

Alzheimer's Association

Needs Assessment Toolkit

SEPTEMBER 2016

Guidance and Resources for
State Public Health Agencies
on Comprehensive Needs
Assessments Related
to Alzheimer's and
Other Dementias



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EXECUTIVE SUMMARY

Alzheimer's and other dementias take a tremendous toll on individuals and families. In 2013, the Alzheimer's Association and the Centers for Disease Control and Prevention (CDC) Healthy Aging Program developed the second in a series of road maps to advance cognitive health as a vital, integral component of public health. *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013-2018*, outlines specific actions that state and local public health agencies and their partners can take to promote cognitive functioning, address cognitive impairment for individuals living in the community, and help meet the needs of family members who serve as caregivers in home settings. Among the actions identified in the road map are several related to increasing the use of information and insights to appropriately respond to the growing public health burden associated with Alzheimer's and other dementias.

Comprehensive needs assessments are at the core of a state's ability to effectively use information to develop, implement, and maintain state plans that are focused either exclusively on Alzheimer's and other dementias, or more broadly on the incorporation of cognitive health and

impairment into other state public health plans. Public health agencies have a high level of expertise related to developing and conducting needs assessments. This toolkit has been developed to help states leverage their expertise in conducting needs assessments to enhance their ability to gather and use information specifically related to Alzheimer's and other dementias.

This toolkit is framed around a series of six steps. The steps — Partner, Plan, Assess, Synthesize, Envision, and Communicate — are designed to help states plan and conduct needs assessments related to Alzheimer's and other dementias. The details provided within each step, along with the collection of tools and resources contained within this toolkit, should be helpful to state public health agencies as they embark upon the process of conducting needs assessments to identify and respond to the needs of those with Alzheimer's and other dementias and their caregivers. The steps are summarized as a Needs Assessment Checklist (Tool G).



INTRODUCTION

The Toll of Alzheimer's and Other Dementias

Alzheimer's disease was first identified over a century ago, but 70 years passed before it was recognized as the most common cause of dementia and a major cause of death.¹ Today, more than 5 million Americans are living with Alzheimer's disease.² Alzheimer's disease is now the sixth leading cause of death in the United States and the fifth leading cause of death among adults 65-85 years of age.³ Unless more effective ways to prevent and treat the disease are identified and implemented, the prevalence of Alzheimer's disease could climb to as high as 13.8 million by 2050.²

The cost of caring for people with Alzheimer's and other dementias has reached an estimated \$236 billion in 2016.⁴ Family and friends who serve as caregivers to persons with Alzheimer's and other dementias provide nearly \$221 billion in additional unpaid care.⁴ The direct costs related to Alzheimer's and other dementias are projected to be more than \$1 trillion (in 2016 dollars) by 2050.⁴

Dementia is an umbrella term that refers to a general loss of abilities involving memory and judgment,

language and abstract thinking, as well as changes in personality. Dementia is not a disease itself, but rather a syndrome defined by a group of symptoms that often occur together in various combinations and with varying degrees of severity. Alzheimer's disease is the most common cause of dementia and — along with other conditions such as stroke and traumatic brain injury — can result in cognitive impairment.

Cognitive impairment and dementia take a tremendous toll on individuals and families. The effects on individuals fall into four categories: cognitive effects (e.g., decreased memory, concentration, ability to recognize people and places); functional effects (i.e., difficulty in completing everyday tasks and activities of independent living); behavioral effects (e.g., loss of social skills, physical

What is Cognitive Impairment?

Cognitive impairment refers to a situation in which a person has trouble with cognitive functions such as: language, thought, memory, executive function (the ability to plan and carry out tasks), judgment, attention, perception, remembered skills such as driving, and the ability to live a purposeful life.

or verbal aggression); and psychological effects (i.e., depression, anxiety, irritability). Family members, especially those who serve as care partners, are at greater risk for anxiety, depression, and poorer quality of life as compared to those who provide care to family members with other conditions.⁵

The Role of Public Health and the Health Care System: Missed Opportunities

A Public Health Approach

Imagine a person with diabetes or another chronic condition. Public health data tell us how many people are affected by diabetes and its precursor, pre-diabetes, and which age and racial/ethnic groups are particularly at risk. We know about risk and protective factors and ways to intervene that can mitigate the burden and impact of the disease in the coming years. We have better insights about how to influence lifestyle behaviors to either prevent diabetes or control it once it is diagnosed. We pursue not only individual messages and interventions, but policy and systems-level changes that make healthy choices easier for an entire neighborhood, community, and population.

From a public health perspective, we apply the tools of epidemiology to determine how many people are affected in a community or region, what the data tell us about the factors that either put people at risk or protect them, which interventions or programs might be helpful to either prevent or mitigate the consequences, and what systems or policy interventions could alter the equation in the future.

For a wide variety of diseases and conditions — injury and violence, infectious diseases, chronic conditions (such

as diabetes, cancer, cardiovascular disease and stroke), birth defects and disabilities, arthritis, oral health, teen pregnancy among them — the public health approach helps us understand why and how adverse health events unfold, what is the burden and impact, and how to improve outcomes for populations, especially through risk reduction, prevention, and early detection. Whether the health issue involves children or seniors, chronic diseases or infectious ones, risk behaviors or mosquitoes, public health approaches have yielded significant progress.

Public Health's Unique Role in Addressing Alzheimer's and Other Dementias

Alzheimer's and other dementias don't yet offer the same potential for prevention and treatment that diabetes and other chronic conditions do. Still, the public health approach has a great deal to contribute by illuminating prevalence data and trends, highlighting the value of early detection, supporting the role of communities in providing resources for individuals and caregivers, and gauging the impact of these conditions on the population as a whole. Moreover, because Alzheimer's and other dementias mostly affect older people, individuals are likely to be experiencing co-morbidities that are on public health's radar. The same is often true of their caregivers.

Unique among the array of agencies and organizations working on Alzheimer's and other dementias, public health agencies have the entire population's health as central to their mission. This, in turn, fosters attention to disparities, inequities, and concern for those who may fall through the cracks — whether they are individuals living with the disease or caregivers — no matter how well designed and accessible local resources may be. Public health agencies

at the state level also have a unique opportunity to identify interventions and policies with the greatest potential impact at a population health level.

