

**ISHLT INTERNATIONAL THORACIC ORGAN TRANSPLANT REGISTRY
DATA USE AGREEMENT (DUA)**

The ISHLT International Thoracic Organ Transplant (TTX) Registry will provide the individual identified below (Requestor) with the non-identifiable data derived from the ISHLT TTX Registry database, **solely for the use specified in the initial data request.**

Every effort has been made to exclude from the computer files identifying information on individual patients and facilities. Certain demographic information such as gender, age, etc. are provided for research purposes but may not be used to attempt to identify individuals or institutions.

In order for the ISHLT TTX Registry to provide a de-identified or another version of data to you, it is necessary that you agree to the following provisions.

1. DATA USE and DATA CONFIDENTIALITY

- A. You will neither use **nor permit others** to use the data in any way other than for statistical reporting and analysis.
- B. You will neither release **nor permit others** to release the files or data therein to any person (including media and subcontractors) except with the written approval of the ISHLT TTX Registry.
- C. You will not present and/or publish data in which an individual or facility may be identifiable.
- D. You will not attempt to sell this data set directly **nor permit others** to sell the data set.
- E. You will neither attempt **nor permit others** to attempt to combine or link the data with individually identified records in another database or source of information or to learn the identity of any person or facility whose data is contained in the supplied file(s).
- F. If the identity of any person or facility is discovered, then you must do the following: a) you will not use this knowledge in any way, b) you will notify the ISHLT TTX Registry of the incident.
- G. If accessing the data from a centralized location on a time-sharing computer system or LAN with any statistical package, you will not share your logon name and password with any other individuals. You will also not allow any other individuals to use your computer account after you have logged on with your logon name and password.
- H. As Primary Investigator, you certify that you are responsible for ensuring any staff assigned to this project with access to these data likewise will follow all of these provisions.
- I. As Primary Investigator, you certify that you have appropriate institutional review board/ethics committee (or equivalent) approval or exemption for your proposed study.
- J. You will respond to queries from the ISHLT TTX Registry for progress reports on the study and compliance with the terms of this agreement.

2. RULES FOR PRESENTATION AND PUBLICATION of results based on ISHLT TTX Registry analyses

- A. All abstracts, manuscripts and presentations must be reviewed by the ISHLT TTX Registry before submission. Abstract, manuscripts and presentations must be provided for review at least 14 days prior to presentation/submission.**
- B. ISHLT TTX Registry Associate Medical Director may be assigned to your project to assist you along the completion of the project and preparation/review of the resulting abstract/manuscript prior to submission. The Registry associate director is well versed in the ISHLT TTX Registry structure and can provide important contributions and feedback with the goal of maximizing the project quality and validity. The assigned associate director must be involved in the project from the start, and if justified by his/her contributions, should be listed as coauthor on resulting work.
- C. All abstracts must be submitted for the ISHLT Annual Meeting and manuscripts must be submitted to the Journal of Heart and Lung Transplantation. If there is an important reason for submitting a sub-study of the main project for presentation or publication elsewhere, an approval must be obtained from the ISHLT TTX Registry director.**
- D. All publications using the released data will contain the standard disclaimer, "The data have been provided by the ISHLT Thoracic Organ Transplant Registry. The interpretation and reporting of these data are the responsibility of the user(s)"
- E. All publications or graphic presentations will note the effective date of the data. For example, "Based on ISHLT Thoracic Organ Transplant Registry data as of April 6, 2018, ..."

If a requestor does not comply with the any requirements in this agreement, the permissions granted for this DUA ma be revoked and the ISHLT TTX Registry may withhold data from future data requests from the investigator and his/her institution.

Project title: _____

My signature indicates that I agree to comply with the above stated provisions.

Signature _____

Name _____

Date _____

Institution Name _____

Street Address _____

State/Country/Postal Code _____

Phone Number (including country code) _____

Email _____