

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

Washington, DC

April 27, 2018

WELCOME AND CHARGE FOR MEETING

Laura Gitlin, Ph.D., Johns Hopkins University, Chair

Dr. Gitlin opened the meeting at 9:08 a.m. and thanked everyone for coming to this, the third, National Alzheimer's Project Act (NAPA) Advisory Council meeting of fiscal year (FY) 2017/2018. She welcomed new member Michelle Dionne-Vahalik and invited those present to introduce themselves and share on which of the three subcommittee they serve. Then members on the telephone introduced themselves: Gary Epstein-Lubow; Lisa McGuire; and Susan Cooley. Amy Berman and Kedar Mate, M.D., joined by telephone later.

UPDATES AND FOLLOW-UP FROM JANUARY MEETING

Laura Gitlin, Ph.D.

Rohini Khillan, Office of the Assistant Secretary for Planning and Evaluation

Since the last meeting, the three subcommittees have met to discuss regulations and the path to achieving the best recommendations. Two essential topics emerged: impact and evaluation. The Council is using the Driver Diagram to target efforts through to impacts. The final report with recommendations from the *National Research Summit on Care and Services* is available online (<https://aspe.hhs.gov/basic-report/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-summit-report>).

To help subcommittees better formulate recommendations and to address questions raised at the last meeting, new columns were added to the Driver Diagram. These were namely: Who will do this and who are the partners? What constitutes success? What is the time frame? What progress has been made? What are the opportunities and next steps? We still need a way to address prioritization. Nevertheless, we want recommendations to be bolder and more future-directed, which gets to the temporality question. We want to frame recommendations in terms of progress. We hope the model will enable looking at what has occurred and what to build off of and begin next year.

Non-federal members are supposed to comment on the Bypass Budget, but this was not done last year. Robert Egge, Alzheimer's Association, expressed support for FY19 Bypass Budget.

The NAPA Council received a letter from Senator Edward Markey (Democrat, Massachusetts). Dr. Gitlin and Ms. Khillan drafted a response and invited him to attend the July meeting.

Dr. Gitlin thought the Council should begin to think through the infrastructure and how to move forward to bring evidence-based treatment into practice. This concerns implementation, information dissemination, and treatment and relates to all goals except the last (tracking). She referred to five new publications of guidelines to practice (e.g., an article on Alzheimer's disease research in the United Kingdom entitled, "Thinking Differently. Preparing Today to Implement Future Dementia Treatments"). We must address disparities with culturally appropriate treatment.

Dr. Gitlin noted that Chile's national plan is entirely focused on care and services rather than a system of implementation. In the United States, however, implementation frameworks need to be revisited. The *Stanford Social Innovation Review* published "Many Ways to Many," (by McCannon, Vassoud, and Zier) discussing coordinated implementation in the United States, which may end as a Research Subcommittee recommendation. That is, rather than asking which is the best method, decide instead which path will work best for a given circumstance. The article lists eight principles for effective ways to disseminate evidence: emphasize shared, quantifiable aims; reject passive dissemination; commit to high-tempo application of knowledge; connect frontline actors to one another; provide just-in-time access to practical details of applying an innovation or solution; provide actionable data over time that gives regular feedback; take advantage of existing networks and infrastructures; and use many technology platforms.

Exploring technology is a continuing recommendation for all groups. We need to think through what will work (e.g., different drug and non-drug treatments). There are now some 64 models of implementation (e.g., the RE-AIM Model, named for the five critical elements--Reach, Effectiveness, Adoption, Implementation, Maintenance).

Comments and Questions

- **Shari Ling:** We should use vehicles we already have (e.g., ones that include quality improvement). When sharing the latest events of practice, it is important to be able to measure effectiveness. Flexibility is required so all receivers, practitioners, or hospitals can see themselves in this work. There are learning and action networks for each, but first we need to know what is already available. We also need the ability to adapt what we know for others' use. Some people are learning how to do what we already know how to do, but they are focusing on the goal and figuring it out for themselves. Success requires that kind of initiative and leadership. **Dr. Gitlin:** We do have models and lessons learned reflected in four of the five goals, namely how these models support achievement of the goals. We need a broad set of ideas to inform subcommittees' discussions.

- **Robert Egge:** How does practice relate to the overall Strategic Plan? **Ms. Khillan** said she would ask the U.S. Department of Health and Human Services (HHS) Strategic Planning team to present at a future meeting to explain this better.

CLINICAL CARE SUBCOMMITTEE AGENDA: ADVANCING CONSENSUS ON DEMENTIA CARE ELEMENTS TO GUIDE NEW OUTCOMES MEASUREMENT

Overview of History of Dementia Care Elements and Quality Measures

Gary Epstein-Lubow, Clinical Care Subcommittee Chair [via telephone]

Our central question is about how we are going to implement innovations and know that they have been delivered. The Clinical Care Subcommittee hopes to shape the federal and non-federal perspectives. This addresses Recommendation 10: “The Advisory Council on Alzheimer’s Research, Care, and Services should devote one meeting to advancing the work the Office of the Assistant Secretary for Planning and Evaluation (ASPE) has conducted with RTI International on defining best practices for comprehensive dementia care.”

Today we address consensus building and quality measures. Quality measures are tools that help measure or quantify health care processes, outcomes, patient perceptions, and organizational structure or systems associated with provision of high-quality health care. The goals of quality care include effective, safe, efficient, patient-centered, equitable, and timely care. Do we have measures available now?

Measures may be related to structure, process, or outcome. Data sources for quality measures include administrative data, medical records, patient surveys, electronic health records, and assessment instruments. Validity testing determines the ability of a measure to record or quantify what it purports to measure. Reliability testing demonstrates that that measure’s results are repeatable and that the measurement error is acceptable, producing the same results most of the time.

The RAND Corporation undertook the study Assessing Care of Vulnerable Elders, which included cognitive and functional screening, medication review, laboratory testing, neuroimaging, cholinesterase inhibitors, caregiver support and patient safety, depression screening, depression treatment, driving privileges, restraints in hospital, and memory loss. (See <https://www.rand.org/pubs/reprints/RP1130.html>). Their final report, “Priority Setting for Healthcare Performance Measurement: Addressing Performance Measure Gaps for Dementia, including Alzheimer’s Disease,” was published in 2014.

Another tool, the Physician Quality Reporting System, was updated to Merit-based Incentive Payment System (MIPS) and is located in the Quality Payment Program (QPP). It contains a dementia measure group for staging, cognitive assessment, functional status, neuropsychiatric symptoms and their management, depression

screening, counseling for safety concerns and driving risks, and caregiver education. Gaps in measures for Alzheimer's disease and related dementias (AD/ADRD) include a comprehensive patient measure, a comprehensive caregiver measure, and a measure of dementia capability. It is a priority to support the research and development necessary to fill these gaps as soon as possible. The Administration for Community Living and National Alzheimer's and Dementia Resource Center adopted the MIPS approach. They surveyed member organizations for "providing specialized services to people with a cognitive impairment or dementia and their caregivers" using the Consumer Assessment of Healthcare Providers and Systems.

