

Alzheimer's Disease (AD) in Underserved Populations

A Landscape Analysis: Situation, Barriers & Solutions

The Problem

- African Americans and Latinos are more likely to develop Alzheimer's Disease than non-Hispanic whites.
- Death from Alzheimer increases in all groups in the United States, but even more in African Americans and Latinos.
- African American's represent ~20% of the 5.4 million Americans with AD, yet they account for less than 5% of trial participants.

Project Goals

- Identify disparities in Alzheimer's Disease, specifically in the African American and Hispanic populations
- Examine what can be done to address these health disparities
- Identify the role Biogen can play in addressing disparities in Alzheimer's Disease

Barriers to Diagnosis and Clinical Trial Participation in African American and Latino Communities

Disease Awareness

- Lack of disease awareness and understanding
- Dementia seen as normal aging
- Focus on other diseases: Diabetes, Heart disease, Colon Cancer

Stigma

- Negative connotation around mental health issues
- Mental health issues seen as curse in some cultures
- Fear and denial barriers to timely diagnosis

Healthcare Providers

- Screening and memory conversations not suggested or initiated
- Little questioning or demand for second opinion
- Little time with patients

Clinical Trials

- Low awareness
- Lack of trust: Previous unethical procedures barrier; belief that enrollment could happen without consent
- CTs not recommended – sometimes lack of options



“We’d been sitting in a waiting room in the Bronx for an hour, in a room filled with people who were struggling, who barely spoke English, who needed help, only to have a smug doctor tell me to Google my mother’s serious condition and devise a plan for her.”

Yvonne, Latino American, caregiver for her mother with Alzheimer's Disease

WHAT CAN BE DONE?

- Targeted disease education in culturally appropriate language
 - Differentiate AD vs normal aging
 - Educate about brain health, cognition and cognitive impairment
 - Increase understanding of the AD continuum: disease starts 15-20 years before the first symptoms
- Identify Ambassadors and Key Influencers in the communities
 - Engage churches and faith organizations
 - Create Ambassador Programs
- Engage Clinical Trial sites – support recruitment of trial coordinators
- Work locally – city to city
- Be present and invest in relationships

WHAT CAN BIOGEN DO?

- Targeted disease education
- Co-development of service models: ensure input and feedback from diverse communities in the development of services and tools in AD
- Primary care physicians education with partners in the community – identify and support initiatives to educate and raise awareness about AD
- Support church organizations and other integrated and credible organizations to promote clinical trials in general
- Engage and support our clinical trial sites

POTENTIAL CHALLENGES

- Credibility of industry and lack of relationships
- Commitment from clinical trial sites, e.g. due to lack of time
- Short timelines and lack of long term commitment

“The first person to be cured of Alzheimer's is a person in a Clinical Trial”

African Americans Against Alzheimer's