

# Alzheimer Disease and Related Dementia (ADRD) Registry

## Georgia Approach

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CCADMR Seminar highlighting the Nation's Alzheimer's Registries

# Outline

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- Background
- Data Sources/Potential Linkages
- Current Data
- Data Access

# Background

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- In 2013, the Georgia General Assembly created the Georgia Alzheimer's and Related Dementias State Plan Task Force (GARD)
  - Recommended the establishment of ADRD central registry
- Based on the GARD recommendation and during the 2014 Georgia Legislative Session, legislator approved the establishment of the Georgia ADRD Registry and placed in within the Georgia Department of Public Health.  
**law (O.C.G.A 31-2a-17)**
- Legislatures allocated \$110,000 for establishing ADRD Registry

# Goals for the ADRD Registry in Georgia

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- Collect and disseminate usable data to inform programs and services for the aging population.
- Determine the burden of ADRD among Georgians.
- Identify epidemiologic trends.
- Bring awareness at the state level to issues of ADRD and increase the potential for positive statewide health outcomes and influence the management of associated healthcare costs.
- Inform stakeholders for planning and for future registry needs.

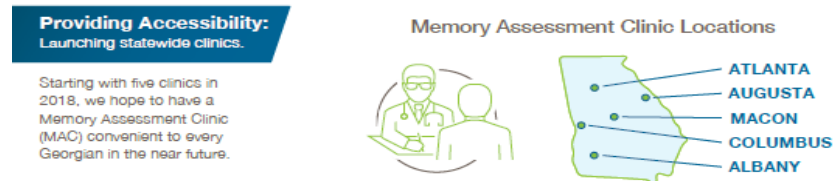
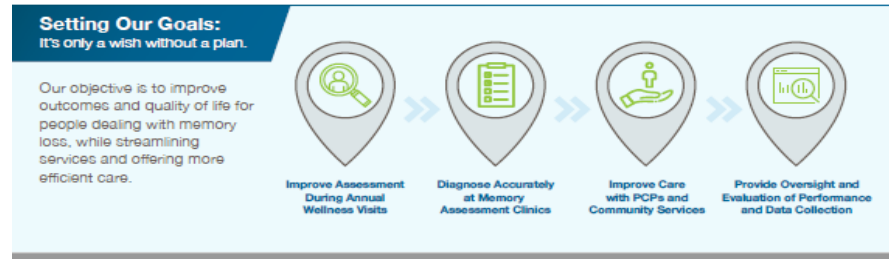
# Georgia Approach/Data Sources & Linkages

## Physician Reporting—Required by Law

- ADRD Reporting Portal –Very few physician report
    - Data Year 2013 to current
  - Created HL7 msg and currently testing with 5 Memory Assessment Clinics
    - Emory Hospital & Grady Memorial, Atlanta
    - University Hospital, Augusta
    - Phoebe Putney, Albany SW GA
    - Piedmont, Columbus GA
- Data January 1, 2020 forward

## Data Items Collected

Diagnosing/Treating Physician	Patient Information
ADRD Information	Chronic Health Conditions
Risk Factors/Exposures	Caregiver Information



