

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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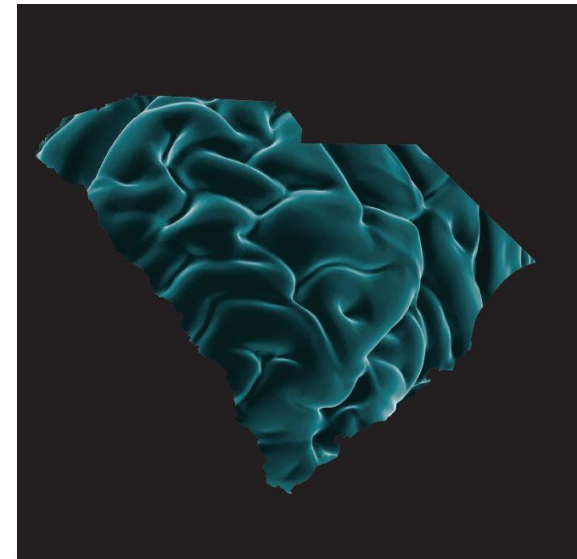
Background

- 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

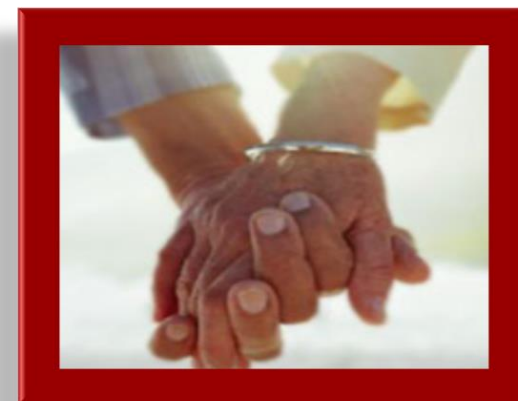


- Authorized/established by state law in 1990
 - Grants permission to contact cases and caregivers
-

