

Participants in dementia prevention research motivated by altruism

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Researchers at University of California San Diego School of Medicine, with collaborators across the country, report that people who participate in dementia prevention trials are primarily motivated by altruism and pleased to help.

The findings are published in the October 5 issue of *Alzheimer's & Dementia*.

"For the most part, people appeared satisfied with their experience in a clinical trial," said first author Mary Sano, Ph.D., professor of psychiatry and director of the Alzheimer's Disease Research Center at Mount Sinai School of Medicine in New York City. "A big takeaway is how altruism and giving back are important to participants. We were also intrigued by the desire for increased social interactions."

The study surveyed 422 non-demented participants, age 75 and older, in the Home-Based Assessment (HBA) study at 27 sites across the country. The HBA study—a four-year, longitudinal study using novel technologies to determine the feasibility of assessing cognitively normal [older adults](#) in their own homes—was coordinated by the Alzheimer's Disease Cooperative Study (ADCS), an initiative of the National Institute on Aging based at UC San Diego School of Medicine.

Almost 6 million Americans are currently living with Alzheimer's disease (AD), according to the Alzheimer's Association, with an American developing the disease every 65 seconds. By 2050, the number

of persons with AD is projected to rise to nearly 14 million, making the need for research critical.

Yet little is known about the factors affecting the motivation and satisfaction of participants in dementia prevention trials, say experts. Beyond a motivation to help, the new study was an attempt to determine how future clinical trials might be made more attractive and effective. The HBA study involved various levels of [technology](#), such as mail-in questionnaires, live telephone interviews, automated telephone calls with [interactive voice response](#) and an internet-connected, home-sited computer kiosk with responses captured via automated speech recognition.

Researchers found that trial participants preferred staff-administered assessments more than automated technologies; greater opportunity to challenge and improve their own mental function (such as a wider variety of activities during testing); and increased interaction with both study staff and other, older adults. They also sought more personal feedback from researchers as the trial progressed.

Sano said it wasn't surprising that participants became bored with repetitive tasks and frustrated by inevitable equipment glitches.

"It's important to understand because it's common for new trials to have more technology and less human interaction," she said. "While advanced technology is clearly essential, we also must remember that people want to feel valued for their own ideas and personalities."

Co-author Jeffrey Kaye, MD, professor of neurology at Oregon Health and Science University and director of both the Layton Aging and Alzheimer's Disease Center and the Oregon Center for Aging and Technology, suggested technology should be used with participant comfort in mind.

"To maximize the advantages that technologies can bring to clinical [trials](#), it is important to ensure that devices or interactions with technology are integrated into participants' everyday lives. Ideally, the technology works in the background and is as unobtrusive as possible. If there are needed interactions, these must be engaging and minimally burdensome, especially when studies may be conducted over many years."

Senior author Howard Feldman, MD, professor of neurosciences at UC San Diego School of Medicine, and clinical neurologist and director of the ADCS said the findings should inform and improve future study design.

"By listening to the concerns and suggestions of our participants, we build better, more effective studies in the future," he said. "It's good to know that participants are feeling the spirit of altruism in this work, as we are essentially relying on successful expansion of this community effort to address the ever increasing size and challenges of Alzheimer's disease.

"It is incumbent on us to listen and plan accordingly. It is also important to note, and not to underestimate, the human element described in this research. Direct human interaction seems to be an important contributor to participant engagement and retention. It is a reminder that human contact provides a benefit to these studies, supporting [participants](#) in a way that technology cannot."

More information: Mary Sano et al. Participant satisfaction with dementia prevention research: Results from Home-Based Assessment trial, *Alzheimer's & Dementia* (2018). [DOI: 10.1016/j.jalz.2018.05.016](https://doi.org/10.1016/j.jalz.2018.05.016)

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