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# International Travel for Organ Transplantation: A Survey of Professional Experiences and Attitudes Toward Data Collection and Reporting

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**Background.** Lack of data regarding international travel for organ transplantation (ITOT) hampers efforts to evaluate, understand, and respond to trends in ITOT activities, such as those suggestive of organ trafficking or “transplant tourism.” This study aimed to assess transplant professionals’ experience of ITOT and their attitudes toward reporting ITOT data to a global registry. **Methods.** An international cross-sectional anonymous survey of transplant professionals was conducted online (from October to December 2022). The English language questionnaire assessed professional experiences in providing care to individuals who had traveled to or from a country for living donation or transplantation, and attitudes toward reporting of ITOT data. Data were analyzed with descriptive statistics. **Results.** Two hundred thirty-nine individuals from 68 countries completed the entire questionnaire, of whom 79% had provided care for  $\geq 1$  patient who had traveled internationally for donation or transplantation. Of these, 60.8% of individuals ( $n = 115$ ) had cared for  $\geq 1$  person who engaged in ITOT between 2019 and 2022, with the most recent case experiences involving 89 countries and 157 unique routes of international travel. Predominant concerns regarding reporting of ITOT data to a global registry related to prevention of harm and protection of patient privacy; most (52.7%;  $n = 126$ ) respondents expressed a preference for anonymous reporting of ITOT data. **Conclusions.** ITOT is a global phenomenon and transplant professionals’ experience with ITOT cases is more common than anticipated. Systems for the collection of ITOT activity data should be carefully designed to address potential ethical concerns of transplant professionals which may influence reporting practices.

(*Transplantation Direct* 2024;10: e1655; doi: 10.1097/TXD.0000000000001655.)

International travel for organ transplantation (ITOT) involves travel to or from another country to receive or donate an organ for transplantation.<sup>1</sup> International travelers for organ transplantation may be transplant recipients (individuals who travel or have traveled to another country for the purpose of receiving a transplant) or living donors (individuals who travel or have traveled to another country for the purpose of donating an organ). Such travel may involve ethically legitimate donation and transplant activities, but sometimes it involves unethical or even illegal activities. ITOT that involves organ trafficking or transplants that undermine the ability of

destination countries to meet the needs of their own residents is termed “transplant tourism.”<sup>1</sup>

Surveys have previously suggested that approximately 40%–60% of transplant professionals in some countries have provided care for an individual who has received a transplant in another country at least once in their career.<sup>2–4</sup> However, little is known about the proportion of professionals who have provided care for international patients who have traveled to the professional’s country for organ donation or transplantation. The global incidence and prevalence of ITOT are unknown, and there is scant information about most countries

Received 21 February 2024.

Accepted 14 March 2024.

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The study was partially funded by the Declaration of Istanbul Custodian Group, the Transplantation Society and the International Society of Nephrology.

G.L.I., R.A.S.F., E.R., S.N., P.T.C., and D.E.M. are members of the Declaration of Istanbul Custodian Group. M.A. declares no conflicts of interest.

G.I. and D.M. designed the initial study protocol and questionnaire, collected and analyzed data and wrote the first draft of the article. R.A.S.F., E.R., S.N., M.A., and P.T.C. participated in design of the protocol and questionnaire, assisted with data analysis, and contributed to revisions of the article.

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ISSN: 2373-8731

DOI: 10.1097/TXD.0000000000001655

**TABLE 1.**  
**International organizations contacted during recruitment in addition to national societies**

International societies (global)	International societies (regional)
International Liver Transplant Society	African Association of Nephrology
International Pediatric Transplant Association	African Society of Organ Transplantation
International Pancreas and Islet Transplant Association	Asia Pacific Society of Nephrology
International Society for Heart and Lung Transplantation	Asian Society of Transplantation
International Society of Nephrology	Central American and Caribbean Association of Nephrology
International Transplant Nurses Society	European Renal Association
The Transplantation Society	European Society of Organ Transplantation
Women in Transplantation	Latin American Society of Nephrology and Hypertension
	Middle Eastern Society of Organ Transplantation
	Scandia Transplant

currently involved in ITOT or the proportion of transplant professionals who may have had recent rather than historical experience with ITOT cases. Lack of data limits efforts to investigate, monitor, and respond where necessary to trends in activity that raise concern, such as increasing travel by transplant candidates that may involve organ trafficking, undermine self-sufficiency in a destination country, or be indicative of unmet transplant needs in the candidates' country of origin.

Longstanding calls to address this data gap include recommendations to develop national ITOT case reporting systems and "identification systems that facilitate tracing each organ from donor to recipient and vice versa."<sup>5,6</sup> Establishment of a worldwide case registry to enable reporting of ad hoc ITOT cases by transplant professionals, particularly for cases suspected to involve organ trafficking has also been proposed.<sup>7,8</sup> However, transplant professionals' willingness to be involved in collection and reporting of information about ITOT cases is largely unknown. Findings from a qualitative Dutch study indicated that some professionals may be hesitant to ask patients about or to report information relating to ethically suspicious ITOT, especially if patient or clinician anonymity is not assured.<sup>8</sup> However, these results may not reflect professional attitudes to systematic data collection and reporting of ITOT cases in general.

