NACC Project #2017-01 (collaborative project)

Retaining participants in longitudinal studies of Alzheimer's disease

Lead Investigator
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Collaborating Centers
University of Pittsburgh
University of Wisconsin

Project Work Dates
2017 – 2019

Project Description
A paradigmatic shift in the study of Alzheimer’s disease (AD) has resulted in a move toward longitudinal studies of younger, symptom-free adults. These studies have a significant perceived research burden associated with biomarker collection procedures and annual assessments of clinical and neuropsychological function. One of the most important but understudied impediments to advancing AD research may be the difficulty recruiting and retaining research participants in longitudinal studies of AD. Recruitment of research participants has recently received considerable attention; retention remains understudied. To address this gap, this multi-center study will identify known and novel facilitators and barriers to longitudinal AD research participation. The study will capitalize on ongoing longitudinal studies across three diverse AD Research Centers (ADRCs). We will conduct a comprehensive survey of enrolled and recently dropped out research participants age 45 and older and use the findings to develop and pilot a set of research design guidelines to increase retention in longitudinal AD studies. The aim of this study is to identify perceived facilitators and barriers to remaining enrolled in longitudinal studies of Alzheimer’s disease. If successful, this study could have immediate positive impact by providing evidence to the National Institute on Aging and the National Alzheimer’s Coordinating Center so they can make informed recommendations to ADRCs on the optimal protocols for retaining participants in longitudinal studies of AD.

Contact Information
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