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Enroll!

Updates from the Enroll-HD global community

Contact us at info@enroll-hd.org

DECEMBER 2023

WELCOME TO *ENROLL!* 2023

Photo: G. Stautner - artifox.com

Robi Blumenstein

This year has been an incredibly important one for Enroll-HD. The 10-year anniversary celebrations provided a valuable opportunity for us to thank the participants and their families who have selflessly given their time to supporting research, and the staff who have been instrumental in making the study so successful. As the most extensive observational study in HD, Enroll-HD goes from strength to strength in providing a rich and comprehensive database that supports clinical research in HD and sets the bar in the study of rare diseases. The contributors to this newsletter share their perspectives and insights into what makes Enroll-HD such a unique and valuable resource. With data from more than 30,000 participants in the database, of whom 21,000 are still currently enrolled at 156 sites in 23 countries worldwide, we are proud of what we have achieved in Enroll-HD. We remain confident of continued success, propelled by the unwavering dedication and enthusiasm of all those who form our global Enroll-HD community.

Photo: EHDN

The 10-year celebrations allowed us to share our immense pride in the successes of Enroll-HD to date. From left to right: Claudia Perandones, Jamie Levey, Selene Capodarca, Cristina Sampaio, G. Bernhard Landwehrmeyer

Robi Blumenstein
President, CHDI

A Personal Perspective on Celebrating 10 Years of Enroll-HD

Selene Capodarca is Enroll-HD's Global Study Director. She has been part of the study from the beginning, and talks about her role in Enroll-HD, engaging with the broader HD community, and last but definitely not least, the 10-year celebrations.

How did you get involved in Enroll-HD?
I've been working with the EHDN for over 10 years and joined about the same time that REGISTRY was transitioning to Enroll-HD. I started out as a LanCo, which is short for Language Coordinator for Italy, and after covering for maternity leave as Regional Manager for Europe, I was offered the position of Global Project Manager. Then, earlier this year, I was appointed Global Study Director. One of the many great things about the Enroll-HD team is the potential to progress and take on new challenges.

What does the role of Global Study Director involve?
A key component is working across different teams, different tasks, and different aspects of the study, mainly from an operational perspective. This includes Data Management teams, the Regional Management team and Regional Director, the Core Project Management team, and, of course, the Enroll-HD Global Platform Director, Olivia Handley. I work to "connect the dots" and help with the overall team effort to keep everything together. I also attend meetings such as the EHDN plenary events and conferences further afield. HDYO's International Young Adults Congress earlier in 2023 is a good example – I was there networking, catching up with people and research, and also celebrating the Enroll-HD 10-year anniversary. It was an amazing experience to connect and celebrate with young people, and it was great to see Enroll-HD and EHDN staff helping out and getting involved.

Photo: Gabriele Stauther · artifox.com

From left to right: Jamie Levey, Selene Capodarca, Jenny Callaghan, Ruth Fullam celebrating at the EHDN Plenary Meeting, Bologna 2022

Alzbeta Mühlbäck (left) and Selene Capodarca in Taufkirchen, Germany

Taufkirchen, Germany; from left to right: Lisanne Walter, Martha Hoyos, Selene Capodarca, Michael Bachmaier, Katrin Barth, Eileen Neacy, Elisabeth Singer-Mikosch, Annika Zeller, Theresia Kelm, Olga Kuvarzina

What do you enjoy most about your role?
For me, meeting HD families at events and conferences is really important. I have the hugest sense of gratitude for what the participants in Enroll-HD are doing in driving forward research. Celebrating the 10-year anniversary this year was an incredibly special occasion because we could update participants and their families on the study and, importantly, truly thank them for what they are doing in support of HD research. My gratitude for what Enroll-HD participants are working towards and achieving motivates me every day.

Ensuring Data Protection and Security

Emily Gantman is Vice President, and David Rankin is the Chief Legal Officer and Data Protection Officer at CHDI. They work to ensure that CHDI follows the highest standards of data privacy for participants in all CHDI studies, including Enroll-HD.

