

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

*Acceptance of the terms and conditions of this Agreement
is precedent before data access will be provided.*

I. Definitions

- A. "The National Longitudinal Study of Adolescent Health" (hereinafter referred to as "Add Health") is the program project undertaken by the Carolina Population Center of The University of North Carolina at Chapel Hill (hereafter referred to as UNC-Chapel Hill) directed by Dr. Kathleen Harris under Grant No. P01-HD31921 from the Eunice Kennedy Shriver National Institute of Child Health and Human Development, data from which is made available to ICPSR for dissemination to third parties.
- B. "Investigator" is the person primarily responsible for supervision of the research project, security of the data, and use of Confidential Data obtained through this Agreement.
- C. "Research Staff" are all persons, excluding Investigator, who will have access to Confidential Data obtained through this Agreement.
- D. "Institution" is the university or research institution that employs Investigator and that is the signatory to this Agreement on behalf of Investigator.
- E. "Representative of Institution" is a person authorized to enter into contractual agreements on behalf of Institution.
- F. "Confidential Data" includes any data from Add Health that might compromise the anonymity or privacy of respondents to that study. Because of the school based study design, Add Health respondents (adolescents, parents, and schools) are at higher risk of deductive disclosure than randomly sampled individuals. Therefore, all data collected from Add Health are considered to be confidential.
- G. "Data File" includes any form of data, whether on paper or electronic media.
- H. "Funding Agency" is a federal office or institute that provided funding for Add Health. Funding agencies are only the offices or institutes providing the funding; other divisions or institutes within the larger organization are not considered funding agencies.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

- I. "Agreement Period" is the three (3) year period that begins immediately after receipt of the official e-mail approval of the IDARS application from ICPSR.
- J. "Processing Fee" is a nonrefundable payment of \$800 (ICPSR member Institution)/\$850 (ICPSR non-member) that covers the expenses of producing and shipping Data Files and codebooks, of consulting, and of administering this Agreement.
- K. "IDARS" is the online Confidential Data application system.

II. Requirements of Investigators

Investigators must meet the following criteria:

- A. Have a PhD or other terminal degree; and
- B. Hold a faculty appointment or research position at Institution

III. Requirements of Institution

Institution must meet the following criteria:

- A. Be an Institution of higher education, a research organization, or a government agency; and
- B. Have a demonstrated record of using Confidential Data according to commonly accepted standards of research ethics

IV. Obligations of ICPSR

In consideration of the promises made in Section V of this Agreement and of receipt of the monies noted in Section V. I., ICPSR agrees to the following, once the application has been submitted via IDARS and approved:

- A. To return one fully signed original to Investigator via e-mail.
- B. To assign the effective dates of the three (3) year Agreement Period on the Institutional Signatures page. The initiation date will begin immediately after receipt

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

of the official e-mail approval of the IDARS application from ICPSR.

- C. To provide the Data Files requested by Investigator as indicated by Investigator via IDARS within a reasonable time frame following execution of this Agreement by appropriate officials of ICPSR and to send the requested Data Files to Investigator on a CD ROM by certified mail (return receipt requested). All Data Files will be compressed and password protected.
- D. To provide codebooks which contain the origins, form, and general content of the Data Files sent to Investigator within the same time frame and manner as specified in paragraph C regarding the Data Files.
- E. To provide up to four (4) hours of consultation to Investigator and/or Research Staff regarding the origins, form, and general content of the Data Files, and regarding required and preferred techniques for data management of those Data Files. Further consultation is available for an additional fee.

V. Obligations of the Investigator, Research Staff, and Institution

Data provided under this Agreement shall be held by the Investigator, Research Staff, and Institution in strictest confidence and can be disclosed only in compliance with the terms of this Agreement.

In consideration of the promises contained in Section IV of this Agreement, and for use of Data Files from ICPSR, the Investigator, Research Staff, and Institution agree:

- A. That the Data Files will be used solely for statistical analyses: that no attempt will be made to identify specific individuals, families, households, schools, institutions, or geographic locations not provided by Add Health; and that no list of Confidential Data at the individual or family level will be published or otherwise distributed.
- B. That if the identity of any person, family, household, school, or institution should be discovered inadvertently, then:
 - 1. No use will be made of this knowledge;
 - 2. ICPSR will be advised of the incident within one (1) business day of Investigator's, Research Staff's, or Institution's discovery of the incident;

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

3. The information that would identify the person, family, household, school, or institution will be safeguarded or destroyed as requested by ICPSR and a written certification of destruction provided to ICPSR; and
 4. No one else will be informed of the discovered identity.
- C.** To avoid inadvertent disclosure of persons, families, or households by using the following guidelines in the release of statistics derived from the Data Files.
1. In no table should all cases in any row or column be found in a single cell.
 2. In no case should the total for a row or column of a cross tabulation be fewer than three (3) cases.
 3. In no case should a cell frequency of a cross tabulation be fewer than three (3) cases.
 4. In no case should a quantity figure be based on fewer than three (3) cases.
 5. Data released should never permit disclosure when used in combination with other known data.
- D.** That no persons other than those identified in this Agreement, or in amendments subsequent to this Agreement, as Investigator or Research Staff, be permitted access to the contents of Data Files or any files derived from Confidential Data Files.
1. That within one (1) business day of becoming aware of any unauthorized access, use, or disclosure of Confidential Data, the unauthorized access, use, or disclosure of Confidential Data will be reported in writing to ICPSR.
- E.** To comply fully with the Data Security Plan included as part of the IDARS application. The Data Security Plan expires at the end of the Agreement Period.
- F.** To respond fully and in writing within ten (10) working days after receipt of any inquiry from ICPSR regarding compliance with this Agreement or the expected date of completion of work with the Confidential Data and any data derived therefrom.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

