The Texas Council on Alzheimer’s Disease and Related Disorders (Council) met on Tuesday, August 25, 2015, at the Texas Department of State Health Services, 1100 W. 49th St., Austin TX 78756.

**Council Members Present**
The Honorable Clint Hackney, Vice-Chair  
Lisa B. Glenn, MD  
Deborah S. Hanna, Chair  
Rita Hortonstine  
Patty Moore, PhD  
Valerie J. Krueger  
Toni Packard  
Laura DeFina, MD  
Kate Allen Stukenberg  
Melissa L. Edwards

**Council Members Absent**
Carlos Escobar, MD  
Ray Lewis, DO  
Susan Rountree, MD  
Nancy Walker  
Grayson R. Hankins  
Ronald Devere, MD  
Robert Vogel, MD

**Guests Present**
Katie Wiechnicki, DSHS – Health Promotion and Chronic Disease Prevention (HPCDP)  
Roberto Rodriguez, DSHS - HPCDP  
Mack Harrison, DSHS – Office of General Counsel  
Nimisha Bhakta, DSHS - HPCDP Office of Surveillance, Evaluation and Research (OSER)  
Erin Wu, DSHS – HPCDP OSER  
Susan Ristine, Texas Alzheimer’s Research and Care Consortium (TARCC)

**Program Staff Members Present**
Lynda Taylor, DSHS - HPCDP
1. Welcome/Call to Order/Roll Call/Excuse Absent Members
   Ms. Debbie Hanna called the meeting to order at 10:35 a.m. Ms. Lynda Taylor certified roll, and a quorum was present. Members and guests were welcomed.

2. Approval of Council Minutes from the February 25, 2015, Meeting
   Ms. Hanna asked Council members to review the minutes from the February 25, 2015, meeting. Kate Stukenberg moved that the minutes be approved as presented. Rita Hortenstine seconded the motion. All were in favor, and the February 25, 2015, meeting minutes were approved as presented.

3. Department of State Health Services (DSHS) Update
   Dr. Patty Moore provided updates from the Texas Department of State Health Services.
   1. Chris Traylor was appointed Health and Human Services Commission (HHSC) Executive Commissioner replacing Dr. Janek.
   2. Kirk Cole was appointed Interim DSHS Commissioner replacing Dr. Lakey.
   3. The Sunset Commission recommended that DSHS, DADS, DARS, and DFPS be merged into HHSC. Senate Bill 200 contained language to do that. The bill leaves DSHS as an independent agency with continued oversight from HHSC. However, a number of DSHS administrative functions and programs will be merged into HHSC over the biennium. Legislative leadership, HHSC, and DSHS are working to determine those functions that will be left with a streamlined DSHS.

4. Presentation on Texas data and barriers to population-level data collection on Alzheimer’s disease
   Dr. Moore stated that at the request of the Chair of the Texas Council on Alzheimer’s disease and Related Disorders, the Health Promotion and Chronic Disease Prevention Section (HPCDPS) Office of Surveillance, Evaluation and Research (OSER) conducted preliminary exploration to determine the feasibility of creating a population data base for persons with Alzheimer’s disease (AD) in Texas. Dr. Moore introduced Erin Wu from OSER to present the initial findings of this report.

   Ms. Wu provided a slide presentation regarding the following:
   - Population-level AD in Texas
     - Current and projected number of Texans
     - Hospital discharge rates and charges
     - Mortality rates
     - County-level prevalence among Medicare beneficiaries
     - Prevalence of comorbidities among Medicare beneficiaries
     - Healthcare utilization among Medicare beneficiaries
• Literature review on barriers to collecting population-level AD data
  - Incidence and prevalence data for Alzheimer’s disease is difficult to find. The data available indicate that the number of Texans with AD is very likely higher than the numbers reflected in the data. There are many barriers to collecting population-level AD data.

5. Texas Alzheimer’s Research and Care Consortium (TARCC) report on funding
Ms. Hanna stated that the Council, as the oversite body for TARCC, reviewed the TARCC budget bills introduced in the 84th Legislature. Ms. Hanna presented a document stating that the bills placed AD research funding as a special item of the University of Texas System (Senate Bill 2) and a special item of the University of Texas at Austin (House Bill 1), both in the same amount of $9,230,625.

To reconcile the difference, the conference committee retained the language of House Bill 1, which makes the University of Texas at Austin (UT Austin) TARCC’s fiscal agent. Ms. Hanna and the Honorable Clint Hackney had no objections because the same amount of money was distributed.

6. University of Texas at Austin – TARCC membership
Ms. Hanna presented a letter from the President of UT Austin, Gregory L. Fenves, requesting membership in TARCC. In the letter, Mr. Fenves stated that the research and clinical activities at the university are directly related to the activities of TARCC and will be expanded with the establishment of the Dell Medical School.

Ms. Hanna presented a letter and curriculum vitae from John C. DeToledo, M.D., of the Texas Tech University Health Science Center requesting to be the Interim PI for the Lubbock TARCC site now that Chuang-Kuo Wu, M.D., has resigned.

Ms. Hanna asked for a motion to approve TARCC membership for the University of Texas at Austin and the appointment of John C. Toledo, M.D., as the Interim PI for the Lubbock TARCC site. Judge Hackney moved to adopt the motion. Rita Hortenstine and Laura DeFina, M.D., seconded the motion. All were in favor, and the motion passed unanimously.

7. TARCC 5-year review
Ms. Hanna referenced the Education Code, Chapter 154.008 (House Bill 1504 of the 76th Texas Legislative Session) requiring the Council to “review and evaluate the performance of the consortium participants and data coordinating center at least every five years.”

Ms. Hanna described the process as follows:
The Council has utilized the services of an External Advisory Committee comprised of distinguished scientists to meet every other year and evaluate the cohort. The site performance review will differ in that it will be more robust and will include an evaluation of the Alzheimer’s research efforts at all funded sites including an audit of the UTSW Tissue Bank, UTSW Data Center (data coordinating center), UTSW subcontract for GWAS, Investigator Grant Program (TAMHSC) and cohort.

- Drs. Doody and Barber will coordinate with Ms. Hanna on the steps necessary to identify processes and parties necessary to conduct this statutory site review.

**Site Annual Reviews**

The Scientific Manager MOU with UTHSC provides that an annual site cohort review for each funded institution be performed by Dr. Barber. These reviews were discontinued but all agreed it is important for Dr. Barber to reinstitute a once per year visit to each site. Dr. Doody will assist Dr. Barber in designing the template for the annual site review. To the extent that financial matters and MOUs are part of the review, that function will be performed by Ashley Nemec, UT Austin.

8. **TARCC budget**

**TARCC Cohort**

Ms. Hanna presented the administrative budget summary for FYE2016 and FYE2017 and FYE 2016 budget summary for TARCC cohort sites.

Each TARCC Steering Committee members prepared the budget request for their site. The requested budgets were funded as requested. In 2016 the Steering Committee working through Dr. Doody will present their 2017 cohort maintenance budgets and additional items based on available funds.

**Funded institutions:**

- Baylor College of Medicine
- Texas Tech University Health Sciences Center
- University of North Texas Health Science Center
- University of Texas Southwestern Medical Center
- University of Texas Health Science Center San Antonio

Texas AMHSC does not participate in cohort enrollment.

Ms. Hanna asked for a motion to approve the FYE 2016 cohort maintenance budget. Clint Hackney moved to adopt the motion. Rita Hortenstine seconded the motion. All were in favor, and the motion passed unanimously.
TARCC 2-Year Budget
Ms. Hanna presented a 2-year TARCC administrative budget summary for FYE2016 and FYE2017.

Ms. Hanna suggested that the Council be open to an increase in the number of meetings each year to four so that matters concerning TARCC can be reviewed if necessary. UT Austin will use TARCC funds for meeting space and Council travel reimbursement for the two additional meetings each year.

Ms. Hanna stated that funds were available in the appropriation to begin planning for TARCC to address the statutory responsibility to address Alzheimer’s care in Texas. Two hundred thousand dollars ($200,000) per year of the TARCC budget will be used for a Care Initiative. A group of four council members, including Rita Hortenstine, and Lynda Taylor, DSHS Alzheimer’s Disease Program Coordinator, will create a plan for the initiative. This planning group will consult with Rachelle S. Doody, M.D., Ph.D., and C. Munro Cullum, Ph.D., and determine ways to collaborate with Texas A&M and the Texas Department of Aging and Disability (DADS) to reach the many counties of Texas through existing resources. For consideration is the national pilot model for dementia-friendly cities.

Ms. Hanna asked for a motion to approve the FYE 2016 and FYE 2017 TARCC administrative budget which includes the Care Initiative. Ms. Hortenstine moved to adopt the motion. Kate Stukenberg seconded the motion. All were in favor, and the motion passed unanimously.

Steve Waring, DVM, Ph.D., resignation
Ms. Hanna stated that Steve Waring, DVM, Ph.D., had resigned from the TARCC External Advisory Committee via email in June 2015 due to reasons of geography. Dr. Waring will not renew his contract with Texas A&M.

Steering Committee Interim Chair
Ms. Hanna recommended that Rachelle S. Doody, M.D., Ph.D., be appointed interim chair of the Site Review Steering Committee for two years.

Mack Harrison, general counsel for DSHS, stated that because the suggested appointment of Dr. Doody as interim chair was not on the meeting agenda, the motion could be challenged at a future time. In lieu of actually appointing Dr. Doody interim chair, Ms. Hanna suggested that Dr. Doody be assigned the tasks of interim chair until an appointment is made.

9. Time and Date for Next Council Meeting
Ms. Hanna said she would consider scheduling a meeting in the next couple of months and will discuss options with the Council members.
10. Public Comment
Ms. Hanna presented a letter on behalf of Dr. Ron Devere, who was not present at the meeting. Dr. Devere's letter described an example of the challenges that occur regarding legal guardianship for those with dementia. State agency representatives present at the meeting were welcomed to contact Dr. Devere for more information.

11. Adjourn
The meeting was adjourned at 12:04 p.m.
Alzheimer's Disease: Texas Data and Barriers to Population-Level Data Collection

Data Requested by
Texas Council on Alzheimer's Disease and Related Disorders

Data Request Prepared by Erin Wu, MPH
Epidemiologist Team Lead
Office of Surveillance, Evaluation and Research
Health Promotion and Chronic Disease Prevention Section
Texas Department of State Health Services

Data Request Prepared and Reviewed by Nimisha Bhakta, MPH
Manager
Office of Surveillance, Evaluation and Research
Health Promotion and Chronic Disease Prevention Section
Texas Department of State Health Services

July 31, 2015
Texas Data on Alzheimer’s Disease

1) Prevalence

Current and projected prevalence estimates were reported in the 2015 Alzheimer’s Disease Facts and Figures report produced by the Alzheimer’s Association.

- In 2015 it was estimated that 340,000 people in Texas age 65 and older have Alzheimer’s.
- In 2025 it was projected that 490,000 people in Texas age 65 and older will have Alzheimer’s.
- The prevalence change from 2015 to 2025 is a 44.1 percent increase over 10 years in the number of Texans age 65 and older who will have Alzheimer’s.
- These state prevalence numbers are based on an analysis of incidence data from the Chicago Health and Aging Project (CHAP), projected to each state’s population, with adjustments for state-specific age, gender, years of education, race, and mortality.
# Hospital Discharge Data

Table 1: Alzheimer's Disease (as Principal Diagnosis) Crude and Age-Adjusted Hospital Discharge Rate Per 10,000 People by Demographics, All Ages, Texas, 2013

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Discharges</th>
<th>Population</th>
<th>Crude Rate</th>
<th>95% CI for Crude Rate</th>
<th>Age-Adjusted Rate</th>
<th>95% CI for Age-adjusted Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>2,266</td>
<td>26,448,193</td>
<td>0.9</td>
<td>0.8</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1,016</td>
<td>13,140,348</td>
<td>0.8</td>
<td>0.7</td>
<td>0.8</td>
<td>1.1</td>
</tr>
<tr>
<td>Female</td>
<td>1,250</td>
<td>13,307,845</td>
<td>0.9</td>
<td>0.9</td>
<td>1.0</td>
<td>0.9</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>1,480</td>
<td>11,460,706</td>
<td>1.3</td>
<td>1.2</td>
<td>1.4</td>
<td>1.0</td>
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<tr>
<td>Black</td>
<td>258</td>
<td>3,044,184</td>
<td>0.8</td>
<td>0.7</td>
<td>1.0</td>
<td>1.4</td>
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<tr>
<td>Hispanic</td>
<td>252</td>
<td>10,340,413</td>
<td>0.2</td>
<td>0.2</td>
<td>0.3</td>
<td>0.6</td>
</tr>
<tr>
<td>Other</td>
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<td>1.3</td>
<td>1.2</td>
<td>1.5</td>
<td>2.9</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>0-17</td>
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</tr>
<tr>
<td>18-44</td>
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</tr>
<tr>
<td>45-54</td>
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</tr>
<tr>
<td>55-64</td>
<td>96</td>
<td>2,888,786</td>
<td>0.3</td>
<td>0.3</td>
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<td>65-74</td>
<td>425</td>
<td>1,750,938</td>
<td>2.4</td>
<td>2.2</td>
<td>2.7</td>
<td>--</td>
</tr>
<tr>
<td>75+</td>
<td>1,733</td>
<td>1,227,799</td>
<td>14.1</td>
<td>13.5</td>
<td>14.8</td>
<td>--</td>
</tr>
</tbody>
</table>