The Health Care System's Role in Accurate Diagnoses

Health care professionals in the public and private sectors are an important source of information and can play a critical role in caring for those with cognitive impairment and dementia, including Alzheimer's. Yet, only 19% of people aged 60 and older who reported worsening confusion or memory loss have discussed these symptoms with a health care provider. Among individuals living independently or in other community settings, an estimated 50% of all who meet the diagnostic criteria for Alzheimer's disease or other dementias have not received a diagnosis. Although there are no medications or therapies that treat the underlying causes of Alzheimer's and other dementias, research suggests that active management can significantly improve quality of life for those with dementia and their caregivers. Diagnosis also is critically important because it opens the door for people living with the disease to access services and benefits for which they may be eligible.

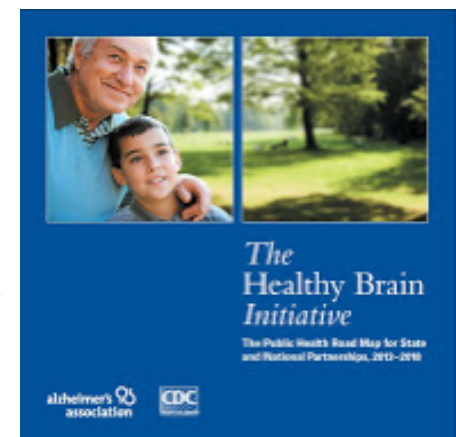
Planning for the Future: The Healthy Brain Initiative Road Map

In recognition of the rapidly escalating public health crisis related to Alzheimer's and other dementias, the National Alzheimer's Project Act (NAPA) was signed into law in 2011 (<https://aspe.hhs.gov/national-alzheimers-project-act>). NAPA calls for a national strategic plan among federal agencies to address Alzheimer's and other dementias and reduce the financial burden on those with these conditions,

their families, and society. The first *National Plan to Address Alzheimer's Disease*, released in May 2012, was notable for recognizing Alzheimer's disease as a major public health issue, providing a blueprint for coordinating Alzheimer's disease efforts across federal agencies, and outlining concrete goals, strategies, and actions for eliminating the burden of the disease.

In 2005, the Centers for Disease Control and Prevention (CDC) integrated Alzheimer's disease, cognitive health, and caregiving into the agency's Healthy Aging Program. CDC and the Alzheimer's Association also established the Healthy Brain Initiative, to cultivate the public health response to cognitive health. Today, Healthy Brain Initiative partners include the National Institutes of Health, Administration on Community Living, Association of State and Territorial Health Officials (ASTHO), National Association of Chronic Disease Directors (NACDD), AARP, and many other public and private sector organizations. The partners developed a series of road maps to guide a coordinated public health response to Alzheimer's disease across agencies and organizations.

In 2013, the Alzheimer's Association and the CDC's Healthy Aging Program released the second in this series of road maps to advance cognitive health as a vital, integral component of public health. *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships*,



2013-2018 outlines specific actions that state and local public health agencies and their partners can take to promote cognitive functioning, address cognitive impairment for individuals living in the community, and help meet the needs of family members who serve as caregivers in home settings.

Two years after the 2013 Healthy Brain Initiative Road Map was finalized, CDC developed an interim progress report to highlight accomplishments for 2013-2015 and share CDC's priorities for moving the Healthy Brain Initiative forward in 2016-2018. Among the priority actions identified in the interim progress report were the following four under the domain of Develop Policy and Mobilize Partnerships:

- Collaborate in the development, implementation, and maintenance of state Alzheimer's disease plans (P-01).
- Integrate cognitive health and impairment into state and local government plans (e.g., aging, coordinated chronic disease, preparedness, falls prevention, and transportation plans) (P-02).
- Promote incorporation of cognitive health and impairment into state and local public health burden reports (P-03).
- Support state and local needs assessments to identify racial/ethnic; lesbian, gay, bisexual, and transgender; socioeconomic; and geographic disparities related to cognitive health and impairment and help ensure materials are culturally appropriate (M-06).

In the past, the task forces and coalitions that undertook the development of state Alzheimer's disease plans may have sought specific data from public health and Medicaid agencies. This toolkit is designed to make it easier for public health agencies to engage in priority Road Map actions by participating more fully in developing, implementing, and maintaining state plans. These plans may be focused exclusively on Alzheimer's and other dementias, or more broadly on the incorporation of cognitive health and impairment into other state public health plans. Either way, public health has an opportunity to contribute in substantive ways — not only to contribute to stronger plans with partners, but to advance public health's mission as well.



OVERVIEW OF THE TOOLKIT

This toolkit was developed by the Alzheimer's Association, in partnership with the CDC. Comprehensive needs assessments are at the core of a state's ability to use information and insights to develop, implement, and maintain state plans that are either focused exclusively on Alzheimer's and other dementias, or more broadly on the incorporation of cognitive health and impairment into other state public health plans.

The data and insights gathered through needs assessments can also assist states in identifying disparities related to cognitive health and impairment based on race/ethnicity, sexual orientation, socioeconomic status, and geography. Needs assessment data can then be used to address disparities related to Alzheimer's and

other dementias and ensure that materials, such as public health burden reports, reflect and respond to these disparities.

Public health agencies already have a high level of expertise related to developing and conducting needs assessments. As such, this toolkit has been developed to help states leverage their expertise in conducting needs assessments that enhance their ability to gather and use information specifically related to Alzheimer's and other dementias.

This toolkit is framed around the following series of six steps, designed to help states plan and conduct needs assessments related to Alzheimer's and other dementias.

Partner

Plan

Assess

Synthesize

Envision

Communicate

The toolkit is based on input from multiple sources:

- Reviews of existing state Alzheimer's disease plans.
- Reviews of existing needs assessment toolkits and guidance.
- Interviews with state health department staff and their partners who have conducted needs assessments as part of their state Alzheimer's disease planning processes.
- Presentation and discussion at a Healthy Brain Research Network meeting.
- Ongoing guidance and feedback from program staff at the Alzheimer's Association.



CONDUCTING A NEEDS ASSESSMENT

Public health agencies are experienced at conducting needs assessments. At both the state and local levels, they routinely gather and use data for a variety of public health purposes, from identifying areas where there may be high prevalence of a particular health condition to conducting more comprehensive community health

What is a Needs Assessment?

A systematic approach that progresses through a defined series of steps to define the gap or need between the current state (i.e., what is) and the desired state (i.e., what should be).

assessments required as part of public health accreditation standards. However, few public health agencies have conducted needs assessments specifically related to Alzheimer's and other dementias.

As a result, **the focus of this toolkit is to help public health agencies conduct needs assessments that**

are specifically related to Alzheimer's and other dementias. A few basic concepts about conducting needs assessments are included here for those who might need a refresher, but users of this toolkit are encouraged to

focus their attention on toolkit topics and resources related to the steps where they need the most guidance about how to conduct needs assessments specifically related to Alzheimer's and other dementias.

