DATA FOR ACTION TOOLKIT

HEALTHYBRAIN INITIATIVE | ALZHEIMER'S ASSOCIATION® | astho®

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BACKGROUND

The availability of population-level data has been central to major transformations in public health efforts to respond to dementia over the last several decades. The effective translation and dissemination of this data has led to unprecedented public health action, supporting policy advancements at the federal, state, territorial and local levels including:

- **National Alzheimer's Project Act (2011)**
- **Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (2018)**
- **State policies and appropriations**

These policies have led to the creation of an Alzheimer's Disease Plan for the nation and now, for every state. They have also supported the development of federally- or state-funded Alzheimer's disease programs in many health departments across the country.

LEVERAGING DATA FOR PUBLIC HEALTH ACTION ON DEMENTIA

Public health leaders, policymakers, and community organizations have a significant opportunity to integrate cognitive health and Alzheimer's data into strategic processes, helping secure resources for the fight against Alzheimer's disease and dementia, increase program efficiency, and improve health outcomes.

The Healthy Brain Initiative (HBI) Data for Action Project, implemented between 2023 - 2025, was a collaboration between the Alzheimer's Association and national partners at the Association of State and Territorial Health Officials (ASTHO). Through the Data for Action Project, state health departments participated in a nine-month program, engaging in cohort meetings, peer and technical support.
Participating departments:

- Conducted data analysis related to brain health, dementia and/or caregiving
- Produced a tool/infographic for strategic dissemination of resulting analysis
- Shared results with key governmental decision-makers, organizations and community members

This project is a part of the wider HBI effort to advance use of the [Behavioral Risk Factor Surveillance System (BRFSS)] and other public health surveillance tools among states. The content of this toolkit is informed by the efforts of the following state health departments who participated in the Data for Action Project: Arizona, Arkansas, Connecticut, Illinois, New Jersey, New Mexico, North Dakota, Ohio and Wyoming. Lessons learned included the value of cross-functional roles and engagement at every step of the process and the unique collaborations made possible through cross-agency collaboration.


HEALTHYBRAIN INITIATIVE
State and Local Road Map for Public Health, 2023–2027
ALZHEIMER'S ASSOCIATION
CDC

The Healthy Brain Initiative Road Map for State and Local Public Health, 2023-2027 provides public health practitioners with priority actions to improve brain health in their communities. The "Measure, Evaluate and Utilize Data" domain of the HBI Road Map highlights the role that public health data plays in identifying issues related to population health and using the results to inform policies and programs.

PURPOSE OF TOOLKIT

This toolkit is a self-guided resource designed to equip users to use data from sources like the BRFSS to improve health outcomes related to brain health and caregiving in their communities. State health departments participating in the Data for Action Project have used or have plans to use their data in several ways to inform or align with state priorities.

- **Health assessment and health improvement planning**
- **Program planning and evaluation**
- **Budget discussions**
- **Grant applications**
- **Policy reports**
- **Community health promotion and awareness**

STEP 1:
BUILD A TEAM

Identify Team Members

When embarking on a Data for Action project, the first step is to bring together a team, often across governmental agencies or other partners, to collaborate on the initiative. Ensuring the entire team's engagement throughout the process helps lead to continued engagement across divisions.

Recommended team members include:

- **Subject matter lead** who is knowledgeable about chronic disease prevention, dementia, or caregiving.
- **Data lead** who can procure and analyze data, create tables or figures and help interpret the findings.
- **Communications lead** who can help develop the final product, manage internal approval processes, and develop a dissemination plan.
- **Health improvement plan lead** who oversees the structured health assessment and health improvement planning process for the state or locality.
- **Alzheimer's Association chapter staff** who can provide input during the development process and assist in disseminating products. Locate your local Alzheimer's Association: alz.org/findus
- **Other partners** as needed, including people with lived experience.

KEY TASKS

Team Lead:
Convene cross-functional team members and discuss organizational priorities
All:
Develop a shared goal and timeline

Create a Shared Goal and Timeline

Once a team is formed, begin by developing a goal statement — a concise description of the team's aim. Questions to help identify a shared goal:

- What data priorities are you currently addressing related to dementia?
- What are priorities in the next one to two years related to dementia?
- How do our goals align and what data-driven outcomes would support our success?

Clearly defining a measurable goal with a specific timeline helps guide decisions about data collection, analysis, messaging and dissemination.

