



TEXAS

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2019 Texas Alzheimer's Disease Partnership Member Survey Report

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Introduction

As directed by Health and Safety Code, Title 2, Subtitle D. Chapter 99, Section 99.001, the Department of State Health Services (DSHS) is responsible for developing and implementing a state plan for education on and treatment of Alzheimer's disease and other dementias. The state plan serves as a resource for diverse stakeholders across the state and describes a public health approach to address Alzheimer's disease and other dementias. The state plan states that "DSHS will begin developing a survey during the first year of the state plan to provide baseline measurements and targets to measure progress in achieving state plan goals."¹

The DSHS Alzheimer's Disease Program convenes the Texas Alzheimer's Disease Partnership, also referred to as the "Partnership," to provide input on the state plan. The volunteer-based group includes members with diverse backgrounds from state, local, and community organizations, academic and research institutions, for-profit and non-profit sectors, businesses, the health care sector, and family members of individuals affected by Alzheimer's disease and other dementias.

In 2019, the DSHS Chronic Disease Epidemiology Branch (CDE) conducted the Texas Alzheimer's Disease Partnership Member Survey to better understand the work stakeholders are doing around Alzheimer's disease and other dementias. The results presented in this report will be used by the Alzheimer's Disease Program to inform the facilitation of the Partnership, and by CDE to provide foundational information that will help to inform future state plan-related data collection efforts that aim to measure progress in achieving state plan goals.

Methods

CDE created the Texas Alzheimer's Disease Partnership Member Survey in Qualtrics. The survey consisted of twenty-four questions and included multiple choice and open-ended response questions. None of the questions were required. A complete list of survey questions can be found in Appendix 1.

An Alzheimer's Disease Program staff member emailed the survey link to all Texas Alzheimer's Disease Partnership members (n=193). The survey was open from November 25, 2019 to December 10, 2019. Survey reminders were emailed on December 2, 2019 and December 9, 2019.

The survey received a 38 percent response rate, with 74 of 193 individuals completing the survey. Some respondents did not respond to every question; incomplete responses were included in the analysis. All responses were exported from Qualtrics to SPSS for cleaning and analysis.

¹ Texas State Plan for Alzheimer's Disease 2019-2023 (September 2019). Texas Department of State Health Services.

