

**OPTN Liver & Intestinal Transplantation Committee** 

Descriptive Data Request

# National Liver Review Board Out-of-the-Gate Report, Four Months Data Report APPENDIX

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**Prepared for:** Liver & Intestinal Transplantation Committee Committee Meeting October 22, 2019 *By:* Samantha M. Noreen, PhD UNOS Research Department

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# **Data and Methods**

## Data Sources:

Liver MELD and PELD exception forms submitted on or after May 14, 2019 to the National Liver Review Board (NLRB) through September 28, 2019.

## Cohort:

The report summarizes all liver exception requests that have been submitted to the NLRB since May 14, 2019 through September 28, 2019.

# This report is based on OPTN data as of September 27, 2019 and is subject to change based on future data submission or correction.

Weeks as presented are defined as the seven day period starting Tuesday through the following Monday, to coincide with the date of implementation on Tuesday, May 14, 2019.



# Appendix

# All Forms By Region

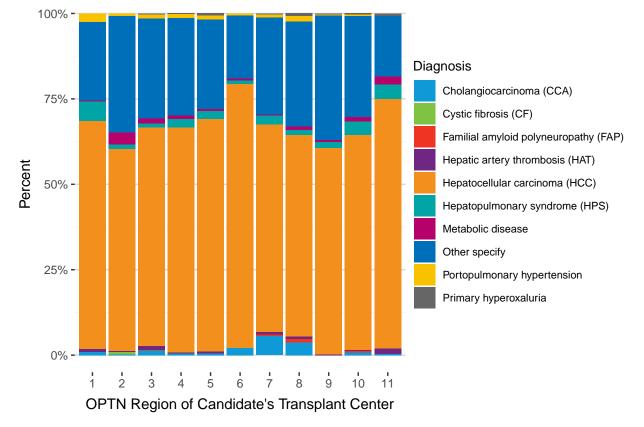


Figure A1: Exception forms by diagnosis and OPTN region of candidate's transplant center

### Table A1: Exception forms by diagnosis and OPTN region of candidate's transplant center

		OPTN Region												
Diagnosis	1	2	3	4	5	6	7	8	9	10	11	Total		
Cholangiocarcinoma (CCA)	3 (0.9%)	1 (0.2%)	7 (1.2%)	4 (0.6%)	6 (0.6%)	4 (2.1%)	29 (5.7%)	10 (3.7%)	0 (0.0%)	3 (0.9%)	1 (0.3%)	68 (1.3%)		
Cystic fibrosis (CF)	0 (0.0%)	5 (0.8%)	1 (0.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	6 (0.1%)		
Familial amyloid polyneuropathy (FAP)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (0.4%)	3 (1.1%)	0 (0.0%)	1 (0.3%)	0 (0.0%)	6 (0.1%)		
Hepatic artery thrombosis (HAT)	3 (0.9%)	2 (0.3%)	7 (1.2%)	1 (0.2%)	6 (0.6%)	0 (0.0%)	4 (0.8%)	2 (0.7%)	1 (0.2%)	1 (0.3%)	5 (1.6%)	32 (0.6%)		
Hepatocellular carcinoma (HCC)	218 (66.7%)	365 (59.1%)	359 (ồ4.0%)	437 (65.9%)	693 (ô7.9%)	146 (77.2%)	311 (ô0.7%)	159 (S8.9%)	308 (ồ0.5%)	206 (63.0%)	222 (73.0%)	3424 (64.6%)		
Hepatopulmonary syndrome (HPS)	19 (5.8%)	8 (1.3%)	6 (1.1%)	17 (2.6%)	25 (2.5%)	2 (1.1%)	13 (2.5%)	4 (1.5%)	9 (1.8%)	13 (4.0%)	13 (4.3%)	129 (2.4%)		
Metabolic disease	1 (0.3%)	22 (3.6%)	9 (1.6%)	6 (0.9%)	5 (0.5%)	1 (0.5%)	2 (0.4%)	3 (1.1%)	3 (0.6%)	4 (1.2%)	7 (2.3%)	63 (1.2%)		
Other specify	75 (22.9%)	211 (34.1%)	164 (29.2%)	190 (28.7%)	268 (26.3%)	35 (18.5%)	145 (28.3%)	83 (30.7%)	185 (36.3%)	97 (29.7%)	54 (17.8%)	1507 (28.4%)		
Portopulmonary hypertension	8 (2.4%)	4 (0.6%)	7 (1.2%)	7 (1.1%)	11 (1.1%)	1 (0.5%)	5 (1.0%)	4 (1.5%)	2 (0.4%)	1 (0.3%)	0 (0.0%)	50 (0.9%)		
Primary hyperoxaluria	0 (0.0%)	0 (0.0%)	1 (0.2%)	1 (0.2%)	6 (0.6%)	0 (0.0%)	1 (0.2%)	2 (0.7%)	1 (0.2%)	1 (0.3%)	2 (0.7%)	15 (0.3%)		
Total	327 (100.0%)	618 (100.0%)	561 (100.0%)	663 (100.0%)	1020 (100.0%)	189 (100.0%)	512 (100.0%)	270 (100.0%)	509 (100.0%)	327 (100.0%)	304 (100.0%)	5300 (100.0%)		

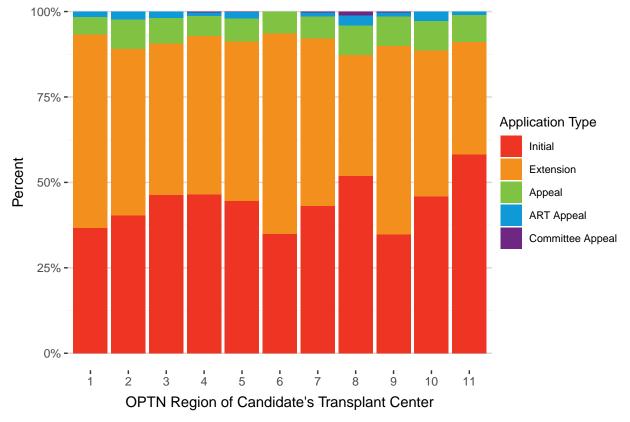


Figure A2: Exception forms by application type and OPTN region of candidate's transplant center

			Application T	уре		
OPTN Region	Initial	Extension	Appeal	ART Appeal	Committee Appeal	Total
1	120 (36.7%)	185 (56.6%)	17 (5.2%)	5 (1.5%)	0 (0.0%)	327 (100.0%)
2	249 (40.3%)	301 (48.7%)	54 (8.7%)	14 (2.3%)	0 (0.0%)	618 (100.0%)
3	260 (46.3%)	249 (44.4%)	42 (7.5%)	10 (1.8%)	0 (0.0%)	561 (100.0%)
4	308 (46.5%)	308 (46.5%)	39 (5.9%)	7 (1.1%)	1 (0.2%)	663 (100.0%)
5	454 (44.5%)	476 (46.7%)	70 (6.9%)	19 (1.9%)	1 (0.1%)	1020 (100.0%)
6	66 (34.9%)	111 (58.7%)	12 (6.3%)	0 (0.0%)	0 (0.0%)	189 (100.0%)
7	221 (43.2%)	251 (49.0%)	33 (6.4%)	6 (1.2%)	1 (0.2%)	512 (100.0%)
8	140 (51.9%)	96 (35.6%)	23 (8.5%)	8 (3.0%)	3 (1.1%)	270 (100.0%)
9	177 (34.8%)	281 (55.2%)	44 (8.6%)	6 (1.2%)	1 (0.2%)	509 (100.0%)
10	150 (45.9%)	140 (42.8%)	28 (8.6%)	9 (2.8%)	0 (0.0%)	327 (100.0%)
11	177 (58.2%)	100 (32.9%)	24 (7.9%)	3 (1.0%)	0 (0.0%)	304 (100.0%)
Total	2322 (43.8%)	2498 (47.1%)	386 (7.3%)	87 (1.6%)	7 (0.1%)	5300 (100.0%)

The figure and table below summarizes form submission by the current status of the form and the submitting candidate's OPTN region. There does not seem to be a large difference in approval rates of exception request forms by OPTN region of the submitting candidate's transplant program.

In the below figure, exception request forms that are "Submitted to Review Board" or "Pending" are excluded to provide a more uniform comparison of approval and denial proportions over time. Forms withdrawn prior to decision are also excluded.

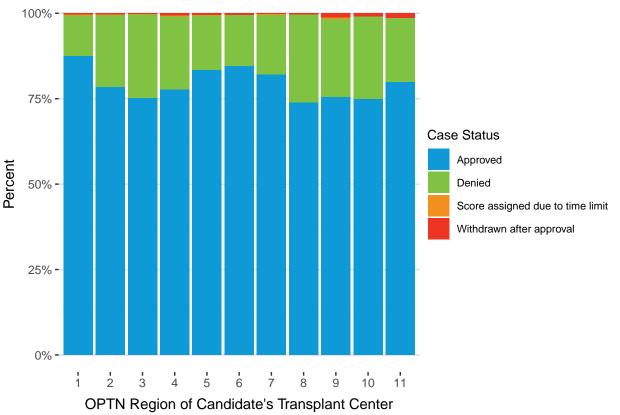


Figure A3:	Number o	f exception	forms l	by	status/outcome	type	and	OPTN	region	of	candidate's
transplant c	enter										

Table A3: Number of exception forms by status/outcome type and OPTN region of candidate's transplant center