EXAMPLE

Goal Setting: State Priority on Caregiving
Caregiving is a recent priority in the state, and policy changes have included implementing paid family leave, state caregiving tax credits, and the potential for a health promotion campaign focused on caregiver health as a part of a healthy aging initiative. The health department, anticipating its upcoming health assessment process, wanted to ensure data on caregiving can be included to inform priorities and goals.

The state develops the following goal: ***"By April 30, 2027, produce a data brief on dementia caregiver health and incorporate findings into the state health assessment process."***

Collaboration Across Agencies

Success with the Data for Action Project was driven by a clear timeline and clear directives for team members at each step of the way.

- Establish a regular meeting cadence to share updates on project activities, make decisions and work through activities or challenges.
- Clarify roles, responsibilities and communication norms, such as through a project charter.
- Identify the approval process to publish products and build it into the timeline.
- Understand each team members motivation for participation in the project

The following is a model timeline with role assignments that you can adapt for your health department.

EXAMPLE

Data for Action Project Roles and Timeline

Goal: By April 30, 2027, produce a data brief on caregiver health and incorporate findings into the state health assessment process.

Data for Action Project Roles and Timeline

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Month	Subject Matter Expert (Team Lead)	Epidemiologist or Data Specialist	Communication Specialist	Health Improvement Plan Lead	Alzheimer's Association or External Partner
Month 1 **Step 1: Build a Team**	Lead team discussion on broader priorities and how this effort aligns	Brainstorm relevant data sources	Brainstorm options for dissemination products	Share information on health assessment (CHA / SHA) process: timeline, type of data, examples of data used	Share information on current public policy priorities, existing resources and potential partnerships
Month 2 **Step 2: Identify Data Sources**	Convene the team to explore data and dissemination options Support team decision-making on priority data and products.	Share information on potential data sources, available data points and dataset limitations	Share examples of resources and products that could be developed	Provide input on typical data sources used for CHA/SHA Identify opportunities to include dementia-related questions if primary data collection is used	Provide feedback on prioritization of dementia topics and existing data products (fact sheets, policy briefs, etc)
Month 3-4 **Step 3: Plan and Analyze Data**	Host team meetings to support continued progress. Support interpretation of findings	Lead completion of the data analysis worksheet (see Appendix) Conduct analysis and share findings with the team for input and questions	Lead completion of the dissemination plan worksheet (see Appendix) Provide input and seek clarification on data points as analysis progresses to ensure messaging remains true to the analysis	Provide input on how data findings fit with current and potential health improvement priorities	Provide input on interpretation of findings
Month 5-6 **Step 4: Share Findings**	Support final design. Ensure key partners/SMEs have opportunity for input on messaging Participate, where appropriate as a part of the CHA/SHA process	Ensure final messaging and visualization of data remains true to findings	Create draft of dissemination product, including messaging and data Seek input from the team and finalize draft, allowing time for approvals	Ensure team members have representation or access to relevant committees and meetings to share findings as a part of the health improvement planning process	Support distribution of messaging and products
Ongoing **Step 5: Sustained Action**	Identify opportunities for continued use of identified data sources and resulting data.				

STEP 2:
IDENTIFY DATA SOURCES

State health departments have access to a number of data sources from within the state government and can often tap epidemiologists on staff to support analysis. In some cases, data available in state government can be analyzed at the regional or county level, depending on sample size and methodology.

Access to data from other agencies often required having a data use agreement in place. Bringing in team members with experience using the specific priority dataset also benefitted the project.

KEY TASKS

Team Lead:
Convene exploratory meeting
Data Lead:
Identify potential data and limitations
Communications Lead:
Identify potential products
Health Improvement Lead:
Share details on SHA/CHA process and opportunities for inclusion

EXAMPLE

Data Selection: Caregiving Data Brief for State Health Assessment
States participating in Data for Action selected a dataset based on a mix of factors: timeline, access, and desired data. Access to data from other agencies often required having a data use agreement in place. In most cases, the Behavioral Risk Factor Surveillance System (BRFSS) ended up being a preferred starting place—due to available population-level information on caregiving, health behaviors, and cognitive changes. Many states indicated plans to seek out partnerships with other divisions to identify alternate sources of data as well—such as datasets maintained by offices including Medicaid, Labor, or Budget.