An international approach is exemplified by the United Kingdom's "National Institute for Health and Care Excellence (NICE)--Dementia" study, which focused on anti-psychotic medication, laboratory assessment, care plans reviewed in a face-to-face meeting, contact details of carers on record, and attendance at a memory assessment service. NICE pathways bring together everything the Institute says on a topic in an interactive flowchart. Pathways are updated as new guidance is published.

Leading physicians, measurement experts, and patients devised the International Consortium for Health Outcomes Measurement (ICHOM). It recommends the outcomes that matter most to persons with dementia: neuropsychiatric, cognitive, social, daily living, overall quality of life and well-being, carer quality of life, length of time until the need for full-time care, falls, disease progression, hospital admissions, and overall survival. ICHOM dementia care categories are: demographic factors; baseline clinical status; associated clinical history; medication variables; symptoms, functioning, and quality of life; carer sustainability; safety; and clinical trials. ICHOM dementia outcomes assessment measures are: Neuropsychiatric Inventory, Bristol Activities Daily Living Scale, Quality of Life, Quality of Well-Being Scale, EuroQOL-5D, Clinical Dementia Rating, and Montreal Cognitive Assessment. A new initiative called New False Negatives has also been launched.

The Centers for Medicare & Medicaid Services (CMS) published "Meaningful Measures," which is intended to promote effective communication and coordination of care, prevent and treat chronic disease, work with communities to promote best practices of healthy living, make care affordable, make care safer by reducing harm caused in the delivery of care, and strengthen person and family engagement as partners in their care. CMS tallied the percentage of long-term care hospital patients who had an admission and discharge functional assessment and care plan that considered personalized care aligned with the patient's goals, end-of-life care according to preferences, and patient's experience and functional outcomes. The overall goal was to be able to advocate a process for a person living with dementia.

Eight programs used illustrative measures: QPP, Hospice Quality Reporting Program, End-Stage Renal Disease Quality Incentive Program, Inpatient Rehabilitation Facility Quality Reporting Program, Skilled Nursing Facility Quality Reporting Program, and Long-Term Care Hospital Quality Reporting Program. These were used to develop 14 categories of dementia care models and to develop five discussion questions: Are there

next steps regarding the 14 dementia care elements from RTI/ASPE? How does the Advisory Council address best practice recommendations? Should there be increased focus on assessing dementia capability and/or on outcome measures? How can the use of a care plan for persons living with cognitive symptoms contribute to improving care quality? What are the health information needs for information technology (IT) interoperability to help advance clinical care and long-term services and supports? Two sessions, which follow, further this discussion: Session 1--Advancing Consensus on Dementia Care Elements, and Session 2--Exemplar Models Informing the Need for New Outcomes Measurement.

SESSION 1: ADVANCING CONSENSUS ON DEMENTIA CARE ELEMENTS

Alzheimer's Association Dementia Care Practice Recommendations

Sam Fazio, Alzheimer's Association

Doug Pace, Alzheimer's Association

Working with experts, Dr. Fazio and his group reviewed the literature and identified 56 recommendations by 27 expert authors applicable to various care settings and throughout the disease continuum. Today we see quality care as the result of evidence-based practices. In contrast, person-centered care is underpinned by detection and diagnosis; assessment and care planning; medical management; information, education, and support; ongoing care for behavioral and psychological symptoms of dementia (BPSD) and support for activities of daily living (ADLs); workforce; supportive and therapeutic environment; and transition and coordination of services.

1. Person-centered care focus recommendations are: know the person, person's reality, meaningful engagement, authentic and caring relationship, supportive community, and evaluation of care practices (i.e., caring about instead of caring for). This approach affects both individuals and staff members. Review articles discuss results of person-centered care in terms of behavioral change and medication change.
2. Detection and diagnosis recommendations (i.e., what the caregiver should know): information about brain health and cognitive aging; signs and symptoms of cognitive impairment; concerns, observations, and changes; routine procedures for assessment and referral; brief mental status tests when appropriate; follow-through of diagnostic evaluation; and better understanding of diagnosis.
3. Assessment and care planning recommendations: regular comprehensive, person-centered assessments and timely interim assessments; information gathering, relationship building, education, and support; a collaborative team approach; accessible documentation and communication systems (once information has been collected, it must be made available); and advance planning.

4. Medical management recommendations: holistic, person-centered approach; role of medical providers; common co-morbidities of aging; nonpharmacological interventions; pharmacological interventions when necessary, considering side effects, risks and benefits; person-centered plan for possible medical and social crises; and end-of-life care discussions.
5. Information, education, and support recommendations: preparation for the future; work together and plan together; culturally sensitive programs; education, information, and support during transitions; and technology to reach more families. This would include early, middle, and late stages (i.e., early stage--becoming familiar with the disease; middle stage--increased care and support needs; late stage--relocation and end-of-life care).
6. Ongoing care ADL recommendations: support ADL functions; person-centered care practices; dressing, with dignity, respect, and choice as to process and environment; toileting, including health and biological considerations; and eating. Mealtime is important. People like to dine in a homelike environment with others and should be offered nutritionally and culturally appropriate food.
7. Ongoing care recommendations--BPSD: social and physical environmental triggers for stress, nonpharmacological practices, investment for implementation, protocols, and evaluation of effectiveness. There has been a 35% increase in the reduction rate for pharmaceutical interventions. However, sensory practices have shown small to moderate benefits (e.g., aromatherapy, massage, multi-sensory stimulation, and bright light therapy). Also beneficial (although small to moderately) are psychosocial practices such as validation therapy, reminiscence therapy, music therapy, pet therapy, and meaningful activities. Structured Care Protocols include mouth care and bathing.
8. Workforce recommendations: orientation and ongoing training, person-centered information systems, teamwork and interdepartmental/interdisciplinary collaboration, a caring and supportive leadership team, relationships, and continuous improvement. Long-term care workforce principles include: adequate staffing levels at all times of day, sufficient training in all aspects of dementia care, adequate staff compensation, improved working environments, career growth, and working with families.
9. Supportive and therapeutic environment recommendations: sense of community; comfort and dignity; courtesy, concern, and safety; opportunities for choice; and meaningful engagement.
10. Transition and coordination of services recommendations: education about common transitions in care (home to hospital to long-term care to hospice); timely communication of information between, across, and within settings; preferences and goals of the person living with dementia; strong inter-

professional collaborative team to assist with all transitions; and evidence-based models.

All recommendations are embedded in person-centered care. The Alzheimer's Association Early-Stage Advisory Group has been established and the subcommittee is now working with all players to impact people living with the disease to increase outcomes research. The complete report can be downloaded from the Alzheimer's Association website (<https://alz.org/>).

