

# Office for the **Study of Aging**

**ARNOLD SCHOOL OF PUBLIC HEALTH  
UNIVERSITY OF SOUTH CAROLINA**

## **The South Carolina Alzheimer's Disease Registry**

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2020 Annual Report  
South Carolina  
Alzheimer's  
Disease Registry



 Office for the Study of Aging  
Arnold School of Public Health

CCADMR Seminar  
November 13, 2020

# Acknowledgements



- SC Department of Health and Human Services
  - SC Department on Aging
  - SC Department of Mental Health
  - USC School of Medicine
  - SC Public Employee Benefit Authority
  - Revenue and Fiscal Affairs Office, Health and Demographic Section
  - SC Department of Health and Environmental Control, Vital Records and Public Health Statistics
  - Arnold School of Public Health at USC
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# Presentation Outline



- South Carolina Alzheimer's Disease Registry
    - Background
    - History
    - Data collection procedures
    - Annual Report
    - Data linkages
  - Accessing Registry data
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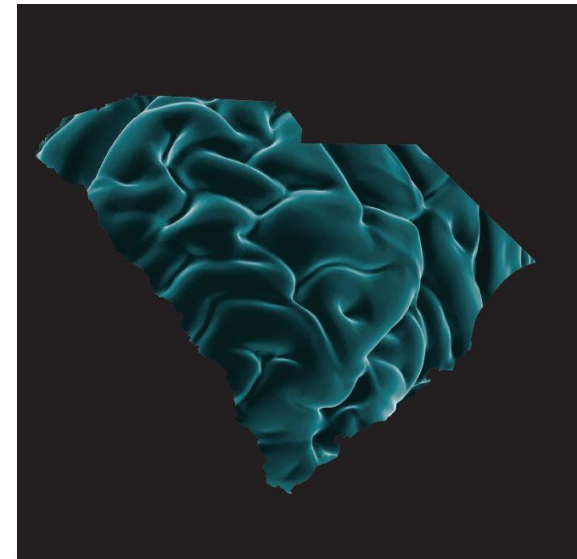
# Background

- By 2030, it is estimated that 1.1 million South Carolinians will be over 65 representing 1 in 5 residents.
- An estimated 5.8 million people in the U.S. are currently living with Alzheimer's disease (AD)
- By 2050, the number of people age 65+ with AD is projected to reach 13.8 million

# Registry History



- The SC Alzheimer's Disease Registry was founded in 1988
- Includes data about individuals with Alzheimer's disease and related dementias (ADRD)
- One of only three population-based state AD registries in the nation



# Registry Legislation



- Authorized/established by state law in 1990
  - Grants permission to contact cases and caregivers
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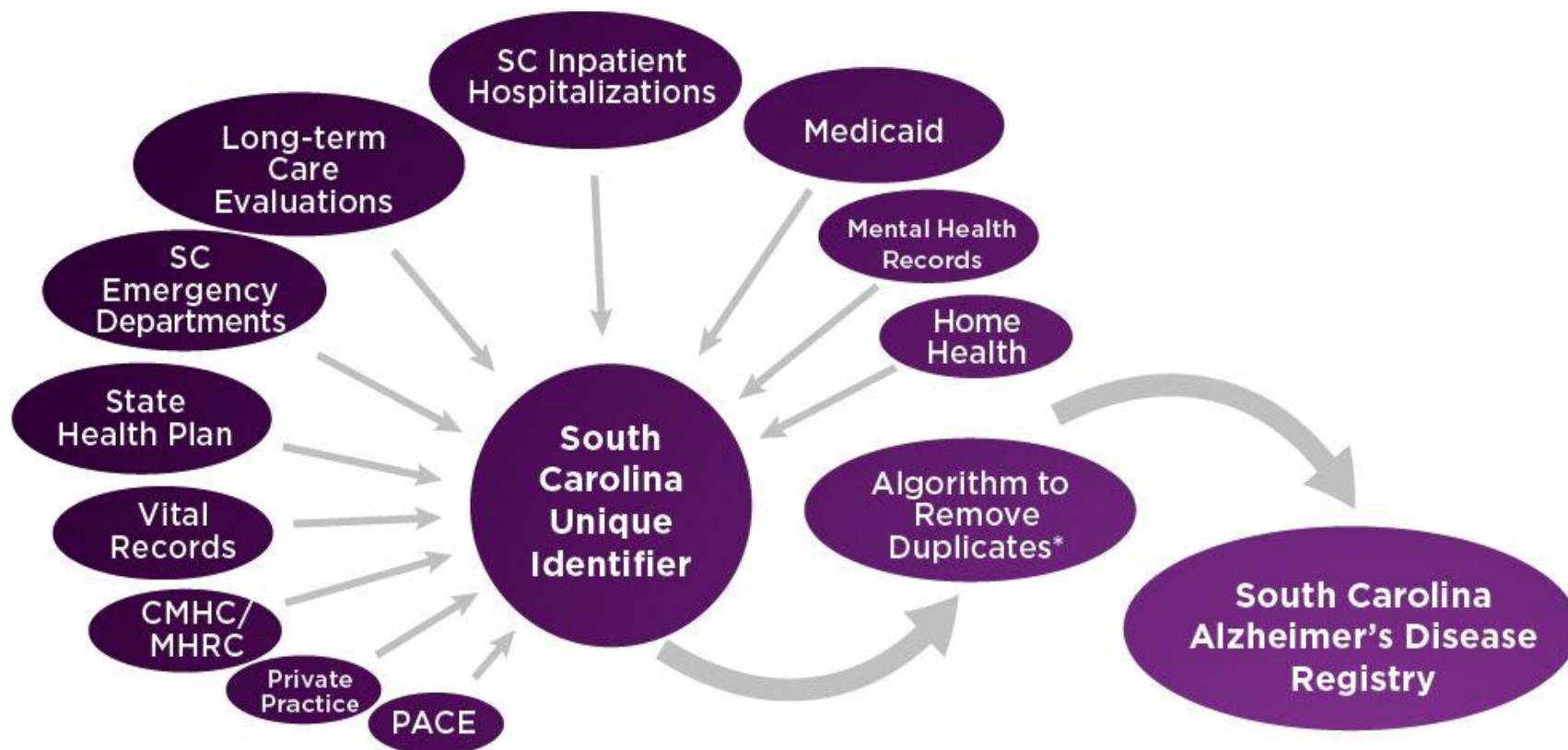
# Registry Goals



- Provide disease prevalence estimates to enable better planning for social and medical services
- Identify differences among groups
- Help caregivers for individuals with ADRD
- Foster ADRD research



# Data Sources



**\*Duplicates** occur because individuals often use more than one name, social security number, or other identifying information when using health or social services.



# Identifying Registry Cases



- Alzheimer's disease (AD)
  - Vascular dementia
  - Mixed dementia (AD + Vascular dementia)
  - Dementia in other medical conditions
    - e.g., alcohol/drug-induced dementia, Parkinson's disease, dementia with Lewy bodies
    - conditions (e.g., HIV) + a dementia code
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# Information in the Registry



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- Diagnosis (ADRD type)
- Sociodemographic Information
  - Age
  - Gender
  - Race
- Location
  - Facility
  - Community
  - Unknown
- Contact information for caregiver (if available)



# 2020 Annual Report Summary



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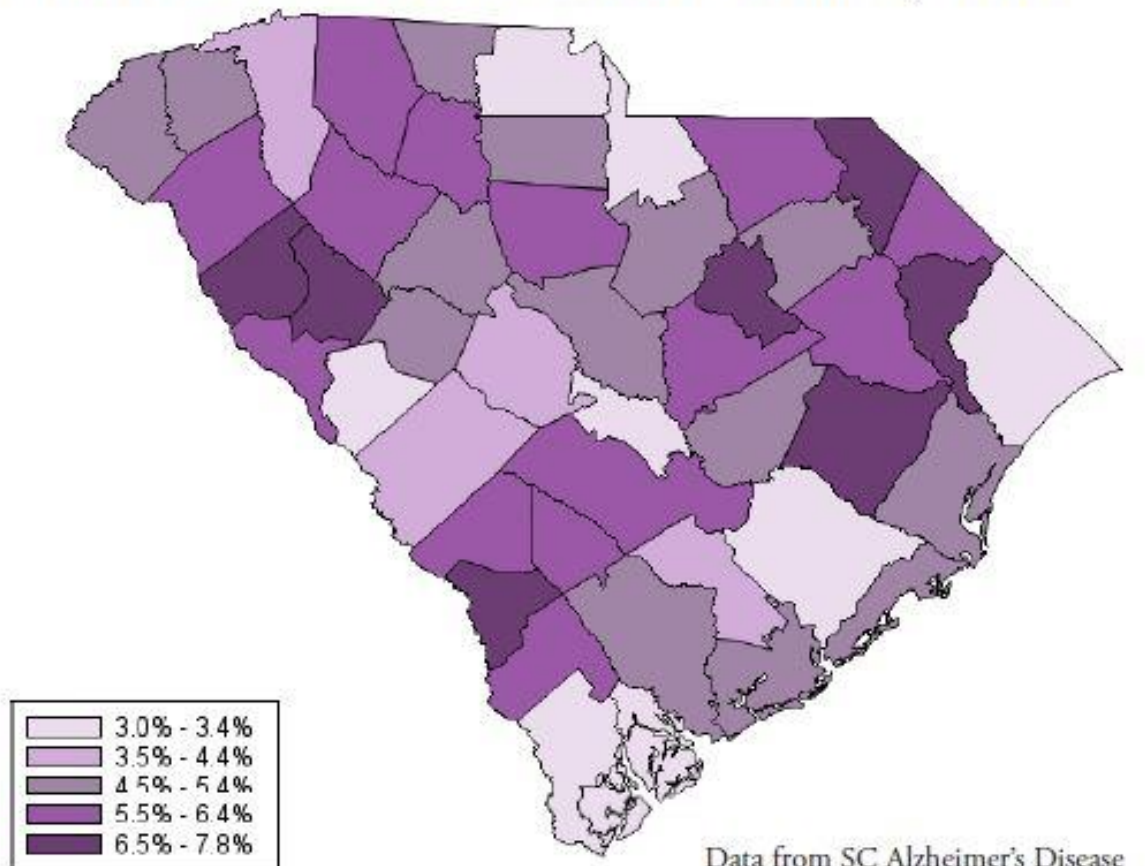
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- 106,223 individuals were living with ADRD in 2016
  - Based on the Registry and US Census estimates:
    - 11% of South Carolinians age 65+ have ADRD
    - 51% of South Carolinians age 85+ have ADRD
  - 63% of South Carolinians with ADRD are women
  - African Americans are at notably higher risk of an ADRD diagnosis than are non-Hispanic whites
    - 20% of South Carolinians age 65+ are African American
    - African Americans represent 27% of Registry cases
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# ADRD Prevalence by County

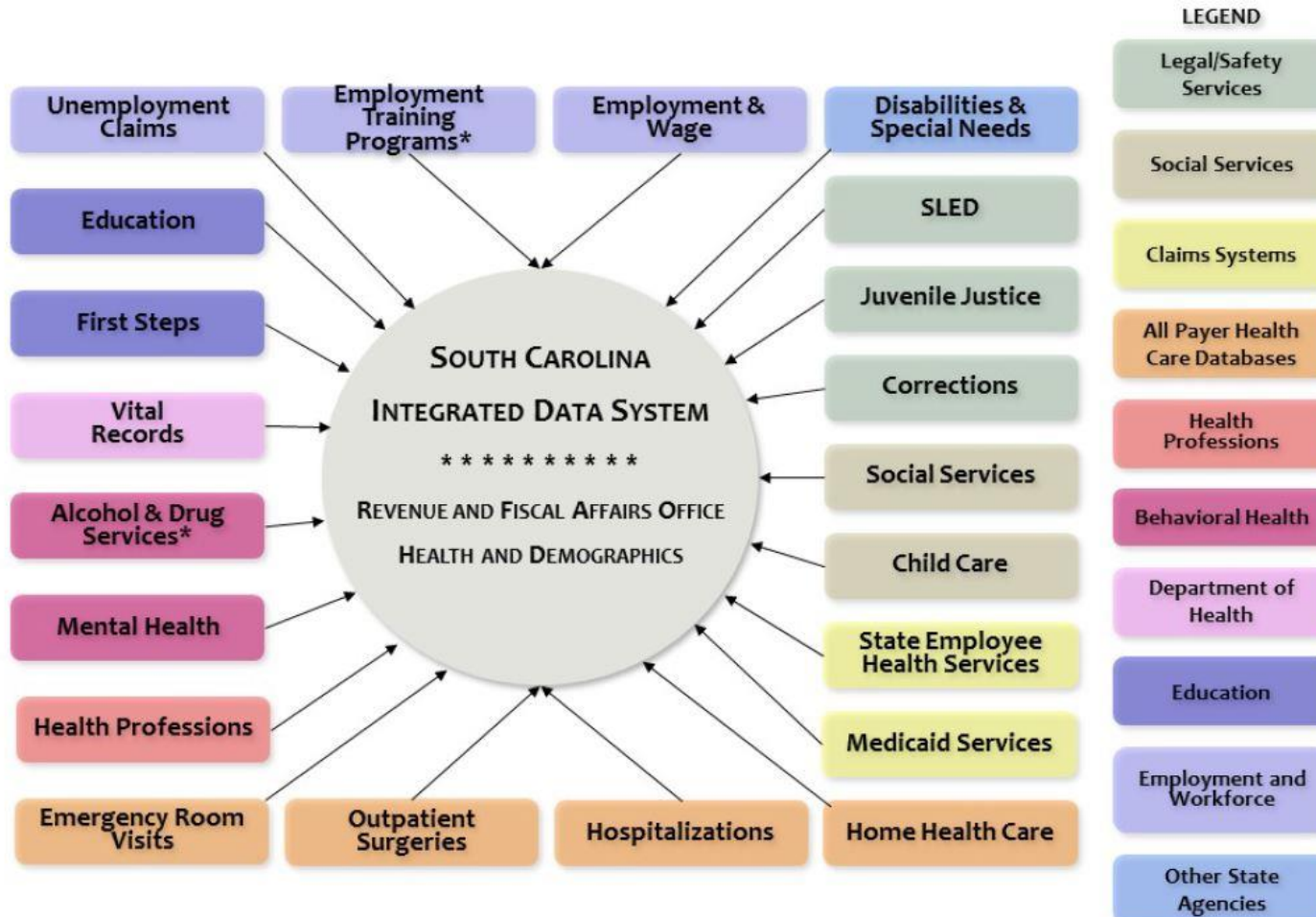


## ADRD Prevalence in South Carolina, 2016



Data from SC Alzheimer's Disease Registry (2016) and Census Annual County Population Estimates (2010-2016)

# Linkages



\* Limited data available

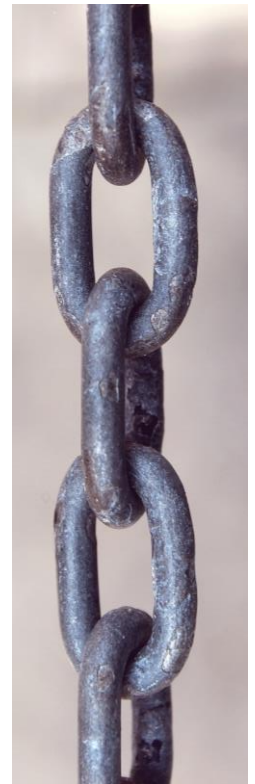
# Registry research using data linkages



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- Behavioral disturbances and nursing home placement
- DUI history and AD
- Neighborhood characteristics and ADRD
- Sedentary behavior in caregivers
- HIV, depression, ADRD
- Health utilization and ADRD



# AD Registry data application



## Alzheimer's Disease Registry

The Alzheimer's Disease Registry is a comprehensive statewide registry of SC residents diagnosed with Alzheimer's Disease and Related Dementias (ADRD). As the nation's most comprehensive registry of its kind, the Alzheimer's Disease Registry has maintained a record of diagnosed cases of ADRD in the state since 1988. The Registry comprises multiple data sources, including inpatient hospitalizations, mental health records, Medicaid, emergency departments, memory clinics, chart abstracts, vital records, and long-term care evaluations. The Registry is maintained by the Arnold School of Public Health at the University of South Carolina, in cooperation with the SC Department of Health and Human Services, the SC Department of Mental Health, the UofSC School of Medicine, and the SC Revenue and Fiscal Affairs Office.

### The goals of the Registry are to:

- Maintain the most comprehensive and accurate state registry of ADRD in the nation
- Provide disease prevalence estimates to enable better planning for social and medical services
- Identify differences in disease prevalence among demographic groups
- Help those who care for individuals with ADRD
- Foster research into risk factors for ADRD

### The Registry is an invaluable data source to those interested in aging research that involves:

- Alzheimer's disease
- Dementia

## 2020 Annual Report South Carolina Alzheimer's Disease Registry



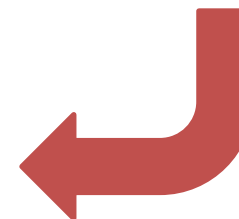
### ALZHEIMER'S DISEASE REGISTRY 2020 Annual Report

View the [2020 Annual Report](#) for the most recent full year of data available from all reporting sources.

### For Researchers

As time and resources permit, the Registry handles routine data requests received from state or local agencies, researchers, and the community. These requests are handled on an individual basis and will be provided free of charge.

**Request access** to the Alzheimer's Disease registry data.



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If you are interested in requesting data or would like to learn more about the Registry contact us at:

[chandlmj@mailbox.sc.edu](mailto:chandlmj@mailbox.sc.edu)

