

A Planning Guide for the Healthy Brain Initiative Road Map for Indian Country

>> PURPOSE OF THE PLANNING GUIDE

Designed for public health professionals who work with American Indian/Alaska Native (AI/AN) communities, this planning guide will help you select Healthy Brain Initiative (HBI) [Road Map for Indian Country](#) (Road Map) strategies and get started with implementation. The guide's six quick steps will direct you to a path for success that best meets your specific needs. Easy-to-use worksheets and resources will help you prioritize, plan, and promote Road Map strategies within AI/AN communities.

>> WHAT IS DEMENTIA? HOW DOES IT RELATE TO ALZHEIMER'S DISEASE?

Dementia is the loss of cognitive functioning that is severe enough to interfere with a person's daily life and activities. Cognitive functioning can include thinking, remembering, and reasoning. Alzheimer's disease is the most common cause of dementia. Other types include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.

Alzheimer's disease is an irreversible, progressive brain disorder that slowly destroys memory and thinking, and eventually, the ability to carry out the simplest tasks. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks. A person may have Alzheimer's for many years before symptoms appear.

10 Warning Signs of Alzheimer's¹

1. Memory loss that disrupts daily life: forgetting events, repeating yourself or relying on more aids to help you remember (like sticky notes or reminders).
2. Challenges in planning or solving problems: having trouble paying bills or cooking recipes you have used for years.
3. Difficulty completing familiar tasks at home, at work, or at leisure: having problems with cooking, driving places, using a cell phone, or shopping.
4. Confusion with time or place: having trouble understanding an event that is happening later, or losing track of dates.
5. Trouble understanding visual images and spatial relations: having more difficulty with balance or judging distance, tripping over things at home, or spilling or dropping things more often.
6. New problems with words in speaking or writing: having trouble following or joining a conversation or struggling to find a word you are looking for (saying "that thing on your wrist that tells time" instead of "watch").
7. Misplacing things and losing the ability to retrace steps: placing car keys in the washer or dryer or not being able to retrace steps to find something.
8. Decreased or poor judgment: being a victim of a scam, not managing money well, paying less attention to hygiene, or having trouble taking care of a pet.
9. Withdrawal from work or social activities: not wanting to go to church or other activities as you usually do, not being able to follow football games or keep up with what's happening.
10. Changes in mood and personality: getting easily upset in common situations or being fearful or suspicious.

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>> THE ROLE OF PUBLIC HEALTH

The public health field seeks to achieve lasting positive change in the health of entire communities. The values underlying a public health approach — promoting wellness and providing care in the community for people who need it — are mirrored in long-standing cultural values and in the spirit of AI/AN traditions. For any health condition, public health plays a unique and critical role in reducing risk factors for illnesses and injuries, improving early detection and diagnosis, and ensuring safety and quality of care.

A public health approach to addressing all forms of dementia — including Alzheimer’s — starts with understanding that these conditions should be viewed as part of a continuum of cognitive health and function that spans an entire lifetime (see Figure 1 – The Development of Dementia across the Life Course for People Who Are At-Risk).

While the causes of dementia are largely unknown, there is growing evidence that it may develop as a result of multiple risk factors over the course of a person’s life. While some risk factors — such as age, family history, and risk genes — cannot be changed, other risk factors can be addressed to help change the path of dementia and keep people healthier longer.²

These include:

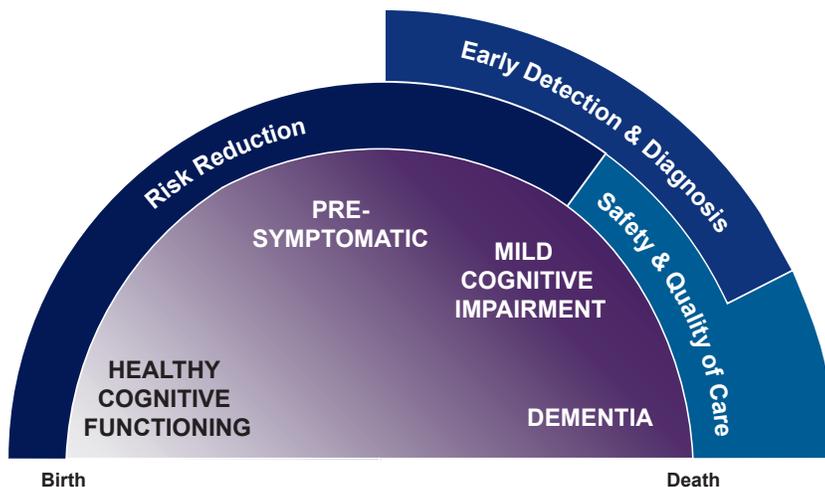
- Diabetes
- High blood pressure
- Smoking
- Mid-life obesity
- Traumatic brain injuries

In addition to avoiding the risk factors that may lead to dementia, there are protective factors that can improve overall physical health and promote healthy aging.

