

# 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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Registry Manager**



CCADMR Meeting  
March 8, 2019

# Acknowledgements



- SC Department of Health and Human Services
  - Lieutenant Governor's Office 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
  - Accessing Registry data
    - Applications
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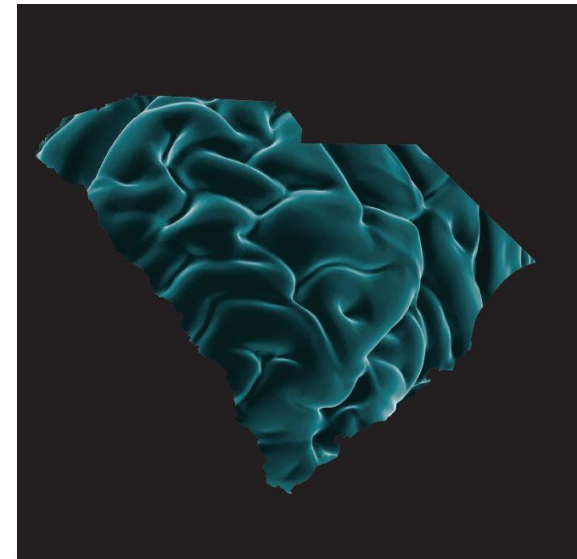
# Background

- In 2018, the percentage of those 65 years and older in SC was estimated to be 17.2% of the total population
- By 2030, it is estimated that 1.1 million South Carolinians will be over 65 representing 1 in 5 residents.
- An estimated 5.7 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

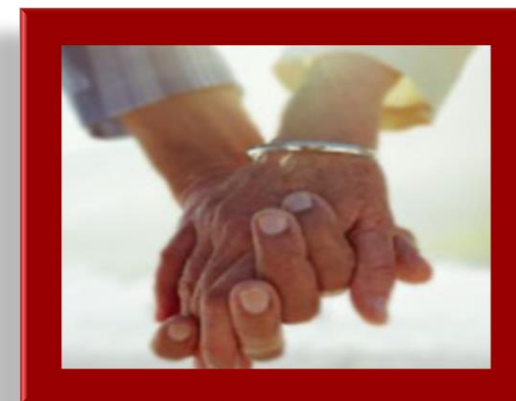


- Authorized/established by state law in 1990
  - Grants permission to contact cases and caregivers
-

