



PARTICIPANT INFORMATION SHEET

PROJECT TITLE: International travel for organ transplantation: surveying professionals' experience

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2022-128

PRINCIPAL INVESTIGATOR: Dr Georgina Irish

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

This research project aims to find out about health professionals' recent experiences of providing care to patients who travel internationally for organ donation or transplantation. This phenomenon is known as international travel for organ transplantation (ITOT) and can involve clinically necessary and ethical travel as well as unethical travel in some cases.

In particular, the study aims to

- Estimate the prevalence of transplant professionals' experience in providing care for patients who travel internationally for organ transplantation.
- Identify common routes of international travel for organ donation and transplantation.
- Assess patterns of international travel for organ transplantation over time.
- Identify gaps in ITOT data collected via routine reporting mechanisms governed by national health authorities.

The information obtained from this anonymous survey will be used to improve our understanding of current global ITOT activities, helping to fill gaps in data collected via national transplant and donation registries. The study will also help to identify countries or regions that may benefit from support in developing transplantation programs or strategies to ensure that ITOT activities promote equity of access to ethical transplantation.

Who is undertaking the project?

This project is being conducted by an international team led by Dr Georgina Irish at the University of Adelaide in Australia and Professor Dominique Martin at Deakin University in Australia. A list of the team members is shown at the end of this information sheet.

Only the research team members listed above will have access to the raw data collected via the survey.



Why am I being invited to participate?

All health professionals with experience in providing care for organ donors or transplant recipients are encouraged to participate in this study. We welcome participation by all professionals, regardless of the country you work in, or what kind of professional role you have in transplantation.

Even if you have not had any experience of providing care to a patient who has been involved in ITOT within the past two years, your participation in the survey is important. This will help to give us a better estimate of the proportion of transplant professionals with such experience.

You may have received an invitation to participate as a member of a professional society which is involved in organ donation or transplantation, or from a professional colleague who believes this may be of interest to you.

You must be aged 18 years or more to participate in the study.

The survey questionnaire is available in English, Spanish, French and Mandarin. This means that you must be able to understand one of these languages sufficiently well to participate. If you are able to understand this information sheet, you should be able to complete the survey without difficulty.

What am I being invited to do?

You are being invited to complete an anonymous online questionnaire.

You will be asked a few general questions about yourself and then a series of questions about any recent experience you may have had providing care for patients who travelled to or from your country for the purpose of organ donation or transplantation. If you have been involved in care of at least one patient who travelled to or from your country to undergo organ transplantation or living donation between 1 January 2023 and 31 August 2024, you will be asked a few additional questions about the most recent cases you have seen.

How much time will my involvement in the project take?

It should take you approximately 5-15 minutes to complete the survey. The time it takes will depend on how much experience you have had since 1st January 2023 in providing care for patients who have travelled internationally for organ transplantation.

Are there any risks associated with participating in this project?

It is possible that some health professionals participating in this project may suffer some distress if the questionnaire prompts them to think about difficult experiences they have had in providing care for patients who have travelled for transplantation or donation. In some circumstances, professionals may experience anxiety if they are currently dealing with a complex case of ITOT.

If you experience any distress or anxiety about your own management of ITOT cases, or about other aspects of ITOT such as local policies or practices, we encourage you to seek support from personal or professional support services in your country. You can also contact the research team and we will help you to identify an appropriate counselling service within your country or region. You will find links to some helpful resources about ITOT on our project website available at: <https://blogs.deakin.edu.au/itotproject/>

There is a small risk that the results of this study could be used in ways that may stigmatise some countries, for example if responses indicate high levels of incoming or outgoing ITOT in specific countries. This is because some people may associate ITOT with unethical practices such as organ trafficking. To reduce this risk, any publication of results from this study will make clear the fact that ITOT frequently involves ethically appropriate travel for



transplantation, and that the data collected in this survey provides only a neutral estimate of ITOT and no estimation of levels of trafficking or other unethical practices. If some countries or regions are underrepresented in the survey, publicly available data about ITOT for these countries will be discussed wherever possible in the publication of the study results. This will help to ensure that a genuinely global overview of ITOT activity is provided and that interpretation of the study results is not skewed as a result of differing levels of participation by professionals in specific countries or regions.

What are the potential benefits of the research project?

This project is expected to produce information that may be used by health professionals and policy makers to prioritise investment in strategies that will help to improve patient care and decision-making about ITOT, and to guide development of donation and transplantation programs around the world.

Can I withdraw from the project?

Participation in this project is completely voluntary. Your participation or non-participation will have no impact on your membership of any professional societies. No professional society will be able to know whether you have participated in the study.

If you agree to participate, you can withdraw from the study at any time prior to completion and submission of your responses to the survey questionnaire. Once your responses have been submitted, it will not be possible to remove your data because all responses are entered anonymously.

If you have provided any information in your responses which may identify you, this will be dealt with as outlined in the following section.

What will happen to my information?

Confidentiality and privacy: participation in this study is anonymous. When completing the survey, you will not be asked to provide any information that could identify you. Although you will be required to answer some questions in order to complete the survey, you will always have the option of selecting a response such as “prefer not to answer” if you are not comfortable providing an answer.

All data collected will be reported only in an aggregated manner, and any details that would potentially identify an individual participant or transplant centre will be withheld from any publications or reports arising from the research. For example, in cases where data relates to countries with known small populations of transplant professionals, or demographic groups known to be of small size such as female transplant surgeons in particular regions, demographic data will be excluded from reported results or reported at the regional level.

Storage: The data will be encrypted and stored on a secure server through the University of Adelaide with password protected access by the principal investigators. The data will be kept for 5 years.

Publishing: The aggregated results of this study will be reported in journal article publications and presentations at professional conferences in transplantation.



Sharing: A plain language summary of the results will also be shared with a range of professional societies who will be encouraged to share it with members. It will also be published on the project website where you will be access it: <https://blogs.deakin.edu.au/itotproject> Information about these publications will also be shared on social media such as X (Twitter) and LinkedIn by members of the research team and supporting organizations.

The research team plans to repeat this study after two years, to see if there are changes in patterns of ITOT activities. To make the comparison, data collected in this survey will likely be used when analysing results from a repeat survey. Any future study will also require ethics approval, and your information will only be used as described in this participant information sheet, except as required by law.

Access to the data from this study will only be approved for use in research that aligns with the goals of this study, and if the proposed study can ensure the same safeguards are in place to protect privacy and confidentiality of the data and to manage any associated risks including those outlined above.

Who do I contact if I have questions about the project?

Please contact the research team at itotcollaborative@gmail.com or Georgina.irish@adelaide.edu.au if you have any concerns or questions about the project.

Has this study been approved by a Human Research Ethics Committee?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2022-128). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research 2023.

What if I have a complaint or any concerns?

Insurance and Compensation

The study has been indemnified by The University of Adelaide which is enforceable by a participant to seek compensation in addition to your right to seek compensation under the common law through the legal system in legal proceedings.

Complaints

If you wish to speak with an independent person regarding concerns or a complaint about this study, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au

Post: Research Services, Level 3, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.



If I want to participate, what do I do?

If you would like to participate in the study, please click this link to [access the online survey in English](#). You will be asked to read through this participant information (if you have not already done so) and to indicate your consent to participate. You can then proceed to answer the survey questionnaire. At the end of the survey, you will need to submit your responses and a page will appear confirming you have successfully completed the survey.

Yours sincerely,

Dr Georgina Irish	University of Adelaide, Australia
Prof Dominique Martin	Deakin University, Australia
Prof Toby Coates	University of Adelaide, Australia
Prof Riadh Fadhil	Hamad Medical Corporation, Qatar
Prof Jayme Locke	University of Alabama Birmingham, United States of America
Dr Maggie Ma	Hong Kong University, Hong Kong
Prof Elmi Muller	Stellenbosch University, South Africa
Dr Benita Padilla	National Kidney Transplant Institute, the Philippines
Dr Alicia Pérez-Blanco	Organización Nacional de Trasplantes, Spain
Ms Lola Perojo	Organización Nacional de Trasplantes, Spain
Mr Mario Martin Gonzales	Organización Nacional de Trasplantes, Spain
Ms Alice Jiang	Deakin University, Australia
Ms Amy Lundgren	Deakin University, Australia
Ms Georgina Soo	Deakin University, Australia