Protective factors include:

- Eating a healthy diet (three sisters soup)
- Exercise the body (walk, traditional dance)
- Exercise the mind (beading, drumming)
- Stay socially engaged and active (elder talking circles)
- Limit tobacco to ceremonial use
- Avoid secondhand smoke

Figure 1. The Development of Dementia across the Life Course for People Who Are At-Risk



This illustration shows the life course for people who will eventually develop dementia, including Alzheimer’s. The semi-circle in purple shows different stages of cognitive functioning from birth to death — beginning with healthy cognition and moving through the pre-symptomatic and mild cognitive impairment stages, and then to dementia. The blue segments show the three major opportunities for public health interventions across the life course consistent with the stage of cognitive functioning: 1) reduce risk of cognitive decline or progressing to other stages, 2) encourage early detection and diagnosis of cognitive impairment and dementia, and 3) ensure quality of care for and safety of people affected by cognitive impairment and dementia. These essential public health strategies help reduce burden, improve health outcomes, and promote health and well-being throughout the continuum. It is important to note that most older adults do not develop mild cognitive impairment or dementia

How Is Public Health Different from Healthcare?

Public health aims to reduce poor health outcomes from occurring within a community as a whole, while healthcare is patient-focused: diagnosing and treating individuals. To make meaningful improvements across Indian Country, communication and collaboration across these sectors is needed. Other sectors can be invited, such as businesses that serve your community, local aging or human services programs, behavioral health services, transportation, housing services, and parks and recreation, among others.



>> ROAD MAP FOR INDIAN COUNTRY STRATEGIES

The following are the eight strategies that can inform and shape the public health response to Alzheimer's and all dementia in AI/AN communities. Tribal and Urban Indian/Urban leaders are encouraged to discuss these strategies with their community and involve members in planning and implementing these community-wide approaches.

EDUCATE AND EMPOWER COMMUNITY MEMBERS

1. Work with community members to understand brain health, early warning signs of dementia, and benefits of early detection and diagnosis for persons with dementia and their caregivers.
2. Encourage community members to use effective interventions, best practices, and traditional wellness practices to protect brain health, address cognitive impairment, and support persons with dementia and their caregivers.
3. Provide information and tools to help older adults with dementia and their caregivers anticipate and respond to challenges that typically arise during the course of dementia.
4. Promote engagement among Tribal and urban leaders in dementia issues by offering information and education on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health approaches in addressing this priority problem.

COLLECT AND USE DATA

5. Support collection and use of local data on dementia and caregiving in AI/AN communities to plan programs and approaches.
6. Promote the inclusion of healthcare quality measures that address both cognitive assessments and the delivery of care to AI/ANs with dementia.

STRENGTHEN THE WORKFORCE

7. Educate healthcare and aging services professionals in Indian Country about the signs and symptoms of dementia and about caregiving for persons with dementia.
8. Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.



>> FIGURE 2. KNOW. PLAN. GO.™ FOR ROAD MAP SUCCESS



- » Familiarize yourself and others with the Road Map and its strategies
- » Understand how the Road Map can be used to integrate and align with existing plans and initiatives
- » Know the Road Map is a credible source to support and prioritize strategies
- » Gather key staff and stakeholders to identify which Road Map strategies best meet these priority needs and are most feasible to implement
- » Be familiar with basic knowledge about Alzheimer's and all dementia, mild cognitive impairment, and warning signs
- » Identify other entities working in the healthy aging space in your community



- » Assess individual, community, and system needs around cognitive health
- » Use resources below to prioritize which strategies to do first and create a plan to implement each
- » Map out a series of proactive communications to promote the importance and urgency of your strategies
- » Identify and incorporate strategies within existing plans and initiatives where possible
- » Plan for communication strategies for different audiences (public health and healthcare workforce, Tribal and community leaders, community members)



- » Engage key staff, stakeholders, and partners to help in implementing strategies
- » Learn about success stories, case examples, and best practices from other departments of health or I/T/Us (Indian Health Service/Tribal Health/Urban Indian Health Providers)
- » Measure achievement of your strategies and share progress to maintain support and mobilize others
- » Seek additional support from the CDC and the Alzheimer's Association, International Association for Indigenous Aging, National Council of Urban Indian Health, National Indian Council on Aging, Inc., and National Indian Health Board
- » Review the Road Map resources on alz.org/publichealth; cdc.gov/aging; ncuih.org/wisdomkeeper; iasquared.org; and nihb.org/brain-health/



- » Create calls to action to inform and motivate a prioritized list of others to be a part of the movement
- » Incorporate updates on progress into standing agenda items, key leadership presentations, newsletters, and other messaging
- » Use the case studies and resources provided in the Road Map to encourage others to take action
- » Strive for policy, system, or environmental (PSE) changes to elevate cognitive health and Alzheimer's as priority public health issues
- » Maintain your relationships — stay in touch with those you have engaged with and provide regular updates
- » Keep track of positive changes so you can tell your community's story
- » Ensure sustainability through securing funds from the organizational budget or other sources

>> SIX STEPS TO PLANNING YOUR PUBLIC HEALTH RESPONSE TO DEMENTIA, INCLUDING ALZHEIMER'S

Make an impact in addressing Alzheimer's and all dementia using the *Road Map for Indian Country* with six steps to guide your planning. The Know.Plan.Go.™ Mobilization Model³ (see Figure 2 on page 4) captures these steps in a quick-reference format so you can turn strategy into action that reaches a broad audience.

