ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, AND SERVICES

Washington, DC

April 29, 2016

Advisory Council Members in Attendance

- *Non-Federal Members Present*: Ronald Petersen (Chair), Gary Epstein-Lubow, Laura Gitlin, Harry Johns, Myriam Marquez, Helen Matheny, Jennifer Mead, Angela Taylor, Sowande Tichawonna, Donna Walberg, Geraldine Woolfolk

- *Federal Members (or Representatives) Present*: Richard Allman (Department of Veterans Affairs [VA]), Susan Cooley (VA), Rod Corriveau and Walter Koroshetz (National Institute of Neurological Disorders and Stroke [NINDS]), Linda Elam (Office of the Assistant Secretary for Planning and Evaluation [ASPE]), Bruce Finke (Indian Health Service [IHS]), Richard Hodes (National Institute on Aging [NIA]), Shari Ling (Centers for Medicare and Medicaid Services [CMS]), Lisa McGuire (Centers for Disease Control and Prevention [CDC]), William Spector (Agency for Healthcare Research and Quality [AHRQ]), Amber Story (National Science Foundation), Jane Tilly and Erin Long (Administration on Community Living [ACL]), Joan Weiss (Health Resources and Services Administration [HRSA]), and Mary Worstell (Office of the Assistant Secretary for Health)

- *Quorum present?* Yes

- *Advisory Council Designated Federal Officer*: Rohini Khillan (ASPE)

General Proceedings

At 9:02 a.m. ET, Dr. Ronald Petersen called the meeting to order.

Council members present in the room, as well as those on the telephone conference line, introduced themselves and indicated on which subcommittees the serve. Erin Long manages the dementia programs for ACL and joined this meeting to provide additional details on the programs under her purview. Dr. Petersen highlighted that the main focus of the meeting was to review the Council's recommendations and vote on them for inclusion in the Plan that is to be submitted to Congress later this year. He also commended the leadership of each Council subcommittee and their work to move the recommendations process forward in between the quarterly Council meetings.

Discussion of Nomenclature

Dr. Petersen introduced the need to assess the current nomenclature used to describe Alzheimer's disease and related dementias (ADRD) and considerations for adopting new language to increase clarity and applicability.

- Given discussions held at the National Institutes of Health (NIH) ADRD summit, as well as developments in the field of dementia, there in a need to increase the flexibility of language used to describe Alzheimer's disease and other dementias. While Alzheimer's disease is a primary cause of dementia worldwide, many other forms exist, and in some individuals, multiple underlying causes of dementia may be present.

- The term dementia is an "umbrella" term that encompasses Alzheimer's disease as well as and other conditions.

- Multiple sets of nomenclature are used to describe and define dementias. Some terms are along the Alzheimer's disease spectrum, other are subsets of ADRD, and others are described by the psychiatric field and linked to medical billing codes. *Mild cognitive impairment* (MCI) and *prodromal Alzheimer's disease* are also used to describe the earlier stages of dementia.

- Originally, dementia diagnoses were fairly binary -- an individual either had dementia or they did not. The field has evolved to understand multiple stages along the process, including early stages where cognition is impaired to a limited degree, but overall function is not and thus, a dementia diagnosis is not appropriate.

- The field is currently considering the inclusion of *preclinical* or *prodromal Alzheimer's disease*, in which persons have no symptoms, yet they have some pathological features of disease.

- It will be useful for therapeutics development and regulatory processes for the field to have descriptive and aligned terminology. As clinical studies identify biomarkers of the disease process, the language describing the stages of dementia should become more specific and accurate.

- MCI and dementia are both syndromes -- characterizations of symptoms–and can have a variety of clinical causes. More accurate language, such as *MCI due to Alzheimer's disease*, or *dementia due to Alzheimer's disease*, may help clarify the condition being described.

- The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) was updated in 2013 and uses language distinct from what has been traditionally used in the ADRD field. MCI is termed "mild neurocognitive disorder", and dementia is termed "major neurocognitive disorder." The DSM-V terminology

may be useful within the medical practice for billing and coding, and to some degree help to broaden language beyond Alzheimer's disease; however, it remains to be seen how the clinical community will adopt this nomenclature.

Discussion

- Understanding the different stakeholder groups (e.g., caregivers, advocacy groups, providers, regulatory, researchers) involved in ADRD work, as well as their needs and practices, will be necessary to develop language that is truly broadly applicable. This effort is not an academic exercise -- there are ADRD-related priorities that will be more readily achieved with uniform language. Also, providing opportunities to include disease etiologies with a diagnosis can improve an individual's opportunity for treatment that can target their particular condition.

- The NIH ADRD Summit led to several recommendations related to nomenclature:
  - Address the inconsistent nomenclature in dementia research and care.
  - Organize a working group of dementia stakeholders (including founding partnerships with disparities communities) to review the current nomenclature used in public awareness, clinical care, and research, and to propose strategies to help advance early differential diagnosis and the understanding of dementia and its underlying causes.

- The Council's federal workgroups have been discussing how to address nomenclature in the recommendations. Consistency in language throughout the Plan and within the recommendations will be an important step. In the past five years, language has become more standardized and inclusive (e.g., ADRD instead of Alzheimer's disease).

Long-Term Services and Supports Subcommittee Recommendations

Jennifer Mead presented the Long-Term Services and Supports (LTSS) subcommittee's recommendations to the Council. The recommendations are listed below, and Council discussions are described thereafter.

The LTSS Committee has identified three overall goals and the following immediate and longer-term recommendations:

1. **Dementia-Capable LTSS: States, Department of Health and Human Services (HHS), and Tribes assure robust, dementia capable LTSS systems to meet the growing impact of ADRD**. ACL has identified core components of dementia-capable LTSS (*Dementia Capable States and Communities: the Basics*, 2014). Dementia capable systems ensure that the public has access to a full array of LTSS that are culturally and linguistically competent, evidence-informed or evidenced-based, and connected to accessible health care services. HHS, states and Tribes

partner with public and private entities to assure access to the full array of LTSS for specific populations of people with Alzheimer's disease and caregivers including younger people, non-traditional families, people with intellectual disabilities, such as Down syndrome, and the racial and ethnic minorities who are at increased risk of acquiring Alzheimer's disease.

