

C3PNO Common Data Elements Index

Introduction

About This Index

C3PNO has identified a list of specific measures of interest referred to as the Common Data Elements.

This document outlines the common data elements collected by each cohort. With each cohort focusing on different populations and many reaching back several decades, there is a wide range of measures and data variables available.

The index shows for each cohort what C3PNO common data elements are available. Data other than what is represented by the Common Data Elements may be available for each cohort. You can visit www.C3PNO.org to contact us to find out.

About C3PNO

The Collaborating Consortium of Cohorts Producing NIDA Opportunities (C3PNO) is the coordinating center for NIDA longitudinal cohorts that represent a combined sample size of 12,000 active and 20,000 historical participants.

C3PNO links behavioral and biological data from cohorts spanning the United States and Canada that follow a diverse group of high-risk HIV-negative and HIV-positive persons. Some cohorts exclusively enroll people who inject drugs (PWID) or HIV-positive persons; most utilize community not clinical care sites for enrollment and follow-up.

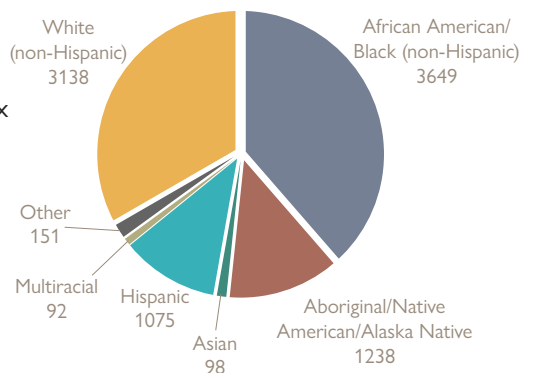
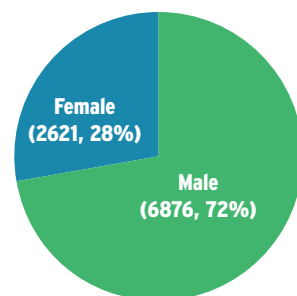
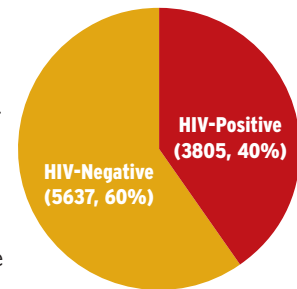
Our Data

The longitudinal cohorts are platforms for additional high-impact research. Each cohort currently supports and has the capacity to support related projects (R01, K01, and pilot studies) by providing researchers access to data, specimens, and participants.

HIV Status: This graph shows current participants both in and out of HIV care. Viral load data is available for 2,825 HIV-positive participants. Of those, 1,749 have HIV-1 RNA \leq 20 copies/mL (62%). For HIV-negative participants, most cohorts also have pre-exposure prophylaxis (PrEP) use data.

Sexual and Gender Minorities: Three of the cohorts recruit men who have sex with men and transgender individuals. These cohorts have more discrete sexual and gender identity data.

Race and Ethnicity: The cohorts collect data from a diverse set of races and ethnicities. This graph shows an overview of current participant demographics.



