What Patients and Members of their Support Networks Ask About Transplant Program Data

Cory R. Schaffhausen, PhD[1], **Marilyn J. Bruin, PhD**[2], **Daryl Chesley, EdD**[3,4], **Maureen McBride, PhD**[3,4], **Jon J. Snyder, PhD, MS**[5,6], **Bertram L. Kasiske, MD**[1,5], and **Ajay K. Israni, MD, MS**[1,5,6]

[1]Department of Medicine, Hennepin County Medical Center, University of Minnesota, Minneapolis, Minnesota

[2]College of Design, University of Minnesota, Minneapolis, Minnesota

[3]Organ Procurement and Transplantation Network, Richmond, Virginia

[4]United Network for Organ Sharing, Richmond, Virginia

[5]Scientific Registry of Transplant Recipients, Minneapolis Medical Research Foundation, Minneapolis, Minnesota

[6]Department of Epidemiology and Community Health, University of Minnesota, Minneapolis, Minnesota

Abstract

Transplant patients often seek specific data and statistics to inform medical decision making; however, for many relevant measures, patient-friendly information is not available. Development of patient-centered resources should be informed by patient needs. This study used qualitative document research methods to review 678 detailed Scientific Registry of Transplant Recipients (SRTR) entries and summary counts of 55,362 United Network for Organ Sharing (UNOS) entries to provide a better understanding of what was asked and what requests were most common. Incoming call and email logs maintained by SRTR and UNOS were reviewed for 2010–2015. Patients sought a wide range of information about outcomes, waiting times, program volumes, and willingness to perform transplants in candidates with specific diseases or demographics. Patients and members of their support networks requested explanation of complex information, such as actual versus expected outcomes, and of general transplant processes, such as registering on the waiting list or becoming a living donor. They sought transplant program data from SRTR and UNOS, but encountered gaps in the information they wanted and occasionally struggled to interpret some data. These findings were used to identify potential gaps in providing program-

Corresponding author: Ajay K. Israni, MD, MS, Scientific Registry of Transplant Recipients, Minneapolis Medical Research Foundation, 701 Park Avenue, Suite S4.100, Minneapolis, MN 55415, Phone, 612-873-6994; fax, 612-873-1655; isran001@umn.edu. DR. AJAY ISRANI (Orcid ID : 0000-0002-7607-0430)

specific data and to enhance the SRTR website (www.srtr.org) with more patient-friendly information.

Keywords

Patient-centered information; qualitative document research; transplant program data

Introduction

Choosing a transplant program is one decision in a long pretransplant process facing patients. Qualitative studies have previously been used to better understand the experiences, attitudes, values, and behaviors of patients at a number of critical pretransplant decision points.[1] For patients with end-stage kidney disease, qualitative studies have identified factors (e.g., sociocultural factors) influencing the decision to pursue transplant or remain on dialysis,[2,3] or general experiences during evaluations.[4,5] Similar pretransplant qualitative studies described liver candidate experiences,[6] and others offered perspectives across the field of transplantation.[7] However, literature is limited describing the patient experience of selecting a desired transplant program based on referral and other available information, or related gaps in the information used to choose a program. Patient support networks, such as friends and family members, are often involved in navigating treatment decisions. This qualitative study sought to better understand the questions patients and members of their support networks ask when choosing a program or pursuing transplant in the United States. A review of actual requests is one way to better understand these needs. Access to transplant information is one potential source of disparities in access to transplant.[8] Providing patient-centered information may improve awareness of patient-specific factors limiting access to transplant, and may allow patients to make informed decisions about specific transplant programs.

The Scientific Registry of Transplant Recipients (SRTR) maintains a database of all solid organ transplant recipients in the United States and disseminates statistical reports, including program-specific reports (PSRs), to the government, researchers, providers, and public stakeholders.[9] United Network for Organ Sharing (UNOS) is the government contractor for the Organ Procurement and Transplantation Network (OPTN), and serves roles including OPTN data collection; allocation technology; policy development; and patient, professional, and public communication and education.[10,11] Since 2000, certain OPTN and SRTR reporting requirements have been defined by a Final Rule, and statistical reports must include specified measures of inter-transplant program variation. The Final Rule also requires "Giving patients, their families, their physicians, and others timely and accurate information to assess the performance of transplant programs."[11] The current PSRs have been developed for use in government and payer quality monitoring, although the same information could potentially be a resource for patients and their families.[9] Both SRTR and OPTN contribute to these reports and share a goal of disseminating program-specific data that are more patient centered.[12] SRTR and UNOS have each implemented systems to respond to external requests and comments, and each organization collects key information

in a database. Requests may arrive via phone, email, or postal mail, and may originate from the public, researchers, providers, patients, their families, or others.

