

**The University of North Carolina at Chapel Hill, Carolina Population Center
National Longitudinal Study of Adolescent to Adult Health
Data Use Contract**

Agreement for the Use of Restricted-Use Data

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This Agreement for the Use of Restricted-Use Data (hereinafter referred to as “Agreement”), is entered into by and between Institution and UNC-Chapel Hill on behalf of Add Health. Each Institution and UNC-Chapel Hill shall be considered a party to this Agreement (“Party”) and collectively the “Parties.”

I. Definitions

- A. “The National Longitudinal Study of Adolescent to Adult Health” (hereinafter referred to as “Add Health”) is a project of the Carolina Population Center of The University of North Carolina at Chapel Hill (hereafter referred to as “UNC-Chapel Hill”) funded by cooperative agreements U01 AG71448 and U01 AG071450 from the National Institute on Aging.
- B. “Investigator” is the person primarily responsible for supervision of the research project, security of the data, and use of Sensitive Data obtained through this Agreement.
- C. “Research Staff” are all persons, excluding Investigator, who will have access to sensitive 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” or “Institutional Representative” is a person authorized to enter into contractual agreements on behalf of Institution.
- F. “Sensitive 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 sensitive.
- G. “Restricted-Use Data” is considered as Sensitive Data as shared under this Agreement.
- H. “Data File(s)” includes any form of data, including Sensitive Data, whether on paper or electronic media, shared under this Agreement.
- I. “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.
- J. “Contract Period” is the three (3) year period that begins and ends on the dates specified on the Investigator and Institutional Signatures page unless this Agreement includes Romantic Pairs data, in which case the “Contract Period” is the two (2) year period that begins and ends on the dates specified on the Investigator and Institutional Signatures page.
- K. “Processing Fee” is a nonrefundable payment that covers the expenses of producing and shipping Data Files, of providing codebooks, of consulting, and of administering this Agreement.
See Attachment G: Contract Processing Fees. Note: There is no processing fee for renewals.

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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
- B. Have a demonstrated record of using sensitive data according to commonly accepted standards of research ethics

IV. Obligations of Add Health

In consideration of the promises made in Section V of this Agreement and of receipt of the monies noted in Section V. I., Add Health agrees to the following, once a copy of the completed Agreement has been received and Attachment A has been approved:

- A. To submit for review by the appropriate officials of UNC-Chapel Hill this Agreement.
- B. To provide the fully executed Agreement to the Investigator and, if requested, to the Institutional Representative.
- C. To assign the effective dates of the Contract Period on the Investigator and Institutional Signatures page. The initiation date will be within fifteen (15) working days of receipt of the executed Agreement from the Representative of UNC-Chapel Hill.
- D. To provide the Data Files requested by Investigator within a reasonable time frame following execution of this Agreement by the Representatives of the Institution and UNC-Chapel Hill. All Data Files will be compressed and encrypted.
- E. To provide codebooks which contain the origins, form, and general content of the Data Files provided to Investigator; these are available on the Add Health website.

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

Data Files provided under this Agreement shall be held by the Investigator, Research Staff, and Institution in 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 Add Health, the Investigator and Research Staff, as employees or agents of the Institution, shall abide by the terms of this Agreement, and the Institution agrees:

- 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 Sensitive Data at the individual or family level will be published or otherwise distributed.
- B. That if the identity of any person, family, household, school, institution or geographic location should be discovered inadvertently, then:
 - 1. No use will be made of this knowledge;
 - 2. Add Health will be advised of the incident within ten (10) business days of Investigator's, Research Staff's, or Institution's discovery of the incident;
 - 3. The information that would identify the person, family, household, school, or institution will be safeguarded or destroyed as requested by Add Health and a written certification of destruction provided to Add Health; 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 ten (10).
 - 3. In no case should a cell frequency of a cross-tabulation be fewer than ten (10) cases.
 - 4. In no case should a quantity figure be based on fewer than ten (10) cases.
 - 5. Data Files 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 Sensitive Data or Data Files.
 - 1. That within ten (10) business days of becoming aware of any unauthorized access, use, or disclosure of Sensitive Data, the unauthorized access, use, or disclosure of Sensitive Data will be reported in writing to Add Health.

