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Objectives

- What exactly is NDWS?
- Overview of survey content
- Overview of linkable data resources
- How to access data
- What comes next

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 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**

What NIA asked for:

NOFO: “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**
- Launch a national survey that can be linked with patient outcomes and other administrative data
- Pilot grants to accelerate use of the data
- Helps advance new AD/ADRD Research Implementation Milestone:
 - 13.J: Care & Caregiving: Dementia care workforce

Our answer? NDWS

- Leadership:
 - 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
- Other partners: UNC-Chapel Hill, Brown, Yale, Alzheimer's Association, and Mathematica
- Data collection: RTI and DLH
- 5 years: September 30, 2023 through August 31, 2028

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.

Community Clinician

- 6 clinician types—primary care (MD/DO, NP, non-surgical PAs), psychiatrists, mental health NPs, and neurologists—who have had a Medicare encounter with 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 (or prescribed to) them in any setting
 - Including “prescribed to” (i.e., pharmacy claims) = 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

Staff surveys

First-stage sampling:

- **Nursing Homes (NH):** list of CMS-certified facilities
- **Assisted Living Communities (AL):** state lists of licensed organizations
 - Year 1: 21 states, NCAL licensure terms
 - Year 2: 50 states + DC, expanded list of licensure terms
- **Home Care Agencies (HC):**
 - Year 1: CMS list of home health agencies
 - Year 2: State lists of registered home care agencies

Staff surveys

First-stage sampling:

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 - Year 2: State lists of registered home care agencies

Second-stage sampling:

- Roster staff from recruited organizations
- Sample from rosters:
 - RNs
 - LPNs
 - “direct care workers”

Eligible staff for rostering

NH	AL	HC
Registered Nurse	Health Care Supervisor	Registered Nurse
LPN/LVN	Registered Nurse	LPN/LVN
CNA	Licensed Practical/Vocational Nurse	CNA
Nurse Aide in Training	Direct Care Worker	Nurse Aide/Assistant
Medication Aide/Technician	Certified Nurse Aide/Assistant	Home Health Aide / Assistant
	Nurse Aide/Assistant	Personal Care Aide / Assistant
	Personal Care Aide/Assistant	Activity staff
	Medical Technician / Medication Aides	
	Activity staff	

How we developed the questionnaires

- Our charge: Develop 7 survey questionnaires
- Literature review, including questionnaires from other studies
 - >120 articles and questionnaires
 - National recommendations such as HRSA's "minimum data set"
- "Call for survey content" to seek input and ideas
 - Received 38 responses our first year
- Survey design team meetings and reviews across sub-teams
- Reviews by 6 consultants & our Project Scientist
- Cognitive testing of all questionnaires
- Translation of staff questionnaires into Spanish
- Available on NDWS website since early Summer 2024

Key survey content domains

- Demographics
- Education, training, experience
- Employment status
- Dementia care knowledge, attitudes, and practices
 - Community Clinician:
 - What type of cognitive assessment is used in your practice? Who administers it?
 - As part of eval for cognitive impairment, what do you order? (e.g., neuropsych testing, biomarkers)
 - Staff:
 - “It is rewarding to work with people who have dementia”
 - “I am comfortable touching people with dementia”
- Working conditions and organization practices
- Worker outcomes

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

Community Clinician

75. Among your patients with suspected cognitive impairment including dementia, how often do you order, or refer to a specialist to order, the following as part of the diagnostic evaluation?

	Never	Rarely	Sometimes	Routinely
a. Comprehensive neuropsychological testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Plasma biomarker testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Cerebrospinal fluid (CSF) biomarker testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. CT scan or MRI of the brain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. PET imaging	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Genetic testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

76. Among your patients with suspected cognitive impairment, including dementia, how often do you refer patients to the following specialists for assistance with diagnosis?