- G.** To make available for inspection by Add Health, during business hours, the physical housing and handling of all Data Files and any other information, written or electronic, relating to this Agreement.
- H.** To supply ICPSR via IDARS the following:
1. Completed Investigator Information Form.
 2. Agreement for the Use of Add Health Confidential Data.
 3. Scanned Institutional Representative signature.
 4. Supplemental Agreement with Research Staff for the Use of Add Health Confidential Data and Security Pledge.
 5. Data Security Plan.
 6. A copy of the document signed by the Institution's Institutional Review Board (IRB), approving the research project AND the secure use, storage, and handling of the Add Health Data Files outlined in the Data Security Plan.
- I.** To provide to ICPSR a nonrefundable Processing Fee in the amount of \$800 (ICPSR member Institution)/\$850 (ICPSR non-member). Payment may be made by check, payable to "The University of Michigan." The nonrefundable Processing Fee will be used to cover the expenses of producing and shipping Data Files and codebooks, of consulting, and of administering this Agreement.

An exemption to the nonrefundable Processing Fee may be made if the request for Data Files is from an Investigator at one of the Add Health funding agencies or institutes. To request a waiver of the nonrefundable Processing Fee, please include a letter from the head of the Funding Agency requesting that the fee be waived.

- J.** To include in each written report or other publication based on analysis of Confidential Data from Add Health, the following statement:

“This research uses data from Add Health, a program project directed by Kathleen Mullan Harris and designed by J. Richard Udry, Peter S. Bearman, and Kathleen Mullan Harris at the University of North Carolina at Chapel Hill, and funded by grant P01-HD31921 from the Eunice Kennedy Shriver National Institute of Child

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

Health and Human Development, with cooperative funding from 23 other federal agencies and foundations. Special acknowledgment is due Ronald R. Rindfuss and Barbara Entwisle for assistance in the original design. Information on how to obtain the Add Health Data Files is available on the Add Health website (<http://www.cpc.unc.edu/addhealth>). No direct support was received from grant P01-HD31921 for this analysis.”

- K.** That all journal articles based on analysis of Confidential Data from Add Health receive a PubMed Central reference number (PMCID). Journal articles must be submitted to PubMed Central to receive a PMCID. The method of PubMed Central submission and Investigator responsibility for submission depend on the journal and journal publisher:
1. Some journals automatically submit published articles to PubMed Central. For a list of journals that submit articles to PubMed Central please visit the NIH website: http://publicaccess.nih.gov/submit_process_journals.htm.
 2. Some journal publishers may submit the articles to PubMed Central automatically or upon request by the author. For a list of journal publishers that submit articles to PubMed Central please visit the NIH website: http://publicaccess.nih.gov/select_deposit_publishers.htm#b.
 3. If neither the journal nor the journal publisher will submit the article to PubMedCentral, the Investigator will be responsible to submit the final peer-reviewed manuscript to PubMed Central via the NIH Manuscript Submission System (NIHMS). For detailed instructions on the process of submitting a journal article to PubMed Central, please see the NIH website: http://publicaccess.nih.gov/submit_process.htm.
- L.** To destroy all Data Files at the originally approved site; submit a letter stating that all Add Health Data Files have been securely erased with the secure erasure program listed in the security plan for the originally approved site; and return all CDs containing Data Files, within thirty (30) days of the expiration of the Agreement Period, as specified on the Institutional Signatures page, or to submit a renewal application. Add Health shall be able to visit within a year of Agreement termination, to confirm the data have been destroyed. This obligation of destruction shall not apply to Investigator's scholarly work produced during the Agreement Period that is based upon or that incorporates the Confidential Data.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

- M.** To notify ICPSR in the event Investigator plans to separate from Institution during the Agreement Period. Such notification must be in writing and must be received by ICPSR at least six (6) weeks prior to Investigator's last day of employment with Institution. Investigator's separation from Institution will terminate this Agreement. Investigator may, however, reapply to receive Add Health Data Files from ICPSR in Investigator's capacity as an employee of his or her new Institution. No fee will be charged for the administration of this process.

Concurrent with Investigator's notice to ICPSR regarding a pending separation from Institution, Investigator must:

1. Return the Data File CDs to ICPSR at the following address:

**DSDR Team / ICPSR
1223 Perry Building
330 Packard Rd.
Ann Arbor, MI 48104-1248**

2. Destroy all electronic and paper files at the originally approved site prior to the date of relocation and submit a letter stating that all Add Health files have been securely erased with the secure erasure program listed in the security plan for the originally approved site. This obligation of destruction shall not apply to Investigator's scholarly work produced during the Agreement Period that is based upon or that incorporates the Confidential Data.
3. Submit an Add Health Agreement for the Use of Confidential Data via IDARS signed by an official representative of Investigator's new Institution.