Why Conduct a Needs Assessment Related to Alzheimer's and Other Dementias?

Most needs assessments are generated for similar reasons — to better **understand the needs and assets** of a population and to **set priorities** for future action. The incentives for public health agencies to conduct a needs assessment specifically related to Alzheimer's and other dementias include:

- To inform the development or updating of a state Alzheimer's disease plan.
- To inform the development of a state plan to support dementia-friendly communities.
- To inform and enable the inclusion of Alzheimer's and other dementias into other state plans, including those related to chronic disease, falls prevention, aging, and emergency preparedness.

There are several elements that are historically included in Alzheimer's disease plans developed by state government agencies. The information obtained by conducting a needs assessment can be used to inform many of these elements.

The following table provides an overview of the elements commonly included in state Alzheimer's plans.

Plan elements that are most likely to be informed by data emanating from a needs assessment are underlined and appear in bold, teal font within the following table.

State Government Alzheimer's Disease Plan Elements

I. Executive Summary

II. State Plan Structure and Process

III. Disease Background Information

a. What is Alzheimer's

b. State Demographics and Projections

i. Percent of adults with key risk factors

ii. Number and description of persons with subjective cognitive decline, with Alzheimer's

iii. Number and description of caregivers

iv. Disparities

c. Stakeholders

IV. Public Awareness, Knowledge, and Attitudes

a. Knowledge gaps

b. Socio-cultural environment (stigma)

c. Availability of information

d. Supportive community environments

e. Recommendations

V. Risk Reduction

a. Health education and health promotion on risk factors

b. Safety

c. Potentially avoidable hospitalizations

d. Recommendations

VI. Diagnosis and Treatment

a. Early detection

b. Access to diagnosis

c. Quality of dementia care

e. Cost of treatment

f. Recommendations

VII. Professional Education and Training

a. Geriatric education (physicians, nurses)

b. Direct-care worker dementia-specific training

c. First responders and other professionals in communities

d. Recommendations

VIII. Caregivers

a. Contributions

b. Supports

c. Family caregiver education

d. Unmet needs

IX. Home and Community Based vs. Residential Care

a. Research efforts

b. State-based research

c. Recommendations

X. Home and Community Based Services

a. Cost to families

b. Access to affordable, quality services

c. Service planning and delivery

d. Workforce

e. Recommendations

XI. Residential Services

a. Cost to families

b. Special care units

c. Recommendations

XII. Financing Long-Term Care

a. Medicare and Medicaid

b. Long-term care insurance

c. Recommendations

XIII. Research and Data Collection

a. Surveillance

b. Recommendations

XIV. Summary and Recommendations

In calling for state public health agencies to become more involved in the needs assessment and other components of state Alzheimer's disease plans, the Alzheimer's Association and CDC recognize that public health agencies face many demands for their expertise and support — demands that often exceed available resources. State Alzheimer's Association chapters can help public health agencies identify partners, strategies, and resources to help make this possible. State public health agencies might also be able to minimize costs associated with conducting a needs assessment by working with graduate students from schools of public health or soliciting advice from a local public health institute. (See Step 1 on partnerships, below, for more ideas.)

Step 1: Build Partnerships

The first step in a needs assessment is to identify internal and external stakeholders who have an interest in the process and/or results of the needs assessment. Internal stakeholders could include offices, bureaus, or

departments within the state public health agency, such as chronic disease, injury and falls prevention, aging, and disabilities. External stakeholders could include other state agencies (e.g., state agency on aging, public housing agencies), community organizations (e.g., Alzheimer's Association local chapters, area agencies on aging, United Way affiliates), health care providers and organizations (e.g., clinicians, hospitals, federally qualified health centers), academic institutions, and people with

Alzheimer's disease and their caregivers.

Quick Tip

When identifying stakeholders be inclusive, not exclusive:

- Strive for broad representation, and regularly assess gaps
- Identify individuals and organizations who look at problems and solutions differently
- Look for those who have a stake in healthy communities, will contribute to the process, and help achieve objectives

This toolkit includes a template that can be useful for conducting a stakeholder analysis (Tool A: Stakeholder Analysis Matrix). The template can be used not only to identify stakeholders, but also to group stakeholders by their level of influence, what is important to them, and/or what they could contribute to the needs assessment. The

template also can be used to describe how each type of stakeholder will be engaged throughout the process of conducting the needs assessment. For example, some stakeholders may be members of the core team or workgroup tasked with conducting the needs assessment, while others might be consulted on a periodic basis and/or kept informed throughout the process.

Efforts might be needed to establish relationships with stakeholders, especially those with which the state public health agency has not previously collaborated. When establishing relationships with new stakeholders, it can be helpful to look for common ground so that each stakeholder can understand how collaborating on the needs assessment will help both organizations to address a common concern and/or obtain information that can assist both organizations to meet their goals.

Step 2: Develop a Needs Assessment Plan

Developing a plan for conducting the needs assessment is an important, although often overlooked, step in the process. Developing a plan involves varied stakeholders from the very beginning of the needs assessment process. This encourages both trust and support, not only for the assessment, but also for whatever actions or recommendations emerge as a result of it. A thoughtfully designed plan will also provide an easy-to-follow guide for conducting an efficient and comprehensive needs assessment. Planning ahead can also save time and effort in carrying out the process.

As part of the planning process, it is important to articulate the needs assessment's goals and objectives. The goals and objectives should be developed and conveyed in a format that is SMART (specific, measureable, attainable, relevant, and time-bound). An example of a SMART objective for conducting a needs assessment related to



Alzheimer's and other dementias is: By August 31 identify and recruit 8 to 10 individuals to participate in the needs assessment core team. This toolkit includes a template that can be used to create SMART goals and objectives (Tool B: SMART Goal and Objective Worksheet).

Although the list of stakeholders related to a needs assessment is likely to include a large number of individuals from numerous organizations, it is important to develop a smaller core team of individuals who will actively participate in the day-to-day activities and decisions related to conducting the needs assessment. Once this core team is established, specify the roles and responsibilities of each member. Roles may be determined based on individual and organizational strengths.

