

# Comparing Pretransplant and Posttransplant Outcomes When Choosing a Transplant Center: Focus Groups and a Randomized Survey

## **Supplemental Materials: Methods**

### **Qualitative Methods**

Dedoose coding software (Dedoose, Hermosa Beach, CA) was used to organize data and identify supporting quotations. Descriptive statistics for focus group participants were calculated stratified by organ type and by local/national site (Table 1).

### **Quantitative Methods**

Descriptive statistics for survey data were calculated for all randomized respondents and for the analysis set (Table 3).

### **Power calculation**

Based on an effect size of 0.15 (consistent with pilot studies<sup>1</sup> and similar health care quality reports<sup>2</sup>), we estimated that a sample size of 1100 (183 in each arm) achieved 80% power to detect a difference between groups.

### **Estimation of relative risks**

Statistical analysis used R, version 3.5.2 (<https://www.R-project.org/>). Multinomial regression used nnet package version 7.3-12.<sup>3</sup> Data management used dplyr version 0.7.8.<sup>4</sup>

The analysis includes both the difference in relative risks and marginal relative risks.

The difference in relative risks captures the effect of the different graphical elements on the relative risks compared to the control presentation. Unfortunately, the differences in relative risks is unable to determine which hospital has the larger probability. Thus, the marginal relative risks illustrate whether, for example, Lake Hospital is more likely to be selected than Meadow Hospital under the impact statement.

### Overview of multinomial regression

Multinomial regression estimates the log-linear probability of selecting Meadow Hospital ( $H = M$ ) or Lake Hospital ( $H = L$ ) relative to Alpine Hospital ( $H = A$ ). Let  $I$ ,  $U$ ,  $T$ , and  $R$  be indicators for, respectively, the impact statement, uncertainty statement, data table, and identifying risks on the waiting list as greater than the risks after transplant. The model was specified as

$$\ln \frac{P(H = l|I, U, T, R)}{P(H = A|I, U, T, R)} = \beta_0^{(l)} + \beta_I^{(l)} \times I + \beta_U^{(l)} \times U + \beta_T^{(l)} \times T + \beta_R^{(l)} \times R,$$

where  $l = \{M, L\}$  for Meadow and Lake Hospital, respectively.

### Hospital-specific probabilities

The conditional probability of selecting, e.g., Lake Hospital after viewing only the impact statement for a respondent that identified risks on the waiting list as greater than after transplant was

$$P(H = L|I = 1, U = 0, T = 0, R = 0) = \frac{\exp\{\beta_0^{(L)} + \beta_I^{(L)}\}}{1 + \exp\{\beta_0^{(L)} + \beta_I^{(L)}\} + \exp\{\beta_0^{(M)} + \beta_I^{(M)}\}}.$$

The marginal probability of selecting, e.g., Lake Hospital after viewing the impact statement was estimated through iterative expectation. Specifically,

$$P(H = L|I = 1) = E\{I[H = L]|I = 1\} = E_{U,T,R|I=1}E\{I[H = L]|I = 1, U, T, R\}.$$

This was further simplified because the inner expectation of an indicator function, e.g.,  $I[H = L]$ , is a probability

$$P(H = L|I = 1) = E_{U,T,R|I=1}P(H = L|I = 1, U, T, R),$$

which was estimated by following the above illustration for hospital-specific conditional probabilities.

### Marginal relative risks

The marginal relative risk of selecting, e.g., Lake Hospital versus Meadow Hospital when viewing the impact statement was  $P(H = L|I = 1)/P(H = M|I = 1)$ . The 95% confidence intervals for the marginal relative risks were estimated with 2.5 and 97.5 quantiles of a nonparametric bootstrap distribution from 2,000 iterations.

## **Supplemental Materials: Tables and Figures**

**Table S1:** Focus Group Discussion Guide Questions. Not All Questions are Related to Analysis of Choosing a Center Based on Viewing a Mockup

Preliminary Discussion Questions Not Included in Analysis	
1.	What information do you remember learning about different transplant centers?
2.	What options were you told about before getting a referral to a center?
3.	Have you done any research about centers on your own [e.g. internet, support groups]?
4.	[If yes] What did you learn?
5.	What centers did you consider?
6.	[If several] Did you compare any of them? How did you compare them?
7.	[If several] What was most important in comparing them?
8.	What could be done to help make choosing a transplant center easier?
Questions Related to Choosing a Center Based on Viewing a Mockup	
1.	Based on what's shown on the screen, if you were to make a hypothetical choice for your own center, which center would you choose?
2.	What is your reason?

