

Overview of Add Health for New Data Users



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Add Health

The National Longitudinal Study of Adolescent to Adult Health

National Longitudinal Study of Adolescent to Adult Health

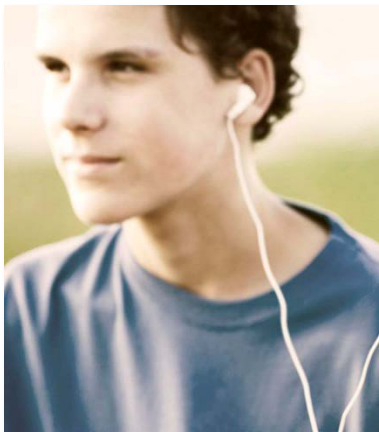
- On-going program project that began in 1994.
- Developed in response to a congressional mandate to fund a study of adolescent health.
- Funded by the National Institute of Child Health and Human Development (NICHD) with co-funding from 23 other federal agencies and foundations.
- Fifth follow-up wave 2016-2018.

Key Features of Add Health

- Nationally representative study that explores the causes of health and health-related behaviors of adolescents and their outcomes in young adulthood.
- Multi-survey, multi-wave inter-disciplinary design.
- Direct measurement of the social contexts of adolescent life and their effects on health and health behavior.
- Unprecedented racial and ethnic diversity and genetically informed sibling samples.

Initial Goal:

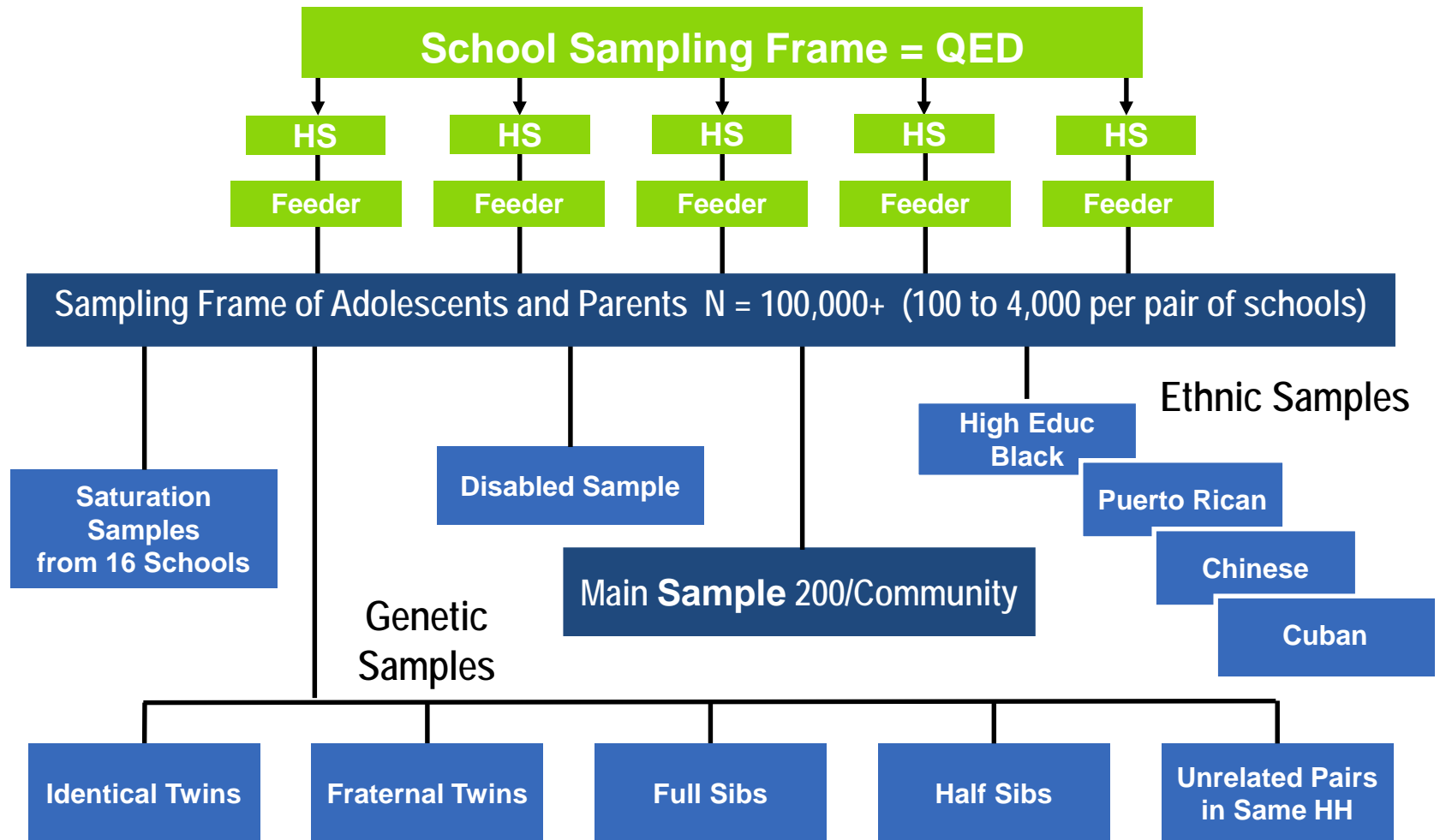
Putting the Individual Into Context



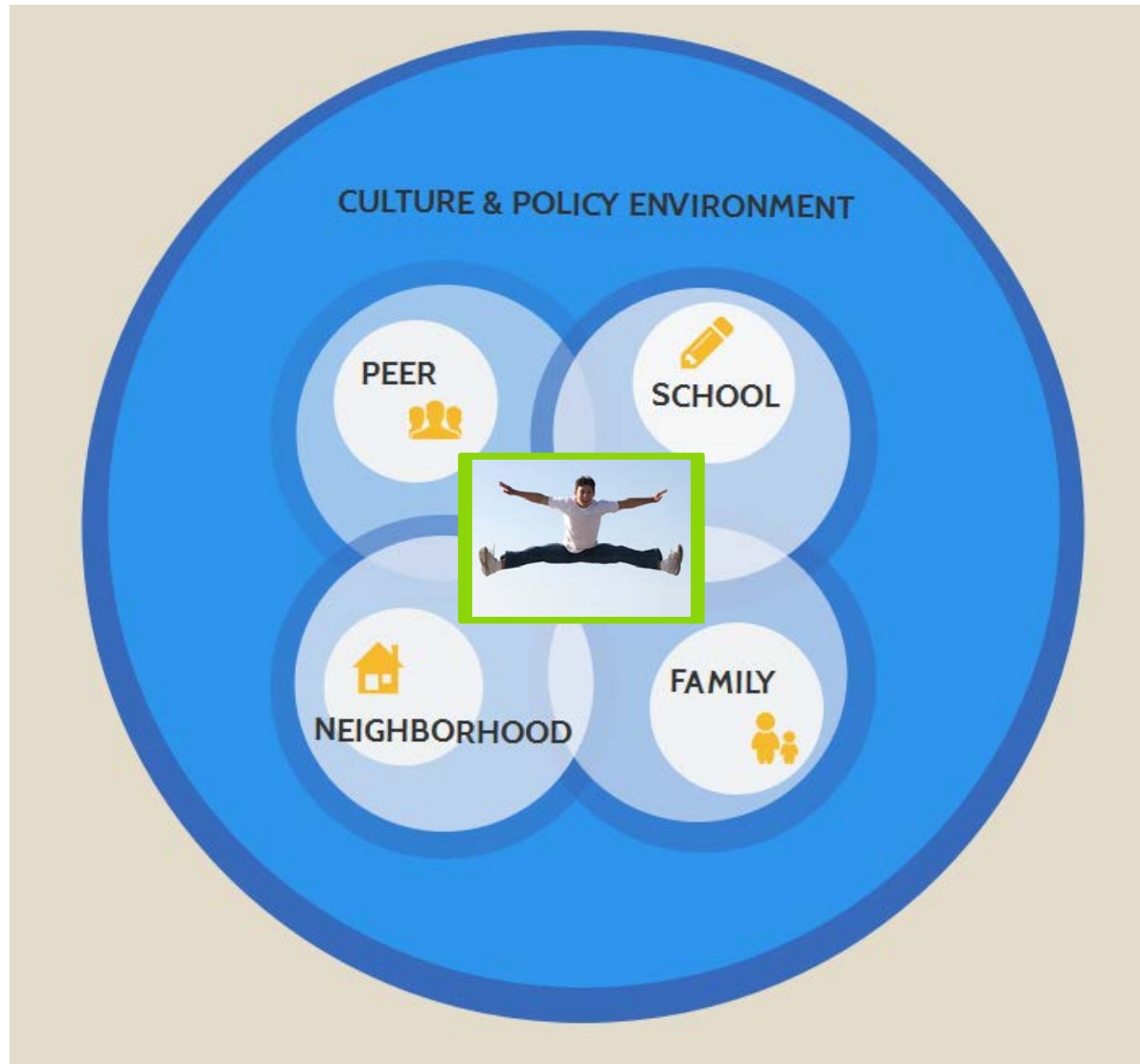
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 **Add Health**
The National Longitudinal Study of Adolescent to Adult Health

