



2021 AARP SURVEY ON THE PERCEPTIONS RELATED TO A DEMENTIA DIAGNOSIS: ATTITUDES AMONG HEALTHCARE PROVIDERS

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KEY FINDINGS

Key Findings

According to healthcare providers (HCPs), **patients want to know if they are at higher risk for or already have dementia** (87% and 92%, respectively). Yet, fewer say patients want baseline readings (74%) and regular screenings (61%) to assess whether or not they have developed dementia.

Most (82%) **disagree that there is “no benefit” to diagnosing cognitive impairment in the early stages.**

HCPs leverage a range of processes to diagnose dementia, with **cognitive assessments** and **eliminating underlying conditions** to be most useful (90% and 91%, respectively, among those who use them). Overall, to diagnose dementia, more than nine in 10 (93%) use cognitive assessments and nearly nine in 10 (88%) eliminate underlying conditions.

Those specializing in **Neurology** (82%) and **Geriatrics** (79%) are significantly more likely than HCPs overall (63%) to be **extremely/very confident that their dementia diagnoses are definitive.**



Key Findings (Cont.)

HCPs acknowledge serious concerns among patients diagnosed with dementia, from a **loss of independence** (e.g., losing one's driver's license, 89%), to **suffering** (e.g., an emotional toll on one's family, 85%), to **financial concerns** (e.g., not being able to get long-term care insurance, 75%).

They are also aware of the **stigma** that is associated with this condition, believing that patients would be **ashamed** of the diagnosis and fear being seen as **incompetent** (each 69%).

Nearly eight in 10 (78%) agree that “**no matter how difficult it is for someone to hear they have dementia, I always tell them the truth.**” This suggests that a fraction of HCPs do not always tell their patients the truth.

There is consensus that a lot can be done for patients – even without a drug available to treat the underlying cause of dementia. **Getting regular exercise** (92%), **engaging in cognitively stimulating activities** (91%), and **engaging socially with others** (89%) are seen as most helpful.





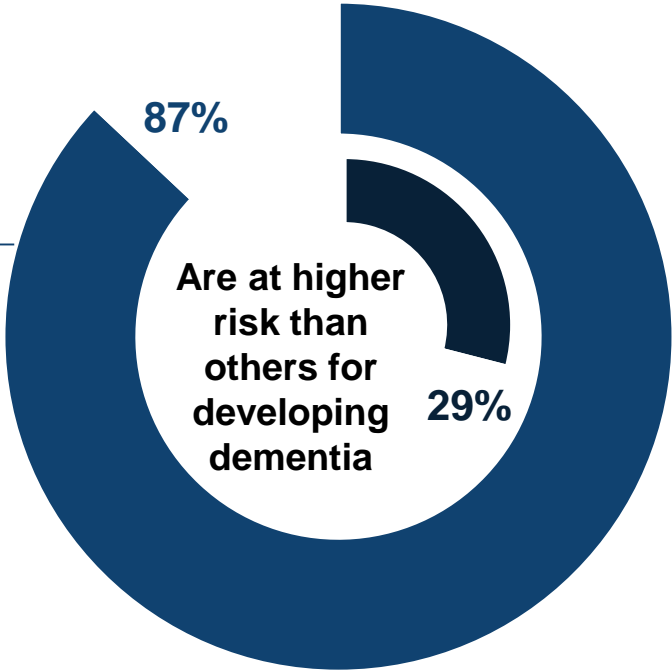
SCREENING FOR DEMENTIA

Healthcare providers (HCPs) say patients want to know their risk for dementia, or if they already have it...

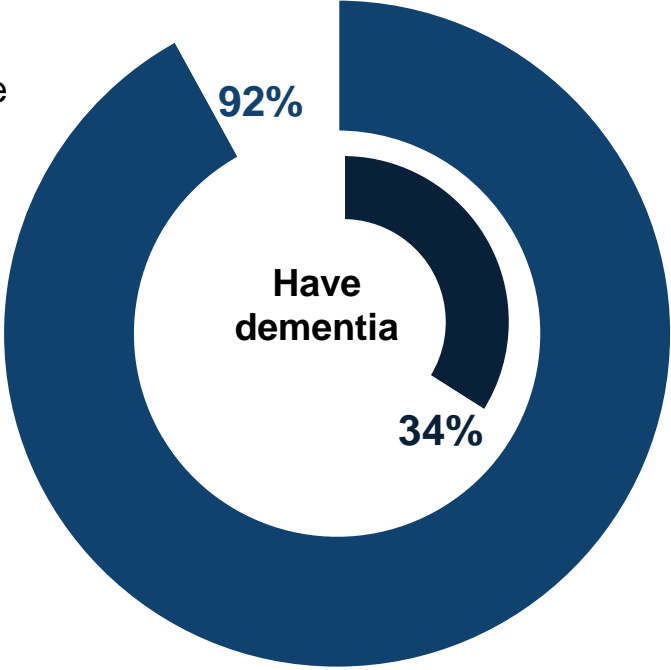
Roughly nine in 10 (87%) HCPs agree with each of these statements, with three in 10 or more *strongly* agreeing.

My patients want to know if they...

Neurologists are above-average on having this view; virtually all (96%) agree



■ Agree/Strongly agree
■ Strongly agree

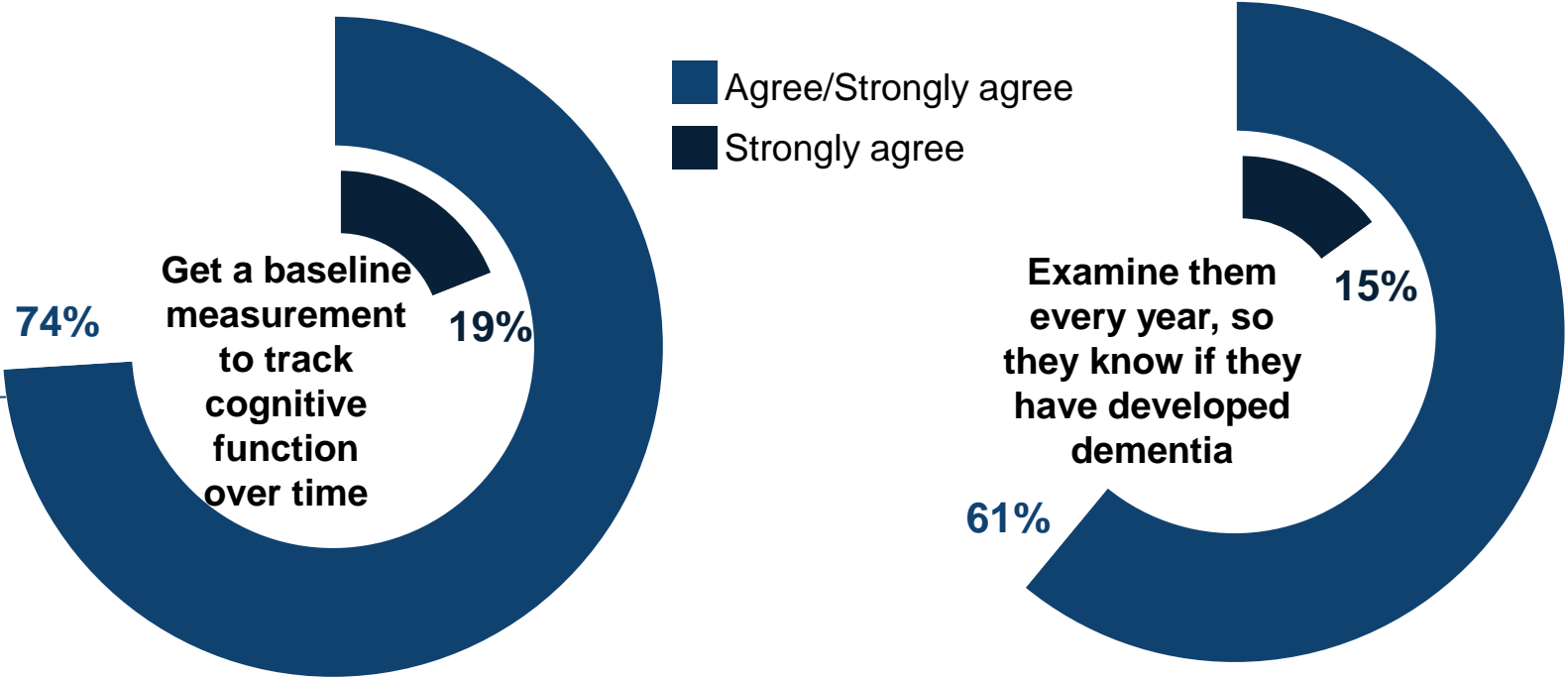


Qs 1-2. For the following series of questions, please indicate whether you agree or disagree with each statement. Base: Total HCPs n=500; Neurologists n=84

