

## Summary of Findings: UsAgainstAlzheimer's A-LIST Survey on Medicare (CMS) Coverage Decision February 7, 2022

UsAgainstAlzheimer's fielded a survey, January 27-February 2, 2022, with responses from 752 people who were diagnosed with Mild Cognitive Impairment (MCI)/Alzheimer's disease (AD) or another dementia, 'at risk' for diagnosis, current/former caregivers and those interested in brain health

Key overall findings include:

- 2/3 of respondents were unaware (43%) or unsure (20%) of the CMS decision
  - Of the group that was aware of the CMS decision, few respondents were able to articulate a full awareness of the implications in an open-ended response; many of those respondents were considering information outside of the CMS decision
- Differences in level of support for CMS decision varied based on awareness of the CMS decision
  - Of the group that was aware of the CMS decision, 27% of total respondents were positive
  - However, 74% of total respondents (regardless of awareness of CMS decision) believed that CMS should cover the cost of new Alzheimer's disease treatments
- 54 diagnosed individuals and 243 current and former caregivers were divided on whether they/their loved ones would take this class of drugs if their doctor thought it might work for them, even if it might have bad side effects
  - Patients: Yes 41%, No 19%, Unsure 41%
  - Caregivers: Yes 41%, No 17%, Unsure 42%

### **Awareness and Understanding of CMS coverage decision**

- Limited awareness of CMS decision among the surveyed population: 37% aware, 43% not aware, 20% unsure
- Of those who stated they were aware of the decision, most provided an inaccurate description of it
  - "Drug not eligible for coverage under Medicare as its effectiveness has not been proven." (person interested in brain health)
  - "They will pay for treatment for patients who are in the early stage (MCI) and fund it by raising the cost of medicare to all subscribers." (current caregiver)
- Several others accurately articulated a portion of the CMS decision
  - "My understanding is that they aren't planning on covering Aduhelm or anything in its class." (current caregiver)
  - "Medicare is only covering Aduhelm and other drugs in the same class if you are in a study." (MCI, ADRD diagnosed)

### **Dichotomy in support of CMS coverage decision**

- Of those aware of the CMS decision, 27% were positive, 30% were neutral, and 43% were negative about it
- Of the total group of respondents (majority of whom were not aware of the CMS decision), 74% thought that Medicare should cover the cost of new drugs to treat Alzheimer's, 6% thought that Medicare should not cover the cost, and 20% were unsure

### **Tradeoffs when taking a new drug for Alzheimer's disease**

- 54 diagnosed individuals responded whether they would take this class of drugs if their doctor thought it might work for them, even if it might have bad side effects – Yes 41%, No 19%, Unsure 41%
  - “I don't exactly have a lot of alternatives; any hope is better than no hope.”
  - “My disease is fatal. What could be worse than that?”
  - “I don't take seizure medication due to the side effects and I have epilepsy. Negative side effects in some cases are worse than the benefit of the medication.”
- 243 current and former caregivers were split on whether they would have their loved one take this class of drugs if their doctor thought it might work for their loved one, even if it might have bad side effects - Yes 41%, No 17%, Unsure 42%
  - “Patients should be able to at least try the drug if there is a reasonable possibility for it to work. I would also expect to monitor for any side effects & report anything concerning to their prescribing physician.”
  - “Because of the side effects and coverage of insurance.”

### **Individuals were asked what they want to ensure that Medicare understands about Alzheimer's when making decisions about paying for Alzheimer's drugs**

- “Without a cure or a way to stop progression, we (persons living with dementia-related illness) will die! Plain and simple!!!”
- “Anything that can either slow down or help cope with memory loss would be a real benefit for millions of people.” (caregiver)
- “It is a ravaging disease that turned my highly intelligent, college professor husband into a shadow of himself. No family, rich or poor, should have to endure that.” (caregiver)
- “It is the most devastating disease out there. You lose a piece of your loved one every day. Absolutely horrendous for the family. I would rather my mom had had cancer than Alzheimer's.” (caregiver)
- “AD is one of the cruellest diseases, slowly stealing every bit of dignity before ultimately killing its victims. Families need hope, need to slow disease progression, extend quality of life and independence, preserve dignity, and increase years spent with their loved ones. No different than cancer drugs, drugs for heart disease, HIV, etc... AD drugs should be treated in the same manner.” (caregiver)
- “The disease is an unimaginable horror. Patients live in stark terror most of the time, and families bear an unbearable burden.” (caregiver)

**Survey Methodology:** *The survey, taken January 27–February 2, 2022, by the UsAgainstAlzheimer's A-LIST®, had n=752 responses, and 731 met study eligibility requirements. N=687 respondents described their status: 54 diagnosed with MCI/AD, 149 current caregivers, 194 former caregivers, 180 people who identify as 'at risk', and 110 people with general interest in brain health. About 8.6% of respondents were non-Caucasian. This research is overseen by the Advarra Institutional Review Board.*