

Supplemental Appendix

Survey

Name of Study or ADC or ADRC: _____

What is your role in this study?

1. Does this study enroll **women**?

- a. Yes b. No

2. If yes, what is the study's definition of "woman" documented in the protocol?

a. Please copy paste exact text:

b. No definition is documented

3. Since when has the study enrolled women?

a. Study inception (part of original design)

b. After study inception (later protocol modification)

i. Enter date when women were enrolled in study: _____

4. Does this study enroll **men**?

- a. Yes b. No

5. If yes, what is the study's definition of "man" documented in the protocol?

a. Please copy paste exact text:

b. No definition is documented

6. Since when has the study enrolled men?

a. Study inception (part of original design)

b. After study inception (later protocol modification)

i. Enter date when men were enrolled in study:

7. NIH defines "sex" or "biologic sex" as characteristics encoded in DNA, such as reproductive organs and other physiological and functional characteristics. "Gender" is defined as social, cultural, and psychological traits linked to human males and females through social context.

In the following section, we would like to know how "sex" and/or "gender" is measured in your study.

If multiple measures were collected in the study, the order that you choose to enter them in this survey does not matter. We will ask you to answer multiple questions that pertain to a given measure.

Please complete a row in the table below for each measure of gender and/or biologic sex in the study.

Name of variable as entered into the data repository or code book	What is the purpose of this variable?	How is it measured? (Circle what applies.) Please attach protocol for each measure.	What year did data collection begin?	Has the data collection protocol been modified for this sex/gender variable since it was first introduced to the study?
		Self-report Biologic specimen Direct observation Other:		Yes No

Please add rows as needed.

If the protocol has been modified over time, please explain when and how it was changed.

Please attach any protocol detailing the data collection process.

Study Point of Contact

Name:

Email:

May we contact you, if needed, for additional information. Yes No

Thank you for your time. Please contact us with any questions.

[Image submitted as separate TIFF file]

Figure 1. Year of Inception of Alzheimer’s Disease Research Centers (ADRCs) and Investigator-Initiated Cohort Study Data Collection of Sex/Gender.

(A) In 1994, National Institutes of Health (NIH) implemented the policy *Inclusion of Women and Minorities in Clinical Research (IWMCR)*. **(B)** In 2014, National Institutes of Health (NIH) implemented the policy titled *Sex as a Biological Variable (SABV)*.

Table A. List of NIA funded Centers and Investigator-Initiated Cohort Studies Approached to Contribute Data to Current Study

Investigator Initiated Aging Cohort Studies	ADRCs
Adult Changes in Thought (ACT) Study	Alzheimer's Disease Genetics Consortium
Baltimore Longitudinal Study on Aging (BLSA)(U.S.; Cardiovascular and Metabolic Factors; 65+)	Alzheimer's Disease Sequencing Project
Baltimore Memory Study	Arizona Alzheimer's Disease Center
Biomarkers of Cognitive Decline Among Normal Individuals (BIOCARD)	Boston University ADC
Cache County Study on Memory in Aging	Cleveland ADRC
Chicago Health and Aging Project (CHAP) (U.S.; Multimodal Risk Factors; Multiracial (Black/ African-American and White); 65+)	Columbia University ADRC
Einstein Aging Study (EAS) (U.S., Multimodal Risk Factors; 70+)	Emory University Goizueta ADC
Established populations for epidemiologic studies of the elderly (EPESE)	Indiana Alzheimer Disease Center (IADC)
Framingham Heart Study	Johns Hopkins Alzheimer's Disease Research Center
Harvard Aging Brain Study (HABS)	KU Alzheimer's Disease Center
Health & Aging Brain among Latino Elders (HABLE) study (U.S.; Multimodal Risk Factors; Hispanic/ Latinos)	Massachusetts General Hospital ADRC
Health and Retirement Study	Mayo Clinic Memory Disorder Clinic, Jacksonville, FL

Health, Aging, and Body Composition (Health ABC) Study (U.S.; Multimodal Risk Factors; 70-79)	Mayo Clinic ADRC Rochester, MN
Healthy Aging in Neighborhoods of Diversity across the Life Span (HANDLS) (U.S.; Multimodal Risk Factors; 30-64)	Mount Sinai ADRC
Honolulu-Asia Aging Study (HAAS) (U.S.; Multimodal Risk Factors; Japanese-Americans; Men only)	NACC UDS
KU Brain Aging Project (U.S., Cardiovascular and Metabolic Factors; 65+)	National Institute on Aging- Late Onset Alzheimer's Disease Family Study (NIA LOAD)
Latino CORE Study	NIA Genetics of Alzheimer's Disease Data Storage Site (NIAGADS)
Mayo Clinic Cohort Study of Oophorectomy and Aging-2 (MOA-2)	Northwestern Mesulam Center for Cognitive Neurology and Alzheimer's Disease
Mayo Clinic Study of Aging (U.S.; Multimodal Risk Factors; 30-89)	NYU ADC
Memory and Aging Project (MAP)	Oregon Health and Science University Layton Aging and ADC
Minority Aging Research Study (MARS) (U.S.; Multimodal Risk Factors; Black/ African-American; 70+)	Rush University ADC
Monongahela-Youghiogheny Healthy Aging Team (MYHAT) study(U.S.; Multimodal Risk Factors; 65+)	Stanford ADRC
National Health and Aging Trends Study (NHATS)	UC Davis ADC
National Long Term Care Survey (NLTC)	UC Irvine ADRC

National Social Life, Health, and Aging Project (NSHAP) (U.S.; Social Connectivity and Health; 20+)	UC San Diego Shiley-Marcos ADRC
Normative Aging Study (U.S.; Multimodal Risk Factors; Veterans, Males only)	UCSF Memory and Aging Center
Nun Study	University of Florida ADRC
Oregon Brain Aging Study (U.S., Multimodal Risk Factors)	University of Kentucky ADC
Rancho Bernardo Study (RBS) of Healthy Aging (U.S.; Cardiovascular and Metabolic Factors)	University of Michigan ADC
Religious Orders Study	University of Pennsylvania Penn Memory Center
Sacramento Area Latino Study on Aging (SALSA) (U.S.; Multimodal Risk Factors; Hispanic/ Latino-Mexican-Americans)	University of Pittsburgh ADRC
Study of Latinos-Investigation of Neurocognitive Aging (SOL-INCA) (US; Multimodal Risk Factors; Latino/Hispanic)	USC ADRC
The 90+ Study	University of Washington ADRC
Vietnam Era Twin Study of Aging (VETSA) (U.S.; Multimodal Risk Factors; Veterans, Males only; 50+)	University of Wisconsin ADRC
Virginia Cognitive Aging Project (VCAP) (U.S., 18+)	Vanderbilt Memory and Aging Project
Washington Heights and Inwood Columbia Aging Project (WHICAP) (U.S.; Multimodal Risk Factors; Multiethnic; 65+)	Wake Forest Sticht Center for Healthy Aging and Alzheimer's Prevention
Wisconsin Longitudinal Study	Washington University Knight ADRC

Wisconsin Registry for Alzheimer's Prevention (WRAP)	Yale University ADC
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Sources:

<https://www.nia.nih.gov/health/alzheimers-disease-research-centers>

<https://iadrp.nia.nih.gov/about/cadro/Population-Studies-Cohorts-and-Studies>