Immediate

- Increase the number of states with an identified state lead entity for Alzheimer's disease to coordinate activity across state agencies and programs (including Medicaid aging services, LTSS, health care, public health, and mental health), and to work with state, local and private sector partners to implement strategies in concert with the National Plan. [States] (*Since 2011, 18 states have identified a lead as part of Alzheimer's Disease Supportive Services Program [ADSSP] dementia-capable grant funding.*)

- National partners should work with HHS and states to assure engagement of state governors and legislatures in state efforts to address dementia capable LTSS, expand use of evidence-based and best practices, and advocate for adequate funding for LTSS. National partners include the Association of State and Territorial Health Officials, National Governors Association, National Conference of State Legislatures, National Association of States United for Aging and Disabilities, National Association of Chronic Disease Directors, and Association of State Medicaid Directors. [National Organizations]

- Double current funding for ADSSP and the Alzheimer's Disease Initiative - Specialized Supportive Services (ADI-SSS) program to increase state and communities' use of evidence-based and evidence-informed strategies, programs, and dementia-capable systems. [Congress] (*Current status: 18 ADSSP states, anticipate five new states funded with $4.8 million in FY16; 21 ADI-SSS projects, anticipate ten new projects funded with $10.5 million in FY16.*)

Longer-Term

- Provide adequate funding to support state lead entities to plan and coordinate public and private activities to assure states are able to address the growing impact of dementia and assure dementia-capable health and LTSS systems. [Congress] (*Estimate $80 million.*)

- Increase state and local public health role in supporting brain health, prevention, surveillance, and community policies to support cognitive health, implementation of CDC's Healthy Brain Initiative: Public Health Road Map, and incorporation of brain health and dementia into other existing public health efforts. [States; CDC in collaboration with ACL and NIA]

- Amend Older Americans Act and expand funding to support making Title III services available to people under age 60 with younger-onset dementia. [Congress]

- Adopt common metrics that states, Tribes, and communities can use to measure and track progress in developing dementia-capable LTSS. [HHS; National Organizations; States]

2. **Caregiver Support: HHS, states, Tribes, health care, and aging services providers assure that family/unpaid caregiver health and well-being is regularly assessed and addressed**. Unpaid caregiving by families and friends results in caregiver illness and mortality that contributes to the enormous personal and financial cost of dementia. The impact on unpaid caregivers' emotional and physical health is borne by caregivers, employers, the health and LTSS systems, and tax payers.

   Immediate

   - Assure that health and related systems funded with federal resources provide chronic disease management and related services for people with Alzheimer's disease, as well as family caregivers. [HHS]

   - Educate and clarify for health care providers and health systems how Medicare care planning and other covered benefits can be provided to a beneficiary with dementia in compliance with HIPAA, when a family caregiver is present and the individual with the disease is not. [CMS; National Healthcare and Aging Partners]

   - Provide full funding for the National Family Caregiver Support Program, including funding to ensure regular evaluation of the impact of the program on family caregivers for people with dementia. [Congress] (*FY2016 funding: $150.6 million.*)

   Longer-Term

   - The process of diagnosis should include engaging individuals and families in care planning and referrals to appropriate community resources to support this planning. Care planning should address health, LTSS, caregiving resources, legal, estate planning, and finances. [HRSA, CMS; Provider Organizations; States]

   - Provide care planning with an unpaid/family caregiver as a covered benefit under Medicare and Medicaid. [CMS; States]

- Identify family/unpaid caregivers in electronic health records of individuals with dementia, as well as in the caregiver's own medical records. [CMS; States; Health and LTSS Systems]

- Expand pilot payment programs in Medicare and Medicaid models that include caregiver support for patients with dementia, many of whom have complex care needs. [CMS]

- Identify and advocate for employment practices and policies that allow employers to balance paid employment with unpaid care. [States; Businesses; Congress]

- Support the expansion to scale of evidence-based and evidence-informed caregiver support programs and their cultural adaptations. [CMS, HHS; States]

3. **LTSS Research and Evaluation: Federal agencies in partnership with national organizations and states, support research to identify model standards and best practices to improve quality of life and LTSS for individuals and families affected by dementia**. Critical topics for further intervention research include: culturally and linguistically appropriate adaptations of interventions into community; services for people in the early stages of dementia, with Down syndrome and other intellectual disabilities, living alone with dementia, or who want to remain in their homes. Other important topics for further research are the impact caregiving has on health and quality of life of their caregivers; and interventions for persons in end stages of dementia that increase their comfort and increase caregiver satisfaction through advance planning.

Immediate

- Convene a national dementia care and services research summit, building on existing work, to identify research priorities to provide care and services to persons with dementia and family caregivers, and to provide recommendations as to best practices and priorities. [HHS; National Organizations]

- Provide training for paid/paraprofessional caregivers in every care setting to address cultural and dementia competence. HHS should identify model state standards of care and policies that promote fair and reasonable compensation and appropriate dementia care training. [HHS; States]

- Assess and share findings on the impact of CMS's 2014 home and community-based settings rule (CMS 2249-F; CMS 2296-F) on individuals with dementia and their caregivers. [HHS]

- Assess and share findings on the impact of states' managed LTSS systems on individuals with dementia and their caregivers. [HHS]

Discussion

- Presentation of recommendations with notes as to which federal agency should assume responsibility may be useful; but given that the Plan is not strictly federal, non-federal stakeholders would need to be considered as well. Non-federal members were encouraged to submit recommendations for inclusion into the plan, inclusive of successful models that may be worthy of replication and/or expansion.

- Care will be taken to ensure that the language used to refer to Alzheimer's disease and other dementias is consistent throughout all recommendations.

- Associating timeframes with recommendations is useful, but the initiation action on longer-term recommendations should not be delayed.

- Work at the legislative level is needed to address reimbursements for long-term care supports that may be directly provided to caregivers who, under current CMS policies, are ineligible for receipt of benefits.

Clinical Services Subcommittee Recommendations

Helen Matheny presented the Clinical Services subcommittee's recommendations to the Council. The recommendations are listed below, and Council discussions are described thereafter.

The Clinical Care Subcommittee has identified four overall goals and the following immediate and longer-term recommendations to improve clinical care for persons with dementia:

1. **Increase early detection and diagnosis by encouraging and promoting cognitive assessment; and confirm measurement strategies to track progress within 2 years**.

