# NHATS DATA COLLECTION PROCEDURES ROUND 1

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# Introduction

This document describes data collection procedures in Round 1 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. Sections III and IV cover administration of the Facility Questionnaire (FQ) and the financial payment in appreciation of SP participation provided in Round 1.

# I. Contacting Approach and Advance Materials

Exhibit I-1 presents an overview of contacting procedures. Exhibit I-2 shows an overview of data collection procedures in Round 1.

Exhibit I-1. Approach for contacting cases for Round 1

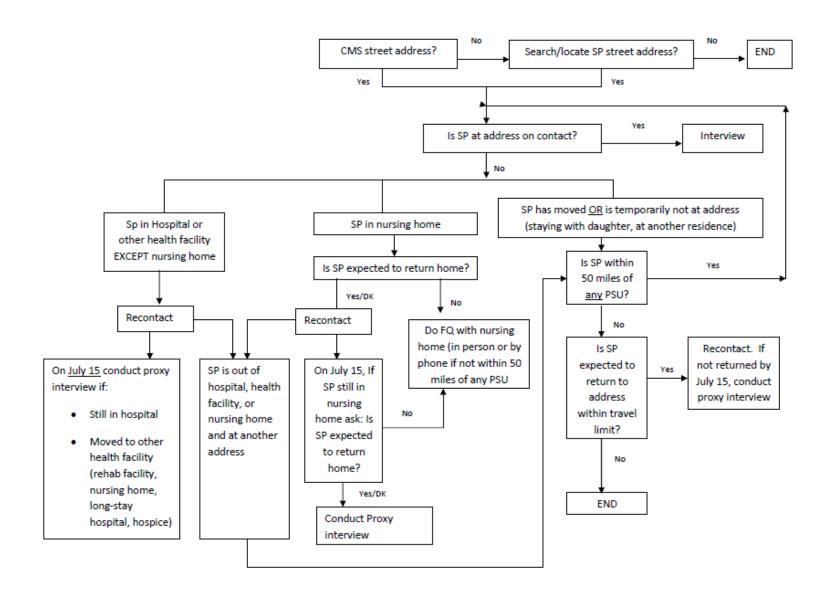
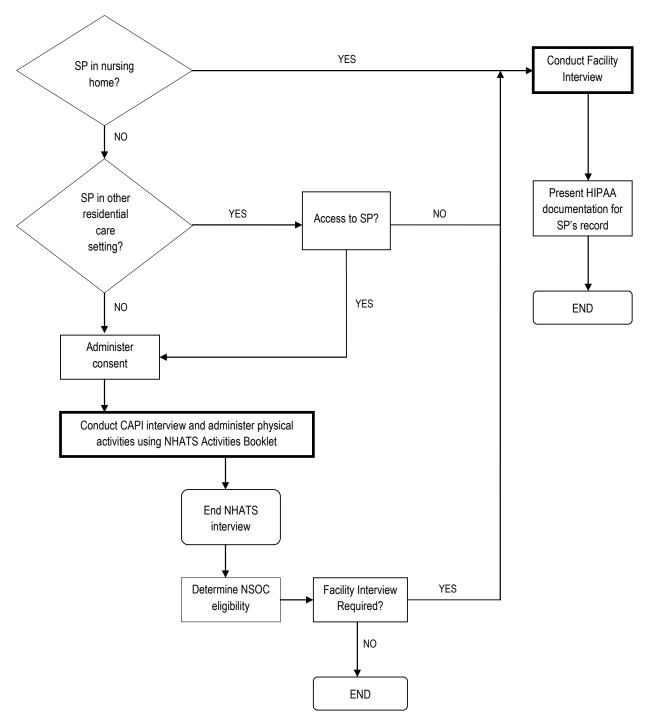


Exhibit I-2. Flowchart for Round 1 Data Collection



### I.A. Advance Materials

### I.A.1. CMS Advance Letter

Prior to the interview, participants were sent an advance letter from CMS (Exhibit I.A-1) announcing the study, stating the study's purpose, and asking for the SP's cooperation.

