



Alliance for Aging Research  
***Key Findings from Public Survey on Early  
Alzheimer's Diagnosis***

Avalere Health | An Inovalon Company  
August 2018

# Methodology

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- Avalere fielded a nationally representative telephone survey of 2,000 adults, age 18+ on behalf of Alliance for Aging Research
  - This included landline telephones as well as cellular phones for optimal representative coverage of the US population age 18+ (40% landline, 60% cell)
  - Final data is adjusted to consider the landline and cell phone portions, and then weighted by age, gender, region, race/ethnicity and education to be proportionally representative of the US adult population
- The survey was fielded from June 21-July 2, 2018 using ORC International's CARAVAN Omnibus survey mechanism
- The data incur a Margin of Error of + 2.0% at the 95% confidence level. Smaller subgroups will have larger error margins
- The questionnaire was designed in conjunction with Alliance for Aging Research, with the core focus being to understand public sentiment toward the concept of early diagnosis of Alzheimer's Disease (AD)
- At the onset of the survey, all respondents were read the following:
  - *"As you may know, dementia refers to the decline in memory or other thinking skills. AD is the most common form of dementia."*

# Key Findings and Implications

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- The concept of early diagnosis of AD is implicitly important to the general public
  - The vast majority say it is “very important” to diagnose AD as early as possible, and many also feel that knowing one’s risk is critically important as well
  - **Implication:** With general sentiment on the side of AD, communications and messaging efforts should be focused on mobilizing that sentiment into what a person can do because they know early diagnosis is important
- The public is also willing to consider taking part in early diagnosis
  - There is baseline receptivity to the concept of getting screened
  - Willingness is soft “somewhat likely” vs. intense “very likely” which can be attributed to the newness of the concept
  - It is also typical for interest to be higher than willingness
  - General interest, however, does usurp concern of developing the disease, which bodes well for moving toward uptake
  - **Implication:** Baseline receptivity can be cultivated to convert an “I’m willing” into a “My family members/loved ones/self should be screened when....”

# Key Findings and Implications

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- Benefits of early diagnosis address a major self-professed pain point and challenge of Alzheimer's disease: lack of certainty
  - Optimal planning is a consistent benefit of early diagnosis
  - It sits alongside a critical challenge: social, emotional, and clinical uncertainties
  - **Implication:** Uptake efforts can directly address challenges. Early diagnosis empowers a person, and their family, to address the social, emotional, and clinical concerns
- Knowledge of AD is largely built through exposure to the disease, either through a family member, loved one, and/or as a caregiver to someone with the disease
  - Self-professed knowledge is limited across the population, and it is even more limited among younger, less educated, and lower socioeconomic audiences, all of whom are important for uptake
  - **Implication:** Traction and receptivity for early detection exists, despite limited exposure knowledge of, exposure to, and fear of the disease. Increasing knowledge about how early diagnosis empowers a person with AD can become a motivating agent for seeking out screening

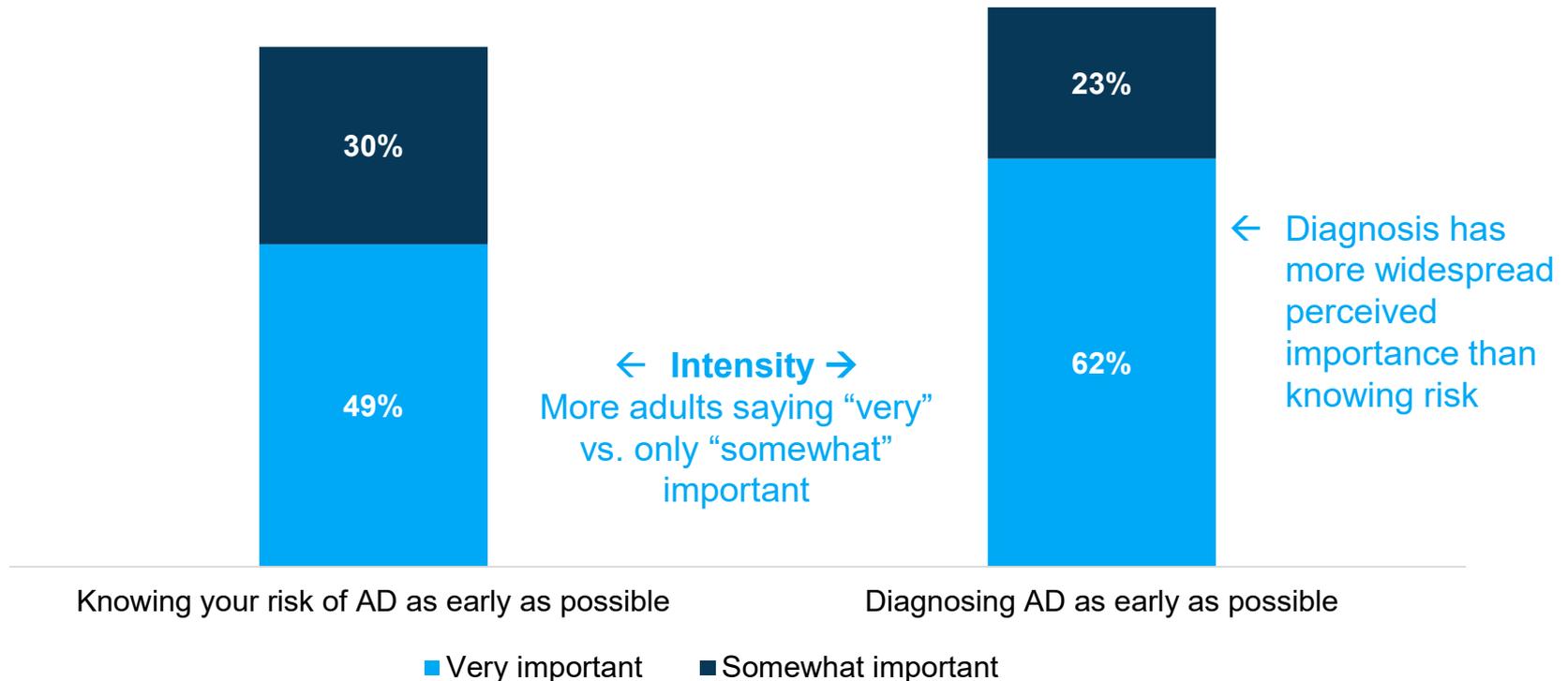


Traction for Risk Assessment and Early  
Detection

# Risk Identification and Early Detection of Alzheimer's Disease Earns Broad Traction Among the General Public

The vast majority feel it is important to know risk and diagnose AD as early as possible.

Perceived Importance of Risk Assessment and Diagnosis of AD  
(Shown: All Respondents)

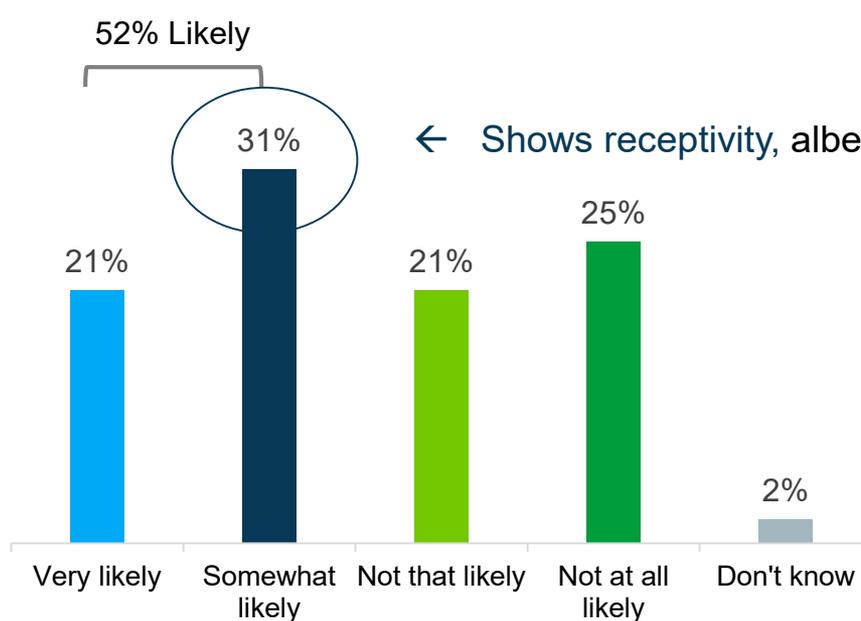


Q: Would you say each of the following is very important, somewhat important, not that important, or not important at all to you? KNOWING YOUR RISK for Alzheimer's disease as early as possible; DIAGNOSING Alzheimer's disease as early as possible

