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The National Dementia Workforce Study: Methods for Surveying Community Clinicians Who Provide Care to People With Dementia

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ABSTRACT

People with dementia have complex medical, functional, and social needs and experience highly variable care quality and outcomes across the U.S. health care system. Community-based physicians, nurse practitioners, and physician assistants serve critical roles in diagnosing and managing dementia, yet little is known about this workforce and factors contributing to variability in care. The National Dementia Workforce Study (NDWS), sponsored by the National Institute on Aging, is conducting large nationally representative surveys of health care workers who provide care to people with dementia in nursing homes, assisted living communities, home care, and community medical practices. In this report, we summarize the methods for one of those surveys, the NDWS Community Clinician Survey, which surveys community-based physicians and advanced practice providers specializing in primary care, psychiatry, and neurology who provide clinical care to people with dementia. This survey captures comprehensive data on these clinicians, including demographics, training, and licensure; where and how they practice; their patient panels; processes of care for dementia diagnosis and management; and job factors influencing retention and turnover. These survey data can be linked with Medicare claims and other administrative data sources to allow for expansive research on this workforce and the care they provide. In turn, this will generate insights into modifiable factors that can be targeted to prepare, expand, and strengthen the clinical workforce to optimize care and meet demand for the growing population of people with dementia.

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Summary

- Key points
    - The Community Clinician Survey of the National Dementia Workforce Study will survey a large, nationally-representative sample of physicians, nurse practitioners, and physician assistants in primary care, psychiatry, and neurology who provide community-based clinical care to people with dementia.
    - Survey domains include: (1) education, training, and experience; (2) employment status; (3) practice settings and characteristics; (4) patient panel and scheduling; (5) processes of care for dementia screening, diagnosis, and management; (6) job outcomes; and (7) demographics.
    - Survey data will be available for linkage to Medicare and Medicaid claims, as well as other administrative data sources such as the Area Health Resources File, Nursing Home Compare, and Payroll Based Journal data.
- Why does this matter?
    - This novel data infrastructure, funded by a major investment from the National Institute on Aging, will capture comprehensive data to answer important questions about the community-based clinical workforce and its impact on care and outcomes for people with dementia.
    - These data will be available to a national network of researchers, representing a major step forward in collaborative efforts to generate critical national evidence to guide training and policy decisions as the U.S. health care system faces the growing public health impact of Alzheimer's disease and related dementias.

1 | Introduction

People with dementia have complex medical, functional, and social needs and experience highly variable care quality and outcomes across the U.S. health care system. Despite a growing recognition of the importance of timely and accurate diagnosis [1], rates of undetected dementia in the U.S. have been estimated at around 61% [2], with delayed diagnosis being more common among people from racial and ethnic minority groups [3, 4], rural communities [5], and socioeconomically disadvantaged communities [6]. There is also known variation in the treatment and management of dementia. This includes differences in the frequency of referrals to community-based resources [7], prescribing patterns for psychotropic medications and cholinesterase inhibitors [8, 9], research participation [4, 9], and end-of-life-care [10–12].

Community-based physicians and advanced practice providers (i.e., nurse practitioners and physician assistants) play key roles in diagnosing and managing dementia. This includes clinicians working in primary care, including geriatrics, who are generally in charge of overall medical management for people with dementia and are often the ones to first recognize cognitive impairment, as well as those in specialty areas such as psychiatry and neurology who have more specific roles around diagnosis and medication management. This workforce is large and heterogeneous, and there is wide variation in how clinicians practice; how these factors contribute to care quality and health outcomes for people with dementia is not well understood.

The growing prevalence and impact of Alzheimer's disease and related dementias [13] on the U.S. health care system has created a heightened demand for primary care clinicians and specialists with the necessary training and competencies to diagnose and manage dementia across the care spectrum. However, the existing health care infrastructure has significant gaps and inconsistencies that limit its ability to meet this demand [3, 4, 7, 14]. For example, Medicare requires a cognitive assessment as part of the annual wellness visit, but fewer than one-third of Medicare beneficiaries report receiving a structured cognitive assessment during that or any other visit [15]. Individuals diagnosed with dementia in research or specialty settings typically undergo extensive cognitive testing conducted by specially trained clinicians, often in addition to neuroimaging and/or biomarker testing [16, 17], but 85% of Medicare beneficiaries with dementia are diagnosed by non-specialists [18]. In primary care practices, factors such as time constraints, insufficient training, low reimbursement, poor connections with community resources, and difficulty accessing specialists all serve as potential barriers to people with dementia receiving appropriate and accurate diagnosis as well as the comprehensive care they need [19]. Growing shortages of primary care clinicians and geriatric specialists [20, 21], combined with the fact that many clinical training programs offer only minimal content on dementia care [22, 23], further compound these issues.

