

**Texas Department of State Health Services** 

# 2024 Alzheimer's Disease Partnership Membership Survey Results

June 2024

Prepared by: Texas Department of State Health Services (DSHS) Chronic Disease Epidemiology Branch (CDE)

### **Background and Methods**

- 400 individuals received a link to the survey via email.
- Survey consisted of:
  - 30 questions
    - ADRD-related work experience questions
    - Partnership and workgroup interest questions
    - Voluntary demographic information questions
- The survey was open from April 3 April 30, 2024.



Texas Department of State
Health Services

### **Survey Results**



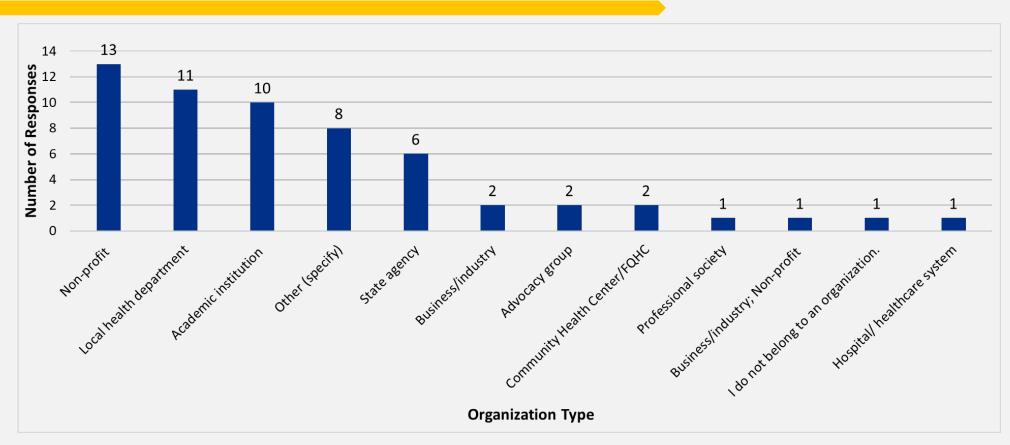
# Personal Experiences with Alzheimer's Disease or Related Dementias (ADRD)

Are you currently caring for someone with Alzheimer's disease or related dementias (ADRD) (or have you in the past)?	Count	% of total
No	25	43%
Yes- professional (such as a healthcare professional)	20	34%
Yes- non-professional (such as a friend, family member, or neighbor)	13	22%
Total	58	100%

### Length of Involvement in ADRD-related Work

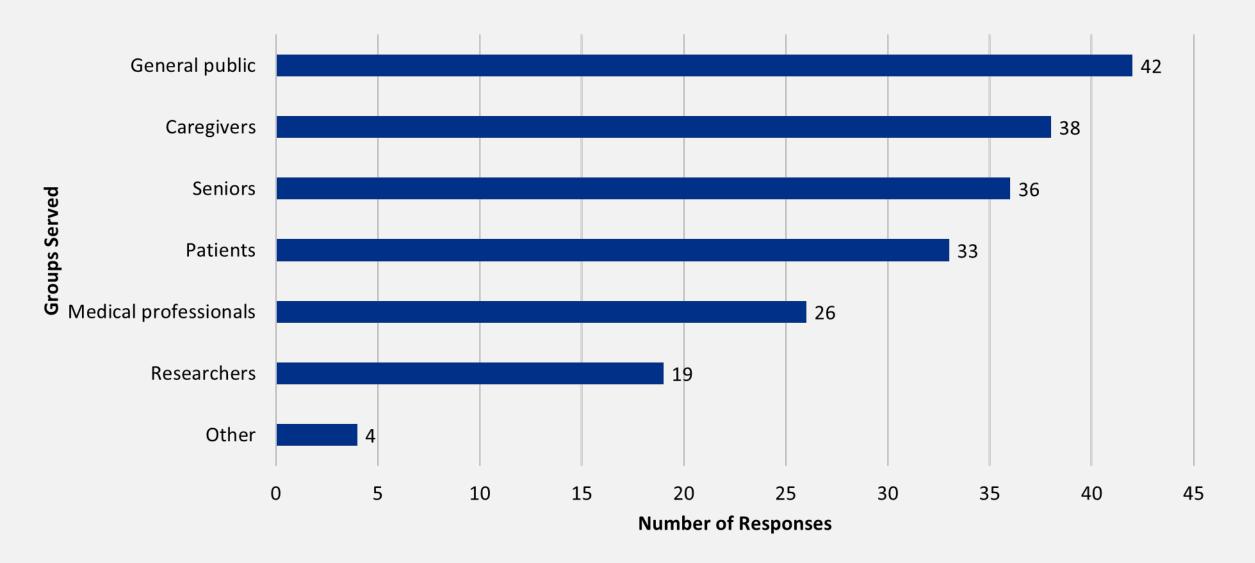
How long have you been involved in or interested in ADRD-related work?	Count	% of total
Less than one year	5	9%
1-5 years	15	26%
6-10 years	9	16%
11-15 years	9	14%
16-20 years	2	4%
21-25 years	4	7%
More than 25 years	11	19%
I prefer not to answer.	2	4%
Total	57	100%