Sampling Structure

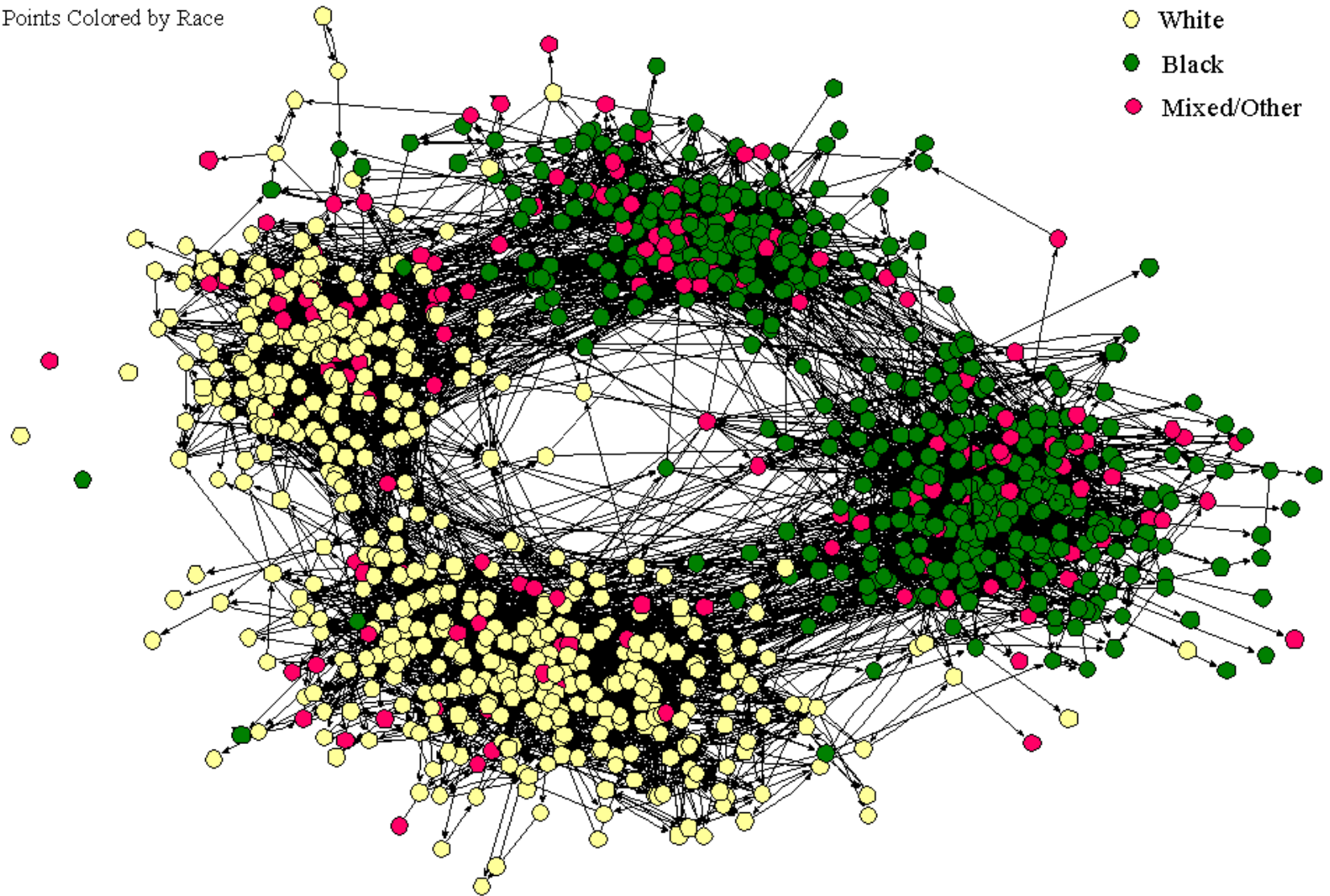


Add Health Contextual model



The Social Structure of “Countryside” School District

Points Colored by Race



Source: Moody, 2001, *American Journal of Sociology* 107: 679-716

Unique Features of Study Design

- Ethnic oversamples produce
 - unprecedented diversity in race and ethnicity in a representative population of adolescents
 - large numbers of youth in immigrant families
- Embedded genetic sample enables researchers to sort out genetic from environmental effects and explore gene-environment interactions.

Race and Ethnic Diversity in Add Health

Race/Ethnicity	N	%
Mexico	1,767	8.5
Cuba	508	2.5
Central-South America	647	3.1
Puerto Rico	570	2.8
China	341	1.7
Philippines	643	3.1
Other Asia	601	2.9
Black (Africa/Afro-Caribbean)	4,601	22.2
Non-Hispanic White (Eur/Canada)	10,760	52.0
Native American (non-Hispanic)	248	1.2
Total N	20,686	100.0

Missing on race/ethnicity=59



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Diversity in Add Health: Immigrant Status

Immigrant Status	N	%
1st generation	1,707	8.34
2 nd generation	2,987	14.59
3 rd generation +	15,774	77.07
Total N	20,468	100.0

Diversity of Family Forms at Wave I

Family Structure	N	%
2 biological parents	10,339	53.3
2 adoptive parents	403	0.7
Bio Mom/Step Dad	2,756	13.6
Bio Dad/Step Mom	591	2.6
Single Mom	4,520	20.4
Single Dad	637	3.1
Surrogate parent(s)	1,499	6.3
Total	20,745	100.0

In-School
Administration



Survey
Administration

Wave I
1994-1995
(79%)

Students
90,118

School
Admin
144

Adolescents
in grades 7-12
20,745

Parent
17,670

Wave II
1996
(88.6%)

School
Admin
128

Adolescents
in grades 8-12
14,738

Wave III
2001-2002
(77.4%)

Partners
1,507

Young Adults
Aged 18-26
15,197

Wave IV
2008
(80.3%)

