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EHR / CMS Data Panel
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Medicare Linkage to Rush Alzheimer's Disease Center Cohorts

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RUSH Rush is a not-for-profit health care, education and research enterprise comprising Rush University Medical Center, Rush University, Rush Oak Park Hospital and Rush Health.

Funding & disclosures

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- Alzheimer's Association (consultant: Facts & Figures Report)
- Eisai, Inc. (Drug Advisory Committee)

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THANK YOU TO

Research Participants

Cohort studies
Clinic participants

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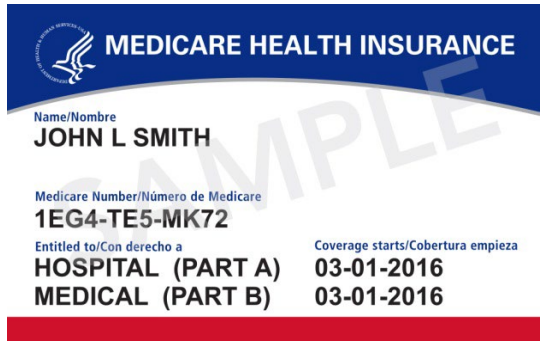
RADC Medicare linkage

Rush Alzheimer's Disease Center (RADC) cohorts

Memory and Aging Project (n=2,144)
Religious Orders Study (n=1,307)
Minority Aging Research Study (n=402)
Clinical Core (n=250)
Latino Core (n=185)



Linkage

- **Health Insurance Claim (HIC) number**
- **Medicare Beneficiary ID (MBI) number**
- **Social Security number**

CMS: Medicare claims records

- Medicare Parts A & B: 1991 - 2021
- Medicare Part D: 2006 - 2021
- Medicare Part C: 2015 - 2019

Requesting RADC cohort data

RADC Research Resource Sharing Hub

Log In

The Rush Alzheimer's Disease Center (RADC), one of 29 Alzheimer's disease (AD) Research Centers across the country designated and funded by the National Institute on Aging (NIA), is dedicated to supporting research about the cause, treatment, and prevention of AD, other dementias, and a range of other common chronic conditions of aging. The many RADC studies generate an enormous variety of unique data and biospecimens to support this effort. RADC faculty and staff are committed to sharing these resources with the wider aging and AD research community to accelerate the pace at which new knowledge is created for the treatment and prevention of dementia and other age-related chronic neurologic conditions, and have distributed data across the United States and the world.

https://www.radc.rush.edu/

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NIA Data LINKAGE Program (LINKAGE)

The NIA Data LINKAGE Program (LINKAGE)* was established in 2021. The purpose of the Program is to link NIA-funded study data with existing datasets from Centers for Medicare & Medicaid Services (CMS) and other sources and establish a cloud-based environment to support data accessibility and sharing. In providing these resources free of charge, LINKAGE aims to reduce resource cost and time barriers and promote access for researchers.

Studies and Researchers will have access to three primary resources:

1. **Linked data sets**. The Program provides data files that link NIA-funded study data to CMS data.
2. **Enclave with free software**. This platform offers a secure, easy-to-navigate, and remotely accessible statistical analysis environment that meets federal data security requirements for protecting personally identifiable and private health information. Users have access to SAS, STATA, R, Python, MS Office applications and more.
3. **Technical assistance**. Participants will receive data analysis and technical support from CMS data analysis experts.

Ready to get started? Explore the NIA Data LINKAGE Program:

- View available data
- Access and share data

Contact: LINKAGE@acumenllc.com

*Formerly known as MedRIC
https://www.nia.nih.gov/research/dbsr/nia-data-linkage-program-linkage

NIA-funded studies linked to CMS data

Below you can view NIA-funded studies that are currently linked to CMS data in the NIA Data LINKAGE Program. Researchers can view and analyze linked data from these studies. Studies marked with an asterisk (*) are currently accepting researcher requests for data sharing. To learn more about gaining access, please contact LINKAGE@acumenllc.com .

- *Boston Early Adversity & Mortality Study (BEAMS): BEAMS brings together diverse data to provide a comprehensive picture on the early life conditions of persons who were born in the late 19th and early 20th century and have been studied closely for most of their lives.
- *Health and Retirement Study (HRS) : Starting in 1992, HRS is a longitudinal panel study that explores the changes in labor force participation and the health transitions that individuals undergo toward the end of their work lives and in the years that follow.
- LONG LIFE Family Study (LLFS) : Established in 2005, LLFS is an international collaborative study of the genetics and familial components of exceptional survival, longevity, and healthy aging.
- Midlife in the United States (MIDUS) : Established in 1995, the Midlife in the United States (MIDUS) study "was conceived by scientists from diverse fields who were interested in how physical and mental health changes across the decades of adult life, for whom, and why."
- *National Health & Aging Trends Study (NHATS) : Starting in 2011, NHATS fosters research to guide efforts to reduce disability, maximize health and independent functioning, and enhance quality of life at older age.
- Panel Study of Income Dynamics (PSID) : Beginning in 1968, PSID is the longest running longitudinal household survey that measures economic and social well-being and has allowed researchers and policy analysts to investigate the dynamism inherent in social and behavioral processes.
- *Rush Alzheimer's Disease Center (RADC) : Established in 1997, RADC is committed to discovering better ways to diagnose, treat, and prevent Alzheimer's and other dementias.

Advantages of Medicare linkage

- Health & healthcare utilization information not captured in cohort assessment
  - Diagnoses, procedures, hospitalizations, preventive care, specialist visits, medications, costs
- Specific dates of medical encounters
- Not reliant on self report
- Predates cohort enrollment (back to 1991)

Current RADC Medicare projects

- **Predictors and Consequences of the Timing and Accuracy of Clinical Dementia Diagnosis**
  R01AG072559 (PI: James & Power)
- **Use of Healthcare Across the Full Continuum of Cognitive Health and Decline in Older Adults**
  R01AG079226 (PI: Grodstein & Bynum)
- Completed: **Cognitive Decline After Hospitalization in Older Adults: Predictors and Pathogenesis**
  K01AG050823 (PI: James)

ARTICLE

Cognitive decline after elective and nonelective hospitalizations in older adults

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Hospitalization, Alzheimer's Disease and Related Neuropathologies, and Cognitive Decline

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OXFORD

Research Article

Identification of Dementia in Recent Medicare Claims Data, Compared With Rigorous Clinical Assessments

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Obstacles to linkage in research

- Disparate data structures
- Temporality: coverage / observation windows
- Incomplete claims coverage
  - consent to linkage, linkage success rate, Medicare Advantage
- Only see what is billed for
- NIA LINKAGE Data Enclave - a tradeoff:
  - Pros: privacy/security, accessibility/sharing, low costs
  - Cons: new environment, learning curve