

Needs Assessment Toolkit

For dementia, cognitive health, and caregiving

Updated January 2023



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EXECUTIVE SUMMARY

Comprehensive needs assessments are a foundational step for jurisdictions to develop, implement, and evaluate community-wide plans to improve health outcomes. Just as needs assessments help shape the public health response to diabetes, heart disease, and stroke, they must do the same for dementia and caregiving. This toolkit guides multisystem teams from public health agencies, aging agencies, community organizations, and other institutions through the steps necessary to complete a comprehensive needs assessment of dementia, dementia caregiving, and cognitive health in their communities. Equity considerations are integrated into the processes and highlighted in each step of this toolkit.

Toolkit users will be able to:

- » Describe the key components of a needs assessment.
- » Use the tools provided to guide a jurisdiction-wide needs assessment.
- » Operationalize health equity within the needs assessment process.

When Brain Health Meets Public Health, a 3-minute video, provides a quick overview of dementia and the Healthy Brain Initiative Road Map.

Our approach to addressing Alzheimer's disease and other dementia (hereinafter referred to as "dementia") has changed over the last decade as research has expanded to include public health policies and systems, new detection tools, and increased public awareness. Dementia affects individuals and communities at all stages of cognitive decline, and it is incumbent on state, local, and tribal governments to coordinate and prioritize supports and services for people living with dementia and their caregivers.

Morbidity Caused by Dementia¹



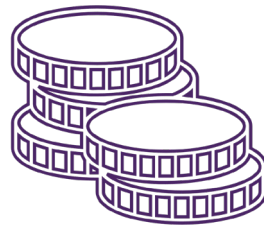
Leading cause of disability and poor health.

Emotional Stress of Caregiving



59% of dementia caregivers report high to very high emotional stress.

Cost of Unpaid Dementia Caregiving



Caregivers provide average of 26 hours/week, valued at \$256.7 billion in 2020.

Disparate Impact of Dementia



Black, Indigenous, and Hispanic people are more likely to live with dementia.

This toolkit is framed around five key steps: (1) Partner, (2) Plan, (3) Collect, (4) Analyze, and (5) Action. Each step builds on the previous step, but users can enter the process at any step depending on need and current work. Each step is summarized succinctly with accompanying fillable tools in the appendix. The steps, tools, and resources are primarily designed for public health and aging agencies, but other groups are also encouraged to use this toolkit.






ABOUT THIS TOOLKIT

This toolkit is designed for a variety of stakeholders interested in dementia who aim to lead a needs assessment process. State and local public health agencies, aging agencies, community health and hospital systems, and community leaders — including state Alzheimer’s planning groups — are best suited to use this toolkit, although others may benefit. The group or person who leads the needs assessment will coordinate meetings and partnerships and move action forward. The lead(s) do not need to be epidemiologists or statisticians, as the toolkit includes resources to support in-depth data collection and analysis. It is designed to be flexible enough to accommodate a range of budgets, organizational capacity, and organizational readiness.

This toolkit is designed to be used in conjunction with the Center for Disease Control and Prevention’s (CDC) and the Alzheimer’s Association’s Healthy Brain Initiative Road Map (HBI Road Map), [State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map](#) and the companion document, [The Road Map for Indian Country](#). The HBI Road Map series aims to prepare governmental and tribal public health agencies and partners to change policies, systems, and environments regarding cognitive health, dementia, and caregiving to improve population health outcomes.

A needs assessment is a foundational step for strategic planning, implementing actions in the [HBI Road Map](#), and making recommendations to jurisdiction-wide plans (i.e., health improvement plans, plans on aging, and state Alzheimer’s plans), which are typically updated every three to five years. A corresponding needs assessment ensures plan updates reflect the changes in the community and offers a means for evaluation over time. This needs assessment toolkit can support efforts toward accreditation, budgeting, grant writing (such as for CDC’s [BOLD Public Health Programs](#)), and implementing actions from the HBI Road Map.

This toolkit was developed through an iterative process, including a virtual consultation, multiple rounds of review by stakeholders, and frequent conversations between authors. The authorship team reconciled more than 1,600 comments to ensure that stakeholders’ voices were included in the toolkit. Ultimately, the processes prioritized for this toolkit are to improve systems of care and well-being for people living with dementia and the people supporting them. The Excel worksheets that align with the appendix include strategic examples focused on dementia. All resources have been developed with the best available science and latest public health approaches, as of 2021, to maximize impact and minimize barriers.

Toolkit Steps	Objectives for Each Step
 Step 1: Partner Estimate: 10-15 hours	Identify internal and external stakeholders, prepare to collaborate with stakeholders, and establish common goals of all organizations/entities.
 Step 2: Plan Estimate: 40-50 hours	Create a comprehensive plan to conduct the needs assessment with inclusivity, strategy, and equity-driven approaches.
 Step 3: Collect Estimate: 60-80 hours	Identify related health data and gather data accordingly. This will include health status data, demographics, and stakeholder/community input.
 Step 4: Analyze Estimate: 60-80 hours	Synthesize the data to set a shared understanding of the findings within your jurisdiction and assess the data’s implications.
 Step 5: Action Estimate: 70+ hours	Outline steps to achieve shared goals and communicate the key findings to decision-makers, policymakers, and other stakeholders.

ACKNOWLEDGMENTS

This toolkit was created through a collaboration between the Alzheimer’s Association and The Association of State and Territorial Health Officials (ASTHO), with support from partners across the fields of public health and aging. Email publichealth@alz.org or healthyaging@astho.org for technical assistance or support with this toolkit.

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This publication is supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$2,795,933, with 100 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. government.

INTRODUCTION

Our Evolving Understanding of Dementia

Dementia is an umbrella term that refers to a general loss of abilities involving memory and judgment, language and abstract thinking, and personality that are severe enough to impact everyday life. Dementia is not a disease itself but a syndrome defined by a group of symptoms that often occur together in various combinations and at varying degrees of cognitive impairment. Alzheimer's disease is the most common cause of dementia.

