## Obtaining National Health and Aging Trends Study Restricted Data From the NHATS Restricted Data Repository

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#### I. Introduction

This document describes procedures for researchers to access Restricted Data files from the National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC) via the NHATS Restricted Data Repository. NHATS and NSOC Restricted Data Files require additional protections to minimize risks of identifying participants. Access to these files is available to qualified researchers through a partnership with the Michigan Center on the Demography of Aging (MiCDA) at the University of Michigan's Institute for Social Research.

Centers for Medicare and Medicaid Services (CMS) files are not available through the NHATS Restricted Data Repository. Researchers interested in using CMS data (with or without Hospital Referral Region files or the Restricted Tracker Files) should apply using "Obtaining Restricted CMS Data for the National Health and Aging Trends Study" available at <a href="https://www.nhats.org">www.nhats.org</a>.

Each application for access to the Restricted Data Repository will be reviewed by NHATS for conformance with the requirements outlined in these materials. Questions regarding the application process may be sent to: NHATS-restricted-data@umich.edu. Please use the subject heading: Application query (Investigator Name).

#### II. The MiCDA Virtual Data Enclave

The MiCDA Virtual Data Enclave (VDE) provides remote access to the NHATS Restricted Data Repository through a virtual desktop infrastructure. Data remain on MiCDA enclave servers and are accessed and analyzed by approved users virtually via an encrypted connection.

Security measures. Login to the enclave requires two-factor authentication. Data files cannot enter or be removed from the NHATS repository by the researcher. Output and programs will be reviewed for disclosure risk by the repository director or their designee prior to removal. Users agree to access data only from locations specified in the MICDA Data Security plan form. Users agree not to transcribe results as specified in MiCDA's Secure Data Enclave Acceptable Use Policy and not to attempt to identify subjects as specified in the ISR Pledge of Confidentiality.

*Software*. Each workstation is equipped with a suite of statistical software (including SAS, Stata, SPPS, MatLab, ArcGIS, R, and Stat/Transfer) and Microsoft Office.

#### III. NHATS Restricted Data Repository Data Availability

Files available to approved users via the NHATS Restricted Data Repository include:

- NHATS Geographic Files
- NSOC Geographic Files
- NHATS Restricted Tracker Files
- NHATS 1940 Census Files
- NHATS 1940 Census Geographic Files
- NHATS COVID-19 Geographic Files
- NHATS Restricted COVID-19 File

Detail on files that may be requested is provided in Table 1. The NHATS Data Repository also includes a complete set of NSOC and NHATS sensitive files that may be requested. In addition, the repository includes all NHATS public use files.

Table 1. File Folders Available in the NHATS Restricted Data Repository

File Folder	Description	Years available
NHATS Geographic Files	Sample person's city, state,	Annual SP Geographic Files
	county, zip code and census tract	
	Sample person's metro/non-metro	
	status¹	Annual Metro files
	Sample person's Hospital Referral	A LUBB CL.
	Region <sup>2</sup>	Annual HRR file
	Sample person's city, state living at	Baseline SP files (e.g. 2011,
	age 15, country of birth if born outside of US	2015)
	Spouse/partner, child, and	Annual OR Coographic Files
	household member city, state	Annual OP Geographic Files
NSOC Geographic Files	Caregiver's city, state, county, zip	2011, 2015, 2017
5 .	code and census tract	, ,
NHATS Restricted Tracker Files	Day NHATS interview conducted	2020 cumulative file
		(includes 2011-2020)
NHATS 1940 Census Files <sup>3</sup>	Sample Person File with SP and	2015
	Household Characteristics	
	Other Person File	
NHATS 1940 Census	Geographic information below	2015
Geographic Files	state (additional justification	
	required)	
NHATS COVID-19	City, state, county, zip code and	2020
Geographic Files	census tract of family members or friends who helped the NHATS	
	Sample Person most during the	
	COVID-19 outbreak.	
NHATS Restricted COVID-19	Answers to open-ended question	2020
File	about how COVID has affected	
	SP's life	

<sup>&</sup>lt;sup>1</sup>The metro/non-metro indicators use the 2013 Rural-Urban Continuum Codes (RUCC). See <a href="https://www.ers.usda.gov/data-products/rural-urban-continuum-codes/">https://www.ers.usda.gov/data-products/rural-urban-continuum-codes/</a> for details.

Plans are also in progress to provide contextual files about geographic areas (e.g. census files, public health data, environmental data, policy data) to be made available through the enclave. Users may also request to bring contextual files into the enclave via an approved research plan and NHATS DUA.

<sup>&</sup>lt;sup>2</sup>Developed by the Dartmouth Atlas of Health Care. See <a href="https://www.dartmouthatlas.org/data/">https://www.dartmouthatlas.org/data/</a> for details. This file lags other geographic files by about a year or two.