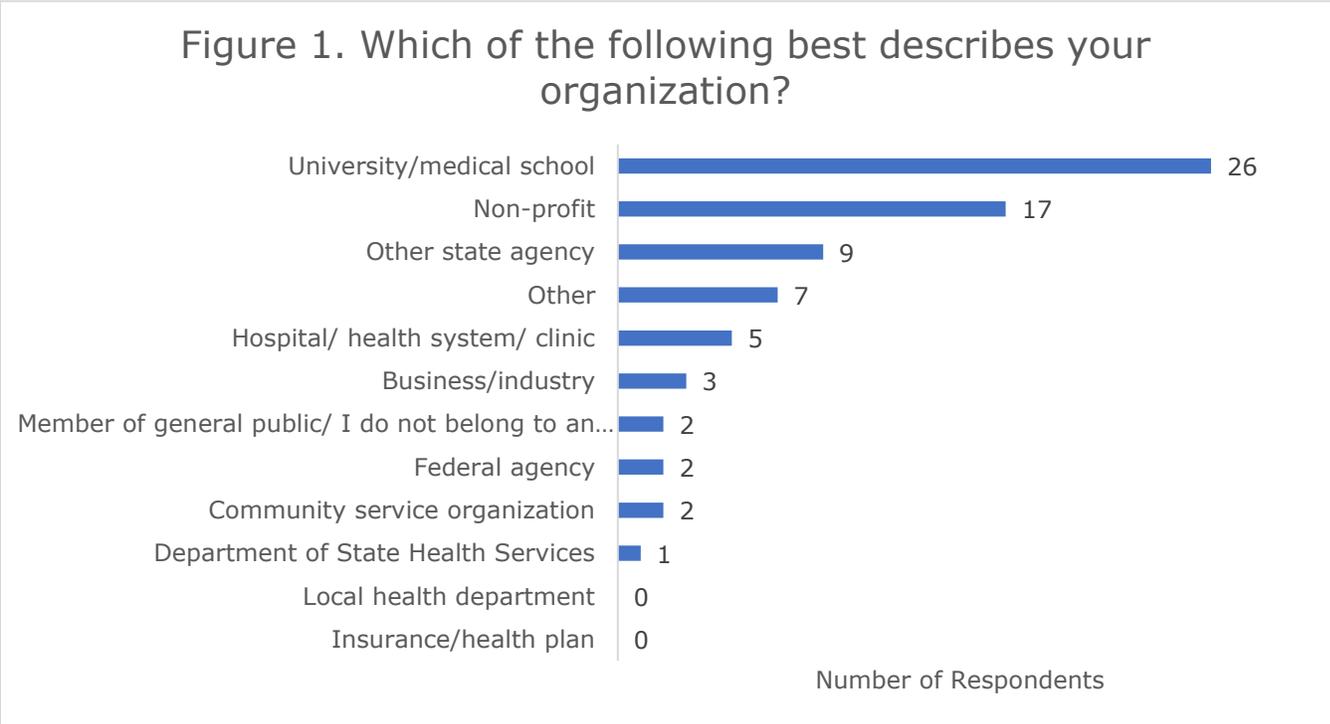
Results

Demographics

Organization Affiliation

Respondents were asked about their organization type (Figure 1). Seventy-four respondents provided a response to this question.

Most respondents said they are from either a university/medical school (35 percent) or a non-profit organization (23 percent). Nine percent of respondents selected “other,” and said they are from an advocacy organization, community college, hospice organization, state association or state government agency.

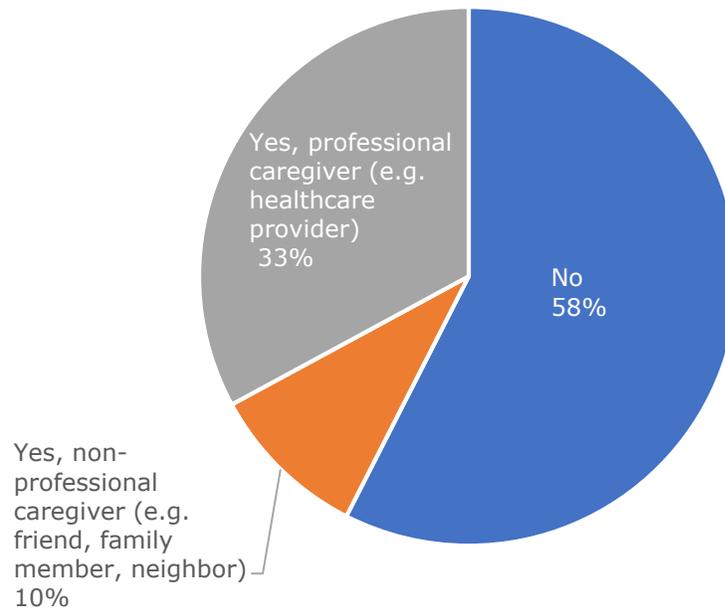


Caregiver Status

Respondents were asked about their caregiver status (Figure 2). Seventy-three respondents provided a response to this question.

A total of 44 percent of respondents said they are caregivers to a person with Alzheimer’s disease or other dementia. Most of these respondents (33 percent) said they are professional caregivers, such as a healthcare professional. The remaining respondents (11 percent) said they are non-professional caregivers, such as a friend, family member or neighbor.

Figure 2. Are you a caregiver (professional or non-professional) to a person with Alzheimer's disease or other dementia?



Work Related to Alzheimer’s Disease and Other Dementias

Work Related to Alzheimer’s Disease and Other Dementias

Respondents were asked how their work is related to Alzheimer’s disease and other dementias (Table 1). Seventy-two respondents provided a response to this question.

