

Draft recommendations

Data Collection and Research

**(Translation?** I think either as part of this or even perhaps separately we need to work on improving access to healthcare delivery, with emphases on:

- 1) early stage assessment/ referral
- 2) prevention-based strategies / health promotion
- 3) improving access to care /reducing health disparities
- 4) promoting and helping to implement established quality standards of care
- 5) increase opportunities for participation in clinical research-related activities to help facilitate medical advances and subsidize clinical activities

Improve data collection on prevalence of Alzheimer's disease

In order to better track the demographic and economic impact of Alzheimer's disease on the state of North Carolina, **dementia advocacy groups** should continue to fund the cognitive impairment module of the Behavioral Risk Factor Surveillance System (BRFSS) on a five-year interval, measuring self-reported cognitive decline. Resulting BRFSS data should be used to inform public awareness campaigns and data dissemination efforts by state policymakers, state agencies, and advocacy organizations. Data should also be analyzed for potential connection with other behavioral and lifestyle risk factors tracked by BRFSS.

In order to improve data collection on rates of death from Alzheimer's disease and related dementia, the North Carolina Office of the Chief Medical Examiner, together with the North Carolina Area Health Education Centers (AHEC) programs should offer continued medical education training on the identification of Alzheimer's disease as cause of death. **(what else here?)**

Other ways to improve data –Diagnostic codes?

[Use of the ICD-10 codes should improve uniformity in reporting.](#) e specificity

**ICD-10 will help standardize diagnostic coding**

[Education of public/families in -recognizing the symptoms related to dementia. Under-reporting as cause of death starts by educating public as to what is normal cognitive aging and what is not.](#)

Support research through the establishment of a state-wide collaborative registry

Academic institutions, including Duke University, University of North Carolina at Chapel Hill, Wake Forest University, North Carolina A&T University, North Carolina State University, and University of North Carolina at Wilmington, should partner with philanthropic organizations to fund, establish, and support a state-wide registry/clinical trials network of diagnosed dementia patients and healthy individuals, in order to better inform research into dementia treatment and prevention. The collaborative network should:

- a) Build on the existing work of MBARC to expand partnerships, establish continued funding, and determine appropriate methods of sustainability
- b) Focus on inclusion of underserved and underrepresented populations in dementia treatment, prevention, and clinical trial participation
- c) Work to apply research findings to education/awareness campaigns on dementia prevalence, symptoms, and opportunity for participation in clinical trial research
- d) Promote the ways in which a state-wide registry may have a positive economic impact on North Carolina

I think a state-wide prevention registry is a good idea, but it would need to not be bound to any one program. The same would be true for any registry –MCI, AD, FTD, DLB, etc. Registries cost a lot of money too—caregivers would be the primary users, and I think the more information / data we have on them—time, expense, stress, etc. would help make a stronger case for state support. I am not sure BRFSS data will be enough to truly capture the scope of the problem.

Something to consider: just as the MBARC research consortium is taking shape, and as part of the a Translational initiative, it might be worthwhile to try to put into place a minimum dataset for different clinical venues across the state. The anchors for this initiative could be the 3 HRSA grants (Duke, UNC, ECU), where a core composite set of assessments, diagnostic criteria, care pathways etc. might be derived by that would help guide primary care and other non-academic practice settings throughout the state. The rationale for this would be quality improvement for care and a core dataset that would facilitate entry into research studies.

Support application of a standardized assessment that addresses the continuum of brain health

Should this tie in with Early Detection and Diagnosis recommendation – around training regarding early detection tools, resources, etc.? [YES!!!!](#)