Deconstructing silos of knowledge around lung transplantation – Supplemental Materials

Contents

Appendix: Study Methods, Results and Table / Figure Legends

Quantitative Methods

This study used outcomes data from the SRTR. The SRTR data system includes data on all donors, wait-listed candidates, and transplant recipients in the US, submitted by the members of the Organ Procurement and Transplantation Network (OPTN). The Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services provides oversight to the activities of the OPTN and SRTR contractors.

We first evaluated the variability in patient and donor characteristics that may impact access to transplant in the US, using data between July 1, 2017 and June 30, 2019. Clinical and demographic factors were first identified following consultation with transplant pulmonologists (M.H and M.V) and a transplant physician (A.I). The list of characteristics shown on prototype images was expanded to include candidate and donor characteristics that varied across programs. Programs were grouped by the total number of transplants performed over the 2-year period: as small (≤ 39), medium (40 - 79), or large (≥ 80). Each group included 18, 21, and 24 programs, respectively. Categories were consistent with presentations by the International Society of Heart and Lung Transplantation (ISHLT).

Quantitative Analysis

Chi-squared tests were conducted to compare characteristics across lung transplant programs and this analysis was carried out using SAS version 9.4 (SAS Institute, Cary, NC USA). Results were considered significant for $p<0.05$.

Qualitative Methods

This report includes a lung transplant-analysis of a study of multiple solid-organ groups (e.g. heart, kidney, liver, and lung). All organ[1] and organ specific analyses of the interviews and focus groups with kidney, heart and liver transplant patients have been published elsewhere.[2–5] The Institutional Review Boards at the University of Minnesota—Fairview (M-HEALTH) and Hennepin Healthcare (HHS) approved the investigation and the study remains compliant to the Istanbul Declaration. All participating patients and family members provided written consent. To contribute to the understanding of the lung transplant patient experience, researchers combined qualitative data from local and national samples (see Table S1 for focus group questions). Feedback from participants informed the information displayed and interactive features on the patient-specific search tool. For examples of the mock profile entry page used in study sessions see Figure S1. See **Tables S1-2** for more detail on the qualitative procedures.

Qualitative Analysis

Analysts (W.M., C.S. and M.B.) utilized Dedoose version 8.2.32 coding software (Los Angeles, CA: SocioCultural Research Consultants, LLC) to code and categorize narrative excerpts to facilitate the analysis of participant feedback. Transcripts were open- and axially-coded through an exploratory strategy that prioritized participants' feedback and reflections on past experiences and decision making.[6,7] Focus group transcripts were analyzed at the group level.[8] To counter analyst bias in the exploratory approach, analysts began by working independently, followed by detailed discussion of identified codes. Based on the disciplinary backgrounds of the analysts (Sociology, Engineering and Human Factors, and Social Science and Research Ethics respectively) a variety of terms were independently used to define codes for similar concepts. Through discussion, analysts discovered consensus at the conceptual level and settled on a vocabulary to label concepts, resulting in 82 codes. All transcripts and excerpts were then reexamined to ensure consistency in code applications.

Themes were identified and elaborated by W.M. following a review of the 519 excerpts and later verified by M.B., C.S., and A.I. Quotations are included below to support the explanation of concepts and relationships.

Results

Variations in Recipient and Donor Characteristics Between Transplant Programs

Clinical recipient characteristics of 5,167 lung transplants between July 1, 2017 and June 30, 2019 are reported in Table S3.Variations in select recipient and donor characteristics exist across differently sized programs (all with $p<0.05$). For instance, the distributions by age of recipient varied significantly ($p<0.001$). Programs of all sizes performed transplants on patients over age 65 (roughly 35% of all transplants), and every large program (80 or more transplants in two years) performed over 21 transplants over two years with this recipient characteristic (Figure S2). For age over 70 however, many programs did not perform transplants in such patients. Similar distributions emerged for body mass index (BMI), with greater limitations around the high (≥ 35) and low (≤ 18) extremes. Programs also varied in the treatment of patients with prior non-transplant lung surgeries (approximately 4.5% of all transplants); with over a 30% of large programs performing zero transplant on patients with prior non-transplant lung procedures. Candidates with these characteristics were present on the waiting list (Table S4).

When considering the utilization of Public Health Service (PHS) Increased Risk Donors (28% of transplants)—now designated "risk criteria present" donors--we saw comparable variation across programs of different sizes ($p<0.001$) (Figure S3). Access to novel therapies such as ex-vivo lung perfusion (4.6% of all transplants) remained highly variable, with many large programs performing zero perfused donor transplants and other large programs performing over 21 in the two year period ($p<0.001$). Similar restrictions exist for access to donor lungs recovered following cardiac death (DCD) (roughly 4.4% of all transplants) and the use of Hepatitis C positive (HCV+) donors for HCV negative (HCV-) recipients (4.17 % of all transplants).