The majority of respondents (71 percent) said they deliver education and awareness programs related to Alzheimer’s disease and other dementias. Almost half of respondents (46 percent) said they are involved in research related to Alzheimer’s disease and other dementias.

Table 1. How is your work related to Alzheimer’s Disease and other dementias? Select all that apply.		
	Number	Percent
Education and awareness programs	51	71%
Research	33	46%
Community support organization	30	42%
Caregiving	28	39%
Medical	21	29%
Volunteer	14	19%
Government agency	13	18%
Other	10	14%

Work Related to the Texas State Plan for Alzheimer’s Disease

Respondents were asked if their work is related to the eight priority areas and actions in the Texas State Plan for Alzheimer’s Disease 2019-2023 (Table 2). Seventy-two respondents provided a response to this question.

Most respondents said their work is related to Priority Area 1: Education and Awareness (79 percent), Priority Area 4: Training (65 percent), and/or Priority Area 3: Partnerships and Engagement (58 percent).

In contrast, less than half of respondents said their work is related to Priority Area 7: Importance of Data Collection (38 percent) and/or Priority Area 8: Advance Research and Collaboration (46 percent).

Six percent of respondents selected “other,” indicating their work falls outside of the scope of the Texas State Plan for Alzheimer’s Disease 2019-2023.

Table 2. Which of priority areas and actions does your work related to? Select all that apply.		
Priority Area	Number	Percent
1: Education and Awareness	57	79%
2: Coordinated Systems of Care and Support	41	57%
3: Partnerships and Engagement	42	58%
4: Training	47	65%
5: Quality Care and Support	41	57%
6: Family Inclusion	38	53%
7: Importance of Data Collection and Evaluation	27	38%
8: Advance Research and Collaboration	33	46%
Other	4	6%

Geographic Location

Respondents were asked about the type of geographic location where their organization does work (Figure 3). Seventy respondents provided a response to this question.

The majority of respondents said their organization does work in urban areas (91 percent). Over half of respondents said their organization does work in suburban (67 percent) and/or rural areas (56 percent).

Figure 3. What type of geographic location does your organization work in? Select all that apply.

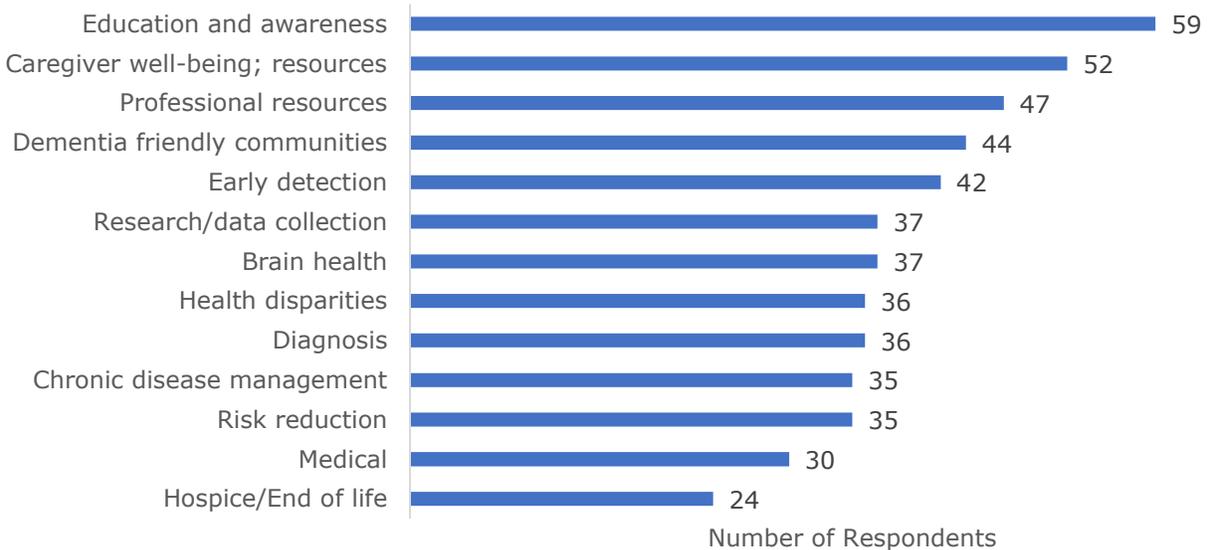


Interests Related to Alzheimer’s Disease and Other Dementias

Respondents were asked about their interest areas regarding Alzheimer’s disease and other dementias (Figure 4). Seventy-two respondents provided a response to this question.

