patients. As part of this comparison, we provide a measure of how certain we are that this program is performing as expected or significantly better or worse than expected. These statements of certainty are provided as footnotes to the figures, so please interpret the numbers in the figures carefully after considering the information in the footnotes. More details regarding these outcome measures are provided in Sections B and C of the report.

The Waiting List Information section contains more detailed information on how many candidates are on the waiting list at the program, the types of candidates on the waiting list, how long candidates typically have to wait for a transplant at this program, how frequently candidates successfully receive a transplant, and how often candidates on the waiting list die before receiving a transplant.

Table B1 shows the activity on this program's waiting list during two recent 1-year periods and provides comparisons to all programs within this program's OPTN region (see <http://optn.transplant.hrsa.gov/members/regions.asp> for information on OPTN regions) and the nation as a whole. Tables B2 and B3 describe the candidates on the waiting list at this program, with comparisons to candidates waiting in the same donor service area (OPO/DSA) the OPTN region, and the nation as a whole.

Table B4 shows how many candidates were removed from the waiting list because they received a transplant. The program's transplant rate is calculated as the number of candidates who received a transplant divided by the person-years observed at the program (person-years is a combination of how many candidates were on the waiting list along with how long each candidate was followed since some candidates are not on the waiting list for the entire year). The transplant rate and comparisons to what would be expected at this center are presented in Figures B1 and B2. Figure B1 shows the transplant rate compared to what was expected at this program. The expected transplant rate is an estimate of what we would expect at this program if it were performing transplants at rates similar to other programs in the US with similar candidates on their waiting lists. The expected rate is only an estimate, and is made with a certain level of uncertainty. This uncertainty is shown in Figure B2. Figure B2 displays the ratio of the observed to the expected transplant rate. A ratio of 1 indicates that the observed transplant rate was equal to the expected transplant rate, while a ratio less than 1 indicates the observed rate was lower than expected rate and a ratio greater than 1 indicates the observed rate

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was higher than the expected rate. However, the level of uncertainty must be considered when interpreting these numbers. The 95% confidence interval is also shown on Figure B2. This confidence interval provides a range within which the true ratio of observed to expected transplant rates is likely to be. If this confidence interval includes (crosses) 1.0, then we cannot say that this program's observed transplant rate is different from what would be expected. The observed deceased donor transplant rate at this program was 99.4 per 100 person-years, and this was not significantly different from what would be expected with a 95% confidence interval of [0.56, 1.45] for the ratio of observed to expected transplant rates. Transplant rates are also provided for adult and pediatric patients separately along with comparisons to adult and pediatric rates in the DSA, the OPTN region, and the nation. Please refer to the PSR Technical Methods documentation available at <http://www.srtr.org> for more detail regarding how expected rates are calculated.

The death rate (also known as the mortality rate) for candidates on the waiting list is presented in Table B5 and Figures B4-B6. These data are presented in the same way as the transplant rate data in the previous section. The intent of these tables and figures is to describe risk of death once candidates are listed rather than while they are listed. Therefore, time at risk and deaths after removal from the waiting list for reasons other than transplant, transfer to another transplant program, or recovery (no longer needing a transplant), and before any subsequent transplant, are included. As with transplant rates, mortality rates should be interpreted carefully taking into consideration the confidence interval displayed in Figure B5. For a complete description of how observed and expected mortality rates are calculated, please refer to the technical documentation available at <http://www.srtr.org>.

Table B6 presents information on what happens to candidates on the waiting list by three different time points after listing: 6 months, 12 months, and 18 months. The table displays percentages of candidates who have died, been removed from the waiting list, been transplanted, or been transferred or lost-to-follow-up. Tables B7 and B8 provide more detail regarding how many candidates have received a deceased donor transplant by certain time points during the first 3 years after being put on the transplant waiting list. Each row of Tables B7 and B8 presents the percent of candidates who received a deceased donor transplant by each time point. Table B9 presents data on the time it took for different percentages of patients to be transplanted for candidates added to the list between 07/01/2010 and 12/31/2015. The time it took for 5% (the 5th percentile) of patients to receive a transplant at this center was 0.4 months. If "Not Observed" is displayed in the table, then too few candidates received transplants before 06/30/2016 to calculate a particular percentile of transplant times.

The Transplant Information section begins with descriptions of transplant recipients in Tables C1 and C2. Data on recipients of deceased donor transplants are presented (Tables C1D and C2D); if applicable, data on recipients of living donor transplants are presented separately (Tables C1L and C2L). Comparisons to the region and the nation as a whole are provided. A description of the deceased donors used at this program is provided in Table C3D, along with characteristics of living donors in Table C3L, if applicable. Finally, information on the transplant procedure for deceased and living donor transplants is presented in Tables C4D and C4L, respectively.

Starting with Table C5, transplant outcomes are presented along with comparisons to what would be expected at this program and what happened in the nation as a whole. Tables C5-C10 present information on graft survival (survival of the transplanted organ), with data presented separately for adult and pediatric recipients. Patients are followed from the time of transplant until either failure of the



## Boston Children's Hospital

Center Code: MACH

Transplant Program (Organ): Heart

Release Date: January 5, 2017

Based on Data Available: October 31, 2016

SRTR Program-Specific Report

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transplanted organ or death, whichever comes first. Please refer to the technical methods for more information on these calculations (<http://www.srtr.org>).

While Tables C5-C10 present data on graft survival, Tables C11-C16 present information on patient survival. For these tables, patients are followed from the time of transplant until death, regardless of whether the transplant is functioning or the patient required another transplant to survive.

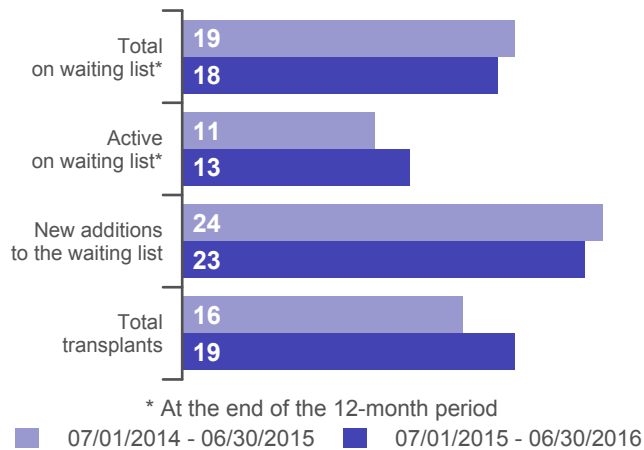
Additional information regarding the technical methods and the risk adjustment models used to estimate expected event rates is available on the SRTR website at <http://www.srtr.org>. We welcome and encourage feedback on these reports. Please feel free to share feedback with the SRTR at the following e-mail: [srtr@srtr.org](mailto:srtr@srtr.org).

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## A. Program Summary

**Figure A1. Waiting list and transplant activity**

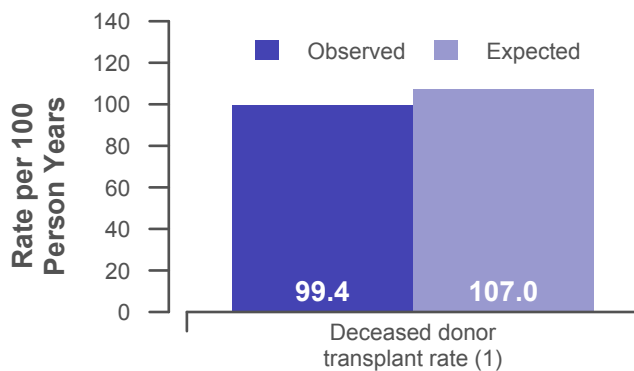


**Table A1. Census of transplant recipients**

Recipients	07/01/2014-06/30/2015	07/01/2015-06/30/2016
Transplanted at this center	16	19
Followed by this center*	108	114
...transplanted at this program	106	111
...transplanted elsewhere	2	3

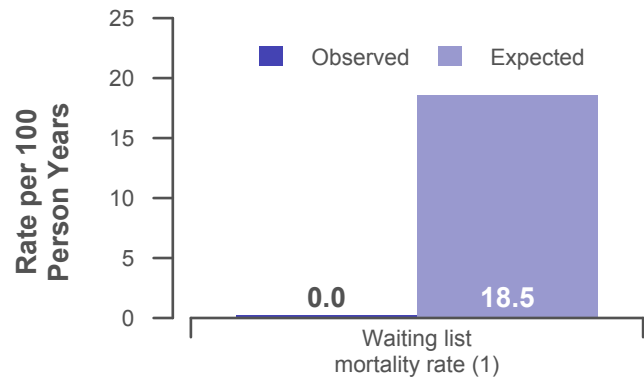
\* Recipients followed are transplant recipients for whom the center has submitted a post-transplant follow-up form for a transplant that took place before the 12-month interval for each column.