As our understanding of dementia, Alzheimer's, and cognitive health evolves, the terms and definitions to describe these conditions change, too. Visit the [Alzheimer's Association](#) and CDC ([English](#) and [Spanish](#)) for up-to-date definitions and research. In this document, the following terms are defined as:

- » **Cognitive impairment:** trouble remembering, learning new things, concentrating, or making decisions that affect everyday life.
- » **Cognitive health** (also known as brain health): the ability to draw on the strengths of the brain to remember, learn, play, concentrate, and maintain a clean, active mind; it involves making the most of the brain's capacity and helping to reduce some risks that occur with aging.²
- » **Risk reduction:** steps that can be taken at systemic and individual levels to lower risk for future dementia.

Clinical research, population health data, and needs assessments have helped our understanding of dementia to evolve. Today, there is actionable data available for statewide assessments through the Behavioral Risk Factor Surveillance System (BRFSS) [optional modules](#) on cognitive decline and caregiving. These data, however, can be difficult to use at the local level and for assessing disparities at the state level.

- » Between 2015 and 2020, all 50 states, the District of Columbia, and Puerto Rico used the optional BRFSS module on subjective cognitive decline at least once.
- » During the same period, 47 states, the District of Columbia, and Puerto Rico used the optional BRFSS module on caregiving.

The CDC Alzheimer's Disease Program has created nationwide, state-, and demographic-specific infographics in English and Spanish with the data from [these two modules](#). The Alzheimer's Association produces nationwide and state-specific [facts sheets](#) with the data as well.

Public health approaches can help reduce risk of cognitive decline, improve early detection and diagnosis, and enhance quality of life for people living with dementia. Risk reduction occurs across the life course and includes actions such as early healthy behaviors education, hypertension prevention, diabetes management, and physical activity promotion. Current disparities in various risk factors for cognitive decline and dementia need to be addressed to effectively promote equitable outcomes for dementia risk reduction and care.

Early detection of dementia is necessary for families to be able to plan while the person living with dementia has the capacity to make major life decisions. Recent developments in our understanding of the impacts of healthy behaviors (e.g., not smoking, engaging in vigorous physical activity, light-to-moderate alcohol consumption, eating a nutrient-rich diet, and brain engagement) and proper management of comorbidities offer more opportunities for coordinating resources and braiding funding to improve cognitive health, dementia outcomes, and the quality of life for dementia caregivers.³ Comprehensive needs assessments can help identify gaps and areas for alignment with these co-occurring conditions and public health interventions.

The CDC [Healthy Aging Data Portal](#) is a fast and easy way to access public health data.

The Importance of Coordinating a Multisystem Response

Comprehensive needs assessments are essential to helping jurisdictions develop, implement, and maintain effective plans and improve health outcomes related to cognitive health, caregiving, and dementia. This needs assessment toolkit can:

- » Ensure that the needs of people living with all types of cognitive impairment and their caregivers are fully assessed and met.
- » Inform development of or updates to a jurisdiction-wide Alzheimer's plan.
- » Support integration of dementia and caregiving policies, systems, and environments into broader jurisdictional plans (i.e., health improvement plans and plans on aging).
- » Provide recommendations for budgets and funding allocations to meet the needs of people living with dementia and their caregivers.
- » Evaluate efforts and stay up to date with available research.

Beginning in 2007, states began drafting (and then eventually updating) plans focusing on Alzheimer's disease and dementia, many sparked by state legislation to address the increasing rate of dementia. State public health agencies are increasingly involved in this planning process alongside state aging services departments, community organizations, elected officials, and citizen groups

Medicaid 1915(c) home and community-based services waivers may be helpful to consider when coordinating or piloting recommendations that the assessment identifies. States can provide these waiver services in home and memory care residences rather than institutional settings. Learn more on Medicaid's [Home & Community-Based Services 1915\(c\)](#) web page.

Public health and aging agencies continue to make strides toward building a public health infrastructure for dementia. Together, these agencies can identify gaps, develop recommendations, and — when financial resources are available — undertake program planning. This needs assessment toolkit offers approaches to continue coordinating and braiding government resources to advance cognitive health, address Alzheimer's disease and dementia, and improve the health and well-being of caregivers.

The Roles of People Living with Cognitive Impairment and Their Caregivers



People living with all forms of cognitive impairment must be included throughout the needs assessment process. Their unique experiences provide necessary perspectives that may otherwise be missing simply by relying on data. Caregivers (also known as care partners), which include family, friends, and neighbors, must also be consulted to paint a full picture of life with cognitive impairment.

Dementia caregivers face significant financial, emotional, and physical stress compared with other types of caregivers. Family, neighbors, and friends in unpaid caregiving roles provided an average of 26.3 hours per week in care (e.g., activities of daily living), valued at \$256.7 billion in 2020. A comprehensive needs assessment must include attention to caregiver health. The chronic stressors associated with caregiving affect all levels of health, making multisystem support important for caregiver well-being.

Throughout the needs assessment process, it is essential to include members from a wide variety of backgrounds, including people from different racial and ethnic populations and geographic locations as well as people with varying levels of socioeconomic status and educational attainment. By ensuring wide representation, the needs assessment process can advance health equity and provide recommendations that best serve the entire community. When inviting people with cognitive impairment and their caregivers, consider the Alzheimer's Association's [stages of communication](#).

The Role of Public Health



Public health agencies have both the authority and influence to change policies, systems, and environments that can advance cognitive health. They can understand the current health status of a population, identify barriers to improvement, and map assets via existing services and supports through a comprehensive and systematic needs assessment.

Public health agencies have an important role in promoting a life course and equity-driven perspective, highlighting the importance of early detection, and supporting early- and midlife protective factors for cognitive health.

Public health systems can work to reduce modifiable risk factors and comorbidities (i.e., chronic disease and traumatic brain injuries) that affect rates of cognitive decline and dementia. These include smoking, traumatic brain injuries, physical inactivity, hypertension, diabetes, and obesity.

By coordinating and braiding resources from programs with shared risk or protective factors, public health agencies can improve population level health outcomes. For more information, see ASTHO’s [Essential Policies for Chronic Disease Prevention and Control](#) and Trust for America’s Health’s [Promoting Health and Cost Control in States](#). The table below includes a sampling of ways that public health agencies play a role in advancing cognitive health.

Authority refers to areas where public health leaders have the ability to act. For example, public health has the authority to create and implement clean air policies.

Influence refers to areas where public health leaders can encourage action by another party. For example, public health has influence in recommending that a housing or transportation authority makes changes in the built environment to support community members living with dementia.

