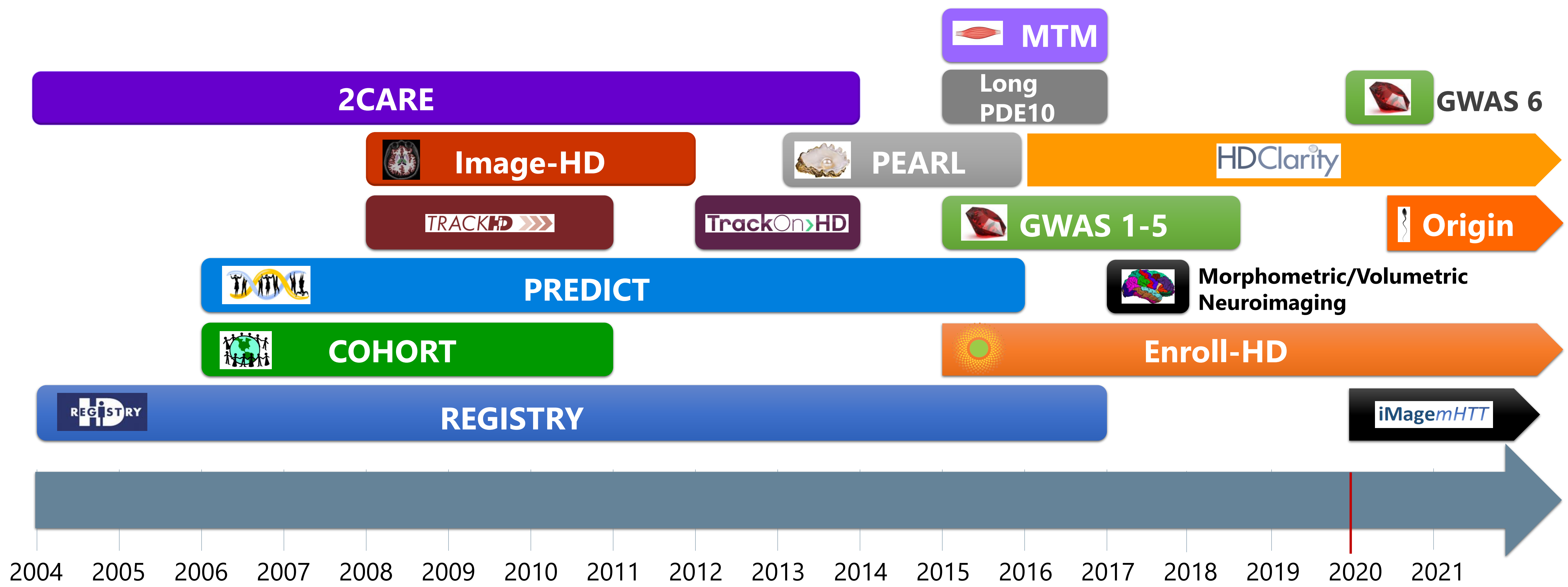


# HD Research Data Access

## 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	GWAS	RNAseq	Other	File format	Data Access
Enroll-HD	Prospective, open-ended, multi-national, multi-center observational study without experimental treatments.	2012-	23,000	<ul style="list-style-type: none"> <li>Manifest HD</li> <li>Pre-manifest HD</li> <li>Genotype negative</li> <li>Genotype unknown</li> <li>Family Control</li> <li>Community Control</li> </ul>	Yes	Yes	No	No	Some	No	MiSeq Methylation	CSV, R	<b>How to access:</b> <a href="http://www.enroll-hd.org">www.enroll-hd.org</a> . <ul style="list-style-type: none"> <li>Periodic Dataset -&gt; easy access,</li> <li>Specified Dataset -&gt; Review by Scientific Review Committee (SRC), No application deadlines.</li> <li>Site's Own Data -&gt; Review by CHDI COO before extraction. Comply with local law, ICF and site agreement.</li> </ul>
REGISTRY	Prospective, open-ended, European, multi-center observational study without experimental treatments.	2004 - 2017	13,000	<ul style="list-style-type: none"> <li>Manifest HD</li> <li>Pre-manifest HD</li> <li>Genotype negative</li> <li>Genotype unknown</li> <li>Family Control</li> <li>Community Control</li> </ul>	Yes	Partly	No	No	Some	No	MiSeq	CSV, R	<b>How to access:</b> Submit application to EHDN's Scientific Bioethic Advisory Board (SBAC), <a href="http://www.ehdn.org">www.ehdn.org</a>
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	550 Goal: 1200	<ul style="list-style-type: none"> <li>Early Pre-manifest HD</li> <li>Late Pre-manifest HD</li> <li>Early Manifest HD</li> <li>Mod Manifest HD</li> <li>Late Manifest HD</li> <li>Control</li> </ul>	Yes	Yes	No	No	Some	No		CSV	<b>How to access:</b> 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	<ul style="list-style-type: none"> <li>Pre-manifest</li> <li>Early Manifest</li> <li>Control</li> </ul>	Yes	No	388 MRI; 237 DTI	Yes	Yes	No	NfL	CSV DCM	<b>How to access:</b> CHDI data use agreement
TRACK-ON	Extension of TRACK-HD	2012 - 2014	245	<ul style="list-style-type: none"> <li>Pre-manifest</li> <li>Early Manifest</li> <li>Control</li> </ul>	Yes	No	242 MRI; 241 fMRI; 239 DTI	Yes	Yes	No		CSV DCM	<b>How to access:</b> 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	<ul style="list-style-type: none"> <li>Manifest HD</li> <li>Pre-manifest HD</li> <li>Genotype unknown</li> <li>Family Control</li> </ul>	Yes	Yes	No	No	No	No		CSV	<b>How to access:</b> Contact Huntington Study Group, <a href="http://www.huntingtonstudygroup.org">www.huntingtonstudygroup.org</a>
PREDICT	Purpose was to study early brain and behavioural changes in premanifest HD gene expansion carriers.	2006 - 2016	1,481	<ul style="list-style-type: none"> <li>Pre-manifest HD</li> </ul>	Yes	No	1,379 MRI; 103 fMRI	Yes	No	No		CSV, NII	<b>How to access:</b> CHDI data use agreement
iMage-HD	Multi-modal longitudinal MRI study in premanifest and early manifest HD patients.	2008 - 2012	1081	<ul style="list-style-type: none"> <li>Pre-manifest</li> <li>Early Manifest</li> <li>Control</li> </ul>	Partly	No	83 sMRI; 77 fMRI; 83 DTI; 83 SMI	Yes	No	No		CSV NII	<b>How to access:</b> CHDI data use agreement
CARE-HD	Co-Enzyme Q10 And Remacemide: Evaluation in HD	1997-2002	347	<ul style="list-style-type: none"> <li>Early HD</li> </ul>	Yes	No	No	No	No	No		SAS	<b>How to access:</b> CHDI data use agreement
2CARE	Coenzyme Q10 (CoQ) in Huntington Disease.	2003-2014	609	<ul style="list-style-type: none"> <li>Clinical features or confirmatory family history of HD</li> <li>OR CAG &gt;= 36</li> <li>Control</li> </ul>	Yes	No	No	No	No	No		SAS XLSX	<b>How to access:</b> 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	No	No	No	Yes	No	No	No		TSV	<b>How to access:</b> 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	<ul style="list-style-type: none"> <li>Premanifest</li> <li>Early Manifest</li> <li>Control</li> </ul>	No	No	No	No	Planned	Yes	Proteomics Methylation mRNAseq	CSV	<b>How to access:</b> CHDI data use agreement