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- E. To comply fully with the Sensitive Data Security Plan, which is included as Attachment A to this Agreement. Approval of the Sensitive Data Security Plan expires at the end of the Contract Period.
- F. To respond fully and in writing within ten (10) working days after receipt of any inquiry from Add Health regarding compliance with this Agreement or the expected date of completion of work with the Sensitive Data and any data derived therefrom.
- G. To make available for inspection by Add Health, at a mutually agreeable time during business hours, the physical housing and handling of all Data Files and any other information, written or electronic, solely relating to this Agreement and which does not constitute the confidential information of a third party.
- H. To supply Add Health with a copy of each of the following:
 - 1. Investigator Information form
 - 2. Agreement for the Use of Restricted-Use Data, each with Investigator and Institutional Signatures page
 - 3. Sensitive Data Security Plan (Attachment A)
 - 4. Data Files form (Attachment B) confirming data order, and including explanatory statements for constructed datasets (if requested)
 - 5. Supplemental Agreement with Research Staff (Attachment C) signed by each Research Staff person and the Investigator
 - 6. Security Pledges (Attachment D) for the Investigator and each Research Staff person
 - 7. A copy of the document, originated by the Investigator and signed by Institution's Institutional Review Board (IRB), approving the research project.
- I. To provide to UNC-Chapel Hill the Processing Fee. Payment may be made by credit card or check payable to "The University of North Carolina at Chapel Hill."

An exemption to the 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 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 Sensitive Data from Add Health, the following statement:

This research uses data from Add Health, funded by grant P01 HD31921 (Harris) from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), with cooperative funding from 23 other federal agencies and foundations. Add Health is currently directed by Robert A. Hummer and funded by the National Institute on Aging cooperative agreements U01 AG071448 (Hummer) and U01AG071450 (Aiello and Hummer) at the University of North Carolina at Chapel Hill. Add Health was designed by J. Richard Udry, Peter S. Bearman, and Kathleen Mullan Harris at the University of North Carolina at Chapel Hill. No direct support was received from grant P01-HD31921 for this analysis.

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- K. That all journal articles based on analysis of confidential Sensitive 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 PubMed Central, 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

(If you have any problems with this process, please contact the NIHMS or PubMed help desk.)

- L. To complete the following protocol upon separation from Institution or the expiration of Investigator's contract:
1. Destroy all Data Files at the originally approved site.
 2. 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.
 3. Destroy all CDs containing Data Files, within thirty (30) days of the expiration of the Contract Period as specified on the Institutional Signatures page and provide documentation of destruction (destroy by scissor cut, submit before/after pictures), or submit a renewal application.

Add Health shall be able to visit within a year of contract termination, at a mutually-agreeable time during regular business hours, to confirm the data have been destroyed. This obligation of destruction shall not apply to Investigator's scholarly work produced during the Contract Period that is based upon or that incorporates the Restricted-Use Data.

- M. To notify Add Health in the event Investigator plans to separate from Institution during the Contract Period. Such notification must be in writing and must be received by Add Health 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 Data Files from Add Health in Investigator's capacity as an employee of his or her new institution. A fee will be charged to the investigator for the administration of this process (see Attachment G: Contract Processing Fees at the end of the contract).

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

1. Destroy all CDs containing Data Files and provide documentation of destruction (destroy by scissor cut, submit before/after pictures by email to addhealth_contracts@unc.edu).
 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 including Data Files have been securely erased with the secure erasure program listed in the Sensitive Data Security Plan for the originally approved site. This obligation of destruction shall not apply to Investigator's scholarly work produced during the Contract Period that is based upon or that incorporates the Sensitive Data.
- N. To obtain approval from Add Health prior to transferring this Agreement to another Investigator at the same Institution. A fee will be charged for the administration of this process (see Attachment G: Contract Processing Fees table at the end of the contract). In order to obtain such approval, Investigator must:
1. Inform Add Health in writing six (6) weeks prior to the proposed date of transfer.
 2. Submit a complete copy of this Agreement in the name of the new Investigator signed by an official representative of Investigator's new institution.
 3. Maintain responsibility for the security of all Data File CDs until the transfer contract has been approved.
- O. To submit annual reports to Add Health on or before each anniversary of the initial date of the Contract 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
 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
 7. A list of users no longer associated with your contract since your last annual report

Such reports shall be signed by Investigator. Add Health reserves the right to terminate this Agreement in the event that the reports are not timely submitted.