Policy, System, or Environment	Example Action	Public Health’s Role	
		Authority	Influence
Policies	Support benefits like paid sick leave, flexible work schedules, and long-term care insurance to build a better care infrastructure.	✓	✓
	Support built environment policies that promote physical activity and reduce injuries.	✓	✓
Systems	Align existing programs to reduce duplication, identify gaps, and promote the life course perspective.	✓	
	Integrate brain health and stigma reduction curriculum in education settings (including K-12 and medical schools).		✓
Environments	Promote universally designed, age-integrated living environments.		✓
	Partner to promote healthy behaviors, including physical activity, smoking cessation, and access to food that comprises a healthy diet.	✓	✓

Prevalence data and trends are available through the optional BRFSS modules, the National Health and Nutrition Examination Survey, existing state Alzheimer’s disease registries, and other sources. Public health’s continued surveillance work — like that performed by BRFSS — is essential to helping inform population-level policy, systems, and environmental changes at all levels of prevention.

The Role of Aging Services



Aging agencies and organizations provide many of the supports and services for people living with dementia and their caregivers. Early movement on building a robust system with and for people living with dementia originated in aging services. Some of the many successes and lessons from those past efforts include functional support for daily living, meal assistance, adult day supervision, and respite care for dementia caregivers. Aging agencies bring extensive experience and expertise to the needs assessment process and are valuable partners that can help map a jurisdiction's current assets and identify barriers to supports.

Aging agencies and organizations also have extensive networks and may identify additional partners, organizations, and individuals who should be involved in the needs assessment process. Service providers are encouraged to connect people living with dementia and their caregivers with public health interventions and health care providers to support well-being. Strong connections between aging and public health agencies can facilitate coordination of state resources and supports.

The Role of Health Care



A comprehensive needs assessment must include a review of health care provider workflows to identify ways to increase cognitive health assessments. Care teams can help identify barriers to early detection and diagnosis and suggest policy or system solutions to reach the entire jurisdiction. Care teams are also essential to help caregivers for people living with dementia maintain their own health and well-being.

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Dementia caregivers will need health care support to manage their own health and well-being, too.

Early and accurate diagnosis is a necessary step for someone living with dementia. A diagnosis allows the person to make decisions for themselves while they still can and to deepen relationships with their caregivers. It also opens opportunities for accessing services they need to maintain their independence and well-being for as long as possible. The Alzheimer's Association has developed dementia [resources for clinicians](#) that cover diagnosis guidelines and care planning.

Provider groups should support patients in care planning, identifying open [clinical studies](#), and accessing available, FDA-approved [pharmaceutical interventions](#). For Medicaid-specific support, check out the Alzheimer's Association's [Explainer on Medicaid](#). Health care professionals can use CPT code 99483 to receive reimbursement for care planning, which includes a functional assessment of activities of daily living, advanced care planning, and a safety assessment. For additional CPT codes specific to dementia care, see the Center for Palliative Care's presentation [Billing for Dementia Care 2021](#). Care teams are encouraged to continue providing sexual and reproductive health screenings, vaccines within age recommendations, and preventive screenings for chronic conditions, cancers, and possible infections for both the person living with dementia and their caregiver(s).

The Role of Community Organizations



Community organizations and organizers serve an important role in building trust, providing coordinated resources, and liaising between community members and outside entities. This may happen through direct services and/or wraparound supports for people living with dementia and their caregivers. A wide variety of community organizations and organizers, including those focused on transportation, housing, supplementary education, and physical activity, can support the comprehensive needs assessment effort.

Multisystem responses must include community organizations that speak to the diverse needs of community members and that are committed to place-based change. When you think about which community organizations to invite, think creatively and cast a wide net. Consider connecting to the [social determinants of health](#) through community organizations and organizers.

Assessing Need in South Dakota

In 2017, South Dakota undertook a comprehensive needs assessment process to inform development of the state's first plan on Alzheimer's disease. The South Dakota Alzheimer's Disease and Related Dementias State Plan Work Group contracted with an outside vendor to plan, conduct, and analyze the needs assessment. The process entailed many of the same steps found in this toolkit, including developing shared goals for the process, ensuring wide and varied participation in the assessment, utilizing multiple methods of data collection, analyzing the findings, and producing a comprehensive yet digestible report.






The needs assessment influenced many of the recommendations of the resulting state plan. Five key areas were identified and reflected in the final plan — access, affordability, workforce gaps, caregiver needs, and public awareness. Further, participants offered lessons learned for implementing the state plan recommendations, offering practical guidance based off their lived experiences.

Read the full [needs assessment](#) and [state plan](#) for additional details. To read other state portfolios, including assessments and plans, visit the Alzheimer's Association's [State Overview webpage](#).



GETTING STARTED

To start the needs assessment process, first select a primary facilitator (or co-facilitators) within the project team. Consider individuals from a public health agency, aging agency, or community organization to coordinate the needs assessment steps described below.

Toolkit Steps	Objectives for Each Step
 Step 1: Partner Estimate: 10-15 hours	Identify internal and external stakeholders, prepare to collaborate with stakeholders, and establish common goals of all organizations/entities.
 Step 2: Plan Estimate: 40-50 hours	Create a comprehensive plan to conduct the needs assessment with inclusivity, strategy, and equity-driven approaches.
 Step 3: Collect Estimate: 60-80 hours	Identify related health data and gather data accordingly. This will include health status data, demographics, and stakeholder/community input.
 Step 4: Analyze Estimate: 60-80 hours	Synthesize the data to set a shared understanding of the findings within your jurisdiction and assess the data's implications.
 Step 5: Action Estimate: 70+ hours	Outline steps to achieve shared goals and communicate the key findings to decision-makers, policymakers, and other stakeholders.

The steps in this toolkit can be used in order or individually, based on what your jurisdiction is already doing. If you are carrying out this assessment as part of another initiative (e.g., a state health improvement plan or state Alzheimer's disease plan), read through each step and align your existing efforts with these objectives. These steps were informed by public health and aging agency leaders with experience working on dementia and caregiving issues and other experts from public health systems and planning.

Advancing equity requires an inclusive, intentional, and systemic approach. Throughout this toolkit, equity considerations are integrated into the steps and highlighted under the "focus on health equity" boxes. This toolkit addresses equity as a process and as outcomes by outlining steps to focus on engagement, power sharing, and shifting focus from what we do to how we do it. A critical component of this equity work is assessing, partnering, and addressing the [social determinants of health](#).

