

NHATS DATA COLLECTION PROCEDURES ROUND 7

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Introduction

This document describes data collection procedures in Round 7 of the National Health and Aging Trends Study (NHATS). Section I describes the approach interviewers followed in contacting respondents. Advance materials, contact scripts, and other information related to contacting respondents also are provided. Section II describes aspects of data collection including the use of proxy respondents, definitions of housing structure, home environment checklist, asking reasons activities are done with/by others, and definitions of mobility devices. Administration of the Cognitive and Physical Activities also is described in Section II, as well as the Dried Blood Spot (DBS) collection. The Last Month of Life (LML) interview is described in Section III. Sections IV and V cover administration of the FQ and the financial payment in appreciation of SP participation provided in Round 7.

I. Contacting Approach and Advance Materials

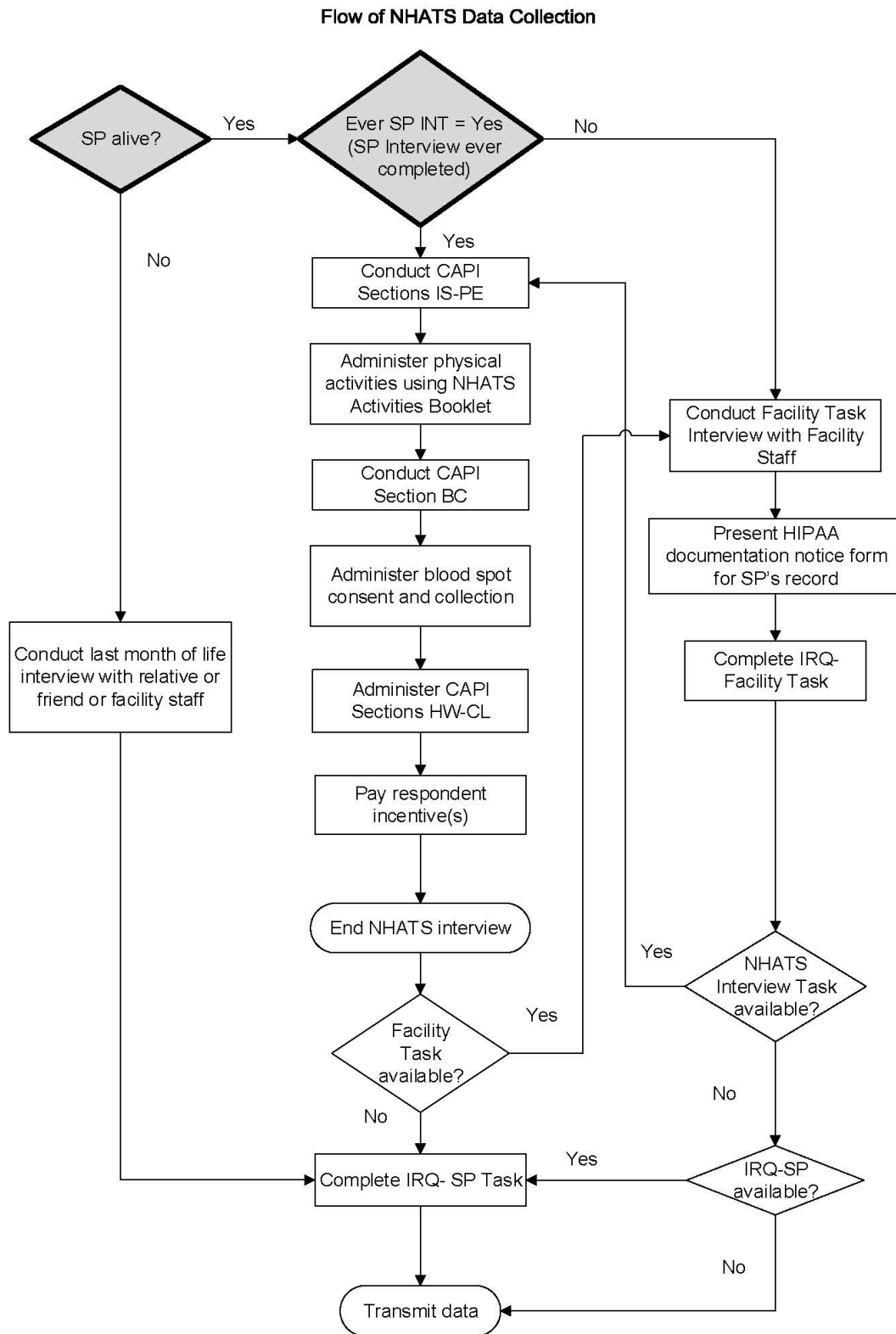
The Round 7 interview type was determined by whether a Sample Person (SP) interview was conducted in Round 6 and whether the SP was alive or deceased:

- SP interviews were conducted for all persons who completed (by self-report or proxy) an interview in Round 6
- Last Month of Life (LML) interviews were conducted with a proxy respondent for deceased SPs

Facility interviews (using the Facility Questionnaire or FQ) were conducted for all persons in residential care or nursing home settings.

The following exhibit shows the path that interviewers followed in administering the SP interview and the FQ interview.

Exhibit I.-1. Flowchart for Round 7 Data Collection



I.A. Advance Materials

In December 2016, respondents were mailed a calendar, along with a letter thanking them for their participation and letting them know they would be called in 2017 for another interview. See Exhibit I.A-1.

Prior to the interview, participants were sent an advance letter (Exhibit I.A-2) letting them know they would be contacted soon and inviting them to call the NHATS toll-free number to set up an appointment at a convenient time for them. The case folder had a generic version of the advance letter interviewers could use in person.

A separate advance letter was sent to some proxies when there is confirmed information that the SP had died since the last interview. This letter was sent to the individual identified as the best respondent for the last month of life interview. See Section III for information about the last month of life interview.

Exhibit I.A-1. Round 7 New Year's letter



National Health &
Aging Trends Study

how daily life changes as we age

Westat
1600 Research Boulevard
Rockville, Maryland 20850

1-888-364-8271

December 16, 2016

{SPFirstName} {SPMiddleName} {SPLastName}
{SPAddress1}
{SPAddress2}
{SPCity}, {SPState} {SPZip}

Dear {SPFirstName} {SPLastName}:

We want to thank you again for continuing to be part of the National Health and Aging Trends Study (NHATS) in 2016. Your participation is so vital to the success of NHATS, and we value your important contribution to the study. The information you provide us each year helps us understand the daily experiences of older Americans. We couldn't do it without you! With your help each year, we are learning more about how to manage the changes that come with age.

Thanks to you and the others like you who joined us for the study this year, it was again a resounding success. NHATS is a crucial source of information that allows us to learn how to improve life for all of us as we get older. We will continue to share what we are learning with you in the coming year.

Beginning in mid-May 2017, a Westat interviewer will call you again to schedule an appointment for the 2017 interview. We can't thank you enough for continuing to give us your time and effort and for working with your interviewer to make this study so successful. We hope you enjoy the enclosed 2017 calendar as a small token of our gratitude.

We wish you a happy and healthy New Year and look forward to seeing you again in 2017.

Sincerely,

Judith D. Kasper, Project Director and Professor
and the staff of the
National Health and Aging Trends Study

Enclosure
{SPID}





National Health &
Aging Trends Study

how daily life changes as we age

Westat
1600 Research Boulevard
Rockville, Maryland 20850

1-888-364-8271

May 2017

Dear NHATS Study Participant:

Thank you again for continuing to be a part of the National Health and Aging Trends Study (NHATS). We are looking forward to seeing you again in the next few months. We truly value your commitment to this important research effort. We have also enclosed a copy of the **NHATS and you** Issue 7.0 newsletter.

Your Westat NHATS interviewer will be contacting you soon about this year's interview and can answer any questions you may have. This year's interview will build on and update information you provided us last year about your health, your family, and your daily activities. We will also ask you to do some simple everyday activities including standing, walking, getting up from a chair, and breathing deeply. You will receive \$20 after taking part in the study in appreciation for your participation.

Please call the NHATS toll-free number at 1-888-364-8271 to schedule a convenient appointment time. If you have moved or would like to speak with someone about the study, please call the NHATS toll-free number. You can also visit our website at www.mynhats.org.

Thank you again for your time and effort in helping to make this study successful. We are looking forward to meeting with you again soon.

Sincerely yours,

Judith D. Kasper, Ph.D., Project Director and Professor
Johns Hopkins Bloomberg School of Public Health

A reminder about your role in NHATS:

- The interview and activities will be about 2 hours or less.
- You are a volunteer. You may choose not to answer any questions or quit at any time.
- If you get tired during the interview, you can ask to take a break or stop at any time.
- You can say that you don't feel safe doing an activity, then you can skip that part of the study.
- There is a low risk that someone who is not part of the study will learn about your answers. To prevent this, we will keep your information private and safe. We will use a unique number code to label your information. Names and addresses will be kept separate from your answers.
- There is no direct benefit from taking part in NHATS. The study is expected to provide important new information about what life is like for older people in the U.S.



I.B. NHATS Study Fact Sheet and Newsletter

The NHATS study fact sheet (Exhibit I.B-1) described the study in a simple question-and-answer format. It included a toll-free telephone number to call for additional information, as well as the NHATS study participant website address.

The *NHATS and you* newsletter, Issue 7.0, April 2017 presented findings using data collected in previous rounds of NHATS. The newsletter was mailed with the advance letter and could be used at the door as an informational handout for all NHATS study participants. The “NHATS & you” newsletters for all rounds are available on the NHATS website.

Exhibit I.B-1. NHATS fact sheet



National Health & Aging Trends Study
how daily life changes as we age



What is this study about?
The National Health and Aging Trends Study (NHATS) is a national study of the ways daily life changes as we age. The study was designed by leading university researchers to help us understand how older people today, and in future generations, can lead fuller, healthier lives.

Who is conducting the study?
NHATS is being conducted by the Johns Hopkins Bloomberg School of Public Health, with data collection by Westat, and support from The National Institute on Aging (NIA), which is part of the National Institutes of Health.

A team of trained data collectors from Westat, a national research company based in Rockville, Maryland, that conducts some of the largest health care surveys in the U.S., is conducting the interviews. All data collectors wear identification badges and use laptop computers to record answers for the study.

Who was selected for this study?
NHATS participants were selected because they were enrolled in Medicare. Because it is impossible to interview all Medicare enrollees, we used scientific sampling procedures to select a representative group of people throughout the country. About 9,000 people participate in this important research study. Each participant's experiences represent thousands of other Medicare beneficiaries.

What is the interview about?
The interview asks about the study participants, their health, their home, how they do everyday activities, how they get around at home and in the community, and about their family. There are also some simple every day activities we will ask the study participant to do. These include standing, getting up from a chair, walking, and breathing deeply. This interview takes about 2 hours or less, but that can vary from person to person.

For study participants who are living in a nursing home or a residential care facility, there is a short 10-minute interview with facility staff about the facility and the services and charges for the NHATS study participant's care. There are also a few questions to confirm some basic information

about the participant including name, birth date, and gender.

For NHATS study participants who are deceased, there is a short 15-minute interview about the study participant's last month of life and care. The best person to answer these questions is someone familiar with the NHATS study participant's daily routine.

Do I have to participate?
No. Participation in this study is voluntary. At any time, you may choose not to be part of the study or choose not to answer any specific questions. Your decision to be part of the study will not affect Medicare, Social Security, or any other benefits you may receive.

Each NHATS participant is important and cannot be replaced. Your participation is vital for the success of the study.

How will the information be kept confidential?
Names and address will be kept separate from answers so no one will know who gave what answers. We follow strict procedures and guidelines to keep the information that identifies study participants private and safe. The data collected will be used for research purposes only.

How will the study results be used?
After the information is collected and compiled, the NHATS data will be available to researchers. The study information will be used to understand trends in health and functioning as we age and the social and economic consequences of health and aging for individuals, families, and society.

What if I have other questions?
If you have questions about this study, please call this toll free number: **1-888-364-8271**
You can learn more about NHATS by visiting the website www.mynhats.org
To learn more about Westat, visit www.westat.com.

Thank you for being part of this important study



This study is sponsored by the National Institute on Aging

I.C. Contacting Respondents

Introductory scripts were developed for interviewers to use in initial contacts in Round 7. The Introductory Contact Script (Exhibit I.C-1) was used for making initial contact for the Round 7 interview. There is also an Introduction contact script (Exhibit I.C-2) to use when contacting the best respondent for the last month of life interview. See Section III for information about the last month of life interview. See Section IV for procedures for contacting facilities and facility staff.

Exhibit I.C-1. NHATS introductory script

National Health and Aging Trends Study

Introduction Contact Script

Hello, my name is _____ from Westat. I'm (calling/here) about the National Health and Aging Trends Study for the National Institute on Aging and the Johns Hopkins Bloomberg School of Public Health.

IF IN PERSON, SHOW ID BADGE.

Are you [SP/PROXY NAME]?

IF R NOT THE SP OR DESIGNATED PROXY, ASK: Is [SP/PROXY NAME] available?

IF [SP/PROXY] IS NOT AVAILABLE ASK: When would be the best time to reach [SP/PROXY NAME]?

NOTE THE RESPONSE AND SAY: I will try to reach (him/her) at that time. Thank you.

IF [SP/PROXY] IS AVAILABLE, SAY: As you may remember, you were interviewed last year about how life changes as we age for NHATS. We recently sent you a letter about the next interview.

IF TELEPHONE, SAY: When would be a good time to schedule an appointment with you?

IF IN-PERSON, SAY: If this is a convenient time, I would like to conduct the interview now.

IF THIS IS NOT A CONVENTIENT TIME, SAY: When would be a good time to schedule an appointment with you?

RECORD DATE AND TIME:

Date: _____ Time: _____

CONFIRM ADDRESS.

REMEMBER TO ADD AN EROC ENTRY.

Exhibit I.C-1. NHATS introductory script (continued)

IF THE SP IS DECEASED, SAY:

I am so sorry to hear that. Please accept my condolences. [SP NAME] participated in the National Health and Aging Trends Study last year.

Who would be the best person to talk to about [SP NAME]? We would like to complete a short follow-up interview (on the phone).

IF CONTACT IS NOT THE BEST PROXY, THEN ASK WHO IS. RECORD INFORMATION BELOW FOR BEST CONTACT.

Name: _____ Phone Number: _____

Relationship to SP: _____

IF CONTACT IS THE BEST PROXY, SAY: **If this is a convenient time, I would like to conduct the interview now. It should only take about 15 minutes.**

IF CONVENIENT TIME, COMPLETE INTERVIEW. OTHERWISE, IF NOT A CONVENIENT TIME, SAY: **When would be a more convenient time for me to call you back? SUGGEST ANOTHER DAY OR TIME.**

SCHEDULE AN APPOINTMENT. RECORD DATE AND TIME AND ADD AN EROC ENTRY.

Date: _____ Time: _____

REMEMBER TO ADD AN EROC ENTRY.

