

NATIONAL STUDY OF CAREGIVING (NSOC) IV
USER GUIDE

Rounds 11-12 (2021-2022)

Beta Release

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Overview

The National Study of Caregiving (NSOC) is a nationally representative study of family and other unpaid caregivers to older persons living with limitations in daily activities. NSOC is conducted in conjunction with the National Health and Aging Trends Study (NHATS). NHATS samples Medicare enrollees ages 65 and older (see Freedman et al. 2022 for a guide to NHATS).

NSOC interviews include questions about activities for which help was provided, duration and intensity of help, effects on helpers providing assistance, support services used, and basic demographic information. The first three rounds of NSOC (NSOC I, II, and III) have been conducted with NHATS at periodic intervals in Round 1 (2011), Round 5 (2015), and Round 7 (2017). Interviews were conducted by telephone with family and unpaid caregivers to NHATS participants who were receiving assistance with self-care, mobility, or household activities (the latter, for health or functioning related reasons). The NSOC I-III User Guide is available at www.nhats.org (Freedman et al. 2019).

NSOC IV began in Round 11 of NHATS (2021). Interviews are conducted annually in conjunction with NHATS and may be completed by web or telephone. In the first round of NSOC IV, a randomized experiment was embedded, in which eligible caregivers were randomly assigned to a mixed mode option (with a choice of responding either by web or by telephone) or to a telephone-only option. This experiment allowed assessment of the impact of changing from a telephone to a mixed mode (web/telephone) design (see also Hu et al. 2020). Starting in 2022, all NSOC participants are given a choice of web or telephone modes.

This Beta Version is an early release of the NSOC IV (Rd 12) files. The user is cautioned that there may be inconsistencies and/or errors in the data that will be addressed before releasing the final files. Users are encouraged to document issues that they find in an email to NHATSdata@westat.com.

This user guide describes the design, collection, files and documentation for NSOC IV, starting in Round 11 of NHATS (2021).

Goals of NSOC

Together NHATS and NSOC form the only national study that provides both care recipient and caregiver perspectives on late-life care. Rather than identify a single primary caregiver to be interviewed, interviews are attempted with all eligible helpers for whom contact information has been obtained. This design yields a caregiver sample that is representative of all eligible caregivers to older adults and allows insights into how caregiving responsibilities are distributed.

NSOC can be used to address a variety of salient questions about family care in the US including:

- What help is provided to older adults and by whom?
- How are caregiving activities distributed within families?
- How does caregiving intersect with work, child care, and other valued activities?
- What out-of-pocket costs do caregivers incur as part of care provision?
- What support services do informal caregivers know about, seek, and use?

- What are the consequences of providing care for health and wellbeing?
- How are care demands and provision changing over time?
- How does care provision and its consequences differ at the end of life?
- What are the reasons that caregiving stops and how do roles change over time?
- How do caregivers spend their time over the day and what are consequences for wellbeing?

A technical paper with frequently asked questions about how to use NSOC data is available for users at www.nhats.org (see Freedman et al. 2020).

Design

Sample. NSOC IV interviews eligible family and unpaid caregivers to the NHATS Sample Person (SP) identified during the NHATS interview. For example, NSOC IV Round 11 interviews caregivers who were identified during Round 11 of NHATS, which was fielded in 2021.

Both NSOC IV Rounds 11 and 12 are considered a “cross-sectional” sample because they consist of caregivers who provided help in the last month or year. For NSOC IV Round 11, interviews were conducted from June 2021 through early January 2022. For NSOC IV Round 12, interviews were conducted from May 2022 to January 2023.

Mode. NSOC I-III interviews were conducted by telephone. Starting in NSOC IV, a mixed mode design was introduced, in which caregivers could respond by web or by telephone. To assess the impact of changing from a telephone to a mixed mode (web/telephone) design, a randomized experiment was embedded in Round 11. About half of the 3,216 eligible caregivers were randomly assigned to a mixed mode design with responses allowed by web or telephone (n=1,600); the other half were randomly assigned to the telephone only mode (n=1,616; as fielded in NSOC I-NSOC III).

Preliminary analysis of the shift to a mixed mode design suggests response rates are slightly higher and field resources slightly lower with the mixed mode design. In addition, key estimates (hours of care, categorical income, and wellbeing scores) appear comparable. However, agree/disagree items in the Aspects of Caregiving (AC) section appear to have different response patterns with telephone only respondents more likely than mixed mode respondents to strongly agree or strongly disagree. A technical paper detailing assigned mode effects at the item level is available at www.nhats.org (see Hu et al. 2020). Users may explore mode effects using the random assignment indicator `op11dmixmode` on the NSOC OP tracker file. The mode in which the interview was completed is also included (`c#dintmode`). For details see derived variables specifications in Appendix B.

Starting in 2022, all NSOC participants are given a choice of web or telephone modes.

Terminology

NHATS identifies all individuals who helped the Sample Person with activities in the last month, whether or not that assistance is related to the older adult’s health and functioning or not. We use

the term “helper” to refer to all individuals who assist the NHATS participant.

Because NSOC is limited to family and unpaid individuals who assist the subset of older adults receiving help related to their health or functioning (a proxy for “needing help”), we refer to NSOC participants as “caregivers” or “family and unpaid caregivers.”

Eligibility

NSOC IV Cross-Sectional File

Caregivers to Living Sample Persons. Eligibility for each round of NSOC is determined separately for NHATS Sample Persons and for helpers of those individuals. The process for NSOC IV mirrors the eligibility process for NSOC I to III cross-sectional samples (Freedman et al. 2019) and is described below.

NHATS Sample Persons with a completed Sample Person interview who reported receiving help with certain activities were eligible for NSOC. A Sample Person was potentially eligible if, in the last month, he or she was receiving help with any of the following activities:

Mobility activities	Self-care activities	Household activities <u>for health or functioning reasons</u>¹
Getting around outside	Eating	Laundry
Getting around inside	Bathing, showering or washing up	Shopping for personal items
Getting out of bed	Getting to or using the toilet	Preparing hot meals
	Dressing	Paying bills and banking
		Keeping track of medications

Once a Sample Person was deemed potentially eligible for NSOC, all helpers identified by the participant (with any activity for any reason) were reviewed for NSOC eligibility. Helpers were eligible for NSOC if they helped a potentially eligible Sample Person with any activity listed below and were either 1) related to the Sample Person (relationship codes = 2-29 or 91) whether paid or not or 2) unrelated to the Sample Person and not paid to help.

Mobility activities	Self-care activities	Household activities <u>for any reason</u>	Other activities
Getting around outside	Eating	Laundry	Money matters other than bills or banking
Getting around inside	Bathing, showering or washing up	Shopping for personal items	Medical activities (physician visits; insurance decisions)
Getting out of bed	Getting to or using the toilet	Preparing hot meals	Transportation

¹ Individuals who lived in residential care facilities and received assistance from a person at the place they lived were assumed to receive that assistance for health or functioning reasons.

	Dressing	Paying bills and banking	
		Keeping track of medications	

If at least one helper was deemed eligible, then the Sample Person was considered NSOC-eligible. If the number of NSOC-eligible helpers for a Sample Person exceeded 5, 5 helpers were selected at random and the remaining helpers were considered ineligible for NSOC. Because of this restriction, a small number of caregivers were not sampled in NSOC IV (e.g., n=46 in Round 11).²

See Appendix A for items in the CC Section (Caregiver Eligibility and Contact Information) administered at the end of the Sample Person Interview to determine eligibility.

Caregivers in the Last Month of Life. Eligibility for the Last Month of Life caregiver sample was determined separately for NHATS participants and for helpers of these individuals. The NHATS Sample Person was eligible if a Last Month of Life interview was completed in NHATS of that round. The caregiver was eligible if they assisted in the last month of life with any of the mobility or self-care activities listed in Table 2; household activities, which were not asked of Last Month of Life helpers in NHATS, were not considered in LML caregiver eligibility.

Sample Sizes

Table 3 presents sample sizes by sample type.

In NSOC IV Round 11, interviews were conducted with 1,642 caregivers to NHATS SPs who were living at the time of the NSOC interview, and 296 caregivers of deceased older adults. In NSOC IV Round 12, interviews were conducted with 2,224 caregivers to NHATS SPs who were living at the time of the NSOC interview, and 207 caregivers of deceased older adults.

Table 3. Sample Sizes for NSOC IV		
	Cross-sectional Samples	
	Living SPs	Last Month of Life
Round 11		
Eligible NHATS participants	1,274	228 ¹
Eligible Caregivers	2,738	478 ²
Interviewed Caregivers	1,642	296 ²
Round 12		
Eligible NHATS participants	2,087	166 ¹
Eligible Caregivers	3,995	357 ²
Interviewed Caregivers	2,224	207 ²

² An additional 86 cases were considered ineligible. Reasons for ineligibility include the caregiver was deceased prior to fielding the survey, the helper was a minor, the helper was a paid nonrelative, the case was a duplicate, there was insufficient information to identify a specific caregiver, or the helper did not assist with any activities in the CA section in the past year.

¹Includes NHATS participants who died following NHATS but prior to NSOC (n=8 in Round 11; n=5 in Round 12).