Data Source: Texas Health Care Information Collection (THCIC), Inpatient Hospital Discharge Public Use Data File, 2013.
Population Data Source: Center for Health Statistics, Texas Department of State Health Services, 2013.
Includes hospital discharges where Alzheimer's Disease was the principal diagnosis (ICD-9 Code 331.0).
Age-adjusted rates were adjusted to the 2000 U.S. Census population.
“*” indicates fewer than 12 hospital discharges reported.
“--” indicates age-adjusted rates were not calculated.
Results do not include HIV and drug/alcohol use patients.
Table 2: Alzheimer's Disease (Secondary Diagnosis Only) Crude and Age-Adjusted Hospital Discharge Rate Per 10,000 People by Demographics, All Ages, Texas, 2013

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Discharges</th>
<th>Population</th>
<th>Crude Rate</th>
<th>95% CI for Crude Rate</th>
<th>Age-Adjusted Rate</th>
<th>95% CI for Age-adjusted Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lower CI</td>
<td>Upper CI</td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>32,274</td>
<td>26,448,193</td>
<td>12.2</td>
<td>12.1</td>
<td>12.3</td>
<td>15.3</td>
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<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11,643</td>
<td>13,140,348</td>
<td>8.9</td>
<td>8.7</td>
<td>9.0</td>
<td>13.2</td>
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<tr>
<td>Female</td>
<td>20,628</td>
<td>13,307,845</td>
<td>15.5</td>
<td>15.3</td>
<td>15.7</td>
<td>16.7</td>
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<tr>
<td>White</td>
<td>18,974</td>
<td>11,460,706</td>
<td>16.6</td>
<td>16.3</td>
<td>16.8</td>
<td>13.3</td>
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<tr>
<td>Black</td>
<td>3,432</td>
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<td>11.3</td>
<td>10.9</td>
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<td>19.7</td>
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<tr>
<td>Hispanic</td>
<td>7,388</td>
<td>10,340,413</td>
<td>7.1</td>
<td>7.0</td>
<td>7.3</td>
<td>16.9</td>
</tr>
<tr>
<td>Other</td>
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<td>11.7</td>
<td>12.8</td>
<td>27.3</td>
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<tr>
<td>Age (years)</td>
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<tr>
<td>0-17</td>
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<td>7,047,199</td>
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<td>18-44</td>
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<tr>
<td>55-64</td>
<td>715</td>
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<td>2.5</td>
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<td>2.7</td>
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</tr>
<tr>
<td>65-74</td>
<td>3,834</td>
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<td>21.9</td>
<td>21.2</td>
<td>22.6</td>
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<tr>
<td>75+</td>
<td>27,601</td>
<td>1,227,799</td>
<td>224.8</td>
<td>222.1</td>
<td>227.5</td>
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</tbody>
</table>

Data Source: Texas Health Care Information Collection (THCIC), Inpatient Hospital Discharge Public Use Data File, 2013.
Population Data Source: Center for Health Statistics, Texas Department of State Health Services, 2013.
Includes hospital discharges where Alzheimer's Disease was any listed secondary diagnosis (ICD-9 Code 331.0).
Age-adjusted rates were adjusted to the 2000 U.S. Census population.
"*" indicates fewer than 12 hospital discharges reported.
"--" indicates age-adjusted rates were not calculated.
Results do not include HIV and drug/alcohol use patients.
### Table 3: Alzheimer's Disease (as Principal or Secondary Diagnosis) Hospital Discharges and Total Hospital Charges by Primary Source of Payment, All Ages, Texas, 2013

<table>
<thead>
<tr>
<th>Primary Source of Payment</th>
<th>Alzheimer's Disease as principal diagnosis</th>
<th>Alzheimer's Disease as secondary diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of Discharges</td>
<td>Percent of Discharges</td>
</tr>
<tr>
<td>Total</td>
<td>2,266</td>
<td>100</td>
</tr>
<tr>
<td>Medicaid</td>
<td>29</td>
<td>1.3</td>
</tr>
<tr>
<td>Medicare</td>
<td>1,894</td>
<td>83.6</td>
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<tr>
<td>Private Insurance</td>
<td>230</td>
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<tr>
<td>Uninsured</td>
<td>85</td>
<td>3.8</td>
</tr>
<tr>
<td>Other</td>
<td>28</td>
<td>1.2</td>
</tr>
</tbody>
</table>

Data Source: Texas Health Care Information Collection (THCIC), Inpatient Hospital Discharge Public Use Data File, 2013.

The ICD-9 Code for Alzheimer's Disease is 331.0.

"Other" includes missing.

Results do not include HIV and drug/alcohol use patients.
### 3) Mortality Data

Table 4: Alzheimer's Disease Crude and Age-Adjusted Mortality Rate Per 100,000 People by Demographics, All Ages, Texas, 2012

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Deaths</th>
<th>Population</th>
<th>Crude Rate</th>
<th>95% CI for Crude Rate</th>
<th>Age-Adjusted Rate</th>
<th>95% CI for Age-adjusted Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>5,168</td>
<td>26,059,203</td>
<td>19.8</td>
<td>Lower CI</td>
<td>Upper CI</td>
<td>25.6</td>
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<tr>
<td>Sex</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Male</td>
<td>1,636</td>
<td>12,936,056</td>
<td>12.6</td>
<td>Lower CI</td>
<td>Upper CI</td>
<td>19.7</td>
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<tr>
<td>Female</td>
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<td>13,123,147</td>
<td>26.9</td>
<td>Lower CI</td>
<td>Upper CI</td>
<td>29.6</td>
</tr>
<tr>
<td>Race</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>3971</td>
<td>11,552,523</td>
<td>34.4</td>
<td>Lower CI</td>
<td>Upper CI</td>
<td>28.7</td>
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<tr>
<td>Black</td>
<td>360</td>
<td>2,986,753</td>
<td>12.1</td>
<td>Lower CI</td>
<td>Upper CI</td>
<td>22.4</td>
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<tr>
<td>Hispanic</td>
<td>787</td>
<td>10,016,357</td>
<td>7.9</td>
<td>Lower CI</td>
<td>Upper CI</td>
<td>19.2</td>
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<td>Other</td>
<td>50</td>
<td>1,503,570</td>
<td>3.3</td>
<td>Lower CI</td>
<td>Upper CI</td>
<td>8.1</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
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<td>0-44</td>
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<td>3,463,445</td>
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<td>55-64</td>
<td>55</td>
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<td>65-74</td>
<td>302</td>
<td>1,658,427</td>
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<tr>
<td>75+</td>
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<td>1,197,040</td>
<td>401.8</td>
<td>Lower CI</td>
<td>Upper CI</td>
<td>413.2</td>
</tr>
</tbody>
</table>


Population Data Source: Center for Health Statistics, Texas Department of State Health Services, 2012.

Deaths due to Alzheimer's Disease were based on ICD-10 Code G30 listed as the underlying cause of death.

Age-adjusted rates were adjusted to the 2000 U.S. Census population.

"*" indicates fewer than 20 deaths due to Alzheimer's Disease were reported.

"--" indicates age-adjusted rates were not calculated.

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According to data from the National Center for Health Statistics, as reported in the 2015 Alzheimer's Disease Facts and Figures report produced by the Alzheimer's Association:

- In 2013, the unadjusted mortality rate in Texas for Alzheimer’s Disease was 20.0 per 100,000 with 5,293 deaths occurring.
- In 2013, the unadjusted mortality rate in the U.S. for Alzheimer’s Disease was 26.8 per 100,000 with 84,767 deaths occurring.
4) Medicare Data

Texas
Prevalence of Alzheimer's Disease/Dementia Disorders Among Medicare Fee-For-Service Beneficiaries by County: 2012

Number of fee-for-service beneficiaries in Texas: 2,340,725
Texas Alzheimer's disease/dementia prevalence: 11.5%
National Alzheimer's disease/dementia prevalence: 9.8%
Table 5. Alzheimer's Disease/Dementia Prevalence (%) By County Among Medicare Fee-For-Service Beneficiaries, All Ages and 65+ Years, 2012

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## Table 5. Alzheimer’s Disease/Dementia Prevalence (%) By County Among Medicare Fee-For-Service Beneficiaries, All Ages and 65+ Years, 2012 (continued)

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Table 5. Alzheimer's Disease/Dementia Prevalence (%) By County Among Medicare Fee-For-Service Beneficiaries, All Ages and 65+ Years, 2012 (continued)

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<td>8.5</td>
<td>Wood</td>
</tr>
<tr>
<td>Jefferson</td>
<td>12.7</td>
<td>14.9</td>
<td>Yoakum</td>
</tr>
<tr>
<td>Jim Hogg</td>
<td>16.5</td>
<td>19.4</td>
<td>Young</td>
</tr>
<tr>
<td>Jim Wells</td>
<td>17.5</td>
<td>21.5</td>
<td>Zapata</td>
</tr>
<tr>
<td>Johnson</td>
<td>12.6</td>
<td>14.5</td>
<td>Zavala</td>
</tr>
</tbody>
</table>

Data source: Centers for Medicaid and Medicare Services (CMS), CMS Chronic Condition Data Warehouse, 2012.

Note: The Medicare beneficiary population is limited to fee-for-service beneficiaries.

A Medicare beneficiary is considered to have Alzheimer’s Disease, Related Disorders, or Senile Dementia ("Alzheimer’s Disease/Dementia") if the CMS administrative data have a claim indicating that the beneficiary received a service or treatment for the specific condition within a 3-year time period.

Alzheimer’s Disease, Related Disorder, or Senile Dementia was identified with the following ICD-9 codes: DX 331.0, 331.11, 331.19, 331.2, 331.7, 290.0, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 294.0, 294.10, 294.11, 294.20, 294.21, 294.8, 797 (any listed diagnosis on the claim).
Table 6. Medicare Spending and Healthcare Utilization Among Medicare Fee-For-Service Beneficiaries with Alzheimer’s Disease/Dementia, All Ages, Texas and Nationwide, 2012

<table>
<thead>
<tr>
<th>Spending or Utilization</th>
<th>Texas</th>
<th>National</th>
</tr>
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<tbody>
<tr>
<td>Actual Spending Per Capita ($)</td>
<td>25,510.55</td>
<td>22,211.35</td>
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<tr>
<td>Standardized Spending Per Capita ($)</td>
<td>25,700.18</td>
<td>20,958.20</td>
</tr>
<tr>
<td>Emergency Department Visits (per 1,000 beneficiaries)</td>
<td>1,314.47</td>
<td>1,341.76</td>
</tr>
<tr>
<td>Hospital Readmission Rate (%)</td>
<td>20.2</td>
<td>21.5</td>
</tr>
</tbody>
</table>

Data source: Centers for Medicaid and Medicare Services (CMS), CMS Chronic Condition Data Warehouse, 2012.

Note: The Medicare beneficiary population is limited to fee-for-service beneficiaries. The Medicare utilization and spending information represents beneficiaries with Alzheimer’s Disease/Dementia. The information should not be used to attribute utilization or payments strictly to the specific condition though since beneficiaries with the Alzheimer’s Disease/Dementia may have other health conditions that contribute to their Medicare utilization and spending amounts.

Medicare spending includes total Medicare payments for all Medicare covered services in Parts A and B and is presented per beneficiary (i.e., per capita). Both total actual payments and total standardized payments are presented.

Emergency department visits are presented as the number of visits per 1,000 beneficiaries. ED visits include visits where the beneficiary was released from the outpatient setting and where the beneficiary was admitted to an inpatient setting.

Hospital readmissions are expressed as a percentage of all admissions. A 30-day readmission is defined as an admission to an acute care hospital for any cause within 30 days of discharge from an acute care hospital. Except when the patient died during the stay, each inpatient stay is classified as an index admission, a readmission, or both. The numerator is the number of readmissions for beneficiaries with Alzheimer’s Disease/Dementia. The denominator is the number of admissions for beneficiaries with Alzheimer’s Disease/Dementia. The admission or readmission may or may not be associated with Alzheimer’s Disease/Dementia.
### Table 7: Prevalence (%) of Alzheimer's Disease/Dementia Among Medicare Fee-For-Service Beneficiaries
#### By Sex, Age Group, and Enrollment, Texas and National, 2012

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Texas</th>
<th>National</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All</td>
<td>Male</td>
</tr>
<tr>
<td>Enrollment in Medicare Only or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare &amp; Medicaid</td>
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<td></td>
</tr>
<tr>
<td>All Ages</td>
<td>11.6</td>
<td>9.1</td>
</tr>
<tr>
<td>&lt;65 years</td>
<td>4.2</td>
<td>4.0</td>
</tr>
<tr>
<td>65+ years</td>
<td>29.4</td>
<td>29.4</td>
</tr>
<tr>
<td>65-74 years</td>
<td>4.4</td>
<td>4.4</td>
</tr>
<tr>
<td>75-84 years</td>
<td>16.0</td>
<td>16.0</td>
</tr>
<tr>
<td>85+ years</td>
<td>38.4</td>
<td>38.4</td>
</tr>
<tr>
<td>Enrollment in Medicare Only</td>
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<td></td>
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<tr>
<td>All Ages</td>
<td>8.8</td>
<td>7.2</td>
</tr>
<tr>
<td>&lt;65 years</td>
<td>2.3</td>
<td>2.2</td>
</tr>
<tr>
<td>65+ years</td>
<td>29.6</td>
<td>29.6</td>
</tr>
<tr>
<td>65-74 years</td>
<td>2.9</td>
<td>2.9</td>
</tr>
<tr>
<td>75-84 years</td>
<td>12.3</td>
<td>12.3</td>
</tr>
<tr>
<td>85+ years</td>
<td>31.8</td>
<td>31.8</td>
</tr>
<tr>
<td>Enrollment in Medicare &amp; Medicaid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All Ages</td>
<td>21.4</td>
<td>17.1</td>
</tr>
<tr>
<td>&lt;65 years</td>
<td>6.1</td>
<td>6.1</td>
</tr>
<tr>
<td>65+ years</td>
<td>30.6</td>
<td>26.3</td>
</tr>
<tr>
<td>65-74 years</td>
<td>14.5</td>
<td>14.5</td>
</tr>
<tr>
<td>75-84 years</td>
<td>33.0</td>
<td>33.0</td>
</tr>
<tr>
<td>85+ years</td>
<td>59.9</td>
<td>59.9</td>
</tr>
</tbody>
</table>

Data source: Centers for Medicaid and Medicare Services (CMS), CMS Chronic Condition Data Warehouse, 2012.

