Overview of Add Health for New Data Users

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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.



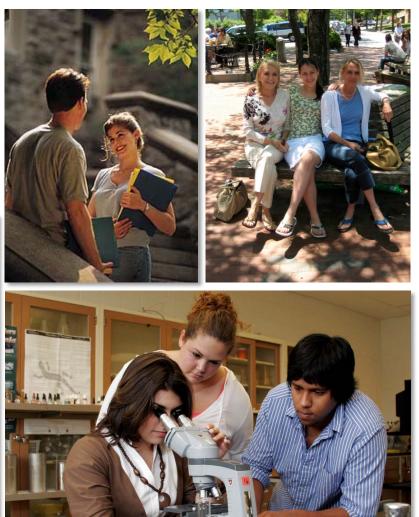


Initial Goal:

Putting the Individual Into Context



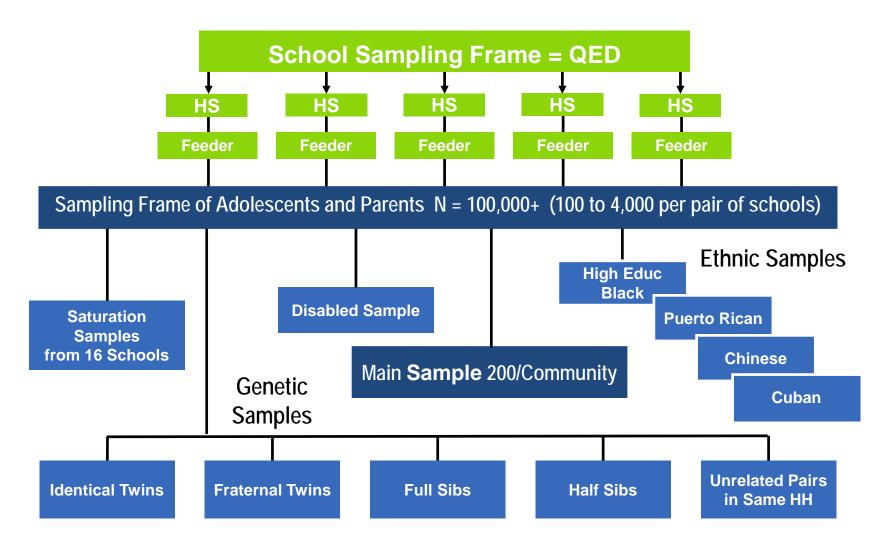




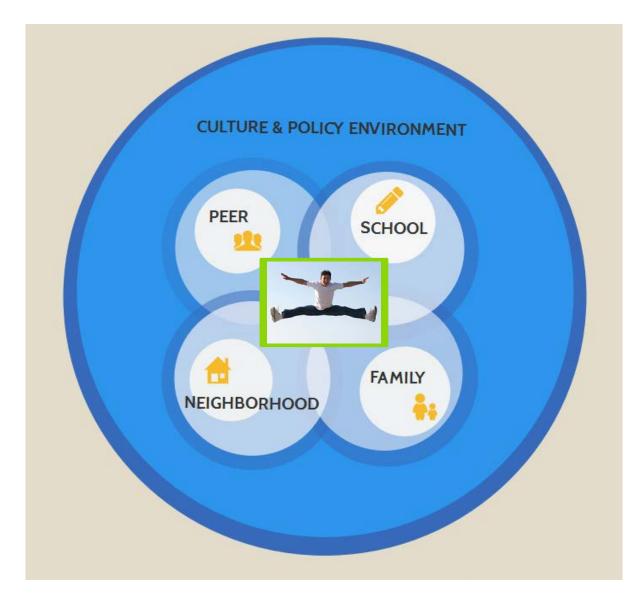




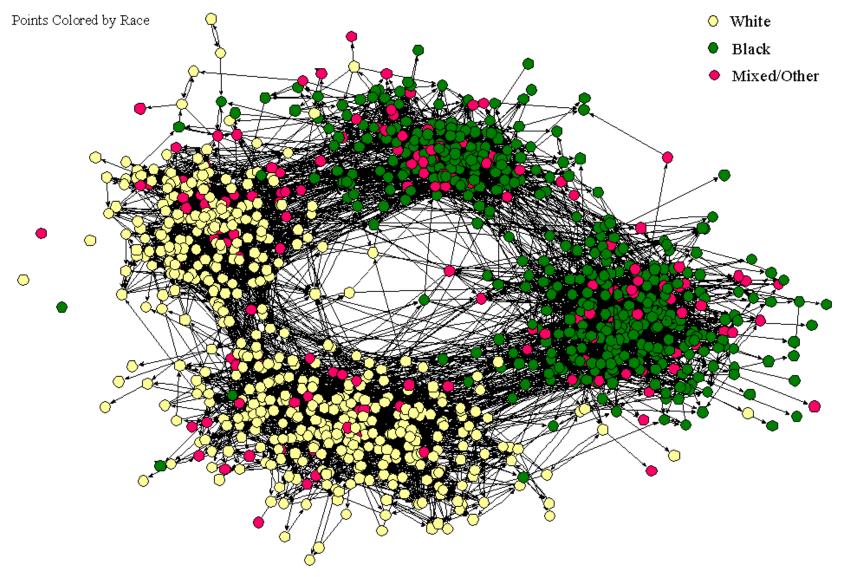
Sampling Structure



Add Health Contextual model



The Social Structure of "Countryside" School District



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





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

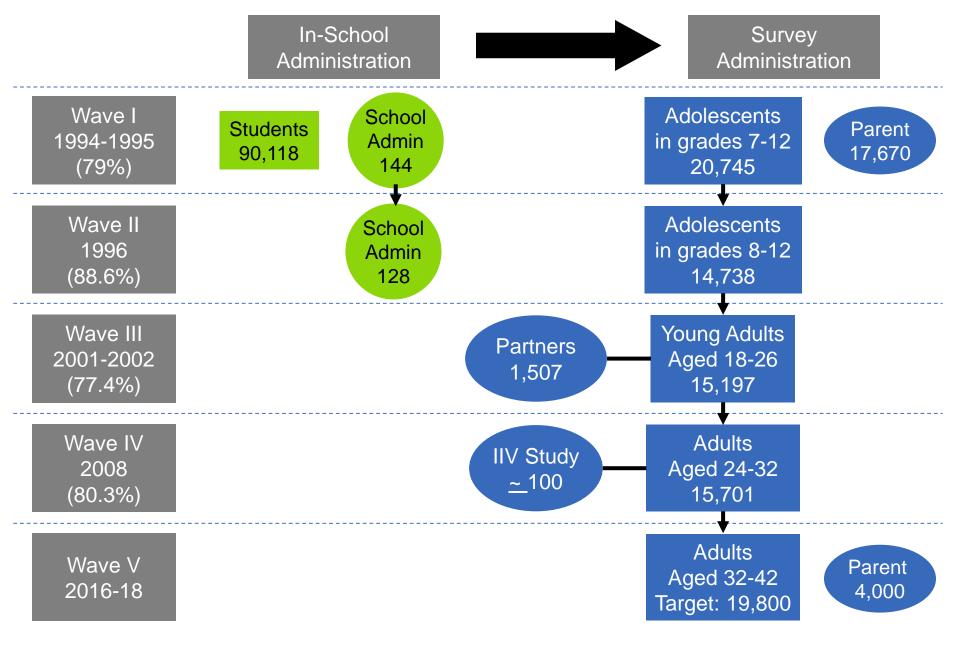
Family Structure	Ν	%
2 biological parents	10,339	53.3
2 adoptive parents	403	0.7
Bio Mom/Step Dad	2,756	13.6
Bio Dad/Step Mom	591	2.6
Single Mom	4,520	20.4
Single Dad	637	3.1
Surrogate parent(s)	1,499	6.3
Total	20,745	100.0



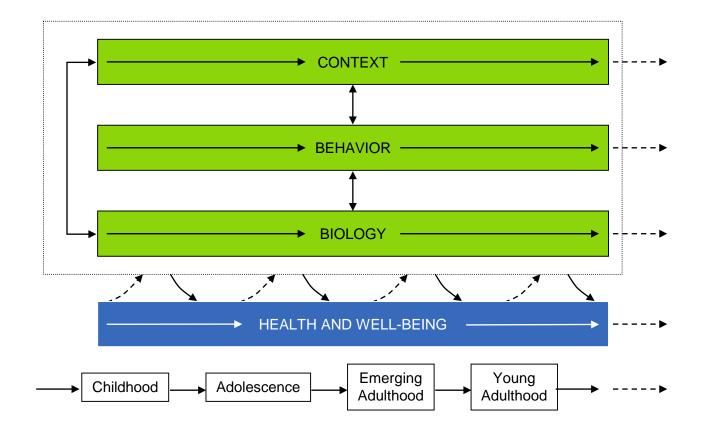




Social, Behavioral, and Biological Linkages Across the Life Course



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 Involvmt 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 Involvmt 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 Involvmt 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 restuarants
 - 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 Young Adulthood Adulthoo		Adulthood
Wave I-II (Ages 12-20)	Wave III (Ages 18-26)	Wave IV (Ages 24-32)	Wave V (Ages 32-42)
Embedded genetic sampl	le 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	;		
Wave I-II (12-20)	Wave III (18-26)	Wave IV (24-32)	Wave V (32-42)
Social enviror school family romantic rel neighborhood community peer	college family	college family romantic rel neighborhood community	work family romantic rel neighborhood community
Biological data Biological reserve height weight BMI		household on 3,000 pa ht, wt, waist, BMI BP, pulse immune inflammation diabetes DNA GWAS	irs ht, wt, waist, BMI BP, pulse immune inflammation diabetes kidney disease

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 12,200 DNA samples available for further testing
- GWAS data will be deposited into dbGaP in 2016.