   Immediate

   - Encourage clinicians to implement the Gerontological Society of America's Workgroup on Cognitive Impairment Detection and Earlier Diagnosis' four-step process; the steps include: (1) "Kickstart the cognition conversation;" (2) "Assess if symptomatic;" (3) "Evaluate with full diagnostic workup if cognitive impairment detected;" and (4) "Refer to community resources and clinical trials, depending on the diagnosis." [HHS, CMS]

   - Promote early detection and diagnosis: support continuing education efforts that improve health care providers' ability to recognize early signs of dementia, including Alzheimer's disease, and to offer counseling to individuals and their

care partners. Sessions should enhance health care provider awareness and understanding of the Medicare Annual Wellness Visit and knowledge of validated cognitive assessment tools, through local and state conferences. [HRSA, HHS; States]

- Determine if and how the Medicare Annual Wellness Visit can be used to measure the rate of screening for cognitive impairment. Also, determine if and how other measures, such as items within the Physician Quality Reporting System, could be used to track progress regarding the rate of screening for cognitive impairment.

- Measure and publicly report data on ADRD diagnostic levels nationally and by state, released within six months of year end. [CMS]

Longer-Term

- Expand Diagnosis Disclosure, Improve Assessment and Care Planning, and Enhance Care Coordination: Develop and implement educational campaigns directed towards: (1) persons at risk for dementia and their family and caregivers; and (2) clinicians capable of conducting cognitive screening assessments. For the education of clinicians, include information about best practices for how to conduct the cognition conversation such that the diagnosis is understood, how to conduct conversations about care planning, and how to enhance care coordination through referrals to community resources. For the education of persons at risk for dementia and their family and caregivers, include information about what to expect after cognitive screening. [HHS, CMS]

2. **Enhance care planning and care coordination by increasing the use of person-centered and caregiver goals, and improving measurement within 3 years**.

Immediate

- Identify standards of care that reflects delivery of a comprehensive assessment to establish the diagnosis of dementia, identification of contributing factors, identification of support needs, and formulation of a care plan.

- Develop and implement a plan to improve measurement capability so that the perspectives and goals of persons with ADRD, their families and caregivers are known.

Longer-Term

- Incorporate best practices from the CMS Financial Alignment Initiative, including guidance provided in "three-way contracts" between CMS, states and health plans to improve care coordination for dementia. One example is the Dementia Cal MediConnect program which implemented care manager training

and technical assistance in response to California's three-way contract specifying that each health plan must have a dementia care specialist.

3. **Increase the number of communities working to become dementia friendly by 50% within 1 year**.

   Immediate

   - Encourage efforts to foster Dementia Friendly Communities. As an example, tools and resources used in Minnesota have been replicated through a privately funded collaboration called Dementia Friendly America (DFA); under this initiative all United States communities have access through a website (http://www.dfamerica.org) to free tools, resources, best practices and technical assistance to support them in working to become dementia friendly. Incorporate examples such as this into an update of the November 2011 Dementia Capability Toolkit and the September 2014 report, "Dementia-Capable States and Communities: the Basics;" and/or promote expanded use of the Toolkit and report.

   Longer-Term

   - Promote the Dementia Friendly Community approach as an organizing vehicle to implement state Alzheimer's disease plans. A public/private collaborative approach should provide funding that is designed to specifically support communities/states with seed money to foster the coordination of community efforts and support technical assistance through a centralized hub and/or state lead entity. In 2016 this collaborative should fund at least 20 communities (via a Request for Proposal process) and a technical assistance hub. The communities chosen should reflect differences in cultural groups, size of community, and rural and urban locales.

4. **Convene a national dementia care and services research summit**.

   - Build on existing work to identify research priorities related to improving early detection and diagnosis, providing care and services to persons with dementia and family caregivers, and providing recommendations as to standards of care, best practices and priorities. [HHS; National Organizations]

Discussion

- A national dementia care and services research summit that accelerates replication of successful care models is critically needed.

- Senior centers operate as aging network providers and can disseminate information on care services.

- Developing the optimal evaluation methodologies is important; aligning assessment strategies among all three subcommittees' recommendations is advisable.

- Increasing provider uptake of annual wellness visits may be an important strategy to improve detection and diagnosis of cognition issues; however, providers need more education and motivation. Assessment tools and practices may vary by provider type and care site, which may complicate diagnoses due to inconsistencies in the medical record.

- The Office on Women's Health (OWH) is collaborating with NIA, the Alzheimer's Association, and other groups to research the presentations of disease in women. A forum on sex and gender differences in Alzheimer's disease will be held later this year.

- Research into detection at any time point, but particularly during the early stages of disease, has great value to the ADRD community and should still be an area of focus.

Research Subcommittee Recommendations

Dr. Petersen presented the Research subcommittee's recommendations to the Council. The recommendations are listed below, and Council discussions are described thereafter.

1. **The 2016 National Plan should continue to provide a robust, comprehensive, and transformative scientific roadmap for achieving the goal of preventing, effectively treating and providing effective care and services for ADRD by 2025**.

   - A roadmap for accomplishing the primary goal of the Plan should include input from experts in the field through research summits on Alzheimer's disease and Alzheimer's disease related dementias including a research summit on care and services.

   - Recommendations from these summits and the research community should be re-evaluated each year and translated into milestones.

   - Include specific research milestones to:
     - Reduce racial/ethnic/socioeconomic disparities in ADRD.
     - Make significant improvements in research recruitment rates and outreach among diverse populations.
     - Re-evaluate research priorities among ADRD across all research areas (e.g., from identifying disease modifying treatments to identifying effective care and services).

- o Include and prioritize specific milestones for populations at high risk for AD (e.g., people with Down syndrome).
- o Increased attention should be paid to person- centered outcomes with respect to research planning and the delivery of care and services.

2. **A top priority remains the urgent need to continue to increase annual federal research funding sufficient to meet the 2025 goal**.

- Initial estimates of that level are $2 billion per year but may be more. This investment would be applied to Alzheimer's research initiatives spanning basic, translational, clinical, care and services research.

- The annual research funding target should be dynamically modified to approximate 1% of the cost of caring for persons with Alzheimer's and related dementias.

- The annual professional judgment budget recommended by the Alzheimer's Accountability Act and prepared by the NIH should reflect the science-driven funding needs for the budget year to enable investigators to reach the 2025 goal of the plan.

3. **The 2016 National Plan should develop research goals aimed at the establishment of evidence-based recommendations to improve delivery of care and services**.

- Enhance methodologies to effectively engage persons with dementia and families in research on care decision making and planning.

- Develop and implement quality care measures across all settings that include person-centered outcomes.

- Identify and evaluate (non-drug) care strategies that reduce disease burden and delay disease progression and evaluate their costs and downstream effects.

- Study comprehensive dementia care from time of diagnosis to end of life and associated costs and cost savings.

- Evaluate effective care programs across diverse settings, disease etiologies and disease trajectories.