Exhibit I.C-2. NHATS introductory script for the last month of life interview

National Health and Aging Trends Study	
Introduction Contact Script for Last Month of Life Interview	
Hello, my name is _____ from Westat. I'm calling about the National Health and Aging Trends Study for the National Institute on Aging and the Johns Hopkins Bloomberg School of Public Health.	
Are you [PROXY NAME]?	
IF R NOT THE DESIGNATED PROXY, ASK: Is [PROXY NAME] available?	
IF [PROXY] IS NOT AVAILABLE ASK: When would be the best time to reach [PROXY NAME]?	
NOTE THE RESPONSE AND SAY: I will try to reach (him/her) at that time. Thank you.	
IF [PROXY] IS AVAILABLE, SAY: We were sorry to hear that [SP NAME] passed away. Please accept my condolences.	
We recently sent you a letter about the National Health and Aging Trends Study that [SP NAME] took part in last year. We would like to complete a short follow-up interview (on the phone) with you about (his/her) last month of life and the care (he/she) received during that time. The interview will only take about 15 minutes.	
This information will help us understand how older Americans experience care at the end of life.	
IF CONTACT IS THE BEST PROXY, SAY: If this is a convenient time, I would like to conduct the interview now. It should only take about 15 minutes.	
IF CONVENIENT TIME, COMPLETE INTERVIEW. OTHERWISE, IF NOT A CONVENIENT TIME, SAY: When would be a more convenient time for me to call you back? SUGGEST ANOTHER DAY OR TIME.	
RECORD MODE, DATE, AND TIME: <input type="checkbox"/> TELEPHONE <input type="checkbox"/> IN-PERSON	
Date: _____	Time: _____
IF CONTACT IS NOT THE BEST PROXY, THEN ASK WHO IS. RECORD INFORMATION BELOW FOR BEST CONTACT.	
Name: _____ Phone Number: _____	
Relationship to SP: _____	

I.D. Respondent Types

NHATS collected data from different types of respondents.

- **Sample Person (SP).** The SP was the preferred respondent for the study. In some instances, the SP was unable to respond fully because of health or memory problems.
- **Proxy Respondent.** A proxy who was familiar with the SP's health, daily routine, and care was used if the SP could not respond. Preference was given to someone who lived with the SP and was familiar with their daily routine. For some SPs in residential care, a facility staff person could serve as a proxy if no relative was knowledgeable or available. In some instances, the proxy identified as the most knowledgeable person was a relative (e.g., daughter or son) who did not live in the primary sampling unit (PSU.) In such cases, the interviewer interviewed him or her if the proxy visited the area during the field period; otherwise, another proxy was selected (i.e., the second most knowledgeable person or someone from the facility who was familiar with the SP's daily routine). Even if a proxy respondent was used, the interviewer asked if the SP was able to participate in the cognitive and physical activities that are part of the interview.
For SPs who are deceased, the LML interview was conducted with someone who was familiar with the SP's daily routine during his or her last month of life.
- **Assistant.** Sometimes the SP could respond to the interview as long as he or she received some help from another person. Like a proxy, the assistant could be someone who lived in the household. If not, the interviewer arranged an appointment so that he or she, the SP, and the assistant could meet, preferably at the SP's home. An assistant differs from a proxy in that an assistant helps the SP to answer factual questions such as dates, but does not take the place of the SP. By contrast, a proxy can respond for the SP in his or her absence.
- **Facility staff.** If the SP lived in a residential care facility (nursing home or other type of facility), the interviewer completed the FQ with a facility staff person. If the SP is deceased and resided in a facility in Round 1, the LML interview was conducted with a facility staff person. The last month of life interview can be completed on the phone with a facility staff person.

I.E. Final Disposition Codes

Final disposition codes describe the ultimate status of all sample cases. Final codes were assigned by the CAPI or by the Field Supervisor. Table I.E-1 presents the final disposition codes available for a NHATS cases.

Table I.E-1. Final disposition codes

Disposition code	Description	Definition	Set by
60	Complete	CAPI assigns this code once all of the interview tasks have been completed for a case.	CAPI
61	Complete, NH facility	CAPI assigns this code once all of the interview tasks have been completed for a nursing home case.	CAPI
62	Complete SP deceased, Proxy Interview	This code is assigned when the SP is deceased and the SP last month of life interview was completed with a proxy.	CAPI
63	Complete SP, FQ not complete	This code is assigned when the SP interview was completed and the FQ was not completed with a facility staff person.	Field Supervisor
64	Complete FQ, SP not complete	This code is assigned when the FQ is completed but the SP interview was not completed.	Field Supervisor
75	Physically/mentally unable, no proxy	This code is assigned when the SP is unable to participate because of physical or mental health and a caregiver or proxy is not available to complete the interview.	Field Supervisor
76	Too ill, no proxy	This code is assigned when the SP is too ill or infirm and a caregiver or proxy is not available to complete the interview.	Field Supervisor
77	Refusal	This code is assigned when the respondent refuses to participate in the study.	Field Supervisor

78	Language barrier	This code is assigned if the SP or proxy does not speak English.	Field Supervisor
79	Unable to locate	This code is assigned once all tracing efforts to locate the SP have been exhausted, and there is no chance of finding the SP within the field period.	Field Supervisor
80	Unavailable during field period	This code is assigned if the SP is unavailable during the field period.	Field Supervisor
82	Outside of PSU	This code is assigned if the SP resides at least 50 miles outside of the PSU.	Field Supervisor
83	Ineligible	This code is assigned if the SP is ineligible to participate in the study for any reason.	Field Supervisor
85	Refusal–facility	This code is assigned if the facility refuses to participate in the study.	Field Supervisor
86	Final Deceased, no proxy	This code is used if the SP is deceased and no proxy is available to complete the SP (last month of life) interview.	Field Supervisor
87	Refusal–proxy	This code is assigned if the proxy refuses to participate in the study.	Field Supervisor
88	Work stopped	This code is assigned if the case cannot be completed during the field period.	Field Supervisor
89	Other specify	This code is assigned for any other final situation not described above.	Field Supervisor

II. Data Collection Components and Administration

II.A. Proxy Interviews

A proxy should be someone knowledgeable about the SP's health and daily routines. Usually the proxy was a relative (e.g., spouse, son, or daughter). He or she may, however, have been a nonrelative, like a close friend or a caregiver. If the SP lived in a residential care facility (other than a nursing home), a facility staff person could have served as the proxy respondent. (See Section I.D. on Respondent Types for additional information.)

When conducting an interview with a proxy respondent, CAPI displayed text wording for each questionnaire item to refer appropriately to the SP. In addition, one section, CP – Cognition (Proxy), was designed to be asked only of the proxy respondent.

The SP had to be present in the household for the NHATS interview so that an attempt could be made to administer the cognitive and physical activities. There were rare situations when the proxy interview was conducted without the SP being present.

For each interview conducted with a proxy, the interviewer attempted to administer section CG – Cognition (SP). For CG, CAPI displayed questions asking the proxy respondent whether the interviewer could speak with the SP about his or her memory. If the proxy agreed, the section was administered.

The Activities Booklet also included questions for the proxy, as well as the SP, to indicate whether it was safe for the SP to attempt each activity.

The Social Network (SN) and Well-Being (WB) sections were not administered to proxy respondents.

II.B. Housing Structure

If the SP had moved to a different residence since the last interview, question RE8 (Exhibit II.B-1) asked the interviewer to code the physical structure of the SP's current residence. The response to this question was used to determine displays for other questions and the path through the instrument. For example, SPs who live in a multi-unit building were later asked what they call their private space (e.g. an apartment or unit) and how often they left their apartment/unit to go around the building. If the interview was conducted at a place other than

the SP's home, this question was coded based on the physical structure of the place where the SP lives and not where the interview was being conducted. Interviewers were instructed not to choose "other" for nursing homes, assisted living, residential care, or retirement settings. The housing structure was coded based on what the physical structure looked like, not on whether care was provided.

Exhibit II.B-1. Screen shot of CAPI question RE8

Forms Answer Navigate Options Help
NHATS (CTRL-N) BREAK OFF (CTRL-B) Person Roster

99990041 ALMA HOROWITZ LAST INT DATE:

CODE PHYSICAL STRUCTURE OF SP'S RESIDENCE.

IF SP OCCUPIES ONE ROOM OF A FREE-STANDING OR ATTACHED SINGLE HOUSE, SELECT THE CODE THAT DESCRIBES THE OVERALL PHYSICAL STRUCTURE.

☐ 1. FREE-STANDING (DETACHED) SINGLE HOUSE
 ☐ 3. MOBILE HOME OR TRAILER
☐ 2. SINGLE HOUSE BUT ATTACHED TO OTHERS (ROW HOUSE, TOWNHOUSE, DUPLEX, TRIPLEX, OR TRIPLE DECKER)
 ☐ 4. MULTI-UNIT (2+) BUILDING
☐ 91. OTHER (SPECIFY)

RE7	SP LIVING AT INT ADDRESS?	1	YES
RE8	PHYSICAL STRUCTURE OF SP RESIDENCE		
RE8a			
RE9			

10/31/15 Navigate NHATS 9:06:22 AM ENG 99990041 RE8 RE.RE8

Housing structures fall into one of four basic structure types:

- A free-standing (detached) single house;
- A row house, townhouse, duplex, or triplex where the house is joined to another house or building by at least one common wall that goes from the ground to the roof;
- A mobile home or trailer; or
- A multi-unit building with 2 or more housing units such as an apartment building, a condo or cooperative building, or a building.

The following are examples of the four basic housing structure types.



Free-standing
detached single house



Townhouse



Multi-unit building



Mobile home or trailer

II.C. Home Environment Checklist

The Home Environment Checklist is a hard-copy form (Exhibit II.C-1) that was completed by the interviewer. Interviewers recorded observations while standing in front of the SP's home or building. Information from the checklist was transferred to IR15 and IR16. The IR Section also contains some questions about the interior of the SP's home environment that were completed based on interviewer observations inside the SP's home.

Exhibit II.C-1. NHATS home environment checklist

National Health and Aging Trends Study Home Environment Checklist			
<div style="border: 1px solid black; padding: 5px; background-color: #f0f0f0;"> <i>Affix SP ID label</i> </div>	<div style="border: 1px solid black; padding: 5px; background-color: #f0f0f0;"> <i>Affix Interviewer ID label</i> </div>		
EC1. Is SP residing in a nursing home or nursing home unit?			
<input type="checkbox"/> 1 Yes <input type="checkbox"/> 2 No			
EC2. When standing in front of the SP's home/building, and looking around in every direction, how much of the following do you see?			
a. Litter, broken glass, or trash on sidewalks and streets?	<input type="checkbox"/> 1 None	<input type="checkbox"/> 2 A little	<input type="checkbox"/> 3 Some
	<input type="checkbox"/> 4 A lot	<input type="checkbox"/> 5 Could not observe	
b. Graffiti on buildings and walls?	<input type="checkbox"/> 1 None	<input type="checkbox"/> 2 A little	<input type="checkbox"/> 3 Some
	<input type="checkbox"/> 4 A lot	<input type="checkbox"/> 5 Could not observe	
c. Vacant or deserted houses or storefronts?	<input type="checkbox"/> 1 None	<input type="checkbox"/> 2 A little	<input type="checkbox"/> 3 Some
	<input type="checkbox"/> 4 A lot	<input type="checkbox"/> 5 Could not observe	
EC3. Standing in front of the SP's home/building, does it have...			
a. any broken or boarded up windows?	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 7 Could not observe
b. a crumbling foundation or open holes?	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 7 Could not observe
c. missing bricks, siding, or other outside materials?	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 7 Could not observe
d. roof problems (e.g., missing material, sagging, or a hole in roof)?	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 7 Could not observe
e. uneven walking surfaces or broken steps in the area leading to the home/building?	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 7 Could not observe
f. continuous sidewalks in both directions?	<input type="checkbox"/> 1 Yes	<input type="checkbox"/> 2 No	<input type="checkbox"/> 7 Could not observe
EC4. Check one: <input type="checkbox"/> 1 In-person visit <input type="checkbox"/> 2 No in-person visit, telephone only			
EC5. Record Date: <u> </u> / <u> </u> / <u> </u> <div style="display: flex; justify-content: space-around; width: 100%;"> Month Day Year </div>			

II.D. Health and Functioning

The Household Activities (HA) and the Medical Care Activities (MC) sections asked about the following activities:

- Laundry;
- Shopping for groceries or personal items;
- Hot meals;
- Handling money; and
- Keeping track of medications.

If the SP reported that someone else did these activities with or for the SP, CAPI displayed a question about the reason someone else was involved in the activity (Exhibit II.D-1). SPs were asked whether involvement of others was because of a health or functioning reason or some other reason. Interviewers could select one or both reasons.

Exhibit II.D-1. Screen shot of sample health or functioning question

Forms Answer Navigate Options Help
NHATS (CTRL+0) BREAK OFF (CTRL+6) Person Roster

99990041 ALMA HOROWITZ LAST INT DATE:

What is the reason someone else did your laundry with you? Was that because of your health or functioning or some other reason?

SELECT ALL THAT APPLY

1. HEALTH OR FUNCTIONING INCLUDES: AGE, MEMORY, VISION, HEALTH CONDITION/DISEASE NAMES, SURGERY, UNABLE TO DRIVE	2. OTHER REASON INCLUDES: SHARED ACTIVITY, ALWAYS DONE THIS WAY, SOMEONE ELSE WANTED TO DO IT, PAY SOMEONE, DOESN'T LIKE TO DO IT
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HA4 WHY RECEIVED HELP WITH LAUNDRY

154/315 Overwrite NHATS 10:47:44 AM ENG 99990041 HA4 HA.HA[1]

Using information from an NHATS pretest, common responses were shown on the screen so that interviewers could accurately code answers that were not direct responses. For example, an SP may not say directly that he or she could not do an activity or needs help for a health or functioning reason. An SP could say something like the following:

- “I’m just not able to get around much these days.”
- “I don’t see well enough for that.”
- “I don’t drive anymore.”
- “I can’t get up the stairs with my knees.”
- “I get dizzy doing those kinds of things.”

If the SP reported any reason that is health or functioning related, then the response was coded as “HEALTH OR FUNCTIONING.”

Alternatively, these activities may be ones that the SP had never done because someone such as a spouse or partner had always done it, or because the SP didn’t like doing the activity. Examples of responses that indicate reasons that are not related to health or functioning are:

- “My wife always does the cooking, and she’s much better at it than I am.”
- “My wife and I like doing the shopping together.”
- “My husband prefers to take care of the bills. I’ve never liked doing that.”
- “That’s not one of my jobs around the house.”

If the SP reported any reason that is not related to health or function, the response was coded as “OTHER REASON.”

If the SP lived in a residential care facility (other than a nursing home) and reported that the person doing the activity with or for the SP was a staff person or the assistance is a service of the place, the reason is not asked. Cognitive interviewing and pretest experience indicated SPs in these situations said the assistance was provided to residents and had difficulty attributing the reason for help.

II.E. Mobility Devices

SPs were asked about a variety of mobility assistive devices including:

- Canes;
- Walkers or rollators (walkers with wheels or rollers);
- Wheelchairs (power or manual); or
- Travel scooters.

Some SPs used more than one assistive mobility device depending on the environment and the situation. The CAPI questionnaire asked about each type of mobility device and how often the SP uses the device in the home or when outside. Information on device use was used in the wording of later questions and in the walking course activity.

II.F. Income and Assets

An abbreviated Income and Assets (IA) section was administered in Round 7. This section collected information on sources of income but not amounts for each source. Respondents were told to refer to any records or other persons that might be of assistance in answering the questions in the IA section. The final question in the section asked for total income from all sources for the last year (i.e. calendar year 2016).

In response to questions, respondents were allowed to report for themselves alone, jointly with a spouse/partner, or for the spouse/partner alone. For example, a respondent could report receiving Social Security income herself, that her spouse received Veterans Administration payments, and that they jointly owned bonds.

The dollar amount of total income in the last year also could be entered separately for the SP or a spouse/partner, or combined. If a respondent didn't know or refused to answer questions about dollar amounts, show cards were provided that gave ranges and respondents were asked to identify a range that is appropriate. The ranges – for individuals and couples – were developed from analyses of 2010 and 2013 data from the Survey of Consumer Finance.

Total income in dollars was imputed for persons who did not report a dollar amount but did report a range, and for persons who did not report either.

II.G. Cognitive Activities

For each SP, the cognitive activities presented in CG-Cognition (SP) were administered. Each of these activities is designed to measure the SP's memory and cognitive functioning. There were five six of cognitive activities:

- SP's rating of his or her own memory;
- Today's date;
- A set of 10 words to recall;
- A clock drawing activity; and

- Naming the president and vice president of the United States.

Each activity is discussed in the following sections.

