

PDS5 | 2020-10-R1

Change Log

Enroll-HD

A worldwide observational study for Huntington's disease families

A CHDI Foundation Project

Overview

This document describes changes made to the dataset structure of Enroll-HD-Periodic-Dataset-2020-10-R1 (i.e., PDS5 R1) with respect to the previous release, Enroll-HD-Periodic-Dataset-2018-10-R3 (i.e., PDS4 R3).

Changes implemented between 2018-10 releases (i.e., PDS4_R1, R2, R3) are *not* described in detail here but are summarized in the appendix for reference.

Note that changes to individual participant data values between PDS5-R1 and PDS4-R3 are captured and listed in a separate spreadsheet, available upon request.

We encourage all users to review the supporting documents *Explore Dataset Structure* - which provides a detailed overview of the structure of the Enroll-HD PDS dataset - and *PDS5 Overview* — which provides a summary of the new PDS release, including information on sample size, total visits, an overview of sample composition, data availability plots, and coverage charts.

Participant ID

No changes have been made to participant ID numbers (HDID recoded) in this release relative to the prior PDS release.

File structure

No changes have been made to file structure in this release relative to the prior PDS release.

Va riables

New or modified variables:

- a. Enroll file: updfh ("Any updates to family history?"). New to PDS5_R1 release.
- b. Registry file: *updfh* ("Any updates to family history?"). New to PDS5_R1 release.

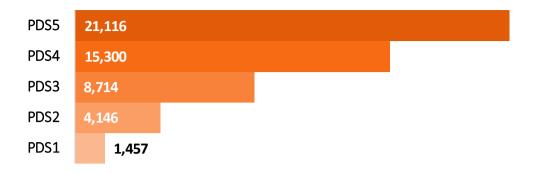
Aggregation thresholds

Aggregated variables and aggregation thresholds remain unchanged in this release relative to the prior release. For further details, refer to supporting document *Understand and Interpret the Data*.

Participants

PDS5_R1 contains data on 21,116 Enroll-HD participants. Sample size by PDS release is presented in Figure 1.

Figure 1. Enroll-HD sample size by PDS release.



Data from 150 participants who were included in PDS4_R3 were not included in the current PDS release. Enroll-HD is an active, longitudinal study. A participant eligible for inclusion for one release may be ineligible the next (e.g., participant data quarantined). Data for PDS4_R3 participants not included in PDS5_R1 may be available through specified dataset (SPS) request.

Participant-level data values

Changes to individual participant data values between PDS releases are captured and listed in a separate spreadsheet, available upon request.

Appendix: Summary of changes implemented between PDS4 releases 1, 2 and 3

Change summary for PDS4_R1 to PDS4_R2

A number of variables were updated from PDS4_R1 to PDS4_R2. Most of these updates were related to coding; coding

systems were updated as well as a number of missingness codes. The impacted and updated variables are listed below:

Comorbid file: mhterm__modify; mhterm__decod

Nutsuppl file: cmtrt__modify; cmtrt__decod

Pharmacotx file: cmtrt__ing; cmindc_decod

Profile file: xgwas; xmorpho; xpheno; ximage; xbsp

Event file: evtterm_modify; evtterm__decod

Participation file: rfendy

A spreadsheet detailing individual changes, and number of entries impacted, is available on request. In addition, these data are coded with WHO-DD and MeDRA. These alternative codes are available upon confirmation that requestor has

applicable licenses.

Change summary for PDS4_R2 to PDS4_R3

One participant was removed from the dataset due to withdrawal of consent, reducing sample size to N=15,300.

Revision History

Document Name	Summary of Changes
Enroll-HD PDS5_R1: Change Log 2020-12-16	First version for fifth Enroll-HD periodic dataset (PDS5; 2020-10-R1)