

### *Perspectives in Brief:*

#### **How the Alzheimer's Community can Support the "Science of Inclusion"**

On February 28<sup>th</sup>, 2022, 25 participants representing 20 organizations convened for 2022's first installation of Biogen's Expert Panel Series to review the changing policy landscape related to diagnosis, treatment, and care of Alzheimer's disease, focusing on meaningfully engaging underserved/underrepresented populations in research and treatment. Attendees listened to a presentation from [Dr. Monica Parker](#), Assistant Professor at the Emory School of Medicine. Dr. Parker discussed with attendees the Emory University Goizueta Alzheimer's Disease Research Center (ADRC)'s outreach program to Atlanta's African American population and shared best practices for engaging underrepresented communities in clinical research.

This discussion explored elements of successful community outreach programs for education, treatment, and research participation related to Alzheimer's disease, including:

- Longevity
- Reciprocity
- Representation
- Generalist Physician Participation

Centered on these areas, Dr. Parker and participants shared insightful experience and wisdom for increasing engagement with underrepresented populations in the Alzheimer's disease research and treatment enterprise.

#### **Challenge: *Engage historically underrepresented groups***

There is a distinct need to diversify the Alzheimer's disease research enterprise. Underrepresented populations, namely non-White groups, are currently less likely to participate in research; however, the same groups are disproportionately likely to suffer from Alzheimer's disease. Heterogeneity in research participation is crucial to understanding the effects of potential new treatments on various populations to ensure Alzheimer's disease treatment plans are developed for optimal patient benefit.

- **Current research is not representative.** Hispanic, Asian American and Pacific Islander, and African American populations are drastically underrepresented in the Alzheimer's disease research landscape. Many groups, including rural populations, face logistical barriers to entry into clinical trials.
- **The burden of Alzheimer's disease is disproportionate.** Different ethnic and racial groups have various likelihoods of developing Alzheimer's disease in their lifetimes, with traditionally underserved groups facing a higher risk.
- **Research needs to reflect diverse populations.** Clinical research serves the purpose of developing Alzheimer's disease prevention and treatment methods. However, using a

homogenous set of research participants skews findings and results in treatments that have demonstrated effectiveness for some segments of the population, while a data gap may exist for others. Various risk factors and medication reactions must be accounted for in clinical trials to explore optimal treatment for all.

### **Opportunity: *Design outreach efforts with intentionality***

Intentionality is the most crucial piece of successful outreach to underrepresented communities. Being intentional means viewing outreach as a long-term investment in people, gaining insight into the community's unique needs, and understanding and working within the cultural context of that community. Mutual trust is of the utmost importance in intrusive research, and intentionality is the key to building that trust.

- **Commit to long-term engagement.** Successful community outreach does not happen overnight. Researchers must commit to longstanding relationships to build mutual trust and respect. Doing so means deploying personnel who will stay the course, communicating regularly, and understanding that building an authentic connection takes time, like any other interpersonal relationship.
- **Embrace reciprocal program-building.** Listen to the targeted community's needs. Rather than anticipating a population's challenges, wants, and needs, discuss those factors with community representatives. Design educational sessions, screenings, and research around community feedback to create more impact and recruit for research.
- **Representation matters.** If possible, a principal investigator and members of the research team should be members of the population they are targeting. For example, outreach to an African American population should be led by a primarily African American research team. If having a representative research team is not feasible, collaborate with trusted leadership organizations from the community, such as a public health group, social group, or faith group.

### **Opportunity: *Involve primary care physicians in the research enterprise***

Currently, the Alzheimer's disease research enterprise mainly consists of specialists and researchers. But primary care and other generalist doctors have the potential to make a significant difference in inclusionary research, as well as Alzheimer's disease diagnosis at large. While research facilities such as the ADRC are somewhat constrained by their geographic location, primary care doctors exist and actively see patients in every part of the country. Already existing within and treating underserved communities, primary care doctors can refer numerous diverse patients to Alzheimer's disease research.

- **Primary care doctors have more exposure to patients.** Older adults without a diagnosis are more likely to visit their primary care doctor than a geriatric or neurology specialist. These primary care doctors should be the first point of contact to observe symptoms of

Alzheimer's disease in patients and make appropriate referrals to specialists and clinical trials. Unfortunately, many generalists are untrained in geriatrics. Primary care doctors should undergo training to identify the risk of Alzheimer's disease, giving patients a chance for early treatment and research participation.

- **Patients trust their doctors.** Primary care doctors are uniquely suited to refer patients for Alzheimer's disease research due to their longstanding relationships. When encouraged by a trusted source, individuals become less resistant and fearful of invasive clinical tests.
- **Primary care doctors know their patients.** Patients should not participate in research if they have a current clinical need. Primary care doctors know better than others the unique circumstances and medical history of their patients and thus, can provide knowledgeable opinions on trial eligibility before referring them.
- **Participants must continue to receive primary care.** Clinical research must go together with the overall delivery of healthcare. Generalist physicians can play a crucial role in providing that necessary healthcare in alignment with research participation.

### ***Call to Action: Support teams dedicated to diversity***

Teams that are dedicated to growing representation in the Alzheimer's disease research enterprise are poised to create a strong impact in underrepresented communities – but this work is both specialized and costly. Acquiring personnel and funding is a challenge. However, the mission is growing stronger with every new stakeholder who commits to the cause, shares best practices, and advocates for resources. Moving forward, Alzheimer's disease experts can strengthen equitable research participation by doing the following:

- Encourage researchers to tailor outreach to underserved communities, with an intentional focus on longevity, reciprocity, and representation.
- Elevate the voices of underrepresented community members.
- Write grants to assist organizations like the ADRC in their many existing activities.
- Urge generalist colleagues to educate themselves on Alzheimer's disease to be prepared to refer patients for treatment and research.

Diversity in Alzheimer's disease clinical research participation is crucial to creating more effective treatment strategies for all. Targeted community outreach is not only beneficial for recruitment; it also educates community members on healthy aging. As influential members of the Alzheimer's disease community, we must commit ourselves to this imperative cause.

### ***Additional Reading:***

- [Improving diversity in Alzheimer's research can help update the 'gold standard' for all medical research \(Stat News\)](#)
- [NIA funds Emory clinical research lab for LGBTQ health-related study \(The Emory Wheel\)](#)

- [\*Together We Make the Difference: National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research \(NIA\)\*](#)
- [\*NIH unveils new online tool to improve Alzheimer's clinical trials recruitment \(NIH\)\*](#)