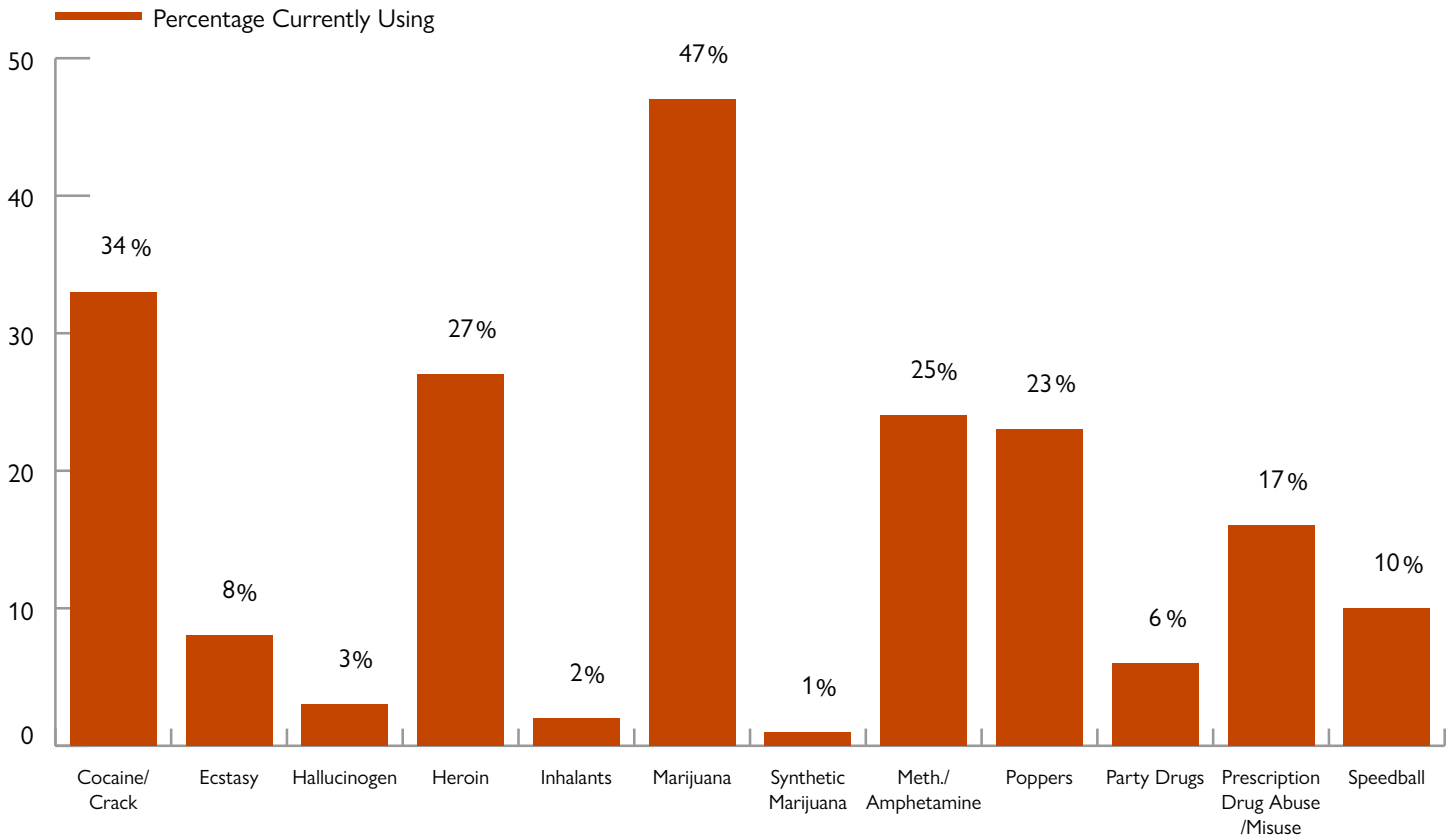
Specimen Availability (right):

The virtual data repository contains information about many specimens that have been collected and stored over time. Below are some details about specimens from the most recent participant visit.

Current Substance Use (below):

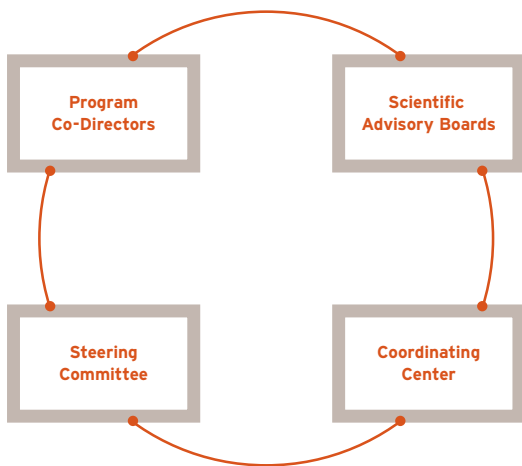
Most participants are currently using at least one substance. Cohorts collect extensive substance use data to access typologies, patterns, frequencies, and volume. This chart shows self-reported substance use. Most cohorts also collect biomarkers of substance use, such as urine toxicology screens.

Specimen Type	Participants	Specimens
Buffy Coat	446	1,403
Hair	187	187
Nail	412	413
Oral Rinse	452	2,691
Passive Drool	490	490
PBMC, Viably Frozen	1,830	6,177
PBMC, Pelleted	183	927
Plasma	3,899	2,5521
Rectal Sponge	123	246
Rectal Swabs	1,414	1,699
Serum	2,744	10,710
Whole Blood	862	862
Total	4,627	51,326



C3PNO Organizational Structure

The C3PNO focuses on cutting-edge science powered by the cohorts’ combined sample size of approximately 12,500 participants. We bring together a team of researchers with global leadership in HIV prevention, clinical science and co-morbidities, immunology, modeling, and bioethics to work with NIDA program scientists to stimulate the highest impact science across NIDA-funded cohorts that have compiled unique repositories of varied and rich data. Our model combines academic and professional research expertise that will stimulate, manage, and support scientific collaboration.