²Includes caregivers to eligible NHATS participants who died following NHATS but prior to NSOC (n=11 in Round 11; n=6 in Round 12)

Response Rates

In NSOC IV Round 11, 1,938 interviews were completed: 1,379 completed by telephone, 543 by web, and 16 using both modes. The final response rate was 60.3%. Response rates for cross-sectional samples of caregivers to living SPs and last month of life (LML) caregivers are comparable (see Table 4).

In NSOC IV Round 12, 2,431 interviews were completed: 946 completed by telephone, 1,445 by web, and 40 using both modes. The final response rate was 59.5%. Response rates for cross-sectional samples of caregivers to living SPs and last month of life (LML) caregivers are comparable (see Table 4).

Table 4. Response Rates for NSOC IV			
		Cross-sectional Samples	
		Living SPs	Last Month of Life ¹
Round 11	Stage 1: Contact info available	94.4%	96.9%
	Stage 2: Response	63.5%	63.9%
Round 12	Stage 1: Contact info available	93.5%	97.8%
	Stage 2: Response	59.5%	59.5%

¹Includes caregivers to eligible NHATS participants who died following NHATS but prior to NSOC (n=11 in Round 11; n=6 for Round 12).

In Round 11, for the living SP caregiver sample, caregiver contact information was unavailable for 154 out of 2,738 eligible cross-sectional caregivers of living SPs, yielding a 94.4% unweighted first stage response rate. Among eligible caregivers with contact information (N=2,584), 942 were not interviewed, yielding a 63.5% unweighted second stage response rate.

For the sample of last month of life caregivers, contact information was unavailable for 15 out of 478 eligible cross-sectional caregivers, yielding a 96.9% unweighted first stage response rate. Among eligible last month of life caregivers with contact information (N=463), 167 were not interviewed, yielding a 63.9% unweighted second stage response rate.

In Round 12, for the living SP caregiver sample, caregiver contact information was unavailable for 260 out of 3,995 eligible cross-sectional caregivers of living SPs, yielding a 93.5% unweighted first stage response rate. Among eligible caregivers with contact information (N=3,735), 1,511 were not interviewed, yielding a 59.5% unweighted second stage response rate.

For the sample of last month of life caregivers, contact information was unavailable for 8 out of 357 eligible cross-sectional caregivers, yielding a 97.8% unweighted first stage response rate. Among eligible last month of life caregivers with contact information (N=349), 142 were not interviewed, yielding a 59.5% unweighted second stage response rate.

Sampling weights are adjusted to account for non-response to NHATS and NSOC (a separate technical paper describes the NSOC IV weights (Hu et al. 2022)).

Content & Questionnaire Sections

Here we provide a brief overview of the content of NSOC IV. We first provide reference period conventions. We then provide an overview of the questionnaire sections by round and sample type and then review the scope of content in each section. The instruments were purposefully designed to be similar to NSOC I-III to facilitate trend analyses, but we note cases when items were moved or added starting in Round 11 (2021). Finally, we provide a summary of skip patterns around and within the cross-sectional and longitudinal samples.

Reference Period Conventions

Conventions for reference periods used in NSOC I-III have been continued in NSOC IV. The NSOC instrument fills questions with a different reference period depending on the type of respondent (see Table 5). Caregivers of living SPs who helped in the last month are asked about the time frame “in the last month.” Caregivers of decedents who helped in the last month of the SP’s life (NSOC III & IV only) are typically asked “in the last month of {his/her/SP’s} life.” Caregivers who did not help in the last month (or the last month of SP’s life) but helped in the last year (or last year of SP’s life) are typically given the fill “in the last month that you helped {him/her/SP}.” In addition, some sections, like Health Care Interactions (HC), use a reference period of the last year.

Sample Person Status	Caregiver Status	Reference Period Fill
Sample Person Living	Helped Last Month	In the last month
Sample Person Living	Helped Last Year (not Last Month)	In the last month that you helped {SP}
Sample Person Deceased	Helped Last Month of Life	In the last month of {SP’s} life
Sample Person Deceased	Helped Last Year (not Last Month) of Life	In the last month that you helped {SP}

Overview of Sections by Round and Sample Type

Questionnaire sections that were administered in NSOC I-III were repeated in NSOC IV (Table 6). New sections were added with questions about: caregiver experience during the COVID-19 pandemic (VS, CV) and employment and caregiving at the end of life (EL). In addition, a new section (LG) was included in NSOC IV to facilitate login using the web. (For more detail on skips within sections, see Table 8.)

	NSOC IV Cross-sectional Sample	
	Sample Person Alive	Last Month of Life
Web Portal Login (LG) ¹	x	x
Care Activities (CA)	x	x
Duration of Care (DC)	x	x
Reasons Stopped (ST) ²	x	x
Last Month of Life (LL) ²	-	x
Health Care Interactions (HC) ²	x	x
Aspects of Caregiving (AC)	x	x
Support Environment (SE)	x	x
Visiting Activities (VS) ¹	x	x
Distance to Sample Person (DI) ^{2,4}	x	x
Participation (PP)	x	-
Health (HE)	x	x ¹
COVID-19 (CV) ¹	x	x
Household and Demographics (HD)	x	x
Race Ethnicity (RL) ³	x	x
Employment and caregiving – LML (EL) ¹	-	x
Employment and caregiving (EC)	x	-
Health Insurance and Income (HI)	x	x
¹ Added in NSOC IV. ² Added in NSOC III. ³ Added in NSOC II. ⁴ DI items were included in CA in NSOC I and II.		

Questionnaire Sections

Care Activities (CA): This section asks about ways in which the caregiver helped the Sample Person in the last month. Questions cover household chores, personal care, mobility, physical assistance, and transportation assistance. Caregivers are asked about the frequency of help in the last month and, for some activities, how help was provided (e.g., by going online to do money management). Questions also ask about helping with a variety of health-related activities and in NSOC I and II distance to the care recipient.³ Differences in placement of CA items across the rounds are summarized in Table 7.

	NSOC I	NSOC II	NSOC III	NSOC IV
Household, personal care, mobility, physical assistance, transportation	CA1-CA10	CA1-CA10	CA1-CA10	CA1-CA10
Health-related activities	CA11a-h	CA11a-h	CA11a-d,	CA11a-d,

³ The health-related items asked at CA11 in NSOC I and II remained in CA in NSOC III and IV, but some were moved (e.g. to CA11A2 and CA6B), so items have a different label in NSOC III and IV (but similar name). Medical activities were moved to HC in NSOC III and IV. Distance items were moved from CA to DI in NSOC III and IV. Starting in NSOC II caregivers are asked how much communicating with the Sample Person’s doctor helped them with caring for the Sample Person (CA12E in NSOC II and HC3 in NSOC III and IV).

			CA11A2a-b, CA6Ba-b	CA11A2a-b, CA6Ba-b
Medical care activities	CA12a-d	CA12a-d, CA12e	HC1,5,6a,6b, HC3	HC1,5,6a,6b, HC3
Distance	CA13- CA14b	CA13- CA14b	DI1-DI2b	DI1-DI2b
Helped in last year, not last month	Box CA15- CA17	Box CA15- CA17	Box CA15- CA17	Box CA15- CA17

For the small number of cases in which the Sample Person died after their NHATS interview but prior to NSOC, month and year of death are recorded in *cca#mthdied* and *cca#yrdied*.⁴ (# is round number, e.g., Round 7 or 11)

Duration of Care (DC): Questions elicit days and hours spent helping the Sample Person in the last month. Caregivers who helped with personal care or mobility also were asked hours spent helping with these activities only. All caregivers were asked when they began providing care in months and years.

Last Month of Life (LL): In NSOC III and IV, caregivers who assisted in the last month of the older adult’s life were asked a series of questions about how they assisted. These items were modeled closely after the LML interview in NHATS. Items focus on managing pain, breathing, and sadness/anxiety, whether the caregiver was provided training, medical decision making at the end of life, and communication with providers.

Reasons Stopped (ST): In NSOC III and IV, caregivers who did not provide help in the last month were asked a series of questions about why they stopped. The response category of “other specify” was dropped in NSOC IV and replaced with a question about whether the reason was concerns related to COVID-19.

Health Care (HC): Questions about interactions with health care providers, added in NSOC III, were continued in NSOC IV. Questions inquire about the frequency and nature of family and unpaid caregivers’ interactions with the Sample Person’s medical providers, including the extent to which the usual care provider: listened to what caregivers had to say, asked about the caregiver’s understanding of the Sample Person treatments, or asked whether the caregiver needed help managing the Sample Person’s treatments. Caregivers are asked whether they helped the Sample Person after an overnight stay in the hospital, whether the Sample Person was discharged directly home or to another facility, and whether they were provided training they needed to manage the Sample Person’s post-hospital care. Caregivers are also asked about health care tasks, including making appointments, logging into an online account to view information about the Sample Person’s health, coordinating care across more than one provider, and helping change or add health insurance or prescription drug plans and handling other health insurance matters. In NSOC IV Round 11, a question item (HC5d) on making an appointment for the Sample Person to get the COVID-19 vaccine was added. In Round IV Round 12, this item asks about making an appointment for the Sample Person to get the COVID-19 vaccine or booster shot. In the NSOC III

⁴Month and year of death for these and all other deceased SPs are recorded in flags at the beginning of this section (*fl#spdied*, *fl#spmthdec*, *fl#spyrdec*).

cross-sectional file, caregivers who helped last year but not last month skipped this section; in NSOC IV, this skip was removed.

