



National Center  
for Advancing  
Translational Sciences

The NIH/NCATS GRDR<sup>SM</sup> Program  
Global Rare Diseases Patient Registry  
Data Repository

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## Data Submission and Access Request

### GRDR Data Submission Request

Organizations wishing to participate in the NIH/NCATS GRDR<sup>SM</sup> Program and share the de-identified data of their registry first need to provide the information requested in the [GRDR Data Submission Request Form](#).

### GRDR Data Access Request

Investigators wishing to access the data in the GRDR Data Repository need first to provide the information requested. There are two levels of access to Data:

**Open Access** allows broad release of non-sensitive data, including general information, trends, and charts of aggregated data or any information that are available to the public without restrictions and can be browsed online. For Open Access, minimal information is requested.

**Controlled Access** allows download of GRDR Data, including individual de-identified Data within a disease and across diseases. Any request for Controlled access requires completing the Data Use Certification (DUC) form. Both forms can be accessed by clicking on the [GRDR Data Access Request Form](#).

OMB No 0925 XXXX

Exp. Date XX/XX/20XX

Burden Disclosure: Public reporting burden for this collection information is estimated to average 15 minutes response, including the time reviewing instructions, searching existing data source, gathering and marinating the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it display a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA#0925-XXXX. Do not return the completed form to this address.

**GRDR<sup>SM</sup> Repository**  
**Request for Controlled Access**  
**Recipient Information and Certifications**

\*Date: \_\_\_\_\_ \*Type of Application: \_\_\_\_\_ New \_\_\_\_\_ Renewal

\*First Name: \_\_\_\_\_ \*Last Name: \_\_\_\_\_

\*Degree: \_\_\_\_\_ \*Academic Position (or Title): \_\_\_\_\_

\*Institution: \_\_\_\_\_ \*Disease Interest \_\_\_\_\_

\*Street Address \_\_\_\_\_

\*City: \_\_\_\_\_ \*State/Province: \_\_\_\_\_

\*Zip/Postal Code: \_\_\_\_\_ \*Country: \_\_\_\_\_

\*Telephone: \_\_\_\_\_ \*Fax: \_\_\_\_\_

\*E-mail Address:

\_\_\_\_\_

Research Project

(Title): \_\_\_\_\_

By signing and dating this DUC as part of requesting access to Data in GRDR, my Institutional Officials and I certify that we will abide by the DUC and the NIH principles, policies and procedures for the use of GRDR Data.

I further acknowledge that I have shared this document and the NIH policies and procedures with any research staff who will participate in the use of GRDR Data.

My Institutional Business Official(s) also acknowledges that they have shared this document and the relevant NIH policies and procedures with appropriate institutional organizations.

*Authorized Institutional Business Official*

\*Name: \_\_\_\_\_ \*Title:<sup>1</sup> \_\_\_\_\_

\*Signature: \_\_\_\_\_ \*Date: \_\_\_\_\_

\*IRB#: \_\_\_\_\_ \*FWA#: \_\_\_\_\_

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<sup>1</sup> Signatory should specify whether he/she is (1) Principal Investigator or; (2) Institutional Official; or (3) Research Collaborator.

***Project Director/Principal Investigator Contact Information (if different from above):***

\*First Name: \_\_\_\_\_ \*Last Name: \_\_\_\_\_

\*Degree: \_\_\_\_\_ \*Academic Position (or Title): \_\_\_\_\_

\*Institution: \_\_\_\_\_ \*Department: \_\_\_\_\_

\*Street Address: \_\_\_\_\_

\*City: \_\_\_\_\_ \*State/Province: \_\_\_\_\_

\*Zip/Postal Code: \_\_\_\_\_ \*Country: \_\_\_\_\_

\*Telephone: \_\_\_\_\_ \*Fax: \_\_\_\_\_

\*E-mail Address: \_\_\_\_\_

***Institutional Official(s)***

\*First Name: \_\_\_\_\_ \*Last Name: \_\_\_\_\_

\*Degree: \_\_\_\_\_ \*Academic Position (or Title): \_\_\_\_\_

\*Institution: \_\_\_\_\_ \*Department: \_\_\_\_\_

\*Street Address: \_\_\_\_\_

\*City: \_\_\_\_\_ \*State/Province: \_\_\_\_\_

\*Zip/Postal Code: \_\_\_\_\_ \*Country: \_\_\_\_\_

\*Telephone: \_\_\_\_\_ \*Fax: \_\_\_\_\_

\*E-mail Address: \_\_\_\_\_

**Other Project Information:**

1. Are human subjects involved?  Yes  No

If YES to human subjects:

Is the project exempt from federal regulations?  Yes  No

If yes, check appropriate exemption number:  1  2  3  4  
 5

If no, is the IRB review pending?  Yes  No

IRB approval date: \_\_\_\_\_

2. Research Use Statement/Project Summary:

*Senior/Key Profile (Collaborating Investigator)*

\*First Name: \_\_\_\_\_ \*Last Name: \_\_\_\_\_

\*Degree: \_\_\_\_\_ \*Academic Position (or Title): \_\_\_\_\_

\*Institution: \_\_\_\_\_ \*Department: \_\_\_\_\_

\*Street Address: \_\_\_\_\_

\*City: \_\_\_\_\_ \*State/Province: \_\_\_\_\_

\*Zip/Postal Code: \_\_\_\_\_ \*Country: \_\_\_\_\_

\*Telephone: \_\_\_\_\_ \*Fax: \_\_\_\_\_

\*E-mail Address: \_\_\_\_\_

\*Project Role: \_\_\_\_\_ \*Other Project Role Category: \_\_\_\_\_





*Senior/Key Person Profile (Collaborating Investigator)*

\*First Name: \_\_\_\_\_ \*Last Name: \_\_\_\_\_

\*Degree: \_\_\_\_\_ \*Academic Position (or Title): \_\_\_\_\_

\*Institution: \_\_\_\_\_ \*Department: \_\_\_\_\_

\*Street Address:  
\_\_\_\_\_

\*City: \_\_\_\_\_ \*State/Province: \_\_\_\_\_

\*Zip/Postal Code: \_\_\_\_\_ \*Country: \_\_\_\_\_

\*Telephone: \_\_\_\_\_ \*Fax: \_\_\_\_\_

\*E-mail Address: \_\_\_\_\_

\*Project Role: \_\_\_\_\_ \*Other Project Role Category: \_\_\_\_\_

Use additional sheets for additional profiles as needed.

For GRDR administrator only:

Access Approved \_\_\_\_\_

Access Denied: \_\_\_\_\_