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Factors Enabling Transplant Program Participation in the Scientific Registry of Transplant Recipients (SRTR) Living Donor Collective: A National Survey

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Abstract

The Scientific Registry of Transplant Recipients (SRTR) Living Donor Collective (LDC), the first effort to create a lifetime registry for living donor candidates in the United States, requires transplant centers to register candidates while the SRTR conducts follow-up. To better understand facilitators and barriers to program participation, we conducted a brief electronic survey of U.S. transplant program staff from 10/26/2021–12/17/2021. We received 132 responses, with at least one response from 87 living donor programs (46 kidney programs, 33 kidney and liver programs, and 8 liver programs alone). We found 86% of program representatives strongly agreed or agreed that funding adequate to cover the cost of data collection would facilitate LDC participation, 92% agreed or strongly agreed with importance of electronic data submission options, and 74% reported that elimination of requirements to submit duplicative pre-operative information to the Organ Procurement and Transplantation Network (OPTN) would be helpful. Other potentially enabling factors include reduction in duration of OPTN follow-up requirements, ease-of-use,

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CONTRIBUTIONS STATEMENT

K.L.L. and B.L.K. drafted the manuscript. K.L.L. and A.W. were responsible for data acquisition and analysis. All authors contributed to study design, data interpretation, and critical editing of the manuscript.

IRB/ETHICS STATEMENT

The survey was approved by the Saint Louis University Institutional Review Board.

COI STATEMENT

KLL, DAA, and BLK are senior scientists for the SRTR. KLL, MAD, FA, ML and ADW contributed to the LDC in roles at pilot sites.

protection from data use for regulation, adequate data security, and equity in data access. Collaboration and investment to overcome barriers to program LDC participation are vital to generate long-term data on living donation for donor candidates, donors, and patients in need of transplant.

Keywords

Follow-up care; Living kidney donors; Registry; Survey; SRTR

INTRODUCTION

The follow-up of living organ donors has been a long-standing challenge in the transplant community. The life-time risks of living donation are thought to be low, but evidence is sparse.[1] Much of the evidence to quantify risks has been limited to retrospective observational studies that lack comparable controls and have short observation periods, a high proportion of loss to follow-up, insufficient statistical power to quantify rare events, and limited racial and ethnic diversity. Starting in 2013, the Organ Procurement and Transplantation Network (OPTN) mandated that transplant centers report routine follow-up laboratory and clinical data for living donors at 6 months, 12 months and 2 years postdonation.[2] In practice, achieving donor follow-up compliance has been difficult, and two years is insufficient to capture the effects of donation that may have life-long implications.[3,4]

Successful models to capture long-term information on living donor outcomes exist in other countries, particularly those with universal healthcare systems. For example, all living donors in Switzerland are registered in the Swiss Organ Living Donor Health Registry, which collects information from general practitioners at one-year after donation and biennially afterwards.[5] In Norway, donors are offered cost-free, life-long medical follow-up and information on each donor is kept in the Norwegian Living Kidney Donor Registry.[6] Australia and New Zealand have similar universal healthcare systems.[7] The United States has lacked a long-term donor registry, but recently the Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services, established the Living Donor Collective (LDC), an effort to create a lifetime registry for all donor candidates evaluated at a U.S. transplant center administered by the Scientific Registry of Transplant Recipients (SRTR).[8,9] 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. Under this model, transplant centers register candidates *and the SRTR is responsible for follow-up*. The project began as a pilot and is now expanding with a goal of universal national participation.[10,11]

The LDC defines a “living donor candidate” as a person who was pre-screened as a potential donor and comes to a transplant center for further donor evaluation.[8] This includes individuals who are pre-screened and evaluated remotely via telemedicine. In addition to forming the foundation of a long-term follow-up registry, registering candidates can provide critical information about candidate-to-donor conversion and barriers to proceeding with

living donation.[10] To better understand potential barriers to voluntary program participation in the LDC, we conducted a brief survey of U.S. transplant program staff.