IIV Study
~100

Adults
Aged 24-32
15,701

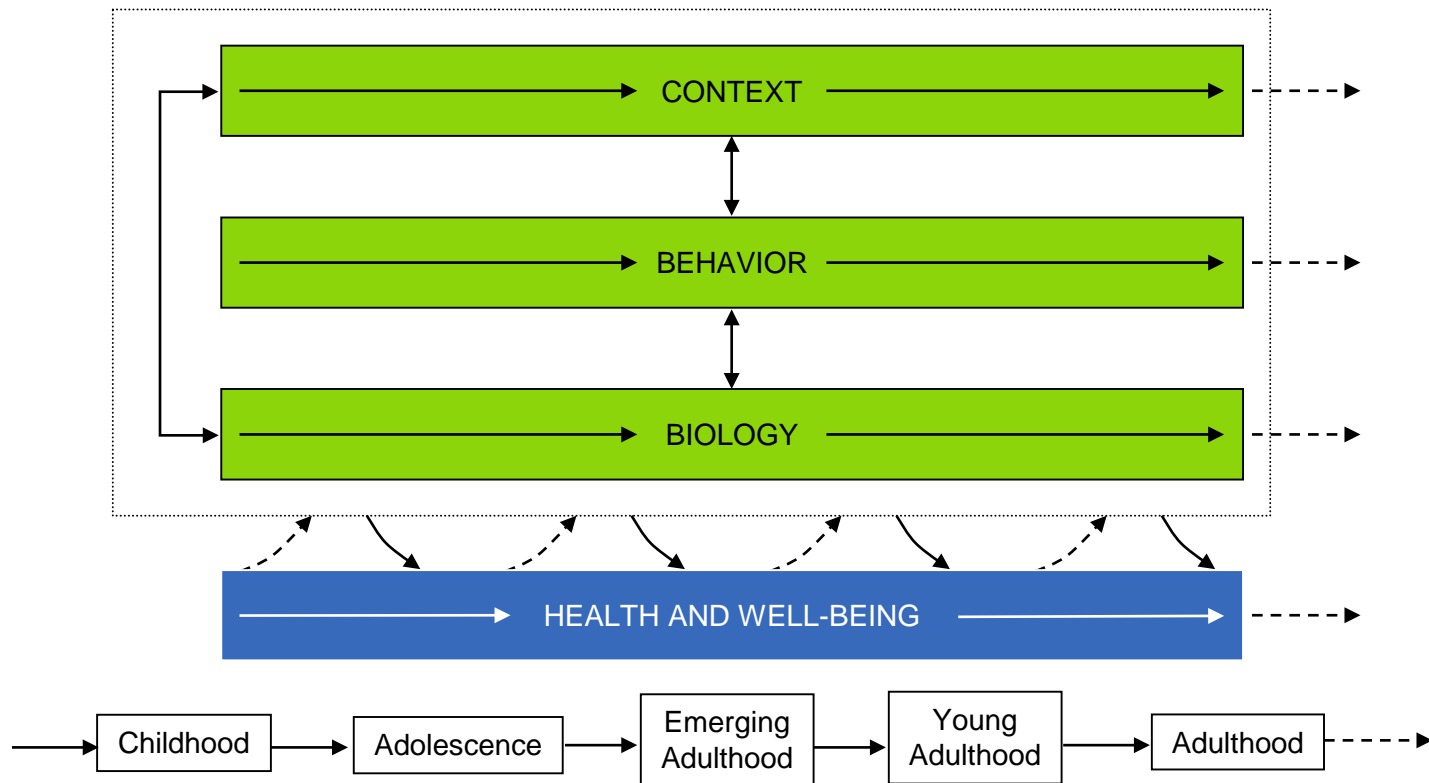
Wave V
2016-18

IIV Study
~100

Adults
Aged 32-42
Target: 12,000

Parent
3,000

Integrative Life Course Theoretical Framework



Questionnaire Content Across Waves

Waves I, II

Demographic
Family, siblings, friends
Education, **work**
Physical and mental health
Daily activities and sleep
Relationships
Sexual, & fertility histories
Substance use
Delinquency and violence
Attitudes, religion
Economics, expectations
Psychological, personality

Wave III

Demographic
Family, siblings, friends
Education, work, **military**
Physical and mental health
Daily activities and sleep
Relationships
Sexual, & fertility histories
Substance use
Involmnt w/criminal justice sys
Attitudes, religion
Economics, expectations
Psychological, personality
Children and parenting
Civic participation
Gambling
Mentoring

Wave IV

Demographic
Family, siblings, friends
Educ, work, **military (records)**
Physical and mental health
Daily activities and sleep
Relationships
Sexual, & fertility histories
Substance use and abuse
Involmnt w/criminal justice sys
Work attitudes and chars, relig
Economics, expectations
Big 5 Personality, stressors
Children and parenting
Civic participation
Cognitive function
Psychosocial factors

Wave V

Demographic
Family, siblings, friends
Educ, work, military
Physical and mental health
Daily activities and sleep
Relationships
Sexual, & fertility histories
Substance use and abuse
Involmnt w/criminal justice sys
Work attitudes and chars, relig
Economics, expectations
Personality, Stressors
Children and parenting
Civic participation
Cognitive function
Psychosocial factors
Retrospective childhood health & SES


Physical and Social Contextual Data

- Census
- CDC (STD prevalence)
- FBI crime statistics
- National Center for Health Statistics
- National Council of Churches
- Questionnaire-based social context data
 - In-School Network Data
 - Adolescent Romantic Pair Data
 - In-School Friendship Nominations
 - In-Home Friendship Nominations
 - Family Context (Parent Interview, sibling information)
 - Wave III Married, cohabiting, and dating couples (“couple context”)

Physical and Social Contextual Data

- Ancillary studies
 - ONEdata - Obesity & Neighborhood Environment Database
 - Waves I, III, and IV
 - E.g., parks, street connectivity, sidewalks, presence of fast food restaurants, alcohol outlets
 - The Adolescent Health and Academic Achievement Study
 - Analysis of respondents' high school transcripts
 - detailed measures of academic progress and high school curriculum

Biological Data Across Waves

Adolescence	→ Transition to Adulthood	→ Young Adulthood	→ Adulthood
Wave I-II (Ages 12-20)	Wave III (Ages 18-26)	Wave IV (Ages 24-32)	Wave V (Ages 32-42)
Embedded genetic sample of ~3,000 pairs			
Physical development 			
Height, weight	Height, weight	Height, weight, waist	Height, weight, waist
	STI tests (urine)	Metabolic	Metabolic
	HIV test (saliva)	Immune function	Immune function
	Genetic (buccal cell DNA)	Inflammation	Inflammation
		Cardiovascular	Cardiovascular
		Genetic (buccal cell DNA)	Genetic (whole blood)
		Medications	Medications
			Renal

Social and Biological Longitudinal Data in Add Health

Adolescence  Adulthood

Wave I-II
(12-20)

Wave III
(18-26)

Wave IV
(24-32)

Wave V
(32-42)

Social environmental data:

school

college

college

work

family

family

family

family

romantic rel

romantic rel

romantic rel

romantic rel

neighborhood

neighborhood

neighborhood

neighborhood

community

community

community

community

peer

peer

Biological data:

Biological resemblance to siblings in household on 3,000 pairs

height

height

ht, wt, waist, BMI

ht, wt, waist, BMI

weight

weight, BMI

BP, pulse

BP, pulse

BMI

STI test results

immune

immune

HIV test results

inflammation

inflammation

DNA

diabetes

diabetes

DNA

kidney disease

GWAS

mRNA

Wave IV Biospecimen Participation

- 96% of respondents consented to provide saliva for DNA
- 94% consented to provide blood spots
- For each specimen, 81% of those consenting to collection also consented to archiving
- Approx 12,000 DNA samples available for further testing
- GWAS data will be available via dbGaP (N~10,000)

Wave V Overall Goals

- Re-interview Add Health cohort members to collect social, environmental, behavioral, and biological data with which to track the emergence of chronic disease.
- Build on the life course history of respondents by adding and refining early-life measures of their birth and childhood:
 - Retrospective questions about birth and early childhood in Wave V survey
 - Birth records of respondents born in a subset of states
- Bring these data together with existing longitudinal data to create a 40-year life course record to test hypotheses about developmental origins of health and disease.

