



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

Tuesday, February 04, 2025
2:00pm- 3:30pm

1610 Forest Avenue, Suite 100
Henrico, VA 23229

<https://dsa-virginia.zoomgov.com/j/1607524302>

Meeting Minutes

Members Present electronically:

Lana Sargent, *Chair*

Stephani Curry

Glynis Boyd Hughes

Annie Rhodes

Karen Roberto

Faika Zanjani

Staff:

Heather Kidd

George Worthington

Guests:

None

Welcome & Introductions

Lana Sargent welcomed members, and the meeting was called to order at 3:04 pm. Attendees introduced themselves.

Lana Sargent, *Chair*

Adopt Agenda

Action Item: Adopt draft Agenda

Ms. Sargent asked whether there were any changes to the agenda and there were none. Annie Rhodes made a motion to accept the agenda as presented, seconded by Faika Zanjani. The motion passed unanimously, and the agenda was adopted as presented.

Lana Sargent

Review and Adopt Minutes for November 12, 2024, Meeting

There were no changes to the minutes, and they were adopted as presented.

Lana Sargent

Public Comment

No public comment was received.

Lana Sargent

StARS (State Alzheimer's Research Support Center) Update: George Worthington, Annie Rhoades

- We are waiting to hear an update from StARS. Last communication was in January.
- At that time, the StARS representative indicated they are in talks with the NIA (National Institute of Aging) regarding favorable adjustments to timeline.
- Mr. Worthington will email them February 10 if he has not heard back before then.

Mr. Worthington and Ms. Rhodes had met previously to discuss a possible plan highlighting the goal of uplifting and demonstrating the importance of care navigation across the state. They reported their discussion as:

- Exploring the question as to how we can use this year of funding to collate data showing different types of care coordination happening across the Commonwealth
- Emphasizing importance of evaluation to show where and how care coordination is being implemented across Virginia
- Tying evaluation to outcomes or set the framework to tie it to outcomes (e.g., the difference care coordination makes in quality of experience in the healthcare environment for the person with dementia)
- Using Virginia Memory Project (VMP) data and uplifting the coordination that is already happening
- Adding qualitative aspects including leveraging the planned Lived Experience (LE) panel, contextualizing quantitative data with qualitative lived experience
- Perhaps quantitative year one and qualitative year two for the pilot
- Effort to have the various care coordination programs collecting similar data, using similar names and codes for easier data harmonization
- Integrating No Wrong Door (NWD) data as well.
- Ultimate Goal: making the cost effectiveness case for care coordination
- The year 2 pilot could be perhaps a comparative study across settings across Virginia of people living with dementia, with and without care coordination services
- Trends: where and who is diagnosing to help with education efforts
- StARS team will help build the LE panel

- Assumption is the Alzheimer's Association would be the main conduit for recruitment for that panel
- Identifying all navigation programs and standardized data collection intervention components. Evaluation to create standardized assessment across all programs
- Stakeholder: satisfaction and outcome survey (e.g., UVA)
- Statewide quantitative data comparing outcomes for people who qualified for Guiding an Improved Dementia Experience Model (GUIDE) and those who did not qualify
- Qualitative data from each institution could be helpful
- How to tie in the Roundtable
- Using some of the funding for institutions to share data
- Stephanie Curry will investigate what state level data regarding GUIDE participants could be utilized and will report back to the group
- Ask questions that are different from the questions that GUIDE may already be asking
- Data regarding diagnosis specifics (e.g., to find out when ADRD diagnosis made in hospital/emergency room)
- Ms. Curry will look into International Classification of Diseases (ICD) codes for diagnoses and hospitalization data
- Exploring what care coordination services are being utilized across the state

Discussion: Workgroup Activities

Draft Language:

The group reviewed Mr. Worthington's 200-word and 500-word texts on the importance of participating in dementia research (aimed at consumers) as well as the list of ten things that have happened in research because of individual participation in studies.

George Worthington,
Lana Sargent

The group discussed the possibility of adding elements of personal benefit for the participants along with the greater good benefit, understanding not all research lends itself to beneficial individual outcomes.

State Plan Objectives:

The group discussed focus areas as follows:

- Previous two documents discussed are efforts to meet Objective 5.3: Strategies to Use DCV (Dementia Capable Virginia) to link to additional resources related to research and to promote awareness and use of existing mechanisms to link potential participants with research opportunities

- Suggest working on the following objective strategies as we start year two of our four-year plan:
- Objective 5.3, the strategy to promote training to improve awareness of the value of research participation – Developing a 2-page-toolkit to help educate CHWs and other frontline workers on a clearer understanding of research and its value so they can disseminate that information
- Objective 5.2, the strategy to build a research consortium network – Use DCV as that place for researchers to advertise their current research (videos, flyers) and to reach researchers so they know about this opportunity. Use this opportunity to make the research opportunities approachable and accessible for possible participants. We could also disseminate infographics of research findings to share back with the community highlighting the human impact, why the community should care about these findings. There is also the possibility of tracking visits to this section of DCV
- Karen Roberto shared link Examples of testimonials from the CareEx project: <https://careex.isce.vt.edu/>

Mr. Worthington and Heather Kidd will work on a draft for the next meeting for the group to review and discuss.

New Business:

No new business was discussed.

Lana Sargent

Meeting Adjournment:

Ms. Sargent adjourned the meeting at 3:53 pm.

Lana Sargent