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

Bethesda, MD

December 2, 2013

Advisory Council Members in Attendance

- *Non-Federal Members Present*: Ronald Petersen (Chair), Laurel Coleman (by telephone), Yanira Cruz (by telephone), David Hoffman, Harry Johns, Jennifer Manly, Helen Matheny, Dennis Moore, David Hyde Pierce, Laura Trejo (by telephone), George Vradenburg, and Geraldine Woolfolk

- *Federal Members Present*: Lynda Anderson (Centers for Disease Control and Prevention), Bruce Finke (Indian Health Service [IHS]), Richard Hodes (National Institutes of Health [NIH]), Shari Ling (Centers for Medicare & Medicaid Services [CMS]), Donald Moulds (Office of the Assistant Secretary for Planning and Evaluation [ASPE]), Anthony Pacifico (U.S. Department of Defense), Marianne Shaughnessy (U.S. Department of Veterans Affairs [VA]), William Spector (Agency for Healthcare Research and Quality), Jane Tilly (Administration for Community Living [ACL]), and Joan Weiss (Health Resources and Services Administration [HRSA])

- *Quorum present?* Yes

- *Advisory Council Designated Federal Officer*: Helen Lamont (ASPE)

General Proceedings

At 9:36 a.m., Chair Dr. Ronald Petersen called the meeting to order.

Dr. Petersen introduced himself and welcomed meeting participants, including reappointed and new council members. Advisory Council members then introduced themselves.

Dr. Peterson provided an overview of the agenda. After updates from federal subcommittees, the council would discuss the issue of "big data." During the afternoon, the council would discuss policy issues and make recommendations for the revision of the 2014 National Plan to Address Alzheimer's Disease (national plan).

Dr. Petersen acknowledged and thanked the NIH for hosting the meeting, which was rescheduled from October due to the Federal Government shutdown.

Update on Federal Activities

Dr. Richard Hodes provided an update on research to address Alzheimer's disease (AD).

- One area of scientific progress focuses on genetics and identifying risk factors for AD. Dr. Hodes provided a list of risk factor genes for AD, categorized by topics. Identifying 11 new genes has been the result of international research efforts.

- In 2012, $50 million in funding was set aside for AD. Of that amount, $25 million was targeted for large-scale sequencing. NIH's Alzheimer's Disease Sequencing Project has pursued efforts on schedule and recently announced that the first batch of genome sequence data is now available. This research can help identify genetic roots for AD and therefore targets for interventions and treatments.

- Additional funding has been made available for 2013. Requests for applications (RFAs) have been released for various studies and will support interdisciplinary and integrative approaches to identify preclinical validation of novel targets for AD treatment and prevention.

- One RFA will fund three targeted studies. One is a systems approach to targeting innate immunity to AD. A second is pathway discovery, validation, and compound identification for AD. A third is looking at an integrative biology approach to the complexity of AD. Researchers will share their data and work as part of a network.

- Another RFA released in 2013 will include phase 2 and phase 3 clinical trials to test pharmacologic and nonpharmacologic interventions. These studies will focus on prevention and will include asymptomatic individuals at high risk for AD. The hope is that these studies can help families in need by identifying possible causative genetic mutations, allowing for treatment before the manifestation of symptoms.

- Prevention trials funded are an APOE4 trial and a trial for stimulating the innate immune system to prevent AD.

- A 2013 RFA for phase 1 clinical trials will provide support for first-in-human studies for promising AD therapeutics. These studies will evaluate the metabolic and pharmacologic actions of drugs, including biologics in humans.

- The National Institute of Neurological Disorders and Stroke sponsored a meeting in May 2013 on AD-related dementias. The conference included a 2-day session that allowed for comments from the general public as well as a closed planning session. More than 500 individuals participated. Although priorities and timelines

for AD and AD-related dementias differ, several recommendations apply to both areas: fundamental research to fill critical knowledge gaps, training, improved diagnostics, optimized repositories, health disparities, and effective interventions.

- The New York Academy of Sciences, in partnership with the National Institute on Aging (NIA), hosted a conference titled "Alzheimer's Disease Summit: The Path to 2025" in November 2013. Emphasizing the importance of public and private partnerships, this meeting brought together industry, academic, and government stakeholders to discuss how to prevent and effectively treat AD by 2015.

- The United Kingdom (U.K.) will host its first G8 dementia summit on December 11, 2013. Canada, France, Germany, Italy, Japan, Russia, and the United States (U.S.) will also be participating.