**Figure A2. Transplant rates  
07/01/2015 - 06/30/2016**



(1) Not significantly different ( $p=0.860$ )

**Figure A3. Waiting list mortality rates  
07/01/2015 - 06/30/2016**

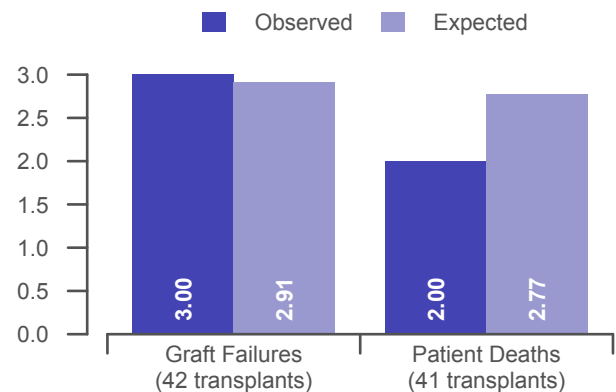


(1) Statistically lower ( $p=0.045$ )

**Figure A4. First-year adult graft and patient survival: 07/01/2013 - 12/31/2015**

This center did not perform any transplants relevant to this figure during 07/01/2013-12/31/2015

**Figure A5. First-year pediatric graft and patient survival: 07/01/2013 - 12/31/2015**



## B. Waiting List Information

**Table B1. Waiting list activity summary: 07/01/2014 - 06/30/2016**

Waiting List Registrations	Counts for this center		Activity for 07/01/2015 to 06/30/2016 as percent of registrants on waiting list on 07/01/2015		
	07/01/2014- 06/30/2015	07/01/2015- 06/30/2016	This Center (%)	OPTN Region (%)	U.S. (%)
<b>On waiting list at start</b>	16	19	100.0	100.0	100.0
<b>Additions</b>					
New listings at this center	24	23	121.1	56.3	102.5
<b>Removals</b>					
Transferred to another center	0	0	0.0	3.5	3.2
Received living donor transplant*	0	0	0.0	0.0	0.0
Received deceased donor transplant*	16	19	100.0	43.4	71.1
Died	3	0	0.0	6.3	8.7
Transplanted at another center	0	0	0.0	1.0	1.0
Deteriorated	1	1	5.3	6.3	8.8
Recovered	1	3	15.8	4.5	5.4
Other reasons	0	1	5.3	4.2	6.7
<b>On waiting list at end of period</b>	19	18	94.7	87.1	97.5

\* These patients were removed from waiting list with removal code indicating transplant; this may not equal the number of transplants performed at this center during the specified period.

## B. Waiting List Information

**Table B2. Demographic characteristics of waiting list candidates**  
Candidates registered on the waiting list between 07/01/2015 and 06/30/2016

Demographic Characteristic	New Waiting List Registrations 07/01/2015 to 06/30/2016 (%)			All Waiting List Registrations on 06/30/2016 (%)		
	This Center (N=23)	OPTN Region (N=161)	U.S. (N=4,332)	This Center (N=18)	OPTN Region (N=249)	U.S. (N=4,119)
<b>All (%)</b>	100.0	100.0	100.0	100.0	100.0	100.0
<b>Ethnicity/Race (%)*</b>						
White	73.9	75.2	60.4	72.2	76.3	61.6
African-American	4.3	11.2	23.7	5.6	13.7	25.9
Hispanic/Latino	13.0	9.9	10.9	16.7	8.4	9.3
Asian	4.3	3.1	4.0	0.0	1.2	2.5
Other	4.3	0.6	0.9	5.6	0.4	0.7
Unknown	0.0	0.0	0.0	0.0	0.0	0.0
<b>Age (%)</b>						
<2 years	39.1	5.6	6.2	44.4	3.2	3.1
2-11 years	26.1	3.7	4.8	16.7	1.2	3.1
12-17 years	30.4	4.3	3.8	22.2	1.6	2.8
18-34 years	4.3	8.1	9.1	16.7	10.0	11.2
35-49 years	0.0	19.3	19.3	0.0	22.1	23.0
50-64 years	0.0	44.7	42.1	0.0	49.4	45.1
65+ years	0.0	14.3	14.7	0.0	12.4	11.8
Other (includes prenatal)	0.0	0.0	0.0	0.0	0.0	0.0
<b>Gender (%)</b>						
Male	69.6	73.9	71.8	83.3	79.1	75.2
Female	30.4	26.1	28.2	16.7	20.9	24.8

\* Race and ethnicity are reported together as a single data element, reflecting their data collection (either race or ethnicity is required, but not both). Patients formerly coded as white and Hispanic are coded as Hispanic. Race and ethnicity sum to 100%.

## B. Waiting List Information

**Table B3. Medical characteristics of waiting list candidates**  
Candidates registered on the waiting list between 07/01/2015 and 06/30/2016

Medical Characteristic	New Waiting List Registrations 07/01/2015 to 06/30/2016 (%)			All Waiting List Registrations on 06/30/2016 (%)		
	This Center (N=23)	OPTN Region (N=161)	U.S. (N=4,332)	This Center (N=18)	OPTN Region (N=249)	U.S. (N=4,119)
<b>All (%)</b>	100.0	100.0	100.0	100.0	100.0	100.0
<b>Blood Type (%)</b>						
O	43.5	42.9	45.1	50.0	55.4	55.3
A	30.4	38.5	35.4	38.9	32.5	30.9
B	21.7	14.3	14.7	11.1	10.4	11.7
AB	4.3	4.3	4.8	0.0	1.6	2.1
Unknown	0.0	0.0	0.0	0.0	0.0	0.0
<b>Previous Transplant (%)</b>						
Yes	0.0	3.1	4.5	5.6	2.0	3.5
No	100.0	96.9	95.5	94.4	98.0	96.5
Unknown	0.0	0.0	0.0	0.0	0.0	0.0
<b>Primary Disease (%)</b>						
Cardiomyopathy	47.8	64.0	57.5	22.2	58.2	56.1
Coronary Artery Disease	0.0	24.2	26.8	0.0	30.9	30.1
Retransplant/Graft Failure	0.0	1.2	3.6	5.6	1.2	3.1
Valvular Heart Disease	0.0	1.2	0.9	0.0	0.4	0.8
Congenital Heart Disease	52.2	8.1	9.8	72.2	7.6	8.8
Other	0.0	1.2	1.4	0.0	1.6	1.2
Missing	0.0	0.0	0.0	0.0	0.0	0.0
<b>Medical Urgency Status at Listing (%)</b>						
Status 1A	69.6	31.7	32.1	27.8	19.7	14.5
Status 1B	21.7	36.6	39.8	33.3	30.1	39.8
Status 2	8.7	30.4	25.0	38.9	49.8	42.5
Temporarily Inactive	0.0	1.2	3.1	0.0	0.4	3.2



## B. Waiting List Information

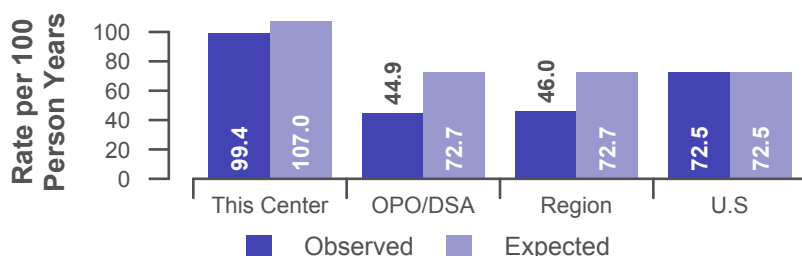
**Table B4D. Deceased donor transplant rates: 07/01/2015 - 06/30/2016**