Quality Care from the Perspectives of People Living with Dementia

Cynthia Huling Hummel, NAPA Council Member

Ms. Huling Hummel thanked Council members for the work and time they put into the recommendations document. The Alzheimer's Association Early-Stage Advisory Group shared hopes, dreams, and perspectives for care. She thanked them for listening to and including people living with dementia.

Some 5.7 million Americans live with AD, including herself. She knows her care needs will change as her disease progresses. This document will guide care and support for her and others. Good care must be based on individual needs. To illustrate, Ms. Huling Hummel read a letter addressed to caregivers.

Meanwhile, fear and isolation continue to grow. Education and resources can improve quality of life for people living with dementia. Person-centered care means engaging in a dialogue *with* her and not *at* her. Caregivers and patients can be partners in putting together a high-quality care plan. The person living with dementia should be involved as long as possible. This requires caregivers to be flexible and amenable to change and to practice tolerance for changing abilities. People want to maintain a sense of autonomy as long as possible. To do this, they need an effective care team that is working together to treat their changing medical, social, and psychological needs.

Another key issue is staff training. Staff must know about best practices for persons living with dementia who need and want to be treated as individuals. Caregivers should provide them and their families with different treatment options to ensure quality of life and a sense of purpose. Person-centered care must be embedded across organizations, and the Alzheimer's Association has provided the road map to do that.

Care Planning and Health Information Technology: How to Aid Dementia Quality Care

Liz Palena Hall, Office of the National Coordinator (ONC) for Health Information Technology

Care planning used to be more like disaster recovery. Now we want to link the patient to care early in the disease. For example, one patient (Mrs. M) was found to have 11 health issues, including congestive heart failure, stroke, unstable gait, occasional falls, osteoarthritis, hypertension, dementia, 12 medications, and isolation. Meanwhile, there

are five basic components of a care plan: care team member information, health concerns/needs, goals/objectives, interventions/activity, and progress/outcomes. A longitudinal person-centered care plan incorporates an emergency care plan, treatment plan, long-term services and support plan, and clinical care plan.

ONC's 2015 Care Plan Criterion requires a Health IT Module for certification to support broader information about the patient. This is distinct from the Plan of Care Section in previous editions. The system must be able to receive the care plan in accordance with standards, but is not required to enable a user to reconcile care plan data.

Funding mechanisms include the CMS QPP, MIPS, and Alternative Payment Models. MIPS measure #47 is a care plan. QPP offers two models, each with specific care plan requirements: the Comprehensive Primary Care Plus (CPC+) model and the Oncology Care Plan Model. CPC+ includes IT requirements that enable providers to electronically capture advance directives and preferences for care, patient health concerns and plans, action plans for specific conditions, interventions and health status evaluations and outcomes, and identified care gaps.

Medicare Chronic Care Management codes include services such as use of certified electronic health records, continuity of care with designated care team members, comprehensive care management and care planning, transitional care management, coordination with home and community-based services clinical service providers, and advance consent.

The State Medicaid Director's Letter 16-003 updated guidance to allow Medicaid Health Information Technology for Economic and Clinical Health Act funds to support all Medicaid providers with whom eligible providers want to coordinate. Interpretive guidance of the final rule for reform of requirements for long-term care facilities includes requirements for a comprehensive care plan. In May 2017, ONC convened four virtual sessions to gather information from 12 health IT vendors on electronic care plans.

We have learned that care plan ownership and management vary depending on the type of care team engaged and the care setting. A care plan is not physician driven; physicians are interested in parts of the plan and depend on the broader care team to manage the plan. The majority of vendors are learning as their clients learn how best to implement electronic care planning. The new CMS Medicare and Medicaid Innovation (CMMI) programs, such as CPC+ and longitudinal care management payment codes (e.g., Medicare Chronic Care Management) are driving care plan technology development and adoption. Moreover, standards are helpful for capturing clinical data but are limited in their ability to capture nonclinical and non-codifiable patient-identified data.

All vendors have implemented Health Level Seven (HL7) Consolidated-Clinical Data Architecture (C-CDA) based document templates, the majority using Release 1.1 instead of the required Release 2.1. The HL7 C-CDA Care Plan document is considered a starting point for effective care planning, but it is limited in the robustness of its data

elements. The HL7 C-CDA and Fast Health Interoperability Resources Care Plan standards need to be further harmonized so that systems can communicate with each other. Vendors see tremendous value in capturing social and behavioral determinants of health in care plans, but this is not yet being done in a standardized way.

The Electronic Long-Term Services and Supports (eLTSS) initiative offers an example. Launched in November 2014, it focused on identification and harmonization of a service plan standard to enable electronic exchange of information relevant to care of persons receiving community-based long-term services and supports. The eLTSS final dataset consists of 56 elements in eight categories: beneficiary demographics (10 elements), goals and strengths (3), personal care programs (11), plan information (1), plan signatures (12), risks (2), service information (12), and service provider information (5). The eLTSS dataset can be integrated into various programs and systems to enable this information to be exchanged broadly. For interoperability, the eLTSS dataset must be represented using nationally recognized vocabularies and content standards. Finally, ONC compiled a table of initiatives with the standards they use. Most important is to interact with persons living with dementia, who are the real experts.

Comments and Questions

- **Gary Epstein-Lubow** asked **Ms. Huling Hummel** what she thought about use of electronic or task-driven care plans for persons living with dementia and how to implement such a plan. **Ms. Huling Hummel** said that when she was first diagnosed, she didn't have a care plan. When she left her doctor's office she had a piece of paper, but she had to develop her own care plan. Now she accesses her medical records on her telephone. Having that information readily accessible is very helpful, but she worries about the privacy issue. She has noticed in her visits to various clinicians that when providers enter information into her records, she feels that she is there as a witness. Caregivers need to truly involve their clients.
- **Angela Taylor** referred to the slide about Mrs. M with her eight team members. At the Lewy Body Dementia (LBD) Association, they include four of the eight symptoms on a Medicaid waiver, but thousands are not represented. How does this fit with what CMS is doing? How can they share that data? How will it become a reality? **Ms. Palena Hall** offered the example of Indiana as one model. They focus on people they have in common and leverage CMS, but she doesn't know all of them. **Ms. Taylor**: Most LBD patients are not on Medicaid and must find other funding sources.
- **Laura Gitlin**: We could add five more symptoms, both in terms of medical and social conditions. This is an important indication for workbook preparation. We have to get a long-term workforce into the plan early, and not in medical offices, but in homes and at work. This document provides guidelines for educating institutions. The electronic world is a real opportunity to change practice. **Ms.**

Khillan: The next step is to see if we do have interactions between clients and health care providers. Or, are they just checking off areas?