Table 1. Data sources on dementia and caregiving available in state government

	Available Data	Potential Uses
BRFSS	Health behaviors, status and risk factors for community-dwelling adults age 18 and older. Includes Cognitive Decline module, Caregiver module and risk factors for dementia.	Characterize prevalence of caregiving, subjective cognitive decline and risk factors for dementia at the state/territory level overall or for specific population subgroups.
Vital Statistics	Cause of death	Measure mortality due to dementia
Medicaid Claims	Documents health services used that are billed to Medicaid	Describe home- and community-based services used by people living with dementia
Claims Data (Medicaid and All-Payer)	Documents health services used that are billed to any health care provider	Characterize the use of health services and cost of care for people living with dementia
Hospitalizations/ Emergency Department Visits	Records of hospital stays and emergency department visits	Identify what the primary reasons for hospitalization/emergency department visits among people living with dementia
Electronic Health Record Data	Treatment information within specific health systems	Describe care utilization for people living with dementia

Table 2. Additional data sources on dementia and caregiving

Data	Provider	Data Level	Description
CDC PLACES	Center for Disease Control & Prevention	• County • Place • Census Tract • ZIP Code Tabulation Area (ZCTA)	Model-based, population-level analysis and community estimates of health measures to all counties
U.S. Census	United States Census Bureau	• Country • State/territory • Census Tract • County	U.S. Population trends
ATSDR Social Vulnerability Index	National Center for Health Statistics	• Census Tract	Uses 16 Census variables to identify areas that may need support related to disasters
AHRQ SDOH database	Agency for Healthcare Research and Quality	• County • Census Tract • Zip Code	Inform approaches to address emerging health issues Five key SDOH domains
National Neighborhood Data Archive (NaNDA)	University of Michigan	• County • Census Tract • Census Block Group	Theoretically derived, spatially referenced, nationwide measures of the physical and social environment
Area Deprivation Index	University of Wisconsin	• Census Tract • County	Freely share measures of neighborhood disadvantage with the public
National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC)	University of Michigan/Johns Hopkins University	• National • Other geographic variables available with approval	Longitudinal interview and performance data collected from Medicare beneficiaries and their family caregivers

Existing Data Summaries and Analyses

The Alzheimer's Association creates fact sheets about these topics at the state level and for specific populations. CDC provides infographics searchable data about cognitive decline, family caregiving, and dementia risk factors. This existing information could be used to develop new products and resources tailored to specific needs.

STEP 3:
PLAN & ANALYZE DEMENTIA-RELATED DATA

Planning Data Analysis

Once the team has gained access to any needed datasets, the Data Lead creates an analysis plan and table shells before beginning. Checking in with the broader team throughout the planning and analysis ensures alignment and allows team members to:

- Consider the products to be developed and align the analyses with the data points that will be most important for the message.
- Provide all team members a chance to review the plan and discuss how the data will be used.
- Envision the specific estimates that will be available at the end and identify gaps early on.
- Contribute to the interpretation of findings and share any additional questions raised based on their own subject matter expertise.

Analytic Notes and Recommendations

Every data source has its own structure, sampling approach and to consider when developing your methodology for the analysis. Consult the codebook, analytic guidance and other documentation as the Data Lead puts together the analytic plan and table shells.the findings.

KEY TASKS

Team Lead:
Host regular meetings. Contribute to interpretation of findings
Data Lead:
Complete data analysis worksheet (appendix). Conduct analysis
Communications Lead:
Complete dissemination planning worksheet (appendix)

Working with Population-level Data: Behavioral Risk Factor Surveillance System (BRFSS)

CDC provides statistical briefs for specific topics on the BRFSS, including the Cognitive Decline and Caregiver Modules.

- BRFSS Statistical Brief: Cognitive Decline Optional Module
- BRFSS Statistical Brief: Caregiver Optional Module

The Cognitive Decline Module

Measures subjective cognitive decline and its impacts.

- Asked of middle-aged and older adults (age 45 and older)
- Prevalence is around 10% nationally and varies by state and year[1]
- Prevalence varies by race and ethnicity[2]

Subjective cognitive decline is not equivalent to Alzheimer's disease or dementia. Subjective cognitive decline (SCD) is the self-reported experience of thinking or memory difficulties that are happening more often or getting worse over time.[3]

SCD has been linked to later developing more serious cognitive decline including Alzheimer's disease and related dementias and can be an early sign of these conditions.[4] Even if SCD does not progress, it can make daily activities more difficult for people experiencing it.[1] Therefore, SCD is an important topic for public health surveillance.[4] SCD and dementia are distinct so the terms should not be used interchangeably.