MATERIALS AND METHODS

Survey Design

The survey instrument was developed by the study investigators and informed by experience with the LDC pilot.[8,9,12] The survey began with a brief explanation of the purpose of the LDC and a link to the program website: https://www.livingdonorcollective.org/. The LDC asks programs to register candidates who were seen for living donor evaluation at the center, and the SRTR conducts follow-up. Participants were asked to "Please indicate the degree to which each of the following would enable your living donor program to participate or continue participation in the Living Donor Collective (LDC)" for 9 considerations and were given the opportunity to respond with free text. This survey study was approved by the Saint Louis University (SLU) Institutional Review Board (IRB Protocol #31418) and conducted at SLU independently of the SRTR. The survey was also approved by American Society of Transplantation (AST) Communities of Practice (COPs).

Survey Administration

The target population was staff at U.S. living donor transplant programs (administrators, nephrologists, surgeons, coordinators, and social workers). Potential participants were derived from the working group's professional connections and solicitation through professional society listservs (e.g., AST Living Donor Community of Practice (LDCOP), Kidney-Pancreas Community of Practice (KPCOP), Liver Intestine COP (LICOP), Transplant Administration and Quality Management (TxAQM COP). COP postings were approved by COP leadership. The survey was distributed between 10/26/2021 and 12/17/2021 through Qualtrics Survey Software. Up to two reminders were provided for non-respondents. The first page of the survey noted that the decision to proceed indicated informed consent to participate, and that responses would be reported anonymously.

Statistical Analysis

Each transplant program was represented once in the primary analysis. Representative responses from programs with multiple respondents were selected using a hierarchical algorithm, similar to previous methods.[13–17] For the current survey, we prioritized responses from from surgeons or nephrologists, followed by administrators, coordinators and other roles. Finally, if there was still more than one response per transplant center, we retained the most recent (latest) response.

Responses to each question were described using percentages reflecting proportions of respondents. To assess possible relationships of survey responses with program volume or follow-up rates, we examined Scientific Registry of Transplant Recipients (SRTR) data (Table S1). For representation of living donor recovery volume, we considered a period of 12 months prior to the beginning of COVID-19 pandemic (March 2019-February 2020). For baseline kidney program follow-up rates, we considered complete 6-month follow up rates (clinical and laboratory testing) for living donations in October 2018–September

2019, to allow time for reporting before the pandemic. Kidney programs were categorized as “smaller” and “larger” volume based on the median (n=18) of all active transplant programs, and as “lower” or “higher” rates of follow-up, based on the median of 6-month follow-up compliance (83%). Volume and follow-up based stratifications were deferred for liver programs due to smaller volume in current practice. Analyses were performed using SAS version 9.4. Stratified response rates were assessed for trends by Chi-square analysis.

RESULTS

Survey Participants

We received 132 survey responses. There was at least one response from 87 living donor programs including 46 kidney programs, 33 kidney and liver programs, and 8 liver programs alone. Only 10 programs were participating in the Collective at the time of the survey (7 kidney and liver programs, 3 kidney-only programs). Kidney program respondents represented 40% (78/195) of living kidney donor recovery programs and 52% of baseline living kidney donation procedure volume. Liver program respondents represented 54% (28/52) of living liver donor recovery programs and 70% of baseline liver donation volume. All geographical areas were represented (Table 1A). Among kidney programs, 24 respondents represented “smaller” volume programs and 55 “larger” volume programs; 36 versus 43 respondents were from centers with “lower” versus “higher” 6-month follow up completion rates, respectively (Table S1). Surgeons were most commonly represented (38%), followed by nephrologists (32%), administrators (9%), coordinators (9%), and hepatologists (8%).