4. **Emphasis should be given to the standardization of terminology in dealing with cognitive and dementing disorders**.

- An integrated conference should be convened to develop consistent language for cognitive disorders among the scientists, care providers and the public.

- Engage all of the stakeholders around these issues to reach a consensus for the benefit of persons with dementia, their family members and caregivers and the scientific and service communities.

5. **As recommended in the National Plan the United States government should support global efforts to address issues of research, care and services**.

- United States public and private entities should acknowledge and scrutinize the work of the World Dementia Council.

- Continued collaborations on international research efforts should be promoted.

Discussion

- Clinical trials on ADRD should be expanded to include research on health disparities among under-represented minority populations, as well as conditions such as Down syndrome.

- Collaborations with the Patient-Centered Outcomes Research Institute (PCORI) may help to advance new areas of research.

- Describing the need for ADRD federal funding as a percentage of overall dementia costs may be a compelling approach to underscore the dire need for sustained financial investments in research.

- Language heterogeneity will still need to be addressed, while maintaining some level of specificity so that distinct disorders can be effectively captured.

- Partnerships with the World Dementia Council maybe be controversial; further discussion is needed to identify if and how the Council should engage with them.

- Community stakeholders should be involved in the recommendations process.

Council Vote on 2016 Recommendations

- The Council members discussed the format in which recommendations would be provided. It was agreed that a cover letter (written by Dr. Petersen) will accompany the recommendations, and will include a summary from each subcommittee to provide context for the recommendations. A high-level list of

recommendations will be provided on the first pages, with supporting details and sub-recommendations captured on subsequent pages. An executive summary may be developed as well, and Council members were reminded that they are permitted to submit recommendations in whatever form they deem appropriate.

- The Council is permitted to develop separate communications to HHS and Congress if they choose to. Council members want to ensure that recommendations are provided with both the clarity and the context that is most relevant to the recipient.

- Subcommittee recommendations were voted upon by Council members; federal members abstained from the vote. Dr. Petersen moved that recommendations be accepted *en bloc*; the motion was seconded. The motion passed unanimously, and there were no abstentions.

Update on Dementia Friendly America Program

Olivia Mastry, co-chair of DFA, provided the Council with an update on the initiative.

- The objective of the DFA initiative is to foster dementia-friendly communities (neighborhoods, town, cities, and states) across the United States. The desired outcomes are to develop community and system capacities that enhance quality of life and positive outcomes for people living with dementia, their care partners, and communities.

- The DFA objective overlaps with NAPA priorities, as dementia-friendly community development includes ensuring communities are equipped to provide care along the dementia continuum, and provide LTSS. DFA also indirectly supports ADRD research by increasing awareness.

- After a 2014 report to the Advisory Council from the State of Minnesota model (ACT on Alzheimer's), DFA was initiated:
  o DFA's national participants include a diverse group of stakeholders representing federal and non-federal entities, service organizations, health care organizations, legal associations, pharmaceutical companies, chambers of commerce, police organizations, and many others.
  o A coalition of stakeholders willing to support DFA was recruited from May to December 2014, and the first DFA National Council was convened in January 2015. During 2015, DFA recruited early-adopter communities for participation.
  o In July 2015, the DFA initiative was announced at the White House Conference on Aging.

- DFA has developed a host of web-based resources and tools to facilitate community awareness and adoption of dementia-friendly activities. The

resources reside on a user-friendly website http://www.dfamerica.org, and provide sector-specific guidance on how to create dementia-friendly communities based on global best practices.

- A DFA Community Toolkit was developed to support communities in developing their own dementia-friendly communities, tailored to the specific needs of their region, culture, and community. The Toolkit outlines four major steps:
  - o **Convene** key community leaders and members to understand dementia and its implications for your community. Then, form an Action Team.
  - o **Engage** key leaders to assess current strengths and gaps in your community using a comprehensive engagement tool.
  - o **Analyze** your community needs and determine the issues on which stakeholders are motivated to act; then set community goals.
  - o **Act together** to establish implementation plans for your goals and identify ways to measure progress.

- DFA recommends several community development steps early in the process of creating a dementia-friendly community:
  - o Identify a champion and coordinator.
  - o Conduct a readiness and commitment check.
  - o Convene a cross-sector action team.
  - o Foster contributions and agreements across partners.

- The DFA-described Action Team is centered on persons with dementia and their caregivers, and can also include: government, social service agencies, transportation providers, legal and financial experts, employers, health care providers, and community members.

- The ACT on Alzheimer's model in Minnesota has made demonstrable progress, as 33 communities have completed all four phases of the Community Toolkit; ten new communities were recently added to the initiative. Outcomes data are not yet available, but progress is being made in many areas, including:
  - o Awareness and education: Dementia Friends.
  - o Caregiver supports.
  - o New, meaningful community engagement opportunities (arts, music).
  - o Cross-sector engagement and training: business, government, law enforcement, youth, first responder and faith.
  - o Health system adoption of optimal dementia care practices.

- Since the announcement of DFA at the White House in 2015, there has been broad media coverage of the initiative, which highlights the multiple opportunities for all persons in all sectors to get involved.

- State-based model for DFA technical assistance could provide a centralized resource that can facilitate "train-the-trainers" model for connecting communities

with training experts at the national and local levels. DFA Council members may also be able to provide specific expertise to communities seeking information.

- DFA has been privately funded to date; however, long-term sustainability will require support for technical assistance, evaluation, and mechanisms for community seeding through dementia capability grants or other funding opportunities.

Mr. Ron Grant, DFA co-chair, was diagnosed with early Alzheimer's disease at the age of 55. He spoke to the Council about his role in the DFA initiative, and his goals for the ADRD field in general.

- Dementia advocacy and awareness need to increase, including efforts to drive research into curative therapies. Progress is being made; however, more needs to be done for persons currently living with dementia. Research holds promise for younger generations, yet the time needed to develop new therapies means that most persons currently living with dementia will not benefit from them.

- DFA is an answer for persons living with dementia, as it can support remaining in one's community and home, and create environments where all community members are equipped with information and tools dementia friendly.

- A robust and sustained level of support from the Federal Government is needed to expand DFA's efforts and promote nationwide adoption and implementation of dementia-friendly practices.

Discussion

- DFA is developing meaningful evaluations of their efforts to help identify outcomes and impact. Currently, DFA is partnering with the Alzheimer's Association to determine levels of awareness and stigma. DFA is also applying for funding to evaluate financial indicators on the impact of dementia-friendly communities. DFA is also considering a pragmatic clinical study to evaluate indicators of "usual care" for persons with dementia (e.g., diagnosis rates, timing if diagnosis, quality of life, cost benefits to health systems).