Note: The Medicare beneficiary population is limited to fee-for-service beneficiaries.

Medicare beneficiaries were classified as dual eligible (eligible for both Medicare and Medicaid) if in any month in 2012 they were receiving full or partial Medicaid benefits.

A Medicare beneficiary is considered to have Alzheimer's Disease, Related Disorders, or Senile Dementia ("Alzheimer's Disease/Dementia") if the CMS administrative data have a claim indicating that the beneficiary received a service or treatment for the specific condition within a 3-year time period.

Alzheimer's Disease, Related Disorder, or Senile Dementia was identified with the following ICD-9 codes: DX 331.0, 331.11, 331.19, 331.2, 331.7, 290.0, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 294.0, 294.10, 294.11, 294.20, 294.21, 294.8, 797 (any listed diagnosis on the claim).
Table 7: Prevalence (%) of 5 or More Comorbidities Among Medicare Fee-For-Service Beneficiaries with Alzheimer’s Disease/Dementia By Sex, Age Group, and Enrollment, Texas and National, 2012

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Texas</th>
<th>National</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All Male Female</td>
<td>All Male Female</td>
</tr>
<tr>
<td>Enrollment in Medicare Only or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare &amp; Medicaid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All Ages</td>
<td>52.6 53.6 52.0</td>
<td>47.0 49.1 45.9</td>
</tr>
<tr>
<td>&lt;65 years</td>
<td>49.7 47.3 52.2</td>
<td>40.7 39.5 42.1</td>
</tr>
<tr>
<td>65+ years</td>
<td>52.7 54.2 52.0</td>
<td>47.3 49.9 46.0</td>
</tr>
<tr>
<td>65-74 years</td>
<td>52.4 51.8 52.8</td>
<td>48.1 48.2 48.1</td>
</tr>
<tr>
<td>75-84 years</td>
<td>53.8 54.6 53.2</td>
<td>48.7 50.6 47.6</td>
</tr>
<tr>
<td>85+ years</td>
<td>52.0 55.1 44.5</td>
<td>46.0 50.2 50.8</td>
</tr>
<tr>
<td>Enrollment in Medicare Only</td>
<td>46.4 48.6 45.0</td>
<td>42.6 45.9 40.6</td>
</tr>
<tr>
<td></td>
<td>38.9 39.4 38.4</td>
<td>34.4 34.2 34.6</td>
</tr>
<tr>
<td></td>
<td>46.6 49.0 45.1</td>
<td>42.8 46.3 40.7</td>
</tr>
<tr>
<td></td>
<td>41.4 42.5 40.5</td>
<td>39.3 41.0 37.9</td>
</tr>
<tr>
<td></td>
<td>47.0 49.5 45.2</td>
<td>43.5 46.7 41.2</td>
</tr>
<tr>
<td></td>
<td>48.2 51.9 46.4</td>
<td>43.3 48.0 41.0</td>
</tr>
<tr>
<td>Enrollment in Medicare &amp; Medicaid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All Ages</td>
<td>51.8 62.8 61.4</td>
<td>54.0 55.7 53.3</td>
</tr>
<tr>
<td>&lt;65 years</td>
<td>54.1 50.9 57.1</td>
<td>43.0 41.5 44.6</td>
</tr>
<tr>
<td>65+ years</td>
<td>62.8 65.3 61.8</td>
<td>55.3 58.9 54.0</td>
</tr>
<tr>
<td>65-74 years</td>
<td>66.7 65.3 67.3</td>
<td>59.9 59.0 60.5</td>
</tr>
<tr>
<td>75-84 years</td>
<td>65.4 66.3 64.9</td>
<td>58.6 60.3 57.9</td>
</tr>
<tr>
<td>85+ years</td>
<td>58.4 63.9 57.1</td>
<td>51.0 56.9 49.7</td>
</tr>
</tbody>
</table>

Data source: Centers for Medicaid and Medicare Services (CMS), CMS Chronic Condition Data Warehouse, 2012.
Note: The Medicare beneficiary population is limited to fee-for-service beneficiaries.
Medicare beneficiaries were classified as dual eligible (eligible for both Medicare and Medicaid) if in any month in 2012 they were receiving full or partial Medicaid benefits.
A Medicare beneficiary is considered to have Alzheimer’s Disease, Related Disorders, or Senile Dementia ("Alzheimer’s Disease/Dementia") if the CMS administrative data have a claim indicating that the beneficiary received a service or treatment for the specific condition within a 3-year time period.
Alzheimer’s Disease, Related Disorder, or Senile Dementia was identified with the following ICD-9 codes: DX 331.0, 331.11, 331.19, 331.2, 331.7, 290.0, 290.10, 290.11, 290.12, 290.13, 290.20, 290.21, 290.3, 290.40, 290.41, 290.42, 290.43, 294.0, 294.10, 294.11, 294.20, 294.21, 294.8, 797 (any listed diagnosis on the claim).

In the Medicare Chronic Conditions data there are 17 chronic conditions that may be included as a comorbid condition: Alzheimer’s disease, related disorders, or senile dementia; Arthritis (including rheumatoid and osteoarthritis); Asthma; Atrial fibrillation; Autism spectrum disorders; Cancer (breast, colorectal, lung, and prostate); Chronic kidney disease; COPD; Depression; Diabetes (excluding diabetic conditions related to pregnancy); Heart failure; Hyperlipidemia (High cholesterol); Hypertension (High blood pressure); Ischemic heart disease; Osteoporosis; Schizophrenia/Other psychotic disorders; Stroke/Transient ischemic attack.
Barrier to Alzheimer’s Disease Population-Level Data Collection

- A diagnosis of AD is not conclusive without an autopsy performed after death. Therefore, misclassification of AD diagnosis is possible in living patients. Also, if an AD case is identified with ICD-9 code 331.0 and/or pharmacy claims for AD-specific medication, undiagnosed cases would not be captured (Zhao et al., 2008). Additional information like duration of disease or severity of disease are often not captured or not able to be captured from hospital or pharmacy claims data.

- AD is likely severely underreported on death certificates (Weuve et al., 2014). Some studies count the number of deaths among patients who were identified as having AD which would be simpler than counting the number of deaths attributed to AD. There is a high likelihood that persons with AD also have comorbid conditions that make choosing a single cause of death more difficult.

- In one study, persons were identified as having AD only if it was indicated as a primary or contributing cause of death on the death certificate. This is a conservative approach since many individuals with AD would not be identified because they were not diagnosed during life or the physician completing the death certificate did not judge AD as leading to death (Kauwe et al., 2013).

- In a major study, estimates of the risk of developing and dying from AD were assumed to be the same for people of Hispanic and non-Hispanic origin. However, if this assumption is not accurate, the current and projected estimated number of deaths among individuals with AD may differ especially in the future in the US (and particularly in Texas) when a larger proportion of the older population will be Hispanic (Weuve et al., 2014).

- A physician’s familiarity with their patient’s medical history plays an important role in whether AD is identified on the death certificate. Therefore, deaths occurring among individuals from nursing homes or long stay psychiatric hospitals are more accurate than deaths occurring in a hospital (Todd et al., 2013).

- In a paper by Wilson et al. (2011), diagnostic criteria were compared for two studies that estimated the prevalence of Alzheimer’s disease in the U.S. The prevalence was estimated to be 2.3 million in 2002 by the Aging, Demographics, and Memory Study (ADAMS) which was nearly 50% less than the estimate of 4.5 million in 2000 derived from the Chicago Health and Aging Project (CHAP). There were several methodological differences between the two studies that could potentially affect AD prevalence estimates, however, the paper focuses on two differences that were likely to account for most of the difference in prevalence estimates.

  - The first is diagnostic criteria for dementia. In ADAMS, the diagnostic criteria were based on Diagnostic and Statistical Manual of Mental Disorders (DSM)III-R and IV, which require that the cognitive decline be of sufficient severity to impair daily function. In CHAP, the diagnostic criteria were based on the National Institutes of Neurological and Communicative Disorders and Stroke and the Alzheimer’s Disease and Related Disorders Association (NINCDS-ADRDA) in which cognitive decline was documented by cognitive performance testing. While both criteria require a history of cognitive decline and impairment in multiple cognitive domains, the DSM requirement of functional impairment would identify persons with a greater degree of cognitive impairment and
may miss persons without functional impairment. Therefore, more people would be expected to meet NINCDS-ADRDA criteria for dementia than the DSM criteria.

- The second is that it is often not always clear where to place the distinction between dementia and normal aging. One response to this problem is to create a new syndrome for individuals with cognitive impairment not severe enough to warrant a diagnosis of dementia. This new syndrome is most commonly referred to as mild cognitive impairment (MCI) or cognitive impairment not dementia (CIND). Within the CIND group, the ADAMS assigned a diagnosis of prodromal AD to what translates to about 1.9 million persons. This is in addition to the 2.3 million persons with AD. The shift in the threshold for dementia towards that of CIND could account for very large differences in AD prevalence between the two studies.

- The AD incidence was estimated from the Chicago Health and Aging Project from 1997 to 2008. In this study, incidence estimation may have been limited by the 3-year data collection cycles in cases with disease onset occurring over an atypically lengthy period of time or cases with death occurring shortly after onset of disease or symptoms. Such cases would be less likely to be identified in the particular study (Rocca et al., 2011).

- Prevalence of dementia was estimated in the Indianapolis-Ibadan Dementia Project comparing 1992 to 2001. In the case of this study and possibly other long-term studies, the recruitment strategy changes in 2001 which resulted in higher refusal rates. Those who refused to participate were significantly older than those who enrolled, which could result in missing cases, leading to an underestimation of prevalence. Differences in participation or differential loss to follow-up in longitudinal studies for persons with and without AD could be problematic for any study on prevalence or incidence of dementia or Alzheimer’s Disease (Rocca et al., 2011).

- If physician claims data are used to identify a person as having AD, it is possible that cases will not be identified if only one diagnosis code is allowed per claim. However, if inpatient hospital data are used where up to 25 diagnoses can be listed, it may be more likely that dementia or AD will be listed as one of the codes. In the case of inpatient hospital data, AD may be listed as a primary or one of many secondary diagnoses. There is also a potential to overestimate the number of cases when using hospital data (Kosteniuk et al., 2015).

- AD prevalence is often calculated from incidence data. Estimating AD prevalence from studies that use a variety of study designs, data sources, and diagnostic criteria, and case definitions leads to differences in estimations of AD prevalence (Brookmeyer et al., 2011). In this article, Brookmeyer et al. (2011) describe and compare four methods of estimating prevalence of AD in the U.S. The first two studies statistically derived prevalence estimates using forward calculations based on incidence and survival data. The first study used incidence rates from multiple published studies and the second study applied incidence rates from their own cohort sample. The third and fourth studies were sample surveys conducted in different cities, using very similar sampling techniques but different disease definitions. The third study used direct estimates and relied on probability sampling nationwide. The fourth study relied on localized prevalence estimates which were projected to the national population. The second and fourth studies used similar disease definitions but different calculation methods and still arrived at similar prevalence estimates which were also significantly higher than from the first and third studies. The author concludes that differences in disease definition or threshold appear to explain the difference in prevalence estimates produced by the four studies.
• Alzheimer's Disease has a gradual onset and develops over time. Identifying the onset of disease is often difficult since a person may not show clinical signs of disease during the early stages. Also, choosing a cut point for classifying disease presence may not be consistent across studies (Hebert et al., 2013).

• When assessing trends in disease incidence rates over time which use data from medical claims databases, changes in billing practices and office procedures may affect records (Akushevich et al., 2013). Identified changes in disease incidence over time may not represent true changes in disease incidence, but instead may be a reflection of changes in reporting practices.

• Many people who have Alzheimer's Disease (AD) are not symptomatic yet and may not be clinically diagnosed. Therefore using a standardized neurologic evaluation, as is used in the CHAP study, to identify persons with AD is preferred to using clinical sources (Hebert et al., 2013).

• In studies where non-institutionalized individuals are included in the study population, persons living in long-term care facilities or nursing homes, would not be included (Lönnroos et al., 2013). This could be lead to an underestimation of AD incidence or prevalence, especially if those excluded from the study are more likely than the general population to be older and therefore at higher risk for developing or having AD.

