

Enroll-HD – Clinical Data and Biosample Access Policy

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The overarching goal of the Enroll-HD platform is to accelerate the development of therapeutics that will benefit HD-affected individuals. As a cornerstone of that goal, the Enroll-HD website hosts various datasets/biosample collections and makes these available to any interested researcher from academia, government institutions, nonprofit organizations, and public and private companies. The aim is to ensure that as many researchers as possible worldwide can access the coded study data and biosamples from [Enroll-HD and other clinical HD studies](#) in a rapid, transparent, straightforward manner, lowering barriers to entry into HD research while safeguarding the identity of research participants.

There is no merit review of project proposals requests for access to most [datasets](#) and or [renewable biosamples](#). Any researcher who wants to access coded clinical data or biosamples will need to submit a data and/or biosample request form as well as information on the organizational data security measures in place to protect the data.

However, a merit review of project proposals is required for [specified datasets](#) or [non-renewable biosamples](#) requests. These requests will be referred to the Scientific Review Committee (SRC), an independent committee of scientists. These proposals will be reviewed based on the merit of the proposed research or prioritization according to available limited resources, respectively.

Researchers will be required to sign a data use agreement and/or a biosamples use agreement, as applicable, either online or downloadable hard copy.

Active communication regarding planned and ongoing data analyses is encouraged to provide opportunity for collaborative work. Researchers accessing datasets are required, as part of the application process, to submit a brief, broad outline (50-200 words) of their proposed research study; this will be [posted publicly on the Enroll-HD website](#) along with the researcher's name and affiliation. Other researchers interested in a particular research project are encouraged to contact the dataset/biosample recipient directly to discuss areas of mutual interest with a view to potential collaboration.