**Table S2:** Full text of survey questions and response options

Question	Response options
<b>Q1:</b> What is your age?	[Text entry field]
<b>Q2:</b> What is your gender?	Male; Female
<b>Q3:</b> What is your highest level of education in years?	9; 10; 11; 12 Completed High School; 13; 14; 15; 16 Completed Undergraduate degree; 17+ Graduate Studies
<b>Q4:</b> Have you ever needed or received an organ or other transplant?	Yes; No
<b>Q5:</b> Have any family members or friends ever needed or received an organ or other transplant?	Yes; No
<b>Q6:</b> An organ transplant, e.g. kidney or liver, is a major surgical procedure, and complications can occur after the transplant, including organ rejection. In addition, there is a potential shortage of organ donors. Unfortunately, some patients have declining health and die before receiving a transplant due to long waits. Select the choice below you believe is correct.	The risk of death is greater due to complications after transplant than due to waiting too long.; The risk of death is greater due to waiting too long than due to complications after transplant.; The risks are about the same.
<b>Introduction text:</b> The following page will display a small portion of a website specifically for patients who need an organ transplant. Even if you are not familiar with this procedure, your understanding of the information will be similar to many patients who are often faced with learning a great deal of complex, new information.	
You will see a comparison of different transplant centers (also called a "program"). This would be one way you could learn about options and decide where to go.	
Some images show information that would be displayed after clicking "See more detail". On the real site, you might see less detail at first.	
Read this as if you were learning about a hospital for a medical procedure.	
[View randomly assigned image]	
<b>Q7:</b> Hypothetically, what hospital would you choose for a transplant based on the information shown?	Lake Hospital; Alpine Hospital; Meadow Hospital
<b>Q8:</b> What was the most important factor in the decision?	Distance; Transplants in a Year; Survival On The Waitlist; Getting a Transplant Faster; One Year Organ Survival; No single factor was most important
<b>Q9:</b> Some transplant centers do not transplant living donors. This question is a test whether or not you are reading carefully. You must answer none of the above.	I do not believe living donor transplants would apply to me.; I believe the living donor transplants would apply to me.; I am not familiar with what these terms mean.; None of the above
<b>Q10:</b> Briefly describe any information that you do not understand. If you understand everything, list something you would like to learn more about to help make a decision.	[Text entry field]

**Table S3:** Factorial design of graphical elements added to each search tool mockup that was randomly assigned to survey participants. Descriptions include the #[image number]: “[Shorthand name]”.

Graphical elements	None	Data Table
None	#1: “Control”	#4: “Data table”
Uncertainty statement	#2: “Uncertainty statement”	#5: “Data table and uncertainty statement”
Impact statement	#3: “Impact statement”	#6: “Data table and impact statement”