## Medicare Data

Requested from CMS Yearly  
Data Years: 2013-2017

## Hospital Discharge

2000 to current year

## Death Data

2000 to current year

## Georgia Behavioral Risk Factor Surveillance System (GA-BRFSS)

Cognitive Decline: 2012, 2013, 2015, 2017, 2019

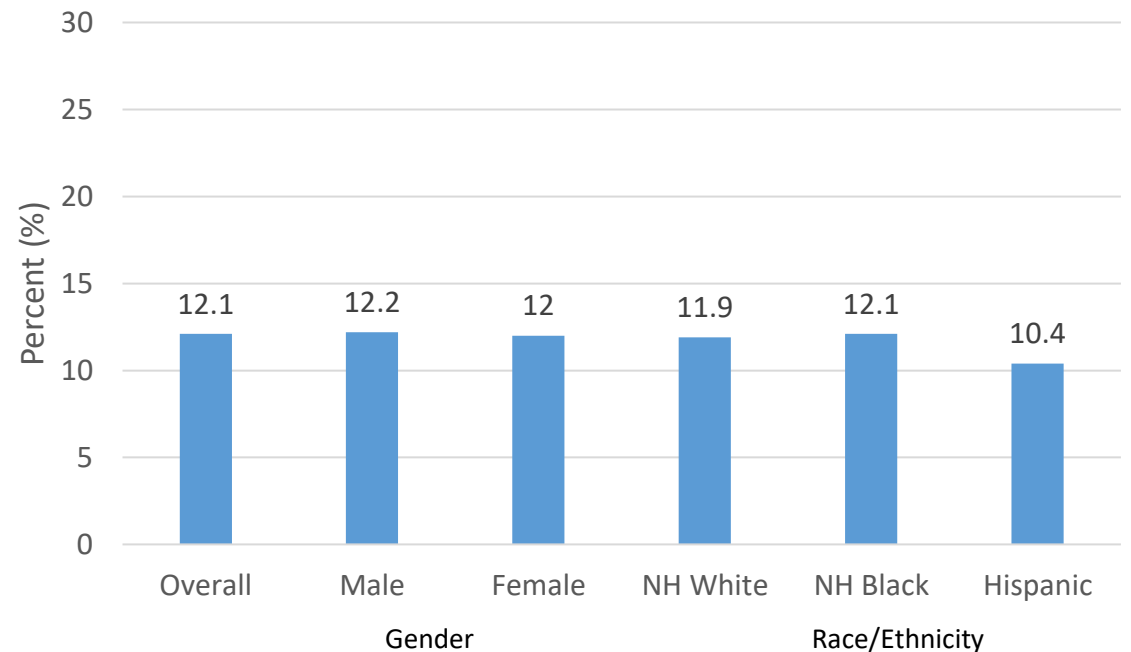
Caregiver: 2012, 2014, 2016, 2018

# Current Data Review

## Respondent 45 years of age or older--Only

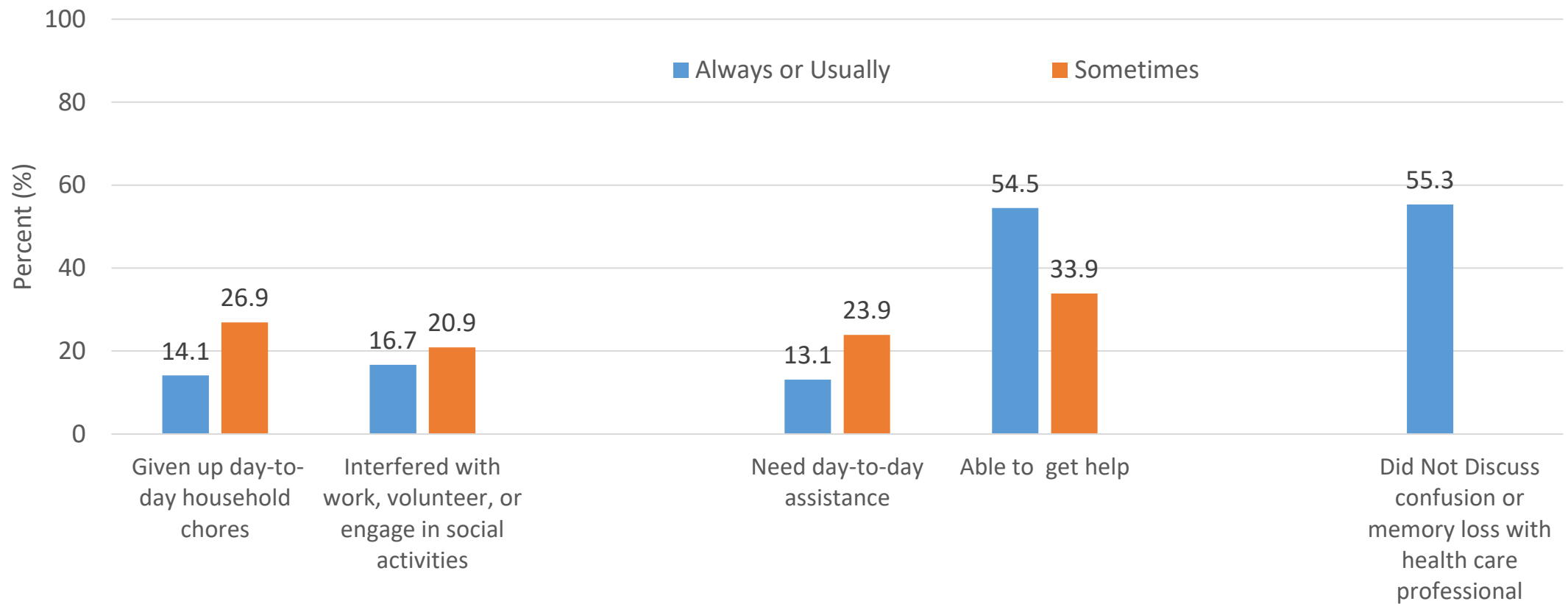
The next few questions ask about difficulties in thinking or remembering that can make a big difference in everyday activities. This does not refer to occasionally forgetting your keys or the name of someone you recently met, which is normal. This **refers to confusion or memory loss** that is happening more often or getting worse, such as **forgetting how to do things you've always done or forgetting things that you would normally know.** We want to know how these difficulties impact you.