Descriptive Characteristics of Study Participants

Participants included two lung transplant candidates from the UMN-Fairview program and 20 national recipients. Demographic and clinical characteristics are listed in Table S5. Participants reported a range of comorbid diagnoses including hypertension, diabetes, and kidney disease. Interstitial lung disease was the most common indication for transplant.

Thematic Synthesis

Focus group and interview participants revealed a range of experiences related to healthcare decision making, patient education, and anxieties over accessing the waiting list and receiving a transplant. Participants highlighted gaps in knowledge and limited access to resources that support patients. Feedback on mockups of the patient-specific search was generally positive and included suggestions for how the tool could improve decision making and provider interactions. Two themes emerged from reflections on experiences of making transplant decisions and prototype feedback(see Table S6 for excerpts).

Theme 1: Patients experience multiple and compounding anxieties while making decisions about transplant care

1a) Patients experience anxieties over eligibility

Nearly all focus group and interview participants described anxiety when making decisions about where to seek a waitlist evaluation. Candidates and recipients perceived variations between transplant program acceptance criteria and struggled to estimate the likelihood that they would be added to waiting lists. Many described fears that they would be too old or that comorbidities and additional clinical need would make them ineligible for transplant (e.g. high BMI, multi-organ candidate). Participants also described concerns for being “too healthy” to be on a waiting list and challenges when determining which program would consider their transplant needs sufficiently urgent. These anxieties were compounded by the limited availability of resources that communicate differences in acceptance criteria and the composition of specific waiting lists. However, multiple participants recalled relying on a robust patient network for guidance and insight into practices at different programs.

1b) Patients experience anxieties about having to travel for transplant needs

Anxieties were exacerbated by concerns for having to travel and possibly relocate. Multiple recipients indicated that pulmonologists identified transplant programs in multiple OPTN regions and several recipients completed evaluations at more than one program. Considerations for the financial cost of temporarily relocating and maintaining access to social support complicated the difficult process of comparing programs' waitlist and transplant outcomes. For some participants, these considerations manifest as a tradeoff between the feasibility of relocating and accessing program-specific services and donor options that may improve outcomes. Others described seeking out transplant care within their insurance provider network; they felt limited to a choice in their immediate area.

.Theme 2: Feedback on Patient-Specific Search

2a) Information display and interpretation

Candidates and recipients approved of the prototypes of the patient-specific search and offered suggestions for improving the clarity of narrative content, graphical icons, and interactive elements. While there were disagreements over individual preferences for receiving information in narrative, graphical, or numerical formats, participants correctly interpret the risk adjusted measures (e.g. survival on the waitlist, getting a transplant faster, and 1 year lung survival) and anticipate the functionality of the patient-specific features. Multiple participants indicated that the search results and graphic icons quickly draw attention to differences between programs and some related the patient-specific search to consumer websites they've used for support in decision-making in other arenas.

2b) Patient-specific search supports decision making

Candidates and recipients reported having limited access to patient-friendly, easy to understand, personalized resources that support decision making. Most indicated that their pulmonologist offered guidance on selecting a program and donor options, but the amount and depth of information varied. Some indicated that they relied on program-specific resources while others used SRTR/OPTN data reports prior to decision making about program selection, but noted that the prototype search offered more accessible support. Overall, participants supported the development of a patient-facing resource that would enable to them to decisions based on the most recent data.

2c) Suggested additions

While feedback was generally positive, participants did offer a number of suggestions for ways to improve the patient-specific search. For instance, participants supported the addition of notifications to inform patients that the search results are based on aggregated data and that each patient will need to consider their own clinical needs when selecting a center. This feedback supported the development of a personalized decision guide that appears before the search results. The decision guide is responsive to information provided by the user and generates a plain language statement of how their profile may affect their access to transplant. Participants also supported the expansion of patient factors and donor options included in the prototype. Suggested additions included profile fields for single versus bilateral lung transplant and search results on the number of highly sensitized recipients at each program.

2d) Patient-specific search may improve provider interactions

Feedback on the patient-specific search suggested that participants would like to review their customized results with a provider. Participants conveyed that reviewing the number of recipients matching their clinical profile at programs under consideration would supplement conversations with providers. At the same time, participants felt that the patient-specific search could enhance their self-efficacy and capacity to participate in shared decision making with providers and other stakeholders (e.g. family members).

The analysis of the variation in transplant recipients and donors across transplant programs coupled with the patient feedback was used to create a functioning website with patient-specific transplant program data: www.transplantcentersearch.org. This tool allows transplant patients to enter their medical profile and receive notifications on characteristics in their profile that may influence access to transplantation. Search results provide a list of programs that have conducted transplants in patients like them. Additional content informs users about options that may improve their access to transplant, such as considering transplant from organs procured after circulatory death (DCD) lungs, Hepatitis C (HCV) positive donors or ex-vivo perfused organs.

