

# Archiving the Rancho Bernardo Study of Healthy Aging

<https://www.neurodegenerationresearch.eu/survey/archiving-the-rancho-bernardo-study-of-healthy-aging/>

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### Country

USA

## Title of project or programme

Archiving the Rancho Bernardo Study of Healthy Aging

## Source of funding information

NIH (NIA)

## Total sum awarded (Euro)

€ 1,066,513.76

## Start date of award

01/09/2016

## Total duration of award in years

1

## The project/programme is most relevant to:

Alzheimer's disease & other dementias

## Keywords

Acquired Cognitive Impairment... Aging... Alzheimer's Disease... Alzheimer's Disease including Alzheimer's Disease Related Dementias (AD/ADRD)... Behavioral and Social Science... Biomedical Information Resources... Biomedical Information Resources and Informatics Research... Brain Disorders... Clinical Research... Clinical Research - Extramural... Dementia... Epidemiology And Longitudinal Studies... Neurodegenerative... Neurosciences... Prevention... Women's Health for IC Use

## **Research Abstract**

**Project Summary/Abstract** The goal of this project is to curate and archive more than 40 years of data from the Rancho Bernardo Study (RBS) of Healthy Aging to ensure that this unique and irreplaceable resource remains available to current and future researchers. RBS is one of the longest, continuously NIH-funded, population-based observational cohorts in existence. Initiated in 1972 as part of the NIH Lipid Research Clinic Prevalence Study, participants have been followed ever since via 12 research clinic visits at approximate 4 year intervals and 30 annual mailers. RBS has focused on cardiovascular disease since its inception, and was expanded to include assessment of cognitive function at the 1988 clinic visit and at each of 7 subsequent visits. Numerous health, lifestyle, biomarker and psychosocial measures were also collected in these visits, as well as in prior visits and yearly mailers. Participants in the RBS Cognitive Function cohort (n=2590; mean age 72 at time of first cognitive assessment) have a maximum of 8 cognitive assessments over a 28-year period, with a wealth of health-related information available stretching back ~15 years prior to the first cognitive assessment, at a time when most participants were middle-aged (mean age 54). This enables investigation of whether and how mid- life health, lifestyle, and psychosocial factors predict trajectories of cognitive function and cognitive outcomes in older age, and enables investigation of whether associations between risk factors and cognitive function change with age, or differ by sex or other effect modifiers. This valuable public health resource is vulnerable to loss because data exist on a local server, or as hard copies in various locations. Access to, and knowledge of the data relies on a small number of long-serving faculty and staff, several of whom are nearing retirement age. Thus in response to one of the particular areas of emphasis, "Electronic archiving of cohort data" in PAR-15- 356: "Major Opportunities for Research in Epidemiology of Alzheimer's Disease and Cognitive Resilience" this project will use modern electronic archiving techniques to organize and archive the vast RBS data onto an easily-searchable, cloud-based relational database. We will immortalize and maximize the usefulness of the RBS database through accomplishment of the following aims. Aim 1. Continued follow-up for morbidity and mortality: We currently have over 94% vital status follow up of the original 6,339 participants with death certificates obtained for 85% of decedents. We will continue to follow surviving participants with yearly mailers to assess health status, clinical events and vitality. Death certificates will be obtained on decedents. Aim 2. Documentation and electronic archiving of all study data: Data will be inventoried, categorized, documented, and a complete data dictionary will be generated. All data and study-related documents will be uploaded to REDCap (Research Electronic Data Capture), a widely used secure, HIPAA-compliant, web-based application for managing databases. Aim 3. Resource sharing and data dissemination: A public website will be developed that describes the RBS and provides access to all study documents and HIPAA-compliant datasets.

## **Lay Summary**

**Narrative** Electronic archiving of the Rancho Bernardo Study of healthy aging, a cohort study that has followed individuals over more than 40 years, from middle-age to late old age, obtaining

a rich set of health, behavioral and cognitive data, will ensure that this unique scientific resource remains available for current and future researchers. It will maximize NIH's long investment in this cohort, and facilitate discovery of factors that protect against cognitive decline with age.

**Further information available at:**

**Types:**

Investments > €500k

**Member States:**

United States of America

**Diseases:**

Alzheimer's disease & other dementias

**Years:**

2016

**Database Categories:**

N/A

**Database Tags:**

N/A