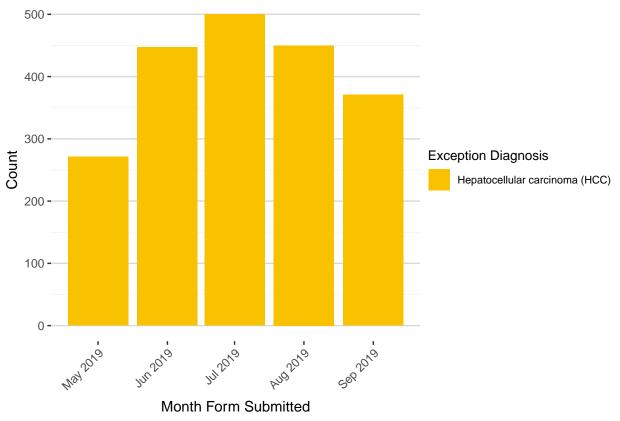
				0	Case Status			
OPTN Region	Approved	Denied	Pending	Score assigned due to time limit	Submitted to Review Board	Withdrawn after approval	Withdrawn prior to decision	Total
1	273 (83.5%)	37 (11.3%)	0 (0.0%)	1 (0.3%)	7 (2.1%)	1 (0.3%)	8 (2.4%)	327 (100.0%)
2	458 (74.1%)	122 (19.7%)	3 (0.5%)	1 (0.2%)	18 (2.9%)	2 (0.3%)	14 (2.3%)	618 (100.0%)
3	400 (71.3%)	130 (23.2%)	0 (0.0%)	1 (0.2%)	10 (1.8%)	1 (0.2%)	19 (3.4%)	561 (100.0%)
4	490 (73.9%)	134 (20.2%)	2 (0.3%)	2 (0.3%)	13 (2.0%)	4 (0.6%)	18 (2.7%)	663 (100.0%)
5	798 (78.2%)	152 (14.9%)	6 (0.6%)	1 (0.1%)	20 (2.0%)	5 (0.5%)	38 (3.7%)	1020 (100.0%)
6	153 (81.0%)	27 (14.3%)	0 (0.0%)	0 (0.0%)	4 (2.1%)	1 (0.5%)	4 (2.1%)	189 (100.0%)
7	374 (73.0%)	80 (15.6%)	0 (0.0%)	1 (0.2%)	11 (2.1%)	1 (0.2%)	45 (8.8%)	512 (100.0%)
8	184 (68.1%)	64 (23.7%)	0 (0.0%)	0 (0.0%)	5 (1.9%)	1 (0.4%)	16 (5.9%)	270 (100.0%)
9	365 (71.7%)	110 (21.6%)	1 (0.2%)	2 (0.4%)	14 (2.8%)	6 (1.2%)	11 (2.2%)	509 (100.0%)
10	234 (71.6%)	75 (22.9%)́	1 (0.3%)	0 (0.0%)	6 (1.8%)	3 (0.9%)	8 (2.4%)	327 (100.0%)
11	227 (74.7%)	53 (17.4%)	0 (0.0%)	0 (0.0%)	8 (2.6%)	4 (1.3%)	12 (3.9%)	304 (100.0%)
Total	3956 (74.6%)	984 (18.6%)	13 (0.2%)	9 (0.2%)	116 (2.2%)	29 (0.5%)	193 (3.6%)	5300 (100.0%)



# **Review Board - Adult HCC**

In this section, a deeper looking into only those forms sent to the Adult HCC board is given.

#### Counts of exception forms by characteristic



#### Figure A4: Exception forms by diagnosis, adult HCC specialty board

Table A4: Exception forms by diagnosis, adult HCC specialty board

Month Form Submitted										
Exception Diagnosis	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total				
Hepatocellular carcinoma (HCC) Total	271 (100.0%) 271 (100.0%)	447 (100.0%) 447 (100.0%)	(	450 (100.0%) 450 (100.0%)	(	2039 (100.0%) 2039 (100.0%)				

There have been an average of 407.8 exception forms submitted to the Adult HCC board per week. The majority of these have been extension forms rather than initial exception applications.

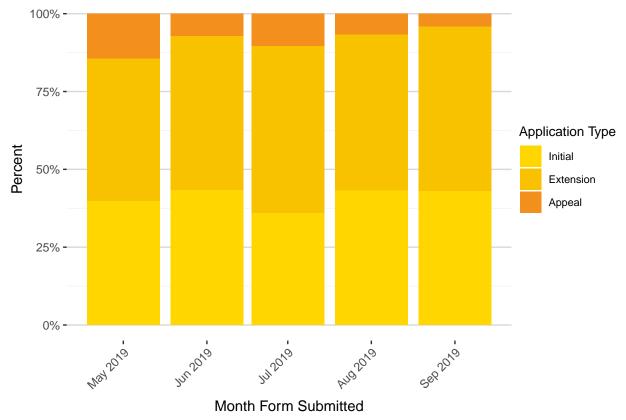


Figure A5: Exception forms by application type, adult HCC specialty board

Table A5: Number of exception forms by application type, adult HCC specialty board

Application Type	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total
Initial	108 (39.9%)	194 (43.4%)	180 (36.0%)	195 (43.3%)	160 (43.1%)	837 (41.0%)
Extension	124 (45.8%)	221 (49.4%)	268 (53.6%)	225 (50.0%)	196 (52.8%)	1034 (50.7%)
Appeal	39 (14.4%)	32 (7.2%)	52 (10.4%)	30 (6.7%)	15 (4.0%)	168 (8.2%)
Total	271 (100.0%)	447 (100.0%)	500 (100.0%)	450 (100.0%)	371 (100.0%)	2039 (100.0%)

The regions with the most forms going to the Adult HCC board are regions 5, 3, and 4.

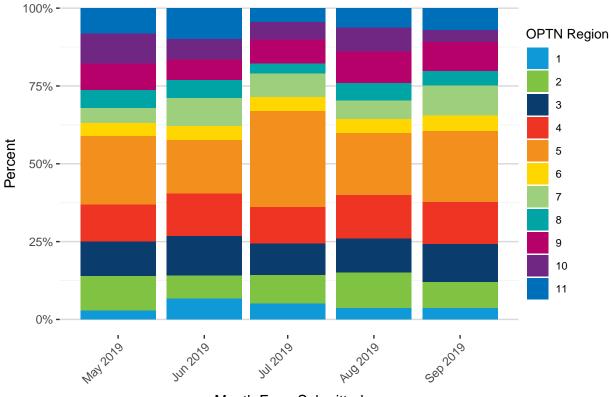


Figure A6: Exception forms by OPTN region of candidate's transplant center, adult HCC specialty board

Month Form Submitted

Table A6: Exception forms by OPTN region of candidate's transplant center, adult HCC specialty board

		Мо	nth Form Submi	tted		
OPTN Region	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total
1	8 (3.0%)	30 (6.7%)	26 (5.2%)	17 (3.8%)	14 (3.8%)	95 (4.7%)
2	30 (11.1%)	33 (7.4%)	46 (9.2%)	51 (11.3%)	31 (8.4%)	191 (9.4%)
3	30 (11.1%)	57 (12.8%)	50 (10.0%)	49 (10.9%)	45 (12.1%)	231 (11.3%)
4	32 (11.8%)	61 (13.6%)	59 (11.8%)	63 (14.0%)	50 (13.5%)	265 (13.0%)
5	60 (22.1%)	77 (17.2%)	154 (30.8%)	90 (20.0%)	85 (22.9%)	466 (22.9%)
6	11 (4.1%)	20 (4.5%)	23 (4.6%)	20 (4.4%)	18 (4.9%)	92 (4.5%)
7	13 (4.8%)	40 (8.9%)	37 (7.4%)	27 (6.0%)	36 (9.7%)	153 (7.5%)
8	16 (5.9%)	26 (5.8%)	16 (3.2%)	25 (5.6%)	17 (4.6%)	100 (4.9%)
9	23 (8.5%)	29 (6.5%)	39 (7.8%)	46 (10.2%)	35 (9.4%)	172 (8.4%)
10	26 (9.6%)	30 (6.7%)	28 (5.6%)	34 (7.6%)	14 (3.8%)	132 (6.5%)
11	22 (8.1%)	44 (9.8%)	22 (4.4%)	28 (6.2%)	26 (7.0%)	142 (7.0%)
Total	271 (100.0%)	447 (100.0%́)	500 (100.0%)́	450 (100.0%́)	371 (100.0%)́	2039 (100.0%)



In the below figure, exception request forms that are "Submitted to Review Board" or "Pending" are excluded to provide a more uniform comparison of approval and denial proportions over time. Forms withdrawn prior to decision are also excluded.

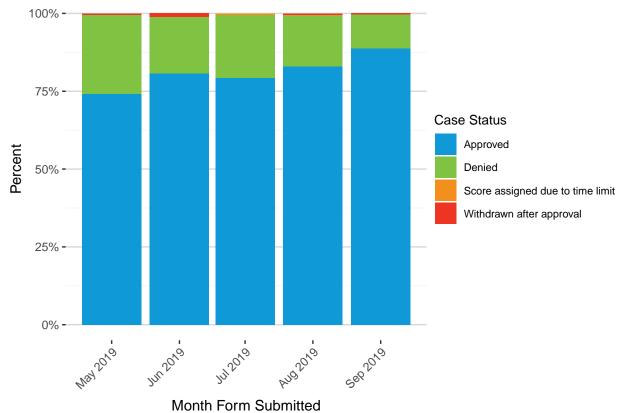


Figure A7: Number of exception forms by status/outcome type, adult HCC specialty board

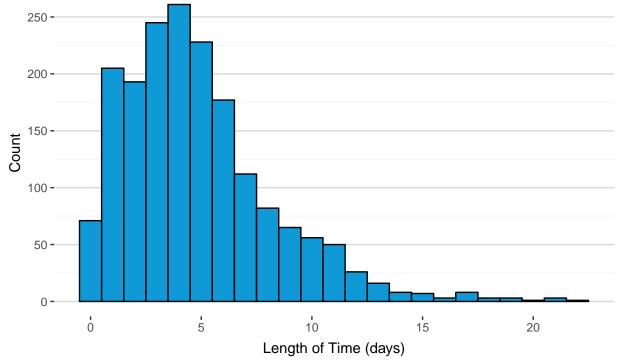
Table A7: Number of exception forms by status/outcome type, adult HCC specialty board