- The next AD research summit will be held February 9-11, 2015, at NIH.

Discussion following Dr. Hodes' presentation included the following comment:

- Delays in funding have affected NIH milestones in AD research. It is unlikely that scheduled milestones can be carried out under the current funding level.

Dr. Shari Ling provided an overview of CMS activities.

- In February 2013 CMS launched the Patient and Family Engagement Campaign (PFEC), which emphasizes the needs of patients and caregivers. Five of the 25 quality improvement organizations involved are targeting the clinical diagnosis of AD. Interventions include providing assistance using Web-based tools, improving quality of life through communication streams, improving the access and use of resources by patients and caregivers, addressing health literacy, and improving self-management and empowerment. All projects will conclude in July 2014, and evaluation of the effectiveness will conclude in July 2015. Dr. Ling will provide more details on PFEC projects at the next council meeting.

- The Center for Medicare and Medicaid Innovation Health Care Innovation Projects includes six dementia-relevant projects. These projects are different from standard research projects in that awardees must submit data on processes and clinical service use, determining what is working and what processes need to be refined to build on quality. The projects must focus on both care and costs. Dr. Ling will provide more details in subsequent meetings on proposals that may be addressing special populations, especially testing care models that are effective for those with dementia.

- Round 2 proposal categories of the Health Care Innovation awards support organizations in four areas: (1) models to reduce Medicare, Medicaid, or Children's Health Insurance Program costs in outpatient or post-acute settings; (2) models that improve care for populations with special needs; (3) models that

improve the health of populations defined geographically, clinically, or by socioeconomic class; and (4) models that test approaches for specific types of providers to transform their financial and clinical models.

- CMS awarded a contract to the National Quality Forum (NQF) to develop a conceptual framework for measuring dementia care quality. NQF will use a multi-stakeholder process to facilitate input from the public. NQF has posted the profiles of those who will be serving on the stakeholder panel on its Web site.

Dr. Joan Weiss provided an update on HRSA activities.

- In 2012, HRSA provided $2 million for continuing education (CE) for the health care workforce. HRSA's 45 Geriatric Education Centers Program partnered with 376 different organizations to provide more than 600 CE programs on AD to more than 30,000 health care professionals representing 25 health professions.

- In collaboration with ASPE, HRSA released a CE course on AD in September 2013, which is available on the Medscape Web site. In the first 2 weeks approximately 18,000 health care practitioners completed the course.

Discussion following Dr. Ling's and Dr. Weiss's presentations included the following comments:

- Medscape markets the CE course for HRSA using the Medscape database of health care providers who need CEs. HRSA also sent the information out to its own grantees and HRSA's accrediting bodies. Medscape will provide periodic updates on course usage that can be shared with the council at a future meeting.

- CMS will be publishing a timeline for scaling and spreading efforts for each of its Health Care Innovation small-scale projects. Between 2015 and 2016, each model in the first round will specify whether it was successful. An assessment period will then follow. Dr. Ling will report the overall timeline to the council at its next meeting.

Dr. Jane Tilly provided an update on the activities of ACL.

- In partnership with CMS, ACL is working to improve dementia care in nursing homes. The National Nursing Home Quality Care Collaborative focuses on providing the highest quality care for nursing home residents, including those with dementia. The collaborative is structured in a way that allows for learning processes to be shared and for nursing homes to practice what they learn.

- Some of the achievements of the partnerships include reducing the use of antipsychotic drugs and providing education through the CMS program Hand in Hand, which educates nurse aides on caring for those with dementia and preventing abuse.

- ACL's Ombudsman Program allows an ombudsman to act on behalf of patients who are unable to communicate, to ensure they are receiving quality care.

- In October 2013, IHS professionals received training on REACH VA. IHS and the VA are piloting the program at six Indian Country sites to assess the best approach to implementing that model across the IHS system.

- ACL issued a new report on closed Alzheimer's Disease Supportive Services Program (ADSSP) grants; the report is a living document and as ACL gets more long-term grants, it will focus more on translating evidence-based programs.

- Four states have grants to create dementia-capable service systems, which include training staff to recognize cognitive impairment and looking at quality measures for home care-based services.

- Under ADSSP, five more states were awarded grants to create dementia-capable home care-based systems, with a lead state agency for AD. These grants also fund states to test innovative programs.