# There Is Also Baseline Receptivity to Taking Part in Tests and Studies About Early Signs and Risks

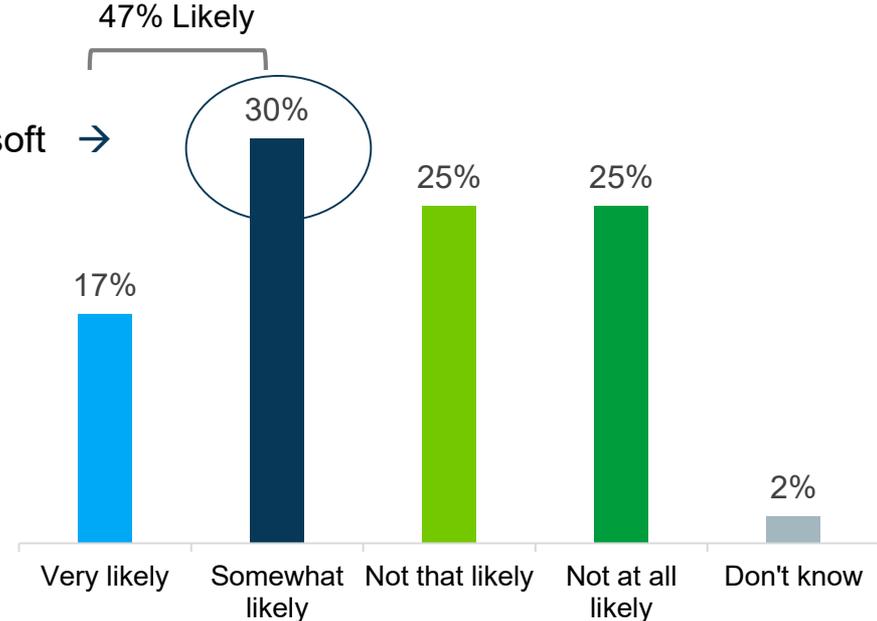
Close to half think they would be likely to partake, even though some of that is a tempered “somewhat” likely.

**Likelihood of Participating in:  
A Test or Scan for Early Signs of AD**  
(Shown: All Respondents)



← Shows receptivity, albeit soft →

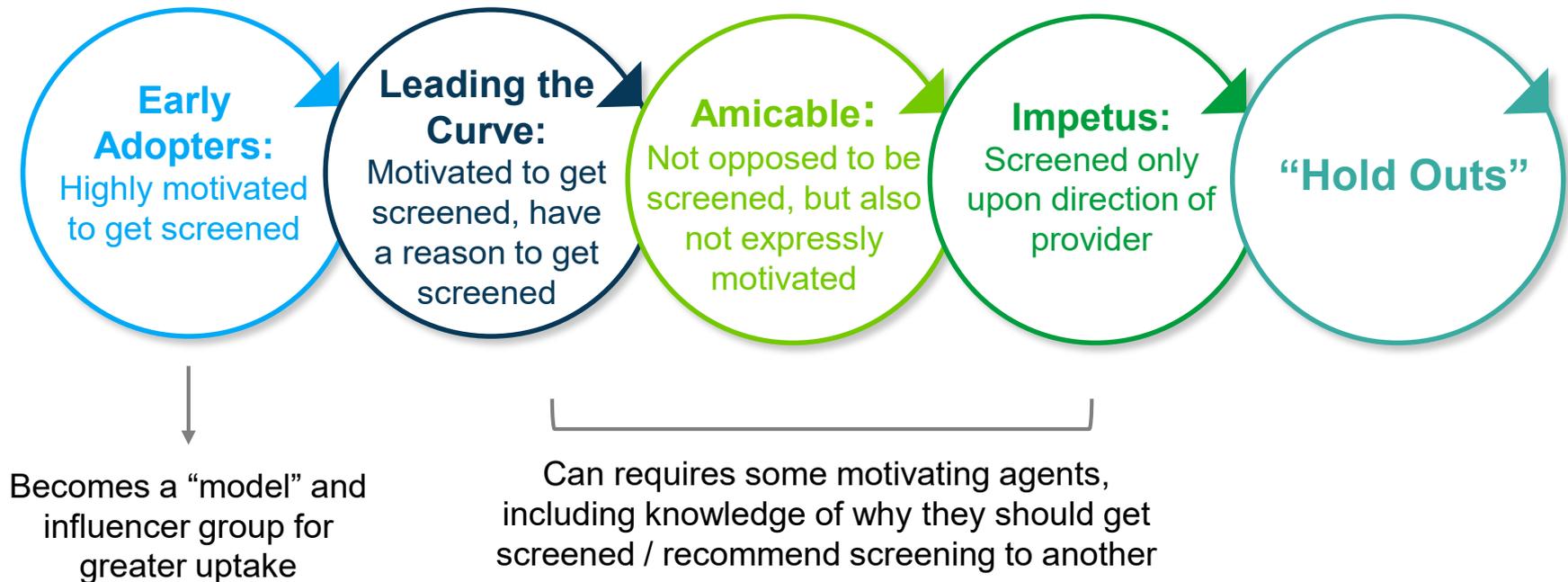
**Likelihood of Participating in:  
A Research Study to Test Prevention or Treatment of AD**  
(Shown: All Respondents)



Q: How likely would you be to participate in the following tests or research for Alzheimer's disease? Would you be very likely, somewhat likely, not that likely, or not at all likely? A test or scan to look for early signs or risks of Alzheimer's disease; A research study to test prevention or treatment of Alzheimer's disease

# Movement Toward Screenings Will Likely Occur in Waves

The concept of early screenings is still new. Baseline receptivity will likely generate an early adopter group, while others will require more motivation to be screened, or recommend a loved one be screened.



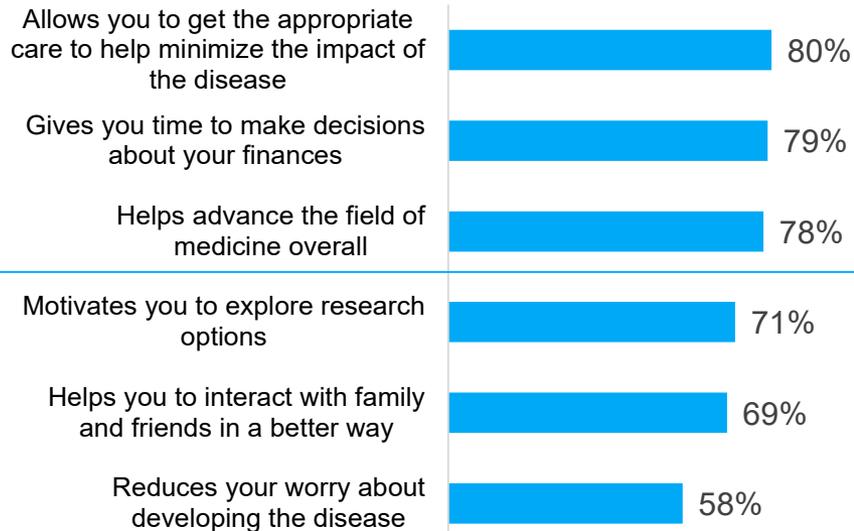
# Optimal Future Planning Could Be a Strong Motivator for Early Diagnosis

The public recognizes many benefits of early diagnosis, most of which center around preparedness.