Photo: Emily Gantman

Emily Gantman

What is data protection, and why is it important?
David: One of the overriding aspects of any study that CHDI is involved in is protecting the confidentiality and privacy of participants. In 2018, the General Data Protection Regulation (GDPR) set out requirements for protecting data collected from EU citizens and residents. But regardless of laws and legal requirements, as an organization, CHDI has always placed the utmost importance on ensuring that data are obtained, retained, and used appropriately.

As Enroll-HD is a global study, do difficulties arise in managing different requirements for different countries and regions?
Emily: No – we apply the highest standard to all of our sites because our primary goal is to protect the identities and the data of participants in our studies, and to ensure that they are comfortable participating in our research. For example, even though the regulations in the United States are different than they are in Europe, we apply the same standards across all Enroll-HD sites to make sure that all participants are protected equally. Participant data privacy is a fundamental component of the Enroll-HD protocol and informed consent.

Are there any issues relating to data protection that are particularly relevant to HD research?
David: We collect genetic data. Given the nature of HD, and that genetic data is classified as particularly sensitive information under the GDPR, this is a particularly relevant issue for data protection. To protect research participants, even at CHDI, we do not know the identity of participants as the data obtained by CHDI are all coded, meaning that names and information cannot be matched up by CHDI. Likewise, any researcher who wishes to use Enroll-HD data receives only coded data and must first enter into a formal contractual agreement with CHDI by which they must agree, among other things, to properly secure and handle the data and not to use the data to determine the identity of any participant.

Emily: HD is a disease of families, not just individuals, and so it is important that we protect the privacy of not only the individual who has consented to participate in our research but also keep in mind that other family members might be impacted by the disease, and that we need to protect their privacy too.

What does this all mean on a day-to-day basis?
David: The whole point of collecting data is to progress HD research. The datasets that we provide routinely have all been carefully checked, analyzed, and curated to make it very difficult to identify anyone. We have committees that

assess requests if a researcher wants a unique, specialized subset from the Enroll-HD data to make sure their intended use of the data is appropriate. For all data requests, we have an internal set of approvals that must be obtained above and beyond the scientific approval, and that also includes due diligence in ensuring that the company or institution that wants to obtain the data from CHDI has adequate security measures in place to effectively protect the data. All of this puts an extra administrative burden on everyone, but it is necessary – and the right thing to do.

Emily: The processes have been constantly evolving. The GDPR came into effect in 2018, and since then, we have been assuming more and more responsibility for what that means to us as a sponsor of Enroll-HD and as good citizens in the research community. We work hard to ensure that our study sites abide by good practices and uphold security standards, as they are the gateway between the participants and the data. We are hugely grateful to our participants and take their contributions to Enroll-HD extremely seriously. This means that we really care about the integrity of keeping participant data safe and secure, and ensuring that it is used properly and for best practices and purposes.

A development for our US study sites this year has been the removal of the National Institutes of Health (NIH) Certificate of Confidentiality (CoC). Noopur Modi, Enroll-HD Regional Manager – Americas/Australasia, explains what happened and why.

Photo: Noopur Modi

Noopur Modi

Recent policy changes at the NIH meant that the CoC would no longer be issued for studies not funded by the NIH and considered research platforms – like Enroll-HD. As such, from July 2023, Enroll-HD sites in the US were no longer covered under the NIH CoC remit, and, therefore, all language pertaining to this had to be removed. We sent revised informed consent forms to all our impacted sites, and they submitted these to their respective institutional review boards. We sincerely thank the sites for their unwavering support – by the expiry date, we had successfully secured approvals for 63% of our sites, and more than 85% of the institutional review boards had given us the go-ahead to continue with follow-up visits until the revised informed consent forms were approved. Presently, we have obtained approvals for 98% of the impacted sites, thanks in large part to the dedication and cooperation of site staff. The study conduct remains unchanged, and all data collected in Enroll-HD continue to be protected by strict security measures and current data protection regulations. The commitment of site staff to the well-being of participants and the advancement of research has been instrumental in navigating these changes effectively, and we are truly grateful for their continued collaboration.

Indianapolis, USA; from left to right: Swati Sathe, Courtney Treharn-Gatza, Christopher James

Understanding the Progression of HD

Swati Sathe is the Medical Vice President at CHDI. In addition to heading up the statistics and modeling team, her role includes providing input on key medical and scientific issues relating to clinical research across a multitude of studies.

