

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: _____

HD Family History

Father Affected: Yes No If yes, age of onset: _____

Mother Affected: Yes No If yes, age of onset: _____

Siblings Affected: Yes No

If yes, please specify:

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

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

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

Other Siblings, age of onset: _____

Subject HD Status

- HD: known Affected (testing data below)
 At risk: unknown gene status
 At risk: gene positive - no motor signs of HD (testing data below)

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: _____