Respondents indicated they are interested in a variety of topics. Most respondents said they are interested in education and awareness (82 percent) and/or caregiving well-being and resources (72 percent).

Figure 4. What is your area of interest regarding Alzheimer's disease or other dementias?

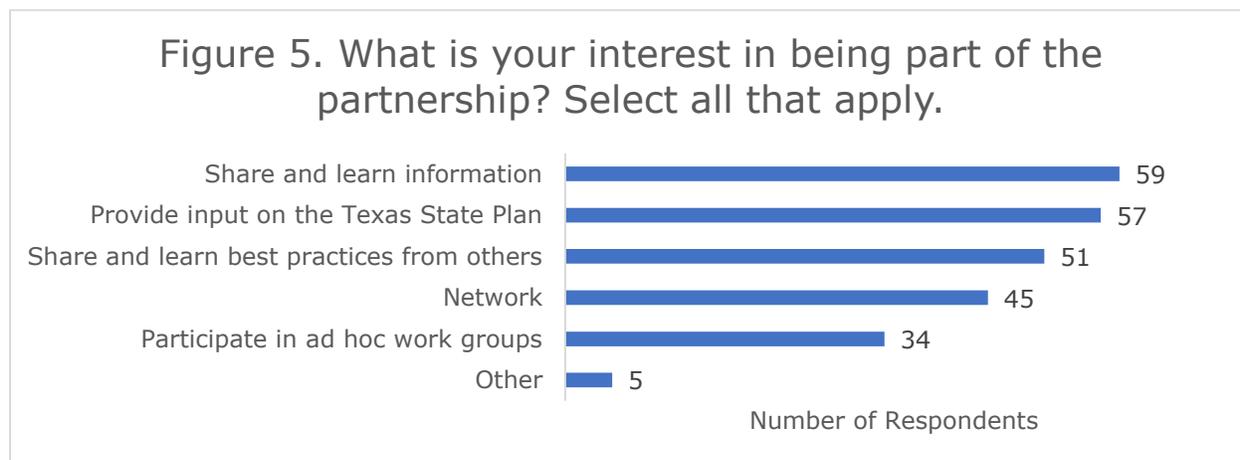


Interest in Texas Alzheimer’s Disease Partnership

Respondents were asked about their interest in being part of the Partnership (Figure 5). Seventy respondents provided a response to this question.

Most respondents said they are interested in sharing and learning information (84 percent), providing input on the Texas State Plan (81 percent), and sharing and learning best practices from others (73 percent).

Seven percent of respondents selected “other.” These respondents said they are interested in helping with Dementia Friendly Texas, supporting individuals with Alzheimer’s and their caregivers, representing dementia friendly interests, connecting with research networks or helping wherever they can.



State Advisory Board (Committee/Council)

Respondents were asked if they were a member of a state advisory body, including committees and councils. Seventy respondents provided a response to this question. About one-fifth of respondents (21 percent) said they are a member of a state advisory body.

In follow-up, these respondents (n=15) were asked the name of the advisory body they belong to. Thirteen respondents provided an open-ended response to this question. Aside from the Partnership, respondents said they belong to the:

- Texas Council on Alzheimer’s Disease and Related Disorders (n=5)
- Aging Texas Well Advisory Committee (n=4),
- Community Care Resource Committee (n=1),
- Southeast Texas Alzheimer’s (n=1),
- Texas Alzheimer’s Research and Care Consortium (n=1), and/or
- Texas Council on Developmental Disabilities (n=1).

In addition, these respondents (n=15) were asked how the advisory body addresses issues related to Alzheimer’s disease and other dementias. Nine

respondents provided an open-ended response to this question.