How are you involved in Enroll-HD?
I work closely with the Enroll-HD team on protocols, informed consent, and medical and scientific aspects as they arise, such as medical monitoring issues that require closer consideration. As the leader of the statistics and modeling team at CHDI, I work with Enroll-HD data on various projects – for example, to understand the progression of HD, and to decipher what might be important endpoints for clinical trials. In this, we work with a number of collaborators, primarily a group of statisticians at the University of Iowa. We also collaborate with IBM, the biotechnology company AITIA, and academics at Yale University, and I oversee a number of other research collaborations, all with the same aim of better understanding the progression of HD and informing the development of effective interventions. Enroll-HD is important to all of this.

What makes Enroll-HD so important?
Enroll-HD is a unique observational study – and perhaps the largest study we have in the field of rare diseases, especially when you consider the number of participants, the fact that it spans four continents, the number of sites involved, the duration of participation, and so on. As a primary study in which data is collected directly from participants, Enroll-HD provides input into all kinds of studies, including clinical research like identifying a meaningful endpoint in clinical trials, determining the usefulness of different assessments, and providing biosamples for further study and exploration in the laboratory.

Enroll-HD also provides data for studies to establish genetic modifiers of the disease, and for when we observe an interesting finding in an animal model and want to establish the relevance to humans. For many rare genetic disorders, we know that the best point to intervene is as early as possible, and by recruiting participants and studying them for years – in fact, decades, as we are in Enroll-HD – we are obtaining a much clearer sense of how HD progresses over time. This knowledge is important for clinical trials to run faster in finely calibrated cohorts with sharp endpoints that will measure efficacy much earlier in smaller cohorts.

Photo: Swati Sathe

Cristina Sampaio (left) and Swati Sathe celebrating Diwali

Why are young participants so critical to HD research?
In all neurodegenerative disorders, but HD in particular, intervention is most likely to be effective early on in the disease. With HD, the projected disease span can be 25 years or more, but by studying the illness very early in its development, we have the greatest potential of finding something amenable to treatment. This task becomes increasingly difficult as the disease progresses. Increasingly, pharmaceutical companies are hoping to treat the disease early in its development – which is the appropriate thing to do – but we don't yet know how to test or demonstrate the success of this. Research in HD is inherently challenging due to its rarity, complexity, and trajectory, which is why we need to better understand it as early as we possibly can – before symptoms are identified.

How will the Huntington's Disease Integrated Staging System (HD-ISS) help in understanding the progression of HD?
The need for a staging system of HD was driven by the regulatory requirements around drug approval. It's important that researchers, pharmaceutical companies, and other stakeholders can use a uniform language to describe the study design and participant cohort in a drug trial and facilitate recruitment. Prior definitions that rolled over from clinical practice were very subjective and didn't fit well within the regulatory framework. We needed to be able to objectively describe the trajectory of HD over the lifespan and at what points we might be able to intervene to progress clinical research.

Enroll-HD provided important data in the development of the HD-ISS. This allowed us to identify and describe four distinct stages from 0–3, with 0 being without symptoms but carrying the genetic mutation and 3 being the most severe stage of disease progression. Being able to stratify HD in this way for research purposes offers the potential for identifying biomarkers even before the overt symptoms of HD are apparent. Pharmaceutical companies want to target the disease in the earliest stages possible – and this research is made possible by the HD-ISS.

How the Enroll-HD Platform Supports Clinical Trials

Jenny Townhill, Enroll-HD Partnerships Director, and Tim McLean, Enroll-HD Platform Co-Leader, explain the dedicated support that the Enroll-HD platform provides for clinical trials in HD.



Photos: Gabriele Stauner · artfox.com

Jenny Townhill and Tim McLean

Jenny: We work closely with companies planning clinical programs in HD at all stages of development and are in a great position to support clinical trials from inception to completion using the resources from Enroll-HD. We typically start by having an introductory meeting with sponsors to discuss the available support, talk about their aims, and then work with them to determine how we can best meet the needs of each specific study. We have dedicated experts in HD and drug development, both within CHDI and on an independent panel [the Enroll-HD Clinical Trial Committee], that can support program and protocol development and provide input on topics such as identifying the optimum target patient population and outcome measures such as neuroimaging, wet biomarkers, digital and patient-reported outcomes.