- **Debra Cherry:** People living with dementia are in the earliest to the latest stages of dementia. However, the Health Insurance Portability and Accountability Act creates a barrier to talking to families. On the other hand, terminology can change behavior and might change systems of care. **Mr. Pace** agreed with the potential of using person-centered care. **Ms. Huling Hummel** added that families are very different from one another.
- **Shari Ling:** It helps patients and caregivers to know they have access to various types of care.
- **Ellen Blackwell** spends hours talking to people about how they see themselves. This is not emphasized, but it is critical. **Ms. Palena Hall** thought this would be covered under “what you should know about me.”
- **Bruce Finke:** This all ties together beautifully, starting with existing opportunities of quality measurement. As Boxer said, “All models are wrong; some are useful,” and by extension we can say, “All measures are wrong; some are useful.” A care plan is a tool to get to quality of care. Then we can see the impact of the use of that tool. **Dr. Gitlin:** We have the evidence. We must not overlook the very important role of the person’s environment. **Ms. Khillan:** Council members need to think about what happens to integrate and coordinate these things.
- **Deborah Olster:** The person and his or her family should be part of the team.
- **Shari Ling:** We have a care plan that is driving the person to go somewhere, but where is that part of the challenge? We can get there by working with available information and not waiting for perfection of the entire system. All the professionals involved need help to understand why cognition affects their role in treatment--how to start and end the role of care contacts. Some students document rather than understand. **Dr. Gitlin:** This is really a paradigm change. Purpose and need are part of the health profile and drive health. If we can model dementia, that model can be used for other diseases.
- **Angela Taylor’s** daughter became suicidal and had access to many services, but when Ms. Taylor’s father showed symptoms of dementia he had too much money to access these services. Families and patients need a pathway to manage their condition from the beginning. For people who have to make their own path, we need to look beyond the public systems in place.
- **Michele Dionne-Vahalik** noted that many people have no family, and we must consider them. **Ms. Huling Hummel** is a person living with dementia who lives alone and who needs access to care.

PUBLIC INPUT

Thomas Buckley, Lucanus Center

Buckley Medical Home for Americans with Dementia Diagnosis Living with Alzheimer's Disease and Related Dementias thanked the Council members for having this discussion. The bottom line is whether it has an impact. The Alzheimer's Association practice recommendations he heard today are excellent; he can understand them with their 14 components. However, person-centered care begins and ends in the family's home. The average age of caregivers is 79.5 and more than half of caregivers have their own co-morbidities. When people are cared for at home, these things are not reported. Patients want their doctors to come to their homes. The new paradigm must be dementia, health care, and accountability. Nothing will change without accountability. Moreover, people who are not willing to learn and change will push back against the Council's proposed changes.

Dr. Buckley gave an example of the financial complications. Among 30 people, each was taking four or five medications prior to a diagnosis of AD. After diagnosis, the number of medications rose to 16, which amounts to \$436 each per month for unneeded medication.

Matthew Sharp, Association for Frontotemporal Degeneration

Mr. Sharp values medical research, but there is an immediate need for better strategies for better care. Families with FTD are seeking state programs to deal with their condition. Many packages are needed because one size does not fit all. A measure of social functioning would be very useful for FTD patients because they are younger and may still be working. Patient-centered care is good, but any set of practices must be extended to people under age 55.

Mary Hogan, National Task Group on Intellectual Disabilities and Dementia Practices

Ms. Hogan referred to the presentation at the last meeting on dominant inherited Alzheimer's dementia and noted the positive outcome of bringing patients together. They had not known that other people with their condition existed and all wanted to change future outcomes for their children. The experience of people with Down syndrome and their families is similar in that it impacts a small group at an early age. Recently, the National Down Syndrome Society hosted a meeting for individuals with Down syndrome and their families, with similarly positive results

SESSION 2: EXEMPLAR MODELS INFORMING THE NEED FOR NEW OUTCOMES MEASUREMENT

Comprehensive Primary Care Plus (CPC+): Exemplar of Governmental Initiative

Gabrielle Schechter [for Laura Sessums], CMS/CMMI

CPC+ is America's largest ever initiative to transform primary care. The model was tested for CMS in 18 regions serving more than 2 million Medicare patients, 3,000 primary care practices, and 15,000 CPC+ practitioners. Multi-pair models included 50 payer partners and 55 public health IT vendors. Five functions guide CPC+ care delivery transformation and are supported by the drivers:

1. Access and Continuity for track 1 begins with 24/7 access, which progresses in track 2 to care delivered outside of traditional visits. Both tracks have empanelment. Track 1 begins and continues in track 2 with organizing care for continuity and measuring continuity of care.
2. Care Management progresses in track 1 from risk stratifying patients and two-step risk stratification to intensification of two-step risk stratification in track 2. Care management, in step 1 progresses to care plans in step 2. Emergency department and hospital follow-up begins in track 1.
3. Comprehensiveness and Coordination in track 1 constitutes identification of specialists, collaborative care agreements, emergency department and hospital information transfers, and behavioral health integration. In track 2, these actions progress to collaborative care agreements, behavioral health integration, social service linkages, development of capabilities for complex patients, psychosocial assessment, addressing psychosocial needs, and comprehensive medication management.
4. Patient and Caregiver Engagement progresses, in track 1, from annual Patient and Family Advisory Councils (PFACs) to biennial PFACs in track 2; from biennial PFACs to quarterly PFACs; assessment of self-management capabilities to self-management support; and self-management support to advance care planning.
5. Planned Care and Population Health categories move from improving population health with data (track 1) to data-driven improvement by care teams (track 2).

The overall goal of the care delivery model is to deliver better care at lower costs. To enable this, practices are given additional resources and support of \$100 per patient per month. Nearly all practices treat beneficiaries with dementia in both tracks. Despite differences in CPC+ payment, track 1 and 2 practices have roughly the same distribution.

CPC+ quality goals are to improve the quality of performance, patient experience, and outcome-based performance and to decrease unnecessary utilization of care. Incentives are based on quality, patient experience, and utilization.

For 2018, the CPC+ 19 outcome and other measures include controlling high blood pressure, hemoglobin A1c control in diabetes, breast cancer screening, cervical cancer screening, colorectal cancer screening, eye exam and medical attention for nephropathy in diabetes, cognitive assessment, and tobacco use. Other tools include the data feedback approach, which includes attribution/payment data, quality and care delivery data, cost and utilization data, and multi-payer aggregation, as well as practice performance and demographics.

These tools offer many opportunities for learning, collaboration, and support. CMS supports practices via live and on-demand events, local collaboratives, CPC+ Connect, CPC+ support, written guidance, and regional outreach for practices in need.

