

Guide to Accessing the Contract Data

Description of the Latino Adolescent Migration, Health and Adaptation Project (LAMHA)

The Latino Adolescent Migration, Health, and Adaptation Project (LAMHA) is a mixed-method, descriptive study of the mental health status and needs of immigrant youth and their families. Researchers are examining mental health symptomatology in recent Latino immigrant youth and their primary caretakers in North Carolina, where there has been a tremendous increase in first-generation immigrants. The study seeks to contextualize mental health symptoms by examining migration stories and experiences as well as current community and school variables. The study is funded by the William T. Grant Foundation for three years and is being conducted in conjunction with the Carolina Population Center (CPC).

Protection

Individuals and families participating in the LAMHA Project were assured confidentiality. Therefore, to protect the privacy and confidentiality of respondents, variables that could potentially reveal the identity of respondents are not disclosed in our files. However, LAMHA recognizes the desire for some in the research community to be able to access this important data. As a result, we are making a contract dataset available to members of the research community who meet eligibility criteria and agree to the requirements of the data agreement. The following materials have been developed by LAMHA staff after reviewing the materials and guidelines from other surveys (such as the Fragile Families Study and the National Longitudinal Study of Adolescent Health) to permit dissemination of LAMHA contract data while satisfying concerns about respondent anonymity and confidentiality.

Eligibility

Access to the LAMHA contract data is limited to researchers who agree to the terms and conditions contained in the *Contract Data Use Agreement*. Institutional Review Board (IRB) approval of the researcher's research and data protection plans are required. Therefore, only faculty and research personnel at institutions which have an Institutional Review Board/Human Subjects Review Committee are eligible to receive access to the contract data. The Institution's IRB must be registered with the U.S. Office for Human Research Protections (OHRP) or the National Institute of Health (NIH). Although nearly all research universities and other research organizations in the United States have IRB's registered with the OHRP, we are aware that some institutions and legitimate researchers will be excluded from access under this condition. We apologize for this and are considering options to expand the pool of eligible researchers while maintaining a high standard of protection for our respondents.

Please note: University students may gain access to the Contract Data for dissertation research, but a faculty advisor must serve as the Investigator and complete the application process for the student. The faculty advisor and institution bear full responsibility for ensuring that all conditions of the agreement are met by the student. The student must also sign the Supplemental Agreement with Research Staff form.

To be given access to the contract data, you must submit THREE copies of the following items to the LAMHA Project:

- 1) An extended abstract describing your project, what you hope to accomplish, and a one-paragraph justification for why you need access to contract data.
- 2) Written assurance by the researcher that his/her institution has an Institutional Review Board (IRB) for Human Subjects which has a Multiple Project Assurance (MPA) or Federalwide Assurance (FWA) from NIH. The MPA or FWA number must be submitted with the application.
- 3) A data protection plan, detailing how you plan to protect the files while they are being used, either on your computer and after they are printed.

Please note: Your university IRB must approve both your final research plan (extended abstract) and your final data protection plan. You are required to submit proof of IRB approval.

- 4) An application fee of \$150 (payable by check, purchase order or money order to LAMHA Project, Carolina Population Center).
- 5) A signed *Contract Use Data Agreement Application* by the Principal Investigator.
- 6) A signed *Contract Use Data Agreement Application* by a senior university official who binds the university/institution. This refers to an individual who has the authority to represent your organization in agreements of this sort, such as a Vice President, Dean, Provost, Center Director, or similar official.
- 7) A signed *Supplemental Research Agreement with Research Staff* for each person who will have access to the data.
- 8) A curriculum vitae for each person who will be accessing the information.
- 9) A copy of the **Human Participants Protection Education for Research Teams** completion certificate from NIH for *all* research staff who will access the contract data. The online certification can be completed at <http://cme.nci.nih.gov/>.

Please note: If co-investigators are from different institutions, you will need separate Contract Data Use Agreements for each institution.

Important: Before beginning work on the full application, researchers should send a draft of their extended abstract, description of data requested, and CV to the LAMHA Project (c/o lamha@unc.edu) in order to get preliminary approval.