	Never	Rarely	Sometimes	Routinely
a. Neurologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Neuropsychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Psychiatrist or other mental health specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Geriatrician or other geriatric specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

AL Staff

53. Thinking about your job at this community, how much do you agree or disagree with each of the following?

	Strongly disagree	Disagree	Agree	Strongly agree
a. I have enough time to give individual attention to residents who need assistance with dressing, bathing, transferring, or using the toilet.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I have enough time to complete other duties that don't directly involve the residents.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Residents and/or families let me know when I am doing a good job.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. My supervisor(s) lets me know when I am doing a good job.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I am encouraged to discuss the care and well-being of residents with their families.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. I participate as a member of a care team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

54. In your job at this community over the past year, how often have you experienced the following:

	Never	Rarely	Sometimes	Often
a. Communication problems with co-workers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Communication problems with supervisor(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Communication problems with residents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Communication problems with residents' family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Disrespectful behavior from residents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Disrespectful behavior from residents' family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

HC Administrator

What benefits are provided to full-time staff? *Select all that apply.*

- ☐ Paid time off (PTO) that combines sick and vacation

How many days of combined PTO do full-time staff receive...

days per year

- ☐ Paid sick time (separate from vacation)

How many sick days do full-time staff receive...

days per year

Have the majority of staff who provide direct care to clients had formal training in the following areas as **continuing education** in the last year? (Formal training is the type of training that is documented, the hours of which can be counted.)

	YES	NO
a. Dementia including Alzheimer's disease	<input type="radio"/>	<input type="radio"/>
b. Person-centered care	<input type="radio"/>	<input type="radio"/>
c. Assessment and care planning	<input type="radio"/>	<input type="radio"/>
d. Dementia-appropriate support for activities of daily living	<input type="radio"/>	<input type="radio"/>
e. Behaviors and communication specific to persons with dementia	<input type="radio"/>	<input type="radio"/>

Survey crosswalk

- Allows for easy comparison of items across the three staff and administrator surveys (i.e., NH/AL/HC)
- Includes item source where from pre-existing surveys

Question Number	Question Label	Question Description	Question Number	Question Label	Question Description	Question Number	Question Label	Question Description	Question Source
NH1	Ownership	Is this nursing home's ownership non-profit, for-profit, or government?	AL1	Ownership	Is this assisted living community's ownership non-profit, for-profit, or government?	HC1	Ownership	Is this home care agency's ownership non-profit, for-profit, or government?	Adapted from: Collaborative Studies of Long Term Care, Program on Aging, Chronic Illness, and Loss (https://www.agingcenter.unc.edu/programs/projects/program-on-aging-disability)
NH2	Ownership	Is this nursing home owned by a person, group, or organization that owns or manages other long-term care facilities? This may include a corporate chain.	AL2	Ownership	Is this assisted living community owned by a person, group, or organization that owns or manages other long-term care facilities? This may include a corporate chain.	HC2	Ownership	Is this home care agency owned by a person, group, or organization that owns or manages other long-term care facilities? This may include a corporate chain.	Adapted from: Collaborative Studies of Long Term Care, Program on Aging, Chronic Illness, and Loss (https://www.agingcenter.unc.edu/programs/projects/program-on-aging-disability)
NH3	Associated With	Is this nursing home currently owned or operated in association with:	AL3	Associated With	Is this assisted living community currently owned or operated in association with:	HC3	Associated With	Is this home care agency currently owned or operated in association with:	Adapted from: Collaborative Studies of Long Term Care, Program on Aging, Chronic Illness, and Loss (https://www.agingcenter.unc.edu/programs/projects/program-on-aging-disability)
NH3a	WHICRC	a continuing care retirement community (CCRC)?	AL3a	WHICRC	a continuing care retirement community (CCRC)?	HC3a	WHICRC	a continuing care retirement community (CCRC)?	
NH3b	WHHosp	a hospital?	AL3b	WHHosp	a hospital?	HC3b	WHHosp	a hospital?	
NH3c	WHNurs	another nursing home?	AL3c	WHNurs	another nursing home?	HC3c	WHNurs	another nursing home?	
NH3d	WHAL	another assisted living community?	AL3d	WHAL	another assisted living community?	HC3d	WHAL	another assisted living community?	
NH3e	WHHC	another home health care agency?	AL3e	WHHC	another home health care agency?	HC3e	WHHC	another home health care agency?	
NH4	Licensed Years	For approximately how many years has this nursing home been licensed under its current owner?	AL4	Licensed Years	For approximately how many years has this assisted living community been licensed under its current owner?	HC4	Licensed Years	For approximately how many years has this home care agency been licensed under its current owner?	Adapted from: Collaborative Studies of Long Term Care, Program on Aging, Chronic Illness, and Loss (https://www.agingcenter.unc.edu/programs/projects/program-on-aging-disability)
NH4a	CertMedicare	Is this agency certified under Medicare?	AL4a	CertMedicare	Is this agency certified under Medicare?	HC4a	CertMedicare	Is this agency certified under Medicare?	
NH4b	CertMedicaid	Is this agency certified under Medicaid?	AL4b	CertMedicaid	Is this agency certified under Medicaid?	HC4b	CertMedicaid	Is this agency certified under Medicaid?	
NH4c	Services	What types of services does this agency provide?	AL4c	Services	What types of services does this agency provide?	HC4c	Services	What types of services does this agency provide?	
NH4d	Services	Home health services (i.e., medical services support care or intermittent skilled nursing care and/or post-acute services) coordinated by Medicare, Medicaid, commercial insurance, or	AL4d	Services	Home health services (i.e., medical services support care or intermittent skilled nursing care and/or post-acute services) coordinated by Medicare, Medicaid, commercial insurance, or	HC4d	Services	Home health services (i.e., medical services support care or intermittent skilled nursing care and/or post-acute services) coordinated by Medicare, Medicaid, commercial insurance, or	
NH4e	Services	Personal home care services not associated with home health services, focused solely on supporting activities of daily living (usually provided privately or by Medicaid).	AL4e	Services	Personal home care services not associated with home health services, focused solely on supporting activities of daily living (usually provided privately or by Medicaid).	HC4e	Services	Personal home care services not associated with home health services, focused solely on supporting activities of daily living (usually provided privately or by Medicaid).	
NH4f	Services	Other types of services	AL4f	Services	Other types of services	HC4f	Services	Other types of services	