Focus on Health Equity in Stakeholder Engagement

Start by stating your agencies' or organizations' definition of health equity to ensure that partners and stakeholders understand potential areas of action and how far upstream to go. Consider integrating the questions listed below throughout the process. These questions were developed by [Human Impact Partners](#), and are intended to be used throughout the needs assessment process to guide partner engagement and process planning, and to understand and act on disparate impacts.

1. What are the key groups that would be affected by the assessment, and how will they be affected?
2. Are the voices of the groups affected by dementia at the needs assessment table? If not, why?
3. How will the needs assessment be perceived by the affected groups, especially given the history of the issue?
4. How will the needs assessment process be designed to support those groups' engagement? How can their participation be ensured?
5. How will the needs assessment and recommendations development process attend to and prioritize disparities?

STEP 1: PARTNER



Identify stakeholders, prepare to collaborate with stakeholders, and establish common goals among all organizations/entities for the needs assessment process. If your jurisdiction already has a dementia coalition, council, or advisory group, review the recommendations here and invite anyone who may be missing from the discussion. (See the appendix to find the tools listed in the table below.)

Measures Of Success For Completing The Step

Convene a group that is representative of the community and who will be most affected by the results of the needs assessment.

Help all stakeholders understand how collaborating on the needs assessment will meet a common goal.

Needed Tools

- 1a. Stakeholder Matrix
- 1b. Operationalizing Equity in Stakeholder Engagement
- 1c. Examples of Stakeholders
- 1d. Invitation for Stakeholders to Participate

Step-By-Step Prompts (Estimate: 10–15 hours)

1. **Identify stakeholders** who are affected by the process and/or the results of the needs assessment. Use Tool 1b to identify stakeholders, then use Tool 1a to organize stakeholders by their level of influence, areas of importance, and possible contributions to the needs assessment.
2. **Invite stakeholders** to participate in the needs assessment process, clearly outlining expectations.
3. **Meet stakeholders** for a kickoff meeting to draft your shared goal(s), agree to the process, and discuss how the results will be utilized.
4. **Outline engagement** opportunities for stakeholders throughout the needs assessment process, including participation in the core and project teams (see next step).
5. **If used in conjunction with other planning process**, include the lead team for coordination.

Examples of stakeholders

See appendix 1a for more detail

- » People living with dementia and their caregivers
- » Governmental agencies (e.g., public health agency, aging agency, housing authority)
- » Community organizations (e.g., Alzheimer's Association local chapters, YMCA/YWCAs, caregiving coalitions)
- » Health care (e.g., Federally Qualified Health Centers, skilled nursing homes)
- » Insurance providers (e.g., state Medicaid agency, private insurers)

Tips and Ways to Focus on Health Equity

Be inclusive, not exclusive

- » Include people who are affected by dementia and the assessment from the beginning and at every step thereafter. Consider providing accessibility requirements and support — such as stipends, transportation assistance, adult caregiving, and child care — to reduce barriers for participating in the process.
- » Think creatively about engaging stakeholders. Consider visiting assisted living facilities, caregiver support groups, or libraries to engage people living with dementia and their caregivers.
- » Assess the demographics and makeup of your teams and stakeholder groups to ensure they reflect deeper values regarding equity and inclusion.
- » Clearly articulate who has the power to make decisions in the needs assessment and communicate that transparently with partners.

STEP 2: PLAN



Create a comprehensive plan to conduct the needs assessment with inclusive, strategic, and equity-driven approaches.

Measures Of Success For Completing The Step

Establish a thoughtfully designed plan with goals, objectives, and a vision for the needs assessment.

Establish a core team to participate in day-to-day activities.

Develop a flow sheet that documents milestones, responsibilities for each task, and dates from start to finish.

Needed Tools

2a. Shared Goals Worksheet

2b. Needs Assessment Timeline

+ Existing plans, previous needs assessments, and/or current state policies to help inform strategies.

Step-By-Step Prompts (Estimate: 40–50 hours)

1. **Develop shared goals/objectives** for the needs assessment using Tool 2a and prepare to revisit them at each following step to remind the group and refine as needed.
2. **Establish a core team** to lead the process, ensure the needs assessment stays on track, and support the project teams.
3. **Organize stakeholders into project teams** based on the shared goals/objectives. Each project team should focus on a specific element of the needs assessment, including a core team to participate in the day-to-day activities and support teams to review and provide input.
4. **Outline plans** for each team based on shared goals.
5. **Draft a timeline** for the assessment process and activities that need to be accomplished within each step. To do this, use Tool 2b, which documents milestones, identifies who is responsible for each task, and assigns deadlines.
6. **Establish a meeting schedule** for the core team and project teams to map out the additional steps and track progress.

As stakeholders organize into project teams, encourage them to consider how they can leverage their **influence** and **authority** toward shared goals.

Tips and Ways to Focus on Health Equity

Focus on sustainability

- » Consider how this needs assessment might contribute to other assessments and planning efforts such as the health improvement plan, dementia plans, plan on aging, and/or HBI Road Map implementation plan.
- » Integrate this work into a larger planning efforts to support sustainability and propel action after the assessment is complete.
- » Address power differentials when setting expectations for stakeholders with different capacities. Identify what is feasible to do, what capacity needs to be built, and the best ways to organize the work for groups that may not typically be involved or for individuals who come from organizations with fewer resources. Prioritize their needs and allow their contributions to guide decisions about timelines and plans.

STEP 3: COLLECT



Collect the necessary data to meet the shared goals. Teams must determine which specific aspects of health to analyze within the needs assessment and gather data accordingly. This will include surveillance and health status data along with stakeholder and community input. Use a health equity lens when thinking about which types of data to gather and how to accurately assess the needs of each community.

Measures Of Success For Completing The Step

Identify available data sources and gaps in existing data. Ensure that data reflect the diversity of the community/jurisdiction.

Identify community resources/assets for people affected by dementia, including caregivers.

Collect data from identified sources.