The Caregiver Module

Measures caregiving status and the details of care provided, including whether the care recipient has Alzheimer's disease or another type of cognitive impairment disorder.

- Asked of all BRFSS respondents (age 18 and older)
- Prevalence for dementia caregivers is around 20% nationally[1]
- Prevalence varies by state and year[1]

The Caregiver Module is a surveillance tool for understanding caregiver prevalence, length and duration of caregiving, and types of care tasks performed. The data can be used to better understand the demographic profile of caregivers in a given state or region and their own health behaviors and health conditions.

When using these questions to estimate dementia caregiver prevalence, one methodological consideration is who to include in the sample.
The module identifies caregivers of people with dementia by asking about the primary health problem or disability—one response option is Alzheimer's disease, dementia or other cognitive impairment disorder. If any other health problem or disability is named, a follow up question asks if the person receiving care also has Alzheimer's disease, dementia or other cognitive impairment disorder specifically.
The team could choose to have the sample include only people caring for someone with dementia as the primary condition or could include caregivers for all people with dementia (using both questions). Using the primary condition alone will result in a smaller number of dementia caregivers than using both questions together.

EXAMPLE

Caregiving Data Analysis
Dementia caregiving can be unique compared with other caregiving due to the intensity, duration and care tasks required. When conducting the analysis of BRFSS caregiving data, the project team has the option to contrast dementia caregivers with caregivers for all other conditions to help understand potential variations. This study is one example looking at caregiver health nationally:

Changes in Health Indicators Among Caregivers

Caregiver demographics, health status and behavioral risk factors can all be analyzed using BRFSS data.

Working with Dementia-Related Clinical and Claims Data

Dementia Diagnostic Codes

When using data from health systems, claims data or vital statistics records, ICD codes may be used to identify diagnoses for Alzheimer's disease, dementia, or risk factors for these conditions. The following are ICD-10 dementia diagnostic codes that have been previously used by the Alzheimer's Association when analyzing claims data.

Sample Dementia Diagnostic Codes

ICD-10 Code	Diagnosis
F03.90	Unspecified dementia without behavioral disturbance
F03.91	Unspecified dementia with behavioral disturbance
G31.84	Mild cognitive impairment
G30.0	Alzheimer's disease with early onset
G30.1	Alzheimer's disease with late onset
G30.8	Other Alzheimer's disease
G30.9	Alzheimer's disease
F01.50	Vascular dementia without behavioral disturbance
F01.51	Vascular dementia with behavioral disturbance
F02.80	Dementia in other diseases, without behavioral disturbance
F02.81	Dementia in other diseases, with behavioral disturbance
F04	Amnestic disorder due to known physiological condition
G10	Huntington's disease
G13.8	Other specified systemic atrophies primarily affecting central nervous system
G20	Parkinson's disease
G31.01	Pick's disease
G31.09	Other frontotemporal dementia
G31.83	Dementia with Lewy bodies
F10.27	Alcohol dependence with alcohol-induced persisting dementia

Please note that effective October 1, 2022, numerous dementia codes were added to the ICD-10 to include more specificity on the stage of disease as well as behavioral and other disturbances. The table above was compiled prior to this change. The below link to the Chronic Conditions Data Warehouse includes the additional new codes.

While the table includes some common ICD-10 codes relevant for dementia, there is currently no consensus on which exact set of codes is best to identify dementia diagnoses within a given population. Which codes are best will depend on the project goals. Project teams should consult agency leadership, clinical partners or the published scientific literature to determine which codes they will use and how they will define these conditions and risk factors.

Examples from government sources include:

- The Chronic Conditions Data Warehouse from the Centers for Medicare and Medicaid Services (CMS) includes recommended codes, time frames and types of claims to use for identifying Alzheimer's disease and/or non-Alzheimer's dementia.
- The National Center for Health Statistics maintains a searchable list of ICD codes to identify conditions of interest including dementia.
- Healthy People 2030 Dementia Objectives includes the list of ICD codes used for identifying the number of adults age 65 and older who have Alzheimer's disease or other types of dementia. This list was compiled before the addition of the new dementia codes.

