



STATE ALZHEIMER'S DISEASE AND RELATED DEMENTIAS (ADRD) REGISTRIES

There are three population-based state ADRD registries in the United States. The following table provides a state-by-state comparison of the key features of these registries. To learn more about each one, please visit their websites and consider watching the recording "[Introduction to Statewide Alzheimer's Disease Registries](#)" at the 2022 National Conference of High Impact Alzheimer's Disease Registry Research.

SOUTH CAROLINA	WEST VIRGINIA	GEORGIA
<i>Website</i>		
https://osa-sc.org/programs/alzheimers-diseases-registry	https://wvadr.hsc.wvu.edu/	https://dph.georgia.gov/AlzheimersDisease
<i>What year was the registry established?</i>		
1988	2011	2014
<i>Who hosts the registry?</i>		
Office for the Study of Aging at the Arnold School of Public Health, University of South Carolina, with support from the South Carolina Department of Health and Human Services (SC DHHS) and the South Carolina Revenue Fiscal Affairs Office	West Virginia Clinical and Translational Science Institute, West Virginia University	Georgia Department of Public Health
<i>What are the goals of the registry?</i>		
<p>The goals of the registry are to:</p> <ul style="list-style-type: none"> • Provide disease prevalence data. • Identify prevalence differences among demographic groups. • Help ADRD caregivers. • Foster research into ADRD risk factors. 	<p>To provide a database to evaluate the incidence and prevalence of ADRD for policy planning purposes and provide non-identifying data to support research on ADRD.</p>	<p>The registry is intended to assist in development of public policy and planning related to ADRD in Georgia:</p> <ul style="list-style-type: none"> • Collect and evaluate data regarding the prevalence of ADRD in Georgia. • Share data for policy planning purposes. • Disclose data to support ADRD research.

- Collect follow-up information from families and physicians of persons who are reported to the registry based.

How is the registry funded?

The registry is funded by a long-standing contract through SC DHHS.

The registry is currently unfunded.

\$110,000 from GA legislature at establishment of the registry.

Is registry reporting required?

Yes, it is enacted by [state law](#). Reporting is voluntary.

Yes, it is enacted by [Procedural Rule](#). Reporting is mandatory.

Yes, it is enacted by [state law \(GA Code § 31-2A-17\)](#). Reporting is mandatory.

How many cases are in the registry?

The registry maintains information on 340,921 cases of ADRD in South Carolina, of those 118,807 were living with ADRD in 2019, the most current year of available and comprehensive data.

Over 28,000 individuals.

To date, the number of cases directly reported into the registry is less than 20,000 cases.

What sources of data does the registry use?

1. PACE program
2. Private practice
3. Community mental health centers
4. Vital records
5. State health plan
6. Emergency departments
7. Long-term care evaluations

1. Healthcare providers
2. Hospital/electronic records
3. Nursing homes
4. Medicare and Medicaid
5. Vital records data
6. Manual, online reporting form submitted by physicians

1. CMS/Medicare
2. Hospital reporting
3. Physicians reporting portal
4. Hospitalizations data
5. Emergency room visits data
6. Vital records data
7. Behavioral Risk Factor

<p>8. Inpatient hospitalizations 9. Mental health records 10. Medicaid 11. Home health records</p>		<p>Surveillance System (BRFSS)</p>
<i>Can individual members of the registry be contacted?</i>		
<p>Yes. The law has strict confidentiality requirements but in 1990 the SC legislature granted registry staff permission to contact the families and physicians of persons diagnosed with ADRD to collect relevant data and provide information about public and private health care resources available to them.</p>	<p>Yes, but only if registry members opt-in to receive more information.</p>	<p>Yes.</p>
<i>How many staff are in charge of the registry?</i>		
<p>1 full-time staff with assistance from 1 research assistant</p>	<p>1 full-time staff</p>	<p>1 full-time staff</p>
<i>What data does the registry collect?</i>		
<ul style="list-style-type: none"> ● Diagnosis (type of dementia) ● Age ● Gender ● Race ● Date of diagnosis ● Length of time included in the registry ● Residence at time of diagnosis (community, facility, or unknown) ● County ● Zip code 	<ul style="list-style-type: none"> ● First name, last name, and middle initial ● Birth date ● Gender ● Last four digits of the social security number ● Maiden name (if female) ● Race/ethnicity ● Address (street, city, county, zip code) ● Contact info, including secondary 	<ul style="list-style-type: none"> ● Patient demographic information, including caregiving information and living arrangement ● ADRD related Information i.e. ICD-10 codes, stage of disease, date of diagnosis if available, current date ● ADRD risk factors/ exposures/occupation &