Aspects of Caregiving (AC): Questions focus on positive and negative views of the caregiver's relationship with the Sample Person and the experience of being a caregiver. Caregivers were asked whether helping is financially, emotionally, or physically difficult and to rate the level of difficulty (from 1 a little difficulty to 5 very difficult). Questions about family disagreements concerning the Sample Person's care and about personal consequences (exhaustion, no time for self) also were included. In NSOC II, a question was added about how well the family shares responsibility for the Sample Person's care. In NSOC III, a series about difficulty with providing care with activities mentioned in CA and LL was added, but these items were only asked if the CG reported physical, emotional or financial difficulty. In NSOC IV, this series was shorted to focus on difficulty managing health care-related tasks and the skip was removed.⁵ A question (AC7AF) on difficulty making the Sample Person an appointment to get the COVID-19 vaccine was added in NSOC IV Round 11. In Round 12, this question asks about difficulty making the Sample Person an appointment to get the COVID-19 vaccine or booster shot. In the NSOC III cross-sectional file, caregivers who helped last year but not last month skipped the AC section. In NSOC IV, this skip was removed. In addition, Last Month of Life caregivers in NSOC IV skipped fewer items in this section.

Visiting Activities (VS): This section was added in NSOC IV. Questions focus on the frequency that nonresident caregivers were in contact with the Sample Person by phone, emails, video calls and visiting in person.

Distance (DI): Previously items CA13-CA14b in NSOC I and II, the Distance section was made a separate section starting in NSOC III. These items capture usual mode of transportation to visit Sample Person and how long it takes to get to SP's home. Caregivers who live with the Sample Person skip these items. In the NSOC III cross-sectional file, caregivers who helped last year but not last month skipped this section. In NSOC IV, this skip was removed.

Support Environment (SE): This section includes questions on availability of friends and family to help with care and other resources of support. Caregivers were asked whether they used services such as support groups, training, and financial help, including Medicaid and, if so, how they found out about services. For services not used, they are asked if they ever looked for services and from what sources. Caregivers also were asked about their role in obtaining devices, environmental supports, and paid help for the Sample Person. In the NSOC III cross-sectional file, caregivers who helped last year but not last month skipped this section and Last Month of Life caregivers who helped in the last month of life skipped SE1-3. In NSOC IV both skips were removed.

Participation (PP): These questions mirror the participation items in the NHATS Sample Person interview. Caregivers were asked about taking part in activities (e.g., visiting family and friends, attending religious services, doing volunteer work, working for pay). Follow-up questions for each activity were about the importance of the activity and whether helping the

⁵ In a small number of cases, when HC5D=1 is the only condition satisfied at Box AC7A, AC7Af was erroneously skipped. A skip error flag (flcac11routing) was included in Round 11 to flag under-collection of this item.

Sample Person kept the person from participating in the activity. In NSOC IV, clarifications were added for religious services and group activities that participation could be in person or online. Last month of life caregivers skip this section in NSOC III and IV.

Health and Wellbeing (HE): In a set of questions that mirror the NHATS Sample Person interview, caregivers were asked whether they had ever been diagnosed with a list of common chronic conditions and height and weight (from which body mass index can be calculated). Caregivers also were asked whether in the last month they had experienced particular impairments and symptoms (e.g., pain, breathing problems, low energy, upper and lower body impairments, sleep quality). If impairments were reported, the severity (degree to which the impairment interfered with daily activities in the last month) was assessed. Subjective wellbeing items included brief depression and anxiety screening instruments (PHQ-2 and GAD-2), positive and negative affect (feeling cheerful, bored, upset, etc.), self-actualization (life purpose and growth), and self-efficacy. For sensitivity, specificity, and recommended cut-points for the PHQ-2, the GAD-2 and a 4-item combined measure, see Kroenke et al. (2003, 2007, 2009) and Lowe et al. (2009). In the NSOC III cross-sectional file, caregivers who helped last year but not last month skipped this section. In NSOC IV, this skip was removed.

COVID-19 (CV): This section was added in NSOC IV. In Round 11, questions on caregivers' experiences with COVID-19 were asked, including whether the caregiver ever had COVID-19 (CV1), (if had it) any health effects from COVID-19 (CV2), and quarantine experience (CV3). In Round 12, the three questions have different time frame compared from Round 11: CV1 and CV3 ask about in the last year or in the last year of the Sample Person's life, and CV2 asks about in the last month or in the last month of the Sample Person's life. Both NSOC IV Rounds 11 and 12 ask whether the caregiver is vaccinated and if not, whether the CG tried to get vaccinated, and if yes, month and year when first vaccinated. In Round 12, questions on whether the caregiver received a COVID-19 booster shot and, if yes, the month and year they received the booster shot were added. For both rounds, questions about whether COVID-19 limited the caregivers' in person time with the Sample Person and whether the Sample Person went without help due to COVID-19 were also asked.

Race and Ethnicity (RL): In NSOC IV, questions on race, and primary race if more than one, as well as Hispanic ethnicity are included. These items were also included in NSOC II and III.

Household Composition and Demographics (HD): This section includes marital status of the caregiver, numbers of children and number under age 18, household size, education, spouse/partner education and age. In the NSOC III cross-sectional file, caregivers who helped last year but not last month skipped this section. In NSOC IV, this skip was removed. Spouse caregivers are asked this section beginning with NSOC IV. In Round 12, if caregiver's or spouse/partner's date of birth is not reported, follow up questions asking caregiver or spouse/partners age were added.

Employment and caregiving – LML (EL): This section was added in NSOC IV for Last Month of Life caregivers. Questions focus on whether the caregiver worked in the last month of the Sample Person's life, whether they had flexible work hours, schedule of work, whether they took time off to help the Sample Person, number of hours of work missed due to helping the Sample Person, and whether they were paid for the work missed. Last month of Life caregivers also are

asked occupation questions in the EC section.

Employment and Caregiving (EC): Labor force participation questions were patterned after those in the NHATS Sample Person interview and include hours of work in the last week and work schedule and current occupation. Persons who were absent from work in the last month were asked reasons for absence, which include vacation, sick leave, time off to help the Sample Person, sick leave for other family members, and personal time. Persons who reported taking time off to help the Sample Person were asked hours and days of work missed. New in NSOC IV, caregivers are asked if they were paid for the time that they missed work in the last month to help the Sample Person. Caregivers who were working were asked whether helping affects work and how much (on a scale from 1: helping makes work a little harder to 10: helping makes work a lot harder); this information can be used to create a work productivity loss indicator (see Wolff 2016). Caregivers are also asked their current and lifetime occupation. In the NSOC III cross-sectional file, caregivers who helped last year but not last month skipped this section. In NSOC IV, this skip was removed.

Health Insurance and Income (HI): This section elicits economic information, including whether the helper has health insurance coverage, checking/savings accounts, retirement accounts, and other stocks or mutual funds; home ownership; and total income for individuals (or couples). The remaining questions in this section ask about payments the caregiver made for care needs of the Sample Person (e.g. medications, mobility devices, in-home help) and financial gifts to or from the Sample Person. Starting in NSOC IV, Question HI11 uses the same income bracket categories for all respondents; previously in NSOC I-III, brackets varied based on published poverty guidelines. In the NSOC III cross-sectional file, caregivers who helped last year but not last month skipped this section. In NSOC IV, this skip was removed.

Skip Patterns

Table 8 presents an overview of skips in NSOC IV (“x” means the section was asked; “-” means the section was skipped). There are several groups that may be eligible to skip sections or items within sections.

Spouses or partners of living NHATS Sample Persons. In NSOC IV, caregivers who were spouses or partners of a (living) NHATS Sample Person skipped items about marital status (HD1) and month and year marriage ended (HD2-HD2A) because this information is available in NHATS. They also skipped questions on income transfers with the Sample Person (HI18-25) because these questions do not apply to spouses or partners. Items that are logically skipped for spouses have a value of -1.

Coresident caregivers. In NSOC IV, items on types of transportation used and how long it typically takes to get to the Sample Person’s home (DI in NSOC IV) and activities related to visiting SP (VI section) were skipped for coresident caregivers because they were not relevant. Items that are logically skipped for coresident caregivers have a value of -1.

Caregivers helping in the last month of life. In NSOC IV, caregivers who helped in the last month of life were asked all modules except Reasons Stopped (ST) and Participation (PP). They

skipped items AC1-4 on relationship with SP, were asked EL1-EL8 instead of EC1-EC18 on work last week and work hours, and skipped items HI18-HI25 on income transfers with the Sample Person

Caregivers helping in the last year (but not last month). In NSOC IV, these individuals were asked Reasons Stopped (ST) and all modules asked of those helping in the last month except Participation (PP). They also skipped income transfers with the Sample Person (HI18-25); EC14c taking time off to help SP (EC14c), and how work was affected in the last month due to helping SP (EC15-18).

Last Month of Life caregivers helping in the last year (but not last month) of life. In NSOC IV, these individuals were asked Reasons Stopped (ST) and all modules asked of Last Month of Life caregivers except Participation (PP) and Last Month of Life (LL). They also skipped how work was work affected in the last month of SP’s life due to helping SP (EL6-8).