- Tribal communities in Minnesota are engaged in preparative work to develop dementia-friendly communities. The first Native community that has selected to develop a DFA initiative is a homestead community in Hawaii, and will be working in partnership with a graduate student researcher.

- The presence of transportation services at the state or local level is key and not unique to DFA-related efforts; there are overlaps with aging services. Additionally, the interpersonal engagement skills of transportation staff (and all community members) are critical and should highlight how to manage challenging encounters in a knowledgeable way. There may be opportunities to

lower barriers in the transportation sector, for example, by providing no-cost transportation for a caregiver to a person with dementia.

- The United Kingdom is currently developing guidelines for dementia-friendly communities and the DFA has provided input into those guidelines. The United Kingdom document includes standards based on steps each community needs to take, and is similar to the guidelines DFA currently has in place.

- The Dementia Friends initiative engages individuals to promote dementia-friendly communities, and could be an important model to help seed and expand additional communities around the world.

Public Input

Five members of the public provided comments to ASPE and they included: a person living with dementia, caregivers of people with dementia, and representatives from the National Task Group on Intellectual Disabilities and Dementia Practices, Association for Frontotemporal Degeneration, and Alzheimer's Foundation of America. Rohini Khillan read one public comment that was submitted prior to the meeting. Commenters present at the meeting read their comments to the Council. The public comments provided perspectives on the following:

- Members of the ADRD community appreciate the ongoing efforts of the Council in elevating the issues and formalizing recommendations to federal entities.

- Persons living with dementia face many difficulties, including comprehension and writing of documents. ASPE should strongly reconsider the current composition of the Council and include additional persons with dementia to both decrease the burden on those members, and to increase the contributions from those living with the disease.

- CMS rules regarding coverage in community settings are vague and difficult to implement, particularly for people with intellectual disabilities. States do not have the clear guidance that would help providers meet the requirements for the rules. A meeting with CMS to determine interpretive guidance was requested to help states support their communities.

- A specially developed curriculum on dementia and intellectual abilities has been in use since 2014 and includes two-day workshops entitled "Dementia Capable Care of Adults with Intellectual Disabilities and Dementia." These efforts are contributing to the larger goals of workforce development.

- Persons providing care for those with intellectual disabilities are often long-term caregivers; these individuals should be included in the planning and execution of

the upcoming National Research Summit as they have expertise that may help inform recommendations.

- The ADRD Summit at NIH earlier this year was compelling and exciting for participants. Promoting new research avenues, building stronger collaborations, and increasing knowledge of ADRD issues are all likely outcomes of the summit, and the inclusion of multiple dementia types, not just Alzheimer's disease, is a critical step to making progress.

- In May 2016, the annual Frontotemporal Dementia (FTD) caregiver conference and board meeting will take place in Minneapolis. Collaboration among multiples stakeholders and across dementia types remains critically important.

- Investing in caregiver supports has the potential to improve outcomes for persons with dementia and reduce health care costs. HHS should fully engage with and support the upcoming caregiver summit in order to fully realize the planned outcomes and successes.

Research Summit on Care and Services Update

The National Research Summit on Care and Services for Persons with Dementia, Family Members, and Caregivers steering committee co-chairs, Laura Gitlin and Katie Maslow, presented an update on the planning for the two-day summit.

- The goal of the summit is to accelerate the development, evaluation, translation, implementation, and scaling up of strategies to improve quality of care and outcomes across settings, including quality of life and the lived experience of persons with dementia, family members, and caregivers.

- Summit themes include: health disparities, etiologies and disease stages, and diversity. The diversity theme captures care and services in diverse environments (e.g., home, community, care facility) and among diverse populations (racial/ethnic minorities, those with lower socioeconomic status, persons with low health literacy).

- The immediate next step in planning is to identify the expected outcomes from the summit. Several possible outcomes have been drafted and are under consideration by steering committee members. The draft outcomes will be shared with Council members at a later date. Outcomes under consideration are:
  - o Identification of gaps in research on dementia care and services, including knowledge needs to support scaling up and widespread implementation of effective care strategies.
  - o Identification of novel methodologies for engaging persons with dementia and family members and measuring person-centered outcomes.

- o Recommended priorities for government and private sector funding for research on care and services for persons with dementia and their families.
  - o Recommended, evidence-based strategies for use by health and human service providers and organizations/agencies to improve delivery of dementia care and services.
  - o Identification of effective implementation strategies for moving proven dementia care and services from research to practice settings.

- As discussed in the January 2016 Council meeting, pre-summit activities are planned to help provide both a foundational understanding for the meeting and recommendations and resources for summit participants.

- The steering committee is actively working to refine and advance summit plans through weekly co-chair meetings and larger committee meetings every six weeks. Small working groups will address logistics, stakeholder engagement, and financial considerations.

- The steering committee is committed to transparency in the summit development process and will share information with the Council on an ongoing basis.

Discussion

- Council members were pleased and impressed by the work conducted thus far to develop the summit. Several expressed optimism about the summit outcomes and that the ADRD community will be able to create meaningful recommendations and next steps following the summit.

- Ensuring representation from a wide variety of ADRD-related groups will be important. Additionally, private industry will be represented, and will include pharmaceutical companies, as well as long-term care facilities and other groups.

- NIA is currently considering how to support or develop pre-summit activities that are linked to increasing or expanding knowledge. No decisions on any activities have been made yet.

- OWH has a committee looking at women's health and Alzheimer's disease; it is possible that this committee could be engaged as part of pre-summit efforts aimed at providing information.

- Summit organizers should bear in mind that health disparities related to sex, gender, and sexual orientation should be considered within the disparities framework.

- Gender-specific needs of caregivers was noted as an important consideration in avoiding a "one-size-fits-all" approach to caregiver support.

- Council members plan to engage staff at PCORI to determine if they have an interest in the topics being considered for summit development.

- Nomenclature research and discussions may be a suitable and important topic to include as a pre-summit activity.

- Many stakeholders have overlapping interests in the summit topics (health disparities, nomenclature); thus, this summit and other efforts could be an efficient and cost-effective approach to addressing issues by identifying the right stakeholders.

NINDS Alzheimer's Disease Related Dementias Summit

Dr. Walter Koroshetz described the NIH ADRD Summit 2016. Dr. Koroshetz briefly reviewed the different causes of dementia and their fundamental pathologies and presentations and highlighted several recommendations that emerged from the Summit.

