Obtaining Sensitive Data From the National Health and Aging Trends Study (NHATS)

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- NHATS Sensitive Data Supplemental Agreement with Research Staff

I. Introduction

NHATS has identified some data fields and data files that require additional protection beyond what is implemented for public use data. Access to these data requires additional information about the researcher requesting the data and agreement to observe restrictions on cell sizes in publications and presentations from these data.

This document describes procedures for researcher access to NHATS Sensitive Data files. These procedures were developed with the aim of ensuring that critical national research on disability trends and trajectories can be undertaken in a way that does not compromise respondent confidentiality.

Each application for access to NHATS Sensitive Data will be reviewed by the NHATS Data Confidentiality Committee for conformance with the requirements outlined in this document. Sensitive Data will only be distributed with the approval of the Committee.

Questions regarding the application process may be sent to: nhatsdata@westat.com. Please use the subject heading: Sensitive Data Question

II. Application Process for Sensitive Data Files

Applicants for NHATS Sensitive Data must be persons with a PhD or other terminal degree (e.g. MD; MPH; Master's degree) who hold a faculty appointment or research position at a university, research institution, or U.S. government agency. Other institutional research settings will be considered upon request.

Students who are pursuing a terminal degree can gain access to NHATS Sensitive Data by having a faculty member in their institution sponsor their request by acting as the requesting Investigator. In these cases, students are identified on the Investigator form and must sign the Supplemental Agreement with Research Staff form. Sensitive data files remain with the sponsoring faculty member once a student is no longer affiliated with the sponsoring faculty member's institution.

The following forms (see Section III. Forms) must be submitted to apply for NHATS Sensitive Data:

- NHATS Sensitive Data Investigator Form
- NHATS Sensitive Data Use Agreement
- NHATS Sensitive Data Supplemental Agreement with Research Staff (if applicable)

Forms should be downloaded, completed and signed, and submitted by email as PDFs to nhatsdata@westat.com. Please use the subject heading: Sensitive Data Application.

Once the application is reviewed and approved, the investigator making the data request will be notified by email and will receive instructions to access and download the files from the NHATS website.

The Sensitive Data Files are only for the use of the approved investigator and supplemental research staff who have signed the Supplemental Agreement with Research Staff. NHATS Sensitive Data files may not be shared or distributed to individuals who have not signed the NHATS Sensitive Data Use Agreement.

III. Currently Available Sensitive Data Files

NHATS Sensitive Data files are:

- Sample Person (SP) Sensitive Demographic Round 1 file, which contains month and year of birth, age in years, race and primary race if more than one race reported, Hispanic subgroup, periods of service as a veteran, types of cancer, month a marriage ended (year is on the public use file), month and year Social Security payments started. These variables are identified on the NHATS Round 1 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).
- Other Person (OP) Sensitive Demographic Round 1 file, which contains month and year of birth of spouse/partner, age in years of spouse/partner, month and year of birth for each household member and child, categorical age over age 90 for social network members. These variables are identified on the NHATS Round 1 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).
- The National Study of Caregiving (NSOC), which may be linked to the NHATS public use files. The NSOC I-III User Guide provides information on the study design, data collection, and contents.

The NSOC Data Release consists of 3 files:

NSOC Round 1 File
NSOC Round 1 Sample Person Tracker File
NSOC Round 1 Other Person Tracker File

- Sample Person (SP) Sensitive Demographic Round 2 file, which contains birth month and year, age in years, month and year of death, age in years at death, month a marriage ended (or spouse/partner died), month and year of birth for a new spouse/partner, age in years of new spouse/partner, month and year of birth for all spouse/partners, age in years of all spouse/partners. These variables are identified on the NHATS Round 2 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).
- Other Person (OP) Sensitive Demographic Round 2 file, which contains month and year of birth of spouse/partners, household members and children and age in years for spouse/partners, household members and children. These variables are identified on the NHATS Round 2 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).
- Sample Person (SP) Sensitive Demographic Round 3 file, which contains birth month and year, age in years, month and year of death, age in years at death, month a marriage ended (or spouse/partner died), month and year of birth for a new spouse/partner, age in years of new spouse/partner, month and year of birth for all spouse/partners, age in years of all spouse/partners. These variables are identified on the NHATS Round 3 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).
- Other Person (OP) Sensitive Demographic Round 3 file, which contains month and year of birth of spouse/partners, household members and children and age in years for spouse/partners, household members and children. These variables are identified on the NHATS Round 3 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).