Consider creating and using a project charter to bring added structure to the workgroup or core team. Charter documents can vary in format and structure, but most contain information about the purpose of the project, justification for the project, scope and objectives of the project activities, and timeline for project activities. The CDC has developed a Project Charter template that can be adapted to be relevant for partnerships and workgroups convened for the purpose of conducting needs assessments. The CDC template can be viewed and downloaded at: http://www2a.cdc.gov/cdcup/library/templates/CDC_UP_Project_Charter_Template.doc

The core team should work together to establish a timeline that maps out the necessary steps for the community needs assessment process. To enhance the efficiency of the needs assessment and avoid duplication of efforts among stakeholders, the core team should 1) establish a timeline for each process step and for the various activities

Core Team Roles:

- Coordinate the overall assessment process
- Identify data sources and data collection methods
- Collect, organize, and analyze secondary data
- Assess the need and feasibility of hiring a consultant for data collection and analysis
- Determine fiduciary responsibility; who will pay for the needs assessment costs and/or provide in-kind support
- Facilitate face-to-face meetings
- Identify priority issues related to Alzheimer's and other dementias
- Make recommendations regarding programs and policies to address priority issues
- Motivate stakeholders to act on priority issues
- Communicate with stakeholders throughout the process

that need to be accomplished within each phase, and 2) create a flow sheet that captures milestones, identifies who is responsible for each task, and records dates from start to finish. This toolkit includes a template that can be used to develop a timeline for the needs assessment (Tool C: Needs Assessment Timeline).

Step 3: Assess the Population Affected by Alzheimer's and Other Dementias

What types of data will we collect in the needs assessment?

The core team should determine which specific aspects of health they want to describe within the needs assessment. Although each needs assessment should be tailored to meet the specific goals and objectives of the state public health agency and its stakeholders, a needs assessment focused on Alzheimer's and other dementias would typically be designed to gather data in the following categories:

Category	Description
Prevalence and Disparities	Number of persons and percentage of population with Alzheimer's and other dementias, 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
Mortality	Number of deaths due to Alzheimer's and other dementias, by key demographic indicators (as available)
Caregiving	<ul style="list-style-type: none"> Number of family (unpaid) caregivers Hours of care provided Economic value of unpaid care Impact of caregiving on caregivers Unmet needs, such as for information, psychosocial support, respite

Category	Description
Modifiable Risk Factors	<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
Costs	<ul style="list-style-type: none"> Use and costs of health care, 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 health care, and case management Financial impact of Alzheimer's and other dementias on families, including annual costs and effect on family income
Assets and Resources	Assets and resources that can be mobilized and employed 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, community resources)

How can we obtain data to describe the impact of Alzheimer's and other dementias?

From their prior work conducting needs assessments for a variety of health topics, state public health agencies are well aware of many data sources that can be used to describe the general health of a population or community. These include sources such as the Behavioral Risk Factor Surveillance System (BRFSS), National Health Care Survey (NHCS), National Health Interview Survey (NHIS), National Vital Statistics System, CDC WONDER and others. Some of these data sources can be used to obtain information not only for a general community needs assessments, but also for a needs assessment specifically focused on Alzheimer's and other dementias.

For example, the BFRSS, which uses telephone interviews to assess the prevalence of health-related behaviors among

U.S. adults, includes two optional modules that states can use to gather information related to Alzheimer's and other dementias. One of these is the Cognitive Decline module, which measures subjective cognitive decline (SCD) (that is,

self-reported increased confusion or memory loss) and its associated effects on function and daily living.

The information can be used to describe problems associated with SCD in states and communities and help inform programs and policies. The BRFSS Cognitive Decline module questions can be viewed at: <http://www.cdc.gov/aging/pdf/2015-brfss-cognitive-decline-module.pdf>.

Quick Tip

The BRFSS includes two optional modules that states can use to measure subjective cognitive decline (SCD) and the impact of dementia on caregivers.

The second optional module is the Caregiver module, which is designed to provide information about persons providing care to people of all ages who require assistance due to a serious health issue or disability. This includes their relationship, the major illness or disability that makes caregiving necessary, and the type of care that they provide for that person. The caregiver also is asked about what types of services they need to assist them in the caregiving role. The information can be used to describe the needs of caregivers and their health status and identify opportunities to enhance caregiver support services. The BRFSS Caregiver module questions can be viewed at: <http://www.cdc.gov/aging/pdf/2015-caregiving-module.pdf>.

The CDC also has developed a Healthy Aging Data Portal, which provides access to a range of national, regional, and state data on older adults. Developed by the National Center for Chronic Disease Prevention and Health Promotion, users can examine data on key indicators of health and well-being of older Americans, such as tobacco and alcohol use, screenings and vaccinations, and mental and cognitive health. Portal users may retrieve CDC data by indicator or geographic area, and then download datasets, develop reports, and create customizable maps, charts, and graphics. The Portal enables public health professionals and policymakers to examine a snapshot of the health of older adults in their states in order to prioritize and evaluate public health interventions. The Healthy Aging Data Portal can be viewed and accessed at: <http://www.cdc.gov/aging/agingdata/index.html>.

The Alzheimer's Association publishes an annual statistical resource that compiles U.S. data related to Alzheimer's disease and other dementia. The most recent report, *2016 Alzheimer's Disease Facts and Figures*, contains the following information that would be relevant to a needs

assessment focused on Alzheimer's and other dementias:

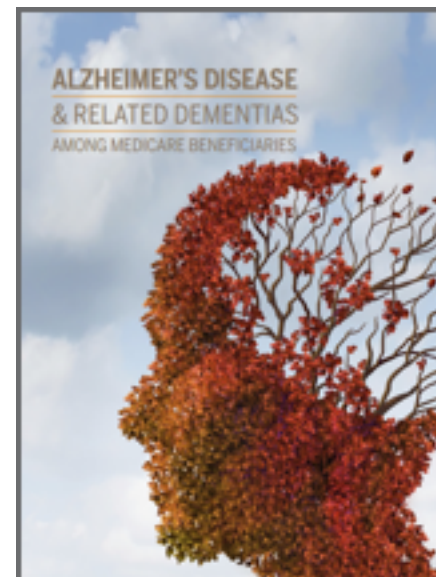
- Revised criteria and guidelines for diagnosing Alzheimer's disease from the National Institute on Aging and the Alzheimer's Association.
- Overall number of Americans with Alzheimer's disease nationally and for each state.
- Proportion of women and men with Alzheimer's and other dementias.
- Estimates of lifetime risk for developing Alzheimer's disease.
- Number of deaths due to Alzheimer's disease nationally and for each state, with death rates by age.
- Number of family caregivers, hours of care provided, economic value of unpaid care nationally and for each state.
- Use and costs of health care, long-term care and hospice care for people with Alzheimer's and other dementias.
- The personal financial impact of Alzheimer's disease on families, including annual costs and the effect on family income.