Caregivers not helping in the last year (or last year of life). Following procedures in NSOC I, II and the NSOC III cross-sectional sample, in NSOC IV, caregivers identified in NHATS as currently helping, who then reported in the Care Activities (CA) Section of NSOC that they provided **no** assistance in the last year, were considered ineligible for the cross-sectional sample. These individuals were only asked CA to determine eligibility. They are coded as ineligible on the NSOC IV OP tracker file and are not included on the NSOC file.

	Sample Person Living		Sample Person Deceased	
	Helped Last Month	Helped Last Year Not Last Month	Helped Last Month of Life	Helped Last Year (not Last Month) of Life
Web Portal Login/Authentication/Consent (LG) ¹	x	x	x	x
Care Activities (CA)	x (skip CA15-17)	x	x (skip CA15-17)	x
Duration of Care (DC)	x	x	x	x
Reasons Stopped (ST)	-	x	-	x
Last Month of Life (LL)	-	-	x	-
Health Care Interactions (HC)	x	x	x	x
Aspects of Caregiving (AC)	x	x	x (skip AC1-4)	x (skip AC1-4)
Support Environment (SE)	x	x	x	x
Visits with SP (VS) ^{1,2}	x	x	x	x
Distance to Sample Person (DI) ²	x	x	x	x
Participation (PP)	x	-	-	-
Health (HE)	x	x	x	x
COVID-19 (CV) ¹	x	x	x	x
Household and Demographics (HD)	x	x	x	x
Race Ethnicity (RL)	x	x	x	x
Employment Last Month of Life (EL) ¹	-	-	x	x (skip EL6-8)
Employment and caregiving (EC)	x	x (skip EC14c and EC15-18)	x (skip EC1-18)	x (skip EC1-18)
Health Insurance and Income (HI) ³	x (skip HI18-25 for spouse/partners)	x (skip HI18-25 for spouse/partners)	x (skip HI18-25)	x (skip HI18-25)

¹Added in NSOC IV.
²Items about distance from the Sample Person and transportation used to get there (in DI in NSOC 2021) and visiting SP (VS section) were skipped for coresident caregivers because they do not apply to them.
³Items HI18-HI25 were skipped for caregivers who were spouses/partners of NHATS Sample Persons (both living and deceased) because these questions do not apply to them. In addition, for caregivers to deceased SPs in NSOC IV, items HI18-HI25 were skipped because the reference period is the last year.

Overview of Changes from NSOC III

To facilitate comparisons with earlier rounds of NSOC, we include here an overview of changes between NSOC III and IV. Changes between NSOC III and earlier rounds are documented in the NSOC I-III User Guide (Freedman et al. 2021).

Changes Related to Mode. Starting in NSOC IV Round 11, web was introduced as an alternative mode. The addition of the web-based self-administered questionnaire (SAQ) to the instrument resulted in minor changes to question wording. For instance, questions asked online did not have answer categories included in the stem whereas those administered by telephone typically had answers embedded in the question. In addition, when collecting amounts (months/years, hours, dollars) the web and telephone instruments followed different paths through the instrument. In these cases, derived variables have been created that combine mode-specific items into a single variable. Starting in Round 12, all caregivers are given a choice of web or telephone modes.

New Sections & Items. Four new sections were added in NSOC IV: Web Portal Login (LG), Visiting Activities (VS), Covid-19 (CV), and Employment and Caregiving for Last Month of Life Caregivers (EL). An item asking if concerns about COVID-19 was the reason for stopping care was added to the Reasons Stopped (ST) section. An item about whether SP was paid for care-related leave was added to the Employment and Care (EC) section (EC16).

Omitted Sections & Items. Time diary-related sections administered in NSOC III – AP and TD – were dropped from NSOC IV. An item about any other reason for stopping care (ST), the CA8 series about frequency of help lifting, being leaned on or holding the SP steady, difficulty helping with non-medical tasks at AC7a, and the SE7-SE9 series on how support was found were dropped from NSOC IV. Gender (HD11-HD12) is no longer confirmed by the CG but instead preloaded from the NHATS interview.

New Skips. In NSOC IV, questions for LML caregivers were expanded and several other skips were removed, so more caregivers were asked sections/items, as shown in Table 9.

Table 9. Skip Pattern Changes between NSOC III and IV Cross-Sectional Files		
	NSOC III	Change in NSOC IV
Caregivers Helping Living SP Last Month		
HD section	Section skipped for spouse/partner caregivers	Section skip removed; only items HD1 (marital status) and HD2 (when marriage ended) skipped for spouse/partners
HI8-HI17 (income, assets)	Items skipped for spouse/partner caregivers (NHATS responses used)	Item skips removed
Caregivers Helping Living SP Last Year but Not Last Month		
HC, AC, SE, DI, HE, HD sections	Sections skipped	Section skips removed
EC section	Section skipped	Section skip removed; only items EC14c (care reason missed work) and EC15-18 (hours work missed helping SP, whether paid for hours helping SP, how helping SP affected work) skipped
HI section	Section skipped	Section skip removed; only items HI18-HI25 skipped for spouse/partners
LML Caregivers Helping Last Month of Life		

HC7-HC9 (help following hospitalization), AC9 (negative aspects of care), SE1-3 (support received)	Items skipped	Item skips removed
EC section	Section skipped	New EL section for LML caregivers added and LML caregivers asked EC19-EC22 (whether working, still working and occupation)
LML Caregivers Helping Last Year but Not Last Month of Life		
HC, AC, SE, DI, HE, HD sections	Sections skipped	Section skips removed; only items AC1-4 (relationship quality) skipped.
EC section	Section skipped	New EL section for LML caregivers added, only EL6-8 skipped (hours work missed helping SP, whether paid for hours helping SP, how helping SP affected work); LML caregivers asked EC19-EC22 (whether working, still working and occupation)
HI section	Section skipped	Section skip removed; only items HI18-25 (family transfers) skipped.
Other Skip Pattern Changes		
AC7a (difficulty helping)	Item skipped if no financial, physical or emotional difficulty reported in AC6a-c	Item skip removed

Minor Wording Changes. In the PP section a clarification “This includes attending in person or online” was added to PP4 (attend religious service) and PP7 (participate in club meetings or group activities). HD6 was changed from “Not counting you, how many other people live here?” to “Not counting you, how many other people live in your household?” In HI11-HI13, categories for income (asked if an exact value is not provided) are the same for all household sizes. Previously, NSOC I–NSOC III included income bracket values that varied for respondents with different household sizes, based on Poverty Guidelines published by the Department of Health and Human Services.

Data Files

Each round of the NSOC IV data release consists of multiple files. Table 10 presents the sample size for each file for Round 11, which has only cross-sectional samples.

Round / File	Cross-sectional Files (N)	Longitudinal Files (N)
Round 11 (2021)		
NSOC File	1,938	-
Sample Person Tracker File	3,817	-
Other Person Tracker File	39,207	-
Round 12 (2022)		
NSOC File	2,431	-
Sample Person Tracker File	6,327	-
Other Person Tracker File	49,691	-

The **NSOC file** provides one record for each caregiver who participated in NSOC (who cared for an older adult in the last year). This file may be linked to NHATS SP files using the spid variable

(Sample Person Identifier) and to NHATS OP files and other NSOC files using the spid and opid variables (Other Person Identifier).

In addition to items shown in the instrument, the NSOC file includes: gender and relationship to the Sample Person (from the NHATS OP file); month of NSOC interview; days between the NHATS Sample Person (or LML) interview and the NSOC interview; whether the caregiver cared for a living or deceased SP; interview mode; and whether the mode changed during the interview (and if so at what question).

In addition, when collecting amounts (months/years, hours, dollars) the web and telephone instruments followed different paths through the instrument. In these cases, derived variables have been created the combine mode-specific items into a single variable: DC11-DC11c number of years helping; EC15-EC15c number of hours of work missed; HI15-HI17 amount paid for SP's care; HI18a-HI21 amount of financial help or gifts to SP; and HI22A-HI25 amount of financial help or gifts received from SP.

Imputed income for Round 11 was provided in the final release of NSOC IV Round 11 along with a technical paper describing the imputation process (Hu & Freedman 2022). Imputed income for Round 12 will be provided in the final release of NSOC IV Round 12.

The *Sample Person Tracker File* includes all persons with a Sample Person interview in the relevant round of NHATS. This file may be linked to NHATS files and other NSOC files using spid. The file includes variables indicating eligibility for NSOC, counts of the number of eligible and sampled helpers, and a flag indicating the vital status (alive/deceased) of the NHATS Sample Person.

The *Other Person Tracker File* includes one observation for each person in the NHATS OP file. This file may be linked to NHATS files using spid and to other NSOC files using spid and opid. The file includes derived variables indicating NSOC eligibility and result status as well as SP's vital status at the time of the NSOC interview.

Variable Names and Missing Data Conventions

Variable names. Variable names in the NSOC cross-sectional files follow a standard convention. Variables start with “c” (for caregiving), followed by section letters (e.g. CA or DC), followed by NHATS round number (e.g. 1, 5, 7, or 11). This “stem” is followed by a name that reflects the question asked. Whenever possible we used the same name across rounds of NSOC, allowing only the round number (or if section changed, the section letters) to vary.

Derived variable names. Variables that are created for users (“derived” variables), use the same naming convention as other variable names, but a “d” is included after the round number. Details on the construction of specific derived variables are provided in Appendix B.

