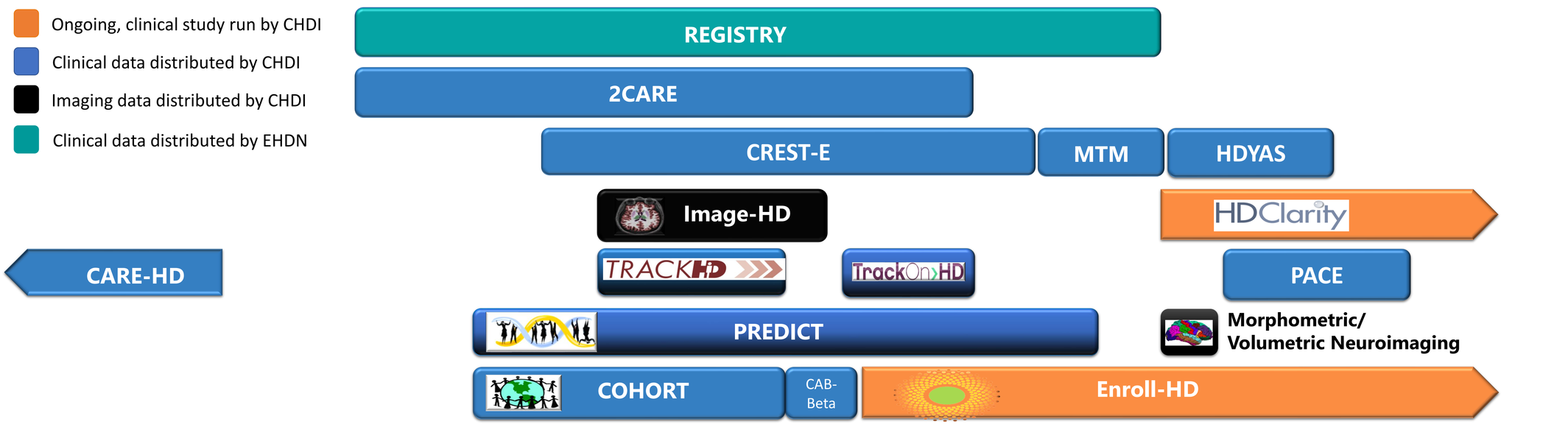
HD Research Data Access

What data do you need?

Longitudinal data? Cross sectional data from multiple studies?

Ask us – we will help you!



Study	Summary	Duration	# participants	Participant segment	Clinical data	Family history	Imaging data	Brain morphometric/ volumetric data	Other	File format	Data Access
Enroll-HD	Prospective, open-ended, multi-national, multi-center observational study without experimental treatments.	2012-	25,900	• Manifest HD • Pre-manifest HD • Genotype negative • Genotype unknown • Family Control • Community Control	Yes	Yes	No	No	GWAS (some). MiSeq (some), Methylation	CSV, R	**How to access:** www.enroll-hd.org.
REGISTRY	Prospective, open-ended, European, multi-center observational study without experimental treatments.	2004 - 2017	13,000	• Manifest HD • Pre-manifest HD • Genotype negative • Genotype unknown • Family Control • Community Control	Yes	Partly	No	No	GWAS (some), MiSeq	CSV, R	**How to access:** Submit application to EHDN's Scientific Bioethic Advisory Board (SBAC), www.ehdn.org
HDCSF/ HDClarity	Study to collect high quality CSF samples for evaluation of biomarkers and pathways that will enable the development of novel treatments for HD. Enroll-HD platform study.	2017-present	600 Goal: 1200	• Early Pre-manifest HD • Late Pre-manifest HD • Early Manifest HD • Mod. Manifest HD • Late Manifest HD • Control	Yes	Yes	No	No	GWAS (some)	CSV	**How to access:** CHDI data use agreement
TRACK-HD	Multi-site international study aiming to establish what measurements were the best to use as 'outcome measures' for clinical trials in HD.	2008-2011	402	• Pre-manifest • Early Manifest • Control	Yes	No	388 MRI; 237 DTI	Yes	GWAS, NfL	CSV DCM	**How to access:** CHDI data use agreement
TRACK-ON	Extension of TRACK-HD	2012 – 2014	245	• Pre-manifest • Early Manifest • Control	Yes	No	242 MRI; 241 fMRI; 239 DTI	Yes	GWAS, NfL	CSV DCM	**How to access:** CHDI data use agreement
COHORT	Observational study designed to collect phenotypic data and samples from people with HD and their family members. North America and Australia.	2006 - 2011	2,318	• Manifest HD • Pre-manifest HD • Genotype unknown • Family Control	Yes	Yes	No	No		CSV	**How to access:** CHDI data use agreement
PREDICT	Purpose was to study early brain and behavioural changes in premanifest HD gene expansion carriers.	2006 - 2016	1,481	• Pre-manifest HD	Yes	No	1,379 MRI; 103 fMRI	Yes		CSV, NII	**How to access:** CHDI data use agreement
CARE-HD	Co-Enzyme Q10 And Remacemide: Evaluation in HD	1997-2002	347	• Early HD	Yes	No	No	No		SAS	**How to access:** CHDI data use agreement
2CARE	Coenzyme Q10 (CoQ) in Huntington Disease.	2003-2014	609	• Clinical features or confirmatory family history of HD OR CAG >= 36 • Control	Yes	No	No	No		SAS XLSX	**How to access:** CHDI data use agreement
HDYAS	Huntington's Disease Young Adult Study	2017-2020	109	• Pre-manifest • Gene Negative (Control) • Family Control • Community Control	Yes	No	No	No	GFAP, hHb, IL6, IL8m mHTT, Neurogranin, NFL, TAU, totHTT, UCHL1, YKL40,	CSV	**How to access:** CHDI data use agreement
CREST-E	Creatine Safety, Tolerability, & Efficacy in Huntington's Disease (CREST-E)	2009-2015	553	• Manifest HD, stage I or II of illness (TFC greater or equal to 7).	Yes	No	No	No		SAS	**How to access:** CHDI data use agreement
MTM-HD	Multi Tissue Monitoring. Improved insight into disease-specific pathway/network alterations; Analysis of tissue samples from participating individuals will help to identify HD-related signatures	2015 - 2017	60	• Premanifest • Early Manifest • Control	No	No	No	No	Miseq, WGS, Proteomics, Methylation, mRNAseq	CSV	**How to access:** CHDI data use agreement
PACE-HD	Physical Activity and Exercise outcomes in Huntington's Disease (PACE-HD)	2018-2020	116	• Manifest HD, up to and including Stage II disease (TFC 7-13)	Yes	No	No	No		TBD	**How to access:** CHDI data use agreement
Morphometric/ Volumetric Neuroimaging	Automated pipeline using the long FreeSurfer analysis method with manual review.	2017 – 2018	449 TRACK 1,313 PREDICT 111 IMAGE-HD		No	No	No	Yes		TSV	**How to access:** CHDI data use agreement

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