- ACL granted the Alzheimer's Association close to $1 million per year for 5 years to continue providing a 24/7 call center that provides advice and counseling across the country in over 100 languages.

- ACL and the NIA are conducting webinars on the latest research on AD, intellectual disabilities and dementia, the needs of diverse populations, young onset of dementia, and advanced stages of the disease.

- IHS nursing leadership was trained on pathways to improve the care system for those with dementia.

- The National Center for Health Statistics released a data brief, *Dementia Special Care Units in Residential Care Communities: United States, 2010.* The report compares residential care communities with and without dementia special-care units. It is available at http://www.cdc.gov/nchs/nsrcf/nsrcf_products.htm.

Discussion following Dr. Tilly's presentation included the following comments:

- States that have competed for dementia-capability grants can serve as a laboratory for the country, and successful states can be models.

- Funding limitations can impact the sustainability of some interventions, requiring the need for sharing successes and raising the quality of services at a state level.

- We need to measure the experience of patients and caregivers for dementia-capable services and include that as part of the metrics for evaluating success (i.e., are measures making a difference in lives?).

- A requirement of the ADSSP state dementia-capability grants is that they must address how they will serve racial and ethnic minorities and report semiannually on progress. If goals are not being met, ACL consults with the grantee. The racial and ethnic identity of participants are also tracked.

- Measuring success with people with dementia rather than what is provided is a challenge. The NQF is one route that might determine how well people with dementia are served, Another channel is through the four original states with dementia-capability grants. The data comes from the local level such as agencies on aging and flows up to the states, and the states condense it and then report it to ACL. ACL is looking at how that existing system could be used to measure progress more effectively.

- Dr. Coleman commended ACL in doing work that makes a difference, especially in reaching underserved populations. She noted that the agency has a history of cross-state collaboration.

Dr. Petersen thanked all the federal agency speakers for their presentations.

Presentations on Big Data

Unlocking Global Collaboration to Accelerate Innovation for Alzheimer's Disease and Dementia

Dr. Zaven Khachaturian, of the Campaign to Prevent Alzheimer's Disease by 2020, presented ideas and options for an action plan for a multinational initiative to accelerate the diagnosis and treatment for chronic brain disorders such as AD and dementia.

- The report of the Organisation for Economic Co-operation and Development (OECD)-Oxford Conference of June 20-21, 2013, provides the rationale for the upcoming G8 summit on dementia, and the October 2013 editorial from Alzheimer's and Dementia (both available at the meeting) provides an update on the current state of what is being done with sharing big data. The editorial document has a supplement identifying 150 ongoing databases and other resources related to dementia and aging.

- The upcoming G8 summit on dementia has several goals:

  o Adopt a bold, decade-long strategic goal that will serve as a unifying vision to generate greater global collaboration and stimulate innovation. An important underlying concept is that a delay of 5 years in disabling

symptoms will cut the prevalence and cost by 50 percent. Metrics are key. Reducing the cost of care is the ultimate metric needed to measure success.

- o Expand efforts to support existing databases, longitudinal studies, and collaborative research networks to facilitate multinational research.

- o Develop a framework for multinational public policies for collaborative research and development capabilities that includes innovations in biologic measures, technology, and computational algorithms to detect the earliest and smallest changes in performance and functioning to predict people at elevated risk for AD.

- o Establish the framework for a governance structure to oversee AD prevention and treatment.

- o Develop a structure for global financing and sustainability. Most longitudinal studies are funded through grants that can be cancelled, or investigators may no longer be available. We need different models of funding, such as public-private partnerships.

- Currently there is no harmonization of national efforts, so the overall goal is to formulate the framework to harmonize public policies to accelerate multinational research and development on chronic brain disorders.

- AD is the appropriate model for accelerating innovations regarding diagnosis and treatment of other chronic brain disorders. If we solve the problem of AD, that solution can be used as a prototype for multiple chronic conditions.

- The cost of care is the ultimate metric for measuring success. The number of people with the disease is increasing because of increasing longevity, and the cost of care is increasing, so a modest delay can have a huge impact on total cost.

- A number of AD programs to validate assessment tools and create an infrastructure to support longitudinal studies began in 1977 at NIH. A consortium was established to create a national data bank. Since 2000 the direction has changed to research on the earlier stages of AD, so now we need new kinds of resources and infrastructure.