Wave V Interview 2016-2018

- Wave I respondents who will be moving through their 4th decade of life (32-42 years)
- Collect the following data:
 - survey data reflecting longitudinal and new information
 - longitudinal and new biological data and specimens
 - geographic locations for longitudinal spatial data
 - State of birth to obtain birth records of Add Health respondents born in a subset of six states
- Main study fieldwork began June 6, 2016

Wave V Data Collection

- Mixed mode survey design:
 - Web/mail with in-person and phone non-response follow up



Wave V mixed mode

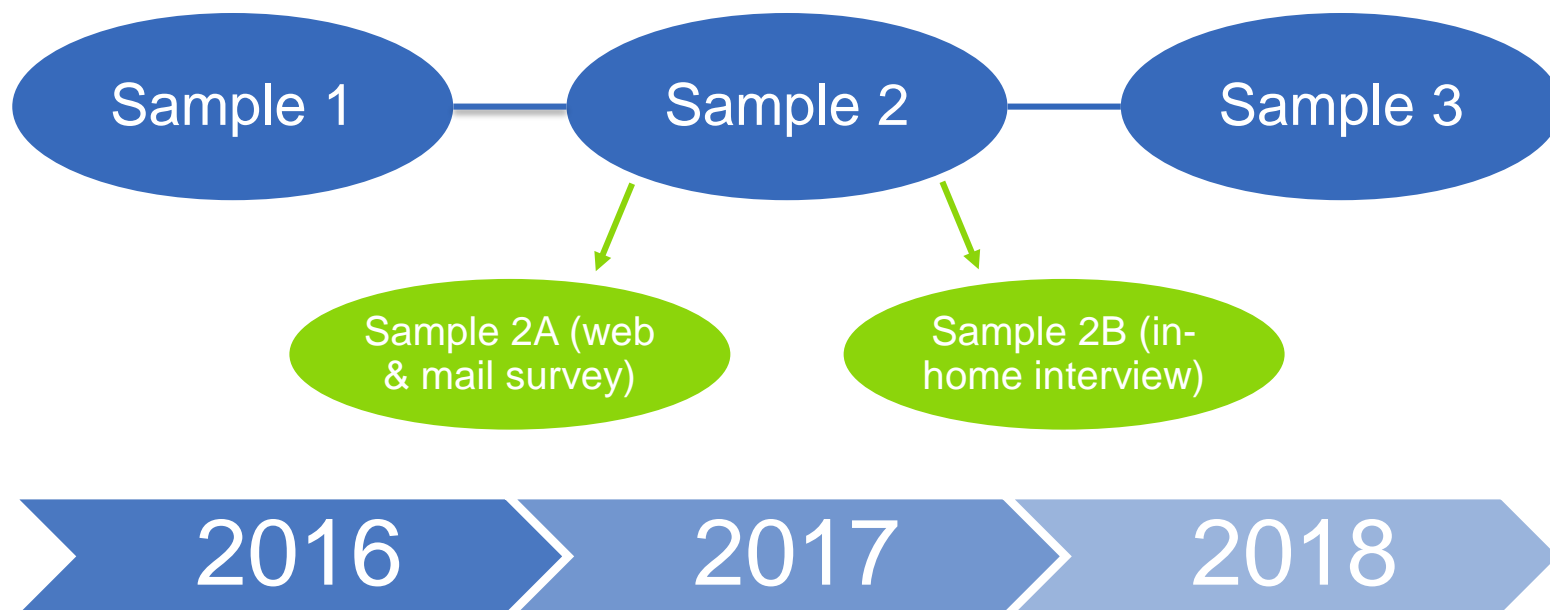
- Collect biological measures and specimens using separate biomarker subcontractor for in-home examination
 - Venous blood draw
- Continuous interviewing 2016-2018

Wave V Data Collection

- Conduct fieldwork on 3 nationally-representative samples sequentially during 2016-2018:
 - *Sample 1*: June 2016
 - *Sample 2a*: January 2017
 - *Sample 2b*: June 2017
 - subsample of 1,100 respondents interviewed in-person by interviewer to replicate Wave IV interview context to estimate mode effects
 - *Sample 3*: Oct 2017

Wave V Sampling Structure

All samples are nationally representative



Mixed Mode Wave V Survey

- Web survey: (50 mins total)
- Paper survey with same visual presentation of modules
- Obtain consent for biomarker collection in follow-up in-home exam
- Nonresponse follow-up
 - Sample nonrespondents and administer web survey in-person (CASI) on laptop or via telephone
 - Abbreviated telephone questionnaire for contact information and request consent for biomarkers.