## Benefits of Early Alzheimer's Diagnosis:

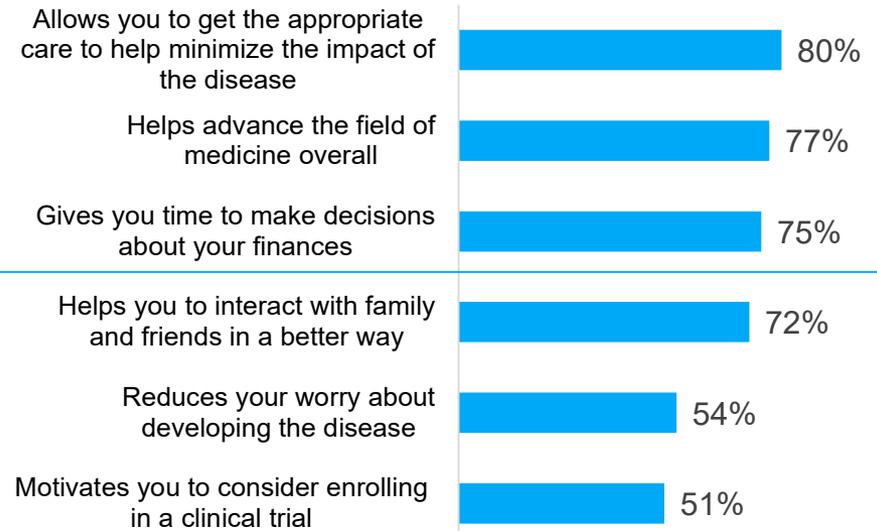
### Before Noticeable Symptoms Develop

(Shown: Split Sample Random, Representative 1000 Respondents)



### When Initial, Mild Symptoms Are Noticeable

(Shown: Split Sample Random, Representative 1000 Respondents)

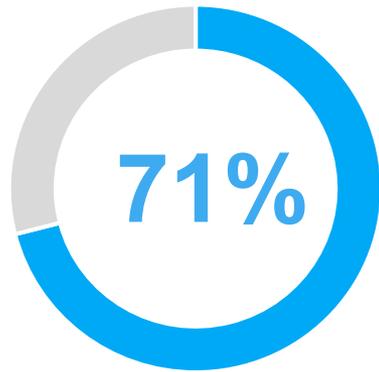


Benefits for diagnosing before, vs. upon early onset of symptoms are on-par and comparable to each other

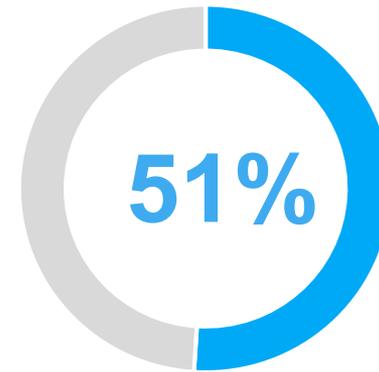
Q: In your opinion, what are the BENEFITS of being diagnosed with Alzheimer's disease BEFORE NOTICEABLE SYMPTOMS DEVELOP and WHEN INITIAL, MILD SYMPTOMS ARE NOTICEABLE? Would you say it...

# There Is Also Traction for Clinical Research and Trials

A majority of adults consider access to research studies, trials a benefit to early diagnosis, which are concepts that typically require more urging.



Think the potential to participate in a research study is a benefit of diagnosing AD before symptoms are noticeable



Consider access to a clinical trial is a benefit of diagnosing AD when mild symptoms are noticeable

Q: In your opinion, what are the BENEFITS of being diagnosed with Alzheimer's disease BEFORE NOTICEABLE SYMPTOMS DEVELOP and WHEN INITIAL, MILD SYMPTOMS ARE NOTICEABLE? Would you say it...



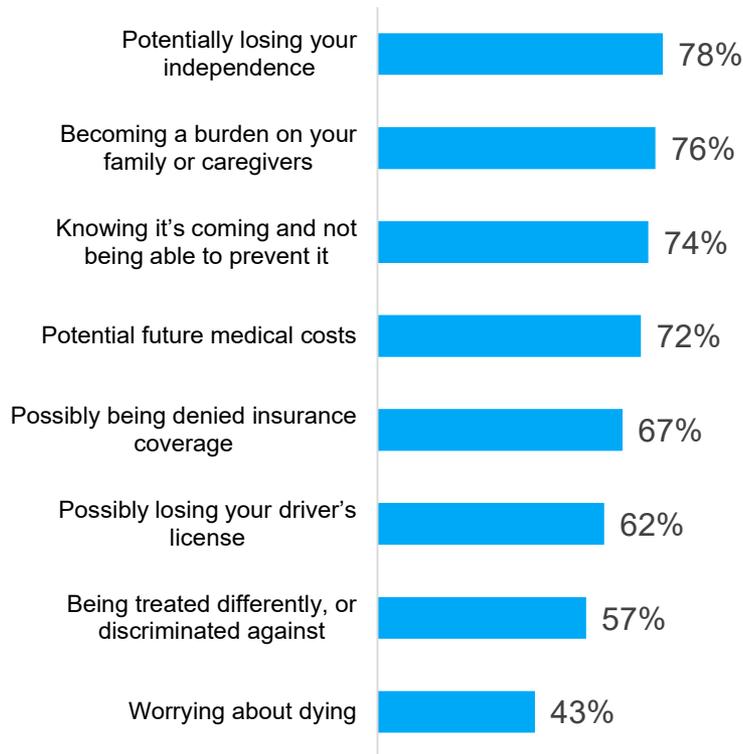
# Perceived Benefits of Early Diagnosis Sit Alongside Realistic Fears

## Early diagnosis raises emotional, social, and financial concerns.

### Challenges of Early Alzheimer's Diagnosis

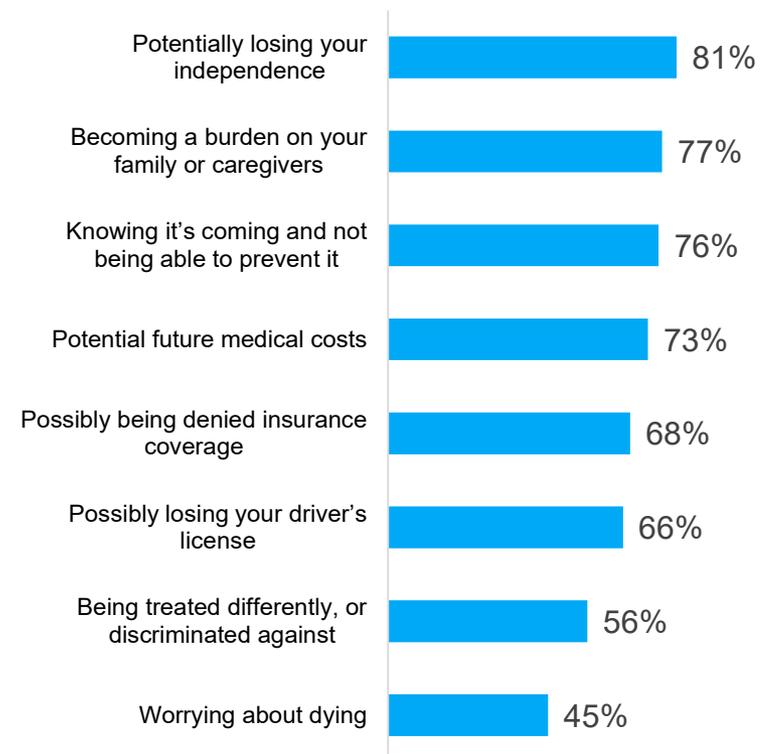
#### Before Noticeable Symptoms Develop

(Shown: Split Sample Random, Representative 1000 Respondents)



#### When Initial, Mild Symptoms Are Noticeable

(Shown: Split Sample Random, Representative 1000 Respondents)

