Resource Summary Report

Generated by ASWG on Aug 3, 2026

GRDR

RRID:SCR_008978
Type: Tool

Proper Citation

GRDR (RRID:SCR_008978)

Resource Information

URL: https://portal.dbmi.hms.harvard.edu/projects/GRDR/

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Description: Data repository of de-identified patient data, aggregated in a standardized manner, to enable analyses across many rare diseases and to facilitate various research projects, clinical studies, and clinical trials. The aim is to facilitate drug and therapeutics development, and to improve the quality of life for the many millions of people who are suffering from rare diseases. The goal of GRDR is to enable analyses of data across many rare diseases and to facilitate clinical trials and other studies. During the two-year pilot program, a web-based template will be developed to allow any patient organization to establish a rare disease patient registry. At the conclusion of the program, guidance will be available to patient groups to establish a registry and to contribute de-identified patient data to the GRDR repository. A Request for Information (RFI) was released on February 10, 2012 requesting information from patient groups about their interest in participating in a GRDR pilot project. ORDR selected 30 patient organizations to participate in this pilot program to test the different functionalities of the GRDR. Fifteen (15) organizations with established registries and 15 organizations that do not have patient registry. The 15 patient groups, each without a registry, were selected to assist in testing the implementation of the ORDR Common Data Elements (CDEs) in the newly developed registry infrastructure. These organizations will participate in the development and promotion of a new patient registry for their rare disease. The GRDR program will fund the development and hosting of the registry during the pilot program. Thereafter, the patient registry is expected to be self-sustaining.The 15 established patient registries were selected to integrate their de-identified data into the GRDR to evaluate the data mapping and data import/export processes. The GRDR team will assist these organizations in mapping their existing registry data to the CDEs. Participating registries must have a means to export their de-identified registry data into a specified data format that will facilitate loading the data into the GRDR repository on a regular basis. The GRDR will also develop the capability to link patients"" data and medical information to donated biospecimens by using a Voluntary Global Unique Patient Identifier (GUID). The identifier will enable the creation of an interface between the patient registries that are linked to

biorepositories and the Rare Disease Human Biospecimens/Biorepositories (RD-HUB) http://biospecimens.ordr.info.nih.gov/.

Abbreviations: GRDR, RaDaR

Synonyms: Rare Diseases Registry Program (RaDaR), Global Rare Diseases Patient Registry and Data Repository

Resource Type: patient registry, data or information resource, people resource, database, data repository, service resource, storage service resource

Keywords: clinical, common data element, global unique patient identifier, clinical trial, drug development, therapy

Related Condition: Rare disease

Funding: NIH

Availability: Public, The community can contribute to this resource

Resource Name: GRDR

Resource ID: SCR_008978

Alternate IDs: nlx_152145

Old URLs: http://www.grdr.info/

Record Creation Time: 20220129T080250+0000

Record Last Update: 20260803T040532+0000

Ratings and Alerts

No rating or validation information has been found for GRDR.

No alerts have been found for GRDR.

Data and Source Information

Source: SciCrunch Registry

Usage and Citation Metrics

We found 1 mentions in open access literature.

Listed below are recent publications. The full list is available at ASWG .

Sosnay PR, et al. (2013) Defining the disease liability of variants in the cystic fibrosis transmembrane conductance regulator gene. Nature genetics, 45(10), 1160.