- Following the 2013 Summit, 13 recommendations were produced, some of which resulted in NIH-funded research initiatives, including:
  - RFA-NS-16-019: Small Vessel Vascular Contributions to Cognitive Impairment and Dementia (VCID) Biomarkers Consortium: Coordinating Center (U24).
  - RFA-NS-16-020: Small Vessel Vascular Contributions to Cognitive Impairment and Dementia (VCID) Biomarkers Development Projects (UH2/UH3).
  - RFA-NS-16-021: Mechanistic Basis of Diffuse White Matter Disease in Vascular Contributions to Cognitive Impairment and Dementia (VCID) (R01).
  - RFA-NS-16-022: Biomarkers for the Lewy Body Dementias (U01).
  - RFA-NS-16-023: Center without Walls for the Identification and Validation of Molecular Mechanisms Contributing to Tau Pathogenesis and Associated Neurodegeneration in Frontotemporal Degeneration (U54).
  - PAR-15-349 (led by NIA, NINDS joined): Health Disparities and AD (R01).
  - RFA-AG-15-010: Interdisciplinary Research to Understand the Vascular Contributions to Alzheimer's Disease -- This project is underway as the M^{2}OVE-AD Consortium (NIA/NINDS collaboration).

- The 2016 Summit prioritized: presentation of a rationale for the research recommendations that arose from the 2013 meeting, discussion among expert participants, and solicitation of feedback from summit participants on future directions and planning.

- The summit generated prioritized recommendations focused on:
  - **Multiple etiology dementias**:
    - Improving diagnostic skills in the community.
    - Promoting basic and clinical research in interactions between dementia pathophysiologies.
    - Determining the role for screening for cognitive dysfunction.
    - Revisiting the nosology of cognitive impairment in late life.

  - **Non-governmental organizations**:
    - Catalyzing research through unique programs and partnerships (including those with non-governmental organizations).
    - Nomenclature standards when discussing dementia.

  - **Health disparities**:
    - Treatment and prevention strategies in health disparities.
    - Monitoring changes in ADRD disparities.
    - Assessment of disparities.
    - Community partnerships, recruitment, and retention.

  - **Lewy Body Dementia (LBD)**:
    - Establish longitudinal cohorts with common measures, culminating in autopsy studies.
    - Discover disease mechanisms through brain mapping and genetics.
    - Develop and validate biological and imaging biomarkers.
    - Model disease processes to develop potential symptomatic and disease modifying therapies.

  - **Frontotemporal Lobar Degeneration**:
    - Basic science: pathogenesis and toxicity.
    - Clinical science.

  - **Small vessel disease and Alzheimer's disease/vascular interactions**:
    - Basic mechanisms and experimental models.
    - Human-based studies.

Federal Workgroup Updates

Long-Term Services and Supports

William Spector, Rohini Khillan, Richard Hodes, Erin Long, Bruce Finke, and Jane Tilly shared updates from the LTSS workgroup.

- AHRQ is funding two projects related to health information technology in ADRD:

- o The University of Minnesota is in year three of research on remote sensory technology for caregivers. The study is still recruiting participants (60 of the planned 100 caregivers have been recruited) and will be completed in 2019. Outcomes include impact on caregiver stress, ability to provide care, and decreased health care utilization.
  - o The University of Wisconsin's "Elder Tree" tool is designed to support older adults with disabilities living alone, as well as caregivers, to increase access to services and reduce isolation or loneliness. Participants wear a device and are supported with: social networking, discussion groups, check-in services, expert advice (e.g., on falls, chronic disease), medication reminders, and other resources. 400 participants from three counties were included in the study, and there are efforts to expand the tool to other areas. Data analysis is underway, and the grant ends in June 2016.

- ASPE is developing a basis for quality standards in dementia care. There are many innovative models that have been created and implemented; however, there has yet to be a robust evaluation of these models. Step 1 of the process includes an environmental scan and stakeholder interviews/panels. Approximately 16 components of quality have been identified for evaluation. The project is expected to be completed in September 2016.

- Two grants funded by NIA serve as examples of work being conducted that is relevant to ADRD:
  - o 1R03AG050232-01A1: Inside the Black Box: Culture Change and Behavioral Outcomes in Dementia.
  - o 1R21AG050018-01A1: 02/01/2016 Long Distance Caregiving: Unique Challenges and Service Needs.

- NIA has issued several funding opportunity announcements (FOAs) through different funding mechanisms. In particular, non-R01 mechanisms were included to increase access for researchers to grant funding. The first FOAs relevant to LTSS were issued in September 2015, reviewed in March 2016, and will be funded soon:
  - o NIA/National Institute of Nursing Research (NINR): Research on Informal and Formal Caregiving for Alzheimer's Disease (R01) - PAR-15-348.
  - o NIA/NINR: Research on Informal and Formal Caregiving for Alzheimer's Disease (R21) - PAR-15-351.
  - o NIA/NINDS/NINR: Emerging Directions for Addressing Health Disparities in Alzheimer's Disease (R01) - PAR-15-349.
  - o NIA/NINDS/NINR: Emerging Directions for Addressing Health Disparities in Alzheimer's Disease (R03) - PAR-15-350.

- ACL's ADSSP has had several successes among its 18 participating states. Training and capacity building continues to progress among program grantees. The Cal MediConnect program, a partnership between the State of California and the Greater Los Angeles Alzheimer's Association, focuses on the dual-eligible

population. A new program in West Virginia, funded in September 2015, has funded mini grants for dementia-friendly communities, and is developing advisory committees.

- o ADSSP has an FOA open that was funded with an additional $1 million as part of efforts to expand dementia-capable communities in every state. As part of this FOA, new grantees are welcome to submit applications, and existing grantees can apply for funding to implement components of their programs that they would otherwise not have capacity or funding to do. Applications are due May 23 and mandatory letters of intent were due April 9.

- ACL's ADI-SSS is in its second year and includes 29 different organizations (states, small organizations, universities). Eleven programs were added in September 2015 and are beginning planning and execution.

- ACL will release an FOA to fund ten additional sites to target previously targeted sites with services for persons living alone in the community, caregivers, and individuals with moderate-to-severe, behavioral symptom management training, and supportive services for people with intellectual and developmental disabilities.

- IHS has implemented the VA's Resources for Enhancing Alzheimer's Caregiver Health model for caregiver support in tribal communities, and continues to make progress. Training is facilitated through the public health nursing program (through IHS) and through the ACL-funded Title VI aging network. The three-year program is approximately 50% complete and currently 29 communities have certified interventionists -- the goal is to reach 50 communities to connect caregivers to services using this model.