Most HCPs believe their patients want a baseline measurement of their cognitive function and an annual dementia screening

Three-quarters (74%) believe patients want a baseline measurement of cognitive function, while fewer – six in 10 (61%) – say the same about annual exams. Compared to annual dementia screenings, a majority of HCPs also believe their patients would like an annual screening for cancer.

My patients want me to...



HCPs specializing in **Geriatrics** are above-average on having this view (94% agree)

A majority of HCPs also feel their patients want to be examined yearly for cancer.

My patients want me to examine them every year so they know if they have developed cancer:

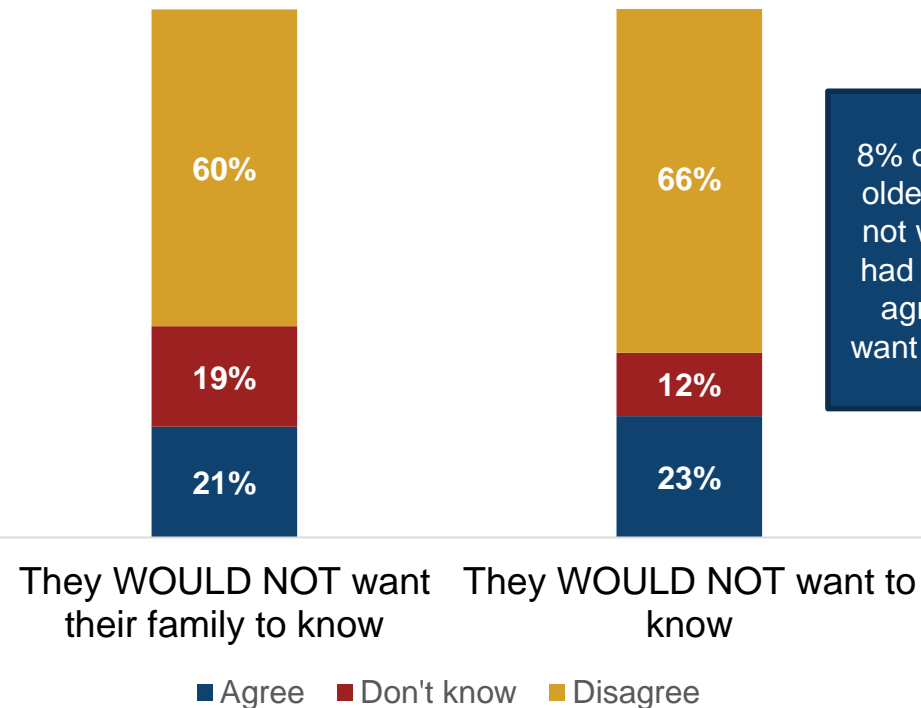
- 56% -- Agree
- 9% -- Don't know
- 24% -- Disagree
- 11% -- Not applicable

Qs 3-5. For the following series of questions, please indicate whether you agree or disagree with each statement. Base: Total HCPs n=500; Geriatrics n=48

Relatively few HCPs believe patients would want their diagnosis to remain secret

Only about one in five HCPs think that their patients would not want their family to know if they had dementia (21%) and would not want to know themselves (23%). However, significantly fewer adults age 40 and older said they would not want to know if they had dementia (8%) and would not want their family to know (10%).

If my patient had dementia...



8% of adults age 40 and older* agree they would not want to know if they had dementia, and 10% agree they would not want their family to know.



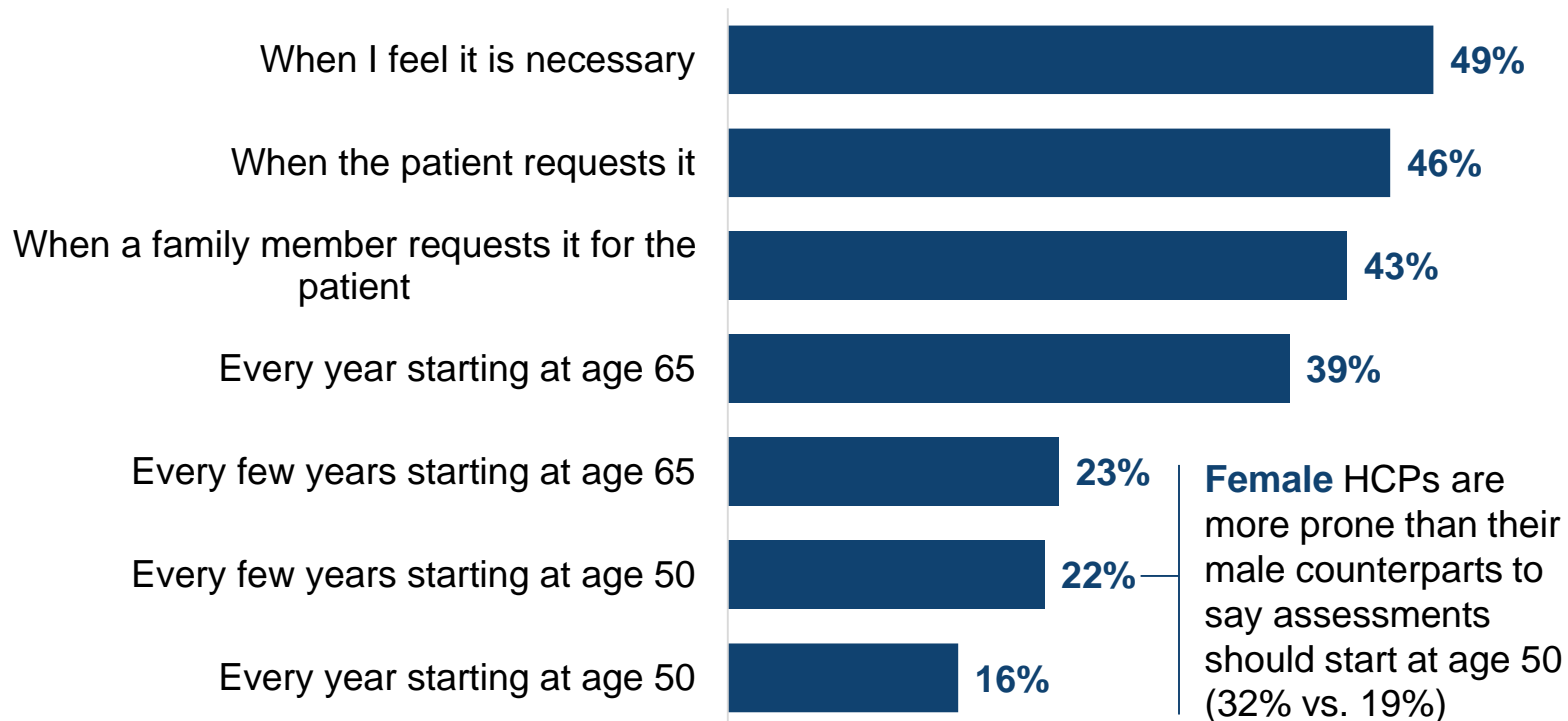
Qs 14-15. For the following series of questions, please indicate whether you agree or disagree with each statement. Base: Total HCPs n=500

*2021 AARP Survey on the Perceptions Related to a Dementia Diagnosis: Adults age 40-plus, <https://doi.org/10.26419/res.00471.001>

Most HCPs do not think their patient's cognitive function should be assessed yearly

Nearly half (49%) of HCPs say their patients should have their cognitive function assessed when the providers feels it is necessary and more than four in 10 HCPs say the assessment should occur when the patient (46%) or their family (43%) request it. Fewer than four in 10 feel a regular cognitive evaluation is indicated.