As part of the agreement, researchers will be required to:

- 1) Submit a copy of their approved annual IRB renewal to lamha@unc.edu.

2) Place the following paragraph on any written report or publication based on the analysis of contract data:

This research uses data from Latino Adolescent Migration, Health and Adaptation (LAMHA) study, a project designed by Mimi Chapman and Krista Perreira, and funded by the William T. Grant Foundation. Persons interested in obtaining data files from LAMHA should contact LAMHA, Carolina Population Center, 123 W. Franklin Street, Chapel Hill, NC 27516-2524 (lamha@unc.edu).

3) Submit to lamha@unc.edu electronic copies of any publications and presentations at professional meetings resulting from the data use.

The *Contract Data Use Agreement* is a legal document binding the researcher, the Receiving Institution, and the LAMHA Project. If the LAMHA Project decides all requirements are met, a representative from the LAMHA Project will sign the *Contract Data Use Agreement* and return a copy of the fully executed agreement to the Investigator along with a password to access the data. Changes in the employment status of the researcher require the completion of a new Contract Data Use Investigator. If during the course of the research project, new staff are added who will have access to the data, signed copies of the *Supplemental Agreement with Research Staff* must be sent to the LAMHA Project. Access to the data cannot be provided to these staff members until the Supplemental Agreements are signed by a LAMHA Project representative and returned to the Investigator.

Delivery

Upon satisfactory completion of all requirements, you will be provided with a password that will enable you to download data. The *Contract Data Use Agreement* expires after two years, with the option of applying for an extension. Upon expiration of the *Contract Data Use Agreement*, researchers should destroy any copies of the data that exist.

Where to submit requests:

All requests for LAMHA Project data should be mailed to:

LAMHA project
Carolina Population Center
University of North Carolina at Chapel Hill
CB # 8120, University Square
123 W. Franklin Street
Chapel Hill, NC 27516-2524
ATTN: LAMHA Project contract data

Any questions about the application process should be directed to:

Krista M. Perreira
Latino Adolescent Migration, Health and Adaptation Project
Carolina Population Center
University of North Carolina at Chapel Hill
Email – lamha@unc.edu
Telephone - (919) 962-8411 Fax – (919) 966-6638

LAMHA Data Use Agreement Application Cover Page

Name of Investigator: _____ Date of Application: _____

Title of Investigator: _____

Title of Research Project: _____

Street Address: _____

City/State/Zip Code: _____

Telephone Number: _____ Fax Number: _____

Email Address: _____ (Used to notify Investigator of receipt of application package.)

Receiving Institution: _____

Please indicate which of the LAMHA data components you are applying to use:

- 1. LAMHA parent mental health survey data _____
- 2. LAMHA youth mental health survey data _____
- 3. LAMHA service use data _____
- 4. LAMHA health belief interview data (PI: Mimi Chapman) _____
- 5. LAMHA adolescent interview data (PI: Krista M. Perreira) _____

Use the following checklist to insure that you are providing all required materials. We must receive **THREE** complete sets of the following documents:

Item	Checklist
This Application for Obtaining Contract Data	
Contract Use Data Agreement Application*	
Completed Supplemental Agreement with Research Staff	
Research Plan (approved by IRB)	
Contract Data Protection Plan (approved by IRB)	
Evidence of IRB's Certification with NIH or OHRP	
Copies of CVs for all research staff	
Copies of Human Subjects Completion Certificates for all research staff	

**each of the three copies of the agreement must have original signatures from the Principal Investigator and Institutional Representative*

A non-refundable fee (\$150), payable to Carolina Population Center, is required.

