



Introduction to The National Dementia Workforce Study

Outline

- What is NDWS?
- Who the surveys include
- What the surveys cover
- Key information of our website

Background

- 6 million Americans lived with dementia in 2020
 - 14 million by 2060
- Costs of health care for a person living with dementia are \$30,000 higher than for those without dementia
 - Total costs in US will be \$1.6 trillion by 2040
- Millions of workers serve this population and have an enormous influence over the quality and costs of care
 - **Particularly direct care workers:** 2.4 million personal care aides, 1.1 million nursing assistants, 800K home health aides
- Very little is known about the dementia care workforce, and how they influence care and quality outcomes for the population they serve

Vision

- NIA-funded data resource focused on the dementia care workforce
 - Advance **AD+ADRD Research Implementation Milestone 13.J** on the dementia care workforce
- Build national surveys that can be linked to outcomes and administrative data to address evidence gaps in how dementia care is supplied across settings
- Designed as infrastructure for the research community (data + documentation)
 - **No-cost access to all NDWS data**, including CMS-linked resources through LINKAGE

Consortium & Partners



- Principal Investigators:
 - Donovan Maust, MD, U Michigan, geriatric psychiatrist (MPI)
 - Joanne Spetz, PhD, UCSF, economist (MPI)
 - James Wagner, PhD, U Michigan Survey Research Center
 - Laura Wagner, PhD RN, UCSF
 - Steven Marcus, PhD, U Penn
- Core team expertise: geriatrics/psychiatry, workforce economics, survey methodology, and data linkage
- Other team members from: UNC-Chapel Hill, Brown, Yale, Rice, Alzheimer's Association, and Mathematica
- Data collection: RTI & DLH

NDWS: Family of Surveys

- Community Clinician survey:

- Primary care (MD/DO, NP, non-surgical PAs)
- Psychiatrists and mental health NPs
- Neurologists

- Organizational surveys:

- Nursing Home
- Assisted Living
- Home Care



Each setting:
Staff survey +
Administrator survey

Sample & Eligibility (Who's in-scope?)

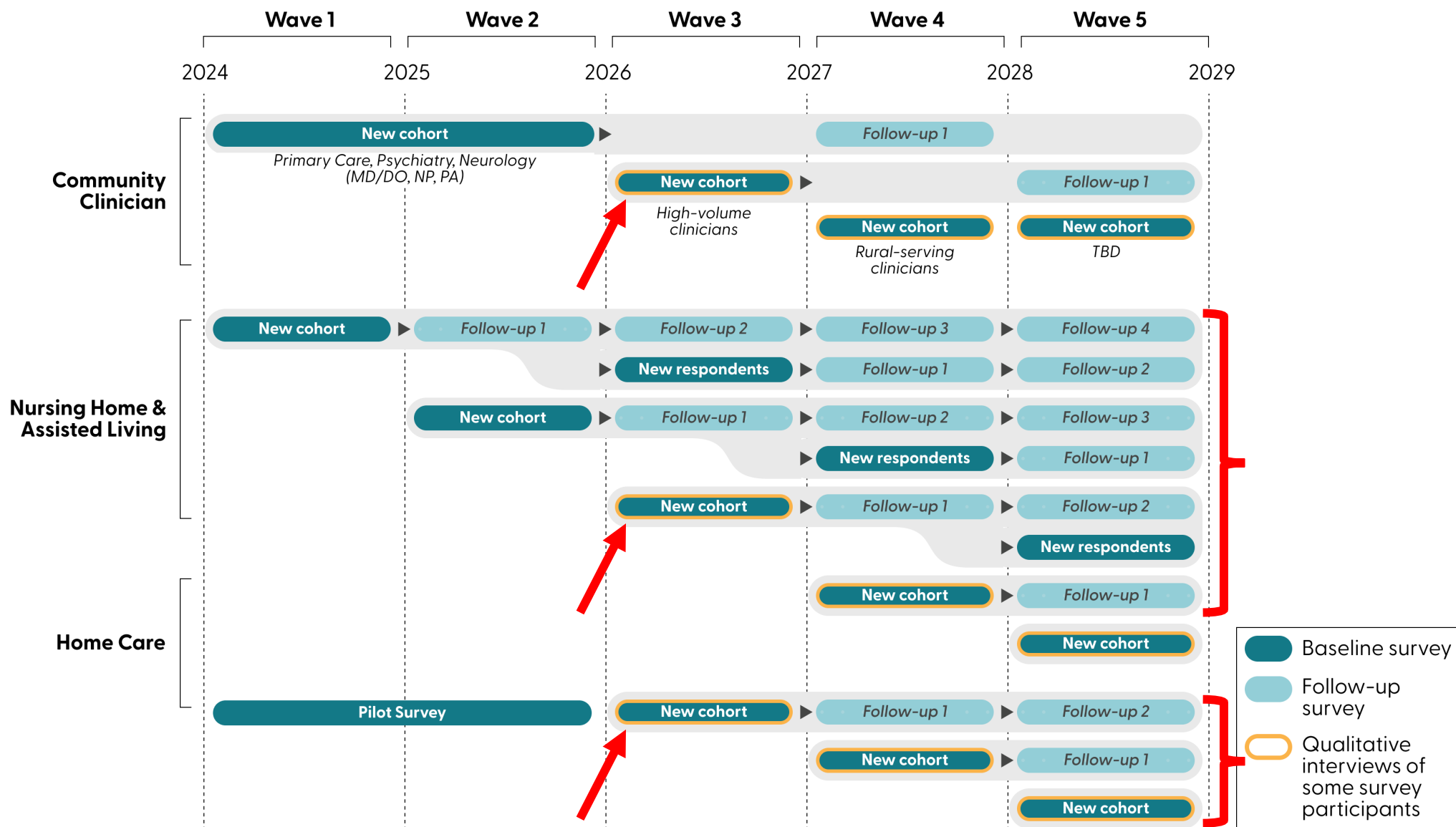
- Community Clinician:
 - Medicare-based frame
 1. Identify Medicare beneficiaries with a dementia diagnosis (in both FFS and MA)
 2. Identify the clinicians (including NPs and PAs) who billed and/or prescribed to those beneficiaries
 3. Stratification variables:
 - Clinician type
 - Rurality
 - Above/below median # low-income patients (i.e., eligible for Medicaid and/or the Part D low-income subsidy)
 - Practice setting
 - Above/below median # patients with dementia