Sample 1 Experimental Treatments

	Factor B: Propensity/Incentive		
	Model-directed Incentive Plan		Standard Incentive Plan
Factor A: Survey Protocol	Low Response Propensity/High Incentive	High Response Propensity/Low Incentive	
Modular Survey	\$35/\$30	\$25/\$20	\$30/\$25
Singular Survey	\$65	\$45	\$55

Current Progress of Wave V

- Anticipated sample size ~12,000 (effective response rate of 80%)
- Completed 11,022 surveys to date
- 66% biomarker consent rate

Survey Mode	N	Percent
Web	8,540	77.5
Paper	361	3.3
In-person	1,882	17.1
Phone	239	2.2
Total	11,022	100

Wave V: Biological data

- Repeat measures of biomarkers:
 - anthropometrics
 - blood pressure
 - Whole blood assays of:
 - Inflammation
 - Lipids
 - Glucose
 - Glycosylated *hemoglobin*
- New biomarkers of kidney disease:
 - Creatinine
 - Cystatin C
- Medications inventory

Wave V Biomarkers

- 66% consent rate for biomarker visit
- Consent rates among those who complete biomarker visit:
 - Venous blood 94%
 - Blood pressure 95%
 - Anthropometrics 99%

Vital Events Data

- Birth records data from respondents in 6 states
 - To date have received vital records approval for 3 targeted states
 - Release birthweight, gestational age, other characteristics of birth circumstances
- Death surveillance
 - To date, 364 deaths identified since Wave I; of which we have collected 344 death certificates
 - Assembling gold standard information on cause of death and circumstances of death

Wave V Data Release

Two data releases:

- Sample 1 data released in Nov 2017 (N~3800)
 - Biomarker data for Sample 1 in Sept 2018
- Full Wave V sample data in 2019
 - All data and samples combined with sampling weights
- Birth records data (with final Wave V release or subsequent)
- Death records data (with final Wave V release or subsequent)

Add Health Data Dissemination

Wave V

Add Health Parent Study Phase 2

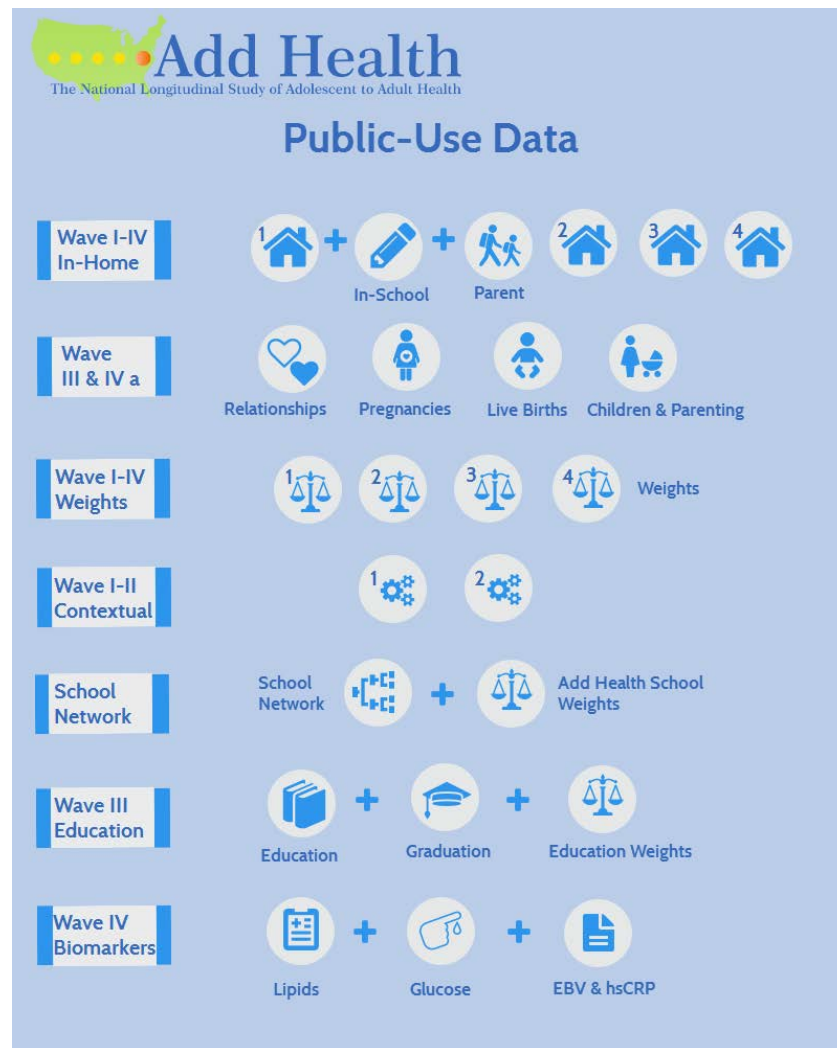
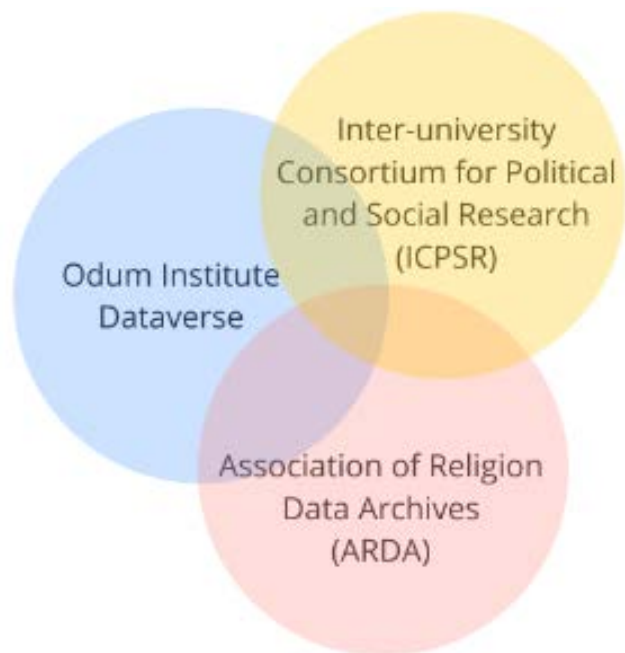
Add Health Data Dissemination

- Data dissemination structure & security
- Restricted-use data contracts
- Data discovery tools and resources
- CPC Data Portal

Four tier data dissemination according to disclosure risks

- Public-use data
- Restricted-use data
- High-security restricted data – Romantic Pairs
- Secure data facility for analyzing high school transcript data and for using geocodes to link contextual data
- dbGaP access for GWAS data (currently deposited)

Public-Use Data can be downloaded from the following places:



Data Security

- **User requirements to protect from deductive disclosure:**
 - Pledge of confidentiality
 - Monitoring of data use
 - Store data securely
 - Deletion of temporary data analysis files every six months.
 - Security of printed information
 - Password protected screen saver, set to activate after **3 minutes** of idle time.
 - Access data only from approved locations.