### Which of the following best describes your organization?



Representatives from <u>non-profits</u>, <u>local health departments</u>, <u>and academic institutions</u> provided the most survey responses.

### Which of the following groups does your organization serve?



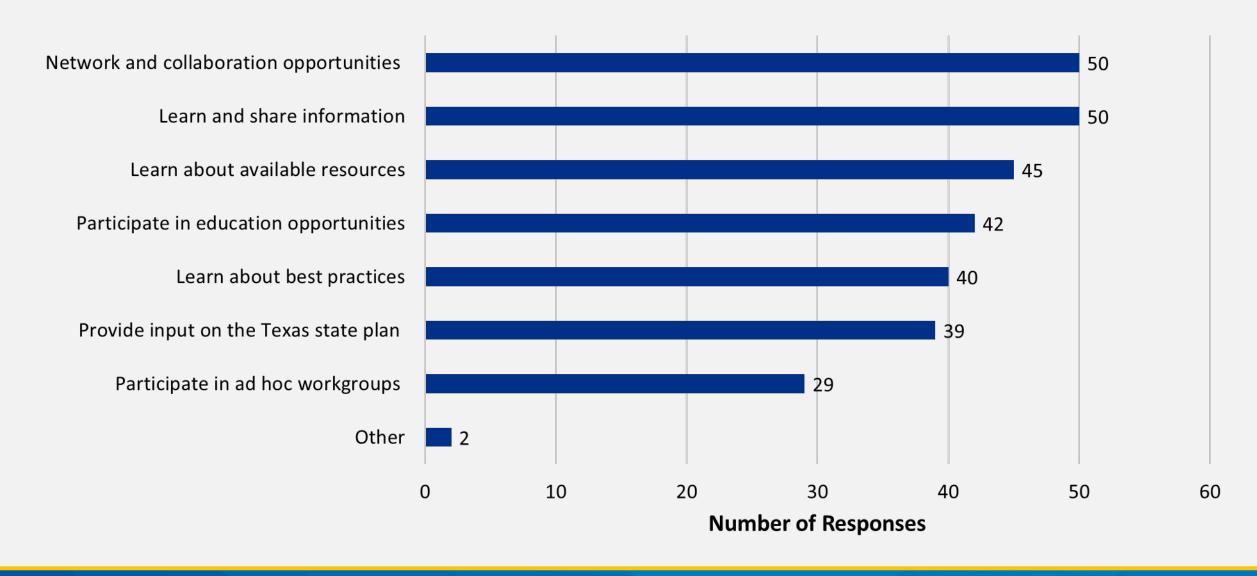
<sup>\*</sup>Respondents could select all that apply.

### Which of the Priority Areas and Actions does your work relate to?



<sup>\*</sup>Respondents could select all that apply.