We report here on selected findings from a cross-sectional survey study that aimed to assess clinicians' attitudes toward reporting of all ITOT cases, not only those suspected to involve unethical or unlawful activities. We also aimed to estimate the proportion of transplant professionals with recent experience in providing care for patients who travel internationally for organ donation or transplantation and to evaluate their willingness to collect and report information about cases of ITOT to a global registry.

## MATERIALS AND METHODS

### Study Design

This was an international cross-sectional anonymous survey of transplant professionals.

### Target Population

All transplant professionals, defined as "registered health professionals with experience in providing care for organ donors or transplant recipients" with sufficient English language proficiency were eligible to participate in the study.

### Recruitment

Between 4 October and November 30, 2022, study information including a link to access the online survey was disseminated via professional society networks. As parent organizations of the Declaration of Istanbul Custodian Group (DICG) and sponsors of the study, the International Society of Nephrology (ISN) and The Transplantation Society (TTS) sent the survey invitation to their members at least twice via email in society newsletters. The research team also personally emailed the current leadership of approximately 130 national and international organ transplantation and nephrology societies asking them to disseminate the invitation to their members (see Table 1). The survey was also promoted via posts on social media platforms X (formerly known as Twitter) and LinkedIn. After the initial round of promotion, a second communication wave approximately 1 mo later reminded individuals and organizations of the survey and encouraged participation.

### Questionnaire Instrument

The questionnaire was designed by a multidisciplinary group including transplant surgeons, nephrologists, and an ethicist. The initial draft questionnaire prepared by authors G.I. and D.M. was reviewed by and revised in response to feedback received from the members of the research team and selected transplant professionals from each region of the world with experience of varying types of ITOT. The questionnaire was also pilot-tested in its final online form by the authors, selected transplant professionals with limited knowledge of ITOT, and those for whom English was a second language to ensure usability and technical functionality.

The questionnaire highlighted a broad, normatively neutral definition of ITOT and used progressive prompts to participants to reflect on their most recent case of each type of ITOT to encourage consideration of all ITOT case experiences not solely those associated with suspicions of organ trafficking.

The questionnaire was presented in English. Confirmation of informed consent to participate in the study was required before accessing the questionnaire. Adaptive questioning was used with branching logic so that participants would only be exposed to follow-up questions if they answered yes to the initial questions. The survey comprised 3 sections addressing participant demographics; experiences of 4 ITOT case types; and practices and attitudes relating to collection and reporting of ITOT data to national and international transplant registries.



**FIGURE 1.** ITOT routes of travel taken between January 1, 2019 and November 30, 2022 in respondents' most recent case experiences. This depicts the unique routes of travel taken between countries in the most recent ITOT cases encountered by respondents, it does not quantify case load or frequency of route use. See Figure 3 for a depiction of countries represented among destinations and origins of ITOT. ITOT, international travel for organ transplantation

Respondents could move forward and backward through the survey. An affirmative response to questions regarding any experience of a particular type of ITOT case triggered further questions soliciting details about the most recent case of that type which the participant had experienced. These details included the donor/recipient's country of residence at the time of travel, the destination country, and the year in which the donation or transplant occurred.

For all questions, participants were able to select an option indicating they did not know, were unsure, or preferred not to answer, enabling analysis to distinguish between missing information that may reflect a reluctance to disclose rather than a lack of recall or knowledge.

### Data Collection

Data were collected between October 4 and November 30, 2022 and managed online using the Research Electronic Data Capture software platform, hosted at The University of Adelaide.<sup>9</sup>

### Analysis

Responses were analyzed using descriptive statistics using Stata/IC 17.0 (Stata Corp, College Station, TX). All continuous variables were presented as means with SDs or as median with interquartile ranges depending on the variable distribution. Categorical variables were presented as proportions. The map shown in Figure 1 was created using Flowmap Blue.<sup>10</sup> Countries were classified by income using the World Bank categories,<sup>11</sup> and by region using the World Health Organization (WHO) categories.<sup>12</sup> ITOT route of travel was defined as the route taken by a person traveling from their country of residence to a country in which they donated or received an organ for transplantation. ITOT route analysis notably quantified unique routes of travel, not the number of reported ITOT case experiences associated with each route.

Responses from those who dropped out after completing the first or second sections of the questionnaire were included in some analysis after manual screening to remove potential duplicate incomplete responses. Only responses from participants who completed the entire survey were used in the analysis of data about ITOT experiences.

### Ethics

Human Research Ethics approval was obtained from the University of Adelaide, Australia H-2022-128.