Table and Figure Legends:

Table S1: COREQ 32 Item Checklist

Table S2: Questions on the Discussion Guide

Table S3: Distribution of clinical and demographic characteristics in lung transplant recipients, July 1, 2017 – June 30, 2019

Less than 1% missing information for the following variables: High BMI at Transplant, HCV+ Donor and Recipient, HCV+ Donor and – Recipient, HIV+ Recipient, Medicaid, Previous Non-Tx Cardiac Surgery, Previous Non-Tx Lung Surgery, Short Stature Adult, Perfused Donor, and Low BMI at Transplant.

Table S4: Clinical and demographic characteristics of lung transplant candidates on the waitlist, July 1, 2017 – June 30, 2019

Less than 1% missing information for the following variables: High BMI at Listing, Willing to Accept HCV+ Donor, Previous Non-Tx Cardiac Surgery, Previous Non-Tx Lung Surgery, Low BMI at Listing

Table S5: Clinical and demographic characteristics of study participants

The clinical factors included under “Comorbidities” were determined by a series of questions asking whether or not a provider has ever told you that you have ____. As a result, factors like “Overweight” are not tied to specific clinical definitions or ranges of values (e.g. weight).

Table S6: Excerpts representing themes derived from focus groups

Figure S1: Example of profile entry page shown to study participants

Figure S2: Distribution of Lung Transplant Programs by Recipient Characteristics, July 1, 2017 – June 30, 2019

Description: Shown are the percentages of transplant programs with counts of recipients by characteristics stratified by program size. For example: in the BMI above 35 category, over 75% of small programs (1-39 transplants over the cohort) did not perform such transplants. At the same time, half of the large programs (80+ transplant over the cohort) performed between 1 and 10. All p-values <0.0001, except BMI below 18, HIV+ Recipient, and Retransplant.

Figure S3: Distribution of Lung Transplant Programs by Donor and Paired Donor-Recipient Characteristics, July 1, 2017 – June 30, 2019

Description: Shown are the percentages of transplant programs with counts of paired donors-recipient and donors characteristics. Donor characteristics include: Perfused Donor and PHS Increased Risk Donor; paired donor-recipient factors include HCV+ Donor and Recipient and HCV+ donors and HCV- recipients. For example: in the Perfused Donor category, over 75% of small program (1-39 transplants over the cohort) did not utilize such donors. Nearly half of medium sized programs (40-70 transplants over the cohort) Notifications indicate that mock user may have restricted access to transplant based on the distance they are willing to travel and their age (67 years old).

Table S1: COREQ 32 Item Checklist

Domain 1: Research team and reflexivity	
Interviewer/facilitator	M.B.; C.S.
Credentials	M.B. PhD; C.S. PhD
Occupation	M.B. Professor; C.S. Post-Doctoral Fellow
Gender	M.B. Female; C.S. Male
Experience and training	M.B. Professor teaching qualitative and mixed methods research; C.S. Engineer with focus on human centered design and evaluation
Relationship established	M.B. and C.S. have no prior relationship with the study participants
Participant knowledge of the interviewer	Participants were informed of the researchers' experience and profession prior to the start of the study activities
Interviewer characteristics	(See Concurrent Methods – Development of Interview and Focus Group Guides)
Domain 2: Study design	
Methodological orientation and Theory	Phenomenology with an exploratory and eclectic coding process
Sampling	(See Concurrent Methods – Site and Sample)
Method of approach	Patients on the waitlist for lung transplant were first sent a letter to introduce the study. Follow-up phone calls established interest in the study and facilitated the scheduling of pilot interviews and focus group sessions. National recipients were recruited with the assistance of a patient advocacy organizations.
Sample size	N=22; 2 local candidates and 20 national recipients
Non-participation	The number of individuals who refused to participate was not recorded.
Setting of data collection	Focus groups met in clinic conference rooms at UMNF and in a hotel conference room in Chicago, IL
Presence of non-participants	A.I. served as a note taker for the local and national focus groups.
Description of sample	(See Table 1)
Interview guide	(See Table S1)
Repeat interviews	Participants only completed one study session.
Audio/visual recording	Focus groups were audio recorded and transcribed verbatim.
Field notes	Team members drafted field notes during the focus groups and used the notes to inform the coding and analysis.
Duration	Focus groups last between 60 and 120 minutes.
Data saturation	Data saturation was discussed for the parent project.
Transcripts returned	Transcripts were not returned to participants
Domain 3: Analysis and findings	
Number of data coders	2, W.M. and C.S.; M.B. and A.I. reviewed codes and excerpts
Description of the coding tree	3 broad categories of codes emerged over the course of the analysis of focus group data relating to: 1) decision making on program selection; 2) past experiences; and 3) feedback on the patient-specific search. Additional sub-codes were created to capture additional details about participant experiences, perceptions of barriers to informed and shared decision making, and feedback on the patient-specific search. An outlier code was also defined to identify unexpected and divergent cases.
Derivation of themes	Themes were derived from a review of 519 excerpts.
Software	Dedoose coding software (Dedoose, Hermosa Beach, CA) was used

	to organize data and identify supporting quotations
Participant checking	Participants did not review transcripts or themes.
Quotations presented	(See Results and Table 2)
Data and findings consistent	(See Results)
Clarity of major themes	(See Results and Discussion)
Clarity of minor themes	(See Discussion)