Waiting List Registrations	This Center	OPO/DSA	Region	U.S.
<b>All Candidates</b>				
Count on waiting list at start*	19	266	286	4,216
Person Years**	19.1	251.7	269.7	4,141.9
Removals for Transplant	19	113	124	3,004
<b>Adult (18+) Candidates</b>				
Count on waiting list at start*	4	251	271	3,898
Person Years**	4.0	236.4	254.4	3,808.8
Removals for transplant	1	95	106	2,544
<b>Pediatric (&lt;18) Candidates</b>				
Count on waiting list at start*	15	15	15	318
Person Years**	15.1	15.3	15.3	333.1
Removals for transplant	18	18	18	460

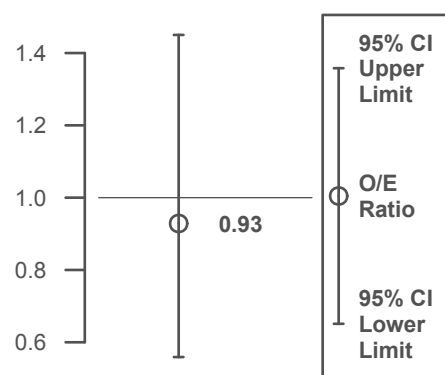
\* Counts in this table may be lower than similar counts in other waiting list tables, such as Table B1. A small percentage (~1%) of patients are found to have died or been transplanted before being removed from the waiting list, so these patients are excluded if the event occurs prior to the start of the study period. Inactive time on the waiting list is included in the calculations for this table.

\*\* Person years are calculated as days (converted to fractional years). The number of days from July 1 or from the date of first wait listing until death, transplant, removal from the waiting list or June 30.

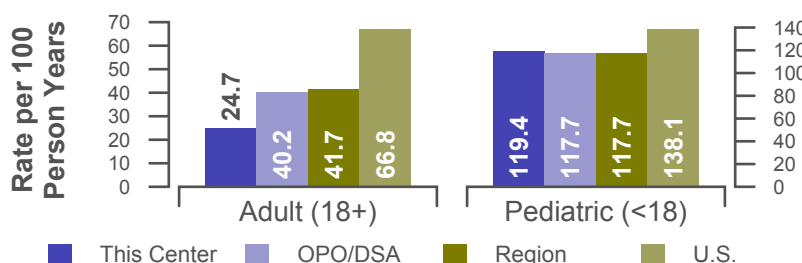
**Figure B1D. Observed and expected deceased donor transplant rates: 07/01/2015 - 06/30/2016**



**Figure B2D. Ratio of observed to expected deceased donor transplant rates**



**Figure B3D. Observed adult (18+) and pediatric (<18) deceased donor transplant rates: 07/01/2015 - 06/30/2016**



(1) Not significantly different  
(p=0.860, 95% CI=[0.56, 1.45])

## B. Waiting List Information

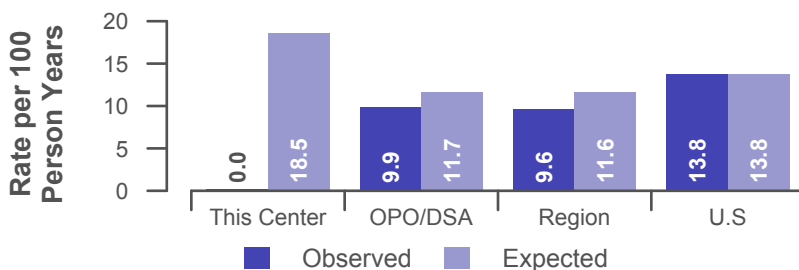
**Table B5. Waiting list mortality rates: 07/01/2015 - 06/30/2016**

Waiting List Registrations	This Center	OPO/DSA	Region	U.S.
<b>All Candidates</b>				
Count on waiting list at start*	19	266	286	4,216
Person Years**	20.5	263.4	282.4	4,400.3
Number of deaths	0	26	27	607
<b>Adult (18+) Candidates</b>				
Count on waiting list at start*	4	251	271	3,898
Person Years**	4.0	246.8	265.7	4,040.9
Number of deaths	0	26	27	532
<b>Pediatric (&lt;18) Candidates</b>				
Count on waiting list at start*	15	15	15	318
Person Years**	16.4	16.6	16.6	359.4
Number of deaths	0	0	0	75

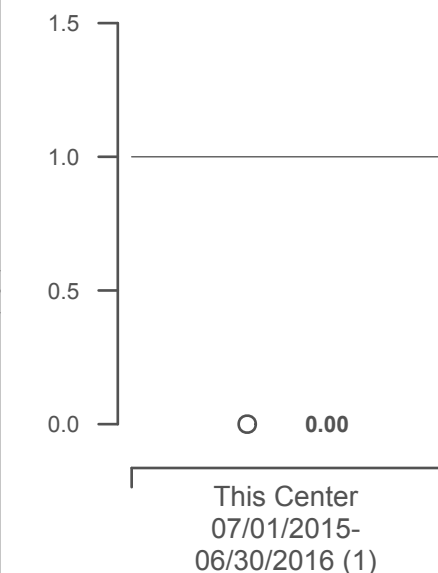
\* Counts in this table may be lower than similar counts in other waiting list tables, such as Table B1. A small percentage (~1%) of patients are found to have died or been transplanted before being removed from the waiting list, so these patients are excluded if the event occurs prior to the start of the study period. Inactive time on the waiting list is included in the calculations for this table.

\*\* Person years are calculated as days (converted to fractional years). The number of days from July 1 or from the date of first wait listing until death, transplant, 60 days after recovery, transfer or June 30.

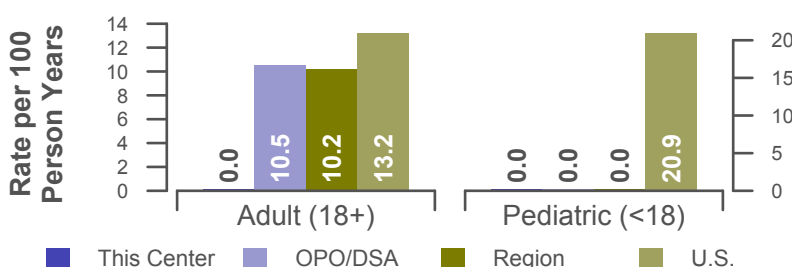
**Figure B4. Observed and expected waiting list mortality rates: 07/01/2015 - 06/30/2016**



**Figure B5. Ratio of observed to expected waiting list mortality rates**



**Figure B6. Observed adult (18+) and pediatric (<18) waiting list mortality rates: 07/01/2015 - 06/30/2016**



(1) Lower than expected  
(p=0.045)

## B. Waiting List Information

**Table B6. Waiting list candidate status after listing**  
**Candidates registered on waiting list between 01/01/2014 and 12/31/2014**

Waiting list status (survival status)	This Center (N=25)			U.S. (N=4,334)		
	Months Since Listing			Months Since Listing		
	6	12	18	6	12	18
<b>Alive on waiting list (%)</b>	48.0	40.0	32.0	46.8	30.3	21.7
<b>Died on the waiting list without transplant (%)</b>	12.0	12.0	12.0	5.9	7.2	7.8
<b>Removed without transplant (%):</b>						
Condition worsened (status unknown)	4.0	4.0	4.0	4.7	6.2	6.9
Condition improved (status unknown)	0.0	0.0	0.0	0.9	1.4	2.2
Refused transplant (status unknown)	0.0	0.0	0.0	0.2	0.3	0.4
Other	0.0	4.0	4.0	1.5	2.8	3.5
<b>Transplant (living or deceased donor) (%):</b>						
Functioning (alive)	32.0	36.0	24.0	36.5	44.4	34.6
Failed-Retransplanted (alive)	0.0	0.0	0.0	0.0	0.1	0.1
Failed-alive not retransplanted	0.0	0.0	0.0	0.1	0.0	0.0
Died	4.0	4.0	4.0	2.4	4.1	5.3
Status Yet Unknown*	0.0	0.0	20.0	0.4	2.2	16.1
<b>Lost or Transferred (status unknown) (%)</b>	0.0	0.0	0.0	0.6	1.2	1.6
<b>TOTAL (%)</b>	100.0	100.0	100.0	100.0	100.0	100.0
Total % known died on waiting list or after transplant	16.0	16.0	16.0	8.3	11.2	13.0
Total % known died or removed as unstable	20.0	20.0	20.0	13.0	17.4	20.0
Total % removed for transplant	36.0	40.0	48.0	39.4	50.8	56.0
Total % with known functioning transplant (alive)	32.0	36.0	24.0	36.5	44.4	34.6

\* Follow-up form covering specified time period not yet completed, and possibly has not become due.

