

**Alzheimer's Disease and Related Disorders Commission:
Data and Research Work Group**

Virginia Department for Aging and Rehabilitative Services
8004 Franklin Farms Drive
Henrico, VA 23229

Tuesday, March 22, 2016 at 8:30 am

MEETING MINUTES

Members Present:

Dr. Patricia Slattum, Ph.D., Chair
Dr. Carol Manning, Ph.D. ABPP-CN
Dr. Connie Coogle, Ph.D.
Sonya Barsness, M.S.G.*

Guest:

Carter Harrison, Alzheimer's Association

Staff:

Devin Bowers, M.P.H., DARS

*Participated via conference call

Meeting Summary:

Agenda Items:	Speaker:
<p>Welcome Dr. Patricia Slattum called the meeting to order at 8:38 am and welcomed members.</p>	Patricia Slattum
<p>Introductions Work group members, guest, and staff introduced themselves.</p>	All
<p>Approve the Minutes Minutes from the previous two meetings were approved.</p>	All
<p>Lowenthal Symposium Report Devin Bowers and Dr. Carol Manning reported that the symposium was attended by approximately 40 people and although the presentation went well the networking hour was only attended by one person, Dr. George Bloom from the University of Virginia. Dr. Patricia Slattum noted that organization of the symposium at the Virginia Commonwealth University School of Pharmacy was shifted to different faculty members during the planning process due to internal changes, which resulted in some challenges. Attendance in previous years has been greater and this was the first year a networking event was included. The VCU School of Pharmacy is willing to continue a partnership with the work group and is open to organizing another networking opportunity in the future. Dr. Manning suggested holding the networking over lunch.</p>	Devin Bowers Carol Manning
<p>Overview of Relevant Dementia State Plan Goals Mrs. Bowers provided copies of goal 2 and 5, and Dr. Slattum walked members through the goals, highlighting achievements and potential areas to focus activities.</p>	Patricia Slattum

<p>Discussion and Selection of 2016 – 2017 Focus</p> <p>Since the researcher focus groups highlighted a desire for networking opportunities, work group members discussed avenues beyond the Lowenthal Symposium for achieving this request. Dr. Manning suggested asking the sponsor of the Lowenthal Symposium to provide funding for a networking event and Dr. Slattum added the Rice Center at VCU may be willing to contribute funding. Discussion turned to the website AlzPossible (www.alzpossible.org), which is supposed to serve as a clearinghouse for dementia related data. The report produced through collaboration between Charlotte Arbogast (Virginia’s first Dementia Services Coordinator) and the work group needs to be updated regularly, perhaps every four years. In California memory centers collect data using a uniform data set. This initiative was supported by state legislation and funding.</p> <p>Dr. Slattum stated that the work group should promote the work of the UVA Memory and Aging Care Clinic (MACC), which will align with efforts around goal 4 of the Dementia State Plan (DSP). The MACC is a research center, but this is not widely known. By providing care coordination and contributing to the body of research around dementia the MACC is fulfilling two major goals of the DSP. There is a need for collaboration between the work of the Data and Research Work Group and the Coordinated Care Work Group due to the scope of services provided by the MACC.</p> <p>Due to the passing of <i>HB 337 Neurodegenerative diseases; informed consent to experimental treatment</i>, legislation around informed consent has changed. Dr. Slattum suggested the work group draft and distribute a statement about these changes to all IRBs. Carter Harrison has arranged a bill signing with the Governor’s office and will be requesting participation from the work group members. Dr. Slattum will send information about IRB training to members.</p>	<p>Patricia Slattum</p>
<p>Future Work and Activities</p> <p>The work group members decided to focus on:</p> <ol style="list-style-type: none"> 1. Providing opportunities for dementia researchers to network. 2. Setting a schedule for updating the data report published in December of 2014 and available on AlzPossible. 3. Expanding and updating the data and research resources housed on AlzPossible. 4. Issuing a statement about the informed consent changes to all IRBs. 5. Participating in the upcoming bill signing for HB 337. 6. Promoting the work of the MACC and identifying opportunities to support and collaborate with the Coordinated Care Work Group. 	<p>Patricia Slattum</p>
<p>Meeting Adjournment</p> <p>Dr. Slattum adjourned the meeting at 9:40 am.</p>	<p>Patricia Slattum</p>