

Document Index

This document provides an overview of all documentation housed on the Enroll-HD Data Support Documentation webpage.

General Study Documents

Enroll-HD

Study specific documentation for the Enroll-HD study and other data sources included in periodic dataset (PDS) releases (e.g., REGISTRY):

- [Enroll-HD Protocol](#)
- [Data Dictionary \[updated – please review\]](#)
- [Enroll-HD Annotated CRF](#)
- [Enroll-HD Data Collection Guidelines](#)
- [REGISTRY 2.0 Protocol](#)
- [REGISTRY 3.0 Protocol](#)
- [REGISTRY 2.0 and 3.0 Annotated CRF](#)
- [REGISTRY 2.0 Data Collection Guidelines](#)
- [REGISTRY 3.0 Data Collection Guidelines](#)
- [Ad Hoc Annotated CRF](#)

HDClarity

Study specific documentation for the HDClarity study:

- [HDClarity Protocol](#)
- [HDClarity Data Dictionary](#)
- [HDClarity CRFs](#)

General

Generic documentation applicable to all above-referenced studies:

- [Coding systems: ISCED \(education level\)](#)
- [Coding systems: medications, comorbidities, occupation](#)

Current Enroll-HD Periodic Dataset Documents

Documentation specific to the current Enroll-HD periodic dataset release.

- [PDS5 Overview](#)
Provides an overview of the dataset, sample size, visits, sample characteristics (sociodemographic and clinical), data availability and completeness, and coverage charts.
- [Download and Import Data](#)
Provides information on file formats and guidance on importing data files, including an illustrated guide.
- [Explore Dataset Structure](#)
Describes dataset structure (including constituent studies, data files, entity relation diagram), variable structure, ordering of visit data, and provides guidance on merging and aligning files.
- [Understand and Interpret the Data](#)
Provides information on HD classification, missing values, imputation, date values, aggregated values, assessment score calculation, derived variables, and HD onset and diagnosis variables.
- [Data Quality Management and Participant Privacy](#)
Provides an overview of data monitoring and quality control procedures, and information on participant privacy and identification risk management.
- [Unusual Findings](#)
Summary of unusual / implausible values identified in the dataset which could not be queried and corrected or were queried and confirmed as correct by site staff.
- [Change Log](#)
Details changes made to the dataset structure of PDS5 (2020-10-R1) with respect to the previous PDS release. Note that changes to *participant data values* between releases are captured and listed in a separate spreadsheet, available on request.

Data and Biosamples Request forms

- [Dataset Request Form \(universal\)](#)
- [Biosamples Request Form \(universal\)](#)

Data and Biosamples Use Agreements

- [Enroll-HD Clinical Data Use Agreement](#)

Please note that Use Agreements for biosamples and HDClarity data are 'created to order'. Please [contact us](#).

Publishing Documents

- [Publication Policy](#)
- [Acknowledgment List \(Enroll-HD\)](#)