

# Clinical Care Subcommittee Recommendations

January 14, 2014

1. **Target the dementia awareness campaign funded in the omnibus appropriations bill toward the following specific efforts: (a) recognition and diagnosis of cognitive impairment and Alzheimer's Disease; (b) the importance of talking to a health care provider about worsening memory problems; and (c) talking with family members and health care providers about preferences for care.**
  - HHS should work closely with the CDC and other public and private partners on this campaign so that the message that Alzheimer's disease is a public health issue is highlighted. A central theme should be to de-stigmatize Alzheimer's and encourage engagement in order to promote health and quality of life. Campaign partners could help in development of messaging as well as to magnify the reach of the campaign.
  - HHS should partner with medical professional groups to launch a parallel awareness campaign targeted at primary care providers about the benefits of early detection and diagnosis of Alzheimer's disease.
  - Both campaigns should emphasize key reasons for early detection, highlight the Medicare Annual Wellness Visit as an important opportunity to discuss any concerns/issues related to cognitive function, and should begin to explain the diagnostic process. In other words, the campaign should stimulate interest AND provide information and next steps for each audience.
  - The campaigns should include specific efforts in diverse communities and populations, including younger-onset individuals, persons with intellectual disabilities, and racial/ethnic groups at higher risk of developing Alzheimer's.
  - Each federal agency involved in the National Plan process should, by April 2014, identify actions it could take, alone and in partnership with private entities, to increase and improve detection of cognitive impairment and diagnosis of Alzheimer's disease. These actions should be subject to an interagency review, prioritized, and implemented by July 2014.

**2. Evaluate the detection of cognitive impairment component of the Annual Wellness Visit and study possible ways to improve detection and diagnosis of Alzheimer's Disease.**

- We recognize that under the current billing system, it is not possible to determine how the Medicare Annual Wellness visit (AWV) requirement to detect possible cognitive impairment is being carried out by physicians (or even if it is being carried out). However, knowing this is important in order to evaluate the effectiveness of the approach and to determine if improvements or changes need to be made in the future. Therefore, the Centers for Medicare and Medicaid Services (CMS) should survey a representative sample of primary care providers to assess whether the AWV is being undertaken, what tools are being used, what percentage of people have a positive detection, and what percentage are being referred for a full diagnostic evaluation.
- HHS should outline the current barriers to greater detection and diagnosis of Alzheimer's disease, the steps needed to increase detection and diagnosis, and set a national diagnosis rate target, as Great Britain is doing.
- Report back to the Council by the fall meeting 2014.

**3. Establish targets and milestones for improving the clinical care for persons with Alzheimer's disease and their caregivers through the following patient-centered goals:**

- a) I was diagnosed in a timely way.
  - b) I know what I can do to help myself and who else can help me.
  - c) Those helping to look after me feel well supported.
  - d) My wishes for my care are respected.
- HHS should establish national targets and milestones for (a) timely diagnosis; (b) the provision of early care planning with options for community support services and legal/financial planning; (c) advance care planning discussions completed and documented; and (d) the number of caregivers who receive a needs assessment.
  - HHS should identify data sources that could be used to measure progress toward those targets and milestones. New sources will likely need to be developed and patient/caregiver surveys need to be considered as an important source of information.
  - HHS should consider partnerships with voluntary health associations and non-profit advocacy groups to develop new data sources.
  - HHS agencies and operating divisions should identify initiatives and programs that can work toward the goals, the national targets and milestones and should contribute toward data collection.
  - HHS should provide an initial report on progress in establishing targets and milestones to the Advisory Council by the September meeting 2014 and should include the targets and milestones in the 2015 update to the National Plan.

- 4. Clarify the privacy protections under the Health Insurance Portability and Accountability Act (HIPAA) to ensure that health care providers can engage in care planning with family members of those diagnosed with Alzheimer's disease or other dementias.**
  - Within six months, the Department of Health and Human Services (HHS) should issue regulations and/or guidance clarifying HIPAA's privacy provisions with respect to communications between health care providers and family caregivers of those diagnosed with dementia.
  - Such regulations/guidance should ensure that health care providers can engage in care planning with family caregivers without the presence of the diagnosed individual.
  - Following the clarification of HIPAA requirements, the Centers for Medicare and Medicaid Services (CMS) should develop appropriate billing procedures for care planning services provided to family caregivers by July 2015.
  
- 5. Evaluate models and demonstrations of payment and care delivery reform on the quality and cost for the subpopulation of participants with Alzheimer's disease.**
  - The Center for Medicare and Medicaid Innovation (CMMI) should ask that all current studies evaluating management of multiple co-morbidities have a specific analysis of those persons with dementia. If they do not sub-analyze persons with dementia then potential strategies for management may be identified that do not succeed in this group.
  - CMMI should evaluate funded payment and delivery reform models to determine separately and explicitly the impact on quality of care and costs for the subpopulation with Alzheimer's disease.
  - In evaluating the impact of the tested models and interventions on individuals with Alzheimer's disease, CMMI should give priority to: (a) models aimed at reducing preventable hospitalizations, readmissions, emergency department visits, and length of hospital stays; (b) the state demonstrations on dual eligibles; (c) models targeting care transitions; (d) medical home and Independence at Home models; and (e) Accountable Care Organizations.
  - Particular attention should be paid in the evaluations to effects on individuals from diverse communities.
  - The evaluations should be ongoing and incorporated into the normal evaluation component of the models in general.
  - CMMI should ensure that all models and demonstrations funded in the future include effective procedures to identify people with Alzheimer's disease in their samples.
  - CMMI should report on its plan to evaluate the Alzheimer's disease subpopulations of its projects, including procedures for identification of people with Alzheimer's in future projects, by June 2014.

**6. Develop and set targets, strategies and milestones for ensuring a dementia-capable primary and specialty care workforce in terms of both the number of professionals needed and ensuring basic competence among health care professionals in caring for persons with Alzheimer's disease and their caregivers.**

- Given the demographic shift toward a larger older population in the US, HHS should determine how many dementia-capable geriatric health professionals the population will require in the short term (10 years) and the longer term (25 years) -- and then set targets, strategies, and milestones for meeting this need. The targets, strategies, and milestones should focus both on how to achieve the number of professionals needed as well as how to ensure they have competency in dealing with and treating individuals with dementia.
- In developing targets, strategies and milestones, HHS should consult with medical, nursing and social work schools; residency programs; professional organizations and boards; as well as patient advocacy organizations.
- HHS should report back to the Advisory Council by the fall meeting 2014.

**7. Increase research funding to improve understanding of advanced dementia.**

- Enable Alzheimer's Disease Centers (ADC's) to gather more information on disease progression and caregiver issues using the existing platforms and survey instruments.
- Increase funding for intervention research to improve advanced dementia care and decision making, including family caregiver education about advanced dementia and decision support tools to align care with family/caregiver preferences.
- NIH and private funders should consider mechanisms to encourage early career investigators to initiate and/or continue pursuing research in advanced dementia as there is a critical shortage of investigators in this area.