



# Research & Data Working Group: Discussion of Recommendations *October 30, 2015*

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# Improve Data Collection on AD Prevalence



- Need to track demographic and economic impact of AD in the State of NC
  - Recommend continue use of the cognitive impairment module of the Behavioral Risk Factor Surveillance System (BFRss) over 5 year interval
  - Measure self-reported cognitive decline
  - Data help inform public health initiatives, awareness campaigns

# Improve Data Collection on AD Prevalence



- Improve data collection on rates of death from AD and related dementia
  - Recommend NC Office of the Chief Medical Examiner together with NC Area Health Education Centers (AHEC) programs offer CME training on identifying AD as cause of death
  - Challenge may be also in capturing this in a data system
    - ✦ Use of ICD-10 codes should improve uniformity of reporting
  - Educating public and families in recognizing the symptoms related to dementia.
    - ✦ Under reporting of causes of death related to lack of recognition of what is disease and what is aging

# Support Research through State-Wide Collaborative Registry



- Meeting September 18 2015 to form coalition of research partners focused on AD and related dementias
  - Goal to set up state-wide registry of clinical trials that would
    - ✦ Facilitate a network of diagnosed dementia patients and healthy individuals
    - ✦ Inform research into dementia treatment and prevention



The grant awarded in 2014 to Duke University and UNC-CH to fund planning and first steps for the North Carolina Regional Consortium for Brain Health in Aging.

*Combining efforts to speed the pace of discovery and hasten translating of key findings into improved health and care for individuals in North Carolina affected by Alzheimer's disease and related dementias.*



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## **Funding from AlzNC (2014)**

# Support Research through State-Wide Collaborative Registry



- **Recommendations**

- Build on the existing work of the Memory and Brain Aging Research Collaboration (MBARK) to expand partnerships, established continued funding and determine appropriate methods of sustainability
- Focus on inclusion of underserved and under-represented populations in dementia treatment, prevention, and clinical trials
- Work to apply research finding in public awareness campaigns
- Promote ways in which the registry may have a positive economic impact on state of NC

# Points for group discussion:



- Translating Research into Care AND Care into Research & Policy
  - Goal of improving access to healthcare delivery, with emphases on:
    - ✦ early stage assessment/ referral
    - ✦ prevention-based strategies / health promotion
    - ✦ improving access to care /reducing health disparities
    - ✦ promoting and helping to implement established quality standards of care
    - ✦ increase opportunities for participation in clinical research-related activities to help facilitate medical advances and subsidize clinical activities

# Points for group discussion:



- Translating Research into Care AND Care into Research & policy
  - Minimum dataset for clinical practices
    - ✦ Anchors- 3 HRSA grants (Duke, UNC, ECU)
    - ✦ Develop a core composite set of assessments, diagnostic criteria, care pathways etc.
    - ✦ This might help guide primary care and other non-academic practice settings throughout the state.