## RESULTS

### Study Participants

The survey had an absolute completion rate of 56.5% with 423 individuals consenting to participate and 239 completing the entire questionnaire; 333 completed Section 1 (participant demographics) and 291 completed sections 1 and 2 (experience of ITOT). Demographics of those who completed the questionnaire and those who dropped out after completing section 1 or 2 are detailed in Table 2. There were no significant changes in the demographics of respondents who completed each section of the questionnaire.

Of respondents who completed Section 1, 51.4% (n = 171) identified as male, 47.1% as female, and 1.5% as nonbinary or preferred not to answer. Respondent ages were normally distributed, with 55.8% (n = 186) aged between 35 and 55 y. Respondents were from 68 countries (see Table 2); the majority were resident in Europe (43.4%, n = 144) and most were from high income countries (77.8%, n = 259). The majority of respondents were nephrologists (63.4%, n = 211) and most worked solely in the public health sector (64.3%, n = 209). Approximately one-third of respondents were members of the ISN (35.5%, n = 119) and/or TTS (34%, n = 114), and 8.4% (n = 28) were members of the DICG. Nearly half of respondents (46.9%, n = 157) were not members of any of these organizations.

**TABLE 2.**  
Participant demographics

Factor	Completed section 1	Completed sections 1 and 2	Completed entire questionnaire
N	333	291	239
Age, y			
18–25	4 (1.2%)	3 (1.0%)	2 (0.8%)
26–35	56 (16.8%)	46 (15.8%)	35 (14.6%)
36–45	94 (28.2%)	83 (28.5%)	64 (26.8%)
46–55	92 (27.6%)	81 (27.8%)	70 (29.3%)
56–65	61 (18.3%)	54 (18.6%)	47 (19.7%)
66–75	23 (6.9%)	21 (7.2%)	18 (7.5%)
>76	3 (0.9%)	3 (1.0%)	3 (1.3%)
Gender			
Female	157 (47.1%)	134 (46.0%)	108 (45.2%)
Male	171 (51.4%)	153 (52.6%)	128 (53.6%)
Nonbinary	1 (0.3%)	1 (0.3%)	1 (0.4%)
Prefer not to answer	4 (1.2%)	3 (1.0%)	2 (0.8%)
Occupation			
Surgeon	44 (13.2%)	41 (14.1%)	34 (14.2%)
Nephrologist	211 (63.4%)	184 (63.2%)	153 (64.0%)
Other Physician, for example, infectious disease, hepatologist	26 (7.8%)	23 (7.9%)	21 (8.8%)
Nurse	23 (6.9%)	22 (7.6%)	16 (6.7%)
Allied health	16 (4.8%)	14 (4.8%)	11 (4.6%)
Prefer not to answer	6 (1.8%)	2 (0.7%)	0
Other	7 (2.1%)	5 (1.7%)	4 (1.7%)
Workforce sector since January 1, 2019			
Public	209 (64.3%)	187 (64.9%)	153 (64.6%)
Private	24 (7.4%)	21 (7.3%)	16 (6.8%)
Both public and private	83 (25.5%)	72 (25.0%)	64 (27.0%)
Neither, not clinically active	9 (2.8%)	8 (2.8%)	4 (1.7%)
Organization member			
ISN	119 (35.7%)	103 (35.4%)	85 (35.6%)
TTS	114 (34.2%)	100 (34.4%)	87 (36.4%)
DICG	28 (8.4%)	24 (8.2%)	23 (9.6%)
WHO region			
Eastern Mediterranean	34 (10.2%)	29 (10.0%)	22 (9.2%)
Region of the Americas	54 (16.3%)	50 (17.2%)	43 (18.0%)
South East Asia	31 (9.3%)	23 (7.9%)	18 (7.5%)
European	144 (43.4%)	127 (43.6%)	101 (42.3%)
Western Pacific	61 (18.4%)	55 (18.9%)	48 (20.1%)
African	8 (2.4%)	7 (2.4%)	7 (2.9%)

(Continued)

**TABLE 2.**  
**Continued**

Factor	Completed section 1	Completed sections 1 and 2	Completed entire questionnaire
World bank income category			
Low income	3 (0.9%)	2 (0.7%)	2 (0.8%)
Low middle income	42 (12.6%)	36 (12.4%)	29 (12.1%)
Upper middle income	29 (8.7%)	24 (8.2%)	15 (6.3%)
High income	259 (77.8%)	229 (78.7%)	193 (80.8%)
Clinical care of transplant recipient or living organ donor since January 1, 2019			
Yes	314 (94.3%)	273 (93.8%)	231 (96.7%)
No	19 (5.7%)	18 (6.2%)	8 (3.3%)
Countries represented by respondents who began the survey and were willing to disclose	Albania, Andorra, Anguilla, Argentina, Australia, Austria, Azerbaijan, Bangladesh, Belgium, Bosnia and Herzegovina, Brazil, Bulgaria, Canada, Chile, China, Congo (Dem. Rep.), Costa Rica, Croatia, Cyprus, Ecuador, Egypt, Fiji, Finland, France, Germany, Greece, India, Iraq, Ireland, Israel, Italy, Japan, Libya, Lithuania, Malaysia, Mauritius, Mexico, Moldova, Morocco, Nepal, Netherlands, New Zealand, Norway, Pakistan, Peru, Philippines, Portugal, Puerto Rico, Qatar, Romania, Russia, Saudi Arabia, Senegal, Singapore, Slovak Rep., South Africa, South Korea, Spain, Sri Lanka, Switzerland, Syria, Tanzania, Trinidad and Tobago, Turkey, United Arab Emirates, United Kingdom, and United States		