Table S2: Questions on the Discussion Guide

Part 1: Background and Decision Making on Program Selection

Interview and Focus Group Topic: What Patients Learned about Transplant Center Options

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?

Interview and Focus Group Topic: Deciding on a Specific Center

1. What centers did you consider?
2. [If several] Did you compare any of them? How did you compare them?
3. [If several] What was most important in comparing them?
4. What could be done to help make choosing a transplant center easier?

Interview and Focus Group Topic: New Information and Hypothetical Decisions

[Questions tailored to participants; e.g. local residents discussed criteria if choosing a non-local program]

Example #1: Imagine if you lived halfway between two cities with transplant centers and needed to decide which one to visit. What information would be important to you to make this decision?

Example #2: Imagine if you were given a list of nearby centers but your doctor did not give a specific recommendation. What information would be important to you to make this decision?

Part 2: Feedback on Mock-Ups of the Patient Specific Search

[Still images of mock-ups were presented sequentially to demonstrate how a user inputs information and receives search results from the patient-specific search. Questions and discussion points elicited feedback on design elements and layout, comprehension, and acceptability.]

Example #1: Would you consult with your provider to discuss patient factors that the search indicates may impact your options (see Figure 1)?

Example #2: How does learning that a center has no recent information on performing transplants on patients with your age or medical profile (see Figure 2) impact your perception of the center?

Example #3: How do you interpret the heading and subheading for the “Before transplant” column (see Figure 2)?

Example #4: Would you feel comfortable using the patient-specific search on your own? Would you want to use it in the presence of a provider, or consult with them before/afterwards?

Table S3: Distribution of clinical and demographic characteristics in lung transplant recipients, July 1, 2017 – June 30, 2019

Characteristic	n (%)
Total	5068
High Age at Transplant:	
Age < 65	3286 (64.84)
Age >= 65	1782 (35.16)
High Age at Transplant:	
Age < 70	4472 (88.24)
Age >= 70	596 (11.76)
High BMI at Transplant:	
BMI < 30	4171 (82.43)
BMI >= 30	889 (17.57)
High BMI at Transplant:	
BMI < 35	5000 (98.81)
BMI >= 35	60 (1.19)
Low BMI at Transplant:	
BMI >= 18	4849 (95.83)
BMI < 18	211 (4.17)
PHS Increased Risk Donor:	
No	3652 (72.06)
Yes	1416 (27.94)
HCV + Donor and Recipient:	
No	5053 (99.86)
Yes	7 (0.14)
HCV + Donor and - Recipient:	
No	4845 (95.75)
Yes	215 (4.25)
HIV + Donor:	
No	5068 (100.00)
HIV + Recipient:	
No	5043 (99.66)
Yes	17 (0.34)
Medicaid:	
No	4652 (91.94)
Yes	408 (8.06)
Diabetes:	
No	3995 (78.83)
Yes	1073 (21.17)
DCD:	
No	4841 (95.52)
Yes	227 (4.48)
Donor status:	
Deceased	5068 (100.00)
Previous Non-Tx Cardiac Surgery:	
No	4954 (98.00)
Yes	101 (2.00)
Previous Non-Tx Lung Surgery:	
No	4844 (95.86)

Yes	209 (4.14)
Donor Used Cigarettes - Ever:	
No	4670 (92.15)
Yes	398 (7.85)
Short Stature Adult (<160 cm):	
No	4236 (83.72)
Yes	824 (16.28)
Perfused Donor:	
No	3766 (95.32)
Yes	185 (4.68)
Retransplant:	
No	4923 (97.14)
Yes	145 (2.86)
Multiorgan Transplant:	
No	4957 (97.81)
Yes	111 (2.19)

Table S4: Clinical and demographic characteristics of lung transplant candidates on the waitlist, July 1, 2017 – June 30, 2019