Age-Friendly Health Systems: Exemplar of Non-Government Initiative

Amy Berman, John A. Hartford Foundation

Kedar Mate, Institute for Healthcare Improvement (IHI) [via telephone]

Age-friendly health systems (AFHSs) are under a triple threat--demography, utilization, and disutility--largely accounted for by the "know-do gap." We have many effective evidence-based models of geriatric care. Yet, most reach only a portion of those who could benefit because they are difficult to disseminate and scale, difficult to reproduce in settings with fewer resources, and do not apply across settings of care (e.g., hospital and home). Programs are now reaching about 4 million of our 46 million older adults. An AFHS is one in which every adult aged 65 or older gets the best care possible, experiences no health care-related harms, is satisfied with the health care, and realizes optimal value.

The evidence-based interventions were derived from a review of 17 models and programs serving older adults as to the population served, outcomes achieved, and core features of the model. To identify places likely to experience the greatest impact, four critical issues (4M's) were adopted: what matters (the patient's specific health goals and care preferences), medication (optimizing its use to reduce harm and burden), mentation (identifying and managing depression, dementia, and delirium), and mobility (maintaining mobility and function and preventing complications of immobility).

IHI health system teams are running some 40 tests to address how to reach more older adults and when health systems get involved; how to improve the model for prototyping units; the What Matters Protocol (at Providence St. Joseph Health); documentation; and, finally, creating AFHSs that reach an increasing number of older adults.

Changes to become age friendly systemwide require support of front-line teams to adopt the 4M's, especially to find out what really matters to the patient. Now is the time

to act. The first five systems are scaling up across their systems and this summer four mini-collaboratives will be launched to engage other institutions around the country. The business case is being formalized with a “What Matters” starter kit, electronic health record guidance, and policy guidance.

Measurable impact is being achieved with grantee partners. For example, the University of California-Los Angeles (UCLA) Alzheimer’s and Dementia Care Program uses nurse practitioner dementia care managers to assess health, offer treatment, develop care plans, and make referrals to community-based services for patient and family caregiver support.

The model shows reductions in hospitalizations, 30-day readmissions, nursing home placement, and cost, as well as improvements in understanding and management of dementia, self-care among caregivers, and access to community-based support.

Moving and scaling home-based primary care (HBPC) is a three-part initiative--data registry, workforce development, and payment policy--intended to improve health for most frail older adults living in the community. The Independence at Home model showed a \$25 million reduction in Medicare costs (\$3,070 per beneficiary). The Veterans Affairs (VA) HBPC Program resulted in reductions in hospital days, nursing home days, and 30-day readmissions for a \$9,000 savings per veteran.

The Benjamin Rose Institute on Aging and Family Caregiver Alliance is an online resource used to compare dementia caregiving programs. It contains some 50 evidence-based programs that address the needs of family caregivers of people living with dementia aimed to help health and social service organizations.

Finally, PACE 2.0 (from the National Programs of All-Inclusive Care for the Elderly [PACE] Association) aims to adapt and expand access to programs. The model provides all needed preventive, primary, acute, and long-term care services for nursing home-eligible patients. Participants report being healthier, happier, and more independent than their counterparts in other care settings. The next phase builds on the PACE Innovation Act and will identify underserved subpopulations currently eligible to enroll, as well as new unserved populations such as younger adults with physical or mental challenges.

Moderated Discussion

Gary Epstein-Lubow & Shari Ling

- ***Gary Epstein-Lubow:*** How do we know that we’ve arrived? ***Ms. Schechter:*** The CPC+ program evaluates results. ***Dr. Finke:*** We should be able to develop this model to adapt it to people living with dementia. The question is not “did it or did it not work,” but “how did it work.”

- **Susan Cooley:** There are many standard measures, but that does not constitute a dementia model. We have been trying to define “gold measures” before this year. How could that same gold be shared? This is an area where we understand the issues. Now workers have to work together.
- **Amy Berman:** IHI is also funding work around priority issues. What is the aim for people looking at the highest priorities? It’s not all or nothing. We need to prioritize patient and employee outcomes. **Dr. Ling** asked about the important but unstated issues. **Ms. Berman** recognized the importance of joy for patients as well as for caregivers.
- **Shari Ling:** The issue becomes how to achieve what we all want (i.e., how to improve our system). **Mr. Egge:** We should be able to have this. But, how does the Advisory Council ask about this? How do we stick with the plot line meeting after meeting? **Ms. Huling Hummel:** Start with what matters most. Start with the patient. It’s a hard question.
- **Michele Dionne-Vahalik:** We should optimize systems in an age-friendly culture. **Dr. Gitlin:** Are those two different initiatives? How does age-friendliness relate and help? It may be appropriate to work in parallel. How can the two be related and interdigitated? **Ms. Dionne-Vahalik:** We have to look at where we are and where we want to go, and then look at how to do that. We have begun to incorporate this with outcomes. **Dr. Finke:** The temptation is to try to figure out what the answer is. But, that approach is not fruitful and is not the direction where we want to go. Today we heard several exciting approaches, such as Independence at Home, the UCLA model, the Specialty-based Model, and other models.
- **Gary Epstein-Lubow** said we should begin to think about a measurement framework for care persons with dementia and their families. If we start to think about a measurement framework to figure out where we are, we will be able to develop and test these ideas. As they show merit, it will relate to the other factors. That removes us from trying to identify everything while it gives us a way of looking at the impacts over time.
- **Angela Taylor:** The 4M approach allows for the progression of care (i.e., in youth, we are self-caring, whereas with increasing age, we need more help). With age we have to maximize wellness; we have to shift the model on its head. There’s momentum building in the system that lends support to those who cannot manage on their own.
- **Becky Kurtz:** Nobody ever asks, “What matters to you?” Maybe that is because what matters to you may not be about health care. It’s not only a health answer, so that may be why the question is not asked. We need linkages to social services, linkages that admit the limitations of health care. It might be productive to discuss those linkages, many of which are broken in many communities. As

linkages are investigated, we could answer some of that. **Bradley Hyman**, echoed this statement, but thought it could not be taken out of the standards. **Dr. Ling** agreed and noted that CMS changed their template to reflect that. **Joan Weiss**, noted that to build the infrastructure is not expensive and may be cheaper than health care.

- **Debra Cherry** was struck by the number of high-quality programs available. She sees a lot of quality interventions that are not getting to enough people.
- **Dr. Gitlin**: Will the various models provide specific lessons learned that apply specifically to dementia? If they would, it would go a long way toward the Council's goals. **Dr. Finke's** idea was very compelling. We may want to agree upon the measures of outcomes, and also the processes, which must be defined locally. She asked Dr. Finke to form a small working group to think through this as it applies to the national programs under discussion, and then the scaling issue. **Dr. Ling** said there are so many measures, we have to learn what we want the measure to be. It's about some core remeasuring. This is a national plan, a systems issue. We need to be technical about who we are looking at and what we want to achieve. **Dr. Gitlin** agreed and asked Council members who want to join this small working group to send an email to Ms. Khillan indicating their interest.