As noted in the Alzheimer's Association report, the prevalence of Alzheimer's



disease is often underestimated due to the fact that the disease is under diagnosed and underreported. Therefore, all prevalence estimates (regardless of source) should be interpreted as conservative estimates of the number of people who have Alzheimer's and other dementias. The report is available on the Alzheimer's Association website at: <http://alz.org/facts>.

Some states have developed Alzheimer's disease registries that can be used to assess the state-level prevalence and impact of Alzheimer's disease, identify epidemiological trends, and obtain information to inform programs and services for older adults. For example, in 2014 the Georgia legislature established the Alzheimer's Disease and Related Dementia State Registry within the Georgia Department of Public Health. The Georgia registry provides access to a portal designed to link data from multiple sources, including hospitals, emergency rooms, vital records, nursing homes, state benefit plans, Medicare, and Medicaid. In 2015, Georgia developed a comprehensive report based on Medicare data accessed and analyzed through their registry. The report, entitled *Alzheimer's Disease and Related Dementias Among Medicare Beneficiaries*, is available at: <http://dph.georgia.gov/sites/dph.georgia.gov/files/ADRD.Alzheimer%27s%20Report.FINAL.LOWRES.SINGLE.LASER.PDF>.



At both state and local levels, another source of data about service needs is the National Information and Referral Support Center, administered by the National Association of States United for Aging and Disabilities (NASUAD), in partnership with the National Council on Independent Living (NCIL). NASUAD conducts surveys of aging and disabilities information and referral/assistance (I&R/A) agencies to identify most commonly requested services. Results of the 2015 survey can be reviewed at: <http://www.nasuad.org/initiatives/national-core-indicators-aging-and-disabilities>.

Local Alzheimer's Association chapters also are excellent sources of data on topics such as use of care consultation services or volume and types of calls to helplines. Local service information and referral systems — such as 2-1-1 call systems — are another potential source of data.

While quantitative data often take center stage in needs assessments, it is equally important to provide context through the appropriate use of qualitative data. Each type of data can provide unique insights. For example, quantitative data are very valuable for answering questions such as:

- How many people are affected by Alzheimer's disease? What are their ages and other demographic characteristics?
- What is the cost of care associated with Alzheimer's disease?
- How many deaths are attributed to Alzheimer's disease?

However, *qualitative data* can enhance our understanding of the situation by answering questions such as:

- What types of services do people with Alzheimer's disease need?

- What are the barriers to accessing services that currently exist within a community?
- What is the non-financial impact of Alzheimer's disease on individuals and their caregivers?
- What factors isolate people with Alzheimer's (e.g., stigma) or work to support them?
- What kinds of intangible assets might a community have in place (e.g., social capital, workforce skills, pools of volunteers, accessible information about services)?

Quick Tip

Qualitative data are very helpful for understanding how Alzheimer's disease and related dementias affect individuals and their caregivers. Explore opportunities to participate in community meetings and listening sessions that might be hosted by a local Alzheimer's Association chapter or other community organizations serving older adults.

Although qualitative data can contribute important insights and findings to a needs assessment, collecting these types of data can be expensive and time consuming. Conducting multiple interviews, focus groups, and community meetings require expertise and logistical support. To reduce these barriers to the use of qualitative data, consider contacting the Alzheimer's Association local chapter or other community agencies that serve older adults to see whether they might be able to share time at meetings or listening sessions that are already planned. If so, these meetings and sessions can be a robust opportunity to hear directly from those with Alzheimer's disease and/or their caregivers, especially those with mild cognitive impairment or early dementia. In Minnesota, the Alzheimer's Association

Minnesota-North Dakota Chapter and Mayo Clinic host a conference, entitled Meeting of the Minds, for persons with dementia, family caregivers, and health professionals. Such meetings provide an invaluable opportunity to gain input and insights, including patient and caregiver stories, from those directly affected by Alzheimer's and other dementias.

How can we identify community resources and assets for people affected by Alzheimer's and other dementias?

In developing a needs assessment, it is important to first document resources or assets that currently exist and can be used to help meet the needs of those affected by Alzheimer's and other dementias. A community can be defined in a number of ways and could be interpreted as either an entire state or local area within a state. At either the state or local levels, assets include organizations, people, partnerships, facilities, funding, policies, regulations, and a community's collective experience.

Two approaches can be used to identify community assets:

1. **Identify the assets that are already known for supporting the needs of those affected by Alzheimer's and other dementias.** This includes community organizations and agencies that currently provide services to those affected by Alzheimer's and other dementias. For example, organizations that provide adult care programs and those that provide health care services to low-income seniors would be included in a community assessment focused on Alzheimer's and other dementias.
2. **Build upon the experiences of other states or communities to highlight resources that may be available.** The community assessment can identify

states or communities with similar demographics that have successfully addressed similar needs and can be used as a blueprint for identifying assets.

In 2009, the Minnesota Alzheimer's Association and other stakeholders advocated for legislation to create a State Government Alzheimer's Disease Plan for Minnesota, which launched the formation of ACT on Alzheimer's. Now with over 60 nonprofit, governmental, and private sector organizations participating, ACT on Alzheimer's serves as a volunteer-driven, statewide collaboration working to prepare Minnesota to address issues and challenges related to Alzheimer's and other dementias. Included in the ACT on Alzheimer's website (<http://www.actonalz.org/assess>) are resources and questionnaires designed to assist communities in identifying and assessing assets that exist in various parts of the community, such as businesses, caregiver support organizations, health care organizations, faith-based organizations, hospitals, and more.

The Arizona Healthy Aging (A-HA) program within the Bureau of Tobacco and Chronic Disease at the Arizona Department of Health Services (ADHS) has been compiling a variety of primary and secondary data to better understand the needs of patients and caregivers, and respond more effectively. Data sources included focus groups, caregiver surveys, a literature review, and

Quick Tip

Minnesota's ACT on Alzheimer's website includes numerous resources and additional tools that are available to help states to build dementia-capable or dementia-friendly communities. Check it out at: www.actonalz.org

assessments of current programs. This was made possible through funding by Maricopa County Department of Public Health in collaboration with the ADHS and local partners to conduct a network analysis of local Alzheimer's and Related Dementias service providers. The contractor was selected through a competitive request for proposals (RFP) process and awarded to the University of Colorado-Denver. The contractor is surveying local service providers to better understand what they offer to patients and caregivers, and where gaps in services might exist. The project was developed, in part, in response to an earlier study that found that while local physicians were accurately diagnosing Alzheimer's disease and other dementias, referrals to follow-up services and other support were lacking. (For more on Arizona Healthy Aging activities, reports, and partnerships, visit: www.AzHealthyAging.com)

Step 4: Synthesize the Data

One of the challenges of conducting a comprehensive needs assessment is synthesizing the large amount of data that will be available after reviewing existing data sources and gathering new information. After analyzing both the quantitative and qualitative data that have been gathered, it will be necessary to interpret the results and develop conclusions and recommendations. During this process of synthesizing the data, it is important to take a step back to consider what the results mean and assess their implications. This is a discussion that is ideal for a group of partners.