Characteristic	n (%)
Total	7730
High Age at Listing:	
Age < 65	5351 (69.22)
Age >= 65	2379 (30.78)
High Age at Listing:	
Age < 70	6991 (90.44)
Age >= 70	739 (9.56)
High BMI at Listing:	
BMI < 30	5948 (77.08)
BMI >= 30	1769 (22.92)
High BMI at Listing:	
BMI < 35	7582 (98.25)
BMI >= 35	135 (1.75)
Blood Type:	
Other	6843 (88.5
B	887 (11.47)
Willing to accept Hep C + Donor:	
No	5015 (64.93)
Yes	2709 (35.07)
Medicaid:	
No	6990 (90.43)
Yes	740 (9.57)
Diabetes:	
No	6224 (80.52)
Yes	1506 (19.48)
Previous Non-Tx Cardiac Surgery:	
No	7167 (95.70)
Yes	322 (4.30)
Previous Non-Tx Lung Surgery:	
No	127 (81.41)
Yes	29 (18.59)
Low BMI at Listing:	
BMI >= 18	7506 (97.27)
BMI < 18	211 (2.73)

Table S5: Clinical and demographic characteristics of study participants

	All Participants
Interview Participants; n	2
Focus Group Participants; n (number of groups)	20 (3 groups)
Age; median (SD); IQR	
Median (SD)	63 (11.65)
IQR	17
>65 ; n (%)	8 (36.37)
Sex; n (%)	
Female	9 (49.91)
Race; n(%)	
Black	1 (4.55)
Hispanic	3 (13.64)
White	18 (81.82)
Other	0 (0.00)
Education; n (%)	
Less than High School	1 (4.55)
High School	3 (13.64)
Some College	5 (22.73)
College	6 (27.27)
Graduate	7 (31.82)
Income; n (%)	
Less than $15,000	1 (4.55)
$15,000 - $30,000	2 (9.09)
$30,000 - $45,000	1 (4.55)
$45,000 - $60,000	2 (9.09)
$60,000 - $75,000	3 (13.64)
More than $75,000	10 (45.45)
Prefer Not to Answer	3 (13.64)
Number of Cohabitants, Mean (SD)	1.9 (0.55)
Prefer Not to Answer; n (%)	2 (9.09)
Employment; n (%)	
Full-time	1 (4.55)
Part-time	2 (9.09)
Unemployed	4 (18.18)
Retired	9 (40.91)

Full-time Homemaker	0 (0.00)
Student	1 (4.55)
Unable to Work	6 (27.27)
Insurance; n(%)	
Private	15 (68.18)
Medicare	15 (68.18)
Medicaid	1 (4.55)
Other	3 (13.64)
Transit to Doctors Appointment; n(%)	
I or a family member, own a car	21 (95.45)
I have access to a car or ride with someone	1 (4.55)
I use public transportation/ bus/ metro	0 (0.00)
I take a taxi	0 (0.00)
I walk	0 (0.00)
Other	0 (0.00)
Indication of Lung Failure; n (%)	
Chronic obstructive pulmonary disease or emphysema	3 (13.64)
Cystic fibrosis or bronchiectasis	3 (13.64)
Interstitial lung disease	18 (81.82)
Pulmonary hypertension	1 (4.55)
Other	1 (4.55)
Don't Know	0 (0.00)
Body Mass Index (BMI)	
Median (SD)	27.0 (5.44)
IQR	6.03
BMI >30; n (%)	5 (22.73)
Comorbidities; n (%)	
High blood pressure (Hypertension)	9 (40.91)
Diabetes	7 (31.82)
Cancer	4 (18.18)
Stroke or cerebrovascular accident	0 (0.00)
High cholesterol	8 (36.36)
Heart Failure	1 (4.55)
Irregular beating of the heart or Cardiac arrest	7 (31.82)
Kidney Disease	7 (31.82)
Overweight	9 (40.91)
Angina or chest pain	0 (0.00)
Bypass heart surgery (CABG)	1 (4.55)
Coronary Angioplasty	2 (9.09)