Needed Tools

3a. Data Types and Sources Reference List

3b. Root Cause Analysis—Five Whys

3c. Strengths, Weaknesses, Opportunities, and Challenges (SWOC) Analysis

Step-By-Step Prompts (Estimate: 60–80 hours)

1. **Revisit shared goals** with the stakeholder team to remind the group and refine as needed.
2. **Evaluate resources/assets** that currently exist and can be used to help meet the needs of those affected by dementia using the root cause and SWOC analyses (Tools 3b and 3c).
3. **Finalize your data collection** plan using Tool 3a.
4. **Collect health status and disparities data.** Make sure to assess any current inequities (e.g., those related to race, income, and gender).
5. **Collect stakeholder and community input data** in synchronous and asynchronous ways in both virtual and in-person platforms.
6. **Collect communication data** to inform the communications plan and action for various audiences.
7. **Compile data** in a centralized hub to prepare for analysis.

Host town hall meetings, focus groups, surveys, or other means of community-based participatory information gathering to engage a broad range of stakeholders.

Tips and Ways to Focus on Health Equity

Dissect systems and root causes

- » Complete a Root Cause Analysis (see Tool 3b and [learn more](#) about the process) to better understand the social determinants of health and their effect on dementia health outcomes. Consider the [Five Whys Technique](#) (Tool 3c) or the [Fishbone Diagram](#) (see ASQ's [template](#)). Incorporate your findings in the Analyze step.
- » Engage stakeholders in a Strengths, Weaknesses, Opportunities, and Challenges (SWOC) analysis ([learn more](#) about the SWOC framework) to assess the jurisdiction's gaps, needs, and strengths — and the possible impacts/challenges of their actions. Prompt engagement of older adults, people living with dementia, and caregivers, especially if they were missed in previous assessments and plans.

STEP 4: ANALYZE



Synthesize the data to establish a shared understanding of the findings and to interpret the data's implications. This step provides an opportunity to connect themes within the data to broader, upstream health equity issues and gaps.

Measures of Success for Completing the Step

Identify patterns and themes within the data.

Translate the analysis in collaboration with stakeholders/project teams.

Consider the end audience and shared goals during this stage.

Needed Tools

4a. Instruments of Health Equity in Analysis from the National Collaborative for Health Equity

1b. Operationalizing Equity in Stakeholder Engagement (from step 1)

+ Compilation of all data gathered in step 3: *Collect*

+ Data on public outreach and communications

Step-By-Step Prompts (Estimate: 60–80 hours)

1. **Analyze the data.** Call on data analysis experts to help with this.
2. **Organize the analysis** for the stakeholder group to review.
3. **Revisit shared goals** with the entire stakeholder team to remind the group and refine as needed. Connect the results of the analysis to the goals.
4. **Meet with the project teams** to discuss the findings. During this meeting:
 - » Include dedicated time to revisit Tool 1b, Operationalizing Equity in Stakeholder Engagement.
 - » Use Tool 4a, from the National Collaborative for Health Equity's [HOPE Initiative](#) to think strategically about promoting protective factors.
5. **Develop recommendations**, with input from project teams, in response to your data and findings. Prioritize the needs of the people and communities most affected by dementia and most at risk for cognitive decline. Develop recommendations that address any identified inequities and obtain feedback from stakeholders.
6. **Begin a communication plan** with your public relations teams to review effective communication strategies to reach different audiences with your recommendations. Keep in focus the influence and authority of specific stakeholders (revisit Tool 1a).
7. **Connect your analysis to the larger planning processes**, including the health improvement plan and Alzheimer's plan. Even if this needs assessment is conducted separately from these plans, share your results with these lead teams to inform their work.

Tips and Ways to Focus on Health Equity

Be inclusive: ask for new perspectives

- » Consider who else should be in the discussions to help interpret the data and invite them to join these meetings. Reassess the data with these new perspectives.
- » Review recommendations with a health equity lens, asking, "How will these recommendations be received in different communities?" and "What barriers still exist to execute these recommendations?" Restructure your recommendations as needed.
- » Similarly, begin planning how to tailor communications and messaging to diverse audiences.

STEP 5: ACTION



This step outlines realistic steps to achieving the shared goals of the stakeholder group and communicating the findings and recommendations to decision-makers, policymakers, and additional stakeholders. This step can also be called the “implementation” or “communication” step.

Measures of success for completing the step

Communicate a shared vision for the future and next steps to address the jurisdiction’s needs identified during the process.

Communicate the results of the assessment to the public as well as to people who have influence and authority within the jurisdiction.

Needed Tools

- 5a. Assessment Report Checklist
- 5b. Communication Planning Template
- 5c. Press Release Template

Step-By-Step Prompts (Estimate: 70+ hours, ongoing with action)

1. **Prepare a written report** to communicate the results and recommendations from the needs assessment to decision-makers, policymakers, and other stakeholders. Use Tool 5a as a guide. Consider including an executive summary in the full report.
2. **Finalize and implement the communication plan** in collaboration with stakeholders using Tool 5b as a guide. Leverage the influence and authority of each stakeholder to lead various communication pathways. Activities should include:
 - » Developing communication materials (e.g., infographics, webinars, press releases). Consider broadband access and technology literacy in the community when creating resources for a general audience.
 - » Publicizing the findings and recommendations to make them widely available. Target both the public and key stakeholders and organizations.
 - » Connecting the results to other planning efforts in the jurisdiction.
3. **Meet with the entire stakeholder group** to revisit the shared goals/vision, recommendations, and communication plans in order to discuss next steps. The group may sunset, change form, or move into action planning.

Tips and Ways to Focus on Health Equity

Represent the community

- » Keep returning to the question, “Where were people living with dementia and caregivers included in our process, and how are their priorities/needs integrated into our needs assessment?”
- » Make report and media messages available in multiple languages, including sign languages, braille, large text, and symbols. For videos, consider closed captioning and American Sign Language interpreters. For written resources, meet accessibility requirements for [508 compliance](#) and [WCAG](#).
- » Move data into action. For example, if you identify a need to address hypertension as a risk factor for cognitive decline, create an action step to align dementia-related activities with existing heart disease and stroke prevention initiatives.

CONCLUSION AND NEXT STEPS

Needs assessments are essential steps for jurisdiction-wide planning and should occur every three to five years. This toolkit outlined five steps for needs assessment project teams: (1) Partner, (2) Plan, (3) Collect, (4) Analyze, and (5) Action.

Our understanding of dementia risk reduction, detection, care, and caregiving evolves as more states, localities, and Tribal nations carry out needs assessments in their ongoing commitment to improving the well-being of people with dementia, their caregivers, and the overall community. Needs assessments, action plans, and jurisdiction-wide plans are instrumental in building the policies, systems, and environments for improving dementia outcomes.