- ACL and IHS are partnering to develop a LTSS conference for tribes; similar meetings have been held every 3-4 years in the past. The next conference, to be held in the fall of 2016 in Minnesota, will have a specific focus on Alzheimer's disease, as dementia is driving much of the need for services in tribal communities.

- VA and ACL are supporting a webinar on May 5 to describe a non-institutional long-term care model entitled Mobile Adult Day Health Care. A mobile care team provides services at various locations, which helps to increase access to care for persons with dementia. This model relies on community partnerships to facilitate locations for the mobile team to engage with persons with dementia.

- The ACL Office of Long-Term Care Ombudsman (LTCO) Program has conducted several activities, including:
  - o Emergency Preparedness and Response: The National Ombudsman Resource Center (NORC) provided in-person training of State LTCO programs in April 2016 with an emphasis on building coalitions to address

emergency preparedness and response including lessons learned from pilots in Colorado, Alaska and Hawaii.

- o ACL staff continues to work with states regarding the implementation of the LTCO rule, which becomes effective on July 1, 2016. ACL/Administration on Aging's Regional Support Centers are incorporating LTCO Rule implementation by states into their 2016 annual reviews.
- o ACL and NORC provided in-person training (April 2016) and technical assistance on person-centered complaint processes, and health care decision-making including examples of supporting individuals living with dementia, building upon past NAPA training activities. These trainings are particularly important for individuals with dementia who may be living alone and/or not have caregiver support.

Clinical Services

Shari Ling, Bruce Finke, Jane Tilly shared updates from the Clinical Services workgroup.

- The VA's Geri-Scholars program has distributed 2,820 toolkits to its program participants, as well as to: VA rural clinics, community living centers, VA officials, and the general public. The toolkit covers 12 clinical topics, including dementia.

- In partnership with HRSA, VA is continuing work to create a unified Alzheimer's disease curriculum to train providers and health care team members. VA also shared a report summarizing the pilot programs for home and community-based services that contained dementia-related components. The final report will be released in the fall of 2016, and a major goal is to understand what quality services look like, how they are best measured, and what gaps exist.

- The National Quality Forum (NQF) performed an assessment of quality measurements in home and community-based care to understand what measures exist and where there are gaps. A final report, including recommendations, will be released in the fall of 2016.

- NQF is also reviewing quality measures related to neurology, which include ADRD measures. In April 2016, NQF endorsed Measure #2872 (Dementia-Cognitive Assessment) for trial use as an "e-measure." NQF also re-endorsed Measure #2111 (Antipsychotic Use in Persons with Dementia). Other dementia measures that have been approved for development include:
  - o 2091: Persistent indicators of dementia without a diagnosis -- long stay.
  - o 2092: Persistent indicators of dementia without a diagnosis -- short stay.
  - o 2111: Antipsychotic Use in Persons with Dementia.

  These measures are aimed at assessing and documenting cognitive impairment.

- The Health Care Innovation Awards have published the reports from round one online. The reports highlight costs, feasibility, and other factors. Two awardees were named in round two that are testing models related to dementia:
  - The Regents University of California, San Francisco -- high quality dementia care targeting caregivers, decision-making, medications, and functional monitoring.
  - The Johns Hopkins University -- a comprehensive care management program for people with ADRD designed to them remain in the community.

- In April 2016, CMS announced a five-year Comprehensive Primary Care Plus (CPC+) model. This model is not specific to dementia; however, it highlights persons with dementia as "high risk" for undesired and costly outcomes. CPC+ includes higher care management fee structures, which recognizes that high-risk individuals can require more care. Currently, CMS is determining in which regions CPC+ will be implemented. This multi-payer model will run for five years and will include over 20,000 clinicians.

- Continued progress is being made reducing antipsychotic use among residents of long-term care facilities. Results vary by region/site, but the trends are moving in a favorable direction and some areas have seen greater than 25% reduction since 2011.
  - As antipsychotic use decreases, CMS is capturing other practices to see what, if any, replacement agents are being used to address the behavioral issues that antipsychotic agents were originally addressing. Work is still being done to determine the best approach to assess to what patient-centered care interventions (pharmacologic and non-pharmacologic) are being provided in this context.

- Nursing Home Compare (https://www.medicare.gov/nursinghomecompare), a publicly available resource on the Medicare website, recently posted six new quality measures, including a new long-stay measure on the percentage of patients who received an anti-anxiety or hypnotic medication. This measure complements the existing measure on antipsychotic use.

- As part of larger goals in creating patient-centered care, CMS can now collect data on staffing of long-term care facilities, so that the quality and type of staff can be considered and not simply the number of staff at a facility. This information collection is authorized by the Improving Medicare Post-Acute Care Transformation Act.

- A Civil Monetary Penalty (CMP) can be imposed on an institution for certain noncompliance issues. Qualified entities (e.g., consumer advocacy groups, private contractors) can request CMP-obtained funds to implement quality improvement work. Improvements through CMP funds can include: innovative person-centered care models, staff training and education, developing spaces for long-term care residents, and providing resources directly to dementia patients.

- In March 2016, CMS launched a new phase of a dual-office demonstration project to provide clinicians with payments for multidisciplinary long-term care planning.

- In February 2016, CMS issued a final rule on home health for Medicaid that addresses several areas, including allowing that supplies and devices used in home health care can be used anywhere "normal life activities" take place. Also, the required documentation of encounters between a clinician and a Medicaid beneficiary now includes telehealth-facilitated encounters.

- IHS is facilitating an ongoing web-based clinical rounds series to train clinicians in fundamentals of dementia (diagnosis and management) and address workforce issues.

- The Medicaid Indian Health Payment Policy was updated in February 2016. When services are provided to IHS/tribal beneficiaries in an Indian health or tribal setting, CMS pays 100% of cost. This new payment policy now extends to non-tribal/IHS service providers, making services more accessible for elderly persons or those with access challenges.

- ACL supports the Brain Health Resource, which is designed to educate older persons and caregivers about brain health. In April 2016, ACL, NIA, and CDC updated Brain Health Resources and includes Spanish-language materials (translated materials were facilitated by the Alzheimer's Association). These resources include information on medications, including a list of medications elderly people should and should not take, and recommendations for communicating with providers.