Step 1: Prioritize potential actions within your area of focus (Know)

Use the HBI *Road Map for Indian Country* as a tool to guide decisions about where to prioritize your efforts to promote cognitive health, expand early detection and diagnosis, improve safety and quality of care for people living with dementia, and attend to caregivers' health and well-being.

The key is to begin, whether you first raise awareness of the HBI *Road Map for Indian Country* with colleagues and leaders, or you create a plan around an easier Road Map action. Initial momentum gives you a base on which to keep building where you have capacity and interest.

Start by reviewing the HBI *Road Map for Indian Country* and its agenda of eight strategies as well as the compelling data presented (find a quick list of all eight strategies on page 3). Educate your staff and other health professionals about dementia. Then, use the Aligning Action Examples (page 6) to identify Road Map strategies that are achievable, that align with existing areas of focus and priorities (Step 2), and fit with available resources and capacity.

Step 2: Integrate and align strategies into your existing plans (Know, Plan)

You do not have to start from scratch. Many Road Map strategies can be integrated into existing plans and initiatives such as community health improvement plans or programs for chronic disease, health promotion, and public safety. Do a scan of current initiatives and strategic plans within your Tribe and by other groups or organizations that you commonly work with. Find places where you can align Road Map strategies with existing initiatives or goals and add the information to your worksheet. See Table 1 for examples (pages 7–11).

Not finding an obvious alignment? Gather a few colleagues for a conversation about using Road Map strategies to create a plan to address all forms of dementia. Together you could conduct a brief environmental scan or needs assessment to uncover priorities or opportunities in your community that relate to cognitive health. Table 2 has potential data sources on pages 15–16.

Step 3: Orchestrate across the I/T/U public health system (Plan)

Whether you serve at a Tribe or an Urban Indian Organization (UIO), your work interfaces with other parts of the health system. It takes us all working together — across community systems — to improve outcomes for all people living with dementia and their caregivers.

Consider how your priority Road Map strategies can be integrated across the entire public health system or community. How might strategies in the Road Map complement the strategic plans and key initiatives that exist? Integration into other areas of health, where appropriate, enables you to leverage resources and build partnerships for sustainable initiatives. Reach out to discuss the possibility of integrating Road Map strategies into those plans or as part of their existing initiatives.

Step 4: Mobilize for action (Know, Go)

Successful public health occurs through collaborative partnerships, planning, and networking to garner support, assistance, best practices, and training. Organize a network of mobilizers, a community coalition, or task force charged with building and taking the action plan to the next level. Consider traditional and nontraditional partners so that engagement is inclusive across all audiences you wish to serve. Suggestions for potential partners are in Engaging Partners and Stakeholders (page 17). Completing a Stakeholder Analysis Matrix worksheet (page 18) may help you prioritize partners to engage now in the planning stage and others to mobilize at a later stage. With these partners, use the Action Planning worksheet (page 14) as a template for determining activities and resources needed to achieve the Road Map action. If you will pursue multiple Road Map strategies, replicate the worksheet template.

As with all plans, identify some measurable goals. Assign accountable people, partners, and measure success. Identify champions to promote the importance and urgency of acting now on the plan.

Step 5: Ask for additional technical support and assistance (Plan, Go)

A plan is only as good as its implementation, and implementation takes forethought, execution, and accountability. Ask for guidance from the Alzheimer’s Association or the Alzheimer’s Disease and Healthy Aging Program at the Centers for Disease Control and Prevention (CDC). They can provide insights into the recommended strategies and suggest other ideas that might work best for your community’s needs. At alz.org/publichealth/IndianCountry and cdc.gov/aging, you can find Road Map resources, emerging implementation practices, and success stories. Additional resources can be found at ncuih.org/wisdomkeeper, iasquared.org/, and nihb.org/brain-health/.

Step 6: Tell the compelling public health story of Alzheimer’s and refer others to the HBI Road Map for Indian Country (Grow)

The goal of the *Road Map for Indian Country* is to enable the public health community and its partners to anticipate and respond to the growing impact of Alzheimer’s and all dementia on every facet of society. Use the compelling data from the Road Map to create your own talking points about why and how you support healthy aging in your work.

As you capture data and anecdotes about your successes, proactively tell the story about how these strategies translate into meaningful outcomes across the lifespan, across other chronic diseases, and support health and safety more broadly. Communicate about your successes to build momentum that can lead to changes to policies, systems, and environments over the long term. Plan forward for sustainability and don’t reinvent the wheel.

>> ALIGNING ACTION EXAMPLES

Incorporating healthy aging practices into your existing wellness, health, or other community programs doesn’t have to be a cumbersome endeavor. Below are examples of how you can do this with varying levels of funding, time, or effort.