**Table S4:** Additional quotations illustrating main themes of focus groups

Organ Type	Theme 1: Outcome metrics have uncertainty relative to individual experiences.	Theme 2: Patients, in particular candidates, describe a focus on posttransplant outcomes.	Theme 3: Individual circumstances factor into decisions.
Kidney	<p><i>"What were the issues after transplant that the survival was better or worse? Is the other question ... Was it kidney rejection or was it the patient didn't follow the protocols?" [Local kidney candidate]</i></p> <p><i>"So it may or may not affect me in particular, or it may, or how do I know?" [National kidney recipient]</i></p> <p><i>"Your survival and your wait list, that's more the individual than the center and care." [National kidney recipient]</i></p>	<p><i>"I would sacrifice a longer wait for survival risk." [Local kidney candidate]</i></p> <p><i>"Well, what's the sense of moving up quickly if you don't survive afterwards?" [Local kidney candidate]</i></p> <p><i>"I mean, you know, quite honestly, I would automatically be leaning towards getting on that list quickly, but, you know, I also understand the importance of making it more than a year after doing that." [Local kidney candidate]</i></p>	<p><i>"I have a friend that's going to be a living donor, so whether to me or to the swap per donation. And so my concern now at 63 years old would be survival." [National kidney recipient]</i></p> <p><i>"I think it provides a source of information with which you can create an interaction and conversation. I think it really is so individual in each individual circumstance as to how deep they're going to want to go. I think this is helpful." [Local kidney candidate]</i></p> <p><i>"I think the longer that I have been on dialysis the more my perspective on transplant changes. Where at one point I might have been willing to wait, I do not [go to the best survival]. Give me that top one [with best transplant rate]." [Local kidney candidate]</i></p>
Liver	<p><i>"They tell you, oh you're number, like I'm number one on the Hope Act, but if somebody else gets cleared and they need it more desperately than I do, and I'm still in good shape, then number one doesn't mean jack. It's kind of like, well, how long am I really going to be waiting? So yeah, it's the uncertainty." [Local liver candidate]</i></p> <p><i>"That's like childbirth, are you going to give birth around the kind of time they tell you?" [Local liver candidate]</i></p> <p><i>"The standard deviation is just so high for the patients so that if they put like maybe six months here and then someone ends up waiting three years for</i></p>	<p><i>"But the way I am reading this s it stands, I would say that Meadow would be my pick because you may not get it as quickly, but your graft rate is going to be better. So if you get it quickly and you graft rate is down, as it would be at Lake, than you are better off to go to Meadow." [National liver recipient]</i></p> <p><i>"I think to fairly [weigh] that, you have to already been to your hepatologist. I don't know, I didn't know how long, you're already in before you, at least to the clinic end before that's a fair chart. I would read it at face value and go for probably higher survival rate even though it might kill me. That would be my personal reaction." [Local liver candidate]</i></p>	<p><i>"I think risk from long waits is something you have to know your risks from your doctor and weigh them... you never know if they are very low risk and you can afford to wait, like me, or if you're high risk, you're going to go to the head of the line right away." [Local liver candidate]</i></p> <p><i>"I mean, it depends on who you are. For instance, if I know I'm a little bit healthier, I don't mind waiting if I know that my one year survival is going to be better. But if I feel like I don't have much time, then I don't really care about after transplant. I just want to get the liver now and then feel like I could take some of that into my hands so I would be okay with Lake Hospital." [National liver recipient]</i></p>

	<i>it, it's to be less direct in terms of the metrics." [National liver recipient]</i>	<i>"I'd rather go somewhere I can get a transplant and get on the path to being healthier rather than waiting ages and then having a better outcome but what if I never get it. So in that case, I would pick Lake Hospital." [National liver recipient]</i>	<i>'It depends on where you are and how many centers are in your region." [National liver recipient]</i>
Heart	<p><i>"Well, people dying on the waitlist is an unnecessary knock against the hospital; it could be a variety of reasons why it's happening." [Local heart candidate]</i></p> <p><i>"[The list of metrics] doesn't really help you make a decision. Because a lot of the factors are out of your control. You don't have any input on that. You can only modify so much from your personal perspective." [National heart recipient]</i></p>	<p><i>"Chance at surviving in that first year. But my experience was since I had the VAD for 16 months and I know people who had a VAD even longer, that's why I chose Meadow because it was like as long as I can stay where I'm at and I'm not getting any worse, then I can wait at a conservative hospital like Meadow probably." [National heart recipient]</i></p> <p><i>I think most people on the list. I mean, you don't get on a heart transplant list in the one category unless you're super sick. The last statistic I heard, it was something like to move to the top of the list, you need a two week life expectancy. We have all been on the cusp of the cusp of the cusp. I think we all want it as fast as possible." [National heart recipient]</i></p> <p><i>"And once I get it, I'm going to live longer if I go with Meadow [highest 1 year organ survival]. I agree 100% with him. I'd take the chance of being proactive while I was on the waitlist doing everything you can because we do have an impact on how long we stay on the waitlist. You know, diet, exercise, mental, spiritual and there's a whole bunch of things, family support that go into surviving while you're on the waitlist. It's not just the machine and you." [National heart recipient]</i></p>	<i>"A waitlist survival ... that might not apply to you, because you—say you got an LVAD and you're doing well... For each individual, you might pick something different because of the situation." [Local heart candidate]</i>
Lung	<i>"Survival on the waitlist, what, exactly, does that mean? Is it because they didn't get the lungs on time, or is it because there wasn't pre care available? I think</i>	<i>"We might be biased in this room about the one-year lung survival, because it—from this vantage point, it is the most important thing, but when you are trying to suck air and you</i>	<i>"I know my first transplant I was totally focused on survival rate. I knew I had some time. But then when I was retransplanted there wasn't much time. In fact, they were worried that I</i>