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
 - Iongitudinal and new biological data and specimens
 - geographic locations for longitudinal spatial data
 - consent to obtain birth records of Add Health respondents born in a subset of six states
- Main study fieldwork began June 6, 2016

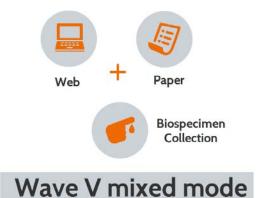




Wave V Data Collection

- Mixed mode survey design:
 - Web/mail with in-person and

phone non-response follow up



- Collect biological measures and specimens using Examination Management Services, Inc. (EMSI) for inhome examination
 - Venous blood draw
- Continuous interviewing 2016-2018





Mixed Mode Wave V Survey

- Web survey: two 25 minute modules (~50 mins total)
- Paper survey with same visual presentation of modules
- Obtain consent for biomarker collection by EMSI who will schedule a follow up in-home exam
- Nonresponse follow-up
 - Sample nonrespondents and administer web survey inperson (CASI) on laptop
 - Abbreviated telephone questionnaire for contact information and request consent for biomarkers.





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





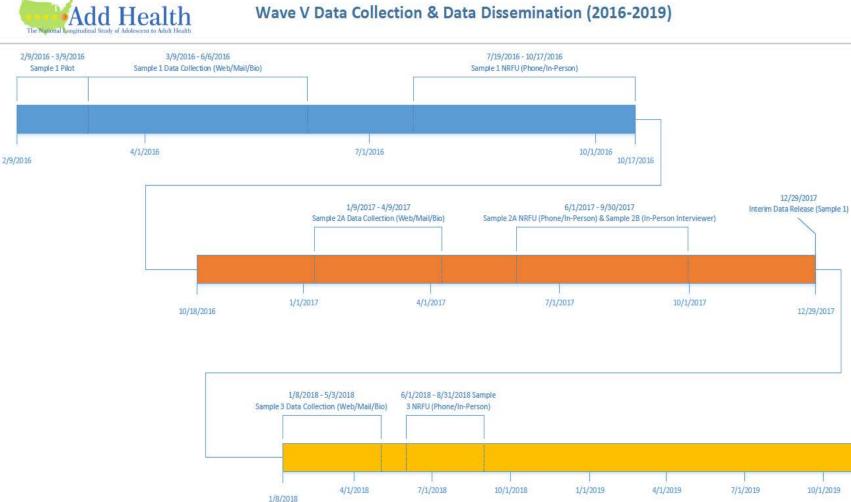
Wave V Data Collection

- 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 1,000 respondents interviewed in-person by interviewer to replicate Wave IV interview context to estimate mode effects
 - Sample 3: January 2018





Wave V Data Collection & Data Dissemination (2016-2019)







12/31/2019 Full Data Release

(Samples 1-3)

12/31/2019

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





Wave V Data Release

- Two data releases:
 - Sample 1 data in late 2017;
 - Full Wave V sample data in 2019 after data cleaning, checking and merging.





Add Health Data Dissemination

Ashley Sorgi Add Health Dissemination Coordinator





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 submission for GWAS data 2016





Data Security

• User requirements to protect from deductive disclosure:

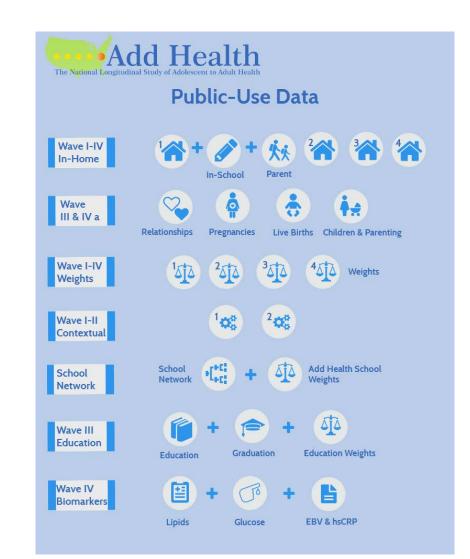
- Pledge of confidentiality
- Monitoring of data use
- Store data securely
- Deletion of temporary data analysis files every six months.
- Security of printed information
- Password protected screen saver, set to activate after 3 minutes of idle time.
- Access data only from approved locations.