Examples from published scientific literature (all of which use pre-2022 codes) include:

- 2025 paper by Bhattacharyya and colleagues that compared dementia diagnoses based on different ICD codes in fee-for-service Medicare claims to a research-based definition.[6]
- 2024 publication by Gianattasio and team that categorized people based on ICD and prescription drug codes using data from Medicare fee-for-service and Medicare Advantage claims.[7]
- 2019 paper by Thunell and colleagues that compared the CMS Chronic Condition Warehouse measure to definitions including pharmacy records and symptoms.[8]

Dementia and Claims Data

Keep in mind that claims data are obtained from systems that are set up for medical billing—as of September 2025, few billing codes require a dementia diagnosis for reimbursement. This may compound existing underdiagnosis and underreporting of dementia on claims—as many as 60% of dementia cases are not diagnosed.[1]

Consider the following, where appropriate to the goals of your analysis, when conducting analyses.

- Incorporating lookback periods to capture multiple claims from any given individual over a period of time. Individual claims may not reflect a dementia diagnosis if it was unnecessary for reimbursement. Further, many people are not diagnosed until later stages.
- Including all diagnostic positions. Dementia may not be listed as the primary condition, but may appear as, for example, a secondary or tertiary diagnosis on a claim.
- Account for underdiagnosis. Disparities in diagnosis rates of dementia among Black, Latino and lower-income populations can affect results.
- Consider the unique aspects of the health system. Given that ICD codes are typically used for billing and reimbursement purposes, health systems and providers may use the codes differently from one another or may tend to use one group of codes more often than others. Comparing across Medicare programs, Veterans Administration Health Care Benefit enrollees, private insurance patients and other groups may require using different code sets or may result in different estimates.

These are just a few of the considerations to keep in mind when working with dementia-related data but many other complexities should also be weighed in the analysis and interpretation. Partnering with your epidemiology team and local universities with expertise on dementia and/or the dataset use helps ensure responsible analysis and interpretation.

STEP 4: DISSEMINATE FINDINGS

Dissemination Planning

Plan strategies early—before or alongside data analysis—to ensure findings fit seamlessly into final products. A dissemination strategy outlines what will be shared, when, through which channels (e.g., radio, TV, social media, print), and who will deliver the message. This plan should be reviewed after analysis to confirm accuracy and relevance.

Product Development

Visualizing Data for Clear Communication

Using charts, graphs and other visual representations of the analysis helps make complex information easier to understand and remember. Consider the following when developing visual representations of the analysis[9]:

Choose the right type of visual:

- Bar charts to compare categories
- Line graphs to show changes over time
- Maps to show geographic differences

Think about the audience:

- Community members: use simple visuals and relatable stories
- Policymakers: focus on clear, high-impact takeaways

Ensure visuals are accessible:

- Use colors with good contrast, and avoid using only color to show differences
- Label charts directly instead of using a legend
- Use large, readable fonts
- Include alternative text for screen readers
- Use plain language when possible

KEY TASKS

Team Lead:
Contribute to final messaging. Support strategic dissemination

Data Lead:
Ensure messaging accurately reflects data findings

Communications Lead:
Produce final product and dissemination strategy

Health Improvement Lead:
Support integration of topic and results into SHA/CHA process

Use different ways to share visual:

- Infographics for reports or handouts
- Dashboards for agencies or programs
- Short videos to reach community members online

Driving Action and Engaging Communities

The goal of dissemination is not only to share data but to inspire specific, measurable action. Every dissemination product should clearly articulate the change needed, the interest-holders responsible, and how the data supports that action.

Approaches to Sustaining Engagement	Description	Examples
Ongoing Updates & Relevance	Ensure materials remain current and are regularly revisited.	• Refresh data products on a set cycle (e.g., annual infographics, quarterly briefs). • Use modular or templated formats that allow easy updates. • Keep case studies and visuals current.
Feedback & Iteration	Create mechanisms for two-way communication between the team developing the product and the audience	• Gather input from partners and interest-holders. • Track how findings are used (e.g., in policy, programming, evaluation). • Adjust formats and messaging for clarity and accessibility.
Long-Term Integration & Strategy	Embed findings into broader systems and long-term planning.	• Align with state/local health plans and policy agendas. • Build adaptable tools that grow with new data. • Host follow-up discussions to support implementation.
Accessibility & Reach	Make data widely available and usable across audiences.	• Provide content in various formats (print, digital, multimedia). • Promote adoption by health departments and community groups. • Maintain a centralized, user-friendly online repository.
Partnership Driven Sustainability	Institutionalize dissemination through ongoing collaborations.	• Formalize roles via MOUs or working groups. • Engage champions in health departments, advocacy, etc. • Connect dissemination to funding and policy priorities.

