

Alzheimer's Disease Working Group

Session 3 – The Early Stage

Vision

People with Alzheimer's disease and their families will receive the support and care they need through early detection and diagnosis, high quality health and long term supports and services, and communities that are prepared to meet their needs.

Bill Moss, Chair

Aging and Long Term Services Administration

January 7, 2015



Welcome



Today's Meeting Goals

- Review the Healthy Brain Initiative and UW's involvement in the project.
- Identify and prioritize potential early stage supports for people with Alzheimer's.
- Receive updates from the subcommittees and provide advice and guidance to them.
- Examine preliminary data from public input and physician surveys and provide advice about how to use the data and comments.
- Address advance planning and legal supports, with an emphasis on how to improve early individual planning.



Agenda Overview

10:00 – 10:15 a.m.	Welcome
10:15 – 10:45 a.m.	The Healthy Brain Initiative – Healthy Brain Research Network
10:45 – 11:45 p.m.	Early Stage Supports for People with Alzheimer’s
11:45 – 12:30 p.m.	Working Lunch
12:30 – 1:30 p.m.	Subcommittee Reports
1:30 – 2:00 p.m.	Update on Survey Results
2:00 – 2:15 p.m.	Break
2:15 – 3:00 p.m.	Advance Planning and Legal Supports
3:00 – 3:15 p.m.	Public Comment Period
3:15 – 3:30 p.m.	Wrap Up and Next Steps



The Healthy Brain Research Network

Basia Belza, PhD, RN
University of Washington



The Healthy Brain Research Network – Q & A

- **In what ways could the HBRN support ADWG efforts?**
- **What advice does HBRN have for ADWG?**
- **What advice do we have for HBRN?**



Early Stage Supports for People with Alzheimer's

Rebecca Logsdon, PhD

Amy Shives

Myriam Marquez

Bob Wellington



Early Stage Supports – Questions for Panel

- **What does a person receiving a diagnosis most need to know at first?**
- **What services or supports were available to you (in your community)?**
- **What did you really want/need that you couldn't find?**



Working Lunch

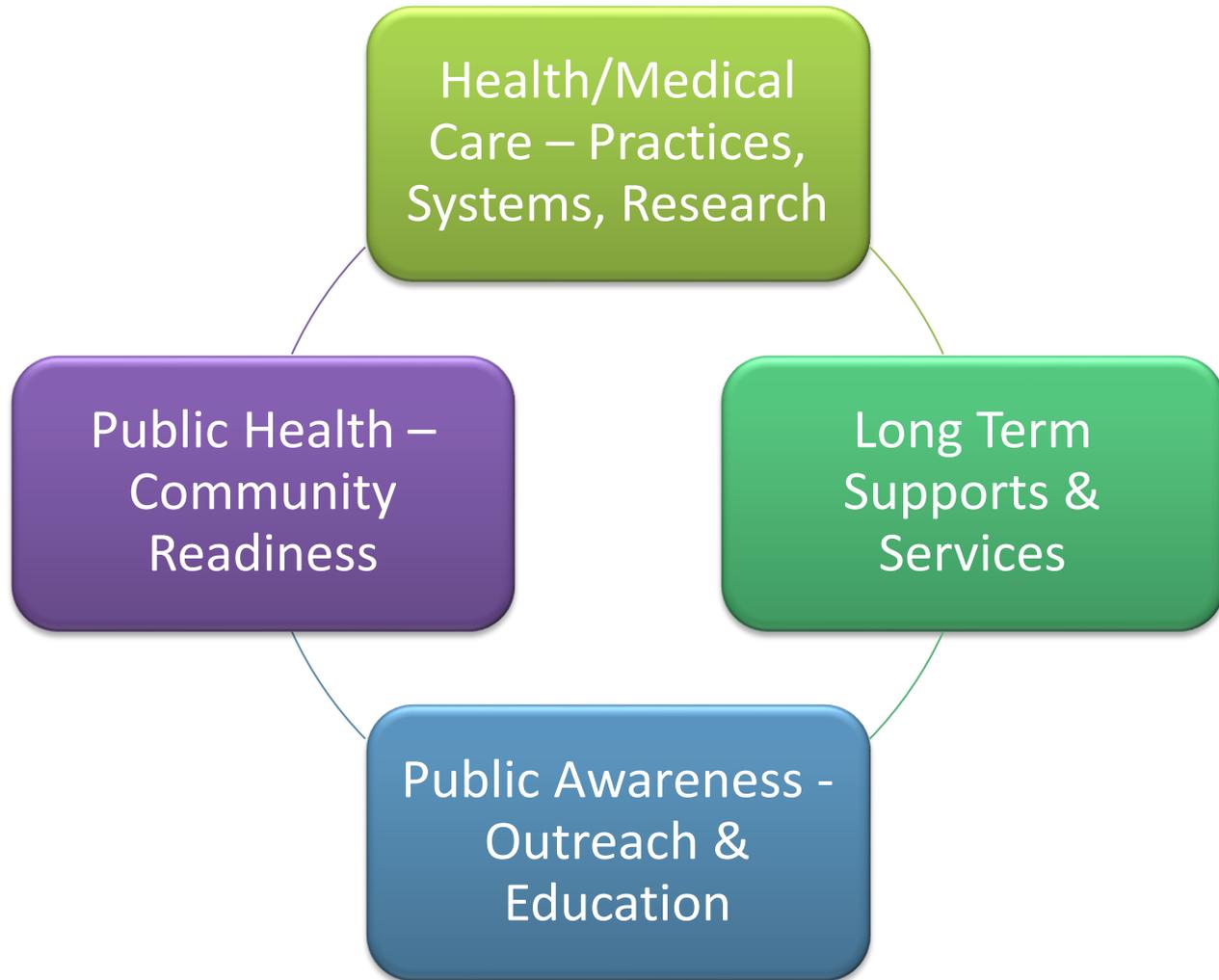
At your table, discuss the following questions:

- 1. What should people be able to expect from their medical provider/community at diagnosis? At a minimum?**
- 2. What other supports/services would be most valuable in the early stages after receiving a diagnosis?**

Be prepared to report out to the larger group.



Subcommittees Reports



Survey Results

- **Preliminary Analysis**
- **Two Surveys: Public and Medical Community**

- **What can we learn from this data?**
- **How should we integrate this information into our report?**



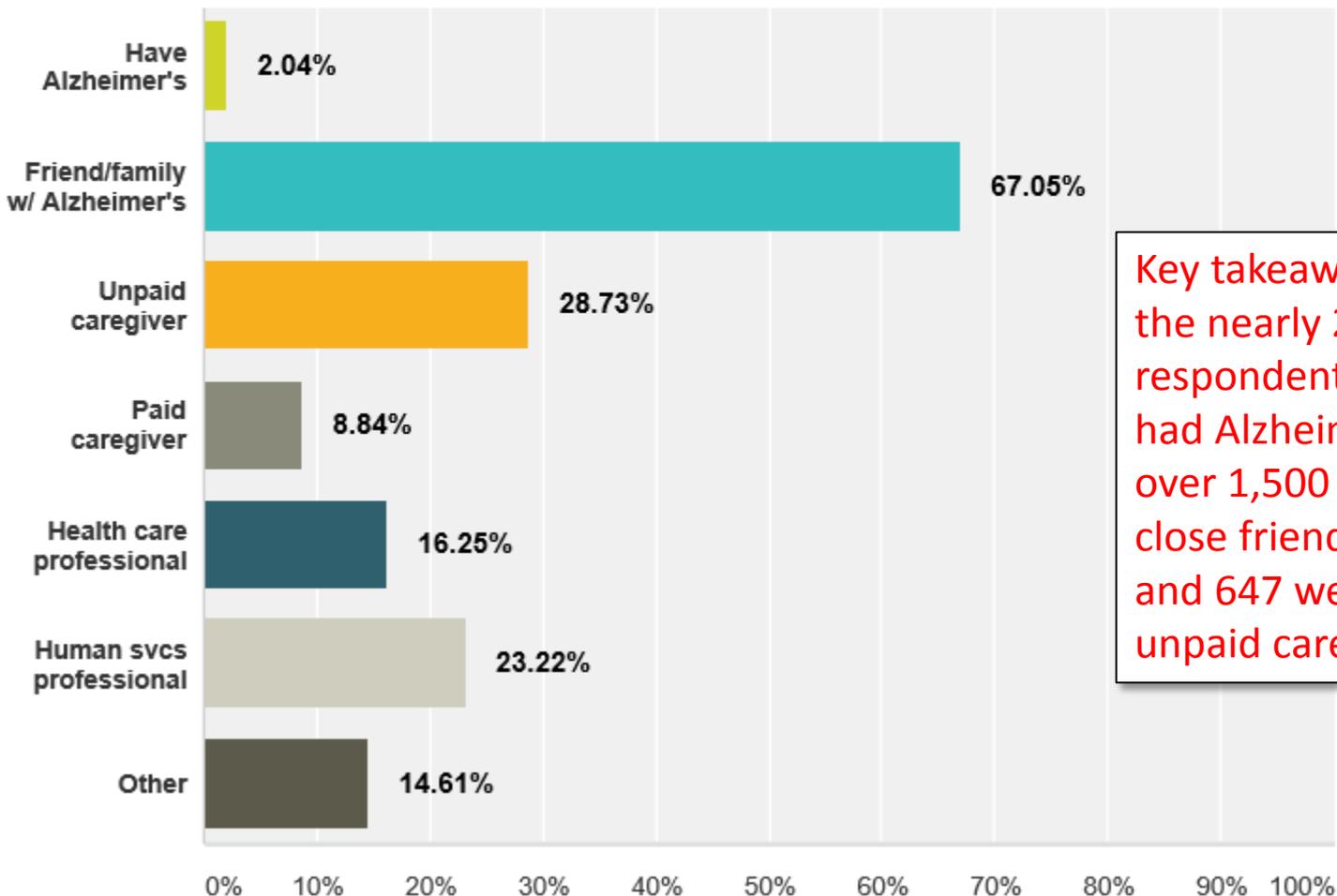
Public Input Survey

- **2,259 responses**
- **2/3 from close friend or family member**
- **46 responses from people with Alzheimer's**
- **November 7 – December 31, 2014**



What is your connection to Alzheimer's disease or related dementias? (Choose all that apply):

Answered: 2,252 Skipped: 7

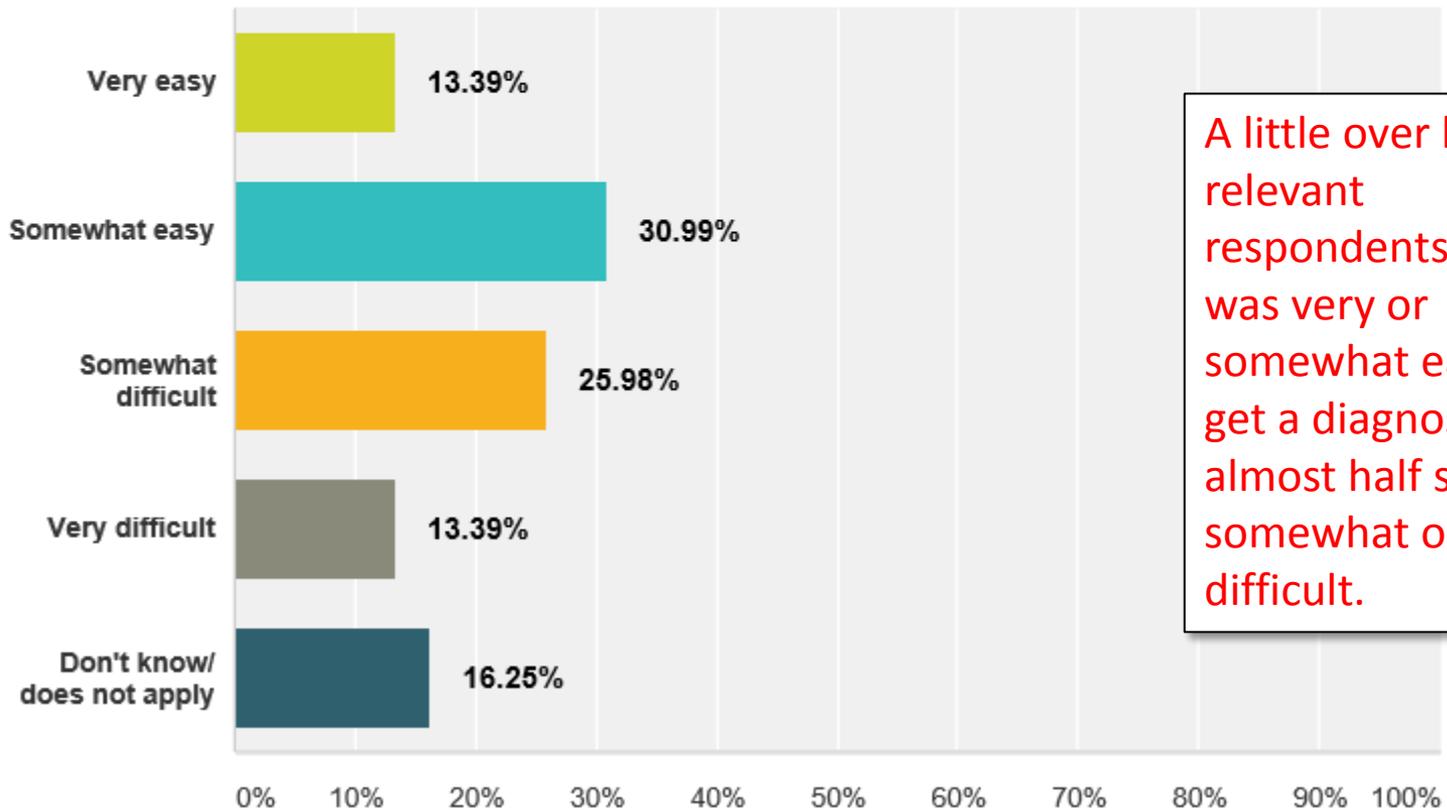


Key takeaway: Of the nearly 2,300 respondents, 46 had Alzheimer's, over 1,500 were close friends/family, and 647 were unpaid caregivers.



How difficult was it for you (or your friend/family member with Alzheimer's/dementia) to get a medical assessment/diagnosis from a local physician?