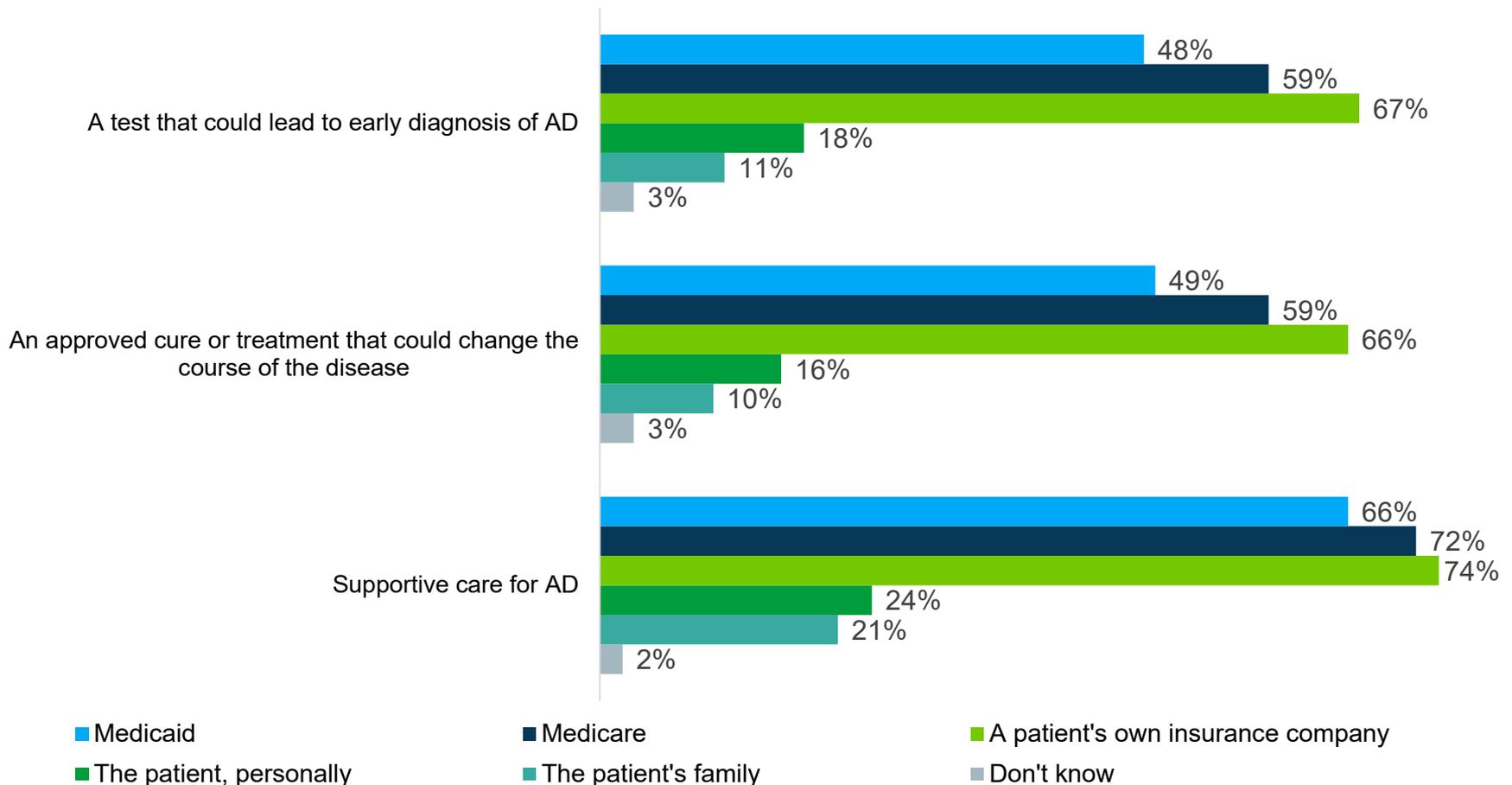


Q: In your opinion, what are the CHALLENGES of being diagnosed with Alzheimer's disease BEFORE NOTICEABLE SYMPTOMS DEVELOP? Would you say...



# There Is General Agreement that Insurers Should Take Responsibility for Access to Early AD Diagnosis

**Cost Responsibility for AD Prevention and Treatment**  
(Shown: All Respondents)



Q: In your opinion, who do you think should cover the cost of each of the following potential scenarios?

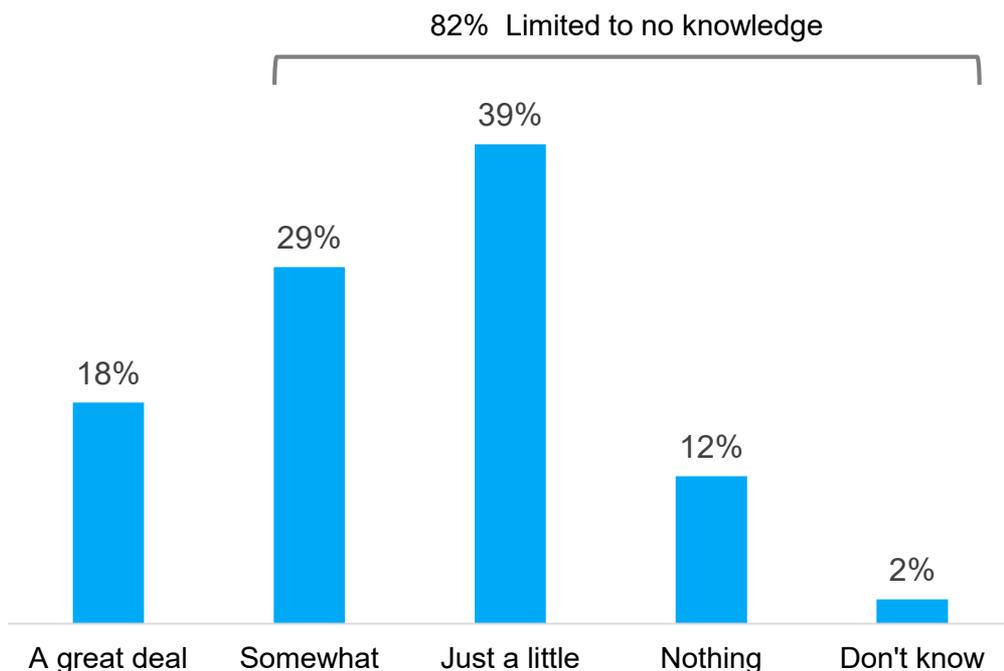


Using Early Detection Messages to Build Knowledge

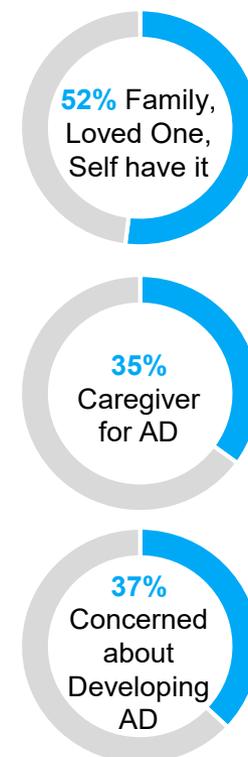
# The General Public Is Largely Unfamiliar With and Not Afraid of Developing Alzheimer's Disease

**Most adults know little about AD, and only half know a family member / loved one with it. Even fewer are concerned about developing AD.**

**Alzheimer's Disease Familiarity**  
(Shown: All Respondents)



**Exposure to Alzheimer's Disease**  
(Shown: All Respondents)



Q: Would you say you know a great deal, somewhat, just a little, or nothing about Alzheimer's disease?

Q: Have you or any of your family members or close friends ever been diagnosed with Alzheimer's disease? More specifically, who has been diagnosed with Alzheimer's disease? Was it...

Q: Have you ever been a caregiver for someone with Alzheimer's disease?

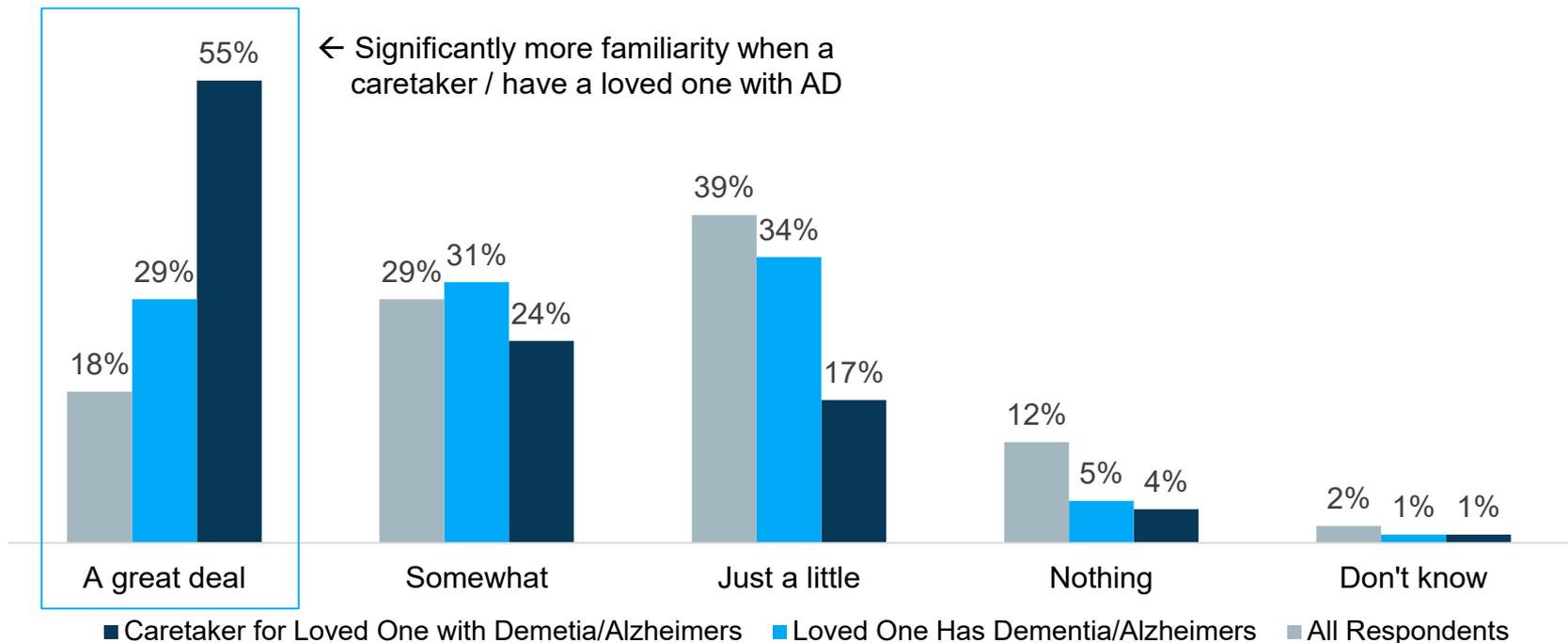
How concerned are you about being diagnosed with Alzheimer's disease? Would you say you are...