- N.** To obtain approval from ICPSR prior to transferring this Agreement to another Investigator at the same Institution. No fee will be charged for the administration of this process. In order to obtain such approval, Investigator must:

1. Inform ICPSR in writing six (6) weeks prior to the proposed date of transfer.
2. Submit an Add Health Agreement for the Use of Confidential Data via IDARS signed by an official representative of Investigator's new Institution.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

3. Maintain responsibility for the security of all Data File CDs until the transfer agreement has been approved.
- O.** To submit annual reports to ICPSR via IDARS on or before each anniversary of the initial date of the Agreement Period. Such reports must include:
1. A copy of the annual IRB approval for the research project
 2. A list of public presentations at professional meetings using results based on the Data Files
 3. A list of papers accepted for publication using these Data Files, with complete citations and PMCIDs
 4. A list of grants that have been awarded for use of the Add Health Data Files
 5. A list of graduate students using the Add Health Data Files for dissertations or theses, the titles of these papers, and the dates of completion
 6. A current data user roster including the names of all Research Staff member(s) who have access to Data Files and their relationship(s) to the project
- P.** That Investigator and Institution hereby acknowledge that any breach of the confidentiality provisions herein will result in irreparable harm to The University of Michigan that are not adequately compensable by money damages. Investigator, Research Staff, and Institution hereby agree to the imposition of injunctive relief in the event of breach, in addition to money damages. Should Investigator, Research Staff, or Institution commit a material breach of this Agreement that is not cured within thirty (30) days after Investigator or Institution receives notice of such breach from ICPSR, ICPSR reserves the right to terminate the Agreement, in which case all electronic and paper files will be securely erased; a letter will be submitted by the Investigator, stating that all Add Health files have been securely erased with the secure erasure program listed in the security plan; and CDs containing Data Files are to be returned. Investigator, Research Staff, and Institution understand and agree that a violation of any of the terms and conditions of this Agreement may constitute a violation of state and federal statutes and may subject Investigator, Research Staff, and/or Institution to the criminal, civil, and administrative penalties associated with violations of those statutes, in addition to constituting a material breach of this Agreement with attendant legal liabilities.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

- Q.** That Investigator and Institution agree to indemnify, defend, and hold harmless The University of North Carolina at Chapel Hill, Add Health, The University of Michigan, the Inter-University Consortium for Political and Social Research and the sources of Confidential Data from any or all claims and losses accruing to any person, organization, or other legal entity as a result of Investigator's, Research Staff's and/or Institution's acts, omissions, or breaches of this Agreement.
- R.** That Institution shall ensure that Research Staff comply with the provisions of this Agreement.
- S.** That ICPSR may provide the name and address of Investigator to the original producer of these data listed in section I(A) above. The data producer may use the Investigator's name and address for the purposes of (1) contacting Investigator to provide information regarding updates to the data, opportunities for user workshops/conferences, or other communications related to the data; or (2) conducting analyses of the types of individuals using the data.

VI. Certificate of Confidentiality

Research subjects who participated in Add Health are protected by a certificate of confidentiality issued by the Department of Health and Human Services in accordance with the provisions of section 301(d) of the Public Health Service Act (42 U.S.C. 241(d)). Institution is considered to be a contractor or cooperating agency of UNC Chapel Hill under the terms of the Confidentiality Certificate; as such, Institution, Investigator, and Research Staff are authorized to protect the privacy of the individuals who are the subjects of Add Health by withholding their identifying characteristics from all persons not connected with the conduct of the study. Identifying characteristics are all Add Health Data Files which are defined as confidential under the terms of this agreement.

VII. Incorporation by Reference

The parties agree that the following documents are incorporated into this Agreement by reference:

- A.** Copy of the IRB approval of the research project, taking into special consideration deductive disclosure risks.
- B.** All appendices included within this agreement (Please note that Appendices G-J are

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

generated by the IDARS system once the Investigator has completed the application):

1. List of Funding Agencies (Appendix A)
2. Description of Deductive Disclosures Risk and the Department of Health and Human Services Confidentiality Certificate (Appendix B)
3. Information Regarding the Data Security Plan (Appendix C)
4. Example of Supplemental Agreement with Research Staff (Appendix D)
5. Example of Pledge of Confidentiality (Appendix E)
6. Add Health Data Files (Appendix F)
7. Data Security Plan (Appendix G)
8. Supplemental Agreement with Research Staff (Appendix H)
9. Pledge of Confidentiality (Appendix I)
10. Order Summary (Appendix J)

VIII. Miscellaneous

- A. The laws of Michigan shall govern the validity and interpretation of the provisions, terms and conditions of the Agreement. In the event the parties are unable to resolve any dispute relating to this agreement, all suits, actions, claims, and causes of action relating to this Agreement shall be brought in the courts of the State of Michigan.
- B. All notices, contractual correspondence, and return of data under this Agreement on behalf of the Investigator shall be made in writing and delivered to the address below:

**DSDR Team / ICPSR
1223 Perry Building
330 Packard Rd.
Ann Arbor, MI 48104-1248
DSDR@icpsr.umich.edu**

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

- C.** Provisions of Data Files, all notices, and contractual correspondence under this Agreement on behalf of ICPSR shall be made in writing and delivered to Investigator at the address listed on the Institutional Signatures page.
- D.** This Agreement shall be effective for the dates indicated on the Institutional Signatures page.
- E.** The respective rights and obligations of ICPSR and Investigator, Research Staff, and Institution pursuant to this Agreement shall survive termination of this agreement.
- F.** In the event of a material breach of this Agreement by the Investigator, Research Staff, or Institution, ICPSR may terminate this Agreement by providing written notice to Investigator and Institution. In this event, ICPSR will not be required to refund of any portion of the nonrefundable \$800/\$850 Processing Fee.
- G.** This Agreement may be amended or modified only by the mutual written consent of the authorized representatives of ICPSR and Investigator and Institution. Both parties agree to amend this Agreement to the extent amendment is necessary to comply with the requirements of any applicable regulatory authority.
- H.** This Agreement contains all of the terms and conditions agreed upon by the parties regarding the subject matter of this Agreement and supersedes any prior agreements, oral or written, and all other communications between the parties relating to such subject matters.
- I.** The obligations of Investigator, Research Staff, and Institution set forth within this Agreement may not be assigned or otherwise transferred without the express written consent of ICPSR.
- J.** Add Health's existing ownership rights in its intellectual property, including its Confidential Data and the Data Files, are not affected by this Agreement. Except as expressly set forth herein, no right, license, title, or interest in any of Add Health's intellectual property or in any invention, process, or product arising out of its intellectual property is granted or implied, whether or not patented or patentable.
- K.** This Agreement may be executed in one or more counterparts (facsimile transmission or otherwise), each of which counterpart shall be deemed an original Agreement and all of which shall constitute but one Agreement.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Agreement for the Use of Confidential Data

- L.** The parties' electronic signatures shall be the legally binding equivalent of a handwritten signature.