Funding and Efficiency

Eighty-six percent of program representatives strongly agreed or agreed that funding adequate to cover the cost of data collection and data entry for candidate registration would facilitate LDC participation, while only 2% disagreed or strongly disagreed (Table 1B). Ninety-two percent agreed or strongly agreed that having options to submit registration data electronically would enable participation. While 74% reported that elimination of requirements to submit pre-operative donor candidate demographic and clinical information to the OPTN when their program submits those data to the LDC would be helpful, 22% were neutral on this topic and 4% disagreed or strongly disagreed. Reduction in the duration of post-donation OPTN-required follow-up data collection, to compensate for effort spent registering candidates in the LDC, was anticipated to enable LDC participation by 59%, while 23% felt neutral, and 17% disagreed or strongly disagreed that such a change would facilitate LDC participation.

Data Sharing and Research Opportunities while Maintaining Privacy

Eighty-six percent of respondents strongly endorsed or endorsed assurance that submitted data remain private and not be used for regulatory or insurance contracting purposes as motivation to participate. Nearly all (91%) identified assurance that participation in the LDC will not preclude their program’s ability to collect living donor follow up data for research or clinical purposes as enabling to participation. Assurance that the LDC will not require programs to provide additional donor contact information in the years after donation was

rated as enabling by 84%. Finally, 88% felt the ability to obtain data from the LDC on the program's donors during follow-up would motivate participation, and 83% were motivated by ability to obtain and use de-identified data on all LDC participants for research projects. Patterns amongst all respondents were similar to patterns among the single representative responses per center.

Trends in Responses Stratified by Program Type, Respondent Role, Volume and Baseline Follow-up

Responses stratified by program type, role, volume and follow-up success did not differ significantly (power limited by sample size) but were examined for trends. Patterns did not differ substantially by represented program type, although respondents representing single organ programs tended to more commonly express strong agreement compared to those representing both kidney and liver programs (Figure 1). Considered by respondent role, administrators tended to agree most strongly with benefits of the option to submit registration data electronically and with importance of assurance that LDC data remain private and are not used for regulation (Figure 2). Responses of kidney program representatives did not differ substantially according to baseline volume or 6-month follow-up rates (Table S1).

Free Text Comments

In free text comments, some respondents expressed support for the importance of the effort, and interest in participating (Table S2). However, some respondents also expressed concerns for adequate funding to compensate for the time of participating, and the importance of ease-of-use, adequate data security, and equity in data access.

DISCUSSION

Successful creation of a national living donor registry in the United States will require collaboration of transplant programs and living donors with a robust registry infrastructure that minimizes burdens to participants. Under the LDC model, the workload for transplant programs focuses on registering candidates, an essential first step in building the denominator for the registry. This national survey of kidney and liver living donor recovery program staff identified factors that transplant program staff believe will enable program participation in the LDC, including cost recovery, electronic data submission, reduction in OPTN data submission requirements, protection from data use for regulation, and opportunities for research.

Obtaining the short- and long-term information that will result from the registering donor candidates will improve understanding of which candidates proceed to donation and potential barriers to donation, provide ongoing information on long-term outcomes, and enable comparison of postdonation outcomes to controls (e.g., candidates who were approved but did not donate for recipient reasons). Such data are relevant to safely expanding living donation, a topic of interest for programs, payers and policy makers. In theory, the cost of staff effort for registering candidates for living donation could be covered

by the Centers for Medicare and Medicaid Services reimbursement of organ acquisition. However, it is unclear whether this is currently being done.

Electronic data submission can streamline the work of registry participation for programs. To date the LDC has developed templates for batch data submission and is developing systems whereby programs can extract data from electronic donor candidate intake systems or electronic health records. Maturation and expansions of these systems are anticipated to create opportunities for program participation with effort limited to initial onboarding and some period maintenance.

The data collected by programs participating in the LDC are limited to candidate registration and, for candidates who did not donate, reasons why donation did not occur.[18,19] The SRTR conducts follow-up. Harmonizing and minimizing living donor data collection by the LDC and the OPTN is a topic of active discussion, and an OPTN workgroup has been formed to discuss and offer recommendations on the best approach to collect meaningful data in the most efficient manner.[20–22]

To share data with stakeholders, programs that participate in the LDC receive semi-annual, private, secure reports summarizing data for their LDC registrants compared to national averages that they may use for program assessment and quality improvement projects. The first LDC Annual Data report was published in 2022,[10] along with periodic publications describing progress transitioning from a pilot to a national registry.[8,9,12] The LDC will also provide a valuable resources and foundation for conduct of research, such as focused surveys of topics of interest to donors like pregnancy issues or long-term quality of life studies.

This survey study has limitations. Survey respondents may include a higher proportion of individuals who are especially interested in the topic. We do not know whether survey respondents were aware of the existence of the LDC. The findings represent facilitating factors as reported by program staff, but we cannot know from this survey whether changes such as covering the cost of data collection, reducing OPTN data collection requirements or other measures would increase voluntary participation in the LDC. While not all programs are represented, the 40–52% center-level response rate is similar to or higher than many contemporary studies of transplant program practices[15,23–27] (where response rates in 30%-range are common), and responding programs represented 52% of living kidney donor recovery volume and 70% of living liver donor recovery volume. This survey assessed the perspective of transplant program staff, and did not capture the perspective of donor candidates and donors, a vital stakeholder group for success with engagement in long-term follow-up.[28]

In response to the information in this survey, the LDC is taking steps to minimize burdens to participating programs, inclucing: 1) Collecting only essential data as determined by the programs participating in the LDC pilot. 2) Ongoing and increasing efforts to make automated, electronic submission of data possible for programs who want to use such data submission options. Specifically, the LDC is working with major electronic healthcare system providers to establish batch upload capabilities of the data collected by the LDC. 3) *Not* requiring programs to provide any additional donor follow-up data. 4) Working

with the OPTN to examining the data living donor data collection holistically, in efforts to collaboratively address the data requested by the community in the most efficient manner.[21,22] These efforts will be ongoing

In summary, this survey presents potential targets to strengthen participation in the effort to create a national living donor registry in the United States. Collaboration and investment to overcome barriers to program participation in the LDC are vital to ensure success and generate long-term data on living donation for donor candidates, donors, patients in need of transplant, and families.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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DATA AVAILAIBLITY STATEMENT

Survey data are available in aggregate form, per IRB requirements. SRTR data reported were supplied by the Hennepin Healthcare Research Institute (HHRI) as the contractor for the Scientific Registry of Transplant Recipients (SRTR). The interpretation and reporting of these data are the responsibility of the authors and in no way should be seen as an official policy of or interpretation by the SRTR or the U.S. Government. SRTR registry data can be obtained from the SRTR.

Abbreviations:

AST	American Society of Transplantation
HRSA	Health Resources and Services Administration
LDC	Living Donor Collective
OPTN	Organ Procurement and Transplantation Network
SRTR	Scientific Registry of Transplant Recipients

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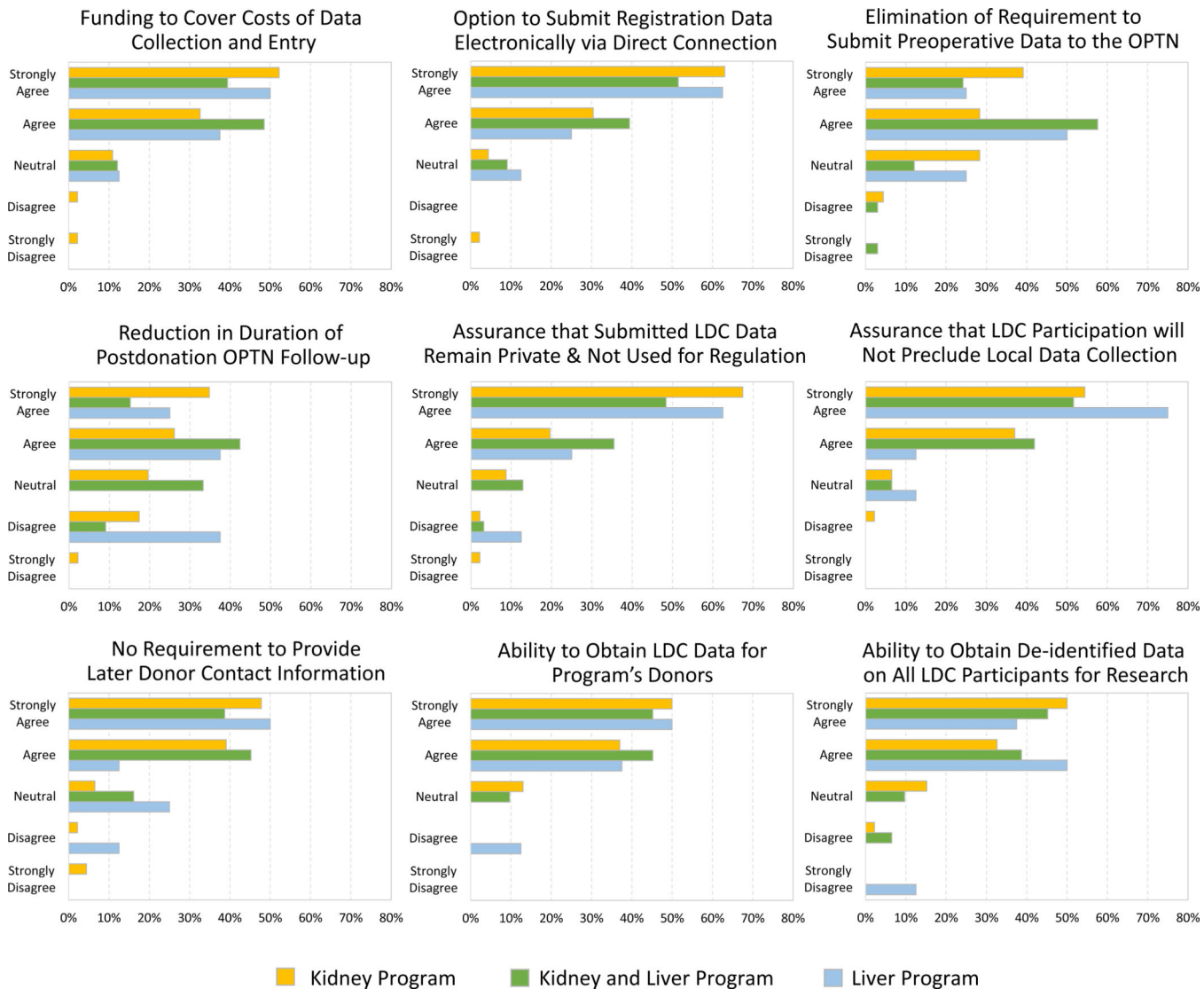

Figure 1.

Facilitating factors for Living Donor Collective participation, by represented program organ type.

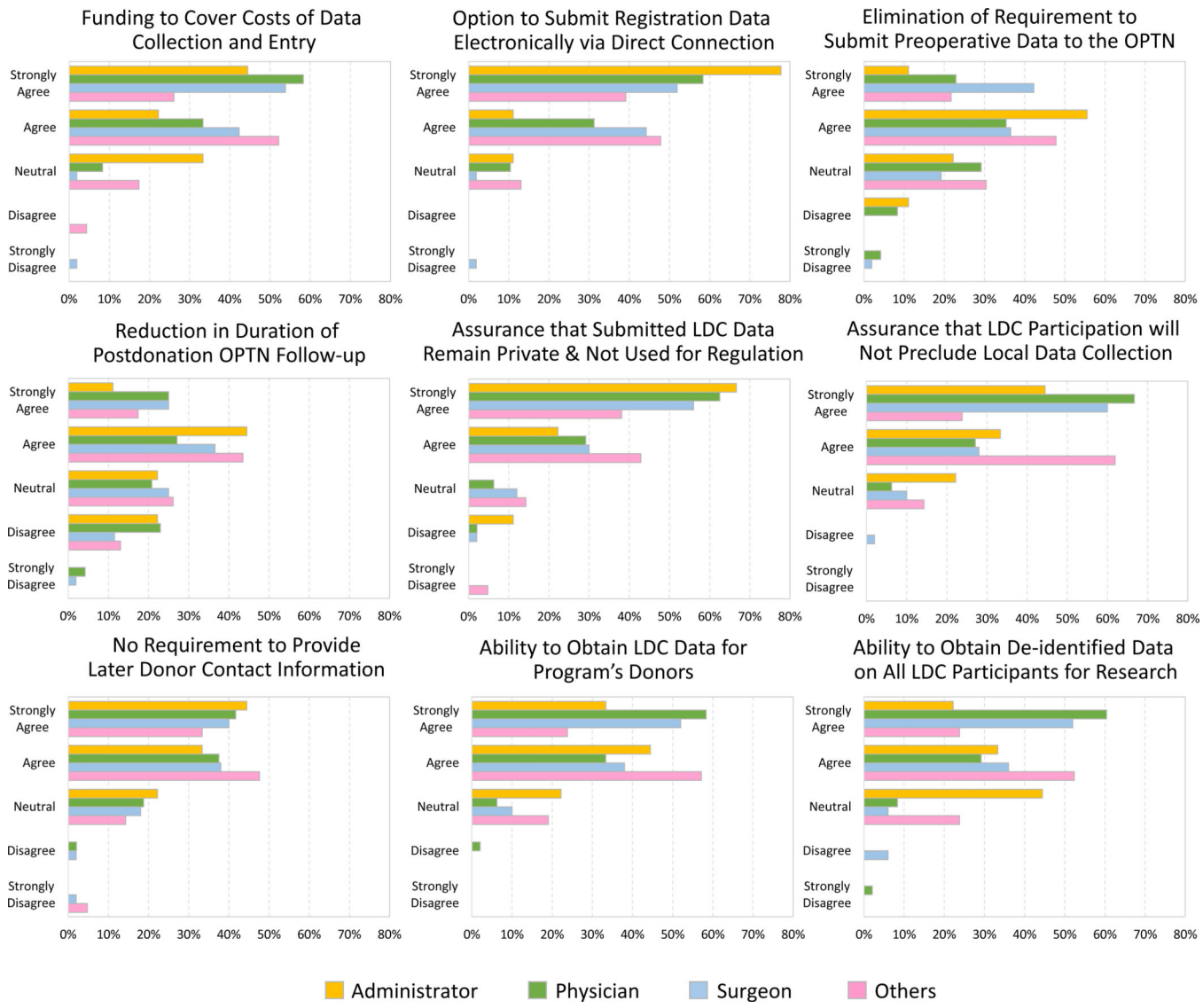

Figure 2.

Facilitating factors for Living Donor Collective participation, by role of representing respondent.

Table 1A.

Participant Role and Representation

Role in Transplant Program	**All Responses**	**Selected Center Responses**
	% (n=132)	**% (n=87)**
Administrator	7% (9)	9% (8)
Surgeon	39% (52)	38% (33)
Nephrologist	29% (38)	32% (28)
Hepatologist	8% (10)	8% (7)
Coordinator	11% (15)	9% (8)
Data Coordinator	0 (0)	0 (0)
Social Worker	2% (2)	0 (0)
Independent Living Donor Advocate	0 (0)	0 (0)
Other *	5% (6)	3% (3)
Geographical Region	**% (n=132)**	**% (n=87)**
Northwest	5% (6)	3% (3)
Southwest	14% (19)	14% (12)
North Midwest	11% (15)	10% (9)
South Midwest	7% (9)	6% (5)
Great Lakes	14% (19)	14% (12)
Southeast	21% (28)	24% (21)
Mid Atlantic	10% (13)	13% (11)
Northeast	17% (23)	16% (14)
Respondent represents a **Kidney** Program, **Liver** Program, or **both** Kidney and Liver	**% (n=132)**	**% (n=87)**
Kidney	52% (68)	53% (46)
Kidney and Liver	41% (54)	38% (33)
Liver	8% (10)	9% (8)

* Other: Compliance Manager; Quality Director; Quality Director; Quality Manager; Research Surgeon

One represenatative response per center was selected by a hierarchical algorithm, per prior methods [13–17] (here prioritizing response from surgeons or nephrologists, followed by administrators, coordinators and other roles; if there was still more than one response per transplant center, the most recent (latest) response was selected)

Table 1B.

