



The VOICE of FTD

FALL 2019

Minority Voices:

Ensuring racial and cultural diversity in the FTD Registry and Research

Research has shown that African-Americans are twice as likely and Latinos are one and a half times more likely than non-Hispanic whites to be diagnosed with Alzheimer's disease. Yet according to an article published in [PubMed Central](#), African-Americans and Latinos make up 30 percent of the U.S. population and account for only 6 percent of all participants in federal-funded clinical trials.

To determine whether a similar diagnosis disparity exists for other dementias, including frontotemporal degeneration (FTD), a greater number of persons from these and other racial and ethnic backgrounds are needed to participate in research.

Regardless of the disease, the effectiveness of most medical treatments have been determined via research and are designed for the "average patient." Unfortunately, this means that treatments may be successful for some patients but not for others, even within a minority subgroup.

The distribution of FTD appears to be equal by gender, but to learn distribution by race and ethnicity, studies need more representation by minority groups, according to Chiadi U. Onyike, M.B.B.S., M.D., and Janine Diehl-Schmid, M.D., in their paper [The Epidemiology of Frontotemporal Dementia](#). [Dr. Onyike](#) is Director of the Frontotemporal Dementias Program at [Johns](#)

[Hopkins University School of Medicine](#) in Baltimore, Maryland; and Prof. Dr. Diehl-Schmid is with the Center for Cognitive Disorders, Department of Psychiatry at [Technische Universität München](#), Germany.

Under-representation in research exists not only for African-Americans and Latinos, but also for other minority populations. Asians are well represented in some foreign trials, but only 2 percent participate in U.S.-based trials, according to a [ProPublica article](#) that examined the lack of diversity in cancer drug clinical trials. Native American participants aren't even involved in almost two-thirds of trials.

Similarly, the FTD Disorders Registry (FTDDR) seeks to encourage all persons affected by FTD – whether diagnosed persons, family members, or caregivers – to participate in the Registry, clinical trials, and other research regardless of their race and ethnic background.

The Importance of Diversity in Research

Research is usually performed using a small portion of the overall population with the goal of providing an effective treatment for the entire population. However, without a diverse group of individuals participating in research, researchers will not know whether the results can be applied to all people equally.

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[Building Trust between Minorities and Researchers](#) (BT), a bioethics research initiative, addressed the underrepresentation of many minority groups in research. The initiative was part of federal recognition of the importance of fostering increased participation rates of racial and ethnic minority populations in research. It was initiated by the [Center for Health Equality](#) at the [University of Maryland's School of Public Health](#).

Diversity in research means that people of different ages, different racial and ethnic groups, and different genders participate in studies.

According to BT, the top five reasons diversity is important in research are:

1. Some groups of people suffer more from certain diseases than other groups.
2. The cause of a disease may not be the same for all groups of people.
3. Medical treatments may not be equally effective for all groups of people, and some groups of people may experience more side effects from medications than other groups.
4. Individuals within the same racial or ethnic group can respond differently to the same treatment.
5. Diversity in genetic samples and databases is needed to guide personalized medicine based on an individual's genetic makeup.

Why are Minorities Underrepresented?

In an attempt to remove this disparity gap, in 1993 the [National Institutes of Health](#) (NIH) mandated including racial and ethnic minorities in federally funded research. However, fulfilling this requirement continues to be challenging.



Various studies focusing on the lack of minority representation in research have offered several possible reasons for this, including:

- ◆ Cultural differences
- ◆ Linguistic differences
- ◆ Financial constraints
- ◆ Time constraints
- ◆ Logistical challenges
- ◆ Lack of studies in minority communities
- ◆ Lack of incentive to recruit
- ◆ Lack of incentive to retain
- ◆ Reluctance and distrust based on past unethical practices
- ◆ Fear of exploitation
- ◆ Higher presence of other health issues, which exclude them

Some minorities do not wish to participate in research due to unethical studies conducted in the past. Two of the most widely known and attributed cases are the [Tuskegee Syphilis Study](#) (African-Americans) and the [Havasupai Tribe Diabetes Project](#) (Native Americans). However, such issues have been addressed through policy statements and increased regulations, including the World Medical Association's cornerstone document on ethical principles for medical research involving human subjects, known as the [Declaration of Helsinki](#), and subsequent U.S. policies including [The Belmont Report](#), the [Common Rule](#), and to a lesser degree by the [Privacy](#)

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[Rule in the Health Insurance Portability and Accountability Act \(HIPAA\)](#). Together these policies have guided changes to recruitment procedures, participant rights, informed consent policies, regulatory oversight, and the electronic transmission of personal health information.

Participation in research studies can create financial challenges. While experimental drugs and other treatments are free and patients are reimbursed for food and travel expenses, people with lower incomes often cannot afford to take time off of work, commute long distances, or find child care. A report on [Patient Income Level and Cancer Clinical Trial Participation](#) showed that households with an income less than \$50,000 per year were 27 percent less likely to participate.

Sometimes minorities are excluded because they are more likely to have other health issues, such as high blood pressure and diabetes, compared to white Americans. For some studies, stringent trial criteria disallow participation of patients with multiple conditions regardless of race and ethnicity.

However, despite the obstacles, research also has determined that many individuals of various racial and ethnic backgrounds are willing to participate in research when given the opportunity and when the research objectives are explained in a culturally relevant context.

Some of the possible solutions that have been suggested to increase minority participation include:

- Locating study sites in areas with diverse residents
- Providing travel support
- Employing staff or providing translation services that speak a participant's native language
- Creating culturally sensitive informational materials that detail how data will be collected and used

Minority Participation Is Increasing

Adequate representation of diverse populations in scientific research is imperative as a matter of social justice, economics, and science. And while minority participation still has a long way to go, overall trial diversity has been increasing.

Race and ethnicity offer important clues to researchers. Clinical trials need to represent all demographic groups so any variations of the disease can be revealed and discovered treatments can aid those determined to benefit.

Here at FTD Disorders Registry, we are always investigating methods to reach out and connect to under-represented populations. Participation in the Registry by all persons, regardless of their race or ethnicity, helps everyone affected by these devastating diseases.

With continued due diligence, clinical trials for FTD will represent an appropriate cross section of the population.

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**Join the Registry.
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"Together, we can make a difference!"

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