

EPIDEMIOLOGY

Información de la Enfermedad de Alzheimer para Latinos: A Study Framework for Alzheimer's Genetic Risk Disclosure in an Urban, Latino Population

Sophia Rodriguez¹ | Daniela Diaz Caro¹ | John Brandon Wetmore¹ | Jonathan D Godinez¹ | Itzel A Camarillo¹ | Jill S Goldman² | Wendy R. Uhlmann³ | Rebecca Ferber⁴ | Drew Blasco⁵ | Maria Caban¹ | Cheng-Shiun Leu¹ | Ana F Abraido-Lanza² | Rafael A. Lantigua¹ | Wendy K Chung^{6,7} | J. Scott Roberts^{4,8} | Karolynn Siegel¹ | Ruth Ottman^{1,9}

¹Columbia University Irving Medical Center, New York, NY, USA

²Columbia University, New York, NY, USA

³University of Michigan Medical School, Ann Arbor, MI, USA

⁴University of Michigan, Ann Arbor, MI, USA

⁵University of Nevada, Las Vegas, Las Vegas, NV, USA

⁶Harvard Medical School, Boston, MA, USA

⁷Boston Children's Hospital, Boston, MA, USA

⁸University of Michigan School of Public Health, Ann Arbor, MI, USA

⁹New York State Psychiatric Institute, New York, NY, USA

Correspondence

Sophia Rodriguez, Columbia University Irving Medical Center, New York, NY, USA.

Email: sr3801@cumc.columbia.edu

Abstract

Background: The IDEAL study is a randomized clinical trial investigating the psychosocial, behavioral, and cognitive impacts of genetic risk disclosure for late-onset Alzheimer's disease (LOAD) among Latinos.

Methods: We used address-based sampling in northern Manhattan to recruit Latinos aged 40–64 for a community-based survey and clinical trial. Data collection encompasses demographics, Alzheimer's disease (AD) family history, knowledge and beliefs about AD and genetics, current mental health status, acculturation, impact of COVID-19, familism, fatalism, caregiver status, and prior AD genetic testing. Eligible participants are invited to complete an education session and provide informed consent before receiving genetic testing for APOE, a key LOAD predictor. The clinical trial component will include 400 participants, who are randomized to learn their LOAD risk by age 85 based on either Latino ethnicity and family history alone or the same factors plus APOE genotype. Risk information is provided through semi-structured genetic counseling sessions. Psychological impacts, health-related behavioral changes, and memory performance are evaluated six weeks, nine months, and fifteen months post-disclosure via surveys and in-depth qualitative interviews.

Results: From 91,433 invited households, 5,542 (6.1%) responded, and 2,087 (2.3%) were eligible and completed the Baseline survey. Most were 40–49 years old (41.2%), women (70.5%), identified as Dominican (53.7%), had some college education (63.2%), and completed the survey in English (74.6%). About half reported a family history of AD (48.6%).

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2024 The Alzheimer's Association. *Alzheimer's & Dementia* published by Wiley Periodicals LLC on behalf of Alzheimer's Association.

Conclusion: This study addresses gaps in understanding of impacts of AD genetic risk disclosure among Latinos and contributes valuable insights through its mixed-methods approach.