• In the Aging, Demographics, and Memory Study (ADAMS), participation rate was lower than expected, which could result in selection bias. The lack of neuroimaging and other medical tests for all participants may have influenced the accuracy with which non-AD dementias were identified. And grouping those with 'dementia, undetermined etiology' with the AD group may somewhat overestimate the prevalence of AD (Plassman et al., 2007).
References


Texas Alzheimer's Disease Data and Barriers to Collecting Population-Level Data

Erin Wu, MPH
Texas Council on Alzheimer's Disease and Related Disorders
August 25, 2015
Outline

- Population-level Alzheimer's disease data in Texas
  - Current and projected number of Texans
  - Hospital discharge rates and charges
  - Mortality rates
  - County-level prevalence among Medicare beneficiaries
  - Prevalence of comorbidities among Medicare beneficiaries
  - Healthcare utilization among Medicare beneficiaries

- Literature review on barriers to collecting population-level Alzheimer's disease data
Population-level Alzheimer's disease data in Texas
Projected Number of People Age 65+ with Alzheimer’s Disease in Texas, 2015 and 2025

Alzheimer’s Disease Prevalence

Projected Number of People Age 65+ with Alzheimer’s Disease in Texas, 2015 and 2025

44.1% increase over next 10 years

Age-adjusted hospital discharge rates for primary diagnosis of AD in 2013:

- Overall Texas rate: 1.0 per 10,000 people.
- No significant difference between males and females.
- Higher among “other” race/ethnicity at 2.9 per 10,000 people compared to white, black, or Hispanic.
- Highest among persons age 75 years and older at 14.1 per 10,000 people compared to all other age groups (age-specific rate).
Age-adjusted hospital discharge rates for any secondary diagnosis of AD in 2013:

- Overall Texas rate: 15.3 per 10,000 people.
- Higher among females (16.7 per 10,000 people) than males (13.2 per 10,000 people).
- Higher among "other" race/ethnicity at 27.3 per 10,000 people compared to white, black, or Hispanic.
- Highest among persons age 75 years and older at 224.8 per 10,000 people compared to all other age groups (age-specific rate).
Hospital Discharges by Payer Source

Percent of Hospital Discharges by Primary Payer Source where the Principal Diagnosis was Alzheimer’s Disease, Texas, 2013

<table>
<thead>
<tr>
<th>Payer Source</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid</td>
<td>1.3</td>
</tr>
<tr>
<td>Medicare</td>
<td>83.6</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>10.2</td>
</tr>
<tr>
<td>Uninsured</td>
<td>3.8</td>
</tr>
<tr>
<td>Other</td>
<td>1.2</td>
</tr>
</tbody>
</table>

Percent of Hospital Discharges by Primary Payer Source where Any Secondary Diagnosis was Alzheimer’s Disease, Texas, 2013

<table>
<thead>
<tr>
<th>Payer Source</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid</td>
<td>0.9</td>
</tr>
<tr>
<td>Medicare</td>
<td>92.0</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>5.4</td>
</tr>
<tr>
<td>Uninsured</td>
<td>1.0</td>
</tr>
<tr>
<td>Other</td>
<td>0.8</td>
</tr>
</tbody>
</table>

Data source: Texas Health Care Information Collection (THCIC), Inpatient Hospital Discharge Public Use Data File, 2013.
### Hospital Charges by Payer Source

**Total Hospital Charges ($) by Primary Payer Source where the Principal Diagnosis was Alzheimer's Disease, Texas, 2013**

<table>
<thead>
<tr>
<th>Source</th>
<th>Charges ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>20,000,000</td>
</tr>
<tr>
<td>20,000,000</td>
<td>40,000,000</td>
</tr>
<tr>
<td>40,000,000</td>
<td>60,000,000</td>
</tr>
<tr>
<td>Medicaid</td>
<td>1,261,952</td>
</tr>
<tr>
<td>Medicare</td>
<td>53,567,501</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>5,120,193</td>
</tr>
<tr>
<td>Uninsured</td>
<td>1,876,506</td>
</tr>
<tr>
<td>Other</td>
<td>826,647</td>
</tr>
</tbody>
</table>

**Total Hospital Charges by Primary Payer Source where Any Secondary Diagnosis was Alzheimer's Disease, Texas, 2013**

<table>
<thead>
<tr>
<th>Source</th>
<th>Charges ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1,000,000,000</td>
</tr>
<tr>
<td>1,000,000,000</td>
<td>2,000,000,000</td>
</tr>
<tr>
<td>Medicaid</td>
<td>17,370,334</td>
</tr>
<tr>
<td>Medicare</td>
<td>1,477,256,662</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>75,166,921</td>
</tr>
<tr>
<td>Uninsured</td>
<td>13,739,195</td>
</tr>
<tr>
<td>Other</td>
<td>13,255,830</td>
</tr>
</tbody>
</table>

Data source: Texas Health Care Information Collection (THCIC), Inpatient Hospital Discharge Public Use Data File, 2013.
According to data from the National Center for Health Statistics, as reported in the 2015 Alzheimer’s Disease Facts and Figures report produced by the Alzheimer’s Association:

- In 2013, the unadjusted mortality rate in Texas for Alzheimer's Disease was 20.0 per 100,000 with 5,293 deaths occurring.

- In 2013, the unadjusted mortality rate in the U.S. for Alzheimer's Disease was 26.8 per 100,000 with 84,767 deaths occurring.
Mortality Rates

Age-adjusted mortality rates for AD in 2012:

• Overall Texas rate: 25.6 per 100,000 people.

• Higher among females (29.6 per 100,000 people) compared to males (19.7 per 100,000 people).

• Higher among whites at 28.7 per 100,000 people compared to black, Hispanic, or other race/ethnicity.

• Highest among persons age 75 years and older at 401.8 per 100,000 people compared to all other age groups (age-specific rate).
Medicare Data: Prevalence

Texas
Prevalence of Alzheimer's Disease/Dementia Disorders Among Medicare Fee-For-Service Beneficiaries by County: 2012

Prevalence
- 5.3% - 8.0%
- 8.1% - 11.0%
- 11.1% - 14.0%
- 14.1% - 17.7%
- No Data

Number of fee-for-service beneficiaries in Texas: 2,340,725
Texas Alzheimer's disease/dementia prevalence: 11.5%
National Alzheimer's disease/dementia prevalence: 9.8%

Centers for Medicaid and Medicare Services (CMS), CMS Chronic Condition Data Warehouse, 2012.
Prevalence (%) of Alzheimer's Disease/Dementia Among Medicare Fee-For-Service Beneficiaries* By Sex and Age Group
Texas, 2012

*Includes beneficiaries enrolled in Medicare only or both Medicare and Medicaid.
Prevalence (%) of 5 or More Comorbidities Among Medicare Fee-For-Service Beneficiaries* with Alzheimer's Disease/Dementia By Age Group
Texas and National, 2012

*Includes beneficiaries enrolled in Medicare only or both Medicare and Medicaid.
Centers for Medicaid and Medicare Services (CMS), CMS Chronic Condition Data Warehouse, 2012.
## Medicare Data: Spending

Table 6. Medicare Spending and Healthcare Utilization Among Medicare Fee-For-Service Beneficiaries with Alzheimer’s Disease/Dementia, All Ages, Texas and Nationwide, 2012

<table>
<thead>
<tr>
<th>Spending or Utilization</th>
<th>Texas</th>
<th>National</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actual Spending Per Capita ($)</td>
<td>25,510.55</td>
<td>22,211.35</td>
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<tr>
<td>Standardized Spending Per Capita ($)</td>
<td>25,700.18</td>
<td>20,958.20</td>
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<tr>
<td>Emergency Department Visits (per 1,000 beneficiaries)</td>
<td>1,314.47</td>
<td>1,341.76</td>
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<tr>
<td>30-Day Hospital Readmission Rate (%)</td>
<td>20.2</td>
<td>21.5</td>
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</table>

Data source: Centers for Medicaid and Medicare Services (CMS), CMS Chronic Condition Data Warehouse, 2012.

Note: The Medicare beneficiary population is limited to fee-for-service beneficiaries. The Medicare utilization and spending information represents beneficiaries with Alzheimer’s Disease/Dementia. The information should not be used to attribute utilization or payments strictly to the specific condition though since beneficiaries with the Alzheimer’s Disease/Dementia may have other health conditions that contribute to their Medicare utilization and spending amounts.
Literature review on barriers to collecting population-level Alzheimer's disease data
Barriers to Data Collection

- A diagnosis of AD is not conclusive without an autopsy performed after death.
  - Misclassification of AD diagnosis in living patients.

- Persons with AD likely have comorbid conditions that make choosing a single cause of death difficult.
  - AD is likely severely underreported on death certificates.

- A physician’s familiarity with their patient's medical history plays an important role in whether AD is identified on the death certificate.
  - Deaths occurring among individuals from nursing homes or long stay psychiatric hospitals are more accurate than deaths occurring in a hospital.
Barriers to Data Collection

- Differences in participation or differential loss to follow-up in longitudinal studies for persons with and without AD could be problematic for any study on prevalence or incidence of AD.

- If physician claims data are used to identify a person as having AD, it is possible that cases will not be identified if only one diagnosis code is allowed per claim.

- AD prevalence is often calculated from incidence data. Estimating AD prevalence from studies that use a variety of study designs, data sources, diagnostic criteria, and case definitions leads to differences in estimations of AD prevalence.
Barriers to Data Collection

• Since AD has a gradual onset and develops over time, choosing a cut point for classifying disease presence or absence may not be consistent across studies.

• Using a standardized neurologic evaluation to identify persons with AD is preferred to using clinical sources, which may miss those who are not symptomatic and have not been diagnosed.

• When assessing trends in disease incidence rates over time using data from medical claims databases, changes in billing practices and office procedures may affect records
  - Identified changes in disease incidence over time may not represent true changes in disease incidence, but instead may be a reflection of changes in reporting practices.
References (1)


Acknowledgements

**Epidemiology team**
- Sylvie Dodell
- Chelsea Frand
- Haruna Miyakado
- Blaise Mathabela

**Manager**
- Nimisha Bhakta
Thank You.

Erin Wu, MPH
Epidemiologist Team Lead
Erin.Wu@dshs.state.tx.us
(512)776-3519

Lynda Taylor, MSW
Coordinator, Alzheimer’s Disease Program
Lynda.Taylor@dshs.state.tx.us
(512)776-6618
The budget bills as introduced in the recently concluded legislative session placed AD research funding as a special item of the University of Texas System (SB 2) and a special item of the University of Texas at Austin (HB 1), both in the same amount of $9,230,625.

The conference committee, required to reconcile the difference, retained the language of HB 1, which makes UT Austin our fiscal agent.

I have already begun the discussion process to effect the transition.

CSHB 1
THE UNIVERSITY OF TEXAS AT AUSTIN
For the Years Ending August 31, August 31, 2016 2017
D. Goal: TRUSTEED FUNDS
D.1.1. Strategy: D K ROYAL TX ALZHEIMER’S INITIATIVE

Darrell K Royal Texas Alzheimer’s Initiative. $ 9,230,625 $ UB

12. Darrell K Royal Alzheimer's Initiative. Amounts appropriated above in Strategy D.1.1, Darrell K Royal Texas Alzheimer's Initiative, are funds trusteed to The University of Texas at Austin, and The University of Texas at Austin may not transfer the amount appropriated to other purposes. All amounts, net of cost of administration, shall be allocated at the direction of the Texas Council on Alzheimer's Disease and Related Disorders as provided by law to the Consortium of Alzheimer’s Disease Centers and for other disease-specific purposes that are part of the Darrell K Royal Texas Alzheimer's Initiative as approved by the Texas Council on Alzheimer’s Disease and Related Disorders. Any unexpended balances at the end of fiscal year 2016 are hereby appropriated for the same purposes for fiscal year 2017. 13.
Ms. Debbie Hanna  
Chair  
Texas Council on Alzheimer’s Disease and Related Disorders  
3520 Executive Center Drive, #150  
Austin, Texas  78731

Dear Ms. Hanna:

I write to request that The University of Texas at Austin be added at the earliest possible opportunity as a participant and voting member in the Texas Alzheimer’s Research and Care Consortium (TARCC), pursuant to Section 154.002(a) of the Texas Education Code.

Many research and clinical activities that are directly related to and complimentary of those of TARCC occur on the UT Austin campus and will be expanded, especially with the establishment of the Dell Medical School.

I will make available at your convenience the curriculum vitae and contact information for UT Austin faculty who conduct scientific activities germane to TARCC so that the Council can offer steering-committee membership to the most appropriate individual from our university. I am confident that the partnerships that would be created by UT Austin’s participation as a member of TARCC will be mutually beneficial.

Thank you for your consideration of this request. We at UT Austin look forward to having the opportunity to work with the Texas Council on Alzheimer’s Disease and Related Disorders and the current membership of the TARCC.

Sincerely,

[Signature]
Gregory L. Fenves  
President

GLF: dwd

cc: Dr. Judith H. Langlois, Executive Vice President and Provost, ad interim  
S. Claiborne Johnston, M.D., Ph.D. Vice President for Medical Affairs and Dean of the Dell Medical School  
Dr. Juan M. Sanchez, Vice President for Research  
Ms. Gwen Grigsby, Associate Vice President for Governmental Relations
August 17, 2015

Debbie Hanna, Chair
Texas Council on Alzheimer’s Disease and Related Disorders
Texas Alzheimer’s Research and Care Consortium
3520 Executive Center Drive, Suite 140
Austin, TX 78731

Re: Lubbock TARCC Site

Dear Debbie Hanna,

With the resignation of Dr. Chuang-Kuo Wu, I request the members of the Texas Council on Alzheimer’s Disease and Related Disorders to consider my request to be the Interim PI for the Lubbock TARCC Site as we proceed in our search for a replacement for Dr. Wu.

On behalf of Texas Tech, I also request to be the TTUHSC Representative in the Steering Committee until we have a replacement for Dr. Wu.

As the Interim PI, I would make myself available to all the activities and responsibilities that come with that position. I request that the Texas Council on Alzheimer’s Disease and Related Disorders approve me as the Interim PI and Steering Committee member.

Sincerely,

John C. DeToledo, M.D.
The Haggenton Endowed Chair
Department of Neurology - Lubbock
Texas Tech University Health Sciences Center School of Medicine
John C. DeToledo, M.D.


Pavis Laengvejkal, Inhyup Kim, Kunut KijSirichareanchai, Sahawat TantikittiChaiKul, John DeToledo. False localizing exam in a lumbar spinal epidural abscess (SEA): right paraspinal pain and contralateral leg weakness. Accepted for a poster presentation at the American Academy of Neurology 66th Annual Meeting, in Philadelphia, PA (P7.306)

Submitted Posters:

MS Consortium:
Avila M, Gorantla S, DeToledo, J. Diffusion restricted lesions in MS

American Academy of Sleep Medicine:
Gorantla S, DeToledo J, Kadiyala S. AVAPS mode BIPAP ventilation as a therapeutic option in complex sleep apnea syndrome: a case report.