DICG, Declaration of Istanbul Custodian Group; ISN, International Society of Nephrology; TTS, The Transplantation Society.

### Experience of ITOT

The majority of respondents who completed the entire questionnaire (79%, n = 189) reported previous experience in providing care for at least 1 patient who had traveled for donation or transplantation (see Figure 2A). Of these, 60.8% (n = 115) had seen at least 1 patient who engaged in ITOT between 2019 and 2022 (see Figure 2B). 48.1% (n = 115) of all completed survey respondents had direct experience of at least 1 ITOT case which had occurred within the last 4 y. Several respondents had experience with more than 1 type of ITOT case.

Between January 1, 2019 and November 30, 2022, 89 countries were involved as destinations or origin countries of ITOT (see Figure 3), when considering the respondents' most recent experiences of specific ITOT case types. As shown in Figure 1, 157 different routes were taken by individuals who traveled between 2019 and 2022 to donate or receive an organ transplant in these most recent cases reported by respondents who completed the entire questionnaire.

### Reporting of ITOT Data

Most respondents who completed the questionnaire (84.1%, n = 201) indicated there was a registry within their country that collects data about organ transplant activities; 9.6% (n = 23) indicated there was not, and 6.3% (n = 15) were unsure. The majority (75.7%, n = 181) indicated that reporting of all donation or transplantation activities to a national, state or provincial registry was mandatory.

When asked to imagine whether information about specific types of ITOT cases would be collected and submitted to various types of registry (see Figure 4), 62.3% (n = 149) of respondents indicated that data about incoming transplants involving international recipients would be reported to a national, state or provincial registry, compared with 52.7% (n = 126) for incoming donor cases, 38.9% (n = 93) for outgoing recipient cases, and 18.4% (n = 44) for outgoing living donor cases.

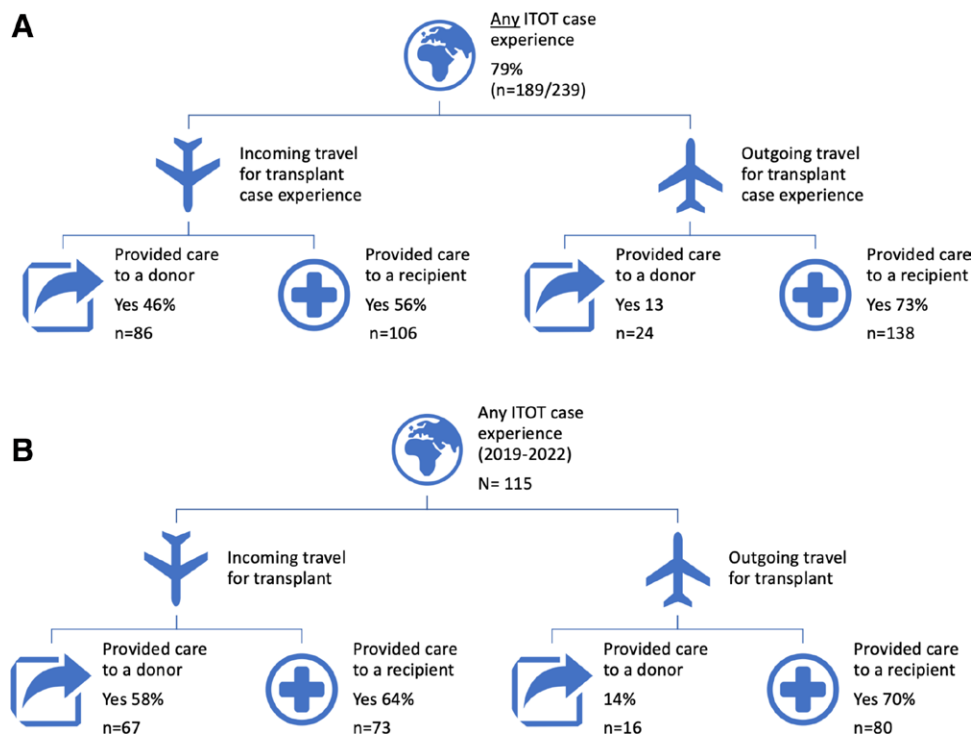
When asked to imagine there was a registry to which data about ITOT cases could be submitted (Table 3), a higher proportion of respondents reported they were very likely or likely (82.8%) to report incoming ITOT case data to a registry located within their own country than to an international registry outside their country (56.6%).