Exhibit I.A-1. CMS advance letter



Centers for Medicare 8 Medicaid Services

7500 Boulevard Baltimore, MD 21244-1850

Dear

The Centers for Medicare and Medicaid Services (CMS), part of the U.S. Department of Health and Human Services, is cooperating with the National Institute on Aging and The Johns Hopkins Bloomberg School of Public Health on the National Health and Aging Trends Study (NHATS).

NHATS is a nationwide study of how life changes as we age. It will survey about 9,000 people aged 65 and over throughout the U.S. The study will be used by researchers to learn how people handle changes in daily life and activities that happen with age.

You are one of over 38 million older Americans with health insurance under the Medicare program. You were chosen to be in NHATS as a result of our sampling. Your participation is voluntary, and you do not have to take part in the study. Your Medicare benefits will not be affected in any way whether or not you take part in the study.

I hope you will decide to take part in this important new study. By doing so, you will represent thousands of other people like you.

Westat, a research company that conducts some of the largest health care surveys in the U.S., is conducting interviews for NHATS. A trained interviewer will visit you within the next few weeks. Enclosed is a brochure that provides more information about the study.

If you have any questions about the study, please call Westat toll free at 1-888-364-8271.

Please join this important study of aging and daily life when you are contacted in the next few weeks by a Westat representative.

Sincerely

Walter Stone CMS Privacy Officer

Enclosure: NHATS Brochure

# I.A.2. NHATS Study Brochure

The NHATS study brochure (Exhibit I.A-2) was sent with the CMS advance letter to each SP. This brochure described the study and presented information about the study in a simple, question-and-answer format. It also included a toll-free telephone number to call for additional information, as well as the NHATS study participant website address.

### **Outside folds**

### What is this study about?

The National Health and Aging Trends
Study (NHATS) is a new study of the
ways daily life changes as we age. It was
designed by leading university researchers
to help us understand how older people
today, and in future generations, can lead
fuller, healthier lives. The study will conduct
in-person interviews with Medicare
beneficiaries who are 65 or older.

### Who is conducting the study?

The 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 that conducts some of the largest health care surveys in the U.S., will conduct the interviews. All data collectors wear identification badges and use laptop computers to record your answers for the study.

### 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 changes 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 web site: www.mynhats.org

To learn more about Westat, visit www.westat.com

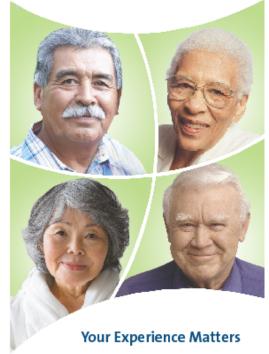
Thank you for being part of this important study.





This study is sponsored by the National Institute on Aging.





Information about the National Health & Aging Trends Study

### Inside folds

### How was I selected for this study?

You were selected because you are 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. You are one of about 9,000 people who will be part of this important new study. Your experiences represent those of thousands of other Medicare beneficiaries.

### What will I be asked to do?

The interview asks about your health, your family, how you do everyday tasks, how you get around at home and in the community, and activities that are important to you. There are also some simple everyday activities we will ask you to do. These include standing, getting up from a chair, walking, and measuring your memory and your breathing. You will receive \$40 for taking part in the study.

### Do I have to participate?

No. Your 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 your Medicare or any other benefits you may receive.

However, each person invited to be in NHATS represents thousands of others and cannot be replaced. Your participation is very important for the success of the study.

# How will my information be kept confidential?

Names and addresses that we need to contact you in the future will be kept separate from your information so no one will know who gave what answers. We follow strict procedures and guidelines to keep the information that identifies you private and safe. The information we collect will be used for research purposes only.



# I.A.3. Welcome Letter

Prior to the initial visit, participants were also sent a welcome package that contained a welcome letter from the study (Exhibit I.A-3), a \$2 bill, and a NHATS pen. This welcome letter described the study, informed the participant about the NHATS website and the \$40 incentive payment, and told the participant that someone from Westat would be visiting soon.