CME course director. Diagnosis and Management of Epilepsy 2012-2013. Lubbock State School and Supported Living Center. Monthly CME lectures for physicians and physician assistants involved in the care of the developmentally disabled.

Presentations:

2011 Program Co-Chair: Advances in the Treatment of Status Epilepticus. DeToledo, J and Treiman D. Sao Paulo, Brazil, June 25, 2011


2012 Speaker: The Annual Epilepsy Update Course. J Kiffin Penny Epilepsy Minifellowship, Winston-Salem, November 14-16

2013 Monthly TTUHS CME course in epilepsy:
Clinical management of seizures 8/19/2013
Newly developed antiepileptic drugs 10/5/2013
Side effects of antiepileptic drugs 10/26/2013
Drug-drug interactions of antiepileptic drugs 11/30/2013
Clinical identification of epileptic seizures 12/29/2012
How to differentiate epileptic seizures from other abnormal, paroxysmal movements
01/18/2013

National Co-Chair. Smith M, DeToledo J. Clinical Viewpoints in Epilepsy. A series of CME lectures presented nationally addressing the management of intractable epilepsy.

DeToledo, J. Featured CME speaker. Clinical Viewpoints in Epilepsy. CME course. Pittsburgh, 2/5/2013
DeToledo, J. Featured CME speaker. Clinical Viewpoints in Epilepsy. CME course. Philadelphia, 2/06/2013
DeToledo, J. Featured CME speaker. Clinical Viewpoints in Epilepsy. CME course. Los Angeles, 1/29/2013
DeToledo, J. Featured CME speaker. Clinical Viewpoints in Epilepsy. CME course. San Francisco, 1/30/2013
DeToledo, J. Featured CME speaker. Clinical Viewpoints in Epilepsy. CME course. Dallas, 11/09/2013,
CURRICULUM VITAE

John C. DeToledo, M.D.

Office Phone: 806-743-3832
Office Fax: 806-743-4998
E-mail: john.detoledo@ttuhsc.edu

Office Address: Department of Neurology
Texas Tech University Health Sciences Center
3601 4th Street - STOP 8321
Lubbock, Texas 79430-8321

EDUCATION

1975-1980 Sao Paulo Medical School, Sao Paulo, Brazil.
Internship- Sao Paulo Hospital/Sao Paulo Medical School.
Internal Medicine, Sao Paulo Cancer Hospital, Sao Paulo, Brazil.
Neurology, Boston University Neurology Program, Boston, Massachusetts.
Internal Medicine (PGY II). Columbia Presbyterian Affiliated Internal Medicine Program,
New York/Morristown.
Private practice neurologist, Sao Paulo, Brazil.
Fellow in Epilepsy and Neurophysiology, Oregon Comprehensive Epilepsy Program,
Portland, Oregon.
Assistant Professor, Oregon Health Sciences University, Portland, Oregon.
Neurologist/Epileptologist, Oregon Comprehensive Epilepsy Program, Portland, Oregon.
Director, Department of Behavior Division, Oregon Comprehensive Epilepsy Program, Portland, Oregon.

Associate Professor of Neurology, George Washington University, Washington, D.C.

Chief, Neurophysiology Department, George Washington University.

1992-1995  Director of the Epilepsy Center at George Washington University.

1993-1995  Associate Professor of Neurosurgery, George Washington University.

1993-1995  Training Program Director, Department of Neurology, George Washington University.

1995-      Visiting Scholar, King Faisal Hospital and Medical Center, Riyadh, Saudi Arabia.

1995-2006  Co-Director, International Center for Epilepsy, University of Miami.

1996-2006  Director EEG-Neurophysiology Laboratory, Jackson Memorial Hospital, University of Miami.

1996-2006  Director Inpatient Telemetry Unit, Jackson Memorial Hospital, University of Miami.

1998-2006  Director, Outpatient neurology clinic, Jackson Memorial Hospital, University of Miami.

1998-2006  University of Miami Medical Group - Governing Board Member

2006-2009  Professor of Neurology Wake Forest University School of Medicine, Winston Salem, North Carolina

2006-2009  Chief of Division of Epilepsy and Neurophysiology, Wake Forest University School of Medicine, Winston Salem, North Carolina

2006-2009  Director, Magnetoencephalography Laboratory Wake Forest University School of Medicine, Winston Salem, North Carolina

2008-2009  Executive MBA Program, Wake Forest University

2009-      Professor of Neurology, Texas Tech University, Lubbock, Texas.
2009- Chairman, Department of Neurology, Texas Tech University, Lubbock, Texas.
2010- Chairman, Texas State Fund Analysis Committee, Texas Tech University
2010- Residency Program Director, Department of Neurology, Texas Tech University
2013- Chair elected — Medical Practice Income Plan, Texas Tech University School of Medicine

PUBLICATIONS


DeToledo JC: Persistent confusion after electroconvulsive therapy. Neurology Clin-Perl, 8:6-7, 1985

Oliveira I, DeToledo JC: Estrogen and glucocorticoid receptors in malignant melanoma. Presented at the XXII Annual Meetings of the Sao Paulo Cancer Hospital.

DeToledo KC. Rabdomyosarcoma of the middle ear: Description of the first case in Brazil. Presented at the XXII Annual Meetings of the Sao Paulo Cancer Hospital.
DeToledo JC, Radvany J: Value of the MRI in the evaluation of tumors in the base of the skull. Presented at the meetings of the ENT Association, Minas Gerais, Brazil, June, 1986.


DeToledo JC: AVM subtypes can be predicted by MRI based on morphologic and signal characteristics. Paper read at the meetings of the Neurology Association, Albert Einstein Hospital, Sao Paulo, Brazil, May, 1987.

DeToledo JC, Marie SK, Handfas BW: Morphologic and signal characteristics of the pituitary gland in health and disease. Presented at the meetings of the Neurological Association, Albert Einstein Hospital, Sao Paulo, Brazil, October, 1988.


Decerce J, DeToledo J, Lowe M, Ramsay RE. Outcome of Video EEG Telemetry in a Cohort of Tertiary Referral Patients Admitted for Diagnosis: Role of Placebo Induction. Epilepsia 38(suppl.8):60, 1997


Ramsay RE, Toledo C, DeToledo J, Lowe M. Conversion to lamotrigine monotherapy in patients with uncontrolled primary (PGE) and secondarily
generalized epilepsy (PSGE) with follow up to 6 months. Epilepsia 38(suppl.8):62, 1997


DeToledo JC, Minagar A, Lowe MR. Persisting aphasia as the sole manifestation of partial status epilepticus Clin Neurol Neurosurg. 102:144-8, 2000


DeToledo JC, Lowe MR. Lidocaine-induced Seizures in Patients with History of Epilepsy - Effect of Antiepileptic Drugs. Anesthesiology 2002,96:

PROFESSIONAL

Editorial responsibilities
1990-1992  Editorial Board of "Progress in Alzheimer's Disease Research", Portland, Oregon
1996-     Reviewer for Neurology
1997-     Reviewer for Epilepsy
2009-     Reviewer Neurological Research
2010-     Member - NIH - Neurological Devices Panel of the Medical Devices Advisory Committee.
2013-     Editor - Clinical Neurology Report

Professional and Honorary Organizations

Member Alzheimer's Disease Center of Oregon
Editorial Board of "Progress in Alzheimer's Disease Research", Portland, Oregon
Strategic Research Committee for the Alzheimer's Disease Center of Oregon.
Curriculum Review & Multidisciplinary Advisory Committee, Alzheimer's Disease Research Center, Portland, Oregon.
Oregon Stroke Club Association
Advisory Board, Memory and Early Alzheimer's Program
Institutional Review Board, Good Samaritan Hospital
Institutional Review Board, Fairview Training Center
Institutional Review Board, George Washington University
Professional Advisory Board, Epilepsy Foundation of America, D.C. chapter
Professional Advisory Board, Epilepsy Foundation of South Florida.
Medical Records Committee, University of Miami.
Texas Council on Alzheimer's Disease and Related Disorders

Responsibilities per statute

TX Council shall:

a. Establish Consortium
   1. Consortium shall
      a. Develop clinical centers
      b. Coordinate and direct clinical services
      c. Establish database
      d. Share data
      e. Facilitate research projects
      f. Provide data to state agencies on specific topics
      g. Distribute research and open clinical trial info

b. Establish Steering Committee rep from each member
   1. Steering Committee shall
      a. Advise Council on Consortium activities
      b. Develop clinical centers striving for centralized uniform services
      c. Review and evaluate data sharing
      d. Make recommendations on the 5 yr. review

c. Establish Data Coordinating Center
   1. Data Coordinating Center shall
      a. Establish database
      b. Make data available

d. Add participants to Consortium

e. Provide funds for Consortium activities

f. Appoint person to administer Data Coordinating Center (DCC)
   1. Person may
      a. employ other personnel
      b. employ Project Coordinator
         i. Project Coordinator shall coordinate activities among Consortium participants, Council & public

g. Solicit and receive funds

h. Restrict access

i. Review DCC and Consortium participants every 5 years
CHAPTER 154. CONSORTIUM OF ALZHEIMER'S DISEASE CENTERS

Sec. 154.001. DEFINITION. In this chapter, "council" means the Texas Council on Alzheimer's Disease and Related Disorders.


Sec. 154.002. CONSORTIUM; CLINICAL CENTERS. (a) The council shall establish a consortium of Alzheimer's disease centers, to be initially composed of the Alzheimer's disease centers at the Baylor College of Medicine, the Texas Tech University Health Sciences Center, the University of North Texas Health Science Center at Fort Worth, and The University of Texas Southwestern Medical Center at Dallas. The council may add additional consortium participants to the consortium as necessary.

(b) The council shall provide funds to the consortium participants to assist those participants to develop clinical centers that meet the standards of the consortium.

(c) A participant's clinical center may employ any personnel necessary to support its activities, including clinical, administrative, and data management personnel.


Sec. 154.003. PROGRAMS. (a) The consortium shall coordinate
and direct its programs to provide to the extent practicable centralized, uniform services among the consortium participants.

(b) The consortium shall:

(1) offer clinical services to all patients of the consortium's clinical centers, notwithstanding the independent status of each participant;

(2) establish a database for:

(A) making data available to each consortium participant according to its specific activities;

(B) providing a resource index to facilitate research projects; and

(C) providing data on patient health outcomes to appropriate state agencies and to researchers in this state; and

(3) with the aid of the council and the National Alzheimer's Association or its affiliate, develop and distribute to patients, caregivers, and health care professionals educational materials and services and inform patients of any research projects and therapeutic trials open for their participation.


Sec. 154.004. STEERING COMMITTEE. To advise the council on consortium activities, the council shall establish a steering committee composed of one representative from each consortium participant.
Sec. 154.005. DATA COORDINATING CENTER. (a) The council shall establish a data coordinating center to be located at the Texas Tech University Health Sciences Center. To the extent practicable, the center shall be operated in association with the data management operations of that institution's Alzheimer's disease center.

(b) The data coordinating center shall establish a database and make data available to each consortium participant according to the specific activities of the participant.

(c) The council shall appoint a physician or other person with a similar clinical background to administer the center.

(d) The person administering the center may employ any personnel necessary to support the center's activities, including a project coordinator. The person may require the project coordinator to hold a master's or doctoral degree related to public health.

(e) The project coordinator shall coordinate the center's activities among the center, the consortium participants, the council, and the public.

Sec. 154.006. FUNDING. (a) The council may receive state appropriated funds for the purpose of supporting the research activities of the consortium under this chapter.

(b) The council may solicit and accept gifts, grants, and donations for purposes of this chapter.


Sec. 154.007. ACCESS TO DATA. (a) The council may restrict access to the data maintained by the consortium or data coordinating center to consortium participants that contribute data as requested by the council.

(b) The steering committee periodically shall review and evaluate the availability and sharing of data under this section.


Sec. 154.008. PERFORMANCE REVIEW. The council, with recommendations from the steering committee, shall review and evaluate the performance of the consortium participants and data coordinating center at least every five years.

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<td>Personnel (list each item on separate line)</td>
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<td>Munro Cullum</td>
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<td>Zohre German</td>
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<td>Kathryn Gaylord</td>
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<td>Kay Modenlnyer</td>
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<td>Subject stipend - 230 subjects at $100 each</td>
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<td>Parking - 230 at $5 each</td>
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<td>Indirect Cost Rate (enter as %)</td>
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<tr>
<td>Total Costs</td>
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</table>

Overhead excludes subject stipend and parking

Authorized Signature                        Date

UTSW CC 1
Texas Council on Alzheimer’s Disease and Related Disorders

UT Southwestern Medical Center Clinic Budget Justification FY16

PERSONNEL:

Physicians: A combined 67% effort for Drs. Rosenberg, Womack, Quiceno, Williams, Nguyen and Nurse Practitioner, Natalie Martinez is budgeted to provide oversight of the TARCC evaluations which includes participating in case conferences. They also perform the physician evaluations of TARCC participants.

Coordinator: Patricia Knowles is the primary TARCC coordinator, FTE at 40% effort, to review the accuracy of TARCC charts prior to data entry and to coordinate the multi-disciplinary visits, perform the necessary evaluations at patient visits, and interact with other TARCC personnel. Patricia Knowles and Barb Davis also participate in coordinator conference calls. Other study coordinators include Jackie Rabb, Gloria Williams and Zohre German who also assist with TARCC visits.

Scheduling Assistant: A 35% FTE, Sarah Brisebois, is needed to recruit and schedule subjects for their TARCC visits and to assist the coordinator with the duties noted above

Phlebotomy/processing: A 20% FTE, Jackie Rabb, is needed to assist with phlebotomy/blood samples and to maintain necessary supplies in clinic area.