Table 1 groups the eight strategies in the Road Map strategies by the type of community-wide approach (see page 7):

- Educate and empower community members
- Collect and use data
- Strengthen the workforce

Table 1 presents the suggested practices in terms of level of potential difficulty or as a “life-course” approach.

Low Difficulty: These are suggested practices that utilize existing staff and resources to gain a better understanding of Alzheimer’s and all dementia and use simple solutions to get information out into the community.

Moderate Difficulty: These are suggested practices to include healthy aging in existing programs that much of Indian Country already has. Blending in cognitive health and dementia may take effort to update an existing workplan or budget.

Greater Difficulty: If you’re ready to invest in healthy aging for your community, these are suggested practices that may take more funding, time, or effort than the previous two levels.

Life Course: Because the continuum of cognitive health and function spans an entire lifetime, suggested practices address risk factors for different generations.

Technical Support and Assistance

To discuss your priorities or request input on your plan, you can contact:

Molly French
Alzheimer’s Association
mfrench@alz.org

Lisa Garbarino
Centers for Disease Control and Prevention
lgt1@cdc.gov

>> TABLE 1: SUGGESTIONS FOR IMPLEMENTING ROAD MAP STRATEGIES BY LEVEL OF DIFFICULTY OR AS A LIFE COURSE APPROACH

| Educate and Empower Community Members Strategies | | | | |
|--|--|---|--|---|
| Benefit(s) for Each Strategy | Low Difficulty | Moderate Difficulty | Greater Difficulty | Life Course |
| 1. Work with community members to understand brain health, early warning signs of dementia, and benefits of early detection for persons living with dementia and their caregivers. | | | | |
| <p>Helping Tribal members take steps to promote brain health, reduce stigmas and myths about dementia, and seek early diagnosis of dementia requires clear and consistent messages delivered by trusted sources.</p> <p>Adding brain health to other efforts to prevent and manage chronic disease has been an effective public health strategy in states and local areas. Tailoring this approach for AI/ AN cultures could have far-reaching impact.</p> | <ul style="list-style-type: none"> Disseminate health education materials from reliable partner organizations such as NCUIH in various locations throughout the health center and other high traffic areas Reach out to your Title VI team to identify resources available to your community Add resources to your webpage (see list of resources on page 13) | <ul style="list-style-type: none"> Engage with other Tribes and Native organizations at the local, regional, and national level in educational efforts Provide education on brain health at existing community events such as pow wows and health fairs Utilize media outlets for public service announcements Include information on Alzheimer’s and other forms of dementia at all clinic visits Host talking circles with your community to understand their knowledge of brain health and work together to identify ways to address any knowledge gaps Conduct educational sessions within existing elder groups and cultural groups that may engage with elders (e.g. drum circles, warrior societies, beading or quilting groups) | <ul style="list-style-type: none"> Integrate brain health education into new or existing curricula; provide in-person or virtual trainings, classes, support groups Create public awareness campaigns on the importance of early detection and ways individuals can reduce their risk of cognitive decline Plan education initiatives — consider training of staff, community health representatives (CHRs), local influential people Train other non-health professionals (educators, childcare educators, business owners, gym or fitness center staff) to recognize the warning signs of dementia and create a referral network | <ul style="list-style-type: none"> Disseminate health education materials about risk and protective factors of dementia at family planning appointments, during diabetes prevention classes, tobacco cessation events, and traditional practices or ceremonies |

Educate and Empower Community Members Strategies

| Benefit(s) for Each Strategy | Low Difficulty | Moderate Difficulty | Greater Difficulty | Life Course |
|--|--|---|--|---|
| <p>2. Encourage community members to use effective interventions, best practices, and traditional wellness practices to protect brain health, address cognitive impairment, and support persons living with dementia and their caregivers.</p> | | | | |
| <p>Well-designed programs have been shown to benefit persons living with dementia and caregivers. These programs should be readily accessible to all in need. Access to these programs and tools is particularly crucial for people living with dementia who live alone.</p> <p>Other support services for older adults could include:</p> <ul style="list-style-type: none"> • Transportation for those who are no longer able to drive • Programs and practices to keep those living with dementia connected to their community • Legal and financial assistance • Training for all community members working with older adults • Long-term care for those whose families live far away | <ul style="list-style-type: none"> • Promote healthy aging during traditional wellness events, calling attention to the benefits to cognition that these activities provide • Provide information on support services in your community (transportation, legal and financial assistance, training for community members working with older adults, peer support groups) • Add resources to your webpage (see list of resources on page 13) • Adapt community events to encourage participation by people living with dementia and their caregivers (such as having a quiet space, adapting event roles so they can readily participate if they choose) | <ul style="list-style-type: none"> • Provide a space for caregivers to network, provide support to each other and discuss their best practices • Modify existing programs or interventions, such as the Special Diabetes Program for Indians, to include information on healthy aging and Alzheimer’s • Identify champions among the community to help spread the message on healthy aging. This can be a Tribal or community leader, a traditional healer, or youth | <ul style="list-style-type: none"> • Create a healthy aging campaign in your community • Develop an app or other message delivery mechanisms to share tips and ways to live a healthy cognitive life | <ul style="list-style-type: none"> • Educate I/T/U health staff on risk and protective factors and give them the tools they need to inform patients on how their behaviors/lifestyle could impact them later in life |