A patient's cognitive function should be assessed...



Q36. How often do you feel patients should have their cognitive function assessed? (check all that apply) Base: Total HCPs n=500, Female HCPs n=117, Male HCPs n=383

Most healthcare providers disagree that there is “no benefit” to early diagnosis of cognitive impairment

In fact, early screenings are seen to offer benefits to patients in terms of both treatment outcomes and preparation.

82%
Disagree

that “there is no benefit to diagnosing a cognitive impairment in the early stages”

Diagnosing dementia at an early stage...



61% **Neurologists** are more likely to hold this view (74%)

Qs 40, 8-13. For the following series of questions, please indicate whether you agree or disagree with each statement. Base: Total HCPs n=500; Neurologists n=84

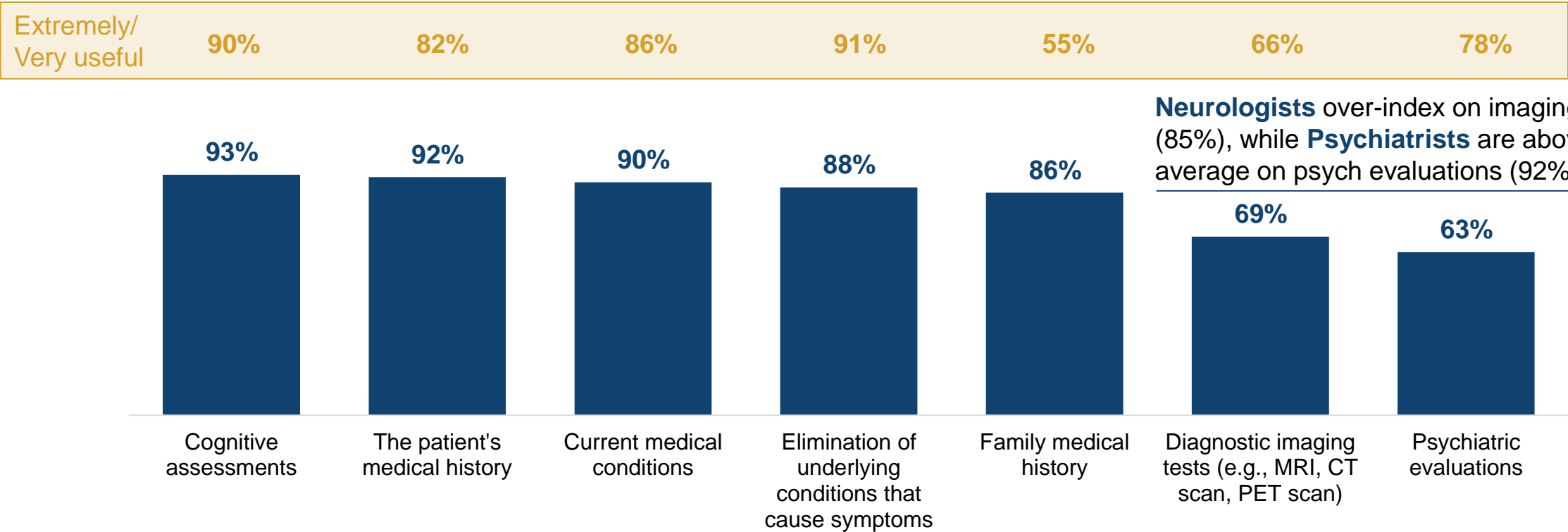


DIAGNOSING DEMENTIA

HCPs leverage a wide range of diagnostics to evaluate patients for dementia

HCPs who leverage these processes find cognitive assessments and eliminating underlying conditions to be most useful – each rated as very or extremely useful by nine in 10.

Diagnostic processes used when evaluating patients for dementia

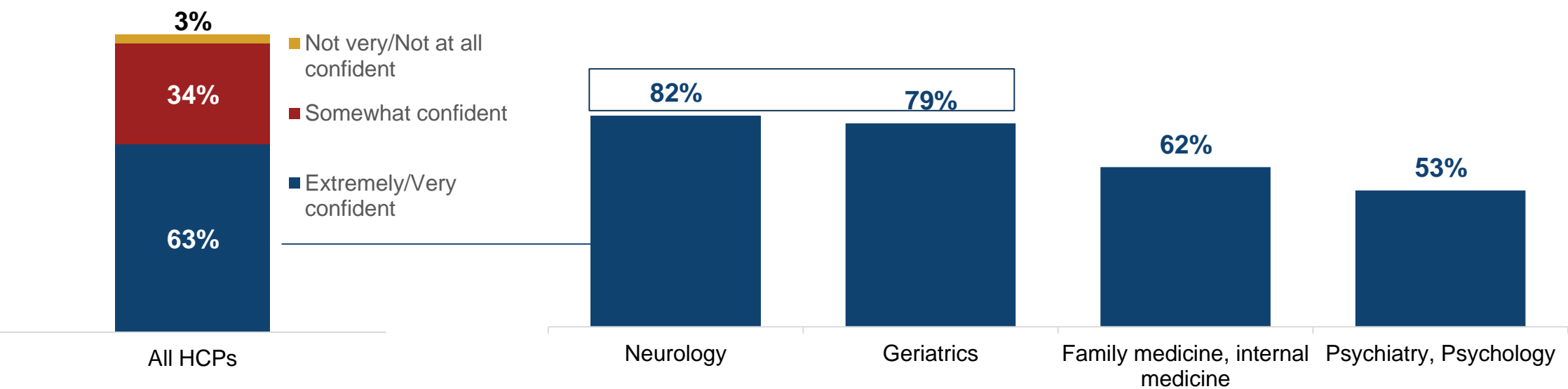


Q49. Which of the following diagnostic processes do you use when evaluating a patient for dementia? Base: Total HCPs n=500, Neurologists n=84, Psychiatrists/Psychologists n=115. Q50. In general, how useful are each of the following tools in evaluating a patient for dementia? Base: Those who use each diagnostic process, varies: Family medical history n=432, Their medical history n=460, Current medical conditions n=450, Elimination of any underlying conditions that are causing cognitive symptoms n=440, Cognitive assessments n=465, Psychiatric evaluations n=314, Diagnostic imaging tests n=344

Non-specialists are significantly less confident in their diagnosis

More than six in 10 (63%) HCPs are extremely or very confident that their dementia diagnosis is definitive. Those specializing in neurology and geriatrics are significantly more likely than HCPs overall to be extremely or very confident. This suggests that non-specialists may benefit from greater education on diagnosing their patients with dementia.