CARE SUMMIT FINAL REPORT

Care Summit Process Report

Sari Shuman, RTI

Ms. Shuman explained how the Research Summit on Dementia Care was planned and convened. They first conducted a number of interviews to learn the history of the project. The overarching goal of the summit was to identify what we know and what we need to know to accelerate the development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, families, and other caregivers. The Summit was focused on research needed to improve quality of care and outcomes across care settings, including quality of life and the lived experience of persons with dementia and their caregivers.

After approval for the Summit was attained, the structure was developed based on AARP's 2015 one-day meeting. In January 2016, a proposal was presented to the NAPA Advisory Council. In March 2016, Dr. Gitlin and Ms. Maslow were appointed co-chairs for the Summit. Steering Committee input and involvement encompassed all aspects through to the report.

Six stakeholder groups were involved, including persons living with dementia. Stakeholder groups, recruited during January 2017, consisted of persons living with dementia (4 co-chairs, 10 members), family caregivers (3 co-chairs, 14 members),

service providers (2 co-chairs, 28 members), state government programs (3 co-chairs, 42 members), workforce development (3 co-chairs, 7 members), and payers (1 chair). Stakeholder group processes were defined as to group, meeting frequency, modes of communication, and additional information. Each stakeholder group developed five or more research recommendations, which were posted on the website and available for comment one month prior to the Summit.

Pre-summit activities included convening scientific meetings conducted to provide foundational knowledge, offering recommendations to be discussed at the conference, providing working documents (e.g., white papers), and leveraging and linking existing scientific activity. All such activities complied with various criteria (e.g., they were “naturally occurring,” funded, topics of relevance to the Summit, contributed a white paper or other publication, and generated recommendations).

The Summit agenda was developed by the end of May 2017 after it was reviewed by the Steering Committee. Chairs for cross-cutting topics helped identify speakers on various topics. Criteria for Summit session co-chairs, speakers, and cross-cutting chairs included research and academic credentials, leadership capability and experience, knowledge about the topic, and ability to collaborate. Steering Committee members nominated co-chairs and session chairs.

Special considerations concerned involvement of persons living with dementia. The Leadership Committee had four co-chairs, two with dementia. Persons living with dementia who could fully participate in discussions were recruited and given monthly 90-minute video conference meetings. Each meeting focused on one topic. They developed their own process to have sessions and speakers from their group. Accommodations for person living with dementia included funding for a travel companion for each. An email survey was used to collect input on travel needs.

The Summit lasted 18 hours over 2 days and moved at a lively pace. The wide range of topics and perspectives helped generate many research recommendations, including recommendations unrelated to research on care and support, such as police and practice recommendations, as well as financing, payment, and reimbursement recommendations. Disadvantages included less time for each speaker, too many topics, less time for audience discussion, few breaks, not enough time for informal networking, and exclusion of some topics due to lack of time.

Final Report on Care Summit

Katie Maslow, Laura Gitlin, & Rohini Khillan

Ms. Khillan received some 700 research recommendations relevant to a wide variety of stakeholders. The final report is modeled after the final report produced by the National Institute on Aging (NIA) and the National Institute on Neurological Disease and Stroke. All materials are available on the website (<https://aspe.hhs.gov/basic-report/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-summit-report>).

Definitions were laid out for terms such as persons living with dementia, caregivers (family members, unpaid or paid, and neighbors, friends, fictive kin, and anyone else who provides care), etc. A table enumerates research recommendations and information sources. Next, recommendations were categorized into 12 broad themes. The recommendations were combined in each theme into four to seven main recommendations for a total of 58 main recommendations.

Ms. Maslow provided a sample recommendation for each of the 12 themes:

- **Theme 1.** Heterogeneity of persons living with dementia and their caregivers. (Individual difference is a tremendous challenge.) Recommendation 1: Develop accurate, up-to-date descriptive information about the characteristics, care needs, and services used by persons living with dementia and their caregivers.
- **Theme 2.** Research methods to develop more effective dementia care, services, and supports. Effective interventions in real-world communities are needed. Recommendation 3: Increase collection of self-reported data from persons living with dementia and develop standards for determining which individuals can self-report about which outcomes at which stages of dementia.
- **Theme 3.** Caregiver relationships, roles, and networks. Recommendation 4: Conduct a review of established research on caregiver programs for dementia stages to determine what additional research and evidence would be needed to incorporate these evidence-based programs as a covered benefit.
- **Theme 4.** Clinical approaches and the lived experience of dementia. Recommendation 2: Conduct studies that combine pharmacological and nonpharmacological strategies to reduce dementia-related symptoms, including behavioral symptoms and functional and cognitive decline, and determine whether reduction in symptoms can slow disease progression.
- **Theme 5.** Engaging persons living with dementia and caregivers in research. Recommendation 2: Develop and evaluate promising practices.
- **Theme 6.** Dementia-related terminology, nomenclature, and stigma--words matter. Recommendation 1: Analyze existing dementia-related terminology, identify confusing or stigmatizing terms, and initiate a process to select or develop terminology that will reduce stigma and support effective communication among individuals and groups.
- **Theme 7.** Comprehensive models for dementia care, services, and supports. Recommendation 3: Evaluate and compare comprehensive models of care and develop new models for subgroups of persons living with dementia who are not effectively served by existing models (e.g., persons who live alone).

- **Theme 8.** Strategies for scaling and disseminating existing evidence, drawing upon implementation science. Recommendation 4: Analyze dementia-related costs to all payers, the division of costs among payers, and cost shifting. This was an issue that came up repeatedly.
- **Theme 9.** Living places, physical and social environments, and processes of care for persons living with dementia, including those who live alone. Recommendation 4: Conduct research to increase our understanding of how physical and social environments and processes of care can help to balance autonomy, independence, and choice vs. safety and protection from risk for persons living with dementia in all types of living places, including persons living alone.
- **Theme 10.** Financial burden and out-of-pocket costs for persons living with dementia and their caregivers. Recommendation 3: Develop information about the impacts of dementia-related out-of-pocket costs and financial burden.
- **Theme 11.** Ensuring an adequate and qualified workforce to support persons with dementia and their caregivers. Recommendation 1: Research impacts of the ever-increasing aging population on workforce infrastructure and numbers, particularly across regions and workforce type, and develop a solid evidence base for issues around recruitment and retention of workforce for dementia care.
- **Theme 12.** Technology to support persons living with dementia and their caregivers. Recommendation 2: Develop a solid evidence base on the efficacy/effectiveness of technology-based solutions for persons living with dementia across various functional categories of use and study how technology can assist caregivers to better manage both the care needs of those they care for as well as their own needs.

We want to get a wide array of interest groups to address these issues, so everyone is welcome to disseminate these research recommendations.

Post-Summit Follow-Up

Rohini Khillan

Lessons learned include the benefits of an open process and the value of including as many stakeholders as possible. The process of developing recommendations is being refined. Topics not addressed due to time constraints included detection and diagnosis of cognitive impairment and dementia and general medical care, including hospital care.