Improving existing information sources (e.g., transplant program data provided on SRTR websites) may better meet the needs of patients and their support networks. To understand who was requesting information, what information was requested, and which requests were most frequent, we used a document analysis of contact database logs maintained by SRTR and UNOS. All patient and support network requests were summarized, and example verbatim and paraphrased requests are provided for common topics.

Materials and Methods

Incoming call and email logs maintained by SRTR and UNOS were reviewed for the 6-year period January 1, 2010, to December 31, 2015. Different analysis methods were required for the two datasets due to different content in each organization's database. The study was approved by the Institutional Review Board of Hennepin County Medical Center.

SRTR call and email logs

This study used data from SRTR. The SRTR data system includes data on all donors, waitlisted candidates, and transplant recipients in the US, submitted by the members of OPTN. The Health Resources and Services Administration, US Department of Health and Human Services, provides oversight to the activities of the OPTN and SRTR contractors.

Most SRTR contacts originated from clinicians and staff at transplant programs; each entry described the date, program, topic area, and other contact details. To meet the objective of describing questions from patients and their support networks, SRTR data were first reviewed to identify a subset of total incoming calls and emails likely originating from patients and patients' support network members. Entries with an identifiable program-based address were excluded from this set. Inclusion criteria for the patient and support network subset were: the field for "topic area" beginning with "patient" and/or the field for "transplant program" listed as "patient" or "public." An analyst manually reviewed additional records and selected cases consistent with a candidate or recipient patient request. These manual reviews were performed for transplant programs listed as "other" or "unknown" and for topic areas listed as "international," "for UNOS," "getting on the list," "other," and "public website."

Any included records were converted to a text-only format, and the text included the date, mode (e.g., phone or email), topic, and full text description. Full text descriptions often included verbatim requests for information (e.g., text from an email) but generally did not include full conversations. Paraphrased statements from SRTR staff rather than verbatim quotes from requestors were common in the database and were included when comparable quotes were not available. The text file was analyzed using hyperRESEARCH (ResearchWare, Inc., Randolph, MA). Document analysis methods included an iterative process of combining content analysis and thematic analysis.[13] Content analysis involves organizing information into categories related to the central questions of the research. One specialized form of content analysis is summative content analysis. In a summative

approach, the data analysis begins with a summary of keywords, phrases, or themes. Counts are reported, but the analysis continues beyond this quantitative phase and includes interpretation of themes from the text.[14] Two analysts reviewed coding strategies, and a single analyst coded the full text for keywords and phrases. Codes were iteratively developed during three reviews of the data. Emerging themes were identified and interpreted. A single statement might include several codes. For example, a request, "He left a voicemail requesting counts and success rates for liver transplants at a handful of Pennsylvania programs," might be coded for "survival or success rates," "counts or volume," and "liver." The requestor type (e.g., "family and fiends") was coded only for entries mentioning a specific relationship, for example, "my father needs a transplant." Family and friends were combined to represent a patient support network. Unexpected themes and frequently coded phrases were explored further using available full text descriptions.

UNOS call and email logs

UNOS maintains a Patient-Services phone line and staff dedicated to providing general information about donation and transplantation to patients and their support network members. Information about each contact is entered into the Patient-Services database and used to improve resources provided by Patient Services and those made available to patients and the public on the OPTN and UNOS web sites. Each entry in the UNOS Patient-Services database describes the type of caller, organ type, a general topic category (e.g., "policies," "data and statistics"), and a subtopic category (e.g., "median wait time"). Data reports included itemized summary counts for each type of caller, organ type, category, etc. Individual entries for each contact were not analyzed, because detailed descriptive text was not recorded. The available reporting tools did not separate patient and family requests from healthcare professional requests. However, summary counts indicated that only 6% were identified as from healthcare professionals.