The Enroll-HD platform has an extensive and well-established international site and investigator network with which our team has long-term working relationships. This infrastructure, and the data collected for the Enroll-HD study enabling computational feasibility analysis, allow the identification of the most appropriate clinical trial sites. The Enroll-HD Clinical Trial Site Certification scheme ensures that sponsors are aware of all certified sites with the capability to conduct HD clinical trials in their regions of interest. In addition, we can support sites by helping to identify potentially eligible participants at the sponsor's trial sites using the up-to-date Enroll-HD database.

Studies can be nested within Enroll-HD to help reduce the testing burden on participants by conducting assessments as part of their annual visit. Meanwhile, independent studies can utilize existing Enroll-HD data to support their own analyses. Historic Enroll-HD data for study participants can also be used to examine how the disease is progressing for each individual prior to study participation.

We offer our support freely to clinical trial sponsors. All we ask is that sponsors keep us up to date with the status of supported trials and, wherever possible, share their data with the HD research community.

Our involvement is a commitment with a sponsor over years of the most intense and dynamic time of clinical program design and execution. The knowledge gained

from the Enroll-HD platform and the wider CHDI team has been critical for many HD trials in informing discussions and Enroll-HD operational support.

What has been achieved so far?

Tim: The Enroll-HD platform provides critical resources for designing and conducting clinical studies and trials. As Jenny describes, the Enroll-HD platform provides invaluable scientific and operational support for designing and conducting academic research and industry-sponsored clinical trials. To date, we have supported more than 20 trials, with more than 10 different sponsors to varying degrees.

We can exemplify the range of support provided by reviewing a close working relationship with one particular sponsor: the relationship started when we were asked to perform an advisory review of the first draft protocol of the initial trial in the clinical program. Following further rounds of review, the final protocol was formally accepted, enabling the full support of the Enroll-HD platform. Initial support included advice on site identification and selection in the sponsor's preferred regions, and operational support included information on the provision of standard rating scales and their translations and on rater certification. The longstanding relationships between the Enroll-HD regional staff and the sites were utilized on several occasions to assist in initial interactions between the sponsor's clinical research organizations and the sites during study site set-up.

As there were particularly challenging study-specific aspects to the recruitment of trial participants, requiring a relatively high level of screening for each participant, recruitment support was provided to the trial sites with potentially eligible participant lists generated from the Enroll-HD database. In addition, advice was provided on referral networks involving sites not participating in the trial. Enroll-HD staff were invited to participate in regional investigator meetings to present on recruitment processes and strategies.

As additional trials were included in the clinical development program, relevant advisory and acceptance reviews were performed on subsequent protocols and protocol amendments. Furthermore, as the recruitment demands of the clinical program evolved, the Enroll-HD team were able to utilize their visibility of the changing demands of competing studies to advise on additional potential sites in the original regions of choice as well as advise on the potential inclusion of additional regions. The Enroll-HD team, which has remained unchanged, has also helped to provide continuity as there has been turnover within the sponsor's project team over the duration of the program.

This long-term clinical program is ongoing, and data from Enroll-HD and HDClarity has been requested by the sponsor to further inform their analyses. There is no doubt that the Enroll-HD platform has made a significant contribution to its progress.

Taking a Closer Look at Enroll's Periodic Data Set

Katrin Barth is the Enroll-HD Platform IT Director and explains the nuts and bolts of the Periodic Data Set (PDS) – one of the largest cohort datasets in any disease that is made openly available to researchers.

What is the PDS?

Participant data are made available to interested researchers as a PDS. From 2015, these have been released every other year. In 2022, the most recent release (PDS6) included data from 25,550 participants. The PDS is also enriched with data from the European REGISTRY study. Before data are included, they undergo a defined set of quality control checks to ensure that the appropriate consents have been obtained and that the data are as accurate and complete as possible.

Photo: Gabriele Stauner · artifox.com

Katrin Barth (right), here with Anne Rosser in Bologna

How is each PDS prepared?
Several Enroll-HD teams are involved – the monitoring team, who regularly visit study sites, the coding team, who ensure the data for medication and comorbidities are available in a comprehensible form, and the statisticians, who do a thorough quality check and assess the identification risk of every individual, ensuring that participants with a high risk of identification are not included. The IT team then extract and transform the data from the database using several predefined rules for eligible participants and visits.