Answered: 1,397 Skipped: 862

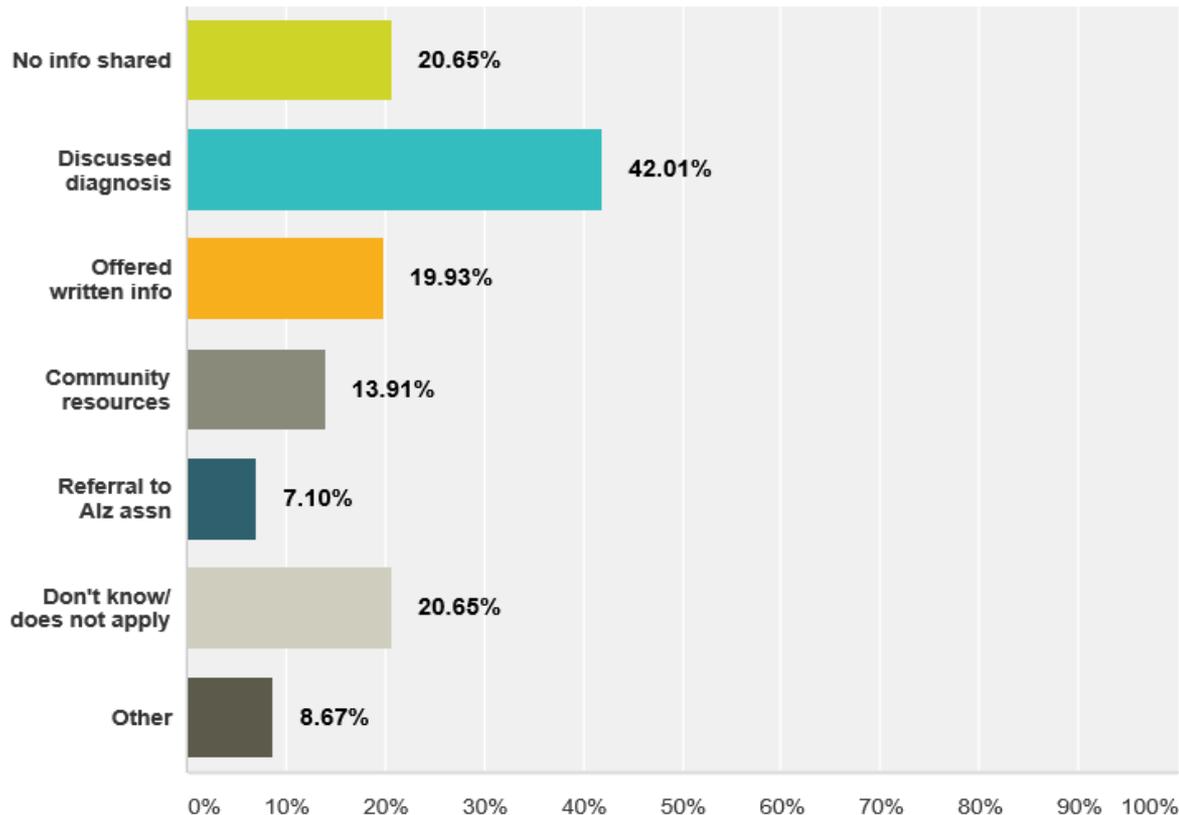


A little over half the relevant respondents said it was very or somewhat easy to get a diagnosis, and almost half said somewhat or very difficult.



When you (or your friend/family member) were given a diagnosis of Alzheimer's or dementia, what kind of information did the provider or medical staff offer about the illness itself, planning for care, community resources or referrals? (Choose all that apply)

Answered: 1,395 Skipped: 864



1 in 5 people didn't get any information about Alzheimer's.

2 in 5 people had a discussion with their doctor about their diagnosis.

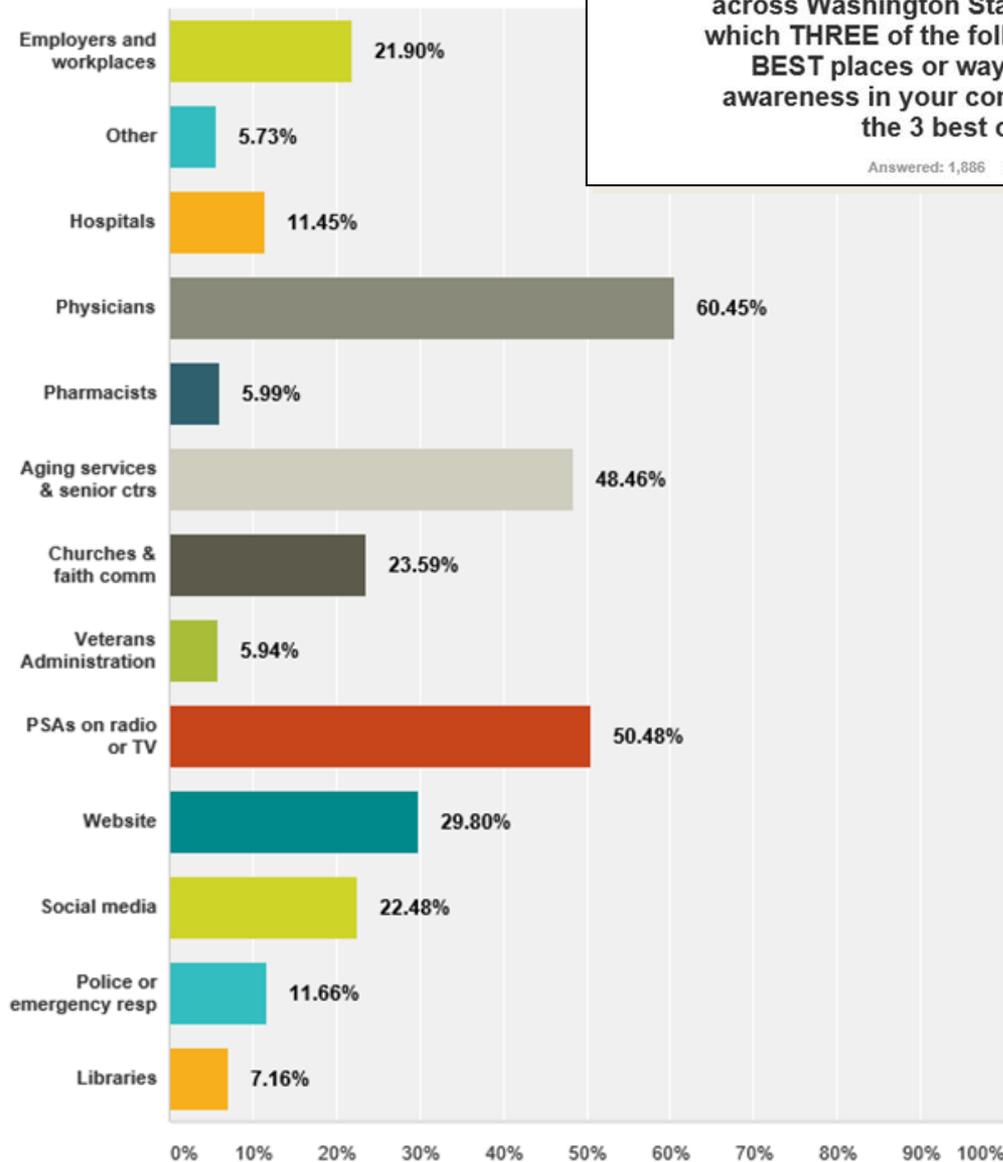
Just 14% received info about community resources.

Under 1 in 10 were referred to an Alzheimer's organization.



The Alzheimer's Disease Working Group wants to increase general awareness and understanding of Alzheimer's disease across Washington State. In your opinion, which **THREE** of the following would be the **BEST** places or ways to raise public awareness in your community? (Choose the 3 best options)

Answered: 1,886 Skipped: 373



The top three recommendations are:

- Physicians (60%)
- Public Service Announcements (50%)
- Aging/Senior Services (48%)

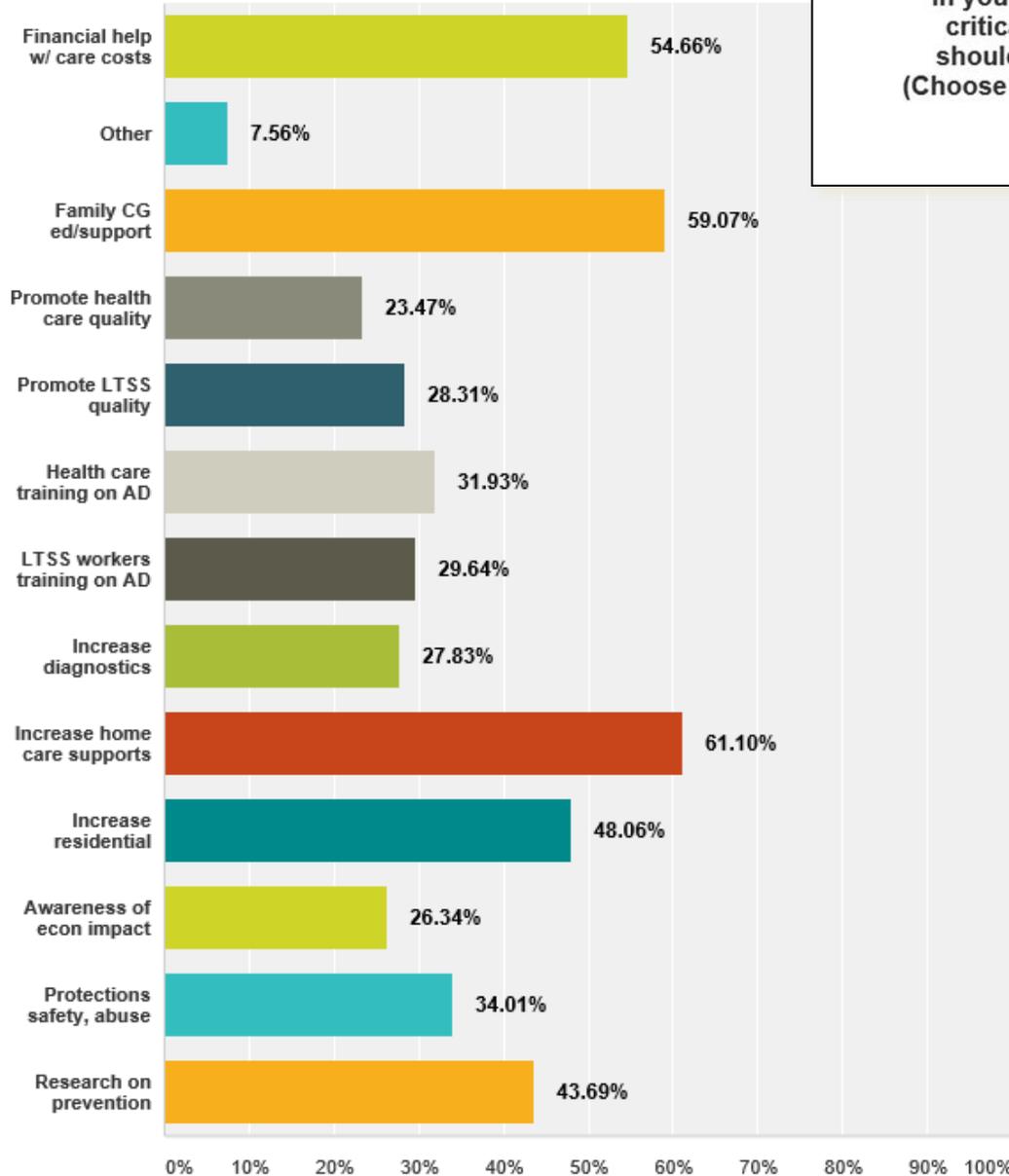
Lowest ranked:

- VA
- Pharmacists
- Libraries



In your opinion what are the **FIVE** most critical issues that Washington State should address in the next five years? (Choose up to 5 priorities that you think are **MOST** important)

Answered: 1,879 Skipped: 380



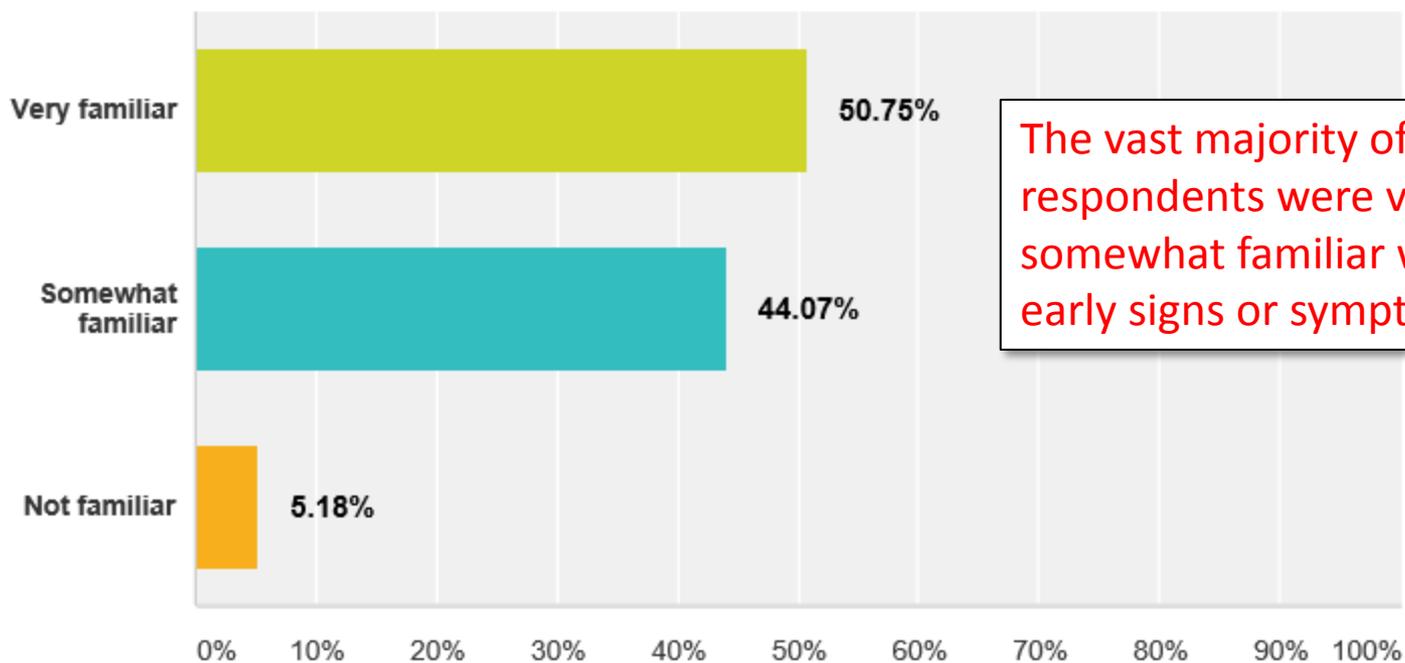
The top five critical issues are:

- Increase home care supports (1,148)
- Family caregiver education & support (1,110)
- Financial help with care costs (1,027)
- Increase residential services (903)
- Research on prevention (821)



How familiar are you with the early signs or symptoms of Alzheimer's or other dementias?