Sample & Eligibility (Who's in-scope?)

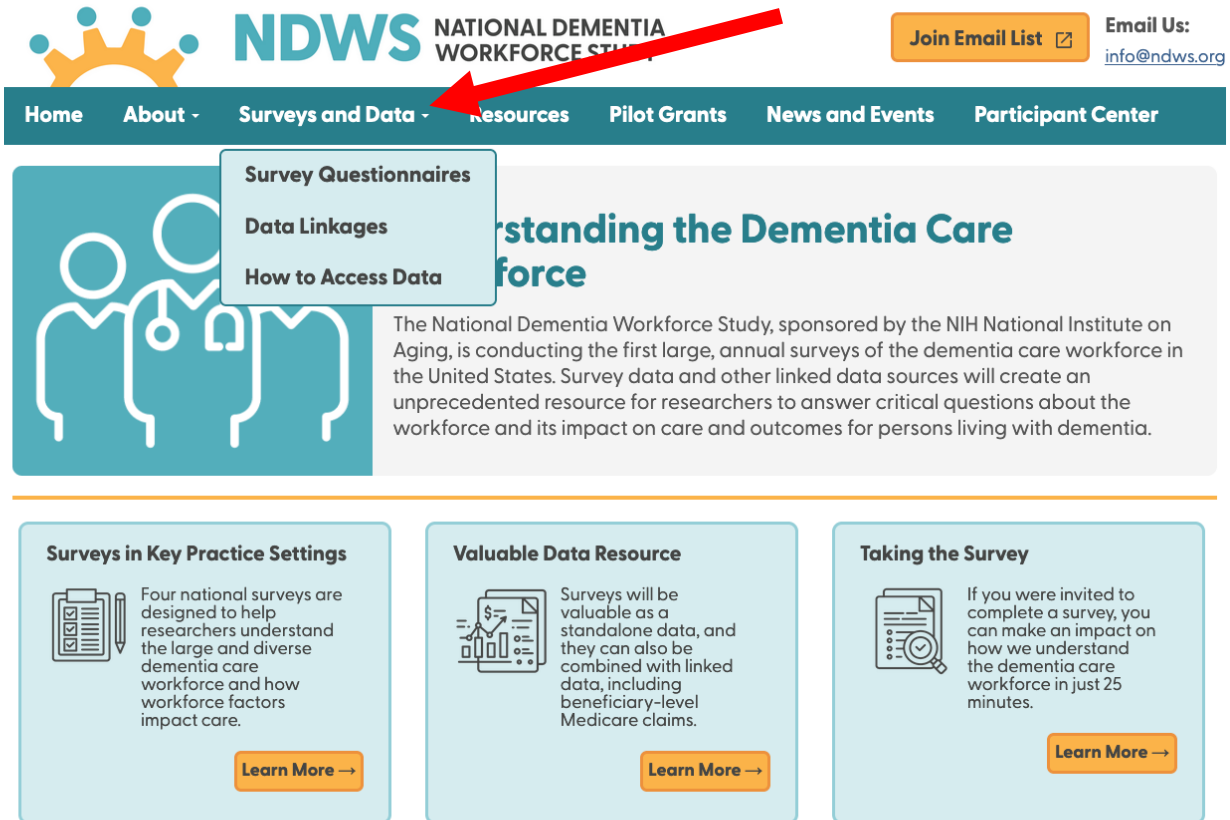
- Staff surveys (org-level):
 - Nursing Home: CMS-certified facilities
 - Assisted Living: the frame built from state licensing lists
 - Home Care: started with CMS-certified agencies; Wave 2 expanded to state-based sources