Case Status	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total
Approved	196 (72.3%)	352 (78.7%)	392 (78.4%)	368 (81.8%)	252 (67.9%)	1560 (76.5%)
Denied	67 (24.7%)	79 (17.7%)	100 (20.0%)	72 (16.0%)	31 (8.4%)	349 (17.1%)
Score assigned due to time limit	0 (0.0%)	0 (0.0%)	2 (0.4%)	1 (0.2%)	0 (0.0%)	3 (0.1%)
Submitted to Review Board	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	71 (19.1%)	71 (3.5%)
Withdrawn after approval	1 (0.4%)	5 (1.1%)	0 (0.0%)	2 (0.4%)	1 (0.3%)	9 (0.4%)
Withdrawn prior to decision Total	7 (2.6%) 271 (100.0%)	11 (2.5%) 447 (100.0%)	6 (1.2%) 500 (100.0%)	7 (1.6%) 450 (100.0%)	16 (4.3%) 371 (100.0%)	47 (2.3%) 2039 (100.0%)

#### **Adjudication Time**

The overall time for form adjudication is described below for initial and extension exception forms sent to the Adult HCC board, in number of days from application date to NLRB decision date. Note that this cannot exceed 21 days, as forms that are not adjudicated in this timeframe are automatically assigned the requested score due to exceeding the time limit. Initial and extension exception request forms, excluding those withdrawn prior to decision, are included. Exception requests that are currently submitted to the NLRB, but not yet adjudicated, are removed due to missing process time.

# Figure A8: Total Process time (Application Date to NLRB Decision Date) for initial and extension exception forms in days, adult HCC specialty board



There were N=118 forms removed due to missing process time. N=68 forms were submitted under Regional Review Boards and adjudicated by the NLRB.

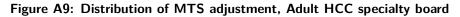
Table A8:	Summary	of	process	time	for	initial	and	extension	exception	forms	in days,	adult	HCC
specialty be	oard												

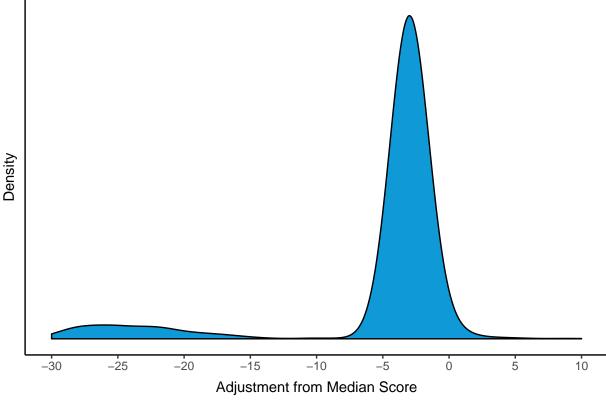
Month Form Submitted	Minimum	Q25	Mean	Median	Q75	Maximum
2019-04-01	13.81	16.96	18.42	20.11	20.72	21.34
2019-05-01	0.02	1.85	4.66	4.19	6.52	14.97
2019-06-01	0.05	2.27	4.81	4.08	6.12	18.08
2019-07-01	0.02	2.45	4.75	4.09	6.07	21.38
2019-08-01	0.06	2.90	5.21	4.38	6.98	21.56
2019-09-01 Total	0.04 0.02	2.27 2.35	4.64 4.86	4.10 4.14	6.14 6.28	13.96 21.56
Iotal	0.02	2.35	4.80	4.14	0.28	21.50



#### **Distribution of Adjustments**

This section provides an understanding of the scores that are being requested through the review board process, relative to median scores. In general, the majority of scores are MMaT - 3, with some between MMaT - 2 and MMaT - 0. or MPaT - 0. The adjustments of -28 to -15 tend to correspond to low requested scores of 6 to 10. In this section, only forms that go the Adult HCC board for review are included.





There were N=893 forms that are not median score-adjusted.

Table A9: Summary of MTS adjustment, Adult HCC specialty board

Review Board Minimum		Mean	Median	Maximum	
1146	-29	-5.1	-3	9	

While the large majority (47.9%) of exception forms request a score that is 3 below the median, 1.9% of forms request scores above this.

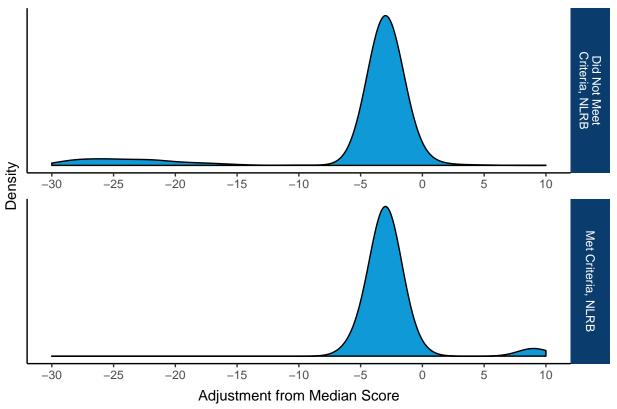


Figure A10: Distribution of MTS adjustment by policy criteria met/auto-approval, Adult HCC specialty board

There were N=893 forms that are not median score-adjusted.

Table A10:	Summary of MTS	adjustment by policy	criteria met/auto-approval,	Adult HCC specialty
board				

Policy Criteria, Auto-Approval Status	Ν	Minimum	Mean	Median	Maximum
Did Not Meet Criteria, NLRB	1123	-29	-5.2	-3	5
Met Criteria, NLRB	23	-5	-2.5	-3	9

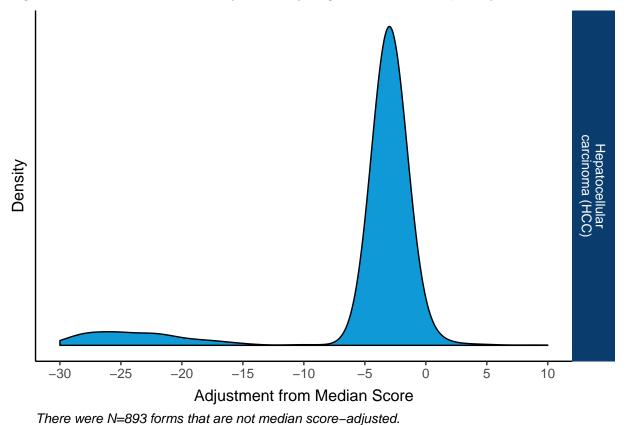
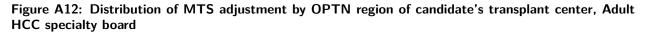
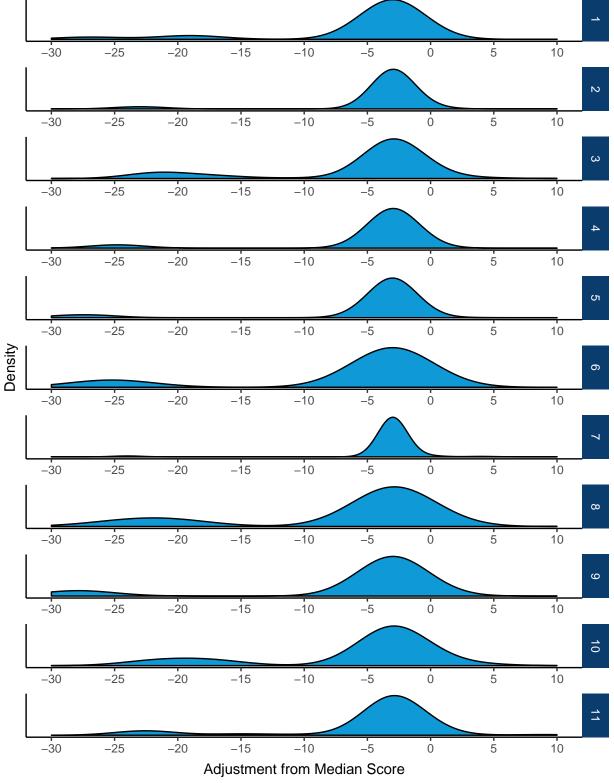


Figure A11: Distribution of MTS adjustment by diagnosis, Adult HCC specialty board

Diagnosis	Ν	Minimum	Mean	Median	Maximum
Hepatocellular carcinoma (HCC)	1146	-29	-5.1	-3	9





There were N=893 forms that are not median score-adjusted.

