Donovan Maust, MD, MS
*University of Michigan*
*VA Ann Arbor*

Joanne Spetz, PhD
*University of California, San Francisco*

# Why do we need the NDWS?

- 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 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

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# What is NDWS?

- From the RFA: "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"

- New $81 million cooperative agreement (U54) with National Institute on Aging to create a data resource for researchers
  - September 30, 2023 through August 31, 2028

- Family of workforce surveys that can be linked with patient outcomes and facility data

- Pilot grants to accelerate use of the data

- Helps advance new AD/ADRD Research Implementation Milestone:
  - 13.J: Care & Caregiving: Dementia care workforce

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# The team

- Leadership:
  - Donovan Maust, MD, U Michigan, geriatric psychiatrist (MPI; contact PI)
  - Joanne Spetz, PhD, UCSF, economist (MPI)
  - James Wagner, PhD, U Michigan Survey Research Center
  - Laura Wagner, PhD, RN, UCSF
  - Steven Marcus, PhD, U Penn
- Other partners: Alzheimer's Association, UNC-Chapel Hill, Brown, Yale, and Mathematica

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# The surveys

A family of 4:

- Community Clinician (including MDs, Nurse Practitioners, Physician Assistants)

- Nursing Home Staff
    + Org-level survey

- Assisted Living Staff
    + Org-level survey

- Home Care Staff
    + Org-level survey

- licensed nurses
- direct care workers

A total of 75,000+ surveys over 5 years starting this summer!

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# Community Clinician survey

- Physicians (primary care internal med, family med, geriatrics, neurology, psychiatry), NPs, and PAs who have billed Medicare or Medicaid for any patient with a dementia diagnosis
  - Step 1: Identify patients with a dementia diagnosis in the past year
  - Step 2: Identify clinicians who have billed for them in any setting
    - Step 2A: pharmacy claims to better identify NPs and PAs
  - Step 3: Stratify frame based on clinician type, clinician setting (e.g., residential?), dementia panel size, rural/urban, % Medicaid and/or Part D low income subsidy
- N=20,300 over 5 waves; some longitudinal surveys
- Link data to Medicare and Medicaid claims (using respondent NPI)

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# Nursing Home Staff survey

- Nursing homes with any dementia residents
  - <u>Step 1</u>: Develop stratified frame of nursing homes, recruit facilities to participate
  - <u>Step 2</u>: Obtain rosters of staff from nursing homes
  - <u>Step 3</u>: Sample from rosters
- N=19,140 over 5 waves; some longitudinal surveys
- Link data to Link data to Medicare and Medicaid claims, Minimum Data Set, Payroll Based Journal administrative data, etc. (using facility CCN)

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# Assisted Living Staff survey

- Assisted living communities
  - Step 1: Develop stratified frame of communities (oversample those with memory care wings), recruit to participate
    - Frame developed using state licensing lists
  - Step 2: Obtain rosters of staff from communities
  - Step 3: Sample from rosters
- N=15,660 over 5 waves; some longitudinal surveys
- ➢ Coming in Y2: We will use methods developed by Thomas et al. and Temkin-Greener et al. to use 9-digit zip to identify Medicare beneficiaries that reside in AL. Researchers can then link with Medicare and Medicaid claims on this basis.

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# Home Care (health) Staff survey

- Home health and care agencies
  - <u>Step 1</u>: In Y1, we are using agencies registered with CMS (i.e., home health will be more represented in Y1) to develop stratified frame of agencies, recruit facilities to participate
    - In administrator survey, will ask to specify the type of services provided
  - <u>Step 2</u>: Obtain rosters of staff from facilities
  - <u>Step 3</u>: Sample from rosters
- N=20,560 over 5 waves; some longitudinal surveys
- Data for linkage will evolve over time.

