# MCD INFORMED CONSENT Data MANAGEMENT AND ShARING Template language

**Version 1.0 (07 Nov 2022)**

**How to use this informed consent form template language:**

* This consent form is written at an 8th grade reading level. Please edit your study’s Informed Consent Form to the appropriate educational level for your participant population.
* Text in **green** indicates example text to include in your informed consent form.
* Text in *italicized black* are instructions and suggestions on what to include in certain sections or scenarios.
* The sample language will need to be tailored to institutional and study specific requirements, but you are **encouraged** to include language that covers:
  + The collection of all NIMHD MCD CDEs, high-value optional (HVO) CDEs, and any other data your project is collecting;
  + The transfer of de-identified data from your P50 center (or other partner data warehouses) to the NIMHD RCC MCD data warehouse;
  + The use of the de-identified data in the NIMHD RCC MCD data warehouse by other researchers for future research (General Research Use);
  + Projects with Tribal Nations partners should only include language that coincides with their agreements with the NIMHD.

# WHAT are the NIMHD and HEAN RCC?

The NIMHD stands for the National Institute on Minority Health and Health Disparities. The NIMHD funds health research in people from groups with more illness or less access to care.

HEAN is the Health Equity Action Network. HEAN is also known as the Multiple Chronic Disease Disparities Research Consortium (MCD DRC). HEAN is a collection of centers across the US studying different long-term illnesses in people with higher levels of illness. HEAN RCC is the HEAN Research Coordinating Center based at University of California San Francisco (UCSF). HEAN RCC supports the HEAN research centers. NIMHD funds the HEAN RCC.

# WHAT WILL YOU ASK OF ME?

If you join this study, we will gather some data (information) from you. *[If other sources are used include “We will gather some data from other places.” and list sources as applicable.]*

Examples of data we might collect include, but are not limited to: *[Tip: Using general categories of all the information that will be collected will help avoid future IRB amendments as common data elements continue to be developed]*

* Race, ethnicity, sex, and main language spoken
* Health history and habits
* Type of health insurance and job
* Years of school and family income
* Family, home, and social support

# What WILL YOU DO WITH MY DATA?

*[The HEAN RCC will only collect de-identified data for current and future research. You* ***must*** *include some version of the following language:]*

We will add a secure code to safely store your data. We will use your zip code to know a little about your neighborhood. Your data will have personal information removed and shared with HEAN RCC at UCSF. Data with personal information removed is called de-identified data. Personal data like name, contact information, and zip code will be removed before sharing. Your zip code will not be shared with UCSF, only a secure code. The neighborhood data will tell us more about your community but keep your identity private. Researchers may use de-identified data to learn more about long-term health among people at higher risk for disease. You will not receive any direct benefit from sharing your data. But, sharing your data may help researchers learn how to better help others like you in the future.

NIMHD chose UCSF to hold the de-identified data from all HEAN studies in a database. Databases are collections of information stored on computer.

UCSF will keep your data securely. This means with extra protection. The database will only hold de-identified data. This means the database information will not hold data that can easily identify you.

* We will send these data to a secure National Institute of Health (NIH) database to store for future researchers to use. No one can easily identify you from these data.
* Other researchers may use these data for future research.

# HOW WILL YOU PROTECT MY PRIVACY?

Your privacy is very important to us, UCSF, and NIMHD. We will all take great care to protect your privacy. We will all do our best to protect your data during storage and when data are shared. However, there remains a small possibility that someone could identify you. There is also the small possibility that unauthorized people might access your data. In either case, we cannot reduce the risk to zero. But, below are a few steps we all will take to protect your privacy as much as possible.

* We will take steps to protect your data.
* Secure applications will collect your data.
* Secure computer systems will store your data.
* We will limit and keep track of who can see your data.
* Your data will be password protected for security.