Comments and Questions

- ***Cynthia Huling Hummel*** thanked organizers for giving persons living with dementia a seat at the table and truly including them.

Dissemination Plan

Laura Gitlin & Rohini Khillan

The Summit was not designed for any specific government agency or group, so one question that arises is how we distill and repackage it for various audiences. Stakeholder groups presented detailed processes with their recommendations. All the recommendations are available on the website.

Comments and Questions

- **Richard Hodes**, didn't want to delay action, so NIA has begun various initiatives by issuing requests for proposals.
- **Anthony Pacifico** reported that the Army has begun several programs and activities. They need to emphasize traumatic brain injury.
- **Laura Gitlin** responding to **Dr. Cherry**: How do these recommendations relate to the recommendation that the working groups are studying? It's a fine line and there's a bit of overlap. Dr. Cherry thought they should not be duplicated but should be referenced from one document to the others.
- **Shari Ling**: We need clarity as to the population who benefits. We're thinking about modifying policy and building programs, so who benefits is a critical issue. As we move forward, we need to consider the accessible parts of the world. Each working group could flesh out a recommendation for particular groups so it does not replicate the recommendation. Change in the ecology of how we do research was a recurrent topic at the March Summit meeting. Some research results cannot be done in this political world (e.g., gender relations). We have to drill down to that level to get that research used. This is not a research question per se, but a question about how we do our research. **Ms. Maslow**: Matching up who benefits goes under the heterogeneity issue. **Dr. Ling** agreed that it was good that heterogeneity had been interwoven throughout. Granularity should also be considered. Who would use the product? What would make the people who come in today think their visit was worthwhile?
- **Laura Gitlin**: We can't help but link this research to policy. There cannot be one program or toolkit for what is reimbursable because it won't fit the different combinations of characteristics. We need a toolkit of the best evidence we have that can be repurposed.

FEDERAL WORKGROUP UPDATES

Susan Cooley, U.S. Department of Veterans Affairs

The VA offers three programs:

1. The Geriatric Scholars Program is a workforce development program intended to integrate geriatrics into primary care practices. It is a collaboration of 12 VA geriatric research, education, and clinical centers in partnership with the VA Employee Education System, academic affiliates, and Health Resources and Services Administration-funded geriatric workforce education programs.
2. FY18Q2 VA Geriatric Scholars Dementia Education and Resources is a rural interdisciplinary team training for the Toiyabe Nation with onsite training for all clinic staff using webinars. It is accredited through the VA Employee Education System and TRAIN interagency learning network for VA and community clinicians.
3. Resources for Enhancing Alzheimer's Caregiver Health in VA (REACH-VA) Caregiver Support Intervention is a national program to provide REACH-VA to caregivers of veterans.

Shari Ling, CMS

Positron emission tomography (PET) amyloid- β ($A\beta$) imaging can exclude AD and enrich clinical trials seeking better treatment. CMS has determined that use of PET for diagnosis is promising, but not yet sufficient. Therefore, CMS will pay for one PET $A\beta$ scan per patient in clinical studies who meet specific criteria. To date, CMS has approved several studies.

CMS presented a geriatric competent care 2018 webinar series that provided an overview of critical issues, beginning in April with "Safe and Effective Use of Medications in Older Adults." It is archived on their website.

In March, CMS released changes in 2019 for the Medicare Advantage Organizations that allow more options and new benefits under Medicare Part D payment and policy updates. Under the new policy, CMS allows supplemental benefits if they compensate for physical impairments, diminish the impact of injuries or health conditions, or reduce avoidable emergency room utilization. More information is available on the CMS website.

Comments and Questions

- **Ellen Blackwell:** This is a real opportunity for population studies.
- **Bruce Finke:** A number of Tribal communities have data on travel, cost, co-morbidities, etc., and we can see their impact on dementia.

Richard Hodes, National Institute on Aging

NIA appropriations have increased from \$1,046 million in 2014 to \$2,574 million in 2018, and the amount designated for research on ADRD has increased accordingly. (The National Plan specifically named LBD, FTD, and vascular cognitive impairment/dementia.) An additional \$50 million was directed to ADRD in 2012, \$40 million in 2013, \$100 million in 2014, and \$25 million in 2015. The progression from over \$1 million in 2013 to over \$2.5 million in 2018 is a tribute to all of the Council members whose work made it possible.

Care summits are convened annually for AD one year and ADRD the next. Milestones are based on broad input; priorities are developed within milestones and are undertaken when monies become available.

In August 2016, the 2018 bypass budget was approved. The FY2020 National Institutes of Health (NIH) Bypass Budget, based on external and internal input, is planned for completion in July 2018. Considerations include past and current appropriations, progress on milestones, incorporation of new milestones, large project needs (e.g., emerging clinical trials), emerging investments by other groups (considered in light of the gaps best filled by the NIA/NIH), and success in recruiting new and established researchers to ADRD research and the capacity of the field.

The NIA-Alzheimer's Association Research Framework has been published. Alzheimer's is now defined by biomarkers--amyloid, tau, and neurodegeneration--instead of only at autopsy. It is now known to be a pathologic continuation from normal biomarkers to AD. This framework is intended to aid researchers in identifying persons at risk for disease sufficiently early to test new prevention strategies as they emerge.

The next research AD/ADRD Care/Services Summit will be held March 24-25, 2020, at Natcher Conference Center, Bethesda, MD. The planned evidence review will be Care Interventions for Individuals with Dementia and Their Caregivers. Hundreds of studies have looked at the efficacy and effectiveness of care/caregiving interventions, but what is the quality of evidence supporting readiness for dissemination of any of these? NIA is funding a two-part study similar to that used for the recent dementia prevention literature review. Initial steps include convening a National Academies of Sciences, Engineering, and Medicine expert panel to provide input on questions and study design, and involving the Agency for Healthcare Research and Quality for evidence review. Draft study questions and other planned study parameters will be posted for public comment (the URL will be shared when available).

The 2018 AD Research Summit was scheduled for March 1-2, 2018, but the second day was canceled due to weather. The second day will be presented at a live videocast on May 24. It will feature emerging therapeutics; understanding the impact of the environment to advance disease prevention; advances in disease monitoring, assessment, and care; and building an open science research ecosystem to accelerate AD therapy development. Register for day 2 at <https://www.eventbrite.com/e/2018-nih-alzheimers-disease-research-summit-rescheduled-day-2-program-tickets-44164510239>.

The next ADRD Summit will be held March 14-15, 2019, in Bethesda, MD.