- M.** Institution hereby appoints Investigator as its designated representative to execute, on behalf of Investigator and Institution, additional forms pursuant to this Agreement.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Institutional Signatures (please use black ink)

Investigator

Signature _____

Date _____

Print Name _____

Title _____

Institution _____

Building/Room Number _____

Street Address _____

City/State/ZIP _____

Telephone _____

Email _____

The person below signing this Agreement has the right and authority to execute this Agreement, and no further approvals are necessary to create a binding agreement.

Representative of Your Institution

Signature _____

Date _____

Print Name _____

Title _____

Institution _____

Building/Room Number _____

Street Address _____

City/State/ZIP _____

Telephone _____

Email _____

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix A: List of Funding Agencies

- Eunice Kennedy Shriver National Institute of Child Health and Human Development
- MacArthur Foundation
- 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 on Aging
- National Cancer Institute
- National Center for Health Statistics, Centers for Disease Control and Prevention, DHHS
- National Institute of General Medical Sciences
- National Institute of Mental Health
- National Institute of Nursing Research
- National Institute on Alcohol Abuse and Alcoholism
- National Institute on Deafness and Other Communication Disorders
- National Institute on Drug Abuse
- National Science Foundation
- Office of AIDS Research, National Institutes of Health (NIH)
- Office of Behavioral and Social Science Research, 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, Department of Health and Human Services (DHHS)
- Office of Research on Women's Health, NIH
- Office of the Assistant Secretary for Planning and Evaluation, DHHS
- Office of the Director, NIH
- Robert Wood Johnson Foundation

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix B: Description of Deductive Disclosure Risk and Department of Health and Human Services Confidentiality Certificate

The problem of deductive disclosure of an individual respondent's identity has become a major concern of federal agencies, researchers, and Institutional Review Boards in the recent past. In essence, deductive disclosure is the discerning of an individual respondent's identity and responses through the use of known characteristics of that individual. This is not unique to Add Health-if a person is known to have participated in ANY survey, then a combination of his or her personal characteristics will allow an individual to determine which record corresponds to that individual. For example, in the Add Health in-school dataset of more than 90,000 cases, a cross-tabulation of five variables can distinguish an individual record.

The Add Health data poses greater confidentiality concerns than many other datasets to deductive disclosure. This is due, in part, to the clustered research design. Add Health surveyed all students in grades 7 through 12 in a pair of schools in each of 80 communities in the United States. The in-school questionnaires were administered by teachers at each school. More than 120,000 students were enrolled in these schools. Informational letters were sent to parents prior to the administration date via students and post. Assuming that most students live with two other persons (parents and/or siblings), 360,000 people know of the participation of at least one, if not many, of the adolescents attending the selected schools. Additionally, approximately 5,000 school administrators, staff and teachers were involved in the in-school data collection efforts.

The in-home selection process increased the number of persons aware of Add Health: about 5,000 participants in the in-home component had not completed an In-School Questionnaire. (Participation in the in-school session was not a prerequisite for eligibility, only the presence of an adolescent's name on the school enrollment roster.)

Given the large number of people who know someone who, they know, participated in Add Health, researchers who use the Add Health Contractual Dataset are obligated to protect respondents from deductive disclosure risk by taking extraordinary precautions to protect the data from non-authorized use. Precautions include, but are not limited to: copying the original dataset only once and storing the original CD-ROM in a locked drawer or file cabinet; saving the computer programs used to construct analysis data files, but not the Data Files themselves; retrieving paper printouts immediately upon output; shredding printouts no longer in use; password protecting Add Health data; signing pledges of confidentiality; and using the data solely for statistical reporting and analysis.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

**Appendix B: Description of Deductive Disclosure Risk and Department of
Health and Human Services Confidentiality Certificate**



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

National Institutes of Health
Eunice Kennedy Shriver National
Institute of Child Health and
Human Development
Bethesda, Maryland 20892

June 1, 2012

Kathleen Mullan Harris
Carolina Population Center
123 West Franklin Street
CB#8120, University Square
Chapel Hill, NC 27515-2524

RE: CC-HD-06-39

Dear Dr. Mullan Harris:

This letter amends the Confidentiality Certificate protecting the identity of research subjects in your project entitled; *"Add Health, Wave IV"* has been amended to extend the Certificate expiration date until 6/20/2014.

If you determine that the research project will not be completed by the expiration date, 6/20/2014 you must submit a written request for an extension of the Certificate three months prior to the expiration date. Any such requests must include the reason for the request, documentation of the most recent IRB approval, consent forms, and the expected date for completion of the research project.

Please advise me of any situation in which the Certificate is employed to resist disclosure of information in legal proceedings. Should attorneys for the project wish to discuss the use of the Certificate, they may contact the Office of the NIH Legal Advisor, National Institutes of Health, at (301) 496-6043.

Correspondence should be sent to:

Steven Hirschfeld, MD, PhD
Associate Director for Clinical Research
Eunice Kennedy Shriver National Institute of Child Health and
Human Development
31 Center Drive, Room 2A03, MSC 2425
Bethesda, MD 20892-2425

Sincerely,

A handwritten signature in black ink, appearing to read "Steve Hirschfeld".