Prevalence of Perceived Cognitive Impairment (PCI) among Adults 45 Years or Older, Georgia, BRFSS, 2015, 2017, & 2019



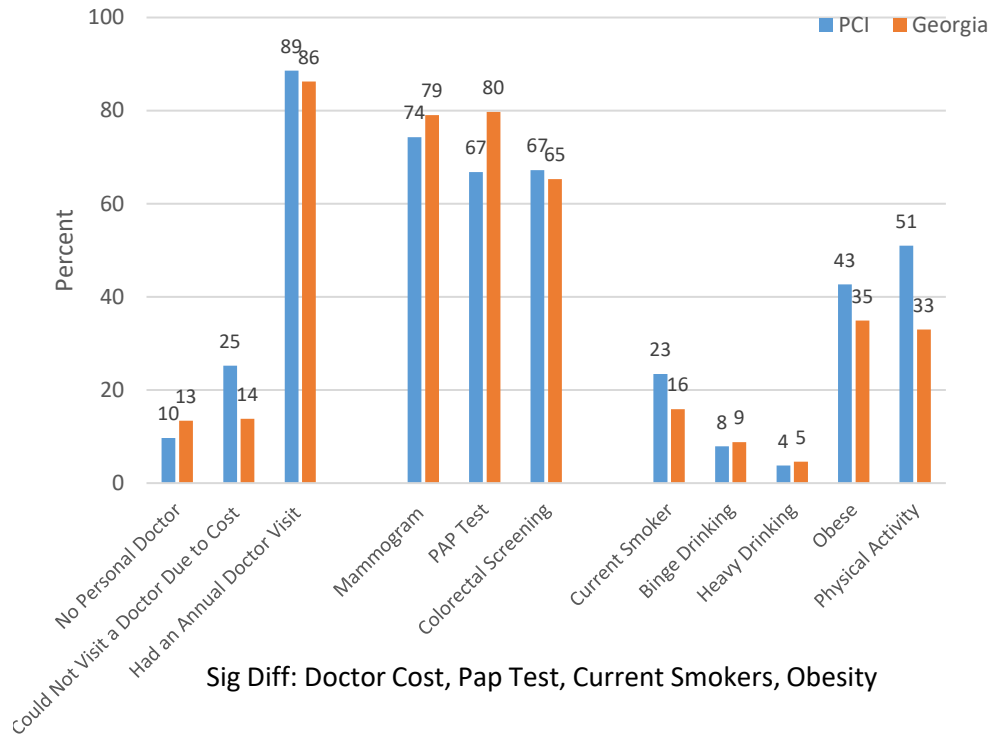
# Current Data Review

Persons with Perceived Cognitive Impairment, Georgia 2015, 2017, 2019

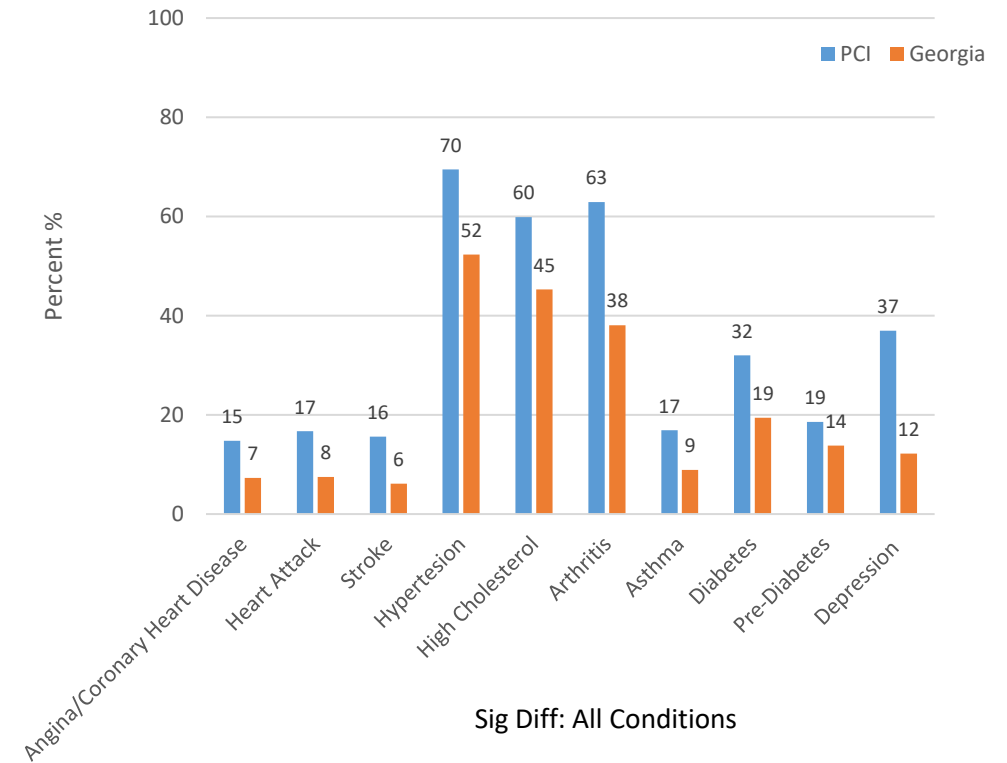


# Current Data Review

Prevalence of Health Care Use, Screening and Health Behaviors among persons with PCI vs Non-PCI, Georgia, 2015, 2017, 2019