Level of confidence in dementia diagnoses



Q51. In general, after an evaluation suggests a dementia diagnosis, how confident are you that the diagnosis is definitive? Base: Total HCPs n=500, Family medicine n=296, Geriatrics n=48, Neurology n=84, Psychiatry n=115

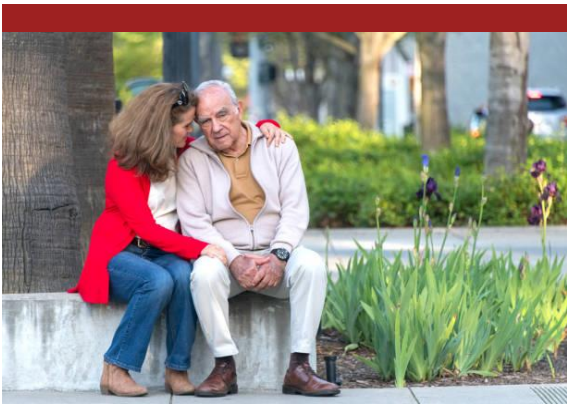
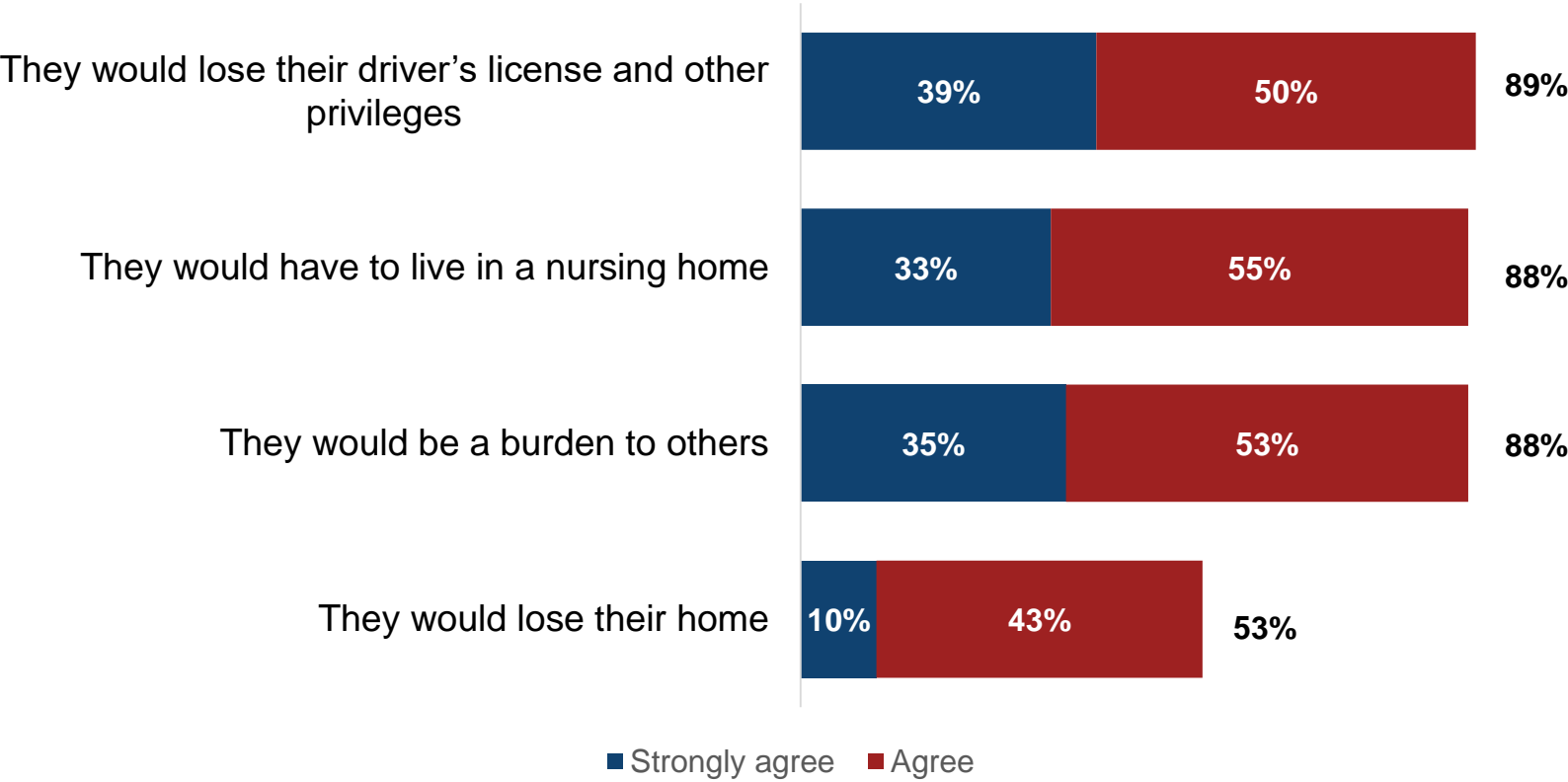


PATIENT IMPACT

HCPs believe if their patient had dementia they would be worried about a loss of independence...

A large majority of HCPs believe that patients fear they would lose their driver's license (89%), be a burden to others (89%), and have to move to a nursing home (88%). One-third or more strongly hold this view.

Strongly agree/agree that patients diagnosed with dementia fear...

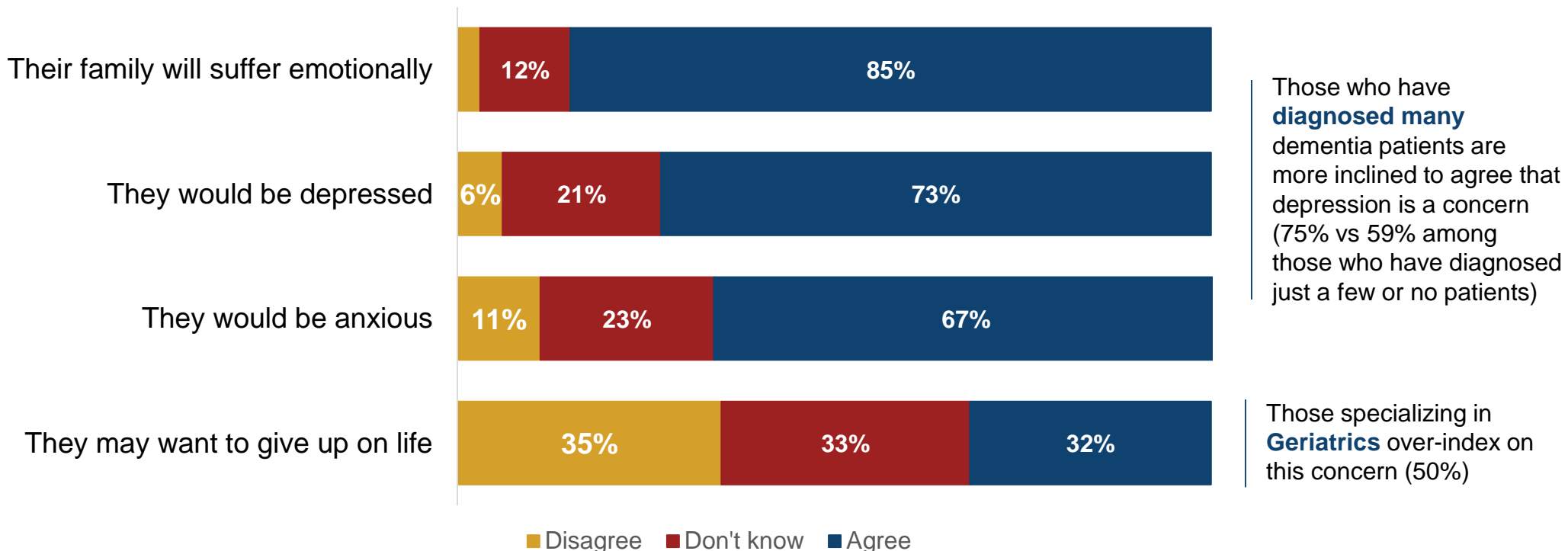


Qs 27-29, 35. For the following series of questions, please indicate whether you agree or disagree with each statement. Base: Total HCPs n=500

...as well as an emotional toll on themselves and family members

Notably, HCPs are divided on whether patients would want to give up on life: roughly one in three each agree (32%), are not sure (33%), and disagree (35%).