After using this toolkit, consider the following next steps toward advancing cognitive health and improving dementia outcomes in your jurisdiction:

1. Integrate recommendations and key opportunities from needs assessment into future jurisdiction-wide plans.
2. Build awareness of issues and recommendations from this assessment with policymakers, planners, and program directors.
3. Continue efforts to implement the [Healthy Brain Initiative Road Map](#).






For additional resources for needs assessments and action planning, visit:

- » The Alzheimer's Association's [public health resource hub](#), which is updated regularly with resources, the best available science, and examples of public health action on Alzheimer's disease in states, communities, and Tribal nations.
- » The ASTHO e-Learning Center [Healthy Brain Initiative Module](#), which is designed to help public health agencies identify priorities and take action to improve the lives of people with dementia and their caregivers.
- » CDC's [resources for building public health infrastructure](#), which are updated regularly with public health data, effective public health strategies and approaches, and funding opportunities.



APPENDIX

This appendix includes the tools identified throughout the needs assessment toolkit to assist you in your needs assessment efforts. (Please note that several of the worksheets are in a complementary Excel spreadsheet for ease of use.)

Toolkit Steps	Tools in the Appendix
 <p>Step 1: Partner Estimate: 10-15 hours</p>	1a. Stakeholder Matrix 1b. Operationalizing Equity in Stakeholder Engagement 1c. Examples of Stakeholders 1d. Invitation for Stakeholders to Participate in the Needs Assessment Process
 <p>Step 2: Plan Estimate: 40-50 hours</p>	2a. Shared Goals Worksheet 2b. Needs Assessment Timeline
 <p>Step 3: Collect Estimate: 60-80 hours</p>	3a. Data Types and Sources Reference List 3b. Root Cause Analysis—Five Whys 3c. Strengths, Weaknesses, Opportunities, and Challenges (SWOC) Analysis
 <p>Step 4: Analyze Estimate: 60-80 hours</p>	4a. Instruments of Health Equity in Analysis
 <p>Step 5: Action Estimate: 70+ hours</p>	5a. Assessment Report Checklist 5b. Communication Planning Template 5c. Press Release Template

Tool 1a: Stakeholder Matrix

The [complementary Excel spreadsheet](#) contains a template for the stakeholder analysis. The table below is an outline of what is included in the spreadsheet.

Contact information			
Name	Affiliation	Email	Phone Number

Stakeholder Analysis			
Authority <i>What is the main way a stakeholder has the ability to act? Describe others in notes.</i>	Influence <i>What is the main way a stakeholder can encourage action by another party? Describe others in notes.</i>	Impacted <i>How is a stakeholder affected by dementia, cognitive health, or caregiving?</i>	Stakeholder Notes <i>Describe in more detail how a stakeholder is affected and its relative authority and/or influence.</i>

Stakeholder Involvement				
Stakeholder Priorities <i>What is most important to this stakeholder?</i>	Engagement Level <i>How does this stakeholder want to participate?</i>	Potential Obstacle <i>If at all, how could this stakeholder impede this assessment?</i>	Invitation to Engage <i>How will you invite this stakeholder to participate?</i>	Engagement Commitment <i>How has this stakeholder agreed to participate? What is the time commitment?</i>

Tool 1b: Operationalizing Equity in Stakeholder Engagement

The [complementary Excel spreadsheet](#) for this tool contains a template for this worksheet. The table below is an outline of what is included in the spreadsheet. The questions derive from various tools developed by Human Impact Partners — most recently, its [Equity Lens Tool](#) for decision-making. It is important to have answers to these questions as you conduct outreach to various stakeholders in order to be transparent about the process.

1. How will this assessment be used to make decisions and develop recommendations?

2. Who are the key groups who would be impacted by the assessment, and how will they be affected?

3. Are the voices of those groups affected by dementia at the needs assessment table? If not, why?

4. How will the needs assessment be perceived by the affected groups, especially given the history of the issue?

5. How will the needs assessment process be designed to support those groups' engagement? How can their participation be ensured?

6. How will the needs assessment and recommendations development process attend to and prioritize disparities?

Tool 1c: Examples of Stakeholders

The list below is more expansive than the sampling outlined in the Step 1 instructions, but is not an exhaustive list. (Note: Stakeholder titles and roles are generic and may vary by jurisdiction.)

Category	Type of Stakeholder
People and support systems navigating dementia care	<p>People living with dementia, including early onset (younger than age 65), and individuals at any stage of cognitive decline.</p> <p>Support systems, including caregivers (consider how family, friends, and community members may approach caregiving in different ways).</p>
Governmental agencies	<p>Public health agencies, state units on aging, housing authorities, boards of education, departments of transportation, state labor offices, departments of parks and recreation, offices of planning, governor and lieutenant governor offices.</p>
Community organizations	<p>Alzheimer’s Association local chapters, YMCA/YWCAs, United Way affiliates, caregiving coalitions, domestic worker alliances, AARP local chapters, aging networks and area agencies on aging, civic groups, voluntary health associations representing conditions that are risk factors for dementia, faith-based organizations (be inclusive of all religious homes).</p>
Health care providers	<p>Clinicians/provider groups, Federally Qualified Health Centers, skilled nursing homes, assisted living communities, hospital systems, community health workers, managed care plans, and other systems of medical care.</p>
Insurance providers	<p>State Medicaid agencies, private payers, and long-term care insurance providers.</p>
Academic institutions	<p>Schools of public health, medical schools, nursing assistant training programs, and other trade schools.</p>

Tool 1d: Invitation for Stakeholders to Participate

If the invitation is for an initial meeting:

Hello **[name]**,

I am reaching out to invite you to join in a **[insert jurisdiction/community]** needs assessment process. I am looking for people across our **[insert jurisdiction/community]** to consult on the state of cognitive health, dementia, Alzheimer's disease, and caregiving. I thought of you because **[insert short description of why they are a good fit]**.

I am hosting an initial planning meeting to discuss the needs assessment process and ways to engage. I am looking for people to contribute in three ways: (1) participate in the core team and day-to-day activities, (2) review written content, and/or (3) provide perspective in **[pick frequency: bi-weekly, monthly, bi-monthly]** meetings. Will you be willing to participate?

[To make meetings equitable and inclusive, consider accessibility by offering assistance like adult caregiving, transportation support, meal coverage, virtual options, options to provide asynchronous feedback, or closed captioning services.]