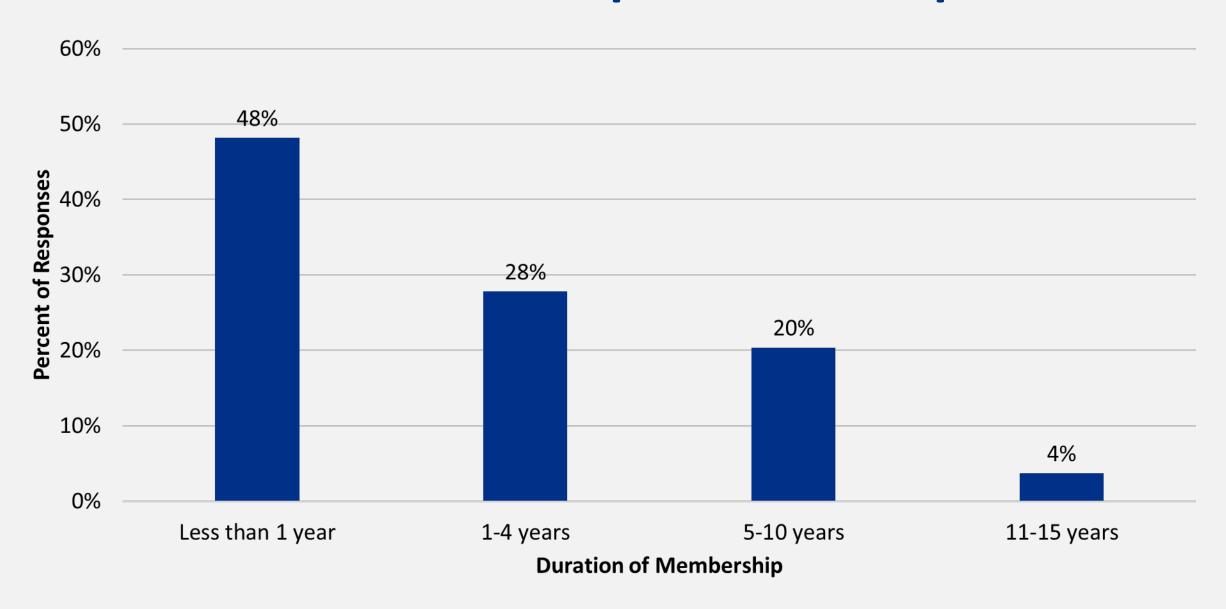
## What do you hope to gain from being a member of the Alzheimer's Disease Partnership?