Educate and Empower Community Members Strategies

| Benefit(s) for Each Strategy | Low Difficulty | Moderate Difficulty | Greater Difficulty | Life Course |
|---|--|---|--|--|
| 3. Provide information and tools to help older adults living with dementia and their caregivers anticipate and respond to challenges that typically arise during the course of dementia. | | | | |
| <p>The challenges facing people living with dementia and their caregivers can be daunting. For example, as dementia progresses, older adults may have trouble recognizing when they are unhealthy or not safe, and they may have difficulty communicating. Tribal public health initiatives can help raise awareness about these challenges and the need to improve quality of life, safety, and well-being among people living with dementia and their caregivers. These can include education on how to use behavioral cues and other strategies to reduce injuries, help manage medication, and keep chronic conditions in check to minimize unnecessary hospitalizations.</p> | <ul style="list-style-type: none"> • Provide resources on the course of dementia and Alzheimer’s for those living with the condition, their family members and professional care providers • Provide resources on recognizing the signs of dementia to family members and caregivers (visit Wisdom Keeper for videos, a social media toolkit and more) | <ul style="list-style-type: none"> • Facilitate support groups for caregivers and family members • Educate caregivers and family members on how to use behavioral cues and other strategies to reduce injuries, help manage medications, and keep chronic conditions in check | <ul style="list-style-type: none"> • Educate local businesses who interact with elders about the signs of dementia and how to help if needed • Provide one-on-one training for caregivers and family members • Create a toolkit for family members that helps guide them on how to assist with basic self-care and everyday living activities as well as how to help with more complex activities like financial management, personal health, and driving | <ul style="list-style-type: none"> • Engage with social service programs, elder meals programs, heating programs, etc. • Engage with tribal housing programs to support home modifications for those in need • Engage with tribal long-term care facilities or elder housing to ensure that they are able to meet the needs of those living with dementia |

Educate and Empower Community Members Strategies

| Benefit(s) for Each Strategy | Low Difficulty | Moderate Difficulty | Greater Difficulty | Life Course |
|--|--|---|---|---|
| 4. Promote engagement among tribal and community leaders in dementia issues by offering information and education on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health approaches in addressing this priority problem. | | | | |
| <p>Access to reliable information and education can enhance tribal community leaders' ability to design effective planning and policy initiatives. This includes expanding understanding of the challenges encountered by older adults with dementia and caregivers, especially in underserved AI/AN communities. Tribal leaders, and their partners in the public and private sectors, will have a strong base to examine potential policies and leverage resources for implementation.</p> | <ul style="list-style-type: none"> • Present information on the state of aging in your community during Tribal council and/or boards of health/directors meetings | <ul style="list-style-type: none"> • Invite Tribal and community leaders to community awareness events and talking circles | <ul style="list-style-type: none"> • Host a healthy aging action institute with Tribal/ community leaders, staff, community members, and stakeholders • Pass tribal and/or board resolutions to expand for healthy aging • Ensure healthy aging is included in your strategic plan, community health assessment, and community health improvement plan | <ul style="list-style-type: none"> • Ensure Tribal leaders are aware of the opportunities to embed information and awareness raising across various programs and social services • Facilitate community awareness meetings/ talking circles with various entities that offer touch points for subpopulations, such as pregnant women and caregivers |

Collect and Use Data Strategies

| | | | | |
|--|--|--|--|--|
| 5. Support collection and use of local data on dementia and caregiving in AI/AN communities to plan programs and approaches. | | | | |
| <p>Data specific to local AI/AN communities can be invaluable in shaping priorities, policies, and programs tailored to the unique needs in those areas. Such data can help track the burden of dementia and caregiving on AI/AN communities and monitor progress in addressing that burden. Existing local data can be supplemented with aggregated data on older AI/ ANs from CDC's Healthy Aging Data Portal.</p> | <ul style="list-style-type: none"> • Contact your Tribal Epidemiology Center to identify available support; data may be available from your state government Indian health or minority health office • Include questions on dementia, cognitive health, and healthy aging into existing intake assessments/surveys • Identify existing data sources at the state or local level (see data sources on page 15) | <ul style="list-style-type: none"> • Assess elders during annual wellness visits and other medical appointments • Incorporate questions on dementia and caregiving in existing community health assessments or other surveys | <ul style="list-style-type: none"> • Initiate a survey specifically on dementia and caregiving • Collect data on the risk and protective factors of dementia • Enact data sharing agreements with other healthcare entities • Advocate for the inclusion of AI/AN-specific data in state and national surveillance and monitoring activities | <ul style="list-style-type: none"> • Ensure data collection efforts can also capture information on younger generations to assess risk and protective factors as a way to inform future public health programming |