OPTN Region	Ν	Minimum	Mean	Median	Maximum
1	61	-27	-5.5	-3	-3
2	101	-24	-4.1	-3	0
3	106	-22	-5.7	-3	5
4	125	-26	-4.7	-3	-1
5	299	-29	-5.1	-3	2
6	57	-26	-6.5	-3	-3
7	93	-24	-3.3	-3	4
8	49	-25	-6.8	-3	0
9	123	-28	-6.0	-3	0
10	57	-22	-5.9	-3	4
11	75	-23	-4.9	-3	9

Table A12: Summary of MTS adjustment by OPTN region of candidate's transplant center, Adult HCC specialty board

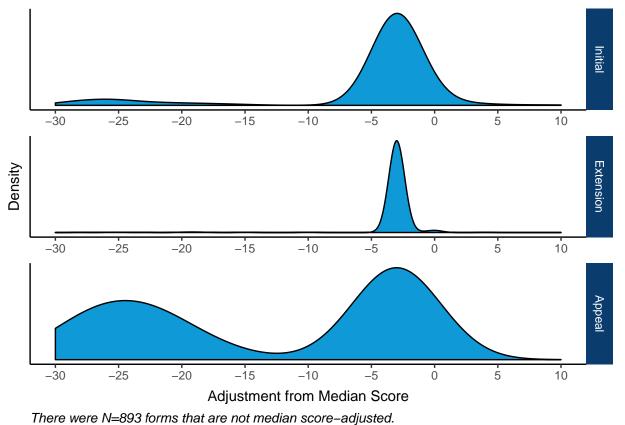


Figure A13: Distribution of MTS adjustment by application type, Adult HCC specialty board

Table A13: Summary of MTS adjustment by application type, Adult HCC specialty board

Application Type	Ν	Minimum	Mean	Median	Maximum
Initial	280	-29	-5.1	-3	9
Extension	698	-28	-3.3	-3	4
Appeal	168	-29	-13.1	-3	-1



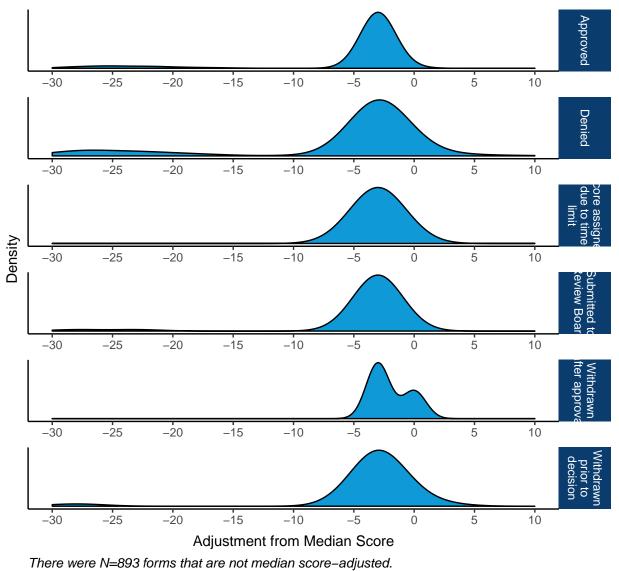


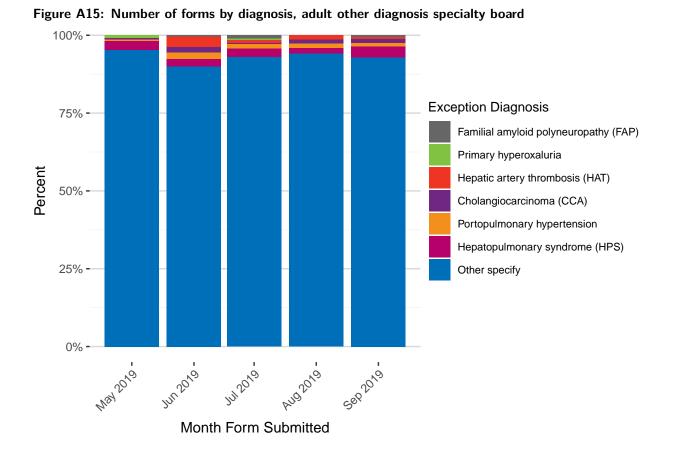
Figure A14: Distribution of MTS adjustment by status/outcome type, Adult HCC specialty board

Table A14: Summary of MTS adjustment by status/outcome type, Adult HCC specialty board

Case Status	Ν	Minimum	Mean	Median	Maximum
Approved	854	-29	-5.1	-3	0
Denied	215	-29	-5.9	-3	9
Score assigned due to time limit	2	-3	-3.0	-3	-3
Submitted to Review Board	42	-28	-4.1	-3	-3
Withdrawn after approval	6	-3	-2.0	-3	0
Withdrawn prior to decision	27	-28	-3.6	-3	2

## **Review Board - Adult Other Diagnosis**

'Other specify' diagnosis accounts for over 90% of the exception request forms sent to the Adult Other Diagnosis board.



#### Counts of exception forms by characteristic

 Table A15: Number of forms by diagnosis, adult other diagnosis specialty board

Exception Diagnosis	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total
Familial amyloid polyneuropathy (FAP)	0 (0.0%)	1 (0.3%)	3 (1.0%)	0 (0.0%)	1 (0.6%)	5 (0.4%)
Primary hyperoxaluria	2 (0.9%)	0 (0.0%)	1 (0.3%)	0 (0.0%)	0 (0.0%)	3 (0.3%)
Hepatic artery thrombosis (HAT)	0 (0.0%)	10 (3.5%)	3 (1.0%)	3 (1.3%)	1 (0.6%)	17 (1.4%)
Cholangiocarcinoma (CCA)	1 (0.5%)	5 (1.7%)	1 (0.3%)	3 (1.3%)	2 (1.2%)	12 (1.0%)
Portopulmonary hypertension	1 (0.5%)	6 (2.1%)	4 (1.4%)	3 (1.3%)	2 (1.2%)	16 (1.3%)́
Hepatopulmonary syndrome (HPS)	6 (2.8%)	7 (2.4%)	8 (2.8%)	4 (1.8%)	6 (3.6%)	31 (2.6%)
Other specify	208 (95.4%)	260 (90.0%)	268 (93.1%)	212 (94.2%)	156 (92.9%)	1104 (92.9%
Total	218 (100.0%)	289 (100.0%)	288 (100.0%)	225 (100.0%)	168 (100.0%)	1188 (100.0%



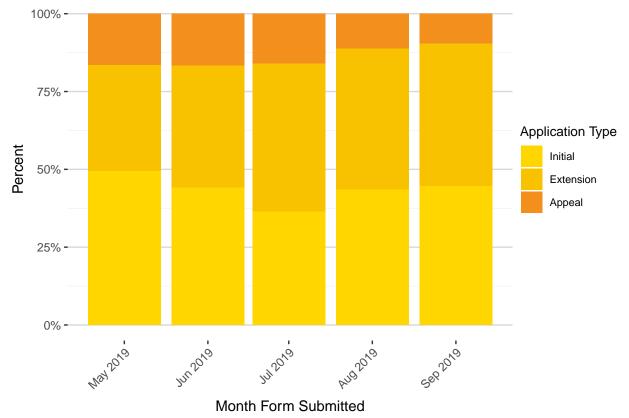
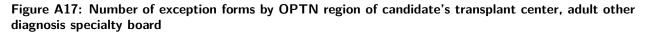


Figure A16: Number of exception forms by application type, adult other diagnosis specialty board

Table A16: Number of exception forms by application type, adult other diagnosis specialty board

Month Form Submitted								
Application Type	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total		
Initial	108 (49.5%)	128 (44.3%)	105 (36.5%)	98 (43.6%)	75 (44.6%)	514 (43.3%)		
Extension	74 (33.9%)	113 (39.1%)	137 (47.6%)	102 (45.3%)	77 (45.8%)	503 (42.3%)		
Appeal	36 (16.5%)	48 (16.6%)	46 (16.0%)	25 (11.1%)	16 (9.5%)	171 (14.4%)		
Total	218 (100.0%)	289 (100.0%)	288 (100.0%)	225 (100.0%)	168 (100.0%)	1188 (100.0%)		

The regions most contributing to exception forms sent to the Adult Other Diagnosis board are regions 5, 7, 9, and 3. Of note, it was discovered during the week of May 21, 2019 that there was a systematic discrepancy in median scores for transplant programs within the LAOP, MAOB, MNOP, and NJTO donor service areas (DSA) when based on median MELD within 250 nautical miles of a transplant center. Because of this, disadvantaged centers particularly in region 7 submitted exception requests to the NLRB for requested scores equivalent to those at the higher-score transplant programs within their DSA. The basis for median MELD scores was changed on Friday, May 24, 2019 after receiving approval from HRSA and the OPTN Executive Committee to median MELD within the DSA of a transplant center, a consideration in line with allocation units being used. The majority of these exception request forms were subsequently withdrawn following this change, given that the discrepancy and inequity was rectified.



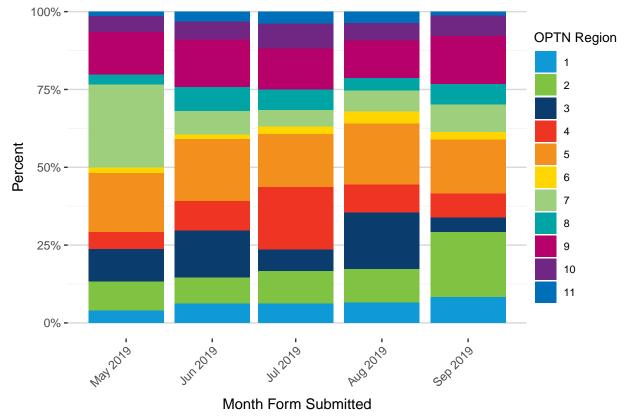


Table A17: Number of exception forms by OPTN region of candidate's transplant center, adult other diagnosis specialty board

	Month Form Submitted								
OPTN Region	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total			
1	9 (4.1%)	18 (6.2%)	18 (6.2%)	15 (6.7%)	14 (8.3%)	74 (6.2%)			
2	20 (9.2%)	24 (8.3%)	30 (10.4%)	24 (10.7%)	35 (20.8%)	133 (11.2%)			
3	23 (10.6%)	44 (15.2%)	20 (6.9%)	41 (18.2%)	8 (4.8%)	136 (11.4%)			
4	12 (5.5%)	27 (9.3%)	58 (20.1%)	20 (8.9%)	13 (7.7%)	130 (10.9%)			
5	41 (18.8%)	58 (20.1%)	49 (17.0%)	44 (19.6%)	29 (17.3%)	221 (18.6%)			
6	4 (1.8%)	4 (1.4%)	7 (2.4%)	9 (4.0%)	4 (2.4%)	28 (2.4%)			
7	58 (26.6%)	22 (7.6%)	15 (5.2%)	15 (6.7%)	15 (8.9%)	125 (10.5%)			
8	7 (3.2%)	22 (7.6%)	19 (6.6%)	9 (4.0%)	11 (6.5%)	68 (5.7%)			
9	30 (13.8%)	44 (15.2%)	38 (13.2%)	27 (12.0%)	26 (15.5%)	165 (13.9%)			
10	11 (5.0%)	17 (5.9%)	23 (8.0%)	13 (5.8%)	11 (6.5%)	75 (6.3%)			
11	3 (1.4%)	9 (3.1%)	11 (3.8%)	8 (3.6%)	2 (1.2%)	33 (2.8%)			
Total	218 (100.0%)	289 (100.0%)	288 (100.0%)	225 (100.0%)	168 (100.0%)	1188 (100.0%)			



In the below figure, exception request forms that are "Submitted to Review Board" or "Pending" are excluded to provide a more uniform comparison of approval and denial proportions over time. Forms withdrawn prior to decision are also excluded.