The teams do several test runs of the data cuts to clean the data and fix any issues that would stop data from being included – this takes about six months. Finally, the documentation accompanying the release is created – these documents describe the PDS and the use and handling of the data. Finally, once the PDS is ready for release, the data management team and the IT teams make sure the PDS is made available to trusted researchers.

When can we expect the next release?
The last PDS6 was released in December 2022 and announced in January 2023. The next release is planned for the first half of 2025 – watch this space!

A Valuable Resource for HD Researchers

To find out more about how data, including Enroll-HD's Periodic Data Sets are used, we spoke with Darren Freeman, Data Manager at CHDI Foundation, and Christine Capper-Loup, Enroll-HD Platform Biosamples/SPS Data Administration Director.

Who can use the Enroll-HD data?
Darren: Part of the mission of CHDI is to make data freely available to HD researchers to reduce the hurdles for anyone wanting to do HD research. However, one of the requirements for this is that the data can only be provided to verified researchers. As part of Enroll-HD, participants give permission for their data to be shared, and this data is, of course, very sensitive, so we take every care possible to ensure it is appropriately used. As David Rankin and Emily Gantman explain, the GDPR is a big consideration for us. Of course, the whole point is to protect the people who have contributed data to the research community. The data requests are coming in fast and furious!

How do researchers apply to use these data?
Darren: It's pretty straightforward. We direct applications to our website, where the researcher provides various details, including details about data security. Typically, if a researcher's institution meets the data security and protection requirements, it's usually just a matter of getting everything together and then preparing the agreement. However, if they ask for specialized information or non-renewable biosamples, that has to go through a review process by the Scientific Review Committee (SRC), as well.
Christine: Sometimes, researchers request specialized


Photo: Christine Capper-Loup
Christine Capper-Loup

data [which we call specified datasets (SPS)]. There are different types of these requests. It can be for information that was collected but isn't routinely provided as part of the PDS, or for unaggregated data. When this occurs, we ask the researcher to provide a project description to be reviewed by the SRC to make sure this additional level of information is justified and appropriate. We also ask if we can post these research question details on the Enroll-HD website because we want the HD research community, study participants and families, and also other communities interested in HD to know what sort of research is being conducted and by whom.

Who asks for the specified data, and how are these data used?
Christine: As we can see from the first figure the majority of data requests are from academics and CHDI, followed by biotechnology and pharmaceutical companies (industry).

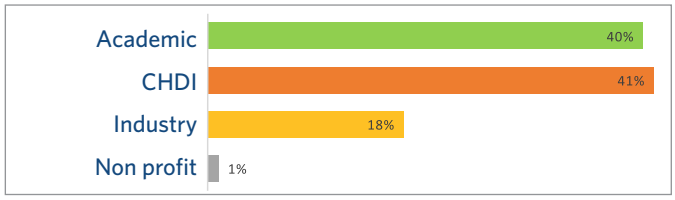


Figure 1

In addition to the requests for data not included in the PDS or unaggregated data (see above), which represent the majority of the SPS datasets requests ("standard SPS" in the second figure), we sometimes need to provide data related to biosamples that were distributed to a researcher, or only metrics information, known as "aggregate data" (e.g., number of participants taking or having taken a certain type of medication). The principal investigators of Enroll-HD sites can also request access to the data from their own participants ("my site data"). Some biotechnology and pharmaceutical companies recruit Enroll-HD participants in their trials and sometimes request access to the Enroll-HD data for these participants (we call this "run-in/historic data"). The Enroll-HD Platform Team can also request access to the data in an "operational request". A recent example of this was a request for data to analyze the distribution of participants that meet the criteria for each stage of the HD-ISS at each site to help define recruitment needs.