There is a critical need for better national evidence to understand and address the systemic underlying mechanisms contributing to variation in clinical care and outcomes for people with dementia, including the factors that influence clinical decisions and practice. To address this need, the National Institute on Aging funded the National Dementia Workforce Study (NDWS) to create a national data infrastructure that allows researchers and policymakers to generate insights into how workforce factors impact care and outcomes for people with dementia. Starting in 2024, the NDWS began fielding an annual Community Clinician Survey to collect data from community-based physicians and advanced practice providers working in primary care, psychiatry, and neurology who provide care to Medicare beneficiaries with dementia in the U.S. This survey complements surveys of nurses and direct care workers employed in nursing homes, assisted living communities, and home care that are described elsewhere in this special collection [24]. In this paper, we summarize the methods for survey design, sample design, and data collection for the first year of the NDWS Community Clinician Survey, referred to from here forward as “Wave 1”.

The Michigan Medicine Institutional Review Board provided oversight and approval of all NDWS study activities, including survey questionnaires, study protocols, and consent forms.

2 | Survey Design

The Community Clinician Survey was developed by a workgroup consisting of researchers and clinicians with diverse areas

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of expertise including dementia, the health care workforce, geriatrics, gerontology, geriatric psychiatry, neurology, neuropsychology, primary care, long-term care, nursing, medical anthropology, health economics, and survey methods. Leaders of the four NDWS survey workgroups (community clinician, nursing home, assisted living, and home care) also met regularly to ensure consistency of common questions such as demographics across the different surveys. Survey development for all NDWS surveys followed similar steps, summarized in Figure 1.

Survey development was guided by the conceptual model used across all NDWS surveys [25] and the U.S. Health Resources and Services Administration's "Minimum Data Set" recommendations for surveys of health professionals. The core survey domains are summarized in Table 1. Four domains were common to all NDWS surveys: Education, Training, and Experience; Employment Status; Job Outcomes; and Demographics. Three domains were unique to the Community Clinician Survey: Practice Settings and Characteristics; Patient Panel and Scheduling; and Processes of Care for Dementia Screening, Diagnosis, and Management.

We conducted a literature review to identify potential survey items for inclusion from relevant past surveys of physicians, nurse practitioners, and physician assistants; surveys pertaining to dementia care; and previously validated measures of key concepts of interest. Additionally, we sent an open call for survey content and suggested questions to key stakeholder groups including organizations representing the different types of health care professionals included in the NDWS surveys, dementia and long-term care advocacy groups, and researchers. Additionally, the NDWS team held a focus group with the Alzheimer's Association Early Stage Advisory Group, which includes individuals diagnosed with mild cognitive impairment and early-stage dementia. Feedback from these stakeholders was organized into themes that informed question development. The workgroup met weekly and reviewed iterative survey drafts, providing feedback on content inclusion and exclusion, question wording, and ordering of questions.

We shared an initial complete draft of the survey with NIA program and scientific officers as well as external consultants with relevant clinical and research expertise to solicit feedback on survey content and question wording. The workgroup also flagged several questions for cognitive interviews to assess the clarity of language and identify potential sources of response error or reporting bias. Cognitive interview participants were recruited via relevant professional groups and networks and screened using eligibility criteria to ensure participants were representative of potential respondents. Interviews lasted 45–60 min, were conducted via Zoom, and consisted of the interviewer showing the participant questions on the screen and asking them to reflect on their understanding of the item, their ability to recall the necessary information, and any other difficulties answering the question. We conducted a total of nine cognitive interviews with four physicians, three physician assistants, and two nurse practitioners.

We revised and finalized the survey based on feedback from both the external consultants and cognitive interviews. The final questionnaire and source documentation are available on the NDWS website (https://www.ndws.org/surveys-and-data/surveys).