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*that there is not enough—this is very general; there is not enough specific information for you to make a decision.”*  
*[National lung recipient]*

*are on so much oxygen—you know, you just want it now. You want relief now. So... I am not sure you know, yeah, I would agree, Meadow would be better from where I am sitting now.”* *[National lung recipient]*

*would even live to the second transplant.”*  
*[National lung recipient]*

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**Table S5.** Characteristics of kidney, liver, heart, and lung transplant candidate populations on the waiting list as of July 1, 2017

	Local candidates				National candidates			
	Kidney UMN	Kidney HHS	Liver UMN	Heart UMN	Kidney	Liver	Heart	Lung
Number of candidates	328	75	72	55	33,987	7,126	3,023	3,023
Age; mean (sd)	52 (13)	51 (13)	56 (9)	54 (12)	52 (13)	56 (11)	54 (12)	54 (12)
Sex; n (%)								
Male	192 (59%)	45 (60%)	43 (60%)	39 (71%)	20,620 (61%)	4,604 (65%)	2,064 (68%)	2,064 (68%)
Race; n (%)								
Black	37 (11%)	19 (25%)	7 (10%)	3 (5%)	10,209 (30%)	541 (8%)	623 (21%)	623 (21%)
White	256 (78%)	37 (49%)	61 (85%)	48 (87%)	20,653 (61%)	6,164 (87%)	2,296 (76%)	2,296 (76%)
Other	35 (11%)	19 (25%)	4 (6%)	4 (7%)	3,125 (9%)	421 (6%)	104 (3%)	104 (3%)
Education; n (%)								
Less than High school	10 (3%)	4 (5%)	3 (4%)	1 (2%)	2,045 (6%)	442 (6%)	87 (3%)	87 (3%)
High school	104 (32%)	33 (44%)	19 (26%)	17 (31%)	1,2836 (38%)	2,755 (39%)	1,151 (38%)	1,151 (38%)
At least some college	153 (47%)	31 (41%)	37 (51%)	31 (56%)	1,4822 (44%)	3,012 (42%)	1,413 (47%)	1,413 (47%)
Graduate education	26 (8%)	4 (5%)	1 (1%)	2 (4%)	2,865 (8%)	543 (8%)	250 (8%)	250 (8%)
Missing	35 (11%)	3 (4%)	12 (17%)	4 (7%)	1,419 (4%)	374 (5%)	122 (4%)	122 (4%)
Primary payer; n (%) *								
Private	188 (57%)	44 (59%)	41 (57%)	28 (51%)	14,601 (43%)	3,801 (53%)	1,499 (50%)	1,499 (50%)
Medicare	80 (24%)	24 (32%)	10 (14%)	22 (40%)	15,758 (46%)	1,849 (26%)	1,051 (35%)	1,051 (35%)
Medicaid	51 (16%)	7 (9%)	20 (28%)	4 (7%)	2,742 (8%)	1,139 (16%)	375 (12%)	375 (12%)
Other	9 (3%)	0 (0%)	1 (1%)	1 (2%)	879 (3%)	337 (5%)	97 (3%)	97 (3%)
Missing	0 (0%)	0 (0%)	0 (0%)	0 (0%)	7 (0%)	0 (0%)	1 (0%)	1 (0%)
Has had previous transplant, n (%)	68 (21%)	11 (15%)	0 (0%)	3 (5%)	4,376 (13%)	221 (3%)	59 (2%)	24 (1%)

**Table S6.** The change in the relative risk for selecting Alpine Hospital or Lake Hospital compared to Meadow Hospital between respondents with the given characteristics. For example, the relative probability of selecting Lake Hospital over Meadow Hospital was 57% higher for respondents who indicated that the risk of complications were greater on the waiting list compared to respondents who indicated that the risk of complications after transplant were similar or worse than on the waiting list. Parentheses contain the 95% confidence interval.