- ➤ Lots of ongoing discussion re: how to build this frame to more fully capture home + personal care

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# Strata

| CC | NH | AL | HC |
|---|---|---|---|
| Number of Patients with Dementia | Number of Certified Beds | Number of Certified Beds | Number of Medicare Episodes of Care |
| Urban/Rural* | Urban/Rural* | Urban/Rural* | Urban/Rural* |
| Total Number of Dually Eligible or LIS Dementia Patients | Proportion of Residents Paying via Medicaid | n/a | Proportion of Population in Local Area Using Medicaid Alone for Insurance |
| n/a | n/a | Census Region | Census Region |
| Setting** | n/a | n/a | n/a |
| Clinician License/Specialty*** | n/a | n/a | n/a |

*Urban=RUCA codes 1-6, Rural=RUCA codes 7-10
**any residential, outpatient (non-residential), Part D prescriber only
***primary care physician, psychiatrist, neurologist, primary care NP, psych NP, non-surgical PA

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# Key survey content domains

- Demographics
- Education, training, experience
- Employment status
- Dementia care knowledge, attitudes, and practices
- Working conditions and organization practices
- Worker outcomes

All 4 surveys will include a longitudinal follow-up component to help us understand workforce exit.

# Administrator surveys

Will be completed by each organization participating in Nursing Home, Assisted Living, and Home Care Staff surveys:

- Practice setting and characteristics

- Training provided

- Dementia-specific care as part of:
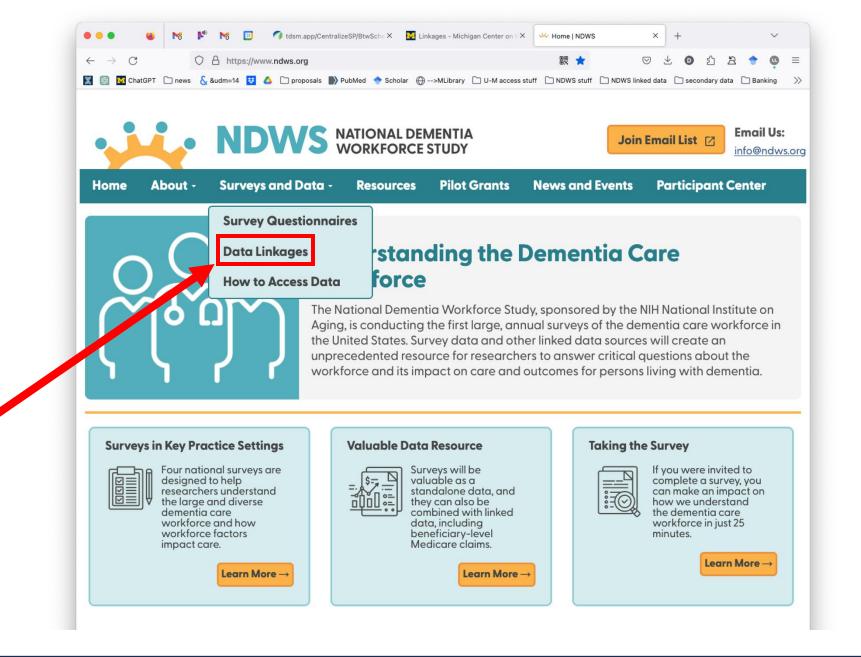  - hiring
  - training
  - ongoing education

# 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

All surveys:

- Will have FIPS state/county codes for matching with:
  - AHRF
  - Social Deprivation Index
  - AARP LTSS state scorecard

- CC and NH surveys will have clinician NPI and facility CCN, respectively, which allows matching with:
  - Any and all CMS data, including
    - Beneficiary-level claims and assessments
    - Various CMS public use files at the provider and facility levels (e.g., PBJ, NH Compare, LTCfocUS)
  - Claims-based summary files that we create (e.g., panel demographics, % antipsychotic use)
  - AL will come in Y2

# Making the data accessible

- Public-use files (unlinked/unlinkable survey data) through NACDA
  - https://www.icpsr.umich.edu/web/pages/NACDA/index.html
- Restricted-use files with linked data through LINKAGE
  - https://www.nia.nih.gov/research/dbsr/nia-data-linkage-program-linkage
- Aim for full Y1 datasets (with available linked data) available March 2025
- All **<u>FREE</u>**, including any/all linked data
  - Given pending changes in CMS data access and prohibitive $$$, **this is a highly accessible option to access CMS data**, esp. for early career researchers

- Pilot awards available to encourage use of the data (up to $100K direct)
- Webinars and information sessions to support users
- Annual data user conferences starting in Year 3

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# Timeline

- Data collection began late **August**
  - RTI is collecting for CC, NH Staff, and AL Staff surveys
  - DLH is collecting for Home Care Staff survey
- RFA for pilot awards was released in August; deadline **Nov 1**
- Final, weighted, linked Y1 datasets available **March 2025**

- Please email us to get on our email list: info@ndws.org

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# Thank you!

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