Erin Long, Administration for Community Living; Long-Term Services and Supports Committee

In collaboration with the National Alzheimer's and Dementia Resource Center, a webinar series has begun:

- January 30, 2018, "International Perspectives on Supporting People with Dementia and Their Caregivers" (576 people trained)
- March 13, 2018, "Using Improvisation to Improve Quality of Life for Persons Living with Dementia" (478 people trained)
- April 10, 2018, "Trauma-Informed Care for Person Living with Dementia" (1,095 trained)
- April 18, 2017, "The Case for Palliative Care for People with IDD (Intellectual Disabilities and Dementia) and Dementia" (819 trained)

Rohini Khillan, ASPE

ASPE will release an evaluation of the Administration on Aging Program to Prevent Elder Abuse.

Susan Cooley, Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention's "Public Health Road Map for State and National Partnerships 2018-2023" will be released this summer and fall. It incorporates a 25-item action agenda tied to four domains of public health and emphasizes five critical overarching issues.

An interactive webinar, "Behavioral Risk Factor Surveillance System Cognitive Decline and Caregiving Modules" will be broadcast May 8.

Bruce Finke, Indian Health Service

Some 55 caregivers have enrolled in "REACH into Indian Country." It is based on the premise that support for caregivers constitutes treatment for persons living with dementia and has engaged the public health nurse workforce. It is similar on the aging network side. Now we need to expand the program and take it further.

CONCLUDING REMARKS

Dr. Gitlin summarized: We want to look at HHS Strategic Plan and we will continue to work on the best ways to disseminate the Council's information.

Ms. Khillan announced that today's meeting is available on the ASPE website.

Dr. Gitlin adjourned the Council meeting at 4:35 PM.

The next meeting will be in July 2018.

Minutes submitted by Rohini Khillan (ASPE).

All presentation handouts are available at <http://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings>.

PARTICIPANTS

Advisory Council Members

Present

Ellen Blackwell, Centers for Medicare & Medicaid Services
Katie Brandt, Massachusetts General Hospital
Debra Cherry, Ph.D., Alzheimer's Greater Los Angeles
Susan Cooley, Department of Veterans Affairs *[via telephone]*
Michele Dionne-Vahalik, Texas Health and Human Services Commission
Robert Egge, Alzheimer's Association
Gary Epstein-Lubow, M.D., Brown University *[via telephone]*
Bruce Finke, M.D., Indian Health Service
Laura Gitlin, Ph.D., Johns Hopkins University, Chair
Richard Hodes, M.D., National Institute on Aging
Cynthia Huling Hummel, Person living with Alzheimer's disease
Bradley Hyman, M.D. Massachusetts General Hospital
Rohini Khillan, Office of the Assistant Secretary for Planning and Evaluation, HHS
Becky Kurtz, Atlanta Regional Commission, Area Agency on Aging
Shari Ling, M.D., Centers for Medicare & Medicaid Services
Erin Long, Administration for Community Living, Administration on Aging
Lisa McGuire, Ph.D., HHS Centers for Disease Control and Prevention *[via telephone]*
Deborah Olster, Ph.D., National Science Foundation *[via telephone]*
Anthony Pacifico, Ph.D., U.S. Department of Defense
Marianne Shaughnessy, U.S. Department of Veterans Affairs
William Spector, Ph.D., Agency for Healthcare Research and Quality
Angela Taylor, Lewy Body Dementia Association
Sowande Tichawonna, Caregiver
Kara Townsend, Office of the Assistant Secretary for Planning and Evaluation, HHS
Brigette Ulin, Centers for Disease Control and Prevention
Joan Weiss, Ph.D., Health Resources and Services Administration

Absent

Richard Allman, U.S. Department of Veterans Affairs
Billy Dunn, HHS Food and Drug Administration
Allan Levey, M.D., Emory University

Public

Speakers

Amy Berman, John A. Hartford Foundation [via telephone]

Sam Fazio, Alzheimer's Association

Liz Palena Hall, Office of the National Coordinator for Health Technology

Katie Maslow, Gerontological Society of America

Kedar Mate, Institute for Healthcare Improvement [via telephone]

Douglas Pace, Alzheimer's Association

Gabrielle Schecter for Laura Sessums, CMS/CMMI

Sari Shuman, Research Triangle Institute

Attendees

Amiee Aloi

Joe Balintfy

Marie Bernard

Thomas Buckley

Erin Cadwalader

Rachel Conant

Phil Cronin

Lori Frank

Laurel Fuller

Jordan Gladman

Matthew Janicki

Melinda Kelley

Gavin Kennedy

Ian Kremer

Charlene Liggins

William Marton

Jennifer Pollack

Matthew Sharp

Michael Simmons

Sarah Smith

Eric Sokol

Elaine Swift

Laura Thornhill

Jane Tilly

C. Grace Whiting

Amy York

April 27, 2018 -- Advisory Council Meeting #28

The meeting was held on Friday, April 27, 2018, in Washington, DC. During the meeting, the Clinical Care Subcommittee took charge of the theme, focusing on advancing consensus on dementia care elements to guide new outcomes measurement. The Council heard speakers in two sessions, one focused on developing consensus about dementia care elements, and the second on models that are informing outcomes measurement. The meeting also included updates on work from the previous meetings, a presentation on the final report from the October 2017 Care Summit, and federal workgroup updates. Material available from this meeting is listed below and at <https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Apr2018>.

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

General Information

Agenda	[HTML Version] [PDF Version]
Meeting Announcement	[HTML Version] [PDF Version]
Meeting Summary	[HTML Version] [PDF Version]
Public Comments	[HTML Version]

Handouts

Main Summit Recommendations	[HTML Version] [PDF Version]
National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers: Report to the National Advisory Council on Alzheimer's Research, Care, and Services	[HTML Version] [PDF Version]

Presentation Slides

Age-Friendly Health Systems	[HTML Version] [PDF Version]
Alzheimer's Disease and Related Dementias Research Update	[HTML Version] [PDF Version]
Care Planning and Health Information Technology: How to Aid Dementia Quality Care	[HTML Version] [PDF Version]

Clinical Care Subcommittee Agenda: Advancing Consensus on Dementia Care Elements to Guide New Outcomes Measurement	[HTML Version] [PDF Version]
Clinical Subcommittee Update	[HTML Version] [PDF Version]
Defining Quality Dementia Care	[HTML Version] [PDF Version]
Final Report to the NAPA Advisory Council	[HTML Version] [PDF Version]
Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
Quality Care from the Perspectives of People Living with Dementia	[HTML Version] [PDF Version]
Research Summit on Dementia Care: Building Evidence for Services and Supports Process Report	[HTML Version] [PDF Version]
Testing the Promise of Primary Care: Comprehensive Primary Care Plus (CPC+)	[HTML Version] [PDF Version]
Updates and Follow-Up from January Meeting	[HTML Version] [PDF Version]

Videos

Introductions and Updates	[Video]
Clinical Care Agenda Session 1	[Video]
Public Comments	[Video]
Clinical Care Agenda Session 2	[Video]
Care Summit Final Report	[Video]
MEETING WRAP-UP: Final Report to the NAPA Advisory Council	[Video]

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