**Clinical Enroll-HD PDS6 request form**

We appreciate your interest in obtaining the Enroll-HD PDS6 dataset for use in your HD research.

Bulleted below are the key steps in the request process. For detailed information on the available data, please visit the [Enroll-HD website](https://www.enroll-hd.org/for-researchers/access-data-biosamples/).

**Key steps/considerations:**

* **Complete this request form for Enroll-HD PDS6 only.** **You will need to provide a title and a brief description of your project which will be posted on the Enroll-HD website along with your name and affiliation.**
* **Because you are requesting the Enroll-HD PDS6 dataset only, a review of your request by the Enroll-HD Scientific Review Committee (SRC) is not required.**
* **To fulfil GDPR requirements, we must review and approve the data security measures of all organizations requesting data. Each requesting organization must provide:**
	+ **the completed data security questionnaire that can be downloaded from the** [**Enroll-HD website**](https://enroll-hd.org/for-researchers/access-data-biosamples/)**, and**
	+ **a document describing the “Technical and Operational Data Security Measures (TOMs)” of the organization (contact your IT department for this document).**

**Once your organization’s security measures are approved, it will not be required to provide this documentation for a period of one year. After one year, we will ask you to confirm that the same measures are still in place or report any changes.**

* **Email: 1) the Enroll-HD PDS6 data request form, 2) the data security questionnaire and 3) TOMs for each organization requesting access to the Enroll-HD PDS6 datasets to:** **AccountSetup@enroll-hd.org****. Use of the data is conditional upon each of the requesting organizations agreeing to the terms and conditions set forth in the Data Use Agreement (DUAs). A copy of the DUA for the datasets you would like to obtain can be requested early in the process for review.**

After submission of your completed PDS6 Dataset Form, you will be contacted within five business days to confirm receipt of your request. Any questions regarding your request will be sent to the email address you provide below.