Answered: 1,872 Skipped: 387

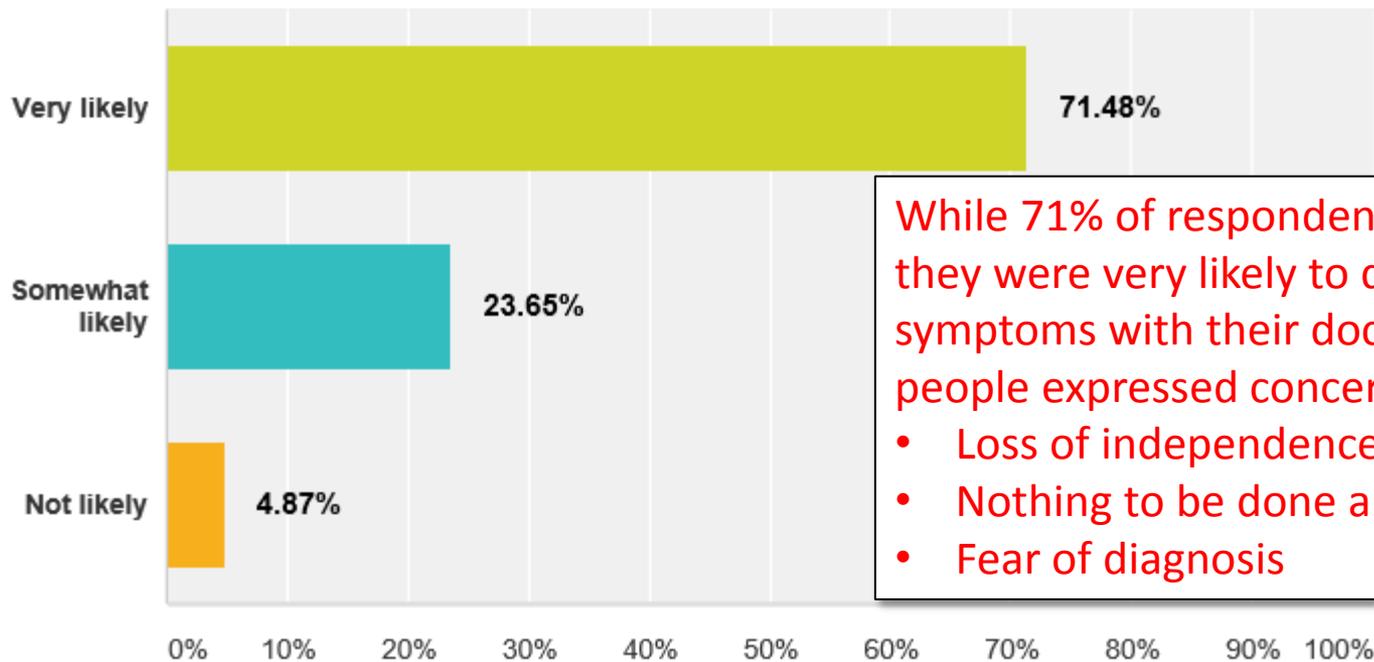


The vast majority of respondents were very or somewhat familiar with early signs or symptoms.



If you noticed early signs or symptoms of Alzheimer's or other dementias in yourself, how likely would you be to discuss them with your physician/health care provider?

Answered: 1,869 Skipped: 390



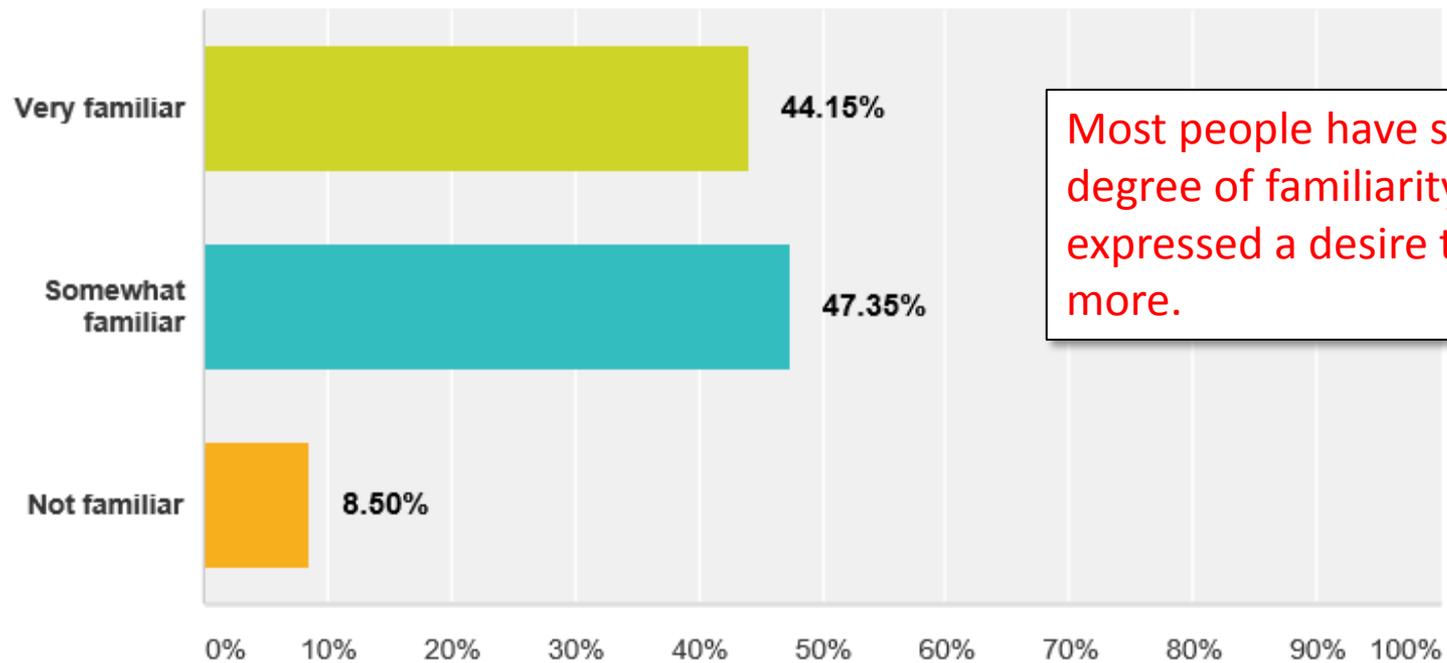
While 71% of respondents indicated they were very likely to discuss signs or symptoms with their doctor, other people expressed concerns about:

- Loss of independence
- Nothing to be done anyway
- Fear of diagnosis



How familiar are you with steps you can take to keep your brain healthier as you age?

Answered: 1,871 Skipped: 388

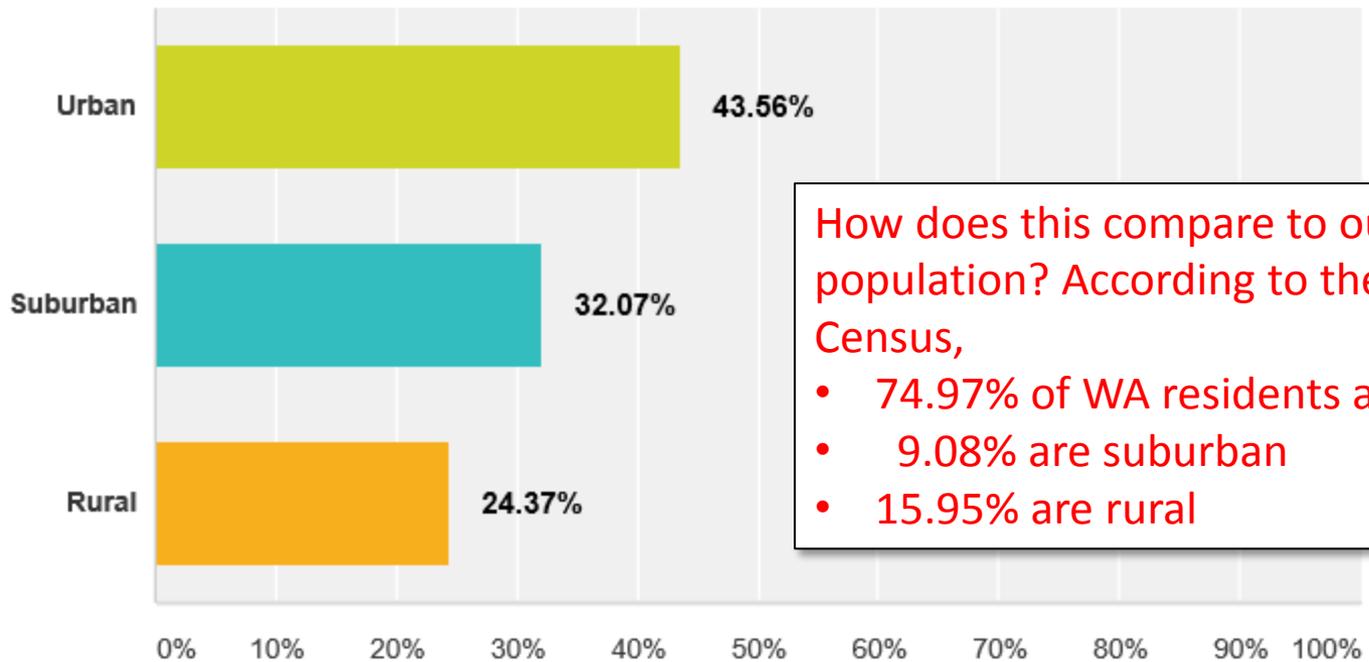


Most people have some degree of familiarity, but expressed a desire to know more.



What best describes the area where you live?

Answered: 1,871 Skipped: 388



How does this compare to our state population? According to the 2010 U.S. Census,

- 74.97% of WA residents are urban
- 9.08% are suburban
- 15.95% are rural



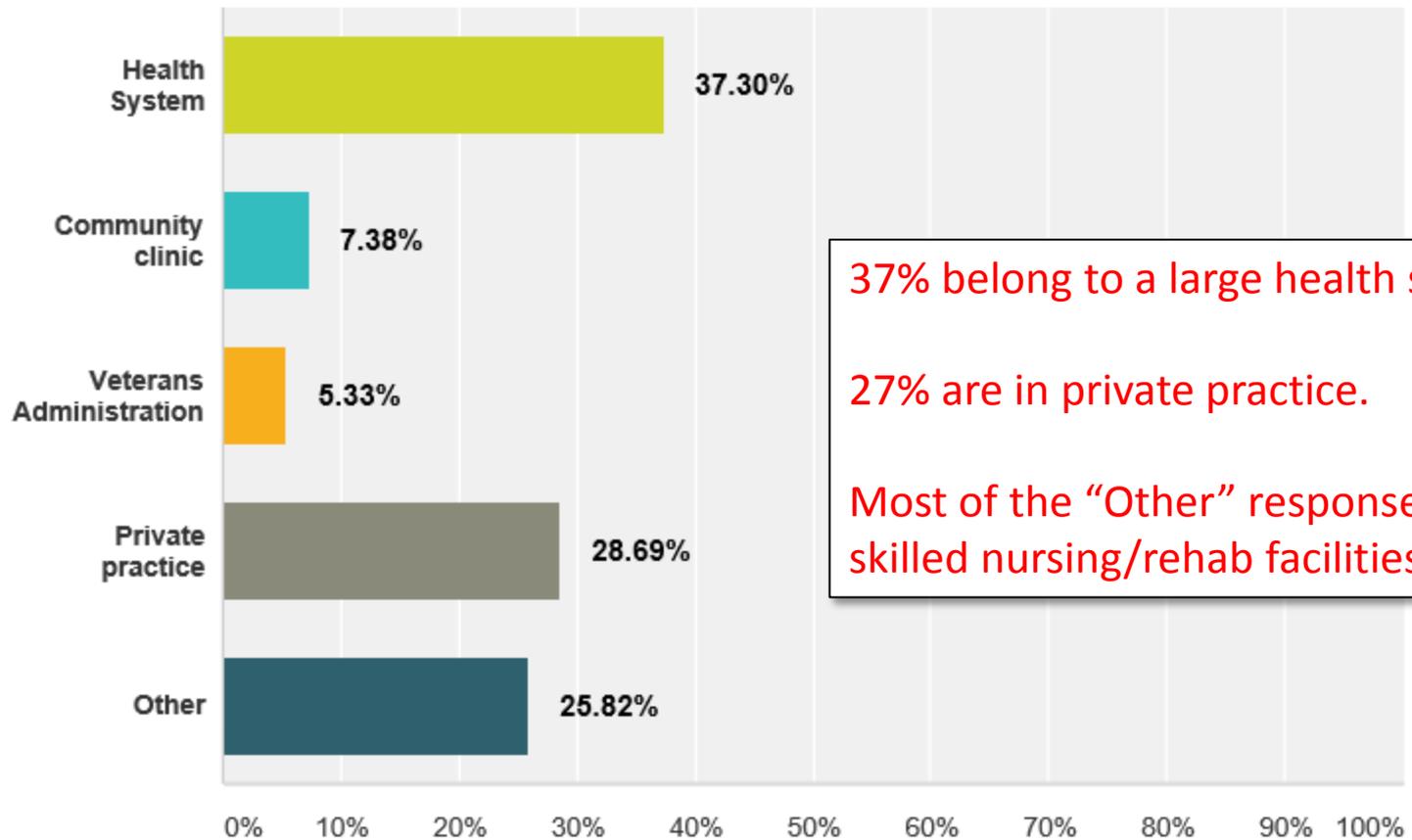
Primary Care Survey

- **247 responses**
- **30% Physicians**
- **24% Nurses**
- **46% Other (PA, ARNP, Naturopath, Psychologist, etc.)**



Please describe your work setting: (Choose all that apply)

Answered: 244 Skipped: 3



37% belong to a large health system.