- The world of public health and epidemiology has historically not communicated well with the world of clinical research and basic biology, and we need the infrastructure to connect the two. Big data can help build the infrastructure to do that.

- We need more large-scale prospective studies to test genetic marker research, to identify who is at risk for AD, because identifying a gene or genes involved could reduce the number of people affected. Commercial companies will not invest in the kind of longitudinal studies needed, which could take 20-30 years. Technology can shorten the duration and cost of clinical trials, so investment in infrastructure is essential.

- The foundation for computational algorithms already exists and needs to be applied internationally, with millions of people recruited for a clinical trial.

- Currently longitudinal studies are funded through grants or contracts that have limited duration. Another barrier is that a grantee dies. Because of these problems, funding for AD should not be funded through NIH research funds, but through a new mechanism, perhaps a public-private partnership, the World Bank, or the International Monetary Fund.

- The new infrastructure will need an administrative structure, a scientific advisory group, a board of governors, and various sponsors and providers to build on the efforts already in place.

Discussion following Dr. Khachaturian's presentation included the following comments:

- A goal at the G8 summit should be to set an economic target for reducing prevalence and cost. Once you reduce prevalence you can reduce costs. The ultimate audience at the G8 summit will be policymakers and industry leaders that make decisions. The emphasis will be to let them see the necessity of streamlining collaborative research across countries.

- Other countries are considering these issues. For example, they are being discussed now on the floor of the U.K. Parliament as well as in France.

- An important focus now is the possibility of using big data to identify the root cause of disease early and to run clinical trials more quickly in order to significantly lower costs. The result conceivably could be to increase the pace of discovering novel treatments. A number of G8 countries are interested in this.

- Using data from electronic health records (EHRs) is a high priority. Challenges in that area are the level of access, the quality of the data, protecting privacy, and getting informed consent. We are at a point now of determining the best way to collect such data.

- Health services research as an entity is an orphan, not having a home for sustained support. Having a database could create infrastructure for doing more systematic demonstration projects on models of care, or combination models. To do systematic clinical trials, very large numbers are needed because culture and regional differences must be taken into account. With the capability of large

populations, groups could be fragmented to improve models and create research programs.

Alzheimer's Disease: A Rapid-Learning System

Lynn Etheredge, director of the Rapid Learning Project, George Washington University, presented a rapid learning health system project to accelerate the process of learning.

- Currently we have the challenge of a complex, disorganized heath care system. Many therapies are used that are not very effective. Health information technology (HIT) has great potential for this sector but is underused.

- Another current challenge is our limited way of learning. We are focused on randomized controlled trials, have limited numbers of patients and researchers, and a system that is slow to learn and use best practices. The time from awarding a grant to publishing results takes 7-10 years; during that interval data can become irrelevant.

- HIT, EHRs, big data, and learning networks are changing aspects of health care. Uses of data at NIH, the VA, the Food and Drug Administration (FDA), and CMS are examples.

- Cancer research provides numerous examples of how research is making faster progress with the use of large-scale databases. Advantages have been seen in both the cost and the speed of research. Even so, 97 percent of the patient data on response to cancer treatment and progression of disease is lost.

- Currently, 61 percent of U.S. oncology practices have advanced electronic medical record systems. Another 15 percent are planning to implement such a system in the next 6 months.

- The FDA is also beginning to use a new model of rapid learning using large databases. The FDA is considering reducing or eliminating the requirement for phase 3 clinical trials, which are very expensive and time consuming.

- We need to implement a rapid learning system that includes everyone and can build a production process to organize a strategy for the rollout of projects.

- The rapid-learning model is being implemented in the CancerLinQ database of the American Society of Clinical Oncologists and in the $10 billion CMS rollout of best practices.

- The following are suggestions to create a rapid-learning system for AD:

  o Build an international data system learning network with large research databases to begin to capture key data. Data sharing has a high pay-back

for institutions because, for example, if 100 institutions share 1,000 cases each, each institution has access to the resulting 100,000 cases.

- o Build the data system as part of a national EHR-HIT strategy, including a downloadable EHR app for patients with AD and dementia. Make it a federal requirement that all U.S. Department of Health and Human Services (HHS)-supported EHRs accept and work with this app.

- o Develop rollout models of best practices for AD. Use CMS's innovation authorities and $10 billion to roll these out nationally for Medicare and Medicaid patients. Include specific timelines and workplans with clear milestones.