# Knowledge Builds with Proximity and Exposure to AD

Knowing or caring for a person with AD drives greater overall knowledge than any other demographic.

**Alzheimer's Disease Familiarity**  
(Shown: All Respondents by Disease Proximity)



Q: Would you say you know a great deal, somewhat, just a little, or nothing about Alzheimer's disease?

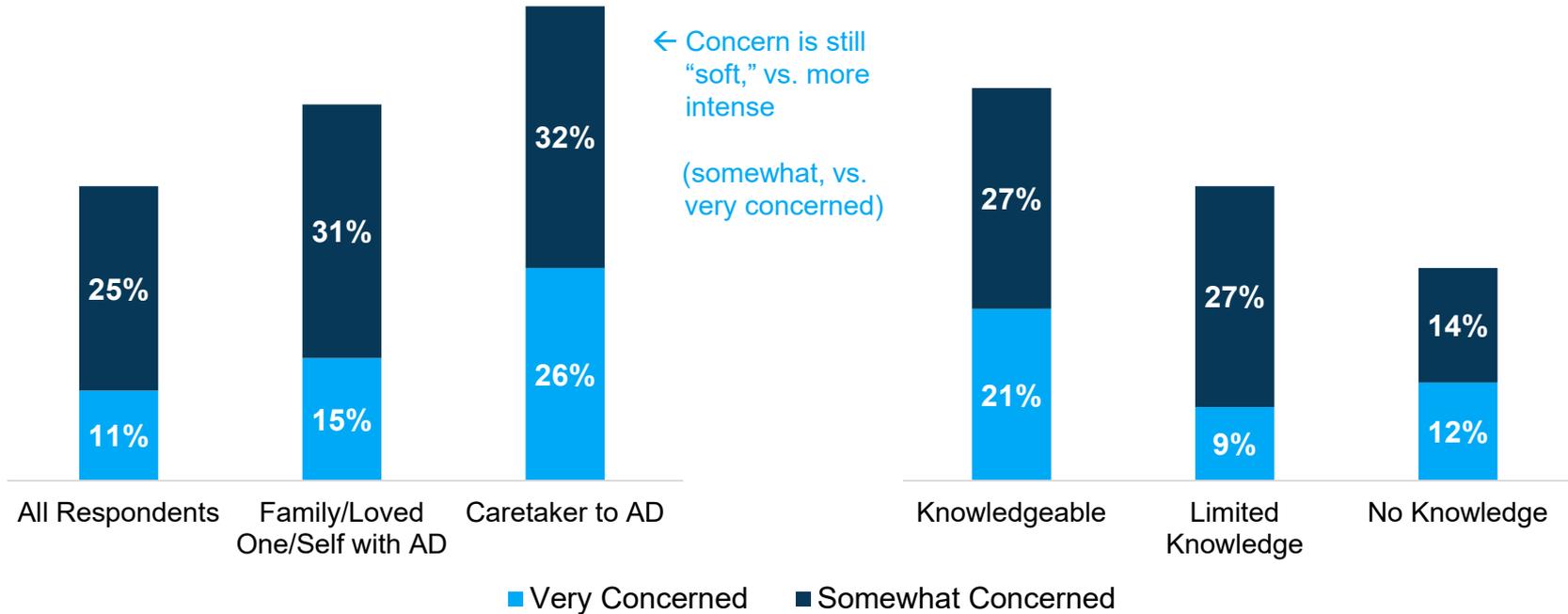
Q: Have you or any of your family members or close friends ever been diagnosed with Alzheimer's disease? More specifically, who has been diagnosed with Alzheimer's disease? Was it...



# Proximity and Knowledge of AD Can Prompt Greater Concern about Developing the Disease

**While contained overall, those who are closer to the disease share some greater concern about developing AD.**

**Alzheimer's Disease Concern**  
(Shown: All Respondents by Disease Proximity and Knowledge)



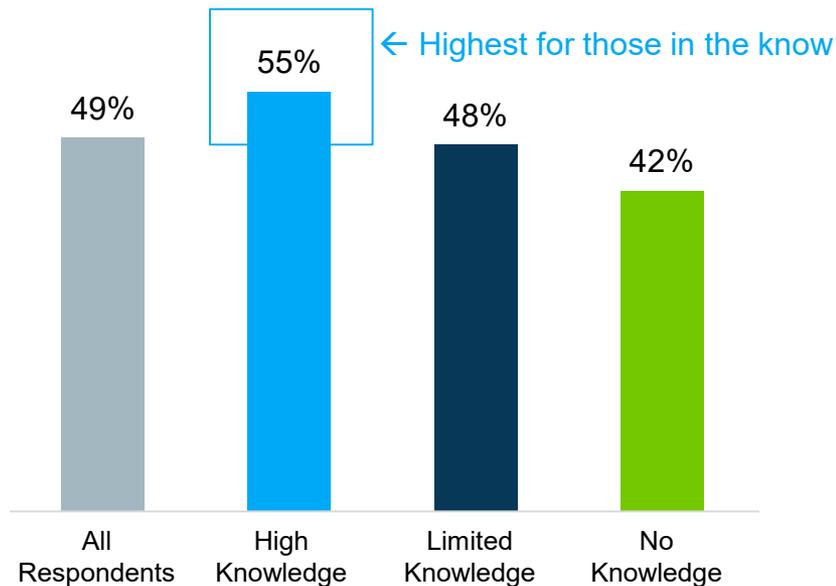
Q: How concerned are you about being diagnosed with Alzheimer's disease? Would you say you are ...  
Q: Have you or any of your family members or close friends ever been diagnosed with Alzheimer's disease? More specifically, who has been diagnosed with Alzheimer's disease? Was it...  
Q: Would you say you know a great deal, somewhat, just a little, or nothing about Alzheimer's disease?

# Knowledge Is Important Because It Can Mobilize Early Detection

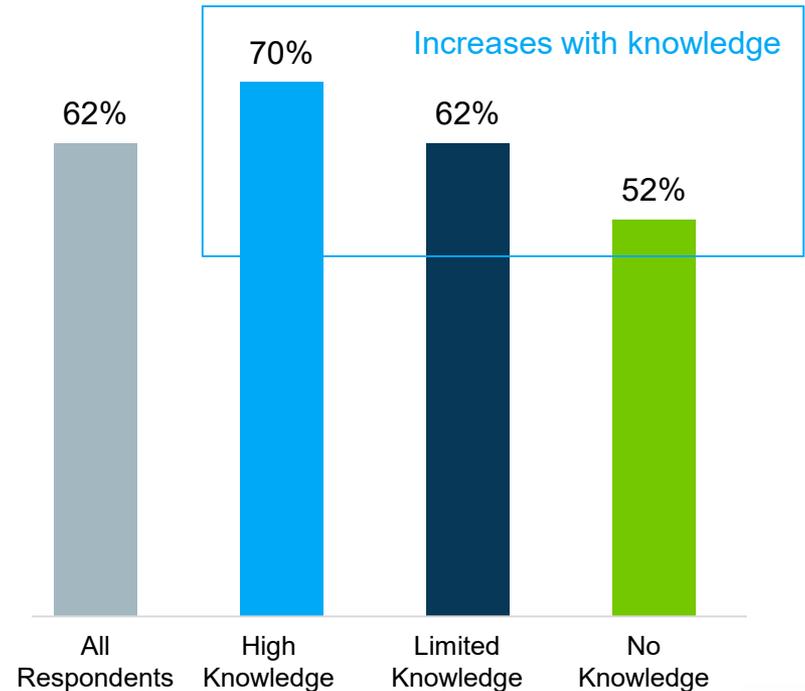
Those with less knowledge are less likely to see the importance of early detection.