3 | Sample Design

3.1 | Sample Frame

Our goal was to identify a nationally representative sample of physicians and advanced practice providers who were likely to provide care for people with dementia in the U.S. To accomplish this, we designed a sample frame using national Medicare data that captures information on both patients and clinicians.

3.2 | Data Sources

We used the following Medicare data files: (1) the Master Beneficiary Summary File (MBSF); (2) fee-for-service (FFS) Medicare Part A and B claims; (3) Medicare Advantage (MA) encounter records; (4) Medicare Part D prescription drug event files; (5) the nursing home Minimum Data Set (MDS); and (6) the National Plan and Provider Enumeration System (NPPES).

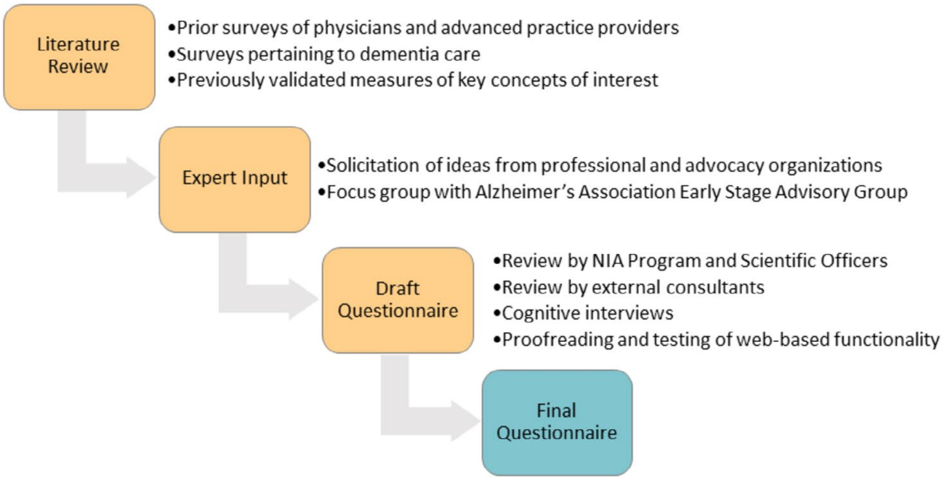

FIGURE 1 | Survey development process.

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TABLE 1 | Survey domains and question content areas.

Domain	Question content areas
Education, Training, and Experience	• Training, licensure, and board certification • Country/U.S. state where education completed • Years of experience • Preparedness to provide dementia care
Employment Status	• Number of jobs • Type of employment
Practice Setting and Characteristics	• Characteristics of principal clinical job including hours worked, on-call coverage, and supervisory responsibilities • Time spent in patient care vs. other activities • Employer characteristics • Practice setting characteristics
Patient Panel and Scheduling	• Size and characteristics of patient panel • Number of visits per day/visit times • Scheduling practices for people with cognitive impairment • Interpreting services
Processes of Care: Dementia Screening, Diagnosis, and Management	• Whether they perform Medicare annual wellness visits • If and how cognitive assessments are conducted in their practice • Confidence with diagnosing mild cognitive impairment, dementia, and dementia sub-types • Use of imaging and biomarkers in diagnosis • Specialist referrals • Prioritization and provision of different aspects of dementia care • Prescribing practices • Familiarity with and access to community-based services • Barriers to care • Guiding an Improved Dementia Experience (GUIDE) model participation
Job Outcomes	• Job satisfaction • Burnout • Intent to leave job
Demographics	• Age • Race and ethnicity • Place of birth • Citizenship • Sexual orientation • Gender • Military Service • Language proficiency • Disability • Family caregiving responsibilities

Note: The full survey questionnaire is available for download at https://www.ndws.org/surveys-and-data/surveys.

The most current files available at the time of sample frame construction for each of these sources varied. The MBSF and FFS files were available through September 30, 2023. Part D event files were available through December 31, 2022. The MA and MDS files were available through December 31, 2021. NPPES data were available through April 2024.

3.3 | Sample Frame Construction

Because of the different time periods of available data, we constructed the sample frame based on two distinct 12-month periods: calendar year (CY) 2021 (January 1, 2021–December 31, 2021) and federal fiscal year (FY) 2023 (October 1, 2022–September 30, 2023). Figure 2 summarizes the construction of the sample frame.