Collect and Use Data Strategies

| Benefit(s) for Each Strategy | Low Difficulty | Moderate Difficulty | Greater Difficulty | Life Course |
|--|--|---|---|--|
| 6. Promote the inclusion of healthcare quality measures that address both cognitive assessments and the delivery of care to AI/ANs with dementia. | | | | |
| <p>Healthcare quality measures are a useful tool for tracking progress about the use of best practices and clinical guidelines. Measures specific to dementia have been developed by the Physician Consortium for Performance Improvement and American Academy of Neurology and American Psychiatric Association Work Group. The National Quality Forum and other experts may develop or endorse additional quality measures and measure concepts in the coming years. These measures are relevant to Indian Country and can help monitor progress in delivering quality care.</p> | <ul style="list-style-type: none"> Assess the quality of existing data (clinical, community health assessment, etc.) and identify opportunities for improvement Ensure your quality improvement (QI) individual/team is aware of the need to assess quality measures that address cognitive assessments and the delivery of care | <ul style="list-style-type: none"> Implement quality improvement on cognitive health Incorporate healthy aging measures in quality improvement plans, strategic plans | <ul style="list-style-type: none"> Begin a healthy aging quality improvement initiative Incorporate dementia assessments in clinical measures, such as the Government Performance and Results Act (GPRA) and in cross-sectoral collaborations (including data sharing agreements) | <ul style="list-style-type: none"> Adopt quality measures and examine the risk and protective factors in your community |

Strengthen the Workforce Strategies

| Benefit(s) for Each Strategy | Low Difficulty | Moderate Difficulty | Greater Difficulty | Life Course |
|---|--|--|--|---|
| 7. Educate healthcare and aging services professionals in Indian Country about the signs and symptoms of dementia and about caregiving for persons with dementia. | | | | |
| <p>Healthcare and aging professionals in I/T/U services need not only training on cognitive health and ways to reduce risk of cognitive decline, but also credible materials they can share with tribal members. Existing training courses or modules can be used or adapted for these new audiences. Outreach to health professionals can call attention to the importance of supporting caregivers' health and their role in managing dementia and other chronic conditions. Integrating cognitive health and caregiving into existing health promotion and chronic disease efforts has the potential to increase the reliability of care and improve related outcomes for many older adults.</p> | <ul style="list-style-type: none"> Disseminate materials and educational information to the workforce Ensure all health and public health staff have access to credible materials for their own education as well as to disseminate to community members | <ul style="list-style-type: none"> Coordinate healthy aging trainings for all staff Require trainings be taken by all staff Integrate healthy aging and caregiving support into existing health promotion and chronic disease efforts (Special Diabetes Program for Indians, tobacco cessation) | <ul style="list-style-type: none"> Dedicate staff to become subject matter experts on dementia and caregiving to serve as in-home resources Create fellowship programs for staff to become subject matter experts on dementias and/or their dementia care certification Create a policy that requires at least one staff member be certified in dementia care | <ul style="list-style-type: none"> Ensure staff understand the life-course approach to dementia and are able to educate their patients |

| Strengthen the Workforce Strategies | | | | |
|---|---|--|---|--|
| Benefit(s) for Each Strategy | Low Difficulty | Moderate Difficulty | Greater Difficulty | Life Course |
| 8. Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia. | | | | |
| Healthcare and aging services professionals can be instrumental in supporting AI/AN caregivers with information and guidance. They can also facilitate access to affordable, evidence-informed services, programs, interventions, and supports for caregivers to reduce their stress and improve coping, self-efficacy, and overall health. Caregivers would benefit from compelling and easy-to-use materials about how to enhance their own health while caring for older adults. | <ul style="list-style-type: none"> • Provide staff with resources on supporting families and caregivers • Disseminate easy-to-use information about enhancing their own health for caregivers | <ul style="list-style-type: none"> • Provide a space for staff to share and learn new ways to support families and caregivers | <ul style="list-style-type: none"> • Develop and implement a robust case-management/referral follow-up process | <ul style="list-style-type: none"> • Ensure staff understand the life-course approach to dementia and are able to educate families and caregivers |

>> ASSETS AND RESOURCES

Assets and resources that can be mobilized and utilized to address needs and issues related to Alzheimer’s and other dementias (e.g., support groups, area agencies on aging, volunteer networks, clinical services, hospitals, adult day care services, home care services, or community resources) are available.