Flags. Flags are special variables that are either set earlier in the interview or derived from

information in the interview. Typically, flags do not originate from a single item in a section. Flags start with “fl”, then the round number, and then “d” if they are derived, followed by a description of the flag.

Routing flags indicate a skip pattern, or in some cases a skip error (see data notices and corrections, below). In NSOC IV, fl#routing is provided, a global indicator of the path followed (e.g. 2-CG helped in the last month and SP was alive; 3-CG helped in the last month of life and SP deceased; 4-CG did not help in the last month and SP was alive; 5-CG did not help in the last month of life and SP deceased).

Missing Data. NSOC use the NHATS convention of assigning -1 to variables with purposeful skips, -7 to refused and -8 to don’t know and -9 to missing.

In NSOC IV, we used an expanded indicator of a purposeful skip to reflect *why* an individual skipped an item as follows:

-9 missing (skipped incorrectly)

-8 don’t know (phone)

-7 refused (phone)

-6 DK/RF (web)

-5 Did not help last month of life, SP deceased

-4 Did not help last month, SP alive-3 helped in last month of life, SP deceased

-2 helped in last month, SP alive

-1 legitimate skip (includes items purposefully skipped for spouses/partners or coresident caregivers and items logically skipped due to a prior response given)

For those who completed NSOC using both modes, the missing values were assigned according to which mode the question was answered. If in phone interview at the current item, -7 or -8 were assigned; if in SAQ at the current item, -6 was assigned.

If a case breaks off before the end of the interview (as indicated by c#breakoffst, with the last item indicated by c#breakoffqt), remaining variables are either filled with -8 (don’t know) or -1 (inapplicable).

Known Issues

AC7Af. In NSOC IV Round 11, in a small number of cases (n=41), when HC5D=1 is the only condition satisfied at Box AC7A, AC7Af (difficulty making COVID-19 vaccine appointment) was erroneously skipped. A skip error flag (flcac1 routing) was included in Round 11 to flag under-collection of this item.

Overview of Weights

The NSOC files include weights that account for differential probabilities of selection and nonresponse along with variables for variance estimation (see Table 11). In NSOC IV separate cross-sectional weights are provided for caregivers to living and deceased SPs. A separate technical paper documents the creation of NSOC IV Weights (Hu et al. 2022). A guide on how

to incorporate the NSOC sample design into analyses is also available (Freedman et al. 2020).

Table 11. NSOC Weights by Sample and File		
Sample	File: weight	NSOC IV
Cross-sectional	NSOC File: caregivers to living SPs	w#cgfinwgt0-56
Cross-sectional	NSOC File: caregivers to deceased SPs	w#cglmlfinwgt0-56

Obtaining NSOC Data

NSOC files are designated as Sensitive for purposes of data release. The Instruments, Variable-Instrument Crosswalk, and Crosswalk of Changes from the Beta Release to Final Release are publicly available at www.nhats.org. To obtain the data files and codebook, go to Sensitive and Restricted Data on the NHATS website and then select Sensitive Data. Download the document titled *Obtaining Sensitive Data from the National Health and Aging Trends Study (NHATS)* and follow the instructions.

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Appendix A. NHATS CC Section Determining NSOC Eligibility

Round 11

Section	CC	[CAREGIVER CONTACT INFO]
BOX CC1	BOX CC1	NOT ON FILE
		<p>If (MO6 = 1 (GETS HELP TO GO OUTSIDE) or MO18 = 1 (GETS HELP GETTING AROUND INSIDE) or MO25 = 1 (GETS HELP GETTING OUT OF BED) or SC3 = 1 (GETS HELP EATING) or SC11 = 1 (GETS HELP WITH BATHING) or SC17 = 1 (GETS HELP USING TOILET) or SC23 = 1 (GETS HELP GETTING DRESSED) or HEALTHREASONHELPWITHLAUNDRY flag = 1 (YES) or HEALTHREASONHELPWITHSHOPPING flag = 1 (YES) or HEALTHREASONHELPWIT`HMEALS flag = 1 (YES) or HEALTHREASONHELPWITHBANKING flag = 1 (YES) or HEALTHREASONHELPWITHHELPTTRACKMEDS flag = 1 (YES) or FACILITY flag = 1 (YES)) and DECEASED flag <>1 (YES), Set SPHIGHNEED flag = 1 (YES).</p> <p>If (MO6 = 1 (GETS HELP TO GO OUTSIDE) or MO18 = 1 (GETS HELP GETTING AROUND INSIDE) or MO25 = 1 (GETS HELP GETTING OUT OF BED) or SC3 = 1 (GETS HELP EATING) or SC11 = 1 (GETS HELP WITH BATHING) or SC17 = 1 (GETS HELP USING TOILET) or SC23 = 1 (GETS HELP GETTING DRESSED)) and DECEASED flag=1 (YES), Set SPHIGHNEEDEOL flag = 1 (YES).</p>
BOX CC2	BOX CC2	NOT ON FILE
		<p>If SPHIGHNEED flag = 1 (YES) or SPHIGHNEEDEOL flag=1(YES), go to BOX CC3. Otherwise, go to BOX CC5 (Determination).</p>

BOX CC3**BOX CC3**

NOT ON FILE

Loop through BOX CC3 for each PERSON ROSTER member with a HELPER flag = 1 (YES).

If INHH flag = 1 (YES), write SP address1, address2, city, state, and zip to PERSON ROSTER for PERSON ROSTER member and set CG ADDRESS flag=1.

If LAST INT INHH flag= 1 (YES) and INHH flag <> 1, write null to address1, address2, city, state, and zip to PERSON ROSTER for PERSON ROSTER member and set CG ADDRESS flag=null.

If PERSON ROSTER member HELPER flag = 1 (YES) and RELATIONSHIP to SP = 1-29 or 91, set CAREGIVER ELIGCG Flag=1 (YES).

Else if PERSON ROSTER member HELPER flag = 1 (YES) and PAIDHELP (from HL5 or HM3) = 2 (NO, NOT PAID), set CAREGIVER ELIGCG Flag=1 (YES).

Otherwise, if PERSON ROSTER member HELPER flag = 1 (YES), set CAREGIVER ELIGCG flag=2 (NO).

Write CAREGIVER ELIGCG flag value to PERSON ROSTER for each member with a HELPER flag=1 (YES).

If NSOC MODE PHONE ONLY Flag = 1 (YES), loop through the PERSON ROSTER and assign roster level CG NSOC MODE PHONE ONLY Flag = 1 (YES) for each member with a CAREGIVER ELIGCG flag=1 (YES).

Loop through the PERSON ROSTER to create NSOC CG ELIGCG COUNT. If CAREGIVER ELIGCG Flag= 1 (YES), increment NSOC CG ELIGCG COUNT by 1.

If NSOC CG ELIGCG COUNT > 5 go to BOX CC4 (Sampling).

Else if 1 <= NSOC CG ELIGCG COUNT <= 5, write CAREGIVER SMPCG flag=1 (YES) to PERSON ROSTER for each member, loop through the PERSON ROSTER to create NSOC CG SMPCG COUNT. If CAREGIVER SMPCG Flag= 1 (YES), increment NSOC CG SMPCG COUNT by 1, and go to BOX CC5. (Determination).

Otherwise, if there are 0 PERSON ROSTER members with CAREGIVER ELIGCG flag=1 (YES), set NSOC CGSMPCG COUNT=0, and go to BOX CC5. (Determination)

BOX CC4**BOX CC4**

NOT ON FILE

When NSOC CG ELIGCG COUNT > 5, generate and assign a CAREGIVER RANDOM NUMBER with an interval of 0-1 for each PERSON ROSTER member with CAREGIVER ELIGCG flag=1 (YES).

Sort the PERSON ROSTER members in ascending order of their random numbers. Assign CAREGIVERSMPCG flag=1 (YES) for the first 5 caregivers. Assign CAREGIVER SMPCG flag = 2 (NO) for the remaining caregivers.

Loop through the PERSON ROSTER to create NSOC CG SMPCG COUNT. If CAREGIVER SMPCG Flag= 1 (YES), increment NSOC CG SMPCG COUNT by 1.

Write CAREGIVER RANDOM NUMBER and CAREGIVER SMPCG flag to PERSON ROSTER for each member

BOX CC5**BOX CC5**

NOT ON FILE

Loop through PERSON ROSTER members with CAREGIVER SMPCG flag=1 (YES) or CG LAST NSOC flag=1 (YES).

If CAREGIVER SMPCG flag=1 (YES) and CG LAST NSOC flag = 1 (YES) set CG TRC flag=1 (CONTINUING).

Else if CAREGIVER SMPCG flag=1 (YES) and CG LAST NSOC flag <> 1(YES) set CG TRC flag=2 (NEW).

Else if CAREGIVER SMPCG flag <>1 (YES) and CG LAST NSOC flag = 1(YES) and CG DECEASED flag <>1 (YES) set CG TRC flag=3 (STOPPED).

Else if CAREGIVER SMPCG flag <>1 (YES) and CG LAST NSOC flag = 1(YES) and CG DECEASED flag =1 (YES) set CG TRC flag=4 (DECEASED).