### Attitudes and Preferences Regarding a Global ITOT Registry

On a scale of 1 (not at all valuable) to 10 (most valuable), 59.8% of respondents (n = 143) rated the value of a potential global ITOT registry as >7; 32.6% rated it 5–7; 7.5% rated as <5. Table 4 shows the potential benefits of a global registry perceived by respondents.

Respondents identified several factors that would encourage them to report ITOT case data to an international registry. The 5 most commonly cited factors were confidence in data security (69.5%); confidence that data use would be beneficial for patients (68.2%); ability to preserve patient anonymity (66.1%); a legal requirement to report cases (65.3%); and mandated or recommended reporting of cases in professional guidelines (64%). Conversely, factors most commonly cited as discouraging reporting to an international registry were the risk of ITOT data use harming patients (67.4%); risk of patient being identified (64.4%); risk of data use harming





**FIGURE 2.** A, Proportion of respondents with any experience of ITOT cases before December 2022. B, Proportion of respondents with experience of ITOT cases that occurred between January 1, 2019 and November 30, 2022. ITOT, international travel for organ transplantation.

respondent, their colleagues or institution (55.6%); uncertainty regarding legality of reporting (55.9%); and the risk of respondents becoming involved as a legal case witness (47.3%).

The majority of respondents 52.7% (n = 126) indicated they would prefer to be anonymous when submitting a case of ITOT to an international registry; 24.77% did not; 22.6% were unsure.

TTS or the ISN was the preferred host of an international ITOT registry for 73.2% of respondents (n = 177); WHO (56.9%), the DICG (50.6%); none of these (3.7%), and other (3.4%).

## DISCUSSION

The need for routine collection of data concerning all organ donation and transplantation activities is well established.<sup>13</sup> The 2023 Santander Statement explicitly recommends that governments should mandate “the reporting of data on every donation and transplant procedure, as well as demographic, clinical, and outcome data of recipients and living donors to a registry established or recognized by the relevant health authority” to “ensure transparency and oversight of practices.”<sup>14</sup> In this cross-sectional international survey, we investigated transplant clinicians’ experiences of and attitudes toward reporting data relating to donation and transplant procedures that involve international travel. Our results indicate that many ITOT activities are not captured in registries within patients’ countries of origin or those to which they travel for donation or transplantation. Despite 75.7% (n = 181) of respondents indicating reporting of “all” transplant data was mandatory in their country, only 52.7% and 38.9% agreed that data about incoming international recipients or donors, respectively, would be reported to a registry within their country.

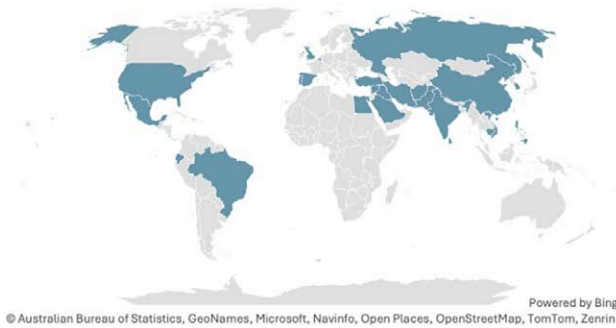
Lack of routine reporting of ITOT activity data are especially concerning as our results suggest that ITOT may be relatively common; 48.1% of transplant professionals may have had at least 1 ITOT experience within a 4-y period and some will have had more. It is striking that many of the most recent experiences reported by respondents occurred during the COVID-19 pandemic, during which transplant activities were reduced in most regions,<sup>15</sup> and international travel was not only profoundly restricted but also considered hazardous—especially for immunosuppressed persons such as transplant recipients.<sup>16</sup>

Previous surveys of transplant professionals in the Netherlands, the United Kingdom, and Australia have reported similar rates of experience with ITOT cases; however, these studies have focused only on experience with patients who returned after receiving a transplant overseas.<sup>2-4</sup> It was unclear whether reported ITOT experience rates between 46% and 63% were the result of cumulative historical career experience of ITOT in specific countries, and whether such experience predominantly reflected cases occurring during the so-called peak in transplant “tourism” observed in several countries during the mid-2000s.<sup>17-19</sup> As shown in Figure 2, retrospective estimates of professionals’ experience of ITOT based on their cumulative experience of at least 1 case are higher (79%) than estimates based on a specified recent time period (48%). Although the limitations of our sample population mean that results cannot be considered representative of all transplant professionals, it seems likely that professional experiences of ITOT cases are more common in contemporary practice than suspected, especially when considering both outgoing and incoming organ donors and recipients.