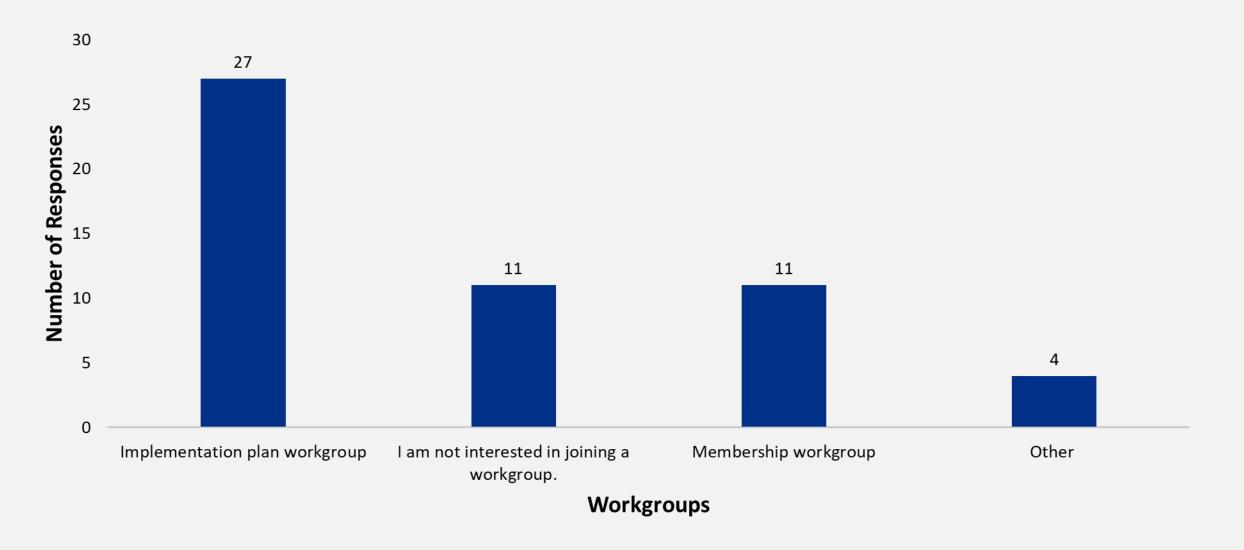
### **Education Topic Interests**

Please rank the following ADRD-related education and training topics of interest to you from most important (e.g., 1) to least important (e.g., 10).	Rank
Early detection and diagnosis	1
Caregiver well-being and support	2
Clinical care and diagnostic practices	3
Brain health and ADRD risk reduction	4
Community linkages to treatment, care, and services	5
Disease management	6
Resources for professionals	7
Research/data collection	8
Hospice or end of life care	9
Other	10

### **Duration of Partnership Membership**



# Which workgroup would you be interested in joining?



### **Workgroup Topic Suggestions**

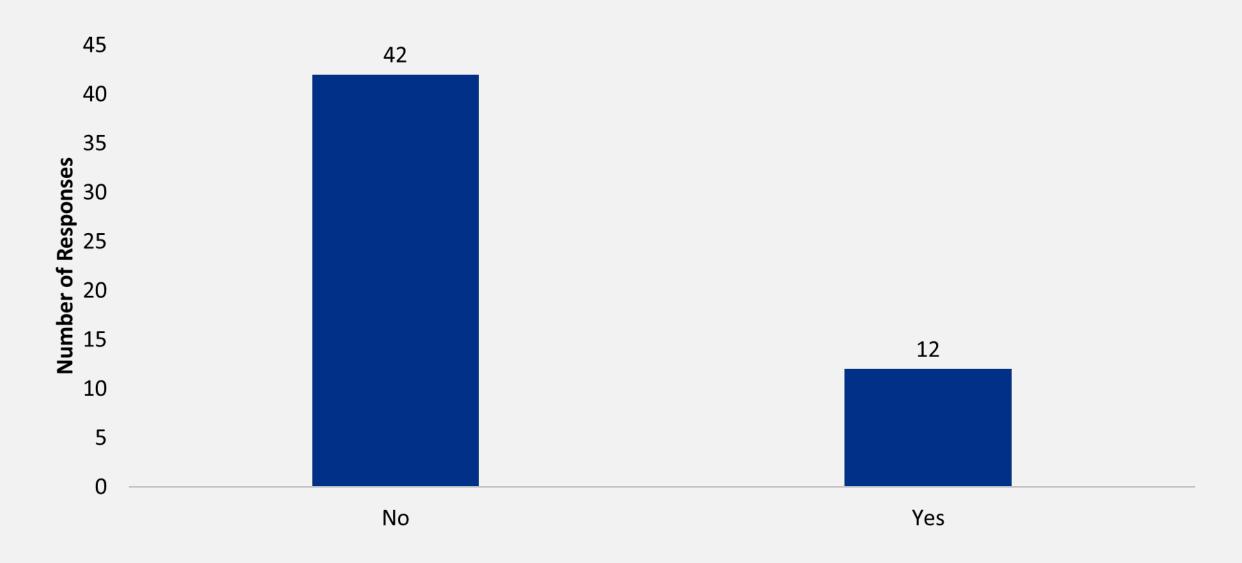
### Respondents provided the following responses for workgroup topic suggestions:

- Board
- Caregiver support
- Education
- Minority inclusion
- Resources
- Data and research
- Clinical care
- Support group for people who have been diagnosed with Alzheimer's Disease
- Memory cafe & Dementia friendly

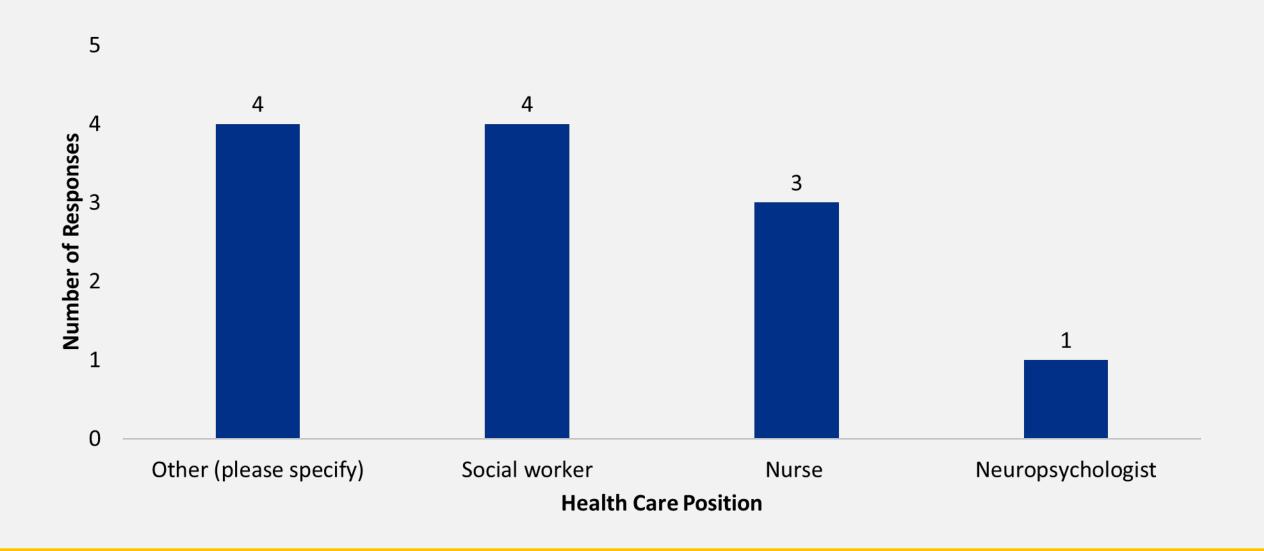
### **Workgroup Activity Suggestions**

- Development of partnerships (e.g., minority communities, low-income clinics)
- Long-term caregiver services
- Establish workgroups (e.g., education and outreach, CHW workgroup, minority-focused workgroup, etc.)
- Promote shared goals vs. competition for funding
- Surveys of community resources/members that specifically serve nonprofessional family caregivers
- Creation of a database of professional education and resources
- Rural health models of care and support
- Leveraging academic medical institutions to increase care
- Incorporating means for optimal health and its benefits throughout varying stages of Alzheimer's Disease

