

The GRDR-GUID: a model for global sharing of patients de-identified data

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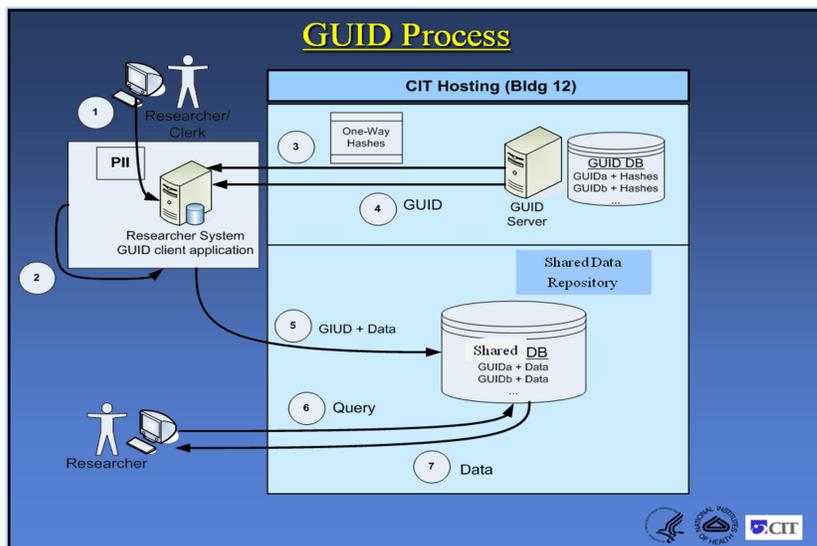
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Global Unique Identifier

The Global Rare Diseases Patient Registry Data Repository-GRDR, aggregates de-identified patient data, using CDEs from various rare disease registries utilizing a Global Unique Identifier (GUID)¹. The GRDR GUID is a unique random alpha-numeric set of characters assigned to each patient-data. The GRDR-GUID is NOT directly generated from personally identifiable information (PII). The GRDR-GUID is not generated or stored on the same server that the PII is entered. The GRDR-GUID is generated in two steps: 1. PII entered on local server to produce the hash codes, 2. The GUID is assigned at central NIH server, using those hash codes. The GUID system allows the patient to be followed across studies, registries and countries can be used also to link to biospecimens.

GRDR-GUID

The GUID is an ID that allows researchers to share data specific to a study participant without exposing PII and to track participants longitudinally, across multiple research studies. RD-CONNECT (IRDiRC framework) is assessing possibilities to implement a GUID strategy in their work and the NIH-GRDR GUID is one of the possibilities under consideration.



The GUID Process

1. User executes the GUID tool client locally
2. PII is entered on the local server
3. PII is combined and one-way hash codes are generated
4. The one-way hash codes are sent to the NIH GUID server
5. If the hash codes match the server's hash codes for an existing GUID, then that GUID is returned
6. If the hash codes do not match, then a new random GUID is generated and returned

To generate a GUID for the subject, the following PII is required

- ❖ Complete legal given (first) name of subject at birth
- ❖ Complete Legal additional name of subject at birth (if the subject has a middle name)
- ❖ Complete legal family (last) name of the subject at birth
- ❖ Day of birth (1-31)
- ❖ Month of birth (1-12)
- ❖ Year of birth (####)
- ❖ Name of city/municipality in which subject was born
- ❖ Country of birth
- ❖ Physical sex of subject at birth (M/F) (the required GUID PII are listed on the GRDR CDEs)

Reference: Johnson SB, Whitney G, McAuliffe M, et al. Using Global Unique Identifiers to Link Autism Collections. J. Am. Med. Inform. Assoc. July 17, 2010. 10.1136/jamia.2009.002063.