Westat 1600 Research Boulevard Rockville, Maryland 20850

1-888-364-8271

### Dear

Welcome to the National Health and Aging Trends Study (NHATS)! You are one of only 9,000 Medicare beneficiaries age 65 and older across the country who will be part of this important new study. NHATS has been designed by leading university researchers to study how daily life changes as we age. This study will help us understand how older people today, and in future generations, can lead fuller, healthier lives.

NHATS is sponsored by the National Institute on Aging which is part of the National Institutes of Health. It is being conducted by the Johns Hopkins Bloomberg School of Public Health, one of the leading schools of public health in the country, and by Westat which conducts several of the largest health surveys in the United States.

A specially trained interviewer from Westat will be stopping by soon to do the interview. The interviewer will ask you questions about your health, your family, and daily activities that are important to you.

The Westat interviewer who stops by will give you detailed information about the study and can answer any questions you have. If you would like additional information please visit our website at <a href="https://www.mynhats.org">www.mynhats.org</a>. You can also call the NHATS toll-free number at 1-888-364-8271 if you have any questions or if you would like to schedule an appointment now instead of waiting for an interviewer to visit.

The experience of every person selected for this study is important in providing a picture of aging in America. In addition to the \$2 enclosed with this letter, you will receive an additional \$40 after taking part in the study as a sign of appreciation for your participation.

We welcome you to NHATS and thank you for your help with this important study.

Sincerely yours,

Judith D. Kasper, Ph.D.

Principal Investigator and Professor

Judith D. Kasper

Johns Hopkins Bloomberg School of Public Health





# **I.B. Contacting Respondents**

Introductory scripts were developed for interviewers to use in initial contacts in Round 1. The Introductory Contact Script (Exhibit I.B-1) introduced the interviewer and the study to the SP and briefly described key aspects of participation. Like the "at-the-door" script for SPs, the Introductory Script for Facility Staff (Exhibit I.B-2) provided an introduction to the study for facility staff who were being asked to respond to the Facility Questionnaire

Exhibit I.B-1. NHATS At-the-door Introductory Script

# NHATS At-the-Door Introduction Sheet Hello, my name is \_\_\_\_\_\_ from Westat. I'm here about the National Health and Aging Trends Study for the National Institute on Aging and the Johns Hopkins Bloomberg School of Public Health. SHOW ID BADGE. Are you [SP NAME]? IF R IS NOT THE SP, ASK: Is [SP NAME] available? You may have received this letter explaining the study and that someone from Westat would be contacting you. INTR INSTRUCTION: HAND RESIDENT A COPY OF THE LETTER

As the letter says, the Johns Hopkins Bloomberg School of Public Health is working with Westat to conduct a new a national study about how daily life changes as we age. The study will be used by researchers to understand how older people today, and in future generations, can lead fuller, healthier lives.

The interview will take 2 hours or less to complete and includes questions I will ask you and some simple everyday activities.

At the completion of the interview, you will receive \$40 as a thank you for taking part in the study.

Do you need time to think it over or talk to your family or someone else?

Let's take a few minutes to go over the letter I just gave you.

INTR INSTRUCTION: REVIEW LETTER. DURING REVIEW STATE: There is a toll-free number in this letter, which you may call to learn more about the study. There is also a website with information.

I'd like to start the interview now if that is convenient. If it isn't convenient for you, we can set up another time.

Hello, my name is \_\_\_\_\_\_ from Westat. One of your residents (SP NAME) has been selected to participate 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.

### INTERVIEWER INSTRUCTIONS

Step 1 – Is the facility a nursing home?

YES: go to Script 1

NO: go to Step 2

Step 2 – Identify whether you can speak with the SP directly

NO: use Script 2.

YES: go to Step 3.

Step 3 – Conduct interview with SP. Identify FQ respondent using Script 3 and conduct FQ.

