



Home Care Surveys Waves 1-2

User Guide

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PLEASE READ

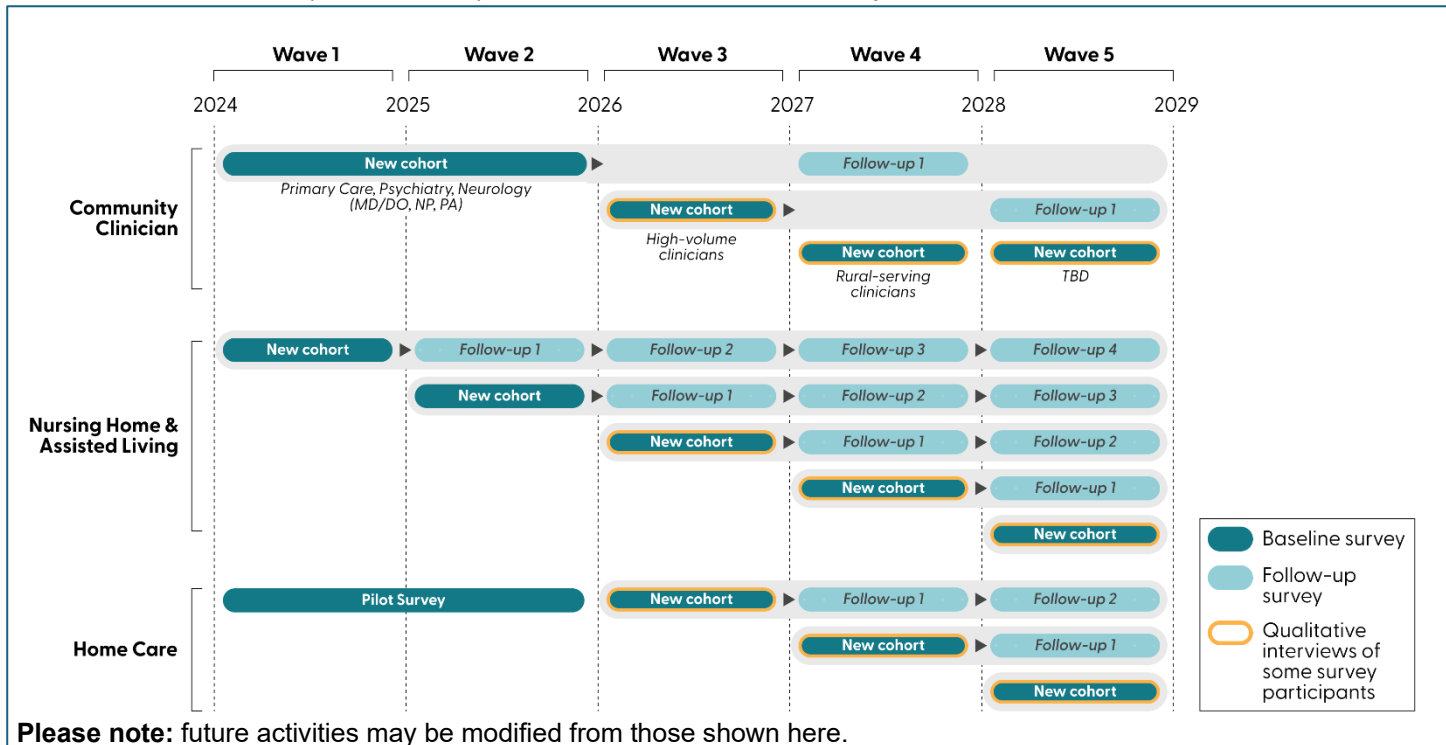
- **All publications using NDWS data should include the following citation:**
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- **All publications should include the following statement in the acknowledgements:**

"The National Dementia Workforce Study data is sponsored by the National Institute on Aging (Grant U54AG084520) and is conducted by the University of Michigan and the University of California, San Francisco."