Loop through PERSON ROSTER members with CAREGIVER SMPCG flag=1 (YES) or CG LAST NSOC flag=1 (YES). If CAREGIVER SMPCG Flag<> 1 (YES) and CG LAST NSOC flag = 1 (YES), increment NSOC CG OTHER COUNT by 1.

Otherwise go to Box CC5A.

Section CC [CAREGIVER CONTACT INFO]

CC1aPRE | **CC1aRE**

DISPLAY INSTRUCTIONS:

If Part 2 (SP Activities) and PROXY Flag = 1 (YES), display "IF NEEDED: ASK FOR PROXY AND CONTINUE INTERVIEW."
Else, blank.

QUESTION TEXT:

{IF NEEDED: ASK FOR PROXY AND CONTINUE INTERVIEW.}

PRESS 1 AND ENTER TO CONTINUE

BOX CC1Pre | **BOX CC1Pe**

If Part 2 (SP Activities) and CAPI PHONE = 2 (LIP), go to BOX CC5A.
If Part 2 (SP Activities) and CAPI Phone = 3 (FIP), and if any ROSTER MEMBER has a CG TRC flag=1 (CONTINUING) or =2(NEW) or =3 (STOPPED)) and CG DECEASED Flag <> 1, go to CC17. Else, go to BOXCC19.
Otherwise, go to BOX CC1.

BOX CC1 | **BOX CC1**

If (MO6 = 1 (GETS HELP TO GO OUTSIDE) or
MO18 = 1 (GETS HELP GETTING AROUND INSIDE) or
MO25 = 1 (GETS HELP GETTING OUT OF BED) or
SC3 = 1 (GETS HELP EATING) or
SC11 = 1 (GETS HELP WITH BATHING) or
SC17 = 1 (GETS HELP USING TOILET) or
SC23 = 1 (GETS HELP GETTING DRESSED) or
HEALTHREASONHELPWITHLAUNDRY flag = 1 (YES) or

HEALTHREASONHELPWITHSHOPPING flag = 1 (YES) or
HEALTHREASONHELPWITHMEALS flag = 1 (YES) or
HEALTHREASONHELPWITHBANKING flag = 1 (YES) or
HEALTHREASONHELPWITHHELPTRACKMEDS flag = 1 (YES) or
FACILITY flag = 1 (YES)) and DECEASED flag <>1 (YES),
Set SPHIGHNEED flag = 1 (YES).

If (MO6 = 1 (GETS HELP TO GO OUTSIDE) or
MO18 = 1 (GETS HELP GETTING AROUND INSIDE) or
MO25 = 1 (GETS HELP GETTING OUT OF BED) or
SC3 = 1 (GETS HELP EATING) or
SC11 = 1 (GETS HELP WITH BATHING) or
SC17 = 1 (GETS HELP USING TOILET) or
SC23 = 1 (GETS HELP GETTING DRESSED)) and DECEASED flag=1 (YES),
Set SPHIGHNEEDEOL flag = 1 (YES).

BOX CC2

|BOX CC2

If SPHIGHNEED flag = 1 (YES) or SPHIGHNEEDEOL flag = 1 (YES), go to BOX CC3.
Otherwise, go to BOX CC5 (Determination).

BOX CC3

|BOX CC3

Loop through BOX CC3 for each PERSON ROSTER member with a HELPER flag = 1 (YES).

If INHH flag = 1 (YES), write SP address1, address2, city, state, and zip to PERSON ROSTER for PERSON ROSTER member and set CG ADDRESS flag=1.

If LAST INT INHH flag = 1 (YES) and INHH flag <> 1, write null to address1, address2, city, state, and zip to PERSON ROSTER for PERSON ROSTER member and set CG ADDRESS flag=null.

If PERSON ROSTER member HELPER flag = 1 (YES) and RELATIONSHIP to SP = 1-29 or g1, set CAREGIVER ELIGCG Flag=1 (YES).

Else if PERSON ROSTER member HELPER flag = 1 (YES) and PAIDHELP (from HL5 or HM3) = 2 (NO, NOT PAID), set CAREGIVER ELIGCG Flag=1 (YES).

Otherwise, if PERSON ROSTER member HELPER flag = 1 (YES), set CAREGIVER ELIGCG flag=2 (NO).

Write CAREGIVER ELIGCG flag value to PERSON ROSTER for each member with a HELPER flag=1 (YES).

Loop through the PERSON ROSTER to create NSOC CG ELIGCG COUNT. If CAREGIVER ELIGCG Flag = 1 (YES), increment NSOC CG ELIGCG COUNT by 1.

If NSOC CG ELIGCG COUNT > 5 go to BOX CC4 (Sampling).
Else if 1 <= NSOC CG ELIGCG COUNT <= 5, write CAREGIVER SMPCG flag=1 (YES) to PERSON ROSTER for each member, loop through the PERSON ROSTER to create NSOC CG SMPCG COUNT. If CAREGIVER SMPCG Flag= 1 (YES), increment NSOC CG SMPCG COUNT by 1, and go to BOX CC5. (Determination).

Otherwise, if there are 0 PERSON ROSTER members with CAREGIVER ELIGCG flag=1 (YES), set NSOC CGSMPCG COUNT=0, and go to BOX CC5. (Determination)

BOX CC4

|BOX CC4

When NSOC CG ELIGCG COUNT > 5, generate and assign a CAREGIVER RANDOM NUMBER with an interval of 0-1 for each PERSON ROSTER member with CAREGIVER ELIGCG flag=1 (YES).

Sort the PERSON ROSTER members in ascending order of their random numbers. Assign CAREGIVER SMPCG flag=1 (YES) for the first 5 caregivers. Assign CAREGIVER SMPCG flag = 2 (NO) for the remaining caregivers.

Loop through the PERSON ROSTER to create NSOC CG SMPCG COUNT. If CAREGIVER SMPCG Flag= 1 (YES), increment NSOC CG SMPCG COUNT by 1.

Write CAREGIVER RANDOM NUMBER and CAREGIVER SMPCG flag to PERSON ROSTER for each member with a CAREGIVER ELIGCG flag=1 (YES).

BOX CC5

|BOX CC5

Loop through PERSON ROSTER members with CAREGIVER SMPCG flag=1 (YES) or CG LAST NSOC flag=1 (YES).

If CAREGIVER SMPCG flag=1 (YES) and CG LAST NSOC flag = 1 (YES) set CG TRC flag=1 (CONTINUING).

Else if CAREGIVER SMPCG flag=1 (YES) and CG LAST NSOC flag <> 1 (YES) set CG TRC flag=2 (NEW).

Else if CAREGIVER SMPCG flag <>1 (YES) and CG LAST NSOC flag = 1 (YES) and CG DECEASED flag <>1 (YES) set CG TRC flag=3 (STOPPED).

Else if CAREGIVER SMPCG flag <>1 (YES) and CG LAST NSOC flag = 1 (YES) and CG DECEASED flag =1 (YES) set CG TRC flag=4 (DECEASED).

Loop through PERSON ROSTER members with CAREGIVER SMPCG flag=1 (YES) or CG LAST NSOC flag=1 (YES). If CAREGIVER SMPCG Flag<> 1 (YES) and CG LAST NSOC flag = 1 (YES), increment NSOC CG OTHER COUNT by 1.

If all ROSTER MEMBERS have a CG TRC flag=4 (DECEASED) go to BOX CC19. (Write out case)

Otherwise go to Box CC5A.

Appendix B. NSOC Derived Variables

NSOC Cross-sectional files

Variable Name VARIABLE LABEL	CODING SPECIFICATIONS	VALUES and VALUE LABELS
c#dintmode C# D INTERVIEW MODE	1 if CATI only 2 if SAQ only 3 if CATI first and then SAQ 4 if SAQ first and then CATI	1 Phone only 2 Web only 3 Phone first then web 4 Web first then phone
c#dmodechg C# D QUESTION WHERE CG CHANGED MODE	If c#dintmode = 3 or 4, section letters and question number of first item displayed in the new mode -9 if c#dintmode =3 or 4 and cannot determine the item where the mode switch occurred Else -1	Section-Item -9 Missing -1 Inapplicable
c#gender C# CG GENDER FROM OP FILE	c#gender = op#gender (from NHATS)	1 Male 2 Female
c#relatnshp C# OPRELATNSHP FROM OP FILE	c#relatnshp = op#relatnshp (from NHATS)	2 Spouse/ Partner 3 Daughter 4 Son 5 Daughter-In-Law 6 Son-In-Law 7 Stepdaughter 8 Stepson 9 Sister 10 Brother 11 Sister-In-Law 12 Brother-In-Law 13 Mother 14 Stepmother 15 Mother-In-Law 16 Father 17 Stepfather 18 Father-In-Law 19 Granddaughter 20 Grandson 21 Niece 22 Nephew

		23 Aunt 24 Uncle 25 Cousin 26 Stepdaughter's Son/ Daughter 27 Stepson's Son/ Daughter 28 Daughter-In-Law's Son/ Daughter 29 Son-In-Law's Son/ Daughter 30 Boarder/Renter 31 Paid Aide/ Housekeeper/ Employee 32 Roommate 33 Ex-Wife/ Ex-Husband 34 Boyfriend/ Girlfriend 35 Neighbor 36 Friend 38 Co-Worker 39 Minister, Priest, Or Other Clergy 41 Deceased Spouse/Partner 91 Other Relative 92 Other Nonrelative
c#intmonth C# MONTH OF NSOC INTERVIEW	Month of the NSOC interview	7 July 8 August 9 September 10 October 11 November 12 December
c#dintdays C# D DAYS BETWN SP INT CG INT	Days between the NHATS Sample Person interview and the NSOC interview	1 30 days or less 2 31 to 60 3 61 to 90 4 91 to 120 5 121 days or more
c#breakoffst C# CASE BREAKOFF STATUS	1 if breakoff -1 otherwise	1 Yes - Breakoff -1 Inapplicable
c#breakoffqt C# CASE BREAKOFF QUESTION	Section letters and question number where breakoff occurred	Section-Item -1 Inapplicable