Data

Two versions of survey data (released summer 2025):

1. Public use files (PUFs) available through NACDA

- <https://www.icpsr.umich.edu/web/pages/NACDA/index.html>
- Do not include the administrator surveys, given the relatively small number of facilities in Wave 1
 - Staff PUFs include small number of variables from admin survey (e.g., ownership type)
- We have identified variables that could serve as indirect identifiers; these are “coarsened” or suppressed in the PUFs
 - e.g., “What year did you complete your highest clinical degree?” → collapsed by decade in the PUF
 - Survey questionnaires have now been updated to include high-level overview of this process and the modified/suppressed variables

2. Restricted version available through LINKAGE

- The only option if you want to link the surveys with anything else

Linked data

Five types:

1. Linking administrator + staff respondent surveys
2. Environment (local context)
3. NDWS-created, claims-based summary files
4. Other files linkable through CMS identifier
5. Beneficiary-level CMS claims/encounter/assessment data

Any/all of these linkages can only be done through through LINKAGE. NDWS surveys deposited in LINKAGE will include:

- FIPS state/county codes
- Respective CMS identifiers (NPI for CC, CCN for NH/HC)

tdsm.app/CentralizeSP/BtwSch... 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 >>

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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 →



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Linked data

All surveys:

- Have FIPS state/county codes for matching with:
 - County: AHRF, Social Vulnerability Index
 - State: AARP LTSS state scorecard, Medicaid spending

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- CC and NH surveys have clinician NPI and facility CCN, respectively, which allow matching with:
 - Claims-based summary files that we create (e.g., panel demographics, % antipsychotic use)

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Claims-based summary files

Problem: Barrier to using raw claims and assessment data is significant, slows research, and narrows the pool of researchers to those with access to the necessary expertise

➤ *Solution:* Using LTCfocus as our inspiration, create claims- and/or assessment-based measures as part of NDWS that researchers can use to accelerate research findings.

Surveys

Data Linkages

How to Access Data

Claims-Based Summary Files

The NDWS team uses patient-level data from the Centers for Medicare & Medicaid Services (CMS) Medicare claims and the Minimum Data Set to prepare annual summary files of clinical characteristics and outcomes of people living with dementia cared for by NDWS survey respondents. These files will facilitate and accelerate researchers' ability to objectively examine the relationship between workforce characteristics and the health care delivered.

Annual summary files are created at the clinician-, facility-, or agency-levels and include demographic characteristics, payer information, clinical characteristics, and health care use.