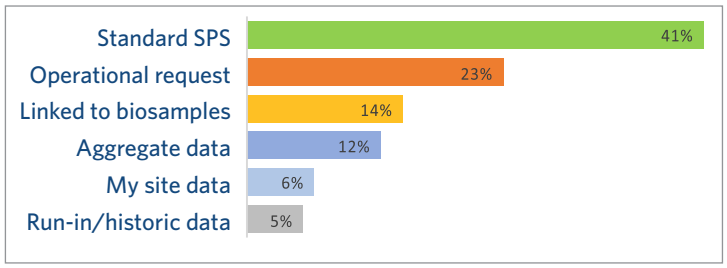
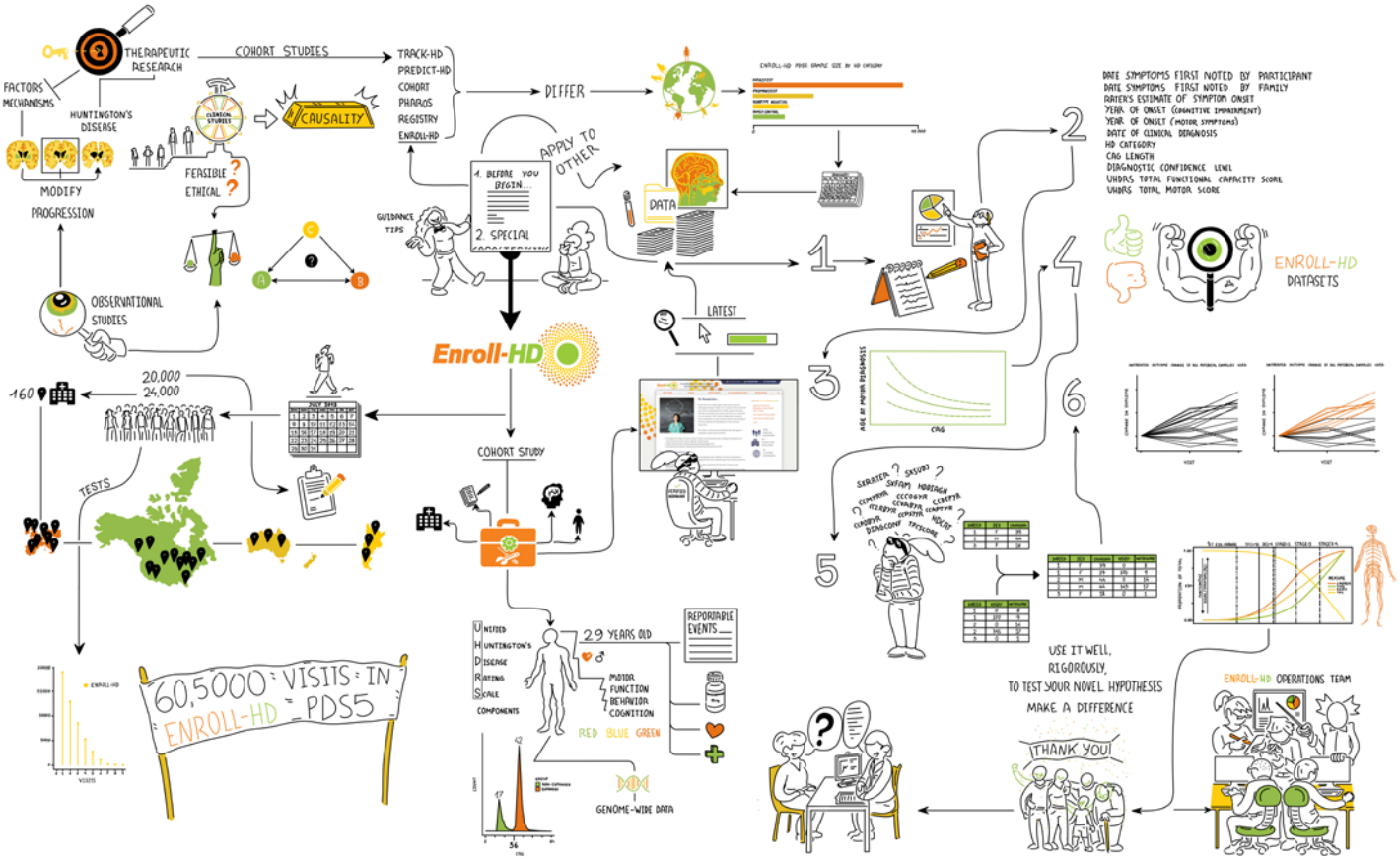