Psychometrician: A combined effort of 95% is needed to administer and score the psychometric measures required by TARCC.

Neuropsychologist: Neuropsychologists, Laura Lacritz (8% effort) and Munro Cullum (8% effort) review the psychometric measures performed by the psychometricians and provide input to case conferences. Dr. Cullum also participates in the monthly TARCC Protocol conference calls.

Administrator: The administrator, Barb Davis, provides oversight of all functions of the clinical component of TARCC and interacts with the other components. She also prepares budgets and other documents as necessary. Dr. Adams will coordinate all activities of TARCC in his role as Steering Committee member and work closely with Drs. Cullum, Reisch, Huebinger and Womack.

OTHER EXPENSES:

Capital Equipment: A new lateral centrifuge is required to adequately handle the processing of 230 research blood samples acquired each year.

Parking expense: 230 participant parking fees are paid at $5.00 each

Subject incentive: 230 participants are reimbursed $100.00 each for their time and effort.

Supplies: Evaluation packets and outreach materials, patient charts, FedEx charges and other necessary supplies.

Travel: Travel expenses are for faculty and staff to attend about 5 meetings in the coming year.

Telecommunications: These funds are requested to cover costs relating to monthly conference calls for TARCC updates.
Institution: University of Texas Southwestern Medical Center - Tissue Bank  
Alzheimers' Disease and Related Disorders  
Program Dates: September 1, 2015 to August 31, 2016

<table>
<thead>
<tr>
<th>Cost Category</th>
<th>Annual Salary and Fringe</th>
<th>Percent of Time Spent on Program</th>
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<tr>
<td>Ryan Huebinger, PhD</td>
<td>$58,600</td>
<td>25.00%</td>
<td>$14,650.00</td>
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<tr>
<td>Tomequa Sears</td>
<td>$38,600</td>
<td>100.00%</td>
<td>$38,600.00</td>
</tr>
<tr>
<td>Nicole Halpin</td>
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<tr>
<td>Ling-yu (Ellen) Chang</td>
<td>$47,250</td>
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<td>$37,800.00</td>
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<tr>
<td>Thomas Harris</td>
<td>$70,175</td>
<td>50.00%</td>
<td>$35,087.50</td>
</tr>
</tbody>
</table>

**Personnel Total** | $221,405 | 240% | **$118,025.50** |

**Subcontracts with Institutions/Consultants Total** | $0.00 |

**Capital Equipment Total** | $34,000.00 |

**Supplies Total** | $7,750.00 |

**Travel Total** | $6,000.00 |

**Other Costs** | | | |
| Shipping | | | |
| Sites -> UTSW (Tissues) | $6,000 |
| Dry Ice | $2,000 |
| Other Costs Total | $8,000.00 |

**Direct Costs Total** | $173,775.50 |

**Indirect Cost Rate (enter as %)** | 20.0% | **$34,755.10** |

**Total Costs** | $208,530.60 |

Authorized Signature  
Date 8/18/15
Ryan Huebinger, PhD will oversee the process of sample collection and maintenance, including receipt and processing of samples at UTSW and curation of the tissue bank. Dr. Huebinger will insure that best practices for tissue banking are followed at all times. Dr. Huebinger will also be responsible for supervising DNA extraction and ApoE genotyping, which will take place at UTSW as well as shipment of samples to of-site analysis centers. Dr. Huebinger will oversee deposition of data received from all assay sites into the database management system. 25% FTE is requested.

Tomequa Sears will be responsible processing of samples returned from each study site. She will maintain the tissue bank and all records pertaining to the collection and disposition of the samples therein, using the FreezerWorks system. Tomequa will remain abreast of all updates and changes to FreezerWorks, to insure that best practice protocols for tissue bank records are maintained to the highest level at all times. She will deliver blood samples to Ellen Chang for DNA extraction and ApoE genotype analysis. Tomequa will also be responsible for shipment of all samples to off-site assay locations. She will log all residual samples that are returned from these sites back into the system and maintain records of which samples have been processed at which sites. 100% FTE is requested.

Ling-yu (Ellen) Chang will be responsible for extraction of DNA from all samples submitted to her by Tomequa Sears. She will also submit DNA samples to the sequence analysis lab at UTSW for genotype analysis of ApoE. Ellen will assess DNA concentration and quality by UV spectrophotometric analysis to insure that high quality is produced in adequate quantity from each blood sample. If less than 25ug of DNA is isolated from a sample, Ellen will notify Tomequa, so that arrangements can be made to save the buffy coat from blood drawn for plasma isolation at a follow-up visit. Ellen will also assist Tomequa in curation of the TARCC tissue bank. 80% FTE is requested.

Thomas Harris will be responsible for assisting in maintaining the tissue bank. He will assist with cataloging of samples in FreezerWorks. He will help in querying the database and pull the appropriate samples from the repository to be shipped to individuals requesting samples from the TARCC repository. Tom will prepare shipping manifests and assist in proper preparation of samples to be shipped from the tissue bank. Tom will also be responsible for the audit of samples conducted this year. 50% FTE is requested.

Equipment: A total of $34,000 has been budgeted for two -80 freezers and racks to be utilized for housing samples collected from patients at the TARCC sites, and a 4D annual server contract.

Travel: A total of $6,000 has been budgeted for TARCC Research and Steering Committee meetings.

Supplies: A total of $7,750 has been budgeted for supplies.

Other: A total of $8,000 has been budgeted for dry ice and shipping of samples (tissue).
<table>
<thead>
<tr>
<th>Cost Category</th>
<th>Annual Base Salary</th>
<th>Percent of Time Spent on Program</th>
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<tr>
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<td>Janet Smith</td>
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<td>Carlos Urbina</td>
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<td>Douglas Menendez</td>
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<td>Juanita Munoz</td>
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<td>Cindy Patterson</td>
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<td>Steering Committee Meetings: 1 individual x 2 meetings</td>
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<td>Travel Total</td>
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<td>$347,563.42</td>
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Authorized Signature _____________________________ Date _____________________________

THECB Expenditure Report

UTSW DCC 1 8/18/15
Budget Justification
Data Coordinating Center
Texas Alzheimer’s Research and Care Consortium
Fiscal Years 2016 and 2017

Personnel

Salaries and fringe benefits for FY 2016 were budgeted based on actual salaries as of September 1, 2015.

Joan S. Reisch, Ph.D. – Data Coordinating Center (DCC) Leader, Professor and Chief, Division of Biostatistics in the Department of Clinical Sciences. Dr. Reisch brings considerable expertise and experience to the position as Leader of the Data Coordinating Center. She has led the Alzheimer’s Disease Statistics and Data Management Core at U.T. Southwestern for more than 10 years. She is active nationally and was one of 3 elected members of the first Data Management Steering Committee for the National Alzheimer’s Coordinating Center, led by Dr. Walter (Bud) Kukull and she served as a member of the External Advisory Committee for the Alzheimer’s Disease Center at Northwestern University.

Dr. Reisch is the administrative leader for the activities of the Data Coordinating Center team. She has local administrative and financial responsibility including preparation of the budget. She communicates and works with Dr. Waring, the Interim Director, and Dr. Barber, the Scientific Coordinator, with respect to matters concerning data storage, quality, reporting, and sharing; and with members of the Steering Committee, participates in the planning process for research studies. Communication with site coordinators is an essential part of the data flow as is training for use of new forms and systems. She coordinates a monthly meeting dealing with TARCC data collection and management considerations. She is budgeted at 20% time.

Linda S. Hynan, Ph.D. – Statistician – Dr. Hynan is a Professor in the Division of Biostatistics in the Department of Clinical Sciences. Dr. Hynan has been the Statistician for the local Alzheimer’s Disease Center in the Statistics and Data Management Core for more than 10 years. She is active as a reviewer nationally and is the Statistical Review Editor for the Pediatric Infectious Disease Journal. Dr. Hynan is a collaborator on many grants and projects at U. T. Southwestern.

Her expertise includes statistical analyses related to clinical, neuropsychological, and demographic data. Dr. Hynan is the DCC statistician for the TARCC and is available to work with research personnel at each of the different TARCC sites as well as with the Interim Director and the Scientific Coordinator. She is budgeted at 10% effort.

Janet P. Smith, B. A. - Database Systems and Information Resources Manager in the Division of Biostatistics in the Department of Clinical Sciences. Ms. Smith is an experienced database systems designer and programmer, working with the Microsoft Access database product and Cold Fusion on the Internet. She has more than 30 years experience in developing forms, data management systems, as well as manuals in support of the data management and statistical system.

Ms. Smith has taken responsibility for creation and modification of the database management system which links clinical and neuropsychological data with biomarker data and results of genomic analyses. She is responsible for modification of current forms and design of new data collection forms. Ms. Smith is adept at querying the database to answer questions that impact the administrative and management of the database. She takes the initiative on issues that can impact modification of the
database and brings them to the attention of Drs. Reisch and Barber. She supervises personnel who are responsible for error reporting and correction as well as other aspects of quality control. She supervises Mr. Carlos Urbina who develops programs for quality control and data reporting systems, and Ms. Carol Goldsmith who is the Research Data Coordinator for TARCC. Ms. Smith’s expertise and experience allow her to respond in a very timely manner to both research and administrative queries for TARCC. Ms. Smith is budgeted at 25% effort.

Carlos Urbina – Database Programmer, Programmer Analyst III in the Division of Biostatistics. Under the direction of Ms. Smith, Mr. Urbina develops programs for quality control and data reporting systems; he communicates with site coordinators at participating institutions with regard to subject data form submission and for resolution of missing data as well as errors; he distributes the monthly and quarterly reports to the sites and develops additional reports as required. His expertise is invaluable in creating ad hoc reports to answer both administrative and scientific questions in a timely manner. He is budgeted at 80% effort.

Carol Goldsmith – Research Data Coordinator, Senior Database Analyst in the Division of Biostatistics. She communicates with site coordinators at participating institutions with regard to subject data form submission. She logs in data forms as they are received and organizes them for efficient retrieval as needed. She is budgeted at 20%.

Dr. Douglas Menendez - Data Entry and Verification, Clinical Data Specialist. Dr. Menendez is the primary data entry operator for the entry of clinical and neuropsychological data from the TARCC forms into the Access data management system. His experience as well as his medical knowledge contributes to the accurate entry of data and his recognition of various anomalies in the site-recorded data that need further exploration before verification. He is budgeted at 60% effort.

Juanita Munoz - Data Entry Operator II, is the secondary data entry operator for the entry of clinical and neuropsychological subject data from the forms into the data management system. She scans packets of forms into the overall data storage system. She is budgeted at 40%.

Cindy Patterson - Senior Administrative Associate – Ms. Patterson handles the accounting and reconciliation for the TARCC funds utilized to support this center. She is responsible for all the Human Resources requirements for personnel. She is budgeted at 15%.

Donna Shafer – Administrative Associate – Ms. Shafer works with Ms. Patterson on administrative functions and particularly with travel. She keeps an inventory of supplies and orders replacements as needed. She carefully reviews forms before scanning them into the overall data storage system. She tracks FedEx expenses for the transfer of data packets from TARCC sites to the DCC. She is budgeted at 20% effort.

Various Supplies
Paper, toner cartridges, and scanner supplies as well as FedEx charges for shipment of data packets from the sites to the DCC are estimated at $1200 with FedEx being the majority of the supply expense category. $3,500 annually covers the maintenance cost paid to the University for the server and the O drive on which the TARCC database is stored.

Travel
The travel budget is $6,000 annually for TARCC Research and Steering Committee meetings.
### Institution: UTHSCSA
Alzheimers' Disease and Related Disorders
Program Dates: September 1, 2015 to August 31, 2016 (year 1, N = 350)

<table>
<thead>
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<td>Maria Sanchez*</td>
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<td>Barbara Giles</td>
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<td>Destiny Ramos*</td>
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<tr>
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Authorized Signature

Date

UTHSCSA 1
JUSTIFICATION: 2015-2017

University of Texas Health Science Center at San Antonio (UTHSCSA):

General Information:

• Fringe benefits for salaried staff are calculated at 30.0% of direct labor and added to the “base” salary.
• Fringe benefits for faculty are calculated at 26.0% of direct labor and added to the “base” salary.
• Dr. Royall’s effort is based upon a 3/8 UTHSCSA position or .38 FTE.
• 370 visits/year are expected to yield 350 eligible subjects
• F/A base excludes subject stipend and taxifare. F&A is calculated at the program limitation of 20% of MTDC.
• Budget costs are flat across both years of the biennium

Personnel:

Principal Investigator: Dr. Donald R. Royall (UTHSCSA Departments of Psychiatry, Medicine, Family and Community Medicine) will serve as Principal Investigator (PI).

Donald R. Royall, MD (UTHSCSA effort – 30% of a .38 FTE appointment. 1.37 cal. mos.): Dr. Royall is a tenured professor in the department of psychiatry at the University of Texas Health Science Center at San Antonio (UTHSCSA), where he directs the Division of Aging and Geriatric Psychiatry. He is jointly appointed in Medicine to the South Texas Veterans’ Health System’s Audie L. Murphy Division Geriatric Research Education and Clinical Center (GRECC). He holds an adjunct appointment in the UTHSCSA Department of Family and Community Medicine. Dr. Royall completed internship and residency training in both Internal Medicine and Psychiatry at the Johns Hopkins Hospital, Baltimore, MD. He is a diplomate of the American Board of Internal Medicine and the American Board of Psychiatry and Neurology.

Dr. Royall has a long-standing interest in dementia phenomenology. He authored the chapter on “Dementia” in the American Geriatrics Society’s Geriatric Review Syllabus, 3rd Ed., 1996. He has served as a consultant re: Executive function, disability, and dementia case finding strategies for the Department of Health and Human Services’ Advisory Panel on Severe Cognitive /Severe Mental Impairment Eligibility Criteria for the Long-Term Care Benefit in the President’s (1993) Health Reform Proposal, the Health and Retirement Survey (HRS) AHEAD study, Hispanic Established Populations for Epidemiological Studies in the Elderly (HEPESE), the National Institute on Aging’s Health ABC study, and Harvard’s Older Americans Independence Center (OAIC). He is an associate editor of the Journal of the American Geriatrics Society.