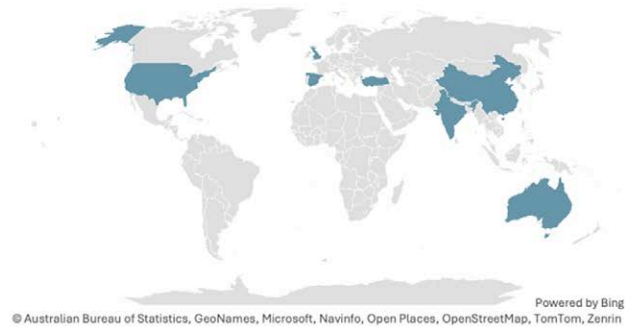
This finding is consistent with recently published aggregated data from the WHO Global Observatory of Organ Donation

# Combined maps of countries for ITOT

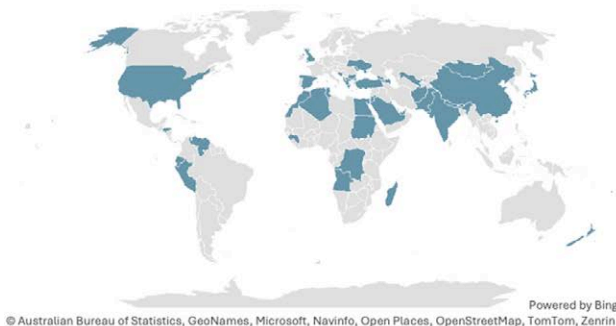
## Outgoing Recipients



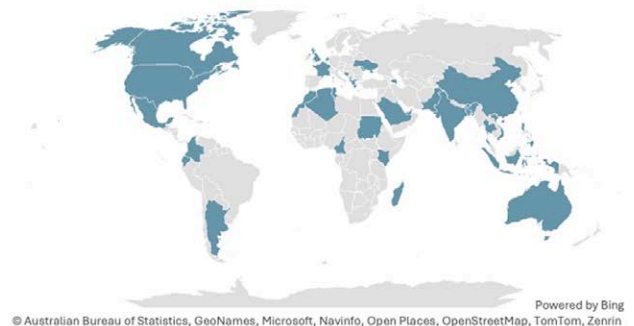
## Outgoing Donors



## Incoming Recipient



## Incoming Donors

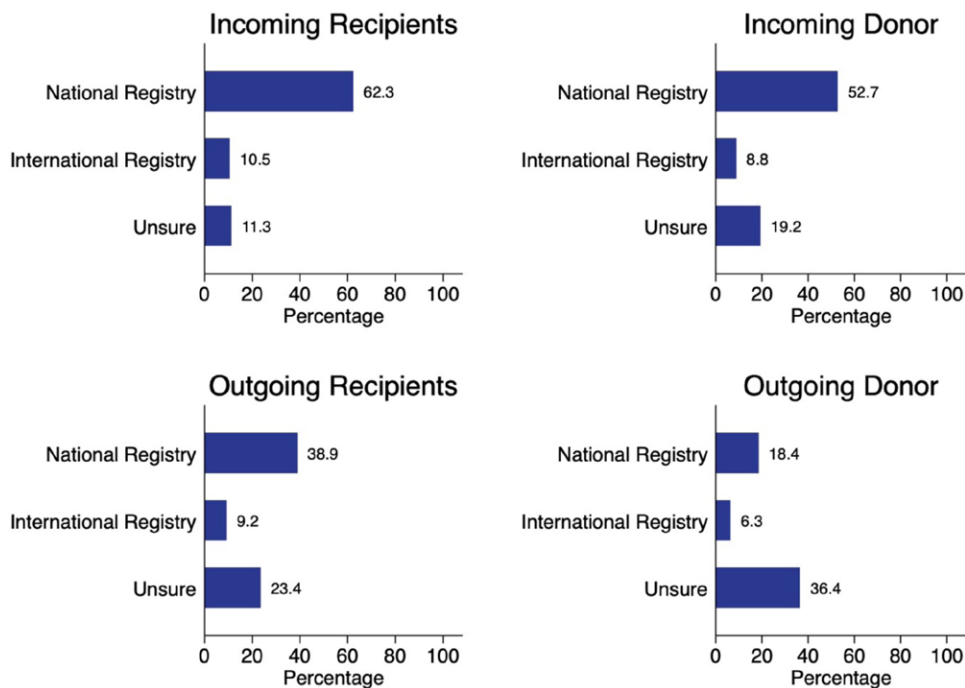


**FIGURE 3.** Countries from (outgoing) and to (incoming) which donors and recipients traveled in the most recent ITOT case experiences of respondents. ITOT, international travel for organ transplantation.

and Transplantation (GODT) that reveal considerable numbers of patients engaging in ITOT each year.<sup>20</sup> The GODT now requests that national health authorities report data concerning transplants performed in “nonresident” patients as part of their annual organ donation and transplantation activity data. According to the GODT, in 2022 “more than 2600 nonresident patients from 22 countries” were reported to receive a transplant from a living or deceased donor, and “at least 600 patients from 31 countries” were reported to have traveled to another country for transplant.<sup>20</sup> The GODT data are not currently published at the individual country level, thus comparative analysis with our results is not possible. It is also unclear how the term “nonresident” may have been interpreted by those submitting data to the GODT, as this was not defined in the GODT questionnaire.<sup>21</sup>