Wave 1 Data

- [Wave 1 Community Clinician Data Dictionary \(PDF, 709 KB\)](#)
- [Wave 1 Nursing Home Data Dictionary \(PDF, 562 KB\)](#)

In subsequent years, these claims-based summary files will be updated and expanded across all NDWS surveys.

CC survey:

- Panel demographics (PWD and full)
- Clinical characteristics (e.g., CCW flags)
- Service characteristics:
 - Annual Wellness Visit
 - Imaging
 - Prescribing

NH survey:

- Facility characteristics (PWD and overall)
- Clinical characteristics
- Service characteristics from Medicare A/B
- Prescribing to residents with dementia

Linked data

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 - State: AARP LTSS state scorecard, Medicaid spending
- CC and NH surveys have clinician NPI and facility CCN, respectively, which allow matching with:
 - Claims-based summary files that we create (e.g., panel demographics, % antipsychotic use)
 - Lots of other CMS data:
 - Public use files at the provider and facility levels (e.g., PBJ, NH Compare, LTCfocus)

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4. **Other files linkable through CMS identifier**
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 - Lots of other CMS data:
 - Public use files at the provider and facility levels (e.g., PBJ, NH Compare, LTCfocus)
 - Beneficiary-level claims and assessments

1. Linking administrator + staff respondent surveys
2. Environment (local context)
3. NDWS-created, claims-based summary files
4. Other files linkable through CMS identifier
5. **Beneficiary-level CMS claims/assessment data**

Beneficiary-level CMS data

Think sample frame creation, but in reverse:

- CC survey:
 - Take NPIs for all clinicians in CC sample frame
 - Identify all beneficiaries that they have cared for using Part A/B/C/D
 - **with and without** ADRD
- NH survey:
 - Take CCNs of participating facilities
 - Through MDS assessments in those facilities, identify all patients/residents that received care there
 - Then identify all their respective Medicare records
 - **with and without** ADRD
- Medicaid + MDS + OASIS also available
- CMS data from 2015 to now

How did we do on Wave 1?

	Wave 1	
Survey	sample	respondents
CC	25,000	4,699
NH org	200	28
staff		394
AL org	200	34
staff		447
HC org	200	4
staff		26

How did we do on Wave 1?

	Wave 1		Wave 2	
Survey	sample	respondents	sample	<i>respondents</i>
CC	25,000	4,699	~20,000	5,300
NH org	200	28	1,000	140
staff		394		1,970
AL org	200	34	1,000	180
staff		447		2,235
HC org	200	4	300	12
staff		26		350*

What is coming?

- Wave 2
 - CC is focused on continuing Wave 1 collection
 - NH and AL
 - New organizations (goal = 145 NH, 180 AL)
 - Longitudinal follow-up of W1 staff respondents
 - HC has expanded to true home care + direct pilot in MI
- Wave 3
 - CC sample = clinicians in top quartile by volume of patients with dementia
 - Wave 4 = rural clinicians
 - NH/AL/HC
 - Continue recruiting new organizations
 - Continue longitudinal follow-up of W1 and W2 respondents
 - Qualitative phase!