First, we identified the universe of Medicare beneficiaries who met criteria for dementia in CY2021 and in FY2023 by applying the Bynum standard algorithm to FFS claims and MA encounter records [26]. For FY2023, we updated the algorithm to capture additional dementia-related ICD-10 codes that became available in October 2022 (Table S1). For CY2021, we also reviewed nursing home MDS assessments and added beneficiaries

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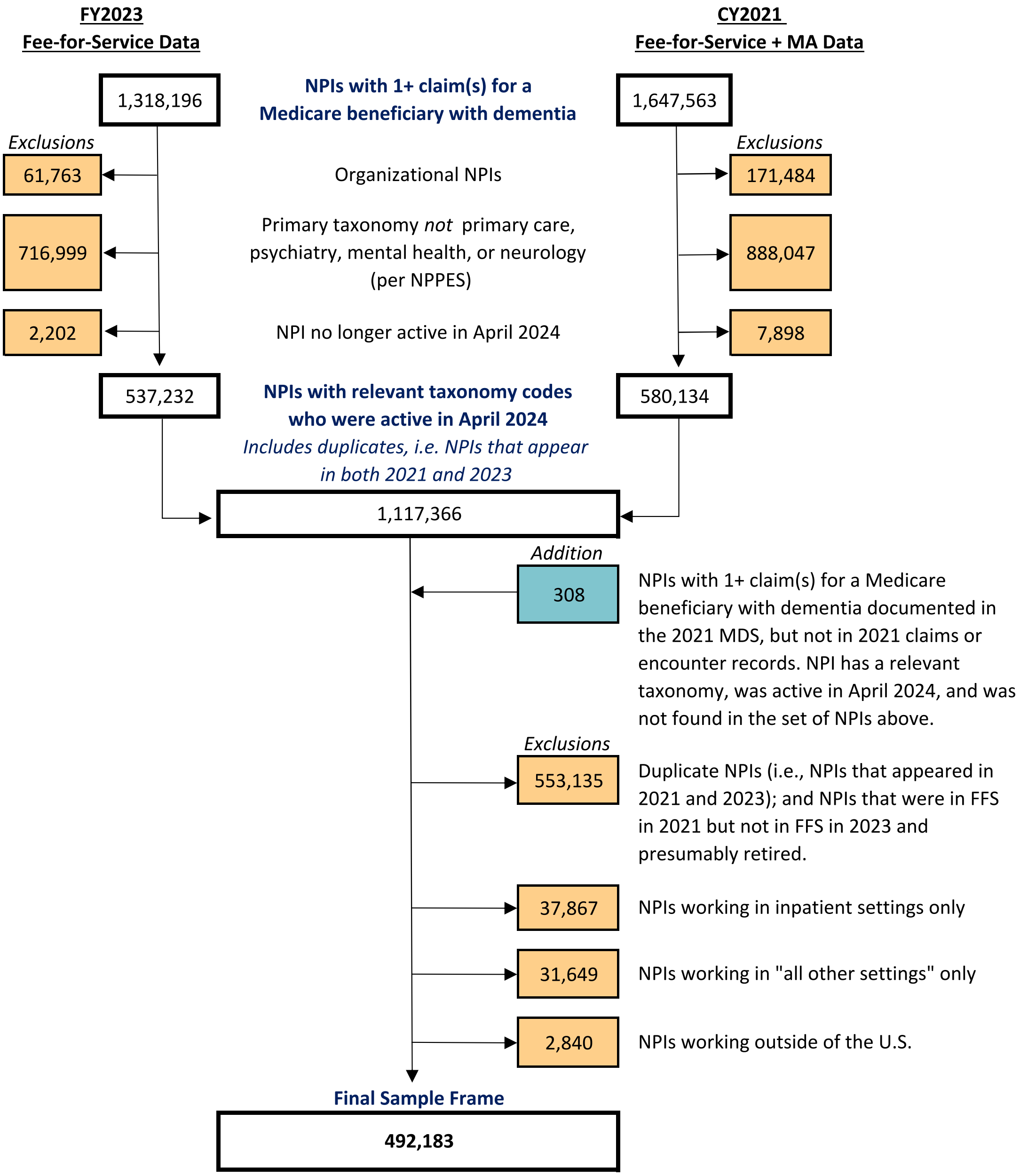