<ul style="list-style-type: none">● Source of identification● Underlying cause of death	<p>contacts</p> <ul style="list-style-type: none">● Brief medical history● History of ADRD● Physician's name● Physician's contact information● Other information considered relevant for policy and planning relative to ADRD	<p>industry</p> <ul style="list-style-type: none">● Chronic health conditions● Diagnosing/treating physician
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Q&A

This brief Q&A provides answers to most commonly asked questions about state ADRD registries. It was created based on the feedback and experience with Georgia, South Carolina, and West Virginia registries.

1. What is a state ADRD registry?

Unlike patient registries, which actively collect information from individuals engaged in dementia research studies and their caregivers and often include medical tests and procedures, population-based registries passively collect information related to ADRD and don't normally seek contact with those enrolled. A state ADRD registry is used largely to answer epidemiological questions, inform public health strategy and decisions about resource allocation, gather stakeholders, and evaluate the prevalence and impact of ADRD across the state. Most commonly caregivers are not involved, and their information is not systematically collected in the registry.

2. What type of data is included in the registry?

The data collected might vary from one registry to another, but generally, includes at least the following elements:

- Dementia type (ICD-10 or ICD-9 diagnostic codes) and date of diagnosis
- Patient demographic information
- Physician information
- Risk factors for ADRD
- Presence of a caregiver, etc.

3. What are some benefits of a state ADRD registry?

The primary goal of a state ADRD registry is to generate new data for research and policy planning related to ADRD. Different interest groups might benefit from having a population-based registry:

- For public health, state ADRD registries can be an important tool for understanding the prevalence of ADRD across the state, identify gaps in services and aid in program development, planning and resource allocation to improve access to social, community and medical services across the jurisdiction.
- For researchers, state ADRD registries are a robust source of high-quality ADRD data. Registries can foster research into ADRD risk factors, improve our understanding of differences in prevalence and health outcomes among different demographic groups, and identify opportunities for policy and public health action that can improve health equity, to name a few.
- For individuals living with ADRD and their caregivers, joining a registry can help identify unaddressed needs, and connect them to needed resources, supports and services in the community that can improve their quality of life and quality of care.
- Physicians and service providers can use registry data to communicate about service gaps and needs of their patients and clients to the public and to policymakers, and to advocate for policy changes and resources that can increase access to medical and social services and improve the quality of care for people with ADRD and their caregivers.

4. What are some key considerations to ensure the long-term sustainability of the registry?

Based on the experience from GA, SC and WV in establishing their respective registries, the following are essential considerations for long-term sustainability of the registry:

- Codifying the registry into state law.
- Engaging with and obtaining support from a variety of interest groups since the beginning, including healthcare providers, patients, family caregivers, as well as local, regional, and state policy makers.
- Securing a long-term stable funding stream to ensure collection of comprehensive, quality ADRD data, and staff to sustain recruitment, train and provide assistance to healthcare providers, analyze and disseminate data, etc.
- Continuously providing evidence of and communicating the benefits of the registry to everyone.
- Establishing and maintaining an integrated electronic health records system.

5. What strategies can help increase data reporting to the registry?

An effective strategy is integrating with and obtaining information directly from electronic health records and other secondary data sources, such as state agency and insurance claims, whenever possible. In addition, dedicating resources for ongoing training and communication with healthcare facilities and providers is key to increasing the visibility and impact of a statewide registry.

6. What opportunities are there for establishing and leveraging ADRD registries in other states?

The following actions would greatly enhance the value of state-wide ADRD registries, improve coordination among states and support a comprehensive, national public health approach to ADRD and caregiving:

- Making ADRD a reportable disease.
- Standardizing disease definition and ADRD data elements across different state registries.
- Facilitating data linkages across state registries to allow for continuity of support and services for people living with ADRD and their family caregivers across state lines.
- Sharing of best-practices, analytical, and linkage tools between registries.