Restricted-Use Data Contract

- Complete contract application – pdf
- Include IRB approval or waiver letter
- Include data processing payment (by check only)
- Make sure to download Attachment A – security plan form and include in application

Don't forget....

- **Your contract expires every 3 years!**
- Email us if you think your contract might be expired or to find out what your expiration date is.
- **Annual reports are due every year!**
- Let us know if you make changes to research staff or data storage locations.



Please visit our **Contracts** Homepage!



Social, Behavioral, and Biological Linkages Across the Life Course

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[Security Plans](#)

[Deductive Disclosure](#)

[New Data Releases](#)

Add Health Restricted-Use Data Contracts

New Contract

To apply for restricted-use data, please download and complete the Restricted-Use Data Contract using the [CPC Data Portal](#). See our [Security Plans](#) page for more information on developing your Data Security Plan. See our [Annual Reports and Publications](#) page for annual report requirements.

Renew Contract

To renew your contract, please email [Add Health Contracts](#) for instructions. Add Health Restricted-Use Contracts must be renewed every three years. Your renewal date is included with your approved contract. Please note that no processing fee is required for renewal. See our [Annual Reports and Publications](#) page for annual report requirements.

Add an Additional Person to Contract

For information on how to add additional researchers, collaborators, officemates, or information technology staff to your Add Health Restricted-Use Contract, navigate to the [Add an Additional Person to a Restricted-Use Data Contract page](#).

Transfer Contract

If you are transferring institutions or transferring your Add Health Restricted-Use Contract to another researcher at your university, you must first obtain Add Health's approval. Please see the [Transfer Restricted-Use Data Contract page](#).

Terminate Contract

If you will not be renewing your contract, please complete the steps found on the [Terminate Restricted-Use Data Contract page](#).

Request Additional Data

If you have a current Restricted-Use Contract and would like to request additional data sets, please complete the [Additional Data Order form](#). This form can be scanned and emailed to [Add Health Contracts](#).

Romantic Pairs Contract

For information on how to request the Romantic Pairs data, navigate to the [Romantic Pairs Data Contract page](#).

Request Remote Access

Current researchers that are accessing Add Health data through a server and would like to gain access from another location (home, other office, etc.) should download the [Security Information for Remote Access form](#) and email it to [Add Health Contracts](#).

Contract Questions

For questions regarding contracts, please navigate to our [FAQ](#) contracts page or email [Add Health Contracts](#).



ADD HEALTH CODEBOOK EXPLORER (ACE)

- Interactive tool, developed in 2015 by the Add Health Team
- Developed in response to feedback that pdf codebooks were difficult to navigate and information on data collected across waves was nearly impossible to find
- Browse by topic or search by variable name, keyword, or phrase to discover the rich volume of data collected by Add Health



ADD HEALTH CODEBOOK EXPLORER (ACE)

BROWSE BY TOPICS



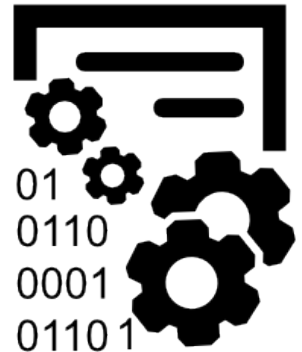
ADD HEALTH CODEBOOK EXPLORER (ACE)

BROWSE BY KEYWORDS



CPC Data Portal








- Restricted-Use data contract applications are now submitted through the CPC Data Portal <https://data.cpc.unc.edu/>
- Expedite and standardize contract application and renewal process for restricted-use Add Health data





Welcome to the CPC Data Portal

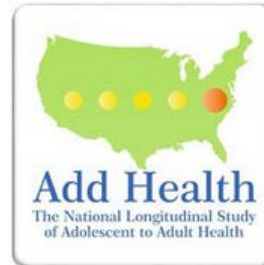
Your gateway to data collected by the Carolina Population Center
and available to the research community

Project	Description
 Add Health	The National Longitudinal Study of Adolescent to Adult Health (Add Health) is a longitudinal study of a nationally representative sample of adolescents in grades 7-12 in the United States during the 1994-95 school year.
 Cebu Longitudinal Health and Nutrition Survey	The Cebu Longitudinal Health and Nutrition Survey is part of an ongoing study of a cohort of Filipino women who gave birth between 1983 and 1984 in Cebu Province in The Philippines.
 China Health and Nutrition Survey	The China Health and Nutrition Survey is an ongoing international collaborative project that was designed to examine the effects of the health, nutrition, and family planning policies.
 MEASURE Evaluation	The MEASURE Evaluation project focuses on strengthening capacity in developing countries to gather, interpret, and use data to improve health. The project creates tools, approaches, and data for rigorous evaluations, providing evidence to address health challenges.
 Measurement, Learning & Evaluation (MLE)	The Measurement, Learning & Evaluation (MLE) Project is the evaluation component of the Urban Reproductive Health Initiative (URHI). URHI is a Bill & Melinda Gates Foundation funded multi-country program in India, Kenya, Nigeria, and Senegal that aimed to improve the reproductive health of the urban poor by increasing the accessibility, quality, and use of family planning services. From 2010 – 2016, the projects have used different interventions, both demand and supply side, to increase use of and access to contraceptives.
 Russia Longitudinal Monitoring Survey of HSE	The Russia Longitudinal Monitoring Survey is a series of nationally representative surveys designed to monitor the effects of Russian reforms on the health and economic welfare of households and individuals in the Russian Federation.
 The Transfer Project	The Transfer Project is an innovative research initiative led by the University of North Carolina at Chapel Hill, UNICEF, and the Food and Agriculture Organization (FAO) to understand the broad impacts of government-led cash transfer programs in sub-Saharan Africa. National governments and local research organizations are key partners in all stages to assure research is utilized to inform the design and expansion of national social cash transfers (SCTs).