Discussion following Mr. Etheredge's presentation included the following comments:

- Larger databases normally do a good job at removing identifiable data. A best practice would be to ensure large datasets do not leave institutions. A distributed database system can protect personal data by having levels of approval.

- Researchers and clinical specialists need to define and agree on what data are needed before an app can be designed.

- Using apps can more rapidly collect data but would need to be a voluntary process and address privacy issues. Determinations must be made about what data are obtained and who gets to use the data.

- The timeline for creation of an app can be fairly short, with a lot of people working on it. It needs some federal requirements to accelerate the system.

- The U.S. does not have a single health system, a fact that creates challenges for coming up with a useful way to use EHRs meaningfully. Some health systems, such as Kaiser, are able to use their existing system.

- The technical problems of developing an app are relatively trivial compared to defining the data desired and persuading people to consent to its use. These are areas in which the council should move forward because they represent a major opportunity.

Global Alzheimer's Association Interactive Network (GAAIN): Transforming the Way Researchers Approach the Study of Alzheimer's Disease

Dr. Arthur Toga presented information on sharing data sets.

- We need to homogenize data sets and change how we collect data; collecting data that are not useful will not get us very far. One solution is to create a global

network that coordinates data from around the world and manages those data for use by any investigator.

- Sharing large data sets is difficult and presents three problems: storage (data growth is outpacing storage), bandwidth (it is no longer feasible to send all data to a researcher), and analysis (resources are needed to analyze data across domains). Image data, in particular, expands considerably; 22 megabytes (MB) of data for a small scan produces 420 MB when it is analyzed. A mechanism for sharing data from large data sets is needed.

- Centralized databases do not provide a solution for aggregating data from around the world. It is best to keep data at a place that allows access to it or have a link to a global infrastructure for interlinked repositories. This requires supercomputers, fast networks, and privacy protection.

- GAAIN provides a hub for aggregating accounts; users apply to partnering consortiums via GAAIN, which is a system with established access limitations.

- The GAAIN Web site has a dashboard to personalize what researchers need and provides data based on levels of authority. Aggregate data can be provided based on gender, ethnicity, and other searchable categories and filters.

- When sharing data, common semantics for labeling and categorizing data from different databases is essential. This points to the need for a mediator to translate different labeling nomenclature.

Discussion following Dr. Toga's presentation included the following comments:

- Besides their use in genetics, another advantage of using large sample sizes is in determining the relative utility of genetics as compared to other risk factors for AD. For example, the variable of years of education would not mean the same thing in different countries.

- All databases collect different data, so we need a system to rate levels of similarity when researchers are collecting it. A metric is needed to indicate which data have high confidence of similarity.

- Another challenge to having repositories of data is that some researchers do not want to share data because they want to reserve data for their own publication uses. A solution to this challenge may be the value added to the investigator by participating in a network, and, perhaps, collaborating in a joint study that would not otherwise have been open to him or her.

- Public health has some experience with open datasets that may be useful to consider.

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- Users of the database would be both basic and clinical researchers. At this point, the database would contain only data collected for research purposes.

- The AD Neuroimaging Initiative (ADNI) is an example of the value of sharing. It has produced much more science from people who use the data who were not originally funded than from those who were originally funded in the ADNI project.

Updates

Long-Term Care Commission

Mr. Vradenburg provided an update on the Long-Term Care Commission (LTCC).

- The LTCC was created to design an integrated and comprehensive long-term support and services (LTSS) plan for the county. Within a 3-month period it had several public hearings and meetings and issued its report at the end of September 2013.

- A clear finding was that the demand for LTSS will grow as the nation ages. In addition, our ability to serve those under age 65 with disabilities has been largely forgotten in national policies. Disabilities include developmental, intellectual, and those resulting from an accident. Only 55-56 percent of those who receive LTSS in the U.S. are over age 65.

- The LTCC noted that many support services are not health care oriented but relate to performing daily activities of living. Reforming the acute care system receives a great deal of focus, but the LTSS system is fragmented and not the object of examination and reform. We need a system that is more patient and family-centric with reimbursement based on services, not provider or setting.

- The nation needs a "one-stop shop" for families to access services. Families currently enter systems through different channels, and a central location would help with increasing access. We also need to incentivize home-based care rather than institutional care.

- Regarding service delivery, the LTCC recommended the following:

  o Accelerate the development of quality measures for home and community-based services and make those measures available to consumers.

  o Reform the payment system to have payment based on service rather than setting.