Instruments & Key Content Areas

- Seven baseline questionnaires:
 - CC: 1 instrument
 - NH/AL/HC: staff surveys + administrator survey for each participating organization
- Development: literature review (120+ instruments/articles) + design reviews + cognitive testing, and Spanish translation
- Core domains
 - Demographics; education/training; experience; employment status
 - Dementia knowledge/attitudes; care practices; teamwork/coordination
 - Working conditions; organization practices; worker outcomes
- Additional instruments developed for staff follow-up, which will occur yearly



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NDWS NATIONAL DEMENTIA WORKFORCE STUDY

Join Email List  Email Us: info@ndws.org

Home About Surveys and Data Resources Pilot Grants News and Events Participant Center

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

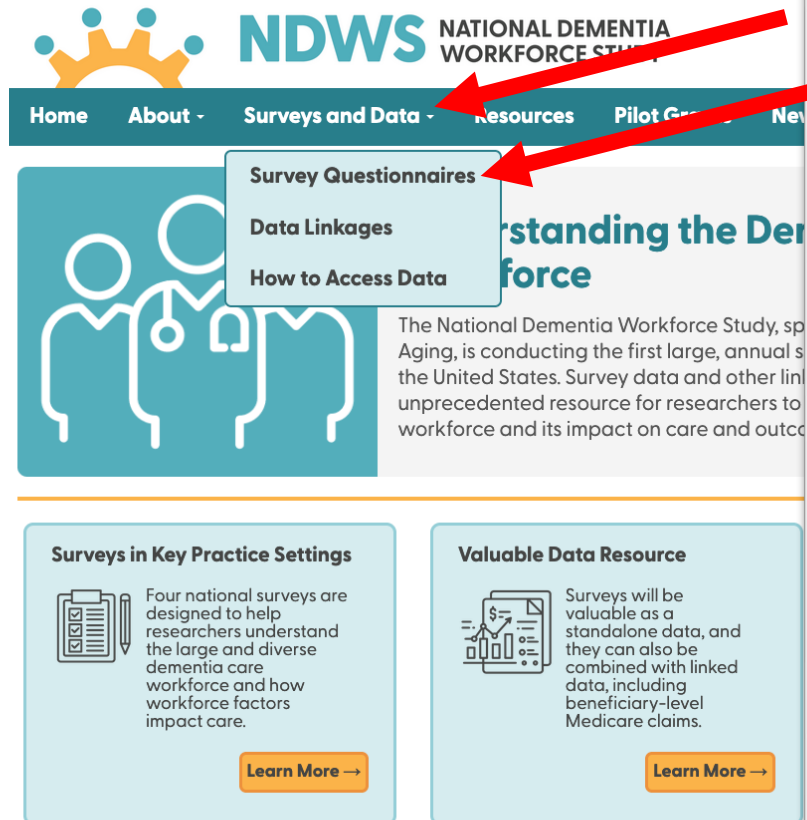


If you were invited to complete a survey, you can make an impact on how we understand the dementia care workforce in just 25 minutes.

[Learn More →](#)

ndws.org/surveys-and-data/surveys

Explore NDWS



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Wave 1

Wave 2

Wave 1 Questionnaires and Sample Frame

Wave 1 survey data are available now. [See the data collection protocol, fielding period, sample size, and respondent rates. \(PDF, 175 KB\)](#)

Visit [How to Access Data](#) to learn more about the tiers of data available.