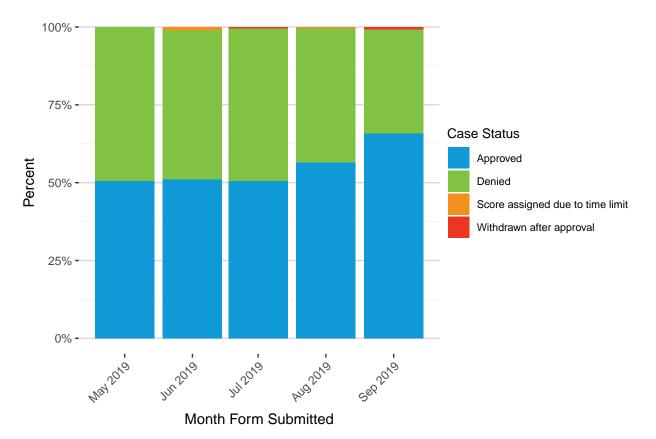


Figure A18: Number of exception forms by status/outcome type, adult other diagnosis specialty board

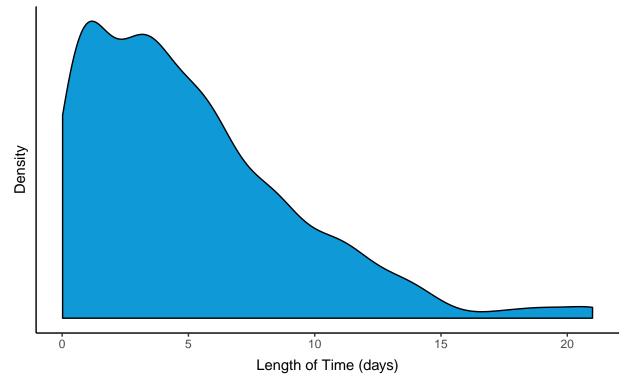
Table A18: Number of exception forms by status/outcome type, adult other diagnosis specialty board

Case Status	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total
Approved	93 (42.7%)	142 (49.1%)	143 (49.7%)	124 (55.1%)	85 (50.6%)	587 (49.4%)
Denied	91 (41.7%)	133 (46.0%)	139 (48.3%)	94 (41.8%)	43 (25.6%)	500 (42.1%)
Score assigned due to time limit	0 (0.0%)	3 (1.0%)	0 (0.0%)	1 (0.4%)	0 (0.0%)	4 (0.3%)
Submitted to Review Board	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	31 (18.5%)	31 (2.6%)
Withdrawn after approval	0 (0.0%)	0 (0.0%)	1 (0.3%)	0 (0.0%)	1 (0.6%)	2 (0.2%)
Withdrawn prior to decision	34 (15.6%)	11 (3.8%)	5 (1.7%)	6 (2.7%)	8 (4.8%)	64 (5.4%)
Total	218 (100.0%)	289 (100.0%)	288 (100.0%)	225 (100.0%)	168 (100.0%)	1188 (100.0%)

#### **Adjudication Time**

The time for form adjudication is described below for inital and extension exception forms reviewed by the Adult Other Diagnosis board, in number of days from application date to NLRB decision date. Note that this cannot exceed 21 days, as forms that are not adjudicated in this timeframe are automatically assigned the requested score due to exceeding the time limit. Initial and extension exception request forms, excluding those withdrawn prior to decision, are included.

Figure A19: Total Process time (Application Date to NLRB Decision Date) for initial and extension exception forms in days, adult other diagnosis specialty board



There were N=95 forms that have not been fully reviewed and removed due to missing process time.

Table A19: Summary of process time for initial and extension exception forms in days, adult other diagnosis specialty board

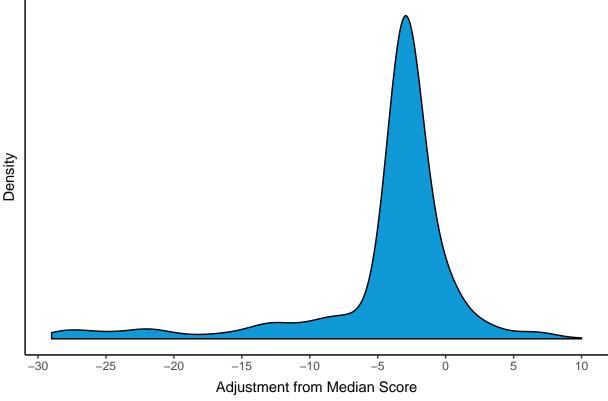
Month Form Submitted	Minimum	Q25	Mean	Median	Q75	Maximum
2019-04-01	13.84	15.69	18.07	18.69	20.35	21.61
2019-05-01	0.04	2.03	5.90	5.26	8.81	21.56
2019-06-01	0.02	1.20	4.65	3.09	7.13	21.44
2019-07-01	0.04	1.94	4.58	3.86	6.18	19.95
2019-08-01	0.07	2.80	5.53	4.78	7.32	21.40
2019-09-01	0.05	1.76	4.11	3.43	5.76	15.12



#### **Distribution of Adjustments**

This section provides an understanding of the scores that are being requested through the review board process, relative to median scores. In general, the majority of scores are MMaT - 3, with some between MMaT - 2 and MMaT - 0. The adjustments of -28 to -15 tend to correspond to low requested scores of 6 to 10. In this section, only forms that go the Adult Other Diagnosis board for review are included.

Figure A20: Distribution of MTS adjustment, Adult Other Diagnosis specialty board



There were N=20 forms that are not median score-adjusted.

Review Board	Minimum	Mean	Median	Maximum
1168	-29	-4.4	-3	10

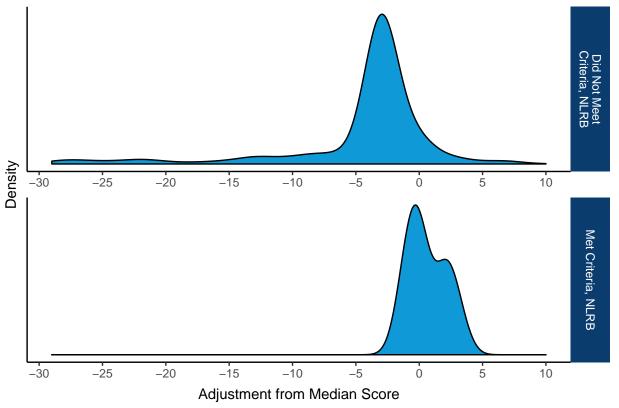


Figure A21: Distribution of MTS adjustment by policy criteria met/auto-approval, Adult Other Diagnosis specialty board

There were N=20 forms that are not median score-adjusted.

Table A21: Summary of MTS adjustment by policy criteria met/auto-approval, Adult Other Diagnosis
specialty board

Policy Criteria, Auto-Approval Status	Ν	Minimum	Mean	Median	Maximum
Did Not Meet Criteria, NLRB	1160	-29	-4.5	-3	10
Met Criteria, NLRB	8	-1	0.6	0	3

Note that the scales on the y-axis to the left of each panel differ by diagnosis in the graph below.

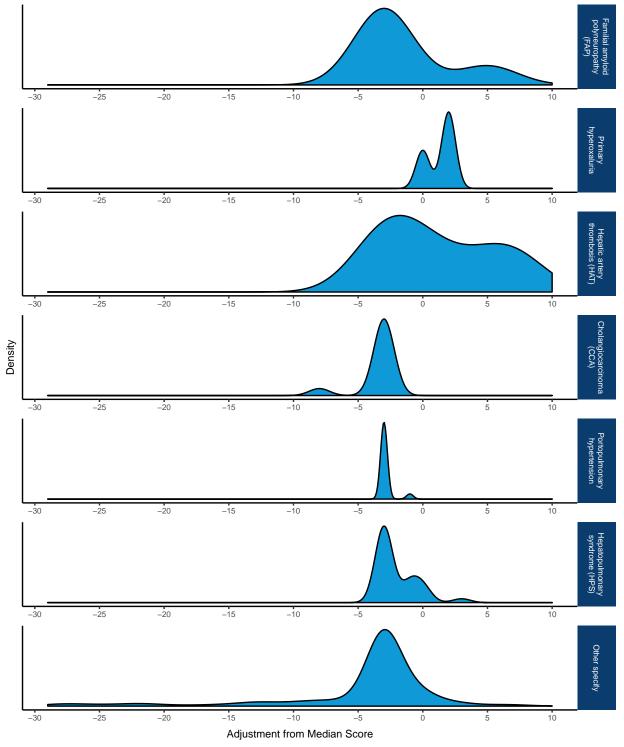


Figure A22: Distribution of MTS adjustment by diagnosis, Adult Other Diagnosis specialty board

There were N=20 forms that are not median score-adjusted.

