

# Data Sharing Plan for the HHEAR Data Repository

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1. **Data Type:** The data being shared with the HHEAR Data Repository involves human data. These data will include individual-level data such as epidemiologic data, information which has been collected and recorded from study participants. These data include, but are not limited to, research and clinical assessments and information obtained via interviews, direct observations, biomarker and environmental exposure data, records reviews, genomic data (e.g., sequence, transcriptomic, epigenomic, and/or gene expression data), psychophysiological assessments, data from physical examinations, etc.. Additionally, information necessary to interpret the data (e.g., study protocols, data collection instruments, survey tools) will be shared.
2. **Data Repository:** The data will be submitted to the HHEAR Data Repository at the HHEAR Center for Data Science at Mount Sinai (HHEAR Data Center). Within the embargo period, the data will be available only to the HHEAR Data Center and the Study PI through controlled-access. After the embargo period, de-identified data will be available to researchers who have agreed to abide by the terms of the HHEAR Data Use Practices and Publication Policy. If appropriate, it is expected that the Study PI will have registered all studies in the database of Genotypes and Phenotypes (dbGaP) in addition to submitting the data to the relevant NIH-designated data repository (e.g., dbGaP, Gene Expression Omnibus (GEO), Sequence Read Archive (SRA), the Cancer Genomics Hub) after registration.
3. **Data Submission and Release Timeline: Defined Embargo Period:**

All de-identified data remain unavailable to the public until one year has passed from whichever of the following occurs last:

  1. The date that the final lab data set has been made available to the HHEAR PI.
  2. The date that the data center returns the first finalized statistical analysis report addressing a minimum of one of the project's specific aims.

Should a manuscript using the HHEAR generated lab data be accepted for publication prior to the end of the defined embargo period, the embargo period will end and all de-identified HHEAR project-related data (both epidemiologic/phenotypic data and lab results) will be made publicly available.
4. **IRB Assurance of the Data Sharing Plan:** The Study PI's Institutional Review Board (IRB) or analogous review body has reviewed the data sharing aspects of the project. The Study PI will provide evidence of approval by their institutional IRB to deposit their data into the HHEAR Data Center repository. This approval will indicate that data submission and subsequent data sharing for research purposes are consistent with the informed consent of study participants from whom the data were obtained. IRB Approval will be submitted prior to use of the data/data sharing.
5. **Appropriate Uses of the Data:** The Study PI agrees that data and supporting materials submitted to the HHEAR Data Repository may be accessed by researchers who have agreed to abide by the terms of the HHEAR Data Use Practices and HHEAR Publication Policy and used broadly for research purposes.

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By signing and dating this Data Sharing Plan as part of submitting data to the HHEAR Data Repository, and I certify that we will abide by the Data Sharing Plan for the HHEAR Data Repository. I further acknowledge that I have shared this document with any research staff who will participate in the use of HHEAR Data Repository.

Submitter Signature: \_\_\_\_\_

Date: \_\_\_\_\_

The signed Data Sharing Plan should be scanned and the electronic version should be uploaded to the Study PI's account on <https://hhearprogram.org>