## B. Waiting List Information

**Table B7. Percent of candidates with deceased donor transplants: demographic characteristics**  
Candidates registered on the waiting list between 07/01/2010 and 06/30/2013

Characteristic	N	Percent transplanted at time periods since listing This Center				N	United States			
		30 day	1 year	2 years	3 years		30 day	1 year	2 years	3 years
<b>All</b>	56	16.1	73.2	76.8	78.6	10,795	17.9	55.4	63.4	66.0
<b>Ethnicity/Race*</b>										
White	42	16.7	71.4	73.8	76.2	7,012	17.4	55.0	63.6	66.2
African-American	6	16.7	83.3	83.3	83.3	2,336	17.3	53.6	61.0	63.7
Hispanic/Latino	7	0.0	71.4	85.7	85.7	990	19.9	58.1	63.8	65.9
Asian	1	100.0	100.0	100.0	100.0	341	25.8	68.0	73.9	76.0
Other	0	--	--	--	--	116	21.6	57.8	66.4	70.7
Unknown	0	--	--	--	--	0	--	--	--	--
<b>Age</b>										
<2 years	18	27.8	72.2	72.2	72.2	678	22.3	64.0	64.7	65.0
2-11 years	20	5.0	65.0	65.0	70.0	520	17.1	65.0	68.7	70.4
12-17 years	18	16.7	83.3	94.4	94.4	435	33.3	76.3	82.8	84.4
18-34 years	0	--	--	--	--	1,051	18.6	52.0	61.0	64.0
35-49 years	0	--	--	--	--	2,044	15.6	51.2	60.3	62.9
50-64 years	0	--	--	--	--	4,633	16.5	53.1	62.1	65.5
65+ years	0	--	--	--	--	1,431	19.1	57.8	65.7	66.7
Other (includes prenatal)	0	--	--	--	--	3	0.0	0.0	0.0	0.0
<b>Gender</b>										
Male	30	13.3	76.7	80.0	80.0	7,610	16.3	53.6	62.3	65.2
Female	26	19.2	69.2	73.1	76.9	3,185	21.8	59.8	66.0	67.7

\* Race and ethnicity are reported together as a single data element, reflecting their data collection (either race or ethnicity is required, but not both). Patients formerly coded as white and Hispanic are coded as Hispanic. Race and ethnicity sum to 100%.

## B. Waiting List Information

**Table B8. Percent of candidates with deceased donor transplants: medical characteristics**  
Candidates registered on the waiting list between 07/01/2010 and 06/30/2013

Characteristic	Percent transplanted at time periods since listing									
	This Center					United States				
	N	30 day	1 year	2 years	3 years	N	30 day	1 year	2 years	3 years
All	56	16.1	73.2	76.8	78.6	10,795	17.9	55.4	63.4	66.0
Blood Type										
O	24	8.3	75.0	79.2	83.3	4,755	11.4	45.8	54.7	58.4
A	17	23.5	58.8	64.7	64.7	4,074	22.3	61.5	69.3	71.0
B	13	23.1	84.6	84.6	84.6	1,458	21.0	62.7	69.9	71.9
AB	2	0.0	100.0	100.0	100.0	505	35.2	76.4	80.0	80.2
Previous Transplant										
Yes	4	0.0	50.0	75.0	75.0	529	17.6	45.7	53.5	55.8
No	52	17.3	75.0	76.9	78.8	10,266	18.0	55.9	63.9	66.5
Primary Disease										
Cardiomyopathy	21	14.3	81.0	85.7	90.5	5,648	19.7	57.6	65.6	68.2
Coronary Artery Disease	1	100.0	100.0	100.0	100.0	3,327	15.9	54.0	63.3	66.1
Retransplant/Graft Failure	4	0.0	50.0	75.0	75.0	457	18.6	46.6	54.0	56.7
Valvular Heart Disease	0	--	--	--	--	161	21.1	53.4	59.0	62.7
Congenital Heart Disease	30	16.7	70.0	70.0	70.0	1,050	15.1	53.6	58.7	60.3
Other	0	--	--	--	--	152	12.5	44.7	50.7	51.3
Missing	0	--	--	--	--	0	--	--	--	--
Medical Urgency Status at Listing										
Old Status 1	0	--	--	--	--	0	--	--	--	--
Status 1A	27	25.9	74.1	74.1	74.1	3,365	34.3	69.8	72.8	73.5
Status 1B	11	18.2	54.5	63.6	72.7	3,929	15.1	58.1	67.1	70.5
Status 2	18	0.0	83.3	88.9	88.9	3,134	5.4	38.8	50.8	54.4
Unknown	0	--	--	--	--	367	6.0	36.8	45.2	46.9

## B. Waiting List Information

**Table B9. Time to transplant for waiting list candidates\***

**Candidates registered on the waiting list between 07/01/2010 and 12/31/2015**

Percentile	Center	Months to Transplant**		U.S.
		OPO/DSA	Region	
<b>5th</b>	0.4	1	1	0.3
<b>10th</b>	0.6	2.4	1.9	0.6
<b>25th</b>	1.9	6.5	5.6	1.9
<b>50th (median time to transplant)</b>	4.7	23.0	20.5	8.6
<b>75th</b>	21.6	Not Observed	Not Observed	Not Observed

\* If cells contain "Not Observed" fewer than that percentile of patients had received a transplant. For example, the 50th percentile of time to transplant is the time when 50% of candidates have received transplants. If waiting times are long, then the 50th percentile may not be observed during the follow-up period for this table. Also, if more than 50% of candidates are removed from the list due to death or other reasons before receiving transplants, then the 50th percentile of time to transplant will not be observed.

\*\* Censored on 06/30/2016. Calculated as the months after listing, during which the corresponding percent of all patients initially listed had received a transplant.

## C. Transplant Information

**Table C1D. Deceased donor transplant recipient demographic characteristics**  
**Patients transplanted between 07/01/2015 and 06/30/2016**

Characteristic	Percentage in each category		
	Center (N=19)	Region (N=124)	U.S. (N=3,004)
<b>Ethnicity/Race (%)*</b>			
White	68.4	74.2	60.8
African-American	5.3	11.3	22.2
Hispanic/Latino	15.8	11.3	11.3
Asian	10.5	3.2	4.8
Other	0.0	0.0	0.9
Unknown	0.0	0.0	0.0
<b>Age (%)</b>			
<2 years	15.8	2.4	5.3
2-11 years	36.8	5.6	5.3
12-17	42.1	6.5	4.3
18-34	5.3	8.1	8.6
35-49 years	0.0	19.4	17.7
50-64 years	0.0	37.9	41.7
65+ years	0.0	20.2	17.1
Unknown	0.0	0.0	0.0
<b>Gender (%)</b>			
Male	63.2	67.7	71.8
Female	36.8	32.3	28.2

\* Race and ethnicity are reported together as a single data element, reflecting their data collection (either race or ethnicity is required, but not both). Patients formerly coded as white and Hispanic are coded as Hispanic. Race and ethnicity sum to 100%.