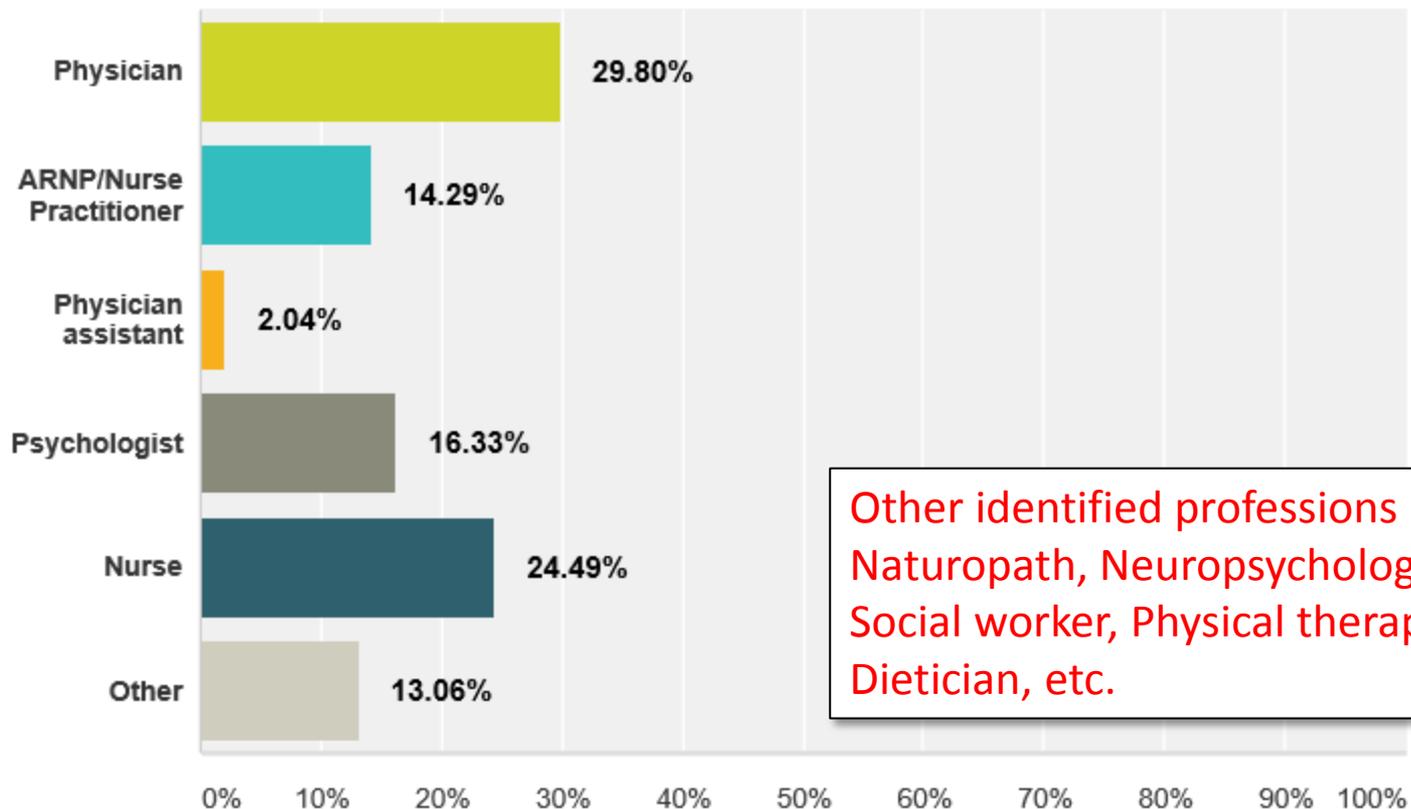
27% are in private practice.

Most of the "Other" responses were skilled nursing/rehab facilities



Please identify your profession:

Answered: 245 Skipped: 2

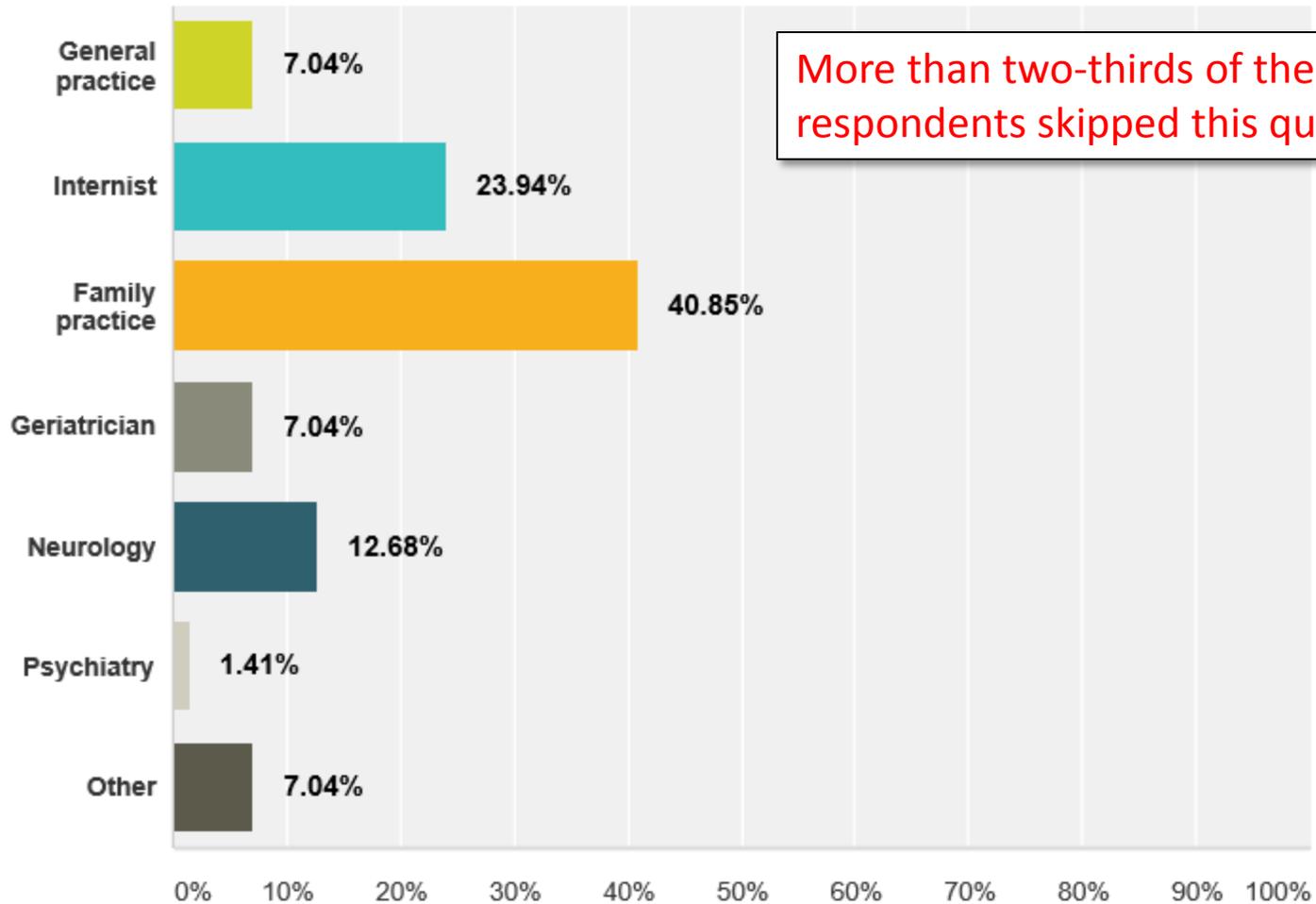


Other identified professions included Naturopath, Neuropsychologist, Social worker, Physical therapist, Dietician, etc.



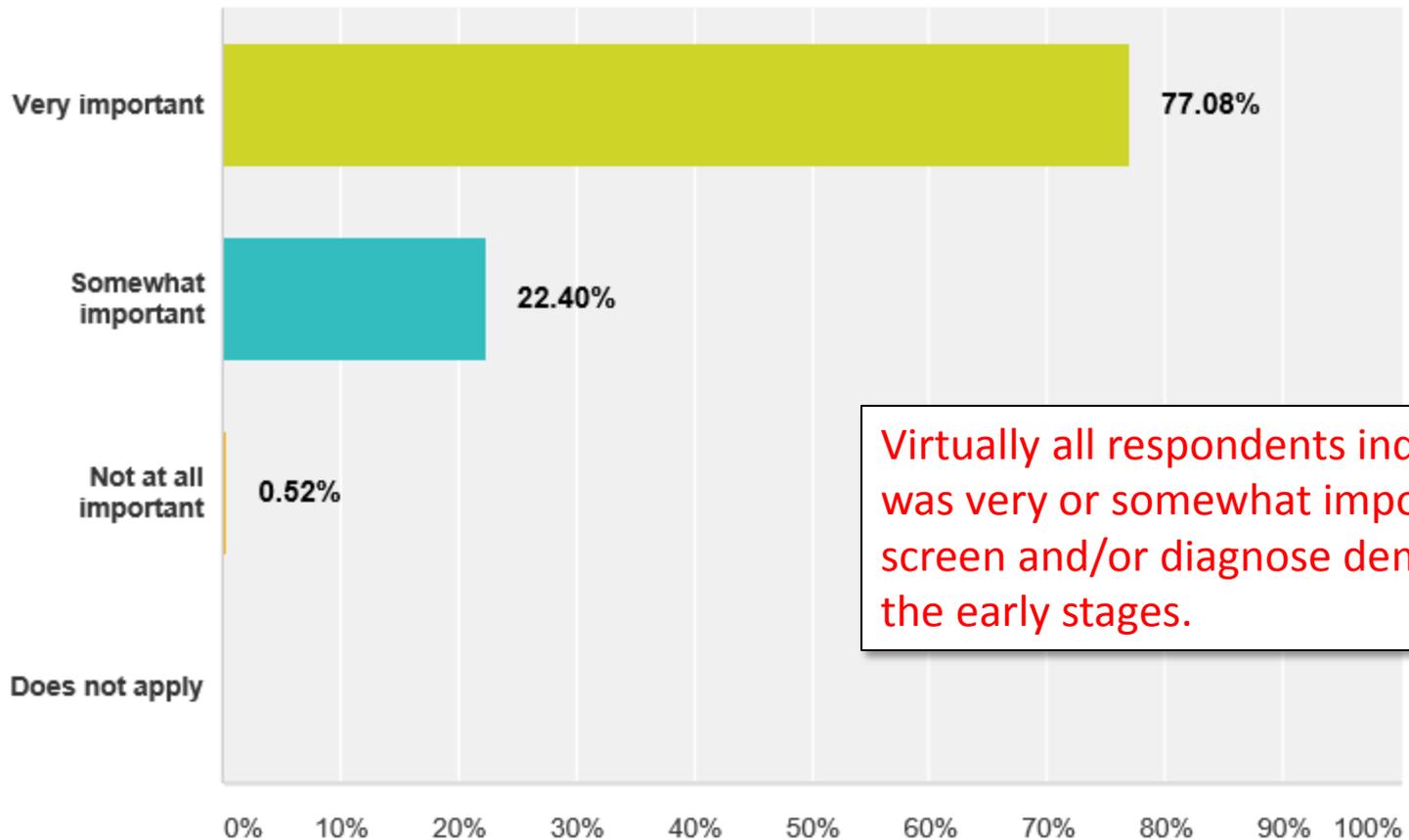
What is your primary specialty?

Answered: 71 Skipped: 176



How important do you feel it is to screen and/or diagnose dementia in the early stages?

Answered: 192 Skipped: 55

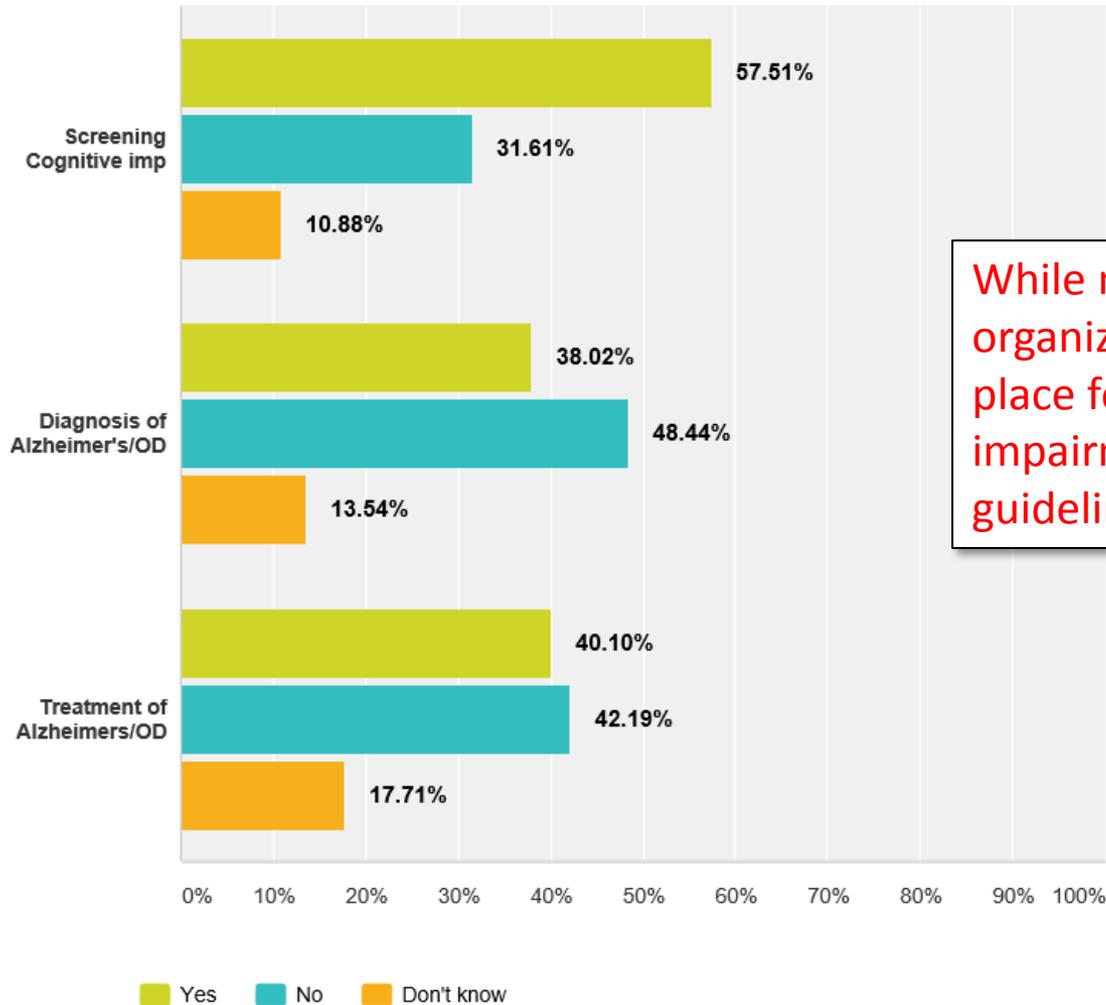


Virtually all respondents indicated it was very or somewhat important to screen and/or diagnose dementia in the early stages.