1. Introduction and Overview

1.1. NDWS Overview

The National Dementia Workforce Study (NDWS), sponsored by the National Institute on Aging (NIA) at the National Institutes of Health (NIH), is a family of nationally representative surveys of the dementia care workforce in the United States. NDWS includes surveys of workers in nursing homes, assisted living communities, home care agencies, and community clinical settings. The following graphic presents an overview of completed (and planned) data collection across the project.



This User Guide documents data collection for the **Home Care (HC)** surveys. It provides an overview of the data collection protocol, survey content, information about sampling, and information necessary to analyze the data.

More information about instruments, sampling frames, other data sources available as part of the study, and instructions for accessing all NDWS data, can be found on the study website: [NDWS.org](https://www.ndws.org).

If you have any questions, please contact info@ndws.org.

1.2. Data Access

NDWS Home Care survey data are released as **Restricted-use files (RUFs)** available through the NIA-funded [LINKAGE](#) platform or the restricted data enclave of the Michigan Center on the Demography of Aging ([MiCDA](#)).

Information about access to other NDWS data is available at: <https://www.ndws.org/surveys-and-data/how-to-access-data>.

Questions may be directed to info@ndws.org.

1.3. Who do the NDWS Home Care surveys represent?

1.3.1. *Home Care Survey*

The HC survey represents staff selected in a two-stage sampling approach, beginning with identifying participating agencies in the first stage from which staff were then sampled. For Wave 1, the sampling frame was a list of home health agencies certified with the Centers for Medicare & Medicaid Services (CMS). For Wave 2, the sampling frame included both the list of CMS-certified home health agencies as well as a list of home care agencies developed by the study team contacting each of the 50 states and the District of Columbia.

- For Wave 1, 200 HC agencies were selected from a sampling frame of approximately 12,000 agencies.
- For Wave 2, 300 HC agencies were selected from an updated and expanded sampling frame of approximately 47,000 agencies.

Within each sampled agency, a roster of eligible staff was obtained to select staff for the survey. Only staff from select direct care roles was eligible. The eligible staff roles—consistent with the Nursing Home and Assisted Living Staff surveys—included:

- Registered Nurse (RN)
- Licensed Practical/Vocational Nurse (LPN/LVN)
- Certified Nursing Aide / Assistant (CNA)
- Nurse Aide / Assistant
- Home Health Aide / Home Health Assistant
- Personal Care Aide / Assistant
- Activity Staff

1.3.2. *Direct Care Worker Pilot in Michigan*

In the process of building the agency-level sample outlined above, we obtained a list of approximately 30,000 direct care workers (DCW) registered with the state of Michigan. To test this direct sampling method as an additional strategy to build the HC survey, we completed a Wave 2 pilot for which we selected a sample of 500 DCWs from this MI list to complete a modified staff survey. Each DCW was individually invited to complete a web survey.

2. Data Collection Results and Content Documentation

2.1. Survey Components

HC Agency data collection in Wave 1 and 2 included two coordinated instruments:

- Administrator Survey, documenting agency-level characteristics. Administrators also provided rosters of eligible staff, which were used to draw probability samples of staff respondents.
- Staff Survey, documenting workforce respondent characteristics and professional experiences.
 - The DCW instrument (for the pilot described in section 1.3.2) included a slightly modified version of the HC Staff survey.

2.2. Response Rates by Survey Wave

Table 1. Sample Sizes and Response Rates			
Survey	Sample Size	Completed Surveys	Response Rate
Wave 1			
Administrator			
Survey	200	24	14.2% ^b
Survey + Roster ^a	200	8	4.7% ^b
Staff	178	40	24.9% ^c
Wave 2			
Administrator			
Survey	300	41	19.4% ^b
Survey + Roster ^a	300	13	6.2% ^b
Staff	259	49	18.9% ^c
DCW Pilot in Michigan	500	138	32.1% ^b

^a These rows are the subsets of the 24 (Wave 1) and 41 (Wave 2) agencies that completed Administrator surveys, who then also submitted a staff roster (i.e., the total number of participating agencies in Wave 1 is 24, not 32 [24+8]).