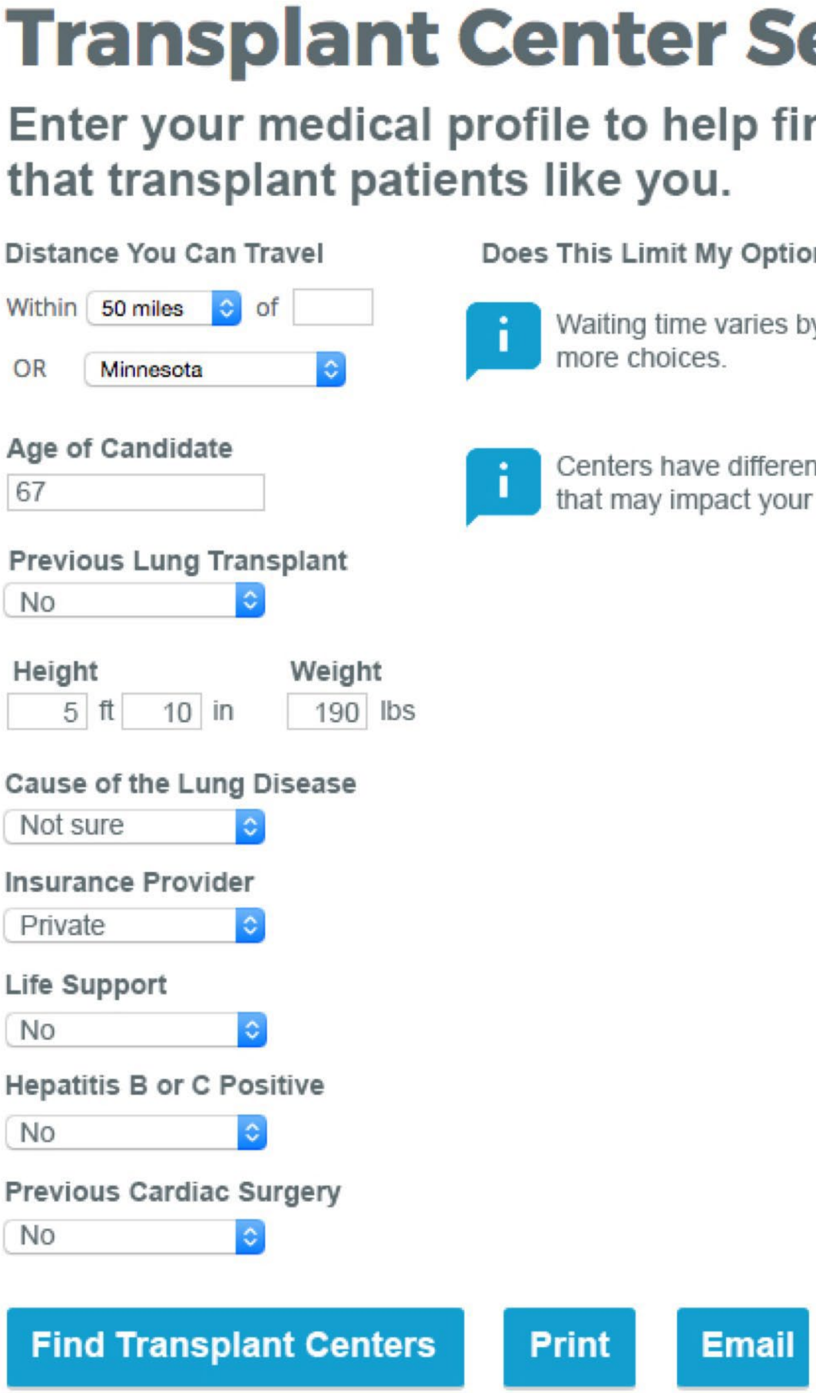
Table S6: Excerpts representing themes derived from focus groups

Theme	Sub-Theme	Excerpt
1) Patients experience multiple and compounding anxieties while making decisions about transplant care	Patients experience anxiety over eligibility	Ex. When I had my transplant, almost 14 years ago, there was an age limit for lung transplants. And it was 65… My greatest fear was I was not going to be able to get my transplant...Some transplant centers still hold to that age limit. (Recipient) Ex. …they [programs] are more selective so they can have good outcomes and mine because of my disease is a little more complicated. It is not quite as cut and dry as some of them maybe...that made them question if they would do it or not. (Candidate) Ex. I see all the time [in support groups], "I'm 73 years old. Do you know of a transplant center that transplants 73-year-olds? Or do you know a transplant center that will transplant someone with an issue or some type of a comorbidity?" (Recipient) Ex. I would be looking for any place—I'm on oxygen, I'm sitting here, thinking, is there a possibility to get a transplant given my age characteristics. (Recipient)
	Patients experience anxiety about having to travel for transplant care	Ex. I think it would be helpful just to see the different locations because… when they gave me five [locations] that were like out of state you were just trying to imagine where they are or how far or what they are good at or not (Candidate) Ex. She [provider] gave me places out of state that we could start looking into for when the time did come. This was never – [a center in my state] was never an option and so we left there kind of shocked. (Candidate) Ex. I spent a couple of years just [meeting with teams],

		chasing, interviewing, and fired the ones I didn't like and kept the ones I did like. So, I spent a ton of money doing that. (Recipient) Ex. Yeah, I think relocation is a big deal if you can't—I don't know how people do it. If you have a family, and you have kids, and you've got to go and … you [have to] have a caregiver that you can't hire. (Recipient)
2) Feedback on Patient Specific Search	Information display and interpretation	Ex. I guess like the bars do help show a rating kind of without being a rating. (Candidate) Ex. …even though I do not like the bars per se, I would understand it easier because […]I am so used to seeing different bars on different web sites going between 1 and 5 (Recipient)
	Patient specific search supports decision making	Ex. Well, any information you can get when you're searching is feeding the foundation of all your decisions. So, the answer is yes it would help. Just so that you felt like the data – my own data that I put in on the left – would give me some way to make decisions (Recipient) Ex. It would have been very helpful to have something like that [patient specific search], so I would have known what options were out there. (Recipient)
	Suggested additions	Ex. I think if you [add] – everybody's results are different. Please review yours with your provider. Something along those lines. I wouldn't go to the extent of caution. You don't want to scare them. You want them to be informed calmly (Candidate) Ex. You know with a custom search, I think if it is going to go back to the prior screen and you can specialize that search, there needs to be something more than just custom search, or maybe go to previous page or something… Because just looking at that, I would not know to do that. (Recipient)