Note: The Wave 1 survey data release does not contain data from the Home Care Staff Survey.

Community Clinician

Wave 1 Questionnaire

- Community Clinician (PDF, 477 KB)

Wave 1 Sample Frame

- Overview (PDF, 386 KB)
- SAS Files (ZIP, 86 KB)

Nursing Home

Wave 1 Questionnaires

- Nursing Home Staff (PDF, 340 KB)
- NH Administrator (PDF, 289 KB)

Wave 1 Sample Frame

- Overview (PDF, 173 KB)
- Wave 1 SAS Files (ZIP, 20 KB)
- Wave 2 SAS Files (ZIP, 21 KB)

Assisted Living

Wave 1 Questionnaires

- Assisted Living Staff (PDF, 352 KB)
- AL Administrator (PDF, 289 KB)

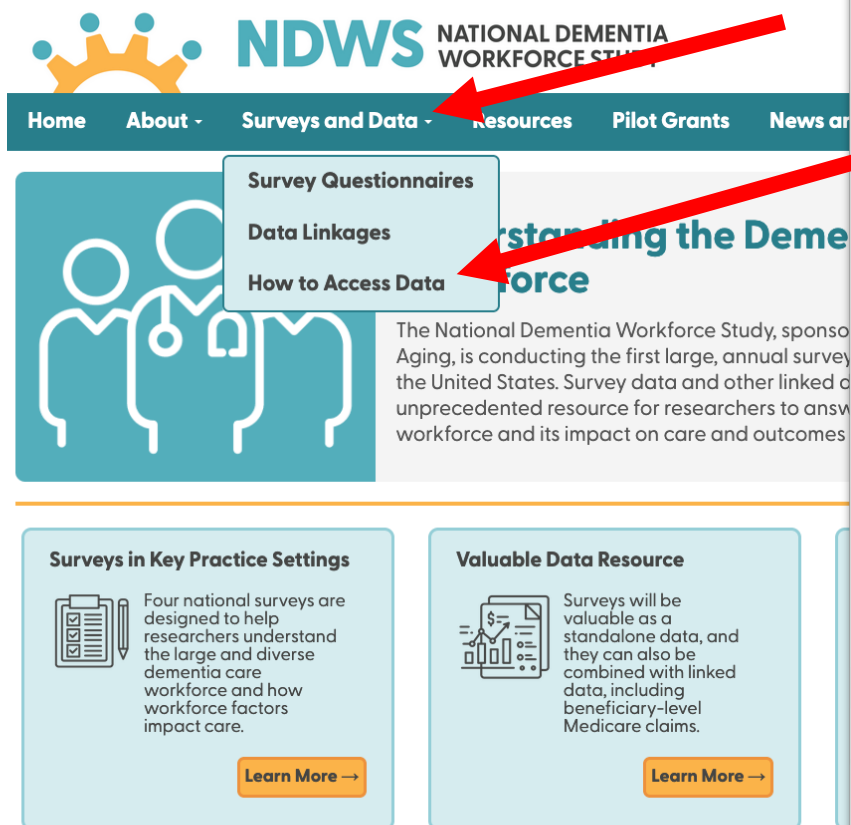
Home Care

Wave 1 Questionnaires

- Home Care Staff (PDF, 330 KB)
- HC Administrator (PDF, 289 KB)

Crosswalk: [Download the Survey Source Crosswalk](#) to see all seven surveys at a glance and how they compare. The crosswalk also includes sources for questions adapted from other surveys. If no source is listed, the question was developed by the NDWS survey team.

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ndws.org/surveys-and-data/surveys

How to Access Data

NDWS survey data and linkable administrative data sources – including beneficiary-level CMS claims data – can be accessed by researchers for free.

Wave 2 data are available now, including Restricted Use Survey Files (RUFs) for all surveys, and Public Use Files (PUFs) for the Community Clinician (Wave 1 Final), Nursing Home Staff, and Assisted Living Staff surveys.