<sup>&</sup>lt;sup>3</sup>See <a href="https://usa.ipums.org/usa/voliii/items1940.shtml">https://usa.ipums.org/usa/voliii/items1940.shtml</a> for details

#### IV. Requirements for NHATS Restricted Data Repository Applications

#### **Investigator (Applicant) Requirements**

To be eligible to apply for NHATS Restricted Data, an Investigator must:

- have a PhD or other terminal degree (e.g. MD-MPH) and hold a full-time faculty-level (or equivalent research) appointment at a U.S.-based university or research institution,
- be affiliated with an Institution that holds a Federal Wide Assurance (FWA) from the Office for Human Research Protection of the Department of Health and Human Services (see <a href="https://www.hhs.gov/ohrp/register-irbs-and-obtain-fwas/fwas/fwa-protection-of-human-subjecct/index.html">https://www.hhs.gov/ohrp/register-irbs-and-obtain-fwas/fwas/fwa-protection-of-human-subjecct/index.html</a>), and
- be a current recipient, as Principal Investigator or Co-Principal Investigator, of research funds from a federal agency. Other sources of support (e.g. foundation, academic institution) will be considered on a case-by-case basis. These funds may be (but are not required to be) a source of support for the proposed work scope.

Investigators collaborating at different institutions must have one Investigator <u>at each institution</u> who meets the qualifications to apply if both institutions are requesting access to the data through the MICDA enclave.

Pre- or Post-doctoral students interested in applying for access to NHATS restricted data must have their mentor/advisor apply as the applicant and may be listed as research staff on the application.

#### **Roles**

**Investigator** - This individual is considered the principal investigator of the project and must meet all applicant requirements

**Co-Investigator** – This individual collaborates with the requesting investigator and must hold a faculty-level (or equivalent research) appointment at the Investigator's institution

**Research Staff** – This individual must have a formal affiliation with the Investigator's institution and be under the supervision of the Investigator

**Receiving Agency Representative** – This individual has authority to sign the NHATS Data Use Agreement on behalf of the Investigator's Institution. The representative must have the authority to bind the institution contractually.

**Users** – This individual is requesting an account in the MiCDA Virtual Data Enclave to access the NHATS Restricted Data Repository and may be the Investigator, Co-investigator or Research Staff listed on the application.

All Investigators, Co-investigators and Research Staff who will work with the NHATS Restricted data must be on the NHATS DUA, must be registered NHATS users (see <a href="https://www.nhats.org/user/register">https://www.nhats.org/user/register</a>), and must have a formal affiliation with the Requesting Investigator's institution.

**Collaborating Investigators at another Institution** - A collaborating investigator at another institution who wishes to access the NHATS Restricted Data Repository must submit a separate application (see Application Process). The individual will be designated the Investigator for their institution and must meet all investigator requirements. They may include additional

coinvestigators and research staff from their institution on their application. All Investigators, Coinvestigators and Research Staff at collaborating institutions who will work with the NHATS Restricted data must be on the collaborating Investigator's DUA, must be registered NHATS users (see <a href="https://www.nhats.org/user/register">https://www.nhats.org/user/register</a>), and must have a formal affiliation with the collaborating Investigator's institution.

#### **Application Process**

The application process requires the following steps:

**Step 1:** Complete and sign the required forms and documents (see Section VII). Be sure all individuals listed on the NHATS DUA are registered NHATS users (see <a href="https://www.nhats.org/user/register">https://www.nhats.org/user/register</a>).

**Step 2:** Submit the application materials electronically to <a href="MHATS-restricted-data@umich.edu">MHATS-restricted-data@umich.edu</a> using the subject heading: Restricted Data Application (Requesting Investigator Name).

**Step 3**: NHATS will review the documents submitted. Any questions, or needed revisions, will be communicated to the Requesting Investigator.

**Step 4**: Once NHATS approves the application, the data use agreement will be countersigned by NHATS and Johns Hopkins University. MiCDA accounts will then be set up and users will be given access to files in the DUA. A fully executed DUA will be sent to the applicant along with instructions on how to log into the MiCDA Virtual Data Enclave.

Investigators collaborating at different institutions must each complete a separate application with a common title, file request form, and research plan. A separate DUA and IRB approval (or proof that another institution serves as the IRB of record) is required for each institution. Only individuals at the applicant's own institution should be listed as co-investigators, research staff or users on a given application. To facilitate sharing within the enclave, both investigators should complete the form for "Investigators collaborating at different institutions".

#### V. Acceptable Uses of the Restricted Data

**Restricted data.** As specified in the NHATS DUA, restricted data – both original files and variables or fields derived from them - can be used *only* for scientific and public policy statistical research purposes that are specified in the Research Plan and only for statistical (summary) reporting that does not permit identification of an individual, family or facility either directly or indirectly.