- o Integrate care, so that the family caregiver or someone associated with the care recipient is included in the team that is planning care for the purposes of Medicare reimbursement.

- o Develop a uniform assessment tool to produce a single care plan across various care settings and provider groups.

- o Urge additional caregiver intervention programs that include costs.

- Regarding the paid workforce, the LTCC encouraged revising the scope of practice to permit delegation to direct-care workers, revising the criminal background checks, enhancing career advancement, integrating direct-care workers into the care teams, and establishing standards and certification for home care workers.

- Financing was a troubling area to the members of the commission. The long-term care insurance industry is anemic because the policies are complex, many families do not think they need insurance, and the industry has been adversely affected by the low interest rate environment.

- The LTCC urged Medicare to eliminate the 3-day prior hospitalization requirement and reconsider the homebound requirement for home health care services.

- The LTCC recommended modifying the current 529 investment plans to allow funds to be invested not just for education but also for disability costs.

- A national advisory committee on LTSS was recommended, beginning with a conference on aging in 2015.

Discussion following Dr. Vandenburg's presentation included the following comments:

- The LTCC report was submitted to the majority and minority leaders in the House of Representatives and the Senate, and to the White House. There is no requirement for Congress to act on these recommendations.

- A number of organizations, think tanks, policy advisory groups, and advocacy groups support action in this area.

New York Academy of Sciences Alzheimer's Disease Summit: the Path to 2025 Meeting

Mr. Vradenburg reported on the November 6-7, 2013 meeting.

- The Global CEO Initiative, comprising a coalition of 12 large private-sector organizations, joined with the New York Academy of Sciences and NIA to hold this meeting as a follow-on to the May research summit at NIH.

- A final report from the November meeting will be available soon and will include a number of action items and recommendations, including the following: (1) infrastructure changes, such as global registries, shortened clinical trials, and data sharing mechanisms; (2) a series of financial workshops to take place in the next year to identify public and private-sector financing; and (3) using technology and big data by setting up technology groups and workshops on big data applications.

- In the next year, a series of workshops will take place on big data applications and the appropriateness of using new technology in scientific publishing.

G8 Summit

Dr. Moulds presented an overview of the upcoming G8 summit.

- The U.K. will host a G8 summit in London, December 10-11, 2013, with a special focus on addressing dementia. Countries not included in the G8 are also participating.

- The summit will identify high-level goals the G8 countries can share. It will include a series of panels and an open discussion among health ministries on, but not limited to, caregiving, prevention, innovation, and financing.

Discussion following Dr. Moulds' presentation included the following comments:

- The Global CEO Initiative will have a meeting the morning of December 12 to try to identify goals and develop action plans for 2014.

- The G8 summit is expected to do a lot more around public health interventions to defer or reduce dementia than the Global CEO Initiative did earlier this year.

- A majority of G8 countries have strategies in place regarding AD. The presence of the head of the World Health Organization and the number-two person at OECD at the conference may help facilitate enough endorsement from a broader set of players to continue the momentum of AD initiatives. The council felt it would be vital for the U.S. to keep the momentum going and continue to push other countries to continue this dialogue.

Panel on Advanced Dementia

Dr. Coleman presented an update from the Institute of Medicine (IOM) Panel on Advanced Dementia.

- Dr. Coleman and Dr. Suzanne Mitchell of Harvard co-chair the panel, which consists of experts on advanced dementia. The IOM is convening three meetings of the panel.

- The panel is charged with: (1) identifying gaps in research on dementia and how to better care for a growing and aging population; (2) looking at innovation, care practices, translational efforts, and putting research into practice; and (3) looking at policy issues that can support or deter efforts.

- The first meeting in January 2014 is focused on research. The findings of the panel will be available to the council for integration into the national plan.

<u>*Health Affairs*</u> *Issue*

- *Health Affairs* is a policy journal. A call for articles, due in December 2013, was put out for a themed issue on dementia.

- This issue on dementia will likely be published in April 2014 and will present "soup to nuts" information on AD. There are high expectations for impact, given the comprehensiveness of the issue. It represents another step in the process of having the world understand the impact of dementia.

Discussion of 2014 Recommendations and Timeline

- The Secretary of HHS is ultimately charged by law with writing the national plan and updating it annually. The council's primary function is to advise her on the plan and the updates.