**Importance of Risk Assessment, Diagnosis of Alzheimer's Disease by Knowledge of Disease**  
(Shown: All Respondents by Knowledge, "Very Important")

**Knowing Your Risk As Soon As Possible**



**Diagnosing As Early As Possible**



Q: Would you say each of the following is very important, somewhat important, not that important, or not important at all to you?  
KNOWING YOUR RISK for Alzheimer's disease as early as possible; DIAGNOSING Alzheimer's disease as early as possible  
Q: Would you say you know a great deal, somewhat, just a little, or nothing about Alzheimer's disease?

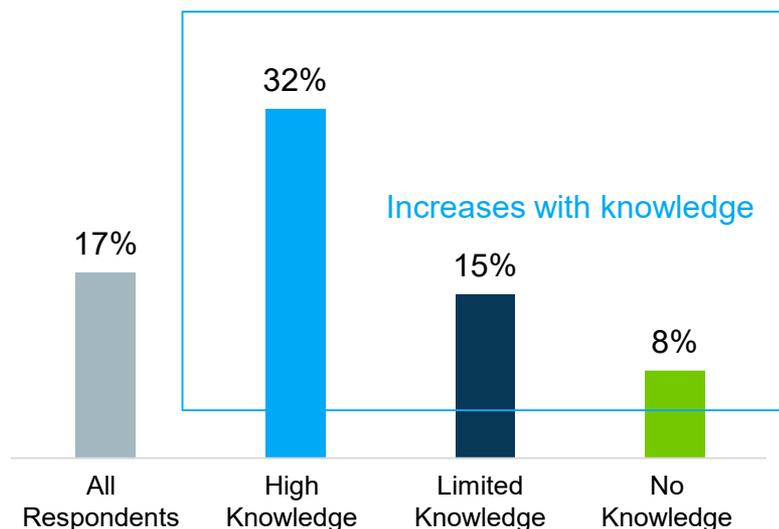


# Limited Knowledge Pervades Participation in Screenings

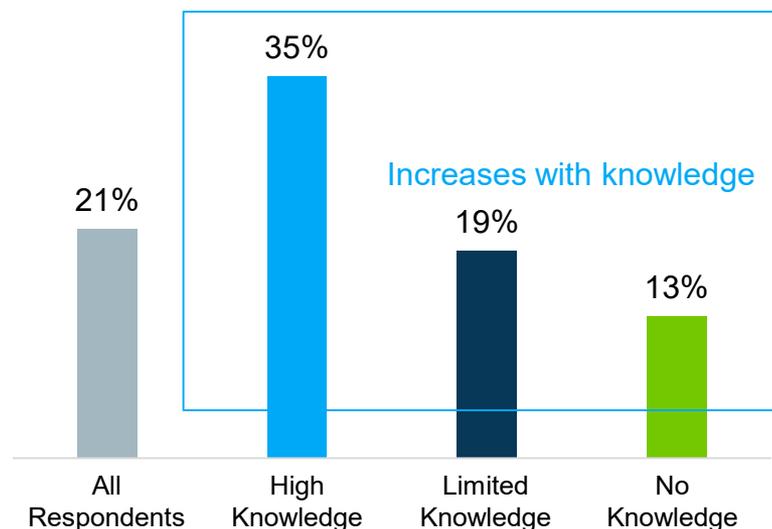
Those with less knowledge are also not as apt to partake in screenings vs. the more acquainted with the disease.

**Likelihood of Participating in Tests or Research for Alzheimer's Disease by Knowledge of Disease**  
(Shown: All Respondents by Knowledge, "Very Likely")

**A research study to test prevention or treatment of Alzheimer's Disease**



**A test or scan to look for early signs or risks of Alzheimer's Disease**



Q: How likely would you be to participate in the following tests or research for Alzheimer's disease? Would you be very likely, somewhat likely, not that likely, or not at all likely? A test or scan to look for early signs or risks of Alzheimer's  
Q: Would you say you know a great deal, somewhat, just a little, or nothing about Alzheimer's disease?