Results

SRTR call and email logs

All requests in the SRTR call and email log totaled 11,234 entries. A total of 678 SRTR entries were identified as originating from patients and members of a support network, e.g., family and friends of a patient. For all summary tables, codes with more than five entries are included. Table 1 shows general categories of requests as well as individual codes and the count of entries with each code. A total of 364 entries were coded for a topic related to data and statistics. A total of 136 entries were coded as related to finding a transplant program or region. Patient and support network requests to SRTR included general topics not related to the data reports produced by SRTR. A total of 331 general requests were coded and are itemized in Table 1. Table 2 shows excerpts of detailed descriptions for questions related to data and statistics. These discussions indicated a wide spectrum of familiarity with existing SRTR reports and methods. Table 3 shows verbatim text from email contacts that were interpreted as general or advanced SRTR requests. Table S1 shows detailed quotes and paraphrases of questions related to general program and patient information.

UNOS call and email logs

The summary counts of UNOS Patient Services data included 55,362 entries. Table 4 shows counts for data and statistics subcategories present in the UNOS database. Approximately 3% of entries (1584) included a request for data and statistics. Approximately 30% of UNOS Patient-Services entries were entered as a general patient information request.

General comparisons for SRTR and UNOS

The UNOS and SRTR logs show nearly 2000 combined requests for data and statistics. For all SRTR entries, approximately 25% (151 entries) included a reference to a friend or family member making a request on behalf of a patient. In the UNOS logs, approximately 20% of entries were identified as a family member or friend of a donor or patient. The UNOS contact log included more complete details for the type of requestor, and these itemized counts are shown in Table 5.

In the SRTR log, approximately 60% (408 entries) were coded with a specific organ in the text. Of these, approximately 50% were kidney and 25% were liver. In the UNOS log, approximately 50% of entries identified a specific organ. Of these, approximately 55% were kidney and 27% were liver. For both organizations, the remainder of entries included heart, lung, pancreas, intestine, multiple organs, and transplant requests that were not related to solid organs. Trends over time were not evident in either SRTR or UNOS logs; therefore, results are reported cumulatively for the 6 year period.

Discussion

The analysis of questions asked by patients and support group members suggests that the presentation of transplant program information could be improved in a number of ways. For example, there is a need to increase support for low health literacy levels and continue to provide complex data. Outreach may be increased by clarifying for the public the intended audiences and objectives specific to SRTR and UNOS. The information provided could better facilitate comparative analyses across programs or regions, communicate the relevance of existing program metrics (pre- and posttransplant), and help patients understand how their personal characteristics affect treatment options.

General challenges in disseminating information to patients

A number of quotes in Table 2 reflect requests for help because the requester did not understand the information presented. As described in Table 3, the variation in questions suggests a wide range of literacy and numeracy among patients and support network members making requests. The examples demonstrate the potential benefit of providing simple transplant program data using patient-friendly formats and plain language, but also enhancing more complex details to support advanced requests. Several strategies have been implemented on the SRTR website, including visual icons that transform complex metrics into a better/worse scale,[15] and "layered" website navigation tools that separate details from summary data.[16]

The number of similar requests in the UNOS and SRTR logs for statistics and for general information suggests that patients and support network members may not have a clear understanding of the complimentary roles of UNOS and SRTR, or of which organization may be best suited to answer particular types of questions. UNOS/OPTN currently collects waitlist and outcomes data and shares data with SRTR for further analysis. UNOS and SRTR describe this information with similar labels, such as "data," although the types of data presented differ. UNOS provides descriptive and summary data on the UNOS website.[17] SRTR provides additional risk-adjusted outcomes and statistics; however, these differences may not be evident to patients. SRTR received fewer entries than UNOS, possibly suggesting a relative lack of awareness of SRTR. SRTR has increased outreach activities to increase awareness of available resources through a newsletter and social media (https://twitter.com/srtrnews).

Understanding variations in waitlist times and program outcomes

While existing SRTR PSRs allow comparisons with regional and national benchmarks, they are not presented to facilitate comparing programs with each other and may have limited utility for patients.[9,12] Table 2 includes requests specifically suggesting the benefit of tools to facilitate comparing programs.