II.G.1. Equipment for the Cognitive Activities

Some of the cognitive activities required special equipment to administer the activity.

Equipment items include:

- A digital stopwatch;
- A blank sheet of paper (8 ½ by 11); and
- A special erasable pen.

The digital stopwatch also was used for the physical activities. Each of the cognitive activities presented in the following sections describes whether equipment was used and how to use it.

Table II.G.-1. Cognition activities equipment and use

Equipment item	Use
Digital stopwatch	Used for timing the clock drawing.
Blank sheet of paper	Used by the SP for drawing the clock. Affix an SP ID label to the paper <u>after</u> the SP attempts the drawing.
Erasable pen	Used by the SP for drawing the clock. The pen is equipped with an eraser if the SP wishes to erase any part of the drawing.

II.G.2. Today's Date

One standard way to measure memory that is frequently used is to ask a person to provide today's date. In Section CG, the SP was asked to tell the interviewer that day's date, without looking at a calendar or watch. It was then recorded whether the SP provided the correct month, day, year, and day of the week, as well as if he or she looked at a calendar, watch or other date aid.

II.G.3. 10-Word Recall

The 10-word recall is an activity designed to look at verbal learning and recent memory. There are 3 parts to the 10-word recall activity. First, the SP was read a list of 10 words. Then, the SP was asked to recall as many of the words from the list as possible. After about 5 minutes, the SP was again asked to recall as many of the 10 words as possible.

For the 10-word recall, CAPI displayed one of three lists of 10 words automatically on the screen timed for the interviewer to read each word at a slow and steady rate. The display rate was approximately one word every 2 seconds. The SPs were randomly assigned to one of the 3 word lists.

The SP could not look at the words or write them down as they are read. After the list was read, the SP was asked to recall every word he or she could.

The interviewer indicated the words the SP correctly recalled, as well as the number of words, if any, that the SP provided which were not on the list. If the SP provided the plural version of a word, it was recorded as a correct recall of the word.

II.G.4. Clock Drawing

The clock drawing activity is a tool to measure an individual's ability to plan ahead, numerical knowledge, concept of time, gross motor functioning, concentration, and comprehension. For the clock drawing activity, the SP was given a blank sheet of paper and an erasable pen and asked to draw a clock with the hands placed at 11:10 (10 past 11). The time could be repeated.

The SP was allowed up to 2 minutes to complete the drawing. After the drawing was completed, an SP ID label was affixed on the front of the drawing in the lower left hand corner of the sheet.

If the SP attempted the clock drawing activity but made few or no marks on the paper, the SP was thanked for working on the activity, even if the paper was blank. The option "SP Attempted Clock Drawing" in the CAPI questionnaire was selected following the activity.

Respondents who were blind were not asked to attempt the Clock Drawing activity. When CAPI presented screen CG10 with the instructions for asking the SP to attempt the Clock Drawing activity. The interviewer coded the activity as "SP did not attempt clock drawing."

II.G.5. Naming President and Vice President

The SP was asked to name the current president and vice president of the United States. It was recorded whether the SP provided the correct first name and last name of the president (Donald Trump) and the first and last name of the vice president (Mike "Michael" Pence).

II.H. Physical Activities/Equipment

Based on the answers to the PE section, the interviewer was instructed if, and in some cases how, to administer each physical activity. The Activities Booklet was used to administer each of the physical activities and to record the results.

Before the interviewer administered each activity, he or she demonstrated the activity and then confirmed with the SP (and proxy if a proxy was used) that he or she felt it would be safe to attempt the specific activity. If there were any objections or concerns, the SP was not asked to perform the activity. The result was coded as “Not attempted” and the reason for not attempting the activity was recorded. Ensuring each SP’s safety was paramount.

In addition to the NHATS Activities Booklet, the interviewer used special equipment to administer the physical activities. Some of the equipment is fragile and specially calibrated to collect accurate measurements.

The following are the specialized equipment the interviewer brought to the home visit for the physical activities:

- Digital stopwatch;
- Walking course chain;
- Digital hand dynamometer; and
- Peak air flow meter with cardboard mouthpieces.

II.H.1. Digital Stopwatch

The Oslo silver digital stopwatch was used in both the cognition and physical activities. The stopwatch has three timing modes:

- Split;
- Lap; and
- Countdown.



For this study, only the lap and countdown modes were used. The lap mode counts up from zero and is used for all Balance Stands, the Walking Course, and Repeated Chair Stands. The countdown mode counts down to zero from a preset time limit, and was used for the clock

drawing activity. All timed activities were conducted without stopping the stopwatch, even when repeating directions.

II.H.2. Walking Course Chain

The Walking Course chain is a 5-meter (16-foot) silver ball-chain with end pieces, and links of colored chain at 1 and 4 meters away from the start end of the chain. The chain was used to determine if there was enough space for the walking course, and to designate where on the floor to mark the course's start and finish lines with masking tape.

II.H.3. Digital Hand Dynamometer

A digital hand dynamometer is a fragile, precision instrument used to measure the force (in kilograms) that an individual can exert by squeezing with his or her hand. It is stored between uses in a padded hard plastic black case. Important features include:

Scale Readout Option. Grip strength readings can be displayed in kilograms (KG) or pounds (LB) by changing the small black switch in the battery compartment. For this study, the KG setting is always used.



Adjustable Handle. To accommodate various hand sizes, the grip handle adjusts to five different grip positions. For this study, the handle was almost always in the second position unless the SP had especially large hands. The handle could then be adjusted to the third position.

Hand-Testing Option. The dynamometer has three different hand-testing options available: L (Left hand), R (Right hand), and L R (Left & Right hands). The hand side determined by the PE section and the Activities Booklet was always tested.

II.H.4. Peak Air Flow Meter

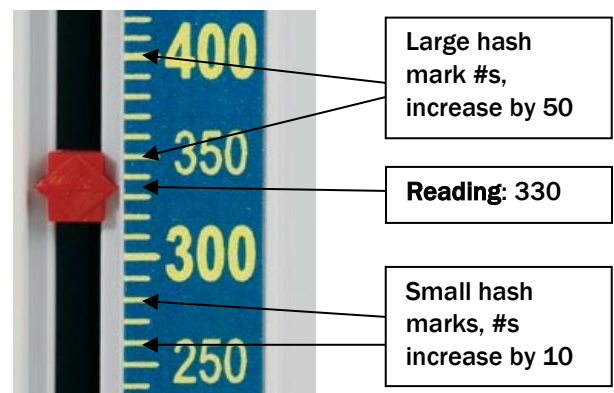
The Peak Air Flow meter measures Peak Expiratory Flow (PEF) rate, the fastest speed a person can blow air out of the lungs after taking as big a breath as possible.

When someone blows into the meter, the sliding marker will move along the scale and record the PEF rate. The meter is stored between uses in a molded clear plastic case to protect the meter and the sliding marker.



When demonstrating the peak air flow activity, the interviewer used his or her own disposable cardboard mouthpiece. For this activity, the SP was given an individually packaged disposable cardboard mouthpiece that was discarded after completing the activity.

The meter scale has readings from 60 to 900 L/MIN (liters per minute). Starting at 100, the printed numbers increase by 50 (150, 200, 250....) and are indicated by large hash marks. The small hash marks between the numbers represent increments of 10 (110, 120, 130....).



An SP's measurement was read by standing next to the SP while he or she was still holding the meter. The interviewer started by finding the large hash-marked number nearest to the marker, but still below it. Then, the interviewer determined how many small hash marks above the number the marker indicated. Finally, the interviewer arrived at the total value by counting up from the marked number by 10's, increasing by 10 for each small hash mark below the sliding marker. If the sliding marker fell between two hash marks, the interviewer rounded down to the next number.

II.H.5. Other Equipment

The following equipment also was used with the physical activities:

- Roll of colored masking tape;
- Flexible measuring tape; and
- A package of antibacterial wipes.

Table II.H.5-1 shows the uses for each of the other physical activities equipment items.

Table II.H.5-1. Other physical activities equipment and use

Equipment item	Activity	Use
Masking tape	Walking Course	To mark the start and end points of the course on the floor
Flexible measuring tape	Chair Stands; Waist Circumference	To obtain the height of the chair used for the chair stands; and waist circumference
Package of antibacterial wipes	Multiple activities	To wipe down equipment that comes in contact with the SP's hands or body

II.I. Administration of Physical Activities

The activities in the NHATS Activities Booklet were presented in a preset administration order with specific scripts provided for each activity.

II.I.1. Setup for Activities

An appropriate, safe place in the SP's residence was selected to conduct the physical activities. The space selected for the activity had to provide sufficient space for the interviewer and the SP so that the SP could perform the activity safely, and the interviewer could position himself or herself to safely support or spot the SP during the activities. The detailed protocol in the Activities Booklet described how to safely administer each activity, including how to support the SP if required.

During the administration of the physical activities, these general safety guidelines were followed:

- The SP (and proxy) was asked to report whether they feel it would be unsafe for the SP to attempt any movement or activity.
- If anyone conveyed uncertainty about trying to perform a task, the interviewer asked "Do you think it would be safe to try this?"
- If the answer was still not clear, the interviewer repeated the question and continued by asking "If you had to say either "Yes" or "No", which would you pick?"

- If the interviewer, the SP, or the proxy, believed the activity could be unsafe, the interviewer recorded the activity as “not attempted” and the reason why it was not attempted.
- If space and chairs were available, the SP could sit between each activity.

II.1.2. Balance Stands

The balance stands measure a person’s ability to hold five different basic standing positions:

- Side-by-side;
- Semi-tandem;
- Full-tandem;
- One leg eyes open; and
- One leg eyes closed.

There were three balance stands that asked the SP to balance with both feet on the ground: side-by-side, semi-tandem, and full-tandem stands. Each of these balance stands had a specific position for the feet:

- Side-by side stand: Inside edges of shoes should be touching at the heels and toes.
- Semi-tandem stand: Inside edge of one foot is touching the big toe of the other.
- Full-tandem stand: Heel of one foot is in front of and touching the toes of the other.

For all balance stands, the interviewer first demonstrated the activity, and then asked if the SP felt it would be safe to try the activity. The SP’s answer to this question was recorded in the appropriate booklet item. If he or she said “No,” the interviewer recorded the result as “Not attempted” and the reason why it was not attempted. If he or she said “Yes,” the interviewer stood slightly behind and next to the SP while lightly holding his or her elbow to help into position. Once the SP had his or her feet correctly aligned, the interviewer asked if the SP was ready.

As soon as the interviewer received acknowledgement, he or she did three actions simultaneously:

- Told the SP to begin;
- Let go of the SP’s elbow and take a half a step back; and

- Began timing.

After 10 seconds for the two-leg stands or 30 seconds for the one-leg stands or when the SP stepped out of position or grabbed the interviewer's arm, the interviewer stopped the stopwatch and recorded the result.

For both one leg stands, the interviewer provided support for the SP until he or she was in position and ready. For the one leg stand with eyes closed, the SP closed his or her eyes first, then lifted his or her leg off the ground. The SP could bend his or her knees and lift his or her legs in any direction, as long as the legs were not touching and the feet were at least a few inches off the ground.

II.I.3. Three Meter Walking Course

In the walking course activity, the SP was asked to walk a short distance (3 meters) at his or her usual pace. A space that was at least 16 feet long and 3 feet wide was needed for this activity. If no such space was available, the result was recorded as "Not attempted" and the reason why as "No appropriate space."

When determining if a space was large enough for the 3-meter, the interviewer used the walking course chain as a guide if it was not obvious. The interviewer then:

- Positioned the chain in the middle of the course area floor, in a straight line, making sure there were no knots or tangles.
- Taped down one end of the chain with a 3- to 5-inch piece of masking tape, positioning the tape just before the end of the chain.
- Pulled the chain tautly so it formed a straight line, and taped down the other end of the chain in the same manner.
- Using an arm's length of masking tape, marked the starting line by feeding the tape underneath one of the portions of black chain. Made sure half of the tape length was on either side of the chain, and then pressed the entire piece onto the floor surface.
- Using another arm's length of masking tape, marked the course finish line by placing the tape on the floor in the same manner, but underneath the other portion of black chain.
- Removed the tape holding the chain to the floor, and picked up the entire chain from the floor.

Once the interviewer had set up the walking course, he or she demonstrated the activity for the SP. The interviewer walked at a normal pace and emphasized the importance of completely crossing the finish line without slowing down. Next, the interviewer used the appropriate questions in the Activities Booklet to guide the administration. Each SP was asked one or more questions to determine if he or she felt safe enough to perform the activity, and if he or she would use a walking aid during it; see Exhibit II.H-1.

A cane or walker or other aid could be used for this physical activity, but if a SP could walk short distances without it, he or she was asked if they felt safe to do so without it. If the SP did not feel it was safe to attempt the activity, even with a walking aid, the interviewer recorded the result as “Not attempted” and the reason why the activity was not attempted.

Exhibit II.I-1. Activities booklet WA3 safety questions

WA3

Mark only one from CAPI

WA3a

Do you think it would be safe to try this?

☐ YES

☐ NO

WA3b

Do you think it would be safe to try this without a cane or walker?

☐ YES

☐ NO

WA3c

You may use a cane or walker if you need to. Do you think it would be safe to try this?

☐ YES

☐ NO

Help SP into position:

- *Stand slightly behind and to the side*
- *Hold stopwatch behind SP's back*
- *Check SP's feet position: both feet on start line*

When I want you to start, I will say "Ready, begin."

YES

NO

Interviewers started at WA3 by reading the marked question.

- If the SP did not use a cane or walker around home, only WA3a was marked. The interviewer asked “Do you think it would be safe to try this?”
- If the SP always used a cane or walker around home, only WA3c was marked. The interviewer asked “You may use a cane or walker if you need to. Do you think it would be safe to try this?”
- If the SP sometimes used a cane or walker around home, WA3b was marked. The interviewer asked “Do you think it would be safe to try this without a cane or walker?” The SP’s response at WA3b determined whether the next safety question at WA3c was asked.

The only time more than one safety question at WA3 was asked was if the SP answered “NO” at WA3b; then WA3c was also asked and the appropriate answer to the safety question at WA3c was checked.

For WA3a and WA3c, if the SP did not feel it was safe to attempt the activity, even with a walking aide, the interviewer followed the booklet directions to record the result in WA5 as “Not attempted” and the reason why.

For WA3a and WA3b, if the SP said that they think it was safe to try, the “broken” green arrows instructed the interviewer to skip the remaining safety questions and help the SP into position for the walking course (see the instruction after WA3 in Exhibit 3-10). For WA3c, if the SP said it was safe to try, the solid green arrow instructed to help the SP into position.

If the SP felt it was safe to try, then the interviewer:

1. Helped the person into position at the starting line, with his or her walking aid if applicable.
2. Once the person had both feet touching the starting line, positioned him or herself slightly behind and to the side, with the stopwatch in his or her right hand.
3. Told the SP to begin after receiving acknowledgement.
4. Started timing as soon as either foot began to move, making sure to walk with the SP in case support was needed.
5. Stopped timing when one of the feet was completely across the finish line.

Reminders to interviewers:

- There should be room for the person to stand before the start line and walk completely past the finish line.
- When looking for an area to lay out the walking course, find the smoothest floor surface possible.
- Avoid high pile carpeting and do not lay the course out over the edge of an area rug, throw rug, or any other irregular surface that could cause the person to trip.
- Clear any obstacles from the activity area, but make sure to ask permission when appropriate.

The interviewer recorded whether a device was used, whether the activity was completed or attempted and if completed, the timing.

II.I.4. Chair Stands

The chair stand activities assess mobility and strength by having the SP stand up from a seated position in a chair one or more times.

Suitable chairs had these features:

- Standard height (no bar stools, hassocks, ottomans, or footrests);
- Stable (no rolling or rocking chairs);
- Minimal padding (no recliners or overstuffed chairs); and
- Preferably a hard straight back and no arms.