Driving Action and Engaging Communities

Key considerations for a strong call to action:

What should change?

Who needs to act?

How does this data support that action?

Example:

Less effective: "Dementia prevalence is rising."

More effective: "Dementia prevalence has gone up 15% over the past decade. We need more caregiver support programs to meet this growing need."

EXAMPLE

Health Department in Action: Illinois Caregiving Data Brief Dissemination

The Illinois Department of Public Health (IDPH) participated in the Data for Action Project in 2023 as a way to advance their work on caregiving. IDPH published two data briefs online developed as part of the Data for Action Project.

Alzheimer's in Illinois Brief **Caregiving in Illinois Brief**

After publication, IDPH disseminated the briefs to key partners starting with the Alzheimer's Disease Advisory Committee, the group established to advise IDPH on Alzheimer's issues. IDPH presented these data in spring 2024 and continue to educate new partners with the data. IDPH created a separate infographic with the data, promoting this visual IDPH health brain newsletter and on social media. In early 2025, these materials were featured during a presentation to approximately 200 health care providers including physicians, nurses and other allied health professionals.

Audience Engagement in Message Development

Audience engagement should be part of every stage of dissemination. Involve key audiences early, especially people with lived experience, health care providers, and caregivers. Also include policymakers, researchers, and other community members as needed. Use focus groups, interviews, surveys, or advisory panels to learn what matters most to them. Their feedback should guide both the content and the format so that final products reflect real needs, address barriers, and are easy to access and use.

Partner with trusted messengers

such as faith-based organizations, community-based organizations, local health departments, and professional associations. These groups can help share messages in ways that are credible and widely received.

Make materials accessible

by translating into needed languages, using plain language for all literacy levels, and providing both printed and digital versions so everyone can access the information.

Use multiple formats

including static infographics for reports and social media, interactive dashboards for agencies and policymakers, and short video explainers for community outreach.

Tailor by audience type

- People with lived experience and caregivers: Use clear visuals, relatable stories, and practical resources that can be applied right away.
- Health care providers: Provide concise data summaries, infographics, and relevant clinical resources.
- Policymakers: Share short, high-impact takeaways with clear recommendations.
- Researchers: Offer detailed, interactive dashboards and full data sets.

Keeping Engagement Over Time

Dissemination is not just about sharing data once, it is about creating lasting change. Including sustainability in the dissemination plan ensures that key findings remain relevant, partners stay engaged and resources developed through the Data for Action Project continue to be used, adapted and updated over time.

To sustain engagement:

- Provide ongoing updates: data should be revisited regularly, not just released as a one-time report.
- Create feedback loops: invite partners in an iterative process to share how they are using the data.
- Ensure materials remain relevant: update key statistics, case studies, and visuals.

SUMMARY

Effectively analyzing and using dementia-related data is essential for driving meaningful change in public health, health care systems, and community support structures.

Get started today using the resources below.

For additional support related to this toolkit, contact:

Alzheimer's Association publichealth@alz.org	ASTHO healthyaging@astho.org

Resources

Healthy Brain Initiative

- Healthy Brain Initiative Road Map
  https://www.alz.org/professionals/public-health/models-frameworks/hbi-road-map
- Healthy Brain Initiative Road Map for American Indian and Alaska Native Peoples
  https://www.alz.org/professionals/public-health/models-frameworks/hbi-road-map-american-indian-alaska-native

Alzheimer's Association

- Alzheimer's in each state
  https://www.alz.org/professionals/public-health/state-overview
- Public Health State Pages – Data Fact Sheets
  https://www.alz.org/alzheimers-dementia/facts-figures#alzInEachState
- Resources and Data
  https://www.alz.org/professionals/public-health/resources-data

Centers for Disease Control and Prevention

- Infographics, BRFSS Cognitive Decline and Caregiver Modules
  https://www.cdc.gov/healthy-aging-data/infographics/index.html
- **Statistical Briefs**
  - Cognitive decline:
    https://www.cdc.gov/healthy-aging-data/media/pdfs/2024/08/BRFSS-statistical-brief-cognitive-decline-5081.pdf
  - Caregiver:
    https://www.cdc.gov/healthy-aging-data/media/pdfs/2024/08/BRFSS-caregiver-brief-5081.pdf
- Healthy Aging Data Portal
  https://www.cdc.gov/healthy-aging-data/data-portal/index.html