## C. Transplant Information

**Table C2D. Deceased donor transplant recipient medical characteristics**  
**Patients transplanted between 07/01/2015 and 06/30/2016**

Characteristic	Percentage in each category		
	Center (N=19)	Region (N=124)	U.S. (N=3,004)
<b>Blood Type (%)</b>			
O	31.6	32.3	41.0
A	31.6	42.7	38.1
B	26.3	17.7	15.1
AB	10.5	7.3	5.8
<b>Previous Transplant (%)</b>			
Yes	0.0	1.6	3.2
No	100.0	98.4	96.8
<b>Body Mass Index (%)</b>			
0-20	63.2	23.4	19.3
21-25	15.8	26.6	28.6
26-30	15.8	25.8	30.1
31+	5.3	18.5	21.2
Unknown	0.0	5.6	0.8
<b>Primary Disease (%)</b>			
Cardiomyopathy	63.2	67.7	60.2
Coronary Artery Disease	0.0	21.8	28.2
Retransplant/Graft Failure	0.0	0.0	0.0
Valvular Heart Disease	0.0	3.2	1.1
Congenital Heart Disease	36.8	6.5	9.7
Other	0.0	0.8	0.7
Missing	0.0	0.0	0.1
<b>Medical Urgency Status at Transplant (%)</b>			
Status 1A	84.2	81.5	69.6
Status 1B	10.5	16.9	27.8
Status 2	5.3	1.6	2.6
Temporarily Inactive	0.0	0.0	0.0
<b>Recipient Medical Condition at Transplant (%)</b>			
Not Hospitalized	73.7	66.9	50.5
Hospitalized	15.8	15.3	17.5
ICU	10.5	12.9	31.4
Unknown	0.0	4.8	0.5
<b>Recipient Mechanical, Ventilated or Organ-Perfusion Support Status at Transplant (%)</b>			
No Support Mechanism	31.6	11.3	15.9
Devices*	42.1	75.0	52.4
Other Support Mechanism	26.3	13.7	31.5
Unknown	0.0	0.0	0.2

\* Devices include ventricular assist devices (VAD), extracorporeal membrane oxygenation (ECMO), intraaortic balloon pump (IABP), and total artificial heart (TAH).



## C. Transplant Information

**Table C3D. Deceased donor characteristics**  
**Transplants performed between 07/01/2015 and 06/30/2016**

Donor Characteristic	Percentage in each category		
	Center (N=19)	Region (N=124)	U.S. (N=3,004)
<b>Cause of Death (%)</b>			
Deceased: Stroke	5.3	11.3	17.7
Deceased: MVA	21.1	16.1	21.9
Deceased: Other	73.7	72.6	60.4
<b>Ethnicity/Race (%)*</b>			
White	36.8	72.6	62.5
African-American	42.1	12.1	18.8
Hispanic/Latino	21.1	13.7	16.0
Asian	0.0	1.6	2.0
Other	0.0	0.0	0.8
Not Reported	0.0	0.0	0.0
<b>Age (%)</b>			
<2 years	21.1	3.2	4.7
2-11 years	21.1	3.2	5.2
12-17	36.8	8.9	8.5
18-34	21.1	45.2	48.0
35-49 years	0.0	30.6	26.6
50-64 years	0.0	8.9	7.1
65+ years	0.0	0.0	0.0
Unknown	0.0	0.0	0.0
<b>Gender (%)</b>			
Male	57.9	62.9	68.3
Female	42.1	37.1	31.7
<b>Blood Type (%)</b>			
O	47.4	39.5	51.9
A	42.1	43.5	34.3
B	10.5	14.5	11.4
AB	0.0	2.4	2.3
Unknown	0.0	0.0	0.0

\* Race and ethnicity are reported together as a single data element, reflecting their data collection (either race or ethnicity is required, but not both). Patients formerly coded as white and Hispanic are coded as Hispanic. Race and ethnicity sum to 100%.

## C. Transplant Information

**Table C4D. Deceased donor transplant characteristics**  
Transplants performed between 07/01/2015 and 06/30/2016

Transplant Characteristic	Percentage in each category		
	Center (N=19)	Region (N=124)	U.S. (N=3,004)
<b>Total Ischemic Time (Minutes): Local (%)</b>			
Deceased: 0-90 min	0.0	1.2	7.0
Deceased: 91-180 min	75.0	41.5	55.4
Deceased: 181-270 min	25.0	45.1	33.2
Deceased: 271-360 min	0.0	2.4	2.5
Deceased: 361+ min	0.0	1.2	0.4
Not Reported	0.0	8.5	1.6
<b>Total Ischemic Time (Minutes): Shared (%)</b>			
Deceased: 0-90 min	0.0	0.0	0.7
Deceased: 91-180 min	6.7	2.4	13.6
Deceased: 181-270 min	73.3	83.3	68.7
Deceased: 271-360 min	13.3	9.5	13.8
Deceased: 361+ min	6.7	2.4	1.9
Not Reported	0.0	2.4	1.4
<b>Procedure Type (%)</b>			
Heart alone	100.0	94.4	94.5
Heart and another organ	0.0	5.6	5.5
<b>Sharing (%)</b>			
Local	21.1	66.1	60.8
Shared	78.9	33.9	39.2
<b>Median Time in Hospital After Transplant*</b>	12.0 Days	14.0 Days	16.0 Days

\* Multiple organ transplants are excluded from this statistic.

## C. Transplant Information

### Table C5D. Adult (18+) 1-month survival with a functioning deceased donor graft

Single organ transplants performed between 07/01/2013 and 12/31/2015

Deaths and retransplants are considered graft failures

This center did not perform any  
transplants relevant to  
this table during  
07/01/2013-12/31/2015

Figure C1D. Adult (18+) 1-month  
deceased donor graft failure HR  
estimate

This center did not perform any  
transplants relevant to  
this figure during  
07/01/2013-12/31/2015

Figure C2D. Adult (18+) 1-month deceased donor graft failure  
HR program comparison

This center did not perform any  
transplants relevant to  
this figure during  
07/01/2013-12/31/2015

## C. Transplant Information

**Table C6D. Adult (18+) 1-year survival with a functioning deceased donor graft**  
**Single organ transplants performed between 07/01/2013 and 12/31/2015**  
**Deaths and retransplants are considered graft failures**

This center did not perform any  
transplants relevant to  
this table during  
07/01/2013-12/31/2015

**Figure C3D. Adult (18+) 1-year  
deceased donor graft failure HR  
estimate**

This center did not perform any  
transplants relevant to  
this figure during  
07/01/2013-12/31/2015

**Figure C4D. Adult (18+) 1-year deceased donor graft failure  
HR program comparison**

This center did not perform any  
transplants relevant to  
this figure during  
07/01/2013-12/31/2015

## C. Transplant Information

### Table C7D. Adult (18+) 3-year survival with a functioning deceased donor graft

Single organ transplants performed between 01/01/2011 and 06/30/2013

Deaths and retransplants are considered graft failures

This center did not perform any  
transplants relevant to  
this table during  
01/01/2011-06/30/2013

### Figure C5D. Adult (18+) 3-year deceased donor graft failure HR estimate

This center did not perform any  
transplants relevant to  
this figure during  
01/01/2011-06/30/2013

### Figure C6D. Adult (18+) 3-year deceased donor graft failure HR program comparison

This center did not perform any  
transplants relevant to  
this figure during  
01/01/2011-06/30/2013

## C. Transplant Information

**Table C8D. Pediatric (<18) 1-month survival with a functioning deceased donor graft**

**Single organ transplants performed between 07/01/2013 and 12/31/2015**

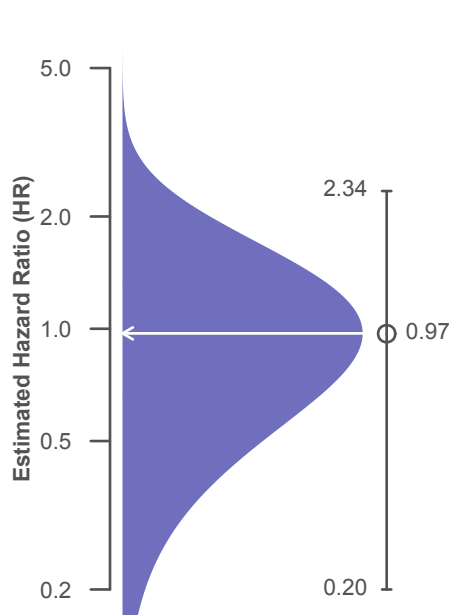
**Deaths and retransplants are considered graft failures**

	MACH	U.S.
Number of transplants evaluated	42	1,065
Estimated probability of surviving with a functioning graft at 1 month (unadjusted for patient and donor characteristics)	97.62%	97.37%
Expected probability of surviving with a functioning graft at 1 month (adjusted for patient and donor characteristics)	97.38%	--
Number of observed graft failures (including deaths) during the first month after transplant	1	28
Number of expected graft failures (including deaths) during the first month after transplant	1.09	--
Estimated hazard ratio*	0.97	--
95% credible interval for the hazard ratio**	[0.20, 2.34]	--