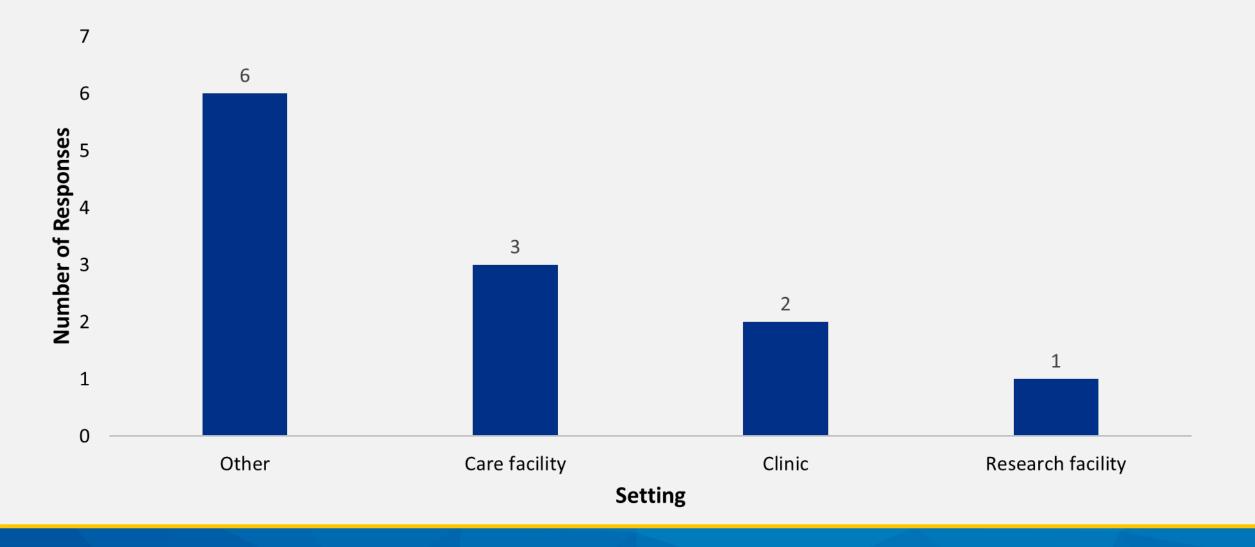
#### **Texas Licensed Healthcare Providers**



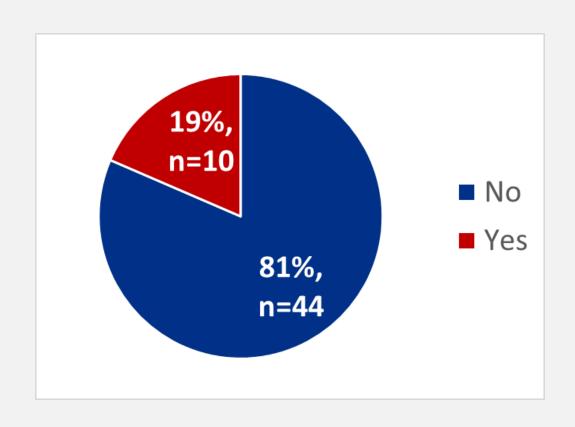
# Which of the following best describes your position?



# Which of the following best describes the setting where you practice?



## Do you conduct research on Alzheimer's or other forms of dementia?



#### **Current Research Efforts**

- Treatment (e.g., care and support of individuals with ADRD, instrumental activities of daily living)
- Prevention
- AD pathophysiology (e.g., pathways of disease)
- AD disparities
- Caregiving (e.g., Youth caregivers, caregivers of color including immigrants and refugees)
- Translational research (e.g., creating dementia-capable health systems to drive risk reduction, early detection, and diagnosis, and enhance quality care)
- Barriers and facilitators to dementia care practice change for primary care organizations serving rural and diverse populations
- Promoting improved dementia capability among different types of sites
- Individual and collective progress towards optimal dementia capability
- Cognition in non-English speakers
- Sexuality
- Genetics
- Non-pharmacological ADRD (intervention research with both caregivers and care recipients and ADRD and non-pharmacological interventions in care)

### **ADRD Collaboration**

- Area Agency on Aging
- Academic institutions
- Alzheimer's Association
- Nonprofit organizations
- State and federal agencies
- Health systems across Texas
- Long-term care facilities
- Faith-based organizations
- Home healthcare organizations
- Other ADRD-related organizations

### **Challenges and Barriers**

- Funding (n=20)
- Knowledge and awareness (n=19)
- Time constraints (n=13)
- Clinical care and training (n=8)
- Research and evaluation (n=7)
- Caregiver challenges (n=6)
- Lack of cultural competence (n=5)
- Stigma (n=2)

