

Summary of Findings: UsAgainstAlzheimer's Survey on Attitudes toward Use of a Disease-Modifying Alzheimer's Therapy January 2021

UsAgainstAlzheimer's fielded a survey January 15-19, 2021. A total of 751 people responded, including 41 individuals who identify as having a diagnosis of MCI/Mild AD, 34 current caregivers for individuals with MCI/Mild AD, and 218 people who identify as 'at significant risk' for developing MCI/Alzheimer's disease, or another dementia. Key overall findings include:

- A strong majority (84%) of diagnosed MCI/Mild AD and at-risk (for MCI/AD/another dementia) respondents want the FDA to moderately or heavily factor in willingness of patients to take a potential Alzheimer's treatment into FDA decision-making regarding approval of it.
- 78% of those diagnosed with MCI/Mild AD and 87% of those at risk for MCI/AD/Other dementia considered it important to have access to a FDA-approved treatment that allows them to experience an additional year without worsening symptoms, even if there is a chance of side effects in some people requiring close management by a physician
- If the FDA approves a disease-modifying therapy, individuals with MCI/Mild AD, their caregivers, and 'at risk' individuals for MCI/AD/another dementia would take action: 55% of those at risk for MCI/AD/another dementia say that availability of a drug to slow MCI/Mild AD would prompt them to seek earlier diagnosis.

People living with a diagnosis of MCI/Mild AD

- 84% believe that the FDA, in reviewing a drug to treat MCI/Mild AD, should factor in the willingness of patients to take the treatment before efficacy is fully studied.
- Nearly two-thirds (63%) said that an Alzheimer's drug that allowed them to maintain their current state of daily functioning for one year would offer some or significant benefit. 10% said they would not perceive a benefit, and 27% were unsure.
- More than three in four (78%) considered it important to have access to an FDA-approved treatment that allows them to experience an additional year without worsening symptoms, even if there is a chance of side effects in some people requiring close management by a physician.
- FDA approval of a drug to slow progression of MCI/Mild AD would prompt this group to consider the following actions: consult with a doctor on personal risks/benefits (80%), work to understand more about the drug (68%).
- Over the last 30 days, the group with a diagnosis of MCI/Mild AD experienced the following symptoms: forgetting events, tasks and/or plans, misplacing things (59%), difficulty concentrating, thinking clearly, losing my train of thought and/or making decisions (56%), getting confused about dates, the time, getting from place to place, and/or where they are (41%), difficulty speaking and understanding others, finding the right words (41%), loss of interest in things previously enjoyed (37%), and trouble sleeping (32%)
- 68% of this group considered themselves to have a slight to moderate loss of function
- Those with this diagnosis described their feelings relating to how they live everyday with MCI/AD: anxiety/worry/stress (44%), down or depressed (32%), irritable /frustrated/agitated (29%), no sense of purpose (27%), and burden to others (24%).

Caregivers of those with a diagnosis of MCI/Mild AD

- More than 3 in 4 (76%) of respondents said that an Alzheimer's drug that allowed their loved one with MCI/mild AD to maintain their current state of daily functioning for one year would offer some or significant benefit, 6% said they would not perceive a benefit, and 12% were unsure.
- FDA approval of a drug to slow progression of MCI/Mild AD would prompt these caregivers to consider the following actions: consult with a doctor on personal risks/benefits (76%), and work to understand more about the drug (55%).
- MCI/Mild AD caregivers noted their loved one's symptoms at higher rates than those diagnosed: forgetting events, tasks and/or plans, misplacing things (88%), difficulty concentrating (91%), getting confused about dates, the time, getting from place to place, and/or where they are (76%), difficulty speaking and understanding others, finding the right words (56%), and loss of interest in things previously enjoyed (59%)
- Caregivers assessed that 88% of their loved ones with MCI/Mild AD have lost some function
- They specifically wished that their loved ones had the following functions back: remember appointments (64%), plan/schedule appointments (61%), take medications correctly (47%), manage money/pay bills correctly (56%), stay safe (44%), and maintain ability to live on their own (35%)

Individuals at risk for MCI/AD/Another dementia

- 85% believe that the FDA in reviewing a drug to treat MCI/Mild AD should factor in the willingness of patients to take the treatment before efficacy is fully studied.
- 87% said that an Alzheimer's drug that allowed them to maintain their current state of daily functioning for one year would offer some or significant benefit, 2% said they would not perceive a benefit and 11% were unsure.
- FDA approval of a drug to slow progression of MCI/Mild AD would prompt this group to consider the following actions: consult a doctor on personal risk (83%), work to understand more about the drug (73%), and seek earlier diagnosis (55%)

Survey Methodology: The survey, taken January 15-19, 2021 by the UsAgainstAlzheimer's A-LIST®, had 751 responses overall from people living with Alzheimer's or another dementia, current and former caregivers, people with a significant likelihood of developing the disease, and those interested in brain health. Of the total respondents, 705 described their status: 218 were individuals who are at risk for MCI/AD, 158 former caregivers, 149 current caregivers, 121 with a general interest in brain health, and 59 individuals with a diagnosis of MCI or Alzheimer's. Of those with a diagnosis of MCI/Mild AD, 41 answered the full set of questions. Of the caregivers, 34 indicated that their loved one had MCI or Mild AD. This research is overseen by the Advarra Institutional Review Board.