### Script 1 – SP in a Nursing Home

As part of this study, we are collecting information from facilities where some of our study participants live. I do not need to collect any information directly from [SP NAME]. I only need to speak to a staff member here at [FACILITY NAME] for about 10 minutes to collect some information about your facility, the types of services offered here, and the amounts and sources of payment that you have received for [SP NAME's] care

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 provide this information?

### Script 2 – SP in (Residential Care Facility – Assisted Living or CCRC)

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 SP's care.

May we 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 UNAVAILBLE, GO TO C.
- A. Is there someone who could help SP answer the questions, such as a relative who lives close by or a staff member who is familiar with {SP's NAME} daily routine?
  - COLLECT PROXY CONTACT INFORMATION. IF PROXY IS AVAILABLE CONDUCT THE INTERVIEW.
  - IF PROXY IS NOT AVAILABLE AT THAT TIME, 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.
- C. When will (SP NAME) be available?

### Script 3 – Identify FQ respondent

As you may know, I am here today because one of your residents, [SP NAME], was selected to participate in the National Health and Aging Trends Study, which 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.

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 [SP NAME'S] care.

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?

# I.C. 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.
- 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.

# **I.D. 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.D.-1 presents the final disposition codes available for NHATS cases.

Table I.D-1. Final disposition codes

Disposition code	Description codes	Definition	Set by
60	Complete	CAPI assigns this code once all of the interview tasks have	CAPI
	complete	been completed for a case.	<b>G</b>
61	Complete, NH facility	CAPI assigns this code once all of the interview tasks have been completed for a nursing home case.	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 to participate, no proxy	This code is assigned when the SP is unable to participate due to 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 other than death.	Field Supervisor
85	Refusal–facility	This code is assigned if the facility refuses to participate in the study.	Field Supervisor
86	Deceased	This code is used if the SP is deceased.	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. Obtaining Consent**

Before beginning data collection, the interviewer obtained a signed informed consent from the SP or the proxy (for interviews conducted using a proxy). The consent form is a 4-page document with the signature page printed in duplicate (see Exhibit II.A.-1).

The respondent was given a copy of the consent form along with the yellow copy of the signature page.



### JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH

### INFORMED CONSENT DOCUMENT

Study Title: National Health and Aging Trends Study

Principal Investigator: Judith Kasper, Ph.D.

IRB No.: #2083 PI Version Date: 02-22-11

### What you should know about this study

- You are being asked to join a research 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 take part and if you join, you may
  quit at any time.

### Purpose of research project

The Johns Hopkins Bloomberg School of Public Health is working with the National Institute on Aging and Westat to conduct the National Health and Aging Trends Study. This is a nationwide study of how life changes as we age. The study will be used by researchers to understand how people handle changes in daily life and activities that happen with age.

About 9,000 people aged 65 and over will take part in the study. People in this study will be interviewed once every year.

### Why you are being asked to be part of the study

Your name was selected at random from among people who are 65 years of age or older and enrolled in Medicare.

### **Procedures**

A trained interviewer will ask you questions about:

- your living situation,
- your home,
- how you do everyday tasks,
- · your health and physical abilities,
- getting around at home and in the community, and
- · managing your health care.

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IRB # 2083 -- NHATS National SP Consent, Version #2, 2-22-11



There are also some simple, everyday activities we will ask you to do. These include:

- standing,
- getting up from a chair,
- · walking a straight line,
- · measuring your grip,
- · measuring your memory,
- · measuring your breathing, and
- measuring your waist.

The interview and activities will take about 2 hours or less.

We will contact you again next year for another interview like the one we will do today. You can decide at that time whether you want to take part in that interview. As this study goes on, you may be asked to participate in related studies. Each time you will be asked whether you wish to participate or not.

Everyone in this study has Medicare coverage and information about health and medical services will be obtained from the Medicare program for all study participants.

### Risks/discomforts

The risks from taking part in this study are low. There is a small risk that someone who is not part of the study will learn about your answers. To prevent this, we will protect your answers as described below.

If you get tired during the interview, you can ask to take a break or stop the interview at any time.

