



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.

## Variables

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)