Steven Hirschfeld, MD, PhD

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

**Appendix B: Description of Deductive Disclosure Risk and Department of
Health and Human Services Confidentiality Certificate**

CONFIDENTIALITY CERTIFICATE

CC-HD-06-39

Issued to

University of North Carolina at Chapel Hill

conducting research known as

Add Health, Wave IV

In accordance with the provisions of section 301(d) of the Public Health Service Act 42 U.S.C. 241(d), this Certificate is issued in response to the request of the Principal Investigator, Kathleen Mullan Harris, Ph.D., to protect the privacy of research subjects by withholding their identities from all persons not connected with this research. Dr. Harris is primarily responsible for the conduct of this research, which is supported by an NICHD grant P01HD31921.

Under the authority vested in the Secretary of Health and Human Services by section 301(d), all persons who:

1. are enrolled in, employed by, or associated with the University of North Carolina at Chapel Hill and their contractors or cooperating agencies and
2. have in the course of their employment or association access to information that would identify individuals who are the subjects of the research pertaining to the project known as, "Add Health, Wave IV,"

are hereby authorized to protect the privacy of the individuals who are the subjects of that research by withholding their names and other identifying characteristics from all persons not connected with the conduct of that research.

Add Health is a longitudinal study to investigate the determinants of health and health-related behavior during adolescence. The study began in 1994 with in-school questionnaires and was followed by three waves of in-home interviews, the last one in 2001-2002.

The current Wave IV will involve the original cohort of participants, now aged 24 to 32. It is designed to study developmental and health trajectories from adolescence into young adulthood, using an integrative approach that combines social, behavioral, and biomedical sciences in its research objectives, design, data collection and analysis.

Researchers plan to locate all eligible Wave I respondents, around 17,000 males and females from all major racial/ethnic groups found in the United States, and complete in-home interviews and a set of measures with each of them.

A Certificate of Confidentiality is needed because the study will collect sensitive information regarding health-related behaviors, emotional and physical health, school and work experiences, relationships with family, friends, spouses/partners and children, and use of alcohol and illegal drugs. The Certificate will help researchers avoid involuntary disclosure that could expose subjects or their families to adverse economic, legal, psychological, and social consequences.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

**Appendix B: Description of Deductive Disclosure Risk and Department of
Health and Human Services Confidentiality Certificate**

All subjects will be assigned a code number and identifying information and records will be kept in locked files at the Institution.

This research began January 1, 2006 and is expected to end on December 31, 2010.

As provided in section 301 (d) of the Public Health Service Act 42 U.S.C. 241(d):


"Persons so authorized to protect the privacy of such individuals may not be compelled in any Federal, State, or local civil, criminal, administrative, legislative, or other proceedings to identify such individuals."

This Certificate does not protect you from being compelled to make disclosures that: (1) have been consented to in writing by the research subject or the subject's legally authorized representative; (2) are required by the Federal Food, Drug, and Cosmetic Act (21 U.S.C. 301 et seq.) or regulations issued under that Act; or (3) have been requested from a research project funded by NIH or DHHS by authorized representatives of those agencies for the purpose of audit or program review.

This Certificate does not represent an endorsement of the research project by the Department of Health and Human Services. This Certificate is now in effect and will expire on December 31, 2010. The protection afforded by this Confidentiality Certificate is permanent with respect to subjects who participate in the research during the time the Certificate is in effect.

Date:

9/15/06


Yvonne T. Maddox, Ph.D.
Deputy Director
National Institute of Child Health
and Human Development

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix C: Information Regarding the Data Security Plan

Below are a number of locations where you might choose to store the Add Health data. Please read the descriptions for each option. More detail regarding the essential components of a good security plan is provided within the automated request system (IDARS) in the section that refers to security plans. It is recommended that you read through this section carefully.

Data Stored on a Non-networked computer

This plan is for researchers who want to store and analyze the data on a stand-alone desktop computer. A stand-alone computer is one that is in no way connected to another computer or networked device such as a switch, hub, or router.

Data Stored on an External hard drive

Select this plan if you will store the restricted-use data on an external hard drive and use a computer not connected to another computer or networked device to analyze the data. In this plan you must physically disconnect the computer from all networks before plugging in the external hard-drive that contains the data.

Data stored on a Private-networked computer

Use this plan if you will store and analyze the data on a private network (two or more computers and/or network devices, e.g., printer, switch, router that are not connected in any way to the Internet or a LAN).

Data Stored on a Networked Windows computer

In this plan the data are stored on a computer that is connected to the Internet or to a local or wide area network. For this plan, the data are also analyzed using software located on the networked Windows machine.

Data Stored on a Networked Macintosh computer

This plan is for researchers who will store and analyze the restricted-use data on a Macintosh desktop computer connected to a network. A network is two or more computers and/or network devices (e.g., printer, switch, router) connected to the Internet or a LAN.

Data Stored on a Windows server

For data stored on a file server running the Windows operating system, use this plan. Researchers access and analyze the data through their own computer.

Data Stored on a NetWare server

If the data will be stored on a NetWare server, choose this plan. Researchers access and analyze the data through their own computer.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix C: Information Regarding the Data Security Plan

Networked UNIX (Linux, AIX, Solaris) computer

Use this security plan for data stored and analyzed on a server running a version of the Unix or Linux operating system.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix D: Example of Supplemental Agreement with Research Staff

By virtue of my affiliation with this research project I have access to Confidential Data identified in this Agreement. I understand that access to this Confidential Data carries with it a responsibility to guard against unauthorized use and to abide by the Data Security Plan. To treat information as confidential means to not divulge it to anyone who is not a party to the Agreement for the Use of Confidential Data, or cause it to be accessible to anyone who is not a party to that Agreement.