Repository use. Only approved individuals may be given an account in the Michigan Center for the Demography of Aging (MiCDA) Virtual Data Enclave (VDE), which houses the NHATS Restricted Data Repository. As specified in MiCDA's Acceptable Use Policy, (1) <u>Users may only access the enclave from approved locations and equipment specified in the MICDA Data Security plan form; (2) Users must position the screen to prevent unauthorized user from viewing the NHATS restricted data and lock the computer when they step away; (3) <u>Users may not print, take screenshots, pictures, screen-share, transcribe or otherwise duplicate data or results of data analysis; and (4) Users may not share login information (account name, password or token values) or permit viewing of their VDE account including output. Finally, as specified in the ISR Pledge of Confidentiality, users may not attempt to identify NHATS subjects.</u></u>

Disclosure review. Prior to removal, all output and programs will be reviewed for disclosure risk by the

NHATS restricted data repository director or their designee. Tabulations with cells/strata < 11, including minimum and maxim values for individual cases, may not be removed from the NHATS restricted data repository. Additional cells may be suppressed if they may lead to uncovering cells/strata size <11 through subtraction. Tabulations and/or visual representations or coefficients based on geographic areas below the Census Division may not be removed from the enclave.

#### VI. Modifications to the DUA

All changes to project team members or institutional affiliations require an updated DUA and MiCDA Enclave application. New study staff members should complete the Restricted Data Supplemental Agreement with New Research Staff form. Substantial changes to the research aims and any new requested linkages also require an updated research plan and/or file request form.

Before access to the data is to be granted to an additional collaborator, or to an existing collaborator at a new institution, a modified DUA with the new collaborator/institution must be submitted and approved, a modified research plan must be submitted (if applicable), and all MiCDA Virtual Data Enclave paperwork must be submitted and approved. It is not permitted for a faculty member to obtain access to the data for his/her own research project and then "share" their account information with a graduate student or a colleague. It is also not permitted for a faculty member who changes institutions to continue accessing the NHATS Restricted Data Repository. Once all paperwork is approved the individual will be given access the restricted data.

DUAs expire once the investigator notifies NHATS that the project has ended or 3 years from date entered on page 1 of the DUA, whichever occurs first. Once the DUA expires, all MiCDA accounts will be closed, unless a 3-year extension has been requested and approved.

#### VII. Sanctions for Violation of the Agreement

The NHATS *Restricted Data Use Agreement* specifies four possible sanctions against researchers who violate the terms of the agreement:

- 1) Denial of future access to NHATS Restricted Data;
- 2) Report of the violation to the Receiving Institution's office responsible for scientific integrity and misconduct, with a request that sanctions be imposed under the institution's scientific integrity and misconduct policy;
- 3) Report of the violation to research funding agencies, with a recommendation that all current research funds be terminated, and all future funds be denied, to the Investigator(s) and to all other persons implicated in the violation; and
- 4) Such other remedies as may be available to NHATS under law.

If NHATS staff determine that there may have been a violation of the Agreement, NHATS will communicate the allegations in writing to the Investigator and offer the investigator an opportunity to respond in writing. NHATS may also, at the time the allegations are communicated, remove access to NHATS Restricted Data by Investigator(s), Co-investigators and Research Staff.

If NHATS determines that the allegations of violations were incorrect, NHATS will restore access under the conditions of the original Agreement. If NHATS determines that the allegations of violations of the

## National Health and Aging Trends Study (NHATS): Restricted Data Repository Application Forms

## VIII. Forms

Investigator Form				
Project Form				
<ul> <li>Project title and abstract</li> <li>Research plan</li> <li>CV or Biosketch for Investigator and Co-Investigator(s)</li> <li>Copy of award letter documenting research funds and the source(s) of these funds</li> <li>Copy of IRB approval</li> </ul>				
File Request Form				
Signed copy of the NHATS Restricted Data Use Agreement				
Signed NHATS Supplemental Restricted Data Use Agreement with Research Staff (if applicable)				
Investigators Collaborating Across Institutions (if applicable)				
List of users requesting MiCDA VDE Access				
For each user				
<ul> <li>Signed MiCDA Sensitive Data Enclave Acceptable Use Policy (for each user)</li> <li>Signed Institute for Social Research Pledge to Safeguard Respondent Privacy (for each user)</li> <li>Signed MiCDA Enclave Virtual Desktop Infrastructure (VDI) Data Security Plan(s) (for each user location)</li> </ul>				

## National Health and Aging Trends Study (NHATS): Restricted Data Investigator Form

Investigator:
NAME
SIGNATURE
NHATS REGISTRATION EMAIL ADDRESS
DATE OF SIGNATURE
PHONE CONTACT
Institution where Investigator holds appointment:
NAME
STREET ADDRESS
CITY, STATE , ZIP
LINK to WERSITE or LIRL of INSTITUTION

## National Health and Aging Trends Study (NHATS): Restricted Data Research Plan

Project Title:		 	 	
Abstract: 250 w	ord limit			

Applicants must provide a short (2-3 page) research plan that includes:

- 1. A statement of the aims of the research;
- 2. A description of the files and variables from the NHATS restricted data that will be used in analyses;
- 3. A description and justification for other data files, if any, that you plan to merge with the NHATS restricted data;
- 4. A statement as to why the unrestricted versions of those variables, if any, are not adequate for your research purposes. For example, "census region" and dichotomous "urban/rural" indicators are available for the Sample Person on the NHATS Public Use Files and "month" of interview is available on the Tracker Files.