Selected program	Dominant metric	Age (per 10 years)	Male	Reference is graduate degree		Needed or received a transplant (respondent, friend, or family)	Risk is greater on waiting list
				High school or less	Some College		
		Survey Question 1	Survey Question 2	Survey Question 3		Survey Questions 4 or 5	Survey Question 6
Alpine Hospital	Waitlist survival	0.94 (0.81-1.10)	1.08 (0.74-1.56)	1.79 (0.87-3.66)	1.28 (0.78-2.09)	1.63 (1.10-2.42)	0.74 (0.51-1.07)
Lake Hospital	Transplant rate	0.96 (0.85-1.08)	0.98 (0.73-1.31)	1.15 (0.66-2.02)	0.84 (0.60-1.19)	1.28 (0.93-1.77)	1.57 (1.17-2.10)

**Table S7:** Proportion of participants in the analysis set selecting each factor as the most important in a decision after viewing a randomly assigned search tool mockup.

Most important factor	Responses to Question #8 for each search tool mockup [What was the most important factor in the decision?]					
	#1: Control	#2: Uncertainty statement	#3: Impact statement	#4: Data table	#5: Data table and uncertainty statement	#6: Data table and impact statement
Distance	0%	2%	3%	7%	4%	6%
Getting A Transplant Faster	27%	27%	39%	21%	25%	34%
No single factor was most important	15%	18%	14%	16%	17%	16%
One Year Organ Survival	44%	36%	31%	39%	36%	22%
Survival On The Waitlist	11%	13%	10%	14%	13%	19%
Transplants In A Year	4%	4%	3%	2%	4%	3%

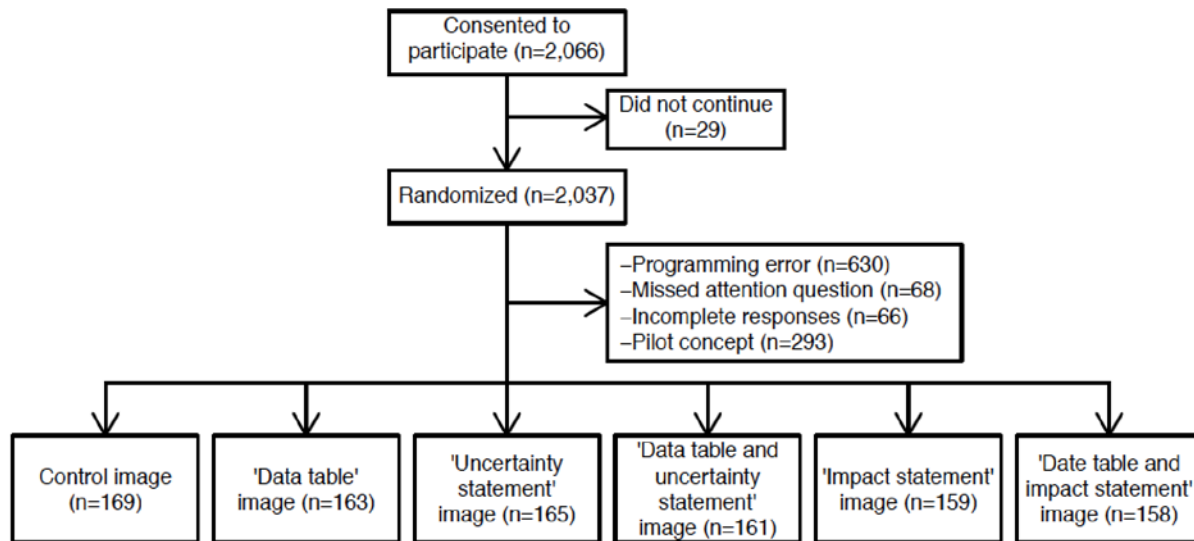


Figure S1: Consort diagram for quantitative phase, randomized survey enrollment. Programming error refers to the first survey distribution when a second image was inadvertently displayed after the final survey question. A missed attention question refers to Question #9 that was included to check attention to detail.

## References

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