- CMS is part of a multi-stakeholder (federal and non-federal participants) workgroup on caregiver efforts. The workgroup meetings are held quarterly in Washington, DC. Telephone call-in lines are available, and the next meeting is May 11, 2016 from 9am-11am ET. RSVPs can be sent to Crystal.Barnes@cms.hhs.gov.

- HHS is looking at ADRD dementia diagnostic codes and practices to better understand administrative data analysis and data reporting. Many codes can capture interactions between a person with dementia and their provider, and there is some overlap in administrative areas. Increasing the alignment and consistency in coding will improve surveillance and tracking of ADRD, including determining prevalence estimates.

- CMS has several tools available to track data (including data on ADRD).
  - The CMS Medicare Chronic Disease Dashboard has conditions by state and includes Alzheimer's disease as well as other forms of dementia. These data also include comorbidities.

- In March, CMS released a new interactive tool https://data.cms.gov/mapping-medicare-disparities that maps geographic disparities among the Medicare population. Users can view geographical differences in disparities to see prevalence at the state and county levels, as well as average costs, hospitalization rates, and other factors associated with a particular diagnosis. Re-hospitalization rates are not yet captured, but may be in the future.

These tools use mature Medicare claims, which will underestimate the true prevalence of ADRD in the community.

Research

Richard Hodes shared updates from the Research workgroup.

- The FY2016 budget and its potential implications were discussed by the Council members. NIH received an additional $32 billion for FY2016. This funding will provide much-needed funds to address many issues related to aging research, including Alzheimer's disease.

- Alzheimer's disease funding received a fairly unprecedented increase of $350 million, a significant increase compared to funding increases for other conditions, and represents a major contribution to the overall funding increase for NIA. An important outcome of the increased federal funding for Alzheimer's disease is the opportunity to fund a greater percentage of research programs.

- In October 2015, ten FOAs were released in the event that additional funds were made available in the FY2016 budget. Nearly 300 applications have been received for the first two FOA submission deadlines. These applications do not include those focused on ADRD research through the typical investigator-initiated routes.

- NINDS has started to release FOAs related to ADRD and NIA is extending support through NIH Institutes for additional relevant projects.

- In general, the rates of successful NIH funding applications are higher for ADRD submissions (22% versus 9% for general submissions less than $500,000), so there are greater opportunities to fund this work.

- One overarching goal is to engage and retain researchers, as well as reach a point at which funding rates for new investigators are similar to those that experienced researchers would experience upon submission.

- Planning for FY2017 has begun, and several initiatives have been announced, including:
  - Alzheimer's Disease Clinical Trials Consortium.

- o Impact of Aging in Human Cell Models of Alzheimer's Disease.
  - o Neurodegenerative Disease Biorepository.
  - o From Association to Function in the Alzheimer's Disease Post-Genomics Era.
  - o Technology to Assess Everyday Functions.

- Research, Condition, and Disease Categorization reports include the FY2015 funding for Alzheimer's disease +ADRD combined and separated, and will continue to track Alzheimer's disease and ADRD separately. Also, the International Alzheimer's Disease Research Portfolio (IADRP) continues to track details of initiatives and awards, both in the public and private sector, which helps identify progress and gaps in research efforts, and can inform the upcoming bypass budget.

- IADRP currently includes 35 public, private, and international funding organizations in ten countries (United States, Australia, Brazil, Canada, Czech Republic, France, Italy, the Netherlands, Poland and the United Kingdom). The portfolio captures over 7,000 unique projects conducted by over 4,000 researchers across over 1,000 institutions representing ~$4.7 billion in basic, translational, and health services research funding. As this portfolio expands, research coordination efforts can be more efficient and better reflect the true level and scope of ADRD research being conducted.

- The FY2018 bypass budget is under development. NIH released a request for information to gain input; information is also being collected from scientific and advocacy groups at conferences and other venues. Additionally, the 2016 NIH ADRD Summit outputs will help to inform the bypass budget. The FY2018 bypass budget is based on the actual FY2016 budget; however, assumptions need to be made about FY2017 funding levels in order to forecast the FY2018 budget. The funding requests made through the bypass budge allow for an acceleration of activity towards milestones should increased funding become available.

- NIA and NINDS launched the Molecular Mechanisms of the Vascular Etiology of Alzheimer's Consortium (M^2OVE-AD) in March 2016. This initiative specifically targets the contributions of vascular factors to dementia. This work includes five projects and is funded for five years at $30 million.

- A new publication was released based on the Framingham Heart Study. Data show that the risk of dementia in study participants declined over the past several decades. This is possibly due to better care of vascular and other contributory factors, but data are not conclusive.

- The VA Research Office recently updated language in its specialty Alzheimer's Disease Request for Applications for biomedical laboratory or clinical research. The revised wording now includes FTD, LBD, and/or vascular contributions, in

addition to Alzheimer's disease. The VA Research Office is also partnering with NIA to enhance collaborative funding opportunities and improve data sharing, clinical trial recruitment, and the optimization of resources.

National Plan Status

- ASPE is currently receiving updates from federal partners, and the request has been extended to several new agencies who are doing work relevant to ADRD. The Consumer Financial Protection Board conducts work on elder abuse and elder justice, and the Social Security Administration has some programs for people with cognitive impairment and their caregivers. Non-federal stakeholders, including Council members, have also been contacted to provide input. Final recommendations from the Council will be included in an appendix, and the Plan is scheduled to be released in July 2016.

International Work Update

Dr. Petersen shared highlights of ADRD-related developments outside of the United States.

- The World Dementia Council was created following the G8 summit in 2014. British stakeholders formed the Council and supported it until 2016. George Vradenberg, Harry Johns, and Dr. Petersen all serve on the Council. The Council will meet in July 2016 at the World Alzheimer's Association International Conference in Toronto, Canada. Thus far, the World Dementia Council has created four global teams focusing on:
  - o Integrated development (financial and regulatory aspects of dementia).
  - o Research, open science, and big data.
  - o Care (led by Harry Johns).
  - o Risk reduction (led by Ron Petersen).

- It was noted that international stakeholders often get the impression that the United States solely focuses on Alzheimer's disease and may not be moving forward in a way that is inclusive of all dementias.

- The Lancet journal has commissioned a report on Alzheimer's disease that is scheduled for publication in 2017. The publication will review the literature and provide some clear direction/way forward for the field.

Concluding Remarks

Chair Dr. Ronald Petersen thanked the members.

The next Advisory Council meeting will be announced at a later date.

The meeting adjourned at 4:07 p.m.

Minutes submitted by Rohini Khillan (ASPE).
All presentation handouts are available at http://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings.