

DMG REGISTRY DATA REQUEST FORM – DE-IDENTIFIED DATA

Address each numbered point concisely. You may use additional pages, if needed. Please e-mail completed materials to dmgdata@unos.org.

- 1. Name of primary investigator(s) and contact person**
- 2. Project title:**
- 3. Project background (*Please be brief.*):**
- 4. Question(s) your study will address (*e.g., ‘We wish to study the effect of x on y’; Please be concise.*):**
- 5. Hypotheses your study will test (*e.g., ‘We hypothesize that transplant recipients with a higher level of x will have better survival than recipients with lower levels of x.’*):**
- 6. List key variables you need for your study so we can confirm the data is available. You may attach a separate list.**
- 7. Will you need updates of the requested dataset in the future? If yes, describe here.**
- 8. Describe, in general, how the data are to be analyzed (*e.g., organ utilization, survival rates*)**
- 9. Describe how you plan to use the data, including any plans to present or publish the data.**

DMG REGISTRY DE-IDENTIFIED DATA USE AGREEMENT

1. You will neither use nor permit others to use the data in any way other than for statistical reporting and analysis.
2. 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 DMG.
3. You will not present and/or publish data in which an individual or facility may be identifiable.
4. You will not use the Data for any commercial purpose that could have a negative impact on patient welfare, such as offering, denying, or allocating insurance.
5. You will neither attempt nor permit others to attempt to combine or link the data with patient level records in another database or source of information.
6. You will neither attempt nor permit others to attempt to learn the identity of any person or facility whose data is contained in the supplied file(s).
7. 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 DMG of the incident, and c) you will not inform anyone of the identity that was discovered.
8. 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.
9. 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.
10. All publications or graphic presentations will note the source of the data as "Data provided by the Donor Management Goals DMG Advisory Group on xx date." where the date will be the database date provided.

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

Recipient

Signature: _____

Date: _____

Name: _____

Title: _____

Organization: _____