SPs who required the use of a wheelchair could use it for this activity, provided they could get up from it unassisted. If no appropriate chair was found, the interviewer followed the booklet instructions to record the result as “Not attempted” and “No appropriate chair.”

The interviewer demonstrated the activity, emphasizing that the SP’s arms should be kept folded across his or her chest. The interviewer then asked the SP if he or she felt comfortable attempting the activity. If the SP did not feel it was safe to attempt the chair stand, the interviewer recorded the result as “Not attempted” and the reason why the activity was not attempted.

If the SP felt it was safe to try the activity, the interviewer ensured the back of the chair was positioned securely against a wall or other stable vertical surface. The interviewer had the SP get in the proper position, and then positioned himself or herself in front of the SP. The interviewer stood close enough to the SP to provide support if he or she had trouble balancing, but far enough away not to crowd him or her.

Once the SP was set up, the interviewer asked if he or she was ready. As soon as the interviewer received acknowledgment, he or she told the SP to stand. If a stand was successfully completed, the interviewer recorded the result, and continued to the repeated chair stands. If the SP could not stand without using his or her arms, the interviewer asked him or her to try again, this time using his or her arms. The result was recorded. The interviewer used the measuring tape to record the height of the chair seat from the floor to the front edge of the seating surface (to the nearest inch) in the Activities Booklet.

Reminders:

- When measuring, plush removable cushions or any excess padding were ignored that would have been completely compressed when the SP sat.
- If a wheelchair was being used, “WHEELCHAIR” was marked in the Activities Booklet.

If the SP successfully completed the single chair stand, he or she was asked to do the repeated chair stands. The interviewer emphasized that the stands should be done as quickly as possible. The interviewer counted out loud (“1, 2, 3, 4, 5”) as each one was completed.

If the SP felt it was safe to try, the interviewer assisted the SP in getting into the proper seated position with arms crossed, and positioned himself or herself in front of the SP with the stopwatch in hand. The interviewer asked if the SP was ready, and as soon as acknowledgement was received, the interviewer told the SP to stand and then began timing. The interviewer counted the number of stands out loud as the SP rose each time, up to five times, and stopped timing when the SP had completely straightened up the fifth time.

Reminders:

- If the SP became tired, short of breath, or stopped before completing five stands, the interviewer asked if he or she felt okay to continue. The interviewer either

continued the activity without stopping timing or stopped and recorded the result as “Attempted”.

- The interviewer stops the activity at any time if he or she observed the SP using his or her arms to aid in standing up, not completing five rises within one minute, or demonstrating any other behavior that causes concern for the SP’s safety.

II.I.5. Grip Strength

The grip strength activity used a digital hand dynamometer to measure the strength of the SP’s grip. The activity was performed with the SP in the sitting position with the dynamometer placed on a stable horizontal surface, which could be a kitchen or dining room table, a desk, arm of a chair, or the SP’S upper leg when no other suitable surface was available.

Setup:

- The interviewer removed the dynamometer from its case and pressed the ON/OFF button until 0.0 appeared on the display.
- The interviewer checked that the correct testing side (as detailed in the Activities Booklet’s Grip Strength Administration box) was selected in the display’s upper left hand corner (“L” for the SP’s left hand, “R” for the SP’s right hand). If not, the interviewer pressed the SELECT TEST button until the correct letter appeared.
- The interviewer checked that the number of trials was set to 1 in the display’s upper left hand corner. If not, the interviewer pressed the TEST button until 1 appeared.
- The interviewer made sure the grip position was set to 2.
- The interviewer wiped the dynamometer handle with an antibacterial cloth to sanitize it.

While seated in a chair, the interviewer held the dynamometer in his or her hand, with its base on the stable surface and the display facing away from him or her. The interviewer demonstrated the activity and proper arm position. The interviewer emphasized that the SP should squeeze as hard as possible even though the metal grip would not move, and that the SP should not begin squeezing until the interviewer said to start. The interviewer asked if the SP felt comfortable attempting the activity. If the SP did not feel it was safe to attempt the activity, the interviewer recorded the result as “Not attempted” and the reason why the activity was not attempted.

If the SP felt it was safe to try the activity, the interviewer did the following:

1. Asked the SP to get into position in the chair and handed him or her the dynamometer.
2. Reset the dynamometer to 0.0.
3. Once the SP was properly positioned, asked if he or she was ready.
4. As soon as the interviewer received acknowledgment, he or she pressed the TEST button as he or she told the SP to begin.
5. Said to the SP “Squeeze, squeeze, squeeze!”
6. When the numbers on the display stopped changing, told the SP to stop and pressed the TEST button again.
7. Recorded result (in kilograms) in the Activities Booklet.
8. If the SP was eligible, repeated steps 1-7 for the second grip strength attempt.

Reminders:

- If no numbers appeared on the display when it was turned on, the interviewer checked that the batteries were connected properly and replaced them if necessary.
- It was important that the SP sat in the correct position for testing, with his or her forearm parallel to the floor, forming an “L” shape.
- If the SP had an exceptionally large hand, the interviewer adjusted the grip position to 3 and marked the position change in the Activities Booklet.
- Only the hand identified in the PE Section for testing was tested. If the selected hand became tired or sore, the interviewer recorded the result on subsequent grip strength test as “Not attempted” and recorded the reason why the activity was not attempted.

II.I.6. Waist Circumference

The interviewer placed the flexible tape measure at the appropriate location on the SP’s abdomen, aligned with his or her navel (belly button). The tape measure was not placed at a lower or higher level, even if this was the location where the SP wore his or her pants. To administer this activity:

1. The interviewer explained and demonstrated the activity to the SP and asked if he or she felt it would be safe to try it. If the SP did not feel it was safe, the interviewer

- recorded the result as “Not attempted” and the reason why the activity was not attempted.
2. If the SP felt it was safe to try the activity, the interviewer handed the measuring tape to the SP and asked the SP to point to his or her navel and then placed the tape measure around his or her waist at the point of the navel. If the SP could not wrap the measuring tape around his or her waist by himself or herself, the interviewer asked the SP to hold one end of the tape at his or her navel while the interviewer walked around to the other end and then handed the measuring tape to the SP.
 3. Once the measuring tape was in place, the interviewer checked that the tape:
 - Was horizontal all the way around the SP’s waist;
 - Was lined up with the SP’s navel;
 - Was snug but not tight;
 - Had the large numbers facing out; and
 - Had the end that starts with 1” overlapping the end with higher numbers.
 4. Once the interviewer had checked the measuring tape, he or she told the SP to take a normal breath and exhale, holding his or her breath at the end of the exhale.
 5. After the SP exhaled, the interviewer recorded the measurement on the tape to the nearest ¼ inch.
 6. The interviewer recorded whether the SP was wearing bulky clothing during the measurement by checking the appropriate box.
 7. The interviewer recorded who conducted the measurement.
 8. The interviewer recorded the result and if the SP had any issues during the activity, such as breathing difficulties; inability to hold his or her breath at end of the exhale; less than full effort given due to illness, pain, or other symptoms or discomforts; less than full effort given for a non-health reason; difficulty or inability to locate the SP’s navel; or something else.

II.I.7. Peak Air Flow

The peak air flow activity assesses lung capacity by asking the SP to blow as hard and as fast as possible into a peak air flow meter. The activity was repeated once, for a total of two attempts, and all SPs were given the opportunity to attempt the peak air flow activity.

The interviewer determined the position in which the SP would perform the activity. The preferred position was standing up, but if the SP had difficulty standing or sitting, the activity

could be done sitting or lying down. Once the position had been determined, the interviewer did the following:

1. Removed the peak air flow meter from its case.
2. Securely attached the disposable mouthpiece.
3. Reset the sliding marker to zero.
4. Demonstrated the activity, emphasizing the importance of taking as deep a breath as possible, and blowing as quickly and hard as possible.
5. Removed the mouthpiece.
6. Asked the SP if he or she felt it would be safe to attempt the activity. If the SP did not feel it was safe, the interviewer recorded the result as “Not attempted” and the reason why the activity was not attempted.
7. If the SP felt it was safe to try the activity, the interviewer wiped the meter with an antibacterial cloth to sanitize it.
8. The interviewer asked the SP to get into position and handed him or her the meter.
9. The interviewer got a plastic bag containing the new disposable mouthpiece, and opened the bag so he or she can reach in and easily remove it from the bag.
10. The interviewer had the SP attach the mouthpiece to the meter securely by fitting it into the slot and then tapping it with his or her palm three times.
11. Once the SP had attached the mouthpiece and positioned the instrument correctly, the interviewer reset the sliding marker to zero (end closest to mouthpiece).
12. The interviewer instructed the SP to take as deep a breath as possible, place the mouthpiece end in his or her mouth and blow as quickly and hard as he or she can.
13. While the SP was still holding the meter, the interviewer recorded the value indicated by the sliding marker in the appropriate space in the booklet.
14. While the SP continued to hold the meter, steps 11-13 were repeated.

Reminders:

- The interviewer made sure that the person holding the meter did not have any fingers obstructing the movement of the sliding marker or the air flow holes.
- The interviewer allowed at least 30 seconds for the SP to rest between each attempt.
- The interviewer reset the sliding marker between attempts.
- The interviewer made sure the SP formed a tight seal between his or her lips and the mouthpiece when blowing into the meter.

- If the SP became fatigued between attempts, he or she could change position from standing to sitting or lying down.
- The interviewer emphasized that the SP should blow as hard and as fast as he or she can.
- If the sliding marker moved from the zero point but read less than 60 L/MIN, the result was recorded as “Attempted.”

II.I.8. Aids

Walking aids could be used only for the walking course activity. Aids could not be used for any of the chair stand or balance stand activities.

II.I.9. Demonstration of Physical Activities

It was very important for the interviewer to demonstrate each physical activity safely and correctly. Experience shows that individuals follow more closely what is done rather than what is said. If the position or the activity was demonstrated incorrectly, it could affect the SP’s ability to fully perform the activity and thus affect the scoring.

If the SP indicated that he or she did not understand the activity, the interviewer demonstrated it again rather than relying on repeated verbal instructions. The demonstration was repeated only once. If the SP still did not understand, the interviewer recorded the result and skipped to the next activity.

The interviewer could remind the person not to begin the movement until the interviewer had demonstrated it. The interviewer could tell the SP it was okay to sit down between each activity if he or she preferred.

II.I.10. Safety Precautions and Prevention of Injuries

For all activities where loss of balance was a possibility (i.e., walking course and tandem stands), the interviewer used the following safety precautions:

- Placed the Activities Booklet on a table or chair during the administration so that his or her hands were free to support the SP and to use the stopwatch.
- Positioned himself or herself slightly to the side and behind the SP.
- Positioned his or her hands near the sides of the SP’s trunk at the hip or waist level, but not touching him/her.
- Was to place both hands on the SP to stabilize him/her if necessary.

- If the SP lost balance, immediately held onto the SP with both hands at the trunk to stabilize him or her.
- If the SP began to fall, the interviewer was instructed not to try to catch him or her. Instead, the interviewer should reach under the SP's shoulders from behind and slowly ease him or her down to the floor.
- The interviewer did not watch the stopwatch continuously during the activities. The interviewer watched the SP and was prepared to stop timing if the SP stepped out of position or grabbed the interviewer's arm. The interviewer glanced at the stopwatch occasionally to see if the position had been held for the appropriate amount of time.
- The interviewer followed the script provided for each physical and cognition activity. The interviewer did not provide any additional encouragement beyond the language provided for the activity. For some SPs, the detailed verbal instructions might have seemed unnecessary. In these instances, the interviewer could say that he or she was going to explain and demonstrate each activity in detail since that is the best way to make sure that everyone does the activity in a similar manner.

The cognition section (CG) of the NHATS interview required the SP to answer questions that required the SP's memory, and SPs had to be able to hear in order to attempt the tasks. If the SP was deaf and a proxy was being used, the interviewer was asked to indicate at question CG1D that questions about memory could not be answered, and specified that the reason was that the SP was unable to hear.

II.J. Person Roster

The person roster was initially during the baseline interview (Round 1 for continuing sample and Round 5 for new sample) and was carried forward or "rolled over" for subsequent interviews. As additions were made to the roster, each person on the person roster was assigned a unique person-level ID. Each time the person roster was displayed, interviewers could select individuals previously added to the roster or add new ones. One row is reserved for the SP and three are reserved for generic roster members, i.e., "Service/Someone from the place SP lives," "Meals on Wheels," and "Restaurants/Takeout".

For existing roster members from the last interview, some information collected about each person roster member was rolled over from the last interview for use in this round of data collection. That information includes, but is not limited to:

- First name;
- Last name;
- Relationship to SP;
- Gender;
- Age; and
- Date of birth (if collected).

For each new person added to the person roster, person-level characteristics were collected such as first name, last name, and relationship of the person to the SP. For some questions, additional information also may be collected, depending on the reason the person was added or selected. CAPI automatically tracked the reason the person was added or selected for specific questions. Once a person is added, he or she could be selected whenever the person roster is displayed.

II.J.1. Relationship Codes

There are 42 relationship codes that were used to specify the relationship of an individual on the NHATS person roster.

1	SP	25	COUSIN
2	SPOUSE/PARTNER	26	STEPDAUGHTER'S SON/DAUGHTER
3	DAUGHTER	27	STEPSON'S SON/DAUGHTER
4	SON	28	DAUGHTER-IN-LAW'S SON/DAUGHTER
5	DAUGHTER-IN-LAW	29	SON-IN-LAW'S SON/DAUGHTER
6	SON-IN-LAW	30	BOARDER/RENTER
7	STEPDAUGHTER	31	PAID AIDE/HOUSEKEEPER/ EMPLOYEE
8	STEPSON	32	ROOMMATE
9	SISTER	33	EX-WIFE/EX-HUSBAND
10	BROTHER	34	BOYFRIEND/GIRLFRIEND
11	SISTER-IN-LAW	35	NEIGHBOR
12	BROTHER-IN-LAW	36	FRIEND
13	MOTHER	37	STAFF PERSON FROM THE PLACE SP LIVES
14	STEPMOTHER	38	CO-WORKER
15	MOTHER-IN-LAW	39	MINISTER, PRIEST, OR OTHER CLERGY
16	FATHER	40	PSYCHIATRIST, PSYCHOLOGIST, COUNSELOR, OR THERAPIST
17	STEPFATHER	91	OTHER RELATIVE
18	FATHER-IN-LAW	92	OTHER NONRELATIVE
19	GRANDDAUGHTER		
20	GRANDSON		
21	NIECE		
22	NEPHEW		
23	AUNT		
24	UNCLE		

In addition, there are three generic person or organization categories that may be displayed on the person roster for selection during the SP interview.

The generic person or organization categories include the following:

- SERVICE/SOMEONE FROM THE PLACE SP LIVES (for SPs living in residential care or a retirement community);
- RESTAURANT/TAKE OUT SERVICES (for questions about meals only); and
- MEALS ON WHEELS (for questions about meals only).

Generally, no person-level characteristics were collected for the generic person or organization categories if they were selected. The names of individual facility staff could be added when the staff person was the proxy respondent or was identified as someone in the SP's social network. If the SP was deceased, a proxy could mention that the SP received help with mobility or self-care tasks from someone in the hospital or hospice or another place where the SP stayed temporarily before he or she died. In this case, interviewers entered on the person roster "Hospital staff," "Hospice staff", etc. rather than a name and chose 92 "Other Nonrelative" as the relationship code.

For most of the relative relationship codes, CAPI automatically computed the gender for the person. If the gender could not be determined by the relationship code, interviewers were prompted to enter it.

II.J.2 Types of Person Roster Members

There are six types of person roster members:

- Proxy respondents;
- Household members;
- Spouse/partners;
- Children including sons, daughters, stepsons, and stepdaughters;
- Social network members;
- Helpers; and
- Persons the SP takes care of.