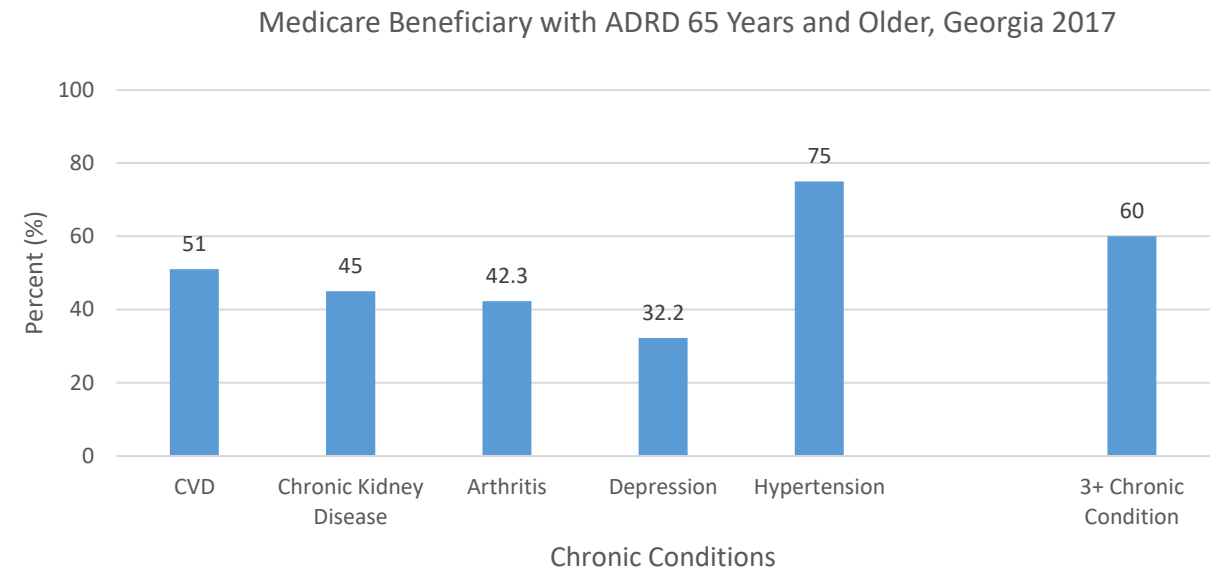
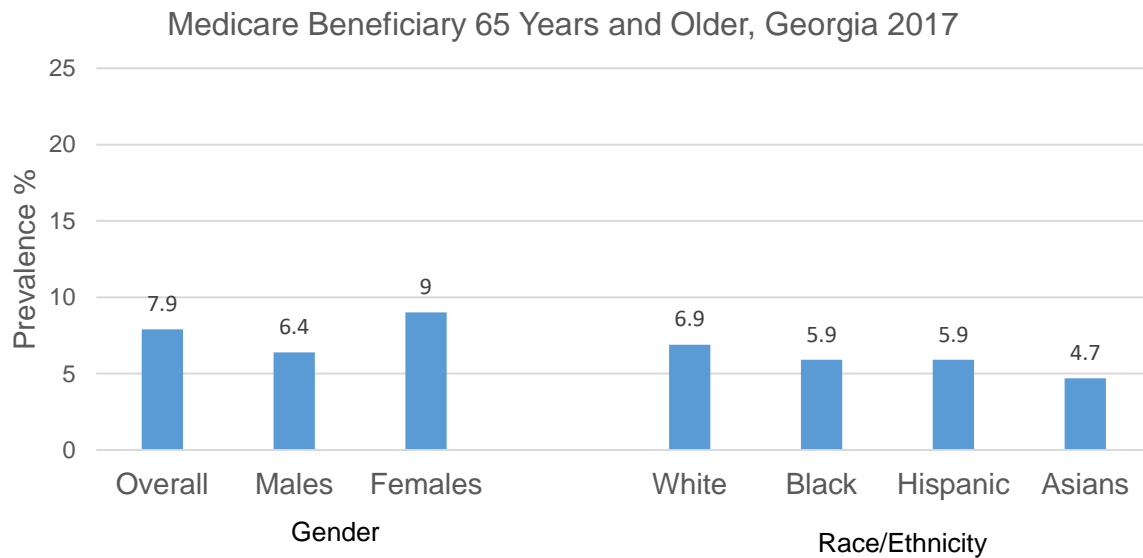
Prevalence of Chronic Conditions among Persons with Perceived Cognitive Impairment vs Georgians 45 Years and Older, Georgia 2015, 2017, 2019