#### Each applicant must also submit:

- 1. For each investigator and co-investigator at your institution, include a curriculum vita or biosketch.
- 2. A copy of your award letter documenting evidence of funding.
- 3. A copy of your project's IRB approval. At the end of this packet is a letter from Jennifer Schrack, PI of NHATS, should your IRB require explanation as to why we are requesting review.

# National Health and Aging Trends Study (NHATS): RESTRICTED FILE REQUEST FORM

Check all folders that are being requested:
Currently available:
<ul> <li>□ NHATS Geographic Files</li> <li>□ NSOC Geographic Files</li> <li>□ NHATS Restricted Tracker Files</li> <li>□ NHATS 1940 Census Files</li> <li>□ NHATS 1940 Census Geographic Files</li> <li>□ NHATS COVID-19 Geographic File</li> <li>□ NHATS Restricted COVID-19 File</li> </ul>
Other available files (Check if you would like access):  ☐ NSOC Sensitive Files ☐ NHATS Sensitive Files ☐ NHATS Sensitive COVID-19 Files ✓ NHATS Public Use Files
List additional files that you plan to bring into the enclave (their purpose/contents should be described in your research plan). Files must be non-identifiable.
Briefly describe any data that you plan to analyze in conjunction with NHATS or NSOC and what variables you plan to use to link.

This agreement is entered into the	day of	, 20 b	etween the Johns Hopkins University o	on
behalf of the National Health and Aging T	rends Study (NHATS)	and the		
(Receiving Agency) wherein	-	(Inv	estigator) is the researcher responsib	le
for the projects using the NHATS restricte	d use files. This agree	ement is in effect ι	until the investigator notifies NHATS th	at
the project has ended or until 3 years fro	m the date enter on	page 1, whichever	occurs first. A 3-year extension may k	эe
requested.				

Whereas, the Investigator and all other persons having access to NHATS Restricted data under this agreement are bound by the precepts of Receiving Agency's Code of Conduct for Employees and the Privacy Act of 1974 (5 USC 552a), which delineate the standards of conduct for individuals relating to the use of nonpublic information and the sanctions and criminal penalties for the misuse or disclosure of such data, and

#### Whereas,

- 1. The Investigator has a permanent, faculty-level appointment at the Receiving Agency, and the Co- Investigator(s), if any, have faculty-level appointments at the Receiving Agency.
- 2. All Research Staff signing Supplemental Agreement with Research Staff have a formal affiliation with the Receiving Agency and with the research project described in the Research Plan, and will have access to Restricted Data only under the supervision of the Investigator(s). The Supplemental Agreements with Research Staff are incorporated by reference into this Agreement.
- 3. The Receiving Agency has an Institutional Review Board/Human Subjects Review Committee registered with the Department of Health and Human Services (DHHS); and proof of the certification has been provided to NHATS.
- 4. A Restricted Data Protection Plan has been submitted by the investigator and approved by NHATS; the approved Restricted Data Protection Plan is incorporated by reference into this Agreement.
- 5. The Investigator's Research Plan and the Restricted Data Protection Plan approved by NHATS (and the portions of the Research Plan approved by NHATS that deal with respondent confidentiality and data security, if any) have been reviewed and approved by the Receiving Agency's DHHS-registered Institutional Review Board/Human Subjects Review Committee, using the standards and procedures for live human subjects, and a certification of that approval has been provided to NHATS. IRB approval must be at either the Full or Expedited level; access to these data does not qualify as exempt secondary analysis.
- 6. The Investigator is a current recipient, as a Principal Investigator, of research funds from an agency of the United States government, or another NHATS-approved funding source, and a copy of the award letter has been provided to NHATS.

In consideration of the NHATS providing access to an NHATS Restricted Dataset to the Investigator, the co-Investigator(s), the Supplemental Users, and the Receiving Agency agree that:

- 1. "Restricted Data" under this agreement includes both the original Restricted Data files provided by NHATS, and any variables or fields derived from them.
- 2. Restricted Data will be used solely for scientific and public policy statistical research, and not for any administrative or law enforcement purpose.
- 3. Restricted Data will be used to generate only statistical summary information that does not permit the identification of any individual person or family (or facility if applicable) either directly or inferentially.
- 4. Aggregate statistical summaries of the data and analyses (frequency tabulations, magnitude tabulations, means,

variances, regression coefficients, and correlation coefficients) are not considered to be Restricted Data. Such information may be freely published by the Investigator and may be used for ongoing research programs approved under this agreement.