Processing of the final application will not begin until all materials have been received. Send materials to:
LAMHA Project

Carolina Population Center
University of North Carolina at Chapel Hill
CB # 8120, University Square
123 W. Franklin Street
Chapel Hill, NC 27516-2524
ATTN: LAMHA contract data

Data Use Agreement for the LAMHA Project

The Investigator and the Receiving Institution agree to the following terms and conditions of this agreement:

I. Definitions

- a. **Contract Data** - The original data collected by the CPC and any variables derived from the original data. Data resulting from merges or matches to the original or derived variables are also included in this definition. Aggregated statistical summaries of data and analyses, such as tables and regression statistics, are not considered “derived” for the purposes of this agreement.
- b. **Investigator** - The individual who serves as the primary point of contact for all communications involving this agreement. The Investigator must hold a faculty appointment or research position at the Receiving Institution and assumes all responsibility for compliance with all terms of this agreement by employees of the Receiving Institution.
- c. **Receiving Institution** - The organization employing the Investigator. The Receiving Institution must have an Institutional Review Board/Human Subjects Review Committee registered with the United States Office for Human Research Protections or the National Institute of Health.
- d. **Research Staff** - Individuals affiliated with the Receiving Institution, other than the Investigator, who are authorized to access the Contract Data.
- e. **Representative of the Receiving Institution** - An individual who has the authority to represent the Receiving Institution in agreements of this sort, such as a Vice President, Dean, Provost, Center Director, or similar official. Note that a Department Chair is not acceptable unless specific written delegation of authority exists.

II. Items Incorporated by Reference

The *Supplemental Agreement with Research Staff*, as approved by CPC, is incorporated by reference into this agreement.

III. Ownership of Data

- a. Ownership of the Contract Data will be retained by CPC. Permission to use the Contract Data by the Investigator and Receiving Institution may be revoked by CPC at any time, at their discretion. The Investigator and Receiving Institution must destroy all originals and copies of the Contract Data, on whatever media it may exist, within 5 days of written request to do so.
- b. The Investigator will not make any claim to copyright ownership of the Contract Data and accompanying documentation. The Investigator will not distribute copies of the Contract Data and accompanying documentation to others or make copies for reasons other than research in accordance with the conditions outlined in this agreement.

IV. Access to the Contract Data

- a. Access to the Contract Data will be limited solely to the individuals signing the agreement or the *Supplemental Agreement with Research Staff*. The data may not be “loaned” or otherwise conveyed to anyone other than the signatories to this agreement.
- b. Copies of the Contract Data or any subsequent variables or data files derived from the Contract Data will not be provided to any other individual or organization.
- c. The Investigator and Research Staff will protect the Contract Data and any data derived from the Contract Data from access by unauthorized individuals. Appropriate protections include keeping computers and portable data storage devices in locked offices or filing cabinets.
- d. The Investigator and Research Staff will not store the data on a networked computer or other electronic storage device without taking steps to prevent unauthorized access. Such steps include password protection of shared devices, data encryption, and the use of firewall technology.

V. Uses of the Contract Data

- a. The Contract Data will be used solely for the purpose of scientific and public policy research, and not for any administrative, proprietary, or law enforcement purposes.
- b. The Contract Data will be used to generate only statistical summary information that does not allow any individual, family, household, school, community, or organization to be identified.
- c. No attempt will be made to identify any individual, family, household, school, community, or organization. If an individual, family, household, school, community, or organization is inadvertently identified, or if a technique for doing so is discovered, the identification or discovery will be immediately reported to the CPC, and the identification or discovery will not be revealed to any other person who is not a signatory to this agreement.
- d. To avoid inadvertent disclosure, the following guidelines will be followed in the release of statistics derived from the datasets:
 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 figure of a row or column of a cross-tabulation be less than 5;
 3. In no case should an age-sex quantity figure be based upon fewer than 10 cases;
 4. In no case should a quantity figure be published if one case contributes more than 60 percent of the amount;
 5. In no cases should data on an identifiable case, or any of the kinds of data listed in preceding items A to C, be derivable through subtraction or other calculation from the combination of tables released on a given study; and,
 6. Data released should never permit disclosure when used in combination with other known data.
- e. No attempt will be made to link this Contract Data with any other dataset without written authorization from the CPC

f. Use of the Contract Data will be consistent with the Receiving Institution's policies regarding scientific integrity and human subjects research.

