

## **Inclusion of Women and Minorities.**

Volunteers for this study will be drawn from a wide geographic region, including urban Boston and the surrounding communities, and will include a representation of women and minorities. We anticipate that 50% of eligible participants will be women. We will make special efforts to include approximately equal numbers of women and men into each of our study subgroups (e.g., MCI/healthy), with an intent to evaluate any differences due to sex as a biological variable. Women constituted approximately 50% of the study samples in our previous research projects.

Historically, neuroimaging studies in aging populations, as well as clinical trials in Alzheimer's disease, insufficiently represented the minority populations, limiting external validity. According to the CDC, among the Americans over 65 years of age, African Americans exhibit the highest prevalence of Alzheimer's disease and related dementias (13.8%), followed by Hispanics (12.2%) and non-Hispanic whites (10.3%). Adequate representation of minorities in research on Alzheimer's disease is urgently needed.

Our group has made a major effort to develop strategies, procedures, and tools to effectively recruit and retain the underrepresented groups in research. As a part of previously and currently funded projects, including the Human Connectome Project for Aging (HCP-A) and the Aging Adult Brain Connectome (AABC), we have built a Diversity Recruitment and Retention Unit (DRRU) that will ensure our ability to recruit and retain a racially and ethnically diverse study sample. Dr. David Salat (Co-Investigator) and Dr. Beau Ances (Consultant) serve(d) as co-PIs on the HCP-A and AABC projects. At our hospital site, 27% of participants enrolled in the HCP-A were members of racial and ethnic minorities, which is substantially higher than in other brain-aging studies (e.g., Alzheimer's Disease Neuroimaging Initiative [ADNI]). 55% of the enrolled participants were women. The current project will utilize and expand the DRRU resources to recruit and retain an adequately proportionate representation of minorities in the study population sample. According to the 2019 report of the Administration for Community Living (ACL), 24% of Americans over 65 years old are members of racial and ethnic minorities (9% are African American, 5% are Asian, and 9% are Hispanic). Based on these data and the prevalence of Alzheimer's disease in different minority populations, we estimate that among patients with late-onset Alzheimer's disease, 13% are African Americans, between 11-12% are Hispanics, and between 4-5% are Asians. We propose to recruit a study population that reflects this distribution.

A unique resource available for our recruitment efforts is a patient registry at our hospital. The registry includes over five thousand older adults who have consented to be contacted about study participation. 25% of the individuals in the registry are members of racial and ethnic minorities. Specifically, 508 African American individuals (331 women) and 407 Hispanic individuals (258 women) have consented to participation in our research. In addition, we will recruit participants from urban Boston and the surrounding communities. Our recruitment and retention efforts will be inclusive and grounded in the NIH Community-Based Participatory Research (CBPR) principles. We will integrate across traditional communication (e.g., focus groups, newspapers, presentations, snow-ball sampling), social media (e.g., Nextdoor, Twitter, Facebook, etc.), and community outreach (e.g., barber/beauty shops, churches, bodegas/markets, clinics, etc. in underserved neighborhoods). Our hospital has satellite sites in several underserved communities (e.g., Chelsea, where the population is 67% Hispanic) that will serve as bases for outreach activities. Our recruitment efforts will be in concert with enrollment efforts for the AABC as we execute the DRRU's thoughtful trust-building approaches developed for the involvement of older adults from underrepresented groups like Blacks and Latinx, including options of Spanish language assessment instruments. In our outreach, we will also partner with Massachusetts Alzheimer's Disease Research Center (MADRC), which has long-standing relationships with faith communities in local neighborhoods (e.g., Mattapan, where the population is 75% Black/African American). Drs. Deborah Blacker and Bradford Dickerson (Collaborators) are members of the MADRC leadership. In our retention efforts, we will adopt the NIA Health Disparities Research Framework in consideration of biological, behavioral, sociocultural, and environmental dimensions. We will have web pages parallel to the new DRRU website where we clearly describe anticipated experiences while participating in our study, with videos illustrating all research procedures. We will have website sections describing the new study findings and new essential results in the field of Alzheimer's disease, explaining any implications for public health and, specifically, the health of members of racial and ethnic minorities – all in literacy-friendly form. The website will also highlight local community health resources and local events promoting brain and general health and provide contact information for a dedicated project ambassador. We will send out quarterly newsletters to all study participants with updates on our research discoveries in the context of broader research efforts in Alzheimer's disease, including fun facts and contact information for any comments or questions. We will invite participants to yearly presentations via Zoom to highlight new research discoveries. In partnership with the AABC, direct community

engagement will include lay-language informational presentations to older adults and their families on healthy aging to benefit diverse local communities.

Our DRRU will also receive feedback on the recruitment and retention operations from a Community Advisory Board (CAB) established by the AABC. This group will involve stakeholders from diverse backgrounds, who will provide advice on recruitment, inclusion and retention strategies, operational aspects of testing and study conduct, enhanced accessibility of resources to support the local community health, and improved dissemination of results and publications. This feedback will supplement the expertise of our research team in working with older adults from diverse backgrounds (Drs. Sitnikova and Salat in neuroimaging in older adults, Dr. Blacker in geriatrics, and Dr. Dickerson in clinical neurology in older adults). Recruitment and retention of diverse study participants are of the utmost urgency to our project. Participants will be given the highest level of respect, and their well-being will be the top priority. Finally, we will ensure that recruitment is conducted fairly and without selection bias.

### Inclusion Enrollment Report 1

1. Inclusion Enrollment Report Title\* : 100 nondemented older adults

2. Using an Existing Dataset or Resource\* :  Yes  No

3. Enrollment Location Type\* :  Domestic  Foreign

4. Enrollment Country(ies):

5. Enrollment Location(s): Massachusetts General Hospital, Boston, MA

6. Comments:

### Planned

Racial Categories	Ethnic Categories				Total
	Not Hispanic or Latino		Hispanic or Latino		
	Female	Male	Female	Male	
American Indian/Alaska Native	1	1	0	0	2
Asian	5	5	0	0	10
Native Hawaiian or Other Pacific Islander	1	1	0	0	2
Black or African American	9	9	2	2	22
White	24	24	8	8	64
More than One Race	0	0	0	0	0
<b>Total</b>	<b>40</b>	<b>40</b>	<b>10</b>	<b>10</b>	<b>100</b>