	Patient-specific search can improve provider interactions	Ex. Recipient: … [patients] don't feel like they can make a decision on their own without asking their doctors. Interviewer: Would this help you have a conversation with your doctor to make that decision? Recipient: I'm hoping that the doctor would talk to you about that. But yes, in case they didn't, yes. (Recipient) Ex. I think if we can maybe get a pulmonologist that deals more with just lung—transplant—instead of just sleep disorders and all the other different issues, we would have more of a chance to look at different centers or even have that option or even be talked to about having a transplant or… So I think if you can get help from the doctors, the actual pulmonologist you know, and have them steer us in the right direction so that we can go to these web sites and you know, make our own choices. (Recipient) Ex. It would be great that the doctor stands there and he could tell you those demographics and general stats. And then he could tell you what he's going to think based on him knowing the surgeon or the team. (Recipient)

Figure S1: Example of profile entry page shown to study participants



Transplant Center Search

Enter your medical profile to help find centers that transplant patients like you.

Distance You Can Travel

Within 50 miles of

OR Minnesota

Does This Limit My Options?

Waiting time varies by region. A larger area gives you more choices.

Centers have different age criteria for candidates that may impact your options.

Age of Candidate

67

Previous Lung Transplant

No

Height 5 ft 10 in

Weight 190 lbs

Cause of the Lung Disease

Not sure

Insurance Provider

Private

Life Support

No

Hepatitis B or C Positive

No

Previous Cardiac Surgery

No

Figure S2:Distribution of lung transplant programs by recipient characteristics, July 1, 2017 – June 30, 2019