VI. Certificate of Confidentiality

Research subjects who participated in the LAMHA Project 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)). Under the terms of the Confidentiality Certificate, the Receiving Institution is considered to be a contractor or cooperating agency of University of North Carolina at Chapel Hill under the terms of the Confidentiality Certificate; as such, the Receiving Institution, the Investigator, and Research Staff are authorized to protect the privacy of the individuals who are the subjects of the LAMHA Project by withholding their identifying characteristics from all persons not connected with the conduct of the study. "Identifying characteristics" are considered to include those data defined as sensitive under the terms of this contract.

VII. Limits on Disclosure of Information

a. Identifying information concerning research participants from the Contract Data will not be revealed to unauthorized individuals through personal communication, publication, or other data release.

b. CPC will be notified immediately if the Investigator or Research Staff receive any legal, investigatory, or other demand for disclosure of the Contract Data, including any request or requirement to provide data to any State agency or State contractor under conditions that are inconsistent with any requirement of this agreement. CPC is authorized to revoke this agreement and take possession of the Contract Data, or take any other action necessary to protect the absolute confidentiality of the data.

VIII. Data Confidentiality Procedures

a. CPC will be notified immediately if the Investigator or Research Staff discover a suspected breach of security or any actual disclosure of subject data to unauthorized individuals.

b. The Receiving Institution will treat allegations, by CPC or other parties, of violations of this agreement as allegations of violations of its policies and procedures on scientific integrity and misconduct. If the allegations are confirmed, the Receiving Institution will treat the violations as it would treat violations of the explicit terms of its policies on scientific integrity and misconduct.

IX. Reporting and Publication Requirements

a. The Investigator will provide CPC with annual reports which will include a copy of the annual approval of the project by the Receiving Institution's Institutional Review Board/Human Subjects Review Committee, a copy of published works or reports based wholly or in part on the LAMHA Contract Data, and a listing of presentations at professional meetings based upon the LAMHA Contract Data.

b. A notification copy of any publications and presentations developed by the Investigator or Research Staff from LAMHA data will be provided to CPC. In the case of publications

specifically, the copy will be sent concurrent with submission of the manuscript. Publications are considered to be any work that is made available to the public in a distributed fashion, including but not limited to journal articles, book chapters, and articles distributed through a Web site.

c. The Investigator and Research Staff will acknowledge the CPC and LAMHA in any publication or presentation based wholly or in part on the CPC Contract Data. This acknowledgement should read as follows:

This research uses data from Latino Adolescent Migration, Health and Adaptation (LAMHA) study, a project designed by Mimi Chapman and Krista Perreira, and funded by the William T. Grant Foundation. Persons interested in obtaining data files from LAMHA should contact LAMHA, Carolina Population Center, 123 W. Franklin Street, Chapel Hill, NC 27516-2524 (lamha@unc.edu).

X. Destruction of Data Upon Completion of Research Project

The Investigator will certify to the CPC that all copies of the contract data, on whatever media, will be destroyed at the completion of the research project or within 5 days of written request from the CPC.

XI. Duration of this Agreement

This agreement will go into effect upon its approval by the University of North Carolina at Chapel Hill and will remain in effect until the completion of the research project, or 24 months from its effective date, whichever comes first. If, at the end of 24 months, access to the Contract Data is still desired, the Investigator must apply for an extension to the agreement.

XII. Liability

The Investigator and Receiving Institution jointly and severally shall indemnify University of North Carolina at Chapel Hill, their officers, agents, and employees against any liability, including costs and expenses, incurred as the result of the violation of copyrights, or right of privacy or publicity, arising out of the Institution's or Investigator's creation, delivery, publication, or use of data furnished under this agreement or the breach of any of the terms of this agreement. University of North Carolina at Chapel Hill shall provide the Investigator and Receiving Institution of timely notice of any claim or suit, afford the Investigator and Receiving Institution an opportunity under applicable laws, rules, or regulations to participate in the defense thereof, and obtain the Investigator's and Receiving Institution's consent to the settlement of any suit or claim other than as required by final decree of a court of competent jurisdiction.