FIGURE 2 | Sample frame development. Abbreviations: FFS, fee-for-service; FY2023, federal fiscal year 2023 (October 1, 2022–September 30, 2023); CY2021, calendar year 2021 (January 1, 2021–December 31, 2021); MA, Medicare Advantage; MDS, Minimum Data Set; NPI, National Provider Identifier; NPPES, National Plan and Provider Enumeration System. NPIs that appeared only in MA encounter records in 2021 and not in FFS claims were retained in the sample frame. We assumed there was a high likelihood that these clinicians were still providing MA-only care in 2023, for example, due to employment in a managed care model.

to the sample who had a dementia diagnosis documented in MDS (items I4200 or I4800) but who had not been identified in the claims or encounter data.

After identifying Medicare beneficiaries with dementia, we then identified clinicians whose National Provider Identifier (NPI) number was associated with at least one claim or encounter record for those beneficiaries in each period, CY2021 and FY2023 (Figure 2). We did this by searching the FFS and Encounter Carrier files for clinician services billed to Medicare and MA plans, respectively. We also searched the Outpatient File for clinician services delivered in Federally Qualified Health Centers, Rural Health Clinics, and Critical Access Hospitals. Finally, we used Medicare Part D event files to identify clinicians who prescribed to beneficiaries with dementia but who were not otherwise found in the claims or encounter data as having provided services to beneficiaries with dementia. This was to ensure that we adequately captured nurse practitioners and physician assistants who might bill for their services under a collaborating physician's NPI, and thus be underrepresented in Carrier claims [27].

Next, we used place of service codes (Carrier claims) and revenue center codes (Outpatient claims) to assign each clinician encounter to one of the following patient care locations: outpatient, inpatient, residential, or “all other settings” (Table S2).

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Because Part D claims do not specify a place of service, we classified clinicians identified only through Part D records as providing care to beneficiaries with dementia by checking Carrier and Outpatient claims to identify the setting in which they most often provided care to other Medicare beneficiaries without dementia.

We next limited the sample frame to the specific clinician specialties and licensures of interest, using clinicians' primary taxonomies as classified in NPPES data (Table S3). The six categories of interest were: primary care physicians (including geriatrics), primary care nurse practitioners, non-surgical physician assistants, psychiatrists, psychiatric-mental health nurse practitioners, and neurologists. We further limited the sample frame to clinicians whose NPI was still active as of April 2024, according to the NPPES file.

With these criteria, we identified 580,442 clinicians in CY2021 and 537,232 clinicians in FY2023. Given that many clinicians were represented in both years, we next de-duplicated this sample frame, dropping 553,135 clinicians from the CY2021 file for either of two reasons: (1) they were also found in the FY2023 file, or (2) they served FFS beneficiaries with dementia in CY2021 but not in FY2023, indicating that they may have retired or were otherwise no longer in practice. After this step, the only clinicians retained in the sample frame from CY2021 were those who served only MA-enrolled beneficiaries with dementia. These clinicians were retained in the frame under the assumption that they were likely still clinically active, since FY2023 MA data were not available to confirm this at the time of sample frame construction. Finally, we excluded clinicians who had encounters only in inpatient settings ($n = 37{,}867$) or only in the "all other settings" group (e.g., emergency room or community mental health center, $n = 31{,}649$); or who worked in U.S. territories ($n = 2840$). The final sample frame included 492,183 clinicians (Figure 2). Further technical documentation, along with the programming code used to build the sample frame, is available on the NDWS website at https://www.ndws.org/surveys-and-data/surveys.

3.4 | Sampling

After identifying the final group of clinicians eligible for the sample frame, we then sampled clinicians using both explicit and implicit stratification. The explicit strata were based upon: (1) clinician licensure and specialty; (2) the proportion of the clinician's panel comprised of beneficiaries with dementia who were low income, defined as being dually eligible for Medicaid or eligible for a Part D low-income drug subsidy during the reference year (determined from the MBSF and dichotomized as at or above vs. below the sample frame median); and (3) rurality of the clinician practice. To determine rurality, we used a commercial vendor to update the clinician address information available in NPPES and then geo-coded the updated clinician primary practice address to determine census tract and its associated Rural–Urban Community Area Codes. Values 7 to 10 were classified as rural [28]. Additionally, sampling considered clinician panel size of patients with dementia and practice setting as implicit stratification variables. Psychiatrists, psychiatric-mental health nurse practitioners, and neurologists were oversampled to ensure adequate sample size given the smaller number of these clinicians in the sample frame relative to the primary care specialties.