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- P. That Institution hereby acknowledges that any breach of the confidentiality provisions herein may result in irreparable harm to UNC-Chapel Hill that may not be adequately compensable by money damages. Institution hereby agrees that UNC-Chapel Hill may seek the imposition of injunctive relief in the event of breach, in addition to money damages to the extent allowable by applicable law. 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 Add Health, Add Health and UNC-Chapel Hill reserve 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 and Data 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 and Research Staff understands, and Institution agrees, 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.
- Q. That to the extent permitted under applicable law, both Parties agree to be responsible for the negligent acts or omissions of its employees and agents with respect to this Agreement, and nothing herein shall be considered a waiver of sovereign immunity. Sections V.P and V.Q shall survive the termination of the Agreement.
- R. Institution shall ensure that Investigator and Research Staff comply with the provisions of this Agreement. Institution shall be solely responsible for the compliance of Investigator, Research Staff and/or Institution and no legal action will be taken by Add Health against individual members of Institution staff, except in the case of willful misconduct or injunctive relief.

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)) (a "Confidentiality Certificate"). 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 sensitive under the terms of this contract.

VII. Incorporation by Reference

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

- A. A copy of the IRB approval of the research project, taking into special consideration deductive disclosure risks.
- B. The Sensitive Data Security Plan proposed by Investigator and approved by Add Health.
- C. The Department of Health and Human Services Confidentiality Certificate, a copy of which will be sent with the signed contract.

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VIII. Attachments

- A. Security Plan for the Use of Restricted-Use Data from the National Longitudinal Study of Adolescent to Adult Health
- B. Data File Order for the Use of Restricted-Use Data from the National Longitudinal Study of Adolescent to Adult Health
- C. Supplemental Agreement with Research Staff for the Use of Restricted-Use Data from the National Longitudinal Study of Adolescent to Adult Health
- D. Security Pledge for the Use of Restricted-Use Data from the National Longitudinal Study of Adolescent to Adult Health
- E. List of Funding Agencies for the National Longitudinal Study of Adolescent to Adult Health
- F. Description of Deductive Disclosure Risk from the National Longitudinal Study of Adolescent to Adult Health
- G. Contract Processing Fees

IX. Miscellaneous

- A. The Parties agree to abide by all applicable laws and agree to remain silent on governing law and venue.
- 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:

Add Health Contracts
Carolina Population Center
UNC-Chapel Hill
Carolina Square, Suite 210
123 West Franklin Street
Chapel Hill, NC 27516
- C. Provisions of Data Files, all notices, and contractual correspondence under this Agreement on behalf of Add Health shall be made in writing and delivered to Investigator at the address listed on the Institutional Signatures page. Any contractual correspondence shall be made with the Institutional Representative as 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 Add Health 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, Add Health may terminate this Agreement by providing written notice to Investigator and Institution. In this event, Add Health will not be required to refund of any portion of the Processing Fee.

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- G. This Agreement may be amended or modified only by the mutual written consent of the authorized representatives of Add Health 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 Representatives of the Institution and UNC-Chapel Hill signing this Agreement have the right and authority to execute this Agreement, and no further approvals are necessary to create a binding agreement.
- J. 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 Add Health.
- K. Add Health's existing ownership rights in its intellectual property, including its Sensitive 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.
- L. This Agreement may be executed in one or more counterparts each of which counterpart shall be deemed an original Agreement and all of which shall constitute but one Agreement.
- M. The Parties' electronic signatures shall be the legally binding equivalent of a handwritten signature.
- N. Institution agrees that Investigator can execute Attachments A, B, C, and D independent of an Institutional Representative.

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Investigator and Institutional Signatures

Understood and Acknowledged by:
Investigator

Agreed by:
Institutional Representative

SIGNATURE DATE

SIGNATURE DATE

NAME TYPED OR PRINTED

NAME TYPED OR PRINTED

TITLE

TITLE

INSTITUTION

INSTITUTION

BUILDING ADDRESS

BUILDING ADDRESS

STREET ADDRESS

STREET ADDRESS

CITY, STATE ZIP

CITY, STATE ZIP

Representative of Add Health

Representative of UNC-Chapel Hill

SIGNATURE DATE

SIGNATURE DATE

Robert A. Hummer - Principal Investigator
Add Health Contracts
Carolina Population Center
UNC-Chapel Hill
Carolina Square, Suite 210
123 West Franklin Street
Chapel Hill, NC 27516

Emily Linz,
On behalf of University of North Carolina
at Chapel Hill
Chapel Hill, NC 27599

For Add Health Use Only:

Security Plan & Contract Period: _____ through _____