Facilitating factors for Living Donor Collective participation.

	All responses	Selected Center Responses
Funding adequate to **cover** the **cost of data collection** and data entry for candidate registration	**% (n=132)**	**% (n=87)**
Strongly disagree	1% (1)	1% (1)
Disagree	1% (1)	1% (1)
Neutral	9% (12)	11% (10)
Agree	39% (52)	39% (34)
Strongly agree	50% (66)	47% (41)
Options to **submit registration data electronically** via a **direct data connection** to the LDC system	**% (n=132)**	**% (n=87)**
Strongly disagree	1% (1)	1% (1)
Disagree	0% (0)	0% (0)
Neutral	8% (10)	7% (6)
Agree	38% (50)	33% (29)
Strongly agree	54% (71)	59% (51)
Elimination of requirements to submit pre-operative donor candidate demographic and **clinical information** to the **OPTN** when your program submits those data to the LDC	**% (n=132)**	**% (n=87)**
Strongly disagree	2% (3)	1% (1)
Disagree	4% (5)	3% (3)
Neutral	25% (33)	22% (19)
Agree	39% (52)	42% (36)
Strongly agree	30% (39)	32% (28)
Reduction in the **duration** of **post-donation OPTN-required follow-up** data collection, to compensate for effort spent registering candidates in the LDC	**% (n=132)**	**% (n=87)**
Strongly disagree	2% (3)	1% (1)
Disagree	17% (22)	16% (14)
Neutral	23% (31)	23% (20)
Agree	35% (46)	33% (29)
Strongly agree	23% (30)	26% (23)
Adequate **assurance** that data your program submits to the LDC **remain private** and **not be used for regulatory** or **insurance contracting** purposes	**% (n=128)**	**% (n=85)**
Strongly disagree	1% (1)	1% (1)
Disagree	2% (3)	4% (3)
Neutral	9% (12)	9% (8)
Agree	31% (40)	26% (22)
Strongly agree	56% (72)	60% (51)
Adequate **assurance** that participation in the LDC **will not preclude your program's ability** to **collect living donor follow up data** for **research** or **clinical purposes**	**% (n=128)**	**% (n=85)**
Strongly disagree	0% (0)	0 (0)
Disagree	1% (1)	1% (1)
Neutral	10% (13)	7% (6)

	All responses	Selected Center Responses
Agree	34% (43)	36% (31)
Strongly agree	55% (71)	55% (47)
Adequate **assurance** that the LDC **will not require your program to provide additional donor contact information** in the years after donation	**% (n=128)**	**% (n=85)**
Strongly disagree	2% (2)	2% (2)
Disagree	2% (2)	2% (2)
Neutral	18% (23)	12% (10)
Agree	39% (50)	39% (33)
Strongly agree	40% (51)	45% (38)
Ability to **obtain data** from the LDC on **your program's donors** (in either individual or aggregate form) during follow-up	**% (n=128)**	**% (n=85)**
Strongly disagree	0% (0)	0% (0)
Disagree	1% (1)	1% (1)
Neutral	11% (14)	11% (9)
Agree	40% (51)	40% (34)
Strongly agree	48% (62)	48% (41)
Ability to **obtain** and **use de-identified data** on all LDC participants for **research** projects	**% (n=128)**	**% (n=85)**
Strongly disagree	1% (1)	1% (1)
Disagree	2% (3)	4% (3)
Neutral	13% (16)	12% (10)
Agree	36% (46)	36% (31)
Strongly agree	48% (62)	47% (40)