Does your practice or organization have guidelines in place related to any of the following?

Answered: 194 Skipped: 53

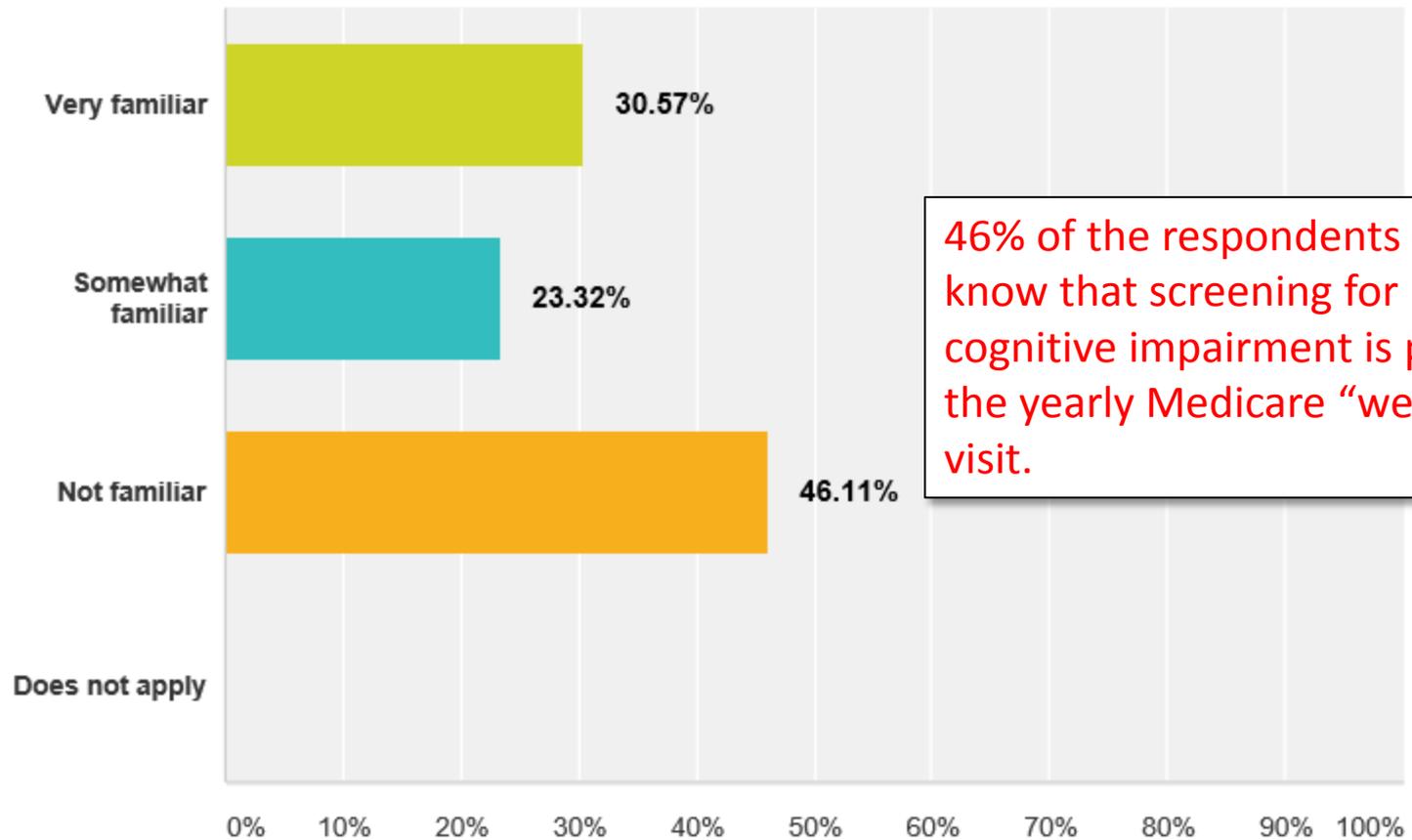


While nearly 60% of respondent's organizations have guidelines in place for screening of cognitive impairments, less than 40% have guidelines for diagnosis.



Are you familiar with the Medicare Wellness Visit benefit that includes assessment of cognitive impairment?

Answered: 193 Skipped: 54

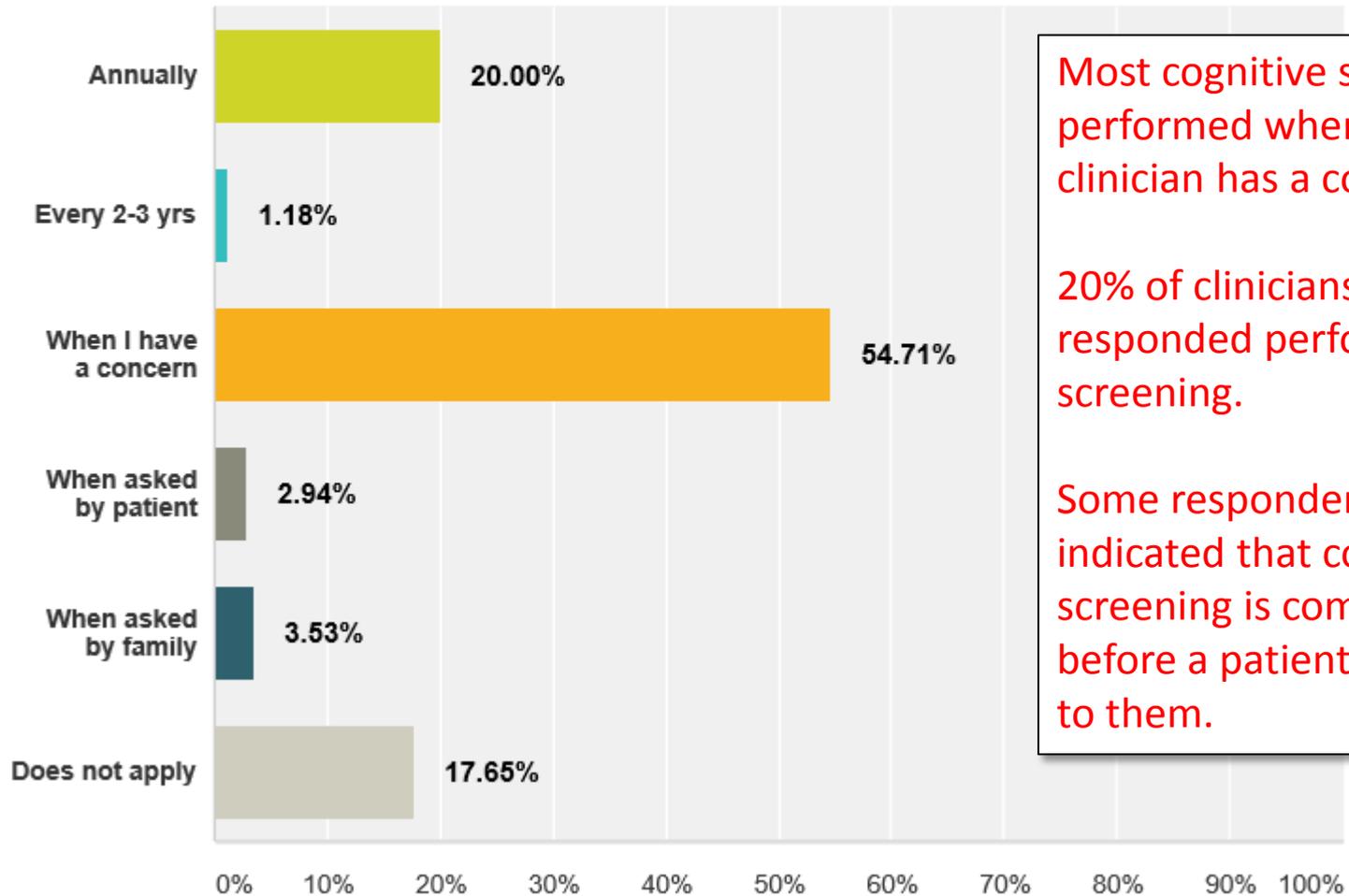


46% of the respondents did not know that screening for cognitive impairment is part of the yearly Medicare “wellness” visit.



In your practice, when do you conduct cognitive screening with older adult patients? (Select ONE response)

Answered: 170 Skipped: 77



Most cognitive screening is performed when the clinician has a concern.

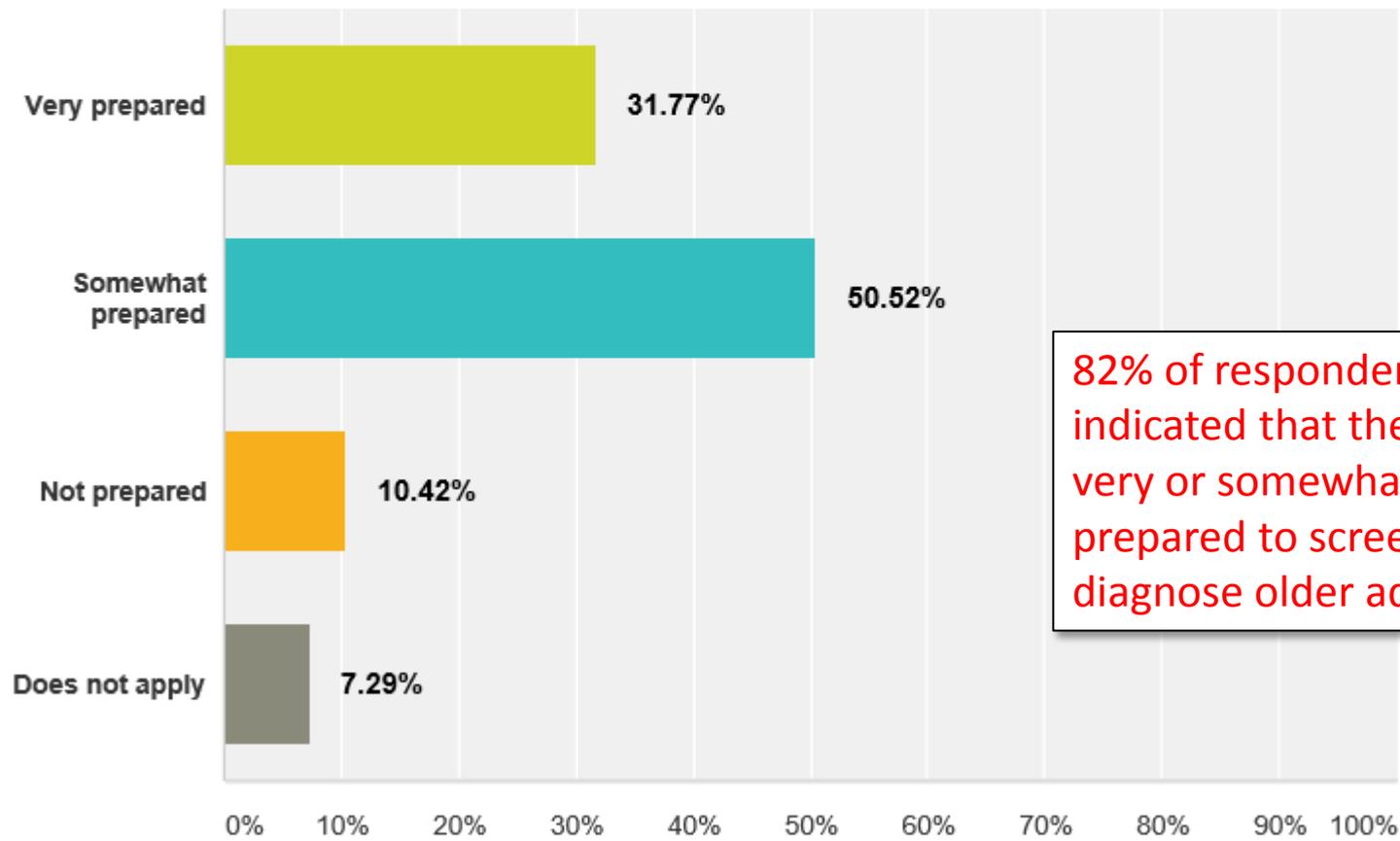
20% of clinicians who responded perform annual screening.

Some respondents indicated that cognitive screening is completed before a patient is referred to them.



The presentation of cognitive impairment can be difficult to assess/diagnose. How prepared do you feel you are to screen and diagnose older adults (60+)?