Big Picture: Sample & Data Collection

Table 2. NDWS semi-structured interview counts by survey and project year

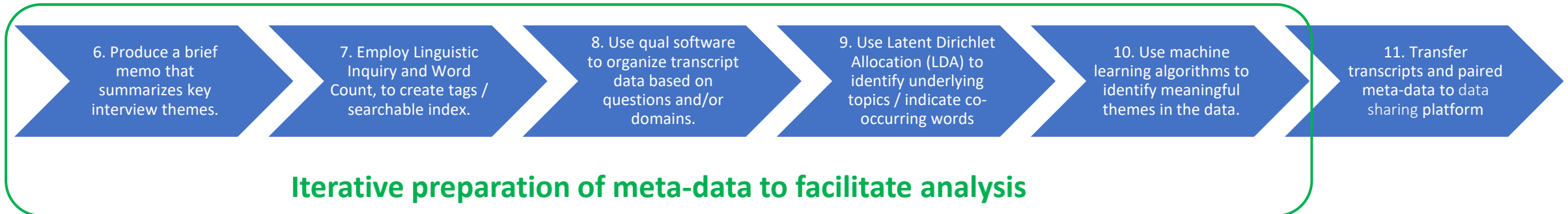
	Participants	Wave 3	Wave 4	Wave 5	Total Interviews
Community Clinicians	<ul style="list-style-type: none"> Survey respondents 	120	100	100	320
Nursing Home	<i>Per sampled home:</i> <ul style="list-style-type: none"> 1 administrator, 3 survey respondents <ul style="list-style-type: none"> 1 RN/LPN, 2 direct care 	200 (from 50 homes)	200 (from 50 homes)	200 (from 50 homes)	600
Assisted Living	<i>Per sampled community:</i> <ul style="list-style-type: none"> 1 administrator, 3 survey respondents <ul style="list-style-type: none"> 1 RN/LPN 2 direct care 	200 (from 50 communities)	200 (from 50 communities)	200 (from 50 communities)	600
Home Care	<i>Per sampled agency:</i> <ul style="list-style-type: none"> 1 administrator 1 survey respondent <i>Independent providers</i>	200 (2 each from 50 agencies, plus 100 independent?)	160 (2 each from 50 agencies, plus 60 independent)	160 (2 each from 50 agencies, plus 60 independent)	520
Total		720	660	660	2040

Logistics & Infrastructure

Data Collection



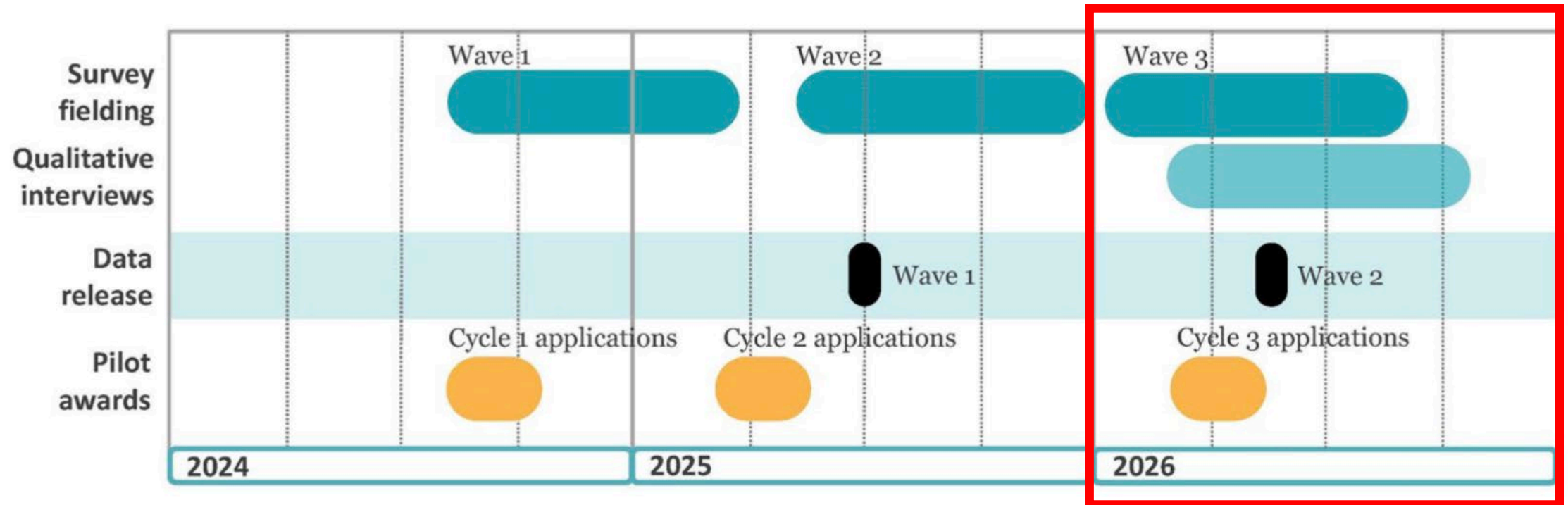
Prepare Data for Use by Researchers



Wrap-up: Data Summary

- 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>
- Full Y1 datasets (with available linked data) available now!
- All **FREE**, including any/all linked data
 - Given prohibitive cost of CMS data access, **this is a highly accessible option to access CMS data**, esp. for early career researchers

Wrap-up: Timeline





*JAGS Special
Collection*

Thank you!

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