Geographic disparities in waiting times and mortality are substantial,[18] as are inter-transplant program variations in offer acceptance[19–21] and mortality rates.[22] While these measures are relevant to the general patient population, little is known about how patients factor this information into a decision. Of note, requestors specifically sought data on median time to transplant even after it had been removed from summary reports. Multiple alternate metrics describe time to transplant (including the percentage of the waiting list who undergo transplant within a certain time period) and the variability in what may be presented to patients warrants additional research. Patients also requested survival or "success" data; however, the requests to clarify the meaning of "expected" outcomes (e.g., after risk adjustment) suggest that additional patient-friendly materials for this complex outcome would be of benefit. According to the Agency for Healthcare Research and Quality guidelines for public quality reporting, report sponsors should minimize cognitive demand, for example by omitting confidence intervals from reports for a public audience and by interpreting the meaning of results in lay language.[23]

Prominent role of candidate support networks

Nearly a quarter of all analyzed contacts were received from someone in the candidate's support network. This included parents advocating for children, children advocating for parents, aunts, uncles, siblings, and a range of additional relationships. When organizations disseminate patient-friendly materials to aid transplant candidates, the materials must be created with the support network in mind. A significant portion of the audience for these materials may not have previously had access to clinicians and transplant staff to learn about the complexities of the listing process and the meaning of medical outcome data.

Unfamiliarity with referral and how to choose a program

The most common general topic that arose in SRTR data was how to get on the waiting list, and the most common request in UNOS data related to the "transplant process." SRTR data also included numerous examples of requests for help choosing a program; many specifically asked for help identifying a program that would treat a specific condition or accept a patient with a specific characteristic (e.g., age). While decision points related to choosing to undergo transplant and being evaluated have been studied,[2–5] to date, research on patient experiences during referral is limited to pediatric transplantation.[24] Studies describe disparities in adult transplant referral and listing practices due to socioeconomic status, ethnicity, income, and insurance status.[25,26] However, the patient experience of beginning the transplant journey by choosing a program or seeking a referral is not well understood.

One standard informational pamphlet for patients provided by UNOS describes choosing a transplant program as "one of the biggest decisions you will make as a transplant candidate."[27, p. 10] The pamphlet discusses the topic in terms of trust and convenience, and patients are informed of the option to seek statistical data from OPTN and SRTR. It is unclear how patients go about searching for and finding this information and whether the information they find aids in making a decision.

Understanding variations in candidate acceptance across programs

Patient-specific characteristics such as age, body mass index, and insurance coverage are associated with decisions not to inform patients about transplant, and patient perceptions about being informed also influence access to transplant.[28] In addition, selection criteria vary across programs with regard to use of higher-risk organs,[29] use of living donors,[30] and candidate age and body mass index.[31] In some programs, 50% of patients evaluated are not listed,[25] and given the variability across programs for geographic and patient-specific criteria, some patients who were declined may have been listed had they been evaluated at another program.

As shown in Table 2, many patients specifically requested help identifying a program that performs transplants in patients with their characteristics. Examples of reasons for seeking this information were older age or other medical risk factors (e.g., previous carcinoma). Several requests specifically mentioned having been refused access to the waiting list after a previous evaluation.

Limitations and conclusion

The study had several important limitations. The call and email log systems at SRTR and UNOS were developed independently and definitions of data categories were not explicitly shared or aligned. Comparisons across databases are limited to general trends and themes. Importantly, this information was not originally collected for the purpose of detailed analysis and lacked some information, such as demographics. The level of detail for a question may be insufficient to allow understanding of the question's intent, and the summarized information entered into the database was not shared with individuals who called or emailed as a member-check to insure accuracy. UNOS data did not include descriptive details to

allow analysis of quotes and were reported with patient and provider inquiries combined; however, entries identified as from healthcare providers comprised only 6% of the total.

The data from call and email logs may be biased toward the interests of a more computer literate subset of patients than the general patient population, limiting the ability to generalize from these findings. However, the data represent a national sample of actual website users making real-world decisions. Many additional resources are available to answer patient questions, and the findings here apply only to patients and members of their support networks who contacted the organizations included in the study. Data from call and email logs do not include topics patients do not know they could or should ask about. Requests generally related to materials that currently exist rather than to potential new types of information. The degree of satisfaction with a response to questions was not consistently recorded. The full text descriptions available for analysis were more limited than transcripts from in-depth discussions and did not permit the same detail in thematic analysis. Further research is warranted; therefore we are conducting additional qualitative interviews and focus groups for local and national patient populations, and surveying national patient groups and the public to better understand priorities for information and decision making.