Program Co-Directors: C3PNO is led by Co-Directors, Pamina Gorbach, DrPH (UCLA) and Suzanne Siminski, MBA (Frontier Science Foundation). Dr. Gorbach will be primarily responsible for the scientific management while Ms. Siminski directs the bioinformatics projects.

Scientific Advisory Boards: The C3PNO Advisory Boards are comprised of content experts from UCLA and other institutions who advise on overall goals, priorities, and concept sheets related to the cross-cohort collaborations.

Steering Committee: Features cohort principal investigators (PIs) and NIDA program staff. This group will identify scientific priorities and cross-cohort opportunities. Members will review and advise on C3PNO policies and procedures and individual PIs will participate in concept sheet reviews related to their cohort data.

Coordinating Center: UCLA and Frontier Science project staff and PIs dedicated to facilitating communications and data transfers across the cohorts.

Data Collection Process

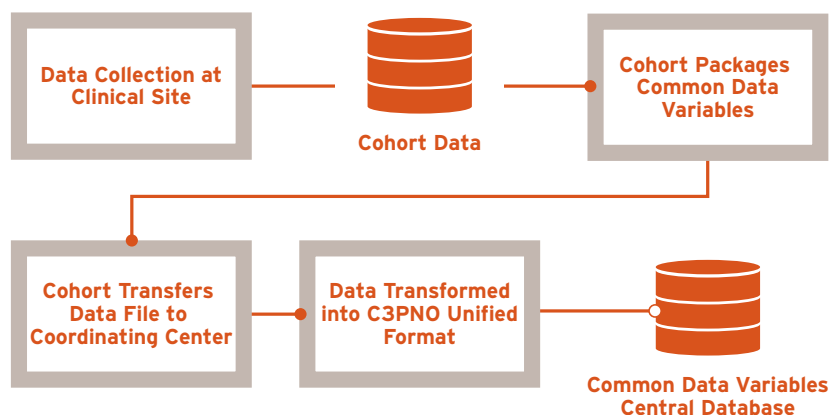
The cohorts are responsible for their own data collection and management and storage their data in a variety of database tools.

A select set of data variables (referred to as the common data variables) were identified by the C3PNO Steering Committee for central aggregation in the C3PNO system. Each cohort is responsible for packaging and transmitting their common data elements to the C3PNO Coordinating Center.

Personally identifiable information (PII) is not accepted for inclusion in the common data variables.

Virtual Data Repository Search Tool

There is a data search tool available on C3PNO.org that provides aggregate counts for current participant and specimen collection data.



This tool allows an investigator to specify a population and data of interest, and perform a search of the virtual repository to ascertain the number current participants and specimens that match the specified criteria.

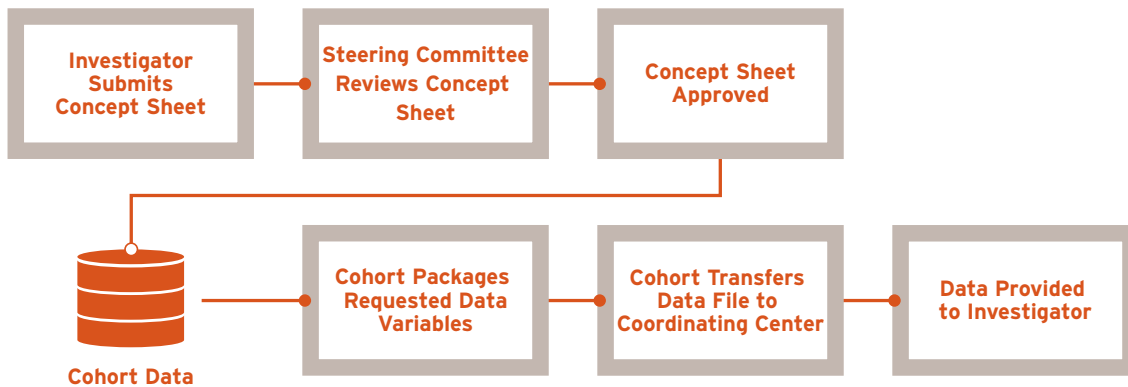
The search tool is limited to participants with a recent visit (defined by most cohorts as within the past six months) and to data within the common data elements central database.

Data Request Process

In order to obtain data for research purposes, you must submit a concept sheet on C3PNO.org.

When submitting your concept sheet, you will need to provide details about your research idea. You can use information from this catalog, as well as the data search tool on C3PNO.org to help you write your concept sheet.

Concept sheets are reviewed by the C3PNO Steering Committee and the cohorts that may be participating.



Let's get started. Take a look through this data catalog and the search tool on C3PNO.org. When you have a research idea, submit a concept sheet on C3PNO.org.