^b In each wave of data collection, some of the units (agencies or staff) were determined to be ineligible and were excluded from the denominator when calculating the response rate.

^c The final staff response rate is conditional on the administrator submitting a roster and therefore a product of admin and staff response rates (4.7% x 24.9% = 1.2% for Wave 1 and 6.2% x 18.9% = 1.2% for Wave 2)

2.3. Survey Instruments

Tables 2 and 3 describe the content domains of the data collection instruments used in NDWS, with items described in the order presented to respondents. Where applicable, information on item sources and references is provided.

Table 2: NDWS Nursing Home and Assisted Living STAFF Survey Content-at-a-Glance ^a	
Section	Key Topics Covered
Education, training & experience	<p>Licensure and certification, education level, training experiences, and preparedness for dementia care</p> <p><i>Includes content from:</i></p> <ul style="list-style-type: none"> • A Minimum Data Set for the Behavioral Health Workforce • NPALS Direct Care Worker Pilot Study, United States Department of Health and Human Services
Employment status	<p>Years in long-term care, current employment status, multiple job holding, hours, shifts, supervision, wages, benefits, scheduling, transportation, childcare</p> <p><i>Includes content from:</i></p> <ul style="list-style-type: none"> • United States Department of Health and Human Services. National Center for Health Statistics. National Nursing Home Survey, 2004. National Nursing Assistant Supplement • Measuring Precarious Work Schedules • NPALS Direct Care Worker Pilot Study, United States Department of Health and Human Services • Pew Research Center, American Trends Panel Wave Survey (Wave 2 Reinterview Addition)

Table 2: NDWS Nursing Home and Assisted Living STAFF Survey Content-at-a-Glance ^a	
Section	Key Topics Covered
Dementia care knowledge, attitudes & practices	<p>Attitudes toward people with dementia, confidence in care tasks, team functioning, environment and safety, PPE, and resource availability and emergency preparedness</p> <p><i>Includes content from:</i></p> <ul style="list-style-type: none"> • The DAS-6: A Short Form of the Dementia Attitudes Scale • Sense of Competence in Dementia Care Staff (SCIDS) Scale • SOPS ® Workplace Safety Supplemental Item Set for the SOPS Nursing Home Survey
Worker outcomes	<p>Job satisfaction, workplace climate, discrimination, harassment, injuries, burnout, retention intentions</p> <p><i>Includes content from:</i></p> <ul style="list-style-type: none"> • RN4CAST Study • NPALS Direct Care Worker Pilot Study, United States Department of Health and Human Services • NIOSH Worker Well-Being Questionnaire • Development of the Practice Environment Scale of the Nursing Work Index (Wave 2 Addition) • Sheps Center for Health Services Research, University of North Carolina at Chapel Hill • Maslach Burnout Inventory • Relatives of the Impaired Elderly: Correlates of Feelings of Burden (Wave 2 Addition)
Demographics	<p>Age, race/ethnicity, immigration, language, disability, household composition, marriage status, caregiving responsibilities, health</p> <p><i>Includes content from:</i></p> <ul style="list-style-type: none"> • California Board of Registered Nursing 2022 Survey • United States Census Bureau - Citizenship • KFF LA Times Survey of Immigrants • Centers for Disease Control and Prevention - Sexual Orientation • United States Census Bureau - Veterans • National Center for Women and Information Technology Demographics Guide • National Health Interview Survey (Wave 2 Addition) • NPALS Direct Care Worker Pilot Study, United States Department of Health and Human Services • NIOSH Worker Well-Being Questionnaire
<p>^a The NH and AL Staff follow-up surveys included questions on employment status, role and compensation changes, organizational and supervisory shifts, job start and end dates, reasons for leaving positions, job search activity, characteristics of new roles, and comparisons between prior and current employment. Full Wave 2 instruments and the crosswalk are available here: https://www.ndws.org/surveys-and-data/surveys</p>	