There is a low risk of harm from some of the activities we ask you to do. We will ask you whether you feel safe and about a few health problems before some activities. You can say that you don't feel safe doing an activity, then you can skip that part of the study. The activities in this study have been used in many other studies of older people without any harm or problems.

### **Benefits**

There is no direct benefit to you for taking part in this study. This study is expected to provide important new information about what life is like for older people in the U.S.

### **Payment**

You will receive \$40 for taking part in the study.

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### Protecting data confidentiality

We will keep your information private and safe. We use a unique number code to label your information, and your name and address are kept separate from that number code. We will store all of your information in a secure computer database in a secure facility. Names and addresses will be kept so that we can contact you in the future, but these will be kept separate from your information so no one will know who gave what answers.

### Who do I call if I have questions or problems?

- Call the Principal Investigator, Dr. Judith Kasper, toll free at 1-888-364-8271 if you have questions, complaints, or are injured as a result of being in this study.
- 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: 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: <u>irboffice@jhsph.edu</u>



### 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 risks and benefits.
- You have been given the chance to ask questions before you sign.
- · You have voluntarily agreed to be in this study.

NHATS ID:		
Print name of Sample Person	Signature of Sample Person	Date
Print name of Proxy	Signature of Proxy	Date
Print name of Interviewer	Signature of Interviewer	Date
Give yellow copy to the	ne participant and keep white origir	nal in study records

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IRB # 2083 -- NHATS National SP Consent, Version #2, 2-22-11

# **II.B. 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, and daughter). He or she may, however, have been a non-relative, 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.C. 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 (see Section I. – Contacting Procedures and Advance Materials).

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.C. Housing Structure**

Item RE1 (Exhibit II.C.1) asked the interviewer to code the physical structure of the SP's residence using the guide below. If the interview was not being conducted at the SP's home, this question was asked.

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 with "retirement" or "assisted living" in the name.

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









Free-standing detached single house

Multi-unit building

Townhouse

Mobile home or trailer

Exhibit II.C.1. Screen shot of CAPI question RE1



Responses to this question are used in routing respondents through questions in the HT and HO sections.

### **II.D. Home Environment Checklist**

The Home Environment Checklist is a hard-copy form (Exhibit II.D.1) that was completed by the interviewer. The form recorded interviewer observations while standing in front of the SP's home

or building. For cases where the SP resided in a nursing home, the form was not completed. 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.

# **National Health and Aging Trends Study**

# **Home Environment Checklist**

	Affix SP ID label			Affix I	nterviewer ID label
EC1.	Is SP residing in a nursing h	nome or nursing ho	ome unit?		
	☐ 1 Yes → Go to <b>EC4</b>				
	☐ 2 No → Go to <b>EC2</b>				
EC2.	When standing in front of the direction, how much of the fe			around in eve	ry
a.	Litter, broken glass, or trash, sidewalks and streets?	on □ 1 None	□ 2 A little	□ 3 Some	□ 4 A lot
b.	Graffiti on buildings and walls	s? □ 1 None	□ 2 A little	□ 3 Some	□ 4 A lot
C.	Vacant or deserted houses or storefronts?	r □ 1 None	□ 2 A little	□ 3 Some	□ 4 A lot
d.	Houses with foreclosure sign	s? □ 1 None	□ 2 A little	□ 3 Some	□ 4 A lot
EC3.	Standing in front of the SP's	home/building, doe	es it have		

a.	any broken or boarded up windows?	_	] 1 es	□ 2 No	☐ 3 Could not observe
b.	a crumbling foundation or open holes?		] 1 es	□ 2 No	☐ 3 Could not observe
C.	missing bricks, siding, or other outside materials?		] 1 es	□ 2 No	☐ 3 Could not observe
d.	roof problems (e.g., missing material, sagging, or a hole in roof)?		] 1 es	□ 2 No	☐ 3 Could not observe
e.	uneven walking surfaces or broken steps in the area leading to the home/building?		] 1 es	□ 2 No	☐ 3 Could not observe
EC4.	Record Date:/	//	—— Year		