Table 2 summarizes, by specialty and licensure, the number of eligible clinicians in the sample frame and the number of

TABLE 2 | Number and characteristics of community clinicians in the sample frame and sample.

		Sampled clinicians			
Clinician type	**Sample frame, *N***	***n***	**% sampled**	**Clinicians in rural practice,[b] *n* (% of sample)**	**Clinicians with high share of low-income patients,[c] *n* (% of sample)**
Primary care physician[a]	197,435	7925	4%	479 (6%)	3102 (39%)
Primary care nurse practitioner	163,747	6575	4%	502 (8%)	1782 (27%)
Non-surgical physician assistant	84,273	3750	4%	204 (5%)	660 (18%)
Psychiatrist	19,563	2250	12%	46 (2%)	552 (25%)
Psychiatric-mental health nurse practitioner	11,823	2250	19%	113 (5%)	651 (29%)
Neurologist	15,342	2250	15%	17 (1%)	791 (35%)
Total sample frame	492,183				
Total sample		25,000	5%	1361 (5%)	7538 (30%)

[a] For example, of the 197,435 primary care physicians in the full sample frame, 7925 (4%) were sampled to participate in NDWS; of those, 479 (6%) practiced in a rural location and 3102 (39%) had a high proportion of low-income patients.

[b] Clinicians were classified as being in rural practice if the census tract of their primary practice address had a Rural–Urban Commuting Area (RUCA) code of 7 to 10.

[c] Clinician were considered to have a high share of low-income patients if the proportion of their patients who were dual-eligible for Medicaid or who qualified for a Medicare Part D low-income drug subsidy was at or above the overall median of clinicians in the sample frame.

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clinicians who were ultimately sampled. Additionally, we show the proportion of sampled clinicians working in rural practice and with a high share of low-income patients. The sampling rates were set based on power calculations that ensure adequate sample sizes overall and for each type of clinician to meet a robust set of analytical objectives. Based on our power calculations, we set sample sizes of 2250 for each of the smaller clinician types (i.e., neurologists, psychiatrists, and psychiatric-mental health nurse practitioners) and then distributed the remaining sample proportionately across the larger types.

4 | Data Collection

4.1 | Preparation

To prepare for survey administration, we implemented a multistep process to attempt to obtain and confirm contact information for all sampled clinicians and to identify any who may be ineligible due to factors such as retirement, death, or residence outside the U.S. First, we submitted the clinician sample to an external vendor to update NPPES contact details, including mailing addresses, phone numbers, and email addresses. Next, we sent all sampled clinicians a pre-notification letter requesting updated contact information, along with a study brochure to promote trust in the legitimacy of the study. This letter included a QR code and web URL with a secure PIN, directing clinicians to a brief web page where they could update or verify their contact information.

4.2 | Data Collection

Data collection for Wave 1 of the survey took place from September 2024 to March 2025. We sent survey invitations to all sampled clinicians via email and mail (letters and postcards). Invitations included the NDWS logo, noted that the project was sponsored by the National Institute on Aging, and contained a cover letter signed by the principal investigators. All materials and the survey questionnaire were in English. Sampled clinicians were asked to complete a web-based survey that was estimated to take approximately 25 min, and informed consent was obtained at the start of the survey. Upon completion, respondents received a $100 incentive, paid as an electronic gift card emailed to the respondent within minutes of completing the survey. In mid-November 2024, we mailed paper versions of the survey to individuals who had not responded to the web-based survey. Respondents completing the paper survey were mailed a physical gift card. Finally, to further encourage response, we increased the incentive to $250 in the final months of data collection.