Each type can only be selected or added in the sections of the CAPI instrument that collect information about these types of members.

Proxy Respondent. If a proxy respondent was used, this person was identified in the Interview Setup (IS) section and entered or selected on the person roster. Other information such as date of birth was collected in IS about the proxy.

Household Members. The SP was always a household member and was automatically identified in CAPI as a household member. There were two sections where household members could be identified: Interview Setup (IS) and Household (HH). If a proxy was identified in IS, interviewers asked if that person lived with the SP. If the proxy was reported in IS to be living with the SP, CAPI automatically assigned the proxy as a household member. The HH section collected information about the SP's spouse or partner and household members.

The HH section updated and collected information about the SP's spouse and household members. If there was a change in the SP's marital status since the last interview (that is the SP had become widowed, separated, or divorced) the appropriate relationship or deceased status was automatically updated for the person identified as spouse/partner from the last interview. If the SP married, re-married, or started living with a partner, the new spouse/partner could be either selected or added to the roster. If a spouse/partner was identified as living in the household in HH11, CAPI automatically assigned the spouse to the person roster as a household member. For SPs in facilities, no other household member information was collected in section HH.

For SPs not in facilities, interviewers asked about the rest of the roster members, besides the SP, proxy, or spouse/partner (if applicable) that were reported as living in the household during the previous interview. Interviewers confirmed whether each member still lived in the household, the reason why they didn't if they no longer lived in the household, and confirmed the spelling of first and last names.

Once all members of the household were confirmed, or if no other members lived in the household, interviewers could add or select from the roster anyone else living in the household. Depending on the relationship of the person to the SP, you may be asked to provide or confirm date of birth, age, and gender in addition to the member's first and last name.

Spouse/partner. The HH section asked questions about the SP's marital status, the SP's spouse/partner, and whether the spouse/partner lived with the SP.

Children. Children could only be selected or added to the person roster in the following sections:

- A proxy in section IS;
- A household member in section HH; or
- A child or stepchild living outside of the household in section CS.

Interviewers confirmed the first and last names and city and state of residence for any children reported in the previous interview and not already confirmed in section IS or HH. Only new stepchildren could be added to the roster in section CS for SPs with a new spouse or partner. For new stepchildren, interviewers collected first and last names, date of birth, age, city and state of residence, level of schooling, marital status, and number of children.

Social Network. Social network members were added in section SN. Up to 5 people could be named as part of the SP's social network. For SPs in residential care, if the Social Network member was a staff person from the place SP lives, interviewers entered the person's name and selected the relationship code 37 SERVICE/SOMEONE FROM THE PLACE SP LIVES.

Helpers. Helpers are individuals who helped the SP with self-care activities like bathing or dressing, or with getting around inside or getting outside. They also could have done household activities, such as laundry or shopping, with or for the SP. They also could assist with medical care activities, managing money, or with transportation needs. Helpers could be selected or added to the person roster in any of these sections:

- Mobility (MO);
- Driving & Transportation (DT);
- Household Activities (HA);
- Self-Care Activities (SC); and
- Medical Care Activities (MC).

The generic roster category "SERVICE/SOMEONE FROM THE PLACE SP LIVES\LIVED" was displayed for SPs who lived in a facility and could be selected if help was provided by any facility staff person(s).

Additional questions about the nature and frequency of help were asked in the HL section about all persons identified as helpers.

Other Types of Persons. If the SP provided care to a person or child, the name and relationship of this person could be selected from the roster or added at PA22. Children who helped SP financially or were helped by SP could be selected from the roster in EW9 and EW13.

II.J.3. Roster Updates and Corrections

There were instances in which interviewers needed to correct or update person roster information that was entered incorrectly during the last interview. Table II.J.3-1 details person roster member types and information that could be added for each type in the different questionnaire sections. Sections HH and CS guided interviewers in updating and confirming previous information for the SP's spouse, household members, and children. The following guidelines are for person roster updates that required special care or could not be readily made in the CAPI program. These updates and corrections were later incorporated into the data files as appropriate.

Changing Existing Data Fields. In fields where information already exists, the CAPI program always positions the cursor at the end of the data field. To change an entry, interviewers had to press the delete or backspace key to update a CAPI field. This included updating existing text to replace it with new information, such as when editing names, birth dates, addresses, or any numeric response.

Relationship Codes. With the exception of some household members, interviewers could not change the relationship code or gender of a roster member from the last interview. This is to help ensure the integrity of the characteristics of the previous roster entries. If interviewers encountered an incorrect code, they entered a comment with the correction at the screen where they first noticed the problem.

Unreported Children. Except for new stepchildren identified as a result of a marital status change or new children reported in the household, interviewers could not add children or stepchildren to the person roster. It was expected that living children and stepchildren were all reported in Round 1. If interviewers found that a child or stepchild was not added to the person roster in Round 1, they added the person to the roster and coded as an "other nonrelative" and added a comment.

Duplicate or Erroneous Entries. If a roster member entry was a duplicate or an error from the last interview, or if interviewers entered an erroneous roster entry and are unable to change or

remove it, interviewers could enter a comment with the correction at the screen where they first noticed the problem.

II.K. Dried Blood Spot Equipment

Dried blood spots (DBS) were collected from study participants (SPs) in Round 7. To collect DBS, the SP's finger was pricked with a sterile lancet. Informed Consent was obtained for the DBS collection. DBS was not collected when a proxy interview was conducted. This section details the various pieces of equipment and supplies used for the dried blood spots collection. These include:

- DBS Job Aid
- DBS Kit (1 per SP)
- Bagged gloves
- Hand warmer
- Sharps container
- Drying case (1 per SP)
- Hand sanitizer
- Scanner
- Pen
- Stopwatch
- Trash bag (1 per SP)
- Extra supplies

Detailed information for each supply item and equipment is provided in the next sections.

II.K.1. DBS Kit

The DBS kit is a pre-assembled set of supplies that was packaged in a large resealable plastic bag. Each DBS kit was labeled with a unique ID number, beginning with an "F" that was scanned into CAPI. This unique ID number was used to associate the DBS specimens with the SP.

All supplies in the DBS kit are **single-use items**. Each DBS kit contained the following items:

Item	Qty per DBS Kit
DBS Card	1
Lancet	1
Safety drape	3
Alcohol prep pad	1
Sterile gauze pad	2
Bandage	1
Warmer cover	1

II.K.2. DBS Card

Each kit contained one DBS card, individually packaged in a plastic bag. DBS cards were used to collect and store the dried blood specimens for the DBS activity. Blood was collected in the circles in the filter paper area of the card.

Each card was labeled with a unique ID number that was scanned into the interviewer's computer.



II.K.3. Lancet

Each kit contained one sterile lancet, which was used to puncture the SP's skin for the blood spot collection.

The lancet could only be used once. Each lancet featured a plastic tab which was twisted to break the device's seal. The device was designed so that it was only activated when it was pressed against the skin. After it had been activated once, the lancet automatically retracted to prevent injury or accidental reuse. To prevent exposure to blood-borne pathogens, the lancet was placed in a sharps container immediately after use.



II.K.4. Safety Drape

Each kit contained three safety drapes. The safety drapes are disposable sheets of sterile material that are lined with plastic so that liquids cannot pass through. One safety drape was placed on the table and



used as a work area during the DBS administration. One was placed on the SP's lap and one on the interviewer's lap to protect clothing. The lining runs between both sides of the safety drape so either side could be face-up during administration.

II.K.5. Alcohol Prep Pad

Each kit contained one alcohol prep pad. The alcohol prep pad was used to sterilize the collection site on the SP's finger prior to pricking. The alcohol pad is a single-use item.



II.K.6. Sterile Gauze Pads

Each kit contained two sterile, individually packaged gauze pads. One gauze pad was used to wipe away the first drop of blood from the SP's finger. The second pad was used to apply pressure to the puncture site on the finger after blood collection.



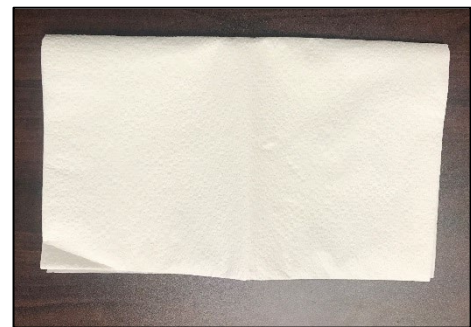
II.K.7. Bandage

Each kit contained one adhesive bandage. The bandage was applied to the SP's finger after the collection.



II.K.8. Warmer Cover

Each kit contained one large non-sterile warmer cover. The hand warmer was wrapped in the disposable warmer cover to prevent the fabric on the warmer cover from coming into direct contact with the SP's skin.



II.K.9. Scanner

The scanner was used to scan the bar code IDs on the DBS kit and the DBS card. The scanner was placed so the scanning window faced down on a flat surface and was then plugged into the USB port on the laptop as instructed. The bar code was centered between 2 and 9 inches in front of the scanner, so that the aiming pattern cross hairs were on the bar code. Interviewers then held the trigger until the scanner beeped, indicating the bar code was successfully decoded. When the scanner was on but not in use, interviewers placed it so the scanning window was face down on a flat surface. This prevented the scanner laser from projecting into someone's eyes or onto other surfaces.



II.K.10. Hand Sanitizer

The alcohol-based hand sanitizer was used to clean the interviewer's hands and the SP's hands before and after the DBS collection.

II.K.11. Gloves

The disposable nitrile gloves come packed with 10 pairs per bag. Gloves were worn during the DBS administration to protect against blood borne pathogens and to maintain the quality of the specimen collected. A new pair of gloves was used when administering the DBS collection for each SP. A new pair of gloves also was used when preparing DBS cards for shipment back to the Westat home office. Gloves were removed using proper glove removal procedures and discarded after using with the other disposable supplies.

II.K.12. Hand Warmer

The hand warmer was used to promote blood flow in the SP's hands prior to the blood collection. During administration the disposable hand warmer cover included in the DBS kit kept the fabric on the hand warmer from coming into direct contact with the SP's skin.



II.K.13. Sharps Container

A leak-proof sharps container was used to dispose of and store used lancets from administrations. The container came with an absorbent pad inside. The sharps container could hold about 75 used lancets. If the container was two-thirds full, i.e., the contents were approaching the fill line marked on the outside of the container, the interviewer requested a new container. The sharps container was shipped to a designated disposal site.



II.K.14. Drying Cases

Four drying cases were used to store the DBS cards after collection and until cards were shipped to the Westat home office. DBS cards were stored individually in the drying case after collection with the card flaps and drying case flaps open to allow the specimens to properly dry. Before leaving the SP's home, the interviewer closed the drying case and placed it in the DBS kit bag. Drying cases were wiped with an alcohol prep pad after the DBS cards were shipped and were reused for subsequent DBS collections.



II.L. Administration of the Dried Blood Spots Activity


Administration of the DBS activity was guided by the BC section of the CAPI instrument and the NHATS DBS Job Aid (Exhibit II.L-1) and followed the physical activities administration. DBS collection took approximately 10 minutes to complete.


Exhibit II.L-1. NHATS DBS Job Aid

NHATS Dried Blood Spot (DBS) Job Aid


ORGANIZE SUPPLIES

▪ DBS Kit	▪ Scanner
▪ Bagged gloves	▪ Pen
▪ Sharps container	▪ Stopwatch
▪ Drying case	▪ Trash bag
▪ Hand sanitizer	▪ Extra supplies
▪ Hand warmer	▪ SPID label




- 


1. GET OUT HAND WARMER
I'll warm up your hand to aid in the collection. Please let me know which hand you prefer we use for this activity.

 - **PLUG IN WARMER AND SET ON HIGH** and place on folded warmer cover
 - **ADJUST SEATING POSITIONS**
- 


2. USE HAND SANITIZER
Now we're going to clean our hands with sanitizer. Please follow along with me.


 - **APPLY HAND SANITIZER** to your hands and SP's hands.
Rub this into your hands and then shake below your waist to dry them.
 - **DEMONSTRATE** rubbing hands with sanitizer and shaking below waist to dry.
- 

3. WARM SP'S HAND
I'd like to begin warming up your hand.

 - **PLACE SAFETY DRAPE OVER SP'S LAP**
 - **WRAP WARMER IN WARMER COVER**
 - **HAVE SP PLACE HAND WITH WARMER IN LAP WITH PALM FACE DOWN**
 - **START STOPWATCH**
- 

4. OPEN SAFETY DRAPE AND PLACE ON TABLE
PLACE AND ORGANIZE SUPPLIES ON THE SAFETY DRAPE:










 - 2 gauze pads
 - Lancet
 - Alcohol prep pad
 - DBS card (place empty bag back into kit bag)
 - Bandage
 - Open sharps container
- 

5. WRITE DATE AND NHATS ID ON DBS CARD
Now I'm going to scan the collection kit ID into my computer, then we'll get started.
- 

6. RETURN TO CAPI – follow instructions to scan kit ID and DBS card ID

Version 7.6 – 03/27/2017

Exhibit II.L-1. NHATS DBS Job Aid (continued)

	7. GET INTO POSITION AND PUT ON GLOVES
	8. OPEN COLLECTION SUPPLIES: 2 gauze pads, bandage, alcohol prep pad
	9. AFTER 5 MINUTES REMOVE HAND WARMER <i>Would you prefer to use your middle or ring finger for this activity?</i>
	10. CLEAN SP'S FINGER with alcohol prep pad – then OPEN DBS CARD FLAP <ul style="list-style-type: none">▪ PLACE SAFETY DRAPE, DBS CARD, AND 1 GAUZE PAD ON YOUR LAP▪ POSITION SP'S HAND OVER SAFETY DRAPE ON LAP
	11. POSITION LANCET ON SIDE OF THE PAD OF THE SELECTED FINGER CLOSEST TO PINKY Place the lancet perpendicular to the SP's fingerprint on fleshy part of the finger <i>I'm going to press down and you will feel a pinch.</i>
	12. FIRMLY PRICK THE FINGER
	13. IMMEDIATELY PUT LANCET INTO SHARPS CONTAINER
	14. USE GAUZE TO WIPE AWAY FIRST FULL BLOOD DROP
	15. COLLECT 5 DROPS ON DBS CARD - starting with leftmost circle
	16. PLACE NEW GAUZE ON FINGER - ask SP to hold gauze with fingers pointed toward ceiling for about 30 seconds or until bleeding has mostly stopped
	17. APPLY BANDAGE TO COLLECTION SITE
	18. PLACE THE DBS CARD IN EMPTY DRYING CASE ON A FLAT SURFACE Leave card flap and drying case flap open to dry for remainder of interview
	19. CLEAN UP COLLECTION MATERIALS <ul style="list-style-type: none">▪ Place all non-sharps trash in safety drape, roll up, and place in trash bag▪ Remove gloves according to procedures and place in trash bag
	20. USE HAND SANITIZER
	21. PACK UP all DBS equipment and supplies except for drying case with DBS card <ul style="list-style-type: none">▪ Turn off stop watch and hand warmer
	22. RETURN TO CAPI AND RECORD RESULTS
	23. At end of interview, place an SPID label on the kit bag, snap close drying case with DBS card, place drying case back in DBS Kit bag, and pack in DBS equipment bag

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II.L.1. Obtaining Consent from SP

Before conducting the DBS activity, signed consent was obtained from the SP.

Question BC1 displayed the text that was read to the SP to introduce the DBS activity.

Exhibit II.L.1-1. Screen shot of CAPI question BC1

The screenshot displays a CAPI (Computer Assisted Personal Interview) interface. At the top, there is a menu bar with options: Forms, Answer, Navigate, Options, Help, and Show Watch Window. Below this, a status bar shows 'NHATS (CTRL-N) | BREAK OFF (CTRL-B) | Person Roster'. The main content area is yellow and contains the following text:

99990001 GENE WILLIAMS LAST INT DATE: June 2, 2016

This year we are collecting blood spots from participants to get other markers of health. This will help researchers better understand health and functioning of older people.