- [The Healthy Brain Initiative Road Map for Indian Country](#)
- Alzheimer’s Association 24/7 helpline: 800.272.3900
- [Alzheimer’s Association](#) (alz.org)
- [Wisdom Keeper from the National Council of Urban Indian Health](#)
- [International Association for Indigenous Aging](#)
- [CDC Alzheimer’s Disease and Healthy Aging Program](#)
- [Brain Health Resources from the National Indian Health Board](#)
- [National Indian Health Board’s Public Health in Indian Country Capacity Scan](#) for local training data
- [Tribal Epidemiology Centers](#)
- Network analyses or surveys of local Alzheimer’s Association chapters and partners
- [The Indian Health Service](#)

>> ACTION PLANNING WORKSHEET

Once you have identified and prioritized your Road Map strategies, use this worksheet to determine what activities and resources will be needed to achieve the action. Create one worksheet for each Road Map action.

| Activities to accomplish this action | By when? | Staff to work on this activity | Partners and Stakeholders (coalitions, organizations, govt. agencies, healthcare systems) | Funding Sources Available | Potential Barriers | Measure of Success/ Outcomes |
|--------------------------------------|----------|--------------------------------|--|---------------------------|--------------------|------------------------------|
| | | | | | | |
| | | | | | | |
| | | | | | | |
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>> TABLE 2: POTENTIAL DATA SOURCES

The following references can be used to gather citations, data points, and information to support pursuing specific Road Map strategies.

| Category and Description | Examples and Links |
|--|--|
| <p>PREVALENCE AND DISPARITIES Number of persons and percentage of population with Alzheimer’s and other dementias or subjective cognitive decline by key demographic indicators (as available) such as: age, gender, race, ethnicity, marital status, sexual orientation, income, educational attainment, home ownership, employment status, disability status, veteran status</p> | <p>Behavioral Risk Factor Surveillance System (BRFSS)</p> <ul style="list-style-type: none"> • CDC infographics for AI/AN adults regarding subjective cognitive decline and caregiving • Background information on BRFSS Cognitive Decline and Caregiving Modules • CDC Healthy Aging Data Portal <p>Other</p> <ul style="list-style-type: none"> • Tribal Epidemiology Centers • State Alzheimer’s disease registry data or data portals (e.g., Georgia Department of Public Health Alzheimer’s Disease and Related Dementia State Registry) • Alzheimer’s Association Alzheimer’s Disease Facts and Figures |
| <p>MORTALITY Number of deaths due to Alzheimer’s and other dementias, by key demographic indicators (as available)</p> | <ul style="list-style-type: none"> • Tribal enrollment and death certificate data • Tribal Epidemiology Centers • State registries or data portals, such as death certificate records • CDC WONDER • Alzheimer’s Association Alzheimer’s Disease Facts and Figures |
| <p>CAREGIVING</p> <ul style="list-style-type: none"> • Number of family and other unpaid caregivers • Hours of care provided • Economic value of unpaid care • Impact of caregiving on caregivers • Unmet needs, such as for information, psychosocial support, or respite | <p>Behavioral Risk Factor Surveillance System (BRFSS)</p> <ul style="list-style-type: none"> • CDC infographics for AI/AN adults regarding subjective cognitive decline and caregiving • Background information on BRFSS Cognitive Decline and Caregiving Modules • CDC Healthy Aging Data Portal <p>Other</p> <ul style="list-style-type: none"> • Tribal Epidemiology Centers • Service needs from state or regional information, referral/ assistance networks, such as 211 call systems, or Aging and Disability Resource Centers (ADRCs)** • National Information and Referral Support Center has background information • Alzheimer’s Association chapters may have local data about requests for assistance or care consultations • Alzheimer’s Association Alzheimer’s Disease Facts and Figures • Qualitative data from focus groups or stakeholder input sessions (example from South Dakota) |

| Category and Description | Examples and Links |
|---|--|
| <p>MODIFIABLE RISK FACTORS</p> <ul style="list-style-type: none"> • Number of persons and percentage of population who smoke, have diabetes, are obese, have hypertension, are physically inactive, or eat an unhealthy diet • Health status of caregivers | <ul style="list-style-type: none"> • Tribal/Community Health Assessments • Tribal Epidemiology Centers • CDC Healthy Aging Data Portal BRFSS data on subjective cognitive decline and caregiving for AI/AN communities • Caregiver surveys • CDC's PLACES project provides county-, place-, census-tract-, and Zip Code Tabulation Area-level estimates for chronic disease risk factors, health outcomes, and clinical preventive service use • CDC and National Association of Chronic Disease Directors Coronary Heart Disease, Myocardial Infarction and Stroke data brief |
| <p>COSTS</p> <ul style="list-style-type: none"> • Use and costs of healthcare, long-term care, and hospice care for people with Alzheimer's and other dementias • Use and costs of community services, such as transportation, meal delivery, home healthcare, or case management • Financial impact of Alzheimer's and other dementias on families, including annual costs and effect on family income | <ul style="list-style-type: none"> • Indian Health Service • Tribal Epidemiology Centers • Alzheimer's Association Alzheimer's Disease Facts and Figures • State Emergency Department Databases (SEDD) • Hospital, vital records, home and community-based services, nursing home, health plans, all-payers claims databases, and similar Medicare and Medicaid data* • Silver Alert data • Community service providers • Information and referral/assistance network records |

*The BRFSS Cognitive Decline module measures the prevalence of “subjective cognitive decline” (SCD) — a non-medical term that identifies the percentage of individuals who self-report they are having increasing memory problems. A growing number of studies have shown that SCD is associated with an increased risk of future dementia; these data indicate potential future problem and burden of dementia.