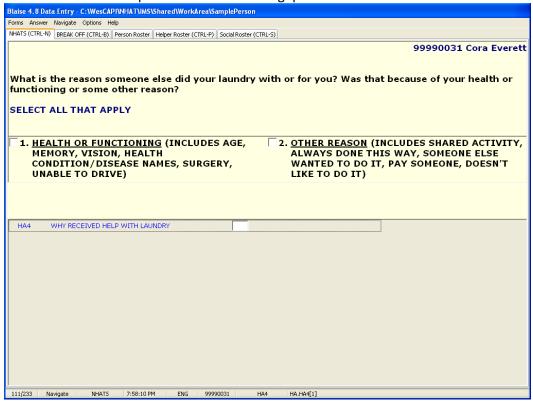
# II.E. Health and Functioning

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

- Laundry;
- Shopping for groceries or personal items;
- Making 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 (Exhibit II.E.1) about the reason someone else was involved in the activity. 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.E.1. Screen shot of sample health or functioning question



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 to do 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.F. Income and Assets**

Income and asset data were collected for the sample person or sample person and spouse/partner. 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 section was structured so that income sources and assets were identified first, followed by questions about income amounts and asset values. The final question in the section asked for total income from all sources for the last year (i.e. calendar year 2010). The worth of homes and cars were asked about in separate sections (HP and CO respectively). Earned income in the last month was asked about in the Labor Force section (LF).

A fixed reference period of the month prior to month of interview was used for amounts e.g., for interviews occurring in June, the amount received for the month of May was asked. A few items used an annual reference period e.g., withdrawals from retirement plans are asked for both the last month and the last 12 months.

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.

Dollar amounts – income or the worth of assets—also could be entered separately for the SP or a spouse/partner, or combined. If a respondent said "don't know" or "refuse" in response to 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 data from the Survey of Consumer Finance for specific types of income and assets.

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. 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 the wording of later questions (see flag table in Section III.B.4) and in the walking course activity.

# **II.H. Cognitive Activities**

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

# II.H.1. Equipment for the Cognitive Activities

Some of the cognitive activities required special equipment to administer the activity. Those equipment items included the following:

- 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.H.1. Cognition activities equipment and use

<b>Equipment item</b>	Use
Digital stopwatch	Used for timing the clock drawing.
Blank sheet of paper	Used by the SP for drawing the clock. An SP ID label is to be affixed to the paper after 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.H.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.H.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.H.4. Clock Drawing**

The clock drawing activity is a simple 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 to be 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.H.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 (Barack Obama) and the first and last name of the vice president (Joseph "Joe" Biden).

# **II.I. 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 is 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.I.1.** Digital Stopwatch

The digital stopwatch (Oslo Silver model) 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.I.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.I.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 grip positions. For this study, the handle was almost always in the 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.I.4. Peak Air Flow Meter

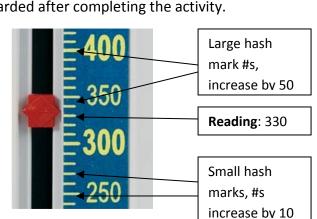
The Peak Air Flow meter measures Peak Expiratory Flow (PEF) rate, the fastest speed a person can blow air out of the lungs after taking as big a breath as possible.

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 in 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.I.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.I.5.1. Physical activities other 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.J. 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.J.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 felt 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 to do 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.J.2. Balance Stands

The balance stands activities measure a person's ability to hold the following 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; and
- 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 took 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.J.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 walk, 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.

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.

#### To administer the test, the interviewer:

- 1. Helped the SP into position at the starting line, with his or her walking aid, if applicable.
- 2. Once the SP had both feet touching the starting line, the interviewer positioned himself or herself slightly behind and to the side of the SP, with the stopwatch in his or her right hand.
- 3. As soon as the interviewer received acknowledgement, he or she told the SP to begin.
- 4. The interviewer started timing as soon as either of the SP's feet began to move, making sure to walk with the SP in case support was needed.
- 5. The interviewer stopped timing when one of the SP's feet was completely across the finish line.