If you are interested, please respond to me at **[insert email]** by **[insert date]**.

If you are not available, there will be other opportunities for you to support this project in the future, and I hope you will consider them.

Please reach out to me with any questions you might have.

If the invitation is for an upcoming meeting after the process has started:

Hello **[name]**,

I am reaching out to invite you to join in a **[insert jurisdiction/community]** needs assessment process. I am looking for people across our **[insert jurisdiction/community]** to consult on the state of cognitive health, dementia, Alzheimer's disease, and caregiving. I thought of you, because **[insert short description of why they are a good fit]**.

The **[insert jurisdiction]** planning team is meeting to discuss **[insert where in the process you are]** and ways to engage. We are working toward **[insert brief description of next meeting]**. Will you be willing to participate?

[To make meetings equitable and inclusive, consider accessibility by offering assistance like adult caregiving, transportation support, meal coverage, virtual options, options to provide asynchronous feedback, or closed captioning services.]

If you are interested, please respond to me at **[insert email]** by **[insert date]**.

If you are not available, there will be other opportunities for you to support this project in the future, and I hope you will consider them.

Please reach out to me with any questions you might have.

Tool 2a: Shared Goals Worksheet

The [complementary Excel spreadsheet](#) contains a template for this worksheet. The below table is an outline of what is included in the spreadsheet. To use this worksheet, include as much detail as possible within each row. Keep the SMART goal framework in mind: be **S**pecific, **M**easurable, **A**ttainable, **R**elevant, and **T**imely with your goals.

Intended Impact <i>Where do you want to go with this goal? What does success look like?</i>	Responsible Team <i>Who will lead, review, and/or inform this goal?</i>	Location or Resource <i>Where will this step happen? What resources are needed?</i>	Attainable <i>Is it achievable, feasible, or ambitious?</i>	Context in Jurisdiction <i>How is this step relevant to jurisdictional goals and/or plans? Consider health improvement plans and plans on aging.</i>	Time Estimate <i>When do you plan to work toward this goal? Make sure it's documented in the timeline.</i>	Progress/ Updates <i>Use this section to track progress and document changes.</i>

Tool 2b: Needs Assessment Timeline

The [complementary Excel spreadsheet](#) contains a template for this worksheet. The below table is an outline of what is included in the Excel spreadsheet. To use this worksheet, use dark shading to show the timeline for each of the five major steps in the process and use light shading in the rows under each step to show the timeline for various activities within each step.

Step and Description of Activity	Month																	
	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Month 7	Month 8	Month 9	Month 10	Month 11	Month 12	Month 13	Month 14	Month 15	Month 16	Month 17	Month 18
Example: Use timeline																		
Sample activity A																		
Sample activity B																		
Step 1: Partner																		
Identify stakeholders Lead: Support role:																		
Invite stakeholders Lead: Support role:																		
Host initial meeting Lead: Support role:																		
Create shared goals Lead: Support role:																		
Outline roles Lead: Support role:																		
Step 2: Plan																		
Agree to shared goals Lead: Support role:																		
Outline objectives Lead: Support role:																		
Develop project teams Lead: Support role:																		
Establish meeting schedule Lead: Support role:																		
Draft timeline for steps 3-5 Lead: Support role:																		

Step 3: Collect

Outline data collection plan Lead: Support role:																				
Collect health data Lead: Support role:																				
Gather community input Lead: Support role:																				
Identify community assets Lead: Support role:																				
Compile data/prep for step 4 Lead: Support role:																				

Step 4: Analyze

Analyze data Lead: Support role:																				
Organize data for review Lead: Support role:																				
Review data with project team Lead: Support role:																				
Start communication plan Lead: Support role:																				
Connect analysis to state plans Lead: Support role:																				

Step 5: Action

Draft written report Lead: Support role:																				
Implement communication plan Lead: Support role:																				
Define next steps Lead: Support role:																				
Close out project teams Lead: Support role:																				

Tool 3a: Data Types and Sources Reference List

The [complementary Excel spreadsheet](#) contains a template for this worksheet. The below table is an outline of what is included in the Excel spreadsheet. This reference list highlights existing data sources that may be consulted throughout the needs assessment. Sources will vary based on jurisdiction and additional sources not listed below may be available on a community-by-community basis.

National and State Data Sources	Data Description	Website
Behavioral Risk Factor Surveillance System (BRFSS)	State-based data on subjective cognitive decline and caregiving (including dementia caregivers).	cdc.gov/brfss/index.html
Healthy People 2030: Dementias Objectives	National data on diagnosis disclosure, preventable hospitalizations, and subjective cognitive decline.	health.gov/healthypeople/objectives-and-data/browse/objectives/dementias
Medicare Current Beneficiary Survey (<i>note: requires approval and fees to access</i>)	Data on Medicare expenditures, including utilization and health status over time.	cms.gov/Research-Statistics-Data-and-Systems/Files-for-Order/LimitedDataSets/MCBS
Eldercare	Community and local database for resources and supports for older adults.	eldercare.acl.gov/Public/Index.aspx

State-Specific Data Sources	Data Description	Webpage to access
State Alzheimer's Disease or Dementia Registries	Select states collect and record dementia-related data.	<i>Examples:</i> South Carolina Alzheimer's Disease Registry Washington State Alzheimer's Disease Patient Registry
State Alzheimer's Plan Task Force	Select states maintain Alzheimer's task forces or councils which may publish state-specific information.	<i>See individual state websites</i> <i>Example:</i> Virginia Alzheimer's Commission AlzPossible Initiative
State or Community Health Improvement Plan (S/CHIP)	Information related to older adults, risk factors, and community resources.	<i>See individual state or local websites</i>
Death Certificates	Reported deaths from dementia.	wonder.cdc.gov/mcd.html

Tool 3b: Root Cause Analysis—Five Whys

The [complementary Excel spreadsheet](#) contains a template for this worksheet. The table below is an outline of what is included in the spreadsheet. The Five Whys technique is an iterative process to explore cause-and-effect relationships underlying a particular issue. To use this worksheet, ask your team “why?” or “how?” five times. The technique aims to uncover a root cause of the problem that may point to larger, systemic issues that can be addressed through robust planning efforts.