The following questions can help the coalition/community begin to interpret the results from the needs assessment:

- What patterns and themes emerge in the results?

- Are there any deviations from these patterns? If yes, are there any factors that might explain these deviations?
- Do the results make sense?
- Are there any findings that are surprising? If so, how can the results be explained?
- Are the results significant from a clinical or statistical standpoint? Are they meaningful in a practical way?
- Do any interesting stories emerge from the responses?
- Do the results suggest any recommendations for improving interventions or support for the population being assessed?
- Do the results lead to additional questions? Do they suggest that additional data may need to be collected?

Step 5: Envision the Future

Once the population affected by Alzheimer's and other dementias has been assessed, along with existing assets and gaps, the core team should work together to discuss and articulate a shared vision for the future. Every initiative can benefit from a shared vision that keeps efforts focused. A shared vision is needed for the overall, broader perspective of the collaborative process and to foster buy-in and accountability for the direction the needs assessment core team will take.

Visioning need not be a long and protracted process. Rather, the level of effort may depend on how well acquainted the partners are and whether they have previously worked together. The overall goal is to develop a challenging or aspirational vision of what future success would look like, while staying realistic.

There are many resources available to assist in the development of vision and mission statements. Some of these resources are especially relevant to public health and could inform the development of vision and mission statements that are specific to Alzheimer's and other dementias. For example, Mobilizing for Action through Planning and Partnerships (MAPP), developed by the National Association of City and County Health Officials (NACCHO), provides a step-by-step overview of a broader framework for mission and vision statements within a strategic planning process, as well as specific steps for developing a shared vision. Additional information about NACCHO's MAPP approach can be found at: <http://archived.naccho.org/topics/infrastructure/mapp/framework/phase1.cfm>.

Another approach would be to pose a set of questions, with or without a facilitator, to the needs assessment core team or broader Alzheimer's state plan stakeholder groups. The questions below are adapted from a visioning exercise for a public health nonprofit:

- How would the world for people with Alzheimer's and other dementias be improved or changed if we were successful in achieving our purpose?
- What are the most important services and linkages that we should continue to provide, change, or begin to offer in the next 3 years?
- What staffing, organizational, or partnership changes are needed to achieve this?
- What level of resources would be required?
- What infrastructure changes are necessary — systems, technology, facilities, communications?
- How could these services be provided more effectively or efficiently?

- If we could wave a magic wand and make 3 changes that would make this possible, what would they be?
- What do people with Alzheimer's disease and their caregivers consider most important, and what do they need from us?

Step 6: Communicate Findings for Action

After the assessment has been completed, data have been synthesized, and a vision has been articulated, it is time to take action. As the first step, a written report should be prepared to communicate the methods and results of the needs assessment to decision-makers, policymakers, and other stakeholders. Preliminary assessment findings should be shared with key stakeholders for input before the final report is complete. The report should include the following:

- ✓ Title Pages, Table of Contents, and Acknowledgments
- ✓ Executive Summary
- ✓ Background and Introduction
- ✓ Brief Description of Population or Community
- ✓ Data Collection Process
- ✓ Key Findings
- ✓ Implementation and Vision
- ✓ Communication Plan

Additional detail about what should be included in each of these sections is provided as part of the Assessment Report Checklist included in this toolkit (Tool D: Assessment Report Checklist).

After the report has been written and other potential communication materials have been developed, it is time to take action on the recommendations and priority actions identified in the assessment. One of the first steps toward taking action is to develop a communication plan. The communication plan should specify audiences, channels, key messages, and who is responsible. This process should be linked back to the key stakeholders identified during the earlier steps in the needs assessment process. A template that can be used to develop a communications plan is included in this toolkit (Tool E: Communication Planning Template).

The core team might also want to consider developing supplemental communication materials to share the findings from the needs assessment. The North Carolina Institute of Medicine collaborated with the North Carolina Department of Health and Human Services Division on Aging and Adult Services to develop an infographic depicting the challenges associated with Alzheimer's disease and caregiving (http://www.nciom.org/wp-content/uploads/2016/03/updatedNCIOM_Infographic.pdf). Infographics, such as the one produced in North Carolina, can be very useful in conveying key facts or statistics lay audiences and decision makers.

The core team should be briefed in person on the findings of the needs assessment and provided with a copy of the full report. In addition to sharing the needs assessment report with the core team and other stakeholders, it is important to publicize the work and findings associated with the needs assessment. Key findings from the assessment, whether in the form of the full report, executive summary, infographic, fact sheet, or other format, should be shared and made widely available to a wide range of individuals and organizations that may be interested in reviewing or

Share the Findings from the Assessment with Groups, Such As:

<ul style="list-style-type: none"> • Policymakers • Other state agencies • Local health agencies • Hospitals • Health care providers • Area agencies on aging • Aging and disability resource centers • Nursing homes • Elected officials • Grant makers • Tribal entities • Non-profits • Housing agencies 	<ul style="list-style-type: none"> • Faith-based organizations • Public safety and law enforcement • Emergency preparedness • Civic organizations • Transportation providers • Planning and zoning • Media • Human services agencies • Public health community at large
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using the results of the assessment. One way to share the findings of the needs assessment is to conduct a webinar for colleagues in the public health agency. It might also be possible to host a webinar for external stakeholders or present the findings at a public health conference.