Diagnosis	Ν	Minimum	Mean	Median	Maximum
Familial amyloid polyneuropathy (FAP)	5	-3	-1.4	-3	5
Primary hyperoxaluria	3	0	1.3	2	2
Hepatic artery thrombosis (HAT)	8	-3	1.1	0	7
Cholangiocarcinoma (CCA)	12	-8	-3.4	-3	-3
Portopulmonary hypertension	16	-3	-2.9	-3	-1
Hepatopulmonary syndrome (HPS) Other specify	30 1094	-3 -29	-2.1 -4.6	-3 -3	3 10

# Table A22: Summary of MTS adjustment by diagnosis, Adult Other Diagnosis specialty board



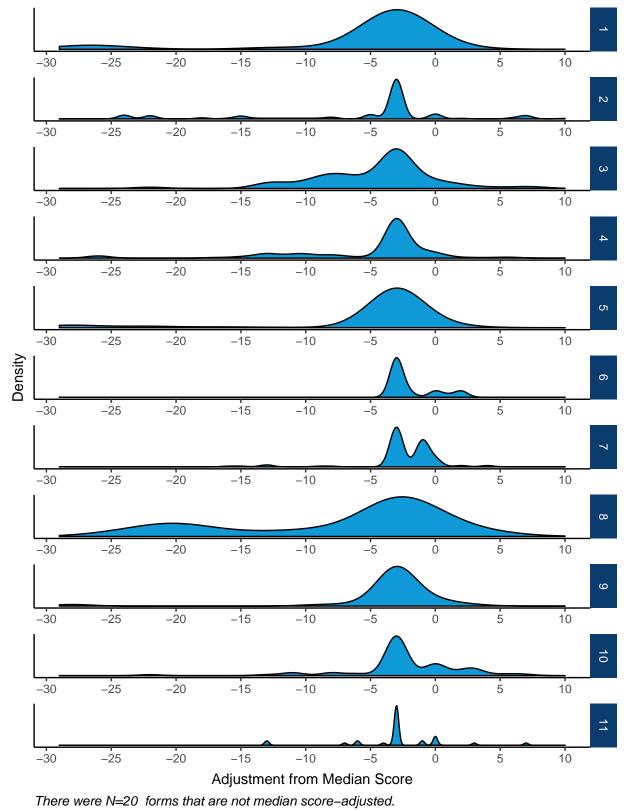
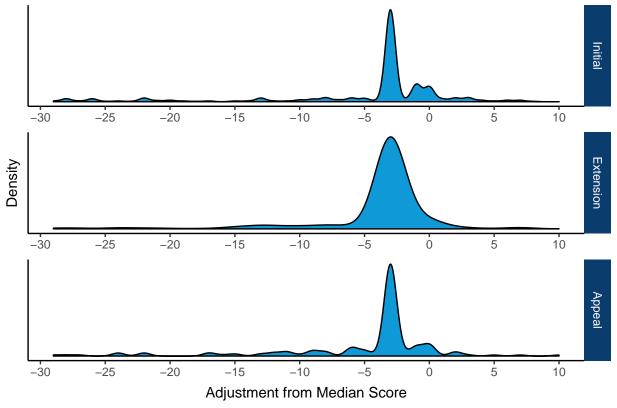


Figure A23: Distribution of MTS adjustment by OPTN region of candidate's transplant center, Adult Other Diagnosis specialty board

OPTN Region	Ν	Minimum	Mean	Median	Maximum
1	74	-27	-5.5	-3	3
2	131	-24	-5.5	-3	10
3	131	-22	-4.6	-3	8
4	126	-26	-5.1	-3	6
5	217	-29	-5.1	-3	3
6	28	-3	-1.9	-3	2
7	123	-16	-2.4	-3	4
8	67	-25	-7.2	-3	5
9	164	-28	-3.5	-3	3
10	75	-22	-2.5	-3	7
11	32	-13	-3.0	-3	7

Table A23: Summary of MTS adjustment by OPTN region of candidate's transplant center, Adult Other Diagnosis specialty board



# Figure A24: Distribution of MTS adjustment by application type, Adult Other Diagnosis specialty board

There were N=20 forms that are not median score-adjusted.

Application Type	Ν	Minimum	Mean	Median	Maximum
Initial	498	-29	-4.7	-3	8
Extension	501	-29	-4.0	-3	7
Appeal	169	-29	-5.0	-3	10

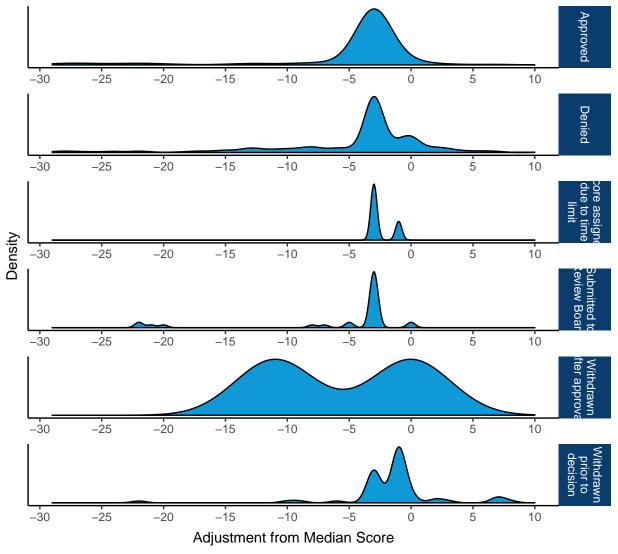


Figure A25: Distribution of MTS adjustment by status/outcome type, Adult Other Diagnosis specialty board

There were N=20 forms that are not median score-adjusted.

Table A25:	Summary of MTS	adjustment by	status/outcome	type,	Adult	Other	Diagnosis	specialty
board								

Case Status	Ν	Minimum	Mean	Median	Maximum
Approved	582	-29	-4.6	-3.0	7
Denied	487	-29	-4.5	-3.0	10
Score assigned due to time limit	4	-3	-2.5	-3.0	-1
Submitted to Review Board	31	-22	-5.6	-3.0	0
Withdrawn after approval	2	-11	-5.5	-5.5	0
Withdrawn prior to decision	62	-22	-1.5	-1.0	8

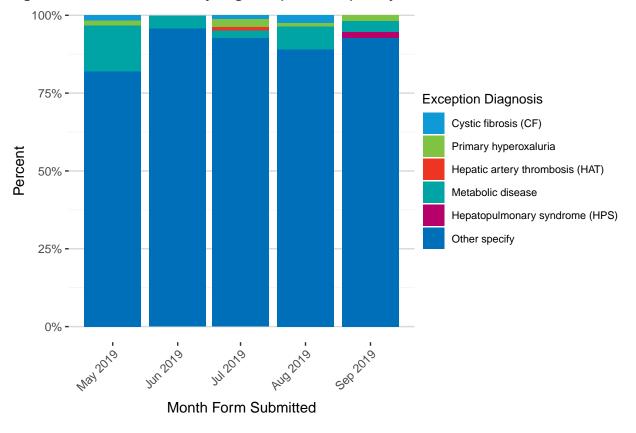
**OP** 

# **Review Board - Pediatrics**

Note that MELD and PELD exception requests for pediatric candidates less than 18 years old are reviewed by this specialty board.

#### Counts of exception forms by characteristic

Most exception forms sent to the Pediatrics board are for 'Other specify' diagnoses. The Pediatrics board has seen the smallest volume of exception request forms of the three specialty boards thus far.



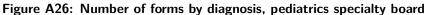


Table A26: Number of forms by diagnosis, pediatrics specialty board

Exception Diagnosis	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total
Cystic fibrosis (CF)	1 (1.6%)	0 (0.0%)	1 (1.2%)	2 (2.4%)	0 (0.0%)	4 (1.1%)
Primary hyperoxaluria	1 (1.6%)	0 (0.0%)	2 (2.4%)	1 (1.2%)	1 (1.8%)	5 (1.4%)
Hepatic artery thrombosis (HAT)	0 (0.0%)	0 (0.0%)	1 (1.2%)	0 (0.0%)	0 (0.0%)	1 (0.3%)
Metabolic disease	9 (14.8%)	3 (4.2%)	2 (2.4%)	6 (7.2%)	2 (3.6%)	22 (6.2%)
Hepatopulmonary syndrome (HPS)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.8%)	1 (0.3%)
Other specify Total	50 (82.0%) 61 (100.0%)	69 (95.8%) 72 (100.0%)	77 (92.8%) 83 (100.0%)	74 (89.2%) 83 (100.0%)	52 (92.9%) 56 (100.0%)	322 (90.7%) 355 (100.0%)

Just under one third of exception request forms reviewed by the Pediatrics board are for adolescent (aged 12-17 years) candidates.

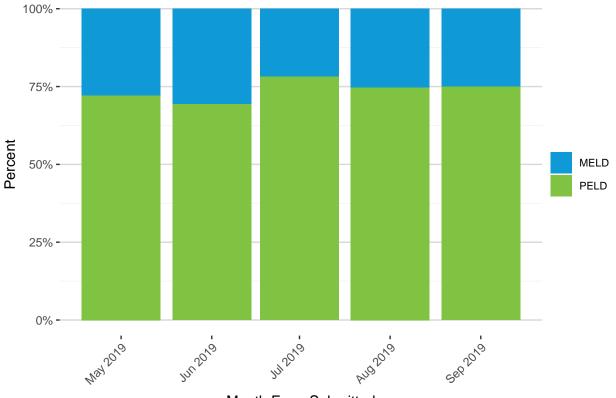


Figure A27: Number of exception forms by MELD or PELD form type, pediatrics specialty board

Month Form Submitted

Table A27: Number of exception forms by MELD or PELD form type, pediatrics specialty board

		Mor	nth Form Submi	tted		
MELD or PELD Form	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total
MELD	17 (27.9%)	22 (30.6%)	18 (21.7%)	21 (25.3%)	14 (25.0%)	92 (25.9%)
PELD	44 (72.1%)	50 (69.4%)	65 (78.3%)	62 (74.7%)	42 (75.0%)	263 (74.1%)
Total	61 (100.0%)	72 (100.0%)	83 (100.0%)	83 (100.0%)	56 (100.0%)	355 (100.0%)

