2020 ILIAD Protocol Details
(cor 1029)

This document is written for researchers who want to better understand the protocols WLS and ADRC employed to create a research diagnosis of ADRD.

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With funds from the National Institute on Aging the WLS partnered with UW Madison's Alzheimer Disease Research Center (ADRC) to conduct a new round of interviews starting in 2019. ILIAD 2020 (Initial Lifetime's Impact on Alzheimer's Disease and Related Dementias) includes either one or two interviews for each participant for whom we had a prior measure of cognition or another criterium.

Diagnosis via consensus panel

First, we conducted a "short" phone-based interview that took 30 to 40 minutes. The focus was on memory and thinking where we repeated cognitive measures collected in prior rounds of WLS, and for the first time, administered the Telephone Interview for Cognitive Status-modified (TICS-M) to broadly assess global cognition. We also updated select family and health measures. Next, we identified participants at risk for dementia based on a TICS-m score below the established cutoff of <29 to participate in a "long" interview with both a trained survey interviewer (IV) and an Advanced Practice Provider (APP) also known as a nurse practitioner. The “long” interview consisted of detailed cognitive testing through administration of the neuropsychological battery from the National Alzheimer’s Coordinating Center (NACC) – Updated Data Set 3 (UDS3) to assess the cognitive domains of memory, language, attention, visuospatial abilities, and executive functioning. Collateral report of cognitive abiliites and level of independence with instrumental activities of daily activities (IADLs) was obtained from a designated “study partner” using the Clinical Dementia Rating Scale (CDR) and other structured questionnaires (Functional Activities Scale (FAS), and the Informant Questionnaire of Cognitive Decline in the Elderly (IQ-Code)). The APP portion entailed a clinical interview with the respondent to thoroughly assess medical history and current medication usage, psychiatric symptoms, as well as completion of a physical and neurological exam, when possible.

We had initially planned for the long interview to be an in-person interview with both the IV and APP present. Because of the Covid-19 pandemic, we stopped in-person interviews shortly after we started. We restarted the long interviews after developing a comparable phone instrument (using telephone-based versions of the NACC neuropsychological battery and omitting the in-person physical and neurological exams). As vaccines and testing became available, we were able to return to in-person visits. By the end of our fielding period for the long follow-up interview, participants who completed the 2020 long instrument did so in one of four ways. See measure q1a942re for the four different combinations of modes for the long interview.

Data collected during the “long” interviews (i.e., among respondents selected as “at risk” for dementia based on TICS-m) was reviewed by an interdisciplinary consensus panel of clinicians consisting of an APP, a geriatrician, and a neuropsychologist to establish a research-based cognitive diagnosis. Diagnostic protocols closely adhered to the standards followed by the NACC consortium and were based on all relevant data collected during the “long” interview. Taking into account other medical conditions and symptoms, the clinicians assigned each participant a level of impairment (q1a951re). A subset of participants selected for the “long” interview demonstrated intact cognitive abilities on further testing and did not meet criteria for a cognitive diagnosis. Mild cognitive impairment (MCI) indicated cognitive functioning was considered impaired in one or more domains, alongside maintained functional independence in all IADLs. Those with MCI were further subtyped by the number of domains affected (single, multi), and the presence of memory impairment (amnestic) (see q1a952re). Dementia was defined by impaired cognitive functioning in two or more cognitive domains that significantly impacted independence performing IADLs. Among those classified as MCI or Dementia, suspected primary and contributing etiologies were established by clinician judgement considering cognitive testing profile, medical history, reported symptoms and course, and any other relevant data. Cognitive impairment due to Alzheimer’s Disease was the most common etiology (consistent with base rates of Alzheimer’s Disease within this age range), and we report whether Alzheimer's Disease was considered to be the primary etiology, a contributing etiology, or not present for each case. Although other etiologies were also documented across the various cases (such as vascular, Lewy Body Disease, Parkinson’s Disease, Traumatic Brain Injury, etc), these other etiologies do not include enough cases to make available on the public release of the data. Researchers needing these additional measures should contact wls@ssc.wisc.edu.

Diagnosis via Proxy interview

If we learned that the intended participant died or was too ill to be interviewed, we recruited an informant to answer questions about the participant's cognitive health. These informant interviews used the Dementia Questionnaire (DQ) which was scored for dementia. See measure stat20DQ for the number and type of interviews we completed using the DQ. The information collected on the DQ was first processed using an algorithm to approximate a dementia diagnosis. (Kawas C, Segal J, Stewart WF, Corrada M, Thal LJ. A validation study of the Dementia Questionnaire. Arch Neurol. 1994 Sep;51(9):901-6. doi: 10.1001/archneur.1994.00540210073015. PMID: 8080390.) Next a clinician looked at the outcome of the algorithm as well as the detailed notes that the interviewers captured during their conversations. The clinician confirmed the diagnosis and also assigned a level of confidence to the diagnosis based on the DQ. See measures q1a954re and q1a955re.

Finally for the ease of researchers wishing to combine cases that completed the long interview with cases for which we only have proxy data we create a combined diagnosis measure (q1a956re)

We are currently repeating the same protocol with the same participants for ILIAD 2023.

Additional Information about the ILIAD protocol is available here:

Williams VJ, Carlsson CM, Fischer A, Johnson SC, Lange K, Partridge E, Roan C, Asthana S, Herd P. Assessing Dementia Prevalence in the Wisconsin Longitudinal Study: Cohort Profile, Protocol, and Preliminary Findings. J Alzheimers Dis. 2021;81(2):751-768. doi: 10.3233/JAD-201422. PMID: 33843672.