I agree to fulfill my responsibilities on this research project in accordance with the following guidelines:

1. I have read the associated Agreement for the Use of Confidential Data.
2. I am "Research Staff" within the meaning of the Agreement.
3. I will comply fully with the terms of the Agreement, including the Data Security Plan.
4. I agree not to permit Confidential Data access to anyone not a party to the Agreement, in either electronic or paper copy.
5. I agree to not attempt to identify private persons as defined in the Agreement for the Use of Confidential Data.
6. I agree that in the event an identity of any private person is discovered inadvertently, I will (a) make no use of this knowledge, (b) advise the Investigator of the incident who will report it to ICPSR, (c) safeguard or destroy the information as directed by the Investigator after consultation with ICPSR, and (d) not inform any other person of the discovered identity.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix E: Example of Pledge of Confidentiality

By virtue of my affiliation with this research project I have access to Confidential Data identified in this Agreement. I understand that access to this Confidential Data carries with it a responsibility to guard against unauthorized use and to abide by the Data Security Plan. To treat information as confidential means to not divulge it to anyone who is not a party to the Agreement for the Use of Confidential Data, or cause it to be accessible to anyone who is not a party to that Agreement.

I agree to fulfill my responsibilities on this research project in accordance with the following guidelines:

1. I agree not to permit Confidential Data access to anyone not a party to the Agreement for the Use of Confidential Data, in either electronic or paper copy.
2. I agree to not attempt to identify private persons as defined in the Agreement for the Use of Confidential Data.
3. I agree that in the event an identity of any private person is discovered inadvertently, I will (a) make no use of this knowledge, (b) report the incident to ICPSR, (c) safeguard or destroy the information after consultation with ICPSR, and (d) not inform any other person of the discovered identity.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix F: Add Health Data Files

- Data will be delivered in format specified by applicant.
- Data will be sent on a CD by trackable delivery and the Investigator will be notified by email when the data are shipped.
- All data will be compressed and password protected.
- Codebooks will be delivered in electronic form on a CD.

The following data will be sent automatically, upon execution of your agreement:

In-home Interview Files (#27021)

- Wave I
- Wave II
- Wave III
- Wave IV

School Files (#27021)

- Wave I School Administrator
- Wave II School Administrator
- School Information
- In-School Questionnaire

Weight Files (#27021)

- Wave I Grand Sample Weights
- Wave II Grand Sample Weights
- Wave III Grand Sample Weights
- Wave IV Grand Sample Weights
- School Administrator Weights
- In-School Weights

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix F: Add Health Data Files

The constructed datasets listed below are available by special request.

To receive one or more of these datasets, please include a brief statement in your IDARS application explaining the necessity and relevance of the data to your research agenda.

Friend Files (Study #27022)

- Wave I In-Home Nominations
- Wave II In-Home Nominations
- In-School Nominations
- Wave III Friend IDs

Sibling Files (Study #27023)

- Adolescent Pair Data
- Wave III Sibling IDs

Contextual Files (Study #27024)

- Waves I, II, III Contextual
- Wave I Spatial Analysis
- Wave I and II Neighborhood
- Wave III Grouping
- Wave III Region
- Wave III Supplemental Tract-Level Contextual
- Wave IV Region
- Wave IV Grouping
- Wave IV Supplemental Tract-Level Contextual

Supplemental Files (Study #27025)

- Wave III ASHA Call
- Wave III BEM Scores
- Wave III Cotinine Assays
- Wave III HPV-MGEN Assays
- Wave III Mentor
- Wave III Urinalysis
- Wave III HPV-MGEN Assay Weights

Weight Components (Study #27026)

- Wave I, II, III Weight Components
- In-School Weight Components
- Add Health School Weights
- Wave IV In-Home Weight Components Data

Education Files (Study #27030)

- Academic Courses
- Academic Networks
- Context
- Curriculum
- Linking
- Primary
- Transition
- Weights

Genetic Files (Study #27031)

- Wave III DNA Results
- Wave IV DNA Results

Constructed Variables (Study #27033)

- School Network
- Wave IV Constructed

Disposition Files (Study #27034)

- Wave III Disposition
- Wave IV Disposition
- Wave I and II Disposition

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix F: Add Health Data Files

ONE Files (Study #27881)

- Wave I and III Climate
- Wave I, III Street Connectivity
- Wave I, III Crime
- Wave I, III Geocode Source
- Wave I, III Land Cover
- Wave I, III Parks
- Wave I, III Resources
- Wave I, III Urban Distances
- Wave I, III Weather
- Wave I 1990 Population Density
- Wave III 2000 Population Density
- Wave I School Distance
- Wave III Mobility
- Wave III MSA Dataset
- Wave I, III ACCRA Cost of Living Index
- Wave I, III Employment
- Wave I, III Length of Day Dataset
- Wave I, III Road Type Length
- Wave I, III Rural-Urban Commuting Area

Alcohol Density File (Study #28841)

- Wave III Alcohol Outlet Density

Political Context Files (Study #28843)

- Wave I, II, III Political Context Data

Wave IV Medication File (Study #29261)

- Medication File Data

Wave IV Biomarker Data (Study # 33443)

- Glucose-HbA1c
- CRP-EBV
- Wave IV Consent
- Lipids

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix F: Add Health Data Files

Description of Data Files

Core Files

Wave I In-home- A merged file containing the Wave I In-home Interview data, the Parent Questionnaire data (when available), the In-school Questionnaire data (when available), and the Add Health Picture Vocabulary Test (when available), collected in 1994-1995, weights included.

