The South Carolina Alzheimer's Disease Registry

Maggi Miller MS, PhD
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
Presentation Outline

• South Carolina Alzheimer’s Disease Registry
  • Background
  • History
  • Data collection procedures
• Accessing Registry data
  Applications
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.

Sources: US Census Bureau and Alzheimer’s Association.
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

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

SOUTH CAROLINA INTEGRATED DATA SYSTEM

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REVENUE AND FISCAL AFFAIRS OFFICE
HEALTH AND DEMOGRAPHICS

LEGEND
- Legal/Safety Services
- Social Services
- SLED
- Juvenile Justice
- Claims Systems
- Corrections
- All Payer Health Care Databases
- Health Professions
- Behavioral Health
- Department of Health
- Education
- Employment and Workforce
- Medicaid Services
- Other State Agencies

Unemployment Claims
Employment Training Programs*
Employment & Wage
Disabilities & Special Needs
SLED
Juvenile Justice
Corrections
Social Services
Child Care
State Employee Health Services
Medicaid Services
Home Health Care

Education
First Steps
Vital Records
Alcohol & Drug Services*
Mental Health
Health Professions
Emergency Room Visits
Outpatient Surgeries
Hospitalizations

* 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

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

Request access to the Alzheimer's Disease registry data.
## Registry Data Application:

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<th>Name of Requestor</th>
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<td>Job Title, Organization, Department, Address,</td>
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<td>Phone Number, Email Address</td>
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<td>Brief description of the project or study</td>
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<td>Describe the data elements needed</td>
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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