Respondents said the state advisory body provides support and/or oversight to a state plan (n=3), provides education and/or resources (n=3), coordinates activities (n=2), provides guidance to stakeholders (n=2), funds research (n=1), supports policies and programs (n=1), and/or maintains a database (n=1).

Health Care Providers

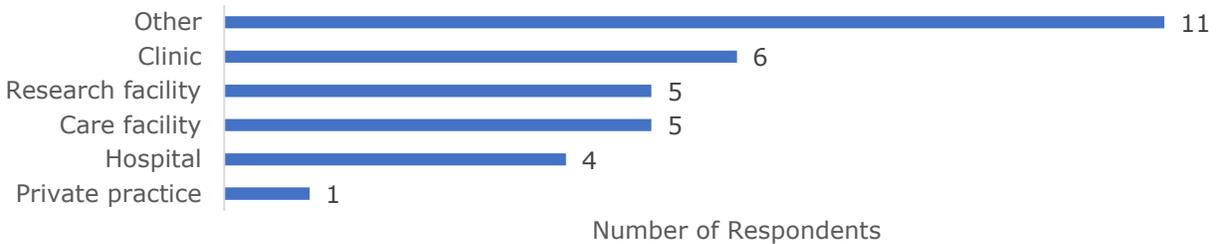
Respondents were asked if they are a health care provider licensed in Texas. Seventy-one respondents provided a response to this question. Almost half of respondents (45 percent) said they are a health care provider licensed in Texas.

Respondents that said they are a health care provider licensed in Texas (n=32) were asked to describe their position (Figure 6). Most respondents (25 percent) said they are a mental health professional, such as a psychiatrist, psychologist or social worker. Thirty-four percent of respondents selected “other,” and specified they are a speech language pathologist, geriatric psychiatrist, geriatric physician, neurology physician assistant, researcher, personal services assistant, nursing facility staff member or assisted living staff member.



Respondents that said they are a health care provider licensed in Texas (n=32) were also asked to describe the location where they practice. Most respondents (19 percent) said they practice in a clinic. Thirty-four percent of respondents selected “other,” and said they practice in a state agency, academic facility, non-profit organization, faith-based organization, or client’s home.

Figure 7. Which of the following best describes the location where you practice?



Researchers

Respondents were asked if they conduct research on Alzheimer’s disease and other dementias. Seventy-one respondents provided a response to this question. Less than half of respondents (41 percent) said they conduct research on Alzheimer’s disease or other dementias.

Respondents that said they conduct research on Alzheimer’s disease and other dementias (n=27) were asked to list the topics they research. Twenty-seven respondents provided an open-ended response to this question. Respondents said they conduct research on a variety of topics. The most reported research topics were caregiving (n=12) and/or treatment (n=8).

Experience in Alzheimer’s Disease Work

Collaboration

Respondents were asked to list the organizations they regularly collaborate with on Alzheimer’s and other dementia related activities. Fifty-seven respondents provided an open-ended response to this question.

Almost all respondents (96 percent) said they regularly collaborate with at least one organization, including government agencies, faith-based organizations, non-profits, private organizations, health care professionals and facilities, senior living facilities, and collaboratives. The most reported partner was the Alzheimer’s Association, with 80 percent of respondents stating they regularly collaborate with the organization.

Challenges

Respondents were asked about the challenges they have faced while working to promote Alzheimer’s disease awareness and treatment. Forty-eight respondents provided an open-ended response to this question.

The most reported challenge was funding (n=26). For example, one respondent said the “highly competitive research environment makes it difficult to secure

adequate research funding.” However, the respondent stated that the Texas Alzheimer's Research and Care Consortium (TARCC) has helped to address this challenge. Another respondent emphasized the importance of funding for local agencies because it is challenging to raise money to “keep up with the demand for supportive services.”

Available Resources

Respondents were asked to list the resources their organization has available regarding Alzheimer's and related dementias. Sixty respondents provided an open-ended response to this question. Respondents said their organizations have a variety of resources available, including websites, publications, print materials, support groups, helplines and trainings.