Patients diagnosed with dementia fear ...

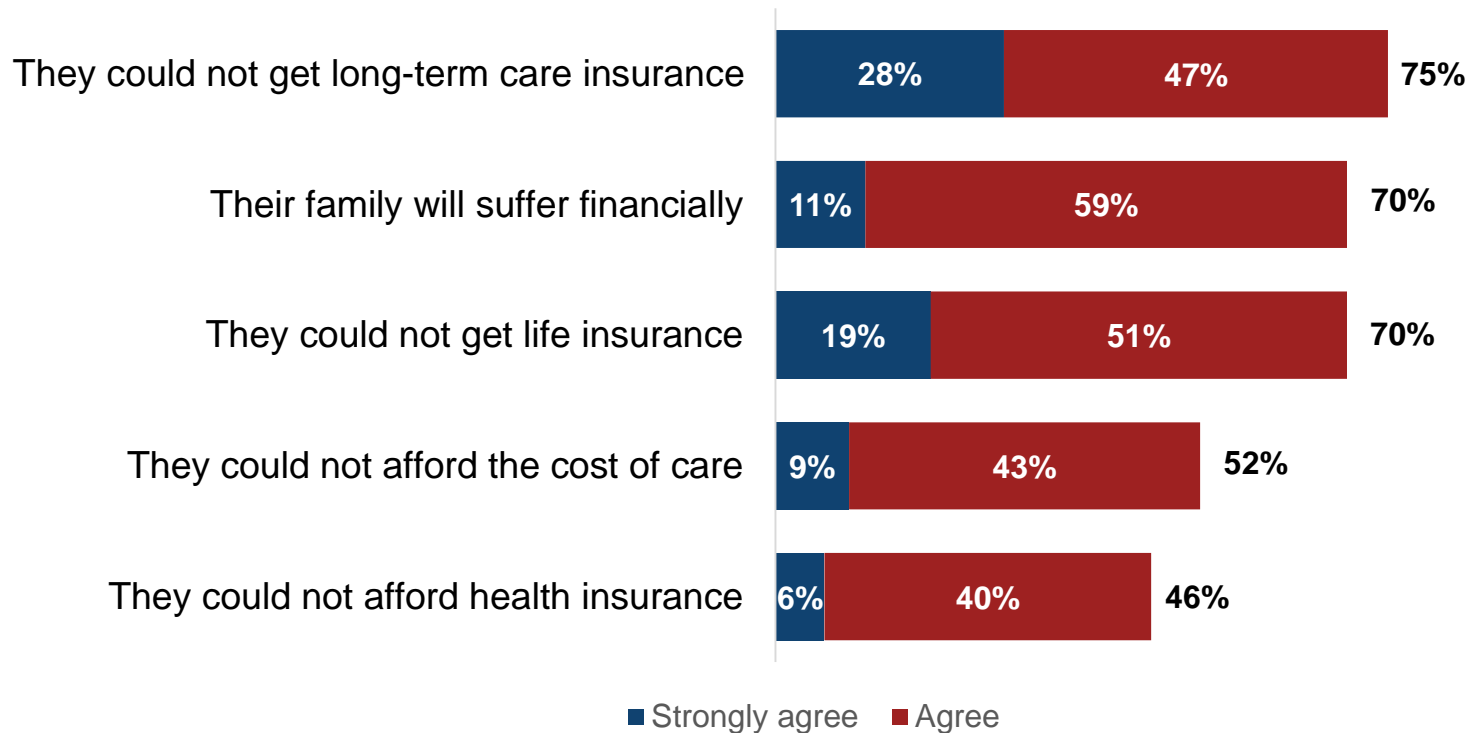


Qs 20, 32-34. For the following series of questions, please indicate whether you agree or disagree with each statement. Base: Total HCPs n=500, Diagnosed dementia just a few times or never n=63, Diagnosed dementia many times n=437, Specializing in Geriatrics n=48

Many also see dementia patients anticipating financial challenges

Three-quarters believe patients fear being unable to get long-term care insurance, with more than one in four (28%) *strongly* holding this view.

Strongly agree/agree that patients diagnosed with dementia fear ...

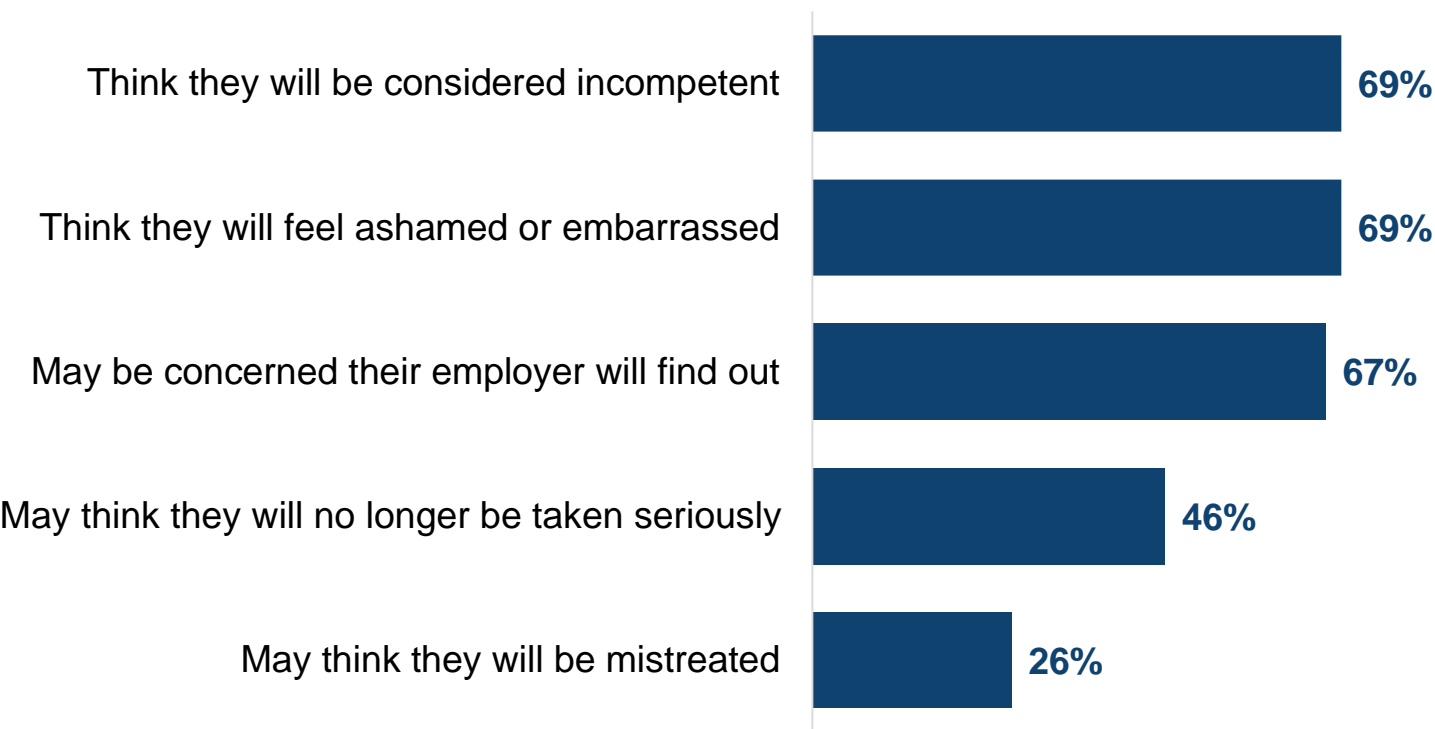


Qs 24-26, 30-31. For the following series of questions, please indicate whether you agree or disagree with each statement.
Base: Total HCPs n=500

Survey results point to a negative association with dementia

However, fewer HCPs feel that their patients will think they will not be listened to or not receive the best medical care from their doctor.

Agree that if their patient had dementia they...



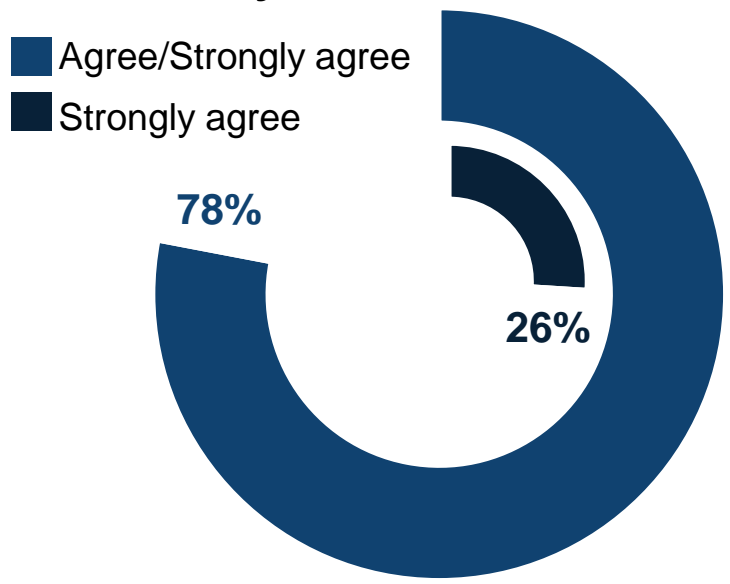
Fewer HCPs agree that their patients think they will:

- Not be listened to by HCPs (33%)
- Not receive the best care for other medical problems (28% overall and even lower among those specializing in Neurology, 14% agree)

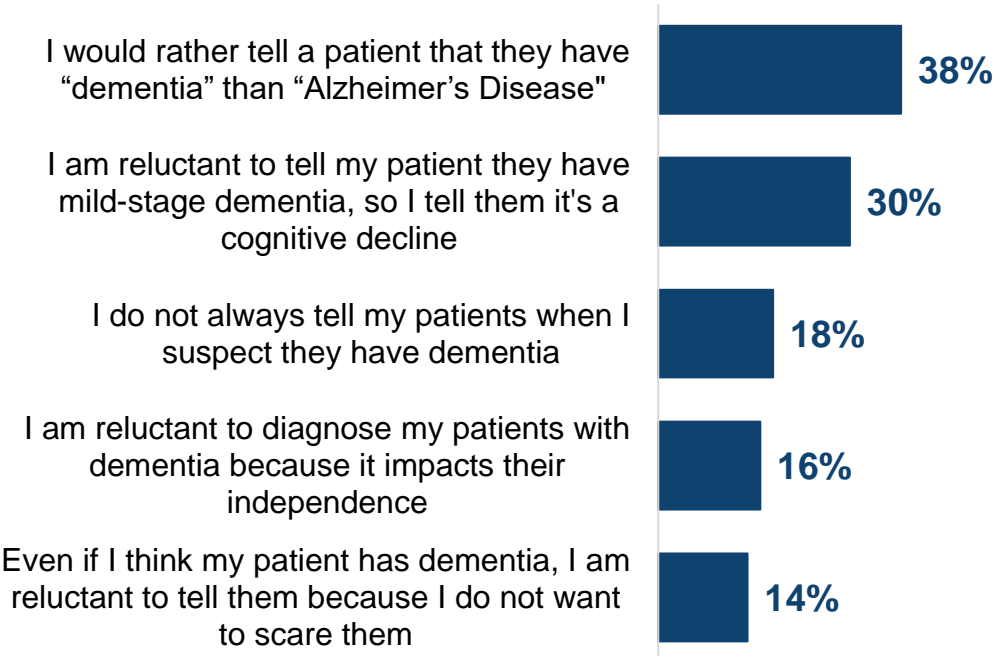
HCPs discomfort with dementia leads some to “sugar coat” the diagnosis

Nearly eight in 10 (78%) HCPs say they always tell patients the truth no matter how difficult it is for them to hear. However, nearly four in 10 (38%) would rather tell a patient they have dementia instead of Alzheimer’s disease and three in 10 would rather tell a patient they have a cognitive decline. The reluctance some HCPs feel when faced with telling a patient they have dementia potentially perpetuates the stigma associated with this diagnosis.

Agree that “no matter how difficult it is for someone to hear they have dementia, I always tell them the truth”



When considering a dementia diagnosis, *healthcare providers agree that ...*



Qs 41, 43-46, 48. For the following series of questions, please indicate whether you agree or disagree with each statement. Base: Total HCPs n=500



PATIENT INFO, SUPPORT, & TREATMENT

The American Academy of Neurology (AAN) diagnostic and treatment best practices

In 2018, the AAN published guidelines for healthcare providers in the diagnosis and treatment of their patients who may have a mild cognitive impairment (MCI). The authors noted that deficits in cognition should not be attributed to normal aging and in some cases MCI progresses to dementia. Below is a summary, in simplified terms, of those guidelines.

Healthcare providers:

- Should assess for MCI with validated tools.
- Should evaluate patients with MCI for modifiable risk factors and functional impairment.
- Should treat behavioral/neuropsychiatric symptoms.
- Should monitor their patients' cognition over time.
- Should discontinue medications that cause cognitive impairment where possible and treat behavioral symptoms.
- May choose not to offer cholinesterase inhibitors; if offering, they must first discuss the lack of evidence.
- Should recommend regular exercise.
- May recommend cognitive training.
- Should discuss diagnosis, prognosis, long-term planning, and the lack of effective medicine options.
- May discuss biomarker research with patients with MCI and families.

*Petersen, R. C., Lopez, O., Armstrong, M. J., Getchius, T. S. D., Ganuli, M., Gloss, D.,...Rae-Grant, A. (2018). Practice guideline update summary: cognitive impairment. *Neurology*, 90, 126-135. doi: 10.1212/WNL.0000000000004826

Disease progression and lifestyle changes are most often discussed with newly diagnosed dementia patients

Disease state: current & future

What to expect re disease progression	77%
The cause of their dementia if known	68%
The stage of dementia they are in	54%
What their likely prognosis is	53%
Life expectancy	24%

Disease treatment / management

Lifestyle changes that may slow disease progression	75%
Prescribe medication to relieve symptoms	74%

Additional expertise / testing

Evaluate for hearing loss	49%
Refer them to a memory disorders clinic	35%
Refer them to an HCP with more dementia experience	27%
Order a PET scan	12%
Enroll them in a clinical trial	10%
Order a lumbar puncture	4%

Information

Provide them with informational literature about dementia	56%
Refer them to online resources or informational websites	43%

Living with dementia: importance of...

Healthcare planning	69%
Financial planning	57%
Keeping appointments	46%

Social-emotional / local support


Refer the family to counseling	29%
Refer the individual with the diagnosis to counseling	25%
Refer them to community resources	5%


Q38 Which of the following actions do you take after you have diagnosed someone with dementia?


Q52. In general, after an evaluation suggests a dementia diagnosis, what do you communicate to your patients? I tell my patients... Base: Total HCPs n=500

HCPs differ on info and disease management plans given to patients diagnosed with dementia

Significant differences are seen by specialty, by gender, and by where HCPs practice

By Specialty		
		
Geriatrics are above average on:	Specialty Total	
Discussing the importance of financial planning	73%	57%
Providing Info / literature on dementia	73%	56%
Evaluating for hearing loss	65%	49%
Discussing life expectancy	46%	24%
Neurologists are above average on:		
Prescribing medications to relieve symptoms	86%	74%
Discussing the cause of dementia	82%	68%
Ordering a PET scan	23%	12%
Enrolling patients in clinical trials	19%	10%
Order a lumbar puncture	10%	4%
Psychiatrists/Psychologists are above average on:		
Referring to memory disorder clinics	47%	35%

By Gender		
		
Discussing disease progression	Women	Men
Discussing disease progression	85%	74%
Advising on lifestyle changes to slow disease progression	83%	73%
Discussing the importance of healthcare planning	80%	66%
Discussing the importance of financial planning	65%	54%
Discussing the importance of keeping appointments	61%	42%
Providing online resources or informational websites	52%	40%
Referring the family to counseling	38%	27%
Referring patient to a more experienced HCP	35%	25%
Referring the patient to counseling	33%	22%

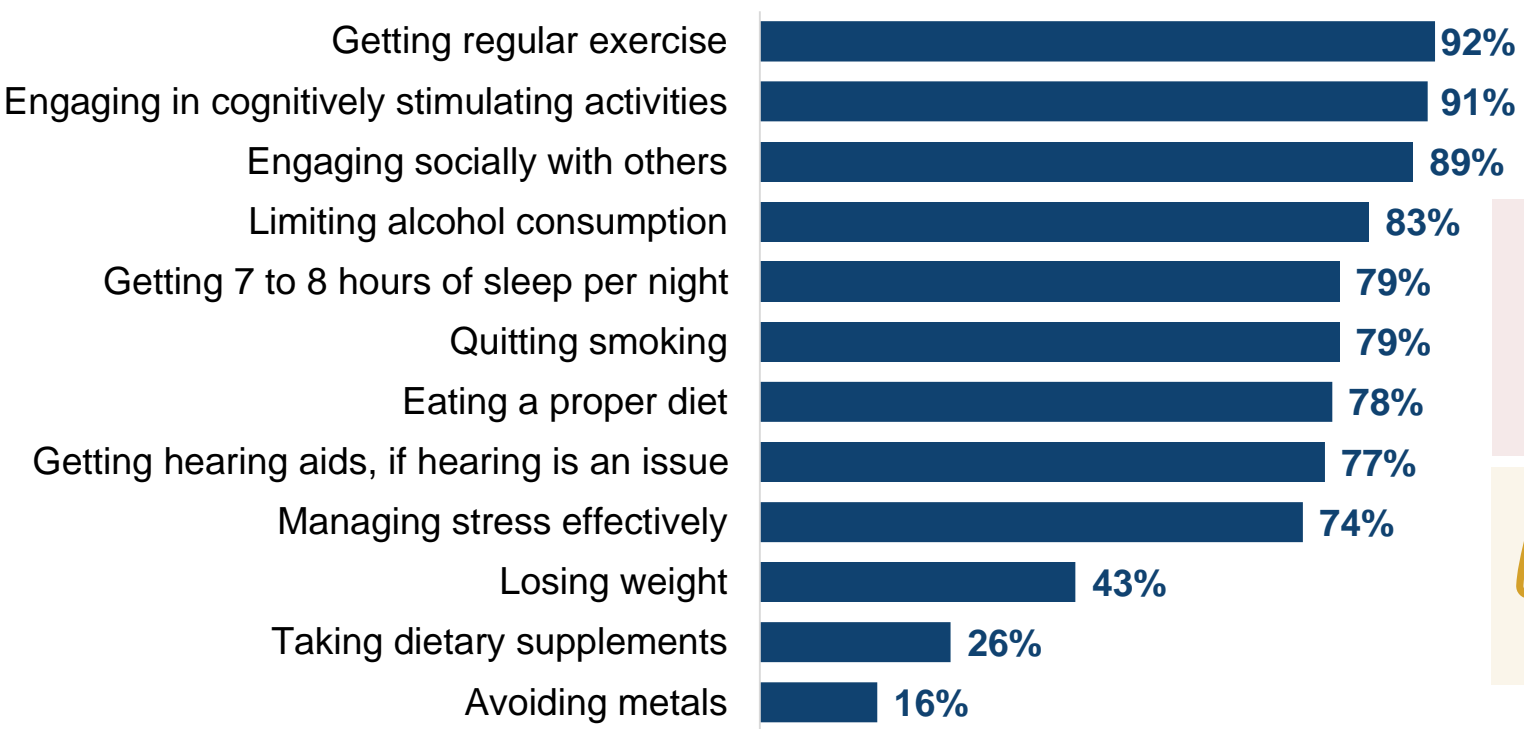
By Location		
		
Those practicing in urban areas are above average on:	Area	Total
The importance of keeping appointments	57%	46%
Referring the individual with the diagnosis to counseling	34%	25%
Discussing life expectancy	33%	24%
Those practicing in rural areas are above average on:		
Advising on lifestyle changes to slow disease progression	87%	75%

Q38 Which of the following actions do you take after you have diagnosed someone with dementia? Q52. In general, after an evaluation suggests a dementia diagnosis, what do you communicate to your patients? I tell my patients... Base: Total HCPs n=500, Geriatrics n=48, Neurology n=84, Psychiatry n=115, Female HCPs n=117, Male HCPs n=383, Urban HCPs n=151, Rural HCPs n=87

HCPs know that regular exercise, cognitively stimulating activities, and socializing with others helps with dementia’s symptoms

A large majority of HCPs feel that different lifestyle or health-related changes will help with the symptoms of dementia. Four in 10 (43%) feel losing weight may help the symptoms and relatively few feel that dietary supplements (26%) and avoiding metals (16%) would be helpful.

Help with dementia’s symptoms



	By Gender	Women	Men
	Engaging in cognitively stimulating activities	96%	90%
	Quitting smoking	86%	77%
	Managing stress effectively	84%	70%
	By Frequency of Diagnosis	Many times	No/ a few times
	Getting regular exercise	93%	84%
	Engaging socially with others	90%	79%

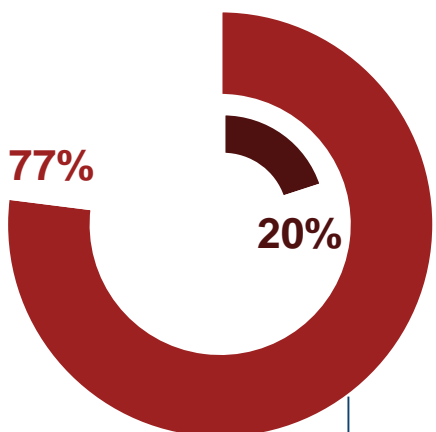
Healthcare providers know treatments are available for dementia busting the myth that nothing can be done

Most disagree that nothing can be done to help dementia patients – and disagree that they are hesitant to diagnose because of it. With one in five or more **strongly disagreeing** with each of these statements. However, one in five HCPs need additional information on treatments for dementia, especially those who infrequently diagnose dementia.