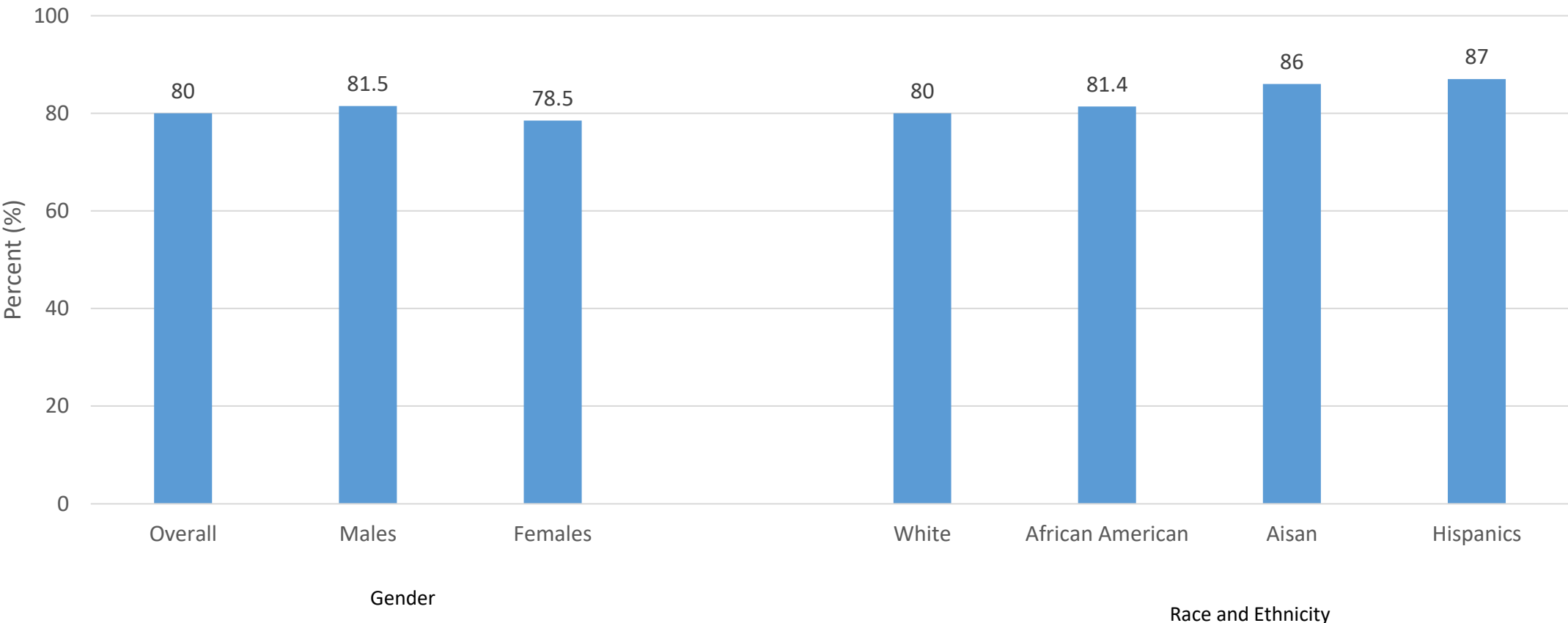


# Medicare Data -2017

- 118,878 Georgians had ADRD related Medicare claims in 2017.
  - 93.4% (111,033/118,878) were to beneficiaries that are 65 Years and older
  - 6.6% (7,845/118,878) were beneficiaries that a are less than 65 years of age.