Patients and patient support networks seek transplant program data from SRTR and UNOS; however, they encounter gaps in patient-friendly information. The results demonstrate a wide range of requests for data and statistics across each organization. Patients are currently given some information, such as actual versus expected outcomes, that is not sufficiently understood by a non-technical audience. Patient support networks, including family and friends, also sought information. Patients and support networks were unfamiliar with the process of registering on the waiting list, and many were seeking information to help select a program that performs transplants in patients with their characteristics. The study results provide a better understanding of potential gaps in the way program-specific data are given to patients. This information helped inform improvements in content and presentation for patient-friendly SRTR data reports and websites.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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Table 1

SRTR Patient and Support Network Requests

Data and Statistics Requests	Number
Average or median wait or shortest wait	70
General information or interpreting statistics	60
Survival or success rates	38
Counts or volume of transplants	37
Data for a specific disease or condition	35
Program-specific reports	28
Patient qualifications and characteristics for transplant	19
Annual Data Report	17
Data based on blood type	14
Long-term survival or longest survival	14
Data based on age or age limits	12
Average or median MELD	8
Explain an abbreviation	7
Explain "expected" (risk adjusted) outcome	5
Total	**364**

Requests about Finding a Program or Region	
Finding a program or contact information	76
Interest in multiple listing	27
Interest in a good or best program	12
How to choose a program	8
Variation in program waitlist acceptance	8
Finding an OPO or region	7
Rejected after evaluation or not evaluated	6
Total	**136**

General Patient Information Requests	
How to get on the waiting list	101
Wants to be living donor	89
International or undocumented patient	49
How much will procedure cost	11
Insurance question	10
Soliciting/selling organs	10
Spot on the waiting list	9
Candidate for living donor	8
Living donor risks or outcomes	8
Finding a donor	6
Higher-risk or expanded-criteria organ	6
Second opinion about options	6

Data and Statistics Requests	Number
Outreach or sharing inspirational message	5
Thank you message (for the information)	5
Total	331

MELD, model for end-stage liver disease; SRTR Scientific Registry of Transplant Recipients; OPO, organ procurement organization.

Table 2

Excerpts of SRTR Patient and Family Requests for Data and Statistics

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Average or median wait or shortest wait

- Called with questions on choosing a transplant center. Wondering about how median time to transplant worked and how valuable it is for him choosing a center.

- "The waiting list here in California is very long and would like to look for other options for her to get listed at. If possible, I would like to know what are the states with the less waiting time."

- "Could you please advise how a patient can obtain kidney median wait to transplant time for B blood type between different centers/regions? I can see this information for each individual center, but is a single compassion [sic] report between the centers publicly available?"

- Called because we removed median time to transplant.

General information or interpreting statistics

- "I was looking at the [Table] 06 - Time to Transplant, Waitlist Patients. Under 5th and 10th percentile there is a 0.1 and 0.3 (months to transplant) - what I am wondering is what does that number represent?"

- Called to ask how to interpret the table on the public website.

- What does the label on the internet summary table "Higher or Lower" than expected mean.

- Sister of patient wanted help interpreting the reports.

- "I could not understand your online report."

- Looked at out website and wanted to know why the rates of transplants were better in Florida than at the hospitals in [Massachusetts].

- Called asking how to rank a transplant center and asking what the numbers mean.

- "Please explain the term 'Person Years' & 'Rate per 100 Person Years'? Can you show calculation that would make it easier to understand?"

- Looking for data to compare [Florida program 1] and [Florida program 2].

Survival or success rates/Counts or volume of transplants

- Emailed asking for the survival rate predictions at 3 months, 1 year, 5 years, and 10 years given a set of specific characteristics.

- He left a voicemail requesting counts and success rates for liver transplants at a handful of [Pennsylvania] programs.

- "Where is survival rate data by various years by transplant center?

- "I'm wanting to check which centers has done more liver re-transplantation from your site."

- "My husband has liver failure and I am interested in becoming a live liver donor… I am particularly interested in the volume of procedures and the success measures."

- "How do I get to find out how many transplants each transplant center did last year?"

Data for a specific disease or condition

- He stated he is HIV positive and transplant hospitals he talked to would not list him.

- Called and asked that one hospital won't put her on the list cause she is too sick. Wants to know why that is and what she should do.

- Patient called to ask about the Kidney transplant list, in particular how having a comorbidity of COPD [Chronic obstructive pulmonary disease] may affect their chances to be listed.

- Called and asked for help with finding centers that do PKD [polycystic kidney disease] patients

- "What (if any) is the specific waiting period before a patient would be eligible for a liver transplant following a diagnosis of colon cancer."

- Patient has Immunotactoid Glomerulonephritis was looking for information on centers that have done transplants on patients with this.

- Friend is in need of a liver and the hospital she is receiving care at won't transplant her because she has BC/BS [Blue Cross Blue Shield].

- Called to ask how to look for liver transplant centers for people with diabetes.

- "We have been waiting for a cholangiocarcinoma liver transplant for a year now at [California program]. We are willing to move to wherever we can in order to get a transplant."

Program Specific Reports

- Patient looking at print outs of Program Specific Reports (PSRs) and wondering if we could send him more information.

- Called to get help with interpreting the PSRs and what he should do.

Characteristics for transplant

- "I am interested in becoming a living liver donor. What would be the qualifications?"

Annual Data Report (ADR)

- "Called about living donation metrics in our ADR."

Data based on blood type

- "Can you suggest which state would have the shortest waiting list. He is 0 positive blood type."

Long-term survival or longest survival

- "I would like to know the longest living Kidney and Pancreas transplant person. My husband just celebrated his 20th year of having both organs."

Data based on age or age limits

- "I am trying to locate lung transplant facilities that will do an evaluation on someone 65 y/o or older"

- "One suggestion is that you start to track who will do transplants over 70."

- "Do you have data for liver transplants by age of recipient?"

Average or median MELD

- "How do you find out the Median MELD per Liver Transplant Center?"

- "What are the qualifications for someone to be place on the transplant list? Is there a specific MELD score that they must have?"

- "I was hoping to find the specific MELD score that hospitals put you on the transplant list"

Explain an abbreviation

- "What does # of Txs [transplants] mean on your chart listing Kidney Transplant Centers?"

- "How do you know what the abbreviations mean on the charts and reports?"

Explain "expected" outcome

- Asked specific questions about the "As expected" label and how we determine that.

Note: Statements in quotations were verbatim requestor quotes; other statements were paraphrased by SRTR staff.

COPD, chronic obstructive pulmonary disease; MELD, model for end-stage liver disease; PKD, polycystic kidney disease; SRTR Scientific Registry of Transplant Recipients.

Table 3

Range of Data and Statistics Requests From General to Advanced

General or Basic Data and Statistics Requests and Comments
• "Also, what is the difference between adult graft survival and adult patient survival?"
• Several simple questions about the meaning of things on the site including what does percentile mean in waitlist table.
• "I'm not entirely familiar with how your database obtains transplant data. Could you provide a brief explanation?"
Advanced Data and Statistics Requests and Comments
• "I am trying to compare this process (plasmapheresis using a live donor with a different blood type) vs. Using a deceased donor with the same blood type, with the deceased donation occurring both before dialysis and after dialysis to understand which has the higher survival all [sic] rates."
• "My sister is on the liver transplant list at the [Western region program] and has been on it for quite a while. Recently we started to use the liver transplant outcomes calculator to look at the potential outcomes at [Western region program]…compared to other centers."
• "The individual outcomes are not significantly different when measured against the expected outcomes of each transplant center after risk adjustment."

Table 4

UNOS Patient Services Entries

Data and Statistics Requests	Number
Program-specific information	1078
Long-term survival rates	227
Median waiting time	222
Monthly snapshot [monthly overview of national waiting list]	57
Total	1584
General Patient Information Requests	
Transplant process	3114
UNOS corporate	2214
Transplant program/OPO phone number	2160
Transplant program list	2142
Organ donation	1554
Medical questions	1309
Financial issue	788
Insurance issue	472
Thank you letter [e.g., letter to donor family]	455
Program or doctor concerns	381
Coalition referral [e.g., refer to non-UNOS organization]	349
Contact donor/recipient family	349
Ethical issue	255
Product catalog	161
Patient profile, article, news	160
Total	15,863

OPO, organ procurement organization; UNOS, United Network for Organ Sharing.

Table 5

UNOS Patient Services Entries by Type of Requestor

Entry	Number
Unknown	18 535
Transplant candidate	13 661
Family/friend of a patient	10 497
Living donor	3870
Healthcare professional	3420
Potential donor	2187
Other	2110
Transplant recipient	726
Family/friend of a donor	356

UNOS, United Network for Organ Sharing.