Dr. Royall is PI of the UTHSCSA TARCC site and a member of TARCC’s Steering Committee. He has published widely on dementia case-finding in Hispanic persons, and on the cross-cultural validation of psychometric measures.
Dr. Royall has an appointment with the University of Texas Health Science Center at San Antonio (UTHSCSA) and the Veterans Administration (VA). This arrangement is defined in a formal UTHSCSA-VA Joint Appointment Memorandum of Understanding (MOU). The institutional base salary used in this application represents only the salary from UTHSCSA. Dr. Royall's university committed effort on this proposal is 1.37 calendar months (.30 x 12 mos. x .38 FTE) of which salary has been requested. It is further clarified that Dr. Royall receives salaries from both the UTHSCSA and VA and that there is no dual compensation from these two sources for the same work nor is there an actual or apparent conflict of interest regarding such work.

Dr. Royall will oversee all aspects of the work. He will oversee Ms. Polk and the UTHSCSA administrative staff and provide oversight to Dr. Salazar and other clinical collaborators.

Raymond F. Palmer, Ph.D. (5% effort, 0.6 calendar months): Dr. Palmer is an Associate Professor with tenure in the UTHSCSA department of Family and Community Medicine, where he directs the statistical core. He received his Ph.D. from the University of Southern California, Los Angeles, in 1996, where he served as a Senior Biostatistician. Dr. Palmer received additional training in the analysis of longitudinal datasets and latent variable modeling at Penn State University.

Drs. Palmer joins our team to increase research productivity. He and Dr. Royall have established a very productive collaboration spanning 12 years. Dr. Palmer works closely with TARCC's dataset. He and Dr. Royall have published eight papers using TARCC data since 2012 (one in press).

Dr. Palmer will oversee dataset download, maintenance and management, and conduct analyses with TARCC data in collaboration with Dr. Royall and other UTHSCSA investigators. Dr. Palmer will assist Dr. Royall in report generation.

Ricardo. Salazar, M.D. (40% effort, 4.8 calendar months): Dr. Salazar completed his psychiatry residency and geropsychiatric fellowship training at UTHSCSA. He joined the faculty in 2006 and is now an assistant professor. Dr. Salazar is fluent in Spanish and has been the site's main clinician-investigator since 2011.

Project Coordinator: Marsha S. Polk, MA (50% effort, 6.0 calendar months): Ms. Polk serves as project coordinator. She has a background in psychometrics and has served as Dr. Royall's project coordinator on many studies. Ms. Polk is experienced in the conduct of all aspects of clinical research.

Ms. Polk's responsibilities will include 1) providing administrative /financial management under Dr. Royall's supervision, 2) supervising the quality of data collection and transfer, 3) oversee all ancillary personnel, 4) oversee clinical throughput and scheduling, 5) perform psychometrics and contribute to consensus conferences.
Research Assistant: Maria Sanchez (20% effort, 2.4 calendar months): Mrs. Sanchez is primarily responsible for the accounting of subject stipends. She also assists Ms. Polk in patient scheduling. Mrs. Sanchez is bilingual in English and Spanish.

Research Assistant: Barbara Giles (70% effort, 8.4 calendar months): Mrs. Giles is being trained to assume responsibility for the accounting of subject stipends, under Mrs. Sanchez' and Ms. Polk's supervision. She also assists Ms. Polk in patient scheduling.

Research Assistant: Destiny Ramos (80% effort, 9.6 calendar months): Ms. Ramos is primarily responsible for subject phlebotomy and specimen handling. She also assists Ms. Polk in data management. Ms. Ramos is bilingual in English and Spanish.

Research Assistant: Javier Gallegos (40% effort, 4.8 calendar months): Mr. Gallegos assists Ms. Govea in patient scheduling. He also assists Ms. Polk in psychometrics.

Research Assistant: Bernice Govea (80% effort, 9.6 calendar months): Ms. Govea is primarily responsible for patient scheduling. Assists in subject phlebotomy and specimen handling. She assists Ms. Polk in data management. She is bilingual in English and Spanish.

Psychometrician: Eddie Kurtz (41% effort, of .49FTE, 2.41 cal. mos.): Mr. Kurtz serves TARCC as a psychometrician. He has over 25 years experience. Salary requested has been calculated based on 41% of a .49 FTE UTHSCSA appointment = 20% FTE or 2.4CM.

Promotora: Elena Maria DeBrickman (90% effort, 10.8 calendar months): Mrs. DeBrickman is primarily responsible for recruitment of new Hispanic subjects. She designs advertising, makes presentations, and screens potential subjects in the field. She also assists Ms. Polk in patient scheduling. Mrs. DeBrickman is bilingual in English and Spanish.

Promotora: Joe Zapata (10% effort, 1.2 calendar months): He will assist Mrs. DeBrickman to design advertising, make presentations, and screen potential subjects in the field. He will also assist Ms. Polk in patient scheduling. Mr. Zapata is bilingual in English and Spanish.

Capital Equipment:

$7,000 is requested for a CF48-R: Bench Top Refrigerated Centrifuge in year one to process serum samples.

Supplies:

$4,200 is requested for blood drawing supplies. These costs have been estimated @ $12.00 /visit x 350 visits, as specified by the Steering Committee.
Travel:

$8,000 is requested in support of TARCC research meetings (3 individuals x 2 meetings) and Steering Committee meetings (1 individual x 2 meetings).

$1,800 is requested for the Promotora’s gas and mileage, based on recent experience.

Other Direct Costs: These costs are largely estimated from our experience in TARCC.

Psych Forms:

$4,440 is requested to offset the purchase of psychometric test forms (e.g., the Mini-Mental Status Examination). $12.00 is estimated /assessment x 370 assessments (to achieve 350 evaluable subjects).

Subject Stipends:

$35,000 is requested for subject visit compensation based on a projected volume of 350 assessments /yr. Subjects (including screen failures) will be reimbursed $100 for their participation.

Labwork:

$2,800 is requested for labwork in association with dementia workups. This represents 20% x 350 evaluable subjects per year (N = 70) x $40 /workup. This estimate is based on past experience. Because none of our subjects are seen as patients, these costs must be borne by TARCC.

Subject Transportation:

Disabled and non-driving subjects will be reimbursed for roundtrip taxi fare to UTHSCSA. $12,000 is requested based on past experience and a projected volume of 200 rides /year. This represents 57% x 350 projected visits per year x $60 /ride.

Neuroimaging: We estimate that 20% of 350 evaluable subjects (N = 70) may need neuroimaging as part of a dementia work up. Because none of our subjects are seen as patients, these costs must be borne by TARCC. Total neuroimaging costs are composed of two components: the imaging itself (CT or MRI) ($650) and subject stipend ($50 / scan) = $700 /scan. Scans = $45,500, subject scan stipends = $3500.

Total neuroimaging costs estimated @ $700.00 per scan x 70 scans /yr (i.e., 20% x 350 evaluable subjects /yr) = $49,000.
### THECB Expenditure Report

**Institution:** University of North Texas Health Science Center  
**Alzheimers' Disease and Related Disorders**  
**Program Dates:** September 1, 2015 to August 31, 2016

<table>
<thead>
<tr>
<th>Cost Category</th>
<th>Annual Base Salary</th>
<th>Percent of Time Spent on Program</th>
<th>Total</th>
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<tr>
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<tr>
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<td>Glenda Dwight</td>
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<td>Douglas Mains</td>
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<td><strong>Capital Equipment</strong></td>
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<td>Horizontal Centrifuge (included in FY 2016 budget only)</td>
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**Authorized Signature**

UNTHSC1 1

**Date:** 8/13/15
University of North Texas Health Science Center  
TARCC Budget Justification: FY 2016

Project Personnel Costs

Site Director: Thomas Fairchild, PhD  10% Effort
- Oversight and planning on all TARC projects and research protocols
- Ensures achievement of patient recruitment and follow-up goals
- Manages budget and personnel
- Liaison with TARCC Steering Committee, TARCC Project Coordinator, and TARCC Scientific Coordinator

Geriatrician/Study Physician: Janice Knebl, DO  10% Effort
- Serves as primary study physician for the site
- Conducts medical evaluations of study patients
- Oversight of laboratory acquisitions, including storage and handling of tissue
- Responds to clinical questions and adverse events

Site Project Coordinator: Lisa Alvarez  100% Effort
- Assists PI in implementing research protocols at the site
- Liaison with other site coordinators, TARC Scientific Coordinator and TARC Data Base Coordinator
- Supervises all clinical contacts with patients including laboratory acquisitions, tissue storage and handling.
- Coordinates IRB submission and renewals, and adverse event reporting
- Interviews subjects and reviews records
- Administers informed consent
- Processes and ships tissue samples
- Assists with completion of data forms

Psychologist: James Hall, PhD  16% Effort
- Provides expertise in neuropsychological assessment and data analysis and/or patient and family services such as counseling to enhance recruitment and retention to the project
- Oversight of neuropsychological testing
- Assists with TARCC research and publication activities

Psychometrician/Psychologist: Sol Azimipour  30% Effort
- Administers neuropsychological tests
- Interviews patients, reviews records, assigns CDR and Hachinski scores
- Assists with recruitment and retention activities
- Assists with TARCC research and publication activities

DataManager/Administration: Doug Mains, DrPH  10% Effort
- Database management
- Technical planning and design
- Assists with budgeting and accounting

Administrative Support Staff: Glenda Dwight  40% Effort
- Assists Site Project Coordinator in the maintenance of project-related records and report
- Assists current and potential study participants in person and over the phone
Clinical Support Staff: Barbara Harty, GNP  0.5% Effort
- Collects and processes DNA and serum samples on an as needed basis

Longevity, Incentive, and Salary Increases
- A total of $14,038.00 is budgeted for longevity pay, annual incentive pay, and state-mandated salary increases.

Non-Personnel Costs

Capital Equipment
- $7,000 for a horizontal centrifuge
- $2,578 for computer equipment

Maintenance and Operations
- $6,171.41 for consumable supplies
- $2,760 for blood draw and glucose testing supplies (230 participants @ $12 per subject)
- $2,300 for Medical Services (Quest Lab costs for blood processing – 230 @ $10 per subject)
- $2,000 for conference registrations and other services/fees
- $360 for postage
- $600 for telephone service (1 voice line and 1 line for freezer alert system)
- $2500 for participant recruitment and promotion materials (calendars, cards, etc.)

Travel
- Budgeted $8,000 for project personnel to travel to TARCC meetings and related conferences

Participant Incentives
- $23,000 for participant incentives (230 @ $100 per subject)
Institution: UNTHSC
Alzheimers' Disease and Related Disorders
Program Dates: September 1, 2015 to August 31, 2016

<table>
<thead>
<tr>
<th>Cost Category</th>
<th>Annual Base Salary</th>
<th>Percent of Time Spent on Program</th>
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<td>Leigh Johnson, PhD, HABLE PI</td>
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<td>Blood draw &amp; processing supplies, neuropsych</td>
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<td>Research Meetings: 1 individual x 2 meetings</td>
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<td>Other Costs:</td>
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<tr>
<td>Printer, phone, postage</td>
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<td>MRI Scans</td>
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<td>Base: Cohort Maintenance</td>
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</tbody>
</table>

Authorized Signature
Date

THECB Expenditure Report

UNTHSC21

8/13/2015
Cohort Maintenance Budget

Personnel

Sid O'Bryant, PhD (UNTHSC Mexican American Site PI) will spend 15% of his annual effort on this project as the overall site PI. He will focus on overall input into cohort status and throughput. Other efforts will be focused on TARCC biomarker service sub-project, input to Drs. Waring and Barber regarding Mexican American expansion protocol, Mexican American-specific research aims and projects as well as the biomarker subcommittee. He will also work with Drs. Waring and Barber as needed for other TARCC-related projects. Lastly, he will be involved in preparation of grants, manuscripts and presentations leveraging the TARCC cohort and data.

Leigh Johnson, PhD (UNTHSC Mexican American Site Co-PI) will spend 25% effort towards the daily management of the UNTHSC Mexican American site cohort. She is the Co-PI of the UNTHSC Health & Aging Brain among Latino Elders (HABLE) study and runs the daily operations of that study. She provides direct supervision to all staff, manages the HABLE and TARCC Mexican American-related IRB questions/processes, oversees outreach efforts, etc. She will also be involved in manuscript generation utilizing TARCC data.

Adriana Guzman (UNTHSC Mexican American Site Project Coordinator) will spend 100% of her time devoted towards completion of TARCC-related activities. She is responsible for scheduling participants, maintaining files, shipment of files to the TARCC database, communicating with the TARCC database as needed and conducting examinations with patients.

Tori Como (UNTHSC wet-lab) will spend 100% of her time managing the TARCC blood specimens (processing and storage), managing the biorepository, communicating with the TARCC biobank, preparing and shipping samples and appropriate files for biological samples, and communicating and working with the UTSW TARCC Biorepository for all other related activities relevant to biomarkers/biobank.

RA/Promotora (TBD) will spend 100% of his/her time conducting examinations, preparing files and other duties as needed under the supervision of Mrs. Guzman and Dr. Johnson. S/he will also work with Mrs. Como as needed.

Sub-Contract (UTSW)

Benjamin Williams, MD, PhD (UTSW, collaborator) will spend 20% effort as the behavioral neurologist for the TARCC Mexican American site. He will conduct medical
examinations as needed and participate in consensus reviews. He will also participate in the generation of manuscripts leveraging TARCC data.