- Sample Person (SP) Sensitive Demographic Round 4 file, which contains birth month and year, age in years, month and year of death, age in years at death, types of cancer, month a marriage ended (or spouse/partner died), month and year of birth for a new spouse/partner, age in years of new spouse/partner, month and year of birth for all spouse/partners, age in years of all spouse/partners. These variables are identified on the NHATS Round 4 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).
- Other Person (OP) Sensitive Demographic Round 4 file, which contains month and year of birth of spouse/partners, household members and children and age in years for spouse/partners, household members and children. These variables are identified on the NHATS Round 4 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).
- The Round 5 National Study of Caregiving (NSOC), which may be linked to the NHATS public use files. The NSOC I-III User Guide provides information on the study design, data collection, and contents. The NSOC Data Release consists of 3 files:

NSOC Round 5 File

NSOC Round 5 Sample Person Tracker File

NSOC Round 5 Other Person Tracker File

- Sample Person (SP) Sensitive Demographic Round 5 file, which contains month and year of birth, age in years, month and year of death, age in years at death, types of cancer, race and primary race if more than one race reported for sample persons added in Round 5, Hispanic subgroup for sample persons added in Round 5, periods of service as a veteran, month a marriage ended (year is on the public use file), year or age that the sample person came to live in the USA for sample persons added in Round 5, month and year Social Security payments started. These variables are identified on the NHATS Round 5 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).
- Other Person (OP) Sensitive Demographic Round 5 file, which contains month and year of birth of spouse/partner, age in years of spouse/partner, month and year of birth for each household member and child, categorical age over age 90 for social network members. These variables are identified on the NHATS Round 5 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).
- Sample Person (SP) Sensitive Demographic Round 6 file, which contains birth month and year, age in years, month and year of death, age in years at death, types of cancer, month a marriage ended (or spouse/partner died), month and year of birth for a new spouse/partner, age in years of new spouse/partner, month and year of birth for all spouse/partners, age in years of all spouse/partners. These variables are identified on the NHATS Round 6 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).
- Other Person (OP) Sensitive Demographic Round 6 file, which contains month and year of birth of spouse/partners, household members and children and age in years for spouse/partners, household members and children. These variables are identified on the NHATS Round 6 Crosswalk between Instruments and Codebook: Final Release (S in the column for Restricted or Sensitive Variable).

- Sample Person (SP) Sensitive Demographic Round 7 file, which contains birth month and year, age in years, month and year of death, age in years at death, types of cancer, month a marriage ended (or spouse/partner died), month and year of birth for a new spouse/partner, age in years of new spouse/partner, month and year of birth for all spouse/partners, age in years of all spouse/partners. These variables are identified on the NHATS Round 7 Crosswalk between Instruments and Codebook (S in the column for Restricted or Sensitive Variable).
- Other Person (OP) Sensitive Demographic Round 7 file, which contains month and year of birth of spouse/partners, household members and children and age in years for spouse/partners, household members and children. These variables are identified on the NHATS Round 7 Crosswalk between Instruments and Codebook (S in the column for Restricted or Sensitive Variable).
- The NHATS Round 7 Dried Blood Spot (DBS) Based Biomarkers file contains the results of four assays
 that were conducted to foster study of the biologic risk of disability progression. Variables related to
 eligibility and data collection also are included.
- The NHATS Round 7 Polygenic Scores (PGS) files provide polygenic scores (PGSs) for a variety of phenotypes for NHATS respondents who provided dried blood spot-based DNA (DBS).
- The Round 7 National Study of Caregiving (NSOC), which may be linked to the NHATS public use files.
 The NSOC I-III User Guide provides information on the study design, data collection, and contents. The NSOC Data Release consists of 3 data packages:

NSOC Round 7 Cross-Sectional File
NSOC Round 7 Cross-Sectional Sample Person Tracker File
NSOC Round 7 Cross-Sectional Other Person Tracker File

NSOC Round 7 Longitudinal File NSOC Round 7 Longitudinal Sample Person Tracker File NSOC Round 7 Longitudinal Other Person Tracker File

NSOC Round 7 Time Diary File
NSOC Round 7 Time Diary Tracker File

- Sample Person (SP) Sensitive Demographic Round 8 file, which contains birth month and year, age in years, month and year of death, age in years at death, types of cancer, month a marriage ended (or spouse/partner died), month and year of birth for a new spouse/partner, age in years of new spouse/partner, month and year of birth for all spouse/partners, age in years of all spouse/partners. These variables are identified on the NHATS Round 8 Crosswalk between Instruments and Codebook (S in the column for Restricted or Sensitive Variable).
- Other Person (OP) Sensitive Demographic Round 8 file, which contains month and year of birth of spouse/partners, household members and children and age in years for spouse/partners, household members and children. These variables are identified on the NHATS Round 8 Crosswalk between Instruments and Codebook (S in the column for Restricted or Sensitive Variable).

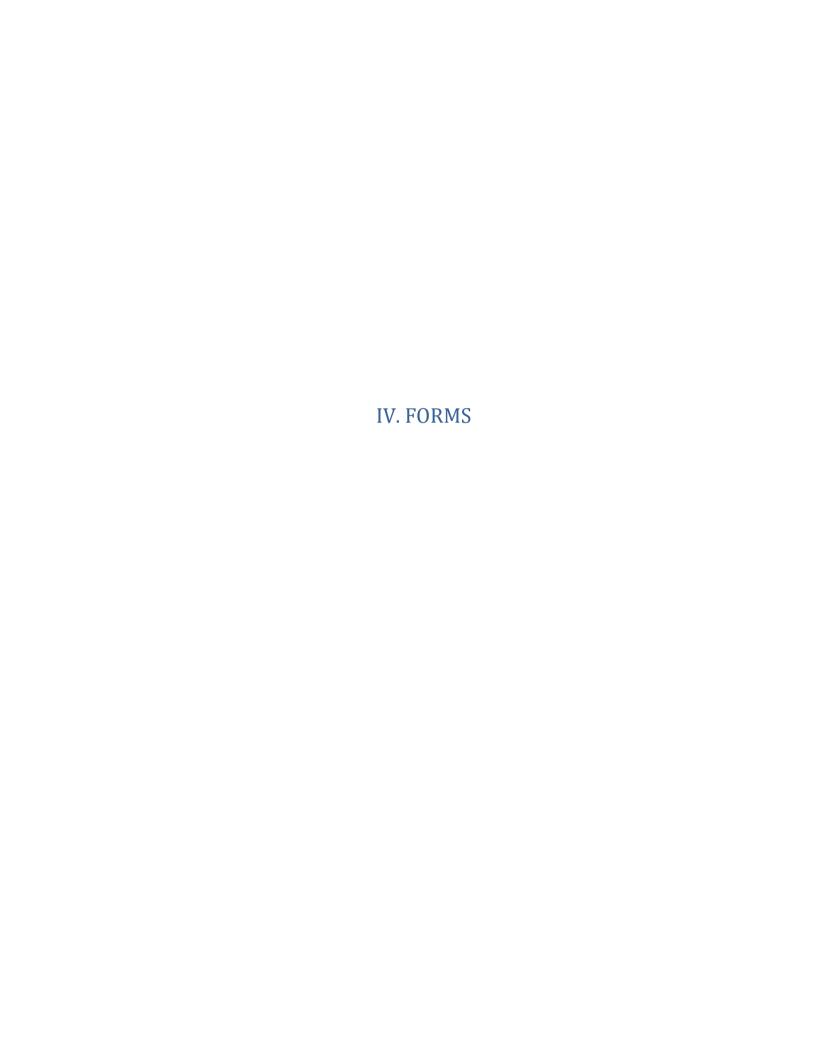
- Sample Person (SP) Sensitive Demographic Round 9 file, which contains birth month and year, age in years, month and year of death, age in years at death, types of cancer, month a marriage ended (or spouse/partner died), month and year of birth for a new spouse/partner, age in years of new spouse/partner, month and year of birth for all spouse/partners, age in years of all spouse/partners. These variables are identified on the NHATS Round 9 Crosswalk between Instruments and Codebook (S in the column for Restricted or Sensitive Variable).
- Other Person (OP) Sensitive Demographic Round 9 file, which contains month and year of birth of spouse/partners, household members and children and age in years for spouse/partners, household members and children. These variables are identified on the NHATS Round 9 Crosswalk between Instruments and Codebook (S in the column for Restricted or Sensitive Variable).
- COVID-19 Family Members and Friends (FF) File includes up to two responses from the two family members or friends who helped the NHATS participant the most during the COVID-19 outbreak.
- Sample Person (SP) Sensitive Demographic Round 10 file, which contains birth month and year, age in years, month and year of death, age in years at death, types of cancer, month a marriage ended (or spouse/partner died), month and year of birth for a new spouse/partner, age in years of new spouse/partner, month and year of birth for all spouse/partners, age in years of all spouse/partners. These variables are identified on the NHATS Round 10 Crosswalk between Instruments and Codebook (S in the column for Restricted or Sensitive Variable).
- Other Person (OP) Sensitive Demographic Round 10 file, which contains month and year of birth of spouse/partners, household members and children and age in years for spouse/partners, household members and children. These variables are identified on the NHATS Round 10 Crosswalk between Instruments and Codebook (S in the column for Restricted or Sensitive Variable).
- Sample Person (SP) Sensitive Demographic Round 11 file, which contains birth month and year, age in years, month and year of death, age in years at death, types of cancer, month a marriage ended (or spouse/partner died), month and year of birth for a new spouse/partner, age in years of new spouse/partner, month and year of birth for all spouse/partners, age in years of all spouse/partners. These variables are identified on the NHATS Round 11 Crosswalk between Instruments and Codebook (S in the column for Restricted or Sensitive Variable).
- Other Person (OP) Sensitive Demographic Round 11 file, which contains month and year of birth of spouse/partners, household members and children and age in years for spouse/partners, household members and children. These variables are identified on the NHATS Round 11 Crosswalk between Instruments and Codebook (S in the column for Restricted or Sensitive Variable).
- The Round 11 National Study of Caregiving (NSOC), which may be linked to the NHATS public use files.
 The NSOC IV User Guide provides information on the study design, data collection, and contents.
 The NSOC Data Release consists of 3 files:

NSOC Round 11 File NSOC Round 11 Sample Person Tracker File

NSOC Round 11 Other Person Tracker File

- Sample Person (SP) Sensitive Demographic Round 12 file, which contains month and year of birth, age
 in years, month and year of death, age in years at death, types of cancer, race and primary race if more
 than one race reported, Hispanic subgroup, periods of service as a veteran, month a marriage ended
 (year is on the public use file), year or age that the sample person came to live in the USA. These
 variables are identified on the NHATS Round 12 Crosswalk between Instruments and Codebook.
- Other Person (OP) Sensitive Demographic Round 12 file, which contains month and year of birth of spouse/partner, age in years of spouse/partner, month and year of birth for each household member and child. These variables are identified on the NHATS Round 12 Crosswalk between Instruments and Codebook (S in the column for Restricted or Sensitive Variable).
- The Round 12 National Study of Caregiving (NSOC), which may be linked to the NHATS public use files. The NSOC IV User Guide provides information on the study design, data collection, and contents. The NSOC Data Release consists of 3 files:

NSOC Round 12 File NSOC Round 12 Sample Person Tracker File NSOC Round 12 Other Person Tracker File



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

nvestigator:
NAME
SIGNATURE
EMAIL ADDRESS
DATE OF SIGNATURE
PHONE CONTACT
☐ Check here if Investigator is applying on behalf of a student pursuing a terminal degree and indicate student name below:
STUDENT'S NAME: STUDENT'S USERNAME:
Candidate for (check one):
Institution where Investigator holds appointment:
NAME
STREET ADDRESS
CITY, STATE , ZIP
LINK to WEBSITE or URL of INSTITUTION