Healthy People 2030

- Dementia Objectives & ICD 10 Codes
  https://odphp.health.gov/healthypeople/objectives-and-data/browse-objectives/dementias/increase-proportion-older-adults-dementia-or-their-caregivers-who-know-they-have-it-dia-01/data-methodology

Product Examples

Illinois Department of Public Health Data Brief

- Topic: Dementia Caregiving
  https://dph.illinois.gov/content/dam/soi/en/web/idph/publications/idph/topics-and-services/diseases-and-conditions/alzheimers/caregiver-burden-brief-2024-il-dph-03-07-2024.pdf

Ohio Department of Health Infographic

- Topic: Cognitive Decline and Mental Health
  https://odh.ohio.gov/know-our-programs/behavioral-risk-factor-surveillance-system/data-and-publications/subjective-cognitive-decline

Arkansas Department of Health Journal Article

- Topic: Social Vulnerability Index and Cognitive Decline
  https://academic.oup.com/innovateage/article/8/Supplement_1/478/7936584

APPENDIX

Worksheets on the Following Pages

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[9] Johns Hopkins University Sheridan Libraries & Museums. (2025, April). Introduction to data visualization. Data visualization guide.

WORKSHEET: CREATING THE DATA ANALYSIS PLAN: HEALTHY BRAIN INITIATIVE DATA FOR ACTION PROJECT

This worksheet is a companion to the Data for Action Toolkit and supports planning for and conducting analysis of data on brain health, dementia, and caregiving.

- **When:** This worksheet can be completed in the data identification and in steps 2 & 3 of the toolkit.
- **Who:** The Data Lead should complete this worksheet, with full team input to ensure the most impactful data points are selected based on team and state priorities and that the interpretation of findings remain true to the subject matter.

Focus Area

Identify the focus are of your project. Examples and related data sources below.

☐ Risk Reduction (BRFSS Cognitive Decline Module)
☐ Cognitive Decline & Early Detection (BRFSS Cognitive Decline Module)
☐ Caregiving (BRFSS Caregiver Module)
☐ Quality of Care (Hospital Discharge Data and/or Medicaid Data)
☐ Other (define):

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Goal Statement

What is the goal for this Data For Action Project? Who is the target audience?

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Data Source

Which data source(s) and year(s) will the Data for Action Project use? For example, 2023 Behavioral Risk Factor Surveillance System data from the Cognitive Decline module.

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Personnel Plan

Please identify the team member who will be responsible for each of the following activities:

1. Acquiring data:________________________________
2. Cleaning data and running analyses:________________________
3. Creating tables/figures:____________________________
4. Writing a summary of the methods and results:

Analysis Plan

In 1-2 paragraphs, describe the general types of analyses needed for this project. This might include calculating weighted prevalence estimates and confidence intervals, using statistical tests to make comparisons (e.g., chi-square tests or model-based comparisons), or estimating the association between two variables.

Planned Output

Develop table shells or mock figures that you expect to create for your project. These may include tables/figures you plan to use internally only for decision making and/or those you expect to be part of the final dissemination product. Examples from the BRFSS Cognitive Decline and Caregiver Modules below. **Yours do not need to look the same or include as many variables; these are only intended to provide ideas.** Below each example table there is a sample statement for interpreting data from within the table.

Example: Family Caregiving

Table 1. Characteristics of Care Provided by Family Caregivers in [jurisdiction], Behavioral Risk Factor Surveillance System, [year(s)].

Variable	**Category**	**All Caregivers** (N=) Weighted %	**Caregivers of People with Dementia** (N=) Weighted %	**Caregivers of People without Dementia** (N=) Weighted %
Example interpretation: Among adults caring for a family member or friend with dementia in [jurisdiction], X% spend 20 hours or more each week providing care.				
Care Recipient's Relationship	Parent or parent-in-law			
	Grandparent			
	Spouse/Partner			
	Child			
	Grandchild			
	Other relative			
	Non-relative/ friend			
	Missing			
Caregiving Duration	<6 months			
	6 months-2 years			
	≥2 years			
	Missing			
Average hours of care per week	8 hours/week			
	9-19 hours/week			
	≥20 hours/week			
	Missing			
Help with personal care tasks	Yes			
	No			
Help with household tasks	Yes			
	No			

Example: Modifiable Risk Factors for Dementia

Table 1. Prevalence of Modifiable Risk Factors for Dementia among Adults in [jurisdiction], Behavioral Risk Factor Surveillance System, [year(s)].

