Assessment of Trends and Disparities Committee
Progress Report to the Alzheimer’s Disease Work Group, April 24, 2018

Legislative Charge Tasked to this Committee

“The working group shall consider and make recommendations and findings on the following...analysis and assessment of public health and health care data to accurately determine trends and disparities in cognitive decline.”

Committee Members

Steve Waring, Interim Director of Research and Research Scientist, Essentia Institute of Rural Health
Joe Gaugler, U of M School of Nursing and Center for Aging
Ray Willis, retired U of M faculty
Kirsten Hall Long, K Long Health Economics Consulting
John Selstad, retired from Minnesota Board on Aging
Don Bishop, Center for Health Promotion, MDH
Rachel Zmora, U of M graduate student
Colleen Peterson, U of M graduate student
Dick Olson (“Injured reserved”)
Darrell Foss, ADWG Chair

Meetings Completed: three

Sampling of Meeting Conversation Themes

- Leveraging existing infrastructure: The All Payer Claims Database (visited with Stefan Gildemeister and Pamela Mink from MDH to learn more about this and current work on the state’s health quality measurement framework.)
- Identification of family caregiver in health record data
- Dementia care quality indicators for health systems to consider
- Obtaining reports from innovations at Essentia, Allina, HealthPartners: synchronizing data and findings
- With the removal of cost plans, how can the state save money by delivering good dementia care?
- Identifying best practices for standardizing mortality data for Alzheimer’s and dementia
- Creating mechanisms to track completion of 2018 report recommendations
- Quality indicators across care settings that can be extracted and usable
Data Sources

To assess the state of Alzheimer’s and dementia data in Minnesota, the committee is populating two critical lists. The first, is a list of Minnesota Epidemiology cohorts and the second, is a list of all existing Minnesota-focused studies informative to dementia and Alzheimer’s disease. Work Group and committee members can view the list in the Assessment of Trends and Disparities library on SharePoint.

The Minnesota Epidemiology Cohorts list will include the following information:

- Cohort name
- Start date
- Region
- Investigator
- Current Status
- Cognitive Testing
- Size
- Description and research focus

The Data Sources list will include references to the following information for each source:

- Sampling frame
- Alzheimer’s diagnosis information
- Caregiver identification
- Mortality/reason for death
- Medical service utilization
- Race/ethnicity
- HCBS/LTSS utilization
- Identification of dementia care coordination/care planning
- Race/Ethnicity Information

Work Group Question: Please let us know after the presentation about data sources and cohorts you are aware of so we can examine them and add them to our evolving list.
Emerging Recommendations

1. **Install Recommendation Tracking System**
   Since the 2011 *Preparing Minnesota for Alzheimer's Disease Report*, we do not believe demonstrable progress has occurred in creating, developing, or leveraging statewide data sources to effectively document trends and disparities in dementia. **We recommend that a mechanism is created to track whether and how these recommendations are met following final delivery of the report.**

2. **Encourage Culturally Aware Data Collection**
   Encourage existing and future data sources to improve culturally competent data collection on minority populations including immigrant (Hmong and Somali), Native American/American Indian, rural dwelling, and LGBT individuals in order to identify existing disparities.

3. **Improve Overall Quality of Data Collection**
   Leverage existing data sources to better understand trends and disparities in dementia in Minnesota.
   a. Consider strengths and weaknesses of existing data sources that provide statewide data on persons with dementia and their caregivers.
   b. Consider other epidemiological studies that may serve as:
      i. Design templates for either future efforts to track dementia trends and disparities; or
      ii. Candidates for "piggybacking" dementia-related questions onto existing cohort studies.
   c. Combine and merge existing data sources to address key questions of interest (e.g., examine the results of changed patterns of care and quality improvement efforts).