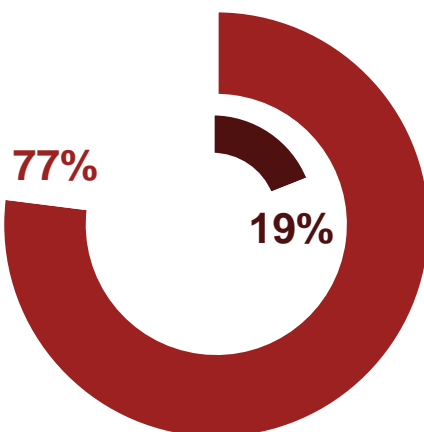
- Disagree/Strongly disagree
- Strongly disagree

HCPs DISAGREE that...

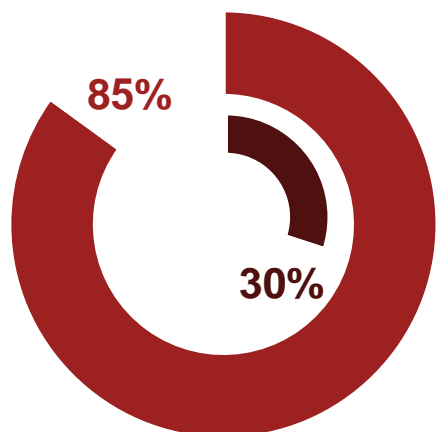
There are no available treatments for dementia



Until there is a drug that can modify the disease that causes dementia, there is nothing that can be done to help patients



I am reluctant to diagnose my patients with dementia because there is nothing that can be done to help them

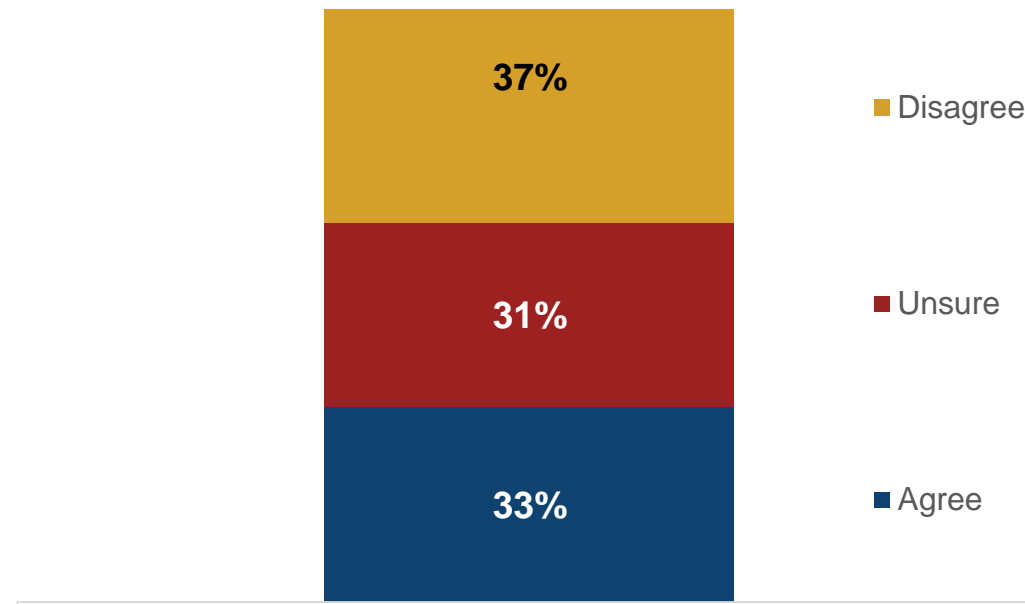


Those who have **diagnosed many** dementia patients are more inclined to disagree that no treatments exist (78% vs 65% among those who have diagnosed just a few or no patients)

Yet, many are unsure whether or not patients believe there are available treatments for dementia

This is true across key subgroups, like specialty or frequency of diagnosis, suggesting an opportunity for clearer communication with patients.

“My patients do not believe there are currently any treatments available for dementia”



Q48a. For the following series of questions, please indicate whether you agree or disagree with each statement. Base: Total HCPs n=500



IMPLICATIONS

Implications

Despite the very real fear and stigma surrounding dementia, patients do not want to be in the dark about their risk for developing this condition. Moreover, the medical community supports early screenings, which allow patients to get ahead of their condition, both in planning for the future and in making lifestyle changes that can reduce symptoms.

Strengthening the style and tone of communication with respect to screening and diagnosis could go a long way in setting patients up for the best possible outcome, without adding emotional stress.

HCPs differ widely on information and disease management plans given to patients diagnosed with dementia and – to a lesser extent – the steps patients can take to help with symptoms. **Patients could benefit from clear, consistent communication on disease management** so that all patients are operating on a level playing field when it comes knowledge of, and expectations for, their condition.

The reluctance of some healthcare providers to provide their patients with an accurate diagnosis of dementia potentially adds to the perceived stigma of the condition. Whereas **an honest diagnosis with clear strategies to treat dementia will aid in reducing stigma.**





METHODOLOGY

Methodology

- **Objectives:** To understand the stigma associated with a diagnosis of dementia from the point of view of health care providers (HCPs)
- **Methodology:** Online survey via a range of established healthcare panels
- **Sample / Qualifications:** n=500 interviews with physicians, nurse practitioners, physician assistants, and psychiatrists / psychologists; must evaluate people for the presence of cognitive impairment; approximately 25% or more of patients must be age 50 and over. Achieved a mix of specialties including:
 - Family medicine/Internal medicine (n=296)
 - Geriatrics (n=48)
 - Neurology (n=84)
 - Psychiatry/Psychology (n=115)
- **Interviewing Dates:** March 11-17, 2021 (this survey was fielded prior to FDA approval of the Biogen drug to combat Alzheimer's disease).
- **Questionnaire length overall:** 10 minutes (median)



This description was provided to HCPs at the start of the survey:

For the purpose of this survey, we are using the following definition of dementia: Dementia is a decline in cognitive function that interferes in the ability to perform activities of daily living. Some common causes of dementia include Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia.

Important notes about the survey and data analysis

- Totals may not add up to 100%: (1) Due to rounding and (2) The exclusion of refusals from the charts and tables.
- The survey instrument is based on the PRISM survey administered and validated in 2008 by Malaz Boustani, MD and colleagues.¹
- A parallel survey of 3,022 adults age 40 and older was administered at the same time. The parallel questions between this survey of healthcare providers and the survey of adults age 40 and older from the general population are reported in the document entitled *2021 AARP Survey on the Perceptions Related to a Dementia Diagnosis: Adults age 40-plus*.²

¹Boustani et al. (2008) Measuring primary care patients' attitudes about dementia screening. *Int J Geriatr Psychiatry*. 2008 Aug;23(8):812-20. doi: 10.1002/gps.1983.

²Mehegan, L. and Rainville, G. (2021). *2021 AARP Survey on the Perceptions Related to a Dementia Diagnosis: Adults age 40-plus*. doi: <https://doi.org/10.26419/res.00471.001>



APPENDIX

Respondent and Patient Profile

Primary profession

Physician	97%
Nurse practitioner	1%
Physician assistant	1%

Provided a diagnosis of dementia

Yes, many times	87%
Yes, once or a few times	11%
No	2%

Regularly conduct dementia screening

Yes	91%
No	9%

23.5

Mean years in practice

Current specialty

Family medicine	51%
Psychiatry	23%
Neurology	17%
Internal medicine	10%
Geriatrics	10%
Emergency medicine	1%
Psychology	1%
Other	1%

Practice location & setting

Urban	30%
Suburban	52%
Rural	17%
Private clinic/ office based	84%
Teaching/ university hospital	9%
District/ regional/ community hospital	5%
Other	1%

Respondent gender

Male	77%
Female	23%

56% Mean % of patients 50+

50% Mean % of patients 65+, among those 50+

37% Mean % of patients 75+, among those 50+

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About AARP

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