Data Use Agreements

A data use agreement is a contract that is used to define the terms and conditions upon which data is transferred or shared between organizations. Also called data transfer agreement (DTA) or data transfer and use agreement (DTUA)

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DUAs

• When do I need one?

- Whenever data is leaving the University of Rochester. By leaving the University we mean being shared with a non-employee, this includes students.
- Whenever the Contracting Party sending you data, requires one or sends you one.
- When in doubt ask.

• What do you mean by Data?

- Usually Patient related information
 - Personal Health Information (PHI)
 - Limited Data Set
 - De-Identified Data
- Can also be research results or non-health related Personal Identifiable Information (PII)



Why do I need a DUA?

Some regulations/laws require a DUA: HIPAA FERPA GDPR – EU countries Some State Privacy laws



How do I get a DUA?

How do I get a DUA?

- The agreement request needs to be entered in our online system, IORA located at: <u>https://rochesteragreements.huronresea</u> <u>rchsuite.com/Agreements/</u>
- On the 1st Smartform mark the box under Question 3 indicating "Institution to generate first draft."
- The Contracting Party sent me a DUA what do I do next?
 - You need to enter the agreement in IORA and upload the Agreement you received under Question 3 of the 1st Smartform instead of checking the box.

Creating New: Agreement

Agreement Upload

- 1. Principal investigator:
- 2. *Agreement creator: Amy Crosby ... 3

4. Project/Study Title:

5. * Agreement type:

3. * Upload agreement draft: (or check the box below) (? [None] 1 Upload

Institution to generate first draft?

Commonly asked Questions about DUAs in IORA

Who is the Contracting Party?

- This is the external entity that you are sharing data with.
- The contact name, email and phone number for the contracting party refer to the contract negotiator at the external entity. (ORPA's counterpart)

What comes first RSRB or DUA?

• They can be done together, however ORPA will require to see the approved (or waiver) RSRB protocol before the DUA can be signed. Who can help me enter the information in IORA?

Amy Crosby

• acrosby@orpa.Rochester.edu

Help Center in IORA under the Agreements Tab

• <u>Unfunded Agreement Guide 9.2</u>

Lydia Moore

• <u>lmoore12@orpa.Rochester.edu</u>

What type of Data is it?

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;
- I. 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

What type of Data is it? cont.

Limited Data Set

- Limited Data Set (LDS)
 - Contains dates, city, state, or zip code information
 - <u>Requires</u> a DUA for PHI under HIPAA, if no patient consent

Fully Identifiable PHI

- Fully-Identifiable PHI/PII Data Set
 - Contains HIPAA identifiers other than dates / city, state or zip codes
 - RSRB verifies consent form matches party sending data to
 - Security questionnaire

Still have questions: Contact Kathleen Tranelli, UR Privacy Officer at Kathleen_Tranelli@URMC.Rochester.edu

Questions?

- What do I do if I have questions?
 - Ask Amy in ORPA for help:

acrosby@orpa.Rochester.edu

- Ask Lydia in ORPA for help: lmoore12@orpa.Rochester.edu
- E-mail the MTA mailbox at <u>MTA@Rochester.edu</u>



• Any Questions Now?