Respondents indicated they can share a variety of data resources with partners, including program datasets, client/patient datasets, research datasets, and data reports. For example, one respondent said they can share data on complaints received and investigated in nursing homes and assisted living facilities. Another respondent said they can share the Facing Rural Obstacles to Healthcare Now Through Intervention, Education and Research (Project FRONTIER) dataset.

Needed Resources

Respondents were asked the Alzheimer's disease- or other dementias-related topics they needed more education and resources on. Thirty-seven respondents provided a response to this open-ended question.

Most respondents said they need more education and resources on treatment (n=10), with one respondent specifying they would like more information on evidence-based, non-pharmacological treatment options. Some respondents (n=7) said they would like more education and resources on caregiving.

Conclusion

Respondents said they represent a variety of organizations. Nearly half of respondents said they are caregivers to a person with Alzheimer's disease or other dementia.

Respondents said they are involved in a variety of activities related to Alzheimer's and other dementias. Furthermore, respondents said their work is specifically related to the Texas State Plan for Alzheimer's Disease 2019-2023, which includes eight priority areas and actions.

Respondents said they are interested in a variety of areas related to Alzheimer's and other dementias, with the majority of respondents stating they are interested in education and awareness. Most respondents said they are interested in the Partnership to share and learn information, provide input on the Texas State Plan,

and share and learn best practices from others.

About one-fifth of respondents said they are members of a state advisory body. Almost half of respondents said they are a health care provider licensed in Texas. Less than half of respondents said they conduct research on Alzheimer's disease or other dementias.

Almost all respondents said they regularly collaborate with at least one organization, including government agencies, faith-based organizations, non-profits, private organizations, health care professionals and facilities, senior living facilities, and collaboratives.

Most respondents said funding is a challenge with working to promote Alzheimer's disease awareness and treatment. Respondents said their organization can provide a variety of resources and datasets to partners. Respondents said they would like more education and resources on a variety of topics, with most respondents stating they would like information on treatment.

Appendix 1. Texas Alzheimer's Disease Partnership Member Survey

The Texas Department of State Health Services (DSHS) Alzheimer's Disease Program requests your participation in the Texas Alzheimer's Disease Partnership Membership Survey. The purpose of this survey is to better understand the work stakeholders are doing around Alzheimer's Disease and Other Dementias. The results of the survey will be used by the DSHS Alzheimer's Disease Program to inform future needs assessment and Alzheimer's State Plan related activities.

The following survey should take approximately 10 minutes to complete. Please complete this survey by December 10, 2019.

If you have any questions about this survey, please contact Lynda Taylor at Lynda.Taylor@dshs.texas.gov.

Thank you in advance for your participation!

CONTACT INFORMATION

1. Please provide your contact information.
 - a. Name
 - b. Credentials
 - c. Title
 - d. Organization/State Agency/Advisory Committee
 - e. Mailing address
 - f. Phone
 - g. Email

2. If applicable, please provide your assistant's contact information. (This person will receive all emails that the Partnership member receives.)
 - a. Name
 - b. Credentials
 - c. Title
 - d. Organization
 - e. Mailing address
 - f. Phone
 - g. Email

3. Which of the following best describes your organization?
 - a. Department of State Health Services (DSHS)
 - b. Local health department
 - c. Other state agency
 - d. Non-profit
 - e. Community service organization
 - f. Insurance/ health plan
 - g. University/medical school

- h. Business/industry
 - i. Hospital/ health system/ clinic
 - j. Member of the general public/ I do not belong to an organization
 - k. Other (please specify) _____
4. Are you a caregiver (professional or non-professional) to a person with Alzheimer's disease or other dementia?
- a. Yes- professional (such as a healthcare professional)
 - b. Yes- non-professional (such as a family, friend, or neighbor)
 - c. No

