

Huntington's Disease Clinical Data Elements

Principal Investigator Responsible for Accuracy of Data (Name): _____ **Subject ID Number:** _____

Is this data Longitudinal (Follow-Up) Data? Yes ☐ No ☐

Subject Zip Code (1st 3 digits): _____ **Country of Residence** _____

Family Member Samples in Repository? Yes ☐ No ☐ Unknown (subject adopted) ☐ If Yes, list subject ID/s: _____

Year of birth: _____ **Gender:** Male ☐ Female ☐

Ethnic Category (as reported by subject)-Check one: Hispanic or Latino ☐ Not Hispanic or Latino ☐

Racial Categories (as reported by subject) Check One:

American Indian/Alaska Native ☐ Asian ☐ Native Hawaiian/ Other Pacific Islander ☐

Black/African American ☐ White/Caucasian ☐ More than One Race ☐ Other ☐ Unknown ☐

Additional Racial and Ethnicity Information: ☐ Other: _____

Diagnosed By: Neurosurgeon ☐ Neurologist ☐ Pediatric Neurologist ☐ Pediatrician ☐ Other ☐
Primary Care Physician ☐ Psychiatrist ☐ Psychologist ☐ Does Not Apply (Population or Family-Based Control) ☐

Data Collected By: Neurosurgeon ☐ Neurologist ☐ Pediatric Neurologist ☐ Primary Care Physician ☐ Pediatrician ☐
Psychiatrist ☐ Psychologist ☐ Research Coordinator ☐ Registered Nurse ☐ Research Coordinator/ RN ☐ Other ☐

HD Past Medical History

Indicate past or current symptoms that you feel are suggestive of HD?

- ☐ Motor (e.g., clumsiness, involuntary movements, poor balance)
- ☐ Cognitive (e.g., trouble with memory, judgment, concentration)
- ☐ Psychiatric (e.g., personality change, irritability, mood swings, depression, decreased motivation)
- ☐ Oculomotor
- ☐ Other (e.g., weight loss, insomnia) Please Specify: _____
- ☐ None: no clinical signs of HD

HD Family History

Father Affected: Yes ☐ No ☐ If yes, age of onset: _____ Repository ID (if applicable): _____

Mother Affected: Yes ☐ No ☐ If yes, age of onset: _____ Repository ID (if applicable): _____

Siblings Affected: Yes ☐ No ☐

If yes, please specify:

Brother ☐ Sister ☐: Age of onset: _____ Brother ☐ Sister ☐: Age of onset: _____

Repository ID (if applicable): _____ Repository ID (if applicable): _____

Brother ☐ Sister ☐: Age of onset: _____ Brother ☐ Sister ☐: Age of onset: _____

Repository ID (if applicable): _____ Repository ID (if applicable): _____

Brother ☐ Sister ☐: Age of onset: _____ Brother ☐ Sister ☐: Age of onset: _____

Repository ID (if applicable): _____ Repository ID (if applicable): _____

Other Siblings, age of onset: _____

Repository ID(s) (if applicable): _____

Subject HD Status

- ☐ HD: known Affected (testing data below)
- ☐ At risk: unknown gene status; subject with affected parent(s) and/or sibling(s)
- ☐ At risk: gene positive (CAG repeat length greater than or equal to 36) but without clinical signs of HD (testing data below)
- ☐ Unaffected: gene negative (CAG repeat length less than 36) and without clinical signs of HD (testing data below)
- ☐ Unaffected: unknown gene status; subject with unaffected parents and siblings

Has subject had Genetic Testing? Yes ☐ No ☐

Genetic Testing results (if known). Required for all known affected individuals

CAG Repeat Length: Allele 1:_____ Allele 2:_____

Optional Data

UHDRS Total Motor Score: _____

UHDRS Total Behavior Score: _____

UHDRS Total Functional Capacity (TFC) score: _____