# ADRD Medicare Beneficiaries-Survival

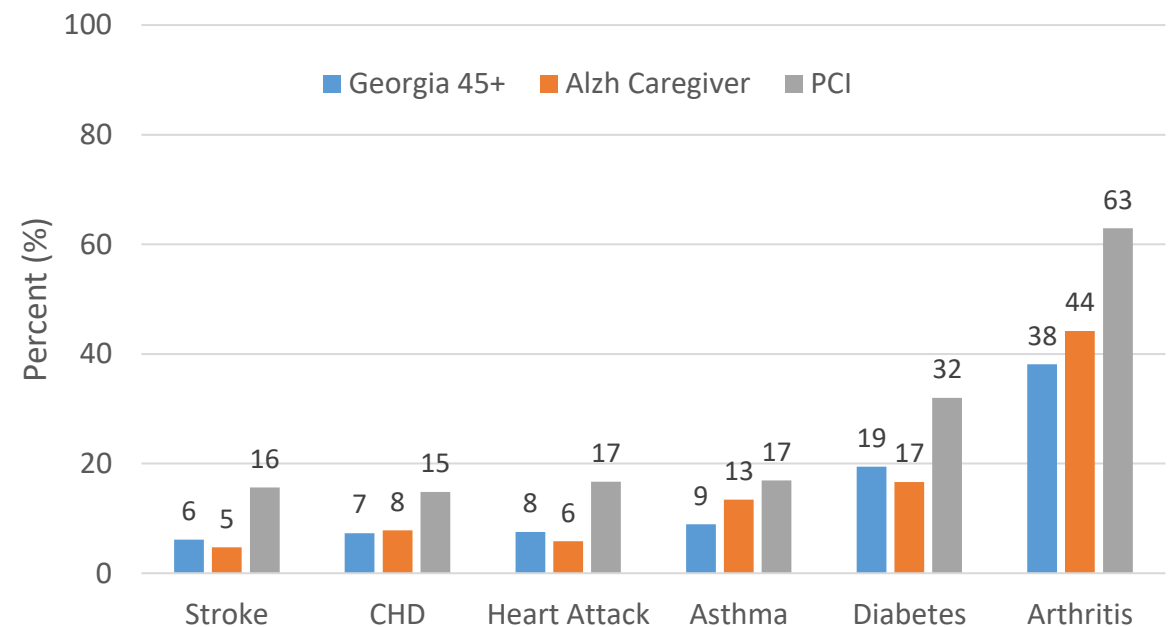


80% (89,288/111,033) of Georgians with ADRD claims in 2017 were alive by December 31, 2017.

# Alzheimer Patients Caregiver Description

- One out of 5 caregiver (21.7%) in Georgia cares for an Alzheimer patient.
- Two out of 3 (2/3) Alzh caregivers are females
- Median age of Alzh caregiver is 56 years of age
- 48.8% of the Alzh Caregivers are family members (parent)
- 43% of the Alzh patients' caregivers needed services of these 22% stated needed home and community-based services

Health Conditions of Alzheimer Caregivers, Georgians 45+ and Persons with PCI, Georgia BRFSS



# Data Access -- <https://dph.georgia.gov/institutional-review-board>



Home > About DPH > Institutional Review Board

About DPH
Mission Statement
Commissioner's Message
> Board of Public Health
> Public Health Regulations
> Institutional Review Board
IRB Board
> General Information
Blog
> Contact DPH
> Georgia Public Health Laboratory
> Emergency Medical Services
Health Data and Statistics
> District and County Relations
Capitol Hill Fitness Center

## Institutional Review Board

The Department of Public Health (DPH) maintains an Institutional Review Board which is charged with assuring that the rights of human subjects of research conducted or sponsored by the Department are protected as outlined in federal and state policies and regulations. All research projects that involve human subjects must be submitted to the Board for review and approval prior to their initiation.

### Who Should Apply

Approval must be obtained for all research involving human subjects when:

1. the research is conducted by or sponsored by the Department;
2. the research requires access to the Department's subject pool;
3. the subjects are employees of the Department;
4. the research requires access to data held by the Department; and
5. before implementing any amendments to previously approved research protocols.

Approval must be obtained prior to any involvement of the subjects. The approval by the Board is limited to no more than a 12-month period and must be renewed at least annually to continue the involvement of subjects.