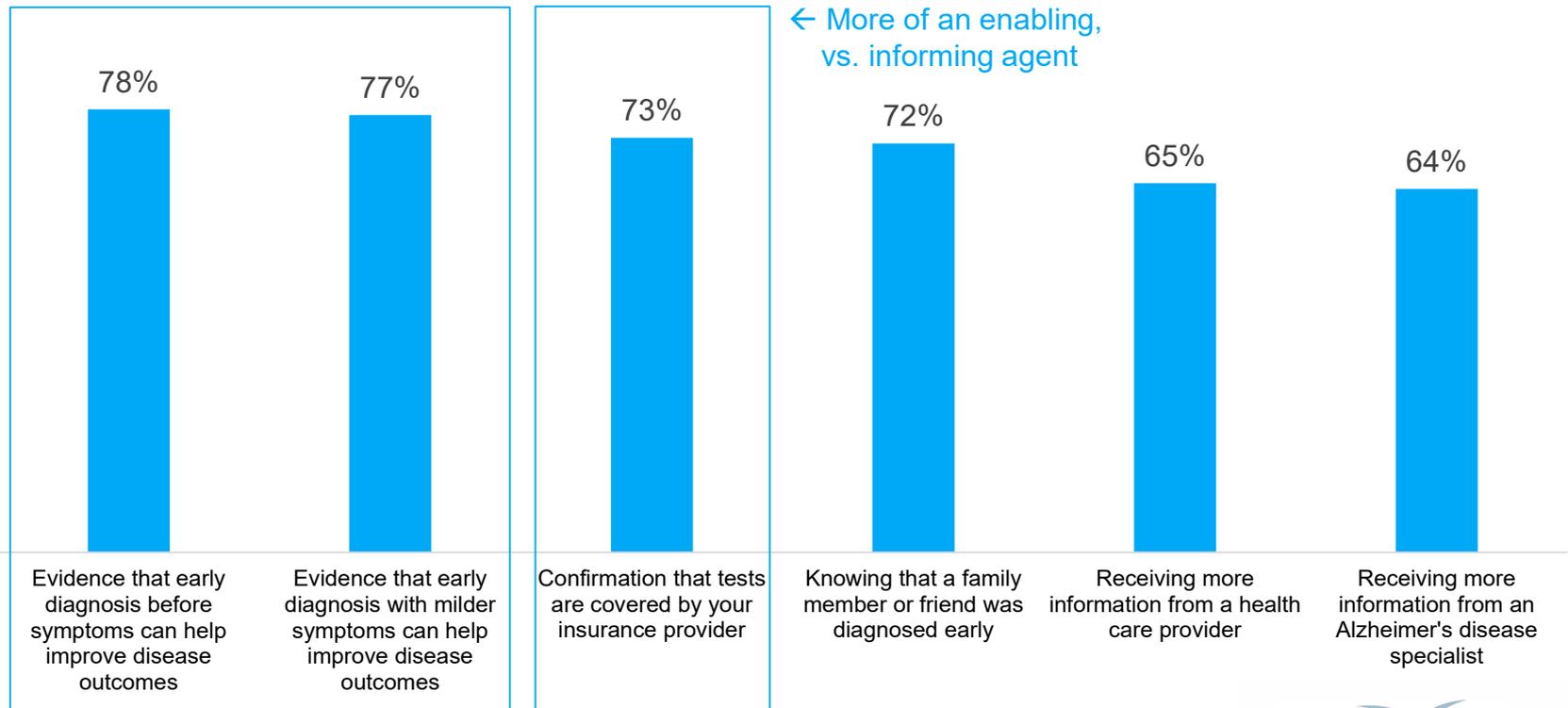


# Benefits of Early Diagnosis and Coverage of Tests Are a Combined Powerful Tool to Build Knowledge and Motivate

**Evidence of better outcomes, and coverage of tests make the concept of early diagnosis more relevant, and plausible.**

**Which of the Following Would Make You Want to Learn More about Early Diagnosis of Alzheimer's Disease?**

*(Shown: All Respondents, Multiple Responses Accepted)*



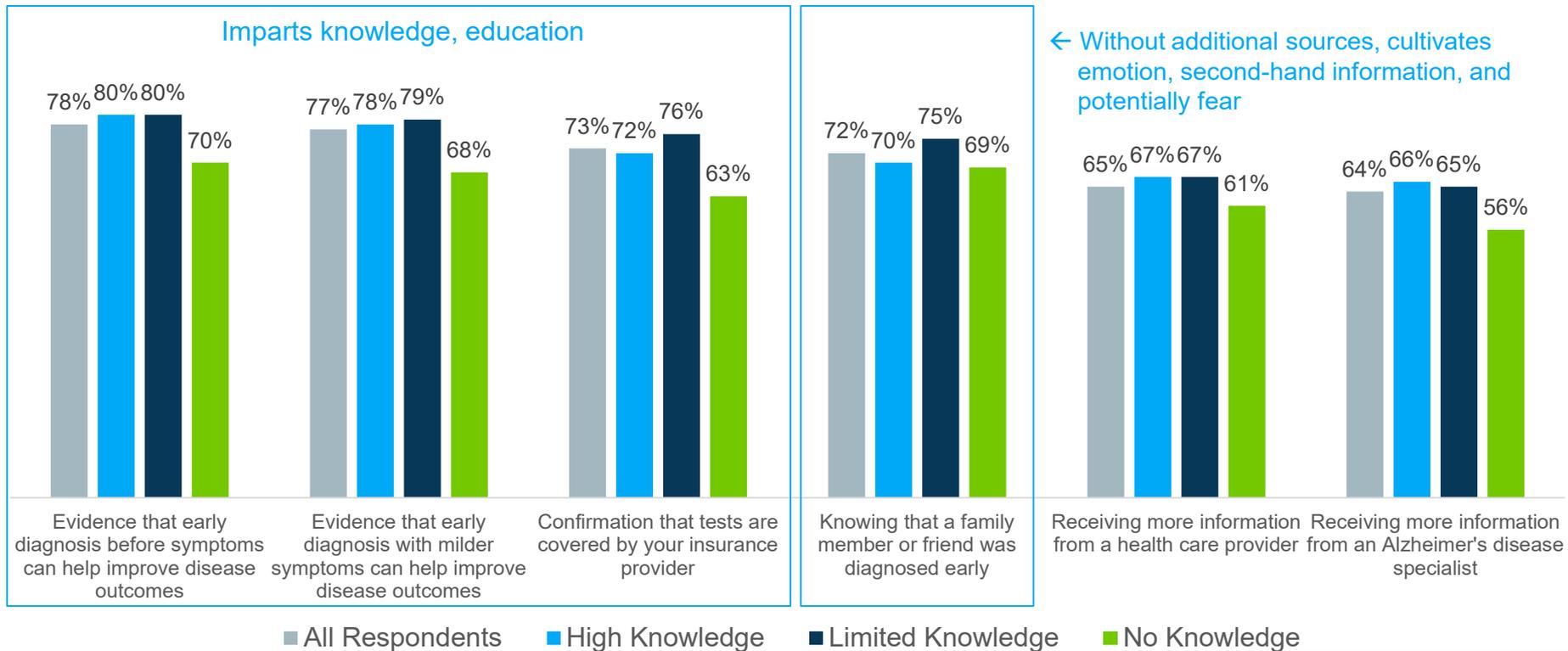
Q: Which of the following would make you want to learn more about early diagnosis of Alzheimer's disease? Would you say...



# Benefits of Early Diagnosis Even Resonates with Less Informed Audiences

Educating on early diagnosis means that knowledge grows by informing and empowering, versus frighten audiences.

**Which of the Following Would Make You Want to Learn More about Alzheimer's Disease?**  
*(Shown: All Respondents by Knowledge, Multiple Responses Accepted)*



Q: Which of the following would make you want to learn more about early diagnosis of Alzheimer's disease? Would you say...

Q: Would you say you know a great deal, somewhat, just a little, or nothing about Alzheimer's disease?





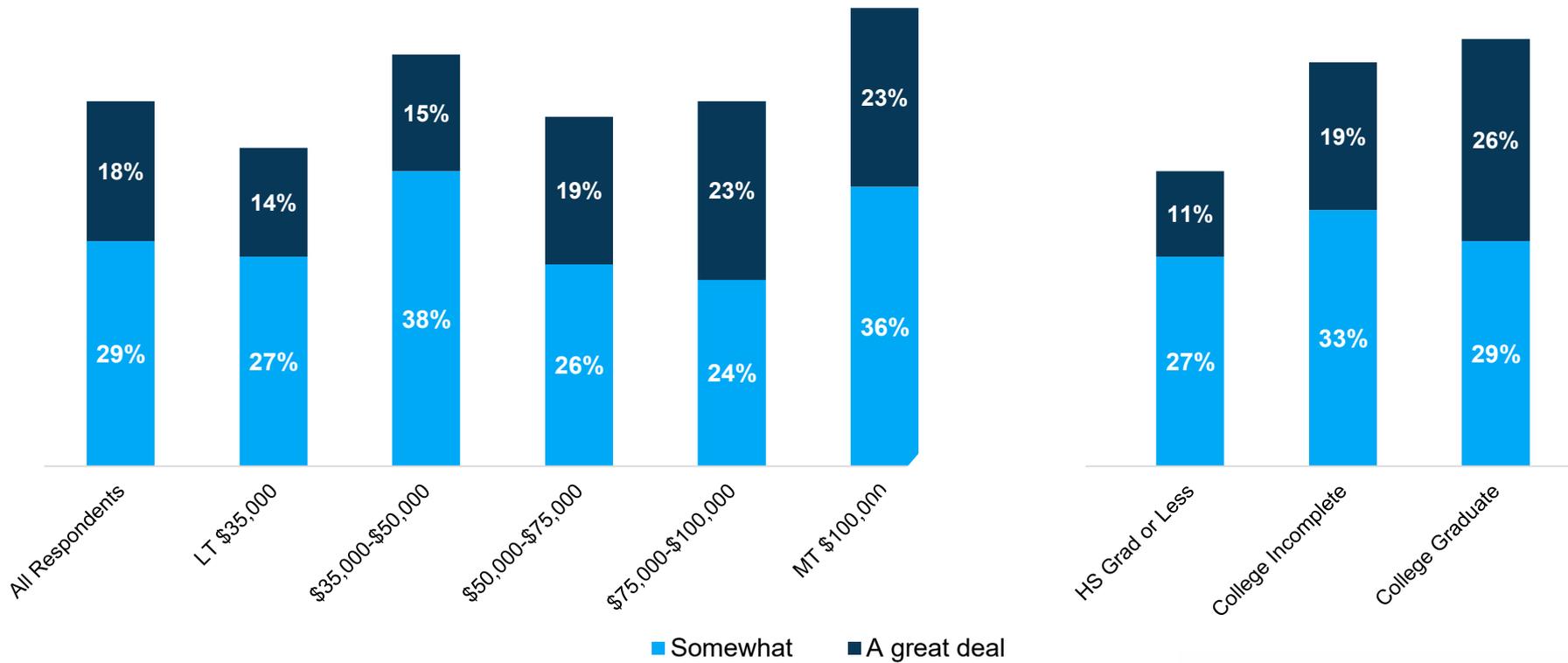
## Targeting Critical Demographic Groups for Early Detection Uptake

# Knowledge Building Is Also Essential for Reaching Underserved Populations Who Can Be at Risk for AD

**Lower income, less educated adults know even less about AD than the general population.**

## Alzheimer's Disease Familiarity

(Shown: All Respondents to "A Great Deal" or "Somewhat" by Knowledge, Income, Education)



Q: Would you say you know a great deal, somewhat, just a little, or nothing about Alzheimer's disease?