YOUR WORK AND/OR WORK OF YOUR ORGANIZATION

5. How is your work related to Alzheimer's Disease (AD) and other dementias?
- a. Education and awareness programs
 - b. Medical
 - c. Research
 - d. Community support organization
 - e. Government agency
 - f. Care facilities
 - g. Volunteer
 - h. Other: _____
6. The [Texas State Plan for Alzheimer's Disease](#) features eight priority areas and actions. Which of the Priority Areas and Actions does your work relate to? Select all that apply.
- a. Education and awareness
 - b. Coordinated systems of care and support
 - c. Partnerships and engagement
 - d. Training
 - e. Quality care and support
 - f. Family inclusion
 - g. Importance of data collection and evaluation
 - h. Advance research and collaboration
 - i. Other (please specify): _____
7. Please briefly describe the Alzheimer's and other dementias work that your organization does. Please be as specific as possible. IE: Not just "caregiver support" but "weekly caregiver support groups held at our location."
- a. Open text box
8. What type of geographic locations does your organization work in? Select all that apply.
- a. Urban
 - b. Rural

- c. Suburban

INTEREST IN PARTNERSHIP

- 9. What is your interest in being part of the partnership? Select all that apply.
 - a. Share and learn information
 - b. Share and learn best practices from others
 - c. Network
 - d. Participate in ad hoc work groups
 - e. Provide input on the Texas state plan
 - f. Other (please specify): _____

AREAS OF INTEREST REGARDING AD AND OTHER DEMENTIAS

- 10. What is your area of interest regarding AD and other dementias?
 - a. Education and Awareness
 - b. Medical
 - c. Diagnosis
 - d. Early detection
 - e. Brain Health
 - f. Risk reduction
 - g. Disease Management
 - h. Hospice/End of life
 - i. Health disparities
 - j. Dementia friendly communities
 - k. Caregiver well-being; resources
 - l. Professional resources
 - m. Research/ Data collection

STATE ADVISORY BODY (COMMITTEE/COUNCIL)

- 11. Are you a member of a state advisory body (committee/council)?
 - a. Yes (*If yes is selected, display q12 and q13*)
 - b. No (*If no is selected, skip to Healthcare Providers section*)

- 12. What is the name of the advisory body (committee/council) you belong to?
 - a. Open textbox

- 13. How does this advisory body address issues related to AD and other disorders?
 - a. Open textbox

HEALTH CARE PROVIDERS

- 14. Are you a health care provider licensed in Texas?
 - a. Yes (*If "yes", display 15 and 16*)

b. No (*If "no", skip to 17*)

15. Which of the following best describes your position?

- a. Primary care physician
- b. Neurologist
- c. Nurse
- d. Nurse practitioner
- e. Physical therapist
- f. Mental health: psychiatrist, psychologist, social worker
- g. Other: _____

16. Which of the following best describes the location where you practice?

- a. Care facility
- b. Private practice
- c. Hospital
- d. Research facility
- e. Clinic

RESEARCHERS

17. Do you conduct research on Alzheimer's and other dementias?

- a. Yes (*If "yes", display 18*)
- b. No (*If "no", skip to 19*)

18. What Alzheimer's or other dementia topics do you do research on (i.e.: treatment, caregiving, prevention)

- a. Open textbox

EXPERIENCE IN ALZHEIMER'S WORK

19. Which, if any, organizations do you regularly collaborate with on Alzheimer's and other dementia related activities?

- a. Open textbox

20. What challenges have you faced while working to promote Alzheimer's awareness and treatment? IE: funding, time, stakeholder interest

- a. Open textbox

WHAT YOU CAN SHARE

21. What resources does your organization have available about Alzheimer's and related dementias? IE: website, publications, webinars, print outs. Please be specific

- a. Open textbox

22. What, if any, Alzheimer's and related dementias data sets you are able to share with other partners (perhaps with an MOU)?

a. Open textbox

23. What Alzheimer's- or other related dementias-related topics do you need more education/resources on (i.e.: caregiving, prevalence, treatment)?

a. Open textbox

SHARING CONTACT INFORMATION

24. Do you agree to have your name and organization on a partnership list visible by the public? (Name and organization only)

a. Yes

b. No