XIII. Amendments to the Submitted Materials After Initial Approval

a. A change in the employer of the Investigator requires the execution of a new *Contract Data Use Agreement*. The Investigator and/or Receiving Institution shall notify CPC of the planned change at least six weeks prior to the relocation.

b. When Research Staff join the project, they will submit the *Supplemental Agreement with Research Staff*. Such Supplemental Agreements must be submitted before the new Research Staff may have access to the Contract Data.

c. When Research Staff leave the project, the Investigator will notify CPC that these individuals are no longer authorized to access the Contract Data.

XIV. Violation of this Agreement

If CPC determines that the agreement may have been violated, CPC will inform the Investigator and Receiving Institution of the allegations in writing and will provide an opportunity to respond in writing within 10 days. CPC may also, at that time, require immediate destruction of all copies of the Contract Data in possession of the Investigator and Research Staff. Failure to do so will be considered a material breach of this agreement. If CPC deems the allegations unfounded or incorrect, the Investigator may be granted access to the data again under the terms of the original agreement. If CPC deems the allegations in any part to be correct, CPC will determine and apply the appropriate sanction(s). If CPC determines that any aspect of this agreement has been violated, the Investigator and/or Receiving Institution will be subject to one or more of the following penalties:

- a. Criminal or civil penalties as described in the Privacy Act of 1974, 5 U.S.C. 552a.
- b. Report of the violation to the Receiving Institution's Institutional Review Board/Human Subjects Review Committee and/or National Institute of Health with a request that the institution's sanctions for misconduct be imposed.
- c. Report of the violation to the Federal Office for Human Research Protections, which may result in investigation of the Investigator and Receiving Institution.
- d. CPC may report the violation to the Investigator's funding agencies with a recommendation that current funding be terminated, and future funding denied, to the Investigator, Research Staff, and any other person implicated in the violation.
- e. Revocation of the existing agreement and denial of all future access to CPC data.
- f. Payment of damages awarded by a court to any individual harmed by the unauthorized use or disclosure.

I certify that all materials submitted with this request for the LAMHA Project Contract Data are truthful. Furthermore, I acknowledge that I am legally bound by covenants and terms of this agreement, and that violation will constitute unethical professional practice and may subject me to the sanctions listed above.

Investigator

Signature of Investigator: _____ Date of Signature: _____

Name of Investigator: _____

Title of Investigator: _____

Receiving Institution: _____

Street Address: _____

City/State/Zip Code: _____

Telephone Number: _____ Fax Number: _____ Email Address: _____

Representative of the Receiving Institution:

By signing this agreement, this institution agrees that access to these confidential data will be granted only to authorized persons whose names appear on this agreement and the Supplemental agreements with Research Staff, and that this institution is legally bound by the covenants and terms of this agreement.

Signature: _____ Date of Signature: _____

Name: _____

Title: _____

Receiving Institution: _____

Street Address: _____

City/State/Zip Code: _____

Telephone Number: _____ Fax Number: _____ Email Address: _____

LAMHA Principal Investigator

University of North Carolina at Chapel Hill

Krista M. Perreira

Tony G. Waldrop
Vice Chancellor for Research and Econ Develop

**Supplemental Agreement with Research Staff
for the Use of Contract Data from the LAMHA Project**

I. The undersigned Research Staff, in consideration of their use of sensitive data from the LAMHA Project, agree:

- a. That they have read the *Contract Use Data Agreement Application* from The LAMHA Project and the Contract Data Protection Plan incorporated by reference into it.
- b. That they are “Research Staff” within the meaning of the agreement.
- c. To comply fully with the terms of the agreement, including the Contract Data Protective Plan.

II. The undersigned Investigator, agrees that the persons designated herein are Research Staff within the meaning of the associated Agreement for the Use of Sensitive Data from the LAMHA Project.

Research Staff

_____	_____	_____
Name	Title	Signature
_____	_____	_____
Name	Title	Signature
_____	_____	_____
Name	Title	Signature
_____	_____	_____
Name	Title	Signature

Investigator

_____	_____	_____
Name	Signature	Date

Description of Parameters for Data Protection Plan

Researchers must provide a concise but detailed data protection plan as part of their application to receive LAMHA Project Contract Data.