Figure 2

A full list of publications made possible by Enroll-HD data is available on the website: https://enroll-hd.org/for-researchers/publications/)

Making Statistics and Analysis of Clinical Data Accessible



Our animated video provides a brief introduction to Enroll-HD, alongside an overview of each article in this series

Photo: Jen Ware

Jen Ware

Jen Ware is Director, Experimental Design, at CHDI. She recently created a video and article series to assist researchers in understanding and analyzing observational HD data: https://enroll-hd.org/for-researchers/analyzing-data/

The original intent was to develop a classic field guide focused on analyzing data from Enroll-HD and other observational HD datasets that was to be made available as a downloadable resource for the community. The goal was to highlight best practices in epidemiological research and call out the benefits and challenges of working with observational data, providing practical examples based on Enroll-HD data throughout.

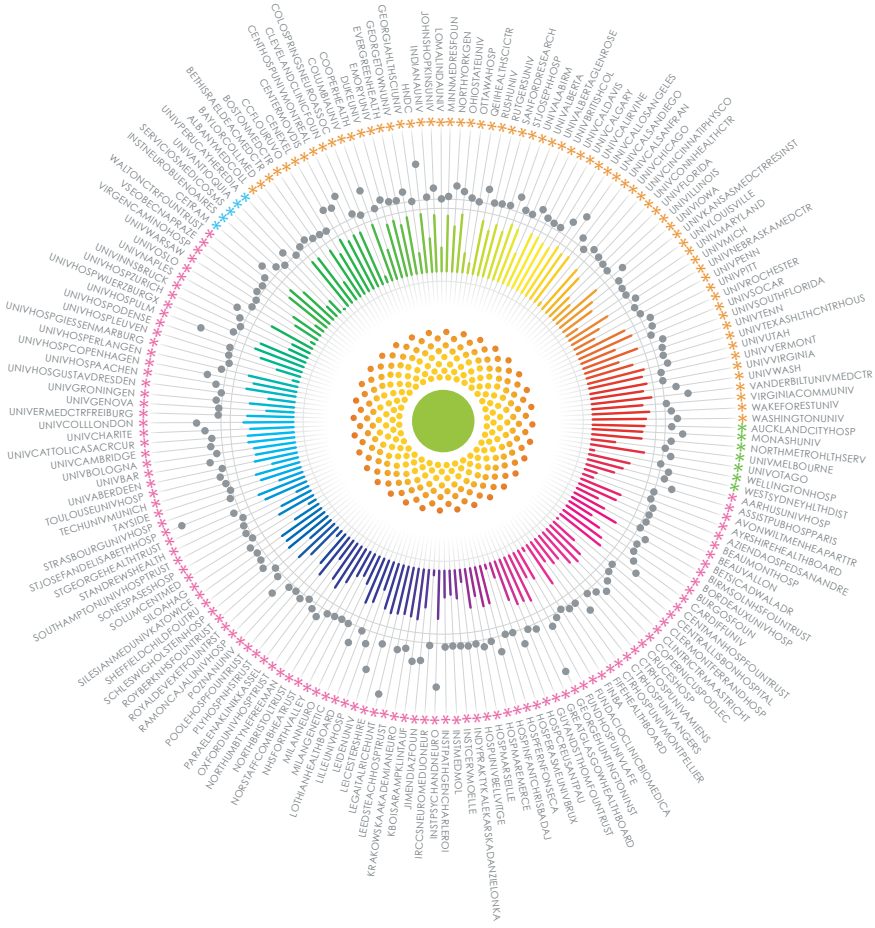
Critically, we wanted this information to be approachable, digestible, and accessible – which is why we decided to change the format from a traditional hard/soft copy publication to that of a web-based article series – each article focused on a bite-sized topic – with an accompanying introductory video.