Showing 1 to 7 of 7 entries



CPC Data Portal



PUBLIC-USE

RESTRICTED-USE

Public-Use Data | Restricted-Use Data (Group View)

Quick link to the public-use data below +

Wave I Data

[Download Data](#)

The public-use dataset for Wave I contains information collected in 1994-95 from Add Health's nationally representative sample of adolescents. This dataset consists of one-half of the core sample, and one-half of the oversample of African American adolescents with a parent who has a college degree, chosen at random. The total number of Wave I respondents in this dataset is **6,504**.

The Wave I public-use dataset includes information from each of the following sources (as available):

- Wave I In-Home Data File, includes Wave I In-School Questionnaire Data, Wave I Parent Questionnaire Data and Add Health Picture Vocabulary Test Scores
- Contextual data
- In-school network data
- Weights

Topics

- Demographic Characteristics
- Contextual Data
- Family
- Education
- SES, Labor Market & Occupation
- Physical Health
- Psychological Well-being & Cognition
- Friends & Social Network
- Medication & Substance Use and Abuse
- Reproductive Health
- Crime/Delinquency/Victimization
- Romantic Relationships
- Risk Behavior

Wave II Data

[Download Data](#)

The public-use dataset for Wave II contains information collected in 1996 from Add Health's nationally representative sample of adolescents. The interview was generally similar to that at Wave I. Questions about attributes that should not change, such as ethnic background, were not repeated. A total of **4,834** of the original Wave I respondents were re-interviewed between April through August 1996.

The Wave II public-use dataset includes information from each of the following sources (as available):

- Wave II In-Home Interview
- Contextual data
- Weights

Topics

- Demographic Characteristics
- Contextual Data
- Family
- Education
- SES, Labor Market & Occupation
- Physical Health
- Psychological Well-being & Cognition
- Friends & Social Network
- Medication & Substance Use and Abuse
- Reproductive Health
- Crime/Delinquency/Victimization
- Romantic Relationships
- Risk Behavior

Public-Use Data | **Restricted-Use Data (Group View)**

Quick link to the restricted-use data group below +

Core Files

Requirements: [Add Health Investigator Information](#) [Add Health DUA](#) [Add Health Security Plan\(s\)](#) [Add Health Supplemental Agreement](#) [Add Health Data Processing Fee](#) [Add Health IRB approval letter](#) [Add Health Sensitive Data Security Plan](#) [Add Bundle](#)

Friendship Files

Requirements: [Justification description for Add Health](#)

Sibling Files

Requirements: [Justification description for Add Health](#)

Contextual Data Files

Requirements: [Justification description for Add Health](#)


Wave III Supplemental Files

Requirements: [Justification description for Add Health](#)

Wave IV Supplemental Files

CPC Data Portal

How to apply

- Go to **Add Health** page
- Select Restricted-Use Data (*Group View*)
- Click “**Add to Cart**” to the desire datasets.
- Click the shopping “**Cart**” in the header menu
- Under Shopping Cart click the button
Proceed to checkout
- Log in using a Microsoft Account

(*Personal, work or school account*)
- Email confirmation will be sent to the user and
CPC Data Portal Administrator



<https://data.cpc.unc.edu/projects/2/view>

CPC Data Portal

Parent Study Files

☒ Parent Study Files

Requirements: Justification description for Add Health

Parent with Spouse/Partner Data

Add to Cart

The Parent data file contains social, demographic, behavioral, and health data collected in 2015-2017 on a probability sample of the parents of Add Health sample members who were originally interviewed in 1995. Data for 2,013 Wave I parents, representing 2,245 Add Health sample members, are available. Additionally, 988 current spouse/partner interviews are available.

Add Health Co-Funders

- National Institute of Child Health and Human Development
- National Cancer Institute*
- National Center for Health Statistics, Centers for Disease Control and Prevention, DHHS
- National Center for Injury Prevention and Control, Centers for Disease Control and Prevention, DHHS*
- National Center for Minority Health and Health Disparities*
- National Institute of Allergy and Infectious Diseases*
- National Institute of Deafness and Other Communication Disorders*
- National Institute of General Medical Sciences
- National Institute of Mental Health
- National Institute of Nursing Research*
- National Institute on Aging*
- National Institute on Alcohol Abuse and Alcoholism*
- National Institute on Drug Abuse*
- National Science Foundation*
- Office of AIDS Research, NIH*
- Office of the Assistant Secretary for Planning and Evaluation, DHHS*
- Office of Behavioral and Social Sciences Research, NIH*
- Office of the Director, NIH
- Office of Minority Health, Centers for Disease Control and Prevention, DHHS
- Office of Minority Health, Office of Public Health and Science, DHHS
- Office of Population Affairs, DHHS*
- Office of Research on Women's Health, NIH*

- **Questions or Feedback?**

- Contract Inquires:
- addhealth_contracts@unc.edu