

New studies give clear guidance on how to better recruit volunteers for Alzheimer's clinical studies

July 12 2009

Partnering with local physicians, working with local clinics, and conducting educational seminars and health fairs were found to be the most effective tools in recruiting people for Alzheimer's clinical studies, according to new research reported today at the Alzheimer's Association 2009 International Conference on Alzheimer's Disease (ICAD 2009) in Vienna.

Surprisingly, patient registries and Internet recruiting were found to be much less successful recruitment strategies, according to staff at the U.S. Alzheimer's [Disease Centers](#) (ADCs). The National Institute on Aging (NIA) funds 30 ADCs at major medical institutions across the nation. (<http://www.nia.nih.gov/Alzheimers/>)

"Second only to inadequate funding, recruiting participants for clinical studies is the single greatest barrier to developing better treatments for Alzheimer's disease," according to William Thies, PhD, Chief Medical & Scientific Officer at the Alzheimer's Association. "These studies give us clear information - from people who are conducting large scale clinical trials now - on how we may recruit participants better and faster in the future."

In another study looking specifically at recruiting African Americans for Alzheimer's genetics studies, researchers in North Carolina and Florida found that having a relative with the disease, use of minority study

personnel, and monetary compensation were the most powerful incentives for participation in research.

Successful Recruitment Strategies from the U.S. Alzheimer's Disease Centers

Tamara Markgraf, MBA, Research Program Manager at the Wisconsin Alzheimer's Disease Research Center in Madison and colleagues interviewed 22 administrators and outreach staff from 20 ADCs about their recruitment strategies and outcomes.

They found that all ADCs utilize community outreach and educational seminars to promote clinical study participation. 17 centers visit health-fairs; 15 recruit from patient clinics. 10 centers reported that the most successful recruitment strategy was recruitment from clinics. Other successful strategies included word of mouth (4) and referrals from [physicians](#) (3).

All the ADCs reported partnering with outside organizations such as the Alzheimer's Association. Several have linked with churches, church groups, or church leaders in efforts to boost recruitment, in particular minority recruitment. Many tried sending out postcards to high density postal codes, and other mass mailings. Advertising was not an option for most of those who reported, due to budget constraints.

Recruitment hurdles reported included minority recruitment (8) and inclusion/exclusion criteria (6). Half of ADCs utilize a recruitment registry with databases ranging from 200 to more than 1,500. Interestingly, only six of 20 sites reported their registry as a "beneficial" recruitment tool. In addition, although all ADCs have a website, few (7) see it as a beneficial, active tool for clinical study recruitment. In fact, the Internet was found to be the least successful reported strategy.

Despite identified hurdles, 13 of the ADCs report meeting annual recruitment goals.

"Our data suggest that successful recruitment is a result of a comprehensive recruitment plan," Markgraf said. "The successful ADCs promote study participation while conducting community educational events, and they actively partner with outside physicians. The professionals we interviewed told us that they best way to meet recruitment goals is to get the support of the local community and [physicians](#)."

Encouraging African American Participation in Alzheimer's Genetics Studies

Despite government regulations on inclusion of women and minorities in clinical research, such as the 1993 Revitalization Act, ethnic minorities continue to be underrepresented in biomedical research studies and clinical trials, including Alzheimer's studies. As part of an effort to recruit African Americans for an Alzheimer's disease genetics study, Goldie S. Byrd, PhD, Nathan F. Simms Endowed Professor in the Department of Biology at North Carolina A&T State University, and colleagues surveyed 500 African American adults to investigate perceptions and inform recruitment efforts for Alzheimer's research participation.

They found that having a relative with the disease, use of minority study personnel, and monetary compensation were the most powerful incentives for participation of African Americans in Alzheimer's genetic research. In addition, partnerships with churches and influential community leaders were found to yield significantly greater interest and participation.

"Among survey respondents who had never participated in a research study, 60 percent of those in the 60 to 69 age range with a family history of Alzheimer's were very willing to participate, independent of their knowledge of historical research atrocities such as the Tuskegee Syphilis Study," Byrd said.

The researchers found that African Americans were willing to participate in several types of research studies, including surveys, focus groups, clinical trials, and genetic studies - surveys were the most preferred form of participation in all age groups. Though 72% of respondents indicated a willingness to participate if blood samples were needed, enthusiasm for such studies diminished as age increased.

"Large percentages of African Americans are willing participants for Alzheimer's genetic studies, if culturally sensitive techniques are used to recruit them," Byrd said.

Why People with Alzheimer's and Their Relatives Participate in Clinical Studies

In order to further inform the clinical study recruitment process, Ulrika Akenine, MS, a registered nurse at the Memory Clinic, Geriatrics Department, Karolinska University Hospital, Stockholm, and colleagues investigated the motives and expectations of people with dementia and their relatives for participating in Alzheimer's research trials.

For the study, 19 people with mild to moderate Alzheimer's, average age 66 years, and their relatives (20 caregivers) participating in five different vaccination studies at the clinic answered a questionnaire during October and November 2008. Primary motives to participate for both patients and their relatives were helping science and contributing to research, hope for easing of symptoms or cure, and getting access to more

information about the disease. Patients and relatives reported that access to medical expertise and regular health checkups were advantages of study participation.

Among the disadvantages were the risk of receiving placebo, discomfort/pain during sample-taking and exams, and the risk of side effects. People with Alzheimer's reported to a greater extent than caregivers that they did not see any disadvantages to participating in a research study.

"Research on Alzheimer's is intense, and there is great hope for new drugs that will ease the impact of the disease," Akenine said. "Many people with dementia and caregivers will face the question of whether to participate in clinical trials. We hope our research helps inform healthcare providers, advocacy organizations, and pharmaceutical companies who have increasing need to address these questions."

Source: Alzheimer's Association

Citation: New studies give clear guidance on how to better recruit volunteers for Alzheimer's clinical studies (2009, July 12) retrieved 27 April 2024 from <https://medicalxpress.com/news/2009-07-guidance-volunteers-alzheimer-clinical.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.