The video is available on the website alongside the following accompanying articles:

- Before you begin...
- Special characteristics of HD data
- Age and CAG length in HD data analysis
- Benefits and challenges of working with observational (Enroll-HD) data
- Enroll-HD data handling and management tips
- Using observational data to inform clinical trial design

Enroll-HD 10-Year Anniversary Data Visualization

The *Enroll-HD Study Sites: 2012–2022 | Region, Recruitment, Tenure* Data Viz was designed and created by Jen Ware, Daisy Abreu (Statistician; AIDFM, University of Lisbon), and Gabi Stautner (Graphic Design; ARTIFOX.com) to recognize and acknowledge the incredible hard work and tenacity of the staff at 183 study sites who have contributed to Enroll-HD during its first 10 years. The visualization was printed on glass and delivered to each site as a token of appreciation for all their work. As you can see, each site is listed around the periphery of the image. The radial design depicts three metrics for individual sites: Geographical region is illustrated around the circumference by a color-coded star (purple = Europe; yellow = North America; green = Australasia; blue = Latin America). Total recruitment (on July 25, 2022) is represented



by a filled grey circle, positioned on a radial axis with larger numbers displayed towards the edge of the image (range = 1 to 1030). Finally, site tenure – bound by the first time a participant was seen at that site and last/most recent visit – is illustrated by the length of the central rainbow-colored bar (range = 0 to 10 years).

Excitingly, the visualization was longlisted for the 2023 Information is Beautiful Awards – a celebration of excellence and beauty in data visualizations, infographics, and information art. Congratulations, Jen, Daisy, and Gabi!

Georgetown University, Washington DC, USA; from left to right: Erin Koppel, Mara McCartin, Jamie Levey, Karen Anderson, Samantha Abbruzzese, Robin Kuprewicz, Emilee Piechota

And Finally...

We conclude our 2023 issue of *Enroll!* with reflections and insights from Jamie Levey, Enroll-HD Platform Co-Leader, at CHDI. Jamie has been closely involved in advancing HD research for almost 20 years, and shares with us her per-spectives on the progress we've made so far and her hopes for the future.

Jamie Levey (left) with Ralf Reilmann, George Huntington-Institute, Münster, Germany

Reading through this issue of *Enroll!*, I feel proud to be a part of this remarkable global effort that has achieved so many milestones and contributed so much value to advancing HD research in the many ways noted in this issue – and then some! Our close-knit HD community of study sites, researchers (academic and industrial), and families has come together since the beginning to ensure the objectives of Enroll-HD are met. It was not so long ago that only a handful of companies were working on HD, and access to datasets was either non-existent or proving challenging. Now, thanks to the collaborative nature of our community and our collective Enroll-HD contributions, there is a wealth of research and clinical development programs bringing us closer to the ultimate goal of effective treatments. I believe that Enroll-HD has achieved everything that could have been hoped for in developing a resource dedicated to facilitating progress in HD research.

St Joseph And Elisabeth Hospital, Bochum, Germany; Jannis Achenbach (left) and Tim McLean

Going forward, Enroll-HD will continue to serve the HD community, as we home in on specific data and samples needed for the most promising research advances, and recruit specific populations for a variety of study procedures (including imaging, additional biosample collections, and novel assessments) needed to further our mission. The entire Enroll-HD team is looking forward to working together as we get closer to the ultimate goal.

St George Health Trust, UK; from left to right: Marianne Novak, Fiona Loveday, Hae-Ree Seo, Merrie Gowie, Venessa Miller, Nayana Lahiri, Akshay Nair, Patricia Ribeiro

University of Alabama, Birmingham, Alabama, USA; from left to right: Tenisha Franklin, Eileen Neacy, Marissa Dean, Victor Sung, Candace Cromer

CHU, Angers, France; from left to right: Marie-Anne Guerid, Charlotte Abrial, Adrien Tchatalian, Marie Chene, Mireille Loiseau, Marie Bost, Audrey Olivier, Pr Christophe Verny, Jamie Levey, Adriana Prundean, Clarisse Scherer-Gagou, Jeanne Muller, Eric Décorte, Philippe Allain

Charité, Berlin, Germany; from left to right: Tina Mainka-Frey, Christos Ganos, Eike Spruth, Maria Gemenetzi, Diana Prychynenko, Josef Priller, Elisabeth Singer-Mikosch

Enroll! is a publication of CHDI Foundation, Inc., a nonprofit biomedical research organization that is exclusively dedicated to collaboratively developing therapeutics that will substantially benefit those affected by Huntington's disease. As part of that mission, CHDI Foundation sponsors and manages Enroll-HD. More information can be found at: www.chdifoundation.org

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