When producing tabulations for distribution, the following guidelines are to be employed:

- Magnitude Data: Ensure that no cells/strata with n < 11 are produced.
- Frequency Data: Apply a marginal threshold of n >= 11 and cell threshold of n >= 11 to all tabulations.
- Protecting against complementary disclosure: Additional cells may be suppressed, i.e., complementary disclosure, to make sure the primary suppressions cannot be derived by subtraction from published marginal totals.
- 5. To cite NHATS as the data source in any publications or research based upon these data. The following citation should be included in any research reports, papers, or publications based on these data:
  - *In text:* "National Health and Aging Trends Study (NHATS) is sponsored by the National Institute on Aging (grant number NIA U01AG32947) and was conducted by the Johns Hopkins University."
  - *In references*: "National Health and Aging Trends Study. Produced and distributed by <u>www.nhats.org</u> with funding from the National Institute on Aging (grant number NIA U01AG32947)."
- 6. Researchers are prohibited from publishing, or distributing in unpublished form, results that identify geographic areas below the level of Census Division. Under certain circumstances restricted data users with access to state-level geographic information may wish to report state-level summary information. In such cases, analysis results must be submitted to NHATS for review and approval. Researchers agree to remove from presentation or publication any results identified by NHATS reviewers that identify geographic areas below the level of Census division.
- 7. No attempt will be made to identify any individual person, family, or facility. If an individual person, family, or facility is inadvertently identified, or a technique for doing so is discovered, the Investigator, Co-Investigator, or Research Staff person who made the identification or discovery will promptly report the identification or discovery to NHATS (email: nhatsdata@westat.com; subject line: Director of NHATS).
- 8. No attempt will be made to link Restricted Data with any other dataset, except as specified in the Research Plan reviewed and approved by NHATS.
- Use of Restricted Data provided by NHATS will be confined to the research described in the IRB-approved Research
  Plan submitted to and approved by NHATS; the approved Research Plan is incorporated by reference into this
  agreement.
- 10. Use of Restricted Data provided by NHATS will be in accordance with the Restricted Data Protection Plan submitted to and approved by NHATS.
- 11. Access to Restricted Data provided by NHATS will be limited **solely** to the Investigator(s) who are signatories to this agreement, and to research staff who are signatories of the Supplemental Agreement with Research Staff.
- 12. The NHATS Restricted Datasets are and remain the sole property of the NHATS and Johns Hopkins University. The Investigator will not disclose them to any third party. The Receiving Agency agrees that in response to any request for Restricted Data under the federal Freedom of Information Act, 5 U.S.C. 552, it will refuse to disclose the Restricted Data on grounds that it is not a Receiving Agency of record subject to disclosure under that Act or is alternatively exempt from disclosure under that Act. Receiving Agency will immediately notify NHATS and Johns Hopkins University of any such requests.

- 13. The Investigator(s) will provide the following:
  - a. Project title, Investigator(s), and current contact information
  - b. Detail of changes or modifications in the research and/or data protection plans
  - c. To provide citations for any publications (and PMCIDs) from these data to NHATS (<a href="mailto:nhatsdata@westat.com">nhatsdata@westat.com</a>; subject line: NHATS citations) upon request
  - d. Proof of current IRB approval for projects using restricted data. Note that only Full or Expedited IRB reviews are acceptable. Projects using restricted data do not qualify for IRB Exemption as secondary data analysis.
  - e. Updated list of authorized users under this agreement. A new Supplemental Agreement with Research Staff must be completed and signed for each new user. List should include access termination dates for those no longer requiring access to the restricted data.
  - f. A description of the location(s) of the restricted data users—including street address, building number and office number(s).
- 14. The Receiving Agency represents that it has in place policies and procedures on scientific integrity and misconduct. The Receiving Agency recognizes that certain violations of this agreement might constitute actions covered by such policies and procedures. If the NHATS notifies the Receiving Organization's office responsible for scientific misconduct that a violation of this agreement has occurred and alleges that the violation constitutes scientific misconduct, the Receiving Organization will handle the allegation according to its policies and procedures applicable to scientific integrity and misconduct.
- 15. The Receiving Agency agrees to allow NHATS to conduct unannounced and unscheduled inspections of the restricted data site(s) to assess compliance with the terms of this Agreement.
- 16. The Representative of the Receiving Agency is a person authorized to enter into contractual agreements on behalf of the Receiving Agency.
- 17. If NHATS determines that this Agreement, or documents required to use the NHATS Restricted Data Repository, have been violated, NHATS may:
  - a. prohibit any of the signatories of this Agreement, and of any Supplemental Agreements with Research Staff, from obtaining access to any NHATS Restricted Data.
  - b. report the violation(s) to the Receiving Agency's office responsible for Code of Conduct on the safeguard of confidential information, and request that sanctions be imposed on the person(s) responsible for the violations.
  - c. report (directly or through the National Institute on Aging) the violation(s) to funding agencies with a recommendation that current funding be terminated, and future funding denied, to the Investigator(s), the Research Staff, and any other person implicated in the violation(s).
  - d. utilize such other remedies as may be available to it under law.
- 18. To the extent permitted by law, to hold harmless and indemnify NHATS, the University of Michigan as the entity responsible for the NHATS Restricted Data Repository, and the Johns Hopkins University, its agents and employees, for any claims of breaches of confidentiality arising out of his/her research, defined as failure to abide by any section of this agreement or any accidental or intentional violation of privacy of any contributor to any NHATS data resource.
- 19. Incorporation by reference
  - a. NHATS Restricted Data Repository MiCDA-Virtual Data Enclave Acceptable Use Policy
  - b. Institute for Social Research University of Michigan Pledge to Safeguard Respondent Confidentiality
  - c. MICDA Enclave Virtual Desktop Infrastructure Data Security Plan