Table 3. NDWS Nursing Home and Assisted Living ADMINISTRATOR Survey Content-at-a-Glance	
Section	Key Topics Covered
Organization structure and services	Ownership type, private equity involvement, chain affiliation, years licensed, Medicare/Medicaid certification

Table 3. NDWS Nursing Home and Assisted Living ADMINISTRATOR Survey Content-at-a-Glance	
Section	Key Topics Covered
	<i>Includes content from:</i> <ul style="list-style-type: none"> • Sheps Center for Health Services Research, University of North Carolina at Chapel Hill
Workplace resources and practices	Services, volume of clients/beds, client payer mix, memory care designation, private-pay base rates, EHR adoption <i>Includes content from:</i> <ul style="list-style-type: none"> • Sheps Center for Health Services Research, University of North Carolina at Chapel Hill
Staffing	Staffing, employee benefits, union representation <i>Includes content from:</i> <ul style="list-style-type: none"> • The Office of the National Coordinator for Health Information Technology, Data Brief #39 • Sheps Center for Health Services Research, University of North Carolina at Chapel Hill
Training practices	New-hire training, continuing education <i>Includes content from:</i> <ul style="list-style-type: none"> • Sheps Center for Health Services Research, University of North Carolina at Chapel Hill

2.4. Data and Codebooks

NDWS HC data are released as Restricted-use files available through the NIA-funded LINKAGE platform or the MiCDA enclave.

HC Agency and Staff data are stacked so that both Waves 1 and 2 are reported in one dataset with a variable that indicates the wave of data collection.

The data from the DCW Pilot in Michigan is reported in a separate dataset.

Data dictionary codebooks are intended to support data interpretation and analytic use of the survey files. For each item, the codebooks include the variable name, label, response options, and a frequency distribution of responses, including special values used to represent missing data.

2.5. Special Values for Missing Data

NDWS survey datasets use standardized special values to represent different forms of missing or inapplicable data in the survey. These special values are documented in the data dictionary codebooks and are reflected in the frequency distributions provided for each survey item. **Table 4** below describes the special values used across NDWS surveys, and the example illustrates how these values appear in a codebook frequency table for an individual survey item.

Table 4. Special Values for Missing Data	
Missing value	Represents
“.” Or “ ”	The item was not displayed for this type of respondent (e.g., only Nurse Practitioners saw item <i>Field</i> ; other respondents would have “.”)
-9	The item was displayed but they did not provide answer

Table 4. Special Values for Missing Data	
-8	Respondents selected “don’t know”
-7	Respondents provided an out-of-range value (the web version did not allow this; only possible where the respondent used a paper instrument)
-5	Legitimate skip

The following example shows the distribution of the *OwnershipType* variable available in the HC Admin survey (Restricted Use File).

OwnershipType

Label: Is this home care agency's ownership non-profit, for-profit, or government?

Type: numeric | **Length:** 8

Frequencies for OwnershipType		
Value	Count	Percent
-9=Refuse	1	1.53
1=Non-Profit	6	9.23
2=For-Profit	55	84.61
3=Government	3	4.61

3. Data Analysis

Although HC surveys employed multistage, stratified probability sampling designs, the datasets released in RUF do not include weights given the relatively small samples. Given the lack of weights and small sample sizes, findings derived from analysis of the currently posted HC survey data should not be reported as national estimates of the population of HC staff and agencies in the U.S. It would be more appropriate to consider these data as if coming from a convenience sample, and report them as such. All findings obtained from the unweighted data should be interpreted purely as directional. Any findings derived from analysis of the DCW pilot in Michigan should be only interpreted as directional findings in the context of that state.