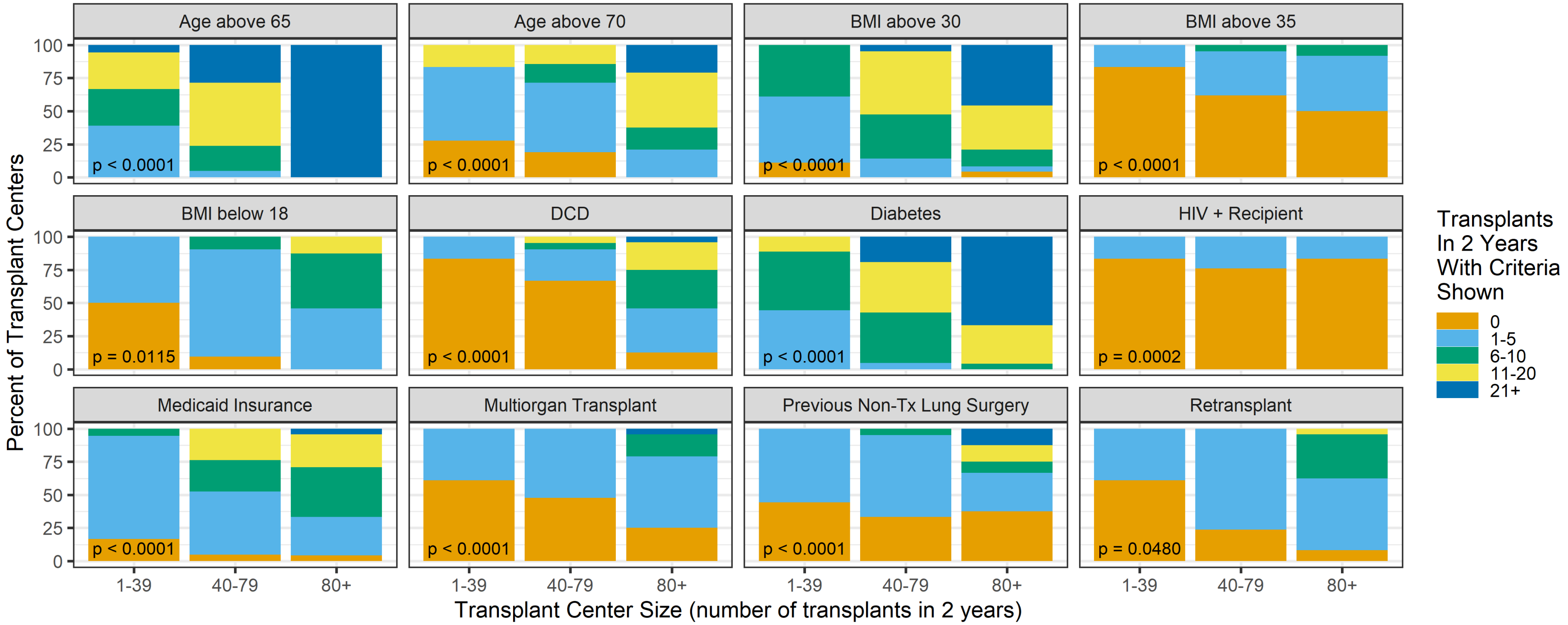
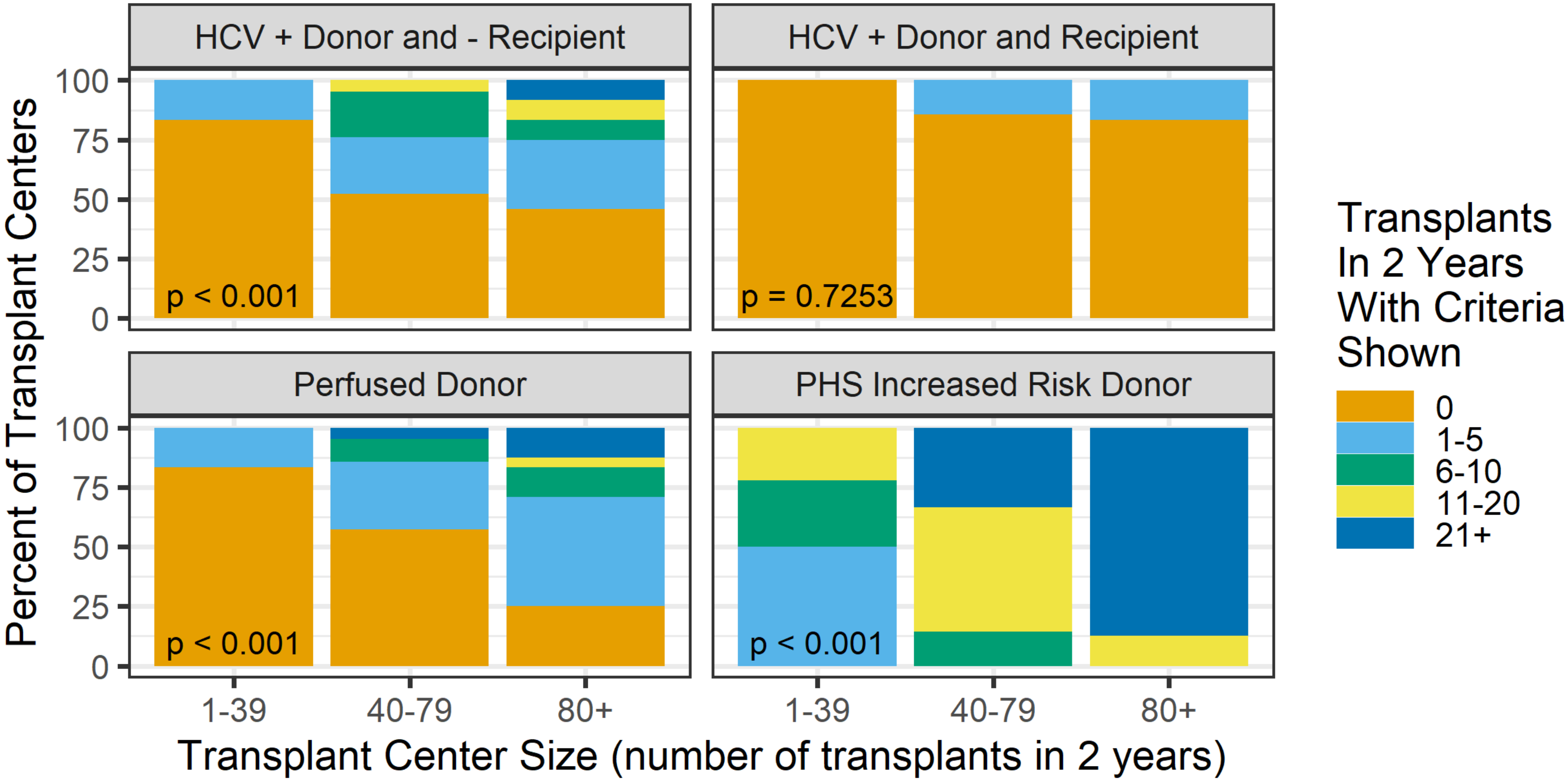


Figure S3:Distribution of lung transplant programs by donor and paired donor-recipient characteristics, July 1, 2017 – June 30, 2019



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