**Access to such data varies and may not be universally available due to inconsistencies in data collection and management. Consider consulting the state aging department to learn more about state/regional data sets.

>> ENGAGING PARTNERS AND STAKEHOLDERS

Who do you need to engage for support in implementing your selected Road Map strategies? Partners would be organizations or persons who would likely be involved or provide other support, such as funding, a venue, radio show, or supplies. Stakeholders would be organizations, groups of people, or influential persons who may be affected by Alzheimer's and dementia, but may not be directly involved. Examples of stakeholders might be families caring for older relatives and businesses.

Government

- Tribal leadership
- Governor/mayors/county supervisors
- State or local public health officer
- Chronic disease director
- State epidemiology/surveillance branch
- Division of aging services (state and county level)
- State and local policymakers, legislators, state/regional planning commissions
- Public safety (police, fire, transportation)

Healthcare

- Indian Health Service
- Area Indian Health Boards
- Tribal Epidemiology Centers
- Substance use and misuse programs
- Diabetes prevention programs
- Wellness centers
- National Native health and public health organizations (NCUIH, NIHB, IA²)
- State hospital association
- State provider associations (primary care, specialty care, pharmacy)
- Rural and urban health associations, clinics or health systems
- Federally Qualified Health Centers (FQHCs)
- Physician practices (primary care, family practice, geriatrics, internal medicine, neurology)
- Other healthcare service providers (EMS, physical therapy, home health, hospice, pharmacy, community health workers)

Aging Service Providers and Organizations

- Elder programs
- State and local chapters of the Alzheimer's Association
- Area Agency on Aging (AAA) and Aging and Disability Resource Centers (ADRC)
- Nursing home and assisted living communities at local level as well as state associations
- AARP chapters
- Local foundations and non-profits serving seniors and caregivers
- Senior centers

Other Entities

- Tribal colleges
- Tribal enterprises (e.g., casinos)
- State public health association
- Healthy living coalitions/livable communities
- American Heart Association and American Diabetes Association
- Area Health Education Centers (AHEC)
- Schools of public health/Public health institutes
- Large employers (help in reaching caregiver population)
- Academic institutions
- Geriatric Workforce Enhancement Programs (GWEP)
- YMCA or community wellness center
- Religious organizations/faith community
- State or local dementia-friendly coalitions
- Organizations serving populations at higher risk for dementia (Hispanic, African American)

>> STAKEHOLDER ANALYSIS MATRIX

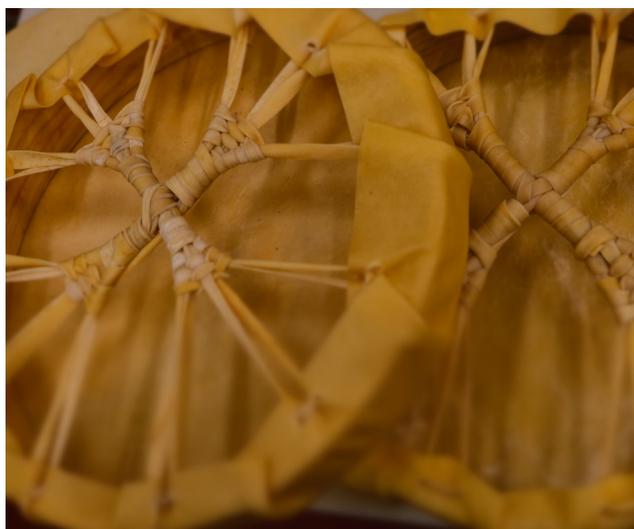
Use this template to identify stakeholders for activities related to Road Map strategies, including their level of influence, which issues are important to them, and how they will be engaged.

| Stakeholder Name and Affiliation | Contact Person <i>Email, Phone</i> | <i>Impact</i> How much does the activity impact them? <i>(Low, Medium, High)</i> | <i>Influence</i> How much influence do they have over the activity? <i>(Low, Medium, High)</i> | What is important to them? | How could they contribute to the activity? | How could they hinder the activity? | Strategy for engaging the stakeholder |
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| Stakeholder Name and Affiliation | Contact Person <i>Email, Phone</i> | <i>Impact</i> How much does the activity impact them? <i>(Low, Medium, High)</i> | <i>Influence</i> How much influence do they have over the activity? <i>(Low, Medium, High)</i> | What is important to them? | How could they contribute to the activity? | How could they hinder the activity? | Strategy for engaging the stakeholder |
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>> ENDNOTES

1. Learn more at: <https://www.alz.org/media/Documents/10-warning-signs-road-map-for-indian-country.pdf>
2. Alzheimer's Association and Centers for Disease Control and Prevention. Healthy Brain Initiative, *Road Map for Indian Country*. Chicago, IL: Alzheimer's Association; 2019
3. Blais LM, Beatty C, Solomon M. (2015). *Know. Plan. Go.™ Strategic Planning*. [Process]. Atlanta, GA: Emory Centers for Training and Technical Assistance, Emory University.