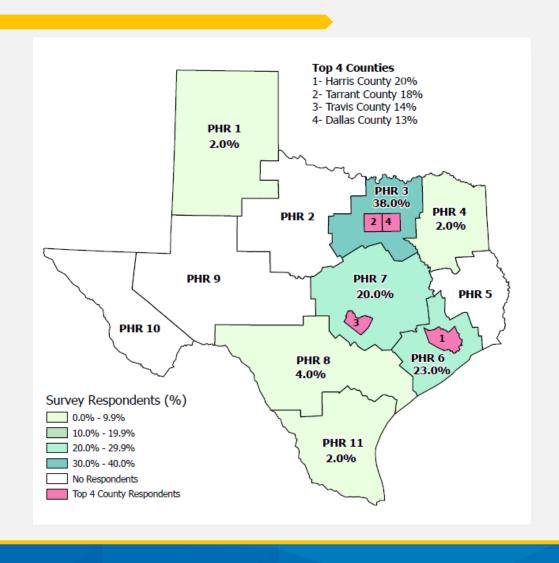
### **Available Resources**

- Training
- Educational materials
- Presentations
- Social media
- Other public resources

### Partnership Additional Comments or Ideas

- Share Partnership education and resources (i.e., translational work, trainings, directory of Texas ADRD resources, up-to-date standards, best practices etc.).
- Identify other Texas ADRD researchers for research collaboration.
- Enhance education and outreach in rural communities.
- Provide monthly newsletters (i.e., include funding, new programs, best practice programs, state government interest/involvement).
- Implement strategic ADRD funding in Texas for dementia (i.e. funding allocation for 28 local AAA chapters).

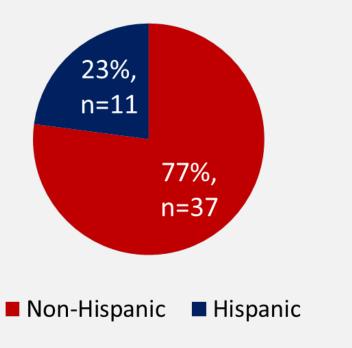
### Respondent Residence Map



### **Race and Ethnicity**

How would you describe your race? Select all that apply.	Count	% of total
White	37	76%
Black/African American	5	10%
Asian	3	6%
Indigenous American or Alaskan Native	2	4%
Two or more races	1	2%
I prefer not to answer.	1	2%
Total	49	100%

### How would you describe your ethnicity?



### Age

What is your age range? (Years)	Count	% of total	
25 - 34	7	14%	
35 - 44	7	14%	
45 - 54	17	34%	
55 - 64	10	20%	
65 or older	7	14%	
I prefer not to answer	2	4%	
Total	50	100%	

### **Highest Educational Level Attained**

What is the highest level of education you have completed?	Count	% of total
Associate degree (e.g., AA, AS)	3	6%
Bachelor's Degree (e.g., BA, BS)	10	20%
Master's Degree (e.g., MA, MS, MEd, MSW, MBA)	26	52%
Doctorate Degree (e.g., PhD, EdD, DrPH)	9	18%
Professional degree beyond bachelor's degree (e.g., MD)	2	4%
Total	50	100%

#### Conclusions

- Partnership members have relevant expertise in three priority areas and actions including education and awareness, partnerships and engagement, and training that can be beneficial to amplifying ADRD work in Texas.
- ADP leadership should prioritize providing the Partnership with education topics relevant to early detection and diagnosis, caregiver wellbeing and support, and clinical care and diagnostic practices.
- Funding, lack of knowledge and awareness of ADRD, and time constraints are the most mentioned challenges and barriers among the Partnership.
- Partnership workgroups should identify opportunities to collaborate with current researchers and academic institutions, providers, minority populations, and caregivers to address gaps in membership.
- The majority of respondents hope to engage in network and collaboration opportunities, learn and share information, and learn about available resources.

### Thank you!

2024 Alzheimer's Disease Partnership Membership Survey Results

For more information about the Partnership, please email <a href="mailto:Vanessa.pierce@dshs.texas.gov">Vanessa.pierce@dshs.texas.gov</a>.