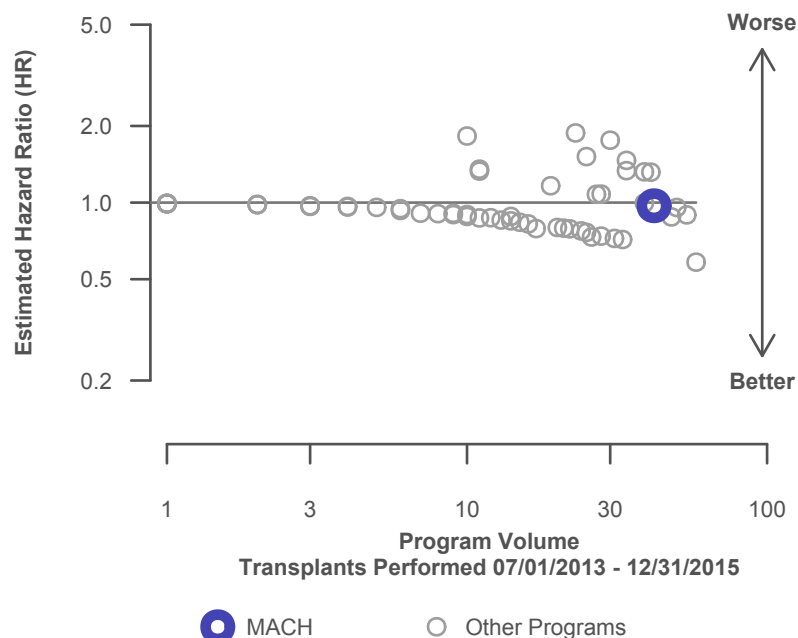
\* The hazard ratio provides an estimate of how Boston Children's Hospital (MACH)'s results compare with what was expected based on modeling the transplant outcomes from all U.S. programs. A ratio above 1 indicates higher than expected graft failure rates (e.g., a hazard ratio of 1.5 would indicate 50% higher risk), and a ratio below 1 indicates lower than expected graft failure rates (e.g., a hazard ratio of 0.75 would indicate 25% lower risk). If MACH's graft failure rate were precisely the expected rate, the estimated hazard ratio would be 1.0.

\*\* The 95% credible interval, [0.20, 2.34], indicates the location of MACH's true hazard ratio with 95% probability. The best estimate is 3% lower risk of graft failure compared to an average program, but MACH's performance could plausibly range from 80% reduced risk up to 134% increased risk.

**Figure C7D. Pediatric (<18) 1-month deceased donor graft failure HR estimate**



**Figure C8D. Pediatric (<18) 1-month deceased donor graft failure HR program comparison**



## C. Transplant Information

**Table C9D. Pediatric (<18) 1-year survival with a functioning deceased donor graft**

**Single organ transplants performed between 07/01/2013 and 12/31/2015**

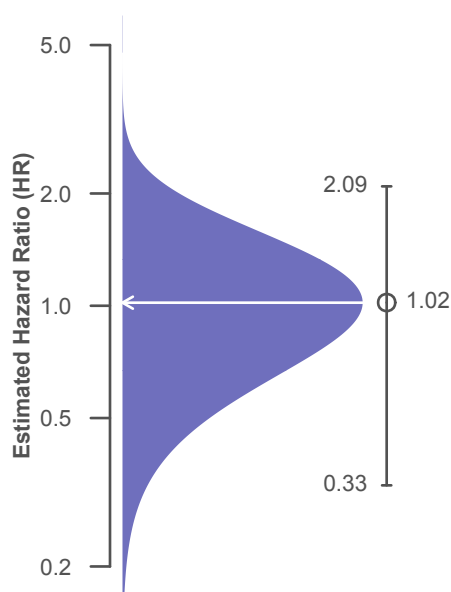
**Deaths and retransplants are considered graft failures**

	MACH	U.S.
Number of transplants evaluated	42	1,065
Estimated probability of surviving with a functioning graft at 1 year (unadjusted for patient and donor characteristics)	92.86%	92.63%
Expected probability of surviving with a functioning graft at 1 year (adjusted for patient and donor characteristics)	92.57%	--
Number of observed graft failures (including deaths) during the first year after transplant	3	75
Number of expected graft failures (including deaths) during the first year after transplant	2.91	--
Estimated hazard ratio*	1.02	--
95% credible interval for the hazard ratio**	[0.33, 2.09]	--

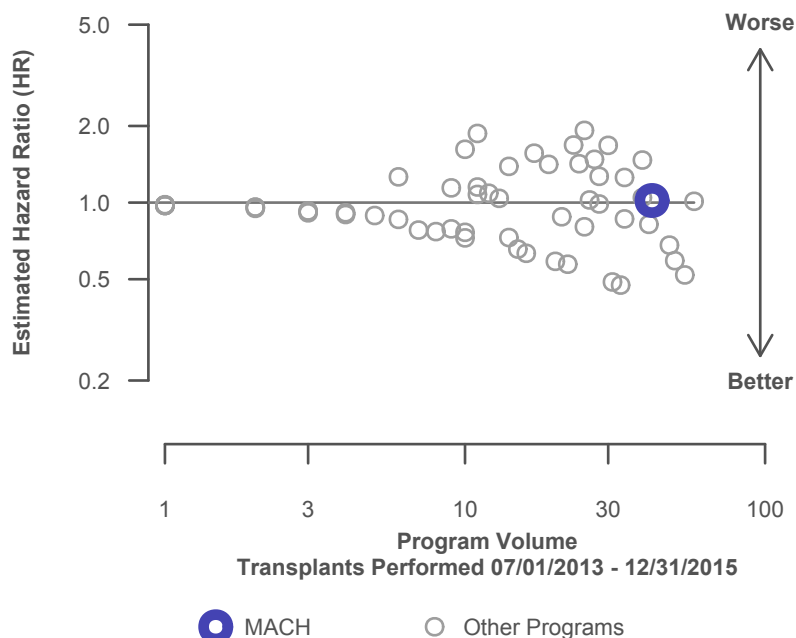
\* The hazard ratio provides an estimate of how Boston Children's Hospital (MACH)'s results compare with what was expected based on modeling the transplant outcomes from all U.S. programs. A ratio above 1 indicates higher than expected graft failure rates (e.g., a hazard ratio of 1.5 would indicate 50% higher risk), and a ratio below 1 indicates lower than expected graft failure rates (e.g., a hazard ratio of 0.75 would indicate 25% lower risk). If MACH's graft failure rate were precisely the expected rate, the estimated hazard ratio would be 1.0.

\*\* The 95% credible interval, [0.33, 2.09], indicates the location of MACH's true hazard ratio with 95% probability. The best estimate is 2% higher risk of graft failure compared to an average program, but MACH's performance could plausibly range from 67% reduced risk up to 109% increased risk.

**Figure C9D. Pediatric (<18) 1-year deceased donor graft failure HR estimate**



**Figure C10D. Pediatric (<18) 1-year deceased donor graft failure HR program comparison**



## C. Transplant Information

**Table C10D. Pediatric (<18) 3-year survival with a functioning deceased donor graft**

**Single organ transplants performed between 01/01/2011 and 06/30/2013**

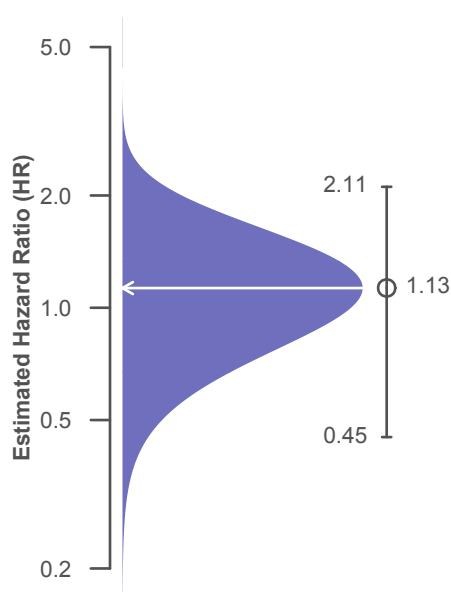
**Deaths and retransplants are considered graft failures**

