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Majority Of Americans Would Consider Participating In An Alzheimer's Clinical Trial. So, Why Are Enrollment Numbers So Low?

Global Alzheimer's Platform (GAP) Foundation is promoting innovative and easier-to-use clinical trial participation tools, including the Brain Health Registry

WASHINGTON, D.C. (July 18, 2016) – In a first-ever poll conducted online by Harris Poll on behalf of the Global Alzheimer's Platform (GAP) Foundation, nearly 60% of Americans report they are definitely willing or would consider participating in Alzheimer's disease clinical trials, but participation rates show that less than 10% are actually doing so ([source](#)). The failure to provide willing Americans more information and easier-to-use tools for participation could be seen as weakening the attack on America's most feared disease ([source](#)).

At this very moment, 17 Alzheimer's disease treatments are in Phase 3 clinical trials and on pace to get to market in the next five years, if successful in their trials and approved by the FDA ([source](#)). Any successful drug would be the first new therapy on the market in over a decade. To make this five-year aggressive timeline a reality, clinical trial participants are needed now. Recent data collected by the GAP Foundation finds that Americans are ready and willing to help, but lack of participation suggests they do not have the information and tools to do so.

Obtaining qualified trial participants has been one of the greatest challenges in getting clinical trials off the ground, which is why the GAP Foundation commissioned a survey to examine Americans' perceptions about Alzheimer's disease and to gauge their willingness to participate in clinical trials.

"We're closer than ever to finding a treatment for Alzheimer's, but we need an engaged army of citizen scientists to push these drugs over the line," said George Vradenburg, co-founder of GAP Foundation and USAgainstAlzheimer's. "Clinical trials are the ticket to making a cure happen. The first person cured of Alzheimer's will be in an Alzheimer's clinical trial."

John Dwyer, president of the GAP Foundation, added, "One of the reasons we founded the Global Alzheimer's Platform Foundation was because we heard from dozens of research institutions across the country that they were having difficulty finding and enrolling trial-ready candidates. GAP Foundation's role in this ongoing effort has been to build better tools and greater awareness of Alzheimer's clinical trials to accelerate clinical trials."

The GAP Foundation's national survey of 2,056 Americans ages 18 and older revealed two clear themes:

- 1. A majority (59%) of Americans are definitely willing or willing to consider taking part in an Alzheimer's clinical trial.**

- **20%** of Americans said they would definitely be willing to take part in a clinical trial. 22% of Millennials ages 18-34 said they would definitely be willing and 13% of adults ages 65+ said they would definitely be willing.
- **39%** of Americans said they would be willing to consider taking part in an Alzheimer’s clinical trial.

Dwyer continues, “Data shows us that the willingness to participate in clinical trials is there, so our next step is to bridge the gap between willingness and actual participation. The way we do that, is to make it as simple as possible for people to learn about what clinical trials they qualify for and how to sign up.”

2. Among those surveyed, willingness to participate in Alzheimer’s clinical trials remains relatively strong among African American, Hispanics* and Whites. In reality, far less a percentage of African Americans and Hispanics are enrolled in clinical trials, making minority recruitment into clinical trials a high priority ([source](#)).

- **20%** of Americans are definitely willing to take part in a clinical trial, including **24%** who are African American, **16%** who are Hispanic and **20%** who are White.
- **39%** of Americans said they would consider taking part in an Alzheimer’s clinical trial, including **34%** who are African American, **41%** who are Hispanic and **39%** who are White.

“African Americans are two to three times more likely to experience Alzheimer’s than Whites, and Hispanics are one and a half times as likely to experience Alzheimer’s as non-Hispanic whites, making their greater representation in clinical trials a matter of the highest priority,” said Vradenburg.

The Global Alzheimer’s Platform Foundation urges the following actions to help in the fight against Alzheimer’s disease:

1. Register free at www.brainhealthregistry.org. The Brain Health Registry (BHR) is a free, online platform designed to speed the path to cures for Alzheimer’s disease and other brain disorders. BHR gathers data from volunteers who have registered and completed questionnaires and cognitive tests via its website. BHR aims to reduce the cost of patient recruitment for clinical trials by building a large online pool of potential, trial-ready candidates.
2. Recognize the beginning signs and symptoms of Alzheimer’s disease, such as:
 - Memory loss
 - Difficulty planning and solving problems
 - Difficulty completing familiar tasks
 - Difficulty determining time or place
 - Difficulty finding the right words
 - Misplacing items often
3. If you are experiencing memory loss that disrupts your daily life, please seek the help of a medical professional right away.

Additional Findings:

- **25%** of Americans have/had a family member with the disease.
- **17%** of Millennials ages 18-34 believe, incorrectly, that there is a cure for Alzheimer's disease today.
- **More than 3 in 5 Americans (62%)** believe Hillary Clinton will do more than Donald Trump (**38%**) to help in the fight against Alzheimer's disease.
- **73%** of Americans who do not have Alzheimer's disease say that if they were to develop the disease, their biggest fear would be not knowing how their family would pay for their care.
- **28%** of Americans believe that health insurance usually covers most of the cost of care for someone with Alzheimer's disease.
- **23%** of Americans most feared developing Alzheimer's disease, more than the 18% who said they most feared having a heart attack and 7% who most feared getting shot. 27% most feared another major economic crisis, while 26% said they most feared being targeted in a terrorist attack.

Notes to Editors:

Representatives from the Global Alzheimer's Platform and Brain Health Registry are available for interview. Please contact Ashley Boarman at O: (415) 359-2312 | C: (443) 248-4532 or ashley@landispr.com.

*Caution: small base size (n=86); results should be interpreted as directional in nature.

About the Survey

This survey was conducted online within the United States from June 17-21, 2016 among 2,056 adults ages 18 and older, among which 394 are Millennials ages 18-34, 511 are adults ages 65+, 138 are Black/African American, 1,785 are White, and 86 are Hispanic by Harris Poll on behalf of the Global Alzheimer's Platform via its Quick Query omnibus product. Figures for age, sex, race/ethnicity, education, region and household income were weighted where necessary to bring them into line with their actual proportions in the population. Where appropriate, this data were also weighted to reflect the composition of the adult online population. This online survey is not based on a probability sample and therefore no estimate of theoretical sampling error can be calculated. For complete survey methodology, including weighting variables, please contact Ashley Boarman.

About Global Alzheimer's Platform Foundation

The Global Alzheimer's Platform Foundation was launched in 2015 by UsAgainstAlzheimer's and the Global CEO Initiative (CEOi) on Alzheimer's Disease with the vision of creating an integrated global clinical trial network to reduce the time, cost and risk of Alzheimer's disease clinical trials, a critical factor in the pacing of efforts to speed an effective treatment of Alzheimer's disease to those with or at risk of the disease. Global Alzheimer's Platform Foundation, headquartered in Washington, D.C., aims to create a faster pathway to a treatment for Alzheimer's disease by 2025. It intends to do so by building a standing global clinical trial platform of willing individuals through novel web-based recruitment techniques coupled with a network of high performance clinical trial sites. Global Alzheimer's Platform Foundation also provides an organizational framework that links prominent research institutions, the private sector and government agencies in multiple countries to fight Alzheimer's disease. For more information, please visit www.globalalzplatform.org.

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