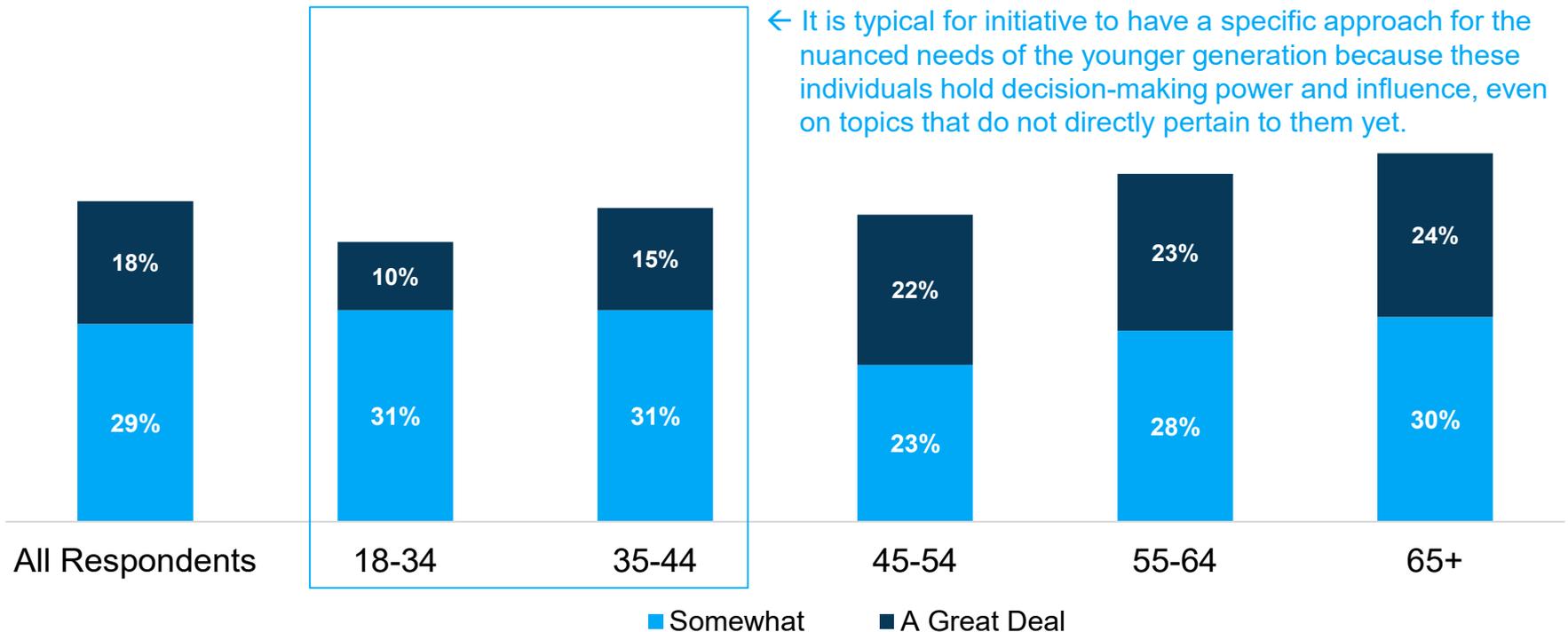


# Knowledge Building Is Also Essential for Uptake Among Next Generation of Caregivers

Younger adults, especially under 34, are more disconnected from the disease and will benefit from the early diagnosis message as they age into caregiver roles for loved ones.

**Alzheimer's Disease Familiarity**  
(Shown: All Respondents to "A Great Deal" or "Somewhat" by Age)

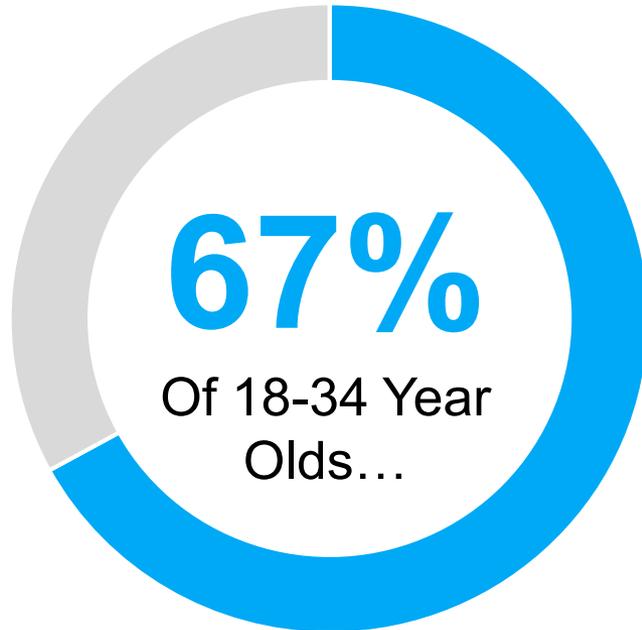
← It is typical for initiative to have a specific approach for the nuanced needs of the younger generation because these individuals hold decision-making power and influence, even on topics that do not directly pertain to them yet.



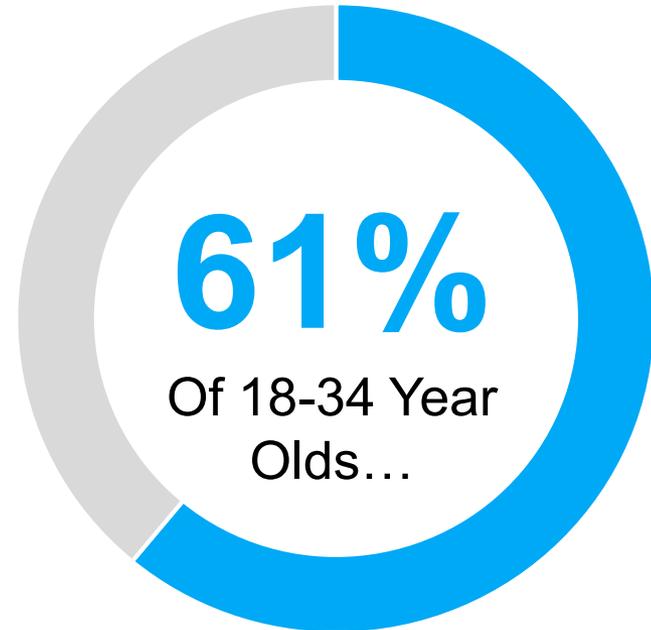
Q: Would you say you know a great deal, somewhat, just a little, or nothing about Alzheimer's disease?

# Peace of Mind Is Particularly Important for the Rising Generation

Younger adults (under 34) are more likely to consider “reducing worry” as a benefit of early diagnosis.



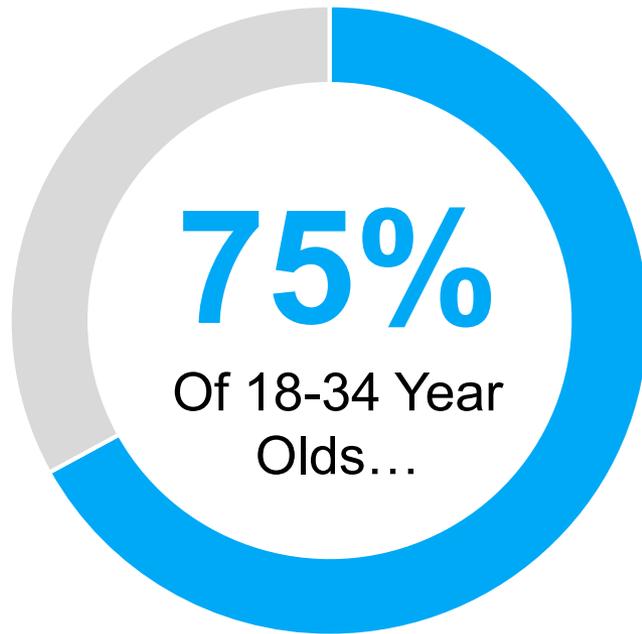
Consider “reducing worry” as a benefit of pre-symptomatic diagnosis  
(vs. 58% overall)



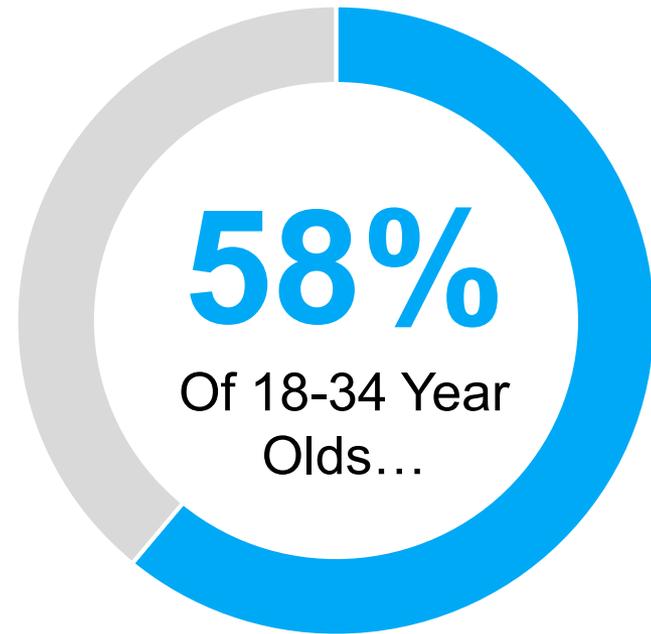
Consider “reducing worry” as a benefit of diagnosis upon initial, mild symptoms  
(vs. 54% overall)

# Knowledge Can Also Condition Baseline Receptivity to Treatment and Clinical Trials Among Younger Adults

**Younger adults (under 34) are more likely to consider research studies, clinical trials” a benefit of early diagnosis, and that bodes well for them as caregivers.**



Consider “motivates you to explore research options” as a benefit of pre-symptomatic diagnosis( vs. 71% overall)



Consider “enrolling in a clinical trial” as a benefit of diagnosis upon initial, mild symptoms (vs. 51% overall)