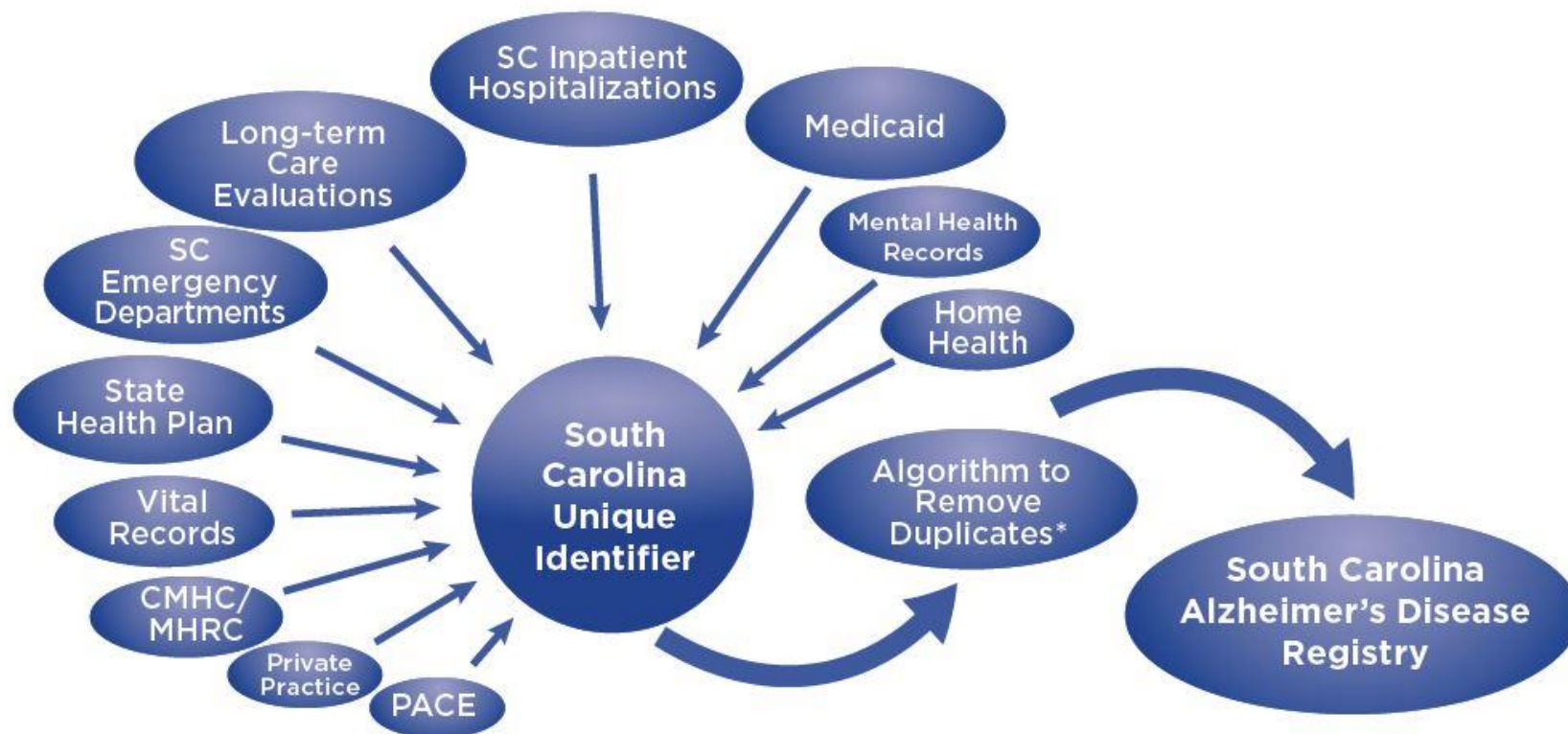
Registry Goals



- 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
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Information in the Registry



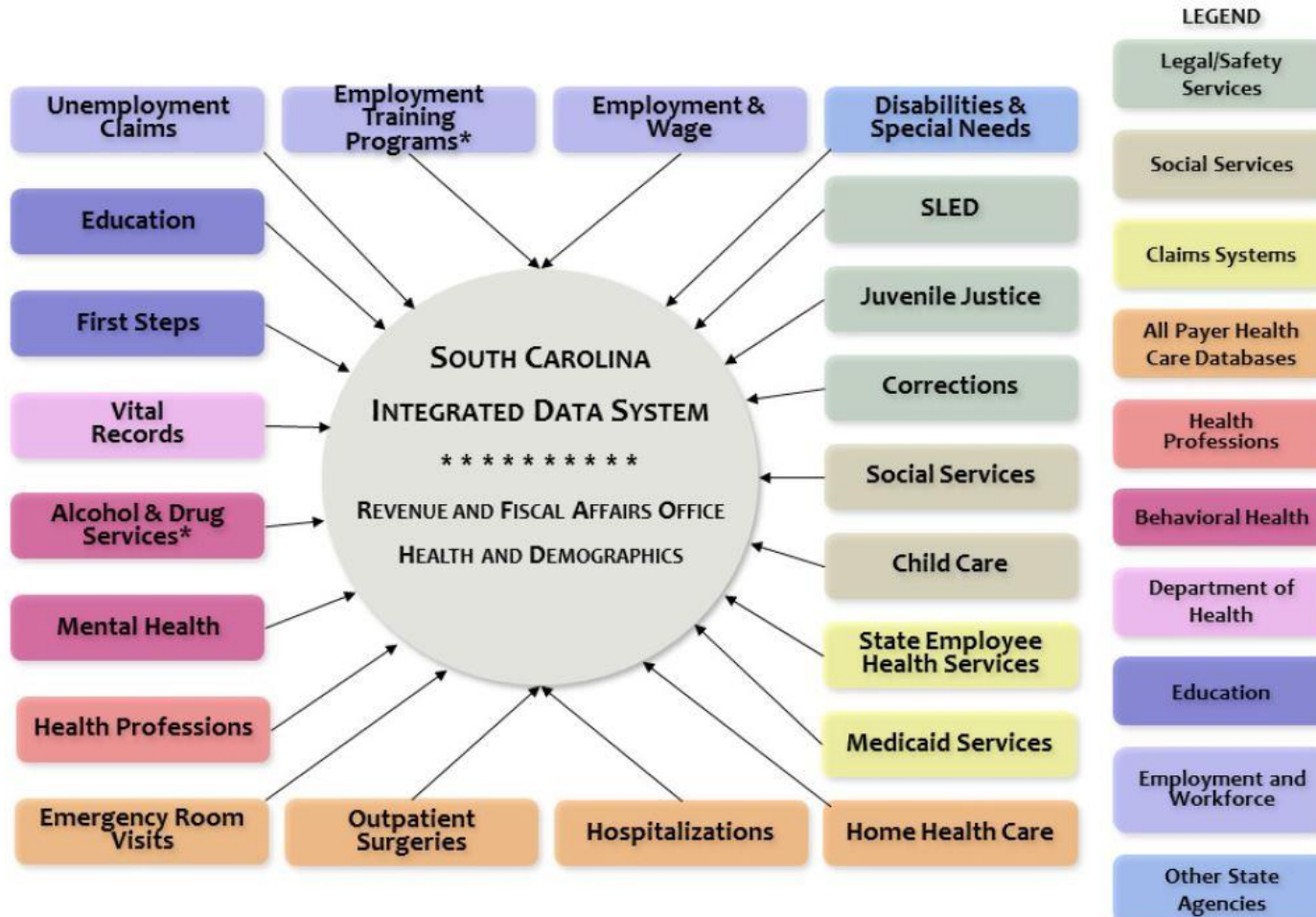
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- Diagnosis (ADRD type)
- Sociodemographic Information
 - Age
 - Gender
 - Race
- Location
 - Facility
 - Community
 - Unknown
- Contact information for caregiver (if available)