Equipment (FY16 only)

A new centrifuge ($7,000) is being purchased to meet the recently generated international guidelines for pre-analytic processing of blood samples for AD biomarker research.

Supplies

A total of $3,000 per year has been allocated towards the purchase of supplies for blood draws, neuropsychological testing, etc.

Travel

A total of $2,000 per year has been allocated towards travel for presentation of findings at national/international conferences. These funds are to be utilized for site PI (O’Bryant) travel to two conferences annually ($1,000/conference).

Other Costs

Operations – A total of $3,000 per year has been allocated towards operations (printer, phone, postage, etc.).

MRI scans – a total of $5,000 per year has been allocated towards obtaining MRI scans of newly identified MCI and AD cases where such scans are not available and are deemed necessary for research diagnostic purposes.

Participant payments – A total of $30,000 is allocated towards standard TARCC payment of $100 per person (300 participants annually).
### Institutional Description
**Institution:** TTUHSC  
**Program:** Alzheimer's Disease and Related Disorders  
**Dates:** September 1, 2015 to August 31, 2016  
**Subcontracts with Institutions/Consultants**

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**Participant Stipends**

- **300 participants x $100**  
  $30,000.00  

**Total Costs**

- **$468,696.97**

**Fringe and Benefits**

- Total: $76,907.00

**Supplies**

- Total: $3,500.00

**Travel**

- Total: $8,000.00

**Other Costs**

- Maintenance and Repair: $500.00
- Hart Moving & Storage (inactive files storage): $20/mo: $240.00
- Outreach, recruitment & retention activities: $1,500.00

**Other Costs Total**

- $2,240.00

**Direct Costs**

- **$466,456.94**

**NOTE:** IDC not charged on equipment ($7,000)

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**THE COE Expenditure Report**  
**Date:** 8/13/2015  
**Authorized Signature:**

**TTUHSC 1**
TTUHSC TARCC Budget Justification FY16

Salary

John DeToledo, M.D. – Dr. DeToledo will spend 10% of his time overseeing all aspects of the TTUHSC TARCC site. He will also conduct medical examinations and supervise all physicians/mid-levels conducting examinations. He will monitor budget expenditures and provide timely feedback to the Steering Committee. He will also serve as the TTUHSC site representative to the Steering Committee.

Henrik Wilms, M.D. – Dr. Wilms will spend 35% of his time overseeing all aspects of the TTUHSC TARCC site. He will also conduct medical examinations and supervise all physicians/mid-levels conducting examinations.

Kimberly Johnson, M.D. – Dr. Johnson will devote 10% of her time to the TTUHSC site of the TARCC as the site neuropsychologist. Dr. Johnson will oversee all participant testing, review all testing files and participate in the consensus diagnostic process.

Vicki Perez – Site Coordinator. Ms. Perez will spend 100% of her time coordinating the TTUHSC site activities. She will conduct interviews with patients and care-givers completing requisite TARCC forms, review forms prior to submission to the TARCC Database Management Team at UTSW. She will conduct and score neuropsychological testing under the supervision of Dr. Johnson. She will participate in weekly Coordinator/Data Management calls and attend in-person TARCC meetings as deemed necessary by Dr. Wu.

Michelle Hernandez -Coordinator. Ms. Hernandez will spend 100% of her time coordinating the TTUHSC site activities. She will conduct and score neuropsychological testing under the supervision of Dr. Johnson. She will be responsible for all participant scheduling and retention activities (i.e. thank you cards, birthday cards, holiday cards, sympathy cards). She will attend in-person TARCC meetings as deemed necessary by Dr. Wu.

Allison Lee – Part-time Coordinator. Ms. Lee will spend her time conducting and scoring neuropsychological testing from the clinic-based participants of the TTUHSC TARCC site. This individual will provide timely scoring of files under the supervision of Dr. Johnson.

Linda Yin, Lab. Ms. Yin will spend 40% of her time handling blood samples per TARCC protocols. She will provide regular updates to Dr. Wu on lab activities. He will ship samples to UTSW per protocols in a timely manner.

Bobby Pierson, PA – Mr. Pierson will spend 10% of his time conducting medical examinations on TARCC participants under the supervision of Dr. Wu.

Kriss Morrow, RN – Mrs. Morrow will spend 10% of her time collecting blood samples on TARCC participants.
Evelyn Silvas, BAS – Ms. Silvas will spend 10% of her time administratively overseeing TARCC budget, in the area of daily operations, leave requests, time sheets and payroll.

**Non-Salary**

**Capital Equipment**  
$7,000 for a horizontal centrifuge: CF48-R: Bench Top Refrigerated Centrifuge

**Supplies**  
$1,000 for printing of advertising materials  
$3,500 for office supplies and equipment  
$3,500 for medical supplies  
$100 for postage and shipping

**Travel**  
Budgeted $8,000 for project personnel to travel to TARCC meetings and related conferences

**Other Costs**  
$500 for maintenance and repair  
$240 for moving and storage of inactive files ($20 per month)  
$1,500 for outreach, recruitment and retention activities

**Participant Incentives**  
$30,000 for participant incentives (300 @ $100 per subject)
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Authorized Signature

BCM 1

Date: 7/29/2015

THECB Expenditure Report

7/29/2015
Baylor College of Medicine
TARCC Budget Explanation

Personnel

Dr. Doody is the Site Director who oversees all personnel and, she provides patient assessments as a neurologist. Dr. Doody also serves on the TARCC Steering Committee (0.305 FTE). Dr. Dang provides patient assessments as a neurologist and back up to Dr. Doody in administrative matters (0.25 FTE). Our total clinician time is therefore (0.555 FTE).

Some of the patients who are enrolled in TARCC also receive annual clinical assessments as part of their medical care including neuropsychological testing. These tests that overlap with TARCC data are billed outside of our group on a fee for service basis. We therefore do not include extensive Neuropsychologist or Psychometrician time related to these assessments as part of the TARCC budget. Ms. O'Connor provides psychometrics for those patients who need only TARCC testing, not associated with clinically-indicated annual visit, and for TARCC tests that must be done only for TARCC and are not included in the clinical battery (0.10 FTE), as does Ms. Ansari, the Back-up Project Coordinator (0.73 FTE of which 0.10 is for psychometric testing). Overall effort for psychometric testing is estimated as 0.20 FTE shared between these two individuals. Ms. Rodriguear is the Project Coordinator (100 FTE). It is necessary to have a coordinator as well as a back-up coordinator because there are often more patients seen in one day than can be processed by a single person and to cover tasks when the coordinator is out of the office. Both the coordinator and the back up coordinator recruit patients, assess patients, complete data forms, process blood and DNA samples, and ship samples. Both perform all other coordinator duties in the TARCC procedural guidelines. Dr. Glosch, Clinical Psychologist (0.35 FTE) provides counseling to TARCC patients and their families, which aids in recruitment and retention. She will oversee production of communications with subjects. Dr. Massman oversees the conduct of all TARCC psychometric assessments, and represents us on the Neuropsychology Subcommittee (0.10 FTE). Dr. Pavlik is responsible for regulatory oversight, and represents us on the Biomarkers Subcommittee (0.10 FTE).

Clinical support staff are necessary to assist the physicians in clinic with duties like scheduling patients, performing vital signs, and escorting patients between TARCC procedures, and these duties are performed by Ms. Flores (0.30 FTE). Ms. Flores also plays a role in completion of some of the data forms. Mr. Bishop gives physical examination, physician estimates of duration (0.25 FTE). Scheduling is handled by Ms. Wedow (0.25 FTE). Ms. Gilboa-Fried (0.25 FTE) provides the on-site data support for TARCC, including cross referencing the EPIC scheduling system with TARCC patient due reports, and assisting Ms. Darby with sample tracking through the Freezerworks software package. Ms. Gilboa-Fried also supplies reports to Dr. Doody that are necessary to maximize recruitment and coordination of TARCC patient visits. Ms. Patterson is an administrative assistant (0.30 FTE) who handles front office contact between TARCC and Dr. Doody, Dr. Doody and the business office, and Dr. Doody and Grants & Contracts. She reviews monthly TARCC budget reports with Dr. Doody, and pays stipends to study subjects. These Clinical support staff positions total 3.53 FTE.
Data management and data programming are handled by Ms. Darby (0.25 FTE). She writes the programming that interfaces TARC data forms with our Alzheimer's Disease and Memory Disorders Center relational database, updates the TARC tickler files that prompt scheduling of patients and controls, and manages the Freezerworks software and data files for the specimens before they are shipped. Ms. Darby or Ms. Gilboa-Fried must be present at the end of every clinic day to log in samples and ensure their proper handling and filing. Our total database support is 0.25 FTE.

Second year budget includes 3% salary increase.

**Supplies and Expenses**

We currently have 320 active subjects and anticipate ongoing recruitment of replacements for drop outs. We have agreed to add 20 Hispanic subjects per year increasing our cohort to 340 in year one and 360 in year two. We must pay a fee to a vendor for each blood sample drawn. Supplies include office supplies, telephone, paper, and miscellaneous computer supplies. We have also been asked to take over ordering of supplies previously sent to us by the TARCC Tissue bank. Travel is for TARCC research meetings and steering committee meetings. Subject stipends are mandated by the TARCC protocol.

**Travel**

The PI is required to attend Steering Committee meetings, and scientific meetings (estimated four trips). The clinical neurologist, coordinator, and assistant coordinator each attend one operations meeting per year. Dr. Pavlik, Dr. Massman, and Dr. Glosch attend operations or scientific meetings.
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July 30, 2015

Ms. Debbie Hanna, Chair
Texas Council on Alzheimer’s Disease
Austin, Texas

Dear Debbie,

As a board member of this council, a board certified neurologist, and director of the Alzheimer’s Disease and Memory Disorders center, I would like to discuss a very worrisome set of events that is ongoing with one of my cognitive patients.

I saw my patient, PW, initially on July 25, 2011. He was 80 years old at the time, and was accompanied by his wife who told me of his progressive memory loss for two years. PW did not recognize his memory changes and this initial office visit suggested that he had primarily had a memory disorder. After an extensive evaluation, including neuropsychological testing and MRI of the brain, I diagnosed amnestic mild cognitive impairment, with no evidence of dementia. I recommended memory therapy and aerobic exercise and that he follow up with me in four months.

The next time I saw PW was March 30, 2014 and he was accompanied by his daughter because his wife (her mother had died). She mentioned his continued cognitive decline and that he was not aware of it. He was living in Longhorn Village with his wife until her passing in early 2014, and now was living alone in the same apartment in the independent part of the village. He scored mildly abnormally on his my in office cognitive test, but his Activities of Daily Living assessment by his daughter suggested much more impairment. Memory, orientation, problem solving, shopping for himself, and simple tasks like heating water for a cup of coffee and preparing a meal, were all impaired. He was having trouble paying his bills and reconciling his check book, and having trouble with simple reasoning and comprehension of very basic information. I recommended to PW and his daughter that he needed to be in assisted living to help with his care and medications. I also recommended repeat neuropsychological testing to help
verify that he likely had progressed from mild cognitive impairment to dementia. The repeat neuropsychological study was done on April 24, 2014 and revealed mild to early moderate dementia with particular impairment in executive function and memory. He underwent a Driver Evaluation at St David's and failed the driving test in June 2014. I wrote a letter “To Whom It May Concern” that PW had mild to moderate Dementia of the Alzheimer type and needed 24/7 care. I stated he was incapable of making financial, business, personal or health care decisions. I last saw PW on May 15, 2014 and discussed his diagnosis and recommended treatment with him and his daughter. Subsequently, I had a family conference with his daughter on September 3, 2014 and stressed further he needed 24/7 care in an assisted living environment. She told me he was drinking wine regularly and also not likely taking his medications as directed.

His daughter told the staff at Longhorn Village independent living that PW needed to be in assisted living so he would get his medication as directed and monitor his excessive wine drinking. She was always told by them that her father is competent to live independently based on their observation.

I contacted the director at the independent living part of Longhorn village on May 12, 2015. I told her who I was and why I was calling and about my concerns with his dementia. She told me PW was doing well and qualified for independent living. She was not at all interested in what I had to say. She said they have a number of mild dementia patients in independent living and they do not have any problems with them. When I asked what their criteria were for assessing cognitively impaired patients in independent living, she hung up on me. Another director talked to me as well and said they were not interested in my comments, and would continue to treat him as independent. They also told me they suggested to PW that they could get someone to come into his apartment and give him his medications. He refused, and they said they could not force him to do this given his independent status at their facility. Next I called a member of the Board of Trustees of Longhorn Village who told me he was an attorney. He said the only way they could fulfill the family request to put PW in assisted living was for the daughter to obtain a guardianship. The daughter is very timid where her father is concerned and had hoped it would not come to that, but she is now working with an attorney to get a guardianship.

PW remains in independent living. He may or may not take his medication as directed, and he continues to drink unlimited quantities wine at their club. No staffer at independent living part of the Village ever once told his daughter that she needed pursue a guardianship before they decided to make any changes in his care. They merely continued to disagree with the daughter about her knowledge of her father’s condition. They were rude to PW’s daughter and to me, and would not even listen when I tried to have a conversation about his cognitive impairment.

I have heard from other cognitive professionals, and this is not a new problem. My sense is that this is not an isolated event—it likely occurs in all facilities that have more than one level of assisted living available plus independent living. I believe this needs be looked at state-wide, including involvement from Adult Protective Services to be sure individuals with dementia receive the proper care, including safety measures, as their dementia continues to progress. Families need to feel secure that their loved ones are being cared for responsibly at each phase of decline. I recently spoke to one of the directors of
APS in Texas and he was very concerned about this particular case. He suggested PW's daughter and I file a formal complaint with APS so that they can begin a formal investigation.

Your truly,

Ronald Devere MD, FAAN