I'd like to collect just a few drops of blood by pricking your finger. This procedure is simple and quick. Like the rest of the study, this part is also voluntary. As a token of appreciation, we are offering an additional \$50 if you agree to the blood spot study.

Before we begin, please read and sign this consent form. Let me know if you have any questions.

REVIEW CONSENT FORM AND SIGNATURE PAGE WITH SP. ANSWER ANY QUESTIONS.

PRESS 1 AND ENTER TO CONTINUE


Below the yellow area, there is a list of questions on the left and a corresponding input field on the right:

Question ID	Question Text	Input
BC1	CONSENT FORM REVIEW	1
BC2	CONSENT TO COLLECT BLOOD SPOTS	
BC3		
BC4PRE		
BC4		

After reading the introduction text, the consent form and signature page were reviewed with the SP. The consent form is a 4-page document with the signature page printed in duplicate (see Exhibit II.L.1-2).

The SP signed and dated the form and indicated “YES” or “NO” for **both** statements about future research use of stored blood spots.

Exhibit II.L.1-1. NHATS DBS Informed Consent Form

	Approval Date: December 8, 2016 Approved Consent Version No.: 2 PI Name: Judith Kasper IRB No. 00002083
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JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH

**INFORMED CONSENT DOCUMENT FOR
BLOOD SPOT DATA COLLECTION IN THE
NATIONAL HEALTH AND AGING TRENDS STUDY**

Study Title: National Health and Aging Trends Study – Blood Spot Collection

Principal Investigator: Judith Kasper, Ph.D.

IRB No.: #2083

PI Version Date: December 1, 2016

What you should know about this study

- You are being asked to join the blood spot study because you are in the National Health and Aging Trends Study.
- This consent form explains the research study and your part in the study.
- Please read it carefully and take as much time as you need.
- You are a volunteer. You can choose not to be in the blood spot study. You will still be in the National Health and Aging Trends Study if you do not participate in the blood spot study.

Purpose of research project

The purpose of this study is to collect blood spots to get other markers of health and functioning of older people. We will do several tests on the blood spots we collect. These tests will provide measures of how well glucose levels are controlled (hemoglobin A1C) and markers of inflammation (levels of IL-6, C-reactive protein, and CMV). Research has shown these are related to health outcomes, but tests based on blood spots like we are collecting are not used in medical treatment at this time.


We also will store some blood spots for future research on health and functioning of older people. We will ask you separately about storing some blood spots for this purpose.

Procedures

We will be pricking your finger to collect a few drops of blood. We will first warm your hand and then prick your finger with a sterile instrument. We will collect the drops of blood on a small card. The card will not have your name or other personal information on it. It will take about 5 to 10 minutes to complete the blood spot collection.

Some blood spots will be used to do the blood glucose and inflammation tests at a laboratory at the University of Washington in Seattle, Washington. Any remaining blood spots on the card will be stored for future research.

Exhibit II.L.1-1. NHATS DBS Informed Consent Form (continued)

	Approval Date: December 8, 2016 Approved Consent Version No.: 2 PI Name: Judith Kasper IRB No. 00002083
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Future Research Use of Stored Blood Spots

The blood spots that are stored for future research will be used to learn about health, aging, and disability. We will keep the blood spots indefinitely. If at any time you want to have your blood spots removed from storage, you can send a written request to the principal investigator listed at the end of this consent form asking that your blood spots be removed from storage and destroyed. We will not be able to get back test results that have already been shared for research.

Future research on your stored blood spots may include genetic research. Genetic information about you and other participants in the blood spot study may be sent to the National Institutes of Health (NIH) Genome-Wide Association Studies (GWAS) repository. All data sent to the NIH repository is coded and de-identified to protect confidentiality. The National Institutes of Health GWAS repository stores genetic information from many studies and shares that information with researchers who are approved by the National Institutes of Health. The researchers who receive data must promise to keep the data confidential and to use it only for the research purposes approved by NIH.

Risks/discomforts

The risks from taking part in the blood spot study are low. Pricking your finger may be briefly uncomfortable.

All test results done from the blood spots being collected will be kept private and safe like the rest of the data collected in the National Health and Aging Trends Study. We use a unique number code to label your information, and your name and address are kept separate from the number code. We will store the blood spot test results in a secure computer database in a secure facility. The blood spots that are stored for future research will have a unique number code but will have no other personal information.

Benefits

There is no direct benefit to you for taking part in the blood spot study. The blood spot collection provides new information that may help researchers understand changes in health and functioning in older people.


Payment

You will receive \$50 for taking part in the blood spot study.

Who do I call if I have questions, problems, or wish to cancel my consent?

- Call the principal investigator, Dr. Judith Kasper, toll-free at 1-888-364-8271 if you have questions or problems as a result of being in this study. To cancel your consent, write to:

Exhibit II.L.1-1. NHATS DBS Informed Consent Form (continued)


	Approval Date: December 8, 2016 Approved Consent Version No.: 2 PI Name: Judith Kasper IRB No. 00002083
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Dr. Judith Kasper
Department of Health Policy and Management
Johns Hopkins Bloomberg School of Public Health
Room 641, 624 N. Broadway
Baltimore, MD 21205

- Call or contact the Johns Hopkins Bloomberg School of Public Health IRB Office if you have questions about your rights as a study participant. Contact the IRB if you feel you have not been treated fairly or if you have other concerns. The IRB contact information is:

Address: IRB Office
Johns Hopkins Bloomberg School of Public Health
615 N. Wolfe Street, Suite E1100
Baltimore, MD 21205
Telephone: 410-955-3193
Toll Free: 1-888-262-3242
Fax: 410-502-0584
E-mail: JHSPH.irboffice@jhu.edu

Exhibit II.L.1-1. NHATS DBS Informed Consent Form (continued)

	Approval Date: December 8, 2016 Approved Consent Version No.: 2 PI Name: Judith Kasper IRB No. 00002083
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Choice for Future Research Use of Stored Blood Spots

Please mark an X in the YES or NO box for both statements about future research use.

☐ YES ☐ NO My blood spots may be stored and used for future research to learn about health, aging, and disability.

☐ YES ☐ NO My blood spots may be used for genetic research to learn about health, aging, and disability.

What does your signature on this consent form mean?

Your signature on this form means:

- You have been informed about this study's purpose, procedures, possible benefits, and risks.
- You have been given the chance to ask questions before you sign.
- You have voluntarily agreed to be in this study.
- You have indicated whether your stored blood spots may be used for future research.

Print Study Participant Name Study Participant Signature Date

Print Interviewer Name Interviewer Signature Date

SP ID

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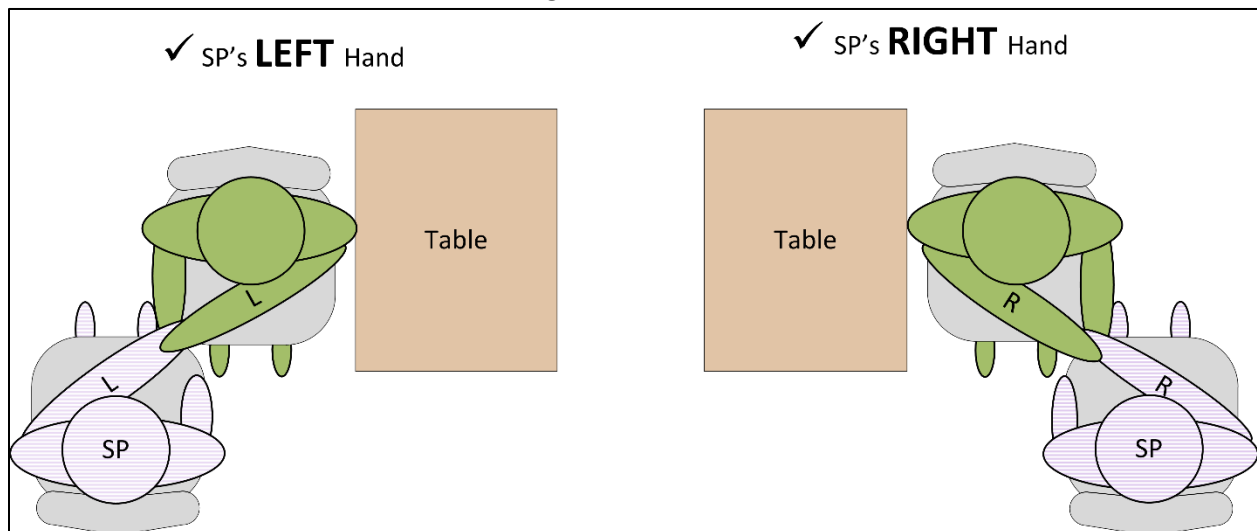
Give yellow copy to the participant and keep white original copy in study records

II.L.2. Preparing for DBS Administration

Determine the collection location in the SP's home. The best place for the DBS collection was at a table with two chairs and a nearby power outlet to plug in the hand warmer. It was best to have a table space about 2' x 3' to use as a work area.

After the SP said which hand was preferred, the interviewer sat diagonally from the SP, as shown in the diagrams in Exhibit II.L.2-1. The palm of the SP's selected hand was positioned so that it faced the interviewer as if he or she were to reach straight forward. This position provided a good view of the SP's hand during collection and allowed the SP's hand to remain in his or her lap (or the interviewer's lap), which helped the blood flow with, rather than against, gravity.

Exhibit II.L.2-1. DBS Administration Positioning Guidelines



1. **Get out the hand warmer and warmer cover. Plug in the warmer and set on high.** The warmer was placed on top of the warmer cover. The interviewer read the DBS Job Aid text "I'll warm up your hand to aid in the collection. Please let me know which hand you prefer we use for this activity."

Interviewers avoided using hands and fingers with any of the following conditions:

- Callouses at the administration location
- An open sore, wound, gauze dressing, or rash
- A cast, shunt (a semi-permanent draining tube), or splint

- Swollen, withered, or paralyzed
 - Below an intravenous catheter (IV) or other attached medical device
2. **Apply hand sanitizer to interviewer and SP's hands to clean them.** The interviewer told the SP "Now we're going to clean our hands with sanitizer. Please follow along with me."

The interviewer rubbed their entire hands, including palms, the tops of hands, and in between fingers and shook their hands vigorously below the waist to dry them. The SP followed. This process served two purposes: to clean the SP's hands for collection and to increase the blood flow to the SP's hands to aid in the collection.

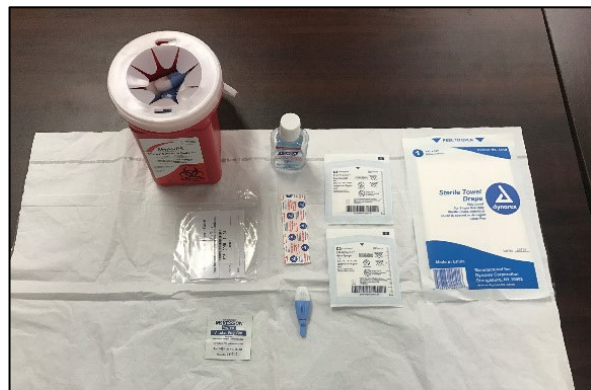
3. **Warm SP's hand.** The interviewer removed one safety drape from its packaging, unfolded it, and placed it on the SP's lap. The warmer cover was wrapped around the warmer. The interviewer wrapped the SP's hand in the warmer palm face down in his/her lap and tuck the cord under the warmer and had the SP place his or her other hand on top of the warmer.

At this point, the interviewer started the stopwatch. It was important to warm the SP's hand for approximately 5 minutes to aid in the collection.

4. **Remove one safety drape from its packaging, unfold it, and place it on the table in front of the SP.** The drape does not have a designated top or bottom, so either side could be placed face-up. It could also be partially refolded as needed.

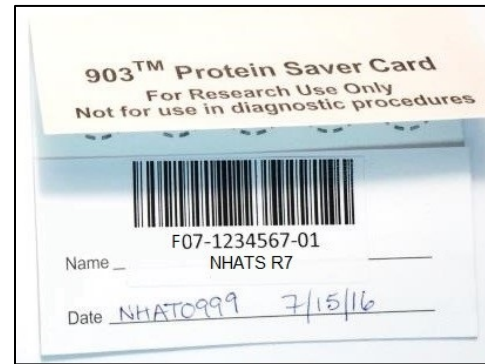
Take out the supplies from the DBS kit bag and lay them on the safety drape. While the SP's hand was being warmed, the interviewer removed the following supplies from the kit and placed them on the table. The interviewer did not open any of the sterile materials from their outer wrappings yet.

- Two gauze pads
- Alcohol prep pad
- Bandage
- Lancet
- One DBS card in bag
- One safety drape



The interviewer also opened the sharps container before putting on gloves.

5. **Write the date and interviewer NHATS ID on the DBS card.** The interviewer took the DBS card out of the bag and placed it on the drape. He or she placed the empty bag back into the kit bag for reuse when shipping the card back to the Westat home office. The interviewer wrote the date and interviewer NHATS ID in the Date field on the bottom line of the card. The card flap remained folded down to ensure that the collection area was not touched.



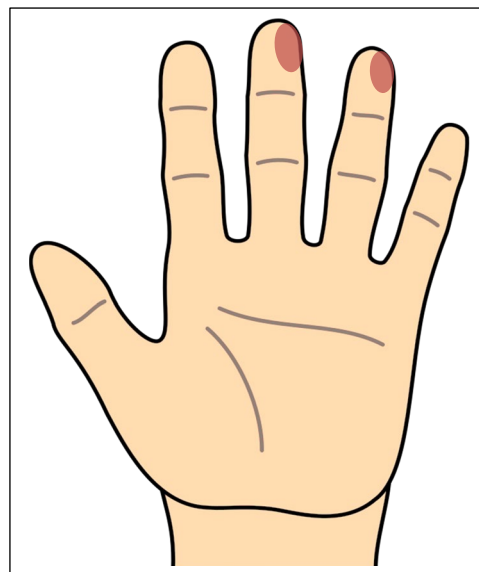
6. **Return to CAPI and connect scanner.** The interviewer followed the on screen instructions to connect the barcode scanner to the computer's USB port and scan the DBS kit and card ID.
7. **Get into position and put on gloves.** The interviewer removed two gloves from the plastic bag and did a quick check to ensure there are no holes or tears in the gloves. If there were any, the gloves were discarded and the interviewer used new ones. Interviewers were instructed not to lay the gloves on any surface besides the drape while putting them on.
8. **Open the remaining collection supplies.** While wearing gloves, the interviewer opened the wrappers of the bandage, both gauze pads, and the alcohol prep pad so that they were ready to use when needed.
9. **Remove the hand warmer after 5 minutes and determine the finger to be used for the collection.** After 5 minutes, the interviewer removed the hand warmer. Either the ring finger or middle finger was used for the DBS collection. The interviewer asked the SP "Would you prefer to use your middle or ring finger for this activity?"

II.L.3. DBS Administration

10. **Clean the SP's finger with the alcohol pad.** The interviewer thoroughly wiped the fingertip of the SP's selected finger with the alcohol pad. The entire fingertip area where the lancet was used was wiped. The interviewer waited for the SP's finger to dry after applying the alcohol. Interviewers were instructed not to blow on it or dab it dry. The drying process was important for the antiseptic effect of the alcohol. Blowing on the finger could introduce bacteria onto the clean site. While waiting for the finger to dry, the interviewer placed a sterile drape on his/her lap. The flap to the DBS card was opened and the DBS card was placed on the drape with one gauze pad. The SP's hand was positioned over the safety drape on the SP's (or interviewer's) lap.