National Health and Aging Trends Study (NHATS): Sensitive Data Use Agreement

Data Set Requested (Check one or more):

NHATS Sample Person Sensitive Files			NHATS	Other Person Sens	itive Demogi	raphic Files	
	Round 1		Round 7 PGS		Round 1		Round 7
	Round 2		Round 7 DBS		Round 2		Round 8
	Round 3		Round 8		Round 3		Round 9
	Round 4		Round 9		Round 4		Round 10
	Round 5		Round 10		Round 5		Round 11
	Round 6		Round 11		Round 6		Round 12
	Round 7		Round 12				
	NHATS Round 10 COVID-	19 Fa	amily Members and Fr	iends File	!		
	NHATS Round 1 National	Stuc	ly of Caregiving (NSOC	() Files			
	NHATS Round 5 National	Stuc	ly of Caregiving (NSOC	() Files			
	NHATS Round 7 National	Stuc	ly of Caregiving (NSOC	Cross-S	ectional Files		
	NHATS Round 7 National	Stuc	ly of Caregiving (NSOC	Cross-S	ectional and Time	Diary Files	
	NHATS Round 7 National	Stud	ly of Caregiving (NSOC	() Longitu	dinal Files		
	NHATS Round 11 Nation	al Stu	idy of Caregiving (NSO	C) Files			
	NHATS Round 12 Nation	al Stu	idy of Caregiving (NSO	C) Files			

By signing this form and obtaining the requested data set(s) from NHATS, the User agrees:

- 1. To use the data set solely for statistical reporting and analysis.
- 2. Not to share these data with, or provide copies of these data to, any other person or organization. Note: <u>Each individual</u> working on the research project, such as a research assistant/associate or graduate or undergraduate student, must sign the Supplemental Agreement with Research Staff form.
- 3. To return or destroy the data set, and any derivative data files, upon request from NHATS.
- 4. To make no attempt to link this data set with individually identifiable records from any source, or in any other way to attempt to identify the persons in this or other NHATS datasets.
- 5. That if the identity of any person in this data set is inadvertently discovered, then (a) no use will be made of this knowledge, (b) the Director of NHATS will be advised of this incident immediately [email nhatsdata@westat.com; subject line: Director of NHATS], (c) the information that would identify any individual will be safeguarded or destroyed, as requested by NHATS, and (d) no one else will be informed of the discovered identity.
- 6. To employ the following guidelines when producing tabulations for distribution:
 - Magnitude Data: Ensure that no cells/strata with n < 5 are produced.
 - Frequency Data: Ensure that no cells or categories with n < 5 are produced.
- 7. Aggregate statistical summaries of the data and analyses (frequency tabulations, magnitude tabulations, means, variances, regression coefficients, and correlation coefficients) are approved under this agreement and may be freely published by the User, subject to the provisions above.
- 8. 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 U01AG032947) 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 U01AG032947)."

- 9. To provide citations for any publications (and PMCIDs) from these data to NHATS (nhatsdata@westat.com; subject line: NHATS citations).
- 10. To the extent permitted by law, to hold harmless and indemnify NHATS 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.

User ID from NHATS data registration at (www.nhats.org):	
Investigator Signature	Title
Name (printed or typed)	Employer/Institutional Affiliation

National Health and Aging Trends Study (NHATS): Sensitive Data Use Agreement

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

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

The Investigator named in the Sensitive Data Use Agreement agrees that the persons designated herein are Research Staff within the meaning of the associated Data Use Agreement for Sensitive Data from the National Health and Aging Trends Study.

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

Research Staff

NAME TYPED OR PRINTED	SIGNATURE	DATE	
User ID			
NAME TYPED OR PRINTED	SIGNATURE	DATE	
User ID			
NAME TYPED OR PRINTED	SIGNATURE	DATE	
User ID			
<u>Investigator</u>			
NAME TYPED OR PRINTED	SIGNATURE	 DATE	