Wave II In-home- Data collected during the 1996 In-home interview, and weights included.

Wave III In-home- Respondent-level data collected during the 2001-2002 In-home interview includes field interviewer characteristics, AHPVT, and weights.

Wave IV In-home- Respondent-level data collected during the 2008-2009 in-home interview.

Wave I School Administrator- Information from the Wave I self-administered questionnaire answered by an administrator at the school.

Wave II School Administrator- Information from the Wave II phone-administered interview answered by an administrator at the school.

School Information- Additional information about the individual schools.

In-school Questionnaire- Adolescent responses to the In-school Questionnaire administered September 1994 through April 1995.

School Files

School Network- Network variables constructed from the In-school questionnaire data and friendship nominations.

Network Structure- For each school pair, these files contain a valued friendship network and information on sex, grade in school, race, school pair, and total number of nominations made, including those to non-matchable or out-of-school friends. The files are stored as arc/edge lists in the PAJEK.PAJ format. Information on this freely available network software is at <http://vlado.fmf.uni-lj.si/pub/networks/pajek/>. Users should contact addhealth@unc.edu if they would like a copy of the Network Structure Data.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix F: Add Health Data Files

Description of Data Files

Friend Files

In-School Nominations- Identification numbers of the friends that the respondent nominated during the In-school questionnaire.

Wave I In-home Nominations- Identification numbers of the friends that the respondent nominated during the Wave I In-home interview.

Wave II In-home Nominations- Identification numbers of the friends that the respondent nominated during the Wave II In-home interview.

Wave III Friend IDs- In Wave III, respondents in the 7th or 8th grade at Wave I were asked to identify, from a list of 10 computer-generated names, which ones were current friends or which ones were their friends when they were in school together. This dataset contains the IDs of the 10 computer-generated names.

Sibling Files

Adolescent Pair Data- Information that links and describes the sibling pairs.

Wave III Sibling IDs- In Wave III, respondents were asked questions about their siblings who also participated in the Wave I or II In-home interviews; this dataset contains the IDs for these siblings.

Contextual Files

Waves I, II and III Contextual- Community contextual variables based on state, county, tract, and block group levels derived from the Waves I, II and III addresses.

Waves I, II and III Grouping- Pseudo state, county, tract, and block group variables that allow respondents to be aggregated geographically based on Waves I, II and III addresses.

Spatial- X, Y coordinates that can be used to calculate distances between friends in a school community.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix F: Add Health Data Files

Description of Data Files

Wave III and IV Region-- This file contains the Census region codes for the respondents' Wave III and IV residential locations.

Wave IV Grouping - The pseudo FIPS codes in this file allow you to geographically group respondents by their Wave IV locations.

Wave III Supplemental Tract-Level Contextual – This file contains supplemental Wave III contextual data that include transportation and commuting measures, climate descriptors, amenities, and state-level tobacco control influences. These variables are available at the census tract-level unless otherwise specified.

Wave IV Supplemental Tract-Level Contextual – This file contains tract-level measures, based on the Wave IV respondent locations, reported by the U.S. Census Bureau's 2009 American Community Survey (ACS), the Climate Atlas of the United States, the USDA Economics Research Service, Esri Data and Maps, ImpacTeen Tobacco Control Policy and Prevalence Data, and the Uniform Crime Reports. When tract level measures were not available or appropriate, state and county level variables were used.

Wave III Supplemental Files

Urinalysis- This file contains nitrate, specific gravity, pH level, white blood cells, protein, glucose, ketone, urobilinogen, bilirubin, microalbumin, urine creatinine, and blood values from the Wave III urine specimens.

ASHA Call- To receive the results of their STD assays, Wave III respondents called an Add Health dedicated number at the American Social Health Association. This file provides information on who called the results hotline and the date and time of the call.

HPV MGEN- Assay results for human papillomavirus and mycoplasma genitalium are available for a subset of the Wave III respondents who provided a urine sample.

Mentor Codes- For Wave III respondents who reported having a mentor, the open-ended

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix F: Add Health Data Files

Description of Data Files

responses to the question "How did {HE/SHE} help you?" have been coded and are available in this file.

BEM Scores- The masculinity and femininity raw and standard scores from the 30 item short form BEM Sex-Role Inventory are available in this file.

Cotinine- This file contains the cotinine and 3-hydroxycotinine assay values for 963 Wave III respondents.

Genetic Files

Wave III DNA Results- Twin and full siblings interviewed at Wave III were asked to provide saliva samples for DNA analysis. This file contains the genotype values for DAT1 (dopamine transporter), DRD4 (dopamine receptor), and SLC6A4 (serotonin transporter), MAOA_V (monoamine oxidase A-uVNTR), DRD2 (dopamine D2 receptor), and CYP2A6 (cytochrome P450 2A6) from these samples. Also included are values for the following SNPs: rs2304297, rs892413, rs4950, rs13280604.

Wave IV DNA Results- The Wave IV DNA Data File contains genotyping results for all Wave IV respondents who agreed to provide a saliva sample for DNA testing. This dataset has values for DAT1(dopamine transporter), DRD4 (dopamine receptor), MAOA (monoamine oxidase A- uVNTR), 5HTTLPR (serotonin transporter), HTTLPR La-Lg-S, and triallelic activity bins for the serotonin transporter 5HTTLPR adjusted for rs25531.

Education Files

Academic Courses- These files contain academic status and/or performance indicators for math, science, foreign language, English, history, social sciences, physical education, and a combined overall category.

Academic Networks- The Network files provide information on social networks based on the respondents' course-taking patterns.

Context- School level contextual data are from the Common Core of Data (CCD), Private School Survey (PSS), the 1990 and 2000 Census, and the Office of Civil Rights.

Course-Level- The data in this file are needed for merging the course-level curriculum data

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix F: Add Health Data Files

Description of Data Files

with other Education Files.

Curriculum- These math and science curriculum data are derived from coding the textbooks] schools reported using for each course offered in these two subjects.

Linking- This file contains variables designed to link transcript data to academic or school years and to Add Health.

Primary- The Primary Component contains several types of indicators based on information collected from participating schools and listed directly on student transcripts such as student exit or graduation status and materials gathered from schools during the data collection process.

Transition- This file contains variables explaining the respondents' movement through the educational system

Weights- This file contains weights for the education data along with the school weights needed for HLM analyses.

Weight Files

Weight Components- A weight component for each level of sampling (school and adolescents) has been created for each wave of data collection. This file contains the weight components needed for computing multilevel weights.

HPV MGEN Weights- Sample weights for respondents with HPV and MGEN assay results are in this file.

The Obesity and Neighborhood Environment (ONE)

Wave I and III Connectivity Files- These files contain road network connectivity measures within 1, 3, 5, and 8.05 km (5 miles) of the Wave I and III respondent locations.

Wave I and III Crime Files- The county level crime data in these files are based on the Wave I and III respondent locations.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix F: Add Health Data Files

Description of Data Files

Wave I and III Geocode Source- The data sources of the Wave I and III respondent residential geocodes (latitude and longitude) are provided in these files.

Wave I and III Land Cover Data- These files contain land cover metrics within 1, 3, 5, and 8.05 km (5 miles) of each respondent's location.

Wave I and III Parks Data- The counts of public parks within a Euclidean distance of 1, 3, 5, and 8.05 km (5 miles) of each respondent at Wave I and III are in these files.

Wave I and III Resources Data- The Add Health files provide data on the presence of various physical activity (PA) resources situated near respondent residences at Wave I and III.

Wave I and III Urban Distances- W1URBDST contains Euclidean distances to both 1990 and 2000 U.S. Census Urbanized Areas (UAs) for each Wave I respondent. W3URBDST contains the Euclidean distance to 2000 U.S. Census-Bureau-defined urbanized areas (UAs) for each Wave III respondent.

Wave I School Distance Measures- This file contains the distance between the geocoded point locations of each respondent's Wave I location and that respondent's school.

Wave III MSA Pseudo Codes- The MSA pseudo code created for each respondent's Wave III location is in this file.

Wave III Mobility Data- W3MOBIND reports the distance between each respondent's geocoded point location for each survey wave and that respondent's school location, along with the respondent's move distance between each survey wave.

Wave I, III Climate Data- This file contains the climate data for each Wave III respondent based on the nearest climate station. Information is available on precipitation, total snowfall, sky cover, temperature, and total hours of sunshine.

Wave I, III Population Density- The Wave I population density file contains the proportion of 1990 U.S. Census block group population and area (in square meters) within 1, 3, 5, and 8.04672 km (5 mi) of each Wave I respondent. The Wave III population density file contains the proportion of 2000 U.S. Census block group population and area (in square meters) within 1, 3, 5, and 8.04672 km (5 mi) of each Wave III respondent.

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix F: Add Health Data Files

Description of Data Files

Wave I, III Weather Data- This file contains weather data for each Wave III respondent based on the nearest weather station reporting data for the correspondent survey month and year.

Wave I, III ACCRA Cost of Living Index- These Add Health Data Files contain ACCRA Cost of Living Index based on the location of the Wave I and Wave III respondents.

Wave I, III Employment- These Data Files contain county-level employment data attached to each Wave I and Wave III respondent location.

Wave I, III Length of Day Datasets- These Data Files contain the number of hours of daylight at each Wave I and Wave III respondent location on that respondent's survey date.

Wave I, III Road Type Length- These Data Files contain road type length calculations within radii of 1, 3, 5, and 8.05 kilometers (5 miles) of Wave I and Wave III respondent locations.

Wave I, III Rural-Urban Commuting Area (RUCA)- These Data Files contain Rural-Urban commuting area (RUCA) codes at the U.S. Census tract-level based on the location of Wave I and Wave III respondents.

Alcohol Density Files

Wave III Alcohol Outlet Density Data- This Add Health Data File measures the prevalence of alcohol outlets in respondent communities by reporting the tract-level density of establishments possessing on- and/or off-premise alcohol licenses.

Political Context Files

Wave I, II, III Political Context Data- The Add Health Political Context Database provides an array of measures that describe the political environments in which Add Health respondents reside. These contextual variables include measures of commuting, election results for gubernatorial, presidential, and senatorial races, and voter registration law.

Wave IV Medication File

**The University of Michigan, ICPSR
National Longitudinal Study of Adolescent Health
Restricted Use Data Agreement**

Appendix F: Add Health Data Files

Description of Data Files

The files contained in this component of the Add Health restricted data include the type of medication used by participants during Wave IV

Wave IV Biomarker Data

Glucose and HbA1c Data- This file contains two measures of glucose homeostasis based on the assay of the Wave IV dried blood spots.

CRP and EBV Data- The results of the assays for CRP (C-reactive protein) and EBV (Epstein-Barr virus) are in this Data File.

Wave IV Consent- In this file are variables indicating the types of consent (archive, no archive, refused, incarcerated) obtained for the Wave IV blood spot and saliva DNA collections.

Lipids Data- The Lipids data file contains measures of triglycerides (TG), total cholesterol (TC), high-density lipoprotein cholesterol (HDL-C), low-density lipoprotein cholesterol (LDL-C), non-high-density lipoprotein cholesterol, and total cholesterol to high-density lipoprotein cholesterol ratio.