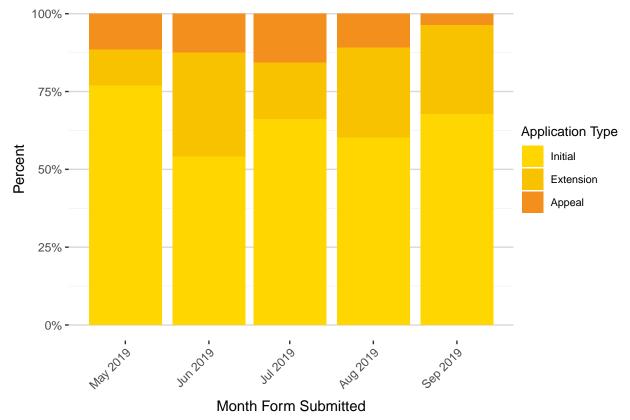


Figure A28: Number of exception forms by application type, pediatrics specialty board

Table A28: Number of exception forms by application type, pediatrics specialty board

		Mor	th Form Submi	tted		
Application Type	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total
Initial	47 (77.0%)	39 (54.2%)	55 (66.3%)	50 (60.2%)	38 (67.9%)	229 (64.5%)
Extension	7 (11.5%)	24 (33.3%)	15 (18.1%)	24 (28.9%)	16 (28.6%)	86 (24.2%)
Appeal	7 (11.5%)	9 (12.5%)	13 (15.7%)	9 (10.8%)	2 (3.6%)	40 (11.3%)
Total	61 (100.0%)	72 (100.0%)	83 (100.0%)	83 (100.0%)	56 (100.0%)	355 (100.0%)

The largest proportions of exception forms submitted to the Pediatrics board were from regions 2, 4, 3, and 5.

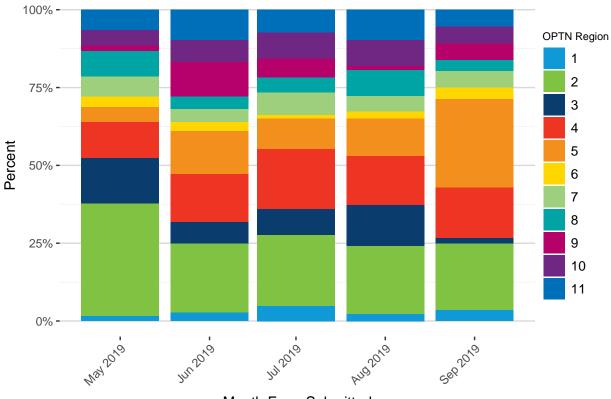


Figure A29: Number of exception forms by OPTN region of candidate's transplant center, pediatrics specialty board

Month Form Submitted

Table A29: Number of exception forms by OPTN region of candidate's transplant center, pediatrics specialty board

		Mor	nth Form Subm	itted		
OPTN Region	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total
1	1 (1.6%)	2 (2.8%)	4 (4.8%)	2 (2.4%)	2 (3.6%)	11 (3.1%)
2	22 (36.1%)	16 (22.2%)	19 (22.9%)	18 (21.7%)	12 (21.4%)	87 (24.5%)
3	9 (14.8%)	5 (6.9%)	7 (8.4%)	11 (13.3%)	1 (1.8%)	33 (9.3%)
4	7 (11.5%)	11 (15.3%)	16 (19.3%)	13 (15.7%)	9 (16.1%)	56 (15.8%)
5	3 (4.9%)	10 (13.9%)	8 (9.6%)	10 (12.0%)	16 (28.6%)	47 (13.2%)
6	2 (3.3%)	2 (2.8%)	1 (1.2%)	2 (2.4%)	2 (3.6%)	9 (2.5%)
7	4 (6.6%)	3 (4.2%)	6 (7.2%)	4 (4.8%)	3 (5.4%)	20 (5.6%)
8	5 (8.2%)	3 (4.2%)	4 (4.8%)	7 (8.4%)	2 (3.6%)	21 (5.9%)
9	1 (1.6%)	8 (11.1%)	5 (6.0%)	1 (1.2%)	3 (5.4%)	18 (5.1%)
10	3 (4.9%)	5 (6.9%)	7 (8.4%)	7 (8.4%)	3 (5.4%)	25 (7.0%)
11	4 (6.6%)	7 (9.7%)	6 (7.2%)	8 (9.6%)	3 (5.4%)	28 (7.9%)
Total	61 (100.0%)	72 (100.0%)	83 (100.0%)	83 (100.0%)	56 (100.0%)	355 (100.0%)

In the below figure, exception request forms that are "Submitted to Review Board" or "Pending" are excluded to provide a more uniform comparison of approval and denial proportions over time. Forms withdrawn prior to decision are also excluded.

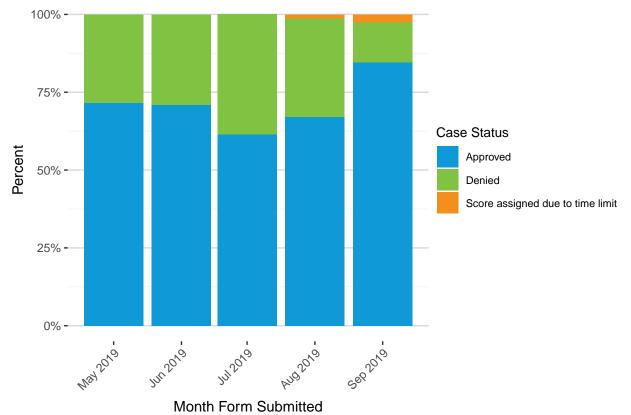


Figure A30: Number of exception forms by status/outcome type, pediatrics specialty board

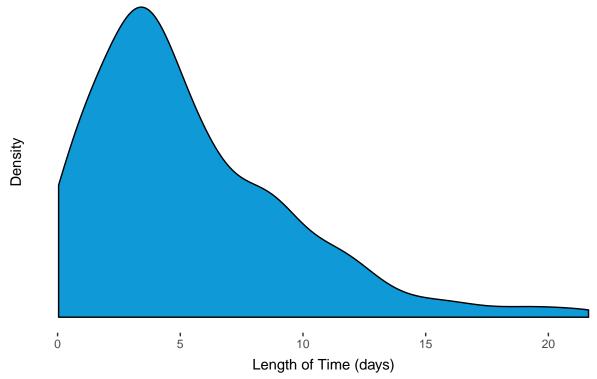
Table A30: Number of exception forms by status/outcome type, pediatrics specialty board

		Mor	nth Form Subm	itted		
Case Status	May 2019	Jun 2019	Jul 2019	Aug 2019	Sep 2019	Total
Approved	43 (70.5%)	49 (68.1%)	51 (61.4%)	53 (63.9%)	33 (58.9%)	229 (64.5%)
Denied	17 (27.9%)	20 (27.8%)	32 (38.6%)	25 (30.1%)	5 (8.9%)	99 (27.9%)
Score assigned due to time limit	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.2%)	1 (1.8%)	2 (0.6%)
Submitted to Review Board	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	14 (25.0%)	14 (3.9%)
Withdrawn prior to decision	1 (1.6%)	3 (4.2%)	0 (0.0%)	4 (4.8%)	3 (5.4%)	11 (3.1%)
Total	61 (100.0%)	72 (100.0%)	83 (100.0%)	83 (100.0%)	56 (100.0%)	355 (100.0%)

#### **Adjudication Time**

The time for form adjudication is described below for inital and extension exception forms reviewed by the Pediatrics board, in number of days from application date to NLRB decision date. Note that this cannot exceed 21 days, as forms that are not adjudicated in this timeframe are automatically assigned the requested score due to exceeding the time limit. Initial and extension exception request forms, excluding those withdrawn prior to decision, are included. Exception requests that are currently submitted to the NLRB, but not yet adjudicated, are removed due to missing process time.

Figure A31: Total Process time (Application Date to NLRB Decision Date) for initial and extension exception forms in days, pediatrics specialty board



There were N=24 forms removed due to missing process time.

Table A31:	Summary	of	process	time	for	initial	and	extension	exception	forms	in	days,	pediatrics
specialty bo	ard												

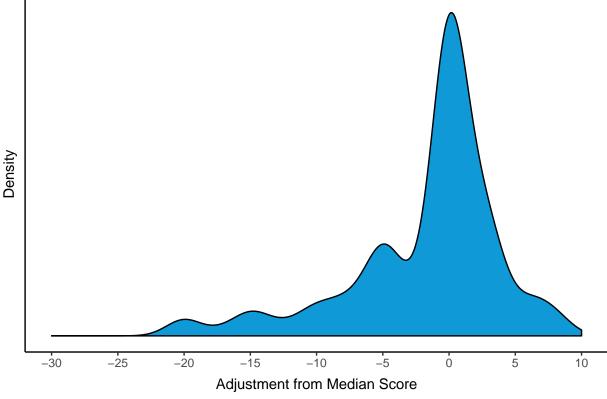
Month Form Submitted	Minimum	Q25	Mean	Median	Q75	Maximum
2019-05-01	0.04	3.00	5.57	4.88	8.54	16.18
2019-06-01	0.09	2.91	5.51	4.35	6.88	19.09
2019-07-01	0.04	2.17	4.51	3.82	6.15	15.73
2019-08-01	0.10	2.86	6.03	4.16	8.18	21.64
2019-09-01	0.17	2.18	5.26	4.14	6.73	21.33
Total	0.04	2.42	5.38	4.18	7.93	21.64



#### **Distribution of Adjustments**

This section provides an understanding of the scores that are being requested through the review board process, relative to median scores. In general, the majority of scores are MPaT - 0, but there are more adjustments that are higher than the median than below. In this section, only forms that go the Pediatrics board for review are included.





There were N=100 forms that are not median score-adjusted.