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

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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

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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



*Type of ADRD

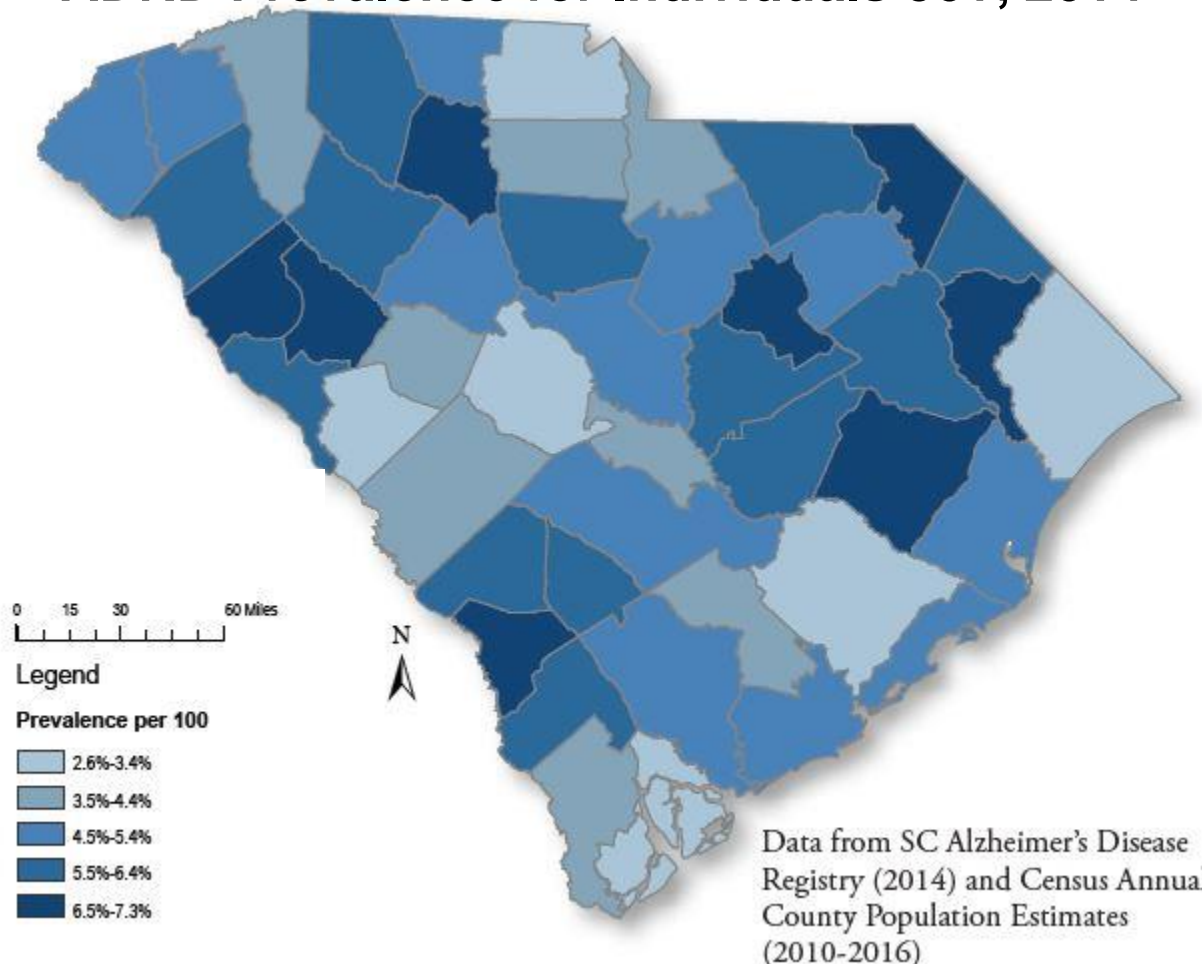


Dementia in Other Medical Conditions	Total
Other cerebral degenerations	15,303
Dementia with other conditions	7,079
Dementia with Lewy Bodies	2,343
Alcohol dementia	1,734
Parkinson's disease	1,725
HIV/AIDS dementia	192
Frontotemporal	170
Drug-induced dementia	65
Pick's disease	55
Chronic Traumatic Encephalopathy	25
Huntington's disease	24
Organic brain syndrome	14
Creutzfeldt-Jakob disease	8
Traumatic Brain Injury Dementia	1
Total (N)	22,951

?ADRD Prevalence by County



ADRD Prevalence for Individuals 50+, 2014





*Strengths of the Registry

- Statewide population-based registry
- Multiple data sources with a history of validity checks
- Diagnosis by physicians of all specialties
- Potential for expanded research



*SC AD Registry



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- The South Carolina Alzheimer's Disease Registry is a unique resource for statewide ADRD surveillance and research, and it is an asset for community planning in both health and social services.

AD Registry Data application



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Office for the Study of Aging

Welcome to the Arnold School of Public Health Office for the Study of Aging (OSA). OSA is committed to advancing research and education in aging issues. In the coming decades, older adults will reach record numbers in our state and nation. Many of those individuals will face the risks of age-related disease, frailty, and dependence. This growing population presents unique opportunities and challenges in both healthcare and long-term care.

Visit:

https://www.sc.edu/study/colleges_schools/public_health/research/research_centers/office_for_the_study_of_aging/projects_programs/alzheimers_disease_registry.php

About OSA

As baby boomers age, South Carolina's older population will be more interested and involved in health and long-term care decisions and will demand more personalized services. OSA seeks to prepare our state to meet the needs of a growing older adult population and to enhance the quality of life for these individuals as they age.

Of unique importance, OSA is the home of the state's **Alzheimer's Disease Registry**. This registry is the nation's most comprehensive statewide registry of residents diagnosed with Alzheimer's disease and related dementia. Through the use of this registry, OSA promotes collaborative research to advance understanding of this disease and identify solutions to the challenges faced by those affected.