

Office of Rare Diseases Research

Global Rare Diseases Patient Registry and Data Repository-GRDR

Vocabulary and Common Data Elements

The list of common data elements (CDEs) was developed by the Office of Rare Diseases Research (ORDR)/Global Rare Diseases Patient Registry and Data Repository-GRDR Vocabulary and CDEs Steering Committee and was designed to capture the information that is needed for all or most clinical research on rare diseases at a minimum level. These CDEs are not meant to satisfy all the needs of rare disease-specific registries. Rare disease-specific data elements will be developed at a later stage. A specific registry could choose to use a more precise level of detail for a data element. If that is done, however, it should map to the original CDE.

In this list you will find the CDEs that the steering committee selected as Required (checked with ✓) and Optional (labeled Optional). Required CDEs are elements that should be used in any registry. Optional CDEs are elements that can be added to the required elements based on the needs of the specific registry.

In addition to the list of CDEs, we provided information such as definitions of each element and the permissible values (how the information should be provided), the source for each element, and the reference/link. This list is a mix of required and optional elements based on different categories:

- Current Contact Information
- Socio-demographic
- Diagnosis
- Family History
- Birth and Reproductive History
- Anthropometric
- Patient Reported Outcome
- Medications, Devices, and Health Services
- Clinical Research Participation & Biospecimens
- Contact & Communication Preferences

The development of the CDEs will be an evolving process and over time some CDEs may be revised to serve the rare diseases community better.

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