### Table A32: Summary of MTS adjustment, Pediatrics specialty board

Ν	Minimum	Mean	Median	Maximum
255	-20	-1.7	0	8

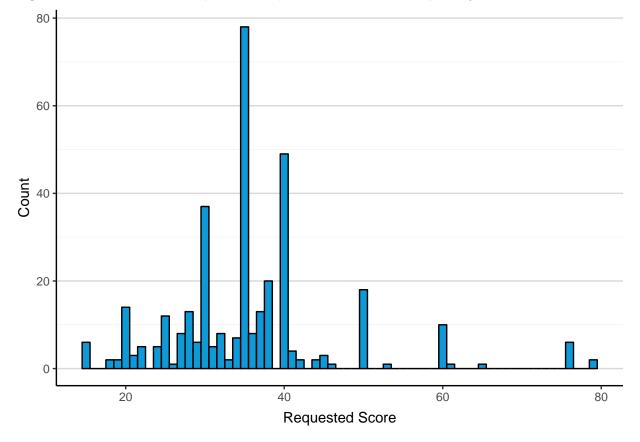


Figure A33: Distribution of requested exception scores, Pediatrics specialty board



N	Minimum	Mean	Median	Maximum
355	15	35.7	35	79



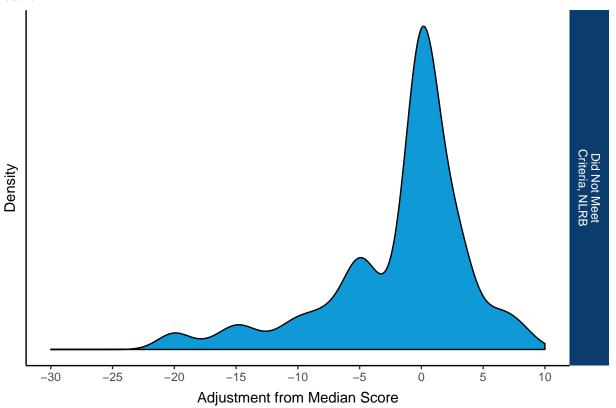


Figure A34: Distribution of MTS adjustment by policy criteria met/auto-approval, Pediatrics specialty board

There were N=100 forms that are not median score-adjusted.

Table A34: Summary of MTS adjustment by policy criteria met/auto-approval, Pediatrics specialty board

Policy Criteria, Auto-Approval Status	Ν	Minimum	Mean	Median	Maximum
Did Not Meet Criteria, NLRB	255	-20	-1.7	0	8

Note that the scales on the y-axis to the left of each panel differ by diagnosis in the graph below.

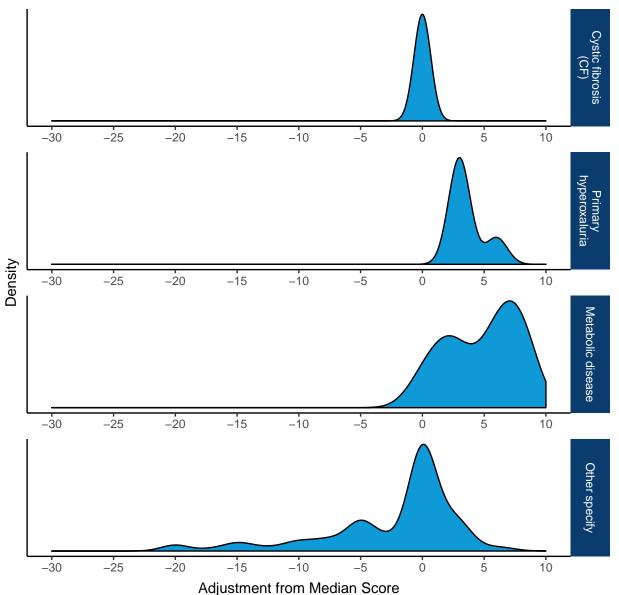


Figure A35: Distribution of MTS adjustment by diagnosis, Pediatrics specialty board

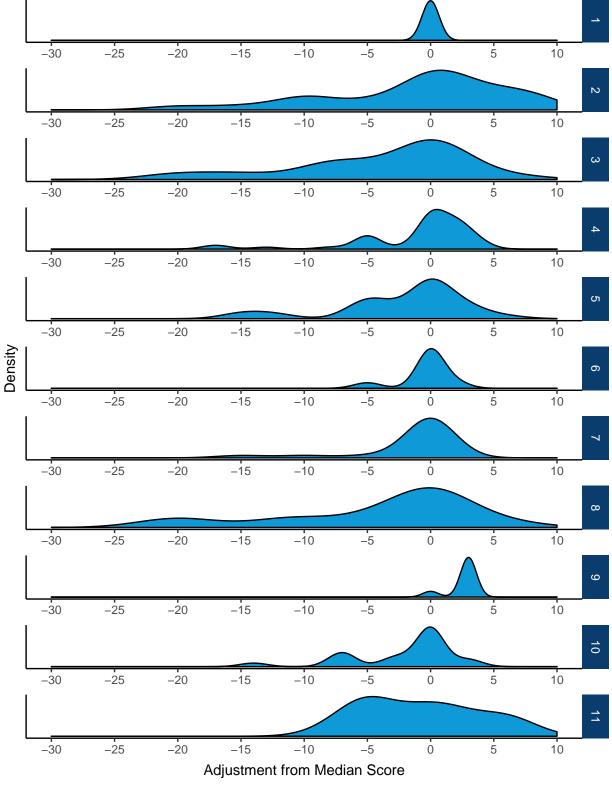
There were N=100 forms that are not median score-adjusted. Groups with < 2 observations are dro

Table A35: Summary of MTS adjustment by diagnosis, Pediatrics specialty board

Diagnosis	Ν	Minimum	Mean	Median	Maximum
Cystic fibrosis (CF)	4	0	0.0	0	0
Primary hyperoxaluria	5	3	3.6	3	6
Hepatic artery thrombosis (HAT)	1	0	0.0	0	0
Metabolic disease	21	0	4.9	6	8
Hepatopulmonary syndrome (HPS)	1	-5	-5.0	-5	-5
Other specify	223	-20	-2.5	0	7







There were N=100 forms that are not median score-adjusted.

OPTN Region	Ν	Minimum	Mean	Median	Maximum
1	4	0	0.0	0	0
2	50	-20	-1.3	0	8
3	27	-20	-4.0	0	7
4	46	-17	-1.1	0	4
5	33	-15	-2.3	0	6
6	9	-5	-0.3	0	2
7	20	-15	-1.5	0	0
8	15	-20	-4.2	0	6
9	8	0	2.6	3	3
10	21	-14	-2.1	0	3
11	22	-8	-0.8	0	7

Table A36: Summary of MTS adjustment by OPTN region of candidate's transplant center, Pediatrics specialty board

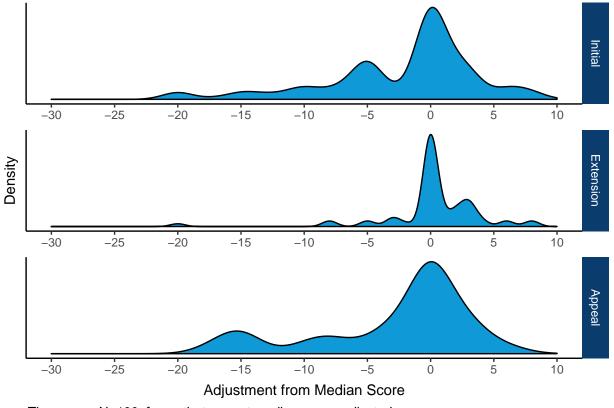
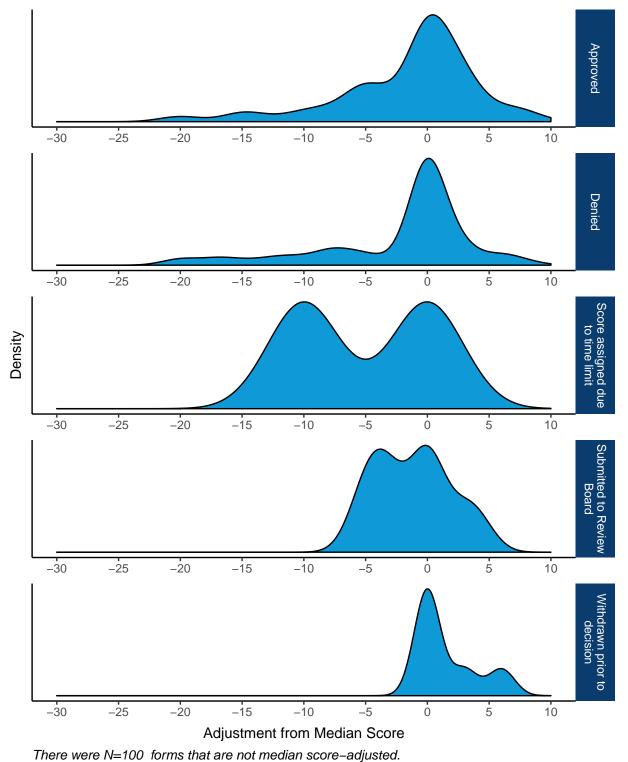
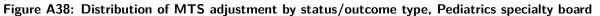


Figure A37: Distribution of MTS adjustment by application type, Pediatrics specialty board

There were N=100 forms that are not median score-adjusted.

Application Type	Ν	Minimum	Mean	Median	Maximum
Initial	163	-20	-2.3	0	8
Extension	63	-20	0.2	0	8
Appeal	29	-17	-2.9	0	6





## Table A38: Summary of MTS adjustment by status/outcome type, Pediatrics specialty board

Case Status	Ν	Minimum	Mean	Median	Maximum
Approved	174	-20	-1.6	0	8
Denied	62	-20	-2.4	0	8
Score assigned due to time limit	2	-10	-5.0	-5	0
Submitted to Review Board	11	-5	-1.2	0	4
Withdrawn prior to decision	6	0	1.5	0	6