

## 2. SPECIFIC AIMS

Community-engaged research is an effective strategy for addressing health-related disparities. It involves authentic partnerships with high-risk populations, community leaders, and stakeholders and can lead to increased knowledge, improved behaviors, and capacity and trust building.<sup>1-6</sup> This R01 will be the first large-scale community-based study to enhance a partnership between South Carolina and Puerto Rico to advance research and outreach on dementia for Hispanics – an extremely understudied group in general and specifically regarding dementia. The fastest growing population group in the nation (and in South Carolina),<sup>7</sup> Hispanics experience significant health disparities.<sup>8,9</sup> Hispanics are 1.5 times more likely than non-Hispanic whites to have Alzheimer' disease and related dementias (ADRD) due to the higher prevalence of cardiovascular disease and diabetes associated with increased risk for dementia.<sup>10-15</sup> Puerto Ricans are the second largest U.S. Hispanic subgroup and awareness and education about dementia is particularly important since they experience higher mortality from dementia than individuals in the contiguous U.S.<sup>16,17</sup> Due to the tremendous human and financial burden, dementia has risen to the forefront of the U.S. public health agenda.<sup>18-24</sup> By engaging Hispanic subgroups living in distinct geographic and social contexts, this community-based research will contribute significantly to advancing the science of culturally tailored health promotion strategies.<sup>25</sup>

The proposed R01, entitled *MENTOR (Modeling and Engaging Networks through Outreach and Relationships)* is guided by (1) national reports and initiatives developed in part based on previous work of members of this research team and partners;<sup>23,26,27</sup> (2) principles of community-engaged research;<sup>1,3,28-31</sup> (3) a federal report of the National Hispanic Council on Aging;<sup>32</sup> (4) Healthy People 2020 dementia focused objectives;<sup>20</sup> and (5) the strategic plan of the National Institute of Nursing Research (NINR),<sup>33</sup> specifically understanding the physical, behavioral, cultural, and environmental influences on health in order to develop culturally tailored interventions and provide communities and caregivers with relevant education and resources. The aims of this proposal are aligned with and will contribute to these important national initiatives.

There are two Specific Aims:

(1) Conduct community-engaged formative research with Hispanic communities, dementia caregivers, and providers, increasing and enhancing the knowledge base about Hispanics' perceptions, understanding, and communication practices regarding dementia in South Carolina and Puerto Rico; and  
(2) Use data from Aim 1 to adapt, implement, and evaluate targeted and evidence-informed health promotion programming for multiple audiences (Hispanic community members and caregivers, providers) in both settings. To achieve Aim 1, we will retrieve and integrate existing statewide and territory-wide data to determine the impact of dementia on intended communities, and conduct key informant interviews, focus groups, surveys, and a community Photovoice project. Findings from Aim 1 will inform the dissemination, implementation, and evaluation of evidence-informed programming for Hispanic communities, dementia caregivers, and providers (Aim 2).

In terms of institutional context and support, researcher expertise, and existing connections and collaborations, we are extremely well-positioned to conduct the proposed research. The University of South Carolina (USC) was a continuously-funded CDC Healthy Aging Research Network (HAN) for over 10 years and a co-leader of the national HAN Healthy Brain Workgroup and is currently funded specifically as a Healthy Brain Research Network (HBRN) Center within the USC Prevention Research Center. This interdisciplinary research team has the necessary knowledge and experience to ensure success, contributing expertise on healthy aging, community-engaged formative research, cognitive health, caregiving, partnership assessment, culturally appropriate messaging, program development, implementation and evaluation. Furthermore, this team is well-connected to relevant local, regional, and national resources and has strong, established partnerships with public health departments, aging service networks, and diverse community-based organizations and stakeholders for research and dissemination. Finally, the established collaborative history between USC and the Puerto Rico Department of Health includes previous funding, co-authored publications, and partnership on evaluating evidence-informed dementia messaging.<sup>34,36</sup> This is a unique partnership in that South Carolina and Puerto Rico are two of only five states/territories that have ADRD registries. Enhancing this collaboration will increase impact in understudied populations through the translation of critical health promotion and dementia programming.

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