



Linked Data

Year 1

Fulfilling the NIA's intent

Language from the RFA that funded NDWS:

- “*What is missing from this literature is how care is supplied to PLWD and what decisions are made by providers and institutions that lead to **wide variations in care** for PLWD.*”
- “*The survey . . . will be **linked to administrative data to provide insight on costs, intensity of care provided, guideline-concordant care received by PLWD, and quality of care experienced by PLWD.***”

The surveys



A family of 4:

- Community Clinician (Physicians, Nurse Practitioners, Physician Assistants)
 - Nursing Home Staff
+ Administrator
 - Assisted Living Staff
+ Administrator
 - Home Care Staff
+ Administrator
- licensed nurses (RN & LPN)
- direct care workers (aides & assistants)


Watch videos on
questionnaires and
sample frames!


So what can these be linked to?

tdsm.app/CentralizeSP/BtwSche X Linkages - Michigan Center on X Home | NDWS


https://www.ndws.org

ChatGPT news &udm=14 proposals PubMed Scholar -->MLibrary U-M access stuff NDWS stuff NDWS linked data secondary data Banking >>

 **NDWS** NATIONAL DEMENTIA WORKFORCE STUDY

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 **Survey Questionnaires**
Data Linkages
How to Access Data

Understanding the Dementia Care Workforce

The National Dementia Workforce Study, sponsored by the NIH National Institute on Aging, is conducting the first large, annual surveys of the dementia care workforce in the United States. Survey data and other linked data sources will create an unprecedented resource for researchers to answer critical questions about the workforce and its impact on care and outcomes for persons living with dementia.


Surveys in Key Practice Settings



Four national surveys are designed to help researchers understand the large and diverse dementia care workforce and how workforce factors impact care.

[Learn More →](#)


Valuable Data Resource



Surveys will be valuable as a standalone data, and they can also be combined with linked data, including beneficiary-level Medicare claims.

[Learn More →](#)

Taking the Survey



If you were invited to complete a survey, you can make an impact on how we understand the dementia care workforce in just 25 minutes.

[Learn More →](#)

Linked data

4 types:

1. Linking administrator + staff respondent surveys
2. Environment (Local context)
3. Claims-based summary files
4. Beneficiary-level CMS claims/encounter/assessment data

From this point forward, when I say “surveys” it means the survey version available in LINKAGE and not the public use files (PUFs).

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From this point forward, when I say “surveys” it means the survey version available in **LINKAGE** and not the public use files (PUFs).

You are going to hear “LINKAGE” a lot

<https://www.nia.nih.gov/research/dbsr/nia-data-linkage-program-linkage>

DBSR Home

NIA Data LINKAGE Program

About LINKAGE

Available data

Access or share LINKAGE data

Migrate shipped CMS data

NIA Data LINKAGE Program (LINKAGE)

The NIA Data LINKAGE Program (LINKAGE)* was established in 2021. The purpose of the Program is to link NIA-funded study data with existing datasets from Centers for Medicare & Medicaid Services (CMS) and other sources and establish a cloud-based environment to support data accessibility and sharing. In providing these resources free of charge, LINKAGE aims to reduce resource cost and time barriers and promote access for researchers.

Studies and Researchers will have access to three primary resources:

1. **Linked data sets.** The Program provides data files that link NIA-funded study data to CMS data.
2. **Enclave with free software.** This platform offers a secure, easy-to-navigate, and remotely accessible statistical analysis environment that meets federal data security requirements for protecting personally identifiable and private health information. Users have access to SAS, STATA, R, Python, MS Office applications and more.
3. **Technical assistance.** Participants will receive data analysis and technical support from CMS data analysis experts.

Ready to get started? Explore the NIA Data LINKAGE Program:

- [View available data](#)
- [Access and share data](#)



Linked data

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Linked data: linking the NDWS surveys

- The PUFs will ***not*** uniquely identify organizations.
 - The Administrator surveys will not be available as PUFs
- To conduct analyses combining staff respondent + administrator surveys from the same organization, this can only be conducted on LINKAGE.