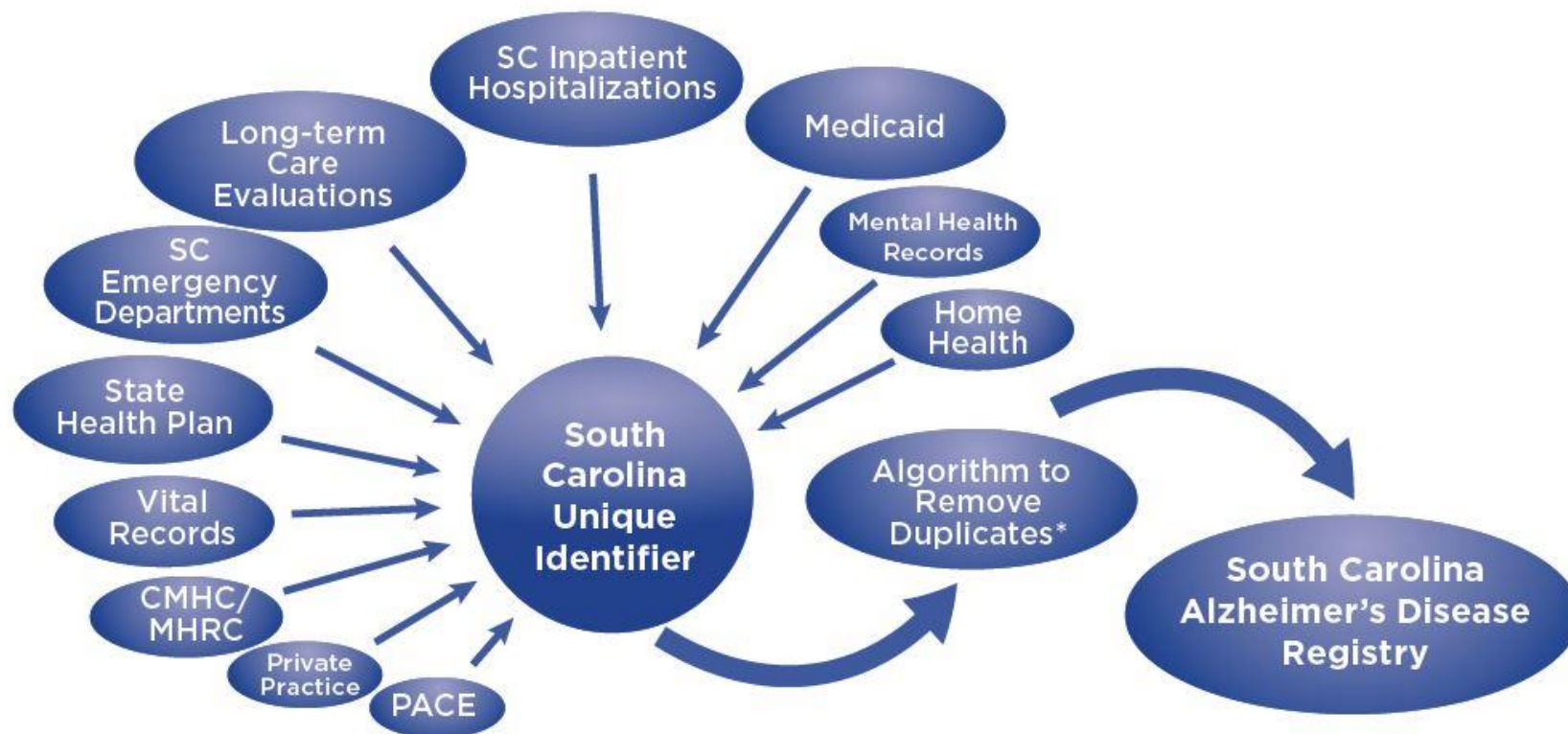
# Registry Goals



- Maintain the most comprehensive state registry of ADRD in the nation
- 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



CMHC = Community Mental Health Center; MHRC = Mental Health and Rehabilitation Clinics; PACE = Program of All-inclusive Care for the Elderly

\*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
-

# Information in the Registry



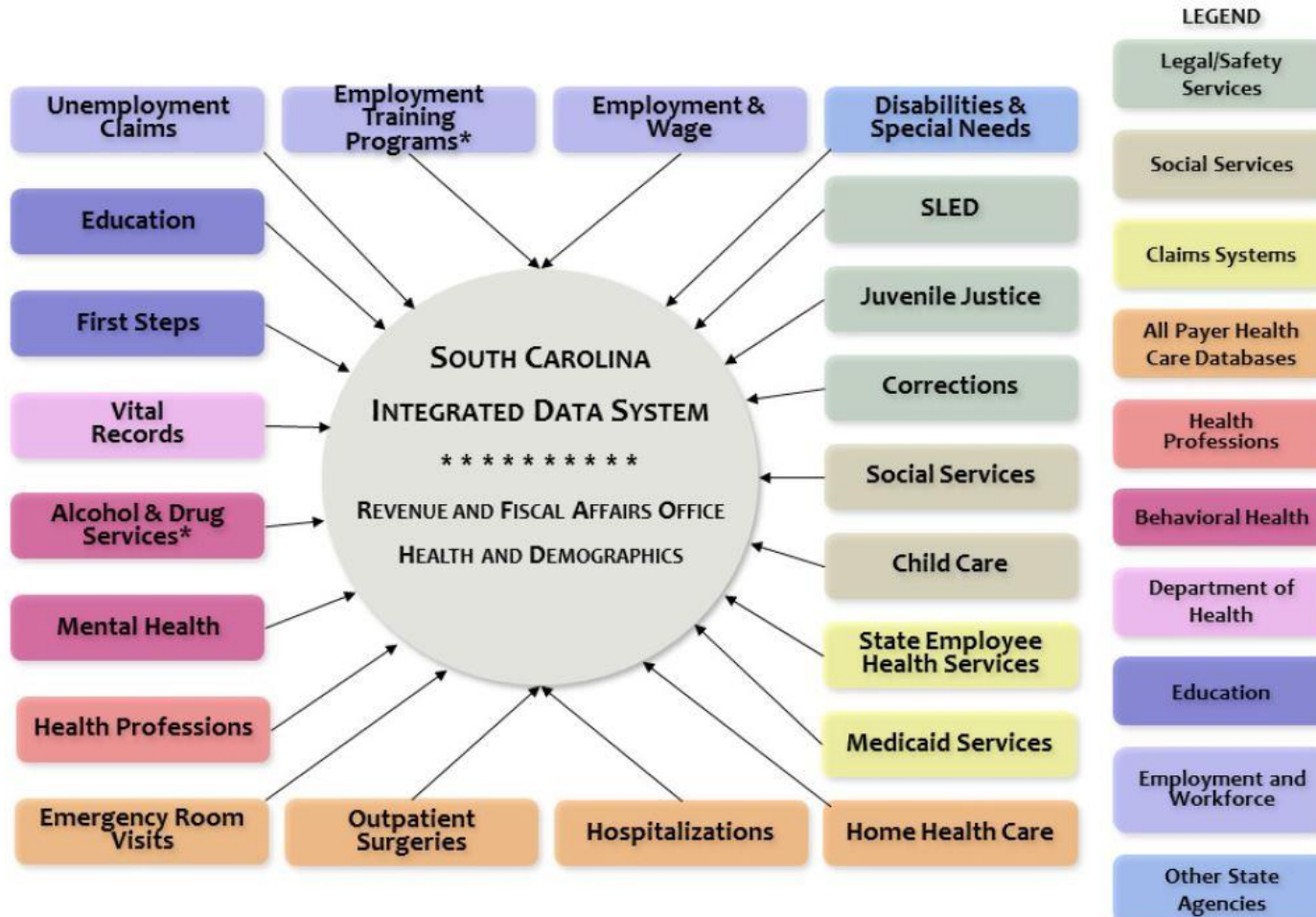
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- Diagnosis (ADRD type)
- Sociodemographic Information
  - Age
  - Gender
  - Race
- Location
  - Facility
  - Community
  - Unknown
- Contact information for caregiver (if available)



# Linkages



\* Limited data available

# AD Registry data application



[https://www.sc.edu/study/colleges\\_schools/public\\_health/research/research\\_centers/office\\_for\\_the\\_study\\_of\\_aging/projects\\_programs/alzheimers\\_disease\\_registry.php](https://www.sc.edu/study/colleges_schools/public_health/research/research_centers/office_for_the_study_of_aging/projects_programs/alzheimers_disease_registry.php)

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## 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 USC 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
- Types of dementia
- Alzheimer's disease prevention

### ALZHEIMER'S DISEASE REGISTRY

#### 2018 Annual Report

**30 YEARS**

2018 Annual Report  
South Carolina  
**Alzheimer's Disease Registry**

Celebrating 30 years of promoting broader research, training, and other collaborative activities that enhance quality of life for our state's older adult population, their families, and the caregivers.

View the **2018 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.**

# Data application cont.



Registry Data Application:
Name of Requestor
Job Title, Organization, Department, Address, Phone Number, Email Address
Brief description of the project or study
Describe the data elements needed
Time frame for requested data
Requested delivery method
Requested data format
Agreements

# Office for the **Study of Aging**

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

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