Purpose of the Data Protection Plan

The *Data Protection Plan* is an important part of the signed agreement between CPC and the Contract Data Investigator. If the agreement is executed, all members of the research team with access to the data are contractually obligated to follow all aspects of the *Data Protection Plan*. The fundamental goal of the protections outlined in this plan is to prevent persons who are not signatories to the *Contract Data Use Agreement* or the *Supplemental Agreement With Research Staff* from gaining access to the data. CPC will not provide Contract Data if the plan is not written with sufficient specificity, or if CPC does not deem the data protections to be adequate.

Elements of the Plan

The *Data Protection Plan* applies to the original LAMHA Project data files received from CPC (regardless of its format), to any copies made by the research team, and to any new data derived solely or in part from the original LAMHA Project data files. The plan also should address how computer output derived from the data will be kept secure.

The *Data Protection Plan* should list and describe all locations where the original and copies of the data will be kept. In addition, the *Data Protection Plan* should describe the computing environment in which the data will be used, including:

- a. Computing platform, such as personal computer, workstation and/or mainframe, and operating system
- b. Number of computers on which data will be stored or analyzed
- c. Whether PCs used in the research project will be attached to a network or will operate independently as a stand-alone
- d. Physical environment in which computer is kept, such as in room with public access or in room locked when not in use by research staff
- e. List and describe device(s) on which data will be stored, such as on network server, on mainframe computer storage device, on PC hard drive, on removable storage device such as CD, floppy drive, or zip drive
- f. Describe methods of data storage when data are not being used
- g. Describe methods of transmitting the data between research team members, if applicable
- h. Describe methods of storage of computer output both in electronic form and in hard copy or on paper or other media

- i. Describe the instruction in data protection policies that will be provided to each staff member and student before they receive access to the data

Types of Protection Expected

Although they will vary with the version of the contract data and may vary across research projects and depend on the host institution, a successful *Data Protection Plan* should include some or all of the following features:

- a. Password-protected access to all computers storing the data.
- b. Password protection on all computers should be activated whenever a data user leaves the office or after five minutes of non-activity.
- c. All files containing data stored in password-protected, encrypted form,
- d. No storage of the data on laptop computers, network servers, etc.
- e. No automated backup copying of the data.
- f. Removable devices holding the data, such as CDs, diskettes, zip drive disks, etc., should be stored in a locked compartment or room when not in use.
- g. Data on removable devices should be stored in password-protected, encrypted files.
- h. Detailed printouts derived from data analysis stored in a locked compartment or room when not in use.
- i. Shred all detailed printouts that are no longer needed.
- j. Prepare and maintain a log of all data files acquired. The date on which materials are received, copied, or destroyed should be recorded.
- k. Note that all files containing contract data will be destroyed at the end of the project.
- l. Note that all violations to the *Data Protection Plan* will be reported to the Principal Investigator and the appropriate IRB official(s).
- m. No transmittal of data or detailed tabulations via e-mail or e-mail attachment, either over the Internet, an Intranet system, or within a local area network. Data can be transmitted by FTP provided that the data files are password protected and encrypted and the files are not placed on a public server that is accessible without a password.
- n. Use of e-mail, e-mail attachment, FTP, or any other means of electronic transfer to transmit *only* results from regression analyses and aggregate descriptive analyses.

o. Briefing procedures for research staff who have access to the Contract Data about the *Data Protection Plan*, appropriate data use, and penalties for inappropriate use. The Contract Data Investigator must regularly monitor procedures for use of the data by staff and colleagues. He/she should post clear rules about Contract Data use in a location that is readily visible to staff. At the conclusion of the research project, researchers are required to destroy all data files and unpublished printouts.

Disclosure Rules

The *Data Protection Plan* must carefully describe how researchers and staff members will avoid inadvertent disclosure of respondents' geographic locations or identity in all working papers, publications, and presentations. At minimum, researchers must agree to exclude listings of individual cases and description of individual cases from any type of publication or presentation. Users can see detailed instructions for acceptable data protection plans for the National Longitudinal Study of Adolescent Health (<http://www.cpc.unc.edu/projects/addhealth/contract.html>) as references for developing an acceptable data protection plan.