Investigator	Co-Investigator
Signature/Date	Signature/Date
Typed Name	Typed Name
Title	Title
Institution	Institution
Building Address	Building Address
Street Address	Street Address
City, State, Zip	City, State, Zip
Phone	Phone
Fax	Fax
Email	Email
NHATS User Name	NHATS User Name

NOTE: NHATS User names may be obtained by registering at <a href="nhats.org/user/registration">nhats.org/user/registration</a>. For additional co-investigators, reproduce this page. The requesting investigator should sign with each co-investigator.

RECEIVING AGENCY REPRESENTATIVE
Signature/Date
Typed Name
Title
Institution
Building Address
Street Address
Street Address
City, State, Zip
Phone
Fax
Email
NHATS REPRESENTATIVE
Signature Date
Jennifer Schrack, PhD, Principal Investigator
National Health and Aging Trends Study Johns Hopkins University School of Public Health 615 N. Wolfe Street E7144 Baltimore, MD 21205
Phone: 410-502-9328 Email: jschrac1@jhu.edu
JOHNS HOPKINS UNIVERSITY REPRESENTATIVE
Signature Date

## National Health and Aging Trends Study (NHATS): Restricted Data Supplemental Agreement with Research Staff

The undersigned Research Staff, in consideration of their use of Restricted Data from the National Health and Aging Trends Study, agree:

- A. That they have read the associated National Health and Aging Trends Study (NHATS) Restricted Data Use Agreement.
- B. That they are "Research Staff" within the meaning of the NHATS Restricted Data Use Agreement.
- C. To comply fully with the terms of the Agreement.

The Investigator named in the NHATS Restricted Data Agreement agrees that the persons designated herein are Research Staff within the meaning of the associated NHATS Restricted Data Use Agreement.

Investigator agrees to ensure that each Research Staff person signs this Supplemental Agreement.

#### Research Staff

NAME TYPED OR PRINTED	SIGNATURE	DATE
JOB TITLE & INSTITUTION		NHATS User Name
NAME TYPED OR PRINTED	SIGNATURE	DATE
JOB TITLE & INSTITUTION		NHATS User Name
NAME TYPED OR PRINTED	SIGNATURE	DATE
JOB TITLE & INSTITUTION		NHATS User Name
Restricted Data Investigator		
NAME TYPED OR PRINTED	SIGNATURE	DATE

## National Health and Aging Trends Study (NHATS): Restricted Data Use Agreement Extension Request

We request a 3-year extension of the agreement entered in	nto the, 20
between the Johns Hopkins University on behalf of the Na	tional Health and Aging Trends Study (NHATS) and
the	_ (Receiving Agency) wherein
(Investigate	or) is the researcher responsible for the projects
using the NHATS restricted use files.	
Investigator	Co-Investigator
Signature/Date	Signature/Date
Typed Name	Typed Name
Title	Title
Institution	Institution
Building Address	Building Address
Street Address	Street Address
City, State, Zip	City, State, Zip
Phone	Phone
Fax	Fax
Email	Email
NHATS User Name	NHATS User Name

NOTE: NHATS User names may be obtained by registering at <a href="nhats.org/user/registration">nhats.org/user/registration</a>. For additional co-investigators, reproduce this page. The requesting investigator should sign with each co-investigator.

## National Health and Aging Trends Study (NHATS): Restricted Data Use Agreement Extension Request

RECEIVING AGENCY REPRESENTATIVE	
Signature/Date	
Typed Name	
Title	
Institution	
Building Address	
Street Address	
Street Address	
City, State, Zip	
Phone	
Fax	
Email	
NHATS REPRESENTATIVE	
Signature Date	
Jennifer Schrack, PhD, Principal Investigator	
National Health and Aging Trends Study Johns Hopkins University School of Public Health 615 N. Wolfe Street E7144 Baltimore, MD 21205	
Phone: 410-502-9328 Email: jschrac1@jhu.edu	
JOHNS HOPKINS UNIVERSITY REPRESENTATIVE	
Signature Date	

## National Health and Aging Trends Study (NHATS): Restricted Data Supplemental Agreement with New Research Staff

The undersigned Research Staff, in consideration of their use of Restricted Data from the National Health and Aging Trends Study, agree:

- D. That they have read the associated National Health and Aging Trends Study (NHATS) Restricted Data Use Agreement.
- E. That they are "Research Staff" within the meaning of the NHATS Restricted Data Use Agreement.
- F. To comply fully with the terms of the Agreement.

The Investigator named in the NHATS Restricted Data Agreement agrees that the persons designated herein are Research Staff within the meaning of the associated NHATS Restricted Data Use Agreement.

Investigator agrees to ensure that each Research Staff person signs this Supplemental Agreement.