	MACH	U.S.
Number of transplants evaluated	32	934
Estimated probability of surviving with a functioning graft at 3 years (unadjusted for patient and donor characteristics)	84.38%	86.83%
Expected probability of surviving with a functioning graft at 3 years (adjusted for patient and donor characteristics)	86.84%	--
Number of observed graft failures (including deaths) during the first 3 years after transplant	5	123
Number of expected graft failures (including deaths) during the first 3 years after transplant	4.20	--
Estimated hazard ratio*	1.13	--
95% credible interval for the hazard ratio**	[0.45, 2.11]	--

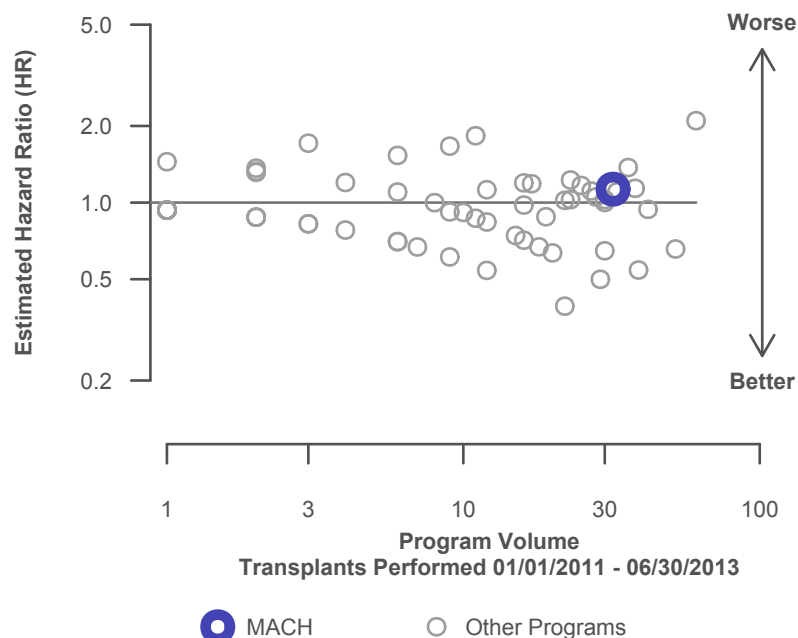
\* The hazard ratio provides an estimate of how Boston Children's Hospital (MACH)'s results compare with what was expected based on modeling the transplant outcomes from all U.S. programs. A ratio above 1 indicates higher than expected graft failure rates (e.g., a hazard ratio of 1.5 would indicate 50% higher risk), and a ratio below 1 indicates lower than expected graft failure rates (e.g., a hazard ratio of 0.75 would indicate 25% lower risk). If MACH's graft failure rate were precisely the expected rate, the estimated hazard ratio would be 1.0.

\*\* The 95% credible interval, [0.45, 2.11], indicates the location of MACH's true hazard ratio with 95% probability. The best estimate is 13% higher risk of graft failure compared to an average program, but MACH's performance could plausibly range from 55% reduced risk up to 111% increased risk.

**Figure C11D. Pediatric (<18) 3-year deceased donor graft failure HR estimate**



**Figure C12D. Pediatric (<18) 3-year deceased donor graft failure HR program comparison**





## C. Transplant Information

### Table C11D. Adult (18+) 1-month patient survival (deceased donor graft recipients)

Single organ transplants performed between 07/01/2013 and 12/31/2015

Retransplants excluded

This center did not perform any  
transplants relevant to  
this table during  
07/01/2013-12/31/2015

### Figure C13D. Adult (18+) 1-month patient death HR estimate (deceased donor grafts)

This center did not perform any  
transplants relevant to  
this figure during  
07/01/2013-12/31/2015

### Figure C14D. Adult (18+) 1-month patient death HR program comparison (deceased donor grafts)

This center did not perform any  
transplants relevant to  
this figure during  
07/01/2013-12/31/2015

## C. Transplant Information

### Table C12D. Adult (18+) 1-year patient survival (deceased donor graft recipients)

Single organ transplants performed between 07/01/2013 and 12/31/2015

Retransplants excluded

This center did not perform any  
transplants relevant to  
this table during  
07/01/2013-12/31/2015

### Figure C15D. Adult (18+) 1-year patient death HR estimate (deceased donor grafts)

This center did not perform any  
transplants relevant to  
this figure during  
07/01/2013-12/31/2015

### Figure C16D. Adult (18+) 1-year patient death HR program comparison (deceased donor grafts)

This center did not perform any  
transplants relevant to  
this figure during  
07/01/2013-12/31/2015

## C. Transplant Information

### Table C13D. Adult (18+) 3-year patient survival (deceased donor graft recipients)

Single organ transplants performed between 01/01/2011 and 06/30/2013

Retransplants excluded

This center did not perform any  
transplants relevant to  
this table during  
01/01/2011-06/30/2013

### Figure C17D. Adult (18+) 3-year patient death HR estimate (deceased donor grafts)

This center did not perform any  
transplants relevant to  
this figure during  
01/01/2011-06/30/2013

### Figure C18D. Adult (18+) 3-year patient death HR program comparison (deceased donor grafts)

This center did not perform any  
transplants relevant to  
this figure during  
01/01/2011-06/30/2013

## C. Transplant Information

**Table C14D. Pediatric (<18) 1-month patient survival (deceased donor graft recipients)**

**Single organ transplants performed between 07/01/2013 and 12/31/2015**

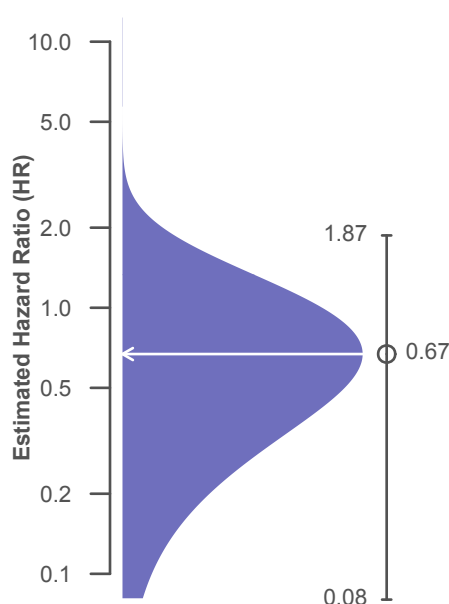
**Retransplants excluded**

	<b>MACH</b>	<b>U.S.</b>
Number of transplants evaluated	41	1,016
Estimated probability of surviving at 1 month (unadjusted for patient and donor characteristics)	100.00%	97.54%
Expected probability of surviving at 1 month (adjusted for patient and donor characteristics)	97.63%	--
Number of observed deaths during the first month after transplant	0	25
Number of expected deaths during the first month after transplant	0.99	--
Estimated hazard ratio*	0.67	--
95% credible interval for the hazard ratio**	[0.08, 1.87]	--

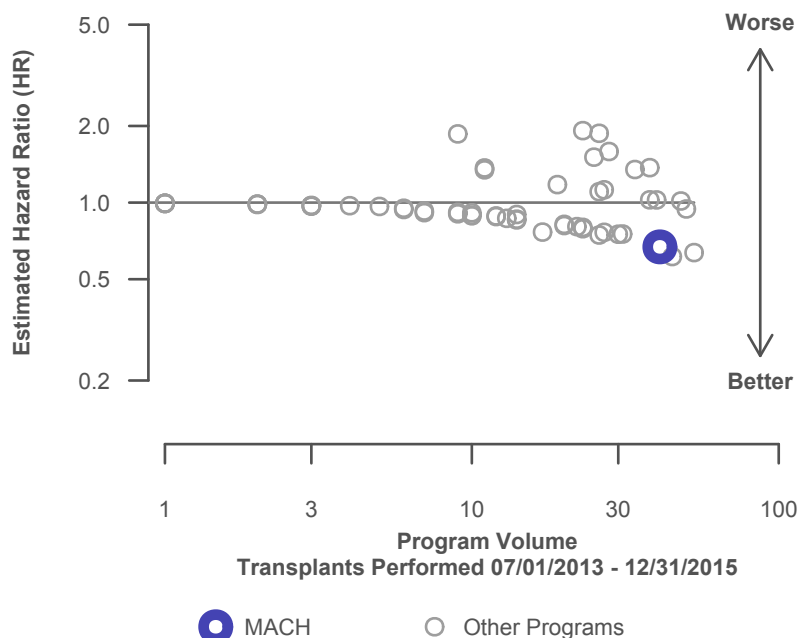
\* The hazard ratio provides an estimate of how Boston Children's Hospital (MACH)'s results compare with what was expected based on modeling the transplant outcomes from all U.S. programs. A ratio above 1 indicates higher than expected patient death rates (e.g., a hazard ratio of 1.5 would indicate 50% higher risk), and a ratio below 1 indicates lower than expected patient death rates (e.g., a hazard ratio of 0.75 would indicate 25% lower risk). If MACH's patient death rate were precisely the expected rate, the estimated hazard ratio would be 1.0.