Answered: 192 Skipped: 55

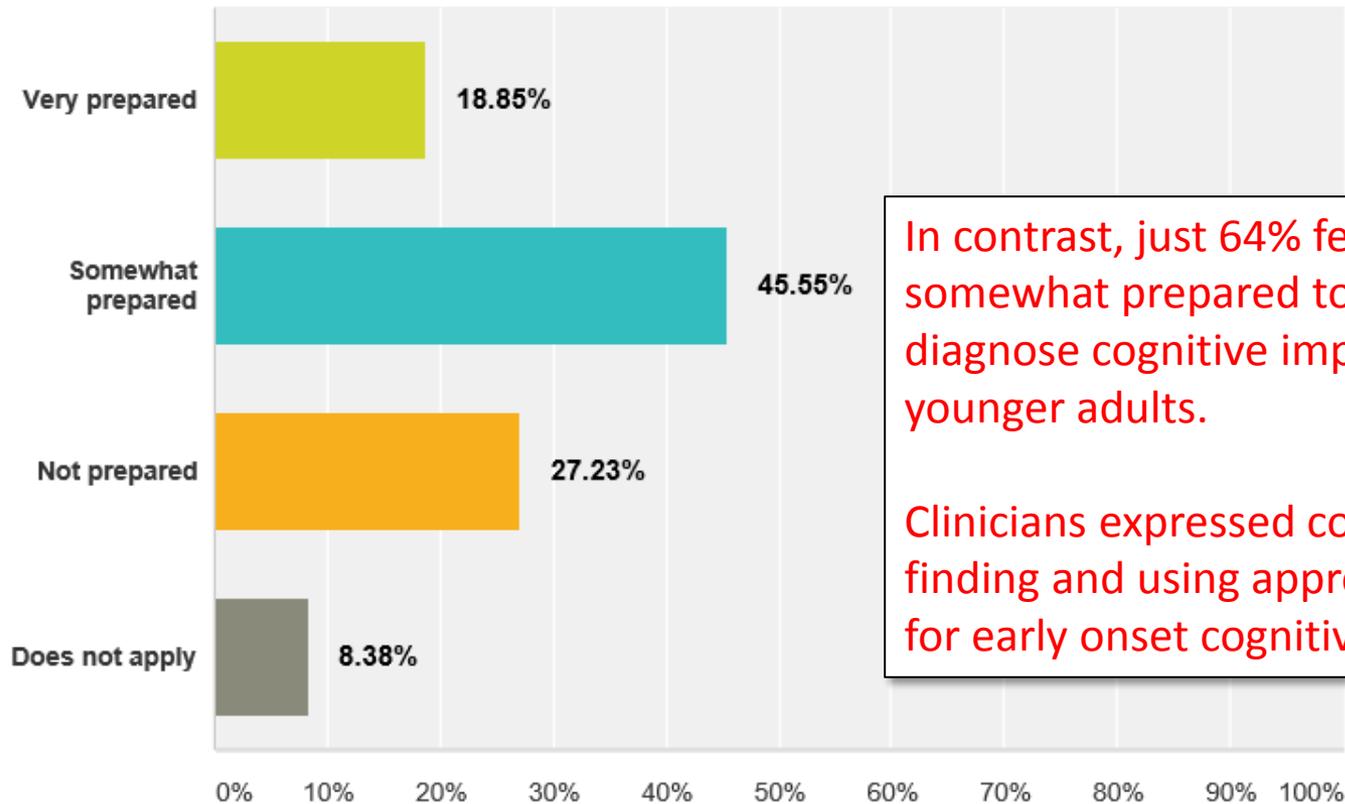


82% of respondents indicated that they were very or somewhat prepared to screen and diagnose older adults.



The presentation of cognitive impairment in younger adults (under the age of 60) can be even more difficult to assess/diagnose due to its lower frequency. How prepared do you feel you are to screen and diagnose such younger individuals?

Answered: 191 Skipped: 56



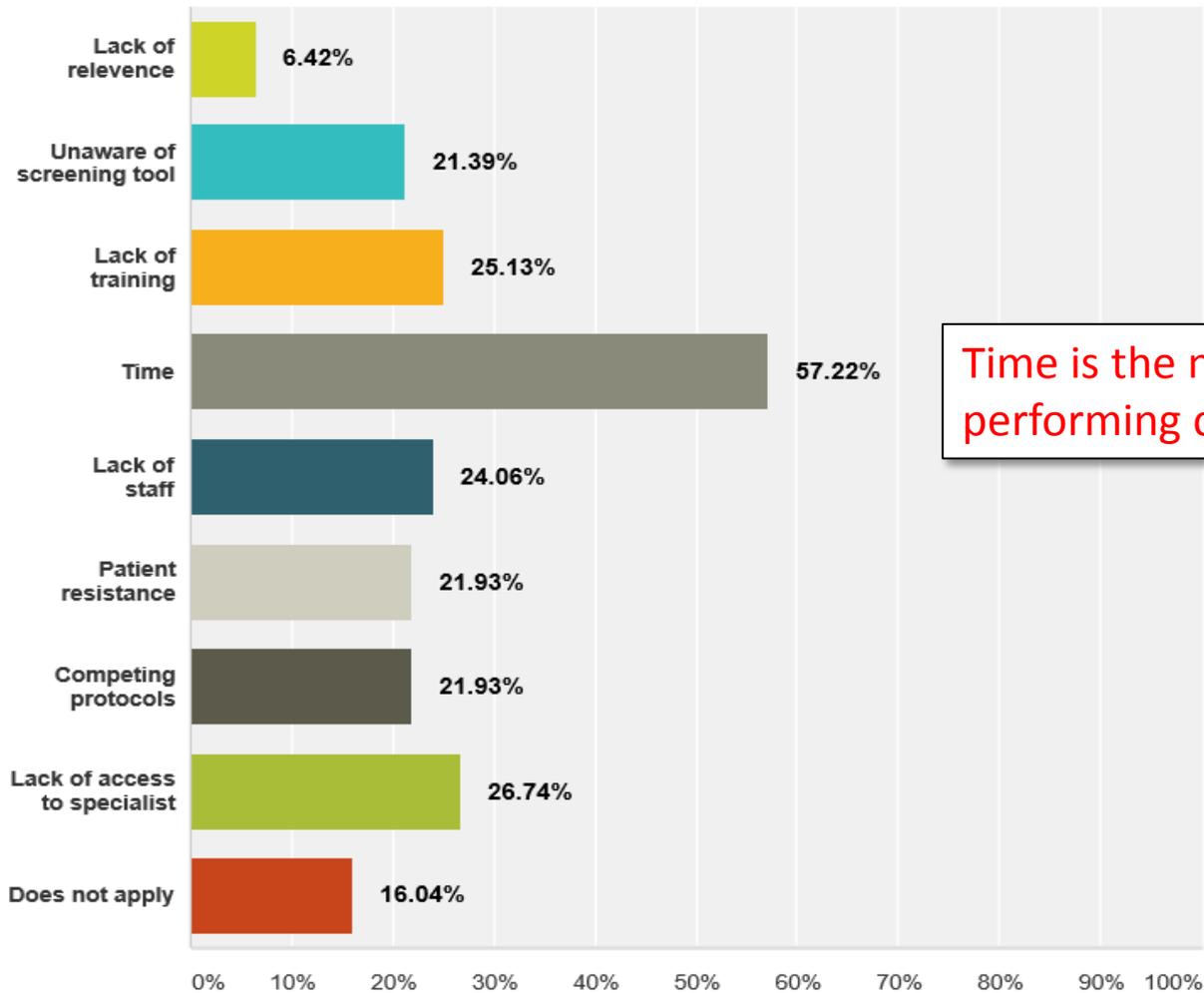
In contrast, just 64% feel very or somewhat prepared to assess and diagnose cognitive impairment in younger adults.

Clinicians expressed concern about finding and using appropriate tools for early onset cognitive impairment.



What are challenges or barriers in performing cognitive screening in your practice? (Choose your top THREE)

Answered: 187 Skipped: 60

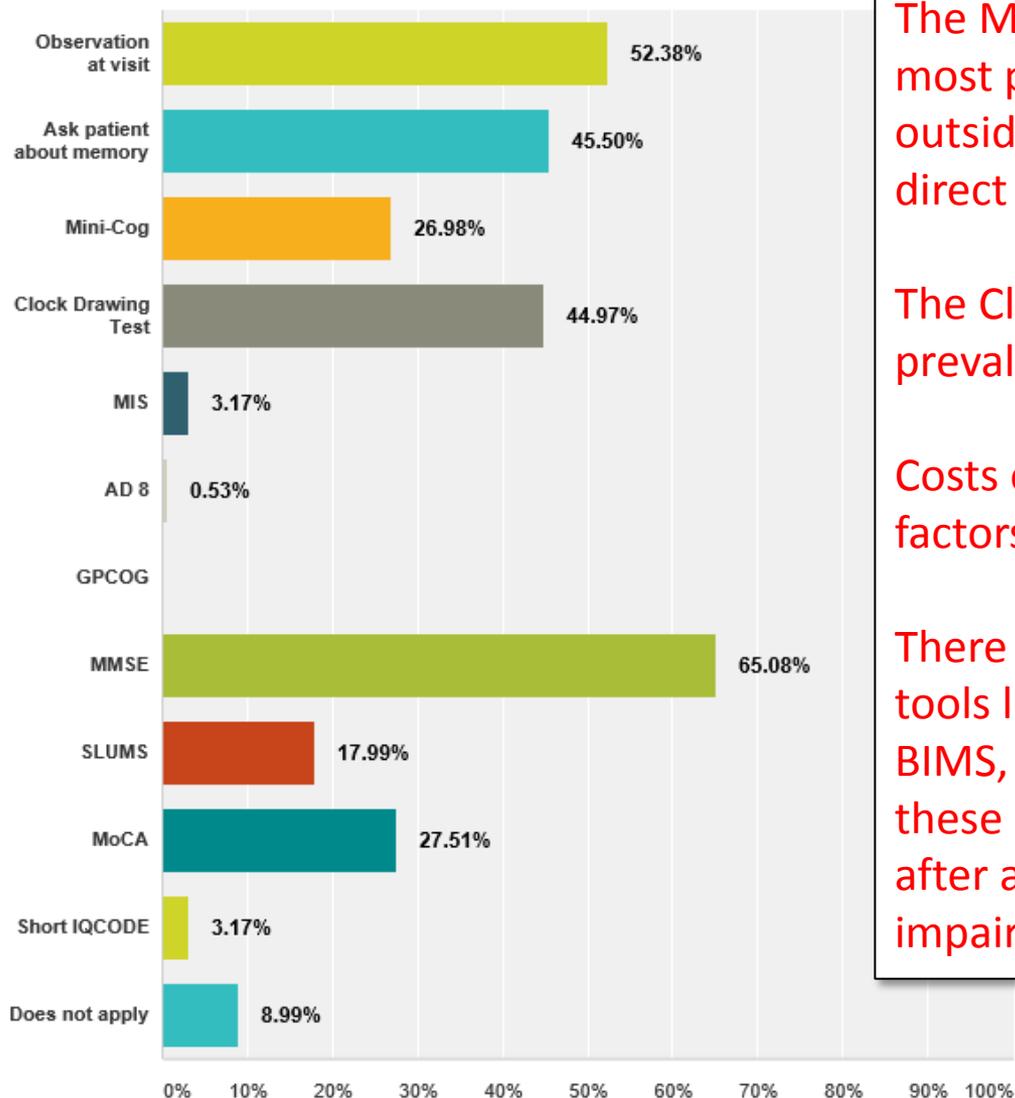


Time is the number one barrier to performing cognitive screening.



What screening tool(s) do you use to perform a cognitive screening? (Choose all that apply)

Answered: 189 Skipped: 58



The Mini Mental Status Exam is the most prevalent assessment tool outside of general observation and direct conversation with the patient.

The Clock Drawing Test is also prevalent.

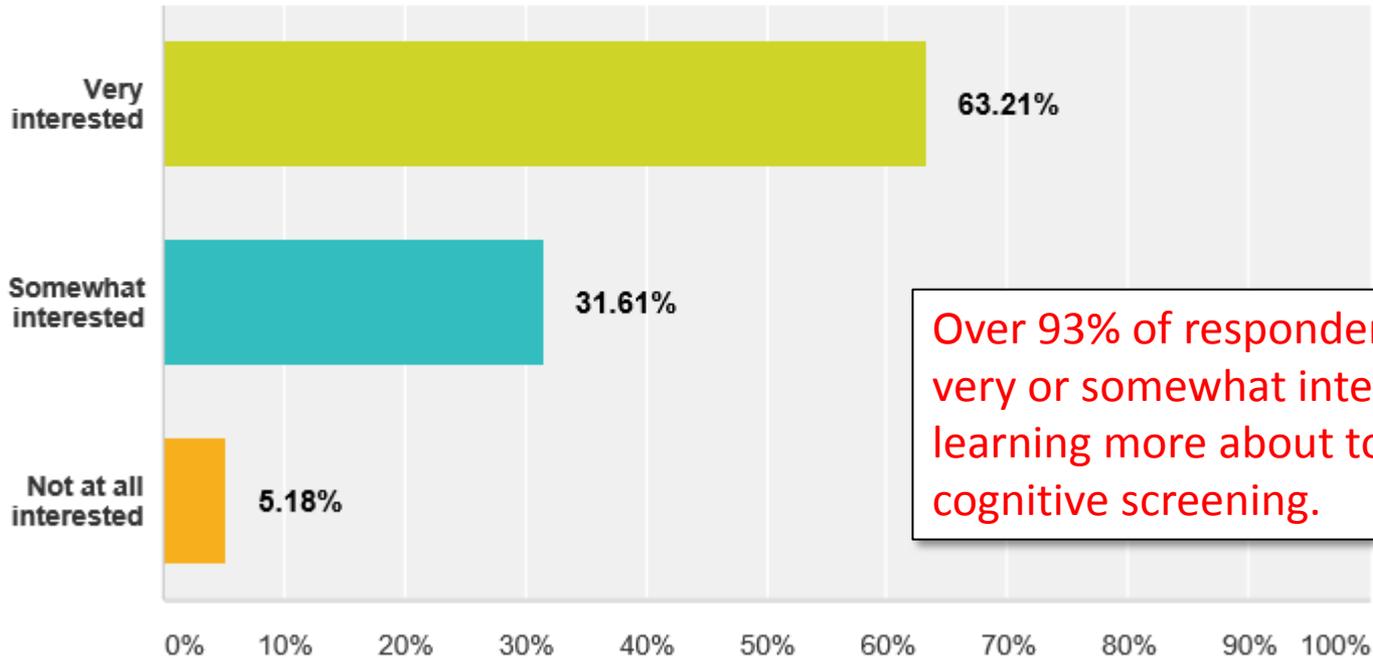
Costs of using the assessment tools factors into the choices.

There were many other assessment tools listed in the comments, like BIMS, SAGE, and others. Some of these are used to assist with diagnosis after a referral for suspected cognitive impairment.



How interested would you be in learning more about tools for cognitive screening?