#### Research Staff

NAME TYPED OR PRINTED	SIGNATURE	DATE
JOB TITLE & INSTITUTION		NHATS User Name
NAME TYPED OR PRINTED	SIGNATURE	DATE
JOB TITLE & INSTITUTION		NHATS User Name
Restricted Data Investigator		
NAME TYPED OR PRINTED	SIGNATURE	DATE
NHATS Representative		
Jennifer Schrack		
NAME TYPED OR PRINTED	SIGNATURE	DATE

## National Health and Aging Trends Study (NHATS): Collaborating Investigators at Other Institutions

If applicable, list collaborating investigators at <u>other institutions</u> who will be requesting access to NHATS restricted data for this project. List only one collaborating investigator per institution.

Collaborating Investigator #1	Collaborating Investigator #2		
Name	Name		
Title	Title		
Institution	Institution		
Email	Email		
Collaborating Investigator #3	Collaborating Investigator #4		
Name	Name		
Title			
Title	Title		
nac	Title		
Institution	Title Institution		

<u>Note:</u> Do not list co-investigators or research staff at the collaborating institution here. A separate application must be submitted by the collaborating Investigator at each institution and co-investigators/research staff at those institutions should be listed on the collaborating Investigator's application.

## National Health and Aging Trends Study (NHATS): List of Users Requesting MiCDA Enclave Access

List all users who will require access to the MiCDA Virtual Data Enclave to work on the project. Copy this sheet to add more users. All users must be listed on the NHATS Data Use Agreement either as investigator, co-investigator or research staff.

First Name	Last Name	
Title	Department	<u> </u>
Institution		
#2		
First Name	Last Name	
Title	Department	
Institution		
#3		
First Name	Last Name	
Title	 Department	

Forms to be completed by <u>each</u> user requesting access to the NHATS Restricted Data Repository

# NHATS Restricted Data Repository MiCDA-Virtual Data Enclave Acceptable Use Policy (AUP)

- 1. I understand that I have the primary responsibility to safeguard the information contained in the MiCDA Virtual Data Enclave (VDE) from unauthorized use, disclosure, inadvertent modification, destruction, or denial of service.
- **2.** Access to the VDE is for authorized purposes only. Access to these resources is a revocable privilege and is subject to content monitoring and security testing.
- 3. I will only use equipment approved by the sponsoring project to access the VDE.
- **4.** I will only access the VDE from the location approved by the sponsoring project.
- **5.** I will position my computer screen to prevent unauthorized user from viewing VDE data. I will lock my computer if I step away from it.
- **6.** I will use approved data transfer procedures for uploading or downloading information from any system or storage media. I will not introduce unauthorized software.
- 7. I will not print or reproduce VDE data.
- **8.** If I observe anything on the VDE (or system that I use to access it) which indicates inadequate security, then I will immediately notify my Enclave representative.
- **9.** The following activities are specifically prohibited by any user on the MiCDA VDE:
  - **9.1.** Use of information systems for unlawful or unauthorized activities such as file sharing of media, data, or other content that is protected by Federal or state law, including copyright or other intellectual property statutes.
  - **9.2.** Attempts to strain, test, circumvent, or bypass network or VDE security mechanisms, or to perform network or keystroke monitoring.
  - **9.3.** Disabling or removing security or protective software and other mechanisms and their associated logs from the VDE.
  - **9.4.** Modification of the VDE, software installed therein, use of it in any manner other than its intended purpose, or adding user-configurable or unauthorized software such as, but not limited to, commercial instant messaging, commercial Internet chat, collaborative environments, or peer-to-peer client applications.
  - **9.5.** Installation of software, changing configuration of the VDE, or connecting the VDE to an unauthorized computer.
  - **9.6.** Sharing personal accounts and authenticators (passwords and/or token values) or permitting the use of remote access capabilities to any unauthorized individual.
  - **9.7.** Taking screenshots, pictures, screen-sharing, transcribing or otherwise duplicating images of any Enclave systems or their interfaces. This includes data, whether original or derived, and the results of data analysis.

- 10. I acknowledge and consent to the following conditions when I access the MiCDA VDE:
  - **10.1.** The Survey Research Center (SRC) routinely intercepts and monitors communications on the Enclave for purposes including, but not limited to, penetration testing, communications security monitoring, network operations and defense, and personnel misconduct investigations.
  - **10.2.** SRC may inspect, and if necessary remove, data stored on the VDE.
  - **10.3.** Data stored on the Enclave are not private, are subject to routine monitoring and inspection, and may be disclosed to the sponsoring project, my employer, and any regulating bodies.
  - **10.4.** The VDE includes security measures (e.g., authentication and access controls) to protect the sensitive data stored within--not for my personal benefit or privacy.
- **11.** I will immediately report suspicious system activity or concerns to my VDE representative.

