



For more than thirty-five years the Cooperative Human Tissue Network has provided high-quality biospecimens and associated data, including clinical and demographic data, to investigators in support of their research. This includes race and ethnicity, which are predominantly self-reported and obtained from the medical records of the participating institutions. Currently, federal law and NIH policies require the collection of gender, race, and ethnicity data where appropriate.

The CHTN is aware of and continues to learn about evolving scientific rationales and methodologies for describing the attributes and group labels of research participants. The National Academies' publication on using population descriptors in genetics and genomics research provides a thorough review of the current state and recommendations/suggestions for improving genetic and genomic science in the future. (Link: [Using Population Descriptors in Genetics and Genomics Research: A New Framework for an Evolving Field | The National Academies Press](#)) Investigators should carefully consider the appropriateness of existing population descriptors and the possible need for multiple descriptors to represent the participants best.

Currently, the CHTN cannot recontact our sample donors to obtain additional demographic or other data not available in the medical record. Investigators can consult with CHTN Principal Investigators and/or Program Leadership if they have specific questions about how we can best support their clinical data annotation needs.