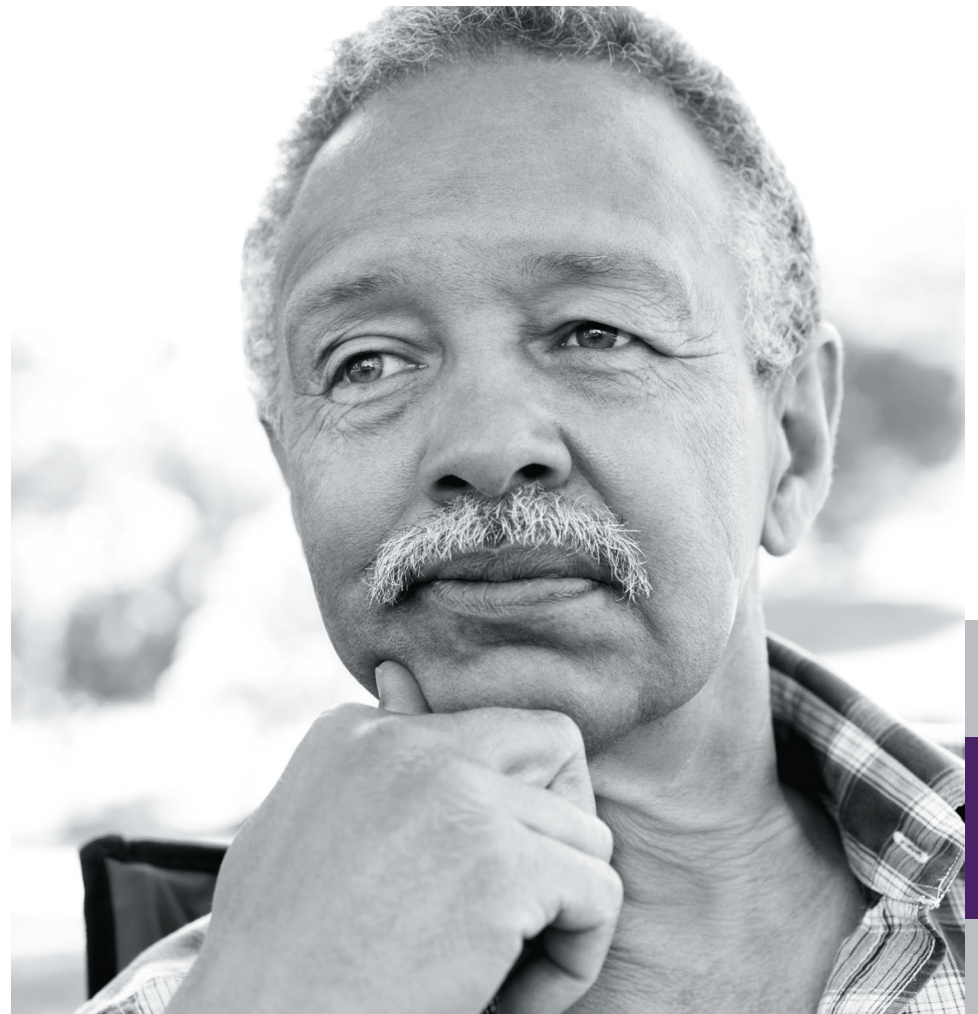
One of the goals of needs assessments is typically to inform the work of a broad range of stakeholders, so key findings from the assessment should be shared with the media after they have been incorporated into the overall state plan. A template that can be used to develop a press release is included in this toolkit (Tool F: Press Release Template).



CONCLUSION

This toolkit has been designed to assist state public health agencies to conduct needs assessments that are specifically focused on Alzheimer's and other dementias. The guidance provided in this toolkit is framed around a series of six steps that lead the assessor through a process that includes partnering, planning, assessing, synthesizing, envisioning and communicating.

The Alzheimer's Association hopes that this toolkit will be helpful to state public health agencies that wish to develop or update a state plan related to Alzheimer's disease, incorporate Alzheimer's and other dementias into other state plans, or develop other types of documents to convey the scope and burden of Alzheimer's and other dementias on individuals, caregivers, and communities.





TOOLS

- A. Stakeholder Analysis Matrix
- B. SMART Goal and Objective Worksheet
- C. Needs Assessment Timeline
- D. Assessment Report Checklist
- E. Communication Planning Template
- F. Press Release Template
- G. Needs Assessment Checklist

Tool A. Stakeholder Analysis Matrix

Instructions: Use this template to identify the stakeholders for the needs assessment, including their level of influence, which issues are important to them, and how they will be engaged.

[illegible]

Source: <http://www.tools4dev.org/resources/stakeholder-analysis-matrix-template/>

Tool B. SMART Goal and Objective Worksheet

Instructions: Work through this worksheet, including as much detail as possible under the heading in each columns. When you have completed the worksheet you will be able to write SMART goals and objectives for your needs assessment.

Goals and Objectives					
Intention	Specific	Measurable	Attainable	Relevant	Time Bound
What is it that you want to achieve?	Who? What? What? Where? When?	How much? How often? How many?	Achievable? Feasible?	Is it important to what you ultimately want to achieve?	When will goal be reached?

Tool C. Needs Assessment Timeline

Instructions: Use dark shading to show the timeline for each of the six major steps in the process; use light shading in the rows under each step to show the timeline for various activities within each step.

Phase / Description of Activity	Month/Year																	
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun
Step 1. Build Partnerships																		
• Identify stakeholders																		
• Establish relationships																		
• Form a workgroup																		
Step 2. Develop a Plan																		
• Identify goals and objectives																		
• Define roles and responsibilities																		
• Confirm the timeline																		
Step 3. Assess the Population																		
• Define the population to be assessed																		
• Identify community assets																		
• Create community description																		
Step 4. Synthesize Data																		
• Review qualitative/quantitative data																		
• Review trends/implications																		
Step 5. Envision the Future																		
• Create a vision																		
• Identify priorities for improvement																		
Step 6. Communicate Findings																		
• Draft/vet report with stakeholders																		
• Develop a dissemination plan																		
• Implement plan to share findings																		

Tool D. Assessment Report Checklist

Use this checklist to be sure that the following information is included in the final report from the needs assessment:

- ✓ **Title Pages, Table of Contents, and Acknowledgments**
 - ☐ List of core team members and/or the organizations they represent, as well as their contributions toward the needs assessment
- ✓ **Executive Summary**
 - ☐ Provide a brief overview and description of the population assessed, as well as the health, social and environmental issues identified during the assessment. The executive summary should be brief enough so that it can be easily reproduced for distribution to key stakeholders, but long enough to clearly convey the most important findings from the needs assessment.
- ✓ **Chapter 1. Background and Introduction**
 - ☐ Describe the rationale for conducting the needs assessment.
 - ☐ Comment on the collaborative relationship between the public health agency and the organizations represented on the core team.
 - ☐ Describe the process used to establish the core team, including information on stakeholder identification and/or mapping and recruitment of the core team members from the broader list of stakeholders.
 - ☐ Describe how the core team functioned during the process (e.g., committees, subcommittees, roles and responsibilities).
 - ☐ Discuss how key partnerships were formed or strengthened during the process.
- ✓ **Chapter 2. Brief Description of Population or Community**
 - ☐ Geographic: Describe the defined geographic area that is covered in the needs assessment (e.g., entire state, select counties or regions).
 - ☐ Historical: Describe any historical information that could be relevant to understanding health status or health behaviors of the population.
 - ☐ Demographic: Describe the population by key variables (as available) such as age, race, ethnicity, gender, urban/rural/suburban, educational attainment, household income, language, etc.
 - ☐ Environmental Context: Include information about any economic, political, environmental and/or social conditions that could be relevant to understanding the health status or health behaviors of the population.
- ✓ **Chapter 3. Data Collection Process**
 - ☐ List data sources and data sets used in the assessment.
 - ☐ Describe the process used to collect primary and secondary data, and briefly review any tools (e.g., questionnaires, interview guides) used. Include copies of any tools in the appendix.
 - ☐ Outline the process used to analyze or synthesize the data.
 - ☐ Discuss the method used to set priorities.
- ✓ **Chapter 4. Key Findings**
 - ☐ Describe the overall health status of the population, and needs of the population based on the data collected during the assessment.
 - ☐ Describe assets and resources available to address relevant issues among the population.
 - ☐ Identify gaps between needs and assets
 - ☐ Use charts, graphs and map, as appropriate, to illustrate key findings.
- ✓ **Chapter 5. Implementation and Vision**
 - ☐ Identify and discuss most highly prioritized issues/gaps in the population
 - ☐ Summarize the results
- ✓ **Chapter 6: Communication Plan**
 - ☐ End the report by communicating the actions that will be taken to address the needs identified during the assessment, including, as appropriate:
 - What practical alternative(s) could be pursued to address this gap/issue?
 - What are the barriers to doing so?
 - What major initiative should be pursued to move ahead?
 - What specific actions (with existing resources) should be taken right now? What are other resource implications – e.g., if new funds are secured or current funds lost?
 - What additional steps (6 months - 1 year from now) should be taken?
 - How does the action rank in terms of acceptability to key decision-makers and stakeholders, impact on the agency and its partners, integration/alignment with other strategies and activities, technical feasibility, cost-effectiveness, long-term impact, timing, or other criteria?

Tool E. Communication Planning Template

Instructions: Work through this worksheet, including as much detail as possible under the heading in each columns. When you have completed the worksheet you will have the information necessary to guide communication strategies with stakeholders.

Stakeholder	What	When	How	Who
Identify the name of the individual stakeholder and/or organizational affiliation	Describe what needs to be communicated (i.e., results of assessment)	Indicate the start and/or end date(s)	Describe the communication method (i.e., presentation to stakeholders)	Indicate the person or organization responsible for ensuring this communication is completed

Tool F. Press Release Template

[Insert logo(s) here]

FOR IMMEDIATE RELEASE

Contact:

Phone:

E-mail:

[Name(s)] Shares Initial Findings from Needs Assessment Related to Alzheimer's and Other Dementias

Location – [Name(s)] have completed a major milestone in their efforts to define the needs of persons with Alzheimer's and other dementias and their caregivers. The preliminary findings from the needs assessment represent several months of research collecting and analyzing data. The assessment includes [specify community area(s)].

The last needs assessment related to Alzheimer's and other dementias was conducted in [year] - or - [This is the first time that XX has conducted a needs assessment specifically related to Alzheimer's and other dementias]. With these new data, health officials have the information needed to [develop and implement a state plan for Alzheimer's and other dementias] - or - [incorporate issues related to Alzheimer's and other dementias into the state plan for chronic disease, falls prevention, healthy aging, etc.], with the goal of improving health and guiding future decision making based on the strengths and needs of the community.

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

[Name]

[Email]

[Phone]

###

[Insert Boilerplate(s)]

Tool G: Needs Assessment Checklist

✓ 1. Partner

- ☐ Identify internal and external stakeholders (Tool A: Stakeholder Analysis Matrix)

✓ 2. Plan

- ☐ Articulate needs assessment goals and objectives (Tool B: SMART Goal and Objective Worksheet)
- ☐ Identify and convene core team
- ☐ Consider a project charter for added structure
- ☐ Establish a timeline (Tool C: Needs Assessment Timeline)

✓ 3. Assess

- ☐ Identify data categories requiring data collection (e.g., prevalence and disparities, mortality, caregiving, modifiable risk factors, costs, assets and resources)
- ☐ Identify state and national data sources
- ☐ Identify data methods (quantitative and qualitative)
- ☐ Identify community resources and assets

✓ 4. Synthesize the Data

- ☐ Compile results of data collection
- ☐ Convene partners to interpret preliminary results as a group
- ☐ Identify questions to pose to the group

✓ 5. Envision the Future

- ☐ Convene partners for a visioning process

✓ 6. Communicate Findings for Action

- ☐ Prepare a written report to communicate needs assessment methods and results (Tool D: Assessment Report Checklist)
- ☐ Develop a communications plan (Tool E: Communication Planning Template)
- ☐ Develop supplemental communication materials (e.g., infographics)
- ☐ Share results with the media (Tool F: Press Release Template)

ADDITIONAL RESOURCES

Organization Name	Website
ACT on Alzheimer's	http://www.actonalz.org
Administration on Aging (AOA)	http://www.aoa.gov/
Alzheimer's Association (National Organization)	http://www.alz.org/
Alzheimer's Association Local Chapters	http://www.alz.org/apps/findus.asp
Centers for Disease Control and Prevention, Healthy Aging Program	https://www.cdc.gov/aging/index.html
Centers for Disease Control and Prevention, Healthy Brain Initiative	https://www.cdc.gov/aging/healthybrain/index.htm
Centers for Disease Control and Prevention, Healthy Brain Research Network	https://www.cdc.gov/aging/healthybrain/research-network/index.html
Centers for Disease Control and Prevention, Healthy Aging Data Portal	http://www.cdc.gov/aging/agingdata/index.html
Dementia Friendly America, Dementia Friendly Communities Toolkit	www.dfamerica.org
National Alzheimer's Project Act	https://aspe.hhs.gov/national-alzheimers-project-act
National Association of Area Agencies on Aging	http://www.n4a.org/
National Association of States United for Aging and Disabilities	http://www.nasuad.org/about-nasuad/about-state-agencies/list-members
National Institute on Aging	https://www.nia.nih.gov/
National Network of Public Health Institutes	https://nnphi.org/



ENDNOTES

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