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

- Odum Institute
 Dataverse
- ICPSR
- Association of Religion Data Archives







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







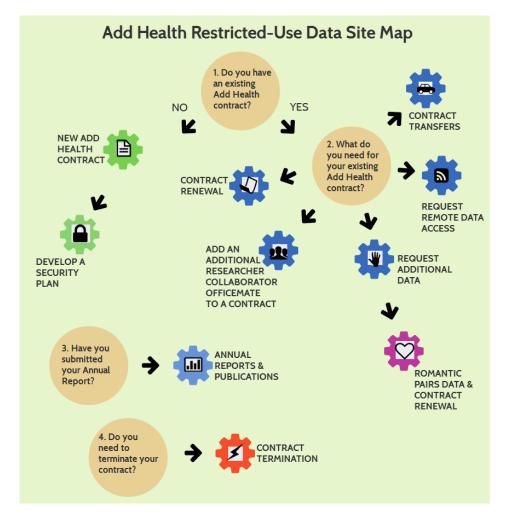
- Your contract expires every 3 years!
- Email us if you think your contract might be expired or to find out what your expiration date is.
- Annual reports are due every year!
- Let us know if you make changes to research staff or data storage locations.







Please visit our Contracts Homepage!







ADD HEALTH CODEBOOK EXPLORER (ACE)

- New 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)

The Add Health Codebook Explorer tool allows you to see how variables are related to each other, either topically or across time. This tool helps you identify which variables you may want to use in your analysis.

Search				Browse
Field	Matches	Search Text		Topics
Question or Response V	contains 🗸		Find	Instruments

Topics

Expand All

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

BROWSE BY TOPICS

ADD HEALTH CODEBOOK EXPLORER (ACE)

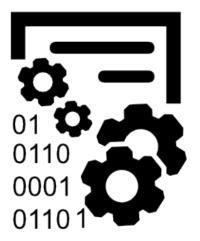
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SearchFieldMatchesSearch TextQuestion or Response VcontainsSleep	Browse Topics Find	
Search Results (14)	BF	ROWSE BY KEYWORDS
Question	Instrument(s)	Topic(s)
Based on what you have noticed or what others have told you, are there times you snore or you stop breathing during your sleep?	when Wave IV In-Home Interview	Sleep
Do you usually get enough sleep?	Wave I In-Home Interview; Wave II In-Home Interview	Sleep
During the first few hours of not drinking, do you experience withdrawal sympto such as the shakes, feeling anxious, trouble getting to sleep or staying asleep, nausea, vomiting, or rapid heart beats?	ms Wave IV In-Home Interview	Alcohol; Sleep; Stress/Anxiety; Substance Use/Abuse
During the first few hours of not using marijuana, do you experience withdrawa symptoms such as craving marijuana, feeling depressed, anxious, restless or irritable, having trouble concentrating, feeling tired or weak, having trouble slee or a change in appetite?		Depression; Illicit Drug Use; Marijuana; Nutrition; Sleep; Stress/Anxiety; Substance Use/Abuse
During the first few hours of not using {favorite drug}, do you experience one or more withdrawal symptoms such as craving {favorite drug}, feeling depressed, anxious, restless or irritable, having trouble concentrating, feeling tired or weak having trouble sleeping, or a change in appetite?		Depression; Illicit Drug Use; Nutrition; Sleep; Stress/Anxiety; Substance Use/Abuse
Have you ever been homeless for a week or longerthat is, you slept in a place where people weren't meant to sleep, or slept in a homeless shelter, or didn't h a regular residence in which to sleep?		Residence/Location
How many hours of sleep do you usually get?	Wave I In-Home Interview; Wave II In-Home Interview	Sleep

CPC Data Portal

- Restricted-Use data contract application process is moving to online application in the next year.
- Expedite and standardize contract application and renewal process for restricted-use Add Health data
- This system will also be the backbone for implementing restricted-use data file
 FTP transfers as the new mode of dissemination in the next year.







CPC Data Portal

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



Public Data



CPC Data Portal

Public Data Restricted Data (Single Study View) Restricted Data (Group View)
Quick link to the restricted data group below -
Core Files Requirements: Add Health Data Processing Fee Add Health IRB approval letter Add Health Security Plan
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 I Supplemental Files Requirements: Justification description for Add Health





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*



AROLINA OPULATION ENTER

*Wave IV co-funders

Wave V co-funders



• Questions or Feedback?

- Contact Information:
- <u>sorgia@email.unc.edu</u>
- Contract Inquires:
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