**PLEASE NOTE: THIS IS NOT A FUNDING APPLICATION**

**Information about Recipient Researchers**

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| **RECIPIENTS*** **List all recipients who require access to the data.**
* **Each dataset recipient needs to sign a Data Use Agreement (DUA) as applicable.**
* **If you are a student, your advisor will need to be the Recipient Researcher.**
* **If the data will be sent to a third party for processing, please list the third party as well and include that information in your detailed description.**
 |
| *List each collaborator for your research project below along with their contact information. The primary data recipient should be listed as Recipient Researcher #1. Each collaborator that needs access to the data must be listed as a recipient researcher (add additional fields if needed).* *At least one individual per organization needs to sign the data use agreement (DUA).* **Background questions:**1. Will the research project be a collaboration among multiple researchers (including biostatisticians) **within the same organization**? [YES / NO]*Each collaborator that wishes access to the data must review and agree to the terms of the DUA; one DUA must be signed per institution.* 2. Will the research project be a collaboration among multiple researchers (including biostatisticians) **at different organizations**? [YES / NO]*If you have collaborators outside your organization who will access the dataset, their institution must also sign a Data Use Agreement (DUA) and they must be listed as Recipient Researchers below. For collaborators who do not require direct access to the data, please provide researchers names and departments here****. Per the DUA it is not permitted to transfer any of the data to any entity that is not listed in the agreement.***3. Are/were any of the data requesters site staff in Enroll-HD, HDClarity, TRACK or any of the other clinical studies forming the basis of the below datasets? If yes – what study(ies) and at what clinical site(s)? |
| **RECIPIENT RESEARCHER #1 (Primary recipient.** Anyone who uses the data within the organization must be under the direction and supervision of the Recipient Researcher**)****Organization** (proper legal name):**Type of organization** (i.e., nonprofit, academic, public/private company, institution)**:** |
| First name: |  |
| Last name: |  |
| Title/position: |  |
| E-mail address: |  |
| Telephone: |  |
| Department: |  |
| Business address: | Street:  | City: |
|  | State/Province: | Country: | Postal Code: |
| **Need access to requested data?** |  |
| **Need to combine any of the requested datasets? If yes, please describe which datasets?** |  |
| Are you a fee for service provider?   | [YES/NO] |
| If you are a fee for service provider, are you requesting data to provide services to any third-party?   | [YES/NO]Please detail what third-party(ies) you are providing services to?Full legal name of each third-party:Type of third-party (i.e., client, fee for service provider; other third-party;)Individuals' Name:Address:Phone:Facsimile:Email:Country:The purpose of services and use for such third-party(ies): |
| Are you planning on transferring the data to any third-party recipient in any of the following categories?1. Any affiliate [YES/NO]2. Any fee for service providers (e.g., CROs) [YES/NO]3. Any other third-party [YES/NO]4. Any third-party hosting providers (e.g., AWS) or managed services providers [YES/NO] | Please provide the following for each of the third-party recipients:Full legal name of each third-party recipient:Type of third-party recipient (i.e., affiliate; fee for service provider; other third-party; third-party hosting providers)Individuals' Name:Address:Phone:Facsimile:Email:Country:The purpose for the transfer and use by such third-party recipient: |
| Have (or will) all listed third-party recipients where the data are planned to be used/processed, hosted or stored sign an agreement covering such use/processing, hosting and storage of the data? | [YES/NO] |
| **LEGAL CONTACT FOR RECIPIENT** **#1** (For legal/contract/notice purposes)**Name and title of signatory of the agreement(s):**  |
| Name of legal contact: Person handling the agreement(s) on behalf of the organization |  |
| Title/position: |  |
| E-mail address: |  |
| Telephone: |  |
| Department: |  |
| Business address:Address of legal or contracts department. This is where legal letters and notices will be sent. | Street:  | City: |
|  | State/Province: | Country: | Postal Code: |
| **RECIPIENT RESEARCHER #2 (**If different organization than for Recipient Researcher 1 then anyone who uses data within this organization must be under the direction and supervision of Recipient Researcher 2**)****Organization** (proper legal name):**Type of organization** (i.e., nonprofit, academic, public/private company, institution)**:** |
| First name: |  |
| Last name: |  |
| Title/position: |  |
| E-mail address: |  |
| Telephone: |  |
| Department: |  |
| Business address: | Street:  | City: |
|  | State/Province: | Country: | Postal Code: |
| **Need access to requested data?** |  |
| **Need to combine any of the requested datasets? If yes, please describe which datasets?** |  |
| **Need to transfer data to any third parties? If yes, please describe to whom and why.** |  |
| Are you a fee for service provider?   | [YES/NO] |
| If you are a fee for service provider, are you requesting data to provide services to any third-party?   | [YES/NO]Please detail what third-party(ies) you are providing services to?Full legal name of each third-party:Type of third-party (i.e., client, fee for service provider; other third-party;)Individuals' Name:Address:Phone:Facsimile:Email:Country:The purpose of services and use for such third-party(ies): |
| Are you planning on transferring the data to any third-party recipient in any of the following categories?1. Any affiliate [YES/NO]2. Any fee for service providers (e.g., CROs) [YES/NO]3. Any other third-party [YES/NO]4. Any third-party hosting providers (e.g., AWS) or managed services providers [YES/NO] | Please provide the following for each of the third-party recipients:Full legal name of each third-party recipient:Type of third-party recipient (i.e., affiliate; fee for service provider; other third-party; third-party hosting providers)Individuals' Name:Address:Phone:Facsimile:Email:Country:The purpose for the transfer and use by such third-party recipient: |
| Have (or will) all listed third-party recipients where the data are planned to be used/processed, hosted or stored sign an agreement covering such use/processing, hosting and storage of the data? | [YES/NO] |
| **LEGAL CONTACT FOR RECIPIENT** **#2** (For legal/contract/notice purposes):**Name and title of signatory of the agreement(s):**  |
| Name of legal contact: Person handling the agreement(s) on behalf of the organization): |  |
| Title/position: |  |
| E-mail address: |  |
| Telephone: |  |
| Department: |  |
| Business address:Address of legal or contracts department. This is where legal letters and notices will be sent | Street:  | City: |
|  | State/Province: | Country: | Postal Code: |

***Add additional recipient researchers as needed***

**Project title and summary (required for ALL requests)**

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| **PROJECT DESCRIPTION (Needed for all dataset requests)** |
| **Project title:** |  |
| **Summary** (50-200 words) of the research project.***This summary will be posted on the Enroll-HD.org webpage – do not include confidential information.***  |  |

**I agree with having the Project Description Summary above posted on the** [**https://enroll-hd.org/**](https://enroll-hd.org/) **webpage:**

**Yes** [ ]

**No** [ ]

**Request PDS6 datasets**

**Please indicate in the ‘Request’ column in the table below if you want to get access to the PDS6 dataset.** You will need to sign a Data Use Agreement (DUA) for this dataset.

**Clinical Assessment Datasets:**

|  |  |  |  |
| --- | --- | --- | --- |
| **Request** | **Study**  | **Dataset Name** | **Data Category** |
|  | **Enroll-HD** | **Enroll-HD PDS6-R1** *(Periodic dataset)* | Clinical Assessment |