Linked data

4 types:

1. Linking administrator + staff respondent surveys
- 2. Environment (Local context)**
3. Claims-based summary files
4. Beneficiary-level CMS claims/encounter/assessment data

Linked data: Environment

Each survey will go to LINKAGE with the FIPS code that uniquely identifies state and county. Using this FIPS code, you can link to:

- AARP Long-Term Services and Support Scorecard
 - 50 indicators measured at the state level across five dimensions of LTSS:
 - Affordability and Access
 - Choice of Setting and Provider
 - Safety and Quality
 - Support for Family Caregivers
 - Community Integration

Linked data: Environment

Each survey will go to LINKAGE with the FIPS code that uniquely identifies state and county. Using this FIPS code, you can link to:

- Area Health Resources Files
 - An *enormous* data source from the Health Resources & Services Administration (HRSA)
 - County-level data about health and health care provider supply

Linked data: Environment

Each survey will go to LINKAGE with the FIPS code that uniquely identifies state and county. Using this FIPS code, you can link to:

- Medicaid Long-Term Services and Supports Annual Expenditures Report
 - Report on state-level Medicaid spending including breakdown of institutional vs. HCBS

Linked data: Environment

Each survey will go to LINKAGE with the FIPS code that uniquely identifies state and county. Using this FIPS code, you can link to:

- Social Deprivation Index:
 - Based on seven demographic characteristics from the American Community Survey:
 - % living in poverty
 - % with <12y education
 - % single parent households
 - % living in rented housing unit
 - % living in overcrowded housing unit
 - % households w/o a car
 - % nonemployed adults <65 years of age

Linked data

4 types:

1. Linking administrator + staff respondent surveys
2. Environment (Local context)
- 3. Claims-based summary files**
4. Beneficiary-level CMS claims/encounter/assessment data

Linked data: claims-based summary files

- Working with beneficiary-level CMS data requires significant technical expertise and time
- CC and NH survey sample frames are prepared with clinician NPI and facility CCN, respectively.
 - **Goal:** prepare annual claims-based summary files to facilitate and accelerate researchers' work examining variation in care delivered to PLWD
- In Year 1, these will be available for the CC and NH Staff surveys
 - In Year 2, will use zip code methods established by Thomas and Temkin-Greener to expand to the AL Staff survey
 - Aim to also eventually expand to Home Care Staff survey

Linked data: claims-based summary files

- Examples of measures included in CC file:
 - Respondent panel size of PLWD and overall
 - Visits by clinician to PLWD by setting (e.g., OP, IP, residential, home)
 - Panel characteristics, e.g.:
 - Race/ethnicity
 - Dual-eligible and/or Part D low-income subsidy (LIS)
 - MA- and Part D-enrolled
 - Distance from clinician
 - Top 2 deciles of Area Deprivation Index (ADI)
 - CCW conditions
 - Prescribing (e.g., opioids, antipsychotics, anticholinergics)
- Draft data dictionary available on NDWS website.

Linked data: claims-based summary files

- Year 1 measures will be prepared using panel information from FFS beneficiaries
 - Once MA data for same time frame available, Year 1 measures will be updated to include MA patients
- Currently finalizing the NH file.

Linked data

4 types:

1. Linking administrator + staff respondent surveys
2. Environment (Local context)
3. Claims-based summary files
4. **Beneficiary-level CMS claims/encounter/assessment data**

Linked data: bene-level CMS data

- CC and NH surveys will be uploaded to LINKAGE with clinician NPI and facility CCN, respectively.
 - (NPI and CCN will not be available in the PUF)
 - With clinician NPI, you can link NDWS CC surveys to CMS claims/encounters for all beneficiaries to whom the respondent clinicians provided care
 - Similarly, with CCN, you can link NDWS NH Staff surveys to MDS assessments for all beneficiaries who receive care in facilities of respondent clinicians
 - Can also obtain access to these beneficiaries' other CMS data (e.g., Medicare claims)
- At this time, researchers are not able to combine these beneficiary-level CMS data with the geographic data available through FIPS code

Thanks for watching and stay tuned...

- March 2025: Y1 survey data + linked data sources are available
 - We are currently getting established as a study within LINKAGE so our data access process are currently being developed

The website (www.ndws.org) and email list (write us to join! info@ndws.org) are best ways to stay up-to-date.



Thank you!

www.ndws.org • info@ndws.org