4. **Leverage Minnesota All Payer Claims Database**
   Consider the Minnesota All Payer Claims Database (housed and managed by the Minnesota Department of Health) to address several key questions and more fully advance existing studies of dementia in Minnesota. Specifically:
   a. Develop a process or mechanism for researchers and others to link individual or family caregiver clinical data with Minnesota All Payer Claims Database records.
   b. Collaborate with the University of Minnesota or some other entity to utilize the APCD to address the following questions:
      i. Building on recent reports commissioned by MDH, use the APCD to examine prevalence of dementia and dementia trends not only by age group, but also by geographic location, race/ethnicity, and gender.
      ii. Similarly, examine per person costs for persons with dementia and dementia attributable spending (overall and by cost category) currently and over time by geographic location, race/ethnicity, and gender.
      iii. Per point 3.b.i and 3.b.ii, avoidable hospitalizations, psychotropic medication use (and trends in use), long-term services and supports (LTSS), and/or nursing home use/costs should also be reported in any updated Minnesota dementia prevalence and trends report using the APCD.
5. **Care Giver Status on Health Records**
   Similar to recommendations from the National Academies of Sciences, Engineering, and Medicine (2016), we recommend that caregiving status be considered for inclusion in health records.

6. **Synchronize Quality Indicators**
   Relying on representative stakeholder groups such as the Minnesota Brain Aging Research Consortium (M-BARC), obtain reports/updates from Minnesota-based health care systems that have implemented programs designed to improve dementia care across their systems to synchronize quality indicators that are able to be implemented across other systems.

**Work Group Questions:**

- Are there any recommendations that the committee should revisit conceptually? Why?
- Do any recommendations connect to recommendations emerging from other committees that we should be aware of in terms of shaping the final report?
- What recommendations are missing?
- Collectively, are these recommendations “pitched” at the right level?

**Next steps for Assessment of Trends and Disparities Committee**

- Set up conference call to discuss feedback from Work Group.
- Plans in works to have more substantive conversation with Gretchen Ulbee, DHS and Work Group member, to better understand the richness of Medicare and Medical Assistance data on beneficiaries and its longitudinal character.
- Formulate the best feasible ways of tracking implementation of each recommendation.
- Finalize recommendations and submit to Work Group.
For your reference:

The following are the recommendations related to assessment of trends and disparities from the 2011 report:

**Nursing home report card**
- The commissioners of health and human services shall revise the nursing home report card to measure and report quality indicators and quality of life for persons with Alzheimer’s disease and other dementias. (Achieve Quality and Competence in Dementia Care/Legislative Actions p. 38)

**Home and community based services**
- The commissioner of human services shall include a measure for dementia care competence within the home and community-based services report card currently under development. (Achieve Quality and Competence in Dementia Care/Legislative Actions p. 38)
- Include measurement of Alzheimer’s care outcomes in the recently awarded Medicare MAPCP demonstration of the health care home (a.k.a. medical home) that will begin in Minnesota in 2011. (Pursue Cost-Saving Policies p. 43)

**Health outcomes, care quality and costs**
- The commissioner of human services, in conjunction with the commissioner of health and the Minnesota Board on Aging and other appropriate state offices, shall jointly estimate differences in the outcomes and costs of caring for those with Alzheimer’s disease and other dementias (using current practice as a baseline), compared to the outcomes and costs resulting from: 1) earlier identification of Alzheimer’s and other dementias, 2) improved support of family caregivers, and 3) improved collaboration between medical care management and community-based supports. (Pursue Cost-Saving Policies/Legislative Action p. 44)
- The commissioner of health, in consultation with the commissioner of human services, within the department’s responsibility for implementation of the health care home, shall collect baseline data and then compare the annual costs and quality of health care for individuals diagnosed with Alzheimer’s served through health care homes, to the cost and quality for comparable individuals served in non-health care home clinics. (Pursue Cost-Saving Policies/Legislative Action p. 44)

**Prevalence and screening in MN**
- Use the new cognitive screening that is part of an annual wellness visit covered by Medicare as a means of developing better statewide prevalence data on cognitive impairment in Minnesota, by reporting the data to Minnesota Community Measurement for further research, validation and development of estimates. (Intensify Research and Surveillance p. 45)
- The commissioner of health shall request that Minnesota Community Measurement include rates and results of cognitive screening as a measurement for physician and clinic services for Minnesotans 65 years of age and older. (Identify Alzheimer’s Early/Legislative Actions p. 33)

**Increase participation of diverse populations in research**
- Increase the participation of diverse populations in research on Alzheimer’s and other dementias. (Intensify Research and Surveillance p. The director of the office of minority and multicultural health of the Minnesota Department of Health shall report on the barriers and incentives for expanded participation of persons from ethnic, immigrant and tribal communities in research on Alzheimer’s disease and other dementias. (Intensify Research and Surveillance/Legislative p. 46)