#### Reminders to interviewers:

- There should be room for the SP to stand before the start line and to walk completely past the finish line.
- When looking for an area to lay out the walking course, the interviewer tried to find the smoothest floor surface possible.
- High pile carpeting was avoided and the course was not laid out over the edge of an area rug, throw rug, or any other irregular surface that could cause the SP to trip.
- Any obstacles from the activity area were cleared, but the interviewer made 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.J.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 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.J.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 wass 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.

#### 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 sit 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.J.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:

- 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 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 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.J.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.

#### 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.J.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.J.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.J.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 the SP.
- Was ready to place both hands on the SP to stabilize him or her if necessary.
- If the SP lost balance, the interviewer 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.K. Person Roster**

Sections of the CAPI questionnaire were used to build a person roster that was used throughout the interview and carried forward for future interviews. Each person added to the person roster was assigned a unique person-level ID. Each time the person roster was displayed, interviewers were able to add individuals to the roster or select individuals previously added to the roster.

In addition to the SP, who is automatically added to the person roster, people who may be added to the roster during the interview included the following:

- A proxy respondent if one is needed;
- SP's spouse;
- Household members;
- Children of the SP;
- Members of the SP's social network;
- Other individuals who may help the SP with everyday activities; and
- Other individuals the SP takes care of.

Each row in the person roster represented one person. For each 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.K.1.** Relationship Codes

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

The full list of relationship codes is as follows:

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

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.

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.K.2 Types of Person Roster Members**

There are seven types of person roster members:

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

Each type could only be selected or added in the sections of the CAPI instrument that collected 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 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.

**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.

For each child or stepchild, first and last names, date of birth, age, city and state of residence, level of schooling, marital status, and number of children were collected.

**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.

# **III. 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.

For SPs who resided in nursing homes, only the FQ was conducted with a facility staff person (usually the facility administrator or his or her designee). For SPs living in other residential care facilities, the NHATS was conducted with the SP (or a proxy), and the physical activities were administered. In addition, a facility staff questionnaire (FQ) was administered.

## III.A. Nursing Homes and Other Residential Care Settings

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.

## III.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 would need 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 he or she needs care, like 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) [meals on wheels not included]?

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. A letter from CMS was given to facility respondents to explain the study's purpose.



Centers for Medicare & Medicaid Services

7500 Security Boulevard Baltimore, MD 21244-1850

#### Dear Facility Administrator:

The Centers for Medicare and Medicaid Services (CMS), part of the U.S. Department of Health and Human Services, is cooperating with the National Institute on Aging and The Johns Hopkins Bloomberg School of Public Health on the National Health and Aging Trends Study (NHATS).

NHATS is a new national study designed by leading university researchers to study how daily life and activities change as we age. It will survey about 9,000 Medicare beneficiaries aged 65 and over throughout the U.S.

NHATS includes people who live in all types of residences including retirement communities, nursing homes, assisted living and other forms of residential care. As part of the study, we are gathering information about the types of places people live and the services offered in some residential settings.

The experience of every person selected for this study is important in providing a picture of aging in America. A resident in your facility has been selected to participate in NHATS. For that reason, we want to ask you a few questions about your facility and the services it offers.

NHATS is sponsored by the National Institute on Aging which is part of the National Institutes of Health. It is being conducted by the Johns Hopkins Bloomberg School of Public Health, one of the leading schools of public health in the country, and by Westat which conducts several of the largest health surveys in the U.S.

The information collected for this study will be used only for research and statistical purposes. The study protocol has been approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board and has been granted a HIPAA authorization waiver.

Trained interviewers from Westat are conducting the interviews for NHATS and can answer any questions you have about the study. You can also call Westat toll free at 1-888-364-8271 to ask any questions regarding the study.

We appreciate your time and participation in this important study.

1.01

Walter Stone CMS Privacy Officer

## III.C. 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.

# IV. Financial Payment in Appreciation of SP Participation

At the end of each interview, the SP or proxy received an incentive check for \$40. 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.