Answered: 193 Skipped: 54

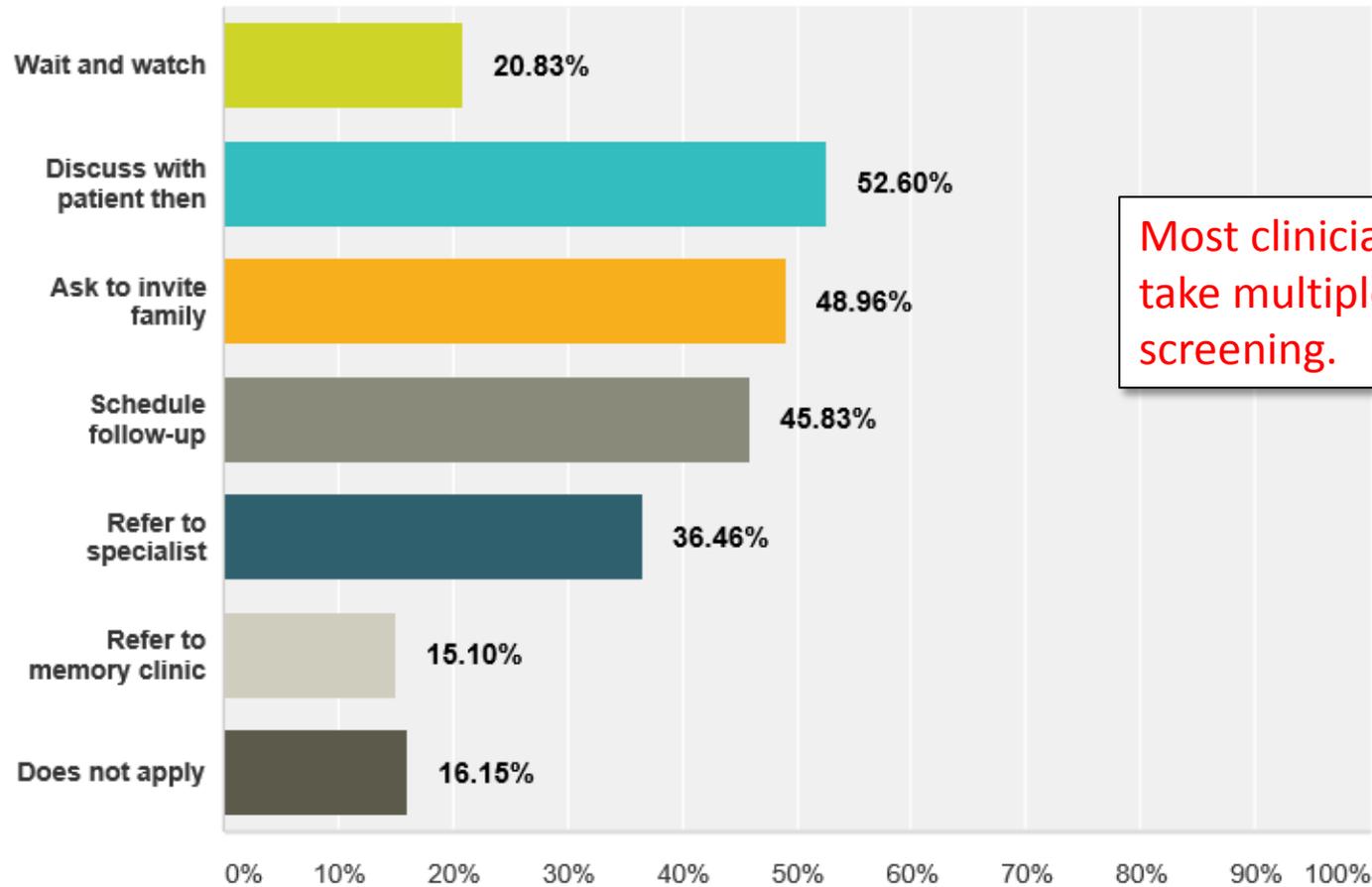


Over 93% of respondents were very or somewhat interested in learning more about tools for cognitive screening.



When a patient exhibits cognitive impairment during a SCREENING, which of the following options do you typically take? (Choose all that apply)

Answered: 192 Skipped: 55

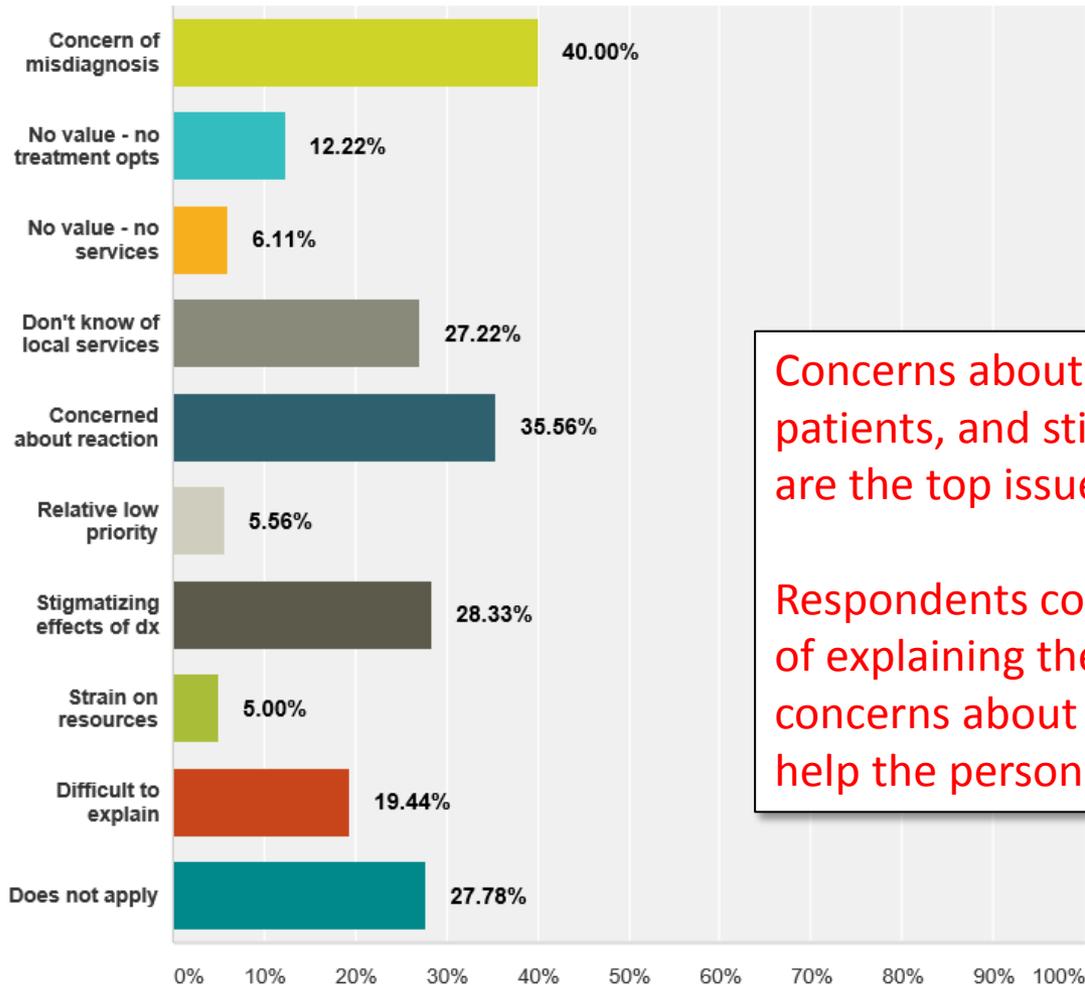


Most clinicians typically take multiple steps after screening.



What are your main concerns about making and disclosing a diagnosis of Alzheimer's or other dementia? (Choose your top THREE concerns)

Answered: 180 Skipped: 67



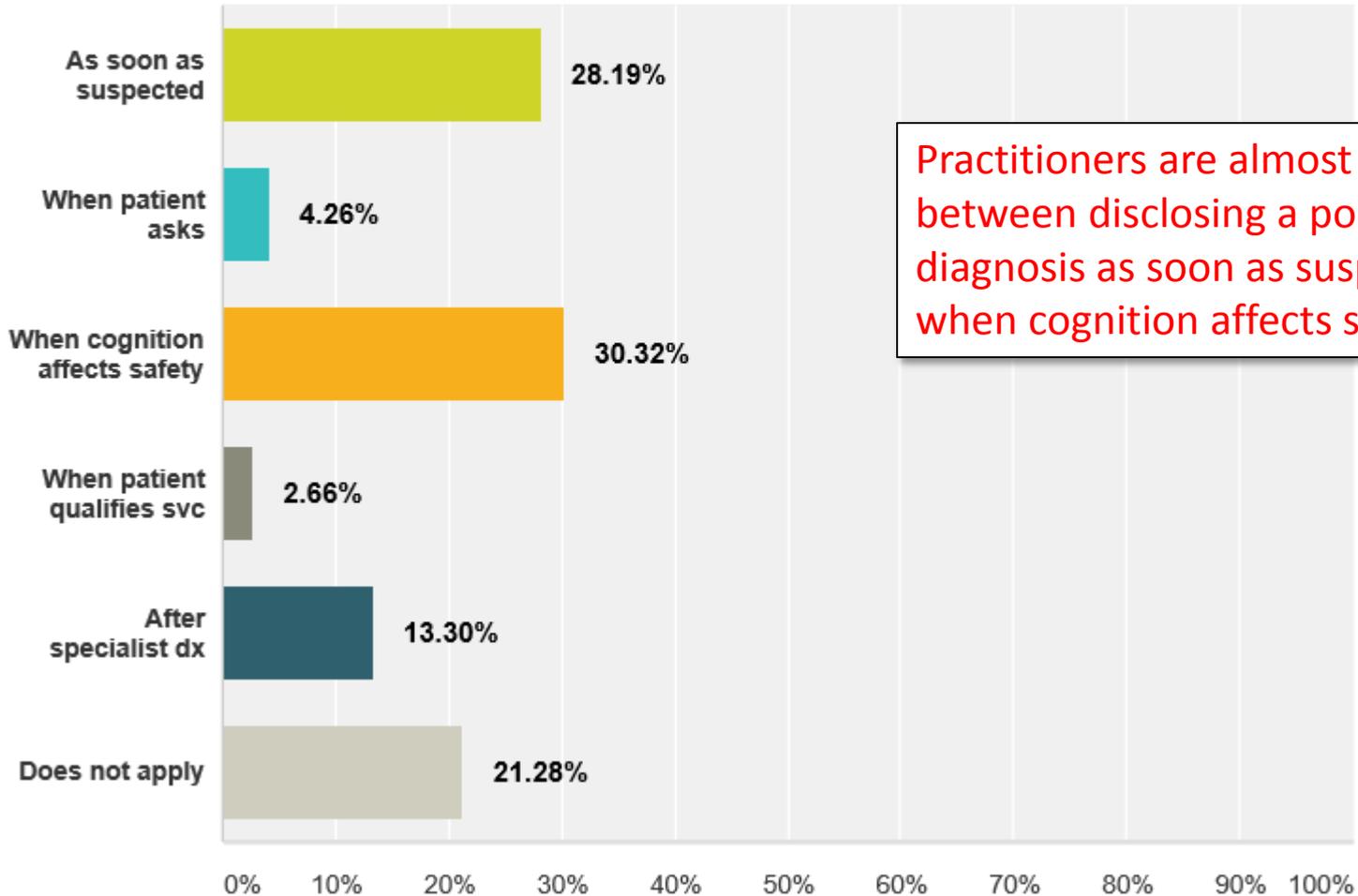
Concerns about misdiagnosis, reactions from patients, and stigmatizing effects of diagnosis are the top issues selected by respondents.

Respondents commented on the complexity of explaining the diagnosis and expressed concerns about the lack of local resources to help the person.



At what point does disclosure of a possible or probable diagnosis of Alzheimer's or dementia typically occur in your practice?

Answered: 188 Skipped: 59

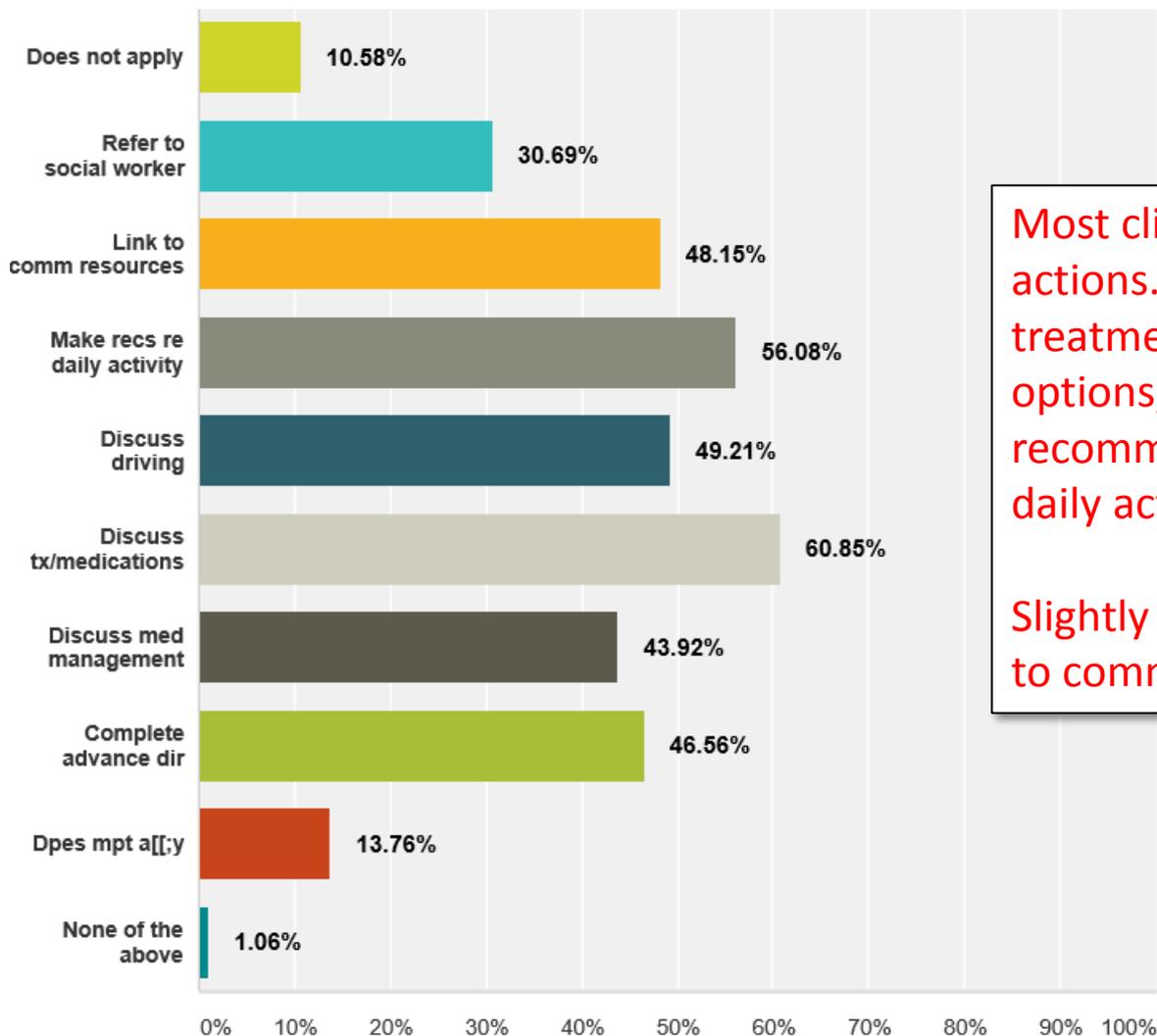


Practitioners are almost evenly split between disclosing a possible diagnosis as soon as suspected and when cognition affects safety.