### Processing Fees

All projects funded from sources external to DPH are subject to a processing fee. The fee is non-refundable regardless of the outcome of the review and must be paid before the initial review of the application. The fee schedule is as follows:

#### Initial Applications

- \$1,500 for expedited or full reviews
- No Fee for studies meeting the criteria for exemption from IRB review

#### Amendments

- \$250 for major changes that must be reviewed by the full Board.
- No Fee for minor changes that can be reviewed using the expedited review procedures

#### Continuing Reviews

- \$750 for studies with ongoing data collection/contact with human subjects
- \$250 for studies where only data analysis/manuscript preparation is ongoing

The following types of projects are exempt from the processing fees

1. Projects conducted by faculty, unless the project is funded from sources external to DPH
2. Projects conducted by undergraduate or graduate students, unless the project is funded from sources external to DPH
3. Projects where the Principal Investigator is a Georgia state employee, unless the project is funded from sources external to DPH

Checks should be made payable to DPH IRB. Include a short version of the project title and the name of the Principal Investigator on the check. Mail payment to:

Georgia Department of Public Health  
Attention: Financial Services - IRB  
2 Peachtree Street, NW, 15th Floor  
Atlanta, Georgia 30303

### Meeting Schedule

DPH IRB meets on the last Friday of each month. Meeting schedule is subject to change without prior notice. Applications must be received by the 1st of the month to be included on the agenda for that month's meeting.

### Contact Information

Brian Kirtland, Ph.D.  
IRB Coordinator and Chair  
Institutional Review Board  
Department of Public Health  
2 Peachtree Street, 15-414  
Atlanta, Georgia 30303  
404-657-1528  
[Brian.Kirtland@dph.ga.gov](mailto:Brian.Kirtland@dph.ga.gov)  
Submissions: [DPH-irb@dph.ga.gov](mailto:DPH-irb@dph.ga.gov)

Page last updated: 03/09/2018

### Institutional Review Board - Related Files

- [Amendment to an Existing Protocol \(Revised Jan 6, 2012\)](#) (510.37 KB)
- [Initial Application \(Revised Jan 6, 2012\)](#) (599.91 KB)
- [Continuing Review Application \(Revised Jan 6, 2012\)](#) (512.48 KB)
- [IRB Guidance to Research Using Human Subjects Manual \(Revised Feb 1, 2012\)](#) (183.15 KB)
- [Digital Signatures - Instructions](#) (64.61 KB)

# Public Health Information Portal

<https://dph.georgia.gov/phiip-data-request>



Home > PHIP Data Request

## PHIP Data Request

The Public Health Information Portal (PHIP) is an online system where you can request public health data from the Georgia Department of Public Health. You will need to create a user account and complete the data request form.

[Click here](#) to access PHIP.

### First Time User Resources

[Data Request Training Video](#)

[Data Request Training Manual](#)

[Data Request FAQs](#)

### Processing Fees

All data requests are subject to a processing fee, representing a reasonable estimate of the Department's cost to prepare and transmit the Data. The fee is non-refundable regardless of the outcome of the search and must be paid before the data request is filled. The fee schedule is as follows:

Individual data requests:

### Processing Fees

All data requests are subject to a processing fee, representing a reasonable estimate of the Department's cost to prepare and transmit the Data. The fee is non-refundable regardless of the outcome of the search and must be paid before the data request is filled. The fee schedule is as follows:

Individual data requests:

- \$200 base fee + \$25 per variable used, per data year

Ongoing data requests / Subscriptions:

- \$200 base fee + \$25 per variable used for the initial request and \$200 for each renewal of the same data request

Fees will be determined upon initial review of the data request and can be paid online via DPH's secure payment portal. DPH reserves the right to customize variables for the request to fit the needs of the data request. There is no additional charge for variables customized at DPH's discretion

The following Payment Methods are accepted:

- Visa
- Mastercard
- Discover

The following types of projects are exempt from the processing fees:

1. Requests from academic faculty, unless the data will be used for projects funded from sources external to DPH
2. Requests from undergraduate or graduate students, unless the data will be used for projects funded from sources external to DPH
3. Requests from DPH employees if the data will be used for work related activities

For questions regarding the data request system please contact:

Demetrice Jordan, M.A., Cert. GIS  
Data Coordinator  
Office of Science, Research and Academic Affairs  
Department of Public Health  
2 Peachtree Street, 10-204  
Atlanta, Georgia 30303  
[dph-datarequest@dph.ga.gov](mailto:dph-datarequest@dph.ga.gov)



## Contact

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