- 11. Position the lancet on the side of the pad of the selected finger closest to the pinky.** The interviewer removed the blue tip from the lancet to activate it. The correct location for the collection site was on the side of the fleshy pad of the SP's fingertip. The collection site was in the upper quadrant, on the side closest to the pinky finger (Exhibit II.L.3-1). Interviewers were instructed not to prick the middle of the finger pad or at the top of the finger pad near the nail.

Exhibit II.L.3-1. DBS Collection Site Area



The lancet was positioned perpendicular to the lines of the SP's fingerprint on the fleshy part of the finger. This placement allowed for the greatest amount of blood flow, allowed the SP to extend his or her arm comfortably while the blood drops are falling, and allowed the interviewer to see the blood drops forming from a good angle.

Before pricking the SP's finger, the interviewer said to the SP: "I'm going to press down and you will feel a pinch."

- 12. Firmly prick the SP's finger.** The interviewer placed the lancet down firmly on the SP's finger with the lancet to activate it. The lancet was not removed until there was a click, indicating the lancet had been released
- 13. Immediately place the used lancet into the sharps container.**
- 14. Use one of the gauze pads to wipe away the first drop of blood.** The interviewer turned the SP's hand so that the palm was facing the interviewer. The interviewer waited for a full drop of blood to form on the SP's finger, and then wiped it away, placing the gauze pad in the trash pile. Wiping away this drop of blood ensured that any contaminants on the surface of the SP's finger did not make it into the blood specimen.
- 15. Collect up to 5 drops of blood on the DBS card.** While keeping the SP's hand in their lap (or the interviewer's lap) below their heart with a downward angle, the interviewer carefully positioned the collection paper below the finger and allowed the drop to fall on its own. The interviewer started with the leftmost circle on the DBS card.

There were a few things to remember during the collection to ensure high quality of the spots:

- **Be patient! Allow a large drop to form before depositing on the card.** A large drop would fill the circle completely. Whenever possible, letting a large drop form (so

that it was nearly ready to fall on its own) would significantly increase the quality of the blood spots collected.

- If needed, the interviewer would apply gentle pressure to the SP's finger below the collection site to increase blood flow. The interviewer did not use the whole hand and did not squeeze the SP's finger too hard as this would dilute the sample. If blood stops flowing, the interviewer attempted to wipe away the collection site with a piece of the sterile gauze. This would help wipe away any blood that had begun to clot and re-start the blood flow.
 - The interviewer did not touch the SP's finger to the card. When handling the cards, even with gloves on, the interviewer touched only the exterior paper, not the filter paper where the spots were placed.
 - The interviewer did not dab or wipe the blood onto the card; he or she would let blood drop onto the card.
 - Each circle was filled with only one drop of blood. Once blood had been dropped inside a circle, the interviewer did not allow another drop to fall on top of it.
 - If the drop of blood appeared to pool on the card rather than spreading out to fill the circle, the interviewer gently tapped the card to spread the blood.
 - Once 5 drops were collected, or blood flow had stopped, the interviewer moved to the next step.
 - If fewer than 3 spots were collected, and if the SP volunteered, the interviewer attempted another finger stick on a different finger (ring or middle finger) on the same hand. The interviewer used a new alcohol prep pad, lancet, bandage and 2 gauze pads from the extra supply bag. The hand was not rewarmed.
- 16. Place a new sterile gauze pad on the SP's collection site.** The interviewer asked the SP to firmly hold the gauze on the collection site and raise his or her hand toward the ceiling for about 30 seconds or until the bleeding had mostly stopped.
- 17. Apply a bandage to the SP's collection site.** The interviewer removed the gauze from the SP's finger, checking that the bleeding had mostly stopped. The interviewer applied the bandage to the SP's finger, but not too tightly.

DBS Card Collection Examples and Reminders

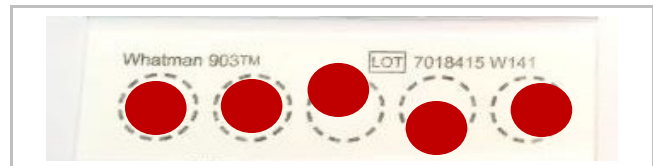
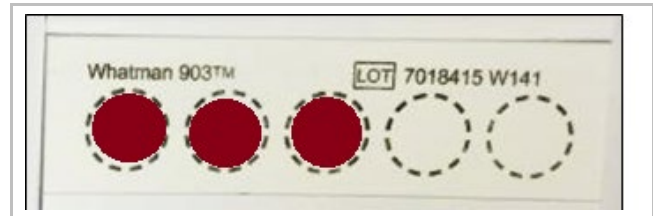
When collecting the blood spots onto the DBS cards, there were several guidelines to follow:

- The interviewer always started collection by filling the leftmost circle on the card
- The interviewer centered the drop within the dashed circle on the card

- The interviewer did not blot or shake the blood drop onto the card
- The interviewer did not bring the card up to touch the drop of blood
- The interviewer only put one drop in each circle. The interviewer did not layer successive drops of blood in the same collection circle
- The interviewer did not overlap spots

The following pictures show blood spots that were acceptable for use by the laboratory. They are completely filled with large drops of blood and the blood spots are not overlapping. They provide sufficient quantity for analysis.

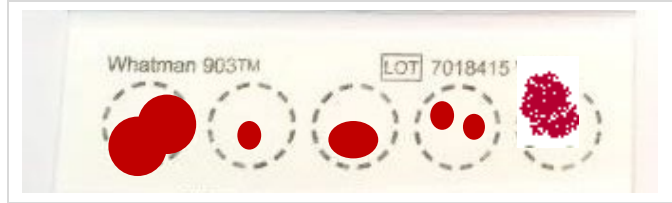
✓ Acceptable



The following picture shows a blood spot card with spots that are unacceptable for use by the laboratory.

- The first circle has spots that are overlapping. Overlapping spots have varied concentrations and reduce the amount of analyzable sample.
- The next three circles contain small drops of blood. The laboratory will not be able to analyze it if the spots are not completely filled by large drops of blood.
- The last circle is an example of a drop of blood that was smeared on to the card. Smeared blood spots will also not provide sufficient quantity for analysis.

X Unacceptable



II.J.3. Post-Administration

- 18. Place the DBS card in an individual drying case on a flat surface.** The interviewer inserted the card into the drying case with the flap open, so the collection area on the card did not touch the drying case surface. The case flap was left open so that the spots could dry during the remainder of the interview. It was very important that the cards were dry before packing them away.
- 19. Clean up the DBS collection materials.**
- 20. Apply hand sanitizer.** The interviewer also washed his/her hands with soap and water as soon as possible.
- 21. Follow the instructions in CAPI and on the job aid to pack up all DBS equipment and supplies except for the drying case with the DBS card.** The drying case flap was left open for the remainder of the interview.
- 22. Return to CAPI and record the DBS collection results.** The interviewer indicated the number of blood spots that were collected on the DBS Card. Spots only counted as collected if they matched an acceptable spot as shown in the pictures above.
- 23. Place the drying case securely in the DBS kit bag, and then pack it into the DBS equipment bag.**

II.L.4. Storing Specimens for Drying Overnight

Interviewers used a secure location in their home where the DBS card collected could be stored and left undisturbed and away from people, pets, direct heat, or other contaminants (e.g., cigarette smoke), as well as away from where eating, drinking, or applying cosmetics could take place.

The interviewers stored and dried the DBS card overnight following the steps listed below. It was very important that the cards were dried sufficiently. Wet cards could not be analyzed by the laboratory.

1. The interviewer removed the DBS kit bag from NHATS DBS equipment bag.
2. The interviewer removed the DBS card drying case from DBS kit bag.

3. The interviewer unsnapped and opened the drying case flap to allow air in for drying.
4. The interviewer left the card to dry overnight. Interviewers were instructed not to blow on filter paper to dry spots.
5. If the interviewer collected a DBS card for more than one SP Interview, he/she organized the drying cases with the SP-specific kit bag.

II.L.5. Shipping Specimens to the Westat Home Office


Once the card had dried overnight, interviewers prepared it for shipment back to the Westat home office following the steps outlined in the DBS Shipping Job Aid (Exhibit II.L.6-1).





Exhibit II.L.6-1. NHATS DBS Shipping Job Aid


NHATS Dried Blood Spot (DBS) Shipping Job Aid

ORGANIZE SUPPLIES

▪ Gloves	▪ Hand sanitizer
▪ NHATS ID mini-label	▪ FedEx shipper pack
▪ Drying case with card inside	▪ FedEx preprinted shipping label
▪ DBS Kit bag	▪ Alcohol prep pad
▪ DBS Card bag	▪ Permanent marker
▪ One desiccant	



1.  Put on a new pair of gloves.
2. Remove DBS card from the drying case.
3. Fold the top card flap down so it sits underneath the barcode labeled portion of the card.
4. Confirm your NHATS ID and data collection date are filled out completely.
5. Put your NHATS ID mini-label on back of the card above the biohazard symbol.
6. Place the card in the individual resealable plastic bag it came in.
7. Add 1 desiccant to the individual resealable plastic bag with DBS card; seal the bag.
8. Place the small resealable plastic bag in the larger DBS kit bag; seal the DBS kit bag.
9. Clean the inside and outside of the drying case with an alcohol prep pad and allow it to dry out so it is ready for re-use.
10. Remove and discard gloves.
11.  Wash your hands with soap and water.
12. Insert the case folder and DBS kit bag into a FedEx shipper pack.
13.  On the online IMS shipment link, mark the appropriate items that you are shipping back such as the DBS consent signature page, DBS kit bag with card, and incentive receipt form.
14. Write your NHATS ID on the shipping pack with a permanent marker.
15.  Ship the case folder back that day using a preprinted shipping label to the NHATS field room (FedEx Priority Overnight) unless weekend or holiday



All DBS cards must be shipped to the Home Office regardless of whether blood was collected

II.L.6. Shipping Sharps Container to Disposal Site

Sharps containers were prepped for mailing either when the container became full or at the end of the field period. Sharps containers were mailed directly from the interviewer's home to a central disposal processing site using the box in which the container was packaged.

III. Deceased SPs and the Last Month of Life Interview

If the SP died since the last interview, a short 15-minute interview was conducted with a proxy about the SP's last month of life and the care that the person received. The best proxy for the LML interview was someone knowledgeable about the SP's health and daily routines in the last month of the person's life. Usually the best proxy was a relative (e.g., spouse, son, or daughter) or friend identified during the last interview. If the last interview was conducted with a proxy, that proxy respondent was likely the best person to contact. For the cases that did not have an SP interview in Round 6 (final disposition codes 61 or 64), the LML interview was conducted with a facility staff person.

Specifically, in the LML interview, interviewers asked about the place of death, where the SP resided prior to that place, and the care the SP experienced in the last month of life. Additional questions focused on whether the SP moved between the time of the last interview and the person's death, whether the SP received help or used special equipment, and how things changed between the time of the last interview and the person's last month of life.

The following covers specific issues about several of the CAPI sections for the LML interview.

Residence (RE). In this section of the LML interview, the last place the SP considered to be his or her residence was recorded. This is not the address of the place where the SP may have stayed briefly before death. The information about the place of death is captured in section PD. If the proxy mentioned that the SP stayed in a hospital just before death, interviewers probed to find the last place that the SP considered his or her home or residence. If the SP died in a nursing home, interviewers probed to determine if this was the SP's residence or just a short-term stay.

Exhibit III-1. Screen shot of CAPI question RE4f

NHATS (CTRL+V) | BREAK OFF (CTRL+B) | Person Roster

99990281 CHANDRA PATEL LAST INT DATE: June 8, 2015

SPECIFY IF SP LIVED AT SAME ADDRESS AS LAST INTERVIEW:

CURRENT ADDRESS: **ADDRESS AT LAST INTERVIEW:**

678 Hillpoint Blvd **678 Hillpoint Blvd**

Baltimore, MD 21201 **Baltimore, MD 21201**

IF NEEDED: Is the place CHANDRA PATEL was living at the time she died the same place that she was living at the time of the last interview?

ENTER 1 IF SAME ADDRESS.

ENTER 2 IF DIFFERENT ADDRESS, INCLUDING A DIFFERENT APT# OR UNIT #.

ENTER 3 IF SAME ADDRESS WITH MINOR ADDRESS CORRECTIONS (SPELLING, ZIP CODE, FACILITY NAME).

☐ 1. YES, SAME ADDRESS

☐ 2. NO, DIFFERENT ADDRESS

☐ 3. YES, SAME ADDRESS WITH MINOR CORRECTIONS

RE4f SAME ADDRESS AS LAST INT

Place of Death (PD). This section of the LML interview collected the type of place where the SP died. Some of the more common places are listed in PD3.

Exhibit III-2. Screen shot of CAPI question PD3

Forms Answer Navigate Options Help

NHATS (CTRL+V) | BREAK OFF (CTRL+B) | Person Roster

99990271 THERESA JAMISON LAST INT DATE

Where did THERESA JAMISON's death take place?

☐ 1. AT SP'S OR SOMEONE ELSE'S HOME

☐ 2. IN A HOSPITAL

☐ 3. IN A NURSING HOME

☐ 4. IN A HOSPICE RESIDENCE

☐ 5. IN TRANSIT (AMBULANCE TO HOSPITAL)

☐ 91. SOMEWHERE ELSE (SPECIFY)

PD3A MONTH SP DIED 10

PD3B YEAR SP DIED 2015

PD3 PLACE OF DEATH

PD3A

PD3B

PD3C

PD3D

PD3E

21/215 | Navigate | NHATS | 11:23:55 AM | ENG | 99990271 | PD3 | PD.PD3

For code 1 “AT SP’S OR SOMEONE ELSE’S HOME,” SP’s home includes any place the SP considered home, except a nursing home. For example, a room in an assisted living or other residential care setting, other than a nursing home, or in a private home of any kind including apartment would be coded as 1. A follow-up question at PD3B distinguished between SP’s and someone’ else’s home. If the SP received hospice services in his or her home (where most hospice care is provided), this information was not collected.

Code 2 “IN A HOSPITAL” included anywhere in a hospital including in a hospice care unit of a hospital. A follow-up question at PD3) allowed interviewers to select which type of unit or part of the hospital.

Code 3 “IN A NURSING HOME” included anywhere in a nursing home, whether it was a special care unit or a hospice care unit or the regular part of the nursing home. Code 2 was used if the SP was living in a nursing home or was transferred there just before death. A follow up question allowed interviewers to indicate if it was in a hospice care unit in a nursing home that provides end of life care to patients receiving hospice services.

Code 4 “IN A HOSPICE RESIDENCE” defined a hospice residence as a freestanding place where people live, that was not part of a hospital or nursing home, and that was specifically designed to take care of people who are receiving hospice services at the very end of life.

Code 5 “IN TRANSIT” was selected if the SP died while moving between places (e.g. in an ambulance to or from the hospital).

If a respondent died in the hospital a follow-up question PD3c identified the type of unit.

Exhibit III-3. Screen shot of CAPI question PD3c

Forms Answer Navigate Options Help			
NHATS (CTRL-N) BREAK OFF (CTRL-B) Person Roster			
99990271 THERESA JAMISON			
LAST INT DATE: .			
Was that in an intensive care unit, palliative care unit, inpatient hospice unit, or some other part of the hospital?			
<input type="radio"/> 1. INTENSIVE CARE UNIT <input type="radio"/> 4. EMERGENCY ROOM <input type="radio"/> 2. PALLIATIVE CARE UNIT <input type="radio"/> 5. SOME OTHER PART OF THE HOSPITAL <input type="radio"/> 3. INPATIENT HOSPICE UNIT			
PD2A	MONTH SP DIED	10	
PD2B	YEAR SP DIED	2015	
PD3	PLACE OF DEATH	2	HOSPITAL
PD3A			
PD3B			
PD3C	WHAT KIND OF HOSPITAL UNIT		
PD3D			
PD3E			

21/315 Navigate NHATS 11:27:27 AM ENG 99990271 PD3C PD.PD3C

The following describes the codes for the types of hospital units presented in this screen:

1. Intensive care unit – Also known as critical care unit - a special department in a hospital that provides intensive-care or critical-care medicine. May include intensive care for specialties including coronary intensive care unit, medical intensive care unit, surgical intensive care unit, shock/trauma intensive care unit, or overnight intensive-recovery unit.
2. Palliative care unit – a special department in a hospital that provides a team approach to addressing physical, emotional, spiritual, and social needs of patients with advanced illness. The emphasis of treatment is on alleviating symptoms rather than curing the underlying disease.
3. Inpatient hospice unit – a special department in a hospital that provides care to patients who are at the end of their life and receiving hospice care.
4. Emergency room – a special department in a hospital that provides urgent care without appointment for trauma or severe, life threatening illness
5. Another kind of unit – any other unit in the hospital including (regular) inpatient care that is not included in the other units presented as response options.