By signing this user agreement, I am acknowled and conditions described above.	lging that I accept and will abide by all the terms
Signature	Date
Printed Name	-

#### **Institute for Social Research University of Michigan**

#### PLEDGE TO SAFEGUARD RESPONDENT CONFIDENTIALITY

I have read the Institute for Social Research Policy on Safeguarding Respondent Confidentiality, and pledge that I will strictly comply with that Policy. Specifically:

I will not reveal the name, address, telephone number, or other identifying information of any respondent (or family member of a respondent or other informant) to any person other than an employee directly connected to the study in which the respondent is participating.

I will not reveal the contents or substance of the responses of any identifiable respondent or informant to any person other than an employee directly connected to the study in which the respondent is participating, except as authorized by the project director or authorized designate.

I will not contact any respondent (or family member, employer, other person connected to a respondent or informant) except as authorized by the project director or authorized designate.

I will not release a dataset (including for unrestricted public use or for other unrestricted uses) except in accordance with authorization, policies and/or procedures established by ISR and the Center with which I am affiliated.

I will take all necessary precautions to avoid unintended disclosure of confidential information, including securing of paper and electronic records, computers, user IDs and passwords.

I agree that compliance with this Pledge and the underlying Policy is: 1) a condition of my employment (if I am an employee of ISR), and/or 2) a condition of continuing collaboration and association with ISR (if I am an affiliate of ISR). I understand that violation of this Policy and Pledge may result in disciplinary action, up to and including termination of employment or severance of any relationship with ISR and the applicable research project.

If I supervise affiliates who have access to ISR respondent data (other than unrestricted public release datasets), I will ensure that those affiliates adhere to the same standards of protection of ISR respondent privacy, anonymity, and confidentiality, as required by this Pledge and the associated Policy.

Signature:		
Typed or printed name:	Date:	
Affiliation:		

## MICDA Enclave Virtual Desktop Infrastructure (VDI) Data Security Plan Complete ONE Form for EACH User and EACH User Location

Work Location: From where we Address (*Office address shown ————————————————————————————————————	will you log in? CHOOSE ON	—	Office*
Workstation Specifications:			
Make/model: ☐ Desktop	□ Lanton		·
Operating System (Please  Windows Ve	e note version #):		
Workstation Login Access: W Yourself: Other(specify	ho can log into your workst ):		
What information is required User name: ☐ Yes ☐ No			
Workstation Monitor Position (check windows and doors):	n: Describe how workstation	is positioned to prever	nt unauthorized viewing
	_	McAfee	lled on workstation:
Other(specify brand/version:			
Data Resource(s) Requested	<b>I</b> :		
✓ NHATS			
Other(specify):			
	lest, fastest, and most cost-effe	ective method for two-fa	wo-Factor Authentication  ctor authentication. If this is not possible,  re costs associated with these methods.
Investigator Name			
User Name	NHATS User Name	User Instituti	ion
User Signature	Date	User Email	
Provide signature of an IT Rep *Required unless it is a personal			ped.
IT Department Contact Name	IT Contact Title	IT Contact Te	elephone
IT Contact Signature	Date	IT Contact En	nail

#### **Memorandum to IRB/Human Subjects Review Committees**

#### **MEMORANDUM**

**TO:** Institutional Review Boards/Human Subjects Review Committees

FROM: Jennifer Schrack , PhD, Principal Investigator, National Health and Aging Trends Study (NHATS)

**RE:** Review of Proposals for Analysis of NHATS Restricted Data

The National Health and Aging Trends Study (NHATS) is an ongoing longitudinal study of Americans ages 65 and older, sponsored by the National Institute on Aging (UO I AG09740). The National Study of Caregiving periodically interviews caregivers of NHATS participants.

NHATS makes available to researchers both public use datasets, available to all researchers, and restricted datasets, available only under agreement to researchers who meet rigorous conditions. Public use datasets contain no identifying information and pose minimal risk of respondent identification. These files are distributed via download from the NHATS website (<a href="www.nhats.org">www.nhats.org</a>); conditions of use require agreement by the user not to attempt to identify study participants. Restricted datasets contain information that NHATS believes increases the potential risk of identification of study participants.

Because of the potential risk of identification of participants, we request that you review portions of proposals to use restricted data from NHATS, and to do so using the same standards you would use for studies of live human subjects. Although researchers using NHATS restricted datasets are conducting "secondary data analysis", the increased potential risk for identification of NHATS study participants (who are, for NHATS, live human subjects) makes inappropriate the usual "exemption" applied to "secondary analysis" of anonymized datasets. We have attempted to minimize these risks by offering data through a secure virtual data enclave at the University of Michigan's Institute for Social Research. Nevertheless, the researcher is still responsible for adhering to a data security plan in order to ensure respondent confidentiality and privacy.

We are not asking that you review the entire National Health and Aging Trends Study. That review has been conducted by the relevant committees at the Johns Hopkins University and the National Institute on Aging, the primary sponsor of NHATS.

If you have any questions about the nature and scope of this request, please contact:

Jennifer Schrack, PhD, Principal Investigator National Health and Aging Trends Study Johns Hopkins University School of Public Health 615 N. Wolfe Street E7144 Baltimore, MD 21205

Phone: 410-502-9328 Email: jschrac1@jhu.edu