

NHATS User Guide for Dementia HCBS Research

Community Care Network for Dementia (CaN-D) Data Hub Resource

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Background

The National Health and Aging Trends Study (NHATS), begun in 2011, is a nationally representative longitudinal panel study of late-life disability and function among Medicare beneficiaries aged 65 years and older. Over 8,000 sampled individuals or their proxy respondents are interviewed annually. The sample is refreshed periodically. For individuals who die, proxy respondents complete a last month of life (LML) interview focused on quality of end-of-life care. Periodically, caregivers of NHATS respondents are interviewed in the supplemental National Study of Caregiving (NSOC), which focuses on the experiences of family and unpaid caregivers.

NHATS can be used to study national disability trends and individual trajectories. The data collected annually for NHATS respondents includes health conditions and treatment, physical impairments and symptoms, cognition, physical capacity, activity limitations, negative consequences related to unmet need for assistance, social environment, physical environment, technological environment, service environment, transportation, hours of assistance received from paid and unpaid helpers, wellbeing, and economic status.

Citation: Vicki A. Freedman. Late-Life Disability and Care: An Update from the National Health and Aging Trends Study at Its 10-Year Mark, *The Journals of Gerontology: Series B*, Volume 77, Issue Supplement_1, May 2022, Pages S1–S8, <https://doi.org/10.1093/geronb/gbac042>

Data Access and Version

Public use files can be obtained from <https://nhats.org/researcher/data-access/public-use-files>

An account is needed to obtain the files. Sensitive and restricted files require additional application processes to obtain. Current documentation and do files are based on NHATS Rounds 1-12 Beta Release. Latest user guide:

Vicki A. Freedman, Jennifer A. Schrack, and Maureen E. Skehan. 2023. National Health and Aging Trends Study User Guide: Rounds 1-12 Beta Release. Baltimore: Johns Hopkins Bloomberg School of Public Health. Available at www.NHATS.org.

NHATS File Organization

There have been 12 rounds of annual NHATS surveys since 2011. The latest data release is the Beta version, so Round 12 crosswalks and documentation may change when the final version is released. After the initial sample in 2011, replenishment of the sample to maintain representation occurred in 2015 and 2022-2023. Interviews changed from wave to wave, sometimes substantially, requiring crosswalks to merge across the waves.

Each round of the NHATS survey includes three raw data files:

- SP (sample person or a designated proxy for the sample person) is the main interview file with data on the sample person. The Facility Questionnaire (FQ) is completed with a staff person when the SP resides in a residential care setting, such as a nursing home. The Last Month of Life interview (LML) is done with a proxy respondent if the SP is deceased.
- OP (other person) is the file for other persons identified in the SP interview. They can be a proxy respondent, spouse/partner, household member, child, social network member, helper, caregiver, and a contact person.
- Tracker includes all persons ever sampled for NHATS and their weights.

Variables

Raw and derived variables from SP and OP files are listed under ***NHATS variables.xlsx***. The file contains the variable names and short descriptions of the variables. Please refer to the NHATS Data Collection Instrument files (available on NHATS.org) for more details.

Dementia Classification: NHATS collects the following information on dementia and cognition:

- A report by the sample person or a proxy respondent that a doctor told the sample person they had dementia or Alzheimer's disease
- Alzheimer's disease 8 (AD8) Screening Interview – a brief informant interview used to detect dementia (**completed by proxy respondent only**)
- Cognitive tests to evaluate the sample person's memory (immediate and delayed 10-word recall), orientation (date, month, year, and day of the week; naming the President and Vice President), and executive function (clock drawing test)

The following criteria are used to classify respondents as having probable dementia, possible dementia, or no dementia (i.e., ***demclas***):

- Probable dementia
 - A report by either the sample person or a proxy respondent that a doctor told the sample person they had dementia or Alzheimer's disease **AND/OR**
 - Score of 2 or higher on the AD8 **AND/OR**
 - cognitive tests indicate impairment (1.5 or more standard deviations below the mean) in **two or more domains** (memory, orientation, and/or executive function)
- Possible dementia
 - Respondent does not meet the above criteria for probable dementia, but cognitive tests indicate impairment (1.5 or more standard deviations below the mean) in **one or more domains** (memory, orientation, and/or executive function)
- No dementia
 - All others (excluding respondents who were permanent nursing home residents in the initial round, as NHATS did not interview these respondents at baseline)

See [NHATS technical papers and dementia classification code](#) from NHATS.org for more detail:

Kasper, Judith D., Freedman, Vicki A., and Spillman, Brenda. 2013. Classification of Persons by Dementia Status in the National Health and Aging Trends Study. Technical Paper #5. Baltimore: Johns Hopkins University School of Public Health. Available at www.NHATS.org.

Kasper, Judith D., Freedman, Vicki A., Spillman, Brenda C., Skehan, Maureen E., and Hu, Mengyao. 2015. Addendum to Classification of Persons by Dementia Status in the National Health and Aging Trends Study for Follow-up Rounds. Baltimore: Johns Hopkins Bloomberg School of Public Health. Available at www.NHATS.org.

Dementia Harmonization with Other Cohort Studies: This [technical paper](#) describes how NHATS dementia classification compares to the Health and Retirement Study (HRS) Aging Demographics, and Memory (ADAMS) criteria:

Kasper, Judith D., Freedman, Vicki A., and Spillman, Brenda. 2013. Classification of Persons by Dementia Status in the National Health and Aging Trends Study. Technical Paper #5. Baltimore: Johns Hopkins University School of Public Health. Available at www.NHATS.org.

HCBS Variables: NHATS includes information on help with daily activities (self-care, household, and medical) in the past month: eating, getting out of bed, showering, toileting, dressing, laundry, shopping, meal preparation, medication management, getting around outside, bills and banking, addressing money matters, going to the physician. For each task requiring assistance, a helper is identified, along with the following information about the helper: relationship to respondent, hours of help provided, whether care was paid/unpaid, and payment source if applicable.

This [technical paper](#) provides guidance and code to create comparable hours of care variables across rounds of the NHATS:

Freedman, Vicki A., Brenda C. Spillman, Judith Kasper. 2014. Hours of Care in Rounds 1 and 2 of the National Health and Aging Trends Study. NHATS Technical Paper #7. Baltimore: Johns Hopkins University School of Public Health. Available at www.NHATS.org. This technical paper was prepared with funding from the National Institute on Aging (U01AG032947).

Stata Programs

NHATS_op_variables.do combines all OP variables for each SP. It first combines OP data from all rounds and keeps only OPs that identify as helpers (paid and unpaid). It then collapses the data at the SP-level, to describe:

- How many paid and unpaid helpers helped with a task/activity
- How many hours per day/days per week/days per month paid and unpaid helpers helped
- How many helpers each payment source covered

NHATS_sp_variables.do combines all SP variables across rounds (including corrections to account for cross-round differences in these variables), creates dementia classification variables (demclas and ad8_dem, code adapted from NHATS.org), and merges in the OP variables for helpers.

Raw and intermediate data files are stored under the folder, "raw data files."

The final data file is called **NHATS_CAND.dta**, created by running NHATS_op_variables.do and NHATS_sp_variables.do.