NDWS Data

There are **three tiers** of data available as part of NDWS, depending on your project's needs:

1. NDWS survey Public Use Files (PUFs) on NACDA ↓

- **Contents:** De-identified NDWS surveys (excluding administrator surveys)
- **Restrictions:** No prior approval needed

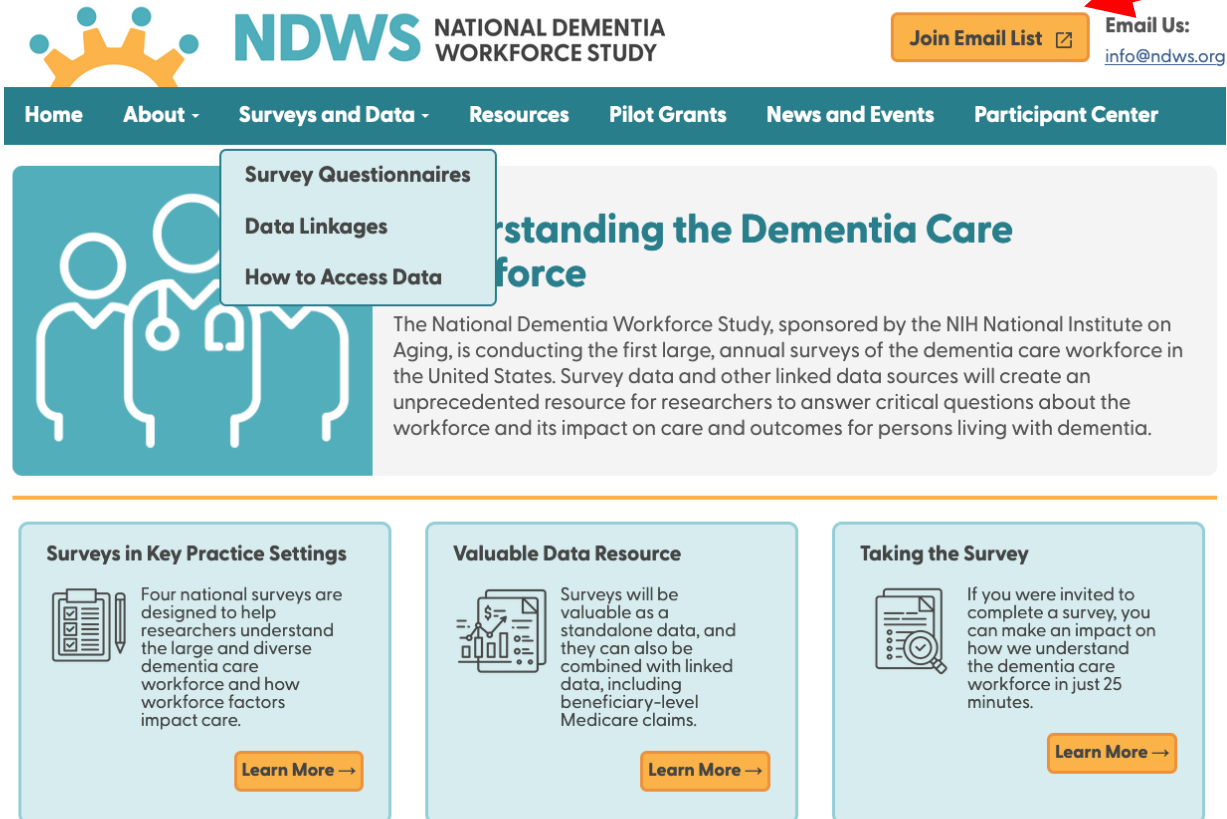
2. NDWS survey Restricted Use Files (RUFs) and non-CMS linkable data on MiCDA ↓

- **Contents:** Full NDWS RUF surveys (including administrator surveys) and the Environment, Process, and Quality of Care data sources available to link with surveys
- **Restrictions:** NDWS and IRB prior approval required; data users must be located in the USA at a US-based institution or company

3. NDWS survey Restricted Use Files (RUFs) and Beneficiary-level CMS data and NDWS claims-based summary files on LINKAGE ↓

- **Contents:** All NDWS Restricted Use Files as described in Tier 2, *plus* the CMS data available through LINKAGE
- **Restrictions:** NDWS and NIA Privacy Board prior approvals required, requestor must be a U.S. citizen or permanent legal resident, and an IRB determination that your project is human subjects research must be provided

Explore NDWS Website



The screenshot shows the NDWS website header with the logo and navigation menu. A red arrow points to the 'Join Email List' button. Below the navigation menu is a large banner for 'Understanding the Dementia Care Workforce' with a dropdown menu showing 'Survey Questionnaires', 'Data Linkages', and 'How to Access Data'. Below the banner are three columns: 'Surveys in Key Practice Settings', 'Valuable Data Resource', and 'Taking the Survey', each with a description and a 'Learn More' button.

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Understanding the Dementia Care Workforce

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Data Linkages
How to Access Data

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Acknowledgement

Funding provided by the National
Institute on Aging (U54AG084520)



*JAGS Special
Collection*

Thank you!

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