<p>cdc#dhlpys C# D NUMBER OF YEARS HELPING</p>	<p>If CATI: if DC11=1: cc#dhlpys = number of years reported at DC11a if DC11a >= 0 if DC11=2: cc#dhlpys = 2021 – year reported at DC11b if DC11b >= 0</p> <p>If SAQ: dc#dhlpys = number of years reported at DC11c if DC11c >= 0</p> <p>-8 if CATI & (DC11 = -8 or DC11a = -8 or DC11b = -8) -7 if CATI & (DC11 = -7 or DC11a = -7 or DC11b = -7) -6 if SAQ & DC11c is left blank by respondents Else -1</p>	<p>0 to 67 -9 Missing -8 DK (phone) -7 RF (phone) -6 DK/RF (web) -1 Inapplicable</p>
<p>chd#dmartstat C# D HD1 MARITAL STATUS</p>	<p>chd#dmartstat = hh#dmarstat if c#relatnshp=2 and fl#spdied = -1 chd#dmartstat = -6 if SAQ & HD1 is skipped Else chd#dmartstat=HD1</p>	<p>-9 Missing -8 DK (phone) -7 RF (phone) -6 DK/RF (web) 1 Married 2 Living with a partner 3 Separated 4 Divorced 5 Widowed 6 Never married</p>
<p>chd#dnuminh C# D HD6 NUMBR OF PEOPLE LIVE IN HH INCLUDING CG</p>	<p>-6 if SAQ & HD6 is skipped Else chd#dnuminh=chd#numinh +1 if chd#numinh >=0 Else chd#dnuminh=chd#numinh</p>	<p>1 to 16 -9 Missing -8 DK (phone) -7 RF (phone) -6 DK/RF (web)</p>
<p>chd#dage C# D HD9 CG AGE</p>	<p>Round 11: -6 if SAQ & (HD9A or HD9B or HD9C is skipped) -8 if CATI & (HD9A or HD9B or HD9C =-8) -7 if CATI & (HD9A or HD9B or HD9C =-7) Else calculate age based on birth date in HD9 and NSOC interview date</p>	<p>-9 Missing -8 DK (phone) -7 RF (phone) -6 DK/RF (web) Age in years</p>

	<p>Starting in Round 12: -6 if SAQ & ((HD9A or HD9B or HD9C is skipped) & HD9D is skipped) -8 if CATI & ((HD9A or HD9B or HD9C =-8 or -7) & HD9D =-8) -7 if CATI & ((HD9A or HD9B or HD9C =-8 or -7) & HD9D =-7) Else if HD9 is a valid date, calculate age based on birth date in HD9 and NSOC interview date Else age at HD9D</p>	
<p>chd#dspouage C# D HD10 SPOUS PARTR AGE</p>	<p>Round 11: -6 if SAQ & (HD10A or HD10B or HD10C is skipped) & chd#dmartstat=1 or 2 -8 if CATI & (HD10A or HD10B or HD10C =-8) & chd#dmartstat=1 or 2 -7 if CATI & (HD10A or HD10B or HD10C =-7) & chd#dmartstat=1 or 2 -1 if chd#dmartstat != 1 & chd#dmarstat != 2 Else calculate age based on birth date in HD10 and NSOC interview date</p> <p>Starting in Round 12: -6 if SAQ & (HD10A or HD10B or HD10C is skipped) & (chd12dmartstat=1 or 2) & HD9D is skipped -8 if CATI & (HD10A or HD10B or HD10C =-8 or -7) & (chd12dmartstat=1 or 2) & HD10D =-8 -7 if CATI & (HD10A or HD10B or HD10C =-8 or -7) & (chd12dmartstat=1 or 2) & HD10D =-7 -1 if chd12dmartstat != 1 & chd12dmarstat != 2 Else if HD10 is a valid date, calculate age based on birth date in HD10 and NSOC interview date Else age at HD10D</p>	<p>-9 Missing -8 DK (phone) -7 RF (phone) -6 DK/RF (web) -1 Inapplicable (not married or living with partner) Age in years</p>
<p>crl#dcgracehisp C# D CG RACE AND HISPANIC ETHNICITY</p>	<p>1 if (crl#yourrace1 = 1 and crl#primarace = - 1 and crl#hisplatno = 2 or -7 or -8 or -6) or (crl#primarace = 1 and crl#hisplatno = 2 or -7 or -8 or -6) 2 if (crl#yourrace2 = 1 and crl#primarace = - 1 and crl#hisplatno = 2 or -7 or -8 or -6) or (crl#primarace = 2 and crl#hisplatno = 2 or -7 or -8 or -6)</p>	<p>1 White, non-Hispanic 2 Black, non-Hispanic 3 Other (Am Indian/Asian/Native Hawaiian/Pacific Islander/other specify), non-Hispanic 4 Hispanic</p>

	<p>3 if [(crl#yourrace3 = 1 or crl#yourrace4 = 1 or crl#yourrace5 = 1) and crl#primarace = - 1 and crl#hisplatno = 2 or -7 or -8 or -6] or (crl#primarace = 3 or 4 or 5 and crl#hisplatno = 2 or -7 or -8 or -6)</p> <p>4 if crl#hisplatno =1</p> <p>6 if (crl#yourrace1 through crl#yourrace5 and crl#hisplatno) = 2 or -7 or -8 or -6 or -1</p> <p>ELSE 5 if crl#primarace = -7 or -8 or -6 or -1</p>	<p>5 More than one and DKRF primary</p> <p>6 DKRF</p>
<p>cec#dmswkunit C# D HRS MISS WORK HELP UNIT</p>	<p>-5 if fl#routing=5</p> <p>-4 if fl#routing=4</p> <p>-3 if fl#routing=3</p> <p>1 if SAQ & hours entered at EC15c</p> <p>If CATI, cec#dmswkunit = cec#mswkunit (EC15)</p> <p>Else -1</p>	<p>-9 Missing</p> <p>-8 DK (phone)</p> <p>-7 RF (phone)</p> <p>-6 DK/RF (web)</p> <p>-5 Did not help last month of life, SP deceased</p> <p>-4 Did not help last month, SP alive</p> <p>-3 Helped last month of life, SP deceased</p> <p>-1 Inapplicable</p> <p>1 Hourly</p> <p>2 Daily</p>
<p>cec#dmswkhlp C# D NUM HRS MISS WORK HELP</p>	<p>Calculate numbers of hours missed work</p> <p>If CATI and EC15=1: cec#dmswkhlp = number of hours reported at EC15a</p> <p>If SAQ: cec#dmswkhlp = number of hours reported at EC15c</p> <p>-5 if fl11routing=5</p> <p>-4 if fl11routing=4</p> <p>-3 if fl11routing=3</p> <p>Else -1</p>	<p>-9 Missing</p> <p>-8 DK (phone)</p> <p>-7 RF (phone)</p> <p>-6 DK/RF (web)</p> <p>-5 Did not help last month of life, SP deceased</p> <p>-4 Did not help last month, SP alive</p> <p>-3 Helped last month of life, SP deceased</p> <p>-1 Inapplicable</p> <p>1 to 190 hours</p>
<p>cec#dworktype C# D TYPE WORK DURNG LIFETIME</p>	<p>1 if (CATI & cec#worktype = 1) or (SAQ & EC20^=EC22)</p> <p>2 if (CATI & cec#worktype = 2) or (SAQ & (EC20=EC22 or ("same" or other similar text in EC22)))</p>	<p>-9 Missing</p> <p>-8 DK (phone)</p> <p>-7 RF (phone)</p> <p>-6 DK/RF (web)</p>

	<p>97 if (CATI & cec#worktype = 97) or (SAQ & (EC22 = "never worked" or other similar text)) -8 if CATI & EC21 = -8 -7 if CATI & EC21 = -7 -6 if SAQ & (EC20 or EC22 is left blank) Else -1</p>	<p>-1 Inapplicable 1 Enter occupation 2 Current occupation same 97 Never worked for pay</p>
<p>cec#docpdscr C# D LIFETIME OCCUP DESCRIPT</p>	<p>Use occupation at EC21a if CATI & EC21=1 Use occupation at EC20 if CATI & EC21=2 Use EC20 if SAQ & EC22 = "same" or other similar text Use EC22 if SAQ -8 if CATI & EC21 = -8 -7 if CATI & EC21 = -7 -6 if SAQ & (EC22 is left blank) Else -1</p>	<p>-9 Missing -8 DK (phone) -7 RF (phone) -6 DK/RF (web) -1 Inapplicable 1 Management Occupations: 0010-0430 2 Business and Financial Operations Occupations: 0500-0950 3 Computer and mathematical Occupations: 1000-1240 4 Architecture and engineering Occupations: 1300-1560 5 Live, Physical, and social Science Occupations: 1600-1965 6 Community and social Service Occupations: 2000-2060 7 Legal Occupations: 2100-2160 8 Education, Training, and Library Occupations: 2200-2550 9 Arts, Design, Entertainment, sports, and Medic Occupations: 2600-2960 10 Healthcare Practitioners and Technical Occupations: 3000-3540 11 Health care Support Occupations: 3600-3655 12 Protective Service Occupations: 3700-3955 13 Food Preparation and Servicing Related occupations: 4000-4160</p>

