

**UNIVERSITY OF ROCHESTER**  
**DATA USE/TRANSFER AGREEMENT CHECKLIST**  
**(Sending Data)**

A Data Use/Transfer Agreement (DUA) is a contractual document used for the transfer of data that has been developed by nonprofit, government or private industry, where the data is nonpublic or is otherwise subject to some restrictions on its use. Often this data is a necessary component of a research project and it may or may not be human subject data from a clinical trial, or limited data set information as defined in HIPAA.

**University of Rochester Scientist(s):** \_\_\_\_\_

**Location: MEDICAL CENTER** \_\_\_\_\_ **RIVER CAMPUS** \_\_\_\_\_

**Date:** \_\_\_\_\_ **Phone Number(s)** \_\_\_\_\_ **UR BOX #** \_\_\_\_\_

**1) Description of the Data to be transferred (Please list variables to be sent):**


RSRB Number: \_\_\_\_\_ Award Number \_\_\_\_\_

CTA Number: \_\_\_\_\_

TITLE OF STUDY: \_\_\_\_\_

**2) Does the Data originate from:** Humans \_\_\_\_\_ Non-human Samples \_\_\_\_\_

**3) Will you be sending de-identified Data\*\*?** Yes \_\_\_\_\_ No \_\_\_\_\_

\*\*De-identified data is data that does not contain any direct identifiers of the individuals according to HIPAA.

**IF YES - Select one of the following:**

\_\_\_ Data was collected in a de-identified manner approved by the RSRB;

\_\_\_ Data was collected in an identifiable manner approved by the RSRB and will be shared in a de-identified manner; or

\_\_\_ Data was obtained in a de-identified manner with no RSRB approval as it did not meet the definition of a human subject, or did not meet the definition of research.

**Please complete Form 25.5.1 located at:** <http://intranet.urmc-sh.rochester.edu/policy/HIPAA/Research.asp>

Upon completion, please forward a copy to the Material Transfer Administrator electronically.

**If NO, answer questions below, then continue to page 2 and answer questions 4-7.**

Are you sending a Limited Data Set (LDS)? Yes \_\_\_\_\_ No \_\_\_\_\_

**If YES, please complete Form 25.6.1 located at:**

<http://intranet.urmc-sh.rochester.edu/policy/HIPAA/Research.asp>

Upon completion, please forward a copy to the Material Transfer Administrator electronically.

Have you obtained RSRB approval for sharing a LDS? Yes \_\_\_\_\_ No \_\_\_\_\_

What are you sending as identifier(s)? *Using the attached Description of Limited Data Set, specify identifiers here:* \_\_\_\_\_

**NOTE: If sending fully identified data (i.e. patients name, social security number, etc.) please contact your RSRB specialist.**

4) Will Materials be provided with the data: Yes \_\_\_\_\_ No \_\_\_\_\_

If Yes, please provide a description of the Materials: \_\_\_\_\_

\_\_\_\_\_

5) Please indicate who will be receiving the Data: Academia / Nonprofit \_\_\_ or Industry \_\_\_

Recipient Scientist: \_\_\_\_\_

Institution: \_\_\_\_\_

Address: \_\_\_\_\_

Recipient Scientist's Email: \_\_\_\_\_

Recipient Scientist's Phone Number: \_\_\_\_\_

6) Please identify any 3<sup>rd</sup> party funding source for the research generating this Data.

\_\_\_\_\_

7) How will the Data Use/Transfer Agreement be sent?

(Check one) 1st Class Mail \_\_\_\_\_ FedEx \_\_\_\_\_ Electronic \_\_\_\_\_

If FedEx was selected, please provide:

FEDEX Account # \_\_\_\_\_

FEDEX Reference # \_\_\_\_\_

**Please direct ONLY RSRB related questions to your RSRB specialist.**

## **Description of Limited Data Set and De-Identified Data Set**

### **De-Identified Data Set:**

**The De-Identified Data Set must EXCLUDE all of the following direct identifiers of the individual or of the individual's relatives, employers or household members to be considered De-Identified Data:**

- a. Names;
- b. All geographic subdivisions smaller than a State, including: street address, city, county, precinct, zip codes and their equivalent geocodes, except for the initial three digits of a zip code if, according to the current publicly-available data from the Bureau of Census:
  - (1) the geographic unit formed by combining all zip codes with the same three initial digits contains more than 20,000; and
  - (2) the initial three digits of the zip code for all such geographic units containing 20,000 or fewer people is changed to 000.
- c. All elements of dates (except year) for dates directly related to an individual, including: birth date, admission date, discharge date, date of death; and all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older;
- d. Telephone numbers;
- e. Fax numbers;
- f. E-mail addresses;
- g. Social Security numbers;
- h. Medical record numbers;
- i. Health plan beneficiary numbers;
- j. Account numbers;
- k. Certificate/license numbers;
- l. Vehicle identifiers and serial numbers, including license plate numbers;
- m. Device identifiers and serial numbers;
- n. Web Universal Resource Locators (URLs);
- o. Internet Protocol (IP) address numbers;
- p. Biometric identifiers, including finger and voice prints;
- q. Full face photographic images and any comparable images; and
- r. Any other unique identifying numbers, characteristics or code

### **Limited Data Set (LDS):**

Researcher may use or disclose a LDS without an authorization from a research subject(s) if the following conditions are met:

**A LDS is defined as Protected Health Information that must exclude all of the above identifiers with exception of the following identifiers:**

- 1) town, city, state and zip code;
- 2) all dates related to an individual, including birth date, admission date, discharge date and date of death; and
- 3) unique codes or identifiers not listed as direct identifier.