Alzheimer Disease and Related Dementia (ADRD) Registry

Georgia Approach

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CCADMR Seminar highlighting the Nation's Alzheimer's Registries
Outline

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

• 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

• 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
- ADRD Information
- Risk Factors/Exposures
- Patient Information
- Chronic Health Conditions
- 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)
- Caregiver: 2012, 2014, 2016, 2018
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.
Persons with Perceived Cognitive Impairment, Georgia 2015, 2017, 2019

<table>
<thead>
<tr>
<th>Activity</th>
<th>2015 (%)</th>
<th>2017 (%)</th>
<th>2019 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Given up day-to-day household chores</td>
<td>14.1</td>
<td>16.7</td>
<td>13.1</td>
</tr>
<tr>
<td>Interfered with work, volunteer, or engage in social activities</td>
<td>26.9</td>
<td>20.9</td>
<td></td>
</tr>
<tr>
<td>Need day-to-day assistance</td>
<td>13.1</td>
<td>23.9</td>
<td>54.5</td>
</tr>
<tr>
<td>Able to get help</td>
<td></td>
<td></td>
<td>33.9</td>
</tr>
<tr>
<td>Did Not Discuss confusion or memory loss with health care professional</td>
<td></td>
<td></td>
<td>55.3</td>
</tr>
</tbody>
</table>
Current Data Review

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

Sig Diff: Doctor Cost, Pap Test, Current Smokers, Obesity

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

Sig Diff: All Conditions

Georgia Behavioral Risk Factor Surveillance System (GA-BRFSS)
Medicare Data -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 are less than 65 years of age.
80% (89,288/111,033) of Georgians with ADRD claims in 2017 were alive by December 31, 2017.
Alzheimer Patients Caregiver Description

- One out 5 caregiver (21.7%) in Georgia cares for an Alzheimer patient.
- Two out of 3 (2/3) Alzheimer caregivers are females.
- Median age of Alzheimer caregiver is 56 years of age.
- 48.8% of the Alzheimer Caregivers are family members (parent).
- 43% of the Alzheimer 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

Georgia Behavioral Risk Factor Surveillance System (GA-BRFSS)
Data Access--https://dph.georgia.gov/institutional-review-board

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 human research experimentally approved research protocol.

Approval must be obtained prior to any involvement of the subjects. The approval by the Board is limited in time to no more than 12-month periods 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
- $1,000 for expedited or full reviews
- No Fee for studies meeting the criteria for exemption (non IRB review)

Amendments
- $50 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 payments to:

Georgia Department of Public Health
Attn: Financial Services
BBB
2 Riverside Drive, NE, 16th Floor
Atlanta, Georgia 30305

Meeting Schedule

EEIRB meets on the last Friday of each month. Meeting schedule is subject to change without prior notice. Applications must be received by the 15th of the month to be included on the agenda for that month’s meeting.

Contact Information

Rebecca Karch, Ph.D.
BBB Coordinator and Chair
Institutional Review Board
Department of Public Health
2 Riverside Drive, NE, 16th Floor
Atlanta, Georgia 30305
404-639-3120
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Submission: EEIRB@dph.georgia.gov

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Institutional Review Board - Related Files
- Amendment to an Existing Protocol (Version 3 01/01/2012) (PDF, 49.93 KB)
- IRB Conference to Research Using Human Subjects Manual (Revised 02/1, 2012) (PDF, 131.53 KB)
- Initial Application: Institutional Review Board (PDF, 154.33 KB)
Public Health Information Portal

https://dph.georgia.gov/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:
• $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 $250 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 adjust 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:
Demetris 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

phipdatarequest@dph.georgia.gov
Contact

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