\*\* The 95% credible interval, [0.08, 1.87], indicates the location of MACH's true hazard ratio with 95% probability. The best estimate is 33% lower risk of patient death compared to an average program, but MACH's performance could plausibly range from 92% reduced risk up to 87% increased risk.

**Figure C19D. Pediatric (<18) 1-month patient death HR estimate (deceased donor grafts)**



**Figure C20D. Pediatric (<18) 1-month patient death HR program comparison (deceased donor grafts)**



## C. Transplant Information

**Table C15D. Pediatric (<18) 1-year patient survival (deceased donor graft recipients)**

**Single organ transplants performed between 07/01/2013 and 12/31/2015**

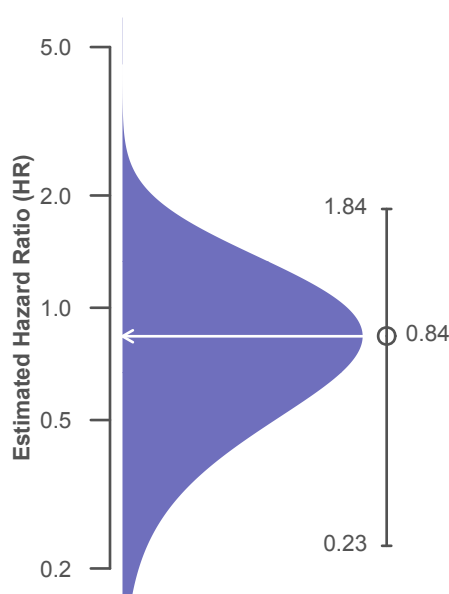
**Retransplants excluded**

	MACH	U.S.
Number of transplants evaluated	41	1,016
Estimated probability of surviving at 1 year (unadjusted for patient and donor characteristics)	95.12%	92.77%
Expected probability of surviving at 1 year (adjusted for patient and donor characteristics)	92.91%	--
Number of observed deaths during the first year after transplant	2	70
Number of expected deaths during the first year after transplant	2.77	--
Estimated hazard ratio*	0.84	--
95% credible interval for the hazard ratio**	[0.23, 1.84]	--

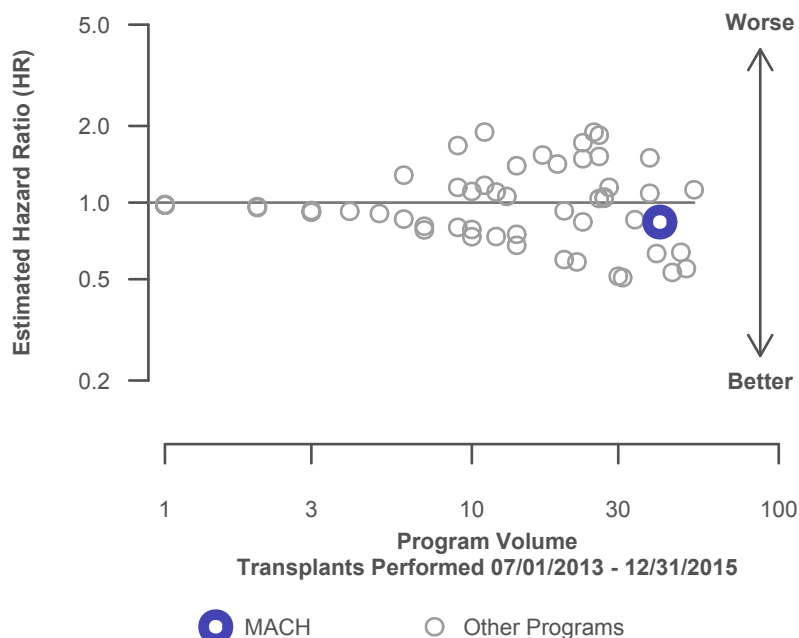
\* The hazard ratio provides an estimate of how Boston Children's Hospital (MACH)'s results compare with what was expected based on modeling the transplant outcomes from all U.S. programs. A ratio above 1 indicates higher than expected patient death rates (e.g., a hazard ratio of 1.5 would indicate 50% higher risk), and a ratio below 1 indicates lower than expected patient death rates (e.g., a hazard ratio of 0.75 would indicate 25% lower risk). If MACH's patient death rate were precisely the expected rate, the estimated hazard ratio would be 1.0.

\*\* The 95% credible interval, [0.23, 1.84], indicates the location of MACH's true hazard ratio with 95% probability. The best estimate is 16% lower risk of patient death compared to an average program, but MACH's performance could plausibly range from 77% reduced risk up to 84% increased risk.

**Figure C21D. Pediatric (<18) 1-year patient death HR estimate (deceased donor grafts)**



**Figure C22D. Pediatric (<18) 1-year patient death HR program comparison (deceased donor grafts)**



## C. Transplant Information

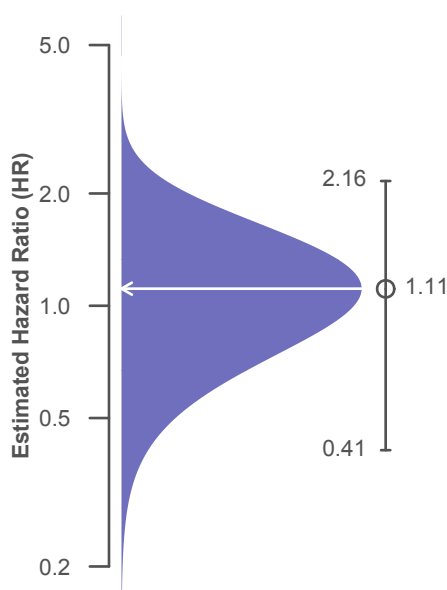
**Table C16D. Pediatric (<18) 3-year patient survival (deceased donor graft recipients)**  
**Single organ transplants performed between 01/01/2011 and 06/30/2013**  
**Retransplants excluded**

	MACH	U.S.
Number of transplants evaluated	29	872
Estimated probability of surviving at 3 years (unadjusted for patient and donor characteristics)	86.21%	88.42%
Expected probability of surviving at 3 years (adjusted for patient and donor characteristics)	88.43%	--
Number of observed deaths during the first 3 years after transplant	4	101
Number of expected deaths during the first 3 years after transplant	3.40	--
Estimated hazard ratio*	1.11	--
95% credible interval for the hazard ratio**	[0.41, 2.16]	--

\* The hazard ratio provides an estimate of how Boston Children's Hospital (MACH)'s results compare with what was expected based on modeling the transplant outcomes from all U.S. programs. A ratio above 1 indicates higher than expected patient death rates (e.g., a hazard ratio of 1.5 would indicate 50% higher risk), and a ratio below 1 indicates lower than expected patient death rates (e.g., a hazard ratio of 0.75 would indicate 25% lower risk). If MACH's patient death rate were precisely the expected rate, the estimated hazard ratio would be 1.0.

\*\* The 95% credible interval, [0.41, 2.16], indicates the location of MACH's true hazard ratio with 95% probability. The best estimate is 11% higher risk of patient death compared to an average program, but MACH's performance could plausibly range from 59% reduced risk up to 116% increased risk.

**Figure C23D. Pediatric (<18) 3-year patient death HR estimate (deceased donor grafts)**



**Figure C24D. Pediatric (<18) 3-year patient death HR program comparison (deceased donor grafts)**