Exhibit III-4. Screen shot of CAPI question PD5

Question PD5 captured where the SP was staying just before the place of death. For this question, code 1 “AT SP’S HOME” was used if the SP was in an apartment, assisted living unit, or anywhere else the respondent considered home (other than a nursing home). If the SP was at someone else’s home, code 91 “SOMEWHERE ELSE” was entered. The appropriate code was entered if the SP was in a hospital (code 2), nursing home (code 3), or hospice residence (code 4). For all other responses, code 91 “SOMEWHERE ELSE” was entered and the place was specified in the follow-up text field.

Two questions at the end of PD were used to guide the questionnaire path in the LML interview. Question PD6 asked how much the SP was alert and able to communicate during the last month of life and PD7 asked how much the SP was able to get out of bed. Some follow-up questions about activities in the last month of life were skipped if the SP was not alert at all in the last month of life and questions about mobility were skipped if the SP was not able to get out of bed at all in the last month of life.

Last Month of Life (LM). In this section, the introduction screen LM1PRE helped to set the stage for the questions in this section. Because it is possible that some SPs died suddenly with no care, some questions did not apply. The code “DOES NOT APPLY/NO CARE IN THE LAST MONTH” was used in these instances.

Exhibit III-5. Screen shot of CAPI question LM1PRE

Forms Answer Navigate Options Help

NHATS (CTRL-H) BREAK OFF (CTRL-G) Person Roster

99990271 THERESA JAMISON DATE OF DEATH: October 2015 LAST INT DATE:

These next few questions are about THERESA JAMISON's care in the last month of life. If she did not receive any care in the last month, a few of these questions might not apply. If this is the case, just let me know, and we'll go on to the next question.

PRESS 1 AND ENTER TO CONTINUE

LM1PRE		<input type="checkbox"/>
LM1	EXPERIENCED PAIN	<input type="checkbox"/>
LM1A		
LM1B		
LM2	TROUBLE BREATHING	<input type="checkbox"/>
LM2A		
LM2B		
LM3	ANXIETY OR SADNESS	<input type="checkbox"/>

24/3/15 Navigate NHATS 11:42:36 AM ENG 99990271 LM1PRE LM.LM1PRE

The last question in this section did not have “Does Not Apply/No Care in Last Month”. If a proxy could not answer question LM11 about quality of care in the last month of life because the SP did not have care, the interviewer selected DK and added a comment that the SP had no care in the last month.

IV. Facility Staff Questionnaire

The interviewer completed the Facility Staff Questionnaire (FQ) with a staff person from the facility if the SP lived in a nursing home or other type of residential care facility. The FQ asked about type and levels of care and services that were offered, the sources of payment for the SP’s care, and the amount of money that each source paid to the facility for the respondent’s care.

The FQ is conducted with a facility staff person, usually the facility administrator or his or her designee. For SPs who had moved to a nursing home since their baseline round and for SPs who live in other residential care facilities, the NHATS interview was conducted with the SP (or a proxy), and the physical activities were administered. In addition, a facility staff questionnaire (FQ) was administered.

For SPs who are deceased and who lived in a facility in their baseline round, the FQ was not conducted; instead, interviewers administered the last month of life interview using the NHATS Interview task with a facility staff person. (See Section IV on Deceased SPs and the Last Month of Life Interview.)

IV.A. Nursing Homes and Other Residential Care Places

Nursing homes are residential care facilities for persons with chronic illness or disability, usually older people who require 24-hour nursing care and have significant difficulties with activities such as bathing, dressing, toileting, eating, or mobility. The FQ has questions that ask whether a nursing home is a free-standing facility or part of a larger place that has different types of residential settings in addition to a nursing home.

There are a variety of other residential care facilities and types of supportive housing for older people. Residential care facilities provide varying levels of services that might include meals, housekeeping, laundry, and personal care assistance with basic daily activities such as bathing, eating, dressing, and toileting. They sometimes help with medications by storing and distributing these to residents. Some also provide services such as organized activities, recreational trips, and transportation to their residents.

Residential care facilities go by different names including assisted living, board and care homes, rest homes, personal care homes, and adult family care homes. Continuing Care Retirement Communities (CCRCs) have a continuum of living arrangements from independent living to assisted living and nursing home care. Examples of supportive living residential environments are senior housing complexes, retirement villages, and retirement hotels that provide only housing and services that cater to independent residents.

The SP interview and the FQ have questions that identify whether the place the SP is living is one of these residential settings.

IV.B. When the Facility Staff Questionnaire Was Required

It was usually obvious whether the SP resided in a nursing home. For SPs who lived in some other type of residential care facility, the interviewer usually needed to talk with someone such as a receptionist to locate the SP within the facility so that he or she could conduct the interview. The Housing Type (HT) section of the NHATS CAPI questionnaire was designed to determine whether the SP lived in a residential care setting and contained a series of questions about the place the SP lived. Respondents were asked to describe the place they live (HT3).

Those who answered “assisted living facility or CCRC” or “a group home, board and care, or supervised housing” were considered residential care. Anyone else living in a retirement community or multi-unit building was asked questions about whether the place the SP lived had the following:

- Different areas or units that the SP can move to if care is needed such as an assisted living, a special unit for memory care, or a nursing home (HT5)?
- Help with medications or with activities such as bathing or dressing (HT6)?
- Meals for residents (HT7)?

If the answer to any of these questions was “Yes,” or the SP was in residential care based on HT3, the Facility Questionnaire was required. In cases where there was no permanent onsite staff person in the building, it may not have been possible to identify a respondent for the FQ.

IV.C. Facility Advance Materials

IV.C.1. Facility Advance Letters

A facility advance letter was sent to facilities where only an FQ interview was completed in Round 6 (disposition code 61 and 64).



National Health &
Aging Trends Study

how daily life changes as we age

Westat
1600 Research Boulevard
Rockville, Maryland 20850

1-888-364-8271

{DATE}

{FACILITY STAFF FIRST NAME} {FACILITY STAFF LAST NAME}, {FACILITY STAFF TITLE}
{FACILITY NAME}
{FACILITY ADDRESS 1}
{FACILITY ADDRESS 1}
{FACILITY CITY}, {FACILITY STATE} {FACILITY ZIP}

Dear {FACILITY STAFF FIRST NAME} {FACILITY STAFF LAST NAME}:

Last year an interviewer from Westat spoke with you about one of your residents, {SP FIRST NAME} {SP MIDDLE NAME} {SP LAST NAME}, because {he/she} is part of the National Health and Aging Trends Study (NHATS). We thank you for your help and appreciate your commitment to this important research effort.

A Westat interviewer will contact you soon to schedule a convenient appointment time for this year's interview. As before, we are collecting information from the facilities where some of our study participants live. The interview will take about 10 minutes and will include questions about your facility, the types of services offered, and the amount and sources of payment that you received for {SP FIRST NAME} {SP MIDDLE NAME} {SP LAST NAME}'s care. We will also ask a few questions to confirm {his/her} name, date of birth, and gender.

Enclosed is a copy of the HIPAA waiver granted by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB).

The Westat interviewer will answer any questions you have. If you would like to speak with someone before the next interview, please call the NHATS toll-free number at **1-888-364-8271**. You can also visit our website at www.mynhats.org.

Thank you again for your time and effort in helping to make this study successful. We look forward to talking with you soon.

Sincerely,

Judith D. Kasper, Ph.D.
Project Director and Professor
Johns Hopkins Bloomberg School of Public Health

Enclosure
{SP ID}



IV.C.2. Facility Introductory Contact Scripts

Two contact scripts were used when contacting facilities: one for telephone contact with the facility (Exhibit IV.C.2-1) and one for in-person contacts with the facility (Exhibit IV.C.2-2). Each contact script provided language that was used for the interviewer to introduce himself or herself and the study. For facilities that were not contacted during the previous round or for new facility staff, additional information about the study was provided.

Exhibit IV.C.2-1. Round 7 facility telephone script

<div style="border: 1px solid black; padding: 2px; display: inline-block;">AFFIX SP ID LABEL HERE</div>	
National Health and Aging Trends Study Facility Telephone Contact Script	
<p>Hello, my name is _____ from Westat. I'm calling about the National Health and Aging Trends Study for the National Institute on Aging and the Johns Hopkins Bloomberg School of Public Health.</p> <p>May I speak with [PREVIOUS ROUND FACILITY CONTACT PERSON NAME]?</p> <p>One of your residents [SP NAME] is part of NHATS. Last year, we conducted a brief interview about the facility and the care (he/she received) with (you/ PREVIOUS ROUND FACILITY CONTACT NAME).</p> <p>IF NEEDED: NHATS is a study about how life changes as you age. The interview takes about 10 minutes and includes questions about the types of services offered to your residents, and the amount and sources of payment that is received for [SP NAME's] care.</p> <p>We can fax you our introductory letter with additional information about the study and a copy of the HIPAA waiver from the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB). Would you like me to fax this information to you?</p> <p><input type="checkbox"/> YES FAX INFORMATION FAX NUMBER: _____</p> <p>CONFIRM INFORMATION FOR SENDING FAX</p> <p>NAME: _____ TITLE: _____</p> <p>FACILITY: _____</p> <p>PHONE NUMBER: _____</p> <p>I would like to schedule an appointment for this year's interview.</p> <p>RECORD DATE AND TIME</p> <p>Date: _____ Time: _____</p> <p>CONFIRM INFORMATION FOR INTERVIEW</p> <p><input type="checkbox"/> SAME AS ABOVE</p> <p>NAME: _____ TITLE: _____</p> <p>FACILITY: _____</p> <p>PHONE NUMBER: _____</p> <p style="text-align: center;">1</p>	

Exhibit IV.C.2-1. Round 7 facility telephone script (continued)

IF FACILITY REPORTS SP IS DECEASED, SAY: We are so sorry to hear (SP NAME) passed away.

We would like to complete a short 15-minute interview on the phone. The interview includes questions about (his/her) last month of life and the care (he/she) received. Who would be the best person at the facility to talk to about [SP NAME]?

RECORD INFORMATION FOR BEST PERSON TO CONTACT FOR LAST MONTH OF LIFE INTERVIEW

NAME: _____

TITLE: _____

PHONE NUMBER: _____ EXT: _____

RECORD INTERVIEW DATE AND TIME

Date: _____ Time: _____

Exhibit IV.C.2-2. Round 7 in-person facility script

National Health and Aging Trends

In-Person Facility Contact Script

General Introduction

Hello, my name is _____ from Westat. One of your residents [SP NAME] is participating in the National Health and Aging Trends Study, which is being conducted by the Johns Hopkins Bloomberg School of Public Health with support from the National Institute on Aging. This study examines how daily life changes as we age.

INSTRUCTIONS:

Is the SP able to speak to you directly?

- YES: Conduct the interview with the SP.
Then, identify an FQ respondent using Script 2 and then conduct the FQ.
- NO: Cannot speak with SP because of health or functioning.
Use Script 1 with a facility respondent.

Script 1 – SP is living in a nursing home or other residential care facility

As part of this study, we are collecting information from facilities and from the NHATS study participant. The interview with [SP NAME] will take 2 hours or less, and includes questions about (his/her) daily activities. It also includes some everyday activities like walking and standing. I'll also need to speak to a staff member here who can answer a few questions about the types of services you offer, and the charges and sources of payments for (his/her) care.

IF NEEDED: This study has been granted a HIPAA waiver [SHOW FORM] by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB). This waiver permits you to make limited disclosures of protected health information for research without an individual's authorization for public health purposes and for research that has been approved by an IRB under the HIPAA privacy rule.

IF NEEDED: I would like to speak with [SP NAME].

- IF "NO" AND REASON IS BECAUSE SP IS UNABLE TO RESPOND DUE TO PHYSICAL OR MENTAL IMPAIRMENTS, GO TO A.
- IF "NO" AND REASON IS FACILITY REFUSAL/FACILITY POLICY/CONCERNED ABOUT SP'S PRIVACY, GO TO B.
- IF "NO" AND REASON IS BECAUSE SP IS TEMPORARILY UNAVAILABLE, GO TO C.

A. Is there someone who could help [SP NAME] answer the questions, such as a relative who lives close by or a staff member who is familiar with (his/her) daily routine?

- COLLECT PROXY CONTACT INFORMATION. IF PROXY IS AVAILABLE, CONDUCT THE INTERVIEW.
- IF PROXY IS NOT AVAILABLE, MAKE AN APPOINTMENT TO RETURN AND CONDUCT THE INTERVIEW.

B. We understand your concerns. All the answers to the questions will be protected and identifying information will be kept separate from your answers and kept private and safe. Here is a letter that introduces the study along with a fact sheet.

HAND FACILITY ADVANCE LETTER AND FACT SHEET

C. When will [SP NAME] be available?

Exhibit IV.C.2.-2. Round 7 in-person facility script (continued)

Script 2 -- Identify FQ respondent

As you may know, I am here today because one of your residents, [SP NAME], is participating in the National Health and Aging Trends Study that is being conducted by the Johns Hopkins Bloomberg School of Public Health and Westat with support from the National Institute on Aging. This study examines how daily life changes as we age.

I have conducted this year's interview with [SP NAME]. As part of this study, we are also collecting some information from facilities where our study participants live. I'd like to ask you a few questions about your facility, including the types of services offered to your residents, and the amounts and sources of payment that you have received for (his/her) care.

IF NEEDED: Here is a letter that introduces the study along with a fact sheet about the study.

HAND NHATS FACILITY ADVANCE LETTER AND FACT SHEET

This study has been granted a HIPAA waiver [SHOW FORM] by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB). This waiver permits you to make limited disclosures of protected health information for research without an individual's authorization for public health purposes and for research that has been approved by an IRB under the HIPAA privacy rule.

Who would be the best person to help us with this information?

IV.D. Health Insurance Portability and Accountability Act (HIPAA)

HIPAA regulations allow medical providers, such as nursing homes, assisted living, and other residential care facilities, to fill requests for medical records without getting consent from the individual or the individual's family.

The HIPAA Privacy Rule allows limited disclosure of protected health information (PHI) for research without an individual's consent or authorization, as long as a waiver from a properly constituted Institutional Review Board (IRB) or Ethics Review Board (ERB) is obtained.

To meet this requirement, the study has been reviewed by and received approval from the Johns Hopkins Bloomberg School of Public Health's (JHSPH) IRB. The JHSPH IRB found that this research study presents no more than minimal risk of harm to subjects and approved the request for a HIPAA waiver of informed consent for individuals living in nursing homes and other residential care facilities.

For each completed interview in a nursing home or other type of residential care facility, the interviewer offered the facility director a copy of the NHATS Documentation Notice for HIPAA Accounting. The facility could place this form in the SP's file, indicating that information from the file was collected by NHATS.

V. Financial Payment in Appreciation of SP Participation

At the end of each interview, the SP or proxy received an incentive check for \$20. An incentive check was preprinted for each SP and included in the case folder. No incentive payment was given to facility staff respondents for completing the FQ. SPs who agreed to participate in the Dried Blood Spot (DBS) collection received an additional check for \$50.