		14 Building and Grounds Cleaning and Maintenance Occupations: 4200-4250 15 Personal Care and Service Occupations: 4300-4650 16 Sales and Related Occupations: 4700-4965 17 Office and Administrative Support Occupations: 5000-5940 18 Farming, Fishing, and Forestry Occupations: 6000-6130 19 Construction and Extraction Occupations: 6200-6940 20 Installation, Maintenance, and Repair Occupations: 7000-7630 21 Production Occupations: 7700-8965 22 Transportation and Material Moving Occupations: 9000-9750 23 Military Specific Occupations: 9800-9830* 24 No current occ (Unemployed, no work in the last 5 years, never worked): 9920 94 Uncodable
chi#dpaycat C# D PAY CATEGORY TO HELP	1 if (SAQ & HI15A=1) or (CATI & HI17=1) 2 if (SAQ & HI15A=2) or (CATI & HI15=2 & HI17=2) 3 if (SAQ & HI15A=3) or (CATI & HI15=1 & HI16=2) 4 if (SAQ & HI15A=4) or (CATI & HI16=1) -8 if CATI & HI15=-8 or HI16=-8 or HI17=-8 -7 if CATI & HI15=-7 or HI16=-7 or HI17=-7 -6 if SAQ & HI15a is skipped Else -1	-9 Missing -8 DK (phone) -7 RF (phone) -6 DK/RF (web) -1 Inapplicable 1 Less than \$500 2 \$500 to less than \$1,000 3 \$1,000 to less than \$2,000 4 \$2,000 or more
chi#dgiftospcat C# D FINANCIAL GIFT TO SP CATEGORY	1 if (SAQ & HI18A=1) or (CATI & HI21=1) 2 if (SAQ & HI18A =2) or (CATI & HI19=2 & HI21=2) 3 if (SAQ & HI18A =3) or (CATI & HI19=1 & HI20=2)	-9 Missing -8 DK (phone) -7 RF (phone)

	4 if (SAQ & HI18A =4) or (CATI & HI20=1) -8 if CATI & HI19=-8 or HI20=-8 or HI21=-8 -7 if CATI & HI19=-7 or HI20=-7 or HI21=-7 -6 if SAQ & HI18A is left blank Else -1	-6 DK/RF (web) -1 Inapplicable 1 Less than \$100 2 \$100 to less than \$500 3 \$500 to less than \$1,000 4 \$1,000 or more
chi#dfromspcat C# D FINANCIAL GIFT FROM SP CATEGORY	1 if (SAQ & HI22A=1) or (CATI & HI25=1) 2 if (SAQ & HI22A =2) or (CATI & HI23=2 & HI25=2) 3 if (SAQ & HI22A =3) or (CATI & HI23=1 & HI24=2) 4 if (SAQ & HI22A =4) or (CATI & HI24=1) -8 if CATI & HI23=-8 or HI24=-8 or HI25=-8 -7 if CATI & HI23=-7 or HI24=-7 or HI25=-7 -6 if SAQ & HI22A is left blank Else -1	-9 Missing -8 DK (phone) -7 RF (phone) -6 DK/RF (web) -1 Inapplicable 1 Less than \$100 2 \$100 to less than \$500 3 \$500 to less than \$1,000 4 \$1,000 or more
FLAG fl#routing C# F NSOC ROUTING	2 if fl#spdied=-1 and fl#helpstmth=1 3 if fl#spdied=1 and fl#helpstmth=1 4 if fl#spdied=-1 and (fl#helpyear=1 or fl#nohelpyear=1) 5 if fl#spdied=1 and (fl#helpyear=1 or fl#nohelpyear=1)	2 Helped last month, SP alive 3 Helped last month of life, SP deceased 4 Did not help last month, SP alive 5 Did not help last month of life, SP deceased
FLAG flcacl1routing C11 F AC7AF MISSING DUE TO ROUTING ERROR	Flag indicating records with missing data (-9) in AC7Af	-1 Inapplicable 1 Yes
FLAG chi#incimf C# F IMPUTED INCOME LAST YEAR FLG	1 if income value reported in HI10 2 if income missing in NSOC, and reported income values in NHATS were brought over (Spouse/partner of SP) 3 if income imputed in NSOC 4 if income missing in NSOC, and imputed income values in NHATS were brought over (Spouse/partner of SP)	1 = Reported in NSOC IV 2 = Reported in NHATS R11 (Spouse/partner of SP) 3 = Imputed in NSOC IV 4 = Imputed in NHATS R11 (Spouse/partner of SP)

fl#dnsoc R# F CC Sample Person IS ELIGIBLE FOR NSOC	1 if SP has any OP with op#dnsocelig = 1 -1 otherwise	1 Sample Person eligible for cross-sectional NSOC -1 Inapplicable
fl#dnsocent R# F CC CNT HLPRS ELG FOR NSOC	NSOC I, II and III: Number of caregivers eligible for NSOC (op#dnsocelig = 1; up to 5) for each eligible SP	1 to 5 -1 Inapplicable
fl#dcgcontactinfo R# F CNT HLPRS WITH CONTACT INFO	Number of eligible caregivers that eligible Sample Person provided contact information for	0 to 5 -1 Inapplicable
fl#dnsocomp R# D CC CNT HLPRS WITH NSOC COMP	If fl#dnsoc = 1: count of OPs who completed NSOC and with op#dnsocelig = 1 Else -1	0 to 5 -1 Inapplicable
fl#dtrackspstat R# F D SP VITAL STATUS AT INTERVIEW	1 if [r11status = 60 or 63 and CA1PRE NE 7] and fl11dnsoc = 1 2 if r10status=62 and fl11dnsoc = 1 3 if r11status=62 and fl11dnsoc = 1 4 if [r11status = 60 or 63 and all op11dnsocelig=1 caregivers completed NSOC with CA1PRE=7] and fl11dnsoc = 1 5 if r11status = 60 or 63 and (at least one op11dnsocelig=1 caregiver has CA1PRE=7 and at least one op11dnsocelig=1 caregiver has CA1PRE NE 7 (including any eligible caregivers where CA1PRE was not asked at all because NSOC wasn't completed)) and fl11dnsoc = 1 Else = -1 (all OPs for SP are op11dnsocelig = -1 or r11status = 61 or 64)	1 SP interview at Round 11 NHATS & alive at NSOC 3 SP Round 11 LML 4 SP interview at Round 11 & deceased at NSOC 5 SP interview at Round 11 & more than 1 caregiver & at least 1 caregiver reports SP deceased at NSOC -1 Inapplicable

NSOC OP Tracker Files (Cross-Sectional)

op#dnsocelig R# D CAREGIVER IS ELIGIBLE FOR NSOC	1 if OP meets eligibility criteria -1 otherwise	1 Helper eligible for cross-sectional NSOC -1 Inapplicable
op#dnsoc R# D NSOC STATUS	1 = Eligible helper who was interviewed 2 = Eligible helper refused interview 3 = Eligible helper not interviewed other reasons 4 = Eligible helper and not interviewed SP did not provide contact information 5 = Eligible helper not fielded for interview	1 Eligible and interviewed 2 Eligible and caregiver refused 3 Eligible and caregiver not interviewed other reasons 4 Eligible and not interviewed SP did not provide contact information

	6 = Helper ineligible because Sample Person had more than 5 caregivers and helper not sampled 7 = Named by Sample Person as a helper but determined ineligible (caregiver under age, caregiver died) -1 = all other persons on the NHATS OP file	5 Eligible caregiver not fielded for interview 6 >5 caregivers and not sampled 7 Named by SP but Ineligible -1 Inapplicable
op#dnsoccomplete R# D CAREGIVER NSOC COMPLETE	1 = NSOC interview complete -1 = Inapplicable	1 NSOC interview complete -1 Inapplicable
op#dtracksstat R# D Sample Person VITAL STATUS AT INTERVIEW	1 if [r#status = 60 or 63 and CA1PRE NE 7] and op#dnsocelig = 1 3 if r#status=62 and op#dnsocelig = 1 4 if [r#status = 60 or 63 and CA1PRE=7] and op#dnsocelig = 1 Else = -1 (if op#dnsocelig = -1)	1 SP interview at Round # NHATS & alive at NSOC 3 SP Round # LML 4 SP interview at Round # & deceased at NSOC -1 Inapplicable
op#dnamedhelper R# D OP NAMED AS HELPER IN NHATS	1 if OP named as helper in NHATS interview -1 otherwise	1 OP named as helper in NHATS interview -1 Inapplicable
op11dmixmode R11 D RANDOMLY ASSIGNED TO MIXED MODE OR PHONE ONLY	1 assigned to mixed mode group 2 assigned to phone-only group *Round 11 only	1 Assigned to mixed mode 2 Assigned to phone only