Variable	**Category**	**All Adults** (N=) Weighted %	**Adults Age 45+** (N=) Weighted %
Example interpretation: Among adults in [jurisdiction], X% are deaf or have serious difficulty hearing			
Physical inactivity	Do not engage in physical activity outside of work		
Smoking status	Currently smoke every day/some days		
Heavy alcohol consumption	Men ≥5 drinks on one occasion; women ≥4 drinks on one occasion		
Binge drinking	Men ≥5 drinks on one occasion; women ≥4 drinks on one occasion		
Obesity based on Body Mass Index (BMI)	Obese (BMI≥30.0)		
Hypertension	Ever diagnosed		
Diabetes	Ever diagnosed, except during pregnancy; pre- or borderline diabetes considered no diabetes		
Depression	Ever diagnosed		
Hearing loss	Deaf or have serious difficulty hearing		

Table 2. Characteristics of Adults with and without Modifiable Risk Factors for Dementia in [jurisdiction], Behavioral Risk Factor Surveillance System, [year(s)].

Variable	**Category**	**All Adults** (N=) Weighted %	**Adults with ≥1 Dementia Risk Factor** (N=) Weighted %	**Adults with no Dementia Risk Factors** (N=) Weighted %
Example interpretation: Among adults in [jurisdiction] who have at least one risk factor for dementia, X% are employed.				
Sex	Female			
Age Group	18-24			
	25-34			
	35-44			
	45-54			
	55-64			
	65-74			
	75+			
Highest level of education	Less than high school			
	High school graduate			
	Some college			
	College graduate			
Employment status	Emploed/Self-employed			
	Retired			
	Unable to work			
	Other (out of work, homemaker or student)			
Marital status	Married/Coupled			
Children in household	At least one cild under the age 18 lives in the household			
Race/ethnicity	Asian or Pacific Islander, non-Hispanic			
	American Indian or Alaska Native, non-Hispanic			
	Black, non-Hispanic			
	White, non-Hispanic			
	Multiple races, non-Hispanic			
	Other race, non-Hispanic			
	Hispanic (any race)			

HEALTHY BRAIN INITIATIVE DATA FOR ACTION WORKSHEET
CREATING THE DISSEMINATION PLAN

This worksheet is a companion to Step 4 of the Data for Action Toolkit and supports planning for a final dissemination product to share data findings on brain health, dementia, and caregiving.

- **When:** This worksheet benefits from early completion alongside the data identification and analysis in steps 2 & 3. Early completion ensures the final product vision is kept in mind while figuring out what data the team wants to prioritize.
- **Who:** The Communications Lead should complete this worksheet, with full team input to ensure the content and design remain true to the subject matter and the analysis.

Target Audience

Based on the data analysis plan, identify the audience of focus. Recommendation: prioritize a single audience to ensure the product is truly tailored to what they need.

☐ Internal health department officials (agency director, chronic disease director, aging director, etc.)

☐ Governmental executive leadership (e.g. Governor's Council on Aging)

☐ External Partner Organizations (health care providers and clinicians, patient advocacy organizations, etc)

☐ General Public & Community (frontier, rural, urban, suburban, ethnic and cultural)

☐ Other (define): ______________________________

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Goal Statement

In 1–2 sentences, what is the main message intended to reach your audience? ______________________________

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- How will you visualize your data for your desired audience? ______________________________

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- Based on that information, what is your call to action for your priority audience? In other words, what would you like them to do next after engaging with your message and data?

Personnel Plan

Identify the team member who will be responsible for each of the following activities:

1. Visualizing data (Creating tables/figures):
2. Cohesive language and feel of materials and products:
3. Formatting, proofing and editing, publishing/ dissemination, departmental approval:
4. Audience representatives to review:

Dissemination Plan

Please briefly describe the steps you will take in the following:

- How will you effectively share data-informed messaging with your audience?

Maximize the impact of this project.

- Which groups, organizations or individuals within your audience will you prioritize in disseminating your messaging?

- How will that maximize impact?

- What methods will you use to reach them?____

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- How will you measure the success of your efforts?____

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Resources

For more information on strategies for visualizing data, reference the Johns Hopkins Data Visualization Guides.

For inspiration, visit the CDC's Alzheimer's Disease and Healthy Aging Infographics page or the Alzheimer's Association Facts and Figures or Public Health State Overviews to access facts, figures, and state-specific information.