Data Catalog

A ✓ indicates this cohort collects this type of data. Information is not currently available for ACCESS and V-DUS cohorts.

Behavioral Data

	ACCESS	ALIVE	Heart	HYM	JHHCC	MASH	mSTUDY	RADAR	V-DUS
Depression Results Availability	Not available for this cohort yet	✓	✓	✓	✓	✓	✓	✓	Not available for this cohort yet
Homelessness or Unstable Housing				✓		✓	✓	✓	
Incarceration				✓		✓	✓	✓	
Main Sex Partner				✓				✓	
Number of Female Sex Partners		✓		✓		✓	✓	✓	
Number of Male Sex Partners		✓		✓		✓	✓	✓	
Number of Transgender Female Sex Partners				✓					
Number of Transgender Male Sex Partners				✓					

Biospecimens

	ACCESS	ALIVE	Heart	HYM	JHHCC	MASH	mSTUDY	RADAR	V-DUS	
Buffy Coat	Not available for this cohort yet				✓				Not available for this cohort yet	
Hair							✓			
Nail							✓			
Oral Rinse							✓			
PBMCs		✓				✓	✓	✓		✓
Passive Drool							✓			
Pellets							✓			
Plasma		✓	✓			✓	✓	✓		✓
Rectal Sponge								✓		
Rectal Swabs								✓		✓
Serum		✓				✓	✓	✓		
Whole Blood							✓			

Clinical

	ACCESS	ALIVE	Heart	HYM	JHHCC	MASH	mSTUDY	RADAR	V-DUS	
ALT	Not available for this cohort yet	✓			✓	✓	✓		Not available for this cohort yet	
AST		✓			✓	✓	✓			
Current Height (cm)		✓	✓	✓	✓	✓	✓	✓		
Current Weight (kg)		✓	✓	✓	✓	✓	✓	✓		
Hemoglobin		✓				✓	✓	✓		
Hemoglobin A1C		✓				✓	✓			
Hepatitis C Antibody Test		✓	✓	✓	✓	✓				
TB Diagnosis						✓				
Year Since HIV Diagnosis				✓	✓	✓	✓			✓

General

	ACCESS	ALIVE	Heart	HYM	JHHCC	MASH	mSTUDY	RADAR	V-DUS
Age at Visit	Not available for this cohort yet	✓	✓	✓	✓	✓	✓	✓	Not available for this cohort yet
Current Employment Status		✓	✓	✓		✓	✓	✓	
Ethnicity		✓	✓	✓	✓	✓	✓	✓	
Gender		✓	✓	✓	✓	✓		✓	
Race		✓	✓	✓	✓	✓	✓	✓	
Sex at Birth		✓	✓	✓	✓	✓	✓	✓	

HIV/AIDS

	ACCESS	ALIVE	Heart	HYM	JHHCC	MASH	mSTUDY	RADAR	V-DUS
CD4 (Count)	Not available for this cohort yet	✓	✓	✓	✓	✓	✓	✓	Not available for this cohort yet
Current HIV Status		✓	✓	✓		✓	✓	✓	
PEP Usage							✓	✓	
PrEP Usage					✓		✓	✓	
Viral Load (Copies/mL)		✓	✓	✓	✓	✓	✓	✓	

Substance Use

	ACCESS	ALIVE	Heart	HYM	JHHCC	MASH	mSTUDY	RADAR	V-DUS
Alcohol (Ethyl Alcohol)	Not available for this cohort yet		✓	✓	✓			✓	Not available for this cohort yet
Amphetamine			✓	✓	✓	✓	✓	✓	
CNS Depressants		✓			✓		✓	✓	
Cocaine		✓	✓	✓	✓	✓	✓	✓	
Fentanyl				✓			✓	✓	
GHB					✓			✓	
Heroin		✓	✓	✓	✓		✓	✓	
Inhalants					✓	✓	✓	✓	
Ketamine					✓			✓	
MDMA (Methylenedioxymethamphetamine)					✓			✓	
Marijuana		✓	✓	✓	✓	✓	✓	✓	
Methamphetamine					✓		✓	✓	
Nicotine		✓	✓	✓	✓	✓	✓		
Opioid Pain Relievers				✓	✓	✓			
Opium						✓			
PCP and Analogs					✓				
Prescription Pain Killer		✓			✓		✓	✓	
Speedball		✓	✓						
Spice					✓			✓	
Stimulants		✓			✓	✓	✓	✓	
Unspecified Hallucinogen	✓			✓	✓	✓	✓		
Unspecified Opiate				✓	✓	✓	✓		

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