Following a DIAGNOSIS of Alzheimer's or dementia, which of the following actions do you typically take? (Choose all that apply)

Answered: 189 Skipped: 58



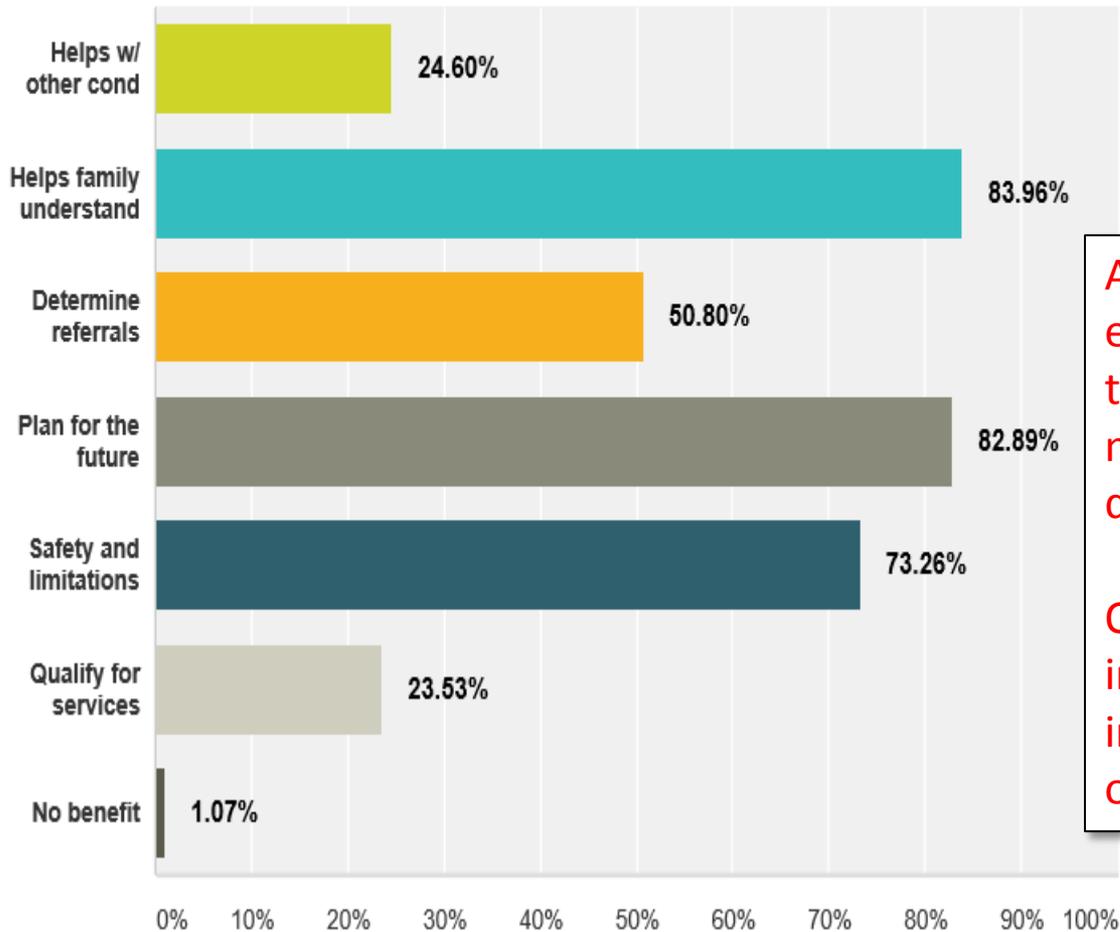
Most clinicians perform multiple actions. Over half discuss treatment and medication options, and make recommendations regarding daily activity.

Slightly under half provide links to community resources.



What do you see as the main benefits of providing a medical diagnosis? (Choose up to THREE)

Answered: 187 Skipped: 60



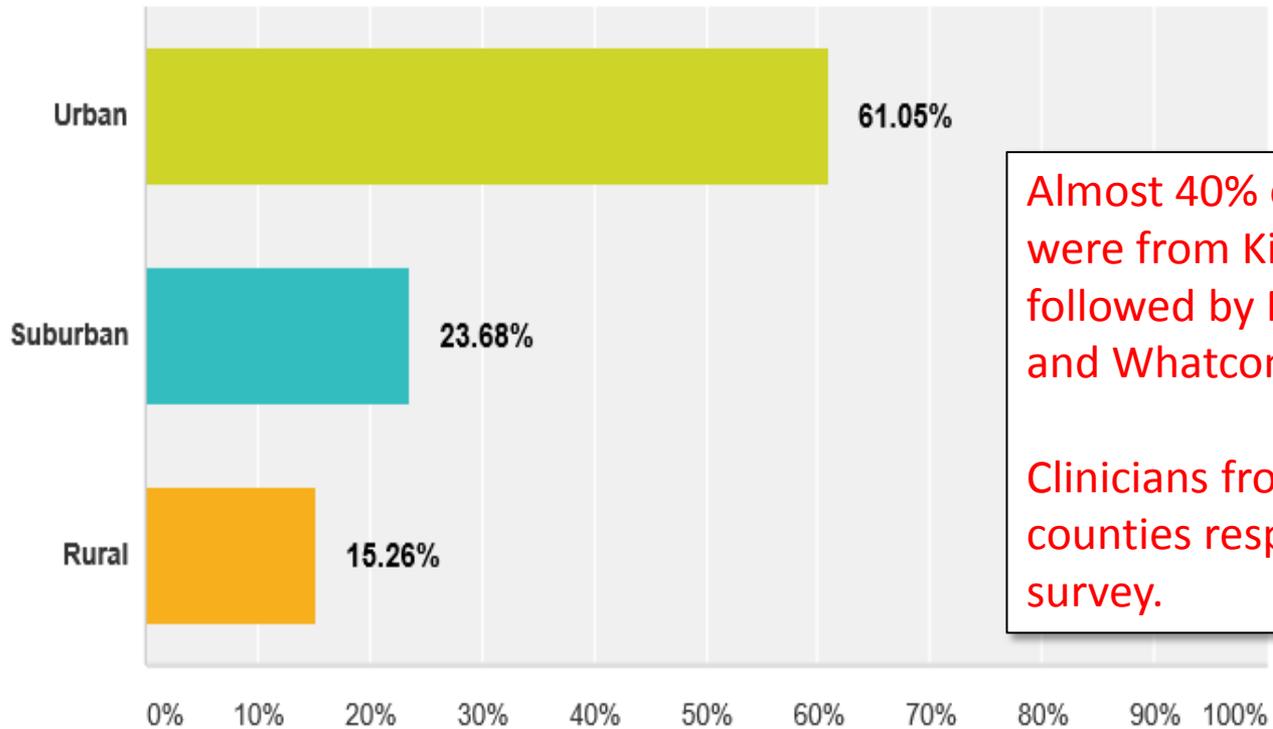
A few respondents expressed that they see all the response options as main benefits of a diagnosis.

Only 25% recognize the importance of how it may impact management of other conditions.



What best describes the area where you practice?

Answered: 190 Skipped: 57



Almost 40% of respondents were from King County, followed by Pierce (12%), and Whatcom (11%).

Clinicians from 22 out of 39 counties responded to the survey.



Break



Advance Planning and Legal Supports

Christopher Henderson, JD



Advance Planning – Table Discussions

The reality is that many people don't engage in advance planning. What ideas does the group have to improve this situation?

Be prepared to report out to the larger group.

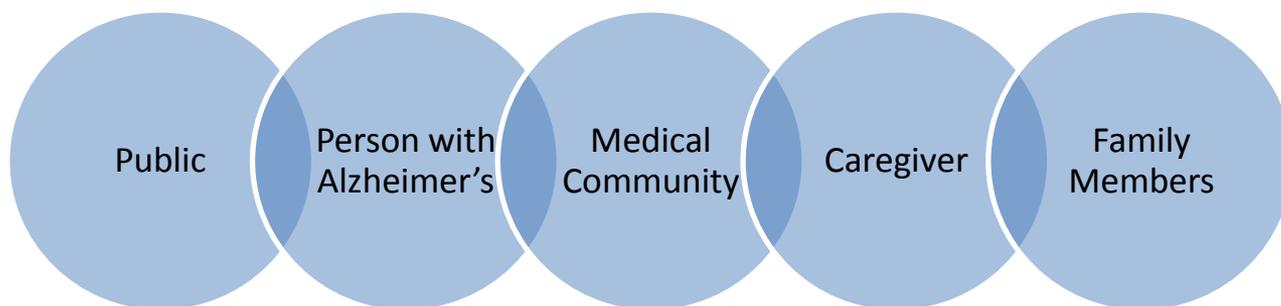


Public Comment Period



Individual Exercise

What is the one thing you wish people knew about early stage Alzheimer's?



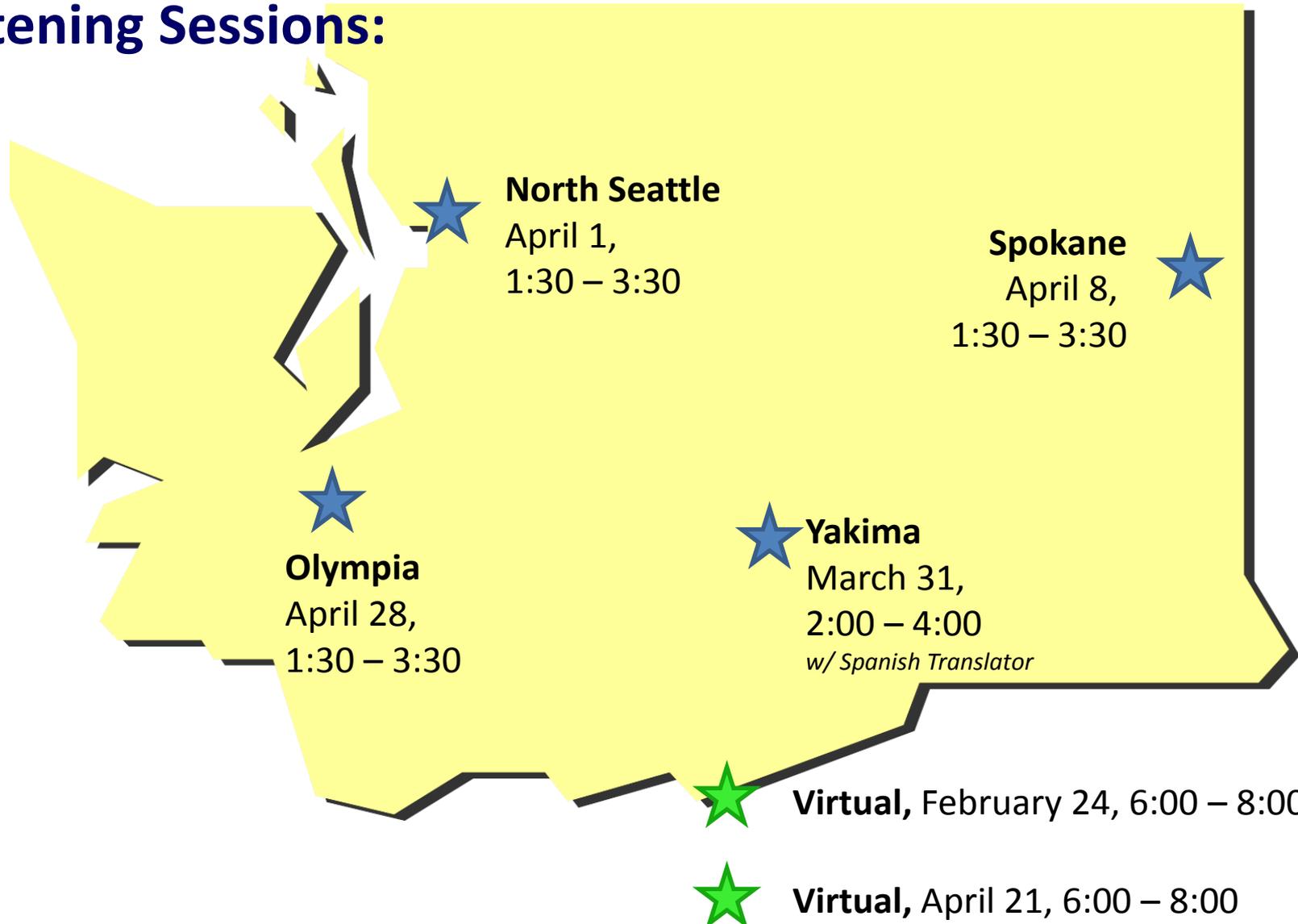
*I wish that all caregivers knew
that people with early stage Alzheimer's still can make many decisions.*



Wrap-Up



Listening Sessions:



Staff Support

**Lynne Korte, Program Manager
Alzheimer's Disease Working Group
(360) 725-2545
Lynne.Korte@dshs.wa.gov**



Action Items

- **Next ADWG Meeting:**
 - **Wednesday, March 4th, 2015**
 - **10:00 am - 3:15 pm**
 - **AL TSA, Lacey**



Thank you



Session Evaluation

Session Evaluation Form

1
★

2
★★

3
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4
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Content	Process
Outcomes	Facilities

Comments:

Are there other topics you would like to hear about?