Although our data reflect experiences predominantly in Western countries, the results demonstrate that ITOT is a truly global phenomenon, involving at least 89 countries and 157 different routes of ITOT in the most recent case experiences reported by respondents that occurred after January 1, 2019. Al Ammary et al<sup>22</sup> reported that international living donors traveling solely to the United States during the period 2015–2016 were from 71 different countries, suggesting that our ITOT route numbers may be a significant underestimate. Nevertheless, the complex dynamics of travel revealed in this snapshot of 157 routes provides a clearer picture than is currently available via the more systematic data collection activity of the GODT.

It is evident from this study that clinicians may face several barriers in reporting ITOT case data locally, which in turn limits the data available for reporting internationally. As the majority of our respondents indicated, transplant professionals in several countries record information about organ donation and transplantation activities and outcomes in national registries, under the oversight of government health authorities.<sup>23,24</sup> However, there is considerable variation between existing registries, with some designed for scientific purposes and others for more regulatory oversight purposes. Similar registry types may vary in collection of baseline data such as number of transplants performed annually and organ donor type.<sup>25–27</sup> 15.9% of respondents indicated there was no transplant registry within their country or were unsure if one existed. Many countries lack the necessary resources to maintain regular data collection and reporting systems, or governmental support for such systems, and in many countries reporting of data to national registries may be optional, with some transplant centers not reporting data.<sup>23,28</sup> When data are collected, details relating to the nationality or residency status of donors or recipients may not be included. Data regarding outgoing or incoming ITOT cases may not be collected at all, with individuals who travel for living donation perhaps at greatest risk of being excluded from registries. Just over half of respondents indicated they would collect data about incoming international donors, and few such donors are likely to have their data



**FIGURE 4.** Proportion of respondents who believe that specific types of ITOT cases are currently reported to registries within their country or to international registries. The unsure responses indicate respondents' uncertainty whether particular types of ITOT cases involving their country are currently reported to national or international registries. \*national = national, state, or province-wide registry. ITOT, international travel for organ transplantation.

**TABLE 3.**

**Reported Probability of Submitting ITOT Case Data to a National or International Registry**

Type of ITOT Case	How Likely to Submit Data to a Registry Within Your Country?	How Likely to Submit Data to an International Registry?
Incoming (donation or transplant procedure within your country)		
Very unlikely	11 (4.6%)	18 (7.5%)
Unlikely	7 (2.9%)	15 (6.3%)
Unsure	23 (9.6%)	73 (30.5%)
Likely	64 (26.8%)	59 (24.7%)
Very likely	134 (56.1%)	74 (31.0%)
Outgoing (donation or transplant procedures outside your country)		
Very unlikely	11 (4.6%)	14 (5.9%)
Unlikely	10 (4.2%)	23 (9.6%)
Unsure	36 (15.1%)	75 (31.4%)
Likely	65 (27.2%)	58 (24.3%)
Very likely	117 (49.0%)	69 (28.9%)

ITOT, international travel for organ transplantation.

reported on returning home, as only 18.4% of respondents would collect data about those who donated abroad. This is particularly concerning as it may reflect a lack of follow-up for individuals who have donated an organ in another country. Our findings favoring collection of data about incoming patients appear consistent with experience at the GODT, to which only 46 of 91 countries reported cases of outgoing travel for transplant in 2022, whereas 51 reported on transplants of nonresident patients.<sup>20</sup>

Some transplant professionals may also evidently be reluctant to report ITOT case data, especially to an international registry. Individual and aggregated data about ITOT activities may be considered politically or ethically sensitive, because of concerns that provision of transplants for international patients may be perceived as undermining access

for residents, or that incoming or outgoing travel for transplantation may be associated with suspicions of organ trafficking. Over half of respondents identified concerns about data privacy and protection of patient identity as influential on their willingness to report ITOT data to an international registry; fear of causing harm to patients or professionals and institutions was the most cited factor discouraging reporting.

**Implications for a Global ITOT Case Registry**

Our results highlight significant gaps in and barriers to collection and reporting of ITOT activity data. They also make clear the need to improve availability and use of these data or risk leaving substantial numbers of patients who travel for donation or transplantation in a proverbial blind spot.



**TABLE 4.**  
**Potential benefits of a global ITOT registry**

	Percent (n = 239)
Ability to quantify and evaluate ITOT activities at the global level	82.8
Ability to compare ITOT activities involving various countries	66.5
Ability to assess outcomes of ITOT	69.5
Ability to estimate proportion of ITOT that may involve organ trafficking	74.1
Use of data to advocate for government policy change	68.6
Use of data to guide clinical policies and decision-making	68.6
Address a gap in local registry data	38.1

ITOT, international travel for organ transplantation.