Describe the problem <i>Consider the causes or effects.</i> <i>Use one row per problem your team identified.</i>	1st Why <i>Ask your team why or how.</i>	2nd Why <i>Ask your team why or how.</i>	3rd Why <i>Ask your team why or how.</i>	4th Why <i>Ask your team why or how.</i>	5th Why <i>Ask your team why or how.</i>

Tool 3c: Strengths, Weaknesses, Opportunities, and Challenges (SWOC) Analysis

The [complementary Excel spreadsheet](#) contains a template for this worksheet. The table below is an outline of what is included in the spreadsheet. To use this worksheet, include as much detail as possible within each row to fully work through the related strengths, weaknesses, opportunities, and challenges (also known as threats).

Steps of SWOC Analysis <i>Can be completed in any order →</i>	Strengths		Weaknesses	
	<i>What are the strengths?</i>	<i>What actions will need to be taken to preserve and enhance the current strengths?</i>	<i>How can any rigid weaknesses be made transparent?</i>	<i>What can mitigate any weaknesses to reduce their power or influence?</i>
Issue 1				
Issue 2				
Issue 3				

Steps of SWOC Analysis <i>(continued)</i>	Opportunities		Challenges (also called threats)	
	<i>How can we leverage these opportunities to improve dementia outcomes?</i>	<i>How can these opportunities be integrated into jurisdictional plans, policies, or programs?</i>	<i>How can these challenges be avoided in the future?</i>	<i>How can these challenges be mitigated?</i>
Issue 1				
Issue 2				
Issue 3				

Tool 4a: Instruments of Health Equity in Analysis

The list below comes from the [HOPE Initiative](#), which consists of [27 indicators](#) to measure and advance health equity, including a detailed methodology. Consider referring to and/or using the below condensed list of indicators most related to dementia outcomes to move from identifying disparities to closing disparities.

SOCIAL AND ECONOMIC FACTORS

- » Affordable Housing: Portion of households spending no more than 30% of monthly household income on housing and related expenses.
- » Employment: Portion of people age 16 and older in the U.S. labor force who are employed.
- » Livable Income: Portion of adults living in households with income greater than 250% of the Federal Poverty Level.
- » Post-secondary Education: Portion of adults age 25 and older who have attained at least some college education after graduating from high school

PHYSICAL ENVIRONMENT

- » Food Security: Portion of people living in census tracts that are not food deserts.
- » Housing Quality: Households with no severe housing problems are defined as having good housing quality. These spaces have complete kitchens and functioning plumbing and are not overcrowded or severely cost-burdened.
- » Low Liquor Store Density

ACCESS TO HEALTHCARE

- » Access to Primary Care
- » Access to Psychiatric Care
- » Affordable Health Care: Portion of adults who did not delay or forego any necessary medical care due to cost in the past year.
- » Dedicated Health Care Provider: Portion of adults age 25 and older who have someone they consider their personal health care provider.
- » Health Insurance Coverage: Portion of people under age 65 who have any kind of health insurance.

COMMUNITY AND SAFETY FACTORS

- » Low Poverty Concentration: Portion of people in neighborhoods with fewer than 20% of residents living in poverty.

Tool 5a: Assessment Report Checklist

This checklist for the written needs assessment report should be used for disseminating the report and establishing long-term documentation of the process. Use this checklist as a guide when drafting.

Corresponding Step(s)	Report Section and Description of Activity	Completed?
1 and 5	Executive Summary	
	» Specify shared goals of project team	
	» Summarize key trends	
	» Outline next steps	
	» Include call to action	
1 and 2	Introduction	
	» Acknowledge stakeholders	
	» Include shared goals and vision	
	» Briefly describe steps and timeline	
	» Summarize major themes from analysis	
3 and 4	Methodology	
	» Outline data collection plan	
	» Describe analysis	
	» Share weaknesses in assessment methods	
4 and 5	Findings	
	» Describe key trends from the data analysis	
	» Highlight data visualizations where impactful	
	» Connect analysis to state plans and call to action	
5	Action	
	» Include dissemination plan	
	» Highlight key messages	
	» Define next steps and call to action	

Tool 5b: Communication Planning Template

The [complementary Excel spreadsheet](#) contains a template for this worksheet. The table below is an outline of what is included in the spreadsheet. To use this worksheet, refer to the communication data analysis done in Step 4. In each column, describe as much detail as possible. When you complete the worksheet you will have the information necessary to guide communication strategies.

Health Equity Tip: Consider how people with dementia and those affected by this assessment want to be described and written about. Use person-centered language whenever possible (e.g., “people living with dementia” instead of “dementia patients”).

What <i>Describe what key information needs to be communicated, including the call to action.</i>	Audience <i>Describe who the communication is intended for.</i>	How <i>Describe the communication pathways, include written, audio, and data visualizations.</i>	Who <i>Select who from the project team will lead the communication. Outline support/coordination, where possible.</i>	When <i>Outline time range for communication.</i>

Cost <i>Estimate budget for communication materials (i.e., graphic design, editing).</i>	Updates <i>Feedback from communication, as plan is implemented. This is helpful for your next needs assessment.</i>

[Insert logo(s) here]

FOR IMMEDIATE RELEASE

Contact:

Phone:

E-mail:

Successes and Opportunities from Needs Assessment Related to Dementia by
[Insert name(s)]

Location – [Name(s)] have completed a major milestone in identifying, analyzing, and outlining opportunities to improve dementia outcomes and dementia caregiver well-being. The preliminary findings from the needs assessment represent several months of research collecting and analyzing data.

The assessment includes [specify community area(s)]:

- » Highlight top three findings
- »
- »

The last needs assessment related to dementia was conducted in [year] - or - [This is the first time that [insert names] has conducted a needs assessment specifically related to dementia]. With these new data, our jurisdiction has the information needed to [insert call to action].

For more information and to view the needs assessment report, please visit [www.\[insert web address\]](#) and/or contact:

[Name]

[Email]

[Phone]

###

[Insert Boilerplate(s)]

Endnotes

- 1 Unless otherwise stated, statistics come from the Alzheimer's Association 2021 [Facts & Figures Report](#).
- 2 A 2020 [report of the Lancet Commission on Dementia](#) underscores the role of modifiable risk factors such as heart disease, diabetes, and traumatic brain injuries, to name a few.
- 3 Research published in June 2020 found that those who adhered to four or all five of the healthy behaviors had a 60% lower risk of Alzheimer's disease.