- Last year around 39 recommendations were put forth, which may have been too many, but it is important not to overlook important issues.

- The council's three subcommittees will meet in the next few weeks and report back to the council at its February 2014 meeting. Including milestones and priorities in the plan is a challenge because of the time constraints.

Other Business

- Dr. Moulds announced he is leaving federal service by the end of the year and commended the council's chair, subcommittees, and participants for their great work. Dr. Petersen acknowledged Dr. Mould's leadership on the council and for serving as a liaison with HHS.

- On the basis of the presentations on big data, consideration will be given to developing an ad hoc committee to look at ethical issues across the issues of research, clinical care, and LTSS.

Public Input

The public comments portion of the meeting was moderated by Dr. Lamont.

Twelve members of the public presented testimony, including persons living in the early stages of AD; family members and caregivers of persons with AD; and representatives from the Alliance for Aging Research, the Alzheimer's Foundation of America (AFA), the Association for Frontotemporal Degeneration (AFTD), the Dementia Society of America (DSA), Connected Health Resources, Leaders Engaged on Alzheimer's Disease, the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), and the Physicians Committee for Responsible Medicine.

Speakers made the following recommendations and observations:

- We need to continue research for effective treatment while we wait for a cure and we also need to help fund employment opportunities and create safe work environments for those in the early stages of the disease.

- Navigating the Medicaid eligibility process is extremely burdensome and difficult for family members who are trying to help loved ones with dementia.

- The response to the crisis of AD will define Baby Boomers, and the aftermath will define the next generation as well.

- The AFA implemented a webinar on best practices, tools, and strategies to implement a state-level AD plan.

- AFTD and other related dementia organizations are disappointed that their nominees were not appointed to the council.

- The council should take advantage of the http://www.alzheimers.gov Web site to provide more information about the council meetings and promote the public comments section.

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- At council meetings, it would be great to hear from grantees who are receiving federal funds for research projects and to hear from representatives from area agencies on aging, in lieu of presentations on particular topics.

- The Obama Administration should be bold and push for more funding in FY 2015, such as $2 billion for AD research, prevention, and treatment, which has bipartisan support. This could be a legacy of the Administration.

- All non-federal members of the council and advocacy groups should voice their opinion to members of Congress about including AD funding in the next budget.

- There needs to be more dignity in receiving a diagnosis and doctors need to talk with patients and caregivers without any stigma or shame around a diagnosis.

- The diagnosis of AD should not be withheld from the individual who has the disease.

- The recommendations for the 2014 national plan should include metrics for areas such as rates of caregiver depression, falls, or pressure sores. Goals should relate to how many lives are saved and transformed, not to processes and reports.

- The U.S. Preventive Services Task Force recommendations on the value of diagnosis were offensive because they denied the intrinsic value of an individual's knowing what he or she is facing.

- NTG has developed a screening instrument and practice guidelines and is developing a national curriculum to enhance the workforce capabilities of people with cognitive impairment.

- The national plan should focus on services as opposed to just basic research, should mention intellectual disabilities more, and should promote enhancing the capability of clinicians to diagnose dementia.

- People dealing with the public, such as those in retail, banking, hospitality, and restaurants, are not adequately trained to deal with someone experiencing dementia or AD. The disability of those with dementia is not obvious from appearances.

- The DSA works to educate and raise awareness regarding all forms of dementia, including vascular dementia, mild cognitive impairment, and dementia resulting from traumatic brain injury or chronic traumatic encephalopathy.

- We need to coordinate efforts to prevent the waste of duplicating resources, time, and money. A Web portal should be developed that provides searchable

information about programs and research so that everyone can learn about studies and clinical trials.

- Dementia-friendly communities and businesses are needed. We must create environments that enable and encourage those living with dementia to live a full and productive life within their community.

- More research is needed on the role of nutrition and physical activity and other modifiable lifestyle factors in the prevention and treatment of AD.

- More research should be focused on humans, such as tissue biobanks, observational studies, and therapeutic clinical trials, rather than having research using animal models.

Concluding Remarks

Chair Dr. Ronald Petersen thanked the public participants for their input, noting that such contributions help ground the council's feelings about dementia.

The next Advisory Council meeting will take place on February 3, 2014.

The meeting adjourned at 4:27 p.m.

Minutes submitted by Helen Lamont (ASPE).

All presentation handouts are available at http://aspe.hhs.gov/daltcp/napa/.