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
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)
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

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

<table>
<thead>
<tr>
<th>Name of Requestor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Job Title, Organization, Department, Address, Phone Number, Email Address</td>
</tr>
<tr>
<td>Brief description of the project or study</td>
</tr>
<tr>
<td>Describe the data elements needed</td>
</tr>
<tr>
<td>Time frame for requested data</td>
</tr>
<tr>
<td>Requested delivery method</td>
</tr>
<tr>
<td>Requested data format</td>
</tr>
<tr>
<td>Agreements</td>
</tr>
</tbody>
</table>
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

<table>
<thead>
<tr>
<th>Dementia in Other Medical Conditions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other cerebral degenerations</td>
<td>15,303</td>
</tr>
<tr>
<td>Dementia with other conditions</td>
<td>7,079</td>
</tr>
<tr>
<td>Dementia with Lewy Bodies</td>
<td>2,343</td>
</tr>
<tr>
<td>Alcohol dementia</td>
<td>1,734</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td>1,725</td>
</tr>
<tr>
<td>HIV/AIDS dementia</td>
<td>192</td>
</tr>
<tr>
<td>Frontotemporal</td>
<td>170</td>
</tr>
<tr>
<td>Drug-induced dementia</td>
<td>65</td>
</tr>
<tr>
<td>Pick’s disease</td>
<td>55</td>
</tr>
<tr>
<td>Chronic Traumatic Encephalopathy</td>
<td>25</td>
</tr>
<tr>
<td>Huntington’s disease</td>
<td>24</td>
</tr>
<tr>
<td>Organic brain syndrome</td>
<td>14</td>
</tr>
<tr>
<td>Creutzfeldt-Jakob disease</td>
<td>8</td>
</tr>
<tr>
<td>Traumatic Brain Injury Dementia</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total (N)</strong></td>
<td><strong>22,951</strong></td>
</tr>
</tbody>
</table>
?ADRD Prevalence by County

ADRD Prevalence for Individuals 50+, 2014

Legend
Prevalence per 100
- 2.6%-3.4%
- 3.5%-4.4%
- 4.5%-5.4%
- 5.5%-6.4%
- 6.5%-7.3%

Data from SC Alzheimer’s Disease Registry (2014) and Census Annual County Population Estimates (2010-2016)
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
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

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.