5 | Discussion

Strengthening the professional dementia care workforce is a key national priority for improving the quality of care that people with dementia receive in the U.S., as evidenced by the inclusion of multiple workforce-related goals and milestones into both the National Plan to Address Alzheimer's Disease [1] and the National Institute on Aging's Alzheimer's Disease and Related Dementias Research Implementation Milestones [29]. These strategic frameworks highlight the need to improve education and training around dementia diagnosis and management; better understand characteristics of the workforce including factors affecting labor supply; and assess the impact of dementia care workforce variation and composition on outcomes for people with dementia and their care partners. Furthermore, as new therapeutics and diagnostics emerge, including anti-amyloid treatments and biomarkers, and as new care models such as the Guiding an Improved Dementia Experience (GUIDE) Model [30] evolve, it will be critical to understand how workforce factors affect their implementation and integration into routine care and, ultimately, affect care outcomes.

Encompassing a nationally representative sample of community physicians and advanced practice providers working across the care spectrum, the data collected through the NDWS Community Clinician Survey presents a novel opportunity to understand more about how and from whom people with dementia receive clinical care. The survey will capture characteristics of these clinicians, including demographics, training, and licensure; information about where and how they practice, and to whom they provide care; information about dementia-specific processes of care, including diagnosis and management; and data on important job outcomes influencing retention and turnover. These survey data, designed to be used alone or in combination with linked data sources such as claims and other administrative data, will allow for expansive research on a core component of the dementia workforce—community clinicians working in primary care, psychiatry, and neurology—who play key roles in diagnosing and managing dementia and are important health care providers for people with dementia and their families.

There are some key challenges to identifying and surveying physicians and advanced practice providers who provide care to people with dementia that are worth noting. The first challenge is defining who exactly provides "dementia care" since people with dementia receive care across a broad spectrum of clinicians who manage different aspects of their overall health. In this first wave of the NDWS Community Clinician Survey, we focused on clinicians most likely to be involved in the diagnosis and primary management of dementia, namely those practicing in primary care, psychiatry, and neurology. This meant excluding other clinicians who also provide important aspects of care to people with dementia, such as hospital-based clinicians or medical subspecialists; though these groups may be the focus of future survey waves.

A second related challenge is identifying at what patient volume threshold a clinician becomes knowledgeable enough about dementia care to be worthwhile to survey. Clinicians with a higher volume of patients with dementia may be more likely to see addressing dementia as within their purview and be more likely to respond. However, focusing solely on such clinicians would not produce a sample representative of the broader clinical workforce from whom people with dementia receive care. We chose to cast a wide net in the first wave of the Community Clinician Survey, including all clinicians who provided care to at least one Medicare beneficiary with dementia, but will likely focus in future years on more

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dementia-focused clinicians. These sampling decisions will be informed by the Wave 1 data and made in consultation with NIA.

Third, data collection from this sample requires finding accurate clinician contact information. Clinicians were identified by their NPI using NPPES data, but clinicians are not required to update the practice address used to initially obtain their NPI. Therefore, preparing for survey fielding entailed substantial efforts to update and confirm contact information for sampled respondents.

6 | Conclusions

The Community Clinician Survey is one of multiple surveys in the NDWS data infrastructure, complementing companion surveys of nurses and direct care workers in nursing homes, assisted living communities, and home care [24]. Together, the NDWS survey data, in combination with linked data sources, provide a robust and comprehensive picture of the paid professional dementia workforce and the care that they provide to people with dementia. These data will be released in Summer 2025 and can be used by researchers across the U.S. at no cost, allowing for the generation of evidence to inform workforce training and policy decisions, and help to equip the U.S. health care system to deliver high-quality care to the growing population of people with dementia.

Author Contributions

Concept and design: All authors. Acquisition, analysis, or interpretation of data: Not applicable. Drafting of the manuscript: E.M.W., J.W., K.S., H.G., D.T.M. Critical revision of the manuscript for important intellectual content: All authors. Final approval of the published version: All authors.

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Conflicts of Interest

The authors declare no conflicts of interest.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Table S1:** ICD-10 diagnosis codes to identify Medicare beneficiaries with dementia. **Table S2:** Practice setting assignment based on place of service codes (Carrier claims) and revenue center codes (outpatient claims from Federally Qualified Health Centers, Rural Health Clinics, and Critical Access Hospitals with Method II billing). **Table S3:** Taxonomy codes used to identify clinicians with primary care, neurology, and psychiatry specialties.

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