Support for systematic collection of data relating to all organ donation and transplant activities via national or regional registries should be the priority for transplant professionals and health authorities in each country, as recommended by the WHO and the Santander Summit.<sup>13,14</sup> However, additional measures for ITOT data collection may be helpful given the current gaps in registries and potential barriers to reporting via governmental systems.

The DICG accordingly intends to conduct a pilot trial of a global registry to which transplant professionals may report ad hoc cases of ITOT they experience, with the aim of collecting more detailed data about ITOT cases that could be used to guide efforts to prevent organ trafficking and transplant “tourism.” Many cases are currently reported informally by professionals to the DICG but there is no mechanism for standardized data collection and analysis, and there is limited governance in place to facilitate responsible sharing and use of such data. Establishing a registry with independent ethics oversight, formal data protections, a standard questionnaire aligned with existing data collection tools used by the GODT and the Council of Europe, and a protocol in place for regular analysis and reporting may facilitate collection and use of ITOT data that may not be reported elsewhere.

Regular surveillance of global ITOT activities via audit of a global ITOT case registry or repetition of standardized surveys such as this could provide timely and valuable insights to guide policy and practice. In the absence of reliable and comprehensive regular data collection via health authorities, data that are collected in the form of voluntary reporting by individual clinicians may be used to monitor indicative activity trends over time or to identify routes and locations of ITOT that may not be reported via governmental registries. If designed collaboratively to complement rather than distract from existing data collection mechanisms and registries such as the GODT, a global ITOT registry may also help to support analysis and validation of data reported via other systems, for example by revealing ITOT activities that may be missing from national registries or withheld from international registries.

The design of the DICG’s planned pilot registry will be informed by the results of this study. We note in particular the high proportion of respondents who preferred professional anonymity in reporting to an international registry. This likely reflects concerns about patient privacy or the risks to patients or professionals, especially in cases which may be known or suspected to involve illegal or unethical activities.<sup>8</sup> Providing an option for anonymous reporting

and establishing robust safeguards for patient and professional privacy will be essential, although such mechanisms may have implications for data collection, analysis and use. For example, the need to protect anonymity or privacy may prevent the public identification of some countries in which ITOT activities may raise concerns as a result of submitted case reports. Publication of some disaggregated data that identifies countries with little transplant activity, single centers or few transplant professionals, may effectively reveal sources. Reporting aggregated case data from a registry may also risk unfair stigmatization of countries in or about which professionals are more willing to report ITOT data, requiring careful analysis and contextualization of data in publications.

## CONCLUSIONS

The results of this study provide a high-level snapshot of recent ITOT activities but are not comprehensive, given the limited diversity of the participant population and the use of questions soliciting information only about the most recent case experiences. Nevertheless they make clear that it is not only transplant professionals working in well-known ITOT destination countries such as India, Singapore, Turkey, and the United States who must grapple with ITOT cases, nor those working within regions where limited access to transplant may drive outgoing ITOT such as in Africa and Asia.<sup>29,30</sup> ITOT should concern transplant professionals and health authorities in all countries. Urgent improvements to existing national and international systems for transplant data collection are needed to address the substantial gaps in knowledge of ITOT activities and support achievement of the United Nations’ request to Member States to ensure “the transparency of practices and the quality and safety of human organs” for transplantation.<sup>5</sup>

## Study Limitations

Selection bias is a significant limitation of the study. The predominance of nephrologists, Europeans and professionals working in the public health sector among respondents means that the results may not reflect the experiences or attitudes of other transplant professionals who may have considerable experience of ITOT, such as those working in the private health sector where most transplants involving international patients are believed to take place, or in liver transplantation. Because of small numbers, the study lacks the power to draw inferences about differences in respondent demographics.

Of note, 94 people who completed the first section of the questionnaire did not complete the survey (28.2%), which also represents a potential source of bias in the results reported of ITOT case experiences. There are multiple potential explanations for this dropout rate, in particular fatigue because of the survey length. Alternative hypotheses include the possibility that some respondents were hesitant to provide data that may be perceived as sensitive despite having anonymity and the assurance that results would be presented in aggregates. It is also possible that increased language complexity in the later sections of the survey may have discouraged respondents with more limited English proficiency. There were no substantial differences in the demographic profile of respondents who completed the whole questionnaire compared with those who dropped out as shown in Table 2.

## ACKNOWLEDGMENTS

The authors thank Dr Benita Padilla for her valuable advice on the study questionnaire and Dr Beatriz Domínguez-Gil and Dr Marta López-Fraga for helpful conversations regarding the project. The authors are especially grateful to Ms Jennifer Groverman (DICG), Ms Anne Hradsky (ISN), and staff at ISN, TTS, and the many national professional societies who assisted in the promotion of the study.

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